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Room for Improvement: Mothers' Perspectives on Children's End-of-Life Care

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Background

Quality end-of-life care is the right of every Canadian according to the Senate of Canada. There is not a reliable and valid method to measure whether or not high quality care is provided to dying children and their families.

Purpose

To report results from the final phase of development and testing of an instrument to measure quality of pediatric end-of-life care from the mother's perspective.

Study Overview

- Phase 1: Literature review & focus groups with bereaved parents used to identify quality domains and indicators.
- Phase 2: Items developed to assess quality indicators & tested for content / face validity with health professionals and parents.
- Phase 3: Instrument administered & psychometric testing of subscales conducted.

Phase 3 Methods

- Mothers recruited through 10 children's hospitals / hospices across Canada to complete written instrument.
 - Inclusion criteria: 6 to 36 months since child's death, child age ≤ 19 years, child died in hospital / hospice after minimum 24 hour admission, mother reads English
- Validity:
 - Exploratory factor analysis
 - Hypothesis testing
- Reliability:
 - Internal consistency
 - Test – retest

Phase 3 Sample Demographics

- 128 mothers from 10 hospitals/hospices completed instrument.
 - Overall response rate 18.6%
- Mothers:
 - Mean age 36.5 years
 - 80.5% married
 - 82.8% born in Canada
- Children:
 - Mean age 4.1 years
 - 23.4% had a congenital malformation or chromosomal anomaly
 - 64.8% died in ICU settings
 - 42.2% received care from a Pediatric Palliative Care Team

Phase 3 Results

- Good evidence for the reliability and validity of 7 instrument subscales: Connect with Families, Involve Parents, Share Information with Parents, Share Information among Health Professionals, Support Parents, Provide Care at Death, and Provide Bereavement Follow-up.
 - Support for at least 2/3 of hypotheses tested for each subscale
 - Internal consistency: Cronbach's alpha .76 to .96
 - Test-retest reliability: Intra class correlation coefficient .53 to .90
- Three additional domains consisted of stand-alone items: Support the Child, Support Siblings, Structures of Care.

Subscale Scores

Subscales	Summary Score*	Satisfaction Rating*
Connect with Families	77.7	80.8
Involve Parents	72.9	77.9
Share Information with Parents	69.8	76.4
Share Information among HP	74.2	78.1
Support Parents	69.8	77.0
Provide Care at Death	83.9	N/A
Provide Bereavement Follow-up	65.0	61.6

*scores and ratings are expressed on a 0 to 100 scale

Additional Results

- 'Constant' or 'a lot' of suffering from pain (28%), difficulty breathing (63%), anxiety (13%), all symptoms (44%).
- Nearly 25% wished the possibility of death would have been discussed sooner.
- Overall ratings (out of 100):
 - Peacefulness of atmosphere: 64.8
 - 'Good death': 60.0
 - Quality of end-of-life care: 71.8

Study Contributions

- Identification of 10 domains of quality children's end-of-life care (7 subscales + 3 additional domains).
- Development of a reliable and valid instrument for measuring care quality and identifying areas for improvement in care.

Conclusions

- A child's death causes immense suffering.
- Health Professionals can add to that suffering or give families the support to cope with that suffering.
- There is room for improvement in how care is provided to dying children and their families.

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