

Pediatric palliative and hospice care at home: What matters most to parents?



STUDY DESIGN

STUDY PURPOSE: To explore how parents rate and prioritize domains (or features) of high-quality pediatric palliative and hospice care at home (listed below).



PARTICIPANTS: 47 parents of children who had received palliative or hospice care in the home, including 33 parents who were caring for their child and 14 bereaved parents.

SURVEY: A discrete choice survey that asked parents to select the most and least important domain among sets of 4 domains each. This task was repeated across different combinations of the domains (listed below).

DOMAINS (FEATURES) OF PEDIATRIC PALLIATIVE & HOSPICE CARE

Access to care team

Care coordination

Care continuity

Caregiver support at end of life

Communication

Communication about physical care

Communication at end of life

Cultural care

Ethical and legal support

Knowledge & skills of care providers

Practical support

Psychological & emotional care for child, parent(s), sibling(s), & family's social network

Relationship between family and care team

Social care for parent(s), child

Spiritual & religious care

Symptom management

WHAT DID PARENTS TELL US?



The 5 top-ranked domains were:

1. Symptom management
2. Psychological & emotional care for the child
3. Care coordination
4. Access to the care team
5. Psychological & emotional care for the sibling(s)

DID DIFFERENT GROUPS OF PARENTS TELL US DIFFERENT THINGS?



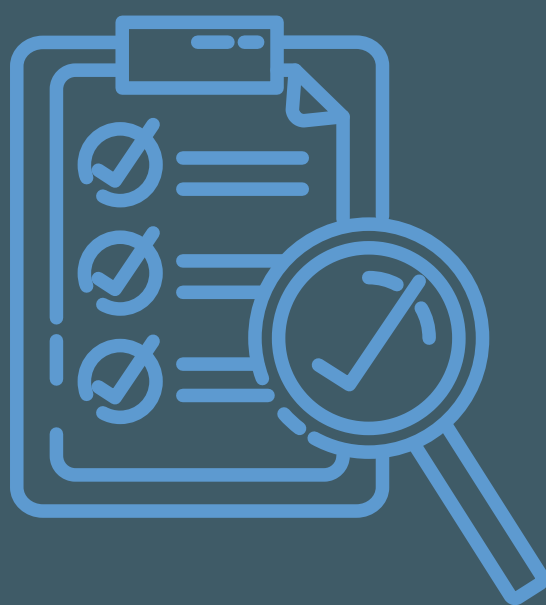
Across all domains,

the only domain that was rated significantly differently between parents who were caring for their child and bereaved parents was the *Caregiver support at the end of life* domain.

Bereaved parents rated this domain 1.5 times as important than parents who were caring for their child.

For the sibling-specific domain,

parents who had other children rated the *Psychological & emotional support for the child's sibling(s)* domain over twice as important as parents who did not have other children.



WHAT DOES THIS MEAN FOR ME AND MY FAMILY?



This study underscores the importance of asking parents about what matters most to them and their family, which can help palliative and hospice teams to meet families' most important needs.

Our research group is working on developing a questionnaire to understand how parents prioritize care for their families, at the time they are receiving care and over time. The ultimate goal of this questionnaire is to provide information that health care teams can use to improve the care they provide to children and families in the home. More information about this questionnaire will be coming soon.

WHOM DO I CONTACT WITH QUESTIONS ABOUT THIS STUDY?

Jackie Boyden, PhD, MPH, RN
Children's Hospital of Philadelphia
Email address: boydenj@email.chop.edu

A heartfelt thank you to all parents who participated in this study!