

# Pilot Study of Symptom Burden and Quality of Life among Families in Pediatric Palliative Care or Hospice

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## Abstract

**Purpose:** To prospectively assess symptom burden and quality of life (QOL) among children with life limiting conditions and to examine concordance across multiple informants (i.e., mother, father, child, nurse).

**Methods:** Families of 25 children (ages 5-18) enrolled in palliative care or hospice were recruited at two pediatric hospitals shortly after their referral to the programs. Mothers, fathers, nurses, and children (who were alert and able to provide self-report) completed questionnaires to assess the child's symptom burden. Parents and children also reported on the child's quality of life (QOL).

**Results:** A similar number of symptoms were reported for children by mother, father, and child self-report, but nurses reported about half as many symptoms. For composite symptom scores (i.e., weighted for frequency, severity, distress), nurses reported the highest scores, followed by mothers, fathers, and children. Paired t-tests showed differences between nurse and mother, nurse and father, and mother and father composite scores. QOL was well below norms according to mothers, fathers, and children. Higher symptom burden was strongly and consistently associated with worse QOL across informants.

**Conclusions:** Preliminary findings indicate high symptom burden in children at end-of-life (EOL) and its negative impact on the child's QOL. Nurses report significantly fewer symptoms than families but higher composite scores when considering frequency, severity, and distress. Additional research using multiple perspectives, particularly patient reported outcomes, is needed to inform improvements in care for children at EOL.

## Background

- Over 15,000 children in the U.S. die each year from chronic conditions and might benefit from palliative or hospice care.
- Despite calls for improvement, advances in pediatric palliative care and research have lagged far behind adult palliative care.
- Evidence suggests that children often experience high symptom burden and suffering at EOL.
- Research is limited and has focused primarily on children with cancer, relying heavily on chart review and retrospective reports from mothers or nurses.
- Prospective research assessing symptom burden and quality of life is needed to inform improvements in the care of children with life-limiting conditions and reduce suffering.

## Hypotheses

- Mothers and nurses would report a higher total symptom score and a higher symptom composite score for children relative to father or child self-report.
- Mothers would report lower QOL scores for children relative to father and child-self report.
- Higher total symptom scores and symptom composite scores would both be associated with lower QOL scores within and across informants.

## Methods

### Procedures

Following IRB approval, families of children (ages 5-18) were recruited at two pediatric hospitals shortly after their referral to hospice or palliative care. Nurses familiar with the family described the project to assess level of interest. Ph.D. level study staff followed up with a phone call to fully explain the study. Questionnaires were mailed to families shortly after initiation of services and collected during visits to the family's home. Parents and children (who were alert and able to provide self-report) completed questionnaires. All families were compensated for their time.

### Children (n = 25)

Self Report (n = 13)  
M<sub>age</sub> = 11.4 years (SD = 3.4)  
52% Female (n = 13)  
72% White  
60% Complex chronic conditions (n = 15)  
40% Cancer (n = 10)

### Mothers (n = 25)

M<sub>age</sub> = 38.5 years (SD = 8.6)  
79% White  
60% Married  
M<sub>edu</sub> = 14.8 years (SD = 3.5)

### Fathers (n = 14)

M<sub>age</sub> = 40.4 years (SD = 6.3)  
87% White  
73% Married  
M<sub>edu</sub> = 16.7 years (SD = 4.3)

### Nurses

5 nurses provided data on the 25 participants

### Measures

**Memorial Symptom Assessment Scale (MSAS).** The MSAS assesses the presence or absence of a variety of physical and psychological symptoms (e.g., pain, fatigue, worry). If present, a follow-up question assesses the frequency, severity, and distress associated with each symptom on a 4-point scale. Scores include a total symptom score, as well as a symptom composite score, which also takes into account frequency, severity, and distress of symptoms. Children ages 5-9 completed the short 8-item version, while adolescents ages 10-18, parents, and nurses completed the 24-item version.

**Pediatric Quality of Life Inventory (PedsQL)** The PedsQL is a 23-item questionnaire assessing health-related quality of life. This measure uses a 5-point scale to measure a child's frequency of problems in four domains of functioning: (a) physical, (b) emotional, (c) social, and (d) school. Parents and children completed the PedsQL.

### Analyses

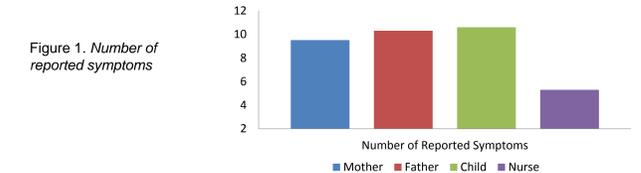
- Paired t-tests examined differences in reported symptoms and QOL by mother, father, child, and nurse.
- Pearson's correlations were computed to examine associations between symptom burden and the child's quality of life.

## Results

### Number of symptoms

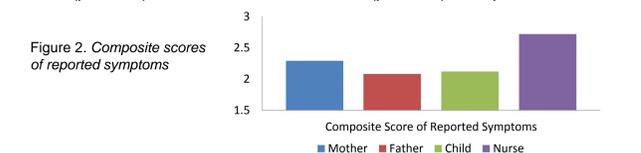
Total symptom scores were similar across to mother (M = 9.5, SD = 3.3), father (M = 10.3, SD = 3.0), and child self-report (M = 10.6, SD = 3.3), but nurses (M = 5.3, SD = 3.3) reported about half as many symptoms (p < .01) See Figure 1.

## Results Continued



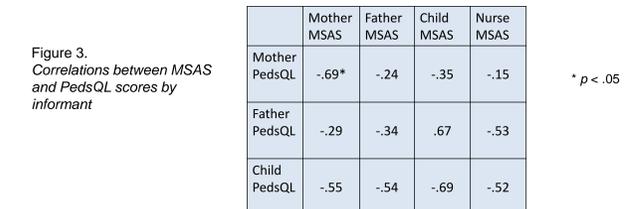
### Composite symptom scores

- Nurses reported the highest symptom composite scores, followed by mothers, fathers, and children.
- Paired t-tests showed differences between nurse and mother (p < .08), nurse and father (p < .01), and mother and father (p < .01) composite scores. See Figure 2.



### Symptom Burden and Quality of Life –

- QOL was consistently reported well below norms according to mothers (M = 50.4, SD = 22.1), fathers (M = 40.9, SD = 18.7), and children (M = 53.2, SD = 17.6).
- Higher symptom burden was strongly and consistently associated with worse QOL within and across informants (r = -.34 to -.69). Figure 3



## Discussion

- Preliminary findings indicate high symptom burden in children at EOL and its negative impact on the child's QOL.
- Nurses report significantly fewer symptoms than individual family members but higher composite scores when considering frequency, severity, and distress.
- Our work suggests gaps in communication between families and healthcare providers as indicated by the discrepant reports of symptom burden.
- More research is needed to prospectively assess symptom burden in children with life-limiting illnesses and their families to improve care and quality of life at EOL.



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