

SUPPORTING FAMILIES THROUGH LOSS: A QUALITATIVE STUDY EXPLORING PEDIATRIC BEREAVEMENT CARE IN A TERTIARY CARE HOSPITAL IN PAKISTAN

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BACKGROUND

In Pakistan, most children with life-threatening illnesses present at advanced stages and succumb to death, leaving families emotionally traumatized. Parental bereavement leads to long-term psychosocial and financial hardships for families, thus highlighting the need of bereavement care as a crucial part of pediatric palliative care.

OBJECTIVES

This study aims to explore key challenges around lack of bereavement care in the healthcare infrastructure in Pakistan and identifies opportunities to establish this program for grieving families.

METHODOLOGY

A qualitative study at Aga Khan University Hospital, Karachi, involved semi-structured interviews with bereaved parents 2–5 years after their child's death from oncology or non-oncologic illnesses. Data collection stopped at saturation. Inductive thematic analysis was performed using DeDoose software.

CONCLUSION

This is the first study ever conducted in Pakistan which highlights critical gaps and provides context-specific recommendations for establishing bereavement services based on parental recommendations. Key opportunities for improvement include institutional initiatives for structured bereavement care and addressing societal taboos around grief expression. These changes can foster an environment where bereaved families receive the support they need.

REFERENCES

1. Weaver MS, Nasir A, Lord BT, Starin A, Linebarger JS, Nasir AA, et al. Supporting the Family After the Death of a Child or Adolescent. *Pediatrics*. 2023;152(6).

2. Lam CG, Howard SC, Bouffet E, Pritchard-Jones K. Science and health for all children with cancer. *Science*. 2019;363(6432):1182-6.

RESULTS

Nineteen bereaved parents were interviewed, including parents of children with oncological (n=10) and non-oncological (n=9) diseases. Thematic analysis identified 4 major themes and showed no significant differences between the two groups.

Participants with a Primary Diagnosis of Oncological/Hematological Diseases:	N = 10
AML	3
Infantile ALL	1
High Risk ALL	1
Medulloblastoma	1
Neuroblastoma	1
Aplastic Anemia	1
Rare Solid Tumor	1
Metastatic Embryonal Tumor	1

Location of Residence:	N=19
Karachi	17
Lahore	1
Hyderabad	1

Participants with a Primary Diagnosis of Non-Oncological Diseases:	N = 9
SCID	1
Cystic Fibrosis	2
Epidermolysis Bullosa	1
Chronic Granulomatous Disease	1
Spinal Muscular Atrophy	2
Ectodermal Dysplasia with Dilated Cardiomyopathy	1
Rare Gene Mutation IGHMBP2	1

Mode of Interview:	N=19
In-Person	10
Telephonic	9

Psychosocial and Emotional Support

Parents reported gaps in communication and limited access to psychological care due to stigma, cost, and lack of awareness. *“There should be a team to counsel parents daily, ask how they’re feeling, and give them someone to open up to. Having such support would ease their hearts and make a big difference during these times.”*

Support from Other Parents

Families valued the idea of peer support, though cultural norms around grief often restricted open sharing. *“For parents without family support, there should be someone to share their grief and help them cope. Connecting them with other parents facing serious illnesses would also give mutual support.”*

Support for Siblings

Surviving children were often overlooked, with little guidance or resources available to help them process grief. *“I had no support and made the mistake of involving my 7-year-old, reassuring her everything was fine despite the heavy atmosphere at home. It was my fault—driven by lack of knowledge, support, and professional help.”*

Institutional Bereavement Support

Lack of condolence practices, follow-up, and educational materials reinforced feelings of neglect. *“I believe doctors should at least call after a patient’s death to ask how the family is doing. It shows they remember us and that we mattered as their patients.”*