

Research Priorities in Pediatric Palliative Care: A Delphi Process

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BACKGROUND

- ❖ Pediatric palliative and end of life care is an emerging area of health care and is increasingly recognized as a specialized type of care that requires specific skills and knowledge.
- ❖ Health care providers face new and diverse challenges associated with illness trajectories that continue to manifest in different ways.
- ❖ It is important to strategically identify research agendas that address the changing experience of pediatric palliative care.
- ❖ Currently in the literature there is relatively very little research regarding pediatric palliative and end of life care.
- ❖ The New Emerging Team (NET) *Transitions in Pediatric Palliative and End of Life Care* determined to facilitate a formal approach to identify research priorities in this area.

OBJECTIVE

- ❖ To identify research priorities that are considered significant and meaningful to researchers and frontline clinicians in pediatric palliative care.

METHODS

Delphi Technique

- ❖ First developed by the RAND corporation for forecasting purposes.
- ❖ Is a structured method intended to synthesize a diverse range of expert opinions until a consensus is achieved.
- ❖ Is an iterative process that comprises 2 to 3 rounds of questionnaires.
- ❖ Primary advantage of this technique is that it provides an opportunity for participants to confidentially present and respond to ideas without the pressures of face to face influences.

METHODS

Phase One

- ❖ A list of 25 national pediatric palliative care health professionals and researchers was generated by the study investigators and from the Canadian Network of Palliative Care for Children. Attempts were made to formulate a list that would be representative of interdisciplinary palliative care.
- ❖ The first round involved an open-ended question e-mailed to potential participants that requested identification of 5 research priorities that they believed were especially important for pediatric palliative and end of life care.
- ❖ 16 of the 25 participants returned their survey, for a response rate of 64%.
- ❖ The sample was comprised of nurses (N=5), physicians (N=6), and a social worker, medical anthropologist, recreation therapist, play therapist, and administrator (N=1 of each).

Phase Two

- ❖ Phase one generated 74 questions – these were content analyzed and collapsed into 11 themes.
- ❖ All 74 questions were compiled into a questionnaire and sent out via e-mail to the same participants requesting review and evaluation.
- ❖ Participants were requested to indicate level of importance of each of the questions from their perspective. Responses were ranked on a 5-point Likert scale, ranging from 'Not Important' to 'Very Important'.
- ❖ 15 of the 16 participants returned the survey, for a response rate of 94%.
- ❖ All returned survey results were statistically analyzed to establish consensus on most highly rated research priorities.
- ❖ A minimum level of consensus of 66% was attained in phase two indicating that 14 of the 74 questions were either 'quite' or 'very' important.

FINDINGS

Phase Two Top Research Priorities

1. What are the bereavement needs of families in pediatric palliative care?
2. What strategies are effective in caring for the needs of bereaved siblings?
3. What is the impact of bereavement follow-up programs (and good quality end of life care) on parents and siblings long term ability to cope with a child's death?
4. What bereavement programs or interventions are most helpful?
5. What matters most for patients and parents receiving pediatric palliative care?
6. How do siblings cope? What kinds of support are effective for them?
7. How can we prepare children for their siblings' death?
8. How best to improve palliative care services into a children's hospital?
9. What are the best practice standards in pain and symptom management?
10. How do we treat irritability/agitation in children at the end of life?
11. Pharmacological studies to understand control of symptoms including pain.
12. What symptoms are most prevalent and what are the best treatments for them?
13. How do we manage withdrawal of artificial nutrition and hydration?
14. What are effective strategies to alleviate suffering at the end of life?

DISCUSSION

- ❖ The Delphi method facilitated the identification of current and meaningful research priorities according to respondents across Canada who participated in this national survey.
- ❖ Although the Delphi panel of respondents is comprised primarily of physicians and nurses, the results reflect an extensive and diverse range of interdisciplinary interests.
- ❖ Of the priorities identified in phase one and two, the areas of pain and symptom management, family experiences and bereavement generated the most questions and the highest ranking of importance.
- ❖ The consensus established by phase two and three will inform direction of future research projects for the NET and other researchers in the area of pediatric palliative and end of life care.

NEXT STEPS

- ❖ Phase three is currently underway and participants have been asked to identify their top five priorities with the aim to establish further consensus regarding research priorities.

It is important to strategically identify research agendas that address the changing experience of pediatric palliative care.

The Canadian Institutes for Health Research New Emerging Team (NET) *'Transitions in Pediatric Palliative and End of Life Care'* is a 5-year project to study children/families with life-threatening diseases. Three lenses – biomedical/clinical, families, and health services – are used to guide research. The NET is multi-centre and multi-disciplinary. www.pallpednet.ca