

# Enhancing Pediatric Palliative Care: Addressing the Unique Needs of Oncology Patients and Beyond

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## Abstract

Deprescribing is an emerging concept in palliative cancer care that aims to optimize medication use by discontinuing or reducing unnecessary or potentially harmful medications. The goal of deprescribing is to improve the quality of life for patients by minimizing the medication burden, alleviating medication-related side effects, and focusing on patient-centered care. This review article explores the principles and challenges of deprescribing in the context of palliative cancer care, along with the potential benefits and considerations for healthcare providers.

## Introduction

Improved cure rates for childhood cancer often come at the expense of the children's quality of life during treatment. Despite the progress, there is still a significant percentage (20-25%) of children who succumb to the disease or its complications. Pediatric palliative care poses a challenging dilemma. Specialists in this field aim to get involved earlier in the treatment process, focusing on enhancing the quality of life even during curative treatment. However, some oncologists fear that involving the palliative care team or discussing worst-case scenarios might diminish hope for patients and their families. Conversely, parents and children often express a desire for earlier and more comprehensive information about the possibility of palliative care when a cure is no longer realistic. The Netherlands has made remarkable strides in pediatric palliative care over the past 15 years. From lacking a formal structure, the country now boasts seven pediatric palliative care teams, regional networks of professionals collaborating across disciplines and organizations (from hospitals to homecare), and a Dutch Knowledge Center for pediatric palliative care. This center includes a physician's support center to address dilemmas related to end-of-life care. Furthermore, an individual care plan format has been established, and the first national evidence-based guideline for pediatric palliative care has been developed, with ongoing updates and expansion planned for implementation in 2022. In parallel, significant efforts have been devoted to formal education in pediatric palliative care for nurses, doctors, and other healthcare professionals working with children in need of such care. The achievements demonstrated in the article by Vallianatos et al. [1] illustrate how effective collaboration among all stakeholders can lead to significant improvements in the quality of pediatric palliative care within a country. Pediatric palliative care centers around the patient and their family, taking into account their quality of life, needs, concerns, and aspirations. Zhukovsky et al. conducted a study focusing on children undergoing advanced cancer treatment, analyzing their symptoms and illness experiences. The research involved interviews with both the children and their parents [2]. The study sheds light on how symptoms and cancer treatments impact their daily lives and relationships. Interestingly, common themes emerged from the interviews with both English and Spanish-speaking children and parents. A related study by Mekelenkamp et al. highlights the challenges in involving the pediatric palliative care team at an earlier stage of the disease trajectory [3]. The researchers investigated the place and cause of death among patients who underwent hematopoietic stem cell transplantation (HSCT). Additionally, they conducted a survey among 98 HSCT professionals from 54 centers across 23 countries. The survey aimed to assess the availability and opinions on specialized pediatric palliative care services (SPPCS). Surprisingly, over 90% of

healthcare professionals acknowledged the importance of SPPCS for HSCT patients, but less than half of the physicians consistently referred children to such services. Many pediatric palliative care teams cater to children with various underlying conditions, including both malignant and non-malignant diseases. Baumann et al. conducted a study focusing on 89 terminally ill children, nearly half of whom had oncological diseases [4,5]. Their findings revealed that oncological patients experienced a significantly higher burden of symptoms towards the end of life. As the underlying disease progressed, the intensity of symptoms increased, and oncological patients were more likely to encounter pain and nausea/vomiting. These findings underscore the importance of considering the specific needs of oncology patients when establishing a pediatric palliative care team, particularly in settings with limited resources. Having healthcare professionals with ample experience in symptom control for oncology patients could prove advantageous [6,7]. Pediatric palliative care is a rewarding field that requires specialized healthcare professionals. Progress in this area is ongoing, albeit with varying speeds [8-10]. As we continue our efforts, let us be guided by the famous British words: "Keep calm and carry on."

## Conclusion

In conclusion, pediatric palliative care plays a crucial role in providing specialized support and care to children with various underlying conditions, including both malignant and non-malignant diseases. The research by Baumann et al. highlights the significant symptom burden experienced by terminally ill children with oncological diseases, underscoring the need for tailored approaches to symptom management in such cases. As we strive to develop and improve pediatric palliative care teams, it becomes essential to consider the specific requirements of oncology patients, especially in settings with limited resources. Having healthcare professionals with expertise in symptom control for oncology patients can be a valuable asset in

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enhancing the quality of care provided.

While progress in pediatric palliative care is evident, there are ongoing challenges to overcome. This discipline requires dedicated and compassionate healthcare professionals who are committed to addressing the unique needs and aspirations of young patients and their families. By staying focused on improving and expanding pediatric palliative care services, we can continue to make a meaningful difference in the lives of children facing life-limiting illnesses. Let us be inspired by the famous words "Keep calm and carry on," as we work together to ensure that every child receives the best possible care and support during their journey.

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