Palliative care

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ABSTRACT

Palliative care is an essential component of comprehensive care for children and adolescents undergoing hematopoietic stem cell transplantation (HSCT), yet it remains inconsistently integrated into clinical practice. This consensus chapter establishes principles and recommendations for the systematic incorporation of pediatric palliative care within HSCT programs. It emphasizes early integration, shared decision-making, and alignment of care with patient and family values throughout the transplant trajectory, regardless of prognosis. Key domains addressed include eligibility criteria, functional and prognostic assessment, communication strategies, ethical and legal considerations, and multidisciplinary collaboration. The chapter also reviews existing institutional models of palliative care integration and highlights adaptable frameworks suited to diverse resource settings. By standardizing approaches and clarifying roles, this consensus seeks to reduce variability in care, improve quality of life, and promote ethically sound, patient-centered decision-making. Integrating palliative care as a core element of pediatric HSCT policy is critical to improving both quality-of-life and end-of-life outcomes for patients and families.

Keywords: Palliative Care. Pediatrics. Hematopoietic Stem Cell Transplantation. Quality of Life.

INTRODUCTION

Palliative care (PC) is a specialized approach aimed at improving the quality of life for patients—both adults and children—and their families as they navigate the challenges of life-threatening illnesses. It focuses on preventing and alleviating suffering through early identification, accurate assessment, and effective management of pain and other physical, psychosocial, or spiritual concerns[1].

Children and adolescents with cancer who receive palliative care experience improve quality of life, reduce symptom burden, enhance advance care planning discussions, and less intensive end-of-life therapies. Parents also report better quality of life and greater preparation for end-of-life[2].

A recent cross-sectional survey of transplant physicians showed that most of them trust palliative care providers but have concerns regarding palliative care providers' knowledge of hematologic stem cell transplantation (HCT) and patients' perception of the term *palliative care*. Thus, there is an imminent need to foster this collaboration, improve perceptions and increase integration[3].

WHO CAN BENEFIT FROM PALLIATIVE CARE?

In pediatrics, congenital and genetic diseases are the leading causes for the indication of this type of care, followed by chronic neurological conditions, and then by oncological-hematological disorders. More than half of the patients had more than one diagnosis (55%), and it was observed that the end-of-life stage still predominantly occurs in the hospital setting[4]. Table 1 lists the conditions eligible for palliative care in children, according to the World Health Organization[1].

Table 1. World Health Organization categories.

Group	Description	Examples of diseases and conditions
Group 1	Children with acute life-threatening conditions, recovery may or may not be possible	Any critical illness or injury, severe malnutrition
Group 2	Children with chronic life-threatening conditions that may be cured or controlled for a long period, but may also result in death	Cancers and stem cell transplantation, multidrug-resistant tuberculosis, human immunodeficiency virus/acquired immunodeficiency syndrome
Group 3	Children with progressive life-threatening conditions for which no curative treatment is available	Chronic conditions: cystic fibrosis, Duchenne muscular dystrophy, cerebral palsy, severe combined immunodeficiency, Sickle cell disease
Group 4	Children with severe neurological conditions that are not progressive but may cause deterioration and death	Congenital anomalies: severe congenital heart defects, spinal muscular atrophy, static encephalopathy, spina bifida
Group 5	Newborns who are severely premature or have multi-system involvement, in which care is required for managing symptoms and supporting families in decision-making	Severe prematurity, anencephaly, congenital diaphragmatic hernia, trisomy 13 or 18
Group 6	Family members of a fetus or child who dies unexpectedly	Fetal death, hypoxic-ischemic encephalopathy, overwhelming sepsis in previously healthy child, motor vehicle accident trauma, burns, etc.

Source: Elaborated by the authors.

PLANNING CARE IN HEMATOLOGIC STEM CELL TRANSPLANTATION SCENARIO

When planning and implementing palliative care, key stages must be addressed for success[5]:

- Understanding the disease and its limitations: a thorough understanding of the diagnosis, treatment, and prognosis is essential. Consensus within the team helps integrate palliative care with ongoing treatment. Palliative care can benefit patients with life-limiting diseases, regardless of their terminal phase. In irreversible conditions, the discussion should involve the entire team and later the family, as an ongoing process that can be revisited as needed;
- Defining goals and medical interventions: the team should focus on the patient's best interests in collaboration with the family. It is essential for the family to participate in decision-making, but the responsibility for determining care rests with the healthcare team. The family should feel respected and supported throughout the process;
- Addressing individual needs and anticipating events: recognizing each patient's uniqueness is vital. Understanding the disease stage and family values helps tailor the care plan. Anticipating events enhances comfort and allows both the patient and family to navigate the illness more effectively. The focus should be on symptom control, prioritizing meaningful care, and avoiding unnecessary interventions. Environmental adjustments may be needed to ensure comfort. A multidisciplinary approach is essential, especially as the patient approaches the terminal stage, and for supporting the family in their grief after death.

An objective tool to assess the patient and guide decision-making is helpful for anticipating events and managing care effectively, such as Lansky Scale[6], which can be used until 16 years old and has accurate correlation with Karnofsky Scale[7] for patients older than 16 and life expectancy[8], as shown in Table 2.

Table 2. Functional assessment scale and correlation with palliative care planning and prognosis.

Lansky score	Performance assessment	Palliative care classification according to life expectancy
	Able to carry on. No special care is needed.	Early palliative care: death from the underlying disease is unlikely at this stage. In case of acute clinical instability, transfer to intensive care unit and advanced life support may be required. The priority is curative or restorative treatment, based on the principles of beneficence and autonomy. Prognosis: months to years.
100	Totally active, normal	
90	Slight restriction in strenuous physical activity	
80	Active, but tires more easily	
	Mild to moderate restriction	
70	Greater restriction in recreational activities and less time spent on them	
60	Gets up and walks, but plays minimally; plays while resting	Complementary palliative care: the patient has a life-threatening illness and intermediate functional status (Lansky 40–60%). The patient is unlikely to respond fully to curative treatment but may benefit from procedures or treatments that improve symptoms and quality of life, respecting the patient's or their legal representatives' wishes. In case of acute clinical instability, intensive care unit transfer should be considered, taking into account potentially reversible conditions, with limits on therapeutic effort or care proportionality. Prognosis: weeks to months.
50	Dresses independently but remains in bed most of the time, does not play actively, but can participate in all activities and games while resting	
	Moderate to severe restriction	
40	Spends most of the time in bed; plays while resting	
30	In bed, requires assistance, even for playing while resting	Predominant palliative care: the patient has a life-threatening illness and poor functional status (Lansky < 40%), with irreversible disease. Focus is on the best possible quality of life and symptom control (infection treatment, correction of electrolyte imbalances, pain relief, etc.), using the principles of autonomy and nonmaleficence. Do not continue futile therapies. Intensive care unit transfer should not be considered, respecting the patient's or their legal representatives' wishes. Prognosis: weeks to days.
20	Frequently sleeping; playing is restricted to very passive games	
10	Does not play; stays in bed	Exclusive palliative care (end-of-life): the patient has a life-threatening illness, low functional status (Lansky < 20%), and rapid, irreversible decline. Marked deterioration is evidenced by changes in consciousness and cardiopulmonary instability. Discontinue futile therapies, focusing solely on symptom control. Intensive care unit transfer should not be considered, respecting the patient's or their legal representatives' wishes. Prognosis: hours to days.
0	Unresponsive	

Source: Elaborated by the authors.

DEMYSTIFYING PALLIATIVE CARE

We address three common questions that may hinder the implementation of palliative care in HCT:

1. When should palliative care be initiated in a pediatric patient undergoing HCT?

Palliative care should be introduced early, ideally during transplant planning, especially for patients at high risk of complications. Early integration improves pain management, conditioning-related toxicities, nutritional support, and the psychosocial well-being of the child and family.

2. How should communication with the family be handled in cases of a poor prognosis post-HCT?

Communication should be clear, compassionate, and centered on the family's values and understanding. Key strategies include:

- Using communication tools as the SPIKES technique (Setting, Perception, Invitation, Knowledge, Empathy, Summary) to deliver difficult news[9];
- Reinforcing that the focus will be on the child's comfort, regardless of future treatment decisions;
- Engaging a multidisciplinary team for emotional and psychosocial support.

3. How should the decision to withdraw advanced life support (mechanical ventilation, dialysis) be approached in a post-HCT patient?

This decision should be shared among the medical team, the patient (when possible), and the family. Indicators such as graft failure, irreversible disease progression, refractory graft-*versus*-host-disease, and multi-organ failure must be considered. Communication should be transparent and guided by bioethical principles, ensuring that the focus remains on the patient's comfort and dignity.

LEGAL ASPECTS

The team must feel secure in developing their practices without fear of violating ethical principles or legal standards. The following documents can support medical teams in this process:

- Medical Ethics Code[10]:

Chapter I – Fundamental Principles. Article 22: In irreversible and terminal clinical situations, physicians should avoid unnecessary diagnostic and therapeutic procedures and provide appropriate palliative care to patients under their care;

Chapter V – Relationship with Patients and Families. Article 41: Physicians are prohibited from shortening a patient's life, even at the request of the patient or their legal representative;

Sole Paragraph: In cases of incurable and terminal illness, physicians must offer all available palliative care without undertaking unnecessary or obstinate diagnostic or therapeutic actions, always considering the expressed wishes of the patient or, in their inability, those of their legal representative.

- Conselho Federal de Medicina's Resolution No. 1.805/2006[11]:

Article 1: Physicians are allowed to limit or suspend procedures and treatments that prolong life in terminal patients with severe and incurable illness, respecting the wishes of the patient or their legal representative.

MODELS OF INTEGRATION

Multiple models for integrating palliative care into oncology have been proposed, ranging from primary palliative care delivered by oncologists with referrals to specialist palliative care in a consultative framework, to systems utilizing trigger-based prompts, and fully embedded models of care. Given the variability in oncology practices and across diverse clinical settings, no single model serves as a universal standard. In the context of HCT, various models have been implemented depending on institutional and clinical needs, including innovative approaches developed at St. Jude Children's Research Hospital and Dana-Farber Cancer Institute/Boston Children's Hospital, as well as previously established models at institutions such as Children's National Medical Center, the University of California, in San Diego, California, United States of America, and Western Pennsylvania Hospital[12]. Table 3 summarizes a comparison.

MULTIDISCIPLINARY TEAM COLLABORATION IN PALLIATIVE CARE FOR HEMATOPOIETIC STEM CELL TRANSPLANTATION

Medical, nursing, psychological, and spiritual care providers have key roles in the palliative care team for HCT, as detailed in Table 4.

Table 3. Comparing models of palliative care integration in hematologic stem cell transplantation[12].

Characteristic	Universal consult (*e.g.*, CNMC)	Universal consult/ tier-based involvement (*e.g.*, St. Jude)	Triggered consult (*e.g.*, DFCI/BCH)	Primary team-initiated consult with palliative care proximity (*e.g.*, WPH/UCSD
Patient benefit	Reaches all who may benefit	Likely to reach all who may benefit	Targets those most likely to benefit	HCT determines who can benefit, with palliative care prompting through proximity
Resources	Resource intensive	Moderately resource / intensive	Optimizes resources by targeting those most in need	Conservation of resources for consulted patients, additional time spent with HCT team
Message	All can benefit from palliative care; normalizes palliative care by meeting all at the start of HCT	All can benefit from palliative care, although needs vary; normalizes palliative care by meeting all at the start of HCT	Ties palliative care to higher risk and worse prognosis; normalizes palliative care for some by starting it at the start of HCT	Ties palliative care to higher risk and worse prognosis

CNMC: Children's National Medical Center; DFCI: Dana-Farber Cancer Institute; BCH: Boston Children's Hospital; WPH: Western Pennsylvania Hospital; UCSD: University of California, San Diego; HCT: hematopoietic stem cell transplantation. Source: Elaborated by the authors.

Table 4. Multidisciplinary team.

Team member	Role
Pediatric oncologist/hematologist	Oversees the child's hematopoietic stem cell transplantation treatment plan and ensures coordination with palliative care interventions
Pediatric palliative care physician	Provides specialized symptom management and decision-making support
Pediatric nurses	Provide direct care, monitor for symptoms, and communicate changes in the child's condition
Social workers	Offer emotional support and facilitate family discussions on care goals
Psychologists	Address psychological challenges, such as anxiety, depression, and post-traumatic stress, assist with coping strategies
Chaplains/spiritual care providers	Provide spiritual support for families, respecting diverse religious and cultural backgrounds

Source: Elaborated by the authors.

CONCLUSION

Through this consensus, we aim to initiate a promising process of integration. Despite palliative care still being underutilized, it is crucial for palliative care to work collaboratively with pediatric HCT teams to enhance both quality of life and end-of-life outcomes for our patients and their families.

CONFLICT OF INTEREST

Nothing to declare.

DATA AVAILABILITY STATEMENT

Not applicable.

AUTHORS' CONTRIBUTIONS

Substantive scientific and intellectual contributions to the study: Garcia JL. **Conception and design:** Garcia JL, Silva AO, Ikeuti PS, Franco SCR, Michalowski MB and Boldrini E. **Analysis and interpretation of data:** Garcia JL. **Technical procedures:** Garcia JL and Boldrini E. **Manuscript writing:** Garcia JL, Silva AO, Ikeuti PS, Franco SCR, Michalowski MB and Boldrini E. **Final approval:** Garcia JL, Silva AO, Ikeuti PS, Franco SCR, Michalowski MB and Boldrini E.

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