Original Article

Patterns of End-of-Life Care in Children With Advanced Solid Tumor Malignancies Enrolled on a Palliative Care Service

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Abstract

Context. Pediatric patients with solid tumors can have a significant symptom burden that impacts quality of life (QoL) and end-of-life care needs.

Objectives. We evaluated outcomes and symptoms in children with solid tumors and compared patterns of end-of-life care after implementation of a dedicated institutional pediatric palliative care (PC) service.

Methods. We performed a retrospective cohort study of children with solid tumors treated at St. Jude Children's Research Hospital, before and after implementation of the institutional QoL/PC service in January 2007. Patients who died between July 2001 and February 2005 (historical cohort; $n = 134$) were compared with those who died between January 2007 and January 2012 (QoL/PC cohort; $n = 57$).

Results. Median time to first QoL/PC consultation was 17.2 months (range 9–33). At consultation, 60% of children were not receiving or discontinued cancer-directed therapy. Within the QoL/PC cohort, 54 patients had documented symptoms, 94% required intervention for ≥3 symptoms, and 76% received intervention for ≥5 symptoms. Eighty-three percent achieved their preferred place of death. Compared with the historical cohort, the QoL/PC cohort had more end-of-life discussions per patient (median 12 vs. 3; $P < 0.001$), earlier end-of-life discussions, with longer times before do-not-resuscitate orders (median 195 vs. 2 days; $P < 0.001$), and greater hospice enrollment (71% vs. 46%, $P = 0.002$).

Conclusion. Although children with solid tumor malignancies may have significant symptom burden toward the end of life, positive changes were documented in communication and in places of care and death after implementation of a pediatric PC service. J Pain Symptom Manage 2015;50:305–312.

Key Words

Palliative care, pediatric oncology, pediatric, end of life

Introduction

Cancer is the leading cause of childhood nonaccidental death in the U.S., with approximately 17% dying of their disease.[1] Children with malignancies often face unique challenges, with some experiencing longer disease trajectories, frequent recurrences, and high symptom burdens.[2,3] Anticipating transition goals toward comfort care becomes critical when prognosis worsens. Suboptimal communication about prognosis and maintaining goals for cure near the end of life can result in substantial suffering and increased use of aggressive life-sustaining measures.[3,4] Children diagnosed with advanced high-risk solid tumors are especially prone to poor outcomes and

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death. Integration of palliative care (PC) for these children improves end-of-life care, enhances advance care planning, and substantially decreases suffering by improving communication, providing optimal symptom control, and emphasizing quality of life (QoL).[3–7]

In 2007, St. Jude Children's Research Hospital (SJCRH) began its integration of the QoL/PC service into the multidisciplinary approach to children with cancer to improve end-of-life care outcomes. The QoL/PC service began as a pilot program in 2007, focusing on the development and provision of quality care for children with solid tumors. Through ongoing assessments and identifying patient and family preferences, goals, and needs throughout a child's illness during consultations, regular inpatient/outpatient follow-up, team meetings, and home visits, the QoL/PC Service quickly expanded into an institution-wide PC program available to all SJCRH patients beginning in the first quarter of 2008. This interdisciplinary team offered symptom management expertise; addressed psychosocial and spiritual needs throughout the continuum of care, coordinated care, and ensured communication between providers at times of transition, facilitated end-of-life/do-not-resuscitate (DNR) discussions, and provided decision-making and bereavement support. The QoL/PC Service provided PC and hospice support services for children and their families once transferred to their home institutions to facilitate continuity of care.

We hypothesized that children with advanced solid tumors will have a high symptom burden, need for psychosocial support, and be likely to achieve desired location of death; furthermore, that integration of the QoL/PC Service in the institution would result in earlier end-of-life/DNR discussions and advance care planning compared with a historical cohort of patients treated before the team's establishment. We also wanted to evaluate end-of-life conversations before and after PC involvement.

Methods

Study Population

This was a retrospective chart review of patients younger than 21 years with solid tumors (QoL/PC cohort, $n = 57$), enrolled on the PC service through death (January 2007–January 2012). During this period, 10 additional patients also were eligible for enrollment but were not referred for QoL/PC consultation because of various treating physician or parental personal preferences. The historical cohort ($n = 134$) with solid malignancies and death (July 2001–February 2005) was a published database[8] before January 2007. The SJCRH Institutional Review Board approved this study with parental informed consent waiver because patients were deceased.

Data Acquisition

The following data for the QoL/PC cohort were obtained: sex, race, religion, birth date, diagnosis, date/cause of death (disease progression vs. treatment-related complication), cardiopulmonary resuscitation or intubation, hospice enrollment, DNR orders, and interventions during the last month of life (antibiotics, antifungals, antivirals, blood products, chemotherapy, haloperidol, fluids, parenteral nutrition/tube feeds, intrusive procedures, laboratory draws, mechanical ventilation, oxygen, radiation, surgery, vasopressors, hemodialysis/continuous veno-venous hemofiltration (CVVH), pain medication, steroids, benzodiazepines, anticonvulsants, and antidepressants). After DNR implementation, the QoL/PC and historical cohorts were compared to identify further care preferences and symptom management strategies.

Additional information from QoL/PC and oncology initial consultations, inpatient and outpatient follow-ups, home visits, and phone service notes included relapses, protocol enrollment, transplant status, symptoms, care goals, hospitalizations, cancer-directed therapy during QoL/PC consultation and the last month of life, sibling and bereavement support, content of end-of-life discussion (e.g., high likelihood of death, transitioning care home), and death location. Data entry accuracy was verified for every third case, with records maintained by additional team members at ≥95% accuracy. If discrepancies were identified, two abstractors reviewed the chart, and consensus determined final data entry. For comparison, historical cohort demographics, death location, and end-of-life discussions were used.[8]

An end-of-life discussion was identified by patient record documentation and/or family conference with clinician(s) of any discipline or a member of the interdisciplinary team (e.g., QoL/PC, oncology, social work). The discussion had to specifically address poor prognosis, disease progression and implications, and patient and/or family preferences for care when cure was no longer realistic. The first documented end-of-life discussion with the patient and/or family was defined as the first statement reflecting no realistic chance for cure, Phase I protocol enrollment, home health for terminal care, referral to hospice, or DNR status discussion or DNR order.

Statistical Analysis

Demographics, clinical parameters, and study outcomes were summarized using descriptive statistics. The Wilcoxon signed rank test determined whether end-of-life discussion number differed before/after