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)

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).

Phase 3 Sample Demographics
128 mothers participated (RR 18.6%); 31 completed test-retest

<table>
<thead>
<tr>
<th></th>
<th>Mothers</th>
<th>Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age</td>
<td>36.5 yrs</td>
<td>4.1 yrs</td>
</tr>
<tr>
<td>Married</td>
<td>80.5%</td>
<td>64.8%</td>
</tr>
<tr>
<td>Completed college/university</td>
<td>64.1%</td>
<td>23.4%</td>
</tr>
<tr>
<td>Born in Canada</td>
<td>82.8%</td>
<td>42.2%</td>
</tr>
<tr>
<td>Died in ICU</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Congenital/Chromosomal anomaly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Received care from PPC Team</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

Subscale Psychometric Properties

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

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.

Acknowledgements
Kimberley’s doctoral work was supported by:
- Innovation Fund in Children's Palliative Care Research, The Hospital for Sick Children
- Fellowship, Canadian Institutes for Health Research
- Career Enhancement Program, Canadian Child Health Clinician Scientist Program

Special thank you to parents who shared their experiences and health professionals at each site who assisted with Phase 3 recruitment.