Exploring Children’s Experiences of Cancer Treatment in Low- and Middle-Income Countries: A Framework for Enhancing Care – A Multi-Institutional Study from Pakistan

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INTRODUCTION

- The majority of children in low- and middle-income countries (LMICs) undergo their cancer journeys without critical psychosocial support and play therapy.
- Limited research exists to understand children’s perceptions of their oncologic care, especially in LMICs.
- This study explores children's experiences to develop a framework focused on addressing their concerns and strengthening patient-physician relationships in these settings.

METHODOLOGY

- Participants included children aged 8–18 years with an oncologic diagnosis, treated at three pediatric oncology units in Karachi, Pakistan.
- A qualitative, phenomenological design was implemented, with semi-structured interviews serving as data collection.
- Data collection ceased at saturation, and inductive thematic analysis was performed utilizing DeDoose software.

STUDY PARTICIPANTS

Nineteen children were interviewed, representing all stages of treatment:

1. 4 children were newly diagnosed
2. 6 children were in treatment
3. 5 children were off treatment
4. 4 children were on palliative treatment

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Understanding Pediatric Oncology Patients in LMICs’ Experiences During Different Phases of Cancer Journeys

Newly Diagnosed and Receiving Treatment	Off Treatment	Receiving Palliative Treatment
▪ Distress from needle pain ▪ Distress from medication side effects ▪ Anxiety due to separation from family and school ▪ Financial burden on family ▪ Impact of frequent hospitalizations	▪ Concern for long-term recovery ▪ Uncertainty regarding impact on education ▪ Concern for survival outcomes	▪ Concern for impact of disease on family ▪ Prioritization of loved one’s well-being over own struggles ▪ Maintained aspirations for recovery and education ▪ Demonstrated desire to help others
“Baar baar lagti hai needle…darr lagta hai in se itna ziada” – 16 y/o patient *“They give me needles again and again…I’m really scared of them” – 16 y/o patient*	*“[Darr] Yeh tha k main theek hoti hun k nahi” – 18 y/o patient* *“[My concern is] if I’m going to be okay or not” – 18 y/o patient*	*“Mujhy han apny ami abu k liay parayshani hti hai unhny apna sara time sari cheezay mjhy dy di” – 17 y/o patient* *“I worry about my parents, as they’ve given all of their time and everything to me” – 17 y/o patient*

Pediatric Oncology Patients in LMICs’ Recommendations for Support During All Phases of Cancer Journeys

Communication Framework	▪ Clear and empathetic communication from healthcare providers ▪ Involvement of multidisciplinary teams ▪ Incorporation of coping strategies such as faith, prayer, utilization of personal technology, walking around hospital into healthcare plan ▪ Encouragement of in-house recreational support to support mental well-being

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RESULTS

- Four major themes were identified, across these treatment stages.
- Children undergoing treatment commonly experienced distress from needle pain, medication side effects, separation from family and school, financial burdens, and frequent hospital visits.
- Children who completed treatment expressed fears, uncertainties, and aspirations, including concerns about long-term recovery, education and survival.
- Children receiving palliative treatment expressed deep concern for their families, often prioritizing their loved one’s well-being over their own struggles. Despite these challenges, they maintained aspirations for recovery, education and their desire to help others.
- Clear communication and empathetic involvement from doctors and multidisciplinary teams were highly appreciated by all children.
- Coping strategies included faith, prayer, using mobile phones for distraction and entertainment, and walking around the hospital.
- They expressed a strong need for in-house recreational support to enhance their mental well-being.

CONCLUSION

Conceptualizing cancer treatment as a journey emphasizes the importance of addressing children’s concerns about adjusting to a new normal while considering their phase of treatment fostering patient-centered communication, integrating psychosocial services, and supporting healthy coping mechanisms.