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# COMFORT NEEDS OF THE PERSON IN PALLIATIVE SITUATION IN THE LAST DAYS OR HOURS OF LIFE: SCOPING REVIEW

# NECESSIDADES DE CONFORTO DA PESSOA EM SITUAÇÃO PALIATIVA NOS ÚLTIMOS DIAS OU HORAS DE VIDA: SCOPING REVIEW

# NECESIDADES DE CONFORT DE LA PERSONA EN SITUACIÓN PALIATIVA EN LOS ÚLTIMOS DÍAS U HORAS DE VIDA: REVISIÓN EXPLORATÓRIA

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# Abstract

**Introduction:** 90% of deaths occur during a chronic and progressive disease, making it possible to anticipate and prevent situations of suffering. The last days or hours of life correspond to the final phase of end-of-life, where the needs of the person in a palliative situation undergo significant changes. **Objective:** To map the comfort needs of the person in a palliative situation during the last days or hours of life. **Method:** Follows the Joanna Briggs Institute (JBI) methodology according to PRISMA-ScR. Guidelines. Research conducted in Medline Complete and CINAHL Complete databases. Articles in Portuguese, Spanish, and English from 2019 to 2024 were included. Inclusion criteria were defined based on Population, Context, and Concept (PCC) elements: (P) person in a palliative situation during LDHL, (C) palliative care, (C) comfort needs, to answer the question: what are the comfort needs of the person in a palliative situation during LDHL? **Results:** Fifteen articles were included in the study after analyzing the selected articles. Needs in the psycho-spiritual (n = 12) and socio-cultural (n = 12) contexts were the most mentioned, followed by the physical context (n = 10), with no results obtained for the environmental context (n = 0). The presence of significant people, the preference to die at home, emotional and spiritual support, communication/information, symptom control, especially pain, are some of the comfort needs highlighted in the three identified contexts. **Conclusion:** Mapping the comfort needs of a person in palliative care in UDHV contributes to the nurse's proactive intervention, providing holistic care that promotes a peaceful death.


**Keywords:** Comfort Needs; Last Days or Hours of Life; Palliative Care.


# Resumo

**Introdução:** 90% das mortes ocorrem no percurso de uma doença crónica e progressiva, sendo possível antecipar e prevenir situações de sofrimento. Os últimos dias ou horas de vida correspondem à última fase do fim de vida, onde as necessidades da pessoa em situação paliativa sofrem mudanças significativas. **Objetivo:** Mapear as necessidades de conforto da pessoa em situação paliativa nos últimos dias ou horas de vida. **Método:** Segue a metodologia de Joanna Briggs Institute (JBI) de acordo com as Guidelines do PRISMA-ScR. Pesquisa realizada nas bases de dados Medline Complete and CINAHL Complete. Incluídos artigos em português, espanhol e inglês, entre 2019 e 2024. Critérios de inclusão definidos, com base nos elementos da População, Contexto e Conceito (PCC): (P) pessoa em situação paliativa nos UDHV, (C) cuidados paliativos, (C) necessidades de conforto, para responder à questão: quais são as necessidades de conforto da pessoa em situação paliativa nos UDHV? **Resultados:** Analisados os artigos selecionados, foram incluídos quinze artigos no estudo. As necessidades nos contextos psicoespiritual (n = 12) e sociocultural (n = 12) foram as mais mencionadas, seguidas pelo contexto físico (n = 10), sendo que não foram obtidos resultados para o contexto ambiental (n = 0). A presença de pessoas significativas, a preferência por morrer em casa, o suporte emocional, espiritual, a comunicação/informação, o controlo sintomático, em especial a dor, são algumas das necessidades de conforto evidenciadas nos três contextos identificados. **Conclusão:** O mapeamento das necessidades de conforto da pessoa em situação paliativa nos UDHV contribui para a intervenção antecipada do enfermeiro, atendendo ao cuidado holístico, promotor de uma morte tranquila.


**Palavras-chave:** Cuidados Paliativos; Necessidades de Conforto; Últimos Dias ou Horas de Vida.


# Resumen

**Introducción:** El 90% de las muertes ocurren durante el curso de una enfermedad crónica y progresiva, lo que permite anticipar y prevenir situaciones de sufrimiento. Los últimos días u horas de vida corresponden a la fase final del fin de la vida, donde las necesidades de la persona en situación paliativa sufren cambios significativos. **Objetivo:** Mapear las necesidades de confort de la persona en situación paliativa durante los últimos días u horas de vida. **Método:** Sigue la metodología del Instituto Joanna Briggs Institute (JBI) de acuerdo con las directrices PRISMA-ScR. Investigación realizada en las bases de datos Medline Complete y CINAHL Complete. Se incluyeron artículos en portugués, español e inglés, entre 2019 y 2024. Se definieron los criterios de inclusión basados en los elementos de Población, Contexto y Concepto (PCC): (P) persona en situación paliativa durante los UDHV, (C) cuidados paliativos, (C) necesidades de confort, para responder a la pregunta: ¿cuáles son las necesidades de confort de la persona en situación paliativa durante los UDHV? **Resultados:** Se incluyeron quince artículos en el estudio después de analizar los artículos seleccionados. Las necesidades en los contextos psicoespiritual (n = 12) y sociocultural (n = 12) fueron las más mencionadas, seguidas por el contexto físico (n = 10), y no se obtuvieron resultados para el contexto ambiental (n = 0). La presencia de personas significativas, la preferencia por morir en casa, el apoyo emocional y espiritual, la comunicación/información, el control de los síntomas, especialmente del dolor, son algunas de las necesidades de confort evidenciadas en los tres contextos identificados. **Conclusión:** El mapeo de las necesidades de confort de la persona en situación paliativa en las UDHV contribuye a la intervención anticipada del enfermero, atendiendo al cuidado holístico, promotor de una muerte tranquila.


**Descriptores:** Cuidados Paliativos; Necesidades de Confort; Últimos Días u Horas de Vida.

# Introduction

It is estimated that only 1 in 10 people worldwide who need palliative care receive it, and demand is expected to double by 2060[1]. In Portugal, the ageing index shows a ratio of 181.3 elderly people for every 100 young people, and the average life expectancy is 80.72 years, which places us as the seventh most aged country in the world and, by 2050, it is predicted to be the second[2]. Associated with the increase in population ageing is a higher prevalence of chronic and progressive diseases, with the onset of frailty, multimorbidity, functional dependence and cognitive decline, with thousands of people each year reaching the end of their lives[3]. Alongside technological development, there will be greater longevity, which justifies a greater need for CP for an equally longer period, ideally supported by specialised care based on scientific evidence[4].

In 90% of people, death occurs in the course of a chronic disease in which it is possible to identify evolutionary stages[5]. UDHVs correspond to the last phase of the end-of-life journey and are part of the subgroup of patients in palliative and terminal situations[6]. It can be difficult to define the concept due to each person's individual patterns[7], however, the definition adopted here refers to UDHV as the period usually occurring between 12-14 days prior to death, which may be longer in young people. It is a physiological phase that follows advanced chronic illness and the causes are irreversible[8], where there is functional decline with the appearance of new symptoms and/or worsening of existing ones[9]. At this stage, the needs of the patient and family undergo significant changes, which requires the organisation of care that promotes a peaceful death and healthy mourning[10]. The aim is to achieve the greatest possible comfort and well-being for the terminally ill person so that the process of dying takes place with respect for human dignity[11].

In the search for a consensus among experts on the definition of good end-of-life care, it was concluded that it should provide for death in the person's chosen location, without pain, with respect for their dignity and with the best possible care[12]. However, the reality still falls short of what is desired. The place of death is mainly the hospital, and the trend is set to continue to increase until 2030, particularly among the elderly over 85 years of age[13,14]. This reality has contributed to the removal of death from a humanised setting, as the hospital environment is often unprepared and ill-equipped to meet this request[15], where the needs of patients requiring palliative care are overlooked, as they go against the culture of institutions geared towards acute illnesses, whose motto is to treat and give life[13]. This should not be considered a minor phase of disinvestment and withdrawal by the clinical team. On the contrary, UDHV requires intensified care that is ethically appropriate and clinically specific[9].

Regardless of the diagnosis, palliative care focuses on the needs of the patient/family, as defined in Law No. 52/2012 of September 5.

As nurses are the health professionals closest to the patient and family, they should be responsible for assessing patients' needs and ensuring their comfort[7]. Katharine Kolcaba's Theory of Comfort (1991, 2003) is taken as a reference for nursing, where the concept of comfort is defined as the immediate experience of being strengthened through the satisfaction of the needs for relief, tranquillity and transcendence in four contexts: physical, psycho-spiritual, socio-cultural and environmental[16,17].

In this sense, a preliminary search was conducted in the PubMed database, JBI Evidence Synthesis[18], OSF and PROSPERO, and no similar scoping review was found, either completed or with a registered protocol. This scoping review aims to map the comfort needs of people in palliative situations in UDHVs.

# Method

This scoping review study was conducted in accordance with the JBI methodology[18,19], and the research strategy and analysis of articles were based on the guidelines for systematic reviews and meta-analyses: PRISMA-ScR[20].

This scoping review was prospectively registered in the Open Science Framework, and its protocol is available at https://doi.org/10.17605/OSF.IO/9QUNC

### Selection criteria

The eligibility criteria were determined based on the elements of Population, Context, and Concept (PCC), in accordance with the guiding principles of the Joanna Briggs Institute[18]. In this sense, the research question was constructed: What are the comfort needs of PSP in UDHV?

Population: People in palliative care, with incurable, progressive and terminal illness, aged 19 or over, in UDHVs.

Concept: Comfort needs (expressed by the patient, family, or observed by the nurse);

Context: Palliative Care (Home, Hospitals, Nursing Homes, Palliative Care Units, Primary Health Care, others).

People under the age of 19 were excluded from the analysis, as were contexts other than palliative care. All articles unrelated to comfort needs, with a defined objective, and opinion pieces or editorials were excluded. This review includes studies with qualitative, quantitative, and mixed designs and also encompasses other systematic reviews conducted previously, with a time limit of the last 5 years.

### Search strategy

Considering the Peer Review of the Electronic Search Strategies (PRESS) checklist[21], two authors developed the search strategy, which was validated by a third author.

The following electronic databases were used in the search: MEDLINE and CINAHL Complete (both via EBSCOhost), retrospectively from January 2019 to October 2024. The search was conducted in October 2024 using keywords and respective descriptors validated in Medical Subject Headings (MeSH) and CINAHL Complete. Studies written in English, Portuguese, and Spanish were analysed to ensure a high-quality selection and data extraction procedure. The search strategy used is presented in Table 1.

**Table 1: MEDLINE (EBSCOhost) and CINAHL Complete search strategy.**

| Search in 9/10/2024 | CINAHL descriptors | MEDLINE descriptors |
|---|---|---|
| S1 | (MH "Terminally Ill Patients") OR (MH "Hospice Patients"). | (MH "Terminally Ill"). |
| S2 | (MH"Needs Assessment") OR (MH "Health Services Needs and Demand") OR (MH "Human Needs (Psychology)") OR (MH "Human Needs (Physiology)") OR (MH "Patient Preference"). | (MH "Needs Assessment") OR (MH "Health Services Needs and Demand") OR (MH "Patient Preference"). |
| S3 | (MH "Palliative Care") OR (MH "Hospice Care") OR (MH "Terminal Care") OR (MH "Hospice nursing") OR (MH "Palliative Medicine"). | (MH "Palliative Care") OR (MH "Hospice Care") OR (MH "Terminal Care") OR (MH "Palliative Medicine") OR (MH "Hospice and Palliative Care Nursing"). |
| S4 | S1 AND S2 AND S3. | S1 AND S2 AND S3. |
| S5 | S4<br>Limiters — publication date: 2019.01.01 – 2024.31.12 | |

### Article selection process and eligibility criteria

All documents were selected based on their title and abstract, taking into account the objective defined for the scoping review, as well as the selection criteria explained. Duplicate articles were eliminated using the Mendeley® 19.4 tool (Mendeley Ltd., Elsevier, Amsterdam, The Netherlands). Data were extracted and systematised as follows: author(s), year of publication, country of origin, objective, type of study, study population, sample composition, care context, and results. Disagreements regarding the inclusion or exclusion of articles were resolved through discussion and consensus among the researchers. Studies that met the selection criteria were read in full and evaluated in detail according to the criteria mentioned above.

# Results

## Characteristics of the included studies, context, and population

The search strategy retrieved 211 articles, of which 5 were excluded because they were duplicates in the databases. In the next step, 206 articles were analysed based on the titles and abstracts, which led to the exclusion of 147 articles. Fifty-nine articles were considered eligible for full-text reading, of which 44 were excluded because they did not answer the research question. The final sample of this scoping review comprises 15 articles, which were read in full and analysed descriptively according to the previously established criteria. Figure 1 illustrates the selection process and final inclusion of studies.

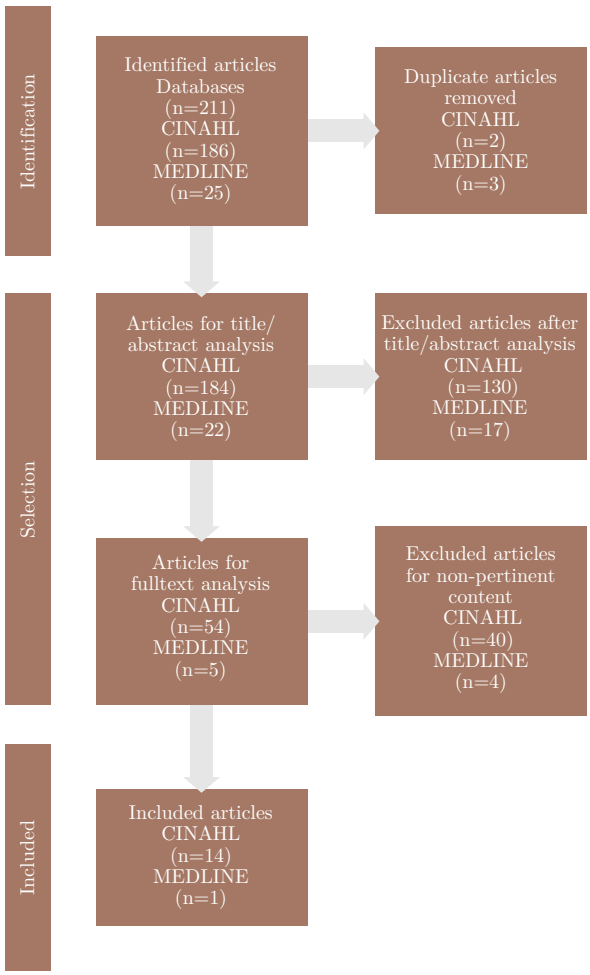


Figure 1: PRISMA flowchart of the article selection process.

The 15 articles included are all international, originating from 12 countries: United States of America two – one in partnership with Lebanon and the other with the Netherlands; Canada and Spain, with two studies each; Australia, China, Bhutan, Korea, India, Ireland, Mozambique, Singapore, and Switzerland with one study each. The studies were published between 2019 and 2024 in various international journals in English.

Taking into account the different study designs included, it is possible to verify that qualitative studies predominate (n = 11), followed by quantitative studies (n = 4).

The context in which the studies were conducted is diverse, including: hospitals (n = 2), homes (n = 3), residential palliative care units (n = 2), and unspecified contexts (n = 5). In three articles, the study was conducted in more than one context.

Regarding the population, most of the articles included reflect the perspective of the person in palliative care (n = 14), together with third parties or not. It was also found that the identification of the comfort needs of people in palliative care in UDHVs is done through the perception of other participants, such as health professionals (n = 1). All studies encompass adults in palliative care, with oncological pathology being the predominant condition (n = 6), followed by patients with non-oncological pathology (n = 3), studies encompassing both oncological and non-oncological patients (n = 1), and studies that do not specify the pathology of the population (n = 5).

Regarding the concept, the comfort needs mapped fall into three of the four comfort contexts cited by Kolcaba[17], with needs in the psycho-spiritual (n = 12) and socio-cultural (n = 12) contexts being the most mentioned, followed by the physical context (n = 10), with no results obtained for the environmental context (n = 0). The results by context are shown in the summary table of results by context (Table 2).

**Table 2: Summary of results by context.**

| Contexts | Summary of results |
|---|---|
| Psycho-spiritual (22,25,27,28,29,30,31,32,33,34,36) | – Effective communication of emotions related to illness, dependence, and death, as well as concerns, preferences, and feelings.<br>– Feeling listened to.<br>– Need for information about diagnosis and prognosis.<br>– Need for respect, preservation of dignity, and autonomy.<br>– Need for healthcare professionals to be kind, friendly, competent, and attentive, to be open to talking about the approach of death, and to promote a person-centered approach, maintaining quality care until death.<br>– Care and protection of identity, roles, and purpose in life, as well as self-image and self-esteem, seeking distractions, or maintaining emotional and social relationships.<br>– The need to discover one's purpose in life and the importance of achieving inner peace for spiritual comfort.<br>– Living in the present/enjoying every moment until death.<br>– Maintaining hope.<br>– Respect for self-determination, the right to knowledge, and the prospect of a good death.<br>– Confirming needs and unfinished business.<br>– Validating beliefs and faith, and the availability of religious services.<br>– Religious and spiritual guidance and practice to receive emotional support from God or a Higher Power.<br>– Resilience and reconciliation with God, others, and oneself to resolve internal conflicts or conflicts with others.<br>– Closeness to a supreme power (strong belief in praying to God) and spiritual growth.<br>– Availability of space for the construction of existential meaning. |
| Sociocultural (22–25,27–31) | – Consideration for family histories, traditions, language, clothing, and customs.<br>– Respecting the preferred place of death for people in palliative care, with home being the most commonly requested location.<br>– The family's ability to provide care without overburdening the caregiver.<br>– A relationship of trust between the patient/family and healthcare professionals.<br>– Meeting the quality of care.<br>– Need for more professionals and more teams in community palliative care services.<br>– End-of-life needs, to enable the person to remain at home (in order of importance): management of physical symptoms and management of loss and grief (equally important); coordination between members of the care team; coordination between family and friends; management of death (e.g., desire to remain at home until death); psychological support; support with basic needs and spiritual care.<br>– Need to establish an advance care plan.<br>– Need to maintain the social relationships of the person in UDHV with family, friends, and other significant people, such as healthcare professionals, as social contact allows for communication, self-esteem, and identity to be maintained.<br>– Need for financial support from the family. |
| Physical (22,25,27,28,29,31,34,36) | – Need for symptom control, distinct from other physical needs, with pain being the most commonly specified symptom.<br>– Need for hygiene care, oral care, or grooming.<br>– Need to maintain physical activity, independence, or the ability to self-care.<br>– Need for technical aids for walking as the disease progresses and mobility changes.<br>– Need to address preferences for managing urinary and fecal incontinence.<br>– Need for quality sleep and rest.<br>– Respecting the preference for comfort care over life-sustaining measures, preventing pain and discomfort.<br>– Importance of knowing the prognosis, clarifying wishes regarding life-prolonging measures, and respecting advance directives. |

### Data presentation

The summary of the characteristics of the included studies, such as authors, year of publication, country of origin, objective, type of study, study population, sample composition, care context and results, can be found in the data extraction table (Table 3), providing an easier understanding of the main information contained therein.

# Discussion

The comfort needs of people in palliative care in UDHVs fall into three of the four contexts of comfort according to Kolcaba's theory[17]: psycho-spiritual, socio-cultural, and physical. For the discussion of the data obtained, we chose to analyse and organise them according to the predominance of articles addressing each context, in descending order:

### Needs arising in the psycho-spiritual context

Psycho-spiritual comfort combines mental, emotional and spiritual components. It is what gives meaning to life, which implies self-esteem, self-concept, sexuality and the relationship with a higher being or order[17]. The results are grouped into two broad categories: one psychological and emotional, and the other spiritual.

The authors Laabar *et al*[30], López-Salas *et al*[31] and Wajid *et al*[32] report on psychological and emotional needs in their studies and include the possibility of support at these levels[30-32] in order to mitigate loneliness or isolation during the process[33]. The same authors[31,32] and Wang *et al*[22] add that effective communication of needs and emotions[22,31,32] related to illness, dependence and death[31,32], as well as concerns, preferences and feelings, constitute psychological and emotional needs that contribute to the comfort of people in palliative care in UDHVs. Also in this context, the research by Cithambarm *et al*[28] and Garcia-Navarro *et al*[33] highlights the importance of maintaining hope as a psychological and emotional need[28,33]. Garcia-Navarro *et al*[33] and Lewis *et al*[25] illustrate, as a need for comfort for people in palliative situations in UDHVs, the need to feel listened to[25,33], in order to clarify desires or demands regarding the disease, care and measures to prolong life[27] and to be able to maintain communication with one's spouse[29]. Wang *et al*[22], Lewis *et al*[25], Lee, J. *et al*[27], Laabar *et al*[30] and Geerse *et al*[34] evoke in their studies the need for information about diagnosis and prognosis[22,25,27,30,34] and that this information should be accurate and reliable in order to support decision-making[31], since knowing how much time they have left allows them to make important decisions about

**Table 3: Systematization of studies included in the Scoping Review.**

| | Article title | Authors/Year/Country | Participants | Type of Study | Objectives | Results/Conclusions |
|---|---|---|---|---|---|---|
| E1 | Development and Validation of the Home Hospice Care Needs Questionnaire for the Dying Old Adult (HHCNQ-DE) in Mainland China. | Wang *et al*[22]. 2024. China. | 199 cancer and non-cancer patients at the end of life, in a home setting. | Qualitative: Harmony Nursing Theory, Home Hospice Care Needs Scale, bibliographic research (conversations with adults at the end of life, group discussions among the research team, predictive questionnaire — 31 items). | Develop and validate the instrument for assessing the palliative needs of terminally ill individuals in the home setting among the Chinese population. | The authors report the following results:<br>– Physical needs: symptom control (especially pain) and daily living care (eating and sleeping).<br>– Psychological needs: communication of emotions.<br>– Spiritual needs: discovering the purpose of life and achieving inner peace; living in the present; maintaining hope and looking forward to a good death; respect for self-determination.<br>– Information needs: from family and healthcare professionals.<br>– Most of the Chinese population believes that the best place to die is at home, emphasizing the idea that "fallen leaves return to their roots." |
| E2 | Preferred place of death for patients with terminal illness: A literature review. | Yamout *et al*[23]. 2021. Lebanon/EUA. | 22 studies included, with participants aged >18 years, in end-of-life situations, based on preferences identified by patients, caregivers, and healthcare professionals. | Qualitative: literature review. | To analyze the preference for place of death among people in end-of-life situations and highlight the factors that contribute to this decision. | The authors report that the preferred place to die is at home, followed by hospitals, hospices, nursing homes, or palliative care units. The authors raise issues related to: the patient's quality of life, the family's ability to care for them, concerns about being a burden to the caregiver, relationships with healthcare professionals, and the quality of care. |
| E3 | Impact on place of death in cancer patients: a causal exploration in southern Switzerland. | Kern *et al*[24]. 2020. Switzerland. | 116 participants with cancer in the end-of-life stage and their families; 14 of whom had a Karnofsky Performance Status between 10-60%; in a hospital, at home, or in a nursing home. | Quantitative: (development of an application using artificial intelligence). | Identify predictors and favorable patterns for death to occur in a home environment. | The authors note that home is the preferred place to receive end-of-life care and die, but acknowledge that death mostly occurs in hospitals and that preferences are often only addressed close to death, which reinforces the need to establish an advance care plan. |
| E4 | End-of- life priorities of older adults with terminal illness and caregivers: A qualitative consultation. | Lewis *et al*[25]. 2019. Australia. | 24 participants: 10 individuals in end-of-life situations, other than cancer; 14 caregivers. Interviews conducted in the home setting with non-oncological patients (n = 6). Focus groups: conducted with patients and caregivers at a university institution (n = 18). | Qualitative: interviews and focus groups. | Explore the experience of the terminally ill patient and caregiver, as well as identify the factors considered important for the quality of end-of-life care. | The authors mention six topics related to the patient:<br>– Quality of life: not prolonging death; respecting advance directives.<br>– Sense of control: being heard; preserving dignity.<br>– Need for support from the healthcare system: navigating the healthcare system.<br>– Being at home: remaining at home for as long as possible; involving the patient in the decision; discussing realistic options.<br>– Talking about death: openness to talk about the proximity of death, honesty, and transparency between patients, families, and healthcare professionals; (patients more reluctant than family members).<br>– Competent and attentive healthcare professionals: person-centered approach; professionals with a compassionate, respectful approach that ensures the dignity of the person. |
| E5 | End-of-Life Preferences and Priorities of Community Dwelling Mozambicans: An Evaluation of Measurement Tools. | Heller[26]. 2024. Mozambique. | Patients at the end of life. | Qualitative: Literature review. | Assess preferences at the end of life. | The results reveal the comfort needs of people at the end of life:<br>– The comfort of the family above individual comfort; A preference for prolonging life;<br>– The hospital as the preferred place to die, as it is the place that has the most resources to prolong life. |
| E6 | Care Needs of Patients at the End of Life With a Noncancer Diagnosis Who Live at Home. | Lee, J. *et al*[27]. 2019. South Korea. | 49 nurses specializing in home care responded to the questionnaires. Review of 115 clinical records of people with chronic non-cancerous diseases who received home care between the stable phase and the end-of-life phase; deceased between 09/2014 and 12/2015. Initial phase: first week after the start of home care; Stable phase: second week after the start of home care until one week before the patient's death; End-of-life phase: week before death. | Quantitative: review of clinical records and questionnaires for nurses specializing in home care. | Assess the physical, psychological, social, and spiritual care needs of people with chronic, non-cancerous diseases who received home care, considering the end-of-life phase, from the perspective of nurses specializing in home care.<br>It also aims to identify the importance of patient-centered needs and the difficulties inherent in the care process. | The authors highlight the conditions that make it possible to remain at home, responding to eight areas of care needs in the end-of-life phase, in order of importance ("management of physical symptoms," "management of loss and grief," of equal importance):<br>– Management of physical symptoms: dyspnea is the symptom requiring the most care, followed by dysphagia, skin changes, digestive tract symptoms, and fluid balance, diet, and nutritional status, with equal weight; followed by control of fever or symptoms of infection; pain control; and finally, causes of fatigue and other symptoms of physical suffering.<br>– Loss and grief: family agreement on the management of death.<br>– Coordination between care team members: possibility of making emergency calls; family's ability to care; patient/family understanding of treatments; patient/family understanding of medical devices and how to handle them.<br>– Coordination between family and friends: health status of the family caregiver; knowledge and skills of the caregiver; roles of the primary caregiver and the decision-maker in the family and their ability to coordinate care.<br>– Death management: the patient's desire to remain at home until death; the patient's/family's understanding of the progression of the disease; confirming where they want to die; fear and anxiety about death and the worsening of the disease; clarifying wishes about the disease and measures to prolong life.<br>– Psychological support: confirming the patient's wishes and requirements regarding treatment and care.<br>– Support with basic needs: changes in urinary/bowel elimination; personal hygiene; ability to self-care in activities of daily living.<br>– Spiritual care: confirmation of the patient's needs and unfinished business; beliefs or faith; loneliness due to loss of personal relationships; validation of living will; spiritual suffering or pain due to feelings of meaninglessness. |
| E7 | What constitutes good quality end-of-life care? Perspectives of people with intellectual disabilities and their families. | Cithambaram *et al*[28]. 2021. Ireland. | 11 patients with mild to moderate intellectual disabilities at the end of life and 8 family members.<br>Context: residential institution for people with intellectual disabilities. | Qualitative: Grounded theory (approach with 19 semi-structured individual interviews). | Identify the care needs of people with intellectual disabilities at the end of life. | The authors refer to the importance of staying at home until death and highlight the following needs:<br>– Personalized attention: physical care—due to increased dependence (maintaining daily routines of personal hygiene, oral hygiene, incontinence management, and feeding); increased supervision (attention, support from doctors and nurses; on the other hand, respecting those who want to be alone).<br>– Social contact (in order to maintain self-esteem and identity): meaningful company (family, friends, and caregivers—holding hands, touching) and maintaining communication (talking about concerns and feelings; listening to professionals so they can ask questions and clarify care issues)—hope.<br>– Spiritual reconciliation: prayers by others and by the terminally ill person themselves; the search for inner peace; reconciliation with God, with others, or with oneself to resolve conflicts with oneself or with others. |
| E8 | Physical, psychological, social, and spiritual aspects of end-of-life trajectory among patients with advanced cancer: A phenomenological inquiry. | Lee, G. L. & Ramaswamy[29]. 2020. Singapure. | 11 participants: with terminal cancer with a prognosis of < 6 months in 3 stages of the disease trajectory:<br>– Initial stage: participants newly enrolled in the home palliative care program;<br>– Intermediate stage: worsening of the disease;<br>– Final stage: last days before death.<br>(The data extracted from the study correspond to the final stage) | Qualitative: phenomenological research (with semi-structured serial interviews over time, in three stages:<br>– Initial stage;<br>– Intermediate stage;<br>– Final stage. | To understand how participants gave meaning to their experiences, integrated them psychologically into their lives and relationships with others, and how their needs evolved throughout the disease. | The results of the study show:<br>– Psychosocial care (consisting of psychological, social, informational, communication, and spiritual needs).<br>– Maintaining close personal relationships.<br>– Maintaining daily activities as a need for comfort.<br>– Managing decline and loss in relation to the strong bond with life among older adults.<br>– Support from siblings for car rides and financial support;<br>– Social support from friends is a blessing for living well and passing the time easily.<br>– Technical aids for moving around the house as the disease progresses and mobility changes.<br>– Emotional support: support from spouse and siblings; ability to maintain communication with spouse; mere physical presence of spouse.<br>– Spiritual aspects of the end-of-life journey: hope for taking short trips; leaving the house; having someone who understands what you are going through emotionally; dying at the right time; "talking to God"; emotional support from God or a Higher Power; availability of space for the construction of existential meaning. |
| E9 | Palliative care needs among patients with advanced illnesses in Bhutan. | Laabar *et al*[30]. 2021. Bhutan. | 70 participants with advanced disease and some in a UDHV situation.<br>Context: Admission to 2 regional hospitals, 1 district hospital, 1 basic health unit. | Quantitative: descriptive cross-sectional. | Explore palliative care needs among patients with advanced diseases. | The results highlight the following needs:<br>– Physical: control of physical and dietary symptoms.<br>– Psychological and emotional: psychological, emotional, and cognitive support.<br>– Spiritual: spiritual support.<br>– Financial support.<br>– Information: about the diagnosis, treatment options, and side effects. |
| E10 | End-of-life care needs in cancer patients: a qualitative study of patient and family experiences. | López-Salas *et al*[31]. 2024. Spain. | Cancer patients at the end of life (n = 3) and family caregivers of patients at the end of life who have experienced bereavement (n = 12). | Qualitative: semi-structured interviews. | To deepen knowledge about the needs of terminal cancer patients who are close to death. | The authors highlight the following needs of patients approaching death:<br>– Physical well-being, from the assessment and control of symptoms—pain and adverse effects of medication. Sleep and rest, as well as cleanliness and personal hygiene. Nutrition, which includes adapting diet and eating habits to alleviate weight gain or lack of appetite, and maintaining physical activity.<br>– Emotional well-being, which involves monitoring well-being, addressing emotional needs related to illness, dependency, and death, as well as having access to assistance to express and communicate these needs effectively. Emotional well-being also encompasses seeking distractions, the need for care and protection of one's identity, roles, and purpose in life, as well as one's self-image and self-esteem, maintaining emotional and social relationships, spending quality time with loved ones, and obtaining support to engage in rewarding activities, such as hobbies and everyday pleasures.<br>– Information and autonomy in decision-making, based on accurate and reliable information, whereby informed decision-making is associated with the desire to ensure the inclusion and autonomy of the patient in decisions made throughout the end-of-life period, as well as to satisfy their wishes and preferences.<br>– Social well-being, which involves being able to afford technical and/or orthopedic and prosthetic devices, as well as professional care, personal space, mobility at home, and a vehicle for transportation. |
| E11 | What enhances the quality of death and dying? A perspective from patients with terminal cancer. | Wajid *et al*[32]. 2024. India. | 21 cancer patients at the end of life, in two hospices and one hospital. | Qualitative: prospective study (semi-structured interviews and content analysis). | To determine what participants consider necessary for a good quality death and how they would like to be cared for at the end of life. | The results highlight that spirituality and religion enable involvement in spiritual and religious activities, as well as closeness to a supreme power (strong belief in praying to God).<br>The results also highlight social and emotional support, from having the possibility of emotional venting, moral and emotional support, and empathy.<br>They also emphasize the importance of breaking the silence about the stage of the disease, that is, talking about the disease and what will happen, as well as preparing for death, from preparing to accept death (mostly through internal resources and less dependence on others) to the need for medical care (continuity of quality care until death). |
| E12 | How to manage the suffering of the patient and the family in the final stage of life: A qualitative study. | García-Navarro *et al*[33]. 2023. Spain. | 36 participants: 16 patients at the end of life and 20 family members, integrated into the Process of Integrated Palliative Care Attention. | Qualitative: content analysis of semi-structured interviews and focus groups. | Identify what patients and families need during the end-of-life process to feel effectively supported during this period. | The results show the following needs:<br>– Presence: real companionship to mitigate loneliness and isolation rather than "accompanied loneliness."<br>– Communication: conspiracy of silence is a barrier. It is essential to express preferences and concerns; overcome taboos and fears related to the dying process; open communication between patient, family, and healthcare professionals.<br>– Spiritual support: space for reflection and the search for meaning in life; feeling accompanied by healthcare professionals, family, and friends; resilience and reconciliation; spiritual growth (better understanding of life and death, strengthening of beliefs and religious practice, or greater connection with the world and others); farewell.<br>– Emotional support (due to fear and uncertainty about the moment of death and the possibility of causing suffering to family members): feeling listened to by family members or healthcare professionals; avoiding feelings of isolation; religious practice; saying goodbye.<br>– Autonomy: deciding on the place of care; active participation in care; planning the process of dying (will and final wishes).<br>– Dignity and respect (need to receive personalized and humanized care): preservation of privacy and intimacy; avoiding therapeutic obstinacy. |
| E13 | A qualitative study of serious illness conversations in patients with advanced cancer. | Geerse *et al*[34]. 2019. EUA/The Netherlands. | 25 participants: cancer patients (some at the end of life) receiving treatment at the Dana-Farber Cancer Institute. | Qualitative: (analysis of conversations about serious illnesses, recorded on audio, using an evidence-based guide). | Characterize the content of conversations about serious illnesses and identify opportunities for improvement. | The study highlights the following results:<br>– Dealing with the end of life and death with dignity.<br>– Preference for being with family, if they provide good support and are not an emotional or financial burden.<br>– Not being subjected to invasive means of artificial life support.<br>– Need for information. |
| E14 | A prospective study with patients and families on the usefulness of accurate prognosis for palliative care patients. | Piovesan *et al*[35]. 2024. Canada. | 285 patients with and without cancer, in a Palliative Care Residence, and their families. | Quantitative: prospective study of patients admitted to a Palliative Care Residence. (Application of a short questionnaire during the first week of admission, over a year between June 2021 and June 2022). | Analyze the importance/usefulness of patients and families having an accurate prognosis and its impact on planning activities before death. | The results showed that patients (and their caregivers) want to know how long they have left to live so they can prepare for death and make important decisions about care, which, in order of importance, involve: facilitating communication and end-of-life decisions, planning visits, setting and achieving pre-death goals, and preparing for the funeral.<br>The authors emphasize that patients may have conflicting needs regarding prognostic information, wanting doctors to be both hopeful and honest. |
| E15 | Bladder and bowel preferences of patients at the end of life: a scoping review. | Smith *et al*[36]. 2020. Canada. | Four studies included participants at the end of life, of both sexes, with or without incontinence prior to admission to hospital, nursing home, or community setting (including hospice). | Qualitative: Scoping review. | Identify preferences for bladder and bowel care in patients at the end of life. | The study results identify dignity and autonomy: having a sense of control and self-determination and greater involvement in end-of-life decision-making.<br>Management of urinary and fecal incontinence. |

their care and set goals prior to death[35]. The research by Lewis *et al*[25]; Garcia-Navarro *et al*[33]; Geerse *et al*[34] and Smith *et al*[36] also highlights the need for respect, preservation of dignity and autonomy[25,33,34,36] in various forms, including through the guarantee of privacy and intimacy, the ability to decide on the place of care, avoiding therapeutic obstinacy, planning the process of dying, particularly in the form of a will and final wishes[33], shared decision-making[31,33,36], and the fulfilment of wishes and preferences[31], which contributes to a sense of control[25,36]. With regard to healthcare professionals, Lewis *et al*[25] point out the need for them to be kind, friendly, competent and attentive[25], through their openness to talk about the proximity of death and to promote a person-centred approach[25], maintaining quality care until death[32]. In this sense, in the research by Piovesan *et al*[35], the authors add that information about the prognosis and what will happen throughout the disease is desired, but it is also desired that healthcare professionals give hope[35]. García-Navarro *et al*[33] point to the conspiracy of silence as a barrier to open and effective communication of feelings and emotions. To mitigate loneliness or isolation, felt at the end of life, the presence of others increases in importance at this stage, with mere physical presence, referred to as "accompanied loneliness", not being enough; rather, it is important to feel truly accompanied[33]. Conversely, research by Lee, G. L. *et al*[29] shows that the mere physical presence of a spouse is sufficient to provide emotional support[29]. López-Salas *et al*[31] add to emotional well-being the needs for care and protection of identity, roles and purpose in life, as well as self-image and self-esteem, and the search for distractions or maintaining emotional and social relationships[31].

As for spiritual needs, which encompass religious and spiritual practice, research by Wang *et al*[22]; Lee, J. *et al*[27]; Cithambarm *et al*[28] and Garcia-Navarro *et al*[33] demonstrates a variety of ways that contribute to spiritual comfort, from discovering the purpose of life and the importance of achieving inner peace[22,27,28,33], to living in the present, enjoying every moment until death[22] and maintaining hope[22], for example, to take short trips or leave home[29]. Wang *et al*[22] add that spiritual needs, capable of contributing to spiritual comfort, also involve respect for self-determination, the right to knowledge and the prospect of a good death[22]. In this context, Lee, J. *et al*[27] mention that confirming needs and unfinished business[27], as well as validating beliefs and faith[27], and confirming living wills[27], are also spiritual needs. The authors Wajid *et al*[32] and García-Navarro *et al*[33] further argue that spiritual needs involve the availability of religious services and support, religious and spiritual practice[32,33], as well as the capacity for resilience[33], farewell[33] and reconciliation[33] with God, with others and with oneself, to resolve internal conflicts or conflicts with others. In this sense, the studies by Cithambarm *et al*[28], Lee, G. L. *et al*[29] and Wajid *et al*[32] illustrate, as spiritual needs, the importance of prayers by others or oneself[28] to receive emotional support from God or a Higher Power[29], to draw closer to a supreme power (strong belief in praying to God)[29,32], with a view to spiritual growth and, naturally, the availability of space for the construction of existential meaning[29], reinforcing spiritual comfort.

### Needs arising in the sociocultural context

According to Kolcaba[17], sociocultural comfort refers to the satisfaction of needs such as interpersonal, family and social relationships, where nurses can be the primary source of social support if the patient lacks or is limited in this regard. At the cultural level, consideration is given to family histories, traditions, language, clothing, and customs.

In the research by Wang *et al*[22], Yamout *et al*[23], Kern *et al*[24] and Lewis *et al*[25], it is found that the main evidence concerns the preferred place to die for people in palliative care, with the home being the most frequently mentioned place[22–25].

The hospital is mentioned only by Heller[26] as the preferred place to die.

The same author[26] adds that in certain African cultures, family comfort takes precedence over individual comfort, and also, since the hospital is the place that has the most resources to prolong life, it becomes the first choice[26]. In the study by Yamout *et al*[23], the authors identified a hierarchy of preferences: if it is not possible to remain at home, the hospital or hospice emerges as the second option, due to quick access to equipment or medical care. Nurs-

ing homes or palliative care units emerge as the last options, with nursing homes being pointed out as unsafe places[23]. The same authors[23] raise issues related to: the patient's quality of life, the family's ability to care for them, concern about being a burden on the carer, relationships with healthcare professionals and the quality of care. In this context, Geerse *et al*[34] reinforce the preference for being with family, if they have good support and are not an emotional or financial burden. Similarly, Lee, J. *et al*[27] and Cithambarm *et al*[28] consider the condition of remaining at home until death. Based on its cultural influence, the study by Wang, *et al*[22], conducted in China, illustrates how relevant the idea that "fallen leaves return to their roots" is[22]. In this study[22], most Chinese elderly people believe that the best place to die is at home, and as such, community palliative care services have been established. However, this requires more professionals and more teams to respond to growing demands, given the ageing population, which is an obstacle to meeting this need[22].

Lee, J. *et al*[27] also illustrate the conditions that make it possible to remain at home by responding to eight end-of-life needs (in order of importance): management of physical symptoms and management of loss and grief (equally); coordination between members of the care team (e.g., being able to make emergency calls or easily contact professionals); coordination between family and friends; death management (e.g., desire to remain at home until death); psychological support; support for basic needs; and spiritual care. In this context, Kern *et al*[24] recognise that although the preferred place to die is at home, death mostly occurs in hospital and preferences are often only addressed close to the time of death, which reinforces the need to establish an advance care plan[24].

Cithambarm *et al*[28] demonstrate the need to maintain the social relationships of people in palliative care in UDHVs, whether with family members, friends, other significant people (such as health professionals), or the mere presence of others. The same authors[28] emphasise that social contact allows communication, self-esteem and identity to be maintained[28], with the support of friends seen as a blessing for living well and passing the time easily. Lee, G. L. *et al*[29], in their study, mention that the support of siblings is considered necessary for car travel and financial support[29]. Laabar *et al*[30] and López-Salas *et al*[31] also highlight social well-being, such as being able to pay for professional care, technical and/or orthopaedic devices[30,31]. Furthermore, as comfort needs in the sociocultural context, in the research by Piovesan *et al*[35], the authors demonstrate that patients and their carers want to know how long they have left to live, so that they can plan visits, fulfil pre-death goals and make funeral arrangements.

### Needs arising in the physical context

Physical comfort refers to bodily sensations and homeostatic mechanisms that may or may not be related to a diagnosis. This context includes the satisfaction of bodily needs such as hygiene, positioning, and symptom control[14,15].

Wang *et al*[22], Lee, J. *et al*[27] and López-Salas *et al*[31] illustrate that the need for symptom control stands out from the rest and that pain is the most specified symptom[22,27,31]. However, in the study by Lee, J. *et al*[27], the authors add that when symptoms are ranked in the context of home care, dyspnoea emerges as the symptom requiring the most care, followed by dysphagia, skin changes, digestive tract symptoms and fluid and food intake management. This is followed by fever or symptoms of infection, pain and, finally, causes of fatigue and other sources of physical suffering. The same author[27] emphasises that the need to manage physical symptoms is considered to be of greater importance when compared to others[27].

Lee, J. *et al*[27], Cithambarm *et al*[28] and López-Salas *et al*[31] state that other needs arise in the physical context, ranging from those related to personal hygiene, oral care or grooming[27,28,31]. The same authors[27,31] point out that the needs of the physical context include maintaining physical activity, independence, and the ability to self-care[27,31]. Wang *et al*[22] and Cithambarm *et al*[28] also mention, with some specificity, the need for assistance with eating[22,28] and technical aids for walking as the disease progresses and mobility changes[29]. In the research by Lee, J. *et al*[27], Cithambarm *et al*[28] and Smith *et al*[36], the

need to address preferences for managing urinary and fecal incontinence is highlighted as being as important as or more important than managing pain or nausea[27,28,36]. The need for quality sleep and rest is mentioned in studies by Wang *et al*[22], Lee, J. *et al*[27] and López-Salas *et al*[31].

With regard to symptom management or increasing functional dependence, the need for greater personalised attention and greater supervision and support by doctors and nurses is mentioned, as pointed out by Cithambarm *et al*[28]. Still in the physical context, the authors Lewis *et al*[25], Lee, J. *et al*[27] and Geerse *et al*[34], in their research, demonstrate the importance of respecting the preference for comfort care over life-sustaining measures (such as invasive ventilation, cardiopulmonary resuscitation, nasogastric tube or antibiotics in the last week of life)[25,27,34], even if it means living less time, rather than prolonging life that involves pain and discomfort. Thus, for this to occur as desired, the authors[25,27] add that it is important to know the prognosis, clarify wishes regarding life-prolonging measures, and respect advance directives[25,27]. Only Heller[26] expressed a preference for prolonging life, arguing that the physical and spiritual components are inseparable in several African countries, since unless someone dies at a very advanced age, death is considered unnatural and premature. Such cultural norms pose a problem for advance care planning and compromise the ability of professionals to consider the priorities of the patient and family, as discussions about death are considered taboo and often avoided.

### Study limitations

The number of electronic databases consulted was considered a limitation of this study, as articles with potentially relevant results for the topic may have been excluded. Another limitation was the lack of studies conducted in Portugal, which could have provided contributions contextualised to our reality, both socially and culturally. This study is replicable and meets the scientific requirements characteristic of the JBI. However, the possibility cannot be ruled out that other researchers, with a larger team and more resources available (time, financial or other), may obtain different results.

## Conclusion

This scoping review mapped the comfort needs of people in palliative care in UDHVs. Most of the participants in the studies are people in palliative care, which gives greater quality to the results, taking into account the perception of the care recipients, rather than data obtained only through third parties (family or health professionals).

The needs mapped can be classified into three of the four contexts of comfort according to Kolcaba's theory, with no new evidence emerging in the literature reviewed, which demonstrates some homogeneity across different cultures and regions. The sociocultural context is the one that possibly poses the most challenges for healthcare professionals and families, given that the preferred place to die is mostly the home, but mainly occurring in hospitals. This reflects the need for greater investment in community resources, which contribute not only to the quality of life of people in palliative care in UDHVs, but also to the quality of the health system.

The environmental context is not mentioned in the articles, which may raise questions about holistic care.

As for contributions to nursing practice, it should be noted that recognising the needs of people in palliative care in UDHVs allows for the anticipation of care that promotes holistic comfort conducive to a peaceful death. This scoping review sheds light on the needs of this population; however, it requires an individualised and personalised assessment, given the person- and family-centred care according to the needs for relief, tranquillity or transcendence arising in contexts of comfort.

Addressing the progression of the disease, death, or prognosis contributes to shared decision-making and the development of an advance care plan which, considering the uncertainty involved, allows for the needs, preferences, desires, and wishes of people in palliative care in UDHVs to be respected whenever possible.

With regard to suggestions for future studies, the work carried out identified gaps in two main areas: 1) no evidence was found on comfort needs arising from the environmental context; 2) concepts often used as synonyms (end of life, terminally ill, near death, dying patient) hinder the analysis and interpretation of results and may increase the risk of bias. Both gaps could serve as a starting point for further investment and research into the subject under study.

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RM: Study coordination, study design, data collection, storage and analysis, review and discussion of results.
MC: Data analysis, review and discussion of results.
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