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After reading the article “Pediatric Palliative Care in the Community” the learner should be able to:
1. Describe the scope of pediatric palliative care and community-based pediatric palliative care.
2. Review the indications for referral of children with cancer to pediatric palliative care and community-based pediatric palliative care.
3. Discuss the benefits of and barriers to referral of children with cancer to pediatric palliative care and community-based pediatric palliative care.

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Pediatric Palliative Care in the Community

Erica C. Kaye, MD1*; Jared Rubenstein, MD2; Deena Levine, MD3; Justin N. Baker, MD4; Devon Dabbs, BBA5; Sarah E. Friebert, MD6

Early integration of pediatric palliative care (PPC) for children with life-threatening conditions and their families enhances the provision of holistic care, addressing psychological, social, spiritual, and physical concerns, without precluding treatment with the goal of cure. PPC involvement ideally extends throughout the illness trajectory to improve continuity of care for patients and families. Although current PPC models focus primarily on the hospital setting, community-based PPC (CBPPC) programs are increasingly integral to the coordination, continuity, and provision of quality care. In this review, the authors examine the purpose, design, and infrastructure of CBPPC in the United States, highlighting eligibility criteria, optimal referral models to enhance early involvement, and fundamental tenets of CBPPC. This article also appraises the role of CBPPC in promoting family-centered care. This model strives to enhance shared decision making, facilitate seamless handoffs of care, maintain desired locations of care, and ease the end of life for children who die at home. The effect of legislation on the advent and evolution of CBPPC also is discussed, as is an assessment of the current status of state-specific CBPPC programs and barriers to implementation of CBPPC. Finally, strategies and resources for designing, implementing, and maintaining quality standards in CBPPC programs are reviewed. CA Cancer J Clin 2015;65:315-333. © 2015 American Cancer Society.

Keywords: pediatric, palliative, care, community, home, hospice, communication, end of life, quality of life

Introduction

John is a previously healthy 14-year-old young man who excels academically and is a star athlete. In the fall of his freshman year of high school, John develops intermittent abdominal pain, which he initially ignores. As his abdominal pain and distension gradually worsen, however, he presents to a local emergency department for evaluation. Diagnostic imaging reveals a large intra-abdominal mass involving his adrenal gland, and further comprehensive workup confirms a diagnosis of stage IV high-risk neuroblastoma. Although John’s diagnosis is unusual for an adolescent patient, he is eligible for enrollment on a clinical trial to treat his high-risk disease. John undergoes cancer-directed therapy with curative intent, but his disease continues to progress despite chemotherapy, surgical intervention, autologous hematopoietic stem cell transplantation, radiation, and immunotherapy. His course is complicated by multigorgan dysfunction, including hepatoportal syndrome with severe portal hypertension resulting in refractory abdominal ascites, as well as bilateral pleural effusions leading to respiratory distress. Because of these complications, John spends most of his time in the hospital. John frequently expresses his desire to be at home, but he also wishes to continue pursuing therapy with the goal of cure. Recognizing the long road ahead and the need for enhanced resources for John and his family, John’s oncologist orders a palliative care consult to assist with pain and symptom management, care coordination and continuity, and advance care planning.

For nearly 15 years, the American Academy of Pediatrics has advocated for all children with life-threatening illness to receive access to palliative care in an integrated model, offering the components of palliative care at diagnosis and continuing throughout the disease course, whether the outcome is cure or death.1 Pediatric palliative care (PPC) offers a comprehensive approach to providing holistic care to children and adolescents with life-threatening conditions and their families.

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and should be provided together with curative/life-prolonging therapy.1,2 PPC aims to address physical, psychosocial, and spiritual concerns from a family-centered perspective, providing continuity of care that bridges different events and care locations. Fundamental PPC principles often center on the tenets of symptom relief, quality of life (QOL), communication, relationship-building, and goal-directed decision making, with a focus on interdisciplinary collaboration to address issues from multiple perspectives.3-5 In an optimal family-centered model, PPC begins at the time of diagnosis of a life-threatening condition and is introduced as another pillar of support within the standard-of-care paradigm.6,7 Once integrated into the child’s management plan, PPC extends throughout the illness trajectory, threading between inpatient and outpatient settings to promote continuity of care.8

Community-based PPC (CBPPC) is a branch of PPC that bridges hospital, home, and hospice settings; as such, CBPPC programs play an integral role in the coordination and provision of complex care for children with life-threatening conditions and their families.9 More than a decade ago, the Institute of Medicine (IOM) released a report entitled Improving the Palliative and End-of-Life Care for Children, in which they called for improvements in CBPPC through better collaboration among individual health care professionals, children’s hospitals, home care services, and hospice agencies.2 In September 2014, the IOM released another comprehensive analysis of the current status of end of life (EOL) care in America, in which they again advocated for better access to home care as a means to attaining higher QOL, including better understanding and communication, emotional and spiritual support, well being and dignity, care at the EOL, and a lighter symptom burden.10

Supported by these national consensus statements, PPC experts have endorsed the inclusion of home-based PPC services as a key component of an effective holistic care model.11 Here, we describe the fundamental tenets intrinsic to the delivery of effective CBPPC in the United States, particularly as they pertain to the care of children with cancer, with an emphasis on how pediatric oncologists can partner with CBPPC practitioners to cooperatively enhance the scope of care for patients with life-threatening conditions and their families. Because palliative care terms may be open-ended with overlapping meanings, we define 4 key terms that are used throughout our discussion (Table 1).

**Benefits of CBPPC**

Although children and adolescents with life-threatening malignancies typically receive therapy at pediatric cancer centers, these patients and families often have opportunities to return home between cancer-directed treatments, at the conclusion of treatment, or at the EOL. At each of these time points, CBPPC principles and resources are helpful in easing transitions between the hospital and home and improving the overall home experience. Unfortunately, at present, few institutions have the requisite infrastructure to subsidize formal CBPPC services. The majority of pediatric cancer centers have access to PPC clinicians and resources exclusively in the hospital setting, if at all.15

Despite advances over the past decade, early integration of PPC, let alone CBPPC, is inconsistently practiced as standard of care in the management of children with high-risk cancer.16,17 However, integration of CBPPC principles and services for pediatric oncology patients is not merely compassionate practice; it is an imperative component of holistic care that is rooted in evidence-based medicine.

Specifically, CBPPC involvement in the care of children with cancer improves symptom management,18 QOL,19-22 and other valuable self-reported outcomes for children and their families. Parents of children with life-threatening conditions who used CBPPC services before their child’s death described the death as “very peaceful,” reporting that

**TABLE 1. Palliative Care Terminology**

| **Term** | **Definition** |
|----------|----------------|
| Pediatric palliative care (PPC) | Interdisciplinary services that address the needs of infants, children, adolescents, and young adults with life-threatening or life-limiting conditions, along with the needs of their families and caregivers; treatments aim to relieve suffering across multiple realms, including physical, psychosocial, spiritual, and practical; interdisciplinary palliative care teams focus on improving the child’s quality of life while helping families through illness and bereavement, facilitating informed decision making, and assisting with care coordination (Feudtner 201315) |
| Community-based pediatric palliative care (CBPPC) | PPC that is provided outside of the hospital setting with the goal of offering PPC resources and services in private residences, community-based clinics or settings, long-term care facilities, and local respite or hospice facilities; CBPPC may be managed through formal PPC programs, home health or hospice agencies, or other community-based clinicians, with support provided in person, by telephone, or by electronic correspondence; when linked with hospital-based PPC services, CBPPC programs provide continuity of care for patients who journey between inpatient and outpatient settings, optimizing quality of life across the care continuum (Meyers 201414) |
| Hospice care | A form of palliative care in which hospice agencies bundle medical, psychosocial, spiritual, and volunteer services in synergy with the provision of durable medical equipment and diagnostic and therapeutic interventions that align with the goals of care of the child and family; these services are usually financed by an all-inclusive per-diem rate and may be provided either in the home or in a separate hospice facility (Feudtner 201315) |
| Subspecialty palliative care | PPC practiced by an expert provider (or a team of experts) with formal training in PPC, typically including (but not limited to) subspecialty board certification in Hospice and Palliative Medicine as recognized by the American Board of Pediatrics; subspecialty PPC clinicians possess expert knowledge and skills honed to prevent and relieve suffering in patients with life-threatening conditions, and they work within an interdisciplinary team model to maximize quality of life while addressing the physical, psychosocial, and spiritual needs of patients and families (American Board of Pediatrics 201516) |
CBPPC involvement led to highly significant ($P < .001$) improvements in their child’s symptoms and QOL, enhancement of aspects of communication, and reduction in administrative barriers.\textsuperscript{19} Parents also reported highly significant ($P < .001$) improvements in their own QOL, with decreased parental reports of self-perceived burden and psychological stress.\textsuperscript{20,21} Even health care providers themselves reported significant ($P < .001$) improvements in all care domains, particularly in the areas of cooperation, communication, and family support.\textsuperscript{19}

In addition to the aforementioned proven benefits accrued from involvement before EOL, CBPPC also significantly improves the EOL experience for children and families. Parents of children with life-threatening conditions increasingly report a preference for their child’s death to occur in the home,\textsuperscript{23,24} and CBPPC services have been shown to increase the percentage of children who die at home in accordance with the family’s wishes,\textsuperscript{25} with improved congruence between the actual and preferred location of EOL care ($P < .01$).\textsuperscript{26}

CBPPC teams are well positioned not only to provide continuity of care to children and families but also to facilitate communication among numerous subspecialty services and to help prevent unwanted readmission to the hospital. In this way, CBPPC programs benefit not only the child and family who wish to remain at home but also potentially benefit the affiliate hospital, which may be fiscally incentivized to decrease frequent and/or lengthy inpatient admissions. Few medical professionals consider fiscal remuneration as an imperative prerequisite when trying to improve the quality of care for suffering children; nevertheless, the potential for financial incentivization of CBPPC should not be discounted when advocating for the creation of more widespread CBPPC programs. In a retrospective analysis of children with life-threatening conditions and their families, enrollment in CBPPC services was associated with decreased length of stay in the hospital and emergency department and lower overall hospital charges.\textsuperscript{27} Thus, it is reasonable to believe that the delivery of high-quality, home-based PPC has the potential to reduce health care costs by minimizing rehospitalizations in select children with life-threatening conditions.\textsuperscript{22} Because EOL care patterns remain key cost drivers in the current health care model, subsidization of CBPPC resources might yield considerable fiscal savings in this context.\textsuperscript{28}

### CBPPC: For Whom, By Whom, and When

Any child with a chronic, complex, life-threatening condition is eligible to receive PPC services, including CBPPC.\textsuperscript{6,8,29} However, given the lack of consensus about standard eligibility or referral criteria for CBPPC and prevalent misconceptions, we frame our discussion using referral criteria set forth by the Center to Advance Palliative Care\textsuperscript{6} (Tables 2 and 3). Although these criteria use “automatic” and “suggested” designations, they are offered here not as a mandate, but as a signpost indicating the breadth of what palliative care experts consider to be appropriate populations for possible CBPPC involvement. In all instances, involvement of a palliative care team is meant as an extra layer of support, to collaborate with, not supplant, the primary oncology team.

Ultimately, we believe that the decision about who receives CBPPC referral depends on the resources and interdisciplinary supports available to the primary oncology team and PPC/CBPPC team at a specific institution. The criteria proposed in these published guidelines can and should be modified according to the resource capabilities and needs of individual patients, families, and care teams.

### TABLE 2. “Green Lights” to Consider Pediatric Palliative Care Consult for a Child With Cancer

| • Child with a new diagnosis of high-risk disease |
| • Difficult pain or symptom management before, during, or after cancer treatment |
| • Three or more unplanned hospitalizations for serious medical issues within a 6-month period |
| • Prolonged hospitalizations lasting >3 weeks, without evidence of improving medical status |
| • Prolonged intensive care hospitalization lasting >1 week, without evidence of improving medical status |
| • Introduction of new technology (eg, tracheostomy, tunneled chest tube) |
| • Child and/or family with complex psychosocial needs, limited social support, or both |
| • Child is followed by >3 subspecialty services, with challenges in interdisciplinary communication |
| • Child with complex care-coordination needs during transitions between hospital and home or other care settings |
| • Child and/or family at the crossroads of making difficult decisions |
| • Difficulty reaching consensus among child, family, and medical team about goals of care or management plan (eg, resuscitation status, use of medical nutrition/hydration or continuation of chemotherapy at the end of life) |
| • Child and/or family struggling with decision-making around resuscitation status |
| • Ethical issues related to palliative care domains raised by child, family, or medical team* |
| • Need for hospice services or other home-based resources, including durable medical equipment or home laboratory monitoring, if these services are not readily accessible to the primary team |
| • Anticipation of complex survivorship issues, such as serious long-term treatment toxicities |
| • Anticipation of complex bereavement needs |

*Despite appreciable overlap in the fields of Pediatric Palliative Care and Ethics, we believe that Pediatric Palliative Care consultation should be a distinct event that is mutually exclusive from Ethics Committee consultation (Feudtner & Nathanson 2014).
TABLE 3. Possible Triggers for a Pediatric Palliative Care Referral for a Child With Cancer

| AT TIME OF DIAGNOSIS                                                                 | DURING COURSE OF ILLNESS                                      |
|-------------------------------------------------------------------------------------|--------------------------------------------------------------|
| Diffuse intrinsic pontine glioma                                                    | Disease refractory to treatment                              |
| Stage IV neuroblastoma                                                              | Disease progression (eg, new metastases)                    |
| Metastatic solid tumors                                                             | Disease relapse after remission                              |
| Any other cancer with projected 5-y EFS <40 % with current available therapies      | Disease refractory or relapsed after bone marrow transplant   |
| New diagnosis with complex pain or other symptom management issues                  | Development of life-threatening complications (eg, organ failure, prolonged intubation) |
| Any disease in which hematopoietic stem cell transplantation is part of the upfront treatment plan | Development of new and significant treatment-related toxicities and/or psychosocial stressors |

EFS, event-free survival.

Cornerstones of CBPPC: Communication, Relationship Building, and Family-Centered Goal Setting

John initially is skeptical of the PPC team, which he associates with hospice and therefore rejects, stating, “I am not dying.” The PPC team explains that their role is to help John and his family manage his distressing symptoms, identify their goals, support them in making decisions that align with these goals, and ensure that their wishes are honored over different points in time and different care locations. The PPC team meets with John and his family multiple times during his frequent and prolonged hospitalizations, gradually establishing personal relationships and building trust. John shares with the PPC team that he loathes the hospital, and his two greatest wishes are to “get better” and to “go home.” The medical team believes that John would benefit from a chest tube to drain his pleural effusion, but he is unwilling to leave the hospital with a chest tube. Over the next week, the PPC team explores the rationale and motivation behind John’s strong feelings about the chest tube. As John learns to trust the PPC team, he shares his fear that the chest tube will become infected as well as the shame he feels about the appearance of an external tube. Dignity and his physical appearance emerge as themes that carry extreme importance for John. Knowing this information, the PPC team helps John, his family, and the inpatient team to think creatively, and the unanimous decision is made to place a tunneled chest tube catheter.

Optimal continuity of care that transcends illness stage and care location necessitates frequent, honest, clear, and empathetic communication between health care providers and patients and families. Describing the foundation of a therapeutic relationship, Mack and Grier note that conversation is vital, trained providers with expertise in their field allow for the delivery of care in its most advanced and effective form.
framework for successful, family–centered identification of goals to help inform difficult decision making. Pediatric oncology clinicians interested in developing communication expertise are advised to explore the resources outlined in Table 4.

The gradual process of building trust takes time and is best achieved during periods of stability and low stress. Unfortunately, clinicians seldom have a chance to discuss goals of care and other emotionally fraught issues when a child and family are at ease within their familiar environment; more often, these difficult conversations transpire in the hospital during times of high stress and disruption of routine. Whenever possible, the safe and familiar environment of the home is more ideally suited for allowing relationships and conversations to evolve over time based on the changing needs of the child and family. In this capacity, CBPPC affords children and families a way to make thoughtful, unrushed care decisions that best align with their values.

Once trust and relationships are securely established, CBPPC providers also have an opportunity to provide context–specific anticipatory guidance, empower children and families to identify care goals, and formulate strategies to tailor management plans to their hopes and preferences. As an illness trajectory declines, CBPPC providers who have formed trusting relationships with the child and family are likewise well positioned to help facilitate the regoaling process, a phenomenon that occurs when the patient or family members allow old goals (eg, cure) to metamorphose into new hopes (eg, maintaining QOL as defined by the patient or family). From within the home setting, CBPPC providers can serve as the eyes and ears of the primary oncology team, relaying and conveying information in collaboration to deliver the best possible individualized management across care settings.

Effective communication is required for trust building and relationship building not only among children/families and health care providers but also between members of the interdisciplinary team. A successful CBPPC team must participate in collaborative communication among all caregivers, including interdisciplinary members from the primary team and the inpatient PPC consulting service. Effective CBPPC teams promote communication and improve continuity of care through a myriad of strategies, including comprehensive documentation in the patient’s electronic medical record; organization of interdisciplinary team care conferences; and facilitation of informal phone calls, electronic correspondence, and in-person conversations with various team members. Both parents and health care providers recognize that PPC involvement improves communication and collaboration among families and care teams, diminishing administrative barriers to providing compassionate care.

### TABLE 4. Resources for Clinicians to Develop Communication Expertise

| Resource                                                                 | Description                                                                                     |
|-------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------|
| Oncotalk (depts.washington.edu/oncotalk/)                                | An online educational curriculum specifically designed to improve the communication skills of oncologists. |
| Vital Talk (vitaltalk.org)                                              | An educational resource forum with guidance for clinicians regarding conversations about goals of care as well as oncology workshops designed for dissemination in cancer centers. Resources are available in telephone app format, and online curricula will be available for Continuing Medical Education credit in 2015 via the Center to Advance Palliative Care (CAPC) (capc.org). |
| Education in Palliative and End-of-Life Care Program (EPEC)—Pediatrics (epc.net/epec_pediatrics.php) | A pediatric-specific conference designed to provide in-person training on effective teaching strategies as well as access to comprehensive educational materials. |
| Program in Palliative Care Education and Practice (PCEP)—Pediatric Track (hms.harvard.edu/pallcare/PCEP/PCEP.htm) | An in-person, intensive conference focusing on advanced topics in pediatric palliative care offered through Harvard Medical School’s Center for Palliative Care. |
| The Conversation Project (theconversationproject.org)                    | A grass-roots movement dedicated to helping people talk about their wishes for end-of-life care, including access to pediatric “starter kits” to help clinicians, children, and families broach these difficult conversations. |

The CBPPC Bridge: Facilitating the Transition From Hospital to Home/Hospice

With a tunneled catheter in place, John is medically and emotionally ready to be discharged from the hospital and return home. Although excited, John’s family is anxious about managing his new catheter at home. The inpatient PPC team introduces the concept of CBPPC in the form of home care services, including skilled nursing to help with management of the tunneled catheter and home nursing to monitor vital signs, assess and manage symptoms, and draw blood for laboratory tests. In particular, the ability to have blood drawn at home instead of traveling to the hospital appeals to John. “I don’t need hospice at home,” John reminds the team. “But it would be awesome if you come to me so I don’t ever have to go back to the hospital.” John’s family is relieved to have the PPC team help with logistical coordination of details as John transitions from the hospital to home. With the support of home-based services, John and his parents also gradually develop comfort and confidence in navigating John’s new medical technology.

A key finding from the 2014 IOM report *Dying in America* was that many patients with life-threatening conditions experience numerous transitions between various health care settings, including a high frequency of potentially avoidable hospitalizations that fragment the delivery of care and create burdens for patients and their families. Children with life-threatening conditions are particularly affected by this phenomenon given recent trends demonstrating that this patient population spends an increasing amount of time at home during their final year of life. To best care for this unique group of children and their...
families, CBPPC serves as an integral component of the interdisciplinary care team, coordinating frequent and often complex transitions between hospital, home, and/or hospice.

In addition to fostering communication, relationships, and goal-directed decision making, CBPPC providers also manage numerous pragmatic logistics to minimize stressors and allow the child and family to remain in their comfortable and familiar environment. These services may include organization of the following resources: delivery/repair of durable medical equipment, home infusions, prescriptions, and other medications and medical supplies; coordination of home-based laboratory monitoring, physical therapy, occupational therapy, speech therapy, and other home-based services; provision of respite services; access to patient/sibling/parent support groups; and bereavement resources. In our experience, a CBPPC program should aim to incorporate fundamental aspects of holistic home-based care (Table 5), although further research is needed to better understand and prioritize these services. The key components of CBPPC do not need to be delivered under the auspices of a unified CBPPC program but, rather, may be provided through multiple organizations. For example, a home nursing agency may work with a company responsible for durable equipment or infusions, with both of these services coordinated by a primary oncologist or a community-based pediatrician, with guidance from PPC specialists, if available. Together, these collaborating components comprise the optimal infrastructure of CBPPC.

In addition to facilitating collaboration between inpatient and outpatient realms, CBPPC programs also offer opportunities to promote education and research. In an ideal CBPPC model, interdisciplinary oncology and PPC teams within a pediatric cancer center foster alliances with local providers, including partnerships with community hospitals, home health agencies, and hospice organizations. In addition to providing CBPPC to patients and families in remote regions, these partnerships enable the dissemination of PPC principles to a broader range of clinicians, thereby advancing the field through collaborative educational programs, quality-improvement projects, and research initiatives.

Identifying, Respecting, and Maintaining Desired Care Locations: CBPPC as a Mobile “Medical Home”

John enjoys being at home, and he continues to excel in academics through home schooling while spending quality time with family and friends. Over several months, John begins to develop a close relationship with the CBPPC clinicians who visit his home. As his trust grows, he feels increasingly comfortable sharing his hopes and goals of care. John remains adamant that he wishes to be at home as much as possible and does not wish to be readmitted to the hospital for any reason. As his abdominal ascites progressively worsens; however, his pain becomes difficult to control without paracentesis. The PPC team helps John weigh the pros and cons of his options: traveling to the hospital for paracentesis, outpatient or home-based paracentesis, or no further paracentesis with escalation of an opioid infusion at home. John does not want to feel overly sedated from pain medication and chooses to undergo the procedure. John has difficulty moving because of pain, so the PPC team helps his family to coordinate transportation to and from the hospital. Hospital policy typically mandates that all patients who undergo this procedure remain inpatient for a minimum of 24 hours of observation; however, given John’s goals and the availability of CBPPC services, the team advocates for a brief postprocedure observation period, and John is allowed to return home immediately afterward.

Additional important responsibilities of the PPC team include identifying the location of care desired by the patient, family, and medical team and making arrangements to maintain this preferred care location. Data demonstrate that the majority of parents of children with cancer rank home as their preferred location for EOL care, with greater congruence between actual and preferred location of EOL care transpiring in cases with PPC team involvement, highlighting the important role that PPC clinicians serve in this capacity.

Data also suggest that children at the EOL spend the majority of their last 6 months of life at home. In such cases, CBPPC can contribute substantially to the care and comfort of these children and their families. In a retrospective analysis of 36 children who died while enrolled in a CBPPC program (of whom more than half had a cancer diagnosis), children spent most of their time at home and received a variety of home-based services to ensure comfort, continuity of care, and maintenance of desired care location. Specifically, these children received a median of 24

| TABLE 5. Helpful Components of a Community-Based Pediatric Palliative Care Program* |
|---------------------------------|-------------------------------|
| Hospice, preferably with pediatric expertise | Rehabilitation resources |
| Home health | Psychosocial and spiritual resources |
| Skilled nursing | Social work |
| Durable medical equipment | Volunteer services |
| Infusion resources | Respite locations and services |
| Liaisons with hospital setting | Bereavement programs |

*Community-based pediatric palliative care (CBPPC) programs should have access to these services, but they do not necessarily need to provide these services directly; rather, services may be delivered by multiple agencies that collaborate to deliver holistic CBPPC. Rehabilitation resources should include physical, occupational, and speech therapy. Ideally, these resources should be independent from hospice-based programs to provide access to patients and families who are not enrolled in hospice.
PPC team home visits during their final 6 months of life, comprised of visits from physicians, nurse practitioners, nurses, social workers, child life specialists, and expressive therapists. Such supportive services historically have been available most consistently within the structure of an inpatient care setting. The advent of CBPPC, however, enables children and families to receive these services even when they opt to spend as much time as possible within their home environment.

CBPPC teams are well positioned to perform longitudinal assessments of the preferences and goals of care of the child and family; thus, they are optimally positioned to introduce and guide difficult conversations about location of care and location of death. It has been demonstrated that children with life-threatening conditions and their families are able to identify hopes and wishes better if they are fully informed and demonstrate an understanding of their options for receiving care (eg, hospital vs home vs hospice). Within a community-based paradigm, PPC clinicians who have had the chance to build trusting relationships with children and families over time are well suited to share information, promote understanding about choices, and guide difficult decision making, including preferred location of care and location of death.

If the child and family elect home care in lieu of hospitalization, then considerable coordination of services and resources is required to implement and maintain the desired care location. In an ideal model, CBPPC programs operate as mobile medical homes to bring interdisciplinary clinicians and resources directly to the desired care location. To effectively accomplish this goal, CBPPC programs collaborate with local home hospice organizations to provide comprehensive services. Depending on the acuity of illness and extent of symptoms, required resources may vary both between patients as well as over time for the same patient. Regularly scheduled home visits often are important to facilitate a successful home experience around the time of death, as the medical and emotional needs of the child and family may evolve rapidly.

On the basis of information learned from frequent home assessments, CBPPC clinicians are also well positioned to assist with symptom management. In an ideal CBPPC program, trained clinicians are available over the phone or in person 24 hours a day and 7 days a week to provide real-time assessments and make adjustments to medications. Appropriate medications and supplies can be transported directly to the patient’s home, thereby preventing unwanted trips to the clinic or hospital. Moreover, the development of certain symptoms may cause significant physical and emotional distress for children and families, and CBPPC clinicians play a critical role in anticipating symptoms to educate patients and families about what to expect and do in the event of new or worsening symptoms. For example, a child with an inoperable brain tumor may develop difficulty swallowing as the tumor progresses. Home-based clinicians can prepare the child and family for these changes before they occur, educating them about the risks of aspiration with thin liquids and providing thickeners to mix with liquids if the child develops coughing or sputtering while drinking. As dysphagia worsens, the child might have difficulty handling oral secretions, a symptom that can cause significant distress for both child and family. Anticholinergic agents can be prescribed ahead of time and placed in the home for the family to use if distressing symptoms arise, and nonoral formulations of medications can be ordered and delivered in anticipation of the need to change delivery route when swallowing is no longer possible.

CBPPC programs are not limited merely to the coordination of medical care; they also offer several psychosocial services tailored to the needs of the child and family. For example, a family with limited financial means might benefit from frequent communication with an assigned social worker, ideally someone working with (or, at a minimum, familiar with) the CBPPC program and available resources. Specific children and families might also benefit from psychology services geared toward counseling and offering strategies to help process and cope with difficult situations and decision making. In one study, parents of children with life-threatening conditions described psychosocial support by CBPPC teams as the most helpful aspect of their child’s care. Child life specialists also can play a key role in helping the ill child and his/her siblings adjust to an ever-changing reality; expressive therapists (eg, art and music) are likewise valuable in providing nonverbal outlets for communication and coping. For many families, spiritual care services are also an invaluable part of coping with the illness process. Finally, volunteer services and other respite care options may be helpful for families with multiple children or concurrent stressors in the home.

Access to CBPPC services, such as those delineated above, have been shown to result in statistically significant improvements in patient symptoms and QOL for both patients and families, as well as significant decreases in psychological distress and burden of home care. In a prospective analysis of 43 families of children receiving CBPPC, caregivers reported statistically significant improvements in all of the following parameters: patient symptom control, patient QOL, caregiver QOL and stress level, caregiver perception of burden on self and on the patient, psychological support, support for activities of daily living, communication with the patient and with local health care providers, quality of medical and nursing care, quality of medical and nursing information, support in provision of care for the patient, clarification of important
### TABLE 6. Checklist of Individualized Care Planning and Coordination Processes for Children Who Experience the End of Life at Home and Their Families

| Advance Care Planning<sup>2</sup> |
|-----------------------------------|
| • Participation of child and family in decision-making around EOL issues (before period of imminently dying) |
| • Preferred location of care |
| • Understanding of prognosis and goal-directed treatment options |
| • Use of cancer-directed therapies (eg, chemotherapy, radiation, surgery) |
| • Use of life-prolonging measures (eg, invasive or noninvasive ventilator support) |
| • Use of medically provided hydration and nutrition |
| • Use of transfusion therapies (eg, blood, platelets, fresh frozen plasma, cryoprecipitate, IVIG) |
| • Use of antibiotics |
| • Documentation/paperwork |
| • DNAR signed and available in the medical record |
| • State-specific DNAR form completed and available at the bedside |
| • Appointment of Health Care Agent/Proxy in chart, if applicable |
| • Advance Care Plan/5 Wishes/My Wishes in chart, if applicable |
| • Unique child/family requests identified, documented in chart, and distributed to staff |
| • Autopsy/organ donation consent forms (if applicable) |
| • Consent form placed in chart, if applicable |
| • Consent form placed in chart, if applicable |
| • Organ donation conversation |
| • Discussion around time of imminent death |
| • Family notified that patient is imminently dying |
| • Discussion about signs/symptoms to expect as part of the dying process |
| • Educational/resource materials offered to family |
| • Family conference offered to share the gravity of the patient’s status with family members, if desired by patients’ primary care-givers |
| • Medical decisions around time of imminent death |
| • Review medications; add medications for symptom control and stop medications that are not needed |
| • Need for vital signs, physical examination, or laboratory monitoring |
| • Need for imaging, other diagnostic tests, or invasive/painful procedures |
| • Need for nonessential equipment in the home (remove any unnecessary equipment, particularly if it makes noise or takes up space at the bedside) |

### Symptom control

- Comfort optimized
  - Physical symptoms addressed
  - Psychological symptoms addressed
- Function optimized
  - Rehabilitation services involved, if applicable

### Emotional, social, and spiritual care

- Assessments reviewed by a family member
  - Patient’s needs
  - Siblings’ needs
  - Parents’ needs

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| TABLE 6. Continued |
|---------------------|
| • Assessments reviewed by clinician (eg, social worker, chaplain, child life specialist) |
| • Patient’s needs
  • Siblings’ needs
  • Parents’ needs |
| • EOL cultural concerns addressed, if applicable |
| • Financial burdens assessed and support optimized, if applicable |
| • Assistance with funeral arrangements |
| • Make-A-Wish or other wish agency notified of the death |

#### Care coordination and continuity

- List of key health care members to contact in urgent situations
- List of key health care members to contact at time of death
- List of other individuals or organizations to notify at time of death (eg, family, friends, school, church)

#### Bereavement

- Anticipatory needs for bereavement process
- Assist family with staying connected to the child
- Facilitate communication between child and family
- Address decisional regret
- Facilitate the creation of memorial objects and other legacy-building activities
- Educational/resource materials provided
- Risk assessment for complicated bereavement
- Bereavement materials provided
- Sympathy booklet available for staff to sign
- Bereavement support for staff

#### Forms/phone calls to complete after death

- Record of death
- Final disposition
- Death Certificate
- Call the appropriate county medical examiner
- Autopsy/organ donation consent forms (if applicable)

DNAR, do not attempt resuscitation; EOL, end of life; IVIG, intravenous γ-globulin. *This checklist has been adapted from the checklist used by the Quality-of-Life/Palliative Care Service at St. Jude Children’s Research Hospital (Memphis, TN; 2013) and published by Johnson and colleagues (Johnson L-M, Snaman JM, Cupit MC, Baker JN. End-of-life care for hospitalized children. Pediatr Clin North Am. 2014;61:835-85445). Ideally, these items should be completed before the child enters the phase of imminent death.

**Questions regarding diagnosis and prognosis, and support in sociolegal issues.**

Ultimately, home care involvement has been shown to increase the likelihood of planning a child’s location of death, which, in turn, is significantly associated with fewer hospitalizations, more home deaths, and increased parental report of feeling prepared for the child’s EOL and comfortable with the location of death. Specifically, in one cross-sectional study of 140 parents of children who died from cancer, those parents whose child had home-based...
care at the EOL were more likely to plan the location of death. When this occurred, children were more likely to die at home (72% vs 8% of those who did not plan; P < .001) and less likely to be admitted to the hospital (54% vs 98%; P < .001). Of importance, parents who planned the location of death also reported feeling more prepared for the EOL (33% vs 12%; P = .007) and more comfortable with the location of death (84% vs 40%; P < .001) and were less likely to have preferred a different location (2% vs 46%; P < .001). In this way, CBPPC programs have an opportunity to improve EOL experiences and positively impact the bereavement process.

Dying at Home: An Evolving Paradigm

During John’s previous prolonged hospitalizations, he had refused to discuss EOL issues, including his resuscitation preferences. After returning home, however, John and his family feel more comfortable engaging in conversations about his wishes at the EOL. The CBPPC team helps John to recognize that his goal of remaining at home is not possible in the context of resuscitation, and John agrees with his primary team’s recommendation not to receive cardiopulmonary resuscitation or to be intubated in the face of deterioration. John’s family supports his decision, agreeing that remaining at home at the EOL is in John’s best interest. As John’s disease progresses, he becomes weaker and has difficulty moving or speaking due to fatigue and pain. His opioid infusion is titrated to achieve comfort. Over the next few weeks, the CBPPC team explores John’s thoughts about hospice and how hospice-based resources might benefit him and his family. John gradually warms to this conversation, and he ultimately agrees to hospice enrollment. Fortunately, John’s CBPPC program encompasses both home health and hospice resources, allowing him to transition seamlessly between the two arms with minimal disruption in his continuity of care. Through close collaboration with John’s primary oncologist and his CBPPC team, hospice clinicians offer 24-hours-a-day, 7-days-a-week support to John and his family over the phone and in person. During the final weeks, the CBPPC team coordinates home visits from primary oncology and PPC nurses, nurse practitioners, and physicians to offer support and additional resources to John and his family. John dies peacefully, surrounded by his family in their home, in accordance with his wishes.

Historically, children dying of cancer died from their illness in the hospital. In this era, however, increasing numbers of children with life-threatening conditions spend much of the final year of their life at home, and approximately 33% to 50% of patients with chronic illnesses in the United States die at home.24,36 Specifically regarding children with incurable cancer, data from the United Kingdom suggest that more than 75% of these patients die at home.43 These data are strengthened by the results of a retrospective cohort study from the United States, in which 70% of parents and 87% of clinicians of children with cancer reported a preference for home-based EOL care.26 Interestingly, congruence between actual and preferred location of EOL care was more likely to occur in the context of PPC involvement (P < .01).26 In another retrospective cohort from Germany, children with cancer who had access to PPC services had a decreased risk of dying in the hospital, with nearly 75% receiving home-based care at the EOL.18

Why are parents more likely to prefer that their child die at home rather than in the hospital in the context of PPC involvement?25,43 One explanation is that PPC clinicians may offer clear information about the different options available at the EOL, thereby empowering families to choose the option that best fits their needs. Parents who are aware that their child will die from a malignancy are more likely to prefer for their child to receive care at home during the last month of life compared with parents who are not aware,44 demonstrating that information is power for some families. Another explanation is that CBPPC and home-hospice programs provide resources that allow children to die comfortably and with dignity in the home, thereby making the EOL at home a viable alternative to hospitalization.37 Indeed, older studies demonstrating family preference for a child’s death at home noted the caveat that families need to feel adequately supported to feel comfortable with this preference,45 suggesting an important role for CBPPC programs within an evolving care paradigm for children at the EOL.

At the EOL, the coordination-of-care logistics are similar to those previously described for maintaining the preferred location of death, including the ready availability of trained clinicians to manage evolving symptoms and provide medications to ensure comfort. Similarly, social workers, chaplains, and child life specialists are needed to provide emotional and spiritual care to patients and families at the time of death as well as bereavement services in anticipation of loss and in the time to follow.

An “EOL checklist” can be a useful tool for children who die in the hospital; generally, these guides include tasks that fall within 5 main categories: 1) advance care planning; 2) symptom control; 3) emotional, social, and spiritual care; 4) care coordination and continuity; and 5) bereavement care.45 We propose that a similar checklist might be useful for clinicians in a CBPPC program to ensure high-quality care for children who die at home and their families (Table 6).

Barriers to the Provision of CBPPC

Over the past 2 decades, the field of PPC has taken significant strides toward establishing itself as a valuable and vital
clinical and research community. Nevertheless, multiple barriers remain that prevent timely access to high-quality CBPPC for children with life-threatening conditions and their families. In the following section, we systematically review the principal factors that impede access to PPC and CBPPC programs for eligible children and families.

**Provider-related barriers**

The personal characteristics, beliefs, and attitudes of primary health care providers inevitably and unsurprisingly influence the likelihood and timing of referral of eligible patients for PPC or CBPPC services.46 Although most PPC programs encourage an interdisciplinary consultation model in which any involved clinician (or even patients and families themselves) may request a PPC referral, some caregivers may be reluctant to “go behind the back” of the primary oncologist for fear of inciting anger or abandonment. Frequently cited barriers to PPC referral also include a provider’s uncertainty about prognosis, hesitation about the timing of palliative care consultation, perception that the family will be unwilling to accept palliative care, and feelings of failure incurred by the realization that the patient may die.47-50 Pediatric oncologists also have expressed concern that PPC involvement may generate redundancy in provider roles, resulting in confusion, erosion of trust, and loss of control by the primary oncologist.46

Likewise, the erroneous perception of PPC as a “conflicting philosophy” relative to oncology is frequently cited by pediatric oncologists as an obstacle to PPC referral, predicated on the fear that PPC principles may hinder curative/life-prolonging therapy efforts.51 Another oft-referenced barrier is the phrase “palliative care” itself, which many providers regard as stigmatizing for patients and families; to this end, pediatric oncologists have suggested changing the name of the consult to “supportive care” as one tactic to enhance referral palatability.46,50 Unfortunately, the stigma associated with PPC not only impedes the dissemination of PPC/CBPPC services and resources but also adversely affects treatment options for patients, with some institutions refusing to enroll PPC patients in clinical trials despite their meeting eligibility criteria.15

Furthermore, discrepancies among the perceptions held by pediatric oncologists, other members of the team, and parents can obstruct integration of PPC/CBPPC into the patient’s care plan. Unfortunately, physicians do not always recognize unmet patient needs as perceived by other caregivers, particularly in the area of pain management. For example, pediatric oncologists historically rate themselves as competent or highly competent in pain management, with approximately one third reporting that 0% of their patients died with pain and 32% reporting pain in only 10% to 24% of patients at the EOL; however, concurrent studies suggest a contrary reality, with 89% of children who died of cancer experiencing pain at the time of death.42 Despite ongoing efforts to improve symptom control in children at the EOL, nearly a decade after this seminal study 50% of parents still report that their child suffered from “a great deal” or “a lot” of pain at the time of death, suggesting a potential disconnect between the perceived needs recognized by providers and families. Physicians and parents may also differ in their opinions about which PPC principles are most important, with physicians placing higher value on conversations about death and dying and involvement of social work and bereavement support, whereas parents prioritize spiritual support and having the option to receive cancer-directed therapy during the last month of life.53

A lack of formal PPC education for pediatric oncologists likely compounds each of the above barriers to care, with 90% of pediatric oncologists reporting that they learned how to manage dying children on the job, without access to structured PPC didactics or role modeling.50 Although this percentage has improved over the past decade, the 2014 IOM report describes both inadequate attention to palliative care in medical and nursing school curricula and failure to equip physicians with sufficient communication skills, such that health professionals do not always have adequate preparation to deliver “basic” or “primary” palliative care to patients who are not currently hospitalized.50

The provision of effective CBPPC relies on active buy-in and collaboration between hospital-based and community-based providers. This “shared care” model of CBPPC can assume myriad forms but typically involves the PPC team in the role of consultant to a local provider (eg, local oncologist, community-based PPC clinician, hospice agent, or primary pediatrician), with the local clinician acting as the driver of care.55 However, because the coordination and provision of CBPPC require a level of expertise and time commitment that may be beyond the scope or comfort of local providers, in certain circumstances, it may be preferable to use a model in which CBPPC clinicians directly manage and provide care, as opposed to lending expertise via consultation. The caveat, however, is that this CBPPC-led model is not sustainable in the long term without adequate funding, resources, and staffing.55 Lack of reimbursement from insurance companies, insufficient clinical personnel to manage large patient volumes, and inadequate ancillary support to track and process paperwork contribute to suboptimal access to CBPPC.56

**Patient-related and family-related barriers**

Preferences, beliefs, or desires of the patient or family unit irrefutably affect access to PPC/CBPPC. Depending on how PPC is introduced to a family, the act of consultation may be mistaken as synonymous with “giving up” or “setting up hospice” (as seen in John’s case), which can lead
to refusal of services.\textsuperscript{58-60} Certain patients and families may erroneously presume that CBPPC involvement precludes curative/life-prolonging therapy\textsuperscript{47}; this misperception should be clarified as early as possible to minimize confusion and consequent loss of potentially beneficial services. Patients and families may also decline PPC consultation if they feel unready to discuss a poor prognosis; in these cases, it is important to respect the family’s mindset while explaining how CBPPC services may align with their goals of care and enhance QOL.

Preconceived notions about logistical and emotional aspects of receiving home-based or hospice-based care also create challenges. For some families, CBPPC carries a negative connotation that is linked with fears about the EOL or abandonment by the primary team.\textsuperscript{59} Families may struggle to welcome new providers into their home, as unfamiliar faces can feel intrusive and disruptive to the family’s effort to maintain a modicum of control in their daily lives.\textsuperscript{60} Patients and families who have spent substantial time in the hospital may have difficulty adjusting to home care and may feel overwhelmed by their child’s needs in the absence of support from hospital staff. Moreover, patients and families often grow attached to hospital caregivers and develop a sense of security in the hospital, and the idea of separating from this support system can be anxiety-provoking, particularly in the context of fear about the potential for uncontrolled symptoms at home.\textsuperscript{58} Furthermore, parents may worry about the family’s ability to remain in their home after the death of a child or may wrestle with the effect that a child’s death at home might have on siblings; however, recent data demonstrate that siblings who experience open communication about the EOL process, receive preparation about imminent death, and have an opportunity to say goodbye report less long-term psychosocial distress,\textsuperscript{61} and these mitigating supportive processes can be readily provided to siblings in the community setting. It is the responsibility of health care providers to assuage each of these common apprehensions by clearly explaining that CBPPC is not synonymous with abandonment, hospice, or EOL and by providing interdisciplinary support from CBPPC clinicians in synergy with the primary team to help patients and families make the transition to home-based care as smoothly as possible.

Resource-related barriers to CBPPC

As increasing numbers of children with life-threatening conditions receive CBPPC,\textsuperscript{18,24,36} we have begun to see the strain of a health care system not yet fully equipped to meet the needs of this growing population. At present, insufficient numbers of clinicians have the requisite training to provide home-based care to medically complex children, and increased funding on both national and state levels is needed to support education and development of CBPPC programs. In contrast, hospital-based PPC programs continue to expand at an impressive trajectory: in 1998, only 33% of pediatric oncologists reported having access to a PPC team\textsuperscript{50}; whereas, in 2005, 60% of Children’s Oncology Group institutions reported having an inpatient PPC team.\textsuperscript{15} In 2012, the largest recent survey of US children’s hospitals demonstrated that there were PPC services in approximately 70% of institutions.\textsuperscript{62} CBPPC programs, however, are in their nascent phase, not altogether unlike the early stages of hospital-based PPC programs 15 years ago. Increased awareness and promotion of CBPPC is imperative to intensify momentum within this growing field.

Obtaining a referral for CBPPC or hospice is a critical first step, but the next challenge is to identify a local program that is comfortable with providing care to children with life-threatening conditions. Although some hospital-based PPC programs possess sufficient resources to provide CBPPC, many still do not. Moreover, the existence of a hospital-based PPC program does not necessarily speak to the depth or breadth of services provided in the outpatient setting, particularly because the composition of a team can vary dramatically among programs. For example, many teams operate without social workers, psychologists, child life specialists, chaplains, bereavement counselors, nurses, or midlevel providers.\textsuperscript{15} In the absence of interdisciplinary expertise, facilitating and maintaining a successful transition from hospital-based care to CBPPC can be difficult.

In addition, few hospice programs in the United States advertise the provision of pediatric services, and those that do may have such a low pediatric census that they fail to acquire or maintain comfort and expertise with this patient population.\textsuperscript{63,64} Despite increasing community-based needs, the percentage of hospices offering pediatric care actually decreased from 2002 to 2008, and increasing competition among hospices has been associated with a decreased probability of having pediatric services.\textsuperscript{65} In particular, skilled pediatric nursing is not universally available, and children who live in rural areas often lack access to these services.\textsuperscript{55,58} Hospice nurses without pediatric expertise face unique challenges when caring for children in the community, including difficulties with preparing and administering medications at correct pediatric dosages, interacting with grieving families, and coping with the emotional toll of caring for a dying child.\textsuperscript{66} In these contexts, hospital-based PPC programs can be helpful in providing long-distance anticipatory guidance, medical recommendations, and psychosocial support to local providers.

Even when CBPPC and pediatric hospice services are available in a local community, precautions are still necessary to bypass barriers to effective care, such as breakdowns in communication between inpatient and community services. For instance, when community teams are not involved early in the discharge process, patients and families may develop unrealistic expectations about available home-
based services, and community teams may receive insufficient medical information to provide optimal continuity of care.\textsuperscript{57} Promoting effective communication becomes even more important when providing CBPPC to families from different countries or families with distinct cultures or faith systems. Individuals with disparate geographic, ethnic, and religious backgrounds may confront death and dying in unique ways, and it is critical that cultural competency be practiced as an integral tenet of CBPPC. Logistically speaking, materials discussing EOL care should be written in a culturally sensitive manner and provided in the preferred language of the patient and family;\textsuperscript{68} likewise, an effort should be made to find CBPPC providers who are fluent in the preferred language (or, at a minimum, available interpreters to assist the CBPPC clinician) to provide optimal care in the home.\textsuperscript{64,67}

Financial barriers also affect the provision of CBPPC, particularly as they pertain to insurance reimbursement. As mentioned above, the current fee-for-service paradigm is inadequate to subsidize the services needed to provide high-quality care in the community for children with life-threatening conditions and their families. Although physician and advanced practice provider services are billable in the current system, other interdisciplinary CBPPC clinicians are not eligible to bill for services rendered.\textsuperscript{48,55,58,66} In addition, programs caring for children with cancer who receive parenteral nutrition, transfusions, and chemotherapy concurrently with CBPPC or hospice often lack sufficient reimbursement. Despite recent legislative efforts to surmount this barrier (eg, the Concurrent Care for Children [CCC] Requirement of the Patient Protection and Affordable Care Act [ACA]), reimbursement for concurrent life-prolonging therapy with hospice varies across states, and additional insurance regulation is required to ensure universal coverage for all children and families who need these services.\textsuperscript{54,64}

The answer to overcoming each of these barriers involves intensifying efforts to promote CBPPC research, education, funding, and advocacy. A call to action is imperative to improve CBPPC education for all clinicians who provide care to children with cancer and other life-threatening conditions and their families. Ongoing advocacy efforts are likewise essential to spotlight CBPPC as a key feature of the national public health agenda to obtain the requisite political and fiscal support to adequately fund these vital programs and make CBPPC services accessible to all eligible children and families.

**Pediatric Concurrent Care: CBPPC and the ACA**

One of the largest barriers to the successful implementation of early PPC is the erroneous dichotomy that consigns PPC and cancer-directed therapy to diametrically opposed ends of the care spectrum.\textsuperscript{3} This myth has various roots dating back to US legislation from 1982, in which Medicare hospice regulations mandated a choice between continuation of disease-directed therapy or hospice-based services. In this paradigm, choosing one option automatically precluded the other, effectively forcing patients, families, and clinicians to view PPC and curative/life-prolonging therapy as competing entities. Despite the fact that PPC best serves patients when it travels in parallel with disease-directed treatment, this legislation ironically relegated PPC to “last resort” status—the “do nothing” option suspended in stark opposition to the “do everything” mantra of curative/life-prolonging therapy.\textsuperscript{69}

Fortunately, the face of PPC has gradually evolved over the past decade, with more clinicians recognizing the value of using synergistic curative/life-prolonging and palliative care strategies throughout the illness trajectory. In 2003, the IOM published a report advocating for the inclusion of comprehensive PPC models in both public and private insurance reimbursement plans.\textsuperscript{2} The US Congress subsequently supported this recommendation with enactment of the CCC provision of the ACA in 2010. Specifically, the CCC states that patients younger than age 21 years are legally eligible to receive hospice services while still undergoing curative/life-prolonging therapy.\textsuperscript{70} This provision clearly aims to revise the misleading “all or nothing” dichotomy that has stigmatized PPC as a threat to disease-directed treatment.\textsuperscript{71} As such, this legislation has the potential to significantly alter how clinicians perceive and practice CBPPC alongside cancer-directed treatment (Table 7).

The CCC contains several limitations, however, the most notable of which is the requirement that a child who is under the auspices of Medicaid or the State Children’s Health Insurance Program must have a life-threatening illness with documentation of anticipated death within 6 months to qualify for hospice enrollment concurrent with curative/life-prolonging services.\textsuperscript{70} For these eligible children and their families, hospice services depend on individual clinician prognostication, yet few guidelines exist to direct the pediatric oncologist toward accurate predictions regarding EOL trajectory.

Importantly, the lack of a 6-month prognosis does not preclude early CBPPC involvement, because this legal parameter of the CCC refers exclusively to those patients who seek hospice resources. A patient like John would benefit from timely integration of CBPPC many months (or even years) before his need for hospice involvement, and his use of concurrent cancer-directed therapy and CBPPC would be espoused by the spirit of the CCC. As John’s disease progressed and his home-based needs grew, he also would have benefited from earlier introduction to hospice services given his medically fragile condition and high risk for foreshortened lifespan. Pediatric oncologists often have difficulty accurately predicting the timing of death for
The movement to embrace CBPPC originated in the national legislature, much of the momentum has been shouldered by individual states working to institutionalize and integrate CBPPC principles into the medical-legal vernacular. Embedded within the Social Security Act, the home and community-based service program became a formal Medicaid state plan option in 2005, empowering states to provide home-based medical services to patients as an alternative to hospitalization. Colloquially referred to as “wrap-around services,” these programs brought specialized nurses, case workers, respite care, and expanded Medicaid eligibility to children and families in the community, effectively creating holistic medical homes within patients’ home environments.74

As individual states work to build CBPPC models that incorporate the tenets of the CCC, strategies have emerged to expand basic hospice services and broaden eligibility to include children with a life expectancy greater than 6 months. These approaches, however, remain at the discretion of each state’s legislature and require approval by the Centers for Medicare and Medicaid Services. If a state wishes to expand services and eligibility, a minimum of two principal steps are required: 1) formulation of a state-specific plan amendment, and 2) filing of a Medicaid waiver. More information on this topic, as well as other information pertinent to the CCC, is available at the Mary J. Labyak Institute for Innovation at the National Center for Care at the EOL (nhpco.org/sites/default/files/public/ChiPPS/Continuum_Briefing.pdf; accessed April 12, 2015).

### Successful State-Specific CBPPC Models

In 2005, Florida became the first state to develop and implement an innovative model of PPC with the creation of “Partners in Care: Together for Kids.” This unique program mandated home-based and community-based services to children and families at the time of diagnosis of a life-threatening disease, throughout the illness trajectory, and into the bereavement period.48 In this model, state-employed care coordinators identify and enroll eligible children, and a separate hospice team provides CBPPC in the home. Concurrent curative/life-prolonging and PPC therapies are subsidized through a Medicaid waiver, bypassing a life-expectancy requirement that might preclude early integration of CBPPC.76 Response to this model has been positive thus far, with parents reporting high levels of satisfaction with the CBPPC services rendered.48

Following in Florida’s footsteps, California created Partners for Children, a CBPPC program that offers services to children with life-threatening illness irrespective of life expectancy. This model operates under the auspices of a Medicaid waiver with support from the Nick Snow Hospice and Palliative Care Act (named after a cancer patient-

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**TABLE 7. Key Points From the Concurrent Care for Children Provision**

| ENACTED ON MARCH 23, 2010, IN SECTION 2302 OF THE PATIENT PROTECTION AND AFFORDABLE CARE ACT |
| --- |
| • Mandates that children enrolled in either state Medicaid or Children’s Health Insurance Programs may receive concurrent curative/life-prolonging treatment and hospice care |
| • Does not expand services for children with life-threatening conditions who are expected to live more than 6 months (it specifically refers to concurrent curative/life-prolonging treatment and hospice services, as opposed to concurrent curative/life-prolonging treatment and PPC) |
| • Allows pediatric patients with life expectancies of 6 months or less (eg, hospice-eligible) to continue receiving disease-directed therapy while transitioning to care that focuses more on comfort and QOL, thereby allowing for a smoother evolution of care |
| • Patients may continue to receive disease-directed treatment (eg, chemotherapy or hemodialysis) while concurrently benefiting from hospice services |
| • Applies only to patients younger than 21 years |

PPC, pediatric palliative care; QOL, quality of life. *Modified from 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.*70
turned—advocate who was frustrated by the loss of hospice services when he chose to pursue disease-directed therapy), which asserts that PPC/CBPPC concurrent with curative/life-prolonging therapy allows for an optimal continuum of care throughout the illness experience. 75,76

Colorado and Illinois use analogous waivers and reimbursement mechanisms to subsidize their CBPPC programs. 75 Interestingly, New York and North Carolina offer similar models, yet they have expanded CBPPC services to include “medically fragile” (eg, physically disabled) children in an effort to preclude the need for prolonged hospitalizations or chronic confinement in skilled nursing facilities.75

In comparison, Washington State’s CBPPC model uses a combination of Medicaid programs, private payers, and collaboration with local hospice and home care agencies.76 This model allows for early integration of CBPPC with curative/life-prolonging therapy, offering up to 6 home-based PPC visits per month to children at any point on their illness trajectory.75

CBPPC in Massachusetts differs from the above models in that it is exclusively state funded. The Massachusetts Health Care Reform Act of 2006 included appropriation of $800,000 to support the education of PPC clinicians and the design and implementation of effective CBPPC via the Pediatric Palliative Care Network (PPCN). The PPCN partners with regional hospice organizations to provide CBPPC to children with life-threatening illness, of which approximately 33% have cancer; services provided include pain and symptom management via pharmacotherapy and complementary therapy, care coordination, psychosocial support, volunteer and respite resources, and bereavement support.77

Similar to the PPCN, the Children’s Hospital of Philadelphia Pediatric Advanced Care Team (CHOP PACT) collaborates with external programs to facilitate community-based PPC. Specifically, they work with Partners in Pediatric Palliative Care, a program that coordinates home-based PPC services involving a wide range of hospice and home care agencies across 5 states, using outpatient resources in synergy with services available at the academic tertiary-care hospital to provide optimal continuity of care. In a retrospective review of the CHOP PACT experience, of the 142 children who died during a 2-year span, 50% were engaged in hospice; among those with home-based hospice services, 78% died at home.38 Although not stratified by cancer diagnosis, these data suggest that CBPPC programs affect the care of children who die at home. The hospital-based QOL team facilitates continuity of care by following enrolled patients and families in an outpatient QOL clinic within the hospital. This team also coordinates CBPPC by enrolling locally based patients in a home-based PPC and hospice bridge program known as Quality of Life for All Kids (QOLA Kids). The QOLA Kids program is a collaborative effort encompassing the St. Jude Children’s Research Hospital QOL team, Le Bonheur Children’s Hospital, and Methodist Community Hospice, and patients are enrolled on either the hospice or palliative arm of the program, depending on their individual needs. CBPPC services and resources are analogous in both the hospice and palliative arms. Home-based services include the following components: hospice, home health, infusions, durable medical equipment, rehabilitation (eg, physical, occupational, and speech therapy), physician and/or nurse practitioner home visits, and laboratory monitoring. For local patients with poor prognoses who receive early referrals to PPC and have a projected life expectancy of greater than 6 months, QOLA Kids provides interdisciplinary CBPPC that is not limited by time or illness. In the context of children who live outside of the catchment area of QOLA Kids, the QOL team coordinates local CBPPC resources by partnering with external home health agencies and hospices.

Akron Children’s Hospital’s Palette of Care (POC) Team is composed of physicians, nurse practitioners, nurse case managers, social workers, a bereavement specialist, a dietitian, expressive therapists, a massage therapist, a chaplain, a psychologist, rehabilitation therapists, home care liaison personnel, and volunteers. Patients are seen in the hospital, in a palliative care clinic, in affiliated hospital clinics, at primary care offices, at long-term care or other facilities, and at home. CBPPC is provided on a continuum with hospital-based PPC, and all members of the team are available as needed in the community to assist with medical management, informed decision making, EOL planning, emotional support, and coordination with school, insurance companies, and durable medical equipment providers. Care is coordinated with patients’ primary care and subspecialty providers. Because the program spans a large geographic area (47 of Ohio’s 88 counties, with no mileage or distance restriction) and offers coverage 24 hours a day, 7 days a week, the POC works collaboratively with several regional hospice programs and long-term care facilities to provide support that is above the capacity of the team’s core personnel. Patients who meet hospice eligibility criteria are enrolled in local programs; the POC Team retains medical management of enrolled patients and makes joint visits with hospice and home care staff (and pediatric oncology clinicians coordinating holistic patient-centered and family-centered services concurrently with cancer-directed therapies managed by the primary oncology team. The hospital-based QOL team facilitates continuity of care by following enrolled patients and families in an outpatient QOL clinic within the hospital. This team also coordinates CBPPC by enrolling locally based patients in a home-based PPC and hospice bridge program known as Quality of Life for All Kids (QOLA Kids). The QOLA Kids program is a collaborative effort encompassing the St. Jude Children’s Research Hospital QOL team, Le Bonheur Children’s Hospital, and Methodist Community Hospice, and patients are enrolled on either the hospice or palliative arm of the program, depending on their individual needs. CBPPC services and resources are analogous in both the hospice and palliative arms. Home-based services include the following components: hospice, home health, infusions, durable medical equipment, rehabilitation (eg, physical, occupational, and speech therapy), physician and/or nurse practitioner home visits, and laboratory monitoring. For local patients with poor prognoses who receive early referrals to PPC and have a projected life expectancy of greater than 6 months, QOLA Kids provides interdisciplinary CBPPC that is not limited by time or illness. In the context of children who live outside of the catchment area of QOLA Kids, the QOL team coordinates local CBPPC resources by partnering with external home health agencies and hospices.
staff in cases of enrolled children with cancer) to enhance comfort and collaborative decision making.

Quality and Standards for CBPPC

Table 5 describes several key features intrinsic to the delivery of holistic CBPPC, offering a broad overview of the infrastructure needed to create an effective community-based program. The structure of CBPPC programs varies based on the geographic, demographic, and legislative factors unique to each region. However, universal standards for the provision of CBPPC are nationally mandated to ensure consistent, high-quality care.

The Center to Advance Palliative Care created standards for the development of hospital-based palliative care programs, including 22 recommendations stratified by “must-have” and “should-have” features. Although these metrics are designed with inpatient PPC in mind, they may offer a starting place for the development of CBPPC programs. The Center to Advance Palliative Care also sponsors the Improving Outpatient Palliative Care project, which offers online resources to teach clinicians how to begin an outpatient palliative care clinic or home-based program (capc.org/ipal/ipal-op; accessed April 12, 2015). In addition, the Joint Commission specifies criteria for palliative care that pertain to inpatient PPC but may still be useful in the construction of CBPPC programs. For further details about eligibility for advanced certification in PPC, please refer to the Joint Commission website (jointcommission.org/certification/eligibility_palliative_care.aspx; accessed April 12, 2015).

The National Hospice and Palliative Care Organization (NHPCO) also offers excellent resources to help guide the development of CBPPC programs. In 2006, NHPCO advocated for “10 components of quality in hospice care” to serve as a template in designing an optimal CBPPC program. More specific information can be found in the NHPCO’s Standards for Pediatric & Hospice Care: Advancing Care for America’s Children, a resource easily downloaded from the NHPCO website (nhpc.org/quality/nhpcos-standards-pediatric-care; accessed April 12, 2015).

The Children’s Project on Palliative/Hospice Services has developed additional standards predicated on the NHPCO’s 10 components of quality care but modified specifically for pediatric patients. This detailed report may also be helpful to newly developing CBPPC programs, and it is available on the NHPCO website (nhpc.org/quality/nhpcos-standards-pediatric-palliative-and-hospice-care; accessed April 12, 2015).

The National Quality Forum, an organization with the mission of advancing the quality of health care, published A Framework for Preferred Practices for Palliative and Hospice Care Quality: A Consensus Report, in which they highlighted 38 practices associated with quality palliative care. This publication may be downloaded from the National Quality Forum website (qualityforum.org/publications/2006/12/A_National_Framework_and_Preferred_Practices_for_Palliative_and_Hospice_Care_Quality.aspx; accessed April 12, 2015).

Reimbursement for CBPPC

Concurrent PPC services in any setting can be reimbursed both on an individual level (eg, for clinicians) and on an infrastructure level (eg, for hospitals, clinics, or outpatient programs). CBPPC programs that operate separately from the financial auspices of hospice organizations require distinct billing mechanisms. Both outpatient clinic and CBPPC services may be billed with the use of appropriate coding, and it is critical to the growing success of the field that correct reimbursement procedures be practiced consistently (for additional information about billing, please refer to capc.org; accessed April 12, 2015).

Hospice programs are reimbursed by a per diem model, receiving payment for each enrolled patient to cover the expenses associated with daily care, including nursing, psychosocial, chaplain, and volunteer services, as well as the provision of durable medical equipment and pharmacotherapy (for specific information on hospice billing, please refer to nhpc.org/search/node/billing; accessed April 12, 2015).

One of the major barriers preventing widespread availability of PPC/CBPPC infrastructure is the lack of financial sustainability of this care model in today’s health care reimbursement market. CBPPC teams need to be creative in their partnerships, networking, and procurement of community resources (including local grants and state funding programs, such as Title V reimbursement for certain components of care, as well as philanthropy) to offer in-depth services. In states where waivers or specialized PPC benefits do not exist, program income depends on billable services generated from members of the team who can bill and from sources like tele-health and bundled payments that may be negotiable with larger payers in the local market. In the current era, which emphasizes less fee-for-service and more accountable-care models (eg, value-based purchasing, shared savings, risk contracting, or payments based on quality metrics), CBPPC offers an opportunity to provide clinically and fiscally advantageous care for children with life-threatening conditions.

As stated by the IOM in their recent review Dying in America, typically Medicare fee-for-service incentives result in more use of services (eg, hospital days, intensive care, emergency care), more transitions between care settings, and later enrollment in hospice, all of which can jeopardize the quality of EOL care and add to its costs. In addition, the IOM indicated that payment silos contribute to the fragmentation of care, hinder coordination across providers, and encourage the inappropriate use of resources.
According to the IOM’s formal recommendations, larger scale implementation of CBPPC programs is mandatory to improve patient outcomes and reduce health care costs, and incentives must be embedded within the health care system to prioritize the provision of comprehensive CBPPC. We advocate for an ideal CBPPC model rooted in the philosophy of preventive medicine, with proactive, early integration of CBPPC as a core tenet of the field. In the current market, this care model is not yet fiscally advantageous; however, with the advent of population health and value-based care, profitability can be a reality. For example, payers may incentivize institutions to prioritize CBPPC to avoid mortality in the hospital, lower the risk of hospital-acquired infections or complications, improve person-centered and/or family centered care and satisfaction, or encourage throughput.

Ultimately, as the future of medicine moves away from fee-for-service reimbursement, we believe that CBPPC will serve as a paradigm for the effective provision of subspecialist care. As a field, CBPPC intrinsically encompasses the triple aim championed by the Institute for Health Care Improvement (ie, improve care, improve health, and reduce per capita costs); and as such, the PPC community is well positioned to play a pivotal role in the construction of innovative health care models with the goal of providing comprehensive, compassionate, and cost-effective care.

Conclusion

Over the past decade, tenacious advocacy and educational efforts have chipped away at barriers to CBPPC provision, enabling more children with cancer and other life-threatening conditions to receive high-quality PPC in their homes and communities. Although significant work remains to be done, the CBPPC movement continues to gain momentum, and rapid growth is projected to continue over the next decade. Ultimately, the development, promotion, and long-term sustainability of CBPPC programs rely on support and collaboration from medical, political, and financial arenas to champion the need for improved access to CBPPC services.

Early integration of CBPPC in the care of children with cancer improves symptom management, EOL care, QOL, psychosocial well being, and caregiver burden. It is likely only a matter of time before it is established that CBPPC extends not only quality but length of life as well, as has been demonstrated in adults with life-threatening cancer diagnoses who received early palliative care. For these reasons, ubiquitous endorsement and enactment of CBPPC principles and programs is not merely a judicious and compassionate practice: we believe it is also a medical and ethical mandate, and we thereby propose a call to action that encompasses medical, legal, and political stakeholders to promote CBPPC on the national agenda with the ultimate goal of providing optimal care to children with cancer and other life-threatening conditions and their families.

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