Chapter 3
Communicating Prognosis at Diagnosis and Relapse or Progression

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Evidence for Honest Communication

Why Is Honest Communication Difficult?

The importance of honest communication in medicine, specifically oncology, has emerged over the past several decades. Prior to the late 1970s, the norm was not to tell patients the truth regarding their diagnosis [1], following the Hippocratic dictum to "first do no harm." Studies in the 1950s–1960s began to look at physicians' attitudes toward truth telling and found the norm was a strong and general tendency to withhold information regarding a cancer diagnosis [2]. Standards have certainly changed over the past several decades, and at present, it is routine practice in Western medicine to inform patients and their families of a cancer diagnosis. In the late 1970s, the shift toward increased disclosure practices was driven by bioethics and legal emphasis on patient autonomy rather than scientific data [1]. In more recent decades, scientific evidence has shown the practice is preferred by patients and leads to better patient outcomes [3].

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At the same time, advances in oncology have made conversations regarding bad news, prognosis, and end-of-life care more difficult. First, treatment options make the future less certain and clinicians report difficulty in talking about uncertainty. Second, the proliferation of options has forced clinicians to consider whether the balance between risks and benefits of a therapy is favorable for a particular patient. These decisions are often very patient dependent and require a clinician to be able to talk about values with patients. Finally, talking about how to change goals when more chemotherapy may not help is difficult for both clinicians and patients who have come to expect that other options will always be present. Oncologists surveyed at the 1999 Annual Meeting of the American Society of Clinical Oncology noted an average of 35 bad news discussions per month [4]. They felt that discussing the cancer diagnosis was the least difficult task when giving bad news and found that discussing cancer recurrence, failure of a treatment to produce an intended result, and the lack of further curative treatment options were more difficult [4].

Despite the common occurrence of these discussions, particularly in oncology, clinicians have struggled for decades with these conversations, due to worry about how they will affect their patients and families. Communicating difficult news is sometimes seen as counterintuitive to clinicians' inclination to "do no harm," as they worry about the psychological welfare of their patients and their families when they are informed of a poor prognosis, progressive disease, or cancer relapse [5, 6]. Thus, refraining from prognostic communication may stem from clinicians' compassionate inclinations [7]. Clinicians may desire to shield their patients and their families from the undeniable anguish, fear, sadness, and anger that breaking bad news can invoke. These tendencies persist despite data, discussed in section "Why Is Honest Communication Important?", indicating that patients welcome these conversations. Perhaps, then, clinicians run the risk of projecting their own negative emotions regarding prognostic discussion onto their patients.

Comfort level and confidence in any task in medicine is typically built through formal medical training. Ironically, although these conversations are difficult, many physicians have had little to no formal training in how to conduct these conversations. For example, a survey of adult oncology fellows found that they were more likely to have received formal training and feedback on routine procedures than end-of-life communication [8, 9]. An informal survey that assessed attitudes and practices regarding breaking bad news, defined as "any information which adversely and seriously affects an individual's view of his or her future," [10] was conducted at the 1998 Annual Meeting of the American Society of Clinical Oncology and found that the minority of respondents had received any formal training in breaking bad news and only slightly over half rated their own ability to break bad news as good or very good [11].

Why Is Honest Communication Important?

These conversations are important for two reasons. First, as bioethics has emphasized, we have an ethical responsibility to the child and his or her parents. Second, the empirical data suggests that parents desire prognostic information. Finally, despite fear that distressing conversations will cause lasting emotional damage to patients and their families, there is ample evidence to support the beneficial impact of these conversations.

Parents and their children have an ethical right to know their medical information, regardless of its nature. Respect for autonomy requires honest disclosure of the child's medical condition, its prognosis, and treatment options, or lack thereof. Stemming from this, the parent's ethical responsibility to make medical decisions in the best interest of the child requires receipt of honest counsel from the physician [12].

Beyond the parental right to know is the fact that they also want to know. In a pediatric study of 194 parents of children with cancer, 87% of parents desired as much information about prognosis as possible. Although 36% of these parents found information about prognosis to be extremely or very upsetting, those parents were more likely to want additional prognostic information than those who were less upset [13]. Thus, despite the distress of bad news, parents still desire an honest discussion that does not seem to be associated with higher rates of overall distress. In another study that evaluated parents' ability to find peace of mind in the first year of their child's cancer treatment, peace of mind was not found to be associated with prognosis. Rather, parents noted greater peace of mind when the oncologist disclosed detailed prognostic information and provided high-quality information about the cancer and when parents reported greater trust in the oncologist's judgment [14].

Recent studies have underscored the beneficial nature of sharing this information to both the parent and the physician. In the adult oncology setting, it has been shown that there are no higher rates of depression or worry in patients with advanced cancer that had discussed end-of-life care planning with their physician than compared to those who had not [15]. Additionally, in the same study the caregivers of patients who had discussed end-of-life care with their loved one's physician had lower rates of depression in the bereavement period [15]. In a study conducted with 144 parents of children who died of cancer and 52 pediatric oncologists to ascertain both parents' and physicians' assessments of the quality of end-of-life care for children with cancer, parents were especially likely to rate physician care positively when they believed that communication with physicians had gone well. Specifically, parents were more satisfied when they received clear anticipatory guidance during the end-of-life period, news was delivered with sensitivity and caring, and doctors communicated directly with the child when appropriate [16]. In contrast, medical outcomes such as pain control and time spent in the hospital in the last month of the child's life were not important determinants of parental ratings of care. These findings emphasize that when a cure is not possible, the physician's care of the child and family remains highly valued and that the relationship itself can be a therapeutic agent [16].

Why Is Honest Communication Vital to Decision Making?

Parents of children with cancer are faced with countless decisions that must be made regarding their child's care. The choices that they are confronted with regarding their child's life when faced with poor prognosis, relapse, or progression of disease are understandably some of the most difficult decisions a parent will ever have to make [17]. Parental expectations of outcomes often guide their decision making; however, parental hopes and expectations regarding the outcome of their child's medical care are often incongruent. Physician disclosure of information, therefore, is important in shaping these hopes and expectations and thus the parental choices regarding care that follows.

The link between uncertainty and fear is strong and hinders decision making. Families require clear and honest information about their child's medical condition in order to make good decisions for their children. There is a temptation, however, for clinicians to base the depth of their communication on the family's emotional reaction, as opposed to recognizing and acknowledging a strong reaction as normal. While it is imperative to respond to emotion, it is equally important to ensure the family receives all of the relevant medical information. Clinicians who withhold medical information for fear of harming the family or child risk increasing parental uncertainty and thus impairing decision making. The desire to receive detailed prognostic information despite emotional upset was nicely demonstrated in a survey of 194 parents of children with cancer and their children's physicians. In this sample, the degree to which parents found prognostic information to be upsetting was directly correlated to the parent wanting more detailed information [13]. Parents who found information about prognosis very or extremely upsetting were no less likely to believe that prognostic information had helped them with decision making than other parents. Interestingly, parents who were upset were more likely to report that the oncologist had never discussed prognosis. The authors concluded that the tendency to tailor information on the basis of the reaction of the parent, whether consciously or unconsciously, may leave parents who display greater emotional distress less informed [13]. This should be kept in mind, as prognostic discussions often need to be re-reviewed once the acute stress of the initial conversation has passed. This evidence suggests that subsequent conversations regarding prognosis should not be tailored based on the emotional reaction to the initial conversation.

Studies have shown that parents make better decisions if they are aware of the doctors' knowledge of the medical situation. In one study, parents of children who died of cancer as well as their primary oncologists were interviewed to determine whether an understanding of the child's prognosis alters parents' treatment goals [18]. The time from realization that there was no realistic possibility of cure to the time of death was measured in both groups. For parents, the first recognition of this occurred at a mean of 106 days prior to death; for physicians it occurred much earlier with documentation that the child had entered the end-of-life period at a mean of 206 days prior to the child's death [18]. The outcomes for the group of children in which both the physician and the parent recognition occurred more than 50 days prior to death revealed that there were statistically significant earlier documentation of hospice, better parental ratings of the quality of care delivered by the home care team, earlier institution of do-not-resuscitate orders, less use of cancer-directed treatment in the last month of life, and higher likelihood that both physician and parent identified the primary goal of cancer-directed therapy to be to lessen suffering [18]. These findings underpin the importance of high-quality, accurate clinician communication with parents of children with terminal cancer for improved decision making regarding end-of-life care.

Are We Taking Away Hope?

Hope is central to the practice of oncology and oncologists have faith in this concept. It can be defined as a feeling of expectation and desire for a certain thing to happen. In the medical setting, most clinicians assume that the definition of hope as it relates to disease is the belief that cure is possible. Hope and cure may not coincide in every situation, however, and even if the initial hope was for a cure, patients with realistic perceptions of their disease can transform hope into other reasonable and equally meaningful possibilities [19–22]. In other words, hope does not need to end with the recognition that death is likely. Similarly, while a physician's initial hope may be for a cure, when that is not possible, oncologists may hope for lack of suffering, a sense of fulfillment, and a dignified death for their patients.

One of the most commonly cited reasons to avoid detailed prognostic conversations when the outcome is suspected to be poor is the clinician's concern for the disruption of patient and family hope when faced with bad news [11], that when faced with a poor prognosis, for example, patients and their families may "give up." Thus, clinicians may limit prognostic information based on their belief of its effect on patient/family's hope.

However, patients and families do not believe that clinicians should withhold information in order to preserve hope. Among adult patients with incurable metastatic cancer who were surveyed to identify preferences for the process of prognostic discussion, almost all (98%) wanted their doctor to be realistic, and most (82%) noted that the use of euphemisms would not facilitate hope, but rather foster hopelessness [23]. These patients defined hope as being "that you can still enjoy a good quality of life even if life expectancy is uncertain" [23]. In other words, disclosure of bad news is not incongruent with hope. The clinician has to decide what information to give and how to give it. There is a need to deliver clear and compassionate information regarding prognosis and goals of treatment while creating realistic hopes and expectations. The idea that optimism for a prolonged life is a prerequisite for patient hope often leads to the use of euphemisms rather than clear honest disclosure of bad news.

Interestingly, the data suggests that better communication, even of bad news, promotes hope. In a single-center survey of 194 parents of children with cancer in their first year of treatment and the children's physicians, the relationship between parental recall of prognostic disclosure by the physician and outcomes of hope, trust, and emotional distress was evaluated. Parents were more likely to report communication-related hope when they also recalled increased prognostic disclosure, and this increased recall of prognostic disclosure was associated with communication-related hope even when the child's likelihood of a cure was less than 25% [24]. Not only does this finding dispute the notion that diminution of hope follows disclosure of poor prognosis, but it also indicates that communication of prognostic information, regardless of likelihood of cure, supports the hope that parents of children with cancer derive from high-quality communication with their child's physician.

A subsequent study collected prospective data among parents of children with advanced cancer [25]. In this qualitative study, conversations between 32 pairs of parents and clinicians of children with relapsed or refractory cancer were audiotaped, followed by interviews with the parents about their experiences with prognostic communication [25]. When these parents were asked to reflect on prognostic statements, most (69%) described feeling upset and used statements such as being "hit over the head" and "crushing" to describe their reaction [25]. Although this may seem to confirm fears of taking away hope, most parents (69%) also noted that they valued honest and straightforward communication about prognosis and that a potential threat to parental hope is actually excessive clinician optimism. One family said, for example, "[Clinician] has always from day one said, 'I will never try to hide anything from you. I will be 100% honest with you the whole time.' And that is all I ever asked her to do is, 'Don't try to cover the sky with your hands. Don't try to cloud this up for us.' I want the nitty-gritty down to the bottom line" [25]. For these parents, honest communication was a component of hope because it led to making the best decisions for the child and the family [25].

Finally, while it may be tempting to misinterpret parental maintenance of hope in the face of a poor prognosis as denial or ignorance, data indicates that parents of children with incurable cancer find many different things to hope for, including cure, while acknowledging the reality of the situation. In the same cohort described above [25], parents were asked specifically about their hopes and expectations for their children in order to understand the extent to which parents can feel hopeful when faced with their child's impending death [26]. Statements the parents made in the interviews indicated a high degree of understanding of the incurable nature of the child's disease. In fact, the statements the parents made often mirrored the recorded statements of the physician during the prognostic discussion [26]. Despite acknowledgment of a poor prognosis, parents were able to express hopes, which ranged from prognosis/treatment-related (cure, treatment response, a long life, etc.) to non-treatment focused (quality of life, normalcy, and minimal suffering). Further, the majority of parents (72%) were able to acknowledge that their hopes differed from their expectations [26], indicating that their choice to speak in a language of hope did not mean they failed to understand the terminal nature of their child's disease. Probing for a parent's hopes and expectations not only increases the physician's understanding of how a family or patient is handling prognostic information but also may enhance the therapeutic patient-parent-physician alliance.

Parental Decision Making: Other Considerations for the Clinician

Parents of children with cancer are responsible for making a number of difficult decisions regarding their child's care, the majority of which are made late in the course of treatment [27]. In a study where 39 parent participants of children with cancer responded about factors that were important when making the decision to continue care, the most frequently reported difficult decisions were choosing between a phase 1 study drug, conventional chemotherapy, maintaining or withdrawing life support, or no further cancer-directed treatment [27].

Studies have shown that parental decision making is guided by more than prognostic information and assessment of risks and benefits. A central concept that comes up in the literature is the sense of whether the decision is consistent with the parents' identity – e.g., is it something that shows that they are a good parent? In a study of families who had to make decisions regarding phase 1 trials, adoption of a do-not-resuscitate order, or initiation of terminal care [28], the families were questioned about what helped them make a decision. Considering the facts, explanations, opinions, and preferences of experts and others (e.g., family members, ill child, and other bereaved parents) and then choosing the option most consonant with an internal definition of a caring, competent protector of their child was a driving influential factor for 84% of participating parents [28]. In another study, feeling like they made a decision consistent with being a good parent helped parents cope emotionally after the loss of their child [27].

Understanding what exactly "being a good parent" means in the context of a parent of a child with incurable cancer may allow the clinician to address these ideas and communicate strategies to help parents achieve this important goal. This was investigated in a cohort of 62 parents, who had made one of these difficult noncurative treatment decisions for 58 patients, by collecting responses to open-ended questions about the definition of a good parent and about how clinicians could help them fulfill this role [29]. The theme that was most common among these parents was that of "doing right by my child," with 89% of parents reporting this definition [29]. Parents said, for instance, "We tried as much as we could to get her the best treatment," and "This is simple – doing what is best for your child" [29].

This study also explored which clinician behaviors reinforce the parent's view that they were "good parents." Overwhelmingly, parents (>80%) indicated that they wanted medical personnel to continue to treat their child with the same level of dedicated and compassionate care they had become accustomed to. In other words, they did not want to be treated differently based on the decision they had made, whether it was to continue cancer-directed therapy or not. Further, acknowledgments that their child would not be forgotten, that the family would be given time to consider all options, that honest communication would continue, and that staff would not "give up" on their child were extremely important in the maintenance of the "good parent" role [29].

Consideration of Cultural Variations

Within the context of communication of poor prognosis, we would be remiss not to mention the importance of the consideration of cultural differences that exist in terms of preferences for receipt of bad news. In a previously mentioned cohort of patients, English speakers were more likely to prefer realism as compared to those who spoke another language at home [23]. It is possible that this latter group is influenced by a culture where avoidance and paternalism are more common. Additionally, in some cultures, communication of poor prognosis is viewed as harmful and brutal [30].

Likewise, cultural differences in methods of clinician communication surrounding disclosure of unfavorable medical information to cancer patients exist. For example, oncologists in non-Western countries are more likely to avoid direct disclosure of a grave prognosis to the patient, use euphemisms, withhold information from the patient at the family's request, and offer patients treatment that they knew was unlikely to work so as to maintain hope [4]. These behaviors are less prevalent in Western countries, which may explain why Western physicians report having more discussions about treatment failure and resuscitation with patients as well as more difficulty in handling patients' emotions after giving bad news [4]. Despite these findings, the practice of selective conveyance of information still occurs in Western countries. Among the physicians in Western cultures, 33% said that they occasionally, and 19% frequently, used euphemisms in discussing grave prognosis; 24% occasionally administered treatment that was not likely to work in order to maintain hope in the patient [4].

It should be emphasized that although cultural differences are present and clinicians should be aware of this possibility, the need to explore individual patient and family preferences, regardless of cultural background, is never obviated.

Nuts and Bolts of Honest Communication

Conveying Prognostic Information

While the value of honest communication between medical providers, children with cancer, and their families cannot be overstated, many physicians find it extremely difficult to have these conversations [5, 31]. Inherent to any prognostic discussion in pediatric oncology is acknowledgment that the proposed treatment plan may be unsuccessful, even when the diagnosis is associated with a very high cure rate. Clinicians may also find themselves giving information to families they have just met, such as during the "day one talk," or to families with whom they have become emotionally invested during discussions at a time of relapse or progression. While the dynamics of these conversations are different, a protocol for delivering prognostic information can be extremely helpful in allowing physicians to navigate emotionally charged conversations.

In outlining their SPIKES method (Table 3.1), Baile and colleagues identified four essential goals of difficult conversations: gauging the patient/family's understanding of the situation, transmitting medical information, providing support to the family, and establishing a collaborative relationship to plan for the future [11]. Achievement of these goals begins with preparation. Arranging for a quiet space free of interruptions, making sure the parents and child have appropriate support, and sitting down are all vital components to these conversations [32, 33].

Table 3.1 The "SPIKES" framework

S	Setting	Arrange for privacy Manage interruptions (e.g., pager, phone) Review chart & clarify medical facts Discuss goals of meeting with team & who will lead Involve others (i.e., family, staff) Sit down & introduce everyone
P	Perception	Always *get* information before *giving* information "What have the doctors told you?" "What is your understanding of…?"
I	Invitation	Ask how patient/family likes to receive information (i.e., "big picture" or details) Ask who else should be present
K	Knowledge	Consider giving "warning shot" of bad news No jargon Give information in chunks Check understanding frequently
E	Empathy/ emotion	Let them know you have connected with the emotion Use "NURSE" statements (see Table 3.2) STOP TALKING
S	Summary/ strategy	Check overall understanding & recap goals Ask permission to move forward (e.g., treatment plan, support services) Probe for questions Document discussion

A six-step framework for delivering bad news and conducting family meetings. The method is designed to help the clinician gauge understanding, transmit medical information, provide support, and establish a collaborative relationship. (From Baile et al. [11])

Prior to conveying any information, it is extremely important to understand the family's perception of the disease up to the point of the conversation. Beginning the conversation with a statement such as "What have the doctors told you so far?" allows the interviewer to ascertain the level of understanding and any misconceptions from the start. Importantly, starting a conversation with a question also gives the family control over the pace and direction of an otherwise intimidating meeting and indicates to the family that they are collaborating in the effort. Asking a child or their parents how much they want to know or how detailed they want the information to be furthers this perception. Acknowledging that difficult conversations may need to occur in more than one sitting relieves the stress of trying to address issues the child or family may not be ready for and also allows for the fact that much of the medical information conveyed will not be retained [34]. In a situation where the family or child is not receptive or ready to receive detailed prognostic information, it may be best to focus first on building a relationship with the family and to give the information later when they are emotionally ready to receive it.

Sharing medical information with a child and his or her family is complicated by the technical nature of the information, the natural tendency of clinicians to use medical terminology, and the desire to share all information at one time [3]. Firing a warning shot is often a good way to begin the process of sharing diagnostic or prognostic information. A statement such as “I’ve had the opportunity to look at your child’s blood under the microscope, and I’d like to take some time to talk with you” alerts the parent and child to the gravity of the discussion but also gives them a moment to focus their attention on what is about to be said. This statement could be followed by “based on what I’ve seen, Landen has leukemia, which is a form of cancer.” It is important to avoid the natural tendency to hedge or to obscure the headline of the conversation with a lot of supporting information. Hearing the word “cancer” is likely to cause strong emotions such that continuing at this point would inundate the child and family with a tsunami of information which will not be heard or remembered [35], while hedging will only serve to cast doubt or confuse the information being shared. Even though it may be uncomfortable, a better strategy is to pause after giving distressing information and allow the family and patient time to process the information.

Receipt of diagnostic and prognostic information is obviously distressing, and responding to the emotions of both the child and the parents is challenging [11]. Displaying empathy, however, further engages the medical provider with the family and sets the stage for collaboration and goal setting [16, 36]. The NURSE method (Table 3.2) is helpful in constructing responses to strong emotions [37]. Naming the emotion is the first step in conveying that you are feeling the parent or child’s emotion. “This news is very shocking” can be followed by a statement of understanding such as “although you knew something was wrong, nothing could have prepared you for this.” An acknowledgment that the parent or child’s disbelief is valid and normal humanizes the response and shows respect for their role as either a good parent or a good patient in the disease-fighting process. Offering support through the process with a statement such as “although this isn’t the news we wanted to hear, I am in this with you, and we will face this together” reinforces the idea that the child is not alone and will not be abandoned by the medical provider whatever the outcome. “Is there more information you need, or should we just take a minute to think right now?” further explores the direction of the conversation and also gives control back to the child or family.

The final goal of prognostic conversations is to talk about options for the child and how best to move forward. Key to this process is the establishment of clear treatment goals because they will define the approach to therapy. At the beginning of cancer-directed therapy, the goal of cure is almost always the focus of the child,

Table 3.2 The “NURSE” pneumonic

N	Name	“It sounds like you are angry.”
U	Understand	“I can’t imagine what you’re going through.”
R	Respect	“I see how hard you have been fighting for her.”
S	Support	“I’m here for you.”
E	Explore	“Tell me more about what you’re thinking.”

This pneumonic provides guidance for constructing responses to strong emotion in difficult conversations. (From Medical Oncology Communication Skills Training, Fundamental Communication Skills, Learning Module 1 2002) family, and physician. These conversations tend to focus on disease eradication. When a poor prognosis is given (e.g., relapsed or progressive cancer), goals may become focused on life prolongation or quality of life [38]. Patients and families who successfully navigate transitions in goals tend to move their focus from a need to continue therapy to fighting for quality of life, time, and ease of suffering [39]. Helping children and their families view the treatments they choose through the lens of their goal of care encourages decisions that lead patients closer to their goal and shifts focus away from the false perception of deciding between life and death.

Complications in Communication

Even the most skilled communicators experience roadblocks to effective communication. Prognostic uncertainty and parental disagreement are common areas that cause clinicians difficulty.

Conveying prognostic information can be complicated by medical uncertainty. Pediatric cancer-directed therapy is unique in that patients often have an undulating course marked by periods of good health and low points of severe or even critical illness. Further, despite advances in basic and clinical science, it remains difficult to predict which children will or will not respond to therapy from the outset, especially when certain prognostic details, like cytogenetic information, are not available until after the beginning of therapy. Up to this point, we have focused on situations where the information is clear (e.g., "your cancer is back"). More commonly, particularly when discussing the future (e.g., prognosis), the information being discussed is tinged with uncertainty. Predictions of the future are, by their very nature, probabilistic and thus uncertain. How, then, do we discuss this information with parents? We know that parents who recognized no chance for cure earlier were more likely to rate high quality of care by the medical team and choose less cancer-directed therapy while focusing on lessening suffering, rather than curative measures [18]. On the other hand, we often don't know when there is "no chance." Such uncertainties can lead to vague, overly optimistic discussions about possible outcomes [40, 41]. Encouraging optimism rather than helping parents understand that uncertainty exists is problematic because it may encourage parents to shape their decisions based on unrealistic expectations.

The first step in addressing prognostic uncertainty is to acknowledge its existence, for example, "we are not sure what the future will bring." Doing so signals to the family that the clinician is considering all potential outcomes and increases transparency. It also creates an opportunity for the clinician to address treatment options or poor outcomes prior to crisis situations [42] and to ask about hopes and expectations throughout the treatment process [43]. A communication technique that has been used to talk about an uncertain prognosis is to describe the best, worst, and most likely outcomes. This strategy clearly lays out the possible future and can lead to a discussion of how we will know which outcome is most likely and what is "worth" going through given these options [44].

In addition to attending cognitively to uncertainty, it is important to acknowledge its emotional impact. It is hard for parents to be unsure what is going to happen to their child and to worry about whether they are making the right decisions [45]. Acknowledging the emotional worry brought on by uncertainty (e.g., “it is so hard to not know how this is going to turn out”) and discussing parents’ coping strategies (e.g., “how are you dealing with the uncertainty?”) can help build a therapeutic alliance.

Another difficult situation is when parents disagree with each other regarding the care of their children. The majority of subjects in the existing data on communicating prognosis with parents in pediatric oncology have been mothers. Fathers, however, often approach setting goals of care for their seriously ill child differently than mothers [46] and may have a more dichotomous view of treatment decisions [47] even when consensus on the meaning of prognostic information exists. Additionally, a study comparing the views of mothers and fathers of children with cancer [48] found a great deal of agreement in the understanding of prognostic information and treatment goals at the beginning of cancer-directed therapy. Differences emerged, however, when the child was felt to have incurable cancer. In this scenario, fathers, both as a group and within matched couples, were more likely to focus on continued cancer-directed therapy. While many of these differences resolved in the last month of life, continued parental disagreement with regard to focusing on comfort was associated with an increased parental perception that the child suffered at the end of life.

Typically when one parent perceives a need to continue with cancer-directed therapy, such therapy is sought even if the other parent does not completely agree. Unfortunately, such decisions often lead to regret in retrospect [49, 50]. Further, greater parent-physician agreement in children with incurable cancer is associated with improved end-of-life care [18]. Thus, helping parents confront and resolve differences in opinion is important for both the care of the patient and of the parents in the bereavement period.

When such differences exist, it is helpful to not only name the disagreement (e.g., “I can see you have different views on the next steps”) but also to assure both parents that you will continue to provide support regardless of their decision. It is important for the clinician to recognize that disagreements among parents are both common and normal. Understanding that both parents are making decisions out of love, or as a “good parent” would, is important not only for the clinician but also for each parent. One could say, “Having walked this journey with other families, it is not uncommon for parents to feel differently about what is best for their child. What’s clear to me is that you are both good parents trying to do right by and love your child.” Beyond helping disagreeing parents identify their common ground, it may also be helpful to ask them to think about how they have dealt with other disagreements or to reflect on other times during the child’s therapy when they worked through an uncertain circumstance. In some cases it may be very hard to find agreement, and at that point it may be helpful to involve other professionals with more expertise in family dynamics. Regardless of the situation, it is important for the clinician not to be perceived as taking sides. While offering a medical opinion is always warranted, remaining neutral in such disagreements allows the oncologist to support both parents moving forward.

Communicating with Children

Pediatric oncologists also must decide when and how much information to convey when they talk to their patients about their cancer. Protecting children from harm is a natural instinct for both parents and physicians, and non-disclosure is often falsely justified by beliefs that difficult information will either depress or confuse the child [3]. Feelings of failure, sadness, or anticipatory grief over the loss of a patient are also deterrents to the oncologist caring for the child [51]. Regardless, establishing open and honest communication with the child is important and can be rewarding.

Generally, children, and especially adolescents, want to know and understand their prognosis [52] even if the news is grim [53]. As such, they deserve the ability to understand their disease, prognosis, and treatment and to participate in shared decision making to the extent they desire [54]. Even very young children are capable of understanding the concept of death [55] and are often aware of the potential terminal nature of their cancer diagnosis simply by being in the milieu of the pediatric cancer ward and clinic. Involvement of the child in these conversations engenders trust between the oncologist and the child [32] and allows them to better express their wishes with regard to treatment, end-of-life preferences, and code status [28]. Although not every patient desires to know their prognosis [56, 57], avoidance of addressing these questions with children may result in significant behavioral issues including anxiety, anger, poor school performance, and fear [58]. Concurrently, helping parents discuss prognostic issues, like death, with their child reduces decisional regret in bereaved parents [59], and physician participation in this process relieves the parent of the burden of telling the child about their illness alone.

Beale and colleagues [60] have outlined an effective strategy for communicating prognostic information with children (Table 3.3). The first step is to establish permission from the parent to approach the child with this information. Parents may find it difficult to accept the need to share distressing information with their child, and some may indicate a desire to avoid the conversation with the child. The physician should explore these feelings with the parent, express the importance of open communication, and set guidelines early on in the therapeutic relationship regarding honesty [42]. It may help the parents if the clinician emphasizes they are going to offer information to the child and that if the child does not want to talk, the clinician will not push.

Parental refusal to grant such permission can be distressing to the healthcare team, but in these circumstances maintaining trust and communication with the parent is important, as many will change their feelings on this over time. In this situation, a physician may agree to comply with the parental request so long as the parent understands that the issue will be revisited and that the physician will reply truthfully to questions directly asked by the child [56].

Table 3.3 The "six Es" for communication with children

*E*stablish	Establish an agreement with parents, children, and caregivers early on in the relationship with them concerning open communication.
*E*ngage	Engage the child at the opportune time. Signs of significant behavior change can suggest that the child is struggling with emotions and will provide an opening for discussing the illness.
*E*xplore	Explore what the child already knows and wants to know about the illness.
*E*xplain	Explain medical information according to the child's needs and age. "What would you like to know?" and "what have you been worrying about?" allow for identification of specific information needs.
*E*mpathize	Empathize with the child's emotional reactions. "I can see that you've really been worried about this."
*E*ncourage	Encourage the child by reassuring him or her that you will be there to listen and to be supportive.

The "six Es" provide guidance for communicating prognostic information with children. (From Beale et al. [60])

Prognostic discussions should occur on the child's timeline. A child may open the door to conversation at any point, and so it is helpful for the provider to look for opportunities to talk. Instead of having an agenda for the conversation, exploring what the child knows or wants to know about their condition is a good way to open the door. If a child expresses anxiety about their disease course, a question such as "what is giving you the most worry?" essentially tells the child that you are willing to listen to their concerns if they want to talk about them. Allowing the child to direct the course of the conversation gives the clinician the opportunity to identify the patient's major concerns and correct any misconceptions about the illness.

Answering the questions of a seriously ill child can be emotionally difficult, especially in the case of a terminal prognosis. If a child asks, "am I going to die?," the clinician is faced with the prospect of being too blunt versus being overly optimistic or evasive. One strategy for addressing this question is to answer it with a question such as "sometimes we don't have the medicines we need to make kids better. Is that something you are worried about?" Doing so allows the child an opportunity to decide if the statement applies to their situation while the answer gives the clinician clues as to how deep the child wants the explanation to be. As with any difficult conversation, addressing the emotions of the child is of paramount importance. Validating and empathizing with a child's feelings toward his or her illness experience solidifies the notion that the provider will help the child moving forward. In the end, simply demonstrating that the clinician will not abandon the child opens the door to communication along the spectrum of the illness experience.

Conclusion

Communicating diagnostic and prognostic information to children with cancer and their parents is an important yet daunting task for pediatric oncologists. Honest and well-timed sharing of information is the cornerstone of a healthy physician-parent-child relationship. Rather than destroying hope, honesty between providers and their patients increases trust and expands the definition of hope even when sharing poor prognostic information. Children have a right to know and understand their disease process and trajectory, and navigating disagreements between parents and their thoughts on disclosure to the child requires patience and a willingness to allow both parents and children the time they require to fully process and hear this information. Communication based on understanding, respect, empathy, and non-abandonment can transform the provider-patient relationship into a therapeutic agent, even in dire circumstances.

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