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Perception of health professionals regarding palliative care

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Abstract

A growing body of evidence based on experience shows the importance of observing and refining knowledge about palliative care. This integrative literature review focuses on identifying the perceptions of health professionals towards patients in palliative care, an occupational phenomenon that results in instability in the emotional, occupational and social life of professionals and negative impacts on the care provided. This is a qualitative, exploratory and descriptive study, with data analysis by categorization in which, after assessing the evidence, the understanding of health professionals with patients in palliative care is drawn. The main contributions of works on the proposed topic are collected, drawing attention to the problem.

Keywords: Palliative Care, Perception, Health Professionals.

Resumo

Percepção de profissionais de saúde frente aos cuidados paliativos

Um corpo crescente de evidências baseado na experiência mostra a importância de observar e refinar o conhecimento sobre cuidados paliativos. Esta revisão integrativa literária concentra-se no objetivo de identificar as percepções de profissionais de saúde frente a pacientes em cuidados paliativos, um fenômeno ocupacional que resulta em instabilidade na vida emocional, ocupacional e social do profissional e impactos negativos ao atendimento prestado. O estudo obedece a uma metodologia de abordagem qualitativa e de caráter exploratório e descritivo, com análise de dados por categorização em que, após apreciação das evidências, desenha-se o entendimento dos profissionais de saúde com pacientes em cuidados paliativos. Além disso, reúne as principais contribuições de trabalhos sobre o tema proposto, atraindo atenção para a problemática.

Palavras-chave: Cuidados Paliativos. Percepção. Profissionais de Saúde.

Resumen

Percepción de los profesionales sanitarios sobre los cuidados paliativos

Un creciente conjunto de evidencia basada en la experiencia muestra la importancia de observar y perfeccionar el conocimiento sobre los cuidados paliativos. Esta revisión integradora de la literatura tiene como objetivo identificar las percepciones de los profesionales de la salud sobre los pacientes sometidos a cuidados paliativos, un fenómeno ocupacional que causa inestabilidad en el ámbito emocional, ocupacional y social del profesional, además de impactos negativos en el cuidado brindado. Este estudio utiliza una metodología cualitativa, de carácter exploratorio y descriptivo, con análisis de datos por categorización en el que, después de evaluar la evidencia, se perfila la comprensión de los profesionales de la salud con los pacientes en cuidados paliativos. Además, reúne los principales aportes de trabajos sobre el tema propuesto llamando la atención sobre el problema.

Palabras clave: Cuidados paliativos. Percepción. Profesionales de la Salud.

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The National Academy of Palliative Care (ANCP) was founded in 2005 by a group of physicians from different specialties, such as geriatrics, pediatrics, oncology and family medicine, with the main objective of clarifying, disseminating and promoting palliative care (PC) in Brazil.

When analyzing the approach of the World Health Organization (WHO) to PC, Sepúlveda [1] stated that the WHO's understanding of this form of care has been broadened to include more than just pain relief, which is an important component but by no means the only factor to consider. Patients' physical, emotional and spiritual needs are important concerns in PC. Furthermore, the WHO has broadened its definition in that it does not only take the patient into account, but also includes reflections on the health and well-being of the family members and caregivers involved, extending beyond the period of patient care and including support and advice for those who are grieving [1].

The importance of medical specialty in PC, as well as of training the multidisciplinary teams working in this area, has been emphasized by the aging of the population and the human need to receive biopsychosocial care that focuses not only on the patient, but on all those involved in the follow-up. Health professionals are faced with the responsibility and ethical dilemma of establishing the extent to which the principles of beneficence, non-maleficence and justice are being correctly applied in the care of patients with life-threatening illnesses. They are also faced with concerns about understanding and managing the principles of euthanasia, dysthanasia and orthothanasia.

The comprehensiveness of palliative care extends to the management of the grieving process of patients and their families or loved ones. For this reason, understanding the process of dying and death is essential for the health care teams involved in providing care, since living involves countless small deaths [2].

In a culture that believes that death must be conquered, rather than understood as an inexorable part of a natural process, it is important to emphasize, as Batista and Seidl [3] point out, that unlike euthanasia and dysthanasia, PC does not anticipate or prolong the death of a patient with a progressing advanced disease, but rather allows for a natural process of death, without unnecessary interventional measures. In other words, PC allows for a dignified death.

In addition to symptom management, other objectives of palliative support are: to set care goals in line with the patient's wishes; to establish effective communication between the patient and all those involved in their care; and to strengthen a support network with psychological, psychosocial and spiritual care and comprehensive care facilities for patients and their families or other informal caregivers. In view of this, the ANCP [1] states that the success of PC is directly related to the teamwork of the specialist physician and the multidisciplinary team.

The physician acts as a facilitator so that the whole team can work with the patient and help them exercise their autonomy. As a result, choices and decisions are shared between the patient, their family and the PC team. In this way, everyone shares responsibility for the production of health and life, thus fulfilling the purpose of caring for the patient in an integral, individualized way, with a focus on their well-being and quality of life, regardless of how advanced their illness is [4].

Based on reflection and a reading of the *Manual da Academia Nacional de Cuidados Paliativos* [5], it was understood that teamwork is one of the preconditions for PC and that, for this form of care to be effective, interpersonal and inter-area difficulties must be minimized. In this way, clinical practice can be effective and the team can care for patients in their biological, psychological, family, social and spiritual dimensions. For this to happen, each member of the team—physician, nurse, psychologist, social worker, nutritionist, physiotherapist, speech therapist, occupational therapist, spiritual assistant, dentist, among others—must perform their duties in harmony with the others, as explained by Consolim [4].

When faced with the patient's suffering, each professional uses their skills and abilities to offer unique and comprehensive assistance to the patient and family, ensured by the diversity of the team, as confirmed by Consolim [4]. The practice of PC requires the involvement of a multidisciplinary team with a synchronized architectural configuration. According to Peduzzi [6], teamwork follows a hierarchical order between physicians and non-medical staff, with the aim of distributing functions according to each professional's degree of subordination.

According to Andrade and collaborators[7], PC extends treatment to the individual rather than focusing solely on their pathology, thus requiring knowledge that goes beyond the control of signs and symptoms. According to Couto and Rodrigues[8], the lack of experience and knowledge hinders and compromises the quality of care. In this sense, Desanoski and collaborators[9] explained that, at present, it is noticeable that professional qualification in PC still suffers from deficiencies in training, and more encouragement is needed.

The daily experience with patients suffering from life-threatening illnesses allows health care teams to participate directly and indirectly in these patients' daily lives, identifying their worries and concerns, monitoring their progress and providing care. As a result, professionals come to live with a wide range of feelings, such as satisfaction and emotional involvement when providing care, or insecurity and anguish when there is a lack of information or communication between team members for curative professional action.

In view of the above, taking into account the scale of the subject and the importance of expanding and adding knowledge to corroborate the existing literature, the following question was raised as a problem to be investigated: what is the perception of health professionals regarding the palliative care process? This question is considered important not only to understand the situation of patients under palliative care, but also to contribute to the professionals involved in their treatment.

This study aims to identify health professionals' positive and negative perceptions of providing assistance to patients in palliative care.

Method

This is an integrative, descriptive and exploratory review of literature on health, with data processed using a qualitative approach and analyzed by categorization. Based on this, a search was carried out in the electronic databases of the U.S. National Library of Medicine and National Institutes of Health (PubMed), the Virtual Health Library (VHL) and the Scientific Electronic Library Online (SciELO), using the following Health Sciences Descriptors (DeCS), searched in three languages (Portuguese, English and Spanish): "Palliative care," "End of life," "Health professionals," "Perception" and "Emotions." The search resulted in 14,428 records, and after eliminating duplicates and applying the eligibility criteria, 34 articles were included in the study, as shown in Figure 1.

The inclusion and eligibility criteria for the articles included in this study were: originality of the studies, both quantitative and qualitative; presence of the terms and keywords of this study, as well as their combination, in the title and abstract; availability of the full text online; indexing in one of the bibliographic databases used, in Portuguese, Spanish and English; and publication from 2011 to 2023. Studies that were duplicates, incomplete or in correspondence format; published before 2011; or that did not address the variables in the research descriptors were automatically excluded. However, it is worth noting that two studies conducted before 2011 were included because of their importance to the theoretical framework of this article.

Four independent researchers selected the articles and extracted the data. Based on the descriptors, a survey was carried out in the electronic databases mentioned above, and by reading the title and abstract of the articles, those that met the inclusion and eligibility criteria were selected. After reading the full texts, the researchers selected the articles that would support the theoretical basis of this study and extracted the necessary data in order to fill in a Microsoft Excel 2010 spreadsheet for better systematization and general visualization of the studies, with the following pieces of information: author and year of publication; title of the article; type of study; country; target population; and perceptions of health professionals regarding patients in palliative care.

After extracting the data, the thematic-categorical analysis proposed by Bardin[10] was applied, which is divided into three stages: pre-analysis; exploration of the material; and treatment of the results, inference and interpretation. After the first two steps, which involved reading the texts and identifying health professionals' perception of patients undergoing PC, the central ideas of the selected articles were grouped together and condensed into thematic categories or analysis nuclei. Lastly, to encourage theoretical reflection in relation to the thematic categories, approximations were made with other findings in the literature, using theoretical references.

Results and discussion

This study sought to identify the perceptions of health professionals about the care provided to patients undergoing PC. The results are presented in two categories: positive and negative perceptions.

Of the 34 articles selected, 26 pointed out positive perceptions, while 31 emphasized negative aspects, with some texts being repeated. For better ordering, the subcategories that best encompass the ideas raised are listed below.

Positive perception: palliative care and a dignified process of death

By reading the articles researched, it was possible to identify the importance of PC for a dignified end of life in the words of health care professionals, noting that the main and most frequent themes addressed were: early prevention of suffering, providing a dignified death; provision of assistance to the patient in the face of physical and mental symptoms; humanized and integrated care with family members; and comfort for the patient.

Notably, physicians identify the need to manage the patient in a comprehensive way, involving PC in their conduct, with the aim, at this stage, of offering quality of life and death, relieving physical and mental symptoms, providing comfort and well-being, as well as specialized and qualified treatment, and welcoming the patient's needs, as explained by Freitas and collaborators [11].

The priority of PC is to offer comfort to the patient with measures that relieve pain in a humanized way, without intervening in the physiological process of the disease and respecting the patient's wishes, as well as providing family integration during this phase. In this way, it is possible to offer a dignified death by applying measures so that the patient does not feel pain in the face of a terminal illness, according to Silva Júnior and collaborators [12].

The implementation of PC in patient treatment was found to improve quality of life and survival, in addition to guiding the team in implementing interventions according to the needs of each patient. As it also acts to control conditions such as anxiety and depression, which are sometimes present in terminally ill adults, the support of a professional or caregiver is essential in this process, as stated by Dellon and colleagues [13].

Professionals understand that the purpose of PC is to alleviate suffering rather than reverse the disease process, offering resources that are pleasurable and respect the patient's wishes. The approach should focus on the patient, offering comfort, and also on treating the family, which is one of the essential pillars in the PC method and deserves care, according to Mendes and collaborators [14].

Good communication is essential in the process of dying, so as to provide quality care at a delicate time. Maintaining an active dialog between health professionals, patients and their families is also crucial, as is communicating possible necessary measures and consulting the patient's wishes, together with family members. In addition, the diagnosis and progression of the condition must be informed to the patient and family, as this is essential for understanding the situation. Religion is also addressed in PC practice, proving to be of great value in making it easier to cope with the dying process, according to Fearon and collaborators [15].

Positive perception: welcoming attitude of health professionals

The health professional's understanding of the fragility and vulnerability of the patient and family members strengthens the relationship with the patient and favors excellence in care, a fact highlighted in most of the studies included in the research as a strong and important point of palliative care.

According to Ngwenya, Ambler and Archary [16], continuity of care in the community requires training, since lack of skills and insecurity make family members see health networks as the only alternative for caring for sick loved ones, overloading the units and, in a way, distancing the patient at times when they most need comfort and family support. Furthermore, the number of professionals is not sufficient to deal efficiently with all the palliative care patients who are discharged.

The observations of Harasym and collaborators[17] indicated difficulties on the part of families in understanding the fragility and accepting the condition of their loved one, as they had unrealistic views and expectations and believed in curative medicine, expressing grief in a very pronounced way. Faced with the patient's suffering and the grief of their relatives during the dying process, health professionals must know how to guide them during a time of many feelings and uncertainty. Among the feelings presented, those of incapacity and fragility in the face of the patient's organic pain and psychological suffering are strong, and it is important to welcome and promote comfort, as advocated by Fernandes and collaborators[18], emphasizing that quality of life is achieved by relieving pain and suffering.

In this way, welcoming patients means welcoming their families, establishing a physician-patient-family link and providing support and training so that they have quality of life, in a process in which the health professional is the mediator.

Positive perception: the patient as the protagonist of their own care

It is clear that patients need to understand the whole process of their illness so that the measures to be implemented take account of their situation and aim to improve their quality of life, ensuring that they are the protagonists of their own care. It is essential that the medical and multidisciplinary team realize that self-care can be affected by the course of the disease and that their work will be one of conscious mediation, aimed at improving the condition of the patient and the family members involved.

The study by Tarberg and collaborators[19] endorses the importance of the participation of patients and their families in palliative care at different stages, as well as the crucial role of physicians in promoting this participation. Person-centered care allows health professionals to encourage the patient's autonomy and participation in decision-making, enabling them to become an active part of their care. However, there can be difficulties on the part of both the patient and the physician, due to misperceptions about palliative care, reinforcing the importance of good communication and early clarification, as well as therapy[20].

Klop and collaborators[21] approached the subject with a focus on homeless people, who usually have psychiatric or intellectual disorders and alcohol and drug dependency, as well as conflicting relationships and less autonomy, which impacts on their understanding of the importance of self-care and generates low adherence.

Another group that deserves special attention are adolescents. With challenges that differ from those of adults, such as multigenerational involvement, self-esteem, school absence and moral distress, adolescents have peculiarities that must be taken into account. Thus, professional training is needed to manage and succeed in playing a leading role in caring for this public[16].

The results of the studies confirm that care must be planned and carried out in harmony, involving the multidisciplinary team and respecting the patient's decisions. In addition, the patient should be involved in assisting with the care plan, as well as family members in the event of the patient's inability to be autonomous, not only by providing individualized care, but also by explaining the meaning and importance of good palliative care practices and understanding the limitations of the body, so as to include the social, emotional and spiritual spheres for the success of this process.

Negative perception: lack of knowledge, professional and structural incapacity

In terms of the difficulties in understanding PC, most of the articles addressed the lack of trained professionals and the inadequacy of the structure for care. The most cited issue was the lack of contact with the topic of PC during graduation, which makes it difficult to deal with the patient[11].

The study by Freitas and collaborators[11], for example, reported a lack of professionals trained for PC. It was found that the real problem lies at the level of undergraduate medicine and health courses, which do not offer PC as a subject for undergraduates and do not provide training for them to learn how to deal with terminally ill patients—the main teaching approach is the identification and treatment of diseases. Consequently, the lack of information and training in palliation makes it difficult to make decisions about, for example, starting and ending treatments, talking about death with patients and their families and deciding on the most appropriate courses of action in these situations, which impairs care and can cause pain and suffering for patients, their families and the multidisciplinary team.

This problem is common in all fields of health care. Nurses, for example, report having difficulties in managing patients who need PC, as they have a lack of academic training on the subject, emphasizing that, during the course, the focus of learning is directed towards the treatment and rehabilitation of diseases. It was observed that the main concern of health care courses is work with patients who are going to recover. As a result, there is a shortage of professionals trained to deal with the process of death and there is a lack of communication with patients and in dealing with the situation [22].

This lack of knowledge is common and persists in postgraduate courses, reinforcing the fact that since PC is widely used in hospital environments, it should be a subject during the training of professionals. According to Alcântara [23], many of the problems faced in the practice of PC are linked to the technical and scientific unpreparedness of professionals. The shortage of professionals experienced in PC makes it difficult to manage patients, mainly due to the lack of preparation to use equipment, as many professionals do not have adequate training to deal with the structure and technology of the intensive care unit (ICU).

In addition, professionals report environments that are not very welcoming, without a comfortable and pleasant structure, which should be implemented to meet the need for humanized approaches. The environment is an important factor for PC, and hospitals in general do not offer suitable places for end-of-life situations [24]. This difficulty is prevalent in rural areas, where there is a shortage of physicians, which restricts the practice of PC, along with a shortage of resources and specialized services to manage terminally ill patients in a dignified manner [16].

Negative perception: family resistance to palliative care

Family resistance to PC is described in the study by Harasym and collaborators [17] as being motivated by a lack of knowledge, family fragility, unrealistic expectations and emotional reactions to grief and uncertainty. Also contributing to this are feelings of anger, hostility and denial, which come along with difficulties in accepting the process of dying [25]. Health professionals report that communication with patients' families can be stressful and difficult, which is related to the relatives' difficulty in accepting that they cannot save their loved ones' lives [12].

The results of studies on PC are revealing in terms of practices that promote family acceptance and understanding of end-of-life care [17]: validating family concerns, having adequate symptom assessment tools, providing guidance on PC and adapting the physical and social environment to support death and grief with dignity. Therefore, professionals trained in PC play an important role in managing and dealing with this resistance, comforting and assisting family members during the process of death and dying.

Negative perception: difficulty in dealing with mixed feelings

Health professionals described the emotional and cultural challenges, as well as those related to beliefs, that make it difficult to work with caregivers or children in life-threatening conditions. These professionals often felt that there was little or no opportunity to reflect on the emotional impact of their work with colleagues, due to the large number of patients. They described feeling ill-prepared to give adequate support to families with serious illnesses, which affected their confidence in working with these groups of patients. They also described that they acknowledged the need to respect patients' beliefs regarding the use of traditional (non-medical) methods to treat illnesses [26].

Many professionals experience different emotions when dealing with patients and their families. Vázquez-García and collaborators [27] pointed out that when professionals are unable to provide an adequate level of care for terminal illnesses, they become frustrated and unprepared, causing greater suffering for family members.

The studies carried out by Costa and collaborators[25] verified, using interviews, the emergence of ambiguous feelings in nursing professionals after the death of patients who had been under their care for a considerable period of time. They pointed out that there was a lack of professional preparation for the feeling of loss, even if it was to relieve the patient's suffering. In turn, the studies by Monteiro, Mendes and Beck[28] showed physicians' own perception of how others perceive their indifferent stance towards death, which contrasts with the way they see themselves or act.

In view of the above, it is clear that health teaching institutions should include a subject in their curriculum that qualifies and psychologically prepares professionals to provide palliative care.

Final considerations

By searching data, this article identified health professionals' positive and negative perceptions of patients in palliative care. As a result, divergent and convergent perceptions were observed among members of health care teams. Using an integrative, descriptive and exploratory approach, the study found points that need to be improved so that the care provided to PC patients achieves quality and efficiency goals, benefiting health professionals, patients and families.

For common benefit, with the support of the proposal in CNE/CES Resolution No. 3, of June 20, 2014[29], ratified in 2022, it is proposed that medical students be given a compulsory subject covering palliative care. Raising awareness among the technical staff of health institutions by developing and improving teams in this area, via training and extension courses is an important task.

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Participation of the authors

Cláudia Cordeiro Guerra developed the scientific project, defined the methodology and bibliographical research and took part in the discussion of the results, drafting and writing of the manuscript, critical review of the article, writing of the final considerations and final review. Jardson Ladeira de Lucena developed the scientific project, determined the topic and the bibliographical research and took part in the discussion of the results, drafting and writing of the manuscript, critical review of the article and final review. Maria Beatriz Silva de Andrade took part in the scientific project, bibliographical research, data analysis, data collection and drafting and writing of the manuscript; and assisted with the analysis of the material and the final review. Suellen da Silva Evangelista Alves took part in the scientific project, bibliographical research, data analysis, data collection and drafting and writing of the manuscript; and assisted with the analysis of the material and the final review. Caroline Lima Garcia supervised the research, developed the scientific project, determined the methodology and bibliographical research and took part in the discussion of the results, drafting and writing of the manuscript, critical review of the article, writing of the final considerations and final review.

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Appendix

Figure 1. Flowchart of the articles found with the descriptors set and those selected for the study.