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Communication in the Pediatric Oncology Setting

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Case Vignette

Charlie is a 13-year-old boy with newly diagnosed Ewing sarcoma. He is the youngest of three children and is very close with his older brothers and his parents. From the time of diagnosis, Charlie's parents requested that Charlie be given minimal information about his disease. This dynamic quickly became difficult for the clinicians involved in Charlie's care. They felt that by not being able to freely speak with Charlie and answer his questions, they were not providing appropriate care. Charlie started experiencing multiple symptoms of anxiety including panic attacks and began to withdraw, often refusing to participate in aspects of medical care.

Introduction

Communication skills and relational abilities are essential core competencies in patient-centered care and are associated with improved patient health outcomes, better patient adherence, fewer malpractice claims, and enhanced satisfaction with care (Meyer et al. 2009). However, for communication to contribute to healing and reduce suffering, clinicians must have the skills necessary to engage in patient-centered communication. When caring for pediatric patients, clinicians must not only find ways to effectively communicate with the child or adolescent patient but also engage meaningfully with the parents or caregivers. In the United States, parents have the legal authority to make medical decisions for a child under the age of 18. The American Academy of Pediatrics Committee on Bioethics recommends that healthcare providers communicate information to pediatric patients in a way that is truthful and developmentally appropriate and include them in medical decision-making to the greatest extent possible; however, there is limited guidance about how to translate these recommendations into clinical practice. This lack of guidance results in significant stress for patients, parents, and providers and large variations in care, as each member of the triad may have differing ideas about what their own role and the role of the other members should be.

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Effective communication with pediatric oncology patients and their caregivers is critical to improving the disease outcome and emotional well-being of these vulnerable patients (Rutishauser 2003). Effective communication has been shown to be related not only to parent satisfaction with medical services but also adherence to medical treatment. In fact, insufficient and inadequate doctor/patient/family communication is one of the most important causes of medical nonadherence in pediatric patients (Spinetta et al. 2002). There are noted benefits in providing pediatric cancer patients with age-appropriate information, to both the patient and the family, and doing so fulfills the ethical responsibility of the provider (Mack and Joffe 2014).

Psychosocial clinicians can play a crucial role as an active member of the clinical care team for pediatric oncology patients. Unique contributions by psychosocial providers include helping the medical team understand the family context, including individual and family preferences around communication with the care team, identifying complicated family dynamics that may serve as a barrier to communication, and developing skills in facilitating group and family discussions that honor the preferences of the patient and family while also ensuring a productive conversation. In addition, psychosocial clinicians can enhance communication through providing education to medical providers about the issues discussed below.

General Principles of Communication

Goals and Purposes of Communication

Communication between pediatric patients, caregivers, and clinicians involves the sharing of words, thoughts, and feelings. Communication moves both ways, to and from the clinician, so that patients and families can both take in new information and also feel heard and understood. Because of this, one of the most critical communication skills for all clinicians is *listening*. *Telling*, which is sometimes perceived as the core communication skill, is nearly always secondary.

Communication Has Three Central Purposes, No Matter the Forum or Clinical Scenario

1. To allow for the development of shared knowledge
2. To build a relationship
3. To facilitate shared decision-making

The *development of shared knowledge*, often thought of as the central purpose of communication, starts with learning about the child and family. Doing so allows the clinician to understand the unique history and experiences of the child and family and to understand the state of the child and family's present knowledge about the medical situation, both of which help when the time comes to provide information and make decisions about care.

Initial communication between the medical provider and the family, which usually takes place in the context of the shock associated with a new cancer diagnosis, is often focused on learning about the child and caregivers. The presence of a psychosocial clinician can be helpful during such conversations to ensure that information is obtained regarding the developmental needs of the child, challenges to understanding and learning new information, and other relevant information. The clinician may start with general questions about how the child would describe herself as a person, questions that affirm the clinician's caring for the child as an individual and begin to create a relationship in which the child feels known. Caregivers, too, can provide their perspective on what makes their child unique. This information helps the clinician to understand core values for the child and family and offers the opportunity to reinforce those values over time. For example, a child who is most focused on friends and school as central aspects of identity may need additional acknowledgment and support if treatment disrupts these critical areas.

Because these conversations often occur over time, a continued relationship allows the clinician to deepen conversations over the ensuing days or months, to consider issues such as the meaning of illness for this child and family, religious and spiritual beliefs, and sources of both psychological resilience and distress. The opportunity to be part of a child's and family's search for meaning is often quite powerful for the clinician as well. Building a relationship over time is particularly helpful when it comes to communication with children; the relationships and mutual understanding that develop often require an experience of clinician presence, constancy, and trustworthiness over time. Clinicians also need to be alert to opportunities to build on relationships, especially moments in which a child opens a door to important information that can be explored.

Listening also allows the clinician to understand caregivers' and children's perceptions of the child's medical condition. This can help the clinician know where to start when it comes to sharing medical information. Thus, we often suggest opening conversations by asking a question such as, "Can you tell me what your understanding of the medical situation is so far?" Some families and children will begin with a level of knowledge that only requires confirmation of their own statements; others will have misconceptions or limited knowledge, even if information has been previously shared. In addition, hearing information directly from the child and family first allows the clinician to hear their own words, which can be instrumental to communication going forward. For example, within oncology, some families feel worried about using the word "cancer" around a child; others will use it freely, and the clinician can usually discover which strategy they have chosen with that simple first question. While the clinician may then wish to suggest greater openness about the diagnosis, understanding the parents' own phrasing can help clinicians to be respectful in this conversation, rather than wandering into this difficult territory thoughtlessly.

Once this information has been established, the medical clinician can move forward toward the sharing of important medical information, which we address more fully in the section below (General Strategies for Communication).

The second primary purpose of communication is *building a relationship*. Many of the tasks described above, especially eliciting information about the child and family, form the basis for this relationship. Along with this work, clinicians can develop relationships by identifying emotions and creating an atmosphere of emotional understanding and empathy. Relatively simple techniques can allow clinicians to bring emotion into the conversation. For example, naming an emotion can help children and families to feel that their feelings are understood and also allow for conversation about that emotion. Alternatively, especially when emotions are not clear, clinicians may wish to ask the child or caregiver how they are feeling. Once emotions have been shared and explored, clinicians may wish to respond by acknowledging emotions and expressing empathy. Although words are important, listening is often more important; in addition to empathic words, the clinician may wish to respond with a listening silence and attention. Words are not the only way to help children and families to feel known, respected, and understood.

The final core purpose of communication is *facilitation of shared decision-making*. Once medical information has been shared, children and families often have to use that information to make decisions about care going forward. But children and families need not be alone in that process; medical and psychosocial clinicians who know them well and understand what is most important to them can join in that process with recommendations and support.

Caregivers and children have a variety of preferences for the decision-making process, ranging from wanting to hold primary responsibility for decision-making themselves, to wanting to share in decision-making with the medical team, to preferring to delegate all decision-making to the clinician. In addition to asking about what framework feels best to the family, a second important approach is to use goals to inform recommendations from the medical team. The clinician may first wish, for example, to ask about values and goals for the future – "As you think about your future, what is most important to you? What are you most worried about? What are you hoping for the most?" Near diagnosis, goals typically center on cure, but asking about all of the child's and family's goals can help the clinician to understand what matters and also establish a framework for goal-oriented decision-making over time.

Once the child's and family's goals are understood, the clinician can provide recommendations about decisions to be made, with an eye toward supporting personal values. For example, a clinician may be able to say, "I understand that supporting your child's quality of life is very important to you. Here are some ways that I feel we can do that." Making such statements affirms to the child and family that what is important to them has been heard and is important to the medical team (Beale et al. 2005).

General Strategies for Communication

Many general strategies for communication have been developed. For example, Walter Baile's SPIKES model (Baile et al. 2000) is thoughtful and lends itself well to pediatric communication. This model suggests that clinicians first *S*et up the interview, letting children and families know that an important conversation is to take place. For example, one might say, "Tomorrow, I'd like to spend some time hearing about how the treatment is affecting you, so that we can think together about how to best get you through this." Second, once the conversation has begun, the clinician can assess the patient's *P*erceptions: "Can you start by telling me about what you think is the hardest part of treatment?" A third step is to obtain the patient's *I*nvitation, asking for permission to give information and recommendations. One might ask, for example, "Would it be okay for me to give you some of my thoughts and suggestions about how to deal with this?" Next, with the child's and parent's permission, the clinician can give *K*nowledge and information to the patient. A fifth step suggests that the clinician address the patient's *E*motions: "This can be a hard topic; what is it like for you to hear this information?" Finally, offering *S*trategy and summary reminds the child and family of the important points of the conversation and allows for a shared agreement on next steps. This model can be especially effective for teaching less experienced clinicians (both medical and psychosocial) to consider all of the relevant steps in preparing for important communication tasks.

Box 2.1: SPIKES Model of Communication

1. *S*et up the interview
2. *P*erceptions
3. *I*nvitation
4. *K*nowledge
5. *E*motions
6. *S*trategy

A related model proposed by Back et al. (2005) and others presents a somewhat simpler way to approach these difficult communication scenarios: Ask, then tell, and then ask again. For example, one might first ask for a child's understanding of medical information; then provide information, correcting any misconceptions; and then ask again for the child to tell the clinician what he will be taking away from the conversation, in his own words.

When disclosing medical information, the clinician may first wish to seek permission to embark on these topics ("Would it be helpful to hear more about what is happening medically?"). Although in some cases medical disclosure is a necessity rather than an option, children and families may still wish for the opportunity to negotiate the timing and extent of disclosure. In such cases, the clinician may wish to say something like, "Our medical team would like to discuss more of the medical information with you. We can do that now or later today and with just the four of us or with others. What do you think would be the most helpful to you?" Caregivers may also wish for the opportunity to discuss whether the child will be present for these conversations; as we discuss later in this chapter, allowing for a separate discussion with the parents in advance can allow the clinician to identify and address their fears.

Special Dynamics in Pediatric Oncology

Multidisciplinary Collaboration

Effective communication and collaboration between multidisciplinary team members are essential in providing high-quality clinical care within the pediatric oncology setting. Implementing mechanisms for ensuring ongoing, accurate communication can assist in maintaining a cohesive, well-informed team of clinicians. Concretely, the effectiveness of multidisciplinary collaboration can be maximized by providing documentation of clinical encounters in a thorough and timely manner, coordinating team meetings when appropriate, and seeking consultation prior to or after encounters when discussion of case material is warranted.

Triadic Communication and Decision-Making

When caring for pediatric oncology patients, clinicians must not only find ways to effectively communicate with the patient but also negotiate the triadic communication with the patient and the caregiver. “Patient-centered care” in this setting is best conceptualized as family-centered care, as children exist within families (as defined as any system of caregivers who participate in the child’s care), and each member of the family plays a critical role in the patient’s adjustment and ability to cope with treatment. For effective communication to occur, it is essential that providers are able to communicate with the child, the caregiver(s), and the family as a unit. As noted in the previous section, effective communication not only allows for the successful exchange of information but also serves as the foundation of the relationship between the clinician and the family and is essential for the execution of shared decision-making.

Clinician-Caregiver Communication

For clinicians to communicate effectively with caregivers, they must recognize that caregivers know their child best and are the experts on their child and their family. Naming this for caregivers can often be helpful as it provides them with a specific role as an essential member of their child’s healthcare team. This framework allows clinicians the opportunity to learn about the patient and their family, who they are as individuals outside of the hospital setting, their beliefs and dreams, their hopes, their goals, and their fears. It also allows for open discussion about family communication and decision-making style.

Within pediatric illness, caregivers often act as gatekeepers, managing the information their child has given about their illness (Ranmal et al. 2008). Caregivers want to be involved in the decision regarding how their child is informed about their illness (Levetown 2008). While some prefer that medical information come from them, others prefer that medical providers have these discussions with the child, either alone or in their presence. In general, communication is most straightforward when the medical provider communicates serious medical information directly to the child in the presence of the parents. Clinicians can share the language that they plan to use with the parents ahead of time and even offer to role-play conversations with parents so the parent is comfortable with the information that will be delivered. While the majority of caregivers acknowledge the benefit of open communication with their child about their medical illness (Young et al. 2011), many are uncertain about how to initiate and engage in these conversations. As noted by Mack and colleagues (2006), there may be a natural reluctance to share serious information with a child due to a caregiver’s fear about the child’s emotional reaction or fear that the child will lose hope about the situation. Clinicians are able to help caregivers understand that research has demonstrated improved adherence to the plan and resultant health outcomes when the child is treated as a partner, included in treatment planning, and provided accurate and developmentally appropriate information (Sawyer and Aroni 2005).

Clinician-Child Communication

There is a strong ethical and legal obligation for medical providers to discuss information about health and illness with the pediatric patient. The principle of self-determination applies to children as well as adults. Involving children in communication about their illness and in treatment decisions demonstrates respect for their capacities and may provide opportunities for further development (McCabe 1996). National and international policies (e.g., American Academy of Pediatrics, International Society of Pediatric Oncology) recommend that best practice for providers includes encouraging all pediatric patients to express their views and to participate in their own healthcare (Spinetta et al. 2009). Research has uniformly shown that better information leads to lower levels of general distress including lower levels of symptoms of depression and anxiety (Clarke et al. 2005) and that children report feeling valued and less anxious about their medical condition when they are included in discussions about their healthcare treatment (Dixon-Woods et al. 2002; Kelsey et al. 2007; Moore and Kirk 2010).

However, children are often not treated as active participants in their own medical care. A review on triadic communication in the pediatric primary care setting found that children often had little involvement in the consultations. Their involvement was often limited to the history and examination phases of the encounter, with very little participation during the explanation and planning phases (Cahill and Papageorgiou 2007). Research examining the type of communication between pediatric patients and doctors has found that communication often seems to be restricted to the affective domain, typified by some researchers as a “joking relationship” (Aronsson and Rundström 1989; Tates and Meeuwesen 2001). While there is not a robust literature about communication preferences of pediatric patients, observational studies have shown many children express a desire to be more involved in the communication process and decision-making (Björk et al. 2006; Lambert et al. 2008). The act of engaging children in decision-making and treatment planning can be complicated, but thoughtful consideration of their developmental stage and experience with illness may help both clinicians and caregivers in decisions regarding specific language used in conversations, frequency of conversations, and depth of material covered (Bluebond-Langner et al. 2010).

Enhancing Triadic Communication and Decision-Making through Shuttle Diplomacy

Communication in pediatric oncology requires providers to delicately balance the often overlapping but sometimes distinct needs of both the patient and their caregivers. While it is understood that the clinical team has a legal, moral, and ethical obligation to include children in discussions about their own healthcare, there is limited guidance about how to translate these recommendations into clinical practice. This lack of guidance creates challenges for patients, caregivers, and clinicians and large variations in care, as each member of the triad may have differing ideas about what their own role and the role of the other members should be. Furthermore, existing family dynamics and the natural difference in authority between children and caregivers can complicate the treatment decision-making process. Clinicians must continually assess the extent to which children are granted their own “voice” within the family system, the degree to which children are aware of and wish to support their caregivers’ preferences, and the possible discrepancy in amount and type of information provided to both parties, as all factors can significantly influence the outcome of the decision-making process.

Shuttle diplomacy, coined in the pediatric illness context by Bluebond-Langner and colleagues (2005), is an approach for involving children in the decision-making process that both formally and respectfully recognizes three participants: the clinician, the caregivers, and the child. In political shuttle diplomacy, a diplomat conducts discussions with each of the parties (e.g., countries, political groups) separately before moving on to negotiations between the parties. This strategy can be particularly helpful when discrepancies arise within the triad. Within the context of pediatric oncology, clinicians can serve as the diplomat, meeting with caregivers and the child to understand their preferences about communication. These meetings provide the framework for exploration of how decisions have historically been made in the family from the perspective of the caregiver(s) and the child. It provides an opportunity for clinicians to understand any caregiver concerns about providing the child with information about their illness and to address common misconceptions. For the child, it provides an opportunity for the clinician to get to know them better, to provide honest and developmentally appropriate information in a manner that is consistent with family values and preferences, and to understand their perspective on the current circumstance. Within this approach, clinicians are better able to understand the preferences of all participants involved and "negotiate" an individualized plan for ongoing communication and decision-making.

Principles for Communicating with Parents

1. Build a relationship with parents. Factors predictive of effective communication between providers and parents include perception of interest, caring, warmth, and responsiveness (as cited in Levetown 2008).
2. Solicit information about family communication style, past decision-making experiences, and cultural considerations.
3. Recognize the parent as the expert on their child.
4. Openly discuss child involvement from day 1:
    (a) Provide information to the child:
        (i) Consider the order of delivery (all together, parents first, then child).
        (ii) Consider the delivery of information to the child (by parent, provider).
        (iii) Consider what information is delivered.
    (b) Respect the role of the child in treatment decision-making.

Plan in advance for challenging circumstances: What if the child's preference and the parent's preference are different?

Developmental Considerations

Infants and Toddlers (Ages 0–3)

The period between birth and age three is a critically formative time when children are developing attachment and trust through their relationships with their primary caregivers. Separation, pain, exposure to strange people and unfamiliar situations, and disruption of normal routines can all impact the child's ability to cope with their illness. Very young children do not have the ability to comprehend verbal explanations or the idea of "cancer." Intervention should focus on helping parents establish (or reestablish) a daily routine including feeding, baths, naptime, and bedtime, which will help maximize consistency and predictability, increase the family's sense of agency and control, and decrease stress for both the children and their parents.

Preschool Children (Ages 3–5)

Cognitive development during this period is characterized by egocentric and magical thinking, along with associative logic. Therefore, preschoolers will benefit from receiving simple and consistent explanations about their illness and treatment. It should be made very clear to preschoolers that nothing they did or said caused the illness, as in the absence of this information they

Principles for Communication with Pediatric Patients

1. Never underestimate the importance of taking time to establish rapport and build a relationship with the patient.
2. Elicit from the patient what is important to them (e.g., attending school, minimizing needle sticks, playing soccer).
3. Ask the patient (every time) who they would like to be present during the conversation.
4. If the parent is in the room, focus attention on the patient. Look at them, speak directly to them, and elicit their opinion.
5. Listen actively. Children are attuned to when they do not have an adult's undivided attention.
6. Consider the use of communication tools – iPads, drawing, etc. Many children are visual and may benefit from the use of multiple modalities to help them understand information.
7. Put information into a context that resonates with the patient (importance of pearl 1 in section "Clinical Pearls for Communicating with Patients and Caregivers in distress"):
   (a) If the patient's main desire is to attend school as much as possible, discuss the treatment within this frame (e.g., you should be able to attend school on these days; one of the side effects of the medicine is feeling tired, so to keep this from interfering with school, we are going to do X, Y, Z).

are capable of creating their own, likely egocentric, explanations such as "I didn't listen to Mommy and that is why I got sick." It is important to include factual information such as the name of the illness, basic and concrete information about the treatment, and the expected impact on the child's normal routine. For example, "You have a tumor called neuroblastoma, which is why your stomach has been hurting. You need special medicine called chemotherapy to make the tumor go away and this will be given at the clinic. You will get the chemotherapy through your tube. On days that you are getting the medicine you will not go to daycare." Children at this age can report on situation-specific symptoms (e.g., what hurts right now). The use of play or other communication techniques such as drawing can be both very helpful to communicate information to preschool children and also serve as a way of helping them report on their subjective experience. Stuffed animals or dolls with a central line or a port (e.g., Chemo Duck; www.chemoduck.org) are also useful tools for facilitating communication for clinicians, parents, and children.

School-Age Children (Ages 6–12)

School-age children have an increased capacity to think logically and to differentiate between themselves and the outside world. Thinking patterns continue to be relatively concrete with a focus on cause and effect and on fairness. When talking to school-age children, it is again important to clearly state that nothing they did caused them to get cancer and that their cancer is not a punishment for something they did. Children may have heard the word cancer before, and asking them about their understanding of what cancer is and what causes it can be helpful so that any misconceptions can be addressed directly. As children will vary widely in their desire for information, participation in discussions about their illness, and their role in the decision-making process, it is important to address each of these topics specifically with the child and their family.

Adolescents (Ages 13–18)

Adolescence is a period of great cognitive development, with a transition from concrete thinking to formal logical operations. As the ability to understand and to use abstract concepts begins to develop, adolescents become increasingly capable of making independent and informed decisions. Adolescent patients should be given a say in how they would like to receive information and what role they would like to have in the decision-making process (McCabe 1996). It is helpful to encourage providers to routinely meet with adolescent patients individually, giving them a time to discuss their own feelings without worry about parental reaction.

Special Topics

Discussing Bad News

At Diagnosis

Delivering news about a child's cancer diagnosis often comes in phases – first, when a cancer diagnosis is suspected but not confirmed, or when the details of the pathologic diagnosis are still in question, and then again later when the specifics of the diagnosis and treatment are known. At each phase, a commitment to honesty and timely disclosure of medical information is critical; at the same time, disclosing a probable diagnosis before it is final can also create unnecessary distress. Thus, during the initial phase of uncertainty, clinicians must find a balance between disclosing what is known and waiting to discuss information that holds significant uncertainty. This time period tends to be particularly difficult for children and families, who often express relief when clear information is available, no matter how difficult the content of that information may be.

Once a diagnosis and treatment plan or clear options for treatment are known with greater certainty, the clinician can sit down with the child and family for what is termed the Day One Talk (Mack and Grier 2004). As in other important conversations, the team (including medical providers and the psychosocial clinician) start by asking the child and family about their understanding of the child's illness. This helps us to understand where the conversation should start and whether there are misconceptions we should correct. In addition, this sets the stage for listening as one of our most important roles.

As we begin to share information, we focus our communication on three major points. Although these conversations can be quite long, we emphasize the three main aspects of the Day One Talk as the issues we want them to hear and remember:

1. The diagnosis – that we know what this is. This is particularly important because, as noted, this conversation tends to follow a period of uncertainty. In addition, we make sure to use the word cancer, to ensure that families understand that the child has cancer, even if the name of the type of cancer is something like Hodgkin's disease or leukemia, where cancer is not explicit. In addition, the word cancer has history and meaning in many families, and using that word allows us to ask about and address that meaning, which may or may not apply to their child.
2. We have treatment for the child's cancer. Along with this, we detail the goals of treatment. Often, for children with newly diagnosed cancer, we have good treatment and the goal of the treatment is cure. When cure is not possible, however, we explain that also. Along with this, we ask families whether they would like to hear any prognostic information. Research has shown that most families do indeed wish to hear about prognosis (Mack et al. 2006), and offering them the most accurate information possible can help them to make good decisions for their children going forward.
3. Cause of the child's cancer. Although much of the time no known cause exists, families often try to understand why this event would have happened in their lives and blame themselves. Making this an explicit part of the discussion allows us to address this as clearly as possible. We therefore tell children and families that childhood cancer has very few known causes and that we know of nothing that they or their child did, or didn't do, to cause this. In rare cases where potential causality exists, such as a genetic cause for the cancer, we explain this directly as well. Along similar lines, caregivers often wonder if they should have come in

sooner for evaluation or if other physicians should have recognized signs of cancer sooner. Most of the time, we are able to reassure caregivers that everything they (and the pediatrician) did was appropriate and that finding this even sooner would not have changed what we would have done for the child or her prognosis. In the rare cases where we know there has been a delay, we acknowledge that fact. While we cannot know whether a child's outcome would have been different if the cancer had been found sooner, we can at least acknowledge their sadness and fear. Of note, children, like their parents, also need to hear that the cancer is not their fault; if the child was not present for this conversation, we make sure to address this issue with him or her later.

After we have addressed these three main points, we then turn to the details of the child's cancer and its treatment. We describe where the cancer begins, how it can spread, and what we know about whether the tumor has spread to other parts of the body. A treatment plan can be introduced, with written information for the child and family to follow, so that they can review the information again later. If a research study is an option, we explain what taking part in the research means and what the standard treatment is. Because families often believe that research studies offer improved outcomes (Cousino et al. 2012), we also explain that the purpose of research is to benefit future patients, but that it could be better, worse, or the same as existing standard treatment.

We discuss treatment in general terms with an emphasis on the phases of treatment (e.g., induction or local control) and its expected impact on the child's life during the different phases, such as time in the hospital or when the child may return to school. We describe side effects of chemotherapy in general, with an emphasis on common side effects, such as myelosuppression and hair loss, and then discuss more specific side effects of each medication. We tell children and families that everyone gets some side effects, but no one gets all of the possible side effects; we also make sure to discuss which side effects are expected, which are unlikely, which could be permanent or life-threatening, and which are reversible.

Once the basic medical information has been discussed, the psychosocial clinician will discuss other important issues, such as sources of support, ways that friends and family can be helpful (and the ways they sometimes are not), information resources, and the structure of our team. Finally, after this very long conversation, we return to our first three points as those that should be remembered – we know what this is, we have treatment for it, and the cancer diagnosis is neither the child's nor the family's fault.

At Relapse

When children experience a cancer relapse, they and their families come to a very similar conversation with greater experience with cancer and its treatment and also new worries about whether the recurrent cancer can be cured. Because a recurrence means that all the child already went through was not effective, and because recurrent cancer can be much harder to treat, these conversations can be particularly painful. However, in most cases, the clinical team now has a long-standing relationship with this child and family. This can therefore be a particularly important time to come together with a shared history and deep caring.

The structure of the Day One Talk remains appropriate at the time of relapse, but with some changes. The clinical team again starts by telling the child and family that we know what this is, and we offer them a name for the cancer. This is usually a name that they know, as it is the same tumor, but because it can recur in new locations, it is important to confirm that we are indeed talking about the same cancer type. Second, we discuss treatment and its goals, including whether it may be possible to cure the child's recurrent cancer or whether treatment can offer symptom palliation and longer life. Finally, we again review the topic of causation, this time discussing the fact that we usually never know why cancer recurs for some children but not for others. Nonetheless, whenever possible, we reaffirm that the child and family did everything they possibly could and everything we asked them to do. Sometimes families question whether the cancer was treated properly in the first place, and we discuss those worries openly. When our own opinion is not enough to dispel fears, we offer families the chance to seek a second opinion and hear this information from others.

At the Transition to Palliative Care

Ideally palliative care is integrated early for all children with cancer, soon after diagnosis, with attention to symptom management, personal goals and values, and quality of life throughout care. Even in these cases, however, children and families who move away from curative measures to palliation have special communication needs.

One issue is that of communication about prognosis. While most families want to hear about prognosis even from the time of diagnosis, knowledge of prognosis is particularly salient for decision-making about end-of-life care; caregivers (and children) who do not know the child is dying are more likely to continue to pursue aggressive measures, even near death. Thus, rather than deferring to caregiver preferences about prognosis communication, clinicians may have special obligations to discuss prognosis even if caregivers find it painful. Reflecting on whether prognosis communication is essential, and the best timing for this discussion, is important before the conversation starts. The medical providers might then either offer prognostic information ("Would it be helpful to hear more about your child's prognosis?") or, alternatively, express the importance of such a conversation ("I think it's important that we talk about his future, including his prognosis.") Prognosis can then be stated in clear and unambiguous terms, albeit with caring and empathy (e.g., "I am so sorry to say this, but we no longer have a way to cure his cancer. We expect that it will continue to come back, no matter what we do, and that eventually he will not be able to survive it.")

Caregivers and children who understand a child's poor prognosis can begin to make decisions about care, with support and input from the clinical team. We suggest focusing on their goals as a path toward value-driven decision-making. A conversation about goals can begin with questions for the child and family – "as you think about the future, what is most important to you? Is there anything you are especially worried about? Is there anything you are especially hoping for?" Some families may continue to express hopes for cure, even when it is no longer possible. In this case, it can be helpful to ask, "and what else are you hoping for?" or, alternatively, "And what if what you are hoping for were no longer possible? What kind of things might you hope for in that situation?" Asking gently about alternative hopes can allow parents to express a full range of hopes, without forcing them to acknowledge that cure will never be.

Once goals are known, then recommendations for care can be made that reflect those goals. For example, if a child values being at home and in school, the medical team might recommend against intensive chemotherapy, which could detract from those goals. Alternatively, a family who wishes to prolong life may wish to use more intensive measures, even if they are associated with greater symptoms. Understanding goals can help to frame each decision and allows affirmation of the patient's and parent's goals all along the trajectory of care.

A final issue in palliative care communication is what to expect at the end of life. For many children and families, understanding what is ahead can take away some of the painful uncertainty of this period of time. Please see Chap. 14 on Palliative Care for further details. Although this is a difficult topic, some find that this information offers a sense of control and, for caregivers, an ability to anticipate the needs of the child even during her last days. As the clinical team, we therefore offer this information "Would it be helpful to talk about what to expect as the end of life grows closer?" to those who are looking ahead to this phase.

For children and adolescents, the conversation can begin with a focus on fears, worries, and hopes. The clinician might ask, for example, “As you think about the time ahead, is there anything you are most worried about? Anything you are hoping for?” Understanding worries and hopes can then serve as a starting point for talking about what is likely to happen and how symptoms will be managed. This can also be an opportunity for understanding wishes for the location of care near death and for addressing worries about loved ones and a desire to be remembered beyond death. Tools such as “Voicing My CHOICES” can offer adolescents and young adults the opportunity to think about their wishes for end-of-life care and make those wishes known to loved ones (Wiener et al. 2012; Zadeh and Wiener 2014).

For families who are interested in knowing more about what to expect, we similarly discuss topics such as location of death (eliciting their preferences) and avenues of support (such as home hospice, inpatient hospice, or inpatient hospital care.) In addition, family members may find it helpful to understand changes that the child may go through in her last days. This includes discussion of decreased perfusion of extremities, decreased urine output, and decreased consciousness, as well as respiratory depression, noisy breathing, and irregular breathing patterns. We talk about signs of discomfort or distress and how we will ensure the child is as comfortable as possible during this time. Finally, we also try to offer some discussion about autopsy before death occurs, as well as care of the body after death, to help parents prepare for those moments after the child has died. Not every family wishes for this information, but many do, and of those, many are afraid to ask (Wiener et al. 2014).

Communication with Patients and Caregivers in Distress

Cancer diagnoses and associated care planning are inherently stressful and understandably distressing for patients and their caregivers. In this context, it is likely that patients and caregivers experience strong feelings, such as fear, anger, and sadness, and it is also expected that such feelings will be present and perhaps even heightened, during interactions with clinicians in the position of sharing complex and often unpleasant information. Such strong emotional expression is a complicated component of already delicate interactions. The recommendations in the following sections are designed to assist medical and psychosocial clinicians in navigating interpersonally complex interactions with patients and their caregivers in a manner that maximizes effective communication and prioritizes the execution of high-quality medical care.

Proactive Interventions

We know, even before such situations present themselves, that these types of communication challenges are likely to emerge within our work in pediatric psycho-oncology. Therefore, proactive measures that may positively impact clinician-patient and clinician-caregiver relationships should be implemented whenever possible to maximize understanding of medical information and minimize the likelihood of miscommunication and associated negative feelings.

Relationship Factors

All clinical team members would benefit from making an active effort to develop positive working relationships with patients and their family members as early as possible and to maintain them throughout the course of treatment. The establishment of a positive working relationship characterized by trust, mutual respect, and collaboration should not be underestimated. This relationship will not only facilitate the effective exchange of information throughout one’s course of treatment, but it may also aid in the resolution of any strong negative feelings by providing a foundation upon which such feelings can be explored in a supportive, nonjudgmental, and productive manner.

Communication Preferences

Beginning early on in treatment, it would behoove clinicians to discuss, document, and accommodate family preferences in regard to communication. For example, in an effort to minimize anxiety and maximize the extent to which information is understood during important conversations (Schwabe and Wolf 2010), individuals may request, or clinicians may observe, that patients and/or their family members benefit from the following:

The provision of written information to read and review independently and to reference, as needed (e.g., a summary of information discussed with the medical team, medication teaching sheets, published research papers)
The presence of a specific family member, close family friend, or spiritual or religious representative
That meetings be held in a specific location, such as a private conference room, as opposed to a shared clinic space or exam room
The inclusion of as few clinicians as possible in conversations, which may feel less intimidating or overwhelming than the inclusion of multiple clinicians from the oncology service and perhaps consulting services.

Team-Family Meetings

At any point after the initiation of care, if any member of the multidisciplinary team has a sense that communication may be especially challenging due to patient or caregiver distress, consideration of regularly scheduled team-family meetings may be warranted. The specific purpose, timing, and composition of such meetings can be individualized, but the general goal of a team-family meeting is to provide a scheduled opportunity to review relevant information, to preview upcoming treatment needs and potential interventions, and to address any clinician or family concerns. Such meetings have been shown to be effective in facilitating discussions in the context of intensive care admissions and end-of-life decision-making (Marik et al. 2009; Nelson et al. 2009; Radwany et al. 2009), and such principles can be applied to improving communication at any point in the treatment course.

The nature and structure of the discussion may be similar to that of a routine medical visit, but the distinction as a separate meeting can be valuable in that (1) teams can meet separately prior to the meeting to ensure all providers are on the same page and invite relevant multidisciplinary clinicians and/or consulting services to attend, if appropriate, (2) family members can prepare questions and discussion points in advance that clinicians may not have time to address during routine appointments, and (3) it provides an opportunity to repeat, reinforce, or clarify important information that was presented during routine visits, which can be particularly helpful for patients and caregivers whose distress may in some form interfere with the reception, retention, or understanding of important medical information.

Communication Skills

In addition to such preventive methods, the effective and consistent implementation of the basic communication skills described earlier in this chapter is particularly important during interactions with distressed patients or caregivers.

Utilize Active Listening Skills

During challenging exchanges, active listening, acknowledging emotions, and expressing empathy are essential. In addition, maintaining a nonjudgmental approach and validating a family's experience can help clinicians navigate such interactions in a manner that fosters a positive working relationship. Among adult patients, adopting a warm, empathic, emotionally supportive approach has been associated with reduced anxiety and distress, as well as improved recall of medical information (van Osch et al. 2014); this approach is likely to be helpful when interacting with caregivers and patients in pediatric settings, as well.

Flexibly Maintain Structure

Core components of an effective clinical conversation include establishing the purpose of the conversation, eliciting patient and/or caregiver preferences and involvement in decision-making, reviewing options and recommendations, acknowledging patient/caregiver emotions, and eliciting patient and/or caregiver comprehension. The trajectory of conversations with individuals expressing strong negative emotion may be somewhat unpredictable, so remaining mindful of the key aspects of the interaction while maintaining flexibility will likely result in a more successful and satisfactory exchange from the perspective of both the clinician and the patient/caregiver.

Affective and Cognitive Strategies for Clinicians

It is important to acknowledge that the experience of communicating with individuals in distress, whether they are sad, angry, or anxious, naturally elicits emotional reactions in clinicians. After all, communication is a dynamic process. Therefore, when communicating with individuals in distress, depending on the type and intensity of their emotional response, it may be experienced by clinicians as sad, uncomfortable, awkward, frustrating, or even offensive. In order to utilize the communication strategies described above in a genuine and consistent manner, and to remain nondefensive and fully present and available to offer one's clinical expertise, it is helpful for clinicians to remain cognizant of their internal affective and cognitive experience. A clinician's emotional and cognitive experience may be reflected in verbal and nonverbal expressions and, therefore, may have a significant impact on the ongoing communication process. Clinicians benefit from acknowledging feelings, judgments, and assumptions made about patients and caregivers, especially those that fail to foster productive, patient-centered, mutually respectful communication.

If negative feelings or cognitions are identified, the use of internal statements by clinicians may be helpful in minimizing the extent to which such internal experiences interfere with the genuine expression of empathy. For example, when interacting with a frustrated caregiver who is raising her voice, speaking over the clinician, and ruminating on past events that have been discussed repeatedly over the course of many days, a clinician may feel equally frustrated, defeated, or angry. If the clinician is able to recognize those feelings in the moment, she will be much better prepared to redirect or channel them in a productive way. They may serve as cues to use internal statements that recognize the nature of the family's experience or positive intentions, qualities, or abilities, such as the following: "This mother is petrified that her child is going to die," "This mother is doing the very best that she can," or "This family's life has been devastated by their child's diagnosis." Individualized internal statements may help clinicians empathize with families during the most interpersonally challenging moments. In doing so, a clinician may be more likely to maintain a family-centered perspective, to use active listening skills, and to navigate the conversation toward a collaborative end, as opposed to further escalating a vulnerable patient or caregiver.

Practical Interventions

There are a number of very practical interventions that can be containing and reassuring to patients and families in distress, as well as effective for clinicians and staff.

Ensure Safety

Distress is expected and is completely understandable for patients and family members affected by a cancer diagnosis. While that is always true, safety of patients and staff must always be a top priority. Therefore, if expressions of anxiety, anger, or sadness, on the part of a patient or family member ever pose a physical threat or are interpreted as aggressive or disruptive to patients or staff, steps must be taken immediately to de-escalate the individual and to prevent such events from occurring in the future. At the first sign of potential escalation during conversations with clinical staff, it is helpful to clearly and firmly communicate hospital policies and the rationale for such policies, namely, protecting patients and staff. Ideally, clinicians would be able to do so in a gentle, empathic manner, but boundaries around safety must always be maintained and respected. Joining with the family around a mutual responsibility and shared interest in safety and the provision of high-quality clinical care, above all else, may help in navigating situations in which hospital or clinic policies are referenced and reinforced. A discussion of decision-making around issues of child protection is beyond the scope of this chapter, but would also be highly relevant in circumstances of this nature if child abuse or neglect is suspected or observed by clinical staff.

Psychosocial Referral

As patient or caregiver distress may present at any point along a patient's treatment trajectory, access to specialized psychosocial assessment and intervention services is crucial both for families and medical teams. Mental health clinicians who are well integrated and familiar with both administrative and clinical personnel on medical teams will be best suited to address clinical issues in a timely, thorough, and well-informed manner. When providing psychosocial services to patients and families in this context, particularly those exhibiting significant emotional or behavioral distress, it is essential to have a solid understanding of the medical factors at play, as well as knowledge and experience navigating the complex medical systems within which the family and medical teams are operating. Interventions often involve engaging multiple team members and mobilizing hospital-based supports. Mental health clinicians who are easily accessible, available to meet with patients and families throughout their course of treatment, and who have established collaborative relationships with medical providers will be best equipped to effectively and efficiently meet the mental health needs of the pediatric oncology population.

Lessons from the Case Vignette about Charlie

Charlie, the 13-year-old boy with Ewing sarcoma, whose parents did not want anyone to discuss his care needs with him, demonstrates a situation in which the medical team, the parents, and the patient are not on the same page. The following clinical recommendations may be helpful in situations similar to this:

- Early involvement and inclusion of a psychosocial provider on the clinical team
- Relationship building and understanding multiple perspectives:
  - Learning about the parent's fear regarding giving Charlie medical information and correcting misperceptions
  - At parent's request, provision of written material about this topic
- Team communication and collaboration
  - Identification of effective and ineffective communication strategies for this family
  - Multidisciplinary support for staff around disagreement with parent approach
- Established family meetings above and beyond usual clinic appointments that included key medical, psychosocial, and nursing providers

After establishing a relationship with Charlie's parents, they became more receptive to suggestions from the clinical team about providing developmentally appropriate information to Charlie. As Charlie became a more active participant in his clinic appointments, discussions about treatment and decision-making became more inclusive of Charlie. It was notable that as this was occurring, despite ongoing physical side effects, Charlie's symptoms of anxiety began to decrease and he independently started taking a more active role in his care at home, such as requesting to be in charge of his pill box and scheduling his daily routine.

Clinical Pearls

- Discuss, document, and accommodate family preferences in regard to communication.
- The effective use of active listening skills is essential to maintain rapport, understand the ever evolving patient and family experience, and ultimately navigate the conversation toward a mutually beneficial and productive end.
- If challenges in communication are noted, consider the potential benefits of establishing a regularly scheduled team-family meeting.
- Remain aware of internal affective and cognitive experiences and use internal statements, as needed, in order to consistently approach interactions in a nondefensive, nonjudgmental, and empathic manner.
- If emotional expressions are ever interpreted as aggressive or disruptive, join with the family around the establishment of a safe and healing atmosphere for their child, and adopt a gentle but firm approach to de-escalate the individual and to prevent such events from occurring in the future.

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