

Pediatric Oncology, Palliative Care and Low- or Middle- Income Countries: A Call for Action

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Abstract

Pediatric oncology, which includes cancer screening and therapy in children, poses significant challenges in low- and middle-income countries (LMICs). Palliative care improves children's and their families' quality of life. In LMICs, palliative care resources are scarce, resulting in poor symptom management, psychological support, and spiritual care. All relevant English-language articles on pediatric palliative oncology were searched in PubMed, Google Scholar, Scopus, and Medline databases using the following keywords: "Pediatric Oncology," "Pediatric Palliative Oncology," "Pediatric Palliative Care," "Palliative Care," "Child Cancer," and "Lower- and Middle-Income Countries." This study highlights the significance of incorporating palliative care early in therapy and the recommendations may improve the competence of information provided by medical professionals to patients and families. LMICs have the potential to improve overall treatment and outcomes for child cancer patients and their families by prioritizing the integration of palliative care, guaranteeing a compassionate and dignified attitude toward the disease.

Keywords

pediatric oncology, cancer, palliative care, pediatric palliative oncology, LMICs, global health

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Bullet Points

- Pediatric palliative care is the multidisciplinary holistic care of the child and the family throughout the illness continuum. Children with cancer experience physical symptoms and reduced quality of life.
- Palliative care referral improves quality of life, confers symptom management benefits, provides emotional support, enhances end of life care experience, and supports children and their families' needs.
- The purpose of this review is to describe the evolution of palliative care in pediatric oncology, the needs of children and their families in a pediatric oncology setting, palliative care referral practices in pediatric oncology, outcomes of palliative care referral in pediatric oncology, and models of palliative care in pediatric oncology.
- Cancer constitutes 5.2% of the palliative care needs in children. Approximately, 90% of children with cancer live in low and middle-income

countries, constituting 84% of the global burden of childhood cancers. Children in low and middle-income countries have low cure rates and high death rates making palliative care relevant in a pediatric oncology setting.

- Palliative care referral in children with cancer improves physical symptoms, emotional support, and quality of life. It enables communication

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between families and health care providers. It improves end-of-life care support to children and their families and facilitates less invasive diagnostic and therapeutic interventions at the end of life. Worldwide children with cancer are infrequently referred to palliative care and referred late in the illness trajectory. Most of the children referred to palliative care receive some form of cancer-directed therapy in their last days. Children in low and low-middle-income countries are less likely to access palliative care due to a lack of awareness amongst pediatric oncologists about palliative care and the reduced number of services providing palliative care.

- There are several palliative care models in pediatric oncology practiced globally. However, no one model was considered better or superior, and the choice of model depended on the need, preferences identified, and available resources. Children with cancer are sparingly referred to palliative care and referred late and oncologists and hematologists gatekeep the referral process. Knowledge of palliative care referral in pediatric oncology settings might enhance collaboration between pediatric oncology and pediatric palliative care.
- To identify, in scientific productions, nursing interventions in palliative care in children and adolescents with cancer.
- We conclude that greater emphasis should be given to palliative care in academic and professional training and that further studies in search of the best evidence should be conducted to support nursing Evidence-Based Practices.

Highlights

- Palliative care is essential in pediatric oncology because children in poor and middle-income countries have a low cure rate and a high death rate.
- Children in poor and low-middle-income countries are less likely to get palliative treatment owing to a lack of understanding among pediatric oncologists about palliative care and a lack of palliative care resources.
- We believe that palliative care should be given more priority in academic and professional training and that more research should be performed to promote nursing Evidence-Based Practices for Low and Middle-Income Countries.
- Knowledge of palliative care referral in pediatric oncology settings may improve cooperation between pediatric oncology and pediatric

palliative care in LMICs to improve the quality of life of children in these underserved nations.

Introduction

After accidents, cancer is the second highest cause of death in children aged 1 to 14. It was estimated that in the year 2022, cancer will claim the lives of about 1050 children under the age of 15 out of 10,470 diagnosed cases in the United States alone.¹ Pediatric cancer research has recently taken a fascinating turn, leading to revolutionary findings extending well beyond pediatric malignancies. When a kid is diagnosed with cancer, it impacts their entire family and existence. The cancer diagnosis affects both the patient and their family, causing disruptions in their personal and professional lives and their usual tasks and commitments.² Some of the constraints that may affect impacted families include restrictions on daily living, marital conflict, uncertainty, long-term side effects, and financial and employment problems. With the recognition of the importance of Pediatric Palliative Oncology (PPO), new training programs in pediatric cancer and palliative care have been developed to capitalize on this newly discovered expertise.³

Every year, around 400 000 children and adolescents aged 0 to 19 are diagnosed with cancer. Over 80% of children diagnosed with cancer in high-income countries may very well be cured. One of the primary factors contributing to the need for palliative care in LMICs is the prevalence of pediatric cancer and the resulting fatalities.⁴ LMICs have a 30% cure rate compared to high-income countries (HICs). PPO is a relatively young specialty that aims to include palliative care elements early in a child's cancer experience.⁵ It is the goal of pediatric palliative care to alleviate pain, improve quality of life, and give support to the families of children with life-threatening conditions. Palliative treatment for cancer patients in kids, teenagers, and early adulthood has resulted in significant improvements for patients and family members.⁶ The discipline of pediatric palliative oncology differs from that of adult palliative care in that it focuses on providing treatment for the child and the family as a whole. The interdisciplinary oncology team provides primary palliative care, while the palliative care team provides specialist palliative care for more complicated situations.⁷

Palliative care for children in LMICs is still in its infancy and faces a number of obstacles at its current stage of development. One of the significant problems is poverty, and under this, many obstacles exist, that impact the overall healthcare system of these countries.⁸ Malnutrition is also a significant factor, especially in children with Acute Lymphocytic Leukemia (ALL) who

require a high nutrient intake parallel to their treatment. Additionally, LMICs have a contentious problem with the necessary drug at the treatment level: many children die because there are no drugs available on the market even before getting PPC, which is underdeveloped in these countries. Moreover, even though the questioned medications exist on the market, most people cannot afford them, which leads to inequity in the health sector.⁹ Additionally, lack of knowledge is a significant issue. The decision-making process is complicated by the low level of public awareness of the issue, which also extends to patients and family members.¹⁰ Furthermore, we might state at this level that our health information systems have not developed well. In addition, LMICs lack a robust evidence-based system, which further contributes to the lack of healthcare organizations. A data shortage results in a significant underestimation, meaning that a patient's chances of being diagnosed and treated are missed or even delayed, that is late diagnosis.¹¹

The establishment of international organizations such as the International Society of Paediatric Oncology (SIOP) and Pediatric Oncology in Developing Countries (PODC) has led to significant advancements in the provision of cancer services to patients in LMICs.¹² This is evidenced by the progress made by nations in the global ranking of palliative care. Insufficient investigation into pediatric palliative care has contributed to the slow pace of advancement in this field in these nations. The identification of various types of pediatric palliative care systems in LMICs, as well as the application of experiences and innovations from other nations, and the assessment of the degree of success in meeting palliative care standards through quality evaluation indices, can aid in the establishment and development of this care system in these countries.¹³

The Need for Palliative Care: Global Overview and Low- and Middle-Income Countries

Complex life-threatening disorders in children are becoming more common throughout the globe. The frequency of severe and potentially fatal illnesses increased from 12 per 10 000 people in 2003 to 16 per 10 000 people in 2007.¹⁴ There is currently a shortage of information on the frequency of these illnesses in Latin America. Palliative care (PC) has been recommended by the World Health Organization (WHO) as a treatment option for such illnesses. As a result, healthcare systems throughout the globe are faced with an increasing burden and a moral duty as a result of the increasing prevalence of these illnesses.¹⁵

There is an unmet shortage of access to palliative care and pain treatment across the globe, particularly in LMICs.¹⁶ When the first integrated PPC service was recorded in 2011, 66.7% of South American nations had no PPC activity. The field of palliative care has grown in recent years and is now a hotbed for new ideas, research, and activism.¹⁷ Health care in Latin America, despite the availability of a new definition of the term, has concentrated on enhancing access to specialized adult services. As a result, there is a shortage of PPC services and inexperienced health staff in the field of pediatrics. Colombia's 2012 Atlas of Palliative Care in Latin America featured 13 tertiary care facilities, 1 second-level service, and 1 for adults and children.¹⁸

In spite of this, the incidence of pediatric cancer in the United States from 1977 to 2011 was equivalent to that in wealthier nations, according to the Childhood Cancer Outcomes Surveillance System. National Palliative Care Services is estimated to have grown by more than 500% in the previous 5 years.¹⁹ As a consequence of the lack of palliative care academic training for pediatricians and the absence of related teaching approaches for other healthcare practitioners. As per the data published by the World Health Organization in Global Atlas of Palliative Care at the end of Life, children from Low-Income and Lower Middle-Income families make up 84% of the total population of children requiring palliative care at the end of their lives. Nearly 14% belong to the Upper Middle-Income category, while approximately 2% are in the high-income group, as shown in Figure 1.²⁰

For this reason, as well as the fact that there is a lack of scholarly research on the topic, promoting PPC in LMICs may seem like an insurmountable challenge. This article addresses strategies for developing a multidisciplinary program for children experiencing fatal diseases like cancer, with the objective of easing the pain of patients and their loved ones and improving their quality of life via PPC.

Problems Faced by Low- and Middle-Income Countries (LMICs)

We can mention that the healthcare systems are poorly developed in comparison with High-income countries (HICs). Besides, LMICs have a lack of healthcare systems, specifically a lack of healthcare workers and equipment. Notably, in some LMICs, we lack knowledge regarding PPC; thus, courses and formations for healthcare workers should be held to emphasize the importance of PPC along with following updates in this growing branch to ensure the best possible healthcare.²¹

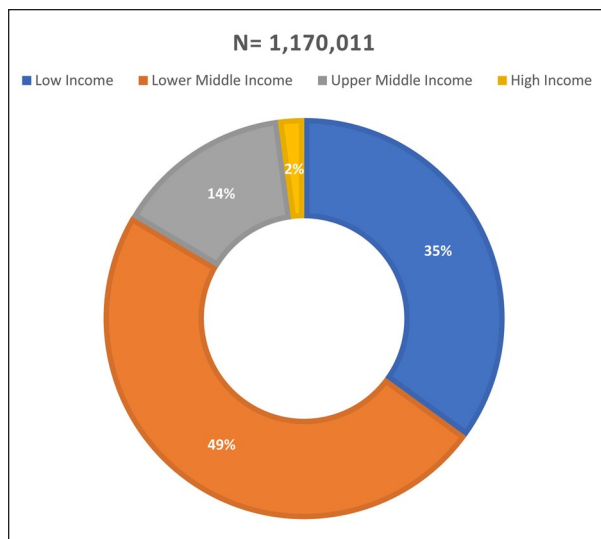


Figure 1. The proportion of children requiring end-of-life palliative care by World Bank national income categories.

As an example, PPC formations take place in the African Sub-Saharan Region. Additionally, most physicians who practice in LMIC are trained in HIC, which makes it difficult for them to deal with the present equipment.²² At this level, not only physicians are concerned but also nurses: we can observe a lack in nurse staffing and support, as we can note the ratio of nurses to the patient is considerably low in LMIC, and if it were acceptable, nurses aren't well educated about the subject: LMIC highly needs to incorporate nursing education and specialization, especially in PPC. Furthermore, the work environment and relationship between nurses and physicians constitute a preeminent factor that may contribute to better service in PPC.²³

The main hurdle to PPC in LMICs is the lack of clear communication with patients and their families regarding the illness, the treatment, and the prognosis. Even in tertiary cancer centers, there are very few professional counselors; therefore, doctors or nurses are left to handle this responsibility since they don't have enough time for proper counseling and don't have the necessary knowledge or training. Accessibility to general health services, including palliative care, is hampered in some LMICs by steep topography.²⁴ Palliative care must be integrated into the community health system in order to be accessible to all individuals who need it. The majority of healthcare practitioners in remote regions are mid-level government employees, such as health support staff and accompanying healthcare staff who are enthusiastic about learning about palliative care and providing it to the local population.²⁵

Moreover, the shortage of means in LMIC is a significant concern: people's access to drugs is problematic; for example, access to blood products in cases of ALL in children is controversial on different levels: reliability, expense, and scarcity of donors.²⁶ All of these factors contribute to the capacity to provide intense chemotherapy to ALL patients.²⁷

Spiritual Aspect in PPC

When it comes to children, spirituality is described as the capacity to draw personal significance and transcend oneself via interactions with others, most often with one's parents or other members of the family. For a duration exceeding 15 years, the World Health Organization has acknowledged and integrated spiritual care as an indispensable component of palliative care within its definition.²⁸ Unlike many people, younger children may perceive spirituality and religion as distinct entities, even if they share many of their parents' religious convictions.²⁹ The capacity to express gratitude and delight, as well as the ability to overcome problems, were all found in qualitative interviews with children with cancer. Spirituality was linked to greater psychological, cognitive, and physical functioning in children with cancer, according to the Pediatric Quality of Life measure. Spirituality may be especially useful for Adolescents and Young Adults (AYAs) patients as they battle with both physical and mental adaptation to the condition in the setting of continual development and advanced illness.³⁰

While its significance has been demonstrated, spiritual care remains an under-established and neglected component of palliative care. Consequently, ongoing scientific investigation and medical intervention endeavors have underscored this aspect of palliative medicine. In 2010, the European Association for Palliative Care (EAPC) established a Spiritual Care Taskforce with the aim of promoting evidence-based spiritual care.³¹ This was achieved by outlining a research agenda, enhancing staff proficiency and assurance, and improving patient and carer outcomes. National Health Service (NHS) Scotland has generated spiritual care data and instructions for all healthcare practitioners within the United Kingdom. The International Society for Health and Spirituality (IGGS) was established in Germany in 2011 with the aim of imparting knowledge on spirituality and spiritual care to German-speaking healthcare practitioners. The Global Network For Spirituality And Health (GNSAH) in the United States was established in 2013 to broaden the knowledge and evidence base concerning the relationship between spirituality and health.²⁸

Table 1. Estimations of the Amount and Rate of Children Requiring Palliative Care by WHO Region.

World Health Organization's Regions	Estimated number of Children in Palliative care needs	The estimated rate for children in palliative care need (Per 100,000 Population)
World	66 625	3.6
South-East Asia	17 594	3.3
Africa	15 571	4.3
Western Pacific	11 715	3.2
Eastern Mediterranean	10 508	5.2
Region of Americas	6 644	2.9
European	4 590	2.9

The predominant body of research pertaining to spiritual care in Paediatric Palliative Care has been conducted on a global scale using the English language. The integration of qualitative research on spiritual care in palliative care is imperative in LMICs where multiple languages are spoken, owing to the aforementioned limitations. The task of delivering suitable medical care and knowledge to individuals with diverse life experiences, belief systems, values, faiths, languages, and healthcare perspectives poses a challenge for healthcare practitioners in low- and middle-income countries with evolving multicultural societies.³² A holistic comprehension of cultural distinctions is imperative. However, healthcare professionals must also acknowledge the inter-individual variability of such customs within populations of identical heritage. Through a comprehensive analysis of personalized requirements and objectives, inquiring about familial inclinations and customs serves to mitigate the likelihood of perpetuating stereotypes.³³ There should be a continuous evaluation of the spiritual needs of adolescents and children with other life-altering conditions, including cancer since their beliefs and perspectives are likely to evolve over time. In one research, religious parents were more inclined to speak about death with their terminally ill children than non-religious parents.³⁴

Discussion

Enhancing care for children seeking palliative care is a top concern for many countries. PPC programs are emerging in the area, regardless of family economic conditions. Results indicate that growth has indeed been uneven, with higher-income countries having more services, specialists, and professional activities.³⁵ European standards intended for PPC have been produced as a result of national needs assessments conducted in a number of countries before. This report provides the first European overview of the nations' reactions to the highlighted requirements. According to the findings of

this research, high-income nations are more likely to have guidelines and regulations governing the supply of PPC.³⁶

An estimated 1.2 million children globally will need palliative care at the end of their lives. Men outnumber females by a tiny margin, with males accounting for 52% and females accounting for 48%. Table 1 depicts the global reach of the rates of children requiring palliative care toward the end of life. South-East Asia (17 594), Africa (15 571), and the Western Pacific region have the greatest percentage of children requiring palliative care for cancer.³⁷ In addition, there is an underlying association between rates of children requiring end-of-life palliative care and socioeconomic status. The highest rates are seen in the lowest income brackets. Children requiring palliative care due to progressively non-malignant illness represent the great majority of cases in all regions, while palliative care for Human Immunodeficiency Virus-Acquired Immunodeficiency Syndrome (HIV-AIDS) and cancer at the end of life represent a minor percentage.³⁸

The vast majority of children requiring palliative care for all major illnesses at the final stages of life reside in LMICs, with 83% being in the lowest economic brackets, which have the highest rates.³⁹ More than 25% of end-of-life therapy is caused by congenital abnormalities, followed by neonatal illnesses (nearly 15%) and protein energy shortages (14%). The regions of Africa account for over half of all children requiring palliative care, following Southeast Asia as well as the Eastern Mediterranean. Palliative care for children with progressive non-malignant disease accounts for the great majority of cases across all sectors; however, palliative care for HIV-AIDS and cancer accounts for a modest proportion. When presented as a percentage of total mortality, this research indicates that 37.4% of people who die from all causes will need palliative care.⁴⁰ This is an average value that varies substantially depending on location and income level. The proportion of total mortality in higher-income countries with aging people may

exceed 60%, while in low- and middle-income countries, the percentages are much lower due to increased death from communicable diseases and traumas.⁴¹

Inequality in pediatric palliative care access and pain treatment in LMICs is a worldwide health problem that has yet to be resolved. Adults have typically been the focus of palliative care efforts, leaving the pediatric population out of the data.⁴² Examples of such services are limited and should be documented for the benefit of policymakers and service providers in low-and middle-income nations to better understand better how to address the burden of PPC in these LMIC countries.⁴³ There are various successful techniques and model for implementing PPC programs has been successfully working in many developed countries like the US, UK, etc., and the execution of those programs necessitated the creation of a number of specialized tactics and procedures to raise public awareness and educate the general public in LMICs.⁴⁴

Future Aspects and Recommendations

Expecting a child's and family's future is largely concerned with accomplishing particular care goals shared by both families and healthcare professionals. Establishing realistic preparations ahead of time and anticipating a child's deterioration in the short term is a really important aspect of PPC.⁴⁵ A more open approach, awareness, and proper medication could assist parents in anticipating and incorporating their preferences into their child's care.⁴⁶ Here are a few of the recommendations:

- 1 At every level of health and social care, education is significant. Kaye et al suggested a 3-tier approach in 2016 to deliver palliative care in pediatric oncology.⁴⁷ These models may be implemented in LMICs as well with PPC professional training that should be given in 3 distinct phases:
 - 1.1 The palliative care method, a first-level training for undergraduate/pre-registration students and skilled professionals to incorporate PPC in non-specialist settings.
 - 1.2 General PPC course, a course intended for people who deal with PPC more regularly but not as their primary work.
 - 1.3 Specialist PPC, this was directed at companies whose primary business is providing PPC. Programs at this level may be multi-professional or may have a strong concentration on a certain cadre, such as physicians or nurses.
- 2 In many nations, access to essential medications for palliative care, such as oral morphine, is limited. The new Lancet Commission research examines these disparities in cost and availability. WHO and the International Association for Hospice and Palliative Care (IAHPC) have adopted vital medicine lists for palliative care, and the Lancet study proposes a package that includes Kenya, South Africa, and Zambia have increased access to PPC drugs, among other LMICs.⁴⁸
- 3 LMICs have a spectrum of PPC delivery methods. With the aid of community health professionals and volunteers, home-based care enables parents to look after their children at home. PPC in distant rural locations has significant hurdles; hence, effort has to be done to resolve this issue to make it more accessible to those areas.⁴⁹
- 4 PPC development requires raising awareness to support the continuous expansion of PPC service provision; awareness is needed throughout all levels of the healthcare system, including hospitals, communities, health centers, the government, law enforcement agencies, lawmakers, and worldwide.⁵⁰ LMICs, where PPC is emerging, include examples of advocacy activities. Advocacy at the community level informs patients and families about palliative care, how it may assist them, and how they can become engaged.
- 5 Previously not a priority, research has become a critical pillar in palliative care development, along with legislation, medication availability, education, and implementation.⁵¹ In many LMICs, service delivery resources are limited, so it's important to do research to ensure we use them properly and change them as needed. Thus, evidence collection must be regarded as an inherent component of PPC service delivery in order to provide substantial proof, economical, and inclusive PPC not just in LMICs but throughout the world.
- 6 It is recommended that Low- and Middle-Income Countries (LMICs) allocate resources toward the implementation of spiritual care competency training programs for healthcare personnel, encompassing physicians, nurses, and psychosocial support teams.⁵² This measure is expected to enhance their capacity to cater to the spiritual requirements of pediatric palliative care patients and their families.

- 6.1 Synergistic efforts among regional medical establishments, spiritual and social groups, and global palliative care networks have the potential to propel holistic spiritual care initiatives forward.⁵³
- 6.2 A set of spiritual care standards and resources that are culturally sensitive may aid healthcare professionals in managing diverse religious and cultural perspectives while providing considerate and comprehensive care.⁵⁴
- 6.3 Awareness of the significance of spiritual care within the context of pediatric palliative care among policymakers, healthcare professionals, and communities has the potential to mitigate social stigma and enhance the incorporation of spiritual care provisions.⁵⁵

Conclusion

Across the region, PPC services are booming, but in nations with low to moderate incomes, this growth is more subdued. To tackle the unmet concerns of PPC in LMICs, efforts must be undertaken to conceptualize and define treatment paradigms. There should be more research on the need for specialist services. Each country's health care system should have its own unique approach to regulating and covering those in need. With the topic of whether specialist services are necessary, efforts need to be made to conceptualize and define models of care utilized to deal with the problem. Each country's health system should be considered while developing strategies for regulating and providing coverage for those in need. For patients with life-threatening and debilitating diseases, the formation of a specialist PPC service promotes referrals and supports a holistic approach. PPC initiatives cannot function and have an effect without the help of institutions, philanthropy, public awareness, and education in LMICs, where the resources are limited and inaccessible. More can and should be done to improve patient referral times and deaths, as well as bereavement follow-up for those who have lost a loved one to cancer. There are a few limitations to this review of pediatric palliative care and LMICs that should be noted as well. The presence of immigrants in LMICs is characterized by a wide range of nationalities, cultures, languages, and customs, posing a significant challenge in accurately capturing all cross-cultural variations. The inadequacy of the data has resulted in an insufficient investigation of both group and individual cultural variations. It is recommended that forthcoming investigations adopt a systemic methodology to examine cultural disparities, education, clinician acclimatization, and the reactions

of patients and their families to child mortality. This is due to the fact that the majority of scientific inquiries into cultural distinctions in pediatric palliative care have centered on the adult population. The implementation of PPC programming in certain countries presents a significant challenge. We expect this article will facilitate the creation of novel PPC initiatives and policies in these regions. Furthermore, we believe that this work will inspire both beginner and experienced researchers to investigate optimal practices in diverse LMIC nations, with the ultimate goal of delivering high-quality end-of-life care for pediatric patients.

Author's Note

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Author Contributions

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