

Palliative care for children with cancer

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Abstract | Over the past two decades, paediatric palliative care has emerged as both a primary approach and as its own medical subspecialty, the overall aim of which is to ease suffering for children with life-threatening illness and their families through a concurrent model of care. However, most discussions have been focused on the transition to palliative care when no realistic hope for cure exists. We believe that, because the course of cancer is so unpredictable, this idea is misleading. Indeed, palliative care is increasingly being recognized as being about not just how to cope with the process of dying, but also about how to engage in living when faced with a life-threatening illness. This article will examine our current understanding of several areas of palliative care, with the ultimate message that palliative care is simply a novel term for the total care of a child and family, an approach that should be applied consistently and concurrently regardless of disease status. By improving familiarity with palliative care and building relationships with palliative care specialists, the paediatric oncology clinician will ensure that the best care possible for children and families is provided, regardless of outcome.

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Introduction

Over 12,000 children are diagnosed with cancer each year in the USA alone and, despite advances in both treatment and supportive care, more than 2,000 of these children will die of cancer-related causes.¹ At any one time, thousands of children are living with cancer. Evidence suggests that these children experience substantial suffering from physical and emotional symptoms, which, in turn, has a long-term effect on children who survive cancer and their families.² Over the past two decades, paediatric palliative care has emerged as an approach that aims to ease suffering for children and their families coping with any life-threatening illness. This evolving concept of introducing the subspecialty of palliative care as a concurrent model of general oncology care has led to new ideas about how palliative care teams should be organized and operated.^{3–6} In oncology, although palliative care teams will always have a role in challenging cases, promoting palliative care as a model of care routinely provided in combination with standard treatments also means that the oncology team should be comfortable with palliative care concepts and be able to act not only as the primary oncology team, but also as the primary palliative care team. The nature of paediatric oncology; the prognostic uncertainty; the great risks taken with treatment choices; the significant physical and psychosocial suffering; and the widespread effect of cancer on all aspects of the life of the patients and their families requires paediatric oncology clinicians to be familiar with the principles of palliative care. Familiarity and comfort with elements of palliative care also includes the development of solid partnering with specialized

palliative care staff. The relationship between the primary oncology staff and their patients will always be unique; children and their families will almost always look first to their primary team for guidance. By improving familiarity with palliative care and building relationships with its specialists, the paediatric oncology clinician will ensure that the best care possible is provided regardless of outcome.

In this article we will examine our current understanding of several areas of palliative care, with the ultimate message that palliative care is simply a novel term for the total care of a child and family, an approach that should be applied consistently and concurrently regardless of disease status.

Team-based paediatric cancer care

Approximately 80% of children diagnosed with cancer in high-income countries will be cured of their disease.¹ However, although there has been an improved understanding of the risk factors that affect outcome, when it comes to the fate of an individual child with cancer, prognosis is always uncertain.⁷ Experience suggests that the reason parents are typically devastated by the disclosure of the diagnosis of cancer is the primal fear that their child will die; the child's life is threatened, and treatment is typically intensive, long-term and disruptive. Taken together, these factors mandate an intensive interdisciplinary supportive approach to the care of children with cancer and their families throughout the course of the illness and beyond. This is, indeed, the definition of palliative care according to the WHO (Box 1). Palliative care is about helping children, and families make choices consistent with their carefully considered goals of care, a concept central to planning therapy strategically from

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Competing interests

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the moment of diagnosis. Indeed, paediatric oncologists, in weighing treatment toxicity versus benefits of therapy, are already applying principles integral to palliative care, though they may not recognize it as such.

Central to the integration of palliative care in paediatric oncology is the interdisciplinary team, typically composed of physicians, nurses, psychosocial clinicians, and others (including, for example, child-life specialists and chaplains). This team delivers primary palliative care throughout the course of the child's illness. Additionally, for more-complex patient, family, and team needs, the palliative care team—when available—may be invited to care for the child and family.

The composition of the palliative care team may change depending on the setting (inpatient or outpatient) and circumstances. For example, a patient and family's initial need for palliative care may change with time, as more support may be needed at home, or to help with meaningful outpatient activities such as school, hobbies, and seeing friends. Through the course of their illness, many children set survival goals around important upcoming life events such as family trips, graduations, or other social functions.⁸ When prognostic uncertainty is involved, a simple event such as a sibling's birthday or a baseball game may be of great importance for the family.

Often, with a diagnosis of cancer, a patient is confronted with new limitations on their life: foods they cannot eat, sports they cannot play, and events they cannot attend. Palliative care focuses on how to live better, taking into consideration not just new limitations, but what patients' new goals may be and how the medical staff may help facilitate their achievement. Recently developed tools such as the "Voicing my Choices" document are an excellent example of how palliative care concepts such as advanced-care planning may be tailored to the needs of children with cancer to help them and their families define and achieve their goals within the context of life-threatening illness.⁹

Becoming a functional interdisciplinary team can be challenging as individuals who might otherwise function either separately or in a hierarchical fashion must learn to work together, each contributing their own unique skill set. Several principles, outlined by the Canadian Health Services Research Foundation, may be useful in guiding effective teamwork in the face of these challenges.¹⁰ Teams must have a clear sense of purpose; good communication, protocols and procedures; and mechanisms to resolve conflict when it arises. Importantly, patients and their families must be viewed as team members, and should be educated about how the team works and how they themselves can participate.

Developing partnerships with resources outside the hospital setting, such as insurers and home-care agencies, is also an important element of team building.¹¹⁻¹⁴ Should the disease progress, many families choose to spend as much time as possible at home, possibly up to and including death. Most children and families may prefer death at home if possible, and there may even be long-term psychological benefits for family members to home death.^{12,15,16} Early planning allows better

Key points

- Palliative care is the concomitant, complete care of a child and family facing a life-threatening illness, regardless of current disease status
- Prognostic uncertainty, and not likelihood of survival, should determine the need for palliative care
- Palliative care depends on an interdisciplinary team approach
- Exploring goals of care is key to guiding management and decision making
- Primary oncology services should be familiar with, and comfortable when applying, principles of palliative care

Box 1 | WHO definition of palliative care for children

- 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
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited
- It can be provided in tertiary care facilities, in community health centres and even in children's homes

Permission obtained from WHO © WHO <http://www.who.int/cancer/palliative/definition/en/> (2012).

integration of home-care services and ensures that death occurs in the place that is best for the child and family.¹⁵ In addition, in the USA, hospice care remains a largely underused resource, the reasons for which need further exploration.¹⁷ Notably, included in the USA Affordable Care Act, children under the age of 21 years who have been diagnosed with a life-limiting illness and are eligible for Medicaid or the Children's Health Insurance Program can receive all services that are related to the treatment of a child's life-limiting illness. This provision enables these young people to have palliative-care and hospice-care services while receiving other disease-related treatments, which was previously not funded concurrently. The effect of this critical change has yet to be measured, although data from projects in Massachusetts and Florida provide evidence that the impact will be both positive and meaningful.^{18,19}

Communication

Excellent communication is a central tenet of good palliative care. This interaction includes conveying diagnosis and prognosis to the patient and family, as well as ongoing communication regarding treatment choices, expectations, and parental suffering.

Prognosis, diagnosis and treatment options

In paediatric oncology, the challenge of effective communication begins with the very first conversation. Although most parents recall the initial conversation about diagnosis vividly, only slightly more than half of parents feel that they absorbed any meaningful information beyond the diagnosis.^{20,21} Additionally, parental satisfaction with initial disclosure talks varies widely, ranging from about 20% to 97% from study to study.^{21,22} This finding strongly implies that conveying information

Box 2 | Exploring goals of care

The critical element in navigating the decision-making process—and the central tenet of good palliative care—is a careful exploration of goals of care. Understanding goals of care is much more important than defining the intent of cancer-directed therapy. Once goals are delineated, decisions surrounding therapy often fall into place. This convergence is especially true when clinicians apply models of shared decision making, where exploring goals of care along with the patient and family may lead directly into an exploration of how those goals may be best met using the available options. Of course, exploring goals of care is a skill that, like any other medical procedure, must be practiced over time. Using one or more of five key questions may be useful in guiding such exploration. Goals of care must be well delineated to aid in guiding decision-making. Five cardinal questions are critical in exploring a family's goals of care:

- Who is your child (as a person)?
- What is your understanding of your child's illness? What does the illness mean to you and your family?
- In light of your understanding, what is most important regarding your child's care?
- What are your hopes for your child? What are your fears and concerns regarding your child?
- Where do you find support and strength?

is not a simple procedure that can be accomplished in a one-time meeting. Communication surrounding prognosis is particularly challenging in paediatric oncology: every diagnosis of cancer carries with it an element of prognostic uncertainty, the degree of which might change throughout the course of the illness. Because of this complexity, effective communication requires multiple conversations over time, involving the building of trust and exploration of goals of care, issues far beyond a simple conveyance of facts (Box 2). Effective communication surrounding prognosis is critical to enable patients and their families, along with their primary team, to make informed treatment decisions consistent with their goals of care.

Another challenge arising from the moment of diagnosis is determining to what extent children should be involved in conversations and decision making. From about the age of 14 years many children already have an adult-level comprehension of their situation, and there is even evidence that children as young as 3 years old are aware of their prognosis without having been told.^{23,24} However, parents have mixed feelings about including their child in conversations about diagnosis and planning.²⁵ A major factor is the parental desire to protect their child.²⁶ This instinct is not limited to parents: in dealing with adolescent and young adult (AYA) patients, many physicians acknowledge leaving patients out of discussions for the sake of shielding them.²⁷ This impulse only becomes more pronounced with disease progression. One of the great struggles in paediatric oncology—shared equally by parents and clinical staff—is discussing with a child the possibility, or even likelihood, of their death. Significantly, a recent study reported that no parent who spoke to his or her child about death later regretted doing so. By contrast, 27% of parents who did not discuss death with their child did later regret it, and these same parents were at higher risk for long-term morbidities, including depression and anxiety.²⁸ Another notable study suggested that most children with advanced-stage cancer between the ages of 10–20 years demonstrated an understanding

that they were engaging in discussions about end of life, understood the consequences, and were capable of participating in the decision process.²⁴ Interestingly, an important number of children considered the potential effect that their death would have on others, including family, medical staff, and future patients. Taking this level of understanding into account, parents and clinicians should be encouraged to keep children—at least from the AYA age group onwards—informed and involved.

Parental grief

Open communication about prognosis has very concrete consequences. Doctors recognize the lack of a realistic chance of cure about an average of 3 months sooner than parents do.²⁹ The sooner parents come to this realization, the more benefit will be obtained from integrating palliative care into treatment planning, with more attention paid to symptoms and suffering. Closing the gap between medical staff and parental understanding allows for better overall planning and management, whereas lag time translates into a delay in engagement in end-of-life decision making and a loss of valuable time when families could be re-evaluating goals of care. Additionally, parental concordance on judging a child's quality of life is often variable, especially when considering issues such as psychosocial health, emotional frustration, anxiety, and communication.³⁰ These findings highlight the need to include both parents in open, frank communication. An interdisciplinary team may best facilitate such communication because when a psychosocial clinician is involved in conversations about prognosis and treatment decisions, there is greater concordance between physician and parental understanding.²⁹

Parental goals for their child frequently differ at the end of life, which affects the perception and management of patient suffering.³¹ Parental sense of pain and suffering around the time of death directly affects long-term morbidity. Indeed, parents who do not resolve their grief are at significantly increased risk of long-term physical and psychological morbidity, and, for poorly understood reasons, even increased mortality due to both natural and unnatural causes.^{32–36} The risk of parental disagreement surrounding management at the end of life can be reduced by early introduction of the principles of palliative care, providing ample opportunity for family members to work out their differences.³¹ Good communication with medical staff is associated with greater parental sense of symptom control and less long-term parental feelings of guilt.^{33,37} Remarkably, parents who receive news of poor prognosis do not lose hope, and even parents who report being upset by bad news still say they prefer receiving it to having it withheld.³⁸ Studies have also highlighted both a lack of and desire for better long-term follow-up and bereavement counselling, which are both critical in helping parents resolve their grief (Figure 1).³⁵

A family-centred approach

Good palliative care is only possible when the entire family is included in planning approaches to care. The

family-centred approach is especially important when the patient is extremely young, and may not have a voice of his/her own, or when the medical condition—such as a brain tumour causing significant cognitive impairment—precludes participation in discussions. In the case of infants diagnosed with cancer, exploring goals of care and providing support often depends on how the child fits into the family as a larger entity more than on the child as an individual patient.

Understanding the effect of cancer on siblings is challenging, as the evolving literature on siblings is somewhat contradictory.^{39,40} Some studies have suggested a negative effect, such as increased risk of psychological morbidity and psychosocial problems, whereas other studies have even suggested positive effects, such as improved maturity and empathy.^{39,41} Regardless, simply having a sibling diagnosed with cancer, let alone one who dies, is a life-altering event. From the moment of diagnosis the rhythm of daily life and relations at home change. The financial burden and work disruption inherent in caring for a child with cancer affects the entire household.^{42,43}

Effect of new therapies

The emergence of new therapies and salvage regimens presents a particular challenge to the traditional concept of ‘transitioning’ to palliative care. Physicians have cited the absence of effective therapy as the greatest impetus towards transitioning to palliative care; however, defining ‘effective’ therapy is increasingly difficult and subjective. The very definition of palliative chemotherapy remains controversial, although a common suggestion is that palliative chemotherapy is the chemotherapy that is administered without intent to cure, for the purpose of alleviation of symptoms and/or extending life. But at what point does chemotherapy truly become palliative as opposed to therapy with hope for cure? With every instance of disease progression and every change in treatment protocol, prognostic uncertainty grows, with realistic chance for cure getting smaller. Depending on the country, anywhere from 25% to 50% of children with cancer receive chemotherapy in their last month of life.^{2,44,55} It remains unclear from these studies what role (palliative or curative) treatment was meant to have at that point, which is concerning as increased use of chemotherapy at the end of life also correlates with increased symptom burden.⁴⁵ Only a few studies have looked at how parents make choices about experimental therapies, and these studies agree that although parents try to do ‘what is right’, the dynamics of this dilemma are complex.^{46,47} There is also relatively little information on the use of palliative chemotherapy in paediatric cancer. Some parents feel so strongly about continued cancer-directed therapy and the importance of hope for cure that they would give chemotherapy even if it led to a reduction both in quality of life and in survival time and, sometimes, against the clear recommendations of the medical team to not pursue such therapy.^{48,49} Nevertheless, at a certain point, quality of life does become a major factor in guiding parental decision making at end of life, and parents become influenced by both hope for quality of life

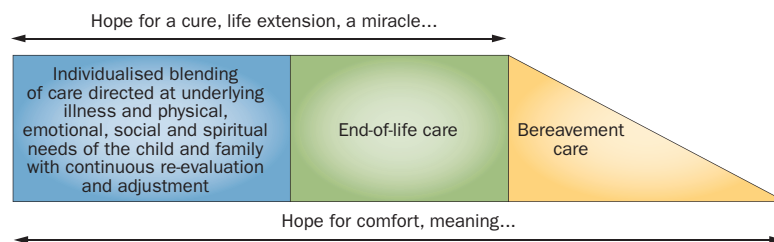


Figure 1 | Model of paediatric palliative care. Paediatric palliative care includes individualized integration of palliative care principles to manage expectations of life extension and comfort, both of which can be important issues throughout the child’s life. End-of-life care is an important component of palliative care when the focus is almost entirely on comfort, though hope for a miracle can persist. Bereavement care begins well before the child dies and is often helpful in the long term. Permission obtained from Elsevier © Liben, S. *et al. Lancet* **371**, 852–864 (2008).

as well as for increased survival time.^{49,50} Unfortunately, towards the end of life these are often mutually exclusive goals. Highlighting the risks of this complex decision-making process, some parents who pursued aggressive cancer-directed therapy despite a poor prognosis later regretted the decision and would not make the same recommendation to other parents in a similar situation.⁵¹

Troubling symptoms management

Symptom management is often the initial and main reason for a palliative care consultation. However, as most publications tend to focus on prevalence of symptoms rather than on symptom management, advances in understanding the pathophysiology of these troubling symptoms have been slow. As a result, surveys continue to show that many concerning symptoms have remained constant over time. In particular, fatigue remains a poorly understood, but stubbornly persistent, complaint.⁵² Children with leukaemia and lymphoma, older AYA patients, and patients undergoing stem-cell transplantation may be at particular risk for poorly managed symptoms.⁵³

Symptom control can be particularly challenging in end-of-life care, especially when dealing with refractory symptoms such as pain, dyspnoea, and agitation. Fortunately, recent data suggest that some children may be experiencing less pain and dyspnoea, which is perhaps an indication that there is increasing awareness of the need to reduce these symptoms.^{54–58} In recent years, palliative sedation for refractory symptoms has evolved from being a barely-discussed procedure executed with no oversight or standardization, to a largely accepted medical procedure to use in very specific circumstances. Studies in adults demonstrate that palliative sedation is ethical and can be safely achieved without hastening patient death; many hospitals are adopting formal guidelines to avoid its abuse or misuse.⁵⁹ However, there are few data in the paediatric population. Based on just a few studies, there is still disturbing evidence that administration of palliative sedation in children is not standardized, and might at times still be initiated with intent to hasten death.⁶⁰ Emerging reports suggest guidelines for use when considering paediatric palliative sedation. However, if palliative sedation is to gain widespread legitimacy and acceptance as an infrequently used but important tool in

end-of-life care, further data are needed to formalize the means and manner of its use.⁶¹

Troubling symptoms are not limited to the end of life and are often present from the moment of diagnosis. There is a tendency to focus on end of life, in part because this period is particularly fraught with emotional challenges, and also because poor symptom-control at end of life increases the risk of long-term parental morbidity.³² However, the prognostic uncertainty inherent in all diagnoses of cancer demands early application of the principles of palliative care, with rigorous attention paid to symptom control and quality of life regardless of stage of therapy.

Integrative or complementary therapies, such as acupuncture, hypnosis, and herbal and nutritional treatments, among others, are of growing interest, both as symptom management modalities and as cancer-directed therapies.⁶² These therapies may look increasingly attractive as diseases progress and options dwindle; parents often seek treatments beyond what is offered by their oncologist, especially when standard therapy has been unsuccessful.⁴⁹ Studies suggest that up to 84% of children with cancer are using some form of integrative medicine.^{63–65} Alarming, only 50% of families who choose to use integrative medicine discuss their choice with their clinical team.⁶³ Clinicians must be aware of and inquire about the use of integrative therapies, and should create partnerships with trusted integrative medicine practitioners for consultation and referral.

Other aspects in palliative care

Economic impact

Another way in which a child's diagnosis of cancer affects the family as a whole is through its economic impact, an area just beginning to be investigated. Costs can be direct or indirect, due to both treatment-related expenses as well as loss of income from work disruption, and when sufficiently high, these costs can have a larger psychosocial effect as well.⁴² Given an already difficult and stressful situation, financial hardship is just one more stressor that may contribute to poor outcome and it has been identified as a predictor for depression and prolonged grief.³² Staff must be mindful of such burdens, and further work needs to be done to identify ways in which staff may intervene to help reduce the risk of economic hardship.

Spirituality

The role of spirituality in paediatric palliative care is poorly understood, and likely varies among patients. One must also consider the parent and child separately, as their spiritual beliefs and needs may be very different. Studies addressing the importance of spirituality in supporting and guiding parents are contradictory.^{66–69} However, ensuring that parents have access to proper spiritual support, should it be desired, is always a priority.

Determining the role of spiritual support for the child is especially challenging. Addressing spirituality in adult patients helps to provide guidance, meaning, and resolution of spiritual distress.^{70–72} However, paediatric patients encompass a wide spectrum of developmental stages, and

understanding whether or not to address spirituality—or even what language to use when doing so—is a matter of debate. Fowler has proposed a model of spiritual development similar to Eriksonian life stages, a convention that may prove useful in guiding spiritual interventions for children.^{73,74} Comprehensive spiritual care lies beyond the skill set of most clinicians. To address spiritual care effectively through routine long-term spiritual assessments of both the patient and family, chaplaincy must be ensured a place on the palliative care team. Different models for integrating chaplaincy into palliative care have been proposed; which model works best depends on the specific setting and on the resources available.⁷⁵

Adolescents and young adults

Despite advances in curing paediatric cancer in recent decades, mortality rates in the AYA population remain to a large extent stubbornly unchanged.⁷⁶ Additionally, the AYA period, even in the best of circumstances, comprises a challenging developmental phase, in which issues of identity, life goals, peer relations, body image, and intimacy are being confronted for the first time.^{8,77–79} A diagnosis of cancer disrupts normal socialization, shrinks social networks, and has the potential to destroy a patient's prior identity. Addressing fertility preservation at the outset confronts the AYA patient immediately, with profound questions about the future and prognostic uncertainty. Careful and ongoing exploration of goals of care is critical in guiding management decisions in AYA patients, as treatment choices carry important implications for long-term development and morbidity. For the long-term survivor, issues of identity, fertility, spirituality, impaired organ function, and fear of recurrence may linger indefinitely, and should be addressed as early as possible to facilitate coping.

The question of how involved an AYA patient should be in decision-making is fraught with psychosocial as well as ethical and legal ramifications. By strict legal definition, any patient under the age of 18 years must have the consent of a responsible adult for any medical decision; this legal requirement, combined with the parental instinct to shelter their child, can easily lead to situations in which AYA patients become disenfranchised and are left out of the decision-making process. Indeed, medical staff may be no less at fault, as they often omit information to AYA patients.²⁷ AYA patients generally want to be informed and involved in decision-making, and respecting those wishes is an important part of fostering a sense of dignity and control.⁸⁰

Because of the critical role of socialization and peer groups during adolescence, both AYA patients with cancer and survivors benefit from engaging in peer support groups.^{78,79} Such groups help replace the psychosocial network that may otherwise be lost during treatment. Technological advances, including online forums and voice, video, and instant messaging make participation in peer support groups easier than ever, even for patients with severe physical limitations, and medical staff should remain alert to opportunities to facilitate and encourage such activities.

Low-income countries

Although most of the innovations that have occurred in paediatric palliative care are taking place in industrialized countries, over 90% of global child cancer deaths occur in low-income and middle-income countries.⁸¹ Put another way, about 80% of the 250,000 children diagnosed with cancer around the world annually, or 500 children a day, will die without even basic cancer treatment or pain relief.⁸² Unsurprisingly, the symptoms of greatest concern at end of life in these countries are similar to those identified in high-income countries.⁸³ Translating advances in palliative care to underserved countries successfully could, therefore, have an enormous effect on both paediatric cancer treatment and paediatric palliative care worldwide. Barriers to care include delayed diagnosis, limited access to therapies, insufficient and undertrained personnel, and lack of infrastructure.⁸⁴ Where services do exist, financial barriers can remain a significant concern.⁸⁰ Especially frustrating is the fact that access to even cheap and easy-to-use treatments, such as morphine, remains inadequate due to both physical and psychological barriers.^{82,85}

A number of strategies for meeting these challenges are emerging. First, partnering and building of alliances.^{84,85} Many hospitals in industrialized countries are cultivating partnerships with less-developed medical centres. This partnership includes sending staff to treat and educate onsite, and creating opportunities for local practitioners to travel abroad for further training. This training is especially important in light of recent studies suggesting that even basic education on topics such as communicating with children is deficient.⁸⁶ The WHO and various regional associations are working to facilitate communication, growth, and partnering, helping build networks both locally and internationally.⁸² Emerging technologies, such as internet videoconferencing and video telephony, allow for real-time teaching and consultation from afar.⁸⁷ Finally, international organizations such as the WHO, which has defined palliative care as a human right, continue to lobby for improved services, to set standards of care, and to press local governments to make these issues a priority.^{84,85,88}

Increasing awareness

An important shift in thinking about palliative care is the recognition that the development of specialized palliative care teams alone is insufficient; we must raise the level of knowledge about palliative care and make providers among all disciplines comfortable with this subspecialty. Ideally, the primary oncology team should manage symptoms and exploration of goals of care, with formal palliative care consultation reserved for more-complex cases. Despite increasing awareness of the need for better education, actual changes in programming remain frustratingly slow. Surveys published as recently as 2006 demonstrate no progress from 1998, revealing that about 75% of paediatric oncologists have no formal end-of-life training.^{17,89} Distressingly, these studies reported that over 90% of paediatric oncologists felt that they were competent in managing pain at end of life and

thought that most of their patients did not die in pain, contradicting contemporary studies suggesting that over 80% of children did, in fact, experience pain in the last month of life.¹

Efforts at improving palliative care awareness at the level of residency training have been slow to progress. In 2006, paediatric residents reported minimal training in—and minimal comfort with—almost all areas of paediatric palliative care.⁹⁰ Those same residents expressed a desire for such education and felt that palliative care should not be the provenance of subspecialists alone. A study carried out in 2008 looked at the implementation of a year-long course in palliative care for oncology residents, demonstrating improvement in knowledge across the board.⁹¹ By contrast, a day-long workshop for paediatric oncology fellows produced a lack of a long-lasting effect, highlighting the importance of reinforcement of education over time.⁹² Although directors of paediatric haematology–oncology fellowship training recognize the importance of palliative care education, most programmes have no formal agenda or even a designated time for significant teaching.⁹³ Adult haematology–oncology training programmes have recently set the incorporation of a mandated 1-month rotation in palliative care as a goal by 2020; hopefully paediatric haematology–oncology fellowship programmes will soon follow.⁹⁴ Compounding the challenge, at present, a lack of palliative care-trained staff available for teaching remains a real concern.⁹⁵

It is encouraging to note that, despite the challenge of introducing palliative care into training programmes, an increasing number of hospitals do offer formal palliative care services. The presence of a formal palliative care consult team for adult patients has been shown to provide significant educational benefit for trainees.⁹⁰ In 2008, 58% of Children's Oncology Group affiliated institutions had paediatric palliative care teams, up from 36% in 1998.⁹⁶ There is still much work to be done, but with increasing awareness and advocacy, the numbers should continue to rise.

Educational opportunities tailored to meet the needs of clinicians at all levels of training and from various disciplines continue to be developed. The Program in Palliative Care Education and Practice and the Education in Palliative and End-of Life Care (EPEC) are examples of courses designed to both provide education in palliative care as well as to teach trainees the necessary skills to become educators.⁹⁷ Finally, there is a growing number of paediatric palliative care fellowships from the Accreditation Council for Graduate Medical Education (ACGME) that continue to produce new clinicians trained to become leaders in this evolving field.

Conclusions

So where does this leave us? The answer lies in the changing paradigm of what paediatric palliative care is and when it should be offered. Neither the likelihood of survival, nor the assessment of risk of suffering should determine the need for palliative care. Rather, the uncertainty about prognosis inherent in each and every diagnosis of cancer should serve as the trigger for introducing

palliative care concepts, which are fundamentally about helping children and families to making choices consistent with their goals of care, regardless of disease status.

Becoming familiar with the principles of palliative care might be beneficial to clinicians from any specialty. This awareness is particularly important in the case of paediatric oncology, in which the prognostic uncertainty inherent to every diagnosis demands that members of the primary clinical team become comfortable with applying principles of palliative care. Primary oncology teams must be flexible and possess a wide set of skills, highlighting the importance of creating interdisciplinary teams drawn from different clinical areas, and of building strong relationships with specialty palliative care teams.

In this way, we may truly bring the best elements of palliative care to those who matter the most, our patients and their families.

Review criteria

PubMed was searched in September 2012 for English language articles published between 1997 and 2012. The search terms included combinations of "pediatric", "palliative care", "end of life", "decision making", "parental", "children", "spirituality", "chemotherapy" and "cancer". Relevant review articles and original articles were retrieved and their reference lists researched for additional articles.

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Author contributions

E. Waldman researched data from the article. Both authors made a substantial contribution to the discussion of the content, wrote the manuscript, and edited and reviewed the article prior to submission.