4 Communication with Children with Cancer and Their Families Throughout the Illness Journey and at the End of Life

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> *"Speak clearly, if you speak at all; carve every word before you let it fall."*
>
> Oliver Wendall Holmes

> *"The way you tell the truth to families makes a huge difference…if you know the person that's coming in there and they're telling the truth, as hard as it is, but you know they care about you and they love your child, it's okay. As hard as it is, it's okay and it makes all the difference."*
>
> Bereaved parent

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J. Wolfe et al. (eds.), *Palliative Care in Pediatric Oncology*, Pediatric Oncology,
https://doi.org/10.1007/978-3-319-61391-8_4

4.1 What Is "Good Communication" in the Context of Pediatric Oncology and Palliative Care?

Skillful communication has long been considered a key pillar in the "art" of practicing medicine (Feudtner 2007; Kaye et al. 2015). "Good communication" is integral to the development of meaningful connections between individuals and is a critical aspect of the therapeutic alliance (Mack and Hinds 2011). Yet the practical definition and real-life application of "good communication" can vary among individuals. What exactly does "good communication" mean? And how do we interpret and further uncover the nuanced meaning of this phrase within the context of pediatric oncology and palliative care?

Communication is defined both as "a process by which information is exchanged between individuals" and as "personal rapport" (Merriam-Webster Dictionary). Effective transmission of information is necessary, but not sufficient, to achieve good communication; forging and nurturing human connection and trust are also essential (Mack and Hinds 2011). Simply stated, good communication in the medical setting requires a synergy of effective information sharing and trust building, with the ultimate goal of developing meaningful relationships that inform and guide the illness experience for patients, families, and healthcare providers (HCPs).

Although skillful communication is important across all fields of medicine, it becomes particularly critical at the intersection of pediatric oncology and palliative care. In many settings, conversation might be the primary way (and, at times, one of the only ways) for HCPs to alleviate the suffering of children with cancer and their families (Mack and Grier 2004). Moreover, effective communication is required to build trust and relationships not only among children, families, and HCPs but also among members of the interdisciplinary team (Feudtner 2007; Kaye et al. 2015). Sharing information in an honest, clear, and compassionate manner facilitates the building of relationships and trust among HCPs, patients, and families, which in turn promotes optimal holistic continuity of care that transcends illness stage or care location (Kaye et al. 2015). Through the establishment of relationships and rapport, transparent and empathic communication also creates a framework for successful family-centered identification of goals as a means by which to guide difficult decision-making (Feudtner 2007; Kaye et al. 2015).

In recent years, the importance of communication has been increasingly recognized as a key aspect of providing optimal care to children with high-risk cancer and other life-threatening illnesses. The American Academy of Pediatrics (AAP) and the Institute of Medicine have published statements advocating for the promotion of effective communication among HCPs, patients, and families in pediatrics and palliative care (American Academy of Pediatrics 2000; Fallat and Glover 2007; Institute of Medicine 2003, 2014). A similar consensus regarding the need for good communication has been seen in the oncology setting, with the American Society of Clinical Oncology, the American Society of Pediatric Hematology-Oncology, and the International Society of Pediatric Oncology all highlighting the importance of improving communication among HCPs, patients with high-risk cancer, and families (Peppercorn et al. 2011; Arceci et al. 1998; Spinetta et al. 2009; Jankovic et al. 2008; Masera et al. 1999; Masera et al. 1997). Recently, experts in pediatric oncology and palliative care identified communication as both a standard of care and a top research priority within both fields (Weaver et al. 2015; Baker et al. 2015), further solidifying the critical importance of good communication in caring for children with high-risk cancer and their families.

In the context of this call to action, the following chapter will review the literature on the practical benefits of effective communication for HCPs working in the fields of pediatric oncology and palliative care. We also will discuss domains, models, and strategies for achieving good communication among HCPs, children with high-risk cancer, and their families as well as among members of the interdisciplinary medical team. Using a patient's story, we will review common communication scenarios ranging from sharing a difficult diagnosis and prognosis to discussing goals of care at the end of life (EOL). We also will discuss barriers and pitfalls to effective communication and offer strategies to overcome these issues. Finally, we will offer interdisciplinary recommendations for effective communication from the valuable perspectives of a psychologist, chaplain, child life specialist, and music therapist who specialize in the care of children with high-risk cancer and their families.

4.2 Why Is Communication so Important in Pediatric Oncology and Palliative Care?

> "The right word may be effective, but no word was ever as effective as a rightly timed pause."—Mark Twain

Clear, honest, and empathic communication is the cornerstone of collaborative decision-making in both pediatric oncology and palliative care. Caregivers who make decisions for children with high-risk cancer consistently express the need for compassionate delivery of truthful information that uses nontechnical language; this type of communication builds trust and deepens the therapeutic alliance (Feudtner 2007; Kaye et al. 2015; Masera et al. 1998; Levetown 2008; Mack et al. 2006, 2007a, 2009a), while enabling families to make informed decisions about treatment preferences and goals of care (Mack et al. 2006; Wolfe et al. 2000; Weeks et al. 1998; Wright et al. 2008; Apatira et al. 2008). In addition, clear and open communication helps promote the child's participation in decision-making (Levetown 2008).

At the intersection of pediatric oncology and palliative care, the integration of excellent communication principles and practices not only fulfills the legal and ethical mandates regarding informed consent and assent, but it also augments hope and improves coping for children with high-risk cancer and their families (Apatira et al. 2008; Ranmal et al. 2008; Kaye and Mack 2013; Mack et al. 2009b; Hagerty et al. 2005; Davison and Simpson 2006). In addition, skillful communication alleviates suffering (Mack and Grier 2004; Mack et al. 2009a), including anxiety and depression related to the illness and treatment (Last and van Veldhuizen 1996), while improving quality of life (QOL) (Hays et al. 2006) and the overall EOL experience for patients and families (Mack et al. 2009a; Apatira et al. 2008; Davison and Simpson 2006; Hechler et al. 2008). Furthermore, effective communication facilitates collaboration among members of the interdisciplinary team (Feudtner 2007) and reduces administrative barriers to providing holistic care (Vollenbroich et al. 2012), which often leads to improved satisfaction with care for patients and families (Schaefer and Block 2009). Interestingly, the effects of excellent communication are not limited to the illness trajectory of the child: effective communication is also an essential component of grief management and may even mitigate complicated bereavement (Wright et al. 2008; Schaefer and Block 2009; Garrido and Prigerson 2014; Meert et al. 2001). Conversely, ineffective communication often leads to increased distress for patients and families (Contro et al. 2002, 2004; Wallin et al. 2016; Eilertsen et al. 2013; Rosenberg et al. 2015) as well as additional uncertainty, which can adversely impact hope (Hsu et al. 2003).

4.3 What Are the Elements of "Good Communication" in Pediatric Oncology?

> "The difference between the right word and the almost right word is the difference between lightening and a lightening bug."
> – *Mark Twain*

> "It is more fun to talk with someone who doesn't use long, difficult words but rather short, easy words like 'What about lunch?'"
> – *A.A. Milne*

Effective communication involves more than just providing information: it entails the exchange of information in an open, compassionate manner that is responsive to the needs of the patient and family. The AAP has identified three important domains in the communication among the physician, child, and parent: informativeness, interpersonal sensitivity, and partnership building (Levetown 2008) (Table 4.1). A HCP who tailors his or her communication strategy to meet these three domains is encouraging a shared decision-making process, ensuring that difficult conversations about diagnosis, prognoses, treatment, and EOL issues align with the goals of care of the patient and family. Table 4.2 provides the reader with several high-yield models that have been developed to promote effective communication between HCPs, patients, and families, which may be used in conjunction with the fundamental elements of communication outlined by the AAP.

The literature is ripe with strategies for achieving effective communication (Feudtner 2007; Levetown 2008; Eden et al. 1994; Ahmann 1998; Mahany 1990), from which emerge several core tenets pertinent to pediatric oncology and palliative care. First, HCPs should be cognizant that good communication always takes place within the context of a specific patient/family (Clarke et al. 2005; Young et al. 2011; Hinds et al. 2002). Second, HCPs should acknowledge that the patient and family are highly knowledgeable about the patient's experiences and needs, respecting them as "experts" on these issues during difficult conversations (Zwaanswijk et al. 2007). Third, child and adolescent patients should be included in discussions in age-appropriate ways (Parsons et al. 2007; Oshea et al. 2007; Snethen et al. 2006; Young et al. 2003; Hinds 2004; Ruhe et al. 2016; Zwaanswijk et al. 2011; Coyne et al. 2014). Fourth, good communication necessitates conversations about both medical and psychosocial issues, recognizing these spheres as overlapping and inextricably linked (Hinds et al. 2002; De Trill and Kovalcik 1997). Fifth, cultural competency is a fundamental aspect of effective relationship building and communication (Parsons et al. 2007; De Trill and Kovalcik 1997; Surbone 2008; Mystakidou et al. 2004). Perhaps most importantly, when striving to communicate well with young patients, HCPs should remember one simple principle: listen to the child and talk to the child; but listen more than you talk (Zwaanswijk et al. 2007; Beale et al. 2005; Ishibashi 2001).

Table 4.1 Important communication elements for HCPs, children, and parents (Levetown 2008)

Informativeness	The quantity and quality of health information provided by the physician to the patient or family
Interpersonal sensitivity	The relational behaviors that reflect an HCP's interest in eliciting and understanding the feelings and concerns of the family; these behaviors can be verbal or nonverbal and allow the child's or family member's concern to be heard
Partnership building	The extent to which the HCP invites the parents and child to share their concerns, ideas, and expectations; when this is conducted with empathy and a desire to build rapport, the patient and family might be more comfortable sharing their questions, fears, beliefs, and values with the HCP

4.4 Communication Topics Specific to Pediatric Oncology

4.4.1 Sharing a Difficult Diagnosis

Carly is a 9-year-old girl who is energetic, playful, and active in sports. While playing basketball, she injured her left leg, and her pediatrician obtained an x-ray to evaluate for possible occult fracture. The x-ray revealed a large lesion in her left femur, and she was referred to your oncology clinic. She underwent biopsy of the lesion that established a diagnosis of Ewing sarcoma, and an initial staging evaluation revealed multiple bilateral metastatic pulmonary nodules. As her primary oncologist, you sit down with Carly and her parents to inform them of the diagnosis and recommend treatment with standard chemotherapy, limb salvage surgery, and bilateral lung irradiation. Even with the use of these intensive combined treatment modalities, however, you know that Carly's prognosis for long-term survival is around 30%, and if the disease recurs she will be incurable.

Patients with cancer and their families experience high levels of psychosocial stress, and they need HCPs to provide them with accurate timely

Table 4.2 Models to promote “Good Communication”

Communication elements	SPIKES	PACE	SEGUE	Six E’s of communication
Preparation	• *S*et up the interview • Assess *p*erceptions of the patient/family • Obtain an *i*nvitation from the patient/family	• *P*lan the setting • *A*ssess the knowledge and needs of the patient/family	• *S*et the stage • *E*licit information	• *E*stablish an agreement about communication • *E*xplore what the patient/family already knows
Informativeness	• Give *k*nowledge and information	• *C*hoose appropriate strategies for information delivery	• *G*ive information	• *E*xplain information according to patient’s developmental status and needs
Interpersonal sensitivity	• Address *e*motion with *e*mpathic responses	• *E*valuate the understanding of the patient/family	• *U*nderstand the perspective of the patient/family	• *E*ngage the patient/family at the opportune time • *E*mpathize with the emotions of the patient/family
Partnership building and decision-making	• Offer a *s*trategy and *s*ummarize		• *E*nd the encounter	• *E*ncourage the patient/family that you will be there when needed

Adapted from Mack JW, Hinds PS. Practical Aspects of Communication. In: *Textbook of Interdisciplinary Pediatric Palliative Care*; 2011:179–189

information as well as emotional and social support throughout the illness trajectory (Sanson-Fisher et al. 2000; Stark et al. 2002; Zabora et al. 2001). Ideally, optimal communication should begin at the time of a cancer diagnosis, thereby setting the stage for subsequent high-quality communication about future sensitive topics such as prognosis and treatment options. In this way, HCPs can alleviate some of the distress associated with the illness experience (Hack et al. 2012; Zachariae et al. 2003) and improve QOL for patients and families (Girgis et al. 2009).

The period of time when a child receives an initial cancer diagnosis is highly stressful and full of uncertainty, often resulting in significant emotional anguish for patients and families. Compounding these early stressors are other illness-related issues, such as pain related to the underlying pathology and/or the need for invasive procedures to confirm the cancer diagnosis. Tremendous variation exists among patients and families regarding their level of understanding about current health status, diagnosis, prognosis, and treatment options. Therefore, these issues must be communicated in a way that is respectful and responsive to the specific needs of the patient and family. Communication should begin by eliciting the current knowledge, questions, and concerns about the diagnosis from the patient and family. Table 4.3 summarizes several key points to sharing a difficult diagnosis with a child and family.

4.4.1.1 Including Children and Young Adults in Conversations About High-Risk Diagnoses

Decisions about how or when to involve children in discussions about diagnosis and prognosis must be made in consultation with the child’s family, recognizing that they know their child best (Young et al. 2003). Whenever possible and reasonable, HCPs should encourage a family to include the child in these conversations. Children who receive upfront, clear, and age-appropriate information about their diagnosis are likely to be better equipped to cope with their illness experience, adhere to medications, communicate openly with their families about fears and concerns, and place trust in their HCPs (Clarke et al. 2005). In a study

Table 4.3 Sharing an initial cancer diagnosis with the child and family

Who	Ask the child and family whom they would like to have present during this conversation
	Encourage parents to include young children in the discussion in an age-appropriate manner
	Advocate for adolescent patients to be present and have a voice in the discussion
	Invite ancillary staff (e.g., nurse, nurse practitioner, social worker, child life specialist, chaplain) to be present for the conversation to provide additional support
Where	Select a quiet, private space. Ideally, the space should have a door that can be closed, sufficient seating for all participants, and tissues positioned for easy access on a side table
	Allow family members to choose their seats; if possible, try not to block their route to the door
When	Initiate the conversation as soon as you have results to share; delaying the communication of bad news only makes the process more difficult
How	Turn your pager and phone to silent before starting the conversation
	Begin with a "warning shot" (e.g., "I am so sorry to tell you this…" or "unfortunately, I have some difficult news to share…")
	Share the news in one to two concise sentences. Speak clearly and slowly. Avoid medical jargon. Use the word "cancer" in your explanation; avoid euphemisms or phrases such as "the C word." Naming the illness is an important step in mitigating uncertainty and fear for both the child and family
	Pause to allow the patient and family space and time to process the information. Allow for silence. Allow for emotions. Resist the urge to fill the silence
	After the patient and family has had a chance to express their emotions, provide 1–2 min of additional information about the next steps
	Reassure the patient and family that this diagnosis is not anyone's fault. Emphasize the fact that they could not have done anything to prevent it
	Ask for questions. Try to encourage questions by asking, "What questions do you have?" (instead of asking, "Do you have questions?"). Validate all questions as excellent. Use simple and clear language in answering questions. Resist the temptation to share additional information if the family has not asked for it. Often, the family is so overwhelmed after receiving a cancer diagnosis that it will remember little of the information that you present in this first meeting
	Sharing a cancer diagnosis is not a "onetime" conversation. Most patients and families will need multiple discussions to help them process this difficult news. Set up a time to meet again in the near future at the convenience of the patient and family. Provide your contact information and encourage the family to be in touch if it has additional questions or concerns before the next meeting

examining the effect of open communication about diagnosis and treatment options, children who received a high level of information experienced less anxiety about undergoing treatment, being in the hospital, and interacting with physicians (Sato et al. 2015). Research on long-term survivors of childhood malignancies likewise indicates that early knowledge of the cancer diagnosis results in improved psychosocial adjustment. In addition, the majority of cancer survivors, parents, and siblings report that they believe a cancer diagnosis should be shared with young patients early on in the disease course (Slavin et al. 1982).

Understandably, some families might still hesitate to include children in difficult conversations at the time of diagnosis, particularly if the child is young and/or the diagnosis carries a poor prognosis. Interestingly, the literature demonstrates that even young children can possess a nuanced, albeit age-appropriate, understanding of their serious illness in a way that enables them to participate in discussions about future treatment options and EOL decisions (Hinds et al. 1999; Weir and Peters 1997; Nitschke et al. 1986).

Despite this data, some parents still struggle to balance their desire to maintain open communication with their child with the desire to protect their child from hearing bad news. In these circumstances, HCPs can ask parents what they think their child already knows. Often times, children are highly perceptive and in tune with their immediate environment, and HCPs can help parents recognize the degree to which the child is already cognizant of his or her illness and encourage honest, age-appropriate conversations to help the child better understand and cope with the new challenges that lie ahead. Some parents also report that involving children in difficult discussions about diagnosis and prognosis is easier if they have an opportunity to first discuss the information with the physician when the child is not present (Young et al. 2011). At the discretion of the family, HCPs can consider offering antecedent separate meetings to parents before including the child, with the goal of helping parents convey honest, age-appropriate information to their child at their preferred time and location and in a manner that aligns with their family's values. Most importantly, however, HCPs should individualize their approach to communication, respecting the cultural and personal preferences of the patient and family unit as much as possible.

In the context of adolescent patients, the literature demonstrates that the vast majority of chronically ill teenagers wish to be involved in the medical decision-making process, with most adolescents preferring to discuss their wishes earlier in the disease course (Lyon et al. 2004). Thus, we strongly recommend that HCPs invite adolescent patients to participate in all medical discussions. This recommendation is consistent with recent literature supporting that adolescents should be enabled and empowered in the medical decision-making process (Weaver et al. 2016). That said, it is also important to recognize that the communication preferences and needs of adolescent and young adult patients are unique (Essig et al. 2016); despite lacking the legal authority for decision-making, they may strive for autonomy and wish to have a voice distinct from their parents during difficult conversations. Depending on developmental stage, individual personality and preferences, and family culture and dynamics, it may be helpful to offer adolescents an opportunity to meet with clinicians without their family present to allow them a safe space to ask questions or express worries that they otherwise might not have expressed.

We also recommend that HCPs encourage an interdisciplinary team approach when communicating a difficult diagnosis in order to provide additional layers of support for the child and family. If the child or family has already bonded with a particular HCP, it can be helpful to invite that clinician to be a part of the conversation; if not, then consider including a clinician who will be providing future care to the patient and family. In addition to inviting physicians, advance practice nurses, and nurses to join the discussion, HCPs should strive to include the patient's social worker, child life specialist, chaplain, or other psychosocial providers to offer additional support to the child and family whenever possible. However, it is essential that HCPs ask permission from the patient and parents before inviting others to participate in these and other sensitive conversations.

4.4.1.2 How Is a Cancer Diagnosis Best Communicated?

Communicating difficult information to patients and families, often in the context of high levels of distress, is among the most challenging and meaningful aspects of an HCP's role within the therapeutic alliance (Arnold and Koczwara 2006). The initial delivery of information can have significant effects, both positive (Ptacek and Ptacek 2001) and negative (Essex 2001; Ablon 2000; Strauss et al. 1995), on a patient's adjustment to the diagnosis. Importantly, patient and family understanding of prognosis also affects future choices for therapy (Fried et al. 2002), and understanding of the burden and likely outcome of treatment may significantly influence goals of care (Fried et al. 2002).

Given the recognized importance of communicating difficult information and the complexity of this information exchange, established guidelines exist to help HCPs navigate the sensitive process of communicating a cancer diagnosis. Table 4.4 highlights key points from two commonly used guidelines related to communicating a diagnosis of cancer to pediatric patients and their families. Additional guidelines to help HCPs provide difficult information to patients and families are detailed in the previous section and in Tables 4.2 and 4.3; each of these strategies may be readily applied to the pediatric oncology context. In particular, the PACE paradigm (*Plan*

Table 4.4 Guidelines for communicating a pediatric cancer diagnosis

SIOP guidelines for communication of the diagnosis[a]	The day one talk[b]
1. Establish a protocol for communication 2. Communicate immediately at diagnosis and follow up later 3. Communicate in a private and comfortable space 4. Communication with both parents and other family members if desired 5. Hold a separate session with the child 6. Solicit questions from parents and child 7. Communicate in ways that are sensitive to cultural differences 8. Share information about the diagnosis and the treatment plan 9. Share information on lifestyle and psychosocial issues 10. Encourage the entire family to talk together	1. Plan the meeting: select a quiet location, minimize interruptions, include important family members or staff 2. Determine if the pediatric patient should be included in the conversation; discuss this with the patient and family ahead of time 3. Ask the patient/family about their understanding of the illness 4. Give the diagnosis; explain certainty or uncertainty; use the word "cancer" to avoid future confusion 5. Discuss treatment options and goals of treatment, assess preferences for receiving information, and provide prognostic information in accordance with these preferences 6. Address causation; offer reassurance (if appropriate) that no one is to "blame."

[a] Masera G, Chesler MA, Jankovic M, et al. SIOP Working Committee on Psychosocial Issues in Pediatric Oncology: Guidelines for Communication of the Diagnosis. Medical and Pediatric Oncology. 1997;28:382–385

[b] Adapted from Mack JW and Greer HE. The Day One Talk. *J Clin Oncol.* 2004;22(3):563–566

the setting, *A*ssess the family's background knowledge and experience, *C*hoose the strategy that best fits the family's particular situation, and *E*valuate the family's understanding of the information) is particularly applicable to communicating a cancer diagnosis to pediatric patients and their family (Garwick et al. 1995). Several iterations of the PACE model exist, incorporating helpful techniques such as the use of a "warning shot" (Fox et al. 2005), which are readily translatable to the pediatric oncology setting.

Regardless of which specific communication guide is used, HCPs who relay difficult diagnostic information to patients and families might consider the following several simple steps. First, HCPs should select a quiet location that allows for a private conversation to occur with minimal interruptions or distractions. Once the patient, family, and HCPs are seated comfortably, one clinician should take the lead in beginning the conversation. Beginning with a "warning shot" can be helpful to allow the patient and family to prepare themselves for hearing bad news. For example, a HCP might open with, "Unfortunately the labs results show us something concerning" or "I am afraid I have some bad news to share."

When conveying a diagnosis of cancer, the actual word "cancer" should be said aloud at the beginning of the conversation to ensure that patients and families understand the situation. The use of euphemisms (e.g., "the monster inside of you") or abbreviations (e.g., "the C word") can be confusing to children and lead to increased stress and fear. Likewise, children and families might not understand that medical words such as mass, tumor, or leukemia are synonymous with cancer, and they might be shocked or upset to learn it at a later time. To preempt this issue, HCPs should avoid medical jargon and technical terms as much as possible. It is common for patients and families to express disbelief of a devastating diagnosis; HCPs should respond with a gentle and consistent message that reiterates the certainty of the diagnosis with a clear explanation of the evidence supporting the diagnosis. After sharing difficult information, HCPs must give patients and families adequate time and space to digest the news. HCPs should be physically and emotionally present for the patient and family and respond to whatever emotions (e.g., tears, anger, frustration, questioning, denial) that arise during this difficult time:

After asking Carly whether she would like to be a part of the discussion, you and your clinic nurse sit down with Carly and her parents. You open by saying, "Tell me about what you think is going on," speaking directly to Carly. You validate Carly's

> *concern that something serious is happening, and then you say gently, "Carly, I am sorry to tell you this, but we have found that you have cancer." Then you stop speaking, and you sit quietly with the family and allow them time and space to express their thoughts and feelings.*

After sharing a cancer diagnosis, the discussion should move toward specifics of medical treatments, including the goal of the treatments. For the majority of pediatric patients with a new cancer diagnoses, the goal of treatment is curative. However, for some cancers that have extremely poor prognoses, the goal of any treatment (including upfront cancer treatment) may not be curative, and this information should be honestly and gently disclosed. Some patients and families wish to know comprehensive details regarding diagnosis and prognosis, whereas others prefer to learn information in generalities. HCPs cannot assume to know the preferences of patients and families; for optimal communication, they must ask what type of information the patients and families wish to hear. This can vary from vague statements such as "Overall, most children with this type of cancer do well with treatment" to more specific prognostic statements such as "About 80% of patients with this type of cancer will survive." How much of this information the patient and family absorbed should be reassessed by the team at a later time by asking the family to summarize their understanding of the diagnosis, prognosis, and treatment plan:

> *"Carly, the biopsy of your leg tells us that you have Ewing sarcoma, which is a type bone cancer." You again pause and allow for silence. "We have good treatments available, but we also know that when the cancer spreads to other places in the body, such as the lung in your case, it is more difficult to treat. I can share with you more specific information, including numbers or percentages, if this is something that you feel might be helpful."*

As HCPs take cues from the patient and family regarding information preferences, they should be flexible and adapt to the conversation as necessary. Some patients and families might desire more abstract discussion or analogies (e.g., the weed in the flower garden analogy (Jankovic et al. 1994)), whereas others might prefer to receive more technical information with details regarding pathophysiology and therapeutic options.

After discussing the diagnosis and treatment plan, HCPs should address unspoken issues such as the possible cause of cancer and/or parental guilt associated with delayed diagnosis. Patients and families seeking meaning for the devastating event of a new diagnosis might blame themselves or others for the shocking news (Strauss et al. 1995; Weaver 2014). HCPs can help mitigate guilt and shame by providing reassurance (when appropriate) that no one could have predicted or prevented the cancer from occurring. This reassurance is particularly important for young children (and their siblings) who might experience age-appropriate "magical thinking" and fear that they caused the illness to strike. The unfairness of the situation should also be validated at this time: "I wish I knew what to say…you are right, this is so unfair." Such statements may open the door to further discussions about how the patient and family are feeling and processing the news, thereby offering HCPs insights into how best to offer additional support:

> *You say, "Carly, sometimes children worry that they might have done something to bring on cancer. I want you know that although we do not know exactly why you developed cancer, we do know that it was not because of anything that you did or did not do. There is nothing that you could have done to prevent this from happening." You pause, and then look at Carly's parents. "The same is true for the rest of the family. We are still learning more about what causes cancer in children, but I want to assure you that there is nothing that you missed or could have prevented. You did exactly the right thing by going to the hospital when you did, and you have brought your child to the right place for her to receive the treatment that she needs."*

It is important to remember that communication of a cancer diagnosis is not a one-time event; it is an ongoing communicative process involving multiple conversations, often with various members of the medical team. Commonly, the stress surrounding the diagnosis of a serious medical condition is associated with poor retention of information by both patients and families (Mack and Grier 2004; Kodish et al. 2004), affirming the need for ongoing and iterative exchanges of information among HCPs, patients, and families.

In fact, the majority of parents who receive difficult information about their child's diagnosis understand less than half of the information provided to them at the initial consultation (Mack and Grier 2004; Kodish et al. 2004). Even after iterative discussions with HCPs, parents might continue to misunderstand their child's treatment regimen (Greenley et al. 2006), which underscores the need for information to be conveyed consistently across serial time points.

Given these potential road blocks to clear communication of a diagnosis, HCPs must balance their desire to provide comprehensive medical information during the initial visit with patients' and families' need for adequate time to absorb, understand, and process the provided information. After receiving difficult news, patients and families should be allowed time apart from the medical team and each other to process the information at their own pace (Hinds et al. 2002). In the interim, HCPs may provide a variety of information delivery formats (e.g., written pamphlets or links to accurate and vetted online resources) to help increase the absorption and retention of information, giving families an opportunity to review information after the initial conversation. In our experience, multiple short meetings bolstered by the inclusion of multimedia information offer an effective strategy for communicating an initial cancer diagnosis, prognosis, and treatment plan.

"Carly, I want to pause here to see what question you have," you say. Carly looks at the wall without answering. After about 20 seconds of silence, she shrugs and says, "I don't know." You reply, "That's perfectly ok. Whenever you have a question, you can always ask it at any time." You then turn to her parents and ask, "What questions do you have?" They silently shake their heads, clearly overwhelmed. "There will be plenty of opportunities to ask questions as we move forward," you say. "With your permission, I would like to share with you some information about Ewing sarcoma from our hospital's website, as well as a copy of the treatment plan that we briefly discussed today. There is no rush to start right now, and I want you to take some time to look over everything. We will talk more about it after you have had a chance to talk with one another. I would like to meet with you again tomorrow morning, and I will be happy to answer any questions and talk more about the treatment at that time. In the meantime, please write down any questions or thoughts that occur to you in this notebook, so I can be sure to answer all of your questions. The phone number for our clinic is written on the front of this notebook, in case you need to reach us before tomorrow."

In summary, sharing the difficult news of a new cancer diagnosis with children and families is a challenging process. Key themes to ensure good communication and relationship building during this first conversation include providing clear, individualized communication of information, avoiding euphemisms or medical jargon, paying attention to the emotional aspects of communication, letting the patients and families guide the flow of conversation, and ensuring that HCPs are available to answer questions and concerns raised by patients and families (Ahmann 1998).

4.4.2 Discussing Prognosis in the Context of Disease Progression or Relapse

Carly begins treatment, and she tolerates the chemotherapy and radiation therapy well. She undergoes limb salvage surgery without complications, and she and her parents feel optimistic that she will "beat this cancer." Unfortunately, repeat imaging for disease reevaluation reveals multiple new metastatic lesions in her lungs. You sit down with Carly and her parents to discuss the results of the scans.

Communication with patients and families about devastating information such as disease progression or relapse is distressing for all involved, including HCPs who might delay or "sugar coat" the information (Eggly et al. 2006). Unsurprisingly, parents of children with progressive cancer report that disease progression triggers feelings of uncertainty and fear, further compounding their distress. Patients and families are anxious and overwhelmed when trying to receive, comprehend, and integrate information about prognosis, treatment options, palliative care, EOL care, and hospice near their child's death (Hinds et al. 1997). Unfortunately, parents of children with cancer often feel that they do not receive high-quality information about prognosis at diagnosis or during disease progression (Kaye and Mack 2013; Singh et al. 2015). In the context of disease progression, parent–provider concordance about prognosis and goals is often poor, such that parental understanding that their child will die from the cancer occurs many months after it has become clear to the medical team (Wolfe et al. 2000; Rosenberg et al. 2014; Gordon and Daugherty 2003; Lamont and Christakis 2003). This discordance is exacerbated, at least in part, by the frequent delay of prognosis-related conversations until late in the disease trajectory (Morita et al. 2005; Thompson et al. 2009).

For these reasons, prognosis-related conversations and parental integration of the information early in the disease course are essential to the provision of optimal medical care to children with cancer and their families. Parents who have these conversations and come to an earlier understanding that their child will die report better ability to balance cancer-directed treatment and QOL-focused care, improved satisfaction with care, and opting for less "intensive" EOL care and more hospice care (Mack et al. 2005, 2006, 2007a, b, 2008, 2009b; Hinds et al. 1997; Valdez-Martinez et al. 2014; Mack and Smith 2012; Hill et al. 2014; Feudtner and Morrison 2012; Hinds et al. 2000; Bluebond-Langner et al. 2007). However, it is important to note that "more" is not necessarily better in the context of difficult conversations; excessive discussions about a poor prognosis might be as harmful to patients and families as avoidance of the issue. Many of the strategies for communicating a difficult diagnosis discussed in the previous section can and should be applied in this context as well. Tables 4.5 and 4.6 offer advice for additional communication strategies to use when discussing disease relapse or progression with patients and families and recommendations for language to facilitate a "goals of care" conversation, respectively.

Table 4.5 Communication strategies at the time of disease relapse or progression

Avoid saying…	Try saying…
There is nothing more that we can do	There is no chemotherapy that can cure your cancer. But there is always more that we can do to help you live as well as possible for as long as possible. We will never give up on you, and we will walk with you every step of the way during this difficult journey
It is up to you to decide; I can't make this decision for you	There is no right or wrong answer; the right answer is the one that is best for you and your family. I am here to help you talk through the different options and figure out which one is best for you
Most families choose this option	Different families make different choices. Loving families sometimes choose to receive cancer-directed treatment in the hospital, or to receive outpatient treatment, or to go home with no further cancer-directed treatment. Based on your goals and values, we will work with you to determine which choice is the right one for your child and your family. Any decision that we make together will be rooted in a place of love and wanting the best for your child, and this is how we will know that it is the "right" decision. Regardless of which path we take, our goal will be for your child to live as well as possible for as long as possible
I think that you need to do this option	I am here to help you decide which option is right for you and your family, and I will support and honor your decision to the best of my ability

Table 4.6 Language to "open the door" into a conversation about goals of care

In light of what we have discussed, what is most important to you and your family?
What are your worries?
What are you hoping for? *Validate and share in their hopes, and then ask a follow-up question:* And what else are you hoping for?
Where do you find strength in times of difficulty?
How can we best support you? What would be most helpful to you right now?

During these difficult conversations, HCPs should emphasize that, even if treatment is not working, there is always more that we can do to help the child and family. "More" may refer to further cancer-directed therapy, intensive supportive care, and/or interdisciplinary palliative care. HCPs should never tell a patient of family that "there is nothing more that we can do," as this may be interpreted as abandonment by the patient and family at their time of greatest distress. Instead, HCPs should truthfully acknowledge that there is no intervention that can cure the cancer, but there is always more that can be done to help the patient live as well as possible for as long as possible. HCPs also should inform patients and families that, when faced with difficult decisions, there is not one "right" choice; rather the "right" option is the one that best aligns with the values and goals of care of the patient and family. Additionally, HCPs should be prepared that patients and families might express two seemingly conflicting emotions: understanding of incurability and simultaneous hope for a miracle (Hagerty et al. 2005). This is a normal reaction and does not necessarily imply that the patient or family is in denial or lacks comprehension of the gravity of the situation; rather, it simply demonstrates how hope can serve as a powerful coping mechanism in the process of confronting a painful reality. HCPs should strive to provide honest information while still affirming the right of the patient and family to maintain hope.

You bring Carly and her parents into a private room, and you silence your pager and phone to minimize interruptions. You have invited Carly's primary clinic nurse and her child life specialist to join the conversation, and you wait until everyone is comfortably seated in a circle and then thank everyone for coming. You anticipate that Carly and her parents are very anxious to receive the scan results, so you skip the small talk and open the conversation with a warning shot: "I know that you are anxious to hear the results, and I am so sorry to tell you that the scans show bad news." You pause and allow this information to sink in.

After a few moments, Carly says, "But I did everything right, and you said that my treatments were going well." You nod and affirm her comment: "Yes, you did everything right. Your body handled the medications, radiation, and surgery well, and we were glad that you felt well during the treatments. But sometimes, even when everyone does everything right, the cancer still grows. It is nobody's fault. But it means that we need to talk about what choices we have going forward." Carly's father quickly says, "We want to keep going with the treatment, to beat the cancer once and for all!" You pause and wait to see if anyone else wishes to speak. After a few moments, Carly's mother whispers, "What good will more chemotherapy do, if it didn't stop the cancer from growing?"

You say, "These are both important points for us to talk about. With Carly's type of cancer, once the disease progresses our chances of curing the cancer become very small." You pause again to allow everyone time to process this bad news. No one speaks, and you continue: "I wish that we had better treatments that could cure the cancer. But the truth is that Carly's cancer has progressed despite our best interventions, and we do not have a medication that can cure her disease. But there are still many things that we can do to help her live as well as possible for as long as possible. We are not giving up on Carly, and we will continue to walk with all of you along every step of this difficult journey."

After a moment, Carly's father asks, "So, what are our options now?" You explain that there are 4 possible paths: experimental chemotherapy on a study, with the understanding that the goal of the study is not cure; standard intravenous chemotherapy with the goal of life prolongation, which may entail more severe side effects and more time spent in the hospital; outpatient oral or intravenous chemotherapy administered in the clinic, with the goal of minimizing side effects while still prolonging life; going home with no further cancer-directed care, but with a great deal of supportive care and resources to maximize quality of life. You emphasize that there is no right or wrong answer; loving families chose different paths, and the right choice is the one that best aligns with the goals and needs of Carly and her family.

You pause again, and no one speaks. You sit in silence for several minutes. Then Carly asks, "So, I can go home?" Her mother says tearfully, "I don't know what to do." Her father interrupts, "No! We are going to try an experimental therapy, and pray for a miracle!" You allow for another moment of silence, and then say, "We do not need to decide anything today. Let's plan to meet tomorrow to talk more about the different options. No matter what you choose, I will support and honor your decisions to the best of my ability. And regardless of the path you take, l will hope and pray for a miracle every step of the way along with you."

4.4.3 Discussing Enrollment in Phase I Trials

Clinical research in pediatric oncology often involves the enrollment of children with cancer in clinical trials to study new treatment plans. If the cancer is refractory to available curative therapies, the option to enroll the child in a phase I clinical trial may be presented to the family. By definition, a phase I clinical trial is a dose-finding study conducted to identify the maximum tolerated dose of an investigational therapy; it is not intended or expected to provide a direct benefit to participants, and few phase I clinical trial participants receive any disease-directed benefit (Levine et al. 2015). Unfortunately, often parents (along with HCPs and researchers) possess an overly optimistic view about their child's chance of benefit and believe that participation in a phase I trial will afford their child a disease-directed benefit (de Vries et al. 2011). Parental comprehension of the primary intent of phase I research is reported to be quite low (Cousino et al. 2012; Simon et al. 2004), with little improvement in this understanding over time despite high-quality communication (Marshall et al. 2012). Despite widespread misconceptions about the therapeutic benefit of phase I trials, the majority of parents who attend a consent conference for a phase I trial ultimately enroll their child in the trial (Baker et al. 2013).

Multiple reasons contribute toward the desire of a patient or parent to enroll on a phase I trial, including a wish to prolong life and improve quality of life, altruism, and legacy building (Hinds et al. 2009; Miller et al. 2013). Participation in a phase I trial often aligns with the goals of a patient and family, particularly when the treatments are fairly well tolerated and readily facilitated in an outpatient setting. However, given the potential for iatrogenic harm secondary to participation in a phase I study, HCPs should explain the voluntary nature of phase I trials, the primary intention behind the research, and the low likelihood of direct benefit to participants. Unfortunately, HCPs who discuss phase I protocols with parents often inadequately convey the distinction between medical care and research, as well as frequently incorporate hopeful and persuasive messages when explaining the trial, which encourages enrollment (Miller et al. 2014a). HCPs should ensure that patients and families understand that participation in a phase I trial is unlikely to alter the trajectory of a poor prognosis. Moreover, patients who opt to participate in a phase I trial should be offered concomitant cancer-directed therapy as part of their holistic care (Miller et al. 2014a).

Interestingly, HCPs communicate about phase I trial enrollment more often with parents than with patients. However, direct communication between HCPs and patients is associated with greater levels of patient understanding regarding disease and prognosis (Miller et al. 2014b), which may alleviate some of the stress and uncertainty that plagues the illness experience. We strongly encourage that HCPs engage in an age-appropriate dialogue with children and adolescents with cancer and advocate that informed assent be obtained from all underage patients before participation in phase I trials (Spinetta et al. 2003). A phase I communication model that integrates recommendations from both HCPs and families has been described in the literature; it entails a two-part educational process, including the provision of an informative phase I fact sheet to patients and families prior to the formal informed consent discussion (Johnson et al. 2015).

Communication about enrollment in phase I clinical trials often involves complex interpersonal, psychosocial, and ethical issues (Oppenheim et al. 2005), which fall beyond the scope of this chapter. Open communication and age-appropriate participation of children with cancer in the decision-making process prior to enrollment in a phase I trial, as well as assent to participate, should be prerequisites to their participation.

4.4.4 Communication Around Advance Care Planning

Following Carly's disease progression, you led Carly and her family in multiple conversations about their goals. Carly expressed a desire to go home, but her father remained adamant that she enroll on a Phase I trial in the hopes that she might still be cured. Unfortunately, Carly's pulmonary metastases progress rapidly, making her ineligible for enrollment in a Phase I trial. Over several long conversations, you help the family reach a compromise: since Carly's greatest goals are to visit Disney World and spend time with her friends at *home, you coordinate a regimen of chemotherapy with the goals of prolonging her life, minimizing her time spent in the hospital, and allowing her to take short trips in between treatment cycles. Carly and her family use her Make-a-Wish to visit Disney World, and they have a wonderful time.*

Carly's father initially declines a palliative care consult, as he equates palliative care with "giving up." You continue to encourage the family to consider consultation, describing the team as "a group of experts whose job is to improve Carly's quality of life and provide support to your family, in whatever way is most helpful to Carly and your family." Eventually, Carly's parents agree to meet with the palliative care team, and they are pleased to learn that they are eligible for a number of home services and resources through a local hospice. Carly's father frequently reminds you, "We are only using hospice because they help us at home, not because Carly is dying." You tell him that you are glad to hear that the services are helpful and that Carly is doing well and enjoying her time at home.

Unfortunately, several days later, Carly acutely develops respiratory distress, and she is admitted to the hospital. Once she is placed on supplemental oxygen, she feels more comfortable. Repeat scans show significant disease progression throughout her lungs, and you share this bad news with Carly and her parents. "What treatment am I going to get next?" Carly asks. You gently reply, "I am so sorry, Carly, but your chemotherapy is not working, and I worry that it may be causing you more harm than good. But we have many different treatments to help your breathing and to make you feel as comfortable as possible." Carly thinks about this for a moment. "Does this mean that I going to die?" she asks you. Her parents are silent, waiting for your response.

Clear, empathic communication from HCPs, while always important, is particularly essential as patients experience further illness progression. Unfortunately, many oncology clinicians self-report a lack of formalized training in communication around difficult topics including advance care planning (Hebert et al. 2009; Buss et al. 2011), leading to a lack of comfort and proficiency in communicating with patients and families during this exceedingly stressful time.

It is important for HCPs to recognize that effective communication about advance care planning does not spring out of a vacuum; it requires a certain degree of preemptive legwork. When HCPs have relationships with patients and families that are built upon trust and mutual respect, communication about prognosis and goals of care can gradually metamorphose into conversations about the EOL in an organic and nonthreatening way (Baker et al. 2007). However, before jumping into a conversation about advance care planning, HCPs should ensure that the right people are present for the conversation, that an appropriate environment is selected, and that all participating HCPs have a comprehensive understanding of the current medical situation (von Gunten et al. 2000) (Table 4.7).

HCPs should begin a conversation about advance care planning by establishing what the patient and family understand. Open-ended questions are valuable for achieving this goal. HCPs

Table 4.7 Steps to follow prior to initiating a conversation about EOL goals

Invite the right people	Whenever possible, the HCP leading a conversation about EOL goals should be someone whom the patient and/or family trust. If this is not feasible due to extenuating circumstances, every effort should be made to include in the discussion other providers (e.g., social worker, child life specialist, chaplain, psychologist) with whom the patient or family have an established rapport
	Ask the patient and family ahead of time about whom they would like to have present in the discussion. Encourage patient participation as much as possible. If the family expresses hesitation about including the patient, explore their feelings and rationale. Invite child life specialists and other psychosocial support providers to help parents and HCPs present information in the most age-appropriate way possible
Plan your time and setting	Select a private, quiet space with minimal distractions. For hospitalized patients, offer to hold the conversation at a location that is separate from the "safe space" of their hospital room, if preferred
	Choose a time at which HCPs will not be rushed or interrupted; ensure that this time is convenient for the patient and family
Do your research	HCPs who plan to attend the conversation need to ensure that they have a good understanding of the patient's medical history, current clinical status, and future potential treatment options
	HCPs need to discuss and resolve any differences of opinion before meeting with the patient and family

should deliver information in a sensitive and straightforward manner, responding empathically to any emotions expressed by the patient and family, validating their shared values and experiences, and affirming the HCP's role as their advocate (Levine et al. 2013). If the HCP feels unsure about what a patient or family member means during a conversation, they should always ask for clarification. For example, a child who asks, "Am I dying?" might be asking a number of different things. She might be experiencing a new or worsening symptom, which she believes to be a harbinger of imminent death. Alternatively, she might be worrying about who will take care of her beloved pet or how her family will get along when she is gone. She might be wondering whether death will hurt or whether she will meet her grandparents in heaven. If we do not ask for clarification, we might miss an opportunity to explore the EOL issues that are most important to the patient and family:

> *You feel startled when Carly bluntly asks, "Am I dying?" You want to respond honestly to her question, but you feel unsure about exactly what information she is hoping to receive. You gently ask her, "What makes you ask this question?" Carly thinks quietly for a few moments, and then she responds, "I felt like I could not breathe this morning. If I cannot breathe, then does this mean that I am dying today?"*
>
> *You reply, "I am very glad that you asked this question. You are right that the cancer in your lungs can make it feel hard to breathe. This does not mean that you are dying right now, but it does mean that your lungs are very sick." You pause, and then ask Carly if this makes sense, and she nods "yes." You continue, "We will give you medicines so that your breathing feels more comfortable. Hopefully this will allow you to do the things that you have told me are important to you, like playing with your friends and watching Disney movies." You pause again, and Carly smiles and nods emphatically in agreement.*
>
> *You turn towards Carly's parents, who have been sitting silently during this exchange. "Carly is so smart, and she is asking such important questions," you tell them. Carly's father looks down at the ground, while her mother nods and begins to cry. "These are such difficult things to talk about," you say. "But perhaps we should begin talking about what might happen when Carly's lungs get sicker. I think it is important for us to discuss what goals you and Carly share, and how we can make sure that our treatments match your goals moving forward."*

Initiating and facilitating conversations about advance care planning can be challenging for many reasons. The patient and family might have conflicting goals, or they might share the same goals yet face disagreement from HCPs. To complicate things further, the patient (or parent) might express multiple goals at the same time, some of which might appear contradictory to HCPs, making it difficult to create management plans in alignment with fluctuating goals of care. However, it is important to remember that hoping for cure does not necessarily preclude the recognition of incurable disease and a wish for prolonging a life with quality. HCPs should validate both of these hopes, even if they seem contradictory, and help guide the patient and family toward making decisions that best match their values and goals:

> *Carly's father says, "I know that she is very sick. I just want Carly to be cured. I feel like she can be cured, if we just pray hard enough." You notice that Carly is watching her mother cry. You tell Carly, "Sometimes your mom cries because she loves you so much, and she wants you to feel better." Carly nods, squeezes her mother's hand, and then goes back to watching her Disney video.*
>
> *You turn to Carly's parents and say, "I also hope and pray with you that Carly will be cured." You pause for several moments, and then say, "What other things are you hoping for?" There is a long silence. Finally, Carly's father whispers, "I hope that Carly can have as much good time as possible. I pray that she will be comfortable and not suffer." You reply, "I also share this hope with you. We have excellent treatments for Carly's symptoms, and we will do everything possible to ensure that Carly feels comfortable and has as much good time as possible."*
>
> *You then turn to Carly and ask, "What are you hoping for?" Carly looks at her father and says, "I want to be at home. I hope that I never have to stay overnight in the hospital again." Her mother slowly nods in agreement, while her father remains quiet. "Thank you for sharing this with me," you tell Carly. "Why don't you talk about this with your parents more tonight, and then we can make a plan tomorrow. If this is what your family decides, then we can certainly make arrangements for you to be at home as much as possible. Based on everything that you'd told me, I think that this is very much aligned with your hopes and goals. And as we've discussed before, I recommend that we ask our hospice team to continue helping us achieve these goals. They can bring medications and supplies directly to your home, as well as help you*

> *manage symptoms so that you do not have to come into the hospital as frequently. I will work closely with them, and I will continue to walk with you through every step of this journey."*

As a patient's illness progresses, it is critical to assess and address the physical, spiritual, and emotional needs of the patient and family (Baker et al. 2008). Including other providers such as psychologists or chaplains in the discussion can ensure additional layers of support as HCPs broach difficult topics such as advance care planning, preferred location of death, limitation or discontinuation of life-sustaining support, and anticipatory grief and bereavement (Rabow et al. 2004). Table 4.8 offers high-yield communication topics to address during a discussion about advance care planning, while Table 4.9 provides examples of statements to avoid and alternative statements to use while communicating with patients and families about EOL issues.

Timely communication about EOL preferences is critical to ensure that care plans honor

Table 4.8 High-yield topics to cover during advance directive discussions over time

Resuscitation status (including ways to ensure that their wishes are followed in the community)
Use of antibiotics, intravenous hydration, parenteral nutrition, and other life-prolonging interventions
Preferred location of care/location of death
Which individuals should be present or called during the dying process (or after death)
Rituals/family traditions/legacy-building wishes at (or after) the time of death
Autopsy

Table 4.9 Communicating with patients and families about EOL issues

Statements to avoid	Alternative statements	Clinical pearls
"Do you understand what I have just told you? Do you have any questions?"	"I have a tendency to use big words and medical language. I have given you a lot of information today. Can you summarize where you think we are right now?"	The term "understand" can be loaded. Consider asking what the family has heard from the medical team instead
"What do you want us to do in case your child's heart stops?"	"Other families have found it helpful to hear recommendations from the team. Would this be helpful to you?"	Always ask permission before giving opinions or recommendations Reference previous discussions about goals of care
"It is time to pull back."	"Let us think about discontinuing treatments that are not helping and may be causing discomfort or harm."	Echo language or phrases that the family has used previously. For example, "You told me that you do not want your daughter to suffer any longer. Let us talk about ways that we can do that."
"There is nothing more that we can do."	"I wish there was more that we could do that would halt the progression of this disease, but none of the treatments we have are able to do this. We are still devoted to taking care of your child and will do everything in our power to keep pain and discomfort away."	Doing everything includes recognizing when the limits of medicine have been reached
"I know/understand how you feel."	"What might be helpful to you at this time? Would you like me to talk with other family members or be with you when you talk to them?"	Bring in a multidisciplinary team and consultants and allow team members to be useful to the family
"This will make you a better/stronger person."	May I sit here with you?	Be present physically and emotionally. Avoid distractions; feel free to respond to the situation with emotions

the wishes of the patient and family, particularly in the context of advance care planning and limitation of life-sustaining treatments that are not in alignment with the goals of the patient and family (Freyer 1992). Parents' choices regarding limitation or discontinuation of medical therapies can be influenced by their past experience, intrinsic personality, emotional state, religious affiliation, or opinions of other family or community members (Sharman et al. 2005). Parents value the recommendations of their child's HCPs (Meert et al. 2000; Carnevale et al. 2006), particularly if they have previously established a trusting relationship with them (Meert et al. 2000). In this way, HCPs can empower patients and families to make decisions that align with their values and represent the best interest of their child and family:

> *You work with the palliative care and hospice team to allow Carly and her family to leave the hospital and remain at home on supplemental oxygen with close home-based supportive services. Carly continues to come to the outpatient clinic once a week to receive blood products and discuss her symptom management. At her visit today, Carly appears quite comfortable. She tells you, "It is awesome to be at home, since I have all of my toys and my friends come over to play with me." Carly then leaves the room to meet with her child life specialist, who has been working with Carly to explore her hopes and questions about going to heaven through play therapy.*
>
> *After Carly exits, her parents share that the hospice team has been very helpful in ensuring that Carly has sufficient supplies and medications at home to control her shortness of breath. Carly has grown attached to her hospice nurse, who visits them 2–3 times a week to provide ongoing symptom assessment and management. You tell Carly's parents how glad you are that Carly is feeling well and enjoying quality time at home. You then say, "I wonder if now might be a good time for us to plan ahead, like we discussed at our last visit. Just as we made a plan to control Carly's shortness of breath, we always want to prepare for the worst while still hoping for the best."*
>
> *You pause, and sit in silence for several moments as Carly's mother nods and her father stares at the floor. You then say, "I am so sorry that we are having this conversation. It is so difficult to talk about this. But in my experience, it is better to have these discussions while Carly is doing well, as opposed to waiting until a time when she is very sick. Would it be okay if we talked about what you and Carly would want, in the event that her lungs become very sick and she was unable to breathe on her own?" Carly's mother begins to cry, and she takes her husband's hand and nods again, inviting you to speak.*
>
> *You briefly summarize Carly's current medical situation: "We know that the cancer is in Carly's lungs, and our treatments are not able to stop it from growing. I think it is likely that Carly's lungs will continue to worsen over the next few weeks. We will give her medications and do everything possible to keep her comfortable so that she does not feel shortness of breath. But unfortunately, we do not have treatments that can make her lungs healthy again." You pause, and then ask Carly's parents what questions they have; both parents shake their heads and remain silent.*
>
> *You continue, "Eventually, Carly's lungs will become so sick that she will stop breathing, and this will cause her heart to stop beating. We could put a breathing tube into her lungs and connect her to a machine that breathes for her, and push on her chest and shock her with electricity to try to make her heart beat again. But I worry that these interventions would cause harm to Carly, without offering her any benefit or changing the progression of her disease. Even if we were able to keep Carly alive, she would not be able to breathe without the machine, and she would need to be very sedated to prevent her from suffering." You pause again to allow Carly's parents time to process this information.*
>
> *After a minute, you say, "Based on what Carly and you both have told me in the past, it sounds like your goals are for Carly to be able to spend as much quality time as possible at home and to avoid being in the hospital. Given your goals, my recommendation would be for Carly to remain at home and to receive medications to ensure that she is comfortable at the end of her life." Her mother quietly says, "I do not want Carly to go through any more suffering. I want her to stay at home." Her father does not speak, but eventually he nods. You tell her parents that this is a loving decision and that the team will do everything possible to prevent Carly from suffering. You then provide Carly's parents with state-specific paperwork that delineates your mutually-agreed upon recommendation for "Do not attempt resuscitation," explaining that this form will ensure that all healthcare providers respect these wishes in the community.*

4.4.4.1 Involving Pediatric Patients in End-of-Life Discussions

HCPs should encourage families to include children and adolescents in EOL discussions in age-appropriate ways in order to address fears, answer questions, and provide anticipatory guidance (Levine et al. 2013). The use of open-ended

Table 4.10 Recommendations for responding to the question, "Am I dying?"

Strategy	Example language
Begin with reassurance that you will answer the child's question	"I promise to answer your question…"
Obtain more information about the child's motivation for asking the question	"…but first it would be helpful for me to know why you are asking this question." "Are you willing to share with me what you are thinking about?"
Elicit information about the child's concerns	"What are you most worried about?"
Validate the child's questions and worries	"You are asking very important questions." "What a good question. I can see that you are worried about [x] and/or feeling [y]."
Ask the child to share his/her preference for receiving information	"What would be most helpful for you to know right now?"

questions is a valuable strategy for eliciting what the patient believes about his or her condition, addressing misconceptions, and providing reassurance. Children with life-threatening conditions often possess a more advanced understanding of death and dying than do their healthy peers, and they may benefit greatly from having opportunities to communicate openly about their thoughts and feelings regarding their illness experience (Masera et al. 1999). Table 4.10 offers several recommendations for language to consider using in response to a child's question, "Am I dying?"

Adolescents similarly benefit from having an invitation to express their EOL preferences by using communication and advance care planning tools such as *Voicing My Choices* (Wiener et al. 2012). Unfortunately, adolescents often feel marginalized during medical discussions (Young et al. 2003); including them in important conversations and allowing them to participate in decision-making is an important strategy to empower them, increase hopefulness, and overall impact their care in a positive way (Hinds 2004).

Despite the data to support the need for open communication with pediatric patients about EOL issues, many families struggle to discuss such difficult topics with their children. This is understandable, and HCPs should meet families where they are and help them begin to work toward improving communication in a way that feels right for their family. For certain families, HCP might consider sharing the results of a study that found that none of the bereaved parents who communicated with their children about death regretted this decision (Kreicbergs et al. 2004). HCPs should also share with families that many children and adolescents at the EOL are cognizant of their imminent death, encouraging them that addressing the "elephant in the room" may actually alleviate stress for both the patient and family (Wolfe 2004). We recommend that HCPs use an interdisciplinary approach, involving child life specialists, chaplains, psychologists, social workers, and any other supportive clinicians to work with parents who are reticent to communicate with their dying child, encouraging them to consider how open communication might benefit the patient and family as a whole. Further recommendations about including siblings in these important conversations are discussed in a following section.

4.4.5 Communication During the Bereavement Period

Over the next 2 weeks, Carly's shortness of breath and pleuritic chest pain acutely worsen. With help from the palliative care team and the local hospice group, you are able to ensure that her symptoms remain well-controlled at home. During this time, multiple members from Carly's interdisciplinary care team remain closely involved in her care, speaking daily with her parents to provide them with support, manage her evolving symptoms, and offer information about what to expect at the EOL. Ultimately, Carly dies peacefully at home surrounded by her family. Over the following months, her parents struggle to regain a sense of normalcy. They later reflect that losing their

> *daughter was made more difficult by the simultaneous loss of the community of HCPs who had become like family to them during their difficult journey.*

The death of a child is an unimaginable and devastating event that results in profound grief for parents. Bereaved parents frequently experience debilitating feelings of shock, helplessness, and guilt (Higgs et al. 2015), and for many the grief journey can be intense and prolonged (Michon et al. 2003; Snaman et al. 2016a). These grief reactions may be compounded by other losses, such as the loss of support from the child's medical team (Back et al. 2009). Parents might experience the loss of this bond as a type of abandonment, thereby exacerbating the bereavement journey (Contro et al. 2004).

In addition, intrinsic factors such as language barriers can interfere with adjustment during the bereavement process (Koop and Strang 1997). Situational factors surrounding the death and bereavement period can also influence the grief response. Some situational factors, such as the suddenness of an unexpected death, cannot be changed; however, other factors, such as the availability, emotional attitudes, and communication skills of HCPs, can be optimized (Steele et al. 2013). Parents' cognitive coping resources, emotional attitudes of staff, and adequacy of the information provided to parents can predict the intensity of long-term grief (Koop and Strang 1997). As expected, parental perception of an uncaring emotional attitude of staff has a detrimental effect on coping with short- and long-term bereavement, whereas a caring attitude by staff has beneficial effects on coping with short- and long-term bereavement (Meert et al. 2001).

As we have discussed above, a HCP's ability to provide transparent and empathetic information to families is a critical aspect of holistic care (Weaver et al. 2016), and this includes delivery of compassionate, honest, complete, and caring information (Contro et al. 2004; Mack et al. 2005; Meert et al. 2008a, 2009; Neidig and Dalgas-Pelish 1991). Empathetic delivery of difficult news or discussion of EOL topics, including prognostication delivered in the context of a caring relationship, is associated with lower levels of long-term parental grief (Mack et al. 2007b; Zelcer et al. 2010). Specifically, discussions held near the EOL that center on goals of care are associated with the use of less aggressive medical care near death, which in turn is associated with better adjustment to bereavement (Wright et al. 2008). In one study, more than 50% of caregivers of pediatric cancer patients reported regret about their EOL care; however, communication about advance care planning helped caregivers adjust better to bereavement (Garrido and Prigerson 2014).

Communication with families of children who are managed in the intensive care unit (ICU) is particularly important to mitigate complicated bereavement. Empathic communication skills with families of patients in the ICU can improve family satisfaction and reduce adverse bereavement outcomes (Schaefer and Block 2009). Parents whose children died in the pediatric ICU have highlighted the critical importance of the communication style of the physician who gave the "bad news." (Meert et al. 2008b) The most common communication issue identified by parents is physician availability and attentiveness to their informational needs. Other communication issues are honesty and comprehensiveness of information, affect with which the information was provided, withholding of information, providing false hope, complexity of vocabulary, pace of providing information, contradictory information, and physicians' body language.

The significant sequelae experienced by grieving parents highlight the need for ongoing care and resources targeted specifically to this bereaved population (Michon et al. 2003). A multidisciplinary approach is needed to provide optimal bereavement care to parents (Higgs et al. 2015). Pediatric palliative care emphasizes the provision of holistic care designed to address the physical, psychological, social, and spiritual needs of patients and families throughout the illness course and into the bereavement period (Kaye et al. 2015). Importantly, parents were more likely to have received EOL anticipatory guidance and bereavement support if their child was referred to a palliative care team (Kassam et al. 2015), which highlights the important role of pediatric palliative care providers in the holistic care of children with cancer and their families.

Unsurprisingly, bereaved parents identify communication as a top priority during both the EOL and bereavement periods (Hinds et al. 2005) and highlight the importance of continuity of care extending beyond death (Steele et al. 2013). Specifically, families express a desire to remain connected to their child's HCPs even after the child's death (Steele et al. 2013; Snaman et al. 2016b). Unfortunately, the bulk of supportive services are offered during illness and at the EOL, with limited resources available to families after a child's death. Thus, many families receive little or no bereavement follow-up (Bradshaw et al. 2005). Yet parents who lose a child to cancer specifically express a desire to talk with those HCPs who cared for their child as an important aspect of their grief process (Snaman et al. 2016a, b; Jankovic et al. 1989; Lichtenthal et al. 2015). Even a simple phone call from a member of a deceased child's healthcare team to a bereaved parent affords an opportunity to remind a family that their child is not forgotten, screen bereaved relatives at risk for complicated grief for potential adverse outcomes, and link families to helpful resources in their local communities (Jankovic et al. 1989; Lichtenthal et al. 2015). Whether formal or informal, contact between HCPs and families during the bereavement period offers valuable meaning-making opportunities for parents, including making sense of their child's death, exploring positive outcomes such as volunteering or giving back to other families going through similar hardships, and promoting legacy-building opportunities to strengthen bonds with the decreased child (Snaman et al. 2016a; Meert et al. 2015).

The fact that bereaved families often wish to continue relationships with their child's HCPs suggests the importance of developing an institutionally based bereavement program to support families throughout their grief journey (Mullen et al. 2015). Table 4.11 offers a list of recommendations for HCPs to consider when providing support for bereaved parents (Snaman et al. 2016a).

4.4.6 Communication About Spirituality

Spiritual conversations are a significant and vital avenue for HCPs to explore in an effort to improve QOL for cancer patients and their families (Peteet and Balboni 2013). Communication about spirituality influences goal-directed decision-making and may reduce the use of intensive interventions in patients with advanced cancer at the EOL (Peteet and Balboni 2013; Balboni et al. 2013). Acknowledging the spiritual needs of children and adolescents with cancer, in particular, can help them cope with their illness (Proserpio et al. 2014). Because the concerns of

Table 4.11 Directives for providing grief support to bereaved parents

Communicate with patients and families clearly and honestly, providing accurate and timely information to allow them to participate in shared medical decision-making while taking into account goals of care and working to support decisions made by families
Involve bereaved parents in the design and implementation of communication training for healthcare staff
Show empathy as a part of a continuing and strong bond between HCPs and the patient and family. Find ways to continue to be involved with the family after the child's death, and work to continue the established therapeutic alliance
Acknowledge that the HCP identify might shift from a cure-focused medical provider to a companion on the parent's grief journey. Do not try to "fix" the hole in the heart of bereaved parents. Instead, recognize, acknowledge, and bear witness to its presence
Embrace the opportunity and challenge of initiating difficult conversations with patients and families throughout the disease process. Avoid giving false hope or offering unrealistic treatment choices. Enhance efforts at communication and ensure continuity of care around times of transition (e.g., between different care settings)

Adapted from Snaman JM et al. Helping parents live with the hole in their heart: The role of healthcare providers and institutions in the bereaved parents' grief journeys. *Cancer* 2016;122(17):2757–65 children and adolescents are primarily relational, spiritual chats with a trusted HCP can help them examine significant relationships with others, the sacred, and the self (Kamper et al. 2010). Spiritual conversations enable children and adolescents to deepen their feelings of personal value, personal empowerment, and overall peacefulness (Hart and Schneider 1997).

Although HCPs acknowledge that spiritual care is an important part of holistic care, cancer patients report that HCPs do not frequently provide spiritual care (Peteet and Balboni 2013). Even clinicians who recognize the benefits of spiritual care and are attentive to patient cues face professional and personal barriers that might prevent them from engaging in spiritual communication. Professional barriers include lack of professional training in spiritual care, time constraints, role uncertainty, and lack of administrative support (Rassouli et al. 2015). Personal barriers include fear and ambiguity about how they can talk with their patients about things they personally do not believe in or do not understand.

Let us consider a scenario in which our patient Carly, during a routine clinic, visit suddenly asks, “Why does God let kids get sick, and some die?” This question might feel unsettling, but it offers a great opportunity to promote positive spiritual well-being and enhance Carly’s overall care. Before responding, it is important to recognize that children react to difficult circumstances according to their personal developmental trajectories (Hart and Schneider 1997). Key spiritual needs for a 9-year-old child include acceptance, love, recognition, security, compassion, and trust. Important spiritual concerns for a 9-year-old child include abandonment, chaos, guilt, fear, isolation, lack of trust, feelings of being punished, shame, and violation.

Carly’s question might make us speculate that she feels any or all of the above spiritual concerns. However, we do not want to operate on speculation or come across as if we have an answer or “easy fix” for her difficult question. Our goal should be to frame the conversation in an age-appropriate way that allows Carly to define what is most important to her (Lima 2013).

Our first instinct might be to respond to Carly’s difficult question with a spiritual cliché, such as “We must trust in God’s will.” Offering one of these comments might make us feel better, but it will likely not address Carly’s specific concerns nor assuage her spiritual distress. Carly may be contemplating the impossible to answer such as mystery, justice, meaning, and mortality. Rather than wanting an answer, she wants someone to listen. She might even be testing you to see how honest, open, and nonjudgmental you are. She is seeking compassion, someone to suffer with her, and someone with the courage to hear her pain (Hart and Schneider 1997). She needs someone willing to be flexible, honor her pace, and not push an agenda onto her.

We also must remember that children process large issues in small bites. They typically do not spend hours having complex, nuanced discussions. They might talk for a few minutes, self-distract, and then return to the conversation later. When responding to a child’s spiritual inquiry, it is best to provide short responses and then pause to see if he or she wishes to continue the conversation. Table 4.12 details those spiritual clichés that HCPs should try to avoid and potential responses to use instead during spiritual conversations. The responses in Table 4.12 help us model our human vulnerability for children. Professional competency is not compromised by vulnerability; rather, relationships are enhanced by it. Such responses invite the child to explore spiritual needs and help us identify potential concerns that reflect negative religious coping (Balboni et al. 2010). Soothing appropriate responses also help create a safe place for trust and leave the door open for future communication.

Often, prayer is an appropriate and welcome response to a spiritual concern (Hart and Schneider 1997). It is not, however, a magic bullet or a tool to pull out of our bag every time we feel uncomfortable. Prayer should be used sparingly and potently, and it needs to reflect the content of the conversation. Before praying, it is important to ask the patient or family if there is anything specific that they wish to include in the prayer. Table 4.13 describes the steps in introducing the idea of prayer to the child and

Table 4.12 Communicating with children about spiritual issues

Spiritual clichés to avoid	Possible responses to try
"You know, Carly, we have to accept God's will. He knows best."	"I struggle with the same questions. It does not seem fair does it?"
"You do not have to worry about dying. You are going to be okay."	"I can see that you feel worried. These are very normal feelings to have. Can you share with me what things are worrying you the most right now?" "It must make God very sad when a child gets cancer or dies. Do you think it makes God sad?"
"God knows more than we know. Perhaps it is best not to question."	"It can be hard to have questions or worries, and not know the answers. Is there something specific that is keeping you up at night?" "Sometimes when I have questions for God I ask God. Do you talk to God when you have questions? Are there other people you talk with when you have questions or worries?"
"Sometimes God needs to bring a child to heaven for a special mission."	"I'm very sorry you are sick. I really love (or like) you and I believe that there are many other people who love you, too." "I also believe that God loves you. Do you believe God loves you?" "What does heaven mean to you?"

Table 4.13 Strategies to introduce the idea of prayer to children with cancer: specifically for use by chaplains or other clinicians who feel comfortable with prayer

Steps to introduce the idea of prayer	Example language to use
If appropriate in the context, offer an invitation for prayer	"Carly, sometimes it helps people feel better when someone prays for them. Would you like me to pray with you?"
If the patient (or family) says "No," do not try and talk them into it or proceed without their assent	"Not everyone likes to pray, and that is okay. If you change your mind, you can let me know."
If the patient says "Yes," ask her to help you shape the prayer	"Carly, is there anything special you would like for us to pray about together?"
Before praying, position yourself at eye level, or close proximity, of the child	–
Some people like to hold hands or place a hand on the patient. Use your best clinical judgment in doing so; some people appreciate touch whereas others do not	–
Make the prayer short and to the point	"Dear God, Carly and I do not understand why children have to be sick and die sometimes. It seems unfair and makes us feel sad. Carly is a sweet and special girl. Everyone at our hospital loves her. We pray that she will not be in pain. We pray that when she feels afraid she will know we are here for her. And we pray that she will know that both you and I care about her. Amen."

family. Lastly, HCPs should not offer or accept an invitation to pray if they do not feel comfortable doing so. Particularly for patients with religious and cultural traditions different from those of the HCP, professional assistance from a chaplain or clergy person familiar with the patient's faith might be helpful.

In summary, children and adolescents have unique spiritual needs. As they deepen their relationships with their loved ones, their caregivers, and with God, they can derive personal value and empowerment (Hart and Schneider 1997). As practitioners, we have the responsibility and privilege to assist in nurturing the spiritual lives of children and adolescents with serious illnesses. Being alert, present, competent, and self-aware can help us identify the right moment—the sacred moment—at which to participate in the spiritual conversations that lead to optimal holistic care and deepen our patients' and our own humanity.

4.5 Communication Barriers in Pediatric Oncology and Palliative Care

> *"The most important thing in communication is hearing what isn't said."*
> *– Peter Drucker*

Although most HCPs strive to communicate effectively with patients and families, several barriers can hinder the best of intentions. Oncologists self-report that fear of causing distress and fear of abrogating hope are impediments to clear and honest communication of difficult prognostic information (The et al. 2000; Kodish and Post 1995; Miyaji 1993). Prognostic uncertainty (Lamont and Christakis 2003; Christakis and Iwashyna 1998) and paternalism involving a perception that the patient or family will be unable or unwilling to hear bad news (Parsons et al. 2007; Singh et al. 2015; Goldie et al. 2005) also contribute to ineffective or misleading communication. Oncologists acknowledge that poor communication secondary to avoidance of difficult information can stem from feelings of failure born from a realization that the patient might die (Thompson et al. 2009; Davies et al. 2008; Knapp and Thompson 2012; Knapp et al. 2008; Hilden et al. 2001). In addition, effective communication with children carries a unique set of challenges and requires specialized training in age-appropriate communication styles and strategies, which many oncologists do not receive. Non-physician providers who care for children with cancer face similar challenges as do their physician colleagues, which can result in self-reported feelings of anxiety during discussions about prognosis and goals of care with seriously ill children and their families (Masera et al. 1997; Contro et al. 2004; Feudtner et al. 2007).

Many of the above barriers are exacerbated by insufficient training in communication skills (Contro et al. 2004; Singh et al. 2015; Sanderson et al. 2015; Collins 2002) and lack of adequate communication role modeling (Hilden et al. 2001) for trainees and clinicians early in their career. In pediatric oncology, the lack of formalized palliative care education is increasingly recognized as a critical deficit in training (Fowler et al. 2006). In a 1998 survey, 90% of pediatric oncologists reported that they learned to manage dying children on the job and did not receive structured didactics or role modeling (Hilden et al. 2001). Although this percentage has decreased over the past decade, a 2014 Institute of Medicine report highlights the insufficient attention given to palliative care training and the failure to equip physicians with adequate communication skills (Institute of Medicine 2014). At the end of this chapter, we discuss the current status of communication-based training specific to pediatric oncologists and offer strategies for overcoming some of the barriers described above through formalized educational paradigms.

However, not all barriers to communication arise from HCPs; patients and parents can also contribute to the obstruction or delay of effective communication. The emotional state and receptiveness of patients or families to receiving difficult news can affect an HCP's ability to successfully transmit information or build rapport (Eden et al. 1994). Providers must be sensitive to the emotional fragility of patients and families. Good communication is a marathon and not a sprint: if the child or family cannot participate in an in-depth conversation for emotional reasons, the HCP should consider rescheduling the meeting to allow the patient and family time to collect themselves prior to engaging in the conversation.

The preferences, beliefs, and past experiences of the patient or family can also influence their ability to share or receive information from HCPs. For instance, depending on the patient's or family's frame of mind and prior circumstances, communication about goals of care can be mistaken for "giving up," which can result in fracturing of the therapeutic alliance (Jünger et al. 2010; Friedman et al. 2002; Claxton-Oldfield and Marrison-Shaw 2014). It is imperative that HCPs make careful language choices that facilitate reframing goals of care (Hill et al. 2014), as opposed to engendering feelings of abandonment. Patients and families might also have differing opinions about which topics are the most important to discuss. In one study, HCPs placed a higher importance on having conversations about death and dying whereas parents prioritized discussions about spiritual support and having the option for their child to receive cancer-directed therapy during the last month of life (Kassam et al. 2013). As such, even the most honest and empathic communication is only effective if it offers content valuable to the listener. Effective communication begins with the HCP asking what the child and family hopes to learn and in what way they wish to receive the desired information.

Parents might also choose to withhold difficult information from children in an effort to protect them, thereby compromising open lines of communication and placing the HCP in a difficult position (Last and van Veldhuizen 1996; Parsons et al. 2007; Singh et al. 2015; Gupta et al. 2010; Case Conference 1985). Balancing clinician respect for both the autonomy of the patient and the values of the family unit can be challenging (Young et al. 2003; Hinds 2004). We discuss strategies to overcome this barrier in the next section.

4.6 When Communication Does Not Go Well

Although honest communication with children about EOL care has been shown to be beneficial for both children and families (Kreicbergs et al. 2004), initiating these conversations can be challenging. A particularly difficult scenario for HCPs occurs when parents wish to withhold information from an ill child. In this section, we will discuss the difficulties inherent to this situation and offer strategies to help open the lines of communication while fortifying the therapeutic relationship among the HCP, patient, and family:

> *Imagine a scenario in which Carly's parents refused to discuss her cancer with her. Perhaps they felt that they needed to shield Carly from the truth about her illness in order to fulfill their roles as "good parents." Or perhaps they worried that if Carly knew that she was dying, she would "give up." Alternatively, her parents might have felt that telling Carly the truth would cause anxiety or be too much for her to bear. For whatever reason, consider a situation in which Carly's parents ask you not to tell Carly that her disease is progressing.*

Children, like adults, need information to help them prepare for the future and cope with receiving a potentially life-altering diagnosis such as cancer (Clarke et al. 2005). If they do not receive clear information about their illness, children may generate their own ideas about what is wrong by imagining a scenario worse than the truth, seeking out information from friends, or looking on the internet for answers. Very young children also employ "magical thinking," in which they harbor the misconception that their illness is a form of punishment for something that they thought, said, or did. Despite the fact that children who receive honest information about their diagnosis have less anxiety than those who are not told, some parents still prefer not to disclose diagnostic or prognostic information in an effort to protect their child (Clarke et al. 2005). This act of withholding information often results in discomfort and ethical consternation for HCPs (Slavin et al. 1982; Claflin and Barbarin 1991).

It is important for HCPs to remember that parents who wish to withhold information from their children do so because that they believe that it is in the child's best interest. Parents might feel that their child is too young to fully understand the complexities of a diagnosis such as cancer, and they might wish to shield their child from abstract concepts such as illness and death (Zwaanswijk et al. 2011). However, even children who are too young to understand the implications of disease are capable of perceiving changes in their environment and routine and may act out as they try to make sense of unpredictable deviations from the daily norm. Changes in behavior, however subtle, suggest that the child feels the need to communicate a question or fear. Children might not understand the medical language used by physicians to discuss illness and treatment; however, children come to understand their diagnosis and prognosis over time by reading the expressions on the faces of people they love, the body language of their medical teams, the tone and pace of speech used to talk about them, the urgency with which they receive treatment, and the signals they receive from their own bodies. HCPs need to help parents understand that these collective experiences often culminate into a sophisticated understanding of death and dying that can be expressed by children as young as 3 years of age (Bluebond-Langer 1980).

When parents express concerns about their child's ability to understand, it can be helpful to involve the services of a certified child life specialist (CCLS). CCLSs are trained to assess a child's individual informational needs and break down complex medical information into language appropriate to the child's cognitive and social-emotional stage of development. CCLSs are also trained to provide play-based interventions to assist children in assimilating new information about their changing world and to help them share thoughts, worries, and wishes that they might not be able to express with words alone. Children often reveal much of what they understand through their art or dramatic play. These moments can serve as evidence to resistant parents that their child does indeed comprehend far more about his or her condition than the parents believe. Thus, the child's play becomes an avenue for continued discussion between the parent and specialist about the importance of disclosing developmentally appropriate information. Working directly with a CCLS often allays the common parental fear of saying the wrong thing or saying too much.

For some parents, objections might not be related to the child's age or development, but rather stem from a fundamental parental instinct to protect the patient from an ugly reality. In an attempt to shelter the patient, some parents might refuse to engage their children in conversation or refuse to allow others to share information with them (Young et al. 2003). In these extreme cases, a well-intentioned desire to protect the child may result in considerable harm by damaging the trust between parents and the child. Conversely, children and adolescents who have a better understanding of their illness and mortality possess a sense of autonomy and control that enables coping and resiliency (Bates and Kearney 2015).

HCPs shoulder the responsibility of informing hesitant parents of the benefits of involving children and adolescents in conversations about their illness. Ideally, a child's early involvement will enhance his or her skills in the process of participating in future decision-making (Levetown 2008). Some families might require an extended period of time to adjust to receiving a cancer diagnosis; for these parents, a stepwise approach to including their child in conversations can be beneficial. Explaining that diagnostic disclosure is a process and that prognosis needs to be treated as a separate issue can also help parents to accept diagnostic disclosure (Cole and Kodish 2013).

If parents explicitly state that they do not wish for anyone to speak with their child about diagnosis or prognosis, it is important to recognize that this is where conversations *begin* and not where they end. HCPs need to approach this situation with respectful curiosity and use the inherent opportunity to learn more about the family's values and concerns. Refusal to talk is often a reflection of fear, and HCPs need to better understand the nature of this fear before attempting to address it. This often involves talking with parents about who they believe their child to be and listening with a willingness to be influenced by what the parents share. HCPs can approach these conversations in different ways; the ultimate goal is not to change the parents' mind but to communicate a genuine desire to see the child through the parents' eyes.

Misconceptions about the child's illness and treatment, previous negative medical experiences, and worry that the truth will depress or steal hope away from the child also may adversely impact a parent's willingness to disclose information to their child. It is important to explore these themes when there is parental resistance against open communication with the child. Table 4.14 offers open-ended questions to help guide a difficult conversation between HCPs and resistant parents.

In the worst-case scenario, parents might not waver from their intention to conceal the truth from their child. In this case, it is the ethical responsibility of the medical team to set clear boundaries with the parents going forward. HCPs should explain in a frank but compassionate manner that they will not lie overtly to the child. If the patient asks a direct question, it is the HCP's obligation to answer it truthfully and in a manner appropriate to the child's

Table 4.14 Open-ended questions or statements to guide difficult conversations between HCPs and resistant parents

"I hear how important this is to you. Can you please tell me more about your concerns?"
"How are you and your family talking about this illness at home?"
"What words are you comfortable with or not comfortable with?"
"What has this illness been like for you/your child/your family?"
"What questions do you think your child will ask?"
"What do you believe your child to understand about his/her illness?"
"What are your fears/hopes for your child?"
"What concerns you the most right now?"
"Does your family have a faith tradition that your child shares in?"
"I can't imagine what this must be like for you."

developmental level. However, HCPs can offer to compromise with parents by answering the child's questions in a language that aligns with the family's belief system or by providing parents with the language and skills to disclose the information themselves.

Methods for sharing medical information with children can vary significantly, depending on the child's social-emotional and cognitive developmental levels, the spirituality and culture of the family, and the individual preferences of the child and family. To effectively engage children in medical conversations in a meaningful way, all these factors need to be individually assessed and incorporated into the HCP's approach toward the patient and family. There is no one right way or answer for every child or parent; however, these considerations can help the HCP determine an appropriate starting point and identify the subsequent steps for facilitating honest communication about the life-threatening illness with the child and parents.

4.6.1 Practical Suggestions to Improve Communication in Difficult Situations

Traditional models of communication within the medical system generally involve asking direct questions to the patient and/or the family and receiving a series of "yes" or "no" responses. The nature of this design places the HCP in control of the exchange and creates little opportunity for the patient or family to identify areas of personal concern or ask the questions that are most relevant from their perspectives. Although this HCP-driven process was once thought to be time-efficient, it is effective only if the HCP asks the right questions. Otherwise, the HCP can spend the entire interaction asking about issues that the patient and family do not perceive as pertinent to their health or circumstance (Boyle et al. 2005). This strategy becomes particularly problematic in the context of a fractured therapeutic alliance.

When communicating with the patient and family in difficult situations, an open-ended approach to communication is often a more time-efficient method for gathering information, assessing the problem, and identifying potential solutions. As HCPs listen carefully to the patient and family, differences in perception and perspective are revealed: a "problem" can appear quite different from varying viewpoints. For example, the medical team might perceive the primary problem to be disease progression, while the family might perceive it to be the team's lack of faith that a miracle is possible. Asking the family to share its sense of the current situation and what it means to them can enable the medical team to compare and contrast the assessments of the situation. Promoting this inquiry might reveal that the discord between HCPs and the patient and family arises because each party focuses on different issues. In such cases, reframing the goals of HCPs and the patient and family into a mutually shared purpose can resolve the conflict (Feudtner 2007).

Although interview styles vary by HCP, certain standard questions can help HCPs and the patient and family resolve the differences in perception and perspective. Table 4.15 offers questions to assist HCPs in aligning the medical team's goals with those of the patient and family.

4.6.2 Interdisciplinary Communication: The Importance of Debriefing After Difficult Encounters

Regardless of a HCPs discipline or years of clinical experience, walking with a family at the time of the child's death can be physically and emotionally taxing. HCPs might experience disenfranchised grief, which is the grief one feels when he or she has suffered a loss that is not recognized as meaningful by society, such as the loss of a patient (Kaye 2015). Learning to manage grief responses to patient deaths is a crucial, yet underemphasized, skill for HCPs. HCPs who cannot manage their grief in healthy and constructive ways might find themselves avoiding patients who evoke heightened emotional responses or find their personal lives affected by unresolved feelings of angst or sadness (Keene et al. 2010).

In such instances, debriefings can serve as a high-yield tool for supporting staff as they experience emotional reactions to patient deaths and can also improve communication across disciplines. Team debriefings build emotional resiliency, strengthen team bonds, and reduce a sense of isolation in the workplace (Granek et al. 2015). Debriefings are frequently used to assist teams that might be dealing with physical or emotional signs of distress after the traumatic death of a patient or other challenging events within the hospital (Berg et al. 2014). Integrating debriefing sessions into the standard training of residents and fellows can provide opportunities for staff to learn effective strategies for dealing with patient deaths from experienced physicians (Granek et al. 2015; Eng et al. 2015). Offering debriefing sessions is one example of support that an institution can provide as part of a multifaceted approach to support staff. Table 4.16 offers basic guidelines for facilitating successful debriefing sessions within medical teams.

Table 4.15 Identifying the root of conflicts between HCPs and patients/families

"You have talked with multiple physicians about ___. Can you please share with me what you have heard so far and what you are most worried about?"
"A moment ago you mentioned___. It seems as though this is something that is very important to you. Can you please tell me more about that?"
"The last time we met we talked about several difficult and complicated things. Can you tell me which part of our conversation have you found yourself thinking about the most?"
"Can you please tell me what has been most difficult for you to hear so far? What has made this the most difficult piece of news to receive?"
"What do you worry will happen next?" Or, "Now that we know more about what your child is up against, what are you hoping to happen next?"
"___ seems quite important to me as we consider next steps. Is this something that you also see as important?"

Table 4.16 Basic guidelines for conducting debriefings sessions for the medical team

Participation is voluntary
Participants are invited to share their thoughts, feelings, and reactions freely
The facilitator makes every effort to clarify misconceptions about the event or patient death
The discussion remains staff-centered and focused on personal expression and support; suggestions for improving the process might be useful in some instances, but individual performance review should be reserved for a separate conversation

4.7 Facilitating Communication Within the Family Unit

Although communication with the patient and parent is a priority for HCPs, facilitating communication within the whole family unit is also highly important in both pediatric oncology and palliative care (Feudtner 2007; Levetown 2008; Contro et al. 2002; Snethen et al. 2006; Mullen et al. 2015). In particular, the inclusion of siblings in the communication process impacts the family unit's adjustment to the illness experience (Gaab et al. 2014). Bereaved parents of children with high-risk cancer report appreciation for HCPs who actively engaged their family in conversations about their child's care (Contro et al. 2002). Likewise, bereaved siblings of children who died from cancer who report receiving adequate preparation for their sibling's death and/or satisfaction with communication during the end of their sibling's life also report significantly lower levels of long-term maladjustment (Eilertsen et al. n.d.; Rosenberg et al. 2015).

Conversely, compared with siblings who report being satisfied with the extent or nature of communication at the end of their sibling's life, those who are dissatisfied have higher levels of anxiety 2–9 years later (Wallin et al. 2016). Further, siblings who recollect perceptions of inadequate social support during the last month of their sibling's life and at the time of the sibling's death often experience more anxiety later in life (Eilertsen et al. 2013). Correspondingly, the International Society of Pediatric Oncology highlights the importance of active back-and-forth communication with siblings of children with cancer (Spinetta et al. 1999). Nonetheless, many siblings recall poor knowledge and a lack of communication about their sibling's EOL experience and what to expect (Lövgren et al. 2016) and suggest that HCPs focus on improving communication with siblings and the family unit (Lövgren et al. 2015).

The Family Management Style Framework (FMSF) represents one possible framework for improving communication within the family unit (Knafl et al. 2008). This framework highlights the integral role of each family member, as well as the family unit as a whole, in caring for a child with a chronic and/or life-threatening condition. The FMSF posits that, when deciding about the most appropriate approach to use for family communication, one must consider how each family member defines the situation of having a child with a serious condition (definition of the situation), what each family member does to attempt to manage or address the condition (management of behaviors), how each family member perceives the effect of the child's condition on family life (perceived consequences), and unique thoughts about what affects family life and what affects the responses of family members to the child's condition (Knafl et al. 2008).

Knowledge about decision-making patterns within families is also useful for optimizing communication (Snethen et al. 2006). HCPs should devote time to acquiring a sufficiently complete understanding of the family's differing perspectives, as well as to recognizing and learning to manage their own heuristics, interaction styles, responses, automatic thoughts, and resultant intrapersonal and interpersonal processes; all of these factors significantly impact an HCP's ability to communicate with families (Feudtner 2007). In order to communicate effectively with the family unit, demonstration of respect and compassion for individual family members and the family unit as a whole is imperative (Feudtner 2007; Clarke et al. 2005; Meert et al. 2008b; Mullen et al. 2015). Tables 4.17 and 4.18 present strategies for parents and HCPs, respectively, for facilitating communication within and between the family unit.

4.8 Communicating Without Words

> "To communicate through silence is a link between the thoughts of man."
> – *Marcel Marceau*

> "The most basic and powerful way to connect to another person is to listen. Just listen. Perhaps the most important thing we ever give each other is our attention.... A loving silence often has far more power to heal and to connect than the most well-intentioned words."
> – *Rachel Naomi Remen*

Table 4.17 Strategies to help parents communicate with siblings of children with cancer

Consider family preferences and cultural norms during discussions with parents
Encourage parents to be open and honest with the patient's sibling(s); however, ensure that you remain respectful of the parents' preferences and wishes
Help parents find developmentally appropriate language. If appropriate, explain how children typically understand death at various developmental stages
Stress the importance of using clear language such as "death," "dying," "dead," "cancer," and "stopped working."
Suggest that parents follow the lead of the sibling(s). Some children ask many questions, whereas others do not ask any questions. Tell parents that there is not necessarily one "right way" to communicate and remind them that children will often tell what will work best for them
Reassure parents that it is okay for their children to see them sad and/or to see them cry. Parents can be encouraged to say something like "Mommy is crying because she is so sad that *[patient's name]* is sick/dying."
Encourage parents to actively listen to sibling(s) and remain sensitive to their feelings. Explain the benefit of allowing the sibling(s) to demonstrate strong emotions, but note that it is also okay if sibling(s) do not outwardly demonstrate feelings
Remind parents that they do not need to have all the answers. It is perfectly appropriate to say "I do not know the answer to that but we can ask the doctor" or "I wish I knew the answer to that."
Explain to parents that sibling(s) might ask questions about their own mortality or their parents' mortality

Table 4.18 Strategies to help HCPs communicate with siblings of children with cancer

Obtain parental permission and respect parental wishes
Avoid communication about the situation with a sibling when a parent/caregiver is not present or before parents/caregivers have initially communicated with the sibling(s) about the situation
Consider the sibling's age and developmental level
Use clear, specific, and concrete language; use correct words such as "death" or "dying." Avoid vague, unclear, and/or confusing language such as "passing away" or "will go be with the angels."
Be honest and encourage open communication
Remember it is okay to say "I do not know the answer to that but will try to find out," or "I wish we knew the answer to that."
Follow the lead of the sibling. Never force a child to discuss more than what is comfortable for him or her
Listen actively and be accepting of the sibling's feelings. You can say something like, "It is okay to feel any way you feel" or "Sometimes people cry when they hear something like this, but sometimes they do not." You might even find it appropriate to say something like "It is okay to cry" or "It is okay that you did not cry. It does not mean you do not love your sister."

Table 4.19 Strategies to achieve meaningful silent presence

Silence can feel uncomfortable, as we often want to feel like we are "doing something." Remind yourself that quietly bearing witness is, in fact, doing something very powerful for the child and family
If you feel compelled to fill the silence, consider counting slowly backward from 30 in order to give the child or family space to experience their emotions without interruption
If a child or family member is crying, you do not always need to speak in order to validate the emotions and offer support. Empathic listening can be reflected powerfully through your facial expressions and body language
If the child or family member is receptive to touch, consider offering your hand to hold. Another way to offer comfort through touch is to rest your hand on the forearm or shoulder of the child or parent; this type of physical contact is typically considered gender neutral and culturally and religiously acceptable for most individuals

4.8.1 Bearing Witness

While providing care to children with cancer and their families, HCPs sometimes face situations so difficult and painful that they struggle to find the words to express their empathy. At times, they feel the need to "fill the silence" with words, even if they are unsure of what to say. However, sometimes the most powerful way to communicate with patients and families is through silent presence (Himelstein et al. 2003). Table 4.19 gives suggestions on how HCPs can use silent presence with patients and families.

4.8.2 Communicating Through Play

Children often express themselves differently than do adults. Although children absorb information readily, they often need help with interpreting and applying this information to their lives. They might also struggle to find the right words to express their feelings. Nonverbal therapeutic modalities can help facilitate communication under these circumstances.

Psychosocial professionals such as CCLSs are trained to help children develop both verbal and nonverbal skills to identify emotions and improve communication with family members and HCPs. CCLSs meet children where they are and follow their lead, offering modalities such as therapeutic play and other creative activities to offer children an outlet to express their emotions about the illness experience (Rollins 2005).

Children play for several reasons, including normal development, entertainment, and normalization of stressful environments. CCLSs focus on age-appropriate play as a strategy for providing education and anticipatory guidance, facilitating therapeutic interventions, and offering emotional support. During therapeutic play, CCLSs can focus on sensory inputs (e.g., what can the child expect to hear, see, feel, smell, or taste) and cognitive skills (e.g., what is happening, why is it happening, where am I going, and how is it going to happen). Through play, CCLSs build trust and relationships with patients and families, with the goal of enabling the sharing of thoughts and feelings in order to enhance medical care and the overall illness experience.

Like adults, however, children require a nonthreatening environment to share their thoughts and emotions. HCPs need to listen with intention, offer sufficient space and silence to encourage sharing, and validate that the child's words and thoughts are valuable and worthy of their attention. HCPs can help children express their thoughts by supporting them in whatever activity they feel most comfortable doing, be it therapeutic play, role playing, drawing, or playing video games.

Even when children are able to express their opinions or emotions, they might still experience difficulty in answering direct verbal questions. In these cases, HCPs need to mobilize alternative strategies to communicate effectively and in an age-appropriate manner with patients (Sposito and de Montigny 2015). Various modalities of therapeutic play, including the use of medical dolls or puppets, have been extremely useful to communicate with hospitalized children with cancer and can encourage patients to share their illness experience in ways that improve their medical care (Sposito and de Montigny 2015). The use of drawing as a form of therapeutic play can also improve communication between children with cancer and medical providers (Rollins 2005). Likewise, dance or movement therapy is another nonconventional way to promote communication about the illness experience, and it can facilitate improved coping in children and adolescents with cancer (Cohen and Walco 1999).

4.8.3 Communicating Through Music

Music therapy is an effective supportive modality for children with cancer and their families (Tucquet and Leung 2014). Parents of children with cancer perceive music as a beneficial aspect of their child's holistic care (Kemper and McLean 2008). Music therapy can increase verbalization, interaction, independence, and cooperation in children with cancer as well as improve their relationships with their family and HCPs (Standley and Hanser 1995). Music therapy can be paired effectively with other psychosocial interventions to improve patient communication, adjustment, and coping (Standley and Hanser 1995).

Music therapy can also be a highly effective intervention and source of support for parents and siblings of children with cancer. In this context, the common goals of music therapy include (1) strengthening the attachment between the patient and family at the EOL, (2) creating memories and communicating important messages, (3) expressing fears and anxieties, (4) creating a space for the patient and family to be together in music of quiet contemplation or reflection, and (5) continuing the story of the patient with the family in bereavement (Wheeler 2015).

4.9 Educational Interventions to Improve Communication

As discussed in detail previously in this chapter, effective communication regarding prognosis and advance care planning leads to better QOL and EOL care for patients, as well as improved bereavement outcomes for families. While the delivery of good communication is an "art," it is also a fundamental skill that requires extensive instruction, role modeling, and practice in order to execute proficiently. Unfortunately, many HCPs do not receive adequate training in the provision of effective communication (Hilden et al. 2001; Sanderson et al. 2015; Boss et al. 2009). Moreover, educational interventions to train HCPs in communication about EOL issues are particularly lacking (Chung et al. 2016), highlighting an area in need of significant research and clinical intervention.

Pediatric oncologists in particular identify deficits in their communication training, with the vast majority (92%) reporting that they learned communication through trial and error (Hilden et al. 2001). Pediatric oncologists also report a lack of formalized instruction in palliative care principles and a need for strong role models to share communication strategies (Hilden et al. 2001). Yet while formalized training, rather than trial and error, is increasingly recognized as an essential aspect of medical communication education, little data or consensus exists regarding how best to achieve this training process (Bays et al. 2014; Curtis et al. 2013; Dickson et al. 2012; Moore et al. 2013).

In the context of this perceived deficit, the Institute of Medicine and the American Cancer Society have issued a call to action for the development of programs to improve clinical communication skills for HCPs (Kirch et al. 2016). Although the optimal method or combined methods to teach this critical skill remain undefined, a number of studies have investigated different strategies to enhance communication skill building for HCPs, including didactic lectures, small-group workshops, online modules, standardized patient simulations, and role-play with communication experts and bereaved parent educators (Moore et al. 2013; Downar et al. 2017; Fellowes et al. 2004; Szmuilowicz et al. 2012; Tulsky et al. 2011; Bragard et al. 2006; Delvaux et al. 2005; Razavi and Delvaux 1997; Snaman et al. 2017). A variety of creative sociodramatic techniques, including the use of theater, reflective writing, and Balint-type case discussion, have also been used to engage oncology trainees in the development of effective communication skills (Epner and Baile 2014). Additionally, a number of educational tools and opportunities exist with the goal of developing communication expertise in oncology clinicians, including Oncotalk (Fryer-Edwards et al. 2006), VitalTalk, EPEC (Widger et al. 2016), PCEP (Palliative Care Education and Practice (PCEP)), and The Conversation Project. These resources are summarized in Table 4.20 (Kaye et al. 2015).

However, although multiple training programs and resources have been developed to better prepare HCPs to sensitively and effectively communicate with children with cancer and their families, interventions to improve communication in pediatric oncology have not been widely or rigorously assessed (Ranmal et al. 2008). We advocate for formalized communication training to be a mandatory component of pediatric oncology training programs (Snaman et al. 2016c). Ongoing investigation is needed to better understand the optimal strategy for teaching effective communication skills to HCPs who care for children with cancer and their families.

Table 4.20 Resources to promote communication expertise in HCPs

Oncotalk (http://depts.washington.edu/oncotalk/): An online educational curriculum designed to improve the communication skills of oncologists
VitalTalk (http://www.vitaltalk.org): An educational forum with resources for HCPs about leading conversations about goals of care and oncology workshops designed for use in cancer centers. Resources are available in phone app format and online curricula are available for CME credit via the Center to Advance Palliative Care (CAPC: http://www.capc.org)
Education in Palliative and End-of-life Care Program (EPEC)—Pediatrics (epec.net/epec_pediatrics.php): A pediatric-specific conference that provides in-person training on effective teaching strategies, as well as access to comprehensive educational materials
Program in Palliative Care Education And Practice (PCEP)—Pediatric Track (http://www.hms.harvard.edu/pallcare/PCEP/PCEP.htm): An intensive conference on advanced topics in pediatric palliative care offered by Harvard Medical School's Center for Palliative Care
The conversation project (http://theconversationproject.org): A grass-roots movement dedicated to helping people talk about their wishes for end of life care, with access to pediatric "starter kits" to help clinicians, children, and families broach these difficult conversations

Adapted from Kaye EC, Rubinstein J, Levine D, et al. Pediatric palliative care in the community. CA Cancer J Clin 2015;65(4):316–33

4.10 Key Points

- Effective communication is a key pillar of optimal cancer care, espoused by the Institute of Medicine, American Academy of Pediatrics, and multiple national oncology societies.
- Good communication is necessary for building trust, promoting shared decision-making, and encouraging discussion of goals of care and quality of life.
- At times, conversation may serve as a therapeutic intervention itself, enabling clinicians to reframe hope, alleviate suffering, and mitigate complicated bereavement.
- Established guidelines exist to help clinicians navigate the challenging experience of communicating difficult news, whether about a new diagnosis, disease progression, relapse, goals of care, advance care planning, or anticipatory guidance toward the end of life.
- Conversations about prognosis early in the disease course establish a foundation of honesty and trust upon which to provide optimal medical care throughout the illness trajectory.
- Clinicians should strive to provide honest information while still affirming the right of the patient and family to maintain hope; hoping for cure does not preclude the recognition of incurable disease nor a wish for prolonging a life with quality.
- Communication is most effective when offered through an interdisciplinary approach, integrating expertise from physicians, nurses, child life specialists, chaplains, psychologists, social workers, and other supportive clinicians.
- Effective communication with children carries a unique set of challenges and requires specialized training in age-appropriate communication styles and strategies.
- Sometimes the most powerful way to communicate with patients and families is through silence, simply by offering one's presence and bearing witness.
- Formalized communication training should be an integral and mandatory part of pediatric oncology training programs.

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