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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 Schwint'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

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 Schwinn'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 transparent care for

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
