

Comprehensive Insights into Home-Based Pediatric Palliative Care: Challenges, Strategies, and Recommendations

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Abstract

This study explores the complex landscape of home-based pediatric palliative care, providing a thorough exploration of the hurdles and approaches associated with delivering empathetic care within a child's familiar surroundings. Utilizing an in-depth narrative case study, the report enriches our understanding of the nuances involved in care delivery, offering valuable insights into the methods, timing, and rationale behind administering such care. The results contribute practical recommendations for professionals engaged in comparable settings, with the goal of improving the effectiveness of home-based pediatric palliative care initiatives. The primary aim is to enhance the quality of life for children and families grappling with life-limiting conditions.

Keywords: Pediatric palliative care; Home-based care; Compassionate healthcare; Holistic care strategies; Life-limiting conditions in children

Introduction

Pediatric palliative care plays a crucial role in addressing the intricate needs of children with incurable diseases and their families. While home-based care provides a familiar and supportive environment, delivering comprehensive services in this context poses a formidable challenge. This qualitative narrative inquiry delves into the organization and provision of home-based pediatric palliative care. Healthcare practitioners contributed to the study through conversations, storytelling, and reflective journaling. The synthesis of the data was accomplished using Schwind's Narrative Reflective Process, resulting in a detailed case description. The narrative approach sheds light on the complexities associated with home-based pediatric palliative, end-of-life, and after-death care. Key findings emphasize the significance of early care coordination, interprofessional collaboration, effective symptom management, emotional and psychosocial support, and comprehensive end-of-life planning. Through the exploration of a specific case involving a child patient, this study delineates the challenges and strategies involved in providing holistic, family-centered care within the home environment. The practical insights gleaned from this report have the potential to inform the development and enhancement of home-based palliative care programs. This, in turn, can be beneficial for researchers, practitioners, and policymakers aiming to optimize care for children and families facing similar contexts. The study contributes valuable knowledge to the field, fostering a more nuanced and effective approach to pediatric palliative care within the home setting. Despite remarkable progress in pediatric cancer treatment, a significant portion of children, approximately 15-20% in developed nations, ultimately succumb to the disease [1]. Additionally, children may be diagnosed with non-malignant life-limiting conditions that curtail their lifespan [2]. In these challenging circumstances, irrespective of a nation's economic status, pediatric palliative care emerges as a comprehensive solution, addressing the physical, emotional, spiritual, and social concerns of both the child and their family [3]. Consequently, pediatric palliative care has garnered recognition as an integral sub-specialty, playing a pivotal role in optimizing outcomes for children and their families facing incurable diseases [4,5].

Acknowledging that there is no universally right or wrong place for palliative and end-of-life care, many families, whenever feasible, opt for such care within the familiarity of their own home [6]. The home

environment not only provides a sense of security and normalcy but also serves as a refuge, offering comfort to both the child and family that is challenging to replicate elsewhere [7]. This decision is deeply personal, often made to respect the child's wishes or maintain the family's role as the primary caregiver in a familiar setting [8].

Nevertheless, opting for home care introduces intricate challenges; children approaching the end of life often endure a high burden of symptoms, including pain, fatigue, dyspnea, irritability, anxiety, and fear [9]. Parents and siblings grapple with the heartbreaking prospect of losing a loved one, leading to anxiety, fear, and grief. Home care requires them to navigate their child's end of life while remaining capable of managing difficult symptoms. Addressing these factors and mitigating the resulting distress on both the child and the family are crucial aspects of holistic pediatric palliative care [10]. Hospitals and hospices offer access to dedicated staff and resources to manage the unpredictable path of a child's dying. Replicating the same range of supports in the home environment poses challenges on many levels [11]. The variations in service components and multiple service providers, coupled with the highly emotional nature of the situation and the home environment, make this a complex intervention [12]. Despite the existing literature extolling the benefits of home-based pediatric palliative care, examples illustrating how to organize such complex care are limited. Specifically, there is a dearth of comprehensive guidance or detailed descriptions of practical strategies for organizing and delivering high-quality home-based pediatric palliative care. This underscores the imperative for an in-depth exploration and documentation of the processes, challenges, and best practices involved in establishing and managing home-based pediatric palliative care programs. The objective of this paper is to utilize these methods to delineate the provision of home-based

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pediatric palliative care, contributing knowledge and guidance for practitioners.

Methods

We employed qualitative narrative inquiry to present a case report centered around a singular pediatric patient, aiming to capture the unfolding events over time. Both narrative inquiry and case report methodologies are employed to gain insights into complex phenomena by comprehensively understanding and analyzing how various components interconnect [13]. These relational methodologies delve into intricate real-life experiences, extracting meaning, amplifying voices, and presenting perspectives to offer a profound understanding of a specific sociocultural context [14]. The richly detailed and personal narrative serves as an authentic source of knowledge, dissecting complex phenomena [15].

Concentrating on a single case study allows for a meticulous exploration of the particular context and distinctive dynamics of the care provided. The philosophical foundation of this approach posits that experience is relational, temporal, and situational. When intentionally examined over time, it can serve an educational purpose. The process of engaging in deliberate reflection on experiences has the potential to derive meaning and broaden perspectives on being (ontology), knowing (epistemology), and doing (praxis). The knowledge thus gained offers understanding and insights that can be applicable to the reader's context. The selection of this particular case was deliberate, as it exemplified a scenario of home-based care involving a collaboration of multiple healthcare professionals. Data collection centered around four healthcare professionals actively engaged in providing home care for the subject of the study. These professionals were prompted to reflect on their individual contributions to home-based care for the child and family under consideration. Initially, dialogues among the healthcare professionals were utilized to contemplate their personal roles in the case and the subsequent impact on their professional lives. The next phase involved storytelling to elaborate on the case study, transitioning from individual experiences to a collective depiction of actions, timing, and rationale. Subsequently, reflective journaling was employed to extract detailed descriptions of the processes and purposes of care, offering multiple perspectives. Each professional was encouraged to document their unique experiences, focusing on the actions taken, when, and why. Guided prompts facilitated the elicitation of information, promoting further reflection on the social, temporal, and spatial dimensions of the inquiry. These data were shared within the group, fostering additional discussion and reflection on care provision. The synthesis of data adhered to principles from Schwind's Narrative Reflective Process, culminating in a rich case description that allowed for the articulation and interpretation of tacit knowledge and fragments of experience. This approach is grounded in the acknowledgment that personal experiences and narratives play a significant role in shaping perceptions and understanding. The collected data were then synthesized into a chronological narrative, ensuring credibility through member-checking and the maintenance of audit trails. This thorough method facilitated an exploration of personal care experiences in a reflective manner, with a specific emphasis on the interactions among all involved in home care. The findings are presented as a narrative storytelling of the subject case, guided by the principles of pediatric palliative care.

Our research protocol and methods underwent review and approval by the local Human Research Ethics Committee. Following ethical standards, written parental consent was obtained for the

publication of this case study. The parents actively participated in the review of the manuscript and expressed a desire to include the child's name and details in the publication, honoring their son's life. While adhering to the standards for obtaining informed consent, it is essential to note that the issues discussed herein primarily focus on the organization and processes of home care. In this context, the case study serves as a narrative about the individuals engaged in providing and receiving care. Preparing for Riordan's passing and the subsequent care post-mortem was just as significant as the care provided during his life. Families hold vivid memories of this time, and the quality of care provided during this period remains etched in their minds for a lifetime. The team's overarching goal is to ensure that families remember this phase marked by peace and reverence. To navigate these sensitive moments, initiating conversations with parents and siblings about their preferences for information and inclusion can guide discussions. Anticipating symptoms and potential events is crucial to ensure the child's comfort and alleviate the distress of the family. It is imperative that these conversations commence as soon as it becomes apparent that a child is entering the final phases of life. This early initiation allows parents, siblings, and extended family members the time to ask pertinent questions, prepare for the child's death, and bid their farewells. Parents may find solace in the knowledge that there is the option to shift the location of care to a hospital or children's hospice if the child's symptoms cannot be adequately managed at home. In such instances, reframing expectations and acknowledging the substantial care provided at home becomes essential.

After-death care: Honoring children's bodies and facilitating meaningful memories

Ensuring a child's body is treated with utmost respect in the aftermath of their passing is a critical aspect of comprehensive after-death care. A well-thought-out plan considers the timely transfer of the child's body to a funeral home, accommodating the family's needs. Families may desire to observe cultural practices or rituals in caring for their child's body, and documenting these preferences in the after-death care plan ensures not only understanding but also profound respect for these wishes. This period also presents an opportunity for memory-making, fostering poignant and lasting impressions that aid in the grieving and healing process. Collaborations with support charities, such as Precious Wings, are instrumental in providing resources like memory boxes, supporting the broader education of health professionals, and serving as a healing resource for grieving families. In regions with humid, hot climates, innovative collaborations with the industry empower families to extend after-death care for their child. Portable frozen dry-ice products can be used at home to cool the child's body, enabling families to care for their child for several days. Health professionals can now assist families in this process, ensuring the integrity of the child's body through the rotation of dry-ice sheets and providing ongoing care, including bathing, moisturizing, painting nails, and brushing hair, offering comfort to grieving families.

Discussion

In the intricate process of end-of-life and after-death care, active family involvement in developing plans is paramount. This inclusion ensures that cultural practices and rituals are not only acknowledged but also integrated into the care framework. Addressing the emotional and psychological needs of the child and their family is facilitated by allied health professionals specializing in therapy, along with appropriate pastoral care and support services. Riordan's case exemplifies the use of music therapy, providing the entire family a space to unite and create

enduring memories. Addressing the emotional well-being of both the child and the family is an integral facet of holistic pediatric palliative care. Elisabeth Kübler Ross's seminal work delineates the emotional aspects of coping with death and dying. However, contemporary literature recognizes the complexity and individualized nature of grief. Best practice recommendations underscore the parents as experts in knowing their child, emphasizing the critical role health professionals play in supporting parents. Decisions involving whether to include a child in discussions about their care or inform them about their condition are profoundly sensitive and should always prioritize the child's best interests. Palliative care practice, being emotionally complex and evocative, often leaves healthcare professionals feeling unprepared. Factors contributing to this include limited formal education about palliative care, a lack of confidence in managing patient and family care, and the practitioners' personal experiences of grief and loss. Recognizing the impact of these challenges on practitioners is crucial. The case study of Riordan provides valuable insights into optimizing care for both the child and the family, as well as ensuring robust support for practitioners. Interprofessional teams and peer support play pivotal roles in preventing professional isolation among practitioners. Whether through formal meetings, supervision, or ad hoc telephone support, practitioners engaged in home-based care must have access to support mechanisms. This is indispensable for maintaining their well-being and emotional resilience, enabling them to provide holistic and compassionate care to families in need.

Conclusion

This extensive report thoroughly explores the complex realm of home-based pediatric palliative care, shedding light on the challenges and strategies inherent in delivering compassionate and comprehensive care within the familiar confines of a child's home. Utilizing a narrative case study, this examination not only deepens our comprehension of this nuanced field but also furnishes actionable recommendations aimed at enhancing the provision of holistic and compassionate home-based pediatric palliative care. The detailed account of care nuances provides valuable insights into the intricacies of how, when, and why care is delivered, making it an invaluable resource for practitioners engaged in similar contexts of caring for children and their families. The insights and recommendations presented have the potential to significantly impact the refinement and optimization of home-based pediatric palliative care programs. Ultimately, this contribution seeks to improve the quality of life for children and families grappling with life-limiting conditions, fostering a more compassionate and supportive healthcare environment.

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Conflict of interest

Author declares no conflict of interest.

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