Research Priorities in Pediatric Palliative Care

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Objective To synthesize the perspectives of a broad range of pediatric palliative care (PPC) clinicians and parents, to formulate a consensus on prioritization of the PPC research agenda.

Study design A 4-round modified Delphi online survey was administered to PPC experts and to parents of children who had received PPC. In round 1, research priorities were generated spontaneously. Rounds 2 and 3 then served as convergence rounds to synthesize priorities. In round 4, participants were asked to rank the research priorities that had reached at least 80% consensus.

Results A total of 3093 concepts were spontaneously generated by 170 experts and 72 parents in round 1 (65.8% response rate [RR]). These concepts were thematically organized into 78 priorities and recirculated for round 2 ratings (n = 130; 53.7% RR). Round 3 achieved response stability, with 31 consensus priorities oscillating within 10% of the mode (n = 98; 75.4% RR). Round 4 resulted in consensus recognition of 20 research priorities, which were thematically grouped as decision making, care coordination, symptom management, quality improvement, and education.

Conclusions This modified Delphi survey used professional and parental consensus to identify preeminent PPC research priorities. Attentiveness to these priorities may help direct resources and efforts toward building a formative evidence base. Investigating PPC implementation approaches and outcomes can help improve the quality of care services for children and families. *(J Pediatr 2015;167:467-70).*

P alliative care aims at improving the quality of life (QOL) for patients and their families throughout the course of life-threatening conditions, with hospice care provided at the end of life (EOL). Pediatric palliative care (PPC) is a holistic interdisciplinary care approach with the goal of evaluating and minimizing suffering while promoting personal and spiritual growth. The American Academy of Pediatrics recommends initiation of PPC at diagnosis,[1] which could improve QOL for the more than 400 000 pediatric patients and for their families living with life-threatening or serious health conditions in the US.[2] PPC also can reduce suffering and improve satisfaction with care among dying children and their families.[3]

PPC differs fundamentally from adult palliative care in that it involves parents in decision making and is attentive to the diverse developmental stages represented within service cohorts. Identifying patients for whom PPC is appropriate may be hindered by definitional and prognostic criteria, as well as by limited access to programs and lack of database registries within those programs. 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.[2]

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.[4] 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[5] to identify and prioritize areas of PPC research through a consensus of PPC providers and parents of patients.

EOL	End of life
PPC	Pediatric palliative care
QOL	Quality of life
RR	Response rate

Methods

After obtaining Institutional Review Board approval, we identified potential participants 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. Participants (n = 368) were informed of the continued commitment involved in the multistep, iterative Delphi technique (pareonline.net/pdf/v12n10.pdf), with continued eligibility for participation requiring responses in consecutive rounds. Demographic information for participants was collected in round 1 only.

Solicitation of Opinions

After pilot testing, in round 1 an anonymous, open-ended questionnaire was administered online via SurveyMonkey. Respondents were asked to name the top-5 research priorities in PPC. A study-team panel comprising 2 physicians, 1 research nurse, and 1 social worker (all trained in qualitative coding) evaluated the responses and used content-analysis techniques to identify and group priorities. Discrepancies were resolved through discussion until consensus was reached.

Synthesis of Perspectives

In round 2, participants ranked each listed priority as: (1) very important: urgent priority; (2) moderately important: intermediate priority; (3) somewhat important: low priority; or (4) not important: not a priority. Consensus on priority was determined from the percentage of respondents who ranked the item as "very important" or "moderately important." The frequency and mean of each item's rankings were calculated and recirculated to participants to enable further priority convergence in round 3. The standard of consensus was a >80% frequency of priority selection.[6] Individual rankings of priorities from incomplete surveys were still included in data analyses to ensure the broadest representation possible.

Stratification of Priorities

In round 4, participants received a list of the priority items that had reached >80% consensus and were asked to rank ordinally the top 10 priorities. A total prioritization score was calculated, and priorities constituting >10% of the total (the predetermined standard of consensus[6,7]) were considered high priorities.

Results

The **Figure** (available at www.jpeds.com) depicts the multistep iterative Delphi technique used and the results for each round. A total of 242 individuals, including 72 parents, participated in round 1 (a 65.8% response rate [RR]). Demographic information and self-reported experience measures of participants are presented in

Tables I and **II**, respectively. In round 1, 53 parents (72%) identified themselves as bereaved, and 39 parents (54%) also identified themselves as professionals in a pediatric-relevant field. Round 1 yielded 3093 individual responses that led to 1010 free-text priorities after duplicate priorities were removed. These items were organized into 78 priorities by qualitative theme coding. Although duplicates were removed and responses were thematically consolidated, no response items were omitted.

Round 2 included 130 respondents (53.7% RR) with 119 completed surveys (91.5% completion rate). In round 3, 98 participants responded (75.4% RR) with 83 completed surveys (84.7% completion rate). Round 3 reduced the spread of rankings, with 31 priorities now reaching >80% consensus. Fifty-seven participants (58%) elected to create an ordinal top-10 list from 31 circulated priorities. Twenty items reached consensus level[7] as research priorities (**Table III**; available at www.jpeds.com); these 20 items were then thematically grouped by using content analysis into 4 categories: decision making (priorities 1, 3, 6, 8, 10, 15, and 18), care coordination to include mechanisms of support (priorities 2, 5, 7, 16, and 20), symptom management (priorities 9, 12, and 19), and quality improvement (priorities 4, 11, 13, 14, and 17).

Discussion

The priorities most commonly identified emphasize communication with patients and families and shared medical

Table I. Demographic information for round 1 respondents

Self-identified role	Responses, n (%)*
Nurse, nurse case manager, or nurse practitioner	96 (27)
Certified in hospice/palliative medicine	23 (24)
Physician	82 (23)
Specialization	
Board-certified in hospice/palliative medicine	35 (43)
Other	22 (29)
Pediatrics	16 (20)
Critical care	15 (18)
Hematology/oncology	14 (17)
Neonatology	8 (15)
Parent	72
Diagnosis of child	
Neurologic diagnosis	24 (34)
Oncologic diagnosis	14 (20)
Multiorgan diagnosis	5 (7)
Neonatal condition	4 (<1)
Other diagnosis	24 (34)
Parent self-identified as bereaved	53 (73)
Parent self-identified as healthcare professional	39 (54)
Social worker	51
Chaplain	18
Administrator	13
Child life specialist	10
Psychologist	7
Pharmacist	3

*Participants may have selected multiple responses. For example, 52 parents of children who had received PPC services also self-identified as health professionals. Pediatric providers may have self-identified pediatrics as their primary field in addition to a subspecialty, such as oncology, or may have self-identified as administrators if that role was relevant to their work.