Palliative care in young cancer patients: humanitarian and clinical challenges

Cuidados paliativos em pacientes oncológicos jovens: desafios humanitários e clínicos

Cuidados paliativos en pacientes oncológicos jóvenes: desafíos humanitarios y clínicos

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RESUMO

Objetivo: Os cuidados paliativos visam melhorar a qualidade de vida de pacientes com doenças graves, oferecendo suporte físico, emocional, espiritual e social. No caso de adolescentes e jovens adultos (15- 39 anos) com câncer, há lacunas significativas na implementação desses cuidados, frequentemente iniciados tardiamente ou sequer oferecidos. Essa população ocupa uma posição de transição entre a pediatria e a oncologia adulta, enfrentando piores desfechos clínicos, maior risco de recidiva, mortalidade por progressão e prejuízos psicossociais. Estudos indicam que a ausência de protocolos específicos e de equipes treinadas compromete a continuidade do cuidado e a autonomia do paciente, sobretudo em contextos de baixa disponibilidade de recursos. Este estudo tem como objetivo investigar os principais desafios clínicos e humanitários na oferta de cuidados paliativos a jovens oncológicos, destacando barreiras institucionais, estruturais e subjetivas que limitam a efetividade dessa abordagem.

Descritores: Cuidados paliativos 1; Oncologia 2; Adulto jovem 3.

ABSTRACT

Objective: Palliative care aims to improve the quality of life for patients with serious illnesses by offering physical, emotional, spiritual, and social support. In the case of adolescents and young adults (15-39 years) with cancer, there are significant gaps in the implementation of this care, which is often initiated late or not at all. This population occupies a transitional position between pediatrics and adult oncology, facing worse clinical outcomes, a higher risk of recurrence, mortality from progression, and psychosocial impairments. Studies indicate that the absence of specific protocols and trained teams compromises the continuity of care and patient autonomy, especially in low-resource settings. This study aims to investigate the main clinical and humanitarian challenges in providing palliative care to young cancer patients, highlighting the institutional, structural, and subjective barriers that limit the effectiveness of this approach.

Descriptors: Palliative Care 1; Medical Oncology 2; Young Adult 3.

RESUMEN

Objetivo: Los cuidados paliativos buscan mejorar la calidad de vida de los pacientes con enfermedades graves, ofreciendo apoyo físico, emocional, espiritual y social. En el caso de los adolescentes y adultos jóvenes (15-39 años) con cáncer, existen lagunas significativas en la implementación de estos cuidados, que a menudo se inician tardíamente o ni siquiera se ofrecen. Esta población ocupa una posición de transición entre la pediatría y la oncología de adultos, enfrentando peores resultados clínicos, un mayor riesgo de recidiva, mortalidad por progresión y perjuicios psicosociales. Los estudios indican que la ausencia de protocolos específicos y de equipos capacitados compromete la continuidad del cuidado y la autonomía del paciente, especialmente en contextos de baja disponibilidad de recursos. Este estudio tiene como objetivo investigar los principales desafíos clínicos y humanitarios en la oferta de cuidados paliativos a jóvenes oncológicos, destacando las barreras institucionales, estructurales y subjetivas que limitan la efectividad de este abordaje.

Descriptores: Cuidados Paliativos 1; Oncología Médica 2; Adulto Joven 3.

Introduction

Palliative care (PC) constitutes a framework of interventions to improve the quality of life for individuals with serious illnesses. Actions encompass symptomatic relief, psycho-spiritual support for the patient and their family members, and guidance on therapeutic decisions. For the adolescent and young adult (AYA) population, who are transitioning between pediatrics and adult oncology, the implementation of PC requires an analysis adapted to their unique characteristics. The concomitance of an oncological diagnosis in the 15 to 39 age group imposes a substantial impact, with studies indicating adverse clinical outcomes. The prevalence of late or non-existent PC in this population is notable, with only 23% of young adults with recurrent childhood-onset disease having received follow-up from PC teams.[1] The fragmentation of care between pediatric and adult services, the lack of transition protocols, the scarcity of resources, and the insufficient number of qualified professionals contribute to the discontinuity of treatment. The difficulty of professionals in addressing topics such as finitude with young patients culminates in the postponement of decisions fundamental to their quality of life.[2-4] Given this, the investigation of clinical and humanitarian challenges becomes imperative to support the development of public policies and patient-centered clinical practices.

Objective

This study aims to investigate the challenges in providing Palliative Care to adolescents and young adults with cancer, analyzing both the clinical and humanitarian barriers and the effectiveness of interventions in this specific population.

Methodology

This study was designed as an integrative literature review, investigating humanitarian and clinical dilemmas of palliative care in young cancer patients. The bibliographic research, covering 2015 to 2024, was guided by the PICO question: "What are the main clinical and humanitarian challenges in palliative care for young cancer patients and how can they be overcome?". The systematic search was conducted in the PubMed and SciELO databases, using descriptors such as "palliative care," "adolescent cancer patients," "humanitarian challenges," "clinical management," and "quality of life."

The initial search resulted in 1,230 records (1,200 PubMed, 30 SciELO). Rigorous inclusion criteria were applied: articles in Portuguese, English, or Spanish, full text, peer-reviewed, and focusing on PC for young cancer patients (15 to 39 years). After initial screening, 1,100 articles were eligible. In the first selection stage, 800 articles were excluded due to lack of alignment with the criteria. Of the 300 remaining, 150 were selected for detailing. 25 duplicates/inconsistencies were

identified, resulting in 125 studies for qualitative evaluation. After methodological and content analysis, 10 articles were selected for the integrative synthesis, based on their relevance to the challenges of PC in young cancer patients, including psychosocial aspects, transition of services, communication, and clinical management.

Results

Table I summarizes the scientific findings, presenting a comparative analysis of the selected works. The analysis revealed significant challenges and notable advances in Palliative Care (PC) for young cancer patients. This synthesis serves as a foundation for the subsequent critical discussion.

Table I – Comparative synthesis of the analyzed works.

Author/Year/Database	Title	Results
Zhang et al. (2025), Psychooncology (PMC)	*The Current State of Palliative Care Research for Adolescents and Young Adults With Cancer: A Systematic Review and Meta-Thematic Analysis of Empirical Literature*	Gaps were identified in research on palliative care for adolescents and young adults with cancer, highlighting the need for more qualitative studies and personalized interventions. Something is needed to provide emotional support, autonomy, and help combat the stigmas associated with palliative care.
Schuetze et al. (2022) / Palliat Med (PMC)	*Care practices of specialized outpatient pediatric palliative care teams in collaboration with parents: Results of participatory observations*	Observed that specialized outpatient pediatric palliative care teams work closely with parents, as they are active in care, promoting open communication and shared decision-making.
Levine et al. (2017) / JAMA Oncol (PMC)	*Patients' and Parents' Needs, Attitudes, and Perceptions About Early Palliative Care Integration in Pediatric Oncology*	Patients and parents value the early integration of palliative care in pediatric oncology, focusing on the relief of symptoms, such as pain and fatigue, and psychosocial support. It was also noted that when PC is introduced, many patients and family members perceive it as an abandonment of treatment, requiring re-education on the topic.
Camargo et al. (2022) / Can Oncol Nurs J (PMC)	*Survival of cancer patients under treatment with the palliative care team in a Brazilian hospital in São Paulo*	Cancer patients in palliative care had variable survival, with improved quality of life, even in advanced stages. In contrast, it was shown that the search for PC, unfortunately, is late, with patients being referred only in the terminal stage.

Ngwenya et al. (2019) / BMJ Open (PMC)	*Qualitative situational analysis of palliative care for adolescents with cancer and HIV in South Africa: healthcare worker perceptions*	Healthcare professionals reported challenges such as lack of resources and stigma but highlighted the importance of multidisciplinary approaches for palliative care in adolescents.
Meyerheim et al. (2021) / BMJ Open (PMC	*MyPal-Child study protocol: an observational prospective clinical feasibility study of the MyPal ePRO-based early palliative care digital system in paediatric oncology patients*	Study protocol evaluating the feasibility of a digital system (MyPal) for early palliative care in pediatric oncology, focusing on electronic reporting of symptoms.
Healy & Piracha (2024) / Health Care Transit (PMC)	*Evaluating the transition of adolescents and young adults with palliative care needs from pediatric to adult care*	Identified barriers in the transition of palliative care needs from pediatric to adult care, such as lack of professional preparedness and differences in health systems, suggesting improvements in the continuity of care.
Wager et al. (2022) / BMC Palliat Care (PMC)	*Expert survey on coverage and characteristics of pediatric palliative care in Europe - a focus on home care*	Revealed variations in the coverage of home-based pediatric palliative care in Europe, highlighting the need for standardization and expansion of services.
Holmen et al. (2023) / BMC Palliat Care (PMC)	*Patient-reported outcome measures in children, adolescents, and young adults with palliative care needs-a scoping review*	The review highlighted the scarcity of validated Patient-Reported Outcome Measures (PROMs) for pediatric populations in palliative care, suggesting the development of new tools.
Gebel et al. (2024) / Ann Hematol (PMC)	*Palliative care for patients with hematologic malignancies in Germany: a nationwide survey on everyday practice and influencing factors from the perspective of treating physicians*	Physicians reported barriers such as lack of training and cultural resistance but acknowledged the importance of palliative care in hematology, especially in advanced stages.

Source: Developed by the authors, 2025.

Discussion

The advance of contemporary oncological therapy has altered the prognosis of neoplasms, transforming cancer into a chronic illness.[5] Essa reconfiguração impõe uma abordagem assistencial holística e integrada, incorporando os cuidados paliativos (CP) desde o diagnóstico. This reconfiguration imposes a holistic and integrated care approach, incorporating palliative care (PC) from diagnosis. The effective application of PC in adolescents and young adults (AYA) with cancer presents idiosyncratic challenges that demand specialized attention. Adapting PC to the specificities of the psychosocial development inherent to adolescence and youth is an imperative. This transitional period is marked by transformations, where patients confront oncological morbidity and crucial issues such as identity consolidation and the interruption of life projects. The complexity of these factors requires a differentiated approach in PC that addresses the unique

psychosocial needs of this age group. Studies demonstrate that the early integration of PC can confer substantial benefits in controlling physical and emotional symptoms, in addition to fostering adherence to the therapeutic regimen.[6]

The global disparity in access to PC is a considerable challenge; in low- and middle-income nations, the scarcity of resources and the lack of qualified professionals represent significant barriers, aggravated by the limited incorporation of palliative principles into medical training and public health policies. Overcoming these barriers requires investment in education and training, and the formulation of public policies that prioritize the integration of PC.

Communicating unfavorable prognoses and discussing the finitude of life with AYA patients and their families constitute an ethical and emotional challenge. The reluctance of professionals to address such topics can deprive patients of the opportunity to actively participate in decisions, meaning that promoting open, honest, and empathetic communication is fundamental to ensuring patient autonomy and mitigating psychosocial suffering. Training professionals in advanced communication skills and developing support tools are essential.

Another relevant aspect is the transition from pediatric to adult care. AYA patients frequently find themselves in a care limbo. Creating well-structured transition programs that ensure the continuity of care and coordination between pediatric and adult teams is crucial to guaranteeing quality, patient-centered assistance. In short, optimizing PC for young cancer patients requires a multifaceted approach that addresses the clinical, psychosocial, ethical, and structural dimensions. Overcoming the challenges requires a joint effort from health professionals, public policy makers, and researchers, aiming at the implementation of innovative and patient-centered care models.

Final Considerations

The complexity inherent in the provision of palliative care to young cancer patients underscores the imperative nature of care approaches that transcend conventional models, incorporating a holistic perspective adapted to the unique characteristics of this age cohort. The challenges identified, from gaps in professional training to institutional barriers and cultural resistance, highlight the urgent need for a paradigmatic restructuring in the provision of this care.

The early integration of palliative care, the continuous training of health professionals in communication and management of sensitive topics, the formulation of public policies that guarantee equitable access, and the creation of transition programs from pediatric to adult care are fundamental pillars for optimizing the quality of life and promoting the autonomy of these patients. Continued research and the dissemination of knowledge are crucial for the improvement of clinical practices and for the consolidation of a culture of palliative care that recognizes the intrinsic dignity of every individual in their journey of coping with the illness.

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