

Developing a Measure of Quality Pediatric End-of-life Care: Engaging Parents in the Process

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Background

Quality end-of-life care is the right of every Canadian according to the Senate of Canada. Quality end-of-life care is important to the dying child as well as to short and long-term health outcomes for parents, siblings, and extended family members.

Purpose

To report on beginning development of an instrument to measure quality of pediatric end-of-life care including:

- parents' perspectives on key components of quality care,
- impact on parents of participating in study,
- recruitment challenges,
- parents' suggestions on how to conduct this research.

Study Overview

- Phase 1: Literature review & Focus groups
- Phase 2: Develop items & Initial testing
- Phase 3: Administer instrument & Psychometric testing

Phase 1 Methods

- Systematic review of research on parent perspectives of pediatric end-of-life care
 - 67 manuscripts reviewed to identify key components of quality care
- Focus groups with bereaved parents to verify and extend literature review findings and provide guidance on conduct of subsequent study phases
 - 3 focus groups held with 10 parents (8 mothers, 2 fathers)

Phase 1 Results and Challenges

- **Key components of quality pediatric end-of-life care:**
 - Connect with Families
 - Involve Parents
 - Alleviate Suffering
 - Share Information
 - Provide Bereavement Support
- **Impact of participation in study on parents**
 - Why did you participate?
 - 100% to help others
 - 80% so I could talk about my experiences
 - How painful was it to participate?
 - 50% A little
 - 50% Not at all
 - *Inviting [parents] to participate in evaluating what happened is just respectful...healing in a sense. It's another way of honouring that experience and saying your child's not forgotten and your experience might make it better for other people.* (Bereaved Mother)
- **Recruitment Challenges**
 - Very slow recruitment
 - Ads in newsletters and websites of grief support groups
 - Most participants heard about study informally
 - Parents may have felt little connection to study and questioned impact of study results.
 - *We need reassurance where the information goes and how it actually impacts the people in the process that we experience along the way. It becomes even more purposeful when we know that it's getting back to the caregivers.* (Bereaved Father)
- **Parents' Suggestions for Phase 3**
 - Make clear that study results will be shared with hospital where child received care
 - Prefer face-to-face or written survey
 - Contact parents at least 6 months after child's death

Phase 3 Changes

- **Original Plans:**
 - Same recruitment methods as Phase 1
 - Administer survey by telephone
 - Contact parents 12 - 18 months after child's death
- **New Plans:**
 - Parents initially contacted through centre where child received end-of-life care (9 pediatric hospitals/units and 2 pediatric hospices)
 - Administer written survey
 - Contact parents 6 - 36 months after child's death

Current Status

- Instrument items developed
- Testing of content & face validity complete
 - 8 health professionals
 - 6 parents
- Phase 3 recruitment underway
 - Sample size of 150 – 300 parents needed
 - 50 participants to assess test re-test reliability

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