• Discuss the value of studying prognostic communication, including discussion of palliative care principles and advance care planning, through qualitative analysis of conversations between clinicians, patients, and families recorded at high-intensity time points (e.g., disease reevaluation discussions) across the illness trajectory.

• Describe the timing and content of discussion related to palliative care principles and advance care planning across the illness trajectory for children with high-risk cancer as found in this study, as well as review the commonalities that emerged regarding linguistic style, context, and prompts for discussion of these sensitive topics.

Importance. In the field of medical oncology, palliative care principles and advance care planning are often discussed late in the illness trajectory, limiting the time available for nuanced discussions to guide goal-concordant care. Presently, the timing, frequency, context, and content of these critical discussions in the setting of pediatric cancer is not well understood.

Objective(s). To determine the frequency and timing of pediatric palliative care and advance directive discussions across the progressive illness course for children with progressive cancer and their families; to explore the linguistic styles/strategies used to introduce these sensitive topics and explore the statements that precede or prompt discussion.

Method(s). Serial disease reevaluation conversations between pediatric oncologists, children with progressive cancer, and their families were recorded across the illness trajectory. Following codebook development, mixed methods analysis of audio-recorded medical dialogue was conducted using MAXQDA software.

Results. Approximately 38 hours of prognostic communication conversations were recorded for 16 patient-parent dyads across months to years, out of which a total of 44 minutes (2%) involved discussion related to palliative care principles or advance directives. Advance directives were discussed less frequently than palliative care principles, with 7 minutes’ worth of coded dialogue (0.3% of total recorded dialogue). The vast majority (98%) of dialogue occurred following significant disease progression while on study. The most frequent codes were quality of life, palliative chemotherapy, and goals of care. Common linguistic patterns emerged in the conveyance of these topics, along with similar contexts prompting discussion.

Conclusion(s). Palliative care principles and advance directives are discussed infrequently across the disease course for children with high-risk cancer. When discussed, patterns emerge regarding linguistic style, context, and prompts.

Impact. These data offer opportunities to develop targeted interventions to encourage earlier discussion of palliative care principles and advance care planning for children with high-risk cancer and their families.

Exploring Parental Decision Making Regarding Long-Term Ventilation for Children with and Without Severe Neurological Impairment (RP408)


Objectives

• Describe what is known about illness trajectory and risk for mortality in children with SNI who have LTV.

• Analyze the differences between parents’ recollection of clinician counseling regarding LTV between parents of children with SNI and without SNI.

Importance. Decisions around long-term ventilation (LTV) in children should consider the child’s illness trajectory. Data suggest that children with severe neurologic impairment (SNI) are at increased risk of LTV being lifelong once placed (permanent) and have increased mortality compared to those without SNI due to their underlying medical complexity.

Objective(s). To evaluate whether parents of children with SNI perceive clinician counseling regarding LTV differently than parents of children without SNI.

Method(s). We interviewed parents from three academic centers who were faced with a decision about LTV for their child within the last 5 years. Interviews were audio recorded and transcribed. Content analysis was performed within and across groups of parents according to their child’s SNI status.

Results. A total of 37 parents were interviewed; 24 with children with SNI and 13 with children without SNI. Among children with SNI, 46% had LTV and 83% were alive. Among children without SNI, 69% had LTV and 85% were alive. Parents of children with SNI perceived less certainty from clinicians regarding LTV permanence than parents of children without SNI. Despite this, mortality related to LTV was discussed with both groups and honesty about
risk of death was appreciated by all parents. In contrast to parents of children without SNI, parents of children with SNI more often recalled detailed descriptions or examples provided by clinicians detailing how their child might die. This often caused distress and felt insensitive to parents.

Conclusion(s). Parents of children with SNI perceived less clarity from clinicians regarding LTV permanence compared to parents of children without SNI. Parents of children with SNI often experienced insensitive counseling about risk of death.

Impact. More research and education are needed to improve clinician counseling of parents regarding LTV that meaningfully reflects the child’s illness trajectory and provides honest information in a sensitive manner.

Poly-Symptomatology in Pediatric Palliative Care Patients: Baseline Evaluation of SHARE Parent-Reported Data (RP409)


Objectives
- Describe the study design of this study.
- Specify the 5 most prevalent symptoms in pediatric palliative care.
- Describe how symptom count, frequency, and severity contribute to poly-symptomatology.

Importance. Pediatric palliative care (PPC) teams care for patients with a wide variety of conditions, often with substantial medical complexity, making symptom management challenging. Parental report data regarding the frequency and severity of symptoms in these patients has been limited.

Objective(s). Characterize the prevalence, frequency, and severity of specific symptoms, as reported by parents of patients receiving PPC.

Method(s). Parent-reported data were gathered from baseline questionnaires in a two-year longitudinal study being conducted at 7 children’s hospitals in the Pediatric Palliative Care Research Network (PPCRN) SHARE project. Data included child’s demographic and clinical characteristics, and 15 symptoms measured via the Memorial Symptom Assessment Scale, which scores symptom frequency (1, almost never; 2, sometimes; 3, a lot; 4, almost always) and severity (1, slight; 2, moderate; 3, severe; 4, very severe).

Results. Of the 501 PPC patients thus far enrolled with completed data, 55% were male, 66% white, mean age of 7.3 years (±7.3 SD); the most prevalent complex chronic morbidities included neurologic (48%), cardiovascular (47%), and respiratory (34%) conditions; 72% were technology-dependent. Parents reported an average of 4.9 (±3.3 SD) symptoms per patient. The five most common symptoms were pain (55%; among patients with pain, mean frequency, 2.6; mean severity, 2.3), lack of energy (53%; 2.8; 2.4), irritability (47%; 2.4; 2.1), drowsiness (43%; 2.6; 2.2), and shortness of breath (39%; 2.7; 2.4). 10% of patients had markedly elevated level of symptoms (minimal frequency and severity scores of “a lot” and “severe” for each symptom), with the typical patient in this subgroup having 6 symptoms.

Conclusion(s). A majority of children receiving palliative care are experiencing poly-symptomatology. An important sub-group of patients suffer frequently from numerous severe symptoms.

Impact. Assessment and management of poly-symptomatology is a critical aspect of PPC.

Quality of Life of Children and Adolescents Undergoing Hematopoietic Stem Cell Transplantation Is Negatively Affected by Psychological Distress Experienced by Their Parents: A Case for Pediatric Palliative Care (RP410)

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Objectives
- State the elements and trajectory of distress for parents caring for children and adolescents undergoing hematopoietic stem cell transplantation (HSCT) or chimeric antigen receptor (CAR) T-cell therapy.
- Examine the impact of parent distress on symptoms and quality of life (QoL) experienced by children and adolescents undergoing HSCT or CAR T-cell therapy.