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Research Article

Dimensions of the Human Being in Oncological Palliative Care from the Nursing Perspective. A Systematic Review

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Abstract

Objective: To learn about the experiences, obstacles and needs of nurses concerning palliative care at the end of life in adult cancer patients.

Methods: A systematic review of scientific evidence. Data collection was based on the reading and analysis of research published between 2015 and 2018. The sample was composed of ten studies.

Results: Four categories of analysis were established: physical dimension, psycho-social dimension, cultural dimension and emotional and religious dimension.

Conclusion: The data show that nursing professionals are concerned and interested in providing care in each of the dimensions. However, due to multidisciplinary factors, care subjects, institutions and training, the quality of care in some dimensions is not as desired.

Keywords: *Nursing; Palliative Care; End of Life; Oncology*

Introduction

Palliative care is designed to improve the quality of life of people in a situation of oncological illness, among other diseases. Care depends on the needs of patients, families and the state of the disease. Today, palliative care is becoming increasingly comprehensive and integrated. Care is focused on the patient, making him/her an active participant. Consequently, it must respond to each of the dimensions of the human being, physical, psycho-social, cultural, spiritual and religious, led by a multidisciplinary team [1,2].

However, despite progress and recognition of the importance of its practice, palliative care faces difficulties in its approach [2]. Among these problems are the lack of time of health professionals, human resources, communication and training in palliative care [3]. Additionally, there are limitations at the cultural level derived from moral and religious conceptions and principles about cancer, palliative care and death, as observed in some studies of French, Chinese, and Australian origin [3-5]. Factors that influence the different dimensions of the human being and can compromise an adequate provision of palliative care at the end of life.

Moreover, nurses are often the first health professionals to detect and address the emotional, physical and cognitive concerns of each patient [6]. In fact, patients may feel more comfortable disclosing their symptoms, anxieties and fears to their nurses as they learn to cope with their diagnosis and treatment [7]. Besides, as the health care team becomes involved with the patient and family, close relationships are formed during the cancer experience [8].

However, during the end-of-life stage, emotions and distress are present in the subjects of care [9]. Nursing addresses this through communication, presence and management of symptoms [6]. Therefore, it is necessary to know the experiences and challenges that nurses face during their professional practice in order to propose improvements. In this way, contribute to better care and welfare of patients and families.

Method

This study aimed to understand the experiences, obstacles and needs of nurses working with adult oncology patients, concerning end-of-life palliative care. To achieve this goal, a systematic review method was proposed [10]:

1. Definition of criteria for inclusion and exclusion from studies. The criteria for including a study were: articles showing the experiences of nursing professionals during palliative care practice in oncology at the end of life. The exclusion criteria were: editorials, theses, dissertations and that it did not answer the question or research objective (paediatrics, non-oncological palliative care).

2. Subsequently, the bibliographic search was carried out through virtual access to the databases. The databases consulted were PubMed, Web Science, Scielo and Dialnet. The exploration was carried out by the researcher, using the Boolean operators "AND" and "OR". Descriptors were also used in health sciences: terminal care, oncology nursing, nursing process. The search covered a period from 2015 to 2020, in the languages of Spanish, English and Portuguese.

3. The exploration in the different databases generated a total of 549 studies. After excluding duplicate research and by title, abstracts of 265 documents were read to verify compliance with the inclusion criteria. Of these, 250 studies were excluded for not meeting the criteria. Of the 15 texts read in full, four were excluded because their contributions did not fit the proposed objectives. Therefore, ten studies were included in this review. For the selection of research, the recommendations of the preferred reporting elements for systematic reviews and meta-analyses (PRISMA) were followed [11].

4. In the fourth stage, information was extracted from the selected studies. This stage was done by reading the texts thoroughly and identifying relevant information. The results were then organised, and four categories of analysis were established.

5. Finally, the analysis of results was carried out. After interpreting the findings, each of the proposed categories was discussed. The relevance of the information obtained was contrasted with scientific evidence and reviewed by the second researcher.

Results

The studies included belonging to the years 2015 to 2018. Of these ten studies, four were conducted in the United States, two in China, one in Spain, one in Saudi Arabia, one in Lithuania and one in Brazil. The characteristics of the included studies are specified in table 1. Finally, after reading the research findings, four categories were established for analysis, corresponding to the dimensions of human care, physical support, psycho-social support, cultural, spiritual and religious support.

Year	Title	Objective	Study type	Participants	Results	Country
2015 [4]	Caring for dying cancer patients in the Chinese cultural context: A qualitative study from the perspectives of physicians and nurses.	To explore the experiences of Chinese doctors and nurses caring for dying cancer patients in their practical work.	Qualitative study using semi-structured face-to-face interviews. The data were analysed by qualitative thematic analysis.	Fifteen doctors and 22 nurses from a cancer centre in China participated.	The disclosure of information about death and cancer to dying cancer patients is a taboo in traditional Chinese culture. Decrease in effective communication. Both physicians and nurses emphasised the importance of maintaining the hopes of dying patients in the cultural context of death denial.	China
2015 [19]	Communicating with patients and their families about palliative and end-of-life care: comfort and educational needs of nurses.	To determine the perceived needs of inpatient nurses for communicating with patients and families about palliative and end of life care.	A non-experimental design was utilised. End of Life Professional Caregivers Survey (EPCS), which examines three domains: patient- and family-centred communication, cultural and ethical values, and effective delivery of care.	Sixty inpatient nurses completed the end of Life Professional Caregiver survey.	The years of experience the nurses had, and the unit they worked in had a significant effect on their comfort in talking about End-of-life and palliative care with patients and their families. Oncology nurses felt more comfortable with the patient- and family-centred communication.	United States

2015 [20]	Comfort for a good death: the perspective of an intensivist nursing team	Know what nursing care entails for a good death from an intensive care team perspective.	Symbolic interactionism was adopted as the theoretical framework. Bardin's Content Analysis as a methodological framework for analysis.	Ten nurses from the Intensive Care Unit of a hospital specialising in oncology were interviewed.	The meaning of caring for a good death focuses on the promotion of comfort as the main category and three subcategories: relief of physical discomfort, social and emotional support, and maintenance of body integrity and positioning.	Brasil
2016 [17]	Perceptions of dying well and distressing death by acute care nurses	Identify the perceptions of nurses practising in four adult inpatient units regarding their actions to provide quality end-of-life care for dying patients, their definitions of dying well and their symptoms of distress, and the actions they took to alleviate them.	The data from the qualitative questionnaire	49 nurses, in four hospitalisation units	Three main concepts emerged that describe the definition of nursing as dying well. Eight categories of nursing actions to promote death were identified.	United States
2017 [15]	From Vulnerability to passion at the end of life care: The lived experiences of nurses	How end-of-life nurses interpret their care experience and how they transform their experience and mindset	Reflexive group based on the concept of group analysis for oncology and hospice nurses. Phenomenological data analysis. The data extracted from the group dialogue were derived from six digitally recorded sessions and then analysed only with the researcher's journals and the participants' comment sheets.	Thirteen nurses from a medical centre in northern Taiwan participated.	Nurses providing end-of-life care experience suffering by witnessing the suffering of patients. However, suffering drives nurses to induce a change in mentality and to provide and maintain passion in End-of-life care continually.	China

2017 [14]	Palliative and End-of-Life Care Education Needs of Nurses Across Inpatient Care Settings	Determine nursing education needs related to palliative and end-of-life care.	This is a descriptive correlation study. The data were analysed with the SAS® software version 9.4. Means were calculated for each end-of-life domain subscale to identify areas of increased competence and perceived deficiency.	608 nurses from Intensive Care Units and acute care units in paediatrics and adults were interviewed	Data analysis revealed that the perceived competence in palliative and end-of-life care is significantly higher in ICU nurses. Open-ended responses indicated concerns regarding improved communication behaviours, decision-making, and facilitation of continuity of care.	United States
2017 [13]	Oncology nurses' perceptions of obstacles and role at end-of-life care: a cross-sectional survey	To examine obstacles faced by oncology nurses in providing end-of-life (EOL) care and to examine roles of nurses in providing care.	A descriptive, cross-sectional, correlational design was applied. Data collection tool included a questionnaire about assessment of obstacles and supportive behaviours, nursing roles, and socio-demographic characteristics.	The study was conducted at two major University Hospitals of Oncology in Lithuania. The study sample consisted of 239 oncology registered nurses.	The two items perceived by respondents as the most intense obstacles to providing EOL care were. The nurse's opinion on immediate patient care is not welcome, valued or discussed and. The family has no access to psychological help after being informed about the patient's diagnosis. The majority of respondents self-assigned the role of Supporter.	Lithuania
2017 [18]	Variability in professional practice among departments explain the type of end-of-life care but not the difficulty of professionals with decision-making	To determine the perspectives and experience of physicians and nurses concerning clinical, psycho-social, and ethical actions at the end of life and to determine any variability between departments.	Observational, descriptive, transversal and multicenter study. Filling out a questionnaire. The analysis of variance (ANOVA) and Bonferroni's post hoc test were applied to compare the answers.	One hundred twenty-three doctors and one hundred and eighty-nine nurses participated. General and regional hospitals. Primary Care Centers.	The results of the questionnaire differed significantly depending on the department in which the participants worked. The least attention was paid to psychological actions, advance directives, and ethical dilemmas. Oncology, palliative care, and primary care professionals showed higher and less variable scores compared to surgery, internal medicine, or intensive care departments.	Spain

2018 [12]	Operating in the dark": Nurses' attempts to help patients and families manage the transition from oncology to comfort care	To investigate the challenges, nurses face when providing care for oncology patients transitioning from curative to palliative care and to identify educational and support opportunities for nurses.	The constant comparative method was used to analyse the data.	Twenty-eight nurses working in oncology (n = 14) and palliative care (n = 14) settings participated.	Four themes emerged that characterise oncology and palliative care nurses' experiences: (a) coping with interprofessional communication errors during the transition, (b) responding to patient/family reactions to miscommunication about the goals of care, (c) navigating emotional connection to patients, and (d) adapting to sociocultural factors that influence information exchange.	United States
2018 [16]	Caring for terminally ill Muslim patients: Lived experiences of non-Muslim nurses	To explore non-Muslim nurses' experiences in caring for terminally ill Muslim patients and their families regarding physical, social, cultural, spiritual, and religious practices. The study also sought to investigate the context or situations that influence these experiences as described by the nurses.	This is a qualitative descriptive study. A modified Stevick–Colaizzi–Keen method was employed for data analysis.	Ten nurses working in medical, oncology, and oncology/palliative care units in a tertiary care hospital in Saudi Arabia were interviewed.	Three main themes constituted the nurses' lived experiences: family matters, end-of-life practices and nurse challenges. Cultural values, religious practices, and a family approach to the process of care influenced nurses' experiences. Issues related to an absence of palliative care integration and the unavailability of members in the interdisciplinary team also influenced their experiences. Nurses showed a lack of cultural knowledge of some practices due to a lack of awareness of cultural diversity and the unavailability of formal cultural education.	Saudi Arabia

Table 1: *Characterization of research included in the review, year of publication, title, objective, type of study, participants, results and country of execution 2020.*

Physical support

In the context of physical care, some of the selected research addressed the dimension from different perspectives. Canzona., *et al*. [12] in their study noted in their research that nurses in the United States during palliative care received conflicting information about the goals of care. This caused challenges in care with patients, as in some situations, they did not receive complete information about their health status [12,13]. In a Chinese study, it was found that younger health care providers were more limited in communicating with patients or family members. As a result, professionals were silent or lied to when patients or families asked challenging questions [4].

On the other hand, given the communication and information limitations, some people in a situation of oncological disease received with surprise negative news about the progression of the disease and prognosis [12]. Also, when they understood the objective of the transition to comfort care in their current health situation, as visualised in a study in Lithuania [13]. For Price., *et al*. [14] the late communication and information on the progression of the disease caused that the specialists of the palliative care were not consulted in time. As a result, patients were found at the end of life phase, with advanced medical treatment during their last days as analysed in the investigations in United States, China and Saudi Arabia [4,14-16], as well as the continuation of blood analysis [16].

However, nursing through knowledge, permanence and trust built with patient and family established therapeutic communication [16]. Also, a continuous assessment was carried out to find out about needs and to establish care [17]. Furthermore, according to studies carried out in Spain and the United States, nursing professionals in the areas of oncology and palliative care provided more information to patients and families, concerning other specialities [18,19]. It also provided education on primary physical care, promoting self-care [4].

About care practices aimed at physical comfort, the most relevant were the control of pain, other symptoms, suffering, and distress, through the use of medicines and therapies [4,17,18,20]. In this category, the use of traditional medicine was also observed. Abudari., *et al*. in his research highlighted that patients and families commonly use traditional medicines to generate comfort and convenience [16]. Likewise, studies in China and Brazil highlighted that maintaining the integrity and positioning of the body guarantees the right to physical integrity. This was achieved through the preservation of good body image, hygiene and the avoidance of bodily injury [4,20]. As well as maintaining the patient unit clean, with low noise levels, using aromatherapy or music therapy [17].

Psychosocial dimension

As mentioned in the previous category, deficiencies in communication and information by the professional team towards the patient and his/her family affect the care of the subjects in care. For this reason, there are also consequences for psycho-social support. As reported by the experiences of nurses in China, Lithuania and Spain, it became evident that on some occasions the interventions in this dimension of care, provided at the end of life, were insufficient [4,13,18]. Additionally, the time factor was revealed as a limitation for an adequate psycho-social intervention. According to the included study carried out in Lithuania, nurses reported that they usually did not have enough time to discuss the patients' wishes [13]. Consequently, to this lack of time and other factors, an important finding was the absence of patient autonomy in the decision-making process. In this scenario, the responsibility fell on the family as observed in this same study, another developed in China and one in Saudi Arabia [4,16].

On the other hand, cultural elements also influenced psycho-social care. Research in China, the United States, Saudi Arabia, showed that by presenting taboos on issues such as cancer, death, coping conversations were very complex to address. In such situations, the family chose not to communicate the poor prognosis to the patient and to continue with the care. They asked the professional team to maintain hope and not to inform the person in an end-of-life situation. This led to the professionals having difficulties in dealing with the psycho-social situation. Besides, they referred to an ethical dilemma between maintaining hope and telling the patient the truth [4,12,15,16]. Thus, like the change of the word cancer for another that did not have the meaning of death [4,13].

However, nursing showed support for the terminally ill person and their family through demonstrations of accompaniment, listening and messages of support. The use of relaxation and leisure strategies by health professionals was also observed in studies carried out in the United States and Brazil [17,20]. In addition, it offered support to family members, helping them to understand the state of health and inevitability of the patient's death [20]. During the dying phase, nurses were present, accompanying as described by research in China and Saudi Arabia [4,15,16]. With respect to the family, spaces for meeting and family union were favoured, making the hospital rules and routines more flexible as studies from China and Brazil [4,20].

Cultural dimension

During their practice, the nurses learned and understood the culture of the patients to integrate it into the plan of care taking into account the descriptions of the research developed in the United States, China and Saudi Arabia [12,15,16]. According to an American study, oncology nurses were more comfortable dealing with cultural and ethical values than their peers in other specialities [19]. However, among the difficulties that nurses presented during the provision of palliative care at the end of life, they referred to the language difference. However, in the Saudi Arabian study, patients and their families were receptive and appreciative because the professionals tried to learn the language and cultural traditions [16].

On the other hand, the taboo against cancer and death is palpable in some cultures. For example, in traditional Chinese culture, death is a taboo subject. For this reason, professionals were asked not to discuss the event of death with patients, especially in the terminal stages [4,15]. However, a study in the United States also found that this situation occurred in some patients [12]. Secondary to this taboo and lack of information, nurses were afraid to talk about death in front of patients and relatives [15], although they asked to review cases to inform the patient [4,12].

Spiritual and religious dimension

The review found research in Saudi Arabia, the United States and China in which nursing observed the involvement of families with the spiritual and religious needs of patients (praying, accompanying, accommodating, anointing oil) [4,16,17]. Besides, the establishment of meaningful relationships with their patients by showing respect, care and kindness [4]. In some cases, however, spiritual aspects and religious beliefs were a challenge to the nursing profession, as studies from the United States and Spain point out [12,18,19].

In terms of religious practice, the search found that nurses contributed to their value, through respect, acceptance and understanding of their religious practices, according to explorations in China, Saudi Arabia and the United States [4,16,19]. In addition, nurses learned and understood patients' religious beliefs to integrate them into the plan of care [4,12,16]. Finally, in the United States, it was noted that nursing recognised the importance of involving pastoral care and offering spiritual support, involving other disciplines of care [17].

Discussion

Physical dimension

During the end of life stage, nursing professionals, patients and families show that a timely approach to symptomatology is essential to ensure comfort, convenience and avoidance of distress [21]. However, cases were observed where patients continued with life-prolonging treatments, generating a detriment to their quality of life and psychological distress [22]. In addition to late referral to palliative care, which hinders adequate and timely nursing care [23].

At present, it is the treating oncologist who considers the assessment by the palliative care service to be appropriate. This approach requires oncologists to identify patients who have specific symptoms and supportive care needs and to initiate a referral. However, this process depends on other factors that would delay the inclusion of a person with cancer disease in palliative care [24].

In the context of palliative care, it is crucial to consider the incorporation and integration of traditional medicine into the institutional treatment established during palliative care. According to the World Health Organization [25] these practices are different, depending on the culture and the country. However, they are available worldwide, and patients have access to them according to their culture or preferences. Consequently, the contribution of these therapies will be seen in health, well-being and person-centered care [25].

Psycho-social dimension

From the diagnostic phase of an oncological disease, some patients and families associate cancer with a near-death [26]. This associative thinking can produce anxiety, fear and uncertainty [27]. In this regard, it is essential to identify changes in patients' thinking or emotional patterns that may require interventions and to assess these changes on time effectively. This is the reason nursing is in an ideal position to carry out the identification phase, to help caregivers cope with the process and to provide meaningful support [27-29].

However, during her professional life, nurses are concerned about the psycho-social needs of patients and families [30]. However, they present difficulties for assessment and intervention. In this regard, an Australian study identified that some ethnic minority patients and their families received less psycho-social care, secondary to less exploration and awareness of their emotions during the consultation [30]. Consequently, this limitation can be reflected in the different symptoms that patients present at the end of life [31].

In this respect, the causes of this obstacle in psycho-social care are diverse. Some precedents include ineffective communication with the multidisciplinary team and the state of health of the patient [27,32]. As seen in the included research, there are findings of biased information from medical professionals to nurses and patients [12]. Also, patients and families are surprised at the transition to palliative care because they do not have all the information about the disease [13]. Besides, it observes the associative thinking of cancer with death in nursing professionals, as highlighted by research in Turkey [27]. Finally, the lack of professionals and time to provide accompaniment, intervention and direction, adds to the difficulties faced when intervening in this dimension [33].

On the other hand, end-of-life care is a dynamic process that is discussed on several occasions among patients, families and health professionals. This cycle is influenced by individual values, culture, religion, knowledge about the disease and care preferences [21,34,35]. For this reason, conversations based on empathy and honesty decrease the risk of ineffective and unwanted treatment at the end of life. In addition, timely decision making, in which the caregiver is actively involved, contributes to high-quality palliative care and well-being for patients and families [7,36].

Cultural dimension

Population migration produces a transculturality among people, which must transcend borders and generate common cultural spaces [37,38]. Because the cultural values of individuals provide information about their customs, this vital aspect must be addressed by nurses [39]. Intervention from communication, generating strategies and practices, to give solutions to adverse situations that arise in professional work [40]. At the same time, maintaining a sensitivity to the culture of patients and families when discussing end-of-life issues [30].

However, there are some differences in the approach to palliative care between the West and the East. For Montecino and Pavez [38] "The diversity of thoughts and beliefs allows us to point out that palliative care is a consequence of culture, since the West helps its patients from a highly caring sphere, integrating the palliative care team as one more within the family. On the other hand, in other cultures, the relatives are the protagonists of the care" (Pg. 24).

As shown in the review, countries such as the United States, Lithuania, China provided evidence of the challenges faced by nurses in communicating and reporting on death. In some cases, taboo topics generate ethical dilemmas and compromise the quality of care and the well-being of the caregiver as is the case in a study in the United States [41]. However, these limitations can also be observed in countries such as Malaysia and India. In which, the decision-making is in the hands of the older man in the family. Also, information on the evolution of the disease and the prognosis is usually not discussed with the patient. Similarly, issues of end-of-life care and process are not usually discussed [9].

Additionally, in both the East and the West, language differences influence the process of care at the end of life. Two studies in Australia and the United States reflect this difficulty [30,42]. In consideration, this barrier does not allow for effective communication and linkage with the multidisciplinary team, which will be reflected in non-patient centered care; furthermore, with regular results in their well-being and quality of life. Finally, the change in terminology by doctors is observed. They change the words cancer, end of life or terminality for tumours, supportive care, among others, to soften and limit the stigma they have in society, as mentioned above. In this way, hope will continue to exist among patients and families, according to research carried out in Australia [5]. This would lead in some cases to therapeutic obstinacy.

On the other hand, in some cases and for different reasons, patients and relatives are not aware of the preparation for death. In these situations, educational intervention by nursing professionals is essential, as highlighted in research in China [4]. In this regard, two US studies recommend that professional care providers understand the cultural beliefs and norms of patients and families. In addition, to repeat the explanations as many times as necessary and in different ways in order that the subject of care understands the message therapeutics [42]. The verbal and non-verbal language used by the professionals must be clear and straightforward, which does not generate confusion in the receiver and establish a therapeutic relationship [41,42]. Finally, learning a few words and helping oneself with people close who can contribute to communication through translation is one of the solutions to the cultural limitations recommended by Iranian research [29].

Spiritual and religious dimension

For the World Health Organization [43], the spiritual aspect of human life is integrated with the physical, psychological and social components. It refers to a reflection on the meaning and purpose of life. Furthermore, in the final stages, it is associated with forgiveness, reconciliation and affirmation of values.

Spirituality and religiosity are fundamental throughout the health-sickness process. Its importance depends on how each person defines and expresses it [21]. According to Ramezani., *et al*. [44] spiritual care has characteristics that allow it to define itself. Which are the healing presence, the therapeutic use of the self, the intuitive sense, the exploration of the spiritual perspective, the focus on the patient, the therapeutic intervention centered on meaning and the creation of a spiritually enriching environment.

Taking into account the findings of the review, the nurses showed interest in and respect for the patients' preferences. They contributed to their realisation, despite not being sympathetic or unaware of them. According to research conducted in the Netherlands, nurses must have specific characteristics to provide adequate spiritual care. For example, they must be sensitive, humane, warm, attentive, caring, well informed and involved [45]. By contrasting the findings with the characteristics, it could be said that nurses develop the care of this dimension in an appropriate way, which contributes to the well-being of the patient and his/her family.

However, there were some limitations in the nurses' ability to provide spiritual and religious care. For example, in an Iranian study, some nurses considered searching for beliefs in patients inappropriate or did not know how to address this dimension of care [46]. In Australia, one research nurse felt more comfortable intervening with Christian patients, because she could offend someone of another religion, due to ignorance [23].

These barriers can be due to different factors. They include a lack of training in spiritual care, personal preferences and a lack of time for listening to and interacting with the patient and family [23,46]. However, nursing can favour spiritual care. This would be achieved through a more in-depth assessment, showing the patient's preferences and revealing the needs in this area. The construction of a plan of care should be continuously evaluated and adjusted according to the findings. Besides, the support of the multidisciplinary team should be available [47].

Conclusion

The difficulties that nurses face during their practice can be considered to stem from the lower priority that psycho-social, cultural and religious dimensions have in the comprehensive care of the patient and family. Although the integration of the other dimensions of the self into palliative care is increasing, the biophysical approach still predominates. In this scenario, the resolution of symptoms such as pain, nausea, among others, predominates in end-of-life care.

Experience shows that nursing has a committed and humanised attitude to the critical care of the human being within palliative care. It seeks to investigate the needs of the subject of care and provide an effective solution. However, it does not have enough training and other resources to contribute to the provision of high-quality holistic care.

When analysing each dimension of care, it becomes evident that the cultural factor is present in each of the other dimensions and with strong involvement of nursing. For this reason, it is essential to recognise the importance of culture in lifestyles, the meaning of life, health, illness and death, in order to provide patient-centred care.

Conflict of Interest Statement

The objective of the development of this article is professional enrichment. For this reason, it is an academic purpose in which there is no conflict of interest.

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