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CIÊNCIAS DE ENFERMAGEM

# The Guided Imagery in Comfort in Palliative Care

Adriana Neves Coelho

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Adriana Raquel Neves Coelho





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## THE GUIDED IMAGERY IN COMFORT IN PALLIATIVE CARE

**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 you, Mia.*



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## SCIENTIFIC PUBLICATIONS

### Articles published in peer-reviewed journals

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**Coelho, A.,** Parola, V., Apóstolo, J., & Escobar-Bravo, M. (2016). The use of nonpharmacological interventions for the comfort of patients in palliative care: a scoping review protocol, In Livro de Atas do Simpósio Internacional de Cuidados de Saúde baseados na evidência, Suplemento ao nº9 da Revista Referência, Coimbra.

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**Coelho, A.** (2017). Experiência de Conforto em Cuidados Paliativos: Um estudo fenomenológico, Terceiro encontro do Fórum Clínico Académico em Cuidados Paliativos da Região Centro, Leiria.

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## ABSTRACT

**Background:** One of the non-pharmacological intervention that is increasingly implemented in different clinical contexts, in order to provide comfort is Guided Imagery. However, there are no studies on its effect on comfort in the palliative care context. If this intervention is demonstrated to be effective in palliative care, its implementation can translate into a significant increase in the comfort levels of a number of patients in palliative care. The development of the research was supported by Katharine Kolcaba's theory of comfort.

**Objectives:** To map the non-pharmacological interventions implemented and evaluated to provide comfort in palliative care; To understand the comfort and discomfort experienced by inpatients at palliative care units; Translate, adapt and validate the Hospice Comfort Questionnaire for use in the palliative care Spanish context; Develop and validate a Guided Imagery program adjusted to the comfort needs of inpatients at palliative care units. The purpose of these objectives was to prepare the necessary instruments to achieve the final objective: To evaluate the effect of a Guided Imagery program in the comfort of inpatients at palliative care units.

**Methodology:** In the Phase 1 a Scoping Review was performed guided by the methodology proposed by the Joanna Briggs Institute. In the Phase 2 a qualitative study of a phenomenological nature was made. In the Phase 3 a methodology for the semantic, idiomatic and conceptual equivalence of items` content and psychometric equivalence by assessing the reliability, validity and content approach was adopted. In the Phase 4 a Guided Imagery program was developed based on the guidelines for developing complex interventions from the Medical Research Council. In the Phase 5 was performed a quasi-experimental study of pretest-posttest design with a single group.

**Results:** The Scoping Review conducted identified eighteen studies, covering 10 non-pharmacological interventions implemented and evaluated to provide comfort, being music therapy and massage therapy were the most common interventions. The qualitative study revealed that four themes reflect the essence of the lived experience: The Palliative Care as a response to the patient's needs with advanced disease, attempt to naturalize advanced disease, confrontation with their own vulnerability, openness to the spiritual dimension. The results of the Phase 3 show that the Spanish version of the Hospice Comfort Questionnaire is an instrument for evaluating comfort in palliative care with psychometric quality assurance. In the Phase 4, the process of developing a Guided Imagery Program resulted in a program consisting of two Guided Imagery sessions to be implemented in the same week. Each session consisted of a process of relaxation and induction of mental images, accompanied

by music. The Phase 5 demonstrated that the intervention of the Guided Imagery program increased comfort ( $p < .001$ ), decreased pain, ( $p < .001$ ), decreased heart rate ( $p < .001$ ), and respiratory rate ( $p < .001$ ) of inpatients at palliative care units.

**Conclusions:** There are no studies on the effect of guided imagery on the comfort of inpatients at palliative care units. Inpatients at palliative care units revealed experience comfort through differentiated and humanized care, symptomatic control, hope and relationships established. Revealing also that discomfort emerges from the multiple losses and powerlessness feeling. The Hospice Comfort Questionnaire - Spanish version proved to be a reliable and valid instrument to evaluate the comfort of inpatients at Spanish palliative care units. The validity of the developed Guided Imagery program is based on the experts' consensus opinion, nurses and inpatients at palliative care units, about the relevance of the intervention, and the positive quantitative and qualitative evaluation carried out during the field test. This study demonstrates that the use of Guided Imagery increases the comfort of inpatients at palliative care units, and their use should be encouraged.

### **Keywords**

Comfort; complex interventions; guided imagery; nursing; palliative care.

## RESUMO

**Enquadramento:** Uma das intervenções não farmacológicas que é cada vez mais implementada em diferentes contextos clínicos, com o objetivo de proporcionar conforto, é a Imaginação Guiada. Porém, não há estudos sobre o seu efeito no conforto no contexto dos Cuidados Paliativos. Se se demonstrar que esta intervenção é efetiva neste contexto, a sua implementação pode traduzir-se num aumento significativo dos níveis de conforto dos doentes internados em Unidades de Cuidados Paliativos. O desenvolvimento da investigação foi sustentado pela teoria do conforto de Katharine Kolcaba.

**Objetivos:** Mapear as intervenções não farmacológicas implementadas com o objetivo de promover conforto em Cuidados Paliativos; Compreender as vivências de conforto e de desconforto dos doentes internados em Unidades de Cuidados Paliativos; Traduzir, adaptar e validar o *Hospice Comfort Questionnaire* para uso no contexto dos Cuidados Paliativos Espanhóis; Desenvolver e validar um programa de Imaginação Guiada ajustada às necessidades de conforto dos doentes internados em Unidades de Cuidados Paliativos. Estes objetivos tiveram como propósito preparar os instrumentos necessários para atingir o objetivo final: Avaliar o efeito de um programa de Imaginação Guiada no conforto de doentes internados numa Unidade de Cuidados Paliativos.

**Métodos:** Na primeira fase do estudo foi realizada uma Scoping Review com base nos princípios preconizados pelo *Joanna Briggs Institute*. Na segunda fase foi realizado um estudo qualitativo de cariz fenomenológico. Na terceira fase adotou-se uma metodologia que visou a equivalência semântica, idiomática e conceptual do conteúdo dos itens, bem como a equivalência psicométrica, realizando a avaliação da confiabilidade e da validade de critério. Na quarta fase foi desenvolvido um programa de Imaginação Guiada com base nas diretrizes para desenvolvimento de intervenções complexas do *Medical Research Council*. Na quinta fase foi realizado um estudo quase-experimental de desenho antes-após com grupo único.

**Resultados:** A Scoping Review realizada identificou dezoito estudos, abrangendo dez intervenções não farmacológicas implementadas e avaliadas com o objetivo de proporcionar conforto, sendo as mais frequentes a musicoterapia e a massagem terapêutica. O estudo qualitativo revelou que quatro temas refletem a essência da experiência vivida: O Cuidado Paliativo como resposta às necessidades da pessoa com doença avançada; tentativa de naturalizar a doença avançada; confronto com a própria vulnerabilidade; e abertura à dimensão espiritual. Os resultados da terceira fase evidenciam que o *Hospice Comfort Questionnaire – Versão Espanhola* é um instrumento de avaliação de conforto em Cuidados

Paliativos com garantias psicométricas de qualidade. Na quarta fase, do processo de desenvolvimento de um Programa de Imaginação Guiada, resultou num programa composto por duas sessões de Imaginação Guiada a serem implementadas na mesma semana. Cada sessão foi constituída por um processo de relaxamento e indução de imagens mentais, acompanhado por música. A quinta fase demonstrou que a intervenção com o programa de Imaginação Guiada aumentou o conforto ( $p < 0,001$ ) e diminuiu a dor ( $p < 0,001$ ), a frequência cardíaca ( $p < 0,001$ ) e a frequência respiratória ( $p < 0,001$ ) dos doentes internados numa Unidade de Cuidados Paliativos.

**Conclusões:** Não existem estudos sobre o efeito da Imaginação Guiada no conforto de doentes internados em Unidades de Cuidados Paliativos. Os doentes internados em Unidades de Cuidados Paliativos revelam vivenciar uma experiência de conforto através da receção de um cuidado diferenciado e humanizado, do controlo sintomático, da esperança e dos relacionamentos estabelecidos. Revelam que o desconforto emerge das múltiplas perdas e do sentimento de impotência. O *Hospice Comfort Questionnaire – Versão Espanhola* revelou ser um instrumento fiável e válido para avaliar o conforto dos doentes internados em Unidades de Cuidados Paliativos espanholas. A validade do programa de Imaginação Guiada desenvolvido encontra-se suportada na opinião consensual de peritos, enfermeiros e doentes internados na Unidade de Cuidados Paliativos, acerca da relevância da intervenção, e na positiva avaliação, quantitativa e qualitativa, realizada durante a fase de teste de campo. Este estudo demonstra que o uso da Imaginação Guiada aumenta o conforto dos doentes internados em Unidades de Cuidados Paliativos, pelo que a sua utilização deve ser encorajada.

### **Palavras-chave**

Conforto; intervenções complexas; imagens guiadas; enfermagem; cuidados paliativos.



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## ABBREVIATIONS AND ACRONYMS LIST

<b>ABTI</b>	Abstract and Title
<b>ABTIK</b>	Abstract, Title and Keywords
<b>CAPES</b>	Coordenação de Aperfeiçoamento de Pessoal de Nível Superior
<b>CE</b>	Comissão de Ética
<b>CEIC</b>	Comitè ètic d'Investigació Clínica
<b>COREQ</b>	Consolidated criteria for reporting qualitative research
<b>DE</b>	Desviación estándar
<b>DT</b>	Desviación típica
<b>e.g.</b>	Example
<b>EVA</b>	Escala visual analógica
<b>Fig.</b>	Figure
<b>FORES</b>	Fundació d'Osona per a la Recerca i l'Educació Sanitàries
<b>GI</b>	Guided Imagery
<b>HAJC</b>	Hospital Arcebispo João Crisóstomo de Cantanhede
<b>HCQ</b>	Hospice Comfort Questionnaire
<b>HCQ-PT-DC</b>	Escala de Conforto Holístico
<b>HCQ-Version ES</b>	Versión española del HCQ
<b>HIV</b>	Human Immunodeficiency Virus
<b>HSBs</b>	Health-seeking behaviours
<b>IAD</b>	Incurable and advanced disease
<b>ID</b>	Identification
<b>JI</b>	Joanna Briggs Institute
<b>M</b>	Media
<b>MH</b>	MeSHTerms
<b>max</b>	Maximum
<b>min</b>	Minimum
<b>MRC</b>	Medical Research Council
<b>n</b>	Number
<b>No.</b>	Number
<b>p.</b>	page
<b>PC</b>	Palliative Care
<b>PCC</b>	Population, Concept and Context
<b>PCU</b>	Palliative Care Unit
<b>PhD</b>	Doctor of Philosophy
<b>PICO</b>	Population, Intervention, Comparator, and Outcomes
<b>RCAAP</b>	Repositório Científico de Acesso Aberto de Portugal
<b>SPSS</b>	Statistical Package for Social Sciences
<b>TI</b>	Title
<b>T</b>	Time
<b>t</b>	Time
<b>TDX</b>	Tesis Doctorales en Xarxa
<b>Teseo</b>	Base de datos de Tesis Doctorales
<b>UK</b>	United Kingdom
<b>USA</b>	United States of America
<b>VAS</b>	Visual Analog Scale
<b>WHO</b>	World Health Organization



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**Appendix 2:** Ethics committee authorization to perform the study: *Comfort experience in palliative care: a phenomenological study* (CE HAJC)

**Appendix 3:** Permission to use the Hospice Comfort Questionnaire for Patients

**Appendix 4:** Ethics committee authorization to perform the study: *The validation of a Comfort assessment scale for Palliative Care patients: Spanish version of the Hospice Comfort Questionnaire*

**Appendix 5:** Confirmation of the publication acceptance of the study: *Spanish version of the Hospice Comfort Questionnaire: Validation of a Comfort assessment scale for Palliative Care patients*

**Appendix 6:** Permission to use the “*Escala de Conforto Holístico HCQ - PT-DC*”

**Appendix 7:** Ethics committee authorization to perform the study: *The effects of guided imagery on comfort in palliative care*

**Appendix 8:** Permission to reproduce the articles: *The use of non-pharmacological interventions for the comfort of patients in palliative care: a scoping review protocol; Use of non-pharmacological interventions for comforting patients in palliative care: a scoping review*

**Appendix 9:** Permission to reproduce the article: *Spanish version of the Hospice Comfort Questionnaire: Validation of a Comfort assessment scale for Palliative Care patients*

**Appendix 10:** Permission to reproduce the Taxonomic structure of Comfort and Conceptual Framework for Comfort Theory

**Appendix 11:** Permission to reproduce the article: *The effects of guided imagery on comfort in palliative care*



# INTRODUCTION

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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.

This thesis is written in the first person plural to acknowledge the contribution of supervisors and co-authors. However, I have been responsible for running the entire projects including data collection and analyses, and writing of papers and thesis.

The choice of theme, "The Guided Imagination in Comfort in Palliative Care", had underlying professional and evidence-based reasons.

As a nurse emerged the need to have a non-pharmacological intervention that would be useful to nurses working in Palliative Care Units (PCUs), that culminate in the comfort state of the patients hospitalized in these units. Thus, with the evidence that the intervention of Guided Imagery (GI) is related to an increase of comfort in different clinical contexts and having as inspiration the works previously developed by Prof. Dr. Katharine Kolcaba (Kolcaba, 1997) and Prof. Dr. João Apóstolo (Apóstolo, 2010), this project was initiated.

The increase in life expectancy and chronic and progressive diseases have had an impact on the organization of health systems and on the need for PCUs (*Programa Nacional de Cuidados Paliativos*, 2010).

According to the World Health Organization (WHO) (2002) palliative care (PC) is an approach that improves the quality of life of patients and their families facing problems associated with an incurable and/or severe disease with a poor prognosis, through the prevention and relief of suffering. It is an active, rigorous, and total health care approach where aggressive therapeutic measures give way to intensive comfort care (Twycross, 2003).

The comfort, purpose of the PC and nursing care process (Apóstolo, 2009; Kolcaba, 1994; Twycross, 2003) is defined by Kolcaba (1994), as a condition in which the basic needs for relief, tranquillity, and transcendence are satisfied. These are developed in four contexts: physical, socio-cultural, psycho-spiritual, and environmental.

With this objective, in the context of PC there has been an increase in the development and implementation of non-pharmacological interventions that can be implemented autonomously and in complementarity to other therapeutic approaches (Kraft, 2012). This has contributed to an increase in patient comfort and satisfaction with end of life care (Demmer & Sauer, 2002). However, there are obstacles to its implementation, including the need to hire external professionals with specific training, the lack of scientific evidence regarding the effectiveness

of the interventions (Osaka et al., 2009), and the economic expenditure that their implementation entails for the institutions (Olotu, Brown, Barner, & Lawson, 2014).

According Kolcaba (2003; 2004) comfort care entails at least three types of comfort interventions that can be implemented to achieve the goal of enhancing patients' total comfort: 1) standard comfort interventions; 2) coaching; and 3) "comfort food for the soul". This last intervention targets the need for transcendence through memorable connections between the nurse and patient or family, making that the patients feel strengthened in intangible, personalized ways, and helping to fortify patients for the difficult tasks such as death and includes, for example, GI.

In fact, one of the non-pharmacological interventions increasingly implemented in different clinical contexts is GI (Apóstolo & Kolcaba, 2009; Dillard & Knapp, 2005; Gonzales et al., 2010; Hart, 2008; K. Y. Kolcaba & Fox, 1999; Onieva-Zafra, García, & Del Valle, 2015; Roffe, Schmidt, & Ernst, 2005; Shenefelt, 2003). GI is defined as a process of intentional use of mental images and sensory attributes that are the result of imagination or memory, to achieve a desired therapeutic goal (Apóstolo, 2010; Hart, 2008; Roffe et al., 2005). The person's involvement with mental images is so intense that their body tends to respond as if responding to a genuine external experience, producing psychophysiological consequences (Apóstolo, 2010; Hart, 2008; Roffe et al., 2005). GI is an intervention that can be implemented by nurses, which requires little effort for the patient, and is of economic value (Davenport, 1996; Hart, 2008; Onieva-Zafra et al., 2015).

The research literature sustains that GI intervention is related to increased comfort in women with breast cancer (K. Y. Kolcaba & Fox, 1999), in psychiatric patients (Apóstolo & Kolcaba, 2009), those subject to dermatological procedures (Shenefelt, 2003), those undergoing chemotherapy (Roffe et al., 2005), those using emergency services (Dillard & Knapp, 2005), those in a pre-operative situation (Gonzales et al., 2010), people diagnosed with fibromyalgia (Onieva-Zafra et al., 2015), and others.

However, a scoping review performed by Coelho et al. (2017) identified the lack of studies on the effect of GI on comfort in the PC context. Since the research literature shows that the patients in PC experience discomfort, namely due to a lack of control of physical symptoms; to physical, social, and freedom losses; and to guilt and fear, it justifies the implementation of interventions that result in their comfort (Coelho et al., 2017; Pinto, Caldeira, & Martins, 2017).

In the light of the aforementioned studies in other contexts, the potential effects of GI in PC should not be underestimated. If this intervention is demonstrated to be effective in PC, its

implementation can translate into a significant increase in the comfort levels of a number of patients in PC.

Considering the above, we opted to investigate the effect of a GI program.

To carry out the research, four preparatory studies were performed: a scoping review; a phenomenological qualitative study; cultural adaptation and validation of an instrument to measure comfort; development of a GI program for inpatients at PCUs. The accomplishment of these studies allowed the realization of the final study: a quasi-experimental study on the effect of a GI program in the comfort of inpatients at palliative care units.

The thesis report is organized in seven chapters.

The first chapter presents the theoretical and scientific framework that supports the development of the studies. The second chapter presents the course of research. The third chapter presents a scoping review on non-pharmacological interventions implemented with the aim of providing comfort in PC. In the fourth chapter we present a phenomenological study about the comfort and discomfort experienced by inpatients at PCUs. In the fifth chapter is presented validation of the Hospice Comfort Questionnaire (HCQ) for use in the PC Spanish context. The sixth chapter describes the process of development and validation of GI intervention. In the seventh chapter we present a quasi-experimental study on the effect of a GI program in the comfort of inpatients at PCUs. To conclude, we present a summary of the most relevant results, discussing their relevance and their implications for nursing practice.



# **CHAPTER I**

## **THEORETICAL AND SCIENTIFIC BACKGROUND**

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The first chapter presents the theoretical and scientific framework that supports the development of the studies, and is divided into three sub-headings.

The first sub-heading presents a brief contextualization of the past and the present of the PCs. In the second sub-heading is presented the Theory of Comfort, which was adopted to support the GI intervention in the context of PC. Finally, in the third sub-heading, the GI non-pharmacological intervention is presented.





## 1.1. The past and the present of the Palliative Care

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The modern PC movement began in the United Kingdom in the late 1960s as a result of the vision and inspiration of Cecily Saunders (Nurse, with later medical training), founder of St. Christopher Hospice in London. Cicely Saunders guided his professional work in finding solutions to the specific needs of terminally ill patients, patients with no chance of cure, trying to provide them with a more dignified death (Lutz, 2011).

In the early 1970s, the PC movement expanded to the United States of America, followed by Canada and in 1988 the European Association of Palliative Care was created, which marked the enlargement of this movement in Europe (Lutz, 2011).

In Portugal, specifically, the PC movement began in the early 1990s due to a few pioneers keen to treat suffering in patients with advanced stages of incurable diseases (Comissão Nacional de Cuidados Paliativos, 2016).

In June 2016, the Government of Portugal nominated the National Commission for Palliative Care to design a Strategic Plan for the Development of Palliative Care and implement a PC network in Portugal, based on the 2012 Palliative Care Law. This law enshrines palliative care as a citizen's right, under the supervision of the Ministry of Health.

PC was defined by the World Health Organization in 2002 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” (2002, p. 84).

Currently, World Health Organization advocates that PC should not be limited to the last days of life but rather be applied progressively as the disease progresses and according to the needs of patients and families. PC has thus gone from a traditional approach, used in cases where the curative therapeutic resources (active treatments) are exhausted, to an approach of symptomatic treatment and complementary active care to the medical treatment of the underlying disease, at any stage of the disease.

It is now internationally recognized that PC, when applied early, bring benefits to users and families, reducing the symptomatic burden of patients and the burden on caregivers (Dionne-Odom et al., 2015; Gomes, Calanzani, Curiale, McCrone, & Higginson, 2013).

Historically PCs have started focusing on the needs of cancer patients. However, it is currently recommended that they be applied to all people with serious and / or advanced and progressive diseases who need them, regardless of their diagnosis (cancer or non-cancer) and their age and wherever they are (Comissão Nacional de Cuidados Paliativos, 2016; Worldwide Palliative Care Alliance, 2014).

Approximately one-third of people who require PC suffer from oncological disease, however, most have progressive non-oncological diseases that affect the heart, lungs, liver, kidneys, brain, or life-threatening chronic diseases (Worldwide Palliative Care Alliance, 2014).

Thus, it is estimated that each year more than 20 million people need PC at the end of their lives, 94% of whom are adults. The number of people requiring this type of care rises to 40 million, if we include the people who could benefit from PCs, in a stage prior to the end of life (Worldwide Palliative Care Alliance, 2014). However, only 10% of these receive PC (Worldwide Palliative Care Alliance, 2014).

Specifically in Portugal, the National Commission for Palliative Care estimated that 71.500 to 85.000 patients need palliative care (Comissão Nacional de Cuidados Paliativos, 2016).

In summary, the advance of science and technology are an evidence that is expressed in an increase in the average of life expectancy (Organización Mundial de la Salud, 2015). Thus, the aging population in a society where death can be increasingly delayed allows predicting a progressive increase in the prevalence of degenerative, incapacitating and irreversible diseases and it is therefore urgent to find answers that promote patient comfort.

Despite this aspiration, the literature reveals that inpatients at PCUs still experience discomfort (Coelho, Parola, Escobar-Bravo, & Apóstolo, 2016; Currow, Ward, Plummer, Bruera, & Abernethy, 2008; Pinto et al., 2017) so it is imperative to develop research that culminates in the development of comfort interventions for PC patients.

## 1.2. Kolcaba's Comfort Theory

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Comfort is a concept that has been identified as an element of nursing care, is linked to its origin, and has assumed, throughout history, different meanings that relate to the historical, political, social and religious evolution of humanity and technical-scientific developments (Apóstolo, 2009).

In fact, a considerable number of authors, such as Callista Roy, Hildegard Peplau, Jean Watson, Madeleine Leininger, Josephine Paterson, Loretta Zderad, Janice Morse, among others contributed to the theoretical development of nursing and to the perception of comfort as one of the its main objectives (Apóstolo, 2009; Mussi, Freitas, & Gibaut, 2014). However, until 1991, comfort had not been operationalized (Kolcaba, 1991, 2001).

It was Katharine Kolcaba who developed a theoretical framework for the care of comfort and presented, for the first time, the taxonomic structure of comfort (Kolcaba, 1991; Kolcaba & Kolcaba, 1991).

The present research is based on the middle-range Comfort Theory proposed by Katherine Kolcaba (1995; 2001; 2003).

Kolcaba defines Comfort as the immediate, holistic experience of being strengthened when one's needs are addressed for three types of comfort (relief, ease, and transcendence) in four contexts (physical, psychospiritual, sociocultural, and environmental) (Kolcaba, 1994).

Major concepts, theoretical propositions and major assumptions are described in table 1.

**Table 1:** Description of major concepts, propositions and assumptions of Comfort Theory

<b>MAJOR CONCEPTS</b>
<b>Comfort</b>
“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” (Kolcaba, 2003, p.14).
<u>Types of Comfort:</u>
Relief - the state of having a specific comfort need met.
Ease - the state of calm or contentment.
Transcendence - the state in which one can rise above problems or pain.” (Kolcaba, 2003, p.15).
<u>Contexts in Which Comfort Occurs:</u>
Physical - pertaining to bodily sensations, homeostatic mechanisms, immune function, etc.
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.
Environmental - pertaining to the external background of human experience (temperature, light, sound, odor, colour, furniture, landscape, etc.)
Sociocultural - pertaining to interpersonal, family, and social relationships (finances, teaching, health care personnel, etc.). Also to family traditions, rituals, and religious practices.” (Kolcaba, 2003, p.15).
<b>Comfort Interventions</b>
Are nursing actions and referrals designed to address specific comfort needs of recipients (Kolcaba, 2001) .
<b>Health care needs</b>
“Deficits in any context of comfort that arise from stressful health care situations and which the patient’s natural support system cannot meet” (Kolcaba, 2010).
<b>Institutional integrity</b>
“Stability and ethics of any hospital, health care system, region, state, or country. When institutions do better, patients do better and vice versa” (Kolcaba, 2010).
<b>Intervening variables</b>
“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.” (Kolcaba, 2010).
<b>Health seeking behaviors</b>
Internal or external behaviors in which the patient engages that facilitate health or a peaceful death (Schlotfeldt, 1975 as cited in Kolcaba, 2010).
<b>Best Policies</b>
Institutional or regional policies ranging from protocols for procedures and medical conditions to access and delivery of health care (Kolcaba, 2010).
<b>Best Practices</b>
The use of health care interventions based on evidence to produce the best possible patient and family (Kolcaba, 2010).
<b>PROPOSITIONS</b>
“1. Nurses identify patients’ comfort needs that have not been met by existing support systems. 2. Nurses design interventions to address those needs. 3. Intervening variables are taken into account in designing interventions and mutually agreeing on reasonable immediate (enhanced comfort) and/or subsequent (HSBs) outcomes. 4. If enhanced comfort is achieved, patients are strengthened to engage in health-seeking behaviors. 5. When patients engage in health-seeking behaviors as a result of being strengthened by comforting actions, nurses and patients are more satisfied with their health care. 6. When patients are satisfied with their health care in a specific institution, that institution retains its integrity; institutional integrity has a normative and descriptive component.” (Kolcaba, 2001, p.90).
<b>ASSUMPTIONS</b>
“1. Human beings have holistic responses to complex stimuli. 2. Comfort is a desirable holistic outcome that is germane to the discipline of nursing. 3. Human beings strive to meet, or to have met, their basic comfort needs; it is an active endeavor. 4. Institutional integrity has a normative and descriptive component that is based on a patient-oriented value system.” (Kolcaba, 2001, p.90).
Nursing - Process in which nurses perform the intentional assessment of comfort needs, the design of comfort interventions to address those needs, and reassessment of comfort levels after implementation compared with a baseline (Kolcaba, 2003).
Patient- families, institutions, or communities in need of health care (Kolcaba, 2003).
Environment - Any aspect of patient, family, or institutional settings that can be manipulated by to enhance comfort (Kolcaba, 2003).
Health - optimal functioning of a patient, family, or community (Kolcaba, 2003).

The four context in which comfort occurs (Physical, Psychospiritual, Environmental and Sociocultural), when combined with the three senses of comfort (ease, relief, transcendence) form a taxonomic structure of 12 cells (figure 1). The cells are not mutually exclusive; there is considerable overlap in the attributes of comfort. In other words, discomforts that patients experience in the PC setting (or other), such as pain, or nausea, may have physiological, psychological, environmental, and sociocultural components (Kolcaba, 1991; Kolcaba, 2003). According to Kolcaba (1991; 2003), the holistic, interrelated, and individualized nature of comfort needs is better understood when nurses mentally place their patients' needs within the cells on the grid. This approach makes it easier for nurses to identify and implement comfort interventions targeted to meet those needs.

		TYPE OF COMFORT		
		Relief	Ease	Transcendence
CONTEXT IN WHICH COMFORT OCCURS	Physical			
	Psychospiritual			
	Environmental			
	Social			

**Figure 1:** Taxonomic structure of Comfort

Adapted from *www.thecomfortline.com* (Kolcaba, 2010), with permission of Professor Kolcaba (Appendix 10).

Comfort theory can be divided and described in three parts (Kolcaba, 2001; Kolcaba, 2003).

Part 1 states that Comfort is a desirable holistic outcome that is germane to the discipline of nursing (Kolcaba, 1994). As a result, nurses assess the holistic (physical, psychospiritual, sociocultural, and environmental) comfort needs of patients and implement a variety of interventions to meet those needs.

These interventions can only be considered comforting if the patient defines them as such (Kolcaba, 2003). Thus, patients' comfort levels must be evaluated before and after those interventions.

Assessment and reassessment may be intuitive or subjective or both, such as when a nurse asks if the patient is comfortable, or objective, such as in observations of wound healing or changes in laboratory values (Kolcaba, 2003).

This part of comfort theory also describes positive and negative intervening patient variables, that are interacting forces that influence recipients' perceptions of total comfort, although the nurse has little control over these, such intervening variables have an impact on planning and success of patient comfort care interventions. Examples of these variables are the past experiences, age, attitude, cognitive status, extent of social support, prognosis, patient's financial situation or education (Kolcaba, 1994).

Part 2 of comfort theory states that enhanced comfort strengthens patients to consciously or subconsciously engage in behaviors that move them toward a state of well-being (Wilson & Kolcaba, 2004). These behaviors are called health-seeking behaviors (HSBs) and include internal, external behaviors and a peaceful death (Kolcaba, 2001; Kolcaba, 1994).

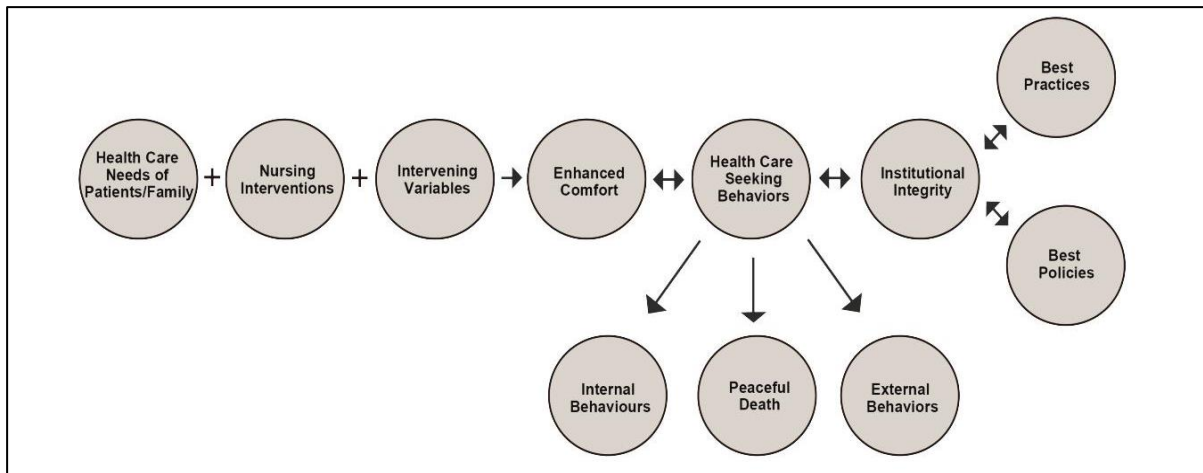
Patients who are empowered to actively engage in HSBs are satisfied with their health care (Kolcaba, 2001; Vendlinski & Kolcaba, 1997).

In part 3 of comfort theory, HSBs are related to what is called institutional integrity. That is, when people have the necessary support to commit to health-seeking behaviors, such as rehabilitation or recovery, institutional integrity is also better.

Institutional integrity is defined as the quality or state of health care organizations in terms of being complete, sound, upright, professional, and ethical providers of health care (Kolcaba, 2003). That is measured by many indicators, including cost of care; length of stay; staff turnover rate; and patient, nurse, and staff satisfaction.

In summary, the comfort interventions promote greater patient satisfaction, greater satisfaction and creativity of nurses, and echoed in a benefit to the institution (Kolcaba, 2003)

Figure 2 presents the Conceptual Framework for Comfort Theory (Kolcaba, 1994, 2010). This diagram presents the major concepts and assumptions, as well the relations among them.



**Figure 2:** Conceptual Framework for Comfort Theory

Adapted from *www.thecomfortline.com* (Kolcaba, 2010), with permission of Professor Kolcaba (Appendix 10).

According Kolcaba (2003) comfort care entails at least three types of comfort interventions that can be implemented to achieve the goal of enhancing patients' total comfort:

The first are standard comfort interventions (or technical comfort measures) that are designed to maintain homeostasis such as monitoring vital signs and laboratory result. Standard comfort interventions also include attention to pain, administration of medications, or repositioning. These comfort interventions are designed to help the patient maintain or regain physical function and comfort and prevent complications.

The second type of comfort interventions is "coaching." Coaching helps to relieve anxiety, provide reassurance and information, and instill hope. It involves listening and offering an optimistic plan for recovery in a culturally sensitive way.

The last group of comfort interventions is described as "comfort food for the soul." Examples of interventions that provide comfort food for the soul are GI, massage, music therapy and touch. These comfort interventions make patients feel strengthened in intangible, personalized ways.

Comfort food for the soul targets the need for transcendence through memorable connections between the nurse and patient or family. These connections help to fortify patients for the difficult tasks like the end of life or death.

According Kolcaba (1991; 2003), the holistic comfort intervention can be used to target many comfort needs at one time and the results of this study support this.





### 1.3. Guided Imagery

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GI is a mind-body therapy that has been used for decades to influence health outcomes, being increasingly used as an adjunctive therapy to a conventional treatment approach for various conditions (Davenport, 1996; Hart, 2008).

GI is a technique that utilizes stories or narratives to influence the images and patterns that the mind creates. that is, GI use the imagination to create images that bring about beneficial emotional and physical effects (Hart, 2008).

According Naparstek (1994), imagery is any perception that comes through any of the senses including sight, sound, smells and feel, and can seem as real as actual events.

The GI, in turn, consists in the creation of a mental experience through images that are the product of the imagination. It is conducted because the therapist's voice, in person or audio-taped, directs the attention and imagination of the person to the creation of mental images, through the induction of an organized set of stimuli such as: objects, scenarios, emotions, personal relationships, colors, smells, sounds, textures, tastes, kinesthetic sense, etc. (Apóstolo, 2010; Naparstek, 1994; Payne, 2003).

GI can evoke psychophysiological changes in the body that mimic the changes that occur when an actual event occurs.

Through imagery, changes can be stimulated in many physiological functions, usually regarded as inaccessible to the influence of consciousness (Rossman, 2000). Triggering a movement, such as bringing the hand to the nose, is done voluntarily, and it can be explained which brain, muscle, or nerve structures have been involved in this movement. However, salivating is not achieved voluntarily, because it is not under conscious control (Naparstek, 1994; Rossman, 2000). While the central nervous system regulates voluntary movements, the autonomic nervous system regulates salivation as well as other functions that operate without conscious control. The autonomic nervous system does not readily respond to common thoughts such as salivation, but responds to imagery (Rossman, 2000).

In fact, if we imagine that we are picking up a lemon, feeling its texture and weight, cutting it in half, squeezing one of the parts into a glass, touching the glass on the lips and drinking the

respective juice we will surely salivate (Rossman, 2000). If we salivate it is because the autonomic nervous system responded to the imagery. In the same way as we look at the menu of a meal, the mind creates images of how the meal can be, relative to the smell, taste, texture, etc. (Naparstek, 1994).

According to specialists in this approach (Hart, 2008; Naparstek, 1994) if frightening or negative imagery has the ability to increase pain and other unwanted symptoms, then positive or calming imagery may lessen pain and unwanted symptoms.

However, GI also may utilize aggressive thinking as in the case of a person who has cancer and visualizes cancer cells in his or her body being destroyed, which can lead to increased feelings of power and control in that individual (Hart, 2008; Naparstek, 1994; Van Kuiken, 2004).

### **Types of guided imagery**

There are many types of GI, with a variety of purposes.

Van Kuiken (2004), for example, in a review on the effects of GI on outcomes, described four types of GI:

- 1) Positive imagery (or pleasant imagery), that consist in imagining a calm and confort place;
- 2) Physiologically focused imagery, focusing on the physiologic function that needs healing, as for example, visualization of cancer cells being destroyed;
- 3) Reframing imagery (or mental rehearsal), that consist in imagining a specific task or performance before the event occurs or reframing a prior event. This can be applied, for example, to athletes in the development of a physical task;
- 4) Receptive imagery, which refers to scanning the body to direct healing. For this type of GI involve a self-assessment with diagnostic objectives the author did not consider it as intervention.

In its turn, Naparstek (1994) considers:

- 1) Physical imagery, relative to what happens microscopically at the cellular level. The patient might envision, for example, immune system cells as part of an army that attacks malignant cells.
- 2) Metaphoric imagery, which uses symbols to envision illness or healing such as visually representing radiation as sunshine, or a tumour as an enemy encampment.

- 3) Psychological imagery that involves patients' perceptions of themselves. For example, patients who feel overly responsible may imagine the weight of the world being lifted from their shoulders.
- 4) Spiritual imagery, that instructs patients to make contact with God or the Divine. Patients find guidance and inspiration by imagining their deity.
- 5) End-state imagery, in which patients imagine already being in the situation or circumstance that they wish for. Examples include seeing oneself as healthy or successful.
- 6) Energetic imagery, that involves imagining life force energy free flowing through the body. Patients may imagine, for example, pull up energy from the earth through the soles of the feet.
- 7) Feeling state imagery, that helps patients change their mood in a generalized way. This can be done by imaging a favourite place, such as a beach or cabin in the woods.

As can be seen, the classifications attributed by these authors are distinct. In fact, although in the literature, several types of GI arise, described by a group of authors, often under different classifications, there is an overlap with the content of some of the different types of imagery. In this regard, Naparstek (1994) refer that none of these categories is absolutely distinct from the others, and there may be a cross between the different categories and classifications.

In particular, in the previous classifications presented by Naparstek (1994) and Kuiken (2004), we verified that there is overlap of the content of the mental images relative to some types of imagery, as for example, between physical imagery and physiologically focused imagery, between end-state imagery and reframing imagery.

In the context of this work, the "positive imagery" that comes closer to the "feeling state imagery" is of more interest. Naparstek (1994) exemplifies that this type of imagery may include mental images of the personal favorite place, real or imaginary, or an encounter with a special person.

In this type of visualization, individuals, in a state of relaxation, are invited to follow a series of imagined scenarios, mainly natural scenes, rich in sensations, full of peace and beauty. A reference figure (familiar, friend, health care professional) is evoked, which the individual "visualizes" and receives, reporting their needs, followed by a counseling dialogue (Payne, 2003; Samuels, 2003).

## **Use of Guided Imagery as a therapeutic intervention**

GI may be delivered by a practitioner, a video, or an audio recording. A typical guided-imagery session usually begins with relaxation in which the participant takes some deep breaths and releases tension in his or her mind and body. Then, the participant starts to visualize pleasant or effective imagery (Hart, 2008).

It is agreed among GI specialists that the therapeutic use of GI should be preceded by some form of relaxation, such as progressive or passive relaxation (Naparstek, 1994; Payne, 2003; Rossman, 2000; Samuels, 2003), as well as accompanied by music (Eller, 1994; Naparstek, 1994).

Relaxation is defined as a state of consciousness characterized by feelings of peace and relief from tension, anxiety and fear (Payne, 2003). Progressive relaxation is a type of active relaxation achieved through the contraction and relaxation of muscle groups. Relaxation may, however, be passive, not by using contraction exercises, but only the passive relaxation of the various muscle groups. This is used in situations where muscle contraction may be contraindicated or impossible (Payne, 2003), as is the case of some of the participants in the studies of this thesis. One of the advantages of passive relaxation scripts is that they take less time to execute than tension-strain.

Relaxation is intended to allow the mind to open and expand, and is the first step towards improving the ability to "visualize" and the success of GI. In a state of relaxation, the mental image is easier to generate and its effects are more effective (Payne, 2003; Rossman, 2000).

Concerning music, this plays a powerful and underappreciated role in increasing the power of GI, since besides increases the healing power of the imagery, adding interest and emotional flavour to the experience.

In one study by GI expert Eller (Eller, 1994), with Human Immunodeficiency Virus (HIV) patients, the recorded interventions tested were GI and progressive relaxation. The music track was removed from the imagery tape, so that both treatment conditions would be "pure" and would match each other. The study found that the GI was less impactful than anticipated. The HIV patients still reported a reduction in anxiety and depression, but the results were far less dramatic than previous reports had led investigators to expect. The explanation was that without the music, the imagery had lost some of its potency.

Nevertheless, Naparstek (1994) draws attention to the importance of choosing music that is compatible, pleasant, and not too obtrusive, because the objective is not to compete with the imagery but to support it.

Thus, the GI technique begins with a relaxation process, inviting the person to let their eyes close by focusing on the breath. The breath should be calm, deep, regular and abdominal, exhaling all the air effortlessly, relaxing with each breath. The person must focus attention inward, releasing it from outside disturbances. Respiratory exercise should be followed by muscle relaxation, which may involve sixteen muscle groups with simpler or more complex combinations (Payne, 2003).

As previously mentioned, the literature considers that, in the development of positive imagery, favorite places, natural environments, peaceful and relaxing scenes should be selected. Thus, after relaxation exercises, people should be gently induced to create mental images. In the case of positive imagery, the approach underlying the intervention we develop, participants should be led to think of themselves in an imaginary place where they feel safe, calm, and protective. It should be encouraged, focusing on the vivid details of the landscape, sounds, and smells, and a global feeling of being in a quiet, special place that induces serenity and peace. It is also mentioned the possibility of scenes alluding to a meeting with a special person who provides support, confidence and can serve as a confidante (Naparstek, 1994).

The greatest difficulties to perform this technique may be the lack of concentration, which can be overcome with practice (Naparstek, 1994). As regards the duration of the intervention, Naparstek (1994) recommends that GI should be used between five to twenty minutes, depending on the person's ability to maintain concentration and also points out that GI becomes increasingly effective with time and practice. Kuiken (2004), in turn, states that the time required for the GI to have effective results is unknown. Apóstolo (2010) says that effectiveness will be related to the type of intervention, the sample, the expected results and the possibility of intervention.

In this line, Naparstek (1994) states that one of the adverse effects of prolonged GI interventions is the saturation of individuals, which may jeopardize therapeutic adherence. To minimize this effect, some authors advocate different types of recording used interchangeably.

The use of mental imagery can still put the person in touch with the most intimate parts of themselves, so it is possible to succeed strong emotional reactions such as anger, resentment, guilt and frustration, so there must be adequate supervision (Apóstolo, 2010). Seaward (2002) also draws attention to the possible adverse effects that some images may cause on some people. For example, someone who develops anxiety at heights or enclosed spaces may be counterproductive to induce images of a mountain or a narrow path.

Finally, it should be noted that Naparstek (1994) discriminates GI from meditation and hypnosis, referring that hypnosis generally includes verbal suggestions without images, and meditation commonly focuses on one thing, such as the breath or a mantra. But GI, can be considered a form of meditation.

### **Research about Guided Imagery**

GI is one of the non-pharmacological interventions increasingly implemented in different clinical contexts.

A quasi-experimental study conducted by Onieva-Zafra, García and Del Valle (2015), in a sample of 60 patients diagnosed with fibromyalgia revealed GI intervention is related to reduction in pain and depression in this patients.

In the study carried out by Gonzales et al. (2010), in 44 adults scheduled for head and neck procedures were randomly assigned into 2 groups for this single-blind investigation it has been proven that the use of GI in the ambulatory surgery setting significantly reduce preoperative anxiety and pain.

In the study of Lewandowski (2004), 42 chronic pain sufferers randomly assigned to treatment and control groups, revealed a decrease in pain in the GI intervention group.

In another randomized controlled trial study developed by Shahriari, Dehghan, Pahlavanzadeh and Hazini (2017), 50 elderly patients with breast or prostate cancer, revealed statistically significant improvement in quality of life in the group submitted to guided imagery.

One more quasi-experimental study implemented by Hosseini, Tirgari, Forouzi and Jahani (2016), 55 eligible breast cancer patients were evaluated, pre and post intervention with GI. The frequency and severity of nausea and vomiting pre and post chemotherapy decrease significantly in these patients.

Nooner, Dwyer, DeShea and Yeo (2016), realized in their randomized study with 12 adult patients with cancer, that patients submitted to a GI intervention reported a high degree of satisfaction and showed a trend toward improvement in fatigue and sleep disturbance scores.

In addition, Charalambous et al. (2016), in randomized control trial with 208 patients receiving chemotherapy, verifies that patients in the intervention group (submitted to GI) experienced lower levels of fatigue and pain, and experienced better quality of life, compared to those in the control group.

In relation to studies on the effect of GI on the increase of holistic comfort, there are the works of Kolcaba and Fox (1999) and Apóstolo and Kolcaba (2009).

In the study of Kolcaba and Fox (1999), performed with the aim of measure the effectiveness of customized guided imagery for increasing comfort in women with early stage breast cancer, it was conducted a experimental longitudinal, random assignment to groups, in a sample of 53 women (26 in the experimental group, 27 in the control group) with stage I or II breast cancer about to begin radiation therapy. The results indicated a significant overall increase in differences in comfort between the treatment and control group, with the treatment group having higher comfort over time.

The study developed by Apóstolo and Kolcaba (2009), describes the efficacy of a guided imagery intervention for decreasing depression, anxiety, and stress and increasing comfort in psychiatric inpatients with depressive disorders. In this study was performed a quasi-experimental design sampled 60 short-term hospitalized depressive patients selected consecutively. The experimental group listened to a guided imagery compact disk once a day for 10 days. The results revealed that the treatment group had significantly improved comfort and decreased depression, anxiety, and stress over time.





# **CHAPTER II**

## **COURSE OF INVESTIGATION**

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This chapter introduces the research course, and consists of two sub-headings.

The first sub-heading presents the objectives and the hypothesis of the study. The second sub-heading presents an explanation of each of the Phases that comprise the study as well as a diagram of the study design.

Specific information about the methodological approach, population and ethical procedures is described in each study.



## 2.1. Aims and hypothesis

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The development of this research was supported by the theory of the comfort of Katherine Kolcaba (1995; 2001; 2003). The objectives of this thesis are:

- 1) To map the non-pharmacological interventions implemented and evaluated to provide comfort in PC;
- 2) To understand the comfort and discomfort experienced by inpatients at PCUs;
- 3) To translate, adapt and validate the HCQ for use in the PC Spanish context;
- 4) To develop a GI script as intervention of non-pharmacological comfort in patients hospitalized in PCU;

The knowledge derived from the achievement of these objectives has the purpose of preparing the evaluation instrument and the necessary intervention to reach the final objective:

- 5) To evaluate the effect of a GI program in the comfort of PCU inpatients.

Regarding the objective five, the following hypothesis was addressed:

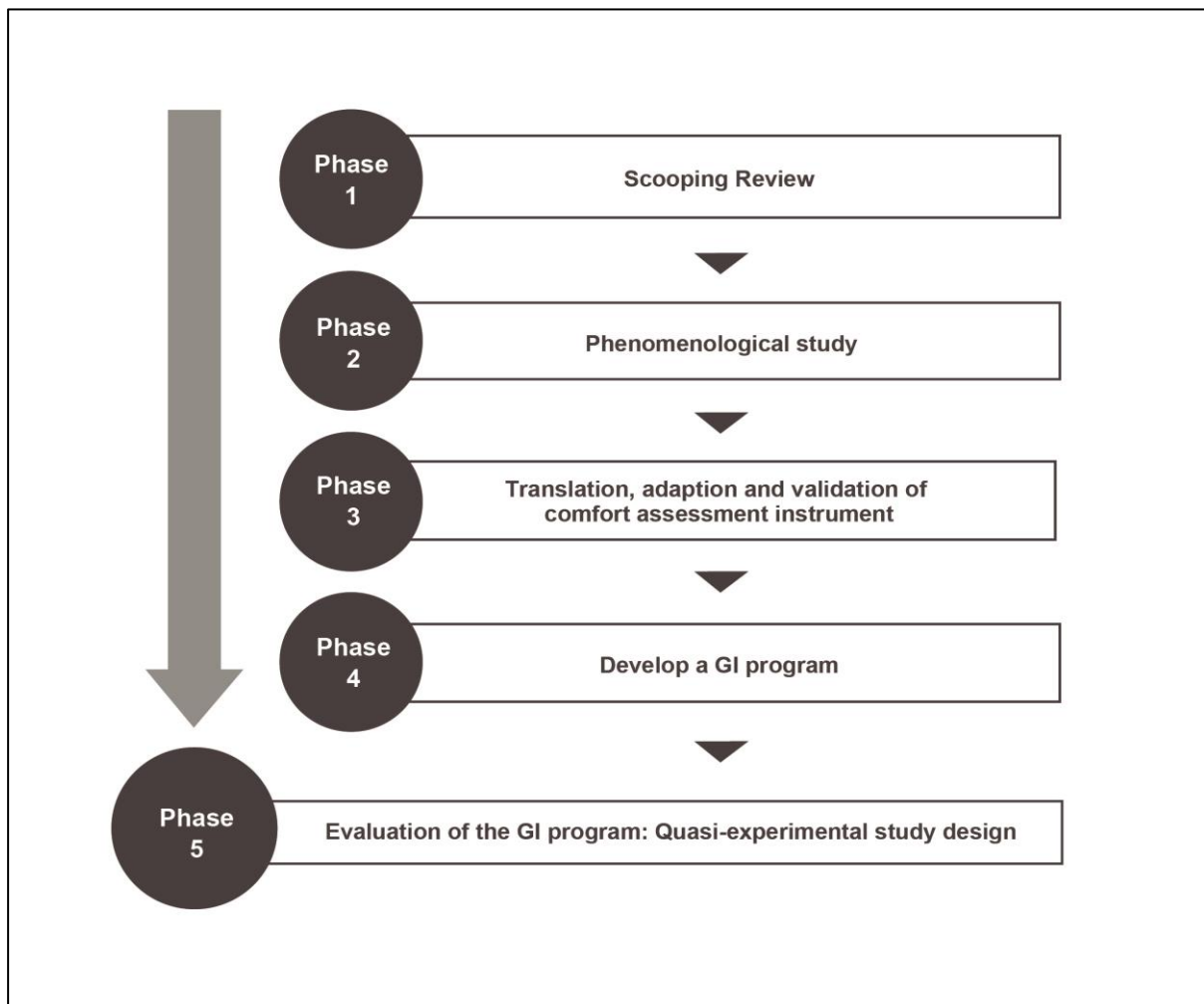
Inpatients in PC who received a program of GI will experience improved comfort and reduced pain, heart rate, and respiratory rate.



## 2.2. Study design

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Each objective of the study represents a Phase of the same. Thus, to improve clarity and provide a better understanding of the course of research, the following illustrative figure of the process was made (figure 1):



**Figure 1:** Study Design

In the Phase 1, a protocol was carried out and the respective Scoping Review that maps the non-pharmacological interventions implemented in PC with the objective of providing comfort. This scoping review provided relevant information on other complex interventions implemented in this context, their characteristics, the characteristics of the target population, and the methods used to assess them (Coelho et al., 2017). In addition, it revealed the lack of GI programs adapted to the context of the PCs, which reinforced the need to carry out the present study.

In the Phase 2, a qualitative study of a phenomenological nature was carried out, which allowed to understand the experiences of comfort and discomfort of inpatients at PCUs, providing evidence for the development of a GI Program adjusted to the comfort needs of inpatients at PCUs.

In the Phase 3 was validated for Spanish the HCQ (Novak, Kolcaba, Steiner, & Dowd, 2001). It was our objective, at the moment in which this project of thesis was designed, to develop and to implement two programs of GI. The first program to be implemented in a Portuguese PCU and the second program to implemented in a Spanish PCU. In this line, it would be necessary instruments of evaluation of comfort validated transculturally. In the Portuguese context there is already an instrument for evaluating comfort (HCQ-PT-DC). However, in the Spanish context, this instrument did not exist. For this reason, the HCQ was adapted, translated and validated. Although in the course of the research it was opted to develop and implement the GI program only in the Portuguese context, it was considered opportune to contemplate this validation as a Phase of the present thesis.

In the Phase 4, with the support of the information from the first two Phases, a GI program adjusted to the comfort needs of inpatients at PCUs was developed and validated in order to provide comfort to them. This Phase underlies the Medical Research Council<sup>1</sup> (MRC) (Craig et al., 2008, 2013) guidelines for the development of complex interventions.

The Phase 5 consisted in the implementation and evaluation of the previously developed GI program, through a quantitative study of a quasi-experimental nature of pretest-posttest design with a single group, thus contemplating only one group of subjects (experimental group), analyzing the comfort levels of the participants before and after the GI intervention.

The purpose of this study is to contribute to the promotion of the comfort experienced by inpatients at PCUs.

---

<sup>1</sup> The guidelines for the development of complex interventions do Medical Research Council consist of 3 steps: *Identifying existing evidence*; *Identifying and developing theory*; and *Modelling process*. The Phase 1 of this thesis (Scoping Review), corresponds to *Identifying existing evidence*. The Phase 2 (*Phenomenological study*), integrates the *Identifying and developing theory*. The Phase 4 describes the *Modelling Process*.

## **CHAPTER III**

### **USE OF NON-PHARMACOLOGICAL INTERVENTIONS FOR COMFORTING PATIENTS IN PALLIATIVE CARE**

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This chapter addresses the Phase 1 of the study, and is divided into three sub-heading. Since Scoping Reviews are a recent methodological approach, the first sub-heading presents it.

The second sub-heading presents the protocol developed for the Scoping Review, according to the JBI methodology.

The third sub-heading presents the report of the Scoping Review developed.

This Scoping Review, revealed the lack of GI programs adapted to the context of PCs, reinforcing the need to carry out the present study, provided in addition, relevant information on other complex interventions implemented in this context, their characteristics, the characteristics of the target population, and the methods used to assess them. This information was essential for the achievement of the study.





### 3.1. Systematic scoping review

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Reviews of primary research are becoming more common as evidence-based practice gains recognition as the benchmark for care, and the number of, and access to, primary research sources has grown. With the increase of authors conducting reviews to integrate research findings, various review types have evolved with their corresponding methodologies, developing in precision and clarity. One of these review types is the 'scoping review' (Peters, Godfrey, Khalil, et al., 2015).

Although the first framework for scoping reviews was published in 2005 (Arksey & O'Malley, 2005), scoping reviews are still a relatively new methodology that, as yet, do not own a universal definition or definitive method (Anderson, Allen, Peckham, & Goodwin, 2008; Arksey & O'Malley, 2005; Hsieh & Shannon, 2005; Levac, Colquhoun, & O'Brien, 2010).

The more relevant value of scoping reviews to evidence-based practice is the examination of a broader area to identify gaps in the research knowledge base, clarify key concepts, and also report on the types of evidence that address and inform practice in the field. Scoping reviews may be carried out to determine not only the extent of the research available about a topic but also the way the research has been conducted (Arksey & O'Malley, 2005; Colquhoun et al., 2014; Levac et al., 2010; Peters, Godfrey, Khalil, et al., 2015; Peters, Godfrey, McInerney, et al., 2015).

To support the greater breadth of scoping reviews, a diversity of study designs are usually included.

Scoping reviews, also called 'mapping' reviews, are useful when a body of literature has not been yet comprehensively reviewed, or reveals a large, complex, or heterogeneous nature not amenable to a more precise systematic review. Scoping reviews undertaken with the aim of providing a map of the range of the available evidence can be undertaken as a preliminary exercise prior to the conduct of a systematic review, clarifying that others more specific questions can be posed and valuably addressed (Levac et al., 2010; Peters, Godfrey, Khalil, et al., 2015; Peters, Godfrey, McInerney, et al., 2015).

While scoping reviews can be conducted to determine the value and probable scope of a full systematic review, they could also be undertaken as exercises in and of themselves, namely

to examine the extent, range, and nature of research activity, to summarize and disseminate research findings, and to also to make recommendations for future research (Levac et al., 2010; Peters, Godfrey, McInerney, et al., 2015).

Different of other reviews that address relatively specific questions, such as a systematic review of the effectiveness, scoping reviews may be used to map the key concepts underpinning a research area as well as to clarify working definitions, and/or the conceptual boundaries of a topic (Arksey & O'Malley, 2005), besides to map evidence in relation to time, location and/or source (Anderson et al., 2008).

Similarly, "policy maps" could also be developed by scoping reviews that pursue to identify and map evidence such as policy documents and reports that guide practice in a specific field (Anderson et al., 2008).

A typical systematic review aims to response a specific question based upon the PICO (Population, Intervention, Comparator, and Outcome) elements of its inclusion criteria. However, a scoping review will have a broader approach, commonly with the aim of mapping literature and addressing a broader research question, with fewer restrictive inclusion criteria and based upon the PCC (Population, Concept and Context) elements of the inclusion criteria (Peters, Godfrey, McInerney, et al., 2015).

The scoping review question may draw upon data from any type of evidence and research methodology, and is not circumscribed to quantitative studies or any other study design alone. However, reviewers may decide that certain study designs not be appropriate or useful for consideration (Peters, Godfrey, McInerney, et al., 2015). Another important distinction between scoping reviews and systematic reviews is that, unlike systematic reviews, scoping reviews offer a view of breadth and depth of existing evidence, regardless of quality. This is because scoping reviews aim to provide a map of what evidence has been produced as opposed to pursuing only the best available evidence to response a particular question related to policy and practice (Brien, Lorenzetti, Lewis, Kennedy, & Ghali, 2010; Levac et al., 2010; Peters, Godfrey, McInerney, et al., 2015; Rumrill, Fitzgerald, & Merchant, 2010).

Therefore, while implications for research could be made from the results of scoping reviews, implications for practice are limited since a formal assessment of methodological quality of the included studies of a scoping review is not performed (Peters, Godfrey, Khalil, et al., 2015; Peters, Godfrey, McInerney, et al., 2015).

Guidelines or frameworks for conducting scoping reviews have been developed and improved upon over time. The most consistently used is the Arksey and O'Malley (2005) framework. Their framework has been further enhanced by the work of Levac, Colquhoun

and O'Brien (Levac et al., 2010). Levac and colleagues provide additional explicit detail concerning what occurs at each stage of the scoping review process and this enhancement increases both the clarity and rigor of the review process (Colquhoun et al., 2014; Levac et al., 2010) (Table 1).

**Table 1:** Arksey and O'Malley framework stages for the conduct of scoping reviews combined with the Levac et al. enhancements. Adapted from Levac et al.(2010, p. 4)

Arksey and O'Malley framework	Description of scoping review stage	Levac et al. enhancements
<u>Stage 1</u> Identifying the research question	The scoping review question must be clearly defined as it plays a role in all subsequent stages. In order to examine and summarize breadth, scoping review questions are broad.	<ol style="list-style-type: none"> <li>1. Despite the broad nature of the question, ensure adequate clarity to guide the scope of inquiry including concept, target population, and health outcomes of interest.</li> <li>2. Determine the research question in conjunction with the purpose for conducting the scoping review.</li> <li>3. Stipulate the outputs (e.g, framework, list of recommendations) that will be the result of the review.</li> </ol>
<u>Stage 2</u> Identifying relevant studies	This stage involves identifying the relevant studies and developing a plan for where to search, which terms to use, which sources to search, time span, and language.	<ol style="list-style-type: none"> <li>1. Use the research question and purpose to guide decision-making around the scope of the review.</li> <li>2. Justify all decisions for limiting the scope of the review and acknowledge any potential limitations as a result.</li> <li>3. Ensure the team has the content and methodological expertise necessary for the review.</li> </ol>
<u>Stage 3</u> Study selection	Study selection involves inclusion and exclusion criteria. These criteria are based on the specifics of the research question and on familiarity with the subject matter through reading the studies.	<ol style="list-style-type: none"> <li>1. Study selection is an iterative process that involves searching the literature, refining the search strategy, and reviewing articles for study inclusion.</li> <li>2. Improved clarity in decision-making for study selection can be achieved using the following steps: <ul style="list-style-type: none"> <li>-Conduct an initial team meeting to discuss inclusion and exclusion criteria;</li> <li>-Use two reviewers to independently review abstracts and full text articles;</li> <li>-Incorporate a third reviewer in situations of disagreement.</li> </ul> </li> </ol>
<u>Stage 4</u> Charting the data	A data charting form is developed and used to extract data from each study. A "narrative review" or "descriptive analytical" method is used to extract contextual or process-oriented information from each study.	<ol style="list-style-type: none"> <li>1. The research team should collectively determine which variables to extract in order to answer the research question.</li> <li>2. Charting should be considered an iterative process in which reviewers continually extract data and update the data charting form.</li> <li>3. Reviewers should pilot the charting form on five to ten studies to determine whether their approach to data extraction is consistent with the research question and purpose.</li> <li>4. Contextual or process-oriented data may require a qualitative content analysis approach.</li> </ol>
<u>Stage 5</u> Collating, summarising and reporting the	An analytic framework or thematic construction is used to provide an overview of the breadth of the literature. A numerical analysis of the nature and extent of studies	<p>Researchers should undertake the following three steps:</p> <ul style="list-style-type: none"> <li>-Analyze;</li> <li>-Report the results;</li> <li>-Discuss the findings as they relate to the study</li> </ul>

results.	using tables and charts is presented. A thematic analysis is then presented.	purpose and implications for future research, practice and policy.
<u>Stage 6</u> Consultation	This optional stage provides opportunities for consumer and stakeholder involvement to suggest additional references and provide insights beyond those in the literature.	<ol style="list-style-type: none"> <li>1. The value of consultation should be considered for every scoping review.</li> <li>2. The process for consultation should include the following steps: <ul style="list-style-type: none"> <li>- Establish a clear purpose for the consultation;</li> <li>-Use preliminary findings to inform the consultation;</li> <li>- Clearly articulate the type of stakeholders to consult;</li> <li>-Incorporate opportunities for knowledge transfer and exchange with stakeholders in the field.</li> </ul> </li> </ol>

Most recently, based on the framework proposed by Arksey and O'Malley (2005) and on the improvements proposed by Levac et al. (2010), the JBI developed guidelines for standardizing the conduct and reporting of scoping reviews, this standardization aims to improve the utility and robustness of the results of scoping reviews (Peters, Godfrey, Khalil, et al., 2015; Peters, Godfrey, McInerney, et al., 2015).

As all JBI systematic reviews, scoping reviews initiate with the development of a protocol, followed by a rigorous, replicable, and extensive search of the international literature (Peters, Godfrey, Khalil, et al., 2015).

The protocol is developed before the commencement of the scoping review to enhance the rigor of the process and provide clarification as questions occur during the analysis of the evidence obtained from the review (Cacchione, 2016). This is a systematic approach to the conduct and reporting of the review and allows transparency of process (Peters, Godfrey, McInerney, et al., 2015).

The additional guidance proposed by JBI on the components that should comprise the final report of a scoping review and the information that each component should contain are presented in table 2.

**Table 2:** Guidelines for conducting / writing a Scoping Review Report for JBI (Adapted from Peters, Godfrey, McInerney, et al. (2015, pp. 16–22) and (Peters, Godfrey, Khalil, et al. (2015, pp. 143–146).

Necessary components	Description
Title	Should be clear, explicit, and reflect the core elements of the review (Population, Concept and Context)
Executive Summary	Structured abstract which includes the main features of the scoping review (Objective, Inclusion Criteria, Search strategy, Extraction results, Presentation of results, Conclusions) without abbreviations or references
Background	Comprehensive section of all the main elements of the review topic, important definitions, and the existing knowledge in the field.
Review question/objective	The objective may be broad and will guide the scope of the enquiry. The review question(s) should be consistent with the title and direct the development of the specific inclusion criteria.
Inclusion Criteria	The types of participants and the concept examined by the scoping review, and the context should be defined clearly and unambiguously as possible and the types of sources used
Search Strategy	Should be comprehensive in order to identify both published and unpublished (grey literature) evidence. It is made in three-steps: -The first step is an initial limited search of a selection of relevant databases, followed by an analysis of text words contained in the title and abstract, and of the index terms used to describe the article; - A second search using all identified keywords and index terms is then undertaken across all included databases; - Thirdly, the reference list of all identified reports and articles should be searched for additional studies.
Methods (Extraction results)	Should include extraction of all data relevant to inform the scoping review objective and question/s. Charting table or forms may be used.
Results (Presentation of results)	May be presented as a 'map' of the data in a logical, diagrammatic, or tabular form, and/or in a descriptive format that aligns to the objective/s and scope of the review.
Discussion	Should include an in-depth discussion of the results of the review, as well as any limitations of the sources included in the scoping review. Results presented should be discussed in the context of the current literature, practice, and policy.
Conclusions	Overall conclusion that matches the objective or question with implications for research and practice.



### **3.2. The use of non-pharmacological interventions for the comfort of patients in palliative care: a scoping review protocol**

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## The use of non-pharmacological interventions for the comfort of patients in palliative care: a scoping review protocol

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### Review question/objective

The objective of this scoping review is to examine and map the non-pharmacological interventions implemented and evaluated to provide comfort in palliative care.

More specifically, the review will focus on the following questions:

1. What non-pharmacological interventions have been implemented and evaluated to provide comfort in patients with incurable and advanced diseases?
2. What are the characteristics (duration, dose and frequency) of these interventions?
3. In what contexts (home care, palliative care unit or hospice) are the non-pharmacological interventions implemented and evaluated?
4. In which populations (cancer and non-cancer patients) are the non-pharmacological interventions implemented and evaluated?

## Background

The outcome of advancements in science and technology is increased life expectancy.<sup>1</sup> Therefore the aging of populations in societies where death may be delayed allows us to predict a gradual increase in the prevalence of degenerative and disabling diseases and consequently sources of suffering.<sup>2,3</sup> This is a challenge for health services and demands attention to the person in a holistic way, based on the biomedical model which focuses on the somatic aspects, i.e. beyond psychological, social and spiritual ones.<sup>4</sup> This new holistic paradigm requires finding procedures that alleviate suffering and provide comfort. These are central goals of medicine, especially in palliative care (PC).

Callahan<sup>5</sup> proposed two main goals for the 21<sup>st</sup> century medicine: first, to prevent and cure diseases; second, to help human beings die in peace. Since death is inevitable, enabling people to die in peace is as important as preventing and curing diseases, thus the advent of PC as a response to the suffering associated with the process of dying.<sup>6</sup> According to the World Health Organization, PC is “an approach that improves the quality of life of patients and their families facing the problem 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.”<sup>7(p84)</sup>

Confronting mortality, the gradual worsening of his condition, the debilitating physical symptoms, as well as the emotional and spiritual struggles experienced by a person with an incurable and advanced disease (IAD) make the process of living with the disease longer than necessary, painful and characterized by intense suffering.<sup>8,9</sup> In addition, these people sometimes undergo treatments which have secondary effects, increasing their anxiety, depression and body discomfort, which can consequently have a significant effect on their comfort and wellbeing.<sup>10,11</sup>

In this regard, pharmacological techniques have advanced, leading to better control of physical pain. However, PC extends beyond the relief of physical symptoms. It seeks to integrate the psychological, spiritual and social aspects in order to provide even more comfort to people with IAD.<sup>1,12</sup> In fact, Kolcaba, in her theory of comfort defined it as “the satisfaction (actively, passively or co-operatively) of the basic human needs for relief, ease or transcendence arising from health care situations that are stressful” in the physical, social, psych spiritual and environmental contexts.<sup>13(p1178)</sup> Therefore, pain, suffering, fatigue, depression or anxiety, are factors that influence the level of comfort<sup>14,15</sup>, and for this reason we the reviewers use these related elements to describe the concept of comfort.

With the increase in the need for PC units<sup>1,16</sup> comes a pressing requirement for improved care at the end of life to minimize suffering and to provide comfort. At the core of this work, as referred by Cicely Saunders,<sup>17</sup> are nurses who pass on to patients a great feeling of comfort. In fact, nurses, given the proximity and amount of contact time with the person who is ill, are in a unique position to promote comfort.<sup>8</sup> Indeed, from its origins until today, nursing has emphasized that its concern and goal is the promotion of comfort.<sup>18</sup>

Literature reveals that comfort is a concept that has been identified as a key element of care by theorists of the nursing discipline.<sup>19</sup> However, its meaning is often implicit, hidden in the context and usually leading to ambiguity.<sup>20</sup> The comfort theory, developed by Kolcaba, maintains that comfort is a desirable holistic purpose of the nursing discipline. Thus, nurses must perform an assessment of the needs of

health care arising from stressful situations (such as advanced disease). These needs can be presented verbally and nonverbally by patients.<sup>13</sup>

Designing comfort measures to meet these needs is part of nursing interventions, as well as the reevaluation of comfort levels after the implementation of these measures. As advocated by Kolcaba, "assessment (intuitive or formalistic) precedes intervention".<sup>21(p107)</sup>

The evaluation can also be intuitive (as when a nurse asks the patient if he is comfortable) or formalistic (such as through the observation of wound healing, by the administration of visual analogue scales or traditional questionnaires).<sup>21,22</sup>

Comfort interventions make patients feel strengthened in a personalized and intangible way. In this context it should be noted that patients who feel comfortable have a more peaceful death.<sup>23,24</sup> "A peaceful death is one in which conflicts are resolved, symptoms are well managed, and acceptance by the patient and family members allows for the patient to 'let go' quietly and with dignity."<sup>21(p80)</sup>

Therefore, the use of non-pharmacological interventions as an intervention strategy to promote comfort, in the context of PC, has been increasing.<sup>25,26</sup> It has been demonstrated that the use of complementary therapies in PC units increase patient satisfaction with care at the end of life.<sup>27</sup>

In this regard, some studies have been carried out on the implementation and evaluation of non-pharmacological interventions to provide comfort or other outcomes related to this concept, such as wellbeing, pain, suffering, stress, fatigue, anxiety or depression, particularly in patients with IAD.<sup>28-31</sup>

In these studies, hypnotherapy<sup>28</sup> implemented in hospice patients and measured by the Anxiety and Depression Scale have been reported to have an effect on improving anxiety; and art therapy,<sup>29</sup> implemented in PC units and measured by the Edmonton Symptom Assessment Scale have been reported to have an effect on improving pain, fatigue, depression and anxiety. Other studies have been carried out on the experiences of patients with IAD of non-pharmacological interventions. In these, aromatherapy, relaxation and mental images were used as interventions which provided feelings of relaxation, serenity and comfort.<sup>30,31</sup> It should be noted that the aforementioned studies were performed only with cancer patients.

However, information on implemented and evaluated interventions, their characteristics, contexts of application and population is dispersed in the literature,<sup>25,32,33</sup> which impedes the formulation of precise questions on the effectiveness of those interventions and therefore the conduct of a systematic review.

In other words, the literature on non-pharmacological interventions in PC reports in which much attention has been given to the somatic aspects of comfort<sup>33-35</sup> have not identified the other dimensions of comfort covered by the different non-pharmacological interventions. Furthermore, it is known that different interventions have been implemented in different contexts;<sup>32,33</sup> however, a summary of non-pharmacological interventions implemented in the context of PC does not exist. Furthermore the literature does not clarify the characteristics of the different non-pharmacological intervention programs. Finally the existence of non-pharmacological interventions implemented and evaluated in non-oncologic populations is unclear.

Thus, the objective of this mapping will be to clarify the above aspects. Without this clarification, it is not possible to proceed to the conduct of a systematic review on the effectiveness of an intervention aimed

at comfort, in a particular context and/or population, or the effectiveness of certain characteristics intervention aimed at comfort.

Consequently, there are important questions about the nature of the evidence in this area that need to be answered before formulating a precise question on effectiveness. This scoping review aims to provide answers to these questions.

Since the use of non-pharmacological interventions can improve patient comfort with incurable and advanced disease (IAD), mapping the evidence on this issue as an initial step in the conduct of a systematic review is imperative.<sup>34,35</sup>

This scoping review will be guided by the methodology proposed for Joanna Briggs Institute for the conduct of scoping reviews,<sup>36,37</sup> and aims to examine and map non-pharmacological interventions implemented and evaluated to provide comfort in people with IAD, their characteristics, their contexts and the type of advanced disease of these patients.

According to the Joanna Briggs Institute, "scoping reviews undertaken with the objective of providing a map of the range of the available evidence can be undertaken as a preliminary exercise prior to the conduct of a systematic review."<sup>36(p6)</sup> Therefore, this map will allow identify relevant issues in order to help advance evidence-based health care, develop knowledge, identify possible gaps and inform systematic reviews.

This scoping review is part of a research project which may lead to a systematic review focusing on the best evidence on the effects of non-pharmacological interventions on the comfort of people with IAD. In addition, this mapping will be help inform the development of appropriate and effective intervention(s) for patients with IAD in order to provide them with comfort.

An initial search of the JBI Database of Systematic Reviews and Implementation Reports, the Cochrane Library, Medline and CINAHL revealed that currently there is no scoping review (published or in progress) on this topic.

## **Keywords**

Palliative care; review; end of life; non-pharmacological interventions; comfort

## **Inclusion criteria**

### ***Types of participants***

This scoping review will consider all studies that focus on patients with IAD, 18 years or over, assisted by palliative care teams.

### ***Types of studies***

This scoping review will consider all studies that address non-pharmacological interventions implemented to provide comfort. These interventions may include, but will not be limited to, guided imagery, relaxation, therapeutic touch and massage.

It will consider non-pharmacological interventions implemented to provide not only comfort but also wellbeing and relief of pain, suffering, anxiety, depression, stress and fatigue that are concepts related to comfort.

### **Context**

This scoping review will consider all non-pharmacological interventions implemented and evaluated in the context of PC. This will include specifically home care, hospices or palliative care units.

### **Types of sources**

This scoping review will consider quantitative, qualitative studies and systematic reviews.

Quantitative designs include any experimental study designs (including randomized controlled trials, non-randomized controlled trials, or other quasi-experimental studies, including before and after studies), and observational designs (descriptive studies, cohort studies, cross sectional studies, case studies and case series studies).

Qualitative designs include any studies that focus on qualitative data such as, but not limited to, phenomenology, grounded theory and ethnography designs.

Systematic reviews include meta-analysis and meta-syntheses.

### **Search strategy**

The search strategy aims to find both published and unpublished studies. A three-step search strategy will be utilized in this review. An initial limited search of MEDLINE and CINAHL will be undertaken followed by an analysis of the text words contained in the title and abstract, and of the index terms used to describe the articles. A second search using all identified keywords and index terms will then be undertaken across all included databases. Thirdly, the reference list of all identified reports and articles will be searched for additional studies. Studies published in English, Spanish and Portuguese will be considered for inclusion in this review. Studies published in any year will be considered for inclusion in this review to capture how non-pharmacological interventions implemented and evaluated to provide comfort in palliative care has been researched and understood over time.

The databases to be searched include:

CINAHL Plus with Full Text

PubMed

Cochrane Central Register of Controlled Trials

LILACS

Scopus

Library, Information Science & Technology Abstracts

Scielo – Scientific Electronic Library Online

PsycINFO

The JBI Database of Systematic Reviews and Implementation Reports

Cochrane Database of Systematic Reviews

The search for unpublished studies will include:

ProQuest – Nursing and Allied Health Source Dissertations

Banco de teses da CAPES ( Brasil)

Teseo – Base de datos de Tesis Doctorales (Spain)

TDX – Tesis Doctorals en Xarxa (Spain)

RCAAP – Repositório Científico de Acesso Aberto de Portugal

Initial English language keywords to be used will be:

comfort OR pain OR suffering OR anxiety OR depression OR stress OR fatigue OR well-being

palliative; hospice; “home care” ; “end of life”; intervention

Articles searched will then be assessed for relevance to the review, based on the information provided in the title and abstract, by two independent reviewers. The full article will be retrieved for all studies that meet the inclusion criteria of the review. If the reviewers have uncertainties about the relevance of a study from the abstract is unclear, the full article will be retrieved.

Based on full texts, two reviewers will examine independently whether the studies conform to the inclusion criteria. Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer.

Studies identified from reference list searches will be assessed for relevance based on the study's title and abstract.

### **Data extraction**

Data will be extracted from papers included in the review using a charting table aligned to the objective and question of this research (Appendix I), as indicated by the methodology for scoping reviews developed by the Joanna Briggs Institute.<sup>36</sup>

A data extraction instrument was developed (Appendix I); however this may be further refined for use at the review stage.

Two reviewers will extract data independently. Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer.

The two reviewers, independent of each other, will chart the “first five to ten studies using the data-charting form and meet to determine whether their approach to data extraction is consistent with the research question and purpose”, as suggested by Levac, Colquhoun and O'Brien.<sup>38(p6)</sup> In addition, if it is necessary, primary authors will be contacted for further information/clarification of the data, as suggested by Arksey and O'Malley's framework.<sup>39</sup>

### **Data synthesis**

The overview of the reviewed material will, where possible and appropriate, be synthesized and presented in a tabular summary (Appendix II) with the aid of narrative and figures.

For question 1, the tables and charts may include data indicated in Table 1:

**Table 1: Template data presentation for Question 1**

<b>Non-pharmacological intervention</b>	Guided Imagery	Meditation	Therapeutic touch	Massage	(...)
<b>Concept</b>					
Comfort					
Pain					
Suffering					
Anxiety					
Depression					
Stress					
Fatigue					
Well-being					

For question 2, the tables and charts may include data indicated in Table 2:

**Table 2: Template data presentation for Question 2**

<b>Non-pharmacological intervention</b>	Guided Imagery	Meditation	Therapeutic touch	Massage	(...)
<b>Characteristics of intervention</b>					
Duration of intervention					
Dose of intervention					
Frequency of intervention					

For question 3, the tables and charts may include data indicated in Table 3:

**Table 3: Template data presentation for Question 3**

<b>Non-pharmacological intervention</b>	Guided Imagery	Meditation	Therapeutic touch	Massage	(...)
<b>Context</b>					
Home care					
Hospice					
Palliative care unit					

For question 4, the tables and charts may include data indicated in Table 4:

**Table 4: Template data presentation for Question 4**

<b>Non-pharmacological intervention</b>	Guided Imagery	Meditation	Therapeutic touch	Massage	(...)
<b>Advanced diseases</b>					
Oncology					
Non-oncology					

The narrative analysis, made by categories, will describe the aims of the studies and the results related to the review question.

### **Conflicts of interest**

The authors declare that there are no conflicts of interest.

### **Acknowledgements**

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**Appendix I: Data extraction instrument**

**Review title:** The use of non-pharmacological interventions for the comfort of patients in palliative care.

**Review questions:**

1. What non-pharmacological interventions have been implemented and evaluated to provide comfort in patients with incurable and advanced diseases?
2. What are the characteristics (duration, dose and frequency) of these interventions?
3. In what contexts (home care, palliative care unit or hospice) are the non-pharmacological interventions implemented and evaluated?
4. In which populations (cancer and non-cancer patients) are the non-pharmacological interventions implemented and evaluated?

**Inclusion criteria (PCC):**

**Population**

- Patients with 18 years of age or older, assisted by palliative care teams.

**Concept**

- Non-pharmacological interventions implemented and evaluated in palliative care, to provide comfort.

Notes:  
 These interventions may include, but not be limited to, guided imagery, relaxation, therapeutic touch, and massage.  
 Will be considered the "comfort" or these related concepts: pain, suffering, anxiety, depression, stress, fatigue and well-being.

**Context**

- Palliative Care. This will include, exclusively, home care, hospices or palliative care units.

**Study details and characteristics extraction**

Author(s) \_\_\_\_\_

Year of publication \_\_\_\_\_

Country of origin \_\_\_\_\_

Aims \_\_\_\_\_

Study population (oncologic or non-oncologic) and sample size \_\_\_\_\_

Context (palliative care unit/hospice/home care) _____
Non-pharmacologic intervention_____
Duration of the intervention_____
Dose of intervention_____
Frequency of intervention _____
Concept(s) of significance to the review question_____

**Appendix II: Results extraction instrument**

<b>Non-pharmacological intervention</b>	Guided Imagery	Meditation	Therapeutic touch	Massage	(...)
<b>Concept</b>					
Comfort					
Pain					
Suffering					
Anxiety					
Depression					
Stress					
Fatigue					
Well-being					
<b>Non-pharmacological intervention</b>	Guided Imagery	Meditation	Therapeutic touch	Massage	(...)
<b>Characteristics of intervention</b>					
Duration of intervention					
Dose of intervention					
Frequency of intervention					
<b>Non-pharmacological intervention</b>	Guided Imagery	Meditation	Therapeutic touch	Massage	(...)
<b>Context</b>					
Home care					
Hospice					
Palliative care unit					
<b>Non-pharmacological intervention</b>	Guided Imagery	Meditation	Therapeutic touch	Massage	(...)
<b>Advanced diseases</b>					
Oncology					
Non-oncology					

### **3.3. Use of non-pharmacological interventions for comforting patients in palliative care: a scoping review**

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SYSTEMATIC REVIEW

## Use of non-pharmacological interventions for comforting patients in palliative care: a scoping review

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### EXECUTIVE SUMMARY

#### Background

Palliative care aims to provide the maximum possible comfort to people with advanced and incurable diseases. The use of non-pharmacological interventions to promote comfort in palliative care settings has been increasing. However, information on implemented and evaluated interventions, their characteristics, contexts of application, and population is scattered in the literature, hampering the formulation of accurate questions on the effectiveness of those interventions and, consequently, the development of a systematic review.

#### Objective

The objective of this scoping review is to examine and map the non-pharmacological interventions implemented and evaluated to provide comfort in palliative care.

#### Inclusion criteria

##### Types of participants

This scoping review considered all studies that focused on patients with advanced and incurable diseases, aged 18 years or older, assisted by palliative care teams.

##### Concept

This scoping review considered all studies that addressed non-pharmacological interventions implemented and evaluated to provide comfort for patients with advanced and incurable diseases.

It considered non-pharmacological interventions implemented to provide not only comfort but also well-being, and relief of pain, suffering, anxiety, depression, stress and fatigue which are comfort-related concepts.

##### Context

This scoping review considered all non-pharmacological interventions implemented and evaluated in the context of palliative care. This included home care, hospices or palliative care units (PCUs).

##### Types of sources

This scoping review considered quantitative and qualitative studies, and systematic reviews.

##### Search strategy

A three-step search strategy was undertaken: 1) an initial limited search of CINAHL and MEDLINE; 2) an extensive search using all identified keywords and index terms across all included databases; and 3) a hand search of the reference lists of included articles.

This review was limited to studies published in English, Spanish and Portuguese in any year.

##### Extraction of results

A data extraction instrument was developed. Two reviewers extracted data independently. Any disagreements that arose between the reviewers were resolved through discussion, or with a third reviewer. When necessary, primary authors were contacted for further information/clarification of data.

##### Presentation of results

Eighteen studies were included covering 10 non-pharmacological interventions implemented and evaluated to provide comfort. The interventions included one to 14 sessions. The interventions lasted between five and 60

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There is no conflict of interest in this project.

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minutes. Most of the interventions were implemented in PCUs and hospice settings. Ten of the 18 interventions were implemented and evaluated exclusively in cancer patients.

#### Conclusions

Ten non-pharmacological interventions were identified, of which the most common were music therapy and massage therapy. Their characteristics differed significantly across interventions and even in the same intervention. They were mostly implemented in palliative care units and hospices, and in patients with a cancer diagnosis. These data raise questions for future primary studies and systematic reviews.

#### Implications for research

Future research should focus on the implementation of interventions not only with cancer patients but also with non-cancer patients and patients receiving palliative care at home. Systematic reviews on the effect of massage therapy and music therapy should be conducted.

**Keywords** Comfort; literature review; non-pharmacological intervention; palliative care; scoping review

*JBI Database System Rev Implement Rep 2017; 15(7):1867–1904.*

## Background

Increased life expectancy is an outcome of scientific and technological advances.<sup>1</sup> Therefore, population aging in societies where death can be delayed is an indicator of a steady increase in the prevalence of degenerative and disabling diseases, and consequently of sources of suffering.<sup>2,3</sup> This represents a challenge for healthcare services and requires a holistic approach based on the biomedical model and focused on somatic symptoms that go beyond the psychological, social and spiritual domains.<sup>4</sup> This holistic paradigm calls for new measures to reduce suffering and provide comfort which are the key goals of medicine, particularly in palliative care (PC).

Callahan<sup>5</sup> proposed two main goals for 21<sup>st</sup>-century medicine: first, to prevent and cure diseases, and to help human beings die in peace. Since death is inevitable, enabling people to die peacefully is as important as preventing and curing diseases, hence the advent of PC as a response to the suffering associated with the dying process.<sup>6</sup> According to the World Health Organization, PC is “an approach that improves the quality of life of patients and their families facing the problem 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”.<sup>7(p.84)</sup>

Confrontation with death, gradual deterioration in health, debilitating physical symptoms, and emotional and spiritual distress experienced by people with incurable and advanced disease (IAD) make the process of living with the disease longer

than necessary, more painful, and one of intense suffering.<sup>8,9</sup> In addition, treatments sometimes increase patients’ levels of anxiety, depression and physical discomfort, with a significant negative impact on their comfort and well-being.<sup>10,11</sup> Incurable and advanced diseases are incurable conditions associated with a limited response to specific treatments, a high emotional impact, and a decreased life expectancy. In this situation, therapeutic strategies focus on optimizing comfort.<sup>12,13</sup>

Pharmacological techniques have improved and are now more capable of managing physical pain. However, PC extends beyond the relief of physical symptoms as it seeks to strengthen the psychological, spiritual and social domains in order to provide greater comfort to people with IAD.<sup>1,14</sup> Kolcaba defined comfort as “the satisfaction (actively, passively or co-operatively) of the basic human needs for relief, ease or transcendence arising from health care situations that are stressful” in the physical, social, psychospiritual, and environmental contexts.<sup>15(p.1178)</sup> Therefore, pain, suffering, fatigue, depression and anxiety were analyzed in this review as factors that influence the level of comfort.<sup>16,17</sup>

The increasing need for PCUs<sup>1,18</sup> requires better end-of-life care to minimize suffering and provide comfort. According to Cicely Saunders,<sup>19</sup> given their closer contact with patients, nurses are in a unique position to promote comfort.<sup>8</sup> Indeed, over time, the promotion of comfort has become a central focus and concern of nursing.<sup>20</sup>

Research shows that comfort is a key element of care;<sup>21</sup> however, its meaning is often implicit, and usually leads to ambiguity.<sup>22</sup> Based on Kolcaba’s<sup>23</sup>

theory of comfort, it is a desirable holistic purpose of the nursing discipline. Thus, nurses must assess the healthcare needs verbally and nonverbally reported by patients in stressful situations, namely, IADs.<sup>15</sup>

Nurses should implement comfort measures to meet these needs, as well as reassess comfort levels after their implementation. According to Kolcaba, “assessment (intuitive or formalistic) precedes intervention”.<sup>23(p.107)</sup> Assessment may be intuitive, for example, when a nurse asks if the patient is comfortable, or formalistic, such as in the observation of wound healing, and the administration of visual analogue scales or traditional questionnaires.<sup>23,24</sup>

Comfort interventions make patients feel strengthened in a personalized and an intangible way. Comfort allows patients to experience a more peaceful death,<sup>25,26</sup> which Kolcaba defines as “one in which conflicts are resolved, symptoms are well managed, and acceptance by the patient and family members allows for the patient to ‘let go’ quietly and with dignity”.<sup>23(p.80)</sup>

Therefore, non-pharmacological interventions have been increasingly used in PCUs to promote comfort<sup>27,28</sup> and improve patient satisfaction with end-of-life care.<sup>29</sup> Some studies on the implementation and evaluation of non-pharmacological interventions to promote comfort or other comfort-related outcomes, such as well-being, pain, suffering, stress, fatigue, anxiety and depression, particularly in patients with IAD,<sup>30-33</sup> have shown that hypnotherapy<sup>30</sup> (measured through the Anxiety and Depression Scale) reduces anxiety in hospice patients, and that art therapy<sup>31</sup> (measured through the Edmonton Symptom Assessment Scale) reduces pain, fatigue, depression and anxiety in patients admitted to PCUs.

Other studies have also analyzed the impact of non-pharmacological interventions on cancer patients with IAD and concluded that interventions based on aromatherapy, relaxation and mental images provide feelings of relaxation, serenity, and comfort.<sup>32,33</sup> However, data on the characteristics, contexts and populations of these interventions are scattered in the literature,<sup>27,34,35</sup> hindering the development of a systematic review on their effectiveness.

Moreover, non-pharmacological interventions implemented in PC are yet to be summarized, and research tends to focus on the somatic aspects of comfort<sup>35-37</sup> instead of addressing the multiple

comfort-related dimensions. Furthermore, these studies do not describe the characteristics of the different non-pharmacological interventions, so the implementation and evaluation of non-pharmacological interventions in non-cancer patients remain unclear.

Therefore, the purpose of this review was to analyze the above-mentioned aspects so that a systematic review can be conducted on the effectiveness of interventions for improving comfort in specific contexts and/or populations, or on the effectiveness of certain characteristics of the interventions aimed to promote comfort. As a result, this scoping review aimed to address important questions about the existing evidence on this area before a specific question can be formulated on the effectiveness of these interventions.

Since non-pharmacological interventions can improve the comfort of patients with IAD, it is imperative to map the evidence on this issue as an initial step for the development of a systematic review.<sup>36,37</sup>

This scoping review was guided by the methodology proposed by the Joanna Briggs Institute for scoping reviews,<sup>38,39</sup> and aimed to examine and map non-pharmacological interventions implemented and evaluated to provide comfort to people with IAD, their characteristics and contexts, as well as the type of advanced disease. According to the Joanna Briggs Institute, “scoping reviews undertaken with the objective of providing a map of the range of the available evidence can be undertaken as a preliminary exercise prior to the conduct of a systematic review”.<sup>38(p.6)</sup> Therefore, this mapping allows the identification of relevant issues to help advance evidence-based healthcare, increase knowledge, identify gaps and inform systematic reviews.

This scoping review is part of a research project involving the conduct of a systematic review on the effects of non-pharmacological interventions aimed at providing comfort to people with IAD. In addition, this mapping will inform the development of appropriate and effective interventions to improve the comfort of people with IAD.

An initial search of the *JBI Database of Systematic Reviews and Implementation Reports*, the Cochrane Library, MEDLINE and CINAHL revealed that there was no scoping review (published or in progress) on this topic.

The objectives, inclusion criteria and methods of analysis for this review were previously established and documented in a protocol.<sup>40</sup>

### Review question/objectives

The objective of this scoping review was to examine and map the non-pharmacological interventions implemented and evaluated to provide comfort in PC.

More specifically, the review focused on the following questions:

1. What non-pharmacological interventions have been implemented and evaluated to provide comfort to patients with IAD?
2. What are the characteristics (duration, dose and frequency) of these interventions?
3. In what contexts (home care, PCU or hospice) have the non-pharmacological interventions been implemented and evaluated?
4. In which populations (cancer and non-cancer patients) have the non-pharmacological interventions been implemented and evaluated?

### Inclusion criteria

#### *Types of participants*

This scoping review considered all studies that focused on patients with IAD, aged 18 years or over, assisted by PC teams.

The term IAD is understood to be an incurable condition associated with limited response to specific treatments, high emotional impact and decreased life expectancy. In these situations, therapeutic strategies focus on optimizing comfort (comfort treatment).<sup>12,13</sup>

Therefore surviving cancer or cancer patients receiving curative treatment were excluded.

#### *Concepts*

This scoping review considered all studies that addressed non-pharmacological interventions implemented and evaluated to provide comfort.

It considered non-pharmacological interventions implemented not only to provide comfort but also well-being and relief of pain, suffering, anxiety, depression, stress and fatigue, which are comfort-related concepts.

#### *Context*

This scoping review considered all non-pharmacological interventions implemented and evaluated in the context of PC. This included home care, hospices or PCUs.

#### *Types of sources*

This scoping review considered quantitative and qualitative studies, and systematic reviews.

Quantitative designs included any experimental study designs (including randomized controlled trials, non-randomized controlled trials, or other quasi-experimental studies, including before and after studies), and observational designs (descriptive studies, cohort studies, cross-sectional studies, case studies, and case series studies).

Qualitative designs included any studies that focused on qualitative data such as, but not limited to, phenomenology, grounded theory and ethnography designs.

Systematic reviews included meta-analyses and meta-syntheses.

### Search strategy

The search strategy aimed to find both published and unpublished studies. A three-step search strategy was used in this review. An initial limited search of MEDLINE (via PubMed) and CINAHL was undertaken followed by an analysis of the text words contained in the title and abstract, and of the index terms used to describe the articles. A second search using all identified keywords and index terms was then undertaken across all included databases. Thirdly, the reference list of all identified reports and articles was searched for additional studies. Studies published in English, Spanish and Portuguese were considered for inclusion in this review, regardless of their year of publication to capture how non-pharmacological interventions implemented and evaluated to provide comfort in PC have been researched and understood over time.

The search was conducted in the following sources:

- CINAHL Plus with Full Text
  - PubMed
  - Cochrane Central Register of Controlled Trials
  - LILACS
  - Scopus
  - Library, Information Science and Technology Abstracts
  - SciELO – Scientific Electronic Library Online
  - PsycINFO
  - JBI Database of Systematic Reviews and Implementation Reports*
  - Cochrane Database of Systematic Reviews
- The search for unpublished studies included:
- ProQuest – Nursing and Allied Health Source Dissertations
  - Banco de teses da CAPES (Brazil)
  - Teseo – Base de datos de Tesis Doctorales (Spain)
  - TDX – Tesis Doctorals en Xarxa (Spain)
  - RCAAP – Repositório Científico de Acesso Aberto de Portugal

The following initial keywords in English were used: comfort OR pain OR suffering OR anxiety OR depression OR stress OR fatigue OR well-being palliative; hospice; “home care”; “end of life”; intervention

The full search strategy is presented in Appendix I.

Articles searched were then assessed for relevance to the review, based on the information provided in the title and abstract, by two independent reviewers. The full article was retrieved for all studies that met the inclusion criteria of the review. If the reviewers had doubts about the relevance of a study from the abstract, the full-text article was retrieved.

Two reviewers examined the full-text articles independently to check whether they met the inclusion criteria. Any disagreements that arose between the reviewers were resolved through discussion, or with a third reviewer.

Studies identified from reference lists were assessed for relevance based on their title and abstract.

**Extraction of results**

Data were extracted from articles included in the review using a charting instrument aligned with this research objective and question (Appendix II), as

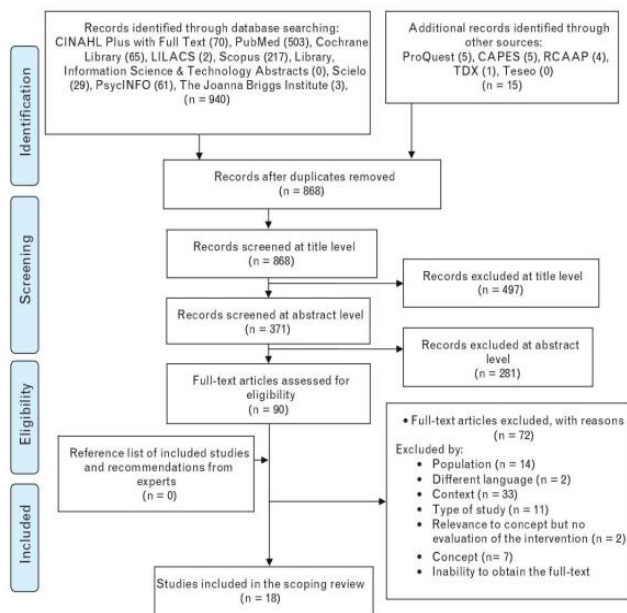
indicated by the methodology for scoping reviews developed by the Joanna Briggs Institute.<sup>38</sup>

Two reviewers extracted data independently. Any disagreements that arose between the reviewers were resolved through discussion, or with a third reviewer.

Both reviewers independently charted the “first five to ten studies using the data-charting form and meet to determine whether their approach to data extraction is consistent with the research question and purpose”, as suggested by Levac et al.<sup>41(p.6)</sup> In addition, when necessary, primary authors were contacted for further information/clarification of data, as suggested by Arksey and O’Malley.<sup>42</sup>

**Results**

After the duplicates were removed, 868 records were identified for study selection. A total of 90 documents met the inclusion criteria, based on the titles and abstracts. The full-text articles were then obtained. Full-text articles were read, and 18 articles met the inclusion criteria (the reasons for exclusion of full-text articles are presented in Appendix III). Figure 1 shows the study selection process. Details on the studies are presented in Appendix IV.



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097

**Figure 1: PRISMA flowchart of the study selection and inclusion process**

**Table 1: Studies included by country**

Author	Country	No. of studies per country
Berger <i>et al.</i> <sup>28</sup>	Canada	2
Giasson and Bouchard <sup>57</sup>	Canada	
Horne-Thompson and Grocke <sup>52</sup>	Australia	2
Horne-Thompson and Bolger <sup>53</sup>	Australia	
Osaka, <i>et al.</i> <sup>46</sup>	Japan	3
Nakayama, Kikuta and Takeda <sup>47</sup>	Japan	
Kohara <i>et al.</i> <sup>48</sup>	Japan	
Kolcaba <i>et al.</i> <sup>43</sup>	USA	3
Polubinski and West <sup>44</sup>	USA	
Wilkie <i>et al.</i> <sup>45</sup>	USA	
Plaskota <i>et al.</i> <sup>30</sup>	England	2
Soden <i>et al.</i> <sup>49</sup>	UK	
Leow, Drury and Poon <sup>55</sup>	Singapore	1
Tsai <i>et al.</i> <sup>50</sup>	Taiwan	1
Rhondali <i>et al.</i> <sup>31</sup>	France	1
Louis and Kowalski <sup>54</sup>	Nevada	1
Warth <i>et al.</i> <sup>51</sup>	Germany	1
Dietrich <i>et al.</i> <sup>56</sup>	India	1

*Country of publication*

Most of the studies included in this scoping review were conducted in the USA<sup>43-45</sup> and Japan,<sup>46-48</sup> as shown in Table 1.

*Research design*

Eleven studies used a quantitative design,<sup>30,43,45,47-54</sup> one a qualitative design,<sup>55</sup> and three a mixed-methods design.<sup>28,31,56</sup> Table 2 shows the studies included in this scoping review by study design.

*Year of publication*

Included studies were published between 1998 and 2015. Table 3 shows the year of publication of studies included in this scoping review.

*Non-pharmacological interventions*

The 18 included studies implemented and evaluated 10 non-pharmacological interventions to provide comfort (or related concepts): aromatherapy, reiki and therapeutic touch;<sup>28</sup> aromatherapy, footsoak, and reflexology;<sup>48</sup> aromatherapy;<sup>54</sup> aromatherapy massage;<sup>49</sup> massage therapy;<sup>43-46</sup> noncontact

**Table 2: Studies included by study design**

Author	Study design	No. of studies per design
Berger <i>et al.</i> <sup>28</sup>	Mixed methods: Quasi-experimental design: pre-test/post-test Qualitative	3
Dietrich <i>et al.</i> <sup>56</sup>	Mixed methods: Prospective case study Qualitative study (hermeneutic)	
Rhondali <i>et al.</i> <sup>31</sup>	Mixed methods: Quasi-experimental design: pre-test/post-test; Grounded theory	
Giasson and Bouchard <sup>57</sup>	Time-series design with control group	14
Horne-Thompson and Grocke <sup>52</sup>	Randomized controlled trial	
Soden <i>et al.</i> <sup>49</sup>	Randomized controlled trial	
Tsai <i>et al.</i> <sup>50</sup>	Randomized controlled trial	
Warth <i>et al.</i> <sup>51</sup>	Randomized controlled trial	
Wilkie <i>et al.</i> <sup>45</sup>	Randomized controlled trial	
Kolcaba <i>et al.</i> <sup>43</sup>	Experimental design: randomized	
Osaka <i>et al.</i> <sup>46</sup>	Experimental design: pre-test/post-test	
Polubinski and West <sup>44</sup>	Pre-post treatment design	
Horne-Thompson and Bolger <sup>53</sup>	Quasi-experimental design: pre-test/post-test	
Kohara <i>et al.</i> <sup>48</sup>	Quasi-experimental design: pre-test/post-test	
Louis and Kowalski <sup>54</sup>	Quasi-experimental, repeated-measures, one-group design	
Nakayama, Kikuta and Takeda <sup>47</sup>	Quasi-experimental design: pre-test/post-test	
Plaskota <i>et al.</i> <sup>30</sup>	Quasi-experimental design: pre-test/post-test	
Leow, Drury and Poon <sup>55</sup>	Qualitative	1

**Table 3: Studies included by year of publication**

Author	Year of publication	No. of studies per year of publication
Giasson and Bouchard <sup>57</sup>	1998	1
Wilkie et al. <sup>45</sup>	2000	1
Louis and Kowalski <sup>54</sup>	2002	1
Soden et al. <sup>49</sup>	2004	3
Kolcaba et al. <sup>43</sup>	2004	
Kohara et al. <sup>48</sup>	2004	
Polubinski and West <sup>244</sup>	2005	1
Tsai et al. <sup>50</sup>	2007	1
Horne-Thompson and Grocke <sup>52</sup>	2008	1
Nakayama, Kikuta and Takeda <sup>47</sup>	2009	2
Osaka et al. <sup>45</sup>	2009	
Horne-Thompson and Bolger <sup>53</sup>	2010	2
Leow, Drury and Poon <sup>55</sup>	2010	
Plaskota et al. <sup>30</sup>	2012	1
Berger et al. <sup>28</sup>	2013	2
Rhondali et al. <sup>31</sup>	2013	
Dietrich et al. <sup>56</sup>	2015	2
Warth et al. <sup>51</sup>	2015	

therapeutic touch;<sup>57</sup> music therapy;<sup>47,51-53,55,56</sup> hypnotherapy;<sup>30</sup> art therapy;<sup>31</sup> and electromyography biofeedback-assisted relaxation.<sup>50</sup> The most implemented and evaluated interventions to provide comfort were music therapy (six studies)<sup>47,51-53,55,56</sup> and massage therapy (four studies).<sup>43-46</sup>

Only three studies evaluated the total comfort provided by the interventions.<sup>28,43,55</sup> The remaining studies evaluated comfort-related concepts: pain,<sup>28,31,44,45,49-52,54,56</sup> anxiety,<sup>28,30,31,44,47,49,52-54</sup> depression,<sup>28,30,31,47,49,52,54</sup> stress,<sup>43,46,47</sup> fatigue<sup>31,47,48</sup> and well-being.<sup>31,51,52,54,57</sup> None of the included studies evaluated suffering.

Table 4 shows the non-pharmacological interventions that implemented and evaluated to provide comfort.

*Characteristics of non-pharmacological interventions*

The frequency of interventions ranged from one to 14 sessions and their duration five to 60 minutes. Table 5 shows the characteristics of

**Table 4: Non-pharmacological interventions found in the included studies that were implemented and evaluated to provide comfort (or related concepts)**

Author	Non-pharmacological intervention	Concept							
		Comfort	Pain	Suffering	Anxiety	Depression	Stress	Fatigue	Well-being
Berger et al. <sup>28</sup>	Aromatherapy, reiki and therapeutic touch	x	x		x	x			
Kohara et al. <sup>48</sup>	Aromatherapy, footsoak and reflexology							x	
Louis and Kowalski <sup>54</sup>	Aromatherapy		x		x	x			x
Soden et al. <sup>49</sup>	Aromatherapy massage		x		x	x			
Polubinski and West <sup>44</sup>	Massage therapy		x		x				
Wilkie et al. <sup>45</sup>	Massage therapy		x						
Osaka et al. <sup>46</sup>	Massage therapy (hand massage)						x		
Kolcaba et al. <sup>43</sup>	Massage therapy (hand massage)	x					x		
Giasson and Bouchard <sup>57</sup>	Noncontact Therapeutic touch								x
Horne-Thompson and Grocke <sup>52</sup>	Music therapy		x		x	x			x
Horne-Thompson and Bolger <sup>53</sup>	Music therapy				x				
Dietrich et al. <sup>56</sup>	Music therapy (with Body Tambura)		x						
Nakayama, Kikuta and Takeda <sup>47</sup>	Music therapy				x	x	x	x	
Warth et al. <sup>51</sup>	Music therapy		x						x
Leow, Drury and Poon <sup>55</sup>	Music therapy	x							
Plaskota et al. <sup>30</sup>	Hypnotherapy				x	x			
Rhondali et al. <sup>31</sup>	Art therapy (painting)		x		x	x		x	x
Tsai et al. <sup>50</sup>	Electromyography biofeedback-assisted relaxation		x						

**Table 5: Characteristics of non-pharmacological interventions of included studies that were implemented and evaluated to provide comfort (or related concepts)**

Author	Non-pharmacological intervention	Characteristics of intervention		
		Frequency of intervention	Duration of intervention	Dose of intervention
Berger <i>et al.</i> <sup>28</sup>	Aromatherapy, reiki and therapeutic touch	One or two sessions	Data not reported	Data not reported
Kohara <i>et al.</i> <sup>48</sup>	Aromatherapy, foot-soak and reflexology	Eight sessions on average	Patients received aromatherapy together with footsoak in warm water containing lavender essential oil for 3 min, followed by reflexology treatment with jojoba oil containing lavender for 10 min.	Aromatherapy was accompanied with footsoak in warm water (40°C) containing two drops of lavender essential oil and reflexology with jojoba oil containing 1% lavender.
Louis and Kowalski <sup>54</sup>	Aromatherapy	One session	60 min	3% essential lavender oil ( <i>Lavandula angustifolia</i> ).
Soden <i>et al.</i> <sup>49</sup>	Aromatherapy massage	Four sessions (one session weekly week for four weeks)	30 min	The lavender essential oil was mixed in sweet almond oil (an inert carrier oil) to a dilution of 1%.
Polubinski and West <sup>44</sup>	Massage therapy	A quarter of the patients (n = 8) received one session, whereas the other patients received multiple therapy sessions: half of the patients (n = 16) received between 2 and 7 treatments, and a quarter (n = 8) received between 8 and 14 sessions.	58 min	Not applicable
Wilkie <i>et al.</i> <sup>45</sup>	Massage	Six sessions (four twice a week for three weeks)	30–50 min	Not applicable
Osaka <i>et al.</i> <sup>46</sup>	Hand massage	One session	5 min	Not applicable
Kolcaba <i>et al.</i> <sup>43</sup>	Hand massage	Six sessions (twice a week for three weeks)	5–8 min	Not applicable
Giasson and Bouchard <sup>57</sup>	Noncontact therapeutic touch	Three sessions	15–20 min	Not applicable
Horne-Thompson and Grocke <sup>52</sup>	Music therapy	One session	20–40 min	Not applicable
Horne-Thompson and Bolger <sup>53</sup>	Music therapy	Three sessions: a live music therapy session, a recorded music intervention, and a control intervention, for three days of one week	Participants experienced 30 min each of the three interventions.	Not applicable
Dietrich <i>et al.</i> <sup>56</sup>	Music therapy with Body Tumbura	Two sessions	10 min	Not applicable
Nakayama, Kikuta and Takeda <sup>47</sup>	Music therapy	One session	40 min	Not applicable
Warth <i>et al.</i> <sup>51</sup>	Music therapy	Two sessions	15 min	Not applicable
Leow, Drury and Poon <sup>55</sup>	Music therapy	Patients attended at least one individual music therapy session	Data not reported	Not applicable
Plaskota <i>et al.</i> <sup>30</sup>	Hypnotherapy	Four sessions	Data not reported	Not applicable
Rhondali <i>et al.</i> <sup>31</sup>	Art therapy (painting)	One session	60 min	Not applicable
Tsai <i>et al.</i> <sup>50</sup>	Electromyography biofeedback-assisted relaxation	Six sessions in four weeks	45 min	Not applicable



non-pharmacological interventions in studies included in this scoping review that were implemented and evaluated to provide comfort (or related concepts).

*Contexts where non-pharmacological interventions were implemented and evaluated*

This scoping review considered non-pharmacological interventions implemented and evaluated in PC settings, which included interventions specifically implemented and evaluated for home care patients, and hospice and PCU inpatients.

The majority of the analyzed interventions were implemented in PCUs<sup>28,31,46,48-50,52,57</sup> and

hospices.<sup>30,43,45,47,53,55,56</sup> Only three interventions were implemented in home care.<sup>43,44,54</sup>

Table 6 shows the contexts where the non-pharmacological interventions included in this scoping review were implemented and evaluated.

*Populations in which the non-pharmacological interventions were implemented and evaluated*

Ten of the 18 analyzed interventions were implemented and evaluated exclusively in cancer patients,<sup>30,31,45-50,54,57</sup> four in cancer and non-cancer patients,<sup>43,44,51,52</sup> and two in non-cancer patients;<sup>53,56</sup> two did not mention the participants' diagnosis.<sup>28,55</sup>

**Table 6: Contexts where non-pharmacological interventions included were implemented and evaluated to provide comfort (or related concepts)**

Author	Non-pharmacological intervention	Context		
		Home care	Hospice	Palliative care units
Berger et al. <sup>28</sup>	Aromatherapy, reiki and therapeutic touch			x
Kohara et al. <sup>48</sup>	Aromatherapy, footsoak and reflexology			x
Louis and Kowalski <sup>54</sup>	Aromatherapy	x		
Soden et al. <sup>49</sup>	Aromatherapy massage			x
Polubinski and West <sup>44</sup>	Massage therapy	x		
Wilkie et al. <sup>45</sup>	Massage		x	
Osaka et al. <sup>46</sup>	Hand massage			x
Kolcaba et al. <sup>43</sup>	Hand massage	x	x	
Giasson and Bouchard <sup>57</sup>	Noncontact therapeutic touch			x
Horne-Thompson and Grocke <sup>52</sup>	Music therapy			x
Horne-Thompson and Bolger <sup>53</sup>	Music therapy <sup>53</sup>		x	
Dietrich et al. <sup>56</sup>	Music therapy with Body Tambura		x	
Nakayama, Kikuta and Takeda <sup>47</sup>	Music therapy		x	
Warth et al. <sup>51</sup>	Music therapy			x
Leow, Drury and Poon <sup>55</sup>	Music therapy		x	
Plaskota et al. <sup>30</sup>	Hypnotherapy		x	
Rhondali et al. <sup>31</sup>	Art therapy (painting)			x
Tsai et al. <sup>50</sup>	Electromyography biofeedback-assisted relaxation			x

**Table 7: Populations and age in which the non-pharmacological interventions included were implemented and evaluated to provide comfort (or related concepts)**

Author	Non-pharmacological intervention	Population with IAD		Age in years
		Cancer	Non-cancer	
Berger <i>et al.</i> <sup>28</sup>	Aromatherapy, reiki and therapeutic touch	Unknown diagnosis		≥18
Kohara <i>et al.</i> <sup>48</sup>	Aromatherapy, foot-soak and reflexology	x		Median: 64 Range: 47–79
Louis and Kowalski <sup>54</sup>	Aromatherapy	x		Mean: 61.8 Range: 42–79
Soden <i>et al.</i> <sup>49</sup>	Aromatherapy massage	x		Mean: 73 Range: 44–85
Polubinski and West <sup>44</sup>	Massage therapy	x	x	≥18
Wilkie <i>et al.</i> <sup>45</sup>	Massage	x		Mean: 64 Range: 30–87
Osaka <i>et al.</i> <sup>46</sup>	Hand massage	x		Mean: 67 Range: 44–78
Kolcaba <i>et al.</i> <sup>43</sup>	Hand massage	x	x	Mean: 52.9 Range: 40–80
Giasson and Bouchard <sup>57</sup>	Noncontact therapeutic touch	x		Range: 38–68
Horne-Thompson and Grocke <sup>52</sup>	Music therapy	x	x	Mean ± SD: 76.2 ± 10.4
Horne-Thompson and Bolger <sup>53</sup>	Music therapy		x	Mean ± SD: 61.7 ± 0.6
Dietrich <i>et al.</i> <sup>56</sup>	Music therapy with Body Tambura		x	Mean ± SD: 57.8 ± 17.8
Nakayama, Kikuta and Takeda <sup>47</sup>	Music therapy	x		Mean ± SD: 73.1 ± 9.7
Warth <i>et al.</i> <sup>51</sup>	Music therapy	x	x	Mean ± SD: 63 ± 13.4
Leow, Drury and Poon <sup>55</sup>	Music therapy	Unknown diagnosis		Range: 43–82
Plaskota <i>et al.</i> <sup>30</sup>	Hypnotherapy	x		Mean: 60 Range: 46–80
Rhondali <i>et al.</i> <sup>31</sup>	Art therapy (painting)	x		≥18
Tsai <i>et al.</i> <sup>50</sup>	Electromyography biofeedback-assisted relaxation	x		≤40 (n = 2) (16.7%); 41–50 (n = 7) (58.3%); 51–60 (n = 1) (8.3%); ≥61 (n = 2) (16.7%).

IAD, Incurable and advanced disease; SD, standard deviation.

Ten of the 18 interventions were implemented and evaluated in people with IAD with a mean age of 60 years or older.<sup>30,45-49,51-54</sup>

Table 7 shows the results of studies included in this scoping review in relation to the populations and age of participants in which the non-pharmacological interventions were implemented and evaluated.

### Discussion

The purpose of this scoping review was to examine and map non-pharmacological interventions implemented and evaluated to provide comfort in PC.

To address this question, 18 primary studies were included. Although it would have been ideal to

include systematic reviews, none of those identified in the database search met all the inclusion criteria.

Although 12 reviews reached the full-text analysis phase, five of them were excluded after full-text reading because they reported data from interventions implemented and evaluated in contexts other than the PCU, hospice or home care (e.g. oncology department). The same applied to their population: four reviews were excluded after full-text reading because they included studies in which participants were not diagnosed with IAD (e.g. participants were cancer survivors). In addition, another review was excluded since it included studies addressing concepts (e.g. mood) which was not defined as an inclusion criterion in the protocol of this scoping review. Finally, two reviews were excluded because they were not systematic literature reviews, a necessary criterion for inclusion. The reference lists of these studies were analyzed, but no new studies were found.

It should also be noted that evaluation results are not required for the descriptive data necessary for the elaboration of a scoping review. However, the inclusion criteria defined in the protocol mention that "this scoping review considered all studies that address non-pharmacological interventions implemented and evaluated to provide comfort".<sup>40</sup> As such, it was decided by consensus among the authors not to include the two studies<sup>58,59</sup> that only mentioned the non-pharmacological intervention implemented, but without an evaluation of it (related to the concept but did not evaluate the intervention). In addition, one of the objectives of this scoping review was to inform future systematic reviews of the literature. Therefore, it would not be appropriate to guide future researchers to perform a systematic review on the effectiveness or meaningfulness of a certain non pharmacological intervention, when in reality there was no qualitative or quantitative evaluation of the intervention in the primary studies.

The reasons for excluding studies after full-text reading are presented in Appendix III.

Thirteen of the 18 studies included mentioned the study design.<sup>43-46,49-57</sup> In the remaining five studies, the study design was identified by the review authors.<sup>28,30,31,47,48</sup>

An increase was observed in the number of non-pharmacological interventions implemented and evaluated to provide comfort since 2002. This

may be explained by the fact that this was the year when the World Health Organization extended the definition of PC, emphasizing the importance of preventing and relieving suffering, promoting comfort and developing research to improve complex clinical situations.<sup>7</sup>

#### *Non-pharmacological interventions implemented and evaluated to provide comfort to patients with IAD*

Palliative care is the active, total care of patients, in which aggressive therapeutic interventions give way to intensive comfort measures.<sup>60,61</sup> In this field, the development and implementation of non-pharmacological interventions has increased.<sup>27,62</sup> However, although the main objective of PCUs is to provide comprehensive comfort care to the person with IAD, as mentioned in the results section, only three of the 18 included studies assessed the total level of comfort resulting from the interventions. This mapping has clearly identified the need for research on comprehensive comfort care provided through non-pharmacological interventions. It should be noted that previous studies have identified that the lack of scientific evidence on the effectiveness of non-pharmacological interventions is a barrier to their implementation.<sup>63,64</sup>

Another barrier to the implementation of non-pharmacological interventions is the inconsistency of results obtained in different studies on the same non-pharmacological intervention. For example, two studies included in this scoping review assessed the impact of therapeutic massage on stress levels,<sup>43,46</sup> and reached differing results. The same applies to three studies on the effect of music therapy, which obtained divergent results in terms of anxiety and pain levels.<sup>51-53</sup>

The diversity of populations, contexts and characteristics of these interventions may help to explain the variability of results regarding some concepts. However, systematic reviews should be conducted in order to guide practice through the identification of the best available evidence on the effect of those interventions.

The following barriers to the implementation of non-pharmacological interventions were identified in these studies: the lack of scientific evidence on their effectiveness, the need to hire external professionals with specific training, and the financial cost for institutions.<sup>63,64</sup>

Guided imagery is one of the easiest and less expensive non-pharmacological interventions that nurses can implement, requiring little effort from patients. Moreover, the literature argues that guided imagery is associated with a significant increase in patient comfort in various clinical settings.<sup>65-71</sup> However, none of the studies included in this scoping review had implemented and evaluated this intervention.

This scoping review revealed the lack of studies on the impact of this comfort intervention in PC, which clearly limits its implementation. If this intervention proves to be effective in this context, its implementation may translate into a significant increase in the comfort levels of patients with IAD. Therefore, primary studies should be carried out to implement and evaluate the effect of this intervention in PC.

*Characteristics of non-pharmacological interventions implemented and evaluated to provide comfort to patients with IAD*

The need to implement non-pharmacological interventions in PC that require little effort for participants was reinforced by Kolcaba, author of the Theory of Comfort.<sup>43</sup> Given the multiple characteristics of the non-pharmacological interventions implemented in the included studies, it would be important to examine the reason why these prolonged and recurring interventions do not generate the opposite effect and promote discomfort.

Once again, Kolcaba<sup>23</sup> advises that, even though proper comfort interventions are intentionally provided, comfort may not be sufficiently enhanced. In this case, nurses should analyze the characteristics of the interventions and the reasons for their ineffectiveness in providing the desired comfort.

*Contexts where the non-pharmacological interventions were implemented and evaluated to provide comfort to patients with IAD*

Although the person at the end of life may prefer dying at home,<sup>72</sup> the reality is that this experience is increasingly occurring in a hospital environment. Hospitals are viewed as having better facilities and human resources, and better comfort and safety conditions when compared to the home. Additionally, since life expectancy is increasing, families often lack the ability to care for their sick relatives, thus leading to their hospital admission.<sup>73,74</sup>

These are some of the reasons why most of the analyzed interventions were implemented in

PCUs<sup>28,31,46,48-50,52,57</sup> and hospices.<sup>30,43,45,47,53,55,56</sup> In addition, the difficulty in recruiting patients receiving PC at home and the low receptivity of family members has also hindered the development of studies in this context.<sup>43</sup>

*Populations in which non-pharmacological interventions were implemented and evaluated to provide comfort to patients with IAD*

According to the World Health Organization, PC should be provided to people facing problems associated with life-threatening cancer or non-cancer diseases. Indeed, a great majority of adults in need of PC die from cardiovascular diseases (38.5%) and cancer (34%), followed by chronic respiratory diseases (10.3%), HIV/AIDS (5.7%) and diabetes (4.5%).<sup>1</sup>

Since the early 1980s, the need for PC for cancer patients has been increasingly acknowledged worldwide. More recently, there is increased awareness of the need for PC for other chronic diseases. However, there remains a huge unmet need for PC for these chronic (non-cancer) life-limiting conditions in most parts of the world.<sup>1</sup>

Worldwide, over 20 million people are estimated to require PC at the end of life every year. The majority (69%) are adults over 60 years.<sup>1</sup>

With the increased need for PC, there is also a need to improve patients' comfort levels, namely, through non-pharmacological interventions.<sup>23</sup>

For this reason, there is an urgent need to develop studies on the implementation and evaluation of non-pharmacological interventions that provide comfort to cancer and non-cancer patients.

*Limitations of the included studies*

Although the methodological quality of the included studies was not assessed, since it is not relevant for a scoping review, some limitations should be reported so as to provide valuable information to future research studies/systematic reviews. These limitations are related to small sample sizes,<sup>30,46,49,50,52,54</sup> study designs,<sup>30,44,46,53,54</sup> lack of assessment of the long-term impact of interventions,<sup>48,50</sup> use of unclear measurement instruments,<sup>54</sup> and differences in the number of sessions received by participants in the same study.<sup>44</sup>

These limitations hinder the rigorous assessment of the impact of non-pharmacological interventions on comfort and should be addressed since the lack of accurate scientific evidence on their effectiveness is a barrier to their implementation in PC.<sup>63</sup>

However, the difficulties associated with recruitment in studies with populations of patients with IAD should be taken into account.<sup>43,46,49,52,53</sup>

Another limitation of some included studies was the lack of information on the duration of the interventions<sup>28,30,55</sup> or the time lapse between sessions.<sup>28,30,44,48,51,56,57</sup> This aspect limited the analysis and mapping of the characteristics of the interventions described in the included studies.

#### *Limitations of the scoping review*

A limitation of this scoping review was the fact that only studies published in English, Portuguese and Spanish were included. Articles published in other languages could also have been important to this review. Another limitation was the fact that only studies conducted in home care settings, hospices and PCUs were included. Interventions implemented in all patients receiving PC (other hospital units or with day-care patients) could also have been important to this review.

Furthermore, since the objective of this scoping review was to examine and map non-pharmacological interventions implemented and evaluated to provide comfort in PC, no rating of methodological quality is provided and, therefore, recommendations for practice cannot be graded.

#### **Conclusions**

This scoping review aimed to map non-pharmacological interventions implemented and evaluated to provide comfort in PC and identify their characteristics, contexts and populations.

Ten non-pharmacological interventions were identified. Music therapy and massage therapy were the most common interventions. Characteristics differed significantly across interventions and even in the same intervention, both in terms of number of sessions (between one and 14 sessions) and their duration (between five and 60 minutes). Interventions were implemented mostly in PCUs and hospices, and in patients with cancer diagnosis. These data raise questions for future primary studies and systematic reviews.

#### *Implications for research*

Future primary studies should clearly identify characteristics of the interventions, type of study, context and patient diagnosis.

Furthermore, future primary research should perform in-depth qualitative studies on the experience

of patients who have received non-pharmacological interventions and focus on the implementation of interventions in cancer and non-cancer patients, and patients receiving PC at home.

Since the main purpose of PC is to provide the maximum comfort possible to patients with IAD, further research needs to be undertaken to evaluate the effectiveness of non-pharmacological interventions and their impact on comfort.

Systematic reviews on the effect of massage therapy and music therapy should be performed.

Due to the existence of several primary studies on massage therapy and music therapy that have different characteristics and report different results, systematic reviews on the effects of massage therapy and music therapy should be performed to determine the best available evidence about their effect on comfort and to guide clinical practice.

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**Appendix I: Search strategy**

PubMed – search conducted on November 24th, 2015

Search ID#	Search terms	Results
#33	Filters: (English[lang] OR Portuguese[lang] OR Spanish[lang])	503
#32	#29 AND #30 AND #31	580
#31	#14 OR #15 #16 OR #17 OR #18 #19 OR #20 OR #21 OR #22 OR #23 OR #24 #25 OR #26 OR #27 OR #28	275896
#30	#8 OR #9 OR #10 OR #11 OR #12 OR #13	106180
#29	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7	677852
#28	MH “complementary therapies”	185155
#27	ABTI “Complementar* therap*”	21040
#26	ABTI “alternative* therap*”	82593
#25	ABTI “non-pharmacolog* intervention*”	2229
#24	ABTI “non-pharmacolog* therap*”	2614
#23	MH “art therapy”	1153
#22	MH “Massage”	4917
#21	MH “music therapy”	2525
#20	MH “hypnosis”	10814
#19	MH “Guided Imagery	1266
#18	MH “Relaxation”	14999
#17	MH “Relaxation therapy”	7434
#16	MH “Therapeutic Touch”	688
#15	MH “Transcutaneous Electric Nerve Stimulation”	6255
#14	MH aromatherapy	577
#13	MH “end of life care”	42453
#12	MH “hospice”	9081
#11	ABTI “hospice*”	8728
#10	ABTI “end of life”	14252
#9	MH “palliative care”	42501
#8	ABTI “palliative*”	45242
#7	MH “depression”	162160
#6	MH “anxiety”	59701
#5	MH “fatigue”	21820
#4	MH “stress, psychological”	97969
#3	MH “pain”	322708
#2	ABTI “well being”	47146
#1	ABTI “comfort*”	32181



CINAHL Plus – search conducted on November 23th, 2015

Search ID#	Search terms	Results
#33	Limiters: English; Portuguese; Spanish EXCLUDE Medline	70
#32	#29 AND #30 AND #31	187
#31	#15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 #25 OR #26 OR #27 OR #28	32153
#30	#10 OR #11 OR #12 OR #13 OR #14	41545
#29	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9	47028
#28	ABTI “art therapy”	
#27	ABTI “Massage”	
#26	ABTI “music therapy”	
#25	ABTI “hypnosis”	
#24	ABTI “Guided Imagery	
#23	ABTI “Relaxation”	
#22	ABTI “Relaxation therapy”	
#21	ABTI “Therapeutic Touch”	
#20	ABTI “Transcutaneous Electric Nerve Stimulation”	
#19	ABTI aromatherapy	
#18	ABTI “non-pharmacolog* intervention*”	
#17	ABTI “non-pharmacolog* therap*”	
#16	ABTI “alternative* Therap*”	
#15	MH “Alternative therapies”	
#14	MH “hospice care”	
#13	ABTI “hospice”	
#12	ABTI “end of life”	
#11	MH “palliative care”	
#10	ABTI “palliative”	
#9	MH “well-being”	
#8	MH “comfort”	
#7	MH “depression”	
#6	MH “anxiety”	
#5	MH “fatigue”	
#4	MH “stress, psychological”	
#3	MH “pain”	
#2	ABTI “well being”	
#1	ABTI “comfort*”	

Scopus – search conducted on November 24th, 2015

Search ID#	Search terms	Results
#29	Filters: AND (English[lang] OR Portuguese[lang] OR Spanish[lang]) Medline	217
#28	#25 AND #26 AND #27	776
#27	#12 OR #13 OR #14 OR #15 #16 OR #17 OR #18 #19 OR #20 OR #21 OR #22 OR #23 OR #24	40048
#26	#9 OR #10 OR #11	78459
#25	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8	2755113
#24	ABTIK “Complementary therapy”	
#23	ABTIK “alternative therapy”	
#22	ABTIK “non-pharmacological intervention”	
#21	ABTIK “non-pharmacological therapy”	
#20	ABTIK “art therapy”	
#19	ABTIK “Massage”	
#18	ABTIK “music therapy”	
#17	ABTIK “hypnosis”	
#16	ABTIK “Guided Imagery”	
#15	ABTIK “Relaxation therapy”	
#14	ABTIK “Therapeutic Touch”	
#13	ABTIK “cutaneous stimulation”	
#12	ABTIK “aromatherapy”	
#11	ABTIK “hospice”	
#10	ABTIK “end of life”	
#9	ABTIK “palliative”	
#8	ABTIK “depression”	
#7	ABTIK “anxiety”	
#6	ABTIK “fatigue”	
#5	ABTIK “stress”	
#4	ABTIK “pain”	
#3	ABTIK “suffering”	
#2	ABTIK “well being”	
#1	ABTIK “comfort*”	

SYSTEMATIC REVIEW

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Banco de teses da CAPES (www.capes.gov.br) – search conducted on November 24th, 2015

Search ID#	Search terms	Results
#1	ABTI “comfort”	5

LILACS – search conducted on November 24th, 2015

Search ID#	Search terms	Results
#28	Filters: (English[lang] OR Portuguese[lang] OR Spanish[lang])	2
#27	#24 AND #25 AND #26	2
#26	#12 OR #13 OR #14 OR #15 #16 OR #17 OR #18 #19 OR #20 OR #21 OR #22 OR #23	604
#25	#9 OR #10 OR #11	1079
#24	#1 OR #2 OR #3 OR #4 OR #5 OR #7 OR #8	30407
#23	ABTI “Complementary therapy”	
#22	ABTI “alternative therapy”	
#21	ABTI “non-pharmacological intervention”	
#20	ABTI “non-pharmacological therapy”	
#19	ABTI “art therapy”	
#18	ABTI “Massage”	
#17	ABTI “music therapy”	
#16	ABTI “hypnosis”	
#15	ABTI “Guided Imagery”	
#14	ABTI “Relaxation therapy”	
#13	ABTI “Therapeutic Touch”	
#12	ABTI “cutaneous stimulation”	
#11	ABTI “hospice”	
#10	ABTI “end of life”	
#9	ABTI “palliative”	
#8	ABTI “depression”	
#7	ABTI “anxiety”	
#6	ABTI “fatigue”	
#5	ABTI “stress”	
#4	ABTI “pain”	
#3	ABTI “suffering”	
#2	ABTI “well being”	
#1	ABTI “comfort”	

Library, Information Science and Technology Abstracts – search conducted on November 24th, 2015

Search ID#	Search terms	Results
#22	#19 AND #20 AND #21	0
#21	#15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 #25 OR #26 OR #27 OR #28	446
#20	#10 OR #11 OR #12 OR #13 OR #14	257
#19	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9	3605
#28	ABTI “art therapy”	
#27	ABTI “Massage”	
#26	ABTI “music therapy”	
#25	ABTI “hypnosis”	
#24	ABTI “Guided Imagery	
#23	ABTI “Relaxation”	
#22	ABTI “Relaxation therapy”	
#21	ABTI “Therapeutic Touch”	
#20	ABTI “Transcutaneous Electric Nerve Stimulation”	
#19	ABTI aromatherapy	
#18	ABTI “non-pharmacolog* intervention*”	
#17	ABTI “non-pharmacolog* therap*”	
#16	ABTI “alternative* Therap*”	
#15	MH “Alternative therapies”	
#14	MH “hospice care”	
#13	ABTI “hospice”	
#12	ABTI “end of life”	
#11	MH “palliative care”	
#10	ABTI “palliative”	
#9	MH “well-being”	
#8	MH “comfort”	
#7	MH “depression”	
#6	MH “anxiety”	
#5	MH “fatigue”	
#4	MH “stress, psychological”	
#3	MH “pain”	
#2	ABTI “well being”	
#1	ABTI “comfort*”	

PsycINFO – search conducted on November 24th, 2015

Search ID#	Search terms	Results
	Filters: (English[lang] OR Portuguese[lang] OR Spanish[lang])	61
#20	#1 AND #18 AND #19	61
#19	#5 OR #6 OR #7 OR #8 #9 OR #10 OR #11 #12 OR #13 OR #14 OR #15 #16 OR #17	238145
#18	#2 OR #3 OR #4	14022
#17	ABTIK “Complementar* therap*”	
#16	ABTIK “alternativ* therap*”	
#15	ABTIK “non-pharmacolog*intervent*”	
#14	ABTIK “non-pharmacolog*therap*”	
#13	ABTIK “art therapy”	
#12	ABTIK “Massage”	
#11	ABTIK “music therapy”	
#10	ABTIK “hypnosis”	
#9	ABTIK “Guided Imagery”	
#8	ABTIK “Relaxation therapy”	
#7	ABTIK “Therapeutic Touch”	
#6	ABTI “cutaneous stimulation”	
#5	ABTI “aromatherapy”	
#4	ABTI “hospice”	
#3	ABTI “end of life”	
#2	ABTI “palliative”	
#1	ABTI “comfort*”	15615

Teseo - Base de datos de Tesis Doctorales – search conducted on November 24th, 2015

Search ID#	Search terms	Results
#1	TI “comfort”	1

TDX - Tesis Doctorals en Xarxa – search conducted on November 24th, 2015

Search ID#	Search terms	Results
#1	ABTI “comfort” AND “palliative” OR “end of life” OR “hospice”	0

Cochrane Library – search conducted on November 23th, 2015

Search ID#	Search terms	Results
#29	Filters: Review Trials	7 58
# 28	#25 AND #26 AND #27	68
#27	#12 OR #13 OR #14 OR #15 #16 OR #17 OR #18 #19 OR #20 OR #21 OR #22 OR #23 OR #24	6996
#26	#9 OR #10 OR #11	3525
#25	#1 OR #2 OR #3 OR #4 OR #5 OR #7 OR #8	167772
#24	ABTIK “Complementar* therap*”	
#23	ABTIK “alternativ* therap*”	
#22	ABTIK “non-pharmacolog*intervent*”	
#21	ABTIK “non-pharmacolog*therap*”	
#20	ABTIK “art therapy”	
#19	ABTIK “Massage”	
#18	ABTIK “music therapy”	
#17	ABTIK “hypnosis”	
#16	ABTIK “Guided Imagery”	
#15	ABTIK “Relaxation therapy”	
#14	ABTIK “Therapeutic Touch”	
#13	ABTIK “cutaneous stimulation”	
#12	ABTIK “aromatherapy”	
#11	ABTIK “hospice”	
#10	ABTIK “end of life”	
#9	ABTIK “palliative”	
#8	ABTIK “depression”	
#7	ABTIK “anxiety”	
#6	ABTIK “fatigue”	
#5	ABTIK “stress”	
#4	ABTIK “pain”	
#3	ABTIK “suffering”	
#2	ABTIK “well being”	
#1	ABTIK “comfort*”	

JBIG Database of Systematic Reviews and Implementation Reports – search conducted on November 24th, 2015

Search ID#	Search terms	Results
#2	Filters: Systematic Reviews	3
#1	ABTIK “comfort”	

RCAAP - Repositório Científico de Acesso Aberto de Portugal – search conducted on November 24th, 2015

Search ID#	Search terms	Results
#27	#24 AND #25 AND #26	4
#26	#12 OR #13 OR #14 OR #15 #16 OR #17 OR #18 #19 OR #20 OR #21 OR #22 OR #23	577
#25	#9 OR #10 OR #11	884
#24	#1 OR #2 OR #3 OR #4 OR #5 OR #7 OR #8	44360
#23	ABTI “Complementary therapy”	
#22	ABTI “alternative therapy”	
#21	ABTI “non-pharmacological intervention”	
#20	ABTI “non-pharmacological therapy”	
#19	ABTI “art therapy”	
#18	ABTI “Massage”	
#17	ABTI “music therapy”	
#16	ABTI “hypnosis”	
#15	ABTI “Guided Imagery”	
#14	ABTI “Relaxation therapy”	
#13	ABTI “Therapeutic Touch”	
#12	ABTI “cutaneous stimulation”	
#11	ABTI “hospice”	
#10	ABTI “end of life”	
#9	ABTI “palliative”	
#8	ABTI “depression”	
#7	ABTI “anxiety”	
#6	ABTI “fatigue”	
#5	ABTI “stress”	
#4	ABTI “pain”	
#3	ABTI “suffering”	
#2	ABTI “well being”	
#1	ABTI “comfort”	

ProQuest – Nursing and Allied Health Source Dissertations – search conducted on November 24th, 2015

Search ID#	Search terms	Results
#1	AB (“end of life” OR hospice OR palliative OR “home care”) AND AB (comfort* OR pain OR suffering OR anxiety OR depression OR stress OR fatigue OR well-being) AND AB (intervention*)	5

SciELO – search conducted on November 24th, 2015

Search ID#	Search terms	Results
#4	Filters: Language: English; Portuguese; Spanish	29
# 3	#1 AND #2	29
#2	(ti:(("palliative" or "end of life" or "hospice"))) OR (ab:(("palliative" or "end of life" or "hospice")))	855
#1	((ti:(("comfort")) OR (ab:(("comfort"))))	871



**Appendix II: Data extraction instrument**

**Review title:** The use of non-pharmacological interventions for the comfort of patients in palliative care.

**Review questions:**

1. What non-pharmacological interventions have been implemented and evaluated to provide comfort in patients with incurable and advanced disease?
2. What are the characteristics (duration, dose and frequency) of these interventions?
3. In what contexts (home care, palliative care unit, or hospice) are the non-pharmacological interventions implemented and evaluated?
4. In which populations (cancer and non-cancer patients) are the non-pharmacological interventions implemented and evaluated?

**Inclusion criteria (PCC):**

**Population**  
 - Patients aged 18 years or older, assisted by palliative care teams.

**Concept**  
 - Non-pharmacological interventions implemented and evaluated to provide comfort in palliative care.  
 Notes:  
 These interventions include guided imagery, relaxation, therapeutic touch, and massage, among others.  
 The review will consider "comfort" related concepts: pain, suffering, anxiety, depression, stress, fatigue, and well-being.

**Context**  
 - Palliative Care. This will include home care, hospices, or palliative care units.  
 -

**Study details and characteristics extraction**

Author(s) \_\_\_\_\_

Year of publication \_\_\_\_\_

Country of origin \_\_\_\_\_

Aims \_\_\_\_\_

Study design \_\_\_\_\_

Study population (cancer or non-cancer) and sample size \_\_\_\_\_

Context (palliative care unit/hospice/home care) \_\_\_\_\_

Non-pharmacologic intervention \_\_\_\_\_

Duration of the intervention \_\_\_\_\_

Dose of intervention \_\_\_\_\_

Frequency of intervention \_\_\_\_\_

Concept(s) relevant to the review question \_\_\_\_\_

Main results \_\_\_\_\_

**Appendix III: List of excluded studies after eligibility assessment based on full-text reading**

Ahmed HE, Craig WF, White PF, Huber P. Percutaneous electrical nerve stimulation (PENS): A complementary therapy for the management of pain secondary to bony metastasis. *Clin J Pain. Dept. of Anesth. and Pain Management, Eugene McDermott Ctr. for Pain Mgmt., Univ. TX Southwestern Med. Ctr. D., Dallas, TX, United States; 1998;14(4):320–3.*

**Reason for exclusion:** This study did not meet the inclusion criteria (context).

Archie P, Bruera E, Cohen L. Music-based interventions in palliative cancer care: a review of quantitative studies and neurobiological literature. *Support Care Cancer. Germany; 2013 Sep;21(9):2609–24.*

**Reason for exclusion:** This study did not meet the inclusion criteria (context).

Ben-Arye E, Israely P, Baruch E, Dagash J. Integrating family medicine and complementary medicine in cancer care: A cross-cultural perspective. *Patient Educ Couns. 2014;97(1):135–9.*

**Reason for exclusion:** This study did not meet the inclusion criteria (context).

Benney S, Gibbs V. A literature review evaluating the role of Swedish massage and aromatherapy massage to alleviate the anxiety of oncology patients. *Radiography. 2013;19(1):35–41.*

**Reason for exclusion:** This study did not meet the inclusion criteria (context).

Bullock M. Reiki: a complementary therapy for life. *Am J Hosp Palliat Care. United States; 1997;14(1):31–3.*

**Reason for exclusion:** This study did not meet the inclusion criteria (context).

Elkis-Abuhoff D, Goldblatt R, Gaydos M, Corrato S. Effects of clay manipulation on somatic dysfunction and emotional distress in patients with Parkinson’s disease. *Art Ther J Am Art Ther Assoc. 2008;25(3):122–8.*

**Reason for exclusion:** This study did not meet the inclusion criteria (context).

Dunwoody L, Smyth A, Davidson R. Cancer patients’ experiences and evaluations of aromatherapy massage in palliative care. *Int J Palliat Nurs. 2002;8(10):497–504.*

**Reason for exclusion:** This study did not meet the inclusion criteria (context).

Engelman SR. Palliative care and use of animal-assisted therapy. *Omega. United States; 2013;67(1–2):63–7.*

**Reason for exclusion:** This study did not meet the inclusion criteria (context).

Fleming U. Relaxation therapy for far-advanced cancer. *Practitioner. England; 1985 May;229(1403):471–5.*

**Reason for exclusion:** This study did not meet the inclusion criteria (context).

Gallagher LM, Lagman R, Walsh D, Davis MP, Legrand SB. The clinical effects of music therapy in palliative medicine. *Support Care Cancer. 2006;14(8):859–66.*

**Reason for exclusion:** This study did not meet the inclusion criteria (context).

Gambles M, Crooke M, Wilkinson S. Evaluation of a hospice based reflexology service: a qualitative audit of patient perceptions. *Eur J Oncol Nurs. Scotland; 2002 Mar;6(1):37–44.*

**Reason for exclusion:** This study did not meet the inclusion criteria (context).

Gutgsell KJ, Schluchter M, Margevicius S, DeGolia PA, McLaughlin B, Harris M, et al. Music therapy reduces pain in palliative care patients: a randomized controlled trial. *J Pain Symptom Manage. 2013;45(5):822–31.*

**Reason for exclusion:** This study did not meet the inclusion criteria (context).

Hokka M, Kaakinen P, Polkki T. A systematic review: non-pharmacological interventions in treating pain in patients with advanced cancer. *J Adv Nurs. England; 2014 Sep;70(9):1954–69.*

**Reason for exclusion:** This study did not meet the inclusion criteria (context).

Huntley A, Ernst E. Complementary and alternative therapies for treating multiple sclerosis symptoms: a systematic review. *Complement Ther Med. 2000;8(2):97–105.*

**Reason for exclusion:** This study did not meet the inclusion criteria (context).

Jane S-W, Wilkie DJ, Gallucci BB, Beaton RD, Huang H-Y. Effects of a full-body massage on pain intensity, anxiety, and physiological relaxation in Taiwanese patients with metastatic bone pain: a pilot study. *J Pain Symptom Manage.* 2009 Apr;37(4):754–63.

**Reason for exclusion:** This study did not meet the inclusion criteria (context).

Krout RE. The effects of single-session music therapy interventions on the observed and self-reported levels of pain control, physical comfort, and relaxation of hospice patients. *Am J Hosp Palliat Care.* 2001;18(6):383–90.

**Reason for exclusion:** This study did not meet the inclusion criteria (context).

Kutner JS, Smith MC, Corbin L, Hemphill L, Benton K, Mellis BK, et al. Massage therapy versus simple touch to improve pain and mood in patients with advanced cancer: a randomized trial. *Ann Intern Med.* 2008;149(6):369–79.

**Reason for exclusion:** This study did not meet the inclusion criteria (context).

Kyle G. Evaluating the effectiveness of aromatherapy in reducing levels of anxiety in palliative care patients: results of a pilot study. *Complement Ther Clin Pract.* 2006 May;12(2):148–55.

**Reason for exclusion:** This study did not meet the inclusion criteria (context).

Lafferty WE, Downey L, McCarty RL, Standish LJ, Patrick DL. Evaluating CAM treatment at the end of life: a review of clinical trials for massage and meditation. *Complement Ther Med.* 2006 Jun;14(2):100–12.

**Reason for exclusion:** This study did not meet the inclusion criteria (context).

López-Sendín N, Albuquerque-Sendín F, Cleland JA, Fernández-de-las-Peñas C, Lopez-Sendin N, Albuquerque-Sendin F, et al. Effects of physical therapy on pain and mood in patients with terminal cancer: a pilot randomized clinical trial. *J Altern Complement Med.* United States; 2012 May;18(5):480–6.

**Reason for exclusion:** This study did not meet the inclusion criteria (context).

Magill L, Berenson S. The conjoint use of music therapy and reflexology with hospitalized advanced stage cancer patients and their families. *Palliat Support Care.* 2008 Sep;6(3):289–96.

**Reason for exclusion:** This study did not meet the inclusion criteria (context).

McDonald A, Burjan E, Martin S. Yoga for patients and carers in a palliative day care setting. *Int J Palliat Nurs.* England; 2006 Nov;12(11):519–23.

**Reason for exclusion:** This study did not meet the inclusion criteria (context).

Mitchinson A, Fletcher CE, Kim HM, Montagnini M, Hinshaw DB. Integrating massage therapy within the palliative care of veterans with advanced illnesses: an outcome study. *Am J Hosp Palliat Care.* United States; 2014 Feb;31(1):6–12.

**Reason for exclusion:** This study did not meet the inclusion criteria (context).

Partridge RA, Matulonis UA, Rosenthal DS, Penson RT. Why use complementary and alternative medicine during cancer treatment? Patient perspectives on acupuncture and other alternative therapies. *J Cancer Integr Med.* 2005;3(1):27–37.

**Reason for exclusion:** This study did not meet the inclusion criteria (context).

Pollak KI, Lyna P, Bilheimer A, Porter LS. A brief relaxation intervention for pain delivered by palliative care physicians: A pilot study. *Palliat Med. Cancer Control and Population Sciences, Duke Cancer Institute, Durham, NC, United States: SAGE Publications Ltd; 2015 Jun 1;29(6):569–70.*

**Reason for exclusion:** This study did not meet the inclusion criteria (context).

Serfaty M, Wilkinson S, Freeman C, Mannix K, King M. The ToT study: helping with Touch or Talk (ToT): a pilot randomised controlled trial to examine the clinical effectiveness of aromatherapy massage versus cognitive behaviour therapy for emotional distress in patients in cancer/palliative care. *Psychooncology.* 2012 May;21(5):563–9.

**Reason for exclusion:** This study did not meet the inclusion criteria (context).

Singh BB, Wu W-S, Hwang SH, Khorsan R, Der-Martirosian C, Vinjamury SP, *et al.* Effectiveness of acupuncture in the treatment of fibromyalgia. *Altern Ther Health Med.* United States; 2006;12(2):34–41.  
**Reason for exclusion:** This study did not meet the inclusion criteria (context).

Smithson J, Britten N, Paterson C, Lewith G, Evans M. The experience of using complementary therapies after a diagnosis of cancer: a qualitative synthesis. *Health (London).* England; 2012 Jan;16(1):19–39.  
**Reason for exclusion:** This study did not meet the inclusion criteria (context).

Spiller J. Acupuncture, ketamine and piriformis syndrome - a case report from palliative care. *Acupunct Med.* England; 2007 Sep;25(3):109–12.  
**Reason for exclusion:** This study did not meet the inclusion criteria (context).

Toth M, Kahn J, Walton T, Hrbek A, Eisenberg DM, Phillips RS. Therapeutic Massage Intervention for Hospitalized Patients with Cancer: A Pilot Study. *Altern Complement Ther.* 2003 Jun;9(3):117–24.  
**Reason for exclusion:** This study did not meet the inclusion criteria (context).

Waissengrin B, Urban D, Leshem Y, Garty M, Wolf I. Patterns of Use of Medical Cannabis Among Israeli Cancer Patients: A Single Institution Experience. *J Pain Symptom Manage.* 2015 Feb;49(2):223–30.  
**Reason for exclusion:** This study did not meet the inclusion criteria (context).

Wilkinson S, Aldridge J, Salmon I, Cain E, Wilson B. An evaluation of aromatherapy massage in palliative care. *Palliat Med.* 1999 Sep;13(5):409–17.  
**Reason for exclusion:** This study did not meet the inclusion criteria (context).

Yamamoto K, Nagata S. Physiological and psychological evaluation of the wrapped warm footbath as a complementary nursing therapy to induce relaxation in hospitalized patients with incurable cancer: a pilot study. *Cancer Nurs.* 2011 Jan;34(3):185–92.  
**Reason for exclusion:** This study did not meet the inclusion criteria (context).

Hsu C-C, Chen M-J, Tseng Y-H, Hwang S-F, Huang H-M. Improving constipation in patients at terminal stage: A pilot study on the efficacy of using abdominal meridian massage with essential oil. *J Nurs Healthc Res. Palliative Care Ward, Veterans General Hospital-Taichung, Taiwan: Taiwan Nurses Association;* 2009;5(4):256–64.  
**Reason for exclusion:** This study did not meet the inclusion criteria (language).

Chang SY. Effects of aroma hand massage on pain, state anxiety and depression in hospice patients with terminal cancer. *Taehan Kanho Hakhoe Chi.* 2008 Aug;38(4):493–502.  
**Reason for exclusion:** This study did not meet the inclusion criteria (language).

Safrai MB. Art Therapy in Hospice: A Catalyst for Insight and Healing. *Art Ther.* 2013 Jul 3;30(3):122–9.  
**Reason for exclusion:** This study did not meet the inclusion criteria (related to the concept but did not evaluate the intervention).

Cooksley V. An integrative aromatherapy intervention for palliative care. *Int J Aromather.* 2003;13(2–3):128–37.  
**Reason for exclusion:** This study did not meet the inclusion criteria (related to the concept but did not evaluate the intervention).

Zadow L. Utilising hypnosis for palliative care: The case of PB. *Aust J Clin Exp Hypn.* 22 Norman Road, Yatala Vale, SA 5126, Australia; 2004;32(2):170–88.  
**Reason for exclusion:** This study did not meet the inclusion criteria (concept).

Buday KM. Engage, empower, and enlighten: Art therapy and image making in hospice care. *Prog Palliat Care.* 2013 May;21(2):83–8.  
**Reason for exclusion:** This study did not meet the inclusion criteria (concept).

Freeman L, Caserta M, Lund D, Rossa S, Dowdy A, Partenheimer A. Music thanatology: Prescriptive harp music as palliative care for the dying patient. *Am J Hosp Palliat Med.* 2006 Mar 1;23(2):100–4.

**Reason for exclusion:** This study did not meet the inclusion criteria (concept).

Meek SS. Effects of slow stroke back massage on relaxation in hospice clients. *Image J Nurs Scholarsh.* United Kingdom: Blackwell Publishing; 1993;25(1):17–21.

**Reason for exclusion:** This study did not meet the inclusion criteria (concept).

MacDonald JM, Barrett D. Companion animals and well-being in palliative care nursing: a literature review. *J Clin Nurs.* 2015 Nov.

**Reason for exclusion:** This study did not meet the inclusion criteria (concept).

Nelson JP. Being in tune with life: complementary therapy use and well-being in residential hospice residents. *J Holist Nurs.* United States; 2006 Sep;24(3):152–61.

**Reason for exclusion:** This study did not meet the inclusion criteria (concept).

Meek S. Perceptions and selected physiological effects of slow stroke back massage in hospice clients. University of Texas - Austin; 1991.

**Reason for exclusion:** This study did not meet the inclusion criteria (concept).

Akechi T, Okuyama T, Onishi J, Morita T, Furukawa TA. Psychotherapy for depression among incurable cancer patients. *Cochrane Database Syst Rev.* Department of Psychiatry, Nagoya City University Medical School, Mizuho-cho, Mizuho-ku, Nagoya, Aichi 467 8601, Japan; 2008;(2).

**Reason for exclusion:** This study did not meet the inclusion criteria (population).

Berger AM, Yennu S, Million R. Update on interventions focused on symptom clusters: what has been tried and what have we learned? *Curr Opin Support Palliat Care.* United States; 2013 Mar;7(1): 60–6.

**Reason for exclusion:** This study did not meet the inclusion criteria (population).

Bowers TA, Wetsel MA. Utilization of music therapy in palliative and hospice care: An integrative review. *J Hosp Palliat Nurs.* School of Nursing, Clemson University, 528 Owl Nest Rd, Landrum, SC 29356, United States: Lippincott Williams and Wilkins; 2014 Jun;16(4):231–9.

**Reason for exclusion:** This study did not meet the inclusion criteria (population).

Caires JS, Andrade TA de, Amaral JB do, Calasans MT de A, Rocha MD da S. A utilização das terapias complementares nos cuidados paliativos: benefícios e finalidades. *Cogitare Enferm.* Departamento de Enfermagem da Universidade Federal do Paraná; 2014;19(3):514–20.

**Reason for exclusion:** This study did not meet the inclusion criteria (population).

Chan CWH, Richardson A, Richardson J. Managing symptoms in patients with advanced lung cancer during radiotherapy: results of a psychoeducational randomized controlled trial. *J Pain Symptom Manage.* 2011 Feb;41(2):347–57.

**Reason for exclusion:** This study did not meet the inclusion criteria (population).

Choi T-Y, Lee MS, Kim T-H, Zaslowski C, Ernst E. Acupuncture for the treatment of cancer pain: a systematic review of randomised clinical trials. *Support Care Cancer.* Germany; 2012 Jun;20(6): 1147–58.

**Reason for exclusion:** This study did not meet the inclusion criteria (population).

Downey L, Diehr P, Standish LJ, Patrick DL, Kozak L, Fisher D, et al. Might massage or guided meditation provide “means to a better end”? Primary outcomes from an efficacy trial with patients at the end of life. *J Palliat Care.* 2009;25(2):100–8.

**Reason for exclusion:** This study did not meet the inclusion criteria (population).

Harlow T, Jones P, Shepherd D, Hong A, Walker G, Greaves C. Hypnotherapy for relief of pain and other symptoms in palliative care patients: A pilot study. *Contemp Hypn Integr Ther. Hospiscare (Exeter and District Hospice), United Kingdom: Crown House Publishing; 2015;30(4):163–74.*

**Reason for exclusion:** This study did not meet the inclusion criteria (population).

Kaufman K, Salkeld EJ. Home hospice acupuncture: a preliminary report of treatment delivery and outcomes. *Perm J. United States; 2008;12(1):23–6.*

**Reason for exclusion:** This study did not meet the inclusion criteria (population).

Leng G. A year of acupuncture in palliative care. *Palliat Med. England; 1999 Mar;13(2):163–4.*

**Reason for exclusion:** This study did not meet the inclusion criteria (population).

Mansky PJ, Wallerstedt DB. Complementary medicine in palliative care and cancer symptom management. *Cancer J. 2006;12(5):425–31.*

**Reason for exclusion:** This study did not meet the inclusion criteria (population).

Posadzki P, Moon T-W, Choi T-Y, Park T-Y, Lee MS, Ernst E. Acupuncture for cancer-related fatigue: a systematic review of randomized clinical trials. *Support Care Cancer. Germany; 2013 Jul;21(7):2067–73.*

**Reason for exclusion:** This study did not meet the inclusion criteria (population).

Teut M, Dietrich C, Deutz B, Mittring N, Witt CM. Perceived outcomes of music therapy with Body Tambura in end of life care - A qualitative pilot study. *BMC Palliat Care. Institute for Social Medicine, Epidemiology and Health Economics, Charité Universitätsmedizin Berlin, Luisenstr. 57, Berlin 10117, Germany: BioMed Central Ltd.; 2014;13(1).*

**Reason for exclusion:** This study did not meet the inclusion criteria (population).

Vandergrift A. Use of complementary therapies in hospice and palliative care. *Omega. 2013 Jan;67(1–2):227–32.*

**Reason for exclusion:** This study did not meet the inclusion criteria (population).

Bowers LJ. To what extent does aromatherapy use in palliative cancer care improve quality of life and reduce levels of psychological distress? A literature review. *Int J Aromather. 2006;16(1):27–35.*

**Reason for exclusion:** This study did not meet the inclusion criteria (type of study).

Collette N. Patient's plastic expression of pain. *Med Paliativa. Departamento de Pintura, Facultad de Bellas Artes, Universitat Politècnica de València, Spain; 2004;11(3):141–7.*

**Reason for exclusion:** This study did not meet the inclusion criteria (type of study).

Collette N. Arteterapia y cáncer. *Psicooncología. Hospital de la Santa Creu i Sant Pau, Unidad de Cuidados Paliativos, Institut de Recerca, Calle Sant Quintí, 90, 08025 Barcelona, Spain; 2011 Jun 1;8(1):81–99.*

**Reason for exclusion:** This study did not meet the inclusion criteria (type of study).

Dias GA. A massagem como promotora de conforto à pessoa em fim de vida. *Relatório de Estágio para obtenção do grau de Mestre em Enfermagem à Pessoa em Processo de Doença na Comunidade. 2012.*

**Reason for exclusion:** This study did not meet the inclusion criteria (type of study).

Gamus D, Kedar A, Kleinhauz M. Hypnosis in palliative care. *Prog Palliat Care. 2012 Nov;20(5):278–83.*

**Reason for exclusion:** This study did not meet the inclusion criteria (type of study).

Hilliard RE. Music therapy in hospice and palliative care: A review of the empirical data. *Evidence-based Complement Altern Med. Music Department, State University of New York at New Paltz, New Paltz, NY, United States; 2005;2(2):173–8.*

**Reason for exclusion:** This study did not meet the inclusion criteria (type of study).

Kraft K. CAM for depression, anxiety, grief, and other symptoms in palliative care. *Prog Palliat Care*. 2012 Nov;20(5):272–7.

**Reason for exclusion:** This study did not meet the inclusion criteria (type of study).

Miles P. Palliative care service at the NIH includes Reiki and other mind-body modalities. *Adv Mind Body Med*. United States; 2004;20(2):30–1.

**Reason for exclusion:** This study did not meet the inclusion criteria (type of study).

Seki NH, Galheigo SM. The use of music in palliative care: humanizing care and facilitating the farewell. *Interface - Comun Saúde, Educ*. 2010;14(33):273–84.

**Reason for exclusion:** This study did not meet the inclusion criteria (type of study).

Price A, Hotopf M. The treatment of depression in patients with advanced cancer undergoing palliative care. *Curr Opin Support Palliat Care*. United States; 2009 Mar;3(1):61–6.

**Reason for exclusion:** This study did not meet the inclusion criteria (type of study).

Leow Q, Drury V, Poon WH. Experience of terminally ill patients with music therapy: a literature review. *Singapore Nurs J*. 2010;37(3):48–52.

**Reason for exclusion:** This study did not meet the inclusion criteria (type of study).

Wilkinson S. Aromatherapy and massage in palliative care. *Int J Palliat Nurs*. 1995;1(1):21–30.

**Reason for exclusion:** Compliance with the inclusion criteria could not be determined (full-text could not be obtained from other research centers and the available databases, and the author did not reply to our contact).

Pauli R. How does massage therapy make a difference in palliative care? *J Aust Assoc Massage Ther*. 2011;9(1):13–5.

**Reason for exclusion:** Compliance with the inclusion criteria could not be determined (full-text could not be obtained from other research centers and available databases, and author could not be contacted).

Corner J, Cawley N, Hildebrand S. An evaluation of the use of massage and essential oils on the wellbeing of cancer patients. *Int J Palliat Nurs*. 1995;2(1):67–73.

**Reason for exclusion:** Compliance with the inclusion criteria could not be determined (full-text could not be obtained from other research centers and available databases, and author could not be contacted).

Appendix IV: Extraction instrument detailing characteristics of included studies

Author(s) Year of publication Country	Non-pharmacological intervention	Objectives	Study design	Study population and sample size	Context	Concept(s) relevant to the review question	Characteristics of intervention	Main results
Berger et al. <sup>28</sup> 2013 Canada	Aromatherapy, reiki, and therapeutic touch	To determine if therapies could enhance symptom management.	Mixed methods: Quasi-experimental design: Pre-test/post-test Qualitative	31 participants (unknown diagnosis)	Palliative care unit	<ul style="list-style-type: none"> <li>• Pain</li> <li>• Anxiety</li> <li>• Depression</li> <li>• Comfort</li> </ul> Instrument: Visual Analogue Scale	<ul style="list-style-type: none"> <li>• Frequency of intervention: 1 or 2 sessions.</li> <li>• Duration of intervention: -</li> <li>• Dose of intervention: -</li> </ul>	Data showed a significant decrease in severity of pain, anxiety, depression, and discomfort (p < 0.01, 95% confidence interval) and conclusive narratives on increased comfort.
Dietrich et al. <sup>56</sup> 2015 India	Music therapy with body tambura	To record perceived effects of a treatment with the Body Tambura in palliative care patients.	Mixed methods: Prospective case study and Qualitative analysis (hermeneutic)	10 participants (non-cancer patients)	Hospice	<ul style="list-style-type: none"> <li>• Pain</li> </ul> Instrument: Visual Analogue Scale	<ul style="list-style-type: none"> <li>• Frequency of intervention: 2 sessions.</li> <li>• Duration of intervention: 10 minutes.</li> <li>• Dose of intervention: -</li> </ul>	Pain intensity at baseline was reduced from 8.3 ± standard deviation (SD) 1.16 to 4.6 ± 1.52 (day 1) and from 4.6 ± 2.07 to 2.4 ± 1.58 (day 2).
Giasson and Bouchard <sup>57</sup> 1998 Canada	Noncontact therapeutic touch	To examine the effect of three Non-contact Therapeutic Touch treatments in terminal cancer patients' well-being.	Time-series design with control group	20 participants (cancer patients):  Control group: 10 patients Experimental group: 10 patients	Palliative care unit	<ul style="list-style-type: none"> <li>• Well-being</li> </ul> Instrument: Well-Being Scale	<ul style="list-style-type: none"> <li>• Frequency of intervention: 3 sessions.</li> <li>• Duration of intervention: 15–20 minutes.</li> <li>• Dose of intervention: -</li> </ul>	The experimental group showed a mean increase of 1.70 (SD = 1.28) in sense of well-being, whereas the control group showed a decrease of 0.31 (SD = 1.12). A significant difference was found in the mean evolution of the sense of well-being between the experimental group and the control group (t = -3.73; p = .0015).
Horne-Thompson and Grocke <sup>52</sup> 2008 Australia	Music therapy	To examine the effect of music therapy in anxiety in palliative care patients.	Randomized controlled trial	25 participants (24 diagnosed with cancer and 1 diagnosed with end-stage organ failure):  Experimental group: n = 13; control group: n = 12	Palliative care unit	<ul style="list-style-type: none"> <li>• Anxiety</li> <li>• Pain</li> <li>• Depression</li> <li>• Well-being</li> </ul> Instrument: Edmonton Symptom Assessment Scale.	<ul style="list-style-type: none"> <li>• Frequency of intervention: 1 session.</li> <li>• Duration of intervention: 20–40 minutes.</li> <li>• Dose of intervention: -</li> </ul>	Significant reduction of anxiety levels in the experimental group (p = 0.005). A <i>post-hoc</i> analysis found significant reductions in other ESAS scores in the experimental group, specifically pain (p = 0.019). No significant results were obtained in depression and well-being scores.
Osaka et al. <sup>46</sup> 2009 Japan	Hand massage	To examine if hand massage reduces stress in terminal cancer patients.	Pre-test/post-test experimental design	34 participants (cancer patients)	Palliative care unit	<ul style="list-style-type: none"> <li>• Stress</li> </ul> Instrument: (salivary chromogranin A)	<ul style="list-style-type: none"> <li>• Frequency of intervention: 1 session.</li> <li>• Duration of intervention: 5 minutes.</li> <li>• Dose of intervention: -</li> </ul>	Brief hand massage seems to reduce stress levels, assessed by salivary CgA (p < 0.05).



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Author(s) Year of publication Country	Non-pharmacological intervention	Objectives	Study design	Study population and sample size	Context	Concept(s) relevant to the review question	Characteristics of intervention	Main results
Horne-Thompson and Bolger <sup>53</sup> 2010 Australia	Music therapy	To compare the effectiveness of live music therapy, recorded music, and silence in reducing anxiety.	Quasi-experimental design: Pre-test/post-test	21 participants (amyotrophic lateral sclerosis/motor neurone disease)	Hospice	<ul style="list-style-type: none"> <li>Anxiety Instrument: Hospital Anxiety and Depression Scale; Edmonton Symptom Assessment Scale.</li> </ul>	<ul style="list-style-type: none"> <li>Frequency of intervention: 3 sessions: one live music therapy session, one recorded music intervention, and one control intervention, over a 3-day period in 1 week.</li> <li>Duration of intervention: 30 minutes for each session.</li> <li>Dose of intervention: -</li> </ul>	Results were not significant in either the music therapy or the recorded music groups.
Kolcaba et al. <sup>43</sup> 2004 USA	Hand massage	To determine the efficacy of bilateral hand massage in hospice patients' comfort.	Experimental randomized design	31 participants (cancer and non-cancer patients)	Hospice and Home care	<ul style="list-style-type: none"> <li>Comfort</li> <li>Stress Instrument: Hospice Comfort Questionnaire; Symptom Distress Scale.</li> </ul>	<ul style="list-style-type: none"> <li>Frequency of intervention: 6 sessions (twice a week for 3 weeks)</li> <li>Duration of intervention: 5–8 minutes for each hand.</li> <li>Dose of intervention: -</li> </ul>	Differences in comfort over time were not significant between the treatment and comparison groups (time X group interaction: $F = 0.837$ , $p = 0.445$ ). There was no significant overall change with time (time main effect: $F = 0.862$ , $p = 0.434$ ) or overall difference in comfort between groups (group main effect: $F = 0.511$ , $p = 0.481$ ). For symptom distress, the comparison group started with higher symptom distress and remained higher than the treatment group throughout the study (group main effect: $F = 3.886$ , $p = 0.060$ ). Differences in symptom distress over time were not significantly different between groups (time x group interaction: $F = 0.617$ , $p = 0.548$ ) and changes in symptom distress over time were flat for both groups (time main effect: $F = 0.366$ , $p = 0.698$ ).

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Author(s) Year of publication Country	Non-pharmacological intervention	Objectives	Study design	Study population and sample size	Context	Concept(s) relevant to the review question	Characteristics of intervention	Main results
Plaskota et al. <sup>30</sup> 2012 England	Hypnotherapy	To explore the impact of hypnotherapy on the anxiety management and associated symptoms in palliative care patients.	Quasi-experimental design: Pre-test/post-test	21 participants (cancer patients) participated in the study - 11 completed the intervention.	Hospice	<ul style="list-style-type: none"> <li>• Anxiety</li> <li>• Depression</li> </ul> <u>Instruments:</u> Hospital Anxiety and Depression Scale; Edmonton Symptom Assessment Scale.	<ul style="list-style-type: none"> <li>• Frequency of intervention: 4 sessions.</li> <li>• Duration of intervention: -</li> <li>• Dose of intervention: -</li> </ul>	After the second hypnotherapy session, there was a statistically significant reduction in mean anxiety ( $p = 0.0066$ ) and symptom severity ( $p = 0.0094$ ), but not in depression ( $p = 0.2910$ ). After the fourth session, there was a statistically significant reduction in anxiety, ( $P = 0.0016$ ), symptom severity ( $P = 0.0329$ ), and depression ( $P = 0.0466$ ).
Kohara et al. <sup>48</sup> 2004 Japan	Aromatherapy, Footsoak, and Reflexology 1st Aromatherapy 2nd Footsoak in warm water containing lavender essential oil 3rd Reflexology treatment with jojoba oil containing lavender.	To examine the effectiveness of a combined modality treatment, consisting of aromatherapy, footsoak, and reflexology, in fatigue.	Quasi-experimental design: Pre-test/post-test	20 participants (cancer patients)	Palliative care unit	<ul style="list-style-type: none"> <li>• Fatigue</li> </ul> <u>Instrument:</u> Cancer Fatigue Scale	<ul style="list-style-type: none"> <li>• Frequency of intervention: 8 sessions on average.</li> <li>• Duration of intervention: Patients received aromatherapy accompanied with footsoak in warm water containing lavender essential oil for 3 minutes, followed by reflexology treatment with jojoba oil containing lavender for 10 minutes.</li> <li>• Dose of intervention: Aromatherapy was accompanied with footsoak in warm water (40°C) containing 2 drops of lavender essential oil, and reflexology treatment with jojoba oil containing 1% lavender.</li> </ul>	Fatigue improved significantly after treatment (from $25.6 \pm 11.0$ to $18.1 \pm 10.0$ , $p < 0.001$ ). In the three Cancer Fatigue subscales, physical and cognitive subscale scores were reduced significantly ( $11.3 \pm 6.1$ to $6.7 \pm 6.1$ , $p < 0.001$ ; $4.5 \pm 3.2$ to $2.4 \pm 2.4$ , $p < 0.001$ ).

(Continued)

Author(s) Year of publication Country	Non-pharmacological intervention	Objectives	Study design	Study population and sample size	Context	Concept(s) relevant to the review question	Characteristics of intervention	Main results
Louis and Kowalski <sup>54</sup> 2002 USA	Aromatherapy	To measure patients' response to aromatherapy.	Quasi-experimental, repeated-measures, one-group design. • Pre- and post-measurement with no intervention for control purposes (Day 1); • Pre- and post-measurement with humidified water intervention (Day 2); • Pre- and post-measurement with humidified lavender essential oil treatment (Day 3).	17 participants (cancer patients)	Home care	<ul style="list-style-type: none"> <li>• Pain</li> <li>• Anxiety</li> <li>• Depression</li> <li>• Well-being</li> </ul> <u>Instrument:</u> Visual Analogue Scale	<ul style="list-style-type: none"> <li>• Frequency of intervention: 1 session.</li> <li>• Duration of intervention: 60 minutes.</li> <li>• Dose of intervention: 3% lavender essential oil (<i>Lavandula angustifolia</i>).</li> </ul>	All participants showed a positive response to lavender aromatherapy, which translated into lower scores in pain, anxiety, and depression, and an increase in the sense of well-being. Scores showed a mild improvement, and pre- to post-treatment paired t-test results were not statistically significant.
Nakayama, Kikuta, and Takeda <sup>47</sup> 2009 Japan	Music therapy	To determine the effectiveness of music therapy.	Quasi-experimental design: Pre-test/post-test	10 participants (cancer patients)	Hospice	<ul style="list-style-type: none"> <li>• Stress</li> <li>• Fatigue</li> <li>• Depression</li> <li>• Anxiety</li> </ul> <u>Instruments:</u> Measurement of salivary cortisol levels; Mood Inventory	<ul style="list-style-type: none"> <li>• Frequency of intervention: 1 session</li> <li>• Duration of intervention: 40 minutes.</li> <li>• Dose of intervention: -</li> </ul>	Results showed a significant reduction in salivary cortisol levels after the therapy session. Fatigue score before music therapy (1.750 ± 0.790) showed no significant changes after music therapy (1.550 ± 0.550). Both depression and anxiety decreased after music therapy. Anxiety level was of 1.600 ± 0.774 before music therapy and 1.200 ± 0.483 after music therapy (p = .0690), whereas depression level was of 1.600 ± 0.809 before music therapy and 1.250 ± 0.540 after music therapy (p = 0.0898)

(Continued)

Author(s) Year of publication Country	Non-pharmacological intervention	Objectives	Study design	Study population and sample size	Context	Concept(s) relevant to the review question	Characteristics of intervention	Main results
Polubinski and West <sup>44</sup> 2005 USA	Massage therapy	To evaluate the implementation of a Massage Therapy Program for pain and anxiety management	Pre-post treatment design	32 participants (cancer and non-cancer patients)	Home care Hospice	<ul style="list-style-type: none"> <li>• Pain</li> <li>• Anxiety</li> </ul> <u>Instruments:</u> Visual Analogue Scale	<ul style="list-style-type: none"> <li>• Frequency of intervention: 8 (25%) of the patients received only one treatment, and the remainder received multiple therapy sessions: 16 (50%) received between 2 and 7 treatments, and 8 (25%) received between 8 and 14 treatments.</li> <li>• Duration of intervention: 58 minutes</li> <li>• Dose of intervention: -</li> </ul>	On average, between the beginning and end of a therapy session, patients reported a 52% reduction in pain scores and similar improvements in anxiety levels (53%).
Rhondali et al. <sup>31</sup> 2013 France	Art therapy (painting)	To evaluate the short-term effect of an art therapy session in symptoms experienced by advanced cancer patients, and to qualitatively assess these patients' perceptions of the impact and value of the session on their physical and psychological distress.	Mixed methods: Quasi-experimental design: Pre-test/post-test; Grounded theory.	12 participants (cancer patients)	Palliative care unit	<ul style="list-style-type: none"> <li>• Pain</li> <li>• Fatigue</li> <li>• Depression</li> <li>• Anxiety</li> <li>• Well-being</li> </ul> <u>Instrument:</u> Edmonton Symptom Assessment Scale.	<ul style="list-style-type: none"> <li>• Frequency of intervention: 1 session.</li> <li>• Duration of each intervention: 60 minutes</li> <li>• Dose of intervention: -</li> </ul>	One hour before and after the art therapy session, there was a statistically significant improvement in pain (p = 0.002), fatigue (p = 0.001), depression (p = 0.022), and anxiety (p = 0.027), and a statistically significant reduction in the sense of well-being (p = 0.015). During the semi-qualitative interviews, patients expressed that they had experienced relief from physical pain during the art therapy session. Two patients reported increased fatigue. However, this was not a barrier to continuing the session and was not considered an undesirable feeling.

(Continued)

Author(s) Year of publication Country	Non-pharmacological intervention	Objectives	Study design	Study population and sample size	Context	Concept(s) relevant to the review question	Characteristics of intervention	Main results
Soden et al. <sup>49</sup> 2004 UK	Aromatherapy massage	To compare the effects of aromatherapy massage with and without essential oil in cancer patients' physical and psychological symptoms.	Randomized controlled trial	42 participants (cancer patients): • 16 were randomly allocated to the aromatherapy group, • 13 to the massage group, and • 13 to the control group, • 6 did not complete the study.	Palliative care unit	• Pain • Anxiety • Depression <u>Instruments:</u> Visual Analogue Scale; Hospital Anxiety and Depression Scale	• Frequency of intervention: 4 sessions (1 weekly session, for 4 weeks). • Duration of intervention: 30 minutes • Dose of intervention: The lavender essential oil was mixed in sweet almond oil (inert carrier oil) to a dilution of 1%.	Study was unable to demonstrate any significant long-term benefits of aromatherapy or massage in terms of improving pain control or anxiety. There were statistically significant reductions in depression scores in the massage group. In this study, the addition of lavender essential oil did not appear to increase the beneficial effects of massage.
Tsai et al. <sup>50</sup> 2007 Taiwan	Electromyography biofeedback-assisted relaxation	To determine the potential usage and possible mechanisms of electromyographic biofeedback for pain management in patients with advanced cancer.	Randomized control study	37 participants • Experimental group n = 20; • Control group n = 17. 30 patients discontinued the study, resulting in: Total of 24 participants (cancer patients): 12 in the experimental group, and 12 in the control group.	Palliative care unit	• Pain <u>Instrument:</u> Brief Pain Inventory	• Frequency of intervention: 6 sessions in 4 weeks. • Duration of intervention: 45 minutes. • Dose of intervention: -	Post-test pain intensity was significantly lower in the experimental group than in the control group (95% CI = -2.96 to -0.21, p = .011). The experimental group showed decrease of 2.29 points in pain intensity compared to baseline, and the reductions were statistically significant when compared to those of the control group (95% CI = 1.46-3.79, P < .001). Relaxation training supplemented with visual and auditory EMG biofeedback signals is effective in reducing cancer-related pain in advanced cancer patients between 30% and 50%.
Wilkie et al. <sup>45</sup> 2000 USA	Massage	To compare the effects of hospice care with or without the addition of four massage treatments performed twice a week in pain intensity, analgesic dosing, hospital admission, and quality of life.	Randomized controlled clinical trial	173 referred participants (cancer patients): • 29 completed the study: • 14 in the control group, • 15 in the massage group.	Hospice	• Pain <u>Instrument:</u> Visual Analogue Scale	• Frequency of intervention: 6 sessions in 4 weeks. • Duration of intervention: 30-50 minutes. • Dose of intervention: -	Pain intensity was significantly reduced immediately after the massages. At baseline, the massage group reported higher pain intensity (2.4/2.8 vs. 1.6/2.1) which decreased by 42% (1.4/1.5) compared to a 25% reduction in the control group (1.2/1.3) (p > 0.05).

(Continued)

Author(s) Year of publication Country	Non-pharmacological intervention	Objectives	Study design	Study population and sample size	Context	Concept(s) relevant to the review question	Characteristics of intervention	Main results
Warth et al. <sup>51</sup> 2015 Germany	Music therapy	To examine if relaxation interventions as part of music therapy could be successfully used to: <ul style="list-style-type: none"> <li>• Improve self-rated relaxation, well-being, and acute pain</li> <li>• Trigger a physiological relaxation response,</li> <li>• Improve health-related quality of life.</li> </ul>	Randomized controlled trial	84 participants (cancer and non-cancer patients): <ul style="list-style-type: none"> <li>• 42 were randomly allocated to the experimental group - 4 patients did not complete the study;</li> <li>• 42 to the control group - 12 did not complete the study.</li> </ul>	Palliative care unit	<ul style="list-style-type: none"> <li>• Well-being</li> <li>• Acute pain</li> </ul> Instrument: Visual Analogue Scales	<ul style="list-style-type: none"> <li>• Frequency of intervention: 2 sessions.</li> <li>• Duration of intervention: 15 minutes.</li> <li>• Dose of intervention: -</li> </ul>	Analyses of covariance revealed that music therapy was more effective than the control treatment at promoting relaxation (F = 13.7; p < 0.001) and well-being (F = 6.41; p = 0.01). This effect was supported by a significantly greater increase in high-frequency oscillations of the heart rate (F = 8.13; p = 0.01). The effect of music therapy in pain reduction did not differ from the control treatment (F = 0.4; p = 0.53).
Leow, Drury, and Poon <sup>55</sup> 2010 Singapore	Music therapy	To explore patients' experience, expectation, and perception toward music therapy.	Qualitative study	Five participants (unknown diagnosis)	Hospice	<ul style="list-style-type: none"> <li>• Comfort</li> </ul>	<ul style="list-style-type: none"> <li>• Frequency of intervention: At least one individual music therapy session.</li> <li>• Duration of intervention: -</li> <li>• Dose of intervention: -</li> </ul>	All participants agreed that music therapy provided them comfort. Comfort was associated with feelings of peace, relaxation, and the motivation to improve their physical condition. Comfort could arise from playing an instrument, listening to someone play an instrument, or listening to music on tapes. Participants described music as bringing a type of comfort which would help them battle their illness. When describing how they felt about music therapy, participants used words such as 'peace', 'relaxation', and helping them 'feel good'.

## **CHAPTER IV**

### **COMFORT EXPERIENCE IN PALLIATIVE CARE**

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This chapter addresses the Phase 2 of the study, and presents the phenomenological study, carried out with the objective of understanding the comfort and discomfort experienced by inpatients at PCUs. The accomplishment of this study was fundamental for the development of a GI intervention adjusted to the comfort needs of inpatients at PCUs.





## **Comfort experience in palliative care: a phenomenological study**

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## RESEARCH ARTICLE

## Open Access



# Comfort experience in palliative care: a phenomenological study

Adriana Coelho<sup>1\*</sup>, Vitor Parola<sup>1</sup>, Miguel Escobar-Bravo<sup>2</sup> and João Apóstolo<sup>3</sup>**Abstract**

**Background:** Palliative care aims to provide maximum comfort to the patient. However it is unknown what factors facilitate or hinder the experience of comfort, from the perspective of inpatients of palliative care units. This lack of knowledge hinders the development of comfort interventions adjusted to these patients. The aim of this research is to describe the comfort and discomfort experienced by inpatients at palliative care units.

**Methods:** A phenomenological descriptive study was undertaken. Ten inpatients were recruited from a Spanish palliative care unit and seven from a Portuguese palliative care unit. Data were collected using individual interviews and analysed following the method of Giorgi.

**Results:** Four themes reflect the essence of the lived experience: The Palliative Care as a response to the patient's needs with advanced disease, attempt to naturalize advanced disease, confrontation with their own vulnerability, openness to the spiritual dimension.

**Conclusions:** Informants revealed that they experience comfort through humanized care, differentiated environment, symptomatic control, hope and relationships. The discomfort emerges from the losses and powerlessness against their situation. Even if such findings may seem intuitive, documenting them is essential because it invites us to reflect on our convictions about what it means to be comfortable for these patients, and allows incorporating this information in the design of focused interventions to maximize the comfort experience.

**Keywords:** Palliative care, End of life care, Inpatients, Qualitative research, Phenomenology, Comfort

**Background**

The development of science and technology is expressed in an increase in life expectancy [1]. Therefore the population's aging in a society in which death may be delayed ever more, allows us to predict a gradual increase in the prevalence of degenerative and disabling diseases. Also in recent years the process of dying was displaced from the home environment for the hospital context [2].

In this sense, there has been an increment of palliative care units (PCUs) with the aim of provide the greatest comfort and dignity possible to patients and their families facing the problem associated with life-threatening illness [1, 3].

However, patients with advanced disease still experience discomfort [4]. This could be explained by the fact that these patients often have comfort needs that extend

beyond physical symptoms management [5]. Nevertheless the literature continues to give more attention to the physical comfort [6–8], and little attention is given to other aspects of comfort commonly observed among these patients [9].

Indeed, Kolcaba [10], defines comfort as the immediate experience of being strengthened by having the needs for three types of comfort (relief, ease, or renewal) met in four contexts of human experience (physical, psychospiritual, environmental, and social).

In this sense, knowing the experiences of comfort and discomfort of patients are a relevant aspect for the practice of care, guiding the care provided for the patients' needs and maximizing the effect of comfort interventions.

Some researchers have sought to understand the comfort experience in the view of patients in other contexts [11–14]. These studies are important efforts to the comprehension of the phenomenon. However, in the context of Palliative Care (PC), such investigations are scarce [8].

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There are only studies that describe this experience, in some of the contexts of comfort, but from the professional [15–18], or families perspective [19, 20]. However, it is important to note that both family and health professionals tend to describe the physical [21–24], and emotional symptoms [21, 25–27], differently to the patient. Therefore it is not clarified what is the patient comfort experience, and known that the patient's comfort is an important objective of PC, their comfort experience should be taken into account.

Furthermore, the analysis of the literature evidence that the comfort interventions in PC are intuitive or based on medical principles [28].

Therefore being comfort/discomfort subjective states that can only be understood in the light of the patient's experiences, starting from a concrete reality [29], and with the conviction that intervention processes must take into account the complexity and subjectivity of the patient experience, it was conducted this study in order to describe the comfort and discomfort experienced by inpatients at PCUs.

## Methods

### Study design

The present study is a secondary aim of a larger project about comfort interventions.

This study was conducted using a qualitative phenomenological descriptive design. A descriptive phenomenology was chosen, in order to study the complex phenomenon of human experience, giving emphasis to how the life-world is described by the participants voices [30].

This study conforms to Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines (see Additional file 1).

### Participants and setting

Study participants were recruited from a Portuguese and Spanish PCUs, between March and May 2015.

The heads nurses, invited face-to-face those who were eligible to participate (Table 1).

A purposive sampling strategy was performed to ensure a sample that included a wide spectrum of participant gender, ages, hospitalization time, and diagnoses [31].

A total of 17 inpatients participated (Table 2).

### Data collection

Data were collected through non-structured interviews. Interviews were chosen taking into account the vulnerability of participants [32]. Furthermore this technique facilitates a personal narrative by the participant [33].

Non-structured interviews were conducted, supported by the original question: How did you live the experience

**Table 1** Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
- Adult patients with incurable and advanced disease;	- Patients with cognitive alterations;
- Able to consent;	- Dying patients.
- Able to speak Spanish or Portuguese;	
- In health conditions that allow them to tolerate an interview of at least 20 min;	
- Stay period in the PCU equal or superior to 3 days.	

of being hospitalized in this unit?, with the intention of the significant experience of comfort and discomfort to emerge freely.

Follow-up questions in order to deepen understanding of the experience of the informants were also carried, such as: How would you describe this in more detail? What does that mean to you?

A pilot test with two patients was conducted in order to adjust the interview question. These interviews were not included.

Interviews were individual, mean duration was 32 min, and were held in a location of the participants' choice (their room or an intimate space in the PCU). They were digitally audio-recorded and transcribed verbatim.

It was assumed that saturation had been reached after the 10 Spanish PCU and 7 Portuguese PCU interview. Non-participants refused to participate in the study or dropped out during the interview.

Data collection was carried exclusively by one of the investigators (AC) in order to avoid significant differences in conduction the interview. Transcripts were reviewed by the interviewer (AC) to verify their accuracy.

The findings were not returned to participants for confirmation because of participants' declining health.

**Table 2** Participants

		Spanish PCU	Portuguese PCU	Total
Gender	Male	5	3	8
	Female	5	4	9
Age	Range: 58–90 years	Range: 56–78 years	Mean: 70.5	
	Mean: 74 years	Mean: 67 years		
Hospitalization time	Range: 4–44 days	Range: 9–76 days	Mean: 22.5	
	Mean: 14 days	Mean: 31 days		
Diagnoses	Oncologic	7	7	14
	Non-oncologic	3	0	3

The patient's vulnerable conditions constituted a limitation to the rigor of the study, since it was not possible to confirm the findings with the interviewees. Thus, during the interviews were performed cross-checks to clarify and confirm the coherence of the mentioned for patients in their reports.

#### Data analysis

Consistent with Giorgi method [30, 34, 35], analysis involved four steps. The first step was a reading of transcripts, several times, to get a sense of the whole experience. This was done without a critical reflection on the experience. Posteriorly, in the second step, was performed a subsequent readings of the transcripts with the purpose of identify the meaning units (seccions of the collected data that could reveals potentials aspects of the phenomenon under investigation). Each meaning unit is delimited by a change in the thematic content.

In third step the delineated meaning units identified in the previous step were transformed in appropriate language to the phenomenon under study and grouped into common themes and sub-themes that represent the essence of comfort experiences. In this step, the researchers performed imaginative variation by changing qualities of the object under analyzed so as to determine which data are essential. The imaginative variation permitted to determine the essence of the phenomenal structure of the experience.

The fourth analysis step consisted in synthesize all of the transformed meaning units into a consistent and descriptive statement regarding the subject's experience of confort.

According to Giorgi [30, 34, 35], how or where the meaning units are delineated is not absolute, different researchers may delineate the meaning units in different places in the same data. To ensure rigour, each authors performed individual analyses. Every step of analysis were compared and discussed to strengthen the validity of analysis.

To manage the data was used the QSR NVivo version 10 software.

#### Ethical considerations

Ethical approval was obtained by the Research Ethics Committees of the Fundació d'Osona per a la Recerca i l'Educació Sanitària (reference 2015873), Arcebispo João Crisóstomo Hospital (04 February 2015) and Health Sciences Research Unit: Nursing (reference 228-10/2014). Participating organisations' ethical requirements were met.

The interviewer works in the Spanish Center; however during the data collection period did not work in the

PCU. Participants were not acquainted to the researchers prior to the study commencements. They were made aware of the aim of the study, place of work and role of interviewer to inform their decision-making.

Participation was voluntary and they were informed of their right to withdraw from the study at any time. Complete confidentiality was guaranteed and a written consent was obtained by the main researcher before each interview.

#### Results

The analysis of the findings allowed the access to a comprehensive scheme (Fig. 1) organized in an interactive structure.

##### The PC as a response to patient's needs with advanced disease

Informants acknowledge that, to find responses to their health care needs, they need to be hospitalized in a PCU:

*P16 "(...) the pain and the shortness of breath, that is the thing I was not able to control, and that was creating some fearful respect. At the hospital I am well, arriving home, I stay there for a little longer and that's it...loss of control."*

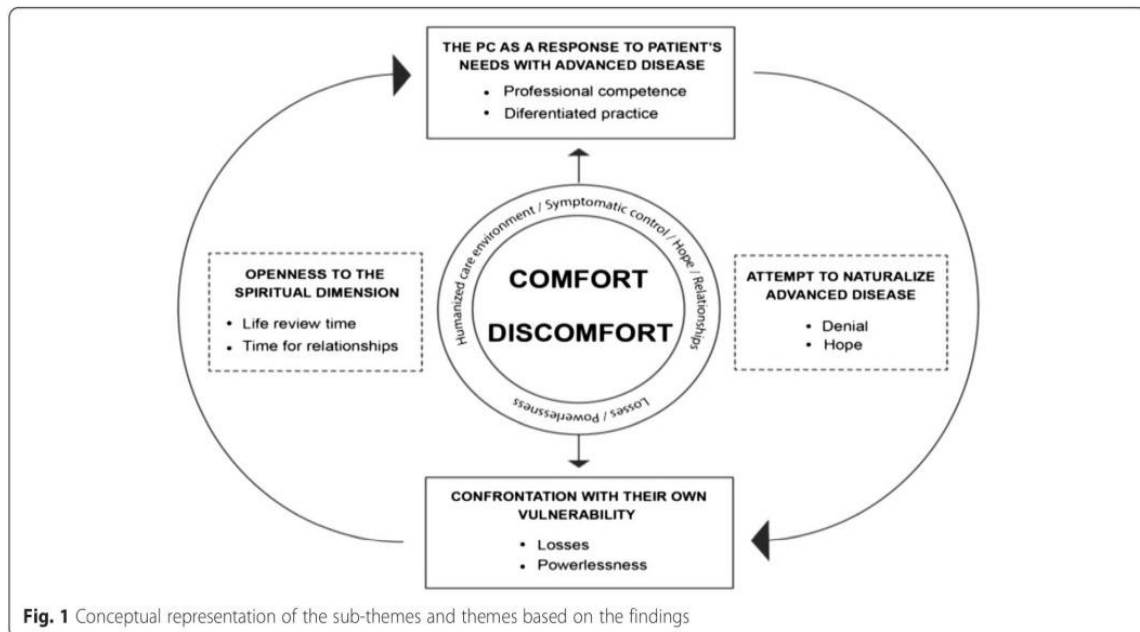
The PCU is perceived as a relief space of physical discomfort, but also a space of comfort by the human competence, by the surrounding environment and by rapidly attention to the patient's needs:

*P12 "If you need a nurse, a nurse will come immediately. If you need anything, just call them and they will come here straightaway. It is the comfort of knowing that if I need to call the nurses, they come here immediately."*

By making reference to these comfort factors, the informants establish constant comparison with the experience lived in other services in which they were previously hospitalized:

*P10 "I had never been in a facility with such human quality as this one. Here the staffs are attentive to everything, I mean everything. And always smiling"*

*P9 "It is a fact that here I have practically the same things as in the other hospital, my blood pressure is assessed, my medication is given to me. Nevertheless, here, besides it, there is a place where I can go down and go for a walk."*



**Attempt to naturalize advanced disease**

Symptomatic control obtained through the hospitalization in PCU leads to some informants naturalized the advanced disease, denying the proximity of death:

P1 "(...) this is a temporary situation of one or two months which will end. This situation does not worry me, everyday I improve greatly and I am very positive."

In this sense, they described a sense of hope regarding recovery and return home.

P15 "My hope is to recover the least independence which I know is possible, so I can go home to my little dog and to my kittens.(...) I believe that there is always a tomorrow, that there is hope."

The informant reports also reveal the conviction that it is possible to interfere with the course of the disease by the optimism:

P14 "By saying: I am fine! The disease goes away quicker ... "

**Confrontation with their own vulnerability**

Even if the PCU be recognized as an area that provide comfort, it is also seen as a discomfort space, where physical and social losses, the feeling of helplessness, confronts informants with their vulnerability and finitude.

P3 "The problem that I now have is a breathing one... I have difficulty even speaking...my body has given all it has got"

P1 "Always the bedpan...I feel dependant. I am always waiting for someone to do everything for me."

P17 "(...) watch the land, listen to the birdies and look at the things I have...the yards, the trees... until this got to me in a stronger way and everything ended. To be comfortable is not to have anything, not to have any problem, it is to be at my home."

Informants of Portuguese PCU even describe as uncomfortable experience the loss of freedom, which corresponds with the lack of an exterior space intended for patients (this space exists in Spanish PCU and was described as comfort proportioning)

P17 "This means a jail. It's a prison to be locked here, a prison."

In the Spanish context, the loss of freedom, for some informants it relates to the fact that they have to share a room with another patient.

P3 "I have a neighbour who wants the blinds always closed...I like to read the newspaper and because of that I can't read and that also makes me feel uncomfortable."

The experience of all these losses generates impotence and devaluation feelings on the informants:

*P14 "I feel inferior... I wanted to go alone (to the toilet) but I can't. Asking for help means wanting and not being able to."*

Due to those experienced losses and powerlessness that they generate, some informants sense the imminence of the end of life:

*P17 "That was why I was sent here... perhaps it was so that I could end my days in here... "*

#### Openness to spiritual dimension

The confrontation with their own vulnerability raises in some patients the opening to the relationship intrapersonal, to the need to do a review of his personal history.

*P14 "I believe I have not affected anybody...here we think about everything, we weigh everything, and here some things are left to be concluded and others left halfway."*

This time dedicated to the life review allows the revaluation of what is really important.

*P10 "I lost too much time scolding my family...and today I can only think of that everything we lived was wonderful... We don't regard things until they are lost."*

During this process the world of relations contains a special importance. Thus, from the speech of the participants emerges comfort that comes from affection with peers, with friends, with family and with the professionals themselves.

*P6 "I have a perfect partner. That means I can share with him my problems, that I can trust him as if he was my family."*

*P15 "It is to feel loved, to feel nurtured, to feel spoiled." (have friends visit)*

*P17 "There is a moment which is special, which is my wife's visit who comes here everyday."*

*P9 "This team that cares us so well, with such kindness... I think that for a patient it is as important a good medication or treatment as it is a humanised and nurtured care."*

The speech of patients also points to the comfort that comes from the relationship with the transcendent – with Nature and with God.

*P9 "To be able to go outside for a walk is to inflate an internal joy which makes me feel alive."*

*P17 "It is him (God) who comforts me, he is my saviour."*

#### Discussion

In previous research under the comfort in PC, comfort often appears associated with the physical dimension of the person [7, 36, 37]. However, this study showed that in addition to physical symptoms, there are other factors that promote significantly comfort and discomfort experiences of inpatients in PCU that should be taken into account.

Therefore, informants recognize as comfort sources, technical competence and human competence with which they feel care in PCU.

The findings suggest that although some comfort interventions seem simple and of little technological complexity (such as availability, fondness, support), they had the ability to significantly affect the state of comfort.

Informants also make a clearly positive assessment of care received in PCU compared to other units in which they have already been admitted, stating that the PCU is a different human and environmental structure. Kolcaba [38, 39], to define environmental comfort makes reference to the environment and to internal and external conditions such as noise, light, temperature or natural elements.

Previous researches report the environment of the PCU [40, 41]. However, this study brings new data since patients emphasize the PCU environment as evidence of the comfort experience through the external environment adjusted (Spanish context) and reduced noise (Portuguese context). The setting was also described as a comfort factor in the study of Hamilton [42], reported however to the presence of homelike elements to patients.

The satisfaction of needs that required hospitalization, leads to some patients try to naturalize advanced disease and make a denial of the proximity of death.

According to Kubler-Ross "denial is usually a temporary defence and will soon be replaced by partial acceptance" [43] (p.39). The patient does not want to believe in what is happening, there is a threat that it is necessary to deny to continue living. Thus, the informants speak about a future recovery.

This experiencing is congruent with findings obtained by Quill et al. [44], according to which one of the most important aspects to reach to the patient with advanced disease, would be the ability to change the trajectory of their illness.

The findings suggest that hope is a comfort factor, since patients trust that they still have some control over their health situation. Or even that it is possible to interfere with the course of the disease, as was also reported by other studies [45, 46].

According to Broggy [47], sometimes denial is so intense that resists victoriously to the reason evidence, under surprising hopes. Nevertheless, the body, through physical losses that are becoming more evident, restrictive and generators of impotence, indicates every day more clearly what will be the end.

As mentioned by Charmaz [48], there is a loss of identity, a loss of the "self". Likewise, Cassel [49], described suffering as the state of discomfort induced by the person disintegration threat.

Physical losses and lack of autonomy favor the experiences of psycho-spiritual discomfort, since the self-esteem of the patient is affected.

Besides somatic vulnerability, informants are confronted with social vulnerability. The disease traps the patient and is a source of profound limitations, as the impossibility to return home.

The fact of sharing a room represents, for some patients, social comfort, letting them share their experience with other patients. For others, this is a discomfort factor since sharing a room deprives them of their freedom.

These findings are consistent with the study of Williams y Gardiner [50], which states that PCU should have collective and single rooms since the choice between these two types of room is not unanimous among patients.

These findings indicate that experienced losses and the feeling of powerlessness to solve them are the main source of discomfort experienced by the informants.

Indeed, according Kolcaba [10], one dimension of comfort is transcendence, defined as the state in which the person feels it has the potential to control their destiny, solve their problems.

The discomfort allows informants to intuit their finitude, which could lead them to the denial but also to a personal growth. There is no social or biological restriction that is so powerful that can overcome the freedom to take a stand, the freedom to choose what attitude to adopt in the face of suffering [51].

Thus, some informants choose to open up to spirituality, through intensification of the relationships and affections. Previous research in PC states that interpersonal relationships are strengthened at the end of life [52]. Nevertheless this study provides a new understanding by suggesting as comfort factors the intrapersonal relationships (making a recapitulation of his life and an evaluation of what is really important), interpersonal (with professional, family and friends) but also transpersonal relationships (with God and nature), since these relationships generate love towards themselves, others and the transcendent.

Indeed, Viktor Frankl [51], states that the core of the human being is the spirit, that is, the existence is always directed to something that is not only the very existence

itself, but also a sense of life that must be met or someone to love.

This study supports the experience of comfort and discomfort as a balanced process, in which there is an oscillation between the losses and the valorisation of relationships. If in a sense discomfort prevails, in other the intensification of the affections predominates.

Even we mentioned the patient's perspective, the majority of the interviewed (82 %) had cancer-related diagnoses, so the focus of the study was almost on palliative cancer patients. As pointed out in our introduction, ageing populations will lead to an increase in chronic conditions. Data indicates that these conditions could have a different dying trajectory than cancer [53].

So, grouping the experience of all PC patients together (cancer/non-cancer) does not take these differences in comfort experience into account.

We believe that our data covers the comfort experiences, but of course, the inclusion of more patients, with non-cancer diagnoses, and do the data analysis by separate in future research, might reveal additional relevant experiences.

## Conclusion

The experience of comfort, in the patient's perspective, has been ignored by the literature on PC.

This study demonstrated that the PCU can be perceived as a space of comfort where the patient finds a suitable therapeutic context to their needs, but also as a place of discomfort where the patient is confronted with its vulnerability. It can be a space where there is a process of denial or openness to spirituality. The discomfort has underlying the experienced losses and the inability to transcend. The patient feels comfortable through the symptomatic control, compassionate care, the PCU differentiated environment, hope, interpersonal, transpersonal and intrapersonal relationships.

Even if such findings may seem intuitive, documenting them is crucial because it invites the reader to reflect on their beliefs about what it means to be comfortable for these patients, and allows the incorporation of this information in the design of focused interventions to maximize the comfort experience. Unless one offers patients the opportunity to be heard on their experience, their perspective will remain hidden and you could hardly provide comfort to them.

In addition, the findings provide useful information that leads us to two major future research lines: the need to develop and implement comfort interventions adapted and adjusted to these patients' comfort needs; and the need to validate cross-culturally, to the contexts in study, an instrument for evaluating comfort, in order to assess the comfort interventions implemented.



## Additional file

**Additional file 1:** Consolidated criteria for Reporting Qualitative research (COREQ): a 32-item checklist for interviews and focus groups. (DOCX 17 kb)

### Abbreviations

PCU, palliative care unit; PC, palliative care; COREQ, cOnsolidated criteria for reporting qualitative research.

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### Authors' contribution

AC, VP, JA, and MEB designed the study. AC conducted and transcribed all the interviews. AC and VP analysed the data and drafted the manuscript. All authors contributed to data analysis and helped in revising and making substantial contributions to the manuscript, and also read and approved the final manuscript.

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### Competing interests

The authors declared that they have no competing interests.

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### Ethics approval and consent to participate

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Participation was voluntary and they were informed of their right to withdraw from the study at any time. Complete confidentiality was guaranteed and a written consent was obtained by the main researcher before each interview.

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# CHAPTER V

## THE VALIDATION OF A COMFORT ASSESSMENT SCALE FOR PALLIATIVE CARE PATIENTS

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This chapter addresses the Phase 3 of the study, which consisted in the validation of the HCQ (Novak, Kolcaba, Steiner, & Dowd, 2001). This instrument was validated for Spanish given the initial objective of implementing the GI program not only in the Portuguese context but also in the Spanish context.

In this line, it would be necessary instruments of evaluation of comfort validated transculturally. In the Portuguese context there is already an instrument for evaluating comfort validated (HCQ-PT-DC). However, in the Spanish context, this instrument did not exist. For this reason, the HCQ was adapted, translated and validated.

Although in the course of the research it was opted to develop and implement the GI program only in the Portuguese context, it was considered opportune to contemplate this validation as a Phase of the present thesis, since it was validated in the context of the realization of the present a thesis and is a useful tool for nurses / researchers who wish to continue the work developed.



**The validation of a Comfort assessment scale for Palliative Care patients: Spanish version of the Hospice Comfort Questionnaire**

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**Versión española del Hospice Comfort Questionnaire para evaluar el confort en pacientes en cuidados paliativos: Adaptación transcultural y validación**

**Spanish version of the Hospice Comfort Questionnaire: Validation of a Comfort assessment scale for Palliative Care patients**

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**Conflicto de intereses**

Los autores declaran no tener ningún conflicto de intereses.

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**Sección de la revista**

Originales

**Versión española del *Hospice Comfort Questionnaire* para evaluar el confort en pacientes en cuidados paliativos: Adaptación transcultural y validación**

**Spanish version of the Hospice Comfort Questionnaire: Validation of a Comfort assessment scale for Palliative Care patients**

**Resumen**

**Objetivo**

Traducir, adaptar y validar el *Hospice Comfort Questionnaire* para su utilización en el ámbito de los Cuidados Paliativos españoles.

**Método**

Han participado en este estudio un total de 67 pacientes ingresados en una Unidad de Cuidados Paliativos. El instrumento empleado ha sido el *Hospice Comfort Questionnaire*.

Se adoptó una metodología dirigida a la equivalencia semántica, idiomática y conceptual del contenido de los ítems y la equivalencia psicométrica, mediante la evaluación de la fiabilidad, la validez de contenido y de criterio.

**Resultados**

Respecto a la fiabilidad, se observaron comportamientos poco consistentes con el resto de la escala en 7 ítems, que presentaran una correlación inferior a 0.20. Teniendo en cuenta los datos estadísticos y el análisis crítico de contenido de los ítems, se decidió eliminar solamente 3 ítems. Una vez reducida la escala a 46 ítems, se midió la consistencia interna del total de la escala con un  $\alpha$  de *Cronbach* de 0,89 y de cada grupo de ítems de cada estado del confort. El alfa de *Cronbach* del alivio fue de 0.72, de la tranquilidad 0.73, y de la trascendencia 0.75. Se constató validez de criterio a través del coeficiente de correlación de *Spearman*, obteniendo una correlación de 0.805 entre el *Hospice Comfort Questionnaire* versión española y la Escala Visual Analógica de Confort.

**Conclusiones**

Los resultados muestran que la versión española del *Hospice Comfort Questionnaire* es un instrumento de evaluación de confort en Cuidados Paliativos con garantías psicométricas de calidad (buena fiabilidad y validez).

La adaptación al castellano del *Hospice Comfort Questionnaire* proporciona el acceso a una herramienta que permite a los profesionales elaborar un plan de cuidados lo más adecuado posible a las necesidades de confort de pacientes ingresados en Unidades de Cuidados Paliativos.

**Palabras Clave**

Confort; Cuidados Paliativos; Estudios de Validación; Cuidado Terminal; Cuidados Paliativos al final de la vida.

**Abstract**



### Objective

To translate, adapt and validate the Hospice Comfort Questionnaire for use in the context of palliative care Spanish.

### Method

A total of 67 patients admitted in the Palliative Care Unit have participated in this study. The instrument used was the Hospice Comfort Questionnaire.

A methodology for the semantic, idiomatic and conceptual equivalence of items` content and psychometric equivalence by assessing the reliability, validity and content approach was adopted.

### Results

Regarding reliability, results inconsistent with the rest of the scale were observed in 7 items, with a correlation of less than 0.20. Taking into account the statistical data and critical content analysis of the items, it was decided to eliminate only 3 items. Once the scale was reduced to 46 items, the internal consistency of the total scale was measured with a Cronbach's  $\alpha$  of 0.89 and each group of items in each comfort state. Cronbach's alpha of relief was 0.72; ease 0.73 and transcendence 0.75. Criteria validity was found through the Spearman correlation coefficient, obtaining a correlation of 0.805 between the Spanish version of the Hospice Comfort Questionnaire and the Visual Analog Scale of Comfort.

### Conclusions

The results show that the Spanish version of the Hospice Comfort Questionnaire is an instrument for evaluating comfort in Palliative Care with psychometric quality assurance (good reliability and validity).

Spanish adaptation of Hospice Comfort Questionnaire provides access to a tool that allows professionals to develop more suitable care plan for comfort needs of patients admitted to palliative care units.

### Keywords

Comfort; Palliative Care; Validation studies; Terminal Care; Hospice care.

## INTRODUCCIÓN

La práctica de los Cuidados Paliativos nace como respuesta al sufrimiento que el proceso de morir puede generar y procura integrar el alivio de los síntomas físicos, los aspectos psicológicos, espirituales y sociales, a fin de ofrecer el mayor confort y dignidad posible a los pacientes que se enfrentan a problemas asociados con enfermedades amenazantes para la vida<sup>1-4</sup>.

De hecho, Kolcaba<sup>5-7</sup>, en su teoría del confort, define confort como la experiencia de fortalecerse gracias a la satisfacción de las necesidades de alivio, tranquilidad y trascendencia. Según la autora, estas necesidades se desarrollan en cuatro contextos: físico, social, psicoespiritual y ambiental.

La conceptualización holística del confort es especialmente relevante para la atención en Cuidados Paliativos, ya que los pacientes que se sienten confortables además de que superan mejor los obstáculos tienen una muerte más serena<sup>8,9</sup>.

A pesar de que el confort se define continuamente como un importante objetivo de los Cuidados Paliativos, en nuestro idioma y contexto, no existen instrumentos para realizar su evaluación. En la actualidad se dispone de un amplio abanico de herramientas de evaluación que permiten realizar la valoración del paciente en situación avanzada de una manera unidimensional<sup>10-16</sup>. Probablemente, dicha variedad, sea debida a que ningún instrumento se ha mostrado lo suficientemente útil como para ser aceptado de forma unánime<sup>17</sup>.

Sin embargo, la evaluación multidimensional constituye la esencia del proceso de atención integral en Cuidados Paliativos<sup>17</sup>, y, como tal, debe lograr información sobre el nivel de confort/disconfort de los enfermos. Disponer de esta información permitirá a los profesionales elaborar un plan de cuidados lo más adecuado posible a las necesidades de confort (físicas, sociales, psicoespiruales y ambientales) de cada paciente, definir la dirección para el cuidado interdisciplinario, realizar una mejor toma de decisiones terapéuticas e implementar intervenciones de confort ajustadas a las necesidades del paciente.

Se hace entonces imperativo disponer de un instrumento fiable y válido, que evalúe el confort y facilite además de una atención integral, la evaluación de los resultados de intervenciones de confort, congruentes con los objetivos de los Cuidados Paliativos.

Dada la falta de instrumentos para medir específicamente el confort total de los pacientes con enfermedad avanzada, Novak et al.<sup>9</sup>, en base a la teoría del Confort de Kolcaba, han desarrollado el *Hospice Comfort Questionnaire* (HCQ).

El HCQ evalúa, específicamente, la satisfacción de los tres tipos de confort: alivio, tranquilidad y trascendencia. El alivio fue definido como estado de un paciente que ha visto cumplida una necesidad específica. La tranquilidad fue definida como un estado de calma y satisfacción, es un

estado duradero y positivo que es más que la ausencia de incomodidad. La trascendencia específica el potencial del paciente, siendo definida como un estado en el cual un individuo está por encima de sus problemas o dolor.<sup>8,18-20</sup>

Los tres tipos de confort son evaluados en los cuatro contextos de la experiencia de confort: físico, psicoespiritual, social y ambiental. El contexto físico, pertenece a las sensaciones corporales, como el dolor. El contexto psicoespiritual pertenece a la consciencia interna del yo, como la autoestima, el significado de la vida, o la relación con un orden o estado superior. El contexto social se refiere a las relaciones interpersonales, familiares y sociales. Finalmente, el contexto ambiental, perteneciente al entorno, las condiciones y las influencias externas como la luz, el ruido o la temperatura.<sup>8,18-20</sup>

En síntesis, todos estos aspectos fueran cruzados en una tabla, constituyéndose así la estructura taxonómica del confort, que permite identificar e interpretar los varios componentes del confort para cada individuo.<sup>8,18-20</sup> Los ítems del *Hospice Comfort Questionnaire* distribuidos de acuerdo con la estructura taxonómica del confort, pueden observarse en la tabla 1.

Hasta donde sabemos, el HCQ es el único instrumento creado específicamente para la evaluación del Confort en el contexto de los Cuidados Paliativos.

Por lo anterior, se establece como objetivo de este estudio, traducir, adaptar y validar el HCQ para su utilización en el ámbito de los Cuidados Paliativos españoles.

## MÉTODOS

### Participantes

En el estudio han participado pacientes hospitalizados en la Unidad de Cuidados Paliativos (UCP) del Hospital de la Santa Creu de Vic.

Los criterios de inclusión fueron tener más de 18 años de edad; estar en condiciones de salud que le permitiesen realizar el cuestionario (no presentar síntomas, en el momento de realización del cuestionario, que imposibiliten la auto o heteroadministración del mismo, como por ejemplo somnolencia, dolor, disnea, náuseas...); ausencia de deterioro cognitivo (mediante el test de Pfeiffer<sup>14</sup>); duración de estancia en la UCP igual o superior a 2 días (con el objetivo de proporcionar un periodo de tiempo que permitiera mejorar el control de síntomas, adaptación a cuestiones de orden práctico y a la propia hospitalización) y fluidez de la lengua castellana.

Como criterio de exclusión se consideró estar en situación de últimos días.

El tamaño muestral se calculó aceptando un nivel de confianza de 0.95, una precisión de 8 y una desviación estándar de 27 (obtenida del estudio original<sup>9</sup>). Se estimó que el tamaño de la muestra

sería de 44 participantes. En previsión de posibles pérdidas teniendo en cuenta el riesgo de presentación de cuestionarios incompletos<sup>9</sup>, se aumentó en un 15% el tamaño muestral, administrándose finalmente el cuestionario a una muestra de 52 pacientes. Cabe señalar que este tamaño muestral es mayor que el del estudio original de validación que se realizó con una muestra de 38 participantes.

## **Materiales**

Las escalas que se incluyeron en este estudio fueron:

### 1) *Hospice Comfort Questionnaire* (HCQ)<sup>9</sup>

El HCQ, desarrollado por Novak et al., fue validado con 38 pacientes de dos UCP, y ha demostrado una alta fiabilidad al obtener valores del Alfa de Cronbach de 0,98.

El HCQ está formado por 49 ítems que puntúan en una escala con formato tipo Likert, con anclajes que van de 1 («totalmente en desacuerdo») a 6 («totalmente de acuerdo»). La puntuación resultante puede variar entre 49 y 294, si se presenta la suma de las puntuaciones asignadas a cada ítem. Puntuaciones más altas indican un mayor nivel de confort. Los 49 ítems están formulados de forma positiva y negativa, para evitar sesgos<sup>8</sup> y se plantean con la instrucción: “Las frases siguientes hacen referencia a su confort actual. Junto a cada pregunta encontrará seis números; rodee con un círculo el número que mejor refleje su estado. Responda a las preguntas según su confort en el momento actual.”

Los ítems invertidos se encuentran discriminados en la tabla 1.

### 2) Escala Visual Analógica de Confort

Se trata de una línea recta de 10cm con un extremo marcado con “confort” y otro extremo que indica “disconfort”. Se solicitó a cada participante que marcara en la línea el punto que mejor describía su nivel de confort en ese momento. La medición fue realizada en milímetros para proporcionar una medición precisa del confort total.

## **Procedimiento**

El estudio se desarrolló en dos etapas: traducción y adaptación cultural del HCQ; y validación del HCQ en el idioma español.

Primera etapa: traducción y adaptación cultural del HCQ

En esta etapa se tradujo el HCQ partiendo de su versión original en inglés. Se contactó con una de las autoras de la versión original (K. Kolcaba) y se le solicitó y obtuvo la autorización para su validación. El objetivo fue conseguir que el instrumento resultante mantuviera la equivalencia semántica, idiomática y conceptual con el cuestionario original.

Para ello se siguió la metodología de Beaton<sup>21</sup> y Escobar<sup>22</sup> para la traducción-retrotraducción de instrumentos, que incluyen los siguientes pasos:

Traducción directa: se realizó una traducción conceptual del instrumento. En esta traducción participaron dos grupos de traductores bilingües independientes, cuya lengua materna era la española. Cada grupo estuvo compuesto por dos traductores. Uno de los grupos de traductores conocía los objetivos y los conceptos considerados en el cuestionario. El otro grupo de traductores no tenía conocimientos previos sobre el cuestionario y desconocía los objetivos del estudio.

Síntesis de traducciones: Los traductores y el equipo investigador discutieron las discrepancias entre las versiones traducidas hasta alcanzar el consenso, generando la primera versión del cuestionario en el idioma español.

Traducción inversa (retro traducción): la versión de síntesis fue retro traducida al idioma original, por dos grupos de traductores bilingües cuya lengua materna era la inglesa. Los grupos de traductores trabajaron de forma independiente, desconociendo la versión original del cuestionario, sin tener conocimientos previos sobre el tema y desconociendo los objetivos del estudio.

Se confirmó que la traducción no dio lugar a diferencias semánticas o conceptuales importantes entre el cuestionario original y la versión de síntesis obtenida en el paso anterior.

Consolidación por un comité de expertos: En este paso se utilizaron las traducciones directas (paso 1), la versión de síntesis (paso 2) y las retro traducciones (paso 3). Se constituyó un comité pluridisciplinario compuesto por el equipo investigador (experto en metodología: ME y JA, Expertos en cuidados paliativos: AC y VP, Expertos en confort: JA y AC), los traductores de la etapa preliminar, la autora del HCQ original (experta en confort) y una profesional sanitaria experta en cuidados paliativos. Este comité comparó y discutió estas versiones, generando la segunda versión del cuestionario en el idioma español.

Pretest: El objetivo del pretest era determinar si los ítems que componen la versión experimental de la escala eran claros y estaban redactados sin ambigüedades, con un lenguaje ajustado al de la población diana. Entre Diciembre de 2015 y Enero de 2016, una muestra de 20 pacientes respondieron al cuestionario. Se pidió a estos pacientes que señalaran toda expresión o ítem ambiguo. No fueron señalados ítems ambiguos por los participantes. Así se obtuvo una versión traducida del HCQ adecuada en concepto y expresión a la versión original.

### Segunda etapa: validación del HCQ en el idioma español

Para esta etapa, previo consentimiento informado verbal y/o escrito del paciente y su aceptación en participar, así como previa autorización de la dirección del Hospital Universitario de la Santa Creu de Vic y de la valoración positiva del comité de ética de la *Fundació d'Osona per a la Recerca i l'Educació Sanitàries* (2015892 PR123), con el fin de garantizar un adecuado nivel en las propiedades psicométricas del instrumento, la versión final traducida del HCQ (tabla 2) fue cumplimentada por una muestra de 47 pacientes que cumplían los criterios de inclusión.

El cuestionario fue autoadministrado y, cuando hubo necesidad por cuestiones de debilidad y fragilidad, fue heteroadministrado por uno de los miembros del equipo investigador. La duración de la cumplimentación del cuestionario osciló entre 12 y 15 minutos. La recogida de los datos se realizó desde Diciembre de 2015 hasta Marzo de 2016.

Así mismo, se administró una escala EVA de Confort total a cada participante y un cuestionario relativo a las variables sociodemográficos. Los datos relativos a las variables clínicas se obtuvieron de la historia clínica de los pacientes. Estos datos pueden observarse en la tabla 3.

Los datos resultantes se introdujeron en una base de datos y se realizó un análisis de la validez (validez de contenido y validez de criterio) así como un análisis de la fiabilidad (consistencia interna) con el programa informático *Statistical Package for Social Sciences* (SPSS), versión 20.

### **Análisis de datos**

En primer lugar, se calcularon estadísticos descriptivos y se estudió la consistencia interna de la escala, a partir de las correlaciones ítem-total corregidas y el alfa total de la escala si se elimina el ítem (tabla 4).

Según Streiner y Norman<sup>23</sup>, la correlación ítem-total de la escala inferiores a 0.20 deben ser eliminados. Sin embargo, el equipo investigador no tuvo solamente en cuenta los datos estadísticos, sino también el análisis crítico del contenido de los ítems en que se observaron comportamientos poco consistentes con el resto de la escala con vista a determinar su eliminación o no.

Con los ítems restantes, se estimó la consistencia interna del HCQ – versión ES mediante el coeficiente alfa de Cronbach. Se considera que existe una buena consistencia interna cuando el valor de alfa es superior a 0.7 y se considera una excelente consistencia cuando el valor es superior a 0.9<sup>24,25</sup>. Sin embargo, una puntuación demasiado alta (superior a 0.9) puede hacer suponer que los ítems del instrumento miden un aspecto demasiado restrictivo del concepto<sup>22</sup>. Posteriormente, se estimó la validez de criterio (validez concomitante) del HCQ – versión ES mediante la medición del grado de

correlación entre los resultados del HCQ – versión ES y de la EVA de Confort aplicadas al mismo tiempo y en los mismos sujetos.

## RESULTADOS

### Resultados

#### Características de los pacientes

Han participado en el estudio un total de 72 pacientes ingresados en la UCP, 20 en la primera etapa y 52 en la segunda etapa. 5 participantes de la segunda etapa fueron excluidos del estudio por encontrarse el cuestionario incompleto y por imposibilidad de volverlo a administrar por debilidad clínica.

Los 47 participantes incluidos en la segunda etapa del estudio presentaban una edad media de 73 años, de los que un 62% eran mujeres y 79% presentaban una enfermedad oncológica. Las características de la muestra pueden observarse en la tabla 3.

#### Propiedades psicométricas del instrumento

La revisión se realizó por traductores bilingües y profesionales sanitarios con altos conocimientos en inglés, expertos en el tema y una de las autoras del instrumento original que compararon la versión original con la versión obtenida. Este proceso, proporciona garantías sobre la validez de contenido de la nueva escala.

Respecto a los resultados referentes a la fiabilidad, se observaron comportamientos poco consistentes con el resto de la escala en 7 ítems: 3, 5, 19, 20, 25, 26 y 27, que presentaran una correlación inferior a 0.20.

Teniendo en cuenta los datos estadísticos y el análisis crítico de contenido de los ítems, se decidió eliminar solamente los ítems 5, 25 y 26. Se decidió mantener los ítems 3, 19, 20 y 27 por considerar su contenido muy relevante para la evaluación del confort, y, además, porque la eliminación de estos ítems no generaba un aumento del Alpha de Cronbach (alfa de la escala con los 49 ítems = 0,88).

Se decidió eliminar el ítem 5 (“Me siento hinchado/a”) por generar ambigüedad entre los participantes, ya que el término “hinchado” tuvo doble interpretación (edema y/o estreñimiento). Lamentablemente esta ambigüedad no fue detectada en el pre-test. Se decidió eliminar los ítems 25

(“Me gusta que mi habitación esté silenciosa”) y 26 (“Me gustaría que el médico me visitase más a menudo”) por , además de ser los únicos ítems que presentaban una correlación negativa con el resto de la escala, se consideró su contenido/interpretación ambiguo/a: la necesidad de silencio no necesariamente representa confort, ya que puede representar soledad<sup>26</sup>; y el deseo de aumento de periodicidad de visitas por parte del médico no necesariamente significa discomfort. Muchas veces el médico es el portador de “malas noticias” y pacientes que estén en negación no desean un aumento de visitas por parte del médico.

Una vez reducida la escala a 46 ítems, se realizó el análisis de la consistencia interna del total de la escala (0.89) y a cada grupo de ítems de cada estado del confort. El alfa de Cronbach del alivio fue de 0.72, de la tranquilidad 0.73, y de la trascendencia 0.75. Todas las estimaciones indicaron una buena consistencia interna del HCQ-versión ES.

Posteriormente, para determinar la validez de criterio, se calculó el grado de correlación entre el HCQ- versión ES y la EVA, a través del coeficiente de correlación de Spearman, obteniendo una correlación elevada (0.805), que demuestra la validez de la escala.

Finalmente, se calcularon los estadísticos descriptivos para la puntuación global de confort, que reveló una media de 204.7 (DE = 26.2), con puntuaciones que oscilaron entre 121 y 257.

Destacar que no fueron encontradas diferencias estadísticamente significativas en el nivel de confort total de hombres y mujeres ( $p=0.192$ ), de los pacientes con enfermedad oncológica y no oncológica ( $p=0.535$ ), de los pacientes casados, divorciados y viudos ( $p=0.191$ ), de los pacientes con edad inferior o igual a 65 años y superior a 65 años ( $p=0.832$ ), ni de los pacientes sin estudios, con educación primaria, secundaria y superior ( $p=0.423$ ).

## DISCUSIÓN

### Discusión

Puesto que el confort es un importante objetivo de los cuidados paliativos, la evaluación del estado de confort y la detección de discomfort es de suma importancia.

El presente estudio aporta una herramienta de diagnóstico y de evaluación de los resultados de la implementación de intervenciones de confort que era inexistente hasta al momento.

El estudio de la validez concomitante reveló una correlación elevada entre el HCQ-versión ES y la EVA. Este dato confirma la validez de la escala, pero también suscita algunas cuestiones respecto a la necesidad de implementar un cuestionario tan extenso como el HCQ-versión ES. Así, es importante subrayar que el HCQ-versión ES, al contrario de la EVA, permite a los profesionales elaborar un plan



de cuidados lo más adecuado posible a las necesidades específicas de confort físicas, sociales, psicoespiruales y ambientales de cada paciente.

El HCQ- versión ES, además de evaluar y ayudar a la detección precoz de necesidades de confort, sirve como guía terapéutica y favorece la comunicación entre profesionales y pacientes. Es decir, si bien la aplicación del HCQ versión ES puede resultar demasiado extenso para pacientes en situación vulnerable como los de Cuidados Paliativos, en los que resulta complicado pasar diferentes escalas de valoración para su adecuada atención dependiendo de su estado clínico, también es importante señalar que la aplicación del cuestionario a la muestra del estudio no ha supuesto un esfuerzo físico o emocional inapropiado para los participantes. Además, tal y como recomiendan los autores del instrumento original<sup>9</sup> y los autores de otros instrumentos con vista a su aplicación en el contexto paliativo<sup>27</sup>, en situación de imposibilidad de que el cuestionario fuera autoadministrado, se optó por la heteroadministración.

Cuando el cuestionario fue heteroadministrado, su administración constituyó un momento de elevada importancia para el participante y el investigador, dado que todos los participantes han manifestado interés en hablar de forma más profunda respecto a cada ítem, añadiendo información que superaba los objetivos de la presente investigación pero con elevado interés en el ámbito del estudio del confort en cuidados paliativos, y en el ámbito de la prestación de cuidados con vista a la satisfacción de las necesidades de confort del enfermo.

A pesar de que la versión original del HCQ esté destinada a ser auto administrada y hetero administrada<sup>1</sup>, se sugiere que el instrumento sea heteroadministrado y se estima que la actitud con la que el profesional sanitario se acerque al paciente para administrar el HCQ-versión ES pueda influir en el verdadero sentido del HCQ-versión ES.

Entre las limitaciones de este estudio destacamos el reducido tamaño de la muestra que se justifica por las características de vulnerabilidad y fragilidad de los participantes, y por que el estudio fue realizado en una misma ubicación. Esta limitación imposibilitó la estimación de la validez de constructo<sup>23</sup>.

La progresiva debilidad de los participantes y el respeto por la dignidad humana que siempre está por encima de los intereses de la investigación, llevó al equipo a no estudiar la estabilidad del instrumento (Test-retest).

De cara a posteriores investigaciones, dadas las dificultades y limitaciones a nivel del tamaño de la muestra en estudios con pacientes con enfermedad avanzada<sup>28</sup>, sería adecuada la realización de un estudio multicéntrico.

Así mismo, el HCQ – versión ES, se ha administrado a pacientes oncológicos y no oncológicos avanzados hospitalizados en una UCP, por lo que su posible aplicación a pacientes con enfermedades avanzadas hospitalizados en otras unidades que también reciban a pacientes con necesidad de atención paliativa, debería verificarse en otros estudios.

Finalmente, los niveles de funcionalidad de los participantes, además de no haber sido definidos como criterio de inclusión del estudio, tampoco fueron tenidos en cuenta en la recogida de datos clínicos. Es recomendable que en futuras investigaciones los niveles de funcionalidad de los participantes, y otras variables clínicas, sean tenidos en cuenta para posibilitar la estimación de la relación entre los niveles de confort presentados por los participantes y su nivel de funcionalidad.

En este sentido, sería interesante la validación de este instrumento en un estudio multicentrico donde estuvieran representados pacientes de cuidados paliativos de diferentes centros y diferentes complejidades clínicas.

No obstante a lo anterior, el HCQ – versión ES se ha revelado como un instrumento fiable y válido para evaluar el confort de los pacientes ingresados en UCP, con lo cual ya se puede disponer de una herramienta complementaria de trabajo clínico para la valoración del grado de confort de estos pacientes.

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**Tabla 1 - Ítems del *Hospice Comfort Questionnaire* distribuidos de acuerdo con la estructura taxonómica del confort**

CONTEXTOS (en que ocurre el confort)	TIPO DE CONFORT (ESTADOS)			Numero de ítems
	Alivio	Tranquilidad	Transcendencia	
<b>Físico</b>	2* ; 5* ; 12* ; 14* ; 16 ; 19* ; 27* ; 31	1 ; 36	29	11
<b>Psicoespiritual</b>	24* ; 34* ; 46	7 ; 15 ; 17* ; 35	9 ; 22* ; 41 ; 45*	11
<b>Ambiental</b>	3 ; 49	11 ; 18 ; 25 ; 32* ; 42	21* ; 30* ; 33 ; 38*	11
<b>Social</b>	13* ; 26* ; 37 ; 48*	4 ; 8 ; 20 ; 23 ; 39* ; 40* ; 43*	6* ; 10 ; 28 ; 44 ; 47	16
<b>Numero de ítems</b>	17	18	14	49

\*Ítem invertido

Fuentes - Adaptado de: Apóstolo<sup>29</sup>; Kolcaba<sup>5,8,18</sup>; Matos<sup>30</sup>

**Tabla 2. Versión española del Cuestionario de confort en cuidados paliativos**

Muchas gracias por ayudarnos en este estudio de enfermería en cuidados paliativos. Las frases siguientes hacen referencia a su confort actual. Junto a cada pregunta encontrará seis números; rodee con un círculo el número que mejor refleje su estado. Responda a las preguntas según su confort en el momento actual.

	Totalmente en desacuerdo			Totalmente de acuerdo		
1. Mi cuerpo esta relajado en este momento	1	2	3	4	5	6
2. Me cuesta respirar	1	2	3	4	5	6
3. Tengo suficiente intimidad	1	2	3	4	5	6
4. Siempre encuentro a alguien en quien confiar cuando lo necesito	1	2	3	4	5	6
5. Me preocupa mi familia	1	2	3	4	5	6
6. Mis creencias me aportan tranquilidad	1	2	3	4	5	6
7. Mis enfermeros/as me dan confianza	1	2	3	4	5	6
8. Mi vida vale la pena	1	2	3	4	5	6
9. Yo sé que soy querido/a	1	2	3	4	5	6
10. Este entorno es agradable	1	2	3	4	5	6
11. Tengo problemas para descansar	1	2	3	4	5	6
12. Nadie me entiende	1	2	3	4	5	6
13. Mi dolor es difícil de soportar	1	2	3	4	5	6
14. Me siento en paz	1	2	3	4	5	6
15. Duermo bien	1	2	3	4	5	6
16. Me siento culpable	1	2	3	4	5	6
17. Me gusta estar aquí	1	2	3	4	5	6
18. Siento náuseas	1	2	3	4	5	6
19. Puedo comunicarme con mis seres queridos	1	2	3	4	5	6
20. Esta habitación hace que me sienta asustado/a	1	2	3	4	5	6
21. Tengo miedo al futuro	1	2	3	4	5	6
22. Tengo a una(s) persona(s) especial(es) que hace(n) que me sienta atendido/a	1	2	3	4	5	6
23. He sufrido cambios que me hacen sentir incómodo/a	1	2	3	4	5	6
24. Me gusta que mi habitación esté silenciosa	1	2	3	4	5	6
25. Estoy satisfecho/a con mis relaciones personales	1	2	3	4	5	6
26. Puedo sobreponerme a mi dolor	1	2	3	4	5	6

27. El ambiente de este lugar es triste	1	2	3	4	5	6
28. Me siento cómodo/a físicamente	1	2	3	4	5	6
29. La silla (cama) me provoca dolores	1	2	3	4	5	6
30. Estas vistas me animan	1	2	3	4	5	6
31. Pienso constantemente en mi malestar	1	2	3	4	5	6
32. Me siento seguro/a espiritualmente	1	2	3	4	5	6
33. Me siento lo suficientemente bien como para hacer cosas por mi cuenta	1	2	3	4	5	6
34. Sé que mis amigos me recuerdan, porque me escriben y/o me llaman	1	2	3	4	5	6
35. Aquí me siento fuera de lugar	1	2	3	4	5	6
36. Necesito estar mejor informado/a sobre mi enfermedad	1	2	3	4	5	6
37. Me siento desamparado/a	1	2	3	4	5	6
38. Dios me ayuda	1	2	3	4	5	6
39. Esta habitación huele a fresco	1	2	3	4	5	6
40. Me siento solo/a	1	2	3	4	5	6
41. Soy capaz de decir lo que necesito	1	2	3	4	5	6
42. Estoy deprimido/a	1	2	3	4	5	6
43. He encontrado el sentido de mi vida	1	2	3	4	5	6
44. Mirando atrás, he tenido una buena vida	1	2	3	4	5	6
45. El estado de ánimo de mis seres queridos hace que me sienta triste	1	2	3	4	5	6
46. La temperatura de la habitación está bien	1	2	3	4	5	6
¿Hay alguna otra pregunta que querría que le formulásemos?						

Notas:

- La puntuación resultante puede variar entre 46 y 276, si se presenta la suma de las puntuaciones asignadas a cada ítem. Puntuaciones más altas indican un mayor nivel de confort.
- Para la validación del cuestionario se solicitó la autorización de K. Kolcaba (autora de la versión original<sup>9</sup>), obteniendo su autorización.



Tabla 3 - Características de los pacientes incluidos en la fase de validación

<b>Características</b>	<b>Valores</b>
<b>Edad (media)</b>	73 (47-89)
<b>Genero</b>	
Mujeres	62% (n=29)
Hombres	38% (n=18)
<b>Diagnostico</b>	
Oncológico	79% (n=37)
No oncológico	21% (n=10)
<b>Estado civil</b>	
Casados	79% (n=37)
Viudos	17% (n=8)
Divorciados	4% (n =2)
<b>Nivel de escolaridad</b>	
Sin estudios	28% (n=13)
Educación primaria	38% (n=18)
Educación secundaria	23% (n=11)
Educación superior	11% (n=5)

Tabla 4 - Estadísticos descriptivos de los ítems de la escala

Ítem	M	DT	r total elemento corregida	$\alpha$ si se elimina el elemento
1	4,89	1,005	,453	,879
2	4,26	1,621	,219	,882
3	4,53	1,365	,184	,882
4	5,55	,544	,228	,881
5	4,36	1,905	,069	,885
6	2,34	1,845	,266	,881
7	4,36	1,405	,388	,879
8	5,36	,705	,226	,881
9	5,04	1,233	,492	,878
10	5,55	,544	,240	,881
11	5,30	,976	,445	,879
12	3,91	1,863	,638	,874
13	4,32	1,795	,465	,877
14	3,30	1,667	,406	,879
15	5,19	1,116	,353	,880
16	4,70	1,382	,576	,876
17	4,87	1,715	,292	,881
18	4,30	1,743	,226	,882
19	5,04	1,367	,072	,883
20	5,51	,748	,093	,882
21	5,06	1,436	,528	,877
22	3,72	1,942	,426	,878
23	5,32	,726	,356	,880
24	2,66	1,478	,242	,881
25	5,06	1,150	-,036	,884
26	2,91	1,265	-,072	,885
27	2,06	1,275	,042	,884
28	5,04	1,197	,242	,881
29	4,72	,800	,383	,880
30	3,96	1,615	,622	,875
31	4,30	1,140	,617	,876
32	3,94	1,660	,341	,880
33	5,15	1,215	,525	,877
34	3,43	1,815	,322	,880
35	5,02	1,093	,320	,880
36	3,79	1,429	,455	,878
37	5,32	,629	,511	,879
38	3,83	1,698	,409	,878
39	3,11	1,735	,217	,882
40	5,04	1,334	,688	,875
41	4,32	1,656	,426	,878
42	5,11	,759	,320	,880
43	4,79	1,614	,577	,876

44	5,40	,771	,377	,880
45	3,98	1,648	,520	,876
46	3,96	1,532	,368	,879
47	4,91	1,231	,373	,879
48	3,40	1,849	,435	,878
49	5,09	1,100	,336	,880



# **CHAPTER VI**

## **DEVELOPMENT OF A GUIDED IMAGERY PROGRAM**

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This chapter addresses the Phase 4 of the study, and is divided into two sub-heading.

The first sub-heading presents various methods that have been proposed for development and evaluation of complex interventions with a highlight for the Medical Research Council framework.

The second sub-heading presents the description of the process of the development and validation of a GI program adjusted to the comfort needs of inpatients at PCUs in order to provide comfort to them.



## 6.1. Develop and evaluating complex interventions

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Demographic changes and increasing numbers of people with chronic diseases have increased the need for nursing care. This has led to multiple calls to improve nurses' knowledge and for that knowledge to rest on a solid evidence-base (Richards & Borglin, 2011).

Indeed, under the motto "Nursing as a complex intervention", the European Academy of Nursing Science (2011a) argues that the study of complex interventions is a priority in nursing research for the development of more feasible interventions.

According Hallberg (2009) most current nursing research as descriptive rather than experimental; cross-sectional rather than longitudinal; context specific rather than generalizable; and also introspective rather than implementation focused.

In this sense arises the need to develop nursing knowledge that can be readily translated into practice (The European Academy of Nursing Science, 2011b)

Complex interventions are frequently described as activities that contain a number of component parts with the potential for interactions between them which, when applied to the intended target population, produce a range of possible and variable outcomes (Craig et al., 2008, 2013), this description fits nursing perfectly (The European Academy of Nursing Science, 2011b).

Several methods have been proposed for the development and evaluation of complex interventions in order to make them more effective (Blackwood, 2006). The first method was proposed by Bradley et al. (1999). In this methodology, the development of the intervention consists of three phases: 1) Review of the theory and scientific evidence underpinning the intervention; 2) Essential tasks and processes involved in applying the intervention; 3) Evaluation of aspects related to the population and environment in which the intervention takes place.

In 2000, the MRC proposed a methodology to develop and evaluate complex interventions, similar to the methodology often used to test new drugs (Medical Research Council, 2000). This approach consists of 5 phases: 1) Preclinical or theoretical phase; 2) Modelling; 3) Exploratory trial 4) Definitive Randomized Control Trial; 5) Long-term implementation. This

method has been described as a pioneer and has been much cited in the health literature since its publication. However, several papers (Craig et al., 2008, 2013) have identified limitations in the framework, recommending, for example, greater attention to early phase piloting and development work, a less linear model of evaluation process, integration of process and outcome evaluation, recognition that complex interventions should not be completely standardized, but rather evaluated in each context.

In 2004 Van Meijel et al. (2004) proposed another method, organized in four stages: 1) Problem definition; 2) Accumulation of building blocks for intervention design by reviewing literature and analyzing current practice and needs; 3) Intervention design; 4) intervention validation by pilot testing using a range of mixed methods.

In 2008, with a view to presenting a more comprehensive model that could be adapted to different areas of knowledge within the context of health, and recognizing the previously mentioned limitations, the MRC proposed a new detailed protocol for the development, evaluation and implementation of complex interventions (Craig et al., 2008) highlighting the following updates:

- The process of developing and evaluating a complex intervention has several phases, although they may not follow a linear sequence;
- Experimental designs are preferred to observational designs in most circumstances, however are not always practicable. Thus, alternatives to randomized trials should be considered;
- Understanding processes is important but does not replace evaluation of outcomes;
- Complex interventions might work best if tailored to local circumstances rather than being entirely standardized;
- Reports of studies must include a detailed description of the intervention to enable replication, evidence synthesis, and wider implementation.

The figure 1, presents the key elements of the development and evaluation process according to the MRC framework.



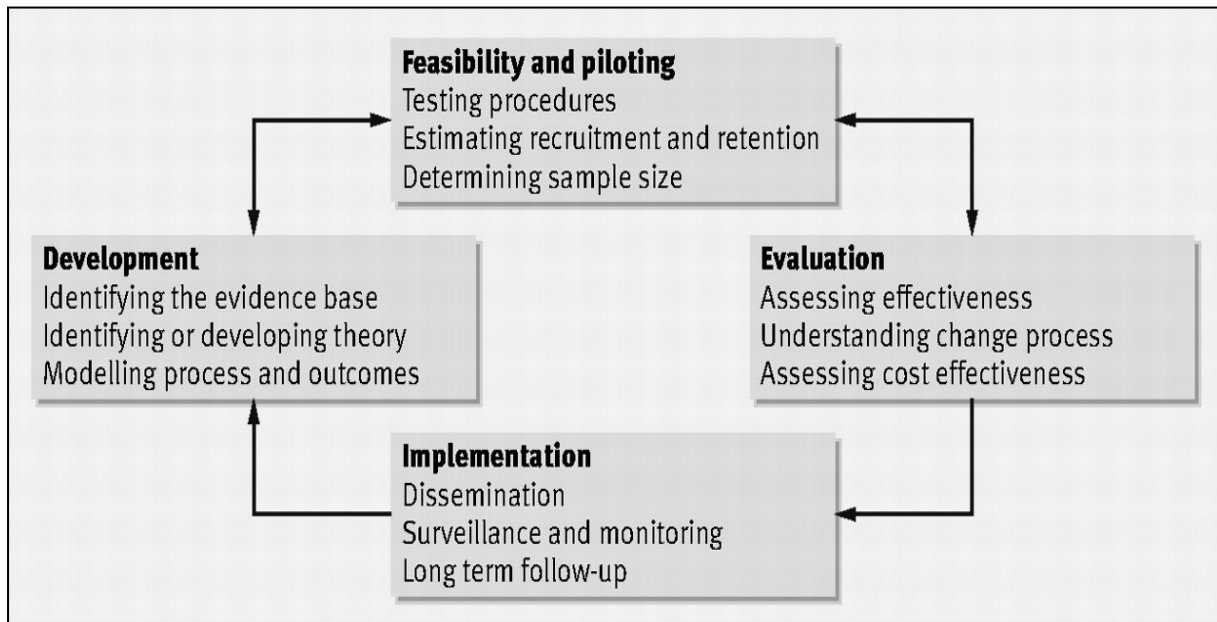


Figure 1: The MRC framework for the development and evaluation of complex interventions (in Craig *et al.*, 2008).

Although several methods have been published for the same purpose (Blackwood, 2006), the MRC Framework is the best known, cited in the literature (Craig *et al.*, 2008, 2013) and recommended for the study of complex interventions in health care delivery (The European Academy of Nursing Science, 2011b). However, in nursing research, the use of MRC framework in the study of complex interventions is recent (Pinto, Caldeira, & Martins, 2018).

In an systematic review performed by Pinto *et al.* (2018), on the use of the MRC-framework in the development of complex interventions in nursing, the authors identified 13 studies, with the selected studies were in the development phase (n=7) or pilot/ feasibility study phase(n=5). According to the same authors (Pinto *et al.*, 2018) the MRC framework enhances the design of more feasible, effective and reproducible interventions, developed through a systematic and consistent approach. However, this is a lengthy and exhaustive process that needs time. Also in our study we stick to the development and pilot phases (testing procedures).

The following subchapter presents the process of developing the Guided Imagery intervention adjusted for patients admitted to a Palliative Care Unit, based on MRC framework.



## **6.2. Development of a guided imagery program for patients admitted to palliative care units**

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RESEARCH PAPER (ORIGINAL)  
ARTIGO DE INVESTIGAÇÃO (ORIGINAL)**Development of a guided imagery program for patients admitted to palliative care units**

Construção de um programa de imaginação guiada para doentes internados em unidades de cuidados paliativos

Construcción de un programa de imaginación guiada para pacientes internados en unidades de cuidados paliativos

Adriana Coelho\*; Vítor Parola\*\*; Olga Fernandes\*\*\*; Ana Querido\*\*\*\*; João Apóstolo\*\*\*\*\*

**Abstract****Background:** Guided imagery (GI) is being increasingly used as a non-pharmacological intervention in different clinical settings. However, GI intervention programs have not yet been developed and adapted to patients admitted to palliative care units, which impedes their implementation. Thus, the need emerges to develop and validate a GI program.**Objective:** To develop and validate a GI program.**Methodology:** A descriptive study was conducted following the guidelines of the Medical Research Council for the development of complex interventions in 3 phases: identifying the evidence base, identifying/developing appropriate theory, modelling process and outcomes.**Results:** The development process resulted in a program consisting of 2 GI sessions to be implemented in the same week. Preliminary results on the implementation of a GI session suggest that the intervention is effective in increasing comfort.**Conclusion:** The characteristics of the GI program proved to be adjusted to the context and target population. The effectiveness of the GI program will be tested in a quasi-experimental study.**Keywords:** palliative care; nursing; palliative nursing; guided imagery; research design**Resumo****Enquadramento:** Uma das intervenções não farmacológicas cada vez mais implementada em diferentes contextos clínicos é a imaginação guiada (IG). Porém, não existem programas de intervenção de IG desenvolvidos e adaptados aos doentes admitidos em unidades de cuidados paliativos, o que impossibilita a sua implementação. Assim, emerge a necessidade de se desenvolver e validar um programa de IG.**Objetivo:** Construir e validar um programa de IG.**Metodologia:** Estudo descritivo, seguindo as diretrizes para desenvolvimento de intervenções complexas do *Medical Research Council* que consiste em 3 fases: identificação da evidência existente, identificação e/ou desenvolvimento de teoria, modelagem do processo e resultados.**Resultados:** O processo de desenvolvimento resultou num programa composto por 2 sessões de IG a serem implementadas numa mesma semana. Resultados provisórios relativamente à implementação de uma sessão de IG sugerem que a intervenção é eficaz na melhoria do conforto.**Conclusão:** O programa de IG demonstrou ter características ajustadas ao contexto e população-alvo. A eficácia do programa será provada num estudo quasi-experimental, a desenvolver.**Palavras-chave:** cuidados paliativos; enfermagem; enfermagem de cuidados paliativos; imagens guiadas; projetos de pesquisa

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**Resumen****Marco contextual:** Una de las intervenciones no farmacológicas que se implementan cada vez más en diferentes contextos clínicos es la imaginación guiada (IG). Sin embargo, no existen programas de intervención de IG desarrollados y adaptados a los pacientes admitidos en unidades de cuidados paliativos, lo que imposibilita su implementación. De este modo, surge la necesidad de desarrollar y validar un programa de IG.**Objetivo:** Construir y validar un programa de IG.**Metodología:** Estudio descriptivo, que sigue las directrices para el desarrollo de intervenciones complejas del *Medical Research Council*, que consiste en 3 fases: identificación de las pruebas existentes, identificación y/o desarrollo de la teoría, modelado del proceso.**Resultados:** El proceso de desarrollo dio lugar a un programa compuesto por 2 sesiones de IG para implementarse en una misma semana. Los resultados provisionales de la implementación de una sesión de IG sugieren que la intervención es eficaz en la mejora del confort.**Conclusión:** El programa de IG demostró que tiene características ajustadas al contexto y la población objetivo. La eficacia del programa se probará en un estudio cuasiexperimental que se desarrollará más adelante.**Palabras clave:** cuidados paliativos; enfermería; enfermería de cuidados paliativos; imágenes guiadas; proyectos de investigación

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## Introduction

The increase in average life expectancy and the high prevalence of chronic progressive diseases are having an increasing impact on the organization of health care systems and the need for palliative care units (PCU; Comissão Nacional de Cuidados Paliativos, 2016). According to the World Health Organization (2002), palliative care (PC) is an approach aimed at improving the quality of life of patients and their families facing problems associated with an incurable and/or severe disease with limited prognosis, through the prevention and relief of suffering. These are active total care where aggressive therapeutic measures are replaced by intensive comfort care.

Comfort is the purpose of PC and the nursing care process. It is defined by Kolcaba (1995) as the state of having the needs for relief, ease, and transcendence met in four contexts: physical, sociocultural, psychospiritual, and environmental.

To this end, non-pharmacological interventions have been increasingly developed and implemented in PC, both independently and in combination with other therapeutic approaches, which has also been reflected in improved patient comfort (Coelho, Parola, Cardoso, Escobar-Bravo, & Apóstolo, 2017).

However, the need for hiring outside professionals with specific training, the lack of scientific evidence on the effectiveness of interventions (Osaka et al., 2009), and the institutional costs involved in their implementation are some of the barriers to their implementation (Olotu, Brown, Barner, & Lawson, 2014).

Guided imagery (GI) is being increasingly used as a non-pharmacological intervention in different clinical settings.

GI is the process of intentional use of mental images and sensory attributes, resulting from imagination or memory, to achieve a desired therapeutic outcome (Naparstek, 1994). The person's involvement with the mental images is so intense that the body tends to respond as it would to a genuine external experience, which has profound psychophysiological consequences (Apóstolo, 2010; Hart, 2008). It is a simple, low-cost intervention that can be implemented by nurses and that requires little effort of patients.

The literature shows that the intervention with GI is associated with increased comfort in women with breast cancer (Kolcaba & Fox, 1999), in psychiatric patients (Apóstolo & Kolcaba, 2009), among others.

In PC, however, a scoping review conducted by Coelho et al. (2017) found no studies on the effects of GI in comfort, which clearly limits its implementation. Based on the above-mentioned studies, the potential effects of GI in PC should not be underestimated. If this intervention proves to be effective in this context, its implementation can result in a significant increase in the comfort level of patients admitted to PCU.

In this way, the need emerged to develop and validate a GI program for patients admitted to PCU. The Medical Research Council guidelines and recommendations for the development of complex interventions were followed (Craig et al., 2008). This article aims to describe the different stages of this process.

## Background

No GI program has yet been designed specifically for PC (Coelho et al., 2017). Hence, to address this challenge, a GI program was developed and validated for patients admitted to PCU.

In the method proposed by the Medical Research Council, complex interventions are characterized by a significant number of interactions between components; difficulty of behaviors required by those delivering or receiving the intervention; a significant number of groups or organizational levels targeted by the intervention; variability of outcomes; and degree of flexibility or tailoring of the intervention permitted (Craig et al., 2008). When applied to a group of people, complex interventions produce one or several outcomes, with health gains for these people.

Their development should be based on identifying the evidence base; identifying/developing appropriate theory; and modeling process and outcomes (Craig et al., 2008).

## Research question

What is the validity of the GI program being developed for patients admitted to PCU?

## Methodology

Given the nature of the object under analysis, a descriptive mixed-methods study was conducted which indicates the different phases of development and validation of a GI program based on the above-mentioned recommendations of the Medical Research Council (Craig et al., 2008).

### Phase I - Identifying the evidence base

This phase consisted of identifying the existing evidence on similar interventions and the methods used to assess them (Craig et al., 2008). Thus, the strengths and limitations of existing programs were identified, starting from the evidence emerging from primary studies (Apóstolo & Kolcaba, 2009; Hosseini, Tirgari, Forouzi, & Jahani, 2016; Kolcaba & Fox, 1999; Spiva et al., 2015) and systematic literature reviews (Roffe, Schmidt, & Ernst, 2005; Van Kuiken, 2004), which confirmed the therapeutic potential of GI for promoting comfort in different clinical areas. A scoping review was also conducted with the purpose of mapping the non-pharmacological interventions to provide comfort in PC. This scoping review revealed a lack of GI programs adapted to PC settings and provided relevant information about other complex interventions implemented in this context, their characteristics, the characteristics of the target population, as well as the methods used to assess them (Coelho et al., 2017).

### Phase II - Identifying/developing appropriate theory

This phase consisted in the development of a theoretical understanding of existing evidence and theory, supplemented by primary research (Craig et al., 2008). Thus, the literature on GI, including scripts suggested by renowned authors in this area (Apóstolo, 2007), and the literature about comfort, including Katherine Kolcaba's theory of comfort (1995), were analyzed. A qualitative phenomenological study (Coelho, Parola, Escobar-Bravo, & Apóstolo, 2016) was conducted to understand the comfort and discomfort experiences of patients admitted to PCU.

### Phase III - Modeling process and outcomes

This phase consisted of gradually modeling the intervention, before a full-scale evalu-

ation. It was composed of three sub-phases (Craig et al., 2008): preliminary, field testing, and consensus conference.

### Preliminary

In this sub-phase, the analysis of the information resulting from the two first phases (Identifying the evidence base and Identifying/developing appropriate theory) supported the first version of the GI script. Six experts (nursing graduates, master's and doctoral degree holders, and doctoral students in areas related to PC, comfort, and GI) were asked to analyze the first version. The consulting process focused on the acceptability of the first version of the GI script to be applied to patients admitted to PCU. The experts were asked to give their opinion on the relevance and feasibility of the development and implementation of this program, the need for GI interventions in PC settings, the barriers to their implementation, as well as to make any relevant suggestions. A questionnaire was also applied to each expert with the purpose of obtaining their opinions on the clarity of instructions as well as their adaptation to patients admitted to PCU. The answers were based on a 5-point Likert scale, ranging from *strongly agree* to *strongly disagree*. Based on collected data, the script was revised, resulting in a second version.

### Field testing

Taking into account that the data collected in the preliminary sub-phase were limited to the experts' professional and academic experience, which resulted in a purely theoretical analysis of the GI program, the need emerged to model the intervention script to the practical context. Thus, the second version of the GI script was audio recorded aimed at optimizing its content, adjusting speech fluency and the time period between each instruction on respiratory exercises, muscle relaxation, and formation of mental images, and validating the adequacy of the intervention to the target population through field testing. This second version was audio recorded and, subsequently, tested in two nurses, who had been working at the PCU for more than one year and voluntarily accepted to participate in the study, and in two patients, who had been admitted to the PCU and met the inclusion and exclusion criteria listed in Table 1.

Table 1  
Inclusion and exclusion criteria of patients admitted to the PCU

Inclusion criteria	Exclusion criteria
Being in good clinical conditions to participate in the intervention program;	Patients with cognitive impairment;
Being hospitalized at the unit for at least 2 days;	End-of-life patients.
Accepting to participate in the study.	

The sessions with the nurses took place in a private room of the PCU. The sessions with the patients took place in each patient's room. All sessions were conducted by the principal investigator and lasted 13 minutes.

After field testing, a questionnaire was applied to the participants, which had been developed and previously used by Apóstolo (2007) in a similar study, about the following topics: recording quality, voice, sound, and background music; clarity of instructions on breathing and relaxation; relaxation period; ability to relax; ability to follow the mental images; and the time allowed for creating and visualizing each image. The answers were rated on a 5-point Likert scale, ranging from *strongly agree* to *strongly disagree*.

In addition, patients were also administered a Comfort Visual Analog Scale (VAS), and relevant qualitative data were collected.

Based on these data, a third version of the GI script was developed.

### Consensus conference

Finally, the consensus conference strategy was applied in which the different versions of the GI script, the quantitative and qualitative results of field testing, and all comments and suggestions were submitted to an expert panel for analysis and discussion. In this panel, the different versions of the GI script were compared, and the significant changes and potential program strengths and limitations were discussed. This sub-phase completed the process.

With regard to the ethical and legal principles, the authors requested permission from the Ethics Committee of the Hospital Arcebispo João Crisóstomo of Cantanhede (08/02/2017) to conduct the study. Throughout the different phases, all procedures were

followed to respect the participants' anonymity, confidentiality, and informed consent.

## Results

The results obtained in each methodological phase will be described below, underlining the different contributions obtained for the analysis and redesign of the program.

The analysis of data from Phases I (Identifying the evidence base) and II (Identifying/developing appropriate theory) resulted in the first version of the GI program. Thus, the intervention program will include two GI sessions which, due to clinical instability and vulnerability, will be implemented in the same week.

The content of the script is divided into three main sections: (1) General indications that include the name of the technique and instructions on the attitude and posture to be adopted; (2) Breathing and muscle relaxation exercises to eliminate any existing tension. Therefore, participants are encouraged to take slow deep breaths, as well as to relax the head, face, eyelids, lips, back, abdomen, legs, and feet. By following these instructions, participants enter into a deeper state of relaxation, being encouraged to adopt a comfortable position and free their mind from negative thoughts; (3) Induction of a series of mental images. With the purpose of leading the patient to create comforting and soothing mental images, the assumptions underlying the development of the script were based mostly on positive imagination. Thus, the mental images include a (real or imaginary) special place for the patients where they can feel secure, comfortable, safe, and free. Patients are asked to elaborate a sequence of



mental images, evoking natural scenarios in which they can move around, focusing particularly on the sensory component of these scenarios through sight, hearing, smell, and touch. Indeed, the results of the phenomenological study (Coelho et al., 2016) carried out in Phase II suggest that the lack of a green space outside the PCU intended for patients can create a feeling of discomfort by depriving them of their freedom.

Given that several authors find it important to suggest a path to communicate with the inner self, or simply for a person to walk in the scenario, this instruction was included in the script (Payne, 2003; Samuels, 2003).

Therefore, after the breathing and muscle relaxation exercises, patients are asked to “imagine a perfect place where you would like to be right now”, “a place where you feel comfortable . . . A place where you feel secure, safe, and free”. To choose a place that better fits their preferences, they are given the following possibilities: “It could be a clearing in the woodland . . . a valley . . . a meadow in the countryside . . . or a garden full of flowers.” Subsequently, patients are asked to pay attention to the sensory content of the environment, with instructions such as: “Now take a moment to listen . . . What do you hear? Perhaps you can hear the birds singing . . . or the leaves rustling.”

Then, patients are asked to imagine walking down a path to meet with someone special “Who would you like to be with? Imagine . . . Sit calmly next to this person . . . This person can hear you and help you feel better . . . What would you like to tell him/her? Feel free to tell him/her whatever you want”.

After having experienced this imaginary encounter, patients are asked to leave that place and bring with them the good experiences, coming out of the relaxation state.

Finally, patients are asked to consider the PCU as a place where the professionals can help them feel comfortable.

Phase III (Modeling) was composed of three sub-phases: preliminary, field testing, and consensus conference.

In the preliminary sub-phase, the experts found that the intervention was relevant and feasible and that the participants’ weakness could be the main limitation to its implementation. For this reason, they found it important to conduct two GI sessions in the same week.

The experts strongly or somewhat agreed with all statements, with the exception of the adaptation of the breathing and muscle relaxation instructions to the patient with advanced disease, in which they showed a lower degree of agreement (Table 2).

Among the experts’ suggestions are the need to simplify the breathing and relaxation exercises due to the “patients’ difficulty, due to their frailty and physical weakness, to follow the breathing and relaxation instructions” (Expert No. 2, January, 2017) and “these patients’ difficulty in controlling their breathing” (Expert No. 4, January, 2017). Thus, these instructions were simplified and instructions such as “breathe slowly and deeply” were replaced by “breathe in and out calmly”, “take the time you need”, since the word *slowly* implies control over breathing.

In their suggestions, the experts also underlined that “The majority of people may already have lost their functional skills and the ability to walk”. In these cases, the instruction “prepare to take a walk”, without reinforcing the bodily sensations of lightness and floating, can force the patient to be confronted with the reality of disability and leave the state of imagination”. Thus, the instruction “prepare to take a walk” “could be reinforced with the imagination that the body is light and floating.” (Expert No. 5, January, 2017). Given this suggestion, prior to the instruction “imagine that you are going for a walk”, patients were asked to imagine that their body “was light and floating”.

Table 2  
Program assessment by experts in Phase II – preliminary sub-phase

Question	Strongly agree	Somewhat agree	Agree	Somewhat disagree	Strongly disagree
The breathing instructions are clear	33%	67%	0%	0%	0%
The breathing instructions are adapted to the patient admitted to the PCU	0%	50%	50%	0%	0%
The relaxation instructions are clear	16.7%	83.3%	0%	0%	0%
The relaxation instructions are adapted to the patient admitted to the PCU	0%	33.4%	66.6%	0%	0%
The GI instructions are clear	33.3%	66.7%	0%	0%	0%
The GI instructions are adapted to the patient admitted to the PCU	33.3%	66.7%	0%	0%	0%

In the field testing sub-phase, in line with the experts' assessment (preliminary sub-phase), both nurses and patients admitted to PCU reported that the implementation of this type of interventions in the PCU is an added value for patients because it could increase their comfort, as well as for nurses because it is a comfort intervention. Nurses also agreed with the im-

plementation of two sessions in the same week. In relation to the questionnaire, all participants strongly or somewhat agreed with all statements, with the exception of the time allowed for each image, in which there was a lower degree of agreement since only one participant (nurse) somewhat agreed with that statement (Table 3).

Table 3  
Program assessment by nurses and patients admitted to a PCU (Field testing sub-phase)

	Strongly agree	Somewhat agree	Agree	Somewhat disagree	Strongly disagree
Overall, the recording helped me relax	100%	0%	0%	0%	0%
The voice is relaxing	75%	25%	0%	0%	0%
The music helped me to relax	100%	0%	0%	0%	0%
The sound volume made it difficult to relax	0%	0%	0%	0%	100%
The breathing instructions are clear	0%	100%	0%	0%	0%
The breathing instructions are easy to follow	25%	75%	0%	0%	0%
The relaxation instructions are clear	25%	75%	0%	0%	0%
The relaxation instructions are easy to follow	0%	100%	0%	0%	0%
The time allowed for relaxation is enough	75%	25%	0%	0%	0%
The mental images helped me to relax	25%	75%	0%	0%	0%
It was easy to follow the suggested images	0%	75%	25%	0%	0%
The time allowed for each image is enough	0%	25%	75%	0%	0%

Participants also suggested that the script was not audio recorded because then the instructions and time elapsed between each instruction could be customized and adjusted to each patient, leaving the possibility to repeat the instructions, if needed, without having to rewind the audio.

In addition, nurses suggested that the sea could be used as a comforting mental image given that, according to their experience, some patients ask if they can leave the hospital to see the ocean again, which they are not always allowed to do because of their poor health conditions. It should be noted that the experts (preliminary sub-phase) were concerned about water phobia: “The reference to sounds could include the sound of the water from a distant stream (the fact that it is a distant stream ensures protection for water phobia/discomfort due to fear of drowning)” (Expert No. 5, January, 2017).

As regards the duration of the program, even though one of the experts (preliminary sub-phase) found it potentially excessive, this opinion did not prevail among the participants in this sub-phase.

In relation to the VAS administered to the patients, both of them improved their level of comfort (VAS before the intervention, 3 and 4; VAS after the intervention, 7 and 8, respectively). The following qualitative comments should be highlighted: “This was the first time in a very long time that I was able to stop thinking about death even for a few minutes” (Participant No. 2, February, 2017), “It was really nice to talk to my mother . . . I even feel less pain” (Participant No. 1, February, 2017). Both quantitative and qualitative data reveal the potential of the intervention. Both patients were interested in repeating the session.

During the consensus conference sub-phase, which was the final phase in the process of development and validation of the GI program, the divergences and convergences found along the different phases and sub-phases were analyzed. It should be noted that the research group gave special attention to a specific aspect: the suggested mental images about the water, the beach, and the sea.

Although initially the mental image of the sea was not used due to possible water phobia and

discomfort for fear of drowning, this opinion did not prevail among the nurses participating in the field testing sub-phase. In fact, they even had a contrary opinion because they believed that the induction of mental images that did not include environments capable of providing a high level of comfort to some patients could be a weakness of the script. It should be noted that the qualitative study (Phase II) showed that the lack of contact with nature (trees, flowers, countryside) led to an experience of discomfort among patients admitted to the PCU.

Based on these results, the third version of the GI script was developed. In addition to including the above-mentioned changes, in its third section (induction of a series of sequential mental images), each participant will, prior to the first session, select the most comforting environment (countryside vs. sea). Both sessions will be accompanied by relaxing music consistent with the selected environment.

Taking into account the pilot participants' suggestion, the intervention will not consist of listening to an audio-recorded script, but will rather be tailored to each participant. Thus, the speed and rhythm of each instruction and, consequently, the duration of each session will be adjusted to each patient. The intervention will be implemented by the principal investigator (nurse).

## Discussion

The increase in average life expectancy and the high prevalence of chronic diseases call for the development of complex interventions which result in patient comfort. Given the lack of GI scripts adjusted to PC settings, the GI script, which was developed and validated, emerges as a potential contribution to clinical practice and comfort gains for patients admitted to PCU.

The GI script development and validation process is recommended by the Medical Research Council (Craig et al., 2008) as a way of safeguarding researchers from facing limitations related to acceptability, compliance, delivery of the intervention, retention of participants, and smaller-than-expected results,

which can weaken the evaluation of an intervention's effectiveness.

The development of this program was based on previously existing evidence, the production of new evidence, the assessment of experts with training in the area and extensive experience in the implementation of therapeutic interventions, as well as on the field testing conducted with patients admitted to PCU; it went beyond the theoretical component and gave patients an opportunity to express their opinion. The result is a program that is adjusted, adapted, and appropriate to the comfort needs of patients admitted to PCU.

The consensus among experts, nurses, and patients hospitalized in the PCU about the relevance of the intervention, the quantitative and qualitative evaluation during the field testing sub-phase, and the obtained results point towards the likely effectiveness of the intervention in terms of comfort.

These data are consistent with the results found in the literature which reveal the potential effectiveness of GI in increasing comfort, although they have been obtained in other clinical areas.

Nevertheless, and even though the implementation of guidelines by the Medical Research Council for the development of complex interventions is a best practice in clinical research, this process does not ensure the effectiveness of the intervention. Therefore, as proposed by the Medical Research Council (Craig et al., 2008), the intervention program has to be evaluated on a larger scale with the purpose of assessing its actual contribution to increasing comfort in patients admitted to PCU.

## Conclusion

Based on the Medical Research Council guidelines for the development of complex interventions, a program was designed and adapted to the comfort needs of patients admitted to PCU. This program consists of two GI sessions to be implemented in the same week.

Each session is composed of a process of relaxation and induction of mental images, complemented by music.

The validity of the program is supported by

the consensus among experts, nurses, and patients admitted to the PCU about the relevance of the intervention, and the positive quantitative and qualitative assessment during the field testing phase.

This program has implications for clinical practice and research through its transferability and possible use in clinical practice.

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## **CHAPTER VII**

### **THE EFFECTS OF GUIDED IMAGERY ON COMFORT IN PALLIATIVE CARE**

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This chapter presents the Phase 5 of the study, which consisted in the implementation and evaluation of the previously developed GI program, through a quantitative study of a quasi-experimental nature, analyzing the comfort levels of the participants before and after the GI intervention.





**The effects of guided imagery on comfort in palliative care:  
Quasi-experimental study design**

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## Feature Article

# The Effects of Guided Imagery on Comfort in Palliative Care

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Guided imagery (GI) is a nonpharmacological intervention that is increasingly implemented in different clinical contexts. However, there have been no studies on the effect of GI on the comfort of inpatients of palliative care (PC) units. Therefore, the aim of this study was to evaluate the effects of GI on the comfort of patients in PC. A 1-group, pretest-posttest, pre-experimental design was used to measure differences in heart rate, respiratory rate, pain, and comfort in patients ( $n = 26$ ) before and after a 2-session GI program. The intervention featuring GI increased comfort, measured by an Abbreviated Holistic Comfort Scale and the visual analog comfort scale ( $P < .001$ ), and decreased heart rate ( $P < .001$ ), respiratory rate ( $P < .001$ ), and pain, as measured by the (numerical) visual analog pain scale ( $P < .001$ ). This study demonstrates that the use of an intervention featuring GI increases the comfort of oncology patients admitted to a PC unit. The use of GI by nurses is inexpensive, straightforward to implement, and readily available and may result in the provision of comfort care.

## KEY WORDS

comfort care, guided imagery, nursing, palliative care

The increase in life expectancy and chronic and progressive diseases has had an impact on the organization of health systems and on the need for palliative care units (PCUs).<sup>1</sup>

According to the World Health Organization,<sup>2</sup> palliative care (PC) is an approach that improves the quality of life of patients and their families facing problems associated with an incurable and/or severe disease with a poor prognosis, through the prevention and relief of suffering. It is an active, rigorous, and total health care approach where aggressive therapeutic measures give way to intensive comfort care.<sup>1,3</sup>

The purpose of comfort in the PC and nursing care process is defined by Kolcaba,<sup>4</sup> as a condition in which the basic needs for relief, tranquility, and transcendence are satisfied. These are developed in 4 contexts: physical, sociocultural, psychospiritual, and environmental.

With this objective, in the context of PC, there has been an increase in the development and implementation of nonpharmacological interventions that can be implemented autonomously and in complementarity to other therapeutic approaches. This has contributed to an increase in patient comfort and satisfaction with end-of-life care.<sup>5-7</sup> However, there are obstacles to its implementation, including the need to hire external professionals with specific training, the lack of scientific evidence regarding the effectiveness of the interventions, and the economic expenditure that implementation entails for the institutions.<sup>8</sup>

According to Kolcaba,<sup>4</sup> comfort care entails at least 3 types of comfort interventions that can be implemented to achieve the goal of enhancing patients' total comfort: (1) standard comfort interventions, (2) coaching, and (3) "comfort food for the soul." This last intervention targets the need for transcendence through memorable connections between the nurse and patient or family, making the patients feel strengthened in intangible, personalized ways and helping to fortify patients for difficult tasks, such as death. Guided imagery (GI) is one intervention that can address these aspects.

One of the nonpharmacological interventions increasingly implemented in different clinical contexts is GI.<sup>9-13</sup>

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Guided imagery is defined as a process of intentional use of mental images and sensory attributes that are the result of imagination or memory (preceded by a process of relaxation and assistance music) to achieve a desired therapeutic goal.<sup>14,15</sup> The person's involvement with mental images is so intense that his/her body tends to react as if responding to a genuine external experience, producing neurochemical changes with profound psychophysiological consequences.<sup>15</sup> Guided imagery is an intervention that can easily be implemented by nurses, requires little effort for the patient, and is of economic value.<sup>13</sup>

The research literature states that GI intervention is related to increased comfort in patients with pain and sleep disturbances,<sup>9</sup> women with breast cancer,<sup>10</sup> elderly patients with prostate cancer,<sup>11</sup> individuals undergoing chemotherapy,<sup>12</sup> people diagnosed with fibromyalgia,<sup>13</sup> and others. However, a scoping review performed by Coelho et al<sup>16</sup> identified a lack of studies on the effect of GI on comfort in the PC context. Since the research literature shows that patients in PC experience discomfort due to a lack of control over physical symptoms; to physical, social, and freedom losses; and to guilt and fear, PC justifies the implementation of interventions that result in the increased comfort of oncology patients.<sup>16,17</sup>

In light of the aforementioned studies in other contexts, the potential effects of GI in PC should not be underestimated. If this intervention is demonstrated to be effective in PC, its implementation can translate into a significant increase in the comfort level of a number of patients in PC.

### Aim

The aim of this study was to evaluate the effects of GI on the comfort of patients in PC.

### Hypotheses

Inpatients in PC who received a program of GI will experience improved comfort and reduced pain, heart rate, and respiratory rate.

## METHODS

### Design

This study used a 1-group, pretest-posttest, pre-experimental design.

### Setting and Participants

Participants were patients hospitalized in the PCU of a hospital located in the central region of Portugal. All patients were assessed for eligibility according to the following criteria: patients' health condition allowed them to tolerate the program intervention, duration of stay in the PCU of at least 2 days, and having consented to participate in the study. Patients with cognitive deficits and those patients

who were dying were excluded. Patients meeting these criteria were identified through collaboration with the chief nurse of the PCU. The sample consisted of all patients eligible for inclusion in the study during the data collection period, which occurred between February and July 2017.

### Procedures

The intervention procedures are shown in the Figure. Patients eligible for inclusion in the study were contacted and informed about the intervention program and study objectives by the first author. Patients who agreed to participate in the study provided informed consent.

Before the first GI session, sociodemographic data were collected, and the chief nurse of the PCU provided data about diagnostics and days of hospitalization. Before and after each GI session, measurements of patients' heart rate, respiratory rate, and pain were provided. Because of the fragility of the participants and the length of the Holistic Comfort Scale (HCQ-PT-DC), this scale was abbreviated and was administered only twice (T1 and T4). The application of 2 comfort scales allowed triangulation of the results.

When the measures could not be self-administered, measures were carried out by a different researcher. These researchers did not participate in the GI program implementation, which was carried out by the first author.

Qualitative comments were collected after each session, obtained in response to the questions: "How do you feel?" and "Are you all right?"

### Intervention

The intervention comprised a 2-session GI program. The construction and validation of the adjusted GI program incorporated the guidelines and recommendations of the Medical Research Council<sup>18</sup> for the development of complex interventions. The construction and validation process is described in detail by Coelho et al.<sup>14</sup>

Briefly, this construction and validation process resulted in a script for the intervention that was structured into 3 main sections, which were implemented in our study:

1. general indications that included the name of the technique and instructions on the attitude and posture to be adopted;
2. smooth breathing exercises and muscle relaxation, in an effort to eliminate some existing tension; and
3. induction of a sequential set of mental images that include special, quiet, and comfortable places enhancing the security and freedom of the patient. Prior to the first session, each patient chose the most comforting environment for him/her: a field or a beach (the script was built in order to provide both possibilities, according to preference). Thus, the patient was invited to elaborate on a sequential set of mental images, evoking natural scenarios in



Feature Article

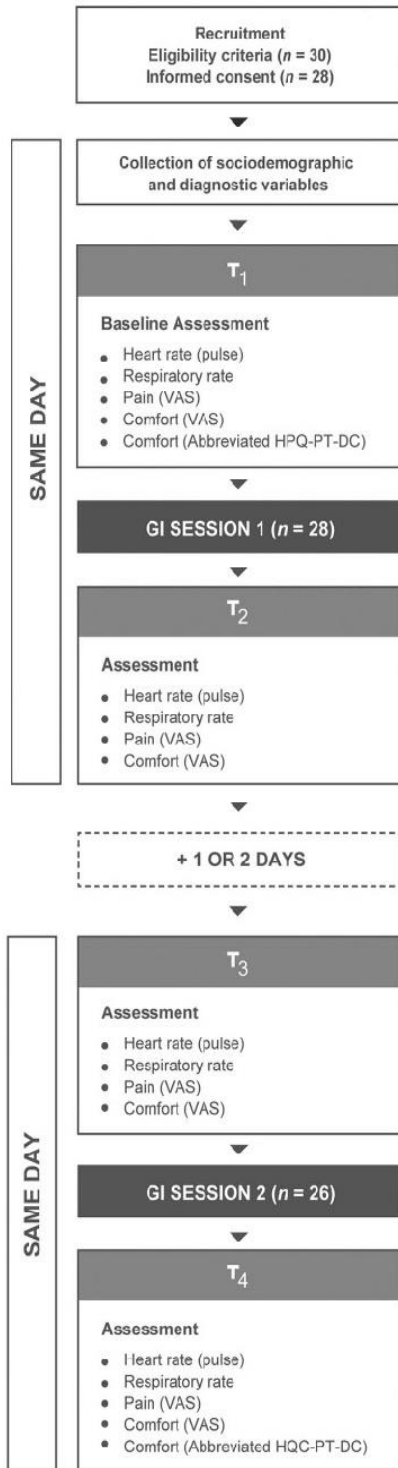


FIGURE. Flow diagram of the intervention.

which to move, focusing particularly on the sensory content of these scenarios through vision, hearing, smell, and touch. Then it was suggested to the patient to move from this place and to take a walk, during which it was suggested that he/she imagine a meeting with someone special, allowing his/her a moment for meeting and sharing. After having lived this imaginary encounter, the patient was invited to leave the place and to bring with him/her what felt good, leaving the state of relaxation. Finally, it was suggested that the patient look at the PCU as a space where there are health care professionals who can help them feel comfortable.

Because music enhances the effect of the mental images,<sup>14,15</sup> both sessions were accompanied by relaxing music concordant with the selected environment. Each session was personalized for each patient, with the speed and rate of each indication and duration of each session adjusted for each patient. The decision to perform 2 sessions with a short interval between them was due to the medical instability and clinical weakness of the participants.<sup>14</sup>

Measurements

Differences in patients' heart rate, respiratory rate, pain, and comfort were measured before and after a 2-session GI program.

1. The HCQ-PT-DC is an instrument that can specifically measure holistic comfort in patients at end of life. It is based on Kolcaba's Holistic Comfort Theory and has been translated and validated for the Portuguese population by Querido and Dixe.<sup>19</sup> The scale is composed of 26 affirmations with responses on a Likert-type scale from 1 ("I strongly agree") to 5 ("I strongly disagree") and evaluates 2 dimensions: the states of need satisfaction and the contexts in which comfort occurs. Higher scale scores correspond to a higher level of comfort. The administration of the instrument can be done face-to-face or by self-completion. In the case of the present study, whenever possible, the instrument was self-administered. Given the fragility of the target population, with the author of the scale's permission, a reduced version of this instrument was constructed of 19 items. The decision to use these 19 items and eliminate the remaining 7 was based on the consensus analysis of 4 experts (including the author of the instrument itself) regarding which items are likely to be sensitive to GI intervention. In this study, the Abbreviated HCQ-PT-DC revealed a Cronbach  $\alpha$  value of 0.95 (item-total correlation ranging between 0.33 and 0.90) at baseline, and after the GI program, Cronbach  $\alpha$  was 0.92 (item-total correlation ranging between 0.19 and 0.89).



2. The visual analog comfort scale<sup>20</sup> was used to quantify the participants' comfort. The scale is a straight line, 10 cm in length, and each participant was asked to indicate on the line the point best describing his/her level of comfort.
3. The visual analog pain scale<sup>21</sup> was used to quantify the participants' pain intensity. The scale is a straight line, 10 cm in length, and each participant was asked to indicate on the line the point best describing his/her level of pain.
4. The evaluation of heart rate was conducted through the pulse palpation method at the level of the radial artery.
5. The evaluation of respiratory rate was conducted by observing the movements of the thoracic wall.

### Data Analysis

Data were analyzed using Statistical Package for the Social Sciences for Windows (SPSS version 20.0; IBM Corp, Armonk, New York ) software.

Primarily, a descriptive analysis of the variables under study was carried out by calculating the minimum, maximum, mean, and SD for numerical variables and calculating the frequency and percentage for categorical variables. The internal consistency of the Abbreviated HCQ-PT-DC was then estimated with a Cronbach  $\alpha$  coefficient.

As the sample consisted of 26 participants and not all variables followed a normal distribution (verified using the Shapiro-Wilk test), it was decided to use nonparametric tests. Thus, to verify the hypotheses of the study, inferential analysis of the data was performed using Wilcoxon signed rank tests. In this analysis, differences were considered statistically significant at  $P < .05$ . Given that there were statistically significant differences in the participants' changes over time, the effect size ( $r$ ) was calculated.<sup>22</sup>

### Ethical Considerations

This research project was approved by the Ethics Committee of the Hospital Arcebispo João Crisóstomo de Cantanhede (August 2, 2017). All participants were invited to participate in the study voluntarily, and the confidentiality of their information was ensured. To facilitate decisions regarding participation, participants were informed regarding the nature and objectives of the study and other ethical aspects.

### RESULTS

Thirty patients were identified for participation in the study. Of these, 28 agreed to participate, but 2 died before completing the intervention. The 26 participants who completed the program were aged between 45 and 93 years. On the whole, they were not highly educated (65.4%

studied for first to fourth grade—elementary school); 57.7% were married, and 50% were male. All of the participants were oncology patients. Table 1 provides a summary of the participants' characteristics.

All participants selected the field scenario as a place of comfort. The 2 sessions were conducted with an interval of 1 or 2 days. On average, each session lasted 17 minutes.

### Comfort

After the GI program (T4), all of the participants reported a significant increase in comfort with a large effect size in comparison to baseline scores (T1) as measured by the Abbreviated HCQ-PT-DC ( $z = -4.46$ ,  $P < .001$ ,  $r = 0.62$ ) and measured by the visual analog comfort scale ( $z = -4.49$ ,  $P < .001$ ,  $r = 0.62$ ).

After the first session (T2), compared with baseline scores (T1), all of the participants reported a significant increase in comfort with a large effect size ( $z = -4.51$ ,  $P < .001$ ,  $r = 0.63$ ). Between the evaluations performed after the first session (T2) and prior to the second session (T3), 96% of the participants reported a significant decrease in comfort with a large effect size ( $z = -4.43$ ,  $P < .001$ ,  $r = 0.61$ ). Although a significant reduction in comfort from T2 to T3 was observed, the levels obtained in T3 were still higher than those obtained at baseline (T1). Thus, despite the reduction from T2 to T3, the first GI session had a significant influence on improving comfort at T2 and T3 compared with T1 ( $P < .001$ ).

After the second GI session (T4), once again, all of the participants reported a significant increase in comfort with a large effect size compared with T3 ( $z = -4.50$ ,  $P < .001$ ,  $r = 0.62$ ).

**TABLE 1** Baseline Sociodemographic and Diagnostic Characteristics (n = 26)

Variables		n	%
Sex	Male	13	50
	Female	13	50
Education	0 y	3	11.5
	1st-4th Grade	17	65.4
	5th-9th Grade	6	23.1
Marital status	Single	3	11.5
	Married	15	57.7
	Divorced	2	7.7
	Widowed	6	23.1
Diagnostic	Oncologic	26	100
	Nononcologic	0	0
Age, y		Min, 45; max, 93; mean, 65.69 (SD, 12.26)	
Days of hospitalization		Min, 3; max, 14; mean, 6.58 (SD, 2.97)	

**TABLE 2** Change of Heart Rate, Pain, and Comfort in Patients Participating in the GI Program Over Time

(n = 26)	Outcomes	Change	Change (T2-T1)				Change (T3-T2)					
			n	%	z	P	r	n	%	z	P	r
Heart Rate (pulse)	Positive change <sup>a</sup>		26	100	-4.47	<.001	.62	6	23.1	-2.29	<.05	.32
	Negative change		0	0				15	57.7			
	Without change		0	0				5	19.2			
Respiratory Rate	Positive change <sup>b</sup>		25	96.15	-4.42	<.001	.61	2	7.7	-3.24	<.01	.45
	Negative change		0	0				18	69.2			
	Without change		1	3.85				6	23.1			
Pain (VAS)	Positive change <sup>c</sup>		26	100	-4.50	<.001	.62	4	15.4	-3.45	<.001	.48
	Negative change		0	0				18	69.2			
	Without change		0	0				4	15.4			
Comfort (VAS)	Positive change <sup>d</sup>		26	100	-4.51	<.001	.63	0	0	-4.43	<.001	.61
	Negative change		0	0				25	96.15			
	Without change		0	0				1	3.85			
Comfort (Abbreviated HCQ-PT-DC)	Positive change <sup>e</sup>		—	—	—	—	—	—	—	—	—	—
	Negative change											
	Without change											

Abbreviations: GI, guided imagery; HCQ-PT-DC, Holistic Comfort Scale; VAS, visual analog scale.

<sup>a</sup>Decreased heart rate is considered a positive change.

<sup>b</sup>Decreased respiratory rate is considered a positive change.

<sup>c</sup>Decreased pain (VAS) is considered a positive change.

<sup>d</sup>Increased comfort (VAS) is considered a positive change.

<sup>e</sup>Increased comfort (Abbreviated HCQ-PT-DC) is considered a positive change.

### Pain, Heart Rate, and Respiratory Rate

An analysis of the change in pain between the first evaluation (T1) and the last evaluation (T4) revealed that 100% of the participants reported a significant decrease in pain with a large effect size ( $z = -4.48$ ,  $P < .001$ ,  $r = 0.62$ ). This same pattern was observed with heart rate ( $z = -4.46$ ,  $P < .001$ ,  $r = 0.62$ ). Moreover, 96.15% of the participants showed a significant decrease in respiratory rate with a large effect size ( $z = -4.40$ ,  $P < .001$ ,  $r = 0.61$ ).

Table 2 presents the changes over the course of GI program participation in terms of the PCU inpatients' heart rate, respiratory rate, pain, and comfort.

### Qualitative Evaluation

Patients described having the opportunity to explore interpersonal (with others), transpersonal (with nature), and intrapersonal relationships (with oneself) and reported

physical comfort and a feeling of freedom that emerged from the intervention.

Among the qualitative comments, participants widely used the expression "inner peace" to describe how they felt after each GI session. One patient stated, "...I am very afraid of death, and I am always thinking of it. I do not sleep thinking about it... for the first time in a long time, I could not think about death, that's good... (I) feel this inner peace." Another patient expressed, "I cannot explain how I feel, but I can say that I feel at peace... made me think well about certain things... and be with her [mother]... and to apologize."

The relationship experienced with nature was also highlighted, with one participant stating, "It was like walking back through my pine forests... breathe in that air... wonderful." The feeling of freedom experienced was highlighted, with one participant commenting, "...after so many days here (feeling) confined... during these



Change (T3-T1)					Change (T4-T3)					Change (T4-T1)				
n	%	z	P	r	n	%	z	P	r	n	%	z	P	r
22	84.6	-4.14	<.001	.57	24	92.4	-4.33	<.001	.60	26	100	-4.46	<.001	.62
0	0				1	3.8				0	0			
4	15.4				1	3.8				0	0			
18	69.2	-3.53	<.001	.49	25	96.15	-4.39	<.001	.61	25	96.15	-4.40	<.001	.61
2	7.7				1	3.85				0	0			
6	23.1				0	0				1	3.85			
22	84.6	-4.18	<.001	.58	22	84.6	-4.22	<.001	.59	26	100	-4.48	<.001	.62
0	0				0	0				0	0			
4	15.4				4	15.4				0	0			
24	92.3	-4.36	<.001	.60	26	100	-4.50	<.001	.62	26	100	-4.49	<.001	.62
0	0				0	0				0	0			
2	7.7				0	0				0	0			
	—	—	—	—	—	—	—	—	—	26	100	-4.46	<.001	.62
										0	0			
										0	0			

minutes I felt free... I usually look out the window and see the trees... but this was different.”

In addition, improvements were described at a physical level. One participant said, “Even the pains have calmed... maybe because it gave me something important to think about.” Another patient stated, “Now yes, I feel relaxed and sleepy.”

**DISCUSSION**

Results from this study suggest that GI is an appropriate nonpharmacological intervention to promote comfort. This is consistent with results of studies on other interventions.<sup>23</sup> However, no other study has evaluated the effect of GI on the comfort of inpatients in PCUs.<sup>16</sup> Therefore, as far as we are aware, our study is the first to investigate the effectiveness of GI on comfort in PCU inpatients,<sup>16</sup> indicating that GI increases levels of comfort and decreases

pain, heart rate, and respiratory rate. Our findings are consistent with those from other studies that implemented nonpharmacological interventions in the context of PC. However, in these studies, the interventions were not implemented by nurses, but by specialized therapists,<sup>23-25</sup> therefore requiring the hiring of professionals who were external to the PCU team. One limitation to the implementation of nonpharmacological interventions is precisely the need to hire external professionals and therefore the associated expense.<sup>8</sup> The GI program presented in this study is a nursing intervention that can be used as a holistic comfort intervention at any time of the day and night.

Corroborating the statistical significance, the qualitative comments of the participants reveal the clinical significance of the intervention program. Patients reported having the opportunity to explore interpersonal, transpersonal, and intrapersonal relationships, as well as physical





## Feature Article

comfort and a feeling of freedom that emerged from the intervention.

In fact, a qualitative study carried out with the objective of understanding the experiences of comfort and discomfort of patients hospitalized in a PCU suggests that the experience of comfort emanates from dedicating time to relationships.<sup>26</sup> The same study revealed that the discomfort experienced by these patients was due to the loss of freedom and the absence of contact with an external green space. Perhaps this is the reason why all participants opted for images related to a field or nature rather than the beach or sea. This fact reinforces the need for a space in the PCU that invites contact with nature, but it also highlights the importance of this GI program for patients who cannot access a natural space.

Although GI is an example of a “comfort food for the soul” intervention, according to Kolcaba,<sup>4</sup> the holistic comfort intervention can be used to target many comfort needs at one time, and the results of this study support this. This study suggests that GI interventions fulfill the comfort needs of oncology patients at physical (decrease of pain, heart rate, and respiratory rate), social (promoting the establishment of interpersonal relationships), spiritual (promoting intrapersonal and transpersonal relationships), and environmental (inducing images that promote the feeling of freedom) levels.

In conclusion, even though comfort is a goal of PC, patients continue to experience varying levels of discomfort, so it is essential to implement interventions that culminate in the comfort of the patients.<sup>16,17</sup> This study suggests that an intervention with GI is effective in improving comfort in PCU oncology inpatients.

This study has some methodological limitations. First, a quasi-experimental design was used because of the small sample size, which resulted from a limited period of data collection and the implementation of the study in a single PCU.

It should be noted that researchers have taken different stands regarding the ethical justifiability of random assignment for populations of severely ill patients because withholding potentially effective treatments/interventions due to randomization can be particularly problematic.<sup>27</sup>

Finally, it was the intention of the authors to conduct phenomenological qualitative interviews after each GI session in order to understand the experience lived by the participants. However, because of the participants’ state of relaxation, emotion, and introspection after each session and because the patients’ interests outweigh the interests of research, it was considered inappropriate to conduct such interviews.

## CONCLUSIONS

This study suggests that the use of GI improves the comfort of oncology patients in PCUs and decreases pain, heart

rate, and respiratory rate. It may also promote the establishment of interpersonal, transpersonal, and intrapersonal relationships. The use of GI is inexpensive, straightforward to implement, and readily available and can be used without great material investment to improve the comfort of patients in PCUs. However, nurses need to receive prior training about the intervention in order to implement it.

Although more qualitative and quantitative studies (with a larger sample) should be carried out to validate the presented results, this study provides an autonomous nursing intervention that is complementary to the treatment that patients in PC receive.

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## CONCLUSIONS

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In this section, it is presented a systematization of the most relevant results related to the various studies developed, and discussed the relevance and implications for research and clinical nursing practice. Key Statements about the study are presents at the end of the section (Figure 1).



This work was designed with the primary objective of providing comfort to inpatients at PCU. To achieve this, the present investigation was structured in five Phases that culminated in the evaluation of the effectiveness of a GI program.

In the Phase 1 (chapter III) a Scoping Review was carried out with the objective to map the non-pharmacological interventions implemented and evaluated to provide comfort in PC.

The results revealed the existence of eighteen studies, covering ten non-pharmacological interventions implemented and evaluated to provide comfort. Music therapy and massage therapy were the most common interventions. Characteristics differed significantly across interventions and even in the same intervention, both in terms of number of sessions (between one and fourteen sessions) and their duration (between five and 60 minutes). Interventions were implemented mostly in PCUs and hospices, and in patients with cancer diagnosis.

This mapping has clearly identified the need for research on comprehensive comfort care provided through non-pharmacological interventions, since only three of the eighteen included studies assessed the total level of comfort resulting from the interventions.

This study also allowed giving visibility to interventions already implemented in this context, constituting a contribution to future interventions. However, it also revealed that systematic reviews should be performed to determine the best available evidence about the effect on non-pharmacological interventions on comfort.

The analysis of the characteristics of others non-pharmacological interventions already implemented and evaluated allowed transposing those characteristics into the GI program developed in Phase 4 of this study.

Although the literature reveals that GI is associated with a significant increase in patient comfort in various clinical settings, this scoping review also evidenced the inexistence of studies on the effect of GI in comfort in PC, which clearly limits its implementation.

In the Phase 2 (chapter IV), a qualitative study of a phenomenological nature was carried out, with the aim to understand the experiences of comfort and discomfort of inpatients at a Portuguese and Spanish PCUs. Although all the data analysis was performed separately (by contexts), given the overlap of findings, they were presented together.

The findings of this study evidenced that four themes reflect the essence of the lived experience: The PC as a response to the patient's needs with advanced disease, attempt to naturalize advanced disease, confrontation with their own vulnerability, openness to the spiritual dimension. The theme "The Palliative Care as a response to the patient's needs with advanced disease" represents the experiences of comfort. The theme "Confrontation with

their own vulnerability” represents the experiences of discomfort. The themes “Attempt to naturalize advanced disease” e “Openness to the spiritual dimension” express double experiences of comfort and discomfort. That is, despite representing discomfort, are also described as essential for the patient to meet and experience comfort. Documenting such findings them is crucial because it invites nurses and researchers to reflect on their beliefs about what it means to be comfortable for these patients, and allows the incorporation of this information in the design of focused interventions to maximize the comfort experience. Unless one offers patients the opportunity to be heard on their experience, their perspective will remain hidden and it could be hardly to provide comfort to them.

This study also suggests the need to develop and implement comfort interventions adapted and adjusted to the comfort needs of inpatients at PCUs and furthermore provides useful information for its development in both Portuguese and Spanish contexts. The information from this study was used to develop a GI program adjusted to the comfort needs of these patients.

The Phase 3 (chapter V) describes the process of translate, adapt and validate the HCQ for use in the PC Spanish context. The HCQ is an instrument for assessing comfort in the context of PC. The results show that the Spanish version of the HCQ is an instrument for the assessment of comfort in PC with quality psychometric guarantees (good reliability and validity). Regarding reliability, inconsistent with the rest of the scale were observed in 7 items, which presented a correlation lower than 0.20. Taking into account the statistical data and the critical analysis of the content of the items, it was decided to eliminate only 3 items. Once the scale was reduced to 46 items, the internal consistency of the total scale was measured with a Cronbach's  $\alpha$  of 0.89, and of each group of items of each comfort state. Cronbach's alpha of relief was 0.72, tranquility 0.73, and transcendence 0.75. Criteria validity was verified through the Spearman correlation coefficient, obtaining a correlation of 0.805 between the HCQ Spanish version and the Visual Analogue Comfort Scale.

The HCQ Spanish version has been revealed as a reliable and valid instrument to assess the comfort of inpatients at PCUs, with which we can already have a complementary clinical work tool for assessing the comfort degree of these patients in the Spanish context.

The Phase 4 (chapter VI) describes the process of construction and validation of a GI Program for inpatients at PCU, the evidence from the studies performed in the first two phases was fundamental for its achievement. Following the guidelines for developing complex interventions from the Medical Research Council, it resulted in a program adapted to the comfort needs of inpatients at PCU, consisting of two GI sessions to be implemented in the same week.

Each session consisted of a process of relaxation and induction of mental images, accompanied by music. The validity of the program is supported by the consensus opinion of experts, nurses and inpatients at PCU, about the relevance of the intervention, and the positive, quantitative and qualitative, evaluation performed during the field test phase.

The Phase 5 (chapter VII) consisted in the realization of a one-group, pretest-posttest, and quasi-experimental design with the objective to evaluate the effect of a GI program in the comfort of inpatients at PCUs. To achieve this aim, the GI program developed in the Phase 4 of the study was implemented. The intervention of the GI program increased comfort measured by the Holistic Comfort Scale and Visual Analog Comfort Scale ( $p < .001$ ), decreased pain measured by Visual Analog Pain Scale ( $p < .001$ ), decreased heart rate ( $p < .001$ ), and respiratory rate ( $p < .001$ ).

Corroborating the statistical significance, the qualitative comments of the participants reveal the clinical significance of the intervention program. Patients reported the opportunity to open up to interpersonal, transpersonal, and intrapersonal relationships, and the physical comfort and feeling of freedom that emerges from the intervention.

Thus, this study suggests that GI interventions fulfill patients' comfort needs at a physical (decrease of pain, heart rate, and respiratory rate), social (promoting the establishment of interpersonal relationships), spiritual (promoting intrapersonal and transpersonal relationship), and environmental level (inducing images that promote the feeling of freedom)

This study suggests that the use of GI by nurses should be strongly encouraged as it is inexpensive, straightforward to implement, and readily available, and can be used without great investment in material or training to improve the comfort of patients in PCUs.

Although more qualitative and quantitative studies (with a larger sample) should be carried out to validate the presented results, this study provides an autonomous and complementary nursing intervention to the treatment that the patients in PC receive, representing a contribution with great impact on the comfort state of inpatients at PCU. From the point of view of scalability, it is expected not only that this study will boost the development of other non-pharmacological interventions adjusted to the comfort needs of these patients, but also encourages the development / adaptation of new GI scripts with application in other contexts (e.g. palliative home care) and in other countries (e.g. Spain). In short, this thesis, consisting of a set of research work, contributed to the expansion of knowledge frontiers and culminated in a complementary intervention that contributes to the provision of comfort care consistent with the goal of PC and Nursing.

**What is already known about the topic?**

- Comfort is a holistic experience resulting from the satisfaction of relief, ease and transcendence needs in the contexts physical, psycho-spiritual, sociocultural and environmental;
- Comfort is a core concept in nursing profession, particularly in PC;
- Patients in the context of PCs still present discomfort;
- The intervention with GI is related to an increase of comfort in different contexts of clinical practice;
- The effect of GI on comfort in the PC context is unknown.

**What does this study add?**

- Phase 1: provide a mapping of the research activity on non-pharmacological interventions for patient comfort in PC;
- Phase 2: provide understanding about the experiences of comfort and discomfort of inpatients at a Portuguese and Spanish PCUs;
- Phase 3: provide an instrument of diagnostic and assessment of comfort interventions, reliable and valid for use in the Spanish context;
- Phase 4: provide a GI program adjusted to the comfort needs of inpatients at PCU;
- Phase 5: provide the evaluation of the effectiveness of the developed GI program.

**Implications for practice, theory or policy.**

- Phase 1: Systematic reviews should be performed to determine the best available evidence about the effect on non-pharmacological interventions on comfort;
- Phase 2: Invites the nurses, researchers and stakeholders to reflect on what it means to be comfortable for patients, and allows the incorporation of this information in the design of focused interventions to maximize the comfort experience;
- Phase 3: The HCQ - Spanish Version is a complementary clinical work tool for assessing the comfort degree of these patients;
- Phase 4: The developed GI program is transferable and of possible use in clinical practice;
- Phase 5: This study demonstrates that the use of GI improves the comfort of patients in PCUs and provides an autonomous and complementary nursing intervention to the treatment that the patients in PC receive.

**Figure 1:** Key Statements about the study.



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

The remaining references are presented in this section.



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# APPENDICES

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## Appendix 1

Ethics committee authorization to perform the study:

*Comfort experience in palliative care: a phenomenological study (CEIC FORES).*



### Informe del CEIC d'aprovació de l'estudi

Dr. Eduardo Kanterewicz, President del Comitè Ètic d' Investigació Clínica de la Fundació d'Osona per a la Recerca i l'Educació Sanitàries (FORES)

Faig constar

Que d'acord amb els antecedents documentals que existeixen en els arxius del CEIC,

**ADRIANA RAQUEL NEVES COELHO**

consta en qualitat d'investigador/a principal del projecte:

**"Vivencias de confort en el contexto de los cuidados paliativos"** Codi CEIC 2015873

Que s'acompleixen els requisits d'idoneïtat del protocol en relació als objectius de l'estudi.

Que la capacitat de l'investigador i els medis disponibles son apropiats per dur a terme l'estudi.

I que l'estudi ha estat aprovat per aquest CEIC el 31/03/2015.

**Eduardo Kanterewicz**




Vic, 10 d'abril de 2015




## Appendix 2

Ethics committee authorization to perform the study:

*Comfort experience in palliative care: a phenomenological study (CE HAJC).*

 Administração (FF) - Hospital do Arcebispo João Crisóstomo 📧 Responder | ▾

qua 04-02-2015 16:06  
Para: [adriana.nevescoelho@hotmail.com](mailto:adriana.nevescoelho@hotmail.com) 

Cantanhede HAJC

Exmª Senhora  
Adriana Raquel Neves Coelho

Informa-se V. Exª que o Conselho de Administração do Hospital Arcebispo João Crisóstomo, autoriza o seu pedido nos termos do parecer da Comissão de Ética para a Saúde desta Instituição, que a seguir se transcreve:  
"Relativamente ao pedido para realização de estudo apresentado por Adriana Raquel Neves Coelho – "Vivências de conforto/desconforto da pessoa internada em Unidades de Cuidados Paliativos", não tendo sido identificados quaisquer aspetos suscetíveis de levantar questões de natureza ética, o mesmo foi aprovado por unanimidade, com a ressalva de, previamente à sua aplicação, a autora dever explicar e apresentar aos responsáveis da Unidade de Cuidados Paliativos o método e todos os materiais a utilizar no estudo."

Com os melhores cumprimentos,


O presidente do conselho de administração,  
Dr. Aurélio Rodrigues



## Appendix 3


Permission to use the *Hospice Comfort Questionnaire for Patients*.


Permission to use the Hospice Comfort Questionnaire

 Adriana Neves Coelho  
seg 12-10-2015, 10:17  
kathykolcaba@yahoo.com; Prof. Apostolo (apostolo@esenfc.pt); Miguel Ángel Escobar Bravo (miguel.escobar@infermeria.udl.cat) ↕

Dear Dr. Kathy Kolcaba,  
My name is Adriana Neves Coelho. I am a PhD student from the University of Lleida – Spain, writing my doctoral thesis titled “The Guided Imagery in Comfort in the context of Palliative Care”.  
I would like to ask if I have your permission to use the **Hospice Comfort Questionnaire for Patients** in my research study, with the intention of doing a cultural adaptation and validate the Questionnaire to the Spanish context.  
Look forward to your response.  
Kings Regards,


Adriana Coelho,  
RN, MD, PhD student.  
Nursing Department - University of Lleida.

 Responder | v

 Kathy Kolcaba  
seg 12-10-2015 14:01  
Para: Adriana Neves Coelho (adriana.nevescoelho@hotmail.com) ↕

You have my permission to do as u described below. Perhaps one of the translations on my web site will be of help. Dr. K

Sent from my iPhone

 Responder | v





## Appendix 4

Ethics committee authorization to perform the study:

*The validation of a Comfort assessment scale for Palliative Care patients: Spanish version of the Hospice Comfort Questionnaire.*

**FORES**

### Informe del CEIC d'aprovació de l'estudi

Dr. Eduardo Kanterewicz, President del Comitè Ètic d' Investigació Clínica de la Fundació d'Osona per a la Recerca i l'Educació Sanitàries (FORES)

Faig constar

Que d'acord amb els antecedents documentals que existeixen en els arxius del CEIC,

**NEVES COELHO ADRIANA RAQUEL**

consta en qualitat d'investigador/a principal del projecte:

**Validación del Hospice Comfort Questionnaire**

Codi CEIC 2015892

Codi Propi PR123

Va ser aprovat per aquest CEIC el 24/11/2015.

Promotor **HOSPITAL DE LA SANTA CREU**



**Eduardo Kanterewicz**

**FORES**  
COMITÈ ÈTICA  
D'INVESTIGACIÓ CLÍNICA  
C. Francesc Pla «El Vigatà», 1  
08500 VIC

Vic, 21 de desembre de 2015



## Appendix 5

Confirmation of the publication acceptance of the study:

*Spanish version of the Hospice Comfort Questionnaire: Validation of a Comfort assessment scale for Palliative Care patients.*

Medicina Paliativa <eesserver@eesmail.elsevier.com>

sex: 16-06-2017 07:46

Para: adriana.nevescoelho@hotmail.com; vitor.parola@hotmail.com

Responder | v

Reencaminhou esta mensagem a 16-06-2017 10:31

Apreciada Miss Coelho:

Le comunicamos que su manuscrito "Versión española del Hospice Comfort Questionnaire para evaluar el confort en pacientes en cuidados paliativos: Adaptación transcultural y validación. Spanish version of the Hospice Comfort Questionnaire: Validation of a Comfort assessment scale for Palliative Care patients" (Ref. MEDIPAL-D-16-00049R2) ha sido aceptado para su publicación en Medicina Paliativa.

Recuerde que en su momento le remitiremos las pruebas de autor en formato pdf a esta misma dirección electrónica.

Reciba un cordial saludo,

Dr. Alonso Babarro  
Subdirector  
Medicina Paliativa

Medicina Paliativa

Contact us Help ?

Username: adriana.nevescoelho@hotmail.com

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Submissions with an Editorial Office Decision for Author Adriana Coelho, M.D., PhD Student

Page: 1 of 1 (1 total completed submissions) Display 10 results per page.

Action	Manuscript Number	Title	Initial Date Submitted	Status Date	Current Status	Date Final Disposition Set	Final Disposition
<a href="#">Action Links</a>	MEDIPAL-D-16-00049	Versión española del Hospice Comfort Questionnaire para evaluar el confort en pacientes en cuidados paliativos: Adaptación transcultural y validación. Spanish version of the Hospice Comfort Questionnaire: Validation of a Comfort assessment scale for Palliative Care patients	01/08/2016	16/06/2017	Acceptado / Accepted		

Page: 1 of 1 (1 total completed submissions) Display 10 results per page.


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## Appendix 6

Permission to use the “*Escala de Conforto Holístico HCQ - PT-DC*”.

Pedido de consentimento para a utilização da Escala de Conforto Holístico HCQ - PT-DC 1

 Ana Isabel Fernandes Querido <ana.querido@ipleiria.pt>  
seg 14-11-2016 21:35  
Para: Adriana Neves Coelho (adriana.nevescoelho@hotmail.com); querido.ana@gmail.com  
Cc: Prof. Apostolo (apostolo@esenfc.pt)

  ESCALA DE CONFORT...  
437 KB

Transferir Guardar no OneDrive - Pessoal

Boa noite Adriana

Antes de mais gostaria de a felicitar pela escolha do tema e pelo seu processo doutoral. Acredite que está a ser orientada pelo perito mais competente e conhecedor do conforto em Portugal, tal como o conhecemos na taxonomia de Kolcaba, o que garante a qualidade do trabalho que irá realizar.

Tenho todo o gosto em conceder-lhe autorização para a utilização da escala de conforto holístico HCQ-PT-DC.

Estarei disponível para a colaboração que entender necessária, incluindo a disseminação dos resultados sob a forma de artigo.

Junto anexo o instrumento com as instruções de utilização. Estarei ao dispor para qualquer esclarecimento adicional.

Grata pela preferência, fico a aguardar o desenvolvimento do trabalho.

Votos de muito sucesso neste seu percurso,

Cumprimentos



## Appendix 7

Ethics committee authorization to perform the study:

*The effects of guided imagery on comfort in palliative care.*



SNS SERVIÇO NACIONAL  
DE SAÚDE



Exm<sup>a</sup> Senhora

Dr<sup>a</sup> Adriana Raquel Neves Coelho

Conforme requerido por V. Ex.<sup>a</sup> vimos confirmar a aprovação pela Comissão de Ética do H.A.J.C. na sua reunião de 8 de fevereiro de 2017 o estudo “A Imaginação Guiada no Conforto em Contexto dos Cuidados Paliativos” na Unidade de Cuidados Paliativos.

Hospital Arcebispo João Crisóstomo, 08 de fevereiro de 2017

A Presidente da Comissão de Ética para a Saúde

(Dr<sup>a</sup> Maria de Lurdes Sá Tenreiro)





## Appendix 8

Permission to reproduce the articles:

- *The use of non-pharmacological interventions for the comfort of patients in palliative care: a scoping review protocol;*
- *Use of non-pharmacological interventions for comforting patients in palliative care: a scoping review.*



The Joanna Briggs Institute  
Faculty of Health and Medical Sciences  
The University of Adelaide  
SA 5005, AUSTRALIA  
CRICOS Provider Number 00123M

22nd November 2017

Adriana Neves Coelho  
PhD student, MSc, RN  
Guest Assistant at the Nursing School of Coimbra (EsenfC).  
Research Collaborator at the Portugal Centre for Evidence-Based Practice (PCEBP): a Collaborating  
Centre of the Joanna Briggs Institute - Health Sciences Research Unit: Nursing (UICISA: E).

Telephone: +61 8 8313 4880  
Email: [jbi@adelaide.edu.au](mailto:jbi@adelaide.edu.au)  
Web: [www.joannabriggs.org](http://www.joannabriggs.org)

Dear Adriana,

**Re: Permission to reproduce JBI Systematic Review and Protocol in doctoral thesis.**

The Joanna Briggs Institute provides permission/non-exclusive licence for you to include in your doctoral thesis:

1. Coelho A, Parola V, Cardoso D, Escobar M, Apóstolo J. The use of non-pharmacological interventions for the comfort of patients in palliative care: a scoping review protocol. *JBI Database Syst Rev Implement Reports*. 2016;14(2):64-77. doi:10.11124/jbisrir-2016-2440.
2. Coelho A, Parola V, Cardoso D, Escobar M, Apóstolo J. Use of non-pharmacological interventions for comforting patients in palliative care: a scoping review. *JBI Database Syst Rev Implement Reports*. 2017;15(7). doi:DOI: 10.11124/JBISRIR-2016-003204.

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Sincerely,

Associate Professor Edoardo Aromataris  
Director, Synthesis Science  
Editor-in-Chief, *JBI Database of Systematic Reviews and Implementation Reports*  
The Joanna Briggs Institute




## Appendix 9

Permission to reproduce the article:

*Spanish version of the Hospice Comfort Questionnaire: Validation of a Comfort assessment scale for Palliative Care patients.*

Ref. MEDIPAL-D-16-00049R2: Consulta

 Adriana Coelho <eesserver@eesmail.elsevier.com>  
seg 17-11-2017 13:20  
Para: medicinapaliativa@elsevier.com  
Cc: adriana.nevescoelho@hotmail.com

Responder | v

Por favor, introduzca su nombre y su correo electrónico, y a continuación escriba su consulta. Cuando termine, haga clic en "Preview and Send".

Nombre:  
Correo electrónico:  
Consulta:

\*\*\*\*\*  
Please enter your name, e-mail address and query below, then click 'Preview and Send'.

Name:Adriana Coelho  
E-mail address:adriana.nevescoelho@hotmail.com  
Query:

Dear Dr. Editor,  
My name is Adriana Coelho I have an accepted manuscript in The Journal Medicina Paliativa entitled "Versión española del Hospice Comfort Questionnaire para evaluar el confort en pacientes en cuidados paliativos: Adaptación transcultural y validación. Spanish version of the Hospice Comfort Questionnaire: Validation of a Comfort assessment scale for Palliative Care patients".  
This study was part of my PhD in nursing science, which I intend to finish next December.  
I want to ask your permission (and also, Elsevier permission) to reproduce the article in my doctoral thesis. Is there a forecast date of publication of the article, to use the published version in the thesis?  
I appreciate your support and look forward to your authorizations.  
Regards,  
Adriana Coelho

Por favor, no modifique la información que aparece debajo de esta línea.  
Please do not modify the text below this line.

Autor de correspondencia: Miss Adriana Coelho  
Revista: Medicina Paliativa  
Título del artículo: Versión española del Hospice Comfort Questionnaire para evaluar el confort en pacientes en cuidados paliativos: Adaptación transcultural y validación. Spanish version of the Hospice Comfort Questionnaire: Validation of a Comfort assessment scale for Palliative Care patients  
Ref: MEDIPAL-D-16-00049R2

Ref. MEDIPAL-D-16-00049R2: Consulta [171117-008005]

 Medicina Paliativa <medicinapaliativa@elsevier.com>  
seg 20-11-2017 12:15  
Para: adriana.nevescoelho@hotmail.com

Responder | v

 How was our service today? 

Dear Dr. Coelho,

Thank you for your email.  
In relation to your query, we inform you that there is no problem in reproducing the article in your doctoral thesis.  
About the date of publication, given the high volume of manuscripts and the amount that is published by number, priority is given to the oldest ones so at this time we do not have a date for the publication of your article.

Best regards


Paz Fernandez  
Journal Manager  
ELSEVIER Global Journals Production EMEA/LA  
Tel +34 93 200 07 11  



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## Appendix 10

Permission to reproduce the Taxonomic structure of Comfort and Conceptual Framework for Comfort Theory.

 **Adriana Neves Coelho**  
ter 12-12, 00:30  
kathykolcaba@yahoo.com; Prof. Apostolo (apostolo@esenfc.pt) ✓

 Responder | v

Dear Dra. Kolcaba,

I hope this email finds you well.


I'm Adriana Coelho the PhD student of Prof. João Apóstolo.  
I'm writing to you, to request your permission to reproduce your diagrams about the conceptual Framework and Taxonomic structure of Comfort, on my PhD thesis, since I have a chapter about your theory.


Once again, thank you for your support in my journey.

Kind regards,

Adriana Neves Coelho

Request to reproduce your diagrams (Comfort theory)

 **Kathy Kolcaba**  
ter 12-12, 11:39

 | v

So glad to hear you are working with Dr. Apostolo. You have my permission to use or adapt or translate anything on my web site. Dr. Kolcaba

Dr. Kathy Kolcaba Associate Professor  
(Emeritus) The University of Akron  
[www.TheComfortLine.com](http://www.TheComfortLine.com)  
...



## Appendix 11

Permission to reproduce the article:

*The effects of guided imagery on comfort in palliative care.*

18/10/2018

Correio – Adriana Neves Coelho – Outlook

**Re: Permission to reproduce the paper -The Effects of Guided Imagery on Comfort in Palli...**

Ferrell, Betty <BFerrell@coh.org>

seg 08/10/2018, 16:24

Para: Adriana Neves Coelho <adriana.nevescoelho@hotmail.com>

Hello -

There should be no problem for you to include it. The publisher provides copyright permissions.

Congratulations on all your good work.

Betty Ferrell

Sent from my iPad

On Oct 8, 2018, at 4:46 AM, Adriana Neves Coelho <[adriana.nevescoelho@hotmail.com](mailto:adriana.nevescoelho@hotmail.com)> wrote:

---

[Attention: This email came from an external source. Do not open attachments or click on links from unknown senders or unexpected emails.]

---

Dear Dr. Betty Ferrell,

My name is Adriana Coelho and last August I published an article in The Journal of Hospice and Palliative Nursing entitled "The Effects of Guided Imagery on Comfort in Palliative Care".

This study is part of my PhD in nursing science, which I intend to finish next November.

I want to ask your permission (and also, Lippincott Williams & Wilkins permission) to reproduce the article in my doctoral thesis.

I appreciate your support and look forward to your authorizations.

Regards,

Adriana Neves Coelho

PhD student, MSc, RN

Guest Assistant at the Nursing School of Coimbra (ESEnFC).

Associate Research at the Portugal Centre for Evidence-Based Practice (PCEBP): A Joanna Briggs Institute Centre of Excellence - Health Sciences Research Unit: Nursing (UICISA: E).

---

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1/2





