PERCEPTION OF HEALTH PROFESSIONALS WORKING IN PRIMARY CARE ABOUT PALLIATIVE CARE

PERCEPÇÃO DE PROFISSIONAIS DA SAÚDE QUE ATUAM NA ATENÇÃO PRIMÁRIA SOBRE CUIDADOS PALIATIVOS

PERCEPCIÓN DE LOS PROFESIONALES SANITARIOS QUE TRABAJAN EN ATENCIÓN PRIMARIA SOBRE LOS CUIDADOS PALIATIVOS

https://doi.org/10.56238/sevened2025.021-065

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RESUMO

Os Cuidados Paliativos constituem uma abordagem centrada na qualidade de vida de pacientes e seus familiares, frente a doenças que ameaçam a continuidade da vida. Este artigo tem o objetivo de analisar a percepção de profissionais da saúde que atuam em equipes da Atenção Primária, sobre os cuidados paliativos. Foi realizada uma pesquisa de campo do tipo qualitativa, utilizando-se de uma entrevista destinada a profissionais que trabalham em equipes da Estratégia Saúde da Família (ESF) de Unidades Básicas de Saúde (UBS) num município localizado na Região de Saúde do Extremo Oeste de Santa Catarina. Participaram do estudo, 15 profissionais de saúde, dentre os quais, 6 enfermeiros, 7 técnicos de enfermagem e 2 médicos. A análise das informações obtidas, permitiu compreender, percepções, sentimentos e desafios enfrentados no contexto dos Cuidados Paliativos. Embora, os profissionais reconheçam a necessidade do cuidado voltado para a dignidade, o alívio da dor e o suporte ao paciente em fim de vida, há limitações que comprometem a qualidade da assistência. Como, lacunas na formação profissional, ausência de protocolos institucionais e desconhecimento sobre as Diretivas Antecipadas de Vontade (DAV). Para que os Cuidados Paliativos sejam efetivos e humanizados, é importante o investimento em Educação Permanente, políticas públicas específicas, valorização da equipe multiprofissional e fortalecimento da rede de apoio ao paciente e sua família. Assim, será possível oferecer um cuidado digno, ético e compassivo, que respeite a vida em todas as suas fases, inclusive em seu desfecho.

Palavras-chave: Cuidados Paliativos. Bioética. Saúde Pública.

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ABSTRACT

Palliative Care is an approach focused on the quality of life of patients and their families, when faced with life-threatening diseases. This article aims to analyze the perception of health professionals who work in Primary Care teams, about palliative care. A qualitative field study was conducted, using an interview with professionals who work in Family Health Strategy (ESF) teams of Basic Health Units (UBS) in a city located in the Health Region of the Far West of Santa Catarina. Fifteen health professionals participated in the study, including 6 nurses, 7 nursing technicians and 2 physicians. The analysis of the information obtained allowed us to understand the perceptions, feelings and challenges faced in the context of Palliative Care. Although professionals recognize the need for care focused on dignity, pain relief and support for patients at the end of life, there are limitations that compromise the quality of care. Such as gaps in professional training, lack of institutional protocols and lack of knowledge about Advance Directives (ADs). For Palliative Care to be effective and humanized, it is important to invest in Continuing Education, specific public policies, appreciation of the multidisciplinary team and strengthening of the support network for the patient and their family. This will make it possible to offer dignified, ethical and compassionate care that respects life in all its phases, including its outcome.

Keywords: Palliative Care. Bioethics. Public Health.

RESUMEN

Los Cuidados Paliativos son un enfoque centrado en la calidad de vida de los pacientes y sus familias ante enfermedades potencialmente mortales. Este artículo busca analizar la percepción de los profesionales de la salud que trabajan en equipos de Atención Primaria sobre los cuidados paliativos. Se realizó un estudio de campo cualitativo mediante entrevistas con profesionales de la Estrategia de Salud Familiar (ESF) de Unidades Básicas de Salud (UBS) de una ciudad de la Región de Salud del Extremo Oeste de Santa Catarina. Participaron en el estudio quince profesionales de la salud: seis enfermeros, siete técnicos de enfermería y dos médicos. El análisis de la información obtenida permitió comprender las percepciones, los sentimientos y los desafíos que enfrentan en el contexto de los Cuidados Paliativos. Si bien los profesionales reconocen la necesidad de una atención centrada en la dignidad, el alivio del dolor y el apoyo a los pacientes al final de la vida, existen limitaciones que comprometen la calidad de la atención, como las deficiencias en la formación profesional, la falta de protocolos institucionales y el desconocimiento de las Instrucciones Anticipadas (IDA). Para que los Cuidados Paliativos sean eficaces y humanizados, es importante invertir en Educación Continua, políticas públicas específicas, valorar al equipo multidisciplinario y fortalecer la red de apoyo para el paciente y su familia. Esto permitirá ofrecer una atención digna, ética y compasiva que respete la vida en todas sus etapas, incluyendo su desenlace.

Palabras clave: Cuidados Paliativos. Bioética. Salud Pública.

INTRODUCTION

Palliative Care refers to a set of approaches aimed at improving the quality of life of patients and their families in the face of terminal or life-threatening illnesses. These interventions aim to prevent and alleviate suffering, including the identification of the disease, treatment and monitoring of pain, as well as other physical, social and psychological symptoms (Alecrim; Miranda; Ribeiro, 2020).

Anyone affected by a life-threatening illness, whether acute or chronic in nature, regardless of age, is eligible for Palliative Care. The need for care needs to be present at all levels of health care: primary, secondary, and tertiary, with specialized services (D'Alessandro et al., 2023).

Palliative Care is considered as the line of care whose main objective is to preserve quality of life and provide comfort as the disease progresses. This type of care requires a trained team to be able to attend to all dimensions of the patient (INCA, 2023).

The perception of terminality often awakens feelings such as sadness, impotence, frustration and anguish in professionals, especially when it is perceived that the possibilities of cure have been exhausted. The daily experience with the finitude of life provokes a process of anticipated mourning and reflection on the meaning of professional performance, generating internal conflicts between the desire to preserve life and the acceptance of the natural cycle of death. In addition, emotional involvement with patients can generate psychic overload and affect the mental health of professionals (Guerra et al. 2024).

The most convenient form of excellence in care is the Permanent Education of the entire team responsible for patient care in Palliative Care, with a qualified team, a satisfactory result is possible (Cardoso et al., 2013; Vasques et al., 2013). Comprehensive care requires assistance to different needs of patients and families, in addition to the physical aspect, there are emotional, psychological, social and spiritual demands that arise during this process. In this aspect, the multidisciplinary approach facilitates communication between professionals, patients and family members, allowing an individualized care plan adjusted to changes in clinical status. Joint action not only improves the quality of care, but also promotes a supportive and welcoming environment (WHO, 2020).

Despite the difficulties, many professionals report that working in Palliative Care also provides a deep feeling of empathy, humanization and resignification of care. The experience of accompanying the end of life in a compassionate way allows for a broader understanding of health care, centered on respect, active listening, and welcoming. Health professionals who deal with patients in Palliative Care intensely experience the suffering and pain of the other, and often feel as if "life is ending", not only for the patient, but also as a feeling of helplessness in the face of death. Even so, this practice can be transformative, both personally and professionally, by strengthening human and ethical bonds in care (Hermes; Lamarca, 2013).

Palliative care is part of the Health Care Network in the Unified Health System (RAS-SUS) through the care of a multiprofessional team, according to Ordinance No. 825 of April 25, 2016 (Brasil, 2016). Therefore, it is considered important to understand how Primary Care professionals who work in Family Health Strategy (ESF) teams perceive Palliative Care care in their daily work.

METHODOLOGY

The research was carried out in a municipality located in the Far West Health Region of Santa Catarina, using a qualitative approach. The study was exploratory, the participants included were health professionals working in the Basic Health Units (UBSs) of the city and linked to the Family Health Strategy (ESF) teams. Among them: doctors, nurses and nursing technicians of both sexes and of legal age. Professionals who were on medical leave, leave or vacation during the data collection period were excluded from the survey.

The survey was conducted from February 20 to March 14, 2025 and the interview was applied at the participants' workplace. The answers were transcribed and the information was analyzed, using the Thematic Content Analysis, proposed by Minayo (2014), which consists of three stages: 1) pre-analysis - organization of the material for later analysis, based on floating reading; 2) exploration of the material - cutting of common and significant information, creating thematic categories; and, 3) treatment of the results obtained and interpretation - interpretation of the results, based on the objectives of the study. With the intention of maintaining confidentiality and preserving the identification of the participants, they will be named as E1 sequentially until E15 in the presentation of the research results.

The research project was submitted to and approved by the Research Ethics Committee (CEP) under Opinion No. 7,261.

RESULTS AND DISCUSSION

A total of 15 professionals participated in the study, including 6 nurses, 7 nursing technicians and 2 physicians. All participants are part of FHS teams in the city studied. The results obtained reveal perceptions about Palliative Care, limitations in practices and gaps in professional training. There was a manifestation of a participant who had a specific orientation or discipline in his professional training, about Palliative Care and another acquired a course on the subject to better understand the subject.

Let us see the manifestations that illustrate the apprehension of the participants:

"No, but in the last semester of the course I acquired a course with visas for oncology and palliative care" (E9).

"I didn't have any specific discipline, only guidance within other subjects" (E3).

According to Costa, Poles and Silva (2016) there is a training gap in universities regarding the preparation of future professionals for the humanized, ethical and competent handling of the death and dying process. Under this focus, it is necessary to strengthen both theoretical teaching and clinical practices related to Palliative Care, recognizing that the care of terminally ill patients requires specific knowledge, communication skills and an empathetic posture, centered on human dignity.

By emphasizing and encouraging research aimed at qualifying training in Palliative Care, Costa, Poles and Silva (2016) point to the need for scientific production that complements educational and care policies that are more sensitive to the demands of patients and their families. Such academic and pedagogical investment is essential for the dying process to be understood as part of comprehensive health care, ensuring quality until the end of life.

Participants associated the finiteness of patients' lives with end-stage illnesses and with easing pain and comforting family members. It is noted in the reports, the apprehension about Palliative Care:

"Comfort measures offered and patients in the final stage of life" (E1).

"An action that the team must provide to the patient with a life-threatening diagnosis, addressing not only the patient's physical health but also the mental health, as well as the social health of his family" (E2).

"Comfort for death. I understand that this is care that extends to patients who will not have their health restored" (E8).

"The objective is to improve the quality of life of people with serious diseases, with no possibility of cure" (E11).

Palliative Care seeks to prevent and alleviate suffering through early identification, assessment, and effective treatment of pain and other physical, psychosocial, and spiritual symptoms (WHO, 2020).

When asked about their feelings when caring for palliative patients, the professionals demonstrate emotional involvement. The answers indicate feelings such as empathy, emotional discomfort due to the lack of prior preparation, responsibility, and even impotence, associating palliative care with terminal patients with no possible curative treatments.

"Most of the time palliating the patient is similar to sentencing him to death. There is no adequate care and, several times, the situation is not respected, resulting in dysthanasia" (E1).

"I feel emotional discomfort in knowing that there is nothing more to be done" (E4).

"I feel the responsibility to redouble the care ensuring the patient's comfort" (E7).

"I feel emotional unpreparedness and lack of knowledge" (E10).

"I often feel unprepared for fear of not knowing how to say the right thing" (E11).

"Frustration, impotence for not being able to do anything else" (E13).

"Empathy for the patient" (E14).

Filizola and Ferreira (1997) highlight that health professionals experience ambiguous feelings in the care of patients in Palliative Care. They report emotions such as sadness, impotence, frustration, depending on institutional preparation and support. The study recommends improvements in training and professional practice, such as the mandatory inclusion of Palliative Care in medical curricula. They also emphasize the importance of continuous improvement of the teams, through training and qualification, aiming at a more efficient, ethical and humane care for patients, families and professionals.

Regarding Palliative Care protocols and the frequency they are used, the participants informed that they are unaware of the existence of a specific protocol in the Unit

"There is no protocol at the UBS" (E3).

The inclusion of a Palliative Care protocol, with a combination of pharmacological and non-pharmacological therapies, occupational therapy and physiotherapy, contributes to the effectiveness of symptom relief. Studies have indicated that Palliative Care protocols have a positive impact on the quality of life of patients with chronic diseases. Interventions such as pain management, management of associated symptoms (e.g., nausea, dyspnea, and fatigue), and management of psychosocial symptoms have consistently been effective (Carminate *et al.* 2024).

However, the participants recognize that Palliative Care should be provided by a multidisciplinary team, with nurses, doctors, psychologists, nutritionists, physiotherapists, as well as family members and trained caregivers. Some mention that the provision of care must be individualized, according to the needs of each patient, and that the emotional and psychological care of the family is also essential.

"It should be applied in a multidisciplinary manner, with a return time for reassessments, as well as care for the family" (E2).

"It should be performed by family members or caregivers together with the health team as the main objective of the patient's quality of life" (E3).

"By properly trained health professionals" (E9).

Palliative Care presupposes the action of a multiprofessional team, the integrated approach allows different demands to be solved together, promoting more effective and humanized care (Hermes; Lamarca, 2013).

In Palliative Care, especially in the context of Primary Health Care, the medical professional assumes a central and multifaceted role, which involves everything from clinical diagnosis to the promotion of comfort and dignity of the terminal patient. The physician is responsible for diagnosing diseases and defining the most appropriate therapeutic conduct, always with the objective of promoting the relief of physical suffering and ensuring the quality of life of patients, especially in the home environment.

In this context, the importance of Advance Directives (AVDs) as an instrument that can guarantee respect for patients' autonomy and personal values is highlighted (Cetolin *et al.*, 2024). In the end, as at any other time in life, human dignity must be respected, and it is necessary to guarantee the involvement and autonomy of the patient in the decision-making process about his own finitude.

In the research, all participants manifested ignorance in relation to the VAD, *"I don't know of any Advance Directive"* (E10).

Vanzella *et al.* (2023), advises that knowledge about DAV is important, but recognizes that the absence of legislation on advance directives in Brazil represents an obstacle to the effective implementation of this right to the population, since it can generate legal uncertainty and lead laypeople to question its validity and applicability. In view of this, it is essential to make legal, cultural, and structural changes in health institutions, professional entities, and educational institutions that regulate AVDs, ensuring legal support for both health professionals and patients, strengthening individual autonomy, and promoting safer clinical decisions aligned with the values and desires of patients.

Death is inherent to life, it is inseparable from it and, therefore, it should be thought of and discussed like all other aspects related to being alive (Cortiano, 2015).

FINAL CONSIDERATIONS

The analysis of the information obtained from health professionals working in Primary Care allowed us to understand the perceptions, feelings and challenges faced in the context of Palliative Care. It was evident that, although professionals recognize the importance of care focused on dignity, pain relief and support for patients at the end of life, there are important limitations that compromise the quality of care.

Emotionally, the participants reported feelings of helplessness, frustration, fear and anguish in the face of death, especially because they did not feel sufficiently prepared to deal with this delicate moment. This scenario reveals not only a deficit of academic and technical training, but also the lack of institutional support aimed at caring for the health professional himself.

Another point highlighted was the lack of specific protocols in the units, which contributes to practices that are far from the principles of Palliative Care. The lack of knowledge about Advance Directives (AVD) on the part of the participants demonstrates a gap in the exercise of patient autonomy and in the promotion of ethical and personalized care.

In view of this panorama, it is necessary to rethink health education, incorporating specific disciplines on Palliative Care into the curricula, with an emphasis on the development of technical, communicational and ethical skills. In addition, it is necessary to promote the continuous training of teams, with regular training that addresses both clinical and emotional aspects.

The institutionalization of clear protocols and the encouragement of the adoption of VADs are ways to ensure greater legal certainty, respect for the patient's autonomy, and care that is more aligned with their needs and desires. The importance of creating spaces for listening and psychological support for professionals is also highlighted, allowing them to cope with the emotions that emerge in the care process in a healthy way.

It is concluded that, for Palliative Care to be effective and humanized, it is essential to invest in Permanent Health Education, specific public policies, valuing the multiprofessional team and strengthening the support network for patients and their families. Only in this way will it be possible to offer dignified, ethical and compassionate care, which respects life in all its phases, including its outcome.

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