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BEST NURSING JOURNAL AWARD UESCE

INTERNATIONAL CONGRESS  
**Research  
Innovation &  
Development  
in Nursing 2017**  
Conference Proceedings

DIGITAL SUPPLEMENT

# Presentation

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[https://www.researchgate.net/profile/Carlos\\_Sequeira2](https://www.researchgate.net/profile/Carlos_Sequeira2)

The International Congress in Research, Innovation and Development in Nursing was organized by a group of researchers of CINTESIS – Center for Health Technology and Services Research, integrated into the Nursing research group (NursID). The event was held between 6 and 7 July 2017 at Escola Superior de Enfermagem do Porto (Nursing School of Porto), Porto, Portugal.

NursID 2017 focused on health research, with no disciplinary boundaries and included lecturers from several areas of knowledge, aiming at contributing to the dissemination of research in teaching, research units and clinical practice.

The event provided an excellent opportunity for the sharing of knowledge, experience and evidence deriving from research, fostering partnerships between researchers, with particular emphasis on the ongoing research projects of the Nursing Research Group (NursID), integrated in CINTESIS.

The programme included different presentations – conferences, workshops, posters, oral communications and project displays, assembling national and international lecturers and enabling the dissemination of research projects and outcomes, the development of research skills and gave an important contribution to the discussion of several core topics:

- The importance of research in health.
- The impact of research on social change.
- The importance of scientific evidence.
- The transfer of knowledge to clinical contexts.
- Simulation as a pedagogical tool to support decision-making.
- Research findings on violence in older people.
- The relevance of research in health literacy.

215 researchers from several countries registered in the Congress and participated in:

- 7 Displays of ongoing research projects of NursID:CINTESIS.
- 4 Workshops on research subjects.

- 101 Poster presentations (5 minutes each).
- 95 Oral communications (10 minutes each).
- 7 Lectures presented by persons of recognized national and international merit.
- 1 Debate on clinical academic centers –bridging the gap between researchers/research and clinical practice institutions/the Academy (Research units/universities).

This supplement comprising 50 articles, focuses on health problems, the identification of needs and intervention strategies throughout the lifespan –children, adolescents, adults, older people; and specific contexts– Hospital, Health Centres; Family Context, Community Context, among others.

The articles address some main topics:

- Data on family needs and more effective types of intervention.
- Epidemiological data on multiple nursing diagnoses.
- Data on the effectiveness of Nursing interventions.
- Data on the importance of evidence in Health.
- Data on violence in older people.
- Data on active ageing and the importance of falls prevention.
- Data on the main problems reported by students.
- Data on health communication strategies.
- Data on the importance of Literacy in Health and in Mental Health.
- Data on the advantages of simulation in medical and nursing teaching – contributions to patient safety.
- Data on the development of palliative care in dementia – the importance of establishing guidelines, the importance of creating the caregiver status, empowerment and evaluation of the caregiver.
- Data on the importance of healthy work contexts and health promoters.

The Congress videos are available at:

- Link day 1: <https://www.youtube.com/watch?v=kNERW2uxgXc>
- Link day 2: [https://www.youtube.com/watch?v=KH7Nk\\_XrJ3A](https://www.youtube.com/watch?v=KH7Nk_XrJ3A)

# Introduction

Jane Salvage defines 2018 as *a landmark year for nursing worldwide* (Salvage, 2018), based on the *Triple Impact report*, a document that highlights nurses' important role play in changing the focus of health professionals to cost-effective health promotion and disease prevention, directing nurses attention to a better health, a greater gender equality and stronger economies (All Party-Parliamentary Group on Global Health, 2016), embedded in the "Nursing Now" initiative.

Following this line of thought, the 50 articles included in the supplement of *Revista ROL de Enfermería* address a set of four major significant areas of nursing sciences for the twenty-first century, focused on health conditions, on the identification of needs and intervention strategies throughout the lifespan (children, adolescents, adults and aged populations) and specific contexts in which nurses can play a pivotal role.

The first major group of papers is directed to the complex management of nursing teams. The importance of communication is highlighted in another important set of works (addressing several domains such as its effectiveness or conflict management), encompassing interconnectedness, job satisfaction and patient-oriented quality of care, stressing the importance of communication in nurses' teams. Secondly, the reader will find a set of papers related to nursing education and health literacy that approach and identify trends for the new millennium and pinpoint key elements likely to shape the future in nursing education and health literacy, as essential areas to successfully access care and health services. Thirdly, a set of essential papers focus on chronic disease management in several age groups and health conditions, by stressing the importance of designing and defining interventions on chronic disease aiming at a person-centered health

promotion underpinned by a targeted model. The last group of presented works draw attention to health promotion in community and family contexts. Important aspects are set forward such as working with people in order to prevent, prepare and respond to health problems; promoting healthy lifestyles; empowering families with the necessary skills to promote their own health; and improving assessment and intervention targeted at families' health and wellbeing.

The collection of papers is the result of a solid analysis work (a blind review process) of the best contributions gathered from the International Congress in Research, Innovation and Development in Nursing held at Porto, Portugal, in July 2017 and organized by the Nursing School of Porto and CINTESIS Research Unit – Center for Health, Technology and Services Research. In an overall number of 196 oral communications and posters, the supplement assembles the best 50 papers presented in this Congress focused on health research with no disciplinary boundaries, which included lectures from several areas of knowledge, providing an excellent opportunity for the sharing of knowledge, experiences and evidences deriving from research and fostering partnerships between researchers.

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- Salvage, J. (2018). A new story of nursing. *Revista de Enfermagem Referência*, IV(17), 3-12.

**8. Needs in palliative care in institutionalized people with advanced dementia: a multidimensional approach**

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**16. A family intervention for symptom management in children with asthma: development and feasibility of a complex intervention**

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**21. Communication problems between nurses and patient's family**

António Calha, Anabela Silva, Noélia Vieira.

**26. Determining factors of communication effectiveness in nursing teams**

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**32. Interpersonal conflict management strategies in nursing teams**

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# Needs in palliative care in institutionalized people with advanced dementia

## A multidimensional approach

### Summary

Palliative Care is an appropriate typology of care for institutionalized older people with Advanced Dementia. It is necessary to take into account their unique needs and circumstances to guarantee a good quality of life and satisfaction with the health care received. The aim of this study was to identify the needs in Palliative Care associated with institutionalized people with Advanced Dementia. An exploratory two-stage qualitative study was developed. After a narrative literature review, all the phenomena related to the subject were identified as being a possible need in palliative care. This data was discussed and evaluated by two focus group with Portuguese and Spanish experts in the fields of Geriatrics, Psycho-geriatrics, Neurology, Geriatric Nursing, Psychology and Continuity Care. The needs in Palliative Care were identified and categorized into seven dimensions: physical, psychological, social, spiritual, economic, legal and environmental. The identification of these needs is the first step to ensure the provision of Palliative Care with quality and adapted to the particularities of each older person institutionalized.

KEYWORDS: NEEDS; PALLIATIVE CARE; DEMENTIA; INSTITUTIONALIZATION.

### Introduction

Dementia is a major challenge for today's global public health. According to the World Alzheimer Report 2014 there are about 44 million people living daily with a dementia. It is expected that this number will double in 2030 and that there are around 7.7 million new cases per year worldwide<sup>1</sup>.

Dementia is a syndrome, of a chronic and progressive nature, caused by a variety of brain illnesses that affect memory, thinking, behaviour and ability to perform everyday activities<sup>2,3</sup>. This disease is a leading cause of disability and dependency among older people<sup>4,5</sup> which may become an overwhelming situation for the patient, their caregivers and families<sup>4</sup>.

As dementia progresses and it develops into an advanced stage, cognitive impairment, physical dependence and other symptoms presented by the elderly, as well as their health needs, are similar regardless the type of dementia presented<sup>6</sup>.

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The advanced stage of dementia, according to the Clinical Dementia Rating (CDR), is characterized by severe memory loss, absent of spatio-temporal orientation, disability in decision making and problem solving and inability to participate in social events outside home; the individual with Advanced Dementia needs help in all activities of daily life and in his personal care; and is often incontinent<sup>7</sup>.

Dementia is associated with complex needs<sup>8,9</sup> which include identification, diagnosis and symptom management as well as long-term support. These often challenge the skills and capacity of the health services<sup>2</sup>. The development of institutionalization units related to the long-term care of the elderly provided permanent and appropriate services to this population<sup>10,11,12</sup>. “Institutional care” stands for institutions and living arrangements where care and accommodation are provided jointly to a group of people residing in the same premises<sup>12</sup>.

In developed countries, institutionalization is a relevant typology of care for people with moderate to advanced dementia and is considered to be an appropriate strategy in meeting the needs and care provision of this population<sup>5,13</sup>. In fact, recent studies suggest that around 80% of the



institutionalized elderly have a diagnosis of dementia or significant memory problems<sup>14</sup>.

Providing care to these residents requires knowledge and skills specific to their medical, physical, cognitive and supportive domains<sup>15</sup>. Institutionalized older people with Advanced Dementia have specific care needs, particularly related to palliative care<sup>16-18</sup>. This raises challenges for medical, nursing and other practitioners in terms of dealing with physical and psychological symptoms, spiritual and social needs and other aspects of palliative care<sup>19</sup>.

## Need

Health care is based on the identification of individual and collective needs that require some type of intervention<sup>20</sup> to achieve the nearest possible state of health as it is defined by the World Health Organization since 1946: “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”<sup>21</sup>. This is evidenced by Culyer, stating that medical care is commonly cited as a service to be distributed according to “need”<sup>22</sup>.

Needs represent an imbalance, gap or lack of adjustment between the present situation and a new or changed set of conditions; they may be viewed as the difference between “what is” and “what ought to be”<sup>20</sup>. Green & Kreuter consider that need is everything that is involved in obtaining health and comfort<sup>23</sup>; and it may be defined as the gap between a current and a desired state of being<sup>24</sup>. Doyal & Cough claim that health needs are universal and even a basic human right<sup>25</sup> and to Culyer, need is a prospective concept because it identifies and enhances the interventions that can be done to improve the health status of an individual or population<sup>22</sup>.

Currently, a large number of health professionals use the needs assessment as the starting point of their professional activity<sup>26</sup>. According to Leagans, people’s needs are identified by finding the actual, the possible, and the valuable through situation’s analysis<sup>20</sup>.

The concept of need includes some disturbance in the state of health and well-being of an individual and need is defined by phenomena that require health care<sup>27</sup>. In their study, Lawrence and collaborators state that “there is a need to ‘dementia proof’ end-of-life care for people with dementia. If end-of-life care does not take into account the unique circumstances and needs of people with dementia, it is likely to fail them”<sup>28</sup>.

## Methods

Frequently, the older person with Advanced Dementia has lost the ability to communicate his needs. This reflects a main problem to the health care team: they don’t know the desires, tastes, wills and needs of the recipient of care. If a professional caregiver is not aware of the specific needs in Palliative Care of an older person who is unable to express them, how can he/she implement adequate interventions to that person? It is in this context that was developed the research question of the present study: What are the Palliative Care needs of the institutionalized people with advanced dementia?

In this sense, this investigation aims to identify the needs in Palliative Care associated with institutionalized people with Advanced Dementia.

This article refers to the first stage of an investigation that pretends to identify and describe the needs in Palliative Care of institutionalized people with Advanced Dementia. This first stage refers to a qualitative exploratory study consisted of two phases: a literature review of the phenomena associated with palliative care, advanced dementia and institutional care (phase 1) and the organization, discussion and evaluation of this information through an expert’s focus group (phase 2). The present study obtained informed

consent of the Ethical Committee of Fundación Matia.

## Data collection

A detailed literature review was conducted on Palliative Care, Long-term Care, Institutionalization and Advanced Dementia. It had the purpose of finding all the phenomena related to these topics, including signs, symptoms, diagnosis, treatments, interventions, health care, health objectives and needs. This research involved the use of databases, namely Medline, Elsevier and SciELO. The search was performed using the following keywords (mesh terms): needs, palliative care, dementia and long term care and their translation in Spanish and Portuguese. A resume of the literature review conducted and the included/excluded studies can be found in figure 1.

Additional searches were made through PsycINFO, Google Scholar and health libraries in Oporto (Medical School of the University of Porto) and in San Sebastián (Gipuzkoa Nursing Association). As a result it was obtained a set of phenomena related to the topics mentioned above.

According to the characteristics of each phenomenon found, it was made an initial categorization which included them in one of the dimensions that constitute the human person, in particular the institutionalized older person with Advanced Dementia: physical, psychological, social, spiritual, economic, legal and environmental. This initial list was then evaluated and criticised by Portuguese and Spanish experts in the fields of Geriatrics, Psycho-geriatrics, Neurology, Geriatric Nursing, Psychology, Continuity Care and relatives of institutionalized elderly with Advanced Dementia who work in health care (nurses). All the experts had experience with Palliative Care.

This expert’s revision was conducted in two different focus groups due to the number of experts participating. Due to a geographical impossi-

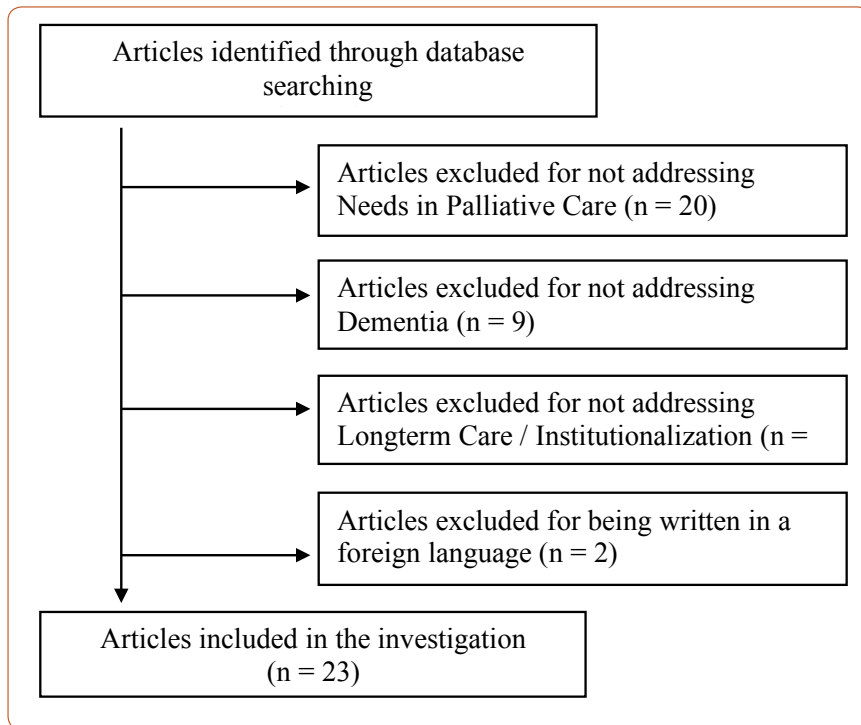


Figure 1. Chart of included and excluded studies

bility to attend and participate in the focus groups, one interview was held and two reports were received by e-mail.

All the analysis, comments and discussions were documented and those who were found to be relevant by the experts were integrated in the list of needs. The objective of the focus groups was not to achieve a high consensus about each need but to include all the relevant items related to needs in Palliative Care.

In the first and second phases of the investigation there were no human subjects involved. The experts who participated in this study were chosen by their professional relation with the Medical School of the University of Porto and Fundación Matia; and they are recognized by their work and experience in the fields described above.

An invitation to participate in the study was sent to all the experts by e-mail. It was explained to them the objective and methodology of the study; they had the opportunity to question the different aspects of the investigation and they could abandon it in any moment. The experts who participated in the investigation have all accepted to do it voluntarily. More information on focus groups and participants can be found in table 1.

## Results

Through the literature review, focus groups, interview and reports were identified several needs which were categorized into seven different dimensions: physical, psychological, social, spiritual, economic, legal and environmental. In both focus groups it was decided to put the different needs in alphabetical order in each dimension as a strategy to avoid any kind of judgment about its importance or relation. These needs in Palliative Care are described in table 2.

The physical dimension is characterized by multiple phenomena and in order to facilitate the organization of information it has been carried out a sub-categorization of this dimension in the different body systems. In Fo-

cus Group 1 was suggested the integration of hiccups and hiperacusis (by geriatrician, MD and psycho-geriatrician, MD) as physical needs, although it has not been found in the literature references to these phenomena. The inclusion of these phenomena was consensual in both focus groups.

Also in the physical dimension was included the domain of Vital Signs as the basis of the initial individual's physical assessment. In geriatric institutions is a common procedure the evaluation of oxygen saturation and blood glucose so these were included as other parameters. The domain of the General Aspects is characterized by phenomena that are often present at the end of life period and which are common to a large number of advanced and terminal pathologies.

In the Psychological Dimension (also differentiated into domains) were included the Basic needs defined by Tom Kitwood<sup>29</sup> that are considered as one of the central aspects in the care of people with dementia. The assessment of cognitive function, a complex task in this population, is facilitated by the identification of three aspects: Comprehension of simple sentences, Cooperation in care and Expression of a message (verbal or non-verbal). Although these aspects are also relevant in the social dimension and communication, it was consensual in both focus groups that they are crucial to the understanding of the cognitive function.

Under the Social Dimension (differentiated into domains), the family member (RN) with whom it was held the interview discussed the capability of a person with Advanced Dementia in establishing a relation with another person: "my mother almost doesn't recognize me, how can she relate with someone new and strange?". Through this testimony, in Focus Group 2 was decided to include the term "interaction" in the domain Social Contact. It may be

## FOCUS GROUPS, INTERVIEWS AND RECEIVED REPORTS CHARACTERISTICS 1

		FG 1	I	R	FG 2	Total
Field of Expertise	Geriatrics	1			1	2
	Psycho-geriatrics	1				1
	Neurology	1		1		2
	Geriatric Nursing	2			2	4
	Psychology	1			1	2
	Continuity Care			1		1
	Family relatives		1		1	2
Sex	Male	2		1	1	4
	Female	4	1	1	4	10
Nationality	Portuguese	2		2	2	6
	Spanish	4	1		3	8

FG: focus group; I: interview; R: report.

suitable in more advanced cases of dementia (for example, stage 7 of the Global Deterioration Scale<sup>30</sup>). This discussion raised some discomfort for the experts, and one of Geriatric Nurses (RN) affirmed: “if we consider that an older person is not able to relate with another person, we will be closer to consider her less as a person and aren’t we diminishing her dignity? Shouldn’t we have a positive attitude and enhance the relationship even if it’s difficult to get a feedback?”.

The Legal Incapacity of an individual with Advanced Dementia is seen as relevant by health professionals since it identifies a legal guardian and the person who will be a member of the interdisciplinary healthcare team. However, this is not shared by the family member (RN) present in Focus Group 2 who suggested that the legal incapacitation is a secondary process and a formality: “Me and my sister take the decisions in relation to my mother together. It is true that in situations of family conflict or absence of family or caregivers it would be necessary to identify a guardian but in most cases it is simply a legal process and a source of stress for the family”.

One of the experts in Continuity Care (RN, MSc, PhD) who sent a report questioned the health objectives of identifying the different needs: “In the different dimensions, domains and systems what is intended? Risk assessment? Monitoring? Prevention? Treatment?” This question was raised in Focus Group 2 and it was consensual that in this phase of the research the objective is to identify the main and general needs in Palliative Care; the determination of an objective would only be appropriate in individuals and specific situations.

Upon completion of the focus groups was consensual that it was achieved a good articulation between dimensions, domains and systems and that these allow a global and comprehensive understanding of the needs in Palliative Care of the institutionalized older person with Advanced Dementia.

### Discussion

It is often described in the literature that older people with Advanced Dementia have multiple and complex health needs<sup>2,9,31</sup>. However, it is not common their description and the present study aims to address this subject by identifying and describing the needs in Palliative Care of this population in the context of Institutionalization and Long Term Care.

The categorization of needs according to the several dimensions that constitute the human person allows a good comprehension of these needs<sup>32</sup> and the way in which they influence the living of the person with Advanced Dementia. It is widely recognized that the provision of Palliative Care

includes the physical, psychological, social and spiritual dimensions. In the World Health Organization’s definition, Palliative Care includes the “assessment and treatment of pain and other physical, psychosocial and spiritual problems”<sup>33</sup>.

Several of the described physical needs are often present in the same individual and may constitute a set of morbidities for the older person, a very common situation in Advanced Dementia. Although some of these aspects are not specific to this disease, they are often presented by the population under study.

The psychological dimension is composed with very particular needs of Advanced Dementia: the cognitive deficits and behavioral disorders are intrinsically linked to this disease<sup>34</sup>; they have a great affectation in health care and are one of the main factors leading to institutionalization<sup>14</sup>. The diagnosis and management of these disorders with pharmacological and non-pharmacological interventions requires training and expertise from the interdisciplinary team.

The Person Centred Care Theory developed by Kitwood identifies as common basic needs for people with dementia: Attachment, Comfort, Identity, Inclusion and Occupation<sup>29</sup>. These phenomena can be considered as needs, goals in health care and allow a result’s evaluation. This model combines the social dimension (is based on the relationship with other people and on the realization of significant activities), the spiritual dimension (by enhancing the identification with the person itself and by performing activities according to their life history, preferences and culture) and the environmental dimension (to adapt the physical structure into a cosy and familiar atmosphere and by enhancing a close relationship with the health professionals) that also facilitate the intervention in physical and psychological needs.

Reflecting on the discussion related to the person’s with Advan-

## NEEDS IN PALLIATIVE CARE OF THE INSTITUTIONALIZED PERSON WITH ADVANCED DEMENTIA

2

	<b>Domain</b>	<b>Needs</b>	
Physical Dimension	Vital Signs and additional signs	Blood Pressure. Body Temperature. Heart Rate. Respiratory Rate. Glycemia. Oxygen Saturation.	
	General Aspects	Anorexia. Bleeding. Cachexia. Edema. Infectious Process. Inflammation. Odor. Pain.	
	Digestive System	Bowel incontinence. Constipation. Diarrhea. Dysphagia. Fecaloma. Hiccups. Nausea/Vomit. Sialorrhea. Xerostomia.	
	Integumentary System	Dry/flaky skin. Ecchymosis/Hematoma. Hyperhidrosis. Moisture lesion. Pallor. Pressure ulcer. Pruritus. Wound.	
	Nervous System	Daytime sleepiness. Delirium/Acute Confusional State. Dizziness. Hallucination. Paresis. Seizure. Sleep disturbances (Insomnia). Syncope.	
	Respiratory System	Airway obstruction/Choking. Aspiration. Cough. Cyanosis. Dyspnea. Sputum/Secretions.	
	Skeletal / Muscular System	Immobility. Joint stiffness. Sarcopenia.	
	Sensory System	Decreased visual acuity. Hyperacusis. Hypoacusis.	
	Urinary System	Oliguria. Urinary Incontinence. Urinary Retention.	
	Nutrition	Assessment of Body Mass Index, albumin and hematocrit. Decreased food intake. Dehydration. Hydration. Negativity to feeding. Weight loss.	
	Psychological Dimension	Basics	Attachment. Comfort. Identity. Inclusion. Occupation.
		Cognitive	Comprehension of simple sentences. Cooperation in care. Expression of a message (verbal or non-verbal).
		Behavioral	Aggression (physical or verbal). Agitation. Anxiety/Nervousness. Calm. Demanding/Calling attention behavior. Interaction with objects. Irritability. Isolation. Negativity to care. Passive involvement. Repetitive behavior. Restlessness. Sadness/Cry. Self-care. Self-injury.
Emotional		Anger/Rage. Body Language (tense/relaxed posture, repetitive movements, balancing, protect a body part, abnormal posture...). Emission of sounds (moans, cries...). Emotional lability. Facial expression (smiling, closed, tense...). Fear.	
Personal Integrity		Appearance and physical aspect. Inability to ask for help. Security. Support.	
Social Dimension	Communication	Empathy. Information/Orientation. Non-verbal communication (posture, gestures / physical movements, tone of voice, expression...). Physical contact. Time spent in the communication. Visual Contact.	
	Social Contact	Family conflicts. Recognition of faces/people. Relationship with family, friends and informal carers. Visits from family, friends and informal carers. Interaction with other users. Relationship with other users. Interactions with healthcare professionals. Relationship with health professionals.	
	Social Isolation	Knowledge of the reason for the institutionalization. Loss of previous relationships. Separation from close cohabitants.	
	Culture	Knowledge of daily habits. Knowledge of the history of life (experiences and memories). Traditions and cultural preferences.	
	Vocational	Interests. Leisure activities.	
Spiritual Dimension	Beliefs		
	Religion	Rituals associated. Visit from the priest or representative of a religion.	
Economical Dimension	Economic Support.		
	Social Support.		
Juridical Dimension	Legal Incapacitation (identification of the legal guardian).		
	Living Will/Declaration of Wills.		
Environmental / Structural Dimension	Adequate environment.		
	Adequate human resources (interdisciplinary team).		
	Adequate physical structure (light, sound, technical equipment and materials).		

ced Dementia capability to maintain a relationship (social dimension) and adding to consideration that an interpersonal relation can be associated to an affective bond between two people<sup>35</sup>, it can be affirmed that people with an Advanced Dementia are in fact able to relate with another person. In fact the interpersonal relationships should be enhanced, avoiding the social isolation that occurs with some frequency in dementia patients<sup>36</sup>. As already mentioned Kitwood uses the term Attachment which may be understood as another term to describe this relationship<sup>29</sup>. In very advanced dementia situations, where there is a severe limitation of integration and emission of messages<sup>30</sup>, the ability to relate may be diminished and the term interaction, developed in this study, appears to be appropriate. However, there was consensus among the experts that the relationship/interaction and social contact should be enhanced continuously.

In the context of the institutionalized older population, economic and environmental/structural dimensions gain a special emphasis in ensuring the provision of dignified health care and have a great influence on the quality of life experienced by the older person<sup>10,37</sup>. The institutionalization is a form of social support often used in developed countries in cases of Advanced Dementia<sup>5,11,12</sup> due to the physical and cognitive dependence, the occurrence of behavioral disorders and comorbidities and the need for continued care<sup>8,38</sup>.

In the case of people with Advanced Dementia, where there is a cognitive incapacity for the decision-making process<sup>30</sup>, the legal dimension is also relevant. Situations of total or partial legal incapacity and the presence of legal guardians are quite frequent in this population. However, as observed in the present study, this dimension may be considered as less important by the family members, even though there have been recent developments in this area (the development of the living will legislation in Portugal for example).

The need's description in this study did not followed a theoretical model in particular and wasn't used a specific classified language because it wasn't identified a scientific language or theoretical model valid and accepted by all the disciplines who participated in this research.

The presence of a relatively small number of experts is considered a limitation of the present study. Moreover, with the representation of only two nationalities it is possible that other needs could be identified in different contexts. One of the difficulties faced in the need's categorization consists on the interdependent relation between these needs, which is also relevant for its understanding.

In a later stage of this investigation, the needs identified in the present study will be applied to institutionalized older people with Advanced Dementia in order to confirm the data obtained and the needs in Palliative Care with greater relevance.

## Conclusion

Advanced Dementia is associated with complex needs that often challenge the skills and capacity of the workforce and services<sup>2,31</sup>.

According to World Health Organization, the main goals for care in dementia are early diagnosis; an optimal physical and cognitive condition; activities and well-being; the identification and treatment of co-morbidities; and the detection and treatment of behavioral/psychological symptoms<sup>4</sup>. The first step to achieve these objectives is the identification of the needs presented by an individual. This will allow an appropriate diagnosis, planning of care and its execution.

A set of needs presented by a specific individual is always unique according to the characteristics of each person. The findings of this study should

be considerate as a foundation in the process of identification Palliative Care Needs with Advanced Dementia but don't determine them. It's essential an individualized evaluation and an interdisciplinary approach to guarantee that the needs identified and the care planned and received are suitable for each person.

In a posterior phase of the study these findings were transformed into questionnaires and were applied to an institutionalized population with Advanced Dementia in Spain as a way to explore their incidence and significance.

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# NURS ID

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# 19

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#### » Workshops

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#### » International Congress

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# A family intervention for symptom management in children with asthma

## Development and feasibility of a complex intervention

### Summary

Asthma is the most common chronic illness in childhood, manifesting through persistent symptoms such as shortness of breath, tightness in the chest, wheezing and coughing, unpredictable and irregular symptomatic episodes (Global Initiative for Asthma, 2015<sup>1</sup>), being one of the main causes of school absenteeism and hospitalization (Observatório Nacional das Doenças Respiratórias, 2015<sup>2</sup>; Direção-Geral da Saúde, 2014<sup>3</sup>). It is considered as a complex disease, because it can depend of several factors and has impact on several functional domains, including physical, psychological, social and family (Iley, 2007<sup>4</sup>). The impact of asthma has repercussions not only on children and parents, but also on families, due to it being an episodic disease requiring that the family consistently adjust to the requirements and consequences of this condition (Santer, Ring, Yardley, Geraghty & Wyke, 2014<sup>5</sup>), making it relevant to know the profile of symptom management, comprehending the needs and possibilities of intervention.

This article focuses on the design of a complex intervention aimed at children with asthma and parents, methodologically orientated in Complex Interventions in Health, multi-study and multi-method planning based on the guidelines of the Medical Research Council (Craig et al., 2008<sup>6</sup>) and the Criteria for Reporting the Development and Evaluation of Complex Interventions in health care (CReDECI 2) (Möhler, Köpke & Meyer, 2015<sup>7</sup>).

KEYWORDS: ASTHMA; CHILD; NURSING CARE; NON-RANDOMIZED CONTROLLED TRIALS; CLINICAL TRIALS; HEALTH LITERACY; SYMPTOM ASSESSMENT; CAREGIVERS.

### Introduction

Asthma is a chronic and inflammatory disease of the airways characterized by episodes of reversible bronchial obstruction and can be triggered by several factors (Global Initiative for Asthma (GINA), 2015<sup>1</sup>). It is the most common chronic illness in childhood (Observatório Nacional das Doenças Respiratórias (ONDR), 2015<sup>2</sup>) and therefore a public health problem (Direção-Geral da Saúde (DGS), 2014<sup>3</sup>, GINA, 2016<sup>8</sup>). It is associated with high morbidity, being responsible for the use of unscheduled care and constituting the main cause of hospitalization in children in Portugal (Sais et al., 2013<sup>9</sup>).

The complexity of this disease, which correlates with environmental, physiological and psychosocial factors, implies constant changes and adaptation needs of the child and family in all their functional domains (Schulte, Mu-

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sof, Meurer, Cohn & Kelly, 2004<sup>10</sup>). The high incidence and prevalence of asthma in children, associated with its chronic nature, leads to a significant impact on the delivery of health care (DGS, 2013<sup>11</sup>). It is therefore relevant to know the practices of symptom management and disease control adopted to understand the needs and intervention possibilities.

Nursing as a complex discipline with caring dynamics (Davidson, Ray & Turkel, 2011<sup>12</sup>) focuses on the individual as a challenge to care for the need for complex interventions and in various care settings (Richards, 2015<sup>13</sup>). It is in this context that the present article of research project is developed that has the ultimate purpose of integrating asthma as an aspect of the life of the child and parents, enabling them to manage the symptoms and consequently the disease, making them autonomous.

Based on the scientific evidence that supports the benefits of Respiratory Rehabilitation in children with asthma, by increasing their knowled-



ge and symptom management capacities, it is congruent to propose the design of a complex nursing intervention to parents and children, with an educational and intervention component specialized in Rehabilitation, thus contributing to person-centered management (Milani & Lavie, 2015<sup>14</sup>) and also reducing associated costs (Jain *et al.*, 2014<sup>15</sup>). For the development of the complex intervention were designed three research studies and in order to evaluate the feasibility of the complex intervention was planned one research study.

## Background

The needs felt by children with asthma have not been systematically studied from their point of view (Mcnelis, Musick, Austin, Larson & Dunn, 2007<sup>16</sup>) significantly increasing the negative impact of the disease on their quality of life (Goldbeck, Koffmane, Lecheler, Thiessen & Fergert, 2007<sup>17</sup>). Children with asthma experience feelings of anxiety, disillusionment due to limitations in activities, social isolation and obstacles to adjustment and maintain social relationships, and this impact is predisposed by the high expressed need for knowledge and support (Mcnelis, Musick, Austin, Larson & Dunn, 2007<sup>16</sup>).

The management of asthma is a cornerstone of the therapy of the disease, and this role is played by the parents when we focus on children's asthma, however, the child needs to feel responsible as the child grows. Management takes place on an experimental and developmental continuum for both parties, configuring itself as a challenge to person-centered care (Stewart, Masuda, Letourneau, Anderson & McGhan, 2011<sup>18</sup>).

Parents recognize that learning the skills for disease management is often of the experimental type, that is, trial and error, giving visibility to the lack of information for decision-making, training and skills to care for (Archibald, Caine, Ali, Hartling & Scott, 2015<sup>19</sup>). Due to the constant challenges of the need for disease management, parents express frustration and feelings of inadequacy and anxiety, also revealing insecurity regarding treatment options (Jonsson, Egmar, Hallner & Kull, 2014<sup>20</sup>). Changing family roles and dynamics, with the necessary interruptions to their routine due to the demands of the children's illness, this is a negative aspect of the parents involvement (Wales, Nadew & Crisp, 2007<sup>21</sup>).

## Nursing as guideline for interpretation of the phenomenon

"Nursing is also a complex intervention" (Richards & Borglin, 2011, p. 531<sup>22</sup>), which focuses attention is the person in the care perspective (Fawcett, 2015<sup>23</sup>) as a complex phenomenon (Davidson, Ray & Turkel, 2011<sup>12</sup>) and which contains a series of components with potential interactions between them that when applied to a person produce a succession of possible variables and results (Craig *et al.*, 2008<sup>6</sup>). This nursing perspective brings with it the "need for a new research model that can deal with complexity", in a unifying model that encompasses complex care dynamics, in a holistic, complex, dynamic approach with a focus on complex phenomenon (Davidson, Ray & Turkel, 2011, p. 41<sup>12</sup>).

In the line of thought of the phenomenon under study, which has as a basis the experience of asthma by the child and parents, more specifically the symptom management interventions and the results obtained, we chose a middle range theory, Symptom Management Theory (SMT) to respond more objectively than intended, however, from a conceptual, ontological and epistemological point of view, Orem's guidelines are fundamental pillars of guiding theoretical thinking. The SMT assumes itself as a deductive symptom management model focused on three interactive dimensions: the symptom experience, the symptom management strategies and the results

obtained, as can be seen in figure 1 (The University of California, 1994<sup>24</sup>).

According to the SMT a symptom is defined as a subjective experience that reflects changes in the biophysical-social functioning, sensations or cognition of an individual, with the presence of indicators of change in the person's life (Humphreys *et al.*, 2014<sup>25</sup>; Dodd *et al.*, 2001<sup>26</sup>, The University of California, 1994<sup>24</sup>). Recognized as a multidimensional process, this theory requires the integration of all elements to be effective.

Asthma control, as a result of the implementation of symptom management strategies, is determined in part by parental health literacy, as evidenced by the literature, where we conclude that low parental health literacy can put at risk the acquisition of health knowledge, access to care and adherence to the proposed therapeutic regimen (Wood, Price, Dake, Telljohann & Khuder, 2010<sup>27</sup>). Considering the preponderance of health literacy in the symptom management, we chose as the theoretical reference for this project the Integrated Model of Health Literacy developed by Sorensen *et al.* (2012<sup>28</sup>). This model focuses the main dimensions of literacy, formed from social and environmental determinants that can be characterized in context and personal determinants, as well as the factors that have an impact on it.

## Characterization of asthma in children

Childhood asthma is a chronic inflammatory disease of the airways, manifested by hyperactivity of the trachea and bronchi in response to various stimuli, resulting in airflow obstruction, reversible spontaneously or as a result of the implementation of strategies (GINA, 2015<sup>1</sup>). The ethology of asthma, the causes are not fully understood, according to World Health Organization (WHO) (2013<sup>29</sup>) risk factors are related to genetic predisposition and environmental exposure to in-

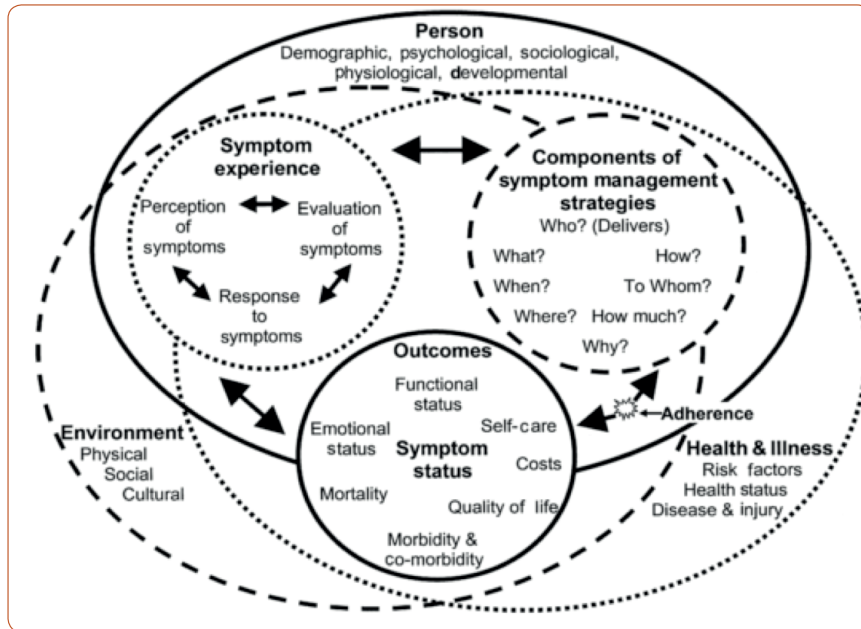


Figure 1. Symptom Management Theory (Reference: Dodd *et al.*, 2001<sup>29</sup>).

haled substances or particles that cause allergic or irritative reactions in the airways, environmental factors such as cold, or emotional factors such as anxiety.

WHO (2013<sup>29</sup>) data show that in the world context, asthma is the most common non-infectious disease in children, with high costs due to being under-diagnosed and under-treated, considered as a public health problem and having repercussions on quality of life. The Portuguese reality reflects the world trend, occupying the tenth place of the most prevalent chronic diseases in Portugal, affecting 5% of the population (4.1% male and 5.9% female) (Instituto Nacional de Estatística & Instituto Nacional de Saúde Doutor Ricardo Jorge, 2015<sup>30</sup>).

The quality of care in asthma involves initial diagnosis and treatment to control the disease and its exacerbation, as well as long-term treatment aimed at providing regular follow-up care to maintain its control (GINA, 2015<sup>1</sup>). In this line of thinking, GINA (2015<sup>1</sup>) states that the effective symptom management of asthma requires the development of a partnership between the person / child / parents / caregiver and the health professional, in order to promote greater knowledge about the disease, responsibility, confidence and abilities to assume an important role in the management of the disease, being “a very important therapeutic practice for asthmatics” (Cano-De La Cuerda, Useros-Olmo & Muñoz-Hellín, 2010, p. 601<sup>31</sup>). Respiratory Rehabilitation is considered a component that promotes the symptom management and is indicated for the moments between crises (Cano-De La Cuerda, Useros-Olmo & Muñoz-Hellín, 2010<sup>31</sup>). This can be defined as a set of “rehabilitation programs for users with chronic respiratory diseases and constitutes as a means of improving standard therapy in order to control and alleviate symptoms and optimize functional capacity” (Ries *et al.*, 2007, p. 6<sup>32</sup>).

## Methods

As a starting point we have the following research question: What is the feasibility of a Respiratory Rehabilitation Program in the symptom management in children with asthma?

## Purpose of the study

As main purposes, we can point out:

- To propose the design of a Rehabilitation complex intervention, which focuses in children with asthma and their parents, namely in the area of Respiratory Rehabilitation in the field of Primary Health Care.

- Contribute to the development of the knowledge of the Nursing discipline, in the area of the Rehabilitation Nursing intervention, more specifically in Respiratory Rehabilitation.

## Research methods

For the defined purposes, four studies were planned, which are explained below.

## Systematic review

According guidelines of the Medical Research Council (Craig *et al.*, 2008<sup>6</sup>), the first phase consists in development of a complex intervention. For its implementation we opted for a Systematic Review, which, according to Campbell *et al.* (2007, p. 457<sup>33</sup>) offers the context of “exploring opportunities and barriers to change” and the capacity for improvement that the intervention can achieve.

This aims to: identify the effective interventions of Respiratory Rehabilitation that have been applied and tested to promote the management of asthma symptoms in the child.

In order to respond to the stated purpose, the following question was elaborated, which meets the criteria of the PICO (Population; Intervention; Comparison and Outcome) format: What is the effectiveness of respiratory rehabilitation interventions in the symptom management of asthma in children?

## Parental literacy in health, knowledge of disease and perception of symptoms

This study constitutes the descriptive element that intends to characterize the sample of the main study of this Project and to explore the relations

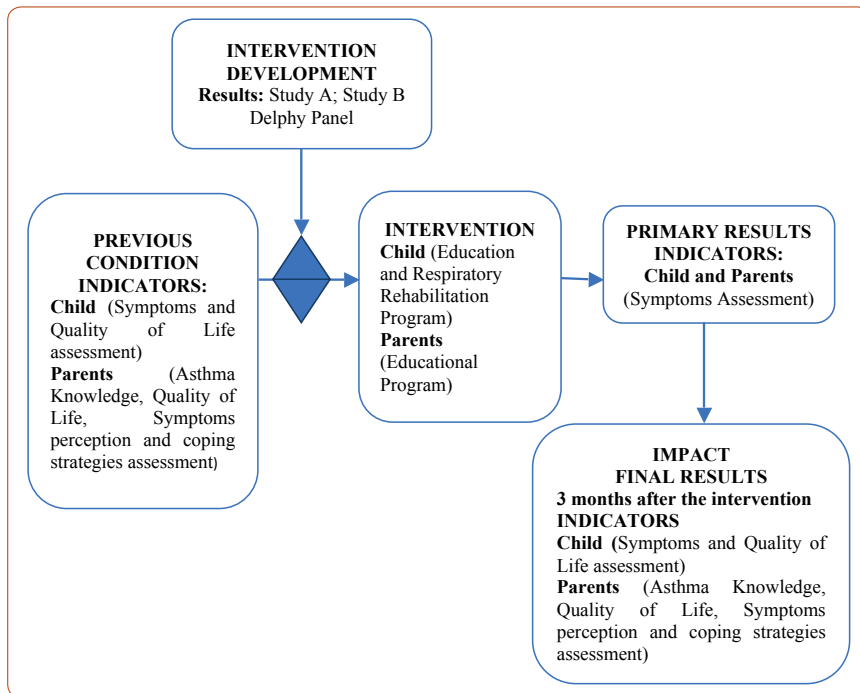


Figure 2. Complex Intervention feasibility study design

between variables. In this sense, it is a quantitative, exploratory and transversal study whose objectives are:

- Identify level of health literacy in parents, knowledge about children's asthma, and parental perception of the severity of symptoms.
- To evaluate the degree of parental perception about the severity of the children's symptoms and their relationship with the degree of severity diagnosed.
- To analyse the relationship between the sociodemographic characteristics and the disease with the knowledge about the disease, the level of parental literacy in health and the perception about the severity of symptoms.

### Complex intervention feasibility study

Due to the second phase of the methodological framework of the Complex Interventions in health, namely the evaluation study of the feasibility of the intervention, modelled in the two previous studies, we present this study, which consists in testing the intervention designed for children with asthma and parents, in the sense of acquisition of abilities and competences of symptom management and adaptation to the disease, in a perspective of Respiratory Rehabilitation intervention in the child and educational intervention to both the child and the parents, with the purpose of becoming autonomous, capacity for self-care and informed decision making, in a framework of the provision of care at primary health care.

Regarding the methodology, this study can be considered as mixed, since it contemplates a qualitative and quantitative approach, in a quasi-experimental design and with a non-randomized sample, which meets the methodological profile of the feasibility studies defined by Taylor et al. (2015<sup>34</sup>). This study has a longitudinal character, since it presents information collection, through the application of scales, and educational and rehabilitation intervention, over time, with evaluations at determined times, as we can see in figure 2.

With the accomplishment of this study we intend, more specifically, as objectives:

- To develop an intervention with educational component and respiratory rehabilitation for the child with asthma and parents.
- Evaluate the viability of the modelled intervention.

In order to achieve this component, we propose the development of the study based on the Theory of Change applied to the development structure of complex health interventions, increased by Silva & Lee (2014<sup>35</sup>). For these authors the use of this theory allows an approach a better understanding of how, why and to what extent the changes happen as a result of the implementation of an intervention (Silva & Lee, 2014<sup>35</sup>).

### Results

As this article refers to a Research Project, no results will be presented.

### Discussion

Asthma is the most common chronic illness in children, being symptom management and disease control dependent of family factors, such as management behaviours adopted and knowledge about the disease. The characteristics of asthma, especially the variability of symptoms and the existence of multiple triggering factors, require symptom management, informed decision making and successive adaptations and changes by the child and family. Based on this problem, the focus of attention of this Project appears.

### Conclusion

Nursing as a constantly developing human discipline and has in research its main mechanism for developing, testing and evaluating interventions (Richards & Borglin, 2011<sup>22</sup>). In this context, and considering Nursing as a complex science centered on the person, the methodological orientation of this Project focuses on Complex Interventions in health, with the option of designing empirical

research in multi-studies and multi-methods. This study project, which focuses on the child with asthma and their parents, may have the potential to develop knowledge in the Nursing discipline and consequently the improvement of the care provided to the person and their training in the symptoms management.

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# Communication problems between nurses and patient's family

## Summary

Communication between the nurse and the patient's family is a significant aspect of nursing practice. This paper presents the results of a research aimed to characterize problematic situations that occur in the relations involving nurses and patients' relatives: i) the type and frequency with which nurses deal with problematic situations involving the patient's relatives in the context of their professional activity; ii) the level of difficulty in dealing with these situations; and iii) the psychological exhaustion they cause.

The research focused on nurses of two clinical services of a public hospital: an Intensive Care Unit and an Emergency Department. The methodological approach to this study is quantitative and has a descriptive and correlational nature. A questionnaire was elaborated for the collection of data, contemplating questions related to the objective of the research. From a total of 99 nurses of the two clinical services, 50 were interviewed.

The results show that there are statistically significant differences between the two services regarding the frequency with which nurses are threatened and intimidated, being more frequent in the emergency department. The insistent demand for information on the part of the family members constitutes the situation with greater occurrence and, simultaneously, the situation that causes greater impact on nurses. The lack of preparation stands out for the way it correlates with the weariness of nurses caused by requests of confidential information by the family on the patient's health status ( $r_s = -0,473; p < 0,05$ ) and the insistent search for information on the part of the relatives ( $r_s = -0,416; p < 0,05$ ).

KEYWORDS: NURSING, COMMUNICATION, DISTRESS, CONFLICT.

## Introduction

Communication between the nurse and the patient's family is a significant aspect of nursing practice. This paper presents the results of a research aimed to characterize problematic situations that occur in the relations involving nurses and patients' relatives. It is characterized the type and frequency with which nurses deal with problematic situations involving the relatives of the patient in the context of their professional activity, the level of difficulty in dealing with these situations and the psychological overload they cause.

Nurses face several problematic situations on a daily basis that can be potentially stressful, from an ethical, moral, emotional and physical perspective. The relations established between the nursing staff and patients' relatives is not always peaceful, constituting a problem to both parties.

Interaction between the patient's family members and the health profes-

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sional can assume different forms in different contexts. These experiences can be pleasant but also problematic, involving verbal violence, psychological violence or even physical violence, both inside and outside the hospital. Nurses often suffer from verbal and physical aggression both inside and outside the institution where they perform functions, and who end up accepting them as if they did part of their day to day professional life<sup>1</sup>. However, according to the same author this is a concern that has been growing and generating interest at a generalized level.

Dealing with illness and pain of close relatives is not always a rational feeling and can be translated in many ways. This affects relations of the family with the patient and with health care professional. The health professional has the moral dilemma of knowing how to deal with the patient's relatives although they do not always understand exactly the gravity of the situation, or refuses to admit the real situation. Moral distress is considered an anguish that can affect interpersonal relationships in the workplace, jeopardizing its performance, since it causes internal conflicts<sup>2</sup>. As mentioned by Serra<sup>3</sup> situations that cause stress are related to problems and uncomfortable issues that are very frequent in daily activities of nurses which provide continuous care delivery. Thus, these internal and external conflicts will place the nursing professional in a difficult situation, or in suffering that can potentially cause damage, undermining their motivation which will contribute to low productivity and putting at risk the quality of care provided. In some cases, when family members' requests are not met, nur-

ses are threaten or even victims of verbal and physical aggression. There is a lack of preparation within nursing training for conflict management, which is a major flaw, as mentioned in previous researches<sup>4</sup> the phenomenon of violence at work related to health professionals has been the subject of several studies at international level, in order to characterize acts of violence. However the strengthening of internal security in health organizations and preparation of health professionals are still necessary.

Nurses in their daily activities face decision-making with moral implications, which can provoke tensions and conflicts with the patient's family<sup>5</sup>. This makes it difficult for professionals to withstand these situations and can compromise the efficiency and quality of the health care. As noted by the authors, moral stress is a recognized phenomenon that affects nurses in the different areas of practice during their care practice, and that can provoke conflicts with other health professionals.

Taking into account the previously mentioned about the importance of the relationship between the nurses and the patients' relatives, we stated the following research questions: i) what type, and frequency, of problematic situations do nurses face in their relationship with patients' relatives?; ii) What is the level of difficulty and psychological distress that nurses feel when facing problematic situation?

The purpose of this study was to characterize the typical conflict situation involving nurses and patients' relatives and to determine how it affects nurses. Therefore, the research can provide an effective contribution to conflict prevention in healthcare organizations as well as the quality and outcome of nursing care.

## Methods

The research focused on nurses of two clinical services of a public hospital: an Intensive Care Unit and an Emergency Department. The methodological approach to this study is quantitative and has a descriptive and correlational nature. A questionnaire was elaborated for the collection of data, contemplating questions related to the objective of the research. From a total of 99 nurses of the two clinical services, 50 were interviewed.

## Results

The sample is predominantly composed by female nurses, representing 70% of the total, as it can be verified on table 1. With respect to the age of the respondents, 45.2% are between the middle age of 30-39, followed by the age group 50-59 (21.4%). Regarding the years of professional experience, 40.8% of respondents performed less than 10 years, the range between 10 and 19 years of professional practice represents 28.6% of the sample, followed by the 20- 9 years of experience. As regards to the health service unit 52.0% of the respondents work in the Emergency Department and 48.0% in the Intensive Care Unit. It is also possible to verify that none of the nurses felt 'very well prepared' to deal with problematic situations and consider 'very appropriate' the training received to face those situations (table 1)

The data presented in table 2 refers to the frequency with which nurses deal with potentially problematic situations in the context of their professional activity. The frequency was measured through a Likert scale of five points, so the values presented on the table range from 1 (corresponding to a lower frequency) to 5 (corresponding to the highest frequency level).

The statistical analysis of the data collected in the survey demonstrated that the insistent demand for information is the more frequent problematic situation ( $M = 3.94$ ) and the situation that causes greater psychological overload ( $M = 3.04$ ). The lack of preparation stands out for the way it correlates

with the overload of nurses caused by the requests of confidential information by the family on the patient's health status ( $r_s = -0.473$ ;  $p < 0.05$ ) and in the insistent search for information on the part of the relatives ( $r_s = -0.416$ ;  $p < 0.05$ ).

When comparing the responses obtained in the Emergency Department and the Intensive Care Unit, it was verified that only at the level of intimidation and threats were found statistically significant differences between the two health service units in relation to the frequency with which nurses are threatened and intimidated in the services, being more frequent in the emergency department ( $M_{\text{Emergency}} = 2.38$ ,  $M_{\text{ICU}} = 1.50$ ,  $U = 135.00$ ,  $p = 0.000$ ). Regarding the individual characteristics of the respondents, it has been noted a statistically significant correlation between the frequency with which confidential information was requested by the family members about the patient's health status and the years of professional experience ( $r_s = -0.378$ ,  $p < 0.05$ ) and the age of nurses ( $r_s = -0.308$ ,  $p < 0.05$ ).

Table 3 presents the level of reported difficulty felt in dealing with each of the problematic situations. The data presented were measured on the basis of a scale ranging from 1 (corresponding to the lowest degree of difficulty) and 5 (corresponding to the highest possible degree of difficulty). With regard to the degree of difficulty in dealing with problematic situations, no statistically significant differences between men and women were found, nor any association with the age and years of experience of nurses.

From the data shown on table 4 it is observed that the lack of preparation and the inadequacy of training are correlated with the difficulty in dealing with insistent search for information by family members. The persistency of the patient's relatives is sometimes hard to deal that it becomes uncomfortable to nurses the attempts of "invasion" of the profes-

**SAMPLE CHARACTERIZATION**

**1**

	n.	%
<b>Gender</b>		
Male	15	30.0%
Female	35	70.0%
<b>Age group</b>		
<30 years old	7	16.7%
30-39 years old	19	45.2%
40-49 years old	7	16.7%
50-59 years old	9	21.4%
<b>Years of professional experience</b>		
<10 years	20	40.8%
10-19 years	14	28.6%
20-29 years	10	20.4%
30-39 years	5	10.2%
<b>Health service unit</b>		
Intensive Care Unit	24	48.0%
Emergency	26	52.0%
<b>Self-confidence to deal efficiently with the request for information about the patient's situation by their relatives</b>		
Fully secure	4	8.0%
Secure	29	58.0%
Nor secure or unsecure	15	30.0%
Unsecure	2	4.0%
Fully unsecure	0	-
<b>Frequency of feeling stressed in situations information requests about the patient's situation by their relatives</b>		
Never	0	-
Rarely	18	36.0%
Sometimes	27	54.0%
Often	5	10.0%
Always	0	-
<b>Preparedness to deal with such situations</b>		
Very well prepared	0	-
Well prepared	18	36.0%
Reasonably prepared	23	46.0%
Insufficiently prepared	8	16.0%
Not at all prepared	1	2.0%
<b>Level of adequacy of the training received in relation to the requirements of those situations</b>		
Very appropriate	0	-
Appropriate	14	28.0%
Fairly appropriate	16	32.0%
Little appropriate	17	34.0%
Not at all appropriate	3	6.0%

sional space. Results shown on table 5 indicate that ‘insistent demand for information by family members’ (M = 3.04) and ‘intimidations and threats’ (M = 3.00) are the situation that impact the most with psychological distress of nurses. These situations add to other problematic circumstances nurses deal in the everyday routine, like dealing with suffering and death. In some cases the insistent search for information, wanting to know more as if something important were hidden or the complete information was not provided, assumes the form of intimidations.

In table 6 it can be observed several correlations between variables.

From this correlations it is possible to highlight: i) the less ‘security and the preparation to deal with problematic situations’ the more greater psychological distress arises from ‘demand for confidential information’ ( $r_s = 0.473$ ), ‘insistent search for information’ ( $r_s = -0.416$ ) and by ‘requests from family members to exceed the number of visits’ ( $r_s = -0.382$ ); ii) the ‘less prepared nurses are to deal with problematic situations’ the more psychological distress is caused by ‘insistent search for information by family members’ ( $r_s = -0.395$ ) and ‘breakdown of service rules’ ( $r_s = -0.369$ ).

**Discussion**

Results from this study showed that older nurses are the most sought-after by patient’s relatives, possibly because they are usually considered professionals with more experience and maturity transmitting more security in solving problems. Certainly a professional with many years of experience has more knowledge and experience than a young professional and probably knows how to respond to a greater number of situations in a more efficient and effective way. Competence is a multidimensional individual process, which arises through a set of experiences obtained in practice, where it is required a reflection, sometimes daily and retrospectively, of all situations experienced. According to Ordem dos Enfermeiros<sup>6</sup> competency is related to general and specific attributes, being decomposed into knowledge, skills and operations that must be performed and applied in different situations at work.

Regarding the problematic situations in the context nursing health care activity the data collected in the survey demonstrated that the insistent demand for information is the more frequent problematic situation and the situation that causes greater psychological overload. The preparation for situations of confrontation with the anxiety of family members

**LEVEL OF FREQUENCY, IN A MONTH, NURSES DEAL WITH THE PROBLEMATIC SITUATIONS**

**2**

	<b>M. (s.d.)</b>
Requests from family members to exceed the number of visits and the time of visit	3.94 (0.93)
Request of confidential information by the family members about the patient's state of health	3.68 (1.02)
Insistent search for information by family members	3.94 (0.89)
Patients' relatives intimidation and threats	1.96 (0.85)
Breakdown of service rules.	2.70 (1.11)

**LEVEL OF DIFFICULTY IN DEALING WITH PROBLEMATIC SITUATIONS**

**3**

	<b>M. (s.d.)</b>
Requests from family members to exceed the number of visits and the time of visit	2.70 (0.86)
Request of confidential information by the family members about the patient's state of health	2.84 (0.93)
Insistent search for information by family members	2.90 (0.86)
Patients' relatives intimidation and threats	3.48 (0.89)
Breakdown of service rules.	3.00 (0.90)

**CORRELATION OF DIFFICULTY IN DEALING WITH PROBLEMATIC SITUATIONS AND LEVEL OF SELF-CONFIDENCE, LEVEL OF STRESS, PREPARATION AND ADEQUACY OF TRAINING**

**4**

	Level of security in dealing effectively within the situation	Frequency of feeling stressed in situations of information requests about the patient's situation	Preparation to deal with the situations	Adequacy of training received
Requests from family members to exceed the number of visits and the time of visit	-0.157	0.191	-0.173	-0.147
Request of confidential information by the family members about the patient's state of health	-0.110	0.170	-0.192	-0.177
Insistent search for information by family members	0.262	0.213	-0.315*	-0.332*
Patients' relatives intimidation and threats	-0.095	0.082	-0.176	-0.192
Breakdown of service rules	-0.200	0.321*	-0.089	0.025

\*  $p < 0.05$

who are distressed, because the health of their loved one, is precious in that moment. During the graduation course there's a lack of training in that matter, in fact it is over the years of professional experience that nurses acquire personal experience to respond to the needs that arise daily. It is also verified a correlation between 'stress feeling in situations of information requests about the patient's situation' and 'family members requests that entail breaking the institution's rules'.

The results obtained reveal that coercion, like threats, can cause impact over nurses. Health professionals can feel observed and judged, in all the gestures and procedures of the practice. In this situations there's a need of maintain calm and posture, trying not to demonstrate the embarrassment or even the fear that may arise. It is in this context that, on a daily basis, health professional takes decisions involving ethical issues, the suffering of all the parts involved in the care process and the vulnerability of patients and their families. As Oh and Gastmans point out<sup>7</sup>, nurses make ethical decisions every day, even without realizing the consequences they may suffer, do not

control the actions of others, and decide according to their way of thinking and acting in various situations as it is in the case of illness, suffering and even death.

**Conclusion**

How effective interpersonal relationships are established depends on the use of appropriate communication and interpersonal skills. There are, however, different factors related to the configuration of the communicative process that can constitute a disruptive element of the communicational process and bring conse-



LEVEL OF PSYCHOLOGICAL DISTRESS WHEN DEALING WITH PROBLEMATIC SITUATIONS

5

	M. (s.d.)
Requests from family members to exceed the number of visits and the time of visit	2.48 (0.74)
Request of confidential information by the family members about the patient's state of health	2.68 (0.65)
Insistent search for information by family members	3.04 (0.73)
Patients' relatives intimidation and threats	3.00 (0.81)
Breakdown of service rules	2.82 (0.66)

CORRELATION OF THE PSYCHOLOGICAL DISTRESS AND THE LEVEL OF SELF-CONFIDENCE, LEVEL OF STRESS, PREPARATION AND ADEQUACY OF THE TRAINING

6

	Level of security in dealing effectively within the situation	Frequency with which nurses feel stressed within the situations	Preparation to deal with these situations	Adequacy of training received
Requests from family members to exceed the number of visits and the time of visit	-0.215	0.245	-0.382*	-0.234
Request of confidential information by the family members about the patient's state of health	-0.377*	0.212	-0.473*	-0.263
Insistent search for information by family members	-0.293*	0.375*	-0.416*	-0.395*
Patients' relatives intimidation and threats	-0.075	0.303*	-0.207	-0.224
Breakdown of service rules	-0.373*	0.331*	-0.336*	0.369*

quences for professionals. When employment is demanding and agitated it can affect the worker by questioning their well-being, and these feelings will interfere with their professional performance<sup>8</sup>. Therefore, stress in daily work, direct contact with life and death, with illness and pain, with feelings of impotence, giving the appropriate response to the unexpected situation, psychological support for the patient, family and even to colleagues, the nursing professional becomes more susceptible and sensitive to face these scenarios.

Ethical issues in nursing practice have been a growing concern, especially in health organizations. Despite the few studies and research in this area, ethical competence begins to raise issues that need to be answered. In this way there seems to be a greater concern about this topic in nursing practice, suppressing itself a little to the execution of techniques. Many healthcare institutions in Europe are developing services to solve ethical problems, because several studies have shown that health professionals often deal with problematic situations and that institutions are not prepared to support them<sup>9</sup>. As the results of this research reveal, one of the first step in the preparation of health professionals will require them to learn about their own attitudes and emotional responses to communication problems with patient's relatives.

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# Determining factors of communication effectiveness in nursing teams

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## Summary

The quality and effectiveness of nursing care depends on, among other factors, communication processes configuration between health care team members. The objectives of this study were: i) to determine how nurses evaluate the different dimensions of the communicative process; ii) to identify the main obstacles to communication; iii) to gauge how nurses evaluate the adequacy of different communication channels in health services. This was an investigation of quantitative descriptive and correlational. A structured questionnaire was developed to obtain relevant data on the matter. The research was carried out in four health services (Neonatology, Medicine II, Emergency and Basic Emergency) and a total of 75 nurses were surveyed. A comparative analysis between the four services revealed no statistically significant differences in how nurses evaluate the communicative process. This fact indicates that the way in which communication is configured and evaluated is transversal to nursing practice and independent from the context in which it occurs. The research reveals the generally positive way how nurses evaluate the communication process. However, some weaknesses of communication in the clinical context are identified, mainly related to the mode in which information of organizational nature is disseminated within each department.

KEYWORDS: COMMUNICATION; EFFICIENCY; NURSING; TEAM WORK.

## Introduction

Communication is the basis of all human interaction and a fundamental tool within organizations, since it is part of their everyday life and encompasses all forms of interaction<sup>1</sup>. Communication is prior to the establishment of an organization and constitutes a fundamental dimension through which information, ideas or values are shared. Communication in organizations is a process of sense making<sup>2</sup>, that is, a reciprocal interaction of people in the search for information and attribution of meanings, occurring in a context of organizational cultures that links formal and informal relations. In order to understand the concept of organizational communication, it is necessary to analyze flows and communication structures. According to Rego<sup>1</sup>, there are two types of communication within the organizations: i) formal communication, which involves the transference of information through the hierarchy based on the official channels established by the organization, and the ii) informal communication, more of a casual nature, which does not necessarily follow the channels established.

Information has always been present in society, however, nowadays in the era of human capital, it assumes new roles, causing mutations in the

modes of communication, access to knowledge, thinking and work. Its germination, storage and transfer are immediate, profoundly altering the forms of production, possession, ownership and transmission, as well as changing the profile of users and their ways of coexisting, redefining identities and relationships, transforming the way people live, work and interact<sup>3</sup>.

The way information circulate and flow, has become a management tool, constituting a basic instrument for the decision, implementation and control of activities. Considering an organization as a complex system of networks and as a product of the communication process, coordination is fundamental to regular activities that take place. Consequently, all the organizational practices are inherently communicational. Knowing how to communicate properly assumes greater importance in all productive sectors, and health sector is no exception. Although we are facing a highly technological world with so many transformations, the success of health organizations continues to be people-centered. As stated by Gonçalves and Oliveira<sup>4</sup> it is important to prospect organizations as places where is possible to cultivate relationships.

The communication process in nursing is related to the improvement of health outcomes through

information, with the objective of influencing individuals and communities. Nurses, in the context of care delivery, need to have certain interpersonal and communication skills in order to promote the quality and safety of the patient, contributing to the reduction of clinical error through sufficient and effective team communication. Effective communication and individual responsibility should be the basis of any organizational culture so that the end result reflects effective health gains<sup>5</sup>. Information is essential in the area of nursing, since it is the basis of the whole process of care, however, this only has value if the circulation is effective. As Santos concludes<sup>6</sup>, about fifty percent of the information is acquired through team members, rather than being consulted in the patient's clinical process, implying an almost blind relationship of trust, thus being the preferred interaction through dialogue. Establishing a relationship of empathy, trust, knowing how to listen and understanding different perspectives are defined essential skills for these professionals, along with a clear and assertive verbal and written communication. The teaching of these skills is fundamental to enable them to deal with various situations, contributing to the technical excellence and quality of care provided. In the message transaction it must be taken into account that often the message sent is not the message received. People interpret something heard not according to what the sender actually said, but according to its own code<sup>7</sup>. In this way effective communication in the teams is not an automatic activity or natural consequence of individual technical or professional capacity, but a quality to be developed from a collective point of view.

In this context, the research has the following questions: i) How do to nurses evaluate the different dimensions of the communicative process of the service in which they carry out their professional activity?; ii) What are the main obstacles to communication identified by nurses?; iii) How nurses evaluate the adequacy of different communication channel in health services? The purpose of this study is to contribute to the understanding of how communication constitutes an important aspect of work in health organizations. The results allow a better knowledge of the way nurses evaluate the communicative process, thus contributing to its improvement.

## Method

A structured questionnaire was developed to obtain relevant data on the matter. The research was carried out in four health services (Neonatology, Medicine II, Emergency and Basic Emergency) and a total of 75 nurses were surveyed. The inclusion criteria for the sample were to be a nurse and to work on one of the health services considered in the research. The methodological approach to this study is quantitative and has a descriptive and correlational nature. The questionnaire was applied during the month of April 2017. The study complied the ethical principles guiding scientific research. In the data collection process the participants were informed of the research objectives and voluntarily participated in the study. Respect, confidentiality and anonymity of the data were also guaranteed. Data analysis was performed using the SPSS software version 19, with a significance level of  $p < 0.05$  being used for the interpretation of the results.

## Results

The values presented in table 1 show the predominance of female nurses (81.1%) on the total of the sample, the predominant age group was 30-39 (52%) and professionals with less than 10 years of professional experience (45.3%). In relation to the evaluation of the effectiveness of the way information is disseminated in the service, 49.4% of the nurses consider it to be effective, but very close to that value (48%) states that it is not very effective.

The evaluation of the effectiveness of organizational communication made by the enquired nurses are presented on table 2. The values showed on the table range from 1 (corresponding to the lower level of effectiveness) to 5 (corresponding to the highest level of effectiveness possible). It can be observed that, in comparison to the other dimensions, personal information registered higher values in all components (efficacy, sufficiency, timing, explicitness and applicability).

For each of the facets of the communicative process, an index was elaborated, taking into account the internal reliability of the variables that compose it through the value obtained in Cronbach's alpha: Communication efficiency ( $\alpha = 0.82$ ); Information sufficiency ( $\alpha = 0.84$ ); Information timing ( $\alpha = 0.85$ ); Explicitness of the message ( $\alpha = 0.90$ ) and Practical applicability ( $\alpha = 0.087$ ). Likewise, five indexes were created regarding the nature of the information in the communicative process: Information of a clinical nature ( $\alpha = 0.88$ ); Organizational information ( $\alpha = 0.89$ ); Service information ( $\alpha = 0.91$ ); Team information ( $\alpha = 0.92$ ) and Personal information ( $\alpha = 0.93$ ). The different indices have a range of variation between 1, corresponding to the worst possible appraisal and 5, corresponding to the best possible appraisal. Table 3 shows the results obtained.

We sought to determine the existence of statistically significant differences in the way in the four health services included in the research, evaluate the different facets of the communicative process. The results obtained, through the Kruskal-Wallis test, allow to conclude that the differences observed are not statistically significant: communication efficiency ( $\chi^2_{KW(3)} = 3.19$ ;  $p = 0.363$ ); sufficiency of information ( $\chi^2_{KW(3)} = 4.36$ ,  $p = 0.225$ ); timing ( $\chi^2_{KW(3)} = 2.56$ ,  $p = 0.464$ ); clarity ( $\chi^2_{KW(3)} = 3.96$ ,  $p = 0.266$ ) and practical applicability ( $\chi^2_{KW(3)} = 6.61$ ,  $p = 0.086$ ). Regarding

SAMPLE CHARACTERIZATION		
	n.	%
<b>Gender</b>		
Male	14	18.9%
Female	60	81.1%
<b>Age group</b>		
<30 years old	15	20.0%
30-39 years old	39	52.0%
40-49 years old	13	17.3%
50-59 years old	8	10.7%
<b>Years of professional experience</b>		
<10 years	34	45.3%
10-19 years	25	33.3%
20-29 years	12	16.0%
30-39 years	4	5.4%
<b>Service</b>		
Neonatology	16	21.1%
Inpatient care	20	26.3%
Basic Emergency Services	15	19.7%
Emergency Services	25	32.9%
<b>Evaluation of the effectiveness of the way information is disseminated in the service</b>		
Very effective	1	1.3%
Effective	37	49.4%
Slightly effective	36	48.0%
Not effective	1	1.3%

the participants' individual characteristics, gender, age and years of professional experience, no statistically significant relationships were identified between the variables.

Regarding how the communicative process was evaluated in the four different health services according to the nature of the information conveyed, it is the information of organizational nature ( $M = 2.96$ ) that nurses evaluate worse, especially in the timing it reaches them ( $M = 2.76$ ). However, statistically significant differences were not identified in organizational information ( $\chi^2_{KW(3)} = 5.72, p = 0.126$ ); service information ( $\chi^2_{KW(3)} = 5.58, p = 0.134$ ); ( $\chi^2_{KW(3)} = 3.69, p = 0.297$ ) and personal information ( $\chi^2_{KW(3)} = 4.03, p = 0.258$ ). Only at the clinical information level was observed a significant difference ( $\chi^2_{KW(3)} = 7.92, p = 0.048$ ), although not very expressive. At the level of participants' individual characteristics, gender, age and years of professional experience, no statistically significant relationships were identified between the variables.

Table 4 presents the results of the nurses' evaluation of the main obstacles to the circulation of information in the institution to which they belong. To evaluate the evaluation of each of the considered items a Likert scale was used, ranging from 1, corresponding to totally disagree and 4, corresponding to totally agree.

We sought to determine the existence of differences between each of the four health services respecting to the evaluation of the main obstacles to communication. The results obtained through the Kruskal-Wallis test allowed the identification of differences regarding the consideration of conflict as an obstacle to the communication process ( $\chi^2_{KW(3)} = 30.01, p = 0.000$ ) and

overvaluation of personal and professional relations ( $\chi^2_{KW(3)} = 12.60, p = 0.006$ ). No statistically significant differences were identified respecting poor organization of the message ( $\chi^2_{KW(3)} = 7.76; p = 0.051$ ), channel of transmission ( $\chi^2_{KW(3)} = 5.69, p = 0.128$ ), demotivation ( $\chi^2_{KW(3)} = 3.18; p = 0.365$ ) and at the intersection of messages ( $\chi^2_{KW(3)} = 3.56, p = 0.313$ ). In the data analysis, it was also possible to identify the existence of a statistically significant correlation between the age of respondents and the way they assess conflict situations as an obstacle to communication ( $r_s = -0.349; p < 0.05$ ).

Table 5 present the correlations between the different variables considered in the evaluation of the communicative process and the obstacles to communication.

Regarding the adequacy of different channels of communication in health services, the evaluation performed by the inquired nurses is presented in table 6.

It was tested the existence of statistically significant differences between gender in the evaluation of the adequacy of the means of communication in the service. The results indicate that there were differences in the adequacy of e-mail ( $M_{man} = 3.86, M_{woman} = 3.13, U = 268.5, p = 0.049$ ) and in the assessment of the adequacy of social networks ( $M_{man} = 3.36, M_{woman} = 2.73, U = 285.5, p = 0.050$ ).

**Discussion**

The results obtained indicate that the evaluation of the communicative process is independent of the personal and contextual variables where they occur. This means a transversality of the communication configuration and evaluation in different contexts.

According to the regulation of the exercise of the profession, nurses, in their professional activity, develop competences of organizational and interpersonal communication, using effective strategies in order to esta-

	M.	s.d.
<b>Clinical information</b>		
Efficiency	3.26	0.70
Sufficiency	3.16	0.65
Timing	3.05	0.76
Explicitness	3.28	0.74
Practical applicability	3.22	0.68
<b>Organizational information</b>		
Efficiency	3.00	0.82
Sufficiency	2.91	0.77
Timing	2.76	0.71
Explicitness	3.11	0.74
Practical applicability	3.00	0.77
<b>Service Information</b>		
Efficiency	3.11	0.83
Sufficiency	3.03	0.75
Timing	2.92	0.76
Explicitness	3.26	0.72
Practical applicability	3.14	0.72
<b>Team information</b>		
Efficiency	3.22	0.86
Sufficiency	3.16	0.67
Timing	3.14	0.76
Explicitness	3.29	0.76
Practical applicability	3.23	0.75
<b>Personal information</b>		
Efficiency	3.46	0.72
Sufficiency	3.33	0.66
Timing	3.27	0.74
Explicitness	3.34	0.66
Practical applicability	3.23	0.69

blish relationships with elements of the multidisciplinary team and clients. On the other hand, communication in health organizations have very similar channels of flows and organizational communication structures, whether formal or informal, influencing identically the understanding of communicational phenomena.

It was possible to observe how demotivation becomes an obstacle to communication, in all the variables that integrate the evaluation of the communicative process. It confirms the existence of a correlation between the variables 'conflict situations' and the 'practical applicability of the information' (more conflict less applicability). By analyzing the data it was observed that cross-messages constitute an obstacle to the circulation of information in two strands, in sufficiency and in timing. Based on the values presented in table 5, we find as main obstacles to communication the overvaluation of personal relationships with professionals regarding information of a clinical nature, the crossing of messages with regard to service information and personal information and, one more time, demotivation reveals to be transversal to all types of information considered. Motivation is understood as the impulse to exert efforts to reach the organizational objectives and, also,

to be able to satisfy some individual need. Other than that, there is a lack of motivation that influences the organizational climate (psychological and social environment), conditioning the behaviour of its members<sup>8</sup>.

Currently, e-mail has become increasingly important in health organizations, replacing other traditional means of communication such as: telephone, fax, meetings, among others<sup>9</sup>. The use of e-mail allowed the information to be transmitted quickly, thus enabling interaction with groups that, until now, was a difficult task. E-mail, in addition to facilitating the process of exchanging ideas, information, orders and complaints, made it possible to reduce costs as well as increase the flexibility of the time of receiving and sending messages.

Regarding the suitability of team meetings, it was verified that in the evaluation made by the inquired nurses presents the lowest value. Meetings, as a communication strategy, can be quite useful for organizing and planning work, maximizing productivity and team satisfaction. However it is necessary to ensure the effectiveness and efficiency of the meetings, clarifying the objectives for all participants, preparing them in advance, ensuring dynamism and evaluating the results obtained in practice, in order to guarantee continuous improvement in the quality of care provided<sup>10</sup>. They are usually carried out in an attempt to solve emergency problems by not providing a space for discussions, reflections, manifestations of expectations, opinions and feelings, and thus the necessary exchange of ideas and dissemination of knowledge, which may explain the results obtained.

The change-of-shift was indicated by nurses as the most appropriate means of communication in their services (M = 3.46). The change-of-shift is one of the most important and privileged moments in the communication process of nursing professionals, being a moment *par*

EVALUATION OF THE COMMUNICATIVE PROCESS IN ITS DIFFERENT DIMENSIONS **3**

	M.	s.d.
<b>Evaluation of the different facets of the communicative process</b>		
Efficiency	3.21	0.60
Sufficiency	3.12	0.55
Timing	3.03	0.59
Explicitness	3.26	0.62
Practical applicability	3.15	0.58
<b>Evaluation of the communicative process according to the nature of the information</b>		
Clinical information	3.19	0.58
Organizational information	2.96	0.64
Service Information	3.09	0.65
Team information	3.20	0.66
Personal information	3.32	0.62

EVALUATION OF THE DIFFERENT OBSTACLES TO COMMUNICATION PROCESS **4**

	M.	s.d.
Conflict situations	2.55	0.72
Overvaluation of personal relationships in relation to professional relationships	2.70	0.83
Demotivation	2.89	0.73
Information transmission channel	2.72	0.72
Poor organization of the message	2.63	0.73
Crossing messages	2.75	0.68

*excellence* of exchange of relevant information in order to ensure continuity of care. Often seen as one of the fundamental pillars of constant personal and professional development<sup>11</sup>.

### Conclusion

Based on the results we can highlight that the objectives of the research were achieved. Research reveals the generally positive way in which nurses evaluate the communication process. Nevertheless, some weaknesses of communication in the clinical context are identified, mainly related to the way in which information of organizational nature is disseminated in the services. Hence the importance of the creation of mechanisms in order to promote the circulation of this information, on time, is patent on the results.

The main obstacle to communication was the lack of motivation, which is why it is essential to put into practice actions that reinforce the motivation of nurses, given their influence on the effectiveness of communication and quality of care. Communication, when functional, is a good predictor of team performance. Successful teams communicate informally more frequently than the less successful ones when they share task-related or socio-emotional messages. The teamwork achieved based on effective communication among professionals is a reason for professional and personal satisfaction and is considered a positive catalyst in the interpersonal relationship as well as in the process of collective development. Communication and exchange of information produce gains in terms of visible coordination mechanisms in cohesion and sharing of objectives<sup>12</sup>. Communicating in nursing and on nursing means being undoubtedly contributing to the improvement of quality and effectiveness of care<sup>13</sup>.

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**CORRELATION BETWEEN OBSTACLES TO COMMUNICATION AND EVALUATION OF THE COMMUNICATIVE PROCESS AND THE EVALUATION OF THE NATURE OF THE INFORMATION**

**5**

**Correlation between obstacles to communication and evaluation of the communicative process**

	Efficiency	Sufficiency	Timing	Explicitness	Practical applicability
Conflict situations	-0.051	-0.171	-0.059	-0.154	-0.250*
Overvaluation of personal relationships in relation to professional relationships	-0.052	-0.151	-0.039	-0.086	-0.180
Demotivation	-0.295*	-0.333*	-0.374*	-0.339*	-0.355*
Information transmission channel	0.001	-0.009	-0.009	0.053	0.036
Poor organization of the message	-0.083	-0.129	-0.145	-0.043	-0.46
Crossing messages	-0.145	-0.235*	-0.355*	-0.094	-0.195

**Correlation between obstacles to communication and evaluation of the nature of the information**

	Clinical information	Organizational information	Service information	Team information	Personal information
Conflict situations	-0.221	-0.021	-0.070	-0.137	-0.177
Overvaluation of personal relationships in relation to professional relationships	-0.310*	0.019	0.008	-0.152	-0.038
Demotivation	-0.309*	-0.330*	-0.336*	-0.372*	-0.247*
Information transmission channel	0.211	-0.079	-0.172	0.023	0.100
Poor organization of the message	0.083	-0.162	-0.220	-0.045	0.067
Crossing messages	-0.10	-0.199	-0.250*	-0.225	-0.250*

\* $p < 0.05$

**EVALUATION OF THE ADEQUACY OF THE COMMUNICATION CHANNEL IN THE SERVICE**

**6**

	<b>M.</b>	<b>s.d.</b>
E-mail	3.28	1.02
Social networks	2.86	1.02
Change-of-shift	3.46	0.82
Board posts	3.09	0.94
Occurrence book	2.82	1.00
SMS	3.09	0.97
Phone call	3.22	0.96
Team meetings	2.79	1.09

# Interpersonal conflict management strategies in nursing teams

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## Summary

Nursing is par excellence a teamwork activity and is, consequently, exposed to the vulnerabilities of the dynamics of group functioning. Based on this assumption, conflicts management in nursing teams gains particular relevance. The main objective of the research is to assess the frequency with which nurses are confronted with situations of conflict, to identify the main causes of conflict, and the strategies adopted by nurses to deal with conflict situations. The methodological approach to this study is quantitative and has a descriptive, exploratory and correlational nature. A questionnaire was elaborated for the collection of data and a total of 35 nurses from an emergency department of an Hospital of the Serviço Nacional de Saúde were inquired. The results show that the conflicts in the nursing teams assume identical configuration with other activities, standing out five strategies: Commitment, Avoidance, Accommodation, Confrontation and Collaboration. Confrontation is the most mentioned strategy by nurses and this can be explained by the limitation and dispute of resources. The conclusions show that conflict management by nurses is determined by the nature of the conflict. The data obtained indicate that the scarcity of material resource reserves leads to confrontation, contributing to the degradation of the organizational environment.

KEYWORDS: INTERPERSONAL CONFLICT; TEAM WORK; NURSING; EMERGENCY SERVICE.

## Introduction

Conflict is a reality that is always present in human relations and in working relationships. Conflicts are originated in the diversity of points of view between people, in the plurality of interests, values, experiences, needs and expectations, in the difference between the ways of acting and thinking. The situations in which there are a greatest number of conflicts between people are the environments of daily living, among them the work places. The world of work has changed with the advancement of technologies. Today, the professional lives under multiple tension, because in addition to his/her usual responsibilities, the high competitiveness demands a constant challenge, and permanent updating, thus affecting work environments and professional relations. The health care sector, especially nursing, is not excluded from this reality and, as such, the teams experience frequent conflict experiences. The growth of the complexity and multidimensionality of health problems and the increase of the specializations of the care providers

promoted a greater interprofessional collaboration and the development of interdisciplinary teams<sup>1</sup>. As nursing is based on teamwork, nurses need to learn how to be effective team players, which implies: communication, trust, bonding, mutual respect, recognition of each other's work and collaboration<sup>2</sup>. The objectives of this research are to assess the frequency with which nurses in their professional activity are confronted with situations of conflict; identify the strategies adopted by nurses to deal with conflict situations; as well as the main causes attributed to the conflict in an organizational context.

Organizations today tend to be increasingly complex. This complexity arises from different causes such as the production process, the level of the requirement for its employees and the interpersonal relationships between workers and hierarchy<sup>3</sup>. Analyzing specifically the current context of nursing, nurses often does not have the opportunity to develop its autonomy and their knowledge is secondarily<sup>4</sup>. Chan, Sit and Lau<sup>5</sup> define conflict as a misunderstanding that results from different thoughts, values and feelings between two or more individuals. The health sector is not exempt from this reality and, as such, the teams experience frequent conflict experiences. As the size of the teams increases the com-



munication between its members becomes more complex and challenging and can even overreach the benefits of teamwork. So, achieving collaborative interprofessional teamwork is considered fundamental for quality of health care, safety and patient satisfaction and health professionals<sup>2</sup>. In relation to collaborative team work, the most emphasized attribute is communication, through which the remaining elements of collaborative practice are constructed. Communication is considered fundamental in negotiation, bonding and trust. In nursing communicative action, based on dialogue, enables professionals to develop collaboration. However, this communication is often restricted to the instrumental logic, only for the transmission of information<sup>2</sup>. Recent studies<sup>1</sup> suggest that the good functioning of the multidisciplinary team benefits the health of its professionals and improves the quality of care provided. Teamwork improves delivery, motivation, tolerance, and commitment of all members to the rest of the team.

Nursing is *par excellence* a profession of multi and interdisciplinary teamwork, this attribute promotes situations that can lead to conflicts. Thus, the styles of conflict management in the nursing team are a theme that is a daily concern of nurses' work, becoming an unavoidable theme in the profession. In this context, interpersonal conflicts between nurses interfere in the continuity of care and reinforced that the community is the essence of nursing care, without this understanding people replicate individualistic, alienated and fragmented practices<sup>6</sup>. The research also pointed out some strategies that can contribute to conflict management, among them the practice of dialogical leadership. This consists of the ability of the superior to influence his or her collaborators in a reflexive and critical activity about individual and collective performance, promoting knowledge sharing and autonomy. Conflict management is a task that usually causes susceptibilities and resistance. Conflicts can have positive or negative results, this outcome depends on several factors, from the cause of the conflict to the way it was treated. In a research about the impact of role, work, and organizational characteristics on stress and well-being related to nursing work<sup>7</sup>, the overload of roles and conflict were identified as the most important predictors of stress. This conclusion is coincident with other studies<sup>8</sup>.

There are several ways to approach and manage conflicts. The methodology developed by Kenneth Thomas and Ralph Kilmann is considered as one of the most effective<sup>9</sup>, it consists of five ways of managing conflicts, which is known as "Conflict Management Styles". When facing a conflictive situation individual behavior tends to be inserted in one of two basic domains: i) assertiveness, understood as the way each person meets their own interests and goals or; ii) integrated cooperation, comprises how the individual can achieve the interests of others. In this sense, competition, accommodation, withdrawal, agreement and collaboration are five methods of managing conflicts shaped by this two-dimensional behavior. As Santos refers<sup>10</sup>, the use of the most appropriate strategies will have a greater efficiency depending on the competence of the communicator. In the daily work, the nurse is the mediator of the multidisciplinary nursing team in the solution of several conflicts and uses several strategies to deal with these situations. Lack of ability, theoretical knowledge of power relations and how to exercise leadership, as well as practical experiences to successfully manage interpersonal relationships are professional difficulties encountered by nurses<sup>11</sup>.

Therefore, successful teamwork, based on effective communication among professionals, is a source of professional and personal satisfaction. To this end, it is essential that each member of the team recognize his/her role and that of others acting in an interdependent way so that their focus is the patient as a whole it's needs and expectations<sup>12</sup>. However, it is

not realistic to expect all teams to function harmoniously, since they are the natural extension and at the same time the ground of development of interpersonal relationships, which also do not flow without friction. In this way people are involved in conflict situations in which even the most effective techniques are able to solve<sup>10</sup>. Thus, the competitive strategy involves is an assertive and non-cooperative attitude, where the use of power prevails. It is an aggressive and antagonistic style where the individual makes use of the power to win; this is a form of competition or confrontation. When trying to score a position, confrontation can be a useful strategy, showing an aggressive face<sup>10</sup>. On the other hand, accommodation implies resignation of personal interests to satisfy the interests of the other party. It is an unassertive, cooperative and self-sacrificing attitude, the opposite of competing. Therefore, accommodation is identified by a generous, selfless, docile behaviour at the will of the other person. The individual places himself, diplomatically, on the fringes of the conflict, sometimes retreating from a situation of physical, emotional, or intellectual threat. In these situations successful communication can occasionally transform it, especially in a professional context<sup>10</sup>. The withdrawal occurs in the situations where the subject adopts the posture of putting the problem at a more propitious moment. The strategy commitment is an intermediate position between assertiveness and cooperation. The individual seeks mutually acceptable solutions that partially satisfy both sides. The agreement means bartering concessions, or looking for a quick half-way solution. With regard to collaboration, it is an affirmative and cooperative mean of conflict resolution, capable of resulting in a win-win solution for both parties. Those involved set aside their original goals and work together to establish a common goal. It is both assertive and cooperative.

## SAMPLE CHARACTERIZATION

1

	n.	%
<b>Gender</b>		
Male	5	14,3%
Female	30	85,7%
<b>Age group</b>		
<30 years old	7	20,6%
30-39 years old	14	41,2%
40-49 years old	9	26,5%
50-59 years old	4	11,8%
<b>Years of professional experience</b>		
<10 years	12	35,3%
10-19 years	11	32,4%
20-29 years	8	23,5%
30-39 years	3	8,8%
<b>Frequency with which the respondent was involved in situations of conflict with colleagues of the nursing team</b>		
Never	2	5,7%
Seldom	19	54,3%
Sometimes	14	40,0%
Often	0	-
Almost always	0	-
<b>Frequency with which the interviewee witnessed situations of conflict between colleagues of the nursing team</b>		
Never	0	-
Seldom	5	14,3%
Sometimes	20	57,1%
Often	9	25,7%
Almost always	1	2,9%

Thus, in the field of human relations and communication, strategies of commitment and joint resolution are the most valued, because both guarantee an equalitarian status among the interlocutors<sup>10</sup>.

Despite the five styles mentioned, different people use different strategies to moderate conflicts. There is no universally valid style of conflict resolution, it is closely related to the situation in question, so it is necessary to know the situations in which each of them will be the most appropriate. However, if it is solved with assertiveness, conflict can have positive consequences<sup>13</sup>. In this dynamic, the assertive team members are individuals who adequately express their feelings, reinforce and receive reinforcement from others. Several studies mention that show that individuals with high levels of assertiveness transmit more affirmative and facilitative assertive practices, relying on their capacity to respond effectively and, consequently, waiting for more positive results of this assertive performance assertive<sup>4</sup>.

Taking into account the research objectives, three questions were formulated: i) what is the frequency with which nurses in their professional activity are confronted with situations of conflict?; ii) which are the strategies adopted by nurses to deal with conflict situations?; which are the main causes attributed to the conflict in an organizational context? The purpose of this study is to contribute to the understanding of how conflict emerges in nursing teams and how it affects work in health organizations. The results allow a better knowledge of the way nurses evaluate the interpersonal con-

flict process, thus contributing to its improvement.

### Methods

The methodological approach to this study is quantitative and has a descriptive, exploratory and correlational nature. A questionnaire was elaborated for the collection of data and a total of 35 nurses from an emergency department of an Hospital of the Serviço Nacional de Saúde were inquired. Taking into account the objectives of the research, the questions of the questionnaire were formulated in order to assess the frequency with which nurses in their professional activity are confronted with situations of conflict. The data collection was carried out between April 16 and May 2 of 2017. The data collection instrument consisted of open and closed questions in the socio-demographic characterization. The second part of the instrument was composed of statements, which the respondents were asked to answer to the questions using a Likert scale, with a semantic gradation of five points and trying to describe the following components: situations of conflict in an organizational context; strategies adopted in the management of conflict situations and causes attributed to conflicts.

The study complied with all ethical principles guiding scientific research. The data collection instrument was sent via e-mail and responses were obtained online. In the data collection process the participants were informed of the research objectives and voluntarily participated in the study. The anonymity of all participants was equally guaranteed and respected.

### Results

It is observed (table 1) that the sample is marked by a significant number of women (85.7%) on the total of the sample, the predominant age group was 30-39 (41.2%) and professionals with less than 10 years of professional experience (35.3%). When

**LEVEL OF AGREEMENT WITH THE DIFFERENT STATEMENTS THAT COMPOSE THE CONFLICT STRATEGIES SCALE**

**2**

	<b>M.</b>	<b>s.d.</b>
<b>Commitment</b>		
I try to reach a compromise acceptable to both parties.	2.46	1.120
I am willing to not get what I want to maintain the harmony of the team	2.09	0.818
I find it hard to admit that I am wrong.	1.74	0.701
<b>Avoidance</b>		
I try not to get involved in conflicts.	2.26	0.886
I try to meet the expectations of others	2.57	0.917
<b>Accommodation</b>		
I keep what I feel for myself in order to avoid resentments	1.97	0.514
I avoid resentments by keeping the disagreements with others just for me	3.37	1.031
To resolve disagreements I try to reach a middle ground	2.57	0.850
I negotiate to get at least part of what I propose	3.51	0.781
<b>Confrontation</b>		
I find conflicts challenging, I like to win a discussion	2.11	0.900
I present my position as the best point of view	3.97	0.923
When I meet in a discussion, I usually say what I think	3.26	1.067
<b>Collaboration</b>		
I try to identify and discuss what is wrong with the position of others	3.03	0.822
I accept the suggestions of other professionals	2.91	1.095

**STRATEGIES ADOPTED IN THE MANAGEMENT OF CONFLICTIVE SITUATIONS**

**3**

	<b>M.</b>	<b>s.d.</b>
Commitment strategy	2.09	0.73
Avoidance strategy	2.41	0.79
Accommodation strategy	3.07	0.61
Confrontation strategy	3.11	0.84
Collaboration strategy	2.97	0.72

questioned about the frequency of involvement in situations of conflict, most of the nurses reported that they were rarely involved, however, regarding the frequency of conflict situations witnessed, 57.1% stated that they sometimes observed these situations.

Taking into account the objectives of the research, a scale of attitudes was elaborated in order to assess the nurses' strategies in situations of conflict with which they are confronted. The scale consists of 14 statements regarding five possible strategies (Commitment, Avoidance, Accommodation, Confrontation and Collaboration). Respondents were asked the level of agreement with each of the statements using a Likert scale with a range of variation between 1 (Strongly Disagree) and 5 (Strongly Agree). The results obtained are presented in table 2.

Based on the results, five indexes were constructed corresponding to five different strategies to deal with conflict situations in an organizational context. The indices were calculated based on the average results obtained in each one of the questions included in the different strategies. The internal consistency of the indices was measured using the Cronbach alpha and the following results were obtained: i) commitment strategy ( $\alpha = 0.745$ ); ii) avoidance strategy ( $\alpha = 0.699$ ); iii) accommodation strategy ( $\alpha = 0.745$ ); iv) confrontation strategy ( $\alpha = 0.618$ ) and collaboration strategy ( $\alpha = 0.698$ ).

The different strategies adopted in the management of conflictive situations are listed on table 3, revealing that accommodation (M= 3.11) and confrontation (M= 3.07) are the most common strategies.

With regard to causes of conflicts, they are presented on table 4. The incompatibilities of personal interests (M = 3.63) and the difficulty in dealing with the professional ambition of others (M = 3.54) assumes particular relevance as causes of or-

## CAUSES ATTRIBUTED TO CONFLICTS

4

	M.	s.d.
Incompatibility between my personality and that of others	2.11	1.022
Interference with my personal/family problems in my professional life	2.37	0.942
Difficulty in dealing with the professional ambition of others	3.54	0.701
Scarcity of human resources	3.46	0.950
Scarcity of material resources	2.66	0.968
Lack of professional recognition	3.37	0.808
Disrespect for hierarchies	3.51	0.702
Incompatibilities of personal interests	3.63	0.690
Disrespect for job functions and responsibilities	3.37	1.140

## CORRELATION BETWEEN CONFLICT RESOLUTION STRATEGIES AND THE CAUSES ATTRIBUTED TO CONFLICT

5

	Commitment	Avoidance	Accommodation	Confrontation	Collaboration
Incompatibility between my personality and that of others	0.193	0.052	0.400*	-0.026	0.255
Interference with my personal/family problems in my professional life	0.103	0.093	0.058	0.020	0.113
Difficulty in dealing with the professional ambition of others	-0.149	-0.111	0.106	0.181	0.054
Scarcity of human resources	-0.331	-0.244	0.171	-0.162	0.024
Scarcity of material resources	-0.093	-0.073	-0.358*	0.155	-0.265
Lack of professional recognition	-0.018	0.314	-0.107	0.084	0.124
Disrespect for hierarchies	-0.199	0.045	-0.244	0.134	0.012
Incompatibilities of personal interests	-0.417*	0.038	0.059	0.235	0.210
Disrespect for job functions and responsibilities	-0.112	0.010	-0.087	0.302	0.029

\* $p < 0.05$ 

ganizational conflict. Analyzing the correlation between conflict resolution strategies and the causes attributed to conflict (table 5), it is observed that the strategy of accommodation as a statistically significant positive correlation between the strategy with the incompatibility of personalities ( $r_s = 0.400$ ,  $p < 0.05$ ) and a negative correlations with the scarcity of material ( $r_s = -0.358$ ,  $p < 0.05$ ) as cause of conflict.

### Discussion

Results from this study showed that in this sample the individuals mostly opted for antagonistic conflict management strategies, given that the person choosing the accommodation strategy focuses on the aspects that exist in common to satisfy the interest of the other, while the person who uses the strategy of confrontation seeks by all means to achieve its goal and for this it often ignores the needs and expectations of the other. Conflicts cannot be omitted, and as it is extremely important to construct new ways of managing them, which encompass knowledge of health policies and their operationalization, as well as the enhancement of skills and leadership in nursing<sup>6</sup>.

It was possible to observe that interpersonal relations is the common

element of the causes of conflict highlighted by the inquired nurses. The emergency department team is a large multidisciplinary team, and as teams increase in number of elements, interpersonal communication tend to be more difficult and ends up being a challenge for all elements the daily clinical practice<sup>1</sup>. It was, also, identified that compromise strategy is correlated with the incompatibility of personal interests. The research of Chan, Sit and Lau<sup>5</sup>, where the authors analyzed styles of conflict management, emotional intelligence and implicit personality theories of nursing students, concludes that emotional intelligence was

significantly associated with all five modes of conflict management. Other researchers<sup>14</sup> report that interpersonal relationships is associated with a collaborative practice, such as trust and mutual respect among health professionals, where shared decision-making and ethical and professional standards, are the cornerstones of decision-making and results. In addition, Pfaff, Baxter, Jack, Ploeg<sup>15</sup> reinforce that interprofessional collaboration depends on various complexities, such as organizational and team culture, and may challenge the involvement of new nurses.

Confrontation is the most mentioned strategy and that can be explained by the limitation and dispute of resources. In other words, the limitation of resources has repercussions on conflict management strategies and organizational climate. The data obtained in this exploratory study seem to confirm the idea, recurrent in the discourse of the different actors in the health sector, that the scarcity of resources leads to confrontation and, consequently, conflict between professionals.

### Conclusion

In the discussion of the results it is verified that the accommodation is the preferred strategy of conflict management when the nature of the conflict involves aspects of the personality of the individuals. A negative correlation between accommodation and scarcity of resources was also observed, which means that situation where there is a scarcity of material resources the members of nurses teams tend to discard accommodation attitudes. The results obtained allow to conclude that the management of the conflict by the nurses is determined by the nature and context of the conflict.

In this sense, nurses need to develop interpersonal skills in communication, leadership and management, these being their main instruments of work, in order to provide quality and effective health care and to be able to promote satisfactory results in the performance of the teams. Conflict management is an essential skill or tool that nurses can and should use as a basis of sustainability and development of nursing practice. By investing in the development of these skills, they are contributing to improve the performance of organizations, with long term positive effect. In this context, nurses are responsible for the articulation between different health professionals and the provision of care centred on the person, which makes him/her an agent of convergence and power in interprofessional relations.

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# Legislation for ostomates in Portugal

## Components of the attention to health model

### Summary

Ostomy refers to the opening created surgically in the body for waste discharge (IOA CC, 2016) to maintain communication with the external environment by a fistula, which may connect to a tube or a pouch depending on the patient's clinical outlook. In Portugal, the number of ostomized patients is about 15 thousand, among whom 80% to 90% are people who suffer or have suffered from oncological diseases. The aim of this study is to describe the Portuguese legislation that deals with attention to ostomates and to identify records that contain the elements of a theoretical model (TM) of this intervention in these official sources. This is a descriptive documental study covering the period between May 1989 and February 2017. The study revealed that the vast majority of the legislation ensures the rights of ostomized people. The stomatologist was identified as a human resource required to develop care practices. The physical resources identified in the documents referred only to the collecting devices. The other structural resources required for the development of activities, such as physical space, adapted bathroom, environment, doctor's surgery, computer resources, information systems, etc. were not found in the study sources. Conclusions: There is a wide range of legislation with rights focused on prevention, rehabilitation and integration of ostomized people, as well as social protection schemes such as disability pensions, special leave and free medical devices. We propose creating a regulation based on existing legislation to establish national guidelines for ostomized people at different levels of care.

KEYWORDS: OSTOMY; DOCUMENTARY RESEARCH; STOMATHERAPY; EVALUATION.

### Introduction

According to the International Ostomy Association Coordination Committee, ostomy and stoma are general descriptive terms often used interchangeably. An ostomy (or stoma) refers to the opening created in the body surgically to discharge waste<sup>1</sup>, in order to maintain communication with the external environment by a fistula, which may be connected to a tube or a pouch depending on the patient's clinical condition. In Portugal, the number of ostomy patients is about 15 000, of whom 80% to 90% are people who suffer or have suffered from oncological diseases<sup>2</sup>.

The country considers them disabled, according to parameters defined by both the World Health Organization or by Decree Law No. 9/89, of May 2, which deals with the Base Law on Prevention and Rehabilitation and Integration of People with Disabilities. This law was repealed by Law 38/2004<sup>3</sup> which extends the concept of disabled person as one who, by loss or congenital or acquired anomaly, functions or body structures, including psycho-

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logical functions, who presents particular difficulties in conjunction with environmental factors which are likely to limit or hinder activity and participation on an equal basis with others.

Thus, despite bearing varying types and degrees of disabilities, these people have the same rights, freedoms and guarantees enshrined constitutionally as other citizens, such as, the right to quality of life, liberty and security, the right to work, to social security, housing, education and vocational training.

The aim of this study is to analyse primary documents, specifically the legislation dealing with people with an ostomy, identifying within the different contexts features of intervention models in Portugal, highlighting existing gaps in order to construct a logical model for this intervention. This study is part of broader research being carried out in the Oporto Nursing School in Portugal, in partnership with the

Aurora Afonso Costa Nursing School at Fluminense Federal University in Brazil. It is funded in part by the Doctoral Scholarship in Health Care Sciences of CAPES (no. 88881.132388/2016-01) of the scholarship programme Programa Doutorado Sanduiche no Exterior (PDSE).

The research into the literature handled here is the first phase of this study. The other phases, consisting of a case study and the construction of a representation of the model of attention to ostomates are being developed within ambulatory stomatherapy care in a Portuguese hospital with the intention of being addressed in later publications. The premise of the study is that the appropriate practices of care for ostomates, in line with national guidelines and suggestions proposed by skilled health professionals, result in quality of care and well-being for this group. Characterizing the different objectives of the legislation applying to ostomates and identifying the existence of elements that can serve as a basis for the design of a logical intervention model was considered for the purposes of analysis in this literature research.

According to Champagne et al.<sup>4</sup>, an intervention, whether a programme or a policy, can be conceived as an organized system of actions which include, in a given environment, the agents who are the actors, a structure corresponding to the set of resources and rules, processes, understood as the relationship between resources and activities, and a goal as a future state for which the process is oriented. According to Cassiolato<sup>5</sup>, the aim of the logical model is to explain the theory behind the programme, the application of which results in a process that facilitates planning and communicates what the programme intends and what its expected operation. The actual practices of attention to ostomates in Portugal have emerged in health care where stomatherapy assistance is highlighted.

Moreover, it is important to identify constituent components in legal documents to construct the logical model of an intervention, since it will contribute to instrumentalizing that knowledge for the benefit of ostomized people living with limitations imposed by the ostomy itself and with too many confrontations arising from their condition.

Therefore, the aim of this study is to investigate the official legal documents of Portugal dealing with attention to ostomates, related to the existence of components for the construction of the theoretical intervention model. For this, we attempted to outline the following specific objectives: to describe the Portuguese legislation dealing with attention to ostomates and to identify in the official source records that contain the elements of a theoretical model of this intervention.

This paper is organized as follows: in the next section, the methodology used in the research is presented along with the characterization of the components of a logical model of care. Then, the test results will be shown, listing the components that emerged from the study and the gaps in the legislation. Finally, proposals to effect guidelines for national attention to ostomates are presented.

## Methodology

This is a descriptive, documental study of the Portuguese legislation on the issue of care for ostomates. According to Cellard<sup>6</sup>, the documental study through a qualitative approach allows researchers to describe and understand the content of documents, in order to answer their questions through description and analysis.

Calado and Ferreira<sup>7</sup> consider that documents are sources of raw data for the researcher and their analysis implies a set of transformations, operations and confirmations performed through them in order to attribute a relevant meaning to them with regards to a research problem.

Besides being extremely valuable for research, documentation is an additional source of information, allowing the researcher to become familiar with the history of a social group, its culture, its organization or with important events related to the research undertaken; and it comes in various forms, including newspapers or the internet<sup>8</sup>. Content analysis was the method chosen to analyse documents collected for this study, using the methodology proposed by Bardin<sup>9</sup>. This method considers content analysis a set of communication analysis techniques whose aim is to obtain quantitative indicators, or not, through systematic procedures and description objectives of message content, in order to allow knowledge relating to the conditions of production/reception (inferred variables) of the messages to be inferred. The research was conducted in four stages: a survey of the reference databases available on the Internet; the construction of a database with publications; categorization of publications; reading and analysis of publications.

To ensure the authenticity, credibility and representativeness of the documents, the survey of the reference databases available on the Internet was conducted on the websites of official government bodies such as the *Diário da República Eletrónico* (DR) [Electronic Journal of the Republic]<sup>10</sup> and the National Health Service of Portugal<sup>11</sup>. The portals of the Portuguese Ostomy Association<sup>12</sup>, the Portugal Ostomy League<sup>13</sup> and the Portuguese Association of Stomatherapy Care Nurses<sup>14</sup> was also consulted. In addition to these sources of information, articles in indexed journals on the issue of this research from the Virtual Health Library (VHL) were also examined.

We searched for documents published from 1989 as that was the year Portugal passed the law which established the social protection scheme under special conditions for people suffering from oncological

diseases, which may include ostomates. A Microsoft Excel spreadsheet was constructed to organize the databases. It included the description of the items related to the topics of this study, the year in which such publications were produced, their objectives and sources as shown in table 1.

Publications, which enabled a discussion on the relationship between ostomy and the various elements of the theoretical intervention model, were selected. In other words, articles that considered the objectives, structure, processes and results necessary components to construct a Portuguese model of care for people with ostomy were examined.

At this stage, publications that dealt with the elements of structure and processes already mentioned in the legislation with the same content were excluded.

To aid in discussion of the results, it is worth listing some advantages of modelling a given intervention. According to Champagne et al.<sup>15</sup>:

*modelling enables the connexions between an intervention and its effects to be made explicit [...] The logical model allows the meaning of a programme to be documented through the conceptualization of the connexions between the structures, the processes and the outcomes [...] The following questions can be answered: What is done with the available resources? What are the effects of the programme, and who benefits from them?*

According to Chen in Champagne et al.<sup>16</sup>:

*the main elements of the logical model include the programme components and its objectives and desired effects [...] in possibly different forms such as text, table, hierarchy of objectives, diagrams [...] identify the structures, processes and results [...] and relationships between structure, process and...*

...the structure, process and outcome components of the logical model, observed in the study's legislation have been based on the concepts of normative assessment according to Champagne et al.<sup>17</sup>:

*the regulatory assessment is based on comparison of the all of the intervention components with regard to criteria and standards. It consists of issuing a judgment on an intervention comparing the committed resources (structure), the goods and services produced (process) and the results obtained on one hand with the criteria and standards on the other. The structure includes the following resources: financial, human, real estate, technical and informational, laws, regulations, conventions and administration rules. Processes are the services or activities, and the results are the expected effects.*

In all, 36 publications were read, among which 20 were used in this study. The survey of this material was carried out from 12 April to 17 July 2017.

## Results

After the steps of selecting, identifying, prioritizing, synthesizing articles and interpretative reading, we proceeded to analyse the findings resulting in 20 documents in full, distributed among 02 laws, 05 decree-laws, 02 ordinances, 03 rules and 08 orders relating to issues that include attention to ostomates since the enactment of the first law in 1989. The main issues highlighted in the readings of each document were related to public policies; rights to retirement; entitled to special leave; assurance of medical devices; stomatherapy assistance; and clinically indicated norms for the various types of ostomy.

From the interpretative reading of the documents studied, five thematic categories emerged in accordance with aspects considered for the condition of the ostomate: oncological diseases; people with disabilities; medical

devices; stomatherapy assistance and clinical indications. The results are described in table 1.

The relationship between the themes that emerged from the analysis and the elements to build the logical attention to ostomates intervention model, according to the normative assessment of an intervention, are presented in table 2.

## Discussion

The relationship between the themes and the components required to construct the theoretical attention to ostomates model showed the following:

For the category/component – structure: the categories with constituent elements of the structure for the intervention model were medical devices, stomatherapy assistance and clinical indications.

We found that a great majority of the laws in the category-medical devices were directed towards the structural component of the physical resources called ostomy devices.

These resources were demonstrated in nine legal documents starting in 1990, when the National Health Service (NHS) established a co-payment system for patients who lack of ostomy bags. In 1995, the co-payment system was increased to 90% and expanded not only to underprivileged patients, but to all ostomates enrolled with the NHS.

In 2015, the creation of the National Health Technology Assessment System provided for the co-payment medical devices, establishing that they can be the object of co-payments established by the order member of the government responsible for health.

In 2016, three laws related to ostomy devices also passed to define a strategy that would lead to electronic prescription and distribution in community pharmacies of these support products. It established rules governing public supply contracts (PSC) for the supply of colostomy equipment, and establish a co-pa-



ymment scheme for medical devices to support ostomates entitled to NHS benefits. This was to ensure the ostomized patients had access to ostomy materials, products and supplies, thus improving their quality of life and social integration.

The co-payments and tax benefits ostomates were entitled to prior to February 2017 were concerned with the reimbursement of a percentage of the cost of the devices (bags and skin barriers) and accessories. These ranged from 90% if the ostomy patient belonged to the National Health Service (NHS), in accordance with Order 25/95 of 09/14/1995, to 100% in the case of employees and agents of the public administration (ADSE) in accordance with Order – DR (2nd Series) no. 224 of 26/09/2001).

In the year 2017, the value of State co-payments to provide ostomy devices increased to 100% of the sale price to all ostomates, regardless of their NHS or ADSE entitlements. That year, the general technical requirements applicable to specific medical devices to support patients with urinary incontinence or retention in the co-payment system were also determined.

The recommendations published in the International Ostomy Guideline by the World Council of Enterostomal Therapists (WCET)<sup>18</sup> in 2014 contemplated medical devices for patient support, and that these devices and barriers to stoma effluent containment should provide a secure seal and maintain protection of peristomal skin.

This category showed documents mainly relating to the provision for co-payment of ostomy collection devices. However, other structural features such as physical space with a doctor's surgery equipped for medical assistance and stomatherapy, bathroom fitted with mirror and hygienic shower, computer material resources, information systems, etc. were not identified in this study's sources.

Regarding the legislation containing the structural component of human resources, the order of 24/02/1995 addresses nurses who provide stomatherapy assistance, and development of special skills in nursing care in hospitals and health centres with qualified nurses, providing a register of these sites and the nurse's functions in stomatherapy assistance.

Three other standards published in the year 2017, relating to clinical indications and intervention in feeding ostomy, intestinal and urinary elimination in children and adults, also contain elements of the structural component of human resources, doctors and nurses in particular. These standards require that the nursing consultation should be carried out by experienced nurses with specific training and recognized stomatherapy care and medical consultation should be in the hospital's speciality consultation or in primary and paediatric health care. Stomatherapy assistance provided by specialized or experienced professionals in stomatherapy care has been identified as human resources required to develop care practices.

In the guidelines published in 2017 relating to clinical indications, elements inherent to human resources (doctors and nurses), activities, products and the outcomes of these actions.

Stomatherapy is a differentiated area of health care, which integrates scientific and technical knowledge, the principles of the relationship of assistance and, through information, education and counselling. It allows the person who will undergo or has undergone ostomy to carry on as quickly as possible with their personal, family, professional and social lives with the necessary modifications, fulfilling their goals and objectives (APECE, 2010).

The view of the Portuguese Association of Stomatherapy Care Nurses (APECE) as stated in an interview with the *Jornal do Enfermeiro*<sup>19</sup>:

*the concept of competence assumes acquired knowledge that supports inferences, an-*

*ticipations, generalizations and decision-making. For this, it is necessary to provide training to nurses interested in this area – but training that is recognized by its content, training organizations, teachers and that can achieve the criteria defined by the International Council of Stomatherapy and develop research in the field (Jornal do Enfermeiro, 2017).*

The European Council of Enterostomal Therapy Council (ECET)<sup>20</sup> is a non-profit organization that has among its main objectives European recognition of specialist nurses in the area of stoma care, incontinence care and/or treatment of stoma wounds and promoting stoma care according to quality and ethical standards (ECET, 2017).

Thus, participation of multidisciplinary teams for quality of care to ostomates is supported in the literature, such as the study of Nascimento et al.<sup>21</sup> This study considered the patient's active participation along with the multidisciplinary team, important to develop their skills and therefore to contribute towards adapting, since self-care generates a partnership in which problems are identified and determine the actions and the appropriate type of intervention, resulting in the patient's safety and rehabilitation.

According to Simões, "quality of life . . . depends on the existence of an available health professional to accompany patients during the adaptation phase, to whom the patients can turn whenever they have questions or problems with their ostomy"<sup>22</sup>.

Categories/component – the process: the categories constituted by processes or activities for the intervention model were medical devices, stomatherapy assistance, and clinical indications. The activities related to ostomy care were highlighted in the legislation that also contemplated the structural components involving physical and human resources and included the supply of ostomy devices, stomatherapy consultation and

medical evaluation. Activities emerged from the documental analysis, such as nursing intervention with the person undergoing ostomy both pre- and post-ostomy.

It is worth drawing attention in this study to the large number of publications directed at ostomy devices from 2015, representing the last two years of the study. They comprise approximately 50% of the publications throughout the study period.

Categories/Component (results): the categories constituted by results or effects of the intervention model were highlighted in all of the available legislation. This involved public policy, the right to retirement and special leave, the right to free ostomy devices and medical and stomatherapy assistance. These constitute key elements to achieve the objectives and targets needed to construct the model of care.

Two laws dealt with public policy. In 1989, the base law addressing prevention, rehabilitation and integration of people with disabilities was passed – Law No. 9/89<sup>23</sup> of May 2. In 1997, Decree Law No. 225/97<sup>24</sup> of 27 August was passed. It established the creation of the National Council for the Rehabilitation and Integration of Persons with Disabilities whose mission is to enable the participation of public services, social partners and the interventional association movement in the areas of prevention, rehabilitation and integration of disabled people.

The right to retirement for ostomized people due to oncological causes was granted in 1989, 2000 and 2001. In 1989, Law No. 1/89<sup>25</sup>, of January 31 established a social protection scheme under special conditions for people suffering from oncological disease, multiple sclerosis and familial amyloidosis, respectively, which because their gravity and rapid evolution quickly develop into situations of disability. In 2000, Decree-Law No. 92/2000<sup>26</sup> of 19 May established the special social protection scheme for people with severe oncological diseases, with the following types of benefits: disability pension attributable to the beneficiaries of the general system; social disability pension attributable to the beneficiaries of non-contributory system; dependency supplement attributable to the beneficiaries of any of the social security systems.

That same year, Decree-Law No. 327/2000<sup>27</sup> of 22 December was passed, extending the social protection scheme under special conditions not only to people suffering from oncological disease, but also to people with multiple sclerosis and familial amyloidosis, respectively, which because their gravity and rapid evolution quickly develop into situations of disability. Another legal benefit occurred when the calculation of the pensions of people enrolled in the General Retirement Fund was published in 2001 by Decree-Law No. 173/2001<sup>28</sup> of 31 May.

Joint Order No. 861/99 is available at the Portuguese Association of Ostomy<sup>12</sup> website. It establishes a special leave to accompany disabled or chronically ill children, whether adopted or the spouse's child, if they are profoundly disabled or suffer chronic disease confirmed by a statement written by the child's doctor. This information ensures all rights established pertaining to ostomized patients. It is understood that ostomized people have benefitted from public policies and rights to retirement and special leave as they are considered disabled, chronically ill and suffering from oncological disease. These aspects are key elements to achieve the objectives and targets needed to construct the model of care.

## Conclusion

The aim of this study was to examine the Portuguese legislation on the issue of care for ostomized people and their relationship with existing components to construct a theoretical model of targeted intervention for them.

Twenty publications on the subject were found on official websites spanning a period of 28 years.

It was found that in Portugal the rights of ostomates are quite comprehensive according to official documents as presented in this study, with a number of laws on the rights aimed at prevention, rehabilitation and integration of ostomized people as well as social protection schemes such as disability pension, special leave and free medical devices.

Legislation regarding clinical indications for the various types of ostomy is documented in the National Health System standards. The legislation that covers aspects of stomatherapy assistance assigning nursing professionals with specific training and specialists in stomatherapy was perceived as a contribution towards the recognition of the need for stomatherapy as a specialized field in Portugal, since in practice assistance already follows international standards.

Constituent elements to construct the representation of ostomate care in Portugal, through the theoretical care model were found. However, there was a lack of certain elements such as the physical structure of the doctor's surgery and stomatherapy service, adapted bathroom with mirror and hygienic shower, storage location for waste products, computer resources, information systems and the expansion of multidisciplinary teams with physiotherapists, nutritionists, social workers, occupational therapists, etc.

This study proposes the creation of a regulation stemming from existing legislation in order to establish national guidelines focused on attention for ostomized people at the various levels of care including the items mentioned above. In addition, it would be important to use interviews with key informants in ostomy care and hold direct observation in places where assistance occurs for the triangulation of the methods and sources of information.

Year	Legislation	Official documents/objectives	Main Issue	Thematic categories	Sources
1989	Law no. 9/89 of 2 May	Base Law on the Prevention and Rehabilitation and Integration of People with Disabilities	Public policy	People with disabilities	<a href="http://www.apostomizados.pt">http://www.apostomizados.pt</a>
1989	Law no. 1/89, of 31 January	They establish a social protection scheme under special conditions for people suffering from oncological disease, multiple sclerosis and familial amyloidosis, respectively, which because their gravity and rapid evolution quickly develop into situations of disability.	Rights to retirement	Oncological diseases	<a href="http://www.apostomizados.pt">http://www.apostomizados.pt</a>
1990	Order no. 11/90, published in the DR, 2 <sup>nd</sup> Series, 159, 12-7-90	The co-payment to be awarded by the National Health Service to underprivileged patients for ostomy bags was set by Order no. 11/90, published in the DR, 2 <sup>nd</sup> ed., 159 of 12-7-90.	Medical devices	Medical devices	<a href="http://www.apostomizados.pt">http://www.apostomizados.pt</a>
1995	Order 25/95, Ministry of Health, DR, 2 <sup>nd</sup> Series, no. 213, 14-09-1995	Co-payments towards ostomy material by the National Health Service It updates the co-payment in light of the respective prices on the market to 90% of cost. It is aimed at National Health Service patients.	Medical devices	Medical devices	<a href="http://www.apostomizados.pt">http://www.apostomizados.pt</a>
1995	Order of 24/02/1995	Development of special skills in nursing care in hospitals and health centres where there are already qualified nurses	Stomatherapy assistance	Stomatherapy assistance	Printed – Ambulatory nurse of Stomatherapy Consultation São João Hospital Centre (CHSJ)
1997	Decree-Law no. 225/97, of 27 August	Creation of the National Council for the Rehabilitation and Integration of People with Disabilities – Its mission is to enable the participation of public services, social partners and the interventional association movement in the areas of prevention, rehabilitation and integration of disabled people.	Public policy	People with disabilities	<a href="http://www.apostomizados.pt">http://www.apostomizados.pt</a> <a href="https://dre.pt/application/file/194282">https://dre.pt/application/file/194282</a>
1999	Joint Order No. 861/99 -	Characterization of profound disability and chronic disease. It instituted special leave to accompany a child, whether adopted or the spouse's child, who is disabled or chronically ill. Proof of profound disability or chronic disease is through declaration issued by the doctor attending the minor.	Special leave	Oncological diseases	<a href="http://www.apostomizados.pt">http://www.apostomizados.pt</a>

2000	Decree-Law no. 92/2000 of 19 May	Special social protection scheme for people affected by serious oncological diseases. The special protection regulated in this law is concerned with the following types of benefits a) Invalidity pension attributable to the beneficiaries of the general regime b) Social disability pension attributable to the beneficiaries of the non-contributory scheme c) Dependency complement attributable to the beneficiaries of any of the social security schemes.	Retirement rights	Oncological diseases	<a href="http://www.apostomizados.pt">http://www.apostomizados.pt</a>
2000	Decree-Law no. 327/2000, of 22 December	It establishes a social protection scheme, under special conditions, for people suffering from oncological disease, multiple sclerosis and familial amyloidosis, respectively, which because their gravity and rapid evolution quickly develop into situations of disability.	Retirement rights	Oncological diseases	<a href="http://www.apostomizados.pt">http://www.apostomizados.pt</a>
2001	Decree-Law no. 173/2001 of 31 May	Calculation of pensions for subscribers of the General Pension Fund	Retirement rights	Oncological diseases	<a href="http://www.apostomizados.pt">http://www.apostomizados.pt</a>
2015	Decree-Law no. 97/2015, of 1 June	It creates the National Health Technology Assessment System, provides for the co-payments towards medical devices, establishing that the medical devices that can be objects of co-payments are established by ordinance of the member of the government responsible for health.	Medical devices	Medical devices	<a href="http://www.apostomizados.pt">http://www.apostomizados.pt</a>
2016	Order 11233/2016 of 19 September 2016	It establishes provisions to improve accessibility and simplify procedures to access products for absorbing urine and faeces for persons covered under current legislation, as well as, ostomates in obtaining ostomy material, products and accessories. Its aim was to define a strategy that fully leads to electronic prescription for and distribution of these support products in community pharmacies, even though achieving this goal may require a period to develop information systems.	Medical devices	Medical devices	<a href="https://dre.pt/application/file/75353380">https://dre.pt/application/file/75353380</a>
2016	Order 12249/2016 of 11 October 2016	It establishes provisions on awarding public provisioning contracts (PPC) to supply ostomy and elimination material within the scope of public tender (CP 2016/27), issued by the Shared Services of Ministry of Health, E. P. E. (SPMS, E. P. E.) 11/10/2016.	Medical devices	Medical devices	<a href="https://dre.pt/application/file/75504124">https://dre.pt/application/file/75504124</a>

2016	Ordinance no. 284/2016 of 4 November	It establishes the co-payment system for medical devices for the ostomy patients, for beneficiaries of the National Health Service (NHS). It ensures ostomates have access to ostomy materials, products and accessories, thus improving their quality of life and social integration.	Medical devices	Medical devices	<a href="https://dre.pt/application/conteudo/75662180">https://dre.pt/application/conteudo/75662180</a>
2017	Ordinance no. 92-F/2017-1ª of 3 March	It establishes that the State's co-payment amount for the provision of ostomy devices is to be 100% of the product's sale price fixed, for the purposes of co-payment, by terms provided in this order. Its aim is to improve certain aspects, such as the need to make determining products' general and specific requirements autonomous, allowing them to be updated and adapted in accordance with technical progress. It also seeks to identify those products whose prescription may also be written by group name, considering the rule will be to prescribe by brand and model [...] To this end, the government ensures ostomates have access to ostomy materials, products and accessories, thus improving their quality of life and social integration.	Medical devices	Medical devices	<a href="https://dre.pt/application/file/a/106551520">https://dre.pt/application/file/a/106551520</a>
2017	Order no. 2018/2017 of 9 March 2017	It determines the general and specific technical requirements applicable to medical devices to support patients with incontinence or urinary retention in the co-payment system.	Medical devices	Medical devices	<a href="https://dre.pt/application/file/a/106578599">https://dre.pt/application/file/a/106578599</a>
2017	Order no. 2019/2017 of 9 March 2017	It determines the maximum fixed price per medical device group, as well as the general and specific technical requirements applicable to medical devices to support ostomate patients in the co-payment system.	Medical devices	Medical devices	<a href="https://dre.pt/application/file/a/106578599">https://dre.pt/application/file/a/106578599</a>
2017	Rule 014/2016 Date: 28/10/2016 (updated: <b>03/03/2017</b> ) – SNS/DGS [National Health Service/ General Health Directorate]	Clinical Indications and Intervention in Paediatric and Adult Feeding Ostomy	Clinical indications	Clinical indications	<a href="https://www.dgs.pt/.../normas-e...normativas/norma-n-0142016-de-28102016-pdf">https://www.dgs.pt/.../normas-e...normativas/norma-n-0142016-de-28102016-pdf</a>

2017	Rule: 015/2016 Date: 28/10/2016. (updated: 03/03/2017 – SNS/ DGS [National Health Service/ General Health Directorate]	Clinical Indications and Intervention in Paediatric and Adult Colostomy	Clinical indications	Clinical indica- tions	<a href="https://www.dgs.pt/.../normas-e...normativas/norma-n-0152016-de-28102016-pdf">https://www.dgs.pt/.../normas-e...normativas/norma-n-0152016-de-28102016-pdf</a>
2017	Rule: 012/2016 Date: 28/10/2016 (updated: 03/03/2017) – SNS/DGS [National Health Service/ General Health Directorate]	Clinical Indications and Intervention in Paediatric and Adult Urinary Ostomy	Clinical indications	Clinical indica- tions	<a href="https://www.dgs.pt/...da.../normas-e...normativas/norma-n-0122016-de-28102016.asp...">https://www.dgs.pt/...da.../normas-e...normativas/norma-n-0122016-de-28102016.asp...</a>

**THEMATIC CATEGORIES AND CONSTITUENT ELEMENTS OF CARE MODEL FOR OSTOMY FOUND IN THE PORTUGUESE GUIDELINES** 2

Thematic categories	Elements of the Logical Model		
	Structure	Processes	Results
Oncological diseases			x
People with disabilities			x
Medical devices	x	x	x
Stomatherapy assistance	x	x	x
Clinical Indications	x	x	x

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# CINTESIS

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# Assessment of effectiveness of a communication skills program for nursing students

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## Summary

Effective communication promotes the quality of nursing healthcare; therefore, communication skills are considered a basic tool in nursing (Bloomfield & Pegram, 2015). One challenge nursing students and newly-graduated nurses encounter is to improve those skills (Sheldon & Hilaire, 2015; Theisen & Sandau, 2013). In Portugal, intervention programs addressing these competences among nurses are scarce (e.g., Torres, Soares, Ferreira & Graça, 2016; Lopes, Azeredo & Rodrigues, 2013). The purpose of our research is to assess the effectiveness of a communication skills program for nursing students, and also to analyze the impact of the following variables: perceived importance of communication skills for nursing, perceived competence on communicational skills, emotional intelligence, and empathy. To address these goals we will conduct a quasi-experimental study using a nonequivalent control group pre–posttest design. To assess the effectiveness of the intervention program, participants will complete a communication skills test (pre-test and post-test). Participants will rate the importance and self proficiency in communication skills using a 6-point scale. To measure emotional intelligence and empathy we will use Portuguese versions of the following scales: WLEIS - Wong and Law Emotional Scale (Carvalho, Guerrero, Chambel & Gonzáles-Rico, 2016; Wong & Law, 2002), and IRI - Interpersonal Reactivity Index (Davis, 1983; Limpo, Alves & Castro, 2010). The results we present here will contribute to the understanding of variables that influence communication skills among nurses, as well as pedagogical strategies that can effectively enhance those abilities.

KEYWORDS: NURSING; COMMUNICATION SKILLS; EMOTIONAL INTELLIGENCE; EMPATHY.

## Introduction

Communication is a highly complex and dynamic process, involving the continuous giving and receiving of feedback. The inner characteristics of the sender and the receiver (e.g., values, culture, and social roles; knowledge; communication abilities and other psychological variables), along with the features of the social and physical context interact to assign meaning to the message (Bach & Grant, 2009). An important issue of communication is that it relies largely on the interpretation of the message.

Nurses are significantly involved in the care and support of patients and their relatives; hence their communication skills have an important impact (Coyle, Manna, Shen, Banerjee, Penn, Pehrson et al., 2015). Yet, the scena-

rio and circumstances where nurses interact tend to be particularly demanding: besides task overloaded, lack of time, of support, and staff conflict, nurses intervene frequently in critical situations, both physically and emotionally. Consequently, nurses may experience difficulties in accommodating their communication to cope with such situations, fearing the patient may feel even more distressed (Bramhall, 2004). Patient barriers may also impair communication, for example when they are unable to communicate by normal means, due to restrictions imposed by invasive medical procedures (Kourkouta & Papathanasiou, 2014), or to the use of a different language, or to sensorial impairments (Phaneuf, 2005). Patients can also feel difficulties explaining their feelings because of their fears and anxiety of being judged, or because they may be perceived as weak persons, or because they are simply afraid to reveal emotional disturbance. Other sorts of healthcare barriers can have a negative impact on nurse-patient communication, such as the effect of noise, the lack of privacy and control (Bramhall, 2004).

In order to ensure a patient-focused nursing practice, Bramhall (2004) highlights the following com-



munication skills: *empathizing* or recognizing another's emotions and perspectives (e.g., saying something that reveals our appreciation of another's feeling); *active listening* (e.g., acknowledging and summarizing); *use of minimal prompts* (e.g., nodding), *reflecting* (e.g., use of one's own words to ensure that he/she understood the message correctly); *making educated guesses*; *interpreting verbal and non-verbal cues*; *using appropriate pauses and silences*; *keeping the psychological focus* or recognizing and responding to emotions, feelings and concerns (e.g., ask about patient's feelings); and *negotiating*. Beyond that, other authors mention the following skills: the ability to interpret and to use body language (e.g., mirroring); cultural awareness; voice management skills (pitch and intonation); verbal skills; and written communication skills (clarity, coherence, knowledge of medical terminology, abbreviations and acronyms) (Trifkovic, Lorber, Denny, Denieffe & Gönc, 2017).

Since good communication entails benefits for the patients and health-care professionals (Stein-Parbury, 2014), it is generally agreed that effective communication is an essential tool for those professionals. For instance, NMC (Nursing and Midwifery Council) recognizes communication as a cornerstone of high quality nursing care (CCC triad - Care, Compassion and Communication) (Bloomfield & Pegram, 2015). Effective communication enhances the quality of nursing practice, including the client's satisfaction and treatment adherence (Trifkovic et al., 2017); it also fosters the recognition of the patient's physical and emotional needs and his/her beliefs concerning the health-disease process and coping strategies; it motivates patients toward beneficial behavioral change or acceptance of his/her clinical condition; and it increases the patient's perception of control over his/her health condition (Phaneuf, 2005; Kelley & Kelley, 2013; van Vliet & Epstein, 2014; Webb, 2011). Moreover, communication competencies are essential to working successfully in groups, particularly in multidisciplinary teams.

As we mentioned earlier, the nurse's framework, namely his/her self-perception, influences the effectiveness of communication. Some studies show that patients evaluate communication competencies less favorably than the nurses do (Timmins, 2007). Regarding social perceptions, a study with midwives conducted by Kirkham, Stapleton, Curtis and Thomas (2002) illustrates some tendency (among some professionals) to endorse a stereotyped perception about their clients; for example, misjudging their ability and willingness to participate in healthcare. According to these authors, stereotyping is used as a professional defense mechanism, enabling midwives to keep control whenever they lack autonomy and power to produce organizational changes. A hermeneutic phenomenological research, developed by McCabe (2004), also stresses the impact of organizational culture on nurses' communication approaches with their patients. McCabe (2004) found that nurses can communicate appropriately with their patients using a *patient-centered communication*, which encourages the patient to negotiate and decide regarding decisions concerning their own care (Langewitz, Eich, Kiss & Wossmar, 1998), contrary to a *task-centered communication*. However, according to the patient's interview responses, even though nurses have the ability to establish a patient-centered communication approach, the organizational culture and workload can influence them to adopt a task-centered approach (McCabe, 2004).

Another important variable, we believe should be considered, is the effect of the growing use of technology in healthcare, which may encourage nurses, erroneously, to pay less attention to therapeutic communication. As Phaneuf (2005) stresses, when nurses devalue communication skills, they tend to establish an impersonal relation with the patient, which *objectifies the patient*. According to this mechanistic perspective, the person as a whole

lacks real value, leading nurses to direct their care to a *body-object*, and not to a *person-subject*; thus, "*patient care* and *caring about patients* should go hand in hand" (Chochinov, 2103, p. 756).

Research shows that one challenge nursing students and newly-graduated nurses face is to improve their communication skills. A critical review of studies, conducted by Theisen and Sandau (2013) showed that communication is among the six competences that newly-graduate nurses must master to be successful. Sheldon and Hilaire (2015) showed also that half a year after graduation, only 59.7% of the nurses felt confident communicating with patients and families *most of the time*, and approximately the same percentage (50.3%) felt confident communicating within interdisciplinary teams *most of the time*; in addition only 56.5% of the respondents are satisfied with their communication skills *most of the time*. The degradation of communicational competencies, along with insufficient and/or inadequate training (e.g., training with an emphasis on theoretical aspects) might be important variables to explain the difficulties of students and newly-graduated nurses concerning communication abilities (Chant, Jenkinson, Randle & Russell, 2002; Suikkala & Leino-Kilpi, 2005). Despite the development of communication skills being dependent on experience, and not just acquisition of knowledge, according to Sheldon and Hilaire (2015), nursing programs should involve more training and role-playing in order to foster the development of communication skills in the formation of young healthcare professionals.

*Emotional Intelligence* is intricately associated with communication skills. Theoretical approaches to emotional intelligence either conceive it as a set of discrete skills, according to a process information approach, or in a more global perspective, describing a general pat-

tern (Mayer, Salovey, Caruso & Cherkasskiy, 2011). However, there is some consensus that emotional intelligence “involves the ability to carry out accurate reasoning about emotions and the ability to use emotions and emotional knowledge to enhance thought” (Mayer, Roberts & Barsade, 2008, p. 507). A systematic review of the evidence of emotional intelligence in medicine revealed that higher emotional intelligence is positively correlated with communication skills (Cherry, Fletcher, O’Sullivan & Dornan, 2014). Similar research with nurses is scarce. A study conducted by Beauvais, Brady, O’Shea and Griffin (2011) also found that among nurses, emotional intelligence is positively correlated with performance, and especially with relationships and communication skills. A study conducted by Ilieová, Juhásová and Baumgartner (2013) revealed lower levels of social awareness, emotional management and stress management among a group of nursing students. The authors stress that emotional intelligence has an impact on social and communication skills, and that as an ability it can be enhanced through training.

A hallmark of emotionally intelligent behavior is *empathy*, given that it is crucial to perceive and understand other’s emotions (Salovey & Mayer, 1990). In fact, in two studies was shown that emotional intelligence is associated with perspective taking, a cognitive dimension of empathy, according with Davis (1983) (Schutte, Malouff, Bobik, Coston, Greeson, Jedlicka et al., 2001, Studies 1 and 2). Moreover, Harlak, Gemalmaz, Gurel, Dereboy and Ertekin (2008) found that communication skills training had a positive effect on empathic tendency in students that initially scored lower in that dimension.

### Problem statement

Because the ability to communicate is among the major challenges of nursing practice, and because this ability must be developed starting at the initial training stage of nursing students, we aim to evaluate the efficacy of a communication competencies program targeted at first year nursing students. We also aim to analyze the effect of the following variables for communication performance of nursing students: 1) importance attributed to communication skills for nursing, 2) perceived competence concerning communication skills, 3) emotional intelligence, and 4) empathy.

### Research questions

The main research question of the study is to know if the participation in a three week communication skills program will increase the performance of first year nursing students in a post-test. In addition, we aim to analyze how communication skills vary as a function of: 1) students’ perception regarding the importance of communication skills for nursing, 2) competence in communication skills, 3) level of emotional intelligence, and 4) empathy.

We hypothesize that after attending the intervention program, students will show a better performance on the communication skills test, compared with their counterparts. In addition, we predict that the most proficient students at testing will be those that value communication skills for nursing the most, perceive themselves as competent in that dimension, and show higher-than-average levels of emotional intelligence and empathy.

### Purpose of the study

In Portugal, the intervention programs in this area are still scarce (e.g., Torres, Soares, Ferreira & Graça, 2016; Lopes, Azeredo & Rodrigues, 2012; Lopes, Azeredo & Rodrigues, 2013). Therefore, with this study we aim to contribute to the development of strategies that can foster the students’ abil-

ities to communicate effectively in real nursing practice scenarios. We stress the importance of promoting these skills starting at the beginning of their graduation studies, enabling the practice of these skills in several clinical *practicums*, which in Portugal take place in the second or third year of a bachelor in nursing.

## Research methods

### Design

The study will be comprised of a quasi-experimental pre- and post-test design, with an experimental group (subjected to the intervention program) and a non-equivalent group.

### Participants

Both groups will be composed of first year bachelor nursing students attending Fernando Pessoa University. Students that have participated previously in a similar intervention program in the last two years and/or have attended any clinical *practicum* will be excluded from the present research. Participation in the study will be voluntary.

### Procedure

Before the intervention program, at the pre-test stage, both groups will fill out a brief questionnaire comprised of demographic questions, and be instructed to rate their agreement (using a 6-point Likert scale and two verbal anchors *1 - strongly disagree*, and *6 - strongly agree*) concerning importance of communication skills for nursing, and their perceived competence in communication skills. Then, they will be given Portuguese versions of *Wong and Law Emotional Scale* (Wong & Law, 2002) to assess their emotional intelligence and their *Interpersonal Reactivity Index* (IRI) (Davis, 1983) to evaluate their empathy. The pre-test stage will be concluded with a test to check their communication skills. This test will enable us to ensure if the groups were equivalent before the intervention program and to examine differences in performance after the intervention

program. The test will be comprised of a hypothetical situation involving a nurse and a patient, and students will be asked to write down what the nurse should say and do.

One week after the intervention program both groups will perform the post-test, that will be comprised of a test similar to the pre-test (but involving a different situation); and again the students will be asked to answer the same Likert scale items. In addition, the experimental group will be instructed to complete a Likert scale questionnaire to assess the intervention program (comprising statements to be assessed with a 7-point scale with two verbal anchors on the extremities).

### Measures

A Portuguese version of WLEIS - Wong and Law Emotional Scale (Wong & Law, 2002) will be used to assess students' levels of emotional intelligence. The WLEIS is a 16 items scale, divided in four subscales: 1) *self emotion appraisal*, 2) *others' emotion appraisal*, 3) *use of emotion*, and 4) *regulation of emotion*. The scale has a 7-point Likert scale, ranging from 0 - *totally disagree* and 6 - *totally agree* (Wong & Law, 2002). The scale was translated and adapted by Carvalho, Guerrero, Chambel and Gonz ales-Rico (2016). Confirmatory factor analysis supported the distribution of all items across the four factors. Concerning internal consistency reliability, WLEIS showed good reliability: [*Cronbach's Alpha*<sub>(Self Emotion Appraisal)</sub> = 0.83; *Cronbach's Alpha*<sub>(Others' Emotion Appraisal)</sub> = 0.82; *Cronbach's Alpha*<sub>(Use of Emotion)</sub> = 0.89, and *Cronbach's Alpha*<sub>(Regulation of Emotion)</sub> = 0.85]. In addition, convergent and discriminate validity analysis also supported good psychometric properties of the scale (Carvalho et al., 2016).

The Portuguese version of IRI - Interpersonal Reactivity Index (Davis, 1983) was translated and adapted to the Portuguese context by Limpo, Alves and Castro (2010). The IRI is a widely used self-report measurement developed by Davis (1980, 1983), design to assess empathy in affective and cognitive dimensions. The scale comprises four subscales: 1) *perspective taking*, 2) *empathic concern*, 3) *personal distress*, and 4) *fantasy*. The Portuguese version of IRI includes 24 items, four less than the original scale (one for each subscale - 1, 10, 15 and 18). Each item has to be answered on a 5-point Likert scale, ranging from 1 - *does not describe me well* to 5 - *describes me very well*. The factorial confirmatory analysis with 24 items showed that the Portuguese version of IRI is a good measure of the multidimensional analysis developed by Davis (Limpo et al., 2010). Moreover, the four subscales have good reliability [*Cronbach's Alpha*<sub>(Perspective Taking)</sub> = 0.73; *Cronbach's Alpha*<sub>(Empathic Concern)</sub> = 0.76; *Cronbach's Alpha*<sub>(Personal Distress)</sub> = 0.80 e *Cronbach's Alpha*<sub>(Fantasy)</sub> = 0.84] (Limpo et al., 2010).

### Intervention program

The intervention program will be based on the Person-Centered Approach of Carl Rogers (1974) and in I\*CARE (Program for Interpersonal Communication and Relationship Enhancement) developed by Baile of MD Anderson Cancer Center (2014). I\*CARE comprises a set of protocols to guide physicians to communicate effectively with their patients. Since nursing students are familiar with procedure protocols we will teach the skills using protocols. This methodology has also the advantage of facilitating the memorization and retrieval of the key aspects of each class. The following I\*CARE protocols will use: E-V-E to cope with emotional situations; C-L-A-S-S for interviews; S-P-I-K-E-S to inform about bad diagnosis and reserved prognostics; C-O-N-E-S to give bad news; and B-U-S-T-E-R for difficult arguments. Every protocol will be slightly adapted for nursing practice.

The program will be composed of four sessions. Session 1 will be introduc-

tory; after that session students will be able to: identify the advantages of establishing a good interpersonal communication in nursing practice; identify the main characteristics that according with Carl Rogers's humanistic approach (1974) should orient a therapeutic relationship (congruence, unconditional positive regard, and empathy); and to identify verbal and non-verbal behaviors that mirror the mentioned attitudes. The next sessions will be thematic: students will discuss case studies describing an interaction between a nurse and a patient/family member and will learn how to communicate effectively using the referred I\*CARE protocols. In all sessions students will practice the communication techniques in *role-playing* situations.

### Conclusion

The described project, which will be implemented in 2017-2018 academic year, aims to contribute to the understanding of variables that influence communication skills among nurses, and the pedagogical strategies that can effectively enhance those abilities.

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# Parental perception of toddlers body image

## Summary

Currently, weight disorders, have reached a large part of the world population. Obesity in children, including toddlers, is a serious public health problem. There are many parents who do not recognize their children's overweight/obesity and toddlers parents are less likely to recognize this problem.

It is known that identifying overweight/obesity is critical to implementing prevention strategies and interventions as early as possible.

We carried out a descriptive study of quantitative approach. It was applied: "Toddler Silhouette Scale" to parents of toddlers who attend day care centers in located the district of Viseu, Portugal. Data processed using IBM-SPSS24.

It was concluded that 83.3% of the parents reported that their child had normal weight, 13.3% underweight and 3.3% overweight. Regarding the silhouette that they consider ideal, the totality of the parents, select silhouettes referring to the normal weight. In the evaluation of the current silhouette of the child, 6.7% opts for the image 1 (low Weight) and 3.3% for the image 6 (overweight), all the others select images of normal weight. According to the weight records of the individual health report, 3.3% of the children were underweight, 10% overweight and 6.7% obese. Our results corroborate those of the author of the scale who concluded that most parents correctly identify the silhouette that matches their child's actual weight. A study carried out in Portugal, revealed an absence of parental perception about the excess weight of the children.

KEYWORDS: BODY IMAGE; PARENTS; NUTRITIONAL STATUS; TODDLERS.

## Introduction

Currently, weight disorders, both low and overweight, have reached a large part of the world population<sup>1</sup>. Obesity is a chronic disease that presents a higher prevalence than malnutrition or infectious diseases, and is thus presented as the global epidemic of the 21st century<sup>2</sup>.

The increase in the prevalence of overweight and obesity in childhood is considered to be a public health problem worldwide<sup>3,4</sup>, affecting also toddlers (1 to 3 years old).

It is estimated that 42 million children under 5 years old were overweight or obese in 2015, an increase of about 11 million in the last 15 years<sup>4</sup>.

Portugal was no exception, a study carried out<sup>5</sup> revealed that in toddlers the percentage of overweight girls and boys was 15% and 13.3% and with obesity of 2.8% and 3.5%, respectively. The authors also reported that almost 28% of Portuguese children were overweight or obese (19.7% and 8.2%, respectively), with a higher prevalence in girls than in boys.

This problem deserves special attention, since childhood obesity is directly associated with the persistence of this condition in adulthood and with the greater occurrence of associated comorbidities<sup>6</sup>. Eating habits and pref-

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erences built during childhood persist for life<sup>6</sup>, with the family having a strong influence on children's diet and lifestyle<sup>7,8</sup>. Thus, parents play an important role with regard to the nutritional status of children and the prevention of overweight and obesity<sup>6,9</sup>.

Theoretically, the proper nutritional status (eutrophic) results from the balance between food consumption and organic nutritional needs at each stage of life. Imbalances in this relationship are manifested in nutritional deficiencies (general or specific deficiencies of energy and nutrients) or nutritional disorders (caused by scarcity or excess of food that lead to malnutrition or obesity<sup>10</sup>).

Up to 5 years of age, children are experiencing an accelerated growth process, which makes this period vulnerable to the occurrence of nutritional problems. It is therefore fundamental that health professionals evaluate and monitor the growth and development of these children<sup>10</sup>.

The first step in preventing childhood obesity is to identify overweight children. There are many parents who do not recognize the overweight / obesity of the offspring, some authors suggest that the parents of toddlers are less likely to recognize this problem<sup>11</sup>. Parent's

satisfaction or dissatisfaction with their children's bodies, and the assumptions that they are fat or thin, can influence the child's satisfaction with his or her own body. Studies in different populations revealed that most parents could not associate body image and actual weight of their children<sup>12,13</sup>.

Parents need to recognize and be prepared to take precautions about their child's overweight<sup>14,15</sup>. Hence, awareness of the nutritional status of children should be the first approach in the implementation of strategies to prevent or regress the epidemiological picture of childhood obesity, which we are facing today. The efficacy of health programs to combat overweight implies a recognition by the parents regarding the correct nutritional diagnosis of the children and also the possible health consequences in the short, medium and long term<sup>16</sup>.

Obesity is a chronic condition that can have serious health consequences<sup>17</sup>, since it increases the risk of diabetes, hypertension, cardiovascular disease, cancer, sleep apnea<sup>4,17</sup>. Over the years it has been shown that overweight or obesity has negative effects on the psychosocial adaptation of children and adolescents<sup>18</sup>.

Because of the low success rate in treating childhood obesity, prevention is the most appropriate strategy to combat the growing number of overweight children. Family-focused intervention is critical to produce changes in eating and physical activity behaviors, promoting a healthy lifestyle that should support parent-child relationships<sup>19</sup>. The altered perception of the parents about the nutritional state and body image of the children represents an obstacle, with respect to the adoption of healthy habits of physical activity and food. In this sense, the lack of perception of the excess weight of the children can be a factor that contributes to the development of childhood obesity<sup>16,19</sup>. Adequate perception of the nutritional status of the children by the parents is essential for the early recognition of overweight and obesity<sup>9,20</sup>.

The family plays a key role in food education and nutritional monitoring of children, as tastes and food preferences are shaped by the habits and behaviors acquired within the family. It is the responsibility of parents to provide an environment conducive to healthy child growth and to the adoption of healthy behaviors and habits<sup>16</sup>. They determine which foods are available to the child in quantity and quality, and are most responsible for establishing an emotional environment in which obesity can or can not be discouraged.

Food diversification is a crucial factor for the child's growth and development. At 12 months children should be included in the family food standard, provided that it follows the principles of a balanced and varied diet. It is in this age range that food preferences begin to shape and many are maintained throughout life. It is therefore of paramount importance that parents / family be able to reconcile the introduction of new foods with their educational role, helping to build healthy habits<sup>16</sup> in order to avoid underweight or overweight / obesity of their children.

Nutritional surveillance aims to promote and protect the child from the adverse effects that an inadequate nutritional status (sub or overnutrition) can have on children's current and future health<sup>21</sup>. The identification of overweight / obesity in toddlers is fundamental for the implementation of early prevention and intervention strategies<sup>14</sup>. This identification is evaluated by nutritional status. The most commonly used index to characterize nutritional status is the Body Mass Index (BMI) – weight to square of height quotient since it is an easy to use, inexpensive, non-invasive and relatively sensitive method<sup>22</sup>.

Anthropometry is, therefore, the method of measurement that evaluates the process of the body growth of children and adolescents. This allows the assessment of the nutritional state of children and adolescents, at in-

dividual and community level<sup>22</sup>. The Portuguese Directorate-General for Health (DGS) affirms that growth curves are an extremely important instrument for monitoring the nutritional status and growth of children and adolescents, allowing the early identification of excess weight, a problem of concern and high prevalence in Portugal<sup>23</sup> and the identification, not only of children and adolescents who are already obese, but also of those at risk of becoming obese<sup>24</sup>.

The BMI value in pediatric age should be evaluated in percentiles, as well as anthropometric variables, which serve as the basis for its calculation, based on WHO reference tables, is:

- a) BMI values of percentile < 3 allow the diagnosis of low weight;
- b) Values of BMI percentile  $\geq 3$  and < 85 allow to make the diagnosis of normal weight;
- c) Values of BMI percentile  $\geq 85$  and < 97 allow the diagnosis of overweight;
- d) Values of BMI percentile  $\geq 97$  allow the diagnosis of obesity<sup>2,23</sup>.

The use of body image assessment instruments can be an aid in detecting parents' perception of the nutritional status of their children.

The Silhouettes Scales consist of a set of style figures, usually silhouettes or schematic drawings, which vary according to body size. They allow parents to choose the image they consider to be more like their child ("real" body image) and what they would like them to have ("ideal" body image)<sup>15, 25</sup>. The discrepancy between "real" and "ideal" body image is used as an indicator of dissatisfaction with body image<sup>15, 25</sup>.

Parental perception of the nutritional status of the children is essential for the prevention and treatment of nutritional disorders, since it is the recognition of an altered nutritional status that generates concern for the state of health and represents the first step in the search for health care<sup>9</sup>. Several studies that ad-

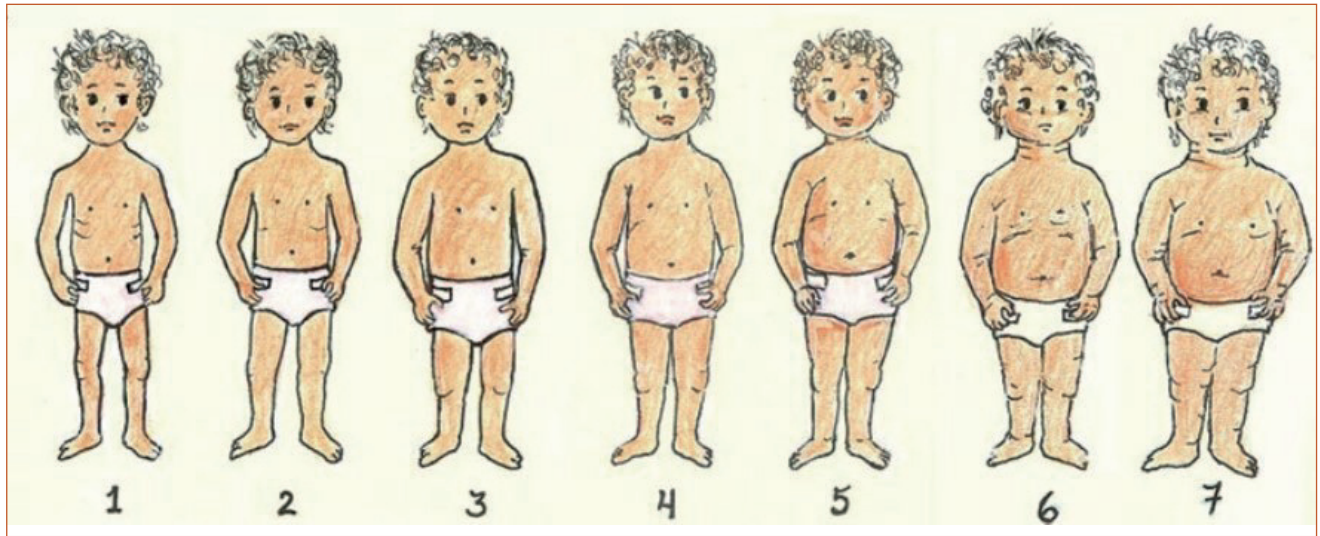


Figure 1. Toddler Silhouette Scale. Hager, McGill & Black<sup>14</sup>.

dress the maternal perception of children's nutritional status indicate that mothers present difficulties in recognizing cases of overweight or obesity<sup>9,13</sup>. Others have shown that this difficulty causes parents to tend to underestimate the nutritional status of their children and therefore do not worry about the consequences of overweight in childhood<sup>13</sup>.

Thus, parents need to be guided and elucidated to the importance of healthy eating as well as habits of physical activity that contribute to the maintenance of family health and quality of life. It is thus essential that the nurse implements strategies that involve the family through health education and alert the importance of acquiring healthy habits.

### Methods

This is a descriptive exploratory study with a quantitative approach. The purpose of the study was to test the instruments that will be used in a study that is being carried out with parents of children between 12 and 36 months in the central region of Portugal, in order to identify the eating habits of toddlers, to determine the prevalence of underweight, weight and obesity in the toddler, identify parental perception about the silhouette of toddlers, analyze parental knowledge, about toddlers feeding.

The population of this study is made up of the parents of children between 12 and 36 months old, of both sexes, attending public and private day care centers in the district of Viseu, Portugal. The convenience sample consisted of 30 parents.

The following inclusion criteria were defined in the sample:

- Being a parent of a child between 12 and 36 months of age, not suffering from chronic diseases that may directly interfere with the nutritional status.
- Accept participation in the study.

For data collection, a questionnaire on toddlers' dietary habits and physical activity was used, encompassing the Toddler Silhouette Scale<sup>14</sup>. The data was collected during the pre-test of the instrument from January to June of the year 2017.

All participants signed the informed consent document.

Data were processed using the IBM Statistical Package for Social Sciences (SPSS) 24. Descriptive and inferential statistics will be used for data processing. For the diagnosis of children's nutritional status, the WHO<sup>2</sup> international criteria were used.

The Toddler Silhouette Scale is a seven-point scale, created and validated in 2010 by Hager, McGill & Black<sup>14</sup> to assess perception and satisfaction with the body size of children between 12 and 36 months of age. It allows you to evaluate the silhouette that parents consider ideal for their child and which one most closely resembles the child's current silhouette.

### Findings and discussion

It was concluded that 83.3% of the parents reported that their child had normal weight, 13.3% underweight and 3.3% overweight. Regarding the silhouette that they considered ideal, the totality of the parents selected silhouettes referring to normal weight (figure 1: image 2, 3, 4 and 5). In the evaluation of the current silhouette, 6.7% opted for image 1 (referring to low weight) and 3.3% for image 6 (overweight) (figure 1) all the others selected images of normal weight.

When comparing the two answers, no parents considered the image 1 (low birth weight) (figure 1) as ideal, but 6.7% thought that their child had this silhouette. No parents considered silhouette 6 to be ideal (overweight) (figure 1) but 3.3% considered it to be the current silhouette of their child. Regarding the silhouettes corresponding to the

normal weight (image 2 to 5) 46.7% of the participants considered them as an ideal silhouette. 43.3% of the parents considered silhouette of the image 4 as the current silhouette of their child.

We concluded that the majority of children (80%) had normal weight and 3.3% low weight, 10% overweight and 6.7% obesity.

Comparing the current percentile of toddlers and parental perception, we verified that 6.7% of the cases identified by the parents as underweight had in fact normal weight and 6.7% cases identified as normal weight were actually overweight. 3.3% of the parents reported that their child was overweight (figure 1: image 6) which did not correspond to reality because the child was in the normal weight percentile. The same percentage of parents reported that their child had normal weight (figure 1: image 3), yet it was found to be in the low weight percentile.

Our results corroborate those of the author of the scale who concluded that most parents correctly identify the silhouette that corresponds to their child's actual weight, although some parents have with difficulty in perceiving the silhouette of their children.

Likewise, our results support those obtained by other researchers. In a study carried out in Portugal, there was an absence of parental perception about children's overweight<sup>26</sup>. Other study comparing the parents' real perception with the nutritional status of the children through the BMI percentile, concluded that parents do not recognize the existence of obesity in their children, since they do not attribute body image proper<sup>27</sup>.

## Conclusion

In this study, as in others, the results indicate that some parents have a distorted perception of the children's body image, and there is a tendency to underestimate the true nutritional status of the children<sup>16</sup>.

The lack of parental perception about the nutritional status of the children can condition the adoption of preventive measures or treatment to states of excess weight. Thus, the identification of low weight / overweight / obesity in toddlers is fundamental for the implementation of prevention and intervention strategies as early as possible.

In order to intervene on the problem of low weight / overweight / obesity in the child, it is important for the nurse to evaluate the parental perception of the child's body image.

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# Topical ozone therapy effectiveness in the treatment of venous leg ulcers

## Systematic review

### Summary

**BACKGROUND.** Topical ozone has been recently used in the treatment of venous leg ulcers due to its immunological, antimicrobial and oxygenation properties, but its efficacy still lacks evidence.

**OBJECTIVES.** To determine the effectiveness of topical ozone therapy in the healing rate, healing time reduction and in the decrease of bacterial load in venous leg ulcers.

**METHODS.** A systematic literature review with meta-analysis of studies published between January 2000 and November 2016 was carried out on PubMed, EBSCO, Scielo, and grey literature. The methodology proposed by Cochrane was followed. Critical appraisal, data extraction, and data synthesis were performed by two independent reviewers.

**RESULTS.** Among 275 studies screened, three controlled trials (one of which randomized) were included, corresponding to a total of 133 participants. All these trials demonstrated that ozone therapy is more effective than conventional therapy in healing rate, as well as in reducing healing time and signs of infection (bacterial load). The meta-analysis confirmed the higher efficacy of ozone therapy in the healing rate (Odds Ratio = 7.28; CI 95% = 3.56 to 14.89;  $p < 0.001$ ). For the other outcomes it was not possible to perform meta-analysis due to the use of different assessment methods.

**CONCLUSIONS.** Topical ozone therapy may be a therapeutic option for the treatment of venous leg ulcers. However, more randomized and controlled studies are needed to evaluate its efficacy in reducing healing time and bacterial load, as well as on the safety of this therapy. It is also important that these studies use uniform therapeutic and assessment methods.

**KEYWORDS:** OZONE THERAPY; VENOUS LEG ULCER; WOUND HEALING.

### Introduction

Medical ozone consists of a mixture of 95% pure medicinal oxygen and 1-5% ozone obtained from an electric discharge through an ozone generator, having a half-life ranging from 45 minutes to 2 years, depending on the storage method<sup>1</sup>. Ozone therapy consists on the topical or systemic application of a mixture of oxygen and medical ozone in low doses, conferring immunological, antimicrobial and oxygenation properties<sup>2</sup>. Topical ozone can be applied by transcutaneous immersion of ozone (ozone in the gaseous

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state), ozonated oil or cream and ozonated water<sup>3,4</sup>.

Dose is a key aspect of this therapy since, like other gases or medicines, ozone can have an ambivalent effect, i.e. toxic or beneficial to the body, depending on whether it is used in high or low doses to induce a moderate oxidative stress and consequent beneficial adaptive response of the organism<sup>4,5</sup>. The mechanism for the improvement of body oxygenation is through the eradication of toxic products of cellular metabolism and consequent improvement of the body's immune defence mechanisms<sup>6</sup>. By reacting with the unsaturated fatty acids in the cell membranes, ozone forms a series of substances that act on oxyhemoglobin, releasing oxygen, thus producing an increase of its availability in the tissues<sup>5</sup>. In turn, this mechanism activates the proliferation of fibroblasts, which will build up the extracellular matrix, providing the migration and proliferation of keratinocytes<sup>7</sup>.

The properties indicated above support the use of ozone therapy in the treatment of wounds, especially

## BOOLEAN FORMULA APPLIED TO THE PUBMED DATABASE

1

Database	Boolean Formula
PubMed	<pre> ((((("Leg Ulcer"[MeSH Terms] AND Humans[Mesh])) OR (("Leg Ulcer"[MeSH Terms] OR "varicose veins"[MeSH Terms] OR varicose vein[Text Word] OR "varicose ulcer"[MeSH Terms])) AND Humans[Mesh])) OR (("venous leg ulcer" OR "Varicose Ulcer" OR "hypertension leg ulcer" OR "venous stasis ulcer" OR "varicose veins")) OR (("Leg ulcer" OR "varicose ulcer")) AND (((ozone) OR ("ozone the- rapy" OR "ozonotherapy" OR "ozone" OR "ozone oil" OR "oxygen-ozone mixture" OR "gaseous ozone" OR "ozone" OR "topical ozone" OR "ozone bag" OR "ozone water" OR "ozone saline" OR "ozone water")) OR "ozone"[MeSH Terms])) AND (((((((("wound healing"[MeSH Terms] OR "re-epithelialization"[MeSH Terms] OR "granulation tissue"[MeSH Terms] OR ("wound size" OR "wound healing rate" OR "cicatrizacion" OR "cicatrizacion rate")) OR ("Heal- ing, Wound" OR "Healing, Wound" OR "Wound Healing" OR "Re-Epithelialization" OR "Wound Epithelialization" OR "Epithelialization, Wound Granulation Tissues" OR "Tissue, Granulation" OR "Tissues, Granulation")) OR "bacterial load"[MeSH Terms] OR "wound infection"[MeSH Terms] OR ("wound infection" OR "infection rate" OR "bacterial load")) OR ("bacterial biofilm" OR "biofilm")) </pre>

those that are difficult-to-heal (i.e. chronic), for which conventional methods have not been effective<sup>8</sup>. Among difficult-to-heal wounds, venous leg ulcers are currently a major public health problem, as they account for about 70% of leg ulcers and affect about 1-1.5% of the world adult population<sup>9</sup>. Their impact in the daily activities of individuals and families is significant, as well as they represent a significant financial burden for the health systems, given the high resource consumption associated with their long evolution and frequent complications such as infections<sup>10</sup>. Microbiological studies suggest that about 80% to 100% of leg ulcers may be colonized<sup>11</sup>.

The gold-standard treatment of venous leg ulcers remains compressive therapy<sup>12</sup>, and a variety of agents can be used concomitantly as primary wound dressings. Among these dressings are debridants, exudate control and/or antimicrobial agents<sup>10</sup>.

In view of the above, this study aims to determine the efficacy of topical ozone therapy in the healing rate, reduction of healing time, and in the decrease of bacterial load in venous leg ulcers.

## Methods

A systematic literature review (SLR) was performed following the guidelines of the Cochrane Handbook<sup>13</sup>.

The following inclusion criteria of the studies were defined:

- Participants: Adults between the ages of 18 and 85 years, with venous leg ulcers.
- Intervention: Topical ozone therapy.
- Comparisons: Conventional treatment (wound dressings and topical antimicrobials, etc.).
- Outcomes: Healing rate, healing time, signs of infection or bacterial load.

We only considered randomized controlled trials (RCTs), quasi-experi-

mental studies/non-randomized trials (NRT) or systematic literature reviews of the theme, published in Portuguese, English, French or Spanish. Exclusion criteria included: studies involving lower limb ulcers of arterial, mixed or diabetic aetiology, animal or in vitro studies, or the systemic application of ozone.

## Search strategy and study identification

The search strategy was defined taking into account the index terms and text words conjugated with the Boolean operators. The search was initiated in PubMed Database (table 1) and subsequently adapted to the other databases: EBSCO (CINAHL Complete, Cochrane Database of Systematic Reviews, Cochrane Central Register of Controlled Trials, Medication, Nursing & Allied Health Collection: Comprehensive), and SciELO. Grey literature was also considered by screening the abstracts notebooks of the International Ozone Therapy Congresses.

Studies published from January 2000 to November 2016 were included. This lower limit was decided since the first published scientific studies on the effects of ozone therapy on human health only emerged at the beginning of the 21st century.

The selection of the studies was performed by two researchers (EE and RF) who decided after consensus which studies to include following the previously defined criteria. If needed a third researcher (MC) participated in this process.

Finally, the list of bibliographic references of all studies included was analysed to identify additional studies.

## Methodological quality assessment of the studies

The critical evaluation of the retrieved studies was performed by two independent reviewers (EE and RF) based on two instruments, namely: i) the "Grid for the critical evaluation of an article describing a prospecti-

Author, Year (Country)	Study design /Population	Interventions	Outcomes	Conclusions	Critical quality appraisal
Hernández & González, 2001 (Cuba)	NRT SG – n=22 CG – n=22	SG – Topical Ozone therapy + conventional treatment CG – Conventional treatment	<p><u>Healing rate:</u> SG = 90.9%; CG = 59% (<math>p &lt; 0.05</math>)</p> <p><u>Wound size reduction:</u> Not calculated</p> <p><u>Healing Time:</u> Not calculated; SG = 20-30 treatment sessions; CG &gt;30 treatment sessions</p> <p><u>Bacterial Load:</u> SG = 90.9%; CG = 68.1% (<math>p &lt; 0.05</math>)</p>	In the SG healing rate was higher, the time to healing was shorter (fewer treatment sessions) and bacterial load was reduced more effectively.	8 Points
Gutiérrez et al., 2009 (Cuba)	NRT SG – n = 30 CG – n = 30.	SG – Topical Ozone therapy + conventional treatment CG – Conventional treatment	<p><u>Healing rate:</u> SG = 66.7%; CG = 23.3% (<math>p &lt; 0.05</math>)</p> <p><u>Wound size reduction:</u> Not calculated</p> <p><u>Healing Time:</u> Not calculated</p> <p><u>Bacterial Load:</u> Evaluated in terms of reduction of infection signs. No percentage data. Only reference to the greater reduction of the signs of infection in the SG.</p>	The effectiveness of topical ozone has been demonstrated in the treatment of venous leg ulcers when compared to conventional treatment.	7 Points
Solovastru et al., 2015 (United States of America)	RCT SG – n = 15 CG – n = 14	SG – Topical Ozone therapy + conventional treatment CG – Conventional treatment	<p><u>Healing rate:</u> SG = 25%; CG = 0 % (<math>p &lt; 0.05</math>)</p> <p><u>Wound size reduction:</u> SG = 73%; CG = 13% (<math>p &lt; 0.05</math>)</p> <p><u>Healing Time:</u> SG = 0.17 cm<sup>2</sup>/day; CG = 0.009 cm<sup>2</sup>/day</p> <p><u>Bacterial Load:</u> Not calculated</p>	Topical ozone therapy demonstrated significantly superior results compared to CG results in both total re-epithelialization of venous leg ulcers and significant and progressive reduction of the ulcer area during the study protocol.	78%

Legend: CG – Control Group, NRT – Non Randomized Trial, RCT – Randomized Control Trial, SG – Study Group

ve, randomized and controlled clinical trial<sup>14</sup> that considers as quality the studies obtaining a score  $\geq 75\%$ ; ii) the “JBI Critical Appraisal Checklist for Quasi-Experimental Studies”<sup>15</sup> for non-randomized clinical trials, which considers as good quality studies those who obtain a maximum of two negative appraisals out of 9 items (i.e.  $\geq 7$  points).

**Data extraction**

The studies’ information and results were extracted by the same two reviewers, using the template of “The Joanna Briggs Institute data extraction form for systematic review of experimental/observational studies”<sup>16</sup> as basis, which included predetermined and consensual information by the investigators, namely: participants’ characteristics, interventions’ characteristics, studies’ methods and results of the included outcomes.

**Data synthesis**

The healing rate was pooled into a meta-analysis using RevMan 5.3 software. The results were expressed in Odds Ratio (OR) with 95% confidence interval (CI), using the Peto method with the Fixed effects model. The choice of this method was due to the fact that one of the groups under study had zero events<sup>17</sup>.

**Results**

The search identified 275 studies (fi-

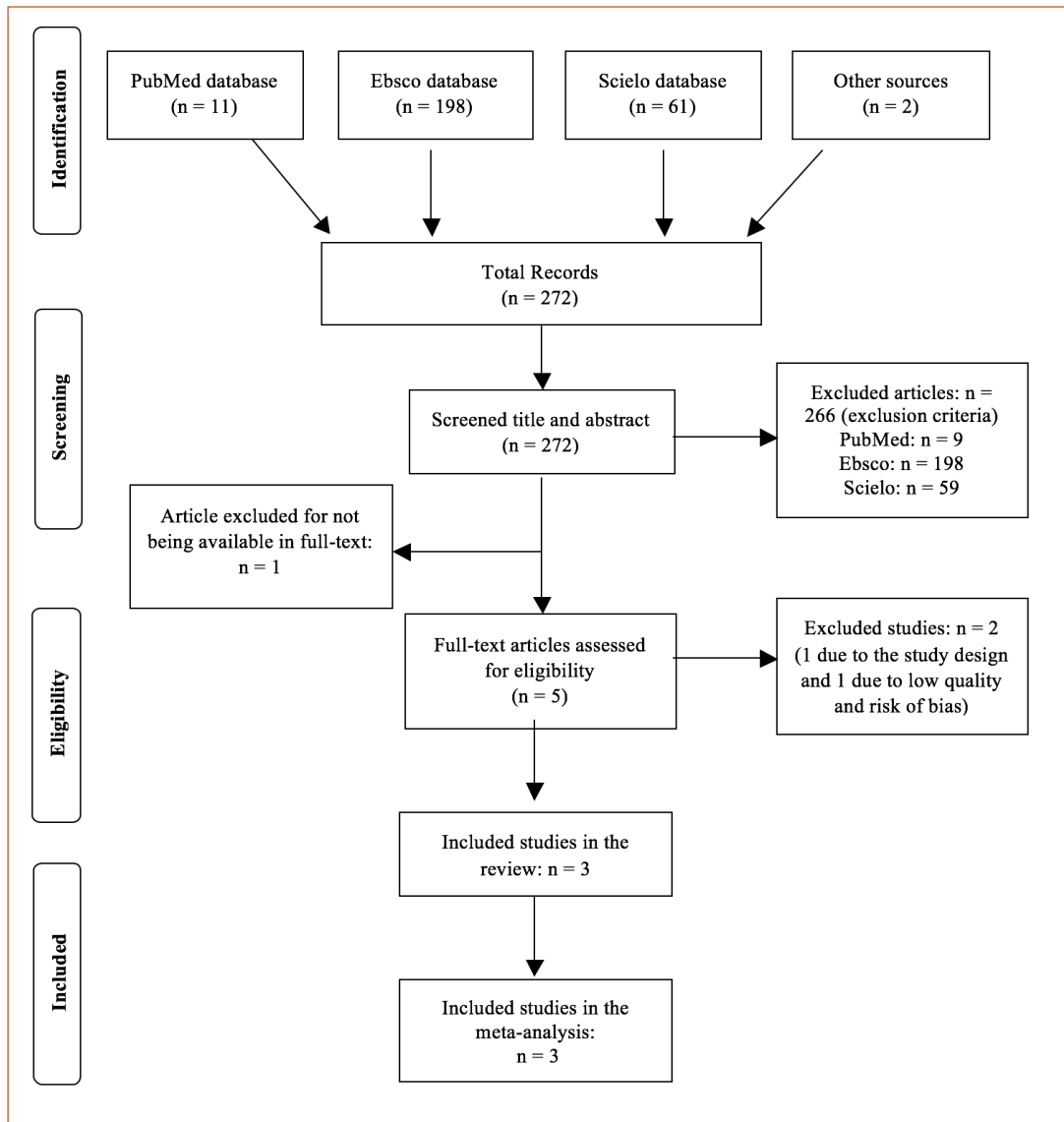


Figure 1. Flow diagram of the study selection process

figure 1), of which 269 studies were excluded after evaluation of the title and abstract. Of the remaining 6 studies, 1 was impossible to obtain (even after contacting with the author), so that only 5 studies were evaluated in full text. Among these 5 studies two were excluded: 1 due to its study design - cohort study<sup>18</sup> and 1 due to its low quality and risk of bias<sup>19</sup> as peer investigators appraisal. Three studies<sup>20,21,22</sup> were selected for narrative synthesis and meta-analysis, including a total of 133 participants treated with topical ozone or with conventional therapy.

### Narrative synthesis

The summary of extracted data, study conclusions and quality critical appraisal result is described in table 2. The detailed quality critical appraisal of the included studies can be consulted in tables 3 and 4.

The first study, by Hernández & González<sup>20</sup>, assessed the healing rate and the negativity of the microbiological cultures of the venous leg ulcers of both study (n = 22) and control (n = 22) groups. In the study group it was applied conventional therapy combined with topical ozone therapy by transcutaneous immersion of ozone and ozonated oil for a maximum of 70 treatment

sessions. After 20 to 30 treatment sessions, it was found a higher healing rate in the study group (90.9% versus 13.6%) and a higher percentage of microbiological culture negativity (90.9% versus 68.1%), with statistically significant differences in favour of ozone therapy regarding the two outcomes ( $p < 0.05$ ).

In the second study, Gutiérrez et al.<sup>21</sup> applied conventional treatment combined with ozonated oil in the study group (n = 30) and compared it with conventional therapy alone (n = 30), in a maximum of 45 treatment sessions. At the end of the 45-day protocol, they found a higher healing rate (expressed as total

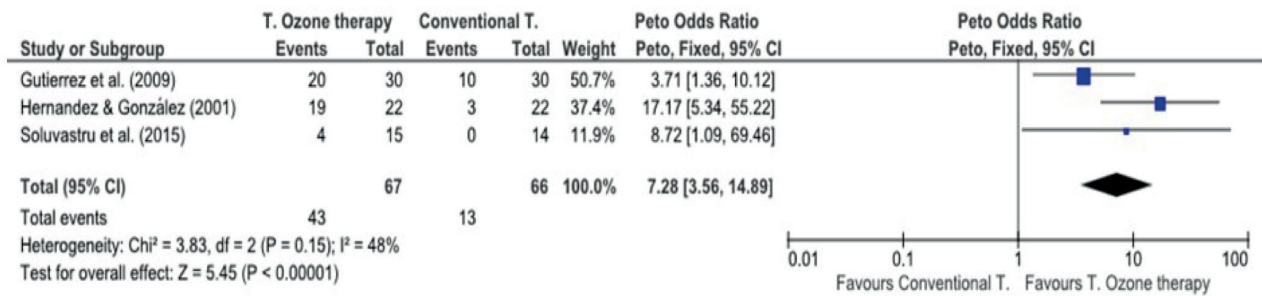


Figure 2. Forest plot of the comparative analysis between Conventional treatment and Topical Ozone therapy for the healing rate

**QUALITY CRITICAL APPRAISAL FOR THE QUASI-EXPERIMENTAL STUDIES INCLUDED.**  
 S1 – HERNANDEZ % GONZALEZ<sup>20</sup>; S2 – GUTIÉRREZ ET AL.<sup>21</sup>

**3**

**JBI Critical appraisal checklist for quasi-experimental studies [15]**

	S1	S2
1. Is it clear in the study what is the 'cause' and what is the 'effect' (i.e. there is no confusion about which variable comes first)?	1	1
2. Were the participants included in any comparisons similar?	1	0
3. Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?	1	1
4. Was there a control group?	1	1
5. Were there multiple measurements of the outcome both pre and post the intervention/exposure?	1	1
6. Was follow-up complete, and if not, was follow-up adequately reported and strategies to deal with loss to follow-up employed?	0	0
7. Were the outcomes of participants included in any comparisons measured in the same way?	1	1
8. Were outcomes measured in a reliable way?	1	1
9. Was appropriate statistical analysis used?	1	1
<b>Total reached a points:</b>	<b>8</b>	<b>7</b>

NOTE: Considers quality studies those who obtain at most two negative responses (≥7 points).

remission, including signs of infection) in the study group (66.7% versus 23.3%), with statistically significant differences in favour of ozone therapy ( $p < 0.05$ ). The healing time and bacterial load were not assessed.

In the third study, by Solovastru et al.<sup>22</sup>, patients were randomized to conventional therapy combined with ozonated oil ( $n = 15$ ) and conventional treatment alone ( $n = 14$ ), with results being assessed after 30 sessions. The healing rate was higher in the study group (25% versus 0%), as well as a higher healing speed (0.17 cm<sup>2</sup>/day versus 0.009 cm<sup>2</sup>/day) and a higher wound size reduction rate (73% versus 13%), with statistically significant differences in favour of ozone therapy for all outcomes ( $p < 0.05$ ).

**Meta-analysis**

It was only possible to perform meta-analysis for the healing rate, since the other outcomes were not assessed using the same methodologies/ instruments. It was confirmed that the healing rate of venous leg ulcers was higher in patients treated with topical ozone therapy (OR = 7.28, 95% CI 3.56 to 14.89,  $p < 0.001$ ). The heterogeneity of the studies was moderate ( $\chi^2 = 3.83$ ,  $df = 2$ ,  $p = 0.15$  and  $I^2 = 48\%$ ) (figure 2).

**Discussion**

This SLR included three studies comparing a total of 67 patients submitted to topical ozone therapy (transcutaneous immersion of ozone and ozonated oil) with a total of 66 patients undergoing conventional therapy alone (dressings and epithelizing creams). The outcomes analysed included the healing rate, healing time, and bacterial load reduction. The narrative synthesis has shown that the healing rate was higher in the study group, with a variation from 25.0% to 90.1% with topical ozone and from 0 to 23.3% in the control groups. The meta-analysis confirmed the superiority of the

QUALITY CRITICAL APPRAISAL FOR THE RCT INCLUDED. S3 – SOLUVASTRU ET AL.<sup>22</sup>

4

Grid for the critical evaluation of an article describing a prospective, randomized and controlled clinical trial [14]	S3
<b>Validity of Results</b>	
1. Was the range of patients well defined?	2
2. Are the inclusion and exclusion criteria logical and clear?	2
3. Was the diagnosis of the disease well characterized?	2
4. Were the patients randomized?	2
5. Has the randomization method been explained?	0
6. Was the distribution concealed?	1
7. Were the patients analyzed in the groups for which they had initially been randomized (intention to treat)?	2
8. Was the sample size statistically well calculated?	0
9. Were the patients in the comparison groups similar in terms of their known prognostic factors?	2
10. With the exception of the study treatment, were all patients treated in the same manner?	2
11. Was the group to which they belong concealed from the patients?	1
12. Were the study groups hidden from the study researchers?	1
13. Were the study groups hidden from the data analyzers?	1
14. Was the final follow-up greater than 80%?	2
<b>Importance of Results</b>	
15. Was the magnitude of the therapeutic effect (RRR, RRA, NNT) important?	1
16. Is the effect estimate sufficiently accurate (CI)?	2
17. Does this effect have clinical significance?	2
<b>Applicability of Results</b>	
18. Are the patients in the study similar to those in the clinical practice of the individual method?	2
19. Were all the important clinical findings considered?	2
20. Do the treatment benefits outweigh the potential risks and costs of its implementation?	2
<b>Total Reached as a Percentage (%) of Critical Analysis (0-100%)</b>	<b>78%</b>

NOTE: Considers quality studies those with a score  $\geq 75\%$

topical ozone therapy for the healing rate outcome with an overall OR of 7.3, which means that patients treated with ozone therapy had around 7 times more probability of having their wound healed than patients with conventional treatment. The OR of individual trials ranged from 3.7 to 17.2, a very significant difference that can be partially explained by the technique/treatment used or by the relative small samples included.

Two of the included studies have shown greater reductions in the signs of infection in their study groups as opposed to conventional therapies, ranging from 77.2% to 90.0% of reduction in signs of infection, favouring the ozone therapy<sup>20,21</sup>.

Reduced healing times were also observed in the study groups as opposed to the results from the control groups, i.e., in order to achieve total wound healing fewer treatment sessions were required for patients treated with ozone therapy. In the study by Hernández and González<sup>20</sup>, the highest percentage of wound healing was achieved in less than 30 treatment sessions (90.9%), compared to 13.6% on the control group for the same time period. The study by Solovastru et al.<sup>22</sup> was the one that more accurately assessed the healing time/speed of the venous leg ulcers, showing a higher speed in the study group (0.17 cm<sup>2</sup>/day), compared to the control group (0.009 cm<sup>2</sup>/day) in the first seven days of the treatment protocol.

This review has limitations and strengths. The limitations were the non-

inclusion of unpublished studies and the limited number (although specific, taking into account the topic under analysis) of searched databases. This was the first systematic review of the efficacy of ozone therapy in venous leg ulcers. Other strengths were the analysis of objective outcomes, the critical appraisal of the quality of the studies and the performance of the meta-analysis.

Till this date, there are no bacterial resistance to ozone documented in literature and topical ozone therapy does not have significant adverse effects, being mostly well tolerated by patients<sup>18,22,23</sup>. Nevertheless, safety and patient tolerance/satisfaction should be assessed in future studies.

Although this study was focused only on venous leg ulcers, the effec-

tiveness of ozone therapy has been tested in other types of complex wounds such as diabetic foot ulcers or burns. Rosales<sup>24</sup> evaluated its efficacy in diabetic foot ulcers (Wagner II classification) and reported the elimination of infection in 45% of SG' wounds *versus* 16.6% in the CG, as well as a total healing rate of 53.4% for SG ulcers *versus* 23.6% of CG. Also in diabetic ulcers, one study has shown a complete healing rate of 60% and partial healing rate of 40% in the SG, compared to 0% and 66.7% for the CG [8], while another study reported differences of 92% *versus* 64%<sup>25</sup>. According to a SLR in this type of wounds<sup>26</sup>, it was concluded that compared to antibiotics ozone therapy could more significantly reduce the size of the diabetic ulcer and decrease the time of hospitalization, in the short term. However, it was not found conclusive evidence that ozone therapy promotes better overall healing or reduces the number of adverse events. The authors pointed out as limitations the fact that the studies had reduced samples and considerable methodological flaws. The same limitation could be pointed out to the studies included in the present SLR.

In a recent study on the effect of topical ozone therapy on second degree burns, it was observed significant improvements in wound pain reduction (80.0% *versus* 33.3%), time and healing rates (80.0% *versus* 26.7% for complete wound healing and 20.0% *versus* 40.0% for partial wound healing), which also translated into lower cost of treatment and into fewer days of hospitalization<sup>23</sup>. In this study it was not observed statistically significant differences in terms of infection, despite the best results of ozone therapy (100% *versus* 81.8% of negativity of microbiological cultures).

The results of the above mentioned studies, with other kind of complex wounds, reinforce those obtained from the studies analysed in this SLR.

Clinical studies in any area, particularly in wounds, should whenever possible, use consensus-based outcomes and instruments in order to make comparability and meta-analysis of results possible.

It should also be mentioned that nurses should always keep in mind the concept of wound bed preparation recommended by the European Wound Management Association<sup>27</sup>. It is also important to have a consolidated knowledge of the healing process enabling to provide the optimal therapeutic option available to patients. Regarding this specific treatment, it is important to strictly follow the ozone therapy protocols recommended by the International Ozone Therapy Consensus document, namely the "Madrid Declaration on Ozone Therapy"<sup>2</sup>, so as to ensure the safety conditions for both users and health professionals.

## Conclusion

Given the results obtained, we can affirm that topical ozone therapy may constitute a relevant therapeutic option to the healing of venous leg ulcers. However, additional RCTs are needed to assess the efficacy of topical ozone therapy in reducing healing time and bacterial load, as well as assessing the safety of this therapy, its cost-effectiveness and its repercussion on the quality of life and other patient reported outcomes.

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# Difficulties of the parents in the promotion of healthy food and physical activity in the child

## Summary

Childhood obesity is a problem that our societies have been facing increasingly over the last decades. This study aims to identify the difficulties that parents feel in promoting healthy eating habits and physical activity to their children in the 1st cycle of Basic Education and to investigate the existence of a relationship between the difficulties experienced and the sociodemographic characteristics of parents and the age of the child.

The research method was descriptive, quantitative, correlational and transversal and a questionnaire developed by the authors was used. A sample of 702 parents whose children attended the 1st cycle of Basic Education in the county of Covilhã was obtained.

The results indicate that parents perceive greater difficulties when their children are exposed to a large number of advertising for high energy foods, to the influence of friends, to the high price of healthy foods compared to high-energy foods, to the price of the extracurricular physical activities available in residence area, to the scarcity of suitable outdoor spaces in residence area for children to play and to the lack of physical activity classes at school. A statistically significant relationship between difficulties perceived by parents and their educational level, marital status, residence area, number of children and the age of the child was found.

This research provides important results because for a specific population it allowed the identification of the obstacles that parents experience in the adoption and promotion of healthy eating habits and the fight against the inactivity of their children.

KEYWORDS: CHILDHOOD OBESITY; DIFFICULTIES; HEALTHY EATING HABITS; PHYSICAL ACTIVITY.

## Introduction

Overweight and obesity in childhood have increased at an alarming rate over the last two decades. Currently, it is estimated that there are 43 million children with excessive weight and that this number may exceed 60 million by 2020<sup>12</sup>.

There is a broad consensus that obesity is a global epidemic that affects all ages, economic strata, ethnicities and continents, being one of the main public health challenges of the 21st century<sup>25</sup>.

The development of childhood and subsequently adult obesity is complex and it involves multiple factors: genetic, metabolic, psychological, en-

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vironmental and behavioural<sup>5,17</sup>. However, inappropriate nutrition associated with a reduced physical activity are pointed out as the main causes for childhood obesity. Thus, it seems to be consensual that when we talk about prevention of childhood obesity, we should focus more on promoting healthy eating habits and physical activity<sup>9,10,24</sup>. This research has focused on this issue on children in the 1st cycle of basic education (1st CBE).

Children between 6 and 10 years old who usually attend the 1st CBE are extremely vulnerable to obesity. At these ages children develop competences in all areas and so it is important to start as soon as possible the preventive process<sup>1,8,14,19</sup>. Education is the key to prevention, and the child should be educated about the benefits of healthy eating habits and regular physical activity<sup>4</sup>.

Thus, it is important to identify and understand the challenges/difficulties that parents face in education/promotion of a healthy lifestyle to their children. This procedure will allow to know the reality and enable health professionals, educators, politicians and local authorities to intervene effectively in order to limit or extinguish these difficulties.

In their daily lives families coexist with several barriers in the promotion of a healthy diet and in the fight

against sedentarism or in the promotion of a healthy lifestyle. Identifying the barriers to a given population will allow them to act on them, mitigating them or even destroying them, thereby expecting a change in lifestyles.

The purpose of this study was to identify the difficulties parents feel in promoting a healthy lifestyle among their children. Thus, the research question “What difficulties do parents feel in promoting a healthy lifestyle in children in 1st CBE?” was asked.

This study aims to contribute to the knowledge on childhood obesity, namely on the difficulty of parents in promoting healthy lifestyles among children of 1st CBE, contemplating the promotion of healthy eating habits and physical activity. Thus, the following objectives were outlined:

- Identify the difficulties parents feel in promoting healthy eating habits and physical activity in the child in the 1st CBE.
- Analyze the existing relationships between the difficulties experienced by the parents and the sociodemographic characteristics of the parents and the age of the child.

## Methods

For the accomplishment of this work, a descriptive and correlational study with a quantitative and transversal approach was elaborated.

The variables of this study were the difficulties experienced by parents in promoting a healthy lifestyle, in the dimensions of feeding and physical activity, and the sociodemographic characteristics of the Parents and the child.

The target population of this research included the parents of children who attended the 1st CBE schools in the county of Covilhã and in the academic year 2015/2016. A sample of 702 parents of the 1435 children, that attending the 1st CBE in the county of Covilhã, was obtained.

The data collection was performed using a questionnaire built specifically for this study, taking into account the literature review.

The questionnaire was divided into two parts. The first part, consisting of open and closed questions related to the sociodemographic characteristics of the child and the parents. The second part consisting of 21 statements (14 in the feeding dimension and 7 in the physical activity dimension), for each one parents indicated their agreement by a five-level Likert scale (1 - totally disagree; 2 partially disagree; 3 - neither disagree nor agree, 4 - partially agree, 5 - strongly agree). The statements were defined based on the literature and with the objective of approaching habits and resources in the family and school contexts, but also in public spaces related with healthy eating habits and physical activity.

For the application of this questionnaire, authorization was requested from the Direção-Geral da Educação (Directorate-General for Education), through the monitoring platform for surveys in schools, and from the school groupings where the questionnaire was distributed, as well as the informed consent of the participants in the study. To the participants in the study were assured the right of non-participation, anonymity and confidentiality of responses. Data collection was carried out from April to June of 2016. Descriptive data analysis provided the sociodemographic characterization and description of parent's perception about their difficulties in promoting healthy eating habits and physical activity to children. According to the type of variables and taking into account the defined objectives the 95% confidence interval (CI) were applied as well as the following statistical inference techniques: Mann-Whitney U test, Kruskal-Wallis test, Dunn's test and Spearman correlation coefficient. The results were analysed for a significance level of 5%.

## Results

Regarding the 702 children of parents who answered the questionnaire, they were aged between 6 and 13 years, with a mean ( $\bar{x}$ ) of 8.3 and standard deviation (SD) of 1.3 years, and the majority (54%,  $n = 379$ ) are female. From the 492 (70.1%) children who have siblings, 267 (38%) are the youngest and 194 (27.7%) are the oldest in the family. It should be noted that 210 (29.9%) were only children.

Concerning the sociodemographic characteristics of the parents, it was found that the majority of mothers and fathers aged between 35 and 45 years (70.9% and 66.3% respectively), were married or in civil partnership (83.3% and 86.2% respectively), had secondary education (34.2% and 37.2% respectively) and lived in urban zone (74.4%,  $n = 522$ ). The families of the sample children have between 1 and 6 children, with mean of approximately 2 children ( $\bar{x} = 1.9$  e  $SD = 0.8$ ).

The parents were questioned about the difficulties in promoting a healthy lifestyle, in terms of eating habits and physical activity, in children and expressed their level of agreement with a set of statements. With regard to statements about the feeding dimension (figure 1), the respondents showed greater agreement with the following items: children's exposure to a large number of advertising of high energy foods, median (M) with level 4; the influence of friends on the child's preference for high-energy foods (M = 3) and the high price of healthy foods compared to energy-rich foods (M = 3). The items for which the parents indicated lower agreement (M = 1) were: the reluctance to perform family meals, the child's reluctance to eat breakfast at home, a high number of meals out of home, the ingestion of an exaggerated portion of food and the family's reluctance to eat a healthy food.

Concerning to the physical activi-



Figure 1. Parents' agreement with feeding statements

ty statements (figure 2), it was observed that the parents mentioned greater agreement with the items related to the high price of extracurricular physical activities available in their residence zone ( $M = 4$ ), the shortage or lack of suitable outdoor spaces in residence area for the child play ( $M = 3$ ) and the shortage or lack of physical activity classes in the school ( $M = 3$ ). In contrast, the parents indicated their lowest agreement ( $M = 1$ ) with the children's reluctance to engage in extracurricular physical activities.

Regarding the degree of agreement with the statements according to the educational level of the parents (tables 1 and 2), the results indicated differences, statistically significant, in the feeding statements (in 9 of the 14 statements for mothers and in 7 of the 14 statements for fathers), and in physical activity statements (in 3 of the 7 statements for mothers and fathers). The results did not allow to establish a relation between the lower or higher education level of mothers/fathers and the degree of agreement with the statements. However, for most of the statements (9 out of 12 in the case of mothers and 6 out of 10 in the case of parents), it was possible to observe a tendency for higher levels of education to be associated with less agreement

(less difficulty) with the statements, compared to lower levels of education.

The results showed that the marital status of the mothers was a factor that influences the degree of agreement with the statement regarding the high number of meals outside home ( $p = 0.037$ ). It was observed that families with married or unmarried mothers showed less agreement with the statement compared to divorced or separated mothers.

The degree of agreement of the parents with the statements were different according to the number of children ( $p = 0.024$ ), more specifica-

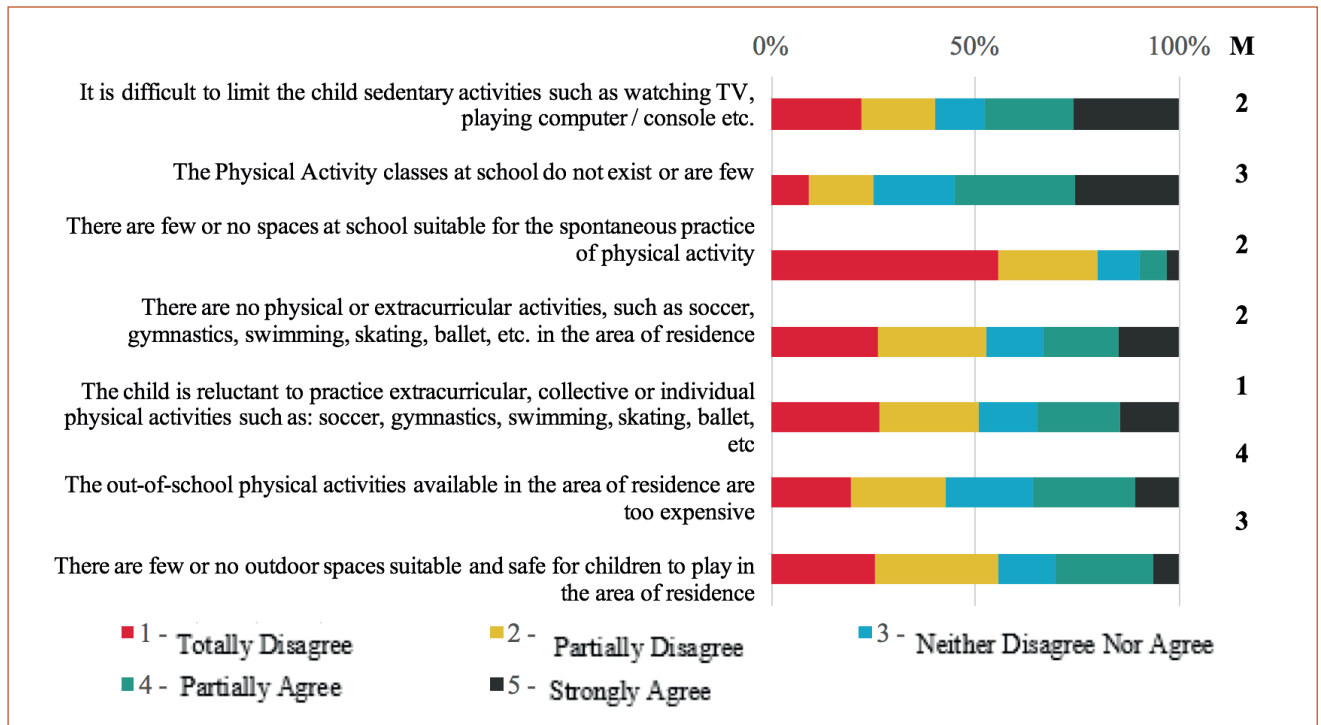


Figure 2. Parents' agreement with physical activity statements

lly between having one or more children. In this context, we highlight the differences in the statement related with the family's reluctance to adopt healthy life habits, with parents who have more than one child expressing greater agreement with the statement.

The results indicated differences in the degree of agreement of the parents with some of the statements (table 3) and allowed to conclude that this is correlated with the age of the child (table 4). This occurs in the feeding dimension (in 6 of the 14 affirmations) and in the physical activity dimension (in 1 of the 7 affirmations). It should be noted that the data did not make it possible to establish a direct or inverse relation between the age of the child and the degree of agreement of the parents in all the affirmations, but in the individual analysis of the affirmations this was already possible. Thus, it was found that the parents with older children expressed their full agreement with the statements regarding the child's reluctance to have breakfast at home and the family's refusal to perform a healthy diet and, conversely, were the parents with young children whom expressed their disagreement with the claims about the inadequate quality of meals at school/institutions with free time activities, inadequate food education in the school curriculum and the child's high number of meals outside home.

In this study, the degree of agreement of the parents with some of the statements differs according to their residence area, in the feeding and physical activity dimensions (table 5). Parents living in urban areas showed greater agreement with the statements regarding the child's exposure to a high number of advertising of high-energy food and the lack of outdoor spaces suitable for the children play. The parents from rural area expressed greater agreement with the statements regarding the family's reluctance to adopt healthy eating habits and the scarcity of extracurricular activities.

**Discussion**

It was possible to determine the Body Mass Index (BMI) percentile for 580

(82.6%) of the children in the sample, with a prevalence of overweight (including excessive weight and obesity) of 33.8% (95% CI 30-37,6) and obesity in 11.6% (95% CI 9-14.2). The prevalence of overweight in the sample is slightly higher than that presented by Rito and Graça for the Portuguese reality (31.6%), but this is within the 95% CI obtained by this research. Although, the prevalence of obesity is lower than that observed by the same authors (13.9%), but it is within the 95% confidence interval obtained with the sample of this study.<sup>20</sup> The prevalence of overweight (including excessive weight and obesity) among boys (34%, 95% CI 28.2-39.8) and girls (33.6%, 95% CI 28.5-38.8) is similar, but a higher prevalence of obesity in boys (16%, 95% CI 11.5-20.5) compared to girls (8%, 95% CI 5.1-11). These results aren't in line with those observed by Rito and Graça, according to which the prevalence of both, overweight and obesity, is higher in girls. These discrepancies may be due to the difference in size and coverage of the study samples<sup>20</sup>.

COMPARISON OF THE DEGREE OF AGREEMENT WITH THE STATEMENTS, ABOUT FEEDING AND PHYSICAL ACTIVITY, ACCORDING TO THE EDUCATIONAL LEVEL OF THE MOTHERS

1

Statements	kruskal-Wallis	
	Q	p
Healthy food is more expensive than the processed / pre-packaged food with high-energy	14.73	0.022
The child is reluctant to perform a healthy diet	19.28	0.004
The child is exposed to a large number of advertising of high-energy food and fast-food chains	28.44	< 0.001
Meals offered at school/institutions during free time activities are inadequate or insufficient	13.60	0.034
The child is reluctant to have a proper breakfast at home	38.50	< 0.001
The child has a high number of meals outside home, especially in fast-food chains	30.77	< 0.001
The child eats at each meal a portion of food exaggerated for their needs	14.57	0.024
The family has a reluctance to adopt healthy eating habits	46.44	< 0.001
Parents have feelings between being good educators and guilt about denying food to the child	36.29	< 0.001
The Physical Activity classes at school do not exist or are few	23.49	0.001
There are no physical or extracurricular activities, such as soccer, gymnastics, swimming, skating, ballet, etc. in residence area	36.63	< 0.001
The child is reluctant to practice extracurricular, collective or individual physical activities such as: soccer, gymnastics, swimming, skating, ballet, etc	34.51	< 0.001

COMPARISON OF THE DEGREE OF AGREEMENT WITH THE STATEMENTS, ABOUT FEEDING AND PHYSICAL ACTIVITY, ACCORDING TO THE EDUCATIONAL LEVEL OF THE FATHERS

2

Statements	kruskal-Wallis	
	Q	p
Healthy food is more expensive than the processed / pre-packaged food with high-energy	14.63	0.034
The family has little time to cook, leading to preferring processed / pre-cooked food or easy cooking	13.01	0.043
The child is exposed to a large number of advertising of high-energy food and fast-food chains	30.14	< 0.001
Meals offered at school/institutions during free time activities are inadequate or insufficient	30.14	< 0.001
The child eats at each meal a portion of food exaggerated for their needs	21.75	0.001
The family has a reluctance to adopt healthy eating habits	22.25	0.001
Parents have feelings between being good educators and guilt about denying food to the child	31.57	< 0.001
There are no physical or extracurricular activities, such as soccer, gymnastics, swimming, skating, ballet, etc. in residence area	25.50	< 0.001
The child is reluctant to practice extracurricular, collective or individual physical activities such as: soccer, gymnastics, swimming, skating, ballet, etc.	16.51	0.011
There are few or no outdoor spaces suitable and safe for children to play in residence area	13.36	0.038

With regard to the objective of identify the difficulties that parents feel in promoting healthy eating and physical activity in children in the 1<sup>st</sup> CBE, in the following we will discuss the main conclusions, based on their degree of agreement with the statements made in the two dimensions mentioned.

Concerning the feeding dimension, it was found that the parents perceive greater difficulty with exposure that the child has to a lot of advertising related with energy-rich foods and the influence of friends in the preference of the child for energy-rich foods. This is corroborated by the literature, with several studies suggesting that food marketing actually seems to influence children's choices, consumptions, acquisitions and requests of these products to parents. Thereby, advertising unadvisable food is a negative influence on children's eating habits<sup>15,16,21</sup>.

It can be seen that the socioeconomic conditions of the parents seem to

influence the promotion of a healthy lifestyle, with the parents agreeing to the statements regarding the high price of healthy foods and the high price of extracurricular activities. These conclusions are in agreement with other studies, there is evidence that the influence of socioeconomic conditions extends beyond food choices, it also affecting the physical activity pattern of families<sup>13</sup>.

The urban planning is targeted by parents, realizing that the safe

## COMPARISON OF THE DEGREE OF AGREEMENT WITH THE STATEMENTS, ABOUT FEEDING AND PHYSICAL ACTIVITY, ACCORDING TO THE AGE OF THE CHILD

3

Statements	kruskal-Wallis	
	Q	p
Difficulty in having family meals	17.610	0.001
Meals offered at school/institutions during free time activities are inadequate or insufficient	18.880	0.001
Food education in the school curriculum is insufficient	15.440	0.004
The child is reluctant to have a proper breakfast at home	11.558	0.021
The child has a high number of meals outside home, especially in fast-food chains	15.942	0.003
The family has a reluctance to adopt healthy eating habits	24.418	< 0.001
The child is reluctant to practice extracurricular, collective or individual physical activities such as: soccer, gymnastics, swimming, skating, ballet, etc	10.372	0.035

## SPEARMAN'S CORRELATION COEFFICIENT BETWEEN THE AGE OF THE CHILDREN AND THE AGREEMENT OF THE PARENTS WITH THE STATEMENTS ABOUT FEEDING AND PHYSICAL ACTIVITY

4

Statements	Spearman coefficient	
	R	p
Meals offered at school/institutions during free time activities are inadequate or insufficient	0.136	< 0.001
Food education in the school curriculum is insufficient	0.112	0.002
The child is reluctant to have a proper breakfast at home	0.106	0.005
The child has a high number of meals outside home, especially in fast-food chains	0.146	< 0.001
The child eats at each meal a portion of food exaggerated for their needs	0.100	0.008
The family has a reluctance to adopt healthy eating habits	0.083	0.027
There are no physical or extracurricular activities, such as soccer, gymnastics, swimming, skating, ballet, etc. in residence area	0.087	0.022
The child is reluctant to practice extracurricular, collective or individual physical activities such as: soccer, gymnastics, swimming, skating, ballet, etc	0.086	0.023

## COMPARISON OF THE DEGREE OF AGREEMENT WITH THE STATEMENTS, ABOUT FEEDING AND PHYSICAL ACTIVITY, ACCORDING TO THE RESIDENCE AREA

5

Statements	U de Mann-Whitney	
	Z	p
The child is exposed to a large number of advertising of high-energy food and fast-food chains	-3.08	0.002
The family has a reluctance to adopt healthy eating habits	-2.00	0.046
There are no physical or extracurricular activities, such as soccer, gymnastics, swimming, skating, ballet, etc. in residence area	-3.32	0.001
There are few or no outdoor spaces suitable and safe for children to play in residence area	-3.25	0.001

outdoor spaces to play are scarce. This result is consistent with the research developed by Nogueira et al., which refers a positive relation between the outdoor spaces availability, quality and perception of its safety, with the prevalence of childhood obesity<sup>11</sup>.

The results obtained in this study seem to allow us to conclude that parents recognize the importance of physical activity in the promotion of a healthy lifestyle. Thus, their opinion is in agreement with the studies that indicate the relevance of physical activity in the context of childhood obesity<sup>3,7</sup>.

As described in the literature, the parents who participated in this study pointed out as a difficulty in promoting a healthy lifestyle the influence of friends on the child's preference for high energy foods<sup>15</sup>.

Emphasizing the above difficulties, to the detriment of many others, in each dimension can be understood as a portrait of the study population and is certainly a result of their specific characteristics.

In the following, the main results concerning the second objective will be discussed, that is the existence of a relationship between the difficulties experienced by the parents and the

sociodemographic characteristics of the parents and the child's age. Regarding the degree of agreement with the statements according to the parents' educational level, the results show statistically significant differences in both the feeding and physical activity dimensions. As previously mentioned, for most of the statements, it was possible to observe a tendency for higher levels of education to be associated with less agreement with the affirmations (less difficulty), compared to lower levels of education. These evidences are in agreement with the results obtained by Patrick et al., who concluded that a high educational level of parents is associated with a lower prevalence of childhood obesity<sup>15</sup>. Likewise, in a study carried out in Portugal by Castro with 219 children in the 1st C BE, there was a positive relationship between low levels of schooling of parents with the prevalence of obesity<sup>2</sup>.

The results showed that mothers with married or union status that was manifested less concordance with the statement "take a high number of meals outside home" compared to those with divorced or separated. This may be due to the fact that in that cases it may happen lower control in relation to the meals that their child makes with the other parent.

There are authors who point out that children, influenced by friends and advertising, tend to more often consume and ask their parents to purchase energy-rich food products<sup>15,21</sup>. Perhaps because of this, in the presented results, the existence of a greater number of children in the family translates into a greater difficulty in promoting healthy eating by parents.

In this study, who lives in urban zone agree more with the statements regarding the child's exposure to a high number of advertising of energy-rich foods and the lack of outdoor spaces in the area of residence suitable for the child to play, and the parents rural residents expressed greater agreement with the statements regarding the family's reluctance to adopt healthy eating habits and the scarcity of extracurricular activities in the area of residence. Regarding the scarcity of outdoor spaces for the child to play in the urban environment and the scarcity of extracurricular activities in rural areas, the results are in line with that described in other studies. Pronto, in a study conducted in the municipality of Lousã, found a positive association between the availability of infrastructures in the area of residence and the practice of physical activity<sup>18</sup>. Steinmayr, Felfe and Lechner, in a study carried out in Germany with children between the ages of 3 and 10, found that the proximity of the children's area to sports infrastructures was positively related to the practice of physical activity<sup>23</sup>. The research points to a link between the exposure of children to a high number of advertising to energy-rich foods with the urban zone, which may be due to the fact that is where the food industry invests more in advertising. It was also identified a relation between the family's reluctance to adopt healthy eating habits and the rural zone. This result may possibly be justified by the persistence of a greater tradition food, which originated in previous generations, which is more resistant to change.

## Conclusions

Childhood obesity is a problem that our societies have been facing increasingly in recent decades. This problem is considered by the World Health Organization as the epidemic of the 21st century and considered one of the most serious public health challenges. Despite the efforts made, child obesity has grown and persisted and is no longer an exclusive condition of developed societies, being a global problem today as it affects underdeveloped and developing countries.

Several studies and efforts have been made in recent years to better understand the phenomenon of childhood obesity and how we can act to pre-

vent and treat it. With this study we wanted to know the difficulties of the parents in the promotion of a healthy lifestyle, in the dimensions feeding and physical activity, to their children and to ascertain the existence of relation between the difficulties felt by the parents and their characteristics and the characteristics of the children.

Parents perceived greater difficulty in exposing the child to a high number of advertising for high-energy foods, the influence of friends on the child's preference for high-energy food and the high price of healthy food compared to food of high-energy. In the scope of physical activity promotion, the parents emphasized the price of extracurricular physical activities available in their residence area, the scarcity of outdoor spaces suitable for the children play in their residence area and the lack of physical activity classes at school.

There are many studies on childhood obesity, but few focus on families' difficulties in promoting a healthy lifestyle. Identifying the difficulties parents face in promoting a healthy lifestyle for their child is another step towards better understanding the problem of childhood obesity. This research provides important results in the sense that it allowed to identify, for a specific population, the obstacles that they experience in adopting and promoting a healthy diet and in the fight against sedentarism. The instruments used can be applied in other populations or even in a family. Two populations or families are not absolutely equal and since the etiology of obesity is complex and often individualized, it is thought that the path of personalization of health promotion actions is the one indicated. The experiences and challenges that a population or family face are different from others. Therefore, it is important the incessant search for a better knowledge about our populations/families.

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# Effectiveness of short-stretch compressive therapy beyond healing of varicose ulcers

## Systematic review

### Summary

**CONTEXT.** Compressive therapy, especially with short-stretch bandage (SSB), is recommended in the treatment of varicose ulcers, with proved effectiveness in the healing rate or reduction of wound size. However, there is still insufficient evidence of the advantages of this type of therapy in terms of pain, quality of life (QoL) and cost of treatment.

**OBJECTIVES.** To compare the effectiveness of SSB with other types of treatments (with or without compression) to improve pain, QoL and cost of the treatment of venous ulcers.

**METHODOLOGY.** A systematic literature review (Cochrane methodology) was carried out on PubMed, EBSCO, Scielo, Google Academic, and grey literature. Only experimental or quasi-experimental studies, with adults with varicose ulcer were included. Two independent reviewers performed critical appraisal, data extraction, and data synthesis.

**RESULTS.** Among 3133 hits screened, 4 randomized controlled trials (RCTs) were included, including a total of 977 patients. From these 4 trials: 2 analyzed the QoL, without significant differences between SSB and multiple layer compression; 2 showed a trend towards greater reduction of pain with SSB, but without statistically significant difference; 2 studies evaluated the cost of treatment, with contradictory results. It was not possible to perform a meta-analysis due to high heterogeneity.

**CONCLUSIONS.** There is no evidence that SSB is more effective than other compression systems in terms of pain, QoL and cost of treatment in people with venous ulcers. More RCT's are needed, using uniform assessment tools, to allow for more robust conclusions, namely through meta-analysis.

**KEYWORDS:** LEG ULCER; VARICOSE ULCER; COMPRESSION BANDAGES; QUALITY OF LIFE; PAIN; HEALTH CARE COSTS.

### Introduction

Varicose leg ulcers are an increasing health problem in the world, with an estimated prevalence of 1% of population in developed countries; 3% if accounting only people above 80 years old<sup>1</sup>. This causes a considerable burden for patients, families and society, namely due to high levels of pain, job

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loss, worse quality of life (QoL), including leisure and social activities, depression, co morbidities and huge overall treatment costs<sup>2,3</sup>.

Clinical guidelines for the treatment of leg ulcers of venous origin emphasize the importance of early identification and diagnosis of patients, but also optimizing treatments, preventing or delaying complications and reducing their recurrence<sup>4</sup>. However, there is still a lack of knowledge about the best way to assess, prevent and manage these ulcers<sup>1,5,6</sup>. More than treating the wound, which includes cleaning and choosing the appropriate dressing to its characteristics, it is increasingly important to treat its causes. Since venous ulcers are a chronic debilitating injury that occurs due to deep vein thrombosis, incompetent function of the twin muscle pump or chronic venous insufficiency<sup>6</sup>, it's essential to improve venous return.

Compression therapy aims to improve venous hemodynamics of the leg, control edema, improve microcirculation and lymphatic drainage, leading to healing rates much superior to no form of compression<sup>1,2,7</sup>. The importance associating pentoxifylline as an adjuvant treatment of compression bandages has also been highlighted<sup>1,8, 9,10</sup>.

There are nowadays multiple compression systems<sup>11</sup>. In order to have an optimized therapeutic effect, it is necessary to take into account the factors of the acronym P-LA-C-E (Pressure - LAyers - Components - Elastic properties) proposed by Partsch et al. (2008). In terms of pressure, compression was classified as light (less than 20 mmHg), moderate (20-40 mmHg), strong (40 to 60 mmHg), or very strong (more than 60 mmHg)<sup>11</sup>. In terms of layers, there are two types of treatment: double layer, characterized by the use of two layers with 50% overlap of the bandage: multi-layer, which results in the use of more layers or overlays. The components of a bandage are the constituent materials, which differ in their functions. As for the elastic properties of bandages, they can be inelastic (rigid or short traction/extension) or elastic (long stretch or long traction).

When pressure levels are adequately applied (> 40 mmHg), the diameter of the main veins is reduced, improving the venous and lymphatic drainage, which has the effect of reducing the local blood volume, decreasing the edema<sup>12</sup>. The application of external compression may, however, generate damages in certain circumstances, namely cutaneous lesions caused by excessive compression or poor technique, or worse, due peripheral arterial disease<sup>2,13</sup>. To exclude vascular disease, a contra-indication for compressive treatment, all patients should have an Ankle Brachial Pressure Index (ABPI) assessment, a procedure that should be performed by a properly trained health professional<sup>1,2,14</sup>.

Several studies, systematic reviews (SR) and meta-analyzes have already shown the effectiveness of compressive therapy using SSB on the rate of healing, the proportion of ulcers healed within the experimental period, and on the reduction in ulcer size (surface area or volume), compared with conventional treatment without compression or with other types of compressive therapy<sup>2,6,7</sup>. However, in other outcomes beyond these directly related with healing, such as pain, QoL or cost of treatment, there is still not enough evidence of superiority of SSB.

This SR aimed to compare the effectiveness of SSB with other types of treatment (with or without compression) in terms of pain, QoL and cost of treatment of venous ulcers.

## Methods

The present SR followed the principles proposed by the Cochrane Handbook<sup>15</sup> and the following selection criteria were defined according to the PICO methodology:

- Participants: Adults ( $\geq 18$  years old) with leg ulcers of venous etiology. Any context of care was eligible. The diagnostic method could vary in the studies presented, but a clear description of the exclusion of ulcers from a non-venous origin is essential.
- Intervention: short traction compressive therapy (for instance, short-stretch compression bandaging (SSB) or two-layer compression bandaging (2LB)).
- Comparison: Treatment without any type of compressive therapy; other types of compression therapy (for instance, three-layer compression bandaging (3LB) or four-layer compression bandaging (4LB)).
- Outcomes: pain, quality of life and cost of treatment.

Only experimental and/or quasi-experimental clinical trials, published

in English, French, Spanish or Portuguese were considered.

## Research strategy and identification of studies

The research strategy consisted of three phases. In the first phase, a naturalistic research was carried out, limited to the PubMed and Google Academic database, in order to infer the importance of research in this area, followed by a keyword analysis in the titles, abstracts and descriptors. Subsequently, a second research was carried out using the identified keywords and descriptors, in all databases which included Portuguese repositories and the abstract database of the website of the EWMA (table 1). Finally, an analysis of the bibliographic references of included studies was carried out to identify additional studies.

The search was performed between October 1<sup>st</sup> and November 13<sup>rd</sup>, 2016, and the selection of studies focused on the publications available from January 1<sup>st</sup>, 2012, date of last review by O'Meara<sup>2</sup>.

## Evaluation of the methodological quality of the studies

For the critical evaluation of the validity of the identified studies, the "Grid for the critical evaluation of an article describing a prospective, randomized and controlled clinical trial" was used, which considers  $\geq 75\%$  as cut-off for a study being considered with quality<sup>16</sup>.

## Data extraction

The data extraction was performed using the instrument "The Joanna Briggs Institute data extraction form for systematic reviews and Research Syntheses"<sup>17</sup>, which included: the characteristics of the participants, the characteristics of the intervention, the methods and the results regarding the outcomes of interest to this study.

## Data summary

It was not possible to perform a

Database	Boolean Formula
Pubmed	[("leg ulcer" OR "varicose ulcer") AND ("compression bandages") AND ("quality of life" OR "pain" OR "Costs and Cost Analysis" OR "Cost-Benefit Analysis" OR "Health Care Costs")] (All fields)
EBSCO (CINAHL Plus with Full Text; MEDLINE Complete; Nursing & Allied Health Collection: Comprehensive; Cochrane Central Register of Controlled Trials; MedicLatina)	[("leg ulcer" OR "varicose ulcer") AND ("compression bandages") AND ("quality of life" OR "pain" OR "Costs and Cost Analysis" OR "Cost-Benefit Analysis" OR "Health Care Costs")] (All fields)
SciELO Scientific Electronic Library Online	[("leg ulcer" OR "varicose ulcer") AND ("compression bandages") AND ("quality of life" OR "pain" OR "Costs and Cost Analysis" OR "Cost-Benefit Analysis" OR "Health Care Costs")] (All fields)
Google Academic	"leg ulcer" OR "varicose ulcer" AND "compression bandages" AND "quality of life" OR "pain" OR "Costs and Cost Analysis" OR "Cost-Benefit Analysis" OR "Health Care Costs"
European Wound Management Association website	"leg ulcer" OR "varicose ulcer" OR "compression bandages"
Portuguese repositories	"úlceras de perna" OR "úlceras varicosas" OR "ligaduras de compressão" OR "terapia compressiva"

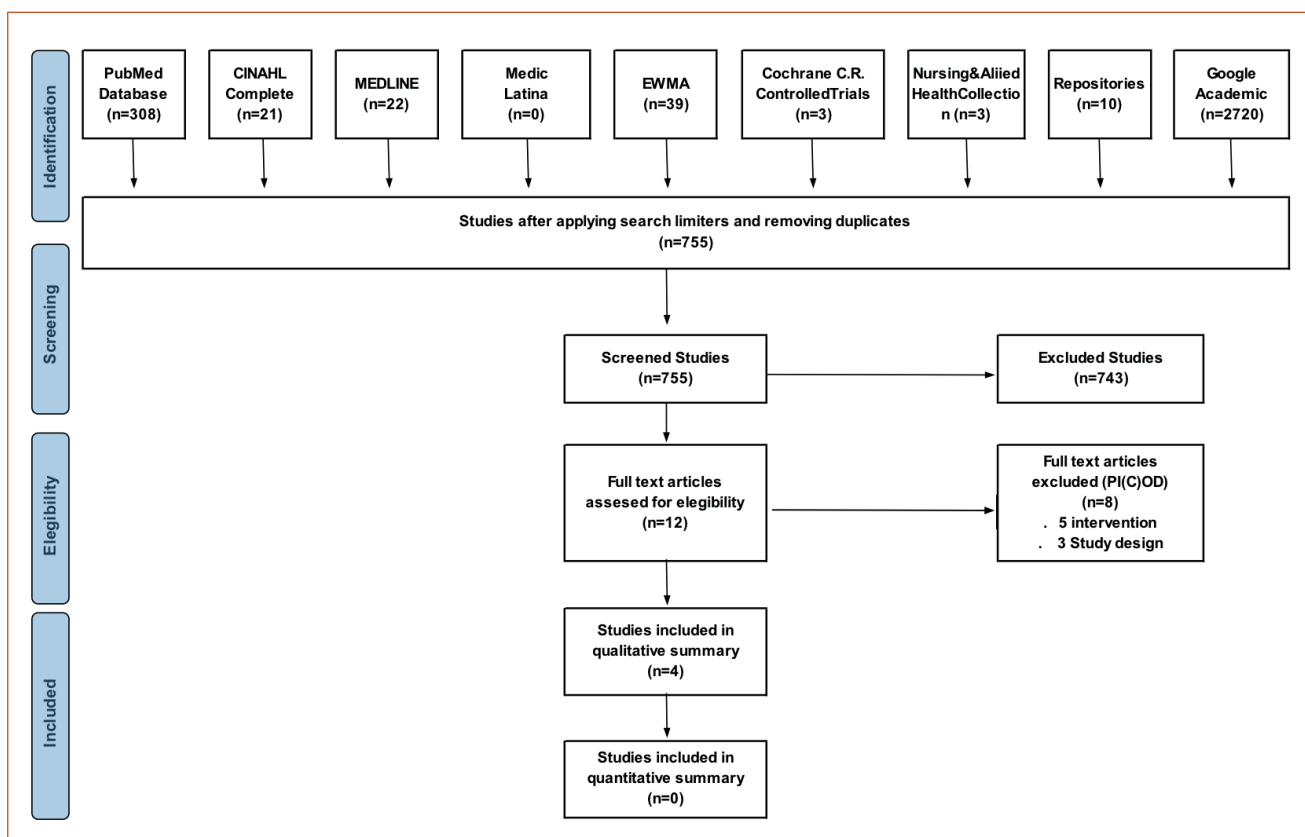


Figure 1. Flow diagram of the study selection process

meta-analysis since the selected articles did not present uniformity in the evaluation instruments, and presented high levels of clinical and statistical heterogeneity<sup>18</sup>.

## Results

Figure 1 presents the flowchart for the studies' selection. A total of 3133 hits were identified, and 2378 after applying limiters and removing duplicates. From the remaining 755 studies, 743 were excluded after analysis of the title

and abstract. 12 studies were selected then for full-text reading, after which 5 studies were excluded because the intervention did not meet the established criteria and 3 studies were excluded for their design, with a final result of 4 studies<sup>3,19,20,21</sup> for qualitative summary.

SUMMARY OF RISK OF BIAS ACCORDING TO THE  
METHODOLOGICAL QUALITY ASSESSMENT

2

	Articles			
	A	B	C	D
<b>Validity of Results</b>				
1. was the range of patients well defined?	2	2	2	2
2. are the inclusion and exclusion criteria logical and clear?	2	2	2	2
3. was the diagnosis of the disease well characterized?	2	2	2	2
4. were the patients randomized?	2	2	2	2
5. has the randomization method been explained?	2	0	2	2
6. was the distribution concealed?	2	1	2	2
7. were the patients analyzed in the groups for which they had initially been randomized (intention to treat)?	2	2	2	2
8. was the sample size statistically well calculated?	2	2	2	2
9. were the patients in the comparison groups similar in terms of their known prognostic factors?	2	2	2	2
10. with the exception of the study treatment, were all patients treated in the same manner?	2	2	2	2
11. was the group to which they belong concealed from the patients?	0	0	0	0
12. were the study groups hidden from the study researchers?	0	0	0	0
13. were the study groups hidden from the data analyzers?	2	0	2	0
14. was the final follow-up greater than 80%?	2	2	2	2
<b>Importance of Results</b>				
15. was the magnitude of the therapeutic effect (RRR, RRA, NNT) important?	0	0	0	2
16. is the effect estimate sufficiently accurate (CI)?	2	1	2	2
17. does this effect have clinical significance?	2	2	2	2
<b>Applicability of Results</b>				
18. are the patients in the study similar to those in the clinical practice of the individual method?	2	2	2	2
19. were all the important clinical findings considered?	2	2	2	2
20. do the treatment benefits outweigh the potential risks and costs of its implementation?	2	2	2	2
<b>Total Reached as a Percentage (%) of Critical Analysis (0-100%)</b>	<b>85</b>	<b>70</b>	<b>85</b>	<b>85</b>

Legend: A: Pham et al., 2012; B: Wong, et al., 2012; C: Lazareth et al., 2012; D: Weller et al., 2012.

The results of the methodological quality appraisal can be observed in table 2. The evaluations varied between 70% and 85%. The concealment of the participants and the investigators (single and double blind) to the study group was not possible in any of the studies. Due to the nature of the object of study, it would be impossible to perform it and, as such, the authors considered that there is no risk of bias in the analyses carried out.

Three of the four studies<sup>3,19,20</sup> compared SSB with four layers compression bandages and one with three layers compression bandages<sup>21</sup>. The sample size ranged from 45<sup>21</sup> to 424 patients<sup>19</sup> comprising a total of 977 patients. Table 3 shows the main characteristics of the four studies included in the SR.

## Discussion

Compression therapy has been a widely studied technique with very positive results, especially in terms of healing rate. Still, it is extremely important

to sustain daily practice with the best evidence available.

This study aimed to update the knowledge regarding which compression method is better for the treatment of venous leg ulcers regarding pain, QoL and cost of treatment. Only four studies were included, not all evaluating the same outcomes neither using the same instruments. For instance, three studies have evaluated the QoL<sup>3,19,21</sup>, all with different instruments: "Quality-adjusted life-years"<sup>19</sup>; SF12 and the "Charing Cross Venous Questionnaire"<sup>3</sup>; SF36 and the CWIS<sup>21</sup>. Previous SR faced the same problem. Gethin<sup>22</sup> concluded that it is urgent to establish guidelines for conducting these studies; among the 102 studies they analyzed, 78 different endpoints were used, the majority related to healing, evaluated at 12 different time points and 95% of the studies did not refer to the validity or reliability of the evaluation methods. Considering this, the EWMA has elaborated recommendations for studies related to clinical investigation in leg ulcers and wound treatment<sup>23</sup>. If these recommendations were followed, it would be possible to standardize procedures, thus allowing for high levels of recommendation for daily clinical practice regarding wound treatment and especially venous leg ulcers.

As for the results of the included studies, regarding the QoL, it was not possible to highlight the greater effectiveness of a compression method compared to the other, but it was evidenced that any compression method is better than no compression. The compression, by its mechanisms to reduce wound exudate and the edema, will reduce pain, improve the walking capacity and also improve self-image and social life, which, in the end, are likely to explain the QoL improvement.

Regarding pain, addressed by two studies<sup>3,20</sup>, the groups to which two-layer bandages were applied, the pain intensity was lower.

Author/Year/ Country	Type of Study/ Population	Interventions	Outcomes and results	Conclusions
Pham, et al., 2012 (Canada)	RCT n = 424	EG: 4LB (n = 215) CG: SSB (n = 209)	<b>Cost of Treatment:</b> There was no statistically significant difference between the two compression systems in direct costs of treatment	Both systems 4LB e SSB present similar costs.
Wong, et al., 2012 (Hong Kong)	RCT n=321	EG1: 4LB (n = 107) EG2: SSB (n = 107)  CG: Conventional Treatment (n = 107)	<b>QoL:</b> Evaluated through the "Charing Cross Venous Ulcer Questionnaire" At week 12, there was statistically significant improvement in both EG but not in the CG (no compression). The same results occurred at week 24. <b>Pain:</b> Evaluated through the "Brief Pain Inventory - BPI" and the visual analog scale "10 points Scale - VAS" With BPI, it was found at week 1 and week 24 that there was a statistically significant improvement in both EG but not in the CG. In VAS the improvement was statistically significant in the 3 groups. There were no statistically significant differences between 4LB and SSB.	Both 4LB and SSB systems offer more significant improvement in QoL and pain compared to conventional treatment. In order to reduce pain, short traction bandages are more likely to have better results in patients' QoL.
Lazareth, et al., 2012 (France, Germany and UK)	RCT n = 187	EG: 2LB (n = 94) CG: 4LB (n = 93)	<b>Pain:</b> evaluated by 4 points VAS 2LB showed a more evident reduction of pain compared to 4LB, although this difference was not statistically significant	The 2LB system showed a tendency for more significant improvement of pain than treatment with 4LB
Weller, et al. 2012 (Australia)	RCT n = 45	EG: 3LB (n = 23) CG: SSB (n = 22)	<b>QoL:</b> evaluated through "Medical Outcomes Study 36-Item Short-Form Health Survey" (SF-36) and Cardiff Wound Impact Scale de Price e Harding (CWIS). There were no significant differences between the 3LB and SSB groups in SF36 or CWIS. For social life scores, they were lower for SSB, and those for QoL were lower for the 3LB group <b>Cost of Treatment:</b> The average cost evaluated during the treatment period was \$ 200 for 3LB and \$ 618 for SSB, a statistically significant difference (p = 0.0001).	Both 3LB and SSB systems offer similar improvements in QoL. The average cost was three times higher for the group and SSB compared to 3LB

Legend: 4LB – 4 layer bandages; RCT – randomized controlled trials; SSB – short-stretch bandage; VAS – visual analogue scale; EG: experimental group; CG: control group; QoL – Quality of life.

The SSB costs were compared in two studies, with 4LB<sup>19</sup> and 3LB<sup>21</sup>; the first was favorable to SSB and the second was unfavorable. It should be noted that the sample of this last study was reduced (n = 45), which may have influenced the statistical power. Weller et al.<sup>21</sup> suggested that, given his small sample, the study must be replicated for more expressive results. Both made an analysis of direct and indirect costs, relating them to the QoL.

Overall, the results of the included studies indicated that the use of the two-layer system is a viable alternative for the treatment of these wounds. O'Meara et al.<sup>2</sup> obtained the same conclusion, noting that SSB or 2LB compression systems are effective in treating leg ulcers of venous origin compared to non-compression. The same author also found no statistically significant difference between 2LB and 4LB.

Two main limitations can be pointed out to the present SR. The first is the impossibility to perform a meta-analysis, since no studies with the same or similar interventions were found nor with the same measurement instruments. The second was the limited number of databases searched.

Health professionals should discuss the best options with the patients,

based on the best available evidence, on their own experience and training, and always based on the perspective/conditions of the patients. How do patients feel with the treatment? How do they manage to afford one type or treatment or another? Patient should always be the center of the care process. Evidence based practice in not an exception and both patient and health professional's experiences should be taken into consideration, altogether with the best available knowledge.

### Conclusion

There is no doubt that compressive

therapy is the best approach for the treatment of leg ulcers of venous etiology. Previous evidence indicated that the short traction is more effective than long traction regarding healing outcomes but the present SR showed that for QoL, pain and cost of treatment there were no statistically significant differences between these different types of compression. However, more high-quality RCTs are needed, using standardized patient-reported outcomes to facilitate their integration into meta-analyses.

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# Health literacy and self-care in adults with type 2 diabetes mellitus

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## Summary

Adequate management of noncommunicable diseases is dependent on self-care<sup>1</sup>. Being diabetes mellitus one of these major diseases<sup>2</sup>, several determinants contribute to the process of health care and outcomes, however, in the last decades the evidence has been illustrating the concept of health literacy as a relevant and influential factor in diabetes<sup>3</sup>.

In this cross-sectional study, developed in the municipal health centres of the Autonomous Region of Madeira, we used a data collection instrument with the sociodemographic and clinical characteristics created for this purpose and use the European Health Literacy Survey for Portugal<sup>4</sup>, the Diabetes Self-Care Activities Scale<sup>5</sup> and the Treatment Adherence Scale<sup>6</sup>, too.

In the sample (n = 138), we observed a low control of diabetes, including glycaeted hemoglobin, low density lipoprotein, blood pressure and weight. About a quarter of respondents already showed complications of diabetes.

In health literacy, we found a higher percentage of individuals with limited literacy in all domains. Adherence to self-care activities was also poor and activities with greater adherence were with medication.

Given the inconsistency in the statistically significant relationship between health literacy and health outcomes, and that the results of this study seem to suggest that nursing interventions can condition the adherence to some of self-care activities, seeking to optimize the promotion of self-care, we suggest further research on the determinants that may influence it, namely the therapeutic relationship between the nurse and the adult with diabetes in the community context.

KEYWORDS: TYPE 2 DIABETES MELLITUS; ADULT; HEALTH LITERACY; SELF-CARE; COMMUNITY.

## Introduction

### Noncommunicable diseases – a 21st century challenge

Noncommunicable diseases (NCDs) are the leading cause of death in the world as one of the great health and development challenges of the 21st century both in terms of human suffering and the socio-economic impact they cause<sup>2</sup>. In 2012, of the 38 million deaths caused by NCDs, more than 40% were premature, affecting in particular people under 70 years of age. One of the main NCDs that contributed to such high mortality was diabetes. Most of these deaths are preventable, and there is encouraging evidence that these premature deaths can be reduced worldwide<sup>2</sup>.

### Diabetes mellitus – one of the major noncommunicable diseases

In 2015 diabetes mellitus (DM) reached 415 million people aged 20 to 79

worldwide, equivalent to 8.8% of the world population and the number of deaths due to diabetes was 5 million. These values will continue to increase in all countries, and in 2040 the overall prevalence of diabetes will be 10.4% (642 million people)<sup>7</sup>. One of the major problems with diabetes is its complications such as retinopathy, nephropathy, neuropathy, amputations and increased risk of coronary heart disease and stroke due to poor metabolic control, increasing morbidity and mortality in these patients<sup>7,8,9</sup>. Total health expenditure with diabetes in 2015 was US \$ 673 billion<sup>7</sup>.

### Self-care in adults with type 2 diabetes mellitus

Individuals with diabetes assume an active role in controlling the disease thus significantly influencing the natural history of diabetes which prevents late complications<sup>10,11,12,13</sup>, by maintaining the levels of glycemia, blood pressure (BP), cholesterol and weight as close as possible to the normal values<sup>7,8,14,15,16</sup> as well as by adopting behaviors of self-care<sup>11,17,13</sup>.

In type 2 DM (T2DM), self-care is closely related to a person's adherence to a healthy diet, regular physical exercise, adherence to the medication regimen, glycemic monitoring, foot care, and smoking and alcohol avoidance<sup>5,18</sup>. Due to self-care being a behavior preceded by self-perception<sup>1</sup>, the meanings people with



chronic illness attribute to it is variable. Thus, it is critical that health professionals take a person-centered approach to managing diabetes<sup>9</sup>.

McCormack & McCance<sup>19</sup> present us with a person-centered nursing model, emphasizing the nurses' need to know the client in addition to the illness. In this key person-centered approach to diabetes management<sup>19,9</sup> it is essential to empower the person with the skills to manage their own health and deal with the health system<sup>17</sup>. However, it is crucial to know what people know and what their skills and attitudes are, in order to change their behaviors conducing to establish behavioral goals and maintain a continuous support to sustain their progress and maintenance<sup>17</sup>. Thus, in order to meet the indicators recommended by the Portuguese General Direction of Health<sup>14</sup> in the National Program for Diabetes (NPD), we can say that adequate self-management of T2DM involves the development of self-care activities aiming at glycated hemoglobin (HbA1c) values  $\leq 6.5\%$ , BP  $< 130/80$  mmHg, low density lipoprotein (LDL)  $\leq 100$  mg/dl and body mass index (BMI)  $< 25$  kg/m<sup>2</sup>.

### Health literacy and self-care in adults with type 2 diabetes mellitus

Sørensen et al.<sup>20</sup> present us with a comprehensive health literacy (HL) concept, which comprises the capacity of being able to read information, adding the ability to interact with health professionals and to exercise control in everyday situations that relate to self-management of the disease or improving health. In addition to personal health benefits, there are social benefits, such as promoting greater involvement in community health actions, and greater commitment to the development of the social capital necessary for health promotion and disease prevention<sup>20,21</sup>.

Low HL was identified in several studies as a risk factor for several diseases, namely those that have modifiable risk factors and that imply self-management of the disease, namely diabetes<sup>21</sup>. A low level of HL is common among people with diabetes, estimating a variation between 15 and 40%. This limited HL is associated with a lack of knowledge about diabetes, self-efficacy and self-care behaviors<sup>3</sup>. It is therefore essential to identify HL levels of the population for the definition of health policies and programs and for professionals to tailor their interventions to the needs of the people<sup>20,21</sup>.

### Research questions

What is the level of HL and self-care in adults with T2DM in a community context in the Autonomous Region of Madeira (ARM)?

### Purpose of the study

Understanding the adult with T2DM and the factors that influence this disease contributing to the future planning of nursing interventions in promoting self-care, promoting the involvement of the person with diabetes in the management of care. In order to obtain answers to our research question, we formulated the objectives: Identify sociodemographic characteristics and clinical data; Describe HL levels and self-care and; Identify possible relationships between characteristics, HL levels and self-care in adults with T2DM.

### Methods

A quantitative cross-sectional study was developed in the municipal health centers of the ARM.

### Population and sample

The population of this study consists of all adults with T2DM residing in ARM and enrolled in municipal health centers (3929 individuals, female

= 1953, male = 1976), and the non-probabilistic sample (n = 138) who answered the questionnaire applied in nursing consultations. The inclusion criteria were: to have a medical diagnosis of T2DM for one or more years, age equal to or greater than nineteen and less than sixty-five years (adult), with sufficient visual capacity to read the questionnaire and cognitive functions that allowed interaction with the interviewer.

### Study variables

The variables studied are HL, self-care, socio-demographic characteristics such as age, gender, marital status, schooling, professional and financial situation and household, and clinical data obtained by the nurse responsible for each person with DM from computerized clinical process (HbA1c, LDL) or measuring (BP, BMI) at the time of data collection.

### Operation of variables

The questionnaire consists of a part with the sociodemographic and clinical characteristics created for this purpose, and for the evaluation of self-care we used the Diabetes Self-Care Activities Scale, a version translated and adapted to Portuguese by Bastos & Lopes in 2004<sup>5</sup> from the Summary of Diabetes Self-Care Activities by Toobert et al in 2000<sup>18</sup>. It asks about the self-care activities with diabetes that the person had in the last seven days, giving options of answer between 0 and 7, representing the number of days per week that the person fulfilled the various activities of self-care, namely the general feeding, specific diet, physical activity, blood glucose monitoring, foot care, adherence to medication and smoking habits.

The evaluation of adherence to the medication was performed using the scale elaborated by Delgado & Lima in 2001<sup>6</sup> (Treatment Adherence Scale). This 7-item version includes 6-point likert scale responses, 1 - Always; 2 - Almost always; 3 - Fre-

quently; 4 - Sometimes; 5 - Rarely and 6 - Never. The quotation is made through the sum of all items and dividing by the number of items. It is understood that a person who obtains a quotation between 5 and 6 adheres to the drug regime<sup>6</sup>.

To evaluate HL levels we used the European Health Literacy Survey (HLS-EU), adapted and validated into Portuguese (HLS-EU-PT) by Saboga-Nunes et al in 2014<sup>4</sup>. The first part (general HL) consists of forty seven questions and the answers are obtained through a likert scale of 4 points, 1 - Very Difficult ; 2 - Difficult; 3 - Easy and 4 - Very Easy, in which the person says the degree of difficulty that he feels in performing relevant tasks in the management of his health. The instrument integrates three domains of health: health care; disease prevention and health promotion, and four levels of information processing: access; understanding; assessment and use, which are essential for decision-making. To distinguish literacy levels the scale has been scaled to vary between 0 and 50. Thus, the authors defined cut-off points that limit four levels of health literacy: inadequate (0 to 25), problematic (25 to 33), sufficient (33 to 42), and excellent (42 to 50). The quotation is made through the sum of all items and dividing by the number of items<sup>22</sup>.

In a second part (functional HL), we used Weiss et al (23) Newest Vital Sign (NVS) where the respondent analyzes information from an ice cream label and then answers six questions about this information. The interpretation of the results is done by assigning one point for each right answer and zero points for each wrong answer, with people with a score between 0 and 1 presenting a high probability (50% or more) of limited literacy, between 2 and 3 indicates the possibility of limited literacy and between 4 and 6 almost always indicates adequate literacy<sup>23</sup>.

### Data collecting procedures

Nurses who had previous specific training applied the questionnaire. The selection of subjects and data collection ran from November 10, 2016 to January 13, 2017 in nursing consultations.

### Data analysis procedures

We used the descriptive data treatment with uni, bi and multivariate analysis through the Statistical Package for Social Sciences (SPSS) version 22.0. We used parametric tests to confirm the relationship between the results obtained through the scales and the sociodemographic and clinical data. The Student t-test (t) was used to compare the results between two independent variables as well as the analysis of variance (ANOVA [F]) to compare more than two means. In order to evaluate the relationship between the variables, we used the Spearman ( $\rho$ ) and Pearson (R) correlation coefficients and we considered the results with statistical significance ( $p < 0.05$ ) and with 95% confidence. The internal consistency of the scales was assessed with alpha de cronbach ( $\alpha_C$ ) values for HLS-EU-PT in all domains  $> 0.91$ , NVS 0.86, Treatment Adherence Scale 0.80 and Diabetes Self-Care Activities Scale dimensions ranging from 0.45 and 0.82.

### Ethical considerations

The study began after the favorable opinion of the Health Ethics Committee of the Regional Health Service of the ARM and the authorization of the Board of Administration of the same service, as well as the authorization of the authors to use the scales. The anonymity and confidentiality of the collected data were guaranteed and written informed consent was previously requested from the research subject.

### Results

The sample is mainly female (57.2%) with a mean age of 58 years, married or in union (72.5%), with the first cycle of basic education (69.6%) and with full time work (26.8%) or retired (26.8%), cohabiting with family members (81.9%). In general, the majority report that their financial situation always allows or almost always meets the needs of housing (86.9%), food (79.9%), health (72.4%) and education (51.6%).

### Clinical data

We found that, on average, T2DM diagnosis time is 7.5, ranging from 1 to 40 years, with 50% having diabetes for at least 6 years. We also found that 68.5% did not have controlled T2DM or updated HbA1c analysis. This study also shows that 92.7% are overweight (BMI  $\geq 25$  kg/m<sup>2</sup>), and 49.2% are obese (BMI  $\geq 30$  kg/m<sup>2</sup>).

We also found poor LDL control with 44% of the individuals presenting high values and 8% with no records of them. This scenario remains regarding the control of BP, where 41.2% of people have high blood pressure (HBP) and 26.1% high normal BP, as 67.3% do not meet the goal proposed for the BP control. In fact, the comorbidities more referred are hypertension (77.5%) and dyslipidemia (37.8%), with 19.6% referring both.

In the present study, 26.1% had several complications, namely retinopathy (44.4%), nephropathy (27.8%), coronary disease (19.4%), arteriopathy (13.9%) and stroke (13.9%). However, in the last year, people had a low adherence to surveillance consultations, except for nursing consultation (NC) for foot care (65.2%).

### Health literacy

With regard to general HL, we found that 65% of people had limited HL (19.7% inadequate and 45.3% problematic). The HL trend in all three domains (health care, disease prevention and health promotion) ac-

companies that of general HL, ie a higher percentage of individuals with limited literacy.

In functional literacy, we observed that the tendency of a higher percentage of people with limited literacy remained with 49.3% presenting a high probability of limited literacy.

The HL score is significantly different [ $F(8; 128) = 2.505; p = 0.015$ ] according to the professional situation, where we observed that the level of literacy is higher in part-time employees (33.6) and full-time employees (33.4), yet at a sufficient level, while others are at the problematic level.

We verified that those who can always satisfy health needs have higher general HL level (33.3) [ $F(3; 133) = 3.099; p = 0.029$ ] and health care (33.5) [ $F(3; 133) = 3.43; p = 0.01$ ] than the remaining elements of the sample. Also, those who can always satisfy the needs of education have a higher level of HL, tending to be sufficient in all domains ( $p < 0,05$ ).

We found a positive and low correlation between the general HL and the general diet ( $R = 0.250, p = 0.003$ ), due to the fact that the correlation coefficients are significant in all HL domains the affirmation is valid for all of them. A similar correlation was found between general HL level and self-care activities with the feet ( $R = 0.246; p = 0,004$ ). There was also an association between adherence to drug treatment, assessed through Treatment Adherence Scale, and general HL ( $t = 2.228, p = 0.028$ ), health care literacy ( $t = 2.342, p = 0.02$ ) and disease prevention literacy ( $t = 2.323; p = 0.022$ ). In general, among individuals adhering to medication treatment, the mean level of HL is higher, but this relationship is not observed in health promotion literacy.

### **Self-care activities with type 2 diabetes mellitus**

#### *Self-care activities with food*

In the scale used the diet is divided into general diet and specific diet. In this study, people presented a sufficient level of adherence (4.7) to the self-care activity with general food. In addition to the correlation already identified with HL, it was verified that those who attended the NC for foot care had a higher level of adherence to general feeding ( $t = 2.426; p = 0.017$ ).

On the other hand, in the specific diet, we observed a low level of adherence (1.6), and respondents who rarely meet their food needs consume, on average, more food such as red meats, bread, rice, pasta, alcoholic beverages and cakes than those that are able to meet them more regularly [ $F(4; 133) = 2.877; p = 0.025$ ].

We found that, although people report that they follow a healthy diet and the recommended eating plan, the truth is that, when asked in greater detail about them, they show the opposite.

#### *Self-care activities with physical activity*

In this study people presented a low average adherence (2.0) to this self-care activity.

#### *Self-care activities with blood glucose monitoring*

A low average adherence (2.1) to this self-care activity was observed and those who attended the NC for foot care (65.2%) presented on average lower adherence to self-monitoring of blood glucose ( $t = 2.518; p = 0.013$ ).

#### *Self-care activities with the feet*

We observed good adherence (5.9) to these self-care activities. In addition to the correlation already identified with HL, it was verified that those who attended the NC for foot care showed, on average, a higher adherence to this

self-care activity ( $t = 2.1; p = 0.036$ ). Effectively few people (11.1%) reported diabetic foot as a complication of DM.

#### *Self-care activities with medication*

In this study, we found an average adherence of 6.8 and that more than 85% of respondents adhered daily to medication. These results are corroborated with the results obtained through Treatment Adherence Scale, that is, a high adhesion (88.4%) to the drug regimen.

Most common therapy for DM control is oral antidiabetic medication, used by 94.2% of the interviewees and 11% also have associated insulin.

As previously mentioned, in general, among the individuals who adhere to the drug treatment the average level of HL is higher. On the other hand, it is among those who rarely can meet the needs of food [ $F(4; 129) = 27.1; p < 0.01$ ], health [ $F(3; 130) = 2.84; p = 0.041$ ] and education [ $F(5; 116) = 11.693; p < 0.01$ ] that there is a lower average adherence to medication.

## **Discussion**

### **Clinical data**

The results we found in diabetes control point to those of García-Pérez et al (10) who report that approximately half of the patients with diabetes do not reach the recommended targets for blood glucose levels.

The high prevalence of overweight was also observed in the studies by Ortiz et al.<sup>13</sup> and Chourdakis et al.<sup>11</sup>, being a determinant factor for the development of DM hampering the treatment and control of DM<sup>10,7,8</sup>.

The poor LDL control, high blood pressure and ignorance of the goal proposed for the blood pressure control is similar to the study by Ortiz et al.<sup>13</sup> In fact, the comorbidities most referred are hypertension and dyslipidemia, confirming what several authors and organizations have been saying, that is, they are common in the person with DM,

contributing to the development of late complications, namely cardiovascular complications<sup>15,16,24</sup>.

These results may indicate an inefficient self-management of DM<sup>14</sup> with the respective appearance of the complications as retinopathy, nephropathy, coronary disease, arteriopathy and stroke.

### Health literacy

The results we found in this study are in line with those observed in the Portuguese population in general<sup>4,21</sup>, however, they show a more disturbing reality when compared with the estimates of a low level of HL in people with diabetes of Cavanaugh<sup>3</sup>, estimating a variation between 15% and 40%, and with the study by Bohanny et al.<sup>25</sup> where 24% of participants had limited literacy.

The correlations we found between the general HL and self-care activities are in line with the results of Sayah et al.<sup>26</sup> who, in their systematic review on HL and health outcomes in T2DM, conclude that there is sufficient evidence to support a positive relationship between HL and self-care activities.

### Self-care activities with type 2 diabetes mellitus

#### *Self-care activities with food*

As food is one of the fundamental pillars for the treatment and control of DM, it is important to adopt an adequate diet, however, we must attend to the complex cultural and habits process that influence the diet of people with chronic illness<sup>27</sup>. In fact this study showed that those who reported difficulties in meeting their needs with food opted for some less healthy and more expensive foods.

The fact that people report that they follow a healthy diet but, when asked in greater detail, they show the opposite, is similar to the results were found in Ortiz et al.<sup>13</sup> and Chourdakis et al.<sup>11</sup> studies. These results are in agreement with what Franz & Evert<sup>27</sup> refer to, that changing the diet is more difficult than changing the other activities that a person with a chronic illness needs to perform.

#### *Self-care activities with physical activity*

Having proven the benefits of regular physical activity in DM control, it is important to adopt and maintain this behavior<sup>28</sup>, however, in this study, similar to the study by Ortiz et al.<sup>13</sup>, people presented a low average adherence to this self-care activity.

#### *Self-care activities with blood glucose monitoring*

Blood glucose monitoring is also understood as a self-care activity with DM, producing results in the metabolic control and quality of life of the person<sup>5,18</sup>. In this study, a low average adherence to this self-care activity was observed, similar to the results found by Ortiz et al.<sup>13</sup> In ARM, people with T2DM regularly attend the NC in the health center to carry out this monitoring, thus diminishing self-monitoring. Perhaps for this reason, those who attended the NC for foot care presented on average lower adherence to self-monitoring of blood glucose. However, we cannot say that this result means negligent behavior in this activity but the fact that it is shared with the nurse. A similar situation occurs in the health centers of Mexico where monthly monitoring of glycemia is performed for people with DM, since most of them have low financial resources<sup>13</sup>.

#### *Self-care activities with the feet*

Foot care in the person with diabetes, such as regular self-examination, is

fundamental given the increased risk of developing ulceration, infection and amputation, so it is important to adopt and maintain this behavior<sup>29</sup>. Similar to Chourdakis et al.<sup>11</sup> in this study we also concluded that, in general, patients reported a high adherence to foot care. On the other hand, we also observe that those who attended the NC for foot care showed, on average, a higher adherence to this self-care activity, which may have contributed for few people reported diabetic foot as a complication of DM.

#### *Self-care activities with medication*

Adherence to the drug regimen is fundamental in the treatment of DM, which is an integral part of self-care activities with this disease<sup>5,18</sup>. As in this study, also Ortiz et al.<sup>13</sup> and Chourdakis et al.<sup>11</sup> found a high adherence to medication in their studies. These results contradict Aikens & Piette<sup>30</sup> when they report that only half of patients with T2DM have high adherence to medication and Ahmad et al.<sup>31</sup> when they conclude that adherence to the medication of the patient with T2DM in the context of primary health care was poor (47%). On the other hand, since this was the self-care activity with the highest level of adherence, these results suggest that it may be easier for those who have diabetes to adhere to the drug regimen than to make changes in their lifestyle<sup>13</sup>.

However, it is not only the medication that contributes to glycemic control, so if the person adheres to the medication regime and not to other self-care activities, as is the case of this sample that presents low levels of adherence to self-care activities with specific diet and physical activity, may have high levels of plasma glucose. Thus, adherence to the various self-care activities is essential for an effective self-management in the treatment and control of DM<sup>5,10,7,8,11,12,18</sup>.

As in the study of Shrestha et al.<sup>32</sup>, in this, the most common therapy

for DM control is oral antidiabetic medication.

The fact of those who rarely can meet the needs of food, health and education have a lower average adherence to medication may suggest the financial situation of the household as a condition for compliance with the medication.

### Conclusion

In this study, we observed an inefficient self-management of diabetes, namely in HbA1c, LDL, BP and weight, with about a quarter of respondents already showing at least one complication of DM.

We found a high percentage of respondents with limited general HL, and this trend remains in all HL domains, namely functional HL. The results suggest the professional activity and the financial situation of the household as possible determinants of HL.

We conclude that, in general, people have a low level of adherence to self-care activities and those who, on average, achieved greater adherence were medication, foot care and general feeding, confirming that those who adhere more to these activities also have, in general, higher levels of HL.

We did not find the direct and statistically significant relationship between HL and health outcomes, which concurs with the various studies that have already been carried out with inconsistent results of this relationship, showing that the evidence is still insufficient or inconsistent to state that HL has a direct impact on the health outcomes of people with DM<sup>26</sup>. On the other hand, there is a correlation between HL and adherence to some self-care activities with DM<sup>3,26</sup>, namely in adults with T2DM in a community context. Through the analysis of this study, we can understand HL as a conditioning factor for self-management of diabetes.

Nurses' focus should be to promote self-care, especially since the results of this study seem to suggest that nursing interventions may condition adherence to self-care activities with the feet, general feeding and glycemic monitoring. In its clinical practice the nurse, in partnership with the person, should establish health education programs with well-defined behavioral goals and maintain a continuous support to sustain their progress and maintenance<sup>17</sup>.

In order to optimize the promotion of self-care, we suggest further research on the determinants that may influence it, namely the therapeutic relationship between the nurse and the adult with T2DM in a community context.

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# Dynamic model for assessment and family intervention

## Impact on families health gains

### Summary

The current Primary Health Care reform is focused on effectiveness patterns, targeted at ensuring the best possible health gains for its users. In regard to this approach the aim is to assess health gains as a result of the implementation of the Dynamic Model for Assessment and Family Intervention.

For this quantitative study, the focus of attention areas described in the operative dimensions of this Nursing Model. Data collection was performed based on the information produced by Primary Health Care Nurses, through the Information System in use. The family health gains indexes computed into the Microsoft Office Excel 2007 were used for data processing and analysis.

In the structural dimension, the major health gains were found in the residential house (50%). In the development dimension, the interventions targeted at family planning were found effective for 85.19% of the families, with the adaptation to pregnancy showing the lowest rates in health gains (50%). As to the functional dimension, the highest rates in health gains were found for an adequate caregiver role in 33% of the families, whilst in the family process, health gains rates were at 5.56%.

The implementation of the MDAIF had a positive impact on health gains outcomes for families, fostering the development of assessment and family intervention competencies as well as the identification of training needs in specific intervention areas.

**KEYWORDS:** PRIMARY HEALTH CARE; FAMILY NURSING; NURSING MODEL; NURSING PROCESS; FAMILY HEALTH; HEALTH STATUS INDICATORS; CLINICAL SKILLS.

### Introduction

The Primary Health Care system in Portugal (PHC) dates back to the 70's, and ever since it has been evolving from an individual care model to family and community care models<sup>1</sup>. Nowadays, primary healthcare is provided in Care Units segmented into different healthcare services: Family Healthcare Units and Personalized Care Units provides care to Families and individuals; Public Health, which according to the study conducted<sup>2</sup> on family healthcare units in Portugal, revealed better health outcomes; Units and Community Care Units, which provide care to Communities and risk groups. The focus of care on families implies competence and effectiveness of professionals in the provision of health care. In what health care is concerned, the Portuguese society developments urge for more specialized and differentiated nursing care and more complex support. Thus, the Portuguese Order of Nurses

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(Ordem dos Enfermeiros) responded to political demands, such as the inclusion of the family as the focus of nursing care, following international directives of Health 21, considering the conceptual framework of health policies for every member state in the European Region of the World Health Organization (WHO) and the Munich Declaration, a joint declaration signed by Portugal and other Europe's member states. Thus, considering the process of creating the new specialty of Family Health Nursing, the profile of Specific Skills of the Nurse Specialist in Family Health Nursing (endorsed by the College of Community Nursing Specialty of the Portuguese Order of Nurses – Ordem dos Enfermeiros), the Official Law Regulation Publication<sup>3</sup> was published, which described the specific skills of specialist nurses in family health nursing: to provide care for the family as the core center of care; to provide specific care at

the different stages of the family life cycle at primary, secondary and tertiary levels.

The Dynamic Model of Family Assessment and Intervention<sup>4</sup> (MDAIF) underlined by the family care practices was co-developed and validated by research teams working in the Primary Health Care context. In 2011 the Portuguese nursing profession regulator decided to adopt MDAIF as the theoretical framework of Family Health Nursing intended to meet the needs of the Portuguese nurses responsible for family care. The MDAIF development emerged from a action-research work conducted with family nurses supported on family nursing assumptions, and by the experiences and episodes related with nurses in the process of interaction with families. This work enabled the creation of knowledge based on interventions and leading to effective changes in nurses' practices. It is focused in relevant fields of family health nursing, using a multidimensional matrix centred in the dimensions: structure (household income; residential building; safety measures; water supply; household pets); development (marital satisfaction; family planning; adaptation to pregnancy; parental role), and functioning of the family system (caregiver role; family process). MDAIF is based on an operative and dynamic structure which intends to be flexible and interactive, allowing nurses to suggest interventions targeted at the specific identified families' care needs. The MDAIF provides a wide framework for family assessment and interventions and suggests actions leading to best practices. It differentiates itself from other assessment models and family interventions through its operational definition of concepts, which allows a generalization of proposals that can be empirically and effectively tested. We highlight this operational component compared to other theoretical referential in family nursing as an effective contribution to the systematization and to the adequacy of nursing practices targeted at families.

The primary health care is the basis of the healthcare system, emphasizing a network intervention and the implementation of multidisciplinary teams, underlying a centered care approach on the family and on the life cycle. Within this framework, the implementation of programmes of family health nursing is considered essential for the development in this area<sup>5</sup> fostering the acquisition of new competencies and consequently better health outcomes. The family health nursing has been developing in the theoretical domain reflected in models and theories of assessment and family interventions, in research through a change in the existing paradigm, emphasizing the family as the core study subject<sup>4</sup>.

Monitoring and evaluating the impact of the studies is fundamental for the transfer of knowledge to the clinic<sup>5</sup>. The implementation of the MDAIF requires a training process adjusted to the nurse's needs enabling the transformation of knowledge into action, through structured learning processes focused on technical approaches to families and integrative methodologies. The studies on the MDAIF implementation<sup>6,7,8</sup>, enabled an in-depth understanding of this specific model as a promoter of the family nurse role, contributing to the development of interdisciplinary work methodologies of family health teams. The improvement of the effectiveness concerning interventions will endow, on one hand, a continuous enhancement in nursing care quality and, on the other hand, an improvement of the levels of assistance provided to the population, taking into account the mission of the primary health care units. The adoption of this model by nurses will allow the documentation of care provided, which can be used as a guideline to nurses in relevant areas of the family's care process.

The assessment of the impact of these practices underlying the MDAIF, based on the effectiveness indicator definition (which allows measuring health

gains arising from the interventions developed with families), will largely contribute to the improvement of innovative practices as a decisive impetus for the new Primary Health Care organization.

The areas of attention included in the multidimensional matrix of MDAIF, are the nurses guidelines for the clinical decision-making in all the stages of the nursing process. The evaluation of the health gains as a result of nursing interventions, grounded by the developed health indicators based on this matrix, enable to answer the following questions:

What are the health gains for the families cared by nurses, based on the theoretical support of the MDAIF, within the areas of attention of the structural dimension?

What are the health gains for the families cared by nurses, based on the theoretical support of the MDAIF, within the areas of attention of the development dimension?

What are the gains for the families cared by nurses based on the theoretical support of the MDAIF, within the areas of attention of the functional dimension?

The current primary health care reform focuses on effectiveness standards, intended to ensure the greatest possible health gains for its users. Considering this approach, the purpose was to assess the health gains as a result of the implementation of the Dynamic Model for Assessment and Family Intervention (MDAIF) in the context of the primary health care.

## Methods

This is an exploratory-descriptive study and quantitative in nature. In order to meet the objectives, and based on the MDAIF<sup>4</sup> as the theoretical and operational referential, the areas of attention variables described in the dimensions of the operational matrix of this model, were considered:

- Structural Dimension: household income, residential building, safety measures, the water supply and household pets.



- Development Dimension: marital satisfaction, family planning, adaptation to pregnancy and parental role.
- Functional Dimension: the caregiver role and family process.

The study was conducted within the context of a health centre of one of the regions of Portugal, targeted at families registered in the family files of 12 nurses working in this health unit, and which were recipients of care according to the MDAIF and data was computed into the Information System developed for this purpose, The Family Nurse Platform (FNP), totalling 210 families.

The information produced by the nurses and documented in the FNP was considered for data collection. The gathered data concerns the areas of attention of the MDAIF, its operational dimensions, as well as its evaluative items, including documentation relating to the diagnostic statements, interventions performed and outcomes assessment. The health gains indicators were considered, which had been previously defined within the multi-centered project involving this study (Dynamic Model for Family Assessment and Intervention: a transformative action in primary health care), describing the relation between: the number of families where there was a change in the clinical judgment (for example, from not adequate to adequate) in the diagnostics produced based on the areas of attention described in the referential (family income, residential building, safety measures, water supply and household pets, marital satisfaction, family planning, adaptation to pregnancy and parental role; the caregiver role and family process), on the number of families which diagnostics had been referred in need for interventions, considering the aforementioned areas of attention.

The data necessary to apply the formulas of the MDAIF indicators were extracted from the computer system, more specifically the global numerical indicators of responses necessary to apply the formulas of the indicators. For the data extracted the documentation relating to the evaluative data of each element of the matrix was also considered (household, type of extended family, wider systems, social status, family vital cycle) which enable an in-depth understanding of the family, as an open system, which transformational process is influenced by the different environment structural levels<sup>4</sup>.

To calculate the number of nursing diagnoses proposed in the operative matrix of the MDAIF and for the results assessment, a period of six months was established for the analysis process and then each item described in the matrix was selected to extract the number of statements and the assessment outcomes (e.g. 1. number of nursing diagnoses “no preservation of marital satisfaction”; e.g. 2. number of records “adequate residential building”).

Data collection was performed over a period of six months of nursing care. The data collected were computed into an Excel, specifically designed for this purpose. Descriptive statistics were applied with regard to the evaluation of data for the characterization of families, as well as for the calculation of the health gains indicators.

## Findings

### Families characterization

The majority of families included in the sample (210) are nuclear families 56.19% (119), and according to this referential (Figueiredo, 2013), it corresponds to the family constituted by man, woman or by individuals of the same gender, either married or not, with at least one biological or adopted child. An extended type of family has an expressive 20.9% (44) either as a couple or nuclear family and other relatives or persons with other ties not specifically connected to kinship or three-generation descendants.

The uniparental family emerges at the third position representing 8.10%

(17), followed by the couple typology 7.14 % (15) described as the family constituted by “man and woman or partners of the same gender that may be legally married or not”, Figueiredo (2012: 74).

In what concerns the remarried families, in which at least one member of the couple has had a previous marital relationship and a child conceived from this relationship, the results show 5.71% (12).

As to the mono-parental families 0.95% (2) is mainly constituted by women and 0.48% (1) by men. The institutional family shows a similar percentage of 0.48%.

With regard to the type of relations within an extended family, the emotional support is the most representative with 28.40% (165); following by the social accompaniment 20.48% (119); the cognitive and advice guide 19.28% (112); material assistance and service 16% (93); social adjustment 8.43% (49); and finally, access to new contacts 7.43% (43).

### Health gains for the families

#### Structural dimension

The highest impact of the nursing interventions, underlying the MDAIF, was reflected in health gains related to the residential building, whose diagnosis was changed from neglected to not neglect, in 50% of the families who showed the diagnosis of a neglected residential building. The interventions proposed to respond to the diagnosis of neglected residential building and lead to the production of health gains, refer, among others suggestions, the request and/or the orientation of families to social services, teach about the risks of a housing with poor hygiene, promote and/or strengthen the house management. Similarly the nursing interventions were effective in 42% (21) of the families who have been given Demonstrated Security Precaution, meaning that families who expressed needs in this area, were able to demonstrate knowledge about the use of heating

equipment, the use of gas equipment and knowledge about strategies of adaptation to architectural barriers. On the other hand, nursing interventions refer to teaching about the use of heating and gas equipment; negotiate on the use of heating and gas equipment. These interventions are also targeted at motivating the family to strategies of adaptation to architectural barriers and guidance on community services. It was found that the families needed guidance on the use heating equipment, more specifically on electric heaters, which included empower them about using this equipment, such as information on security check and location of equipment, which electrical cables should be distanced from any heat source; about maintaining the air circulation to avoid the risk of hypoxia due to the burning of oxygen caused by the equipment.

A Not Insufficient Family Income was expressed by 40.82% (20) of the families included in this intervention. Within the MDAIF, the suggested interventions were mainly aimed at requesting and guiding families to social services and promote the empowerment of the family about the proper management of household income. In this perspective, the family nurse, based on professional competencies, has promoted knowledge and trained families to manage their income in accordance with their expenses to comply with the basic needs of family members, on the 20 families showing health gains.

On the other hand, the lower expressiveness on health gains sensitive to nursing care in the evaluated dimension, was revealed in the area of attention related to Household Pets. Of the total formulated diagnosis requiring nursing interventions (45) – for the Neglected Household Pet, the health gains rate was set at 17.78%, corresponding to 8 families in which there was a change in the diagnose status.

Within the MDAIF, the contribution that nurses can provide to families with a diagnosis of Neglected Household Pet, include interventions such as teaching the families about vaccination and de-worming of household animals, guidance for community services, in addition to encouraging the family to perform these tasks and supervise animal vaccination.

In what concerns the water supply, the 210 families presented appropriate water supply since they were using the public water supply for human consumption and/or private water supply, with the completion of water quality control.

#### *Development dimension*

The highest health gains outcomes are for the areas of attention related to the development dimension, and occurred in Family Planning. In this area, health gains reached 85.19%, corresponding to 46 families who initially had Ineffective Family Planning and in which a change in the diagnostic status was also verified. The interventions suggested by the MDAIF underlying the actions of the family nurse to in promoting positive change in the diagnostic status, which meet the needs identified in each operative dimension showing as examples: teaching the couple on contraception methods; teaching and providing information to the couple on emergency contraception; to provide early guidance on emergency contraception; to teach, inform and train the couple on the use of contraception; to encourage the use of contraceptives, to provide contraceptives; to provide reading material; to inform/guide the couple on pre-conceptive consultation; to teach the couple about the psychologic, family and social aspects of pregnancy; to teach the couple about the woman's sexual cycle, among other aspects.

Also, health gains outcomes for the Marital Satisfaction were registered at 54.17% (26) of the sample families which had initially a diagnosis of marital

satisfaction as Not Maintained. These results suggest the effectiveness of interventions developed by nurses for the majority of families showing Not Maintained Marital Satisfaction. Some of the examples of the developed interventions are; the couple's emotional expressiveness; planning family rituals, motivating the couple to engage in common activities, guidance on medical services, to encourage family therapy and psychology services.

The area of attention Adaptation to Pregnancy shows 50% (6) of health gains, for families with a subsystem couple and pregnancy, which had initially had Adaptation to Pregnancy Not Demonstrated and changed to Adaptation to Pregnancy Demonstrated. The interventions developed by nurses refer among others to informing the couples about social rights in pregnancy; to teach about the different stages of the adaptation to pregnancy; to inform/guide on the course and preparation to childbirth; to teach the couple about fetal development; to teach about the psychologic process related to post-partum; to provide family support by stimulating the couple to express their emotions.

In what concerns the parental role, the families classified in the third stage of the family life cycle (families with children in school) and that were the subject of interventions of nurses benefited from health gains in the four operative dimensions described in the MDAIF: the role knowledge, adherence behaviors, consensus, burden and conflict. The greatest expression, reflected in the change of the diagnosis status of appropriate parental role by conflict No (100%; 8); followed by the adequate parental role burden No (81.82%; 9); the adherence behaviors are demonstrated in 73.68% of families; the role consensus "verified in 66.67% (4); and finally, 59.12% (81) is registered for the knowledge of the role demonstrated.

Then there is a percentage of

59.12% (81) in health gains on the fifth stage of the family life cycle, the family with adult children. The fourth stage of the family life cycle, the family with teenage, shows 10.53% (4) families with health gains through the confirmation of demonstrated adherence behaviours.

In the context of the interventions proposed in the operative matrix of the MDAIF aiming at the effective performance of the parental role, adjusted to the stages of the family life cycle, some examples are presented: teaching and/or instruct parents about eating patterns appropriate for the child; about proper washing teeth; to promote and/or advocate strategies of functional reorganization strategies for the adaptation to the new timetables; to motivate parents to the participation in meetings and activities of the child study; to promote expressive communication of emotions; to evaluate the dimensions of conflict; to motivate the redefinition of family members roles, to renegotiate the definition of parental and family members roles; to promote the involvement of the extended family.

#### *Functional dimension*

Considering the areas of attention included in this dimension, the health gains in the context of the caregiver role are of 23.33%, whilst those who refer to the familiar process, show 5.56%.

The diagnostic caregiver role not suitable was stated by 22 of the families with a dependent family member (36), meaning 88% of families in need for nursing interventions in this area. The diagnostic criteria defined in the MDAIF (Figueiredo, 2012) for the enunciation of the caregiver role not adequate, refer to the knowledge of the role Not demonstrated, and/or adherence behaviours Not demonstrated, and/or consensus of the role No and/or role conflict No, and/or role burden Yes.

This prevalence is due to the knowledge of the role not demonstrated, essentially on the operative dimension of knowledge about "feeding self-care", specifically about the appropriate eating pattern. Also, in the operational dimension of the knowledge of the role, the areas of hygiene self-care and management of the therapeutic regimen also showed needs in nursing care. There were also families with needs in nursing care directed at the areas of hygiene self-care (6), more specifically on the knowledge on proper washing of teeth; clothing self-care (3) and drinking (3), these being due to the knowledge not demonstrated in relation to the stimulation of the dependent family member. Also concerning the self-care in the management of the therapeutic regimen (7) and on the knowledge and learning of abilities of self-administration of medication (4).

Thus, 23% of families showing health gains in the caregiver role, correspond to 7 families where there were changes relating to the knowledge of the role and/or adherence behaviours, and/or role conflict, and/or burden of the role.

Therefore, the suggested interventions to address the caregiver role not suitable, for an effective adjustment in the family, include training, education, planning, advocacy for the leisure activities of the dependent family member, for example, among others, in each knowledge area evaluated and identified with nursing care needs. Naturally, the interventions proposed in the matrix of the MDAIF also include referentiation and request from other services of the multidisciplinary team.

In what refers to the Familiar Process the health gains reach 5.56% (2) of families with the initial diagnosis of a dysfunctional family process. Positioned at a level of approach whose emphasis is given to the family system, in all its dynamics, the familiar process requires interventions that essentially involve the use of systemic communication techniques. The interventions pro-

posed to respond to family needs in this area include: promoting expressive communication of emotions, to negotiate adaptive strategies/coping in the family, to negotiate a redefinition of roles by family members; to optimize the pattern of family ties, to guide to family therapy.

The prevalence of the dysfunctional family process was 31.58% (36). The most relevant evaluation item was related with the non-satisfaction of family members to the way feelings were expressed, which integrates the emotional communication in accordance with the operative matrix of the MDAIF. It should be noted that the dimension of the family roles also presents nursing care needs, in which the consensus of the domestic care role nor established represents 3.77% (4) of these families.

Placed at an approach level whose emphasis is given to the family system, in all its dynamics, the family process requires interventions that essentially involve the use of systemic communication techniques. The interventions proposed to respond to family needs in this area include: promoting expressive communication of emotions, to negotiate adaptive strategies/coping in the family, to negotiate a redefinition of roles by family members; to optimize the pattern of family ties, to guide to family therapy.

#### **Discussion**

This diversity is the reflection of new emerging family configurations which are influenced by factors such as increased life expectancy, a decrease in birth rates, a decrease in marriages, an increase of divorce. In addition to this diversity, it is also important to consider changes in gender roles, the variety of marital relationships and the process of family reorganization.

In what refers to changes in the family structure, according to the results of the 2011 Census, the number of traditional families increased by around 11% between 2001 and

2011 (INE, 2012). The same source considers that despite its smaller relative importance, the typology of couples with children, is still predominant when comparing these two periods (2001-57%; 2011-50%), considering the other family structures, such as childless couples (2001-31%; 2011-35%); single-parent families (2001-12%; 2011-15%). In this case, the single-parent nuclear families constituted by the mother with children are the most prevalent representing more than 86% of all single-parent nuclear families. The 2011 Census also showed a significant increase in the number of remarried families (2001- 46.786; 2011- 105.764)<sup>9</sup>.

According to the latest data from Statistics Portugal<sup>9</sup> in 2016 there were 4.080.230 traditional families in Portugal, the majority, 1.447.809 were families of married couples with children. Corresponding to 35.5% of nuclear families, it is possible to verify that despite the percentual decrease of this type of family, from 2011 to 2016, it remains the predominant type, showing that the prevalent type of family included in this study is in accordance with the most recent statistics.

The family mutual help relates to the family integrity, and influences its transition processes<sup>10</sup> in a context of exchanges between the elements of the social network, which in this case are the members of the extended family, which correspond to the elements of the family of origin and other relatives not necessarily integrated in the family system.

The assessment of the caregiver role, enables an in-depth knowledge for nurses about the way families interact in order to respond to its members needs, in particular when there is one or more dependent family member. These show higher risk of being neglected, when the family member playing this role is either the husband or a son, compared to the case of the wife or a daughter<sup>11</sup>. In this perspective the assessment of all the dimensions in this area of attention is essential, in order to accurately identify general and particular needs, considering the specificities of the family. Usually the members of the family have no training in the health area, nor receive any compensation for the role they play, spending most of their time caring for the family member<sup>12</sup>, somehow confirming the prevalence of needs of the caregiver role. Similarly, the complexity of all domains integrating this area, it is essential to develop more effective strategies, in order to increase health gains for families with a dependent family member.

Globally, the analysis on the family process is the one showing lower outcomes in relation to nursing interventions, suggesting training needs in this particular area<sup>13</sup>. The complexity of this area of attention is characterized by the interrelation between five subdefinitions: family communication; family coping; interaction of family roles; dynamic relationship and family beliefs<sup>4</sup> revealing the international pattern that defines family as a co-evolutionary system.

The changes occurred in families with regard to the areas of attention where needs are identified that require implementation of interventions, translate health gains that may be attributable to nursing care and thus be sensitive to these professionals. These results corroborate other studies<sup>14</sup> referring to the application of assessment models and family intervention, notably the Calgary Family Assessment Model, demonstrating that the implementation of this frame of reference, both in hospitals and primary health care, enables the focus of nursing care is centered on the structure, development and functioning of the family.

## Conclusion

The implementation of the MDAIF produced a positive impact on the production of health gains for families, empowering the development of

assessment skills and family intervention. The highest health gains outcomes were for the development dimension, with rates above 50% in all the areas of attention: marital satisfaction; family planning; adaptation to pregnancy and parental role. Followed by the structural dimension in which all the areas, except for household pet, showed percentages above 40%. In the functional dimension, rates ranged between 33% and 5.56%, corresponding to the caregiver role and family process, respectively.

On the other hand, the use of indicators, as tools for the promotion of healthcare quality in general and in this particular case of nursing care, allowed to confirm that the use of the MDAIF in a practical context, favours the care provided to families within the Primary Health Care. Health gains show that the MDAIF had a positive impact in the way families are cared for nurses, suggesting that nurses may have developed the ability to mobilize, combine and transfer knowledge to clinical situations.

The generalization of this study results in other geographical contexts will allow outcomes that favour:

- The monitoring of the implementation process of the MDAIF and the development of family health nursing, by identifying critical points that lead to the introduction of enhanced strategies for the below related tasks.
- Highlight the most prevalent family diagnosis enabling the establishment of strategies conducive to implementing evidenced-based strategic actions of empowerment of families and communities.
- Define a system of continuous improvement of the quality of nursing care supported by the MDAIF, based on the setting of milestones based on the outcomes.
- Manage resources allowing the adjusted allocation of nurses to the family nursing care needs.

The training in the context of fa-

mily health nursing, integrating content related to the MDAIF, as well as clinical supervision in the contexts will enable the development of skills and consequently lead to better health gains for individuals, families and communities.

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# Mental health literacy

## A pillar for the development of healthy communities

### Summary

An integrated health perspective emphasizes the importance of assessing mental health literacy in different population groups. The level of literacy in Mental Health indicates individual educational needs for maintaining mental balance. Risk and protective factors for mental health are identified, and there is an urgent need to increase community literacy. The article refers to the study that will be carried out to determine and compare mental health literacy in the young and adult population of the Region. It will have two stages: pilot study and main study. In this paper, we will use the Questionnaire for Evaluation of Literacy in Mental Health – QuALIS-Mental, developed by Jorm et al. in 1997, in the version adapted for Portugal of the National Survey of Mental Literacy in Young People – Interview version by Loureiro et al. in 2012 and the Inventory of Beliefs on Mental Illness – short version, also by Loureiro in 2008. The results will be representative of the population in study, resident in the Region's municipalities. The pilot study will cover four groups residing in two municipalities, two aged between 14 and 18 years and two between 19 and 64. It will be a transversal, exploratory and quantitative study, with the collaboration of Health Centres nurses. After analysis, the results will be disseminated in the municipal communities, the population and the local entities. It will be considered useful to identify gaps in mental health literacy and to combine synergies using the knowledge gained to improve community mental health planning.

KEYWORDS: LITERACY; MENTAL HEALTH; HEALTHY COMMUNITIES.

### Introduction

Healthy communities are a goal to be achieved in different countries worldwide, including in Europe. In the Region, this is also a goal to be achieved. With this pretension/prospect on the horizon, several desiderata are to all who dedicate themselves, by profession, to the area of Health. Of the many that are pertinent, one that deserves investment is the adequate training of the professionals who daily act in the promotion and education for the health of the populations and also in the prevention of the different alterations likely to arise, especially in contexts of proximity of the communities as are the health centres. At present, different health protection and risk factors are identified, and there is evidence that the level of health literacy and mental health of citizens should be considered relevant.

Knowledge of regional and local realities in relation to the complex set of health determinants with their multiple dimensions, such as mental health, is fundamental for the planning of strategic and action plans to be delineated

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ted especially when it is imperative to make the most effective use of the resources allocated to the health of the population, which are usually poor in order to satisfy the set of needs that are identified.

In order to provide a sound basis for interventions in the area of community health, it is urgent to ask about the starting point for these, prior to the definition of the point of arrival, as well as about the selection of strategies and methodologies to reach them, thus conferring sustainability theoretical or empirical to the work of the various professionals involved and/or to be involved<sup>1</sup>.

This article aims to share with the broader scientific community a set of issues and ideas formulated by the group, whose attention is focused on mental health literacy of different population groups in the Region, given the importance attributed to it as a determinant of health/mental health<sup>2</sup>. In the Region, the mental health literacy of the population has not been measured until this moment. So, this research project aims to determine the status of health literacy in different groups with distinct socio-demographic characteristics, verifying if those characteristics influence in a significant way the findings in the mental health literacy

that are expected to encounter. It is intended to identify possible gaps in the area, which can be later addressed through planned nursing interventions.

In the course of this article we present in more detail the problem under study, referring to the methodology that is considered adequate to approach it.

### **Problem statement**

At the international level several studies have been carried out on literacy in mental health. From an epidemiological point of view, the incidence and prevalence of mental disorders have increased over the last decades and are expected to continue to accentuate. The Report of the General Directorate of Health – Portugal Mental Health in Numbers 2013<sup>3</sup> which states:

*In Europe, mental health problems account for about 26.6% of the total burden of health problems, with suicide being one of the ten leading causes of premature death “and” Estimates of the European Brain Council indicate that 27.4% of the EU population between the ages of 18 and 65 suffers from any type of mental health problem each year, which has recently been updated to 38.2% after inclusion of data from a comprehensive assessment of childhood and adolescence and the entry of new members into the EU.*

The knowledge of the populations about the actions that can be carried out to reduce the problems in this area has been evidenced in several countries less adequate than the one that exists for the action against the diseases of more physical scope. According to Jorm<sup>4</sup>: “although the benefits of public knowledge of physical diseases are widely accepted, knowledge about mental disorders has been comparatively neglected”. There does not seem to be a distinct reality in this Region.

According to Jorm et al.<sup>5</sup> Mental Health Literacy can be defined as: “Knowledge and beliefs about mental disorders which aid their recognition, management or prevention and includes several components<sup>6</sup>: recognition of disorders facilitating the search for help, knowledge of professional help and treatment available, knowledge about effective strategies for self-help, knowledge and skills to provide first aid and other support and knowledge on how to prevent mental disorders”.

### **Evidence on the implications of mental health literacy**

At present there is evidence on the association between mental health literacy and mental health status, particularly in the adolescent population. As a result of the survey of young people in Australia – the Australian National Mental Health Literacy and Stigma Youth Survey – Lam<sup>7</sup> mentions that: “The results suggest that mental health literacy was associated with mental health status, particularly depression of young people”, and concludes from the clinical and ovulation point of view of this finding, not only in the prevention of mental health problems but also in the improvement of the state of mental health of adolescents.

From the point of view of the implications, the limited or insufficient literacy at the level of the respective components identified in the construct, Mental Health Literacy, has been evidenced through the accomplishment of several studies.

For example, as regards the recognition of mental disorders in order to facilitate the search for help<sup>6</sup>, the substantial delay (for several years) in the search for professional help on the part of those affected, such as mood disturbances, anxiety and substance abuse, as well as a few months for psychotic diseases. The barriers to seeking help are diverse in nature. One of the identified is the lack of self-recognition of the disease symptoms, it being also

known that the recognition of mental disorders when presented in vignettes to the population depends on its type the type, being according to Jorm<sup>8</sup> worse for anxiety than for depression, and varies according to the countries in which the research was carried out. In a study conducted by Loureiro in 2013<sup>9</sup> in Portugal, which covered young people, a quarter of the participants presented deficiencies in the recognition of depression when the situation was presented to them described in a vignette.

As for the knowledge of professional help and available treatments, another component of mental health literacy studied in several countries, it was found that informal help is more sought by the population, whether the family or friends compared to the help of professionals, although the result varies from country to country and according to the age groups covered. In Portugal, Loureiro<sup>9</sup> found the preference of young people for the help of family, friends and professionals in comparison to teachers, social workers or help lines. In other international research, erroneous beliefs concerning, for example, treatment with psychotropic medication have been identified. Regarding the knowledge of the different substances, in a study carried out with young Portuguese, for example, vitamins were mentioned with more positive effects in the treatment of depression than the antidepressants.

In a further component of mental health literacy, in relation to self-help strategies, populations tend to consider them very positive and refer to them frequently. Looking for the most consensual views among professionals (experts and consumers advocates) on the most useful self-help strategies for depressive symptoms minor (mild) Morgan & Jorm, in a 2009 study<sup>10</sup>, report that they recommend a variety strategies linked to lifestyles; psychological strategies, interpersonal strategies as well as a healthy and balanced diet.

These strategies need to be disseminated and worked with the different populations.

### From the reality of the Region

Objectively, it is not possible to determine the situation of different population groups and communities in relation to mental health literacy, as no studies have been done on the subject in the Region.

From direct contact with different health professionals including nurses who work in the health centres of the different municipalities and contact with the various population groups, as well as the knowledge acquired by us as a result of teaching in nursing courses, both at the 1st cycle level and at different nursing specialization courses, which have involved trainee guidance in clinical practice and interaction with nurse tutors, as well as our status as informed/expert citizens in the area of health and mental health, it is considered opportune and justified the formulation of a study that makes possible to determine the literacy in mental health of the population of the region. Here we will explain the main aspects concerning the steps and methods.

### Research questions

What is the mental health literacy of the young and adult population in the Region?

In the various components of mental health literacy are there differences in the various municipalities covered?

Are there differences in literacy components in mental health in populations of the municipalities covered?

### Purpose of the study

The purpose emerges from the different gaps that are identified in the knowledge of the population including adolescents about mental health and how to deal with the difficulties and problems that occur in communities related to mental illness. In the conclusion of a systematic literature review on interventions promoting mental health literacy, Morgado & Botelho<sup>11</sup> state that “studies indicate the need to develop, validate and evaluate interventions that promote adolescents’ mental health literacy”. It emerges from the identification of inadequate beliefs and lack of knowledge on the part of the populations in the identification of the alterations of mental health, like being able of care and treatment by different professionals. It also emerges from the observation that it is often belatedly that problems in the area of mental health are identified just as it is often late to seek help from the health services. It emerges from the existence of several barriers to the recognition by health professionals of the first line of action, the need for differentiated care and treatment in the area of mental health, and the identification of stereotypes, prejudices and stigma related to the disease in the Region. At the same time, it arises from the recognized need to base the practices of health professionals, particularly nurses, on scientific evidence in the area of mental health<sup>12</sup>.

### The study aims to

- To determine the literacy in mental health of the young and adult population of the Region.
- To describe the variations in the different components of mental health literacy in the young and adult populations in the different municipalities of the region.
- To identify significant influential factors in the variations of mental health literacy in different municipalities/communities.

- To compare the results of population groups under study from the point of view of mental health literacy.

### Research methods

It is intended to conduct an exploratory, cross-sectional and quantitative study, the results of which are representative of the mental health literacy of the young and adult populations of the Region.

### Population and sample

- Population: young people aged between 14 and 18 years and adults aged 19-64 years, from the different municipalities of the Region, included in the user card database of the Regional Health Service of the Region.
- Sample: random and representative of the population groups with the characteristics covered.

### Stages of the study

The study will be carried out in two stages:

- 1st stage: a pilot study carried out in only two municipalities of the region, one with more rural characteristics, the other more urban; and encompassing one group of young participants and another group of adults for each of the municipalities.
- 2nd stage: main study covering the eleven municipalities of the region and the two population groups selected.

### Tools

In the version adapted for Portugal of the National Survey of Mental Literacy in Young People – Interview version<sup>5</sup> by Loureiro, Pedreiro & Correia<sup>13</sup> will be applied the Questionnaire of Evaluation of Literacy in Mental Health – QuALISMental. The Qua LISMmental is the only measurement instrument adapted for the young Portuguese population<sup>14</sup>, having revealed “acceptable levels of reliability and a factor structure which is consistent with the theoretical components of mental



health literacy. It allows to evaluate the components of mental health literacy in relation to different disorders and with versions that maintain the fundamental structure with the appropriate adaptations” can be applied in samples of adolescents, young people and adults. According to Wei, MacGrath, Hayden & Kutcher<sup>2</sup>, the Mental Health Literacy Questionnaire (ADHD) by Jorm and colleagues<sup>5</sup> is one of the measures of knowledge that has been most frequently used in studies conducted in various countries, as well as and according to Loureiro<sup>14</sup> in diverse professional, economic, social, situational and cultural contexts of intervention.

The instrument consists of a set of items that evaluate five components: recognition of disturbances, knowledge about professionals and available treatments (16 items), knowledge about self-help strategies (12 items) and knowledge and skills to provide support and first aid to others (10 items), including knowledge of how to prevent mental disorders (8 items). Answers can have multiple formats. The initial part includes identification data and the next one evaluates the five mentioned components, and vignettes with different cases (depression, psychosis and substance dependence) were presented to the participants before their application.

The Belief Inventory of Mental Illnesses (ICDM) in the short version<sup>15</sup> will also be one of the instruments to be applied. The ICDM consists of a set of twenty three statements on which respondents are asked to express their agreement or disagreement with them, positioning themselves on a six-point scale ranging from Disagree Completely to Completely Agree, presenting as positions intermediates I disagree almost completely, I agree almost completely; Disagree slightly and agree slightly.

### **Ethical procedures**

The ethical principles inherent in this type of investigation will be considered. The study will be conducted in accordance with the Helsinki Declaration for Human Research<sup>16</sup>.

Authorization will be requested to carry out the study to the Board of Directors of SESARAM E.P.E and the research project and protocol will be submitted to the Ethics Committee of SESARAM E.P.E.

It will be requested the collaboration in the study of the health centres’ nurses of the different municipalities and the informed consent of all the participants of the population referenced to the Health Centres and selected for the sample.

### **Other procedures**

#### **Pilot study**

It will be carried out in two counties in order to test the study protocol and the research instruments. It will run from January to June 2018.

#### **Main study**

After the pilot the main study will cover all the counties of the region.

After obtaining the necessary consents mentioned in subchapter 5.4, meetings will be held with the Nursing Directorate as well as with the nurses who collaborate in the study in order to present the study protocol, including the methodology and the research instruments as well as to benchmark / train procedures.

Data collection will be performed based on the support of the Health Centres for contacts with randomly selected sample members who agree to participate in the study. It will be asked for informed consent, guaranteeing anonymity and rights available to them, including, at any time, we can refuse to continue participation.

Data collection will take place during the last and first quarter of 2018 and 2019, respectively, in all municipalities in the Region.

Afterwards, data processing will be performed using computer software as well as analysis and discussion of the results obtained.

### **Findings**

The results will be discussed and analysed comparing them with those of other studies with similar purposes and methodology, carried out in other regions of Portugal and in other countries. They will be presented and disseminated in accordance with the ethical and legal principles in academic and regional, national and international scientific field, as well as cooperating entities in the study, in particular responsible for health in the Region. They will be disseminated in the municipal communities involved, either to the local entities of the various sectors including health, social, educational, among others, or to the populations. It shall be considered its usefulness in identifying gaps in mental health literacy, and in combining synergies with nurses using the knowledge derived from the scientific evidence obtained to improve the planning of intervention in mental health literacy in different communities.

### **Conclusion**

The article focused on the study on mental health literacy that is intended to be carried out in the Region, presenting the project to the wider technical and scientific community, in order to give it greater grounding/support. The problem/theme was presented and the pertinence of the choice was justified. Its objectives have been clarified. Briefly described the steps, method and procedures to be followed in achieving them. A commitment was made to safeguard the ethical principles and duties assigned to conduct research with human beings and in the field of health.

Finally the research and reflection implicit in the effectiveness of this article reinforces the authors' awareness of their timeliness and usefulness in the current context of development in the areas of education and health/mental health in the Region.

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# Safe staffing

## Conceptions of primary health care nurses

### Summary

**Aim.** To know the conceptions that nurses, from Primary Health Care clinical practice, have of Safe Nurse Staffing. Safe Staffing is related to safe, high quality, high complexity care, in a variety of contexts. It is well established that safe nurse staffing and the quality of the practice environment are directly associated with client satisfaction, quality and safety of care, and nursing care-sensitive outcomes<sup>2</sup>.

**METHODS.** A descriptive exploratory study of a qualitative nature was carried out, using a questionnaire with open-ended questions. An intentional sample consisting of twenty five nurses was selected. The technique of content analysis<sup>7</sup> was used for data analysis and treatment.

**RESULTS.** Seven categories were identified (and respective subcategories): Safety of Care; Workload; Training and Professional Development; Quality of Care; Client Characteristics; Organizational Environment; Outcomes. These results allow stating that the nurses interviewed conceive the concept of Safe Staffing, on their work context, in accordance with the dimensions described by Aiken and collaborators<sup>1,2,3</sup>.

**CONCLUSION.** Nurses' conceptions of Safe Staffing integrate fundamental aspects associated with this concept, and may influence the strategies developed within the scope of clinical governance.

**KEYWORDS:** NURSING, SAFE STAFFING LEVELS, PRIMARY HEALTH CARE.

### Introduction

Healthcare clients have the right to be cared for by appropriately qualified and experienced staff, in safe environments<sup>26</sup>. In Portugal, these rights are enshrined in the Constitution of the Republic and in the statutes of the National Health Service (NHS). However, the responsibilities in terms of Safe Staffing are defined by the Order of Nurses (ON) in the regulation No. 533/2014 – Calculation standard for Safe Nurse Staffing. Safe nurse staffing, their qualifications level and skill profile are fundamental aspects for achieving safety and quality of care for the target population and organizations. With this purpose, methodologies and criteria that adjust human resources to the real care necessities should be used<sup>24</sup>.

According to the International Council of Nurses (ICN), the concept of Safe Staffing goes beyond the number of professionals required to ensure the delivery of safe and quality healthcare. It also includes other variables such as: workload, environment, client complexity, nurse qualification levels, other health professionals, cost efficiency and effectiveness, and link to client and nursing outcomes<sup>16</sup>. It also defends that Safe Staffing practices incorporate the complexity and intensity of nursing activities, nurses' levels of preparation, skill and experience, management support at the operational and executive levels, the contextual and technological environment of the health facilities, and the provision of whistleblower protection.

The concept of Safe Staffing is multidimensional, referring to a set of

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dimensions such as professional experience and continuing/advanced training, client characteristics/health needs and associated work load, nursing practice environment, client safety, nursing care-sensitive outcomes, client and staff satisfaction, as well as the performance of health organizations. The American Nursing Association considers the nursing team safe when the availability of nursing care is the appropriate shift-to-shift, taking into consideration client needs and a hazard free care environment<sup>5</sup>. The mix of competencies is the combination or grouping together of different categories of workers related to health care, in this case nursing<sup>5</sup> (e.g. nursing specialties, postgraduate training). The professional practice environment can be described as the system that supports nurses' control over nursing care, the environment in which the care is provided, and the organizational characteristics that facilitate or restrict the professional practice<sup>20,21</sup>. A safe work environment for nurses is characterized, among other factors, by good professional relationships, a management style based on support, a balanced work schedule, reconciliation between increased nurses' work and their mix of skills, an adequate profile to meet client needs, professional autonomy, adjustment of resources, and opportunities for professional promotion and development<sup>20,2,27,15,11</sup>.

Several studies have demonstra-

ted the importance of health organizations taking into consideration Safe Staffing on their units. In this context, was concluded that there is a strong relationship between number of nurses and mortality levels, complications and adverse effects and, furthermore, that a higher number of qualified nurses is associated with a lower mortality rate in hospitals<sup>18</sup>. Aiken and collaborators verified a positive relationship between advanced training of nurses and the reduction of early death probability in hospitalized patients<sup>4</sup>. In 2012, was conducted a study involving twelve European countries and the United States of America, where they concluded Safe Nurse Staffing and the quality of the clinical practice environment were directly associated with client satisfaction, quality and safety of care, and with the nursing-care sensitive outcomes<sup>1</sup>. Nursing care-sensitive indicators include, but are not limited to, mortality, internment time, hospital readmissions, and reduction of adverse effects<sup>5</sup>. To the same extent, job satisfaction is an important component of nurses' lives and has an impact on their performance, patient outcomes, safety and quality of care, as well as their commitment to the institution's goals<sup>22</sup>. The impact of work overload, insufficient patient care time, and the high number of patients per nurse are well documented and are associated with high turnover rates of these health professionals. Nursing work overload also has implications for patients, professionals and organizations. A systematic review of the literature was carried out with objective to evaluate the effects of work overload. Twenty one outcome measures in nurses and 19 outcome measures in clients were identified<sup>6</sup>. A strong relationship between extra work, long work period, and adverse outcomes for nurses was detected. As for clients, the authors point out that additional evidence is required to establish a direct relationship between working hours and adverse outcomes. It was demonstrated that increasing nurse workload in one patient per shift increases the patient's probability of dying on the first 30 days after admission by 7%<sup>4</sup>. Wagstaff and collaborators<sup>29</sup> tried to understand the effects of workload and safety. Their main findings are relevant for healthcare in general but their study was not performed with nurses. Work periods exceeding 8 hours represent an increased hazard risk and this risk is two-fold for 12 hour shifts. Shift work brings a significant increase in hazard risk while the so-called "normal period" work may provide protection against hazards. The authors did not detect any relationship between age and gender with either risk or protection factors. I was conducted a systematic review of the literature in order to identify the implications of workload on nurses' error rates, comparing shifts of 12 or more hours with shifts of less than 12h<sup>10</sup>. The main conclusion was that nurses who work shifts of 12 or more hours are more prone to making mistakes.

The starting questions that we are trying to answer are:

1. What is the conception that nurses, from Primary Health Care (PHC), have of Safe Nurse Staffing?

Our purpose with the present work is, therefore, to know the concepts that nurses from CSP have about Safe Staffing.

## Methods

A descriptive exploratory study of a qualitative nature was carried out, using a questionnaire with open-ended questions, in which the participants were asked to freely describe their concept of Safe Nurse Staffing. An intentional sample of twenty five nurses from a Health Center Group (HCG) of the North region was selected.

Since we intended to perform an objective and systematic depiction of the described content, we opted to use the content analysis technique<sup>7</sup>. This technique allows for a methodical treatment of the information contained

in the different communication formats and conforms to a wide field of application. The gathered material was reduced to general sentences and a theme coding system allowed the construction, for each topic, of a system of categories. The nomenclature assigned to the categories derived from the participants discourse and was also based on a review of the literature.

## Results

Data analysis resulted in seven thematic categories: Safety of Care; Workload; Training and Professional Development; Quality of Care, Client/Individual/Family Characteristics; Organizational Environment; Outcomes.

The analysis of the collected data allowed us to identify seven categories that nurses assume as characterizing the concept of Safe Staffing. Generally, their concepts are in line with what is shown in the literature.

## Discussion

However, we consider there are some dimensions of the Safe Nurse Staffing concept that were poorly explored by the respondents, namely organizational environment. As far as this dimension is concerned, only the technical means were mentioned as influencers of organizational environment. According to the literature, this dimension is related to fundamental aspects such as the practice environment, which is highly conditioning of nurse satisfaction and performance, as demonstrated by the conducted studies<sup>25</sup>. These studies aimed to understand the practice environments in the context of primary health care and the measures that promote retention of nurses in the sector. The results obtained by the researchers indicate that nursing professionals feel more satisfied with their performance and less likely to leave their workplaces in organizations that promote a practice environment favorable to nursing, in particular where there is a

CATEGORIES AND SUBCATEGORIES

1

CATEGORIES	REGISTRATION UNITS
<b>Safety of Care</b>	Clients Professionals Professional responsibility
<b>Workload</b>	No. patients/nurse No. families/nurse Task execution time Adequate records
<b>Training and Professional Development</b>	Adequate knowledge Procedures Coherence Professionalism Equity
<b>Quality of Care</b>	Good practice Accuracy Privacy Accessibility
<b>Client Characteristics</b>	Families Individuals Care needs
<b>Organizational Environment</b>	Technical means
<b>Outcomes</b>	Health gains Efficacy Efficiency

positive relationship with doctors and organization administrators, and where their role as nursing professionals has a clear visibility. According to the Canadian Nurses Association<sup>8</sup>, a quality practice environment for nursing underlies a set of requirements such as: respect, meaningful work, clarity of function, autonomy and involvement in the work environment, adequate staff and equipment, strong nursing leadership, management commitment to nurses and nursing, development and promotion opportunities, a collaborative team, open communication at all levels of the organization, and appropriate salaries and benefits. A quality practice environment, therefore, endows nursing with the ability to attract and retain a qualified team; reduce the risk of injury, lower absenteeism; have a more consistent client care with better results; and better quality of professional life and general well-being for nurses<sup>8</sup>.

Another dimension included in the concept under study that, in our opinion, was little addressed in this sample was *client and professional satisfaction*. Although it is not possible to separately analyze this dimension, similarly to other dimensions of the concept, Kutney-Lee and collaborators<sup>19</sup> point to a greater client and professional satisfaction when a set of requirements are met, namely a good practice environment, a mix of skills, and sufficient number of nurses providing care. Providing a healthy practice environment and an adequate level of nurses per unit allows clients to have a real perception of the quality of the nursing care provided. The dimension *safety and outcomes*, reported by the respondents, has been well studied, as can be seen by a number of studies<sup>9,14,17</sup>. The same can be said about the dimension *client safety and quality of care*, namely through the RN4CAST study<sup>4,23,28</sup>.

We verified that the nurses in our sample refer *workload* as one of the

dimensions of the concept, which is implicitly associated with the number of professionals per unit. Studies have shown that a reduced number of professionals and consequent increase in workload, associated with a poor working environment, lead to negative results among clients<sup>13</sup>. These results are also demonstrated by<sup>12</sup> that report a decrease of complications for clients as the number of nurse's increase, particularly at the level of nosocomial infections, falls, and failure to rescue.

### Conclusion

The initial objective of this study was to identify the essential characteristics of the concept of Safe Nurse Staffing in Primary Health Care. The results obtained indicate that the central characteristics of Safe Nurse Staffing are well identified by the respondents and are in accordance with what is proposed by the literature, in particular<sup>16,3</sup>. Thus, this study allows concluding that, in a general way, the respondents are in tune with the concepts of Safe Nurse Staffing and with the research in the field. In spite of this, some dimensions of the concept were less explored by the respondents (namely the organizational environment, and the client and professional satisfaction dimensions).

However, the results obtained make us think these health professionals are endowed with knowledge that can facilitate and actively intervene in the clinical governance of the services they belong to, and contribute to an increase in the quality of nursing care. This, in turn, will enable the demand of proper nursing personnel levels on their services, which may create dynamic and innovative solutions that are adaptable to the evolutionary nature of the populations they attend to and the health environment. There is also an opportunity for training that facilitates the acquisition of new knowledge that may be applied in the field, particularly in team management.

The Order of Nurses argues that the proper nurse staffing, their qualification levels, and skill profile are fundamental aspects for achieving safety and quality of care for the target populations and for the organizations<sup>24</sup>. The present study contributes to this understanding and lays the groundwork for future investigations on the nurse care-sensitive health gains derived from Safe Staffing.

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# Feelings for the acceptance of the family caregivers' role

## Summary

**INTRODUCTION.** Despite the progressive reduction of the members in family aggregations, families continue being the main support source to homebound people, whether in their direct caregiving, or in the psychological support and social contacts. Thus, it is questioned: What feelings lead to the acceptance of the family caregivers' role?

**PURPOSE.** To identify the feelings evolved from the acceptance of the caregiver's role.

**RESEARCH METHODS.** Descriptive, exploratory qualitative research carried out with family caregivers of dependent elderly. Data collection was developed by means of questionnaire application and logbooks. The guiding question was "Why do you have to care?" After the results, it was held the content analysis.

**RESULTS AND DISCUSSION.** Two hundred and twenty-six (226) answers were analyzed. The following categories were elaborated: feeling of recognition, feeling of responsibility, feeling of affection, feeling of obligation, feeling of interest, feeling of availability, feeling of acceptance from the social context.

**CONCLUSION.** Apprehending the feelings involved in the acceptance of the family caregiver's role enables health professionals to elaborate actions and strategies to strengthen such acting.

**KEYWORDS:** FAMILY CAREGIVER; CAREGIVER; FAMILY; HOMEBOUND PERSONS; NURSING.

## Introduction

Along the past decades, average life expectancy has increased worldwide, reaching the global average of around 70 years and around 80 years in developed countries. The outlook for the number of Americans with 65 years or older is to double to 98 million, from 46 million, until 2060, and the participation of the population with 65 years or older, regarding the total population, will increase almost 24%, from 15%<sup>1</sup>.

Such development was reached especially due to sanitation, medical advances, increase in the standard of living and decline in child death rate. Although the increasing life expectation reflects on positive human development, new challenges have been faced, as the severity and speed of cognitive decline, physical frailty and psychological impairment vary among the individuals. Thus, aging is intrinsically associated with biological and cognitive decay<sup>2</sup>.

People with 65 years or older have complex health care needs and use health care services more often when compared with younger people<sup>1</sup>. That occurs because the technological breakthroughs in medicine, and in gene-

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ral, the improvement in socioeconomic conditions have contributed to increase population's longevity, but also to a higher prevalence of chronic diseases and dependence in daily life activities.

In face of the population aging, the increase in need for supporting dependent older people emerges as a priority problem. Thus, families have more and more taken on the role of family caregivers<sup>3</sup>.

Family caregivers are people with stronger affection, kinship, friendship or neighborhood relationships rather than contractual ones, who help dependent individuals in their health care needs<sup>4</sup>. Assumedly, family caregivers are usually single women, housekeepers or unemployed who live with the dependent individuals<sup>5</sup>.

There are essentially four determining factors for the acceptance of the caregiver role, as follows: family relationship, co-habitation, the gender of the caregiver and the cared person and the kinship determinants. However, those factors are not determining for a family member to accept and become a caregiver. Other elements may influence that decision<sup>6</sup> (Martín, 2005).

Considering that such feelings are powerful, pervasive, predictable, sometimes deleterious, sometimes beneficial drivers for decision-making<sup>7</sup>, this study objectified to identify the emerging feelings in the acceptance of the family caregiver's role.

## Research methods

Exploratory, descriptive, qualitative study, with content analysis<sup>8</sup> as the method used for understanding the accounts. Held at a Local Health Unit and two more health care centers in Portugal. Local Health Units comprise a hospital and four health care centers.

The population entailed 266 family caregivers who rendered care for functionally impaired individuals, divided in two groups. The first one was the target of an intervention program, implemented in the six subsequent months before their dependent family members' hospital discharge, and the second one was the control group, which followed the usual procedures of the studied health care services.

The participants were selected according to a time-sequential sample of patients admitted to the medical unit of the aforementioned hospital, functionally impaired, in need of help to carry out the daily life activities.

Data collection was held by means of a questionnaire with 28 questions and logbooks. In this study, the question presented and discussed will be: Why do you have to care?

For data analysis, answer categorization and similarity were held, turning to the logbooks for concept definition. Those answers were classified according to: the questionnaire identification number, the gender of the family caregivers, and whether they belonged to the experimental or the control group. From that identification, designations to each one of the identified feelings were attributed. Concomitantly, definition and correlation with the existing literature were established.

This study was approved by the ethical boards and administrative commissions of the institutions where it was developed. Each participant was informed on the objectives and goals of the study, as well as the procedures used along the investigation. They were also informed on their self-determination right and assured that their refusal would not interfere in the normal course of the health care. Based on the Helsinki declaration of the World Medical Association, participants signed the free informed consent form.

## Findings

Questioned about the reason why they cared, from the total of the participants ( $n = 266$ ), 85% (226) of the answers was obtained. The excluded 15% (40) was due to improper answer or the participants did not answer.

The categorized feelings, according to the answers, were: recognition, responsibility, affection, obligation, availability, interest, and the acknowledgment of their role in face of the social context.

Recognition defined as "to know something for what it is, act or effect of recognizing (to distinguish certain singularities)"<sup>9</sup> occurred when the caregivers justified their behaviour due to the cared person's behaviour, that is, the patient should be awarded for his/her current actions. It usually evolves from gratitude, and it can be seen as a reward or an award for good attitudes. Ex.:

I had to change my life, but my sister deserves it, she cared for our parents by herself, that's why it isn't hard for me to do it (E2).

My mother cared for many elders, that's why there must be someone to take care of her carefully and affectionately, as she did (E41).

Responsibility is the "possibility to predict the effects of one's own behaviour and correct it based on such a prediction"<sup>9</sup>. In this category, answers unveiled that the caregiver felt responsible for caring, as there was nobody else qualified to care for the sick individual. Ex.:

I have no friends, I live alone, but I don't want them in a nursing home (godmother and mother), definitely at home, with all the possible help (C25).

There is nobody else, and I don't want to put her anywhere else (E135).

Affection, considered a positive emotion toward people, is a restricted type of emotions following some interpersonal relationships<sup>9</sup>. That feeling was raised when a family caregiver reported to be concerned with his/her dependent family member, and unfolded answers of a friendly/loving relationship.

Many things, the affection, everything he did to me (C130).

I like him, and he's my father (E132).

The feeling of obligation, defined as "the coercive character imposed on an interpersonal relationship by juridical law or moral regulation" was attributed to answers which unveiled a lack of alternatives on the part of the family caregiver under the conditions of the dependent family member<sup>9</sup>. Thus, the caregiver renders care because there is nobody else to take over him/her.

Because there is nobody (C274).

Where should I take him to? (C267).

The feeling of interest, understood as "something that raises or awakens will or wish for something"<sup>9</sup>, was attributed to those who assumed that the caregiver took on this role in exchange for a self-benefit.

I'm taking care of my brother-in-law, but I don't know what's going to happen, because my wife's sister wants her share in the inheritance, as the house we've lived in belongs to their mother, and if I go to an apartment, I won't take her brother because we can't do it, she'll have to stay with him, or I don't know how they're going to work this out, because she never wanted to take care of him (E24).

My daughter got married, and stayed at my mom's, when her grandmother passes away, she's gonna inherit the house, that's why I think I have to take care of her (C85).

As for availability, "quality of whom is available"<sup>9</sup>, evolved when the caregiver considered him/herself as the most qualified person for



## FEELING WHICH LED FAMILY CAREGIVERS TO CARE PER GENDER

1

Feeling	Experimental Group		Control Group	
	Female % (n = 93)	Male % (n = 19)	Female % (n = 100)	Male % (n = 14)
Recognition	22.6 (7)	10.5 (2)	2.0 (2)	7.1 (1)
Responsibility	24.7 (23)	10.5 (2)	0.2 (20)	14.3 (2)
Affection	23.7 (22)	10.5 (2)	36.0 (36)	50.0 (7)
Obligation	22.6 (21)	57.9 (11)	22.0 (22)	28.6 (4)
Availability	12.9 (12)	0.0 (0)	11.0 (11)	-
Interest	-	5.3 (1)	1.0 (1)	-
Social context	8.6 (8)	5.3 (1)	8.0 (8)	-

## FEELING THAT LED FAMILY CAREGIVERS TO CARE

2

Feeling	Experimental Group		Control Group	
	n = 112	%	n = 114	%
Recognition	9	8.0	3	2.6
Responsibility	25	22.3	22	19.3
Affection	24	21.4	43	37.7
Obligation	32	28.6	26	22.8
Availability	12	10.7	11	9.6
Interest	1	0.9	1	0.9
Social context	9	8.0	8	7.0

the role, then it was outlined as the availability category, ability to dispose of what is one's state of being willing to. Understanding as available what can be used, being accessible, free, not busy.

We're family and live next door (C117).

I was fired on June 30th and my mother had that on July 1st (E207).

And still the acknowledgment of their role in face of the social context, understanding context as "the set of entities (things or events) somewhat correlated where each one of those entities has such a character that other sets of entities may have the same character and be connected by the same correlation"<sup>9</sup>, it is the "Cluster of factors, circumstances where a situation, an event lies within", and social as what belongs to a society, or has its structures or conditions. This category evolved when the caregivers' answers assumed that they cared for because they understood it as their social role.

Law abides, our wedding, and we want to comply with the law (C156).

Because I have a marriage contract (E172).

I'm the only woman (E43).

In table 1, it is evidenced that in the experimental group, obligation to do that was the reason why caregivers took on this role. Moreover, a high number also found that they had responsibility for the cared individual, and also, they were bound by the affection. In the control group, the same categories were mentioned, however, to those caregivers, affection was the most reported reason. In both groups, only one caregiver reported caring for interest.

By looking at table 2, we verify that the most reported reasons by women for caring continue being responsibility, affection and obligation, in both groups. By observing male caregivers, the most reported reason in the experimental group was availability and obligation, unlike males in the control group, who reported affection. Women referred more to caring for their implied role in the social context.

## Discussion

It is assumed that caring means to preserve life, warranting the satisfaction of several essential needs. For dependent individuals, the presence of a caregiver is indispensable, and he/she is usually a close relative<sup>10</sup>. Family caregivers start their job in hospital settings and carry it on to home settings<sup>11</sup>. Among the activities carried out by family caregivers, it can be pointed out bathing, toileting, diaper change and turning in bed, activities which cause physical overloading, mainly if they are carried out every day, without taking turns with other family members, improper physical facilities and equipment<sup>12</sup>.

The role of the family caregiver has been performed by women, single, housekeepers or unemployed who live with the dependent individual<sup>13</sup>. That is explained, among other factors, by the gender-identity factor, which holds women as responsible for family care, by the socio historical context, with moral and religious attributes, and by the historical, cultural inheritance, present in the multigenerational interaction, where the gender division for household-family care is strengthened by elderly individuals' attitude, who prefer to be cared by women<sup>14</sup>.

However, an opposite movement has been observed, and the male presence in caring has redefined new roles, that is, besides their financial share, men have been taking on the caregiving role, formerly carried out by women<sup>15</sup>.

To both genders, daily caring routine is gradually mentioned as stress-generating in caregivers, due to: the recurrent lack of knowledge; insecurity and fear on how care will be delivered at home, the deprivation of social life; the halt or postponing of life projects; the willingness, dependence and/or obligation to share and follow up caring; the scarcity of financial resources; the family conflict to make the decision of whom will be the caregiver; the indecision whether institutionalizing or not; the apprehension for the cared individual's health status; the concern with the other family members, with their jobs, and with the new required adaptations<sup>15</sup>.

Caring a dependent individual is anchored in the idea of exhaustion, obligation. That brings forth anguish, whether by suffering with the cared individual, or by the helplessness felt when something goes beyond their potential of assisting the care recipient<sup>16</sup>.

Becoming a caregiver demands time, coping with difficulties, dedication and, sometimes, family organization, routine, habit changes and balance of activities<sup>15</sup>. Therefore, it is a different event for each person, simultaneously bringing about positive and negative feelings.

The emotional aspect related to follow up and participate in the disease process weakens caregivers' health due to the exposure to stressful situations, and also, due to the number of hospitalizations, tasks to monitor, aggravation of previous illnesses, scarce socioeconomic resources, the feeling of grief for the limitations of the individual and their withdrawal from social life<sup>15</sup>.

Thus, family caregivers' job consists of an exhausting physically and psychologically activity, invisible and hardly recognized by the society most of the time.<sup>17</sup> Other difficulties faced by caregivers include financial stress, patients' conflicts and insufficient social support, bringing about overburden and suffering<sup>18</sup>.

Some feelings described in the literature are gratitude, love, responsibility, satisfaction and closeness, in opposition to feelings such as obligation, displeasure, suffering, commitment to patients' welfare and resignation<sup>15</sup>. The mentioned feelings are mostly related to a pre-existent family relationship<sup>19</sup>.

That leads to reflect on how the occurred changes in family arrangements may interfere with the care of dependent individuals in the future, as there have been several ways of family organization in the current world, which are continuously changing, thus transforming the way family members relate among themselves. That implies a redefinition of roles and a redistribution of duties among the family members<sup>19</sup>.

Disregarding the feeling which led to the onset of caring, family caregivers need to be endowed with the feeling of caring, thus, it is possible to tie caring to the demanding aspects of individuality of the being, leading the subject to have greater autonomy and independence<sup>16</sup>.

Among such decisions and responsibilities, the need for caregivers to find balance is pointed out. Regarding the division of care, it has been observed a moderate trend to the fact that caregivers who do not share their tasks, are prone to having a higher level of overburdening. That finding corroborates what can be observed in the literature<sup>20</sup>. Sharing care with the secondary caregiver contributes to less overburden<sup>21</sup>.

In that sense, professionals from the healthcare team act as mediators between patients and family caregivers<sup>11</sup>, proposing support strategies in order to reduce the levels of overburden, emotional discomfort and stress. Among those strategies, encouragement to participate in interactional groups, self-care teaching and meeting caregivers' health needs<sup>12</sup>. Moreover, caregivers' inclusion in decision making, the increase to information access, the possibility of sharing caring experiences, the existence of a secondary caregiver,

and the connection with social support foster mental health<sup>18</sup>.

Thus, it is deemed necessary higher involvement of patients and their family caregivers in the management of chronic health conditions, encouraging identification and personal goal search in a partnership with health professionals. Therefore, by supporting the practice of defined goals with clinicians, it is promoted higher involvement and reduces the probability for patients to articulate in an unrealistic way or try to achieve unattainable goals<sup>22</sup>.

It is nurses' attribution to interact positively in this process of learning, instructing individuals to care for the other, without neglecting themselves<sup>16</sup>. As resolutions, health interventions, personal welfare and caregivers' social support can be pointed out. For that, there must be nurses' collaboration to qualify family members/caregivers to render care, including them as nursing clients, besides instructing the social network to the importance of sharing and division of tasks<sup>15</sup>.

## Conclusion

The capacity and willingness to take on the long-term responsibility for dependent individuals rely on many circumstances and motivations. Apprehending and understanding the way family caregivers view and experience their new capacity are essential for the development of professional intervention strategies, which facilitate the transition to assure the adaptation according to their health projects.

Such understanding has the potential to reduce family caregivers' overload, as the identification of feelings to accept the role of family caregiver enables nursing to promote health strategies for that population.

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# Promotion of adjustment to the exercise of parental role in adolescence

## Summary

**INTRODUCTION.** Parental exercise itself constitutes a very demanding challenge – however, when pregnancy occurs in adolescence, often unplanned, it converges tasks of different stages of development, irreversibly modifying an identity, roles and functions, not only of the young woman, but also of her family.

**OBJECTIVES.** Applying the Dynamic Model of Family Assessment and Intervention (MDAIF), by Figueiredo (2012), and assessing the impact of nursing care in the promotion of skills for a transition to the parental role's exercise in the teenager and her family.

**METHODS.** Qualitative study, conducted based on MDAIF, as a theoretical and operational reference, in clinical and community context in Primary Health Care, based on the process of family intervention who experienced an adolescent pregnancy. Seven nursing consultations to family were carried out, as a unit, from April to May 2016.

**RESULTS AND DISCUSSION.** Extended family, with several subsystems and strict limits. Middle-class family. Although unplanned, and the antagonistic relationship with her parents, the instrumental and emotional support provided by them became critical in adapting to motherhood and the newborn's development.

**CONCLUSIONS.** With MDAIF's use, nurses have developed their skills for a personalized approach to the family, centered on the adaptation and holistic transition to the parental process. It also made it possible to respond to the identified family needs, not only through the restructuring of a parental and personal identity, based on values, personal and professional goals and priorities (the teenager pursued her academic training), but also promoting a family environment based on trust and harmony.

**KEYWORDS:** ADOLESCENT; PARENTING; EMOTIONAL ADJUSTMENT; PRIMARY CARE NURSING.

## Introduction

According to the World Health Organization, about 16 million girls aged 15 to 19 and some one million under 15 give birth every year<sup>1</sup>. Complications during pregnancy and childbirth are considered the second cause of death among girls with the same age group, globally.

Currently, teenage pregnancy assumes itself as a problematic situation of great interest around the world. In Portugal, despite the recent decriminalization of abortion (2007) and the evident efforts that have been made, either through awareness campaigns for the use of contraceptive methods, through the implementation of Sexual Education in schools or the disclosure

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of free access to planning consultations family and reproductive health; and the delivery, also at no cost, of contraceptive methods in Primary Health Care; it is verified that these strategies, already adopted, are still not enough. To the apparent disinterest, disinformation or inefficient training of the target group, the teenagers, the approach to this subject is particularly important.

Parental exercise itself constitutes a very demanding challenge, as it emerges from the construction of basic skills and knowledge in caring for, protecting, developing and bonding (parents-child), with the birth of the first child. However, when pregnancy occurs in adolescence, often unplanned, it converges tasks of different stages of development, irreversibly modifying an identity, roles and functions, not only of the young woman, but also of her family.

## Factors that may influence the reproductive decision

The factors that can influence a reproductive decision can be divided into individuals (age of the adolescent, adolescent cognitive skills,

RISK FACTORS AND PROTECTIVE FACTORS FOR ADEQUATE ADJUSTMENT TO EARLY PREGNANCY

1

	Risk factors	Protective factors	
Adjustment to early pregnancy	(1) Family restructuring and dysfunctionality	Resilience	Adjustment to early pregnancy
	(2) Minor supervision and parental support	Family support and affective relationships	
	(3) Low educational level	Positive relationship with the baby's father	
	(4) Disadvantaged socioeconomic context	Social support	
	(5) Experience of adverse events		
	(6) Risk behaviours		
	<b>Risk or protective factors</b>		
	Parenting Styles and Practices		
	Characteristics of the peer group		
	Prior personality of the pregnant woman		

Sources: Martins<sup>16</sup>; Carmona<sup>8</sup>; Canavarro & Pedrosa<sup>3</sup>; Pires<sup>21</sup>; Pires et al.<sup>2</sup>

autonomy in the decision-making process and prior birth control), social (social context, family features, school involvement) and environmental (place of residence)<sup>2</sup>.

Canavarro and Araújo Pedrosa argue that the occurrence of a pregnancy in adolescence does not mean, inevitably, that it is an insurmountable challenge that leads to damage situations<sup>3</sup>. The results of greater or lesser success in adaptation depend to a large extent on the contexts in which gestation and birth occur and the degree of support available to the girl and her child.

Currently, particular importance has been given not only to risk factors and their interaction, but also to the protective factors, often determinant for an adequate adjustment to early pregnancy (table 1).

The main risk factors for the occurrence of a teenage pregnancy are (table 1): (1) the fact that the adolescent lives in a dysfunctional and rigid family environment (characterized by stress, pressure and conflicts); (2) less supervision and parental support, based on a unstructured family environment; (3) (4) experiencing poverty and exclusion from the education or employment system; (5) experiencing sexual abuse situations; (6) early sexual activity, ineffective use of contraceptive methods and/or alcohol and drug use. As protective factors for early pregnancy can be highlighted resilience<sup>3</sup>, socio-family contexts, the perception of social and family support, a positive relationship with the baby's father and the characteristics of the peer group.

**Teenage pregnancy: implications**

Adolescent pregnancy is considered an emerging health problem not only because of its physical implications, but also because of its emotional, social, cultural, economic and family implications.

At the physical level, a teenager has not yet fully reached its development and maturity. Situations like trauma, infections and the sperm's pH itself can attack the immature uterine epithelium, increasing the likelihood of cervical dysplasia and carcinoma *in situ* in young adults<sup>4</sup>. Also the peak of bone mass can be impaired, since part of the calcium needed to its construction will be sent to the fetus<sup>4</sup>. In addition, there is a higher incidence of medical obstetric complications (anemia, nutritional deficits, high blood pressure during pregnancy, preterm delivery, higher incidence of elective cesarean sections and increased maternal mortality, as well as a higher incidence of neonatal complications: newborn low birth weight, small for gestational age babies, higher incidence of neonatal mortality, higher risk of subsequent pregnancies, and higher incidence of postpartum depression).

Teenagers who become mothers face multiple changes in their social and relational roles. Often, they are confronted with the need to accept new parental responsibilities and to resolve their developmental tasks divergently.

The way how the adolescent, the family and the significant figures in her social network can negotiate these challenges will be critical to the adaptation and development of her and her baby. Although it is an initially distressing situation, it ends up mobilizing the whole family, triggering not only a financial support network but also emotional<sup>5,6</sup>.

Some authors state that the most frequent situation is the cohabitation of the adolescent and her child with their nuclear or extended family or with newborn's father<sup>7</sup>. However, during this period, "grandparents as parents" may emerge, which due to the urgent need to care for the newborn, end up hindering the process of autonomy and growth of the adolescent as a mother.

At the social level, Carmona states

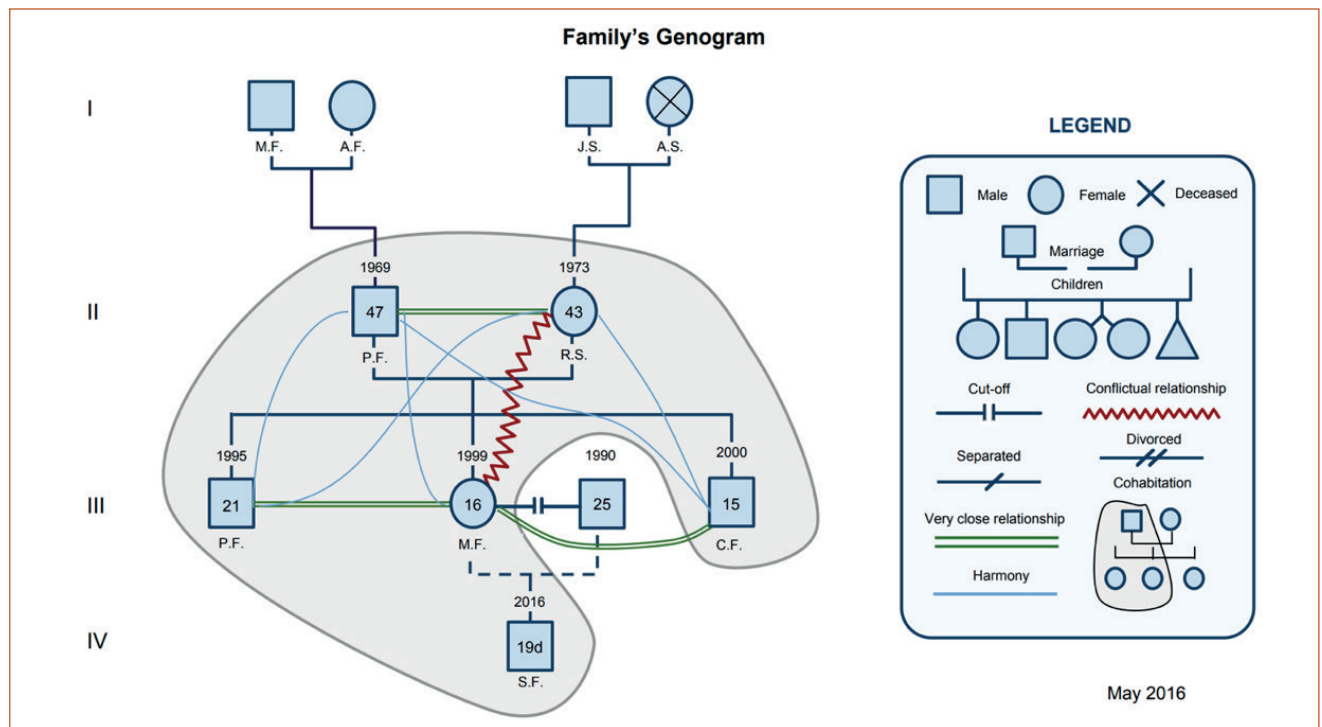


Figure 1. Family's Genogram (May 2016)

that the teenager may suffer losses such as: dropping out or interrupting school or even a precarious and poorly paid early career, with the aggravation of, in some situations, disclaim and disinterest in all aspects related to your child<sup>8</sup>.

Becoming a mother will also imply changes in relationships with peers and the group of friends: less availability for leisure or professional activities, which often culminates in a dissatisfaction with life in general by these adolescent mothers.

Despite all the implications in the different spheres/domains of adolescent life and those closest to her, Fonseca concludes that the high prevalence of adolescent pregnancy is not justified by the lack of knowledge about contraceptive methods, but by the absence of a life project in adolescents<sup>4</sup>.

### Methods

The study was based on the intervention process of a family who experienced an unplanned and unplanned adolescent pregnancy and motherhood up to 24 weeks of gestation, the result of an occasional relationship through virtual correspondence.

It was defined as a general research question “What are the contributions of the Dynamic Model of Family Assessment and Intervention<sup>9</sup> for evaluation and intervention in a family that has experienced an early pregnancy and motherhood?”.

The main objectives of this study are applying the Dynamic Model of Family Assessment and Intervention (MDAIF)<sup>9</sup> and assessing the impact of nursing care in the promotion of skills for a transition to the parental role's exercise in the teenager and her family.

This is a non-experimental, qualitative, descriptive and follow-up case study. It took place over a time horizon from May 2016 to July 2017.

It was used the following data collection instruments: interview, questionnaires and scales –based on the Dynamic Family Assessment and Inter-

vention Model<sup>9</sup>, as a theoretical and operational framework– and also the observation. This model mentions three main categories: structural, functional and developmental.

For the assessment of the structural dimension, it was used the Genogram, the Ecomap and the Gaffar Scale<sup>10</sup>. In Family Development dimension, the Stages and Developmental Tasks in the Family Life Cycle<sup>11</sup> and the Mother-infant Bonding Scale<sup>12</sup>. In the functional dimension, the Family Adaptability and Cohesion Evaluation Scale (FACES III)<sup>13</sup>, Family Apgar<sup>14</sup>, the Social Support Satisfaction Scale<sup>15</sup> and the Healthy Kids Resilience Assessment Module (version 6.0)<sup>16</sup>.

### Participants

Non-random sample, for convenience. The inclusion of study participants obeyed the following criteria: family with adolescent children; being greater than 14 years old; one of the family members be female between the ages of 14 and 18 (exclusively) who has experienced pregnancy and/or maternity in adolescence.

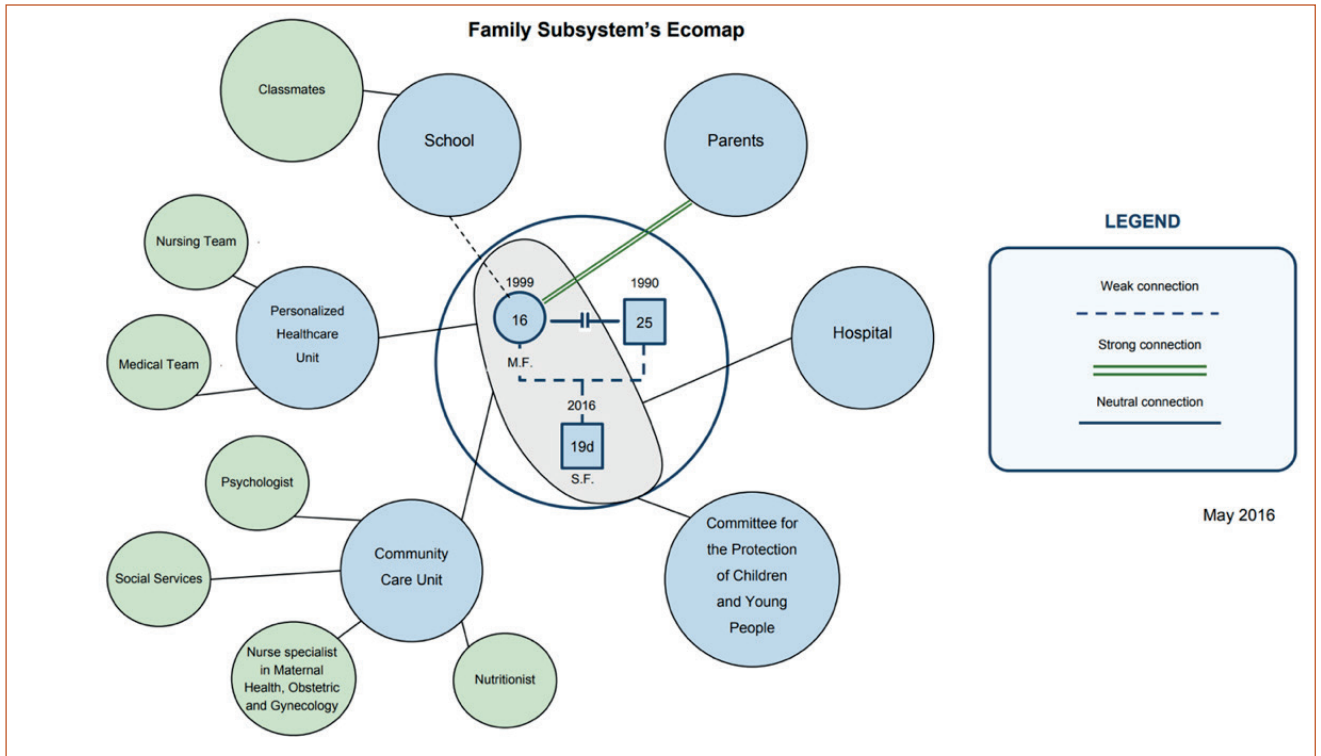


Figure 2. Family subsystem's ecomap (May 2016)

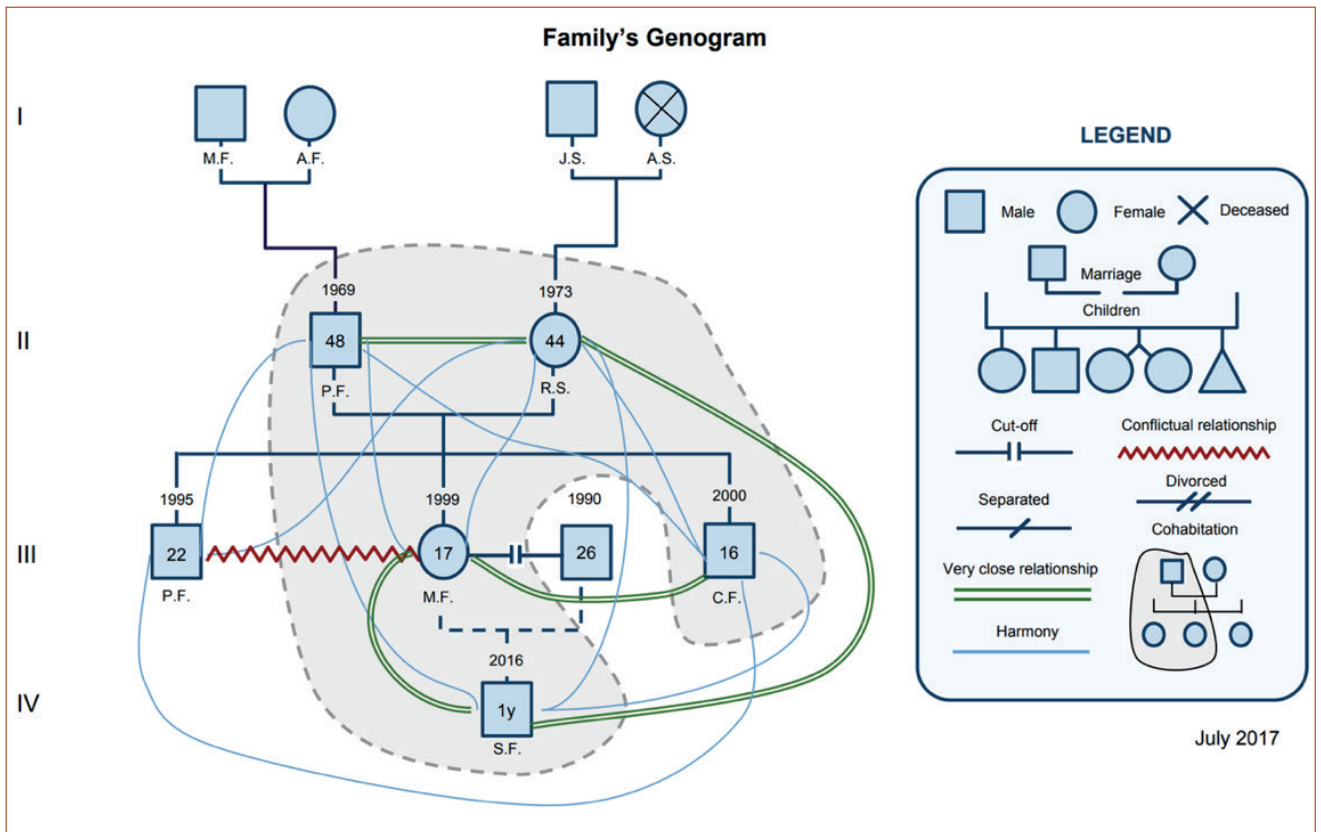


Figure 3. Family's Genogram (July 2017)



## Procedures

Concerning the collection of information, authorizations were requested from Portuguese Data Protection Authority (Comissão Nacional de Proteção de Dados), Ethics Committee of Central Regional Health Administration (Portugal), Health Centers Group of Dão Lafões (Agrupamento de Centros de Saúde Dão-Lafões) and from the Healthcare Unit where the study was conducted.

The data were collected in the months of May to July of 2017, directly and indirectly, through interviews, questionnaires and application of scales. The interview was applied by the researchers and the other data collection instruments delivered in closed envelope, to each participant.

Previously, it was requested the collaboration of the Healthcare Unit (in which it was intended to carry out the study), in order to intermediate a first contact with the family. The researchers only met the family after their prior consent in that contact with the Health Unit.

All data obtained are confidential and the anonymity was guaranteed using fictitious names. Participants were informed, at the first contact, about the optional nature of their participation and the guarantee of confidentiality and anonymity. Family members who agreed to participate in the study signed a free and informed consent. No audio or image recording has been made.

Data were retained up to one month after the end of the study and were destroyed after that date.

## Findings

The evaluation of the interventions effectiveness, sustained in MDAIF, was performed one month after the childbirth and one year after the beginning of the study (follow-up).

**Contextualization:** This is a study of a 15-year-old teenager's family, who met a boy nine years older on social networks (Facebook). From an encounter resulted an unplanned and unsupervised pregnancy until 24 weeks of gestation. In a final phase of gestation, the adolescent interrupted her academic formation to dedicate herself exclusively to the maternity.

### Findings: one month after the study's start

#### *Structural dimension*

It is a tri-generational and extended family, in cohabitation, with strict limits. The Fernandes family is composed by the teenager in the study, Mary (M.F., female, 16 years), by her son Simon (S.F., male, 19 days), by her brothers Peter (P.F., male, 21 years) and Charles (C.F., male, 15 years) and their parents Paul (P.F., male, 47 years) and Rita (R.F., female, 43 years). Currently, Mary does not have any kind of relationship with the newborn's father (not identified with initials), since he did not accept or provide any kind of support after the discovery of pregnancy (figure 1).

By using the Graffar Scale<sup>10</sup>, the Fernandes family is located socially at grade 3 (middle class). The family is dependent only from the male parent income (Paul). All family individuals have a low educational level (9th grade).

Through genogram analysis it is possible to glimpse the family members and realize the links existing between them. The couple Paul and Rita, like the relationship between their children, have a relationship of proximity. The relationship between the couple and their children is harmonious; however, there is a conflictual relationship between Rita and Mary, mother and daughter.

In an early stage after the baby's birth, the grandmother played an over-protective role, preventing the young mother from caring for her newborn.

In this way, Rita impaired the exercise of the parental role of Mary and, consequently, her relationship and bonding with Simon (newborn).

Mary finds some support structure in her community, namely at the School (at Adolescent Support Office (Gabinete de Apoio ao Adolescente) and in the Psychologist), and some classmates and a friend. Every week, the teenager is visited by a nurse of the Community Care Unit (CCU) to support her in the experience of motherhood (figure 2).

The newborn is referenced, since birth, to Committee for the Protection of Children and Young People due to the absence of effective family support. Moreover, an unsupervised pregnancy contributes to an indicator of social risk, so the family is also referred to Social Services (figure 2).

The teenager finds on her parents an important support to meet her needs as well as the needs of her baby. Despite the conflicting relationship she has with her mother, it is in the family that the Mary sees herself comforted and supported.

#### *Dimension of family development*

The Fernandes family, as system, is in the Stage V – Family with teenage children, proposed by Duvall<sup>11</sup>. The family subsystem, constituted by mother and child and integrated in the system, is in Stage II – Family with newborn.

#### *Parental role of the conjugal subsystem*

Parents-children communication was ineffective, since communication was often followed by a conflict. In addition, parents tended to over-see their children, as well as their relationships they had been established with their peer group, often leaving no room for socialization and autonomy.

The desires for autonomy and the search for identity of the adolescent were great factors of parental stress and seemed to be the genesis of the parents' difficulty in dealing with their children. This difficulty worse-

**INTERVENTIONS PROPOSED TO THE FAMILY IN THE DIMENSION OF FAMILY DEVELOPMENT – PARENTAL ROLE PLAYED BY THE YOUNG WOMAN (NEWBORN)**

Diagnosis		Interventions proposed (based on MDAIF)
Focus	Judgment	
Parental role	Not shown	<p><b>Newborn</b></p> <ul style="list-style-type: none"> <li>• To teach/instruct/train the adolescent about care to the umbilical stump.</li> <li>• Teaching adolescents about breastfeeding.</li> <li>• To instruct/train the adolescent about breastfeeding technique.</li> <li>• Teaching the teenager about artificial breastfeeding.</li> <li>• To instruct/train the adolescent about artificial breastfeeding technique.</li> <li>• Teaching adolescents about physiological weight loss.</li> <li>• To teach/instruct/train the adolescent about newborn positioning.</li> <li>• Teaching the adolescent about the transport of the newborn and prevention of Sudden Death Syndrome.</li> <li>• To teach/instruct/train the adolescent about newborn's hygiene.</li> <li>• Teaching the adolescent about warning signs of the newborn.</li> <li>• Teaching adolescents about health surveillance.</li> <li>• Teaching the adolescent about the characteristics of the newborn.</li> <li>• Teaching the adolescent about newborn skills.</li> <li>• Teaching the teenager about bonding process.</li> <li>• Motivating adolescent to adhere the vaccination of the newborn.</li> <li>• Guiding to social services.</li> <li>• Guiding to community services.</li> <li>• Promoting expressive communication of emotions.</li> <li>• Evaluating the non-consensual dimensions of paper.</li> <li>• Encouraging the redefinition of parental tasks by family members.</li> <li>• Negotiating the redefinition of parental tasks by family members.</li> <li>• Promoting coping strategies for the exercise of the role.</li> </ul>
<p><i>Parental role not shown:</i></p> <ul style="list-style-type: none"> <li>• Knowledge about the role (newborn) not shown.</li> <li>• Adherence behaviour not shown.</li> <li>• Conflict yes.</li> </ul>		

ned with the experimentation of risky behaviors by their daughter, which resulted in an unwanted early pregnancy.

*Adolescent's parental role*

Initially, Mary did not assume the parental role of Simon, since it was played by Rita. She felt an excessive preoccupation and exercised an overprotection of the newborn, not allowing Mary to play her role as a mother.

Thus, the role of caring for the newborn relied on Rita, instead of Mary, either because of lack of experience or knowledge, or because of the grandmother's overlap. The mother-child affective bond had not been established – first because it had been an unwanted pregnancy and secondly because there was an overlap of roles, with parental role substitution.

Between 4 and 6 weeks of age, in order to evaluate Simon's development with was used Mary Sheridan Test<sup>17</sup>. After filling it, it was verified that the RN presented a development considered normal for the age.

Around this time, Mary returned to school. Rita, unemployed, was taking care of Simon while his mother was at School. At first, Mary had very difficulties because of the need to fulfil her role as a mother and her role as a student. "I just wanted to do it all by myself and sometimes I couldn't do it. For example, having school homework to do and having Simon calling for me. It was difficult to reconcile it all" (Mary).

In the following table are some of the interventions proposed to enable Mary in the exercise of her parental role (table 2).

*Functional dimension*

In order to evaluate the family's functionality, it was used Smilkstein Family

Apgar Scale<sup>14</sup>. Mary considered her family as highly functional (score 8), indicating that she is almost always satisfied in all the dimensions to which this Scale refers.

**Follow-up (one year after the start of the study)**

*Structural dimension*

Compared to 2016, the Fernandes family became structural, organizational and dynamically more competent. Although specific nursing interventions were not implemented at the level of the structural dimension, those performed in the remaining dimensions had an inevitable impact on the family structure, easily understood through genogram and ecomap analysis (figures 3 and 4).

The main points of change on family structure, development and functionality are reflected in greater family flexibility, with redefinition of roles and limits (having undergone a change from strict to clear limits),

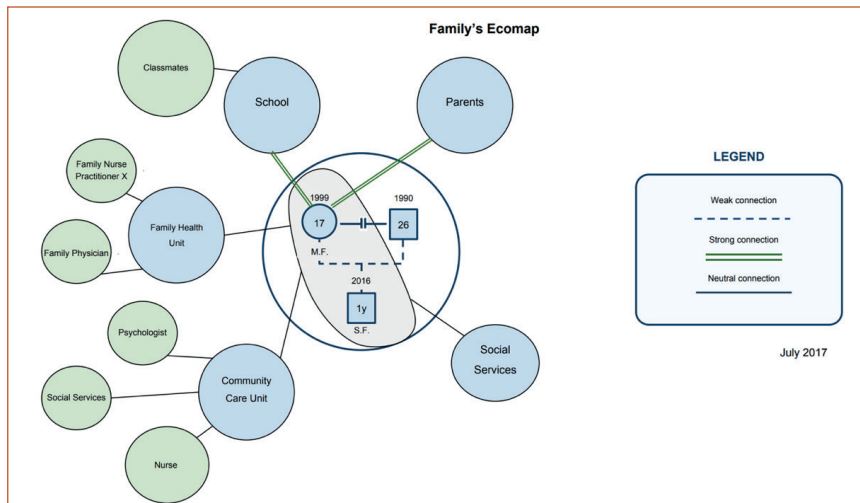


Figure 4. Family subsystem's ecomap (July 2017).

the transition to the exercise of an adequate parental role (either between the parents and their adolescent children, or between the young mother and her child) and the establishment of a strong and healthy bond between Mary and Simon.

At the structural level, the couple Paul and Rita, similarly to the relationship between Mary and Charles, and Rita and Mary with Simon present a relationship of proximity. The relationship between the couple and their children is harmonious (figure 3).

The psycho-emotional development of the young woman and consequent assumption of responsibilities as a mother, as well as the direct intervention of the multi-professional team that accompanied the case, appeased the conflict between mother and adolescent.

Currently, the young woman finds in the School, in her classmates and friends, and also in the Psychologist and CCU's Nurse, a fundamental support (figure 4).

In order to monitor the growth and development of Simon, Mary and Rita go to the Healthcare Unit at the time of consultations on child health surveillance. In addition, Mary is followed up in Consultations on Reproductive Health and Family Planning.

Finally, it is in her parents that Mary finds a fundamental support in all aspects of her life, as well as those of her baby. Improving the relationship between parents and Mary had an unavoidable impact on how the young woman perceived her satisfaction with family support.

#### *Dimension of familiar development*

At the level of the family development dimension, in particular the exercise of parental role that was not adequate, interventions were developed that had as objectives and purposes: to teach the parents (the conjugal/parental subsystem) about the changes levels in adolescence, motivate them to the importance of the frequency of adolescent surveillance consultations and the importance of adolescents' socialization and autonomy; besides these, allowed to promote the familiar communication and the expressive communication of emotions, to evaluate the conflicting dimensions of their roles and to motivate for the redefinition of the roles by the members of the family. This empowerment of parents with knowledge and strategies to improve their parental role has translated into an adequate performance of the same.

As for the ability to allow the privacy of their children, parents are now able to respect the privacy of their children; so does socialization: parents are more flexible about their child's friends chosen by them. However, in the case of the young woman, maternity does not allow her to spend the time she would like with friends.

Currently, Mary does not feel any difficulties in relating to her baby or in understanding his needs. However, tiredness and fear of hurting the baby are emotions and feelings that arise to her more often.

In addition, Mary thinks that she has all the knowledge related to the baby (infant food standard, sleep and rest pattern, hygiene and comfort care, child development, prevention of domestic and non-domestic accidents, oral hygiene...), information validated by the Family Nurse and easily proven by the parameters of growth and development of Simon. The child, like the rest of the family, presents the duly updated vaccination record.

In relation to maternal postnatal bonding, in its entirety and in two dimensions (quality of bonding and intensity of concern), the link between the young woman and her child can be classified as strong and healthy. This interpretation came from the results of the application of the Mother-infant Bonding Scale<sup>12</sup>: at a rate of 19 to 95 points, Mary obtained 87.

As previously stated, Mary, at the end of her pregnancy, had to interrupt her studies. About a month after giving birth, she resumed her school career. Nowadays, she is carrying out her life project, in the different spheres: personal, family and social.

#### *Functional dimension*

The Fernandes family is balanced (showing a better family functioning, in terms of adaptability and cohesion). Mary continues to realize the functionality of her family as

highly functional (score 8)<sup>14</sup>. Mary is more resilient (score 51) compared to how the family (score 41) and the nursing team consider her resilience (score 40)<sup>16</sup>.

She is currently satisfied with the support she receives from the surrounding community, especially with the family (score 14/15), friends (score 23/25) and level of intimacy (score 15/20). However, she is not satisfied with the social activities she performs (score 4/15)<sup>15</sup>.

### Discussion

Regarding the results of the study, although there was no adaptation to pregnancy from the outset (due to the fact that the adolescent concealed it), as soon as it was followed in the context of pregnancy surveillance, health professionals tried to promote the best adaptation to pregnancy.

Some authors<sup>18</sup> argue that the figure of the grandmother is seen as a pillar of support and maintenance of the family structure, being recognized its importance in the emotional aspect, affective and as main source of information during the entire gestational process of the adolescent and, especially, after its termination. Other authors<sup>19</sup> add that the relationship of the pregnant woman to her mother is significantly important in adapting to pregnancy and motherhood.

When grandmothers become the primary caregivers of the children of adolescent mothers, they are more distant and less competent in performing their maternal role<sup>20</sup>. Moreover, they end up hindering the process of autonomy and growth of the adolescent as a mother<sup>7</sup>. In fact, initially there was an overlap of roles; however, the young woman has overcome her difficulties gaining autonomy in providing care for the newborn, always with the help of grandmother.

Currently, the relationship between the mother and the adolescent is close, harmonious and mutually supportive, with the initial conflict being resolved. A well-developed process of interaction between parents and children leads to the constitution of a healthy relationship that, through communication, will define the functioning and roles within the family<sup>7</sup>. Communication between the different elements of the Fernandes family as a whole became effective, not only because they already established a dialogue among all, but also because it fostered family trust and harmony.

The newborn presents being well cared for, not showing neediness or any kind of carelessness, refuting ideas of some authors<sup>22</sup>, when they report that the children of adolescent mothers present greater risks of impairment in the child's development in the short and long term.

In addition, at the social and school levels, the adolescent also suffers losses, such as dropout or school interruption or even a precarious and poorly paid early career<sup>8</sup>. However, Maria only interrupted her school career in the final stages of pregnancy to prepare for motherhood, having returned to school about a month after giving birth and having successfully completed the 9<sup>th</sup> grade. Currently, the adolescent is aware of the importance of a life-long project in her life and is motivated to start a professional career. The success of this case is in contrast with the results of some authors<sup>23</sup>, who report that young adolescent mothers from unstructured families have a lower rate of return to school and academic success than those from a stable and less disadvantaged family environment.

Methodologically, despite the possible limitations, the authors consider that the results obtained are a true picture of the reality and a contribution to qualitative research on the subject. Moreover, additional data about the relationship between Maria and the newborn with the father and the baby. The issues raised by this study indicate the need for further studies, both

qualitative and quantitative, to assess and understand the implications of pregnancy and motherhood in adolescence and how this can impact the development of the child and the lives of these families. In future investigations, the use of the Dynamic Model of Family Assessment and Intervention<sup>9</sup> for further development of the knowledge and skills of health professionals is suggested. It is also suggested to follow the first years of the baby, allowing to study the variables associated with the development of children and, later, adolescents children of adolescent mothers.

### Conclusions

Adolescent pregnancy is a problematic situation as it converges tasks at different stages of development. The experience of an early motherhood has clear implications on family structure and dynamics.

Thus, it can be concluded that the family evaluation and intervention were effective, allowing not only to respond to the family's needs, but also to help the adolescent to continue with the realization of her life project. As there is a link between the different support networks, namely between the Personalized Healthcare Unit, the Community Care Unit (for intervention in the school and home context) and the Commission for the Protection of Children and Young People, the researchers have obtained a broader picture of the situation, its complexity, and the importance of a strong support network working in partnership for the success of the interventions.

At the level of structure, development and family functioning, there is a greater flexibility, with redefinition of roles and limits: Paul and Rita play their parental role adequately, allowing their children to have the right to their privacy and to choose their friends; there is effective communication between them; they are concerned about the balanced and varied diet of the family, encouraging the ingestion of at least five meals a

day; encourage the brushing of teeth at least twice a day, with the use of dental floss and the promotion of family activities.

The support provided by the group of friends it was also an important source of emotional support. The young woman reinforced an increase in the concern for her own well-being by her friends and that this was also decisive for her adaptation. Although she does not spend as much time as she likes with her friends, due to the exercise of her role as mother, she is satisfied with the support received both by the family and by the surrounding community (School and Healthcare Unit).

Another change that occurred with the interventions was the sexual and reproductive health surveillance of Mary, which became a regular surveillance, allowing her to start a contraceptive method suitable for her. Furthermore, currently she knows that the only way to prevent the transmission of sexually transmitted infections is to associate her method with a contraceptive barrier method.

Regarding the performance of her parental role, Mary was able to establish a strong and healthy bond with Simon. Although she says that she has all the knowledge about how to care for and relate to her baby, constant learning and training should be considered.

The newborn is well cared for and there is no food, hygiene, emotional or general neglect of his health. According to the literature, the quality of the care provided to a child in the first years of life, as well as the relationship that it establishes with its mother, are fundamental for a correct development and mental well-being.

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## Implications of the study

Adolescent mothers who benefit from adequate social support are able to achieve a favorable level of adjustment, since it reduces the anxiety associated with the tasks of motherhood. In addition, protective factors of individual, relational and social order are also aspects to be considered in the socioemotional adjustment of the adolescent to the process of maternity.

The use of the Dynamic Model of Family Assessment and Intervention<sup>9</sup> allows to give a prominent place to the whole family as a unit and to guide the practices of nurses to promote family health, considering their real needs and reso

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# More+ oral health with ProSorriso Program

## Summary

**INTRODUCTION AND OBJECTIVE.** The proactive involvement of health and education professionals with a focus on development transition groups is an important pillar for achieving the oral health goals for 2020 established by the World Health Organization and require reinforcement of actions for health promotion and prevention of oral diseases. Thus, it is justified to develop a program of oral health promotion in schools, such as ProSorriso (Costa, 2014), in order to evaluate the effectiveness of the Program.

**METHODS.** Quasi-experimental study, with measures' application before and after the implementation of the ProSorriso Program, in 200 adolescents, aged between 11-16 years (mean of  $13.21 \pm 1.014$  years). This Program is developed in three phases: diagnosis, intervention and evaluation of the oral health of adolescents. The application of the Questionnaires of Eating Habits, Oral Hygiene and Oral Health Knowledge, as well as mouth observation according to WHO criteria (1997), occurred before and after participation in the program.

**RESULTS.** Adolescents improved their oral health after active participation in ProSorriso, presenting fewer decayed teeth and more filled teeth. Their dental plaque biofilm also improved with significant benefits for adolescents who benefited from the Program interventions ( $t = 7.389$ ;  $p = .000$ ). Adolescents' knowledge about oral health and nutrition enhanced significantly after participation in the ProSorriso Program ( $t = -6.510$ ;  $p = .000$ ); ( $t = 2.523$ ;  $p = .012$ ).

**CONCLUSIONS.** Adolescents improved their health status, eating habits, hygiene and oral health knowledge, recognizing the effectiveness of the implementation of the ProSorriso Program as a determinant of adolescents present and future health.

**KEYWORDS:** ADOLESCENT, ORAL HEALTH, PROSORRISO PROGRAM.

## Introduction

The promotion of health has been conceptualized as a public health action oriented to increasing individual control over health determinants, notably through the implementation of health policies and the identification and development of living conditions in their different settings (school, leisure, etc.) that influence the behavior more or less directly<sup>1</sup>. According to the Ottawa Charter, a source of inspiration and guidance for further action<sup>2</sup>, health promotion, based on salutogenic paradigm, aims to control the behavioral, psychosocial, and environmental factors, highlighting the aspects that affect their health positively in order to improve it<sup>3</sup>.

Given its importance, the health promotion is considered a strategy which

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needs to be incorporated into all dimensions of life (individual, social and environmental). For this, on the main factors that determine health, is required the development of diversified activities, based on health promotion actions related and complementary, and that can be systematized in three areas of intervention<sup>3</sup>: health education (process using the pedagogical communication to facilitate the health learning), disease prevention (set of measures to prevent, detect early and treat specific diseases and possible consequences) and health protection (set of measures for the control of environmental risk factors and the conservation of natural resources).

The Declaration of Liverpool on Oral Health Promotion in the XXI century, in September 2005, enshrines the school as a platform for the promotion of health, quality of life and disease prevention in children and adolescents and provides for the involvement of families and rest of the community.

## Methods

The school as a place of election to establish healthy lifestyle habits, should assume that the promotion and health education is a training, participation and accountability process, that should lead children and adolescents to feel competent, happy and valued, by adopting and maintaining healthy lifestyles<sup>4</sup>. It takes rather a response organized around the surrounding system so that health education has influence on people's lives and their daily lives, in order to they acquire skills and thus make an informed choice, thereby contributing to improve their quality of life, development and consolidation of literacy to health<sup>5</sup>.

According to the National School Health Program, one of the priority areas for the promotion of quality of life is the oral health<sup>6,7</sup>. It is in this context that the various partners, the 3rd cycle school clusters and cluster health centers of Lafões region, participated in the implementation of the Program for Promotion of Oral Health – “ProSorriso in Adolescents”.

It was defined as a general research question “What is the impact of the implementation of an Oral Health Program (ProSorriso) on quality of life related to adolescents oral health?”.

The aim of developing this program was to contribute to the improvement of oral health indicators diagnosed in adolescents and the promotion of oral health in adolescents<sup>8</sup>. Looking to be a value added to the National Program for Promotion of Oral Health, which draws a global intervention strategy based on the promotion of health, prevention and treatment of oral diseases, developed over the lifecycle and environments where children and young people live and study<sup>9</sup>.

The study type of the implementation of the educational intervention program in adolescents ProSorriso is quasi-experimental, before and after, without control group<sup>10-11</sup>. The study was commissioned by the General Curriculum Innovation and Development Department and the Ethics Committee of Health School of Viseu.

In the collection of information, the instruments used were: Questionnaire about Oral Hygiene Habits and Knowledge of Oral Health; Health Assessment Form<sup>12-13</sup>.

The completion of the field work required preliminary definitions that would ensure the established planning. Thus, the study was conducted in three phases.

In the first phase was carried out the random selection of four schools of the 3rd cycle of basic education in the central region of Portugal. Were encompassed in the study adolescents who voluntarily participated and presented the consent form signed by parents/guardians, and participated in all education sessions for health and/or data collection, constituting the study sample 200 adolescents.

At this stage we proceeded to the data collection, evaluation of the oral cavity (DMFT and OHI-S) and were given a single oral hygiene kit (toothbrush and toothpaste). The DMFT index record was calculated based on procedures recommended by WHO<sup>14</sup>. The Simplified Oral Hygiene Index (OHI-S) was obtained based on an objective examination of the oral cavity, and was used in the evaluation, a revealing dye plate (solute erythrosine 2%) and analyzed the buccal and lingual surfaces of six predefined teeth, according to the criteria Greene & Vermillion classification and General Health Department (DGS)<sup>15-16</sup>.

In the second phase the educational intervention revolved around the themes of oral health. Health promotion was prioritized based on prior identification of needs of adolescents. It consisted of education sessions for health on oral health and oral hygiene, and practical sessions on oral hygiene/brushing teeth, lasting 90 minutes each.

In the theoretical health education sessions we used the expository method, using audiovisual, and demonstrative method, in order to increase motivation and participation of adolescents. In demonstration of oral hygiene procedures were used macro models (Denture, molar tooth decay, toothbrush and dental floss), for exemplification of the correct technique of brushing teeth.

At the end of each theoretical session we proceeded to the distribution of illustrated leaflets, prepared by the DGS, demonstrating the techniques of oral hygiene (brushing and use of dental floss) and dissemination of the page <http://www.prosorriso.host56.com>.

In the practice sessions we used the demonstrative method, using the material and technique, referred in the theoretical session. Each adolescent had the opportunity to practice the correct technique of brushing teeth in macro models, and in his own mouth.

The third phase began three months after the educational intervention program and was held again the observation of the oral cavity (DMFT assessment and OHI-S) and applied the data collection tool to adolescents.

Processing and analysis of data were used IBM Statistical Package for Social Sciences (SPSS) Statistics 20.

## Findings

### Sample characterization

The sample consists of 200 adolescents who completed ProSorriso Program. It is mostly female (56.0%), aged between 11 and 16 years, with an average of 13.21 (SD = 1.014). Adolescents who participated in the intervention program – ProSorriso, reside mostly in rural areas and attend the 7th (41.0%), 8th (34.5%) and 9th (25.9%) grade.

### Oral health of adolescents

The index of decayed teeth of ado-

DMFT INDEX BEFORE AND AFTER THE PROGRAM – PROSORRISO											1
	n	Min	Max	$\bar{x}$	SD	Sk/error	K/error	CV (%)	Sort Average	Mann Whitney U Test	T test paired samples
<b>Decayed Teeth Index (before)</b>											
Male	88	0	6	0.98	1.422	7.031	6.257	145.10	102.52	U=4750.0	<b>t=4.267</b> <b>p=0.000***</b>
Female	112	0	12	1.05	1.912	13.096	24.985	182.09	98.91	Z=-0.485	
<b>Total</b>	<b>200</b>	<b>0</b>	<b>12</b>	<b>1.02</b>	<b>1.710</b>	<b>16.139</b>	<b>31.029</b>	<b>167.64</b>		p=0.628	
<b>Decayed Teeth Index (after)</b>											
Male	88	0	7	0.64	1.252	10.937	19.702	195.62	100.70	U=4910.0	p=0.957
Female	112	0	7	0.56	1.105	12.885	24.913	197.32	100.34	Z=-0.055	
<b>Total</b>	<b>200</b>	<b>0</b>	<b>7</b>	<b>0.60</b>	<b>1.170</b>	<b>16.686</b>	<b>30.705</b>	<b>195.0</b>			
<b>Missing Teeth Index (before)</b>											
Male	88	0	2	0.17	0.485	11.295	15.042	285.29	102.43	U=4758.0	<b>t=-2.083</b> <b>p=0.039*</b>
Female	112	0	4	0.16	0.623	21.403	57.287	389.37	98.98	Z=-0.787	
<b>Total</b>	<b>200</b>	<b>0</b>	<b>4</b>	<b>0.17</b>	<b>0.565</b>	<b>25.610</b>	<b>66.377</b>	<b>332.35</b>		p=0.431	
<b>Missing Teeth Index (after)</b>											
Male	88	0	2	0.32	0.635	7.085	3.913	198.44	107.00	U=4788.5	p=0.027*
Female	112	0	4	0.19	0.623	17.320	37.792	327.89	95.39	Z=-2.208	
<b>Total</b>	<b>200</b>	<b>0</b>	<b>4</b>	<b>0.25</b>	<b>0.630</b>	<b>16.988</b>	<b>27.295</b>	<b>252.0</b>			
<b>Filled Teeth Index (before)</b>											
Male	88	0	7	1.24	1.788	5.583	2.610	144.19	102.09	U=4788.5	<b>t=-5.243</b> <b>p=0.000***</b>
Female	112	0	9	1.07	1.680	9.061	10.569	157.01	99.25	Z=-0.378	
<b>Total</b>	<b>200</b>	<b>0</b>	<b>9</b>	<b>1.15</b>	<b>1.726</b>	<b>10.186</b>	<b>8.576</b>	<b>150.09</b>		p=0.705	
<b>Filled Teeth Index (after)</b>											
Male	88	0	9	1.64	2.129	5.719	3.877	129.81	96.45	U=4572.0	p=0.362
Female	112	0	10	1.68	1.851	6.346	6.300	110.19	103.68	Z=-0.911	
<b>Total</b>	<b>200</b>	<b>0</b>	<b>10</b>	<b>1.66</b>	<b>1.973</b>	<b>8.447</b>	<b>6.839</b>	<b>118.86</b>			

STATISTICS FOR THE OHI-S BEFORE AND AFTER THE PROGRAM - PROSORRISO											2
	N	Min	Max	$\bar{x}$	SD	Sk/error	K/error	CV (%)	T Student Test	T test paired samples	
<b>Simplified Oral Hygiene Index (before)</b>											
Male	88	0	3	1.53	0.541	0.089	-0.220	35.35	<b>t=1.384</b> <b>p=0.169</b>	<b>t=7.389</b>	
Female	112	0	3	1.41	0.675	0.342	-1.000	47.87			
<b>Total</b>	<b>200</b>	<b>0</b>	<b>3</b>	<b>1.47</b>	<b>0.621</b>	<b>0.016</b>	<b>-0.831</b>	<b>42.24</b>			
<b>Simplified Oral Hygiene Index (after)</b>											
Male	88	0	3	1.33	0.612	0.217	-0.221	46.01	<b>t=2.686</b> <b>p=0.008**</b>	<b>p=0.000***</b>	
Female	112	0	3	1.09	0.621	0.945	0.018	56.97			
<b>Total</b>	<b>200</b>	<b>0</b>	<b>3</b>	<b>1.20</b>	<b>0.626</b>	<b>0.779</b>	<b>-0.392</b>	<b>52.17</b>			



	N	Min	Max	$\bar{x}$	SD	Sk/error	K/error	CV (%)	T Test Student	T test paired samples
<b>Summation of Oral Hygiene Habits (before)</b>										
Male	88	10	19	15.31	1.938	-0.972	0.191	12.66	<b>t=-2.716</b>	
Female	112	11	20	16.13	2.232	-0.859	1.578	13.84	<b>p =</b>	
<b>Total</b>	<b>200</b>	<b>10</b>	<b>20</b>	<b>15.77</b>	<b>2.141</b>	<b>-0.744</b>	<b>1.409</b>	<b>13.57</b>	<b>0.007**</b>	<b>t=-4.591;</b>
<b>Summation of Oral Hygiene Habits (after)</b>										
Male	88	10	20	15.97	2.266	-2.143	0.133	14.19	<b>t=-3.237</b>	
Female	112	11	20	16.96	2.046	-1.618	-0.768	12.07	<b>p =</b>	
<b>Total</b>	<b>200</b>	<b>10</b>	<b>20</b>	<b>16.52</b>	<b>2.196</b>	<b>-2.872</b>	<b>0.085</b>	<b>13.29</b>	<b>0.001***</b>	<b>p = 0.000***</b>

lescents was higher before the program – ProSorrison, with significant differences ( $p < 0.05$ ), i.e., adolescents after participating in the program had fewer decayed teeth.

It was also found that the number of missing teeth and the number of filled teeth increased after participating in the program – ProSorrison, the differences between the two-time points are significant in missing teeth ( $p < 0.05$ ), and the index filled teeth ( $p < 0.05$ ), i.e. there is an increase in the number of missing teeth and the number of filled teeth after participation in the program – ProSorrison.

There was significant differences by gender of adolescents, but only in the lost teeth index after participation in the program – ProSorrison. The girls were fewer missing teeth compared to males ( $p < 0.05$ ) (table 1).

It was found that the adolescents' OHI-S is on average lower after participating in the program – ProSorrison ( $p < 0.05$ ) (see table 2).

Before the program – ProSorrison, the average value of OHI-S was 1.47, showing boys worst oral health, but the differences are not statistically significant ( $p > 0.05$ ). After participating in the program, it was observed that the adolescents had an average OHI-S 1.20, verifying that females have better oral health, less OHI-S, and the differences are statistically significant ( $p < 0.05$ ) (table 2).

### Oral hygiene habits

The study of oral hygiene habits of adolescents showed that before the program – ProSorrison, 71.5% brushed their teeth two or more times per day, 28.5% did so at least once per day. After participating in the program – ProSorrison there is an increase of adolescents to brush their teeth two or more times per day (74%), but the differences are not statistically significant between the two-time points (McNemar test  $p = 0.583$ ).

Before the program – ProSorrison most adolescents (57.5%) never or rarely brushed their teeth before bedtime and after participating in the program the percentage of adolescents who said to brush their teeth at night often or always increased (83%), and the differences between the two moments were highly statistically significant (McNemar test  $p = 0.000$ ).

As for the utensils used by adolescents in their oral hygiene, no significant differences before and after the implementation of the program ProSorrison ( $Z = -0.434$ ;  $p = 0.664$ ), or the frequency of flossing use (McNemar test  $p = 0.742$ ), or the type of brush to use (McNemar test  $p = 0.999$ ).

With regard to oral hygiene, it was found that before the program – ProSorrison, 57% of adolescents brushed teeth, tongue and gums, 31% teeth and

tongue and 6.5% teeth and gums. After the program, there is an increase of adolescents that make an oral hygiene more correctly (brush teeth, tongue and gums: 67% vs. 57%), and the differences between the two moments of evaluation were statistically significant ( $Z = -2.801$ ;  $p = 0.005$ ). As for the time spent on brushing teeth, 62.5% in the pre program spent between 2 to 5 minutes and 30.0% spent less than 2 minutes. After participating in the program, 74.0% spend between 2 to 5 minutes and only 22.0% takes less than 2 minutes. The t test for paired sample showed that the differences between the two time points are significant ( $Z = -3.509$ ;  $p = 0.000$ ).

Making an overall assessment on the oral hygiene habits of adolescents in the time before and after intervention is concluded that they are better after participation in the program – ProSorrison, with statistically significant differences ( $p < 0.05$ ), i.e., adolescents improved their oral hygiene habits after participating in the program. The girls have better oral hygiene habits relative to boys, either before or after ProSorrison, with significant differences ( $p < 0.05$ ) (see table 3).

### Knowledge of oral health

We sought to determine whether the program – ProSorrison helped to increase knowledge of adolescents regarding oral health, it was found that

STATISTICS ON KNOWLEDGE OF ORAL HEALTH BEFORE AND AFTER THE PROGRAM – PROSORRISO

	n	Min	Max	$\bar{x}$	SD	Sk/error	K/error	CV (%)	OM	T Test Student	T test paired samples
<b>Summation of knowledge on oral health (before)</b>											
Male	88	28	54	44.35	4.801	-1.938	1.208	10.82	83.78	<b>t=-4.886</b> <b>p=0.000***</b>	<b>t=-6.510</b> <b>p=0.000***</b>
Female	112	30	53	46.46	3.862	-6.412	8.364	8.31	113.64		
<b>Total</b>	<b>200</b>	<b>28</b>	<b>54</b>	<b>45.53</b>	<b>4.417</b>	<b>-5.627</b>	<b>4.433</b>	<b>9.70</b>			
<b>Summation of knowledge on oral health (after)</b>											
Male	88	33	54	47.07	4.046	-3.455	3.085	8.59	87.67	<b>t=-3.841</b> <b>p=0.000***</b>	<b>t=-6.510</b> <b>p=0.000***</b>
Female	112	33	56	48.62	3.696	-3.745	4.940	7.60	110.58		
<b>Total</b>	<b>200</b>	<b>33</b>	<b>56</b>	<b>47.94</b>	<b>3.919</b>	<b>-5.063</b>	<b>5.286</b>	<b>8.17</b>			

in the issues brushing frequency of teeth, brush type used, oral hygiene performance and brushing time of teeth the values obtained before and after participation in the program - ProSorrISO are similar, with no significant differences between the two moments. As for the utensils used in the brushing of the teeth it was observed that before the program, most of the adolescents (66.5%) considered that should use the brush/folder/dental/pipe cleaner wire. After participating in the program – ProSorrISO there is an increase of participants to consider the use of this set of tools as the most correct (74.5%) (McNemar test: p = 0.057). Most of adolescents (83.5%) before participating in the program states that you should use dental floss once or more per day, and 16.5% report that should never or rarely be used. After the program, it was found that there was a greater number of adolescents to be noted that the dental floss should be used one or more times per day (89.5%). The assessment in the two periods reveals that adolescents after the participation in the program - ProSorrISO have better knowledge about the use of dental floss, but the differences are not statistically significant (McNemar test: p = 0.059).

Regarding the time interval to change the toothbrush, 39.5% of adolescents before the intervention considered that was to take place 3 at 3 months, 33.5% in less than three months, existing 8.0% which meant not know when it had to proceed the tooth brush exchange. After the program - ProSorrISO knowledge of the adolescents have improved, and 48.5% said that it should be changed from 3 in 3 months and only 3.0% persists without knowing when to do it. The differences in the two moments are highly significant (t =-13,018, p = 0.000).

Regarding the age at which you should start brushing teeth autonomously, it was found that before the program – ProSorrISO, 67.5% of adolescents understand that should be between 3 and 6 years and 12.0% from 6 years of age, but after the program knowledge increase since 44.5% of adolescents think it should be from the age of six. The differences between the two time points are significant (Z = -8,224; p = 0.000).

Regarding the definition of plaque before the program – ProSorrISO 60.0% of adolescents do not know what that is, 20.0% consider to be tartarus/yellowish plaque that accumulates on teeth. After intervention 10.5% of participants correctly defined plaque as food / dirt that accumulates on the teeth (6.5%) and bacteria which accumulate on the teeth (4.0%). There was also a decrease of students who do not know what is plaque (52.0% vs. 60%). The differences in the two stages of evaluation reveal that

adolescents after participating in the program - ProSorrISO have better knowledge in the definition of plaque (Z = -3,716; p = 0.000).

After participating in the program – ProSorrISO the percentage of adolescents who think that tobacco use affects the oral health increases (before: 90.0% vs. after: 95.0%) with significant differences between the two time points (p = 0.004). Also regarding the influence of plaque in the oral health has been an increase of knowledge (before: 83.5% vs. after: 91.5%), and the differences in the two moments were significant (p = 0.000).

No significant differences were found in the improvement of knowledge in the following variables: use toothpaste with fluoride (p = 0.496), oral hygiene habits (p = 0.665), alcohol consumption (p = 0.289), use of illicit substances (p = 0.566) and use of oral and perioral piercings in oral health (p = 0.135).

Considering the global knowledge of adolescents on oral health (overall score) it was found that is higher after participation in the program-ProSorrISO, with significant differences (p < 0.05). Due to this result it was concluded that the level of knowledge of adolescents on oral health after participating in the program increased (see table 4).

It was also found that girls have better knowledge on oral health

compared to boys either before or after the program-ProSorriso, and the differences in the two moments were statistically significant ( $p < 0.05$ ) (table 4).

## Discussion

Health education is a key strategy in the formation of behaviors that promote and maintain health. Mastrantonio and Garcia<sup>16</sup> point out that, through it, you can transform attitudes and behavior throughout the life cycle, forming habits in the population for the benefit of their own health. Adolescence “offers a window of opportunity to intervene early, not only preventing the initiation of risk behavior but influencing adherence to healthy behaviors that last throughout life”<sup>18</sup>.

The educational intervention program-ProSorriso proved to be effective, adolescents after participating in the program, improved oral health, oral hygiene habits, reduced plaque index and increased their knowledge of oral health. As refer Ericsson, Ostberg, Wennstrom & Abrahamsson<sup>19</sup>, the effectiveness of a program of oral health in adolescence depends, besides the type of resources used, the active involvement of adolescents and strengthening of oral hygiene education that can improve knowledge, practices, gingival health and reduce plaque levels.

Thus, it is suggested to carry out educational interventions for health, with greater accuracy, particularly with regard to procedures for correct oral hygiene, should parents and teachers be involved; the realization of facilitating partnerships of oral health promotion with local authorities, schools and adolescents/families. These interventions must then be geared towards the empowerment of adolescents to adopt healthy lifestyles and to create environmental and social conditions most favorable to the health of citizens throughout the life cycle.

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## Conclusions

Education for oral health have been addressed based on the directives of the General Health Department. However, there is no reference to educational intervention programs, with this scope, related to oral health in this specific population.

The study shows that adolescents after participating in the program, ProSorriso, improved indicators (decayed and filled teeth) of oral health, oral hygiene habits, reduced plaque index and increased their knowledge of oral health. The results also allowed us to identify some predictors of oral health and suggest ProSorriso’s replication in other contexts and with other samples, as it promotes the development of future investigations and good clinical practices that favor the oral well-being of adolescents.

Finally research evidence as conceptually advocated, which is pertinent to intervention in adolescence as a window of opportunity to promote and protect health with high benefits in the future. The educational intervention in partnership with the family assumes increased health gains, due to its potential to construct salutogenic lifestyles with positive implications in reducing risk factors for oral diseases.

The interventions to be delineated should be based on the recognition of the competences and resources of the adolescents/family, whose decisions should be centered on, contrary to the classic models of (in)formation, being particularly relevant to intervene in the disadvantaged families.

The encouraging results of the study, especially at the level of the implications of ProSorriso for the empowerment of adolescents, provide innovative subsidies for the understanding and scientific incur-sion of the importance of the role of health professionals in the health status and improvement of the oral health indicators of the portuguese adolescents.

# Features of family caregivers of people with dementia attended at a neurology consultation

## Summary

Providing care to someone with dementia is a complex task, that requires a set of specific skills and knowledge that family caregivers often lack. Training family caregivers of people with dementia is paramount, and the first step towards such purpose should be the identification of their features and the evaluation of their needs. The main aim of this study is to identify the major characteristics of family caregivers of people with dementia in early or moderate stage living at home, who attend the dementia consultation at a hospital in the north of Portugal, through a quantitative, descriptive and cross-sectional study. This study is a section from a previous randomized controlled trial, performed to assess the short-term efficacy of a training programme for family caregivers of people with dementia (the programme "Living together with Dementia"). Regarding the findings, we realized that the average age of family caregivers is 52, and these are mostly women, married, with basic education levels and employed. They display intense overload and difficulties levels, but also high degrees of satisfaction. They mostly resort to mixed coping/problem resolution strategies and their main needs are expressed as follows: managing emotions and feelings associated with the caring process; developing strategies to preserve physical and mental health; developing knowledge about dementia and its stages and finally, seeking support from formal institutions.

KEYWORDS: DEMENTIA; FAMILY CAREGIVERS; NEEDS ASSESSMENTS.

## Introduction

Dementia is a progressive syndrome that affects memory, thought, behaviour and performance of daily life activities<sup>1</sup>. Dementia has a greater impact on elderly population but, nonetheless, there have been a progressively greater number of reported cases in people under 65 years of age<sup>1</sup> and its incidence and prevalence tend to increase, which makes of this syndrome a public health problem<sup>2</sup>.

It becomes hereafter necessary to rethink the impact of this health issue in the community and in the families. It is fundamental to educate and support the caregivers and improve life quality of people with dementia in their own

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home environment<sup>1</sup>. The training programmes creation, implementation and effectiveness evaluation for family caregivers of people with dementia living at home should be a target for health professionals. The first step towards this objective is to identify the features and the needs of family caregivers.

Due to psychological and behavioural changes in early and moderate stage of dementia, caregivers deal with great stress and overload levels. Intervention on behalf of these caregivers should therefore be a priority for health professionals with the identification of their features and main needs as a first action to be taken.

## Methods

A quantitative, descriptive and cross-sectional study, which is a section of a randomized controlled trial that aims at evaluating the short-term efficacy of a psychoeducation programme for family caregivers of people with dementia in early or moderate stage living at home ("Living together with dementia" programme). This is a short part of a larger study developed for a nursing PhD thesis<sup>3-5</sup>.

Between October 2015 and March 2016, 48 family caregivers were identified (by neurologists) in the dementia consultation at a hospital in

FAMILY CAREGIVERS FEATURES

1

Family caregivers (n = 27)

Age (SD)	52 (11.7)
Gender	Male – 7 (26%) Female – 20 (74%)
Schooling	0-4 years – 6 (22%) 5-12 years – 17 (63%) > 12 years – 4 (15%)
Marital status	Married – 18 (67%) Not married – 9 (33%)
Occupation	Active – 20 (74%) Not active – 7 (26%)
Duration of family member's illness (SD)	3.0 years (2.2)
Type of dementia of the relative	Alzheimer – 15 (56%) Others – 12 (44%)
Kinship with the person with dementia	Partner – 7 (26%) Son/daughter – 16 (59%) Other – 4 (15%)
Previous relationship with the person with dementia	Good relationship – 26 (96%) Bad relationship – 1 (4%)
Years as a caregiver (SD)	3.3 (2.2)
Hours of day care (SD)	7.5 (7.4)
Help in caring	Yes – 19 (70%) No – 8 (30%)
Previous training as a caregiver	Yes – 1 (4%) No – 26 (96%)
Type of coping/problem-solving strategies	Focused on problem – 9 (33%) Focused on emotion – 1 (4%) Mixed – 16 (59%) None – 1 (4%)
Mean SCB score (SD)	57.1 (13.2) – Intense overload (> 56 score)
Mean CADI score (SD)	62.3 (20.7) – High level of difficulties (90 top score)
Mean CASI score (SD)	89.4 (18,6) – High satisfaction (120 top score)
Legend: SD – Stand Derivation; SCB – Scale of Caregiver Burden; CADI – Caregiver Assessment Difficulties Index; CASI – Caregiver Assessment Satisfaction Index	

the north of Portugal, who met the following inclusion criteria: being the main caregiver of the person with dementia in early or moderate stages; being literate; being motivated to participate in the programme; and residing in Porto. The family caregivers were excluded in the following cases: care recipients did not have dementia in early or moderate stage and the people with dementia suffered from other severe mental pathology. 27 family caregivers agreed to participate in study.

Assessment of the family caregivers who integrated the study was performed by an instrument, containing features of the family caregiver: three open questions regarding the number and type of strategies used as a daily resource; these are: the Scale of Caregiver Burden (SCB) (validated for the Portuguese population)<sup>6</sup>; the Caregiver Assessment of Difficul-

ties Index (CADI) (validated for the Portuguese population)<sup>6,7</sup>; the Caregiver Assessment of Satisfaction Index (CASI) (validated for the Portuguese population)<sup>6,7</sup> as well as pinpoint the 5 major daily needs from a supplied list (the 16-needs list was collected by means of an integrative review of the literature). For data analysis, SPSS software 21 (SPSS® Inc., Chicago, IL, USA) application was used, as well as descriptive statistics. The study was approved by The Health Ethical Commission of the Hospital Centre and all those participating in the study signed a free, prior and informed consent.

Results and discussion

The average age of family caregivers included in the study is 52, they are mostly women, married, and are daughters or wives of the person with dementia. Most of the caregivers' level of education goes from 5 to 12 schooling years, they are employed and have no training or experience as a caregiver. The socio-demographic characteristics found in this study are in accordance with other studies in the area, such as Boise, Congleton and Shannon (2005)<sup>8</sup>, Chien & Lee (2010)<sup>9</sup>, Ducharme et al. (2011)<sup>10</sup>, Hepburn, Lewis, Tornatore, Sherman and Bremer (2007)<sup>11</sup>, Judge, Yarry and Orsulic-Jeras (2009)<sup>12</sup> and Samia, Hepburn and Nichols (2012)<sup>13</sup>.

The previous relationship with the person with dementia was a positive one and most caregivers have a support net for the caring of their loved ones. They have been undertaking this task for about 3 years and devote about 7.5 hours a day to their family member with dementia. Alzheimer's dementia is the most common one among people who are under the care of these family caregivers, whose features can be analysed in table 1.

As can be observed in table 1, the family caregivers who participated in the study resort mostly to mixed coping/problem resolution strategies; in other words, they focus on solving

## FAMILY CAREGIVERS NEEDS

## 2

## Family caregivers (n = 27)

To manage emotions and feelings associated with the caring process	15 (56%)
To manage expectations and requirements associated with the caring process	3 (11%)
To develop effective coping strategies	7 (26%)
To develop problem-solving techniques.	7 (26%)
To develop strategies to maintain physical and mental health	20 (74%)
To develop knowledge about dementia and its stages	12 (44%)
To develop knowledge about psychological and behavioral changes in people with dementia	10 (37%)
To develop knowledge about communication strategies and behavior management	6 (22%)
To develop knowledge about adaptive strategies for daily life activities	7 (26%)
To develop knowledge about adaptive strategies for instrumental life activities	0 (0%)
To develop knowledge about strategies of general stimulation of cognition	2 (7%)
To develop practical skills for the execution of care	10 (37%)
To adapt the environment to the needs of the person	7 (26%)
To manage family, social and work relationships	8 (30%)
To know resources in the community	8 (30%)
To seek support from formal institutions	13 (48%)

the problem, but also on managing the emotion associated with the problem. An instance is asking for the help of other relatives to solve the problem and going for walks with friends to cope with stress.

Family caregivers present high overload and difficulties levels, which is compliant with some studies that state that as a result of the behaviour and psychological changes associated to the early and moderate stages of dementia, family caregivers that undertake this responsibility are more exposed to stress than other caregivers<sup>14</sup>.

However, these caregivers present high levels of satisfaction, which may be related to the positive meanings associated with caring, as some authors claim<sup>6,15</sup> and also due to a prior positive relationship with the person with dementia, which is a predictor of greater satisfaction in caring<sup>16</sup>.

As can be seen in table 2, the main needs expressed by family caregivers were: managing emotions and feelings associated with the caring process; developing strategies to preserve physical and mental health; developing knowledge about dementia and its stages; developing knowledge about psychological and behavioural changes in people with dementia; developing practical skills for the performance of care and seeking support from formal institutions. Developing strategies to preserve physical and mental health – possibly due to the intense overload presented by these caregivers – accounted for 74% of the answers.

## Conclusion

This study made it possible to understand the features of family caregivers

of people with dementia in early or moderate stage, who attend the dementia consultation at a hospital in the north of Portugal and to identify their levels of overload, difficulties and satisfaction. It was also possible to understand their main needs and the type of coping/problem resolution strategies they use.

These results are fundamental for the construction of adapted training programmes. The construction, validation and implementation of training programmes for family caregivers of people with dementia presents itself as a priority in health in the national context. The programme “Living together with Dementia” arises as a response to this need, as well as a guideline for the professionals’ intervention.

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# The added value of narratives in the understanding of adolescent's experiences with diabetes

## Summary

Evidence shows that living with diabetes during adolescence is a challenging experience. Besides the disease and treatment implications, it is important to comprehend how young people make sense of and manage their illness. Illness perceptions have been associated with a range of physical and mental health outcomes in adolescents with chronic disease. In order to contribute to a better understanding of the adolescent's experiences with diabetes, this study aimed at<sup>1</sup> describing illness perceptions of young people with diabetes<sup>2</sup>; understanding whether and in what ways, an in-depth analysis of the adolescent's narratives, offers additional insight into their experience of living with diabetes.

Participants were 32 adolescents with diabetes, aged 12 to 18 years, who completed the Brief Illness Perception Questionnaire and wrote a text about "What it is like to have diabetes".

Narratives were analysed with thematic analysis and illustrate how adolescents experience their disease, and the strategies adopted by them to maintain a sense of normalcy. Significant associations with the scores for illness perceptions were found, as for example, adolescents who reported a better understanding of their illness, evaluated the experience of having diabetes as less restrictive ( $r = -0,445$ ;  $p = 0.011$ ).

The use of narratives proved very informative on the adolescent's experiences with diabetes. For clinical interventions aimed to promote the adaptation of young people with diabetes, this study findings address the need to focus on normalizing their lives, and to promote more positive illness beliefs and coping strategies, to balance the restrictive impact that diabetes has on adolescent's lives.

KEYWORDS: DIABETES MELLITUS, TYPE 1; ADOLESCENT; ILLNESS PERCEPTION.

## Introduction

Type 1 diabetes mellitus (T1DM) is the most prevalent metabolic disorder among children and young people and it is estimated that worldwide about 79,000 young people are diagnosed with diabetes each year<sup>1</sup>. The management of T1DM includes a life-long, multicomponent regimen.

Adolescence may be a demanding developmental stage by itself, and even

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more challenging with a chronic illness such as type 1 diabetes mellitus (T1DM), since complex treatments are not easily integrated into the normative developmental tasks of adolescence<sup>2</sup>. In addition to facing the same challenges as their peers, adolescents with diabetes must cope with intensive medical regimens, regular clinic schedules, complex carbohydrate calculations, and frequent monitoring of blood glucose levels<sup>3</sup>. As such, during adolescence, the adherence to treatments often deteriorates, potentially leading to serious complications and early mortality<sup>4</sup>. This often disturbing reality places diabetes care teams as key players in the promotion of an effective management of the illness, in order to prevent major complications, and to ensure that the health condition does not negatively impact long-term physical and psychological health.

The promotion of self-management is an important goal in the transition from childhood to adolescence and therefore, health care professionals dealing with young people living with Type 1 diabetes need to have a better insight into



how these young people experience and cope with their disease.

Evidence in this topic emerges from quantitative and qualitative studies. Quantitative studies are mainly focused on exploring the adolescent's knowledge and perceptions/beliefs about T1DM<sup>5</sup>, while qualitative research usually addresses a more deep understanding of adolescent's views and experiences of living with the disease<sup>2</sup>. In this particular study, the aim was to articulate both approaches by comparing adolescents' perceptions/beliefs about T1DM with their narratives, to identify in what ways they provide additional insight into the comprehension of how adolescent's experience and live with T1DM.

According to the Common Sense Self-Regulatory Model (CS-SRM)<sup>6</sup> people develop implicit beliefs (cognitions) and emotions about their illness, sorted into five key dimensions: i) identity: perception of the label and symptoms of the illness, ii) timeline: duration of the illness, iii) consequences, and iv) cause: perceptions of the cause of the illness v) cure/control: perceptions of cure/controllability. These beliefs help the individual to respond to health threats, and to cope with symptoms and diagnosis of the illness and health information.

Illness beliefs have been associated to metabolic control in adolescents<sup>7</sup> and with a range of physical and mental health outcomes, in a number of conditions including diabetes<sup>8</sup>. Beliefs such as perceiving an illness as having serious consequences, attributing many symptoms to the illness (strong illness identity), and perceiving the illness as a long-term chronic condition, were found to be negatively associated with physical and mental health outcomes. By contrast, knowledge about the illness, self-confidence in the ability to manage the illness, and high perceived effectiveness of the treatments, are viewed as more positive and helpful beliefs<sup>8</sup>. It is interesting to note that despite worse perceived consequences and identity beliefs showed low correlations with disease state (from  $-.06$  to  $.08$ ), these same beliefs were consistently associated with worse physical and social functioning, higher distress, lower well-being and vitality (with correlations ranging between  $.18$  and  $.67$ )<sup>9</sup>. These associations highlight the impact of illness beliefs on the individual's well-being and functionality.

Although the illness representation model can be applied to children and young people<sup>10</sup>, in this age range, the cognitive-maturational factors are more focused on current symptoms, short-term treatment gains and more immediate consequences<sup>11</sup>.

In addition to quantitative studies, research using qualitative methods has offered important insight into the experience of living with T1DM from the perspective of the adolescent. Qualitative research seeks to gain in-depth understanding of the 'essence' of the meaning and experience of living with T1DM. A recent literature review of qualitative studies exploring the perceptions and experiences of adolescents living with type 1 diabetes<sup>2</sup>, synthesized the findings from eight selected studies (sample sizes ranging from 10 to 32 adolescents). Striving for normality, parental conflict, yearning for peer acceptance, and the emotional burden of living with diabetes were identified as the core themes emerging from adolescents with T1DM reports.

Feeling different from peers and striving for normality is a recurrent theme in adolescents with T1DM. In striving to manage self-care and a good control of the disease, peer support seems to play a critical role<sup>12</sup>. The life experience of adolescents with T1DM can be described as a compromise between being normal and being different, and in particular, trying to be like their friends and feeling supported and understood by peers is an important goal for adolescents with type 1 diabetes<sup>13</sup>. In a study in which interviews were conducted aiming to explore adolescents' views of T1DM in relation to

their sense of self and relationships with others<sup>14</sup> results from thematic analysis revealed that all the 40 adolescents interviewed described T1DM as a significant burden, and many described how T1DM made them feel less "normal". Adolescents reported both positive and negative aspects of self-management in social relationships, although most pointed out benefits in sharing T1DM with friends. Female participants were more likely to share information about T1DM and to describe positive changes in self-perception because of T1DM. The integration of T1DM into the adolescent self-identity should be further explored, specifically in relation to adolescents' self-esteem, social integration, self-management, and glycemic control<sup>14</sup>.

Moreover, some studies have already demonstrated the importance of subjective views and experiences on T1DM management and metabolic control. In a study in which interviews were conducted with adolescents about their perceptions of living with type 1 diabetes, it was found that those with low metabolic control levels did not believe in an imminent cure<sup>14</sup>. Significant associations have also been found between the experiences of parental conflict reported by adolescents with T1DM and reduced adherence to treatment and deterioration of glycemic control<sup>15</sup>.

Recent literature also recommend further in-depth research on adolescents' with T1DM perspectives to enable a better understanding of adolescent's experiences of living with diabetes and associated challenges, and to guide more effective interventions<sup>2</sup>.

## Objectives

This study aimed to understand how adolescents experience T1DM, and more specifically, it was intended to contribute:

- To explore adolescents' narratives about living with diabetes

- To describe illness perceptions of adolescents with diabetes
- To understand whether and in what ways, an in-depth analysis of the adolescent's narratives offers additional insight into their experience of living with T1DM.

By using a mixed approach in studying adolescent's experience with T1DM, this study also seeks to contribute to more innovative ways to help adolescents cope better with their condition.

## Research methods

### Participants

The sample was comprised by 32 adolescents with DM1, aged 12 to 18 years ( $M = 14.78$ ;  $SD = 1.70$ ), from a pediatric endocrinology clinic in a central Hospital of Porto. The inclusion criteria were: being an adolescent aged between 12 and 18 years old, diagnosed with T1DM at least 6 months earlier, and suffering from no other chronic condition or cognitive or sensorial impairment, who freely accepted to participate in the study. Ethical approval was granted by the hospital Ethics Committee. At first, a nurse contacted the adolescents, who, together with their parents, were informed about the study and invited to participate. The adolescents and their parents were both asked to sign an informed consent form.

### Data collection

Participants were asked to complete a questionnaire that included questions with sociodemographic and clinic variables and the Portuguese version of the Brief Illness Perceptions Questionnaire (B-IPQ). An A4 blank sheet of paper was also handed to participants, who were asked to write a text responding to the following prompt "What is it like to have T1DM".

The Portuguese version of the 9-item Brief Illness Perceptions Questionnaire (B-IPQ) (available at the questionnaire's official site <http://www.uib.no/ipq>) includes 8 items. Five items evaluate cognitive representations, (i.e. consequences, timeline, personal control, treatment control and identity); two items assess emotional representation, i.e. concerns and emotional response; and one item assesses illness comprehensibility, understanding. A five-point Likert scale (0 to 4) is used to rate the responses. The remaining item on the B-IPQ is an open-ended causal beliefs question in which individuals rank the three main causes of their illness (this item was not analysed in this study). A total score can be also computed which represents the degree to which the illness is perceived as threatening or benign. To compute the score, items 3, 4, and 7 scores are reversed and added to items 1, 2, 5, 6, and 8. A higher score reflects a more threatening view of the illness. Most studies report that the BIPQ has good internal reliability but in this study, the analysis suggested the exclusion of items 2 and 6. As such, the total score was calculated only for six items with a Cronbach alpha of 0.771.

### Data collection

Since this is a mixed-method study both qualitative and quantitative analysis were performed. Narratives were analysed inductively using thematic analysis<sup>16</sup>. To enhance the analytical framework, two authors (LL, ML) identified and recorded concepts in the narratives independently, then discussed their individual coding choices. Both authors developed and refined the coding structure until it captured all the concepts about adolescent experiences of living with T1DM. The themes were inductively derived from the data through a process of analysis and comparisons.

Results from B-IPQ were analysed through descriptive analysis. To further explore the added value of studying both narratives and illness beliefs, an as-

sociation between illness beliefs and themes that emerged from narratives was tested, using non parametric Spearman correlation test.

## Findings

### Qualitative analysis

The texts were analysed through a thematic analysis<sup>16</sup> and a core theme was identified named as "negotiating a sense of normalcy". The core theme emerged from 7 subthemes. Although those subthemes could be individually identified (figure 1), they were articulated in a sense that they described a process. That is, most adolescents expressed ambivalence or even apparent contradictions in what they identified as both positive and negative aspects in their experience with the disease.

The first subtheme "I'm living a normal life" in some cases worked as an entry into scene, the first statement of the text, through which participants stated that it was normal or OK for them to live with T1DM. One 14-year-old male wrote: "To me, suffering from T1DM is not something special..." and a 12-year-old female "one can be happy even suffering from T1DM". Some participants expanded their statements and justified why they thought that they felt they had a normal life, as for example "My life is the same with or without the disease, I can do everything that I did before I was diagnosed with T1DM!" (15-year-old male), "I'm used to have diabetes, I've been ill for a long time and it didn't make any difference" (13-year-old male). Some also described the process of regaining the feeling of normalcy "Over the years we just have to learn how to live with diabetes" (14-year-old female) or "some days I almost forget about T1DM... in this phase of the disease I still can find alternatives" (16-year-old female).

The second subtheme "I feel that I'm like everyone/others" describes how adolescents used social comparison processes to reflect upon their normalcy and health condition.

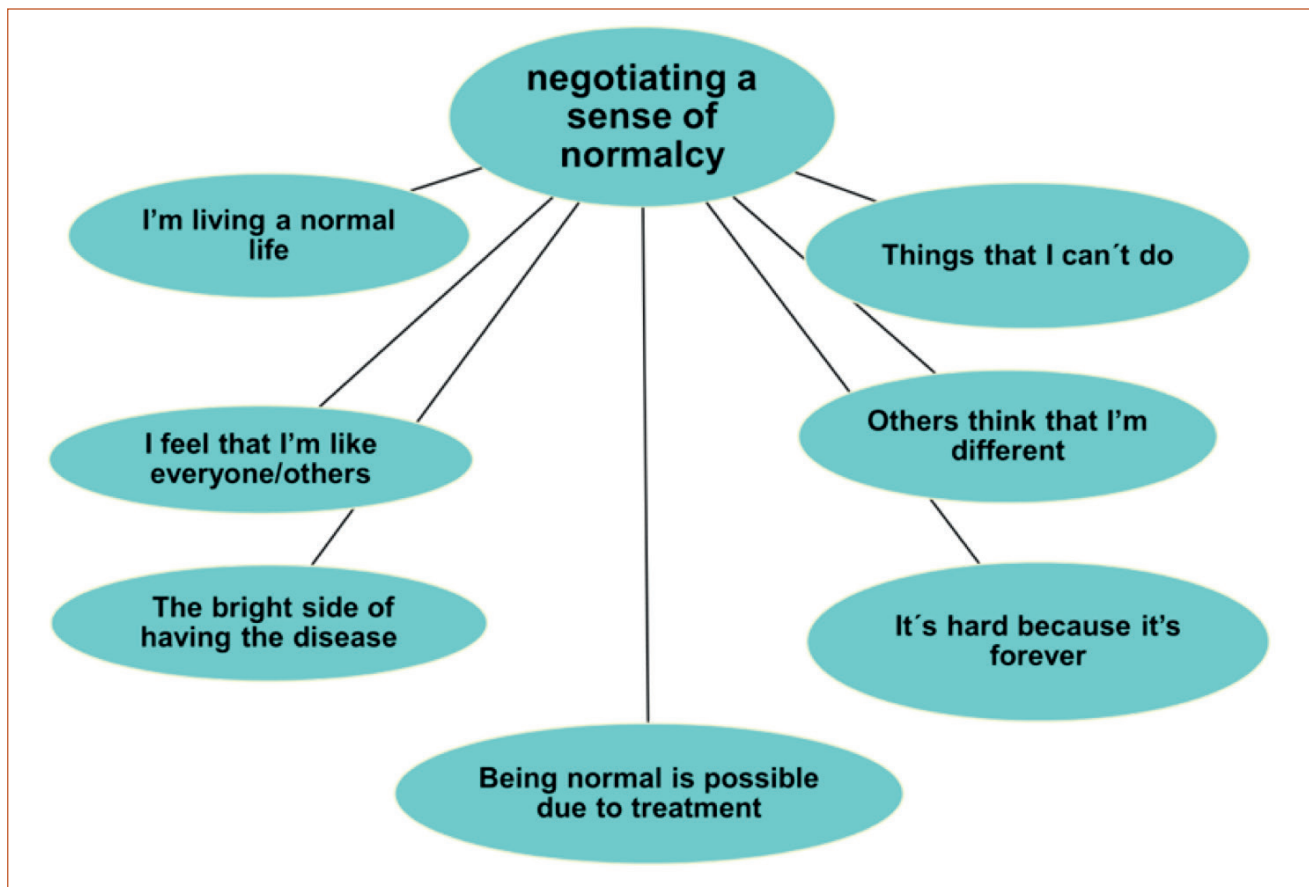


Figure 1. Thematic map – “negotiating a sense of normalcy”

They state they feel like other people, according to a 15-year-old female “I’m a girl like all the others, I’m not different” or share the same lifestyle, as a 15-year-old male “I have to have a normal life, like any other adolescent.

In the third subtheme “Being normal is possible due to treatment”, the experience of normalcy is described as a result/dependent/consequence of the compliance to therapeutic measures. Two of the citations are given as examples, “you can have a normal life if the disease is controlled” (14-year-old female), or “a diabetic person is a healthy person, without diseases, just needs some extra care” (14-year-old male). Treatment is referred as a resource for a possible experiencing of a normal life, and evaluated as simple “treatment is very easy” (14-year-old male). Some participants even referred to some aspects of the therapeutic regimen as behaviours that everybody should have “you just need to have a healthy diet as everyone should and the same with exercise” (14-year-old male).

In the subtheme “The bright side of having diabetes”, adolescents identified gains of having the disease. A 13-year-old girl wrote “Diabetes brought some advantages, as for example in relation to my diet, since I’m a diabetic my diet improved a lot” and a 15-year old girl referred “It’s good because we can control our weight”.

The remaining subthemes express obstacles and difficulties in feeling normal or living a normal life. Participants listed activities which are limited or impaired by the presence of the disease, and these were categorized as “Things that I can’t do”, one participant even used the expression “Diabetes sometimes limits my life” (15-year old male) or “I can’t sleep until late, so my life is different” (16-year old female). The most present restrictions were

related to food, especially sweets, as a 15-year old female mentioned “we can’t always eat what we want” or another 15-year old male “You can’t eat too many sweets because it will damage your health”. Other constraints mentioned were related to social life “Our social life is also affected because when we want to go out we have to take our insulin” 16-year old male.

Another subtheme includes references to the negative emotional impact or the burden of having a chronic disease and it was named “It’s hard and its forever”. Many characterized the experience of having T1DM as bad, hard and difficult as for example “Having diabetes is something that I consider annoying and boring and that I do not enjoy much... people said it’s easy but I don’t think so” (14-year old male). A 18-year old male wrote “To have diabetes is not an easy thing, one has to

be extremely conscious in coping with the disease because one knows that it is a chronic illness and it will be present in our lives forever” and a 16-year old male “to have diabetes is very bad. It’s a disease that is difficult to accept and to take seriously.” Some adolescents also mention the difficulties related to treatment “one thing bad is that we need to inject ourselves many times and that is a little annoying!”.

In the subtheme “Others think that I’m different”, participants expressed that they felt that other people thought or treated them differently, as a 15-year-old female “I felt badly in telling my friends because I was afraid of their reaction”.

Moreover, narratives analysed more globally were characterized by ambivalence since some of the participants stated that they felt they had a normal life and later in the text, they listed all the constraints they encounter in the experience of living of the disease. Again, the analysis revealed that the experience of diabetes in adolescence is like an ongoing process, through which adolescents struggle to feel and act like others. As an example, a 15-year-old male expressed: “I have to have a kind of normal life, like any other adolescent. Nevertheless, diabetes imposes limitations and I have to do choices: I can act like a healthy person and suffer with my diabetes, or I can do what seems the best for me according to the management of my disease and lose the opportunity to have an experience or to have something that makes me happy. Sometimes I make the wrong choice and I damage my health”.

### Quantitative analysis

In order to describe illness perceptions of adolescents with T1DM as measured by B-IPQ, mean values and standard deviation were calculated. Results evidenced that T1DM was perceived as benign by adolescents (maximum possible for total score is 24), indicating the perception of a small impact on their lives and on their emotional responses (table 1). Higher scores (indicating a more threatening perception) were found in relation to timeline, concern about illness and emotional impact. Globally, adolescents did not perceive a strong impact of T1DM in their lives and believed that they had a good control over their illness and that treatment was significantly helpful in controlling the disease. Despite the levels of concern, adolescents believed that they understood their disease very well.

To study the association between illness beliefs and themes that emerged from narratives non parametric spearman correlation tests were undertaken. Significant associations between the scores for illness perceptions and the frequency of subthemes were found, namely: more severe consequences beliefs were associated with fewer references to the subtheme “I’m living a normal life” ( $r = -0.458$ ;  $p = 0.008$ ); with more references to the subtheme “things I can’t do” ( $r = 0.422$ ;  $p = 0.016$ ) and more use of the subtheme “it’s hard because its forever” ( $r = 0.385$ ;  $p = 0.029$ ).

More positive treatment control beliefs were associated with fewer references to the subtheme “things I can’t do” ( $r = -0,590$ ;  $p = 0.000$ ). Higher coherence beliefs were associated with fewer references to the subtheme “things I can’t do” ( $r = -0,556$ ;  $p = 0.002$ ). Stronger emotional impact beliefs were associated to more references to the subtheme “it’s hard because its forever” ( $r = 0.385$ ;  $p = 0.003$ ).

### Discussion

Through narratives, adolescents described living with T1DM as a process of negotiation between accepting the constraints imposed by the presence of the disease and the burden of its treatment and the desire/need to live a normal life. The idea of normality is recurrent in literature that describes

how adolescents cope with T1DM, so the findings of the present study are consistent with many other studies<sup>2,4,13-14,17-18</sup>.

The young people living with T1DM wanted to maintain a sense of normalcy, and this was an area of negotiation in their lives. They struggled between feeling different and feeling the same, and their narratives balanced between stating that they felt just like everybody else but acknowledging that some people still thought they were different. In a literature review, the process of comparison with peers was found critical for achieving a sense of normality<sup>2</sup>, and in another study the support from peers was identified as an important goal for adolescents with T1DM<sup>13</sup>. They described their lives as influenced by the limitations imposed by T1DM, and evidenced minor aspects of life that can become increasingly important as they are associated with the normality of a ‘typical’ teenager. However, they also acknowledge their effort in order to do ‘normal’ things, such as going out with friends<sup>18</sup>.

Another theme that emerged was related to the emotional burden of having a lifelong, chronic illness. The psychosocial implications of living with T1DM were also identified as a core theme in a review<sup>2</sup> and in the present study adolescents evidenced the challenge of living with a condition that is perceived as hard to cope with, can be a serious threat if not treated and for which there is no cure. Nevertheless, the fact that adolescents also recognized the efficacy of treatment was important for attaining a sense of normality. Some adolescents described treatment as hard and intrusive but recognised it as a condition to control the disease and having a normal life. A theoretical model about the concept of “normalizing” was developed in order to understand the adolescent’s experiences of living with diabetes<sup>4</sup>, and “taking on the burden of care” was identified as one of the tasks that

DESCRIPTIVE STATISTICS OF B-IPQ

1

	N	Min.	Max.	Mean
Age	32	12	18	14.78
<b>B-IPQ</b>				
1- Consequences	32	0	4	1.47
3- Personal Control	32	0	3	1.44
4- Treatment Control	32	0	3	.63
5- Identity	32	0	4	1.50
7- Coherence	32	0	3	.81
8- Emotional impact	32	0	4	1.78
<b>Total B-IPQ</b>	32	0	17	7.62
2- Timeline	32	2	4	3.84
6- Concern about illness	32	1	4	2.69
Age	32	12	18	14.78
<b>B-IPQ</b>				
1- Consequences	32	0	4	1.47
3- Personal Control	32	0	3	1.44

youngsters had to achieve in the process. An interesting result from this study, not recurrent in previous studies, is the fact that adolescents also pointed out some gains in living with diabetes. In particular, girls identified the advantage of treatment allowing an easier weight control and the maintenance of healthy lifestyles.

Scores from the Brief IPQ showed that adolescents perceive their illness as relatively nonthreatening as the scores that were obtained from B-IPQ were globally low. The higher scores were found for the items related to timeline, concern about the illness and emotional impact, which is consistent with the chronic nature of the disease. It is also expected that the level of concern and emotional impact depend on the severity attributed to the condition. Evidence associates longer perceived timeline with more negative physical and mental health outcomes<sup>9</sup> and the belief that cure is not eminent has been also related to low metabolic control<sup>19</sup>.

The adolescents participating in this study showed positive beliefs about T1DM, more specifically they reported having a good knowledge about the illness, confidence in their ability to cope with T1DM and a high perceived effectiveness of treatments. All these beliefs have been previously associated with positive outcomes, both in terms of physical and psychosocial adaptation<sup>9</sup>.

The association between the illness perceptions, as measured by B-IPQ, and the use of themes that emerged from the analysis of narratives also showed interesting results.

Some results demonstrate that despite the methodology used to access adolescents' perceptions, similar important issues are evidenced. In fact, associations were found between similar ideas/beliefs, as measured by the B-IPQ or mentioned more freely through narratives. As an example, an association was found between stronger emotional impact beliefs and more references to the subtheme "it's hard because its forever".

Nevertheless, the study of the associations also helps to deepen the understanding of adolescents' experiences of living with diabetes. The adolescents who scored greater perceived consequences in the questionnaire

were the ones who, in their narratives, were less likely to describe their life as normal, who described more restrictions and limitations associated with diabetes, and the ones who evidenced the physical and emotional burden of the illness. More positive treatment control beliefs reported in the B-IPQ were found to be associated with fewer references to the subtheme that described restrictions, reinforcing that the adaptation to treatment is critical for achieving a sense of normality. Although significant correlations were found, findings derived from the adolescents' narratives do not totally overlap with the questionnaire results, and provide richer, more in-depth and nuanced insights into the experiences of living with diabetes.

Finally, higher coherence beliefs were associated with fewer references to the subtheme that included statements to limitations, which suggests that promoting a greater comprehension about the illness helps adolescents to cope with the restrictions imposed by diabetes. The development of educational programs to increase knowledge and supportive behaviors are also recommended<sup>4</sup>.

**Conclusion**

This study evidences that the experience of having diabetes is complex and is more fully understood when in addition to the evaluation of illness perceptions, as described by the Common Sense Self-Regulatory Model, adolescents are asked to describe it in a more open way. Although in the Brief IPQ adolescents reported their illness as relatively benign, their narratives illustrate where they experience limitations and the negative impact of chronicity. An interesting result is that adolescents who understand more about their illness and are more confident in the control provided by treatment, experience their disease as less restrictive.

In what concerns to clinical interventions aimed to promote adaptation of young people with diabetes,

findings of this study highlight the need to focus on normalizing their lives and to foster more positive illness beliefs, namely through the development of psychoeducational programs, as a way to balance the restrictive and undesirable impact that T1DM has on their lives.

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# Twin parenting experience – reshaping the family web

## Summary

Being a parent of twin siblings is a major challenge for parents and requires a family restructuring to adapt to a new family environment.

**OBJECTIVE.** To understand the experiences of parents of twins and meanings attributed to them.

**METHODS:** a qualitative study was conducted, having the symbolic interactionism as a theoretical referential and the interpretative interactionism as the methodological referential. Twenty-nine parents with children under 4 years participated in this study. A semi-structured interview was conducted for data collection.

**RESULTS.** The twins family responses to parenting challenges are conditioned by the management and articulation of their difficulties, their strengths and personal resources. There is a clear choice in being a family with children that privileges negotiation and involvement of the couple in caring for the family, or, at least, part of the family, meaning the children and playing the parenting role.

**CONCLUSIONS.** The family grows as a complex web, including its elements and interactions. The symbolic construction evidences the way the family adjusts to this environment of twin parenting. The health professionals should be able to anticipate the needs of families going through this process.

**KEYWORDS:** FAMILY; PARENTS; TWINS.

## Introduction

The family is still the core of social organization and a unique birthplace to grow and to learn with and from each other. This interaction and development require the adaptation of the family to a particular context, which influences the family structure and dynamics<sup>1</sup>.

During the life cycle, parenthood is the most significant life-changing event in which families are faced with enormous challenges. Families have to deal with the imperative need for personal and family adjustments and to a new mindset within the family core, taking care of a child and redesigning new identities incorporating being a “father” and being a “mother”<sup>2,3</sup>. These are all multiple determinants changes<sup>4</sup>, and the unique characteristics of parents and child, the family functioning and the internal resources, all contribute to the transition to parenthood. The perception of difficulties of the parenting role, alongside with the ability to decide on the number of children has been reflecting on the decrease of the birth rate mainly within developed societies.

Twin parenting is commonly associated with emotions, expectations and

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more intense anxiety levels compared to the situation of a single child. The experiences are increasingly difficult and demanding, with higher levels of tiredness and lower perceived self-confidence and capacity to care for the children<sup>5,6</sup>.

Difficulties are more intense during the children first months, with more stressful routines due to the necessity of balancing both parents and children’s needs. The routines are similar to both children involving continuous tasks. In addition to this demand, and as often referred by parents of twin children, the sleep quality patterns are also affected<sup>7</sup>.

Thus, and with the increased burden of caring for twin children, the family environment is likely to suffer from multiple daily life difficulties. Decreased marital satisfaction is often associated with an increase of conceived births and parents of twin children are more likely to split or divorce<sup>5</sup>.

Family support is essential in the

transition to parenthood. Help from the maternal grandmother is particularly highlighted during the first weeks after birth, in the management of complex tasks, with repercussions at various levels in the family dynamics, contributing to the maintenance of marital relations. As to the mothers' perceptions of their children, the mothers of twin children refer that their children are more difficult to handle compared to the mothers' perceptions of a conceived single child<sup>8</sup>.

### Problem statement

Twin children parental experience is an important challenge for the family, not only for the duplicate role play but also because of societal demands and expectations. Modern societies are more likely to face this challenge because the predominance of nuclear families diminishes the effectiveness of family support. Studies on twin children have been more focused on genetics and in the relations between twins, and therefore the study on the family living experiences is an important factor for the well-being of all family members.

### Research questions

Considering the specificities of families with twin children, our purpose is to understand how these families experience twin parenting. Taking into consideration the complexity and subjectivity of the experiences, we used the first starting question: How do families experience twin parenting?

### Purpose of the study

The aim of this study was to understand the experience of families with twin children aged under 4 years. The purpose was to contribute to enhancing interventions targeted at families living the experience of twin parenting.

A qualitative study was conducted based on the interpretative paradigm favouring the understanding of human experience as a true living experience, subjective and perceived by the ones involved<sup>9</sup>. Participants were selected in the Family Health Units integrating a Group of Health Centers (ACES) in the north of Portugal which aim the promoting and surveillance of persons and families throughout their life cycle.

### Research methods

This study used the Symbolic Interactionism as the theoretical referential, where the object is the subject's action, and depends on the meaning attributed to the object and to the dimension that this experience has for this subject<sup>10</sup>. It incorporates reflection on the analysis of the action and it is used in studies on the daily life of people and interactions, aiming to disclose and learn its meaning<sup>11,12</sup>. The Symbolic Interactionism grounds its theory on three aspects: human beings act in relation to things based on the meaning that these things have to them; meanings emerge from the social interaction that the individual establishes with others; the attributed meanings develop and change through an interpretative process, specific to each person when dealing with things and situations in life<sup>10</sup>. Thus, the Denzin Interpretative Interactionism<sup>13</sup> was used for data analysis. This analysis method is focused on people's experiences, how these experiences change people and which meanings are attributed to these experiences.

We first started with a simple reading of the conducted interviews, in order to get a general idea of the participants' experiences. A further detailed analysis was then performed focused on the identification of phrases and statements that addressed the phenomenon; we interpreted their meaning; we identified the potentially emerging themes and in what ways they could contribute to the phenomenon under study.

We proceeded with the interpretation of the obtained data by producing explanations and trying to capture aspects of the human experience with regard to the experience of families with twin children.

For data collection the inclusion criteria established were: men, women or both living the experience of twin parenting of children under the age of 4 years; living together as a couple; and users of the regional Group of Health Centres (ACES Ave III). To apprehend the phenomenon, the biographical narratives of the participants in the study were obtained through semi-structured interviews. The interviews were conducted in the home of the participants or in the health centre, according to the availability of participants. Interviews were conducted in a single moment, lasted an average of 60 minutes, and were later recorded and transcribed verbatim.

Ethical approval was granted by the Ethics Committee for Health of the Regional Health Administration of the North of Portugal and from the Institute of Biomedical Sciences Abel Salazar. Prior to the interview, participants were asked to sign an informed consent and were informed about the purpose of the interview and that confidentiality was assured.

### Findings

Twenty-nine parents of twin children participated in this study.

In order to preserve the confidentiality of testimonies, we will gather and present the characteristics of every family. Regarding the age of the participants, women showed an average age of 34.6 years with a minimum of 22 years and maximum of 40 years. The average age of men was 36.3 years ranging between a minimum of 21 years and a maximum of 52. Eight of the women participating in this study had higher education, three had completed high school and the remaining the basic education level. Three of the male participants had higher education, two



completed high school and the remaining had basic education.

All participants were married, one of the families was restructured but their twin children were from the current marriage. The average number of years of marriage was 7.31, ranging from a minimum of 3 years and a maximum of 18 years.

In what refers to the number of children, two families had four children at the time of data collection, and one of the families had two pairs of twins, three families had three children with the twin children being the youngest, and the remaining families had two twin children.

Finally, we considered the family composition of participants in the study: six family units were extended families, integrating the parents of one of the spouses and other family members.

From data analysis, two themes and sub-themes emerged that represent the symbolic construction of the participants with regard to how their families have experienced twin parenting.

The quotes extracted from the interviews are identified with "I" for interview followed by the number assigned to the family and "W" or "M" describing woman or man. Names used in the speeches are fictional.

Reshaping the family web to the birth of twin children implies making more or less conscious choices, to make decisions, to adopt strategies and mobilize resources to respond to perceived needs. The themes identified in the participants' discourse analysis helps us to understand how this adjustment process occurs. In this sense, the themes identified were to strengthen the family web, through the adoption of family routines, flexibility, preservation of routines and mobilization and management of aid and enhance parts of the family structure affected by fragilities, conditioned by beliefs, centered on the children's routines and consolidated in family bonds.

Thus, when the focus is on the family, there is a strengthening of the family web through the adoption of family routines that have to be adjusted to the life cycle of the family, age and health conditions. The family environment experiences changes and mobilizations, timetables are changed, the physical structure and the organization of the house. The routines work as a protective factor, promoter of personal and family development. If the pace and family routines prior to the birth of the children were not so well adjusted and individual independence and autonomy had significant impact in the life of the family, this change and adaptation to a new organization are increasingly complex. The participants recognized that an effort was made in order to adapt to the new family organization.

*I've never had routines and so it was difficult, because with them we need to schedule things. Often we would eat midnight (I9M).*

*... but these are important to them, the routines, you had to manage the more grown up, their plays, play with them, dinner, also get to feed the babies, sometimes we had dinner at 10 in the evening, it was hard at first to manage the routine. They are four, it's the adaptation, but time went by (I7W).*

However, the routines must be based on flexibility. The organization and distribution of family tasks should be consensual according to each other's availability. This flexibility is reflected in the actual organization of the family life and domestic life and should be adapted to the family needs.

*... but tasks are not defined, we know what we have to do and we do it as far as we can [...] one thing I've learned is that there's no use in making plans. When I thought I was going to do this and that they wouldn't let me, and I felt frustrated, irritated [...]. I think that most importantly a person has to be practical (I11W).*

*... if they want to play, they'll play, the house is chaos when they're awake, toys all over the place, everything scratched, at night when they go to sleep we arrange everything, it has to be this way, it's their time, they must enjoy it, and if not we wouldn't rest anyway (I10W).*

In view of the challenges of twin parenting, family strengths are emphasized promoting the family involvement and sharing in a common project. Family strengths favour the interaction between its members. The mutual support enhances the ability of the family to deal with adversity and in relation to twin children, this specific need is even more evidenced.

*... in case of twin children, the couple helps each other even more than when there is only one child. It's better. Twins involve more people, more help, no one can take of two children on their one (I13W).*

*I think if it was different (husband involvement) [...]. I was almost having a [...] we were both almost having a breakdown, but if things were different, I would surely collapse.*

To cope with the work overload caused by the birth of twin children, the family, in addition to the aforementioned strategies, also seeks to mobilize available help. The family identifies the resources that may be useful to address stress situations and imbalances within the family dynamics. The grandparents are the main resource, their help is determined by the couple, considering what they think better suits the circumstances.

*... my mother-in-law helps me in the evening (I4W).*

*... my mother helps me a lot, for instance, if I need her to pick the children at the kindergarten or if I stay at work and need her to stay with them, but this is it, she picks the girls and he (husband) meets her there, then she helps him bring them*

*home and then she leaves (I10W).*

*... our mother-in-law helps us whenever needed (I10M).*

When the family is focused on the parental project there is a strengthening of parts of the family web, that is, the trajectory shifts from the sense of being a couple to being a mother/father with a family. In this particular situation the established family dynamics in the initial period of the adaptation to the birth of twin children perpetuates in time and children are the reason and the center of everything and everyone.

*... everything is about them. Everything, just everything, the family here at home and my husband's family (I12W).*

*My parents-in-law are living here with us and this has interfered a lot, I've always valued privacy (I2M).*

Because parenting is complex, the family responses towards changes and challenges are not always adequate to meet their own needs. Some weaknesses are exposed either at the level of relations with others or in what concerns sharing of responsibility on the parental role. The woman is the primary responsible for childcare.

*... it's obvious that I think more than he does, I get much more tired, I work harder because I really have to be there for them (I8W).*

*... at home I'm the one making more decisions, I feel upset because I'm the one who has to decide on things. It's usually my responsibility [...] he said: you're the mother (I2W).*

*... being a mother is a big responsibility. Some time ago I considered the hypothesis of getting a job but he said if you're going to work then who is going to take care of the children (I5W).*

Beliefs are identified relating to family role plays affecting the sharing and involvement of all in the family life and care. Women find that some care should be their sole responsibility because they are the mothers. Personal characteristics add to these conceptions that influence the way personal and family responses evolve in relation to challenges.

*I think the mother should be the one doing certain things (I12W).*

*... the mother does more things than the father. It's natural, I also work a lot of time outside the house, even so, it's natural that the mother does more things than I do (I2M).*

The family routines change according to the children's routines and although these routines are considered an important part in the management of the children and family's needs, they are mainly focused on the children's needs. The family is forced to set priorities and making decisions and it is during this process that responses are constructed and oriented towards the children's needs and routines. These routines demand energy and effort from parents and are likely to become a barrier to the establishment of family routines that are no longer a priority and prevent the family from re-establishing former routines.

*... it's different now, our routines, our schedules are set according to our children (I4M).*

*... we don't re-establish our family routines, it's a big effort (I8W).*

*... everything changed [...] all house routines have changed (I2W).*

*... we still don't have routines (I16W).*

The establishment of alliances evidencing the proximity of two family members, where a third element is separated or in opposite situation, occurs in the presence of difficulties in the articulation and involvement of all family, thus leading to the proximity to a certain family member. If this proximity occurs in relation to the mother's wife, then time is spent close to the origin family. The maternal reference is the one providing more safety and support. Occasionally, the woman may feel safer with her own parents than with her spouse, establishing an alliance with the origin family involving the children.

*I spend my life with my mother, I only go home to sleep (I5W).*

*I'd rather be with my parents than with him (husband), I feel more supported [...] they even sleep over here (I2W).*

*... when my mother stayed at my house it was easier, if it was my husband it was a little harder (I8W).*

The husband might additionally feel that his performance as to the parental role distances from initial expectations, he perceives that the presence of the grandparents in the children's life is more important than his. Men recognize the benefits of this relationship, although it is still not the most desired.

*... my mother-in-law is 100% available, but we are the parents [...] it was*

never my decision, they sleep over there, it's better and they really help my wife but I don't feel good about that. My parents-in-law spend more time with my daughters than I do... they know I'm their father, sometimes I feel put aside but I know it's not their (parents-in-law) intention (I2M).

According to their needs and resources, families are more oriented to care and to the children's needs concentrating their efforts towards them.

According to figure 1, reshaping the family web is a process balancing between family focus and children's focus. In fact, it seems relevant that the family is able to preserve routines, to mobilize help, to understand personal strengths and evidence the adaptation abilities. However, this path involves some difficult choices.

On the other hand, there is a reshape of the family web centered on the children and the parental role. In this process, the family needs are now focused on their children as the sole priority. The woman establishes alliances with the family of origin and focuses on the children's routines.

This adjustment in either direction is continuously been established and its trajectory depends on the family and the specific moment in life.

Throughout this process of reshaping the family web, mothers spend so much time taking care of their children that their time seems to be completely dedicated to that role. Others recognize the women response to such demanding responsibilities.

... during the first six months I had no life of my own, without any doubt. Everything was about both of them (I1W).

... during the day I am fully dedicated to them there's no use in doing differently, because it's really just for them, if you try to escape they'll instantly call for us (I10W).

... the family still asks: how are things going? My god, how do you manage all that? (I3W).

... many of my colleagues say: I think many times how are things going for you! Because they have just one and sometimes... poor of them (I7W).

However and despite the difficulties and concerns, the experience of having twin children is perceived as a very positive experience.

... being a father of twins is something extraordinary (I6M);

I'm very happy I never thought that being a mother was like this, but there are also negative aspects, many, my life has really changed a lot... it's a new experience but very exhausting (I15W);

The best moments... just everyday (I14W);

I think the best of everything is being a mother (I4W);

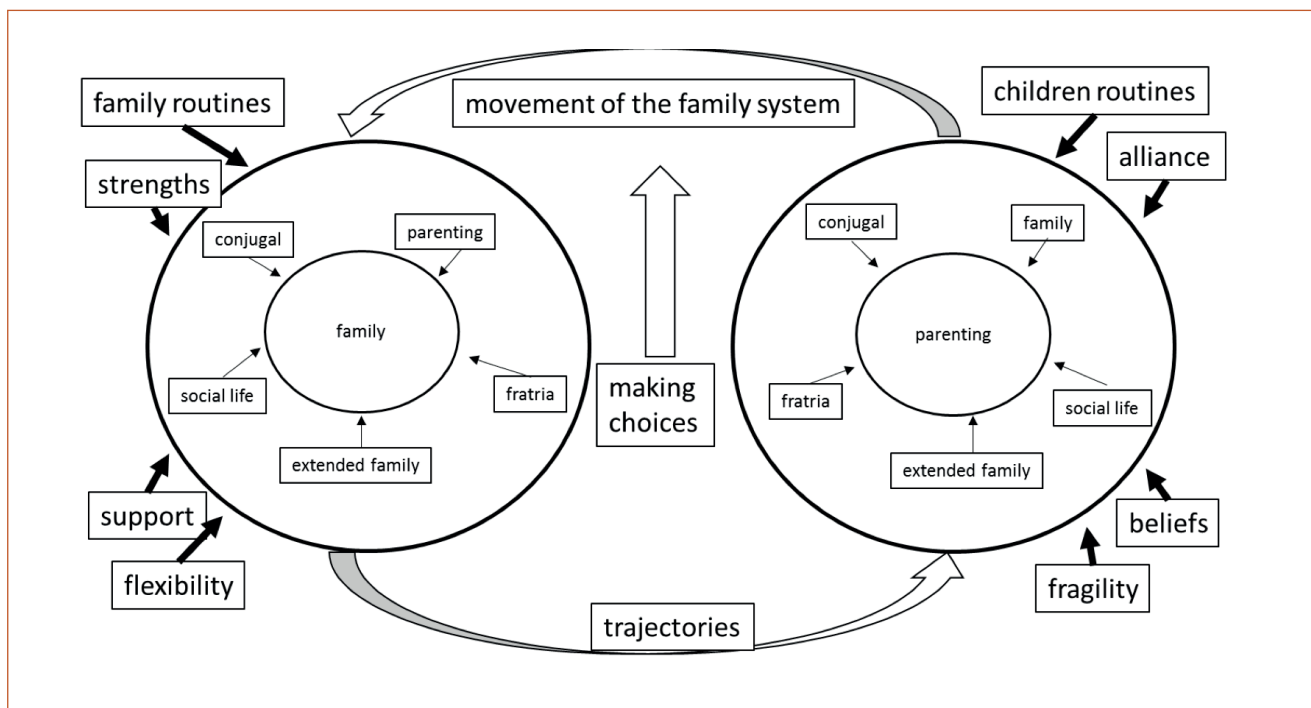


Figure 1. Adjusting the web

*To hug them, it's the best thing. Watch them laughing at us, It's just wonderful (I13W).*

There is evidence of the importance of families being able to preserve family routines, to mobilize help, recognize their strengths and show the ability to adapt. This is a path that often implies difficult choices.

### Discussion

The family continues developing and reconstructing over time setting milestones and joint projects. During this path the personal and/or family transitions are a challenge that imposes the incorporation of new demands, the adequacy and interpretation of new roles and integrating a new identity<sup>1</sup>.

The birth of twin children is one of the family's life changing experiences and an event that inevitably changes the entire dynamics of the family processes. This experience is similar to other families with children, however, it is the intensity of this experience that will dictate the impact in families' lives.

The literature emphasizes the constraints of the experience of twin parenting, suggesting that having twin children is more difficult than expected. Mothers of twins often report the higher impact of the difficulties experienced when compared to mothers of a single conceived child<sup>14,15</sup>.

The transcribed testimonies in this study show that women recognize that they feel some insecurity and have questions about the parental role and that they experienced constant fatigue, especially in the child early months. But these women also report that watching their children grow and the opportunity to interact with them is a unique experience and one of best things in life. Positive experiences were emphasized in their statements, alongside with the difficulties experienced during this process. The experience is influenced by its intensity either in difficult times or in joyful moments.

In family life, the communication, the commitment, the social relationships, the clear roles and shared time are essential aspects, and in this study the positive aspects more referred were: the family bonds and family support, the strong bond between parents and children and the ability to organize and share tasks of daily living which corroborates with other authors' findings. Considering that the involvement of everyone in the family life promotes family strengthening and improves the ability to confront situations, one of the attitudes that favours this interaction is the fact that the woman encourages the man to participate in family care, avoiding isolation and promoting the family's well-being<sup>16</sup>.

In fact, it is during the first months of the children's lives that the life of families suffers major changes. This is a crucial period for the new parents. The physical and emotional involvement of the woman is increasingly higher in case of twin children. The lack of time and the ability to respond to both often matching needs are frequently reported by parents and likely to trigger stress episodes<sup>6,17</sup>.

Usually, the father acts as a support<sup>18</sup>, however, in relation to twin children, his involvement either complements the role of the woman or is replaced by another significant family member, leading to feelings of family and social exclusion. The woman acknowledges that having a partnership with the man is a promoter of an effective parental role and leads to a stronger involvement in the family life. The family strengths are enhanced and the family of origin works as a resource. In addition to the mobilization of resources it is also important to consider a greater sharing and flexibility of the couple, alongside with an effective family communication leading to stronger bonds and helping in the acceptance of the new parental roles<sup>17</sup>.

It should be noted that the family environment has suffered changes and mobilizations, schedules have been changed, the house physical structure and the functional organization, which corroborates with the study conducted by Alves et al.<sup>19</sup> and, although these routines require an additional effort, they were considered beneficial for the functionality of the family, since they created stability and predictability. The routines work as a protective factor, promoting personal and family development<sup>20</sup>.

Because parenting is complex, multi-determinant and influenced by parental personality, values, marital quality and social factors, among others, the family responses when dealing with changes and challenges not always adequately meet their specific needs. Some weaknesses are revealed, either in the relations established with others or when sharing responsibility in the parental role, because the woman is still the main responsible for the care provided to the child and for the daily tasks, as stated by Jager & Bottoli<sup>16</sup>. In these situations the family routines submit to the children's routines and although these routines are considered important in managing the children's and family's needs, they are still mainly focused on the children's needs.

With the children's birth and their needs, the challenge can be so intense for the woman that, in addition to preventing couples of having a time for sharing, which was already recognized by some of the participants, this can often be considered a loss. Women often feel extremely responsible for the inability to respond appropriately to the husband and the daily tasks<sup>21</sup>. The husband withdrawal of this family caring does not have a sole responsible, since the family system itself leads to this exclusion<sup>16</sup>.

The difficulty in managing the time to care for the children affects the time dedicated to the family and in particular, for the spouse

and promotes social isolation. The woman feels this excessive burden and isolation for being confined to the house increasing her vulnerability.

The relationships and family of origin resources are of great importance in families with children. The grandparents' support is crucial for the woman, but it is the maternal grandmother which most often provides this assistance, a finding also found in the study developed by Taubman-Ben-Ari et al.<sup>22</sup> where this support provided is what brings added value in situations of the woman's increased vulnerability. When there is a continuous support of the origin family, whether in their own house, or moving in a more or less permanent way to the couple's house, there are difficulties in establishing the boundaries between the new family and the family of origin. Finally, the qualitative study conducted, in accordance with the study performed by Ellison & Hall<sup>23</sup> evidenced an increased demand when the children are twins and the family relationship can potentially be strengthened, if the man is more committed to the family, enabling a stronger teamwork as a couple.

### Conclusion

From the analysis of this study it is possible to conclude that twin parenting requires clear and decisive choices towards a more united and cohesive family in relation to family care or, in opposite, a family focused only on one of its nuclear elements, and potentially excluding the man and letting another element take his place, usually someone from the family of origin. This last hypothesis is clearly the one more difficult to deal with.

There is also evidence that the first children's months are particularly difficult and the support of the extended family, in particular of grandmothers is highly significant but not always free from conflicts. According to participants, the maternal grandmother and father are the preferred family elements to help take care of the children. The fatigue is experienced by men and women but both agree that in case of a single child, the parental role of the men would be less stressful.

After this initial phase of greater support and involvement of all there are families who get involved in a joint project, in which the resources mobilization and social support is well defined and delimited. If on the one hand, one is looking to meet all needs equally and according to the response capacity, on the other hand, there are families unable to distance from social support and the woman's involvement is oriented to the exterior, mainly towards the grandmother. These are not decisive positioning and it is not common to find a family that fits into a single profile, it changes according to the family's life and the experienced phases.

The family strengthening in response to the twin parenting demands should be a focus of attention to nursing professionals. The support to families in the process of recognising and exploiting their own resources is seen as important, as well as the search for new resources with the help of professionals.

It is also important the identification of family needs and personal, family and social resources, and their mobilization. This intervention should focus on communication processes and anticipatory care.

We understand that these interventions should take place in different moments and be targeted at the needs of each family, considering the following objectives: to discuss the involvement of the couple in the family role; raise awareness for a new family organization; reinforce the identification of strengths and family resources; to monitor the responses of the family to the specific tasks of family development; to monitor family relationships, to encourage free communication between family members; to collaborate with the family in problem solving and adjust expectations.

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# Supervision and mentoring in higher education

## Dynamics of success

### Summary

**INTRODUCTION.** Based on the inherent benchmark of mentoring and perceptoring, and conscious of the challenge of reducing the estimated school dropout rate of 12% for the Polytechnic Institute of Viseu (IPV), the main aim of the project Supervision and Mentoring in Higher Education: Dynamics of Success (SuperES) is to promote the development of pedagogical supervision skills with focus on teacher – student dyads, and thus enhance the quality of teaching in the IPV. The direct beneficiaries are the IPV assistants, and subsequently the students, who will benefit from a pedagogical didactic literacy program (Cunha et al., 2017).

**OBJECTIVE.** To promote the pedagogical supervision skills of the IPV assistants, which can reduce failure and school dropouts.

**METHODS.** The sample will consist of approximately 210 assistants and 900 students. The methodology is based on an experimental research with two groups: the experimental group, which will receive training, and the control group. To monitor the effectiveness of the program, a battery of questionnaires will be applied before and after its implementation.

**RESULTS AND DISCUSSION.** Of the 17 activities executed, the evaluation of the pedagogical supervision skills is highlighted. They are: (i) the construction/implementation/evaluation of the SuperES Program; (ii) the construction of a computer platform/website – Didactics & School Supervision: Caixa Geral de Ajudas; (iii) the creation of a tool, “Supervision +”, used for the self-monitoring of pedagogical skills.

**CONCLUSIONS.** The SuperES program integrates a research action that aims to implement/test training and research tools on the process of pedagogical supervision.

**KEYWORDS:** PROGRAM; PEDAGOGICAL SUPERVISION; STUDENTS; HIGHER EDUCATION.

### Introduction

In Portugal, school failure and dropout in higher education are a reality that have been worrying the most diverse educational agents and government officials. In recent years, they have reached prevalences that in public education range between 13%<sup>1</sup> and 17.4%<sup>2</sup>, figures that are higher than expected. Other European countries present rates of 11.1%<sup>2</sup>. The focus here is therefore an intervention priority recognized by the Portuguese government, since dropouts in higher education are one of the greatest obstacles in the consolidation of the educational system and contribute highly to the perpetuation of social, economic and cultural inequalities. This is even more noticeable in regions of the interior of the country if we bear in mind that

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the ‘Europe 2020’ strategy has defined for Portugal the need to reach 40% of higher education graduates within the age range of 30-34, a goal considered to be still fairly equidistant if we take into account that in 2014 this figure was 31%<sup>3</sup>.

From this referential and conscious of this enormous and daring desideratum, the team of the project “Supervision and Mentoring in Higher Education: Dynamics of Success (SuperES)”, intends to give body to a set of tasks whose main purpose is translated in the promotion of pedagogical supervision skills, which are conducive to reducing failure and dropouts in higher education. The direct beneficiaries will be the IPV teachers with the category of assistants (who, from a survey of training needs in the area of pedagogical supervision skills, will benefit from intervention programs, advanced courses, guidelines and various devices and tools of technological character, promoters of pedagogical didactics literacy), and subsequently the IPV Students with whom they work with. The relationships with partners will also boost synergies of scientific knowledge that are capable of reducing the knowledge gap and improving the good pedagogical



cal practices inherent to the supervision of learning. The need to promote school success has been a challenge acknowledged by the European Commission, which emphasizes, on the one hand, the need for interventions to promote teachers' pedagogical skills as a domain for improving the quality of education and training systems, for improving the process teaching/learning and individualized student guidance throughout the school year. On the other hand, there is a need to promote the skills and intervention of the student mentor as a facilitator of the integration and adaptation of new students in Higher Education, both nationally and internationally.

Within the framework of the Council of Europe and the European Union, Portugal has made a compromise regarding the implementation of investment policies in education, in which continuous teacher training is a privileged setting. As a future investment, the prevention of social inequalities is also built through education. Therefore, the investment in continuous teacher training is a keystone in the construction of solidarity and social justice, thus increasing the country's productivity and the quality of life of its citizens.

In short, the SuperES project, whose goal is to promote the development of pedagogical supervision skills with a focus on teacher-student dyad, mainly aims to increase the skills of the IPV assistants who participate daily in the training of citizens of the future.

The Team who delineates the foundation of this project considered the contributions of national and international theoretical references as a theoretical frame of reference.

## Methodology

### Problem statement

The promotion of pedagogical supervision skills, which are a factor in the reduction of school failure and dropouts in higher education, is the focus of the Project "Supervision and Mentoring in Higher Education: Dynamics of Success, SuperES" (fig. 1). It includes 17 sequential activities with emphasis on the revision of the scientific literature, monitoring and evaluation of the pedagogical supervision skills of the assistants of the Polytechnic Institute of Viseu (IPV), whilst structuring axes for the consolidation of the project's actions.

The project will use active methodologies, since it is acknowledged that "... there is no quality education, [...] nor pedagogical innovation, without an adequate training of teachers"<sup>4</sup>.

In order to fulfil the research unit requirement, a project identification logo was created, shown in figure 1.



Figure 1. Project SuperES Logo

### Research questions

In order to guide the research of the SuperES Project, the following research questions were made: "What pedagogical supervision skills do the IPV assistants hold?"; "What are the expectations of the students attending higher education in the IPV regarding the benefits of the mentor and the pedagogical supervision skills?".

### Purpose of the study

Monitoring the effectiveness of the training intervention program of the SuperEs Project will be done in two different moments (one before and another after its implementation), through a protocol of questionnaires. Their aim is to reinforce the reflective component of the participants in a face-to-face methodology through a participatory evaluation process. The contribution of stakeholders will foster an assessment that is capable of verifying the operationalization of the targets set, analysing the quality of the training program, and will support the introduction of improvements that are conducive to the adoption of good supervision practices. In the line of the so-called "fourth-generation evaluation" or participatory evaluation, the basic philosophy of this model focuses on the recipients of the project as well as partners in the activities to be promoted (School of Health in Oporto, Portugal; Escuela Universitaria de Enfermería, University of La Rioja, Spain).

Within this scope, the main objective of the SuperES Project was defined: To promote pedagogical supervision skills of the IPV assistants, promoters in reducing school failure and dropouts. Accordingly, the following are specific objectives of the project<sup>5</sup>:

(A0) 1. To design the implementation of the project in the best scientific evidence.

(A1) 1. To monitor the training needs on pedagogical supervision skills of the IPV assistants.

INDICATORS OF THE SuperES PROJECT

1

Indicators	2017 Expected	2017 Already achieved	2018 Expected
Books			2
Papers in international journals			6
Papers in national journals			5
Communications in international meetings		3	6
Communications in national meetings			5
Reports	1		1
Organization of seminars and conferences	2		3
Master's Theses			3
Other Theses			2
Models	1		
Non-expected Indicators, but already achieved			
Posters		1	

- (A2) 2. To evaluate the pedagogical supervision skills of the IPV assistants.
- (A3) 3. To monitor students' expectations about the added value of mentoring and pedagogical supervision skills.
- (A4) (A5) (A6) 4. To build, implement and evaluate the effectiveness of the SuperES Program of training intervention in order to train 95% of the participants with pedagogical supervision skills.
- (B1) 5. To provide the assistants of the IPV with the structuring literacy teaching didactic of pedagogical supervision skills.
- (B2) 6. To organize Conferences that favour pedagogical supervision skills and successful learning in higher education.
- (C1) 7. To elaborate prescriptive guidelines so as to support recommendations and guidelines of evidence-based good practices within the scope of pedagogical supervision skills.
- (D1) 8. To provide specialized support to the development of pedagogical supervision skills. 9. To provide updated research data on pedagogical supervision skills.
- (D2) 10. To create a system to support the self-monitoring of pedagogical supervision skills.
- (E1) 11. To increase new knowledge on pedagogical supervision skills and thus define guidelines for their promotion. 12. To participate in the achievement of the objectives of the institutional plan and mission of the IPV.
- (E2) 13. To produce scientific/technical papers.
- (E3) 14. To disseminate the results of the research carried out in scientific events, highlighting those with an implication in the promotion of the pedagogical supervision skills.
- (E4) 15. To create the opportunity of sharing experiences among higher education teachers, favouring the development of pedagogical supervision skills. 16. To disclose results of the research that was carried out.
- (F) 17. To demonstrate the development and evolution of the actions of the Project.
- 18. To document performance indicators.
- 19. To evaluate the effectiveness of interventions...

**Methods**

The target group is made up of 5025 students and 413 teachers of the IPV.

The sample will consider about 210 assistants and 900 students. The methodology is based on an experimental research with two groups: the experimental group consisting of 20% of the population that will receive training, and the control group. To monitor the effectiveness of the program, a battery of questionnaires will be applied in two different moments of 2017 (before and after its implementation).

Students will share their viewpoint on the added value of the Student Mentor.

The research protocol developed by the research team includes data collection instruments aimed at obtaining, among other things, direct information on supervisory practices before and after the training intervention as well as the collection of information supported by the online completion of the following instruments:

- Ad hoc questionnaire Higher education students' opinion on preferences regarding the effectiveness of the pedagogical supervision process and the existence of the student mentor.
- Ideal Mentor Scale by Cunha (2017), with figures adapted from Botas, Gabriel & Welling (1997/1998).
- Supervisor Core Skills Scale.

The study obtained a favourable opinion from the Ethics Committee of the ESSV, it was authorized by the institutional leaders of the organic units of the IPV and the participation of those who volunteered willingly gave their written consent.

### Findings

The main focus of the training intervention is to develop talents/attitudes and skills in the didactics of supervision. Its mobilization and transfer will consolidate favourable changes, which translate into the safeguarding of pedagogical practices and of quality teaching and, consequently, into greater academic success. The SuperES Project, supported by an action research, takes on with the participants a co-path that aims to implement/test training and research tools to lessen the knowledge gap on the process of pedagogical supervision.

It should be noted that the model program of the training intervention SuperES already developed aims to equip assistants with pedagogical supervision skills and foster quality higher education. Therefore, following is: (i) the evaluation of the impact of the training intervention program –SuperES Program– for the assistants; (ii) the construction of a computer platform/website – Didactics & School Supervision: Caixa Geral de Ajudas for training support; (iii) the creation of a tool for the self-monitoring of pedagogical skills “Supervision +” based on new technologies. As for the expected results, regarding the implementation of the 17 activities envisioned during the SuperES Project, the research team planned to materialize the ones described in table 1:

### Conclusions

The SuperES training intervention program integrates an action research, assuming with the participants a co-path that aims to implement/test training and research tools to lessen the knowledge gap on the process of pedagogical supervision. Of the 17 expected activities, the following are highlighted:

- (i) Diagnosis of the training needs on pedagogical supervision skills.
- (ii) Monitoring and evaluation of pedagogical supervision skills.
- (iii) Construction/implementation/evaluation of the SuperES Program.
- (iv) Assessment of the mentor’s added value to the students.

In addition to the aforementioned indicators, the achievement of the project will be relevant and have implications in the loco-regional, national and international community, since scientific knowledge will be built to support the development of guidelines for the promotion of good practices of pedagogical supervision and mentoring with academic success of higher education students.

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# European questionnaire on health literacy- (HLS-EU-PT) in a sample of pregnant women

## Summary

**INTRODUCTION AND OBJECTIVES.** The knowledge and skills that enable pregnant women to adopt healthy lifestyles is broad and complex. In addition to factual knowledge, the adoption of health behaviours also implies a set of emotional, cognitive and behavioural skills that allow the use of this knowledge in the context of pregnancy.

**METHODOLOGY.** Cross-sectional, quantitative, descriptive-correlational study with non-probabilistic, intentional sample by convenience (n = 404 pregnant women) with a mean age of 32 years. They answered the sociodemographic, obstetrical and HLS-EU-PT questionnaire (National School of Public Health, 2014). Following the methodology used in the European Survey, four ways of dealing with relevant health information were recognized.

**RESULTS AND DISCUSSION.** Overall, 36.9% of pregnant women presented a problematic level of health literacy, 40.1%, 39.9% and 38.4%, a sufficient level of health literacy in the area of Health Care, Disease Prevention and Health Promotion, respectively. The factorial analysis demonstrates the validity of its framework. The alpha values of the items are above 0.9. The correlations between the different domains and the overall value are all positive and above 0.8. All dimensions of the scale correlate with each other in a statistically significant way, with values for the different domains. The split-half coefficient was  $\alpha = 0.939$  in the first half and  $\alpha = 0.930$  in the second half.

**CONCLUSIONS.** The results of the present study support the psychometric adequacy of the European Questionnaire on Health Literacy – (HLS-EU-PT) for the population of pregnant women, indicating that it could be used in future trials.

**KEYWORDS:** HEALTH LITERACY, PREGNANCY.

## Introduction

Pregnancy makes up a phase in the life of the couple where there are diverse psychological and physiological transformations in the woman. This requires information so as to acquire abilities to deal with the changes and decision-making power and autonomy of self-care, as well as caring for her child<sup>1</sup>.

Adequate health literacy in pregnancy is critical in order to be able to

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diagnose symptoms that may become complications in pregnancy, and on the other hand it should provide pregnant women with the adoption of well-balanced habits and life-styles conducive to healthy pregnancy without complications<sup>2</sup>. Although the responsibility for the promotion of health literacy is collective, health professionals play a fundamental and facilitating role in their development through the adoption of an open attitude, negotiation and reciprocity in relation to pregnant women, recognition of their skills and of their sociocultural universes. Thus, nurses are assigned responsibility for integrating health education as a fundamental dimension of their intervention, in the context of health promotion and consequently contributing to the increase in health literacy<sup>3</sup>. It is readily apparent to notice the constant concern of health policies in increasing health literacy in communities within the past decades<sup>4</sup>. Given this, and assuming that it is essential for people to successfully manage their health, health literacy is considered a public health goal to be achieved in the 21st century, and health policies are constantly working towards increasing it. The knowledge and skills that

enable pregnant women to adopt healthy lifestyles is broad and complex. In addition to factual knowledge, the adoption of health behaviours also implies a set of emotional, cognitive and behavioural skills that allow the use of this knowledge in the context of pregnancy. "The timely and combined performance of screenings and interventions, associated with health education measures throughout the prenatal period, is related to health gains and decreased maternal and perinatal morbidity"<sup>5</sup>.

Educational actions influence how the woman/couple experiences the pregnancy, since they are considered essential activities to educate future parents about preventive methods of prenatal care and to motivate them to adhere to healthy behaviours, leaving behind harmful habits that contribute for increased perinatal, neonatal and infant morbidity and mortality<sup>6</sup>. "Counselling, informing and supporting the pregnant woman, minimizing the ancillary symptomatology to the pregnancy state and providing a programme of clinical, laboratory and ultrasound screening, ensure the normal course of pregnancy and detect any deviations from normalcy"<sup>7</sup>. The quantity and quality of prenatal care are recognized as important influencing factors on maternal and fetal prognosis during pregnancy and may even be one of the most cost-effective areas for preventive interventions, leading to the reduction of maternal and perinatal mortality<sup>8</sup>.

Early on in the study, Remoaldo<sup>9</sup> identified three barriers that could hinder the use of healthcare by pregnant women: structural barriers: organization of services, effectiveness of care, time and costs; the individual barriers: knowledge (in which health literacy can be included), feelings and behaviours, and finally sociodemographic barriers: age, socioeconomic status and education level. From an educational point of view, these barriers have important implications and should be taken into account in the planning of educational interventions, as well as in the care of the pregnant woman. With regard to health literacy, Speros<sup>10</sup> states that the cognitive skills of critical thinking, analysis, decision making and problem solving in a health-related context combine with social communication skills and questioning individuals to improve not only their state of health, but also the health of the communities that they belong to. Therefore, health literacy is more than simply being able to read information and schedule appointments successfully, it includes the ability to understand instructions and prescriptions of medicines, medical brochures, understand information before giving informed consent and the ability to negotiate health systems, in particular health insurance. It requires a complex group of abilities such as reading, listening, knowing how to make decisions and the ability to apply these skills in health situations<sup>4,11,12</sup>. According to Antunes<sup>13</sup>, if there is a more significant investment in the promotion of health literacy, we can see: "A better use of health services; decreased health risk behaviours; a decrease in health expenditures; a motivation on the part of patients concerning the involvement of their health process, enabling them to make informed and reasoned choices". People with low health literacy show less ability to understand the contents of information material on health, diseases, diagnostic tests, food consumption or on the use of medicine; it is more difficult for them to research, select, read and assimilate health information available on the Internet<sup>11</sup>. Pregnancy literacy empowers women to make decisions during this period of women's due cycle: pregnancy and childbirth<sup>14</sup>.

Adequate literacy in pregnancy is essential for a healthy and safe pregnancy, with the ability to diagnose symptoms that can turn into pregnancy complications. It should also provide pregnant women with the adoption of well-balanced habits and lifestyles conducive to a healthy and uncomplicated pregnancy. In short, it should provide an opportunity for women to

learn ways to manage pain, as well as understand some obstetric interventions, which will allow them to collaborate during labour<sup>2,14</sup>. Health literacy enables pregnant women to understand the danger signs in pregnancy and to respect the advice given by nurses during prenatal consultations in order to live a healthy and safe pregnancy. Therefore, it is necessary that nurses, during consultations and health education sessions, teach and inform pregnant women about what to expect during pregnancy and what to do when they identify warning signs<sup>14</sup>.

Literacy in maternal health is thus reinforced by prenatal education, which is focused on all matters relating to care during pregnancy, childbirth, birth and caring of the new-born. Nonetheless, nowadays, the pregnant woman/couple, when leaving the medical or nursing office, finds an endless supply of information available in communication and information technologies where the internet takes a leading role. All of these resources constitute effective ways for the pregnant woman/couple to increase their health literacy specifically for this period of their life.

In this perspective, it is important to have tools that are capable of assessing the level of health literacy in pregnant women, which will make it possible to identify the aspects where the pregnant woman needs more intervention in order to guarantee effective prenatal care, a healthy pregnancy and pregnancy outcome<sup>14</sup>.

### **Problem statement**

Currently, the health system is increasingly patient-centred, requiring it to play an active role so that it becomes an essential part of decision-making processes in health-related areas. Thus, it is essential that the person acquires knowledge and skills to deal with the health system and the management of their health and illness, as well as the ability to use these tools effectively. An ade-

quate level of pregnancy literacy is critical in order to be able to diagnose symptoms that may become complications in pregnancy, as well as to provide pregnant women with the adoption of well-balanced habits and lifestyles conducive to healthy pregnancy without complications<sup>2</sup>.

### Research questions

Given the importance of knowing the level of health literacy of the pregnant woman to improve her health and that of her child, there was a need to test the HLS-EU-PT on a sample of pregnant women and determine the level of literacy.

### Purpose of the study

The objective of this study was to test the factorial framework of the European Questionnaire on Health Literacy HLS-EU-PT for a sample of Portuguese pregnant women from the central region of Portugal.

### Methods

A cross-sectional, quantitative, descriptive-correlational study performed with a non-probabilistic, intentional sample by convenience of 404 pregnant women from the central region of the country, with a mean age of 32 years. As a data collection instrument, a sociodemographic and obstetric characterization questionnaire and the European Questionnaire on Health Literacy, acronym (HLS-EU-PT) validated for the Portuguese population by the academic network of the National School of Public Health, were carried out<sup>15</sup>. Following the methodology used in the European Survey, four ways of dealing with relevant health information were recognised: The ability to access information; the understanding of information; the ability to interpret and evaluate information; its application or use in various situations.

The self-report questionnaire was filled out by pregnant women in order to guarantee the participants' anonymity and privacy. The data collection instrument was divided into open questions, closed and mixed questions, single and multiple response questions, divided into three groups: I – The sociodemographic characterization questionnaire included data on nationality, age, marital status, place of residence, academic qualifications, current profession and professional situation, monthly family income and the existence of internet at home; II – The obstetric data questionnaire, which includes the obstetric history (previous pregnancy, number of children and type of delivery), the current pregnancy (planned pregnancy, desired pregnancy, number of consultations carried out up to the date of the application of the questionnaire, beginning of pregnancy surveillance, gestational age, surveillance site of the pregnancy, pre-pregnancy health problems as well as during the pregnancy, hospitalization, emergency room visits, supplement medicine intake for pregnancy, and other data such as handing in the pregnant woman's health booklet, the presence of the nurse in the consultations and the intention of attending or already attending a course for childbirth/ parenting preparation); III – The European Questionnaire on Health Literacy - Portugal (HLS EU-PT) of the Academic Network of the National School of Public Health, 2016 and for which authorization was requested. It is a questionnaire with 47 questions organized in a Likert type scale with five answer alternatives, in which 1 is Very Difficult; 2 is Difficult; 3 is Easy; 4 is Very easy; 5 does not apply. The instrument integrates three domains of health - health care (16 questions, items 1-16), health promotion (16 questions, 32-47) and disease prevention (15 questions, 17-31) and four levels of essential information for decision-making: access, understanding, evaluation and use.

In order to ensure the correct calculation of the indices and to ensure a comparison between them, the four calculated indices were standardized on a metric scale varying between 0-50, where 0 is the least possible health literacy and 50 as much health literacy as possible. For the 4 levels, the following cut-off points were identified: scores  $\leq 25$  points = inadequate health literacy; scores between 25-33 points = problematic health literacy; scores between 33-42 points = sufficient health literacy; and scores between 42-50 points = excellent health literacy.

Following the methodology used in the European Survey, four ways of dealing with relevant health information were recognised: The ability to access information; understanding information; the ability to interpret and evaluate information; its application or use in various situations. From the four indices, cut-off points were defined, which represent differentiated levels of health literacy: "excellent", "sufficient", "problematic" and "inadequate".

The self-report questionnaire was filled out by pregnant women in order to guarantee the participants' anonymity and privacy.

- a) The study of internal consistency or homogeneity of items was performed through the following steps.
- b) Determination of the Pearson correlation coefficient between each of the items and the overall score.
- c) Determination of Cronbach's alpha coefficient, which measures the correlation between each item of the scale and the remaining ones belonging to the same universe. The value obtained corresponds to the lower limit of internal consistency. This indicator makes it possible to evaluate how the various items complement each other in the evaluation of the different aspects of a factor, that is to say, belonging to the same subscale. The parameters vary between zero (0) and one (1) considering the internal consistency<sup>16</sup>: very good for alpha greater than

0.9; good if alpha between 0.8 and 0.9; reasonable if alpha between 0.7 and 0.8; weak for alpha between 0.6 and 0.7, and unacceptable if alpha is lower than 0.6.

d) Determination of the split-half coefficient, and through it, the items of a scale divide into two groups and the correlation within each group and between the two groups is examined, in order to verify if one of the halves of the items on the scale is as consistent in measuring the construct as the other half.

### Findings

The sample consists of 404 pregnant women, of whom 371 were Portuguese (91.8%) and 33 were foreign (8.2%), aged 19-48 years (mean of  $31.74 \pm 5.17$  years). The majority of pregnant women (76.2%) present an age up to 35 years, with only 23.8% of the sample being  $\geq 36$  years old, 49.3% of the total sample hold a higher education degree, 152 pregnant women (37.6%) attended 12th grade or equivalent training, and 53 women (13.1%) basic training; and 79.5% are married or living in a non-marital partnership.

### Psychometric Study of the European Questionnaire on Health Literacy - Portugal (HLSEUPT) in a sample of pregnant women

In 2009, a group of European experts, coordinated by the University of Maastricht, gave rise to the consortium Health Literacy Survey – EU, whose purpose was the development, validation and application, in the different European countries, of an instrument to measure the population's levels of Literacy in Health. Hereinto emerged the European Questionnaire on Health Literacy (HLS-EU). The aim was to measure the ability of people to access, understand, analyse and use health information to make informed decisions that allow them to maintain a good level of health, prevent diseases and seek appropriate treatment in case of illness<sup>15</sup>. In the first phase, the following countries were integrated: Spain, Greece, Holland, Ireland, Germany, Bulgaria, Poland and Austria and later on Portugal.

In 2014, the National School of Public Health carried out the cross-cultural validation of the HLS-EU instrument in order to obtain an instrument as equivalent as possible to the original, having undergone a cultural adaptation and validation through the bilingual translation-retroversion method. Once the entire process had been developed, it was submitted to a pre-test, with 251 individuals, so as to evaluate the adequacy and comprehension of the items of the translated version, resulting in the final version of the European Questionnaire on Health Literacy – Portugal (National School of Public Health, 2014).

The assessment of the internal fealty of the HLS-EU-PT scale presents global values of  $\alpha = 0.95$ , and the three dimensions of the same scale also carry high fidelity levels: health care  $\alpha = 0.91$ ; disease prevention  $\alpha = 0.94$ ; health promotion  $\alpha = 0.97$ <sup>15</sup>.

Following the methodology used in the European Survey, four ways of dealing with relevant health information were recognised: The ability to access information; Understanding information; the ability to interpret and evaluate information; its application or use in various situations. Thus, four levels of information processing were formed – access, understanding, evaluation and use – and were essential to what concerns decision making. From the four indices, cut-off points were defined, which represent differentiated levels of health literacy: “excellent”, “sufficient”, “problematic” and “inadequate”. These levels are particularly useful for describing the situation of populations in terms of health literacy and for identifying vulnerable groups. In order to ensure the correct calculation of the indices and to ensure the

comparison between them, the 4 levels were standardized on a metric scale that varied between 0 and 50, in which 0 is the lowest health literacy possible and 50 the highest health literacy possible.

For the four levels, the following cut-off points were identified: Scores  $\leq 25$  points = Inadequate Health Literacy; Scores 25-33 points = Problematic Health Literacy; Scores = 33-42 = Sufficient Health Literacy and Scores  $> 42$ -50 = Excellent Health Literacy. To carry out the calculations of the indices (between 0 and 50) and to simplify the comparison between the 9 countries, the following formula is used:

$$Index = (mean - 1) * \left(\frac{50}{3}\right)$$

Index: the calculated specific index  
Mean: is the average of all items for each individual.

1: is the lowest value possible.

3: is the range of the mean.

50: is the highest value possible.

For the present sample, the psychometric properties were evaluated through the studies of reliability and validity. Table 1 presents the statistics (mean and standard deviation), the correlations obtained between each of the items and the overall value, to facilitate the viewing of their combinations. It can be seen that the alpha values of all items are above 0.9 (ranging from 0.959 to 0.961), which shows a good internal consistency in the scale. The total item correlation on all items is also greater than 0.20, so no items were excluded.

Table 2 shows the convergent/discriminant validity of the items that is observed by comparing the item's correlation with the scale to which it belongs, as well as with the correlations with the scales to which they do not belong. It is considered a good convergent/discriminant validity when the Pearson correlation values with the scale to which it be-

## INTERNAL CONSISTENCY OF THE PREGNANCY HEALTH LITERACY SCALE

1

No.	Items	$\bar{x}$	Sd	Correlation item-total	$\alpha$ sem item
1	Find information about the symptoms of diseases that worry you?	3.07	0.746	0.542	0.960
2	Find Information on the treatment of Diseases that worry you?	2.93	0.785	0.555	0.960
3	Know what to do in case of a medical emergency?	2.90	0.770	0.511	0.960
4	Know where you find professional help when you are ill?	3.35	0.572	0.518	0.960
5	Understand what your doctor tells you?	3.23	0.604	0.599	0.960
6	Understand the leaflet that comes with the medicine?	3.09	0.698	0.589	0.960
7	Understand what to do in a medical emergency?	2.85	0.801	0.597	0.960
8	Understand the instructions given by your doctor or pharmacist about taking the medicine that has been prescribed?	3.37	0.606	0.585	0.960
9	Evaluate how your doctor's information applies to your clinical condition?	3.04	0.751	0.614	0.960
10	Assess the advantages and disadvantages of different treatment options?	2.88	0.866	0.573	0.960
11	Assess the need for a second medical opinion?	2.70	0.957	0.621	0.960
12	Assess whether information on the disease in the media is reliable?	2.53	0.969	0.536	0.960
13	Use your Doctor's information to make a decision regarding your illness?	2.95	0.791	0.592	0.960
14	Follow the treatment instructions?	3.28	0.621	0.596	0.960
15	Call an ambulance in case of an emergency?	3.30	0.713	0.473	0.960
16	Follow your doctor's or pharmacist's instructions?	3.31	0.615	0.635	0.960
17	Find information to manage behaviours that affect your health. such as smoking. lack of physical activity and excess alcohol?	3.28	0.783	0.578	0.960
18	Find information to manage mental health problems like stress or depression?	2.93	0.878	0.641	0.960
19	Find information about vaccines and the tests you can do?	3.00	0.828	0.694	0.959
20	Find information on how to avoid or control conditions such as being overweight. high blood pressure and high cholesterol?	3.12	0.704	0.689	0.959
21	Understand health and behavioural warnings. such as smoking. lack of physical activity and excess alcohol?	3.31	0.599	0.595	0.960
22	Understand why you need vaccines?	3.29	0.671	0.630	0.960
23	Understand why you need to do a physical exam?	3.34	0.699	0.625	0.960
24	Assess how reliable health warnings are. such as smoking. lack of physical activity. and excessive alcohol?	3.31	0.670	0.538	0.960
25	Evaluate when to go to the doctor to get a check-up or undergo a general health examination?	3.15	0.737	0.610	0.960
26	Evaluate which vaccines you need?	2.99	0.864	0.614	0.960
27	Evaluate the medical tests you need to do?	2.86	0.844	0.617	0.960
28	Evaluate whether the information in the media about health risks is reliable?	2.72	0.828	0.597	0.960
29	Decide if you should take the flu shot?	2.75	0.982	0.431	0.961
30	Decide how to protect yourself from an illness based on the advice of family and friends?	2.70	0.843	0.382	0.961
31	Decide how to protect yourself from an illness based on information from the media?	2.61	0.916	0.493	0.960
32	Find information about healthy activities such as physical activity. healthy eating and nutrition?	3.24	0.639	0.585	0.960
33	Know more about activities that are positive for your mental well-being?	3.06	0.801	0.657	0.960
34	Find information on how your residential area can be more health-friendly?	2.58	1.136	0.551	0.960
35	Learn more about policy changes that may affect your health?	2.37	1.164	0.579	0.960
36	Know more about ways to promote your health at work?	2.64	1.037	0.620	0.960
37	Understand the health advice of your family and friends?	2.99	0.663	0.568	0.960
38	Understanding Information on Food Packaging?	3.03	0.755	0.539	0.960



**INTERNAL CONSISTENCY OF THE PREGNANCY HEALTH LITERACY SCALE**

**1**

39	Understand the information conveyed by the media to stay healthier?	3.02	0.723	0.646	0.960
40	Understand information that aims to maintain a healthy mind?	3.00	0.800	0.688	0.959
41	Evaluate how the place you live in can affect your health and well-being?	2.84	1.022	0.687	0.959
42	Evaluate how housing conditions can help you stay healthy?	2.97	0.918	0.696	0.960
43	Evaluate the daily behaviours that are related to your health?	3.12	0.685	0.634	0.960
44	Make decisions that can improve your health?	3.07	0.708	0.609	0.960
45	Join a gym or a gym class if you wish?	3.12	0.801	0.428	0.961
46	Change your lifestyle habits, which affect your health and well-being?	2.94	0.776	0.534	0.960
47	Participate in community activities that improve health and well-being?	2.85	0.831	0.508	0.960

**HLS-EU-PT SCALE-ITEM CORRELATIONS: DISCRIMINANT VALIDITY**

**2**

Item No.	Health care	Prevention of disease	Health Promotion
1	0.651*	0.475*	0.433*
2	0.685*	0.492*	0.424*
3	0.599*	0.424*	0.449*
4	0.609*	0.472*	0.400*
5	0.732*	0.528*	0.444*
6	0.654*	0.544*	0.480*
7	0.674*	0.489*	0.534*
8	0.702*	0.521*	0.441*
9	0.734*	0.547*	0.472*
10	0.696*	0.531*	0.429*
11	0.656*	0.570*	0.549*
12	0.600*	0.518*	0.442*
13	0.701*	0.532*	0.464*
14	0.666*	0.582*	0.447*
15	0.565*	0.446*	0.364*
16	0.708*	0.609*	0.483*
17	0.569*	0.614*	0.473*
18	0.539*	0.664*	0.612*
19	0.617*	0.735*	0.608*
20	0.631*	0.682*	0.622*
21	0.559*	0.644*	0.485*
22	0.577*	0.666*	0.538*
23	0.592*	0.682*	0.502*
24	0.456*	0.634*	0.453*
25	0.524*	0.684*	0.526*
26	0.512*	0.713*	0.530*
27	0.523*	0.702*	0.535*
28	0.489*	0.678*	0.538*
29	0.359*	0.561*	0.367*
30	0.295*	0.509*	0.336*
31	0.420*	0.570*	0.450*
32	0.527*	0.555*	0.566*

longs are higher than the values with the scales to which it does not belong in about 25 points<sup>17</sup>. The same authors refer that under ideal conditions, the correlation values item scale to which it belongs should be above 0.40 and below 0.30 with those to which it does not belong. We verified that all items present higher correlation values in the domain to which they belong, with statistically significant differences ( $p < 0.05$ ). There was only a slightly higher correlation in the “Disease prevention” domain in the case of item 38. However, we chose to keep this item in the “Health promotion” domain, as the authors of the scale defended in their factorial analysis.

In order to finalize the psychometric study of the HLS-EU-PT scale, a Pearson correlation matrix between each domain and the overall value of the scale was performed, in order to determine which domains best explain health literacy. We found that the correlations between the defined domains are positive and statistically significant, ranging from  $r=0.688$  (health care vs health promotion) to  $r = 0.780$  (healthcare versus disease prevention), explaining the 47.33% and 60.8%, respectively. It is therefore inferred that an increase or decrease in the weightings for each of the domains results in an increase or a corresponding reduction in the weightings of other areas (see table 3). Analysing the same table, the correlations between the different domains and the overall

## HLS-EU-PT SCALE-ITEM CORRELATIONS: DISCRIMINANT VALIDITY

2

33	0.497*	0.606*	0.730*
34	0.388*	0.479*	0.705*
35	0.438*	0.480*	0.728*
36	0.484*	0.523*	0.739*
37	0.456*	0.519*	0.617*
38	0.457*	0.545*	0.533*
39	0.494*	0.617*	0.693*
40	0.520*	0.609*	0.780*
41	0.543*	0.595*	0.783*
42	0.549*	0.598*	0.789*
43	0.505*	0.590*	0.674*
44	0.534*	0.523*	0.649*
45	0.336*	0.382*	0.515*
46	0.418*	0.460*	0.627*
47	0.384*	0.423*	0.631*

## PEARSON CORRELATION MATRIX BETWEEN THE DOMAINS OF THE HLS-EU-PT SCALE

3

Domains	Health Care	Prevention of Disease	Health Promotion
Health Care	—	0.780*	0.688*
Prevention of Disease	0.780*	—	0.777*
Health Promotion	0.688*	0.777*	—
Overall Value	0.895*	0.929*	0.912*

## INTERNAL CONSISTENCY IN THE DOMAINS AND OVERALL OF THE HLS-EU-PT SCALE

4

Domains	Split-half Coefficient		Cronbach's alpha coefficient overall value
	First Half	Second Half	
Health care	0.867	0.855	0.911
Prevention of disease	0.882	0.830	0.898
Health Promotion	0.848	0.870	0.918
Overall Value	0.939	0.930	0.961

value of the HLS-EU-PT scale, it is verified that they are all positive and higher than 0.8, ranging from  $r = 0.895$  for “Health care” and  $r = 0.929$  for “Disease prevention”. With the percent variance explained above 60.0%.

Table 4 summarizes the results of Cronbach's alpha coefficients for the different domains that, as observed, oscillate between 0.89 and 0.91, which, according to Pestana and Gageiro<sup>16</sup>, translate into a good internal consistency for the “disease prevention” domain and very good for the remainder. For the global scale, an alpha value of 0.961 was found, which also reveals a very good internal consistency. The split half coefficients, or method of the halves, are good, despite presenting slightly lower indices than the ones observed for the domains that correspond to it. Also, they indicate congruence between the first and second half.

Using the cut-off points used by the authors, 36.9% of pregnant women presented a problematic level of health literacy for the overall HLS-EU-PT scale, and 40.1%, 39.9% and 38.4% a sufficient level of health literacy in the domains of Health Care, Disease Prevention and Health Promotion, respectively.

### Conclusion

Adequate literacy in pregnancy is essential for a healthy pregnancy and includes the development of behavioural, cognitive, emotional and social skills, as well as decision-making and autonomy to make free and informed decisions, and the acquisition of health knowledge in order to diagnose symptoms that may arise complications during the pregnancy.

The results of the present study support the psychometric adequacy of the European Questionnaire on Health Literacy – (HLS-EU-PT) for the population of pregnant women, indicating that it could be used in future trials in order to make known the health literacy of Portuguese pregnant women.

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# Nurses' perception on non-conventional therapies

## Summary

Non-conventional therapies (NCT) still are subject of debate in the health area. Nursing, as a practice in constant social transformation, is also attentive to the emergence of these new therapies. The objective of this study was to evaluate nurses' perception about NCT.

We carried out a pilot study with a convenience sample of 85 nurses. Data was collected by a hetero-administered questionnaire and was analyzed with IBM SPSS V.24.

Most nurses are unaware of or *know little* about Chiropractic, Phytotherapy, Naturopathy and Traditional Chinese Medicine, and are *well aware* of Osteopathy and Acupuncture. About 87% did not have any content that addressed NCT in their initial training, however 76% agreed that some contents should be included in the curricula. More than a half have already tried some NCT as patients, and most were *satisfied or very satisfied* with the therapies; the majority (93%) would recommend their integration into the Health National System. Only 17% completed training in some NCT, but 70% would like to have training in this area. About 45% work or have already worked with NCT professionals and 77% agree that NCT professionals should integrate current health teams.

This pilot study suggests that most nurses have positive perceptions on NCT, in such a time when the regulation of NCT professions presents itself as a new element in the field of health and in multidisciplinary teams and as a training necessity. Nurses' practices and training should follow health trends, including the integration of new therapies.

KEYWORDS: NURSING; NON-CONVENTIONAL THERAPIES.

## Introduction

The effects of the historical evolution of societies are reflected in the field of health, both in what concerns the understanding of health and disease concept, and in intervention practices. The practices resulting from the biomedical model have been creating space for others to emerge and for this contributed, among other factors, the growing globalization and the construction of a networked model of society<sup>1</sup>.

At the end of the millennium, the "health crisis" was identified and defined as the effect of social inequalities within advanced capitalist societies (predominant in the First World), the societies of the so called dependent capitalism (mainly in the Third World), societies derived from the debris of socialism, and the set of Africa's underdeveloped countries, sometimes called the Fourth World<sup>2</sup>.

Nowadays, mass culture and dilution of national and local cultural patterns result in a high degree of homogenization and are translated into a social malaise that has a direct impact on the health of individuals. On the

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other hand, the greater development of ecological awareness has led some populations, especially in urban areas, to take an interest in more naturalistic health practices. The valorization and promotion of health, central to the current biopsychosocial model, are also fundamental elements in the architecture of health policies advocated by World Health Organization (WHO). Greater personal awareness has made the role of individuals more active in the construction of their own health project. The "self-care" culture, that has marked the last decades, has generated an exponential growth in the supply of non-conventional therapies (NCT), which are increasingly sought after. The progressive dependence on technologies, pharmacological interventions' side effects or the lack of humanization / personalization in professional practice also contributed to the implementation of other therapeutic strategies,

generating a greater demand and having a favorable social representation regarding the recognition of its usefulness. Actually, more countries have gradually come to accept the contribution that T & CM can make to the health and well-being of individuals and to the comprehensiveness of their health care systems<sup>3</sup>.

Data from 2013 indicate that in China, for example, there were about 440,700 health institutions offering NCT services, including general hospitals, clinics and health centers, both in cities and in rural areas. About 90% of the hospitals had a Department of NTC for inpatient and outpatient settings and the legislation regulating these services was the same as for conventional health care institutions<sup>3</sup>.

Countries such as Brazil have defined a National Policy on Integrative and Complementary Practices (ICPS) in order to promote knowledge and support the incorporation and implementation of these new practices within the public health system<sup>4</sup>. In this way, the Brazilian Unified Health System provides for access to traditional Chinese medicine / acupuncture, homeopathy, medicinal plants and phytotherapy and social thermotherapy. However, still there are doubts as to what kind of knowledge supports the practice of nurses in the use of ICPS, and what challenges are presented to their applicability in the context of hospital care<sup>5</sup>.

Despite these examples, NCT, due to the novelty they represent, especially in terms of scientific support, have generated several difficulties regarding their appropriation by Health Systems and their use in health institutions, emphasizing the necessary cautions and resistances at various levels.

In Portugal, the publication of Law No. 71/2013<sup>6</sup>, of September 2nd, which regulates the access to professions in the NCT context and its exercise, both in public or private services, constitutes an historical milestone in this area. It regulates Law no. 45/2003<sup>7</sup>, of August 22nd, that addresses the activity and the exercise of NCT professionals' framework, as defined by the WHO and by Ordinance No. 25/2014<sup>8</sup>, of February 3rd. This law also establishes (article 5) that NCT professionals must have a higher education degree, in this case consisting of four years (240 ECTS) study cycle. Therefore, and according to other studies<sup>9</sup>, it is important to analyze the challenges inherent to the acceptance and application of these therapies by nurses, in particular within the National Health System. These challenges become even more pressing considering that WHO defines as one of its key objectives, for the period 2014-2023, to promote the safe and effective use of NCT through the regulation of products, practices and practitioners by increasing knowledge, strengthening safety and quality and regulating and integrating NCT services and self-health care into national health systems<sup>3</sup>.

NCT have been the subject of debate in the health area. Nursing, as a practice in constant social transformation, is also attentive to the emergence of these new therapies. Thus, the objective of this preliminary study was to evaluate the nurses' perception about NCT that are regulated in Portuguese legislation, namely, Chiropractic, Phytotherapy, Naturopathy, Homeopathy, Traditional Chinese Medicine, Osteopathy and Acupuncture: what they think they know about NCT; training in this area; their use of NCT as patients/clients; the representation they have of these therapies; and the integration of these therapies into the NHS.

## Methods

We carried out a descriptive pilot study with a convenience sample of 85 nurses from Vila Nova de Gaia metropolitan area (Portugal). Data was collected using a hetero-administered questionnaire during May 2017, and was analyzed with IBM SPSS V.24.

The sample consisted of 71% females. The majority (79%) of the inquired individuals were aged below 40 years and worked at a hospital (70%). Regarding the number of years of experience in nursing, it ranges from less than 10 (48%) to more than 21 (15%). Only 8% accumulate management functions.

The questionnaire was specifically designed for this study and consists of 10 multiple response questions, and two open-response questions, covering different subjects on NCT such as: knowledge, training, perception, experience and satisfaction as patient, and NCT integration on public health system. The questionnaire also includes other questions to characterize the sample regarding sociodemographic data.

## Results

The objective of this study was to evaluate the nurses' perception about NCT. Results from the descriptive analysis are presented as percentages and/or graphic representations, according to the sequence of the question within the questionnaire.

Regarding the level of knowledge that nurses think to have on NCT, the results indicate that they *reasonably know* or *know well* Osteopathy and Acupuncture therapies and *do not know* or *know little* about Chiropractic, Phytotherapy, Naturopathy and Traditional Chinese Medicine (figure 1).

The majority (87%) did not have any content that addressed NCT in their initial training, which may contribute to the lack of knowledge on these therapies. However, 76% agree that some content should be included in their training.

Results indicate that nurses have already used some NCT as patients/clients and more than half (53%) have already used some NCT as patients; with the exception of chiropractic, the majority were *satisfied* or *very satisfied* with the therapies.

Nurses have a positive perception on NCT. They think they are useful,

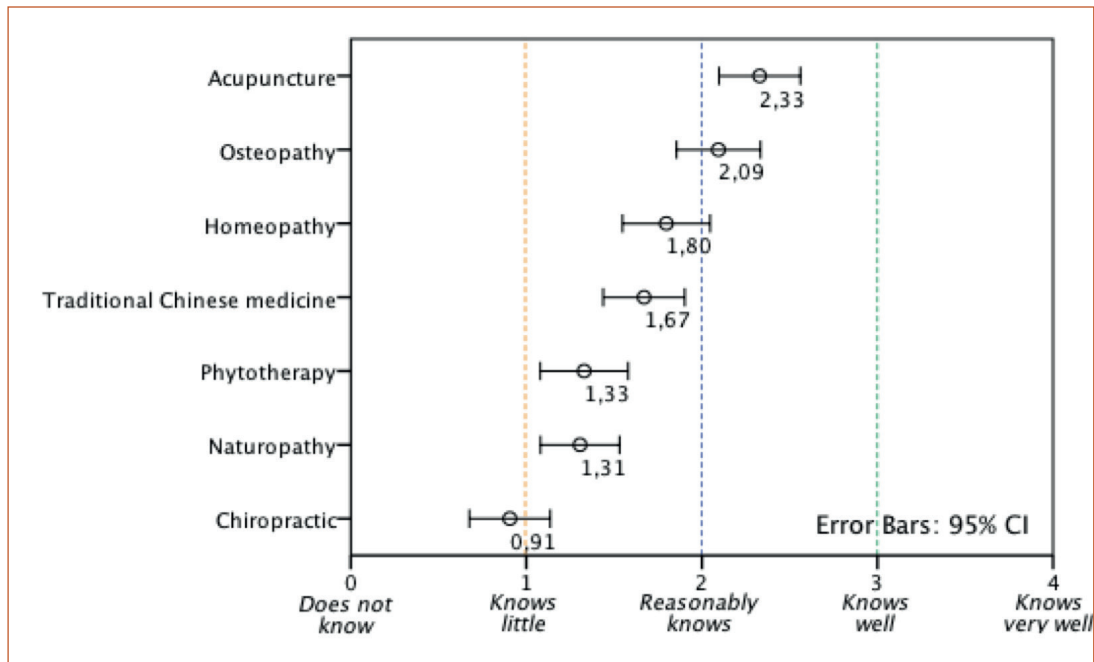


Figure 1. Knowledge on NCT

promote well-being, health and quality of life (figure 2). On the other hand, 89% are unaware of their legal framework.

The vast majority of the nurses (93%) recommends the integration of NCT into the National Health System, especially Acupuncture (83%) and Osteopathy (62%).

Although only 17% of the nurses had undergone some complementary training in NCT, 70% would like to have training in this area. Of these, 79% indicated an interest in Acupuncture, 75% in Traditional Chinese Medicine, 57% in Osteopathy and the remaining areas had less than 35% of interested individuals.

They also agree (77%) with the integration of NCT professionals in the current health teams and 9.45% is actually working (or worked) with these professionals.

## Discussion

Results regarding the level of knowledge that nurses think to have on NCT, indicate that they reasonably know or know well only two of the seven regulated NCT in Portugal, in this case, Osteopathy and Acupuncture, which is in agreement with Gonçalves<sup>9</sup>. This lack of knowledge may, in part, be explained by the fact that the majority did not have any content that addressed NCT in their initial training. Similarly, in Spain<sup>10</sup>, a gap was identified with respect to these areas in nurses' training.

In spite of the lack of initial training on these areas, the majority of nurses agree that some content should be included, indicating their recognition of the need to follow health trends and increase the options of nursing interventions among the caregivers. Similarly, Santos<sup>11</sup>, in her research on this subject, concluded that Nursing Schools should provide with skills to justify the use of these therapeutic resources.

As these therapeutic modalities have a specific rationale, regarding the autonomy of the user in its therapeutic process, the holistic vision of the man and the valorization of health, among other aspects, they also demand specificity in professional training and different strategies have been used to

introduce these contents in nursing training<sup>12</sup>. According to Santos<sup>11</sup>, nurses have already been using NCT (not necessarily those currently regulated in Portugal) principles in their practices, such as modalities of environmental, manipulative, mental-cognitive, energetic and relational nature, and it would be important now to disclose and give visibility to these modalities, legitimizing their therapeutic, social and economic importance. As this author points out, nurses use music, aromas, color, massages, among others, in the development of autonomous practice in different contexts.

In spite of the relative scarcity of literature in the field, we can find several authors who have been concerned with the training of nurses in the NCT area, which can be justified for several reasons: the change of the biomedical paradigm, hegemonic in Western societies and, consequently, in the teaching of health care, which focuses attention on the body and external causes, versus the integrative, holistic paradigm that focuses attention on the body-mind and the more subjective emotions and structures addressed by NCT;

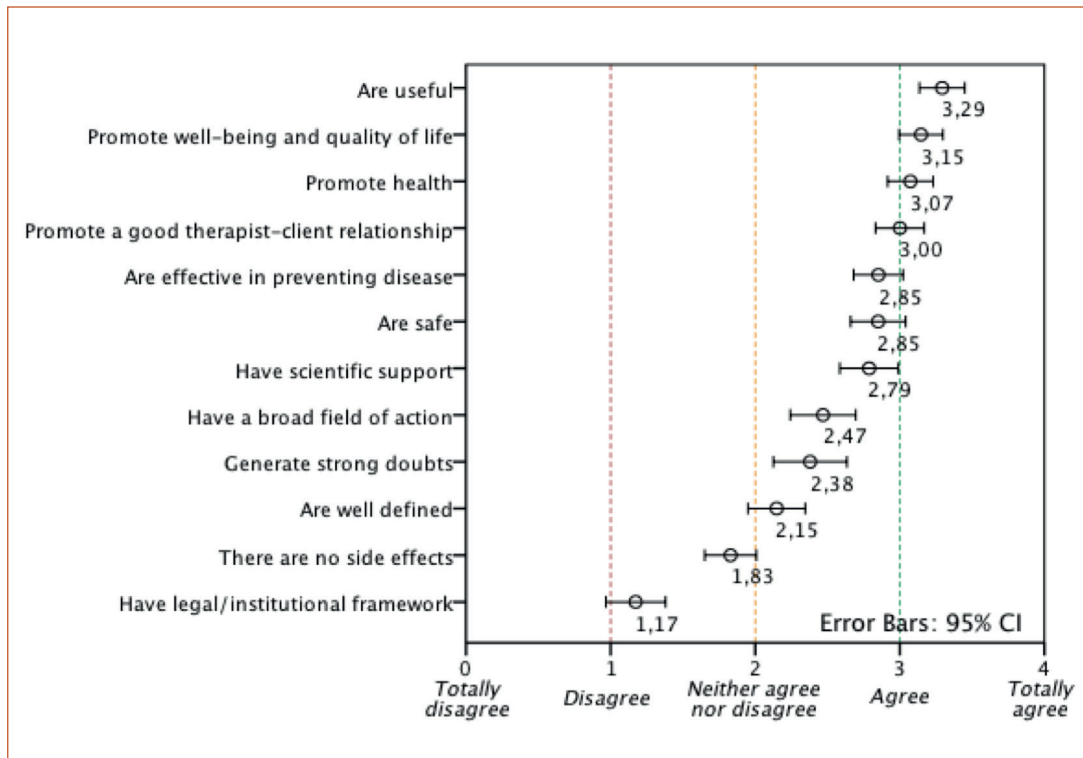


Figure 2. Perceptions on NCT

traditional teaching methodologies, compartmentalized in teaching the biomedical model versus the need for qualitative methodologies that lead to the comprehension of the human being in an integral way, in NCT. Other issues deserve deep reflection when dealing with the training of Nurses in the NCT, related to NCT regulation in nursing practice, such as: integration of biomedical knowledge and NCT; the development of teamwork and the skills of each professional; the NCT as basic (graduate) or complementary (postgraduate) training.

These challenges become even more pressing when WHO defines as one of its key objectives for the period 2014-2023, to support States in promoting the safe and effective use of non-Conventional Therapies through regulation, research and integration of products, practices and professionals in Health Systems<sup>3</sup>.

Some of these issues are being dealt with in Portugal by new legislation, but it still does not provide answers to many of the issues that arise. In accordance with Pennafort<sup>13</sup>, our results show that nurses are unaware of this legal framework. Nevertheless, they have a positive perception on NCT and consider that they are useful, promote well-being, health and quality of life.

The practice in health is collective and complex, the Professional Orders or equivalents are key elements in this important debate. Training institutions, as drivers of new knowledge, of nursing transformation and evolution, also, as pointed out by the authors mentioned above<sup>10,11,12</sup>, are responsible for the training of professionals that respond to the current exigencies in the health area and for the search for new models of care that can be achieved through NCT approaches.

In our study, we did not evaluate the use of NCT in professional practice, but we verified that nurses have already used some NCT as patients/clients, have already completed complementary training in this area and would like to have training. These results are in accordance with other studies<sup>14</sup>, where

it was identified that nurses need to improve their knowledge and skills about NCT to be more confident to assist patients in integrating conventional treatment and NCT for cancer management.

These results also demonstrate the interest and valorization as therapeutic practice of these areas and reinforce the importance of Nursing Schools to provide training that builds competences on NCT. These data are in line with the most recent publications<sup>5,11</sup>, with the national legislation that regulates these therapies and the World Health Organization guidelines.

Indeed, more countries have gradually come to accept the contribution that T & CM can make to the health and well-being of individuals and to the comprehensiveness of their health care systems<sup>3</sup>. Our results indicate that nurses agree with this trend, namely in what concerns integration of NCT into the National Health System and the integration of NCT professionals in the current health teams.

## Conclusion

Most of the participants in this study agree with the integration of NCT in initial nurse training, and not only have experience working with professionals in these areas but also recommend their integration in health care teams. They are, however, unaware of the legal framework of NCT, although they recognize their usefulness and role in health promotion. Among the NCT, nurses demonstrated better knowledge, and even use as clients, of acupuncture, traditional Chinese medicine and osteopathy, and were satisfied with the results. They also expressed their desire to be trained in these areas and recommend their integration into the national health system.

The practices and training of nurses should follow the trends in the health area, namely the integration of new therapies. This study leads to the conclusion that most nurses have a positive perception of NCT, which is particularly pertinent at a time when the regulation of professions in the NCT area presents itself as a new element in the field of health and in multidisciplinary teams and while a new need for training. In this way, Nursing Schools should be concerned with these issues and provide the integration of Nursing in the current NCT debate.

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# Risk factors for acute coronary syndrome

## Systematic review of the literature

### Summary

**INTRODUCTION.** Acute Coronary Syndrome (ACS) is a cardiovascular emergency with high morbidity and mortality rates. The objective of this study is to evaluate the evolutionary trend of modifiable and non-modifiable risk factors for ACS.

**METHODOLOGY.** The Cochrane methodology was applied. We included studies that evaluated risk factors, electrocardiographic and clinical presentation of ACS. Two independent reviewers performed the critical evaluation, data extraction and synthesis.

**RESULTS.** We included 32 observational studies ( $n = 1299381$ ), from the American, African, Asian, European and Oceanian continents, since 1994 to 2014. It was verified that there are no significant changes in the prevalence of risk factors Age and Gender, with age > 65 years exceeding 50% in only 2 of the 10 studies that looked at this variable. The most prevalent gender is male (> 60%) and family history shows an increase in percentage with the course of the studies.

**DISCUSSION.** Modifiable risk factors go through the timeline with some homogeneity, with hypertension being the most prevailing, followed by smoking, dyslipidemia and Diabetes Mellitus. Smoking tends to be more frequent in younger patients, and hypertension, dyslipidemia and diabetes mellitus are more frequent in the elderly patients. Obesity is the risk factor least prevailing and also the least studied.

**CONCLUSIONS.** All the 32 studies present very similar results, regardless of the date of data collection and the region/country where the data was collected, showing a clear cause-effect relationship between these risk factors and ACS.

**KEYWORDS:** ACUTE CORONARY SYNDROME; REVIEW LITERATURE AS SUBJECT; RISK FACTORS.

### Introduction

Acute Coronary Syndrome (ACS) is a cardiovascular emergency that results from a process of acute myocardial ischemia after occlusion of a coronary artery. This occlusion may be total or partial, temporary or permanent, and it will be because of these characteristics that will present electrocardiographically: with ST segment elevation, in this case it is total and permanent, without elevation of the ST segment, which would mean a partial and permanent occlusion. In addition to these two electrocardiographic presentations, ACS may present as Angina pectoris, which requires a partial and temporary occlusion to occur<sup>1</sup>.

Cardiovascular disease is an important cause of death and morbidity, which is predicted by 2020 it will account for 40% of deaths<sup>1</sup>. Angina pectoris may present as stable when it comes to acute pain in the thoracic region that may radiate to the left arm or both arms, around the chest, neck, or jaw and disap-

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pears a few minutes after the cessation of effort and unstable, essentially of intermediate severity between the first mentioned and acute myocardial infarction, in which the clinical event tends to evolve, becoming non stable, this is, to evolve to a regression of symptoms, stable angina, myocardial infarction or sudden death<sup>2</sup>.

The obstruction of a coronary artery by a thrombus interrupts the normal blood flow necessary for a good and necessary tissue perfusion, resulting in acute myocardial infarction (AMI). The presence on the electrocardiogram (ECG) of an elevation on the ST-segment is indicative of acute and complete occlusion of a coronary artery. In patients who do not have ST elevation but who nevertheless present with ACS-compatible symptoms and serum necrosis markers, they should be diagnosed with non-ST elevation myocardial infarction<sup>3</sup>.

The AMI is a recurrent diagnosis in industrialized countries<sup>3</sup>, the result of a higher average life expectancy in these countries, which inevitably is also associated with existing risk factors for this phenomenon that may occur, such as Diabetes Mellitus, Hypertension, Dyslipidemia, smoking and sedentary lifestyle<sup>4,6</sup>.

The risk factor is an “innate or acquired characteristic of an individual, which is associated with an increased likelihood that he or she will suffer or die from a particular disease or condition, and presents four fundamental uses: the prediction of disease, determination of disease etiology, diagnosis of disease and prevention of disease”<sup>7</sup>. In cardiovascular disease there are modifiable lifestyle habits such as smoking, dyslipidemia, obesity, sedentary lifestyle, diabetes, alcohol abuse, and non-modifiable characteristics such as age, gender, and family history<sup>8</sup>. All identified risk factors have an objective impact on the likelihood of a person having or not having a cardiac clinical event. Therefore, with this study, we describe the reality related to risk factors in Acute Coronary Syndrome, and whenever possible, seek to explain its historical evolution.

**Methodology**

**Problem statement**

In order to systematize the state of knowledge about the prevalence and respective impact of the different risk factors in the Acute Coronary Syndrome, a study was carried out based on the methodological principles of a systematic review of the literature. The review followed the methodology proposed by the Cochrane guidelines<sup>9</sup>.

**Research questions**

Accordingly, as to the elaboration of the research question, the PI [C] OD method was used: “What modifiable and non-modifiable risk factors represent a higher prevalence in people with Acute Coronary Syndrome?”.

**Purpose of the study**

Based on the analysis of the theoretical assumptions, the following objective

was defined to evaluate the evolutionary tendency (1994-2014) of the presence / absence of modifiable and non-modifiable risk factors in the genesis of ACS.

**Research methods**

The research strategy only included published studies and was carried out in three moments. In the first phase, a naturalistic research was carried out, limited to the PubMed database. Then, a second search using all the keywords and descriptors identified, in all the included databases. Finally, the bibliographic references of all identified articles were analyzed to identify additional studies. Written studies in English, Portuguese and Spanish were considered to be included in this review and it covered the publication period between the 1st of January 2000 and 31st of March 2016.

Methodological quality was assessed by two independent reviewers using the JBI Critical Appraisal Checklist for Cohort and Case-control

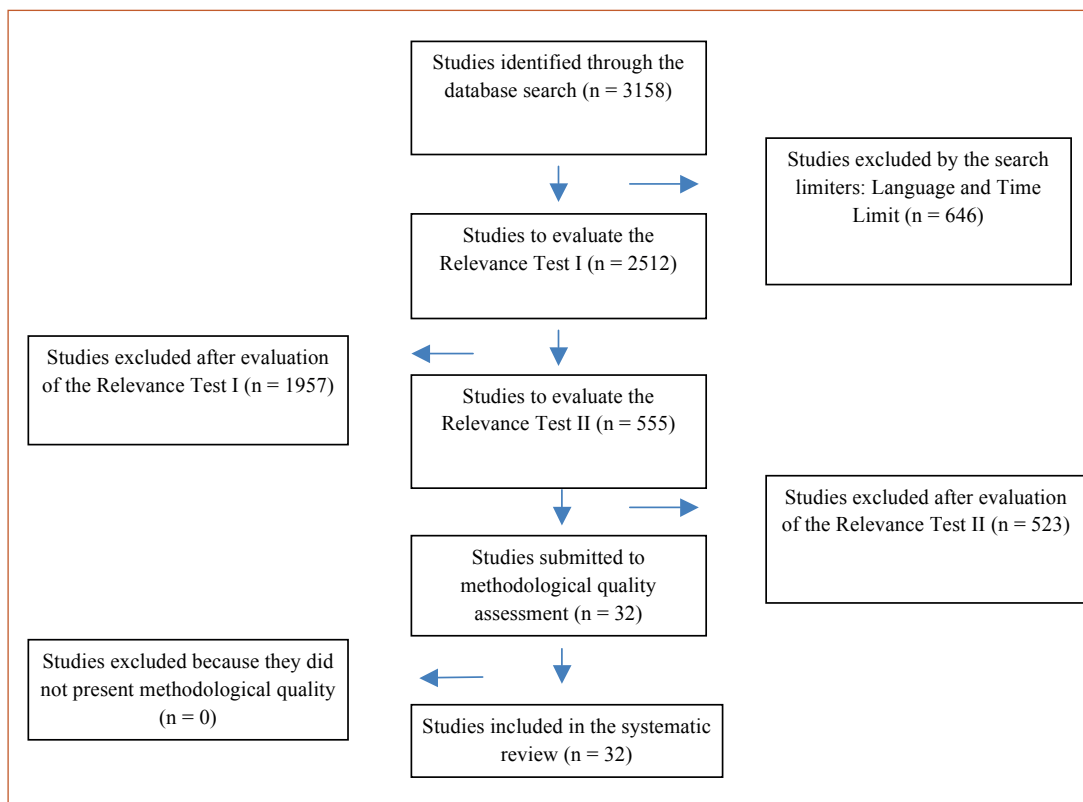


Figure 1. Flowchart of the study selection process

Studies Data collection (year)	Methods and Participants	Age > 65	Male	Fam Hist	DM	HTN	Dysl	Smok	Ob	STE- ACS	NSTE- ACS	K > 1
Rogers et al. (2000) (1994-1999) <sup>11</sup>	It studies temporal trends in the treatment and outcome of AMI through the National Registry of Myocardial Infarction - 1161550.		61.6	28.7	27.1	52.6	27.7	27.3				
Steg et al. (2002) (1999-2000) <sup>12</sup>	It describes the epidemiological data, treatment and results found in people with ACS - 10709.	55	65.7		23.8	57.6	42.5	56.5		31.9	27	
Hasdai et al. (2002) (2000) <sup>13</sup>	It studies the characteristics, treatments and results of people with ACS in Europe and the Mediterranean - 9798.		67.5	28.1	23	58.5	50.8	57.6		42.3	51.2	20.3
Rosengren et al. (2005) (2000-2001) <sup>14</sup>	It studies the hypothesis that the risk factors may be related to the severity of ACS - 10253.	1	68		24	58	47	30	19			
Bettencourt et al. (2004) (2001-2002) <sup>15</sup>	It studies, retrospectively, all patients consecutively hospitalized for ACS- 903.		67.9		26.8	61	38.2	40		29.7	42.3	
Castela et al. (2003) (1998-2002) <sup>16</sup>	It studies the clinical and angiographic characteristics and their evolution ACS - 521.		75	12.3	30.5	58.9	46.1	34.9	6.9			
García-Castillo, et al. (2005) (2002-2003) <sup>17</sup>	It studies the clinical characteristics, therapeutic approaches and hospital outcomes of people with ACS in Mexico - 8098.		72		42	55	27	64		56.2	43.8	
Santos et al. (2006) (2003) <sup>18</sup>	It studies the baseline characteristics, treatment adopted and mortality in people with clinical suspicion of ACS - 860.	44.6	58.3	35	31.6	78.1	53.1	26.5		9.1	27.7	
Mandelzweig et al. (2006) (2004) <sup>19</sup>	Analyze the management of ACS in Europe and the Mediterranean and the adherence to the guidelines of the first Euro Heart Survey on ACS. 4 years before - 6067.		71	31.2	24.1	57.4	47.6	62.9		49.5	50.5	20
Ranjith et al. (2005) (1996-2002) <sup>20</sup>	To study the differences in relation to the main risk factors and the clinical results in Asian Indians of South Africa with ACS - 2290.	21	72.1	49.3	34.8	37.3	68.1	62.7	14.1	83	13	

## METHODS, PARTICIPANTS CHARACTERISTICS, RISK FACTORS, CLINICAL PRESENTATION AND ELECTROCARDIOGRAPHY I

1

Xavier et al. (2008) (2002-2005) <sup>21</sup>	To study the characteristics, treatments and results of people with ACS who were admitted to hospitals in India - 20468.	13.3	76.4	19.1	30.4	37.7		40.2	35.5	61	39	15.8
(Esteghamati et al. 2006) (2002-2005) <sup>22</sup>	To determine the prevalence of diabetes and other risk factors in people with ACS - 514.		64.2		30	90.9	49	42				
Robertson et al. (2014) (2005-2005) <sup>23</sup>	It studies patients with moderate to high risk of developing NSTEMI-ACS after angiography or revascularization - 13819	61	70.6	51.4	27.4	65.6	56	28.5				
Stockins et al. (2011) (2005-2006) <sup>24</sup>	To study the practices, treatments and risk factors in patients with NSTEMI-ACS - 233.		69.4	22	33	84	54	68	27	1	32	
Katayama et al. (2008) (2001-2006) <sup>25</sup>	It studies the etiology of the "smoking paradox" with special interest in its association with inflammation - 528.		68.0	33.5	34.5	56.3	42.4	43.9				42.8
Gaspar A et al. (2009) (2004-2007) <sup>4</sup>	To analyze the clinical characteristics, modes of presentation, treatments, angiographic data and prognosis - 1228		72.3		27.6	62.8	46.7	36.6		51.1	48.9	23.5
Nishiyama et al. (2010) (1993-2007) <sup>26</sup>	It studies the relationship between risk factors and the incidence of AMI in Japan - 6222.		67.1	19.2	27.1	58.1	33.6	41.2	28.3			
El-Menyar et al. (2011) (2007) <sup>27</sup>	It studies the prevalence and impact of risk factors in people with ACS - 6704.	39.3	75.6	14	40	49	32	38	27	39.1	61	

Male - Male; Fam Hist - Family History; DM - Diabetes Mellitus; HTN - Hypertension; Dysl - Dyslipidemia; Smok - Smoking; Ob - Obesity; NSTEMI-ACS - Non ST segment elevation acute Coronary Syndrome; STE-ACS-ST-elevation acute Coronary Syndrome; K > 1 - Killip > 1

studies, as indicated, and after discussion and consensus among reviewers "Quality studies" were assumed to be those that would gather at least six affirmative answers in ten<sup>10</sup>.

Two independent reviewers extracted data using the data extraction form "The Joanna Briggs Institute data extraction for systematic review of experimental / observational studies" and included the number of samples, the characteristics of the participants and their electrocardiographic presentation.

Quantitative data was grouped using Microsoft Excel software.

## Findings

As shown in Figure 1, the survey identified 3158 potentially relevant studies, 646 were excluded by language and time-bound limiters. Of the 2512 result-

ing from this exclusion, 1957 were excluded after applying the Relevance Tests I and 523 after applying the Relevance Test II. The flowchart of the study selection process is described in figure 1. The thirty-two studies resulting from this selection process outweighed the methodological evaluation performed with the JBI Critical Appraisal Checklist for Cohort and Case-control studies. In this review, thirty-two studies total-

Studies Data collection (year)	Methods and Participants	Age > 65	Male	Fam Hist	DM	HTN	Dysl	Smok	Ob	STE- ACS	NS- TE- ACS	K > 1
Lemos et al. (2010) (2007-2008) <sup>28</sup>	To study the risk factors of people with ACS who entered the emergency service of Porto Alegre. Brazil - 152.		63.8	56.6	40.1	75.7	44.7	39.5	77	14.5	50.7	
The ACCESS Investigators (2011) (2007-2008) <sup>29</sup>	To study the epidemiology, practice patterns and results of people hospitalized with ACS in Africa, Latin America and the Middle East - 11731.	21	73.5	31.8	35.9	56.7	41.5	40.3	27.4	46.1	52.8	18.5
Piegas et al. (2013) (2003-2008) <sup>30</sup>	It studies the clinical characteristics, treatment and hospital evolution of people with ACS, using the Brazilian Registry of Acute Coronary Syndrome - 2693.		67.9	43.7	27.8	69.8	45.7	62.7	28.2	35.3	19.6	22.7
Kimeu & Kariuki (2016) (2007-2009) <sup>31</sup>	It retrospectively studies the risk factors, clinical characteristics, treatment and outcomes of persons with AMI admitted to the Intensive Care Unit of the Nairobi hospital - 65.	42.2	87.5	8	25	71.9		35.9		60.9	39.1	
Suwaidi et al. (2012) (2008-2009) <sup>32</sup>	It studies the prevalence and the effect of the different modalities of smoking (Smoking patterns) in patients with ACS - 7930.		78.7	10.2	19.2	47.3	32.7	52.9		45.6	30.1	23
Lu & Nordin (2013) (2006-2010) <sup>33</sup>	To study the impact of ethnicity on the occurrence of ACS among high risk groups in the population of Malaysia - 13591.		75.7	10.9	42.5	61.2	33.8	55.9		46.9	28.2	
Shavadia et al. (2012) (2008-2010) <sup>34</sup>	To study the epidemiological characteristics of people with ACS in sub-Saharan Africa - 111.		75.7	16.2	37	48.7	14.4	23.4		55.9	44.1	10.8
Gautam et al. (2013) (2009-2010) <sup>35</sup>	To study the spectrum of ACS and risk factors for cardiovascular disease in people admitted to the Intensive Care Unit of a University Hospital in Nepal - 57.	50.9	63.1	26.3	43.6	36.9	26.3	50.9	15.8	42.1	31.6	
Goulart et al. (2013) (2009-2011) <sup>36</sup>	It describes the epidemiological characteristics of people with ACS included in the ERICO (Strategy of Registry of Acute Coronary Syndrome) - 738.	42.5	58.5	28.1	39.7	76	55.5	67.2		28.2	39	

METHODS. CHARACTERISTICS OF PARTICIPANTS. RISK FACTORS. CLINICAL AND ELECTROCARDIOGRAPHIC PRESENTATION II

Andrikopoulos et al. (2012) (2011) <sup>37</sup>	To study the epidemiological characteristics, the standard of treatment and the outcome of people with ACS in Greece - 418.	78	29.7	27.5	67.9	57.4	54	44.7	34.2	
Brunori et al. (2014) (2011-2012) <sup>38</sup>	This cross-sectional study seeks to identify the relationship between risk factors and the different presentations of ACS in hospitalized patients - 150.	66	60.7	28.7	66.7	40		21.4	72.7	12.7
Honda et al. (2014) (2013) <sup>39</sup>	It studies the association between smoking and prognosis in the treatment of Japanese people with ACS including subacute stent thrombosis - 266.	69.3		28.6	60.9	47	68.4	73.7	26.3	21.1
Bacci et al. (2015) (2012-2013) <sup>40</sup>	To study the profile of heart disease in hospitalized patients with ACS undergoing coronary angiography in the emergency room - 131.	64.8	58	19.8	76.3	22.9	58	57.3	22.1	
Marino et al. (2016) (2013-2014) <sup>41</sup>	To study the profile of people with ACS in the period that preceded the implementation of the program implemented in the Northern Region of Minas Gerais, Brazil, with the aim of reducing hospital morbidity and mortality-583.	60	40.3	23.8	79.2	43.7	19.9	35	12.5	

Male - Male; Fam Hist - Family History; DM - Diabetes Mellitus; HTN - Hypertension; Dysl - Dyslipidemia; Smok - Smoking; Ob - Obesity; NSTEMI - Non ST segment elevation acute Coronary Syndrome; STE-ACS - ST-elevation acute Coronary Syndrome; K > 1 - Killip > 1

ing 12,9381 people with ACS were included, as well as the relevant information related to the characteristics of the participants, risk factors and clinical and electrocardiographic presentation are presented in table 1 and table 2.

The thirty-two studies resulting from this selection process outweighed the methodological evaluation performed with the JBI Critical Appraisal Checklist for Cohort and Case-control studies. The thirty-two studies included in this review included 12,99381 people with ACS and relevant information related to participants' characteristics, risk factors and clinical and electrocardiographic presentation are presented in table 1 and table 2.

### Meta-analysis of prevalence

#### Modifiable risk factors

The following figures show all the meta-analyses performed regarding modifiable risk factors. The results are presented by outcome, followed by a descriptive and inferential analysis. The statistical analysis showed that the most prevalent are: Dyslipidemia (RR = 0.422; CI 95% = 0.378-0.467) Hypertension (RR = 0.618; CI 95% = 0.589-0.646), Diabetes Mellitus (RR = 0.303; CI 95% = 0.283-0.322), Smoking (RR = 0.467; CI 95% = 0.411-0.524), Obesity

(RR = 0.270; CI 95% = 0.220-0.320).

Arterial Hypertension (61%) is the most prevalent risk factor, followed by smoking (46%), dyslipidemia (42%) and Diabetes Mellitus (30%) and it tends to be more frequent with aging, in contrast with smoking habits, in which ACS is more common in younger people<sup>4,11-15</sup> (figure 2).

#### Unmodifiable risk factors

The following figures show all the meta-analyses performed regarding non-modifiable risk factors. The results are also presented by outcome with the respective statistical analysis that showed that the most prevalent

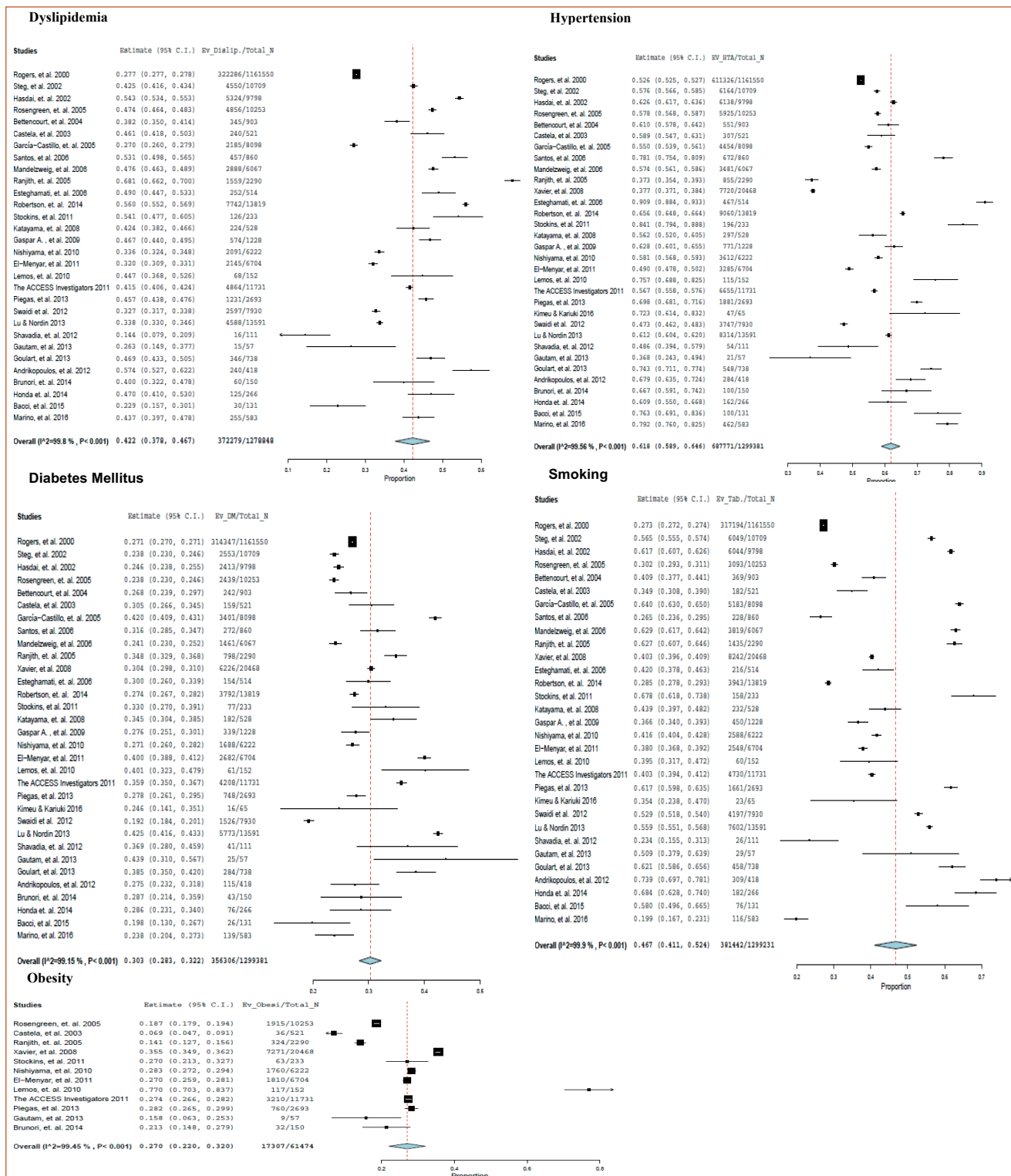


Figure 2. Meta-Analysis of Prevalence from Modifiable Risk Factors

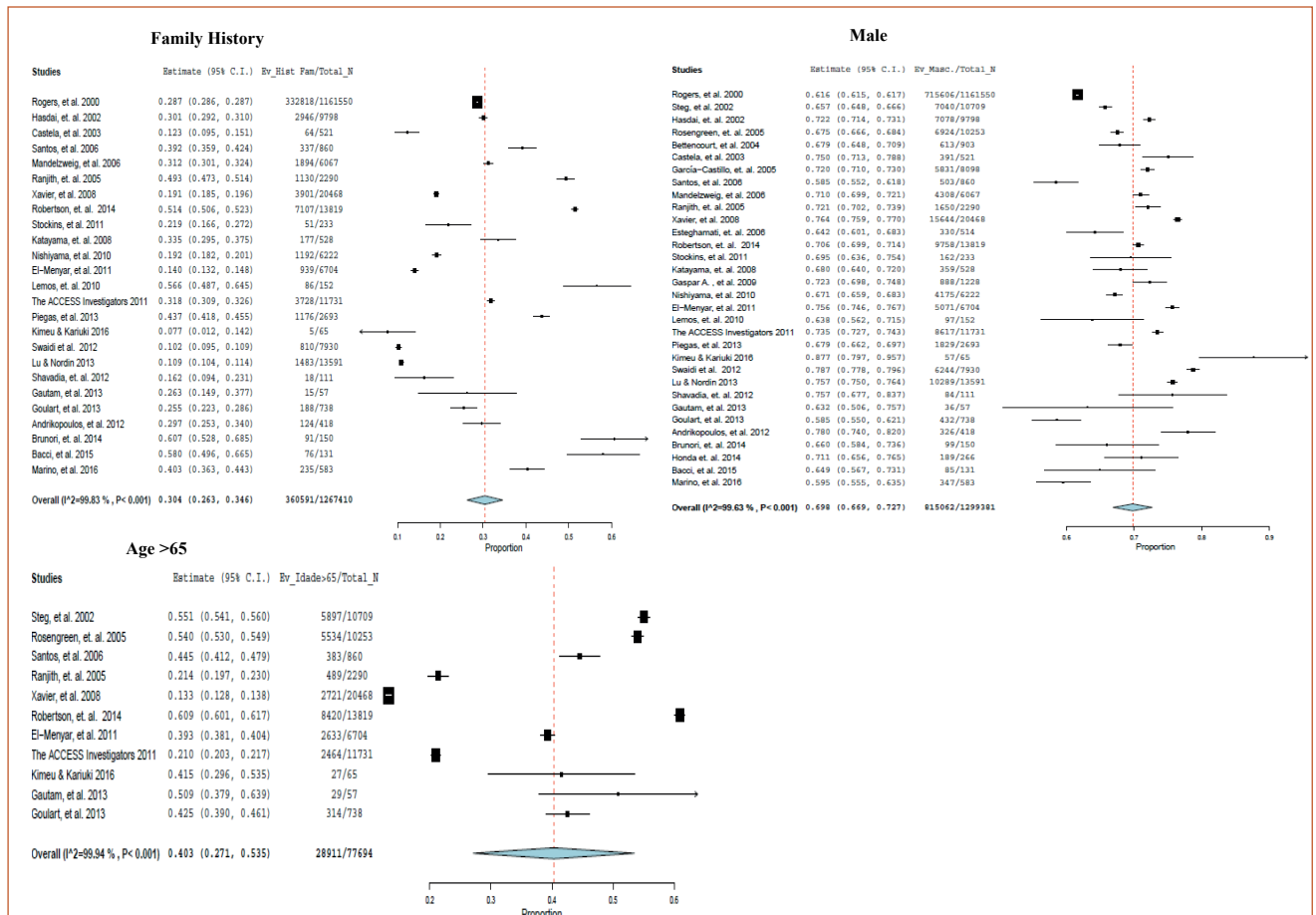


Figure 3. Meta-Analysis of Prevalence from Unmodifiable Risk Factors

are: Family history (RR = 0.304; 95% CI = 0.263-0.346) Male (RR = 0.698; 95% CI = 0.669-0.727), Age > 65 (RR = 0.403; 95% CI = 0.271-0.535) (figure 3).

It is possible to verify that practically 70% of people with ACS are male, 40% are over 65 years old and 30% have a family history of cardiovascular disease. The heterogeneity indexes are in all the meta-analyzes very high, partially explained by the fact that the studies included in this systematic review refer to different time periods, that is, from the end of the XX century until 2014. We can also verify that the included studies include countries of the different continents of the globe.

### Discussion

We tried, with this study, using a systematic literature review, to get to know in detail the Acute Coronary Syndrome etiology, to understand the presence/absence of the modifiable and non-modifiable risk factors in this clinical event, as well as explain its historical evolution. To achieve these goals, data were gathered and organized according to its collection date, instead of the publishing date. The studies included in this review refer the risk factors, modifiable and non-modifiable, as well as their clinical presentation, using the Killip classification, and their electrocardiographic presentation, with or without ST elevation. Studies show also the population from the American, African, Asian, European and Oceania Continents, and countries as Brazil, Chile, Mexico, Nepal, Kenya, Portugal, Greece, Germany, Japan, India, Iran, Malaysia and others. The collected data refer since the end of the 20th cen-

ture till the year of 2014, and allow us to discuss the significance of the changes related to the implementation of health promotion strategic measures, during a twenty years period.

With this study, we should be able to understand the work that the health professionals should develop to reduce the mortality and morbidity levels in the cardiovascular disease.

Observing the non-modifiable risk factors, as age, sex and family history, we can understand that during all the selected time period, and considering the different space contexts in which they were gathered, there are no significant changes, which means that the masculine sex is, in practically all the studies above 60% of the total population, affected by ACS, and in many of them, above 70%.



Concerning the age, we can conclude, from the studies that analyze this criteria, that only in three is shown that the group of people above 65 years old is superior to 50%<sup>15-17</sup>, being inferior to 50% in all the other studies. Is also possible to verify that since the end of the last century till the last concluded study, there is no evidence of significant changes in the average age on which an individual gets ACS, however that is an average, a statistic tool extremely vulnerable to extremes, so the conclusions should be careful. Still, it is challenging and significant to verify that there is a relative homogeneity in this values, independently of the analysed studies. In the Andrikopoulos et al. (2012) study, authors compare the obtained data with a study made five years before, also in Greece, named HELIOS, and concluded that in average, the age on which an individual gets ACS changed from 68 to 63.9 years old. This deserves a deep analysis, as the modifiable risk factors increased their prevalence from one study to the other, because in HELIOS the HTN and dyslipidemia prevalence, for example, increased from 59% and 50% to 68% and 57% respectively.

Regarding family history, we can observe that from the year 2000 to 2016 there was an increase in the prevalence of this risk factor in people with ACS<sup>18,19</sup>. This confirms the statement who alert for the growing of the cardiovascular disease in the global population, what brings disease history for the coming generations<sup>1</sup>.

The analysis of the presence of modifiable risk factors, allowed us to verify that they walk through in a homogeneous way, as well as the non-modifiable risk factors, what means that the arterial hypertension is clearly and repeatedly the most prevalent risk factor, followed by smoking, dyslipidemia and Diabetes Mellitus.

The studies that analyzed the impact of smoking in ACS, forming for this analysis two groups concerning smoking habits, concluded that in the smoking people group, the arterial hypertension (with stronger impact) and the other risk factors are significantly less prevalent when compared with the non-smoking people group<sup>11-15</sup>. Analyzing all the risk factors in the total group of people with ACS, this connection is not so obvious, because HTN is the most important risk factor. This data allows us to conclude that smoking anticipates ACS in approximately ten years, as the other risk factors are not so obvious as they are in the non-smoking group of people, who will only get, in average, this clinical event ten years later. Is also important to note that in a global level, the HTN prevalence seems to be in 30-45% of the general population, with a raise related to age<sup>20</sup>, confirming what was described above, so, with exception of the smoking habit, all the other modifiable risk factors tend to increase its prevalence with age.

It wasn't this study's objective to analyze the medical evolution implemented in the ACS treatment, however, after twenty years, the medicament strategies used to decrease mortality and morbidity associated to myocardium ischemia have suffered a considerable evolution<sup>19</sup>, and it is possible to verified, from 1990 to 1999, an improvement in the time of administration of the intravenous thrombolytic therapy, an increase in the primary angioplasty and consequent reduction of the internment and mortality days, from 8.3 to 4.3 days ( $p = 0.0001$ ), and 11.2% to 9.4% ( $p = 0.0001$ ), respectively. What we see, however, considering that the implemented clinical cares in ACS treatment seem to be more adequate and with better results, is that this improvements are not so clear in health promotion, and in the disease prevention, because the results found in this studies show that the modifiable risk factors didn't suffer big changes, and that its implementation could substantially reduce the prevalence of this cardiovascular disease. This two fundamental public health pillars, associated to the best clinical practice, would

result for sure in much more satisfactory results, by reducing the present risk factors and consequent increase in the age of people with ACS. So, we believe that the translation of this improvement would also result in a decrease of the acute myocardium infarct prevalence in the population.

In the majority of the analyzed studies, there is clearly a focus directed to the investigation of the treatment, and what this data unveil to us, is that public health lacks essentially the primary care intervention. The implementation of prevention measures for cardiovascular disease and the encouragement for healthy behaviors might be a way to develop in order to improve these results.

Data obtained show us also that obesity is the less prevalent risk factor. This phenomenon is observed in all the studies, with only one exception<sup>21</sup>, that presents unusually high obesity levels, when compared with the other studies, this is due to the inclusion by the authors of the excess of weight in obesity Body mass index (BMI)  $> 25 \text{ kg/m}^2$ , being this a methodological option. In this review we tried to include in obesity only the Body mass index (BMI)  $> 30 \text{ kg/m}^2$ . WE verify that the same study identifies high taxes of sedentary lifestyle, giving them high responsibility for cardiac ischemic events. It is known that physical exercise is recommended as cardiac disease prevention, while the sedentary lifestyle, on the other hand, is understood as an important cardiovascular risk factor, and once combined with high analytic cholesterol values, arterial hypertension and smoking habit, the probability of coronary acute events increases considerably<sup>6</sup>.

However, we cannot analyse the impact of sedentary lifestyle and physical exercise in the increase or decrease of ACS, as this was not analyzed in the different studies included in this literature review.

According to the guidelines relative to the arterial hypertension treatment from 2013, the increase of

the relative risk associated to over-weight is higher in younger individuals<sup>20</sup>.

Regarding Diabetes Mellitus, in function of its strong association with the cardiovascular disease, it is understood by the health professionals that there should exist a strong investment in the secondary prevention, even if these patients have never had a vascular event, because the probability of an individual with diabetes, without coronary disease antecedents suffering ACS is similar to the probability observed in non-diabetic patients but with coronary disease antecedents<sup>22</sup>. In our study, the Diabetes Mellitus prevalence is obvious in people with ACS, and this evidence doesn't suffer big changes related with time and geography, showing that this is a global problem and, in a certain way, timeless and unsolvable.

It is also important to say that, according to the Guidelines for the Management of Arterial Hypertension from 2013, the risk of getting ACS might be even bigger in individuals with social problems and who belong to ethnic minorities, in individuals with high glucose levels when fasting and/or unusual glucose levels in people not recognized as diabetic and in individuals with high levels of triglycerides, fibrinogen, apolipoprotein b, lipoprotein levels (a) and high sensitivity C-reactive protein<sup>20</sup>.

Regarding clinic and electrocardiographic representation it is possible to see that the STE-ACS has much more marking incidence levels than NSTEMI-ACS. All studies included in this review do not contemplate, naturally, people who died in the pre-hospital period, because the studies were designed for the in-hospital context, so, we don't know if the group of people who were not studied would have shown the same results of this studies. On the other hand, we don't know if the absence of electrocardiographical elevation of the ST segment delays or even turns it impossible to see ACS, and if because of that, this people end up not being included in the studies, dying or following other path than the other people included in the studies. Even though, it is easy to understand that ACS victims included in the studies shown more usually elevation of the ST segment.

Regarding Killip classification, is possible to verify that it approaches 20% in the majority of the studies, there were no significant changes during the year.

## Conclusion

This review's objective was to systematize the Coronary Acute Syndrome's risk factors. The used methodology has, however, some limitations, as it gathers studies that go back to the XX century, when clinical intervention was clearly different from now and also because it analyses studies that cover different countries in the world. The conclusions should be strictly selected, due to the existent limitations. However, surprisingly, we verified that the studies show very similar results, independently from the date and country of the data collection. This allow us to conclude that, concerning the risk factors, there is still a long way to cross, as the individual prevention measures and the assistance therapeutic interventions, do not lead to significant positive changes in the observed clinical findings.

The arterial hypertension is the most prevalent risk factor, followed by smoking, the Diabetes Mellitus and Dyslipidemia, tending to be more usual with aging, instead of what happens with smoking, which is more frequent in Coronary Acute Syndromes in younger people.

The most common electrocardiographic presentation is ACS with ST segment elevation, and in approximately 20% of the studied population it is presented with a Killip > 1 classification.

It seems clear to us that, more than a temporal association, there is a big causal relationship in the modifiable and non-modifiable risk factors,

as well as between smoking and ACS in younger individuals, and arterial hypertension, Diabetes and dyslipidemia in older people.

The therapeutic and chirurgic approach is offering better answers to the population, translated in better survival indexes, however, it seems clear to us that the introduced campaigns to discourage the smoking habits in children and youngsters and the campaigns to reduce smoking in adults and elder people should continue to be a priority in health politics. Prevention and control of pathologies like Arterial Hypertension, Diabetes Mellitus and Dyslipidemia should deserve special attention from nurses, due to their strong causal relationship with Acute Coronary Syndrome. The need to keep a transversal education to all society regarding signs and symptoms of ACS and the most recommended acting method, should also be a priority.

With this review, we find particularly important to consider the risk factors' influence, when isolated or associated, in the management of ACS treatment.

Explaining with more detail the relationship between the different possibilities of association between the different ACS risk factors, using prospective studies, would contribute to a better intervention from the health professionals, namely nurses, in health promotion and prevention of the disease, in the search of effective earnings in health, resulting in less life years lost, better quality of life and less costs in healthcare.

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# TransCoCon Project

DEVELOPING MULTIMEDIA LEARNING FOR TRANSCULTURAL  
COLLABORATION AND COMPETENCE IN NURSING

2017-2-UK01-KA203-036612

## Main Goal

TransCoCon will facilitate learning relating to professional values in transcultural healthcare for nurses through developing five sustainable Reuseable Learning Objects (RLOs) and associated multimedia for blended learning.

## Execution

01-09-2017 until 31-07-2020

## Overall budget

€ 234.755,00

## Agency

Erasmus+ UK National Agency

## Partners

- » The University of Nottingham (UK) » Fachhochschule Bielefeld (Germany)
- » Escola Superior de Enfermagem do Porto (Portugal) » Hogeschool Gent (Belgium)
- » St. Angela's College (Ireland)

# Explanatory approach to the grounding of the professional nursing practice

## Summary

**INTRODUCTION.** In the current health care environment, the needs of the population provided the perfect opportunity for nurses to (re)define their practice and professional career. Within this framework, this study aimed thus at identifying the bases that are underlying the practice, as well as the factors that stimulate or jeopardise the quality of care and a practice that is consistent with the desired grounding.

**METHOD.** Qualitative study with a phenomenological nature carried out in 19 public hospitals in mainland Portugal with the participation of 56 nurses. The tool used for collecting data was a semi-structured interview.

**RESULTS.** Regarding the factors that stimulate or jeopardise the quality of care a practice that is consistent with the desired grounding, we could highlight features that were perfectly integrated in the triad structure, process and result. In relation to "structure", we could point out the following: organizational resources, human and material resources, service organization, nursing sustainment practices and organization of nursing care. Concerning "process", we could analyse: decision-making process, guiding principles for the professional practice, scientific methodology of health care service, health care documentation process, communication process, collaborative practice and management practice. In what concerns "result", the features were less evident in the participants' speech, and more stressed among clients and nurses.

**CONCLUSION.** The explanatory approach to the grounding of the professional nursing practice, outlined in a three-dimensional perspective, makes clear the theoretical framework that grounds the practice, as well as the factors in hospital environment, that stimulate or jeopardise the quality of the nursing care.

**KEYWORDS:** NURSING; PROFESSIONAL PRACTICE; QUALITY ASSURANCE; HEALTH CARE; HOSPITALS.

## Introduction

The context of health care service in hospitals has been significantly changing in the recent years. Population ageing and its resulting issues involved, in particular chronic diseases and physical disabilities, have gradually encouraged the need for health care, whose satisfaction is not related to the previously diagnosed illness, nor to the medical treatment already prescribed<sup>1,2</sup>, but to the nursing care provided during the transition processes experienced by individuals<sup>3</sup>. In this perspective, we share the idea that despite

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the need of nurses' maximum skills in the exercise of their collaborative role with the practice of medicine during the diagnosis and treatment of the disease, in fact, the people's care needs claim more and more to the nursing practice displayed by the theoretical models<sup>2</sup>.

Consequently, in the current health care environment, the needs of the population have built an ideal opportunity for nurses to (re)define the course of their profession and anticipate a new path for nursing.

Furthermore, as the emergence of themes such as health quality is a reality, in the professional practice contexts, the excellence is encouraged in the professional practice of nurses, which necessarily includes a nursing care service based on the subject's theoretical framework and consistent with the professional practice regulations<sup>4,7</sup>.

However, in an institution whose main goal is still the treatment of the illness, we can confirm the great variability of nurses' practices, often based on habits or strongly embedded routines, rather than based on nursing convictions. Was an important stimulus for the development of this study. Its aim was to contribute to the quality of nursing care through the identification of the bases that ground the nursing practice, as well as the factors that stimulate or jeopardise a practice that is consistent with the desired grounding.

Arising from literature review,

and in the scope of the grounding of the nursing practice in the hospital context, we could observe that although it is comprehensive, it has not comprised the study of the discipline's theoretical framework contribution and, simultaneously, professional practice regulation instruments, for quality assurance of nursing care. From the research performed on the contribution of the discipline's theoretical framework, we verified that it mainly focusses on its applicability in specific contexts and oriented to a specific customer profile. Regarding the professional practice, the nurses' perception about the contribution of regulations to ensure quality has not been identified. In fact, the way nurses ground their practice in the hospital setting in order to ensure the quality of nursing care, as well as factors that stimulate or jeopardise such endeavour, are not clearly defined in the existing studies, in particular in Portugal.

In this context, the need to understand the nurses' perception of on how they ground their practice, as well as the factors that stimulate or jeopardise a practice that is consistent with the desired grounding, impelled us to carry out the present study with the following starting question: How do nurses express their professional practice in a hospital environment?

The following goals have been defined: to understand the nurses' perception regarding their professional practice in a hospital environment; to understand the nurses' perception about the contribution of professional practice to the quality of nursing care; and understand the features that stimulate and jeopardise the quality assurance of nursing care.

## Methods

Assuming that the understanding of the nurses' professional practice in the hospital context and the nursing quality care is a complex task, it is important to mention that, in this study, we were interested in perceiving the phenomena reality, such as it is perceived and experienced by nurses and that justifies the fact that phenomenology has been the adopted framework<sup>8</sup>. Thus, following the adoption of the qualitative paradigm, we sought to achieve reality, unveiling, interpreting and understanding the meanings by those who experience them, in other words, the participants.

As we decided to focus our attention on the national hospital practice, we expected to carry out the study in all health care centres. At the time of the research, there were in the Portuguese mainland 21 Hospital Centres, all of them integrated in the Corporate Public Entity management model. Given that two of these hospitals did not accept to take part in the study, it was conducted in 19 Hospital Centres.

For the identification of the participants, the sampling technique used was intentional. In order to ensure a deeper understanding of the phenomena under study, we integrated representatives of nurse managers, specialist nurses and nurses in the group of participants. Data collection was performed through semi-structured interview. The meetings with the participants was previously scheduled by telephone contact, according to their availability. Interviews took place between August 2015 and February 2016 with an average duration of 60 minutes each. All participants were asked to sign an informed consent, declaring their compliance with the study and a permission to record the interview.

In each of the institutions that accepted to participate in the research, a nurse manager, a nurse specialist and a nurse were informants in the study. Since one nurse manager declined to participate in the research, a total of 56 nurses took part as study informants.

To ensure anonymity, all interviews were coded, using the first letter of the word "interviewed" ("entrevistado" in Portuguese language), followed

by a number. From E1 to E19 correspond to interviews with nurses, from E20 to E38 with specialist nurses and from E39 to E56 with nurse managers.

After the full transcription of the interviews and the content validated by the participants following the guidelines of Bardin<sup>9</sup> and using Atlas.ti<sup>®</sup> software, version 7.5.10, we began a detailed analysis of the documents.

## Results

Regarding the participants' features, the majority of them are female (73.2%), aged between 25 and 60 years old with an average age of 42.5 years old. They are mostly Married/Unmarried partner. In terms of their professional position, since the sample was intentional, the distribution is almost uniform, as there are 19 nurses (33.9%), 19 specialist nurses (33.9%) and 18 nurse managers (32.1%). Concerning the length of professional practice of nurses and specialist nurses, the prevalence is low or intermediate. Among nurse managers, the prevalence is intermediate and high. Regarding their qualifications, the majority hold a Degree.

As a result of the data analysis, in addition to the categorization related to the way how nurses ground their professional practice in a hospital context, the participants stated factors that improve or jeopardise the quality of health care and a professional practice consistent with the desired grounding, which provided us a concomitant identification of those categories.

Given that, throughout the speech analysis, we pinpointed an approach close to the structure, process and result model proposed by Donabedian<sup>10</sup>, we settled data presentation and analysis, integrated in the logic of the components of the mentioned model. Thus, within the scope of the "structure", "process" and "result" components, categories shown in figure 1 emerged.



Figure 1. Categories of the “structure”, “process” and “result” components

### “Structure” component

Integrated in this component, and regarding the *organizational resources*, the participants recognise the importance of a practice that is consistent with vision, mission, values, objectives and procedures of the institution. However, they evidence difficulties when it comes to ground their practice in these components, mainly for two reasons. On the one hand, the constraints related to the conditions and human and material resources necessary for the convergence of interests, on the other hand, the weak control of such intentions, influenced by the absence of proximity to the top management bodies. In reality, and based on intentional research we are in position to state that there are few nurses who are able to integrate the complexity of contents inherent to the strategic planning of the institution where they play a part, and it is obviously difficult to make efforts to put them into practice. Regarding institution’s policies, although the contribution of a training and research policy towards the development of human capital and the quality of care provided is widely acknowledged, nurses report that there is no “support or any kind of backing from the institutions” (E9), which has been jeopardising the involvement of the professionals, as well as their concern to act in line with the organization.

In relation to *human resources*, it is currently agreed that nurses’ allocation and qualification are two structural components with potential to influence the quality of nursing care. The lack of nurses, the inadequate ratios, the need to displace nurses among services are the main constraints. It is for sure unanimous the opinion that “it will not be possible to provide quality care if there are no secure allocations” (E46), which jeopardises the client safety and also makes the theoretical grounding of practices less evident.

Besides human resources, *material resources* might also have an influence on the quality of the nursing care. In the scope of the basic equipment, which is essential to the provision of health care, quality, workability, availability and distribution, which as a result of costs control policies, have not always been ideal, compel in some situations to improvise equipment. Together with the basic equipment and the consumption material, the participants value the peculiarities of facilities, specifically with regard to the maintenance of the infrastructures and also the room/function relation: “the space is

minimal when we need to raise up all patients” (E35); “there is almost no room for the armchairs” (E4).

Regarding *service organization*, the existing procedures are not only crucial for standardisation of care, but also, when they are well performed, contribute to ground the practice. Regarding the organisation of the nursing team, the participants highlighted that the involvement of the different team members will contribute, not only to the appreciation of the contribution of the group, but also to build a team spirit, often vital to a culture of quality in the service. The presence or absence of a training and quality policy in the service is determined by the intermediate management. The topics of improvement projects and in-service training take into consideration the needs of the different contexts, as well as the nurses. However, it is urgent to resort to a more dynamic methodology, based on indicators. The problem is that in Portugal, besides the implementation of indicators which is not even in the different health care institutions, the need to plan and organise improvement projects and training in other perspective rather than the traditional one is still not implemented. In fact, one of the

aspects that has contributed to the difficulty in integrating specific and theoretical nursing contents in the hospital practice environment, is related to the selection of the themes. “The outlined contents should be focused on the less developed issues, which are always the autonomous nursing subjects, because in the other areas [...] the scientific knowledge is more accessible to nurses” (E14), which rarely happens.

Regarding *the grounding of nursing practice*, in the perspective of the participants, the existence of a conceptual guidance for practice, integrated in the theoretical framework for the professional nursing practice, is essential. The approach to the theoretical framework represents, in the perspective of some nurses, the possibility of (re)guiding the conception and provision of care and it should be defined in the scope of the senior management, according to “someone on top has to assume and say: it is excellent, it is for everyone” (E14). At the moment, in some institutions, the opposite is happening: the approach to the theoretical framework has been arising in the contexts, making it more difficult to extend it to the whole institution.

In addition to the theoretical frameworks, the regulating instruments of professional nursing practice have been mentioned, which, due to the lack of acknowledgement, require a greater integration effort. Still in the scope of what is considered to be important to the practice grounding, principles and values involved in the professional practice have aroused, among which stand out the following: principles and values towards the others and principles and values for the profession.

Once the structural basis for the nursing practice is ensured, organisation of care to clients demands the adoption of methods that organise the care provision processes and that are consistent with the mission of the organisation and the adopted nursing orientation. In what concerns *the nursing care organization*, it was evident that the individual method and the reference nurse method are theoretically the most used ones in the different hospital contexts. Despite the recognition that those methods enhance the quality of nursing care, when they are implemented, there are weaknesses. Although in some situations the distribution of patients follows the logic of the individual method, in practice, it is not what it is observed: “it is not the individual method, or the task... we work well as a team [...] It is a mix...” (E38). Although theoretically the functional method is not the adopted methodology, in practice the propensity towards organising care according to tasks seems to prevail, such as in the case of “start positioning in one end and finish at the other” (E10).

### “Process” component

In the scope of the *decision-making process*, when nurses use the nursing theoretical framework and the regulating instruments of the job as basis, the *professional practice guiding models emerge*, even with some weaknesses, oriented to human responses, such as a practice focused on promoting health, promoting self-care, rebuilding autonomy, empowering clients, patients or caregivers, and preparing the return home to make easier transitions experienced by clients.

On the other hand, in contexts in which the proximity to the biomedical model is obvious, the practices focused on the management of signs and symptoms arise, with emphasis on the prevention of complications and the early detection of signs and symptoms of clinical worsening. Some factors emerged to determine a practice focused on management of signs and symptoms: routine practice environments, complex practice environment, exacerbated by the complexity of the patients’ clinical situation, as well as promotion and prioritization of interdependent interventions, associated, on one hand, with

the obligation to render accounts and, on the other hand, the nurses’ perception that, by performing these interdependent interventions, the work is accomplished.

To determine a guideline for practice focused on human responses, some factors were also identified: promotion of autonomous interventions and knowledge about the discipline, awareness of the contribution of the nursing theoretical frameworks for a systematic and intentional practice, as well as the existence of theoretical frameworks as guidelines for practice. Among the participants’ speeches, the influence of the school of needs was obvious, in particular from Virginia Henderson’s perspective. However, the effort should be noted to integrate assumptions from the theoretical frameworks of Afaf Meleis and Dorothea Orem.

Although the integration of theoretical frameworks varies among nurses, the fact that they are stimulated or not to invest in the theoretical grounding of their practices might make the difference. Besides this fact, the participants’ speeches make clear the contribution of training at nursing schools in the definition of the guiding models of the professional practice: “the model in which the practice is based has a lot to do with what they learnt at School” (E9).

Independently of the guiding models of professional practice, the response to the clients’ care needs implies a systematic and intentional approach that is only possible being properly accomplished using a *scientific methodology of care provision*. However, despite the investment made over the last few years aiming at the implementation of the nursing process integrating it in practice, there seem to be some weaknesses, related to the nurses’ difficulty to integrate the essence of the nursing process: “they resort to the nursing process, compulsorily, for compliance [...] not in an integrated way [...] in the working spirit of what is nursing” (E33).



Together with the care conception and provision, even in the scope of *nursing care documentation process*, it is often identified the guiding model of professional practice that is adopted by nurses. And although participants acknowledge the contribution of computerised information systems to the quality and visibility of nursing care to ensure continuity of care and integrate the nursing process, they point out the existence of some weaknesses. The lack of importance assigned to the nursing care documentation, which is shown by the fact that nurses document mainly the routine, more frequent actions, what refers to interdependent interventions and the lack of knowledge about the importance of nursing care documentation and the contribution of this documentation to the creation of indicators which are sensitive to nursing care, were the most often identified weaknesses.

Although the nursing care documentation is important, participants highlighted the *communication process*, due to its complexity and the amount of information that the nurse has to manage. Among the communication strategies among the professionals, shift change was frequently referred. Although since it has been implemented in the health care contexts, its objective is to ensure the continuity of care, the participants' reports highlight a significant improvement regarding the information that is passed. Following this improvement, the content that is being transmitted is specific to nursing and it is an important contribution to the grounding of the practices during the following shift. On the other hand, in other realities, the focus on biomedical aspects is still a reality, which by itself influences the orientation of the nurses and the grounding of their practice in the following shift. Regarding the purposes of communication, besides ensuring the continuity of care, standardization of practices and sharing of knowledge, the reflection on practice was stressed. In the perspective of the participants, the availability for reflection is not usual and simultaneously poorly encouraged: "we don't have that encouragement [...] it is a less good aspect, because reflection is very important for us to improve our practices" (E10).

Throughout the analysis of the speeches, we pinpointed some findings related with the communication process that characterised the relations among the team members, mainly from a perspective of *collaborative practices*. Regardless the adopted care models, the first quality assumption is customer focus, which in fact demands a team approach. Regarding collaborative practices, the participants identified weaknesses regarding care planning, discussion about care as well as discharge planning: "they inform the patient and leave, they don't inform the nursing team" (E27); "there is no talking, no dialogue among the members of the team to prepare discharge" (E6).

Finally, in the hospital practice context, the nurse manager has a crucial role in creating an environment that promotes the quality of nursing. Regarding management and speech analysis, we identified some issues that could be framed in the *management process*. In what concerns planning, participants stress the need to define goals, as well as promoting the participation in the preparation and implementation of the action plan, which is still scarcely substantiated in the services. Regarding organization, they highlight the need to distribute work, identify the right nurses to accomplish the activities and assign responsibilities. In the scope of management, besides the definition of a common goal, it matters to develop leadership and personal development strategies, that promote the improvement of the quality of the care provided. In the field of leadership strategies, contrary to the expected, there was still a reference to the authoritarian and *laissez-faire* style. Within the strategies of professional development, despite the reference to the training promotion, there are some realities in which the intermediate management seems to resist to acknowledge training as well as the nurses' skills. Genera-

lly speaking, there is no opportunity to learn from mistakes, since nurses are afraid of being punished. The motivation, that could be boosted by reward, positive reinforcement, compliment and recognition, has also not been promoted by the nurse managers. Regarding control, the need to supervise nursing care was pinpointed, as well as performance assessment using accurate, fair and transparent strategies, as well as the definition of quality improvement strategies, such as quality assessment of nursing care, indicators and audits.

### **"Result" Component**

Presently, the main challenges for health institution that seek quality care delivery, are focused on results. However, the difficulty still displayed by nurses when it comes to identify the results that are sensitive to the nursing care justifies the fact that, in our study, the findings related to this component were less usual.

Within the scope of *client results*, based on the certainty that their satisfaction is a valuable indicator of quality in health and particularly the quality of nursing care, the participants explored qualitative and quantitative assessment methods. In contrast, in compliance with the most relevant areas for health, defined by the National Strategy for Quality in Health 2015-2020<sup>11</sup>, it is implicit that the contribution of nursing is essentially aimed at preventing complications. In this scope and the context of the present study, the topics referred were prevention of falls, pressure ulcers, aspiration episodes, maceration and infection. On the other hand, as health gains, knowledge acquired by the clients (whether patients or care providers), clients' training and their autonomy were the highlighted aspects.

On the part of the professionals, it is recognised that the great differential among institutions is related to people and the professional performance of the teams. In this perspective, the qualities of the structure

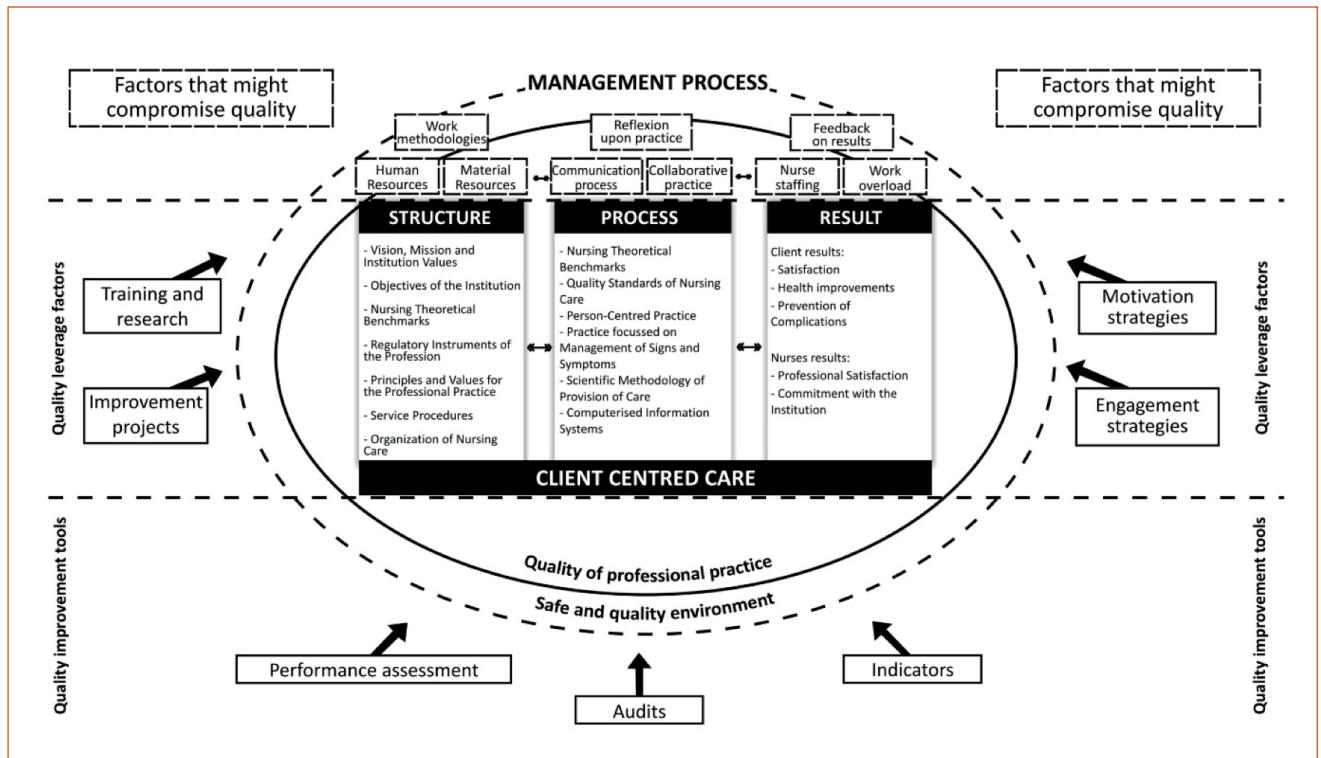


Figure 2. Explanatory model of nursing professional practice grounding

may have little meaning if people are not bond and committed to quality and results obtained in response to the clients’ needs. Professional satisfaction is a crucial condition for the improvement of the organizations’ performance. Nevertheless, in the scope of the *nurses’ results*, it became clear that the sensibility of the institutions regarding assessment and/or promotion of their employees’ satisfaction is not always evident. During the study, besides the reference to the quantitative assessment, there were situations of (dis)satisfaction expressed by the nurses. With repercussions to the commitment to the institution, the motivation at work and professional recognition emerged, especially the absence of each one, which, in the perspective of the participants, might in the future compromise the quality of care: “most nurses are discouraged nowadays” (E20); “then, there is no recognition by the administration” (E6).

**Discussion**

Changes in the health care system and the emergence of new models of care provision challenge professions to display the quality of their contribution to the people’s health. In literature, quality indicators refer to a conceptual framework that included structure, process and results<sup>12-13</sup>. In this sense, and based on the model proposed by Donabedian<sup>10</sup> and on the results obtained in our study, we present in figure 2 the explanatory model of the nursing professional practice grounding that might, simultaneously, be a reference for the investment in the facts that promote or compromise the quality of the nursing care in the hospital context.

By means of a combined strategy, with resource to the three information categories (structure, process and result), it was possible to identify weaknesses concerning quality, as well as propose improvement strategies.

Nurses are the biggest professional group in health care institutions; how-

ever, the findings suggest that they do not always feel as part of them. Given this observation and considering current developments, it is thus necessary to ensure a greater involvement and participation in the organization policies. In addition, considering the need to stimulate the nurses’ professional development, improvement of conditions for the investment in training and research should be guaranteed by the institutions. Since the training policies of the institutions do not keep pace with the evolution of the nursing discipline, new training strategies are required. Training centred in situations that occur in the practice<sup>14-15</sup> focused on the grounding of the clinical decision in an advanced nursing perspective, in which the nurse’s performance may be the starting point emerged as a possibility. The contributions of the indicators for the planning of long-term training and the establishment of continuous quality improvement programmes<sup>16</sup> at the institutions and/or services were also highlighted.

Another relevant aspect of the nurses' speech is the absence of enough human and material resources to meet the nursing care needs. Regarding human resources, it is crucial to ensure allocation in terms of quantity and also quality, so that nurses have the chance to ground their practice to provide safe and quality care<sup>17-18</sup>.

Focusing on what is accomplished with the available resources, it is necessary to reflect on the nursing care organization. Although it is clear for nurses which methodologies are consistent with the quality of nursing care, we identify from the speeches weaknesses that would justify changes in some contexts. Although theoretically it is not the methodology in use, the findings stress practices that "come closer" to the functional method, which, in the perspective of the authors<sup>19</sup>, integrates in the biomedical model vision and not in the conception of guiding practices for human response. In the scope of structure, the nurses, who consider relevant the existence of a conceptual orientation of practice, believe that it has to arise from the management bodies. In this perspective, the use of theories to guide practice is an emerging challenge, ensuring a more efficient nursing practice, but mainly more significant for people<sup>5,7,20</sup>.

Regarding the guiding models of professional practice in the hospital context, it was verified that they are influenced by two perspectives: a theoretical and a practical one. In the scope of the former, the double influence derives mainly from the theoretical frameworks that have arisen throughout the conceptual development of nursing in an international context, as well as the guiding instruments that emerged during the development of the nursing profession in Portugal. Regarding the practical perspective, the influence results primarily from the professional development of nursing along with medicine, in a clear trend towards the biomedical model. Nurses' training, the places where they attended clinical teaching / internships and the previous and current contexts of their professional activity were the issues referred in the speeches as being decisive for the degree of influence of the theoretical and/or practical perspective in their professional practice.

Consequently, and having in mind that the quality of the nurses' professional practice arises from the disciplinary and professional contributions, it becomes clear the need to stimulate an approach of nurses to the frameworks that should ground their practice. In addition, considering the importance given by the participants to the indicators and audits to assess and improve the quality of nursing care, it is urgent to implement/optimize these tools within hospitals<sup>21-22</sup>.

## Conclusion

The constant attempt to improve the quality of the services provided has been a reality in health care institutions. Thus, in a hospital environment, strongly anchored in a biomedical model, the possibility to promote changes in the nursing practices arises, with an aim at enabling a performance that is consistent with the core of the discipline and the social demands of the profession. According to what has been envisaged, to ground the nursing practice in the discipline conceptions, principles and values of the profession, is currently one of the greatest challenges.

The factors that compromise the quality assurance of nursing care and a performance consistent with the desired grounding are from different spheres: institutional, management, human and material resources, as well as other related to the organization of the nursing care itself. However, we should add the lack of motivation of nurses, who are crucial in a hospital environment. They do not feel as a part of the organizations. The lack of involvement and recognition of nurses were strongly stressed in their speeches,

which states the need to promote the participation of these professionals, and consequently, it would have significant repercussions on the quality of care provided in the institutions. Regarding operational management, it is clear the need for nurse managers to develop a culture of appreciation of the nurses' work and promotion of their potential, boosting, supporting and valuing their effort to do better and better. On the other hand, and in environments where time is always scarce, besides the necessary human and material resources' management, it is vital to adopt strategies to make nurses aware of the spirit that will allow them to surpass their performance when it comes to quality patterns. Understanding quality as a continuous process, the creation of conditions for a professional practice based on the theoretical frameworks of the discipline and the guiding instruments of the profession requires a permanent investment, strongly boosted by nurse managers.

It is likely that the results obtained in this research might generate a new form of looking into nursing practices. However, the (re)creation and renovation of the models in use will depend on the contexts, but essentially on the nursing professionals who play a role in these contexts.

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# People with alcohol dependence syndrome

## Perception of the causes

### Summary

**INTRODUCTION.** Alcohol Dependence Syndrome (ADS) and its consequences constitute a serious public health problem, representing a high social cost and compromising several areas of health of the person with ADS, with few nursing studies in this area.

**OBJECTIVE.** To describe the perception that people with ADS have about the cause(s) of the disease and reflect on the nursing interventions.

**METHODS.** Descriptive, cross-sectional and correlational study. Convenience sample consisting of 444 people with ADS. The sociodemographic, the clinical questionnaire and the last section of the Revised Illness Perception Questionnaire (IPQ-R), which assesses the causes of ADS, were used as instruments. We used exploratory and descriptive analysis.

**RESULTS.** Most of the people are male, with 45 years on average, married, unemployed and were diagnosed seven years ago on average. Participants believe that psychological aspects ( $M = 14.87$ ,  $SD = 3.24$ ) and personal aspects ( $M = 7.07$ ,  $SD = 1.85$ ) are the main causes of ADS.

**CONCLUSIONS.** Participants attributed the cause of ADS to external factors, which reduces personal responsibility, as well as confusing the causes and consequences. These results reinforce nursing importance to promote mental health literacy and maintaining abstinence.

**KEYWORDS:** ALCOHOLISM; CAUSALITY; NURSING CARE.

### Introduction

Alcohol consumption has “accompanied” all civilizations with the purpose and expectation of seeking “another mental state”, a stimulus of imaginative processes, facilitating the escape of experiences that cause pain, suffering or anguish.

Actually in Portugal, alcohol consumption is often associated with sports events, student parties and false beliefs, among other things. Alcoholic beverages are a legal drug and accepted by the community, which encourages consumption<sup>1,2</sup>. The behaviors adopted by the individual in relation to maintaining health and preventing diseases, depend on their individual beliefs about it. These beliefs, besides being part of the construction of their cognitive representation of the disease, will influence the strategies to deal with their pathology and with the treatment, as well as guide the evaluation of the

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results of the adopted behaviors<sup>3</sup>.

Alcohol is one of the most important determinants of health in the European Union, with consumption as the main risk factor for a higher incidence of diseases and higher mortality in developing countries and the third largest risk factor in developed countries. According to the WHO “Alcohol in the European Union” report, an average of 12.4 litres of alcohol a year, which is equal to three alcoholic drinks per day<sup>4</sup> is reported on average by the year 2009. In Portugal, in 2010, Portuguese people aged 15 years or more consumed an annual average of 12.9 litres of pure alcohol per year<sup>5-6</sup>.

It is known that there is an omission of the harmful effects of excessive alcohol consumption namely, contributing to family fragmentation, loss of productivity in study and work, and causes of numerous pathologies<sup>5</sup>. Throughout the study, The Global Burden of Disease proved that psychiatric disorders were responsible for 40% of years lived with disablement, highlighting alcoholism among its five main causes<sup>7</sup>. In addition, alcohol ranks fifth among all risk factors for morbidity and mortality, ranking above other

risk factors (e.g., obesity/being overweight, hyperglycaemia, salt intake or dyslipidaemia)<sup>8</sup>.

Alcohol Dependence Syndrome (ADS) is considered to be a chronic, multifactorial disease that is almost always detected at a late stage due to its insidious and prolonged course. In addition, it has physical, psychological, social, professional and family implications<sup>9-10</sup>.

### **Explanatory theories of alcoholism**

There is no single explanation for the aetiology of alcoholism. The greater or lesser probability will depend on the interaction between the different factors, be they biological, psychological or social. Several revisions of etiological factors point to a variety of determinants. These factors include genetic predisposition, cultural, family consumption patterns, alcohol learning history, and the individual's belief system with respect to alcohol, self-control, and other problems.

It started from a moral model, in which the alcoholic individual was considered as a person lacking or with diminishing moral character, weak and unable to resist alcohol, to arriving at a medical model, which supposes that the patient cannot control their behaviour voluntarily, thus removing any responsibility for the development of the problem, its modification and its relapse<sup>11</sup>. Seeing alcoholism as a disease, decreases its stigma, increasing the number of individuals seeking treatment<sup>12</sup>.

Regardless of cultural and environmental influences, the frequency of a genotype of alcoholism, in an individual context, could mark a predisposition through biological processes, later developing problems with alcohol<sup>12-13</sup>.

These models contributed to the emergence of new approaches. The psychoanalytical perspective presupposes that individuals who did not successfully pass the oral phase develop alcohol consumption habits due to the constant need for oral satisfaction, while the behavioural approaches are essentially based on the model of operant conditioning resulting from the learning principles.

Behavioural approaches to alcoholism are based primarily on the operant conditioning model derived from the learning principles, based on data analogous to that of animals<sup>14</sup>. The behavioural approach postulates that all behaviour is learned and that human beings would be particularly shaped and determined by their socio-cultural environment. According to the Social Learning Theory, additive behaviours represent a category of "bad habits", which can be analysed and modified in the same way as other habits. This model aims to study the determinants of additive habits, including antecedents, beliefs, expectations, family history and previous learning experiences, as well as to know the consequences and effects of negative or positive reinforcements<sup>13-15</sup>.

The cognitive approach, associated with cognitive-behavioural therapies, is based on the metaphor of conditioning and cognitive restructuring therapy, with the primary goal of modifying maladaptive beliefs and increasing control over thoughts and behaviours<sup>13,15</sup>. Finally, the systemic approach considers the role of the family. In this perspective, dependence is a symptom of the family and not only of the addict<sup>15-16</sup>.

### **Dependence syndrome**

Dependence is, in fact, accompanied by problems of physical health, relationships with others, and social and economic behaviour<sup>2</sup>. Physical health problems include noncommunicable diseases (e.g., neoplasms, cardiovascular, respiratory or hepatic diseases) and communicable diseases (e.g. HIV/

AIDS, tuberculosis and pneumonia acquired in the community). In addition, perinatal mortality, low birth weight and fetal alcohol syndrome have increased. Concerning the problems of relationships and social and economic behaviour, we face homicide, domestic violence and unemployment. The relevance of these public health problems led to the integration of the approach to the person with excessive consumption of alcohol in the referral/articulation network in the scope of additive behaviours and dependencies<sup>8,17</sup>.

In fact, these comorbidities are very common among people with ADS<sup>18</sup>. The ADS person often uses alcohol as a self-medication to deal with everyday problems and to facilitate the escape of experiences that cause pain, suffering or distress<sup>2,19</sup>. This means that alcohol use can either be the cause of a problem (e.g., being dismissed from work) or, in turn, the consequence of dealing with it.

The treatment of ADS involves interventions at various levels, be they psychotherapeutic, such as group therapies, self-help groups (AA, Al-Anon), or psychopharmacological<sup>15</sup>. The beliefs that the individual has about the causes of the disease, as well as their interpretation, mediate behavioural responses and may or may not lead them to search for health services<sup>20-21</sup>. In the psychotherapeutic follow-up, the motivation is worked out and reflected in the causes that led to ADS.

### **Research questions**

The knowledge of the perception of people with ADS on the cause(s) of their illness is fundamental for nursing work on motivation, and to establish objectives, strategies of treatment and maintain abstinence<sup>12,15</sup>.

In this context, since ADS has such an obvious impact on personal and family functioning, leading to endless challenges and/or changes,

with implications on functioning, well-being and Quality of Life, we are faced with the following questions:

- What is the perception of the causes for people with ADS?
- What are the relationships between the causes and the sociodemographic and clinical characteristics?

### Objectives

Since alcoholism is a common situation in our country and given the lack of research that studies the perception of the causes of ADS and the way people with alcohol dependence perceive these causes, we intend, with this study, to contribute to the development of research in this area. The following objectives were laid out for this study:

- To describe the perception that people with ADS have about the cause(s) of the disease;
- To analyse the relationship between the causes and the sociodemographic and clinical characteristics.

The nurse is one of the main players that integrates the multi professional team in the approach of the caring for people with ADS and their families. One of the objectives of the nursing intervention is to offer the possibility of recovery, aiming to reach the maximum of well-being. From the analysis of the objectives onwards, it was intended to reflect the nursing interventions.

### Methods

In order to achieve the objectives, we opted for a descriptive study, cross-sectional and correlational study.

### Participants

The sample consisted of 444 people with ADS who had been diagnosed for at least one year. A convenience sample was made of all those meeting the previously defined inclusion criteria. The sample was selected from different sub-regions of the Country (North, Centre and Lisbon and Vale do Tejo). To that end, we selected five institutions at a national level, with alcoholology services and self-help groups for people with alcoholism (Alcoholics Anonymous).

Inclusion criteria in the sample:

- Clinical diagnosis of alcohol dependence for at least 1 year.
- Age equal to or above 18 years.
- Know how to read and write.
- Do not present neurological or cognitive alterations that impede the completion of the questionnaire.

### Variables

Our study describes the behaviour and mutual influence of several variables, which is why we chose to define them as main and secondary variables.

- Main variables: Causes of the disease: Generic risk factors; Psychological aspects; Personal Aspects and Heredity/Work overload.
- Secondary variables: Sociodemographic: age, sex, literacy, marital status and employment/professional status; Clinics: duration of alcohol dependence, number of hospitalizations, number of relapses and duration of abstinence.

### Material

The sociodemographic, the clinical questionnaire and the last section of the Revised Illness Perception Questionnaire (IPQ-R)<sup>3</sup>, which assesses the causes of ADS, were used as instruments. This subscale is made up of 18 items

using a Likert scale. It presents an open question, where the person is asked to identify three causes that he considers the most important, classifying them in order of importance. We used exploratory and descriptive analysis.

- Sociodemographic questionnaire – This questionnaire was developed with the purpose of making a sociodemographic characterization of people with ADS through the collection of personal data, such as age, sex, years of schooling, employment/professional status, marital status.

- Clinical questionnaire – We collected data on the clinical characteristics of ADS: age at which they began consuming alcoholic beverages, time of diagnosis of alcoholism, number of hospitalizations, absenteeism, and duration and number of relapses.

- Revised Illness Perception Questionnaire (IPQ-R) - Subscale Causes - In our study, the causes of the ADS evaluated by the last section of the IPQ-R in the Portuguese version, developed by Figueiras and Alves<sup>3</sup>, were analysed. The subscale Causes (Likert-type scale) consists of 18 items and evaluates the beliefs that respondents have about the cause or causes of their disease. Items are not added because each represents a belief in a specific causal attribution. It is suggested, when the sample is constituted by 85 or more cases, to perform a factorial analysis of the main components (PCA) to obtain groups of causal attributions. This subscale also presents an open question, where the patient is asked to identify the three causes that he considers the most important, classifying them in order of importance.

In this way, the PCA was performed, with a criterion of selection of personal or specific values (eigenvalue) above 1 and with varimax rotation (table 1).

From the accomplishment of the PCA of the subscale causes of the disease, four factors explain 52.85% of the total variance, which were deno-

**EXPLORATORY FACTORIAL LOAD OF ITEMS, OWN OR SPECIFIC VALUES (EIGENVALUE), VARIANCE AND CRONBACH'S ALPHA COEFFICIENT OF EACH FACTOR**

1

Items	Factors				h <sup>2</sup>
	1	2	3	4	
<b>Generic risk factors (α = 0.85)</b>					
3. Smoking	0.54				0.36
4. Being overweight	0.59				0.43
5. Being unfortunate or having bad luck	0.58	0.30			0.49
6. Type of nutrition	0.70				0.56
7. Environmental pollution	0.75				0.59
10. Little medical care in the past	0.45				0.30
11. Accident or injury	0.69				0.50
13. Ageing	0.71				0.54
14. A microbe or a virus	0.71				0.53
16. Alteration in the body's defences	0.71				0.52
<b>Psychological aspects (α = 0.67)</b>					
1. Stress or concern		0.67			0.47
8. Emotional state		0.64	0.41		0.57
15. Mental Attitude		0.65	0.34		0.55
17. Family Problems or Concerns		0.69			0.57
<b>Personal aspects (α = 0.56)</b>					
9. Personal behaviour		0.42	0.69		0.65
12. Personality (way of being)			0.82		0.70
<b>Heredity/Work overload (α = 0.10)</b>					
2. Heredity		0.35		-0.57	0.54
18. Work overload				0.74	0.66
Personal or Specific Values (Eigenvalue)	4.42	2.40	1.60	1.09	
Variance (Total = 52.85%)	24.5%	13.3%	8.9%	6.1%	

Note: Orthogonal rotation by the varimax method (with Kaiser Normalization); items with a factorial load greater than 0.30. The items corresponding to each subscale are shown in bold.

minated as *generic risk factors*; *psychological aspects*; *personal aspects and heredity/work overload* (table 1). The overall Cronbach Alpha coefficient of the disease cause subscale presented a value of 0.84.

### Ethical procedures and data collection

Ethical standards have been respected in accordance with the Helsinki Declaration. The Project was approved by the Ethics Committee of the Portuguese Catholic University, Lisbon.

After selecting the places for the collection of data, we contacted, by letter, the various entities with alcoholic services and self-help groups in order to request proper authorization for the study, and the project was sent to the respective Administrative Board and those in charge of self-help groups. They gave a favourable opinion on the implementation of this study. Finally, authorization was required to use the IPQ-R scale in the study. From each person in the sample, after clarifying the objectives of the study and the data collection process, and confidentiality, informed consent and voluntary participation were requested, in accordance with the principle of autonomy.

Participants were also assured of the confidentiality of all information collected. Data was collected over a period of six months in 2010. Appropriate authorizations were requested from the institutions and author of the scale.

At the beginning of the questionnaires, a set of instructions for completing the questionnaire was prepared, followed by the initial questions on sociodemographic and clinical data and the selected material (subscale causes of IPQ-R) was attached. Subsequently, we tested its application on 15 people with ADS. Participants voiced a good understanding of the questionnaire, with no doubts. The questionnaire response time ranged from 15 to 20 minutes.

The indication of the individuals with ADS for this study was made by the doctors, nurses and social workers of the alcoholology services, as well as by the members responsible for the self-help groups.

### Analysis and processing of data

The questionnaires were analysed using the Statistical Program for Social Sciences SPSS-version 23.0<sup>22</sup>. The methodology used, for each scale being studied, was similar to the one used by the authors. In the statistical treatment of the data, statistical inference techniques were used in addition to the descriptive and exploratory analysis of the data<sup>23</sup>.

For the interpretation of the intensity of the relationship between variables, we considered the criterion suggested by Marôco<sup>23</sup>, namely: Poor correlation ( $r < 0.25$ ); Moderate correlation ( $r \geq 0.25$  and  $r < 0.5$ ); Strong correlation ( $r \geq 0.5$  and  $r < 0.75$ ) and very strong correlation ( $r \geq 0.75$ ).

The results of the present study are considered statistically significant at a significance level of 5% or 1%<sup>23</sup>, i.e., for  $p < 0.05$  or  $p < 0.01$ . The results will be presented through tables, if they are considered significant or essential to the interpretative analysis.



**DISTRIBUTION OF SAMPLES ACCORDING TO AGE OF ONSET OF ALCOHOL CONSUMPTION, DIAGNOSIS PERIOD, DURATION OF WITHDRAWAL, NUMBER OF HOSPITALIZATIONS AND RELAPSES**

**2**

Clinical variables	range	M	SD
Age at which they started drinking (years)	4-55	17.86	8.11
Period of diagnosis (years)	1-38	7.73	7.17
Number of hospitalizations	0-21	2.01	2.46
Number of relapses	1-2	1.69	0.46
Duration of abstinence (years)	0.02-43	2.79	5.96

**VARIATION OF RESULTS, MINIMUM, MAXIMUM, AVERAGE, AVERAGE SCORE AND MEAN SCORE OF THE SUBSCALE CAUSES OF IPQ-R**

**3**

Causes of IPQ-R	Number of items	Min./Max.	M	SD	Average score (M / Number of items)
Generic risk factors	9	9-45	24.75	8.14	2.75
Psychological aspects	4	4-20	14.87	3.24	3.72
Personal aspects	2	2-10	7.07	1.85	3.54
Heredity and Work overload	2	2-10	5.82	1.88	2.91

Note: Measurement range (Likert) ranges from 1 to 5.

**Results**

The sample consisted of 81.5% (n = 362) of men. In relation to their marital situation, the majority were married or living together, with 42.3% (n = 188), 27.9% were single (n = 124), and 25.9% divorced (n = 115). Concerning the employment/professional situation, the majority are unemployed (41.9%, n = 186), although there are a significant number of workers (39.4%, n = 175), 13.3% (n = 59) were retired, 4.1% (n = 18) reported another situation and 0.7% (n = 3) were students.

The average age was 45 years (SD = 9.29 and range 21-69). As for the number of years of schooling being on average 7.6 years (full years) (SD = 3.67 and range 0-19), the four participants without schooling knew how to read and write.

Table 2 shows the distribution of the sample according to age of onset of alcohol consumption, diagnosis period, duration of abstinence, number of hospitalizations and relapses.

With the sample of people with ADS, on average, the age at which alcohol consumption started was around 17.86 years and the diagnosis period of ADS is around 7.73 years. Regarding the number of hospitalizations, this varies between no hospitalization and 21 admissions and an approximate average of two relapses. However, the years of abstinence are on average about three and two years (table 2).

Most of the people are male, married, unemployed, diagnosed seven years ago on average, and the average age is 45 years. Participants believe that *psychological aspects* (M = 14.87, SD = 3.24) and *personal aspects* (M = 7.07, SD = 1.85) are the main causes of ADS. As causal factors of the first order, the importance attached to the emotional state (low self-esteem, anxiety, feeling of emptiness and demotivation) was evident, followed by family problems, stress or concerns and influence of companies and environments (table 3). Some studies have reported this similarity<sup>2,18</sup>.

With regard to causal attributions, people with ADS rarely agree with generic risk factors (fate or bad luck, type of diet, smoking, among others), with greater agreement on *personal aspects* (behaviour and personality), and *psychological aspects*, believing that stress or worry, their emotional state, family problems and their mental attitude are the possible causes of their alcohol dependence (table 3).

The results of the open question, posed to our participants, where they were asked to rank three causes that they considered as a priority in the onset of alcohol dependence, showed the importance given to emotional state, such as low self-esteem, anxiety, feeling of emptiness and lack of motivation, followed by family problems or worries, stress or concern resulting from personal experiences and the influence of companies and environments.

Secondary factors include emotional state (the negative way a person feels), stress or worry, family problems or concerns, and the effect of alcohol (e.g., disinhibition, well-being). In the third option of causal assignments, one maintains one's emotional state, one's family problems, one's daily stresses or concerns, and finally one's mental attitude.

The Mann-Whitney test was used to compare the perception of the causes between the sexes, where statistically significant differences were detected with respect to the *psychological aspects* (U = 8637.00, p = 0.006), and it was verified that the women presented higher values (Md = 17.00) than men (Md = 16.00), that is, more believe that the cause of ADS is due to psychological aspects.

From the analysis of table 04, it was concluded that, statistically significant differences were detected, between the subscale *psychological aspects*, the marital situation and the labour/professional situation.

It has been found that married

**RESULTS OF THE KRUSKAL-WALLIS TEST, FOR COMPARISON OF THE SUBSCALE CAUSES OF IPQ-R AMONGST THE CATEGORIES OF MARITAL STATUS AND EMPLOYMENT/PROFESSIONAL STATUS**

**4**

Causes - Psychological Aspects		n	Md	Min./Max.	$\chi^2$	g.l.	p
<b>Marital status</b>	Married/non-marital partnership	162	15.00	4-20	9.80	3	0.02
	Single	115	16.00	4-20			
	Divorced/separated	108	16.00	5-20			
	Widower	6	16.00	12-18			
	Total	391					
<b>Employment/professional situation</b>	Employed	153	15.00	4-20	19.45	4	0.001
	Student	3	13.00	16-19			
	Unemployed	168	16.00	7-20			
	Retired	52	15.00	4-18			
	Other	17	14.00	8-18			
	Total	393					

**PEARSON'S CORRELATION BETWEEN SUBSCALES OF IPQ-R CAUSES AND AGE, YEARS OF SCHOOLING**

**5**

Causes	Age	Years of schooling
Generic risk		-0.38**
Psychological aspects	-0.17**	0.12*
Personal aspects		0.16**

Note: \*p < 0.05; \*\*p < 0.01

people believe less that the cause of their illness is related to the *psychological aspects* compared to the other groups. However, in relation to the categories of the employment/professional situation, the unemployed people believe mainly that the *psychological aspects* are the cause of the ADS (table 4).

The correlation (Pearson) between causal subscales and age, years of schooling, duration of alcohol dependency, number of hospitalizations due to alcohol dependence and relapses were also studied. Only statistically significant differences in age and schooling were detected (table 5).

The results of table 5 indicate that the older people with ADS agree less with the *psychological aspects* as a cause of the disease. On the other hand, more educated people with ADS agree more with the *psychological* and *personal aspects* as causal factors of the disease and disagree with the *generic risk factors*.

**Discussion**

After presenting the results obtained, we proceeded to their discussion and respective critical appraisal, based on the objectives proposed for this study. We will take as main guidelines the main variables (causes of the disease) and their relationship with sociodemographic and clinical variables.

People with ADS attach a high belief to *psychological aspects* (such as stress or worry, emotional state, family problems, and mental attitude) as possible causes of alcohol dependence. Several studies have reported on the similarity between chronic and familial diseases<sup>20,24</sup>.

Regarding the causes of the disease attributed by the respondents, it is interesting to note that the emotional state (psychological aspect) was the most remembered in the three orders of answers. This fact demonstrates the difficulty for the subjects to understand the disease, seeking explanations

about the causes that do not always correspond with reality<sup>24</sup>. This distorted perception can be generated, since people suffering with ADS can often be blamed for their illness.

The maintenance of the use of alcoholic beverages is often related to the relief of anxiety and to the negative perception of the biological response to its interruption (withdrawal syndrome). At the same time, during the period of alcohol abuse, feelings of guilt may arise, which perpetuates anxiety, as well as consumption as a strategy to reduce it<sup>25-26</sup>.

People with ADS who are unmarried, divorced, widowed and unemployed believe that the cause of their illness is more related to the *psychological aspects*. It seems to us that these people live the ADS with fear, worry, anxiety and depression. Do they feel more alone and without family and/or social support?

According to Nunes & Jóluskin<sup>27</sup>, the occupation of the person in employment activities is associated with a slight reduction in heavier consumption. It is concluded, therefore, that the absence of a job occupation leads to the consumption of alcoholic beverages, in order to have company or to not think about the problem of unemployment. The following questions may, however, be raised: Was the drink the cause of

unemployment or was the condition of the unemployed that led to excessive consumption of alcoholic beverages?

It is therefore essential to help people with ADS better understand what alcohol dependence is and what the different stages of the disease are, so that the care provided is effective. However, it should be taken into account that this understanding can be influenced by individual beliefs, based on lived experiences, often confusing causes and consequences. Thus, as long as the person with ADS finds “excuses” to continue drinking, they will not be able to truly address the problem. It should be noted that the perception of the disease will change throughout the course of someone’s life, which affects other types of beliefs, which contribute to explaining the variation of behaviour related to health<sup>21,28</sup>.

It should also be pointed out that people with ADS with more schooling also do not believe in generic risk factors as the cause of the disease. Higher schooling has also been associated with a greater capacity to seek appropriate help and articulate what resources they need<sup>29</sup>. Participants with more schooling probably feel more need for treatment, which influences therapeutic adherence. So when the person is not aware of their problem and has no intention of changing their behaviour (even if the people around them are aware of the problem), then they do not feel the need to seek help either.

It seems that people with ADS often confuse causes and consequences, thus making it essential to discuss the causes that lead to ADS, to establish strategies and objectives that contribute to effective treatment and, of course, to maintaining abstinence.

Nurses occupy a privileged position because, in their essence of care, they contribute to the empowerment of the person with alcohol dependency and their family members, to efficiently manage the disease. As each health behaviour is supported by a varied set of beliefs and feelings, susceptible to change, it is important that the nurse can identify them and then intervene in partnership with the client/family, and promote a more positive and healthy adaptation behaviours. For planning the nursing intervention, it is necessary that the person with ADS and the family be aware of the need for help and the goals outlined. In addition, family involvement in treatment is essential.

In relation to educational valence, it is intended to provide relevant information, i.e. to promote knowledge about the disease, namely on signs and symptoms, early signs of relapse, causes, consequences, possibilities of control (staff and treatment), prognosis and community resources. When considering the dynamic and variable nature of empowerment [30], and assuming that a person is able to learn to use skills to influence life events, even in less beneficial situations, these intervention strategies play a key role in understanding problems and in support of decision-making.

It is important to consider some limitations of this study, such as the use of convenience sampling and it is a cross-sectional study, the evaluation of the various variables was performed only once, and it was not possible to capture the influence of certain vital events on the perception of each participant. The perception of disease is a dynamic entity with variations over time<sup>3</sup>. In this sense, we considered it important to carry out prospective and longitudinal studies in order to investigate the perception of the causes of ADS at other times of the disease, such as at the beginning and at the end of treatment.

## Conclusion

ADS has become one of the most complex public health problems because of the slow and sometimes silent progression of the disease. It affects ev-

eryone indifferently and has implications for the physical, social and psychological dimensions, both for individuals and for their families.

It becomes increasingly relevant to assess people’s perceptions about ADS because it provides information about what they think about their health status. In this way, more effective intervention strategies can be developed. In addition, several studies show that health professionals should be aware not only of physical and/or psychological aspects, but also of people’s subjective perceptions, which may interfere with their behaviour in seeking help.

The results of this investigation allowed it to be concluded that:

- The sample (people with ADS) had an average age of about 45 years and with a low level of schooling (measured in years of schooling). Most participants were either married or in a non-marital relationship and were male and no longer in employment.
- In clinical terms, the average diagnosis period, according to the person with ASD, was eight years, but for the family, it was fourteen years. The beginning of the consumption of alcoholic beverages occurred around the age of 18.
- Participants believed above all that the aetiology of the disease (causal attributions) was due to psychological aspects (e.g., stress or concerns, family problems), or rather external factors, which reduces responsibility confusion of the causes and consequences).
- Understanding the causes of ADS, as well as some sociodemographic and clinical characteristics, should be taken into account in the design of intervention strategies in nursing.

In the treatment of ADS, psychotherapeutic follow-up is essential, where motivation is worked out and reflected on the causes that led to ADS.

We emphasize the relationship of therapeutic help, which plays a major role in identifying beliefs, motivations, difficulties and support that

can turn threats into challenges and encourage adaption behaviours. On the other hand, we emphasize the importance of nursing's contribution to the promotion of mental health literacy and the maintenance of abstinence.

The ADS is responsible for physical, psychological and social suffering, both for the person with the disease and for the family. Thus, our research suggestions are related to the development of knowledge about ADS on the one hand (in the person with ADS and their relatives) and their intervening variables in the processes of perception of the disease; on the other hand, they intend to know the efficiency of health interventions, with the purpose of improving Quality of Life.

We suggest some future work, such as the replication of the present study in a broader context, longitudinal studies and quasi-experimental studies, where the effectiveness of a set of specific interventions and the development of an investigation aimed at the planning of an intervention program for the person with ADS/family dyad.

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# Pressure ulcer (risk) assessment

## Recommendations to improve nursing practice

### Summary

Pressure ulcer (risk) assessment is complex and multifactorial. National and international guidelines give orientations about pressure ulcer (PU) management and provide important recommendations. However, it's necessary to know our reality in order to improve Evidence-Based Nursing. The main aim of this study was to provide some recommendations to improve clinical practice, clinical research, clinical management and continuous education on PU domain. The study was designed as a retrospective cohort analysis of electronic health record database from adult patients admitted to general wards in a Portuguese hospital during one year. The study had a sample of 8147 participants where 34.4% had "high risk" of PU development at the first PU risk assessment, 7.9% had (at least) one PU at the first skin and tissue assessment and 3.4% developed (at least) one PU during the length of inpatient stay. (Im)"mobility" was the major risk factor assessed through Braden Scale for PU development. The systematic PU risk assessment: is sensitive to patient clinical changes; should be performed since the hospital admission; and should be used in combination with nursing clinical judgement. The systematic skin and tissue assessment: identifies early changes in skin and tissue condition; should be performed since the hospital admission; and should identify wounds of different aetiologies. The PU assessment could be improved with the implementation of a validated tool in order to standardised data record, to monitor PU/wounds characteristics and their evolution.

KEYWORDS: INCIDENCE; NURSING; NURSING ASSESSMENT; PORTUGAL; PRESSURE ULCER; PREVALENCE; RISK ASSESSMENT; RISK FACTORS.

### Introduction

Pressure ulcers continue to be a challenge<sup>1-3</sup> to healthcare professionals and institutions and represent an indicator of healthcare quality. The development of pressure ulcer(s) is complex and multifactorial<sup>4,5</sup> and nursing staff needs to manage several pressure ulcer risk factors<sup>5-7</sup> in order to prevent pressure ulcer development.

Nowadays, there are several studies focused on the magnitude of pressure ulcers problem. Each study has a specific methodological design and provides a specific "point of view". In fact, each "photograph" highlights different faces of the problem that allowed us to better understand their complexity.

Nevertheless, we believe that pressure ulcer management should be based on the institutional reality, patients' characteristics, level of risk and patients' specific risk factors.

National<sup>1</sup> and international<sup>2</sup> guidelines give orientations about the "leges artis" on pressure ulcer management and provide important recommenda-

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tions for clinical practice and clinical research. However, there is a lack of knowledge on pressure ulcers problem dimension in medical and surgical wards of Portuguese hospitals; on the characteristics of the patients who had and/or developed pressure ulcers during the length of inpatient stay; and on the influence of the Braden subscale scores on pressure ulcer development. Therefore, it's necessary to know our reality on those domains in order to implement accurate nursing interventions and improve Evidence-Based Nursing.

During the last years we have developed a set of studies that analysed the characteristics of the patients with higher risk of pressure ulcer development at admission and during the length of stay<sup>8</sup>; the characteristics of the patients that already had a pressure ulcer at admission in inpatient setting<sup>9</sup>; the characteristics of the patients that developed a pressure ulcer during the length of inpatient stay<sup>10</sup>; and the influence of some modifiable and non-modifica-

ble risk factors (with special attention on the risk factors assessed by Braden Scale) on pressure ulcer risk, prevalence and incidence<sup>11-13</sup>.

So, the research question that guided this manuscript was: What are the key implications of those evidence studies to improve clinical practice, clinical research, clinical management and continuous education on pressure ulcer domain?

In order to address this research question the main of this manuscript was: To provide some recommendations to improve clinical practice, clinical research, clinical management and continuous education on pressure ulcers domain based on previous evidence studies.

## Methods

Retrospective cohort analysis of electronic health record database from adult patients admitted to medical and surgical wards in a Portuguese hospital during 2012. The study was divided in several tasks with specific aims and inclusion and exclusion criteria. The study was performed after Hospital Council Board and Ethics Committee approval. Data was analysed using the SPSS 21.0 and 23.0. Descriptive statistics were calculated for the sample characterisation, the demographic and clinical variables. Pressure ulcer risk was calculated according to "Direção-Geral da Saúde" orientations<sup>1</sup>. Prevalence and incidence of the participants with pressure ulcers were calculated according to European Pressure Ulcer Advisory Panel orientations<sup>14</sup>. The odds ratio was calculated by univariate logistic regression for each variable of interest. The hazard ratio was calculated by univariate Cox regression for each variable of interest and by multivariate Cox regression for the Braden subscales that were statistically significant. Braden Scale accuracy tests were assessed. In all analyses a p-value < 0.05 indicated statistical significance.

## Results

As we previously referred, the study<sup>12</sup> was divided in several tasks that allowed us to analyse and discuss our results from different perspectives and develop a set of knowledge of our institutional reality.

### Pressure ulcer risk assessment

The study on pressure ulcer risk assessment<sup>8</sup> included a sample of 8147 participants where 34.4% had high risk of pressure ulcer development at the first assessment in inpatient setting. The percentage of participants with high risk of pressure ulcer development significantly decreased in the last assessment when compared with the first one. However, at the time of patient discharge, 14.0% of the participants still had high risk of pressure ulcer development.

### Pressure ulcer (point) prevalence

The study on pressure ulcer (point) prevalence<sup>9</sup> included a sample of 7132 participants and reported a point prevalence of 7.9% participants with pressure ulcer at the first skin and tissue assessment in inpatient setting. At admission 1455 pressure ulcers were documented. Most of the pressure ulcers recorded were category/stage I (42.3%). The heels (28.9%) and the sacrum/coccyx (22.4%) were the most critical areas. There was a ratio of pressure ulcers per participant with pressure ulcer of 2.60.

### Pressure ulcer incidence

The study on pressure ulcer incidence<sup>10</sup> included a sample of 7132 participants and reported a period prevalence of 10.0% participants with pressure ulcer in inpatient setting during 2012 and a cumulative incidence of 3.4% participants with pressure ulcer in inpatient setting in the same period. Du-

ring the length of stay, 320 new pressure ulcers were documented. Most of the new pressure ulcers recorded were category/stage II (43.8%). The sacrum/coccyx (35.6%) and the trochanters (17.7%) were the most critical areas. There was a ratio of pressure ulcers per participant that developed a new pressure ulcer of 1.33. One of the biggest risk factors for pressure ulcer development during the length of inpatient stay was the presence of a previous pressure ulcer at the time of admission. In 2012, 1775 pressure ulcers were documented. Most of the pressure ulcers recorded were category/stage I (39.9%). The heels (25.9%), the sacrum/coccyx (24.8%) and the trochanters (13.7%) were the most problematic areas. There was a ratio of pressure ulcers per participant with pressure ulcer of 2.49.

### Development of the first pressure ulcer

The studies on the development of the first pressure ulcer in inpatient setting<sup>15,16</sup> included a sample of 6572 participants and highlighted the characteristics of 157 participants (2.3%) that developed their first pressure ulcer during the length of stay. For 80 of those participants (52.3%) that critical event occurred during the first week, with higher frequency (27 participants) at day 5 of inpatient stay.

### The influence of Braden subscales on pressure ulcer development

The study on the influence of Braden subscales on pressure ulcer development<sup>11,13</sup> included a sample of 6552 participants and demonstrated that as the total Braden Scale scores decreased, there was a statistically significant increase on the hazard ratio of pressure ulcer(s) development. Our Braden Scale accuracy tests showed a sensitivity of 63.4% (CI 95%: 55.2%-71.0%), a specificity of 73.8% (CI 95%: 72.7%-74.9%) and an area under the curve of 0.69 (CI 95%: 0.64-0.73). The multivaria-

te time to event analysis showed that (im)“mobility” was the major risk factor (assessed through Braden Scale) for pressure ulcer development.

### **Pressure ulcer risk factors**

In all studies it was highlighted that there were important pressure ulcer risk factors not assessed by Braden Scale (such as age, the cause and type of admission, the length of inpatient stay and the presence of a pressure ulcer) that should be considered by nurses when they plan and deliver care.

### **Discussion**

After analysing and discussing our results based on national and international scientific evidence, and comparing them with our current clinical practice, we highlight some key points that may help us to implement accurate nursing interventions and improve Evidence Based-Nursing:

### **Implications to clinical practice, clinical research, clinical management and continuous education**

- The systematic pressure ulcer risk assessment creates a set of (nursing) indicators and identifies patients with higher risk of pressure ulcer development.
- The systematic pressure ulcer risk assessment through Braden Scale identifies changes in the patient condition during the length of stay.
- The total Braden Scale score should be used in combination with nursing clinical judgement in order to identify patients with higher risk of pressure ulcer development.
- There are several (modifiable and non-modifiable) pressure ulcer risk factors not assessed by Braden Scale.
- Nursing interventions should be planned and implemented according to the risk level identified and according to the patients' specific (modifiable and non-modifiable) risk factors.
- Each Braden subscale should be used as a guide to plan more accurate nursing interventions.
- The lack of ability to change and control body position was the major risk factor (assessed through Braden Scale) for pressure ulcer development during the length of stay, independently of the total Braden Scale score.
- The first week was particularly critical for pressure ulcer development and should be a period of highest nursing surveillance and preventive interventions.
- The systematic skin and tissue assessment creates a set of (nursing) indicators and contributes to prevalence and incidence rates analyses.
- The systematic skin and tissue assessment identifies early changes in skin and tissue status.
- The Skin Assessment Tool could be optimised with the inclusion of all pressure ulcer categories/stages preconized by international guidelines.
- The Skin Assessment Tool could be optimised in order to record different wounds of different aetiologies.
- The Skin Assessment Tool template should have a place to describe/identify the anatomical location “others” and/or the wound aetiologies.
- The pressure ulcer assessment could be improved with the implementation of a validated tool to monitor pressure ulcers characteristics and their evolution during the length of stay.
- The nutritional assessment could be improved with the implementation of a validated tool to monitor the nutritional status during the length of stay. The international guidelines for pressure ulcer prevention and treatment proposed the application of a nutritional risk assessment tool that besides

documentation of food and fluid intakes should include anthropometrics evaluations and (ideally) biochemical data.

- Clinical practice should be based on scientific evidence. The documentation of nursing assessment, nursing interventions and nursing outcomes is essential to promote the evidence-based nursing, compare data between services and/or between different periods.
- The systematic pressure ulcer risk assessment and the systematic skin and tissue assessment should be performed since the hospital admission and should be implemented in emergency service.
- Pressure ulcer(s) problem is complex and multifactorial. So, pressure ulcer management should (also) be multidisciplinary. Each Science offers different “points of view” of the magnitude of pressure ulcers problem and provides different theoretical contributions and different technical skills to reduce (and ideally) solve it.
- The undergraduate and graduate students are key elements in research projects and could be the main link between the universities and the health care institutions.
- The clinical nurses are vital to the success of any clinical research. They know their institutional reality and should be involved in the clinical research process.
- This study could (and should) be replicated in different care settings like intensive care units, long-term care units and/or nursing homes.
- The results could (and should) be analysed by the Hospital Council Board and could justify the acquisition of supporting surfaces, assistive equipment, repositioning equipment, prophylactic dressings and/or the improvement of nurse-to-patient staffing ratios.
- The results could (and should) be analysed and discussed in a multidisciplinary way in order to improve clinical practice and patients' outcomes.

- The upgrade and/or the implementation of new assessment tools should be preceded by a training period and followed by continuous education and periodic audits to identify and correct possible problems and optimise the entire process.
- The interaction between the hospital and other care settings and/or home care is essential to improve continuous care. The informal caregivers and the patients themselves are key elements on that empowerment process.
- Universities and health care institutions should work together to promote the bidirectional link between theory and practice; to find answers to clinical problems; to create relations between clinical research and clinical practice; and to involve undergraduate and graduate students in research projects.

### Conclusion

In our studies, approximately one third of all participants had high risk of pressure ulcer development at admission in inpatient setting. The Braden Scale scores significantly increased in the last assessments showing that Braden Scale was sensitive to patient clinical changes during the length of inpatient stay. Although the prevalence and incidence rates were lower than the ones reported in previous national surveys, they followed the trend of current international studies. The presence of a pressure ulcer at the first skin and tissue assessment could be an important measure of frailty. The participants with pressure ulcer(s) commonly had more than one documented pressure ulcer and highest odds of developing a new one during the length of inpatient stay. The first week of inpatient stay was a critical period for the development of pressure ulcer(s). The lack of ability to change and control body position was the major risk factor for pressure ulcer development during the length of stay independently of the total Braden Scale score. The awareness of the existence of modifiable and non-modifiable risk factors (and the influence of each Braden subscale) could contribute to improve nursing care and patients' outcomes. A previous national survey<sup>17</sup> concluded that most pressure ulcers could be avoided if the preventive measures were implemented based on (the best) scientific evidence. We believe that our results were important to improve the knowledge on the magnitude of pressure ulcers problem in general wards (based on our own reality) and have provided important implications to clinical practice, clinical research, clinical management and continuous education.

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# Perception of informal caregivers on planning for the discharge of hospitalised elderly patients

## Summary

Understanding the perception of the Informal Caregivers (IC) about the planning of the discharge of hospitalised elderly patients with dependency, allows Nurses to identify their needs and to help them more effectively so as to provide care at home. Thus, it is intended to know the perception of the informal caregivers about the planning of hospital discharge of the elderly patients and to analyse determinant variables in that sense. The study is quantitative, cross-sectional, descriptive and correlational, using a non-probabilistic sample for convenience, consisting of 41 ICs of elderly patients hospitalised in a Hospital Centre of Southern Portugal. A questionnaire was used for sociodemographic and clinical characterization, as well as the scales of Barthel, Hospital Anxiety and Depression and Planning of the Discharge (PREPARED). 73.17% of the ICs were female, married (78%), children of elderly parents (52.2%) and with a mean age of 78.78 years. The perception of the ICs in the planning of discharge is positive (65.9%), especially in daily living activities. However, they feel that they are not adequately trained. The presence of the formal network support significantly influences the perception in the planning of discharge ( $p = 0.000$ ), in which gender, the family household and the degree of dependence are predictive variables of perception ( $p = 0.000$ ).

Results show the importance of a better discharge preparation on behalf of the Nurses to the IC, in order to provide a better integration of the elderly patient in the family and the search for a better quality for the elderly and caregivers.

KEYWORDS: PERCEPTION; INFORMAL CAREGIVERS; DISCHARGE PLANNING; NURSES, THE ELDERLY.

## Introduction

Population aging in Portugal is being followed by an increase in the prevalence of chronic-degenerative diseases and comorbidities, as well as the coexisting loss of autonomy and an increase in the dependence of third parties to meet daily needs and to maintain quality of life<sup>1</sup>. These health problems increase health care needs, which translate into an increase in hospital admissions. These are known for being neither suited nor geared towards providing care until the full recovery of the patients' capabilities,

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thus leading to more and more premature discharges<sup>2</sup>.

We can therefore understand the importance of discharge planning as a process that identifies and organizes care for the needs of the elderly, as well as their informal caregivers (IC), since the aim of this planning is the continuity of care in the perspective of the patient-family-community triad<sup>2</sup>. To achieve this goal, discharging must be an ongoing process from the moment of the patient's admission to the health units until the time of the discharge instead of being seen as a final step only.

For the Central Administration of the Health System<sup>3</sup>, hospital discharge planning is a crucial moment for the success of social intervention with citizens and their families, either for returning to their home or for integration in social response. In fact, the elderly patient with some level of dependency and informal caregivers should be involved in all aspects related to care. Also, the learning process should begin as early as possible and be transversal to the entire period of hospitalisation, in order to be able to develop skills that promote the quality of life and optimize the rehabilitation process<sup>4</sup>.

The informal caregiver emerges as the figure who assumes the responsibility of home care for dependent persons, and may be family members or significant cohabitants. They usually need help to plan and recover routines, and to become aware of their own needs in this transition process<sup>5</sup>. This transition has been reported as an event with a negative connotation and generally associated with stress, in which ICs express needs. The latter range from the need of information on how to care for the elderly patient, how to identify risk situations and how to control their own emotions. In the opinion of Couto, Castro & Caldas<sup>6</sup>, ICs need information on medication, clinical conditions, daily living activities (DLA) that can be performed, and community service offerings. In this process, Stone<sup>7</sup> emphasizes the role of formal support and Pereira<sup>8</sup>, adds that it is not enough for the caregiver to be “well prepared”, he/she must also “be well”. In order to do so, he/she must denature established practices so as to effectively support the return home and focus on providing information or the acquisition of skills, which must then be continued at home, monitoring the caregiver’s decentralization movement as a way to validate coping mechanisms. Indeed, caring implies performing complex tasks, sometimes for long periods of time, and is associated with physical exhaustion, financial costs, emotional overload, and diminished quality of life<sup>9</sup>.

The IC’s role of transition and assumption is a complex process, with different dynamic stages that require special attention on the part of the health professionals, more specifically of nurses as professionals who, due to their activity and proximity, are the main caregivers and deal with the people in transition<sup>10</sup>. We also stress the Nurses who are specialists in rehabilitation and who, due to the competencies assigned to them, play a preponderant role in the process of rehabilitation as mediators in the continuity of the nursing care process, in order to identify, facilitate and assist ICs. Several studies have been carried out on the planning of discharge and preparation of informal caregivers to care for the elderly at home: Nevertheless, it is verified that there is little research showing the effectiveness of nursing interventions that facilitate this transition process, since the results are inconclusive.

From the foregoing, it should be noted that any nursing intervention with a view to satisfying the needs of the person and the caregiver aims, firstly, to effectively understand the real needs and determinants in the process with the aim of qualifying and empowering citizens, as only in this way can projects of continuous improvement of the quality and satisfaction of the users of health services be developed.

In this sense the following research questions emerged: What perception do informal caregivers have about the planning of the discharge of the elderly people admitted in hospital services? Are the sociodemographic, clinical and psychosocial variables associated with the caregivers’ perception?

The aims of the study are to know the perception of informal caregivers about the planning of the discharge of admitted elderly patients and to verify if there is any relation between this perception and the sociodemographic, clinical and psychosocial variables.

### Research methods

A quantitative, cross-sectional, descriptive and correlational study. A non-probabilistic sample was used for convenience, consisting of 41 informal caregivers of elderly patients admitted to the medical services of a Hospital in Southern Portugal, and data collection took place between November 2015 and March 2016. The data collection instrument included socio-demographic questions, clinical-functional questions (Barthel index), hospital anxiety and depression scale (HADS) and the discharge planning questionnaire

(PREPARED). It is a questionnaire that has already been translated and validated for the Portuguese population by Ferreira, et al.<sup>2</sup>, and is composed of 8 dimensions in which the final result is the sum of the several dimensions. The higher the total score, the better the caregivers’ perception about discharge planning. All procedures were carried out in accordance with strict ethical conduct (with permission by the Directors of the Institutions and respective Ethics Committees), ensuring the anonymity and confidentiality of the data collected. The statistical treatment was carried out through the Statistical Package Social Science version 20.0 for Windows and Microsoft Word, and was processed using descriptive statistics and inferential statistics.

### Findings

The study sample is made up of 41 informal caregivers, mostly female (73.17%), ranging in age from 37 to 86 years, with a mean of 59.18 years old and a standard deviation of 11.81. The majority (78%) are married or live in non-marital partnership and attended the second cycle of schooling (68.2%) as an academic qualification. In professional terms, 39.0% of the ICs are still employed (only 36.6% retired) and working full-time, during the day (34.1%), on a third-party basis and with an indefinite contract.

The IC household varies from one to six people with an average of 3 people and 14.6% still have dependent children. These caregivers are mostly (51.2%) children of elderly parents, female (46.6%) living in the same household (82.9%), provide care (75.6%) on average between 3 and 6 months and 48.8% reported being helped by other family members. Only 24.4% receive support from the formal network, translated into home care.

The majority of the elderly patients (61.0%) of the female gender (only 39.0% men), have ages ranging from 65 to 92 years, (M = 78.78,

Sd = 8.54) and their marital status is specified as widowers (63.4%). They present several co-morbidities, but the most prevalent are cardiovascular diseases (17.1%) and respiratory diseases (14.3%), and only 12.2% of these elderly people were hospitalised within the last year due to surgeries (7.3%). The days of hospital admission ranged from five to 45 days, with a mean of 13.61 days and a standard deviation of 9.84, which were slightly higher in men ( $x = 16$ ;  $sd = 11.15$ ). The present hospitalisation was mainly due to respiratory pathologies (26.8%), cardiovascular pathologies (19.5%), and other related diagnoses (31.7%). The degree of dependence was mild 58.5%, moderate for 19.5% and severe for 22.0%.

The levels of anxiety presented by ICs ranged from 3 to 19, with a mean of ( $x = 10.17$ ;  $sd = 4.73$ ), which was higher in women ( $x = 11.10$ ,  $sd = 5.07$ ) than in men ( $x = 7.64$ ,  $sd = 2.34$ ). Similarly, depression oscillates between 1 and 17, with a mean of ( $x = 8.37$ ;  $sd = 4.06$ ), being also higher in women ( $x = 9.43$ ;  $sd = 3.97$ ) than in men ( $x = 5.45$ ;  $sd = 2.69$ ).

The perception by them expressed concerning the preparation for the discharge was that it was sufficient for 65.9% of ICs, although 34.1% say they do not feel properly prepared. They feel that nurses were attentive and tried to meet their needs (82.9%), yet only 31.7% were satisfied with community support services and the equipment provided (17.3%). They also stated that the preparation was very adequate (67.8%), especially at the level of activities of daily living (ADLs) and the information on medication intake (70.7%). Nonetheless, this was not the case regarding side effects since they (69.5%) remain totally unknown.

The results of the inferential analysis show that ICs that present more positive perceptions about the discharge preparation (with significant statistical differences) are the men ( $p = 0.026$ ), households with 2-3 people ( $p = 0.038$ ), those who receive formal support ( $p = 0.027$ ) and those with lower levels of anxiety and depression ( $p = 0.021$ ). Conversely, age, marital status, academic qualifications, professional status and family ties of the ICs with the elderly patient were not related to ( $p > 0.05$ ) their perception about discharge preparation.

## Discussion

The majority of the informal caregivers in this study are female (73.17%), married, or living in marital status (78%), with an average age of 59.18 years and son/daughter of the recipient of care (51.2%). These findings are in accordance with Gratao<sup>11</sup> & Fuhrmann<sup>12</sup>, that state that the average of age of the informal caregivers is around 66 years, they are mainly female, and the majority is the spouse or son/daughter of the recipient of care. The association between the sociodemographic variables and the perception of the informal caregiver of the discharge planning, shows that men have the most positive perception of the discharge planning, with significant statistical differences ( $p = 0.026$ ). Notwithstanding, age, marital status and schooling are independent of the perception of the discharge planning ( $p > 0.05$ ), contrary to the findings of Loureiro<sup>4</sup> that advocate that caregivers with higher academic qualifications, younger and living with someone have a better perception of the discharge planning ( $p = 0.028$ ).

The family functionality is better as the number of people living with the older dependent person is higher<sup>13</sup> corroborated in this study, since families of three or more members show better perceptions of the discharge planning ( $p = 0.038$ ). Also, 58.5% of the informal caregivers are in the process of care for less than three months, hence still adapting to this new experience. According to Pereira, Paiva & Silva<sup>5</sup> the perception of the informal caregiver role play changes throughout time, with no similar pattern for all the

caregivers. Although there are no significant statistical differences ( $p = 0.766$ ), it is possible to conclude that those who care for the dependent elderly for less than a year are the ones showing more positive perceptions of the discharge planning. It is also shown that around 80% of the families do not receive any formal support, despite 30% wish to get this aid. A special highlight for the existing relation between the formal support networks and the perception of the family caregivers of the discharge planning, since it is observed that the caregivers who receive support from formal networks show better perception of the discharge, when compared to those who do not receive this support ( $p = 0.000$ ), and the home support is the most referred. According to Louro<sup>14</sup> home support comprises organized responses meeting the needs of dependent people, mainly aiding informal caregivers.

The levels of anxiety revealed by the informal caregivers are moderate ( $M = 10.17$ ), with higher levels for women ( $M = 11.10$ ) when compared to men ( $M = 7.64$ ). Similarly, Couto et al.<sup>6</sup> state that the caregivers experience high levels of anxiety, with little knowledge on related risk factors. However, it is known that the informal caregivers' needs are often undervalued and unfulfilled. In view of adverse situations, and lacking of mechanisms on problem-solving, the informal caregiver is faced with a stressful situation likely to lead to a status of psychosocial disruption, often accompanied by negative feelings like fear, guilt, anxiety and depression. In fact, our study corroborates these findings although it shows moderate levels of depression ( $M = 8.37$ ) and also with higher levels for women ( $M = 9.43$ ). The perceptions on the discharge planning are distinct amongst caregivers, since 65.9% considered it sufficient, contrary to 34.1% of participants which expressed unpreparedness. They feel that Nurses are concerned with planning and tried to respond

to the main needs (82.9%), however only 31.7% showed satisfaction with home support services and with supplied equipment (17.3%). They stress the fairly adequate preparedness (67.8%) at the level of the basic activities of daily living (ADLs) and knowledge on medication intake (70.7%). However, different results were found for its side effects, since 69.5% of the participants have no related knowledge. This inadequate/insufficient information often contribute to a poor or lack of adherence to medication at home. These findings corroborate those of Grato<sup>11</sup> & Louro<sup>14</sup> stating that the family is little involved during hospitalization, in the process of care provision and in the discharge planning, and the main difficulties expressed by the caregiver in the provision of care were precisely the lack of information (the therapeutic plan), the technical procedures adjusted to the dependent person, and on using support/transportation services. There is evidence of efforts on training the informal caregivers within ADLs, where the implemented methodologies are focused on exploring contents in practical/participative sessions on training abilities target at the prevention of pressure ulcer, sphincter control, nutrition, positioning, transfer, mobility and communication. However, they still do not include information on the knowledge acquired by the informal caregiver<sup>15</sup>. In a study conducted about the information relating to the nursing diagnosis and its dimensions concerning the caregiver role, Azevedo & Manuel<sup>16</sup> were able to conclude that in many cases there is little or inexistent information, and that at the discharge moment, the nursing diagnosis statements are more focused on the development of cognitive competencies and less concerned with the development of training abilities. It is well known that the return home after an hospital discharge triggers mixed emotions and concerns and that the perception of caring for an elderly dependent person is specific to each caregiver. Notwithstanding, the informal caregiver is often forced to lead this role without proper guidance, changing routines, affecting quality of life. Several authors have stressed out that informal caregivers have a set of needs including training and knowledge, practical aid, financial support, physiological and emotional<sup>15-17</sup>.

The mentioned aspects show that it is crucial to assess the dependency and characteristics of the hospitalized person, since it will enable to better determine the care needs, either in an hospital context, or, latter in a context of home care support (if they exist), setting a tailored intervention model (global health care and social support) which will always depend on the caregiver and the dependent person personal traits.

### Conclusion

This study showed that, although preparation for admission is a concern with the effective intervention by health professionals among dependent elderly relatives, this does not yet correspond to the specific needs of caregivers and the provision of care. In fact, we found that significant groups of ICs (34.1%) do not feel prepared when it comes to providing the care that their elders require; a witness to this fact is the investment made by Nurses (especially Rehabilitation Specialists) in the training of ADLs, as well as managing their feelings and concerns, but they consider there is not enough information on the side effects of medication, community resources and compensation equipment.

In the study of association between variables we found that, although the majority of the ICs are female, it is men, households consisting of two and three people, ICs that are supported by the formal network, who care for moderate dependent relatives. Moreover, those with low levels of anxiety and depression are the ones who display a better perception about the preparation for discharge. Surprisingly, age, marital status, academic qualifications,

professional status and family ties of the IC to the elderly care, were not associated with the perception about the preparation of discharge, which reinforces the subjectivity and plurality of factors that interfere in these processes.

In spite of finding that there are results in favour of the presence of an intervention model, namely in the foci directed to counselling, support, training of technical skills for care and in the development of coping skills, it seems that there is no validated model of intervention that best suits the preparation of the informal caregiver to care for the elderly patients at home.

Thus, knowing the informal caregiver's perception about hospital discharge planning, as well as the whole transition process from taking care of the elderly patient in a hospital context to the home context, allows nurses to assess the real needs of this group, which is reflected in the improvement of the care provided and in the quality of life of the caregiver. In addition, adequate discharge planning also has positive repercussions on the health system, as it contributes to the prevention of hospital readmission since the General Directorate for Health<sup>18</sup> states that 40 to 50% of rehospitalisation episodes are due to social problems, unprepared IC and/or loss of support from the community services. Therefore, systemic and structured discharge planning, according to the needs of the IC and elderly care will become an asset in different areas ranging from hospital management to affirming the importance of the nurses' role in the continuity of care, but above all in the satisfaction of health service users.

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Funding

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# ECare-COPD Project

PROMOTION OF SELF-MANAGEMENT IN COPD: TRAINING PROGRAMME

POCI-01-0145-FEDER-023342

## Main Goal

Strengthening research, technological development and innovation.

» To develop and implement an e-learning training programme aimed at first and second cycle students and nurses.

## Tasks

**1** State of the art  
in COPD, training and simulation

**2** Course planning  
and content identification

**3** Content production  
Clinical scenarios & multimedia content

**4** Integration of content  
into the training e-learning platform

**5** Evaluation  
of perceived usability, easiness and  
intention to use the e-learning platform

**6** Final evaluation  
report

## Execution

01-09-2017 until 01-03-2019

## Overall budget

€ 123.762,93

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## Research team

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# Nurse-led interventions for promoting self-management in oncological patients

## A systematic review

### Summary

Worldwide statistics evidence the increasing number and prevalence of diagnosed chronic diseases such as cancer. Cancer is a chronic condition with uncertain outcomes in what concerns to its cure. Thus, it is crucial that patients develop the right skills to deal with the disease and its profound impact on their activities of daily living. This review aims to identify and critically appraise studies based on the efficiency of nurse-led programmes focused on psychosocial support provided to empower the self-management of adult oncology patients. The research of corpus studies was carried out in the databases of MEDLINE and CINAHL, in the period of January 2017. In compliance with the validation criteria, 22 primary studies were selected and analysed. The results revealed that nurse-led interventions comprised self-management skills aimed to improve symptoms management, self-care activities, health behaviours, social and therapeutic relationships, stress/anxiety management and problem solving. Nursing interventions were implemented individually and/or in a group, applying different methodologies: written material (leaflets, pamphlets, books, manuals, brochures and/or flyers), peer support groups, interactive platforms and telephone calls. Interventions were effective in promoting symptoms management, self-care life and interpersonal relations. Conclusion: Nurses play a key role in providing interventions, health behaviour, stress/anxiety management, psychosocial adaptation, quality of focused on psychosocial support that help people to cope/live with cancer, and promote self-management programmes.

KEYWORDS: CANCER, SELF CARE; REVIEW; SELF-MANAGEMENT; NURSE-LED INTERVENTIONS; PSYCHOSOCIAL SUPPORT.

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### Introduction

Formerly considered acute and lethal, the oncological disease has increasingly become a chronic condition, therefore, likely to affect the person for many years, in several ways. One of the main challenge of living with this condition is to be able to manage the symptoms and potential side effects, aiming a better quality of life and well-being of those suffering from cancer. The available scientific evidence highlights the empowerment and strengthening self-management of the disease as an important facet<sup>1</sup>.

Self-management is a dynamic process in which patients are trained to develop skills to deal with the symptoms, treatments, side-effects and all the changes related to the chronic condition, in order to achieve a better quality of life<sup>1,2</sup>. For instance, a person who is able to identify pain as a symptom and im-

## SEARCH STRATEGY

1

	CINAHL Complete	MEDLINE with Full text
<b>Population</b>	#1 (MH "Cancer Patients") OR (MH "Cancer Survivors") OR (MH "Neoplasms")	(MH "Neoplasms") OR "cancer patient*" OR "oncologic patient*" OR "oncology patient*" OR "cancer survivor"
<b>Intervention</b>	#2 (MH "Support, Psychosocial") OR (MH "Professional-Patient Relations") OR (MH "Nurse-Patient Relations") OR (MH "Professional-Client Relations") OR (MH "Nurses")	(MH "Social Support") OR (MH "Nurse-Patient Relations") OR (MH "Professional-Patient Relations") OR (MH "Nurses")
<b>Outcome</b>	#3 (MH "Self Care") OR (MH "Self-Efficacy") OR (MH "Self Concept") OR (MH "Health Behavior") OR (MH "Patient Compliance+") OR (MH "Control (Psychology)") OR (MH "Self Regulation") OR (MH "Attitude to Health") OR (MH "Health Beliefs") OR (MH "Attitude to Illness") OR (MH "Patient Autonomy")	(MH "Self Care") OR (MH "Illness Behavior") OR (MH "Patient Compliance+") OR (MH "Health Behavior") OR (MH "Attitude to Health") OR (MH "Self Concept") OR (MH "Self Efficacy") OR (MH "Social Control, Informal")
<b>Search</b>	#4 #1 AND #2 AND #3	#1 AND #2 AND #3

plement strategies, such as analgesia to relieve the pain, is efficiently managing the effect of the disease in their life.

In health professionals' led-interventions, particularly the ones conducted by nurses, a special emphasis has been given to psychosocial support<sup>3</sup>, which positively impacts the physical and psychological well-being of the patients, as well as enhances stress management<sup>4</sup>.

The psychosocial support comprises a set of interventions focused on patients' physical, emotional and social needs and are usually categorized into three types: informative, instrumental and emotional. These interventions aim to promote the development of effective coping strategies and patients' quality of life<sup>5</sup>.

Evidence suggests that people with chronic disease, as cancer, can improve their health and quality of life by taking an active role in self-management<sup>6</sup>. Therefore, the patient should be an active participant in the promotion of his own health and also in the process of adaptation to disease. Healthcare providers, particularly nurses, are important promoters and facilitators in the development of such skills, however effectiveness remains rather unclear.

The aim of this systematic review is to gather the best scientific evidence available with regards to the effectiveness of psychosocial interventions developed by nurses to promote self-management of the oncological disease.

## Methods

A good research question needs to be clear, accurate and attainable and should be constructed following the PICOS acronym<sup>7</sup>. The review question was: "What are the effects of nurse-led interventions on psychosocial support (intervention) for promoting self-management (outcome) of adult oncology patients (population)?"

A systematic literature review was conducted in order to summarize relevant evidence, according to Bettany-Saltikov<sup>7</sup> and Cochrane<sup>8</sup>. A peer review protocol was used to set the methodology design and to enable quality assessment, this was registered in the PROSPERO International prospective register of systematic reviews (CRD42015030140) available at: <https://www.crd.>

[york.ac.uk/PROSPERO/display\\_record.asp?ID=CRD42015030140](https://www.crd.york.ac.uk/PROSPERO/display_record.asp?ID=CRD42015030140)

Articles search was performed in January 2017 through MEDLINE with Full text and CINAHL Complete using MeSH terms, CINAHL headings and free text terms (table 1). Keywords and relevant outcomes were identified throughout a process of literature search and a discussion session conducted by a group of experts. Latter and through EBSCO database, a "MH Exact Subject Heading" was used which enabled the automatic inclusion of all variations or synonyms terms for the selected keywords. Retrieved articles were submitted to references review. Researchers did not consider unpublished studies (e.g. dissertations or conference proceeding abstracts).

The review was based on articles meeting the following inclusion criteria:

1. Randomized controlled trials or quasi-randomized trials of nursing self-management interventions provided to adult oncology patients, despite the anatomical location and stage of their cancer.
2. English, Portuguese or Spanish written papers. The high level of



scientific evidence was determinant to select only experimental or quasi-experimental studies.

Two reviewers independently scanned the titles and abstract sections of every record retrieved. Full articles were further assessed whenever relevant data was found and each time there was an uncertainty in the fulfilment of the inclusion criteria, a third reviewer was asked to solve potential disagreements.

An adaptation of the evaluation method used by Law et al.<sup>9</sup> was used to assess the studies' quality. All 15 items of the original checklist were included and three other items from Caldwell et al.<sup>10</sup> and Jadad et al.<sup>11</sup> critical assessment tools, were added. For each individual study, data were collected

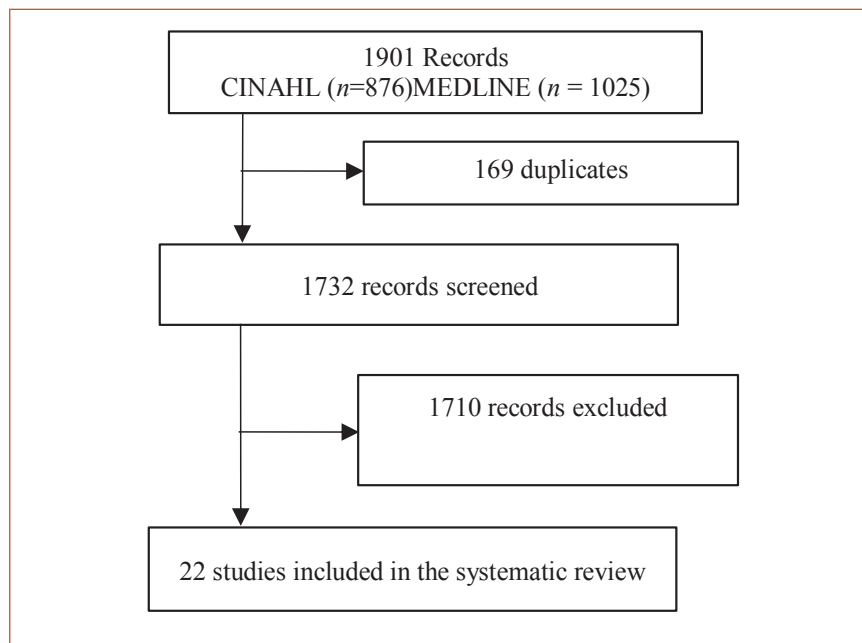


Figure 1. SMA flow diagram

by one reviewer and then checked by other two reviewers. A score of “1” was applied to each item with a “yes” or “not applicable” answer and a score of “0” to a “no” or “not described” answer. The total score was 18 points and studies with values below 9 were excluded.

## Results

Throughout the conducted research, 1901 studies were identified until December 2016. From this total, 169 were excluded because they were duplicates. After applying the established criteria, 22 studies were submitted to methodological evaluation (fig. 1).

## Methodological assessment

Two independent reviewers carried out the assessment of the studies' methodological quality, and, in case of disagreement, a third reviewer was called to make a final decision. Some missing details were found concerning the randomization procedures, however all studies provided precise details on the intervention procedures: a) description; b) method and time set for implementation; c) and content. Considering the study involved psycho-educational interventions, researchers and participants were not blind to

the intervention that a participant was receiving. All studies submitted to methodological evaluation were included.

## Characteristics of the study participants

The selected studies evidenced two types of samples: eight studies exclusively included participants with breast cancer and 14 studies included individuals with different types of cancer. The number of participants ranged from 36 to 367 and involved a total of 2862 participants, of which 2654 were adult cancer patients and 208 were significant others. Table 2 summarily presents the statistical data for each study and study design details, sample characteristics, interventions and results.

## Type of interventions

A great variety was found in terms of the content and procedures of the retrieved interventions. Interventions also differed in terms of length, duration, and number of sessions. The shortest intervention lasted one week (study 2) and the longest 13 months (study 6). All interventions were psycho-educational in nature and were implemented by nurses (16 studies) or multidisciplinary groups (studies 4, 7, 11, 14, 15 e 19).

The majority of skills training interventions comprised self-management skills aimed at symptoms management, self-care activities, health behaviour, social and therapeutic relationships, stress/anxiety management, and problem solving.

## Discussion

The studies included in this review used a variety of outcome measures, as shown in table 2. Improving health outcomes pertaining to symptoms management or disease control were analysed across studies using a wide variety of outcomes.

Nine studies focused on the effect of the intervention on participants' quality of life (studies 1, 3, 4, 7, 11, 14, 18, 20 and 21). In the majority of the studies, the implementation of

## CHARACTERISTICS OF THE INCLUDED STUDIES

2

SAMPLE	INTERVENTION	RESULTS
<b>STUDY 1: An Intervention to Increase Quality of Life and Self-Care Self-Efficacy and Decrease Symptoms in Breast Cancer Patients<sup>12</sup>.</b>		
Study design: experimental. Country: United States of America		
n=53 women with breast cancer  Experimental Group: n=10. Control group: n=8.	<ul style="list-style-type: none"> <li>• Cancer;</li> <li>• Share of experiences;</li> <li>• Coping strategies;</li> <li>• Self-care behaviours;</li> <li>• Relaxation techniques;</li> <li>• Motivation and self-efficacy.</li> </ul>	<p><u>Quality of life</u>: higher for the intervention group compared to the control group (large effect (01) to medium (.06).</p> <p><u>Symptoms</u>: higher reduction of symptoms for the intervention group compared to the control group (big size effect (.14).</p> <p><u>Self-care and self-efficacy behaviours</u>: the intervention group adopted more health promoting strategies compared to the control group, except for decision-making, where no differences were found</p>
<b>STUDY 2: The effectiveness of progressive muscle relaxation training in managing chemotherapy-induced nausea and vomiting in Chinese breast cancer patients: a randomised controlled trial<sup>13</sup>.</b>		
Study design: experimental. Country: Republic of China		
n=71 persons with breast cancer.  Experimental group: n=38; years. Control group: n=33; years.	<ul style="list-style-type: none"> <li>• Muscle relaxation;</li> <li>• Guided imagination.</li> </ul>	<p><u>Blood pressure</u>: significant reduction (.</p> <p><u>Nausea</u>: lower frequency for the intervention group, but only with significant differences ( in the first 4 days after chemotherapy.</p> <p><u>Vomiting</u>: lower frequency for the intervention group, but only with significant differences ( in the first 4 days after chemotherapy.</p> <p><u>Mood disturbance</u>: a decrease in the intervention group and increase in the control group (.</p> <p><u>Anxiety, depression, fatigue and confusion</u>: no differences were found between the groups.</p>
<b>STUDY 3: The effect of progressive muscle relaxation training on anxiety and quality of life after stoma surgery in colorectal cancer patients<sup>14</sup>.</b>		
Study design: experimental. Country: Republic of China		
n=59 persons with colorectal cancer submitted to surgery.  Experimental group: n=30; years. Control group: n=29; years.	<ul style="list-style-type: none"> <li>-<sup>1</sup> Relaxation techniques.</li> </ul>	<p><u>Anxiety</u>: the intervention group showed anxiety levels significantly lower compared to the control group (.</p> <p><u>Quality of life</u>: the intervention group showed quality of life significantly higher in relation to the control group (, although these differences are more visible after 5 weeks.</p>
<b>STUDY 4: Effects of psychosocial intervention on quality of life in patients with head and neck cancer<sup>15</sup>.</b>		
Study design: experimental. Country: Sweden.		
n=144 persons with head and neck cancer.  Experimental group: n=52; years. Control group: n=163; years.	<ul style="list-style-type: none"> <li>• Head and neck cancer;</li> <li>• Treatments and side effects;</li> <li>• Nutrition.</li> </ul>	<p><u>Quality of life</u>: both groups showed clinical deterioration for the majority of indicators analysed in 3, 12 and 36 months. The intervention group showed a lower quality of life compared to the control group.</p> <p><u>Perception of health</u>: the intervention group felt sicker compared to the control group (.</p> <p><u>Depression and anxiety</u>: no significant differences were found, however the intervention group showed higher levels of anxiety and depression.</p>
<b>STUDY 5: The PRO-SELF© Pain Control Program Improves Patients' Knowledge of Cancer Pain Management<sup>16</sup>.</b>		
Study design: experimental. Country: United States of America		
n=179 persons with bone metastases.  Experimental group: n=93; years. Control group: n=81; years.	<ul style="list-style-type: none"> <li>• Pain and pain assessment;</li> <li>• Use of the medication box;</li> <li>• Communication with physician;</li> <li>• Pain control regimen;</li> <li>• Readjustments in the analgesic prescription;</li> </ul>	<p><u>Knowledge about pain and its management</u>: increases 21% in the intervention group (, whilst in the control group there was a non-significant increase of 0,5% ( and a reduction of knowledge in some items.</p> <p>The intervention group did not relate the use of non-pharmacologic methods (such as massage, heat and relaxation) with pain relief (.</p>

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**STUDY 6: The Effect of Telephone Social Support and Education on Adaptation to Breast Cancer During the Year Following Diagnosis<sup>17</sup>.**

Study design: experimental. Country: United States of America

n=106 women with breast cancer	• Experience with diagnosis and treatment;	<u>Mood</u> : all participants showed significant improvement , with no differences found between groups.
Experimental group: n=54; years.	• Decision-making;	
Control group: n=52; years.	• Relaxation techniques;	<u>Symptoms</u> : all participants showed significant improvement , with no differences found between groups.
	• Stress management;	
	• Breast self-examination and others;	<u>Relationships with significant others</u> : all participants showed a significant improvement .
	• Self-image and sexuality;	
	• Fear of recurrence;	
	• Community resources.	No statistically significant differences found between groups.

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**STUDY 7: Efficacy of comprehensive group rehabilitation for women with early breast cancer in South Korea<sup>18</sup>.**

Study design: quasi-experimental. Country: Republic of Korea

n=65 women with breast cancer.	• Cancer, treatments and complications;	<u>Articular movements</u> : significant improvement in the experimental group. No significant differences found in the the control group. Significant differences found between groups .
Experimental group: n=28; years.	• Nutrition and diet;	<u>Psychosocial adaptation</u> : significant improvement in the experimental group . Significant worsening . Significant differences between groups .
Control group: n=27; years.	• Relationships, self-image and sexuality;	<u>Quality of life</u> : significant improvement in the experimental group . No significant differences found in the control groups. Significant differences between groups .
	• Prevention and management of lymphedema;	
	• Breast reconstruction surgery	
	• Rehabilitation exercises.	

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**STUDY 8: Nursing education as an intervention to decrease fatigue perception in oncology patients<sup>19</sup>.**

Study design: experimental. Country: Spain

n=40 persons with gastric and colon cancer.	• Self-management and coping strategies;	<u>Fatigue</u> : the experimental group showed a reduction of 11 points, whilst no changes were found in the control group, however no significant differences were found between participants.
Experimental group: n=23; years.	• Daily changes;	
Control group: n=17; years.	• Stress management;	<u>Satisfaction with intervention</u> : 8,34(SD=0.9), from a total of 10.
	• Nutrition;	
	• Activity and rest;	
	• Community resources.	

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**STUDY 9: Depression and Anxiety in Women With Breast Cancer and Their Partners<sup>20</sup>.**

Study design: experimental. Country: United States of America

n=96 women with breast cancer (years) and 96 spouse (years)	• Breast cancer;	<u>Depression</u> : No significant time effect , but significant for intervention . No significant interaction effect between intervention and time .
Group TIP-C (telephone counseling): n=76.	• Anxiety;	The intervention groups (TIP-C and Physical exercise group) showed higher reduction in depression levels compared to the control group.
Physical exercise group: n=46.	• Stress and adaptation;	<u>Anxiety</u> : A statistically significant effect for time ( and no significant effect for intervention . A significant interaction effect between intervention and time .
Control group: n=70.	• Social support;	The intervention groups showed a significant reduction in anxiety symptoms: TIP-C and physical exercise , whilst no significant differences were found in the control group .
	• Awareness of changes;	
	• Symptoms management;	
	• Physical exercise.	

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**STUDY 10: Effectiveness of a nursing support program for patients with recurrent ovarian cancer receiving pegylated liposomal doxorubicin (Caelyx®/Doxil®)<sup>21</sup>.**

Study design: quasi-experimental. Country: Canada

n=112 women with ovarian cancer	• Ovarian cancer and chemotherapy;	<u>Treatment adherence</u> : 59% of participants completed 4 or more chemotherapy cycles. 75% of participants completed more than 3 chemotherapy cycles; 6.25% withdraw from treatment due to side effects. At the end of the 2 <sup>nd</sup> , 4 <sup>th</sup> and 6 <sup>th</sup> chemotherapy cycles the clinical condition was stable or improved in 65.4%, 54.2% and 67.5% of participants, respectively.
Age: years (32-87 years).	• Management of side effects.	
No control group.		

**STUDY 11: Effect of Educative-Supportive Program on Quality of Life in Breast Cancer Survivors<sup>22</sup>.**

Study design: quasi-experimental. Country: Thailand

n=66 women with breast cancer.

Experimental group: n=33; years.

Control group: n=33; years.

- Self-care activities;
- Coping strategies;
- Uncertainty and hope;
- Health behaviour;
- Stress, fear of recurrence and self-relaxation;
- Stress and relaxation techniques.

Quality of life: a decrease without significant differences were found in all participants (42<sup>nd</sup> day: and 3 months after).

Self-care:

Experimental group: getting back to daily life activities ; perception of changes in daily living ; and self-relaxation using cassette tape provided .  
Control group: guilty feelings ; no adjustments to daily life activities ; and unmonitored relaxation exercises .

**STUDY 12: Effects of a Brief Psychosocial Intervention in Patients With Cancer Receiving Adjuvant Therapy<sup>23</sup>.**

Study design: quasi-experimental. Country: Republic of Korea

n=71 patients with cancer.

Experimental group: n=37.

Control group: n=34.

- Self-care and self-efficacy;
- Symptoms management;
- Coping strategies and problem-solving;
- Relaxation techniques;
- Health behaviours;
- Relationships.

Fighting spirit: significant improvement found in the intervention group compared to the control group

Helplessness/Hopelessness: improved in the control group and decreased in the intervention group, without significant differences .

Self-care: significant improvement found in the intervention group compared to the control group .

Depression: improved in the control group and decreased in the intervention group, without significant differences

Anxiety: no significant differences were found , although the control group showed a higher increase.

**STUDY 13: A pain education programme to improve patient satisfaction with cancer pain management: a randomised control trial<sup>24</sup>.**

Study design: experimental. Country: Republic of China

n=136 (68 patients with cancer and 68 significant family members)

Experimental group: n=68; years.

Control group: n=68; years.

- Pain management;
- Usage of analgesics.

Satisfaction pain management: higher in the intervention group .

Analgesic adherence: participants satisfaction was a mediator between barriers to using analgesics and adherence to the prescribed use of analgesics , accounting for 47-73% of the observed mediation.

**STUDY 14: Evaluation of a Comprehensive Rehabilitation Program for Post-Treatment Patients With Cancer<sup>25</sup>.**

Study design: quasi-experimental. Country: United States of America

n=36 persons with cancer; years.

No control group.

- Physical exercise;
- Self-confidence and autonomy;
- Adaptation;
- Fatigue, anxiety and stress;
- Return to work;
- Nutrition.

Quality of life: significant reduction (.)

Fatigue: significant reduction (.)

Depression: significant reduction (.)

Pain: significant reduction (.)

Dyspnoea: significant reduction (.)

Anxiety; anguish; nausea; insomnia; loss of appetite; bowel obstruction and diarrhea: no significant differences were found.

nursing interventions improved the perceived quality of life of participants, except for study 11 that registered a decreased quality of life of the intervention and control groups, despite no statistically significant differences found between the groups. There was also a decrease in the quality of life of the intervention group in study 4, both after three months and twelve months.

The health condition was analysed in study 17 and all participants showed improvements in this indicator, with no difference found between those receiving usual care and those viewing videos and/or being provided with telephone counselling. Contrarily, in study 4, participants who benefited from the psychosocial intervention felt more ill compared to the other participants. Nurse-led interventions significantly improved self-care (studies 1, 11 and 12), in particular knowledge about the disease and treatments<sup>22</sup>.

Adherence to treatment was assessed in three studies (studies 10, 13 and 22). In the first study, the psycho-educational intervention helped to reduce the severity of the palmar-plantar erythrodysesthesia and mucositis, caused by chemotherapy, which contributed for patients' prolonged adherence to treatment. The results from study 13 showed that the implementation of an educational programme on pain mana-

**STUDY 15: Effects of cancer rehabilitation on problem-solving, anxiety and depression: A RCT comparing physical and cognitive-behavioural training versus physical training<sup>26</sup>.**

Study design: experimental. Country: Netherlands

n=209 patients with cancer.	Group PT (Physiotherapist):	<u>Problem-solving:</u>
Group PT (Physical exercise): n=71; years.	• Exercise and exercise physiology;	At 12 weeks and 3 months the groups PT and PT+CBT show rational problem-solving levels and positive problem orientation, similar to the overall population . At 9 months only the group PT+CBT has maintained the rational problem solving, similar to the overall population.
Group PT+CBT (Cognitive-behavioural training): n=76; years.	• Disease representation;	Participants of groups PT and PT+CBT showed higher negative orientation to the problem and impulsive behaviours compared to the overall population.
Control group (with access to other interactive platforms): n=62.	• Self-management.	No significant differences were found between PT and PT+CBT groups compared to the control group.
	Group PT+CBT (Psychologist + Nurse):	<u>Anxiety and depression:</u>
	• Problem-solving;	A significant reduction was found, with no differences compared to the overall population, except for group PT+CBT that showed higher anxiety levels at 3 and 9 months and higher levels of depression at 9 months , although values were lower in relation to the start moment.
	• Self-management abilities;	The groups PT and PT+CBT showed significant reduction levels in anxiety compared to the control group: PT ( ) and PT+CBT ( ).
	• Fight for personal goals;	As for depression, no significant differences were found between the groups PT and PT+CBT and the control group.
	• Sharing of experiences;	
	• Stress and relaxation techniques;	
	• Fatigue and exercise;	
	• Disease representation;	
	• Optimism and self-efficacy.	

**STUDY 16: The Pro-Self Pain Control Program Improves Patients' Knowledge of Cancer Pain Management<sup>27</sup>.**

Study design: experimental. Country: Norway

n=179 persons with bone metastases.	• Pain and assessment;	<u>Knowledge on pain and pain management:</u> higher for the intervention group compared to the control group ( .
Experimental group: n=87; years.	• Side effects management;	No significant differences were found in the control group for the 9 items analysed. Statistically significant differences in results were found between the intervention group and the control group ( .
Control group: n=92; years.	• Pillbox instructions;	
	• Communication with physician;	
	• Management of the therapeutic regimen;	
	• Readjustment in the analgesic prescription.	

**STUDY 17: The effects of psychoeducation and telephone counseling on the adjustment of women with early-stage breast cancer<sup>28</sup>.**

Study design: experimental. Country: United States of America

n=249 women with breast cancer ( years).	• Coping strategies;	<u>Frequency of side effects:</u> reduction in all individuals, with no significant differences between the groups.
Group 1: Control group.	• Treatments and side effects;	<u>Severity of side effects:</u> increase in all individuals, with no significant differences between the groups.
Group 2: Psycho-educational videos (A).	• Recovery after surgery;	<u>Health condition:</u> improvement in all individuals, with no significant differences between the groups.
Group 3: Telephone contacts (B).	• Cancer experience;	<u>Emotional adaptation:</u> increase in psychologic well-being in group 3 between the beginning of the study and surgery and a decrease after surgery ( ). No differences were found in the psychologic well-being of individuals in the other groups. The impact of side effects increased in the control group ( ). No significant differences were found in the remaining groups.
Group 4: A + B.	• Clarifying questions;	<u>Social adaptation:</u> the impact of the disease in social life increased for all the participants, with no significant differences found between the groups.
	• Community resources;	
	• Health behaviours;	
	• Communication;	
	• Self-conception.	

**STUDY 18: Effects of an Internet Support System to Assist Cancer Patients in Reducing Symptom Distress<sup>29</sup>.**

Study design: experimental. Country: Norway

n=325 patients with breast cancer (n=189) and prostate cancer (n=136).

Experimental group: n=162; years.

Control group: n=163; years.

- Self-monitoring;
- Communication;
- Symptoms management;
- Self-management activities;
- Treatments and side effects;

Emotional disturbance: stress has decreased in the experimental group and increased in the control group ().Depression: significant reduction in the intervention group (), with no significant differences found between groups.Self-efficacy: significant reduction in the control group (), with no significant differences found between groups.Quality of life: significant reduction in the control group (), with no significant differences found between groups.Social support: no significant differences were found between groups.**STUDY 19: Effects of a Psychoeducational Versus a Support Group Intervention in Patients With Early-Stage Breast Cancer<sup>30</sup>.**

Study design: experimental. Country: Norway

n=367 women with breast cancer

Experimental group (PEG):

n=185; years.

Experimental group (SG):

n=182; years.

Multidisciplinary psycho-educational intervention

(PEG):

- Breast cancer and surgery;
- Treatment and side effects;
- Exercise and relaxation;
- Community resources;
- Coping strategies.

Peers group intervention

(SG):

- Treatment and side effects;
- Self-image;
- Misperceptions clarifying;
- Sharing of experiences and feelings;
- Reconstructive surgery;
- Genetic counseling.

Depression and anxiety: at 12 months, the groups showed a reduction of approximately 40% in anxiety and 50% in depression, with no significant differences between the groups.Mental status: at 2 and 6 months the group PEG, compared to the group SG, showed a significant reduction of ineffective coping strategies () and a significant increase of positive attitudes (). At 2 months, participants of group PEG were more optimistic than participants of group SG (). At 6 months, a reduction of pessimist behaviours was found in group PEG compared to the group SG. At 12 months no statistically significant differences were found between the groups.**STUDY 20: A Tailored Web-Based Psycho-Educational Intervention for Cancer Patients and Their Family Caregivers<sup>31</sup>.**

Study design: quasi-experimental. Country: United States of America

n=88 (44 persons with cancer and 44 family caregivers).

No control group.

- Family involvement;
- Symptoms management;
- Coping strategies;
- Fear, uncertainty and optimism;
- Positive aspects of the disease.

Stress: significant reduction (Quality of life: significant improvement (Perception of positive aspects of the disease and caring: significant improvement (.Communication and Social Support: no differences were found.**STUDY 21: The effectiveness of a rehabilitation programme for Chinese cancer survivors: A pilot study<sup>32</sup>.**

Study design: experimental. Country: Republic of China

n=47 patients undergoing a last chemotherapy session.

Experimental group: n=24; years.

Control group: n=23; years.

- Treatment;
- Nutrition and physical exercise;
- Coping strategies;
- Support;
- Self-efficacy;
- Relaxation techniques;
- Fatigue.

Self-efficacy: significant improvement in the experimental group compared to the control group ().Mood disturbance: significant improvement in the experimental group compared to the control group ().Quality of life: significant improvement in the experimental group compared to the control group ().

Self-efficacy is a predictor of quality of life and less mood disturbance.

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**STUDY 22: Impact of tailored patient education on adherence of patients with chronic myeloid leukaemia to tyrosine kinase inhibitors: a randomized multicentre intervention study<sup>33</sup>.**

Study design: experimental. Country: Finland.

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n=68 persons with myeloid leukemia.

Experimental group: n=35; years.

Control group: n=33; years.

- Knowledge of the disease;
  - Importance of the medication regimen;
  - Management of side effects;
  - Psychosocial support.
- Adherence to treatment:** an increase of 51% for intervention group and an increase of 21% in the control group participants. Significant differences were found between groups ().
- Patients were most satisfied with face-to-face counselling and the information booklet and least satisfied with text messages.
- 

gement was a mediator to analgesic adherence, significantly increasing the patients' satisfaction with the pain management provided by nurses. In the intervention group of study 22 adherence to the medication regimen increased in 51%, compared to the control group, with an increase of only 21%.

Nine studies analysed the effect of the intervention on anxiety and depression symptoms (studies 2, 3, 4, 9, 12, 14, 15, 18 and 19). The majority of these studies reported a reduction in anxiety and depression after the intervention, however no statistically significant differences were found in relation to the control group, except for study 3. In study 14 a significant reduction in depression was found, but not in anxiety. The psychosocial adaptation to the disease was examined in nine studies (studies 2, 6, 7, 12, 17, 18, 19, 20 and 21). These studies examined, in particular, the attitudes towards diagnosis, fear of recurrence, acceptance or anger feelings, the ability or motivation for self-management (study 7), the fighting spirit and hopelessness (study 12), mood disturbance (studies 2, 6 and 21), emotional distress (studies 18 and 20), psychosocial well-being (study 17) and mental condition (study 19). The emotional distress of participants in study 20 was significantly reduced. In study 12 an increase in hopelessness was found in control group subjects and a reduction in the intervention group. In study 18 a reduction in stress was found in the intervention group and an increase in the control group. The intervention implemented in study 19 promoted the development of positive attitudes and a decline in the usage of non-adaptive coping strategies. In the majority of studies, the psychosocial adaptation was significantly higher for the intervention group, except for study 6, which showed improvements in all participant's mood, hence, no significant differences were found between the two groups, statically speaking.

Finally, satisfactory results were found in the reduction of symptoms and side effects of the disease (studies 1, 2, 6, 8, and 14). In study 2, participants receiving the muscular relaxation intervention and guided imagination, in the first four months after chemotherapy, showed a significant reduction of frequency and duration of vomiting and nausea compared with those receiving usual care. Contrarily to these findings, the psycho-educational intervention used in study 17 did not produce significant results on the frequency and severity of the side effects of the disease and treatment of women with breast cancer.

Overall, the results of this study show a positive impact of the nurse-led psychosocial interventions, on the self-management of the oncological disease, expressed in multiple outcomes. Several studies have reported a decrease in disease symptomatology, stress, fear and uncertainty feelings, after nurse-led interventions. The benefits of the interventions were also evidenced in the psychosocial adaptation, in self-care, in adherence to the therapeutic

regimen, in the perception of quality of life, in the satisfaction with the nurses' role, in self-efficacy, in stress management and in patients' interpersonal relationships. Nonetheless, in two studies, the results do not clearly confirm the benefits of the provided psychosocial support<sup>22,26</sup>.

Other literature reviews support these results, for example, a study on the effectiveness of interventions to promote self-management of cancer pain, concluded that the three most effective interventions have been implemented by nurses<sup>34</sup>. Similarly, in the assessment of the effectiveness of interventions focused on self-management and the behavioural change in persons with heart disease, hypertension or diabetes type II, nurses played a key role in education, counseling and in promoting adherence to treatment<sup>35</sup>. Alongside these results, other studies were found that did not suggest the same evidence. For example, an intervention provided by specialist nurses targeting womens with breast cancer, did not produce beneficial effects in the process of transition and adaptation to the disease<sup>36</sup>.

Concerning the conceptual framework, only three of the studies included in this systematic review use intervention programmes supported by the theory of self-efficacy<sup>12,23,32</sup>. Self-efficacy proved to be a mediator between mood disturbance and quality of life<sup>32</sup>, to be associated with the improvement in quality of life and the reduction of symptoms of

emotional distress<sup>23,32</sup> and to a positive effect on self-care behaviours<sup>12</sup>. The results of these three studies are similar to the conclusions of another systematic review that analyzes self-management interventions, based on the theory of self-efficacy, in patients with stroke<sup>37</sup>. This systematic review confirms emerging evidence of benefits to be gained from programmes that target self-management based on self-efficacy principles; however, the optimal format of delivering these interventions for stroke survivors is not clear<sup>37</sup>. Since our review included 22 studies, and only three studies use self-efficacy principles, it is not possible to assess the benefits of this theory in intervention programmes. Existing evidence emphasizes the importance for patients to play an active role in the management of the chronic disease<sup>2,37,38</sup> and that communication between patients and health care professionals allows people to feel part of the treatment process, very likely to result in positive health outcomes<sup>24</sup>.

In what concerns the content of interventions, the majority of the studies was focused on the promotion of knowledge and skills training. The knowledge was related to aspects such as: oncological disease (diagnosis, treatments, complications and prognostic), life styles, sexuality, health surveillance and interpersonal relations (family relationships and communication with health professionals). The development of abilities focused on areas related to: self-care, prevention and management of the adverse side effects of treatments, management of symptoms, relaxation and physical exercise.

As for the resources used in the implementation of interventions, the programmes included a wide variety of strategies such as pamphlets, booklets, books, audiovisual material (e.g. interactive CD-ROM), support groups, interactive platforms and telephone contacts. The most adopted resource was written and audiovisual materials, a similar result to the one found in another systematic review addressing the strategies used to control cancer pain<sup>34</sup>. This strategy might have been used considering the need to balance the cost-effectiveness of interventions. As an example, the use of electronic educational material proved to be sufficient for the promotion to the adaptation process of women with breast cancer, particularly compared with the costs associated with telephone contacts<sup>17</sup>.

Notwithstanding, the single dissemination of information through written or electronic material, without the use of educational sessions, can limit the way how people apply that knowledge in the promotion of their own health, adding the difficulty in ascertain the degree to which booklets and leaflets were actually read<sup>38</sup>. The use of written material to provide can highly benefit from other strategies as face-to-face contacts.

In this systematic review, the face-to-face contact was widely used and in seven of the analyzed studies, the face-to-face intervention was complemented with telephone contacts, showing positive outcomes in cancer self-management<sup>14,16,23,24,27,28,32</sup>. The face-to-face contact was also an intervention strategy mentioned in other literature reviews, for example, in the analysis of studies focusing self-management of pain in cancer patients, the face-to-face contact was used in 20 of the 24 retrieved studies<sup>34</sup>.

In four of the analysed studies, the intervention was implemented exclusively through telephone contacts<sup>17,20</sup>, or interactive platforms<sup>29,31</sup>. Literature also suggests the telephone contact as an efficient strategy to promote self-management of the disease in people with colorectal cancer<sup>39</sup> or prostate cancer<sup>40</sup>. On the other hand, interactive platforms are increasingly used to inform and treat patients, allowing quick and easy access to infinite contents, but the evidence was not fully convincing to confirm the effectiveness of e-health interventions for patients with chronic disease<sup>41</sup>. Similarly, in this

systematic review, it is not possible to demonstrate the benefits of interactive platforms in the self-management of the disease in women with breast cancer, particularly with regard to emotional symptoms, quality of life and perception of self-efficacy<sup>29</sup>. Notwithstanding, other review associate interactive platforms to a positive effect on knowledge, social support, behaviours, patient's clinical condition and experience of the oncological disease<sup>42</sup>. The interactive platforms can be important tools for future interventions, however, the face-to-face contacts seem to have a higher impact in self-management of patients with chronic diseases<sup>38</sup>.

It is not possible to establish a direct relationship between the types of contact and outcomes, or to conclude that the educational sessions are more beneficial than the written information. It should be noted that the high mortality rate in one study sample suggests that some participants were not available to participate in all the sessions of the self-management programme<sup>23</sup>. This fact seems to emphasize the importance of using telephone contacts and interactive platforms to overcome patients' constraints to attend the therapy sessions<sup>42</sup>. In addition, this will likely enable participants to complete the programmes, since they are able to assure the intervention sessions in their own homes and at more convenient time<sup>31</sup>.

The programmes were conducted in periods ranging from one week to 13 months, hindering the possibility of establishing the ideal duration of a programme on the promotion of the self-management of the oncological disease. In other literature review studies on the self-management of the chronic disease, the interventions varied between three and 18 months<sup>43</sup>, one month and two years<sup>35</sup>, or 6 days and 16 weeks<sup>44</sup>. It's not possible to establish an association between the duration of interventions and the related outcomes<sup>34,35,44</sup>, however it must also be



considered that, in some studies, the intervention did not last long enough to achieve better outcomes<sup>23,27</sup>. Follow-up sessions seems to be an effective way to overcome constraints related with the reduced duration of interventions, since it provides continuous support and monitoring, encouraging patients to adopt or maintain healthy behaviours<sup>24,35</sup>. For example, the weekly 10-minute telephone contacts promoted self-efficacy and the perception of quality of life in patients undergoing chemotherapy<sup>32</sup>.

Finally, and considering participants involved in the interventions, there seems to be no differences in the approach, whether through individual interventions or in a group context. The support groups can constitute an effective strategy in a way they facilitate the exchange of experiences and feelings, encouraging people to believe that they are also capable of facing the disease challenges<sup>30,32,34</sup>. In three selected studies, the intervention was extended to the significant person and/or family caregiver<sup>20,24,31</sup>, showing positive and synergic effects, enhancing the benefits of the intervention in cancer patients<sup>20,24</sup>.

Through the performed analysis, the following items emerged to be considered in the planning of programmes to promote self-management of cancer patients:

1. The content of the interventions.
2. The duration of the intervention, considering period, number of sessions and duration of each session.
3. The type of contact (face-to-face or other).
4. Used resources.

## Conclusion

Irrespective of the multiplicity and the particularities of the studied interventions, the results indicates that the participation of patients in nurse-led psychosocial intervention programmes is beneficial to physical and psychological health (meaning better quality of life, decreased anxiety and depression) and helps in behavioural change (meaning adherence to medication, symptoms management, lifestyles, communication with health professionals and relationship with significant others) and therefore promotes cancer self-management.

Results also suggest that face-to-face contacts and follow-up through telephone contacts are more effective than the use of written material. The financial constraints and availability of people to attend the sessions can explain why the combination of face-to-face intervention with other strategies (written material, audiovisual material, telephone contacts and interactive platforms) are often more appealing and effective.

Since only three studies reported data on theoretical construct for the development of interventions, it is recommended to focus future study analysis on the importance of the theoretical framework for the planning and implementation of nursing therapeutics. Further research in this area may contribute to determining an optimal duration of interventions and to identify the main contents to be included in nursing programmes aimed at promoting self-management of the oncological disease.

Nurses play an important role in the follow-up and support of people suffering from a chronic disease such as cancer and they should be able to develop self-management programs involving patients, providing them with all necessary information and training skills to cope with the disease, treatments and side effects.

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# Communication: subsidy for a specialized nursing intervention promoting the quality and effectiveness of care

## Summary

Communication is a dynamic, complex and permanent process, composed of expressive discourse (production) and receptive (understanding), with the purpose of mutual understanding between its participants.

This process, which in itself is already complex and where there are several failures in daily life, is often hampered by changes in the health of one of the actors. This is an increasingly present reality in hospital inpatient services either by functional or structural changes becoming a challenge for health professionals.

For nurses communication is especially important because they are in constant relation/interaction with their clients and their families/caregivers.

The quality of care is closely related to the quality of the relationship established and, consequently, to the respective communication. In this way, understanding and understanding are important aspects of the quality of care. These are central and essential to identifying the care needs of each client and their respective family/caregiver.

However, its due value is not always attributed to it, and it should be a specialist nurses' concern to have a mastery of relational and communicational skills.

This article of integrative review of the literature aims to identify how the communication within the scope of the Specialized Nursing Intervention can subsidize the quality and effectiveness of the care provided by nurses in a hospital context.

KEYWORDS: COMMUNICATION; COMMUNICATION SKILLS; QUALITY OF HEALTH CARE; NURSING CARE.

## Introduction

The word communicate comes from Latin and means “putting into common”, “relating to”, sharing (ideas, emotions, culture, etc.). It is a dynamic, complex and permanent process, composed of expressive discourse (pro-

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duction) and receptive (understanding), with the purpose of mutual understanding between its participants<sup>1</sup>.

This process “allows an adaptation to the environment, as well as modifying and transforming it, building social reality”<sup>1</sup>.

Then, the communication presents a comprehensive component between the actors as well as a component of change, especially about their environment. These two components are of the utmost importance for nursing care, where the change in the health / illness status of clients requires a transformation or adaptation of their environment with a view to their autonomy and independence, as well as their social integration.

In other words, communication can lead to health/illness states (depending on the form and content each communicates) or a means by which the nurse identifies needs and proposes their plans of action.

For nurses communication is es-

pecially important because they are in constant relation / interaction with their clients and their families / caregivers.

The quality of care is closely related to the quality of the relationship established and, consequently, to the respective communication. In this way, understanding and understanding are important aspects of the quality of care. These are central and essential to identifying the care needs of each client and their respective family / caregiver.

However, its due value is not always attributed to it, and it should be a specialist nurses' concern to have a mastery of relational and communicational skills.

### Problem statement

Communication is a complex process in which there are several failures in nurses' clinical practice, often hampered by changes in the health of their clients. This is an increasingly present reality in hospital inpatient services either by functional or structural changes becoming a challenge for nurses who are in constant relationship/interaction with their clients and their families/caregivers.

### Research questions

How communication within the scope of the Specialized Nursing Intervention can subsidize the quality and effectiveness of the care provided by nurses in a hospital context?

### Purpose of the study

In the scope of the Specialized Nursing Intervention, we intend to identify the communication subsidy for the quality and effectiveness of care provided by nurses in a hospital context.

With this we seek the development of communication skills with a view to improving the quality of the specialized nursing care provided.

### Research methods

The methodology adopted to do this work had for his base the realization of the protocol of research of literature integrative revision, defining the question of investigation and limited criteria: type of participants, intervention, results and study, as well as research descriptors. For this, it was made a research in database, selection and extraction of information and an evaluation and analysis of results.

### Findings

It was observed that communication is, in the nurses' perception, central to the relationship between the nurse-client-family triad. Narrative procedures require the speaker to identify stages in the process and clear communication, which involves spoken language such as additional, especially gestural, modalities<sup>2</sup>.

According to Ramos & Bortagarai<sup>3</sup>, 65% of the communication is of a non-verbal nature, although verbal communication is more valued. According to the authors, this reality is due to the non-verbal communication being more time consuming and demanding from the interlocutors an increased attention.

It is clear that communication is all the more effective if it contemplates a verbal and non-verbal character, translating into a true interaction. However, priority is given to the use of technical verbal language<sup>4</sup>. The use of more than one communication technique allows an improvement in the nurse-client relationship as well as greater professional satisfaction. It is also

suggested the use of a theoretical model that relates the nursing intervention and the results obtained with the clients<sup>5</sup>.

### Conclusion

Quality in health requires an "optimal professional level", considering available resources, allowing customer compliance and satisfaction, adapting health care to identified needs and expectations, "requires an improvement in the efficiency and effectiveness of health care delivery"<sup>6</sup>.

Improving the quality of care provided translates into gains for health. These include better management of emotions, management of adverse situations, establishment of a relationship of help, information gathering, better construction and transmission of messages and empowerment of people.

Effective communication implies establishing/consolidating a therapeutic relationship, centered on interaction, identifying, understanding and satisfying the needs of clients and families, mirroring this intervention in their records. This is an indicator of the quality of Nursing Care.

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# Medication adherence and management in older people

## Identify and intervene

### Summary

Medication non-adherence rates in older people range between 45 and 75% due to several reasons. A descriptive, quantitative study is being conducted with the purpose of identifying older people's knowledge about medication management, their difficulties, and strategies used. The sample is composed of older people (aged 65 years or over) who use day care centers in Coimbra. Data are collected using a questionnaire designed by the authors. The AGITE (Adesão e Gestão por Idosos da TErapêutica, Older People's Medication Adherence and Management) tool has 4 open-ended questions and 26 closed-ended questions. It is used in combination with the 6-item Cognitive Impairment Test (6CIT) and the Graffar scale. The study was approved by the Ethics Committee of the Health Sciences Research Unit: Nursing, Nursing School of Coimbra. The final version of the questionnaire was applied to a sample composed of 128 older adults with a mean age of 78.24 years.

The preliminary results show that the questionnaire is easy to apply. With regard to its psychometric properties, and based on the exploratory factor analysis, three dimensions emerged with an acceptable internal consistency (0.6-0.8).

The AGITE tool may be an adequate tool for identifying older people's difficulties and designing nursing strategies to help them overcome these difficulties. For this reason, the study should continue being developed.

KEYWORDS: AGED; MEDICATION ADHERENCE AND MANAGEMENT; NURSE.

### Introduction

Medication adherence and management is a public health issue that involves health professionals, patients, and caregivers. Older people, chronically ill patients, and polymedicated patients are at higher risk for non-adherence, which is a growing concern for several institutions, namely the World Health Organization (WHO).

An adequate therapeutic adherence and management is one of the basic conditions for older people's active and healthy aging. Therapeutic non-adherence is a major concern due to older people's characteristics, particularly because, in addition to the demographic trends in Western society, many patients have multiple comorbidities (Parent et al., 2016)<sup>1</sup>.

One of the priorities for the implementation of specific measures for these populations is the identification of how older adults adhere to and manage their medication. This is even more important because, according

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to Culig & Leppée (2014)<sup>2</sup>, 70% of non-therapeutic adherence situations can be explained by health professionals' lack of knowledge about the problem and patients' lack of awareness.

The genetic, environmental, and personal characteristics of each individual influence his/her experience of the aging process. However, the risk of physiological and functional changes is a reality of the elderly population. The increase in average life expectancy leads to a significant increase in the need for an increasingly complex medication regimen, with polymedication rates around 30-70% among the elderly population (Bronskill et al., 2012<sup>3</sup>; Maher, Hanlon & Hajjar; Nobili et al., 2011<sup>4</sup>).

Medication-taking ability refers to a person's ability to accurately follow a prescribed medication regimen (Cross et al., 2016)<sup>5</sup>. This competency is intrinsically associated with the ability to manage, that is "...being in charge of and bringing order to somebody or something ..." (p. 97) and exerts a major influence on adherence rates.

Patients' non-adherence is a ma-

major issue, particularly in developed countries. According to the WHO, only 50% of patients adhere to treatment in these countries (Brown & Bussell, 2011<sup>6</sup>; Culig & Leppée, 2014<sup>2</sup>). The high non-adherence rate is associated both with patients' lack of awareness about the risks and health professionals' lack of knowledge of the situation (Culig & Leppée, 2014<sup>2</sup>).

There are several strategies to assess this multidimensional phenomenon: pill counting, self-reported questionnaires, electronic devices, and scales. However, since there is no evidence on the effectiveness of multiple approaches (Culig & Leppée, 2014<sup>2</sup>; Lam & Fresco, 2015<sup>7</sup>).

There are multiple barriers to older people's therapeutic adherence and management, including those related to the individual, the medication, the health professional, the health system, among others (Yap, Thirumoorthy & Kwan, 2016<sup>8</sup>). In Portugal, Henriques (2011)<sup>9</sup> identified the following barriers: forgetfulness, medication unavailability, economic factors, and the lack of understanding of the importance of medication. This author also identified the need for empowerment strategies aimed at improving older adults' therapeutic adherence and management.

Since Portuguese society is following the demographic trends of Western society, this study aims to understand how Portuguese older adults manage their medication regimen. Therefore, the research project "Older Adults' Therapeutic Adherence and Management" was implemented with the purpose of identifying older adults' medication-taking behaviors (MTBs). The authors designed an instrument for data collection. This article describes the process of design and validation of the data collection tool.

### Methodology

Given the diversity of variables involved in MTBs, research in this area has become a priority. However, the multiple tools used to identify how older people adhere to and manage their medication are not able to encompass as many dimensions as possible, thus preventing the implementation of empowerment strategies for this population. Therefore, the authors decided to design and validate a data collection tool as comprehensive as possible and adequate to the elderly population and the study objectives.

The first step was to identify the wide range of instruments used to identify therapeutic adherence and management behaviors among this population. In addition, a literature search was conducted on this topic with the purpose of identifying the state-of-the-art.

Based on the data obtained, a preliminary version of the instrument was designed, mostly composed of open-ended questions. This version was applied to 20 older adults. The results were analyzed by the researchers and, based on them, a new version of the questionnaire was designed that is more like the current version. After a new application to a sample of 60 older adults, terms were analyzed and adjusted, and some questions were changed. The final version of the tool, entitled AGITE (Adesão e Gestão por Idosos da TERapêutica), is composed of four open-ended questions and 26 closed-ended questions. It is used in combination with the 6CIT and Graffar scale, thus allowing to identify some risk factors for MTBs.

### Research questions

Is the AGITE tool a reliable data collection tool for assessing therapeutic adherence and management in older adults?

### Specific objectives

- To assess the psychometric properties of the AGITE data collection tool;
- To identify the dimensions by analyzing the structure of the AGITE data

collection tool.

### Purpose of the study

To test and validate the AGITE data collection tool with the purpose of identifying and systemizing the medication adherence and management in older adults.

### Research methods

Psychometric properties were tested through a factor analysis of the instrument's items using a Principal Components Analysis (PCA). Orthogonal varimax rotation was applied to maximize loadings. Cronbach's alpha was calculated to assess the internal consistency of the instrument's dimensions.

### Population

Older adults attending social facilities for independent older people (Senior University, Municipal Support, Primary Care Centers, Hospital outpatient consultations).

### Inclusion criteria

Participants aged 65 years or more, perceiving themselves as capable of preparing and managing their medication, with or without the help from others, cognitively competent (maximum score of 7 in the 6CIT), and agreeing to participate in the study by signing an informed consent form.

### Findings

Three dimensions emerged from the PCA and the scree plot (figure 1) obtained using varimax rotation, which explained 39.93% of the total variance: "Engagement", "Neglect", and "External Influences" (table 1). These dimensions showed questionable to acceptable internal consistency ( $0.6 < \alpha < 0.8$ ) (table 2).

With regard to the analysis of the items in each dimension, higher scores of "Engagement" indicate a responsible attitude towards self-management and adherence. Higher scores of "Neglect" reflect a tendency to discontinue medication

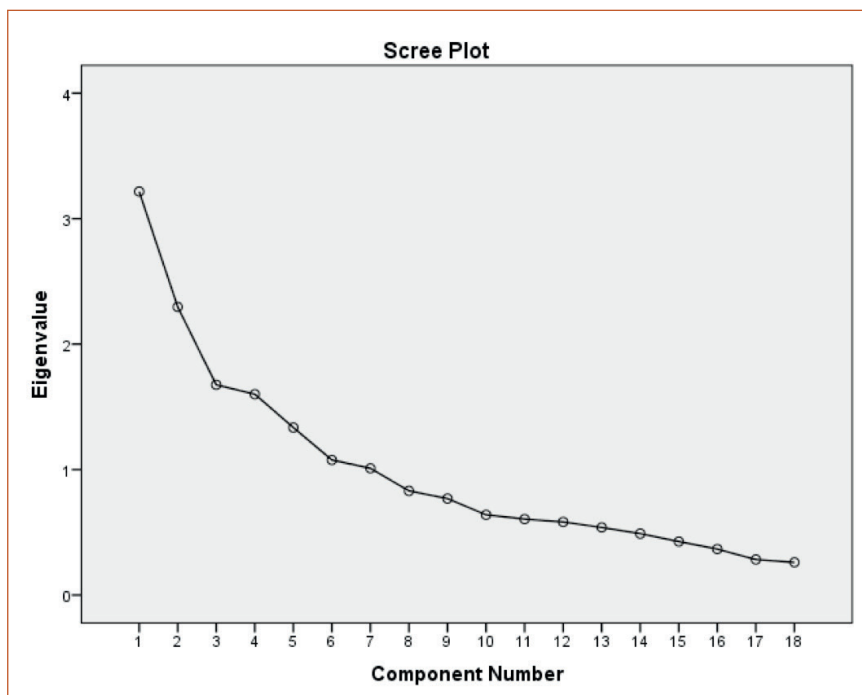


Figure 1. Scree Plot

ROTATED COMPONENT MATRIX USING VARIMAX ROTATION WITH KAISER NORMALIZATION

1

Items	Engagement	Neglect	External Influences
Q1	.797		
Q3	.675		
Q10	.668		
Q9	.611		
Q2	.609		
Q7	.482		
Q11	-.479		
Q13	.368		
Q16		.679	
Q6		-.619	
Q14		.534	
Q15		.522	
Q5		-.476	
Q12		-.456	
Q17			.619
Q8			.594
Q18			.433
Q4			-.418

without professional advice. Finally, high scores of “External influences” show a predisposition to adhere to medication, but without taking responsibility for the process.

### Discussion

The AGITE tool was applied to 128 older adults with a mean age of 78.24 years. The following risk factors for therapeutic management were identified: 24.4% had orientation (time/space) difficulties, 76.4% had a visual impairment, 35.8% lived alone, and 21.8% were illiterate. Most respondents considered that it was important to take their medication daily and believed in the effects of medication on their quality of life. Forgetfulness or memory loss were the most common difficulties reported by them.

Several studies and instruments have been developed to identify MTBs. The authors decided to design an instrument after a review of the existing instruments and an analysis of the specificities of the population under study, namely their literacy levels, sensory and cognitive impairment, and living conditions. Simultaneously, this study aimed to obtain relevant information on the use of other products with therapeutic effects (teas and others), prevailing medication, beliefs, and information needs on the use of medicines, among other elements. The AGITE (Adesão e Gestão por Idosos da Terapêutica, Older People’s Medication Adherence and Management) tool has four open-ended questions and 26 closed-ended questions. It is used in combination with the Six-item Cognitive Impairment Test (6CIT) and the Graffar scale. The exploratory factor analysis allowed identifying three dimensions and the psychometric properties indicate an acceptable internal consistency.

### Conclusion

Several studies and instruments are used to identify MTBs. Following a review of the existing instruments

## INTERNAL CONSISTENCY OF THE DIMENSIONS

2

Dimensions	Cronbach's Alpha
Engagement	0.783
Neglect	0.717
External Influences	0.607

and the analysis of the specificities of the population under study, namely literacy levels, sensory and cognitive impairment, and living conditions, the authors decided to design the AGITE tool. Simultaneously, this study aimed to obtain relevant information on the use of other products with therapeutic effects (teas and others), prevailing medication, beliefs, and information needs on the use of medicines, among other elements.

After one year of data collection and several changes, the final version of the AGITE questionnaire has four open-ended questions and 26 closed-ended questions. It is used in combination with the 6CIT, which allows identifying risk factors for MTBs, and the Graffar scale, which characterizes the socioeconomic conditions of the population under study. Three dimensions emerged from the exploratory factor analysis and the psychometric properties indicate an acceptable internal consistency. In addition, the AGITE tool is easy to apply and well-accepted by those involved and creates a relational space that is cherished by older adults. It can be a useful tool to achieve the objectives set out for this study.

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# Elderly people with limited mobility: their families and the implications of their dependency

## Summary

**INTRODUCTION AND OBJECTIVES.** The family has suffered several changes throughout the times, leading to many elderly people living alone or with other elderly. In a family the situation of the elderly that depended on others can compromise the family's relationships, which leads to little availability to motivate them to mobilization. The objective of the study was to understand the way the family functions in view of to the dependence of the elderly with limited mobility in a community context.

**METHODOLOGY.** Descriptive study, exploratory of a quantitative character. The data was gathered through a questionnaire, including the Lawton & Brody (1969) scales, the lifestyle profile (Nahas, 2013) and the familiar APGAR (Smilkstein, 1978). Non-probabilistic sample, composed by 1298 elderly with limited mobility, from 26 civil parishes from the municipality of Vila Nova de Famalicão.

**RESULTS AND DISCUSSION.** Most of the people polled considered that his own family was a functional one (64.8%) and 49.6% were moderately dependent. By analysing the physical activity lifestyle profile and the familiar functionality one could conclude that 65.2% had a positive profile, presenting typical behaviours of an active lifestyle. We think that the fact that 73.1% are inserted in functional families had something to do with it. We have verified a perfect association ( $p = 0.000$ ) between dependency, lifestyle physical activity and familiar functionality – APGAR.

**CONCLUSIONS:** The results show that the family determines the lifestyle physical activity and the elderly's dependency. A functional family influences a positive physical activity profile, even in the elderly with limited mobility.

**KEYWORDS:** ELDERLY; MOBILITY; LIMITATION; FAMILY; NURSING.

## Introduction

Aging is a “common phenomenon to all living things [...], it is a dynamic and progressive process in which occurs morphologic, functional, biochemical and psychological changes that determine loss of the individual capacity of adaptation to the surrounding environment provoking a greater vulnerability and a bigger incidence of pathological processes”<sup>1</sup>.

In Portugal there is a demographic aging, that “translates into changes in the age group distribution of a population expressing a bigger proportion of the population with an advanced age” (INE, 2015, p. 1), to which one associates high indexes of dependency and limited mobility. “The elderly dependency index that relates the number of elderly people and the number of

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active working people (15 to 64 years old), has increased continuously between 1970 and 2014, going from 16 elderly people for every 100 active working people in 1970, to 31 in 2014”<sup>2</sup>.

The existence of diseases, social exclusion, isolation, inactivity and family dysfunction together with physical and cognitive and emotional dependency makes the all experience harder for the families and the elderly. The family needs support to the care of the elderly that present any kind of physical and/or mental diseases. Despite the social transformations that affect the distribution of roles amongst its members, family continues to be the natural space of protection, emotional and social support for the elderly<sup>3</sup>.

Families have become smaller and with a bigger number of elderly people. In the last decade “there was an increase in the changes that were happening in the family and in the place that it occupies in the society.

Nowadays families are few in number<sup>4</sup>, which causes changes in the familiar functionality and thus compromising the support, in the area of promotion healthy lifestyles.

This reality imposes the need to rethink the support model that is being used, in order to assure a bigger and better quality of life to the elderly and their family preferably in their own house. Our study has tried to identify how the elderly with limited mobility sees/understands/perceives the functionality of its own family, trying to characterise all the variables of the dependency and physical activity and understand its associations, and thus contribute to a more global intervention in the familiar environment.

## Methods

The objective of this study is to show the implications that the elderly dependent with limited mobility have in the families.

- This study is a part of the investigation “To live well with more age from the familiar context to the institutional support” which is being developed in the Escola Superior de Enfermagem do Porto (Porto Nursing School).
- We have defined as an inclusion criteria: all the elderly that say that they spent most of their time sitting down and/or walk short distances.
- Research Question: Is there any kind of association between the dependency and familiar functionality in the elderly with limited mobility?

The following objectives have been defined: to analyse the characteristics of the elderly with limited mobility; to understand the association between the familiar functionality and the dependency of the elderly with limited mobility and also between the familiar functionality and the physical activity of the elderly in a domiciliary environment; to analyse how the elderly with reduced mobility perceive the functionality of their own family in order to contribute to a wider intervention in the familiar environment.

This research is a quantitative, descriptive and exploratory one that was carried out in 26 civil parishes of a municipality in northern Portugal, with a non-probabilistic sample of 1298 elderly with limited mobility.

The variables that were taken into account were the dependency in the instrumental activities of everyday life; lifestyle physical activity and familiar functionality. The tool used to gather the data was a questionnaire that included a set of questions that aimed the social demographic characterisation, the Lawton & Brody scales<sup>5</sup>, the lifestyle profile according to Nahas<sup>6</sup> and the familiar APGAR of Smilkstein<sup>7</sup>.

The Lawton & Brody scale<sup>5</sup> allows the evaluation of the Dependency Index for the Instrumental Activities of Everyday Life that allow the person to adapt to its surrounding and to keep its independence in relation to the community. There are three, four or five different levels of dependency for each item and the highest score corresponds to a higher degree of dependency. This index varies between 8 and 30 points. Up to 8 it means that the person is independent; from 9-20 it means that the person is moderately dependent, it needs certain help; and higher than 20 it is severely dependent, it needs a lot of help<sup>8</sup>.

The Nahas scale<sup>6</sup> of the lifestyle profile, perceives the lifestyle of one individual so that it is possible to create strategies of intervention and directive sessions to reduce less healthy lifestyles. According to the author, the lifestyle profile includes 5 components of the person's lifestyle that influence their global health. The questionnaire includes 15 items with a score of zero (total absence of any characteristics) until three points (complete realization of the behaviour). A final score between 0-5 indicates that the individual is inactive; a score between 6-11 indicates that the individual is less active; a score between 12-20 indicates that the individual is moderately active and a score

of 21 or more points indicates that the individual is very active.

The familiar functionality was evaluated using the Familiar APGAR. This tool allows to measure the satisfaction of a family member in relation to the assistance given by the remaining members of the family, using five items which are defined by: Adaptation, Partnership, Growth, Affection and Resolve. A family can be considered functional or dysfunctional depending on the way that its members interact between themselves<sup>9</sup>. The final result of the Familiar APGAR classifies the kind of the familiar relationship: 7 to 10 points suggests a highly functional family; 4 to 6 points a family with a moderate dysfunction and 0 to 3 a family with an accentuated dysfunction. In the study we chose to group the results in only two categories: 7-10 –functional family and 0-6–moderately functional families.

The study of the variables was conducted through the analyses of the descriptive statistics, using the software program IBM SPSS, version 20.0.

The data collection was done in partnership with the Municipality of Vila Nova de Famalicão and the collaboration of the mayors of the civil parishes in the identification of the elderly over 65 years of age. In the first approach all were contacted regarding the interest and availability to participate in the study and signed the consent form. Right after they received the questionnaire and a date was agreed to retrieve the questionnaire. Later on, in the second contact, when the questionnaire was retrieved all the significant doubts were answered and the questionnaire completed. After the questionnaires were retrieved all the data was inserted in a database and were analysed.

All the ethical assumptions were taken into consideration regarding the health investigation and the human person namely the principles of beneficence, non-maleficence and justice.

ce. This study received a very positive view from the Health Ethics Commission from the Centro Hospitalar de S. João, EPE/FMUP, consent form no. 244/14.

### Findings

According to the results obtained the individuals that took part in the study were mainly women (71%), married (54.70%), with no schooling (54.5%), but who could read (88.6%) and write (77.3%), lives of the retirement pension (55.3%) and lives with an elderly over 65 years of age (81.4%). The age group that is most represented is the one between 70 to 79 years old 40.2%.

### Familiar Functionality and degree of dependency

In relation to the index of dependency one can verify that almost half of the elderly (49.6%) are moderately dependent, needing of some assistance with the Instrumental Activities of the Everyday Life. Over a quarter of the elderly (26.7%) presents itself with a severe dependency (table 1).

When we analyse the association between familiar functionality and the degree of dependency we verify that the elderly that considered their families moderately functional were moderately dependent (52.4%), followed by those who were severely dependent (31.6%), on the other hand those who considered their families as functional were also distributed with a higher frequency into the class of those moderately dependent (48.2%), followed by those who were independent with a representation of (27.8%).

When we analyse the dependency related to the familiar functionality we verify that for the elderly who are independent (76.1%), for those who are moderately dependent (62.9%) and for those who are severely dependent (58.4%) their families were evaluated as functional. Therefore we can say that the most part of the elderly (64.8%) considered their family functional and that in those families occurred all the degrees of dependency.

A statistics non-parametrical analyses was conducted using the test qui-table of Pearson to the nominal variables of dependency and functionality thus obtaining a value of  $p = 0.000$ , therefore we can say that there is a perfect association between functionality and dependency.

When we analyse the distribution of the functionality in all the categories of dependency by using the Kruskal-Wallis test for independent samples the value is 0.000, which confirms the difference of the distribution of the variables.

### Familiar functionality and physical activity familiar

When we analyse the physical activity by classes in these elderly we verify that the inactivity is the most frequent behaviour (43.6%) followed by those moderately active (29.4%). The physical activity is showed as a profile of a positive lifestyle in more than half of the sample (65.2%), more than a quarter of the remaining (34.8%).

By analysing the functional families we conclude that 73.1% had a

**DISTRIBUTION OF THE ASSOCIATION BETWEEN FAMILIAR FUNCTIONALITY AND THE DEGREE OF DEPENDENCY**

**1**

		APGAR		Total	
		Moderately functional	Functional		
Lawton classes	Independent	n	64	204	268
		% in Lawton classes	23,9%	76,1%	100,0%
		% in APGAR	16,0%	27,8%	23,6%
	Moderately dependent	n	209	177	563
		% in Lawton classes	37,1%	58,4%	100,0%
		% in APGAR	52,4%	24,1%	49,6%
	Severely dependent	n	126	177	303
		% in Lawton classes	41,6%	58,4%	100,0%
		% in APGAR	31,6%	24,1%	26,7%
Total	n	399	735	1134	
	% in Lawton classes	35,2%	64,8%	100,0%	
	% in APGAR	100,0%	100,0%	100,0%	

Note: n = number of elements of the sample; APGAR = familiar functionality.

## SAMPLE DISTRIBUTION ACCORDING TO THE ASSOCIATION BETWEEN THE PROFILE OF THE LIFESTYLE PHYSICAL ACTIVITY AND THE FAMILIAR FUNCTIONALITY

2

			APGAR		Total
			Moderately functional	Functional	
<b>Profile activity</b>	Negative Profile Lifestyle	n	226	226	452
		% in profile	50.0%	50.0%	100.0%
		% in APGAR	49.3%	26.9%	34.8%
	Positive Profile Lifestyle	n	232	614	846
		% in profile	27.4%	72.6%	100.0%
		% in APGAR	50.7%	73.1%	65.2%
<b>Total</b>		n	458	840	1298
		% in profile	35.3%	64.7%	100.0%
		activity	100.0%	100.0%	100.0%
		% in APGAR			

Note: n = number of elements of the sample; APGAR = familiar functionality.

positive lifestyle, verifying in the negative lifestyle a symmetrical distribution between the families. The remaining 34.8% that had a negative profile lifestyle were distributed equally (50%) for every type of family relationship.

Analysing the association between the lifestyle of physical activity and familiar functionality we can state that there is an association between the two variables ( $p = 0.000$ ).

The physical activity is showed as a profile of a positive lifestyle in more than half of the sample (65.2%), more than a quarter of the remaining (34.8%) present a profile of a negative lifestyle having the need of an intervention in this area (table 2).

By analysing the functional families we conclude that 73.1% had a positive lifestyle, verifying in the negative lifestyle a symmetrical distribution between the families.

## Discussion

According to the results obtained almost half the elderly that took part in the study are moderately dependent, needing of some assistance with the Instrumental Activities of the Everyday Life.

When we analyse the dependency related to the familiar functionality we verify that for the elderly who are independent (76.1%), for those who are moderately dependent (62.9%) and for those who are severely dependent (58.4%) their families were evaluated as functional. Therefore we can say that the most part of the elderly (64.8%) considered their family functional and that in those families occurred all the degrees of dependency.

The avaluation of a family functionality is a significant contribution to the intervention in the familiar environment because in a functional family there is consensus about the tasks and functions of its members for the resolution of problems. In the dysfunctional family there is no respect and no proper communication therefore it is a disarticulated family system<sup>10</sup>.

By looking at the familiar functionality and the degree of dependency we conclude that the majority had needs of assistance in the Instrumental Activities of the Everyday Life. Considering that 52.4% of the moderately dependent and 31.6% of the severely dependent in their families existed some

kind of commitment in the familiar functionality, which can be explained by the interaction in the family relations inherent to the task itself of taking care is more prone to the raise of stress and conflicts. On the other hand this reality might reveal a lack of preparation of the families to administer proper care to dependent elderly as shown in the study done by Reis et al.<sup>11</sup>

We verified a perfect association ( $p = 0.000$ ) between dependency and familiar functionality.

When we analyse the physical activity by classes in these elderly we verify that the inactivity is the most frequent behaviour (43.6%), what justifies the need to develop an intervention in this area. The elderly can improve and/or prevent the several pathologies that occur with old age through the adoption of healthy lifestyle as the practice of physical activity which should be encouraged<sup>6,12</sup>.

The physical activity is showed as a profile of a positive lifestyle in more than half of the sample (65.2%), more than a quarter of the remaining (34.8%) present a profile of a negative lifestyle having the need of an intervention in this area. Exerci-

se and mobility could improve the functionality and quality of life of older people with reduced mobility<sup>13</sup>.

By analysing the functional families we conclude that 73.1% had a positive lifestyle, verifying in the negative lifestyle a symmetrical distribution between the families. The physical activity should be practiced regularly<sup>14</sup>. By analysing the lifestyle profile physical activity and the familiar functionality we have verified that most of the elderly had a positive profile (65.2%) presenting behaviours and attitudes that promote an active lifestyle. We think that this fact is due to 73.1% of them belong to functional families.

Analysing the association between the lifestyle of physical activity and familiar functionality we can state that there is an association between the two variables ( $p = 0.000$ ). The implications of these results in the practical life reinforce the importance of the rehabilitation nurses to know the profile of lifestyle physical activity of the elderly population as well as their perception about the familiar functionality in order to implement programmes for the promotion of the health of the elderly adapted to the real needs.

### Conclusion

The elderly that took part in this study had limited physical activity, spent most of the time sitting down and walked short distances, thus presenting a positive profile of Lifestyle physical activity and were moderately dependent.

The results show that the family determines the lifestyle and the dependency of the elderly. A functional family influences a positive profile of physical activity, even in the elderly with limited mobility. One still verifies that the elderly need intervention to improve their lifestyles namely the physical activity.

The family functionality is associated with the positive profile of lifestyle and physical activity and independence even in the elderly with limited

mobility. The evaluation of the functionality of the families helps to determine the kind of intervention the rehabilitation nurse has to do with the elderly and their families particularly if these are moderately functional, limiting ways to oversee its functionality.

The rehabilitation nurse is a professional that is an important part of a multi-professional team that provides care to the elderly and their families with the objective to associate healthy lifestyles namely in the profile of lifestyle physical activity and an active aging. So it is important to investigate strategies to be adopted in the implementation of the rehabilitation programmes namely to prevent immobility, that include health education sessions, assuring a well succeeded aging process that includes the familiar context and contributing in this way to the improvement of the quality of the health practices addressed to the elderly.

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# Bullying and engagement among nurses

## Summary

Workplace bullying has become a growing issue among nurses, which can have a negative impact on engagement. Due to the relevance of this matter, the purpose of this study was to identify the presence of workplace bullying and engagement and to analyze the relationship between the two and the sociodemographic and professional variables among nurses.

This is a quantitative, cross-sectional and correlational study. The sample consisted of 173 primary care nurses from one of Azores' Islands (Portugal). The sample was of 88.4% female nurses; 58.4% of which 38 years old or older and with an average of 16.1 years of professional experience. A questionnaire was applied respecting the nurses' confidentiality, consisting of three groups for the nurses' sociodemographic, workplace bullying (NAQ-R) and engagement (UWES) evaluation.

Among the results, there was a prevalence of workplace bullying of 9.2%. Nurses 37 years old or younger, working a rotating shifts and with stressful work, were more exposed to workplace bullying. Good levels of engagement were identified (Mean = 4.3). Female nurses with partners and children, working fixed shifts, with 14 or more years of professional experience and who did not perceive their work stressful, presented higher levels of engagement. There was a negative relationship between workplace bullying and engagement.

The results of this study suggest the need to invest in antibullying policies / procedures and occupational health programs to minimize the impact of workplace bullying and to promote the maintenance of good levels of engagement among nurses.

KEYWORDS: BULLYING; ENGAGEMENT; NURSES; NAQ-R; UWES.

## Introduction

Workplace bullying is a psychosocial occupational risk that compromises working rights, the respect and the dignity of employees, a representative problem among nurses<sup>1,2</sup>.

Workplace bullying has been characterized as a repeated exposure to acts or negative behaviors at the workplace, at least once a week and over a period of at least 6 months<sup>3</sup>. Explanatory models of workplace bullying reveal its multifactorial nature<sup>3</sup>.

Among nurses, workplace bullying translates into harmful consequences at the physiological, emotional and social levels<sup>4</sup>.

While workplace bullying conveys a negative concept, engagement is defined as a positive affective-motivational mental state in relation to work, characterized by vigor, dedication and absorption<sup>5</sup>.

Among nurses, engagement may result in higher levels of personal initiative and motivation, well-being at work, profitability and commitment to the organization<sup>6</sup>.

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Workplace bullying and engagement can be related to each other. The antecedents and consequences of bullying can coexist as factors that reduce levels of engagement<sup>3,7</sup>. Thus, the occurrence of bullying can negatively influence levels of engagement<sup>8</sup>.

Due to the relevance of this subject and its impact on health organizations and nurses, a quantitative, cross-sectional and correlational study was developed, integrated in the Project “INT-SO [International – Occupational Health] – From contexts of work to occupational health of nursing professionals, a comparative study between Portugal, Brazil and Spain”, with the purpose of contributing to the implementation of programs that promote nurses' occupational health.

## Bullying among nurses

Workplace bullying refers to interpersonal or work-related negative acts that aim to humiliate, punish or disturb someone, occurring at least once a week for at least 6 months.<sup>3</sup> Workplace bullying occurs as a gradual process that can begin with a conflict over situations at work that may evolve into interperso-

nal conflicts and progressively into acts of stigmatization<sup>3</sup>. The prevalence of workplace bullying in different countries has been documented. For instance, as to self-labelled prevalence, in Europe, it was established at 5%<sup>9</sup>.

Among nurses, Lee et al.<sup>10</sup> presented an explanatory model of bullying based on four main factors: the aggressor's negative acts (aimed at professional erosion, competence and reputation of the victim through interpersonal and work-related attacks); the unbalance of power between the victim and the aggressor (in which the aggressor generally presents a higher level of formal or informal power); the negative effects on the victim (physical, psychological and professional); and the duration and frequency of the negative acts of the aggressor (workplace bullying is a gradual, cumulative process over time).

Workplace bullying is an emerging problem among nurses. The ICN<sup>1</sup> stated that 25% of nurses reported bullying from supervisors or colleagues.

The occurrence of workplace bullying is multifactorial, with organizational and individual causes.<sup>3</sup> Sociodemographic and professional factors that may precede the occurrence of workplace bullying can refer to younger male nurses, with less years of professional experience, unmarried, with a lower academic degree, experiencing symptoms of anxiety, depression and fatigue, with limited autonomy at work, less commitment to the organization, less job satisfaction, working rotation shifts, with communication problems with colleagues, low social support at work, work overload and, as far as supervision, subject to an autocratic leadership<sup>4,11,12</sup>.

Workplace bullying has a negative impact, such as a decrease in morale, productivity, an increase in absenteeism (due to physical, psychological and emotional damages), an increase in turnover that compromises the safety of patients. It also results in lawsuits, loss of profitability, negative impact on the reputation of organizations, and misrepresentation of the patient's relationship with the health professional<sup>13</sup>. Additionally, it presents increased costs with training and integration of new professionals and indirect losses, such as the impoverishment of labor relations<sup>14</sup>.

### **Engagement among nurses**

While workplace bullying expresses a negative concept, engagement is defined as a positive affective-motivational mental state in relation to work that is characterized by vigor, dedication and absorption. Vigor is characterized by high levels of energy and mental resilience of the professional while working, willingness to invest effort at work and persistence even when facing difficulties. Dedication is characterized with the presence of meaning, enthusiasm, inspiration, pride and challenge at work. Absorption is characterized by concentration and involvement in work<sup>5</sup>.

Through the Job Demands and Resources Model (JD-R), organizational and individual antecedents of engagement can be explained<sup>7</sup>. This model, elevated to theory, explains that engagement acts as a mediator between the resources and the job demands that are its predictors and the performance, which is the result<sup>5</sup>.

According to this theory, work resources and work demands interact with each other. While job demands are the main predictors of exhaustion, work resources are the main predictors of engagement. Thus, in the presence of good work resources to meet the work demands, engagement levels tend to be higher and have a positive impact on workers' performance<sup>7</sup>.

Antecedents to engagement may include, among nurses, in terms of work resources, salary, participation in decision-making, possibilities for career advancement, variety and independence at work, learning opportunities, the perception of organizational and social support and job satis-

faction. In terms of work demands, factors such as workload, emotional and mental demands, lack of control over the work environment, ambiguity at work, rotational shift schedules, stress associated with clinical practice, burnout and uncertainty about the future, may also have a negative impact on nurses' engagement<sup>6,15</sup>.

Engagement among nurses can result in higher levels of personal initiative and motivation, profitability for organizations, well-being and commitment to the organization<sup>6</sup>.

### **Bullying and engagement among nurses**

Workplace bullying and engagement can be related to each other. The antecedents and consequences of bullying can coexist as factors that reduce levels of engagement<sup>3,7</sup>. Considering the JD-R model, workplace bullying is considered to be a hindrance work demand. Thus, the negative impact of bullying as well as its antecedents and consequences may negatively influence engagement levels<sup>8</sup>. Therefore, many of the factors that explain the presence of workplace bullying coexist as explanatory aspects of the decrease of workers' levels of engagement<sup>3</sup>.

In addition to this direct relationship, the presence of workplace bullying can also indirectly reduce engagement through the avoidance of basic psychological and social needs, motivation to work and autonomy<sup>16</sup>.

Studies have shown this relationship among nurses. For instance, Trépanier et al.<sup>17</sup> verified in a study with 1179 nurses that workplace bullying was positively related to burnout, but negatively related to satisfaction, autonomy and competence at work, good interpersonal relations and engagement. They also found that engagement was negatively related to burnout, but positively related to satisfaction, autonomy, work competence and good interpersonal relationships.

### Research question

The following research question was defined: what is the relationship between workplace bullying and engagement among primary health care nurses in one of Azores' Islands (Portugal)?

In order to answer the research question the subsequent aims were formulated: to identify the presence of workplace bullying and engagement among nurses; analyze the variation of workplace bullying and engagement according to nurses' sociodemographic and professional characteristics; and analyze the association between workplace bullying and engagement.

### Purpose of the study

The purpose of this study was to contribute to the research of this subject in the Azores, focusing on primary health care nurses and to the elaboration of programs that promote nurses' occupational health. These programs intend to empower nurses to prevent and minimize the consequences of workplace bullying and to catalyze work resources, meeting the requirements of the same, in order to increase their levels of engagement.

### Methods

The study was quantitative, cross-sectional and correlational.

### Population and sample

The target population consisted of nurses who worked in primary health care on an Azorean island (Portugal). The inclusion criterion defined was that the nurses would have to work for at least 6 months in the Health Institution where the questionnaire was applied. The total eligible population for inclusion in this study was of 235 nurses.

The sampling technique used was non-probabilistic. It was a convenience sample, consisting of 173 nurses, resulting in an accession rate of 73.6%.

All nurses in the sample worked in primary health care. Regarding the sociodemographic variables, the mean age was 39.6 years ( $SD = 7.7$ ), 88.4% of the nurses were female, 58.4% were 38 years of age or older, 65.9% had a partner, 72.3% were registered nurses (without postgraduate education), 70.5% had children, 49.7% did not have dependents, 49.4% had help to take care of dependents, 69.4% did not contribute exclusively to their household, but other family members also contributed, 54.3% practiced leisure activities. Regarding the professional variables, the average number of years of professional experience was 16.1 ( $SD = 7.7$ ), the average number of years of service was 10.4 years ( $SD = 7.9$ ). Additionally, 99.4% of the nurses had a permanent employment contract and 65.3% worked in fixed shifts schedules. Referring to work related stress, 79.2% of the nurses considered their work stressful.

### Data collection instrument

A questionnaire was used that included three groups, for the sociodemographic and professional assessment of nurses, for the evaluation of workplace bullying, using the Negative Acts Questionnaire – Revised (NAQ-R, 23 items), originally developed by Einarsen et al.<sup>18</sup> and adapted to Portuguese nurses by Borges et al.<sup>19</sup>, and for the evaluation of engagement, using the Utrecht Work Engagement Scale (UWES, 9 items), developed by Schaufeli et al.<sup>20</sup>

The NAQ-R allows the objective evaluation of workplace bullying using 22 items that correspond to negative acts in which the respondent is situated in relation to their frequency (from the value 1 - never, 2 - now and then, 3 - monthly, 4 - weekly, up to the value 5 - daily). Additionally, it presents a 23rd

item with a definition of workplace bullying and asks the respondent to self-report as a victim of bullying (it can be found in the following: 1 - no, 2 - yes, but only rarely, 3 - Yes, now and then, 4 - Yes, several times a week, 5 - Yes, almost daily), thus also allowing the subjective evaluation of workplace bullying.

In this study, four NAQ-R subscales were considered: Intimidation, Exclusion, Work Quality / Overload and Undervaluation of Work.

The prevalence of workplace bullying was assessed by three criteria:

1. That the respondent is located in at least one of the 22 items in the value 4 (weekly) or 5 (daily).
2. That the respondent self-reports as a victim of bullying through item 23, with 3 (yes, now and then), 4 (yes, several times a week) or 5 (yes, almost daily).
3. When responded in the first and second criteria positively<sup>21</sup>.

The UWES 9 items are based on the definition of engagement<sup>22</sup>. It includes three subscales: vigor, dedication and absorption. In each item, the respondent is asked to think about their professional tasks and evaluate how often they feel what is stated. In each item, the respondent can select one of seven levels: 0 (never), 1 (a few times a year or less), 2 (once a month or less), 3 (a few times a month), 4 (once a week), 5 (a few times a week) or 6 (every day). For the engagement evaluation, the UWES and subscales' scores can be used. Higher scores reveal greater engagement.

Regarding the NAQ-R fidelity, the Cronbach's alpha was 0.934, in the subscales of Intimidation: 0.866, Exclusion: 0.861, Work quality / overload: 0.735 and Work underestimation: 0.702.

As for the UWES fidelity, the Cronbach's alpha was 0.926, in the subscales of Vigor: 0.891, Dedication: 0.857, Absorption: 0.782. Cronbach's alpha values of both scales indicate good internal consistency<sup>23</sup>.



### Procedures and ethical aspects

The application of the questionnaire required authorization from the Board of Directors of the Health Institution as well as the nurses' informed consent. The collected data and the integrated study in the INT-SO obtained a favorable assent by the ethics committee of Porto's Nursing School. Nurses' confidentiality was guaranteed. For the treatment of descriptive and inferential statistics, the Statistical Package for the Social Sciences, version 22 was used. For the parametric tests, the t-test (*t*) was used for independent samples. Regarding non-parametric tests, the Mann-Whitney test (*U*) was used. As significance level, 0.05 ( $p < 0.05$ ) was defined. For the evaluation of the correlations between two metric variables, the Pearson correlation (*r*) was used.

### Results

In this chapter, the results obtained according to the aims of the study are presented.

#### Bullying and engagement among nurses

The descriptive analysis of the results allowed to verify the distribution of the NAQ-R and subscales scores. In both, the average number of negative acts in the workplace was between 1 (never) and 2 (now and then) (table 1).

As to the prevalence of workplace bullying, the results are presented in table 2. Regarding the frequency of negative acts, when applied to criteria 1 or 3, it was verified that items 3 - Being ordered to do work below your level of competence, 4 - Having key areas of responsibility removed or replaced with more trivial or unpleasant tasks - and 21 - Being exposed to an unmanageable workload, were more frequent (criteria 1 - 11%,  $N = 19$ , 6.9%,  $N = 12$  and 6.9%,  $N = 12$ ; and criteria 3 - 3.0%,  $N = 5$ , 3.0%,  $N = 5$  and 3.0%,  $N = 5$ , respectively).

As for engagement, the descriptive analysis of the UWES and subscales scores indicated that nurses were on average between levels 4 (once a week) and 5 (a few times a week) (table 3).

DESCRIPTIVE ANALYSIS OF NAQ-R AND SUBSCALES

1

NAQ-R	Items	N	Mean	SD	Minimum	Maximum
Intimidation	2, 8, 9, 10, 15, 19, 20, 22	173	1.2	0.4	1	5
Exclusion	1, 5, 6, 7, 12, 13, 14, 17	173	1.4	0.4	1	4
Work quality / overload	11, 16, 18, 21	173	1.5	0.5	1	4
Undervaluation of work	3, 4	173	1.6	0.9	1	5
NAQ-R	...	173	1.4	0.4	1	4

PREVALENCE OF WORKPLACE BULLYING AMONG NURSES ACCORDING TO CRITERIA 1, 2 AND 3

2

Criteria	Prevalence	
	%	N
1. That the respondent is placed in at least one of the 22 items in the value 4 (weekly) or 5 (daily)	22.0	38
2. That the respondent self-labelled as a victim of bullying through item 23, with 3 (yes, now and then), 4 (yes, several times a week) or 5 (yes, almost daily) responding	9.2	16
3. That the respondent answered in the first and second criteria positively	6.9	12

DESCRIPTIVE ANALYSIS OF THE UWES AND SUBSCALES SCORES

3

UWES	Items	N	Mean	SD	Minimum	Maximum
Vigor	1, 2, 5	172	4.3	1.4	1	6
Dedication	3, 4, 7	173	4.4	1.3	0	6
Absorption	6, 8, 9	173	4.3	1.3	0	6
UWES	...	173	4.3	1.2	1	6

## RELATIONSHIP BETWEEN BULLYING (NAQ-R) AND ENGAGEMENT (UWES) AMONG NURSES WITH SOCIODEMOGRAPHIC AND PROFESSIONAL VARIABLES

4

NAQ-R	Age	N	Mean	SD	t(df) p
Work Quality / overload	≤ 37 years old	72	1.6	0.6	2.214 (171) 0.028
	≥ 38 years old	101	1.4	0.5	
Undervaluation of work	≤ 37 years old	72	1.8	1	2.214 (171) 0.029
	≥ 38 years old	101	1.5	0.8	
NAQ-R	Help to care for a dependent person	N	Mean	SD	t(df) p
Undervaluation of work	Yes	42	1.9	1.1	-2.174 (81) 0.033
	No	41	1.4	0.6	
NAQ-R	Workshift	N	Mean	SD	t(df) p
Bullying	Fixed shift	113	1.1	0.2	-3.065 (167) 0.003
	Rotating shift	56	1.4	0.6	
Exclusion	Fixed shift	113	1.4	0.4	-2.146 (167) 0.033
	Rotating shift	56	1.5	0.5	
Work quality / overload	Fixed Shift	113	1.4	0.4	-2.698 (167) 0.009
	Rotating shift	56	1.7	0.7	
Undervaluation of work	Fixed shift	113	1.5	0.7	-2.729 (167) 0.008
	Rotating shift	56	2	1.1	
NAQ-R total	Fixed shift	113	1.3	0.3	-2.909 (167) 0.005
	Rotating shift	56	1.5	0.6	
NAQ-R	Stressful work	N	Mean	SD	t(df) p
Exclusion	Yes	137	1.5	0.4	-2.679 (170) 0.008
	No	35	1.2	0.3	
Work quality / overload	Yes	137	1.6	0.6	-3.717 (170) 0.000
	No	35	1.3	0.3	
NAQ-R total	Yes	137	1.4	0.4	-2.430 (170) 0.016
	No	35	1.2	0.2	
UWES	Marital status	N	Mean	SD	t(df) p
Dedication	Without partner	58	4.1	1.3	-2.029 (170) 0.044
	With partner	114	4.6	1.3	
UWES	Children	N	Mean	SD	t(df) p
Vigor	Yes	121	4.5	1.2	-2.601 (170) 0.011
	No	51	3.9	1.5	
Dedication	Yes	122	4.6	1.2	-3.249 (171) 0.002
	No	51	3.9	1.5	
Absorption	Yes	122	4.5	1.2	-2.854 (171) 0.005
	No	51	3.8	1.5	
UWES total	Yes	122	4.5	1.1	-3.043 (171) 0.003
	No	51	3.8	1.4	
UWES	Help to care for dependent person	N	Mean	SD	t(df) p
Absorption	Yes	42	4.1	1.2	2.339 (81) 0.022
	No	41	4.7	1	
UWES total	Yes	42	4.2	1.2	2.019 (81) 0.047
	No	41	4.7	0.8	

UWES	Professional experience	N	Mean	SD	t(df) p
Absorption	≤ 13 years of age	78	4.0	1.4	-2.395 (171) 0.018
	≥ 14 years of age	95	4.5	1.2	
UWES total	≤ 13 years of age	78	4.1	1.3	-2.013 (171) 0.046
	≥ 14 years of age	95	4.5	1.1	
UWES	Workshift	N	Mean	SD	t(df) p
Vigor	Fixed shift	113	4.5	1.3	2.682 (166) 0.008
	Rotating shift	55	3.9	1.4	
Dedication	Fixed shift	113	4.6	1.2	2.408 (167) 0.017
	Rotating shift	56	4.1	1.4	
Absorption	Fixed shift	113	4.5	1.2	3.004 (167) 0.003
	Rotating shift	56	3.8	1.4	
UWES total	Fixed shift	113	4.5	1.1	2.993 (167) 0.003
	Rotating shift	56	3.9	1.3	
UWES	Stressful work	N	Mean	SD	t(df) p
Vigor	Yes	136	4.2	1.4	3.089 (169) 0.003
	No	35	4.8	0.8	
Dedication	Yes	137	4.3	1.4	3.513 (170) 0.001
	No	35	5	0.8	
Absorption	Yes	137	4.2	1.4	2.442 (170) 0.017
	No	35	4.7	1.1	
UWES total	Yes	137	4.2	1.3	3.351 (170) 0.001
	No	35	4.8	0.8	
UWES	Gender	N	Mean Rank	U p	
Vigor	Male	20	53.58	861.500; 0.001	
	Female	152	90.83		
Dedication	Male	20	58.02	950.500; 0.006	
	Female	153	90.79		
Absorption	Male	20	46.00	710.000; 0.000	
	Female	153	92.36		
UWES total	Male	20	49.58	781.500; 0.000	
	Female	153	91.89		

### Relationship between workplace bullying and engagement with sociodemographic and professional variables

Regarding the comparison between means, there were no statistically significant results in the variables of gender, marital status, literacy, parenthood, responsibility over dependents, contributing exclusively with their salary, leisure activities, professional experience and seniority. As for engagement, there were no significant results in the variables of age, literacy, dependents, exclusively contributing with their salary, leisure activities and professional experience. Statistically significant results are presented in table 4.

Workplace bullying was more frequent among younger nurses ( $\leq 37$  years old), without help to care for dependents, working rotating shift schedules and who perceived stress at work.

Regarding engagement, this was higher in female nurses, with partners, with children, without help to care for dependents, with more years of pro-

fessional experience ( $\geq 14$  years of age), with fixed work shifts and without perceived stress at work.

### Relationship between bullying and engagement

All correlations between NAQ-R and UWES were negative and statistically significant, this is, the higher the workplace bullying scores, the lower the levels of engagement. The correlation between NAQ-R and UWES,  $r(173) = -0.280$ ;  $p = 0.000$  was low<sup>23</sup>. The highest correlation between

NAQ-R subscales and UWES subscales was found between Work quality / overload and Dedication  $r(173) = -0.321$ ;  $p = 0.000$  (low correlation); The lowest was found between the Exclusion and Absorption subscales  $r(173) = -0.158$ ;  $p = 0.038$  (very low correlation).

The NAQ-R Work quality / overload subscale best explains the variance in the UWES scale (9.7%), followed by Exclusion (6.0%). The subscale Dedication best explains the variance in the NAQ-R scale (10.2%), followed by Vigor (6.0%).

## Discussion

In this chapter, the discussion is made accordantly to the aims of the study.

### Bullying and engagement among nurses

The prevalence of workplace bullying found in this study related to the three prevalence criteria are comparable to those observed in other studies that used similar methodology<sup>21</sup>. Prevalence values in the self-labeling method (9.2%) were lower than the objective method (22%), indicating that many of the nurses who are subject to negative acts did not consider themselves victims of bullying. In studies with different methodology there have been discrepant prevalences<sup>24</sup>. In addition, the socio-cultural factors of the regions may also influence the prevalence<sup>9</sup>.

Studies conducted with nurses have revealed that items 3, 4 and 21, when applied to criteria 1 or 3, present high frequencies<sup>21,24</sup>. Negative acts 3, 4 and 21 are acts related to work. They are subtle, indirect and more difficult to detect, which may explain their higher frequency<sup>25</sup>. Furthermore, the results suggest that there are organizational factors that may have fostered the perception of the negative acts associated with Undervaluation of work (items 3 and 4 constitute this subscale) and Work quality / overload (item 21 belongs to this subscale). In Portugal, in recent years, nurses have invested in post-graduate training<sup>26</sup>. However, work contexts do not always make it possible to transpose competencies acquired in a training context into the clinical context, nor do nurses perceive recognition of their competencies through career or monetary means, being able to enhance the perception of negative acts associated to the undervaluation of work. In addition, the high professional demands, both for the nature of the nursing profession as well as for the work overload may have enhanced the perception of negative acts related to Work quality / overload. Nielsen et al.<sup>27</sup> in a meta-analysis found that workplace bullying often occurs in the health sector, especially among nurses due to work overload.

As for engagement, the average engagement levels and all the subscales were good. These results corroborate other studies<sup>28</sup> and may suggest that the complexity of the nursing activity maintain these professionals dedicated and highly committed.<sup>15</sup>

### Relationship between workplace bullying and engagement with sociodemographic and professional variables

The results revealed that workplace bullying was more frequent among younger nurses. This result is similar to that of other studies<sup>4,11,12</sup>. Younger nurses may be less able to manage interpersonal relationships at work and tend to deal less effectively with workplace bullying, becoming more vulnerable to its occurrence<sup>11</sup>.

Nurses without help to care for dependents perceived more acts of bullying. This may suggest that family-based nurses who do not directly assume family responsibilities may be more available for work and professional investment<sup>15</sup>, with a greater perception of negative acts associated with under-

valuation of work, when they do not see their investment matched.

Workplace bullying was more frequent among nurses working rotating shift schedules and who perceived stress at work. Other studies reveal similar results, in which shift working nurses may be more subjected to bullying due to greater unpredictability of working hours, greater emotional demands and fewer opportunities for communication and building positive interpersonal relationships at work<sup>4</sup>. Regarding the relationship between the occurrence of bullying and work stress, this can indeed be a predictor for bullying<sup>29</sup>.

Regarding engagement, this was higher in female nurses. Other studies corroborate this result<sup>15,28</sup>, which may suggest that female nurses presented greater achievement or satisfaction in their work (antecedents of engagement), fruit of the nature and identity of the profession<sup>28</sup>.

Engagement was also higher among nurses with partners, with children and without help to care for dependents, corroborating other studies<sup>15</sup>.

Favorable family-work interaction is positively related to professional achievement<sup>30</sup>. Having a partner and children can be a source of support, stimulating well-being, professional fulfillment and commitment with work, antecedents of engagement<sup>6</sup>. In contrast, nurses without help to care for a dependent person had higher means of engagement. This result may suggest that, even when facing challenges, the nurses feel enthusiastic, inspired and proud of their work, thus increasing their engagement levels.

Nurses with more years of professional experience ( $\geq 14$  years of age), with fixed work shifts and without perceived stress at work presented higher levels of engagement. Nurses with more years of professional experience (associated with being older) can assign greater meaning to the profession, have greater percep-

tion of competence in their work performance, impact on working conditions, and self-determination or autonomy, greater sense of self-efficacy and resilience, leading to higher levels of job satisfaction<sup>31</sup>. Other studies have shown that nurses with higher professional experience have higher levels of engagement<sup>28</sup>. As for the work schedule, a higher emotional requirement related to rotating shifts may explain the higher levels of engagement in nurses working fixed shifts<sup>7</sup>. As for the relationship between engagement and stress, other studies have demonstrated similar relationships<sup>8</sup>.

### **Relationship between bullying and engagement**

The correlations were negative: the higher workplace bullying scores correspond to the lower levels of engagement. In part, these results are explained by the fact that workplace bullying is a type of hindrance demand of the worker's progress<sup>8</sup>. The models JD-R<sup>7</sup> and the theoretical model for the study and management of workplace bullying<sup>3</sup> explain that many of the factors that precede the occurrence of bullying (for example, rotating shift schedules, work overload, stress at work) coexist as factors (or job demands in the JD-R model) that can decrease engagement levels. Studies with nurses<sup>4,12</sup> and with other professionals<sup>8</sup> have demonstrated this relationship directly or indirectly.

### **Conclusions**

The results obtained in this study allowed to respond to the outlined research question and aims. It was possible to identify the presence of workplace bullying and engagement levels, analyze their variation in terms of sociodemographic and professional variables and the relationship between workplace bullying and engagement. It was found that workplace bullying was prevalent and that it was more frequent in younger nurses, who have help to care for dependents, with rotating shift schedules and with perceived stress at work.

Concerning engagement, female nurses, with partners, with children, without help to care for a dependent person, with more years of professional experience, working fixed schedules and without perception of stress revealed higher levels. A negative relationship between workplace bullying and engagement was verified.

### **Study implications**

The study results translate into important implications for nurses and health organizations.

Although in recent years there has been an incentive to implement strategies to prevent psychosocial occupational risks, including in Portugal<sup>32</sup> there is still many opportunities for development and implementation of those<sup>33</sup>.

Therefore, this study suggests the need to implement intervention strategies for workplace bullying at three levels of prevention<sup>34</sup>. At a primary level, by providing continuous information and training about bullying, especially for nursing managers, and by investigating and monitoring bullying antecedents. At a secondary level, by developing anti-bullying policies / procedures that discourage its occurrence and developing nurses' occupational health programs. At a tertiary level, to equip victims and perpetrators with tools to allow them to manage the consequences of workplace bullying.

Engagement levels were considered good. However, for its maintenance and increase it is important that organizational and individual interventions be implemented. In institutions, it is fundamental that nursing managers become involved, who should view engagement as one of the core values of the organization, while promoting positive relationships in the workplace and

while giving opportunity for nurses to express their opinions. This will contribute to the development of social resources at work. It will also positively influence decision-making processes, leading to greater job satisfaction and engagement<sup>35</sup>. Furthermore, it is important to perform the diagnosis of the existing work demands and resources and the training of nurses, in order to develop skills combining work demands with work resources.

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# Facebook: an ally in health promotion

## Summary

**INTRODUCTION.** Social media are widely used in the everyday lives of a large part of the world's population. As one of the most popular networks, Facebook can be used for health promotion.

**OBJECTIVE.** To identify and summarize the characteristics of health promotion programs using social media (Facebook).

**METHODOLOGY.** An integrative literature review was conducted using the PI(C)OD methodology (population, intervention, comparison, outcome, and design). Data were collected in May and June 2016 in the following databases: Regional Business News, Psychology and Behavioral Sciences Collection, MEDLINE with Full Text, SPORTDiscus with Full Text, CINAHL Plus with Full Text, MedicLatina, Academic Search Complete, ERIC, Business Source Complete, and Library, Information Science & Technology Abstracts.

**RESULTS.** Nine articles were included in this review. Their analysis showed that social media are used for health promotion. Facebook is the most widely used social network due to its greater visibility, easier content dissemination, and the possibility for feedback through likes, shares, and comments.

**CONCLUSIONS.** Evidence shows that Facebook is an important platform for the implementation of health promotion programs. Social media are great allies for health promotion in nursing.

**KEYWORDS:** SOCIAL MEDIA; HEALTH PROMOTION; NURSING.

## Introduction

The technological advancements that occurred in the second half of the twentieth century brought about the Digital Revolution. The Internet as we know it today was created at the end of the twentieth century, and caused a shift in the information and communication paradigm. It is now widely present in the daily lives of most people<sup>1,2</sup>.

According to the PORDATA database, 76% of the population in the European Union uses the Internet at least once per week. In Portugal, 65% of the population uses this communication platform, that is, around 7 million Portuguese citizens. The reasons for using the Internet include professional and academic needs, search of information, leisure (entertainment, gaming websites), and use of social media<sup>3</sup>.

Young people are the most frequent Internet users. The percentage of users aged 16 to 24 years increased from 65% to 95%. Internet use, particularly for online gaming, has been the subject of extensive debate. In fact, gaming and Internet addiction was addressed in the 2013 National Plan for Reducing Addictive Behaviors and Dependencies as well as in the National School Health Programs (PNSE) since 2015<sup>4</sup>. According to the PNSE technological resources, such as games and the Internet, influence children and young people's behavior and development and may lead to deviant behaviors and addictions. However, it emphasizes that only a minority group displays these behaviors and that the massive use of the Internet cannot be

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seen as something purely negative. The EU Kids Online is a project funded by the European Commission which analyzes how young people use the Internet and the trends in this increasingly massive and intense use. According to this project, the Internet poses risks but it also presents opportunities that cannot be ignored. Some of its features contribute towards the development of children, adolescents, and young people, namely in terms of education learning, participation and civic engagement, development of creativity and self-expression, and identity and social connection<sup>5</sup>.

Online social networking is defined as a set of relationships between people or organizations who share common interests, knowledge, and values using the Internet. Known as social collaboration software, these applications support the collaboration, knowledge sharing, interaction, and communication between users with common interests, needs, and objectives<sup>6</sup>.

Within the scope of the Net Children Go Mobile project, which is part of the EU Kids Online project, a study was conducted with children/adolescents aged 9 to 16 years in seven European countries (including Portugal). This study found that 63% of the participants used the Internet for social networking and that this phenomenon showed a 20% increase between 2010 and 2014<sup>5</sup>.

The great adherence to social networks derives from the possibility of

social sharing in an informal, dynamic, and appealing environment. Thus, an increasing number of young people is joining this type of social software, particularly Facebook<sup>7</sup>.

The vast majority of online communication takes place in social networks such as Facebook, Twitter, and YouTube. Facebook was initially created as a communication tool for Harvard University students in 2004. This social network quickly spread to other American universities and secondary schools, and later to the rest of the world. Facebook allows users to create an online profile, upload photos/videos, exchange messages with other users, and share public contents that appear in the news feed. Users can also join groups to share and discuss relevant information on a given topic. In Portugal, according to the study *Os Portugueses e as Redes Sociais 2015* (The Portuguese People and Social Media 2015), 94% of social media users have a Facebook account<sup>2</sup>.

Social media are widely used in the everyday lives of a large part of the world's population. As one of the most popular networks, Facebook can be used for health promotion. This integrative literature review aims to identify and summarize the characteristics of health promotion programs using social media, namely Facebook.

### Problem statement

The Internet and social media are used for several purposes: communication among peers, promotion of products and services, creation of thematic groups with users sharing common interests, and organization of events. Several areas, such as the health area, may benefit from their presence in social media. Users increasingly use the Internet to search for useful knowledge, and sometimes they find incorrect or misleading information that may cause harm to their health and that of others. Therefore, there is a need to promote health through social media by adding valid sources of knowledge to one of the networks most widely by the target population. However, when developing online health promotion projects and strategies, it is essential to assess risks, make adjustments to the target audience's needs, and take into account all ethical issues inherent to these processes that pose new challenges<sup>8</sup>.

Therefore, with the purpose of creating a Facebook page as a health promotion tool, this study aimed to identify health promotion programs using social media, as well as to identify the key characteristics that a health promotion campaign using Facebook should have.

### Research questions

Which characteristics of a Facebook page increase user adherence in a health promotion campaign?

### Purpose of the study

To identify and summarize the characteristics of health promotion programs using social media (Facebook).

### Research methods

This integrative literature review followed the steps recommended by the Joanna Briggs Institute: formulation of the question for the integrative literature review; definition of the methods for study selection; data extraction method; analysis of the studies included in the integrative literature review; data extraction and presentation of the review/synthesis of the knowledge produced and published. The PI[C]OD (population, intervention, comparison, outcome, and design) method was used (table 1).

The search was conducted through the EBSCO platform in the following databases: Regional Business News, Psychology and Behavioral Sciences Collection, MEDLINE with Full Text, SPORTDiscus with Full Text, CINAHL Plus with Full Text, MedicLatina, Academic Search Complete, ERIC, Business Source Complete, and Library, Information Science & Technology Abstracts. The following keywords were used: health, promotion, and Facebook. The search was conducted between May and June. The search included only full-text articles that had been published between January 2011 and June 2016 and were written in English or Spanish. A total of 280 records were identified in the databases.

Table 2 shows the inclusion and exclusion criteria applied in this study.

The flow diagram of the study selection process (fig. 1) shows that 175 potentially eligible articles were identified after the removal of 105 duplicates.

The initial study selection step (title reading) identified 40 articles eligible for abstract reading after the exclusion of 72 articles that did not include the word Facebook and/or social media and/or social networking in their title and of 63 articles that were not relevant to the research question. Twenty-one articles were then excluded after abstract reading.

Finally, a full-text reading and analysis was performed to 19 articles, which resulted in the exclusion of 10 articles. Thus, nine articles were included in this integrative literature review ( $n = 9$ ).

### Results

All the studies included in this integrative review ( $n = 9$ ) show programs that use social media, namely Facebook, as a strategy for health promotion. Although the search allowed studies from 2011, a higher incidence was observed in 2015, with six articles, followed by 2012, 2014



**Keywords**

	<b>P</b>	<b>Participants</b>	Facebook users
<b>Health,</b>	<b>I</b>	<b>Interventions</b>	To identify the characteristics of a health promotion program using Facebook
	<b>C</b>	<b>Comparison</b>	(Not applicable)
<b>Promotion,</b>	<b>O</b>	<b>Outcomes</b>	Users' adherence to a Health Promotion Program using Facebook
<b>Facebook</b>	<b>D</b>	<b>Design</b>	Search in scientific databases

INCLUSION AND EXCLUSION CRITERIA

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> <li>• Studies that address the research question. (Participants should use social media; studies should focus on health promotion Interventions using social media; <b>O</b>utcomes relate to effectiveness and adherence to health promotion programs in social media; <b>D</b>esign: Primary studies).</li> <li>• Studies published in the past five years (2011-2016).</li> <li>• Primary studies available in full-text in the searched databases, written in English, Portuguese, or Spanish.</li> </ul>	<ul style="list-style-type: none"> <li>• Systematic literature reviews.</li> <li>• Non-open access studies.</li> </ul>

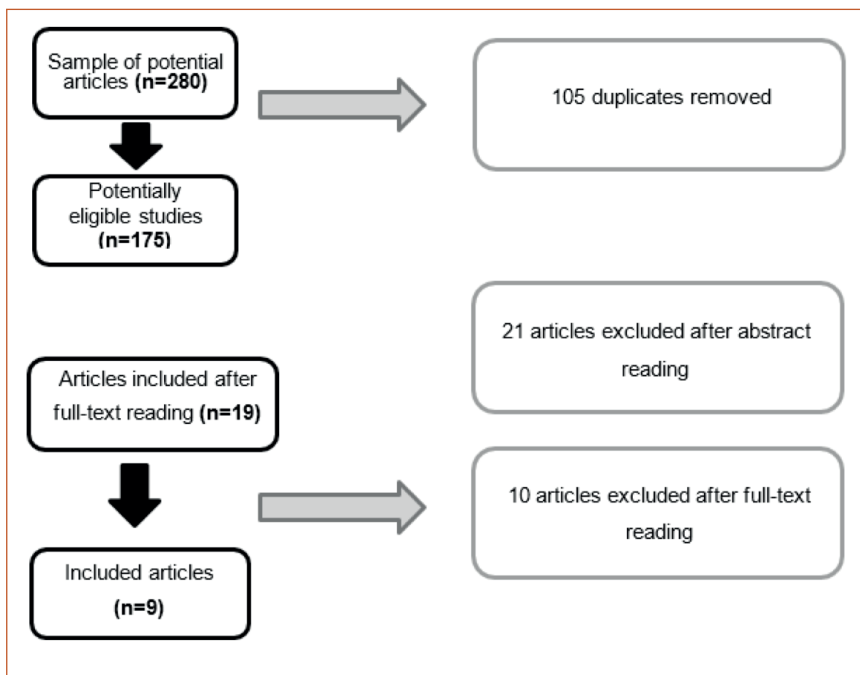


Figure 1. Flow diagram of the study selection process

and 2016, with an article in each year. Table 3 summarizes the studies included in this review, including information on the authors, year, study design, population, objectives and study variables.

**Discussion**

The nine articles included in this integrative literature review address the topic of health promotion using social media.

Several studies show that Facebook is an effective tool for health promotion<sup>9-14</sup>. Richter et al. reported that 70% of hospitals in the United States already use Facebook, and that 91% of them use it for patient education, disease prevention, and health promotion<sup>15</sup>.

Jawad et al. added that the use of social media has the potential for reaching a wider audience and that the specificities of each social network should be taken into account to maximize its use<sup>16</sup>. According to these authors, Twitter was more suited to daily, external links and Facebook is more suited to short health facts and allowed a greater interaction with users.

The studies showed that social media are an effective way to promote health. Tse et al. reported that users showed increased knowledge after the intervention<sup>10</sup> and Su et al. (2015) reported an increase in literacy rates among users after the health campaign using Facebook.

Furthermore, Richter et al. found that health promotion programs disseminated via the Internet and the social media used by hospitals increased patient knowledge, thus contributing to disease prevention and health promotion<sup>15</sup>. The authors also considered that the use of social media is a key strategy in improving the interaction between the hospital and the patient/family, and thereby improving the quality of health care delivery. According to Zaidan et al., Facebook is the best social network for health promotion due to its specific characteristics: it is the social

## LIST OF INCLUDED STUDIES

3

Title	A Social Media-Based Physical Activity Intervention A Randomized Controlled Trial (Cavallo et al., 2012).
Authors/Year	Cavallo D, Tate D, Ries A, Brown J, DeVellis R, Ammerman A. (2012).
Study design	Observational Quantitative Comparative
Population	134 female students attending a public university, divided into 2 groups: 67 participants had access to the website and 67 participants had access to the website and the Facebook group.
Objectives	To test the efficacy of a physical activity intervention that combined education, physical activity monitoring, and social support through Facebook, when compared to an education-only control group.
Study variables	Adherence to physical activity.
Title	Social Media: How Hospitals Use It, and Opportunities for Future Use (Richter, Muhlestein, Wilks, 2014).
Authors/Year	Richter J, Muhlestein D, Wilks C. (2014).
Study design	Observational Descriptive Quantitative
Population	471 hospitals with a website in the United States of America.
Objectives	To identify the reason why hospitals use social media.
Study variables	Prevalence of use of social media among hospitals and the ways in which hospitals use it.
Title	Social Media Use for Public Health Campaigning in a Low Resource Setting: The Case of Waterpipe Tobacco Smoking (Jawad, Abass, Hariri & Akl, 2015).
Authors/Year	Jawad M, Abass J, Hariri A, Akl E. (2015).
Study design	Observational Descriptive Quantitative
Population	Local government organizations (through field activities) and the wider global community (through social media).
Objectives	<ul style="list-style-type: none"> <li>• To describe the use of social media in conducting the campaign to control waterpipe smoking.</li> <li>• To create and assess the impact of a social media campaign about dangers of waterpipe smoking.</li> </ul>
Study variables	<ul style="list-style-type: none"> <li>• Number of social media users.</li> <li>• Page traffic.</li> <li>• Descriptive analysis of posts.</li> <li>• Number of likes and comments.</li> </ul>
Title	The use of social networking platforms for sexual health promotion: identifying key strategies for successful user engagement (Veale et al., 2015).
Authors/Year	Veale H, Sacks-Davis R, Weaver E, Pedrana A, Stoové M, Hellard M. (2015).
Study design	Observational Quantitative Comparative
Population	Active Facebook (n=60) and Twitter (n=40) profiles undertaking sexual health promotion.
Objectives	To identify Facebook and Twitter profiles that were able to engage large numbers of users, and to identify strategies used to attract and engage users in sexual health promotion on these platforms.
Study variables	Number of Facebook page "likes".
Title	Challenges, Alternatives, and Paths to Sustainability: Better Public Health Promotion Using Social Networking Pages as Key Tools (Zaidan et al., 2015).
Authors/Year	Zaidan A, Zaidan B, Kadhem Z, Larbani M, Lakulu M, Hashim M. (2015).
Study design	Observational Descriptive Quantitative
Population	General population in the Middle East.
Objectives	<p>To raise the awareness of the general population about basic public health issues (e.g., sanitation, infectious diseases, mental health) through the online platform;</p> <p>To raise the awareness of the general population about the importance of health education through the online platform, by helping users understand their body and mind and reach their own well-informed decision about any given health condition.</p>
Study variables	<ul style="list-style-type: none"> <li>• Active users.</li> <li>• Daily active users (people who viewed or interacted with the page).</li> <li>• New likes.</li> <li>• Users' demographic data.</li> <li>• Page activity.</li> </ul>

Title	Social Media in Adolescent Health Literacy Education: A pilot Study (Tse, Bridges, Srinivasan, Cheng, 2015).
Authors/Year	Tse C, Bridges S, Srinivasan D, Cheng B. (2015).
Study design	Observational Quantitative Comparative
Population	22 adolescents aged 14 to 16 years.
Objectives	To evaluate the efficacy of three social media outlets – Twitter, Facebook, and YouTube – in improving oral health literacy.
Study variables	Literacy assessment questionnaires before and after the intervention.
Title	Evaluation of an Online Campaign for Promoting Help- Seeking Attitudes for Depression Using a Facebook Advertisement: An Online Randomized Controlled Experiment (Hui, Wong, Fu, 2015).
Authors/Year	Hui A, Wong P, Fu K. (2015).
Study design	Observational Quantitative Comparative
Population	197 users joined the Facebook campaign.
Objectives	To evaluate the effectiveness of an online depression awareness campaign to encourage help-seeking attitudes and to enhance mental health literacy in Hong Kong; to examine the choice between two facial expressions in Facebook.
Study variables	A pre-test and a post-test were conducted to identify the differences in help-seeking behaviors among participants from the campaign and control groups.
Title	Facebook for Health Promotion: Female College Students' Perspectives on Sharing HPV Vaccine Information Through Facebook. (Zhang, Tsark, Campo, Teti, 2015).
Authors/Year	Zhang N, Tsark J., Campo S, Teti M. (2015).
Study design	Experimental Quantitative Descriptive
Population	14 female college students aged 18 to 26 years with an active Facebook account.
Objectives	To examine Facebook's potential for sharing human papillomavirus (HPV) vaccine information among female college students in Hawaii.
Study variables	Number of page followers; Number of posts about HPV.
Title	Promoting a Hand Hygiene Program Using Social Media: an Observational Study (Pan et al., 2016).
Authors/Year	Pan S, Sheng W, Tien K, Chien K, Chen Y, Chang S. (2016).
Study design	Observational Quantitative Descriptive.
Population	5252 views of the video.
Objectives	To evaluate the efficacy of different social media on the promotion of a hand hygiene awareness campaign.
Study variables	Number of video views and their sources (website, Facebook, e-mail).

network with greater visibility and ability to disseminate information; there is more interaction with the author of the post, making it possible to receive feedback, discuss and disseminate information; the Facebook page contents can only be edited by the administrator; and the information is immediately available to all campaign users in their news feed. In addition, the authors reported that Facebook was more efficient in developing health promotion campaigns than other social networks<sup>14</sup>.

Moreover, Zaidan et al. and Richter et al. concluded that, although there are other ways to develop health promotion campaigns and improve the interaction between hospitals and the population, Facebook is a low-cost, easy-to-use service with great dissemination potential, thus promoting user adherence and interaction<sup>14,15</sup>.

Social media are available both in computers and mobile devices and play a major role in the daily lives of those who use them. In fact, companies and brands are increasingly using social media to interact with consumers in a quick and dynamic way.

These studies identified several characteristics that a Facebook page should have to promote user adherence to health promotion programs.

According to Jawad et al. and Zaidan et al., the page should be managed

by several administrators in order to reduce work overload and burnout, as well as also to ensure content diversity and interaction with users<sup>14,16</sup>.

The page should involve its target audience to improve adherence and attract more users<sup>16</sup>, as well as connect with people, friends, acquaintances, neighbors, co-workers who share common interests<sup>14</sup>. In addition, it is important to know the target audience in advance, namely its demographic and cultural characteristics and beliefs, the page should be easy to read and understand, and use the language most commonly used by the target population<sup>14</sup>. Finally, Zaidan et al. also argued that diagnostic surveys should be conduc-

ted to identify the best interventions and contents to be disseminated<sup>14</sup>.

Other important characteristics include the individualized interaction with users<sup>9,16</sup> and the assurance of users' privacy and confidentiality<sup>9,14,16</sup>. On this matter, Zaidan et al. emphasized the creation of groups, where only group members can access its contents<sup>14</sup>. To join a group, users must be accepted by the existing group members. Once accepted, members can post and discuss contents and get notified about group activities.

With regard to posting frequency, Jawad et al. found a positive correlation between the number of posts and the number of active users, while Veale et al. emphasized the importance of regular Facebook posting activity to achieve a high level of user engagement<sup>9,16</sup>.

Other key strategies include uploading multimedia material, namely YouTube videos, to attract users since the use of multimedia improves user engagement<sup>9</sup>. Tse et al. suggest that, whenever necessary, text should be integrated into multimedia content and that message should be short, concise, and clear<sup>10</sup>.

Another relevant aspect identified by Pan et al. was that users are more likely to be influenced by posts shared by people who belong to the same network, which demonstrates the importance of encouraging information sharing among peers<sup>13</sup>. On the other hand, Zhang et al. stated that users may consider shared information as spam<sup>12</sup>.

According to Veale et al., celebrity involvement increases the pages' popularity since people look up to them as role models. Thus, successful interventions based on social media should consider the possibility of involving celebrities according to the target population<sup>9</sup>.

With regard to information management, Jawad et al. also suggested the creation of a website as support tool to allow posting larger volumes of text, images, and files<sup>16</sup>.

Zaidan et al. identified some constraints related to health promotion campaigns based on social media, namely the lack of financial support and project team members' lack of time and availability<sup>14</sup>.

Cavallo et al. and Hui et al. reported that, despite the lack of behavior changes, the use of health campaigns based on Facebook has a positive effect to the extent that the participants in the group using Facebook during the intervention showed increased levels of satisfaction and literacy<sup>11</sup>.

The main characteristics that a Facebook page should have, as identified in the studies, including: clearly defined goals and purposes; adapted to the target audience and culture; regular posting activity; individualized interaction with users; easy-to-read multimedia uploads in the target languages, if necessary; celebrity involvement; and assurance of privacy through other means of communication (e.g., email, private messaging, phone contacts). Nonetheless, the constraints associated with these processes should also be taken into account, namely the lack of financial support and availability of team members for page maintenance, and inadequate knowledge about the target audience and its culture, beliefs, and expectations.

## Conclusion

The studies analyzed in this integrative literature review revealed the need for new approaches to health promotion such as the use of social media, as well as the importance of social media in the dissemination of useful knowledge. Social networking is not only a way of bringing nurses and other health professionals closer to young people, but it is also a key strategy to interact with and motivate them.

Health professionals are increasingly recognizing the importance of social media in health promotion due to their ability to quickly share information,

reach a wider audience (including people who would hardly use health services), and make contents more appealing to users. Studies have shown that using social media is essential to reach a larger number of people. Among the social networks that are most commonly analyzed in terms of their use for health promotion, Facebook was reported as the most widely used one when compared to Twitter and YouTube.

Since Facebook is widely used in Portugal and worldwide, it may be a way of reaching people who usually do not use health services, namely young people. Furthermore, due to its visibility and ability to quickly disseminate contents, Facebook may be an important ally in health promotion. The most distinguishing and appealing feature of Facebook for these campaigns is the availability of many different ways to interact with users. The possibility of receiving feedback from the target audience, through likes, shares or comments, can provide guidance on the contents that should be posted. In addition, private messaging was considered a key feature to the extent that it allows individualized interaction among users.

In order to improve user adherence, the studies mentioned the importance of maintaining an active page with regular posting activity, encouraging individualized interaction with users, uploading multimedia contents, and involving celebrities in the cause. Since the content posted on pages is public, it is important to have other means of communication that ensure users' privacy, namely email, private messaging, or phone contacts. Diagnostic surveys should be applied to identify contents relevant to the target audience. The page should be easy to read and understand, taking into account the culture and beliefs of the target audience, and contents should be translated into any language deemed necessary. The campaign and the page should have clearly defined

goals so that users know their purpose and do not seek for other services other than those provided. When necessary, text elements should be short and used as a supplement to multimedia material.

Health services and health professionals need to adapt to the new means of communication and use them as allies in their clinical practice. The evidence gathered in this study may help nurses to design successful health promotion programs using social media.

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# MDevNet

NATIONAL NETWORK FOR KNOWLEDGE  
TRANSFER ON MEDICAL DEVICES

## THE PROJECT

The project **MDevNet: National Network for Knowledge Transfer on Medical Devices**, promoted by Fraunhofer Portugal AICOS, aims to increase the value of the knowledge on technology based medical devices produced by the entities of the Portuguese scientific and innovation system **through effective processes of technology transfer to the industry.**

## MDEVNET PROJECT INITIATIVES

Activities that promote effective technology transfer processes to the industry such as:

- Initiatives of interaction and knowledge transfer through the MDevNet Network;  
**6 workshops, 3 work meetings**
- Technological development for **incremental improvements** and increase of the value of scientific research results on technology-based medical devices;
- Testing, experimentation and **demonstrative activities in real environment** of the improved research results;  
[the previous 2 points] With the collaboration of ESEP – Escola Superior de Enfermagem do Porto, CICECO – Instituto de Materiais de Aveiro, and i3S – Instituto de Investigação e Inovação em Saúde.
- Activities of dissemination and diffusion of the R&D knowledge and technologies as well as the technology transfer results supported by this project.  
**4 seminars**

## THE NETWORK

The MDevNet network is composed of entities that participate in the process of research, development, certification or commercialization of technology based medical devices, which include R&D organizations, Startups, SMEs and large companies and Healthcare Providers.

# Preparing the return home of the children with cancer

## Summary

Children with oncologic disease, between treatments, if there are no complications, return home until the next treatment. Planning the discharge is essential to promote a continuity of cares at home. An adequate preparation for discharge leads to a better management of collateral effects and to a minor risk of rehospitalisation. The goals of this study were: to identify the preparation for discharge performed to the parents / caregivers of children / adolescents with cancer submitted to chemotherapy; to identify the strategies of preparation for discharge. A qualitative, exploratory, descriptive and transversal study was developed. After the return home, 11 parents of children with cancer submitted to chemotherapy treatment, participated in the study. Data was collected using a semi-structured interview and its treatment made using content analyses, based on Bardin. From the data analyses emerged the domain The Return Home that aggregates the category Preparation for Discharge and its subcategories: Oral Information, Written Information, Comprehensibility of the Information and Information Content. The return home is simultaneously a desired and feared moment. Parents and children return to their environment, but face difficulties in daily life activities, due to the fear that is provoked by the child's vulnerability. This way, the return home should be prepared early and adequate to the singular context of each family. Oral information should be reinforced by written information, given the difficulty to process it. The comprehensibility and the content of information are peremptory components in the preparation for discharge.

KEYWORDS: PARENTS; CHILD; NEOPLASMS; PATIENT DISCHARGE; NURSING.

## Introduction

Oncologic disease is a chronic illness<sup>1</sup>, that affects individuals in all age groups. The duration of the course of the disease and the unpredictability of its evolution lead to profound and permanent changes in the lives of children and families<sup>2</sup>.

Attending to the existent statistic, tumours in pediatric ages are rare. According to the International Agency for Research, in 2018, all over the world, the estimated incidence of infantile cancer in ages below 15 years was 10.2 per 100.000 children<sup>3</sup> and in Portugal the incidence was 16.6 per 100.000 children. The three main types of tumour with higher incidence were leukemia (5.0/100.000), central nervous system tumours (2.8/100.000) and Hodgking lymphomas (1.4/100.000)<sup>4</sup>. As mentioned by RORENO, in 2009 in the North of Portugal, the number of cases of cancer in children with less than 15 years was 77, corresponding to 0.53% of the total number of diagnosed tumours that year<sup>5</sup>.

Chemotherapy is the first treatment modality for the majority of children

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with oncologic disease, and can be combined with surgery and/or radiotherapy. Its goals are: to remove or decrease the size of the tumour, stop or delay its growth, prevent metastization, reduce the recurrence, as well as to relieve the symptoms<sup>6</sup>.

Although chemotherapy destroys the cancer cells and tries to decrease its effects in healthy cells<sup>7</sup>, it presents a wide variety of short, medium and long term side effects, depending on the type of cancer, the performed treatments and on the child's / family's own characteristics.

In the last two decades, there have been significant changes in the organization of Pediatric Oncology services, with shorter hospitalization periods being recommended, so that in the treatment intervals the children stay at home<sup>8</sup>. After the hospitalization period, they return home with a new life condition. So that this transition happens in a smooth way, nurses, who are in the first line of care, have the duty to prepare an adequate and timely return home, focusing on a family centered care.

The child submitted to chemotherapy needs specific home cares, so parents need to acquire knowledge

and practice the execution of procedures related to the treatment and manage eventualities that may occur<sup>8,9,10</sup>. Thus, capacitating parents / caregivers for self-care and self-management at home, takes on particular difficulty, because of the unpredictability of the side effects dimension and emotional vulnerability of parents<sup>11</sup> who have to deal with a life threatening illness.

To succeed in the hospital discharge planning, it is crucial the parents preparation, by the nursing team, during hospitalization<sup>12</sup>. However, the involvement of a multidisciplinary team, is needed in this process so that the discharge is effectively planned. The information and the support provided by the health professionals must be suitable to their specific needs, in order to enable their comprehension about clinical decision-making, and empower them for the decision-making in the management of the health-disease process. The promotion of active listening, the clarification of the doubts and fears of the parents, the verification of their knowledge about the disease, the care they have to provide, the teaching, support and supervision of the care, is part of the professional practice of the nurses and enhances the excellence of care and the efficient preparation to returning home.

The preparation for discharge, shouldn't, therefore, coincide with the moment of discharge, nor end in the time to go home. Parents should have access to an information and support network so that they can feel more confident in providing their child care at home. For that, other resources should be available, like telephone lines and home visits<sup>13</sup>. For even if all the information is provided, in oral and written form, the vulnerability of who faces this disease in a child, may hamper the understanding of its content, or eventually restrain the capacity to retain or even adapt the information to its own situation. This way, the possibility of clarifying doubts, through a phone call and the support provided in the course of a home visit are, without a doubt, promoters of parental self-confidence.

To ensure continuity of care it is mandatory the collaboration of all health professionals and that all pursue the same goals, focusing on the particularities and needs of each child and their parents / caregivers, in order to acquire knowledge and competences to deal with the new experience, living with cancer.

Is undeniable that, oncologic disease in a child is responsible for profound physical changes, emotional and psychological, both for the child / adolescent, as well as for the parents / caregivers and family. This way, the present study emerges as a corollary of the reflexions provided by the practice. This appears in order to fill an important aspect on the cares provided to the child / adolescent with oncologic disease and their parents / caregivers and family, who manifest insecurity in the return home and due to the scarcity of investigation about the subject in Portugal.

This investigation aims to identify the preparation for discharge performed to the parents / caregivers of children / adolescents with cancer submitted to chemotherapy treatment and to identify the strategies of preparation for discharge.

### Research methods

The study is based on the qualitative paradigm, of exploratory, descriptive and transversal nature. The population was constituted by the parents of children with cancer undergoing chemotherapy treatment, in a specialized Hospital Center, located in the north of Portugal, after the return home. The non-probabilistic intentional sample was consisted of 11 parents. The participants were selected by the investigator according to the following inclusion criteria:

- Parents of children with cancer submitted to a chemotherapy treatment,

independently of the number of cycles, in the Hospital Center.

- Parents of children with cancer 48 hours after returning home. It was considered that this time interval would be necessary, so that the participants would obtain a minimal perception about the experience of caring for the child at home, after completing chemotherapy treatment;

- Accepted to be in the study.

As exclusion criteria was defined: participants who don't speak Portuguese fluently.

For this study, the interview script was selected as a data collection instrument, and a semi-structured interview as technique, in order to acknowledge the experiences and needs of the parents of children with cancer.

The investigation obtained a positive consent from the Ethics Committee and the Board of Directors of the institution where it was held. The participants were contacted during the period their children were in hospital and signed an informed consent document.

Between January and June 2016, 10 interviews were conducted at the participants' homes, in a room at the Pediatric Oncology Day Hospital or other location, according to the wishes expressed by the parents. Mostly they took place in the presence of the children, being these entertained to draw or color drawings, provided by the investigator. They took place in one single session with the participation of one of the parents, in only one of the sessions both parents participated. The interviews lasted an average of 58 minutes and were recorded on audio support. They were later transcribed, respecting the language used by participants, including laughs, hesitations and silences, as suggested by Bardin<sup>14</sup>.

As a technique to analyse the content, the thematic or categorical modality was chosen, which consists in a transformation of the text in regis-



tration units and categories, being this technique the most commonly used by the content analyses<sup>14,15</sup>.

The ethical questions were considered from the beginning, in choosing the theme, the type of study, participants' selection, data collection and its interpretation.

With the aim of safeguarding the participants' anonymity and confidentiality, identification codes were used and were recognized by E1 to E10.

## Findings

From the content analysis of the interviews the domain "The Return Home" emerged, which aggregates the category "Preparation for Discharge" and its subcategories "Oral Information", "Written Information", "Comprehensibility of the Information" and "Information Content" (figure 1).

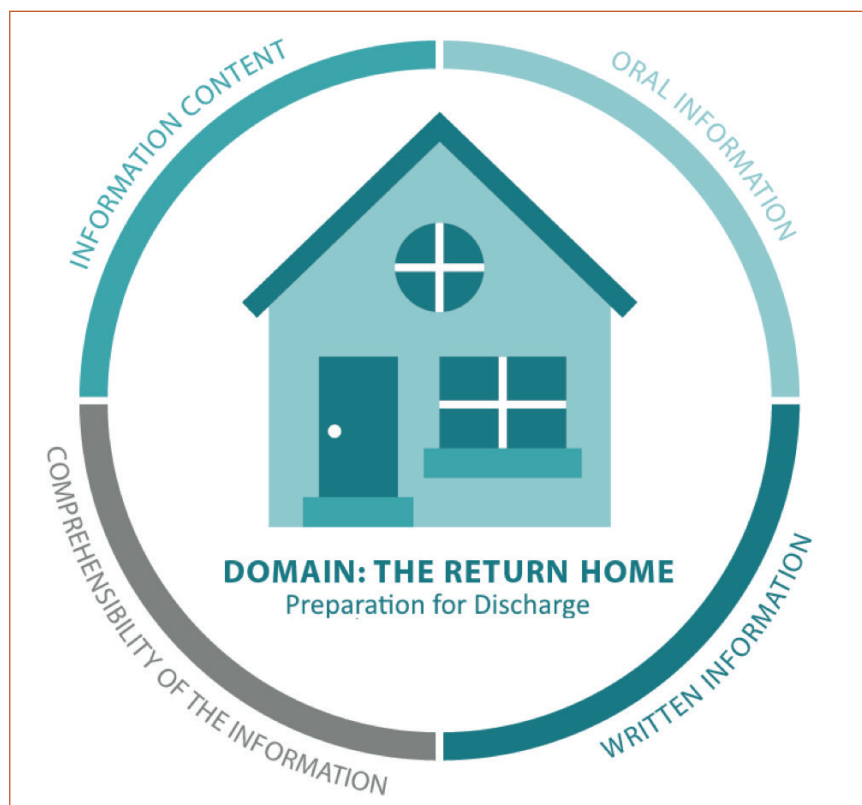


Figure 1. The Return Home

## Preparation for discharge

An adequate preparation for discharge requires the participation of the entire multidisciplinary team, doctors, nurses, nutritionists, psychologists, social workers and parents, with the goal of assessing the needs of the child and parents. In order to plan discharge, one must take into account the individual characteristics of the family, and the care inherent with the condition of the child and the treatment they will need to perform at home.

All the process of preparation for discharge is based on communication between the stakeholders and requires information transmission, which may and should be conducted both orally and written. It is necessary to evaluate if the parents understood the transmitted information and if they have doubts, since the information will only be useful if it is understood.

The information transmitted to parents by health professionals is impor-

tant because it is based on anticipatory care, which helps them know what to expect, how to care for and how to deal with side effects that may arise. In addition, the information / guidance of parents promotes their empowerment, the perception of greater self-control and effectiveness of the exercise of their parental role, which will enhance health gains.

## Oral information

Parents who participated in the study reported that one of the routes used by health professionals to transmit information was oral:

*... before we leave they come [nurses] to ask if we have any questions [...] (E2).*

*... [provided the information] orally [...] (E3).*

## Written information

In the participants' testimony is, also, evident the use by different professionals of written information as a way of information transmission:

*... in the beginning they gave us a leaflet about the effects of chemotherapy [...] it explained effectively the side effects [...] the doctors gave us that sheet, guided us [...] (E2).*

*... in writing [...] the nurse there in, in the hospital, printed a, a leaflet with contraindications [drug], they are very accessible actually (E3).*

*... the nutritionist who came to answer our doubts, gave us a paper with everything that she can and cannot eat [...] (E6).*

The participants highlighted the relevance of the complementarity of oral information with the written in pediatric oncology:

*... were verbal orientations [...] but the information is all very general like that, isn't it? It is an information that is verbally said and is very general not, is not explicit in terms of detail [...] I think*

that, for example, should be written, [...] I think the cares should be given to parents written, so that there are no second interpretations to be in detail what it is [...] (E4).

... because to be talking about everything, half of it passes by, perhaps the information not be so verbal, we are so tired, that things are forgotten very easily, be one more information, those prospects and so (E10).

### Comprehensibility of the information

In the participants' speech, it was possible to perceive the difficulty in the comprehensibility of the information, given the quantity of the same, and the vulnerability in which they live:

... they [nurses] clarify us without a doubt, but after is so much information at the same time that we almost become disorientated, without knowing very well what it is, what do we do. [...] it's a lot of information, lots of information and we cannot assimilate half of it, and then stays..., we get a get a bit lost. [...] we are so disorientated that really no, I couldn't, I couldn't understand (E2).

Sometimes we get confused, because the head is completely exhausted, isn't it? And it is not easy to assimilate everything (E10).

After the initial shock cause by the diagnosis of cancer, parents do not have the capacity to understand the information provided:

... parents, first have an emotional shock, in the first appointments, this is one thing, at the time I couldn't even speak, so, as you can see, they could sometimes say somethings and I wouldn't even listen, so, we have a very strong emotional shock (E4).

### Content of the information

In the parents discourse it was possible to perceive the content of information provided by the health professionals, during the period in which the child was hospitalized, being the nutrition the most pronounced area:

... [nurses] always alert us about the care to be taken in the feeding part [...] (E2);

... not to eat raw food, [...] if he wants to eat sausages, have to open the sausage can and give to the child, at the time, can't give it raw, has to cook it. Ham has to buy those packages of ten slices of ham and give him one or two slices if open at the time, if after is already opened can't give him anymore [...]. This is not advisable because he is a child who is immunosuppressed (E7).

... be more... be more careful with the food could only eat fruit with hard skin, wash very well the food before cooking it, [...] (E8).

Cook the food well, [...] defrost in the fridge, [...], those small bottled water [...], not eat much sugar [...] (E9).

The infection prevention measures were another topic of information transmitted by the health professionals:

... the cares, also, to avoid, avoid, that he contracted diseases, infections, basically that (E1).

What we were told initially was that it wasn't appropriate for her to be in public places, with lots of people, closed spaces, [...] can go out, can go to a park [...] (E2).

If the parents have a cold, put a mask [...] careful about visitors, that cannot be with people with colds [...] (E4).

The hygiene, always clean the house, the house must be always well cleaned, [...] not to dry the clothes outside, ah more... clean very well and disinfect everything very well, the toys, everything that can be disinfected really well [...] not to use public transports [...] (E6).

They said that carpets and everything have to be shaken, outside and vacuumed [...] (E8).

The nurse said it was not recommendable to have stuffed toys and things like that (E10).

The study participants reported that health professionals taught and instructed parents to recognize and treat fever:

... has fever, immediately to the hospital [...] (E6).

In the parents speech it is possible to perceive that nurses teach about the Central Venous Line cares:

[nurses] teach the dressings [...] what you should do, if it comes out. The disinfection, the disinfectant itself, everything that is material that might be needed [...], they provided me, helped me and explained me how to do it (E5).

The cares to have, they spoke about the line, that could not get wet, had to be careful not to pull it (E10).

Teaching about medication administration at home, was also mentioned by the interviewees:

They [nurses] said what was the dose I had to inject it, [...], taught me how I should do to give the vaccine to the girl (E8).

It's easy, because you [nurses] taught me well [medication] [...], I saw there doing it and after they told me and putted

*it in a sheet. And it is easy* (E9).

*... medication, to give the medication always on time* (E10).

The participants of the study mentioned that they were informed about the need to contact the health professionals, in case of secondary effects or questions that could emerge:

*If I see him pale, because the platelets may drop now, vomits, anything different to go to the Hospital [...]* (E9).

*Ah they talked about the fact that if he had any pain, any discomfort we could call there [hospital] or else take him there [hospital]. In case of doubts take him and go, better to go and be nothing, than not go and then be* (E10).

## Discussion

An adequate preparation for discharge is the continuity of cares base, which leads to a more adequate management of the disease process, increasing the caregivers' satisfaction and decreasing the need for readmissions<sup>13</sup>. All the process of preparation for discharge is based on communication between the stakeholders and requires information transmission, which may and should be conducted both orally and written. It is necessary to evaluate if the parents understood the transmitted information and if they have doubts, since the information will only be useful if it is understood.

The information transmitted to parents by health professionals is important because it is based on anticipatory care, which helps them know what to expect, how to care for and how to deal with side effects that may arise. In addition, the information / guidance of parents promotes their empowerment, the perception of greater self-control and effectiveness of the exercise of their parental role, which will enhance health gains.

The discharge from the hospital requires clarity in the transfer of information by health professionals, and verification of its understanding by the parents / caregivers. The training of the parents and the child, when they are old enough for care, will allow better self-management of the disease, reducing adverse events and avoiding unnecessary re-hospitalizations. Health professionals, especially nurses, will be able to assume a relevant roll in all this process, due to the longer stay with children and parents, which will allow them to build a relationship of trust. The oral information should be provided during the hospitalization in a clear and simple way, adapted to each child / family.

From the participants' discourse analysis, we conclude that the preparation for discharge differed according to the professional group, doctors and nutritionists, besides the transmission of information orally, resorted to the written information, providing leaflets. On the other hand, there is reference to the availability of nursing professionals to research and print adequate information to the parents' needs.

The results obtained corroborate those of other researchers who concluded that parents reported that nursing team shows availability to clarify questions, verbalizing that the information was transmitted orally<sup>10</sup>. The majority of families underlined the importance of written information and mentioned that rarely the information transmitted was only verbal<sup>16</sup> and that oral information should be supported by written information<sup>9,17,18,19</sup>.

The comprehensibility of the information is an essential component to the continuity of child cares at home. As information is being provided, knowledge and needs should be assessed, and encourage parents to express

their doubts<sup>18</sup>. The study participants highlight that the oral information is excessive, which associated with tiredness makes it difficult to understand it, which may lead to periods of insecurity / doubts at home.

Other authors as well verified that parents express the need for more time to understand and assimilate the information, preferring that this is provided in a phased manner<sup>16</sup>. Also refer that the fatigue and lack of sleep lead to a lack of concentration and perception about the information transmitted<sup>8</sup>.

The content of information transmitted to parents should address: the prevention and management of secondary effects of chemotherapy such as nausea, vomiting, fatigue, alopecia, diarrhea and mucositis; the food; the prevention of infection; the management of medication and when and who to contact regarding changes in the child's health condition<sup>20</sup>.

Considering the statements of the participants, we conclude that health professionals emphasize the use of a neutropenic diet as a crucial tool, given the susceptibility to infection.

Scientific evidence emphasizes that the potential benefits of a neutropenic diet are very limited. However, it is still prescribed in many institutions, with the aim of preventing infections originated by food and / or bacteremia in patients with neutropenia<sup>21</sup>.

Nowadays, the Safe Food Diet is defined by the United States of America Agriculture Department, by the Food and Drug Administration and by the Centers for Disease Control and Prevention as the main method to prevent diseases related with food in immunosuppressed patients<sup>21</sup>. This diet emphasizes the same hygiene and security rules in the food preparation and confection, the big difference is the possibility of ingestion of raw food and vegetables, that should be carefully washed<sup>21,22</sup>.

Neutropenia occurs between seven and twelve days after the chemo-

therapy treatment. This period, called NADIR, can vary according to the chemotherapy drug and its dose. Therefore, mainly in this timeframe, parents and children should observe carefully the signs and symptoms of infection and minimize the risk of its appearance<sup>7,23</sup>.

The infection prevention measures and the recognition and treatment of fever were another topic of the information transmitted by the health professionals. The fever is the main sign of infection, and sometimes the only, in an immunosuppressed child, so it should be treated as an emergency situation. Health professionals should teach and instruct parents to recognize it and treat it<sup>23</sup>.

The administration of therapy, the responsibility previously assumed by nurses, on the child's return home, transits to the parents. However, the occurrence of errors in medication administration at home is a reality<sup>24</sup>. This way, health professionals play a key role in the parental competencies acquisition, in the administration of medication, to avoid that mistakes happen, both in the preparation and administration.

The participants of the study reported that they were informed about the need to contact the health professionals regarding changes in the child's health condition or questions that could emerge. These results corroborate those obtained by other researchers<sup>25</sup>, who recognized the importance of informing and instructing in an individualized way, to optimize the management of everyday life at home.

The information transmitted to parents about the cares they will have to provide on the return home, as well as, the contact with the health professionals, 24 hours a day, promotes feelings of security and confidence in parents, who return home with their child with a new health condition and needs new cares.

The nursing team assumes a relevant role in the patient and family education<sup>26,27</sup>. However, when it is not effective, the probability of occurrence of adverse events as the error in the administration of medication and the difficulty of recognizing emerging situations increases<sup>9</sup>. Teaching, instructing, training and supervising parents about their child treatment and disease, promotes the development of knowledge and competencies to provide the necessary care at home. Nevertheless, the effectiveness of discharging presupposes the continuity of support at home, which must be flexible according to the needs. Thus, the availability of a telephone contact, as already mentioned can contribute to make parents feel safer, as well as support through the home visit. Social networks, forums can be a support strategy, as long as there are health professionals to give this support.

## Conclusion

The return home is experienced by the child and their family as one of the most awaited moments. However, the new condition of the disease, of the child, the responsibilities in the management of the family social life, the feeding, the body hygiene, the susceptibility to infection, the medication, the chemotherapy effects, the worry and continuous monitoring to prevent and identify possible emergent situation, potentiate feelings of uncertainty and insecurity in parents. This way, the return home should be adequately and timely prepared by all the multidisciplinary team, through oral information complemented by written information, which contemplates all the cares to provide and contacts of the institution. In addition, other support resources should be available, taking into account unpredictable situations that may arise at home.

The moment when the information about the disease and the cares inherent to it is provided, as well as, how it is transmitted, affect the comprehensibility

consequently the preparation for discharge and return home. The information comprehensibility is this way a condition to which the capacitation of the parents is actually effective.

We conclude that the majority of issues was addressed by the multidisciplinary team, highlighting the concern and recognition of the need of parents and children to have enough knowledge and competencies to deal with the new condition of the child's illness at home. However the speech encountered some difficulties, that drive the need for better discharge planning and the creation of a professional support to assist the management of unusual situations that arise in everyday life at home.

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# Children with cancer nutrition at home

## Summary

The children nutrition is one of the problems that parents have to manage at home, after treatment of an oncological disease. Nutritional commitment may prolong episodes of neutropenia and compromise the effectiveness of treatments. The goals of this study were: to identify the needs of parents/caregivers in the management of children/adolescents nutrition with cancer undergoing chemotherapy treatment, at home; to characterize parental strategies in the management of children's nutrition at home, after chemotherapy. A qualitative, exploratory, descriptive and cross-sectional study was developed with eleven parents of children with cancer, who underwent chemotherapy treatment, after returning home. Data were collected through a semi-structured interview and analyzed according to Bardin. From the analysis of content emerged the domain The Life at Home and the category Nutrition. Home Life for parents of the child with cancer presents several challenges, particularly in nutritional management, in the face of reduced food intake and the new rules imposed by the neutropenic diet. Thus, parents resort to several strategies to manage this problem: recourse to new practices in food confectionery; changes in the diet of the whole family; insistence/verbal pressure; distraction; reward after negotiation; supply a varied and nutritious diet; questioning/accepting the food preference; organic food. Despite appealing to the multiplicity of strategies, the subjects of this study require the need for more structured support so that at home, they can respond to the challenges they face in their daily lives.

KEYWORDS: PARENTS; CHILD; NEOPLASMS; DIET; NURSING.

## Introduction

Nutrition is essential to promote the growth and development of children, and when they have an oncological disease, it is critical to improve energy levels, minimize morbidity and improve quality of life<sup>1,2</sup>. The relevance of diet has been proven, in the prevention and improvement of the treatment results of different types of cancers, through various modalities of action such as improvement of the immune system, prevention of obesity, among others<sup>3</sup>.

However, malnutrition frequently occurs during treatment, being common in children with solid tumors such as sarcomas, neuroblastomas, Wilms tumor and brain tumors<sup>4</sup>. The highest prevalence rate (50%) occurs in children with neuroblastoma, estimated that about 30% of children with other solid tumors are at risk of malnutrition both at diagnosis and during treatments. Children with leukemia have a prevalence rate of malnutrition of about 5-10% at diagnosis and up to 5% during treatment<sup>5</sup>. Thus, it is imperative to promote an appropriate nutritional intake, consonant to the child needs.

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Collateral effects of chemotherapy such as nausea, vomiting, anorexia, taste and smell changes, oral mucositis, constipation and pain are responsible for decreased food intake and consequently lead to changes in parental practices at the moment of the meals<sup>2,6-9</sup>. Despite the advances in symptom management, the difficulty in preserving adequate oral intake is a reality, and food should be a focus of attention for all health professionals. The nursing team should advise and report the importance of a balanced and adequate diet, and help parents to find strategies that minimize the commitment of nutritional intake.

Neutropenia and susceptibility to infection require the adoption of new practices in food preparation and selection. These changes associated with the disease and with the side effects of chemotherapy in the gastrointestinal system affect and lead to changes in the children diet.

As mentioned previously, children with cancer are prone to inadequate nutritional intake, both for disease and for chemotherapy<sup>12</sup>. Poor nutritional status reduces treatment tolerance, prolongs episodes of neutropenia, which increases the risk of

infection. On the other hand, these children present increased nutritional needs<sup>11</sup>. Therefore, children/adolescents should ingest a balanced diet with adequate amounts of protein and a variety of fruits and vegetables, without excess of vitamin supplements or extreme diets, which may interfere with cancer treatment<sup>13</sup>. Given the susceptibility to infection, they should avoid aliments more prone to high levels of bacteria's such as raw<sup>14</sup>.

The reaction of children and adolescents to the disease differs. Adolescents and school-aged children are able to understand information about their illness. Typically, schoolchildren are more cooperative in the treatment and care process. Otherwise, adolescents consider the disease as a cause of loss of independence, which constrains their plans for the future. However, several factors affect the reactions of children and adolescents, such as temperament, previous experiences and the effects of illness in the family<sup>10</sup>.

Adequate food intake is undoubtedly associated with improved health status. Thus, when returning home, after cancer treatment, food is a central concern for parents. They face the challenge of getting their child to eat well, striking the balance between their desires and the rules imposed by the treatment.

Adequate nutritional status is essential during and after chemotherapy treatment, to promote the growth and development of the child/adolescent; to increase tolerance to treatments and to contribute to the reduction of the risk of infection. In this sense, food assumes a centrality in the concerns of parents at home. This study aims to contribute to the identification of parents' difficulties in the nutritional managing of the child with cancer at home, in order to outline better support from health professionals.

This study aims to identify the needs of parents/caregivers in the management of home nutrition of children/adolescents with cancer undergoing chemotherapy treatment and characterize the strategies of parents in the management of children's nutrition after discharge from cancer treatments.

### Research methods

The study is based on the qualitative paradigm, of exploratory, descriptive and transversal nature. The population was constituted by the parents of children with cancer undergoing chemotherapy treatment, in a specialized Hospital Center, located in the north of Portugal, after the return home. The non-probabilistic intentional sample was consisted of 11 parents. The participants were selected by the investigator according to the following inclusion criteria:

- Parents of children with cancer submitted to a chemotherapy treatment, independently of the number of cycles, in the Hospital Center.
- Parents of children with cancer 48 hours after returning home. It was considered that this time interval would be necessary, so that the participants would obtain a minimal perception about the experience of caring for the child at home, after completing chemotherapy treatment.
- Accepted to be in the study.

As exclusion criteria was defined: participants who don't speak Portuguese fluently.

For this study, the interview script was selected as a data collection instrument, and a semi-structured interview as technique, in order to acknowledge the experiences and needs of the parents of children with cancer.

The investigation obtained a positive consent from the Ethics Committee and the Board of Directors of the institution where it was held. The participants were contacted during the period their children were in hospital and signed an informed consent document.

Between January and June 2016, 10 interviews were conducted at the

participants' homes, in a room at the Pediatric Oncology Day Hospital or other location, according to the wishes expressed by the parents. Mostly they took place in the presence of the children, being these entertained to draw or color drawings, provided by the investigator. They took place in one single session with the participation of one of the parents, in only one of the sessions both parents participated. The interviews lasted an average of 58 minutes and were recorded on audio support. They were later transcribed, respecting the language used by participants, including laughs, hesitations and silences, as suggested by Bardin<sup>15</sup>.

As a technique to analyse the content, the thematic or categorical modality was chosen, which consists in a transformation of the text in registration units and categories, being this technique the most commonly used by the content analyses<sup>15,16</sup>.

The ethical questions were considered from the beginning, in choosing the theme, the type of study, participants' selection, data collection and its interpretation.

With the aim of safeguarding the participants' anonymity and confidentiality, identification codes were used and were recognized by E1 to E10.

### Findings

From the content analysis of the interviews emerged the domain "Life at Home" and the category "Nutrition" (figure 1).

The parents' concern about their children nutrition, managing the guidelines that were given to them, the child's wishes and daily difficulties were reported by all of the interviewees. The neutropenic diet is recommended by the multidisciplinary team, which causes several changes in the child's eating habits and sometimes to the whole family. In the discourse produced by the participants, it is possible to observe these concerns and changes:

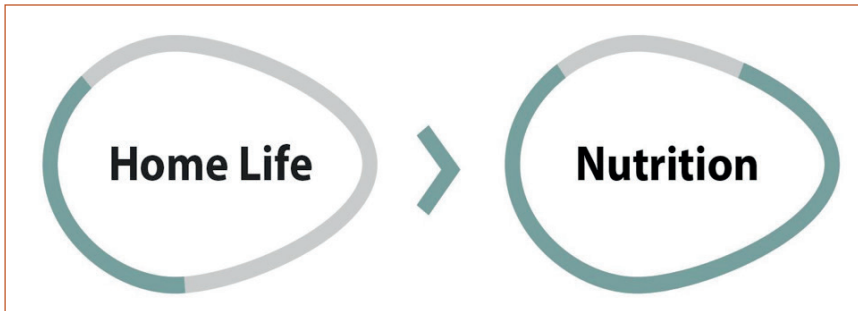


Figure 1. The domain "Life at Home" and the category "Nutrition"

... we are careful, now not so much, but from the beginning it was with the food, because for example the milks, had to be in small packages, the wafers, although still the milk continues, the wafers, I facilitate now. If there is a piece of rice left over, and if he asks us the next day, or sees us eating, I'll give him a little, but, formerly, I did not make it easier. The fruit, [...] he does not eat it cooked, so what I do I wash it very well, I take out a thick bark and he eats a little bit (E3).

I buy fresh bread every day and she eats, [...] [the yoghurts] I go to the supermarket, I choose... with the longest shelf life, go to the fridge, I see if the packaging is not broken, [...] we disinfect the mango with vinegar, we peel and she eats. [...] we also try to make a very varied diet, [...] fortunately she likes a lot of coarse fruit, likes bananas, likes pomegranates, likes, for example, avocado [...] (E4).

The management of the risk of infection associated with nutrition is a central concern, as expressed, in the following grafts:

... we spend a lot of vinegar because we disinfect everything. There is a bottle of our own whenever we open to him that never lasts to the other day [...]. All very carefully indeed. An uncle kills a chicken, [...] comes in an ark, only makes the trip, half an hour, arrives here prepare the chicken, all in individual bags, all frozen (E5).

... the spices before cooking or confection, [...] the food, the vegetables, very well cooked. [...] I do not give him anything that is made out, smoked, nothing. [...] a person always has those care, to do everything homemade, even the cakes and everything, there is nothing bought (E6).

... we are doing our best to [...] him not eat like that, things that are open, right? It has to be more stuffy, is not it? It is different from what a person was accustomed to, a radical change, no doubt. [...] if you had enough to eat at noon, kept, put in the freezer or the fridge and at night ate [...]. Now we cannot do that [...]. The butter, juices have to be those little packages (E8).

The parents who participated in this study also mentioned the need to prepare and confection food at every meal as a new challenge. It is worth mentioning that one of the speakers says that currently facilitates, and does not always comply with all the recommendations.

One of the parents who participated in this study stated that their adolescent son was aware of and complied with the diet proposed by health professionals.

In addition to the restrictions of the neutropenic diet, one participant reported the need to manage the prescribed oral supplements:

... he drinks Fortimel® for breakfast, then in the afternoon he drinks milk, but he has to put the Fantomalt® (E10).

Nutritional issues raise constant doubts:

... his food at home, is where I sometimes have more doubts, [...] we make soup, can I keep from noon to night? [...] one thing I've been doing, is buying that crushed ham, already cut, is it the best option or is it not? [...] can it be a box of familiar butter? [...] or have to be those little ones for him? [...] milk I know that it has to be those little packs [...] at four o'clock I open the milk package, at six o'clock I want milk again, can it be from the same package? [...] it is because I have already made both options [...] I still often get caught up in the prospect that the nutritionist gave me and I already read it, I do not know how many times (E10).

The concern with diet is also expressed in the preference of organic food in order to promote adequate nutrition for their children, as it is said in the affirmations:

... since this happened we started to opt for organic products. Ah whatever he eats, whether of vegetables or meat, whatever is organic (E5).

We had to radically change habits that he had, which was to eat biscuits [...] Heaps of junk [...] We have to look for what is biological, which was produced through organic farming (E7).

However, food is associated with other problems, such as those resulting from the refusal of children, which is evident in the participants' discourse:

The difficulties, hmm, were more to see, even with [...] the rejection of food (E1).

He says no... I put in the mouth and he is lying down [...] before going to bed he drinks milk, he practically stays only with soup. It's only soup, eat the baby food in the morning at breakfast, at lunch it's a sacrifice to give him something, but that's it (E3).



Towards the difficulties they faced with the rejection of their children's food intake, parents used several strategies as changes in the diet of the whole family:

*Everyone followed the food of R. in the same way, what he eats is what others eat, here at home (E5).*

Some of the participants adopted another strategy such as questioning / accepting the child's food preference:

*... I try to give her as much as she likes (E6).*

*I always ask him what he wants, because if he says he does not want to, I'll put him in the face ... and he eat. Yesterday he said he wanted a fresh soup, he ate the fresh soup, then he said he wanted rice with gilthead, he ate rice with gilthead, but he just ate a little. But it was because I asked. [...]. A person asks what he wants, [...] That way he has no excuses (E9).*

Parents who participated in the study verbalized that they insisted with the child to ingest refused food:

*... [after chemotherapy treatment] returning home, is the start to give her food gradually, because she eats badly. First she does not eat, then begins to eat very little and this insistence on our part, to give her, little by little and very often ... to stimulate her to eat, and then start eating, usually after a week, a week and a half (E2).*

*To see if she evolves, we are giving food hourly to see if she develops, otherwise with what she eats if we only give the snack, dinner and lunch we are plotted (E8).*

Some of the participants reported that in addition to providing their child's favourite foods, they urged him to ingest refused foods by offering them throughout the day and night. In this sense, some parents, despite insisting, exert some verbal pressure on their children to feed, as expressed by one of the interviewees:

*I'll put a yogurt in here and I'll give it to him one morning, but I'll give him a spoon, then he'll come, I'll give him another spoon, another spoon and I'll get it. Like milk today, I made simple milk, I got it, it started at 8 and it ended now, two hours, but I got it. It is like this in bits and threatening [...] (E9).*

One parent of this study said he resorted to distraction strategy:

*He never stopped eating [...]. Anything to distract him, as television or a game, anything. Everything is worth at this point. So the important for him is to eat and it is a fact that he never stops eating (E5).*

Reward after negotiation is a strategy reported by one of the participants of this study:

*One thing we cannot eliminate is bread, he continues to eat bread with butter, much less than what he ate, [...] we have had results to give him fruit, like you want to eat bread, [...] eat a banana first and I'll give it to you later (E7).*

One of the participants mentioned that he chose to insert food in his meals, without saying to the child, with the intention that he ingested them,

without being aware of his presence:

*... the difficulties I have felt is in changing the diet habits, [...] yesterday we did an incredible thing, the [mother] cooked shiitake mushrooms and mixed with grilled meat and cut everything and gave it. He barely felt! Incredible [...] that is all brown and, [...] and she insisted two or three times and the third time she ate and from there she began to eat. Oh man, it was a victory (E7).*

Faced with the refusal of children to eat, parents resort to a multiplicity of strategies, as expressed in the following grafts:

*... he rarely eats fruit, so yesterday I was grazing him a series of fruit and he ate it. If he does not eat later at night, but at least he has that whole fruit, I'm going to do like this [...] I try at least to give him the soup. The soup has it all, so if it does not eat the main dish I do not care anymore (E3).*

*May the food not go, but will the soup. [...] I put meat in the soup and everything. It is a way for him to eat a little more meat [...]. we do one thing one time, another time to see if he goes to eat (E10).*

Two participants in this study provided meals with foods that they say are important in fighting cancer:

*... what he ate was soup with [...] pumpkin seeds or sunflower seeds, no one remembers to put quinoa with seaweed [...] The shakes I always made with beets, carrots, oranges and seeds. [...] one thing I always kept was no dairy products, there is no sugar, no refined flour, no processed food. [...] the grandmother only cooks with Monchique® water, because it is more alkaline [...] I have always made several types of teas to detoxify [...] since the dandelion, borututu, I have several (E5).*

*... we have tried to incorporate healthier things into his diet. [...] we make soup daily and the soup is loaded with [...] crucifers, which are a part of the veg-*

*ables that are very good for fighting cancer. The crucifers are broccoli, cauliflower, Brussels sprouts, all kinds of cabbage, arugula, watercress. [...] very important seeds, because they have many vitamins and nutrients, magnesium, selenium, potassium [...] nuts also have lots of vitamins and minerals (E7).*

## Discussion

The parents' concern about their children nutrition was visible in the participants' discourse analysis, we verified the preoccupation and the fulfillment in the choice, storage, preparation and confection of the food. The implementation of the neutropenic diet is a challenge for families, since it requires changing their eating habits. Participants emphasized the challenge of banning raw foods, which meant that their children would stop eating some fruit they appreciated. Other researchers<sup>2,7</sup>, report similar difficulties in participants in their studies, who adhered to the neutropenic diet.

One of the study participants reported that currently facilitates, and does not always comply with all the recommendations, which corroborates the findings of Sari et al.<sup>8</sup> This may be due to the experience acquired by the parents over time, when they are aware of the most frequent adverse effects of their children to the treatments, and when the failure to comply may lead to a higher intake. Thus, parents have to learn to manage the fragile balance between strict compliance with the guidelines they have received, and the will of the child.

Another parent who participated in this study mentioned that his adolescent son knew and complied with the diet proposed, as Sari et al.<sup>8</sup> concluded in their study.

The need for management of nutritional supplements was reported by one of the participants. Nutritional support is a crucial tool in successful care for children undergoing chemotherapy<sup>9</sup>. These investigators concluded that 45% of the children undergoing chemotherapy had a loss of 10% of their weight and consequently met the criteria of malnutrition. To avoid these situations oral supplements are provided to promote a good nutritional status, however, these are not always well tolerated<sup>2,9</sup>.

The father's speech, interviewed on the first homecoming, shows the need for more information about diet, since parents are still in a process of adaptation to the disease, and they already need to take care of the child. From the above, despite the written information that is read and reread, doubts remain, as it does not relate to all the problems / difficulties that have to be managed on a daily basis. Other researchers<sup>2,8,19</sup>, also report the need for parents to provide more information about diet.

The choice of participants for biological products is now widely publicized as a cancer control / management measure. Participants in the study by Sari et al.<sup>8</sup>, also referred to the demand for organic food as an option for better nutrition. The industrialization of food leads the consumer to eat carcinogenic aliments. The oncologist Khayat<sup>20</sup> recommends that the consumption of organic fruit and vegetables in the diet of cancer patients should be favored.

During the chemotherapy treatment, most children have decreased appetite and reduced food intake<sup>9,19</sup>, which potentiates parents' difficulties in promoting adequate nutrition, causing worry and distress<sup>9</sup>.

All these problems, and the inherent weight loss, cause stress in the parents<sup>7</sup>. In this study, food refusal was verbalized by all participants, noting that it was due to both gastrointestinal side effects and changes in dietary habits that lead to alterations in diet, suggested by health professionals.

Parents used various strategies to deal with feeding rejection such as modifying the diet of the whole family to follow the dietary changes experienced by the child is a benefit, helps in the implementation of the new diet,

improves the family's quality of life, and leads to a better adherence by the child. When changing the dietary habits of the family does not occur according to the needs of the child, it impairs the adaptation to the disease and decreases adherence to the therapeutic plan.

In order to combat loss of appetite and lack of interest in food, parents can provide preferred aliments, question the child about what they want to eat and try to take their requests into account, not forgetting the counselling and constraints given by the health professionals<sup>2,7,21</sup>.

Insisting with the child to ingest refused food without imposition and with encouraging words can be a relevant strategy at meal times<sup>21,22</sup>. As the participants verbalized.

However, the recourse to verbal pressure may lead to some conflict between the parents and the child, which may aggravate the situation. In fact, some parents report periods of tension and conflict during meals, referring to resort to verbal pressure with some frequency<sup>7</sup>. Parents' anguish when experiencing weight loss and reduced nutritional intake may have a negative impact on parent-child interactions during meals<sup>7</sup>.

Distraction is a strategy used by many parents at meal times. The interaction with family, playing, stories, drawings and watching television appeals to children and their use facilitates the great challenge that parents face at meal time<sup>2,21</sup>. Playing is considered a therapeutic measure, which promotes child development, and physical and emotional recovery by minimizing the disease process. The playful facilitates the moment of the meals, leading the children to eat better<sup>23</sup>. However, distraction must be adequately performed to avoid that the child is more interested in the strategy than the food offered<sup>21</sup>. Distraction, according to the child's age and preferences, when used correctly, can be a relevant strategy in the nutrition of children.

The recourse to negotiation and

the reward towards the act of refusing food is a tactic with some success and lessening the distress of parents, who exchange the intake of food for something that children cherish. However, the frequency of its use may hinder the child's ability to understand limits and consequently become disobedient<sup>22</sup>. This strategy is also mentioned in the study by Sueiro et al.<sup>17</sup>

Blissett<sup>24</sup> argues that parents with their children's refusal to eat healthy foods should resort to rewarding negotiation strategy rather than imposition, since the former is more likely to succeed in achieving the goals.

Concealment of food makes it difficult for the child to know about it, being a strategy used by the parents<sup>17</sup>, as a way to bring the food that is considered nutritionally adequate. However, exposure to food flavors enhances their acceptance<sup>24</sup>.

Parents believe that nutrients are basic and essential elements for maintaining good health and strengthening the child's immune system, helping them cope with illness and aggressive treatment. Thus, they rely on several strategies to provide a diversified diet to overcome the food aversion that children develop during chemotherapy<sup>2</sup>.

Parents should resort to positive strategies<sup>7</sup>, because recourse to negative strategies may contribute to incorrect eating behaviors<sup>24</sup>.

Nowadays, even in the media, information about the association of food with diseases, namely cancer, is published. Thus, eating habits can increase the risk of cancer, or otherwise help prevent it, or improve the response when facing a cancer.

Food should be diversified, avoiding fried, grilling and processed aliments<sup>20,25</sup>. These authors also mention the aliments that the participants mention because they have compounds with anticancer properties, and their consumption strengthens the immune system and prevents cell alteration. Regarding the type of water that children should ingest, there is no consensus. Some authors state that it should have an alkaline pH, close to 9.5, because there is currently a propensity for the pH of our body to be acidic<sup>25</sup>. Others point out that there is no scientific evidence to prove the benefits of alkaline water intake during cancer treatment, so its consumption should not be advised for both cancer prevention and treatment<sup>26</sup>.

## Conclusion

Being well fed is associated with good health. In this context, the preoccupation with the nutritional practices of children who have a chronic illness, like cancer, assumes a centrality in the daily life at home. In order to promote good ingestion, parents resort to different strategies: changing the diet of the whole family to follow the changes experienced by the child; the insistence on the consumption of food throughout the day; distraction; reward negotiation; providing a varied diet and more nutritious meals; questioning the food preference and providing the meal according to their request; verbal pressure to promote adequate food consumption; the use of organic food. Despite the multiplicity of such strategies, it becomes apparent that parents face issues related to food as a complex challenge.

The present research demonstrates the difficulty, the complexity of food management in children and the need for more structured support so that at home, they can respond to the challenges they face in their daily lives.

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# Perception of caregivers of persons with schizophrenia about a health education program

## Summary

The mental health policy of Brazil has been guided by the search for citizenship, social equality and autonomy of the individuals with mental disorders and it started with the deinstitutionalization process. On the other hand, this paradigm shift contributed to making the patients stay in the family environment and thus the need for family members to play the role of caregivers. The attributions of these care functions have contributed to a physical and emotional overload. Using a psychoeducational approach focused on the family member/caregiver of people with schizophrenia, this study proposed to check the caregivers' perception about the importance of the practice of relaxation activities for the promotion of self-care. The intervention was performed during a six-month period. Participants were 31 family caregivers of mental health cohabitation centers in the city of Belo Horizonte, Brazil. Using the relatives' reports about the perception of the intervention, categories were listed and treated with the support of the software webQDA. The results revealed through the family members' perception, that the intervention program provided them with contributions such as wellbeing, self-control over impulses, increased self-esteem, and encouragement for self-care. The literature reinforces that the educational practice in health is composed of educational activities aimed at the development of individual and collective capacities aimed at improving the health and quality of life of people. The intervention program with relaxation exercises contributed to an improved physical and mental health for family caregivers, awakening them to self-care.

KEYWORDS: FAMILY CAREGIVER; SCHIZOPHRENIA; HEALTH EDUCATION.

## Introduction

The new model of mental health care and psychiatry is the result of a paradigm shift that occurred through national and international movements involved in psychiatric reform in the mid-twentieth century and spread throughout the world resulting in the deinstitutionalization of people with mental disorders. The closure of psychiatric hospitals required the creation of substitutive services for mental health care through a political com-

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mitment that involves strategies in this new model, in which the direct protagonists are health professionals, people with mental disorders and their families<sup>1</sup>.

In Brazil the reform movement was intensified after the Caracas Congress in 1990. Deinstitutionalization took place with the implementation of services, the involvement of professionals and institutions, and the creation of laws to ensure their effectiveness. In this process, the family members occupy the important roles of informal caregivers, to share the care of their sick family members with health professionals. However, attributing care inherently to family caregivers requires knowledge about the disease and skills to deal with the characteristics of mental disorders<sup>2</sup>.

The lack of knowledge about the characteristics of the mental illness causes in the family carers feelings of anguish, stress and suffering, since they are not properly prepared to deal with the disease and its evolution. Due to this aspect, it is common the development of overload in caregivers<sup>3,4</sup>. In this sense, the problematic behavior of the person with schizophrenia is a strong determinant of overload in family caregivers with low self-control<sup>5</sup>.

There is consensus among several studies regarding the need for psychoeducational intervention for family caregivers in the expectation of making them more able to perform their role and ensure their physical and mental health<sup>6,7,5,8</sup>. In this sense, attention is paid to psychoeducational interventions with relaxation exercises so that individuals are able to develop aptitudes to deal with anxiety emerging from the stress situations in everyday life<sup>9</sup>.

Attention is also paid to practices in health education, which, in order to be effective, must be developed in a dialogic, emancipatory, participative and creative perspective. These practices should provide the subjects with information about health education, autonomy, understanding their rights and all the attitudes essential to maintenance of their good health condition<sup>10</sup>.

Regarding training and information, it should focus on promoting health and valuing education in the life of the individual, the family and the community, considering the coexistence in all aspects of social life. In this way, the sum of the knowledge and experiences lived in the daily life of the individual should be considered in order to direct the actions developed by health professionals. In this context, health education is considered an important tool for health promotion because through educational and environmental support it can produce actions intervening in the conditions of life that lead to the health of the individuals and populations<sup>10</sup>.

The implications of the caregiver's responsibilities related to the tasks of caring for the persons with schizophrenia in the daily life result in the unleashing of serious consequences, such as the impairment of physical and mental health. In this sense, it is essential to use resources through support interventions focused on the specific needs of family caregivers to promote functional adjustment both to the disease and the demands of care tasks.

Therefore, and due to high levels of overload in family caregivers of people with mental disorders as verified in the results of studies on the subject, the authors suggest the application of psychoeducational interventions in order to reduce the overload and to improve the health of the caregivers and the people with mental disorder<sup>7,5,8</sup>.

The psychoeducation emerged in the mid-1980s in Germany through the working group called Psychoeducation of Patients with Schizophrenia, and began to be understood as a didactic intervention of a psychotherapeutic nature. This intervention is supported by experimental and scientific methods and is based on the fact that cognition generates emotions and behaviors. The authors state that the cognitive component precedes the affective, considering the transfer of information an emotional response. The actions developed in psychoeducation should not only be informative about the disease, but should also aim at improving the psychological and emotional state of the caregivers in a way that they are able to recognize and establish in their social environment a social support network<sup>11</sup>.

Several scientific studies present the contribution of psychoeducational intervention as an effective alternative, because this intervention model comes along with significant results of improvement in the quality of life of the family caregiver<sup>12,13,14</sup>.

Authors found marked improvements in family caregivers of people with schizophrenia who underwent psychoeducational intervention with an approach related to awareness of the disease, improvement in problem solving skills of communication, the daily life among those involved and the daily tasks performed by the family member caregiver. The authors warn that the intervention should be part of the therapy of mental health services and should be integrated into the routine of patients and family caregivers<sup>12</sup>.

Further in this direction it was found in study, significant improvements in

decreasing the overall level of family burden impact on daily activities and social relationships, improvement in family cohesion and depressive symptoms in family members who cared for patients with schizophrenia for more than 10 years<sup>13</sup>.

Among the diverse psychoeducational practices, physical activity is seen as an important resource that allows the individuals to experience corporal practices performed according to their possibilities, limits and potentialities. It favors social bonds and resuming social roles, enriches the relationship with the environment, and assists in the gain and maintenance of health and psychic, affective and relational development.

Specifically, mental health relaxation exercises offer several benefits that positively influence the routine behavior of the individual<sup>15</sup>, as well as provide improvements in physical and mental health<sup>16</sup>.

Relaxation is defined as a state of consciousness described by feelings of peace, relief from tension, anxiety and fear, favors emotional balance, improved mood, gaining self-esteem, improved memory, reduced risk of depression, improved immune system, reducing muscle tension and improving sleep<sup>9</sup>. It is also understood as a moment of muscular relaxation that requires voluntary rest and provides the pertinent use of the individuals' physical and mental resources, contributing to protect the body from stress-related illnesses and psychopathologies<sup>17</sup>.

In order to better understand the contribution of relaxation activities for reducing burden over family caregivers, this study seeks to verify the perception of family caregivers of people with schizophrenia on the importance of practicing relaxation in order to promote self-care related to the development of caregiver tasks.

## Methods

The present study has a qualitative

nature, whose approach is characterized as an investigation oriented to the analysis of concrete cases in its temporality and location, through expressions and meanings that people attribute to their thoughts, attitudes, behaviors and practices<sup>18</sup>.

In order to use the psychoeducational intervention to intervene on the overload in 31 family caregivers of people with schizophrenia and awaken them to self-care, it was necessary to know better the behavior and the human experiences, in order to use an educational intervention through the practice of systematic physical relaxation activity. Using this intervention as a starting point the research recorded the perception of the participants as a function of the experience of the practice. This approach applies to the study of relationships, representations, beliefs, perceptions and opinions, which are products of people's interpretations of how they live, feel, and think<sup>19</sup>.

The study was carried out in the year 2015, in the period of six months, with a weekly session lasting 30 minutes. Each session was operationalized following the structure: 15 minutes of relaxation and 15 minutes for the reports of the familiar caregivers, recorded in audio. For this study it was selected the family member considered to be the main caregiver of the person with schizophrenia enrolled in the CCC.

After transcribing the reports, we used the Bardin content analysis technique with the support of the software WebQDA.

The study was evaluated and approved by the Research Ethics Committee of the Municipal Health Secretariat of Belo Horizonte via Plataforma Brasil, registry CAAE n° 41787015.6.3001.5140.

## Findings

### Characteristics of family caregivers and people with schizophrenia

The sociodemographic characteristics of the family members show that the average age of the 31 family caregivers is 67 years, (80.6%) female, and of these (54.9%) are mothers. As for marital status, 41.9% are married, 64.5% of the caregivers are retired, 58.1% have low level of education, 87.1% live in the same household with the subject with schizophrenia, and (41.9%) have been caring that person for more than 11 years.

### Categories featured in content analysis

The analysis was performed in two stages, namely: 1st) Pre-analysis, 2st) Exploration of data.

1st) **Pre-analysis:** in this phase the material to be analyzed was organized, making it operational, through the contents of the transcription of the reports, and followed by the identification of subcategories;

2nd) **Exploration:** In a second reading, the subcategories were grouped and distributed into two categories (Relaxation Activities, Meaning of Health Education Intervention Program) (table 1).

For each subcategory of the Relaxation Activities Category, excerpts from relatives will be presented:

#### *Feeling of well-being*

FC28 – *You can see that it relaxes, it calms me, it makes me feel more calm, so I have always been ready too, with both physical and mental well-being.*

FC5 – *After I started to participate in this relaxation, I'm feeling very well on the physical ... the pain I felt behind my legs and that bothered me so much, is over.*

#### *Sensation of relaxation*

FC7 – *It was great for me, I got to relax, I rested, I'm feeling very good. Relaxed, it was very good.*

FC16 – *Every day I'm getting disconnected. ... when I realize, I was already somewhere else, on a beautiful mountain and I went away.*

#### *Strengthening self-esteem*

FC29 – *I feel like a courageous person, after I started doing this gymnastics I have valued myself more, I am feeling very well and I want to continue.*

FC7 – *I'm feeling lucky to be here. Happy to take care of me...*

*Positive perception of self in the other's vision*

FC29 – *My son said that he thinks I'm very willing, more cheerful. I am like this because I am participating of these*

## CATEGORY RELAXATION ACTIVITY AND SUBCATEGORIES

1

Relaxation Activity	Number of References
<b>Subcategories:</b>	
<i>Feeling of Well-being</i>	421
<i>Sensation of Relaxation</i>	145
<i>Strengthening Self-Esteem</i>	101
<i>Positive perception of self in the other's vision</i>	13
<i>Self-control of impulses</i>	85
<b>Social support among Group members</b>	10

**MEANING OF THE HEALTH EDUCATION PROGRAM AND ITS SUBCATEGORIES 2**

Category	Number of references
<b>Meaning of the Health Education Program</b>	
<i>Learning with the intervention program</i>	143
<i>Appreciation of the intervention program</i>	201

*classes. I'm getting more cheerful, doing something that makes me feel better. I want to proceed. I even think about going into the gym.*

FC13 – *This exercise is really good. My son-in-law said that he thinks I'm more relaxed with people and JB, because I was very agitated with him. I'm calmer now.*

*Self-control of impulses*

FC4 – *"I'm much calmer. Today G. made me very angry, ... but I did not pay attention to her. And that's a sign that I can control myself. It's difficult, but I'm having more patience with her. "*

FC21 – *"... I improved the care with my wife, I have more calm, more patience. "*

*Learning with the intervention program*

FC6 – *I'm feeling good, I think it's good to be here. We only take care of our children and we do not take care of ourselves ... I have to take better care of myself.*

FC5 – *I'm doing the exercises at home and my girl is doing it together. I want to continue. "*

*Appreciation of the intervention program*

FC5 – *I'm going to miss it, I learned a lot from these classes. My blood pressure is better controlled after I started to participate in this activity. I improved a lot, it was very good.*

FC13 – *... this activity revived me. If I could I would not let it end. Seriously, for me it was very good. It helped me a lot...*

**Discussion**

The change, reported by family caregivers, caused by Relaxation Activities (Feeling of well-being, Sensation of Relaxation, Strengthening Self-Esteem, Positive perception of self in the other's vision, Self-control of impulse, Social support among Group members) is confirmed by Roeder<sup>15</sup>, who states that physical exercises, specifically, relaxation exercises promote the reduction of anxiety and stress, increase the sense of self-esteem and improve the capacity to manage psychosocial stress, leading the individual to perceive physical and mental well-being. In this sense, it is verified through the results of the present study that the intervention program with the relaxation activity provided the physical and mental well-being in the family caregivers, in concurrence with the studies of Hansen<sup>12</sup>, which stresses that a psychoeducational intervention can provide well-being to the family caregivers, since it protects them from physical and mental impact caused on personal, social

and work life by care tasks. Family caregivers reported issues such as physical and mental fatigue and lack of sleep. However, during the development of the program with relaxation exercises, the family perceived a sense of tranquility and well-being attributed to the exercises. This result is in agreement with Vancampfort<sup>16</sup>. According to this author, relaxation exercises promote improvements in the physical health and mental health of the individual.

The improvements triggered by the relaxation exercises were described by Payne<sup>9</sup> such as perceiving feelings of peace, tension relief, anxiety relief, which favors the practitioner's emotional balance, improved mood, reduction of muscle tension, improved sleep and as an important means of improving self-esteem. Increased self-esteem involves a positive change in various aspects of the caregiver's life, which interferes with one's own health and care of the sick person<sup>17</sup>. In the results of this study it was observed that the family members obtained improvements in their self-esteem, self-esteem awareness, adherence to healthy habits, and feelings of happiness, recognition of changes arising from a new behavior towards the caregiver task and in social life.

According to Salci<sup>10</sup>, self-esteem is the value that each individual has about him/herself, which involves physical and emotional factors and feelings that the person faces throughout life.

It was observed in the reports of family members that participation in the intervention provided them with improvements in self-esteem, awareness of self-worth, adherence to healthy habits, feelings of happiness, recognition of changes arising from a new behavior towards the task of caregiver, as well as in social life.

Being involved in the care of people with schizophrenia has been highlighted in the literature as an experience that generates stress, overload, physical and mental ex-



haustion, and interferes with the quality of life of caregivers. One of the tools that may contribute to the reduction of these symptoms is psychoeducational intervention. This type of sustained intervention in the practice of relaxation exercises can contribute to the increase of the self-control of these relatives<sup>5</sup>. In the present study, the family caregivers in their reports confirm the positive influence that the intervention provided in the emotional state regarding the control of emotions. It was verified that in the course of the development of the relaxation sessions, the relatives showed greater sensitivity in relation to the need to self-control in the face of stress situations.

The Meaning of the Health Education Program at family caregiver has two subcategories, as shown in table 2: Learning with the intervention program and Appreciation of the intervention program, that pointed out psychoeducational intervention as an important support tool in terms of training / informing caregivers by enabling them to increase their problem-solving capacity, which will lead to better management of the disease by reducing levels of stress in the family<sup>12,14</sup>. In this sense, the family caregivers participating in this study, through their reports, confirmed that they improved their learning regarding how to deal with the problematic behaviors of the persons with schizophrenia, greater control over stress, perception of physical and mental improvements, and perception about the need for self-care.

## Conclusion

The innovations in the mental health policy launched by the paradigm shift in psychiatric care attributed to the family the role of caregivers. The fact that they are unprepared for this new responsibility may result in consequences for the physical and mental health of the caregiver and affect family functioning.

It is evidenced through studies in the literature review the need for mental health services to develop psychoeducational intervention, aimed at guiding the family on how to deal with the problematic behaviors characteristic of mental disorders.

In another dimension, and geared towards providing the family caregiver with improvements regarding their physical and mental health and stimulating their self-care, this study proposed the application of a program of relaxation activities.

The results from the program demonstrated that the objective of the study was reached, evidenced by the fact that it was possible to promote in the caregivers a greater awareness about the importance and the valorization that they should have with their self-care.

Therefore, it is proposed that this type of intervention in health education may be incorporated within the activities of mental health services, as a way of appreciating the well-being of the family caregiver.

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# What is the relevance of research for nursing students?

## Summary

**INTRODUCTION AND OBJECTIVES.** The Bologna Process led to the reorganization of the education system into three academic degrees: Bachelor's degree, Master's degree and Doctorate, differentiated by focusing on the research area only after the Bachelor's degree. The present study aims to understand the relevance of research in Nursing for undergraduate students.

**METHODOLOGY.** Through a mixed descriptive-correlative investigation, the data was collected through an online form, sent via social networks. The sample is made up of 250 students, in the 4th year of the Nursing Bachelor's degree, from 17 higher education institutions in Portugal.

**RESULTS AND DISCUSSION.** All students consider nursing research important, but 35.2% of the respondents are undecided about contributing to this area and 5.6% do not intend to contribute to it. It was also noted that, although 99.6% of the students reported they had a curricular unit associated to research, 53.2% of the students considered their ability to analyse a scientific article as "Sufficient". The relevance attributed to this component of research analysis is mostly evaluated as "Very important" (42%).

**CONCLUSIONS.** Most students value nursing research, and are interested in projects that contribute to the subject and to the development of their personal and professional skills, but there is a lack of incentive for investment in this area. It is also possible to identify gaps in learning regarding the analysis and interpretation of scientific articles. It is possible to conclude that in the educational system there must be structural and content changes to respond to the students' needs.

**KEYWORDS:** NURSING; RESEARCH; STUDENTS; BACHELOR'S DEGREE.

## Introduction

The Bologna Process began in 1999 and was revised in 2003 by a Committee of Ministers in Berlin, and it was finally adopted in Europe in 2005. Its main objective is the implementation of an equitable classification of academic degrees between different countries in the European Union, allowing for a greater compatibility, comparison and recognition of the employability and continuity of studies, as well as greater ease in the mobility of students in the European area (MCTES, 2006)<sup>1</sup>.

In Portugal, the follow-up of the strategies outlined in the Bologna Process began in 2006, with the approval of Decree Law No. 74, which presents this project as an opportunity to "encourage higher education attendance, improve the quality and relevance of the courses offered, foster the mobi-

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lity of [...] students and graduates and the internationalization of [...] courses" (MCTES, p. 2242, 2006)<sup>1</sup>.

This shift in the university paradigm, gave origin to structural changes, namely:

- The change of focus from the acquisition of knowledge to the acquisition of skills.
- The implementation of a model of academic degrees according to three cycles: Bachelor's degree, Master's degree and Doctorate.
- The implementation of a curricular credit system.
- The possibility of enrolling in higher education outside the reference age, by modifying the conditions of access (MCTES, 2006)<sup>1</sup>.

In fact, the central issue underlying the paradigm shift in higher education is the transposition of a model that aimed at transmitting knowledge to one whose focus is the acquisition of skills – of a generic and specific nature. Namely generic skills include instrumental skills (cognitive, methodological, technological and linguistic skills), interpersonal skills (personal capacities related, for example, to interaction

and cooperation) and systemic skills (a combination of instrumental and interpersonal skills). These specific skills relate to the area of training (MCTES, 2006)<sup>1</sup>.

However, structurally the reorganization of the education system, with the definition of three academic degrees, was the most meaningful change resulting from the Bologna Process. According to the Dublin Descriptors presented at the Berlin Committee, the goals each student should achieve at the end of each of the academic stages were defined. In the first place, concerning the Bachelor's degree, the goals are: acquisition of application skills of the acquired knowledge in the associated vocational area; acquisition of skills for collection and interpretation of relevant information; and the acquisition of continuous learning skills that allow a high degree of autonomy. As for the master's degree, the final goals involve the capacity to develop and integrate knowledge regarding complex and unforeseen situations, and prompting ethical and social reflections, associated to situations with limited information. Finally, concerning the doctoral degree, it is intended that students can understand and invest in a scientific field, as well as develop a significant research project, with a high level of contribution to the scientific progress in their vocational area (MCTES, 2006)<sup>1</sup>.

When analysing the description of the different degrees, it is possible to see that there is a separation between the Bachelor's degree and the Master's and Doctorate degrees concerning the investment in the research area, since this subject component is almost annulled in comparison to the teaching of technical and professional skills related to the vocational area (MCTES, p. 2243, 2006)<sup>1</sup>.

However, as Rodrigues (2008, p. 74)<sup>2</sup> states, "research is fundamental to the development of any area of knowledge, both for its affirmation and for its consolidation." If one associates this need to Nursing science, the Portuguese Nurses Association (2006, p. 1)<sup>3</sup> defines Nursing Research as "a systematic, scientific and rigorous process that seeks to increase knowledge in this subject, answering questions or solving problems to benefit patients, families and communities".

In fact, continued investment in this area has benefits both for users – in health promotion, disease prevention and lifelong care – and for health professionals, who are better able to provide and optimize health outcomes (OE, 2006)<sup>3</sup>. The encouragement, valorisation and use of developed theory and research, allows for specialization in Nursing practice (Dreyfus and Dreyfus, 1996, quoted by McEwen and Wills, 2009)<sup>4</sup>, serving as theoretical support for teaching (developed in various schools), daily practice, evaluation and management of healthcare provided in different contexts.

When analysing the numbers of the census carried out in 2016 by the Portuguese Nurses Association, there are 69 682 nursing health professionals in Portugal, including Azores and Madeira, 30 138 of whom provide general care, 1,833 provide specialized care and 299 are involved in teaching and research. It is thus possible to see the disparity between the number of professionals who work and have a Bachelor's degree and those whose training has been extended into specialized scientific knowledge. It must also be highlighted the scarce number of those who invest in research.

It should be emphasized, however, that research can be done not only by developing a research project – qualitative, as it is done in social and human sciences; or quantitative, which seeks by means of experimentation to reach the exact verification of phenomena – but also by researching and consequently using such results, as it was previously mentioned, that can be evaluated according to their purpose: instrumental, conceptual and persuasive. Instrumental use refers to the direct application of knowledge in practice.

Conceptual use involves changing rationale, but does not imply a similar change of behaviour. Persuasive use is related to the use of knowledge to promote behavioural changes (Lage et al., 2016)<sup>5</sup>.

### **Problem statement**

According to the Bologna Process, the Bachelor's degree focuses on a practical and professional component, and the research component is postponed to Master's and PhD degrees. However, research is fundamental for the continuous production and renovation of the knowledge of any subject, as in the case of Nursing. When analysing the data of the Nurses Association (2017)<sup>9</sup>, there is a minority of professionals who work based on specialized care or in the field of teaching and research. Consequently, one may question how the research component is encouraged throughout the Bachelor's Degree and what perspectives students have concerning this critical area.

### **Research questions**

Considering the diversity of possibilities to approach this area of research for the development for the nursing subject, this investigation seeks to identify the integration of students in research projects, along their academic training, their will to develop research in the future and their justification for such will, and the perception of skills collection and interpretation of relevant information acquired in the Bachelor's degree.

### **Purpose of the study**

Taking into account the importance of research for the development of the nursing subject and the context defined for the conclusion of a Bachelor's degree, according to the current Bologna Process, this investigation aims to determine the relevance attributed to nursing research by undergraduate students.

### **Research methods**

The methodology for this applied

investigation is descriptive and transversal. The data collection stage was performed using an online form, created by the researchers, with short answers and multiple-choice questions. This form was sent to the students of the Bachelor's degree in Nursing from 39 Higher Education Schools in this area in Portugal, after contacting associative leaders of the corresponding Student Associations. Then these people sent the data collection tool using social networks, and getting a response from 17 higher education schools – totalling 781 responses. The period for the form completion was between April 24 and May 4, 2017.

After analysing the results, it was considered that the present investigation should include only those referring to 4th year students – 256 answers – since they have a higher level of acquisition of skills within the Bachelor's degree and a greater chance of enrolling in a Master's degree, which is an academic degree directly associated to the research area. Afterwards, the 256 responses were screened, and only 250 were considered valid, because they had the different fields of the form completely and adequately filled.

## Results and discussion

Sociodemographic characterization of the sample

The sample for this investigation consists of 250 students attending the 4th year of the Nursing Bachelor's Degree, belonging to 17 higher education schools in Portugal (public and private), of which 34 were male (13.6%) and 216 female (86.4%), aged between 20 and 43.

### Relevance of research for students

Although 250 students (100%) considered important to seek the best scientific evidence for application in clinical practice (table 1), only 79 students (31.6%) integrated any research project throughout their training, as opposed to 171 students (68.4%), who reported that they did not integrate any research project (table 2).

148 students (59.2%) expressed their wish to contribute to Nursing research and innovation, as opposed to 14 students (5.6%), who reported that they did not intend to invest in this area. On the other hand, 88 students (35.2%) reported they were not sure about the possibility of investing in Nursing research (table 3).

Among the students who indicated their interest in contributing, 81 (54.7%) indicated a wish to improve professional and personal skills, while 63 students (42.6%) mentioned their wish to improve Nursing as a profession. The motivation related to the social status, referred to by two students (1.4%) and the encouragement by the higher education school, also mentioned by two students (1.4%), should also be highlighted.

Among the students who did not want to contribute to the area of research and innovation in Nursing, 7 (50%) reported that this is due to the time and dedication involved, 6 (42.9%) said they did not want to contribute because they lacked interest in this area, and 1 student (7.1%) mentioned the lack of research projects in the Nursing area as a justification.

The results presented above show that most students – 249 students (99.6%) – say they had a research curricular unit in their Bachelor's degree curriculum (table 4). However, it will be possible to see if teaching in this area has had significant effects on the students' academic path, not only concerning their capacity to develop research projects, but also as a means of encouraging investment in this area, since, as already mentioned, 5.6% of students do not intend to invest and 35.2% of students are undecided about their will to contribute to research and innovation in Nursing.

31 students (12.4%) perceived the ability to analyse the quality of a

scientific article as *Insufficient*, 133 students (53.2%) as *Sufficient*, 79 students (31.6%) as *Good* and 7 students (2.8%) as *Very Good* (table 5).

In addition, 105 students (42%) consider that to analyse a scientific article correctly is *Very important*, 97 students (38.8%) that it is *Important* and 37 students (14.8%) that it is *Extremely important*. However, 10 students (4%) state that it is *Little important* and 1 student (0.4%) said that it is *Not important* to analyse a scientific article (table 6).

## Discussion

When analysing the results related to the contribution in research and innovation in Nursing (table 3), it can be verified that, although all students consider scientific evidence as an important means for clinical practice and that most students show an interest in developing research projects, there are still students with a non contributing option and a high number (35.3%) of undecided students concerning a possible investment in this area. This may indicate a failure of the education system regarding the monitoring and guidance of students. These justifications may also be associated with the fact that there is a minor integration of students into research projects throughout their academic careers.

Based on these results showed in table 6. The importance of the ability to analyse a scientific article, it is worth noticing that, although 99.6% of the respondents have in their degree curriculum a curricular unit directed to the research area, 53.2% of students classify their ability to analyse a scientific article as *Sufficient*. However, even if this gap is evident in teaching the analysis and interpretation of the research already done, it is possible to highlight the possibility of improvement and the interest demonstrated by students in this area, since 42% classify the capacity to analyse a scientific article as *Very Important* and 38.8% as *Important*.

In addition, it is curious and per-

### THE IMPORTANCE OF SCIENTIFIC EVIDENCE IN CLINICAL PRACTICE

1

Do you consider it important to seek the best scientific evidence for application in clinical practice?	Results	Results (%)
Yes	250	100%
No	0	0%

### INTEGRATION IN RESEARCH PROJECTS

2

Throughout your training, did you integrate any research project?	Results	Results (%)
Yes	79	31.6%
No	171	68.4%

### CONTRIBUTION IN RESEARCH AND INNOVATION IN NURSING

3

Do you want to contribute to research and innovation in Nursing?	Results	Results (%)
Yes	148	59.2%
No	171	68.4%
I don't know	88	35.2%

### CURRICULAR UNIT RELATED WITH RESEARCH

4

In your undergraduate course, did you have any curricular unit directed to research?	Results	Results (%)
Yes	249	99.6%
No	1	0.4%

### PERCEPTION OF EFFECTIVENESS IN ANALYSING THE QUALITY OF A SCIENTIFIC PAPER

5

What is your perception of effectiveness in analysing the quality of a scientific paper?	Results	Results (%)
Bad	0	0%
Insufficient	31	12.4%
Sufficient	133	53.2%
Good	79	31.6%
Very good	7	2.8%

### THE IMPORTANCE OF THE ABILITY TO ANALYSE A SCIENTIFIC ARTICLE

6

How relevant is the ability to analyse a scientific article?	Results	Results (%)
Not important	1	0.4%
Little important	10	4%
Important	97	38.8%
Very important	105	42%
Extremely important	37	14.8%

that only 14.8% of students consider the ability to analyse a scientific article as *Extremely important*, while 4.4% of students consider it *Little important* or *Not important*. This aspect may in fact be associated to the question “Do you consider it important to seek the best scientific evidence for application in clinical practice?”, since it demonstrates an interest in scientific evidence related to clinical practice, but not an interest in its correct use.

### Conclusion

Considering the general analysis of this investigation, it is rated as a success considering that the objectives initially outlined were reached. It is possible to see that the students of the Bachelor's degree in Nursing recognize relevance and importance to the area of Nursing research, and demonstrate a major interest in contributing and developing projects that can improve not only the profession, but also their personal and professional skills. However, there is still a lack of orientation/encouragement for investment in this area. Despite the relevance attributed to the analysis and interpretation of scientific articles, given the perceived self-efficacy revealed, there are evident gaps in learning.

While the higher education school is considered a privileged place to teach how to use the research results (skills for collection and interpretation of scientific articles), as well as to encourage and guide the production of knowledge, it seems to be possible to conclude that the education system shows a need for structural and content changes.

However, the study had some limitations. Firstly, the participation of students in this investigation was difficult and scarce in their own higher education schools, which leads one to consider the data as little representative of each school. Secondly, and as such, the means of sending the form could have been improved, as well as the time gran-

ted to complete it. Thirdly, there are no similar studies, which limits the comparison of results.

In a nutshell, the present investigation is mainly relevant because it serves to enhance the continuity of investment in the research area, in its different fields, and to implement measures that will respond to the problems already identified.

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# Illness perceptions of adolescents with inflammatory bowel disease and the association with distress and well-being

## Summary

Inflammatory Bowel Disease is one of the most common chronic diseases affecting children and adolescents. It requires a lifelong medical treatment, as well as the adoption of a healthy lifestyle. However, little is known about illness perceptions of adolescents suffering from IBD and how they relate to well-being measures. Aims were 1) to describe illness perceptions, distress and well-being of adolescents with IBD; and 2) to associate illness perceptions with distress and well-being of adolescents with IBD.

Thirty-six adolescents aged 12 to 18, diagnosed with IBD, answered the Brief Illness Perception Questionnaire and distress and well-being items from the Health Behaviour in School-aged Children questionnaire.

Overall the disease is perceived as benign. The majority of adolescents show some concerns about the disease but they feel a reasonable self-control over their illness and strongly believe in the benefits of treatment. Globally, adolescents showed positive perceptions of their health status and of their life. However, tiredness, exhaustion and nervousness were referred as frequent symptoms. Significant correlations showed that higher threatening perception of illness was associated with an increased frequency of physical symptoms, of tiredness and exhaustion, of depression and nervousness and with less satisfaction with life (*rs* ranging from .331 to .587). All descriptive and correlational results were significantly stronger in adolescents with active disease compared to those in remission.

Negative illness perceptions will likely trigger distress and malaise in adolescents with IBD. From the evaluation/comprehension of illness perceptions, it is possible to plan interventions to change negative perceptions and illness outcomes.

**KEYWORDS:** INFLAMMATORY BOWEL DISEASE; ADOLESCENTS; ILLNESS BELIEFS; DISTRESS; WELL-BEING.

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## Introduction

Inflammatory Bowel Disease (IBD) is one of the most common chronic diseases that affect children and adolescents<sup>1</sup>. It is an autoimmune disease of the digestive tract, which can be diagnosed during childhood, but more often in adolescence<sup>1</sup>. IBD can be classified into two distinct pathologies, which are ulcerative colitis (UC) and Crohn's disease (CD) according to the affected location in the digestive tract and the type of injury presented<sup>1,2</sup>. It is also common to find extraintestinal manifestations of the disease, meaning that IBD is more than a bowel issue that causes abdominal pain, diarrhoea, blood and weight losses and fatigue<sup>1</sup>. The assessment of the severity of symptoms is useful to determine the activity of the disease, that could range between asymptomatic (remission), mild, moderate and severe. As a recurrent disease, the main objective of treatments is to achieve and maintain the disease remission, heal the intestinal mucosa and relieve all symptoms, preventing future relapses, since the course of IBD is usually unpredictable<sup>3-5</sup>.

Evidence shows that living with a chronic illness during adolescence is a challenging experience<sup>6</sup>. Controlling IBD requires a lifelong regimen management, even in remission periods. This will necessarily include medical treatment, with constant surveillance, as well as the adoption of a healthy lifestyle, with a balanced diet, physical activity, mental well-being and avoidance of risk-taking behaviours, such as substance use. Furthermore, the chronic condition itself and all of the requirements associated with<sup>1,7</sup> the therapeutic regimen may compromise the adolescent's psychosocial adaptation and lead to psychological disturbances, such as depressive symptoms that, alongside with pain, malaise and fatigue, are likely to disrupt daily life activities<sup>8,9</sup>. Thus, when compared with their healthy peers, adolescents who suffer from IBD present a slightly higher risk of suffering from anxiety and depressive symptoms, and this symptomatology may be aggravated during periods of active disease<sup>9,10</sup>. A meta-analysis about depressive symptoms in children and adolescents with different chronic physical illness, such as infection/AIDS, and sickle cell disease, found that the distress level does not differ between adolescents, regardless of their disease<sup>9</sup>.

The psychosocial impact of chronic illnesses on adolescents can be analysed through a biomedical or a psychosocial framework. The biomedical perspective is associated with a categorical or condition-specific approach that focus on the disease specificity, duration and treatment<sup>11</sup>. On the other hand, the psychosocial perspective suggests a non-categorical or generic approach that argues that children with chronic conditions face common life experiences and problems based on generic dimensions of their conditions, rather than on specific characteristics of any particular disease entity. However, and considering the limitations of both approaches, a biopsychosocial or a modified categorical approach was developed that combines aspects from biomedical and psychosocial dimensions, taking into account the adolescent's subjective experience of illness and treatment<sup>11</sup>.

The association between illness perceptions and a range of physical and mental health outcomes have been demonstrated in a number of conditions<sup>12</sup>, therefore, it is important to comprehend how young people make sense of and manage their illness. For example, negative illness perceptions are associated with higher future disability and to the need of healthcare services, and to a slower and poorer recovery<sup>13</sup>, whereas positive illness perceptions are associated with an earlier return to normal daily activities<sup>14</sup>. Illness perceptions can be defined as a cognitive construct that each patient develops about his own disease and that can be described into five components: identity, causal beliefs, timeline, control or cure, and consequences<sup>13,15</sup>. Illness perceptions are influenced by self-experience, others experience, knowledge, culture and personality traits<sup>13,16</sup> and they change over time and according to the disease course<sup>16</sup>. As an individual construct, it is possible to find very different perceptions about the same condition<sup>13,16</sup>, which in some cases are even medically incorrect<sup>15</sup> and these perceptions will trigger emotional responses and coping behaviours adapted to the disease demands<sup>16</sup>. This is the Common Sense Model of Illness Representations, developed by Leventhal and colleagues, in 1980<sup>17</sup>.

Hagger and Orbell (2003) conducted a meta-analytic review of 45 studies about illness perceptions and concluded that worse illness perceptions in consequences, timeline and identity dimensions were related to a poorer physical and social functioning, increased distress and lower levels of well-being and vitality. Moreover, higher perceptions of illness control were related to better outcomes in those variables<sup>12</sup>. The assessment of illness perceptions is also useful to understand the psychological impact of the disease on the individual and to estimate treatment adherence patterns<sup>16</sup>.

From the evaluation/comprehension of illness perceptions, it is possible to plan interventions to change negative perceptions and illness outcomes<sup>12, 16</sup>.

There are also qualitative studies on illness perceptions, using interviews and narratives. As an example, in a study conducted by Woodgate (1998) adolescents described their experience of having IBD as restrictive, painful, annoying and time-consuming, especially when the disease was out of control, causing severe symptoms<sup>18</sup>. In addition, when IBD was active, adolescents perceived less benefits from treatment and less self-control over their life, since IBD disrupted daily life activities, school attendance and family routines<sup>1,7,8</sup>. Lynch and Spence (2008) also questioned adolescents about their perceptions of IBD's cause and found that stress and unknown causes were the most reported<sup>19</sup>.

Despite the numerous studies about illness perceptions on different pathologies, little is known about illness perceptions of adolescents suffering from IBD. As such, the aims of this study were:

- To describe illness perceptions, distress and well-being of adolescents with IBD.
- To associate illness perceptions with distress and well-being of adolescents with IBD.

## Research methods

### Participants

This study sample comprised 36 adolescents (22 male and 14 female) aged between 12 and 18 years ( $M = 14.75$ ;  $SD = 1.90$ ), diagnosed with IBD (21 suffered from Crohn Disease and 15 suffered from Ulcerative Colitis). In relation to disease activity, 12 were symptomatic and 24 were in remission.

A convenience sample was used with the following inclusion criteria: being an adolescent aged between 12 and 18 years, suffering from IBD diagnosed at least 6 months earlier, without any other chronic condition



or cognitive or sensorial impairment, who was willing to participate in the study.

Data were collected between March and June of 2015, in paediatric gastroenterology outpatient services and at non-oncologic paediatric day-hospital service.

### Instruments

• *Portuguese version of The Brief Illness Perception Questionnaire (Brief IPQ)*, translated and adapted by McIntyre, Araújo-Soares and Trovisqueira, in 2004<sup>20</sup>. The Brief IPQ is composed by eight items, to assess the five dimensions of illness perceptions, using a 5-point Likert-scale ranging between 0 and 4. One qualitative open question about the perception of the three main causes of the disease was also added to the questionnaire. According to the scoring instructions of the instrument, for items related to consequences [1], timeline [2], identity [5], concern [6] and emotional impact [8], higher scores mean more negative illness perceptions. For items about personal control [3], treatment [4] and coherence [7], higher scores mean more positive illness perceptions. It is also possible to create a new variable about the global perception of illness as being more or less threatening. To calculate the total score of this variable, a sum must be computed with the initially reversed scores of items 3, 4, and 7. This score ranges between 0 and 32. A higher score indicates a more threatening perception of the illness. In relation to the qualitative item about the causal perception of the illness, answers must be analysed through content analysis and they are usually labelled as stress, lifestyle, and heredity (Broadbent, Petrie, Main, & Weinman, 2006). The internal consistency was calculated for each item and for the total score. Results of the analysis of the internal consistency using Cronbach's Alpha suggested the elimination of the item related to the illness dimension "timeline". This elimination seemed logical, since the IBD is a chronic condition and the factor timeline is usually considered not relevant by respondents. The Cronbach's Alpha value for the IBD sample was  $\alpha = .644$ .

• *Health and well-being scale – Adapted version of the Health Behaviour in School-aged Children (HBSC) questionnaire*. HBSC assesses health and health-related behaviours, in the format of multiple-choice questions and was designed for school-aged children. It was developed within an international collaboration project from World Health Organization and it is applied every four years, at selected schools<sup>21</sup>. For this study only a few items about distress and well-being were selected, in a total of 15 items. These items measured self-rated health; the presence of physical and psychological symptoms, as for example stomach ache and dizziness; life satisfaction; illness as an impairment; and self-rated happiness.

### Procedure

The study was approved by the hospital Ethics Committee. At first, adolescents were contacted by a nurse, and were then informed about the study, together with their parents, and invited to participate. Parents were also asked to sign an informed consent form.

MEAN VALUES, STANDARD DEVIATION AND RANGE OF B-IPQ, AND MANN-WHITNEY U TEST, BY DISEASE ACTIVITY

1

Brief-IPQ Items	IBD		Disease Activity
	SD	Range	M-W U test
1. How much does your illness affect your life?	1.11	0.820	2 U = 110.000 p = .225
2. How long do you think your illness will continue?	3.78	0.485	2 U = 137.000 p = .733
3. How much control do you feel you have over your illness?	2.53	1.320	4 U = 83.000 p = .035
4. How much do you think your treatment can help your illness?	3.47	0.736	2 U = 143.000 p = .985
5. How much do you experience symptoms from your illness?	1.53	1.055	4 U = 114.000 p = .294
6. How concerned are you about your illness?	2.22	1.149	4 U = 78.000 p = .022
7. How well do you feel you understand your illness?	2.81	1.117	4 U = 114.500 p = .300
8. How much does your illness affects you emotionally? (e.g. does it make you angry, scared, upset or depressed?)	1.42	1.1139	4 U = 57.000 p = .003
How much do you perceive your illness as threatening or benign?*	9.4722	4.27943	17 U = 58.000 p = .004

NOTE: \* computed without item 2

## Findings

### Description of illness perceptions, distress and well-being of adolescents with IBD

In order to describe illness perceptions, distress and well-being of adolescents with IBD, mean values, standard deviation and range scores were calculated.

Results evidenced that IBD was perceived as benign by the majority of the adolescents, indicative of the perceived small impact on their lives and on their emotional responses (table 1). The majority of the adolescents showed a reasonable perceived control over their illness and felt that treatment could be highly beneficial. A small number of adolescents perceived a significant impact from their illness' symptomatology, which is probably related to the cyclic nature of the disease. In terms of illness-related concerns, most adolescents reported being worried. Despite the levels of concern, the majority believed that they understood their disease relatively well.

Findings related to the perceived causes of illness were analysed through content analysis, which resulted in a set of 28 possible causes of IBD, grouped into 12 categories, namely: physical efforts, sedentary lifestyle, excessive care of others, fate, self-care, congenital, diet, pathogenic causes, genetics and heredity, emotions, organic causes and unknown causes. The most cited cau-

se was diet (38.9%) associated with poor diet or the intake of a specific food that may have caused injury to the bowel (e.g. cow's milk); followed by unknown causes (27.8%) and genetics and heredity (22.2%). More than half of the adolescents were only able to report a single cause for their illness.

In relation to distress and well-being variables (table 2), the values obtained evidenced that the majority of the adolescents had positive perceptions about their health status and about their life, in terms of satisfaction and happiness. The frequency of physical symptoms and psychological distress was globally low. However, the frequency of symptoms of tiredness, exhaustion and

MEAN VALUES, STANDARD DEVIATION AND RANGE OF HBSC VARIABLES, AND MANN-WHITNEY U TEST, BY DISEASE ACTIVITY

2

Distress and well-being	IBD		Disease Activity
	SD	Range	M-W U test
How is your health? (poor to excellent)	2.25	0.604	2 U = 127.500 p = .527
How often do you feel headaches?	1.31	0.525	2 U = 129.000 p = .519
How often do you feel stomach ache?	1.36	0.683	2 U = 109.000 p = .121
How often do you feel back pain?	1.50	0.697	2 U = 111.000 p = .201
How often do you feel neck and shoulder pain?	1.39	0.549	2 U = 110.500 p = .180
How often do you feel tired and exhausted?	1.75	0.692	2 U = 97.000 p = .084
How often do you feel dizzy?	1.11	0.398	2 U = 143.000 p = .944
How often do you feel sad and depressed?	1.25	0.439	1 U = 108.000 p = .107
How often do you feel difficulties in getting to sleep?	1.50	0.775	2 U = 129.000 p = .546
How often do you feel irritable?	1.42	0.500	1 U = 126.000 p = .480
How often do you feel nervous?	1.61	0.599	2 U = 125.000 p = .472
How often do you feel afraid?	1.22	0.485	2 U = 130.000 p = .495
How much do you think your illness is a barrier to do things you would like?	1.59	0.666	2 U = 29.000 p = .040
How satisfied are you with your life? (scored in a 10-point scale)	8.00	1.656	5 U = 96.000 p = .053
How do you feel? (unhappy to very happy)	1.86	0.487	2 U = 137.500 p = .773

nervousness were the most reported by adolescents. They also perceived the disease as little intrusive, as a barrier to accomplish some of their goals.

The adolescents were grouped into two sub-samples according to the disease activity (active or in remission), and statistically significant differences were found in illness perceptions referring to self-control, concern, emotional impact, threat perception, and self-perception of illness as a barrier to do things (table 2). These findings suggest that adolescents with active disease held more negative illness perceptions and felt a stronger negative impact of IBD on daily life. No statistically significant differences were found when adolescents were grouped into IBD subtype.

#### **Association of illness perceptions with distress and well-being**

Bivariate Pearson's correlations were performed between illness perceptions and distress and well-being. Only statistical significant correlations at the 0.05 and 0.01 levels were considered. The B-IPQ total score was associated with HBSC variables.

Positive statistically significant correlations were found, indicating that a more threatening perception of illness was correlated with an increased frequency of headache ( $r = .379, p < .05$ ); of stomach ache ( $r = .419, p < .05$ ); of tiredness and exhaustion ( $r = .331, p < .05$ ); of sadness and depression ( $r = .376, p < .05$ ); of nervousness ( $r = .408, p < .05$ ); with a higher self-perception of illness as a barrier to doing things ( $r = .458, p < .05$ ); less satisfaction with life ( $r = .587, p < .01$ ); and increased feeling of unhappiness ( $r = .498, p < .01$ ). In relation to the disease activity, results showed that active disease was correlated with a more threatening perception of illness ( $r = .479, p < .01$ ); an increased frequency of tiredness and exhaustion ( $r = .346, p < .05$ ); and with an increased self-perception of illness as a barrier to do things ( $r = .475, p < .05$ ).

#### **Discussion**

The aims of this study were to describe illness perceptions, distress and well-being of adolescents who suffer from IBD, and to study the association of illness perceptions with distress and well-being.

In this study, IBD was perceived as little intrusive on adolescent's lives and on their emotional responses. They perceived satisfactory levels of self-control, benefits of treatment and reported few symptoms. Participants also reported that their disease was not experienced as a great concern, also mentioning a relatively good understanding of the disease, and were even conscious of their life-long disease. All these perceptions summed up into an overall positive illness perception, in which IBD was perceived as benign. Nevertheless, aspects such as the ability to do things, satisfaction with life and happiness, and the presence of physical symptoms and emotional distress are likely to negatively influence illness perceptions. Our findings provide evidence of the influence of negative illness perceptions on distress and well-being. Although no previous studies have analysed illness perceptions of adolescents with IBD using the B-IPQ, our findings are supported by several qualitative studies. In fact, negative illness perceptions, distress and malaise are associated with disease activity, in which IBD is perceived as a more restrictive disease<sup>18</sup>. This was also found by Nicholas and colleagues (2007), that demonstrated that adolescents have different perspectives of the impact of IBD on their lives, according to the disease activity, and that feelings of tiredness and exhaustion are frequent and interfering<sup>8</sup>. Lindfred and colleagues (2012), stated that adolescents with a severe disease course perceived less satisfaction with health and life, while those with inactive disease were able to integrate disease into their lives and expressed an overall well-being<sup>7</sup>.

The causes of IBD were mainly perceived as related to modifiable causes, such as diet, and to unmodifiable ones, such as genetics. For some, the cause was unknown. These findings are similar to previous studies on IBD<sup>19</sup> and are common to the causal beliefs of other chronic conditions, whose causes are attributed to psychosocial stress, genetics and illness behaviours<sup>12</sup>.

According to Broadbent et al. (2015), the B-IPQ was previously used in studies with children who suffered from cerebral palsy<sup>22</sup>, and cancer survivors<sup>23</sup> and with adolescents who suffered from chronic rheumatic disease<sup>24</sup>, and asthma<sup>25</sup>. Similarly, these findings also showed negative illness perceptions were present when disease caused more suffering, restrictions and symptoms. Globally, for these patients, the disease had little impact on life and on emotions, the treatments were viewed as strongly helpful to control the disease, while self-control perception was low. They demonstrated a good understanding of their disease and showed little concern. The patients thought their disease would last for a long time, except for the group of children who had a history of cancer. This similarity among different conditions seems to support a non-categorical view of the psychosocial impact of chronic illnesses on adolescents.

The generalisability of these results is subject to certain limitations. For instance, the sample size, which is relatively small and does not allow a true representation of all adolescents with IBD. In addition, adolescents with Intermediate IBD were not included in this study. On the other hand, the majority of the adolescents were in a remission phase, although it was still possible to identify differences according to disease activity.

#### **Conclusion**

In sum, findings suggest that intervention with adolescents with IBD

should focus on their subjective experience of illness, rather than screening for clinical features, Interventions should be implemented to empower adolescents with more coping skills strategies as a way to improve their perception of self-control over the disease. Importantly, clinicians should also carefully approach illness perceptions of their patients, in order to better understand and change disease-related outcomes, because negative illness perceptions will likely trigger distress and malaise in adolescents with IBD.

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- 5 Management Information**  
System / Workflows (implementation)
- 6 Communication**  
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€ 531.933,78

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### Promoter



# Unipersonal families and literacy

## Economic partner characterization and nursing care needs

### Summary

The maintenance of good health levels is strongly related to personal, cognitive and social skills that compose the concept of health literacy (HL) (Soellner, Lenartz & Rudinger, 2017). Since low HL levels are associated with vulnerable groups (Pedro, Amaral & Escoval, 2016), we intend to analyze the social, economic and social characteristics of a group of unipersonal families with an elder person as well as to identify needs in nursing care.

An exploratory and descriptive study was conducted in unipersonal families with members over 65 years of age, users of primary care. The sample consisted of clients that had the characteristics of the population who used a health unit in the northern part of Portugal requesting a nursing consultation, between March and April 2017. The data collection was performed based on the structural dimension of the MDAIF (Figueiredo, 2012). Data analysis was done through descriptive statistics.

In the sample composed of 15 families, 80% pertained to the lower middle class. All individuals suffer of one or more chronic diseases. The most common nursing interventions were directed to the residential building, safety precaution and water supply.

The assessment of the structural dimension of unipersonal households is an essential resource in identifying potentialities or vulnerabilities, in order to guide nursing interventions to improve patients' levels of HL, or proactively preventing complications arising from their limitations.

KEYWORDS: HEALTH LITERACY; UNIPERSONAL FAMILY; ELDERLY; STRUCTURAL DIMENSION.

### Introduction

The concept of health literacy (HL) has been the subject of much attention in recent years by researchers in the health, education and social sciences, resulting in an increasing differentiation of its meaning.

Their first analyzes date from the seventies of the last century, related to the individual's access to health services and their ability to pay for them<sup>1</sup>. Currently, the World Health Organization (WHO) defines the concept as the "cognitive and social skills that determine the motivation and ability of individuals to gain access, understand and use information in a way that promotes and maintains good health"<sup>2</sup>.

Thus, the assessment of an individual's level of health literacy is multidimensional and attends to his or her ability to access, understand, analyze and use health information regarding the use of services, health promotion and health disease<sup>3</sup>.

The European study HLS-EU – European Health Literacy Survey, in

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which 8 countries participated, demonstrated that there is often a correlation between health status and HL levels. Thus, people with self-perceived negative health tend to have lower levels of HL, as well as those who routinely use health services. The Netherlands was the country with the best rates, with only 27% of people with insufficient HL levels. Bulgaria was the country that got the worst values: about 61% of people with insufficient indexes. The European average of insufficient HL levels is 46%<sup>3</sup>.

A parallel study carried out in Portugal in 2015 showed that the country is slightly below the European average, with insufficient HL levels found in 51% of the respondents<sup>4</sup>. This report has identified a group of vulnerable people, who tend to have low HL levels, such as<sup>4</sup>: people aged over 66, low schooling, incomes up to 500 euros, prolonged illnesses, poor self-perception of health, high

health services utilization and perception of being limited by some chronic illness.

These people present a cumulative vulnerability due to socio-economic, demographic and health conditions, along with their particular tendency towards lower HL levels. Particular attention should therefore be paid to this group of people regarding health policies, and also to health professionals, in order to minimize their potential risks and promote their strengths.

We consider that much of disease prevention is the responsibility of the health system and health professionals in the communication process, so its effectiveness should enable people to hear, understand and learn to act on the basis of the best evidence in order to make the best decisions about their health<sup>5</sup>.

Nutbeam (2000) indicates that HL is an intermediate outcome of health promotion that will result in a better knowledge and understanding of health determinants, changes in attitudes and motivations regarding health behaviors, and better self-efficacy in relation to defined tasks<sup>6</sup>. These may in turn produce higher level results translating into quality of life, equity, functional independence, reduction of mortality and morbidity.

On the other hand, studies suggest that people with low HL levels are less likely to understand the oral and written information provided by health professionals, that they demonstrate more difficulties in using health services in an effective way, as well as in performing the necessary procedures and following the professional indications<sup>5</sup>. Serrão (2014) suggests, along with other studies, that the degree of HL observed in elderly people may condition their ability to use information in interactions with health professionals and is associated with higher rates of hospitalization, longer hospitalization, misuse of services, higher costs, more difficulty in interpreting the instructions of professionals and less use of preventive services<sup>7</sup>.

Thus, the development of educational interventions aimed at the promotion of HL aims not only to increase knowledge about health aspects, but rather to develop personal skills that motivate the improvement of personal results and to make changes at the level of socioeconomic determinants in health.

In order to develop higher levels of HL for the elderly, health professionals must improve their communication skills, as well as adopt mechanisms that allow a fair and objective approach to the person and/or family. Regarding the family, its recognition as a unit of care must presuppose that the nurse is based on a theoretical and operative framework that allows the application of the nursing process. The Dynamic Family Assessment and Intervention Model (MDAIF)<sup>8</sup>, in particular its structural dimension, allows to "Identify the composition of the family, the links between the family and other subsystems such as extended family and broad systems and also specific aspects of the environmental context that can anticipate health risks" (p. 73), as well as show important resources for improving the levels of health literacy of the elderly.

We know that the health condition of an individual is influenced by individual and behavioral characteristics, in which their levels of health literacy are inserted, and significantly determined by the social, economic and environmental differences to which the individual and community are subject<sup>6</sup>. This influence is particularly important when it comes to elderly people living alone, as these two sociodemographic factors increase their vulnerability in health. The use of MDAIF<sup>8</sup>, and specifically regarding the structural dimension, will allow the characterization of important attributes of the unipersonal households in respect to the extended family, wider systems, social class, residential building and supply system. Nursing diagnoses

and interventions capable of promoting health and possibly literacy may emerge through its use, as the intermediate result of health promotion.

This study has the following research questions:

- What are the sociodemographic characteristics (sex, marital status, profession, state of the profession, education and history of chronic illness) of unipersonal households?
  - What is the composition of the social network of unipersonal households?
  - What types of roles represent their extended family?
  - What is the predominant social class in unipersonal households?
  - What are the housing characteristics of families, considering the spaces, the state of conservation, heating, appliances, water/sanitation, electricity, ventilation, natural light, gas and architectural barriers?
  - What are the characteristics of the biological environment of unipersonal households?
  - What are the needs of elderly unipersonal households in nursing care in the following areas of attention: family income, residential building, safety precaution, water supply and domestic animals?
  - What interventions have been developed to meet the needs identified in the areas of attention mentioned?
- The objectives of the study are:
- To identify the sociodemographic characteristics of elderly unipersonal families.
  - Describe the social network of elderly unipersonal families in terms of their composition and functions.
  - Identify the type of housing and its characteristics of elderly unipersonal households.
  - Classify the unipersonal families referring to social class.
  - Identify characteristics related to the biological environment.
  - State identified diagnoses that reflect nursing care needs of elderly unipersonal families.
  - Describe the interventions developed to meet identified needs.

## Methods

Exploratory and descriptive study, whose population corresponds to unipersonal families, with members over 65 years, clients of primary health care. The sample is accidental, consisting of clients with the characteristics of the population that used a functional unit for nursing consultations in a Cluster of Health Centers (ACES) from the north of Portugal, between March and April 2017. An analysis was made of the documentation produced by the nurse, using a record corresponding to the operative matrix of the MDAIF. The data collection was performed relative to extended family, wider systems, social class, residential building and supply system<sup>8</sup>. The data analysis was done through descriptive statistics<sup>9</sup>.

## Findings

From the sample, a total of 15 elderly unit families were found, 13 female and 2 men. Regarding marital status, 11 are widowers and 4 single. All individuals were retired and during their active age most of them were either farmers or domestic workers. Regarding the level of education, 80% of the sample has the first cycle of elementary school education and the remaining 20% do not have any schooling. All (100%) of the sample elements have at least one chronic disease. The most prevalent chronic disease in the sample is hypertension (HTA), followed by diabetes and dyslipidemia. Note that two people have had a stroke (AVC) recently, 2 people fell recently and 4 people are dependent regarding self-care.

### Social network

Most unipersonal families have a personal contact with the extended family, with daily or weekly (in equal proportion) contacts, with some cases where these contacts occurred in a time equal to or greater than 1 month. It was found that the extended family can represent several functions simultaneously, being social company, significant help in materials and services and emotional support. All data are shown in table 1.

The largest system with more importance for the families of the sample was the health unit in 73% of cases, followed by the church, friends and private social solidarity institution (IPSS).

### Housing and social class

The type of housing was classified according to the adapted Graffar scale (cited by Figueiredo, 2012, p. 195). Approximately 73% of the sample has a grade 4 housing, characterized by poor conditions, poor state of repair, without all essential appliances, poor ventilation and without at least one of the following elements: water / sanitation, electricity or natural light. In turn, about 14% live in a grade 3 housing, with a bathroom, kitchen, bedrooms, well maintained, essential appliances, water / sanitation, electricity, good ventilation and natural light. It should be noted that the remaining 14% (2 families) live in a grade 5, tent-like dwelling, in poor condition, no ventilation, no light conditions, no water / sanitation, electricity and little natural light.

About 7% of the families belong to the middle class, 73% to the lower middle class and 20% to the lower class, according to the adapted Graffar scale (Figueiredo, 2012, p. 194).

### Supply system

In 75% of the cases there was the private network as a supply system, so that none of them perform water quality control. Another 13% have a public water supply system and 20% have no water at home.

About 47% of the elements have a septic tank as sewage collection, 33% connect to a public network and 20% do not have any sewage system.

For the most part, these families have an inadequate water supply and waste treatment system, lacking nursing interventions in this area.

### Residential building and biological environment

The majority of the residential buildings of the sample elements use gas cylinders (87%). Almost half of the homes have architectural barriers (47%) and about 13% have insufficient hygiene. 20% do not have any waste system. Thus, residential building is not safe for a significant number of families due to the presence of architectural barriers, gas cylinders, lack of knowledge about their use and strategies adaptive to architectural barriers.

As far as the biological environment is concerned, a total of 4 elderly unit families have at least one domestic animal. Of these, only half of the cases have their animals dewormed and vaccinated.

### Nursing diagnoses and interventions

After the evaluation of all the participants in the structural dimension of the MDAIF, it was possible to carry out the diagnostic activity. Through the presented results, several diagnoses emerged. From these, those that are presented by the negative translate into nursing care needs. They are represented in table 2:

It is verified that the most common nursing diagnosis refers to the *inadequate water supply*. This diagnosis is common for the results related to the knowledge of water quality control and the knowledge about water quality maintenance strategies that have not been demonstrated in 10 families. The unpredictable safety precaution diagnosis arises from the lack of knowledge about the use of domestic gas and the unproven knowledge about strategies for adapting to architectural barriers.



## TYPE, INTENSITY AND FUNCTIONS OF CONTACT WITH EXTENDED FAMILY

1

Extended Family Contact		Frequency
Type of contact	Personal	14
	Telephone	1
Intensity of contact	Daily	6
	Weekly	6
	Monthly	1
	> 1 Month	2
Functions	Social company	7
	Emotional support	4
	Cognitive guide	2
	Social regulation	2
	Help material/services	6

## NURSING DIAGNOSES RESULTING FROM THE STRUCTURAL EVALUATION AND PERCENTAGE OF THEIR FREQUENCY

2

Nursing Diagnostics	Percentage of elderly single-parent families
Neglected residential building	14%
Non-secure residential building	27%
Unexpected safety precaution	33%
Inadequate water supply	67%
Neglected Pet	14%

## NURSING INTERVENTIONS RESULTING FROM THE DIAGNOSTIC ACTIVITY OF THE STRUCTURAL DIMENSION

3

### Nursing interventions resulting from the assessment of the structural dimension

1. Teach about unsafe residential building risks
2. Require social service
3. Teach about risks of poor housing hygiene
4. Teaching about the use of gas equipment
5. Motivating strategies for adapting to architectural barriers
6. Teach about the importance of water quality control
7. Guide to water quality control services
8. Teaching about pet vaccination
9. Teaching about pet deworming
10. Motivate for pet vaccination
11. Motivate for pet deworming

From the nursing diagnoses described above, according to the nursing process, the interventions are described in table 3:

The actions that materialize the interventions described above may be: practical suggestions for housekeeping, (1); request for assistance from the social worker for the mobilization of Community resources (2); sensitization to the hygiene of the spaces, planning of actions of hygiene of the spaces, alert to the possibility of contagious infectious diseases derived from the poor hygiene (3); alert to the risk of using gas equipment, carry out on-site visits to supervise the use of gas equipment, teach about its safe hand-

ling (4); to instruct regarding the use of ramps, suggest changes in the physical environment, including furniture and bathroom (5); describe the risks of using water unhealthy for health (6); encourage a trip to the public health service to require a water quality analysis, refer the family to the public health service (7); to instruct about the need to vaccinate domestic animals, to mention the vaccines that are common to be administered, to state the advantages of vaccination for the family and the domestic animal (8), to educate regarding the need to deworm the domestic animal, to mention the risk for the animal and family of the presence of parasites and their proliferation (9); to praise the integration of domestic animals into the family environment, to publicize community veterinary services for vaccination, to strengthen the benefits of vaccination for the prevention of serious animal and family diseases (10); reinforce the importance of deworming animals for their health as well as family health, encourage physical and affective contact between the animal and the family without risks (11).

### Discussion

The results about the sample characterization meet the characteristics of the vulnerable groups referred by other authors<sup>4,7</sup> with regard to HL levels: females, widows with schooling up to the first cycle and those with chronic disease.

The results also show that almost 75% of the participants belong to the lower middle class, being also compatible with the characteristics pointed out by other authors to the vulnerable groups of health literacy: low social class<sup>4,7</sup>. Another study with approximately 750 elderly people demonstrated that this population with higher levels of HL and financial literacy tended to be less likely to develop dementia when compared to those with lower levels<sup>10</sup> which may suggest an inverse relationship between these variables.

It is important to consider that 100% of the sample elements have at least one chronic disease and the most one is hypertension (HTA) disease. A study with elderly patients with hypertension (HTA) demonstrated that, despite being at an age where there is less capacity to process new content, health professionals should trust and take advantage of the accumulated knowledge that the elderly have about the disease<sup>11</sup>. Formulating learning experiences that require little information processing capacity (use of familiar concepts, explanation of new ideas and concepts using familiar words and terms) improve the HL levels of the aged population with decreased cognitive abilities<sup>11</sup>.

Thus, it is the duty of health professionals to confront ingrained cultural myths, such as the denial of the ageing process of the elderly or the belief that these people are no longer able to understand and make decisions<sup>7</sup>. Only then it will be possible to recognize their potential and seek solutions to problems in appropriate measures.

The application of the nursing process, based on the MDAIF, allowed an initial evaluation to be performed considering important aspects related to the family as care unit. It also allowed for the diagnosis and planning of interventions. These interventions, implemented by actions, may contribute to the increase of HL levels in the elderly, particularly those who live alone, as referred to Nutbeam<sup>6</sup>, HL is an outcome of health promotion. This intermediate result will be the contribution to improve the health levels of individuals, families and communities, since it will contribute to an increase in the quality of life, a decrease in mortality and morbidity, an improvement in equity and functional independence rates. These strategies should include an improvement of the communicational and educational competencies of the health professional<sup>7</sup>, facilitate the access of the elderly, in particular with other vulnerabilities, to health care<sup>4</sup> the acceptance of the ageing process of the elderly and the use of the accumulated knowledge and the use of teaching techniques.

## Conclusion

Older unipersonal families reveal characteristics indicative of health literacy vulnerability. Despite this fact, the social network is an important resource for these families in keeping up with their needs.

Overall, the research suggests that the health system needs to be more proactive in responding to HL deficits to meet the needs of citizens. The use of the MDAIF operational matrix, in particular with regard to the structural dimension assessment, allows nurses to perform an important data collection to estimate HL levels, to know socioeconomic risk factors that when associated with low levels of literacy raise the vulnerability of the individuals. It will also allow knowing the strengths and resources that can lead to an increase of their literacy, as well as to proactively reduce possible risks.

This initial evaluation and analysis will allow triggering the diagnostic activity, the planning of the interventions, its implementation and a new evaluation, thus equivalent to the application of the nursing process. Continuing the nursing process, it will be possible in the near future to evaluate results and move towards new strategies. On the other hand, this family approach also facilitates the use of community resources and articulation with entities to develop synergies for better health outcomes.

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# Sexuality, emotionality, healthy responsibility: take care of yourself

## A sexual education project

### Summary

**INTRODUCTION.** Adolescence is a period of doubt and discovery, during which the biggest problems related to the discovery of sexuality arise. Portugal is part of the European countries with the largest number of teenage mothers. Despite the rising availability of information in this area, this phenomenon still occurs with all the negative consequences involved. This project intends to develop and implement a Sexual Education project named "Sexuality, Emotionality, Responsibility: Take Care of Yourself", which aims at promoting healthy behaviours on an individual and group level (prevention, self-protection and protection of others).

**METHODS.** This is an action research project. During first phase, a questionnaire will be applied to teenagers (10 to 18 years of age), who attend a group of schools in Lisbon area. Subsequently, "Love Workshops" will be implemented, aiming at progressively developing self-responsibilization, promoting physical, psychological, and social health. In schools, dialogue and discussion areas between students, parents, teachers and, eventually, other professionals will be created. Peer education will be one of the used strategies because prevention messages will thus be adapted to different values and needs of each peer group, mediated by "Affection Ambassadors", facilitating behavioural change. At the final phase, people involved will assess the intervention process.

**CONCLUSIONS.** We hope to be able to promote prioritization of sexual education as a determinant of health, contributing to empowerment and emotional development of teenagers, aiming at healthy and responsible sexuality, through nursing interventions that use dynamic methods focused on the teenager and the group.

**KEYWORDS:** ADOLESCENT; SEX EDUCATION; EMOTIONS; NURSING.

### Introduction

Adolescence is a period of great complexity, experienced as a developmental crisis, fulfilled with internal and external conflicts. That is how most authors and society in general characterise it, connoting it with negative meaning, associated with dependence, irresponsibility, emotional struggle, and impulsiveness<sup>1,2</sup>. However, it is also noted as a historically and culturally constructed phenomenon and so, concepts vary according to social context, taking into consideration different criteria for its definition, related with chronological, physical, sociological, and psychological development<sup>3,4,5</sup>. Adolescence is characterized by physical changes, related with puberty, including the

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development of genitalia, biological changes that make the individual apt for procreation. Besides physical changes, adolescence is also defined by discovery and challenges, struggle for personal and emotional independence and by the need to become an adult, which constitutes a new role that modifies the teenager's view of himself, of others and of the world<sup>3</sup>.

Sex and sexuality are amongst the most important transformations that teenagers experience. It is during adolescence that these aspects become essential, leading to active sex life. Simultaneously, it is in this period that personality changes, being in its final structuring phase and sexuality is determinant in the process of defining a person's identity<sup>6,7</sup>.

Freud's<sup>8</sup> psychoanalytic approach also accounts for two currents in sexual life, the affectionate and the sensual one, the latter related to desire that children experience. Thus, Freud describes that in mother-child attachment, the baby becomes satisfied by leaving his mother's breast and deeply falls asleep, smiling. He considers that since birth, the baby tries to satisfy his emotional needs and establish contact with his mother through voice, touch, and eye contact. Freud suggested several stages of psychosexual development in which the subject focuses on a region of the body –erogenous zones– of libidinal interest. From school age

until puberty, independence of the Self and same-sex group identity develops, and so does progressive approximation to the opposite sex – latency stage. However, as the author states, sexuality is influenced by emotional and relational experiences since birth.

This perspective, of great complexity for its time, was not accepted or taken into consideration in children's sexual education. However, in current days, it is consensual that sexuality is intimately related with the affective bond that is early established in mother-child relationship. The importance of friendships with its inherent affects should also be noted, as does the fact that the first established relationship will influence all future ones; that is, the subject tends to replicate the relational pattern that he first experienced<sup>9,10</sup>.

The teenagers' sexual development requires their emotional capacitation, which involves emotional labour<sup>11</sup> performed by nurses that care for them. Working with children/teenagers and their families, nurses face a great emotional challenge that requires emotional management competences and skills. It is also needed to enlighten some concepts related with sexual education in schools, aiming at a new sexual education paradigm, promoting valorisation/acceptance/comprehension of teenagers' sexual life. Diogo<sup>11</sup> advocates that emotional labour encompasses actions/interactions that take place within caring processes, with affective-emotional nature, that aim at positively transforming nursing client's intense and disturbing experiences, promoting their development. While caring for teenagers, nursing facilitates the development of their sexuality in a way that risky behaviour is reduced, by using relational, motivational and educational strategies, particularly in school context<sup>12</sup>.

Nowadays, sexuality and affects are intimately related concepts. Affectivity involves feelings that give a meaning to sexuality, whereas sexuality refers to a bodily experience with others, as a way of relating with other people and to affectively bond. For teenagers, sexuality is as determining as bonding with another body, with its implicit affectivity, and contributes to identity development. Thus, the beginning of active sex life requires an emotional/affective development that results in a satisfying and emotionally healthy sexuality. The number of fifteen-year-old adolescents that have had sexual intercourse varies greatly with the country they live in and gender. One third or more of teenagers in England, Scotland and Ukraine have already had sexual intercourse before fifteen-years-old, in opposite to one fifth of teenagers in Spain, Poland, Lithuania, Latvia, Estonia, Czech Republic, Hungary, Croatia and Macedonia<sup>13</sup>. Considering Spanish students between fifteen and eighteen-years-old, 26% are sexually active and state that they have not used a condom during the latest sexual intercourse<sup>14</sup>. Early beginning of active sex life is associated with a higher number of sexual partners and higher risk of sexual intercourse under the influence of alcohol or other drugs<sup>15</sup>. It should be noted that using the body to reach monetary goals or a higher status within the peer group, like other risk behaviours, might indicate affective immaturity and even emotional disturbances.

To Bowlby<sup>10</sup>, attachment behaviour leads to the development of affectional bonds, firstly between the child and his or her caregivers, posteriorly within the group, during youth, and later between adults. In fact, it is in school that teenagers spend most of their time<sup>16</sup> and it is therefore important that school's healthcare professionals and families work together to approach sexuality, anchored in affectivity. However, most studies indicate that teachers feel a high degree of discomfort and insecurity when approaching issues related to sexuality, limiting themselves to answering direct questions or directing children and adolescents to other professionals<sup>6,7,16,17</sup>. It is relevant

to note that teachers and healthcare professionals should be ready to help children and adolescents be emotionally happier, through dialogue that promotes their emotional development and interventions that protect them from risk situations, as well as addressing their doubts.

It should be emphasised that peer education is a process that occurs during a period of time when well-trained and motivated individuals develop informal or formal educational activities<sup>18</sup>. Therefore, it consists of strategies where a group of people with similar age, in a determined cultural context/social status educate and mutually inform each other in a variety of issues. In a peer group, its members are influenced by each other and simultaneously educate themselves, leading to a(n) (in)formal peer education process.

### **Problem statement**

One-off activities or projects, developed by healthcare professionals that are not aware of the students involved, approaching merely biological or pathological issues are pedagogically ineffective. Research suggests that sexual education in high schools in United Kingdom did not transmit teenagers the knowledge they needed to protect themselves and to be sexually healthy. Statistics related with sexually transmitted infections are worrying<sup>19</sup>. Distributing condoms and creating medical offices did not contribute to reduce the number of teenage mothers in United Kingdom<sup>20</sup>. An analysis of information broadcasted by social media, advertising, television, cinema, papers and magazines revealed that new, incorrect assumptions related with sexuality are released everyday<sup>21</sup>.

Reality does not fit within idealised patterns and that difference generates tension and pathological reactions that often translate into serious emotional and mental disturbances.

Critical thinking, establishment of

stable affective compromise, development of autonomy is essential to teenagers so that they can identify their values within the existing options. Their horizon cannot be a single road, but a set of several possible ways from which they can consciously and freely choose in their growth process as human beings, supported in affective-emotional and relational development. The tasks involve valuing self-esteem, boosting sexual identity, working on assertiveness and many other that are possible related to interaction with others<sup>20</sup>.

We intend to develop and implement a sexual education project “Sexuality, Emotionality, Responsibility: Take Care of Yourself” and to assess the outcomes of this sexual and affective education project with teenagers from 10 to eighteen years-old, in school context.

### Methods

This is an action research project that, according to Lewin<sup>22</sup> and Kemmis<sup>23</sup>, models fit between stages 1 and 2 (plan and act) of the “self-reflective spiral” (fig. 1). Each cycle encompasses three fundamental steps: planification, action and assessment. After this step, the researcher should review his plan of action, considering the outcomes of the implementation of the action and plan the second step, taking this one as a starting point<sup>24</sup>.

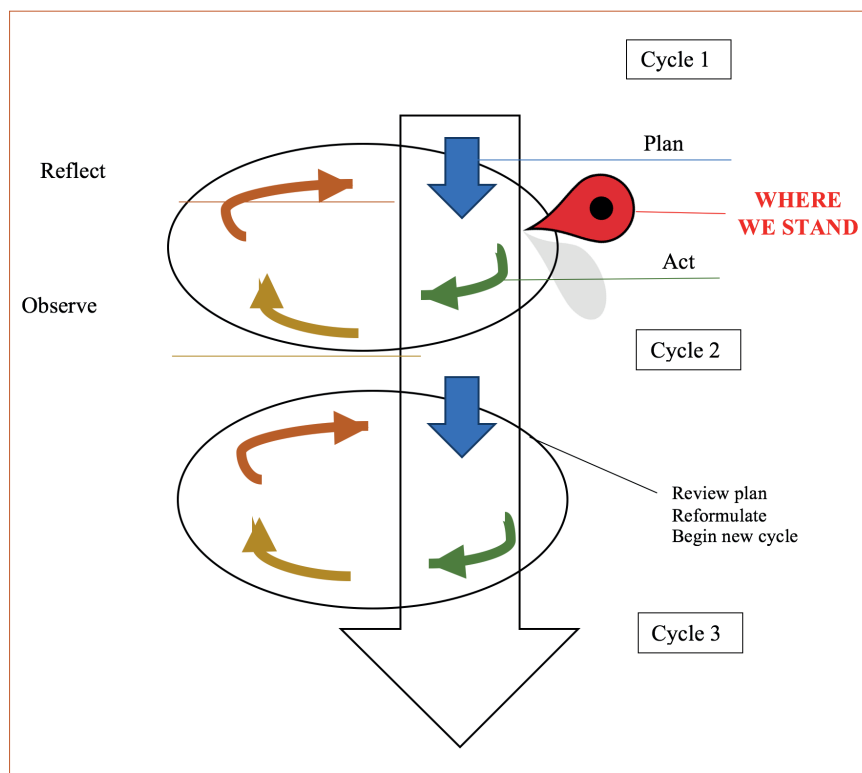


Figure 1. Self-reflective spiral<sup>24</sup>

Action research is characterised as a practical and applied method, moved by the need of solving real problems. The action that results from research aims at transforming reality and, consequently, to produce knowledge. This type of research presupposes the participation and collaboration of all the intervening subjects, because all of them are interested in changing reality. This is a cyclical process, because initial solutions create possibilities to change, which are implemented and assessed as an introduction to the next cycle<sup>16,24</sup>.

Participants in these action research project will be teenagers between ten and eighteen-years-old, parents, teachers from a group of schools in Lisbon

area, and also healthcare professionals, including a research group from “Emotions in Health” research line, from Unidade de Investigação & Desenvolvimento em Enfermagem/Escola Superior de Enfermagem de Lisboa, that coordinates the project.

Data collection instruments will be a questionnaire, currently being applied, and field notes. Data analysis will be of quantitative and qualitative nature.

Regarding the procedures, during an initial stage and after obtaining support of management bodies, the teenagers, teachers and families, a group of people belonging to the educative community that are interested in collaborating will be created; the next stage will involve designing the project itself by the group, considering the organizational characteristics as well as internal and external environment; after diagnosing the situation, we will define the needs and, consequently, objectives, activities and strategies; finally, a presentation of the project will be conducted at the school for analysis and approval.

Before starting field research, researchers will ask for permission from the board of directors of the group of schools, approval from ARSLVT ethics committee and National Committee for Data Protection and, finally, from General-Directorate of Education and Science. Previously to data collection, a free and informed consent form will be given to all participants, who should read and sign it by all of them (or their legal tutor). Anonymity will be guaranteed and data will only be used for project’s purposes.

The project “Sexuality, Emotionality, Responsibility: Take Care of Yourself”, as part of the school curricular plan, takes into consideration the current legislation and encompasses different methodologies and activities, fitted to each of the class-groups, so that initial goals can be fulfilled. This project will be

consistently and continuously developed, being harmonised by the involved educators. We will not strictly follow peer-education guidelines, but our steps involve defining a target group and the context of intervention, the establishment of goals, the development of an action-plan, recruiting, education and training of peer educators and their supervision and support.

## Conclusions

We hope to be able to reinforce human sexuality has an undeniable biological dimension, because all our cells, organs and bodily functions are sexualised. However, it is not possible to define sexuality only through its biological dimension, because our mental and social organisations, as well as our culture are also sexualised. Complex bio-physiological, psychological and social changes are experienced during adolescence and the first romantic relationships also start to occur, even though they are fugacious, and sexual experimentation is part of them, through caressing, kissing or sexual intercourse, with or without penetration. Sexual experimentation sometimes involves intimate contact within same sex peer groups, which results in discovering one-self through mirroring. Sexual education should be a means to minimizing risk behaviours, such as unwanted pregnancy and sexually transmitted infections, but also to increase the quality of interpersonal relationships and intimacy and their contextualisation within the cultural and socio-historical environment. It should allow teenagers the opportunity to explore their attitudes and values and to make informed choices about their sexual life. Sexual education programmes and projects must respect the diversity of beliefs, values and emotions within communities and broaden affectivity-anchored sexual education that children receive through families, religious and community groups as well as healthcare professionals.

The proposed project should guarantee the involvement of school and family as partners in teenager's education and in the maintenance of activities that promote safe, responsible and healthy sexuality. Emotional capacitation of teenagers will contribute to the refusal of violent or coercive sexual expressions as well as relationships of domination and exploitation; respecting differences and others, mainly his or her values, sexual orientation, physical characteristics and the development of affectivity-anchored sexuality.

It is expected that this intervention allow the conditions for a better health, mainly the development of a responsible attitude towards sexuality and conscious future parenthood. We aim at a close collaboration with local health services, as well as student and parents unions.

Globally, this sexual and affectivity education project aims at educating for tenderness, pleasure, sharing of affection, acceptance of one's body, equity, tolerance, self-esteem, self-knowledge, communication, establishment of affective bonds, assertiveness, love and happiness.

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# The return home of the hospitalized elderly

## The nurse in the preparation of the caregiver

### Summary

Preparing for hospital discharge is a care activity inserted in the hospitalization phase, in order to provide care providers with knowledge, skills and responsibility in the management of the health condition and daily activities of nursing. The objective is to identify the strategies performed in the preparation of discharge of the elderly to the informal caregivers in order to enable them to manage the care to be provided.

Descriptive, cross-sectional, correlational and quantitative study. Collection of information by questionnaire. Non-probabilistic sample for convenience, composed by 30 nurses, in a Medicine Service.

The results suggest that the effectiveness of the discharge planning is indicated by 26.7% of the participants, and 33.3% say that it is performed by the doctor. It coincides with the onset of hospitalization in 83.3% of cases, including a set of interventions addressing patients real problems and needs to 96.7%. For patients with autonomic deficit, 100% of the participants mention that the presence of family member or caregiver in the preparation of discharge is promoted. The use of scales, that measure the degree of dependence is only used by 33.3%.

The study concludes that the time of professional experience of the participants does not interfere with the activities of planning of the discharge. Training do not introduce changes in the preparation of discharge, and no significant statistical differences were found.

To establish a customized, assertive and adjusted planning to the patient's real needs, we suggest the use of protocols and the implement of procedures to systematize the nurse's role.

KEYWORDS: NURSE; HIGH PLANNING; INFORMAL CARE PROVIDER; DEPENDENT PATIENT.

### Introduction

As the ability to perform some daily activities independently grows older, they may be compromised by dependence caused by chronic diseases or as a result of the overall loss of physiological functions. Also, the genetic, environmental and social factors seem to condition the propensity for the appearance of dependency tables.

Understanding the factors that exacerbate functional disability in the elderly can be an added value in helping to develop policies in order to reorganize preventive strategies more effective, in order to increase the quality of life of the elderly, reduce health costs and minimizing the family burden.

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The practices of health professionals have been the focus of attention with appeals to new ways of acting and seeing the elderly population, due to the marked aging of the population.

It is imperative to know how to take care and intervene in a holistic, integrating, dignifying and humanized approach, thus responding more adequately to the needs of the elderly.

Care for the elderly is part of a framework for recognizing their needs, centralizing observation in the evaluation of their individual and family capacities and resources.

The preparation of the homecare of the dependent elderly is a primordial process to the nursing care, since it is integrated in the quality standards of this care. The nursing professional, in addition to having a fundamental role in the homecare preparation process, is the closest element of the patient, being the liaison with the other members of the multiprofessional team and with the family/caregivers<sup>1,2</sup>.

A problem often found in hospitals is the poor definition of the role of the health professional, especially nurses, in the preparation of the homecare patient's return home. Evidence of inadequate homecoming planning contributes to poor utilization of community resources and also consecutive readmissions for insufficient education of the patient and their caregivers<sup>1,2</sup>.

Effective discharge planning is extremely relevant; however, it is often inappropriately done, creating difficulties and uncertainties for both the patient and the caregiver. In

many situations, it has been verified the assignment of discharge without all the necessary conditions for the return of the patient to his home, motivated in some cases by a communication deficit between the professionals that compose the health team<sup>1,2</sup>.

It is also verified that in the current context more emphasis is given to brief hospitalization, which ends up being reflected in the decision making of the ideal moment from which to be discharged. Despite identifying a set of needs that require post-discharge clinical care, many older people continue to be discharged without being referred for home care.

To ensure continuity of care and avoid readmissions in health services that contribute significantly to an increase in health care costs, it is necessary that hospital discharge is planned and synthesized in order to ensure greater clarification for both the patient and the patient<sup>2,3</sup>.

Studies report that many patients are more fragile and dependent upon hospital discharge than they were when they were hospitalized, with no planning for reintegration into the family, activity or housing<sup>3,4</sup>.

Short hospital stays, which have so many advantages, can, however, influence the education of the patient and his / her caregivers. If, on the one hand, they limit the time that nurses have to identify needs to educate and inform about self-care, on the other, affect the ability of the patient and caregivers to learn<sup>1,2</sup>.

In clinical practice, the orientation to discharge is often given when the patient leaves the hospital, not being developed during the period in which the patient is hospitalized. In this context, the guidelines provided at the time of discharge, by the nature and quantity of information to be provided simultaneously to the elderly and the family, can contribute to an incorrect or lack of actions associated with care, difficulties in understanding and assimilation, both by the patient and the caregivers, and can contribute to the occurrence of errors<sup>3</sup>.

The preparation of discharge from the patient should be performed from the moment the patient is admitted to the institution and continue during the period of hospitalization until the day of return home. It should be carefully prepared, initiated as soon as possible, with the concern of identifying a set of real needs of the patient and anticipate any difficulties that may occur in the post discharge<sup>2</sup>.

It is believed that discharge planning is an important tool to ensure continuity of care after hospitalization, with teaching being an integral part of the educational process, which includes guidance to the patient and caregivers about what they need to know and understand after discharge, requires an interdisciplinary work and an interaction of the professionals involved<sup>2</sup>.

Nurses must recognize learning needs before they occur. Anticipating needs improves outcomes and facilitates learning, enabling the patient and caregiver to provide adequate health education, adopting clear problem-solving strategies, cooperating for a more harmonious and less confrontational relationship with the dependent patient. It aims to provide care providers with knowledge, skills and responsibility in the management of the health condition and the daily activities of nursing care to be provided to the patient<sup>5,6</sup>.

The nurse has the responsibility to promote specific and guiding teaching to the patient and caregiver in order to guarantee the full restoration of the patient's state of health. Teaching and training are undoubtedly important aspects in terms of the preparation of caregivers, since it is through these that it is possible to develop the knowledge and skills to continue promoting the improvement of the health status of patients. These teachings require the involvement of the family caregiver in the planning of care, individual

and focused on their active participation, in order to promote learning by the nursing team<sup>2,3,4</sup>.

These aspects are of fundamental importance for the caregivers to be able to receive and take care of the elderly, in order to avoid successive rehospitalization for deficient care at home.

The teaching-learning process should be programmed, hoping that it will also be synthesized in information or theoretical aspects, for example, in the prevention of dehydration, adequate nutrition and medication management, or more theoretical aspects such as naso tube feeding the technique of positioning and the technique of transference endowed the caregiver with knowledge and skills for the exercise of a new role<sup>2,3</sup>.

The promotion of discharge planning continues to face many obstacles, with major problems being the insufficient consolidation of medical teams, as well as the unwillingness to participate and cooperate with patient and family discharge planning<sup>1,2,4</sup>.

Inadequate discharge planning contributes to misuse of resources, inadequate follow-up, lack of preparation for self-care and subsequent readmissions. Internment beyond economic costs has physical and psychological costs. The address is the preferred place for recovery provided that the necessary conditions exist.

## Methods

The main objective of this study is to find answers to problems through the use of scientific procedures regarding the identification and recognition of the process of preparation of the informal caregiver at hospital discharge of hospitalized elderly. The following research objectives were defined:

- Identify the information provided to the informal care provider on discharge of hospitalized elderly.
- Identify the factors that can in-



fluence the process of preparation of discharge.

- To identify the strategies performed in the preparation of discharge of the elderly to informal caregivers in order to enable them to manage the care to be provided.

It is a descriptive, transversal and correlational study, inserted in a quantitative methodology. A questionnaire had as its main support the collection of information. We chose a non-probabilistic sample for convenience.

A questionnaire was defined as a source of information collection, with data collection between December 2015 and January 2016, in a Medical Service of a Hospital Center in the North, meeting the inclusion criteria previously defined (being a nurse caregiver; working at a medical service for at least 6 months).

After the application of the instrument of data collection, the need arises to treat them for this, we used statistical analysis techniques. The statistical treatment of the data obtained from the surveys carried out with the participants was carried out using the Statistical Package for the Social Sciences (SPSS) 20. Data analysis using the SPSS tool t-Student and Chi-square.

## Results

The nurses participating in this study are mostly female (90.0%). The average age is 33.2 years. The youngest participant is 27 years old and the oldest is 46 years old. Concerning marital status, approximately half of this group are single (46.7%) or married (46.7%).

At the level of training, 40.0% of the nurses have post-basic training. The average professional practice time (TEPP) of the participants is 9.5 years. It should also be pointed out that the professional practice time at the institution (TEPI) and the professional practice time (TEPS) present very close averages (table 1).

### CHARACTERISTICS OF PARTICIPANTS

1

Characteristics of Participants		n	%	mean/ standard deviation
<b>Gender</b>	Female	27	90	
	Male	3	10	
<b>Age</b>				33.2 (4.1)
<b>Marital status</b>	Not married	14	46,7	
	Married/marriage fact	14	46,7	
	Divorced/separated	2	6,7	
<b>Educational qualifications</b>	Licensed	27	70	
	Master	3	30	
<b>Specialist</b>	No	21	70	
	Yes	9	30	
<b>Postgraduate</b>	No	18	60	
	Yes	12	40	
<b>Time Professional Experience</b>	In the profession			9.5 (3.8)
	In the institution			7.7 (4.5)
	In service			7.2 (4.6)

It is verified that 76.7% of the participants respond that there is planning of the discharges and they identified the existence of one or more responsible for this planning. When the question of who plans the discharges is raised, the answers are disparate, 33,3% who is the doctor who does the planning and 16.7% jointly by the doctor and nurse.

The planning of the discharge made by the multidisciplinary team represents 26.7%. It should be noted that 23.3% of participants indicated that discharges are not planned (table 2).

Nursing discharge preparation is initiated mainly by the participants (83.3%) at the beginning of the patient's hospitalization. However, it should be noted that some participants report starting to prepare the discharge at the time it is reported (16.7%). The preparation of the discharge must be performed from the moment the patient is admitted to the institution, continuing throughout the hospitalization up to the day of discharge<sup>2</sup>.

In response to the question of how the preparation of discharge in the service is carried out, 70% of the participants report that the preparation takes place in an individualized manner and without recourse to interdisciplinarity, with only 30% of the respondents using the explicit service protocol.

Table 3 describes the results to questions posed to the participants and that relate to the real needs of the patient and the use of scales to measure the degree of dependence. In the planning activities of the discharge, the participants (96.7%) have as a concern to elaborate a planning so as to contemplate the real needs of the users.

As for the use of scales for assessment of daily life activity (ABVD) and instrumental activity of daily living (AIVD), only 33%, or 1/3 of the participants declare their use, while the majority 66.7% do not use any type of scale. Participants who

HOSPITAL DISCHARGE PLANNING <b>2</b>		
Hospital discharge planning	n	%
Not planned	7	23.3
Planned by the doctor	10	33.3
Planned by the nurse	5	16.7
Planned by multidisciplinary team	8	26.7
<b>Total</b>	<b>30</b>	<b>100</b>

INTERVENTIONS ADDRESSED TO THE PROBLEMS AND NEEDS OF THE USER <b>3</b>		
Interventions addressed to the problems and needs of the user	Yes	No
The discharge preparation contemplates the planning of interventions directed to the needs	96.7	3.3
The information collected includes the level of dependency for ABVD and AIVD using the Scales	33.3	66.7
<b>Scale used</b>		
• Barthel ABVD	23.3	76.7
• Katz ABVD	0.0	100
• Lawton AIVD	3.3	96.7

ESTABLISHMENT OF A PERSONALIZED EDUCATION PLAN FOR PATIENTS WITH AUTONOMIC DEFICIT <b>4</b>		
Establishment of a personalized education plan for patients with autonomic deficit	Yes (%)	No (%)
Promotion of the presence of family / caregiver in the preparation of patient discharge with autonomy deficit.	100	0
<b>Establishes a personalized education plan that contemplates</b>		
• Objectives/expected results of care provided	53.3	46.7
• Adequate information on the level of knowledge and care needs	90.0	10.0
• Patient/family/caregiver Care Instructions	96.7	3.3
• Skills training	83.3	16.7
• Guidance for social support network	93.3	6.7
• Articulation with primary health care through high card and/or telephone contact	96.7	3.3
• Home Visitation	3.3	96.7

DISCHARGE PLANNING ACTIVITIES <b>5</b>		
Identification of knowledge and information provision:	Yes (%)	No (%)
Therapeutic regimen	83.3	16.7
Dietary regime	53.3	46.7
Hygiene and comfort	100.0	0.0
Placements	100.0	0.0
Transfer	76.7	23.3
Providing written information: pamphlet, care guides... other	60.0	40.0

responded positively to this question mostly resort to Barthel's scale (23.3%).

Table 4 presents the answers to the questions related to whether, in the preparation of discharge of the patient with autonomy deficit, the presence of a relative or caregiver is promoted and, if so, what items are considered as a concern by the participant in determining the degree of informal caregiver knowledge.

In preparing the discharge of patients with autonomic deficit, 100% of the participants report that the presence of a relative or caregiver is required. The next question is to perceive from a set items representative of the needs of a patient with autonomy deficit after discharge, which are included in a personalized education plan.

It was verified that in the item "expected objectives/results of the care instituted", only 53.3% of the participants include this as part of the personalized plan. There is concern about the elaboration of a plan of education at different levels of the patients' needs, being the (90.0%) and patient/family/caregiver care instructions (96.7%). As for the articulation with the social support network, this is effected by 93.3% and with primary health care the articulation is effected by 96.7% of the respondents. The participants value little the home visit, being only included in the personalized plan by 3.3% of the participants.

Table 5 shows the answers obtained regarding the identification of several items, presenting the answers obtained regarding the delivery of written information to the caregivers.

There is a concern on the part of all participants (100%) for the care of hygiene and comfort, as well as for the positioning of the patient. Participants report that in the discharge planning activities, they also focused on the identification and transmission of information about the therapeutic regimen (83.3%), dietary

ACTIVITIES PLANNING OF DISCHARGE

6

Planning of discharge	N	(%)	(p)
Planned	23	76.7	
Not planned	7	23.3	> 0.05
At the beginning of hospitalization	25	83.3	
Only when discharge is reported	5	16.7	> 0.05
<b>Preparing for discharge from the service</b>			
According to protocol	9	30	
Individually (without interdisciplinarity)	21	70	> 0.05
<b>Customized teaching plan</b>			
Objectives; identification knowledge; training of skills; home visitation, primary care articulation.			> 0.05
Providing written information: pamphlet, care guides... other	60	40	> 0.02
Individually (without interdisciplinarity)	21	70	> 0.05

(53.3%), patient transfer (76.7%). It should be noted that in the diet, only 53% mention it as a concern to be observed in the identification of the knowledge that the caregivers have in this area. Transfer techniques, that is, from the bed lift to the highchair, couch or other, and from these to the bed was the second item with less expressiveness in terms of interest.

Table 6, shows the results obtained for the issues related to discharge planning and their relation to the time of professional exercise in the service and in the profession.

Participants who have more exercise time (mean = 10.7) reported providing more written information, such as pamphlets and care guides, compared to those with less exercise time (mean = 7.6). This difference is statistically significant (< 0.05) is a longer exercise time is associated with a higher average frequency in performing this activity.

The association between professional training and discharge planning and its activities using the Chi square test was compared. From the results obtained there were no statistically significant differences between the different variables, it can be concluded that the professional training of the participants has no effect in the planning of the discharge and its activities.

**Discussion**

The results in this study present a profile of the participating nurses, who are mostly female (90.0%), with an average professional experience of 9.5 years. It is observed that the nurses with more professional experience, more often complement the information provided to the informal caregiver, using written documentation, pamphlets and care guides.

Effective hospital discharge planning should be based on the transmission of knowledge and skills to the care process as well as the promotion of the well-being and trust of the patient and the informal caregiver<sup>4,5</sup>. The mobilization of strategies is seen as facilitating the role of caring and consequently favouring this transition process.

Regarding the previous planning of discharge, 76.7% of respondents answered that planning exists, but not in a systematic way and previously defined and agreed. Of these, 33.3% report that it is up to the doctor to plan the discharge, while 26.7% say that the planning is carried out by a multidisciplinary team and 16.7% mention that those responsible for preparing the discharge are the doctor and the nurse. It should be noted that 23% of the total

participants say that the discharges are not planned. These results are in agreement with studies carried out, indicating that the doctor is the main intervener in the discharge process, and this process needs to be carried out by all the health team involved in the treatment<sup>5,6</sup>.

We can therefore infer that there is no consensus on the part of the respondents on this issue. The preparation of the discharge occurs without recourse to interdisciplinarity, which contradicts the bibliography, which alludes to the fact that the decision should be considered and discussed by all the participants, since health care is developed and is inserted in a multidisciplinary context resulting from the sum of the contribution of each of the professionals involved.

Regarding the process of initiating discharge planning, 83.3% of the respondents stated that it was recorded at the beginning of hospitalization, which is in line with other studies. The preparation of discharge should be performed from the moment the patient is admitted to the institution and continue during the period of hospitalization<sup>1,5</sup>.

Most of the participants indicate that the discharge preparation contemplates a whole set of interventions that are concerned with the focus of intervention and the real needs of patients. Nurses should assess a range of patient needs, including surveying aspects of existing resources that will be available to them on their return home<sup>4,5</sup>.

In the preparation for the discharge of the patient with autonomy deficit, there is unanimity on the part of all the respondents, who affirm that the presence of family member or caregiver is promoted, in order to contribute to the elaboration of a personalized education plan. It is imperative that hospital discharge should be planned and organized in order to ensure patient clarification and caregivers, training of competencies, objectives/expected outcomes of established care and

home visitation, focusing on continuity of care and avoiding readmissions in health services<sup>5,2,6</sup>.

The evaluation of the degree of dependence should be made using scales, in a systematic way. In this study only 33.3% of the participants refer to this resource. The use of scales is a valuable tool for determining the abilities of the elderly in relation to ABVD and AIVD. The Barthel Index is one of the instruments most used to perform the functional capacity assessment for the ABVD. It is worth mentioning that the evaluation of the different levels of disability becomes important for the proper planning of health care and the use of the scales is a resource for this evaluation introduced in the platforms for assessing the needs of patients<sup>5,6</sup>.

Concern is expressed during the planning of discharge, by all respondents (100%) in promoting self-care, mobility and patient transfer. The need to promote the therapeutic regime (83.3%) and dietary (53.3) is also highlighted. The effective performance of informal caregivers requires resources such as expertise, supportive capacities that promote effective adaptation to new health challenges. For a good preparation of discharge, it becomes necessary to establish standardized protocols that allow to simplify and to promote the process of implementation of discharge<sup>4,6</sup>.

## Conclusion

Hospital discharge is a concern of all those involved in the care process. Effective planning should be based on the mastery or transmission of knowledge and skills for the care and promotion process of the well-being of the user and caregiver. The main concerns are the continuity of care regarding information, education and / or teaching about life habits, medication, diet, mobility and explanation of signs and symptoms in order to prevent some complicated situation.

The main conclusions of the study point to:

- The effectiveness of discharge planning is indicated by only 26.7% of the participants, and 33.3% say that it is performed only by the doctor. It occurs in an individualized way (70%) and without interdisciplinarity for a large number of participants.
- There is the concern of almost all the respondents in directing the discharge preparation to the planning of interventions directed to the real problems of the users (96.7%). However, the systematic use of scales to assess the degree of dependence is only reported by 33.3%.
- It is verified the care of all the participants in promoting the presence of family member or caregiver in the preparation of discharge of the user with autonomy deficit (100%).
- Most nurses report evaluating the experience of informal caregivers in terms of hygiene and comfort care, settings, therapeutic and dietary regimens.
- Nurses with more PE are those who provide more written information about discharge preparation ( $p = 0.02$ ).

In this sense, the family should be integrated into the team and in the care as early as possible, so that health professionals can develop skills and knowledge about these areas.

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# Vulnerability and cognitive protection factors in older persons

## Summary

Estimates from the Portuguese Statistics reveal that 19.0% of the resident population in Portugal is in the age group with 65 years or older. By 2020, it is expected that the proportion of the elderly ( $\geq 65$  years old) will increase to 20.6%. Cognitive plasticity and reserve capacity are central in studies addressing the ageing process, thus it is extremely important to identify the vulnerability and protection factors.

**OBJECTIVE.** To identify vulnerability and cognitive protection factors in older persons.

**METHODOLOGY.** Epidemiological and transversal study, conducted with a population of 151 persons, with an average age of 70.8 ( $\pm 5.4$ ), in the metropolitan area of Porto.

**RESULTS.** The results indicate that lifestyles involving physical exercise; eating habits; sleep and rest patterns; leisure activities; satisfactory emotional life and the use of health services can act as vulnerability factors or protective factors.

The Mini-Mental State Examination (MMSE) has an average of 26.6 ( $\pm 4.4$ ) and the questionnaire of cognitive reserve of 6.3 ( $\pm 4.6$ ).

The dimensions of the MMSE show an association between items, with emphasis on MMSE guidance and MMSE attention and calculation, with a correlation of  $r = .75$ ;  $p = 0.001$  and  $r = .89$ ;  $p = 0.001$  respectively.

**CONCLUSION.** The healthy lifestyles, involving physical exercise; proper nutrition; the regular sleep pattern; engagement in leisure activities; a satisfactory emotional life and the use of health services can function as protective factors (present) or vulnerability (absent).

**KEYWORDS:** COGNITION; AGEING; OLDER PEOPLE; AUTONOMY.

## Introduction

According to data from Portugal, has a population of 10.561.614 inhabitants, with an ageing index of 129<sup>1</sup>. In 2009 the ageing index was 117.60 and in 2010 of 120.10. These data mean that for every 100 young people there are currently 129 elderly. These statistics show that there is clearly a phenomenon of the double ageing of the population, with the of the older population and a decrease of the younger population. The 2011 Census<sup>1</sup>, (2011), reveals that 15% of the Portuguese population is included in the youngest age group, aged 14 years or less, and about 19% is included in the age group of older people, with 65 years or older. By 2020, it is expected that the proportion of young women (0-14 years) will decrease to 13.8%, and the elderly ( $\geq 65$  years) increase to 20.6%<sup>1</sup>.

The prevalence of Mild Cognitive Impairment (MCI) in the population,

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according to several studies<sup>2,3</sup> in individuals over 60 years old, ranges between 3% and 17% and the incidence rate of new cases per year in people over 65 years old, diagnosed with amnesic MCI ranges between 9.9% and 21.5%<sup>3</sup>.

Several studies demonstrate that the MCI is constituted as a diagnostic entity<sup>4</sup>, which tends to progress to a dementia condition. Several studies show progression rates to dementia of 3% to 48%, from 1 to 5 years<sup>5,6</sup>, so it is essential to develop appropriate interventions targeted at this population with such specific characteristics<sup>6</sup>.

The changes and the impairments caused by the cognitive decline lead to functional decline, with reduction and/or loss of skills essential for the development of the activities of daily living, with significant impact on performing these activities (ADL). In this context, to identify the cog-

nitive and functional abilities of the elderly is fundamental to identify risk groups.

As potential modifiable vulnerability factors for the development of cognitive changes at the pathological level, it is possible to point out the education and professional achievement, cardiovascular risk factors, psychosocial factors and lifestyles involving smoking habits, alcohol abuse, hypertension, diabetes, obesity, physical activity and depression<sup>7</sup>, highlighting the importance of positive emotions<sup>8</sup>, sleep patterns and active cognitive stimulation<sup>9</sup>.

The set of physiological and pathological changes experienced by the elderly will very likely lead to increased dependency, and subsequent need for aid, essential to perform the activities of daily living. However, this is not a definite dependence, but a dynamic process and its evolution may even be prevented or reduced with a proper identification and specific assistance<sup>10</sup>.

Thus, the purpose of this study is to characterize the population at cognitive and functional levels, its associated comorbidities that change the cognitive potential and to analyse the impact of the cognitive deterioration vulnerability factors in older persons, contributing to an effective improvement of the quality of the care provided.

### Cognitive potential

Since 1960 many classifications were developed in order to describe mild manifestations of cognitive impairment. Recently, the MCI emerged as a new category describing the transition phase between regular and pathological ageing, with an increased risk of developing Alzheimer Disease or another type of dementia<sup>11</sup>.

Despite unexisting consensus as to the criteria for MCI, the diagnostic criteria<sup>12</sup> represent the most recent attempt of standardization. In this way, Petersen, *et al.* have defined five essential criteria for the MCI<sup>12</sup>:

- Memory complaints, in particular when confirmed by a family member.
- Object memory deficit as to age and school level.
- Overall regular cognitive function.
- No changes reported in the activities of daily living.
- Dementia symptoms absence.

The most recent diagnostic criteria set by the Work Group of MCI of the European Alzheimer Disease Consortium EADC<sup>13</sup>, suggest that the person with MCI can show mild changes at the level of instrumental and more complex activities of daily living, such as cooking, use public transport or planning trips. To maintain the criterium of deficit absence in the activities of daily living (ADL) would be highly restrictive, and most likely underestimate the prevalence of MCI<sup>14</sup>.

The continuous research enabled to clarify that not all the persons experiencing MCI will develop the Alzheimer Disease, so the concept has evolved in order to include deficits in other cognitive domains<sup>12</sup>. In particular, two subtypes have emerged: amnesic, (includes memory deficit) and non-amnesic (if there is no memory deficit)<sup>4</sup>.

Within the amnesic MCI<sup>4</sup> has defined two subtypes:

- The amnesic MCI of a single domain (when memory is the only domain with deficit).
- The amnesic MCI of multiple domains (in cases that besides the memory, deficits can also be identified in other cognitive domains, such as speech, attention, or the ability to perform some task).

Similarly, the author described the non-amnesic MCI of a single domain or multiple domains, whether it refers to a deficit in one or several domains, except for memory.

These criteria can be complemented with a thorough interview to the

elderly or accompanying person that corroborates the presence of cognitive changes, screening for other possible casual comorbidities and through the use of tests that will determine the existence of cognitive deficits related to age and school level. The maintenance of the activities of daily living must also be tested in the interview and by using appropriate assessment instruments.

This study purpose is focused on the importance of maximizing intervention strategies, based on the promotion of health and disease prevention, in a proximity context, leading to the preservation or improvement of the mental health of the elderly population with mild cognitive impairment.

### Problem statement

Older persons, particularly after 65 years of age, which is coincident with the retirement age, are very likely to reduce their cognitive work and thus being more at risk of experiencing a cognitive decline. Hence, it is crucial to identify factors that can potentially cause greater vulnerability/protection of cognition, in order that the health services contribute with effective interventions so that the risk of cognitive decline in older persons is reduced.

### Research methods

#### Purpose of the study

This is a descriptive, exploratory and transversal study, conducted in a community population of the north of Portugal, performed between January 2014 and June 2015.

#### Research questions

- Which are the protection factors for cognitive preservation in older persons?
- Which are the vulnerability factors for cognitive decline in older persons?

#### Population/sample

This study was performed in a health unit of the north region of Portugal,

with a population of 11.200 people, aged between 65 and 75 years. A random sample was selected with 280 older persons, and for every 40 persons, one person was selected.

From this sample, a total of 129 persons did not meet the inclusion criteria: 66 patients did not meet the inclusion criteria; 32 persons did not attend the consultation; and 31 persons refused to participate in the study.

All persons were invited to attend a consultation in the health services and were evaluated as for the communication skills in order to be able to participate in this study.

The older persons that did not attend the consultation were visited at home to assess the inclusion criteria and a total sample of 151 persons were selected (53.9% of the initially selected persons).

### Data collection

Data collection was performed by the project's researchers, between January 2014 and June 2015.

The elderly involved in this study were previously informed of the objectives of the study and asked to sign an informed consent.

All ethical recommendations of the Declaration of Helsinki were considered.

The project was granted approval by the administration board and the ethics committee with no. 130/13 OP dated 11.07.2013.

The older persons that met the criteria for cognitive impairment were directed to their health teams (physician/nurse), for the reassessment of the clinical condition (10 persons/6.6%).

This study aims to identify the vulnerability and protection cognitive factors in older persons.

An assessment questionnaire was used for data collection, including questions related to sociodemographic, clinical and lifestyles variables and using different scales/assessment instruments:

- The Mini-Mental Status Examination (MMSE), by Folstein et al.<sup>15</sup> With 30 items, using 5 subscales: guidance (10 items); attention (3 items); calculation (5 items); language (3 items); memory (8 items) and constructive ability;
- The Cognitive Reserve Questionnaire (CRQ) developed by Rami et al.<sup>16</sup> With 8 items – 1. School level; 2. Parents school level; 3. Training courses; 4. Professional occupation; 5. Musical training; 6. Languages knowledge (able to keep a conversation); 7. Reading activities; 8. Intellectual games (chess, puzzles, crosswords);
- Subjective Memory Complaints Scale (SMC) de Schmand et al., 1996, adapted to the Portuguese population by Ginó et al., 2008<sup>17</sup>.

With 10 items, in a 4-point Likert Scale (0, nothing, to 3, very), in which marks > 4 points – subjective memory complaints of some relevance and potentially indicative of deficit.

- Clinical Dementia Rating (CDR), Hughes et al., 1982<sup>18</sup>.

With six items (memory; orientation; judgement and problem-solving; community affairs; home and hobbies and personal care), rated between 0 and 3 points: 0 = no cognitive impairment; 0.5 = very mild dementia; 1 = mild dementia; 2 = moderate dementia; 3 = severe dementia.

In terms of rating, the memory is a primary dimension and its rating prevails over the other dimensions, except when there are three dimensions with higher ratings.

- Geriatric Depression Scale (GDS) short version by Yesavage<sup>19</sup>.

With 15 items, where values > 5 – depression and > 11 – severe depression  
To assess functionality, the Lawton Index was used (values ≤ 8 points –

total independence, > 9 ≤ 20 points – moderate dependence, > 20 points – high dependence.

The scales were used to assess items such as perform domestic tasks, wash the clothes, prepare meals, go shopping, use the telephone, use public transport, manage money and medication. The Barthel Index was also applied to assess items such as eating; personal hygiene, use the toilet, bathing, dress and undress, bladder and bowel control, walking, transfer from chair to bed and go up and down stairs. The total score was 100 points: < 20 points - total independence; > 20 ≤ 35 points – severe dependence; 40 to 55 – moderate dependence; 60 to 90 - mild dependence; > 90 points – presence of dependence.

The questionnaire was evaluated by a group of eight experts (one psychiatrist, two psychologists, two professors from the mental health area, three specialist nurses in mental health). A pre-test was applied to ten users of a different health unit in order to assess comprehension and time needed to complete the questionnaire.

Data were inputted through an optical reading software and validated by researchers. These data were computed into SPSS version 2.0 and a statistical analysis was performed (t-test and Pearson correlation).

The internal consistency of the instruments ensured the results trustworthiness with a significant Cronbach alpha.

### Findings

The study sample comprised 151 older persons aged between 65 and 75 years, with an average age of 70.8 (± 5.4) and mode of 67 years. The majority of participants were female: 78 (51.7%), with primary school level (68.9%), and 86.5% were cohabiting with spouse/children and 77.5% were married/living in marital status.

The main household income was from the retirement pension

(96.7%), and 45.7% of the older persons received less than 500 Euros per month and 72.2 % reported major concerns about daily expenses.

The domestic affairs were performed by 62.3% of the sample.

As to the lifestyles that may act as protective or vulnerability factors to these persons, 60.9% reported daily consumption of alcoholic beverages, considered as adequate, and 86.6% had no smoking habits.

As for physical exercise, 45% reported some physical activity, with hiking being the most prevalent (45.7%), followed by gymnastics (7.3%), hydrogymnastics (4.6%) and swimming (3.3%). People who referred physical exercise, 29.1% reported doing it on a daily basis, and 24.5% at least 2 to 3 times a week.

In what concerns the eating habits, 67.5% reported having a good diet, with 89.4% considering to have a balanced diet. The majority of food consumption was related to fruit (76.2%), dairies (56.3%) and vegetables (53%). Despite these indicators, 25.2% of people only ate three daily meals.

As for the sleep and rest patterns, 74.8% considers as sufficient the sleeping hours according to their personal needs, with 52.3% sleeping 6 to 8 hours a day and 27.2% usually taking a nap.

In relation to leisure activities, 55% of the older persons did not usually engage in these activities, however, the most commonly mentioned was watching TV (82.1%), followed by reading (41.1%), listening to music (32.5%) and sewing (32.5%).

Despite not being considered as a leisure activity, 29.1% of participants referred taking care of their grandchildren.

For 84.8% of participants reported having a stable and satisfactory emotional life.

The use of health services is mentioned by 79.5% of the persons and for some it usually occurs every six months (49.7%). The general physician was the most cited as the reference health professional (89.4%) followed by the nursing professional (5.3%).

In relation to health care, 72.2% referred specific needs, with a major incidence of cardiovascular diseases (57.6%).

As to medication consumption, 89.4% of participants reported a daily

consumption, with only 27.8% taking one or two daily medication. The most reported medications were related to cardiovascular diseases (66.2%), sleeping pills (26.5%) and antidiabetic (24.5%). A special emphasis was for medication for depressive symptoms (13.2%) and mental disorders (3.3%), even in cases with no diagnosis.

The associations between the dimensions integrating the different instruments (intercorrelations) were analysed, and it was decided not to exclude results even if they were not statistically significant.

A positive correlation was found between values of CRQ and the MMSE, with  $p \leq 0.001$  and for the GDS, with  $p \leq 0.05$ , total values of the scales.

The correlation between the values of the MMSE and the GDS is statistically significant, with  $p \leq 0.01$ .

The dimensions of the MMSE show an association between items, with an emphasis on MMSE orientation and MMSE attention and calculation, showing a correlation of  $r = .75$ ;  $p = 0.001$  and  $r = .89$ ;  $p = 0.001$  respectively.

As demonstrated in the figure 1, there is a strong correlation between

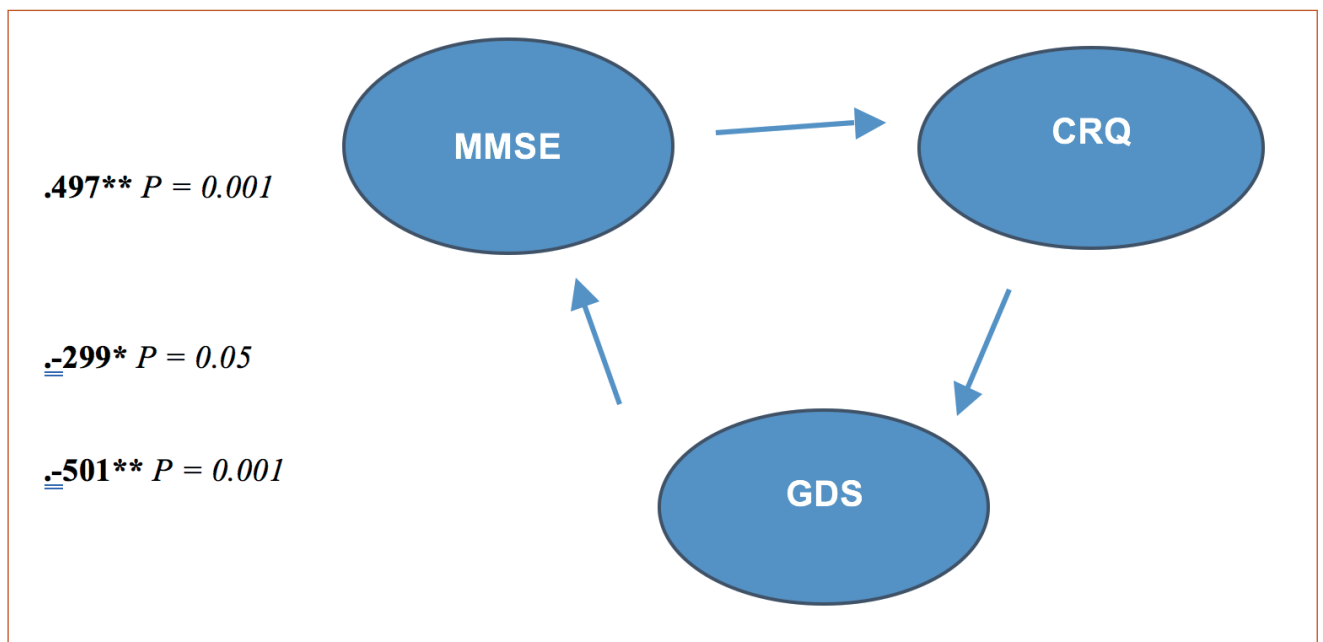


Figure 1. Correlation between the MMSE, the GDS and the CRQ



the cognition values, assessed through the MMSE with the cognitive reserve questionnaire (positive correlation) and with the geriatric depression scale (negative correlation), with statistically significant correlations. These results show a strong association between these variables, which is relevant in a clinical approach, and suggests that working to preserve cognition, positively impacts the cognitive potential and the prevention of depressive symptoms. In addition, there is a negative and statistically significant relation (-0.299), between the cognitive reserve questionnaire and the geriatric depression scale, suggesting that the higher the cognitive potential, the lower the likelihood of depressive symptoms.

## Discussion

The results of this study show that the sociodemographic factors: gender, age, family situation, age, and school level, influence the older person's capacities, also corroborated by several studies<sup>20, 21</sup>.

Importantly, and despite literature refers that older persons experiencing pain often have reduced levels of functionality<sup>22</sup>, this study demonstrates that these people do not report pain, practice daily physical exercise (29.1%) and some (24.5%) engage in this activity at least two to three times a week, particularly doing hiking (45.7%).

The functional capacity characterized by the necessary abilities to maintain an independent and autonomous life, is divided into two categories: activities of daily living (ADL's) and the instrumental activities of daily living (IADL's), since the participants did not need assistance to perform the activities of daily living (62.3%).

In relation to the impact of the physical and psychological resources to the functional autonomy in older age, it is interesting to note that the conclusions of a study<sup>23</sup> indicate that the physical resources are the most useful for the maintenance of the performance in the activities of daily living ADL, and memory is an important psychological resource for the instrumental autonomy.

This study identified vulnerability factors in older persons: the lifestyles (physical activity – 45%); the cardiovascular risk (daily alcohol consumption and smoking habits, 13.4% and 60.9%, respectively); 24.5% of the participants take antidiabetic medication; 26.5% take sleeping pills and 13.2% use antidepressive medication. As an essential biological human function, sleeping highly improves the cognitive ability, specifically in what memory and creativity are concerned. Several studies corroborate that sleeping a short nap is sufficient to improve the memory performance and in some cases the benefits are comparable to a night sleep<sup>24</sup>.

Also importantly, the physical activity, the regular cognitive stimulation and social interaction contribute to the improvement of the cognitive function, namely attention, memory and consciousness, the ability to perform the activities of daily living and emotional and social well-being. All these factors are extremely useful for the reduction of the risk of developing the Alzheimer Disease and controlling its progression<sup>9</sup>. The regular engagement in leisure activities, such as reading, crosswords and games, at least six hours per week will reduce the risk of dementia incidence, which also corroborate the findings of this study<sup>25</sup>.

From the overall sample, 84.8% of the participants refer having a stable and satisfactory emotional relationship<sup>8</sup>, who state that regular positive emotions ease the ability of retention and complex decision making and problem-solving.

These results corroborate that the vulnerability factors aforementioned are the focus of health care in 79.5% of the older persons, although 5.3%

have mentioned the nursing professional.

The present results indicate that the balance between the vulnerability and cognitive protection factors in older persons increase the likelihood of maintaining the abilities to perform the activities of daily living.

## Conclusion

This study confirms that lifestyles involving physical exercise, feeding habits, sleep and rest patterns, leisure activities, a satisfactory emotional life and the use of health services can function as vulnerability factors.

Thus, small improvements or even the balancing of cognitive functions may be considered important health gains. As such, it is recommended that the Cognitive Stimulation Technique is included in care programmes targeted at older persons and performed by technicians specialized in Mental Health and Psychiatric Nursing, in order to contribute to the preservation of the cognitive and functional capacity of the patients, which will very likely enable greater independence and improvement of quality of life.

## Relevance for clinical practice

An important implication for future practice relates to the assessment of vulnerability and cognitive protection factors in older persons, in health professionals' decision-making and in the evaluation in clinical, scientific, administrative and social contexts.

The assessment of the functional status of older persons is crucial to the preservation of the autonomy of life<sup>8</sup>.

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# Knowledge of good nutrition, physical activity and sleeping habits in pre-schoolers

## Summary

Children's knowledge about food and nutrition is very important for the development of appropriate patterns of eating behaviour. Nowadays, because children's input is becoming to get more importance in parents' decisions about nutritional choices it is important to contribute for their knowledge development regarding not only nutrition or food but also healthy habits regarding sleeping and physical activities.

The purpose of this study was to contribute for the assessment of nutrition/food preferences in pre-schoolers and the contribution of gaming for nutrition/food knowledge evaluation. It also intended to establish a relation between children's BMI and the knowledge of nutrition/food and good sleep and physical activities habits.

An observational, cross-sectional, quantitative study was conducted with 364 children's attending preschool from a metropolitan area of the norther region of Portugal and their parents.

Food preferences varied from pasta (13.4%) to meat (8.8%) or tomatoes (6.3%) and undesired foods were, among others, fish (16.2%), soup (13.2%), tomatoes (12.6%) and onions (10.7%). Preschoolers showed high levels of knowledge regarding food categorization (92.3%), good sleeping habits (90.1%) and good physical activities habits (94.0%).

Results showed significant differences for sleeping habits knowledge with lower BMI ( $\text{kg}/\text{m}^2$ ) for children that gave correct answers ( $M = 16.35$ ,  $SD = 2.04$  vs.  $M = 17.62$ ,  $SD = 2.37$ ). Children with increased BMI showed more risk of poor knowledge regarding good sleeping habits (aOR = 1.33, 95% CI = [1.07-1.69]). Parent's low education was found to be a risk factor for children's poor knowledge of good sleeping habits (OR = 8.21, 95% CI = [1.85-35.55]).

KEYWORDS: FOOD; NUTRITION; PHYSICAL ACTIVITIES; SLEEP; BMI.

## Introduction

Children's knowledge about food and nutrition is very important for the development of eating patterns and behaviours<sup>1</sup>. Most of the patterns are built on parents' verbal and non-verbal communication with their children regarding food. Children's also participate and interact in the pattern construction, by their behaviour towards food, namely when new foods are introduced in their diet<sup>1-2</sup>.

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Eating habits have been changing over the time in Europe. In the early 1900's malnutrition was an important concern among children. Nowadays the problem has shifted to excessive exposure to nutritionally low or unbalanced foods with high calorie with poor nutrient contributions<sup>3-4</sup>. The increased prevalence in childhood obesity in developed countries has catalysed the debate about the introduction of dietary and nutrition subjects into schools programmes. Moreover sleeping and physical activities habits can play a key role on diminishing obesity<sup>5</sup>.

It has been a growing tendency for children to fail on meeting the minimum recommended quantities of what can be considered as healthy food<sup>6</sup>. Children are highly dependent on parents' perception about what are and what healthy foods aren't, and parent's knowledge of healthy food does not always correspond to a real healthy food definition<sup>3</sup>. Social context is also an

important determinant regarding food choice, but now more than ever preschoolers are gaining some degree of control regarding their food choices<sup>7</sup>; children that spend more time watching television tend to be more exposed to advertisements regarding energy-dense foods and few or none fruits and vegetables and at the same time engage in less physical activities<sup>8,9</sup>. The time spent in screen-type activities also correlated with poor sleeping habits<sup>9</sup>.

Children's preferences towards food and how these preferences are internalized are important for a better understanding of attitudes towards food and thus to the development of strategies applied to health education programs<sup>10-11</sup>.

Health education programmes can be an effective way of improving parents' and educators' skills related to children's behaviours towards food<sup>10-12</sup>. Nevertheless according to Pyo and Kang (2014) programs directed to nutritional education can be effective even when directed to preschoolers, especially in the range of 4-6 years old<sup>13</sup>.

Holub and Musher-Eizenman (2010) stated that children with at least 3 years old are capable to distinguish healthy from unhealthy food<sup>14</sup>. In the same way Nguyen and Murphy (2003) pointed that children with 4 years old are able to categorize foods into healthy or unhealthy categories<sup>15</sup>.

Some researchers have pointed out that, due to the number of hours spent in school, this environment offers a changing opportunity, if provided the necessary resources for the implementation of nutrition education programmes<sup>16-17</sup>.

This study main goals were:

- 1) To assess the nutrition/food preferences in preschoolers and the contribution of gaming for nutrition/food knowledge evaluation.
- 2) To relate the knowledge of food/nutrition, sleep and physical activities habits of pre-schoolers with their BMI.

### Research questions

What are the nutrition/food preferences of preschoolers?

Can oriented-nutrition/food games contribute for nutrition/food knowledge evaluation?

Is there a relation between nutrition/food knowledge, sleep and physical activity habits and children's BMI?

### Purpose of the study

This study attempts to contribute for determining the level of knowledge regarding nutrition and food in preschoolers and assess the contribution of a game for nutrition/food knowledge evaluation in a sample of children attending preschool from a metropolitan area of Oporto city in Portugal.

Accordingly, the following objectives were delineated:

- Characterize the sample studied by biographical data collection.
- Characterize the nutrition/food preferences in preschoolers.
- Contribute for understanding of the importance of oriented nutrition/food games for nutrition/food knowledge evaluation.
- Contribute for assessing the relation between nutrition/food knowledge, sleep and physical activity knowledge of good habits and children's BMI.

### Research methods

Observational, cross-sectional and quantitative study with a population composed by children attending preschool. Data was collected from September 2016 to February 2017 by used of a questionnaire and consisted in a non-probabilistic sample of 364 children's and their parents regarding 22 classes of six different school establishments from the metropolitan area of Oporto

city in Portugal. Inclusion criteria were children attending preschool without special educational needs, that participated in the anthropometric assessment and whose parents agreed to participate in the study by signing informed consent.

### Instrument and procedures

Instrument was a questionnaire, adapted from the original study of Sancho (2014) and addressed socio-demographics, anthropometric data and knowledge of nutrition/food, sleep and physical activity habits<sup>18</sup>. The study and questionnaire were approved by the ethical committee of Instituto de Ciências Biomédicas Abel Salazar (ICBAS). After approval, a total of 22 meetings (one per class) occurred in the presence of parents/tutors and the kindergarten teacher. After explaining the study, the parents that agreed to participate signed the informed consent and received an open envelop with the questionnaire. Afterwards, filled questionnaires were delivered to the kindergarten teacher or the researcher. Moreover, in this study a gaming strategy was used to assess the contribution of oriented nutrition/food games for nutrition/food knowledge evaluation in preschoolers. For that purpose a game was implemented in each class using different types of food printed in magnet cards. Children were asked to place each magnet card in the correct place of the Portuguese food wheel. The same type of activity was performed regarding sleep and physical activity; children were encouraged to place magnets regarding good sleeping and physical activities habits.

### Statistical analysis

SPSS (version 24)<sup>19</sup> was used to perform statistical analysis. Descriptive statistics were presented as means (*M*) and standard deviations (*SD*) for quantitative variables, medians (*Mdn*) and interquartile ranges (*IQR*) for ordinal variables and fre-

quencies (*n*) and percentages (%) for categorical variables. Percentages were adjusted for missing values always totalizing 100%. Missing values were discharged separately for each analysis. T-tests (for continuous variables) and Mann-Whitney tests (for ordinal variables) were used to assess differences between children that gave correct answers vs. children whose answers were incorrect. Normality was assessed with Kolmogorov-Smirnov test.

Crude and adjusted odds ratios (OR/ aOR) were calculated via logistic regressions for determining the risk of correct/incorrect answers regarding significant variables previously screened by t-tests or chi-square/fisher tests. Statistical significance was based on the analysis of the 95% confidence interval (CI) for the OR. Significance was considered if 1 was not included in the CI.

### Sample

We assessed a total of 364 children, from 2.75 to 6.67 years of age ( $M = 4.48$ ,  $SD = 0.91$ ). Birthweight ranged from 1.32 kg to 4.15 kg ( $M = 3.16$ ,  $SD = 0.50$ ) and current BMI score ranged from 1 to 5 ( $Mdn = 2.0$ ,  $IQR = 1$ ). Regarding family status, 314 (86.4%) were from nuclear families with/

without brothers, 32 (8.8%) from monoparental families and 18 (4.9%) from families in which the mother or father lived with other elements (e.g. partners, uncle/aunt, grandparents). Mother's age ranged from 19 to 51 years old ( $M = 34.51$ ,  $SD = 5.43$ ) and father's age ranged from 22 to 56 years old ( $M = 36.94$ ,  $SD = 5.73$ ). Questionnaire respondents were in the vast majority mothers ( $n = 320$ , 87.9%).

### Findings

#### Variables description

The favourite types of food referenced by children were pasta (13.4%), meat (8.8%), apples (8.8%), tomatoes (6.3%) and lettuce (6.3%). On the other hand, among the most undesired types of food, children selected fish (16.2%), soup (13.2%), tomatoes (12.6%), onions (10.7%), milk (9.6%), meat (8.5%) and salad (6.8%) (table 1).

Preschoolers showed high levels of knowledge regarding food categorization (92.3%), good sleeping habits (90.1%) and good physical activities habits (94.0%) (table 2).

#### Variables association

BMI ( $\text{kg}/\text{m}^2$ ) and BMI (WHO Z-score) were compared with nutrition/food, sleeping and physical activities good habits knowledge (correct vs. incorrect answers). BMI ( $\text{kg}/\text{m}^2$ ) was calculated according to the standard formula ( $\text{weight}/\text{height}^2$ ). BMI (WHO Z-score) were based on WHO recommendations (Onis & Lobstein, 2010) for five progressive intervals based on standardized BMI scores. Table 3 showed significant differences for sleeping habits knowledge with lower BMI ( $\text{kg}/\text{m}^2$ ) for children that gave correct answers ( $M = 16.35$ ,  $SD = 2.04$  vs.  $M = 17.62$ ,  $SD = 2.37$ ).

The association of BMI ( $\text{kg}/\text{m}^2$ ) with the knowledge of good sleeping habits was performed by means of logistic regressions. Crude OR showed higher risk of incorrect answers for children with increased BMI ( $\text{kg}/\text{m}^2$ ) (OR=1.26, 95% CI=[1.05-1.52]).

#### PRESCHOOLERS NUTRITION/FOOD PREFERENCES

1

Type of preferred food	n (%)	Type of undesired food	n (%)
Pasta	49 (13.4%)	Fish	59 (16.2%)
Meat	32 (8.8%)	Soup	48 (13.2%)
Tomatoes	23 (6.3%)	Tomatoes	46 (12.6%)
Lettuce	23 (6.3%)	Onions	39 (10.7%)
Rice	18 (4.4%)	Milk	35 (9.6%)
Fruit	18 (4.4%)	Meat	31 (8.5%)
Potatoes	15 (4.1%)	Salad	25 (6.8%)

#### PRESCHOOLERS NUTRITION/FOOD, SLEEPING AND PHYSICAL ACTIVITIES GOOD HABITS KNOWLEDGE

2

Correct responses	n (%)
Nutrition/Food	337 (92.3%)
Sleeping	329 (90.1%)
Physical activities	343 (94.0%)

#### BMI COMPARISON REGARDING NUTRITION, SLEEPING AND PHYSICAL ACTIVITIES GOOD HABITS KNOWLEDGE

3

Knowledge	BMI ( $\text{kg}/\text{m}^2$ )			BMI (WHO Z-score categories) [1-5]		
	Correct answer	Incorrect answer	p-value (t-test)	Correct answer	Incorrect answer	p-value (MW-test)
Nutrition/food	16.41 (2.08)	16.67 (2.02)	$p = .704$	2.0 (1.0)	2.0 (1.0)	$p = .958$
Sleeping	16.35 (2.04)	17.62 (2.37)	$p = .012^*$	2.0 (1.0)	2.5 (2)	$p = .050$
Physical activities	16.42 (2.09)	16.79 (2.00)	$p = .418$	2.0 (1.0)	2.0 (1.0)	$p = .521$

NOTE: \*  $p < .05$ ; BMI ( $\text{kg}/\text{m}^2$ ) results presented as M (DP); BMI (WHO Z-score) presented as Mdn (IQR)

CRUDE AND AOR FOR SLEEP KNOWLEDGE (CORRECT/INCORRECT ANSWER) RELATION WITH BMI (KG/M <sup>2</sup> )		4
Sleep knowledge (risk for incorrect answer)	BMI (kg/m <sup>2</sup> )	OR (95% CI)
OR	1.26 (1.05-1.52)*	
aOR	1.33 (1.07-1.69)*	

NOTE: \* significant result

CRUDE AND AOR FOR SLEEP KNOWLEDGE (CORRECT/INCORRECT ANSWER) RELATION WITH PARENTS EDUCATION			5
Education <sup>a</sup>	OR (95% CI)	aOR (95% CI)	
Low	8.21 (1.85-35.55)*	4.95 (0.88-27.97)	
Medium	1.36 (0.41-4.50)	1.06 (0.30-3.75)	
High	1	1	

NOTES: <sup>a</sup> maximum level among father and/or mother; \*significant result.

Adjusted OR (aOR) were calculated considering the confounders gender, birth weight, mothers' BMI, pregnancy time and parents highest degree of education. Again, children with increased BMI showed more risk of poor knowledge regarding good sleeping habits (aOR=1.33, 95% CI=[1.07-1.69]) (table 4).

Next, we analysed the association of nutrition/food, sleeping and physical activities good habits knowledge (correct vs. incorrect answers) with parent's education level. We considered basic education as any degree bellow the 9th grade, medium education as degrees between the 9th and 12th grade and high education as university degrees. Overall, parent's education levels ranged from basic to high education. No illiterate parents were found. We considered the highest grade among parents as the aggregate level of education

Chi-square significant differences were found when associating parents' highest education degree with the knowledge of good sleeping habits (p = .008), but not with nutrition/food (p = .173) or physical activities (p = .763). Hence logistic regressions considered only the association between knowledge of good sleeping habits and parents education. Adjusted OR (aOR) were calculated considering the confounders gender, birth weight, mothers' BMI, children's' BMI and pregnancy time. Children's whose parents were low educated showed increased risk of incorrect answers regarding knowledge of good sleeping habits (OR = 8.21, 95% CI = [1.85-35.55]). Significance was lost when adjusting for confounders (aOR = 4.95, 95% CI = [0.88-27.97]) (table 5).

Finally, no significant differences were found when association children's responses regarding good sleeping habits and parents response related with their children sleeping habits (p = .744).

### Discussion

This study aimed to contribute for determining the level of knowledge regarding nutrition and food in preschoolers and assess the contribution of a game for nutrition/food knowledge evaluation in a sample of children attending preschool from a metropolitan area of Oporto city in Portugal. Moreover its scope was also to bring some contribution for the study of the relation of BMI and with knowledge regarding nutrition/food and god habits of sleep and physical activity.

In our sample food preferences varied from carbon hydrates such as pasta to protein (meat), fruit (apple or tomatoes) and vegetables (lettuce). On the other hand, fish was the most undesirable type of food, followed

by soup, tomatoes and onions. These results have some respawn with similar studies<sup>4,12</sup>. In our sample of pre-schoolers there was evidence of high levels of knowledge regarding nutrition/food categorization, but also good sleeping and physical activity habits. Our results are corroborated by other studies like Dias et al. (2016) study, in which children aged 4-6 years old were able to learn and choose in favour of healthy foods<sup>10</sup>. These authors found an important percentage of children aged 4-6 that included fruit and vegetables as their favourite types of food. Similar results were found by Tatlow-Golden et al. (2013) whose conclusions advocate in favour of meaningfully identification of healthy foods by pre-schoolers<sup>4</sup>. Also in the study of Holub and Musher-Eizenman (2010) children with at least 3 years old were capable of "createing" healthy and unhealthy meals in which healthy meals had, in average, significantly less fat and more fruit and vegetables, compared to unhealthy meals<sup>14</sup>. In the study of Nguyen and Murphy (2003) that assessed nutrition knowledge of children with 4 years old results showed significant proportion of correct answers when categorizing foods into healthy or unhealthy categories<sup>15</sup>.

In our study we found an important relation between knowledge of good sleeping habits and BMI. Children with increased BMI showed more risk of poor knowledge regarding good sleeping habits. These results are corroborated by other studies like Cappuccio et al. (2008)<sup>20</sup> and Van Cauter & Knutson (2008)<sup>21</sup>.

We didn't found a relation between nutrition/food knowledge and BMI, contradicting studies like Pyo and Kang (2014)<sup>13</sup> and Grosso et al. (2012)<sup>8</sup> that described a relation between BMI and nutritional knowledge. Peters et al. (2014) found decreased BMI scores in children with healthier habits, compared with other children<sup>6</sup>. In Portugal Durão et al. (2014) as also found a relation between preferences and

consumption for energy-dense foods with increased BMI<sup>22</sup>.

Finally we found a relation between parents' low education and children's poor knowledge regarding good sleeping habits. This result as respawn in the studies of Cappuccio et al. (2008)<sup>19</sup> and Van Cauter & Knutson (2008)<sup>20</sup> that also established a relation between parent's education and children's sleeping habits. Other studies point out the existence of a relation between socioeconomic and education status and the ability do understand the concepts of nutrition/food (Tatlow-Golden et al., 2013), what can be considered as adjacent to educational level<sup>4</sup>.

### Conclusion

This study goals were to contribute for determining the level of knowledge regarding nutrition and food in pre-schoolers and the importance of educational strategies, such as gaming, for evaluation nutrition/food knowledge. It also intended to add some contributions to the study of the relation between nutrition/food knowledge and BMI and also of sleep and physical activity knowledge of good habits and BMI.

Food preferences were mainly carbon hydrates (pasta), protein (meat) and also some fruits and vegetables. The most undesirable type of food was fish, followed by soup, tomatoes and onions. Curiously tomatoes were simultaneously selected as one of the favourite types of food. Regardless of the food preferences, most children were able to categorize correctly different types of food, after engaging a magnet game designed to promote knowledge, revealing good nutrition/food knowledge. These results were extended to knowledge regarding good habits of sleeping and physical activity.

In this study we found an association between knowledge of good habits of sleeping and BMI. Preschoolers with higher scores of BMI showed less knowledge of good

sleeping habits, even in the presence of confounder variables. Children's poor knowledge regarding good sleeping habits was also associated with parents' low education. On the other hand no association was found between knowledge of nutrition/food or knowledge of good habits of physical activity and BMI or parents' education. Based on these results future intervention programs can focus not only in nutrition/food knowledge but also in sleeping habits, since they can be related with higher scores of BMI. Nursing practices could also include more interventions regarding not only the importance of food and nutrition, but also information related to sleeping habits, since they were shown to be related with BMI.

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# Relation of breastfeeding with type of family and parents education

## Summary

Breastfeeding is an important strategy to provide all-around care for newborns during the first six months of life. It has the power to prevent early mortality, malnutrition and obesity of the child and also prevent some diseases and contribute for faster recovery of the mother. Moreover it contributes decisively for the establishment of successful bond between the mother and the child.

The purpose of this study was to contribute for the study of the relation of breastfeeding with parent's type of family and education.

An observational, cross-sectional, quantitative study was conducted with 364 children's attending preschool from a metropolitan area of the norther region of Portugal and their parents.

Results showed an overall breastfeeding proportion of 88.9%, regardless of the duration.

Considering duration, results showed that only 38.6% of the children were breastfed for a period equal or higher to six months, that is WHO's recommendation. Adjusted logistic regressions showed that the risk of not breastfeeding was associated with non-nuclear families (aOR = 3.19) and other types of families (aOR = 4.36). Regarding education, significant associations were found concerning mothers low education (aOR = 8.39) and both parents low education (aOR = 10.98).

No relation was found between breastfeed duration and education on overall, or considering the type of family.

KEYWORDS: BREASTFEEDING; TYPE OF FAMILY; EDUCATION.

## Introduction

Breastfeeding is one of the best strategies to provide all-around care for children in the early stages of their life<sup>1-3</sup>.

According to World Health Organization recommendations children should be breastfed exclusively for the first 6 months and gradually introduce other kinds of food in their diet since then<sup>4</sup>. Some studies have shown that breastfeeding is a good way of preventing malnutrition and obesity, among other problems<sup>5-6</sup>.

Breast milk nutrition strategy has the potential to prevent early childhood mortality for 800,000 children's bellow the age of five all around the world<sup>7</sup>.

Breastfeeding as also benefits for the mother, since it leads to faster post-delivery recovers and reduces the incidence of some chronic diseases<sup>8</sup>. Along with that it also provides a certain protection against a new pregnancy (during the breastfeed period) and for diseases like breast cancer and hyper-

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cholesterolemia<sup>9</sup>.

Moreover, breast feeding strengthens the found between mother and child, providing a solid contribution for children's socioemotional development<sup>2</sup>.

According to Rollins et al. women's breastfeeding behavior is influenced by personal attributes such as age, weight, type of family and education<sup>2</sup>.

There is some evidence of poor adherence to breastfeeding with non-nuclear types of families<sup>10</sup> but it remains controversial, as it has not been consistently replicated<sup>11</sup>.

On high income countries lower education has been associated with reduced odds of breast-feeding<sup>3,12-13</sup>. Despite that, in Portugal there is no evidence of a consistent relation between these variables<sup>14</sup>.

This study aims to contribute for the investigation of the relation between breastfeeding and parents levels of education in Portugal. It also aims to contribute for the study of the relation between breastfeeding and some types of families found in Portuguese reality.



## Research questions

Is there a relation between breastfeeding and parent's type of family and education?

## Purpose of the study

This study attempts to contribute for the study of the relation of breastfeeding with parent's type of family and education in a sample of children attending preschool from a metropolitan area of Oporto city in Portugal.

Accordingly, the following objectives were delineated:

- Characterize the sample studied by biographical data collection.
- To analyze the relation between breastfeeding and type of family.
- To analyze the relation between breastfeeding and education.

## Research methods

Observational, cross-sectional and quantitative study with a population composed by children attending preschool. Data was collected from September 2016 to February 2017 by used of a questionnaire and consisted in a non-probabilistic sample of 364 children's and their parents regarding 22 classes of six different school establishments from the metropolitan area of Oporto city in Portugal. Inclusion criteria were children attending preschool without special educational needs, that participated in the anthropometric assessment and whose parents agreed to participate in the study by signing informed consent.

## Instrument and procedures

Instrument was a questionnaire, adapted from the original study of Sancho<sup>15</sup> and addressed socio-demographics, anthropometric data and breastfeeding variables such as presence and duration. The study and questionnaire were approved by the ethical committee of Instituto de Ciências Biomédicas Abel Salazar (ICBAS). After approval, a total of 22 meetings (one per class) occurred in the presence of parents/tutors and the kindergarten teacher. After explaining the study, the parents that agreed to participate signed the informed consent and received an open envelop with the questionnaire. Afterwards, filled questionnaires were delivered to the kindergarten teacher or the researcher.

## Statistical analysis

SPSS (version 24) (IBM Corporation, 2016) was used to perform statistical analysis<sup>15</sup>. Descriptive statistics were presented as means (M) and standard deviations (SD) for quantitative variables and frequencies (n) and percentages (%) for categorical variables. Percentages were adjusted for missing va-

lues always totalizing 100%. Missing values were discharged separately for each analysis. Crude and adjusted odds ratios (OR) were calculated via logistic regressions for determining the risk of not breastfeeding regarding type of family and parents education. Statistical significance was based on the analysis of the 95% confidence interval (CI) for the OR. Significance was considered if 1 was not included in the CI.

## Sample

We assessed a total of 364 children, from 2.75 to 6.67 years of age ( $M = 4.48$ ,  $SD = 0.91$ ). Birthweight ranged from 1.32 kg to 4.15 kg ( $M = 3.16$ ,  $SD = 0.50$ ) and current BMI ranged from 9.42 to 24.09 ( $M = 16.44$ ,  $SD = 2.08$ ). Regarding family status, 314 (86.4%) were from nuclear families with/without brothers, 32 (8.8%) from monoparental families and 18 (4.9%) from families in which the mother or father lived with other elements (e.g. partners, uncle/aunt, grandparents). Because only three mothers/fathers reported to live with new partners they were included in this last group. Mother's age ranged from 19 to 51 years old ( $M = 34.51$ ,  $SD = 5.43$ ) and father's age ranged from 22 to 56 years old ( $M = 36.94$ ,  $SD = 5.73$ ). Questionnaire respondents were in the vast majority mothers ( $n = 320$ , 87.9%).

## Findings

### Variables description

Table 1 show results for parent's education regardless of their housing status (i.e. living or not with children) and including this variable. We considered basic education as any degree bellow the 9th grade, medium education as degrees between the 9th and 12th grade and high education as university degrees. Overall, parent's education levels ranged from basic to high education. No illiterate parents were found. Medium education was the most frequent degree among fathers (66.1%), mothers (61.2%) and when consi-

PARENT'S EDUCATION EXCLUDING/ INCLUDING HOUSING SITUATION AND QUESTIONNAIRE RESPONDENT

1

Excluding housing situation	Education n (%)		
	Low	Medium	High
Father (n = 336)	57 (17.0%)	222 (66.1%)	57 (17.0%)
Mother (n = 358)	25 (7.0%)	219 (61.2%)	114 (31.8%)
Both <sup>a</sup> (n = 355)	19 (5.4%)	212 (59.7%)	124 (34.9%)
Including housing situation			
Enquired (n = 358)	25 (7.0%)	223 (62.3%)	110 (30.7%)
Partner (n = 336)	57 (17.0%)	218 (64.9%)	61 (18.1%)
Both <sup>a</sup> (n = 355)	19 (5.4%)	212 (59.7%)	124 (34.9%)

NOTE: <sup>a</sup> maximum level among father and/or mother; includes monoparental and other types of families

**CRUDE OR FOR BREASTFEEDING (YES/NO) RELATION WITH TYPE OF FAMILY 2**

Type of family	Breastfeeding		OR (95% CI)
	No	Yes	
Nuclear	29 (9.4%)	281 (90.6%)	1
Non-nuclear	11 (22.0%)	39 78.0%	2.73 (1.27-5.91)*
Monoparental <sup>a</sup>	6 (18.8%)	26 (81.3%)	2.24 (0.85-5.88)
Other	5 (27.8%)	13 (72.2%)	3.73 (1.24-11.20)*

NOTES: <sup>a</sup> 31/32 mothers; \*significant result

**CRUDE OR FOR BREASTFEEDING (YES/NO) RELATION WITH EDUCATION FOR GLOBAL AND NUCLEAR FAMILIES 3**

Education	Parent(s) OR (95% CI)		
	Father	Mother	Both <sup>a</sup>
<i>All types of families</i>			
Low	2.16 (0.61-7.66)	4.64 (1.62-13.28)*	6.42 (1.07-19.92)*
Medium	1.52 (0.50-4.58)	0.94 (0.43-2.04)	1.12 (0.52-2.40)
High	1	1	1
<i>Nuclear families</i>			
Low	1.99 (0.55-7.25)	8.49 (2.54-28.33)*	11.25 (3.05-41.53)*
Medium	1.26 (0.41-3.88)	1.00 (0.40-2.47)	1.22 (0.50-2.99)
High	1	1	1

NOTES: <sup>a</sup> maximum level among father and/or mother; \* significant result.

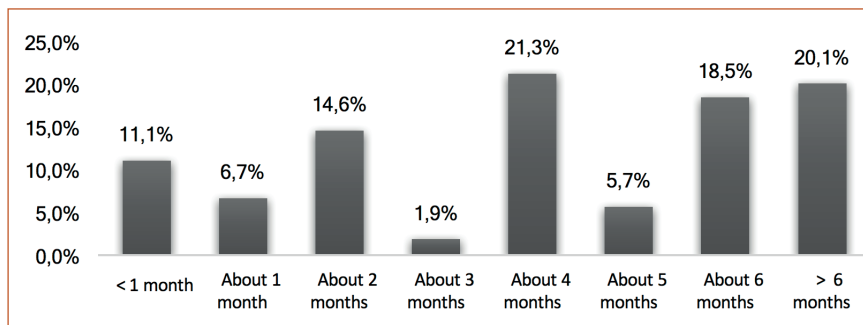


Figure 1. Duration of breastfeed (n = 321)

**CRUDE OR FOR BREASTFEEDING (YES/NO) RELATION WITH EDUCATION (MOTHER/FATHER) FOR NUCLEAR FAMILIES 4**

Education	OR (95% CI)
Both low (n = 16)	8.36 (1.87-37.43)*
Father low – mother medium (n = 39)	0.28 (0.03-2.61)
Father low – mother high (n = 2)	-
Father medium – mother low (n = 6)	3.25 (0.27-39.05)
Both medium (n=151)	1.04 (0.32-3.37)
Father medium – mother high (n = 64)	0.72 (0.17-3.07)
Father high – mother low (n = 0)	-
Father high – mother medium (n = 12)	-
Both high (n = 44)	1

NOTE: \* significant result

dered the top grade between both parents (59.7%). The highest percentage of low educated people was found among fathers (17%); on the other end the highest percentage of high educated people was found among mothers (31.8%). Very similar results were found when considered the person that answered the questionnaire and responses about actual partner. No significant differences were found between groups. These results were expected because most of the respondents were mothers and most of the family types were nuclear.

Most of the children were breastfed (88.9%). Breastfeed duration ranged from less than one month (11.1%) to more than six months (20.1%). A four month duration (21.3%) was the most frequent period of breastfeed; 38.6% had a breastfeed duration equal or higher to six months (figure 1).

**Variables association**

Regarding the association between the type of family and breastfeeding we considered nuclear families the ones in which both parents lived together with/without other elements. All other types of families were considered non-nuclear. We divided non-nuclear families into monoparental (only one of the parents living with the children) and other types of families (mother or father living with other elements, such as partners, uncle/aunt, grandparents). OR were calculated considering nuclear families as reference category. An increased risk of not breastfeed was found for non-nuclear families (OR = 2.73, 95% CI = [1.27-5.91]). A more thorough analysis found that this risk was mainly attributed to families categorized as other type (OR = 3.73, 95% CI = [1.24-11.20]). Despite no significant differences were found for monoparental families a tendency for risk of not breastfeed was also observed (table 2).

When considering the relation between breastfeeding and parents

education global results, considering all types of family and high education as reference category, we found increased risk of not breastfeeding for aggregates with low educated mothers (OR = 4.64, 95% CI = [1.62-13.28]), despite father's education, and for aggregates in which both parents were low educated (OR = 6.42, 95% CI = [1.07-19.92]). The risk of not breastfeeding for aggregates with low educated mothers (OR = 8.49, 95% CI = [2.54-28.33]) and for aggregates in which both parents were low educated (OR = 11.25, 95% CI = [3.05-41.53]) was more prominent when considering only nuclear families (table 3).

No results were presented for non-nuclear families because no significant differences were found for father, mother or both parents education regarding the risk of not breastfeeding.

Next, we selected nuclear families only and calculated crudes OR for the risk of not breastfeed regarding discriminated levels of education. Considering high education for both parents as reference category we found increased risk of not breastfeeding for aggregates with low educated parents (OR=8.36, 95% CI=[1.87-37.43]). The presence of other degrees of education higher than low, for any of the parents removed significance status (table 4).

Finally, adjusted OR (aOR) were calculated for all logistic regression models. Selected confounders were children's gender, birth weight, actual BMI and mother's BMI and pregnancy time. Increased risk for non-nuclear families (compared with nuclear families) maintained its significance in the presence of confounders (aOR = 3.19, 95% CI = [1.38-7.39]); similar results were found for other types of families (aOR = 4.36, 95% CI = [1.36-14.03]).

Considering nuclear families only, the relation between breastfeeding (yes/no) and parents education (low/medium/high) was significant, even in the presence of the confounders. Increased risk of not breastfeed was found for low educated mothers (aOR = 8.39, 95% CI = [1.93-30.22]) and low educated parents (both) (aOR = 10.98, 95% CI = [2.30-52.46]). The relation between breastfeeding (yes/no) and parents education (paired, e.g. low-low; low-medium) was also significant in the presence of the confounders (aOR = 7.13, 95% CI = [1.27-40.07]).

No relation was found between breastfeed duration and education on overall, or considering the type of family. Despite that a slight trend was found with reduced breastfeed duration in higher levels of education.

## Discussion

This study aimed to bring some contributions to the establishment of the relation between breastfeeding and the variables type of family and parent's education.

In our sample, 38.6% of the children were exclusively breastfeed for at least six months, lower than the 89% recommended by WHO<sup>16</sup>, but high than other studies like Holowko et al. (2016) with 15%<sup>13</sup>.

In our sample, non-nuclear families had increased risk of not breastfeed, corroborating results found in Horwood and Fergusson<sup>17</sup> but not in Dubois and Girard<sup>11</sup>. Moreover, in our sample, higher risk was found for families categorized as other type. These families were composed by mothers or fathers living with other elements, such as partners, uncle/aunt, grandparents, and/or others. Hence, in our study, family structure seems to be an important issue for breastfeeding initiation.

Regarding education we found higher risk of not breastfeed for low educated mothers and when both parents had low levels of education suggesting that mother's education has more impact for breastfeeding behaviour. Similar results were found in the studies of Holowko et al.<sup>13</sup> and Napoli, Lallo,

Pezzotti, Forastiere and Porta<sup>18</sup>, but with lower ORs, OR = 2.09 (95% CI = [1.49-5.19]) and OR = 2.78 (95% CI = [1.67-2.62]), respectively. By the other hand in a Portuguese study no association was found between breastfeeding and parent's education, mother or father<sup>14</sup>.

In this study, no relation was found for education and the duration of breastfeeding, corroborating results from the study of Olímpio, Kochinski and Ravazzani<sup>19</sup>. Different results were found by Holowko et al.<sup>13</sup> where low educated women had higher risk of not breastfeed for at least six months. In the same way, Olson and Hayward<sup>20</sup> found that higher education levels of parents was associated with longer duration of breastfeeding. On the contrary Dandekar, Shafee and Kumar<sup>21</sup> found that higher educated mothers were the ones with earlier drop outs concerning breastfeed in the first six months. Hence, relation between breastfeed duration and education seems to remain unclear.

## Conclusion

This study had the purpose of contribute for the study of the relation of breastfeeding with parent's type of family and education in a sample of children attending preschool from rural areas of the north of Portugal. The proportion of children that were exclusively breastfeed up to six months was higher than the one found in other studies, but lower than WHO recommendations. Non-nuclear families were associated with higher risk of not breastfeeding, in particular families composed by mothers or fathers living with other elements, such as partners, uncle/aunt, grandparents, and/or others, categorized in this study as other types of families. Low educated parents, in particular low educated mothers were associated with higher risk of not breastfeeding, but not with duration of breastfeeding.

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### Tasks

- 1 Safety & Quality in Health Care**  
Indicators assessment
- 2 Nurses' needs**  
Identification
- 3 Supervision in Clinical Nursing**  
Model implementation
- 4 Outcomes**  
Assessment

### Execution

01-07-2017 until 03-03-2019

### Overall budget

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### FEDER grant

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### Research team

- (PI) Luís Carvalho
- » Cristina Barroso
- » Fátima Pinho
- » Maria Osório
- » Ana Paula Teixeira
- » Maria Aurora Pereira

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# A mentorship project: promoting emotional competence in nursing students

## Summary

**INTRODUCTION.** Young students' transition to higher education is a particularly challenging and a stressful event, likely to trigger emotions that can potentially affect their adaptation to a new and more demanding learning environment. This issue has been a focus of growing interest for researchers involved in mentorship programmes developed by higher education institutions, which are intended to contribute to a healthy integration of students and, consequently, promote academic inclusion and success. This project intends to understand the role of mentorship in promoting emotional competence and well-being of nursing students.

**METHODS.** A research project of qualitative nature, with an analytical focus, using a sociopoetic approach. Participants will be nursing professors and students (second-year of the undergraduate degree) recruited from several public and private, Portuguese and Brazilian, nursing schools. The methodological procedure includes the creation of negotiation and data production workshops, data content analysis, counter-analysis workshop and socialisation of data production.

**CONCLUSIONS.** We hope with this study to strengthen the relationship established with the mentor may constitute a healthier and more adaptative emotional experience, and potentiate generalization to other social contexts, improving daily life interpersonal skills and promoting emotional competence, essential to personal and professional development. This study will enable the development of the mentorship process in the higher education institutions involved in this type of project, grounded on the mentorees' abilities to learn easily, to increase their socialisation and their networks, to develop feelings of organizational citizenship, to potentiate satisfaction with work and career, to improve their self-efficacy and reduce their stress levels.

**KEYWORDS:** MENTORSHIP; NURSING; STUDENTS; EMOTIONS; PROFESSIONAL COMPETENCE.

## Introduction

Newly admitted higher nursing education students face a highly different environment from that of high school, often triggering different emotions and high levels of stress<sup>1</sup>. The academic environment and culture are unique for each higher education institution. Students have to face new routines and rules, experience changes in their lifestyles and must be able to respond to the increasing demands typical of modern societies' contexts and

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of the labour market<sup>2,3</sup>. Thus, it is common for these students to experience anxiety, as they are constantly striving for success<sup>4</sup>. In addition, feelings of isolation, low self-esteem and frustration add more complexity to these situations<sup>3</sup>.

Concerning the emotional experience of nursing students in clinical practice, a study conducted by Diogo, Rodrigues, Sousa, Martins and Fernandes<sup>5</sup> identified the emotionally intense situations requiring a particular approach on emotional support: integration period, facing suffering and death of a patient, construction of the relationship with the patient, nursing procedures, the emotional condition of the student, conflicts, and assessment. The integration period is one of the most mentioned events, during which experiences are characterized by concern, anxiety, insecurity/lack of confidence, sadness, and also fear and stress. These emotionally intense experiences of stress, emotional burnout, often disturbing and with a negative emotional connotation are likely to harm the health and inter-

nal balance of the students, particularly when they are sufficiently mature and their personality traits enable them to relate and feel empathy towards the persons involved.

These enduring emotionally intense situations can lead students to become highly depressive, obsessive-compulsive, and even develop psychotic psychopathology. In a study performed by Sequeira, Carvalho, Borges and Sousa<sup>6</sup>, findings suggest that feelings of sadness, tension, anxiety, nervousness, and depression are present amongst nursing students, confirming the need for targeted mental health promotion programmes.

The mentorship programmes developed in higher education institutions contribute to a healthier integration of students and, consequently, to a better social and academic success. Mentorship contributes to the development of positive learning perceptions by students<sup>7</sup>. The concepts of tutorship and supervision are different from mentorship, as the latter refers to a person who helps other understanding the system and offers guidance empowering the other to be successful within the organization<sup>8</sup>. Orientation is comparable to leadership, management and learning<sup>9</sup>. Orientation is part of the leader's role, focused on helping the other grow, in this case, enabling students to develop their own academic or professional path<sup>8,10</sup>. The mentor should nurture the students so that they are able, on the one hand, to more efficiently reach their potential<sup>8,11</sup> and on the other hand to facilitate the development of educational and academic competencies<sup>3,8</sup>.

In sum and in what education is concerned, a tutor is a person who contributes to learning within a philosophy of teaching. The mentor has a more extended role, less focused on the teaching itself and more directed at the personal and professional guidance of the student as a whole<sup>12,13</sup>.

If the mentor acts as a facilitator, it is most likely that the students come to him/her for guidance<sup>14</sup>. The positive outcomes of the mentorship programme will provide students with a sense of fulfillment, self-confidence and

encouragement to repeat the same strategy in other similar situations throughout their academic path and personal life<sup>15</sup>. The mentor can work with the students through individual action plans to enhance self-esteem, as a way of increasing resilience. By working with the student, the mentor can help and provide guidance on available resources. Students need to feel valued and the reason why they do not often access the academic resources is that they do not know they exist or because of lack of information on confidentiality issues<sup>16</sup>.

Mentorship seems to be a beneficial approach to manage inadequate academic skills, lack of social and academic resources and anxiety faced by nursing students. Mentorship can also reduce school dropouts and increase success rates in nursing students<sup>17</sup>. The idea underlying a mentorship programme is to provide nursing students with an experienced nursing professor able to help them cope with the various transitions they will experience until they become nurses. The experienced mentor can work both as a role model and instructor and, especially during the first six weeks, work very closely with the student. However, this should be a long-term relationship, developed through four stages in time, from several months to several years<sup>18</sup>.

Thorpe and Kalischuk<sup>19</sup> developed a mentorship model that focuses on assistential aspects involved in the mentorship relationship, promoting trustworthy and open interactions between the mentor and the student (figure 1). This model identifies two contexts: macro and micro. The macro domain focuses on external factors that have an impact on mentorship relationship and includes social, political, and cultural aspects of the institution where it occurs. The micro domain refers to intrinsic factors of the relationship, such as the time,

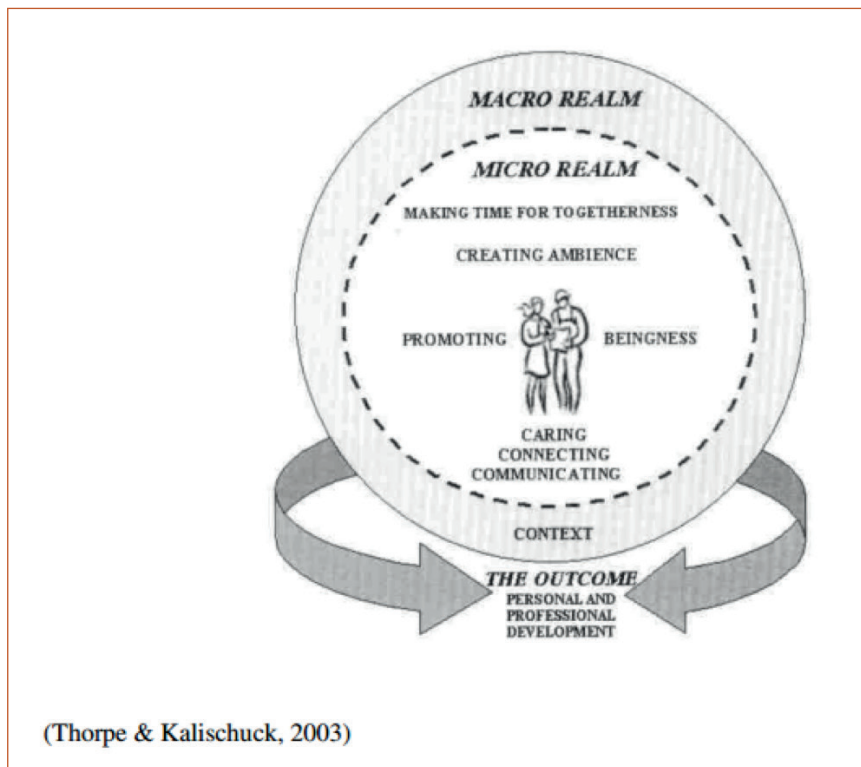


Figure 1. Mentorship model according to Thorpe & Kalischuk<sup>19</sup>

the environment in which the relationship grows, presence, as well as caregiving, connection, and communication between mentor and mentoree.

The original concept of mentorship is a transformational relationship through which a person (mentor) influences the cognitive, social, or emotional development of another person (mentoree). Mentorship brings significant benefits for all parties involved: mentor, mentoree and institution. Mentorees can learn easier, enhance their socialisation processes, their networks, their sense of organisational citizenship, satisfaction with work and self-efficacy and also reduce stress levels.

Nursing education should not be limited to technical and scientific progress, but also focus on the student's personal development by empowering him/her with all the skills, particularly the relational competence<sup>20</sup>; it is not possible to isolate the cognitive, social, affective and emotional dimensions when we intend to clarify the factors that mediate the learning nursing care process.

The emotional dimension, like the others, is also essential for nursing students striving for success, going through complex experiences, thoughts, and emotions, which they need to learn how to manage. The analysis on care as a relational process, embedded with emotions and feelings<sup>21</sup> becomes an exciting goal, because every act of caring triggers an emotional response<sup>22</sup>. According to Watson<sup>23</sup>, emotions are a key-element to establish the connection of the nurse with the Being (body and soul) of the patient. Thus, this relationship becomes an enriching experience for both nurse and patient alike, helping them to grow and mutually learn. In this way, nursing care is a human-to-human process of caring<sup>23</sup>, with an intense emotional component.

The caregiving experience, in different clinical contexts, places nursing students in close connection with patients, establishing a relationship that implies the mobilisation of their emotions, which can often trigger discomfort feelings. Caregiving, particularly in end-of-life, can highly increase the students' need for emotional<sup>24</sup>. These experiences bring the student a sense of powerlessness, inability to manage their own emotions, as well as feelings of abandonment and guilt<sup>24</sup>. Thus, monitoring the emotional needs of students is fundamental, and the mentor working closest to the student, plays a key-role in identifying these needs and in understanding that emotional responses may not be solely confined to relationships with patients, but also be a result of relationships established with colleagues and families<sup>25</sup>. Notwithstanding, these students' experiences and needs require educators to work on the development of emotional competencies. Bisquerra<sup>26</sup> defines emotional competence as the set of knowledge, skills, abilities and attitudes required to understand, express and appropriately balance the emotional phenomenon.

This emotional competence can be enhanced through a mentorship relationship. Students that have close and long-lasting mentorship relationships are very likely to achieve more positive academic outcomes, to build stronger social relationships, and show higher self-esteem. These relationships help students in their growing and learning processes increasing their resilience. The mentors' guidance also enables students to regulate their own external emotions. By providing students with help and the opportunity to engage in discussions, mentors are themselves a resource and an external source for the management of emotions. Through co-regulation of emotions, mentors are able to help students integrate different ways of adapting to the emotions they experience<sup>27</sup>.

### Problem statement

Nursing students often experience emotional burnout and disruptive experi-

ences potentially harmful for their health and internal balance, alongside with having to deal with their own internal frailties, conditioned by their personal life processes and personality development. Intense and negative emotional experiences are very likely to undermine the academic performance of nursing students, as well as the teaching-learning process. This study set out to investigate the mentorship strategies targeted at the orientation and support of nursing students during their undergraduate degree courses, for the promotion of their emotional well-being and resilience, with the purpose of developing emotional competencies, which are essential for the academic success and for the future professional career.

The purpose of this study is to contribute to the design of a mentorship programme and its implementation in the undergraduate degree in nursing, aligned with the higher education institutions involved.

### Methods

This is a research project of qualitative nature, with an analytical focus, using a sociopoetic approach. Sociopoetics provides a different approach to the experience of scientific research as a dialogic form of research, so that the object of study is not dissociated from the reality of the research group. It is considered a social practice of knowledge production that emphasises the importance of the body in the construction of the imaginary, which is the basis for abstraction; the importance of dominated cultures, categories and emerging concepts; the role of artistic creativity in knowledge construction; the role of the research subjects as co-responsible for the produced knowledge and the importance of spiritual, human meaning and the forms and content of knowledge<sup>28,29,30</sup>.

Another singularity of sociopoetics is the production of knowledge as a group action. Thus, the involve-



ment of subjects in research is reinforced, from the negotiation of the issue of research to the interpretation/theorisation of data.

The process of a sociopoetics research is divided into production and data analysis workshops by co-researchers, with a duration of 40 hours; after this stage, the facilitator (formal researcher) analyses each technique (at least two techniques are used), searching for categories that translate the group's idea about the theme. After that, the facilitator delivers these data to co-researchers, in a more synthetic, literary, and communicative way, like poetry, for example. That moment is called counter-analysis and allows co-researchers to know, confirm, rectify, re-examine and, especially, oppose to the facilitator's ideas, adding more accuracy to self-reflections. Finally, a philosophical analysis is performed, usually about the analysis<sup>30</sup>.

### Participants

The co-participant subjects of this study will be professors and students from three public nursing schools, one private school and two Brazilian universities. Inclusion criteria were defined: second-year students of the undergraduate degree in nursing, with no other previous degree; students must have attended the first academic year in the same institution. Students and professors that meet the inclusion criteria will be first contacted by telephone and will be invited to participate in the negotiation workshop.

In sociopoetics, research is developed by a group constituted by the facilitator (formal researcher) and co-researchers. The group must include a maximum of twenty co-researchers.

### Procedures

a) The first moment is the negotiation workshop and the creation of the research group. In this workshop, the researchers will present their knowledge production proposal to a possible subject, as well as an explanation on sociopoetics. A "contract of interaction" will be produced, and participants will be asked to sign a written informed consent for recording of sound and image; finally, a generating theme will be negotiated. The facilitator will present the group a "diary of itinerance" where everyone can express their feelings at any time during the sessions, and can assume a poetic form. The researchers will invite the participants to join the research group and to collectively construct knowledge about the generating theme – Mentorship in Nursing.

b) The second moment involves data production workshops. Each workshop will include two moments. During the first one, a relaxation activity is performed, to allow the group to focus on the research question. Next, data production itself begins, through techniques like painting, drawing, collage or by using the research technique "Experience of Geomythical Places"- considering the question: If this higher nursing school was a geomythical place, what would it be like? After daily production, each co-researcher will verbally present his/her production, discussing, and correlating it with the research theme: mentorship in nursing.

c) The third moment is developed with the research group with the analysis and experimentation of data workshop. The plastic material as transcripts will be returned to the research group so that the participants can discuss all the produced material. In this phase, it is expected that the group reflects on all its constitutive elements, what was experienced throughout life and that can now be used as a referential for analysis. Everything that the group produces in this moment of analysis will also be recorded and transcribed into the research report, next to the analysis of the formal researcher. In a second moment, the verbal production of the group is analysed to maximise the possibilities of meaning production. The analysis techniques of verbal mate-

rial proposed by sociopoetics are: classificatory analysis, transversal, and philosophical studies. In the end, the philosophical study is intended to relate the meanings produced by the group with conventional philosophical/scientific thinking, allowing the understanding of points of convergence, complementarity, or opposition<sup>31</sup>.

d) The fourth moment is data counter-analysis workshop in which the researcher will present the analysis performed to the research-group so that the group can assess it, providing an opportunity to accept, change or reject the analysis and propose a counter-analysis.

e) The last moment is the socialisation of research. The researcher will officially end the process and publish the work and will discuss a proposal of socialisation of knowledge that involves the group. It can be a theatrical play, poetry, music, exhibition of plastic production, among others.

### Conclusions

We hope with this study to mentorship is widely regarded as a method that facilitates the development of several life dimensions. The basis of mentorship is a transformational relationship in which an experienced and empathic person, the mentor, guides, supports and influences other, the mentoree, at personal and professional developmental levels, by establishing an interaction, supported by trust and comprehension. Its main focus is not specifically on problem-solving but rather to help students develop the competencies required to meet their goals. This mentorship project is expected to ease the students' integration in the academic life, enhancing their personal and interpersonal development, as well as their autonomy throughout the learning process, and thus maximize the teaching-learning experience.

In this sense, the aim is that the mentors provide moments for dis-

cussion, working directly with the students, guiding them, and facilitate access to the various support resources. These programmes will enable the development of mentorship projects in higher education institutions, improving the mentorees learning processes, enhancing their socialisation, their relationship networks, their sense of organizational citizenship, satisfaction with work and career, as well as self-efficacy and help to reduce stress levels. Similarly, positive outcomes are also expected in the case of the professors involved in these programmes, since they will be able to have more knowledgeable information about their students and therefore work on the definition of new paths, taking into account the students' real expectations, their potential and limitations.

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# Preparing for childbirth: women's look

## Summary

**INTRODUCTION.** Childbirth preparation is a form of health intervention education performed by specialist nurses in maternal health and obstetrics aimed at promoting self-efficacy during labour. In planning an efficient childbirth education intervention, it is essential that nurses know the pregnant women's/couple's expectations on this specific issue.

**OBJECTIVES.** To understand the pregnant women's expectations related to preparation for childbirth.

**MATERIAL AND METHODS.** This was an exploratory, transversal study of qualitative nature where data was collected through interviews, after an informed consent was signed. The Bardin technique was applied to data analysis. A non-probability sample of 224 pregnant women was made, all over 20 years of age, with 28 weeks or more of gestation. The majority of participants possessed an advanced degree, were married or living in a marital situation, and were experiencing their first pregnancy.

**RESULTS.** From an analysis of the interviews, three categories emerged: knowledge, ability, and self-efficacy to deal with labour, and seven subcategories. These results corroborate findings of other researchers who have concluded that couples wish to be informed regarding how to prepare for labour, and that this preparation is relevant when the acquired knowledge helps the pregnant woman or couple make decisions and exercise control over their labour experience.

**CONCLUSION.** The results enabled nurse-midwives to increase their knowledge and understanding of pregnant women's labour preparation expectations and preferences. Knowledge of this variety can assist these professionals in planning effective, quality interventions, which in turn can clearly contribute to gains in health.

**KEYWORDS:** PREGNANT WOMEN; PRENATAL EDUCATION; MIDWIVES; EXPECTATIONS.

## Introduction

This study is part of a larger research developed within the doctoral thesis "Building Trust to Childbirth: Development and Assessment of a Nursing Intervention Programme". The thesis itself comprises several studies.

Maternity and the birth of a child are unique events embedded with doubts, anxiety, and fear, especially when related to a first gestation. These experiences have resulted in the need to develop education programs aimed at preparing a pregnant woman/couple for childbirth. These programs need to fall within the scope of standard health education and need to be focused on strengthening a woman's self-efficacy during labour. This can be accomplished by providing a woman knowledge, and hence confidence in the labour process and the various decisions that it entails.

The woman is entitled to experience labour according to her own beliefs and values. The expectations on the experience of labour are influenced by

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a set of factors related to individual and family dimensions, to past experiences or the experiences reported by close family or friends, and with cultural and societal norms<sup>1</sup>.

For centuries, women experienced the process of giving birth at home. The skills and procedures for a successful birth were passed down from generation to generation, with various family members working in conjunction with the expecting mother to plan not only the delivery, but also the post-delivery actions. The practices surrounding a woman's labour experience were often done in accordance with the community's beliefs and values. Given the experience, knowledge, and support of a pregnant woman's family and community, the mother-to-be was able to gain a level of confidence that allowed her to respond to her body's changing dynamics due to the pregnancy. In an environment such as this, surrounded by women (girlfriends, midwives, or family members) that provided this kind of support, the pregnant woman felt

secure, confident that her labour would be a natural event. However, high rates of maternal and child mortality eventually compelled the transfer of childbirth to the hospital environment, where physicians were the primary caretakers for the birthing process. In this context, women were no longer the sole facilitators. Labour became an experience taking place in an anonymous, lonely, uncomfortable, and frightening place. Often, it became regarded as a disease rather than a normal, physiological process<sup>2,3</sup>.

This change in environment also had a direct bearing on the pregnant woman herself. Whereas before she was active in the full labour process, her role now became secondary and passive, embedded with fear, anxiety and pain<sup>4</sup>. Dick-Read, an English obstetrician, observed women giving birth in hospitals and realized that they felt lonely, stressed, and frightened. They also experienced more pain in childbirth. In an attempt to reduce the perception of pain during labour, Dick-Read began informing his patients about what was going to happen and what they could do ease their child's birth<sup>2</sup>. Dick-Read is considered one of the pillars of Preparation for Childbirth (PFC), and his methods have been utilized as the basis for many of the existing models<sup>5</sup>.

In Portugal, the PFC is enshrined as a right (as outlined in Law 142/99, 31 August), and is part of the pre-natal routine. However, although a right, is the PFC effective? Several authors<sup>6-11</sup> have studied this issue and concluded that there is some scientific evidence that supports the PFC in having a positive effect on an expectant mother's labour experience, especially with regards to the following: providing information on the experience of giving birth (i.e. what a mother/couple can expect), relaxation techniques for managing pain in labour, and encouraging and promoting the active involvement of the couple (to include the involvement of the mother's mate). In summary, the authors concluded that the majority of women consider the PFC useful.

The PFC success depends on how well it is planned and performed according to a pregnant woman's expectations<sup>3</sup>. In view of the limited evidence on this issue among the Portuguese population, and aiming to plan more effective preparation for childbirth sessions, and in an effort to help nurse-midwives design their practices according to the identified needs.

The objective of this study was to analyse pregnant women's expectations for the Preparation for Childbirth sessions.

### Research method

An exploratory, descriptive, transversal study of qualitative nature was conducted aiming to respond to the set objective.

To collect data for this research four questions related to sociodemographic information and participants' pregnancies, and an open question aiming to gather information on their expectations about the preparation for childbirth, were retrieved from a semi-structured interview guide developed for the original study.

Data collection was performed between January 2011 and September 2012 by the nursing team of the Obstetrics Outpatient department of an institution of the northern region of Portugal. Authorization was granted by the Administration Board, the Ethics Committee and by all responsible Service Heads.

In order to minimize differences in procedures among the research team, a meeting was held with all involved elements in which the objective of the study, the instrument for data collection, and information to be delivered to the participants was all presented.

The pregnant women that met the inclusion criteria were informed of

this study's purpose and methods, and were asked to sign a consent form. Confidentiality of information was assured and a 10-minute interview was conducted with each participant. Information gathered from the interviews was transcribed verbatim during the interview, enabling a more precise transcription of the participants' feedback<sup>12</sup>.

According to Bardin<sup>13</sup>, qualitative data was processed based on the analysis of the feedback. This analysis was divided into three phases: organization of original idea, data coding, and creation of categories *a posteriori*. A descriptive and interpretative transcription of patterns was performed. Some parts of the interviews were added to data description and each part is identified according to the coding assigned to the respective interview: e.g. II – Interview conducted with participant 1.

The target population for this study was pregnant women attending the obstetrics consultation. The inclusion criteria set for this non-probability sample were: pregnant with 28 weeks or more of gestation, and interest in attending sessions of preparation for childbirth at the institution where the research was conducted. The exclusion criteria was women under 20 years old.

The sample was comprised by 224 pregnant women, mostly Portuguese (96.4%,  $n = 216$ ), ranging between 20 and 41 years old, average of 31.3 years ( $SD = 4.4$ ), median and mode of 31 years (table 1).

Regarding the participants' education levels, 57.1% ( $n = 128$ ) of them had obtained an advanced degree, and 13.8% ( $n = 31$ ) had completed basic school. The majority of respondents (71.8%,  $n = 161$ ) were married or living in a marital situation.

Concerning the participants' individual pregnancies, the majority of the Portuguese participants were pregnant with their first child (77.7%,  $n = 174$ ), had no children (89.3%,  $n = 200$ ), planned the preg-

## SAMPLE DISTRIBUTION BY NATIONALITY, SCHOOL LEVEL AND MARITAL STATUS 1

		n	%
<b>Nationality</b>	Portuguese	216	96.4
	Angolan	2	0.8
	Brazilian	2	0.8
	French	3	1.6
	Venezuelan	1	0.4
<b>School level</b>	6 years of schooling	6	2.8
	9 years of schooling	25	11.0
	12 years of schooling	65	28.9
	Bachelor's/Undergraduate Degree	107	47.9
	Master's/PhD	21	9.2
<b>Marital status</b>	Married/Living in marital status	161	71.8
	Single	58	26.0
	Divorced	5	2.0

## PREGNANT WOMEN'S EXPECTATIONS ON THE PREPARATIONS FOR CHILDBIRTH 2

Categories	Subcategories
Knowledge	Labour
	Parenthood
Ability	Management of emotions
	Management of coping strategies
	Self-control
Self-efficacy to deal with labour	Self-confidence
	Sharing of experiences

nancy (83%,  $n = 186$ ), started the sessions of preparation for childbirth between 28 and 29 weeks of gestation (62.5%,  $n = 140$ ).

### Findings

After reading the transcribed feedback, three categories were identified in order to analyse the expectations of participants regarding Preparation for Childbirth: Knowledge, Ability, and Self-Efficacy to deal with labour; and Seven Subcategories (table 2).

### Knowledge

Having knowledge about the labour process was deemed by the participants to be one of the most important and relevant aspects of the preparation for childbirth sessions. According to the transcribed responses:

*With the classes, I would like to receive more information on labour, which I can then use as an added value in this phase (I11); I hope I can get all the knowledge that I need (I13) to be more prepared to deal with pain during labour (I44); [...] to get the maximum information for a normal and peaceful labour experience (I80); [...] I intend to enhance my knowledge (I85); [...] I want to get some knowledge about this stage, namely regarding labour [...] (I148).*

Consciousness of the importance of gaining knowledge for this experience can lead to a less painful and more satisfactory experience. It will also encourage a woman to seek out more education, hence enabling her to set more realistic goals for her labour experience.

Some of the participants also emphasized the importance and expectation of gaining parenting knowledge:

*I want to get more information on [...] caring for the baby (I14); [...] to be guided on caring for the newborn (I19); [...] to learn how to alleviate doubts about parenthood (I33); [...] to learn skills on how to be a good mother (I34).*

This is intimately related to a pregnant woman's need to feel competent in the maternal role. According to some of the transcribed responses:

*To be well prepared [...] for parenthood (I10); [...] to be able to be a better mother (I32); to be prepared to care for the newborn (I37); to feel prepared and self-confident in [...] this new stage of life (I38); to learn skills to be a mother, [...] (I41).*

The birth of a child causes significant changes in the life of every human being. This event leads to changes in family roles and a redefinition of what is possible for the mother within her community and in other activities. Parenthood is a developmental transition that, as demonstrated, demands from the new parents different behavioural, emotional, and cognitive responses. These changes mandate adaptation and a reorganization of priorities. For an effective transition to parenthood the parents need to understand and prepare for lifestyle behavioural changes; essentially, they are adopting a new definition of "self". The preparation for parenthood, developed through the pregnancy, is part of the adaptation process to this new

reality. It involves knowledge and skills training at different levels: physical, emotional, cognitive, and social. A woman's purpose in attending preparation for childbirth sessions is primarily to prepare for parenthood. Thus, it is important that the nurse-midwives, responsible for these sessions, help the woman/couple to distinguish the differences of these two interventions, enabling the expecting parents to adjust their expectations appropriately. This is important in guaranteeing the ultimate success of the interventions.

### Ability

One of the goals of the sessions of preparation for childbirth is to empower pregnant women/couples with the ability to deal with labour.

The study revealed that the prevailing reason for women to attend these sessions was so that they would be able to manage their emotions. As demonstrated, learning ways to deal with emotions is an important concern for the participants:

*I would like to learn how to deal with fear (I155); [...] to reduce fear of labour (I186); I hope that these classes help me to overcome fear and anxiety of labour (I165); [...] to overcome anxiety (I186); [...] to reduce anxiety (I194).*

To feel calm before a stressful event allows a person to feel confident in the event's successful outcome. Conversely, anxiety, stress and fear lead to a reduced confidence in a successful outcome. This lack-of-confidence, in turn, limits the ability to adjust and solve problems during the actual event.

A better childbirth experience is also very likely to be attained through an efficient management of coping strategies. According to these responses:

*I hope to learn some relaxation techniques to perform during labour, [...] (I34); [...] to understand and perform correct breathing techniques during labour, [...] (I46); [...] to understand and feel the benefits of the relaxation techniques (I59); I hope to learn how to use breathing techniques during labour (I108); to be able to control pain during labour (I115); [...] to get information on [...] relaxation techniques (I185).*

Participants reported as one of their objectives the need to acquire the ability to use respiratory and relaxation techniques, both commonly used in the management of pain during labour.

According to the CIPE®<sup>15</sup>, self-control can be defined as "necessary measures adopted for self-preservation; to remain active, to deal with basic and intimate needs and perform the activities of daily living" (p. 41). To learn about self-control is another woman's purpose:

*... to work on my self-control [...] (I5); to learn skills for self-control, to be prepared for any unexpected event (I6); I hope that these classes help me to control labour (I17); I would like to know how to control myself during labour (I25); to learn how to keep calm (I31); I intend to train my self-control [...] so that I can have a better labour experience (I230)*

When this goal is achieved, it helps women to receive the greatest levels of satisfaction during the labour experience<sup>9</sup>.

### Self-efficacy

Beliefs by the expectant mother in her ability to successfully give birth is a basis of motivation in the labour process. Well-being and personal fulfilment play important roles in adopting and changing behaviours. If the

person does not believe that actions are effective, the motivation to act or deal with difficulties will be diminished<sup>16</sup>.

Self-confidence was one of the pregnant women's expectations:

*I want to get self-confidence through these classes [...]. (I47); [...] to increase self-confidence so that I can feel prepared for childbirth (I48); with the frequency of classes I want to enhance my self-confidence to deal with labour [...] (I49); [...] to gain more trust (I85); I hope I can apply what I learn into practice (I186); to feel more self-confident (I194); that these classes help me to feel more confident during labour and enable me to decide how to better act [...] (I204).*

Self-confidence in her ability deal with labour helps the woman to feel safe and to believe that she is able to use the strategies she has learned to cope with the challenges of labour, since people tend to choose tasks and activities in which they feel competent and confident. The higher the perception of success, the higher the mental resilience, since beliefs on self-efficacy influence thinking patterns and an individual's emotional responses<sup>17</sup>.

Sharing of experiences is a learning process which also enables the analysis of others' experiences. The respondents reported that they hope to share experiences in the sessions of preparation for childbirth:

*I hope I can share experiences [...] (I52); to learn about the others experiences (I84).*

This shows that participants consider sharing an important activity in building their own confidence and will enhance their ability to deal with labour.

Despite the majority of women reporting realistic expectations, the fact is that some of the participants had unusually high, unrealistic expectations, as transcribed:

*I hope that these classes help me to have a healthy child, [...] and be a great mother (I24); I hope that these classes help me to experience a quicker and non-painful birth (I234).*

Unrealistic expectations lead to a less satisfactory experience and a reduced perception of the quality of care provided. At the sessions of preparation for childbirth it is essential to help mothers-to-be in setting realistic expectations. This will promote more positive experiences and thus help the woman/couple to be better prepared to actively participate in the labour experience.

### Discussion

The expectations are beliefs or ideas about the future, in this case about labour process, influencing the way the person feels, thinks and behaves<sup>14</sup>. Concerning the preparation for childbirth, the participant responses clearly show that pregnant women expected the sessions would allow them to acquire the necessary knowledge and abilities to deal emotionally and physically with labour, helping them to achieve a level of self-confidence to overcome this stressful event, while also enabling them to share these experiences with their peers.

Knowledge of labour is considered an important factor to increase self-efficacy, in creating a more positive childbirth experience, better pain management, and in reducing the fear and anxiety related to childbirth<sup>18-21</sup>. Many authors<sup>3</sup> agree that knowledge is crucial for women to develop self-control<sup>22</sup> and achieve the necessary inner strength for correct decision-making<sup>23</sup>. The respondents expected to gain knowledge and the abilities to deal with labour. This corroborates with several authors' findings that studied the efficacy of PFC classes and concluded that couples wished to gain knowledge and the ability to deal with labour and childbirth<sup>6,9,24,25</sup>.

Self-efficacy is characterized as the central mechanism of actions performed intentionally. Self-efficacy is important in labour, since a woman giving birth who has high self-confidence is able to actively participate in labour. This in-turn enables her to have a better experience and higher levels of satisfaction from this experience<sup>23</sup>. According to a study conducted by Berntson-Shaw et al.<sup>26</sup>, high outcome expectations and self-efficacy encourage the woman to search for knowledge about labour, to set realistic goals, and to learn techniques for pain relief during labour. Participants in this study expected that the sessions of preparation for childbirth allowed them to increase their self-confidence in dealing with labour.

Some of the women reported unrealistic expectations, hoping that sessions would help them to experience a faster, less painful labour, while also increasing their level of parenting competency. These results indicate that it is necessary for maternal health and obstetric nurses to help pregnant women in setting realistic expectations in order to promote more positive experiences (Prata, 2016).

Concerning the methods used, this study's general approach is, of course, subject to certain limitations, since findings may not be representative of populations in other contexts and data was retrieved only from one institution. Further research is strongly recommended, to include analysing data from other contexts, such as primary health care institutions, private health clinics, and in other country regions.

Despite these limitations, this research enabled significant data and conclusions for the population under study, with strong implications for nursing practice.

### Conclusion

In order to plan effective preparation for childbirth education sessions that are responsive to women's needs and help them to feel confident in their ability to deal with labour, it is essential to know these women first. Understanding their expectations related to the preparation for childbirth will likely help the midwives to plan effective individual or group seminars.

This study helped to enable an understanding of these expectations of pregnant women regarding the PFC, which are in summary, acquiring the knowledge, ability, and self-confidence to deal effectively with labour.

These results can contribute to enable a midwife to identify a pregnant woman's expectations for the preparation for childbirth. Such information will significantly help these professionals in planning effective and enhanced sessions that add to major gains in health.

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# Security and violence

## Young people's risk behaviours profile

### Summary

**INTRODUCTION.** The risk behaviours, safety and violence of young people have been a major concern for societies. Health promotion focused on the importance of a safe environment and the implications that come from incorrect behaviours at this stage of life in which building autonomy is critical.

**OBJECTIVES.** To identify individual health measures adopted by adolescents/youngsters in this case and violence situations to which they are commonly exposed; to determine the level of the risk behaviour; to explore the connections between risk behaviours, school year, and gender.

**METHOD.** A quantitative, correlational and transversal study was conducted. A self-administered questionnaire it was deliver to participants. The sample comprised 1614 young people, of the municipality of Vila Nova de Famalicão, and attending the academic year of 2013/2014.

**RESULTS.** The average age of respondents was 17 years old and the majority were female, attended the secondary school and perceived their family as highly functional. The use of a protection helmet was more frequent when riding a motorcycle than riding a bicycle. The majority of participants reported the regular use of the seatbelt and did not drive nor accompanied a person driving under the influence of alcohol. Most of the respondents have not been involved in situations of violence. The majority showed low levels of risk behaviours.

**CONCLUSION.** These study participants reported a positive image of the risk behaviours. Notwithstanding, young people would still highly benefit from the development of multidisciplinary and innovative interventions leading to the acquisition of a healthy and responsible lifestyle.

**KEYWORDS:** ADOLESCENT; HEALTH BEHAVIOUR; SECURITY BEHAVIOUR; RISK BEHAVIOUR; VIOLENCE.

### Introduction

Adolescence is an important transitional stage in human development characterized by profound transformations at physical, psychological and social levels. During this time, individuals will experience moments of tension, contradictions, ruptures or crisis in the different dimensions, individual, social –family, school, among others–. The World Health Organization (WHO) suggests that this period occurs between the ages of 10 to 19 years, however, for the United Nations for Youth this period is between 15 and 24 years old. Research shows that at this stage risk behaviours affecting young people –with short and long-term implications– are frequently associated to multifactorial stressors – individual, family, social, economic<sup>1,2,3</sup>.

Youth safety is understood as the absence of damage, and for that it is

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crucial the creation of safe environments in order to reduce the number of accidents but also the severity of its consequences<sup>4,5</sup>. This planning includes personal health measures –road, sun protection, and environmental– recycling of residues, residue treatment and others<sup>6</sup>.

According to The Global Status Report on Road Safety, despite all the major progress in road safety, the statistics on road accidents are still high and have important implications on mortality and morbidity rates<sup>7</sup>. However, the death risk by road accident is still a reality, with a major incidence in residential areas and closely related to driving conducts. Portugal has already a specific legislation: on the use of safety belts applied to all passengers, urban speed control with a maximum limit of 50 km/per hour; the use of standard helmets for drivers and passengers of motorcycles and front seat retention systems for children of a specific age, height and weight. To which is added consumption of alcohol and limitations on the percentage of al-

cohol found in the blood, less or equal to 0.05 g/dl and less than or equal to 0.02 g/dl for young drivers and with a recent drivers licence. Despite all these measures, road accidents are still the most prevalent cause of death in Portugal in people aged between 15 and 24 years<sup>8</sup>.

Concerning personal safety measures and solar protection, in 1992, the WHO launched the Intersun Programme, which is still running. Intersun includes a series of awareness programs and screening of the environmental effects of ultraviolet (UV) radiation exposure and practical measures for reducing health risks induced by UV exposure. Studies have already demonstrated a connection between the UV radiation and the occurrence of skin cancer by exposure, in addition to other factors such as skin type, phenotype and family history<sup>9</sup>.

According to the WHO violence is perceived as the use of physical strength or power, as a threat or act against oneself, others or a group or community –which results or might result in suffering, death, psychological damage, impairment or deprivation of growth<sup>10</sup>–. Violence against oneself involves, for example, self-harm behaviours (with no suicide attempt), and suicidal ideation and acts, the latter referring to suicide attempts. The expression of violence is very diverse and usually is a merge of individual, social, cultural, religious and socioeconomic factors. Self-harm can be interpreted as a call for help, to express, resolve or escape from problems, or relieve suffering, as violence against others involves either an effective aggression or is the result of rules and cultural habits<sup>11,12,13</sup>. In 2010 statistics regarding the Portuguese population aged between 15 and 19 years points to a suicide rate of 2.5 per 100,000 inhabitants. However, it is important to highlight the lack of nationwide research in this area and a possible bias regarding its validity and viability evidenced by a high number of undeterred etiologic deaths and inaccuracies in death certificates<sup>12</sup>.

Personal safety and violence connected to risk behaviours in young people. This is an important social concern that requires special attention and development of studies fostering a better health promotion within this age group.

The understanding and tracing of individual health behaviours, violence and risk in the Portuguese young population will very likely contribute to developing interventions targeted at this specific group in what concerns health promotion. Which determined a research question: What is the profile of personal health behaviours, violence and risk in young students of Vila Nova de Famalicão? In addition, outlined the following objectives: to identify individual health measures adopted by adolescents/young people under study and exposure to violence situations; to determine the degree of the risk behaviour; to explore the connection between risk behaviours, school year, and gender.

## Methods

A quantitative, correlational and transversal study was carry out. Vila Nova de Famalicão is a city located in the north region of Portugal. According to the 2011 census, the young population aged between 14 and 21 years totals 12 935 individuals and represents 9.7% of the county population<sup>14</sup>.

The inclusion criteria has defined: age between 14 and 20 years old; attending secondary or higher education schools or institute in the county; and parents and/or the young willing to participate in the study. The participants who did not indicate gender or age were exclude from this study.

From the 30% of the population under study, 3880 participants, the sample reduced to 12.48% (1614) after application of the inclusion criteria. The sample guarantees a sampling error of 3% and a confidence interval of 99%.

The variables under study were sociodemographic, personal security, and violence (table 1) and risk behaviour. The last variable was determine by the number of times for the last 12 months, the person felt extremely sad or hopeless almost all day long for two or more weeks in a row, to the point of stopping one or several usual activities. And also the number of times the person thought of hurting oneself intentionally or tried suicide or was involved in physical fights and the frequency of the use of a helmet riding a bicycle or using sunscreen<sup>15,16</sup>.

A self-administered questionnaire used included sociodemographic characterization, Family APGAR scale<sup>17</sup> and the Health behaviour, risk behaviour and involvement of young people with school and family<sup>16</sup>. We were grouped the questions by areas of thematic proximity. Were used answers types dichotomy, multiple-choice and Likert scale – from zero to two points for family functionality and the sum resulting in a highly functional family (seven to ten), moderate functional (four to six) and dysfunctional family (zero to three).

To determine the risk behaviour degree, were used the proposal of Carter et al. and Santos, initiating with the recodification of questions for this variable and transforming them in dichotomy answers. The sum allowed determining the level: low if equal to zero; medium if equal to one; and high if equal to two<sup>15,16</sup>.

All ethical guidelines were in accordance with the Ethics Committee of Abel Salazar Institute of Biomedical Sciences of the University of Porto, registration no. 057/2013 and the National Protection Commission with the favourable resolution no. 260/2015.

The research team previously contacted the institutions involved, to present the project and invited them to participate. The young participants signed an informed consent and, in case they were underage, a previous consent was necessary from

	Variables
<b>Sociodemographic characterization</b>	<ul style="list-style-type: none"> <li>• Age</li> <li>• Gender</li> <li>• School year</li> <li>• Parents marital status</li> <li>• To whom they talk about problems and concerns</li> <li>• Who notices them when they are worried or angry</li> <li>• Family APGAR</li> </ul>
<b>Personal safety</b>	<ul style="list-style-type: none"> <li>• Use of helmet when riding a motorcycle</li> <li>• Use of helmet when riding a bicycle</li> <li>• Use of seatbelt when driving a car</li> <li>• Use of seatbelt when being a passenger in a car</li> <li>• Frequency of being driven by someone under the influence of alcohol (car or any vehicle)</li> <li>• Frequency of driving a car or any other vehicle under the influence of alcohol</li> <li>• Use of sunscreen when outdoors</li> <li>• Use of hat to avoid sunburns</li> <li>• Use of protective clothing to avoid sunburns</li> <li>• Use of shade to avoid sunburns</li> </ul>
<b>Violence</b>	<ul style="list-style-type: none"> <li>• Number of times they used weapons such as guns, knives or switchblade</li> <li>• Number of days they were in possession of a weapon</li> <li>• Number of days they missed school because of fear of school or on the way there</li> <li>• Number of times they were involved in a physical fight</li> <li>• Number of times they were involved in a physical fight and got hurt to the point of needing medical or nursing care assistance</li> <li>• Number of times where they were involved in a physical fight inside the school property</li> <li>• Having been assaulted or physically hurt by a boyfriend or girlfriend on purpose</li> <li>• Forced physically to intimacy or sexual acts against their will</li> <li>• Number of times they felt sad or hopeless almost all day long for two or more weeks in a row, to the point of stopping one or several usual activities</li> <li>• Number of times they thought of hurting themselves intentionally or attempted suicide</li> </ul>

their legal guardians. The questionnaires were distributed and were collected by teachers in classroom, and later they sent to the research team in closed envelopes in order to guarantee voluntary and anonymous participation.

We was used the SPSS version 24.0 for a descriptive and inferential analysis as non-parametric correlations, Spearman  $\rho$  coefficient used to verify the association between variables and the degree of association and the correlation coefficient proposed by Spearman<sup>18</sup>.

**Results**

**Sociodemographic characterization**

Participants had an average of 17 years (SD = 1.34), with a mode of 17, the

majority (56.8%) were female and were enrolled in secondary education (86.5%).

As to socio-familiar characterization, the majority of the young people lived with both parents (65.7%) and a minority with only one parent (9.2%) or with parents, siblings and grandparents (10.3%). Similarly, for the majority of the young (86.0%) the parents lived together or married, whilst for the rest of the participants, their parents were divorced. In the assessment of family functionality, it was possible to observe in the item analysis, that the majority of the respondents felt usually satisfied with the:

- Family help received to solve their concerns (80.2%).
- Discussion of matters of family interest and their sharing (62.4%).
- Expression of feelings by the family (55.5%).
- Time spent with the family (67.6%).

Although these values were sometimes high, the young people reported being occasionally or almost never satisfied with their family related to the following items: time spent (32.4%), the way of expressing their feelings (44.5%) and how discussed and shared the family matters (37.5%).

The analysis of the total scores of the family APGAR showed that the majority of participants perceived their family as highly functional (76.8%), followed by moderately functional (16.9%) and dysfunctional (4.1%).

**Personal safety**

For the last 12 months previous to fill the questionnaire, about road safety, the majority of younger:

- Did not ride a motorcycle and only a small percentage always wore a helmet.
- Ride a bicycle, with a significant percentage never wearing a helmet.
- Did not drive a car, and as a driver, a quarter of the sample always wore seat belts and the majority, as a passenger, always used it (table 2).

## DISTRIBUTION OF PERSONAL SAFETY MEASURES AND FREQUENCY

2

Personal Safety	Use of helmet		Use of seatbelt		Solar protection			
	% (n)		% (n)		% (n)			
	Bicycle (n = 1055)	Motorcycle (n = 554)	As driver (n = 545)	As passenger (n = 1614)	Sunscreen (n = 1614)	Hat (n = 1614)	Clothes (n = 1614)	Shade (n = 1614)
<b>Never</b>	70.0% (738)	15.0% (83)	2.4% (13)	0.9% (15)	13.5% (217)	53.2% (859)	29.6% (478)	14.8% (239)
<b>Sometimes</b>	16.9% (178)	13.9% (77)	8.1% (44)	9.7% (157)	38.3% (618)	34.5% (556)	44.9% (725)	40.9% (660)
<b>Most times</b>	4.8% (51)	16.8% (93)	15.6% (85)	25.9% (418)	32.2% (520)	9.0% (146)	19.5% (315)	34.2% (554)
<b>Always</b>	8.3% (88)	54.3% (301)	74% (403)	63.4% (1024)	16.0% (259)	3.3% (53)	6.0% (98)	10.1% (163)

## DISTRIBUTION OF THE VIOLENCE TYPE AND FREQUENCY

3

Violence	Against oneself	Interpersonal		
	% (n)	% (n)		
	Suicide attempts	School absence N = 40	Carrying firearms or cold steel weapons N = 81	Physical fights N = 211
Number/time				
1	2.2% (35)	35% (14)	23.5% (19)	43.6% (92)
2-3	1.6% (26)	22.5% (9)	17.3% (14)	27.5% (58)
4-5	0.2% (3)	15.0% (6)	16.0% (13)	9.5% (20)
≥ 6 times	0.1 (1)	27.5% (11)	43.2% (35)	19.4% (41)

Relating to the summer prior to this study, outdoor solar protection measures by participants, used to prevent the effects of ultraviolet radiation, were always adopted by a minority of the participants, highlighting the use of sunscreen and shade as measures of protection (table 2).

In what relates to road safety in the last 30 days, findings show:

- Being driven by a person under the influence of alcohol occurred at least once for almost a quarter (21.8%) of the young people. It should also be noted that for a significant percentage (6.1%) this situation occurred six or more times.
- The majority of participants never drove under the influence of alcohol, although there was a significant percentage (4.8%) who did it at least once.

### Violence

In violence against oneself, 23% of the participants experienced sadness during the last year almost all day for at least two weeks to the point of compromising some of their activities, and 4.1% attempted suicide (table 3).

As for the interpersonal violence, we observed that most of the participants never felt threatened or provoked by peers, in the last 30 days, the reason why they did not miss school activities caused by insecurity feelings at school and on the way to school. Notwithstanding, a significant percentage of the young people, occasionally carried firearms or cold steel, like revolvers, knives or pocketknives. A minority of participants experienced involvement in physical fights in the last 12 months (table 3).

Concerning violence in a relationship, 3.2% of the participants reported having been physically forced to intimacy or sexual acts, against their will and to 2.5% it happened in the 12 months prior to data collection.

### Risk behaviors

According this study the majority of the participants showed low-risk behaviours (52.3%), followed by moderate (42.3%) and high (5.4%).

A very low ( $R < 0.2$ ) and negative association in the relationship between risk behaviour and attended school year was found, meaning that the higher the school year, the lower the risk behaviour of the young people ( $\rho(r\hat{o}) = -.095$ ; sig = 0.001).

As for the relationship between risk behaviour and gender, and considering Spearman's correlation coefficient, it was found statistically

significant, with young males ( $r = 855.36$ ) showing higher values in the behavioural risk.

## Discussion

Studies conducted on young people security, violence and risk behaviours, should focus on the family, because this is the core environment for birth and growth and the centre of individual experiences, either by imitation or opposition, and either a place of protection or conflicts<sup>19</sup>.

In what family is concerned, a nuclear family type characterizes Vila Nova de Famalicão, following a similar incidence of single parent and extended families. The family was perceived by the majority of young people as highly functional, namely as a favourable place for communication processes, providing them with a protection against risk behaviours.

As to personal security, the adoption of road safety measures, like a helmet or seat belt in motorized vehicles were found in the majority of situations, contrarily to the use of a helmet when riding bicycles. In addition, the combination of car driving and influence of alcohol was rarely reported.

In Portugal, the legislation in force to prevent health impairment among young people is still below the European average compared to the security measures directed at teenagers<sup>8,13</sup>. Moreover, the general national index of mortal accidents with cyclists is similar to the European statistics, with results above average registered between 2011 and 2013. These are not encouraging results, since the use of bicycles is not comparable to other countries<sup>20</sup>. Importantly, when promoting young people's health, it is crucial to include activities promoting road safety, since as shown in this study there is a significant percentage of young people adopting behaviours that compromise personal and collective safety.

In what concerns personal safety, the adoption of solar protection measures in outdoor activities, as prevention of the ultraviolet radiation effects, it has were not adopted by most adolescents. It has been relate to the developmental process and/or knowledge of the young. Studies conducted with young people suggest that although the awareness programmes on the use of sunscreen, and better access to information the exposure and sun protection there were continue inappropriate<sup>9,21</sup>.

During adolescence, young people may feel unable to cope with success or challenge, which is why they engage in suicidal acts, experiencing a sense of failure of individual, familiar and/or social nature, and developing a negative self-image. In many situations, the family acts as a protective factor providing cohesion, involvement, sharing of interests and emotional support<sup>22</sup>. The majority of the participants did not engage in suicidal acts, such as suicide attempts or depressive behaviour, as a response to daily sadness, for at least two weeks, with impairment of daily activities. In addition, regarding their family, the majority considered the family involved in solving their concerns, discussing and sharing common interests, allowing the expression of feelings.

Interpersonal violence is a complex and multifactorial phenomenon it which includes individual, relational, communitarian and social determinants. The relational determinants favour the increase of risk, such as those found in relationships within the family, peers, and dating, with special highlight to the involvement in physical fights, conditioned by factors such as family conflict, asymmetries of power and control<sup>13,23</sup>.

In the relationship with their peers, mostly friends of the same age<sup>24</sup>, most of the young participants in the study never felt threatened or provoked by peers, with effects on reduced school absenteeism. Among the most frequent acts of violence involving young, are the acts of fight and threats of

physical force<sup>25</sup>. Participants in this study reported occasional involvement on violent acts, according to data retrieved from the questionnaires, as to the involvement in physical fights and in the use of firearms or cold steel –revolver, knife or pocketknife–.

The dating among young occurs within their peers and the group's experiences, expectations and models, the family models and the media influence it experience dating. For example, the model of parental relationship, may determine the young's attitude with regard to courtship and violent acts within a specific context<sup>13,26,27</sup>. Note that the majority of participants in this study did not experience violence in dating and perceived their family as highly functional.

Studies point to a decrease in the health and well-being levels and for the increase risk behaviours, what it is intimately relate to getting maturation<sup>28</sup>. Notwithstanding, for the majority of the young people in this study, the risk behaviour was low, decreasing with the attendance of higher education schools. As to sexual behaviours, the risk increased in boys.

## Conclusions

The young of Vila Nova de Famalicão, who participated in this study, reported a favourable image, regarding the adoption of safety measures, non-violent behaviours against themselves and interpersonal and risk behaviours. However, young people would still highly benefit from the development of multidisciplinary and innovative interventions leading to the acquisition of a healthy and responsible lifestyle.

The limitation of this study lies in its cross-sectional design and a single measurement used to analyse the phenomenon. This creates difficulties in establishing cause-effect relationships; the collection of data by questionnaire, with risks associated to establish the correct questions

and the trustworthiness of answers, since the type of closed questions may likely to cause incompleteness, precision or erroneous exclusion of elements of interest to the study.

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# The impact on training of the dynamic model for assessment and family intervention

## Summary

**INTRODUCTION.** The Dynamic Model for Assessment and Family Intervention (MDAIF), as an operative theoretical referential underlying the assessment and family intervention practices, was adopted for the family nursing specialty, in Portugal.

**OBJECTIVE.** To assess the impact of the professional practice of MDAIF on the assessment and family intervention practices of Primary Healthcare Nurses.

**METHODS.** A study descriptive case. Forty-nine nurses were invited to participate in the pre-training moment and forty-three in the post-training. Participants were asked to sign a written informed consent and were delivered an open-question form applied in the two moments. The data retrieved were submitted to content analysis with a posteriori categorization.

**RESULTS AND DISCUSSION.** In the pre-training moment, the most common family assessment practices were: "Areas of attention MDAIF"; "Evaluative data of the MDAIF"; "Attention Individual areas"; and for the most common family intervention practices, "action"; "client"; "health programmes"; "prevention levels".

After the training: "MDAIF dimensions"; and "individual areas of attention", with occasional incidence. In the family intervention, the categories identified were: "MDAIF areas of attention" and "action".

It is well known that knowledge transfer into practice in family health nursing is a challenge and that only a relatively small percentage of the training is effectively applied, however, in this study it is possible to observe that training had a positive impact in practice changes. The actions focused on care provided to each member of the family changed to care targeted at the family as a client.

**CONCLUSION.** Training has enabled knowledge transfer to professional performance.

**KEYWORDS:** FAMILY HEALTH; NURSING ASSESSMENT; NURSING MODEL; NURSING; PRIMARY HEALTH CARE.

## Introduction

Over the past decades, the family structure and organization have gone through significant changes. Nonetheless, the family remains the emotional and affective center core and a privileged space of health promotion<sup>1</sup>. Most importantly, in this case, the health practices of each family element determine the family health status, and similarly, this will determine the health status and well-being of each family member. The family is a specific

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focus area for nurses' interventions, directed at the family's life projects, in a systemic approach in which the family is conceived as a continuous transformational unit, namely in what concerns the dynamic process of the adaptation to experienced transitions<sup>2</sup>.

On the one hand, the knowledge on family health nursing has been widely disseminated at national and international levels, with special highlight to the University of Calgary, and the effective transition to clinical contexts. Notwithstanding, literature seems to show little information on the formative processes in this specific nursing area, with insufficient research developed on educational practices, as well as on the learning processes related to family health nursing<sup>3</sup>. Similarly, it was not possible to reach full consensus on content that should be included in curricula, or show evidence of the efficacy of the educators' efforts in this area, and the only relevant data in literature seems to simply describe new educational program-

mes and innovative strategies<sup>4</sup>. However, there is general agreement about the importance of including the theoretical referential in curricula as an important mechanism for competencies development. On the other hand, the continuous education in family health nursing increases the theoretical knowledge and empowers the nurses to work with families, although there are few empirical studies addressing its benefits, as well as little research on the transition programmes to specialized nursing areas<sup>5</sup>.

Some researchers have explored the minimum knowledge required for the teaching of family nursing. These authors state that in 1997, Bell enunciated the what, when and where, related to the teaching of family health nursing theory and key competencies. Hence, there has been an evolution, since educators have been working on curricula focussed on the family, changing the focus on the individual<sup>6</sup>.

Similarly, Friedemann, Bowden and Jones<sup>7</sup> described four levels of the nursing practice targeted at the family: at level I the family is considered as a context of individual development; at level II, the family is viewed as the sum of both parties; at level III, the focus is placed on the family subsystem as a client; and at level IV, the family is considered as a client itself. This latter level refers to the systemic approach, in which the family is conceived as a primary unit for assessment and intervention, regarded as a system in continuous interaction with the supra and intra systems, the goal being the change of processes or the system's structure<sup>1</sup>.

In view of the aforementioned, it is understandable that progressive levels of knowledge and competencies to act in specific contexts are found associated with the increasing levels of complexity of the care practices. The purpose of this study was thus to respond to the needs of Portuguese nurses in Primary Health Care (PHC), for the development of practices targeted at families as the focus of nursing care and in 2009 researchers were able to build the Dynamic Model for Assessment and Family Intervention (MDAIF)<sup>2</sup>.

This model is based on the systemic thinking, with theoretical referential in the Calgary Family Assessment Model and in the Calgary Family Intervention Model. It sets concepts, assumptions and premises as well as an operative matrix enabling the interconnection of the nursing process phases, in a systematic way, based on the three main dimensions: structural; developmental; and functional, translated into eleven areas of attention used as evaluative categories.

The structural assessment focuses on the family structure, aiming to identify its composition, the existing ties between the family and other subsystems, as the extended family and the broader systems and also specific environmental context stressors that may induce health risks. It integrates five areas of attention: Family Income; Residential Building; Security Precautions; Water Supply; and Household Pets.

The development assessment enables the understanding of the phenomena associated with the family growing, and therefore anticipate the provision of care, aiming to empower the family through the development of tasks essential to each stage and preparing all its elements for future transitions. It includes the following areas of attention: Marital Satisfaction; Family Planning; Adaptation to Pregnancy; and Parental Role.

On the other hand, the functional assessment is mainly focused on family interaction patterns, enabling the accomplishment of the household tasks, and includes two areas of attention: the Caregiver role emphasizing the instrumental dimension of the family functioning; and Family process, with an emphasis on the expression dimension, namely the interactions between the family members<sup>2</sup>.

This framework allows to accurately identify the family care needs, as well

as enables nurses to suggest responsive interventions. Hence, the family assessment highlights strengths and the family potential and family intervention aims to the empowerment of the family in problem-solving and preparing the necessary changes in one or several domains of the family functioning: cognitive, emotional, and behavioural, through a systematic and a collaborative approach<sup>2</sup>.

In the operative structure, the International Classification for Nursing Practice (ICNP) is used, with the definition of the minimum data set integrating nursing diagnosis, interventions and outcomes supported by the model's definitions and in the operational connections that constitute its sorting matrix. The indicators on structure, process and outcomes, according to the MDAIF operative definitions, allow identifying health gains for families in their functioning dimensions, sensitive to nursing care<sup>2</sup>.

It is interesting to note that currently and in what concerns the most recent legal framework of the Primary Health Care, the Portuguese Order of Nurses, through its regulation on the Specific Competencies of the Family Health Nurse Specialist<sup>8</sup> highlights the family as the core of care, in such way that the MDAIF was adopted as a theoretical referential for the development of this specialty, supporting a more advanced nursing practice towards families.

In this way and as part of the multidisciplinary team, the nurse specialist in family health cares for the family as a unit of care, empowering it with the necessary skills to respond to the demands and particularities of its development. This process takes place within the three levels of prevention, focusing either on the family as a whole, or on its members individually, providing specific care during the different stages of the family life cycle<sup>8</sup>. The provision of care takes into account the family's internal dynamics and the established relations, the family structure and its



functioning, as well as the relationship between all the subsystems with the family as a whole and the surrounding environment, capable of introducing changes in the interfamily processes and in the interaction of family with its own environment. During this dynamic process, the family nurse provides nursing care in sickness and in health, with particular emphasis on the family responses to real or potential health issues<sup>8</sup>. This intervention is based on a dialectic of partnership with other health professionals and on the identification of nursing diagnosis, prescription and implementation of interventions centered on human responses to health problems and life processes, hence focusing on the family functional empowerment to deal with the transition experiences<sup>2</sup>.

However, the implementation of the MDAIF requires a formative framework adapted to nurses' needs. Hence, and within the scope of the Research Unit of the Nursing School of Porto project, Dynamic Model for Assessment and Family Intervention: A transformative action in Primary Health Care, integrated in CINTESIS (Center for Health Technology and Services Research), training is being developed at a national level, supported on MDAIF, and performed within the professional contexts of the Primary Health Care family nurses, which requires continuous monitoring using different methodologies and instruments, namely in what concerns scientific research.

As part of CINTESIS, this project involves different national and international partner institutions and aims at the maximization of MDAIF in support to nurses' decision-making.

Interesting to note is that the MDAIF has been included in the curricular units of the undergraduate degree in Nursing and in post-graduate courses in the scope of community nursing and family health nursing, in different nursing education institutions, and has also been used as referential in clinical trials and in the initial and post-graduate training.

### **Problem statement**

On the one hand, literature shows the need for knowledge transfer to family health nursing practice<sup>9</sup>, in which new knowledge is applied to practice, in order to develop new interventions, policies or procedures<sup>10</sup>, thus increasing nurses' competencies to assess and intervene towards the family. Importantly, nurses are also able to understand this knowledge transfer, as well as the way this formative process influences their clinical practice<sup>10</sup>.

On the other hand, the legal framework of the Primary Health Care, more specifically, after the regulation of the Specific Competencies of the Nurse Specialist in Family Health Nursing<sup>8</sup>, the approval of the formative programme and quality patterns for the profession of specialist nurses, the adoption of the Dynamic Model of Family Assessment and Intervention (MDAIF<sup>2</sup>), as a theoretical-operative referential to the specialty, as well as the statutory requirement for all nurses working in the Family Health Units to have the title of specialist in family health nursing<sup>11</sup>, all contribute to the importance of developing training in this area fostering the development of competencies.

According to the aforementioned, and taking into consideration that the training in a professional context is a short-term systematic training aimed at empowering trainees with competencies that can be easily applied to a specific activity<sup>12</sup> and that this training must be designed to prepare the transfer of the acquired knowledge<sup>13</sup>, as members of the research team, we have developed a study within the doctoral degree in Nursing Science and included in the first stage of the research project. The aim was to assess the impact of the training developed by the MDAIF in the Primary Health Care nurses in the assessment and family intervention, considering that there can be

behavioural change as a result of the implemented care practices.

### **Research questions**

The main issue underlying this study can be formulated through the following starting question: What is the impact of the MDAIF in the assessment and family intervention practices of Primary Health Care nurses?

### **Purpose of the study**

The purpose of the study is to contribute to enhancing the quality of care provided by Primary Health Care nurses, through the information on the impact of professional training of MDAIF for the clinical nurses' performance at the assessment and family intervention levels. This will enable to optimize training and maximize the potential of intervention competencies development and consequently the increase in health gains and empowerment of families.

### **Methods**

A qualitative, exploratory and descriptive study was performed on the phenomenon under study. Forty-nine Primary Health Care nurses were recruited before initiating the professional training and forty-three after three months of professional training. This is corroborated by several authors that state that the effective behavioural assessment in the professional context can be performed three to six months after training<sup>14</sup>, through the most common techniques: questionnaires; interview guides, behavioural observational grids or the combination of all techniques<sup>15</sup>.

In this way, all the ethical issues were assured through the partnership charter signed between the Nursing School of Porto, the headquarters of the research project in which this study is included, and the Northern Regional Health Administration. Participants were asked to sign an informed consent and an open question form delivered in the

two moments, as previously described. The data collected were submitted for content analysis with *a posteriori* categorization.

### Findings

After the analysis of information, it seemed clear that these data could be categorized according to the operational matrix of the MDAIF, and this was the researchers' decision.

#### Most common practices of family assessment

At the pre-training moment, the following categories emerged:

- “Areas of attention of the MDAIF”, with emphasis on “Family process” in the operative dimensions “communication”, “dynamic relationship” and “role interaction”, as the example of the following data registration: “The interpersonal relationships, the responsibility and the role played by each individual in the family”, followed by the “Residential building”, in what concerns its security, and also the household hygiene (neglected/not neglected): “House physical conditions (water, lighting...)”; “Household hygiene”, among other areas of attention, such as “Marital satisfaction”.
- Evaluative data of the MDAIF”, with emphasis on “Family composition” – e.g. “Household composition”, followed by “Broader systems” – e.g. “Existing physical and social resources”, and then with two registration units each: “Vital cycle” – e.g. “The family’s vital cycle phase”, “Type of family”, “Family beliefs” and “Social status” – e.g. “Socioeconomic conditions”.
- “Individual areas of attention”, including “Evaluative data of the individual”, such as the following registration units: “Integration of each individual in the social life”, “Personal background”, “Physical, social and psychologic well-being”, including “Therapeutic regimen” and “Human development” – e.g. “Ageing development”.

In the post-training, the following categories emerged:

- “MDAIF dimensions”, including almost all registration units and in which nurses reported the three dimensions: structural, developmental and functional, or included in each one of them the “areas of attention of the MDAIF”, such as the registration unit: “The areas of attention are divided into three areas: structural (family income, residential building, safety precautions, water supply, household pets); developmental (marital satisfaction, family planning, adaptation to pregnancy, parental role) and functional (caregiver role and family process).

“Individual areas of attention”, in which there was only two registration units – e.g. “The needs of each family member” and “Health status of each family member”.

#### Most common practices of family intervention

In the pre-training moment, the following categories emerged:

- “Action” such as “Informing”, “Teaching”, “Assessing” – e.g. “To assess the childhood development”, “To perform” – e.g. “Treating and giving injections”.
- “Client” – e.g. “Elderly”, “Child”, “Pregnant”, “Family members”.
- “National Health Plan Programmes”, such as “Child Health”, “Maternal Health” – e.g. “Pregnancy Monitoring”, “The Elderly Health” – e.g. “The Diabetic and Hypertensive Consultation”, “The Elderly Health” – e.g. “Healthy Ageing”, National Vaccination Plan – e.g. “Vaccines”;

“Prevention levels”, in Primary Prevention – e.g. “Education for Health, Health Promotion”, Secondary Prevention – e.g. “Curative” and Tertiary Prevention – e.g. “Rehabilitation”;

In the post-training moment, the following categories emerged:

- “Areas of attention of the MDAIF” such as the registration unit: “Interventions related to ineffective family planning, to inadequate adaptation to pregnancy; parental role, caregiver role”.
- “Action” such as “Teaching”, “Assessing”. “Performing” – e.g. “Performing techniques”.

### Discussion

Considering that the knowledge transfer in family health nursing to clinical practice presents a challenge<sup>9,10</sup>, implying a change and the regular application of knowledge, competencies, behaviours or attitudes as learning deriving from the formative process and also considering that only a small percentage of training is actually applied to the workplace<sup>16</sup>, this study suggests that training had a positive impact in changing nursing care practices in what concerned the assessment and family intervention. In such way that a significant number of interventions focused on care to each family member changed to care focused on the family as a client, thus suggesting a theoretical use of the MDAIF, as well as its specific language, but also the use in a more operative dimension, reflected on the care practices reported by nurses after completing training.

Several studies corroborate these findings, mostly developed within the aforementioned research project and included in CINTESIS. The MDAIF is perceived as a positive change factor in the acquisition of assessment and family intervention competencies, reflected on the provision of care<sup>17-28</sup>.

An effective transfer is only considered when competencies or behaviours are generalized in professional contexts and preserved for a period after training<sup>16</sup>. Hence, this suggests a change in the care approach, in which initially the family is considered the context of care and after the training programme, the family is the focus of care, addressing

the reciprocity of family and individual health, meaning that the focus includes the family as a whole and its members individually alike<sup>2</sup>. This new approach implies a clear comprehension of the complexity involved, taking into account the needs as a whole throughout the life cycle and not merely focused on the individual.

However, despite some studies have stressed that nurses value the establishment of a good relationship with the family, considering it as a powerful resource<sup>29</sup>, other studies advocate the replication of practices based on the biomedical model, considering less important the intervention of the family in the process of care, arguing that the family has little or even nothing to say about caring for the ill family member, clearly showing nurses lack trust in the family<sup>29</sup>. In fact, Martins et al.<sup>30</sup>, refer to several authors and corroborate this statement, since they mention that although nurses acknowledge the importance of the family, they do not always act accordingly, still revealing some discrepancies in the level of involvement, negotiation and participation of the family in decision-making in relation to care. The findings of the study performed by Martins et al.<sup>30</sup>, allowed to show the importance of training contexts (academic and continuous) influencing a more favourable attitude towards the family, strengthening the impact of training in professional practice.

Similarly and in what concerns the evolution of family nursing care in Portugal, it is considered to be in line with the existing legislation on Primary Health Care, highlighting the family nurse's role in health care. This specific care underlies the entire health system, with special emphasis for the Family Health Unit, as proximity care and a privileged context for nursing practice targeted at the family system as a unit of care. An important contribution is also the implementation, in some organizations, of the organizational model of the family nurse, in which each nurse is responsible for the overall provision of care to a specific number of families. However, Figueiredo<sup>2</sup> stresses that although there is a strong understanding that family should be the focus of care and on the importance of family nurses for the monitoring of families, there is still a philosophy of care focused on health programmes in which the family is involved merely as a context of care.

For the above stated and underlying the guidelines of the Portuguese Order of Nurses (2011), it is essential to train nurses capable of mobilizing and combining the different knowledge and resources, to effectively intervene in the family health context. Thus, training emerges as a promoter of these competencies and the MDAIF is used as a conceptual systemic model setting the action, and therefore, as a guide for decision-making in family health nursing.

On the other hand, despite there is a worldwide consensus on the importance of continuous education, there is still little evidence of its empirical efficacy. This is corroborated by Velada (2007) who states that the analysis of the effective impact of professional training is relatively scarce.

## Conclusion

Our study concludes that training has practical implications on the care provided and also reveals that training may have enabled the knowledge transfer to professional performance, by transforming knowledge into action, in such way that learning becomes of substantial utility, and materializes itself in the changes of nursing practices targeted at families.

Similarly, there are other implications on the formative process, since there was positive impact of training based on the MDAIF. The impact on research was equally important, and suggests the need for further studies, either of qualitative or quantitative nature, in order to enhance knowledge

about the factors positively and/or negatively interfering in the transfer of what is acquired in the training context to action, mainly those being developed within the scope of the research project: Dynamic Model of Family Assessment and Intervention; a transformative action in Primary Health Care.

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