

Research Considerations in Pediatric Palliative Care



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Background

While the actual number of patients in pediatric palliative care is small, the scope of the field is vast. There is diversity in the groups that can take part in research (e.g. ill child, parents, siblings, health professionals); types of diseases; stages of disease; biopsychosocial and spiritual facets of illness; developmental aspects of childhood; and care at diagnosis, end-of-life, and into bereavement. The opportunities, joys, and rewards of conducting research in any of these areas are many, but there also are challenges to be overcome or avoided.

Objectives

- To highlight priority areas for research
- To identify methodological and ethical issues inherent in pediatric palliative care research
- To identify methods to overcome research challenges

Priority Areas

- Institute of Medicine identified critical need for research in all aspects of care with a particular focus on:
 - effectiveness of clinical interventions
 - methods to improve communication and decision-making
 - models of care
 - approaches to bereavement care¹
- Canadian Delphi study identified four research priorities:
 - What matters most for patients and parents receiving pediatric palliative care?²
 - What are the bereavement needs of families in pediatric palliative care?
 - What are the best practice standards in pain and symptom management?
 - What are effective strategies to alleviate suffering at the end of life?²

Methodological Issues

- **Research design:** Randomized controlled trials (RCT) are 'gold standard' but difficult due to heterogeneity of diseases, illness trajectories, and ages of participants
 - Consider quasi-experimental studies, qualitative studies, and consensus opinions of experts
- **Outcomes:** Appropriate outcomes are difficult to identify and measure in end-of-life care and in pediatrics.
 - Consider critical review and adaptation of adult outcomes and measures or work to develop own
- **Recruitment and sampling:** Overall number of children is small and many diseases are rare making it difficult to find enough participants for many designs.
 - Consider using multiple centres for recruitment
 - Consider using disease groupings (e.g. ACT quadrants³) rather than single diseases

Ethical Concerns

- **Vulnerability:** Children and those who are dying are inherently vulnerable as research participants.¹
 - Vulnerability does not mean research cannot be done – only that it must be done carefully. Children's point of view is crucial in developing knowledge about their issues.
- **Beneficence:** Lack of direct benefits for children and families who take part in palliative care and end-of-life research.
 - Participants indicate the benefits of taking part in research are to help others, share their stories, and bring meaning to their experience and their child's life.⁴
- **Nonmaleficence:** Discussion of sensitive topics such as a child's death will inflict pain or burdens on participants.
 - While some parents have indicated a small degree of emotional difficulty or stress when taking part in research they still see the research as valuable.^{4,5,6}
 - Proposals must identify areas for potential harm and describe plans to prevent, minimize, or address it should it occur.

Hot Tips

- Ask research questions that you are passionate about answering – this will keep you going!
- Work with a great team with different levels and types of research and clinical experience to conduct research.
- Involve families in designing studies to ensure project objectives and methods of data collection are sensitive and meaningful to participants

Conclusion

The rewards and joys of conducting research that can improve the life and death of a child and the experience of family members and caregivers are well worth the care and effort required to gain research knowledge, skills, and experience; to select important research questions; to design rigorous but sensitive studies; and to overcome the inevitable challenges that all researchers face, but which may be particularly difficult in pediatric palliative care.

References

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