Integration of Palliative Care Practices into the Ongoing Care of Children with Cancer: Individualized Care Planning and Coordination

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To cure sometimes, to relieve often, to comfort always – this is our work.
—Author unknown

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Suffering is nearly universal in pediatric cancer patients and their families. Addressing this suffering is an ethical imperative. High-quality palliative care is now an expected standard during the treatment of children with life-threatening illnesses. An American Academy of Pediatrics policy statement recommends that “all general and subspecialty pediatricians, family physicians, pain specialists, and pediatric surgeons need to become familiar and comfortable with the provision of palliative care to children” [1]. The goal of palliative care is the best quality of life for patients and their families that is consistent with their values and priorities. Pediatric palliative medicine may be further defined as “the art and science of patient- and family-centered care aimed at enhancing quality of life, promoting healing and attending to suffering” [2]. Inherent in these definitions is the need to integrate quality palliative care into the mainstream of medical treatment of all children suffering from chronic, life-threatening, and life-limiting illnesses, regardless of the curative intent of therapy.

**Improving the quality of palliative and end-of-life care through individualized care planning and coordination**

Most parents of children with cancer have dual primary goals: a primary cancer-directed goal of cure and a primary comfort-related goal of lessening suffering [3]. Early introduction of palliative care principles and practices into their child’s treatment is respectful and supportive of these goals. The individualized care planning and coordination (ICPC) model (Fig. 1) is designed to facilitate this integration [4]. Individualized care planning emphasizes the value of subjective experiences in the context of meaningful personal relationships and uses a patient- and family-centered approach to information delivery, needs assessment, and understanding of the patient’s and family’s illness experience. It aims to enhance communication about difficult issues by discerning patient and family values and priorities before critical decision points are reached. Application of the ICPC model helps patients, families, and their clinicians negotiate care options in the presence of uncertainty by assessing the patient’s and family’s understanding of prognosis, elucidating their goals of care, and allowing them to choose from available goal-directed treatment alternatives. A comprehensive, individualized care plan that balances medical and personal goals, based on the relationship that has been established and the treatment options chosen, can then be generated.

Individualized care coordination, the process of implementing the individualized care plan, is detailed here. The authors’ purpose is to address specific clinical gaps in the care of children with cancer. They highlight the deficiencies in the current provision of care, identify the national standards of care, recommend specific processes that should be integrated into pediatric oncology to fulfill the national standards, and identify research and education needs. The specific individualized care coordination processes that are the subject of palliative and end-of-life care quality improvement efforts
Fig. 1. The ICPC model is designed to facilitate the integration of palliative care principles and practices into the ongoing care of children with cancer. The individualized care plan is implemented through individualized care coordination.
and are discussed here include advance care planning; ethics consultation; care coordination; care continuity; symptom control; emotional, social, and spiritual care; end-of-life care; and bereavement care.

The further integration of palliative care into pediatric oncology practice can harness the inherent “healer” nature of cancer clinicians to enhance the quality of patients’ and families’ lives. Clinicians’ strong desire to provide compassionate, competent, and quality care to the seriously ill child and the child’s family can be effectively translated into clinical practice through individualized care planning and individualized care coordination processes, allowing the primary care team as a unit and the health care system as a whole to address their specific palliative and end-of-life care needs. The National Quality Forum, the Institute of Medicine, and the National Institutes of Health have identified palliative and end-of-life care as national priorities and have proposed that palliative care be a key component of high-quality medical care for children with advanced illness. The National Quality Forum has outlined preferred practices for ensuring the provision of high-quality palliative care. These practices are integrated into pediatric oncology programs at present with varying degrees of adequacy, but application of the individualized care coordination processes is likely to fill many of the gaps (Box 1). Obtaining reimbursement for these processes is currently difficult, but codes to facilitate billing can be found in Tables 2 and 3.

Attention to the relational aspects of the ICPC model is of utmost importance because parents’ perceptions of the quality of care emphasize caring and communication themselves more than any specific interventions or biomedical parameters [5,6]. These care processes must be evaluated in regards to the impact on the quality of palliative care delivered (eg, quality indicators for comfort care, interdisciplinary collaboration, enhanced health care provider communication, care of the imminently dying child, and so forth), and on patient and family outcomes (eg, coping, family cohesion, satisfaction with care, improved symptom control, greater patient and family participation in decision making, optimal physical and psychosocial functioning, optimal quality of life for patient and family, or uncomplicated bereavement) [7].

To improve palliative care competence and improve quality, several approaches have been used to reduce the palliative care educational gap [8]. Important needs include curricula to “educate the educators” and faculty guidelines for teaching palliative medicine at the bedside and during rounds; both must be supported by standardization of didactic learning opportunities [9]. Several tools are now available, including education in palliative and end-of-life care (EPEC), end-of-life nursing education curriculum (ELNEC), and initiative for pediatric palliative care (IPPC). However, none of these curricula have been assessed for improvement of the quality of care. Another example is the Harvard Medical School program in palliative care education and practice curriculum for palliative care faculty, which integrates clinical content with educational methods to enhance the clinical faculty’s capacity to model and
Although these interventions have not yet been linked to quality improvement outcomes, any effort to improve the quality of palliative and end-of-life care in pediatric oncology must be accompanied by an educational strategy to enhance the level of competence among health care providers with regard to palliative and end-of-life care skills and understanding of individualized care planning and individualized care coordination processes [11].

**Advance care planning**

Decision making is a challenge for everyone involved in the care of pediatric cancer patients. Parents surveyed 6 months to 2 years after their child died of cancer reported few opportunities to participate in treatment decisions until near the end of their child’s life. The four most common difficult decisions they identified were whether to pursue more chemotherapy or to discontinue disease-directed treatment; whether to choose a phase I therapy versus no cancer treatment; whether to maintain or withdraw life support; and whether to adopt a “do not resuscitate” (DNR) order [12]. Like adult cancer patients, pediatric cancer patients and their parents identify hope for a cure or for longer survival as a major factor in the decision to receive phase I chemotherapy versus comfort care only [13–18]. Not only are each of these decisions emotionally laden, but the ways in which they are approached by patients, families, and care providers often differ.

Evidence suggests that avoiding or delaying discussions about end-of-life decisions may influence the type and quality of care. A survey of bereaved parents and their child’s former physician showed that when both the parent and the physician recognized that no realistic chance existed for cure 50 days or more before the child’s death, there was a statistically significantly earlier discussion of hospice care, better parental ratings of the quality of care delivered by the home care team, earlier institution of a DNR order, and less cancer-directed treatment during the last month of life [3]. The advance care planning process can facilitate end-of-life care decisions by improving parents’ emotional support, quality of information, and medical understanding, and by enhancing the listening skills and sensitivity of health care providers [19,20]. Further, as stated earlier, parents value communication and relationships over biomedical measures of success [5]. Therefore, the advance care planning process supports what parents value and is likely to enhance satisfaction by addressing parents’ perceptions of good quality.

An environment conducive to optimal advance care planning enhances decision making. As described by the American Society of Clinical Oncology, communication should be “both family centered and child focused” [21]. Optimally, end-of-life decisions should flow naturally from an ongoing conversation among the patient, family, and medical care team about care priorities. Essential to this process is a trusting relationship established through individualized care planning in which information can be shared nonjudgmentally [4,21]. Parents value emotional expression and support
Box 1. Preferred practices for quality palliative and hospice care categorized by individualized care coordination processes

**General**
- Provide palliative and hospice care by an interdisciplinary team of skilled palliative care professionals.
- Provide access to palliative and hospice care that is responsive to the patient and family 24 hours a day, 7 days a week.

**Education**
- Provide continuing education to all health care professionals on the domains of palliative care and hospice care.
- Provide adequate training support to ensure that health care providers are competent in palliative care.
- Ensure that hospice care and specialized palliative care professionals are appropriately trained, credentialed, or certified in their area of expertise.

**Advance care planning**
- Formulate, use, and regularly review a timely care plan based on a comprehensive, interdisciplinary assessment of the values, preferences, goals, and needs of the patient and family.
- Present hospice as an option to all patients and families when death within a year would not be surprising; reintroduce the hospice option as the patient declines.
- Assess physicians’ or health care professionals’ ability to discuss hospice as an option.
- Enable patients to make informed decisions about their care by educating them on the process of their disease, prognosis, and the benefits and burdens of potential interventions.
- Determine the primary decision maker or makers within the family unit. If the child is able to participate, determine the degree of his or her participation.
- Document the designated surrogate or decision maker in accordance with state law for every patient in primary, acute, and long-term care and in palliative and hospice care.
- Document the patient’s, parent’s, and surrogate’s preferences for goals of care, treatment options, and setting of care at first assessment and at frequent intervals as conditions change.
- Convert the patient treatment goals into medical orders such as the Physician Orders for Life-Sustaining Treatment (POLST).
- Document advance directives and surrogacy designations.
- For minors with decision-making capacity, document the child’s views and preferences for medical care, including assent for treatment, and give them appropriate weight in decision making.
- Make appropriate professional staff members available to the child and the adult decision maker for consultation and intervention when the child’s wishes differ from those of the adult decision maker.

**Ethics consultation**
- Establish or have access to ethics committees or ethics consultation across care settings to address ethical conflicts at the end of life.

**Care coordination**
- Provide education and support to families and unlicensed caregivers, based on the patient’s individualized care plan, to ensure safe and appropriate care for the patient.
- Conduct and document regular patient and family care conferences with physicians and other appropriate members of the interdisciplinary team to provide information; to discuss goals of care, disease prognosis, and advance care planning; and to offer support.

**Care continuity**
- To the extent that existing privacy laws permit, ensure that the plan is broadly disseminated internally and externally to all professionals involved in the patient’s care.
- Ensure that medical orders such as the POLST are transferable and applicable across care settings, including long-term care, emergency medical services, and hospital care.
- Make advance directives and surrogacy designations available across care settings, while protecting patient privacy and adherence to Health Insurant Portability and Accountability Act regulations (eg, by using Internet-based registries or electronic personal health records).
- Ensure that, on transfer between health care settings, communication of the patient’s goals, preferences, values, and clinical information is timely and thorough, so that continuity of care and seamless follow-up are assured.
• Develop health care and community collaborations to promote advance care planning and the completion of advance directives for all individuals (eg, the Respecting Choices and Community Conversations on Compassionate Care programs).

**Symptom control**
• Measure and document pain, dyspnea, constipation, and other symptoms using available standardized scales.
• Assess and manage symptoms and side effects in a timely, safe, and effective manner to a level that is acceptable to the patient and family.
• Measure and document anxiety, depression, delirium, behavioral disturbances, and other common psychologic symptoms using available standardized scales.
• Manage anxiety, depression, delirium, behavioral disturbances, and other common psychologic symptoms in a timely, safe, and effective manner to a level that is acceptable to the patient and family.

**Emotional, social, and spiritual care**
• Assess and manage the psychologic reactions of patients and families (including stress, anticipatory grief, and coping) in a regular, ongoing fashion to address emotional and functional impairment and loss.
• Develop and implement a comprehensive social care plan that addresses the social, practical, and legal needs of the patient and caregivers, including, but not limited to, relationships, communication, existing social and cultural networks, decision making, work and school settings, finances, sexuality/intimacy, caregiver availability/stress, and access to medicines and equipment.
• Develop and document a plan based on an assessment of religious, spiritual, and existential concerns using a structured instrument, and integrate the information obtained from the assessment into a comprehensive care plan.
• Include spiritual care professionals who are appropriately trained and certified in palliative care.
• Build partnerships with community clergy and provide education and counseling related to end-of-life care.
• Incorporate cultural assessment, including, but not limited to, locus of decision making; preferences regarding disclosure of information, truth telling, and decision making; dietary preferences; language; family communication; desire for palliative therapies and complementary and alternative medicine; perspectives on death, suffering, and grieving; and funeral and burial rituals.
• Provide professional interpreter services and culturally sensitive materials in the patient’s and family’s preferred language.

**End-of-life care**
• Recognize and document the transition to the active dying phase, and communicate to the patient, family, and staff the expectation of imminent death.
• Educate the family on a timely basis regarding the signs and symptoms of imminent death in an age-appropriate, developmentally appropriate, and culturally appropriate manner.
• As part of the ongoing care planning process, routinely ascertain and document patient and family wishes about the care setting for the site of death, and fulfill patient and family preferences when possible.
• Provide adequate dosage of analgesics and sedatives as appropriate to achieve patient comfort during the active dying phase, and address concerns and fears about using opioids and analgesics hastening death.
• Treat the body after death with respect according to the cultural and religious practices of the family and in accordance with local law.

**Bereavement care**
• Develop and offer a grief and bereavement care plan to provide services to patients and families before, and for at least 13 months after, death of the patient.
• Facilitate effective grieving by implementing, in a timely manner, a bereavement care plan after the patient’s death, when the family becomes the focus of care.

from care providers, and “being supported by staff” was among the factors most frequently identified as influencing their decision making [22]. Also, parents indicate that they prefer to know at the time of diagnosis that their child may not survive and want the treating team to alert them to changes in their child’s clinical status and to available care options [12].

Adults identify a sense of control over decisions as an element of quality end-of-life care, and patient involvement in decision making is key [21,23–27]. Less clear is how and at what age pediatric patients should participate in end-of-life decisions. Engaging the child recognizes his or her stake in the decisions being made and respects his or her capacity for informed decision making. Eighty-nine percent of parents of childhood cancer survivors reported that they would allow a child as young as 4 to be involved in a decision to pursue experimental chemotherapy [28]. Also, in a study of end-of-life care preferences, children as young as 10 recognized that they were involved in an end-of-life decision, understood its consequences, and demonstrated the capacity to weigh complex issues, including potential risks to themselves and others [29]. Parents of children with cancer also identify “making decisions with my child” as a major factor in their own decision making [12]. Parents, surrogates, and health care providers must recognize the subjective nature of suffering and must respect the child’s autonomy and capacity to make decisions, particularly if the patient is an emancipated or mature minor [30]. If possible and indicated, caregivers should invite children to participate in decisions about their own care and honor their wishes, recognizing the personal context in which the illness unfolds [26]. Recognition of the unique contributions of the parents and the child to the discussion and integration of their input into the decision process ensures a truly family-centered approach to care.

As a facilitator of decision making, the clinician must understand the child’s and family’s perspective on the illness and its impact on their lives. Beliefs, values, hopes, and fears shape their perspective and must be understood, to guide them through the process. Patients and families also need clear, accurate information about prognosis to weigh the benefits and burdens of treatment options and prepare to make difficult decisions about their care, particularly at the end of life. However, physicians report providing a frank estimate of survival likelihood only 37% of the time, and discrepancies frequently exit; 70% of discrepant survival estimates were overly optimistic [31]. Despite the evident underdisclosure of prognosis, “information from health care professionals” was the factor most frequently reported by parents of children with cancer to influence their decision making [12].

Effective communication of the prognosis is the foundation for establishing realistic goals of care. Over time, goals may shift as prognosis changes or as the patient’s and family’s priorities change. The goals of medical treatment must be integrated with personal goals to ensure holistic decision making. Neglect of the emotional and social aspects of care goals can lead to medical decisions that increase patient and family suffering.
After care goals are established, treatment options can be weighed in terms of their benefits, burdens, and contribution to achieving the identified goals.

The advance care planning process must be documented in the medical record where it can be easily shared with members of the interdisciplinary care team and across health care settings. The authors have found the four-box method for clinical ethics developed by Jonsen and colleagues [33] to be a particularly useful tool for organizing and documenting the rationale behind the decisions made (see Table 1) [20].

**Ethics consultation**

Generally, clear and open communication throughout the illness trajectory yields a consensus about care. Conflict may occur when the patient or family receives inadequate information about prognosis and treatment options or has limited opportunity to process this information and consider their goals and priorities. In pediatric oncology, some families have unrealistic expectations and, even with the best communication (eg, use of the advance care planning process), demand treatments that are medically inappropriate on the basis of existing standards. In these cases, frequent weighing of the benefits and burdens of medical interventions with the help of a patient advocate and the involvement of an ethics committee is recommended to allow deliberation about medical decisions in a safe atmosphere.

In palliative and end-of-life care, the ethics consultation process should function as the back-up of the advance care planning process, because the primary responsibility for medical care and resolution of ethical problems in patient management lies with the physician, the health care team, the patient, and the patient’s parents, family, or guardian. An ethics committee should be available, particularly at times of conflict, to provide consultation about ethical dilemmas related to patient care, facilitate physician–family–patient communication, and assist in the resolution of complex situations. This process should be confidential and aimed at facilitating communication, conflict resolution, and support of relationships rather than making specific treatment recommendations.

The ethics committee also plays a palliative care role with regard to the development and implementation of care policies that support the decision-making process, enhance symptom control, promote care coordination and continuity, and facilitate care of the child and family throughout the illness trajectory, including bereavement and across multiple care settings.

**Care coordination**

The care coordination process involves interdisciplinary communication and collaboration that link children with special health care needs to the appropriate services and resources throughout the disease trajectory. The
goal is to limit fragmentation of care by orchestrating the delivery of medical services while advocating for comfort and quality of life. Children with cancer, and their families, must navigate an extremely complex modern health care system involving multiple caregivers from various backgrounds and disciplines. Pediatric oncology has long functioned as the model for care planning process.
multidisciplinary care, but, in reality, care is extremely fragmented. Families must become experts in inpatient care, outpatient clinics, and the home health system and, to keep their child’s life as “normal” as possible, they must stay connected with community resources, including school, church, and so forth. This process is complicated by economic and sociocultural barriers, because the multiple systems of care do not have a single point of entry [34,35]. The Institute of Medicine has identified care coordination and care of children with special health care needs as priority areas for quality improvement and has recognized the “medical home” as the optimal venue for care coordination and family-centered care [36,37].

Pediatric oncology programs are considered the medical home for children with cancer. The American Academy of Pediatrics describes the medical home as a means of delivering primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective [34,35]. The goals of the medical home are therefore process-oriented rather than static. They include an integrated plan of care; documentation and database management; sharing of information across disciplines, providers and settings; patient and family education and support; and ongoing evaluation.

Barriers to pediatric oncology programs’ achievement of these goals include the use of resources that do not fall under the umbrella of the medical home; inadequate reimbursement for additional administrative responsibilities, including documentation and counseling; lack of continuity in care across multiple service providers; lack of communication and collaboration between the oncologist and other specialists; lack of communication between the care team and community agencies; undefined roles of the care team and community agencies; time considerations; and cultural and language barriers.

Collaboration has been identified as the central principle of care coordination by the American Academy of Pediatrics [35]. The National Institutes of Health also notes that effective communication among disciplines is a particularly important aspect of palliative care in pediatrics [27,38]. Multiple disciplines are well represented in current clinical settings, but they often provide their services in isolation from one another and with limited communication. Interdisciplinary teams share information, and their work is guided by the individual patient’s needs. The medical home is best served by integrating elements of a transdisciplinary approach into an interdisciplinary framework, in which roles and responsibilities are shared, with few seams between the members’ functions [39]. Although this approach is limited in specialized medical procedures and interventions, it is valuable in the exchange of general planning, and psychosocial and spiritual information.

The interdisciplinary team meeting is at the center of the care coordination process and the promotion of an interdisciplinary and transdisciplinary approach to the patient and family. Although pediatric oncology centers
often meet to discuss patients (eg, tumor board, psychosocial rounds, and so forth), the interdisciplinary team meeting seeks active participation of members from various disciplines to discuss specific patient and family care issues. A summary of these meetings is usually documented as part of a comprehensive care plan. Participation of the patient or family in these meetings may be recommended in some circumstances. Their purpose is to come to a common understanding of the patient’s clinical condition and treatment goals. They are the perfect opportunity to communicate as a team about specific decisions made during the advance care planning process and the important physical, social, emotional, and spiritual aspects of care while enhancing interdisciplinary collaboration to implement a comprehensive care plan for the child and family. For better integration of care coordination into the mainstream of pediatric oncology care, interdisciplinary partnership should be promoted, a transdisciplinary approach should be taken, and interdisciplinary team meetings should be implemented as part of routine care, particularly for patients with poor prognosis or those with advanced cancer.

**Care continuity**

The benefits of early integration of palliative care and the many needs of pediatric oncology patients and their families underscore the importance of a coordinated, interdisciplinary approach that links hospital, home health, and hospice settings [40,41]. An increasing number of children with complex chronic conditions in the United States are dying at home, possibly as the result of shifting attitudes and decisions about palliative and end-of-life care and the greater capacity of the health care system to provide home-based services [42]. The care continuity process allows access to coordinated, high-quality palliative care in which key therapeutic interpersonal relationships are maintained throughout the illness and across various settings, which can help the child and family regain a sense of personal control over their care.

The development of partnerships among pediatric oncology programs and local home health and hospice agencies is a key strategy for enhancing the quality of palliative care throughout the patient’s illness. From a hospital perspective, integration of palliative care principles and practices into the continuum of care (ie, elaboration of a comprehensive care plan) and the creation of bridging programs between cancer center care and services provided in the community would be most beneficial. From a community perspective, pediatric hospice programs that are established within or in partnership with a home health agency and that collaborate with the cancer center would allow a more effective response to the patient’s and family’s needs from the point of diagnosis onward.

Until a national health policy is implemented to compensate providers for individualized care coordination processes including advance care
planning, care coordination, and care continuity, individual pediatric oncology centers and home health and hospice programs must find creative solutions to overcome the many structural, financial, professional, regulatory, institutional, and organizational barriers to these partnerships [43]. Possible strategies include identifying local advocates from various disciplines, teaching interdisciplinary palliative and end-of-life care, providing medical leadership, and establishing a liaison nurse to represent palliative and hospice care within the hospital setting [44]. Integrating the palliative care physician consultant and a hospital-based individualized care coordinator into complex pediatric oncology cases is also useful. The value of interdisciplinary care planning and coordination and the use of patient care conferences to promote communication and collaboration among hospital, home health, and hospice providers cannot be overemphasized [4].

Working toward positive partnerships in the palliative and end-of-life care of pediatric oncology patients through the care continuity process also involves critical evaluation of strengths and weaknesses. Useful principles to guide the evaluation process include acknowledgment of the need for partnership, clarity, and realism of purpose; commitment and ownership; development and maintenance of trust; establishing robust care plan arrangements; and organizational monitoring, review, and learning [45].

**Symptom control**

Few things are more heartrending than the suffering of a young patient ravaged by cancer and its treatment. Timely and skilled management of pain and symptoms is the cornerstone of palliating suffering [46]. Integrating palliative care principles and practices into the mainstream of pediatric oncology programs requires appropriate attention to expected and unexpected symptoms, from the point of diagnosis onward, through a specific symptom control process. The patients themselves have told us that distressing symptoms are highly prevalent and of a high intensity during cancer treatment [47,48]. The pediatric pain literature now clearly demonstrates that “there is no such thing as a little stick” and that the effects of underdiagnosed and undertreated pain and unrelieved procedural pain are long lasting [49,50]. The same may apply to many other symptoms yet to be studied in this manner. Symptom management and attention to the suffering of children experiencing a cancer-related death must be comprehensive [51,52].

Children and adolescents who die of cancer experience many physical symptoms, including pain, fatigue, behavior changes, breathing changes and dyspnea, reduced mobility, nausea and vomiting, anemia and bleeding, loss of appetite, and many others [51–56]. Pain, poor appetite, and fatigue are usually cited as the most common symptoms. Many of these symptoms are widely reported to be untreated or unsuccessfully treated [51,52]. This deficiency is at odds with the main goals of parents, which include both cure or life-prolongation and relief of suffering [3].
These children and their families suffer not only physically but psychologically. Patients are reported to experience sadness, difficulty in discussing their feelings about dying with their parents, and fear of being alone. Parents most frequently experience fear of the child’s death and fear of the child’s physical symptoms [57]. Other psychologic symptoms frequently encountered in pediatric oncology include anxiety, excessive worry, depression, and irritability [52,58].

Effective symptom control is essential to provide high-quality palliative care. However, few instruments for measuring symptoms in children are reliable, valid, and developmentally appropriate, and the symptoms that are most concerning to the child at end of life have not been identified [46]. Appropriate instruments to measure these symptoms and the distress they cause in children dying a cancer-related death should be developed and researched. In children with cancer, the presence, or even the severity, of a symptom may not predict the distress it causes to the dying child, family, and health care providers [47,58]. The authors’ experience suggests the need for a specific symptom control process to provide a more systematic approach to symptom assessment. An interdisciplinary approach is crucial because significant spiritual, emotional, and existential distress is frequently identified.

Conscientious symptom assessment and management must be incorporated into mainstream pediatric oncology in a more systematic way. In fact, distressing symptoms should be treated as a medical emergency and monitored at regular intervals. Although the cancer-related death of a child can frequently be anticipated and the symptomatology is well described, many issues interfere with optimal symptom management at the end of life. The literature suggests that palliative care specialists are consulted mainly for children with unmanageable symptoms or for children in the home setting who have complex symptom management needs. Parents indicate that their dying child’s symptoms at the end of life were better controlled or less problematic when a provider with a specialized level of training in palliative care was available [52,59,60]. Clinicians with expertise in symptom management should be integrated into the primary oncology team to allow an ongoing therapeutic relationship with the child and family and to promote symptom control education.

The National Comprehensive Cancer Network has developed clinical practice guidelines for the management of cancer- and treatment-related emesis, anemia, fatigue, distress, and pediatric pain. These guidelines and other appropriate symptom management techniques should be integrated into pediatric oncology programs so that distressing symptoms are managed from the point of diagnosis onward. Evidence-based symptom control practices should be properly implemented and evaluated, including effective nonpharmacologic approaches (eg, hypnosis, acupuncture, relaxation techniques), and continuity of services across settings should be emphasized. Because clinical care providers for children at the end of life report being unfamiliar or uneasy with identifying and treating symptoms, provider
education about symptom management must be promoted [59,61,62]. In addition, pediatric oncology programs must be better equipped for symptom management in the home setting, where parents often choose to have their child die [63,64].

Emotional, social, and spiritual care

Compassionate, competent, and sensitive care of the seriously ill child and the child’s family requires ongoing, interdisciplinary patient- and family-centered assessment of emotional, social, and spiritual needs. This assessment identifies the values and priorities of the parent or parents and the ill child (when possible) and provides an indicator of the effectiveness of the comprehensive care plan [65–67]. Family culture (values, beliefs, attitudes, and dynamics) defines what a family perceives to be medically appropriate care in different situations [68]. Clinicians collaborate with the child and the family to incorporate their values and priorities into care planning and care goals [4,69]. Ongoing, regular assessment of patient- and family-centered needs allows the family and the clinical care team to formulate jointly a care plan to deal appropriately with the immediate clinical situation and lays the foundation for future collaboration in the formulation of comprehensive care plans [70].

An ongoing emotional, social, and spiritual assessment requires that clinicians listen intensely and respectfully to gain an understanding of the child’s and family’s relationships, preferences, and priorities [71]. Such care priorities may shift rapidly with the child’s clinical condition or treatment options. As a result, clinician assessment of patient and family needs must be an ongoing combination of formal and less formal assessment queries. Informal assessments can be brief (e.g., a single query to revisit care priorities after a clinical change). Formal assessments tend to be documented on care planning forms that become a part of the child’s medical record.

A limited number of instruments are available for the formal assessment of emotional, social, and spiritual needs of the child or family. Clinically useful palliative care instruments (which include emotional, social, and spiritual parameters) are developmentally appropriate for children, brief, and clearly worded; use a limited time frame (such as the past 24 hours or current week) because of the likelihood of rapidly changing conditions; and are sensitive to change. Few comprehensive instruments exist and none has been validated in the pediatric oncology setting at the end of life. More such instruments are needed to prevent underassessment and the undertreatment of suffering in children with cancer and their families [72].

Clinically, it is useful to apply a generalist and a specialist approach to the provision of emotional, social, and spiritual care. Physicians, for example, can aim to be psychosocial generalists and medical specialists, whereas social workers and psychologists can aim to be psychosocial specialists and have a general understanding of disease management and assessment of
physical comfort. As another example, doctors and nurses can assess the broad spiritual concerns of patients and families to refer them to appropriate spiritual advisors, whereas chaplains must take into account the medical issues, plan of care, and prognosis to understand the context of spiritual needs and to anticipate impending spiritual crises. All team members, given training, experience, and motivation, have the capacity to provide a generalist level of social, emotional, and spiritual care [73,74]. It is crucial that these assessments be free of judgment and free of the clinician’s own agenda. Collaborative working relationships, interdisciplinary team meetings, care coordination, and patient care conferences are essential in the emotional, social, and spiritual care of children with cancer and their families.

End-of-life care

The principles and practices of palliative care can best be incorporated into the care of children dying a cancer-related death if specific processes are implemented. Parents report that end-of-life decisions are among the most difficult they face on behalf of their seriously ill child [12]. However, parents also state that they want to be involved in care decisions during their child’s final days and they appreciate the opportunity to do so. They want to be kept informed of changes in the child’s condition and to participate in adjustments to the care plan. The end-of-life care process includes advance care planning that focuses on the preferences of the patient and family, including desired location of death, potential care interventions, and other decisions such as DNR status or withholding or withdrawing artificial life-sustaining therapies. We do not fully understand the parental decision process or what factors influence it. Neither do we know the appropriate age at which children should be included in end-of-life decision making. Study findings indicate that many seriously ill children and adolescents can navigate a complex decision process in which risk is considered [29]. The advanced care planning process should be used to support and understand decision making in the care of the imminently dying child by ascertaining the patient’s and family’s priorities, values, and goals. Patient and family preferences may help to determine referral to hospice care, the desired location of death, plans for funeral arrangements, and DNR status.

The end-of-life care process also includes enhanced care coordination to facilitate an interdisciplinary approach to the patient and family. A coordinated interdisciplinary effort is crucial in working with the child and family near the end of life. As death becomes imminent, many parents notice less interaction with the medical team. Certain members of the care team may become less visible as curative efforts are replaced by comfort measures, but this change is difficult for families to comprehend, and parents report feeling abandoned [75]. These feelings of abandonment may complicate grief issues after the child’s death. A change in caregivers during the last, and often the most intense, days of illness can be stressful for the patient and
family. Maintaining open communication is essential for this reason. Parents report that receiving consistent information from a consistent team is helpful at these times [59]. Team members, however, frequently report not knowing the patient’s current clinical status, what decisions have been made, or the content of discussions between other clinicians and the family. A focus on care coordination, including patient care conferences and interdisciplinary team meetings, is essential to effectively maintain the lines of communication and provide the support needed by patients’ families.

The end-of-life care process includes care of the imminently dying patient and the patient’s family but should be implemented well before death is imminent. Cancer patients near death have symptoms that are often not treated or are treated unsuccessfully, despite parents’ great concern that their child not suffer at the end of life [51–57]. Bereaved parents who report unrelieved pain in their dying child have been found to experience long-term distress [76]. Comprehensive, systematic symptom assessment should be ongoing for all children dying a cancer-related death. Aggressive symptom control is crucial during this time because many patients suffer at the end of life, and their suffering also leads to poor family and caretaker outcomes.

Aside from physical symptoms, psychosocial and spiritual needs are consistently identified as very important to patients and their families [22]. Psychologic concerns are frequently underaddressed but should be managed as aggressively as physical symptoms. Many clinicians are not trained to address the spiritual concerns of patients and families so this aspect of care is also frequently unattended. Clinicians may understand and care about the spiritual and religious needs of the patient and family but may not know how to help [77]. Parents and children, however, state that they feel a connection to a religious or spiritual domain at end of life and belief in a “Greater Being” is very important for parents at the time of end-of-life decision making and care [12,78].

Communication is of utmost importance at all times, but its significance is heightened during the final days and hours of a child’s life. Caregivers find it extremely difficult to shift from the “doing” mode to one in which they are willing to sit and “be” with the patient and family, witnessing the mysteries of suffering and death. Open, honest, thoughtful, and caring communication at this time can provide emotional comfort in a situation filled with uncertainty and fear. Finally, conducting end-of-life debriefing sessions can also help the staff cope with the tragedy of losing a patient who is at the dawn of his or her life.

**Bereavement care**

Although survival rates for pediatric cancer are improving, many patients still die, leaving bereaved families trying to cope. Adults experience a higher intensity of grief after their child’s death than after a spouse’s or parent’s death [79–81]. Support for bereaved families must be a priority in pediatric
oncology because bereaved parents have an elevated risk of psychiatric hospitalization even 5 or more years after their child’s death and have a higher risk of early death and poorer health outcomes [82,83].

The treatment of pediatric cancer places many burdens on families. Children receiving treatment for cancer are often hospitalized far from home for lengthy periods, geographically separating family members and reducing access to social support from friends and extended family. Parents often come to depend on the hospital staff for their psychosocial needs. When a child dies and these services are no longer available, families may feel abandoned by hospital staff [84]. Most families desire some continued contact with members of their child’s care team and report that the contact is meaningful to them [59,75,85,86].

Approximately 45% to 59% of pediatric cancer deaths occur while the child is hospitalized [19,80,87]. Unlike hospice, which has clearly established guidelines for the care of bereaved families, many hospitals do not provide formal bereavement care [88]. The bereavement care process should include an interdisciplinary and appropriately trained team; bereavement follow-up services should be offered for at least 12 months; and family members should be clinically assessed to identify those at risk of complicated grief [40].

A practical approach for providing care for bereaved families begins when the child is first admitted for treatment. The foundation is laid for future relationships during the early stages of the child’s treatment. Using a “hope for the best, plan for the worst” approach enables care teams to help prepare a family for loss, which, in turn, may lower the risk of psychologic disturbance after the death. The goal of integrating bereavement care into the mainstream of the child’s care also suggests the need to develop and implement effective evaluation tools that permit the team to identify families at risk of complicated bereavement. Initial assessments by chaplaincy and social work can alert the team to families whose coping may be less than adaptive. The individuals most at risk are often those most reluctant to seek help; this factor can complicate attempts at intervention [89]. Individuals who lack a good social support network and those with a childhood history of neglect and abuse are at highest risk of complicated bereavement.

The eight warning signs of complicated grief are trouble accepting the death; inability to trust others; excessive bitterness toward the death; uneasiness about moving on with life; detachment from other people to whom the person was previously close; the feeling that life is now meaningless, the view that the future holds no prospect for fulfillment; and agitation since the death. These signs must be persistent and disruptive to the bereaved person, and must have lasted more than 6 months [90]. In addition, family members displaying disbelief, yearning, anger, or depression 6 months after the death of the child may need further evaluation [91].

Thus, to identify and help people who may be suffering from complicated bereavement, the bereavement care process should be programmatic and
must include regular contact between trained staff and family members over an extended period, which requires financial commitment to fund such support. A minimal, hospital-based program for families whose child has died might include the following: the creation of a memento of the child, often a hand print or lock of hair, for the family; attendance at the funeral or memorial service by members of the primary care team, when possible; a personalized condolence card sent by the team and telephone or written contact periodically, especially around the child’s birthday, holidays, and the anniversary of the child’s death [59,92–94]. It is important that parents know they have “permission” to contact team members if they are experiencing problems, and that team members have the appropriate resources to make referrals to services in the parent’s community. Many programs send appropriate books and other literature to families. Some hospitals hold annual events to honor the memory of children who have died and invite families to attend. Although all these efforts attempt to meet the needs of bereaved families, little outcomes-based research exists to support their continued existence and justify their expense. Evidence-based practices should be developed and evaluated to improve interventions for bereaved parents. Expert opinion can be a useful starting point, but only formal assessment and outcomes measures can demonstrate that we are truly helping families and justify the expense of bereavement intervention.

Coding and reimbursement for hospice and palliative care services

Reimbursement practices for many of the care processes described in the ICPC model may be possible using existing coding and reimbursement mechanisms [95]. The process used for billing and reimbursement depends on the role of the provider, the relationship of the health care professional with the agency providing the care, and whether or not the patient is hospitalized or receiving home health or hospice services. Billing and reimbursement processes differ between public and private insurers and across states. In general, claims for services provided by health care professionals are submitted by using the Current Procedural Terminology (CPT) evaluation and management code system [96]. CPT codes may be used by physicians and other health care providers for outpatient and inpatient visits for the advance care planning, care coordination, and symptom control processes, and for other psychosocial care processes. Useful CPT codes for qualified physicians are outlined in Table 2. In addition to CPT codes, physicians may describe the reasons for their services by using one of the International Classification of Disease, Ninth Revision, Clinical Modification (ICD-9-CM) codes produced by the National Center for Health Statistics [97]. When the palliative care consultant is also a pediatric oncologist, claims submitted for palliative care services must have a different diagnosis to minimize the risk of having the claim denied. ICD-9 codes commonly used in palliative care are listed in Table 3.
Table 2
Evaluation and management codes for palliative care

<table>
<thead>
<tr>
<th>Attending/managing physician</th>
<th>Prolonged servicesa</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Office/homeb</td>
</tr>
<tr>
<td>New office</td>
<td></td>
</tr>
<tr>
<td>99201 10 min</td>
<td>99221 30 min</td>
</tr>
<tr>
<td>99202 20 min</td>
<td>99222 50 min</td>
</tr>
<tr>
<td>99203 30 min</td>
<td>99223 70 min</td>
</tr>
<tr>
<td>99204 45 min</td>
<td>99224 80 min</td>
</tr>
<tr>
<td>99205 50 min</td>
<td>99225 90 min</td>
</tr>
<tr>
<td>New home</td>
<td></td>
</tr>
<tr>
<td>99324 20 min</td>
<td>99361 30 min</td>
</tr>
<tr>
<td>99325 30 min</td>
<td>99362 40 min</td>
</tr>
<tr>
<td>99326 45 min</td>
<td>99363 50 min</td>
</tr>
<tr>
<td>99327 60 min</td>
<td>99364 60 min</td>
</tr>
<tr>
<td>99328 75 min</td>
<td>99365 70 min</td>
</tr>
<tr>
<td>Consult physician</td>
<td></td>
</tr>
<tr>
<td>Office/home</td>
<td></td>
</tr>
<tr>
<td>99241 15 min</td>
<td>99231 15 min</td>
</tr>
<tr>
<td>99242 30 min</td>
<td>99232 25 min</td>
</tr>
<tr>
<td>99243 40 min</td>
<td>99233 35 min</td>
</tr>
<tr>
<td>Health and behavior assessment&lt;sup&gt;d&lt;/sup&gt;</td>
<td>Assessment</td>
</tr>
<tr>
<td>----------------------------------------</td>
<td>------------</td>
</tr>
<tr>
<td>96150 15 min</td>
<td>96151 15 min</td>
</tr>
<tr>
<td>Psychiatric therapeutic procedures&lt;sup&gt;e&lt;/sup&gt;</td>
<td>Diagnostic interview</td>
</tr>
<tr>
<td>90801 15 min</td>
<td>90811 1 hour</td>
</tr>
<tr>
<td>Office/home</td>
<td>Inpatient</td>
</tr>
<tr>
<td>90804 20–30 min</td>
<td>90816 20–30 min</td>
</tr>
<tr>
<td>90806 45–50 min</td>
<td>90818 45–50 min</td>
</tr>
<tr>
<td>90808 75–80 min</td>
<td>90821 75–80 min</td>
</tr>
<tr>
<td>Group therapy</td>
<td>Family therapy without patient present</td>
</tr>
<tr>
<td>90853 15 min</td>
<td>90846 15 min</td>
</tr>
</tbody>
</table>

<sup>a</sup> These add-on codes are used if the time spent in counseling or information giving is more than 50% of the visit. Proper documentation is required.

<sup>b</sup> Total time the physician spends face to face with a patient. In pediatrics, some but not all payers recognize time spent face to face with the primary decision maker within the family unit. The time spent on activities related to the visit but not face to face with the patient or family is not to be added to the visit.

<sup>c</sup> Total time the physician spends in the hospital unit, including the time spent in face-to-face contact with the patient and family, chart review, documentation, and care coordination.

<sup>d</sup> Used by qualified mental health providers (ie, physician, clinical psychologist, clinical social worker, nurse practitioner, clinical nurse specialist, or physician assistant) in the absence of psychiatric illness (ie, coping, self-care, poor family cohesion, when they interfere with the care of the patient). Each 15 minutes of visit is claimed as a unit; a 60-minute visit is claimed as four units.

<sup>e</sup> Used by qualified mental health providers (ie, psychiatrist, clinical psychologist) for the treatment of a psychiatric condition (ie, anxiety disorders, depression, individual or family dysfunction during complicated bereavement).

<sup>f</sup> Interactive visit codes are used when the health care professional uses equipment and other resources to provide care (ie, rehabilitation unit).
Table 3
Palliative care diagnoses: *ICD-9* codes and descriptions

<table>
<thead>
<tr>
<th>ICD-9 Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>263.9</td>
<td>Inanition</td>
</tr>
<tr>
<td>286.6</td>
<td>Dyspnea</td>
</tr>
<tr>
<td>298.9</td>
<td>Confusion</td>
</tr>
<tr>
<td>783.0</td>
<td>Anorexia</td>
</tr>
<tr>
<td>300.00</td>
<td>Anxiety state</td>
</tr>
<tr>
<td>300.20</td>
<td>Phobia</td>
</tr>
<tr>
<td>307.9</td>
<td>Agitation</td>
</tr>
<tr>
<td>308.3</td>
<td>Acute reaction to stress</td>
</tr>
<tr>
<td>309.0</td>
<td>Maladjustment, depressed mood</td>
</tr>
<tr>
<td>309.28</td>
<td>Maladjustment, anxiety, depressed mood</td>
</tr>
<tr>
<td>309.83</td>
<td>Maladjustment, withdrawal</td>
</tr>
<tr>
<td>311</td>
<td>Depressive disorder</td>
</tr>
<tr>
<td>313.0</td>
<td>Overanxious disorder</td>
</tr>
<tr>
<td>338.3</td>
<td>Neoplasm-related pain</td>
</tr>
<tr>
<td>459.0</td>
<td>Hemorrhage, unspecified</td>
</tr>
<tr>
<td>527.7</td>
<td>Disturbance of salivary secretion</td>
</tr>
<tr>
<td>528.01</td>
<td>Mucositis due to antineoplastic therapy</td>
</tr>
<tr>
<td>528.09</td>
<td>Stomatitis and mucositis</td>
</tr>
<tr>
<td>558.9</td>
<td>Diarrhea</td>
</tr>
<tr>
<td>564.00</td>
<td>Constipation</td>
</tr>
<tr>
<td>698.9</td>
<td>Unspecified pruritic disorder</td>
</tr>
<tr>
<td>707.00</td>
<td>Decubitus ulcer, unspecified site</td>
</tr>
<tr>
<td>728.85</td>
<td>Spasm of muscle</td>
</tr>
<tr>
<td>780.01</td>
<td>Coma</td>
</tr>
<tr>
<td>780.09</td>
<td>Unconscious state</td>
</tr>
<tr>
<td>780.39</td>
<td>Convulsions</td>
</tr>
<tr>
<td>780.4</td>
<td>Dizziness</td>
</tr>
<tr>
<td>780.52</td>
<td>Insomnia, unspecified</td>
</tr>
<tr>
<td>780.54</td>
<td>Hypersomnia</td>
</tr>
<tr>
<td>780.55</td>
<td>Disrupted 24-h sleep–wake cycle</td>
</tr>
<tr>
<td>780.6</td>
<td>Fever</td>
</tr>
<tr>
<td>780.79</td>
<td>Malaise and fatigue</td>
</tr>
<tr>
<td>780.9</td>
<td>Mental status change</td>
</tr>
<tr>
<td>782.1</td>
<td>Rash</td>
</tr>
<tr>
<td>782.3</td>
<td>Edema</td>
</tr>
<tr>
<td>783.0</td>
<td>Anorexia</td>
</tr>
<tr>
<td>783.1</td>
<td>Abnormal weight gain</td>
</tr>
<tr>
<td>783.21</td>
<td>Loss of weight</td>
</tr>
<tr>
<td>784.0</td>
<td>Headache</td>
</tr>
<tr>
<td>785.1</td>
<td>Palpitations</td>
</tr>
<tr>
<td>786.05</td>
<td>Shortness of breath</td>
</tr>
<tr>
<td>786.2</td>
<td>Cough</td>
</tr>
<tr>
<td>787.01</td>
<td>Nausea with vomiting</td>
</tr>
<tr>
<td>787.02</td>
<td>Nausea alone</td>
</tr>
<tr>
<td>787.03</td>
<td>Vomiting alone</td>
</tr>
<tr>
<td>787.2</td>
<td>Dysphagia</td>
</tr>
<tr>
<td>787.91</td>
<td>Diarrhea</td>
</tr>
<tr>
<td>789.06</td>
<td>Abdominal pain, epigastric</td>
</tr>
<tr>
<td>789.07</td>
<td>Abdominal pain, generalized</td>
</tr>
<tr>
<td>789.09</td>
<td>Abdominal pain, multiple sites</td>
</tr>
<tr>
<td>724.5</td>
<td>Backache, unspecified</td>
</tr>
<tr>
<td>724.1</td>
<td>Pain in thoracic spine</td>
</tr>
<tr>
<td>724.2</td>
<td>Lumbago</td>
</tr>
<tr>
<td>724.5</td>
<td>Pain in limb</td>
</tr>
<tr>
<td>733.90</td>
<td>Pain in bone</td>
</tr>
<tr>
<td>786.50</td>
<td>Chest pain</td>
</tr>
<tr>
<td>719.45</td>
<td>Pain in hip</td>
</tr>
<tr>
<td>729.1</td>
<td>Muscle pain</td>
</tr>
<tr>
<td>724.60</td>
<td>Sacroiliac pain</td>
</tr>
<tr>
<td>784.1</td>
<td>Throat pain</td>
</tr>
<tr>
<td>723.1</td>
<td>Neck pain</td>
</tr>
<tr>
<td>799.3</td>
<td>Debility</td>
</tr>
<tr>
<td>V61.8</td>
<td>Other specified family circumstances</td>
</tr>
<tr>
<td>V62.82</td>
<td>Encounter for bereavement</td>
</tr>
<tr>
<td>V66.7</td>
<td>Encounter for palliative care</td>
</tr>
</tbody>
</table>
Attending physicians caring for hospice patients who are not employed by the hospice may use CPT and ICD-9 codes to submit claims directly to Medicaid. Physicians employed by the hospice agency must submit patient care claims directly to the hospice agency. The hospice agency then submits these claims for reimbursement as part of their claims for the care of the patient. Consulting physicians who are asked to see a hospice patient must also submit their claims to the hospice agency, which then reimburses the consultant directly based on preexisting contractual arrangements.

Under the hospice benefit, the per diem payment to the hospice covers all services provided by nonphysician health care professionals. For patients who are not enrolled in hospice, nonphysician professionals may be able to access fee-for-service reimbursement mechanisms through either Medicaid or private insurers. Useful CPT codes that can be used by nonphysician providers are listed in Table 2. Health and behavior assessment codes may be used by qualified health care professionals for grief assessment and counseling (ie, stress, coping, self-care, family cohesion). Neither evaluation and management codes for child life and spiritual care services nor procedure and service codes for care of bereaved family members of the ill child are available. Health and behavior, and psychiatric therapeutic procedure codes may be used for the evaluation of bereavement or management of pathologic bereavement but claims must be submitted to the insurer of the bereaved family member. Billing and reimbursement for physician and nonphysician providers of palliative care services using these billing and coding mechanisms may not be optimal and payment remains a challenge, particularly for bereavement care and when patients are not enrolled in hospice.

Summary

The goal of pediatric oncology and pediatric palliative care involves curing as many children as possible while actively and effectively addressing suffering. According to the World Health Organization, “palliative care for children is the active total care of the child’s body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease” [98]. An integrated palliative care approach to these children and their families requires that we acknowledge the current gaps in the structure of pediatric oncology programs and develop processes to fill these gaps. Implementation of the ICPC model will help meet these needs and facilitate the further integration of palliative care principles into the care of children with cancer. Through these processes, the therapeutic relationships established in the context of the medical home can best address the suffering of pediatric cancer patients and their families. Patient and family values, preferences, goals, and needs will also be elucidated earlier in
the course of illness so that appropriate goal-directed treatment options can be offered in times of uncertainty and emotional duress.

References


