

## REVIEW

## Early Integration of Palliative Care for Children with High-Risk Cancer and Their Families

Erica C. Kaye, MD,<sup>1\*</sup> Sarah Friebert, MD,<sup>2</sup> and Justin N. Baker, MD, FAAHPM<sup>1</sup>

Despite increasing data to support pediatric palliative care (PPC) as an integral component of high-quality care for children with life-threatening conditions and their families, timely integration of PPC is offered inconsistently to children with high-risk cancer. In this review, we summarize the growing body of literature in support of early integration of PPC for children with high-risk cancer and their

families, advocating that PPC principles and resources are imperative to holistic cancer-directed care and rooted in evidence-based medicine. Finally, we offer possible strategies for optimizing integration of PPC into holistic cancer care for children and families. *Pediatr Blood Cancer* 2016;63:593–597. © 2015 Wiley Periodicals, Inc.

**Key words:** communication; early integration; palliative care; pediatric hematology/oncology; psychosocial; quality of life

### BACKGROUND: HISTORICAL PRECEDENT FOR EARLY INTEGRATION OF PEDIATRIC PALLIATIVE CARE

More than a decade ago, the Institute of Medicine (IOM) released a report entitled *When Children Die: Improving Palliative and End-of-Life Care for Children*, in which they called for improvement in patient and family-centered pediatric palliative care (PPC).[1] When the IOM released their follow-up report in September 2014, *Dying in America*, they reiterated the importance of PPC and highlighted the fact that, despite the publication of professional guidelines encouraging healthcare providers to incorporate PPC as best practice in the management of children with life-threatening illness,[2] “wide-spread adoption of timely referral to palliative care appears slow.”[3]

This concept of “timely referral” to PPC is not new to the field of pediatrics. For nearly 15 years, the American Academy of Pediatrics (AAP) has advocated for children with high-risk cancer and other life-threatening conditions to receive access to “an integrated model of palliative care in which the components of palliative care are offered at diagnosis and continued throughout the course of illness, whether the outcome ends in cure or death.”[4] Precedent for this model already exists within the adult oncology paradigm: the American Society of Clinical Oncology (ASCO) released a provisional clinical opinion in 2012 with the recommendation that patients with metastatic lung cancer be offered concurrent palliative care (PC) along with standard oncologic care at the time of initial diagnosis.[5] This consensus statement cited a survival benefit from early integration of palliative care,[6] further supported by substantial evidence from the literature demonstrating that synergistic palliative and cancer-directed care improves patient and caregiver outcomes, including symptom management, quality of life (QOL), overall satisfaction, and caregiver burden.[5–13] Although these data are drawn from the adult cancer population, similar benefits have been shown in children.[14–20] Children with cancer, specifically, are known to experience high symptom burden and suffering throughout their illness trajectory [19,21–23], highlighting this patient population as a high-yield target for early integration of PPC. In response to this growing body of literature, the Palliative Care Special Interest Group endorsed by the American Society of Pediatric

Hematology/Oncology has stated its mission to increase the availability of high-quality palliative care to pediatric oncology patients across the country.[24] Likewise, the International Society of Paediatric Oncology advocates for timely implementation of palliative care for children globally.[25] Each of these recommendations, espoused by reputable national organizations and predicated on research identifying optimal PPC practices, support early PPC involvement as a key component in establishing successful comprehensive care models for children with high-risk cancer and other life-threatening conditions.

Unfortunately, despite this growing body of data identifying PPC as an integral component of high-quality care for all children with life-threatening conditions, timely integration of PPC remains incomplete and inconsistent. As of the most recent assessment of PPC available at Children’s Oncology Group institutions, fewer than 60% of centers offered formal PPC services.[26] Early PPC involvement is particularly variable in children with high-risk cancer: in certain centers, only a minority of children with relapsed, refractory, or progressive cancer are referred to PPC, and a majority of these patients

Abbreviations: AAP, American Academy of Pediatrics; ASCO, American Society of Clinical Oncology; EOL, end of life; IOM, Institute of Medicine; PPC, pediatric palliative care; PPO, pediatric palliative oncology; QOL, quality of life

<sup>1</sup>Departments of Oncology and Palliative Care, St. Jude Children’s Research Hospital, Memphis, Tennessee <sup>2</sup>Akron Children’s Hospital, Akron, Ohio

Grant sponsor: American Lebanese Syrian Associated Charities (ALSAC).

Conflict of interest: Nothing to declare.

Authors’ contribution: E.C.K. conceptualized this manuscript, drafted the initial manuscript, directed the editing process, and approved the final manuscript as submitted, and S.E.F. and J.N.B. revised the manuscript and approved the final manuscript as submitted.

\*Correspondence to: Erica C. Kaye, Departments of Oncology and Palliative Care, St. Jude Children’s Research Hospital, 262 Danny Thomas Place, Mail Stop 260, Memphis, TN 38105.  
E-mail: erica.kaye@stjude.org

Received 18 September 2015; Accepted 15 October 2015

are referred late in their illness trajectory,[27] with one study showing a median of only 8 days between PPC consultation and death.[28] Over the past several years, however, the pediatric oncology community has shown increasing openness for earlier PPC integration in the care of children with high-risk cancer. Following the implementation of a PPC service at one of our institutions, the median time from initial PPC consultation to death was 1.6 months, with the majority of patients no longer receiving cancer-directed therapy by the time of PPC involvement.[29] Furthermore, in a prospective cohort study performed in six academic centers in the United States and Canada, more than 80% of children with cancer who were enrolled in PPC were still alive 1 month after cohort entry and about half were still alive nearly 1 year later,[30] suggesting that PPC principles and resources are beginning to reach eligible patients prior to the end of life (EOL) at some institutions.

In light of accumulating data in support of PPC and strong recommendations from the IOM, AAP, and ASCO, we believe that early integration of PPC for children with high-risk cancer and their families should be considered best practice within the field of pediatric oncology. PPC principles and resources do not merely reflect compassionate practice; they are imperative to holistic cancer care and rooted in evidence-based medicine. For children with cancer, PPC involvement has been shown to improve symptom management [14] and QOL.[15–18] Moreover, parents of children with cancer and other life-threatening conditions enrolled in PPC report significant improvements in their own QOL, with decreased parental report of self-perceived burden and psychological stress.[16,17] Even healthcare providers report significant improvements in all care domains following integration of PPC into the care of complex patients prior to EOL, particularly in the areas of cooperation, communication, and family support.[15] Moreover, the integration of PPC into the ongoing care of patients with high-risk disease across different care settings has been identified by PPC expert clinicians and researchers, parents of children with life-threatening illness, and bereaved parents as one of the top five research priorities integral to improving quality care for children with high-risk disease.[31] However, no consensus exists regarding the optimal strategy for achieving this integration. Multiple conceptual and clinical models have been proposed to promote integration of palliative care into the field of adult oncology,[32,33] but to our knowledge, relatively few models have been described for PPC in the context of pediatric oncology.[34,35]

### PROPOSED CARE MODELS FOR INTEGRATION OF PPC INTO PEDIATRIC ONCOLOGY

The provision of PPC for children with cancer, also known as pediatric palliative oncology (PPO), has been described as “the total care of a child and family.”[35] We believe that this total care philosophy should be guided by the primary oncology team, with collaboration from interdisciplinary clinicians and expert consultants as needed.[33–38] Successful models of collaborative integration of PPC services that complement primary team management are described in the literature and provide a foundation for the generation of effective and sustainable models of care in PPO.[38–42]

In an ideal scenario, PPO principles should be rooted in the culture of an institution (including formalized support of

PPO education, policies, and resources), with expert PPC teams available for consultation in predefined or particularly challenging circumstances (Fig. 1). In this system, the three tiers of PPC services function synergistically to maximize early provision of PPO to children with high-risk disease and their families. We advocate for primary oncology teams to deliver the core elements of PPO from the time of diagnosis [33,43] (e.g., symptom management, alignment of goals of care with treatment), reserving early subspecialty PPC consultation for predefined high-risk scenarios (e.g., uniformly fatal diseases such as diffuse intrinsic pontine glioma or metastatic sarcoma) or more complex cases (e.g., refractory symptom management; mediation of contentious or otherwise challenging family dynamics; negotiation of difficult conversations such as discontinuation of no-longer beneficial life-sustaining therapies in which discordance emerges between the goals of patients/families and those of providers).[44]

We acknowledge that this three-tier system rarely exists in mainstream clinical practice. Many pediatric oncology centers employ an exclusively consult-based PPC paradigm (Tier I: highest resource burden, fewest patients served), in the absence of institutional support or infrastructure to ensure the routine integration of PPO principles within cancer care. We agree that the primary team is optimally situated to appreciate the patient’s needs and triage those families who might benefit most from subspecialty PPC consultation. However, this exclusively consult-based model depends heavily on the experiences, attitudes, and preferences of referring providers, and invariably PPO services reach only a select group of patients and families at the tip of the iceberg.[45,46] To capture a wider breadth of patients, PPC principles should emerge from the ground up, ideally woven seamlessly into each aspect of the interdisciplinary care model. This may occur through institutionally supported PPC didactics for nursing staff (ELNEC-Peds),[47] cancer-specific PPC training models for clinicians,[48] or embedding PPC-trained experts within outpatient and inpatient care settings to provide additional guidance and education as needed.[34] Table I offers specific examples for each PPO integration model as a possible starting point for institutions motivated to improve the integration of PPC into routine pediatric oncology management.

In the field of adult oncology, several models of delivering palliative care to cancer patients have been studied, including embedding palliative care staff within the oncology clinic.[13, 49,50] Within this “embedded” system, oncologists on average rated their overall satisfaction as 9/10, palliative care consultations increased by 87%, and oncology staff saved greater than 160 hr over 12 months.[13] This model has faces certain challenges [32] and has yet to be investigated for PPO, but it warrants consideration as a possible means of creating the infrastructure upon which to build an optimal and sustainable three-tiered PPO integration system.

Ideal conceptual models notwithstanding, a given institution’s culture, available personnel, and resources must be considered in determining effective strategies for early integration of PPO. Each institution should reach consensus regarding those patients and families who might benefit most from early PPO services, while concurrently accounting for the bandwidth of available PPC resources within that institution. PPC referral criteria has been established through the Center to Advance Palliative Care [51] and further modified for use in PPO,[34]

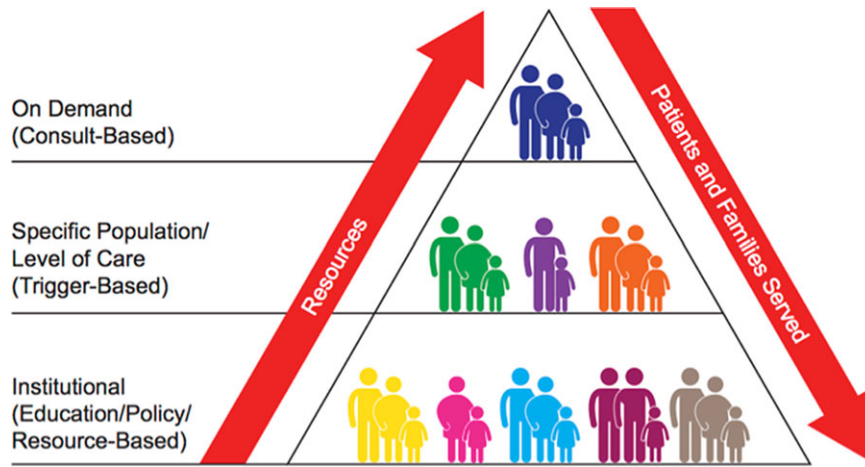


Fig. 1. Three tiers of PPC services within an institution.

TABLE I. Three PPO Integration Models, With Examples of Possible Strategies to Incorporate PPC Into Routine pediatric Oncology Management

PPC integration models	Specific examples
On demand (consult based)	<ul style="list-style-type: none"> <li>Primary oncology team requests expert PPC consultation to assist with complicated symptom management or difficult psychosocial issues</li> </ul>
Specific population/level of care (trigger based)	<ul style="list-style-type: none"> <li>Standard operating procedures (SOPs) for identified populations (e.g., patients with DIPG, metastatic sarcoma)</li> <li>Patients at the EOL (e.g., EOL checklist and EOL SOP implementation<sup>26,47</sup>)</li> </ul>
Institutional (education/policy/resource based)	<ul style="list-style-type: none"> <li>Mandatory nursing didactics (e.g., ELNEC-Peds)</li> <li>Required communication training for clinical fellows</li> <li>Institutional support of outpatient hospice resources</li> <li>Creation of an evidence-based, hospital-wide Pain Management SOP</li> </ul>

offering optional guidelines for pediatric oncology teams to consider when triaging those patients and families who might benefit from early PPO.

**RATIONALE FOR EARLY INTEGRATION OF PPO**

We anticipate that early integration of PPO, like any other novel concept not yet accepted as mainstream, will face institutional or individual resistance over the coming years. We offer the following rationale in support of early integration of PPO principles for all high-risk patients and early contact with trained PPO clinicians in select cases. First, timely introduction to PPO provides adequate time for trust and relationships to de-

velop, both of which improve the later processes of shared decision making and communication of difficult information with patients and families.[52] Second, PPO philosophy advocates for consistent integration of QOL metrics into the management plan throughout the illness process, with equivalent emphasis placed on alleviation of any physical, psychosocial, and spiritual distress experienced by the patient or family. Third, PPO principles entail the provision of anticipatory guidance for children with cancer and their families at every stage of their illness experience, whether the patient is receiving cancer-directed treatment, experiencing relapse or progression, or at the EOL.[37] Fourth, introduction to PPO ideology at the beginning of an illness journey affords the opportunity for early establishment of goals of care, with the expectation that goals will be fluid and evolve to match the recommendations of the primary oncology team and the needs of the child and family over time.[53] In this way, early integration of PPO principles facilitates holistic continuity of care that transcends illness stage and treatment location.

Despite increasing awareness and support for the field of PPO, however, it is important to acknowledge that many patients, families, and healthcare providers retain the false perception of palliative care as mutually exclusive from disease-directed or cure-oriented therapy.[54–56] As a result of this misconception, PPC is often offered at the end of an illness trajectory when no further curative or life-prolonging options exist.[57] This phenomenon is particularly evident in the field of pediatric oncology, in which PPO may be viewed as “giving up.”[58] To the contrary, we strongly advocate that PPO is not exclusive to the dying process; rather the goal is to honor the process of living in the face of childhood cancer.[35] With this philosophy in mind, it stands to reason that PPO can and should begin at the time of diagnosis of high-risk cancer and not be reserved exclusively for disease relapse, progression, or EOL.

Ten years ago, Mack et al. proposed the concept of a “Day One Talk” as a model for sharing bad news at the time of a child’s cancer diagnosis, offering recommendations for building trust and establishing partnerships at the onset of a long and difficult journey.[59] A similar strategy might be considered for the early introduction of PPO into the holistic cancer care plan for a child with high-risk cancer, with the simple goal of

familiarizing the child and family with basic PPO concepts and resources at the time of diagnosis or shortly thereafter. The aims of this strategy from the perspective of the patient and family are threefold: (i) to establish the groundwork for PPO resources offered in parallel with cancer-directed therapy; (ii) to demonstrate a collaborative partnership between the primary oncology team and PPO clinicians from the onset, with the mutual goal of supporting both child and family throughout the illness trajectory; and (iii) to normalize PPO concepts for the child, family, and other members of the interdisciplinary team, thereby preempting stigmatizing language and other preconceived barriers to the provision of PPO. Additionally, with early PPO involvement, more opportunities exist for the child and family to benefit from the continuity of care that PPO offers, including a range of flexible services and resources available to link inpatient and outpatient care.[34,60]

Conversely, in our collective institutional experiences, when PPO principles are introduced late in the illness course, the patient and family are more likely to perceive PPO in a negative light, risking a fracturing of the therapeutic alliance. We hypothesize that two primary factors may contribute to this adverse outcome: (i) after receiving extensive treatment and attention from the primary oncology team, the patient and family may perceive PPO consultation as abandonment by their primary caregivers and/or (ii) the patient and family might view the PPO team as a “second-best” resource employed as a last-resort strategy after all “real” diagnostic and treatment options have been exhausted. In our experience, patients and families with these perceptions may be more likely to have difficulty partnering with clinicians to work collaboratively toward ameliorating symptoms or participating willingly in difficult decision-making processes.

We advocate for a system in which the concept of PPO is introduced to children with high-risk cancer and their families early in the illness journey and described as simply another aspect of the patient’s holistic care plan. We have successfully integrated PPO within the paradigm of a cure-oriented pediatric cancer center, [29,38,61] and we believe that a similar holistic care model should be accessible to all children with high-risk cancer. To introduce the concept of early integration of PPO, the primary oncology team might share the following approach with a high-risk patient and family: “Whenever our team takes care of a child with this type of cancer, we utilize a team approach in order to provide your child with the best possible care. Your child will be evaluated and treated by an interdisciplinary care team, including physicians, nurse practitioners, nurses, dietitians, social workers, psychologists, child life specialists, chaplains, and PPC experts. Each member of this team has an equally important role to play in helping your child feel better and cope with his/her illness.” From the outset, the role of each team member should be outlined clearly, with three goals in mind: (i) to explain the value added by each clinician, (ii) to establish the expectation that multiple providers will work with the child and family toward mutual goals, and (iii) to preemptively allay any possible future sense of abandonment should goals of care change over time. How the primary oncology team chooses to define the role of the PPC expert might vary, depending on what services and resources are available at a given institution. One possible description might be, “a clinician who focuses on helping your child live every day as well as possible, supporting your child and

your family by walking with you throughout every step of this difficult journey.” In this model, both the child and family are set up from the start to expect the delivery of holistic care that includes PPO principles, through an approach designed to lessen stigma and normalize these interventions as standard of care.

When PPO is viewed as a set of principles, resources, and services oriented toward improving QOL for the child and family from the time of diagnosis, continued attention to QOL will not seem like a line drawn in the sand between curative care and palliative care if there comes a time when potentially curative therapy is no longer available; rather, it will simply be an ongoing focus on making every day as good as possible. This philosophy of care says to the child and family: “The day you were diagnosed with cancer, our team cared about the quality of your life. If ever your disease progresses or relapses, we will continue to care about the quality of your life. If the day comes when we no longer have curative therapies, we will still care about the quality of your life.” Such a philosophy obliterates the false sense that PPO implies a new chapter in a child’s cancer experience. Instead, PPO becomes a valuable pillar supporting the entire framework of a family’s illness journey, from the moment in which they received a devastating diagnosis to the end of their treatment, whether resulting in cure or death.

Past and present data suggest that early integration of PPO principles and services optimizes the holistic management of children with high-risk cancer and their families. The adult oncology community has recognized that early integration of palliative care from the time of diagnosis positively impacts patient outcomes,[6] and the question has evolved from whether to integrate palliative care with cancer care to how to best achieve integration.[5,12] Building from the adult experience, PPC experts likewise advocate for integration of PPC as early as the time of diagnosis for children with cancer and other high-risk diseases.[60] However, more research is needed to better understand the impact of early integration of PPC on child and family outcomes, as well as further investigation geared toward identifying those populations with the greatest potential to benefit from early PPC involvement. These data will aid in effective triage of current limited resources in the provision of early PPC. As the field of PPC continues to evolve and grow, it is our hope that PPC principles and resources will become accessible for all children with high-risk cancer and their families as an integral aspect of their holistic management, integrated into the disease-directed care plan at the beginning of treatment and extending throughout the illness journey.

In summary, the integration of palliative care into the management of children with high-risk cancer is an interdisciplinary endeavor, and it must grow from within a strong home with the primary oncology team.[33] PPO in this context should be viewed as a collaborative and evidence-based response to identifying and supporting whatever makes a child’s life better, days fuller, and family’s experience more meaningful. Articulated in this way, PPO is not a harbinger for the EOL, but rather a philosophy that should be embraced at the onset of the illness journey.

## REFERENCES

1. Field MJ, Behrman RE, editors. National Research Council. When children die: Improving palliative and end-of-life care for children and their families. Washington, DC: The National Academies Press; 2003.

2. Feudtner Chris, Friebert Sarah, Jewell J. Pediatric palliative care and hospice care commitments, guidelines, and recommendations. AAP Section on Hospice and Palliative Medicine and Committee on Hospital Care. *Pediatrics* 2013;132:966–972.
3. Institute of Medicine. *Dying in America: Improving quality and honoring individual preferences near the end of life*. Washington, DC: The National Academies Press, 2014.
4. American Academy of Pediatrics. Committee on bioethics and committee on hospital care. Palliative care for children. *Pediatrics* 2000;106:351–357.
5. Smith TJ, Temin S, Alesi ER, Abernethy AP, Balboni TA, Basch EM, Ferrell BR, Loscalzo M, Meier DE, Paice JA, Peppercorn JM, Somerfield M, Stovall E, Von Roenn JH. American Society of Clinical Oncology provisional clinical opinion: The integration of palliative care into standard oncology care. *J Clin Oncol* 2012;30:880–887.
6. Temel JS, Greer JA, Muzikansky A, Gallagher ER, Admane S, Jackson VA, Dahlin CM, Blinderman CD, Jacobsen J, Pirl WF, Billings JA, Lynch TJ. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med* 2010;363:733–742.
7. Parikh RB, Kirch RA, Smith TJ, Temel JS. Early specialty palliative care—Translating data in oncology into practice. *N Engl J Med* 2013;369:2347–2351.
8. Bakitas M, Lyons KD, Hegel MT, Balan S, Brokaw FC, Seville J, Hull JG, Li Z, Tosteson TD, Byock IR, Ahles TA. Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: The project ENABLE II randomized controlled trial. *JAMA* 2009;302:741–749.
9. Bakitas M, Lyons KD, Hegel MT, Balan S, Barnett KN, Brokaw FC, Byock IR, Hull JG, Li Z, McKinstry E, Seville J, Ahles TA. The project ENABLE II randomized controlled trial to improve palliative care for rural patients with advanced cancer: Baseline findings, methodological challenges, and solutions. *Palliat Support Care* 2009;7:75–86.
10. Zimmermann C, Swami N, Krzyzanowska M, Hannon B, Leigh N, Oza A, Moore M, Rydall A, Rodin G, Tannock I, Donner A, Lo C. Early palliative care for patients with advanced cancer: A cluster-randomised controlled trial. *Lancet* (London, England) 2014;383:1721–1730.
11. Temel JS, Greer JA, Admane S, Gallagher ER, Jackson VA, Lynch TJ, Lennes IT, Dahlin CM, Pirl WF. Longitudinal perceptions of prognosis and goals of therapy in patients with metastatic non-small-cell lung cancer: Results of a randomized study of early palliative care. *J Clin Oncol* 2011;29:2319–2326.
12. Ferris FD, Bruera E, Cherny N, Cummings C, Currow D, Dudgeon D, Janjan N, Strasser F, von Gunten CF, Von Roenn JH. Palliative cancer care a decade later: Accomplishments, the need, next steps—From the American Society of Clinical Oncology. *J Clin Oncol* 2009;27:3052–3058.
13. Muir JC, Daly F, Davis MS, Weinberg R, Heintz JS, Paivanas TA, Beveridge R. Integrating palliative care into the outpatient, private practice oncology setting. *J Pain Symptom Manage* 2010;40:126–135.
14. Schmidt P, Otto M, Hechler T, Metzger S, Wolfe J, Zernikow B. Did increased availability of pediatric palliative care lead to improved palliative care outcomes in children with cancer? *J Palliat Med* 2013;16:1034–1039.
15. Vollenbroich R, Duroux A, Grasser M, Brandstätter M, Borasio GD, Führer M. Effectiveness of a pediatric palliative home care team as experienced by parents and health care professionals. *J Palliat Med* 2012;15:294–300.
16. Groh G, Borasio GD, Nickolay C, Bender H-U, von Lüttichau I, Führer M. Specialized pediatric palliative home care: A prospective evaluation. *J Palliat Med* 2013;16:1588–1594.
17. Groh G, Vyhnaček B, Feddersen B, Führer M, Borasio GD. Effectiveness of a specialized outpatient palliative care service as experienced by patients and caregivers. *J Palliat Med* 2013;16:848–856.
18. Gans D, Kominski GF, Roby DH, Diamant AL, Chen X, Lin W, Hohe N. Better outcomes, lower costs: Palliative care program reduces stress, costs of care for children with life-threatening conditions. *Policy Brief UCLA Cent Health Policy Res* 2012;1–8.
19. Friedrichsdorf SJ, Postier A, Dreyfus J, Osenga K, Sencer S, Wolfe J. Improved quality of life at end of life related to home-based palliative care in children with cancer. *J Palliat Med* 2015;18:143–150.
20. Wolfe J, Friebert S, Hilden J. Caring for children with advanced cancer integrating palliative care. *Pediatr Clin North Am* 2002;49:1043–1062.
21. Wolfe J, Grier HE, Klar N, Levin SB, Ellenbogen JM, Salem-Schatz S, Emanuel EJ, Weeks JC. Symptoms and suffering at the end of life in children with cancer. *N Engl J Med* 2000;342:326–333.
22. Wolfe J, Orellana L, Ullrich C, Cook EF, Kang TI, Rosenberg A, Geyer R, Feudtner C, Dussel V. Symptoms and distress in children with advanced cancer: Prospective patient-reported outcomes from the PediQUEST study. *J Clin Oncol* 2015;33:1928–1935.
23. Ullrich CK, Dussel V, Hilden JM, Sheaffer JW, Lehmann L, Wolfe J. End-of-life experience of children undergoing stem cell transplantation for malignancy: Parent and provider perspectives and patterns of care. *Blood* 2010;115:3879–3885.
24. Palliative Care Special Interest Group (SIG). American Society of Pediatric Hematology/Oncology (ASPHO) [Internet][cited 2015 Oct 6]. <http://aspho.org/membership/special-interest-groups/palliative-care>
25. Palliative Care Working Group. International Society of Paediatric Oncology [Internet][cited 2015 Oct 6]. <http://www.siop-online.org/node/2053>
26. Johnston DL, Nagel K, Friedman DL, Meza JL, Hurwitz CA, Friebert S. Availability and use of palliative care and end-of-life services for pediatric oncology patients. *J Clin Oncol* 2008;26:4646–4650.
27. Johnston DL, Vadeboncoeur C. Palliative care consultation in pediatric oncology. *Support Care Cancer* 2012;20:799–803.
28. Zhukovsky DS, Herzog CE, Kaur G, Palmer JL, Bruera E. The impact of palliative care consultation on symptom assessment, communication needs, and palliative interventions in pediatric patients with cancer. *J Palliat Med* 2009;12:343–349.
29. Vern-Gross TZ, Lam CG, Graff Z, Singhal S, Levine DR, Gibson D, Sykes A, Angheliescu DL, Yuan Y, Baker JN. 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(3):305–312.
30. Feudtner C, Kang TI, Hexem KR, Friedrichsdorf SJ, Osenga K, Siden H, Friebert SE, Hays RM, Dussel V, Wolfe J. Pediatric palliative care patients: A prospective multicenter cohort study. *Pediatrics* 2011;127:1094–1101.
31. Baker JN, Levine DR, Hinds PS, Weaver MS, Cunningham MJ, Johnson L, Angheliescu D, Mandrell B, Gibson D, Jones B, Wolfe J, Feudtner C, Friebert S, Carter B, Kane JR. Research priorities in pediatric palliative care. *J Pediatr* 2015;167:467–470.e3.
32. Hui D, Bruera E. Models of integration of oncology and palliative care. *Ann Palliat Med* 2015;4:89–98.
33. Von Roenn JH. Palliative care and the cancer patient: Current state and state of the art. *J Pediatr Hematol Oncol* 2011;33 (Suppl 2):S87–S89.
34. Kaye EC, Rubenstein J, Levine D, Baker JN, Dabbs D, Friebert SE. Pediatric palliative care in the community. *CA Cancer J Clin* 2015;65:315–333.
35. Waldman E, Wolfe J. Palliative care for children with cancer. *Nat Rev Clin Oncol* 2013;10:100–107.
36. Harris MB. Palliative care in children with cancer: Which child and when? *J Natl Cancer Inst Monogr* 2004;32:144–149.
37. Levine D, Lam CG, Cunningham MJ, Remke S, Chrastek J, Klick J, Macauley R, Baker JN. Best practices for pediatric palliative cancer care: A primer for clinical providers. *J Support Oncol* 2013;11:114–125.
38. Baker JN, Hinds PS, Spunt SL, Barfield RC, Allen C, Powell BC, Anderson LH, Kane JR. Integration of palliative care practices into the ongoing care of children with cancer: Individualized care planning and coordination. *Pediatr Clin North Am* 2008;55:223–250, xii.
39. Duncan J, Spengler E, Wolfe J. Providing pediatric palliative care: PACT in action. *MCN Am J Matern Child Nurs* 2007;32:279–287.
40. Toce S, Collins MA. The FOOTPRINTS model of pediatric palliative care. *J Palliat Med* 2003;6:989–1000.
41. Harper J, Hinds PS, Baker JN, Hicks J, Spunt SL, Razzouk BI. Creating a palliative and end-of-life program in a cure-oriented pediatric setting: The zig-zag method. *J Pediatr Oncol Nurs* 2007;24:246–254.
42. Golan H, Bielora B, Grebler D, Izraeli S, Rechavi G, Toren A. Integration of a palliative and terminal care center into a comprehensive pediatric oncology department. *Pediatr Blood Cancer* 2008;50:949–955.
43. Von Gunten CF. Secondary and tertiary palliative care in US hospitals. *JAMA* 2002;287:875–881.
44. Quill TE, Abernethy AP. Generalist plus specialist palliative care—Creating a more sustainable model. *N Engl J Med* 2013;368:1173–1175.
45. Wentlandt K, Krzyzanowska MK, Swami N, Rodin G, Le LW, Sung L, Zimmermann C. Referral practices of pediatric oncologists to specialized palliative care. *Support Care Cancer* 2014;22:2315–2322.
46. Walshe C, Chew-Graham C, Todd C, Cares A. What influences referrals within community palliative care services? A qualitative case study. *Soc Sci Med* 2008;67:137–146.
47. Ferrell B, Malloy P, Virani R. The end of life nursing education nursing consortium project. *Ann Palliat Med* 2015;4:61–69.
48. Gysels M, Richardson A, Higginson IJ. Communication training for health professionals who care for patients with cancer: A systematic review of training methods. *Support Care Cancer* 2005;13:356–366.
49. Prince-Paul M, Burant CJ, Saltzman JN, Teston LJ, Matthews CR. The effects of integrating an advanced practice palliative care nurse in a community oncology center: A pilot study. *J Support Oncol* 2010;8:21–27.
50. Johnston B, Buchanan D, Papadopolou C, Sandeman G, Lord H. Integrating palliative care in lung cancer: An early feasibility study. *Int J Palliat Nurs* 2013;19:433–437.
51. Friebert S, Osenga K. Pediatric palliative care referral criteria. *Center to Advance Palliative Care*; 2009.
52. Jones BL, Contro N, Koch KD. The duty of the physician to care for the family in pediatric palliative care: Context, communication, and caring. *Pediatrics* 2014;133 (Suppl 1):S8–S15.
53. Kang TI, Munson D, Hwang J, Feudtner C. Integration of palliative care into the care of children with serious illness. *Pediatr Rev* 2014;35:318–326.
54. Davies B, Sehring SA, Partridge JC, Cooper BA, Hughes A, Philp JC, Amidi-Nouri A, Kramer RF. Barriers to palliative care for children: Perceptions of pediatric health care providers. *Pediatrics* 2008;121:282–288.
55. Knapp C, Thompson L. Factors associated with perceived barriers to pediatric palliative care: A survey of pediatricians in Florida and California. *Palliat Med* 2012;26:268–274.
56. Friedman BT, Harwood MK, Shields M. Barriers and enablers to hospice referrals: An expert overview. *J Palliat Med* 2002;5:73–84.
57. Thompson LA, Knapp C, Madden V, Shenkman E. Pediatricians' perceptions of and preferred timing for pediatric palliative care. *Pediatrics* 2009;123:e777–e782.
58. Dalberg T, Jacob-Files E, Carney PA, Meyrowitz J, Fromme EK, Thomas G. Pediatric oncology providers' perceptions of barriers and facilitators to early integration of pediatric palliative care. *Pediatr Blood Cancer* 2013;60:1875–1881.
59. Mack JW, Grier HE. The day one talk. *J Clin Oncol* 2004;22:563–566.
60. Mack JW, Wolfe J. Early integration of pediatric palliative care: For some children, palliative care starts at diagnosis. *Curr Opin Pediatr* 2006;18:10–14.
61. Hendricks-Ferguson VL, Kane JR, Pradhan KR, Shih C-S, Gauvain KM, Baker JN, Haase JE. Evaluation of physician and nurse dyad training procedures to deliver a palliative and end-of-life communication intervention to parents of children with a brain tumor. *J Pediatr Oncol Nurs* 2015;32:337–347.