



# Palliative care services in pediatric oncology

Jessica L. Spruit<sup>1</sup>, Maryjo Prince-Paul<sup>2</sup>

<sup>1</sup>Wayne State University College of Nursing, Detroit, MI, USA; <sup>2</sup>Case Western Reserve University Frances Payne Bolton School of Nursing, Cleveland, OH, USA

**Contributions:** (I) Conception and design: All authors; (II) Administrative support: JL Spruit; (III) Provision of study materials or patients: None; (IV) Collection and assembly of data: JL Spruit; (V) Data analysis and interpretation: All authors; (VI) Manuscript writing: All authors; (VII) Final approval of manuscript: All authors.

**Correspondence to:** Jessica L. Spruit. 5557 Cass Avenue, Room 258, Detroit, MI 48202, USA. Email: jessica.diver@wayne.edu.

**Abstract:** Pediatric cancer has experienced significant improvement in overall survival rates over the past several decades. Despite this progress, however, it remains the leading cause of death from disease beyond infancy in children. Among the children and adolescents that survive their cancer diagnosis, significant symptom burden and toxicities of therapy are often experienced. The evidence presented affords great insight in to the current empirical support for pediatric palliative care involvement, current utilization of palliative care services in the care of children with cancer and their families, and barriers that have been identified to date. Positive trends toward increased, appropriate integration of palliative care services in the care of children with cancer and their families have been observed. Continued research, advocacy, and education are necessary to optimize the care of this vulnerable population of patients and their families.

**Keywords:** Pediatric; palliative care; oncology; quality of life

Submitted Mar 05, 2018. Accepted for publication Apr 11, 2018.

doi: 10.21037/apm.2018.05.04

View this article at: <http://dx.doi.org/10.21037/apm.2018.05.04>

## Palliative care services in pediatric oncology

Pediatric cancer has experienced significant improvement in overall survival rates over the past several decades. Despite this progress, however, it remains the leading cause of death from disease beyond infancy in children. An estimated 15,270 children between birth and 19 years of age will be diagnosed with cancer in 2017. Of those, approximately 1,790 will die of their disease (1). Among the children and adolescents that survive their cancer diagnosis, significant symptom burden and toxicities of therapy are often experienced and cannot be underestimated. Additionally, an estimated 60% of survivors will experience late effects of their underlying malignancy and the treatment required to cure it. These late effects may include infertility, muscular deficiencies, organ dysfunction, and secondary cancers (2).

## Pediatric palliative care

*Dying in America*, published by the National Academy of

Medicine (formerly the Institute of Medicine) described the core tasks of high-quality pediatric palliative care (3). These core tasks include enhancing well-being of patients, families, and staff; assisting in coordination of care and logistics across a variety of settings; and support of patients, caregivers, and health care staff in problem-solving and decision-making. This care may be delivered across the care continuum; in ambulatory clinics, outpatient settings, homes within the community, and acute care settings (3). Palliative care involvement can lead to improved health care outcomes including relief of physical symptoms, reduced emotional distress and suffering, and improved coordination and communication among families and health care professionals (3-5). Additionally, the health care team may also benefit from the involvement of palliative care services and improve the experience of those responsible for the care of children with life-threatening illnesses (6).

## Professional organization recommendations

Recent statements published by the American Academy

of Pediatrics and the Institute of Medicine also support the involvement of pediatric palliative care when caring for patients with serious life-threatening and life-limiting illnesses (3,7). The recommendations by the American Academy of Pediatrics (7) highlight the many benefits of involvement of palliative and hospice care services. These benefits include commitments to patient and family-centered care, respect through partnerships with families, access to high-quality services, and continuous care across the life span. Involving palliative care teams also offers support to siblings and healthcare staff who may otherwise go unrecognized or have unmet needs.

Palliative care as a standard of care in pediatric oncology was proposed by Weaver *et al.* (8) in addressing the psychosocial needs of children and adolescents with cancer and their families. The recommendation of access to concepts such as symptom assessment and relief, effective communication, and shared decision-making was made following their review of the literature and synthesis of 73 full-text articles. Application of these concepts should result in effective pain and symptom management, eased suffering, and preventative bereavement care, the authors concluded (8).

Recommendations for the care of adult patients with oncologic diagnoses have also embraced the significance of palliative care services. In 2012, the American Society of Clinical Oncology published a provisional opinion supporting the integration of palliative care for patients with advanced cancer or high symptom burden (9). Based on a review of the literature, including nine randomized control trials and six other analyses, the clinical practice guideline was updated in 2016. This revised guideline recommended that palliative care services be involved early in the disease course, concurrent with active treatment (10).

### Evidence to support involvement of palliative care in pediatric oncology

One of the seminal articles in pediatric oncology described the symptoms and suffering at the end of life for children who died of cancer (11). Researchers interviewed parents of children who had died of cancer in the late 1990s and discovered startling trends in their end-of-life experiences. Among the 103 parents who completed an interview, 89% of them described their child suffering “a lot” or “a great deal” from at least one symptom at the end of their life. Fifty-one percent of children suffered from three or more symptoms, per the parent reports. Among the most commonly reported symptoms were fatigue, pain,

dyspnea, and poor appetite. Although treatment of these symptoms was attempted, the parents in the study reported poor results of that treatment. Less than 30% of parents believed pain treatment was successful and 10% indicated that the nausea, vomiting, or constipation experienced by their child was controlled. When evaluating the quality of life of children in the last month of life, parents described their child as having little or no fun, more than a little sad, and not calm or peaceful most of the time. While this study focused on the end of life, it highlighted the need for attention to symptom control and quality of life, both of which are essential tasks of palliative care.

Symptom distress in children greater than 2 years of age with advanced cancer who were not necessarily at the end of life was also evaluated (12). One-hundred and four patients completed a total of 920 surveys during a 9-month follow-up period. The surveys were largely self-report or combined child-parent report and captured the burden of symptoms experienced by children and adolescents with advanced cancer. A median of five symptoms were reported in each survey, and a median of three of those were experienced with high distress. Among these, pain, fatigue, and drowsiness were common physical symptoms and irritability and sleep disturbances were common psychosocial symptoms.

The quality of life experienced by patients in the above-mentioned study was also described by Rosenberg and colleagues (13). Of the 920 completed surveys, 38% of them revealed a total health-related quality of life score consistent with “fair” or “poor”. Physical and school quality of life subscores ranked the lowest, while emotional and social subscores were decreased much less often. Thirteen symptoms were identified as associated with decreased quality of life; ten of those were consistent with significant reductions in the score. Difficulty concentrating, worrying, dry mouth, pain, sadness, irritability, insomnia, fatigue, vomiting, and anorexia were among those symptoms, many of which can be influenced by high-quality palliative care.

Pediatric patients with cancer and their parents report significant symptom burden early in the course of disease as well. Levine *et al.* (14) completed an evaluation of patient and parent perspectives regarding suffering in the first month of cancer therapy. A majority of patients reported suffering from nausea (84.5%), loss of appetite (75.2%), pain (74.4%), and anxiety (59.7%) in the first month of their therapy. Additionally, nearly half of the patients reported suffering from depression and diarrhea. The majority of these patient-parent dyads reported that the oncology care

team should focus on quality of life “a great deal or a lot” from the beginning of cancer therapy.

Seminal research from the adult population further highlights the importance of early palliative care integration. In 2010, Temel and colleagues published the results of grounding research that set the tone for palliative care delivery (15). This randomized controlled trial of patients with metastatic non-small-cell lung cancer demonstrated the impact of palliative care in addition to standard oncologic care compared to standard oncologic care alone. Recipients of the palliative care intervention were found to have statistically significant higher quality of life and fewer depressive symptoms. Perhaps the most notable finding, however, was that despite less aggressive care at the end of life, the patients randomized to the palliative care cohort experienced longer survival, of both clinical and statistical significance. The patients who received palliative care lived an average of 2.7 months longer than the standard therapy cohort did, while experiencing better quality of life and fewer depressive symptoms.

## Evidence of the impact of palliative care

### *Pediatric end-of-life experiences*

Intensive, medical-directed care at the end of life has been associated with significant suffering. Interventions such as mechanical ventilation and invasive medical procedures as well as the environment of the intensive care unit can contribute to the distressing physical and psychosocial experience of children with cancer and their families. There is evidence that even within the last month of life, significant numbers of patients with cancer receive this type of care. Kaye and colleagues (16) reported that over one-third of 321 patients who enrolled in palliative oncology care received cancer-directed therapy in the last month of life and more than half of the patients cared for by the palliative oncology service were hospitalized in the intensive care unit. In another retrospective analysis of end-of-life care by Kassam *et al.* (17), 40.6% of the 815 patients evaluated received high-intensity end-of-life care such as chemotherapy administration within the 14 days prior to death, or more than one emergency department visit, hospitalization, or intensive care unit admission within 30 days of death.

Snaman and colleagues (18) conducted a retrospective chart review of 69 patients who were hospitalized at the time of death to evaluate the end-of-life care provided to

adolescent and young adult oncology patients at one large pediatric cancer hospital. In addition to identifying a median of 11 symptoms reported within the last month of life, the team found important differences in the care received by the cohort who received palliative care services compared to those who did not. The most common symptoms experienced in the last month of life included pain, fatigue, and edema, all of which were reported in greater than 75% of the patients evaluated. Adolescents and young adults who had palliative care involved were less likely to die in the intensive care unit or be on a mechanical ventilator at the time of death. The palliative care cohort also underwent fewer medical procedures. An additional significant finding is related to the timing of do not resuscitate (DNR) or physician order for scope of treatment (POST) orders; the palliative care cohort had a significantly longer period of time between the establishment of these orders and death. Adult oncology research has associated aggressive treatment at the end of life with poor quality of life, further supporting the need to consider the implications on such treatment for adolescents and young adults.

### *Solid tumor versus hematologic malignancies*

There is some variation in end-of-life experiences in children with hematologic and solid tumor malignancies. Children with a solid tumor malignancies and brain tumors are more likely to enroll in hospice and die at home or in an inpatient hospice (19). This may be related to the slightly more predictable, progressive course of refractory disease in such patients.

Vern-Gross *et al.* (5) conducted a retrospective chart review of patients younger than 21 years of age with solid tumors. Two cohorts of patients were identified over two time periods; participants in the second cohort were enrolled on the quality of life/palliative care service through their death. Comparison of these two cohorts revealed significant differences in the care received based on whether or not the quality of life/palliative care service was involved. The patients receiving care from the palliative care team had a significantly longer time between the first end-of-life discussion and death, and discussions were noted to take place much earlier in the disease trajectory. Although no differences were noted between the cohorts regarding the duration of time between the initial DNR order and death, a significantly greater portion of patients in the quality of life/palliative care cohort had DNR order in place at the time of death. Patients with solid tumors who were also

cared for by the quality of life/palliative care service had a significantly greater frequency of hospice enrollment and both sibling and bereavement support was provided more often for patients within that cohort. In summary, when a pediatric palliative care team is in place, an individualized approach can support the patient and family and reduce discomfort and suffering, as well as improve outcomes for survivors after the death of a child with cancer.

***Pediatric hematopoietic stem cell transplant recipients: unique considerations required***

The intense, cure-focused nature of hematopoietic stem cell transplantation has posed a unique challenge to the integration of palliative care services in the face of common misconception among the public and healthcare providers. There is a tolerance for physical and psychological distress that has not been observed to the same extent in other curative therapies for cancer among families and providers pursuing transplantation. Many patients who are referred for hematopoietic stem cell transplantation have otherwise exhausted their treatment options. Consultation for a hematopoietic stem cell transplant outlines the toxicities and complications that may arise as a result of this intervention; patients and their family caregivers are repeatedly informed of the risk for morbidity and mortality associated with this modality. The treatment-related nature of these complications may contribute to the complexity of this situation and decreased rates of palliative care referral. Providers have a strong desire to reverse treatment-related side effects and often maintain the focus of curative care throughout the transplant continuum.

**Symptoms and quality of life**

Children who undergo hematopoietic stem cell transplantation experience a variety of symptoms throughout the care continuum. Initially, children receive high-dose chemotherapy and radiation. Following an allogeneic transplant, many will experience prolonged periods of immunosuppression, often complicated by infections. The inherent risk of the development of graft versus host disease, either the acute or chronic form, can contribute to further symptoms. Patients who develop acute graft versus host disease may experience significant gastrointestinal distress in the form of cramping abdominal pain or severe, sometimes bloody diarrhea and skin involvement may progress to painful blisters or ulcerations in the most severe forms. Chronic GVHD can significantly

impact quality of life and functional status as it has potential to impact almost any organ system, including the eyes, mouth, musculoskeletal system, integument, and liver.

**End-of-life experiences**

Children and adolescents who underwent hematopoietic stem cell transplantation had significant differences in their end-of-life experiences when compared to patients who did not receive a transplant. Decreased duration between do-not-resuscitate orders and death, decreased hospice enrollment, and decreased deaths at home were among those findings (19). Most children who do not survive following a transplant have prolonged illness courses prior to their deaths. Ullrich *et al.* (20) completed a retrospective chart review of 147 children who underwent hematopoietic stem cell transplantation and then died following treatment. Only 25% received pediatric palliative care consultation. Initial visits by the pediatric palliative care team focused on decision-making and psychosocial support. Pain and non-pain symptom management were also offered. The patients who had palliative care involvement were more likely to have discussions regarding prognosis and resuscitation status. These discussions were noted to occur earlier in the transplant course. Most of the children in the sample received highly medicalized care at the end of life and home deaths or hospice enrollment were relatively rare, whether or not palliative care was involved. The circumstances surrounding the deaths did vary based on palliative care participation, however. Palliative care involvement was associated with decreased likelihood of intubation in the 24 hours before death or dying in the intensive care unit. Additionally, only 3% of patients with palliative care involvement underwent cardiopulmonary resuscitation, compared to 20% of patients who did not have palliative care support. Notably, despite the decrease in intervention-focused medical care, involvement of pediatric palliative care services was not associated with decreased duration of survival.

Snaman *et al.* (21) evaluated two cohorts of adolescent and young adult oncology patients who received care and died while inpatient at a single children's cancer center; one cohort underwent allogeneic hematopoietic stem cell transplantation and the other did not. During the last month of life, patients who received a transplant experienced a median of 11.5 symptoms, most commonly pain, fatigue, and edema or lymphedema. Patients who received transplants had significantly different end-of-life experiences than the cohort of oncology patients who did not. These differences included a greater number of

medical procedures and greater frequency of hemodialysis or mechanical ventilation during the last month of life. Additionally, transplant recipients were more likely to die in the intensive care unit.

### Support for palliative care intervention

Impeccable symptom recognition and management are necessary to support the needs of children and families undergoing hematopoietic stem cell transplantation. Additionally, open communication and ongoing consideration of goals of care are necessary to support this vulnerable subpopulation. To evaluate the impact of a palliative care intervention in the early course of transplantation, El-Jawahri and colleagues (22) completed a randomized controlled trial with 160 adult patients admitted for hematopoietic stem cell transplantation. Eighty-one patients were randomized to the palliative care plus standard care cohort; the palliative care advanced practice nurse or physician visited these patients within 72 hours of admission and at least twice weekly for the first 2 weeks of their hospitalization. The median number of visits by the palliative care team was eight; the median number of days hospitalized was 20. Intervention patients were found to have decreased depression symptoms and decreased anxiety symptoms at week two of their hospitalization. Although both groups experienced a decrease in their reported quality of life, the decrease was less in the intervention group. The control group reported increased anxiety. When assessed at three-months post-intervention, the intervention group continued to report better quality of life and decreased depression scores, anxiety scores, and symptom burden when compared to the control group. Although this work was completed in an adult cohort, it suggests that there is value from multiple perspectives in the early integration of palliative care services. Patients in this study were also evaluated 6 months post-transplant (23). Symptom burden 2 weeks in to hospitalization was found to mediate the effect of the intervention on depression symptoms and post-traumatic stress disorder symptoms at six months post-transplant. Establishment of a relationship this early in the transplant continuum provides support for patients, families, and caregivers throughout the course of illness, whether that ends in cure or death. In addition to relief of symptoms related to the treatment modality, longer-term psychological outcomes may also be impacted by this integration. Early establishment of palliative care relationships is also valuable for recipients of allogeneic hematopoietic stem cell

transplantation due to the risk for morbidity associated with the transplant and decreased quality of life secondary to transplant related complications such as chronic graft versus host disease.

The death experiences described in patients who undergo hematopoietic stem cell transplant are significant for several reasons. One essential goal of palliative care is to reduce the physical and psychosocial suffering that occurs during intensive therapy and at the end of life. Additionally, there is evidence that death in the intensive care unit increases the incidence of complicated grief 6 months after the death of a child and that severe, complicated grief may persist for up to 18 months following that death (24). Bereaved parents of children who received a hematopoietic stem cell had worse psychological outcomes than parents of children who did not receive a transplant.

### Current models of care

#### *Availability of pediatric palliative care services*

Feudtner *et al.* (25) surveyed 162 children's hospitals to determine the availability and extent of palliative care services. This survey included an evaluation of interprofessional team members, funding sources, and services provided by the team. Palliative care teams were available in 69% of the responding institutions. However, wide variations in services provided as well as the composition of professional team members were discovered. For example, one-third of programs did not have weekend or night coverage available. Additionally, allocations of full-time employment for physicians and nurses ranged from 0–3.8 FTE and 0–6.6 FTE, respectively. Although social workers were included in approximately two-thirds of respondent programs, their time appointment was an average of 0.29 FTE, equivalent to approximately 12 hours each week (25).

More recently, Weaver *et al.* (26) evaluated the structure of palliative care teams at centers that care for children with cancer through a cross-sectional online survey. One-hundred and forty-two respondents represented 18 countries and 39 states; three-quarters of these reported having a pediatric palliative care program available. Less than half of the sites reported having around the clock access to palliative care consultations and 28% of the respondents stated their program had been in existence for 5 years or less at the time of the survey. Nearly half of the respondents (49%) reported their palliative care services did not have adequate

capacity when compared to the demand. The existence of programs aligns with the vision of involvement of palliative care services; however, expanded services to provide care in a variety of settings to meet the demand of patient volumes and needs throughout the continuum of illness is necessary to fulfill this vision.

### *Current palliative care utilization in pediatrics*

Since the seminal publication by Wolfe *et al.* (11), changes in the integration of palliative care services has been observed in several studies. Wolfe *et al.* (27) noted that when comparing two cohorts of patients who died of an oncologic diagnosis treated at two different time points, there was increased documentation of discussions regarding hospice and fewer children died in the intensive care unit from the later time point. Additionally, fewer parents of children who received care in the later cohort reported that their children suffered “a great deal” or “a lot” from pain and anxiety. A retrospective chart review of patients who had received a quality of life/palliative care consult over seven years at a single center found similar results (28). Consultation to the quality of life/palliative care service within one month of arrival increased six-fold over the course of the study. Patients cared for over at least one year prior to consultation was decreased by nearly 50% over the study period. Evaluation of 445 patients who died at a single institution between 2002 and 2014 revealed a similar trend (19). When the study time frame was divided in to quartiles, researchers found that patients had greater numbers of DNR and physician order for life sustaining treatment in place over time. Additionally, the frequency of palliative care consultation increased over time. Despite these changes, enrollment in hospice, length of time in hospice, and location of death did not change over time.

## **Perceived barriers limiting involvement of pediatric palliative care**

### *Provider perspectives*

Dalberg and colleagues (29) conducted four focus groups of health care professionals who care for children with cancer. The authors worked with 32 professionals, nearly half physicians, and evaluated themes identified during discussions that followed a presentation proposing involvement of a pediatric palliative care team in the

pediatric oncology population. Physicians included in the focus groups indicated that the oncology teams adequately addressed the palliative care needs of children with cancer. The perception that primary oncologists were providing adequate palliative care was the most frequently reported barrier to palliative care consultation by 142 survey respondents (26). Additional barriers reported in that study included a lack of perceived benefit from palliative care incorporation by primary oncologists and late referral where the disease was too advanced for palliative care to make an impact. A prospective national survey of pediatric oncology providers further validated this reported barrier (30). Over half of the 1,005 respondents of this survey agreed that concern regarding the overlapping roles of the palliative care and oncology teams was a barrier to providing palliative care services to children with cancer.

### *Family resistance*

Fear that families or caregivers may perceive involvement of palliative care as “giving up” was another common barrier reported among providers caring for children with cancer. Nearly all of the 33 participants in interprofessional focus groups described concern that early introduction of palliative care services could increase parental burden (29). Furthermore, half of these participants believed families would not be ready for involvement of pediatric palliative care services at the time of diagnosis due to their misconception that palliative care is inconsistent with curative intent (29). In their cross-sectional survey of 643 Canadian members of oncology-related professional organizations, Wentlandt *et al.* (31) found a statistically significant difference between pediatric oncologists when compared to adult oncologists and their beliefs that families had negative perceptions of palliative care.

Most recently however, Dalberg *et al.* (30) found that over half of 1,005 pediatric oncology provider respondents disagreed that palliative care exposure within one month of an oncologic diagnosis would increase parental anxiety. All of the participants in this survey stated that early introduction of palliative care services does not create an overall burden for parents. This change in perspective may present an important opportunity to overcome one of the previously perceived barriers.

## **Synonymous use of palliative and end-of-life care**

In 2011, the Center to Advance Palliative Care (CAPC)

published a report based on public opinion research that also concluded that most health care professionals believe palliative and end-of-life care are synonymous. The report also notes that approximately 70% of Americans described themselves as “not at all knowledgeable” about palliative care (32). The confusion between the terms palliative care and end of life and their corresponding definitions remains a considerable barrier for health care professionals to provide care consistent with the goals of patients and their families.

The public opinion surveys described by CAPC (32) reported changes in feelings once healthcare consumers were informed. Over 90% of consumer respondents stated they would recommend appropriate palliative care education for families of patients with serious illnesses, believed palliative care services should be available in all hospitals, and would consider palliative care for their own loved one (32). The ability to modify perceptions and overcome resistance demonstrates the need for healthcare professionals to be informed and offer accurate information and support to families prior to introducing palliative care consultation.

The CAPC findings were further validated by palliative care research. All 33 providers who care for children with cancer and participated in the focus groups by Dalberg *et al.* (29) reported that misconceptions about the purpose of palliative care exist. The group believed that education may be effective in overcoming this barrier. In a subsequent study by Dalberg and colleagues (30), providers reported that professionals outside of their own profession were more likely to conflate palliative with end-of-life care.

### **Future directions for pediatric palliative care: evaluation of feasibility and acceptance**

Feasibility of early palliative care consultation in hematopoietic stem cell transplantation was established by Lafond *et al.* (33). In this study at an urban, tertiary, free-standing children’s hospital, referral and consultation to palliative care took place for 12 eligible families. The transplant team agreed to consultation in 100% of eligible cases and families were receptive to that consultation 100% of the time. During a 30-day study period, an average of 11 visits were made per patient. One-hundred percent of families requested supportive care counseling as their palliative care intervention. Additional interventions were provided nearly all of the time; the only service that did not meet the benchmark was related to availability of an

outside acupuncture consultant. Families who received palliative care services reported they were very comfortable receiving care (90%) and rated the palliative care team as helpful or very helpful (100%). Additionally, all of the families who participated felt satisfied to very satisfied with access to services and stated that they were very likely to recommend the palliative care team to others. Providers from the primary team of these patients indicated that the palliative care team was very helpful in managing symptoms and stressors during the transplant admission and that they would be very likely to recommend the palliative care team to other patients and families. On a five-point Likert scale, the average satisfaction score was 4.4 among 20 providers with regards to the provider experience with the palliative care team.

One-hundred and twenty-nine patient-parent dyads from a convenience sample were surveyed within 1 month to 1 year of an oncologic diagnosis by Levine *et al.* (14). Although a minority of patients and parents reported they had heard the term “palliative care”, none of those who were familiar with it reported a negative attitude toward it. When provided with a brief definition of palliative care that focused on symptom management and quality of life, only a minority of children and parents (1.6% and 6.2%, respectively) stated they definitely would not want to meet with the palliative care team. This number increased slightly when patients and parents learned that in addition to symptom management, palliative care could provide end-of-life care (15.5% and 14.7%, respectively). To the contrary, however, 26.4% of patients and 17.8% of parents indicated that definition would make them more willing to meet with the palliative care team. Very few patients and parents responded that they would be concerned that palliative care involvement would interfere with their relationship with their oncologist, cause them to lose hope, or interfere with their therapy.

Levine and colleagues (14) surveyed children between the ages of 10 and 17 years old to find that they were significantly more likely to endorse palliative care integration and its corresponding interventions if they were experiencing challenges in pain or symptom management, if the cancer progressed or recurred, and throughout all of cancer care. Over half of the patients believed that palliative care services should be offered to all children with cancer from the beginning of cancer therapy. Patients were more likely to state that palliative care teams should be involved from the beginning of therapy if they had fair or poor quality of life.

## Conclusions

Children undergoing cancer therapy experience significant symptoms, whether in the early phases of disease or near the end of life. While the evidence presented here affords great insight in to the current empirical support for pediatric palliative care involvement, current utilization of palliative care services in the care of children with cancer and their families, and barriers that have been identified to date, there is still much to be learned. Positive trends toward increased, appropriate integration of palliative care services in the care of children with cancer and their families have been observed. Continued research, advocacy, and education are necessary to optimize the care of this vulnerable population of patients and their families.

## Acknowledgements

None.

## Footnote

*Conflicts of Interest:* The authors have no conflicts of interest to declare.

## References

1. National Cancer Institute. Cancer in children and adolescents. 2017. Available online: <https://www.cancer.gov/types/childhood-cancers/child-adolescent-cancers-fact-sheet>
2. Cure Search. 5-year survival rate. 2018. Available online: <https://curesearch.org/5-Year-Survival-Rate>
3. Institute of Medicine. Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life. 2015. Available online: <http://www.nap.edu/catalog/18748/dying-in-america-improving-quality-and-honoring-individual-preferences-near>
4. Kassam A, Skiadaresis J, Alexander S, et al. Differences in end-of-life communication for children with advanced cancer who were referred to a palliative care team. *Pediatr Blood Cancer* 2015;62:1409-13.
5. Vern-Gross TZ, Lam CG, Graff Z, et al. Patterns of end-of-life care in children with advanced solid tumor malignancies enrolled on a palliative care service. *J Pain Symptom Manage* 2015;50:305-12.
6. Vollenbroich R, Duroux A, Grasser M, et al. Effectiveness of a pediatric palliative home care team as experienced by parents and health care professionals. *J Palliat Med* 2012;15:294-300.
7. Section on Hospice and Palliative Medicine and Committee on Hospital Care. Policy statement: pediatric palliative care and hospice care commitments, guidelines, and recommendations. *Pediatrics* 2013;132:966-72.
8. Weaver MS, Heine KE, Kelly KM, et al. Palliative care as a standard of care in pediatric oncology. *Pediatr Blood Cancer* 2015;62:S829-33.
9. Smith TJ, Temin S, Alesi ER, et al. American society of clinical oncology provisional clinical opinion: the integration of palliative care into standard oncology care. *J Clin Oncol* 2012;30:880-87.
10. Ferrell BR, Temel JS, Temin S, et al. Integration of palliative care into standard oncology care: American society of clinical oncology clinical practice guideline update. *J Clin Oncol* 2017;35:96-112.
11. Wolfe J, Grier HE, Klar N, et al. Symptoms and suffering at the end of life in children with cancer. *N Engl J Med* 2000;342:326-33.
12. Wolfe J, Orellana L, Ullrich C, et al. Symptoms and distress in children with advanced cancer: prospective patient-reported outcomes from the PediQUEST study. *J Clin Oncol* 2015;33:1928-35.
13. Rosenberg AR, Orellana L, Ullrich C, et al. Quality of life in children with advanced cancer: a report from the PediQUEST study. *J Pain Symptom Manage* 2016;52:243-53.
14. Levine DR, Mandrell BN, Sykes A, et al. Patients' and parents' needs, attitudes, and perceptions about early palliative care integration. *JAMA Oncol* 2017;3:1214-20.
15. Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med* 2010;363:733-42.
16. Kaye EC, Gushue CA, DeMarsh S, et al. Illness and end-of-life experiences of children with cancer who receive palliative care. *Pediatr Blood Cancer* 2018;65. doi: 10.1002/pbc.26895.
17. Kassam A, Sutradhar R, Widger K, et al. Predictors and trends in high-intensity end-of-life care among children with cancer: a population-based study using health services data. *J Clin Oncol* 2017;35:236-42.
18. Snaman JM, Kay EC, Lu JJ, et al. Palliative care involvement is associated with less intensive end-of-life care in adolescent and young adult oncology patients. *J Palliat Med*, 2017;20:509-16.
19. Brock KE, Steineck A, Twist CJ. Trends in end-of-life care in pediatric hematology, oncology, and stem cell transplant

- patients. *Pediatr Blood Cancer* 2016;63:516-22.
20. Ullrich CK, Lehmann L, London WB, et al. End-of-life patterns associated with pediatric palliative care among children who underwent hematopoietic stem cell transplant. *Biol Blood Marrow Transplant* 2016;22:1049-55.
  21. Snaman JM, Talleur AC, Lu J, et al. Treatment intensity and symptom burden in hospitalized adolescent and young adult hematopoietic cell transplant recipients at the end of life. *Bone Marrow Transplant* 2018;53:84-90.
  22. El-Jawahri A, LeBlanc T, VanDusen H, et al. Effect of inpatient palliative care on quality of life 2 weeks after hematopoietic stem cell transplantation. A randomized clinical trial. *JAMA* 2016;316:2094-2103.
  23. El-Jawahri A, Traeger L, Greer JA, et al. Effect of inpatient palliative care during hematopoietic stem-cell transplant on psychological distress 6 months after transplant: results of a randomized control trial. *J Clin Oncol* 2017;35:3714-21.
  24. Meert KL, Shear K, Newth CJ, et al. Follow-up study of complicated grief among parents eighteen months after a child's death in the pediatric intensive care unit. *J Palliat Med* 2011;14:207-14.
  25. Feudtner C, Womer J, Augustin R, et al. Pediatric palliative care programs in children's hospitals: a cross-sectional national survey. *Pediatrics* 2013;132:1063-70.
  26. Weaver MS, Rosenberg AR, Tager J, et al. A summary of pediatric palliative care team structure and services as reported by centers caring for children with cancer. *J Palliat Med* 2018;21:452-62.
  27. Wolfe J, Hammel JF, Edwards KE, et al. Easing of suffering in children with cancer at the end of life: is care changing? *J Clin Oncol* 2008;26:1717-23.
  28. Levine DR, Johnson LM, Snyder A, et al. Integrating palliative care in pediatric oncology: evidence for an evolving paradigm for comprehensive cancer care. *J Natl Compr Canc Netw* 2016;14:741-8.
  29. Dalberg T, Jacob-Files E, Carney PA, et al. Pediatric oncology providers perceptions of barriers and facilitators to early integration of pediatric palliative care. *Pediatr Blood Cancer* 2013;60:1875-81.
  30. Dalberg T, McNinch NL, Friebert S. Perceptions of barriers and facilitators of early integration of palliative care: a national survey of pediatric oncology providers. *Pediatr Blood Cancer* 2018;65:e26996.
  31. Wentlandt K, Krzyzanoska MK, Swami N, et al. Referral practices of pediatric oncologists to specialized palliative care. *Support Care Cancer* 2014;22:2315-22.
  32. Center to Advance Palliative Care. 2011 public opinion research on palliative care. 2011. Available online: [https://media.capc.org/filer\\_public/3c/96/3c96a114-0c15-42da-a07f-11893cca7bf7/2011-public-opinion-research-on-palliative-care\\_237.pdf](https://media.capc.org/filer_public/3c/96/3c96a114-0c15-42da-a07f-11893cca7bf7/2011-public-opinion-research-on-palliative-care_237.pdf)
  33. Lafond DA, Patterson Kelly K, Hinds PS, et al. Establishing feasibility of early palliative care consultation in pediatric hematopoietic stem cell transplantation. *J Pediatr Oncol Nurs* 2015;32:265-77.

**Cite this article as:** Spruit JL, Prince-Paul M. Palliative care services in pediatric oncology. *Ann Palliat Med* 2019;8(Suppl 1):S49-S57. doi:10.21037/apm.2018.05.04