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Transforming Pediatric Palliative Care in Low- and Middle-Income Countries: Findings from the PrOTECT Pilot Study

Introduction: Pediatric palliative care (PPC) is critically important yet remains underdeveloped in low- and middle-income countries (LMICs), where the majority of pediatric cancer cases occur. The Pediatric Oncology Tool for End-of-Life Care Treatment (PrOTECT) aims to address this gap by providing a structured approach to improving end-of-life care quality measures in these settings.

Methods: This IRB-approved qualitative study employed a mixed-methods approach to develop and evaluate the PrOTECT tool. The study involved multiple phases: a literature review and expert panel assessment, a modified Delphi process, and discrete choice experimentation with focus groups. The tool was distributed to interdisciplinary palliative care teams at thirteen institutions treating pediatric oncology in LMICs, with responses uploaded into REDCap. Follow-up surveys evaluated the tool's usability, acceptability, appropriateness, and feasibility. Focus group discussions provided qualitative data on implementation barriers and enablers.

Results: The PrOTECT tool was assessed by 39 participants from thirteen institutions in LMICs around the world. Three individuals from each institution comprised of a physician, an interdisciplinary team member, and an institution leader completed the tool. Survey results showed high levels of usability (average score 4.5/5 and standard deviation 0.79), acceptability (4.6/5, 0.75), appropriateness (4.7/5, 0.89), and feasibility (4.4/5, 0.81). Preliminary data from focus group discussions identified key barriers, such as limited access to essential medications and lack of trained professionals, and enablers, including strong leadership support and existing palliative care frameworks. Participants reported that the tool facilitated multidisciplinary collaboration and helped prioritize care improvements.

Conclusions: The PrOTECT tool demonstrates significant potential as a framework to enhance pediatric end-of-life care in LMICs. The high usability, acceptability, appropriateness, and feasibility scores, along with positive qualitative feedback, suggest that PrOTECT can effectively support healthcare providers in these settings. Further refinement and broader implementation of the tool could substantially improve the quality of life for children with cancer in resource-limited environments.