

A quality improvement project to increase palliative care team involvement in pediatric oncology patients

Sana Farooki¹, Oluwaseun Olaiya¹, Lisa Tarbell¹, Nicholas Clark¹, Jennifer Linebarger¹, John Stroh¹, Kelstan Ellis¹, and Karen Lewing¹

¹Children's Mercy Hospitals and Clinics

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Abstract

Background: Pediatric palliative care (PPC) for oncology patients improves quality of life and the likelihood of goal-concordant care. However, barriers to involvement exist. **Objectives:** We aimed to increase days between PPC consult and death for patients with refractory cancer from a baseline median of 13.5 days to [?]30 days between March 2019 and March 2020. **Methods:** Outcome measure was days from PPC consult to death; process measure was days from diagnosis to PPC consult. The project team surveyed oncologists to identify barriers. Plan-Do-Study-Act cycles included establishing target diagnoses, offering education, standardizing documentation, and sending reminders. **Results:** The 24-month baseline period included 30 patients that died and 25 newly diagnosed patients. The yearlong intervention period included 6 patients that died and 16 newly diagnosed patients. Interventions improved outcome and process measures. Targeted patients receiving PPC [?] 30 days prior to death increased from 43% to 100%; median days from consult to death increased from 13.5 to 159.5. Targeted patients receiving PPC within 30 days of diagnosis increased from 28% to 63%; median days from diagnosis to consult decreased from 221.5 to 14. Of those without PPC consult within 30 days after diagnosis, 17% had template documentation of the rationale. **Conclusion:** Interventions utilized met the global aim, outcome and process measures. Use of QI methodology empowered providers to involve PPC. Poor template use was a barrier to identifying further drivers. Future directions for this project relate to expanding the target list, creating long-term sustainability, formalizing standards, and surveying patients and families.

INTRODUCTION:

Approximately 16,000 children are diagnosed with cancer in the United States annually and 20% die of their disease.¹ Many pediatric oncology patients experience suboptimal management of physical and psychosocial symptoms and families receive insufficient communication and support during their child's illness and following their child's death.²⁻⁵ Research suggests these inadequacies could be addressed by early involvement of pediatric palliative care (PPC).⁶⁻⁸

The World Health Organization (WHO) defines palliative care as an approach that improves the quality of life of patients and their families facing life-threatening illness by preventing and relieving suffering through the early identification, assessment and treatment of pain and other problems, including physical, psychosocial, and spiritual problems.⁹ The WHO, the National Academies of Science (formerly the Institute of Medicine), and the American Academy of Pediatrics (AAP) have called for earlier integration of palliative care.¹⁰⁻¹² Provision of PPC for children with cancer results in improved pain and symptom management, better psychosocial support and care coordination, fewer deaths in the intensive care unit, and increased overall patient and family quality of life.^{7,13-15}

The United States News and World Report (USNWR) rankings has benchmarked that 75% of patients with refractory cancer should receive a palliative care consult more than 30 days prior to death.¹⁶ Access

to palliative care services in children’s hospitals is increasing.¹⁷ Yet many children with cancer do not receive palliative care services, and early integration of services is rare.^{11,18,19,20} The barriers to integration of palliative care services in the care of pediatric oncology patients span several socio-ecological domains. In addition to inconsistent and inadequate financing for provision of PPC services and the nationwide shortage of providers with expertise in delivering PPC, there are unique barriers to integration of PPC with pediatric oncology care arising at the provider, patient, and family levels.^{7,11,17,20} Pediatric oncology providers may believe palliative care cannot be delivered concurrently with curative cancer treatments.^{21,22} Pediatric oncology providers may view palliative care as synonymous with hospice or end-of-life care and may avoid conversations about death and dying with patients and families to avoid disrupting the “culture of hope” they attempt to foster.^{7,23} Families may have similar misconceptions about palliative care, perceiving it as a distinct phase in their child’s treatment implemented when curative options have been exhausted.^{7,24,25} Additionally, despite a recent study showing that the oncology providers’ understanding of the role of PPC is expanding from end-of-life care only to the more holistic WHO definition of palliative care, and a recent study showing that most families were open to integrating PPC early in the course of cancer treatment, pediatric oncology providers may not involve a PPC team as they perceive overlap between services provided by both teams.^{21,26-28}

At our institution, no formal guidelines or policies existed within the oncology department with regards to PPC involvement. The decision to involve PPC was made at the discretion of primary oncology teams where some patients, even those with poor prognoses, never received PPC involvement. In 2017 and 2018 our institution reported to USWNR that PPC involvement more than 30 days prior to death in pediatric oncology patients with refractory cancer occurred in 62% and 69% of patients respectively which is less than the USWNR benchmark of 75%. The global aim of our quality improvement project was to increase timely involvement of PPC in oncology patients. Our specific aim was to increase days between PPC consult and death for patients with refractory cancer from a baseline median of 13.5 days to [?]30 days between March 6, 2019 to March 5, 2020.

METHODS

CONTEXT

Our institution is a 367-bed freestanding, quaternary care children’s hospital.²⁹ The Pediatric Hematology/Oncology/Bone Marrow Transplant teams provide comprehensive care to approximately 180-200 newly diagnosed pediatric oncology patients each year. Our catchment areas include mainly the states of Missouri and Kansas; we also receive patient referrals from 7 additional states and the country of Mexico. Primary oncology teams are comprised of an attending oncologist, social worker, advanced practice registered nurse (APRN), and often a hematology/oncology fellow. The palliative care team at our institution continues to expand, meeting 255 new patients in 2017 and 282 in 2019.

In oncology, the event free survival (EFS) is defined as the length of time after primary treatment for a cancer ends that the patient remains free of certain complications or events that the treatment was intended to prevent or delay.³⁰ As the USWNR does not clearly define refractory cancer and the 5-year EFS is a marker of mortality in oncology, we used 5-year EFS < 50% as our criteria to identify patients with a higher likelihood of having refractory cancer. We use the 5-year EFS of <50% to build consensus and create a target list of patients for whom PPC consult was recommended at diagnosis.

MEASURES

The outcome or effect measure was days between PPC consult and death for target list patients. Our goal was to increase from a baseline median of 13.5 days to > 30 days between March 6, 2019 to March 5, 2020. Earlier involvement of PPC in the care of target list patients served as our process measure with a goal to decrease the days between new target list diagnosis and PPC consult from a baseline median of 221.5 days to < 30 days during the same time frame. Data were plotted over time using statistical process control charts to assess effectiveness of interventions. Due to infrequent events, we specifically utilized g-charts to track our measures. Common cause and special cause variation were determined using previously established improvement rules.³¹

This project was deemed exempt as quality improvement by our institution's Office of Research Integrity.

INTERVENTIONS

Planning

The quality improvement study was designed and analyzed according to A3 methodology. The study team included 2 hematology oncology fellows (SF, OO), an oncology APRN (LT), a pediatric hospitalist with expertise in quality improvement and patient safety (NC), the medical director of the palliative care team (JSL), palliative care team faculty (JS, KE) and a pediatric hematology oncology attending (KL).

As mentioned previously, the initial project scope was identified as pediatric patients with cancer diagnoses predicted to have a 5-year EFS of less than 50% based on nationally reported survival curves. The 5-year EFS is a marker of mortality in oncology and informed the creation of a 'target list' of diagnoses for which PPC consult was recommended. The project team met with the oncology clinicians designated as leaders for disease subsets and obtained input on the target list. We also met with the PPC team prior to project initiation to review processes and ensure staffing availability for the anticipated increased consults.

Survey of oncology clinicians to identify barriers to PPC involvement

Members of the project team (OO, SF, KL) developed a 6-question, short answer survey which was emailed to all hematology oncology attendings, fellows, social workers, and APRNs assessing barriers to PPC involvement in pediatric oncology patients. The survey response rate was 65% (n= 76). Identified barriers included concerns that a patient and family may have a negative view of palliative care which would adversely affect the relationship with the oncology team, concerns for potential communication issues, uncertainty about the right time to consult PPC, lack of clarity regarding palliative care roles, and fear that PPC involvement would be a burden to the family. Almost half (47%) of respondents felt that all patients with a 5-year EFS of < 50% at diagnosis should have PPC consulted at time of diagnosis, and more than half (59%) felt that PPC should be involved at the time of relapse or discussion of refractory disease. Based on these responses, the study team created a key driver diagram (**Figure 1**)

Monitoring/Data Collection

During the intervention period, members of the project team identified patients with new cancer diagnoses using the division's diagnosis listserv and database. Per internal policy, an email is sent to the listserv to facilitate efficient coordination of care for patients with new or relapsed cancer diagnoses. Additionally, the certified tumor registrars maintain an oncology database in which each new diagnosis or relapse is noted. Utilizing these resources, the study team kept track of new patients meeting project criteria and monitored for PPC involvement and patient death.

Plan-Do-Study-Act (PDSA) cycles

PDSA #1: In March 2019, confirmation of a list of new diagnoses (target list) for which a PPC consult was recommended within 30 days of diagnosis (**TABLE 1**). This list created by the project team with input from oncology leaders was presented to all oncology physician faculty. Consensus and buy-in was obtained resulting in the final target list.

Information dissemination sessions at three oncology clinician meetings explained the purpose of the project, background on the evidence for PPC involvement, survey results, and education on how to introduce PPC to patients and families.

A standard documentation tool in the electronic medical record was developed for clinicians to note if PPC consult was considered, discussed with patient/family, and placed. If a PPC consult was not placed, the tool included space for documenting why the consult was not applicable. The tool was designed to help identify barriers to PPC consultation, including family refusal (**Supplemental Figure 1**).

PDSA #2: Monthly division emails began in July 2019 and incorporated general updates on the project as well as reminders about the target list diagnoses and the standard documentation tool.

PDSA# 3: Monthly patient review by members of the project team began in October 2019. Following review, targeted reminder emails were sent to the primary oncology team of identified patients regarding the target list diagnoses, PPC consult expectation, and documentation tool.

RESULTS

Baseline Period

During the baseline period of January 1, 2017 to December 31, 2018, the pediatric oncology department cared for 30 children who died of a refractory cancer with a 5-year EFS of less than 50%. Among those 30 patients, PPC was consulted 57% of the time (n=17) and for our outcome measure baseline, the median time from PPC involvement to death was 13.5 days (range 0-206 days). Patients for whom PPC was not consulted prior to death were considered to have 0 days between PPC involvement and death. Of those 30 patients, PPC involvement >30 days prior to death occurred in only 43% (n=13). During the baseline period, 25 patients had a new diagnosis with a 5-year EFS of <50%. PPC was consulted for 14 of these, and for our process measure, the median time from diagnosis to PPC consult was 221.5 days. Of the 25 children with new target list diagnoses, 28% (n=7) had PPC consulted within 30 days of their diagnosis.

Intervention Period

During the intervention period, 6 patients with a target list diagnosis died while 16 received a new diagnosis of a target list cancer. None of the patients with a new target list diagnosis died during the intervention period. Our outcome measure improved from a median of 13.5 days to 159.5 days (**Figure 2**) resulting in an increase from our baseline of 43% to 100% (n=6) of target list patients receiving PPC involvement [?]30 days prior to death. Our process measure of time from target list diagnosis to PPC consult decreased from 221.5 days to 14 days (**Figure 3**) resulting in an increase from our baseline of 28% to 63% (n=10) of patients receiving involvement [?]30 days after diagnosis.

Of those 6 patients without PPC consult <30 days after diagnosis, only 17% (n=1) had template note documentation of the rationale.

Following our interventions, our institution reported to USNWR in 2019 that PPC involvement more than 30 days prior to death in pediatric oncology patients with refractory cancer occurred in 79% of our patients surpassing the national benchmark of 75%.

DISCUSSION

Despite evidence that early involvement of PPC results in improved quality of patient and parent life, a systematic review published in 2019 showed that only half of pediatric oncology patients receive any palliative care service prior to death, and such care tends to be late in the disease course.³² This project utilized improvement methodology and easily replicated interventions to increase the time between PPC involvement and patient death while also reducing the time between PPC involvement and initial cancer diagnosis. The project complimented Division goals of both improving patient care experiences and meeting national benchmarks, leading to clinician buy-in. Establishing standard recommendations for PPC involvement across our Division reduced previous barriers such as uncertainty about the timing of PPC consult. Our work empowered providers to consult PPC early and perhaps helped to minimize the perceived stigma surrounding palliative care documented in previous studies.^{32,33} This initiative was a joint effort between the PPC team and Oncology Division.

Despite overall success, there were ongoing challenges and limitations within the project including EMR documentation and use of a limited target list. Even with the creation of the standard EMR documentation tool about PPC consultation, its utilization was poor which hindered further identification of barriers to PPC involvement. The agreed-upon target list of diagnoses (**TABLE 1**) did not include all diagnoses with EFS <50%. However, we chose to limit this list so as not to overwhelm either our oncologists or PPC while also serving as a test of feasibility. To address these limitations, we identified several next steps. The low use of the standard EMR documentation tool may be because it was not embedded in existing templates. As such,

one solution is to create a standardized new diagnosis note that incorporates documentation about PPC consultation. And given the success of the project, the target list could be expanded. We would also like to note that while we feel our work was instrumental in our institution surpassing the USNWR benchmark of 75% of refractory cancer patients receiving PPC involvement >30 days prior to death, we are unable to definitively tie our work to this outcome and other confounders may have impacted results.

Future directions for this project relate to expanding the target list, creating long-term sustainability, formalizing standards, and surveying patients and families. Expansion of the target list should include all patients with a projected EFS < 50%, all patients with relapsed cancers, and other targeted populations such as those referred to the Bone Marrow Transplant or Experimental Therapeutics teams. As the project team's oncology fellows graduate, sustaining this project will fall upon identified PPC and oncology team champions that are invested in creating an improvement task force to build on our efforts. These champions will need to formalize standard operating procedures for collaboration between PPC and oncology to help improve ongoing collaboration in an effort to reduce role ambiguity. Ongoing evaluation to assess patient and family perceptions of PPC involvement could provide further direction, given that known barriers to PPC involvement include the notions that families may not be receptive to PPC and that providers fear alienating families.^{25,29}

In summary, this project illustrates the feasibility of using improvement methodology to increase PPC involvement in pediatric oncology patients. Lessons learned include building consensus with the clinicians involved, understanding barriers to success, ensuring buy-in from involved parties, and setting guidelines that may be easily tracked. Future directions offer room for ongoing collaboration between members of the PPC and oncology teams.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of financial interest

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LEGENDS

TABLE 1 Target list of diagnoses for which pediatric palliative care consult was recommended

Figure 1 Key driver diagram created prior to interventions

Figure 2 Graph showing improvement in outcome measure

Figure 3 Graph showing improvement in process measure

Triangle - PPC consult

Square - No PPC consult

Open Square - Patient death prior to PPC consult

Supplemental Figure 1 Template to document palliative care involvement discussion with family and underlying decision process

Hosted file

TABLE 1. Table with target list of diagnoses for which pediatric palliative care consult was recommended available at <https://authorea.com/users/342610/articles/469429-a-quality-improvement-project-to-increase-palliative-care-team-involvement-in-pediatric-oncology-patients>



