Evaluating Supportive Care for Children with Cancer: A Multi-Institutional Survey Study of Pediatric Oncology Patients and Parents (TH346-C)

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Objectives

- Discuss effective strategies and challenges for the delivery of early palliative care in pediatric oncology.
- Discuss parent/patient attitudes toward symptom burden and management and early palliative care integration from the time of diagnosis in pediatric oncology.

Original Research Background: Based on strong recent evidence, clinical consensus touts early palliative care (PC) integration in oncology as the optimal care model; however, PC remains underutilized in pediatric oncology (ped-onc), and little is known regarding patient and family attitudes toward early PC.

Research Objectives: We conducted a multi-institutional study of ped-onc patients and parents to determine perception of symptom burden and management early in treatment and assess views on early integration of PC.

Methods: Novel survey tools were developed using validated formats, when available. After IRB approval and pretesting, surveys were administered to 130 patient/parent dyads at three sites (NIH, JH, SJCRH). Eligibility criteria included patient age 10-17 at diagnosis, diagnosis date >1 month and <1 year, and English speaking. Preliminary analysis at 75% accrual was assessed for trends in response content frequencies, percentages, and degree of concordance between parent and child.

Results: Most children/parents (55%/49%) stated they would want to meet with PC around the time of diagnosis with only 2% of children and 6% of parents opposed. Seventy-nine percent of children/parents rated current quality of life (QoL) as good to excellent; 82%/84% considered QoL “somewhat important” or “very important” in decision making, yet 68%/83% prioritized cure over QoL when making treatment choices. Both anticipated improved health (96%) and elevated chance of cure (78%/86%) despite 13% of participants not evaluating expectations with their providers. Of parents whose perception of their child’s suffering from pain lacked concordance with that of their child (72.2%), 43.6% underestimated suffering and 58.7% overestimated their pain control; of those discordant with regard to nausea/vomiting (74.7%), 59.3% underestimated severity and 60.87% overestimated symptom control.

Conclusions: Interim analysis reveals tentative trends that suggest that early integration of PC would be welcomed by the majority of ped-onc patients and families and would likely improve overall care.

Implications for Research, Policy, or Practice: Our findings encourage improved care through early integration of PC in ped-onc and beyond.