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“There When We Need Them”: Assessing Patient/ Family Satisfaction with a Growing Pediatric Palliative Care Program

Background: While palliative care has been established as an important subspecialty, it remains a novel concept to many patients and families experiencing serious illness. The assessment of patient and family satisfaction with pediatric palliative care (PPC) services is crucial to ensuring that the needs of our patients and families are met.

Aim Statement: We will utilize a survey tool to assess at least 30 patients or caregivers' satisfaction with our hospital's PPC services in 1 month.

Methods: A 20-question online survey was created using core and program building questions from the Pediatric Palliative Improvement Network's patient/ family satisfaction survey in addition to several program-specific questions. Participants, including eligible patients and primary caregivers, were recruited via face-to-face contact, telephone and/or email communication. Anonymous responses were collected and stored within SurveyMonkey.

Results: Thirty-eight of 81 eligible participants (46.9%) completed the survey. More than half of participants agreed or strongly agreed that the PPC team improved their child's overall care (79%), quality of life (71.1%), and symptom management (65.8%), communication with the medical team (71.1%), and their understanding of their child's illness (60.5%); the vast majority of other responses were neutral. No participants felt that PPC was introduced too early. An overwhelming majority (94.7%) stated that they definitely or probably would recommend the PPC team to another patient and/or family and would be more likely to recommend the hospital to others because of the PPC team's involvement in their care. Additional praise as well as suggestions for improvement were also identified via qualitative data shared via open-ended questions and opportunities for comments.

Conclusions and Implications: This data demonstrates that a new, growing PCC team is positively impacting the overall experience of their patients and families. Ongoing assessment of patient and family satisfaction is important as PPC programs continue to grow.