



# Development and Testing of an Instrument to Measure the Quality of Children's End-of-Life Care from the Parents' Perspective

Kimberley Widger RN PhD CHPCN(C) and Ann Tourangeau RN PhD

## 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 develop and test an instrument to measure parents' perspectives on the quality of care provided to families before, at the time of, and following the death of a child.

## Initial Development

- Phase 1: Literature review and focus groups with bereaved parents to identify quality domains and indicators.
  - 67 manuscripts included
  - 3 focus groups with 10 bereaved parents
  - 5 quality domains: Connect with Families, Involve Parents, Share Information, Alleviate Suffering, Provide Bereavement Follow-up.
- Phase 2: Items developed and tested with health professionals and parents.
  - 141 items developed to assess structures, processes, and outcomes
  - 7 health professionals assessed content validity (CVI = 0.84)
  - 6 parents did cognitive testing and assessed content /face validity.

## Phase 3 Methods

- Mothers recruited through 10 children's hospitals / hospices across Canada to complete 144 item 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 Testing (exploratory factor analysis & hypothesis testing)
- Reliability (Internal consistency & test – retest)

## Hypotheses Tested

- Subscale scores would be significantly higher when a Pediatric Palliative Care (PPC) Team was involved in care provision.
- Subscale Scores would significantly correlate with:
  - satisfaction with that aspect of care
  - overall quality rating
  - peacefulness of death rating
  - "good death" rating

## Phase 3 Sample Demographics

128 mothers participated (RR 18.6%); 31 completed test-retest

Mothers	Children
Mean age 36.5 yrs	Mean age 4.1 yrs (range 2 days – 20 yrs)
80.5% married	64.8% died in ICU settings
64.1% completed college /university	23.4% congenital/chromosomal anomaly
82.8% born in Canada	42.2% received care from a PPC Team

## Phase 3 Results

- Original 5 domains expanded to 10 domains:
  - 7 subscales with item responses added to give a summary score
  - 3 additional domains consisting of stand-alone items with content and face validity only (Support the Child, Support Siblings, Structures of Care).

## Subscale Psychometric Properties

Subscales	# Items	α (internal consistency)	Hypotheses (supported/ tested)	ICC (test – retest)
Connect with Families	16	0.96	4/5	0.90
Involve Parents	8	0.88	5/5	0.82
Share Info with Parents	9	0.90	5/5	0.81
Share Info among HP	4	0.86	4/5	0.88
Support Parents	11	0.92	5/5	0.83
Provide Care at Death	7	0.76	4/4	0.81
Provide Bereavement Follow-up	6	NA	2/3	0.52

## Further Refinement & Testing

- Through psychometric testing, 17 items were deleted leaving a 126-item instrument.
- Cronbach's α greater than 0.90 indicates redundancy in some subscales.
- Bereavement subscale requires additional refinement and testing as ICC was low, internal consistency could not be tested, and fewer hypotheses were tested and supported.
- Revised instrument should be tested with fathers.
- Instrument could be translated into French and developed as a web-based version for further testing.

## Conclusions

- 10 domains (7 subscales + 3 additional domains) of quality children's end-of-life care were identified.
- The instrument provides a reliable and valid mechanism for evaluative feedback to health professionals, health systems, and policy makers to improve children's end-of-life care.
- This study is a significant step forward in comprehensive measurement of the quality of children's end-of-life care.

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