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**Comfort in Palliative Care:
Development and Evaluation of a Complex Nursing Intervention**

Thesis Application for the Doctor of Philosophy degree in Nursing Sciences, submitted to the Instituto de Ciências Biomédicas Abel Salazar.

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To my sister, Isabel.

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AUTHOR'S DECLARATION

Under the terms of the number 5 of article 4, Order 4889/2015, Decree-Law 90, published in Diário da República, II series, March 11th 2015, it is hereby declared that the following studies are original and were prepared and published in the scope of this dissertation.

The author declares that she afforded a major contribution to the conceptual design of the study, data acquisition, analysis and interpretation of the results, and also in the elaboration, final approval and submission of the published articles.

SCIENTIFIC PUBLICATIONS

Articles published in peer-reviewed journals

- **Pinto, S.**, Martins, J.C. & Barbieri-Figueiredo, M.C. (2014). Investigación en cuidados paliativos y enfermería: Revisión sistemática sobre el estado del arte en Portugal. *Index de Enfermería*, 23(3), 178-182. doi: <http://dx.doi.org/10.4321/S1132-12962014000200014>.
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- **Pinto, S.**, Caldeira, S. & Martins, J.C. e-Health in Palliative Care: Review of the literature, *Google Play* and *App Store*. Article submitted to the *International Journal of Palliative Nursing*.

- **Pinto, S.**, Almeida, F., Caldeira, S. & Martins, J.C. The Comfort app prototype: Introducing a web-based application for monitoring comfort in palliative care. Article submitted to the *International Journal of Palliative Nursing*.

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Oral presentations at international meetings

- **Pinto, S.** & Caldeira, S. (2014). Confortar: Desenvolvimento e avaliação de uma intervenção complexa. In *IV Congresso de Investigação em Enfermagem Ibero-Americano e de Países de Língua Oficial Portuguesa*, Coimbra, Portugal, 21-23 July.
- Caldeira, S., **Pinto, S.** & Aparício, M. (2014). Perdón y bien-estar en cuidados paliativos: Revisión integrada de la literatura. In *X Congreso Nacional de la Sociedad Espanola de Cuidados Paliativos*, Madrid, Spain, 13-15 November.
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- **Pinto, S.** (2014). O doente em suporte paliativo: Confortar em cuidados paliativos. In *7ª Reunião da Associação Portuguesa de Enfermagem Oncológica*, Luso, Portugal, 21-23 May.
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- **Pinto, S.**, Caldeira, S. & Martins, J.C. (2016). Avaliação do conforto na pessoa em fim de vida: Estudo metodológico. In *VIII Congresso Nacional de Cuidados Paliativos*, Lisboa, Portugal, 7-9 April.

Poster presentations at international meetings

- **Pinto, S.**, Cizmar-Carvalho, C. & Caldeira, S. (2014). Revisão sistemática da literatura sobre o holismo em enfermagem no séc. XXI. In *IV Congresso de Investigação em Enfermagem Ibero-Americano e de Países de Língua Oficial Portuguesa*, Coimbra, Portugal, 21-23 July.
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- **Pinto, S.**, Caldeira, S., Martins, J.C. & Rodgers, B. (2016). Defining comfort: A concept analysis research. In *9th World Research Congress of the European Association for Palliative Care*, Dublin, Ireland, 9-11 June.

OTHER WORKS

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- “Perspetivas de morte e bem-estar espiritual em profissionais de saúde que cuidam de doentes terminais”. Dissertation for the master degree in palliative care, Faculdade de Medicina da Universidade do Porto. Arguing member of the academic jury. July 2015.
- “Os aspectos sociais da esclerose lateral amiotrófica e a intervenção do assistente social: Revisão sistemática da literatura”. Dissertation for the master degree in palliative care, Faculdade de Medicina da Universidade do Porto. Arguing member of the academic jury. December 2015.

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ABSTRACT

Background: Comfort is a central concept in nursing practice and in palliative care. It is relevant to patients, nurses and researchers. Despite its importance, comfort is still difficult to define, implement and assess. There is a need to further clarify the definition and nature of the concept of comfort to provide completeness and adequacy along with indicators of comfort to support outcome measures for quality care and patients' comfort. Thus, more feasible, efficient and effective nursing interventions are required in this field.

Aim: This study aims to clarify the concept of comfort and to identify the main attributes of the concept, to adapt and validate an instrument to measure comfort in Portuguese palliative care patients, and to design a feasible intervention to monitor comfort in Portuguese palliative care patients.

Methods: This study was based on the method proposed by the Medical Research Council for the development and evaluation of complex interventions. In the first phase (development), two literature reviews were conducted: one on the state of the art in palliative care in Portugal, and another on the characterization of comfort in literature. The theoretical approach was based on the Kolcaba's Comfort Theory, in the analysis of the concept of comfort, and in a literature review focusing on the differences and similarities among the concepts of well-being and quality of life. The modulation of processes and outcomes included a discussion on the impaired comfort diagnosis of NANDA International, a qualitative study about palliative care patients' experiences of comfort, and the cultural adaptation and validation of an instrument to measure comfort. Finally, the design and feasibility study of a web-based application (app) to monitor comfort in palliative care patients was performed.

Results: A proposal for a new definition of the concept is provided. Comfort is a pleasant experience, related to the satisfaction of needs and to the search for safety and strength. The antecedents include inward and outward factors, and the attributes illustrate the concept as being complex, holistic, dynamic and subjective. Comforting is a process that has consequences for patients and caregivers. The Portuguese version of the End of Life Spiritual Comfort Questionnaire has been validated, and comprises 20 items, organized in five factors ($\alpha=0.84$). These findings underline the results from a qualitative study, in which five themes emerged: *Me and what I feel*; *Me and I how I react*; *Me, a human being in society*; *Me and the meaning of my life*; *Me and the world around me*. Comfort seems to be a human response that integrates several diagnoses, for which nurses should provide different but also similar and simultaneous interventions, specific to the etiological factor. For this reason, a proposal for changing the nursing diagnosis impaired comfort as a

problem-focused diagnosis to a syndrome diagnosis has been submitted to the NANDA International Diagnosis Development Committee. The intervention design comprises a free and web-based app, which is intended to be completed by patients through a smartphone, tablet or computer. The app evaluates 11 items (pain, tiredness, drowsiness, nausea, lack of appetite, shortness of breath, depression, anxiety, fear of the future, peace, and the will to live) assessed on a Likert scale. The intervention is feasible, friendly used, and approved by patients.

Conclusions: Comfort is an important outcome for patients with life-threatening illness, and the assessment of patient's needs is crucial in this endeavour. Nevertheless, this could be difficult in some contexts, such as home care. e-Health technologies can bring an opportunity in palliative care, namely in promoting comfort. The *Comfort app* has shown to be a useful tool in monitoring the comfort of palliative care patients, particularly regarding early and personalized comfort interventions, better communication and organization of care.

Keywords

Comfort; complex interventions; e-health; medical research council framework; nursing; palliative care.

RESUMO

Enquadramento: O conforto é um conceito central na prática de enfermagem e em cuidados paliativos, sendo relevante para doentes, enfermeiros e investigadores. Apesar da sua importância, continua a ser difícil de definir, implementar e avaliar. Subsiste assim a necessidade de clarificar a definição e natureza do conceito, de modo a assegurar a adequação dos atributos do conceito, com vista à obtenção de indicadores de resultado para o conforto do doente e qualidade dos cuidados. Face ao exposto, são necessárias intervenções de enfermagem exequíveis, mais eficientes e eficazes.

Objetivos: Este estudo tem por objetivos clarificar o conceito de conforto e identificar os seus principais atributos, adaptar e validar um instrumento para avaliação do conforto em doentes portugueses em cuidados paliativos e desenhar uma intervenção exequível para monitorização do conforto em doentes portugueses em cuidados paliativos.

Métodos: O estudo baseia-se no método proposto pelo *Medical Research Council* para o desenvolvimento e avaliação de intervenções complexas. A primeira fase (desenvolvimento) centrou-se em duas revisões de literatura: uma primeira relativa ao estado da arte em cuidados paliativos em Portugal e uma segunda sobre a caracterização do conforto na literatura. A abordagem teórica teve por base a Teoria do Conforto de Kolcaba, complementada pelo estudo de análise do conceito de conforto e por uma revisão de literatura acerca das semelhanças e diferenças com os conceitos de bem-estar e qualidade de vida. A modulação de processos e resultados incluiu a discussão do diagnóstico de conforto comprometido proposto pela NANDA Internacional, um estudo qualitativo sobre as experiências de conforto de doentes em cuidados paliativos e, ainda, a adaptação cultural e validação de um instrumento para avaliação do conceito. Por fim, procedeu-se ao desenho e estudo de exequibilidade de uma aplicação (app) web para monitorização do conforto em doentes em cuidados paliativos.

Resultados: O estudo propõe uma redefinição do conceito. O conforto é uma experiência agradável, relacionada com a satisfação de necessidades e com a procura de segurança e força. Os antecedentes incluem fatores de ordem interna e externa e os atributos ilustram a natureza complexa, holística e dinâmica do conceito. Confortar é um processo com consequências para os doentes e cuidadores. A versão portuguesa da Escala de Conforto Espiritual em Fim de Vida inclui 20 itens, organizados em 5 fatores ($\alpha=0.84$). Esta organização é sustentada pelos resultados de um estudo qualitativo, no qual emergiram cinco temas: *Eu e o que eu sinto*; *Eu e como reajo*; *Eu, um ser em sociedade*; *Eu e o sentido da minha vida*; *Eu e o mundo que me rodeia*. O conforto parece ser uma resposta humana que integra diversos diagnósticos, para os quais os enfermeiros podem

implementar intervenções diferentes, semelhantes e/ou simultâneas, dirigidas ao fator etiológico. Por esta razão, propôs-se à Comissão de Desenvolvimento de Diagnósticos da NANDA Internacional a alteração do diagnóstico de conforto comprometido para um diagnóstico do tipo síndrome. A intervenção consiste numa aplicação web, gratuita, destinada a ser utilizada pelo doente através de um *smartphone*, *tablet* ou computador. Esta *app* avalia 11 itens (dor, cansaço, sonolência, náusea, falta de apetite, falta de ar, depressão, ansiedade, medo do futuro, paz e vontade de viver) avaliados numa escala de *Likert*. A intervenção é exequível, simples e aprovada pelos doentes.

Conclusões: O conforto é um resultado importante para a pessoa que enfrenta uma doença ameaçadora de vida, sendo fundamental a avaliação de necessidades neste âmbito. Contudo, esta avaliação pode ser difícil nalguns contextos, nomeadamente no domicílio. As tecnologias *e-health* podem, porém, representar uma oportunidade para os cuidados paliativos, designadamente na promoção do conforto. A *Comfort app* promete ser uma ferramenta útil na monitorização do conforto do doente em cuidados paliativos, possibilitando a implementação de intervenções de conforto precoces e personalizadas e, ainda, uma melhor comunicação e organização dos cuidados.

Palavras-chave

Conforto; intervenções complexas; e-health; medical research council framework; enfermagem; cuidados paliativos.

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ABBREVIATIONS AND ACRONYMS LIST

ANACOM	Autoridade Nacional de Comunicações de Portugal
app	Application
AsyMSp	Advanced Symptom Management System in Palliative Care
CHSJ, CES	Centro Hospitalar de São João - Comissão de Ética para a Saúde
COREQ	Consolidated Criteria for Reporting Qualitative Research
CP	Cuidados Paliativos
EANS	The European Academy of Nursing Science
E	Expert
ed.	Edition
eg.	Example
ENABLE	Educate, Nurture, Advise, Before Life Ends
ESAS	Edmonton Symptom Assessment Scale
GOLD	Global Initiative for Chronic Obstructive Lung Disease
H	Hypothesis
HCP	Health Care Providers
HCQ-PT-DC ®	Escala de Conforto Holístico
HCW	Health Care Workers
HTP	Home Telecare Program
ICF	International Classification of Functioning and Disability
ICN	International Council of Nurses
ICNP ®	International Classification for Nursing Practice®
ICTs	Information and Communication Technologies
IWS	Internet World Stats
ITU	International Telecommunication Union
max	Maximum
MeSH	Medical Subject Heading
min	Minimum
MRC	Medical Research Council
NANDA-I	NANDA International
NHSISE	National Health Service Innovations South East
NYHA	New York Heart Association
O	Objective
p.	Page
PC	Palliative Care
PhD	Doctor of Philosophy
QoL	Quality of Life
QR code	Quick Response code
RCT(s)	Randomized Clinical Trial(s)
RQ	Research Question
SD	Standard Deviation
SPMS	Serviços Partilhados do Ministério da Saúde
STARD	Standards for Reporting Diagnostic Accuracy Studies
SWOT	Strengths, Weaknesses, Opportunities and Threats
TIPS	Telehomecare in Palliation Study
TS	Translation Synthesis
USA	United States of America
WHO	World Health Organization

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APPENDICES

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Appendix 2: Permission to use the *End of Life Comfort Questionnaire*.

Appendix 3: Ethics committee authorization (CHSJ, CES 191-14 20 Nov 2014).

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Appendix 5: Ethics committee authorization (Hospital Arcebispo João Crisóstomo, Cantanhede).

Appendix 6: Permission to reproduce the paper *Investigación en cuidados paliativos y enfermería: Revisión sistemática sobre el estado del arte en Portugal*.

Appendix 7: Permission to reproduce the paper *A systematic literature review toward the characterization of comfort*.

Appendix 8: Certificate of attendance - Poster presentation in the *International Conference on Nursing Knowledge: NNN - From concepts to translation*.

Appendix 9: Permission to reproduce the conceptual diagram for the Comfort Theory from Kolcaba's website.

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INTRODUCTION

This thesis was developed within the Doctoral Program in Nursing Sciences at the Instituto de Ciências Biomédicas Abel Salazar - University of Porto, in partnership with the Escola Superior de Enfermagem do Porto, in order to achieve the degree of Doctor of Philosophy (PhD) in Nursing Sciences.

The theme, “*Comfort in palliative care: Development and evaluation of a complex nursing intervention*”, had underlying personal, professional and evidence-based reasons.

From a personal perspective, since an early age we were sensitized to questions associated with the end of life, and this work is giving continuity to our previous academic training.

The second reason emerges from our professional practice, where every day questions arise regarding patients’ comfort, the complexity of their needs and, therefore, the complexity of nursing care and interventions. Based on these assumptions, the following preliminary research questions arose:

- *What is the meaning of comfort?*
- *What are the parameters being taken into consideration by the health professional to state that a patient is comfortable or not?*

Reporting the evidence-based reasons, this theme embraces several important concepts for nursing, but also for modern societies and for the current health care systems, such as ‘*comfort*’, ‘*palliative care*’, ‘*complex interventions*’, and ‘*e-health*’.

Comfort as a foundation for nursing

Comfort is a concept deeply and historically associated with the nursing profession. In her ‘*Notes on Nursing*’, Nightingale (1860) placed the comfort and patients’ needs ahead of nursing care, highlighting the important role of nurses to help patients to achieve physical and environmental comfort.

However, for modern societies, comfort goes beyond the satisfaction of physical needs, the cosiness of blankets or pillows, and comprises a holistic approach. The Kolcaba’s Comfort Theory (2003) defines comfort as the satisfaction of the needs for relief, ease and transcendence in four contexts: physical, psychospiritual, sociocultural and environmental. Despite this theory, as well many other studies that have been carried out, the concept remains unclear, particularly for clinical nurses, as it is difficult to implement and measure in clinical practice (Oliveira, 2008; Sousa & Costa, 2012; Xavier *et al.*, 2013). The lack of valid and reliable instruments to measure the holistic comfort in Portuguese patients with palliative care (PC) needs is, probably, one of the first difficulties that health care professionals face.

Another difficulty is the lack of guidance and theoretical support provided for the nursing classifications and taxonomies in this field. For instance, the International Classification for Nursing Practice® (ICNP®) (International Council of Nurses [ICN], 2015) defines the concept of comfort as the "*sensation of physical ease and bodily well-being*" (code 10004655), reducing the concept to the physical dimension. Nevertheless, some inconsistencies were also found in the taxonomy II proposed by NANDA International (NANDA-I) (Herdman & Kamitsuru, 2014), namely in the nursing diagnosis impaired comfort (00214). This diagnosis is defined as the "*perceived lack of ease, relief, and transcendence in physical, psychospiritual, environmental, cultural, and/or social dimensions*" (Herdman & Kamitsuru, 2014, p. 437). However, when looking at the taxonomy, it can be observed that the diagnoses related to mental or psychological phenomena are listed in domain 9 ('coping') and diagnoses related to spirituality and values are listed in domain 10 ('life principles'). Regarding Kolcaba's (2003) definition, if comfort is a holistic concept, it seems there is a lack of consistency among theory and the organization of the concepts in the taxonomy II of NANDA-I (Herdman & Kamitsuru, 2014), which can lead to difficulties in clinical practice.

Transitions in palliative care: From the 1960s to the 21st century

The modern movement of PC began in the 1960s, in London, with Dame Cicely Saunders. Firstly a nurse, this iconic name of PC, went on to become a social worker, and then a doctor. In 1967 she founded the St. Christopher's hospice, the first institution dealing with symptom management, compassionate care, teaching and research, revolutionizing the way that societies care for the terminally ill (Lutz, 2011).

According to the World Health Organization (WHO) (Sepúlveda *et al.*, 2002, p. 94), PC is described as:

"an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual".

Although PC was initially more focused on cancer and terminal patients, it is currently facing new challenges. Scientific and technological developments have contributed positively to important changes in social and health conditions, namely in the course of diseases. According to the WHO (2016a) the health of the global population has evolved in a very positive way, and life expectancy has clearly increased since 2000. However, the

number of persons suffering from non-communicable diseases, such as cancer, cardiovascular diseases or diabetes, has also increased (WHO 2014; WHO 2016a).

In Portugal, data are not very different. In 2014, it was estimated that 40.30% of the resident population over the age of 16 years had, at least, one chronic disease. Also, among the 105 219 deaths that occurred in 2014, 75% suffered from an advanced, incurable and progressive disease, while 60.40 % of deaths occurred in hospitals or clinics (Instituto Nacional de Estatística, 2016).

The rise in chronic diseases is the main burden of health care systems worldwide, representing a serious threat to economic sustainability and to an affordable health care system (Kankeu *et al.*, 2013). Although cancer is still one of the principal cause of deaths, other diseases are emerging as important determinants for morbidity. These determinants are leading to a decrease in healthy life expectancy and an increase in the use of health services, as well as costs related with hospitalization (Steiner & Friedman, 2013; Skinner *et al.*, 2016; WHO, 2016a).

Taking these changes into consideration, PC has incorporated conceptual modifications, which are important not only for practitioners but also for researchers. In the 21st century, the patient suffering from a terminal cancer, with a prognosis of weeks or months, gives rise to a patient with a broad spectrum of comorbidities, suffering with an advanced progressive chronic disease with limited life prognosis. Mortality lead to an increase in prevalence and prognosis (the main criteria for PC referral) was supplanted for complexity. For these reasons, the curative/palliative dichotomy gives rise to the need for combined and shared care, with flexible interventions whenever the patient needs. From an organizational perspective, this means that PC is now embracing the need for PC actions in all settings of health, as well as the need for a community approach (Gómez-Batiste *et al.*, 2013).

Complexity is, clearly, emerging as an important topic. But, how complex is complex and how should health care providers manage this complexity (Pask *et al.*, 2016)?

The study of complex interventions

Complex interventions can be defined as a range of interventions involving several interacting components and individuals, such as different professions, organizational levels, contexts or needs, and which can interact either independently or interdependently (Mohler, Köpke & Meyer, 2015).

Nursing has been considered a complex intervention as well, not only because it comprises a large range of activities, but also because nurses interact with several

individuals, in very different contexts, such as acute settings, chronic care facilities, intensive care or community facilities (Richards & Borglin, 2011).

Demographic changes and the growing number of persons with chronic diseases placed more responsibilities in the hands of nurses, and increased the overall need for a solid nursing foundation (Richards & Borglin, 2011). Thus, Corry *et al.* (2013) proposes that nurses should embrace the work carried out in other fields, as a way to improve the advance of nursing practice.

Aware of the difficulty in managing complex interventions in several disciplines, the Medical Research Council (MRC) proposed a framework regarding the development and evaluation of complex interventions (Craig *et al.*, 2008; Craig *et al.*, 2013). This framework aims to make the process more rigorous and clear, in order to achieve more feasible, effective and reproducible interventions (Craig *et al.*, 2008; Craig *et al.*, 2013).

Therefore, the study of complex interventions in nursing is considered a priority in nursing research, both in Portugal and in Europe (Ordem dos Enfermeiros, 2010; The European Academy of Nursing Science [EANS], 2016).

e-Health as a way to manage complexity

e-Health is defined as the use of information and communication technologies in health contexts to treat patients, enhance education, monitor public health or conduct research (WHO, 2016b), and has been highlighted as a valuable contribution to modern societies.

Regarding the specific context of PC, new models are emerging, and more integrated approaches, comprising the patient and family enrolment, are desired (Gómez-Batiste *et al.*, 2013). While transitions between hospital and home are frequently stressful either for patients and relatives (Duursma *et al.*, 2011), innovation and close proximity to PC services have been outlined as facilitators (Sommerbakk *et al.*, 2016).

Thus, although the place of death has been defined as an important indicator of the quality of care (Cohen & Leemans, 2014), international surveys reported a significant contrast between patient preferences and the place of death (Gomes *et al.*, 2012). Portugal follows the international trend, where the vast majority of patients (62%) die in a hospital or clinic (Gomes *et al.*, 2013).

Indeed, e-health can bring several benefits such as improving interaction among patients, relatives and healthcare providers, a better continuity of care and, also, a more effective assessment and more personalized interventions (WHO, 2010; Duursma *et al.*, 2011; Dutta, Geiger & Lanvin, 2015). e-Health can also be a resource to deal with an overcrowded health system, the lack of specialized teams and the difficulties to perform an

optimal patient assessment remotely (McCall *et al.*, 2008; Budyach, Karle & Helms, 2014; Cooley *et al.*, 2015; Hochstenbach *et al.*, 2016).

The present study aims to clarify the concept of comfort and to identify its main attributes, to adapt and validate an instrument to measure comfort in Portuguese PC patients, and to design a feasible intervention to monitor comfort in PC patients.

The study was developed according to the MRC framework for the development and evaluation of complex interventions (Craig *et al.*, 2008; Craig *et al.*, 2013). Although this framework follows a sequential logic, the process is dynamic, which means the project is not static. Indeed, in some moments, several studies were performed at the same time and the research was developed in a very interactive way.

The thesis is presented in the form of scientific articles developed within the scope of this doctoral program. The studies were published in scientific peer review journals, and the candidate contributed greatly to the design of the study, data collection, interpretation and analysis of the results, and preparation of the final manuscript.

Whenever possible, and within the methodological approach, different study designs were implemented and international partnerships were established. In our perspective, this approach not only enriched the study, but also improved the ability to discuss, share and disseminate knowledge, which are core skills for researchers.

In order to improve clarity and a better understanding about the course of investigation, the thesis is organized in three principal chapters, having in mind the different phases of the MRC framework (Craig *et al.*, 2008; Craig *et al.*, 2013) (Figure 1).

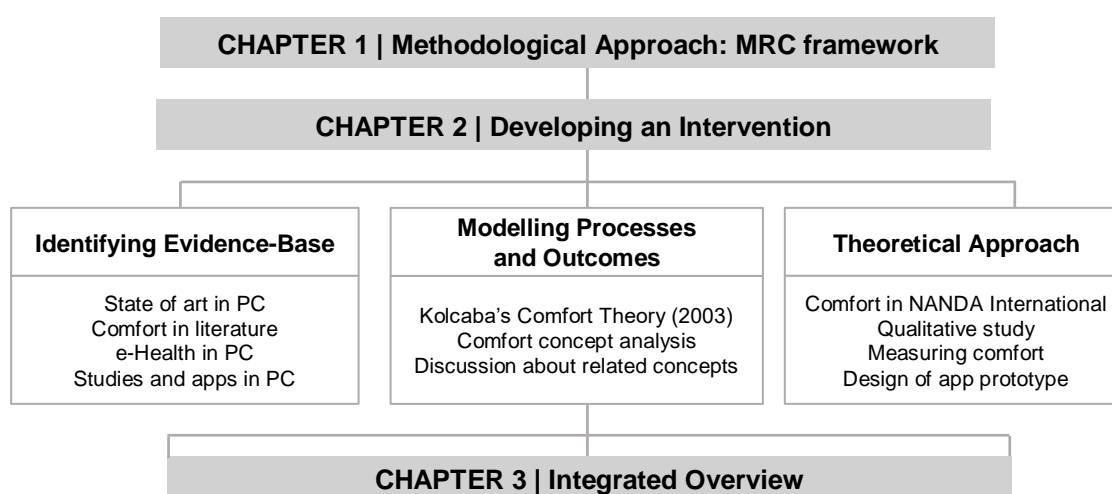


Figure 1: Integrated overview of the thesis organization.

The first chapter introduces the methodology. It was written at the beginning of the study and was used as a guide during the course of research. The second chapter describes the development of the intervention, which comprises several phases: identifying the evidence-base, identifying a theory, and modelling processes and outcomes. In the third chapter, an integrated overview of the performed studies, indicating the study limitations and proposing suggestions for further research, was realized.

Lastly, the study introduces a prototype application (app) to monitor comfort remotely in PC home patients. Although it was not an initial purpose to develop an e-health technology, the results allowed us to work in this field. This instrument can bring more feasible, personalized and effective interventions, and improve holistic comfort.

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CHAPTER 1: METHODOLOGICAL APPROACH

This chapter introduces the methodological approach used in this research: the Medical Research Council (MRC) framework for the development and evaluation of complex interventions (Craig *et al.*, 2008; Craig *et al.*, 2013).

The first sub-heading presents a literature review about the study of complex interventions in nursing. In the following sub-headings, the study design, objectives and ethical procedures followed during the research are presented. Specific information about the methodological approach is described in each study, and is presented in the following chapters.

1.1. Aims, research questions and hypotheses

The act of comforting addresses an important but complex nursing intervention that is difficult to define, implement and evaluate (Oliveira, 2008; Lin, 2010; Sousa & Costa, 2012; Xavier *et al.*, 2013). Given the importance of the theme, and the limitation of the knowledge in this topic, it was designed a research project based on the following preliminary research questions:

- *What is the meaning of comfort?*
- *What are the parameters being taken into consideration by the health professional to state that a patient is comfortable or not?*

Focusing on these questions, the following general objectives (O) were defined:

- O₁:** To clarify the concept of comfort and to identify its main attributes.
- O₂:** To adapt and validate an instrument to measure comfort in Portuguese palliative care patients.
- O₃:** To design a feasible intervention to monitor comfort in Portuguese palliative care patients.

Regarding these objectives, the following specific objectives were formulated:

- To provide a conceptually adequate definition of comfort.
- To analyse the elements that characterize comfort in scientific literature pertaining to nursing.
- To analyse the experience of PC patients about comfort.
- To perform the cultural adaptation and validation of a Portuguese version of the End of Life Comfort Planning Questionnaire in PC patients.
- To explore needs assessment and the existence of competitive validated apps.
- To analyse the use of e-health technologies and mobile apps in PC, in literature, *Google Play* and *App Store* (iOS).
- To introduce a web-based application for monitoring comfort in PC patients.

Regarding the general objectives, the following research questions (RQ) and hypotheses (H) were addressed:

RQ₁: What is the meaning and what are the attributes of the concept of comfort in the literature? (O₁).

RQ₂: Is there empirical support for the semantic and cultural validation of the End of Life Comfort Planning Questionnaire (Novak *et al.*, 2001)? (O₂).

RQ₃: Will it be possible to monitor holistic comfort remotely in Portuguese palliative home care patients through a web-based application? (O₃).

H₁: The *Comfort app* is a feasible web-based instrument to monitor comfort remotely in Portuguese palliative home care patients.

Regarding hypothesis one, the following outcomes were defined, as described on Table 1.

Table 1: Primary and secondary outcomes to assess the app feasibility and acceptability.

	OUTCOME	OPERATIONALIZATION (MEASURES)
PRIMARY OUTCOMES	<p>Feasibility The degree to which the app development is possible or not (The Mobile Assess Review Committee, 2011)</p>	<p>-Experts overall classification about the app and interrater reliability (Cohen's kappa coefficient) -Patient's overall score of the app -Patient's acceptability (measured through secondary outcomes)</p>
	<p>Acceptability The degree to which the app can be used by different users, with different needs (Moody & Woodcock, 2012)</p>	<p>-Measured through secondary outcomes (desirability, stability, responsiveness, aesthetic, ease of use, usefulness, and satisfaction)</p>
SECONDARY OUTCOMES	<p>Desirability The degree to which the app is sought-after by users (Moody & Woodcock, 2012)</p>	<p>-Number of missing data -Number of SOS messages -Patient's answer to the question: "Would you use this app in your daily life?"</p>
	<p>Stability The degree to which the app is robust and error free (Moody & Woodcock, 2012)</p>	<p>-Number of error data or outliers</p>
	<p>Responsiveness The degree to which the speed and app interaction is perceived as acceptable by users (Moody & Woodcock, 2012)</p>	<p>-Loading time (assessed on first and last evaluation) -Patient's answer to the question: "Can you describe any obstacles when using the app?" (open question)</p>
	<p>Aesthetic App visual appearance (Moody & Woodcock, 2012)</p>	<p>-Patient's answer to the question: "What is your opinion about the layout?" (Likert scale between 1 and 5)</p>
	<p>Ease of use The degree to which the app is naturally and readily used by users with success (Moody & Woodcock, 2012)</p>	<p>-Patient's answers to the questions: -"In your opinion, the Comfort app is: Very confuse, confuse, simple" -"In your opinion, how easy is to use this app?" (Likert scale between 1 and 5)</p>
	<p>Usefulness The degree to which the app is helpful for the patient (Moody & Woodcock, 2012)</p>	<p>-Patient's answer to the question "In your opinion the app is: Totally useless, useless, useful, very useful"</p>
	<p>Satisfaction The degree to which the app answer to the users' needs and expectations (Moody & Woodcock, 2012)</p>	<p>-Patient's answer to the question "In your opinion the app is: Totally useless, useless, useful, very useful" -Overall score given to the app by patients (Likert scale between 1 and 10)</p>

Reproduced from Pinto, Caldeira & Martins. *The Comfort app prototype: Introducing a web-based application for monitoring comfort in Palliative Care* (submitted to the *International Journal of Palliative Nursing*). In Chapter 2.

Specific information's regarding each study will be addressed in the correspondent article, in Chapter 2.

1.2. Study design

This study comprises a specific type of research commonly used among nurse researchers entitled *Nursing Intervention Research*.

Nursing Intervention Research embraces a research approach in which the main focus is not the methodology but the process of planning, developing, evaluating and disseminating a nursing intervention (Polit & Beck, 2014).

An intervention can be defined as any treatment based on knowledge and clinical judgment, performed by nurses, in order to enhance patient outcomes (Bulechek *et al.*, 2013). Interventions can be independent or inter-independent and comprise a set of activities that nurses perform to carry out the intervention and enhance the desired outcomes (Bulechek *et al.*, 2013). Indeed, an activity can be defined as the actions or behaviours carried out by nurses to implement a nursing intervention, and that help the patient to achieve the desired outcome (Bulechek *et al.*, 2013).

Nursing interventions have become increasingly autonomous and less dependent on medical orders. However, and as described in the Bulechek *et al.* (2013) definition, nursing interventions require knowledge. Thus, some gaps have been identified between theoretical knowledge and nursing practice. In some aspects, it seems that nursing theory has not been translated to nursing practice and, therefore, is not supporting clinical practice as nurse practitioners expected (Risjord, 2010).

These discussions raised the importance of empirical knowledge to support clinical practice (Risjord, 2010), and highlighted the idea of nursing as a complex intervention (EANS, 2016).

Thus, several methodologies have been used to develop and evaluate complex interventions (Bradley *et al.*, 1999; MRC, 2000; van Meijel *et al.*, 2004; Craig *et al.*, 2008; Craig *et al.*, 2013). These methodological approaches are analysed in more detail in a literature review, in the following topic. Results from this review highlight that the second edition of the MRC framework (Craig *et al.*, 2008) is the most common method, not only in nursing but also in other health-related contexts.

This methodology embraces the principles defined for Polit & Beck (2014) for *Nursing Intervention Research*, namely an in-depth understanding of the problem under study.

Although the relevance of all stages, a strong focus should be placed in the conceptualization of the problem (development phase), because it is the basis for a feasible and effective design (Craig *et al.*, 2008; Craig *et al.*, 2013; Polit & Beck, 2014).

This first phase include several steps, such as critical literature reviews, discussions with experts, and qualitative studies to understand the phenomena directly with the target population (Craig *et al.*, 2008; Polit & Beck, 2014). The intervention design should also be based on a consistent theoretical model, in order to achieve what needs to be done (operationalization of the problem) and the desired outcomes (Craig *et al.*, 2008; Craig *et al.*, 2013; Polit & Beck, 2014).

The second phase, piloting and feasibility, concerns the test of the intervention, to identify important barriers to the evaluation process. Among the principal objectives, this phase comprises the feasibility of the intervention, refinement of theory and protocols, possible problems with sample size recruitment and retention, as well as other variables that have not been identified in the previous phase (Craig *et al.*, 2008; Craig *et al.*, 2013; Polit & Beck, 2014).

Despite the importance of the MRC framework for health sciences (Craig *et al.*, 2008; Craig *et al.*, 2013), it also has limitations. For example, this framework focuses on the outcomes of the piloting and feasibility phase, and does not provide an adequate definition of the concepts (Whitehead, Sully & Campbell, 2014). This conceptual clarification is important because these subjects are often used incorrectly and interchangeably, while having different meanings and purposes.

The distinction among the two concepts is still a grey area, but some authors argue that while the concept of 'feasibility' represents a broader term, the concept of 'pilot' concerns a particular type of study that intends to mimic the final trial design (Whitehead, Sully & Campbell, 2014). In other words, pilot studies represent a smaller version of the clinical trial (Whitehead, Sully & Campbell, 2014; Eldridge *et al.*, 2016). Feasibility studies aim to determine if the study can or not be implemented, through the estimation of important parameters for the final design (Whitehead, Sully & Campbell, 2014; Eldridge *et al.*, 2016). For instance, while a systematic review, meta-analysis review or other study designs can be enough to assess the feasibility, this is not the case for a pilot study (Whitehead, Sully & Campbell, 2014).

The third phase, evaluation, is a classic clinical trial design to test the effectiveness of the intervention in clinical practice. This is an important phase, particularly in nursing sciences, in which effectiveness studies are rare. For instance, and for many years, nursing research focused on exploratory and descriptive studies. However, nursing knowledge needs to

evolve, not only to document the impact of nursing interventions and nursing role, but also to improve a more evidence-based practice (Richards & Borglin, 2011).

To develop evidence base for nursing interventions is, however, a complex and lengthy process (Craig *et al.*, 2008; Richards & Borglin, 2011; Craig *et al.*, 2013). Although it is useful to think in a sequential way, the process can take different approaches, with several interactions among the different phases. Indeed, and with some frequency, the process does not follow a linear sequence (Craig *et al.*, 2008; Craig *et al.*, 2013). For these reasons, Craig *et al.* (2008, 2013) proposed that the dissemination process (fourth phase) should not be implemented as a separate activity, but progressively, in the course of the different stages. This strategy can help to improve clarity as well increase monitoring of the process throughout time.

In this study, the evaluation phase was not implemented, and the research focused on the intervention development and on the feasibility study.

Still with regard to the study design, it is important to state that although *Nursing Intervention Research* (Polit & Beck, 2014) - as well the MRC framework for the study of complex interventions (Craig *et al.*, 2008; Craig *et al.*, 2013) - embraces mixed studies, it should not be reported as having a mixed methods design. According to Polit & Beck (2014, p. 385) mixed methods research can be described as a “*research in which both qualitative and quantitative data are collected and analysed, to address different but related questions*”. On the other side, and as reported before, in *Nursing Intervention Research*, the emphasis goes beyond the method to an overall process developed in several phases: planning, development, evaluation and dissemination. Thus, this type of research not only comprises quantitative and qualitative studies but also methodological studies, and literature reviews, for example (Polit & Beck, 2014).

Detailed considerations about the specific designs addressed at each stage will be provided in the following chapters, namely in the published scientific papers.

1.2.1. The use of the Medical Research Council framework
in the study of complex interventions in nursing: A literature review

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ABSTRACT

Background: The Medical Research Council (MRC) framework is being applied in health care. Nursing care addresses several complex interventions, which have been studied since 1999 using the MRC framework. International research is growing in this discipline and the European Academy of Nursing Science recommends this methodology.

Aim: To review the use of the MRC framework in developing complex interventions in nursing literature.

Review methods: A literature search was conducted using the following databases: PubMed, Web of Science, EBSCO (CINAHL complete, Nursing & Allied Health collection, MedicLatina), for the terms *complex interventions* and *nurs**. All Portuguese, Spanish, French and English papers published up to 26 May 2016 were included. A total of 287 results were identified and the sample comprised 13 papers.

Results/ Discussion: The majority of studies referred to the development or feasibility phase and were performed in the community. They were mainly focused on the physical dimension and few encompassed a holistic approach. The complexity is highlighted in the multiplicity of actors, activities and a multidimensional approach. Telemedicine arises as an emergent area inside nursing care.

Conclusion: The use of the MRC framework in the study of complex interventions within nursing literature is inadequate. The data highlight several difficulties in developing standardised complex interventions due to difficulties in the recruitment of the participants, lack of time, poor financial support, and the subjective nature of these interventions. A multidisciplinary approach may be advantageous when undertaking this type of research.

Implications for practice: Nursing researchers need to develop skills in planning and conducting research about complex interventions. Academic courses may also be helpful in improving such skills.

Keywords: Complex interventions; Medical Research Council framework; Methodology; Nursing.

INTRODUCTION

Many of the healthcare interventions are intrinsically complex, not only because they involve several actors and activities, but also due to the difficulty in defining, implementing and evaluating these interventions. According to the Medical Research Council (MRC), complex interventions are “*interventions with several interacting components, they present a number of special problems for evaluators, in addition to the practical and methodological difficulties that any successful evaluation must overcome*” (Craig *et al.*, 2008, p. 6).

The study of complex interventions using the MRC framework is recent. The first model for the development and evaluation of complex interventions was published by the MRC (2000). In 2008, the MRC (Craig *et al.*, 2008) proposed a new detailed protocol for the development, evaluation and implementation of complex interventions. This process, which aims to make these interventions more feasible, effective and reproducible, is deemed arduous and time consuming but can provide very valuable contributions to science and to society (Craig *et al.*, 2008; Hallberg, 2009).

The concept of ‘intervention’ is particularly important for nurses, for whom clinical practice comprises planning, implementing and evaluating nursing interventions, composed of several activities. The *Nursing Interventions Classification* (Bulechek *et al.*, 2013) states that nursing interventions are based on the knowledge and clinical judgment of nurses, and represent the treatment provided by nurses to obtain health outcomes.

The European Academy of Nursing Science (EANS) (2011) also states that nursing is a complex activity. Under the slogan “nursing as a complex intervention”, EANS defines the study of complex interventions as a priority in nursing research, for the development of more effective interventions. This is of particular importance as research in nursing has been essentially descriptive and exploratory (Hallberg 2009), and thus, research programmes need to be developed to test the feasibility of nursing interventions.

Methodologies for developing and evaluating complex interventions

The MRC framework is the most known and cited in literature (Craig *et al.*, 2008), but other methods have been published for the same purpose (Blakwood, 2006) (Figure 1).

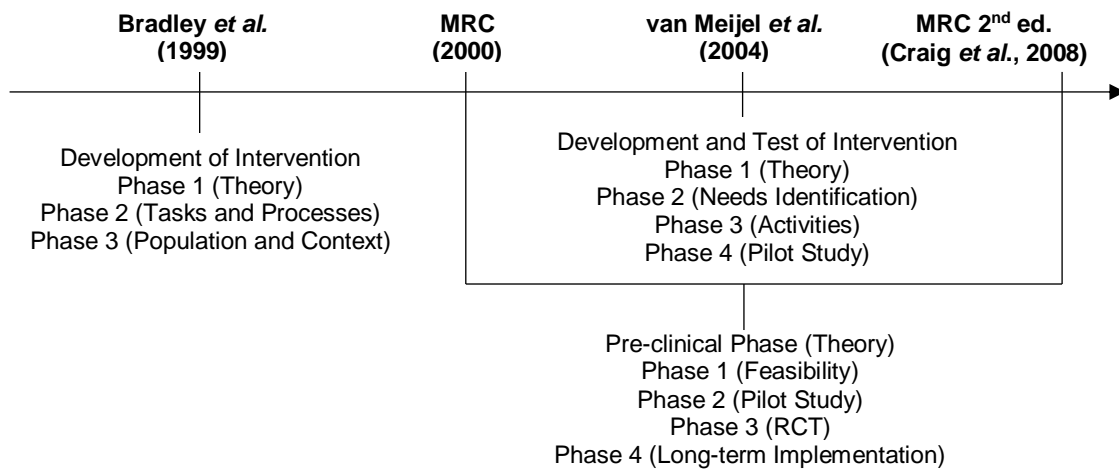


Figure 1: Methods for developing and evaluating complex interventions.

The first method was proposed by Bradley *et al.* (1999). It is based on the development of an intervention, and makes no reference to the testing phase of the intervention. In this methodology, the intervention was designed in three distinct phases: Phase 1 (review of theory and the scientific evidence); Phase 2 (forces and processes involved in the implementation process); Phase 3 (evaluation of aspects concerning the population and context in which the intervention will be performed).

In 2000, the MRC proposed a methodology aiming to develop and evaluate complex interventions that was very similar to the methodology often used for testing new drugs (MRC, 2000). This approach has five stages (Pre-clinical phase; Phase 1 - modelling processes and outcomes; Phase 2 - Pilot Study; Phase 3 – Randomized Clinical Trial (RCT); and Phase 4 – Dissemination of results and long term evaluation). This method was described as pioneering and has been heavily cited in health literature since the date of publication.

However, the first edition was the object of some criticism, which gave rise to a second revised edition in 2008 (Craig *et al.*, 2008) (Figure 2). The first edition was considered to focus mainly on the pre-clinical stage to include a more comprehensive model that could be adapted for different areas of knowledge within the health context, and to recognise that complex interventions should not be completely standardised, but rather evaluated in each context. The 2008 edition (Craig *et al.*, 2008) focused on the same steps but drew more attention to the pre-clinical stage, particularly regarding an extensive literature review and development/ identification of a theory.

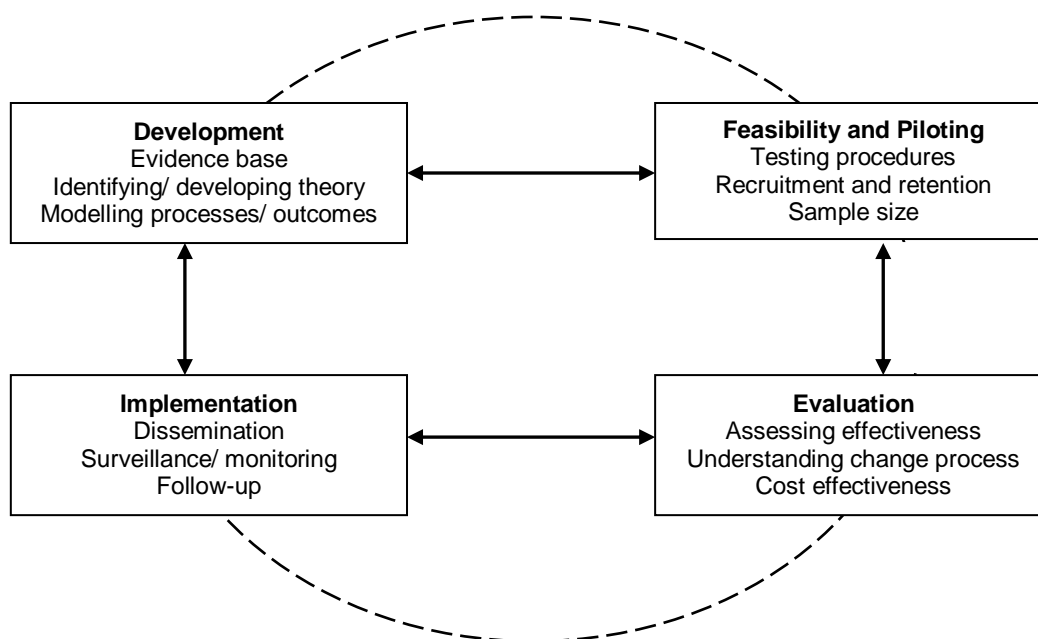


Figure 2: The MRC framework for the development and evaluation of complex interventions.
(in Craig *et al.*, 2008)

Between these two editions, van Meijel *et al.* (2004) proposed another method, organized into four phases. A literature review and identification of unfulfilled needs is recommended in Phases 1 and 2. Phase 3 is the identification and assessment of the feasibility of all activities comprising the intervention. In Phase 4, the authors proposed mixed methodologies and a pilot study to validate the intervention.

All these methods suggest an extensive and rigorous pre-clinical phase, based on a literature review. The method proposed by van Meijel *et al.* (2004) was the first to describe the pilot study as a fundamental step for testing the intervention.

AIM

To review the use of the MRC framework in developing complex interventions in nursing literature.

METHODS

This narrative literature review is based on a research protocol designed and validated by all the authors. The following databases were searched: PubMed, Web of Science, EBSCO (CINAHL complete, Nursing & Allied Health collection, MedicLatina). Firstly, an

exploratory search was conducted, followed by a combined search: (complex interventions [Title/ Abstract]) AND nurs* [Title/ Abstract] AND medical research council [All Text]). References of the selected studies were consulted and, whenever necessary, the authors were contacted to obtain the full versions. Portuguese, Spanish, French and English original papers from peer reviewed journals, published between 1 January 1999 and 26 May 2016 have been included. Additional inclusion criteria included empirical studies within the nursing context and a clear statement about the use of the MRC framework. Opinion articles, editorials, letters to the editor, literature reviews, conference presentations, books, book chapters and study protocols were excluded. The data were insert into an Excel table, and End Note X6 supported search and references management. The studies were analysed using a data grid that included: publication date, author, country, journal, aim of the study, participants and setting, MRC framework identification in the method (2000 or 2008 edition), identification of study phase (development, feasibility/piloting, evaluation or follow-up), type of intervention (preventive, therapeutic, educational), results, and limitations when reported by authors.

RESULTS

A total of 287 results were identified from the initial search and 13 studies were included in this review (Figure 3). Several studies were duplicated. Two studies were excluded (one in German and one in Italian). Among the 78 potentially relevant studies by title, 61 were excluded (literature reviews, protocol studies or studies in other areas than nursing).

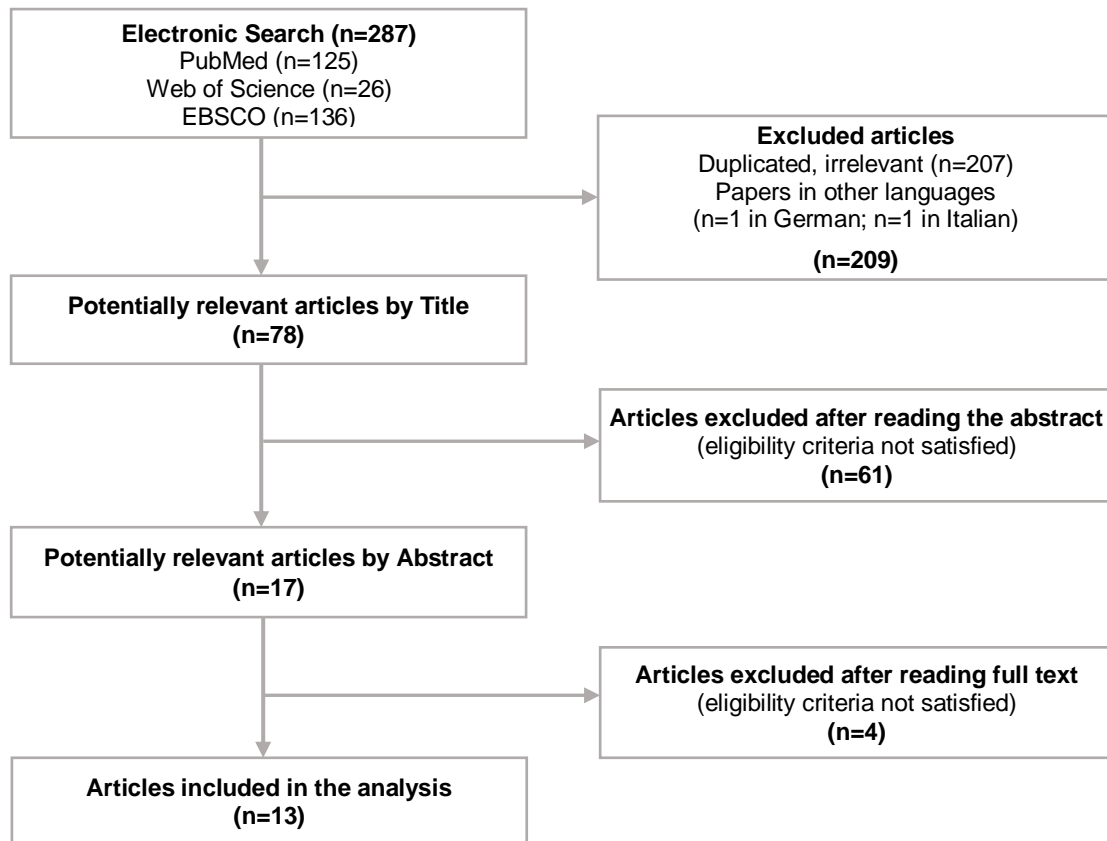


Figure 3: PRISMA diagram.

Journal

The first study was published in 2005. Six studies (46%) were published in non-nursing journals: *Clinical Rehabilitation* (Robinson *et al.*, 2005), *BMC Palliative Care* (Sampson *et al.*, 2008), *BMC Family Practice* (Barley *et al.*, 2012), *BMC Psychology* (Kirkevold *et al.*, 2014), and *BMC Health Services Research* (Kidd *et al.*, 2015).

Country

The majority of studies were conducted in European countries (n=11; 84.62%). United Kingdom has the most published studies (n=5; 38.46%), followed by the Netherlands (n=4; 30.77%), Sweden (n=1; 7.69%) and Norway (n=1; 7.69%). The studies conducted in other countries were published from 2013 onwards.

Study design

Information about the study design and the use of the MRC framework was found within the abstract or methodology section.

The majority of the selected studies were in the development phase (n=7; 53.85%) or pilot/feasibility study (n=5; 38.46%) phase. Only one study was in the evaluation phase (Table 1).

Mixed methodologies (n=6; 46.15%) were the preferred design, particularly for developing the intervention, although qualitative methods were also reported in three studies. One paper reported a RCT (evaluation of the intervention phase).

Table 1: Selected articles (n=13).

Author (Year)/ Country	Aim(s)	Phase of the Study/ Type of Intervention/ Dimension(s)	Setting	Findings	Reported Limitations
Robinson <i>et al.</i> (2005) United Kingdom	"To develop an intervention, (...) to facilitate coping skills in new carers of stroke patients" (Robinson <i>et al.</i> , 2005, p. 560).	Development Phase Preventive Intervention Psychological	Hospital (out-patient)	The theoretical basis of the intervention was established in the pre-clinical phase. The authors adopted a cognitive behavioural model and coping theory; A qualitative study was performed with carers and the intervention was modified according to the results.	Further research is needed to test validity in other carer groups.
Sampson <i>et al.</i> (2008) United Kingdom	"To develop an intervention for patients with advanced dementia and their carers (...) for advance care planning for patients" (Sampson <i>et al.</i> , 2008, p. 1).	Development Phase Preventive Intervention Physical	Hospital (in patient)	Intervention: - Assessment of the patient and carer; - Personalized advanced care planning; - Follow-up.	Difficulty in defining a good outcome in patients with advanced dementia; Difficulties in distinguish the difference between the intervention and usual/ good care.
Barley <i>et al.</i> (2012)* United Kingdom	To develop a nurse-led intervention regarding depression and cardiac outcomes.	Development Phase Preventive Intervention Biopsychosocial	Primary Care	Intervention: - Presentation to the patient; - Assessment of the patient with a standardized assessment form; - Personalized Health plan according to patient goals; - Help the patient to achieve each goal; - Discuss barriers and self-evaluation; - Follow-up care (by telephone).	In a previous phase, researchers defined three goals. However patients disliked this idea because some have more goals to achieve; In the opinion of participants, case manager should be a social contact, who helps them solve their problems.
Bleijenberg <i>et al.</i> (2013) Netherlands	To describe the development process of a primary care program to preserve physical functioning and improve quality of life in older people.	Feasibility, Pilot Study Preventive Intervention Biopsychosocial	Primary Care	- Geriatric assessment at home; - Personalized care plan; - Multiple follow-up visits.	Lack of time for geriatric assessment; Difficulties in providing holistic care to patients with different cultural backgrounds and comorbidities; Lack of financial support to provide proactive care.

Author (Year)/ Country	Aim(s)	Phase of the Study/ Type of Intervention/ Dimension(s)	Setting (continuation)	Findings	Reported Limitations
Milnes <i>et al.</i> (2013)* United Kingdom	To describe “an evidence-based pre-consultation guide for young people to use prior to an asthma review with a practice nurse” (Milnes <i>et al.</i> , 2013, p. 91).	Development Phase Preventive Intervention Biopsychosocial	Community	- The information was in a paper booklet format; - Participants reported information in paper format was a good idea but suggested information should also be on a website ; - Participants considered language “too young” and suggested more mature language.	Not reported. Negative aspects focused on the findings section were reviewed and will be tested in the trial phase.
Lindgren <i>et al.</i> (2013) Sweden	To describe and evaluate the effects of a touch massage intervention on physiological stress/ levels of anxiety in patients scheduled for elective aortic surgery.	Feasibility, Pilot Study (RCT) Therapeutic Intervention Psychological	Hospital (in-patient)	Touch massage during 60 min (arms, hands, feet and legs) decreased anxiety levels in patients scheduled for elective aortic surgery.	The randomization process was simple but blinding was impossible; Difficulty in recruiting participants to the intervention group.
Ettema <i>et al.</i> (2014)* Netherlands	To describe a nursing intervention for application in cardiac patients, in the preadmission period.	Development Phase Preventive Intervention Biopsychosocial	Hospital (out-patient)	Have structured consultation 2-4 weeks before the surgery; General information for all patients; Screen each patient for risk; Preventive information for patients with increased risk of postoperative complications.	Some patients benefit from changing medication but this is not a nurse’s responsibility; Nurses should be trained for structured consultations; Some nurses didn’t feel prepared to implement all actions related with the intervention; Possible selection bias in the selection of participants.
Kirkevold <i>et al.</i> (2014) Norway	To evaluate the content, structure and process of a psychosocial intervention to enhance well-being of stroke survivors, and to assess usefulness.	Feasibility, Pilot Study Preventive Intervention Psychosocial	Hospital (out-patient)	Intervention formats: a) individual dialogues; b) group intervention. Participants reported the “benefits of being supported through a difficult time, having a chance to tell and (re)create their story and being supported in their attempts to cope with the situation” (Kirkevold <i>et al.</i> , 2014, p.1).	Small sample; No control group.

Author (Year)/ Country	Aim(s)	Phase of the Study/ Type of Intervention/ Dimension(s)	Setting (<i>continuation</i>)	Findings	Reported Limitations
Ettema <i>et al.</i> (2015)* Netherlands	To assess the feasibility of a nursing intervention to prepare frail older patients for cardiac surgery, and estimate theoretical costs.	Feasibility, Pilot Study Preventive Intervention Biopsychosocial	Hospital (out-patient)	The programme is cost-effective; Nurses had a 4-hour training course; Data are not always available to determine patient risks and nurses aren't always prepared to determine predictor risks; The programme is acceptable but should be performed in the hospital's cardiac surgery pathway or in home care.	The program is difficult to implement in current hospitals structures; Patients and nurses reported that an additional consult is tiresome for the patient.
Kidd <i>et al.</i> (2015) United Kingdom	To develop a stroke self-management intervention for stroke survivors' in the first year post-stroke.	Development Phase Preventive Intervention Biopsychological	Hospital (outpatient)	Personalized assessment, self-management action plan (needs, goals and levels of activation), and motivational interviewing.	Possible bias in patient selection; Interviews (qualitative study) were not recorded; Small sample.
Lavoie <i>et al.</i> (2015) Canada	To describe "the development of a post-simulation educational intervention aimed at improving nurses' and nursing students' recognition and response to patient deterioration" (Lavoie <i>et al.</i> , 2015, p.181).	Development phase Educational Intervention	Nursing School	Debriefing model in which participants: - receive pre-briefing information on what to expect in the simulation environment; - reflect about what happened in the simulation.	Interventions dependent on students' clinical judgment.
Bleijenberg <i>et al.</i> (2016) Netherlands	"To assess treatment delivery, dose and content of nursing care delivered within the nurse-led care program, and to explore if the delivery may have influenced the trial results" (Bleijenberg <i>et al.</i> , 2016, p. 76).	Evaluation Phase Preventive Intervention Biopsychosocial	Primary Care	All intervention components were delivered but there are differences in the type and dose of the nursing intervention, which is dependent on several factors such as patients' preferences and type of problems.	Not all interventions were reported due to the lack of time; Program based on patients' needs making results evaluation/quantification difficult.
Bergin <i>et al.</i> (2016)* Australia	To describe the development and feasibility of a psychoeducational intervention to improve psychosocial outcomes for gynaecologic-oncology patients under radiotherapy.	Feasibility, Pilot Study Preventive Intervention Biopsychosocial	Hospital (setting not specified)	The intervention is a combination of "tailored nursing consultations with telephone peer support pre-treatment, mid-treatment, end of treatment, and post-treatment" (Bergin <i>et al.</i> , 2016, p.1); The intervention was tested with 6 patients; 50% patients preferred telephone consultation rather than face-to-face.	Consent rate was lower than planned (60% vs 70%); It was not possible to perform a standard intervention; The two weeks post-intervention consultation was modified to a nurse phone call, according to the results of the modelling phase.

Legend: *Studies with funding; RCT (Randomized Clinical Trial)

Participants and setting

Most studies were conducted in hospitals (n=8; 61.54%), and one study does not give clear information on this subject (Bergin *et al.*, 2016). The main goal in the included studies was the development of patient-centred interventions, but two studies focused on the caregivers' needs (Robinson *et al.*, 2005; Sampson *et al.*, 2008).

Complex intervention

Data highlighted several themes and interventions. The majority of the interventions under study had a preventive nature (n=11; 84.62%). In one study the intervention had a therapeutic intention (touch massage) (Lindgren *et al.*, 2013), and another one had educational goals (Lavoie *et al.*, 2015). In most cases, the outcomes were focused on biopsychosocial dimensions (n=8; 61.54%). Two studies focused only on the psychological dimension (Robinson *et al.*, 2005; Lindgren *et al.*, 2013), and another one on the physical dimension (Sampson *et al.*, 2008). One study reported the use of telemedicine as a resource for development of the intervention (Barley *et al.*, 2012).

Findings and limitations of the studies

The studies reported the benefits of using the MRC framework for developing/ evaluating complex interventions. However, some authors (Sampson *et al.*, 2008) described difficulties in developing a standardized intervention due to the complex nature, as the intervention needed a multidimensional approach and included co-morbidities, individual needs and goals of each participant (Box 1).

Pilot studies were described as crucial in this phase of the design. The main difficulties in the pilot studies were: defining the outcome, especially when patients had difficulties in expressing their needs (e.g. patients with dementia in advanced stages) (Sampson *et al.*, 2008); recruiting participants for the study (Lindgren *et al.*, 2013); adapting information and materials according to participants' needs or characteristics (Milnes *et al.*, 2013); and difficulty in preparing research collaborators adequately (Ettema *et al.* 2014). Lack of time and financial support have also been reported as factors that discourage health teams (nurses and doctors) in actively participating in this type of studies (Bleijenberg *et al.*, 2013, 2016), which may compromise the results (Box 1). A study also reported that healthcare professionals might not have documented all interventions due to lack of time, which limited the analysis of the data (Bleijenberg *et al.*, 2016).

Box 1: Limitations in the use of the MRC framework.

Limitations
<ul style="list-style-type: none">- Difficulty in developing a standardized intervention<ul style="list-style-type: none">- Difficulty in defining outcomes- Difficulty in recruiting participants- Lack of time- Difficulty in preparing researchers adequately<ul style="list-style-type: none">- Lack of financial support- Difficulties in documenting all interventions performed along the study

DISCUSSION

The European Academy of Nursing Science (2011) considers the study of complex interventions as a research priority in nursing and suggests the use of the MRC framework (Craig *et al.*, 2008). However, only a few studies in nursing clearly use this methodology. A significant growth in the study of complex interventions since 2008 is observed, and it is interesting to note that one study (Robinson *et al.*, 2005) uses the methodology as proposed in the first edition (MRC, 2000).

Nevertheless, the findings highlight a certain paradox regarding the complexity of the interventions and the holistic nature of the nursing process. The majority of the studies focus on the development of interventions with preventive objectives. Most studies continue to focus on the physical dimension when analysing the effect of the interventions. Even when studies have suggested having a multidimensional approach, several difficulties in the modelling phase related to the development and the assessment of holistic interventions have been reported, particularly in the psychological and social dimensions. No outcomes related to the spiritual dimension were identified in the studies or concerning the impact of the environment or context of the interventions in testing. This fact is especially relevant among other studies since the context in which the intervention is tested (hospital, home, nursing home) may be a confounding factor with important effects on the results of a complex intervention.

Thus, the use of the MRC framework has several benefits and allows researchers to obtain a better look and implement the intervention before the experimental trial. In fact, this framework allows researchers to carry out extensive theoretical work in the pre-clinical phase, which improves the design of more feasible and effective interventions. Another strength of the use of the MRC framework (Craig *et al.*, 2008) is the possibility of

conducting quasi-experimental designs when RCTs are not possible. This possibility is clearly important when taking into account the difficulties expressed in the results sections (small samples, for eg.), but also in other contexts, such as palliative care, or patients suffering from rare diseases. Despite the importance of RCTs in the evaluation of the effectiveness of an intervention, they are limited in these contexts due to the difficulties to recruit adequate sample sizes or develop long follow-up periods, for example (Visser *et al.*, 2015). For this reason, and as proposed in the second edition of the MRC framework (Craig *et al.*, 2008), as well as by other authors (Visser *et al.*, 2015), non-RCTs with equivalent quality should be considered in the development and evaluation of complex interventions.

Despite these considerations, the MRC also has some limitations. As reported before, the framework is extensive and lengthy, and frequently involves several researchers. Thus, this framework (Craig *et al.*, 2008) uses the concepts of feasibility and pilot study interchangeably, while in fact they have different definitions. According to Whitehead *et al.* (2014), feasibility studies aim to determine which parameters are important to the study design, because these may be absent in the theoretical design (such as sample recruiting difficulties, determining sample size or determining standard deviation in the outcomes assessment). Moreover, the final design must be implemented and assessed in pilot studies, as these are intended to ensure the strict implementation of the intervention and not to compare effects between groups (performed at the experimental phase). For instance, the second edition of the MRC framework (Craig *et al.*, 2008) is not absolutely clear in this field, which can cause difficulties among less experienced researchers.

The current study is not also free of limitations. The reference to the MRC framework (Craig *et al.*, 2008) is relatively frequent in the pre-clinical or modelling phases of the studies. However, as studies advance in time, there is a tendency to indicate only the type of study design, without any mention of the study phase in the MRC framework and this raises uncertainty about the design. This missing information in the articles may have introduced a selection bias in the screening phase, and therefore, it is possible that many other studies conducted using the MRC framework may exist.

CONCLUSION

The use of the MRC framework in the study of complex interventions is quite recent in nursing research. The first studies were performed in Europe, with adult participants who were ill in hospital or community contexts. This opens new opportunities for performing research in other clinical areas.

The MRC framework enhances the design of more feasible and effective interventions, developed through a systematic and consistent approach. However, this is a lengthy and exhaustive process that requires time. The lack of time of health care professionals, difficulties in the recruitment of adequate sample sizes, as well as lack of financial support are important limitations reported in the literature. Nevertheless, researchers point out difficulties in developing standardized interventions and defining outcomes.

Also, researchers need to develop skills in planning and conducting research of complex interventions, controlling the bias, and providing guarantees of a rigorous process. Furthermore, specific preparation in academic research degrees and in healthcare institutions would be helpful to develop research skills regarding the development and evaluation of complex interventions in nursing.

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1.3. Population

A population can be defined as the whole group of interest about which some information is required (Polit & Beck, 2014).

Due to the impossibility of accessing the entire group, a set of eligibility criteria are frequently defined, in order to help the researcher find the target-population (the population group in which the researcher is interested) and, consecutively, the accessible population, “*the portion of the target population group that is accessible to the researcher*” (Polit & Beck, 2014, p. 177).

This study aims to design a specific intervention to PC patients. Among this overall population group, the study is particularly targeted to adult PC patients at home (target population).

Specific information related to the sample and participants will be provided in each study, in Chapter 2.

1.4. Ethical procedures

Applied research is important for obtaining knowledge that allows the incorporation of consistent results in clinical practice (Nunes, 2013). Studies with patients have increased ethical responsibilities as the disease exposes the individual to a greater risk of vulnerability (Gysels, Evans & Higginson, 2012).

Scientific evidence has shown that patients, including those who are at the end of life, consider their participation in studies as very beneficial because although it does not always bring direct benefits, it can improve care for other patients (Gysels, Evans & Higginson, 2012).

However, ethical responsibilities are not restricted to participants. It extend to other stakeholders and contexts, and are present from the formulation of the problem to the knowledge dissemination (Nunes, 2013).

A set of formal and ethical procedures have been defined, in order to ensure respect for human dignity and protection of human rights at different stages of the research process (Table 1).

Lastly, it is important to emphasize that the primacy of the human being overrides the interests of research, which is why rights, decisions and needs of the participants were always respected.

Table 1: Ethical considerations throughout the study.
(Adapted from Nunes, 2013)

RESEARCH PROBLEM
<ul style="list-style-type: none"> - The theme, “Comforting in Palliative Care: Development and evaluation of a nursing complex intervention”, is relevant to the practice of nursing care, particularly in the specific context of PC. - Preliminary literature reviews identified gaps in the literature, namely in nursing classifications and taxonomies of nursing knowledge, and more studies are required to clarify the concept. - The development and evaluation of complex interventions is a research priority for nursing research in Portugal and in Europe (Ordem dos Enfermeiros, 2010; EANS, 2016).
LITERATURE REVIEW
<ul style="list-style-type: none"> - The literature review was an ongoing process, based on the rigour and demand for the most current scientific evidence. Whenever possible, primary sources were cited. - The intellectual honesty was ensured in all references.
FORMAL AUTHORIZATIONS
<ul style="list-style-type: none"> - Formal authorization was requested from the head of the institutions and departments where the several studies were developed. - In all departments, there was a nurse to link the researcher and participants. - In the process of adaptation and validation of instruments, prior authorization was requested from the authors of the original instruments (Appendices 1 and 2).
STUDY PARTICIPANTS
<ul style="list-style-type: none"> - Studies with patient’s participation were submitted and approved by the institutional Ethics Committee (Appendices 3, 4 and 5). - Written informed consent was obtained from all participants. The voluntary nature of their participation and the possibility of withdrawal at any time were ensured without any inconvenience.
DATA COLLECTION AND ANALYSIS
<ul style="list-style-type: none"> - The anonymity and confidentiality of the data were a constant concern throughout the investigation. - Questionnaires and interviews were coded. - The data were analysed together, without participant’s identification. - The questionnaires were written clearly, legibly and as succinctly as possible. - Patients with difficulties in completing the questionnaires were assisted by the principal researcher. - The data were analysed in an honest and rigorous manner and confronted with the scientific evidence produced by other authors.
CONCEPTUAL FRAMEWORK
<ul style="list-style-type: none"> - The conceptual framework was developed in a continuous and rigorous way. Whenever necessary partnerships with international experts were conducted to improve discussion, methodological rigour and quality. - The intervention was defined in the theoretical field (concept analysis, nursing classifications and taxonomies) and in clinical practice (development of a web-based prototype to monitor comfort in PC patients).
KNOWLEDGE DISSEMINATION
<ul style="list-style-type: none"> - The anonymity of participants and confidentiality of the responses was ensured in all forms of knowledge dissemination (scientific articles, oral communications, posters, thesis). - The results were published in international journals that were scientifically relevant, indexed and peer reviewed. - Whenever possible, results were presented in international and national meetings with scientific relevance (posters and oral communications).

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Specific references of the scientific papers within this chapter are provided at the end of the paper. The references are in accordance with the journal guidelines.

CHAPTER 2: DEVELOPING AN INTERVENTION

This chapter addresses one of the most important phases of the study: the conceptual framework that was on the basis of the intervention design.

This phase comprises several studies, developed in three stages. In the first one, several literature reviews were conducted in order to a better understanding of the research problem. In the second stage, the theoretical approach was constructed, based on Kolcaba's (2003) Comfort Theory. Still at this stage, a concept analysis study was realized and similarities and differences among related concepts were discussed. Last, in the third phase, several studies were conducted for the modelling of processes and outcomes. These studies include a discussion paper about the impaired comfort (00214) diagnosis proposed by NANDA-I (Herdman & Kamitsuru, 2014), a qualitative study about PC patients' experiences of comfort, a methodological study regarding the cultural adaptation and validation of an instrument to measure comfort, and the prototype design of a web-based intervention to monitor comfort in PC patients.

2.1. Identifying the evidence-base

Evidence-base was searched in a sequential logic, according to the research needs, and guided the course of the investigation. It was a main concern to base the design and the intervention development on the best and more recent evidence.

This sub-heading meets three scientific studies, two of which were submitted/ published in scientific journals.

The first paper concerns a literature review about the state of the art in PC, in Portugal. This was a preliminary paper, written within the first year of the PhD. The first aim was to identify gaps and priorities in research, in order to choose a relevant theme in theory and in clinical practice.

After the topic was decided, a literature review was conducted to characterize comfort, in order to have a better understanding of the phenomena.

The third study is a poster presentation about the comparison of comfort and comforting in the three principal classifications and taxonomies of nursing knowledge: the ICNP® (ICN, 2015), NANDA-I (Herdman & Kamitsuru, 2014), and the International Classification of Functioning and Disability (ICF) (WHO, 2004).

These studies were key to better understand comfort in literature, particularly since the Kolcaba's (2003) Comfort Theory was published, allowing for the design of a more feasible intervention.

2.1.1. Investigación en cuidados paliativos y enfermería:
Revisión sistemática sobre el estado del arte en Portugal

Pinto, S., Martins, J.C. & Barbieri-Figueiredo, M.C.

Article published in *Índex de Enfermeria* (2014), 23(3), 178-182.

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Investigación en cuidados paliativos y Enfermería:

REVISIÓN SISTEMÁTICA SOBRE EL ESTADO DEL ARTE EN PORTUGAL

Sara PINTO,¹ José Carlos MARTINS,² Maria do Céu BARBIERI-FIGUEIREDO³

Resumen Abstract

Objetivo principal: Sintetizar y analizar el contenido y la naturaleza de la evidencia científica producida en el ámbito de los cuidados paliativos en Portugal. **Metodología:** investigación sistemática de la literatura (manual y bases de datos) de los trabajos de investigación realizados en Portugal y publicados en revistas científicas hasta 31 de diciembre de 2012. **Resultados principales:** Se encontraron 49 artículos, predominando los estudios de naturaleza cuantitativa y longitudinal. La mayoría se desarrolló en contexto hospitalario y se relacionó con las necesidades de los enfermos o con las decisiones de los profesionales de salud en materia de fin de vida. En los últimos años, los enfermeros han contribuido de forma muy significativa para la producción científica en cuidados paliativos, lo que significa que en 2012 produjeron el 53% de los trabajos publicados. **Conclusión principal:** Aunque es reciente, la investigación en cuidados paliativos en Portugal se encuentra activa y en crecimiento. Este trabajo sistematiza la producción realizada hasta el momento, abriendo puertas para futuros trabajos.

Palabras Clave: Cuidados Paliativos. Investigación en Enfermería. Revisión.

PALLIATIVE CARE RESEARCH AND NURSING: A SYSTEMATIC REVIEW ON THE STATE OF THE ART IN PORTUGAL

Objective: To summarize and analyze the content of the scientific evidence produced in the context of palliative care in Portugal. **Methods:** A systematic literature review (manual and databases) of research conducted in Portugal and published in scientific journals until December 31, 2012. **Results:** 49 papers were retrieved predominantly quantitative and longitudinal studies. The majority of the studies was developed in the hospital setting and were related to the needs of patients or with health professional decisions regarding end of life. In recent years, nurses have contributed very significantly to the scientific literature in palliative care, and in 2012 held 53% of the published papers. **Conclusions:** Although recent, research in palliative care in Portugal is active and growing. The present work provides further production undertaken to date and opens perspective for future works.

Keywords: Palliative Care, Nursing Research, Review.

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Introducción

Los cuidados paliativos (CP) están definidos por la Organización Mundial de la Salud como un tipo específico de cuidados cuya misión es promover la mejor calidad de vida posible a las personas que enfrentan una enfermedad incurable, grave y con pronóstico limitado. Un enfoque multidisciplinar, el rigor de las intervenciones y la investigación son elementos clave en la prevención y alivio del sufrimiento físico, psicológico, social y espiritual.¹

La visión holística del hombre y la atención a la totalidad de la experiencia humana constituyen preocupaciones centrales en la atención de las necesidades del enfermo y familia, por lo que los CP están íntimamente asociados a la práctica de los cuidados de enfermería. Este movimiento es reciente en Portugal, habiendo ganado relevancia en los últimos 20 años. El gran estímulo surgió con la creación de la primera unidad de CP, en 1992, y se consolidó con la creación de la "Associação Nacional de Cuidados Paliativos" en 1995. En 2004, el Ministerio de la Salud portugués publica el "Programa Nacional de Cuidados Paliativos" y, en 2006, presenta el decreto ley 101/2006, que crea la "Red Nacional de Cuidados Continuados Integrados", cuyo objetivo es descentralizar la práctica de los cuidados del medio hospitalario.²

La investigación y la formación fueron señaladas como promotores importantes para el desarrollo y cualificación de los servicios,^{2,3} existiendo un extenso e importante legado internacional en estas áreas. Según una revisión sistemática, hasta 2002 fueron realizados más de 1000 trabajos de investigación en todo el mundo.⁴ En Portugal, sabemos que el número de estudios está creciendo.³

Debido al envejecimiento de la población portuguesa, los cuidados paliativos son cada vez más pertinentes, siendo prioritario conocer el estado del arte de la investigación realizada en este dominio. Este conocimiento permitirá sistematizar la información y potenciar la eficacia y eficiencia de investigaciones futuras, sobre todo en el ámbito de los cuidados de enfermería.

Este estudio tiene como objetivos: sintetizar la

evidencia científica realizada en cuidados paliativos en Portugal y publicada hasta 31 de diciembre de 2012 en revistas de naturaleza científica; analizar las temáticas más estudiadas y principales diseños de estudio; analizar la producción científica realizada por enfermeros.

Metodología

Pregunta de investigación y criterios de selección. El estudio tuvo la siguiente pregunta de investigación: "¿Cuál es el contenido y la naturaleza de los trabajos de investigación realizados en cuidados paliativos en Portugal y publicados en revistas de naturaleza científica hasta 31 de diciembre de 2012?". Se incluyeron todos los estudios con metodología científica (cualquiera que fuera el diseño), realizados en Portugal en el ámbito de los cuidados paliativos y publicados en revistas de naturaleza científica hasta 31 de diciembre de 2012. Solo se incorporaron estudios publicados en lengua portuguesa, española, francesa e inglesa. Se excluyeron las revisiones narrativas, los artículos de opinión o reflexión, los editoriales y las presentaciones en congresos o conferencias. Se excluyeron igualmente los estudios que, aunque fueron realizados en Portugal o tuvieron la colaboración de autores portugueses, fueron desarrollados por equipos internacionales en distintos países.

Estrategias de búsqueda. La investigación fue desarrollada de forma independiente por tres investigadores. Esta investigación se centró en las bases de datos electrónicas de *PubMed*, *EBSCO (CINAHL)*, *CUIDEN*, *PsycInfo*, *EMBASE*, *SCOPUS* y *Cochrane Library*. Se utilizaron los siguientes términos de búsqueda: cuidados paliativos, palliative care, hospice

care, end of life, terminal care, portugal y portuguese.

La estrategia de búsqueda electrónica podrá resumirse en la siguiente secuencia: (cuidados paliativos OR palliative care OR end of life OR terminal care OR palliat*) AND (portugal OR portuguese OR portug* OR portuguese).

Paralelamente, se hizo una búsqueda manual en dos revistas portuguesas ("Cadernos de Saúde" y "Cadernos de Bioética"), ya que estos, pese a que no se encuentren indexados en una base de datos, publican diversos trabajos en el ámbito de los CP. Se consultaron aún todas las referencias bibliográficas de los artículos seleccionados. Siempre que fue necesario, se comunicó con el autor del estudio, para que se pudiera obtener la versión integral del mismo.

Selección de los estudios. Se analizaron los trabajos a través de su título, resumen y lectura integral. Las divergencias se analizaron y las decisiones se tomaron en conjunto. Después de incluir los artículos en una base de datos a través del programa EndNote X6, estos fueron clasificados como relevantes, potencialmente relevantes o irrelevantes. Se consideraron irrelevantes los artículos duplicados, así como los que no cumplían la totalidad de los criterios de elegibilidad. Se consideraron potencialmente relevantes todos los artículos cuya lectura del título o resumen no era suficientemente clara en cuanto al cumplimiento de los criterios definidos, motivando una lectura más profunda del mismo. Todos los artículos que cumplían la totalidad de los criterios de selección fueron clasificados como relevantes. En total, se identificaron 339 artículos. No se encontraron revisiones sistemáticas sobre el tema en la *Cochrane Library*. Para esta revisión elegimos 49

artículos. La figura 1 presenta, de forma esquemática, el proceso de selección de los artículos.

Extracción, Síntesis y Análisis de los Datos. Se extrajeron datos relativos a la autoría del trabajo (revista, año de publicación, diseño del estudio, participantes, contexto, temática y artículos producidos en el ámbito de la Enfermería). El término "contexto" se refiere al lugar donde se realizó el estudio.

Los datos se introdujeron en una base de datos y

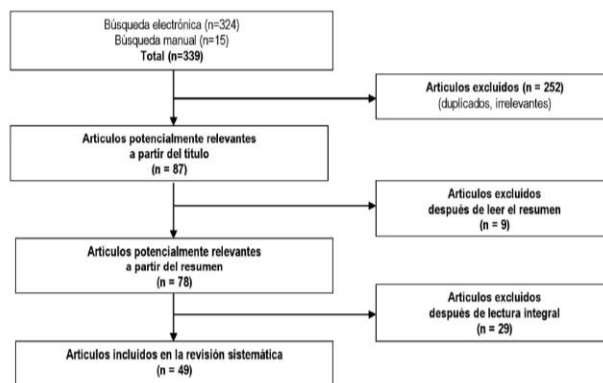


Figura 1. Estrategia de Selección de Artículos

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fueron analizados en conjunto. A continuación se calcularon las estadísticas descriptivas y se analizó el contenido de los estudios.

Resultados y Discusión

Los artículos seleccionados, cuyos datos presentaremos y discutiremos a continuación, se encuentran presentes en la Tabla 1.

Año de Publicación. El primer artículo se publicó en 1995, lo que coincide con la creación de la primera unidad de CP portuguesa.² El número de publicaciones aumentó a partir de 2008, siendo 2011 (n=9) y 2012 (n=17) los años que presentan más artículos publicados. A este aumento habrán contribuido dos eventos científicos importantes: el “Congresso Nacional e Lusófono de Cuidados Paliativos” (2012) y el “Congresso Europeu de Cuidados Paliativos” (2011), ambos realizados en ciudades portuguesas. En 2008 y 2010 – y al contrario de lo que sucedió en 2009 (n=1) – hubo un número considerable de trabajos publicados, lo que podrá justificarse con la edición de suplementos dedicados a los CP por revistas portuguesas.³

A partir de los artículos publicados en 2012, se concluye que el 52.94% de estos se realizaron en el ámbito de la Enfermería, lo que sugiere que hay un creciente interés por parte de los enfermeros por esta área, así como su contribución es importante para una práctica de cuidados sostenida por la evidencia científica.

Revista. Los 49 artículos seleccionados fueron publicados en 26 revistas (Tabla 1). De estas, solamente 11 fueron publicados en revistas del área de los cuidados paliativos. Aunque la mayoría de los trabajos hayan sido divulgados en revistas internacionales (73.46%), dos de las que contienen más artículos publicados son portuguesas: “Acta Médica Portuguesa” (n=5) y “Revista de Enfermagem Referência” (n=7).

Respecto al idioma, constatamos que el 61.22% de los estudios fueron publicados en inglés, idioma de referencia en la comunidad científica. Los otros 38.78% están escritos en portugués o español, lo que podrá constituir una limitación en la divulgación del conocimiento.

No se observó una relación directa entre el factor de impacto de las revistas y el número de artículos publicados, pero se concluyó que los autores suelen elegir

Tabla 1. Artículos seleccionados (n=49)

Autor (Año de Publicación)	Revista (n)
Oliveira y Pimentel (2008) ⁽⁵⁾	Acta Médica Portuguesa (n=5)
Ferreira y Pinto (2008) ⁽⁶⁾	
Carneiro et al (2010) ⁽⁷⁾	
Delalibera, Coelho y Barbosa (2011) ⁽⁸⁾	
Carneiro et al (2011) ⁽⁹⁾	
Sapeta y Lopes (2007) ⁽¹⁰⁾	Revista de Enfermagem Referência (n=7)
Frias (2008) ⁽¹¹⁾	
Pereira y Santos (2011) ⁽¹²⁾	
Fonseca Cruz y Neto (2012) ⁽¹³⁾	
Pinto, Caldeira y Martins (2012) ⁽¹⁴⁾	
Alves, Jardim y Freitas (2012) ⁽¹⁵⁾	
Costa y Antunes (2012) ⁽¹⁶⁾	
Gonçalves et al (2006) ⁽¹⁷⁾	Support Care Cancer (n=5)
Gonçalves y Goyanes (2008) ⁽¹⁸⁾	
Gonçalves (2010) ⁽¹⁹⁾	
Gonçalves et al (2012) ⁽²⁰⁾	
Gonçalves (2010) ⁽²¹⁾	
Pereira et al (2011) ⁽²²⁾	International Journal of Palliative Nursing (n=4)
Pereira, Fonseca y Carvalho (2012) ⁽²³⁾	
Gama, Barbosa y Vieira (2012) ⁽²⁴⁾	
Fonseca, Gonçalves y Pereira (2010) ⁽²⁵⁾	
Gonçalves et al (2005) ⁽²⁶⁾	Palliative Medicine (n=3)
Gonçalves et al (2008) ⁽²⁷⁾	
Gonçalves y Castro (2011) ⁽²⁸⁾	
Gonçalves, Alvarenga y Silva (2003) ⁽²⁹⁾	Journal of Palliative Medicine (n=2)
Gonçalves et al (2005) ⁽³⁰⁾	
Gonçalves et al (2012) ⁽³¹⁾	American Journal of Hospice & Palliative Medicine (n=2)
Gonçalves et al (2012) ⁽³²⁾	
Pereira, Fonseca y Carvalho (2010) ⁽³³⁾	Nursing Ethics (n=2)
Fernandes y Moreira (2012) ⁽³⁴⁾	
Freitas et al (1995) ⁽³⁵⁾	Hepatogastroenterology (n=2)
Amaral et al (2012) ⁽³⁶⁾	
Maciel, Barbosa y Leal (1996) ⁽³⁷⁾	European Journal of Surgical Oncology (n=1)
Ganja et al (2001) ⁽³⁸⁾	Intensive Care Medicine (n=1)
Cardoso et al (2003) ⁽³⁹⁾	Critical Care (n=1)
Braga et al (2007) ⁽⁴⁰⁾	Psycho-Oncology (n=1)
Fonseca y Rebelo (2008) ⁽⁴¹⁾	Revista Brasileira de Enfermagem (n=1)
Oliveira y Pimentel (2008) ⁽⁴²⁾	Progress in Palliative Care (n=1)
Mendes et al (2009) ⁽⁴³⁾	Revista Portuguesa de Cardiologia (n=1)
Carvalho y Botelho (2011) ⁽⁴⁴⁾	Pensar Enfermagem (n=1)
Moura et al (2011) ⁽⁴⁵⁾	Clinics (S. Paulo) (n=1)
Melo y Oliveira (2011) ⁽⁴⁶⁾	Journal of Palliative Care (n=1)
Martins y Basto (2011) ⁽⁴⁷⁾	Journal of Hospice and Palliative Nursing (n=1)
Liberato y Canena (2012) ⁽⁴⁸⁾	BMC Gastroenterology (n=1)
Canena et al (2012) ⁽⁴⁹⁾	Revista Española de Enfermedades Digestivas (n=1)
Pinto, Caldeira y Martins (2012) ⁽⁵⁰⁾	Cuidarte Enfermagem (n=1)
Canena et al (2012) ⁽⁵¹⁾	European Journal of Gastroenterology and Hepatology (n=1)
Ferreira et al (2012) ⁽⁵²⁾	Dis Esophagus (n=1)
Peladinho y Lampreia (2012) ⁽⁵³⁾	Revista Enfermagem UFPE online (n=1)

revistas con factor de impacto y credibilidad para la publicación de sus trabajos. Catorce artículos fueron publicados en revistas que no presentan factor de impacto hasta el momento, pero que, sin embargo, presentan algún estatuto y credibilidad en la comunidad científica y académica: Revista de Enfermagem Referência (n=7), International Journal of Palliative Nursing (n=4), Pensar Enfermagem, Revista Enfermagem UFPE online y Cuidarte (n=1).

Participantes y contexto del estudio. La gran parte de los trabajos se desarrolló teniendo en cuenta las necesidades de los enfermos

que se encuentran en final de vida (53.33%), siguiéndose los estudios que se basan en las experiencias de los profesionales de salud (31.11%). Solo un estudio fue realizado en contexto pediátrico.

A pesar de las dificultades inherentes a la ejecución de los estudios con enfermos terminales, los datos enseñan el reciente cambio de paradigmas en la investigación en CP, sugiriendo que, aunque hay limitaciones impuestas por el hecho de que la enfermedad es terminal, los enfermos se encuentran receptivos a su realización. Su participación en estos estudios puede ser una experiencia importante, incluso terapéutica.

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ética, siempre que se cumplan los principios éticos.^{4,54} La mayoría de los trabajos se llevaron a cabo en contexto hospitalario (71.43%), probablemente asociado al hecho de que la muerte sigue ocurriendo predominantemente en el hospital.²

Diseño del Estudio. Casi todos los trabajos son de naturaleza cuantitativa (n=33), predominando los estudios longitudinales (n=20) y, dentro de estos, los retrospectivos (n=13). Se encontraron 6 estudios cualitativos, 4 metodológicos, 5 revisiones sistemáticas de la literatura, 1 de naturaleza mixta y 3 estudios cuasi experimentales (todos relacionados con la prueba de nuevas técnicas quirúrgicas para la atenuación de síntomas). Como está documentado en otros trabajos, no se encontraron estudios experimentales puros.³

Aunque sean aún poco frecuentes (n=6), los estudios de naturaleza cualitativa empezaron a surgir de manera constante a partir de 2010, sobre todo debido a la contribución de los enfermeros. Estos estudios siguen ganando relieve en CP, sobre todo respecto al estudio de las vivencias, percepciones y expectativas de los enfermos, cuidadores y profesionales de salud.

Hay también un interés creciente por la adaptación y validación de instrumentos de medida y por la realización de revisiones sistemáticas de la literatura. Estudios internacionales confirman la necesidad de estos trabajos, defendiendo el recurso a metodologías que permitan el desarrollo del conocimiento de forma rigurosa, válida, fiable y éticamente aceptable.⁵⁴

Temáticas Estudiadas. Los temas dominantes (Tabla 2) fueron los cuidados prestados al enfermo en la fase final de su vida, en un periodo comprendido entre los últimos 6 meses y las últimas dos horas de vida (n=10), siguiéndose las actitudes de los profesionales ante la muerte del enfermo (n=9) y la evaluación de nuevas técnicas para la atenuación de síntomas (n=7). La diversidad de temas no permitió ejecutar una revisión con meta análisis o revisión integrativa, a semejanza de lo que ya había sucedido en un estudio exploratorio realizado en Portugal entre 2005 y 2010.³

No se observaron trabajos sobre las necesidades de los enfermos en fase terminal, ni siquiera sobre su preferencia sobre el lugar de su muerte, temas estos que son bastante debatidos al nivel internacional. No se encontraron igualmente estudios sobre el impacto económico de un internamiento en CP frente a un internamiento

hospitalario o a la asistencia por un equipo de apoyo domiciliario, ni sobre las dificultades durante la transición o referencia de enfermos para los cuidados paliativos. Estos datos chocan con una revisión sistemática de la literatura realizada en 2002, sobre la evidencia producida hasta aquella fecha al nivel mundial.⁴ Los autores concluyeron que la producción científica es elevada (más de 1000 artículos), pero siguen existiendo áreas poco exploradas, tales como las barreras en el acceso a los CP, el estudio de las dimensiones psicosocial y espiritual y los cuidados prestados a algunos grupos, como lo de los ancianos.⁴

Artículos desarrollados en el ámbito de las Ciencias de la Enfermería. De los 49 artículos, 18 se realizaron por enfermeros, lo que equivale a 36.73% del total de la producción científica encontrada. La producción científica desarrollada en el ámbito de la Enfermería se está volviendo cada vez más importante y ganando más relieve, siendo que en 2012 tal hecho representó 53% de las publicaciones (n=9).

En los temas estudiados se distingue una visión más holística y multidimensional, abordando sobre todo temas como la espiritualidad, las actitudes de los profesionales y expectativas del enfermo. La gran mayoría de los trabajos fueron publicados en revistas internacionales (n=10), pero solamente 5 fueron publicados en revistas del ámbito específico de los CP. Se verifica que un número significativo (n=8) publicó en portugués, lo que podrá constituir una limitación a la diseminación de este conocimiento.

Conclusiones

A pesar de que los CP son recientes en Portugal, la creación de másteres en esta área y la realización de conferencias inter-

nacionales en el país, contribuyeron significativamente a la producción del conocimiento.

Los trabajos producidos por enfermeros representan cerca de 37% del total de la producción nacional pero, en 2012, constituían 53% del total de los trabajos publicados. Estos datos nos alertan para el despertar de la Enfermería como ciencia, pero también para la importancia e impacto que los enfermeros pueden representar en la investigación y en la prestación de los cuidados al enfermo y su familia.

Aunque los temas sean heterogéneos, los cuidados al enfermo en final de vida y el estudio de nuevas técnicas para atenuación de síntomas son los más estudiados. Como los diseños de estudio son igualmente heterogéneos, no es posible llevar a cabo, con los datos que se recogieron hasta ahora, estudios de meta análisis o revisiones integradoras. No se encontraron estudios de naturaleza económica, ni estudios relativos a las necesidades de los enfermos en fin de vida.

La investigación en CP, sobre todo en el ámbito de la Enfermería, se encuentra en una fase activa y de crecimiento, existiendo, sin embargo, un largo camino por recorrer.

Hay aún muchas áreas para explorar y, por lo tanto, la investigación y formación, señaladas como importantes agentes en el desarrollo y cualificación de los servicios, deben ser estimuladas.

El trabajo realizado abre camino a investigaciones futuras, no solo en el contexto de la práctica, sino también al nivel de la educación y del desarrollo de modelos y teorías subyacentes a la prestación de cuidados.

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Tabla 2. Temáticas estudiadas (n=49)

Temáticas	n
Cuidados prestados al final de la vida	10
Actitudes/ decisiones de los profesionales	9
Evaluación y eficacia de técnicas invasivas/ quirúrgicas para la atenuación de síntomas	7
Validación de los instrumentos de medida	4
Transmisión de malas noticias	3
Síndrome de burnout en los profesionales	3
Agitación/ sedación de enfermos	2
Espiritualidad	2
Necesidades de los cuidadores informales	2
Decisiones éticas	2
Calidad de vida	2
Expectativas de los enfermos ante el internamiento en unidades de cuidados paliativos	1
Caracterización de la hora de la muerte	1
Actividad de los equipos de cuidados paliativos	1

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2.1.2. A systematic literature review toward the characterization of comfort

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A Systematic Literature Review Toward the Characterization of Comfort

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Comfort integrates the taxonomies and the classifications of nursing knowledge. Its meaning is not yet clear, although it is an important construct from which theories are developed. This article aims to analyze comfort in nursing scientific literature. The results highlight a particular interest in comfort at crisis situations such as illness, palliative care, or intensive care. Comforting seems to be a complex intervention. More studies are needed to achieve its operational assimilation and implementation in clinical practice, as well as the evaluation of its efficiency and effectiveness. **KEY WORDS:** *comfort, comforting, nursing, review, systematic* *Holist Nurs Pract* 2016;30(1):14–24

Comfort has accompanied the history of nursing care. First, it was related to physical care and pain relief. However, today, it is considered a multidimensional construct that integrates classifications and taxonomies and from which many nursing theories have derived. In spite of these facts and the valuable contribution from Kolcaba's Comfort Theory, its meaning is still not clear. This is particularly true of nursing scientific literature, where comfort is considered a noun, verb, adjective, as well as a state, a process, and an outcome.

The aim of this research project is to analyze the elements that characterize comfort in nursing scientific literature. In response to the research question "Which elements characterize comfort in scientific literature?," a systematic literature review was conducted by searching for the words "*comfort**," "*concept*," and "*definition*" in electronic databases. All Portuguese, Spanish, French, and English articles, published on

December 31, 2013, were included. A total of 1937 results were identified. Then, after analyzing and applying the eligibility criteria, a sample of 52 articles was selected. The results highlight not only a particular interest in comfort at crisis situations (such as illness or end-of-life situations) but also in intensive care and obstetrics. Comforting seems to be a complex intervention. However, more studies are needed to achieve its operational assimilation and implementation in clinical practice, as well as the evaluation of its efficiency and effectiveness.

BACKGROUND

Comfort is an intrinsic concept in the history of nursing care, branding its development not only as a discipline but also as a profession.^{1,2}

Among the different nursing theorists, we highlight the work developed by Ida Jean Orlando (who underlines the importance of comfort in human beings needs' response), Hildegard Peplau (who designed comfort as a basic need associated with food, rest, sleep, and communication), Irma Callista Roy (whose study was centered on psychological comfort), and Madeleine Leninger and Jean Watson (who stated that comfort is an integral part of caring).³

Despite the importance of the aforementioned theories, there are 2 authors whose works stand out for their systematization and projection: Janice Morse (80s) and Katharine Kolcaba (90s).³ These theorists have become so important that, even today, they are frequently quoted in scientific literature and used to

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support research and nursing practice. Morse defines comfort as a final state of well-being that comes from therapeutic interventions undertaken by nurses.^{3,4} Kolcaba states that comfort is a holistic experience lived by those who received comfort care.⁵ This experience is a state resulting from needs satisfaction at 3 different levels, which the author calls “Types of Comfort”: relief, ease, and transcendence.⁵ The first level, relief, concerns the satisfaction of the most basic needs without which the human being cannot behave normally.^{3,5} The second one, ease, allows the person to feel calm and quiet, and these are essential for behaving functionally as well as efficiently.^{3,5} In the third and last level, transcendence, there is an attempt to satisfy the needs that allow someone to make plans, to control his or her destiny, as well as to solve his or her problems.^{3,5} This author also states that comfort—or by contrast discomfort—can take place in 4 different contexts—physical, psycho-spiritual, social, and environmental.^{3,5}

Considering a holistic perspective, the concept has been characterized as a dynamic concept, which integrates processes, experiences, and other complex concepts (such as quality of life, hope, control, and decisions making).⁶ Broader than the cure, illness, or symptoms management, comfort is, generally, associated with the satisfaction of patients’ needs and it is the result of the growing nurse-patient⁷ interaction. For this reason, it has been appointed as the main objective of nursing care.^{8,9} The concept has been changing and currently is very different from the initial and reductionist definition, which restricted it to cozy pillows and warm blankets.^{3,4,10} Nevertheless, in the concept’s theoretical evolution, comfort is still mostly associated with physical factors, such as hygiene care (and comfort), pain relief, or positioning,⁷ often forgetting the assessment of the other human life dimensions.

Despite all the knowledge and research about comfort and comforting, it is still a very complex area, difficult to define, implement, and evaluate.¹ It appears in literature as a noun (comfort), a verb (to comfort/comforting), an adjective (comfortable), and also as a state, a process, or an outcome.¹¹ As a noun, it represents a state or an outcome. As a verb, it refers to an action/a process and it aims to achieve an outcome, also considered a state: “to be comfortable.”

There is no consensual definition in the nursing classifications and taxonomies, as is the case in the scientific literature. The most used include the International Classification of Function and Incapacity,

the International Classification for Nursing Practice—ICNP, and the Nanda-International—NANDA-I.¹²⁻¹⁴

While the ICNP¹³ and the International Classification of Function and Incapacity¹² focus more specifically on the physical dimension (which imposes certain prudence in practice), the taxonomy proposed by NANDA-I¹⁴ presents a multidimensional approach.

According to the current definition proposed by the ICNP, comfort (a nursing care focus) represents a “sensation of physical ease and bodily well-being.”^{13(p45)} This definition seems to be reductionist because it does not include the environmental, social, or psycho-spiritual dimensions. The definition of comforting, “consoling somebody in time of need”^{13(p95)} is also subjective, because it does not define the needs. In this context, it is important to highlight that although the first edition of ICNP was published in 1995 (α version), the terms “comfort” and “comforting” were introduced only as a nursing focus and action in 1999 (β version). Since then, the 2 terms have been integrated in all versions but without further changes. This is the reason why the proposed definitions in version 2 (2011) are exactly the same as those proposed in 1999.

Changing the definitions proposed by a classification is not a simple process. It should be based on validation studies and development of the concepts that can improve the growth of a discipline. Currently, comfort and comforting go beyond the satisfaction of physical needs. It seems important, since the ICNP is a classification proposed by the International Council of Nurses,¹³ to review the current definitions because it is an instrument often used in nursing practice in different countries and settings.

NANDA-I is, therefore, the 1 among the 3 mentioned classifications that proposes the most complete approach since it is based on the definition of comfort as the need for satisfaction of relief, ease, and transcendence in physical, psycho-spiritual, and environmental dimensions.¹⁴ The “*impaired comfort*” nursing diagnosis was proposed by Katharine Kolcaba, while domain 12 of the taxonomy II is composed of 2 classes: physical, environmental, and social. Although the diagnosis relating to psycho-spiritual comfort does not belong to domain 12, it can be found at domain 9 (coping) and domain 10 (life principles). The examples given indicate us that comfort seems to be difficult to define and operationalize.

But, as stated by Tomey and Alligood,¹⁵ the areas of the practical field, featuring a profession, as derived from the theory and theoretical background, may

establish limits in care practice. However, the development of theoretical knowledge is a complex process because it involves not only the characterization of the phenomenon under study but also the assessment of the implications in various contexts and, subsequently, characterizing the most appropriate interventions.¹⁶ Classifications and taxonomies are very important because they contribute not only to the theoretical classification of the phenomenon but also to clarifying the interventions sustaining clinical practice.¹⁶ The research by Krogh¹⁶ underlines the need for coherence, completion, and practical application of the classifications and taxonomies and it served as motivation for a new proposal of NANDA-I, which was recently published. According to this taxonomy (III), comfort is not a domain but a class of the existential domain.¹⁴

In this sense, comfort, as well as comforting, is core to nursing practice. But there is little evidence about the operationalization of comforting and comfort measurement as an important outcome in the health/disease process. Although the concept of comfort integrates nursing classifications and taxonomies, including in the definition of other concepts and diagnoses, they are not objective and clearly limited, as detailed beforehand. This could certainly raise some limitations on nursing care and, consequently, nursing outcomes.

This work aims to analyze the elements that characterize comfort in nursing scientific literature. The target of this article is to contribute to the state of the art, not only by systematizing the scientific evidence but also by identifying research priorities, particularly those related with the conceptual development of comfort and comforting operationalization.

METHODS

Research question and eligibility criteria

This work was based on the following research question: “Which elements characterize comfort in scientific literature?” All original Portuguese, Spanish, French, and English articles, related to nursing and nonnursing research about the concept of comfort, published in peer-reviewed scientific journals up to December 31, 2013, were included. The following elements were analyzed: publishing year, journal, language, country where the research was conducted,

method, participants, and study context. Narrative reviews, opinion and reflection articles, editorials, and presentations at congresses or conferences were excluded.

Search strategies

The search was conducted independently by 3 researchers using a previously prepared research protocol. The electronic databases *MEDLINE with Full text*, *EBSCO (all databases)*, *CINAHL with Full text*, *Scielo*, *Bireme*, *PsYcINFO*, *Cochrane Database of Systematic Reviews*, and *JB Library of Systematic Reviews* were searched. The following search terms were used: *comfort**, *concept*, and *definition*. All references of the selected articles were consulted and, whenever necessary, the study’s author was contacted to obtain full versions. The site *The Comfort Line* (www.thecomfortline.com),¹⁷ developed by Katharine Kolcaba, was also searched, since it is an important space for the dissemination of the researcher’s work.

Selection and assessment of methodological quality of the studies

The studies were selected from the sequential analysis of the title, abstract, and full text. First, all references were screened on the basis of title and abstract. In the second phase, the full text and the reference list of all the selected publications were screened for relevance too. Methodological quality of the studies was analyzed to ensure higher reliability in the selection process. A data extraction form was designed by the authors, according to the following evaluation criteria: clear definition of the problem and clear methodology description (aims, method, and sample). A score of 1 was given to the item that was present and clear and zero when it was doubtful or absent. Deviations were discussed and decided among the research team.

Extraction, data synthesis, and analysis

Descriptive statistics were calculated and the studies’ results were analyzed. Data concerning authorship, journal, publishing year, method, participants, study context, and the characterizing elements of comfort and/or comforting concept were extracted. The study context was considered to be the place where the research was conducted. The comfort/comforting characterizing elements were classified through the focus placed on the concept: noun, verb, adjective or state, process, outcome.

RESULTS

In a first search, 1937 articles were identified. The Figure presents the process of articles' selection.

Current review is composed of a sample of 52 articles (Table 1).

Publishing year

The first scientific study was published in 1993,¹⁸ followed by another in 1994¹⁹ and 2 in 1996.^{20,21} No articles were published between 1997 and 1999, but there has been growing and constant production since 2000. The highest number of published studies was in 2012 (n = 10)^{6,54-62} and 2009 (n = 7).^{3,42-47}

Journal, language, and country

The 52 studies were published in 35 journals, most of them about nursing science (n = 39) and palliative care (n = 6). The data highlight the importance of research about comfort in these expertise fields, in which the concept is considered central and nuclear, not only in philosophy but also in clinical practice (Table 2).

Although nursing journals are the types of periodical with the highest number of studies (n = 39), increasing attention by medical and psychology journals to the

study and publication of this subject is evident. It is important to observe that 28.57% of the 35 journals were Portuguese-Brazilian (Table 2). Although 13 studies were published in journals from other disciplines (audiology, medicine, palliative care, psychology, and occupational therapy) 7 of them were conducted by nurses, which means that just 11.54% of the studies were developed by other health professionals.

The majority of the studies was conducted by North Americans (n = 15), followed by Brazilian (n = 13) and Portuguese (n = 10) researchers (Table 1). This countries' leadership in scientific production is mostly due to the studies developed by Katharine Kolcaba, not only as the lead researcher but also in coauthorship with researchers from other countries. It is also interesting to observe that although 28.85% of total scientific production comes from the United States, this number has been decreasing. On the contrary and despite scientific production in Brazil and Portugal being more recent (first publication in 1996 and 2006, respectively), that share has been growing in both countries. Studies conducted in Australia (n = 4), Canada (n = 2), United Kingdom (n = 2), Iran (n = 1), Israel (n = 1), Japan (n = 1), and France (n = 1) were also identified. Only 1 study was developed in several countries (the Netherlands, Japan, Italy, and Canada) (Table 1).

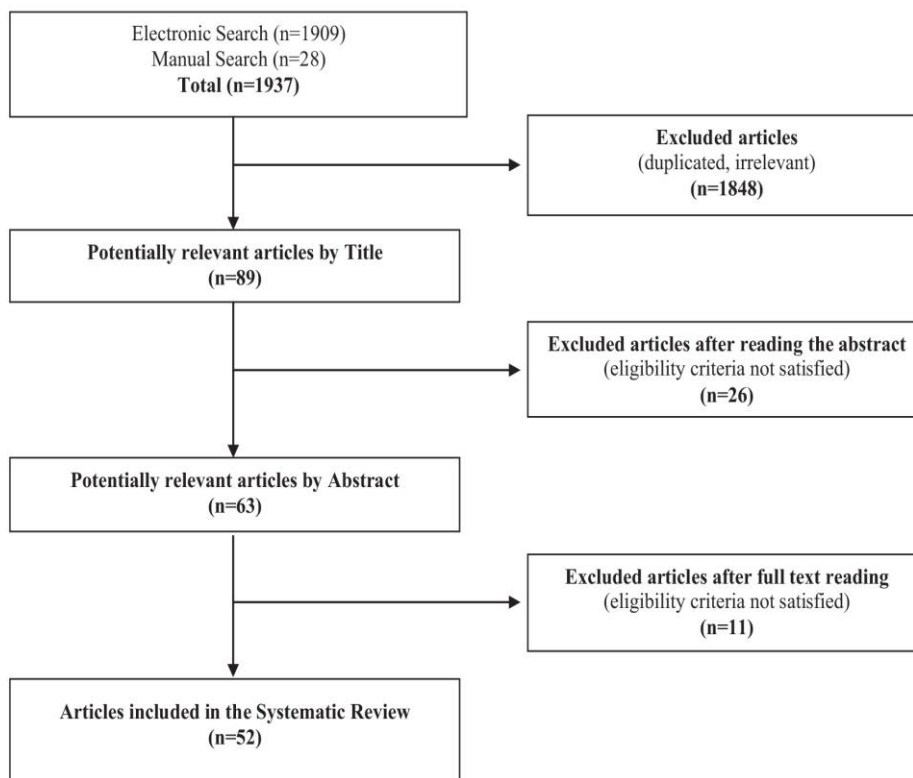


FIGURE. Articles' selection strategy.

TABLE 1. The Articles Selected (n = 52)

Author (y)	Country	Study Design
Cameron (1993) ¹⁸	Canada	Qualitative (grounded theory)
Morse et al (1994) ¹⁹	United States	Qualitative (phenomenology)
Mussi et al (1996) ²⁰	Brazil	Qualitative (content analysis)
Wurzbach (1996) ²¹	United States	Qualitative (descriptive, exploratory)
Kolcaba and Fox (1999) ²²	United States	Quantitative (RCT)
Dowd et al (2000) ²³	United States	Quantitative (RCT)
Kolcaba and Steiner (2000) ²⁴	United States	Quantitative (RCT)
Novak et al (2001) ²⁵	United States	Methodological
Siefert (2002) ²⁶	United States	Rodgers concept analysis
O' Brien et al (2003) ²⁷	Australia	Methodological
Tutton and Seers (2003) ²⁸	United Kingdom	Systematic review
Kolcaba et al (2004) ²⁹	United States	Quantitative (RCT)
Tutton and Seers (2004) ⁸	United Kingdom	Qualitative (ethnography)
Apóstolo et al (2006) ³⁰	Portugal	Quantitative (descriptive, exploratory)
Dowd et al (2006) ³¹	United States	Methodological
Kolcaba et al (2006) ³²	United States	Quantitative (quasi-experimental)
Wagner et al (2006) ³³	United States	Quantitative (RCT)
Williams and Irurita (2006) ³⁴	Australia	Qualitative (grounded theory)
Apóstolo et al (2007) ³⁵	Portugal	Methodological
Apóstolo et al (2007) ³⁶	Portugal	Methodological
Carraro et al (2006) ³⁷	Brazil	Mixed
Dowd et al (2007) ³⁸	United States	Quantitative (RCT)
Rassin et al (2007) ³⁹	Israel	Quantitative (descriptive, correlational)
Currow et al (2008) ⁴⁰	Australia	Quantitative (survey)
Oliveira (2008) ⁷	Portugal	Qualitative (phenomenology)
Rosa et al (2008) ⁴¹	Brazil	Qualitative (descriptive, exploratory)
Apóstolo (2009) ³	Portugal	Systematic review
Apóstolo and Kolcaba (2009) ⁴²	Portugal	Quantitative (quasi-experimental)
Roche-Fahy and Dowling (2009) ⁴³	Ireland	Qualitative (hermeneutic)
Pearson (2009) ⁴⁴	Australia	Systematic review
Szareski et al (2009) ⁴⁵	Brazil	Qualitative (descriptive, exploratory)
Waldrop and Kirkendall (2009) ⁴⁶	United States	Qualitative (grounded theory)
Yousefi et al (2009) ⁴⁷	Iran	Qualitative (phenomenology)
Frello and Carraro (2010) ⁴⁸	Brazil	Qualitative (descriptive, exploratory)
Kalfon et al (2010) ⁴⁹	France	Methodological
Vaz et al (2010) ⁵⁰	Brazil	Bibliometric review
Kunikata et al (2011) ⁵¹	Japan	Quantitative (descriptive, correlational)
Silva et al (2011) ⁵²	Brazil	Qualitative (content analysis)
Steen et al (2011) ⁵³	The Netherlands, Japan, Italy and Canada	Methodological
Apóstolo et al (2012) ⁶	Portugal	Quantitative (descriptive)
Freitas et al (2012) ⁵⁴	Brazil	Qualitative (descriptive, exploratory)
Freitas et al (2012) ⁵⁵	Brazil	Qualitative (grounded theory)
Gratão et al (2012) ⁵⁶	Brazil	Quantitative (epidemiological)
Ponte et al (2012) ⁵⁷	Brazil	Qualitative (descriptive, exploratory)
Ribeiro and Costa (2012) ⁵⁸	Portugal	Systematic review
Schenker et al (2012) ⁵⁹	United States	Mixed
Silva et al (2012) ⁶⁰	Brazil	Integrative review
Sousa and Costa (2012) ⁶¹	Portugal	Qualitative (ethnography)
Zanartu and Matti-Orozco (2013) ⁶²	United States	Quantitative (survey)
Oliveira (2013) ²	Canada	Rodgers concept analysis
Pott et al (2013) ⁶³	Brazil	Quantitative (descriptive, exploratory)
Xavier et al (2013) ⁶⁴	Portugal	Qualitative (descriptive, exploratory)

Abbreviation: RCT, randomized controlled trial.

TABLE 2. Articles' Characterization (n = 52)

Journal	
Area of Knowledge (Number of Articles Published)	Journal Title
Audiology (n = 1)	<i>Journal of Speech, Language, and Hearing Research</i> ²⁷
Medicine (n = 3)	<i>Intensive Care Medicine</i> ^{49, 59} ; <i>The Journal of Medical Investigation</i> ⁵¹
Nursing (n = 39)	<i>Research and Theory for Nursing Practice</i> ² ; <i>Revista de Enfermagem Referência</i> ^{3, 30, 58} ; <i>Pensar Enfermagem</i> ⁷ ; <i>Journal of Advanced Nursing</i> ^{8, 18, 19, 21, 47} ; <i>Revista Latino-Americana de Enfermagem</i> ²⁰ ; <i>Holistic Nursing Practice</i> ^{23, 31, 38} ; <i>Journal of Holistic Nursing</i> ²⁴ ; <i>Nursing Forum</i> ²⁶ ; <i>Journal of Clinical Nursing</i> ²⁸ ; <i>Geriatric Nursing</i> ³² ; <i>AORN Journal</i> ⁶³ ; <i>International Journal of Nursing Studies</i> ³⁴ ; <i>Enfermería Clínica</i> ³⁶ ; <i>Texto & Contexto Enfermagem</i> ^{37, 54, 56} ; <i>International Journal of Urological Nursing</i> ³⁹ ; <i>Revista Enfermagem UERJ</i> ^{41, 48} ; <i>Archives of Psychiatric Nursing</i> ⁴² ; <i>International Journal of Palliative Nursing</i> ⁴³ ; <i>Ciência, Cuidado e Saúde</i> ⁴⁵ ; <i>Cogitare Enfermagem</i> ^{50, 52} ; <i>Escola Anna Nery Revista de Enfermagem</i> ^{55, 57} ; <i>Journal of Nursing UFPE on line</i> ^{60, 64} ; <i>Revista Brasileira de Enfermagem</i> ⁶³ ; <i>ANS Advances in Nursing Science</i> ⁶⁵ ; <i>Oncology Nursing Forum</i> ²²
Palliative Care (n = 6)	<i>American Journal of Hospice & Palliative Care</i> ⁶² ; <i>International Journal of Palliative Nursing</i> ⁴³ ; <i>Journal of Palliative Medicine</i> ^{46, 53} ; <i>Journal of Hospice and Palliative Nursing</i> ²⁹ ; <i>Supportive Care in Cancer</i> ⁴⁰
Psychology (n = 2)	<i>Psychologica</i> ³⁵ ; <i>Journal of Educational and Developmental Psychology</i> ⁶¹
Rehabilitation (n = 1)	<i>Disability and Rehabilitation: Assistive Technology</i> ⁴⁴
Study Context	
Hospital Settings (n = 29)	
Inpatient departments (n = 19) ^{6, 7, 18, 19, 20, 33, 35, 36, 42, 43, 45, 48, 49, 54, 55, 57, 59, 61, 63}	
Outpatient departments (n = 1) ³⁰	
Department (inpatient or outpatient) not specified (n = 9) ^{23, 24, 31, 34, 37, 41, 47, 48, 62}	
Community (n = 4) ^{27, 40, 51, 56}	
Hospital and community (n = 1) ³¹	
Nursing homes (n = 4) ^{21, 32, 46, 53}	
Private clinics (n = 2) ^{22, 39}	
Hospices (n = 2) ^{29, 25}	
Participants	
Patients (n = 17)	
Palliative care patients (n = 2) ^{25, 29}	
Psychiatric patients (n = 5) ^{6, 35, 36, 42, 51}	
Oncological patients (n = 4) ^{22, 24, 30, 41}	
Cardiac patients (n = 2) ^{20, 57}	
Elderly (n = 2) ^{8, 61}	
Women giving birth (n = 2) ^{37, 48}	
Patient's relatives (n = 7) ^{25, 40, 45, 54-56, 59}	
Health professionals (n = 13) ^{7, 21, 34, 41, 43, 46, 47, 52, 53, 59, 62-64}	

Study design/method

The majority of the studies are characterized by qualitative methodologies: descriptive (n = 7), grounded theory (n = 4), phenomenology (n = 3), ethnography (n = 2), hermeneutics (n = 1), and content analysis (n = 2) (Table 1). Sixteen were quantitative studies (6 experimental, 5 descriptive-correlational, 2 surveys, 2 quasi-experimental, and 1 epidemiological). In addition, there are 2 mixed studies, 6 literature reviews (4 systematic reviews, 1 integrative review, and 1 bibliometric review), 7 methodological studies, and 2 studies on concept analysis (Table 1). In this review,

14 tools to evaluate comfort in different contexts and populations were identified (Table 3).

Participants and study context

The majority of the studies (n = 29) were conducted in hospital settings. Among these, 19 were conducted on inpatients and 1 on outpatients departments. Nine of the 52 studies did not indicate their context (Table 2).

Although the majority of the researchers focus their attention on the patient's perspective (n = 17), 13 studies were conducted from the health professionals' perspective and 7 from the family's perspective. Five studies were conducted in the community, 4 in nursing

TABLE 3. Comfort Measurement Tools

Tool	Country	Population	Items	Reliability
General Comfort Questionnaire ^{24,65}	United States	Hospitalized patients	49 items (Likert scale)	$\alpha = .90$
End-of-Life Comfort Questionnaire-Patient ²⁵	United States	End-of-life patients	28 items (Likert scale)	$\alpha = .98$
End-of-Life Comfort Questionnaire-Caregiver ²⁵	United States	End-of-life patients' relatives	49 items (Likert scale)	$\alpha = .97$
Listener Comfort Scale ²⁷	Australia	People who communicate with stammers	9 items (Likert scale)	$\alpha = .42$
Healing Touch Comfort Questionnaire ³¹	United States	People under the healing touch (therapeutic touch/massage)	35 items (Likert scale)	$\alpha = .94$
Psychiatric In-Patients Comfort Scale ^{35,36}	Portugal	Psychiatric inpatients	38 items (Likert scale)	$\alpha = .89$
Inconforts des patients de REAnimation Questionnaire ⁴⁹	France	Former UCI admitted Patients	16 items (Likert scale)	$\alpha = .72$
Scale for the sense of ibasho ⁵¹ (psychological comfortable space)	Japan	Schizophrenic outpatients	8 items (Likert scale)	$\alpha = .86$
Urinary Incontinence and Frequency Comfort Questionnaire ²³	United States	Urinary incontinence patients	27 items (Likert scale)	$\alpha = .82$
Radiation Therapy Comfort Questionnaire ²⁴	United States	Breast cancer women in RT	26 items (Likert scale)	$\alpha = .76$
Comfort Visual Analog Scales ²⁴	United States	Breast cancer women in RT	...	SD = 1.58
Hospice Comfort Questionnaire ²⁹	United States	End-of-life patients	24 items (Likert scale)	$\alpha = .65$
Thermal Comfort Inventory ³³	United States	Preoperating patients	13 items (Likert scale)	$\alpha = .82$
Thermal Comfort Numeric Visual Analog Scale ³³	United States	Preoperating patients	...	Without information

Abbreviations: RT, radiotherapy; ICU, intensive care unit.

homes, 2 in private clinics, and 2 in hospices. One study was simultaneously conducted at the hospital and in the community (Table 2). The majority of the studies were conducted in a disease context and only 2 studies were conducted on healthy subjects. The first one was aimed at building and validating a tool to evaluate the listening comfort of people who come into contact with people who stutter.²⁷ However, even this work aimed to contribute to the importance of speech therapy in people who stutter, considering their discomfort due to interaction. The second one compared the effect of 3 interventions (healing touch, coaching, and a combined intervention) in the holistic comfort of university students.³⁸

There are several studies conducted in specific groups, such as palliative care patients (n = 2), the elderly (n = 2), psychiatric patients (n = 5), oncological patients (n = 4), and cardiac patients (n = 2). Two studies were also found on women's perspective of comfort while giving birth (Table 2).

Elements characterizing comfort

It is common to find the concept as a noun (comfort), a verb (to comfort/comforting), or an adjective (comfortable) and also as a state, a process, or an outcome (Table 4). This review analyzed the way the authors present the concept in their studies.

Comfort is presented as a noun in the majority of the cases. Its use as an adjective (*comfortable*) was identified only in 2 studies^{40,51} and as a verb (*comforting*) in another one.⁷ In the remaining studies,

TABLE 4. Comfort Characterizing Elements

Characterizing Element	Article Reference
Comfort as a state	3, 8, 18-21, 26, 28, 30, 40, 41, 45, 47, 48, 50-52, 54-56, 58-60
Comfort as a process	2, 7, 18, 21, 29, 34, 37, 43, 45-48, 52, 53, 57, 61-64
Comfort as an outcome	6, 19, 22-25, 27, 29-36, 38-40, 42, 44, 49, 56

the concept was always presented as a noun. However, in 3 of those studies,^{19,48,64} it is possible to verify that despite not using it as a verb (comforting), it was clearly the intention of the authors to direct the concept to its verbal form (providing comfort), which suggests action or intervention.

Although it is not completely clear, since some authors use more than 1 form of terminology, it was found that researchers generally approach comfort as a state, trying to extract from there its attributes and inherent interventions in the comforting process. The concept was described as a state in 23 studies (44.23%), as an outcome in 22 studies, and as a process in 18 studies. In some studies, comfort is described as a state and a process (n = 5), a state and an outcome (n = 4), or an outcome and a process (n = 2). It was found that the studies carried out by other health professionals (not nurses) tend to use comfort as an outcome (n = 4).

DISCUSSION

Publishing year

Although the research on comfort has begun in the 1980s,¹¹ the first studies were essentially reflexive or theoretical. This could explain why the first publication was only in 1993. The majority of the publications regarding comfort were based on the research of Katharina Kolcaba. The author's work, the medium range theory—Comfort Theory, is from the 1990s and was conducted during her academic degrees (master's and PhD). Besides these considerations, it is important to underline that the development of the Comfort Theory tuned into the need for further research about the concept, not only for it to be tested but also to be applied in nursing care practice. This could be a reason why the number of published studies has considerably increased since 2006.

Journal, language, and country

The 52 selected studies were published in 35 different journals. Despite the current facilities for literature, including virtual libraries, this data element reflects the lack of one scientific journal that could bring together the studies on this subject and, consequently, facilitate the organization of scientific evidence and future research. This fact represents, on the contrary, the cross-sectional nature of the concept for health and

nursing knowledge and practice. The increasing number of medical and psychology journals publishing research about comfort could contribute to an integrated, multidisciplinary, and holistic approach to the phenomenon.

The data also allowed us to observe that research on comfort has become more frequent among Portuguese and Brazilian researchers. Although English is the official language in the scientific community, 19 of the 52 studies were published in Portuguese.* Therefore, some caution is required in the publishing language since this may lead to bias in the transmission and dissemination of the knowledge.

Study design/method

Six literature reviews^{3,28,44,50,58,60} were found but none in the Cochrane Database of Systematic Reviews. However, a systematic review protocol related to the use of nonpharmacological interventions in the comfort promotion of oncological patients was found in the JBI Library of Systematic Reviews database. This work, although it was important to mention it here, was not in the sample because it is ongoing research.

The study by Cameron¹⁸ is a reference for several studies on comfort, mainly the qualitative and descriptive ones. Only 6 years later, in 1999, the first work using a quantitative methodology was published.²²

Even today, predominance of descriptive studies highlights the need to seek to understand the phenomenon. This could be the reason why exploratory studies^{30,41,45,48,54,57,63,64} or studies of concept analysis² keep being published. These studies help clarify the concept, its antecedents, attributes, and consequences, considering different health and life contexts and conditions.

The lack of experimental or quasi-experimental studies that tie literature reviews to meta-synthesis or meta-analysis (considered important to knowledge synthesis) reflects the difficulty in comfort operationalization. Besides being scarce, the experimental^{22-24,29,33,38} and quasi-experimental studies^{32,42} found were conducted by Kolcaba, as a lead researcher or in coauthorship. Two of these studies^{29,32} have the same approach: the evaluation of manual massage efficacy in a person's comfort. In the first study,²⁹ a random clinic trial on the intervention

*References 3, 6, 7, 20, 30, 35, 37, 41, 45, 48, 50, 52, 54, 58, 61, 63.

effects in terminal patients was conducted. In the second study,³² the sample was not random and was composed of nursing homes patients. The remaining experimental or quasi-experimental studies used different methodologies and were anchored on the study of the effect of different interventions. For these reasons, there is not enough research evidence to support a meta-analysis.

Some prudence should be taken when analyzing the methodological studies. The *Comfort Line* site¹⁷ indicates the existence of 32 tools developed in different contexts and languages and aimed at different populations (15 by Kolcaba and 17 by other researchers). In many cases, it was only possible to access the final tool (without any reference to its construction process or its psychometric properties: validity and reliability). Besides these considerations, some tools, such as the *General Comfort Questionnaire*,^{24,65} were developed over time and were supported by the several studies that formed the basis for Kolcaba's Comfort Theory. Later on, in 2000, after an experimental study conducted by Kolcaba and Steiner,²⁴ the psychometric properties of 3 tools were studied and published: *General Comfort Questionnaire*,^{24,65} *Radiation Therapy Comfort Questionnaire*,²⁴ and *Comfort Visual Analogue Scales*.²⁴ In this context, the first methodological study (regarding the study's aim, design, and methodology)²⁵ was published only in 2001. Afterward, a gradual increase in the construction of new tools (as well as the transcultural adaptation and validation of already existing tools) can be observed. These studies seem to be an important background for quantitative researches, which are more focused on testing the Comfort Theory and its applicability than understanding and defining the phenomenon.

Participants and study context

The data suggest that the research is focused on the patient's comfort. There are few studies on the comfort of health professionals, informal caregivers/family members, or even healthy populations. No studies in a pediatric context were found.

Although comfort is a fundamental need of human life and a central focus in nursing care and philosophy, the data suggest that the research has included vulnerable populations, such as end-of-life patients. There seems to be a natural trend to diminish crisis and suffering circumstances by satisfying patients' needs of relief, ease, and transcendence. Despite this, several

studies were conducted in intensive care units since 2010.^{49,54,55,59} These studies aimed to understand and evaluate comfort from the patient's families' perspective as well as how environmental conditions can interfere with comfort.

Although an holistic practice is desired (the Comfort Theory itself defines the concept as the satisfaction of relief, ease, and transcendence needs), the majority of the studies are still focused on the understanding and analysis of the concept or on a description of comfort related to the perspective of satisfaction of physical needs. Nonetheless, we came across a study in which comfort is analyzed from an ethical perspective as a nurses' moral duty²¹ and also 2 studies on psychological and spiritual comfort.^{34,57}

Comfort characterizing elements

The difficulty in categorizing data illustrates the concept's complexity and the limitations on its operationalization. Also, the gap in research on the concept used as a verb (to comfort/ comforting) and the activities of comforting do not contribute to a clearer definition of comfort. The results highlight that the concept of comfort is predominantly described as state. It also seems clear from results that the studies carried out by other health professionals (nurses), although scarce, tend to describe the comfort as an outcome. Besides these semantic differences, the description of comfort as a state, a process, or an outcome is still unclear. These theoretical difficulties may be reflected in practice. Perhaps for this reason, studies about the analysis of the concept continue to be developed even today, exploring its meanings in different contexts and with different populations as well as the establishing of activities that feature comfort intervention.

LIMITATIONS

The study's limitations are associated to the limits imposed by linguistic barriers and the inclusion criterion, which allowed us to select only published studies in English, French, Portuguese, or Spanish. In the selection process, the researchers identified studies in languages they did not master, such as Chinese and German. In addition to these limitations, some studies are still published in nonindexed journals. Access was possible only through references or by curricula analysis of expert researchers.

SUGGESTIONS FOR FUTURE RESEARCH

This study underlines comfort and comforting intervention's complexity. This complexity imposes some difficulties and limitations in the concept's understanding, not only in theory but also in practice. The results illustrate that the concept should be operationalized by conducting research on clinical practice. There is also a need to conduct more cost-effectiveness-related research and comfort intervention's effectiveness, preferably by using consistent methodological approaches that allow subsequent meta-synthesis and meta-analysis.

CONCLUSIONS

Comfort is considered to be essential in nursing care. A rebirth of the concept was observed in the last century as well as its integration in the development of theory and in practice. There are several elements that characterize comfort in the scientific literature. First, comfort is a complex concept and comforting a complex intervention. Despite efforts to analyze and understand the concept by using Kolcaba's Comfort Theory, this is still difficult to define and, consequently, to operationalize in practice. Many studies aim at comfort's operationalization (by analyzing the concept or by conducting qualitative studies), but there seems to be a lack of follow-up research. Another data element enabled us to conclude that the concept is particularly focused on nursing, but recently, some studies have been conducted in other disciplines, such as medicine and psychology. This highlights the multidisciplinary approach in health care, but it also underlines the duty of developing the knowledge that constitutes the discipline and nursing practice. There is particular interest in comfort analysis in crisis situations (such as disease) or end of life (the elderly, palliative care). However, it is important to note that research in specialized areas (such as intensive care or obstetrics) has increased. Finally, the majority of researchers classify comfort as a state, trying to extract from there its attributes and the inherent interventions in the comforting process. For this reason, from a semantic point of view, it is represented essentially as a noun (comfort) and, less frequently, as a verb (comforting). The concept is also classified as an outcome that can be measured, but its use as an adjective (comfortable) is very rare. Further research would provide a deeper understanding of

the activities that constitute the "comforting" nursing intervention.

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2.1.3. Comfort and comforting: Comparing ICNP®, ICF and NANDA-I

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Background

Comfort is a central concept in nursing and it is in classifications and taxonomies, such as the International Classification for Nursing Practice (ICNP[®]),⁽¹⁾ the taxonomy II of NANDA-I⁽²⁾ and the International Classification of Functioning and Disability (ICF),⁽³⁾ a multidisciplinary classification of the World Health Organization (WHO). According to Kolcaba,⁽⁴⁾ comfort transposes the physical dimension. Represents a holistic experience, expressed in meeting the needs of relief, ease and transcendence, with repercussions in all human's life dimensions. A classification should represent a discipline's knowledge and may have an important impact on nursing practice. In this study, the definitions regarding comfort in the different classifications were analysed.

Aims

To analyse the correspondence between terms, diagnoses, interventions and outcomes related to comfort in the ICNP[®], NANDA-I, and ICF.

Materials and methods

Descriptive study, using the cross-mapping, to determine concept's semantic equivalences among ICNP[®] (version 2), NANDA-I, and ICF.

Results

There isn't a consensual definition between these classifications where the term emerges as a focus, a verb, an adjective and also as a state, process, intervention or outcome. The ICNP[®] (where comfort is presented 32 times, including in other definitions' terms) has three focus: 'comfortable', 'comfort' (*sensation of physical ease and bodily well-being*) and

'discomfort' (impaired status). The term 'comforting' (an action of the relation axis) is not operationalized. Comfort or feel comfortable are the expected outcomes. The proposed diagnosis ('discomfort', 'impaired comfort' and 'readiness for comfort') have semantic correspondence with the NANDA-I diagnoses of 'impaired comfort' and 'readiness for enhanced comfort'. However, the conceptual definitions underlying the two classifications are different. Between the three classifications, NANDA-I is which proposes a more comprehensive approach, presenting comfort (domain 12) in a multidimensional perspective. However the classes don't exhaust these dimensions. As the ICNP[®], the ICF is also reductive, presenting comfort as an activity belonging to the '*caring of own health*' domain and related with the need to ensure physical comfort.

Conclusions

ICNP[®] and ICF are more focused on the physical dimension, which requires some caution in practice contexts'. The NANDA-I taxonomy shows more congruence with the scientific evidence, presenting comfort in a multidimensional perspective. However the classes don't give a complete approach of all field dimensions.

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2.2. Theoretical approach

Nursing research aims to produce knowledge to support and improve clinical practice. Indeed, nursing theory and nursing practice should be closely related, in order to achieve effective nursing interventions (Risjord, 2010).

A theory can be defined as a set of related concepts, statements and propositions, that attempt to characterize a phenomena, and suggests actions to guide nursing practice (McEwen & Wills, 2011; Nilsen, 2015). Nursing theories are organized hierarchically in two main categories, according to their scope or level of abstractness (metatheory, grand theory, middle-range theory, microtheory) and purpose (descriptive, predictive or situation-producing theory) (McEwen & Wills, 2011).

Metatheories represent a kind of theory about the theory development (McEwen & Wills, 2011). Grand theories comprise the most complex and general explanation about broad areas within the discipline (Risjord, 2010; McEwen & Wills, 2011). Middle-range theories are more specific, and aim to describe a concrete phenomenon, provide an explanation about the relation among phenomena's or predict the effects of a particular phenomenon in another one (Risjord, 2010; McEwen & Wills, 2011; Nilson, 2015). Finally, microtheories, also entitled as practice theories, are even more specific, and attempt to produce specific directions for nursing practice (McEwven & Wills, 2011).

Despite this categorization, the literature has been highlighting an important gap between nursing theory and nursing practice (Risjord, 2010; Scully, 2011). Among the principal reasons in the literature, there is the fact many nursing curricula have decreased the emphasis placed on nursing theory. As a result, nursing practice seems to be more focused on the '*doing*' rather than on '*critical thinking*' (Ajani & Moez, 2011; Masters, 2015). However, nursing theory have been recognized as an important issue to the nursing development, not only as a profession, but also as a discipline and a science, with their own body of knowledge. For instance, nursing knowledge has an important impact on a nurse's capacity for clinical judgment (Risjord, 2010; Masters, 2015). For this reason, several authors state that nursing research should be focused on professional needs and should answer to nursing problems (Risjord, 2010; McEwen & Wills, 2011; Meleis, 2012). Regarding the study of complex interventions, the MRC framework (Craig *et al.*, 2008; Craig *et al.*, 2013) emphasizes the importance of the theoretical approach for the design

of an effective intervention. Theory not only provides a better understanding of the research problem, but also enhances the value of the research findings, creating a systematic structure to collect data, describe findings and predict nursing practice (McEwen & Wills, 2011; Polit & Beck, 2014). On the other hand, such findings can add a contribution to the theory validation (Polit & Beck, 2014).

Nursing theories comprise four critical components: I) the definition of central concepts; II) propositions (which explain the relations among the concepts); III) the assumptions on which the theory is based and, finally, IV) the purpose or indications for use (McEwen & Wills, 2011). Additionally, many theories are presented as a schematic drawing or conceptual map showing relations among the several components (McEwen & Wills, 2011; Polit & Beck, 2014).

2.2.1. Kolcaba's Comfort Theory

The present research is based on the middle-range Comfort Theory proposed by Katherine Kolcaba (2003).

Since 1968 several methods for theory evaluation and analysis have been described in the literature. Among other objectives, these methodologies attempt to help nurses select the appropriate theory for their work or research, as well to ensure the validity of the theory and its correct use (McEwen & Wills, 2011).

This topic presents a general overview about Kolcaba's Comfort Theory, according to the synthesized methodology for theory evaluation proposed by McEwen & Wills (2011). This methodology summarizes several steps proposed by other authors, and organizes the process of evaluation in three phases: description, analysis and evaluation (Table 1).

Table 1: Synthesized method for theory evaluation according to McEwen & Wills (2011).

PHASE	TOPICS
Theory description	<ul style="list-style-type: none"> - Purpose - Scope - Origins - Major concepts - Major theoretical propositions - Major assumptions - Description of the context
Theory analysis	<ul style="list-style-type: none"> - Concepts: Are theoretically defined and operationalized? - Statements: Are theoretically defined and operationalized? - Linkages: Are they explicit? - Organization of the theory: Is it logical? - Model or diagram: Exists? Adds a contribution to clarify the theory? - Concepts, statements and assumptions: Are they used with consistency? - Outcomes: Are stated or predicted?
Theory evaluation	<p>Theory:</p> <ul style="list-style-type: none"> - Is it congruent with nursing standards and nursing interventions? - Is it supported by research and empirically tested? - Is it being used by nursing researchers, educators, or administrators? - Is there is social relevance, namely cross-culturally? - Does it contribute to nursing as a discipline? - What are the implications for nursing?

2.2.1.1. Theory description

The Comfort Theory is a middle-range theory (scope) (Kolcaba, 2003) which aims to guide and describe nursing care (purpose) (Kolcaba, 1994). In this theory, nursing is described as holistic, humanistic and focused on the patient's needs (Kolcaba, 2001).

Origins of the theory

The Comfort Theory started to be developed during Kolcaba's PhD in nursing, and was a result of different methodologies applied at different stages: I) induction; II) concept analysis of the concept of comfort and operationalization of components; III) deduction and IV) retrodution (Kolcaba, 2001).

Induction is a type of logical reasoning where generalizations are retrieved from specific observations. At that time, Kolcaba was a head nurse in an Alzheimer's department. Through their observations, she concluded that three major concepts described her nursing practice: "*facilitative environment, excess disabilities, and optimum function*" (Kolcaba, 2001, p. 87). However, when she tried to establish relationships among the concepts, Kolcaba realized that something was lacking. This gap led her to reflect about the complexity of the concept of comfort, to make assumptions about concrete aspects of real life, and to develop a framework for dementia care (Kolcaba, 2001).

After this, and in an early stage, she conducted an extensive concept analysis of the concept of comfort, in order to analyse the semantics and extension of the concept within several disciplines such as nursing, medicine, psychology, psychiatrics, ergonomics and English literature (Kolcaba & Kolcaba, 1991; Dowd, 2004).

The next stage, deduction, involves a logical reasoning in which specific conclusions are formulated through general principles. At this stage, the three types of comfort were defined through the work developed for three nursing theorists. Thus, "*relief was synthesized from the work of Orlando, who stated that nurses relieved the needs expressed by patients. Ease was synthesized from the work of Henderson, who described 13 basic functions of human beings necessary for homeostasis. Transcendence was derived from Paterson and Zderad, who believed that patients could rise above their difficulties with the help of nurses*" (Kolcaba, 2001, p. 88). The Comfort Theory (Kolcaba, 2003) was also embedded by Nightingale's philosophy. Kolcaba argues that the 'whole person holism' is a central core within her nursing theory. This perspective argues that human beings are influenced by environmental conditions, which has an important role on holistic comfort. Similarly, this idea was already defended by Nightingale, who stated that environmental is an important factor to health's recovery (Kolcaba, 2001).

The last stage, retroduction, aims to bring a concept for outcomes research. According to Kolcaba, outcomes should be defined through patient's needs. When these needs are met, patients feel more strengthened and motivated for their own recovery. Consecutively, patient satisfaction increases, and outcomes are more easily achieved (Kolcaba, 2001).

In summary, a *“theory-based practice enables nurses to design interventions that are congruent with desired outcomes, thus increasing the likelihood of finding significant results”* (Kolcaba, 2001, p. 89).

Major concepts, theoretical propositions and major assumptions

Concepts are the principal core of a nursing theory and represent an abstract idea about a phenomenon based on observations of characteristics or behaviours (McEwen & Wills, 2011; Polit & Beck, 2014).

The Comfort Theory comprises six concepts: comfort, nursing interventions (also called comfort measures), health care needs, health-seeking behaviours, institutional integrity, and intervening variables (Kolcaba 2001; Kolcaba, 2010) (Table 2).

In addition to these concepts, which are specific from this theory (Kolcaba, 2003), the four-metaparadigm concepts of '*nursing*', '*patient*', '*environment*' and '*health*' are also defined, as presented below:

Nursing: The process in which nurses a) assess, in an objective or subjective manner the comfort needs of the patients, families or communities, b) develop and implement the most suitable nursing interventions, and c) assess the result of their interventions.

Patient: An individual, family or community who needs health care.

Environment: Aspects surrounding a patient, family or community, that can affect their comfort and which can be manipulated in order to enhance comfort.

Health: Optimum function of a patient, family or community that can be improved through enhanced comfort.

Propositions are principles that may be empirically tested and that describe the relationships among concepts (McEwen & Wills, 2011; Meleis, 2012). In her Comfort Theory, Kolcaba (2001, 2003, 2010) defines eight propositions, as presented on Table 2.

Finally, assumptions are accepted truths that address the values and beliefs on which the theory is based, and are the basis from where major concepts are defined (Meleis, 2012). According to Kolcaba, the theory embraces four major assumptions (Table 2).

Table 2: Major concepts, propositions and assumptions of the Kolcaba's Comfort Theory.

MAJOR CONCEPTS
Comfort
<i>"The immediate experience of being strengthened through having the needs for relief, ease, or transcendence met in the physical, psychospiritual, environmental, and social contexts of experience"</i> (Kolcaba, 2003, p. 14).
This definition highlights three types of comfort in four contexts: <i>"Relief: the state of having a specific comfort need met.</i> <i>Ease: the state of calm or contentment.</i> <i>Transcendence: the state in which one can rise above problems or pain."</i> (Kolcaba, 2003, p. 15)
<i>"Physical: pertaining to bodily sensations, homeostatic mechanisms, immune function, etc.</i> <i>Psychospiritual: pertaining to the internal awareness of self, including esteem, identity, sexuality, meaning in one's life, and one's perceived relationship with a higher order or being.</i> <i>Environmental: pertaining to the external background of human experience (temperature, light, sound, odor, colour, furniture, landscape, etc.)</i> <i>Sociocultural: pertaining to interpersonal, family, and social relationships (finances, teaching, health care personnel, etc.). Also to family traditions, rituals, and religious practices."</i> (Kolcaba, 2003, p. 15)
Comfort measures
Nursing interventions which aim to enhance patient comfort and/or improve desirable health seeking behaviours (Kolcaba & Kolcaba, 1991; Kolcaba, 2003; Kolcaba, 2010).
Health care needs
<i>"Deficits in any context of comfort that arise from stressful health care situations and which the patient's natural support system cannot meet"</i> (Kolcaba, 2010).
Health-seeking behaviours
<i>"Internal or external behaviours in which the patient engages that facilitate health or a peaceful death. They can be internal (healing, T-cell formation, oxygenation, etc.) or external (observable behaviours such as working in therapy, length of stay in hospital, ambulation, functional status)"</i> (Kolcaba, 2010).
Institutional integrity
<i>"Stability and ethics of any hospital, health care system, region, state, or country. When institutions do better, patients do better and vice versa"</i> (Kolcaba, 2010).
Intervening variables
<i>"Factors that each patient brings to the health care situation that nurses cannot change, and that have an impact on the success of the intervention"</i> (Kolcaba, 2010).
PROPOSITIONS
<ul style="list-style-type: none">- Nurses identify comfort needs of the patients and family members.- Nurses design, coordinate and implement interventions to achieve these comfort needs.- Intervening variables should be taken into account in the design of nursing interventions.- If enhanced comfort is achieved, patients will feel more strengthened to engage in a peaceful death or in health-seeking behaviours.- When patients engage in health-seeking behaviours (as a result of comfort interventions), both patients and nurses will feel more satisfied.- When patients are motivated and strengthened, institutions are also able to conduct their work more effectively. <p style="text-align: right;">(Kolcaba, 2001; Kolcaba, 2010)</p>
ASSUMPTIONS
<ul style="list-style-type: none">- Human being have holistic answers when faced with complex stimuli.- Comfort is a holistic and desirable outcome within the nursing discipline.- Each individual strives actively to meet their own basic comfort needs.- Patients will feel more strengthened if their comfort needs are met. <p style="text-align: right;">(Kolcaba, 1992; Kolcaba, 1994; Kolcaba, 2001; Kolcaba, 2010)</p>

Taxonomic structure and operationalization of the concept

Kolcaba (1992) states that comfort is a complex concept, not only due to its multidimensional nature, but also because it comprises a personal experience, with different degrees of intensity. Comfort is also considered a desirable outcome for patients and, consecutively, for nursing care.

The concept is described in a taxonomic structure that comprises three types of comfort or patient needs (relief, ease and transcendence), that can occur in four contexts (also called subscales): physical, psychospiritual, environmental and social (Kolcaba, 1992) (Table 2).

The operationalization of the concept can be conducted through an instrument to measure holistic comfort. Although the author had developed several instruments to measure comfort in different contexts (Kolcaba, 2010), she states that researchers can also develop other instruments based on the proposed taxonomic structure (Kolcaba, 1992).

This taxonomy brings an important way to help nurses evaluate the result of their interventions.

Conceptual diagram

Several conceptual diagrams have been designed in order to clarify the theory and provide a better understanding about the relations among concepts. Figure 1 presents one of the first ones (Kolcaba, 1994; Kolcaba, 2010). This diagram presents the major concepts and assumptions, as well the relations among them.

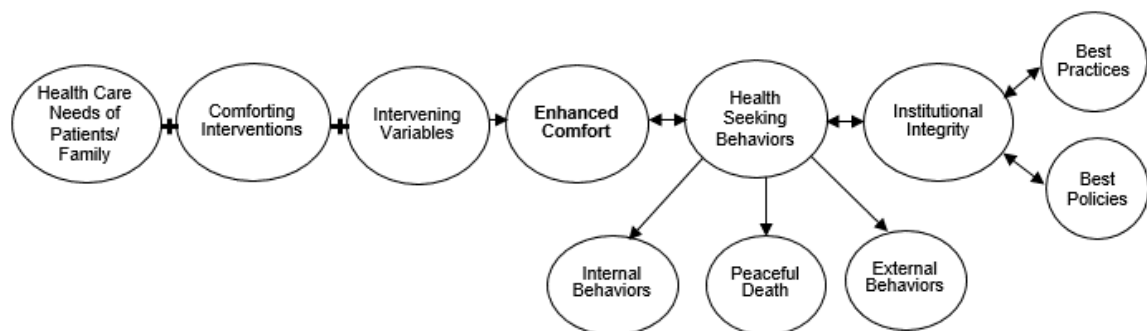


Figure 1: Conceptual framework for the Comfort Theory.

Reprinted from *www.thecomfortline.com* (Kolcaba, 2010), with the kind permission of Professor Kolcaba (Appendix 9).

Context of use

The Comfort Theory can be used in any context or health care setting, and be adapted for patients with different ages, with different clinical conditions or from several cultural contexts (Kolcaba, 2003). Currently, the theory continues to be developed in several contexts such as midwifery, urology, perioperative care, end of life, anaesthesia, paediatrics, psychiatry and, also, in different countries, namely Portugal, Spanish, Italy, Turkey, Brazil and United States of America (Kolcaba, 2001; Kolcaba, 2010).

2.2.1.2. Theory analysis

The Comfort Theory (Kolcaba, 2003) is a straight-forward theory.

The principal concept – comfort – is consistently defined and operationalized, and relations among the several components are presented in a conceptual diagram, which contributes to a better clarification and understanding of the theory (Figure 1).

The author presents several examples and, generally, the theory and the studies on which it is based, were written simply and concisely. The assumptions and propositions are clearly defined and are consistent with the overall work.

Despite being a middle-range theory, its range of action can be extended to several contexts, cultures and individuals. As an example of this are the several studies which have been conducted over time in different contexts, as reported before (Kolcaba, 2010).

2.2.1.3. Theory evaluation

Although the Comfort Theory have been presented in 2003, it is still relevant for nursing. For instance, the Comfort Theory brought the concept to nursing practice again, approaching theory from practice (Lin, 2010).

For many years, comfort was an important imperative of nursing practice (Kolcaba, 2003; Mussi, 2005). Between 1900 and 1929, the principal objective of nursing practice was to help patients to enhance comfort, particularly physical comfort. However, with the advent of the First World War and the economic depression, nurses started to work mainly in the hospital. Nursing practice became more technical and comfort, understood as a minor care, was delegated to nursing assistants (Kolcaba, 2003; Mussi, 2005).

Currently, modern societies continue to experience the repercussions of this historical evolution. Comfort remains a complex concept, associated with feminism and charity (Lin, 2010). When compared with other interventions, comforting is seen as a minor intervention. If nurses have time, they can comfort their patients. But if not, comfort is not

a priority. In fact, it seems that comfort is only seen as a priority at the end of life, when there is 'nothing more to offer' besides comfort (Mussi, 2005; Lin, 2010).

Indeed, the Comfort Theory came to remind nurses that comfort is not only a central core of nursing practice, as well as a desired outcome, that can help patients improve their recovery and health (Kolcaba, 2003; Lin, 2010). As proof of this relevance there are the many studies, developed in several contexts and countries, for nursing researchers, practitioners and educators that have contributed to the empirical confirmation of the validity of the theory. Several instruments have also been adapted or developed worldwide to measure comfort in specific populations (Kolcaba, 2010).

All this extensive work, which started in the 1990s, has clearly contributed to nursing knowledge, not only on a theoretical level, but also in clinical practice. This theory contributed to a better understanding of the concept, as well as to a better assessment of patient needs in all human life dimensions. As a result, assessment of patient needs leads to more effective and personalized nursing interventions. Indeed, comfort was integrated as a desired outcome (Kolcaba, 1992), which can be an important indicator of the quality of nursing care.

Despite these considerations, which are clearly positive, the concept remains complex, difficult to define and implement, which led to a new concept analysis study being carried out.

2.2.2. Evolutionary analysis of the concept of comfort

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ABSTRACT

While comfort is cited as an important component of nursing care, a definition that provides a firm conceptual foundation for research and nursing science is still needed, particularly in nursing classifications and taxonomies. This paper provides a clear and evidence-based definition, improving research, development and implementation of specific nursing interventions.

KEYWORDS

Comfort; comforting; concept analysis; nursing.

INTRODUCTION

Improvement of comfort in many aspects of life may be an area of particular contribution for nurses. However, in recent years, some studies also have been completed in medicine, psychology and ergonomics.¹ Most of these studies focused on physical comfort. Physical needs are basic, yet comfort cannot be exclusively assessed in a physical or bodily perspective²⁻⁴. Kolcaba^{2-3,5} made an important contribution by stating that comfort is a state resulting from the satisfaction of the need for relief, ease and transcendence in physical, psychospiritual, social and environmental contexts. Despite these considerations, the definition of comfort of International Classification for Nursing Practice[®] (ICNP[®])⁶ seems to be restrictive to the physical dimension.¹ The ICNP[®] includes comfort as a term in the axis focus, defined as a “*sensation of physical ease and bodily well-being*” (code 10004655).⁶ This definition was introduced in 1999 (ICNP[®], beta version) and, since then, no further changes were introduced. This underlines a lack of the evolution of nursing knowledge regarding comfort as, for example, comfort is defined in its physical dimension.¹ Last conceptual analysis was performed in 2003⁷ and after this several studies about comfort have been done, but no other concept analysis.

The analysis of a concept is a research methodology by which researchers try to clarify the characteristics of concepts, as well as their connection with other concepts, thus being a fundamental activity in the development of a theory, subject or science.⁸ Analysis also plays a very interesting role in the theory–practice-research interface since it helps to evaluate the consistency as well as the frailty of concepts⁹ and to give a solid background to the development of further research.⁸

This study aims to provide a conceptually adequate definition of comfort as a foundation for knowledge development, having in mind an evaluation of comfort as an outcome. In this study an updated concept is proposed based on an evolutionary method, as it considers the evolution of the concept over time, particularly from empirical studies conducted in the last 13 years. Rodgers’ Evolutionary View⁹ was chosen for this inquiry because it is systematic and rigorous, and closely reflects the development and use of concepts in science. In this methodology, the concept development is dynamic, and previous definitions or studies are not “the true” but a contribute to knowledge. This encompasses a process in which the information is continuously examined, organized and reorganized until a comprehensive set of descriptors has been found.⁹

DATA SOURCES

The search was conducted in electronic databases: *PubMed, EBSCO (CINAHL® Plus with Full text, Nursing and Allied Health Collection, Cochrane Plus Collection, MedicLatina, MEDLINE® with Full text), SciELO, Bireme, PsycINFO, Cochrane Database of Systematic Reviews* and *JBI Library of Systematic Reviews*. The inclusion criteria were research papers written in Portuguese, Spanish, French or English and published in peer-reviewed journals, between January 1st 2004 and December 31st 2015, attending to the date of Kolcaba's Comfort Theory³ and also the previous published concept analysis. Theoretical papers, opinion articles, reflexions, editorials, proceedings, books or book chapters were excluded. A preliminary analysis revealed that the majority of theoretical studies and books or books chapters were related to Kolcaba's Comfort Theory. For this reason, these literature sources were excluded. A total of 28 009 papers were identified. The references were imported to Endnote X6 and duplicates were removed (1937 results remaining). The studies were selected from the sequential analysis of the title (n= 124), abstract (n=98) and full text reading (n=87), by two independent researchers. The critical appraisal was focused on the existence of a clear definition of the research problem (comfort), and a clear description of the methodology (aims, study design, sample). Disparities were discussed and decided among the research team. A total of 59 studies were included in this analysis (Table 1).

Table 1: Studies included on comfort concept analysis.

Author (year)	Country	Context of the Study	Setting	Sample
Kolcaba <i>et al.</i> (2004) ³⁴	USA	Palliative care	Hospice (in-patients)	Patients
Tutton & Seers (2004) ⁴⁹	UK	Geriatrics	Hospital (in-patients)	Patients and HCW
Apóstolo <i>et al.</i> (2006) ⁵⁰	Portugal	Oncology	Hospital (Out-patients)	Patients
Carraro <i>et al.</i> (2006) ¹²	Brazil	Obstetrics	Hospital (in-patients)	Patients
Dowd <i>et al.</i> (2006) ²⁷	USA	People receiving healing touch massage	Hospital and Community	Patients
Kolcaba, Shirm & Steiner (2006) ⁵¹	USA	Long-term care residents	Nursing Home (in-patients)	Patients
Wagner, Byrne & Kolcaba (2006) ³⁹	USA	Surgery (preoperative)	Hospital (in-patients)	Patients
Williams & Irurita (2006) ⁵²	Australia	(unclear)	Hospital (in-patients)	HCW
Apóstolo <i>et al.</i> (2007a) ³⁶	Portugal	Psychiatry	Hospital (in-patients)	Patients
Apóstolo <i>et al.</i> (2007b) ³⁷	Portugal	Psychiatry	Hospital (in-patients)	Patients
Dowd <i>et al.</i> (2007) ²⁶	USA	College Students	Community	College Students
Rassin <i>et al.</i> (2007) ⁵³	Israel	Urology and Gynaecology	Private Clinic (in-patients)	Patients
Currow <i>et al.</i> (2008) ⁵⁴	Australia	Palliative Care	Community	Relatives
Oliveira (2008) ⁵⁵	Portugal	Acute care	Hospital (in-patients)	HCW (nurses)
Rosa <i>et al.</i> (2008) ¹⁵	Brazil	Oncology	(unclear)	Patients and HCW (nurses)
Apóstolo (2009) ²⁵	Portugal	Nursing literature	-----	Nursing Literature
Apóstolo & Kolcaba (2009) ⁵⁶	Portugal	Psychiatry	Hospital (in-patients)	Patients
Roche-Fahy & Dowling (2009) ⁴⁶	Ireland	Acute care	Hospital	HCW (nurses)
Pearson (2009) ¹³	Australia	Plural clinical contexts	(unclear)	Literature
Szareski, Beuter & Brondani (2009) ¹⁴	Brazil	Chronic disease	Hospital (in-patients)	Relatives
Waldrop & Kirkendall (2009) ¹⁸	USA	Palliative Care	Nursing Home	HCW
Yousefi <i>et al.</i> (2009) ⁴	Iran	Medical and surgical contexts	Hospital (in-patients)	Patients
Frello & Carraro (2010) ¹⁶	Brazil	Obstetrics	Hospital (in-patients)	Patients
Kalfon <i>et al.</i> (2010) ³⁵	France	Intensive care	Hospital (in-patients)	Patients
Kunikata <i>et al.</i> (2011) ³⁸	Japan	Psychiatry	Community	Patients
Silva, Carvalho & Figueiredo (2011) ¹⁷	Brazil	(unclear)	Hospital (in-patients)	Patients and HCW (nurses)
van der Steen <i>et al.</i> (2011) ¹⁹	Netherlands, Japan, Italy, Canada	Neurology	Nursing Home	HCW (physicians and nurses)
Apóstolo <i>et al.</i> (2012) ⁵⁷	Portugal	Psychiatry	Hospital (in-patients)	Patients
Freitas, Menezes & Mussi (2012) ⁵⁸	Brazil	Intensive care	Hospital (in-patients)	Relatives
Freitas, Mussi & Menezes (2012) ⁵⁹	Brazil	Intensive care	Hospital (in-patients)	Relatives

Author (year)	Country	Context of the Study (<i>continuation</i>)	Setting	Sample
Gratão <i>et al.</i> (2012) ⁶⁰	Brazil	Geriatrics	Community	Relatives
Ponte <i>et al.</i> (2012) ²⁰	Brazil	Cardiology	Hospital (in-patients)	Patients
Ribeiro <i>et al.</i> (2012) ⁶¹	Portugal	Geriatrics	Hospital (in-patients)	Literature
Schenker <i>et al.</i> (2012) ²¹	USA	Intensive care	Hospital	Relatives and HCW (physicians)
Silva <i>et al.</i> (2012) ⁶²	Brazil	Intensive care	Hospital (in-patients)	Literature
Sousa <i>et al.</i> (2012) ⁶³	Portugal	Geriatrics	Hospital (in-patients)	Patients
Zanartu & Matti-Orozco. (2012) ²²	USA	Palliative care	Hospital (not specified)	HCW (physicians)
Oliveira (2013) ²³	Canada	Nursing and medical literature	(unclear)	Nursing and medical literature
Pott <i>et al.</i> (2013) ⁶⁴	Brazil	Intensive care	Hospital	HCW (nurses)
Xavier <i>et al.</i> (2013) ²⁴	Portugal	Palliative care	Hospital	HCW (nurses)
Hunter (2015) ⁶⁵	USA	Pediatrics	Pediatric clinics	HCW (nurses)
Pedrazza <i>et al.</i> (2015) ³¹	Italy	Medicine, surgery, geriatrics and oncology	Hospital	HCW (nurses)
Tosun <i>et al.</i> (2015) ³²	Turkey	Orthopedics	Hospital (in-patients)	Patients
Aksoy & Pasinlioğlu (2015) ⁶⁶	Turkey	Obstetrics	Hospital (in-patients)	Patients
Katende & Mugabi (2015) ²⁹	Uganda	Pediatrics	Hospital	HCW (physicians and nurses)
Aléx <i>et al.</i> (2015) ⁴⁷	Sweden	Emergency	Out-patients	Patients
Parks <i>et al.</i> (2015) ⁶⁷	USA	Psychiatrics	Hospital (in-patients)	Patients
Aktas (2015) ²⁸	Turkey	University Students	Community	University Students
Hsiung <i>et al.</i> (2015) ⁶⁸	Taiwan	Surgery	Hospital (in-patients)	Patients
Andersen <i>et al.</i> (2015) ⁶⁹	Netherlands	Pediatrics	Hospital (out-patients)	Patients
Lynch <i>et al.</i> (2015) ⁷⁰	USA	Gastroenterology	Hospital	Patients
Nakamura <i>et al.</i> (2015) ⁷¹	Japan	Obstetrics	Hospital (in-patients)	Patients
van Soest-Poortvliet <i>et al.</i> (2015) ⁷²	Netherlands	End of Life	Long Term	Relatives
McGough <i>et al.</i> (2015) ⁷³	USA	End of life	Hospital (in-patients)	HCW (nurses)
Pool <i>et al.</i> (2015) ⁷⁴	USA	Vascular Surgery	Hospital (in-patients)	Patients
Slatyer <i>et al.</i> (2015) ⁷⁵	Australia	Medical and Surgical Wards	Hospital (in-patients)	Patients and HCW (nurses)
Wickson-Griffiths <i>et al.</i> (2015) ⁷⁶	Canada	Long term care	Community	HCW
Albert <i>et al.</i> (2015) ⁷⁷	USA	Cardiology	Hospital	HCW (nurses)
Hansen <i>et al.</i> (2015) ⁷⁸	USA	Palliative Care	Hospice	Patients

Legend: HCW (Health Care Workers).

RESULTS

The concept and associated expressions

Since Nightingale the concept has become more relevant in nursing theoretical development. Comfort is presently seen as a holistic experience, a state of satisfying human needs for ease, relief and transcendence in physical, psychological, social and spiritual contexts.^{3,5} But, there are still theoretical inconsistencies, not only in literature but also in nursing knowledge classifications and taxonomies as in the International Classification of Functioning, Disability and Health - ICF,¹⁰ in the ICNP®⁶ and in the NANDA-I.¹¹ The definitions proposed by ICNP® and by ICF are restrictive,^{6,10} since they only describe the concept as related to physical needs, overlooking the psychological, social and spiritual domains proposed by Kolcaba. According to ICNP®, comfort represents a “*sensation of physical ease and bodily well-being*” (code 10004655),⁶ whereas ICF represents an activity from “looking after one’s health”, related to the need of “*ensuring one’s physical comfort*”.^{10, p.152} These inconsistencies raise questions about a more holistic and evolutionary nature of comfort, although still pointing to comfort as the concept of interest.

Surrogate terms

Surrogate terms are defined as alternative words or expressions for the concept being studied.⁹ When analysing the selected studies, some terminology different from “comfort” was identified: “pain relief”, “palliative measures”, “supporting measures”, “conserving measures”, and “cosiness.” “Comfort” also was discussed in the context of “well-being” and with additional descriptors such as “comfort measures”, “comfort interventions”, “comforting actions”. The terms “pain relief”,¹²⁻¹³ “cosiness”¹⁴ or “well-being”^{12,14-17} are related to the physical domain. The terms “comfort measures”, “comfort interventions” and “comforting actions”^{12, 18-24} represent the idea of comfort as a process and a holistic experience.³

Related concepts

Related concepts can be defined as other concepts that are related to the concept in study, typically exhibiting some but not all of the attributes of the concept of interest.⁹ The following related concepts were identified: “caring”, “quality of life”, “holism/ holistic care”, “spirituality”, “suffering” and “happiness”.

Kolcaba's Comfort Theory³ may be useful in understanding the relationship of the concepts to each other. According to the author, there are three types of comfort (relief, ease and transcendence), which may occur in four contexts (physical, psychospiritual, environmental and sociocultural). The overall comfort is broader than the sum of the parts, a perspective closely associated with the concept of holism.³ According to Kolcaba, comfort is also related to the satisfaction of needs,³ which further is related to the concepts of quality of life, happiness and suffering.^{1, 25} All these concepts express the satisfaction with meeting personal needs and expectation towards life and the perception that the persons may have about their condition. Thus, comfort is a main goal of nursing caring and both comprise action or intervention and relationship as key attributes.

Setting and sample

Context variation (setting and sample) refers to the way the concept is seen in each subject or the way it is used within a certain expertise domain.⁹ The studies included illustrate the use of the concept of comfort both theoretically and increasingly in clinical practice. In the theoretical domain we highlight the literature reviews. In what concerns clinical practice, we were identified the contexts of palliative care, geriatrics, psychiatrics, oncology, cardiology, intensive care, surgery, obstetrics and paediatrics (Table 1). The majority of these studies analysed comfort from the perspective of ill patients. However, some studies have been conducted in healthy populations that have experienced some discomfort in their life, as for example the women perception of comfort during the labour^{12, 16} or college students with anxiety.²⁶ These studies make a valuable contribution to understanding comfort as a state, a process and an outcome across health and life transitions.

References of the concept

The references of a concept illustrate events, situations and phenomena to which the concept has been applied within a certain context.⁹ As evident in the discussion of contexts, studies focused on comfort typically have been developed in contexts of illness. Three studies were developed in the community²⁶⁻²⁸ but studies with healthy sample are not so frequent. Although most studies were focused on the perspective of nurses, three of them approached the perspective of physicians^{21-22, 29} (Table 1).

Social and cultural differences also have been underexplored although the literature revealed that comfort, as a concept, is present in a variety of global settings. Several tools for the assessment of comfort in different clinical contexts were identified (Table 2), such as: acute care,^{5,30-32} end of life,³³⁻³⁴ intensive care,³⁵ oncology,³⁰ psychiatry,³⁶⁻³⁸ surgery,³⁹

urology,⁴⁰ and paediatrics.⁴¹ One instrument was developed for people receiving healing touch therapies²⁷ and another one for people communicating with stammers.⁴²

Table 2: Comfort assessment tools.

Context	Tool Author (year)	Sample
Hospitalization	General Comfort Questionnaire ^{5,30}	Patients
End of life	End of Life Comfort Questionnaire-Patient ³³	
	Hospice Comfort Questionnaire ^{33,34}	
	End of Life Comfort Questionnaire- Caregiver ³³	Caregivers
Intensive Care	Inconforts des patients de REAnimation Questionnaire ³⁵	Patients (Adults)
Oncology (Breast Cancer)	Radiation Therapy Comfort Questionnaire ³⁰	
	Comfort Visual Analog Scales ³⁰	
Orthopedics	Turkish Version of Kolcaba's Immobilization Comfort Questionnaire ³²	
Psychiatry/ Psychology	Psychiatric In-Patients Comfort Scale ³⁶⁻³⁷	
	Scale for the sense of ibasho (psychological comfortable space) ³⁸	
Surgery	Thermal Comfort Inventory ³⁹	
	Thermal Comfort Numeric Visual Analog Scale ³⁹	
Urology	Urinary Incontinence and Frequency Comfort Questionnaire ⁴⁰	
Paediatrics	Comfort Daisies ⁴¹	Patients (Young children)
	Comfort Behavioural Scale ⁶⁹	
Stammers	Listener Comfort Scale ⁴²	People communicating with stammers
Healing Touch	Healing Touch Comfort Questionnaire ²⁷	People receiving healing touch therapy
Acute Care	Nurses' Comfort With Touch Scale ³¹	Nurses

Definition of the concept

As identified through this study, and in an evolutionary perspective, the concept of comfort can be defined as a complex, dynamic, holistic, subjective and positive experience that includes the satisfaction of individual needs. Comfort may be achieved in one or more dimensions (physical, spiritual, psychological, social, environmental), may be preceded by any life transition or challenge, and results in physical relief and/or transcendence.

According to Rodgers,⁹ the definition of a concept is composed of its key characteristics or attributes. The first attribute is that comfort is a complex concept that involves multiple dimensions of human experience and is subject to considerable variation across people and time. Comfort also is a holistic experience, in which the global result is greater than the sum of the parts. Kolcaba proposed three types of comfort: ease, relief and transcendence which can happen in all human life dimensions and several contexts: physical, psychological, spiritual, social, cultural and environmental.³ Literature describes

comfort as feeling strength/ supported and safe, which are also goals of nursing care (Table 3).

Table 3: Antecedents, consequences and attributes of comfort.

ANTECEDENTS	
INWARD	Disease/ Unbalance ^{17,53,56}
	Knowledge/ Empowerment ¹⁹
	Patient–Health Professional Relationship ^{12, 18,20, 55,61, 64}
	Previous Experiences ⁶⁰
OUTWARD	Family Support ^{4, 12, 18,20, 50, 63,78}
	Health Professionals’ Personal and Professional Skills ^{21-22,24 54-55,63,75}
	Institution’s Caring Model ^{4,14,17,46,55,63}
	Environmental Factors ^{4,14,17-18,24,46-47,50,55,57-58,62-63}
CONSEQUENCES	
PATIENTS	Discomfort Relief ^{23-24,47,53,57,61,68}
	Client’s Satisfaction towards the given Cares ^{51,71}
	Increased Health-Professional/ Patient Interaction ^{34,51}
	Decrease Anxiety, Feelings of Guilt and Concerning ^{23,34,39,56}
	Increased Self-Esteem and Ability for Transcendence ⁵⁶
	Increased Security/ Anticipation of Patient Needs ^{17,23}
	Self-Control ^{23,61}
HCW	Better Tolerance to Human Suffering ^{24,65}
	Peace and Inner Strength ²⁴
ATTRIBUTES	
Complex ^{23-25,51,64}	Dynamic: Range over the Time ^{12,16,20,27,34,51-54,61}
Individual ^{49,55,61,63-64}	Something Positive or Good ^{4,20,24,49,52}
Dependent of Individual’s Perceptions ^{23,52,56}	Desired State of Satisfaction and Happiness ^{12,16,24,31,52,56}
Subjective ^{15-16,24,49,63}	Satisfaction of Needs ^{4,12,14-17,18,23-25,46,52,61,64}
Holistic Experience ^{4,14-16,18,20,23,46,50,55,58,61,63-64}	Feeling Strength/ Supported ^{12,14-15,20,24,49,52,55,58}
Pleasant Experience ^{4,12,15,17,50,52,55,58,71}	Feeling Safe ^{12,14,16,20,24,55,59}

Legend: HCW (Health Care Workers).

The complexity of the concept is also due, in part, to the different ways in which it is used. It appears in literature as a noun (“comfort”), a verb (“comforting”, “to comfort”), an adjective (“comfortable”) and also as a state, a process and an outcome.^{1, 43} Despite these semantic differences, some studies related to comfort have in common the idea of comfort as something positive or good. It is a soothing or pleasant experience, a desired state of satisfaction and happiness, weighted by their importance to the individual (Table 3).

In this sense, comfort is a very subjective and individual concept, closely related with individual's perceptions. Aspects of an individual's personality or temperament, age, sociodemographic characteristics, clinical conditions, culture, value system, and beliefs (religious, political or sociocultural) influence the perception of comfort. Comfort is also described as a state of satisfaction of needs, in order to achieve relief, ease and transcendence in all human life dimensions. To feel comfortable means that the individual's needs are satisfied in that moment. However, as needs range across life and different situations, also the perception of comfort may change. We argue that comfort is not straightforward. The person may have achieved comfort in one dimension (physical, for example) but not in another one (spiritual or environmental for example). The global result, which is greater the sum of the parts, may also depend on the importance that each person gives to each unmet need in a particular dimension. At the end, comfort is not a static concept but a dynamic concept, ranging over the time (Table 3).

Antecedents of the concept

The antecedents of a concept represent the factors that precipitate its happening or, in other words, the contexts or events that precede an occurrence.⁹ Previous studies have identified three antecedents, all of them related to the patient: discomfort, distress and suffering.⁴⁴⁻⁴⁵ A comforting experience can have inward and outward factors to the individual (Table 3). Among the inward factors we outline the disease or any situation that causes a state of unbalance, the self-awareness of a certain situation/ problem, the patient–health professional relationship and a patient's previous experiences. The outward factors are: family support, health professionals' personal and professional skills the institution's caring model and environmental factors. In what concerns environmental factors to promote comfort, literature underline a calm, warm and quiet environment⁴⁶⁻⁴⁷ that assures patients' privacy^{12,14,46} and facilitate the practice of spiritual and/or religious rituals and believes.^{4,20}

Consequences of concept

The consequences are what occur after an instance of the concept.⁹ Despite the increase in experimental studies, specific consequences of comfort are rarely documented. The following consequences were identified: discomfort relief, client's satisfaction towards the given cares, a better patient-health professional interaction, lower anxiety, guilt feelings and worry, an increase in self-esteem and in the ability to transcendence, an increase in safety and in anticipating needs, self-control, and a higher tolerance to proceedings and equipment. The studies also highlight that comfort consequences can be looked in the

perspective of formal and informal carers. Such as in patients, consequences of comfort to caregivers are inner peace and strength and, consequently, a better tolerance to human suffering (Table 3).

DISCUSSION

Although literature in four languages was used in this analysis, this does not provide a definitive exploration of comfort from the standpoint of different cultures. Some articles in other languages were excluded, and this may affect the completeness of the evidence about comfort. The study is also based in healthcare, mainly in nursing because the majority was developed in this context. Articles from other areas of expertise, such as ergonomics were excluded. In an evolutionary perspective other studies across different cultures and particular settings are encouraged in order to provide a continuous and comprehensive analysis over the time and around the world.

Research about comfort has improved with Morse's and Kolcaba's theories in the 1980's particularly with the last, in which the author provided a definition and operationalization of the concept.¹ But, comfort has remained unclear on evaluating the outcomes and determining more effective and efficient interventions. Previous analyses of the concept underlined the importance of comfort in nursing and defined discomfort, distress and suffering^{45,48} as main antecedents. In this evolutionary analysis the concept of comfort was considered in a global perspective, as did Malinowski and Stamler,⁴⁴ and was found to be applicable to a state, process, or outcome. The discovery that the concept applies in different forms brought about important variations, particularly in regard to antecedents and consequences, in which previous studies were not clear. In what concerns antecedents, the analysis highlighted comfort as a holistic state depending on patients' inward and outward factors such as disease or health status or situations that can cause unbalance in several dimensions of human life, which were not discussed in previous analysis. These data outline the importance of comfort in health care in regard to illness, transitions and crisis situations, as stated before by Siefert⁴⁸ and Tsai, Lee and Hu.⁴⁵ Illness or crisis situations are not the only antecedents in health care; life transitions, such as pregnancy, are also antecedents in that they can cause unbalance and discomfort.¹²

Another new finding, highlight that previous experiences in illness may also influence the perceptions of comfort, regarding patients' relationship with the health professionals and this can determine the need and direction of the comforting process. Beside these, there are others external factors that can affect not only the patient perception of comfort, but also the comfort as a process, like the social background, the health professionals' skills/belief, the institution's caring model and environmental factors. These antecedents

can interfere with a patient's global comfort and can determine the patient's needs. For example, a patient with a higher social background could perceive less comfort than a patient with lower social conditions. But, as comfort is a holistic concept, other aspects should also be assessed and health professionals' should value small wishes that can be an important when diagnosing comfort needs.

Siefert⁴⁸ and Tsai, Lee and Hu⁴⁵ stated that comfort attributes comprise an effective communication, the presence of family and significant relationships, keeping the functionality, personal features, physical relief and psychosocial interventions, spirituality and feeling safe and sound. However, the attributes are the characteristics that define a concept.⁹ Communication and relationships, which were identified in previous studies as key attributes,^{45,48} are not, from our point of view, an attribute, but an essential way to achieve comfort.

The definition provided through this analysis, presenting an update to work done much earlier and also including several empirical studies, provides a basis for effective use of the concept in nursing practice and research. Assessment of comfort, as a complex concept, should include multiple factors and awareness or subjectivity of the experience. As a dynamic and individual process, the intra and inter-individuals variations should be considered. Instruments developed to study or document comfort must enable these individual interpretations. Several tools to measure comfort were presented in this analysis. The first one, *General Comfort Questionnaire*⁵ is still the basis for many studies and the origin of other tools (which are essentially an adaptation to specific contexts and populations). Although they are important, they are quite long, which can discourage their daily use by carers, and thus are likely to be used only for clinical investigations.

As Kolcaba referred,³ it is not possible to achieve a state of complete comfort in many cases. Comfort may only be the relief of minor discomforts, the fulfilment of little aims and the satisfaction of small wishes. These consequences are particularly important in irreversible situations, such as in a terminal disease. For this reason we stated that comfort is a holistic experience, in which the whole is greater the sum of the parts. As the definition reveals, comfort must be considered as dynamic, varying, individualized, subjective, and needs to be assessed on a continuum rather than as a categorical variable.

Previous studies have identified as main consequences the needs satisfaction, sense of control, sense of inner peace, pleasant experience, feeling cared for, relief of symptoms, reduced suffering, decreased disequilibrium, absence of discomfort.^{45,48} In this study, the comforting process influences not only the patient (or family member/ caregiver) but also the person who provides comfort (formal or informal carer). This study highlights the increase in client-health interaction, anxiety and guilt decrease, and increase in self-

esteem and in transcendence skills. Healthcare providers perceive providing comfort as a process that generates inner peace and help to develop acceptance and tolerance towards suffering they deal with.²⁴

The results are not intended to replace or overlook the data found by other authors, but rather synthesize, analyse and complement the information produced since 2003, providing a new contribution to clarify the inconsistencies present in literature and, also, in nursing classifications.

CONCLUSION

The data illustrate and emphasize the importance of comfort to patients, but also highlight an emergent priority on evaluating the consequences as an outcome on healthcare and as an indicator of quality of care, which is important for health policy. This analysis brings about new perspectives in evaluating antecedents, new attributes and new guidelines in the operationalization and in the assessment of outcomes, because it included empirical studies developed in the last 13 years (since the last concept analysis published in major indices).

The analysis suggests the need to update the elements of the concept using a detailed description of antecedents, which were only assessed from patients' perspective. The study adds that antecedents, both inward and outward, represent an important condition in the state of comfort and also in comforting process. This study identified new attributes and provides a more comprehensive definition of the concept, particularly in terms of the key attributes and principal antecedents. Comfort is a complex and subjective concept and previous analyses didn't reflect the exclusivity of comfort characteristics. In the present analysis comfort is defined as a desired state of satisfaction and happiness, a pleasant and holistic experience closely related with individual's perceptions and needs satisfaction, in order to achieve relief, ease and transcendence in all human life dimensions.

Consequences represent one of the biggest challenges in the understanding of the concept. This difficulty comes from the lack of experimental studies and the difficulty in assessing outcomes. The evidence underlines that a state of complete comfort is not possible in many cases. Thus, more studies to help the operationalization of consequences are needed. It is thus necessary to include all carers, patients, families, caregivers and health institutions in development and translation of knowledge about comfort. Data are consistent with the need to change the concept of comfort in the ICNP[®], which current definition seems reductionist in current nursing knowledge.

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2.2.3. Comfort, well-being and quality of life:
Discussion of the differences and similarities among the concepts

Pinto, S., Fumincelli, L., Mazzo, A., Caldeira, S. & Martins, J.C.

This study arose in the sequence of the analysis of the concept of comfort, in which the concept of well-being emerged as a surrogate term and the concept of quality of life as a related concept. Several inconsistencies have been found in scientific evidence, as well as in nursing classifications and taxonomies of nursing knowledge. For instance, the ICNP® (ICN, 2015), defines the concept of comfort using the concept of well-being (a surrogate term). Nevertheless, in many contexts, as for example PC, the concepts of comfort and quality of life are used interchangeably. Therefore, what are the differences and similarities among the concepts?

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Review

Comfort, well-being and quality of life: Discussion of the differences and similarities among the concepts

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ABSTRACT

Aim: To analyze the differences and similarities of the concepts of comfort, well-being and quality of life (QoL).

Methods: Review of concept analysis research on PubMed, Cinahl (*full text*) and Scielo, using the search terms "Comfort", "Well-being", "Quality of Life" and "Concept Analysis".

Results: Eighteen studies were included. Comfort is a broader holistic concept while well-being is mainly related to psycho-spiritual dimensions. QoL reflects the individual perception of satisfaction with life.

Conclusions: The concepts are not surrogate terms, but related concepts sharing common attributes. Caution should be taken in further research, particularly as regards the correct use and framing of the concepts.

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Introduction

Quality of life (QoL), comfort and well-being have progressively been used as important goals in many contexts such as health, justice, economy or environment.¹ Particularly in nursing, several research papers on these concepts have established the grounds for the development of theories and inclusion in the classifications and taxonomies.²⁻⁶ The distinction of the concepts is not always clear, as the terms are semantically close and this may result in the interchangeable use of the concept of well-being and the concept of comfort, for example. Several concept analysis studies have identified well-being as synonymous with the concept of comfort, and QoL as a related concept.^{5,7} Some inconsistencies have been identified in nursing knowledge classifications that may lead to the promotion of redundancies and gaps, with repercussions on clinical practice. The objective of this study is to analyze the differences and similarities of the concepts of comfort, well-being and QoL, based on a review of concept analysis research.

Background

The concepts of comfort, well-being and QoL have been gaining particular relevance in the health context because of the scientific development and technological changes in the illness journey, and also because of concerns with the defense of human rights, particularly after the Second World War. In general, people live longer but not necessarily better, which has led several authors and disciplines to study the concepts of comfort,^{3,6,8} well-being,⁴ and QoL.^{9,10} Although several theories have been developed that specifically concern each concept, the lack of clarity regarding the use and appropriateness of the concepts sometimes exists.

The first inconsistencies can be identified when analyzing the semantics of the terms in regular dictionaries. Inconsistencies can also be identified in professional classifications, such as the International Classification for Nursing Practice (ICNP[®]). In spite of comfort and well-being being considered separate terms, this classification defines comfort (code 10004655) using the concept of well-being: "sensation of physical ease and bodily well-being".¹¹ The international classification of nursing diagnoses, NANDA-International (NANDA-I), also features a new taxonomy proposal in the last edition, wherein the domain entitled "existential" integrates two distinct classes, entitled "well-being" and "comfort".¹²

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The World Health Organization (WHO) defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”.¹³ This definition proposes that individuals are not healthy unless they have achieved holistic well-being, regardless the absence of spiritual dimension.¹⁴ Also, when considering the changes in the course of diseases and chronic illness, the WHO definition seems to suggest that these patients are definitely ill.¹⁴ Although the several criticisms, namely the completeness of well-being in all human life dimensions, the definition has never been adapted.¹⁴ Redefining health is challenging, but a new definition should comprise a broader perspective, and attempt different conditions and cultures.¹⁴

These inconsistencies formed the basis for the questioning of the similarities and the distinguishing attributes of the concepts of comfort, well-being and QoL, particularly in nursing knowledge, as these concepts have been integrated in nursing theories and research.

Comfort

The term “comfort” derives from the Latin “*confortare*” which means “become strong, comfort or encourage.” In a linguistic dictionary, the term is a synonym of “well-being”, and is defined as aid and solace in moments of affliction.^{15,16} Comfort has always been a central concern and concept in nursing and it is particularly important in the definition of the nature of nursing knowledge, the discipline, and the profession. The work of Morse and Kolcaba is widely recognized among the different theories that have analyzed the theme of comfort. Morse defines comfort as a result of therapeutic nursing interventions and underlines the idea of comfort as a process inherent in the act of comforting.^{15,17,18} The studies of Kolcaba have been based on the well-known theory of comfort, in which the author operationalizes the concept and defines it as “*the immediate state of being strengthened by having the needs for relief, ease, and transcendence addressed in the four contexts of holistic human experience: physical, psychospiritual, sociocultural, and environmental*”.^{8,p.251}

Despite the international projection of the Morse and Kolcaba studies,^{8,17} the concept of comfort is present in other nursing theorists’ studies, such as Ida Jean Orlando (whose study defines comfort as a response to human needs), Sister Callista Roy (who stressed the importance of psychological comfort), Madeleine Leininger and Jean Watson (who defended comfort as essential to the care process), and Hildegard Peplau (who defended comfort as a fundamental human need associated with food, rest, sleep and communication).^{15,18}

Well-being

The word “well-being” derives from the Latin words “*bene*” and “*stare*”, which mean “*being well*”. The Oxford Dictionary defines well-being as “*the state of being comfortable, healthy, or happy*”.¹⁶ When quoted in scientific literature, it is usually identified as a related term to the concepts of happiness, positive experiences or ideas, life satisfaction, pleasure and prosperity.¹⁹ Well-being is also a multidimensional concept, with implications on one’s physical, mental, social and environmental aspects of living.²⁰ It concerns individual care in a healthy way and covers aspects such as awareness of the physical condition, stress reduction and self-responsibility in care. The strategies for achieving well-being help people reach new ways of understanding and controlling their lives, both in an individual and a collective scope.²¹

Orem’s self-care theory and Watson’s transpersonal theory are particularly relevant among the nursing theories that evoke the concept of well-being. In fact, in all Health Sciences theories, including the Nursing theories, well-being is often present as important in

patients’ assessment. Orem’s Self-Care Theory defines self-care as the performance of activities that individuals or caregivers perform for their benefit in order to maintain life, health and well-being.²² Also, in Watson’s Transpersonal Theory,²³ the author advocates the shaping of a system of humanistic and altruistic values, the instillation of faith and hope and the recognition of sensibility and feelings on the part of the nurses themselves as fundamental principles for the development of the nurse-patient relationship, and for promoting well-being.

Quality of life

The concept of QoL has been discussed in several areas of knowledge over time. Although there are several definitions of the concept, the majority of authors define the concept as the individual’s perception of their personal situation in their own life in the physical, social, mental and spiritual dimensions.^{9,10} The study of QoL in the health field is relatively recent. The first studies emerged in the 1930s, but interest only began to grow from the 1960s, due to the unwanted consequences of the post-war period, when a search for the improvement of living conditions for humanity created greater interest in research of the concept by modern societies.¹⁰

Among the various definitions of the concept,^{2,5,24} the definition proposed by the World Health Organization Quality of Life Group is widely used^{9,p.1}: “*individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns*”. This definition considers the person’s physical and psychological condition, the level of independence, social relationships, personal beliefs, the environment and culture. The assessment seems to be subjective and multidimensional, considering the cultural, social and environmental particularities of each person.⁹ It reflects the global condition of human life, personal interests with the enhancement of life dimensions, such as physical, political, moral, social, environmental, and spiritual dimensions.

Similar to previous concepts, several nursing theories have included the concept of QoL, such as Peplau, Rogers, King, Leininger and Parse.²⁵ In Peplau’s theory, QoL is a synonym for well-being or psychological health. Rogers and King describe QoL as a synonym for life satisfaction. Leininger believes that the concept of QoL is culturally constructed, which means, it is dependent on the values, beliefs and symbols of a given culture, representing a powerful force for promoting health and well-being. Parse describes the concept as representing the meaning that each individual attributes to the lived experiences.²⁵

Methods

Review of nursing research using a concept analysis method and concerning the concepts of comfort, well-being and QoL. The search was conducted in the databases PubMed, Cinahl (*with full text*) and Scielo, using the terms “Comfort”, “Well-being”, “Quality of Life” and “Concept Analysis,” in the title and/or abstract. Concept analysis studies, regardless of the method, published in Portuguese, Spanish, English and French, up to 31 December 2015 were included. Narrative reviews, semantic analyses, editorials or letters to the editor, books or book chapters, and proceedings were excluded.

One researcher conducted the search in the first phase. Two researchers independently performed the analysis and screening of the results, and disagreements were subsequently analyzed by all researchers (Fig. 1). All references to the included studies were also analyzed.

The results were exported to EndNote X6, and a database was designed to collect the data according to the study objectives.

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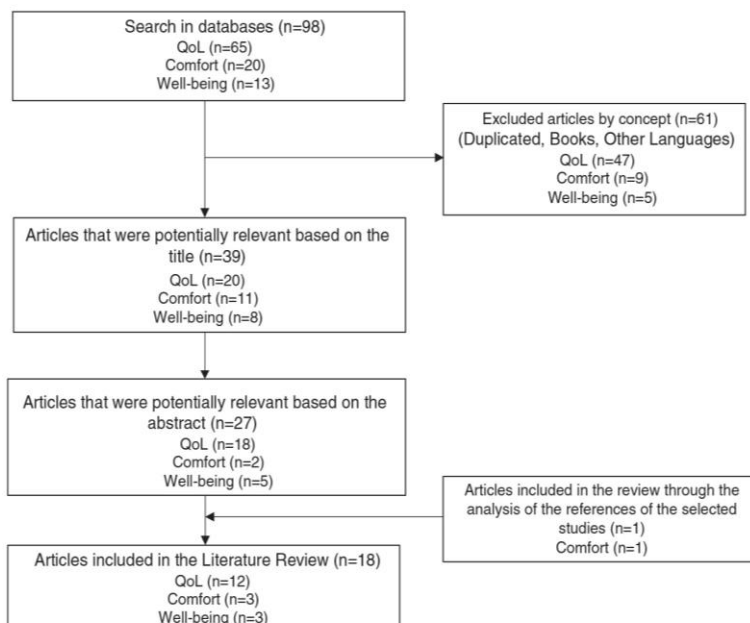


Fig. 1. Studies' selection.

Duplicates and studies that did not meet all the eligibility criteria were excluded. Since no instrument was found for the critical appraisal of concept analysis research, a generic consensual instrument was designed, based on the following criteria and research method procedures: clear definition of the concept, clear definition of the aim, and description of the concept analysis methodology in use. A score of 1 was given when the item was present and zero when it was unclear or absent. The differences in the scores were discussed by the researchers.

Results

A total of 98 results were identified (Fig. 1). After duplicates removal, the full text reading and the screening of the references of the included articles, 18 studies were included in this review. Three studies concern the concept of comfort, three studies the concept of well-being, and 12 studies the concept of QoL (Table 1). The methods of concept analysis used were as follows: Beth Rodgers evolutionary model (n=3),^{26,27} and Lorraine Walker & Kay Avant model (n=15).^{28,29}

The oldest study was published in 1991 and was related to the concept of QoL.²⁴ The majority of studies were developed with adult populations, and some reported specific groups such as critically-ill patients (n=1), cancer patients (n=1), the elderly (n=2), patients with urinary incontinence (n=1), patients with chronic obstructive pulmonary disease (n=2), and renal patients (n=1) (Table 1). One study with neonates was also found.

Two of the studies were in Chinese and only the abstract was in English,^{31,32} but the clarity and completeness of the results in the abstract was considered relevant and both were included in the analysis. One of these studies focused on the concept of comfort,³¹ and the other focused on the concept of spiritual well-being.³⁰ All studies included in the review were analyzed in relation to the attributes and consequents of the three concepts under study (Table 1).

The results demonstrate the complex and subjective nature of the concepts and their relation with the individuals' self-esteem

and perception (Table 2). Despite this, distinct attributes were also observed for each concept. Thus, comfort seems to be more related to the symptom relief and/or reduction of imbalances or discomfort, inner peace, security and effective communication. The concept of well-being lies on a psycho-spiritual basis, associated with happiness and an "internal energy". QoL appears as a broader concept, associated with life improvement, dignity and achieving autonomy and personal goals (Table 2).

Discussion

In spite of all three concepts having been widely studied in different contexts (concept analysis, theory development, empirical studies), the data show that there is still a lot of subjectivity in the definition. Also, no studies of comparison between the concepts were found.

One of the strongest points focuses on defining the attributes of the concept, since it is on this level that weaknesses can be shown to exist. The studies were based on the methods proposed by Beth Rodgers^{26,27} and Lorraine Walker & Kay Avant.^{28,29} Despite the methodological differences, both are similar in the definition of the attributes, which represent the core of the concept or the unique characteristics of each concept. Several studies highlight the complex, multidimensional, subjective, individual and dynamic nature of the concepts of comfort, well-being and QoL.^{4-6,33-35} However, these are not unique qualities of the concepts. The existence of such a wide set of attributes common to the three concepts backs the inherent difficulties in their definition and operationalization. Further specific and exclusive attributes need to be identified to clarify each concept.

By analyzing the attributes of the concept of well-being it is possible to state that the concept can be assimilated to comfort. When looking at the etymological origin of both words, the concept of comfort is derived from the Latin word *confortare* which means to give strength, force, and the concept of well-being refers to a pleasant corporal or spiritual experience. Even though it is identified in literature as a state, a process and an outcome, the etymological

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Table 1
Attributes and consequents of the concepts of comfort, well-being and quality of life.

Article (author, year)	Concept analysis method	Attributes	Consequents
<i>Comfort</i>			
Concept analysis of Comfort ³	Rodgers ²⁷ (2000)	<ul style="list-style-type: none"> - Effective Communication - Family and significant relationships - Maintaining functionality - Personal characteristics - Relief of physical symptoms, condition and interventions - Psychological and spiritual activities and states - Sense of security - Satisfaction of needs 	<ul style="list-style-type: none"> - Inner peace - Pleasant experience - Feeling cared for - Relief from symptoms - Reduction of imbalances - Absence of discomfort - Reduction of suffering
Comfort: A concept analysis ³¹ (abstract only; article in Chinese)	Walker & Avant ³⁰ (2005)	<ul style="list-style-type: none"> - Effective Communication - Family and significant relationships - Maintaining functionality - Personal characteristics - Relief of physical symptoms, condition and interventions - Psychological and spiritual activities and states - Sense of security 	<ul style="list-style-type: none"> - Satisfaction of needs - Self-control - Inner peace - Pleasant experience - Feeling cared for - Relief from symptoms - Reduction of imbalances - Absence of discomfort - Reduction of suffering
Evolutionary analysis of the concept of Comfort ⁶	Rodgers ²⁷ (2000)	<ul style="list-style-type: none"> - Relief from discomfort - Customer Satisfaction - Increased patient-professional interaction - Decreased anxiety, feelings of guilt and concern - Increase in self-esteem and capacity for transcendence - Increase in security and anticipation of needs - Self-control - Better tolerance to equipment and procedures 	<ul style="list-style-type: none"> - Complex - Subjective - Individual - Dependent on the individual's perception - Holistic experience - Feeling strong/supported - Feeling safe - Something positive or good - Pleasant experience - Satisfaction of needs - Dynamic
<i>Well-being</i>			
What is perinatal well-being? A concept analysis and review of the literature ⁴	Walker & Avant ³⁰ (2005)	<ul style="list-style-type: none"> - Complex - Multidimensional - Subjective - Related to individual's perceptions - Related to cognitive or affective self-evaluation of life 	Not specified
Spiritual well-being: A concept analysis ³² (abstract only; article in Chinese)		<ul style="list-style-type: none"> - Subjective feeling of happiness - Affirming self-worth - Managing interpersonal relationships with an open, accepting attitude - Possessing an internal "energy" 	Not specified
<i>Quality of life</i>			
Concept analysis of quality of life ²⁴	Walker & Avant ²⁸ (1988)	- An evaluation of life	-Improvement of life's quality
Quality of life: a concept analysis ²		<ul style="list-style-type: none"> - Feeling of satisfaction with life in general - Mental capacity to evaluate one's own life as satisfactory or not - Acceptable physical, mental, social and emotional state, as determined by the individual - Objective evaluation, made by others, that the living conditions are appropriate and not fatal 	<ul style="list-style-type: none"> -Satisfaction -Happiness -Well-being
Quality of life for critical care patients: A concept analysis ³⁷		<ul style="list-style-type: none"> - Satisfaction with life - Cognitive abilities to evaluate own life - Presence of physical, psychosocial health according to self-criteria - Happiness - Psychological well-being 	Not specified
Quality of life in persons with non-small cell lung cancer: A concept analysis ³³	Rodgers ²⁶ (1993)	<ul style="list-style-type: none"> - Subjective - Multidimensional - Functional status in physical, emotional and mental dimensions 	Not specified
A multidisciplinary concept analysis of quality of life ³⁴	Walker & Avant ²⁹ (1995)	<ul style="list-style-type: none"> - Multidimensional - Dynamic - Subjective and objective - Measured through self-evaluation criteria 	<ul style="list-style-type: none"> - Perception of one's life - Improvement of decision to make changes related to individual's circumstances

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Table 1 (Continued)

Article (author, year)	Concept analysis method	Attributes	Consequents
A concept analysis of quality of life ⁷	Walker & Avant ³⁰ (2005)	<ul style="list-style-type: none"> - Subjective self-evaluation of one's life - The individual identifies their satisfaction with the physical, psychological and social domains of their life - Objective measures can complement the subjective evaluations of the individual 	<ul style="list-style-type: none"> - Happiness - Satisfaction - Physical and psychological health - Empowerment - Self-esteem
Analysis of quality of life concept in the context of older adults with physical disabilities ³⁸		<ul style="list-style-type: none"> - Satisfaction with life - Physical, psychosocial and spiritual well-being - Meaningful occupations - Sense of control - Adapted behaviour - Satisfying functional status 	<ul style="list-style-type: none"> - Harmony - Self-preservation - Update of self-potential - Improvement of personal journey
Concept analysis of health-related quality of life in nursing home residents with urinary incontinence ⁴¹		<ul style="list-style-type: none"> - Sense of control - Self-worth - Independence - Social engagement 	<ul style="list-style-type: none"> - Self-esteem - Sense of dignity - Increased independence - Freedom
Health-related quality of life in patients with moderate to severe chronic obstructive pulmonary disease: a concept analysis ³⁵		<ul style="list-style-type: none"> - Subjective - Multidimensional - Dynamic - Achievement of goals and aspirations - Affected by constraints of illness and treatment. 	<ul style="list-style-type: none"> - Social independence - Social engagement - Decreased depression - Satisfaction/acceptance of one's circumstances - Coping and adaptation to new circumstances
Quality of life in end stage renal disease: a concept analysis ⁴²		<ul style="list-style-type: none"> - Ability to engage in vigorous activities - Ability to perform daily life activities - Ability to engage in social domain 	Not clear
Quality of Life in Chronic Obstructive Pulmonary Disease: An Evolutionary Concept Analysis ³⁶	Rodgers ²⁷ (2000)	<ul style="list-style-type: none"> - Multidimensional - Satisfaction with life domains - Happiness with life 	<ul style="list-style-type: none"> - Outcome in health care contexts - Related to patients, caregivers and care
Quality of life in old age: a concept analysis ⁵	Walker & Avant ³⁰ (2005)	<ul style="list-style-type: none"> - Satisfaction with life conditions - Subjective - General well-being - Subjective fulfilment of human life dimensions 	<ul style="list-style-type: none"> - Personal growth - Increased purpose in life - Self-acceptance - Improvement of relations with others - Autonomy - Environmental mastery

origin of the concept of comfort leads to an action or intervention (to comfort). This intervention, in turn, seems to be centred on the activities that help the person to feel stronger, supported or empowered. The etymology of well-being refers to a state, highlighting at once the Cartesian dualism between body and spirit. Despite the scarcity of concept analysis studies in the area of well-being, one such study uses the terminology "spiritual well-being".³² In fact, while comfort tends to be used in a more holistic perspective, well-being tends to be more confined to the psychological or spiritual dimensions, as in the studies of Bond and Levasseurs and colleagues,^{37,38} in which the authors identify "psychological or spiritual well-being" as attributes of QoL (instead of using the concept of spiritual comfort). This idea is also present in nursing theories, where well-being tends to be presented on a psychological, social and spiritual perspective rather than on a physical perspective. The WHO reinforces this idea through the definition of mental health "as a state of well-being in which every individual realizes his or her own potential".⁴³

This idea is also sustained by Kolcaba's Comfort Theory,⁸ in which the author presents comfort as a holistic concept represented by three types of comfort (relief, ease and transcendence) that may occur in four contexts: physical, psycho-spiritual, social and environmental. Despite the holistic nature of the concept, the environmental perspective seems to represent a unique characteristic of the concept. If, on the one hand, it seems to be more intuitive and consensual to talk about spiritual well-being (instead of spiritual comfort), on the other hand the use of environmental comfort seems to be more intuitive.³⁹ In addition to these ideas, comfort is closely associated with the nature of nursing care, as

Table 2
Summary of similar and different attributes between the concepts of comfort, well-being and quality of life (QoL).

	Attributes
<i>Similar</i>	
Comfort, well-being and QoL	Subjectivity, self-esteem, individual perception
Comfort and well-being	Complexity
Comfort and QoL	Satisfaction, functionality, self-control
Well-being and QoL	Multidimensionality, interpersonal relationships, happiness, well-being
<i>Different</i>	
Comfort	Peace, relief of symptoms, reduction of imbalances, reducing suffering, effective communication, security
Well-being	Happiness; energy
QoL	Development and improvement of life, objective evaluation, empowerment, independence, dignity, achievement of goals and aspirations, capacities, autonomy

previously stated by Nightingale in "Notes on Nursing".⁴⁰ This significant study made it possible, later on, for the development of the well-known Kolcaba's Comfort Theory,⁸ and it is also present in many others, such as the theories of Roy, Leininger, Watson or Peplau.^{15,17} Furthermore, well-being is a concept traditionally associated with psychology.^{37,38,43}

The concept of QoL seems a broad concept, and has been well discussed by authors and defined as the individual's perception of

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their own life through personal beliefs and values.^{5,7,34} Independence and the sense of freedom appear as attributes presented exclusively in the concept of QoL,⁴¹ and satisfaction is a critical attribute. However, studies also emphasize the satisfaction of specific needs,^{3,6,31} since general satisfaction with life is highlighted in QoL.^{2,5,36-38} On the other hand, in both concepts (comfort and QoL), the state of satisfaction across physical, psychological, social and spiritual dimensions is common, although it may depend on the individual's perception of their own values and beliefs and the support they have.

Despite these considerations, the results highlight the paradoxical nature of the concept of well-being. On the one hand, studies demonstrate the use of the concept essentially concerning the psychological and spiritual dimensions. On the other hand, the concept is used in an almost indistinct way in the concepts of comfort and QoL. This suggests that caution should be taken in future studies, particularly as regards the correct use and framing of the concepts.

These three concepts are also related to the health definition proposed by the WHO, and are raised as an attempt to measure the subjective dimensions of health. As highlighted in the results section, the concept of comfort tends to be used more often in a holistic perspective, within the specific context of nursing or life-threatening situations. QoL represents a broader concept, specifically related to the perception and satisfaction of the individual with own life, which is probably more in accordance with the concept of health. Well-being is particularly related with the psychological dimension, which is reinforced by the definition of mental health proposed for the WHO.⁴³

Limitations

Results should be addressed as a contribution to further research and discussion. The search was based in three databases looking for concept analyses studies. No grey literature or other publications were considered. This study explored shared attributes of the concept, but further research should address specific and exclusive attributes in order to clarify each concept.

Conclusions

Comfort and well-being are commonly used interchangeably and both are presented as concepts related to QoL. The inconsistencies at a theoretical level could be the basis of several studies for the analysis of these concepts, as well as knowledge dispersion without any clear direction. This study concerns the results of several concept analysis research studies, supporting the idea that comfort, well-being and QoL are not surrogate terms but, rather, related concepts that share common attributes.

QoL is a broader concept, predominantly characterized by the satisfaction with life in general. It is a state that depends on each person's perception of such. Comfort is a concept that is inherently linked to the practice of nursing care and in a health context. It is characterized by the satisfaction of one's needs, by the person feeling strong, safe, supported and cared for. Well-being tends to be used in a more psychologically or spiritually oriented perspective and, even though it can be used in a broader and more holistic way, it is traditionally linked to psychology-sourced thinking. Thus, it seems that the concept of comfort is particularly used within the nursing profession, while the concept of well-being is particularly addressed to the psychological dimension and the mental health definition. The concept of QoL seems to be more adequate to the overall definition of health, since it is a broader concept, which includes the individual's perception about their own life, including health in all human life dimensions.

This study opens a new perspective about the correct use and framing of the concepts in practice, but also in research and education.

Authorship

SP and LF contributed equally to this study. Conception and design of the work, acquisition of data, or analysis and interpretation of data (SP, LF); drafting the article or revising it critically for important intellectual content (SP, LF, AM, SC, JCM); final approval of the version to be published (SP, LF, AM, SC, JCM).

Conflicts of interest

The authors declare no conflicts of interest.

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2.3. Modelling processes and outcomes: From the nursing diagnosis to the intervention

The modelling phase is an important stage to assess several issues, in order to answer the question “*would it be possible to use this?*” (Craig *et al.*, 2008, p. 9).

From the analysis of the Kolcaba’s (2003) Comfort Theory, namely from the propositions and assumptions, it is possible to draw some practical aspects for the design of a comfort intervention. As Kolcaba (2003) states, nurses are responsible for identifying patient needs, or comfort needs. Thus, each person has different answers to complex stimuli, reason why outcomes are directly related with the needs of each patient (Kolcaba, 2001). These conclusions were reinforced in the concept analysis study, in which the concept emerges as a complex, individual, dynamic and pleasant experience (Pinto *et al.*, 2017).

If nurses are responsible for identifying patient needs, and if enhanced comfort (the desirable outcome) is a result of the satisfaction of these individual needs, a comfort intervention design should address a methodology to assess patient needs. This assumption is consistent with PC goals, which aims to relieve suffering and improve comfort, preferably through preventive measures and through a comprehensive and systematic assessment (Rome *et al.*, 2011).

However, as stated in the previous chapter, the design of complex interventions, particularly in PC settings, is complex as well. PC addresses a large range of patients, with different ages, pathologies, clinical conditions and different access to specialized PC services (Visser, Hadley & Wee, 2015). Thus, the intervention design should be broad enough to cover these differences and, at the same time, allow for an accurate assessment to evaluate the individual needs of each patient.

Regarding all these considerations, an interactive and communication technology was designed to monitor comfort in Portuguese PC patients at home. This idea was based on several assumptions, retrieved from preliminary stages of this study:

- Comfort is a central core of nursing care (Nightingale, 1860; Kolcaba, 2003; Lin, 2010) and a main goal of PC (Rome *et al.*, 2011; Worldwide Palliative Care Alliance & WHO, 2014; van Soest-Poortvliet, 2015);

- Enhanced comfort is a desirable but individual outcome, related to the satisfaction of the patient's needs (Kolcaba, 2001; Kolcaba, 2010);
- A comprehensive and systematic assessment allow to more personalized, effective and, perhaps, preventive measures (Rome *et al.*, 2011);
- The literature highlights that Portuguese patients prefers to dye at home, although a high percentage (62%) is still dying in the hospital (Gomes *et al.*, 2012; Gomes *et al.*, 2013);
- PC teams are still not enough in Portugal, considering the need of PC in the country, and there is geographical inequity in the access to specialized services (Neto, 2010; Bernardo *et al.*, 2016);
- e-Health has been proposed as an important resource to link patients and specialized services (WHO, 2010).

A first conceptual map of the intervention design is presented on Figure 1.

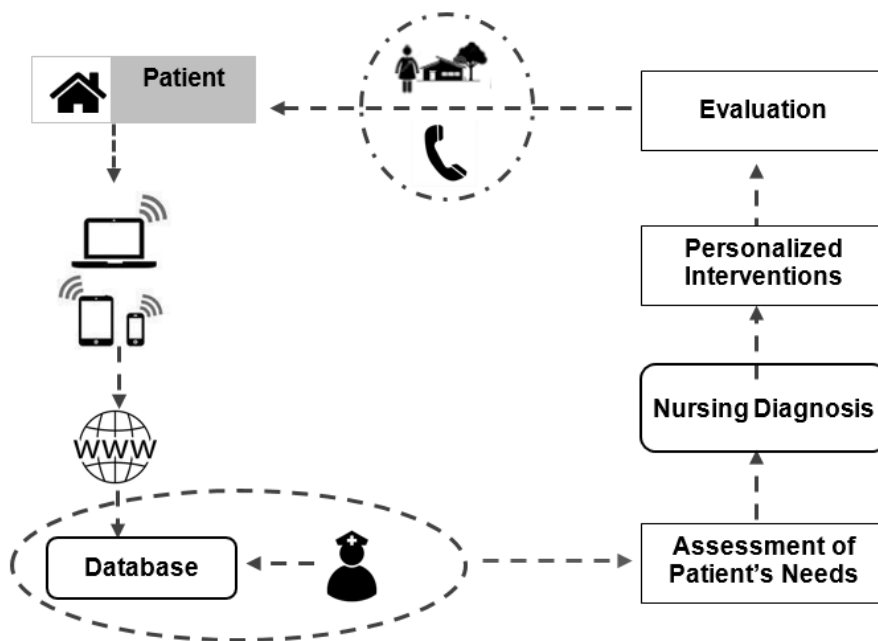


Figure 1: Conceptual design of the intervention.

This conceptual design identifies two principal stakeholders: patients and nurses. Informal caregivers could be included if patients are not able to use electronic devices due to physical limitations. Despite this first design having been developed for nurses as the main stakeholders, in the future the intervention could include other healthcare providers.

The intervention addresses all the nursing care plan, since the need's assessment until the evaluation of nursing interventions.

Sample and setting comprise Portuguese PC patients, at home. It was decided to limit the intervention design to the adult population (age \geq 18 years old), not only for ethical reasons, but also because the paediatric population has specific characteristics that require a particular approach. Indeed, paediatric PC is still recent in Portugal, which could bring further limitations to the study design (Mendes, Silva & Santos, 2012; Decree 343/October 12th 2015).

Preliminary eligibility criteria include access to electronic devices (smartphone, tablet or computer) with Internet.

Results from previous stages, namely from literature review, gave rise to some questions that need to be revised to achieve a feasible design. Firstly, some inconsistencies and gaps were identified on classifications and taxonomies of nursing knowledge. While some of them were already discussed (for example the use of the concept of well-being in the definition of the concept of comfort in the ICNP[®] (ICN, 2015), others need to be clarified. For example, is the impaired comfort (00214) diagnosis proposed by NANDA-I (Herdman & Kamitsuru, 2014), a problem-focused nursing diagnosis or a syndrome diagnosis? Thus, which instruments will be used to assess comfort?

Nevertheless, it is important to perform a literature review to check if there are other e-health technologies or applications that have already been implemented. Lastly, is the intervention feasible?

These issues will be addressed on the forthcoming topics.

2.3.1. Is impaired comfort a nursing diagnosis?

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Is Impaired Comfort a Nursing Diagnosis?

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Search terms:

Diagnosis, health classification, nursing

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Authorship: Conception and design of the work, acquisition of data, or analysis and interpretation of data (SMOP, SMACB); drafting the article or revising it critically for important intellectual content (SMOP, SMACB, JCAM); final approval of the version to be published (SMOP, SMACB, JCAM).

Comfort has always been associated with the history of nursing care (Lin, 2010; Malinowski & Stamler, 2002), marking its development as a science and a profession. Among several research papers on this topic, we highlight the importance of comfort as a response to human needs (Ida Jean Orlando); a basic need associated with food, rest, sleep, and communication (Hildegard Peplau); an integrating part of caring (Madeleine Leninger and Jean Watson); and psychological comfort (Callista Roy) (Apóstolo, 2009; Malinowski & Stamler, 2002). Considered as a core concept in the satisfaction of human needs and nursing care practice, comfort was also an important research subject from

OBJECTIVE: Discussion of the “Impaired Comfort” nursing diagnosis.

METHODS: Discussion paper based on the authors’ ongoing PhD research about the development of comfort as a complex intervention.

FINDINGS: When the patient has impaired comfort, the nursing intervention should be specific to the etiological factor. Some arguments are raised about impaired comfort as a nursing diagnosis and the discussion is led about the possibility of the referred diagnosis being considered a syndrome.

CONCLUSIONS: New proposals are presented for the nursing classification based on theoretical knowledge development and current scientific evidence.

IMPLICATIONS FOR NURSING: The results can contribute to better decision-making and clinical reasoning, namely in terms of the nursing process, and contribute to safer, rational, efficient, and effective nursing care.

the 1980s, particularly through the studies of Janice Morse (Morse, 2000; Morse, Bottorff, & Hutchinson, 1994) and Katherine Kolcaba (1992, 2003). These findings have changed not only the definition of the concept, but also its implementation and the evaluation of clinical practice regarding comfort.

Nowadays, there seems to be a concern about translational research about comfort, as the findings are getting a new direction that is predominantly oriented toward clinical practice. But some difficulties on assessment, diagnosis, implementation, and evaluation of the interventions are highlighted.

Currently, comfort studies are defining a new direction that is predominantly oriented toward clinical practice and focusing the difficulties on assessment, diagnosis, implementation, and evaluation of the interventions. The taxonomies and classifications of nursing knowledge represent adequate and useful tools that can help professionals and researchers to structure their clinical reasoning in a more organized, efficient, and effective way. In this regard, they should be consistent with the classification of the phenomena and should represent the clinical practice that fulfils its purpose (von Krogh, 2008). Although comfort is listed in nursing taxonomies and classifications, particularly in NANDA-I, there are some inconsistencies in its definition that raise some questions about the nature of "impaired comfort" as a problem-focused diagnosis in this moment when a new taxonomy is being proposed.

The aim of this article is to report a discussion about the NANDA-I "impaired comfort" nursing diagnosis (00214) and to propose it as a syndrome diagnosis.

Background

Regarding the comfort in nursing, there are two theories from Janice Morse and Katherine Kolcaba, which stand out in nursing literature.

Morse has defined comfort as a final state of well-being and a result of nurses' therapeutic interventions (Apóstolo, 2009; Morse, 2000). Despite that, her research added an important contribution to the operationalization of the concept in terms of nursing interventions, and it was slightly profitable with regard to the evaluation of the results (Apóstolo, 2009).

On the other hand, Kolcaba contributed not only for the definition, but also for the operationalization of the concept and the development of widely known measurement tools, as shown in Table 1.

Kolcaba conceptualized comfort as a holistic experience lived by the person who receives comfort interventions. At the same time, it is also a state of needs' satisfaction in three different levels called "types of comfort: relief, ease and transcendence" (Kolcaba, 1994, 2003). Kolcaba added

that comfort, or in contrast discomfort, can occur in four distinct contexts—physical, psychospiritual, sociocultural, and environmental (Kolcaba, 1994, 2003).

Despite the variety of contributions and research, comfort remains a complex concept that is difficult to define, implement, and evaluate (Lin, 2010) not only at the theoretical level, but also, and fundamentally, in the clinical domain.

The importance of comfort in the different dimensions of human life (physical, psychological, social, and spiritual) is unquestionable. However, the difficulty in its implementation seems relevant, whether at the level of the conceptualization, classification, diagnosis, implementation, and evaluation of the most efficient and effective nursing interventions.

Knowledge, based on theory, is essential in research as it returns again as new knowledge for the practice and development of new theories, within a cyclical and dynamic process. Research not only contributes to the understanding of the complexity and multidimensionality of the comfort, it also identifies gaps in knowledge about the concept and its operationalization. More deductive research is therefore desirable, which could add empirical knowledge to theories and bring new perspectives and guidance to the analysis and understanding of the variability of the phenomenon in specific contexts and populations (Hallberg, 2009; Tomey & Alligood, 2004).

The Nursing Classifications and Taxonomies

There are several standardized nursing languages and classifications that aim to represent and organize the concepts, to control different meanings, promote communication among peers, and provide orientation for clinical practice (Carvalho, Cruz, & Herdman, 2013).

Among all classifications and taxonomies, the following are critical to nursing knowledge: the International Classification of Functioning, Disability and Health-ICF (World Health Organization, 2004), the International Classification for Nursing Practice ICNP® (International Council of Nurses, 2013), the NANDA-I (Herdman & Kamitsuru, 2014), the Nursing Interventions Classification (Bulechek, Butcher, &

Table 1. The Comfort Tools According to Kolcaba and Colleagues

Comfort tools	Author(s) (Year)
General Comfort Questionnaire	Kolcaba (1992); Kolcaba and Steiner (2000)
Urinary Incontinence and Frequency Comfort Questionnaire	Dowd, Kolcaba, and Steiner (2000)
Radiation Therapy Comfort Questionnaire	Kolcaba and Steiner (2000)
Comfort Visual Analog Scales	Kolcaba and Steiner (2000)
End of Life Comfort Questionnaire-Patient	Novak, Kolcaba, Steiner, and Dowd (2001)
End of Life Comfort Questionnaire-Caregiver	Novak et al. (2001)
Hospice Comfort Questionnaire	Kolcaba, Dowd, Steiner, and Mitzel (2004)
Thermal Comfort Inventory	Wagner, Byrne, and Kolcaba (2006)
Thermal Comfort Numeric Visual Analog Scale	Wagner et al. (2006)
Healing Touch Comfort Questionnaire	Dowd, Kolcaba, and Steiner (2006)
In-Psychiatric Patients Comfort Scale	Apóstolo, Kolcaba, Cruz-Mendes, and Calvário-Antunes (2007)

Dochterman, 2010), and the Nursing Outcomes Classification (Moorhead, Johnson, Maas, & Swanson, 2010). These classifications and taxonomies represent a hierarchical system of organizing concepts, whether they are an organized system of terms, diagnoses, interventions, and results (Carvalho et al., 2013; von Krogh, 2008).

A taxonomy can be "defined as a way of classifying or ordering things into categories in a hierarchical classification scheme" (Herdman & Kamitsuru, 2014). However, the levels should be related to each other (von Krogh, 2008), for example, taxonomy II of NANDA-I and recently published taxonomy III (Herdman & Kamitsuru, 2014). Taxonomies can be based on a very complex structure, organized at different levels in which the following three should be present: domains, classes, and concepts (von Krogh, 2008).

The domains divide a phenomenon into several groups, representing the major levels of this phenomenon. According to NANDA-I, a domain is a sphere of knowledge, classes are a group or set sharing common attributes, and diagnoses are labels composed of terms from different axes (focus of diagnosis, subject of diagnosis, judgment, location, age, time, and status of diagnosis) (Herdman & Kamitsuru, 2014).

In relation to concepts, they represent the level at which the individual phenomenon is named, defined, and numbered (Herdman & Kamitsuru, 2014; von Krogh, 2008). We should highlight that classes should have the same primary qualities or characteristics of the underlying domain and also reflect and include the different variations of the phenomenon. Classes should be mutually exclusive, represent the completeness of the domain, and represent the diagnoses listed in them (von Krogh, 2008).

Diagnoses result from the combination of terms from the seven different axes (focus of the diagnosis, subject of the diagnosis, judgment, location, age, time, and status of the diagnosis) (Herdman & Kamitsuru, 2014). According to NANDA-I, a nursing diagnosis is defined as "a clinical judgment concerning a human response to health conditions/life processes, or vulnerability to that response, by an individual, family, group, or community" (Herdman & Kamitsuru, 2014). Diagnoses are the result of clinical reasoning of the nurse and are especially important for the planning of effective interventions. This judgment, which should be based on a comprehensive and global assessment, is of particular importance as it is the basis of planning the most effective and efficient nursing interventions for achieving positive outcomes in patients' health (Herdman, 2012). This means that the clinical indicators (related factors and defining characteristics) should be well interpreted for an accurate diagnosis as this is essential for the adequacy of interventions and for positive outcomes in patients' health and well-being.

However, the research about nursing diagnoses, the classification of phenomena related to patients and health, remains a complex process and some inconsistencies have been identified in the taxonomy II of NANDA-I (Caldeira, Carvalho, & Vieira, 2013; von Krogh, 2008). This was one of the justifications for the proposal of taxonomy III because

taxonomies should be based on principles of rigorous categorization in order to promote a valid classification, which should include the possible variations of the phenomenon and ensure the minimum possible gaps (von Krogh, 2008). This seems to be particularly important in nursing as the way the diagnoses are classified is considered the most important aspect for clinical practice when nurses "use the taxonomy to find appropriate information on possible related diagnoses" (Herdman & Kamitsuru, 2014).

Discussion about the concepts, diagnoses, and the way they are organized within nursing represents a contribution on nursing knowledge and highlights autonomy in clinical reasoning.

Methods

This discussion paper is based on our own experiences and supported by a literature search and theory based on a research project about the development of comfort as a complex intervention.

Discussion

"Impaired Comfort": Diagnosis or Syndrome?

A nursing diagnosis should represent a clinical judgment in relation to the experiences or responses of a person, family, or community to a current or potential health problem or life process (Herdman & Kamitsuru, 2014). In this context, NANDA-I integrated the "impaired comfort" diagnosis in taxonomy II in 2008, accepting Katharine Kolcaba's proposal. The diagnosis is defined as "perceived lack of ease, relief, and transcendence in physical, psychospiritual, environmental, cultural, and/or social dimensions" (Herdman & Kamitsuru, 2014).

In this context, the diagnoses related to psychospiritual comfort are not listed in this domain despite integrating one of the comfort contexts defined by Kolcaba. Diagnoses related to mental or psychological phenomena are listed in domain 9 ("coping") and diagnoses related to spirituality and values are listed in domain 10 ("life principles"). Although the definition of comfort according to Kolcaba's Comfort Theory is absolutely consensual, the "impaired comfort" diagnosis is listed in three classes within domain 12 ("comfort"). This situation is not recognizing the exclusivity of the classes or diagnosis as, for example, the nursing diagnosis "nausea" (00134) that is only classified in class 1 ("physical comfort").

As comfort is considered a holistic and multidimensional concept, there is a certain lack of consistency from the theoretical, semantic, and operational point of view, when separating the psychospiritual dimension from the physical, environmental, and sociocultural dimensions. Also, the definition of the comfort domain does not include the psychospiritual attribute, relating only to the physical, environmental, and social contexts. But, the psychospiritual

dimension is present when analyzing the definition of the "impaired comfort" diagnosis. Because it is a diagnosis, it should be less embracing and more specific than its own class and domain.

It is interesting to note that the latest issue of NANDA-I, which has been recently published (Herdman & Kamitsuru, 2014), presents a new proposal for taxonomy (III). This new taxonomy constitutes classes of a new domain entitled "existential." This means that the discussion about the completeness of the "comfort" domain is now driven to the discussion of which diagnoses should be included in this new class ("comfort") of this new domain ("existential"). This discussion gets more complex as another class of this domain ("existential") is entitled "well-being." The differences between taxonomy II and III are described regarding domains, comfort domain, definitions, and classes, as shown in Table 2.

The class "comfort" can be defined as "perceptions of symptoms and experience of suffering" (Herdman & Kamitsuru, 2014) and the class "well-being" is defined as "perceptions of life qualities and experience of existential needs satisfaction" (Herdman & Kamitsuru, 2014). Other diagnoses were added to the "comfort" class along with the "impaired comfort" diagnosis.

An analysis of the diagnoses that comprise this new class in taxonomy III has given rise to questions in relation to the differential diagnosis and selection of exclusive and specific nursing interventions for each one. We wonder: in a holistic perspective, and given the multidimensionality of comfort, what specific interventions could the nurse have in a situation of "impaired comfort"? Or are these interventions in accordance with the etiology of "impaired comfort"? Should a nurse develop a different diagnosis among other

diagnoses of the same class, such as "anxiety" (00146), "death anxiety" (00147), "fear" (00148), "acute pain" (00132), "chronic pain" (00133), "labour pain" (00256), "chronic pain syndrome" (00255), and "nausea" (00134)? Therefore, it seems that comfort is a human response integrating various diagnoses, for which nurses will have different, similar, and simultaneous interventions. If the patient has "impaired comfort" related with "pain," "anxiety," and "nausea," interventions will be specific for "pain," "anxiety," and "nausea." We argue that the "impaired comfort" diagnosis could be considered a syndrome diagnosis, which the NANDA-I defines as "a clinical judgment concerning a specific cluster of nursing diagnoses that occur together, and are best addressed together and through similar interventions" (Herdman & Kamitsuru, 2014).

In addition, a review of comfort as an intervention emphasizes activities related to very specific nursing diagnoses such as "pain," "anxiety," "hopelessness" (00124), "spiritual distress" (00066), "impaired comfort" and "fear." Nevertheless, it is important to plan and provide for the interventions in a comprehensive and holistic way, otherwise nurses could be attending just to defining characteristics (signs and symptoms) and reducing the scope of nursing care to symptom management, overvaluing the holistic component that characterizes the profession and the process of comfort.

Another question raised in our reflection is based on the exclusivity and completeness of the classes in the new proposal of taxonomy III. Considering the above definitions of the comfort and well-being classes, the classification of the nursing diagnoses "grieving" (00136), "complicated grieving" (00135), "hopelessness," and "spiritual distress" in the

Table 2. Differences Between Taxonomy II and Taxonomy III Considering General Domains, Comfort's Domain, Classes, and Their Definitions

Taxonomy II		Taxonomy III	
Domains			
Total-13	Health Promotion, Nutrition, Elimination/Exchange, Activity/Rest, Perception/Cognition, Self-Perception, Role Relationships, Sexuality, Coping/Stress Tolerance, Life Principles, Safety/Protection, Comfort, Growth/Development	Total-7	Physiological, Mental, Existential, Functional, Safety, Family, Environmental
Comfort Domain 12	Comfort	Domains 3	Existential
Definitions	"sense of mental, physical, social or well-being or ease" (Herdman & Kamitsuru, 2014)		"experiences and perceptions of life which are essential to health of the human person" (Herdman & Kamitsuru, 2014)
Classes			
3	Physical Comfort, Environmental Comfort, Social Comfort	4	Life Principles, Comfort, Well-Being, Coping

class "well-being" remains unclear. These diagnoses are strictly related to suffering, which is an attribute of the class "comfort" and is not an attribute of the class "well-being."

Here is an opportunity for further discussion about the meaning of concepts and nursing diagnoses as well as the completeness and adequacy of the taxonomy structure, considering its translation to clinical practice.

Although this reflection was based on comfort, other areas and domains of nursing knowledge within the classifications may be discussed in order to provide scientific contributions to the improvement of classifications and to furthering nursing knowledge.

Implications for Nursing

This paper aims to contribute to the knowledge regarding comfort and comforting. The theoretical developments of recent years lead us to reflect on the need for efficient, effective, and feasible practical care, supported by scientific evidence. From the literature review and also from our own experience in clinical practice and in the research that we are currently developing, we find that the current classification may raise doubts in nursing diagnosis, clinical reasoning, and decision making during the nursing process, particularly with regard to the most efficient and effective interventions after an accurate diagnosis.

Given the subjectivity and complexity of the phenomenon, this discussion is needed in order to facilitate nurses' decision-making in the context of clinical practice. The reflection, supported by theory and based on experience from practice, can provide major contributions toward more efficient and effective knowledge, rigorous practice, and safer nursing care that is closer to patient needs, in all dimensions of their life.

Conclusions

Comfort is a core concept in nursing practice and in research. It is part of the classifications and taxonomies of nursing knowledge that, however, are neither consensual in the classification of the phenomenon nor exhaustive in the definition and implementation.

Classifications and taxonomies are very important because they contribute, on the one hand, to the theoretical clarification of the phenomenon and, on the other, to the targeting of interventions that support clinical practice.

The studies highlight the need for consistency, completeness, and practical application of classifications and taxonomies and they have motivated a new proposal for NANDA-I, recently published, in which comfort is still an area to be included as a class in the existential domain. However, this new proposal raises doubts because it presents inconsistencies with the knowledge that has been consolidated in the development of theories. This discussion paper proposes new considerations and contributions to taxonomy III of NANDA-I, in relation to the type of diagnosis

that should place "impaired comfort" as a syndrome. We also appeal to the discussion on the consistency and completeness of the classification of diagnoses, particularly in the classes "comfort" and "well-being."

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2.3.1.1. A qualitative study about palliative care patient's experiences of comfort:
Implications for nursing diagnosis and interventions

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ABSTRACT

Objectives: To analyse palliative care patients' experiences about comfort and contribute to the development of the nursing diagnosis 'impaired comfort' from NANDA International.

Methods: Qualitative study with fifteen participants, using in-depth, semi-structured, face-to-face interviews, tape-recorded, transcribed verbatim and analysed using interpretative content analysis.

Results: Five main themes have been identified. The context of provision of care, the presence of family, the way information is managed, the search for meaning in life, and the need to keep life under control were perceived as important determinants for comfort.

Conclusions: Findings highlight comfort as a complex intervention within multidisciplinary palliative care team and this is supporting the nursing diagnosis 'impaired comfort' as a syndrome. The study adds a contribution to the accuracy and completeness of nursing classifications and nursing practice in palliative care.

Keywords: Comfort; holistic health; interview; qualitative research; palliative care.

1. INTRODUCTION

Comfort is a critical goal of Palliative Care (PC),^[1-2] which aims to provide patients and family the highest quality of life, through the prevention and relief of suffering in all human life dimensions.^[3] Previous research has defined the concept of comfort as holistic, subjective, dynamic and a positive experience based on the satisfaction of the individual needs in one or more dimensions (physical, psychological, social, spiritual, environmental), which may result in physical relief and/or transcendence.^[4-5] Relief is related to the satisfaction of the most basic needs, ease with the feeling of calm and quiet (basilar to functional and efficient performance), and transcendence is related to the needs of self-control regarding decisions, life, future, and the transcendent.^[4]

Despite all the knowledge development, theories and research about comfort and comforting, the concept is often considered complex ^[5-8] and not easy to implement and evaluate in the clinical practice.^[9-11] First, comforting is a broad intervention comprising several activities, performed by different persons, and comprises patients and environmental factors.^[6,10] Secondly, nursing classifications and taxonomies are important instruments of nursing knowledge, but miss clarity and consistency on this topic. For example, the International Classification for Nursing Practice[®] (ICNP[®]) provides a reductionist definition of comfort, only in its physical dimension.^[12] The taxonomy II of NANDA International (NANDA-I) includes a domain 'comfort', and the diagnosis labeled as 'impaired comfort' (00214) is listed in the three classes.^[13] But, in the taxonomy III, this domain does not exist and can be found as a class of a new domain entitled 'existential'. Additionally, a change of the diagnosis 'impaired comfort' (00214) has been proposed, from a problem-focused diagnosis to a syndrome diagnosis.^[14]

Few studies have directly addressed PC patients' experiences of comfort during their illness journey, particularly in non-cancer patients.^[15] Patients' perspectives are crucial in the understanding of the phenomena^[16-17] towards an accurate nursing diagnosis, which is defined as the clinical judgment towards patients' responses.^[13] The better the nurses may know the patients' perspectives, feelings and views, probably the better their needs will be addressed.^[18-20] Research based on patients' perspective could be critical to the diagnosis accuracy and to promote and implement effective interventions in PC.

This study aims to a) analyse PC patients' experiences about comfort, in order to operationalise the complex intervention 'comforting' and b) contribute to the development of the nursing diagnosis 'impaired comfort' from NANDA International.

2. METHODS

Qualitative study using semi-structured and face-to-face interviews, tape-recorded, transcribed verbatim and analysed using interpretative content analysis. The consolidated criteria for reporting qualitative research (COREQ) guidelines ^[21] were used to guide all research procedures.

2.1. Participants and recruitment

Participants were purposively recruited at five in-patient medical-surgical settings from an acute and central hospital in the north of Portugal. Acute settings were chosen because in Portugal the vast majority of patients with PC needs remain in acute settings, due to the shortage of beds in PC units.

Fifteen in-patients, aged over 18 years, with a diagnosed chronic, incurable and progressive disease and followed by the in-hospital PC team were recruited (Table 1). The inclusion criteria were impaired comfort: participants that have recently had (or were still experiencing) uncomfortable experiences, such as agonizing pain, traumatic injuries, breathlessness, nausea, loneliness or spiritual distress. The inclusion criteria were referred from nurses and validated by a retrospective chart review of patient's records on the last seven days. Exclusion criteria were: cognitive impairment reported in the clinical records and by nurses, lack of capacity to give informed consent, and not fluent in Portuguese. Interviews were conducted between January and April 2015, until data saturation.

Table 1: Participants demographic and health data.

	<i>n</i>
Gender	
Male	10
Female	5
Age (years) (range: min-max)	Range 71.27 (36 – 78)
Civil Status	
Single	1
Married	12
Widow	1
Divorced	1
Educational Degree	
Primary education (4 years)	12
Professional course	1
Graduated	2
Professional Situation	
Work absence due to illness	7
Unemployed	1
Retired	7
Diagnoses	
Brain Tumor (Glioblastoma Multiforme)	3
Lung Tumor	4
Pancreatic Cancer	2
End-Stage Renal Disease	1
Chronic Heart Failure (NYHA III, NYHA IV)*	2
Chronic Obstructive Pulmonary Disease (GOLD III)**	2
Chronic Occlusive Arterial Disease of the Extremities	1
Hospitalization Time (days) (range: min-max)	Range 33.5 days (10 – 68)
Agonizing Symptoms reported in nursing records (last 7 days)	
Pain	8
Breathlessness	6
Anxiety	5
Difficulty in resting	5
Nausea	4
Vomits	1
Constipation	4
Spiritual Distress	1

*NYHA: New York Heart Association

**GOLD: Global Initiative for Chronic Obstructive Lung Disease

2.2. Interview procedure

Four patients had moving limitations and the interviews took place in their unit. The remaining eleven interviews were held in a meeting room. The principal researcher conducted the fifteen in-depth, semi-structured and face-to-face interviews. One participant asked for her daughter to be present during the interview, which was allowed. The interviewer also took field notes (particularly non-verbal language). The interview was structured and based on two questions: Please focus on your illness journey, at home or in hospital, and (1) Please describe an episode when you felt comfortable. (2) Please describe an episode when you felt uncomfortable. Socio-demographic and clinical data

were collected in the beginning, before the audio-recording, in order to preserve confidentiality. The interviews ranged from 35 to 59 minutes (median interview length was 45 min).

2.3. Data analysis

The data were analysed using deductive content analysis, which comprises coding, organizing and classifying data by principal themes, concepts, categories and abstraction.^[22] In a first phase, the interviews were transcribed verbatim, read twice, organized in descriptive coding by the principal research and then data were organized into emerging categories. In a second phase, data were independently analysed, coded and organized by another researcher. Findings were then discussed and, whenever necessary, revisited, recoded and re-categorized by the three researchers.

2.4. Ethical considerations

The research was approved by the institutional ethics committee (CHSJ, CES 191-14, 20 November 2014)¹. Participants were given written and verbal information of the study's purpose, their voluntary participation and confidentiality, and the informed consent was obtained. Nurses who collaborate were also asked if they freely agreed to participate.

3. RESULTS

3.1. Participants

The majority of participants was married, had completed primary education (4 years), and was retired or on sick leave. All had a diagnosed chronic, incurable and progressive disease at an advanced stage (brain tumor, lung tumor, pancreatic cancer, end-stage renal disease, chronic heart failure or chronic obstructive pulmonary disease) (Table 1).

3.2. Emerged Themes

Participants' comfort experiences were organized in five main themes: 1) Me and what I feel; 2) Me and I how I react; 3) Me a human being in society; 4) Me and the meaning of my life; 5) Me and the world around me (Figure 1).

¹ Appendix 3

IMPAIRED COMFORT IN ADULT AND OLDER ADULT AS A SYNDROME DIAGNOSIS

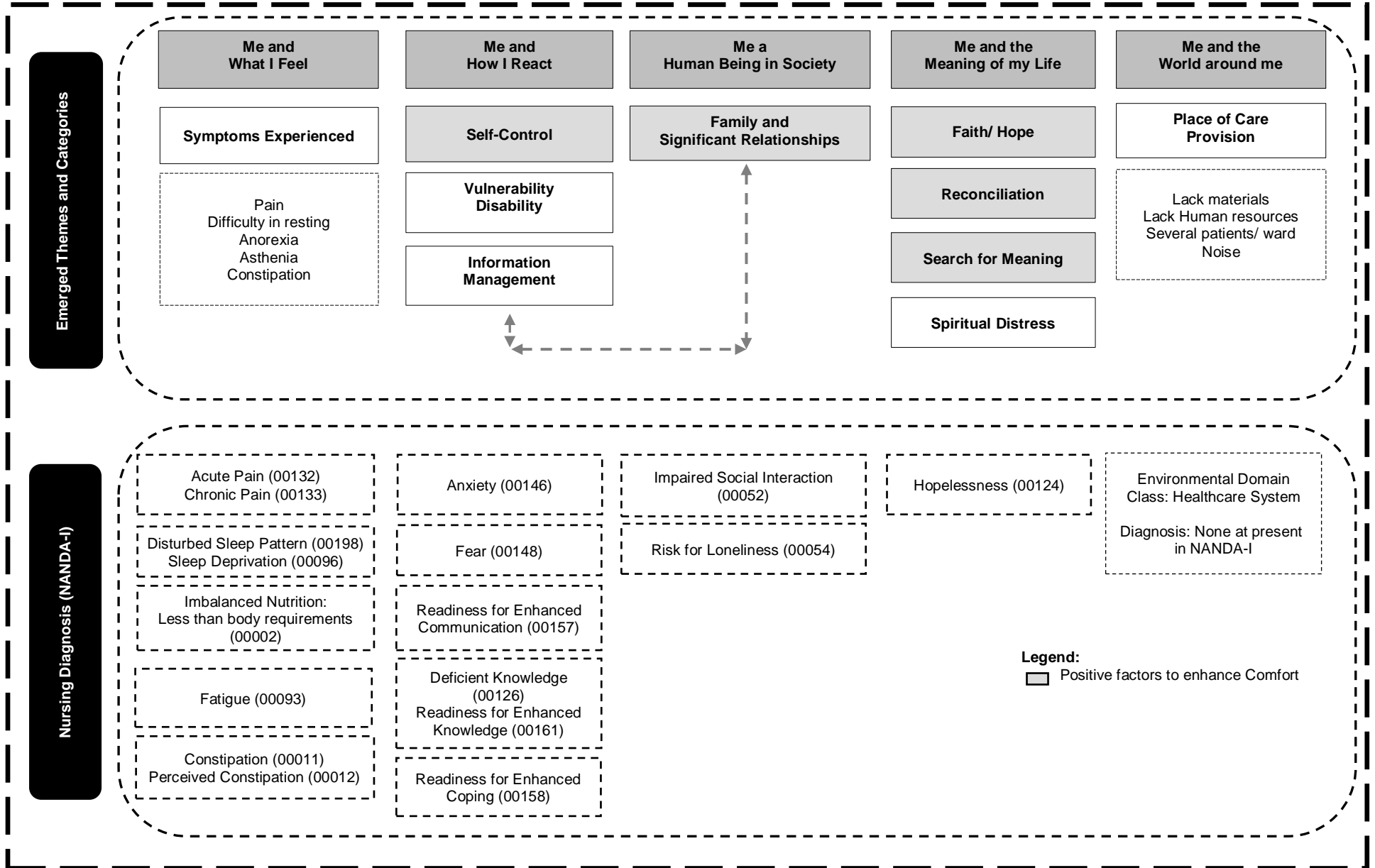


Figure 1: Impaired comfort as a syndrome diagnosis: Themes, categories and nursing diagnosis (defining characteristics).

3.2.1. Me and what I feel

The main uncomfortable symptoms reported by patients were pain, difficulty in resting, anorexia, asthenia and constipation. Pain and difficulty in resting were those with a greatest impact on patients' comfort. "I cannot" and "I do not feel well" are the most frequent expressions. As described by some patients, pain is an uncomfortable experience, which jeopardizes other activities:

"With pain I can't do anything." (P15)

Resting periods are considered insufficient and sporadic, particularly in hospital, not only because of pain and other clinical conditions (eg. nausea or breathless), but also due to healthcare routines (eg. medication) or due to the presence of other patients in the wards. Besides this difficulty in falling asleep, participants state they can't sleep like before:

"It is not easy to rest here. Since I've been here, I still haven't sleep an entire night ..." (P11)

3.2.2. Me and how I react

This theme addresses three categories: self-control, vulnerability and disability and information management.

Self-control

The lack of security and balance were mentioned as factors that interfere with self-control and coping with the disease:

"(...) I'm not well balanced. I don't know what to do with my life. I do not feel safe. And I don't know what will happen next." (P2)

Vulnerability and disability

Physical dependence is a condition that affects patients' comfort and promotes a sense of vulnerability:

"The feeling of being vulnerable and dependent is terrible. [...] Situations as simple as going to the toilet or being constipated and needing help... [pause] I'd rather not say anything than have to speak on this subject." (P12)

Information management

This category concerns the ability to obtain and understand health-related knowledge or messages and how this process can help patients' decision making. Physicians were seen

as providing little and unclear information. For this reason the presence of the family during these conversations seems crucial:

"I think they [the doctors] should tell us ... the best path to follow. (...) Because we need orientation and they are here for that! (...) They have more experience... [pause] They should help us." (P13)

3.2.3. Me a human being in society

This topic highlights the importance of family and significant relationships. The presence, attention, affection and support provided by family and relatives are seen as key-elements for achieving comfort. To love and to be loved is essential for coping with the discomfort imposed by disease and hospitalization. It is, also, a rescue from loneliness, allowing the patient to feel alive, feel like a person and not just a number or a disease, such as expressed by a patient:

"Friends who came to visit and who I was not expecting, or who send me messages ... (...) Feeling in an unimaginable way the love, the affection, the care of the people closest to me is still something that touched me very much." (P7)

Gratitude towards the healthcare team, family and friends was also highlighted in patients' comments:

"(...) I would like to do something to show them how they made me feel so great, I felt really loved ..." (P7)

3.2.4. Me and the meaning of my life

Patient narratives showed that disease and the end of life leads people to question the meaning and purpose of their lives. Faith and hope, reconciliation, meaning of life and spiritual distress were the categories of this topic.

Faith and hope

Faith was considered as a coping strategy decisive for comfort experience:

"I am in a difficult situation and have to resort to my faith in order to calm myself."
(P14)

Hope is strictly associated with faith, and was described as a paradox. Participants stated that is important to keep believing in a solution or miracle. However, the attitudes and behavior of medical staff is, sometimes, inconsistent. Participants reported that their body

language does not always correspond to their words. This inconsistency creates fear, uncertainty and hopelessness, which are negative factors on patients' comfort:

"Sometimes they say one thing but their faces... their faces say another. And I realize that there is something wrong." (P8)

Reconciliation

Reconciliation is the resolution of personal or interpersonal conflicts perceived by patients, and concerns the need of forgiveness and the feelings of guilt and peace. Reconciliation is not only related to reconciling with others but also with self. Feeling guilt about the disease was considered a factor of feeling uncomfortable and grieving:

"Maybe I'm responsible for my illness, so I have to deal with it. If I am responsible, I have to pay for it. [pause] And I have to learn to live with it." (P4)

Peace is seen as a final state of well-being, based on simple things like feeling well with others:

"Comfort for me is to be at peace with everyone." (P6)

Search for meaning

Comfort, particularly with severe illness, was deemed an experience of personal growth, rediscovery of the meaning of life and appreciation of the really important: *"In fact, I hope to keep the meaning of my life in love and connections with people. (...) Seeing this situation not only as a bad situation... (...) This needs to have a positive result. "* (P10)

Spiritual distress

The participants' narratives show a comparison between spiritual and physical pain. While physical pain was considered easier to control, spiritual pain remains:

"Pain can go away. It hurts, but we call, they come here, and it is gone half an hour later. (...) But this [laying his hand to his chest, rubbing it, and look sad] ... This pain does not disappear. [Hand gesture in chest]" (P1)

3.2.5. Me and the world around me

This category comprises environmental factors and their influence on patient comfort. The place of care provision and its characteristics emerged as an important category for achieving comfort.

Place of care provision

Participants referred home as the best place to be. It is a cozy place, where there are no rules, where they feel free, where they can be with their loved ones, and is also a place of personal identification. At home, they don't feel an object, a disease or a number but a person who belongs somewhere and to someone. Although home is considered the best place to be, participants reported that in hospital they get the clinical conditions they need at that moment. In a paradoxical way, hospital is seen as a place that limits their freedom but, simultaneously, offers safety and accepts human suffering.

"If I don't feel confident with being at home, I prefer being in the hospital and then, later, return home. Here, with the nurses, I'm fine ... (...) I believe in them and I feel safe." (P6)

The negative factors affecting patients' comfort during their hospitalization were the lack of materials, human resources and physical conditions. One of the most uncomfortable physical conditions specified in patient narratives is the presence of several patients in a ward and the lack of privacy and limited space.

"The space is small... [pause] And the conditions... The conditions here are not so good ... [pause]." (P9)

Silence is another important factor. The noise caused by other patients, by healthcare professionals in their routines, or even by alarms and monitors are considered causes of discomfort:

"Sometimes I want to rest but I can't. There is always someone who comes to the bell, there is always a machine alarm, there is a patient coughing ..." (P3)

The hospital is also described as a place that threatens the sense of freedom. Participants highlighted among the negative aspects, feeling locked behind closed doors, impossibility of going out to get some air, being restricted to the rules of the institution and living with other patients in the same ward (often neglecting their own needs and desires).

"Here, I have to comply with a general regime. I will not open a window just because I want to open a window. We have to think of the others. And I'm not going to create rules. Of course if I were in my house and I wanted to open a window, I would open the window." (P5)

4. DISCUSSION

Comfort is basilar to PC.^[1-2] Nevertheless, there are many questions about the concept, its definition, implementation, measurement and evaluation remaining unclear.^[23] These theoretical difficulties might have important implications in clinical practice and seems important to understand the meaning of comfort, in order to design, implement and evaluate feasible and effective interventions, centered on patients' experiences and expectations.^[6-7,18,24]

The first aim of this study concerns PC patients' experiences on comfort. Despite patients have been invited to talk about a comfortable and uncomfortable experience, the great majority reported uncomfortable experiences. However, and as reported in previous studies, comfort experience is frequently explored and understood through discomfort experiences or in the absence of comfort.^[25-27]

Participants experienced not only physical symptoms (such as pain, difficulty in resting, anorexia, asthenia and constipation) but also psychological and spiritual problems, such as lack of security, fear, sense of vulnerability, uncertainty, guilt and hopelessness. Expressing gratitude, enhancing hope, promoting reconciliation, searching for meaning in life, loving and being loved, and having the presence of a significant person emerged as important key activities to promote comfort. Illness is seen as a life condition that can increase spiritual growth and promote the journey of searching for the meaning of life, which is described as the main attribute of spirituality.^[28] When looking at the nurses' records is possible to realize the missing information when comparing to what patients' have been expressed.

The narratives have also described several dimensions related to personal characteristics and to environmental context as well. Patients felt that hospital is a safe place and, at the same time, threatens the sense of freedom. Also, comforting depends on different actors such as the self (for example in the self-control, searching for meaning in life or expressing gratitude), the different healthcare team members (for example in symptom management), or the relatives (through their presence or forgiving the patient when he needs). At the same time, comforting appears as an individual and very subjective intervention, dependent of patient's characteristics, clinical condition, clinical setting, and family support. These results have been reported in other research, but not based on patients' perspective from a qualitative study. The results highlight the experience of in-patients and add consistency to the evidence reported in other contexts and countries.^[6, 27, 29-30]

Physical problems seem to have more impact on the psychological dimension and, thus, on holistic comfort. Results showed that being physically dependent, for example, could increase the sense of vulnerability, which makes the person feel even more uncomfortable.

The sense of vulnerability caused by disability and dependence plays an important role in patient self-control, as reported by other authors in previous research.^[31-32] Comfort is perceived as a holistic experience, and psychospiritual dimension is connected to physical, sociocultural and, also, environmental factors.

A second aim of this study is to contribute to the development of the nursing diagnosis 'impaired comfort' (00214) listed in NANDA-I.^[13] The results highlight several patients' comfort needs that match the defining characteristics of this nursing diagnosis (Figure 1).

When looking at the taxonomy II of NANDA-I,^[13] the nursing diagnosis 'impaired comfort' (00214) includes the psychospiritual dimension in its definition. But the domain comfort excludes this attribute and is just comprising the classes related to physical, environmental and social dimensions of comfort. This study is bringing more evidence on the holistic and complex nature of comfort, as the changes that occurred in a given dimension (eg, sleep disturbance) can be caused by several factors (such as pain, nursing routines or noise), and can result in different outcomes (for example, tiredness or irritation) (Figure 1). This is quite important to nurse's clinical reasoning because if a patient is diagnosed with 'impaired comfort' (00214) the nursing interventions should be specific to the etiological factor or situation.^[14] The interventions towards the diagnosis of 'impaired comfort' (00214) may be similar to other nursing diagnosis such as 'hopelessness' (00124), 'spiritual distress' (00066) or 'pain', which should be addressed at the same time. This is underlining the idea of 'impaired comfort' (00214) not as problem-focused diagnosis, but as a syndrome, specifically for adults and older adults – 'Impaired Comfort Syndrome in Adult and Older Adult'. Understanding the meaning of comfort for hospitalized patients was helpful in clarifying the complexity and nature of the concept. At the same time, this study adds a contribution to the nursing knowledge in PC, documenting met and unmet needs of cancer and non-cancer patients in acute care settings, which is very common in Latin countries.

However, caution is need when analyzing the results because some limitations are recognized, mostly cultural. Firstly, it was very difficult to recruit patients for the study because the vast majority were referred to PC in the agonic phase. When considering patients' comfort experiences over their illness journey, multiple interviews are usually the best way to do this, instead of single interviews at one point of time. However, the late referencing of PC patients to specialized teams/ services is a major barrier for recruitment of samples and for research purposes involving patients in Portugal, due to the rapid decline of their health status. Despite these limitations, the study provides a broad and useful overview about in-patient's experiences in acute settings, which may be a first step

to understand the complexity of the concept and the best way to achieve a feasible diagnosis and intervention regarding all patients with PC needs.

5. CONCLUSIONS

Comfort seems to be a human response that integrates several diagnoses, for which nurses should provide different but also similar and simultaneous interventions that are specific to the etiological factor (which is also a diagnosis). For this reason, we propose a new syndrome diagnosis. The study also provides a general overview of the main situations of discomfort of hospitalized patients suffering from chronic and incurable diseases. Agonizing symptoms are widely known as discomforting experiences. However, data emphasizes the importance of other determinants, such as the context of provision of care, the presence of family and significant others during the illness journey, the need to love and be loved, the way information is managed, the search for meaning of life and the need to continue to have control of life until the end. Thus, more studies are needed, with larger samples and in other contexts, such as home care or PC units. Whenever possible, multiple interviews over time are preferred to assess patient's experiences throughout their illness journey.

This study open new perspectives and creates an opportunity for further discussion about the meaning of concepts and nursing diagnoses, as well as the completeness and adequacy of the taxonomy structure, considering its translation to clinical practice. The present reflection was based on comfort, but other areas and domains of nursing knowledge within the classifications may and should be discussed, in order to provide scientific contributions to the improvement of classifications and to furthering nursing knowledge.

These results add a particular contribution to the development of more feasible, personalized and effective nursing interventions.

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2.3.2. Cultural adaptation and validation of the
Portuguese End of Life Spiritual Comfort Questionnaire in palliative care patients

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The Portuguese version of this instrument is presented on Appendix 12.



Original article

Cultural adaptation and validation of the Portuguese End of Life Spiritual Comfort Questionnaire in Palliative Care patients



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ABSTRACT

Background: Holistic comfort is an important outcome in palliative care and an important goal for patients, relatives and healthcare workers. Holistic comfort considers one's acceptance of life circumstances, support from loved ones and health care professionals, and peaceful resolution of relationships during stressful situations. However, this type of comfort is still difficult to measure, particularly in palliative care patients, as there is a lack of instruments available, especially in the Portuguese language. This study aims to provide an accurate and sensitive instrument to assess the spiritual comfort of Portuguese palliative care patients.

Objective: To perform the cultural adaptation and validation of a Portuguese version of the End of Life Comfort Planning Questionnaire in Palliative Care patients.

Methods: Methodological research, with analytical approach. The translation, synthesis, back translation, review, pretest, semantic evaluation and analysis of the psychometric properties were performed. A total of 141 palliative care patients from acute medical-surgical settings at a central hospital in the north of Portugal were recruited. The Ethics Committee approved the research.

Results: The internal consistency analysis of the adapted instrument resulted in a global alpha value of 0.84 and the factor analysis presented a solution with five factors with rational meaning. The Portuguese version comprised 20 items.

Conclusions: The instrument has good psychometric properties. It was reliable, valid and sensitive to the existence of the spiritual comfort of palliative care patients, and appropriate for further research.

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Introduction

Holistic comfort is important in all human life, from the beginning of life to death and grieving. Several authors have been researching the conceptual definition and implementation of comfort in recent years, particularly in the context of illness, crisis situations or life transitions.^{1,2} The most widely known of the abovementioned work is Kolcaba's Comfort Theory, in which comfort is described as a holistic state resulting from satisfaction of

the needs of relief, ease and transcendence in the physical, psycho-spiritual, sociocultural and environmental contexts.¹

Recent studies have identified some inconsistencies and gaps in knowledge, particularly in terms of classifications and taxonomies of nursing knowledge, in which the concept is defined in a reductionist perspective as it is predominantly associated with the physical dimension.^{2,3} These gaps and inconsistencies may be related to the difficulty of measuring the concept. Therefore, Pinto et al.²⁻⁴ supported the idea of comfort as a complex experience, dependent on the behaviors of different actors and factors in every dimension of human life. Nevertheless, current scientific evidence demonstrates the existence of several deficits in the operational implementation and measurement of the concept with patients in palliative care. Problems with measurement in this population

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Table 1
The End of Life Comfort Planning Questionnaire-Patient.

	Strongly disagree					Strongly agree
1. There are those I can depend on when I need help.	1	2	3	4	5	6
2. I don't want to think about planning for end of life care*.	1	2	3	4	5	6
3. My condition gets me down*.	1	2	3	4	5	6
4. I feel confident.	1	2	3	4	5	6
5. I feel my life is worthwhile right now.	1	2	3	4	5	6
6. I am inspired by knowing that I am loved.	1	2	3	4	5	6
7. I trust my doctor to make the right decisions.	1	2	3	4	5	6
8. No one understands me*.	1	2	3	4	5	6
9. My anxiety is difficult to endure*.	1	2	3	4	5	6
10. I am scared when I am alone.	1	2	3	4	5	6
11. My body is relaxed right now.	1	2	3	4	5	6
12. I feel agitated right now.	1	2	3	4	5	6
13. I do not feel healthy right now*.	1	2	3	4	5	6
14. Advance directives makes me feel scared*.	1	2	3	4	5	6
15. I am afraid of what is next*.	1	2	3	4	5	6
16. I am very tired*.	1	2	3	4	5	6
17. I am content.	1	2	3	4	5	6
18. I feel dependent on others to make decisions for me*.	1	2	3	4	5	6
19. My faith helps me be strong.	1	2	3	4	5	6
20. I feel out of control*.	1	2	3	4	5	6
21. I have experienced changes that make me feel uneasy*.	1	2	3	4	5	6
22. My family is aware of my wishes regarding care at the end of my life.	1	2	3	4	5	6
23. I need to be better informed about my health*.	1	2	3	4	5	6
24. I don't have many choices about end of life care*.	1	2	3	4	5	6
25. It helps to get information about end of life care.	1	2	3	4	5	6
26. I feel peaceful.	1	2	3	4	5	6
27. I am depressed.	1	2	3	4	5	6
28. I have found meaning in my life.	1	2	3	4	5	6

In <http://www.thecomfortline.com/resources/cq.html>.¹³

represent a serious limitation to the study and testing of the efficacy and effectiveness of nursing interventions, particularly at end of life.^{2,5}

Currently there are in Portugal some instruments to measure similar constructs in palliative care patients, such as quality of life or wellbeing.⁶ However there are very few tools available worldwide to assess specifically patient comfort at the end of life, and in Portugal there is only one: Escala de Conforto Holístico HCQ – PT-DC®.⁷ Although validated in a sample of palliative care patients, some inconsistencies were found in Querido's instrument which may jeopardize the global score and an accurate evaluation of the implemented interventions. One of these inconsistencies is related to item #13 ("I made the right choice in choosing this place"). Indeed, contrary to what happens in the United States (where the original version is from), the patient in Portugal is rarely able to choose the place to be treated or hospitalized, despite all the developments in palliative care in the country.⁸

Moreover, item #8 ("My pain is difficult to endure") may promote difficulties in the interpretation of the concept of pain, allowing the patient to understand the concept related to total pain exclusively in a physical perspective or, alternatively, from a more holistic point of view, so promoting bias. Furthermore, in the United States, patients rate their physical pain all the time from one to ten. It does not include existential pain. In Portugal, there is a growing effort to implement the pain as the fifth vital sign, but its evaluation is not yet a standardized practice.^{9,10} Also in palliative care, we do not believe that addiction is an appropriate concept when pain is pervasive or severe. In palliative care, many patients may be under the influence of opioids or other analgesics, which may have influenced in their answers.^{11,12}

Taking into account the importance of an accurate assessment (either in the clinical practice, whether for research purposes/evaluation of the effectiveness of nursing interventions), we consider it important to study another instrument. For this project, we adapted and translated the *End of Life Comfort Planning Questionnaire-Patient-Version* found on Kolcaba's website

(www.thecomfortline.com).¹³ This instrument closely approximated the holistic, spiritual qualities we were seeking to capture in palliative care patients in Portugal.

The End of Life Comfort Planning Questionnaire-Patient

The *End of Life Comfort Planning Questionnaire-Patient* (Table 1) was adapted and shortened from the original instrument of the Hospice Comfort Questionnaire-Patient.¹⁴ The new instrument is composed of 28 items, using a Likert scale from 1 to 6 (1 means "Strongly Disagree" and 6 "Strongly Agree"). It assesses spiritual comfort and the final score ranges from 28 to 168. The final score is calculated by the sum of the scores obtained in each item. The lower the score, the lower the comfort of the patient. For the analysis of the results it is important to consider that items #2, 3, 8, 9, 13, 14, 15, 16, 18, 20, 21 and 23 and 24 are reversed.^{1,14} The original instrument had a Cronbach's Alpha of 0.98.¹⁴ Our *End of Life Spiritual Comfort Questionnaire-Patient* excludes pain and other physical symptoms assessment; however, it is very comprehensive in the assessment of psycho-spiritual-social dimensions, which are frequently neglected in health contexts in Portugal.

The instrument has already been adapted to the Brazilian population with Cardiac Insufficiency¹⁵ but there are few instruments concerning the assessment of non-physical comfort in palliative care. Non physical comfort refers to dimensions which do not "pertain to bodily sensations and homeostatic mechanisms",^{1, p. 12} not only in Portugal but also around the world. Given the above, and with the objective of a holistic assessment of comfort, we propose that the Spiritual Comfort instrument supplements a physical comfort assessment. This supplemental assessment could be used in conjunction with a pain scale or in a more comprehensive approach, the assessment of the most prevalent physical symptoms in end of life stages, for example through the revised *Edmonton Symptom Assessment Scale*.¹⁶

Objective

To perform the cultural adaptation and validation of a Portuguese version of the *End of Life Comfort Planning Questionnaire in Palliative Care patients*.

Methods

This was a methodological study including translation, semantic and cultural adaptation, and evaluation of the psychometric properties, according to the guidelines proposed by Beaton et al.¹⁷ and STARD Reporting Guidelines.¹⁸ A research protocol was designed, analyzed and approved by the ethics committee of the institution where the study was conducted (authorization number CHSJ, CES 191-14, 14 November 2014). Participants were recruited at five in-patient medical-surgical settings (medicine, general surgery, vascular surgery, neurosurgery, pulmonology) and day hospital for chemotherapy from a central hospital in the north of Portugal. The sample was obtained after consecutive selection. The inclusion criteria were as following: Portuguese nationality, aged over 18 years old, and being followed by the palliative care team or under palliative chemotherapy. Exclusion criteria comprised cognitive impairment, lack of capacity to agree with the informed consent, and unclear diagnoses. The sample was consecutively recruited and participants were informed of the voluntary nature of their participation, they were given guarantees of data confidentiality and anonymity, and informed consent was obtained from each one.

The following stages composed the translation, semantic and cultural adaptation of the instrument:

1. Linguistic translation of the instrument into European Portuguese by three translators, native in Portugal and fluent in American English. Two translators were unaware of the concepts under study, but the third one had theoretical, practical and research knowledge in palliative care and nursing;
2. Synthesis of the first translation, by the three authors (SP, SC, JCM) (Translation Synthesis I – TS I);
3. Review of the TS-I by the three translators. The final version was obtained from the second version (Translation Synthesis II – TS II);
4. Back-translation of the TS II by two other translators, natives of the USA and fluent in Portuguese. They did the semantic analysis and had an agreement result of 100.0%;
5. Review of all translations by a panel of experts (two in research and methodological studies, one expert in the Portuguese language, one expert in palliative care, one expert in the study of comfort and, also, all translators and back-translators). The Kappa of Cohen value was 0.88.
6. Format the instrument according to the original;
7. Assessment of face validity through a pre-test on a sample of 30 palliative care patients, in January 2015, which aimed to verify the understanding of the items, the ease of using the response set, the font size (given the specifics of the sample in question) and the response time. Although the instrument is designed to be a self-answered questionnaire, these patients had some difficulties because of weakness and/or cognitive deficits. It was decided to change to a form applied as an interview conducted by trained interviewers. No other changes were made. The instrument was easily understood, and the patients answered when requested. The average answer time was 8 min for the entire questionnaire.

After the study of the face validity of the instrument, its psychometric properties were studied. Although the literature proposes the inclusion of 5–10 participants per item for the sample,¹⁹ there were several difficulties in recruiting participants for cultural and

clinical reasons. Most Portuguese patients in end of life are referred to the palliative care teams at an advanced stage and, therefore, some patients were not in clinical conditions to participate. Regardless of this difficulty, the inclusion of five participants per item was estimated and the final sample was composed of 141 cancer patients in palliative care.

Data analysis

Data were analyzed using SPSS, version 23, for Windows. A critical significance value lower than 0.05 was assumed ($p < 0.05$). The answers to the different items of the questionnaire were scored from 1 (Strongly Disagree) to 6 (Strongly Agree) after reversal of reversed items (items 2, 3, 8, 9, 13, 14, 15, 16, 18, 20, 21, 23 and 24).

Results

Participants' characterization

All 141 participants were recruited from acute medical-surgical settings in a central hospital in the north of Portugal (medicine, general surgery, vascular surgery, neurosurgery, pulmonology and day hospital for chemotherapy). All participants had an incurable, chronic and progressive illness and were in palliative care.

The average age was 59.97 years (SD=13.16 years, mode=66years, minimum=21 years and maximum=91 years). The majority of participants were male (60.60%), married (93.00%) and attended four years of school (54.20%). Although the vast majority were already retired (57.70%), a significant proportion of the participants (30.00%) had been working before the illness, and was on sick leave. With regard to spiritual/religious beliefs, 89.40% stated they were Catholic and 10.60% reported other spiritual or religious beliefs.

Reliability

In this study, the assumptions used in the original version were followed and internal consistency reliability was assessed, using Cronbach's alpha. According to the literature, *alpha* values under 0.50 are unacceptable, from 0.50 to 0.60 are questionable, from 0.60 to 0.70 are acceptable, from 0.70 to 0.80 are good, from 0.80 to 0.90 are very good, and over 0.90 are considered excellent.^{20,21} In a first analysis of internal consistency reliability (considering the 28 items of the scale), an *alpha* of 0.727 was obtained. This value, considered "good", did not provide certainty concerning the internal consistency of the instrument, because some items had inverse correlations with the scale's overall score. For this reason, the items that scored negative correlations or very close to zero with the global score were successively removed. At the same time, the global *alpha* was analyzed when removing the items (Table 2), and after several hypotheses it was clear that items #2, 7, 10, 11, 12, 19, 22 and 25 were negatively influencing the global score, both in the value of *alpha* and in their correlation with the total.

Those items were removed after a critical analysis by one of the authors of the original version, resulting in positive correlation between all items and with the global score and a Cronbach's *alpha* of 0.835, which is considered a very good value especially for new instruments.^{20,21}

It was not possible to perform test-retest reliability due to the health condition of the participants. The fatigue and physical weakness of the majority of participants confirmed the decision to apply it as an interview, but this limited the possibility of undertaking a retest. Nevertheless, since the purpose of the instrument was to assess the immediate state of holistic comfort of the person at the

Table 2
Correlation matrix of items and value of *alpha* when items were removed.

Item (English/Portuguese)	Mean	Standard deviation	Corrected item-total correlation	Cronbach's alpha (item removed)
1. There are those I can depend on when I need help. Quando preciso de ajuda tenho sempre alguém com quem posso contar.	5.61	0.841	0.177	0.613
3. My condition gets me down. A minha situação deixa-me em baixo.*	2.91	1.949	0.516	0.571
4. I feel confident. Sinto-me confiante.	5.08	1.466	0.169	0.611
5. I feel my life is worthwhile right now. Neste momento, sinto que a minha vida vale a pena.	5.42	1.344	0.258	0.604
6. I am inspired by knowing that I am loved. Sinto-me encorajado(a) por saber que sou amado(a).	5.70	0.907	0.066	0.618
8. No one understands me. Ninguém me compreende.*	5.06	1.679	0.314	0.597
9. My anxiety is difficult to endure. É difícil lidar com a minha ansiedade.*	3.46	2.044	0.502	0.571
13. I do not feel healthy right now. Neste momento não me sinto saudável.*	2.77	2.016	0.490	0.573
14. Advance directives makes me feel scared. As decisões antecipadas assustam-me.*	3.37	2.102	0.443	0.577
15. I am afraid of what is next. Tenho medo do que virá a seguir.*	3.70	2.228	0.576	0.557
16. I am very tired. Sinto-me muito cansado(a).*	2.89	2.117	0.406	0.582
17. I am content. Estou satisfeito(a).			0.287	0.600
18. I feel dependent on others to make decisions for me. Sinto-me dependente de outras pessoas para tomar decisões.*	3.61	2.321	0.361	0.586
20. I feel out of control. Sinto-me fora de controlo.*	5.20	1.625	0.327	0.596
21. I have experienced changes that make me feel uneasy. Experimentei mudanças que me fazem sentir preocupado(a).*	4.06	2.120	0.342	0.590
23. I need to be better informed about my health. Necessito de mais informação sobre o meu estado de saúde.*	4.24	2.173	0.295	0.596
24. I don't have many choices about end of life care. Eu não tenho muita opção de escolha quanto aos cuidados em fim de vida.*	2.68	2.016	0.451	0.578
26. I feel peaceful. Sinto-me em paz.	5.61	0.930	0.154	0.613
27. I am depressed. Sinto-me deprimido(a).	4.37	2.058	0.530	0.567
28. I have found meaning in my life. Encontrei sentido na minha vida.	5.33	1.367	0.233	0.606

* Reversed items.

end of life, the respect for human dignity always took precedence over the interests of the research.

Construct validity

The items that showed negative correlation with the global score of the scale may be adding a cultural bias and were removed with the author's permission (items #2, 7, 10, 11, 12, 19, 22 and 25) (Table 1). The concurrent validity, convergent-discriminant validity and also the principal component analysis confirmed the factors produced by the instrument and identified the items associated with each factor.

Concurrent validity. With regard to concurrent validity, the correlation between the instrument and another measure of the same concept was studied: *Escala de Conforto Holístico HCQ - PT-DC*⁷ which is the Portuguese version of the *Hospice Comfort Questionnaire-Patient*.¹⁴ This Portuguese instrument was composed of 26 items and measures the holistic comfort in three dimensions: relief, ease and transcendence. However, as explained before, this instrument is not the most suitable to capture comfort of the Portuguese population in palliative care. Nevertheless, and because there is not in Portugal other measure to assess comfort of palliative care patients, we used this instrument as a criterion. In a first analysis a Spearman's correlation (ρ) of 0.74 ($p=0.000$) between the two questionnaires was obtained. The *Escala de Conforto Holístico* had a Cronbach *alpha* of 0.61,⁷ with items #8 and #13 contributing negatively to the global score and were removed from the analysis. Then a Cronbach *alpha* of 0.84 and correlation of 0.74 ($p=0.000$) was obtained. These inconsistencies validated the need for a different measure.

Convergent-discriminant validity. The items with factor loadings greater than 0.30 or lower than -0.30 were removed, since the original study is not absolutely clear on all procedures used.¹⁴ We then performed a principal components analysis with orthogonal rotation (varimax method with Kaiser normalization), according to the original version.

Although the instrument is one-dimensional, the taxonomic structure of comfort created by Kolcaba¹ proposes the evaluation of three types of comfort (relief, ease and transcendence) in four contexts (physical, psycho-spiritual, social and environmental). The factor analysis was only studied by her on the original General Comfort Questionnaire, which had 48 items and was performed with acute care patients and community persons. This analysis excluded palliative care patients, and proposed a 3-factor solution which was consistent with the three types of comfort.¹

The initial exploratory factor analysis of our study proposed six factors. This structure was, however, inconsistent with the theoretical organization of items and had no relationship with the Kolcaba's taxonomic structure nor a coherent conceptual point of view. However, the solution with five factors is aligned with the results of a qualitative study concerning comfort experiences in a sample of hospitalized patients in palliative care.²² The findings of this qualitative study highlighted five themes regarding physical, psychological, spiritual and social dimensions, and also environmental factors. Despite these considerations, the instrument remains unidimensional, which is why the organization in different factors serves to provide a better understanding of the instrument.

The rotation was forced to three, four and five factors and the factor structure with five factors was the one that presented the best correlations between the items and more consistency from a conceptual perspective (Table 3).

The high correlation between the majority of items with the dimension/factor to which they belonged (and not to others dimensions/factors) was a good indicator of convergent validity.

The factor analysis with five dimensions generates a variance of 57.307%, with *alpha* values between 0.43 and 0.84 (Table 4).

The matrix presented corrected item-total correlation values ranging between 0.59 and 0.678.

These values support the high correlation between almost all items of the questionnaire contributing, also, to a high *alpha* value ($\alpha=0.835$).

Table 3
Principal components analysis with orthogonal rotation (varimax method with Kaiser normalization).

Item	Dimension/Factor				
	1	2	3	4	5
1.			0.423		0.487
3 [*] .	0.444	0.628			
4.		0.612			
5.			0.805		
6.					0.796
8 [*] .	0.325				0.602
9 [*] .	0.701				
13 [*] .	0.749	0.558		0.477	
14 [*] .	0.638				
15 [*] .				0.306	
16 [*] .		0.633			
17.			0.355	0.644	
18 [*] .	0.628				
20 [*] .	0.731				
21 [*] .	0.673				
23 [*] .				0.594	0.314
24 [*] .		0.448			0.344
26.				0.603	
27.	0.725				
28.			0.751		

* Reversed items.

Note: Retained values <0.30.

Table 4
Items distribution for dimension and Cronbach's alpha values.

Dimension/ Factor	Items	Cronbach's alpha	Standardized Cronbach's alpha
I	9, 14, 15, 18, 20, 21, 27	0.84	
II	3, 4, 13, 16, 24	0.68	
III	5, 28	0.60	0.84
IV	17, 23, 26	0.43	
V	1, 6, 8	0.49	

Discussion

Regarding the characteristics of the instrument, it was considered more appropriate to designate the Portuguese version as "*Portuguese End of Life Spiritual Comfort Questionnaire*".

As stated by Kolcaba in her website,¹³ "comfort is a larger umbrella term compared to pain" and the discomfort caused by this symptom is "often a significant detractor from comfort". In a holistic perspective, despite the physical origin of pain, comfort is greatly influenced by psychospiritual, sociocultural, and environmental factors, such as loneliness, fear, anxiety or noxious stimuli. Therefore, symptom management is an important goal of palliative care patients. For this reason, the additional evaluation of physical symptoms (not evaluated by the *Portuguese End of Life Spiritual Comfort Questionnaire*) should be considered. The use of the revised Edmonton Symptom Assessment Scale¹⁶ should be considered, as it is commonly used in this population for physical symptom assessment. In addition to these considerations, it is important to note that, in the development of comfort assessments, Kolcaba stated that "For clinical purposes, I prefer Verbal Rating Scales ("How would you rate your total comfort right now from 0 – 10?" 0 being no comfort at all, 10 being highest comfort possible in this situation." Longer instruments (questionnaires) are most appropriate for research purposes (personal communication, 3.05.16).

Regarding the study of the translation and semantic adaptation of the *End of Life Comfort Planning Questionnaire*,¹³ there were no significant changes. Indeed, the items in the Portuguese version (Appendix 1) had very similar translations and meanings, and some were equal to those obtained from the validation of the Brazilian

version beforehand.¹⁵ However the Portuguese and Brazilian population are different, not only regarding their language but also culturally which required a new validation. The semantic similarity supports the theoretical consistency of the instrument and the methodological rigor in the process of translation and back-translation.

The original versions of comfort instruments are intended to be used as self-administration questionnaires or interview questionnaires.¹⁴ It was found during the pre-test, particularly the study of face validity, that palliative participants had serious difficulties in completing the questionnaire. This is why it was decided to perform it as an interview, conducted by trained interviewers. Novak et al.¹⁴ also reported having to conduct their instrumentation study as an interview. This need was not found in the validation study in Brazil,¹⁵ despite the authors' report on the participants' conditions of advanced heart failure, as 60% had class II heart failure – slight limitation on exercise, which tends to disappear with rest – according to the classification proposed by the New York Heart Association. Another requirement was the reduction of items in the Portuguese version (Appendix 1), which did not happen in the Brazilian version, which remained with 28 items.¹⁵ In this study, the initial analysis of 28 items resulted in respectable alpha values ($\alpha=0.727$), but the items were not consistent with each other and some of them had a negative correlation with the global score.

The palliative care movement is relatively recent in Portugal.²³ Death or advance health care directives remains taboo subjects,^{24–25} which may explain why a great majority of Portuguese population refers not knowing what is palliative care (items #2, #7, #22, #25).²⁶ Furthermore, the palliative Portuguese patient has the right to be accompanied by a relative or any other significant person for 24h.²⁷ It is also common the patient to be in hospital wards with other patients, which may reduce their feelings of fear of loneliness (item #10).^{28,29} The vast majority of terminal patients could be under the effect of opioids and/or other sedative therapies that promote a state of relaxation (items #11, #12).^{12,30} The majority of participants were Catholic. These data are in line with the national profile and may justify the biased response to item #19 ("My faith helps me to be strong"). These data support the results of another study carried out in Portugal, with palliative care patients, in which the authors found that age, religious practice and education influence the experience of spirituality. In that study, the elderly and those with fewer academic qualifications tend to put their trust in God.^{31,32}

However, this study has some limitations, and caution is needed when interpreting the results. Participants had incurable, chronic and progressive diseases and their clinical condition associated with a late referral to palliative care resulted in data collection difficulties. Thus we were limited the number of participants in the study, and could not perform test–retest reliability due to the health condition of the participants. The literature reports that studies with terminally ill patients, although difficult (for clinical and ethical reasons), are needed since they contribute to the development of knowledge and contribute to more efficient and effective practice and should be encouraged. The instrument especially important for research purposes. For clinical purposes the use of verbal rating scales is recommended, which is also holistic.

Conclusion

Spiritual comfort is defined in this study as an immediate state and an outcome. It is a central concept in palliative care and, in this sense, should be measured holistically in order to obtain a larger and better assessment of the efficacy and effectiveness of the implemented interventions. Despite these considerations, there are few tools for its evaluation.

This study opens new perspectives for the evaluation of comfort as a holistic outcome and suggests the need for more studies with larger samples. It also suggests the usefulness of shorter instruments, taking into account the clinical characteristics and conditions of the person suffering from a terminal illness.

The *Portuguese End of Life Spiritual Comfort Questionnaire* represents a new approach to this important strategy of measuring a person's overall sense of wellbeing and meaningful life, we propose will should impacts on pain management effectiveness. Using this instrument in conjunction with a pain measure will give us important insight into spiritual comfort and its potential to decrease the amount of pain meds necessary when the patient has more spiritual comfort. The instrument has good psychometric properties and is reliable, valid and sensitive to the study of spiritual comfort of the person in the final stages of life, particularly for research purposes. It is a strong supplement to measures of physical symptoms.

Author's contributors

Conception and design of the work, acquisition of data, or analysis and interpretation of data (Sara Pinto, Sílvia Caldeira, José Carlos Martins); Drafting the article or revising it critically for important intellectual content (Sara Pinto, Sílvia Caldeira, José Carlos Martins, Katharine Kolcaba); Final approval of the version to be published (Sara Pinto, Sílvia Caldeira, José Carlos Martins, Katharine Kolcaba).

Conflict of interest

The authors declare no conflicts of interest.

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Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at doi:10.1016/j.pbj.2016.08.003.

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2.3.3. e-Health in palliative care:

What do research beginners need to know?

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E-health in palliative care: what do research beginners need to know?

Sara Pinto, Sílvia Caldeira and José Carlos Martins

The modern movement of Palliative Care (PC), which began in the 1960s, is an important drive to improve the comfort and quality of life of patients and their families who are facing threatening illness, through the prevention and relief of suffering in the physical, psychosocial and spiritual aspects of life (Sepúlveda *et al.*, 2002). Since then, the demographics, statistics and the course of diseases have rapidly evolved, as did PC in general. Despite all efforts, PC still faces some difficulties - like the late referral of patients to PC - which are common to many countries. Consequently, a great many patients still die in acute care settings (Fukui *et al.*, 2011; Bruera and Hui, 2012).

Patients' prefer to be at home for as long as possible and this is the place in which they often would choose to die (Gomes *et al.*, 2012). However, the lack of specialised resources is a significant limitation to addressing PC patients' will and families' needs, particularly in a home care setting. The implementation of e-health technologies may be of benefit to PC, allowing patients, families and caregivers to be connected at home, monitor the patient's comfort and provide what they need. e-Health technologies have been used previously in PC, although mainly in adult populations and quite timidly (Knapp, 2010; Capurro *et al.*, 2014). The use of e-health technologies in PC is quite recent and has been described as advantageous in this context. This commentary aims to clarify some of the concepts and technical issues in using e-health technologies in PC, which may be of interest to those who are planning or designing a new e-health technology in this field.

The concepts of telemedicine, e-health and telehealth

The concept of telemedicine was introduced in the 1970s. The World Health Organization (WHO) defines telemedicine as the use of information and communication technologies in the promotion of health outcomes by increasing information and access to care (WHO, 2010). Telemedicine aims to provide clinical support, smooth geographical barriers, improve patient health care provider connectivity, regardless of their geographical location, and increase health outcomes (WHO, 2010). The concept has been changing and today it is possible to find a reductionist approach confined exclusively to medical interventions or services. WHO (2010) defines the concept of telehealth as a broader term, comprising the interventions of all healthcare professionals. Some terms have been used interchangeably or as related concepts, such as 'e-health' (Pagliari *et al.*, 2005; Grood *et al.*, 2016), 'telecare' (Solli *et al.*, 2012) and 'telehealth' (Abbot and Liu, 2013; Silva *et al.*, 2014).

Thus, the concept of 'e-health' seems to be broader regarding all information and communication technologies, and the Internet emerged as an important issue to improve or enable health and healthcare (Pagliari *et al.*, 2005; Bashshur *et al.*, 2011; de Grood *et al.*, 2016). Presently, the concept of 'e-health' encompasses new derivations such as 'm-health' (for mobile) (WHO, 2011), 's-health' (for smartphone technologies) (Lee, 2011) and 'u-health' (ubiquitous health, related to the use of ubiquitous computing technologies) (Bashshur *et al.*, 2011; Lee, 2011). u-Health is a much broader concept, meaning 'any anytime, anywhere, using any device' (Bashshur *et al.*, 2011; Lee, 2011), and is associated with the use of wireless.

Native or web-based app?

Those who are planning to design a new e-health technology might at some point have to decide the best operational system for the viability of the technology, and whether that system is native, web-based or a hybrid.

Native technologies are based on a specific operational system (such as Android or iOS), and are therefore limited to their particular coding languages (White, 2013). But, they can be faster than non-native technologies and also allow the use of additional systems (GPS or camera, for example) that may enrich the application (app). Thus, their allocation in the app store of the corresponding operating system favours a greater release, and increases the potential of being used. But this is limited to those who have this operating system, which may constitute a disadvantage (White, 2013). Web-based technologies (also called non-native technologies) are designed based on the idea of using the future application

on several devices and operating systems that are connected to Internet (White, 2013). Between these two types of technologies, hybrid technologies are designed using standard web-technologies, but are wrapped inside a native container, combining the advantages of each system (White, 2013) (Table 1).

Table 1: Comparison between native, non-native and hybrid apps.

	Native	Non-Native	Hybrid
Performance	High (fast)	Low (slow)	Medium
Language	Native (iOS or Android)	Web-based (HTML-5, JavaScript, CSS)	Native or Web-based
Allocation	App stores	Web	App stores
Offline access	Supported	Can be supported (but it is predominantly online)	Can be supported
Costs (development)	High	Low	Medium

Some considerations should be taken into account when choosing the best operative system, as follows:

- Will regular content updates be required? If so, non-native apps might be better, because users will need greater speed to be connected and to download.
- Will the app be accessible to a wide number of users? If so, non-native apps can offer a more feasible way to develop a cheaper app, common to multiple platforms and devices. In this regard, customised user interfaces can be a great help.
- Is there any possibility of short-term increases in the number of users? If so, the service should be universal and accessible to the widest possible number of users. Once again, nonnative apps can represent a better choice (White, 2013).

Regardless of the chosen approach, particularly in PC, technologies should complement, rather than replace the human interaction, serving simultaneously as a support tool for clinical decision-making and as a tool for patient empowerment.

Ethical issues in the use of e-health technologies

e-Health technologies have several advantages, but there are also important ethical issues that need to be considered from planning and design its implementation because “*people are drawn to the Internet as a safe and anonymous place (...), but the reality of how that information is used can be quite different*” (Thompson *et al.*, 2012: 149). This idea underlines a concern for the principle of autonomy, for the patient’s privacy, and for the guarantee of a valid e-consent. In addition, the difficulties of ensuring access and equity

among disadvantaged populations, who may not have access to these technologies, may compromise the principle of justice. Justice relates to the moral obligation to guarantee fairness, usually also described as equality. If all citizens do not have equal access to technologies in urban and rural settings, then the distributive justice may be compromised (Thompson *et al.*, 2012). Regarding the principles of beneficence and non-maleficence, it is important to note that, as e-health promotes a remote interaction between patient and healthcare providers, the risk of an impaired communication is increased. In some situations, however, this may constitute the best answer to patient's needs in a particular context (Thompson *et al.*, 2012). It has been suggested that e-health technologies enhance connectivity between patients and health care providers; improve quality of care, social development and satisfaction with care, and reduce costs (Capurro *et al.*, 2014).

Rippen and Risk (2000) created an 'e-health Code of Ethics', an important set of issues that should be addressed in the development and implementation of e-health technologies:

- Candour: disclose information that could affect the way users understand the use of the e-health technology (such as describing the purpose of the technology and any financial interests).
- Honesty: be truthful and do not provide misleading information. Distinguish promotional or purchase services from educational and/or scientific products.
- Quality: provide information updates based on the best scientific evidence. Use friendly formats that are easy to understand.
- Informed consent: disclose potential user privacy risks. Users should be aware of the data management and use. Clearly disclose information about data collection: who is collecting, how data will be used, who will access the data (with whom and for what purpose).
- Privacy: ensure that unauthorised access to the patient's data is not allowed. Professionalism in online health care: respect ethical obligations and educate patients about the limitations of e-health services.
- Responsible partnering: ensure that the sponsors and partners involved in the project are trustworthy and that they comply with their ethical obligations.
- Accountability: provide users the opportunity to give a feedback. Disclose contact information and encourage the notification of any violation of ethical principles.

Questions related to equity and access remain ethical concerns, although they are not specific to e-health, and are common to different health care contexts. However, the code of ethics aims to ensure the respect for several aspects of equity and access. This

therefore promotes e-health technologies as a complementary strategy to the approach and the support of patient's needs in PC.

CONCLUSION

PC principles include the offer of a support system to help patients and their families, and the use of e-health in PC is an emerging theme for researchers and practitioners. The development of new technologies can bring many benefits to patients, families, practitioners and researchers. Ethical aspects should be taken into account in advance in order to protect the patient's dignity and rights. The use of e-health technologies can be helpful in monitoring patients' comfort and in improving preventive interventions. Those who are planning and designing new technologies should consider several options, and the choice should be based on both knowledge and ethical attitude to decide what is best for patients and families.

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2.3.4. e-Health in palliative care:

Review of the literature, *Google Play* and *App Store*

Pinto, S., Caldeira, S. & Martins, J.C.

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ABSTRACT

Aim: To analyse the use of e-health technologies and mobile apps in Palliative Care (PC).

Study Design: Review.

Methods: Search on PubMed, using “*telemedicine*”, “*ehealth*”, “*mobile Health*”, “*telecare*”, “*health information systems*” and “*palliative care*”. Original Portuguese, Spanish, French and English papers were included. *Google Play* and *App Store* (iOS) were searched for Mobile apps using “*palliative care*”, “*medical apps*” and “*Symptom management*”.

Results: Twenty-five papers and forty mobile apps were analysed. Teleconsultation is the principal e-health technology. Mobile apps focus on communication, drugs, tools/ clinical guidelines, hospice, symptom management and PC information.

Conclusions: e-Health is an emergent topic in PC. Teleconsultation enhances communication among patients, families and PC teams, reinforces partnership, decreases the burden of families and the use of emergency services.

Implications for Practice: e-Health technologies are a good strategy in PC but further research based on different methodological approaches is needed to promote evidence-based practice.

KEYWORDS

Comfort; health information systems; palliative care; telemedicine.

INTRODUCTION

The use of Internet devices has been causing a revolution in the way people communicate with each other and with the world. Internet opens up an unprecedented number of possibilities, services and information (World Health Organization [WHO], 2010). According to the Internet World Stats [IWS] (2016), 49.50% of the world population had Internet access at home (North America 89%, Europe 73.90%, Oceania 73.30%, South America 61.50%, Asia 44.50%, and Africa 28.70 %) in June 2016, which is really surprising considering that only 1% of the population had that access in 1995.

The great majority of e-health technologies are based on industrialized countries such as United Kingdom, Scandinavia, Australia and North America (WHO, 2010), and focuses on diagnosis and clinical management. The WHO predicts that telemedicine “*will profoundly transform the delivery of health services in the industrialized world by migrating health care delivery away from hospitals and clinics into homes*” (WHO, 2010: p. 10). However, the use of e-health technologies is not restricted to industrialized countries. In low-income countries these services have also been used, for example to link health-care teams with specialized centres and specialists (WHO, 2010).

e-Health technologies have been established as an important dimension of social development, enhancing connectivity and improving the access to several services and opportunities (Dutta *et al.*, 2015). Palliative Care (PC) is not indifferent to the scientific and technological development, and the integration of these technologies could be valuable in improving comfort and quality of life of patients, relatives and caregivers.

BACKGROUND

The origins of the concept of e-health (introduced in 2000) are deeply associated with the concept of telemedicine, which appears before in the 70's. The WHO e-health website (2016) defines e-health in a broader perspective as “*the use of information and communication technologies (ICTs) for health*”. However, other authors are more restrictive and specific when defining e-health not only as the use of ICTs, but also including the use of Internet and computers (Eysenbach, 2001; Pagliari *et al.*, 2005; Pinto *et al.*, 2016). e-Health includes other concepts related to the use of mobile technologies (m-health), smartphones (s-health) or wireless (u-health) (Bashshur *et al.*, 2011; Lee, 2011). e-Health (or telemedicine, as it is called by the WHO) smooths geographical barriers, provides clinical support, improves patient-health care provider's connectivity, and increases health outcomes through the use of ICTs (WHO, 2010).

The concept of application or “app” is quite recent and related to the development of mobile technologies. An app is a “*software application, which can be downloaded onto smartphones, tablets and e-readers to provide solutions for an individual problem or to satisfy a niche requirement*” (National Health Service Innovations South East [NHSISE], 2014: p.8). It can be native (which means it were developed using a specific platform), web-based or non-native (the design is compatible with several operating systems and it is available for any smartphone, tablet or computer with Internet access) or hybrid (combines the best and the worst of each system) (White, 2013; NHSISE, 2014; Pinto *et al.*, 2016).

Despite the importance of e-health technologies in several contexts, very little is known about its use in PC. Two literature reviews have been performed in this context (Nwosu and Mason, 2012; Ostherr *et al.*, 2016) but with different results, probably due to the multiplicity of concepts and surrogate terms on this topic. The Nwosu and Mason (2012) review reports the available smartphone apps for iPhone, Blackberry, Android, Palm and Windows in the context of PC (6 apps available for iPhone and Android: 2 PC blogs, 3 apps to provide PC information and 1 drugs calculator). Ostherr *et al.* (2016) analysed ICTs that aim to improve communication between physicians and PC patients.

Thus, analysing the knowledge, mapping the existing technologies, including the limitations and the opportunities, seems to be important in synthetizing the use of e-health in PC. This paper aims to analyse the use e-health technologies and mobile apps in PC.

Research Questions

The following questions have guided the research: i) Which e-health technologies have been used in PC? ii) Which PC mobile apps are available for use at application stores? iii) What are the strengths, weakness, opportunities and threats of these technologies?

METHODS

Literature review, mixed with review in web services. Two different searches were conducted. First, to answer the research questions i) and iii), the search was based on PubMed; Second, to answer the research question ii), *Google Play* and *App Store* (iOS) were searched. The search on PubMed comprised the following: [“telemedicine” OR “e-health” OR “mobile Health” OR “telecare” OR “health information systems”] AND [“palliative care”] (Table 1). This study used the definition of e-health proposed by the WHO (2010).

Table 1: Search strategy on PubMed.

Query	Results
#telemedicine (MeSH) AND #palliative care (MeSH)	117
#eHealth (not MeSH) AND #palliative care (MeSH)	130
#telehealth (not MeSH) AND #palliative care (MeSH)	134
#mobile health (not MeSH) AND #palliative care (MeSH)	202
#telecare (not MeSH) AND #palliative care (MeSH)	21
Total	604

All original Portuguese, Spanish, French and English articles published in peer-reviewed scientific journals until 30 September with abstract available were included. Opinion and discussion articles, editorials, presentations or conferences, and research protocols were excluded. All the references of the selected articles were retrieved for further studies and, whenever necessary, the authors have been contacted to obtain the full text. A total of 604 papers were identified. The references were imported to Endnote X7 and duplicates were removed. The studies were selected from the sequential analysis of the title (n= 86), abstract (n=76) and full text reading (n=40) (Figure 1).

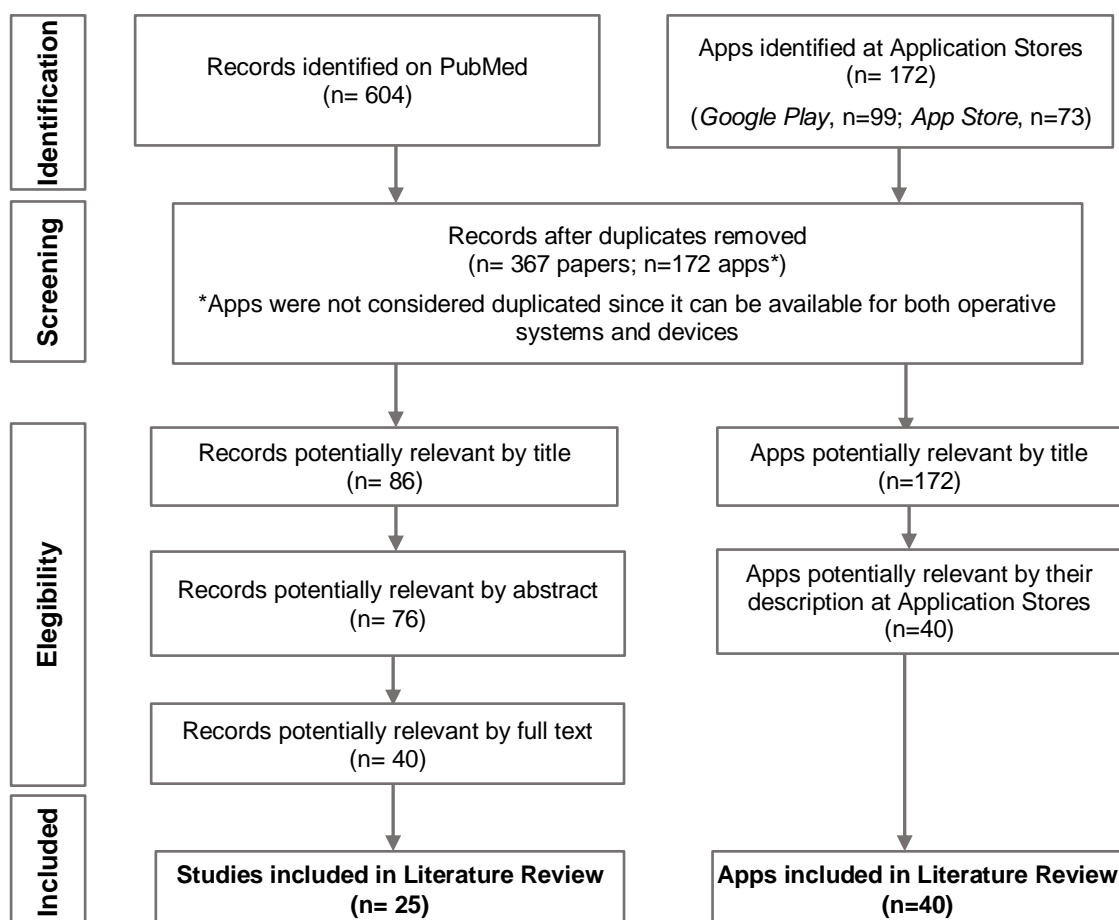


Figure 1: Flow diagram of selected studies.

The search of *Google Play* was conducted on 'Applications', and the search of *App Store* (iOS) was conducted using iOS apps on *iTunes*. The topics 'palliative care', 'medical apps' and 'symptom management' have been used in both searches. Apps concerning PC journals, PC conferences and PC books were excluded (Figure 1).

RESULTS

Results are described according to the research questions.

i) Which e-health technologies have been used and tested in PC?

A total of 25 studies were included in this review (Table 2).

Table 2: e-Health technologies used in palliative care.

Author (Year) Country	e-Health Technology	Setting/ Stakeholders	Conclusions
Coyle <i>et al.</i> (2002) USA	TeleEye® (a commercialized audiovisual system) Equipment: Standard television/ computer monitor and a regular analogue phone line Aim: To improve PC through teleconsultation	Home care Patients Family caregivers PC team	- Patients can be at home, with daily evaluations by the PC team - Visual contact in patients with hearing loss - Less comprehensive than home visits (but more readily available) - Cut down the number of home visits
Saysell and Routley (2003) United Kingdom	Videoconference* Equipment: Monitor, videoconferencing cameras, video recorder, document camera, integrated services digital network Aim: To realize videoconferences between nurses and a PC clinician specialist from another hospital to discuss clinical cases	Hospital Clinical nurses PC clinician	- Opportunity to share knowledge with experts, saving time and money - It reinforces partnership working and patients also have benefits from this cooperation - Optimization of human resources - Requires previous preparation, trust and confidence between participants - Speakers who are not confident prefer contact face-to-face
Bensink <i>et al.</i> (2004) Australia	Internet-based video-phone* Equipment: Ordinary telephone line, computer, web camera and modem Aim: To improve PC through teleconsultation	Home care Patients Family caregivers PC team	- More personalized communications when compared with telephone - Integration of community nurses, improving the continuity of care - Visualization of the patient is possible - Patients, family caregivers and HCP were satisfied - Limited physical evaluation and Internet connectivity problems
Aoki <i>et al.</i> (2006) Japan	Tele-palliative program at the Okayama Central Hospital Equipment: Polycom Viewstation (Polycom, Inc., Pleasanton, CA) using the Integrated Service Digital Network line Aim: To improve PC through teleconsultation	Home care Patients PC team	- Decreases the number of home visits - Patients were not familiar with e-health technologies but they believe it can improve their access to the PC team - Patients felt in connection with the hospital team
Maudlin <i>et al.</i> (2006) USA	Home Telehealth Equipment: Text messaging device (Health Hero®) and videophone Aim: To monitor and manage symptoms remotely	Home care PC patients Family caregivers PC team	- Face-to-face contact, in real time, improving spiritual support to patients and families - Patients felt connected with the hospital team (improving trust and confidence)

(continuation)

Norum and Jordhøy (2006) Norway	Videoconference* Equipment: Videoconferencing material and email Aim: To link an oncologist team from one hospital with another oncologist/ PC team from another hospital, for educational purposes	Hospital PC clinicians and oncologists	- Collaboration between 2 hospitals teams was improved - The study aims to share knowledge but clinical cases were also discussed - Email has advantages (share images, reports) but the low response (>6h) improved the use of telephone - Problems with sound and network were reported
McCall <i>et al.</i> (2008) United Kingdom	Advanced Symptom Management System in Palliative Care (AsyMSp) Equipment: Mobile phone-based technology, using the Symptom Assessment software Aim: To report and manage symptoms of PC home patients remotely	Home care PC patients Healthcare providers	- Useful for remote monitoring of symptoms - Professionals felt confident - The AsyMSp improve early detection of symptom problems and preventive measures - Some patients needed help from family members - Software is not described
Bradford <i>et al.</i> (2010) Australia	Home Telehealth Program (HTP)	Home care	- The HTP is feasible, acceptable, and supports PC consultations, reducing the burden on families
Bradford <i>et al.</i> (2012) Australia	Equipment: Personal computers (desktop or laptops), web cameras and Internet access Aim: To provide specialist consultations to paediatric patients and their caregivers at home	Family caregivers PC team	- It seems to address symptom management but there is no information regarding how this is accessed
Bradford <i>et al.</i> (2014a) Australia		Cost minimization analysis study	- Video consultation is an economical method - The system ensures equity in access
Bradford <i>et al.</i> (2014b) Australia	Aim: To explore the barriers to the implementation of the HTP	PC clinicians	- Limited access to the equipment; concerns about using Internet, and lack of time (clinicians focus on in-patients) are limitations - Families prefers face-to-face contact
Stern <i>et al.</i> (2012) Canada	Telehomecare in Palliation Study (TIPS) Equipment: Video-phone and telephone (the author does not describe the video-phone equipment) Aim: To improve PC through teleconsultation	Home care PC patients Family caregivers PC team	- Telehealth increases access to care - Visual contact was appreciated - Principal reason to start contact was pain management/emotional support - Caregivers reported that it would be helpful if they had access to the system at an early stage of the disease - Principal concerns: lack of integration of services, technical problems related with remote access and lack of portability of the equipment

(continuation)

Takahashi <i>et al.</i> (2012) USA	Intel® Health Guide (Food and Drug Administration-approved device) Equipment: Not described Aim: To assess the relationship between telemonitoring and hospice enrolment	PC patients PC team	- No relation between telemonitoring and referral to hospice care - The Intel® Health Guide is briefly described
Brecher (2013) USA	Skype™ Equipment: Computer, Internet, connection, microphone (often built in), and a webcam (usually built in but can be added) Aim: To provide PC patients a tool for communicate with others	Home care PC patients PC team	- Skype™ as an additional tool to improve communication - Secure website with encryption methods for voice and image - Helps patients to strength relations
Katalinic <i>et al.</i> (2013) Australia	Interact home telehealth project Equipment: Apple iPad®, Internet, Intel Health Guide® (model PHS6000) Aim: To improve PC through videoconferencing	Home care PC paediatric patients PC team	- iPad provide a low-cost method of home based videoconferencing - Age is not a barrier to use home telehealth technologies - iPads have a great potential for clinical and therapeutic purposes - Problems with Internet connectivity
Watanabe <i>et al.</i> (2013) Canada	The Virtual Pain and Symptom Control and Palliative Radiotherapy Clinic Equipment: Not described Aim: To improve access to specialist multidisciplinary PC team through videoconferencing	Home care PC patients Community teams PC team	- Videoconferencing is feasible and may improve symptoms management, users satisfaction, and saves costs and time for patients - Facilitators included an existing telehealth infrastructure and community nurses trained in PC assessment
Bakitas <i>et al.</i> (2009a) USA	ENABLE (Educate, Nurture, Advise, Before Life Ends)		
Bakitas <i>et al.</i> (2009b) USA	Equipment: Telephone (Outpatient PC consultation with telephone follow up) Aim: To educate and provide ongoing support through telephone	Home care PC patients Family caregivers PC team	- Nurse-led interventions can improve patient's quality of life - The intervention is based on early PC integration and crisis prevention - The intervention doesn't have any effect on symptom scores or on hospital length days (ENABLE II) - ENABLE III was used to access family caregiver's depressive symptoms/ grief outcomes. The early PC intervention did not show statistical differences compared with delayed PC
Bakitas <i>et al.</i> (2015) USA			
Dionne-Odom <i>et al.</i> (2016) USA	Aim: To access depressive symptoms and grief outcomes in family caregivers after patients' death		

(continuation)

Hennemann-Krause <i>et al.</i> (2015) Brazil	Telemedicine system for symptom monitoring Equipment: Computer with Adobe Flash Player support, a web browser, access to the Internet, webcam, microphone, and an audio playback device) Aim: To manage symptoms of PC outpatients	Home care PC patients	<ul style="list-style-type: none">- Use of emergency services decreased- Better symptom management- Edmonton Symptom Assessment Scale can be used through telemedicine systems- Training or prior knowledge of the patients/ families in IT is fundamental to the success of e-health technologies- PC team was contacted at the time of the death- Social and legal issues should be taken into account
Menon <i>et al.</i> (2015) USA	Videoconference* Equipment: Videoconference equipment's (not specified) Aim: To improve PC through videoconferencing	Home care Family caregivers PC team	<ul style="list-style-type: none">- PC consultations can be provided through telemedicine- Videoconferences help to assess family members understanding of illness in critically ill patients, gives the possibility to discuss prognosis, treatments and goals of care before possible home transfer
Taylor and Morris (2015) Australia	Flinders Telehealth in the Home Equipment: iPad tablet Aim: To monitor patient health status, namely physical activity and weight	Home care PC patients PC team	<ul style="list-style-type: none">- Effectiveness of home telehealth is equivalent to a home visit- Audio/ video quality is better when patients used fibre for the home services instead of mobile data services- Technical problems (calls cut off and poor audio/ video quality)
Taylor <i>et al.</i> (2015) Australia			<ul style="list-style-type: none">- Customisation of applications and services is required to improve the use of e-health services- The usability and intuitive application's design, and the clinician's training are important issues for the maintenance of the service
Collier <i>et al.</i> (2016) Australia	Telehealth Palliative Care Program in Community Equipment: Not described Aim: To improve PC through teleconsultation	Home care PC patients PC team	<ul style="list-style-type: none">- Telehealth is a complementary resource for PC practice- New technologies can alter the dynamic of relationships between patients-families-healthcare workers- Implementation of telehealth programs should involve clinicians, managers and technical staff from the outset

Legend: * No specific name.

The first study regarding the use of an e-health technology is from 2002 (Coyle *et al.*, 2002). Some of the studies do not concern new technologies but sequential phases of implemented projects under development (Table 2). The majority of the e-health technologies were developed in the United States of America (USA) (n=6) and Australia (n=4), but also in Europe (2 in the United Kingdom and 1 in Norway), Japan (n=1), and Brazil (n=1).

Teleconsultation (or videoconferencing, as called in some studies) has been the principal e-health technology under study (n=15). The majority of these studies used standard equipment to realize video calls such as a standard television or computer, web-cam or video equipment and Internet access. However, some studies used specific software such as the *TeleEye*[®] (Coyle *et al.*, 2002) (a commercial audiovisual system), the *Polycom Viewstation* (Aoki *et al.*, 2006), the Health Hero[®] (a text message device) (Maudlin *et al.*, 2006), the *AsyMSP* software to monitoring symptoms (McCall *et al.*, 2008), *Skype*[™] (Brecher, 2013) or the *Intel*[®] *Health Guide* (Takahashi *et al.*, 2012; Katalinic *et al.*, 2013). Other studies reported the use of specific operating systems (iOS), through an iPad (Katalinic *et al.*, 2013; Taylor and Morris, 2015; Taylor *et al.*, 2015). One study complemented teleconsultation with e-mail messages (Norum and Jordhøy, 2006). Although not always explicit, the majority of the studies require Internet access. The ENABLE project (Educate, Nurture, Advise, Before Life Ends) is an exception, using only the telephone (Bakitas *et al.*, 2009a; Bakitas *et al.*, 2009b; Bakitas *et al.*, 2015; Dionne-Odom *et al.*, 2016).

Improving the connection between PC teams and the patient and/or family caregivers has been the critical objective of the studies, but also to improve communication between healthcare providers, in order to share knowledge or achieve specialised information (Saysell and Routley, 2003; Norum and Jordhøy, 2006). Only one study was found in a paediatric population (Katalinic *et al.*, 2013).

ii) Which PC mobile apps are available for use at application stores?

A total of 99 PC apps have been identified on *Google Play*, 39 PC apps for iPhone at the *App Store* (iOS), and 34 PC apps for iPad. This review included 40 apps developed for the specific context of PC. The apps have been analysed and listed in seven categories, according to their aim (Table 3).

Table 3: Palliative care apps identified at the *Google Play* and *App Store*.

Name (year)	Aim	Stakeholders	Operating System	Costs
COMMUNICATION				
Speak to Me (2014)	To assist interpreters working in healthcare settings, particularly in PC settings	Interpreters working in PC	Android	Free
Clear Conversations (2015)	To improve communication skills	HCP	Android	
VitalTalk Tips (2016)			iOS/ Android	
PathMedo (2016)	Advance Care Planning app to enhance communication	HCP and PC patients	iOS ****	
DRUGS				
ORTHODOSE (2014)*	To provide a drugs calculator and conversor	HCP	Android	Charge
Palliative Care Tools (2014)			Android	
Facts and Myths (2015)	To provide a game about the correct use of morphine and other opioids		iOS****	
Palliate Guide (2016)	To provide PC drugs information and calculations		iOS	
Palliat SD (syringe driver) (2016)	To search for drugs compatibility via subcutaneous infusion		iOS	
Catéter subcutáneo paliativos (2016) **	To talk about the use of subcutaneous medication/ via in PC		Android	Free
PC INFORMATION				
Hospice Connect (2012)	To share information about hospice care	General population	Android	Free
OSCEtoolkit-Palliative (2013)	To provide information for PC students	Students	iOS	
The cost of Dying (2013)	To provide information about PC	General population	iOS****	
Pallimed (2013)			Android	
SICP, Società Italiana de Cure Palliative (2015)			Android	
eHospice (2015)	To provide information about PC and to advertise for jobs and conferences		iOS/ Android	
Palliative Care Fast Facts (2016)	To provide information about PC		iOS/ Android	
On Signing Terms (2016)	To help HCP to care for deaf patients or patients with hearing loss in PC context	HCP	iOS/ Android	
Understand Me (2016)*	To help HCP care for PC patients		iOS	
PalCare (2016)			iOS	
TOOLS AND CLINICAL GUIDELINES				
Four Season CFL, Compassion for Life (2014)	To provide guidelines on hospice about good practice in PC	HCP	iOS/ Android	Free
NHS Scotland Palliative Care Guidelines (2015)			iOS/ Android	
Neonatal Palliative Care (2016)			iOS/ Android	
SECPAL (2016)**			Android	
Echelle PPS, Palliative Performance Score for Android (2016)***	To provide a tool to measure functional status		Android	

HOSPICES				
Benevolent Hospice LLC (2013)	To provide hospice information about the Benevolent Hospice	General population	iOS	Free
Hospice of the Valley (2013)	To help HCP make a direct referral	HCP	iOS/ Android	
Hospice in a minute (2013)	To provide information about PC	HCP and general population	iOS/ Android	
Hospice of Southern Illinois (2014)	To help HCP to make a direct referral	HCP, PC patients and family	Android	
Valley Hospice of AZ (2014)**	To provide support to PC patients and families at home	PC patients and family	iOS	
Charlotte Hospice (2015)	To help HCP to make a direct referral	HCP	iOS	
Hospice Research Governance Toolkit (2016)	To provide a guide for researchers working in hospices	Researchers	iOS	
Aultman Home Care and Hospice (2016)	To provide information about PC To help HCP to make a direct referral	HCP,PC patients and family	Android	
Avow Hospice (2016)	To submit a referral or request a consultation To provide admissions guidelines and medication formularies	HCP	iOS	
Vitas Health (2016)	To provide eligibility criteria for referral of a patient to PC	HCP	iOS	
SYMPTOM MANAGEMENT				
Palliative Care (2009)	To enhance information to reduce symptoms severity	HCP	iOS	Charge
Symptom Management Guides (2013)	To assist HCP in the assessment and management of symptoms		Android	Free
Non-verbal symptom tool (2013) (there is a free version)	To realize symptom assessment in non-verbal people	HCP, family and educators	Android	Charge
OTHER APPS				
Ag-Palliative Care (2016)	To synthesize patient information	HCP	Android	Free
My own voice (2015)	To record end of life wishes	PC patients	iOS	

Legend: HCP: Health Care Providers; PC: Palliative Care; * available in several languages; ** app in Spanish; *** app in French; **** for iPad only.

The beginning of PC apps dates from 2009, with the allocation of the '*Palliative Care*' app to the App Store (iOS). This app is available for a cost and aims to provide Health Care Providers (HCP) information regarding symptom management. Two years later, Google launched a new app ('*Hospice Connect*') on the market. In recent years, several apps were introduced in Google and Apple stores, such as in 2013 (n=8), 2014 (n=6), 2015 (n=7), and 2016 (n= 17).

Among the 40 apps, some seem quite original, such as the '*Speak to Me*' (2015), which aims to assist translators working in PC settings, and the '*Facts and Myths*' app (category: drugs), which consists of a game about some facts and myths concerning morphine and opioids.

The app "*My own voice*" (category: other apps) allows patients to record their wishes, not only to preserve their memory but also to keep this for future decision making.

The number of iOS apps (n=16) and Android apps (n=15) is quite similar, but nine apps are compatible with both operating systems. Among iOS apps, only three are compatible with iPad devices. Most apps are free of charge, but Android users are in advantage because among the four apps available at a cost, three use the iOS operating system. The great majority are available in English. Two apps are available in several languages, two in Spanish and one in French. No app for the paediatric population was found. But, different stakeholders have been identified among adults, such as HCP, PC teams, general population, PC patients and family.

iii) What are the strengths, weakness, opportunities and threats of these technologies?

To answer this question, a SWOT (strengths, weakness, opportunities, threats) analysis was performed and summarized in Table 4.

Table 4: SWOT analysis.

STRENGTHS
Teleconsultation <ul style="list-style-type: none">- Patients can stay at home (Coyle <i>et al.</i>, 2002)- Patients can be monitored by a specialised team (Aoki <i>et al.</i>, 2006; Maudlin <i>et al.</i>, 2006; Stern <i>et al.</i>, 2012)- More personalised interactions when compared with telephone (Bensink <i>et al.</i>, 2004; Brecher, 2013)- Rapidly available, and enables visual contact (Coyle <i>et al.</i>, 2002; Maudlin <i>et al.</i>, 2006; Stern <i>et al.</i>, 2012)- Supportive caring measure, helping to decrease the burden of families (Bradford <i>et al.</i>, 2010; Bradford <i>et al.</i>, 2012)- Reinforces the partnership and knowledge among HCP (Saysell and Routley, 2003; Bensink <i>et al.</i>, 2004; Norum and Jordhøy, 2006)- Decreases the number of home visits and the use of emergency services (Coyle <i>et al.</i>, 2002; Aoki <i>et al.</i>, 2006)
WEAKENESSES
Teleconsultation <ul style="list-style-type: none">- Less comprehensive than home visits (physical assessment might be compromised) (Coyle <i>et al.</i>, 2002; Bensink <i>et al.</i>, 2004)- Requires trust and confidence (some users prefer face-to-face contact) (Saysell and Routley, 2003; Bradford <i>et al.</i>, 2014b; Watanabe <i>et al.</i>, 2013)- Technical problems associated with connectivity, video or sound (Bensink <i>et al.</i>, 2004; Norum and Jordhøy, 2006; Stern <i>et al.</i>, 2012; Katalinic <i>et al.</i>, 2013; Bradford <i>et al.</i>, 2014b)
OPPORTUNITIES
<ul style="list-style-type: none">- The use of Internet and mobile devices is increasing (IWS, 2016; ITU, 2016)- No apps regarding paediatric populations or teenagers- Only one app regarding a validated instrument was found (Echelle PPS), but many other instruments are available in different languages and cultures- Very few instruments to monitor symptoms remotely (which can enhance preventive interventions, and ensure comfort)- Contribution to the optimization of human resources, saving time and money, particularly in countries with PC limited access or great geographical dispersion (Aoki <i>et al.</i>, 2006; Bradford <i>et al.</i>, 2010; Watanabe <i>et al.</i>, 2013)- Age is not a barrier to the use of e-health technologies (Katalinic <i>et al.</i>, 2013)
THREATS
<ul style="list-style-type: none">- Limited access to the required equipment's (Katalinic <i>et al.</i>, 2013)- Ethical issues related with data protection (Thompson <i>et al.</i>, 2012)- Need to find a balance between the use of e-health and the insurance of humanization and ethical principles (Thompson <i>et al.</i>, 2012)- Some patients and families prefer a face-to-face contact (Saysell and Routley, 2003; Stern <i>et al.</i>, 2012)- Clinicians are more focused on in-patients (not having time for teleconsultation) (Bradford <i>et al.</i>, 2014b)- Implementation of e-health in underdeveloped countries, where Internet access and the use of mobile devices is still limited (IWS, 2016; ITU, 2016)

Legend: IWS (Internet World Stats), ITU (International Communication Union).

DISCUSSION

Results highlight an increase in the use of e-health technologies. However, when compared with other contexts, the use of e-health technologies in PC is still well under developed (Nwosu and Mason, 2012; Ostherr *et al.*, 2016). e-Health technologies have been used particularly in industrialised countries, such as USA, Australia and Canada, which is in accordance with previous literature (WHO, 2010). However, the world statistics are changing and e-health seems to be the future in more countries. According to the International Telecommunication Union [ITU] (2016), 95% of the global population is living in an area with mobile-cellular network coverage. Nevertheless, the same report focuses that 53% of the world population is a non-Internet user, and the majority is from Africa and India. The Internet Monitor Dashboard (2016), an international project from the Harvard University, states that countries such as Kenya, Egypt, Nigeria or Morocco have Internet penetration rates higher than the literacy rates.

In this review the vast majority of studies are focused on the use of teleconsultation, aiming to reduce the constraints associated with the follow up of PC patients in rural areas or geographically dispersed countries (Aoki *et al.*, 2006; Bradford *et al.*, 2010; Watanabe *et al.*, 2013). Teleconsultation is an important tool to support clinical practice, to enhance communication among health care providers, and for the optimisation of human resources, and these have been the main advantages previously stated (McLean *et al.*, 2013). Teleconsultation is also a way to improve access to PC specialists, continuity of care and to link PC teams, patients and family.

However some limitations were found. The first study using and testing teleconsultation was published in 2002 (Coyle *et al.*, 2002), but 14 years later other descriptive studies keep focusing on the advantages and disadvantages of this system. It is important to improve new studies, with consistent methodological approaches in order to develop new knowledge (Ostherr *et al.*, 2016). Some methodological details in reporting the studies may compromise the knowledge transfer, such as the samples (often small), and the absence of the setting.

The applications are focused on knowledge promotion in different topics (communication, general information about PC or the correct use of drugs). The number of applications for monitoring symptoms or patient functional status is still poor. The introduction of PC tools in an app format could contribute to a better optimisation of time, resources and organization of care.

SWOT analysis revealed several opportunities and threats in this area, which should be addressed in further research. However some authors state that it is necessary to improve training and to guarantee better integration between hospital and community services

(Saysell and Routley, 2003; Bensink *et al.*, 2004; Watanabe *et al.*, 2013). Thus, further interventions should enhance relatives' education in the use of e-health technologies, namely apps. Threats represent challenges that should be addressed in the development and use of new e-health technologies. However, it should be embraced as an opportunity with educational purposes.

LIMITATIONS

Some aspects should be taken into account when looking at this study. Although the e-health concept is officially used by a number of international entities, such as the WHO (2010), the European Parliament (Scholz, 2015), the National English Health System (NHSISE, 2014), the medical subject heading (MeSH) adopted by PubMed is 'telemedicine'. The search for this word has some limitations, since many studies still use other concepts such as 'telecare', 'telehealth' or 'information and communication technologies'. This limitation has already been identified in other studies (Pagliari *et al.*, 2005). The current search included those surrogate terms and synonyms to avoid bias.

Another limitation is associated with the definition of the concepts of "e-health" and 'telemedicine'. Many authors refer to the use of the Internet as a specific attribute of e-health technologies (Pagliari *et al.*, 2005; Bashshur *et al.*, 2011; de Grood *et al.*, 2016). In this study, the definition proposed by WHO (2010) was used, and it allows studies focusing on the use of the telephone to be included, although some authors may not truly consider it an e-health technology.

Regarding the search on application stores, the health apps are allocated in the category 'medical apps'. Within this category, there are several apps designed for the specific context of PC. However, it does not exclude the possibility that other applications listed in other categories are missed. This study excluded some languages, but three apps in German were found and rejected for analysis. This confirms that the results represent the apps according to the inclusion criteria.

CONCLUSIONS

e-Health is an emergent topic in PC. The search on PubMed found several studies on the use of teleconsultation, but other e-health technologies such as websites or smartphone applications can be used to improve holistic comfort and quality of life.

Several apps are available, with an important increase in 2016. The vast majority aim to improve knowledge, but few apps are particularly focused on symptom monitoring or patients' needs. Little is known about the validity of these apps and more studies are

required about cost analysis and ethical issues. World statistics regarding the use of Internet devices are changing and this seem to be a challenge to PC, which aims to keep patients at home with family, having symptom control, comfort and perceived dignity in their care.

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2.4. From the conceptual design to the feasibility study

This topic introduces the conceptual framework for the development of a nursing intervention to monitor comfort in PC patients. The intervention was designed throughout four years, based on the MRC framework for the development and evaluation of complex interventions (Craig *et al.*, 2008; Craig *et al.*, 2013). For the purposes of publication, and for a better understanding by the reader, it was necessary to summarize the studies carried out, some of which have already been presented in previous topics.

The study introduces a prototype design that needs to be further studied and improved.

2.4.1. Introducing a prototype to monitor comfort
remotely in palliative care patients

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ABSTRACT

Aim: To introduce a web-based application for monitoring comfort in palliative care (PC) patients.

Methods: Longitudinal study, comprising: needs assessment (literature review); content and face validity (literature review, concept analysis, qualitative study, and online survey); construct validity (experts validation); feasibility study (n=7 PC patients).

Results: The app is compatible with Android, iOS and Windows. The results from phase I and II provided the knowledge about comfort. In phase III five experts have analysed the content of the app. The assessment of comfort comprises 11 self-reported items (pain, tiredness, drowsiness, nausea, lack of appetite, shortness of breath, depression, anxiety, fear of the future, peace and the will to live). In phase IV, a total of 117 messages were retrieved. Participants considered the app simple, easy to use, and useful.

Conclusions: This prototype is feasible and user-friendly. Further research is needed to continue the app development, namely in terms of data protection.

KEYWORDS

App; comfort; e-health; palliative care; symptom management.

INTRODUCTION

In recent years we have seen important demographic, epidemiological and health care changes, namely in the course of diseases. While the active population is decreasing, the ageing population is increasing, and often with long-term disease management needs. Originally, hospitals aimed to treat acute health problems, but this situation has been changing and patients with chronic illnesses are now the most frequent population, which is considered a new epidemic (Greenberg *et al.*, 2011). In some points, it seems that health progress is misplaced and we are living a regression in time (Líden, 2014). According to an international survey regarding the place of death, a significant percentage of persons (62%) are still dying in hospital, although the great majority prefer to die at home (Gomes *et al.*, 2013). On the one hand, the healthcare systems are becoming overcrowded, unsustainable and unaffordable (Lueddeck, 2016), while on the other, new models of care are needed and they should be simultaneously holistic, affordable and sustainable (Budysh *et al.*, 2014; Nasi *et al.*, 2015).

According to scientific evidence, e-health plays an important role in modern societies, contributing to the resolution of many of these problems (Nasi *et al.*, 2015). Several authors, and also the World Health Organization (WHO) (2010), reported that e-health has several advantages for patients, healthcare providers and institutions. For example, e-health can enhance the communication and the interaction between patients and healthcare teams, especially outpatients living in areas where specialized teams are not available (Nasi *et al.*, 2015; Hochstenbach *et al.*, 2016). Thus, it could also improve transparency, productivity, and health care systems' accountability. In summary, e-health represents quite a new resource that promises to revolutionize the way healthcare is managed (Nasi *et al.*, 2015).

BACKGROUND

Palliative Care (PC) aims to relieve suffering and enhance holistic comfort and quality of life in patients and families facing life-threatening conditions, particularly through preventive measures (Worldwide Palliative Care Alliance and WHO, 2014). However, comforting has been considered a complex intervention, involving integrated and interdisciplinary attention on the patients' different needs in all human life dimensions (Pinto *et al.*, 2014). Comfort interventions should be personalized and, simultaneously, should take into account the etiological factors (Pinto *et al.*, 2016a).

While PC at patients' homes has been considered a gold standard in several countries (Gomes *et al.*, 2013; Higginson *et al.*, 2013; de Roo *et al.*, 2014), other quality indicators

should be considered in further developments of PC (Dy *et al.*, 2015), as well as the perceived barriers and facilitators towards achieving that (Sommerbakk *et al.*, 2016) (Table 1).

Table 1: Quality indicators, facilitators and barriers to PC.

QUALITY INDICATORS (Dy <i>et al.</i> , 2015)	
	Comprehensive assessment; Screening physical symptoms (namely pain and dyspnoea); Discussion of psychological needs; Discussion of spiritual concerns; Report treatment preferences; Care consistency according to treatment preferences.
FACILITATORS (Sommerbakk <i>et al.</i> , 2016)	
Innovation	Innovations should improve access to care, be easily available, enhance credible data (through validated tools), and avoid being too time consuming.
Personal characteristic of HCP	Motivation or advanced knowledge in PC.
Patient characteristics	Knowledge, skills or compliance.
Social and cultural context	Enthusiastic and supportive leadership, positive attitudes to changes, collaboration among HCP, social and family support.
Organizational context	Available resources (staff/ patient ratio), organization of care, existence of expertise, close proximity to collaborating or PC services, disconnection between services.
Economic and Political factors	Financial arrangements, policies, admission of specialized staff.
BARRIERS (Sommerbakk <i>et al.</i> , 2016)	
PC patient's condition	Poor general condition, late referral to PC teams.
Lack of validated instruments	Validated instruments in several symptom management populations.
Lack of PC expertise	Focus on curative treatments, lack of time, economic and political arrangements.

Legend: HCP (Health Care Providers), PC (Palliative Care).

The literature highlights that PC patients cared for at home usually only report their symptoms during home visits or in cases of symptom distress, which means that symptom assessment is sub-optimal in certain circumstances. Interventions aiming for good symptom management should preferably be preventive, which means that patients' needs should be assessed in a systematic and continuous way (Hudson *et al.*, 2016). These concerns are especially relevant for patients living in rural settings, in dispersed geographical areas, or in areas where the access to specialized PC services is limited (Watanabe *et al.*, 2013).

e-Health technologies seem to be an excellent resource for reporting symptoms over time (Cooley *et al.*, 2015), and to direct access to supportive and accurately composed data for patients and PC teams (Hochstenbach *et al.*, 2016). As a result, these technologies bring patients, families and PC teams closer, enhancing communication and collaborative care (Nasi *et al.*, 2015; Hochstenbach *et al.*, 2016), also contributing to achieving patient's and relatives' needs, and addressing the overcrowding of healthcare systems (WHO, 2010; Budysh *et al.*, 2014).

Despite the importance of e-health technologies, their use in PC settings has been improved only recently and very timidly (Nwosu and Mason, 2012; Ostherr *et al.*, 2016). In their literature review, Capurro *et al.* (2014) identified 17 papers regarding the use of information and communication technologies in PC, and concluded that evidence is very limited, particularly on the study of their effectiveness. In another review, Nwosu and Mason (2012) considered that although e-health tools constitute an opportunity for innovation, only six mobile apps were identified in application stores.

This study aims to introduce the design of the prototype of a web-based application (app) for monitoring comfort remotely in palliative home care patients in Portugal.

METHODS

Study Design

The conceptual framework to design the app was conducted in four phases (Figure 1), based on a longitudinal study design, comprising different methods according to the specific objective of each phase.

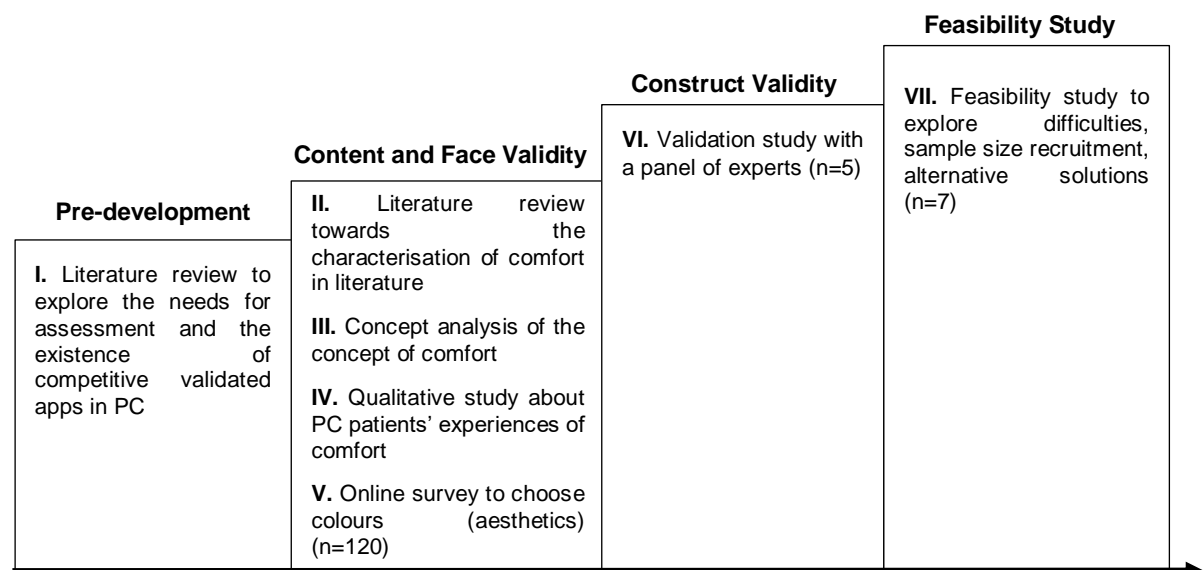


Figure 1: Methodological approach to the conceptual framework.

Sample and sample size determination

The study comprises several phases and in each phase different samples were recruited (Table 2).

There is no single procedure regarding sample size determination (Polit and Beck, 2014). While Polit and Beck (2014) don't have specific recommendations, Hertzog (2008) provides several strategies for sample size determination, such as the opinion of experts, searches in journals about pilot studies on the topic, or power calculations. Power calculations are based on the size of the eligible population. According to Murtagh *et al.* (2014), 62-89% of people who died in a developed country had PC needs. In Portugal, 108 511 deaths occurred in 2015 (Instituto Nacional de Estatística, 2016), and when applying Murtagh's formula, at least 67 277 patients are found to have PC needs. With a confidence level of 95% (margin of error equal to 5%) and a response distribution of 50%, the recommended sample size is 383 patients. Some authors argue that pilot/feasibility studies require 30% of the population (Stallard, 2012), which means that 115 patients should be included.

Few pilot/feasibility studies regarding the development and testing of mobile/web-based applications in PC patients have been found in literature and the majority of samples are not as large: Hennemann-Krause *et al.* (2015) (n=12), Menon *et al.* (2015) (n=12), or Hochstenbach *et al.* (2016) (n=11). Based on these samples, a total of 10 patients were included in this feasibility study.

Data collection

Eligible patients were screened by the nursing staff. Researchers held a first meeting with the patients to explain the study's purpose and the app functioning. Each patient was given a Quick Response (QR) code and whenever necessary a link was also sent by e-mail. In addition, patients received a booklet with all the information.² Patients were invited to use the app during 15 days, using it at least once and whenever necessary (SOS). At the end of this period, one researcher interviewed each patient, based on the following eight questions:

- 1) *In your opinion, the Comfort app is: very confusing, confusing, simple.*
- 2) *What is your opinion about the layout? (answer on a scale of 1 to 5).*
- 3) *In your opinion, how easy is it to use this app? (answer on a scale of 1 to 5).*

² Appendix 14

- 4) *In your opinion the app is: totally useless, useless, useful, very useful.*
- 5) *Can you describe any obstacles when using the app? (open question).*
- 6) *Do you want to recommend any improvements or suggestions? (open question).*
- 7) *Would you use this app in your daily life? (yes/no).*
- 8) *What is your overall opinion about the app? (answer on a scale of 1 to 10).*

Outcomes

Two primary outcomes have been defined for this study: feasibility and acceptability. According to The Mobile Assess Review Committee (2011) the feasibility of an app is the degree to which the app development is possible or not. Acceptability concerns the degree to which the app can be used by different users, with different needs, and can be measured through different outcomes (Moody and Woodcock, 2012). For example, 60 outcomes were identified in a literature review (Moody and Woodcock, 2012). Primary outcomes and secondary outcomes have been defined in this study, according to Moody and Woodcock (2012), and have been described in related measures (Table 2).

Table 2: Primary and secondary outcomes.

	OUTCOME	OPERATIONALIZATION (MEASURES)
PRIMARY OUTCOMES	<p>Feasibility The degree to which the app development is possible or not (The Mobile Assess Review Committee, 2011)</p>	<ul style="list-style-type: none"> - Experts overall classification about the app and interrater reliability (Cohen's kappa coefficient) - Patient's overall score of the app - Patient's acceptability (measured through secondary outcomes)
	<p>Acceptability The degree to which the app can be used by different users, with different needs (Moody and Woodcock, 2012)</p>	<ul style="list-style-type: none"> - Measured through secondary outcomes (desirability, stability, responsiveness, aesthetic, ease of use, usefulness, and satisfaction)
SECONDARY OUTCOMES	<p>Desirability The degree to which the app is sought-after by users (Moody and Woodcock, 2012)</p>	<ul style="list-style-type: none"> - Number of missing data - Number of SOS messages - Patient's answer to the question: "<i>Would you use this app in your daily life?</i>"
	<p>Stability The degree to which the app is robust and error free (Moody and Woodcock, 2012)</p>	<ul style="list-style-type: none"> - Number of error data or outliers
	<p>Responsiveness The degree to which the speed and app interaction is perceived as acceptable by users (Moody and Woodcock, 2012)</p>	<ul style="list-style-type: none"> - Loading time (assessed on first and last evaluation) - Patient's answer to the question: "<i>Can you describe any obstacles when using the app?</i>" (open question)
	<p>Aesthetic App visual appearance (Moody and Woodcock, 2012)</p>	<ul style="list-style-type: none"> - Patient's answer to the question: "<i>What is your opinion about the layout?</i>" (Likert scale between 1 and 5)
	<p>Ease of use The degree to which the app is naturally and readily used by users with success (Moody and Woodcock, 2012)</p>	<ul style="list-style-type: none"> - Patient's answers to the questions: - "<i>In your opinion, the Comfort app is: very confuse, confuse, simple</i>" - "<i>In your opinion, how easy is to use this app?</i>" (Likert scale between 1 and 5)
	<p>Usefulness The degree to which the app is helpful for the patient (Moody and Woodcock, 2012)</p>	<ul style="list-style-type: none"> - Patient's answer to the question "<i>In your opinion the app is: totally useless, useless, useful, very useful</i>"
	<p>Satisfaction The degree to which the app answer to the users' needs and expectations (Moody and Woodcock, 2012)</p>	<ul style="list-style-type: none"> - Patient's answer to the question "<i>In your opinion the app is: totally useless, useless, useful, very useful</i>" - Overall score given to the app by patients (Likert scale between 1 and 10)

Ethical procedures

The research was approved by the ethics committee ³ and the participants were written to and verbally informed of the study's purpose, their voluntary participation and confidentiality. Informed consent was obtained for all participants. Each patient was identified by a code in the feasibility study when using the app to ensure data protection.

³ Appendices 4 and 5

Table 3: Description of the four phases of the longitudinal study design.

Study Phase	Study Identification	Aim	Sample	Methodological Approach
Pre-development	Literature review	<p>-To explore the needs assessment and the existence of competitive validated apps.</p> <p>-To analyse the use of e-health technologies and mobile apps in PC, in literature, <i>Google Play</i> and <i>App Store</i> (iOS).</p>	n=25 papers	<p>Literature <u>Database:</u> PubMed. <u>Search terms:</u> Telemedicine, ehealth, mobile Health, telecare, health information systems, palliative care. <u>Inclusion criteria:</u> All original Portuguese, Spanish, French and English articles published in peer-reviewed journals up to 30 September were analysed. <u>Exclusion criteria:</u> Opinion and discussion articles, editorials, presentations in conferences, and research protocols. <u>Selection strategy:</u> Sequential analysis of the title, abstract and full text reading.</p>
			n=40 mobile apps	<p>Application Stores <u>Stores:</u> <i>Google Play</i> and <i>App Store</i> (iOS). <u>Search terms:</u> Palliative care, medical apps, symptom management. <u>Exclusion criteria:</u> Apps concerning PC journals, PC conferences and PC books were excluded.</p>
Content and Face Validity	Literature review towards the characterisation of comfort in literature	To analyse the elements that characterize comfort in nursing scientific literature.	n=52 papers	<p><u>Databases:</u> MEDLINE® with Full text, EBSCO (<i>all databases</i>), CINAHL® with Full text, Scielo, Bireme, PsycINFO, Cochrane Database of Systematic Reviews and JBI Library of Systematic Reviews. <u>Search terms:</u> Comfort*, concept, definition. <u>Inclusion criteria:</u> All Portuguese, Spanish, French and English papers, published in peer-reviewed journals up to 31 December 2013. <u>Exclusion criteria:</u> Narrative reviews, opinion and reflection articles, editorials and presentations at congresses or conferences. <u>Selection strategy:</u> Sequential analysis of the title, abstract and full text reading, according to the following evaluation criteria: clear definition of the problem and clear description of the methodology (aims, method and sample).</p>

Content and Face Validity (continuation)	Concept analysis of the concept of comfort	To provide a conceptually adequate definition of comfort.	n=59 papers	<p><u>Databases:</u> PubMed, EBSCO (CINAHL® Plus with full text, Nursing and Allied Health Collection, Cochrane Plus Collection, MedicLatina, MEDLINE® with full text), SciELO, Bireme, PsycINFO, Cochrane Database of Systematic Reviews and JBI Library of Systematic Reviews.</p> <p><u>Inclusion criteria:</u> All Portuguese, Spanish, French and English papers, published in peer-reviewed journals between 1 January 2004 and 31 December 2015.</p> <p><u>Exclusion criteria:</u> Theoretical papers, opinion articles, reflections, editorials, proceedings, books or book chapters.</p> <p><u>Data analysis:</u> Method: Rodgers' Evolutionary View (2000).</p> <p><u>Selection strategy:</u> Sequential analysis of the title, abstract and full text reading focused on the existence of a clear definition of the research problem (comfort), and a clear description of the methodology (aims, study design, sample).</p>
	Qualitative study about PC patients' experiences of comfort	To analyse PC patients' experiences about comfort.	<p>n=15 in-patients</p> <p>Male: n=10 Female: n=5</p> <p><u>Age</u> Range 71.27 years (36 – 78)</p> <p><u>Hospitalisation time</u> Range 33.5 days (10 – 68)</p> <p><u>Diagnosis</u> Oncological disease (n=9) Non-oncological disease (n=6)</p>	<p><u>Study design:</u> Qualitative study.</p> <p><u>Setting:</u> In-patient medical-surgical settings from an acute and central hospital.</p> <p><u>Inclusion criteria:</u> Participants who have recently had (or were still experiencing) uncomfortable experiences (eg. agonizing pain, traumatic injuries, breathlessness, nausea, loneliness, spiritual distress).</p> <p><u>Exclusion criteria:</u> cognitive impairment, lack of capacity to give informed consent, and not fluent in Portuguese.</p> <p><u>Data analysis:</u> Deductive content analysis.</p>
	Online survey	To choose the colours of the app aesthetics.	<p>n=120 participants</p> <p>Male: n=29 Female: n=107</p> <p><u>Age</u> 31-40 years (40.40%) 41-50 years (24.30%)</p>	<p><u>Study design:</u> Online survey.</p> <p><u>Sample:</u> Purposely recruited (initially through researchers contacts and after in snowball).</p> <p><u>Inclusion criteria:</u> Age ≥ 18 years, have an e-mail account.</p> <p><u>Exclusion criteria:</u> Not fluent in Portuguese.</p> <p><u>Data analysis:</u> Descriptive statistics, using SPSS.</p>
	Construct Validity	Discussion with a panel of experts	To ensure construct validity.	<p>n=5 experts in PC</p> <p>Female: n=5</p> <p><u>Age</u> Range 37.20 years (32 – 40)</p>

Feasibility
Study

Feasibility study

To explore the difficulties, sample size recruitment and the alternative solutions.

n=7 participants

Male: n=5 | Female: n=2

Age

Range 40.71years (27 – 54)

Diagnosis

Oncological disease (n=4)

Non-oncological disease (n=3)

Study Design: Feasibility study.

Setting: Two hospitals with home care visits to PC patients.

Inclusion criteria: Age≥18 years, diagnosed with a life-threatening illness, be at home, have a computer device with Internet access, be able to answer (themselves). Patients with physical disabilities (eg. decreased visual acuity or fine motor disabilities) could be supported by a caregiver.

Exclusion criteria: Cognitive impairment (assessed through the Portuguese version of the Mini Mental State Examination [Santana *et al.*, 2016]).

Data Analysis: Descriptive statistics, using SPSS.

Instruments

The *Comfort app* assesses 11 self-reported items (pain, tiredness, drowsiness, nausea, lack of appetite, shortness of breath, depression, anxiety, fear of the future, peace and the will to live) assessed on a Likert scale, from 1 (not a problem) to 10 (worst imaginable level of symptom).

The physical and psychological items were extracted from the Portuguese revised version of the Edmonton Symptom Assessment Scale (ESAS) (Presa *et al.*, 2016) (Cronbach's alpha=0.74). This version uses a Likert scale between 1 and 10, and not between 0 and 10, as displayed in the original version (Bruera *et al.*, 1991). Spiritual and social items were extracted from the Portuguese End of Life Spiritual Comfort Questionnaire in PC patients (Pinto *et al.*, 2016b) (Cronbach's alpha=0.84).

Study phases

Pre-development phase

This phase has two main objectives: i) to explore the need to develop an app for monitoring comfort remotely in PC patients, and ii) to explore the existence of competitive and validated apps in this health context. These objectives have been fulfilled through a literature review about e-health technologies in PubMed, *Google Play* and *App Store* (author's reference 1).

Validity

Validity comprises the degree to which an instrument "*measures what it is supposed to measure*" (Polit and Beck, 2014: 205). It embraces the content validity, face validity, construct validity, and criterion-related validity (Polit and Beck, 2014).

Content validity

Content validity ensures that the instrument covers the broad range of items within the construct under study to capture the full content. The core of content validity is based on judgment through literature reviews, concept analysis or findings from qualitative studies. To ensure content validity, three studies have been performed: (1) a literature review for the characterization of comfort in nursing literature; (2) a concept analysis of the concept of comfort using the Rodgers' (2000) evolutionary concept analysis method; and (3) a qualitative study to explore PC patients' experiences of comfort (Table 3). The instrument was discussed by a panel of experts in comfort and in PC (n=5). Criteria for expert

selection was adapted from the criteria proposed by Quatrini *et al.* (2015) for validation studies in nursing (Table 4). Experts evaluate the app through a questionnaire sent by e-mail. The simplicity, the potential access difficulties, the aesthetics and the utility have been assessed using a Likert Scale ranging from 1 to 3. The overall classification was scored between 1 and 10. Agreement among experts was measured using the Cohen's kappa coefficient.

Table 4: Criteria for expert selection and experts' characterization.

Criteria (Scores)	E(1)	E(2)	E(3)	E(4)	E(5)
Clinical experience of at least 4 years in PC (04) *	04	19	04	04	04
Experience of at least 1 year in clinical teaching (01) *	00	08	12	01	01
Experience in research with articles published in reference journals (01)	01	01	01	00	01
PhD in Nursing or PC (02)	00	00	02	00	00
MSc in Nursing or PC (01)	01	01	01	01	01
Nursing residency in PC (01)	01	01	01	01	01
Participation in a research group in PC (01)	00	01	01	00	00
Total	07	31	22	07	08
Expert Classification**	Master Expert	Senior Expert	Senior Expert	Master Expert	Master Expert

Legend: E (Expert)

* One extra point should be added, for each year of either clinical experience in PC or teaching experience.

**Experts Classification: Junior Expert ≤ 5 points; (Clinical Experience of at least 4 years in PC is mandatory)
 Master Expert: 6 points \geq score ≤ 20 points
 Senior Expert > 20 points

Face validity

Face validity is closely related with content validity as it embraces the degree to which non-experts perceive the relevance of the measure, and the degree they believe it is being used to measure what it is intended to measure. Although not considered an important psychometric property, it can have important implications on the stakeholder's motivation and on the use of the instrument (Maroof, 2012). It includes the aesthetics and the difficulties found by stakeholders when using the instrument.

To improve face validity, aesthetics was evaluated through an online survey (n=120). Participants were invited to indicate the colour they associate with the word 'comfort'. In the feasibility study, participants were also invited to give their suggestions and, in the end, a questionnaire was set up to assess their opinion.

Construct validity

While a concept represents a broader and generalized abstraction, the construct represents a concept that it was observed in theory and should be observed in practice. A concept is "an abstraction based on the observations of behaviours or characteristics"

(Polit and Beck, 2014: 376), and represents a broader and generalized perspective. A construct is “*an abstraction or concept that is deliberately invented (constructed) by researchers for a scientific purpose*” (Polit and Beck, 2014: 377).

The construct validity is a major criterion of an instrument, closely associated with theoretical conceptualizations. It means that the instrument is measuring what it is intended to measure (the construct) and not other concepts or variables. This concerns two questions: “*What is the instrument really measuring?*” and “*Does it validly measure the abstract concept of interest?*” (Polit and Beck, 2014: 206). Literature states that there isn’t a single way to ensure construct validity. It should comprise the evidence from a large number of studies. Thus, content validity and the criterion-related validity contribute to construct validity (Kimberlin and Winterstein, 2008).

This study was supported on Kolcaba’s Comfort Theory (2003), in which the author studied and operationally implemented the concept of comfort. The construct validation was assessed by a panel of experts (n=5) (Table 4).

Criterion-related validity

The criterion-related validity concerns how well scores on the new instrument correlate with other validated measures (criterion) of the same construct or related constructs (Polit and Beck, 2014). This study did not include criterion-related validity because the *Comfort app* already comprises two instruments previously validated for the population of the study.

Data analysis

Several data analysis methods were adopted (Table 3), according to each phase. In literature reviews the data were imported to End Note X7. Whenever necessary, descriptive statistics were calculated using the IBM SPSS® programme, version 22 for Windows.

RESULTS

Participants' characterization

The characteristics of the participants are summarized in Table 3, for each phase.

Description of the *Comfort app* prototype ⁴

The app was developed using a free web-based custom domain, compatible with Android, iOS and Windows. It aims to be used by palliative care patients who are at home, via any computer device (smartphone, tablet or computer) with Internet access. The main screen, the first introduced to participants, contains three topics in Portuguese (Figure 2): i) a brief description of the app and its purpose (“Sobre nós”; ii) a telephone number to contact the PC team (“Ligue-nos”); iii) a topic for comfort registration (“Registo do conforto”).



Figure 2: The *Comfort app* prototype.

⁴ For more detailed information see Appendix 14.

This prototype is a free and experimental version. For this reason it is not available from any application stores. Access to the app is possible using a QR code or through a link sent by e-mail. When a participant filled out the app, the data was sent to an Excel database and an automatic e-mail message was received by the researcher managing the app.

In the online survey, nine colours were associated with the word 'comfort': blue (36.80%), white (27.20%), beige (10.30%), pink (8.10%), green (7.40%), purple (4.40%), orange (2.20%), yellow (2.20%) and brown (1.50%). The two favourite colours were adopted (blue and white) and the layout was designed to be simple and easy to read. The logotype was designed using a free website and represents the tree of life, which is also used in several documents to present the PC principles. A circle was used around the tree, to represent the holistic and dynamic nature of comfort. The font size is pre-defined and standardized and cannot be changed.

Panel of experts

The panel of experts (n=5) tested the app prototype through three different operating systems (Android, iOS, Windows), and three different devices with Internet access (smartphone, tablet and computer). Both access via the QR code and the link sent by e-mail were tested.

The app was considered simple, easy to use, very useful and simple to access. In the experts' opinion, patients might also consider the app simple to use. The overall agreement was 84% and Cohen's Kappa coefficient was 0.76. The overall classification (1-10) ranged from 7 points to 10 points (mean=8.6 points). Despite this classification, the experts highlight that it is important to explain the purpose and the advantages of the app to patients. Otherwise, the stakeholders cannot understand the true potential of the app and may think that healthcare providers only want to reduce the number of visits. For this reason, this explanation was reinforced in the first meeting between researchers and patients (feasibility study).

Feasibility study

Participants

This phase included seven patients monitored by PC teams at home. One patient refused and another was excluded due to their health status. The majority of participants are male (n=5), and the mean age was 40.71 years (minimum 27 years; maximum 54 years). All participants attended school for periods from 4 years to 12 years, mean of seven years.

No participant had attended higher education or had specific training in informatics. Diagnosis included oncological disease (n=4), amyotrophic lateral sclerosis (n=2), and multiple sclerosis (n=1). All were able to answer for themselves. However, one participant needed to be helped by the informal caregiver due to severe physical limitations, including decreased visual acuity, severe tremors and impaired fine motor skills.

Operating system, electronic devices and Internet access

Android (n=5) or Windows (n=2) were the operate systems used. No patients had devices with an iOS operating system.

One patient used the app through a smartphone, three through a tablet and two patients through a computer. Patients with amyotrophic lateral sclerosis and multiple sclerosis preferred to access the app through a computer due to severe physical limitations, such as decreased visual acuity and impaired fine motor skills. These patients had already implemented in their personal laptops the use of a keyboard on the computer screen. One patient with amyotrophic lateral sclerosis was able to answer the app questions on his own. However, due to physical limitations (tremors and decreased visual acuity) he cannot use the app independently. For this reason, he was assisted by the informal caregiver, who agreed to participate in the study.

Interestingly, patients stated they preferred using tablets and computers, as the font size (which cannot be edited) was larger in these devices, compared to the smartphone. The main barriers were adherence by the elderly to the app and the lack of devices/ Internet access among many patients.

Acceptability

Acceptability was evaluated through the defined secondary outcomes: desirability, stability, responsiveness, aesthetics, ease of use, usefulness and patient's satisfaction.

Desirability and stability

Patients used the app during 15 consecutive days, and at least once per day it had to be completed. A total of 117 messages were received in the database. Twelve messages were SOS. The main reasons for SOS messages were increased pain and anxiety. PC teams were informed by researchers when the symptom score was greater than 5. Only 1 patient had contacted the PC team directly.

Missing data was found in two patients (one day, each one). When asked for the reasons, they reported they forgot to fill in the data.

Data were sent spontaneously, and participants reported there was no need for any alarm to remind them to use the app. Data were sent between 01:24am and 23:54pm. Mode is 09:18am and median 14:16pm, which means the vast majority sent the data after 14:00pm. SOS messages were sent between 16:45pm and 22:33pm.

Regarding stability, no error data or outliers were found. No problems with Internet were reported. One patient referred that once he couldn't send a message, but an error message was displayed. When he/she tried again, no problems were found.

App responsiveness and aesthetics

Loading time ranged between 11 seconds (access by link) and 18 seconds (access by QR code).

The aesthetics was considered simple and easy to read. When asked for a more attractive layout, three participants reported that more important than the visual appearance was that it was easy to read. When asked to give the app an overall score (measured between 1 and 10), all the participants reported 10.

Ease of use, usefulness and patient's satisfaction

Participants considered the app very simple, clear and easy to use. Participants were aware of the app's limitations and they knew that data were not visualized by the PC team (even knowing that the team would be informed in some cases). However, four participants reported that it was important to know that someone was looking out for them, what they were feeling, and that was really important. One participant reported that "*This app helped me to feel more comfortable, because I know you will see how I was feeling and that gives me more tranquility...Well, I can't explain, but I really felt better*" (P2).

The app was considered very useful. All participants reported they will use the app in daily life if it is available, and all of them gave an overall score of ten to the app.

Improvement suggestions

Participants with neurological diseases (n=3) suggested increasing the font size. One cancer patient suggested an alarm for medication.

Validity

Results highlight that the app is feasible, and has content, face and construct validity. More studies are needed to search for criterion-related validity, as well as reliability.

Participants were asked about the suitability of the items, the adequacy of the Likert scale response (between 1 and 10), and the frequency of app utilization.

All participants considered the items appropriate, even those related with the spiritual dimension. Data highlight slow fluctuations in the items 'fear of the future' and 'peace'. Participants with amyotrophic lateral sclerosis and multiple sclerosis didn't have some symptoms such as pain or nausea, for example, at the time of data collection.

Response options on the Likert scale range from 1 to 10, according to the recommendations of the Portuguese version of the ESAS (Presa *et al.*, 2016). When asked their opinion about giving the answers on a scale instead of a dichotomy answer (yes or no), all participants reported preferring the Likert Scale. As reported by a patient, "*I always have a fear of the future. But I think it is comprehensible. If I put «yes», maybe is not the best answer. But if I put 3 today, which is absolutely normal for me, and 9 tomorrow, this is very different.*" (P5)

The opinions diverged on the frequency. Cancer patients (n=4) considered it important to answer all the items every day. The patient with amyotrophic lateral sclerosis considered it important to answer every day, while the other two patients considered it more appropriate to answer twice in the week or whenever necessary.

DISCUSSION

To our knowledge, this is the first prototype app to remotely measure comfort in palliative home care patients in Portugal. This app can bring several benefits not only to patients but also to families and PC teams. Indeed, this app can help PC teams to perform a more comprehensive assessment and screening of the patient's needs, which were considered quality of care indicators (Dy *et al.*, 2015). As a consequence, it will contribute to better care consistency and to personalized comfort interventions, which have been pointed out as facilitators (Sommerbakk *et al.*, 2016).

Although participants don't have higher studies or specific knowledge in informatics, the results highlight the *Comfort app* is easily accepted, simple to use and the study is feasible.

Data were sent over a large period of time, but the great majority was sent after lunch, and SOS messages were sent between 16pm and 23pm. This is an important topic to explore in further research, as it can help PC teams to identify some profiles in symptom distress,

and also contribute to better management of care, as well as the implementation of preventive and personalized interventions.

While innovation and e-health technologies have clearly been described as important facilitators in PC improvement (Nwosu and Mason, 2012; Sommerbakk *et al.*, 2016), some limitations should be taken into account in further developments, such as the reliability of the instrument, economic limitations, app functionality, and the difficulties in sample recruitment.

In the literature review for the characterization of e-health technologies in PC (author's reference) two PC apps for symptom management were found. These apps used the ESAS for symptom monitoring but no studies were founded regarding the development of these apps, which raise some questions about their validity. For example, some doubts are raised concerning the validation of the tool by the population. Although symptom management is an important theme for patient comfort, other life dimensions should also be addressed and monitored (Kolcaba, 2003).

ESAS is one of the main instruments widely used to assess symptoms in PC (Bausewein *et al.*, 2011) and can be used through telemedicine systems (Hennemann-Krause *et al.*, 2015). Initially developed for cancer patients, this scale has been used in other populations and settings across the world (Ngwa and Koech, 2012). ESAS includes not only physical symptoms, but also items related with the psychological and social dimensions. However, ESAS misses items related to spiritual dimension, which is the reason why the prototype was completed with three items from the Portuguese End of Life Spiritual Comfort Questionnaire validated in PC patients (Pinto *et al.*, 2016b). The *Comfort app* does not access items related to environmental comfort.

Despite the *Comfort app* covering items from the physical, psychological, spiritual and social dimensions, some questions about the suitability of the Likert scale arise. For instance, while the Portuguese version of ESAS (Presa *et al.*, 2016) uses responses between 1 and 10, the Portuguese End of Life Spiritual Comfort Questionnaire in PC patients (Pinto *et al.*, 2016b) uses responses between 1 and 6. To improve simplicity and decrease response errors, the same response (between 1 and 10) was used in all the items. No problems were found during data collection, but further research is needed to ensure the reliability of this option.

Economic limitations were another important topic in this study. This is a problem that many researchers, teams and institutions frequently face (Zhang *et al.*, 2014). For this reason, it was decided to design a web-based app, through a free custom domain. This allows the acceptability and functionality of the app to be tested, and this is important for gathering evidence that could inform on further development of the app and attract funding.

Nevertheless, this app is an innovative resource at the service of health teams in a free and creative way, and this was used before by other researchers (Zhang *et al.*, 2014).

But some disadvantages may also be listed. For instance, the loading time ranged between 11 seconds (access by link) and 18 seconds (access through a QR code), which is considered too much. Literature reported that speed matters and loading times between 1 and 10 seconds capture the stakeholder's attention. In this study this was not a problem, but patients were aware of the limitations. In subsequent stages, it is important to decrease loading time below 10 seconds (Zamfiroiu, 2014). The app is also very exposed to error. Due to the use of a custom domain, it was not possible to introduce the Likert scale and participants needed to answer through an open response box. For this reason, participants can enter any value or information. In the present study, previous education and information of stakeholders proved to be an important issue to decrease error but further developments should address this issue.

The reliability and security of data should also be the subject of serious analysis. The possibility of prior registration by the user should be considered, allowing the collection of socio-demographic and clinical data. Further developments should also allow the increase of the font size.

Regarding the operating system, no patients had devices with the iOS operating system. This is in accordance with Portuguese data, which states that in 2013 the favorite operative systems among Portuguese population was Android (75.00%), followed by iOS (17.30%) and Windows phone (3.20%) (Deco Proteste, 2013). Similar results have been found in global statistics, with the Android operating system clearly leading the telecommunications market between 2015 and 2016 (Statista, 2016). These data are important for further developments.

The feasibility study allows us to explore the stakeholder's profile and difficulties in sample recruitment. Firstly, it was not easy to recruit patients, mainly due to the late referral of patients to PC teams. Thus, most are not able to answer for themselves, and among the eligible participants, the majority are physically weakened, which is the reason why the app needs to be simple and easy to use. Gatekeeping which is defined as "*preventing access to potential research subjects by clinical staff*" was also a barrier (Stone *et al.*, 2013: 318). This problem - along with the high prevalence of cognitive problems, the unstable nature of the disease, and the quick deterioration in clinical condition - have been highlighted as important barriers in other studies developed with PC patients (White and Hardy, 2008; Stone *et al.*, 2013).

If seven patients were recruited in 3 months, 49 months (4 years) might be needed to recruit all 115 patients estimated in the sample recruitment power calculation. Another

more consistent hypothesis is the inclusion of more settings/ institutions for data collection and the extension of the research team.

CONCLUSIONS

This paper introduces a prototype of a web-based app to monitor comfort remotely in palliative home care patients in Portugal. This is a free and experimental app, designed through a customized domain. It allows health care teams to remotely monitor holistic comfort in PC patients at home. Thus, it can provide better knowledge of the patient profile and the course of diseases. Consecutively, this can bring about dynamic interaction between patient and PC teams, and improve preventive and individualized interventions.

Data highlight the app is feasible and easily accepted. Further developments are needed, particularly regarding technical issues, in order to design a more robust and safer application.

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The study includes some author's references, which were excluded for the blind review. These references appear in the text with the designation "author's reference". If necessary, and the paper accepted for publication, these references will be provided in the next stages.

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Specific references of the scientific papers within this chapter are provided at the end of the paper. The references are in accordance with the journal guidelines.

CHAPTER 3: INTEGRATED OVERVIEW OF THE PERFORMED STUDIES

This chapter introduces an integrated overview of the performed studies. The first topic addresses a general discussion. The second one includes the limitations and strengths of the study. At least, the third and last topic comprises implications for clinical practice and directions for further research.

3.1. Discussion

This study started with two preliminary research questions: i) *What is the meaning of comfort?* ii) *What are the parameters being taken into consideration by the health professional to state that a patient is comfortable or not?*

Preliminary questions lead us, in a first phase, to clarify the concept of comfort and to identify its main attributes. Despite the extensive study performed by Kolcaba (2003) and other researchers, such as Morse (2000), Siefert (2002), or Tutton & Seers (2003), the concept remains unclear, namely in nursing practice (Lin, 2010). Since the publication of Kolcaba's Comfort Theory (2003), several empirical studies have emerged which gradually brought forth new evidence.

Some gaps were identified in the classifications and taxonomies of nursing knowledge. When looking to the ICNP® (ICN, 2015), it is possible to observe that the definition of the concept, "*sensation of physical ease and bodily well-being*" (ICN, 2015: code 10004655), presents several inconsistencies, taking into account the current knowledge and Kolcaba's framework (2003). Firstly, and regarding the other contexts in which the concept can occur, this definition excludes the psychological, spiritual, and social dimensions, as well the environmental context (Kolcaba, 2003). Secondly, and regarding the types of comfort proposed by the author (Kolcaba, 2003), the definition neglects the need for relief and transcendence. At least, the concept of comfort is defined through the use of the concept of well-being, often understood as synonymous.

Nevertheless, and as stated before (Pinto, Caldeira & Martins, 2016a), although the first edition of ICNP® (alpha version) was published in 1995, the concepts of comfort (focus) and comforting (action) were only introduced four years later, in 1999 (beta version). Until the moment no further changes were introduced, which is why the definitions used in the last version (2011) have not changed since 1999.

Beyond these inconsistencies, other gaps were found on the taxonomy II of NANDA-I (Herdman & Kamitsuru, 2014). Although the nursing diagnosis 'impaired comfort' (00214) proposed by the taxonomy II of NANDA-I (Herdman & Kamitsuru, 2014) is based on Kolcaba's theory, the psychospiritual comfort is listed in domain 9 ('coping') and spiritual comfort in domain 10 ('life principles'). Nevertheless, the new taxonomy (III) recently proposed by NANDA-I (Herdman & Kamitsuru, 2014) introduced a new domain entitled

'existential', which made the discussion even more complex. Given the holistic and multidimensional nature of the concept of comfort, what are the specific nursing interventions that a nurse needs to implement in a patient with impaired comfort?

The Kolcaba's Comfort Theory (2003), as well the concept analysis study and the literature review toward the characterization of comfort carried out in this research (Pinto, Caldeira & Martins, 2016a), lead us to reinforce the idea of comfort as a human response involving several diagnoses, for which nurses can have different, similar and simultaneous interventions (Pinto, Caldeira & Martins, 2016b). For this reason, in the article "*Is impaired comfort a nursing diagnosis?*" (Pinto, Caldeira & Martins, 2016b) the classification of the 'impaired comfort' diagnosis (00214) as a syndrome diagnosis was suggested. A syndrome diagnosis is a clinical judgment that embraces a specific cluster of nursing diagnosis that can occur at the same time (Herdman & Kamitsuru, 2014). These considerations have important implications for nursing practice, but also for the intervention design. This new reorganization can improve clinical reasoning and decision making in the nursing process. Thus, comfort interventions should address the holistic, dynamic and individual nature of the concept. On the other hand, nurses could be addressing just the defining characteristics (signs and symptoms) and reducing the scope of nursing care to symptom management, overvaluing the holistic component that characterizes the profession and the process of comfort.

Regarding these considerations, it is thought that one of the hallmarks of this study is this contribution to clarification and improvement of the theory-practice. The literature review toward the characterization of the concept of comfort (Pinto, Caldeira & Martins, 2016a) and the concept analysis study (Pinto *et al.*, 2017) performed in the first stage of the study allowed for the construction of the empirical evidence, particularly since Kolcaba's framework (2003) was published. It also led to searching for new evidence that could help propose redefining the concept of comfort in the ICNP[®] and an update of the 'impaired comfort' diagnosis (00214), proposed by NANDA-I (Herdman & Kamitsuru, 2014).

Theory is an important basis for nursing foundation, enhancing nurses to have a better understanding of the reality (McEwen & Wills, 2011). It allows nurses to focus on important information, and provides assistance to organize and analyse data, as well as to predict outcomes. For instance, theory drives an important way to address nursing practice more systematically and, therefore, in a more efficient and effective way (McEwen & Wills, 2011). On the other hand, theory is a dynamic process that requires a continuous and critical appraisal. For this reason, if it is true that theory enhance practice, it is equally true that nurses should question their practice, synthesize empirical evidence and search for better alternatives (McEwen & Wills, 2011).

For our knowledge, the theory-practice gap founded in the ICNP® (ICN, 2015) and NANDA-I (Herdman & Kamitsuru, 2014) is an important issue that must be clarified, not only due to their international scope, but also because it provides an important system to classify and organize concepts, that improve communication among peers, and guides nursing practice in many countries, settings and populations (Carvalho, Cruz & Herdman, 2013). Concepts need to be less ambiguous as possible, in order to be applied in a large range of contexts (Toftthagen & Fagerstrøm, 2010).

The second preliminary question, “*What are the parameters being taken into consideration by the health professional to state that a patient is comfortable or not?*” drives us to other three important issues: attributes of the concept (or defining characteristics), outcomes and measurement.

The concept analysis study (Pinto *et al.*, 2017) outlined that comfort is a complex, individual, subjective, dynamic, pleasant and holistic experience that is dependent on the individual's perceptions. These attributes, although being important characteristics of the concept are not exclusive to it. Other specific attributes were outlined, namely the satisfaction of needs, a desired state of satisfaction and happiness, or to feel safe, strength and supported. These attributes also embrace the topics or parameters in which health care providers should focus on to assess and enhance patient comfort.

In order to clarify the differences and similarities among the concepts of comfort, well-being, and quality of life a literature review of concept analysis studies was conducted. While quality of life represents a broader concept, related with the satisfaction with life in general way, comfort is a more specific concept, widely used within nursing. Lastly, well-being is as a surrogate term that seems to attempt addressing psychological or spiritual issues, and the quality of life a related concept (Pinto *et al.*, 2016a).

These studies have also reinforced the complex nature of the concept. In this stage, Kolcaba's framework (2003) was an important help. In her Comfort Theory (Kolcaba, 2003), the author argues that nurses are responsible to identify patient's needs, and these needs, when satisfied, enhance patient comfort. Nevertheless, comfort is a desired outcome related with the satisfaction of patient's needs (Kolcaba, 2001; Kolcaba, 2003). In a simple and easy way, comfort can be assessed asking the patient if it is comfortable or not, for example through the use of verbal rating scales (Pinto *et al.*, 2016b). However, when regarding the improvement of nursing practice, and the efficiency and effectiveness of nursing interventions, more accurate tools are needed (Ibrahim & Sidani, 2015). Although several instruments have been identified to measure comfort in different contexts and populations (Pinto, Caldeira & Martins, 2016a; Pinto *et al.*, 2016b), only one was found to measure holistic comfort in PC patients, in Portugal: Escala de Conforto Holístico HCQ

- PT-DC[®] (Querido, 2013). However, this instrument has some inconsistencies in items #13 (“*I made the right choice in choosing this place*”), and #8 (“*My pain is difficult to endure*”). Firstly, regarding item #13, a vast majority of PC patients don’t have the possibility to choose the place where they are treated (Gomes *et al.*, 2013). Regarding the item #8, and as clarified with Professor Kolcaba, author of the original instrument (Novak *et al.*, 2001), it embraces the concept of total pain. Nevertheless, this item needs to be clarified, because it can be understood and restricted to physical pain.

These considerations drove us to adapt and validate another instrument widely used to measure comfort in PC patients: the End of Life Comfort Planning Questionnaire (Novak *et al.*, 2011). However, this instrument is not also free of limitations. Although the initial components analysis of the 28 original items resulted in a Cronbach’s alpha of 0.727, some of the items had a negative correlation with the global score, while others were not consistent with each other. The Portuguese version comprises 20 items ($\alpha=0.835$), but physical symptoms are not assessed on this instrument. The instrument addresses a new approach to measure spiritual comfort, and should be used in combination with a symptom management instrument. For this reason, the Portuguese version was designated as “Portuguese End of Life Spiritual Comfort Questionnaire” (Pinto *et al.*, 2016b).

Lastly, in regard to the fourth objective, this study aims to design a feasible intervention to monitor comfort in Portuguese PC patients.

As described before, the lack of specialized resources, the geographical inequity to access specialized PC services and the difficulties to perform an optimal patient assessment in PC patients at home, make e-health an important resource for modern societies (McCall *et al.*, 2008; Cooley *et al.*, 2015; Hochstenbach *et al.*, 2016). Nevertheless, scientific evidence has been highlighting discrepancies between the preferred place to die and the place where death occurs (Gomes *et al.*, 2013). These findings are particularly relevant in an overcrowded health system, not only due to the lack of resources and geographical differences, but also due to the ageing population and the increasing number of chronic conditions (Budysh, Karle & Helms, 2014; Cooley *et al.*, 2015; Hochstenbach *et al.*, 2016). Palliative care has been affected by these demographic, social, and scientific transitions. Palliative care patients are embracing a large range of diseases beyond cancer, facing multiple comorbidities (Gómez-Batiste *et al.*, 2013). Results from the qualitative study carried out in the course of this research (Pinto, Caldeira & Martins, 2016c) highlight hospitals as being paradox places. On the one hand, it offers safety and confidence not only because symptom management seems to be more effective, but also due to the proximity of healthcare professionals. On the other hand, home is the preferred place to be, in which patients found other types of comfort easily, namely relief and transcendence.

This result and the environmental factors highlighted in this study, as well as in the concept analysis of the concept of the comfort, are particularly important for institutions, as a quality indicator. For instance, and according to a normative framework of the Portuguese general health department (Direcção Geral da Saúde, 2013), comfort in hospital settings should be addressed in the physical, emotional and environmental dimensions. Although the normative statement excludes the spiritual and social human life dimensions, it highlights the importance of environmental factors, namely in terms of colours (eg. walls and clothes of health professionals), temperature, and noise.

Regarding the association between comfort and colours, it is interesting to observe that in the survey to choose the colours for the application layout, blue and white were the main favourite colours. As described by Heller (2014) in her book about the psychology of colours, blue is a colour related to harmony, happiness, and affection. Although it is a cold colour, it represents the divine, the intellect and it is associated with respect and confidence. Conversely, white represents peace, innocence, purity, perfection, resurrection, and cleanness.

The intervention design emerged as a combination of several factors outlined in scientific evidence, namely: assessing the patient's needs (Kolcaba 2001; Kolcaba, 2003; Rome *et al.*, 2011), dealing with the inequity to specialized PC services (Aoki *et al.*, 2006; Bradford *et al.*, 2010; Watanabe *et al.*, 2013; Comissão Nacional de Cuidados Paliativos, 2016), ensuring that patients can be at home (Gomes *et al.*, 2013), ensuring an optimal and continuous comfort assessment (Kolcaba, 2001; Kolcaba, 2003; Rome *et al.*, 2011), and ensuring the planning and implementation of personalized comfort interventions (Kolcaba, 2003).

These factors lead us to design an application to monitor comfort remotely in PC patients. The intervention design was a lengthy, extensive and dynamic process, supported for the evidence-based findings. For this reason, this study is introducing the prototype design, which has several limitations, discussed in the following topics. Perhaps, one of the principal questions that arise is the usability of this application in PC, taking into account the ageing population in Portugal, and the inability to use electronic and informatics devices. However, we believe this can be a very useful tool in the future, for several reasons:

- Firstly, and in advance, we are aware of the *Comfort app* limitations. This study was fundamental to design a prototype design, but further research is needed.
- Findings from this preliminary feasibility study revealed that the application is feasible, user-friendly and approved by patients.

- Scientific-evidence has outlined new trends in the use of health information technologies. e-Health seems to be the future, not only due to the advances in informatics, but also as a way to deal with the overcrowding of health care systems (Furukawa & Poon, 2011; Levine, Lipsitz & Lindor, 2016).
- International studies have also outlined new trends in the use of electronic devices in the senior population. According to a survey developed in the United States of America and published in JAMA, the senior population (age over 65 years old) uses digital health at low rates, but with “*modest increases from 2011 through 2014*” (Levine, Lipsitz & Lindor, 2016, p. 539). The same report highlights that 90% of the general population is already using digital health to contact a clinician, obtain prescriptions or address insurance issues, and among these, 60% are doing it through mobile phones. These findings also outline that the use of electronic devices with health purposes by senior population is still moderate, but is increasing. Nevertheless, the general population, which is the future of health care systems, is using these devices largely and systematically.
- In the Portuguese context, e-health has also been pointed out as an important strategy to improve “*access to health care; providing information to enhance the quality and safety of care; contributing to the efficiency of the system; increasing knowledge on population health*” (SPMS & Ministério da Saúde, 2015, p. 2). According to the “eHealth in Portugal: Vision 2020” the maturity of e-Health can be classified in three stages. The first stage comprises a reduced and limited use of e-Health technologies. The second stage is characterized by an increasing use, although still reduced and limited. Lastly, the third stage involves a consolidated use, and in expansion. According to this report, Portugal is in the second stage, but very close to entering the third stage (SPMS & Ministério da Saúde, 2015).
- Moreover, according to the National Authority for Communications in Portugal (Autoridade Nacional de Comunicações de Portugal [ANACOM] 2015), in the fourth trimester of 2014, 94.40% of the resident population in Portugal, aged over 10 years, had a mobile telecommunication service, and some of those had more than a mobile card. Among the total number of users, 78% represented active mobile stations, with effective uses in the last trimester (ANACOM, 2015). In the second trimester of 2015, the penetration rate of the mobile service with actual use was 123.10 per 100 inhabitants, which supports the high utilization of mobile services among the resident population in Portugal (ANACOM, 2015). However, according to the Marktest Telecommunications Barometer, cited by the same source, there has been a continuous growth in the use of smartphones. Approximately 5 million of the population

residing in Portugal, which is the equivalent to about 48% of the resident population, use a smartphone (ANACOM, 2015).

- Finally, nursing research needs to develop the nursing knowledge and answer nursing problems in a proactive way (McEwen & Wills, 2011; Meleis, 2012).

Despite these considerations, and as highlighted in the previous chapters, some difficulties were found in the recruitment of PC patients. Sample recruitments are not an easy process in clinical studies, particularly in PC settings (Gómez-Batiste *et al.*, 2013; Stone *et al.*, 2013; Visser, Hadley & Wee, 2015; Kars *et al.*, 2016). Several reasons have been pointed out worldwide, and Portugal is not indifferent to these problems. Among the principal reasons, the literature highlights the rapid disease progression, the high number of co-morbidities and symptom burden, the poor prognosis of patients, the late referral to PC and the patient protection from clinical staff and families, also called “*gatekeeping*” (Gómez-Batiste *et al.*, 2013; Stone *et al.*, 2013; Kars *et al.*, 2016). Thus, PC embraces a large group of patients, with several and different life threatening diseases (Visser, Hadley & Wee, 2015).

For this reason, the typical randomized clinical trials (RCTs), designed as the gold standard of study designs, is not always applicable. Despite RCTs are considered the best method to assess the effectiveness of an intervention, very few have been addressed in PC. Due to the particular clinical conditions of PC patients, it is not easy to recruit adequate sample sizes. Thus, due to the rapid course of disease, follow up-periods (a core attribute of high quality RCTs) are frequently limited. The future of evidence-based practice in PC settings should comprise several methodological and quality, validity and size conducted approaches in order to achieve patients’ needs. For instance, mixed designs, non-RCTs and collaborative and well-organized research have been pointed out as important strategies to deal with difficulties in PC settings (Visser, Hadley & Wee, 2015).

Lastly, regarding the defined objectives, and hypothesis formulated, this study contributed not only to the clarification of the concept, identification of its attributes and adaptation of a valid and reliable instrument, as well to the design of a feasible intervention to monitor comfort in PC patients. Although still in a very early stage, this study opens new perspectives to the assessment of patient needs and implementation of more efficient and effective nursing interventions.

3.2. Limitations and strengths of the study

Studies are not exempt from limitations and this is no exception.

The first limitation is related to this option to present the thesis as a set of scientific papers submitted or published in scientific and peer-review journals. The core competencies of a researcher embraces several abilities and qualities, such as to demonstrate, apply and develop theoretical knowledge, to formulate solutions for practical problems, to select and apply different research methodologies, to work in collaboration with other researchers, and to develop leadership and communication, among others (Forrest *et al.*, 2009).

This option is, perhaps, one of the strongest points, which allow us to enhance our ability to express, share and disseminate our knowledge in English, “the language of science”. However, journal space is limited and, frequently, it is not possible to place a lot of information in the article (Polit & Beck, 2014). Therefore, it was decided to publish the work in different reviews, according to the scope of each study. Nevertheless, reviews have different audiences, different scopes and, sometimes, there is a need to repeat information, namely in the background section. This strategy is important to introduce the context of the study, but is a limitation for the final reader of this thesis, who will find repeated information in different papers.

On the other hand, this strategy allows us to establish partnerships with other researchers, as well as important theorists of contemporary nursing. Papers were published in international reviews, some of which with an impact factor, meaning that the studies were subjected to criticisms and scrutiny by international reviewers. This experience enhanced the quality of the studies and the development of our critical thinking. Submitting the papers to the peer-review process was, definitely, an important learning experience.

Another limitation, which is also a strength, is related to the study design. The research was based on a strong and robust methodology, which means results are modest but consistent. However, and although already predicted by the MRC framework (Craig *et al.*, 2008; Craig *et al.*, 2013), the process was lengthy. For this reason, and taking into account the several steps to carry out, as well the formal constraints related with authorizations institutions and ethics committees, it was not possible to carry out the evaluation phase. Regarding the specific design of the *Comfort app* prototype, it was not possible to address the perspective of other stakeholders, namely nurses and relatives. Although the study

focused on the perspective of several experts (some of them nursing practitioners), and also of patients, further research is needed in this field.

Moreover, and for several reasons, this prototype was developed through a free and customized web-based platform. This strategy allowed to study the feasibility of the intervention and its acceptability by patients, which is a strength. However, the app presents several limitations such as the standardized font size or assess through an email or QR code. Further stages should embrace a more robust design, and partnerships with other professionals, from other disciplines, need to be established.

Although the problem is relevant for nursing knowledge, PC, clinical practice, patients, families and health care teams, the study is only in the beginning.

Although much further research is needed, the *Comfort app* provides PC patients the possibility to stay at home, while specialized teams can monitor their comfort remotely. The app does not attempt to substitute face-to-face contact, but to provide an additional and supportive measure to enhance the patient comfort. Indeed, this represents an opportunity, since to our knowledge there are no similar technologies in Portugal, and very few worldwide.

3.3. Implications for clinical practice and directions for further research

Comfort is a core concept not only within nursing and PC, but also related to the overall population in a general way. The clarification of the concept and the development of a complex nursing intervention is a relevant problem for several reasons. Firstly, nursing studies are predominantly exploratory and descriptive (Richards & Borglin, 2011), and other research designs are required in order to achieve more efficient and effective nursing interventions.

Nevertheless, without detracting from Kolcaba's Comfort Theory (2003), the concept remained unclear in many aspects, namely in the identification of its specific attributes, in the comfort definition proposed by the ICNP[®] (ICN, 2015), and in the classification proposed by NANDA-I (Herdman & Kamitsuru, 2014) for the 'impaired comfort' diagnosis (00214). The work developed in the preliminary stages of this research add a contribution to nursing knowledge at the theoretical level, namely in the identification of its specific attributes, as well as in the introduction of an updated definition and the consideration of the 'impaired comfort' diagnosis (00214) as a syndrome diagnosis. We are now able to propose a new definition to the International Council of Nurses. Thus, the consideration of the 'impaired comfort' (00214) as a syndrome diagnosis was already submitted to NANDA-I (Appendix 15) and is, presently, under review.

We believe that this study can improve clinical practice, and help decrease the gap between theory and practice. Research was conducted through a systematic and consistent methodology, which improves the validity of the findings. Nevertheless, with the clarification and improvement of previous knowledge, this study opens new perspectives, involving new strategies to assess the comfort needs of the patient. The introduction of an e-health technology to assess the patient's needs and implement more personalized interventions, enhanced nursing knowledge to a new level that was more proactive, visionary, and geared not only to current needs but also to future trends.

In summary, the study is relevant to the nursing discipline, science and profession.

Taking these considerations into account, further research should embrace new partnerships with engineers specialized in informatics and in information and

communication technologies. The next stages should focus on the development of a robust design, in which questions related with data protection and data visualization by the healthcare teams should be seriously addressed. Besides these considerations, further research should focus on the perspective and acceptability by other potential stakeholders, namely nurses, physicians and relatives or informal caregivers. Finally, and if possible, the intervention should be tested through an RCT. However, it requires larger samples, which will necessary require protocols with several institutions and PC teams. Nevertheless, the only way to assess the efficiency and effectiveness of the intervention is through a robust and large study. For this, and as proposed in literature, it is necessary to implement a collaborative model, perhaps with financing. This strategy, however, requires a better identification and control of bias, and the training of other researchers.

In summary, the study is at an early stage, but has potential to be developed, and to enhance comfort care to many patients in the future.

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- Watanabe, S., Fairchild, A., Pituskin, E., Borgersen, P., Hanson, J. & Fassbender, K. (2013). Improving access to specialist multidisciplinary palliative care consultation for rural cancer patients by videoconferencing: Report of a pilot project. *Supportive Care in Cancer*, 21(4), 1201-1207. doi: 10.1007/s00520-012-1649-7.

CONCLUSION

What is already known about the topic?

- Comfort is a core concept in clinical practice, particularly in PC;
- It is a holistic experience resulting from the satisfaction of patient needs in three different levels (relief, ease and transcendence) and four contexts: physical, psycho-spiritual, sociocultural and environmental;
- Despite this, the concept remains unclear, difficult to define, implement and evaluate;
- More feasible, efficient and effective nursing interventions are needed to enhance patient comfort;
- e-Health is an important and emergent resource in health contexts.

What does this study add?

- This study clarifies the meaning of the concept and provides an updated definition;
- Specific attributes were explored and similarities and differences among the concepts of well-being and quality of life were discussed;
- The impaired comfort diagnosis emerges as a syndrome diagnosis and this suggestion was made to NANDA International;
- Comforting is a complex intervention, which involves a multiplicity of components, actors and activities in different contexts and situations;
- The study introduces the prototype of a web-based intervention to monitor comfort remotely in palliative care patients;
- Preliminary results suggest that the intervention is feasible.

Implications for practice, theory or policy.

- The study provides an important contribution to the operationalization and measurement of the concept;
- The results contribute to both theoretical knowledge and also clinical practice;
- The data highlight the importance of health policies for patient comfort;
- Further research is needed to study the cost-effectiveness of the intervention.

Comfort is a core concept within nursing science and PC, relevant to patients, families, health care professionals and the overall population, in a general way.

Nevertheless, from its theoretical evolution, the concept remained unclear, difficult to define and evaluate. Several inconsistencies were identified in the literature, as well as in classifications and taxonomies of nursing practice. Thus, in clinical practice, comfort is still focused on physical factors, such as hygiene care, positioning or pain relief, and considered a minor objective, when compared to other nursing interventions.

This study, which focused on the development and evaluation of a comfort complex nursing intervention, followed the MRC framework for the study of complex interventions. The study was carried out in several phases and stages, in which different objectives were defined and attempted.

In summary, this study presents a literature review about the state of the art in PC, in Portugal; a literature review toward the characterization of comfort in literature; a concept analysis study of the concept of the comfort and a literature review about the similarities and differences among the concepts of comfort, well-being and quality of life. The impaired comfort diagnosis proposed by NANDA-I was discussed and proposed as a syndrome diagnosis. The results were supported by a qualitative study about the perspectives of PC patients. Moreover, the adaptation and validation of the Portuguese End of Life Comfort Questionnaire was carried out for the Portuguese population in PC, and a prototype design of a web-based intervention to monitor comfort remotely was introduced.

Findings highlight that:

- Comfort is a complex, dynamic, holistic, subjective and positive experience, related to the satisfaction of individual needs, and that may be achieved in one or more dimensions (physical, spiritual, psychological, social, environmental). It may be preceded by any life transition or challenge, and result in physical relief and/or transcendence.
- Antecedents include inward (disease/ unbalance; previous knowledge/ empowerment; patient–health professional relationship; previous experiences) and outward factors (family support; health professionals' personal and professional skills; institution's caring model; environmental factors).
- Comforting interventions can have several consequences for patients (discomfort relief; client's satisfaction towards the given cares; increased health-professional/ patient interaction; decrease in anxiety, feelings of guilt and concern; increased self-esteem and ability for transcendence; increased security/ anticipation of patient needs; self-control; increased tolerance to procedures and equipments; increased tolerance towards health care providers (as there is better tolerance towards human suffering, peace and inner strength).
- Several attributes were identified, and similarities and differences among related concepts were discussed. The sense of feeling strength, safe, and supported, and the satisfaction of needs are exclusive attributes of the concept. Comfort is also described as something positive or good, and as a desired state of satisfaction and happiness.
- Comfort seems to be a human response integrating several diagnoses, for which nurses can implement different but, also, similar and simultaneous interventions, specific to the etiological factor. For this reason, the impaired comfort diagnosis is proposed as a syndrome diagnosis.

- The literature highlights the importance of e-health technologies as a way to improve quality care. The literature review toward the use of e-health technologies and the existence of mobile applications in *Google Play* and *App Store*, carried out within the scope of this study, identified a gap in this field, as well as an opportunity to develop an instrument to monitor comfort remotely.
- The prototype of a web-based app to monitor comfort remotely in PC patients was designed, through a free and customized platform. The app is compatible with Android, iOS and Windows, and evaluates 11 symptoms (pain, tiredness, drowsiness, nausea, lack of appetite, shortness of breath, depression, anxiety, fear of the future, peace and the will to live) assessed on a Likert scale. The instrument is intended to be completed by PC patients at home, through a smartphone, tablet or computer, with Internet access.
- The feasibility study highlights that the app is feasible, user-friendly and accepted by patients.

The defined objectives, research questions and the hypothesis were answered. However, further research is needed to create a more efficient and effective design. The app promises to be a useful resource to monitor comfort as a compliment to the work of PC teams in terms of improving communication, organization of care, and promoting early and individual comfort interventions. This study shows new perspectives and creates an opportunity for further discussion about the use of e-health technologies in PC.

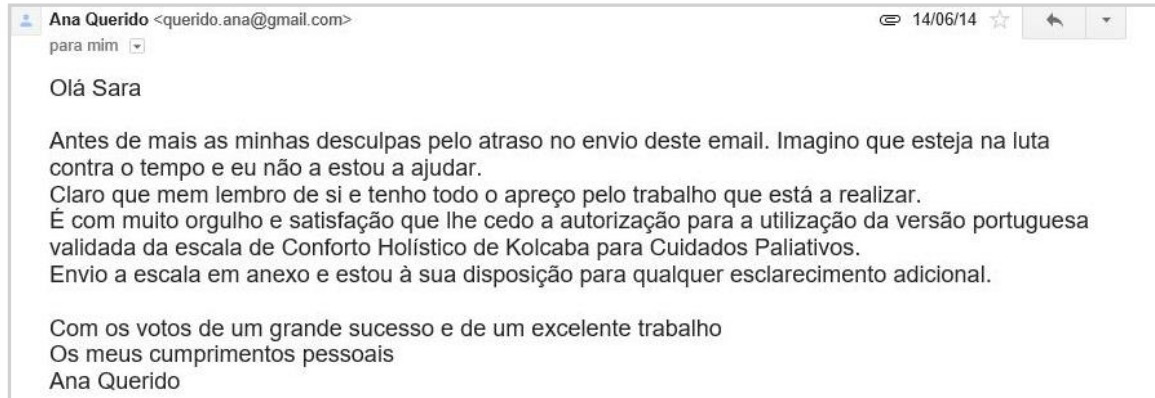
The study also has the potential to influence policy, as well as nursing practice, research, and education. The difficulties in the operationalization, implementation and assessment of the concept are mostly related to a lack of conceptual understanding. These difficulties justify the need to clearly introduce the concept of comfort in the education of both nurses and other health carers. Moreover, this study contributes to a better definition and operationalization of comfort, particularly to standardized nursing languages, and ultimately to the implementation of more effective and efficient interventions.

Based on the definition provided, conceptual clarity provides a solid foundation for health organizations to consider comfort as an outcome of care. The introduction of an e-health technology can help institutions to optimize human resources, to deal with the inequities in the access to specialized services, and to decrease costs. At the same time, it can be an important resource to link health care providers, patients and families, to improve an optimal needs assessment, and to enhance patient comfort.

APPENDICES

Appendix 1

Permission to use the Escala de Conforto Holístico HCQ - PT-DC®



Appendix 2

Permission to use the *End of Life Comfort Questionnaire*

End of Life Comfort Questionnaire-Patient - Request to Cultural Adaptation to Portugal

Caixa de entrada x

Sara Pinto <sara.o.pinto@gmail.com> 01/12/13 ☆ ↶ ▾
para kathykolcaba ▾

Dear Dr. Katherine Kolcaba,

My name is Sara Pinto.
I'm portuguese, nurse, master in palliative care and PhD student in Nursing Sciences at the Abel Salazar Biomedical Sciences Institute-
Oporto University, Portugal.

First of all let me congratulate you on your work, which I so appreciate!

Actually, in my PhD research, I'm studying about comfort of cancer patients in palliative care.
However, in Portugal, there are not any instrument to measure comfort in end of life. I believe that instruments are important for the
evaluation and implementation of comfort care, particularly in palliative care, where comfort is a central objective.
In this context, I would like to request your permission to do the translation and cultural adaptation of the "End of Life Comfort Questionnaire -
Patient" to the portuguese population in palliative care.

If you agree, I would also ask for your cooperation in this cross-cultural validation process, particularly in the back-translation process and
evaluation of the final instrument.

Thank you all for your attention.
With the highest consideration,
Yours Sincerely,

Kathy Kolcaba <kathykolcaba@yahoo.com> 02/12/13 ☆ ↶ ▾
para JOAO, mim ▾

inglês ▾ > português ▾ Traduzir mensagem Desactivar para mensagens em: inglês x

Hello Sara and Dr. Apostolo, Sara I am sending this e-mail to my colleague who lives in Coimbra, Portugal. We have worked together on
several projects and he is willing to help nurses in your country with translations of comfort instruments into Portuguese. You have my
permission to do so, and I would appreciate your letting me put it on my web site when you have completed your study. Thank you very
much for your interest in patient comfort.
Sincerely, Dr. K

Dr. Kathy Kolcaba
Associate Professor (Emeritus)
The University of Akron
Adjunct Faculty, Ursuline College
www.TheComfortLine.com

Kathy Kolcaba
Adic. a circs.
Mostrar detalhes

Appendix 3

Ethics committee authorization (CHSJ, CES 191-14 20 Nov 2014)

CES 191-14
No CA 11 por formal de
10
17.11

AUTORIZADO

CONSELHO DE ADMINISTRAÇÃO DO CENTRO HOSPITALAR DE S. JOÃO 20 NOV 2014

Presidente do Conselho de Administração do Centro Hospitalar de S. João – EPE

Assunto: Pedido de autorização para realização de estudo/projeto de investigação

Nome do Investigador Principal: Sara Maria Oliveira Pinto

Título do projeto de investigação: 'Confortar em Cuidados Palliativos: Desenvolvimento e Avaliação de uma Intervenção Complexa em Enfermagem- Fase I'

Pretendendo realizar no(s) Serviço(s) de Medicina [A e B, Homens e Mulheres), Pneumologia, Cirurgia Geral, Cirurgia Vascular, Neurocirurgia e Otorrinolaringologia do Centro Hospitalar de S. João – EPE o estudo/projeto de investigação em epígrafe, solicito a V. Exa., na qualidade de Investigador/Promotor, autorização para a sua efetivação. Para o efeito, anexa toda a documentação referida no dossier da Comissão de Ética do Centro Hospitalar de S. João respeitante a estudos/projetos de investigação, à qual endereçou pedido de apreciação e parecer.

Com os melhores cumprimentos.

Porto, 01 / Setembro / 2014

O INVESTIGADOR/PROMOTOR

Sara Maria Oliveira Pinto

CES
COMISSÃO DE ÉTICA PARA A SAÚDE

PARECER DA COMISSÃO DE ÉTICA PARA A SAÚDE DO CENTRO HOSPITALAR DE S. JOÃO

emitido na reunião plenária da CES
de 16 Setembro, 2014

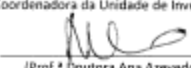
A Comissão de Ética para a Saúde
APROVA por unanimidade o parecer do
Relator, pelo que nada tem a opor à
realização deste projeto de investigação.


Presidente da Comissão de Ética

Appendix 4

Ethics committee authorization (CHSJ, CES 174-16 29 Ago 2016)


AUTORIZADO 174-16

Unidade de Investigação
Tomei conhecimento. Nada a opor.
29 de Agosto de 2016
A Coordenadora da Unidade de Investigação

(Prof.ª Doutora Ana Azevedo)

DIRECÇÃO CLÍNICA
Aprovado. Ao CA 30/8/2016

(Prof.ª Doutora Ana Azevedo)

CONFÉRENCIA DE AVALIAÇÃO E APROVAÇÃO DE PROPOSTAS DE INVESTIGAÇÃO
Pedido do Conselho de Administração 1 SET 2016

<input type="checkbox"/> Dr. António José Gomes	<input type="checkbox"/> Dr. António José Gomes	<input type="checkbox"/> Dr. António José Gomes	<input type="checkbox"/> Dr. António José Gomes
<input type="checkbox"/> Dr. António José Gomes	<input type="checkbox"/> Dr. António José Gomes	<input type="checkbox"/> Dr. António José Gomes	<input type="checkbox"/> Dr. António José Gomes

Exmo. Senhor 
Presidente do Conselho de Administração do
Centro Hospitalar de S. João - EPE

Assunto: Pedido de autorização para realização de estudo/projecto de investigação

Nome do Investigador Principal: Sara Maria Oliveira Pinto

Título do projecto de investigação: Desenvolvimento e avaliação da intervenção complexa confortar: Estudo de Fase I-II (Feasibility e Estudo Piloto) para avaliação de uma tecnologia de informação para monitorização e avaliação do conforto do doente em contexto domiciliário.

Pretendendo realizar no(s) Serviço(s) de Neurocirurgia o estudo/projecto de investigação em epígrafe, solicito a V. Exa., na qualidade de Investigador/Promotor, autorização para a sua efectivação.

Para o efeito, anexa toda a documentação referida no dossier da Comissão de Ética do Centro Hospitalar de S. João respeitante a estudos/projectos de investigação, à qual endereçou pedido de apreciação e parecer.


Com os melhores cumprimentos.

Porto, 06 / Junho / 2016

PARECER DA COMISSÃO DE ÉTICA PARA A SAÚDE DO CENTRO HOSPITALAR DE S. JOÃO/FACULDADE DE MEDICINA DA UNIVERSIDADE DO PORTO

emitido na reunião plenária da CES de 17 de Junho de 2016

A Comissão de Ética para a Saúde APROVA por unanimidade o parecer do Relator, pelo que nada tem a opor à realização deste projecto de investigação.


Prof. Doutor Miguel Ângelo
Presidente da Comissão de Ética

Appendix 5

Ethics committee authorization (Hospital Arcebispo João Crisóstomo, Cantanhede)

Pedido de autorização para realização de estudo-projeto de investigação

Caixa de entrada x

Administração (FF) - Hospital do Arcebispo João Crisóstomo <administracao@hdcantanhede.min-sau> 23/06/16 ☆



para mim

Exmª Senhora
Drª Sara Maria Oliveira Pinto

Encarrega-me a Senhora Presidente da Comissão de Ética para a Saúde de informar V. Exª, que foi aprovado a realização do estudo/projeto de investigação no âmbito de doutoramento em Ciências de Enfermagem do ICBAS da Universidade do Porto, nos Serviços de Cuidados Paliativos e Equipa Comunitária de Suporte em Cuidados Paliativos, subordinado ao tema – "Desenvolvimento e avaliação da intervenção complexa confortar: estudo de Fase I-II para avaliação de tecnologia de informação para monitorização e avaliação do conforto do doente em contexto domiciliário".

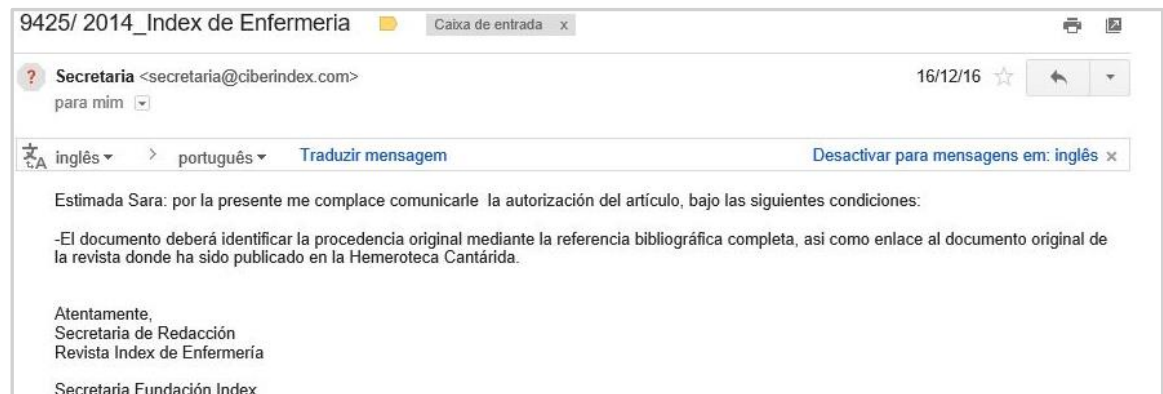
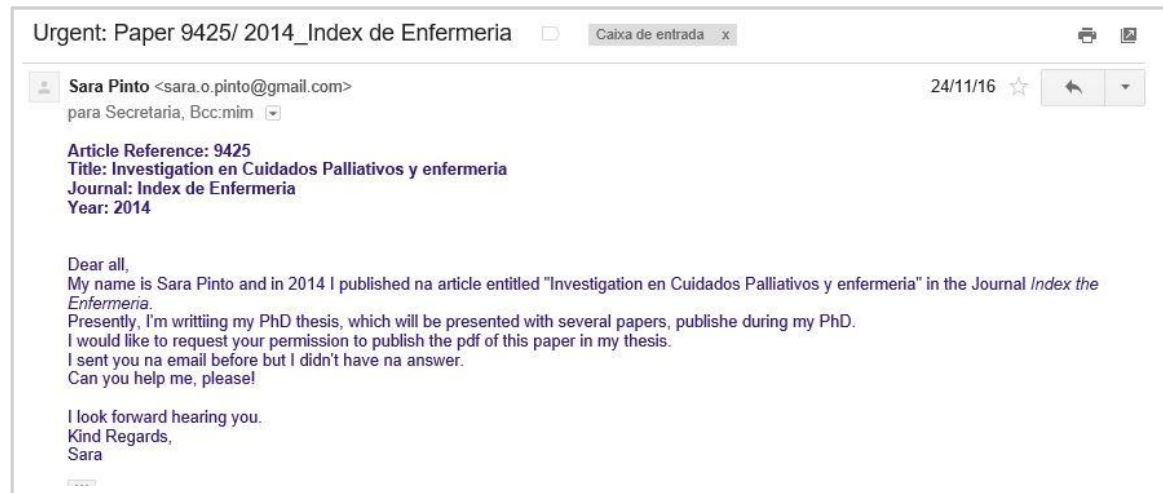
Com os melhores cumprimentos,

Fernanda Faria
Secretariado do Conselho de Administração

  **SNS** SERVIÇO NACIONAL DE SAÚDE

Appendix 6

Permission to reproduce the paper *Investigación en cuidados paliativos y enfermería: Revisión sistemática sobre el estado del arte en Portugal*



Appendix 7


Permission to reproduce the paper *A systematic literature review toward the characterization of comfort*

 **Sara Pinto** <sara.o.pinto@gmail.com> 11/05/16 ☆ ↶ ▾
para Holistic ▾

Dear Dr. Gloria Donnelly,

My name is Sara Pinto and last January I published an article in *Holistic Nursing Practice* entitled "A Systematic Literature Review toward the characterization of Comfort".
This study was part of my PhD in nursing sciences, which I intend to finish next July.
I want to ask your permission (and, also, Lippincot permission) to reproduce this article in my doctoral thesis.
I appreciate your support and I look forward to your authorization.


Yours sincerely,
Sara Pinto

 **Donnelly, Gloria** <gd27@drexel.edu> 11/05/16 ☆ ↶ ▾
para Julie, mim ▾

inglês ▾ > português ▾ Traduzir mensagem Desactivar para mensagens em: inglês x


Sara,
I do not know exactly what you mean by "reproducing the article in your thesis." Can you explain how it would look? I have copied Julie Rempfer, my publisher at Lippincott so that she can assist me in responding to your question. Thanks.

Gloria F. Donnelly, Ph.D, RN, FAAN, FCPP
Dean and Professor
College of Nursing and Health Professions
Editor in Chief, *Holistic Nursing Practice*
Drexel University
10th Floor, Room 1092
1601 Cherry Street, MS 10501
Philadelphia, PA 19102
Tel: [267.359.5935](tel:267.359.5935) | Fax: [267.359.5957](tel:267.359.5957)
gd27@drexel.edu

 **Sara Pinto** <sara.o.pinto@gmail.com> 11/05/16 ☆ ↶ ▾
para Gloria, Julie ▾

Dear Dr. Gloria Donnelly,
Thank you for your quick email.
In my PhD I performed several studies in which I defend the idea of comfort as a complex nursing intervention.
The article that I published in your journal was part of my initial research and it is very important to the theoretical background.
So, I would like to put the original article in my thesis (as published in the journal).
I look forward hearing from you!

Yours sincerely,
Sara

 **Rempfer, Julie** <Julie.Rempfer@wolterskluwer.com> 13/05/16 ☆ ↶ ▾
para mim, Gloria ▾

inglês ▾ > português ▾ Traduzir mensagem Desactivar para mensagens em: inglês x

Hi Sara,
My apologies for the delay in my response. First off, thank you for choosing HNP and congratulations on your dissertation! Secondly, yes, as the author of the article, you can use the entire article in your dissertation as noted in our '[Authors Permissions Document](#)'. Thank you so much for reaching out and best of luck!

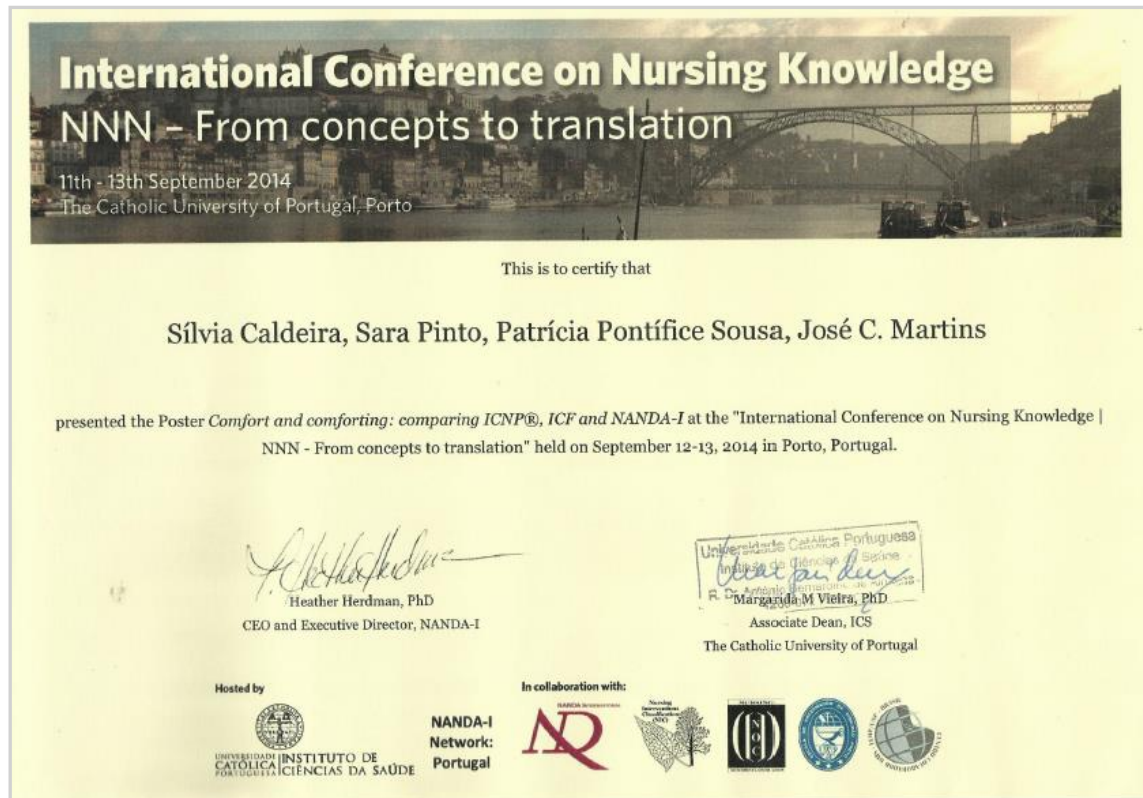
Have a great weekend,
Julie

Julie (Ivers) Rempfer
Publisher, Holistic Nursing Practice
Health Learning, Research & Practice

Wolters Kluwer
Two Commerce Square
2001 Market Street
Philadelphia, PA 19103

Appendix 8

Certificate of attendance - Poster presentation in the International Conference on Nursing Knowledge: NNN - From concepts to translation



Appendix 9

Permission to reproduce the conceptual diagram for the Comfort Theory from Kolcaba's website

Request to reproduce your conceptual diagram (comfort theory) Caixa de entrada x

Sara Pinto <sara.o.pinto@gmail.com>
para Kathy

06/12/16

Kathy Kolcaba
Adic. a circs.
Mostrar detalhes

Dear Professor Kolcaba,

I hope this email finds you well!
I'm Sara, the portuguese nurse who developed the cultural adaptation and validation of the end of life Comfort Questionnaire with you.

I'm writing to you for two reasons:

- The first one is to say you that the paper is already available online. I'm sending to you the pdf of the paper and, if you want, you can place it on your web page.
- The second one is to request your permission to reproduce your diagram about the conceptual Framework on my PhD thesis. In this moment I'm writing the thesis and I have a chapter about your theory. I think it is important to present your diagram, but I would like to have your permission to realize it (I'm not sure if it is enough to place the reference of the paper or if I need a permission to reproduce the diagram, as it is presented).

Once again, thank you so much for your support!
I look forward hearing you!

Warm regards,
Sara

Kathy Kolcaba
para mim

06/12/16

Kathy Kolcaba
Adic. a circs.
Mostrar detalhes

Inglés > português Traduzir mensagem Desactivar para mensagens em: inglês x

Of course Sara, you can use anything on my web site. I would very much like the pdf of your article as well as the online link, so I can post it on my web site. Thank you. (You did not attach it to this e-mail as far as I can see.)

Dr. Kathy Kolcaba Associate Professor
(Emeritus) The University of Akron
www.TheComfortLine.com

Appendix 10

Evolutionary analysis of the concept of comfort: Confirmation of the publication acceptance

HNP Decision Caixa de entrada x

Holistic Nursing Practice <em@editorialmanager.com> 19/06/16 ☆ ↶ ⌵
para mim ⌵

inglês ⌵ > português ⌵ Traduzir mensagem Desactivar para mensagens em: inglês x

Jun 19, 2016

RE: HNP-D-16-00052, entitled "Evolutionary analysis of the concept of Comfort"

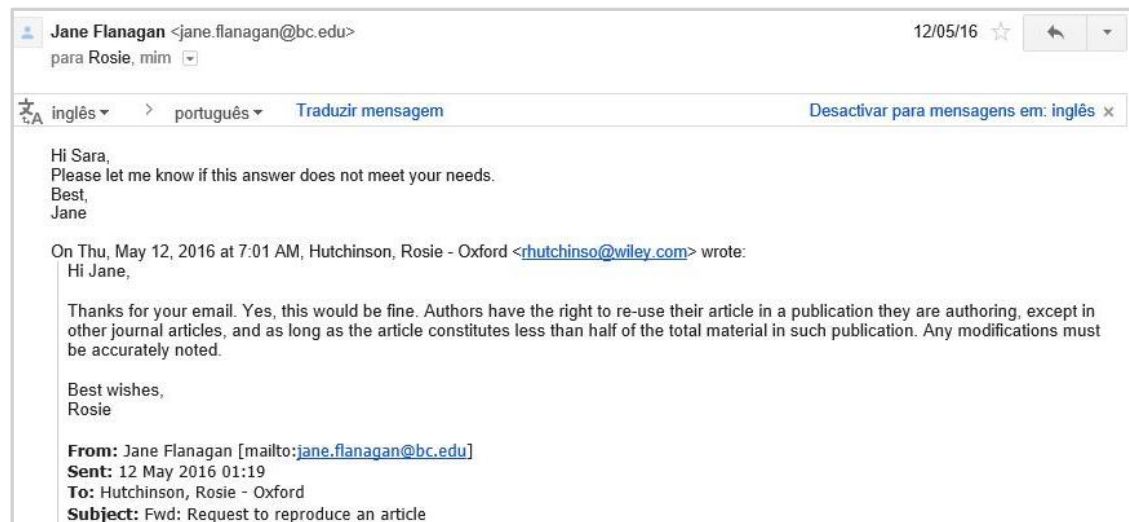
Dear Mrs Pinto,

I am pleased to inform you that your work has now been accepted for publication in Holistic Nursing Practice. All manuscript materials will be forwarded to the production staff for placement in an upcoming issue. Publication is likely in one of the 6 issues to be published in 2017. We will confirm a publication date. Congratulations, we rarely have articles accepted with no revisions.

Thank you for submitting your interesting and important work to the journal.

Appendix 11

Permission to reproduce the paper *Is impaired comfort a nursing diagnosis?*



Appendix 12

Portuguese version of the *Spiritual Comfort Questionnaire*

ECQ-PT: Escala de Avaliação do Conforto Espiritual da Pessoa em Fim de Vida – Versão Portuguesa

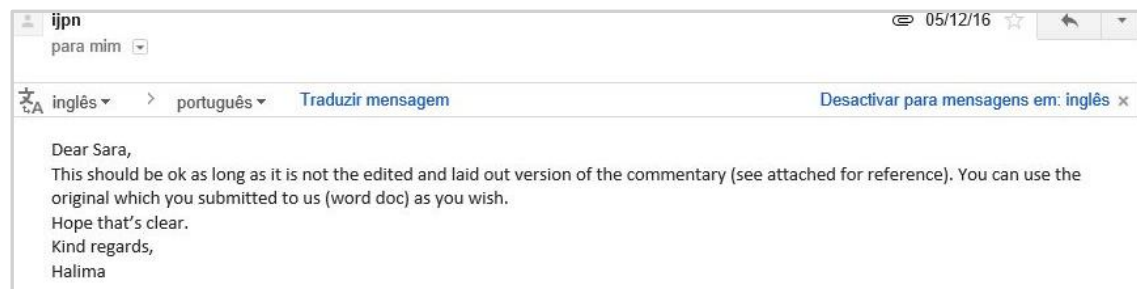
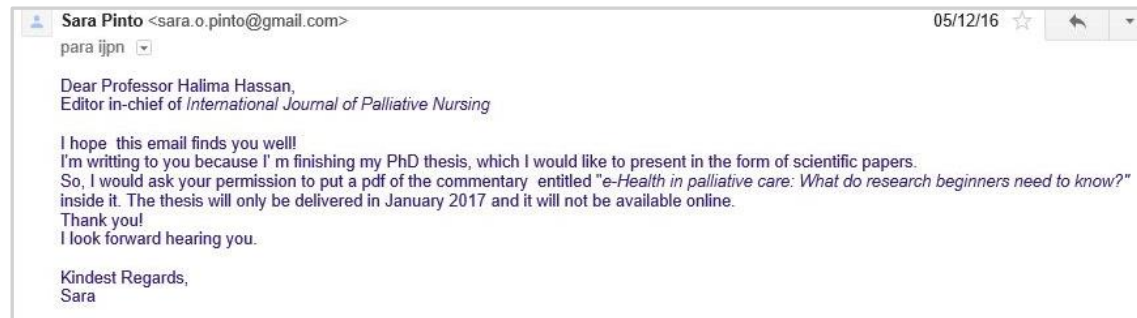
MUITO OBRIGADO pela sua colaboração neste estudo sobre o conceito de CONFORTO. Abaixo apresentamos uma lista de afirmações que poderão descrever o seu conforto **neste preciso momento**. A cada questão correspondem seis números; Por favor, assinale com um círculo o número que mais se aproxima do seu estado atual. **Por favor, responda considerando o seu conforto no momento da resposta.**

	Discordo Totalmente			Concordo Totalmente		
	1	2	3	4	5	6
1. Quando preciso de ajuda tenho sempre alguém com quem posso contar.	1	2	3	4	5	6
2. A minha situação deixa-me em baixo.	1	2	3	4	5	6
3. Sinto-me confiante.	1	2	3	4	5	6
4. Neste momento, sinto que a minha vida vale a pena.	1	2	3	4	5	6
5. Sinto-me encorajado(a) por saber que sou amado(a).	1	2	3	4	5	6
6. Ninguém me compreende.	1	2	3	4	5	6
7. É difícil lidar com a minha ansiedade.	1	2	3	4	5	6
8. Neste momento, não me sinto saudável.	1	2	3	4	5	6
9. As decisões antecipadas assustam-me.	1	2	3	4	5	6
10. Tenho medo do que virá a seguir.	1	2	3	4	5	6
11. Sinto-me muito cansado(a).	1	2	3	4	5	6
12. Estou satisfeito(a).	1	2	3	4	5	6
13. Sinto-me dependente de outras pessoas para tomar decisões.	1	2	3	4	5	6
14. Sinto-me fora de controlo.	1	2	3	4	5	6
15. Experimentei mudanças que me fazem sentir preocupado(a).	1	2	3	4	5	6
16. Necessito de mais informação sobre o meu estado de saúde.	1	2	3	4	5	6
17. Eu não tenho muita opção de escolha quanto aos cuidados em fim de vida.	1	2	3	4	5	6
18. Sinto-me em paz.	1	2	3	4	5	6
19. Sinto-me deprimido(a).	1	2	3	4	5	6
20. Encontrei sentido na minha vida.	1	2	3	4	5	6

Muito Obrigada pela sua Colaboração!

Appendix 13

Permission to reproduce the paper *e-Health in palliative care: What do research beginners need to know?*



Appendix 14

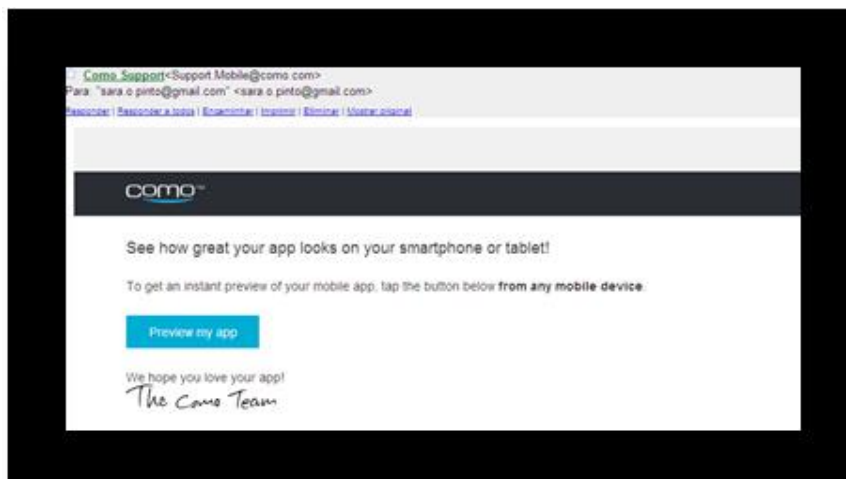
The *Comfort app* prototype

1. How to access?

1.1. QR code



1.2. Email

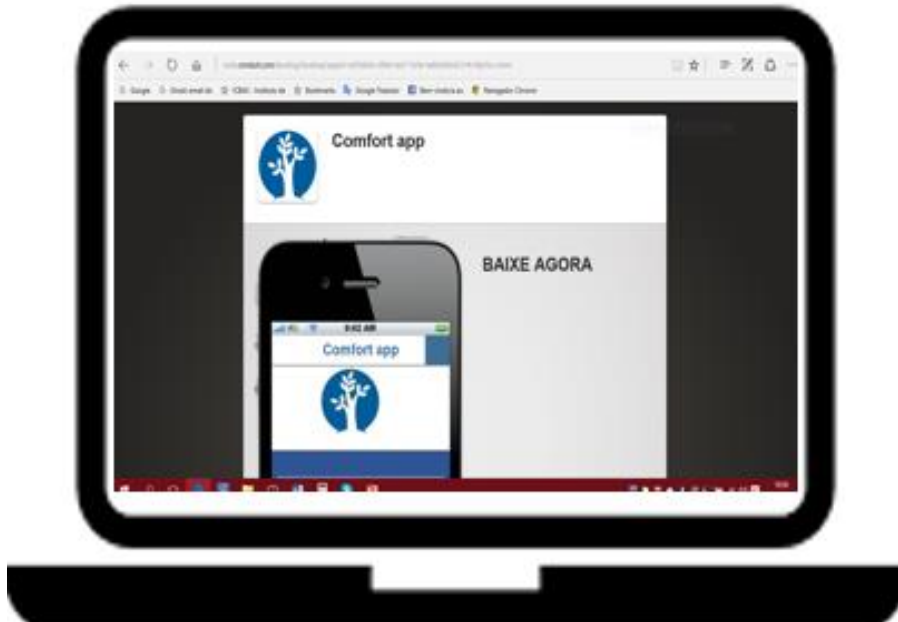


2. Layout

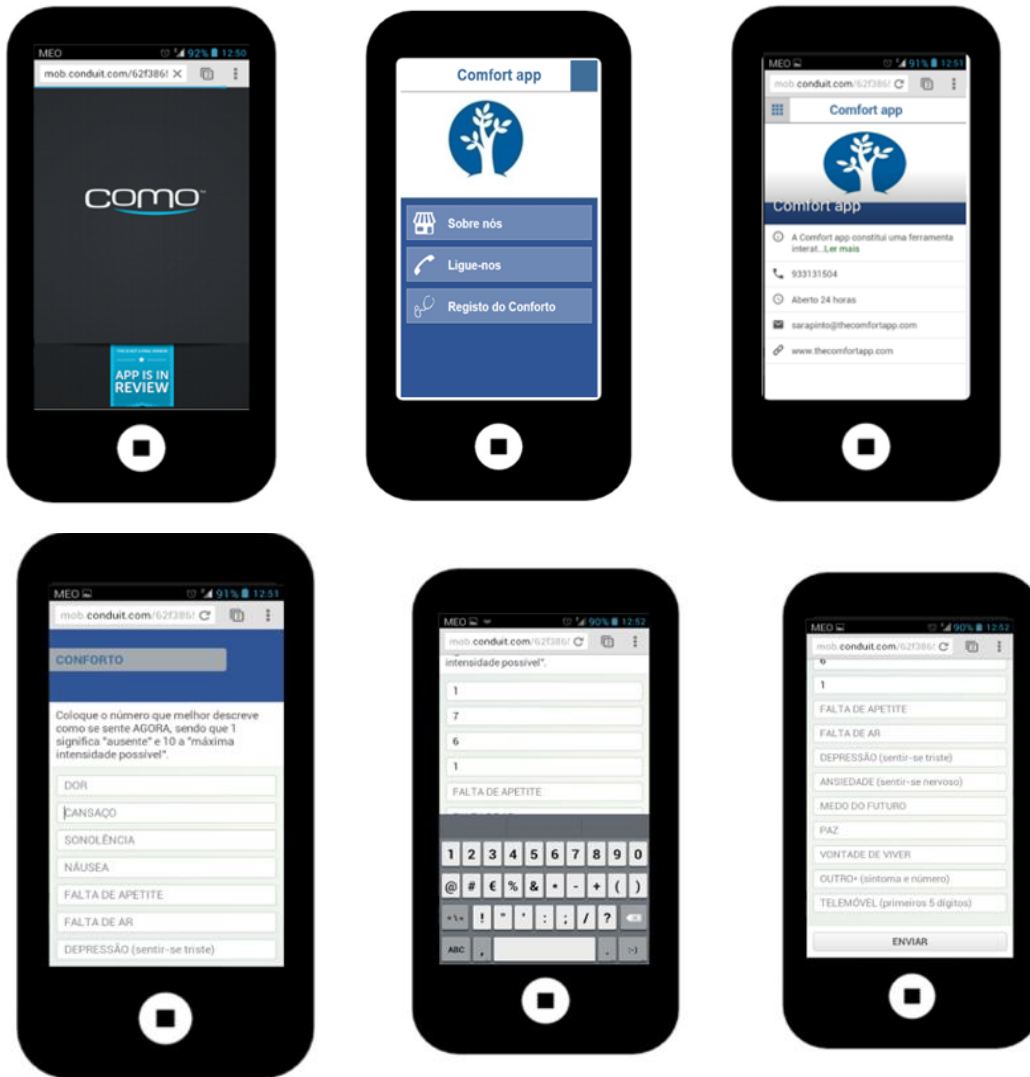
2.1. Tablet



2.2. Laptop



2.3 Smartphone



3. Database

Doente	Data	Hora	Dor	Cansaço	Sono	Nausea	Apetite	Dispneia	Depressão	Ansiedade	Medo_Fut	Paz	Vont_Vivi	Outro
933	23.07.16	21:30	9	8	6	0	0	6	8	2	6	7	4	FEBRE39
96129	23.07.16	07:02	3	7	0	8	7	4	8	5	7	3	4	FEBRE38
91236	25.07.16	10:01	9	8	6	0	0	6	8	2	0	3	4	DIARREIA 2
96256	25.07.16	09:03	1	2	9	0	2	6	5	8	6	2	2	0
93365	26.07.16	23:33	3	7	1	8	7	9	4	2	1	4	9	
93365	26.07.16	13:22	2	3	8	6	3	4	7	7	4	4	2	
93254	31.07.16	16:37	3	4	6	9	7	5	4	3	2	2	0	confusao4
93365	31.07.16	16:39	8	9	2	7	7	1	1	1	5	1	1	

Sintomas doente 93365 23/7 e 31/7

Data	Hora	Dor	Cansaço	Nausea	Apetite
23.07.16	21:30	9	8	0	0
23.07.16	07:02	3	7	8	7
25.07.16	10:01	9	8	0	0
25.07.16	09:03	1	2	0	2
26.07.16	23:33	3	7	8	7
26.07.16	13:22	2	3	6	3
31.07.16	16:37	3	4	9	7
31.07.16	16:39	8	9	7	7

4. Booklet

Que benefícios posso esperar?

Os dados enviados serão diariamente analisados e avaliados pelo seu enfermeiro. Nas situações de desconforto elevado, será contactado por telefone para uma melhor avaliação da sua situação e orientação/ encaminhamento.

E que incómodos devo esperar?

A Comfort app é uma tecnologia segura e confidencial. No entanto, perderá entre 5 a 10 minutos do seu dia para preencher os dados solicitados. O seu contributo pode, contudo, ajudar os profissionais a realizarem uma melhor avaliação do seu estado de conforto. A sua participação permitirá, também, um desenvolvimento da aplicação, podendo ajudar muitos outros doentes no futuro.

.....
A sua participação é livre e voluntária,
podendo desistir a qualquer momento.
.....

Em caso de dúvida não hesite em contactar-nos!
933 131 504



Comfort app

O que é a Comfort app?

A Comfort app é uma tecnologia de informação que tem por finalidade auxiliar a interação entre doente, cuidador e equipa de saúde, particularmente no contexto domiciliário, com vista a uma intervenção precoce, centrada nas necessidades do doente.

Como posso aceder?

A Comfort app é uma versão experimental, gratuita. Poderá aceder à mesma via email. Em alternativa, pode descarregar um leitor de QR code para o seu smartphone ou tablet e aceder através do seguinte Qr code:



Que dados são avaliados?

A Comfort app avalia o seu conforto em 11 domínios, existindo ainda a possibilidade de inserir um 12º sintoma opcional:

DOR
CANSAÇO
SONOLENCIA
NAUSEA (enjoo)
FALTA DE APETITE
FALTA DE AR
DEPRESSAO (sentir-se triste)
ANSIEDADE (sentir-se nervoso)
MEDO DO FUTURO
PAZ
VONTADE DE VIVER

Como preencher os dados?

No ecrã inicial encontra um item denominado “Registo do Conforto”. Ao clicar nesse campo, abrirá uma nova janela na qual acede ao questionário.

Para cada item deverá colocar um valor compreendido entre 1 e 10, sendo que 1 significa “ausente” e 10 “a máxima intensidade possível”. Caso seja cuidador, deverá colocar a resposta do doente e não a sua opinião pessoal.

Como envio os dados?

No final do questionário deve inserir APENAS os 5 primeiros dígitos do seu telemóvel. A informação enviada é confidencial e apenas o seu enfermeiro terá acesso à sua identificação.

A que horas devo preencher?

Deverá preencher a aplicação uma vez por dia, durante 15 dias. Poderá escolher o horário mais conveniente para si, embora idealmente deva fazê-lo à mesma hora.

E se o meu estado se agravar?

Caso o seu estado se agrave, poderá ligar para o serviço. Ao clicar no campo “Ligue-nos” (ecrã inicial), a chamada é automaticamente estabelecida.

(The images are not at full scale.)

Appendix 15

Impaired comfort in adult and older adult as a syndrome diagnosis: Submission to the NANDA International Diagnosis Development Committee

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Submission Form Confirmation

Your submission has been sent, thank you!

We will contact you WITHIN 3 WEEKS, when a member of our Diagnosis Development Committee has been assigned to review your submission.

The NANDA International Diagnosis Submission Full Review Process involves multiple steps and approval points, culminating in the final step of membership approval to add a diagnosis to our terminology. *(Please see the [Diagnosis Submission Review Process Diagram](#) below.)*

Our Diagnosis Development Committee (DDC) members are all volunteers, contributing their time to the work of the organization. Committee members work on submitted diagnoses in three ways:

- Email communication with diagnosis submitters, for discussion on the submission and to advise submission status;
- Committee conversation in our DDC Forum and web conference calls;
- Two Diagnosis Development Committee face-to-face meetings per year.

The time frame of the review of your submission depends on the following factors:

- The timing of your submission relative to the submission review / DDC meeting / membership vote cycle *(see [diagram below](#));*
- The extent of revision that may be required;
- The length of time taken for your response(s) to email(s) from the DDC member assigned to review your submission.

Publication of approved diagnosis submissions will be timed with our 3-year book publication cycle.