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abstract

Establishing Care Priorities for Developing a Paediatric Palliative and End-Of-Life Care Program Based on Bereaved Parents' Experiences at a Tertiary Care Hospital in Pakistan

Shahzadi Resham, Sadaf Altaf, Ayesha Khalid, Syed Muhammad Irtaza Hashm, Areeba Syed, Naveed Rehman, Vardah Bharuchi, Fatima Rahman, Aamena Shafi, Zehra Fadool, Naureen Mushtaq, Fyezah Jehan, Michael McNeil, Lisa Clark, Justin Baker

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Authors: Shahzadi Resham, Sadaf Altaf, Ayesha Khalid, Syed Muhammad Irtaza Hashm, Areeba Syed, Naveed Rehman, Vardah Bharuchi, Fatima Rahman, Aamena Shafi, Zehra Fadool, Naureen Mushtaq, Fyezah Jehan, Michael McNeil, Lisa Clark, Justin Baker

Affiliation: Aga Khan University Hospital

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Introduction: Early integration of specialized pediatric palliative care (PPC) is crucial for addressing suffering in children and families facing severe illnesses, as per the World Health Organization. Over 80% of children needing PPC live in low- and middle-income countries (LMICs) with limited resources. We aim to establish Pakistan's first PPC program by identifying care priorities from bereaved parents.

Methodology: A qualitative study was conducted in Karachi, Pakistan. Bereaved parents between 2 and 5 years after the death of a child with malignant and nonmalignant illnesses caused by disease or complications from treatment, were interviewed in the paediatric or paediatric oncology units at Aga Khan University Hospital. The team conducted semi-structured in-depth interviews about their experiences during and after their child's care. Data collection stopped when a point of saturation was reached. An inductive thematic analysis was conducted, and themes were organized using Dedoose qualitative software.

Results: Nineteen interviews were conducted with bereaved parents of children (n=10 with malignant illness and n=9 with non-malignant illness). Six major themes emerged, including holistic care, effective communication, care coordination, supportive environment and resources, comfort and dignity in end-of-life care, and bereavement support, shared across both groups. Four key priorities were identified: efficient care delivery in a complex healthcare system through effective communication and collaboration, prioritizing end-of-life care for comfort and dignity, addressing bereavement support as a critical need, and enhancing quality of life through compassionate, holistic care based on personal and cultural values facilitated by an interdisciplinary team.

Conclusion: The provision of excellent care for seriously ill children, both during treatment and in times of bereavement, is crucial. Leveraging bereaved parents' recommendations and priorities will help us in developing an innovative strategic plan to establish a comprehensive PPC program.