

Terminal care: An approach from the perspective of palliative care

Assistência terminal: uma abordagem na perspectiva dos cuidados paliativos

Asistencia terminal: Un enfoque desde la perspectiva de los cuidados paliativos

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Abstract

Introduction: Palliative care is a multidisciplinary support practice applicable at all levels of healthcare, effective in improving the quality of life for patients and families facing life-threatening conditions. The dissemination of knowledge about care for terminal patients can broaden understanding of the needs and challenges faced by this population, as well as support the development of more inclusive health policies. **Objective:** Therefore, this article aims to describe care for terminal patients, encompassing the dimensions of palliative care and symptom and pain management. **Methods:** This is a narrative literature review with a qualitative focus. The management of patients in palliative care includes spiritual support, the opportunity to resolve personal matters, having an active voice in the dying process, and minimizing physical and emotional suffering. **Results:** Pain and symptom control involves understanding that the patient's experience is individual and influenced by various factors, such as gender, age, culture, and social support. **Conclusions:** Therefore, a multidisciplinary, integrative, continuous approach with communication skills and an individualized therapeutic plan is essential.

Keywords: Palliative care; Terminally ill; Pain management; Quality of life.

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Resumo

Introdução: Cuidados paliativos são práticas multidisciplinares de suporte aplicáveis em todos os níveis de atenção à saúde, eficazes para melhorar a qualidade de vida de pacientes e familiares enfrentando condições ameaçadoras à vida. A disseminação de conhecimento acerca da assistência aos pacientes terminais pode ampliar o entendimento sobre as necessidades e os desafios enfrentados por essa população, além de subsidiar a elaboração de políticas de saúde mais inclusivas. **Objetivo:** Assim, este artigo tem como objetivo descrever acerca da assistência aos pacientes terminais, abrangendo as dimensões “cuidados paliativos” e “manejo dos sintomas e da dor”. **Métodos:** Trata-se de uma revisão narrativa da literatura com um enfoque qualitativo. O manejo do paciente em cuidados paliativos inclui apoio espiritual, oportunidade de resolver assuntos pessoais, possuir voz ativa no processo de morte e ter o sofrimento físico e emocional minimizados. **Resultados:** O controle da dor e dos demais sintomas inclui o entendimento de que a experiência do paciente é individual e sofre interferência de diversos fatores, como sexo, idade, cultura e suporte social. **Conclusões:** Por isso, é necessária uma assistência multidisciplinar, integrativa, contínua, com habilidades de comunicação e um plano terapêutico individualizado.

Palavras-chave: Cuidados paliativos; Doente terminal; Manejo da dor; Qualidade de vida.

Resumen

Introducción: Los cuidados paliativos son prácticas multidisciplinares de apoyo aplicables en todos los niveles de atención de salud, eficaces para mejorar la calidad de vida de los pacientes y sus familiares que enfrentan condiciones que amenazan la vida. La difusión del conocimiento sobre la atención a pacientes terminales puede ampliar la comprensión de las necesidades y desafíos que enfrenta esta población, además de respaldar la elaboración de políticas de salud más inclusivas. **Objetivo:** Por lo tanto, este artículo tiene como objetivo describir la atención a pacientes terminales, abarcando las dimensiones de cuidados paliativos y el manejo de síntomas y dolor. **Métodos:** Se trata de una revisión narrativa de la literatura con un enfoque cualitativo. El manejo del paciente en cuidados paliativos incluye apoyo espiritual, la oportunidad de resolver asuntos personales, tener voz activa en el proceso de muerte y minimizar el sufrimiento físico y emocional. **Resultados:** El control del dolor y otros síntomas implica comprender que la experiencia del paciente es individual y está influenciada por diversos factores, como sexo, edad, cultura y apoyo social. **Conclusiones:** Por ello, se requiere una atención multidisciplinaria, integradora, continua, con habilidades de comunicación y un plan terapéutico individualizado.

Palabras clave: Cuidados paliativos; Enfermo terminal; Manejo del dolor; Calidad de vida.

INTRODUCTION

Palliative care is a multidisciplinary supportive approach applicable across all levels of healthcare, with demonstrated effectiveness in enhancing the quality of life for patients and families facing life-threatening conditions, particularly terminal illnesses, regardless of age. In addition to promoting improved quality of life, characterized by reduced physical and psychological suffering, increased capacity for social interaction, and greater family acceptance, palliative care has also been shown to extend survival in certain cases. Effective management of these needs relies on coordinated integration among the healthcare team, the patient, and the family.^{1,2}

Although recognized as a human right, palliative care is frequently excluded from health policies and remains limited in terms of public access and professional training. This is largely due to a lack of awareness regarding its benefits, stigma associated with opioid use, socioeconomic and cultural barriers, and the misconception that it is intended solely for specific groups, such as cancer patients.^{1,2} Moreover, palliative care is often restricted to a small number of patients, as it tends to be centralized in hospitals and specialized clinics, thereby limiting accessibility and distancing patients from their home and family environments. Ensuring access to care within a social and familial context near the patient's home significantly contributes to comfort, while also supporting the principles of continuity, comprehensiveness, and proximity of care. These principles, which are central to palliative care, reinforce the humanization of the process and promote broader access, increased comfort for all involved, and the potential for dehospitalization and its associated benefits for eligible patients.³

Disseminating knowledge and increasing awareness of the importance of palliative care are essential steps toward transforming the perception and delivery of healthcare for terminally ill patients, ensuring access to the comprehensive care they deserve, regardless of the underlying condition.⁴ Terminal illnesses are defined as conditions for which curative treatments are either insufficient or ineffective, typically characterized by progressive deterioration that ultimately leads to death. However, in chronic diseases such as Alzheimer disease, AIDS, cardiovascular disease, and chronic obstructive pulmonary disease, predicting the time until death remains challenging.⁵ As such, the care of terminally ill patients presents a complex and multidimensional challenge, to which palliative care offers an essential and appropriate response.

In this context, expanding research on the care of terminally ill patients may enhance understanding of the needs and challenges faced by this population and support the development of more inclusive health policies. Accordingly, the present study aimed to describe the care provided to terminally ill patients, focusing on the dimensions of “palliative care” and “symptom management,” with particular emphasis on pain.

METHODS

This study is a narrative literature review employing a qualitative approach. This methodology is particularly suited for theoretical and conceptual analysis, enabling comprehensive discussion through the examination and interpretation of diverse bibliographic sources. It offers a broad overview of the selected topic.⁶ To ensure the quality of the review, the criteria outlined in the Scale for the Assessment of Narrative Review Articles (SANRA) were applied. According to this protocol, a narrative review should include: 1) justification and relevance of the study; 2) clearly defined objectives; 3) description of the literature; 4) and 5) references and the level of evidence supporting the main arguments; and 6) adequate presentation of the data.⁷

The analysis of the studies involved identifying recurring themes and comparing various perspectives, approaches, and recommendations. The synthesis was conducted interpretatively, taking into account the similarities and contrasts among the findings. Although no formal methodological appraisal tool was employed, preference was given to articles with clearly defined structures, consistent theoretical frameworks, and well-organized presentation of results.

The selected descriptors — (Terminally Ill); (Palliative Care); (Patient-Centered Care); (Pain Management); (Symptom Management) — were combined using the Boolean operator AND in search strategies applied to the PubMed, Latin American and Caribbean Literature in Health Sciences (LILACS), and Scientific Electronic Library Online (SciELO) databases. The exact search strings used were: 1. (Palliative Care) AND (Terminally Ill); 2. (Patient-Centered Care) AND (Terminally Ill); 3. (Pain Management) AND (Terminally Ill); 4. (Symptom Management) AND (Terminally Ill). Strings 1 and 2 were used to assess the dimension of palliative care for terminally ill patients, while strings 3 and 4 focused on pain and symptom management in this population.

Study screening and analysis were conducted manually in August 2024 by two independent reviewers. Articles published between 2020 and 2024 that met the predefined inclusion criteria were selected, while other types of texts, publications outside the specified timeframe, and/or articles unrelated to the topic were excluded. The final bibliographic sample comprised 20 studies.

RESULTS AND DISCUSSION

Palliative care assistance for terminally ill patients

Studies indicate that patients' recognition of terminal illness as a stage in the disease trajectory is associated with increased concern about death, but also with a preference for symptom-focused palliative care rather than life-prolonging treatments. This group of patients also demonstrated higher engagement in end-of-life discussions with their attending physicians, greater completion of advance directives, and fewer hospitalizations during the final month of life.

In contrast, failure to recognize the absence of curative intent was associated with lower adherence to palliative care and prolonged hospitalizations during the 30 days preceding death.^{8,9} These findings highlight the positive impact that a full understanding and acceptance of the prognosis can have on the patient's active involvement in the development of their therapeutic plan and in preparation for the dying process.

Higher levels of concern about death were more strongly associated with a preference for life-prolonging therapies, even when such treatments extended suffering, as well as with lower adherence to advance directives,⁸ reinforcing the significant role of emotional factors in decision-making among terminally ill patients.

Terminal illnesses are accompanied by significant challenges, including progressive physical decline and its psychological impact on both patients and their family members. As such, the provision of dignity throughout the terminal phase of illness is a fundamental principle of palliative care.¹⁰

Anxiety, fatigue, sadness, and depression are highly prevalent symptoms among patients receiving palliative care, alongside physical symptoms such as pain, fever, and nausea.^{3,11} Preserving quality of life requires the assessment, recognition, and treatment of both physical and psychological symptoms that adversely affect well-being.³ Psychotherapeutic interventions, such as Dignity Therapy, have demonstrated a protective effect against further deterioration of mental health by alleviating psychological distress in both patients and their families. This approach fosters a sense of meaning, affirms the value of life, and facilitates patient engagement in decision-making throughout the course of the illness.¹⁰

Spirituality is also a significant factor in terminal palliative care, and its integration into clinical practice requires active listening to the patient's beliefs and respect for their values. A descriptive correlational study conducted in São Paulo found that 92.6% of participants reported having a religious belief. The study also demonstrated a moderate negative correlation between depression and spiritual well-being, indicating that patients with greater satisfaction in their spirituality tend to experience fewer depressive symptoms.¹¹

It is important to inform patients that, as death approaches, certain symptoms may become more pronounced and that while some complaints can be effectively managed, others may persist, requiring the adoption of coping strategies.³ Regardless of the circumstances, it is essential that the healthcare team actively works to prevent mistanasia, that is, the undignified death resulting from lack of access to appropriate care, through timely referrals and the prevention of further complications. This approach ensures a more humanized process and promotes a death with minimal suffering for the patient.

Dying with dignity encompasses spiritual support, the opportunity to resolve personal matters, active participation in the dying process, respect for privacy, and the minimization of physical and emotional suffering. Accordingly, palliative care involves a combination of therapeutic approaches and integrated care, which requires a holistic understanding of each individual's physical, social, emotional, mental, and

spiritual needs.^{10,12} Therefore, palliative care for terminally ill patients must be multidisciplinary, integrative, continuous, and individualized.

Pain and symptom management for terminally ill patients

The most common symptoms experienced by patients at the end of life include pain, nausea and vomiting, constipation, and dyspnea. It is essential for physicians to be proficient in managing these symptoms, with the use of analgesics, antipyretics, anxiolytics, antisecretory agents, and laxatives playing a key role.¹³ Beyond symptomatic management, medical care aimed at “comfort” also involves discontinuing routine diagnostic procedures and maintaining only essential devices, such as intravenous medication access and bladder drainage.¹⁴

Pain associated with terminal illness is not solely physical, and choosing palliative care does not equate to relinquishing the fight for life. Much of the physical suffering intensified during the dying process is linked to what Nassim Nicholas Taleb describes as “naive interventionism” — the tendency to undertake numerous interventions in fragile situations with good intentions but without fully considering the potential adverse effects.¹⁵ In this context, an excess of well-meaning actions, combined with attempts to control what is ultimately uncontrollable, finitude, may undermine the principle of nonmaleficence.

Pain intensity scales vary according to the patient’s condition. Commonly used tools include the *Verbal Numeric Rating Scale* (VNS) for literate adults without cognitive impairment; the *Faces Scale* for children over two years of age; the *Behavioral Pain Scale* (BPS) in conjunction with the *Richmond Agitation Sedation Scale* (RASS) for critically ill, sedated, unconscious adults, or those with communication difficulties undergoing invasive mechanical ventilation; and the *Pain Assessment in Advanced Dementia Scale* (PAINAD) for adults with cognitive impairment, episodes of confusion, or dementia.¹⁶ The classification of pain intensity is essential for guiding appropriate analgesic selection and dosage, in accordance with the *World Health Organization (WHO) Analgesic Ladder*.

The experience of pain is highly individual and influenced by multiple factors, including gender, age, ethnicity, culture, and social support.¹⁷ While pain assessment tools serve as valuable guides for treatment, healthcare professionals must remain attentive to each patient’s unique circumstances. Studies have shown that socioeconomic and cultural factors can impact the adequacy of pain management, often resulting in inequitable treatment outcomes.

A study involving 77 terminally ill cancer patients in northern Palestine found that women and individuals with limited access to healthcare were more likely to receive inadequate treatment or experience greater pain severity.¹⁸ Another study comparing terminally ill cancer patients with and without schizophrenia showed that patients with schizophrenia received fewer opioids during the last month of life.¹⁹ The presence of social stigma and the tendency of some healthcare professionals to misinterpret psychiatric symptoms as pain-related complaints contributed to inconsistent treatment in this population. These findings underscore the importance of utilizing standardized pain assessment tools and developing individualized treatment plans that account for each patient’s specific needs and circumstances.

Pharmacological management is guided by the patient’s classification on pain intensity scales or through the use of patient-controlled analgesia pumps. In cases of severe pain, treatment involves high-dose opioids and should ideally include a combination of a sustained-release formulation administered around the clock and an immediate-release formulation for breakthrough or episodic pain. The analgesic regimen includes non-opioids, opioids — among which morphine is the most widely used due to its

availability in various routes of administration and cost-effectiveness — and adjuvant medications such as corticosteroids, tricyclic antidepressants, and gabapentin, the latter two being commonly used for the management of neuropathic pain.²⁰

Effective pain management has a positive impact on the psychospiritual outcomes of patients at the end of life.²¹ A randomized multicenter study involving 104 patients receiving palliative care found that those who participated in biographical music therapy reported greater spiritual well-being and reduced suffering compared to the control group.²² Thus, in addition to managing physical symptoms, it is essential to implement psychosocial and spiritual interventions, as these domains work synergistically to enhance patient comfort.

Complementary and alternative therapies are also used to improve the quality of life of patients in palliative care. Among these, acupuncture has been shown to contribute to pain modulation;²³ while Reiki therapy has been associated with potential benefits in relieving pain and reducing anxiety and depression.²⁴ However, further research is necessary to validate the efficacy of Reiki in this context, as existing evidence is limited by methodological constraints, warranting caution in its clinical application.

The growing incorporation of alternative techniques into comprehensive pain management, when combined with appropriate pharmacological treatment, reflects the principle of integrality and the dynamic interaction between body and mind. It is well established that the perception of physical pain can be intensified by dysfunctional mental patterns, while effective treatment of physical pain can lead to improved mood, illustrating a fluctuating codependency. These concepts have been extensively discussed since 1964, when Dame Cicely Saunders introduced the term “total pain” or “total suffering,” defining it as a multidimensional experience encompassing physical, psychological, emotional, social, spiritual, and/or existential components, thereby necessitating a multifaceted approach.²⁵

In certain contexts, when conventional treatments are no longer effective or when the potential harms outweigh the benefits, palliative sedation may be considered a measure of last resort for patients nearing the end of life, particularly in cases of refractory symptoms associated with significant suffering. Unlike sedation resulting from unintended drug side effects, this approach is carefully monitored and based on thorough discussion and clinical evaluation.²⁶ A systematic review identified delirium, pain, and dyspnea as the symptoms most frequently requiring palliative sedation, with midazolam being the primary medication used for this purpose.²⁷

Challenges in approach and communication in palliative care

The benefits of palliative care are well established; however, the effective implementation of therapeutic measures for symptom relief remains a significant challenge, with communication representing one of the primary obstacles.¹⁴ Communication is essential not only for the timely referral and initiation of care for eligible patients but also throughout the entire care process, particularly in recognizing and addressing individual care needs as patients experience increasing limitations in their ability to express themselves.

Ineffective communication can elicit feelings of frustration, anxiety, helplessness, and anger. In contrast, collaborative communication, characterized by a welcoming approach, information sharing with the patient and family, and attentiveness to the patient’s psychosocial and spiritual needs, contributes to improved pain control and increased satisfaction.¹⁷ A conversation analysis study involving palliative care providers and terminally ill patients identified key interactional strategies, including: encouraging patients

to express their goals for pain management; addressing their concerns with empathy; and reassuring them of continued support. Such interactions foster the development of a strong therapeutic bond and promote person-centered care that extends beyond the disease itself.

FINAL CONSIDERATIONS

In summary, palliative care has demonstrated clear benefits in the management of terminally ill patients by promoting dignity through an end-of-life perspective. By integrating therapeutic approaches with comprehensive care, palliative care supports the maintenance of quality of life through the assessment, recognition, and treatment of physical, psychological, social, and spiritual symptoms that adversely affect the well-being of patients and their families.

Furthermore, the effectiveness of palliative care relies on multidisciplinary, integrative, continuous, and individualized approaches. Accordingly, professional training is essential to adequately address the specific needs of each patient. In addition, further research is needed to validate the benefits of therapeutic interventions aimed at symptom management, with the goal of ensuring the highest quality of care for terminally ill patients.

CONFLICT OF INTERESTS

Nothing to declare.

AUTHORS' CONTRIBUTIONS

GGCL: Conceptualization, Data Curation, Formal Analysis, Investigation, Methodology, Project Administration, Supervision, Validation, Visualization, Writing – Original Draft, Writing – Review & Editing. LSC: Data Curation, Formal Analysis, Investigation, Validation, Visualization, Writing – Original Draft. RELF: Data Curation, Formal Analysis, Investigation, Validation, Visualization, Writing – Original Draft. AAS: Data Curation, Formal Analysis, Investigation, Validation, Visualization, Writing – Original Draft. FAS: Data Curation, Formal Analysis, Investigation, Validation, Visualization, Writing – Original Draft. LCP: Conceptualization, Supervision, Validation, Visualization, Writing – Review & Editing.

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