

Research Priorities in Pediatric Palliative Care

Baker et al. (2015)

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For which topic were research priorities identified?

pediatric palliative care

In which location was the research priority setting conducted?

North America - USA

Why was it conducted at all?

Ongoing challenges faced by patients, families, and providers include the intrinsic difficulty of caring for those with life-threatening conditions, lack of evidence to guide treatment decisions, complex diversity of disease trajectories, and limited financial resources and personnel. In 2003, the Institute of Medicine recommended the development of PPC training programs, guidelines, protocols, and priorities for research. In a 2008 Delphi study of Canadian palliative care researchers and clinicians, participants identified research priorities based on patient and family needs assessment standards for symptom management, improvement in EOL care, and bereavement. However, because of the evolution of PPC and inherent differences between the Canadian and US healthcare systems, those findings might not reflect current research priorities in the US. The present study used Delphi methodology to identify and prioritize areas of PPC research through a consensus of PPC providers and parents of patients.

What was the objective?

to synthesize the perspectives of a broad range of pediatric palliative care clinicians and parents, to formulate a consensus on prioritization of the pediatric palliative care research agenda

What was the outcome?

a ranking list of 20 research topics

How long did the research prioritization take?

No information provided.

Which methods were used to identify research priorities?

Delphi

How were the priorities for research identified exactly?

Step 1: Delphi round 1: participants were asked to name the top-5 research priorities in PPC. Step 2: content analysis: study team identified and grouped priorities. Step 3: Delphi round 2: participants were asked to rate each listed priority. Step 4: Delphi round 3: participants were asked to re-rate based on frequency and mean ratings of round 2. Step 5: Delphi round 4: participants received list of the priority items that had reached >80% consensus and were asked to rank the top 10 priorities

Which stakeholders took part?

Nurses, physicians (pediatrics, critical care, hematology/oncology, neonatology), parents, social workers, chaplains, administrators, child life specialists, psychologists, pharmacists. 242 participants in Delphi round 1, 130 participants in Delphi round 2, and 57 participants in Delphi round 3.

How were stakeholders recruited?

Potential participants were identified using distribution lists from PPC field conferences. Contacted participants nominated parents whose children had received palliative care or hospice care, thus providing a heterogeneous stakeholder perspective.

Were stakeholders actively involved or did they just participate?

Stakeholders were mere participants of the research prioritization process; they were not actively involved in the process.