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 hospice or palliative care. 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.

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). See 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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