Reflection Article

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Total pain and comfort theory: implications in the care to patients in oncology palliative care

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Dor total e teoria do conforto: implicações no cuidado ao paciente em cuidados paliativos oncológicos

Dolor total y teoría del confort: implicaciones en la atención al paciente en el cuidado paliativo oncológico

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ABSTRACT

Objective: To reflect on the possible connections between Katharine Kolcaba's Theory of Comfort and Cicely Saunders's concept of Total Pain and the implications to the care of the oncology palliative care patient.

Method: Theoretical reflection based on a literature review carried out in May 2020, in the PubMed and LILACS databases, which sought to answer the question: "Are there any theoretical-conceptual connections between Kolcaba's Theory of Comfort and the concept of Total Pain by Saunders?"

Results: The knowledge of the concepts presented allows redirecting the focus of care towards individualized actions to strengthen the patient and his participation in the choices of comfort interventions.

Conclusion: Understanding the connections between the concept and theory presented provides the patient in oncology palliative care with individualized and qualified care, focused on the person and not on the disease and can contribute to a greater effectiveness of nursing interventions aimed at the relief of suffering.

Keywords: Nursing care. Patient comfort. Hospice care. Palliative care. Pain.

RESUMO

Objetivo: Refletir sobre possíveis conexões entre a Teoria do Conforto de Katharine Kolcaba e o conceito de Dor Total de Cicely Saunders e suas implicações no cuidado ao paciente em cuidados paliativos oncológicos.

Método: Estudo teórico-reflexivo baseado em revisão de literatura realizada em maio de 2020, nas bases de dados PubMed e LILACS que buscou responder à questão: "Existem conexões teórico-conceituais entre a Teoria do Conforto de Kolcaba e o conceito de Dor Total de Saunders?"

Resultados: O conhecimento dos conceitos apresentados permite redirecionar o foco do cuidado para ações individualizadas com fortalecimento do paciente e sua participação nas escolhas das intervenções de conforto.

Conclusões: Compreender as conexões entre o conceito e teoria apresentados proporciona ao paciente em cuidados paliativos oncológicos um cuidado individualizado e qualificado, focado na pessoa e não na doença podendo contribuir para uma maior resolutividade das intervenções de enfermagem direcionadas para o alívio do sofrimento.

Palavras-chave: Cuidados de enfermagem. Conforto do paciente. Cuidados paliativos na terminalidade da vida. Cuidados paliativos. Dor.

RESUMEN

Objetivo: Reflexionar acerca de las posibles conexiones entre la Teoría del Confort de Katharine Kolcaba, el concepto de Dolor Total de Cicely Saunders y sus implicaciones para la atención al paciente en cuidados paliativos oncológicos.

Método: Estudio teórico-reflexivo basado en una revisión de la literatura realizada en mayo de 2020, en las bases de datos PubMed y LILACS, que buscaba dar respuesta a la pregunta: "Existen conexiones teórico-conceptuales entre la Teoría del Confort de Kolcaba y el concepto de Dolor Total de Saunders?"

Resultados: El conocimiento de los conceptos presentados permite reorientar el foco de atención hacia acciones individualizadas para fortalecer al paciente y su participación en las elecciones de intervenciones de confort.

Conclusiones: La comprensión de las conexiones entre el concepto y la teoría presentada proporciona al paciente en cuidados oncológicos paliativos un cuidado individualizado y calificado, enfocado en la persona y no en la enfermedad y puede contribuir a una mayor resolución de las intervenciones de enfermería orientadas al alivio del sufrimiento.

Palabras-clave: Atención de enfermería. Comodidad del paciente. Cuidados paliativos al final de la vida. Cuidados paliativos. Dolor.

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INTRODUCTION

According to estimates of the Brazilian National Cancer Institute for the 2020-2022 triennium,625,000 new cases of cancer occur annually in Brazil (450,000, excluding cases of non-melanoma skin cancer). Cancer, a major public health problem, is among the top four causes of death in the Brazilian population under 70 years of age. Aging, population growth and the increased socioeconomic-related risk factors, changes in the population's lifestyle, as well as physical inactivity and poor diet are factors responsible for the higher cancer incidence and mortality rates(1). In less developed countries, particularly, it is estimated that many cancer patients are diagnosed in advanced stages of the disease, requiring follow-up by a palliative care team(2).

Palliative care should be included in continuous care integrated within the scope of the Health Care Networks, according to a shared care model and provided in Primary, Home and Hospital Care, both on an outpatient basis and in urgent and emergency services for the relief of acute symptoms(3). In all care modalities, the work performed by nurses reinforces the importance of their participation in the healthcare team, as they plan and implement actions aimed at ensuring the high quality of care provided and the construction of scientific knowledge. The presence of a multidisciplinary team is essential, given the complexity and the various dimensions involved in this type of care(4).

All people diagnosed with acute or chronic life-threatening diseases have a right to receive palliative care(3). The early inclusion of palliative care in clinical practice, sometimes in parallel with the curative treatment, not only favors a more effective multidimensional approach, but also improves quality of life, which can contribute to an increase in life expectancy(5).

In 2002, the World Health Organization (WHO) defined palliative care as "an approach that promotes the quality of life of patients and their families, who face diseases that threaten the continuity of life, by preventing and mitigating suffering. Early identification, assessment and treatment of pain and other physical, psychosocial and spiritual problems is necessary"(6:xv-xvi). This definition reaffirms the importance of treating other distressing symptoms, in addition to pain, as well as relieving suffering, above all to promote the quality of life and well-being of patients(6).

Although the palliative care approach aims to provide comfort and dignity to patients and their families, many patients with late stage diseases experience discomfort because physical comfort is still prioritized over other aspects inherent to the illness process(7).

Physical pain is still a very frequent research subject and has become the main goal in the care plan, while other aspects intrinsic to the multidimensionality of this phenomenon involved in the construction of the concept of Total Pain by Cicely Saunders are neglected(7–8).

Kolcaba defines comfort as "a fundamental experience of all human beings for relief, ease or transcendence arising from four contexts: physical, psycho-spiritual, social and environmental"(9).

In this scenario, the present study aims to reflect on the possible connections between the Cicely Saunders's concept of Total Pain and Katharine Kolcaba's Theory of Comfort and its implications for the care of patients in oncology palliative care.

METHOD

Theoretical reflection that sought to answer the following question: "Are there any theoretical-conceptual connections between Katharine Kolcaba's Theory of Comfort and the Cicely Saunders's concept of Total Pain? To answer this question, a review of the national and international scientific literature was carried out in May 2020, in the electronic databases PubMed and LILACS. For the selection of the descriptors, a search was made in the Health Sciences Descriptors (DeCS): comfort theory and pain and palliative care. The author filter was also used with the following terms: Kolcaba, Katharine and Saunders, Cicely, in the search for their seminal works. The following inclusion criteria were adopted: articles addressing the themes of pain and comfort, published in the 2015-2020 period in Portuguese, English and Spanish. Publications on themes not related to oncological palliative care were excluded. Based on these criteria, six publications(7,10–14) and two works of the authors were identified(8–9).

After reading and critical analysis of the material, reflections were made on the implications of these connections for patients in palliative care in oncology. For this purpose, documents from the World Health Organization, the National Cancer Institute and the National Academy of Palliative Care, references for scientific development, teaching, dissemination and elaboration of guidelines for the implementation of palliative care were included(1–2,4). Resolution No. 41 of October 31, 2018, which provides for guidelines for the organization of palliative care within the scope of the Unified Health System (SUS) allowed a better understanding of the current scenario(3).

Three thematic categories were built based on the relevant studies identified: "Cicely Saunders and the concept of total pain", "Katharine Kolcaba and the theory of comfort" and "Pain and comfort: singularity of care". Thus, critical analysis of the concepts, application of their references into practice and reflection on the interconnections between the works of Cicely Saunders(8) and Katharine Kolcaba(9), and possible implications for oncology palliative care were made.

CICELY SAUNDERS AND THE CONCEPT OF TOTAL PAIN

Considered a pioneer in the development of the modern Hospice Movement, Cicely Saunders worked as a nurse, then a social worker and finally a physician, obtaining a medical degree in 1957. These different experiences and professional skills are at the heart of her reflections. At that time, most institutions devoted to the care of end-of-life patients were focused on religious, philanthropic and moral aspects, rather than the medical aspect. Her interest in the care of cancer patients began in 1948 when she cared for a Jewish emigrant with rectal cancer. Saunders's conversations with that patient gave her the idea of creating a place where cancer patients would spend their last days enjoying peace, comfort and dignity(8).

After obtaining her medical degree, Saunders devoted herself to the development of this new modality of care, seeking to integrate clinical practice with research and teaching, adhering to scientific rigor, in a compassionate, sensitive way, aware of the vulnerability inherent to all human beings and the importance of valuing spirituality. Her work with one of London's poorest communities, at Hospice St. Joseph, is essential to the beginning of a worldwide movement that would transform ideas and actions in the care of end-of-life patients and culminate in the founding of Hospice St. Christopher in July 1967(8).

Cicely Saunders' reflections on the multidimensionality of the concept of pain appear in her first publications, covering not only physical symptoms, but mental suffering, the social and biographical context of patients and their emotional difficulties, with emphasis on the importance of listening and understanding the experience of suffering from a holistic approach(8).

Her active listening, followed by a careful analysis of medical records, allowed the identification of the physical, emotional, social and spiritual dimensions described in her concept, unveiling issues related to the need for security and the recognition of values that transcend everyday life. These findings reinforce the importance of a care approach that encompasses the various aspects inherent to human beings, in a non-reductionist way. Based on these listening experiences, Saunders creates the expression Total Pain, considering the different dimensions of pain of human beings. The concept "Total Pain" was introduced in her publications in 1964, based on a reflection on a speech by a patient, who, after being asked about her pain, replied: "All of me is wrong"(8,15).

The scope of this concept allows the understanding that pain is more than physical sensations, and this understanding may be the key to providing access to other dimensions related to suffering (Figure 1). Multiple interventions are needed for pain control, as well as holistic care for the individuals, providing dignity and comfort until the last days of their lives (8,15).

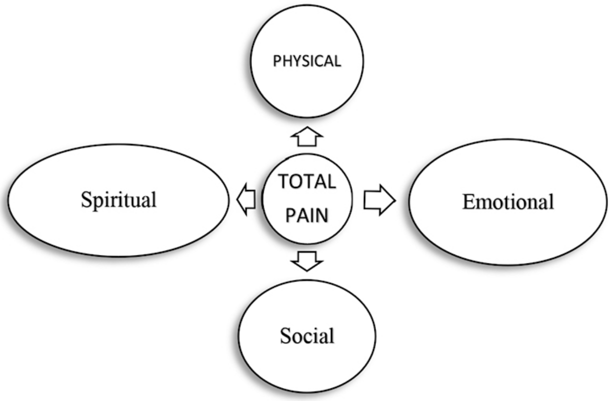

Figure 1 – Total Pain
Source: Developed from the concept of Cicely Saunders.

KATHARINE KOLCABA AND THE THEORY OF COMFORT

Katharine Kolcaba earned her nursing diploma in 1965 from St Luke's Hospital School of Nursing, in Cleveland, in 1965 and started her master's degree in 1987 when she was already working in a unit for patients with dementia (Alzheimer), and began to theorize about the possible effects of comfort on the behavior of her patients. When Kolcaba realized that the slightest physical or emotional change imposed on the inmates could impact their balance, causing agitation, fights, refusal to cooperate and even violence, and that when these inmates were in a situation of "comfort" they were more sociable and cooperative, showing more satisfaction, she named the actions implemented in the unit by nurses, aimed to prevent or treat such situations, as "interventions or comfort measures"(9)

Katharine Kolcaba's first contact with cancer nursing occurred during her brother's illness, a malignant melanoma.

This aroused her interest in what she would come to call "the holistic comfort of cancer patients." Her dissertation, an experimental study with women who had breast cancer, aims to measure the effectiveness of a guided imagery intervention in increasing the comfort of these women. The author believes that the intervention can demonstrate more easily a change in comfort, in an oncology setting whose comfort needs are extremely acute(9).

After several years of analysis, definition and operationalization of the extension of patient comfort in different circumstances, a technical definition of the multidimensional concept of comfort was constructed, as follows: "the state of being strengthened by having needs for relief, ease, and transcendence met in four contexts: physical, psychospiritual, sociocultural and environmental", with a larger effect than the mere absence of pain(9)

Based on this definition, Kolcaba describes the three types of comfort: relief as the experience of a patient who had a specific need for comfort met, ease as a state of calm, contentment or well-being, and transcendence as a state in which one can rise above problems or pain, when the individuals can plan their lives, solve problems, or else, they have the ability to transcend stressful situations, and this is considered the highest level of comfort(9).

The main contexts in which comfort can be experienced, according to Kolcaba's theory, are the physical context, pertaining to bodily sensations and homeostatic mechanisms that may or may not be related to specific diagnoses; the psychospiritual context, which gives meaning to an individual's life and implies their self-esteem, sexuality, self-concept and their relationship with a higher order or being; and the environmental context, pertaining to the external environment, conditions and influences. The social context, on the other hand, refers to interpersonal, family and social relationships, including finance, education, support, family history, traditions, language, customs(9).

Kolcaba also describes the interventions used to provide comfort: technical interventions are those aimed to maintain or restore physiological functions and prevent complications (analgesia, monitoring vital signs and blood levels); coaching, interventions designed to alleviate anxiety, provide security and information, use active listening and help with a realistic planning for recovery, integration or death, and finally, the intervention defined as "comfort food for the soul", which aims at transcendence when relief and ease can no longer be achieved: massage, a quiet and peaceful environment, music therapy, guided imagery, reliving memories (valued as a biographical being)(9) .

Based on the identification of an unmet health need, nurses can plan an intervention that meets this need, thus providing the expected comfort. Variables that can influence this care (dysfunctional families, lack of financial resources, devastating diagnoses, cognitive impairment) must be taken into account when planning actions and determining immediate or subsequent results. With increased comfort, patients feel empowered to engage in "search for health and well-being" behaviors that can be expressed through internal behaviors (hemostatic mechanism, enhanced immune function, cure), external behaviors (improved self-care, rehabilitation, adherence to the care plan) or even achieving a "good death", a peaceful and painless death9). Figure 2 describes the stages of this process.

PAIN AND COMFORT: SINGULARITY OF CARE

The contexts that integrate the Comfort Theory (physical, psychospiritual, environmental and social) in which the patient can experience relief, ease or transcendence, as well as the dimensions that integrate the concept of Total Pain, are part of the Palliative Care approach described by the WHO. Since comfort is the main goal of this approach, understanding the complexity and uniqueness inherent to these concepts is essential for planning individualized care to patients in oncology palliative care(2,6–7,9).

Although palliative care aims to provide comfort, patients continue to experience different forms of discomfort, both physically and socially, spiritually and environmentally(7,11). It is necessary to understand the multidimensionality of pain, the subjectivity of the perception of comfort and its implications for the care offered to patients in palliative care in order to implement unique and individualized actions where the care model is tailored to specific needs and values of each patient.

Studies have shown inconsistency and gaps in nursing knowledge about the concept of comfort, which has been defined in a reductionist way, predominantly related to the physical dimension. The literature continues to prioritize physical comfort and neglects other aspects commonly observed among these patients, in addition to ignoring the comfort experience(7,12).

This knowledge deficit creates difficulties in measuring comfort, which often does not include existential pain. An accurate assessment is important both in clinical practice, for evaluating the effectiveness of nursing interventions, and for research purposes, which can impact the sense of well-being and the quality of life of patients in oncology palliative care(12).

The perception of comfort taking into account the uniqueness of each person is highlighted in a study based on reports from participants about what it means for each

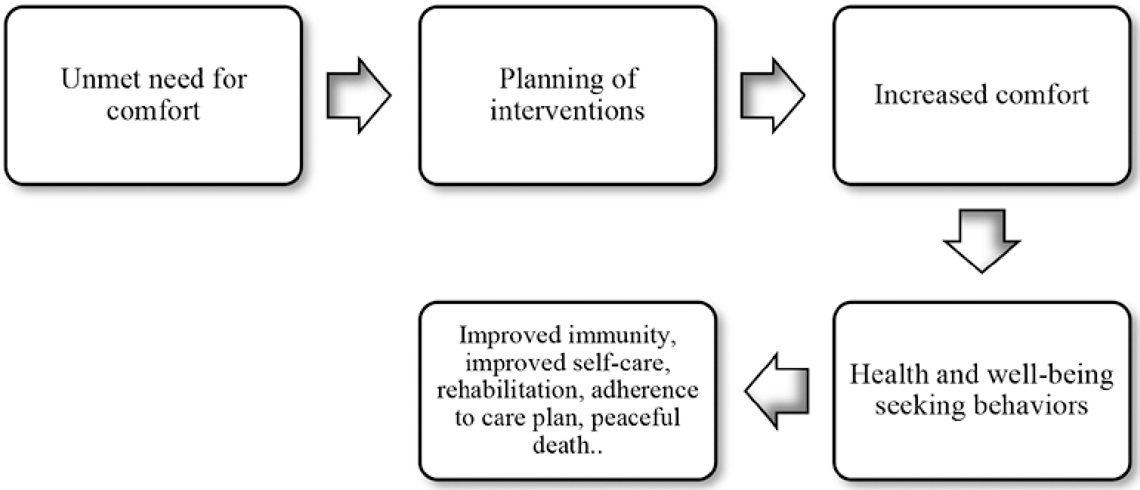

Figure 2 – Theory of Comfort
Source: Developed from Kolcaba's Theory of Comfort, 2003.

person to feel comfortable or uncomfortable. The results of the comfort experience that are more than the mere satisfaction of physical needs are presented(7). The social, family, economic, political and spiritual contexts are directly related to the quality of life of patients and their families. Complex family networks, difficulties in obtaining opioids, difficult access to medical evaluation and treatment, low self-esteem caused by issues related to the progress of the disease were some situations identified in a study carried out in southern Brazil as the causes of increased pain and suffering(13). Such situations reinforce the importance of assessment and care that contemplate the various dimensions of the human being.

The two concepts presented emerge from practices related to listening, with careful clinical observation, continuous reassessments of the care process, and with the enhancement of the patient's personal perception about the totality of their pain and how to seek and achieve comfort. Both Saunders and Kolcaba reinforce the importance of anticipating the situation that generates discomfort, without the need for the patients to ask for a relief intervention. They also point out that patients feel strengthened and able to participate more actively in social and family relationships and in healthy behaviors when they feel more comfortable(9). A discomfort can generate another uncomfortable sensation, not necessarily painful. Seeking comfort when physical pain is not the pressing issue requires an understanding of the concept of Total Pain, as well as an understanding of the difference between pain relief and total comfort.

Prevention and relief of suffering, through early identification, as recommended by the WHO, anticipation of the patient's complaint and the discomfort factor in various contexts, continuous (re)evaluations and implementation of interventions that provide comfort, in its three forms, to physical, psychosocial or spiritual problems are key aspects of patient-centered care (2,6,8–9). Planning based on the patients' perceptions of unmet needs, in which complexity and subjectivity of their personal experiences are considered, can have a positive impact on the outcome of nursing interventions, with a consequent increase in comfort(7).

Obtaining Total Comfort in scenarios where circumstances that are unlikely to change prevail, such as situations of advanced illness or in hospital settings, is challenging. In these cases, the goal to be achieved is comfort perceived as ease, with feelings of contentment or well-being, or even as transcendence, a way of putting themselves above physical pain or other problems, helping patients to preserve, within as much as possible, their autonomy and implement self-care actions(9,14–15). A proactive pattern of care can be established if comfort needs are accessed, in the four contexts, in a holistic way, interconnected, like a Gestalt. The whole, or Total Comfort would then be significantly greater than the sum of its parts(9).

The difficulty of identifying dimensions related to Total Pain, both by patients and nurses, can lead to an overvaluation of physical aspects, often described as physical discomfort. Likewise, the interconnection between comfort needs can make it difficult for patients to distinguish exactly which component is causing the pain, whether physical, psychosocial or spiritual. Therefore, the result expected with the comfort intervention may not be effectively achieved.

However, when the aspect referred to by patients as a priority is addressed, the same interconnection of its components can lead to relief, relaxation or, in many situations, to transcendence, which will reflect in an improvement in their quality of life(9).

Implementing comfort actions based on the needs felt and reported by patients, allows them to feel empowered and encouraged to exercise their own choices and, thus, select the interventions that can increase their sense of comfort. This will help them to overcome critical situations, difficulties and even unwanted but necessary treatments (9). Saunders found that patients make fewer requests for analgesia when they are heard and understood, a type of care focused on the importance of active listening and understanding the experience of suffering(8,15).

When patients' needs are met, we allow them to be concerned with other aspects of their lives, such as personal relationships and existential issues. Thus, when healing is no longer the goal of care, feeling comfortable can be important to allow that patients facing serious illnesses participate in decisions related to their care and have a peaceful death, finding peace and meaning in their lives at the present moment(9).

In an attempt to draw a model that explains the relationship between factors that could affect the comfort of cancer patients, one study cites individual resources of the patient as one of the variables. Family support, included in these resources, would be a fundamental component of palliative care, due to its role in the encouragement of patients, in addition to favoring the continuity of care(10). Interpersonal relationships are described as relevant factors in the comfort experience of patients(7,11).

Given the multiplicity of symptoms and the frequent changes in the clinical condition and functionality of patients in palliative care, at different times, care can be provided in a hospital environment or at home. Moreover, the inclusion of the family in the care process is essential to guarantee the continuity of care. In this context, the patient, his/her family and the multidisciplinary team form the tripod that supports care in all its complexity(4).

Figure 3 shows a diagram of palliative care that points to the need for interconnection of the multidimensional aspects of Total Pain, with pain and suffering, given the need for patient-centered comfort, beyond the mere management of the symptoms of a disease. Thus, in the dynamics of palliative care, care is meant to provide comfort and is the starting point of comfort.

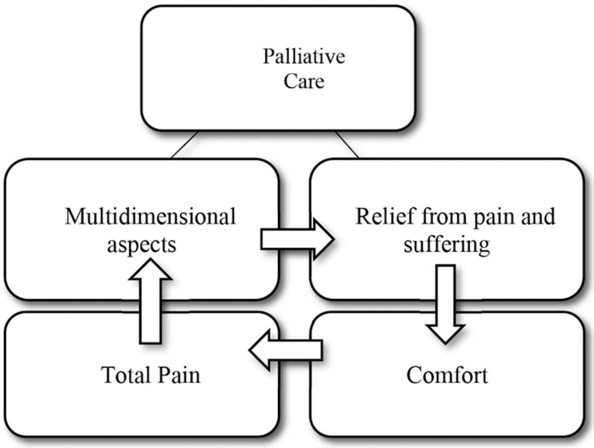

Figure 3 – Total pain and comfort: integrality in the care of patients in palliative care
Source: Elaborated by the authors.

FINAL CONSIDERATIONS

Reflection on the connection between the concept of Total Pain and the Theory of Comfort made it possible to understand the complexity and uniqueness involved in assisting patients in palliative care. The application of these concepts in the elaboration of the planning of actions allows for better care management, avoiding inappropriate actions that would generate suffering, such as the inappropriate use of high doses of painkillers, increasing the possibility of adverse effects and with high costs; frequent visits to outpatient units or repeated visits to Emergency Services, with complaints of refractory symptoms, depriving patients of family and social life; discontinuity of care due to disbelief in the effectiveness of actions and because patients do not feel understood and the possibility of delaying patients referral to other.

We are unable to fully understand the nature of pain because it is a unique and individual experience. Our response to pain is not necessarily dependent on its intensity, but also on factors such as culture, past experiences, state of mind, as well as psychosocial and spiritual aspects. The perception of pain and suffering is different when the goal of care changes from cure to care.

Although palliative care is aimed to provide comfort, patients continue to experience different levels of discomfort, both physically and socially, spiritually and environmentally.

A planning of nursing actions, by valuing the needs reported by the patients, with the construction of a care plan shared with patients and their families, provides individualized and qualified care focused on the person and not on the disease. Taking into account patients' perceptions of their comfort needs, in order to guide care in palliative care, contributes to the greater success of nursing interventions targeted to the mitigation of suffering, improving the quality of life of these patients. As the recipients of comfort care, patients should actively participate in this dynamic process, whenever possible, and can be encouraged to seek their own forms of comfort, with nurses participating in this process as facilitators.

Knowledge of the concepts exposed here helps us to redirect the focus of care to the individuals, and not only to the physical process. Ignorance or neglect of the multiple aspects of care can have a negative impact on patients' ability to manage their care and even their suffering or death.

Further studies on this topic are needed so that it can be discussed in more depth. This will generate high quality care that ensures that patients' needs are individually interpreted and their comfort optimized. Understanding of these concepts and their application in nursing practice can generate a set of data related to the effectiveness of comfort interventions that will support further research in the area of palliative care, providing evidence that contributes to the improvement of the quality of life of these patients.

A limitation of this study concerns its scope. Therefore, more comprehensive studies are needed to extend this reflection to other groups with different realities and experiences and contribute to a better understanding and implementation of the concepts detailed here.

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