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NURSES EMOTIONAL EXPERIENCES REGARDING PALLIATIVE CARE OF PEDIATRICS: A QUALITATIVE STUDY IN PUNJAB, PAKISTAN

Qualitative Study

Shumaila Safdar[1], Irfana Kausar[2], Adeela Qayyum[3]*
[1]Post RN, Specialization in CCU, General Nursing, Head Nurse, Mayo Hospital Lahore, Pakistan.
[2]Mphill Public Health, BSc Nursing, Charge Nurse Punjab Institute of Cardiology Hospital Lahore, Pakistan.
[3]MSc Nursing, Mphill Public Health, BSc Nursing, Assistant Professor Islamia University Bahawalpur, Pakistan.
Corresponding Author: Adeela Qayyum, MSc Nursing, Mphill Public Health, BSc Nursing, Assistant Professor Islamia University Bahawalpur, Pakistan. Adeela1515@gmail.com

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ABSTRACT

Background: Compassion fatigue is prevalent among medical staff treating children with life-threatening conditions, affecting their psychological well-being and job performance. This study aims to explore the emotional experiences of nurses working within a multidisciplinary pediatric palliative home care team.

Objective: To characterize the emotions and sentiments of nurses involved in pediatric palliative care, assessing both the positive and negative impacts of their work.

Methods: A qualitative case study design was employed, involving eighteen participants from a home-based interdisciplinary pediatric palliative care team. Data were collected through semi-structured interviews and field notes, followed by thematic analysis to identify underlying themes related to the nurses' emotional experiences.

Results: Two primary themes emerged from the analysis: (a) 'Improving Life,' highlighting how nurses find personal and professional fulfillment in their roles, valuing life more and gaining compassion satisfaction from assisting children and families; and (b) 'Negative Effects of Work,' which underscored the emotional burdens associated with caring for terminally ill children. These burdens include the risk of burnout and the profound impact of witnessing child suffering and death in hospital settings.

Conclusion: The study elucidates the dual emotional impact of pediatric palliative care on nurses. While the role offers significant personal satisfaction and a sense of purpose, it also poses substantial emotional challenges. Understanding these impacts can guide the development of strategies to support nurses' well-being and enhance the quality of care.

Keywords: Burnout; Child; Emotions; Palliative Care; Pediatrics; Personal Satisfaction; Qualitative Research.

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INTRODUCTION

Pediatric palliative care (PPC) addresses the complex needs of children and adolescents with terminal illnesses or life-limiting conditions, incorporating comprehensive family care to optimize quality of life and alleviate suffering. The interdisciplinary PPC team, comprising various healthcare professionals, is essential in managing care goals, symptom control, and supporting families through the bereavement process following the loss of a child. Given the prolonged care periods typical of PPC compared to adult palliative care, healthcare providers, especially nurses, frequently develop strong emotional bonds with their patients and families, significantly increasing their emotional load (4,5). Nurses in PPC settings are continually exposed to emotionally taxing clinical situations, which can lead to compassion fatigue, characterized by deep emotional and physical exhaustion due to empathetic engagement with suffering individuals (8). Moreover, burnout may manifest in these healthcare professionals as a syndrome of emotional exhaustion, depersonalization, and reduced personal accomplishment, negatively affecting their well-being and job performance (9). Despite these challenges, some nurses experience compassion satisfaction, finding emotional fulfillment in the care they provide, which can buffer against the negative impacts of their demanding roles (10).

Research indicates that while burnout and compassion fatigue among PPC nurses are relatively low, job satisfaction tends to be high, suggesting a complex interplay of factors influencing their professional fulfillment and the quality of care delivered (3, 11, 12, 13). Although prior studies have utilized specific questionnaires to explore predictors of compassion fatigue, burnout, and compassion satisfaction, there remains a significant gap in qualitative research that specifically addresses the emotional experiences of nurses in PPC. Such insights are crucial for developing targeted interventions to support nurse well-being and enhance patient care (14). This study aims to explore and characterize the emotions and sentiments of nurses working in home-based and hospital oncology PPC settings at Jinnah Hospital in Lahore and Nishtar Hospital in Multan. By identifying and understanding the coping strategies employed by these nurses, the study seeks to propose effective measures to improve their psychological health and, consequently, the overall quality of palliative care provided.

METHODS

This qualitative case study was designed following the Consolidated Criteria for Reporting Qualitative Research and the Standards for Reporting Qualitative Research to ensure a rigorous and standardized approach (15, 16). The study employed a case study design, enabling the exploration of complex phenomena within their real-life contexts by collecting data from multiple sources, including different healthcare professionals involved in pediatric palliative care. This approach allowed for an in-depth examination of the interdisciplinary pediatric palliative care (ID-PPC) team as a unit, comprising individuals, groups, and organizational structures within the healthcare setting (17, 19, 20, 21). The study was conducted primarily within home settings where the specialist PPC unit annually managed care for approximately 110 new pediatric patients, providing palliative care directly to about 90 children and overseeing around 180 home hospitalization episodes. This setting facilitated a comprehensive observation of the interactions and practices inherent to home-based pediatric palliative care (22).

Purposive sampling, supplemented by snowball techniques, was utilized to select participants with direct involvement and detailed knowledge of the home-based ID-PPC processes. This sampling method ensured the inclusion of all pertinent nurses, reflecting the study's aim to encompass comprehensive viewpoints from the field (23, 24, 25). Data were collected through a combination of in-depth, semi-structured interviews and researchers' field notes, employing a question guide informed by expert opinions and existing literature. This method allowed for flexibility in exploring significant themes identified by the participants themselves (14, 25). The analysis of the collected data involved several meticulous steps. Transcriptions of all field notes and interviews were first coded line-by-line. Initial codes were then organized into categories, which facilitated the identification of key themes and sub-themes. This thematic framework underwent further refinement through re-coding and the construction of conceptual maps, ultimately defining and confirming the relevance and meanings of each theme (25, 26, 27).

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RESULTS

In this qualitative study, eighteen professionals, consisting of twelve women and six men, provided insights into their experiences with pediatric palliative care. The analysis revealed eight categories, four sub-themes, and two primary themes that captured the essence of the emotional experiences and occupational impacts on nurses involved in home-based interdisciplinary pediatric palliative care (ID-PPC). The first major theme identified was "Changing Life for the Better," which illustrated how nurses perceive the positive impacts of their engagement in palliative care. Nurses reported significant personal and professional growth through their experiences, emphasizing an enriched appreciation of life and a more profound sense of personal and professional fulfillment. They described a shift in life perspective, where caring for terminally ill children and their families encouraged them to prioritize and value aspects of their own lives more deeply, such as family and health, which were previously taken for granted. This shift often resulted in a stronger appreciation for their circumstances and a feeling of gratitude. Moreover, nurses conveyed a profound sense of compassion satisfaction, finding comfort in knowing that their care ameliorated the suffering of children and families during vulnerable times.

Conversely, the second major theme, "Adverse Effects of Work," highlighted the emotional challenges and negative experiences associated with PPC. Nurses spoke about the emotional toll and psychological scars from their prolonged exposure to the suffering and death of children, which they metaphorically described as wounds and dents that accumulate over time. This exposure often necessitated periods of emotional recovery to manage the personal impact of such intense professional experiences. Additionally, nurses shared their experiences with "bad deaths" in other programs prior to joining PPC, which included children dying alone, lack of communication with parents about their child's impending death, and inadequate symptom management. These experiences underscored their commitment to improving end-of-life care in PPC settings, driving them to seek better ways to support not only the patients but also their families during these critical times. This study's findings underscore the dual-edged nature of nursing in pediatric palliative care—while the role is fraught with emotional challenges, it also offers significant opportunities for personal growth and professional satisfaction. These insights are pivotal for developing supportive measures that enhance nurse resilience and ensure the delivery of compassionate, family-centered care.

DISCUSSION

This study highlights the profound emotional and professional impacts of pediatric palliative care (PPC) on nurses, emphasizing both the positive aspects such as compassion satisfaction and personal growth, and the challenges including emotional fatigue and the repercussions of distressing clinical experiences. The findings align with Tedeschi and Calhoun's framework on personal growth, where the participants reported enhancements in their interpersonal relationships, personal strength, and life priorities, echoing similar findings in the literature where healthcare professionals have noted significant personal and professional development through their work in care settings (34, 35). Nurses in the study expressed that their engagement in PPC not only fostered a heightened appreciation for life but also improved their professional capabilities, a sentiment supported by previous studies indicating high job satisfaction among PPC professionals (3, 11, 12, 13). This study further contributes to the under-researched area of compassion satisfaction in healthcare, highlighting its prevalence and importance over burnout and compassion fatigue among PPC professionals (3, 39, 40). The reinforcement of compassion satisfaction, rather than merely mitigating burnout, is underscored as a vital aspect of sustaining healthcare worker well-being in PPC settings.

Conversely, the discussion on adverse effects of work sheds light on the emotional toll experienced by PPC professionals, characterized by emotional scars from witnessing child suffering and death. These findings resonate with existing literature, which identifies personal loss, physical exhaustion, and the emotional strain of clinical conditions as predictors of compassion fatigue (3). Notably, the concept of a 'good death' emerges as crucial within PPC, providing a counterpoint to the negative experiences known as 'bad deaths' occurring outside of palliative care settings, such as in pediatric intensive care units or oncology units where the lack of parental presence or inadequate symptom management during a child's death prevails (48, 49). The geographical focus of this study adds a unique perspective to the existing literature by highlighting how regional practices and cultural contexts influence the execution and reception of PPC. This underscores the need for continued advancement in PPC practices to better support both patients and healthcare providers in various regions (58).

Limitations of this study include its inability to generalize findings across all ID-PPC nurses due to the qualitative nature of the research and the specific contexts of the participants involved. Future research directions suggested include examining the prevalence of burnout,

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compassion fatigue, and compassion satisfaction more broadly within the PPC nurse population, as well as investigating the impacts of major life events, such as pregnancy and parenthood, on professionals in this field. Overall, this discussion not only confirms the dual nature of PPC work as both rewarding and challenging but also offers insights into strategies that could mitigate the hardships while enhancing the rewarding aspects, thereby fostering a more resilient healthcare workforce in pediatric palliative settings.

CONCLUSION

Understanding the emotional impact on nurses within home-based interdisciplinary pediatric palliative care (ID-PPC) is crucial for the enhancement of palliative care practices. Insights gathered from these professionals highlight the necessity of implementing strategies that effectively address stress and burnout while promoting well-being. By prioritizing the mental health and job satisfaction of PPC nurses, the quality of care provided to pediatric patients can be significantly improved, ultimately supporting both patients and healthcare providers in this challenging field. This conclusion underscores the importance of compassionate support systems within healthcare settings, aiming to foster a resilient environment that benefits all involved in the palliative care journey.

AUTHOR CONTRIBUTIONS

Author	Contribution
Shumaila Safdar	Substantial Contribution to study design, analysis, acquisition of Data Manuscript Writing Has given Final Approval of the version to be published
Irfana Kausar	Substantial Contribution to study design, acquisition and interpretation of Data Critical Review and Manuscript Writing Has given Final Approval of the version to be published
Adeela Qayyum*	Substantial Contribution to acquisition and interpretation of Data Has given Final Approval of the version to be published

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