



Texas Children's Hospital®

Communicating with Pediatric Patients and their Families: *The Texas Children's Hospital Guide for Physicians, Nurses and other Healthcare Professionals*

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Texas Children's Hospital is the official pediatric teaching hospital for Baylor College of Medicine.

Communicating with Pediatric Patients and their Families: *the Texas Children's Hospital Guide for Physicians, Nurses and other Healthcare Professionals*

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**This book is dedicated to the healthcare professionals
of Texas Children's Hospital.**

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www.bcm.edu/pediatrics/patient-communication-guide

Preface

Texas Children’s Hospital is delighted to make this book available to healthcare providers who care for children everywhere. We recognize the commitment and dedication of these professionals to the care of children, and we believe that this guide will help them in their task. Skillful communication is the key to understanding our patients and their families—their symptoms, their fears and concerns and their hopes. And it is the way we convey our understanding, our compassion and our empathy to our patients and their families.

I appreciate the time and effort that the physicians, nurses, child life specialists and other healthcare providers at Texas Children’s Hospital have put into creating this book, and I commend them for taking time from their very busy schedules to share their experiences and wisdom with us. I know that what they have provided here will be of immense value to other healthcare providers here and elsewhere.

I am also proud that the impetus for this guide was when Texas Children’s named *Experience* as one of four organizational priorities in 2013. Our system-wide focus on *Experience* is all about creating a better place to work and to experience healthcare, and we’ve launched many patient and family experience initiatives in support of that focus. Our goal is to delight patients, families and co-workers with exceptional, caring service at every opportunity. Skillful patient communication is at the heart of this organizational priority and at the heart of safe, effective and compassionate patient care.

Mark A. Wallace
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Introduction

The primary reason for creating this book was to assist healthcare professionals in communicating with pediatric patients and their families, especially in difficult situations, thereby decreasing miscommunication, lessening patient anxiety and discomfort, helping patients and families deal with bad news and uncertainty, and improving patients' adherence to management plans. The guide will help healthcare professionals convey compassion and empathy and improve patient satisfaction with the care they receive.

Communication skills are increasingly being taught in medical and nursing schools, and the array of resources for teaching and for learning communication is also increasing. Communicating effectively and compassionately with children and their families raises many issues and requires a unique knowledge base as well as special skills. Relatively few of the current curricula and very few of the available resources, however, focus specifically on communicating with the pediatric patient and his or her caregivers.

This book is intended primarily as a resource and a reference. While the editors would be delighted if the user were to read the book from cover to cover, it is designed so that individual chapters can be read free-standing and can be used as references when looking for specific information and guidance. As the chapters are meant to be self-sufficient, and as many principles of communication apply to communicating with patients and parents in more than one setting, some redundancy among chapters is inevitable. The editors and authors have tried to minimize this redundancy by addressing general principles and basic tenets in the first section and by the use of cross-chapter references.

Terminology

Although in some cases the adult accompanying a pediatric patient will be someone other than a parent (e.g., a grandparent, another relative or a foster parent or guardian), for convenience, we use the terms *parent* or *parents* when referring to the accompanying adult(s). The words *parents* and *family* are used interchangeably.

Authors will often refer to *the physician* or *the nurse*, although the point in question may well apply to other healthcare providers. The terms *healthcare providers*, *providers* and *clinicians* are used interchangeably.

This guide is not legal advice and should not be treated as such. The reader's state's laws may differ from those of Texas. It is advisable that you consult with your Risk Management Department or your legal counsel to ensure compliance with the laws of your state.

Consent and confidentiality issues involving pediatric patients are complex, and legal guidance varies based upon state law. The material in this book is intended to provoke thought and illustrate some methods of handling these issues. To determine legality, each situation must be analyzed in accordance with applicable law.

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Section 1.

Principles and Fundamentals of Communication

Section Editor: Teri L Turner, MD, MPH, MEd

Chapter 1

General Principles of Communicating with Pediatric Patients and Family Members

Martin I Lorin, MD

Background and Introduction

Effective communication is not only critical in caring for patients, it is also the healthcare provider's primary tool for conveying respect, empathy and compassion to patients and their families. Studies have shown that skillful communication that is patient-centered, conveys empathy and effectively uses language and non-verbal signals leads to increased patient satisfaction (Griffith et al., 2003 ; Little et al., 2001; Williams et al.,1998). There also is evidence that better communication results in improved patient adherence to treatment and better clinical outcomes (Little et al., 1997; Mainman et al., 1988; Stewart et al., 2000). Finally, there are studies demonstrating decreased cost and fewer malpractice claims associated with more effective and compassionate communication (Adamson et al., 2000; Ahrens et al., 2003). An American Academy of Pediatrics report refers to communication as the most common procedure in medicine (Levetown, 2008).

Although the pediatric patient is not an adult, more often than not, we are dealing with an adult (the parent or guardian) as well as with the child. The classic pediatric encounter, therefore, is triadic—patient, parent and healthcare provider. Even when the patient is an infant or very young child, he or she must be acknowledged as part of the encounter. We try to assess the infant's symptoms through what the parents tell us, and we try to assess the infant's or very young child's emotional state by our observations. Does the child appear comfortable and content, or does he or she appear irritable? Is the child behaving as if in pain? Communicating with the pediatric patient and his or her family presents unique challenges and requires special skills. This chapter will address some of the general principles of communicating with pediatric patients and their family members, will explore the unique challenges of working with children and will offer suggestions for meeting these challenges.

Table 1 highlights some of the more important differences between pediatric and adult medical care that impact communication. Of course, there are also many similarities, such as the current recognition of the importance of patient-centered care, self-advocacy and self-determination (in a developmentally appropriate manner) and shared decision making.

Table 1. Some Major Differences between Pediatric and Adult medicine.

Pediatrics	Adult medicine
Ideally, family centered, involving patient and parent(s).	Ideally, patient centered.
Growth and development are major issues for most patients.	Aging process and chronic disease management are major issues for many patients.
Promoting health is an important area of focus.	Promoting and sustaining health and screening for diseases are areas of focus.
Focus on school and academics.	Focus on work
In most cases the patient cannot legally consent to treatment.	In most cases the patient can legally consent to treatment.

Many patients are preverbal and cannot participate in discussion, planning or decision making.	Relatively few patients are cognitively impaired and cannot participate in discussion, planning or decision making.
Many patients are too young to participate in their care.	Relatively few patients are unable to participate in their care.
Infants, toddlers and young children have little or no responsibility for their care. For older children and adolescents, responsibility is shared with parents.	Most patients are responsible for their own care, sometimes shared with family members. A minority of patients are not capable of being responsible for their care.

Most healthcare providers are competent and well-meaning, and patient complaints, as well as medical errors, are more often due to poor communication than to incompetence, frequently just not listening to the patient or the family (King, 2014; Woolf et al., 2004). In today's healthcare system, physicians, nurses and other healthcare professionals may feel rushed and too busy to listen. It is easy to forget that communication is a two way activity. An editorial entitled, *Talking to Patients in the 21st Century*, Zuger (2013) suggests that the modern physician will have to "talk, think, listen and type at the same time."

Involving the Child in the Conversation

Over the past few decades, pediatricians increasingly have come to include the child in the conversation. Dutch researchers reviewed archived pediatric consultations from the 1970s to the 1990s (Tates and Meeuwesen, 2000) and noted that over these years the physicians' approach had become more child-centered, with more involvement of the pediatric patient in the conversation, but they also noted that parents had not made similar adjustments.

We need to invite children to participate in discussions, not only by describing their physical symptoms but also by discussing their feelings and by contributing to decision making. For example, the physician might say to a child, "Lucy, I'm interested in how you feel about what's going on. Tell me what you think about your upcoming surgery."

Involving the child needs to be conscious and deliberate until it becomes second nature. If the pediatric patient is young or quiet, it is important not to talk over the child as if he or she were not there. (See Chapter 5, *Patient-centered Communication and Decision Sharing*, section, *Essential Elements of Communication from the Child's and Adolescent's Perspective*.)

Starting the Conversation: Introductions and Opening

For an initial visit, make sure you know the patient's full name before entering the room. Once in the room, check what name the child likes to be called and how adults want to be addressed. Always address the patient and family members by name. Do not *address* the mother as "Mom" or "Mother" or the father as "Dad" (Amer and Fischer, 2009). More than once, I have witnessed a parent act surprised or offended when addressed in this manner. I vividly remember a mother looking sternly at the resident and saying, "I'm not your mother!" It is, of course, entirely appropriate to *refer to* the parent by family role. For example, you might say to a child, "Your mother tells me that you're having some headaches again. Tell me about them."

Introduce yourself. If the patient is a verbally competent child or adolescent, it is appropriate to address him or her first. "Hello. So you are Joey (wait for confirmation). Pleased to meet you. I'm Dr. Smith, and (looking at the accompanying adult) who has come with you today?"

If the patient is an infant or toddler, you will address the accompanying adult. "Good morning. I'm Doctor Smith, and you are?" The response not only clues you in as to how the adult wants to

be addressed but also usually confirms his or her relation to the patient. “I’m Mrs. Smith, Charley’s mother.” If the accompanying adult doesn’t explain his or her relation to the patient, ask.

If you can, arrange the seating (or choose where to stand if there is no place to sit) so as to face both the patient and the parent. Video studies of triadic consultations have shown that a six- to twelve-year-old child is most likely to be actively involved in the discussion when the patient, parent and physician are seated in a triangular arrangement with all three being an equal distance apart (Cahill and Papageorgiou, 2007a). If possible, sit; this will make you less intimidating and will encourage dialog. It also will leave the family with the impression that you spent more time with them than if you had been standing (Johnson et al., 2008).

If you must read the patient’s chart or electronic medical record, check laboratory data or read a referral note before taking the history, explain that to the patient. “Just give me a moment to check some data in the computer then we can talk.” You can even invite the patient and parent to look at the computer screen with you.

A bit of social chatter or one or two non-medical questions can help put the child and accompanying adult(s) at ease. Then, asking a child why he or she has come to the office or why he or she has been admitted to the hospital can be a helpful starting point, often revealing misconceptions or fears. Understanding and managing expectations are important so it is appropriate to ask both the patient and the parent(s) about their expectations for the visit or for the hospitalization.

After introductions and rapport-building, the clinician needs to solicit the patient’s and parent’s concerns and reasons for the encounter. It is important to let them voice their concerns without interruption, which usually takes less than a minute (Marvel et al., 1999). If the clinician feels that all concerns cannot be addressed at this encounter, he or she should collaborate with the patient (if age appropriate) and parent to set the agenda, determining which issues will be addressed at this time and which later.

The Conversation

Based on a review of the literature in 2007, Cahill and Papageorgiou (2007b) concluded that children in the 6- to 12-year-old age range had little meaningful involvement during visits with their healthcare providers. They might take part during the information gathering phase but were unlikely to participate in the subsequent discussion or in treatment planning. Clinicians working with children need to make a conscious effort to keep children actively involved in discussions about all phases of their care, not just the data gathering phase. Even though young children are not capable of making most medical decisions, they can participate in these decisions and, if given the opportunity, can voice their concerns, their opinions and their preferences. In a separate publication, the same authors (Cahill and Papageorgiou, 2007a) noted that an accompanying adult was less likely to answer on behalf of a child when that adult was in a position to see that the doctor’s gaze was directed at the child and the doctor addressed the child by name.

It is hard to judge a child’s verbal ability until you try to engage him or her in conversation. A child’s size and chronological age do not always correlate with developmental age or verbal skills. (See Chapter 2, *Age Appropriate Communication and Developmental Issues*.) Engaging the child in the conversation in a meaningful way can be a challenge. Children often have more difficulty with open ended questions than do adults, and they often need more time to answer a question than do adults. Give the child time and show that you are comfortable waiting for a response by your verbal language (“It’s okay Eddie, take your time to get your thoughts together.”), by body language (keep your gaze on the child and have a pleasant, patient, expectant look) and by action (don’t look at your watch).

Children are likely to be influenced by what their parents have said, and they are likely to give answers they think their parents or the doctor wants. Sometimes you have to encourage the child to voice his or her own thoughts. “That sounds pretty much like what your mother and I said. Are you sure that you agree? What would you like to do differently?”

The child’s desire for autonomy (versus having the physician or parent make all the decisions) varies from child to child, depending on the child’s age, developmental level and individual personality. The physician should ascertain the wishes of the child and the parent(s) in this regard.

Closing the Conversation

There are three important components for effective closure of a patient encounter:

Summarizing

Summarizing at the end of a clinical encounter is different than summarizing as a tool while taking a history. Summarizing *while taking a history* (see below, *Summarizing during the Interview* and *The ILS Model*) is meant to ensure that you have correctly understood what the patient has told you. Summarizing *at the end of the clinical encounter* is primarily a technique to be sure that the family understands how you see the situation.

Explaining the Plan

Explaining what is going to happen next helps the patient cope with the illness. Most people have difficulty dealing with uncertainty, and imagined thoughts about what is going to happen are often more frightening than what is really going to happen. The more complex the plan, the more challenging it is to be sure that the patient or parent really understands it. A yes answer to, “Do you understand?” is not a reliable indicator of comprehension. Many patients are embarrassed to admit that they don’t understand or think they understand when they do not. The question, “Is there something that I haven’t made clear or something that you would like me to clarify?” is stronger encouragement for the child or parent to ask for clarification. For the verbal child, asking, “Now Emily, why don’t you tell us what’s going to happen today?” can be very enlightening to both the provider and the parent. For the adolescent or adult, the following is a non-condescending invitation: “So, let’s review what we’ve decided to do. Emily (or Mrs. Jones), why don’t you review the plan for us?”

Soliciting Questions

The typical, “Any questions?” delivered while standing up and moving towards the door is not the most effective incentive. Asking, “What questions do you have?” while remaining seated is more likely to elicit a meaningful response. If you sense that the patient or parent is confused, you can ask, “You look to me to be a bit uncertain. What can I clarify or go over again?” This is less intimidating than, “What don’t you understand?”

The Words We Choose

While there are many facets to how we communicate with patients, the words we use to convey our thoughts are critical to how the message is received. A study in a family medicine clinic dramatically showed the difference that one word can make in eliciting information from patients (Heritage et al., 2007). There were three study groups. In the no-intervention (control) group, patients were seen in the usual manner. For the two experimental groups, the physicians were instructed that after their usual history taking they should ask either “Is there *anything* else you want to address in the visit today?” or “Is there *something* else you want to address in the visit today?” The investigators, blinded to which group the patient was in, met with the patients

and determined how many concerns they had that had not been addressed during the visit. There was no statistically significant difference between the control and the “anything” group. There was a highly significant difference ($P=.001$) between the control and the “something” group, with 78% fewer unmet needs in the “something” group. The authors point out the negative polarity of the word “any” compared to the positive polarity of “some.” One would be comfortable saying, “Yes, there is something else.” One would not say, “Yes, there is anything else.” And one would be more likely to say, “No, there isn’t anything else.” than, “No, there isn’t something else.”

Paul Schenk (2008), a clinical psychologist, has written about words and phrases that he believes trigger a negative response in patients. For example, consider the word, *just*. Have you ever told a patient to *just* relax? If the patient could relax, he or she probably would not need you to tell him or her to do so. When a clinician tells the frantic mother of an infant with a stuffed nose and distressing cough that it is *just* a cold, the phrase *just a cold* trivializes the illness and ignores the mother’s apprehension and distress. It would be more effective and more empathetic (see *Empathy* below) to acknowledge both the patient’s and the parent’s discomfort by saying, for example, “It is a bad cold, a viral infection. I know that it’s hard to see him uncomfortable and coughing like that, but he will get better, and an antibiotic is not going to help.”

Platt and Gordon (2004) also acknowledge the importance of specific words and call attention to the problems with a clinician’s response of, “Okay.” They point out that this word is very imprecise. The patient tells the doctor about a transient episode of dizziness and the doctor says, “Okay,” meaning, “Okay, I hear you.” But the patient interprets the “Okay” as meaning that the dizziness is not a problem or not important.”

Bottom line—words do matter. Choose them carefully.

Communication Is a Dialog (or Trialog)

Communication needs to be two-way (or three-way: patient, parent, clinician). It is not a monologue and not a question and answer exercise. Beware of protocol driven communication. A rigid series of predetermined questions suggests that you are not seeing the patient as an individual. Facing and looking directly at the patient and maintaining active eye contact are powerful tools of engagement. As mentioned above, for the classic pediatric triad, a triangular seating arrangement with equal distance between all parties is ideal. If four persons are involved, a square is the best arrangement (Redsell and Hastings, 2010). The ideal distance is one that is non-intrusive but would permit the clinician to lean forward and touch the patient or parent.

While much of the conversation, especially the early part, should be patient-centered, there are times when the clinician needs to use other approaches. Much of the data gathering phase of the encounter will be problem- or disease-driven, and the concluding part of the interview will be a combination of patient- problem- and clinician-driven.

The Art of Listening

Time is a very precious commodity for all healthcare providers, and it can be tempting to try to save time by making patients *cut to the chase*. However, this often results in miscommunication and patient dissatisfaction that actually can result in requiring more time to sort things out.

Begin by inviting the patient or parent to tell you the story. “Joey, tell me about yourself and the problem that brings you here today?” or, “Mrs. Young, tell me about Joey’s problem and what your concerns are.”

Show that you are listening by simply saying it: “I’m listening.” “I understand.” “Got it. Please go on.” Or use nonverbal signs such as nodding, leaning forward or offering a gentle “hmm” or “uh-huh.” Do not look at your watch. Do not do anything to suggest that you are in a hurry to leave.

Use open-ended questions followed by directed and more specific questions as needed. Some patients need more direction than others, but too much direction or direction too early in the conversation can prevent the patient or parent from telling his or her story and can be misleading.

Platt and Gordon (2004) point out that validation is a critical part of listening. It means explaining to the patient how you interpret what he or she told you and modifying that interpretation if the patient sees it differently. “Let me make sure that I have it right. You were angry because you felt the medicine was actually making the pain worse, but no one would listen.”

What if the patient continues to talk without addressing the issues? Nguyen et al. (2013) suggest asking, “Would it be okay if I interrupt you to ask some specific questions?”

Techniques to Facilitate Communication

There are a number of techniques the clinician can use to facilitate dialog. Successful use of these techniques depends on the clinician being aware of his or her own biases. *Biases* refer to how prior experiences or knowledge influences our thinking. We all have biases, and we need to be aware of them. We have to recognize what makes us uncomfortable and what triggers various emotions such as anger or condescension so that these reactions do not impact the care we deliver to our patients.

Empathy

Empathy is best defined as the capacity to *recognize* emotions that are being experienced by a patient or parent and *showing* that individual that you recognize and appreciate the emotion. Platt and Gordon (2004) contend that an empathetic response is the most effective response to a patient’s strong emotion such as anger, sadness or fear. According to Myerscough and Ford (1996), an empathetic response indicates that the physician is trying to understand how the patient feels. It does not mean that the clinician actually knows how the patient feels, and it certainly does not mean that the clinician feels what the patient feels.

If, for example, you tell a parent that you feel his or her grief, it would not be unusual for that individual to respond, “No, you don’t. You can’t.” In a highly emotional situation, even saying that you understand how a parent feels may elicit a negative response such as, “No, you can’t understand.” A safer way to communicate would be, “I can only imagine what you are going through. It has to be the worst possible pain for you to see your child suffer.”

Suchman et al. (1997) define empathetic communication as the clinician accurately understanding the patient’s feelings and effectively communicating those feelings back to the patient, so that he or she feels understood. Analyzing physician-patient encounters, they found that all too often the physician failed to respond to the patient’s or parent’s feelings and turned the conversation in a more factual and less emotional direction.

Parent: “When he has blood in his stool and looks at me like that, my heart just goes out to him.”

Physician: “Is the blood bright red or dark? How often does that happen?”

Parent: “Yeah, it’s red, and it’s getting more frequent.”

In the response above, the physician either did not appreciate what the parent was feeling and expressing or chose to avoid the issue, perhaps because he or she felt uncomfortable dealing with it. The following is an example of an empathetic response.

Parent: “When he has blood in his stool and looks at me like that, my heart just goes out to him.”

Physician: “I can appreciate that. I’m sure that Tom is disappointed and discouraged that the inflammation hasn’t responded to the medication, and I can imagine how sad it must make you feel to watch.” (Acknowledgment)

Parent: “Yeah, we’re both sad and discouraged.”

Physician: “And you have every right to be discouraged, but I am convinced that we will be able to control the inflammation.” (Validation)

Reflection

This technique involves repeating a significant word or phrase that the patient has just said. It is particularly useful when a patient has talked about his or her feelings. It is a safe technique in that you are not offering an interpretation; you are simply indicating that you heard what the patient said and perhaps are inviting him or her to elaborate on it.

Patient: “Sometimes I wake up at night wheezing and scared because I can’t breathe.”

Physician: “So, wheezing and feeling scared and not able to breathe.”

Clarification

Clarifying is a higher skill level than reflecting. It means rewording or defining what the patient has said. Clarifying can help patients or parents recognize and understand their feelings

Parent: “When he has a tantrum like that and screams for no reason, it gets to me, really gets to me. I feel like screaming myself. I get so angry, so angry. I just want to make him stop. I’m almost as out of control as he is.”

Physician: “So it sounds to me like you’re saying that he makes you so angry that you feel as if you could hurt him.” (It is important to acknowledge that you are offering an interpretation, with which the patient or parent may or may not agree.)

Mirroring

This shows the patient or parent her feelings as you perceive them. For example, “You look very sad when you talk about Edward. You look as if you want to cry.” This can encourage the individual to come to grips with feelings that he or she was not quite ready to express.

Mirroring and clarification are closely related and can overlap.

Summarizing during the Interview

Summarizing *during* an interview is a powerful technique to verify that you understand the patient correctly (Boyle et al., 2005). It also provides the patient with an opportunity to add to the narrative. Explain why you are summarizing. “Could we summarize to be sure that I understand what you told me?”

Silence

Silence can be a tool for communication, and healthcare providers should not be disturbed by silence. There are many reasons for a patient’s silence. It may indicate anger or lack of trust. It may be because the individual is struggling to put his or her feelings into words, or that there is something he or she is hesitant to bring up. Appropriate use of silence gives patients time to gather their thoughts or to summon the courage to talk about something that is perceived as frightening or embarrassing. It is helpful to convey that you are not rushing the patient. “This can be difficult. Take your time.”

If a patient persists in silence, it is reasonable to move on. “I see that it’s hard for you to talk about this. Would you like to come back to this later?”

Appropriate language

Speak in plain language and at the patient’s level of understanding. (See Chapter 27, *Using Communication to Improve Patient Adherence*, section, *Improving Adherence*.) Avoid acronyms and medical jargon (aka *med-speak*). “The marrow was completely packed with blasts.” is not helpful to the parents of a child with newly diagnosed leukemia. “The bone marrow test confirmed

leukemia.” is more easily understood. Not every lay person will understand, “The prognosis is guarded.” but he or she should easily understand, “His condition is very serious.” or “The outlook is not good.”

When using medical terms, explain them, unless you know specifically that the patient or parent understands those terms. Rather than simply saying, “His hemoglobin has been decreasing.” explain, “His hemoglobin has been decreasing. Hemoglobin is the red material in the blood that carries the oxygen. When there is too little, that’s anemia.” Rather than saying, “The CT scan showed a space-occupying lesion.” explain, “The CT scan showed a mass, which might be a tumor.”

Nonverbal Aspects of Communication

Nonverbal signaling, also known as body language, can be as important as what is said verbally. Larsen and Smith (1981) analyzed video recordings of patient visits to a family medicine clinic and concluded that the nonverbal behavior of a physician in a physician-patient interview is important in determining patient satisfaction. In a study of almost 500 patient encounters, DiMatteo et al. (1980) found that physicians who were more sensitive to body movement and posture cues to patient emotion were rated higher by the patients with regard to “the art of medical care delivered.” The same was true for physicians who were more successful at expressing their emotions through nonverbal communications compared to those who were less effective non-verbal communicators.

Nonverbal communication can be divided into four categories: kinesis, proxemics, paralinguistics, and autonomics (Myerscough and Ford, 1996; Platt and Gordon, 2004).

Kinesis

Kinesis refers to communication through body movements such as facial expressions, gestures and posture. When people talk about body language, they usually are referring to kinesis, which is the most studied part of nonverbal communication (Aviezer et al., 2012; DiMatteo et al., 1980; Hillis, 2011; Larsen and Smith, 1981).

The clinician needs to look for and interpret kinetic signs in the patient. Some of these signs are obvious (clenched hands, furrowed brow, folded arms, foot tapping, looking away) others are more subtle (e.g., frequent swallowing as a sign of nervousness).

Clinicians also can use their own kinetic actions as tools for effective communication. Let your body language portray that you are unhurried and attentive. If possible, sit down, face the patient and parent and look at them. Lean slightly forward. Maintain frequent but not intrusive eye contact, an open, relaxed body posture and an appropriate, calm, facial expression. A gentle smile will usually help put the patient at ease but may be perceived as inappropriate when delivering bad news. Keep your chest area unobstructed and arms unfolded to avoid a barrier between you and the patient. Avoid looking over the rim of your glasses, which may be perceived as authoritative or dubious of what you are being told. Avoid leaning back, which may be perceived as withdrawing or being aloof.

Touching the patient or parent is considered a kinetic behavior. If culturally appropriate, shake hands. In a serious conversation, if touching is appropriate, the hand and the forearm are usually perceived as the least threatening areas (Osmun et al., 2000). Many patients appreciate a gentle touch, but others dislike any touch and will flinch or withdraw. The basic rule is, don’t touch if you have any reason to anticipate that the individual would respond negatively.

Proxemics

Proxemics refer to issues of distance and the presence of physical barriers. For example, the

presence of a desk between you and the patient heightens the feeling of separation and diminishes the feeling of working together as a team. In pediatrics, we need to be concerned about vertical as well as horizontal distance. Towering over a small child can be intimidating. Getting down to the child's level, for example, by kneeling at the bedside, is a useful pediatric skill.

Paralinguistics

Paralinguistics are characteristics of the voice, such as tone, volume and emphasis. Examples include the whisper of confidentiality and the rising volume of anger. It is generally useful to match the patient's tone and volume (Ishikawa et al., 2006), but do not answer shouting by shouting. This category also includes utterances that are not really words, for example, *hmm* or *uh huh*.

Autonomics

Autonomics are body reactions generally beyond voluntary control. Examples include the flushing of embarrassment and the pallor of shock or fear. Tears are probably the most common autonomic reaction.

Mnemonics (acronyms) and Models for Communication

Acronyms and other mnemonics are useful tools for remembering steps in dealing with specific situations. They are meant as guides only.

Stop-Look-Listen

This simple model for communication has been in use for a long time. It seems to have arisen in the psychiatric literature but is applicable to any patient encounter. It is especially helpful in challenging conversations.

Stop: stop thinking about anything else and concentrate on the person(s) with whom you are communicating. Be aware of your own mood. Are you feeling harried, defensive or angry?

Look: be aware of the immediate surroundings and everyone in the room. Does the setting provide privacy? What distractions are present? Try to judge the patient's emotional state from his or her facial expressions and body language as well as from his or her words.

Listen: listen to the patient's words and try to understand the feelings behind them. Do not think about what you are going to say while the patient is speaking. Confirm your understanding by checking back with the patient before formulating an answer.

The ILS model

Another simple model for general use is suggested by Platt and Gordon (2004) and by Boyle et al. (2005).

Invite: ask the patient to tell his or her story. Use open-ended inquiries, such as, "Tell me about yourself and what brings you here today."

Listen: give the patient a chance to talk with minimal interruption. Show that you are listening by both verbal and non-verbal responses. Direct the patient with open imperatives, "Tell me more about that." or open questions, "How did you feel about that?" Do not go into specific questions too early.

Summarize: explain how you see the situation. Review the most important clinical findings and how you interpret them. Give the patient the opportunity to ask questions, add information or offer corrections. In the ILS model, summarizing is done repeatedly during the conversation, not just at the end.

The RESPECT model

This acronym is especially useful as a mental checklist in difficult situations (Cullins, 2015).

Rapport: this can begin with some social chatter to *break the ice*, but true rapport requires more. Show the patient that you are interested in his or her story and point of view.

Empathy: this involves understanding the patient's feelings and emotions, acknowledging them and validating the patient's feelings. (See Empathy above)

Support: ask about barriers to care and get assistance for the patient and family. Provide assurance that you will be there for them.

Partnership: be flexible with regard to control issues and be willing to share decision making. Stress working together.

Explanations: avoid acronyms and med-speak. Use verbal clarification techniques. Check for understanding.

Cultural competence: respect the family's culture, and at the same time, be aware of your own cultural biases and preconceptions. Inquire rather than assume how a patient's culture may be influencing his or her feelings or behavior. (See Chapter 28, *Communicating across Cultural Differences*.)

Trust: appreciate that self-disclosure may be difficult for some patients. Be accepting of their negative thoughts and feelings. Be honest and compassionate.

The CARE Mnemonic

The CARE acronym is most helpful as a reminder for how to relate to patients in a caring way (Myerscough and Ford, 1996). It is not intended as an overall checklist for a clinician-patient interaction.

Comfort: to effectively comfort patients and families, the provider must be willing to discuss emotional issues and other difficult topics. The provider must show the patient and parents that he or she is not frightened or put off by sensitive matters such as sexuality, abuse and death.

Acceptance: this means that the provider recognizes, understands and accepts the patient's or parent's feelings about the illness and therapy, even if these feelings are inappropriate or counter-productive. This does not mean that the provider agrees with these feelings, but it does mean that the provider will not respond with anger or by rejecting the patient.

Responsiveness: this includes responding to indirect and incomplete messages as well as to the direct expression of emotion.

Empathy: responding with empathy is generally the most effective way of dealing with a patient's or parent's emotions. (See Empathy above.) The basis of empathy is understanding the patient's or parent's point of view and acknowledging that point of view.

A Repertoire of Rapid Responses

A repertoire of rapid responses refers to the clinician's practiced responses to challenging situations. The rapid response is not a scripted answer so much as a scripted pause, a safe and supportive response while you gather your thoughts for further conversation. It sends the message that you are listening while letting you assess the situation and the patient's emotional state and plan your response. Having a repertoire of these rapid responses keeps you from saying the wrong thing before you have had a chance to think about what is happening. In other words, it helps you *not* to react in a way that will *fuel the fire*.

You undoubtedly have unconsciously developed some rapid responses. This discussion will help you review and fine-tune them, as well as develop additional responses.

The general principles for a rapid response are:

- Diagnose: recognize the circumstances and the emotions
- Validate: show that you recognize the circumstances and the emotions
- Explain: clarify the current situation and explain or inform what will or should happen next

The examples below are meant to illustrate how these general principles can be applied to specific situations and to suggest some appropriate responses. Each clinician will need to find the words that fit his or her style. Mentally rehearsing these responses will not only smooth the rough edges but also will help ensure that they are quickly recalled when needed.

A Grief-stricken Parent

After being told that her child's cancer was not responding to chemotherapy and had spread, a mother cries and appears shocked and devastated.

Effective response: "I appreciate how upsetting this is for you. Are you able to talk about the situation and what you're feeling, or do you need some time to gather your thoughts?"

Suboptimal response: "You're upset, understandably. Do you need a minute to relax?" (How can she relax?)

An Angry Parent

A father is upset by the long wait in the emergency center. When you enter the room, he angrily says, "Finally. We've been waiting forever."

Effective response: "I'm sorry you had to wait so long, and I can appreciate your being upset about it. I'm here now and you have my undivided attention. How can I help you?"

Suboptimal response: "Okay, just tell me why you're here. What's the problem? (Ignores patient's anger.)

An Angry, Shouting Parent

A parent is upset, angry and shouting because an MRI could not be scheduled for a week.

Effective response: "I realize how upsetting this is, but it's hard for us to communicate when you are shouting. Can you try to lower your voice a bit?" (Notice the *try*. You are acknowledging that it may be difficult for him to calm down.)

Suboptimal response: "Okay, you're angry, but that doesn't give you the right to shout at me." (Accusatory and defensive)

An Angry Parent Using Profanity

A six-year-old child has been NPO awaiting a surgical procedure scheduled for 1pm. When told that the procedure has been delayed for two hours, the parent becomes angry and begins using profanity.

Effective response: "I can see that you're very upset and angry, and I understand that, but I have to ask you not to use that kind of language here. It's not helpful, and it makes it hard for us to communicate."

Suboptimal response: "I know that you're upset but that kind of language is unacceptable." (The word "unacceptable" is usually seen as judgmental and often triggers a defensive response. It is best to avoid the word and instead explain why something is unacceptable. Remember, profanity may be the norm in the parent's culture.)

Parents Do Not Want Anyone to Tell the Patient the Diagnosis

The parents of a 15-year-old girl do not want anyone to tell her that she has cancer. "We don't want you to tell her. Don't say anything about cancer."

Effective responses:

Immediate response: “Let’s talk about this. Tell me why you feel she shouldn’t know that she has cancer.”

Follow up responses:

“I understand how difficult this is for the entire family. I wonder how we can be sure what Molly wants to know or not know.”

“I wonder if you’ve thought about some of the practical issues involved in not telling her, for example, how to explain the radiation or the chemotherapy? And she will be going to a clinic with other children who know they have cancer.”

“Almost always these children do know, and by not telling them, we deprive them of the opportunity to share their feelings and fears.”

Suboptimal response: “We have to tell her. She has a right to know.” (Ultimately, this approach may be necessary, but as an initial response it is confrontational and doesn’t explore or acknowledge the parents’ reasons for not telling. (See Chapter 6, *Ethical Considerations in Communicating with or about a Child*, section, *Ethical Challenges between Physician and Parent, Case #2*.)

A Parent Who Talks for the Child

A parent monopolizes the conversation and answers questions directed at the 12-year-old child.

Effective response: “Let me ask Joseph to tell me how he feels to fill in the information a bit. Is that okay? (addressing both mother and patient)

Suboptimal response: “Why don’t you let Joseph tell me?” or “Why don’t you let Joseph speak for himself.” (This is really an order disguised as a question.)

A Parent Objects to the Treatment Plan

Effective response: “We all want to do what’s best for Joey, so would it be all right if we looked at the options.”

Suboptimal response: “I know you want to do what’s best for Joe, but…” (Beware the “but…” It tends to denigrate the preceding statement.)

Who’s Fault Is This?

A child received the wrong medication and the parents are irate. They ask, “Who’s fault is this?”

Effective response: “I’m really sorry that this happened. We’re looking into it and trying to determine how it happened. I will get back to you as soon as we have all the information.”

Suboptimal response: “It’s not anyone’s fault. These things happen.” (Denial.)

(See Chapter 24, *Disclosing an Adverse Event or Medical Error*)

A Few Useful Phrases

Below are a few responses that are useful in a variety of situations. Think of them as tools and consider them for your repertoire.

“The situation is serious but not hopeless.” (In this case the “but” is appropriate.)

“There is still a lot that can be done to keep him comfortable, and we will be with you all the way.”

“Sometimes when people hear upsetting news, they hardly hear another word. Are you okay with

going ahead or do you want me to go over what we've been talking about?"

"What else do we need to talk about?" or "Is there something else you would like to discuss?"

"I wish I had better news."

"I wish we had a cure, but there are things we can do to help keep you as comfortable as possible."

"I am so sorry for your loss."

"Let me take a moment to think about what you have told me."

"May I interrupt you for a moment to clarify..."

Build your own repertoire of effective responses. When you respond in a difficult situation and it works, remember that response. If it doesn't, think about it later and formulate a better response.

Conclusion

Communication is reciprocal. It is not a monologue. Listening is a key feature of effective communication, and whenever possible, the child should be included in the conversation in a meaningful way. Empathy, understanding the patient's feelings and showing the patient that you understand or are trying to understand, is a powerful tool for compassionate and effective communication.

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Chapter 2

Age Appropriate Communication and Developmental Issues

Diane Treadwell-Deering, MD

Introduction: Communicating with a Child in an Age Appropriate Manner

Intuitively, we all know how to communicate with babies. When we communicate with a baby, no matter our age or our language, we sing-song in a highly pitched voice, with elongated vowels and distinct consonants. Our facial expressions are exaggerated, and we draw closer to the infant's face. Scientists are able to show that babies prefer this form of communication—they watch our faces and turn to our voices. This style of communication seems to enhance the learning of language by babies.

Although much of public education is devoted to studying the written word, very little attention is focused on the spoken word. In the United States, many school districts require only a single semester course in oral rhetoric during high school. It seems that oral communication is something we are expected to become expert at solely through life experience. The course of acquisition (i.e., the developmental trajectory of communication skills) falls along some general guidelines in typically developing children. Brain development and intellectual functioning intertwine with environmental, temperamental, psychological, social and cultural factors to determine the speech and language and communication proficiency of each individual.

Communication entails not only verbal and non-verbal output but also the ability to comprehend and interpret input. Those who focus on the care of children and their families are well served to appreciate developmental milestones of communication, to recognize other factors that impact communication and to tailor their own communication styles to maximize interactions.

Understanding the goals and purposes of communication enhances one's success in communicating with patients and their families. These goals vary with the age of the child, but for the healthcare provider, the goals would likely include some combination of the following:

- Relieve distress, soothe anxiety and provide reassurance
- Establish rapport with the child and family members
- Assess the child's speech and language development
- Model appropriate communication strategies and language stimulation for parents and family members
- Obtain cooperation with the conduct of a physical examination and with treatment
- Obtain information needed to make an accurate diagnosis
- Obtain consent (adult patient or caregiver) and assent (pediatric patient) for care
- Improve patient and family adherence to treatment
- Educate patients and families about healthcare conditions
- Develop and model the care provider-patient relationship that the child will recreate as an adult
- Show respect and regard for the individual

Infancy

Comprehension

Communication between infants and their social environment is active from the moment of

birth onward and is thought to be innately programmed because it emerges so quickly. Infants are attuned to the human voice, attracted to the human face and responsive to human interaction. At 3 days of life, the newborn can differentiate his or her mother's voice from that of other women. When listening to a human voice, the infant settles or smiles. By 4 months of age, the infant responds to different tones of voice. At 6 months of age, the infant will inhibit his or her behavior if told "no" in a sharp tone; however, the infant will respond to "yes" in the same manner if it is uttered in that same sharp tone (Paul and Mills, 2002). This shows that the infant does not yet understand the meaning of the word but does comprehend the tone.

Although adults act as if babies understand speech almost from the first day of life, it is not until 8 months that true lexical comprehension begins (Paul and Mills, 2002). This comprehension is very firmly contextually bound. The baby will respond to familiar words that are associated with routines. The baby will clap when the parent says, "Let's play pat-a-cake," but he will not understand the specific meaning of the individual words. At 9 to 12 months, when a mother says, "Give the cup to Mommy." and the baby does so, she may believe that the infant has understood this verbal command. However, the mother looked at the cup, looked to the baby and likely used gestures, such as beckoning, or mimicking drinking from the cup. The typically developing baby will look at the cup when the mother does so (joint attention); the infant will imitate behavior he or she sees, and because the infant's repertoire of behavior is relatively limited, he or she will likely give the cup to the mother, earning her encouragement and praise.

Communicative Strategies

Regardless of the language of the child, acquisition of speech sounds follows a certain general pattern (American Speech-Language-Hearing Association, 2014; Paul, 2002). The principle form of an infant's communication is crying. Within weeks after birth, different cries appear to represent different affective states, such as hunger or pain. These differences are not intentional by the infant but are noticed and responded to by adults. Other sounds, such as burps, sneezes and coughs are also reflexive but are treated as intentional by adults. In this way, infants learn that sounds are communicative. Between ages 2 to 5 months, infants coo in response to social interaction. Anatomy dictates the cooing nature of these vocalizations. Laughing develops at the same time and is frequently accompanied by a social smile. Early forms of babbling (vocal play) emerge at 4 to 8 months. Babies engage in this play when alone and also as a means of responding to or initiating contact with adults. In the second half of the first year of life, *reduplicative babbling* appears. "Ma-ma-ma-ma" or "ba-ba-ba-ba" sounds are dictated by anatomical considerations. Again, much of this vocalization occurs when the baby is alone, as well as when the infant is engaged in interactions with adults. If this babbling is not produced by 10 months of age, the baby is at significant risk for developing a language disorder (American Speech-Language-Hearing Association, 2014; Paul, 2002).

Signposts of Infant Interaction and Communication

- Eye contact at about 1 month
- Vocalization in response to sounds at 4 months
- Use of eye gaze to modulate social interactions by 4 months
- Use of communication as a means to an outcome at 8 to 10 months. Outcomes consist of adult attention or acquisition of objects. Holding up objects and pointing are both used extensively for communication.
- Joint attention attempts are reliably responded to and initiated by 12 months. Joint attention consists of directing another's attention by making eye contact, looking at an object and then re-

establishing eye contact. Shifting eye gaze between the object and the other person may occur repeatedly and is often accompanied by vocalization and later, by verbalization. These attempts are not for the purpose of obtaining the object but are considered purely social in nature. These communications are classified as *protodeclarative* and represent the forerunners of referential speech.

Protoimperative communication consists of requests for objects or acts or requests for the listener to do something or to stop doing something. This communication is accomplished by sounds, miming gestures, pointing and showing.

Goals of Communication with Infants

- Soothe and relieve the infant's distress
- Assess prelinguistic speech development and social development
- Improve quality of physical evaluation by using communication to relax and engage the infant
- Educate parents about appropriate communication with and stimulation of their infants.

Toddlers and Preschoolers

Comprehension

By 12 to 18 months of age, the toddler understands non-routine, single words with some contextual support. At 15 to 16 months, toddlers can point to several of their own body parts. At 18 to 24 months, they can understand single words for objects not in sight and some two-word combinations (American Speech-Language-Hearing Association, 2014; Paul, 2002). Some prepositions and action verbs are understood at 2 years. Context and experience still determine meaning. Vocabulary grows exponentially during this time. *Fast mapping* strategies are employed: the toddler uses a word with a partial grasp of its meaning; based on feedback, his or her knowledge of the word is refined (Paul and Mills, 2002). Adults frequently overestimate the amount of language toddlers truly comprehend. For example, Dad may say, "Let's play ball in the backyard." The child comprehends "ball," knows what balls are for and knows that he or she and Dad play in the backyard so the child follows Dad outside to play. Mom says "Bring me your plate and I will give you some more." may be understood as "Bring plate." By age 4 years, the child has learned the basic grammatical rules of language, but complex sentences, certain conjunctions ("unless", "although") and prepositions ("throughout" or "about") and order of clauses as they affect meaning are not yet understood.

Communication Strategies

First comprehensible words are uttered somewhere between 8 and 18 months. *Expressive jargonizing* (i.e., non-reduplicated babbling) occurs during the second year. First words are usually nouns and something the child sees and knows well. Expressive vocabulary grows exponentially: 3 words at 12 months; 10 words at 15 months; 100 words at 18 months; 300 words at 2 years; 900 words at 3 years; 1,500 words at 4 years; and 2,100 words at 5 years. Around the time that 50 single words are acquired, the toddler combines words into *telegraphic* sentences, containing the most important words and leaving off endings. Sentences are 3 to 4 words long at 36 months. The toddler knows 2 or 3 colors accurately, knows most pronouns and can use "what" and "where." By age 4 years, the typical child is fully intelligible and almost always makes speech sounds accurately. By 5 years, "be" verbs are learned, as are regular past tense verbs, negative sentences, questions and complex sentences with simple conjunctions. Stuttering may occur but remits within months in 75-85% of those affected (American Speech-Language-Hearing Association, 2014; Paul, 2002).

Learning to Converse

Between 18 and 24 months, toddlers can reliably answer simple questions. By 2 years, they learn the obligation to say something (i.e., to reciprocate) in a conversation. Sticking to the conversation topic occurs about 50% of the time at 3 years. From 3 to 5 years, the use of language for more than requesting or getting attention develops rapidly and includes conveying information, recalling past and present events, pretend play and solving problems. Pragmatic skills, such as conversation turn-taking, clarifying comments when asked and avoiding taboo words also emerge (Paul and Mills, 2002).

Social learning occurs through language, and parents are the most important conversation partners. Parents tell children what to do and what to expect, what things mean and how things work. However, between 3 and 5 years of age, the child's realm of conversation partners expands greatly. Operating in the larger community of school, daycare and worship center includes communicating with adults outside the family and with peers. Turn-taking, cooperative play, pretend play, following instructions and pre-academic learning rely heavily on verbal communication. Language mediates socialization.

Signposts of Toddler and Preschooler Communication

- Exponential growth of vocabulary from 1 to > 2,000 words by age 5 years
- Receptive language surpasses expressive language
- Comprehension abilities are typically overestimated by adults
- Basic rules of grammar and conversation are achieved by 5 years of age

Goals of Communication with Toddlers and Preschoolers

- Include all of the goals for communication with infants
- Obtain information about current symptoms

School-aged Children

Cognition

The relationship between cognitive development and language development is often underemphasized, but it clearly plays a substantial role after toddlerhood. Stronger intellectual capacities typically are positively correlated with stronger communication abilities and vice versa. However, this may be confounded by the method by which intellectual abilities are measured. Conversely, one cannot talk about abstract ideas until one can formulate abstract ideas. The nature of the relationship between cognitive and language development is not well understood.

Family Factors

Family factors impact a child's communication style and complexity. In families where there is more talking, children demonstrate greater vocabulary growth and use. Other family factors that promote language development include: increased variation in and amount of nouns and modifiers used; positive feedback tone in conversations with children; responsiveness to requests or questions; and emphasis on details in conversation (Paul and Mills, 2002; Pearson and Hall, 2013).

A Special Issue: Development of Responsibility

An important issue in providing healthcare for children is the development of the child's active participation in maintaining his or her health, making healthcare decisions and assuming responsibility for behaviors that affect health and wellbeing. Developing responsibility and concomitant independence is an ongoing process that continues through childhood into

adulthood. Although cognitive development plays a significant role, socio-cultural factors are key components in this developmental arc. Ochs and Izquierdo (2009) eloquently illustrate this as they describe three very disparate cultures (Peruvian Matsigenka, Samoan and middle class Los Angeles). Matsigenka and Samoan children of similar ages were much more self-reliant in self-care and contributed much more significantly to domestic functioning than children in Los Angeles. This difference was not explained by differing priorities regarding educational accomplishments. Inconsistent messaging regarding independence and inaccurate beliefs regarding children's competency by American parents were found to better account for these differences. Parenting styles and values have important effects on children's emerging abilities to take responsibility for their actions. Positive guidance—including providing opportunities to make developmentally appropriate decisions and to experience the consequences of those decisions—is a crucial component (National Outcomes for Children Work Group, 2014). Parents may have difficulty incorporating these strategies when it comes to healthcare issues, given the serious consequences that may result from poor decision making.

Social and cultural factors

Social and cultural issues greatly impact how a child communicates with others. Every culture defines the roles of children of each developmental stage and has expectations for the ways in which children are expected to interact and communicate with adults—family members, elders, teachers and authority figures, including healthcare providers. In some cultures, children are expected to speak only when adults address them. They are not expected to participate in a conversation with an adult, even during adolescence. For cultural or social reasons, some children may not understand the purpose of or the expected response to open-ended questions. They may not have experience conversing with adults about their thoughts, feelings, experiences or opinions. Non-verbal aspects of communication may be affected as well. For example, children from Latin America and Asia may avoid eye contact with adults in authority as a sign of respect. Of course, these developmental issues occur in the context of more general cultural communication challenges. For example, different cultures assign different meanings to a raised tone of voice—conflict versus passion (Pearson and Hall, 2013). Different attitudes about expressing disagreement or about the appropriate level of disclosure may affect individuals of all ages within a cultural group (DuPraw and Axner, 1997).

Bilingual language development

Half of the world's children grow up exposed to two or more languages because they live in two-language households or in two-language communities (Place and Hoff, 2011). In the United States, bilingualism is largely secondary to immigration and affects about one in four children. Despite this prevalence, language development in two-language environments has not been well studied and is not well understood. The heterogeneity of bilingual households complicates study of this phenomenon. Variability factors include: the amount of exposure to each language; the separation of the child's experience in each language; the number of people from whom he or she hears each language; and the exposure to native versus non-native speakers of each language. Every bilingual child has a unique constellation of language experiences and language skills.

The language background of the parents greatly impacts the language experience of the child. When both parents are native speakers of their heritage language, the child hears more of the heritage language at home and is more likely to acquire that language. The native (heritage) language of the mother (compared to the father) is more important to the child's bilingual language development, likely secondary to the young child's greater exposure to the mother. The parents'

social networks will determine the exposure that the child has to the community language. How much of the community language is heard from non-native speakers and how much the heritage and community languages co-occur are also important factors in the development of bilingualism in the child (Hoff and Core, 2013).

The relative amount of exposure to each language has been shown to be a strong predictor of a child's rate of development of each language. The functional significance of each language to the child learner also impacts language development. Hearing a language from multiple different speakers increases word recognition and word production. Conversational partners who are native speakers and are monolingual positively correlate with acquisition of their language (Hoff and Core, 2013). There has been some concern that intermingling of languages would potentially confuse a child. Families will relegate languages to specific individuals—often with one parent speaking the heritage language and the other parent speaking the predominant community language. There is little evidence to support the benefit of this practice (Werker and Bysers-Heinlein, 2008).

In conclusion, the more exposure to a language, the faster the development of that language. This is true in both monolingual and bilingual language development. Exposure to non-native speech is less supportive of language acquisition than is exposure to native speech. For example, with regard to learning English, hearing English from a native Spanish speaker is not as helpful as hearing English from a native English speaker. Learners need input from multiple, different sources of language. True bilingualism is largely found in the second generation following immigration. Without purposeful language exposure, third-generation speakers are more frequently monolingual in the predominant community language. It is generally believed that coming from a bilingual home does not, in and of itself, confer any disadvantages to language development in a typically developing child.

Comprehension

During school age there is a gradual move away from concrete and literal interpretations to an ability to read between the lines and make inferences. Basic comprehension of figurative language is present at 7 to 8 years of age, by which time the typical child appreciates that it is not really raining cats and dogs. However, improvement in the ability to appreciate tone of voice versus content of speech and to understand idioms, metaphors and proverbs continues through young adulthood. Improvement in vocabulary comprehension continues to grow, although not at the rapid pace of toddlerhood. Wider concepts of temporal relations, spatial relations, emotional expressions and abstract ideas develop. Exposure to literary language, both written and spoken, is a significant factor impacting the extent of this development (Paul and Mills, 2002).

Communication Strategies

By age 7 years, most children make all the sounds of their language accurately. Any problems past this age are not developmental but represent speech sound disorders. Appreciation for dialects and regional accents develops. The significance of differences in syllabic stress (e.g., *pres ent* versus *pre sent*) are now understood and demonstrated. There is steady, continued refinement in the use of language. By 7 years of age, the child develops the ability to relate a coherent narrative that follows a simple story format. The youngster can relate information about another person's feelings and beliefs. He or she can describe causes for actions. During elementary school, an average of nine new words per day are incorporated into use. Children with poor reading skills lag behind their peers in more complex forms of communication.

Language is now used in more numerous and varied social interactions. The child has greater ability to convey the same message in alternative ways. Repairing conversational breakdowns is

more successful. Narrative skills improve. Implying and inferring information is more sophisticated and accurate.

Signposts of School-Aged Child Communication

- Comprehension of figurative language begins and continues to develop
- Improvements in word comprehension develop
- Poor reading skills and lack of exposure affect complexity of communication
- Acquisition of phonologic awareness is predictive of literacy development
- The ability to define words with synonyms or categorical terms (rather than by function or personal association) develops

Goals of Communication with School-Aged Child

- Include all of the goals of communication with infants, toddlers and preschoolers
- Obtain information needed to make an accurate diagnosis and assessment
- Obtain cooperation and adherence with recommendations and treatments
- Obtain assent for care
- Educate about health conditions
- Show respect and regard for the individual

Pre-adolescence, Privacy and Sensitive topics

Age, intellectual functioning, experience, temperament, family dynamics, social, economic and cultural factors all affect the developmental stage of a youngster. An arbitrary dividing line between school-age and adolescence seems unhelpful. Determining when a child is seen without his or her parents, when sensitive topics are addressed and when confidentiality is offered needs to be considered on an individual basis and in context. The issue of confidentiality needs to be addressed with the parent. In some states (e.g., Texas) parents are entitled to information regarding their children's healthcare. An appointment to diagnose and treat the flu is different from an assessment for depression or contraceptives. A mental health professional may see children alone during early school years, but a dermatologist may not offer separate appointments ever, unless specifically requested. The goals of an appointment and the needs of the patient and family must be considered carefully.

Talking about Death: a Special Situation

So far in this chapter we have outlined the developmental trajectory of communication processes and skills. The role of cognitive development *vis-a-vis* communication abilities has been mentioned. Clearly, all domains of development interplay and affect communication. The importance of this is highlighted when the healthcare provider needs to talk with a child about death. The child's understanding of death must be taken into account, as well as his or her level of ability to communicate (Himebauch, 2005). (See Chapter 15, *Point of View: the Child Life Specialist*.)

Table 1 shows a child's understanding of and possible reactions to the idea of death at varying ages. The suggestions for effective communication shown apply to communicating about the death of someone other than the child him or herself. For discussions of communicating with the dying child about his or her death, see chapters 8, *Point of View: the Pediatric Oncologist*; 14, *Point of View: the Child Life Specialist*; and 18, *When the Death of a Child is Anticipated and Imminent*).

Table 1. Developmental Understanding of Death.

	Child's Concept of Death	Child's Likely Reactions to Issue of Death ^Ψ	Suggestions for Communicating with the Child*
0-2 years	No concept of death. No understanding of meaning of death.	Child will react to the emotions of the people around him or her.	To the extent possible, maintain normal routines.
>2-5 years	Death seen as temporary and reversible. May be confused with sleeping or seen as a form of punishment.	Reacts to the emotions of people around him or her. May show little concern. May demonstrate fear as fear of separation or fear of the dark.	Do not use euphemisms. Use the terms dying, death or dead. Tell child what is happening and what he or she can expect, simply and truthfully.
6-9 years	Clearer picture of death emerges. Death seen as possible but not for him or her. Child may feel responsible for death.	May enter a phase of denial. May fear that he or she will die at the same age as the person who is dying or has died. May act out or regress. May exhibit withdrawal and limited emotional reactions. May react with crying, anxiety or guilt.	Respond to difficult questions with, "Tell me what you are thinking." ¹ Explore family's spiritual and cultural beliefs about death and afterlife. Reassure child that his or her fears are normal. Provide truthful explanations for what is happening and the person's death.
10-12 years	Understands that death is biological and universal. Understands that death is final.	Fears the consequences of death. May act out, regress, develop fears or grieve deeply.	Reassure the child that his or her fears and feelings are normal. Provide truthful explanations and open, honest communication.
>12 years	Adult concept of death. Understands the implications of death. Death seems far away.	Varied emotional reactions. Preoccupation with and fear of death. May rely on friends for support. May become isolated. May want to assume a more adult role. Denial may result in risk-taking behavior.	Discuss death openly, honestly and supportively. Discuss role changes that may take place in the family. Discuss plans for funeral, remembrance and moving forward.

* These are the ages where these strategies usually are first employed. Most will apply to subsequent ages.

^Ψ Issue may be raised by death or impending death of a friend or family member.

1. Linebarger JS, Sahler OJZ, Egan KA. Coping With Death. *Pediatr Rev.* 2009;30:350-5.

Importantly, experience with death, such as happens frequently to children with serious chronic illnesses, will alter and may accelerate the child's understanding of death. However, each child must be approached as a unique individual, whose development may not readily fit milestone timetables.

Adolescence

Language Development.

Language development in children is rapid and obvious. In adolescence, it is much more gradual, but significant changes in syntax (the way words are put together to form phrases, clauses and sentences), semantics (the meaning of words, phrases and sentences) and pragmatics (the meaning of language in particular situations) continue (Nippold, 1993).

Syntax

There are three aspects of syntactic development: increased sentence length; increased use of a variety of subordinate clauses; and increasingly sophisticated cohesion devices (Nippold, 1993). Sentences increase in length by use of more complex subject phrases, greater use of prepositional phrases, more appositive constructions and expanded verb phrases. Although subordinate clauses first appear in early childhood, the frequency of their use increases throughout childhood and adolescence. Adverbial conjuncts, such as “moreover,” “therefore” and “nonetheless” are used with greater frequency and sophistication. To some extent, this development is related to exposure to these communication devices. These devices are found in textbooks, in formal lectures and in literary works. Skill in using and deciphering these constructs is associated with greater academic success.

Semantics

Two aspects of semantics that are important to adolescent language development are the understanding of literate lexicon and of figurative expressions (Nippold, 1993). Literate lexicon is the group of words that are commonly used in scholarly writing, textbooks, lectures and seminars. Literate verbs include *infer*, *imply*, *predict* and *interpret*. Competency with these verbs increases in adolescence and is important to academic success. Figurative expressions, such as metaphors, analogies and proverbs are better understood as adolescence progresses. Idiom interpretation becomes more accurate. Reading comprehension improves as these skills develop.

Pragmatics

Improved pragmatic competence in adolescents is demonstrated by the development and extensive use of slang (Nippold, 1993). The purpose of insider language and slang is to separate from others and create an exclusive group. Adolescents use language, along with hairstyle, musical tastes and many other strategies to declare their independence and freedom from parental control and their allegiance to their peer group. Understanding this, effective communicators will not attempt to co-opt slang, but will establish rapport and express their understanding of and concern about an adolescent in other ways.

Confidentiality

Protection of confidentiality is essential to appropriate care of the adolescent. Confidentiality supports provision of truthful information to the healthcare provider by the adolescent and prevents forgoing care to avoid parental knowledge of the adolescent’s behavior and healthcare needs (Ford and English, 2002). Private communication between the healthcare professional and the adolescent patient highlights the primacy of the provider-patient relationship. It also supports the development of the adolescent’s active and responsible role in his or her own care (American College of Obstetrics and Gynecology, 2009; Society for Adolescent Medicine, 2004). (See Chapter 3, *Talking with the Adolescent Patient*, section, *Confidentiality*.)

However, medico-legal, developmental, cultural and social factors support and demand the continued active inclusion of parents in communication with the clinician and the adolescent. In fact, in some circumstances, it may be legitimate for the clinician to see the parents without the adolescent. The parents may have important information to share with the clinician that they are not ready or willing to share with their teens, such as marital or financial problems. They may be asking for advice on how to address difficult issues with their teens, such as discipline, sexuality or substance use. The communication of a serious medical diagnosis may be given to the parents first, so that they are better able to provide comfort and support for the teen when this information is disclosed to him or her. The healthcare provider needs to educate parents and adolescents about the goals and benefits of confidentiality, as well as its specific scope and its limitations.

For example, the practitioner may introduce this change in practice model as follows:

“Chris is now old enough that a portion of our visit will be private. During this time, Chris can talk with me about any of his (or her) concerns. I will want to learn about Chris’s experiences at home, at school and with friends. This will be a time when Chris’s conversation will be confidential. The exceptions are if Chris is in serious danger of hurting himself or someone else. If I feel Chris should share other information with you, I will advise him to do this. However, I will honor my commitment to confidentiality. Are you in agreement with this?”

During this portion of the visit, the clinician should obtain a psychosocial history that includes the sensitive topics described below. The patient should be given the option of having the parent or another adult present during physical examinations. During each visit, it may be important to repeat the parameters of confidentiality. Modifications will be need to be made to delivery of care, including scheduling, billing, recordkeeping and provision of care in order to provide confidential care.

Total confidentiality

Although variable from state to state, minor patients are allowed to consent to healthcare under certain circumstances. These typically include active duty in the armed services, marriage, parenthood and emancipated minor status (>16 years of age, living away from parents and financially supporting oneself). In some states “mature minors” may be granted the ability to consent to or refuse treatment. Typically, such a patient is older than 15 years, has demonstrated the ability to make his or her own healthcare decisions and frequently has experienced chronic health conditions. In most states, minors are legally able to consent to and obtain treatment for specific healthcare services, including birth control, prenatal care (excepting abortion), treatment of sexually transmitted infections and other reportable infectious diseases, addiction, suicide prevention and other mental health services and sexual and physical abuse. State statutes regarding parents’ right to information about the healthcare of their children and issues of payment for care and use of insurance benefits often make confidentiality difficult to maintain. The Health Insurance Portability and Accountability Act (HIPPA) Privacy Rule states that when minors legally obtain services without parental consent, the parents do not have an automatic right to the minor’s health information (U.S. Department of Health and Human Services, 2003; Gudeman, 2003). State laws controlling disclosure of information have priority, but if there are no specific state guidelines, the clinician can use his or her own clinical judgment regarding confidentiality. The Federal Title X Family Planning Program offers strong confidentiality commitments to minors and allows minors to qualify for services based on their incomes rather than their parents’ incomes.

Sensitive Topics

Adolescence, with its cognitive and social developments, necessitates additional topics of

discussion and different ways of communicating if adequate history-taking and care are to occur. Some disorders develop more frequently in adolescence (e.g., depression) and routinely need to be included in history-taking. Standard categories of social, developmental and psychological history include:

- Home life and relationship with parents
- Education and employment—current and future plans
- Social media activity
- Activities with peers—formal (organized, such as sports and Scouts) and informal
- Mood, affect and suicidal ideation
- Substances use
- Sexual activity
- Sleep

For information about the use of the HEADDDSS and other instruments in eliciting information from adolescents, see Chapter 3, *Talking with Adolescents*, section, *Conducting the Interview*.

Approaching sensitive topics in a manner that allows the adolescent to respond without fear of judgment or criticism increases the likelihood of honest disclosure. Initially, topics can be approached more obliquely. Instead of asking “Are you heterosexual or homosexual?” the provider might say, “This is a time of life when people are sorting out who they are sexually—who are they attracted to and what are they comfortable doing sexually. What are you thinking about for you?” The adolescent’s responses direct further and more specific questions. An approach to substance use might include: “What is it like in your home? Is anybody there misusing drugs or drinking? How about at your school? How about your friends? What have you decided is right for you? Are there things that you have tried?” Again, the teen’s responses direct additional questions.

If the teenager is engaged in dangerous or unhealthy behavior, the focus should remain on the behavior rather than the person. Adolescents are accustomed to adults catastrophizing the consequences of their behavior. Therefore, feedback needs to be specific, factual and realistic. Risks should be reported matter-of-factly. Possible solutions or alternatives should be discussed. What behavior is thought to be an exception to confidentiality needs to be clearly defined to both the adolescent and his parents.

Signposts of Adolescent Communication

- By the end of adolescence, cognitive and language ability allows for complex, in-depth conversations about far-reaching topics and themes
- Co-opting slang is an ineffective way to establish rapport with adolescents
- Protection of confidentiality is crucial to the assessment and care of adolescents
- Active and respectful listening is a crucial element of communication with an adolescent

Goals of Communication with Adolescents

- Include prior goals stated for infants, toddlers, preschoolers and school-aged children.
- Develop and model the doctor-patient relationship that will serve patients as they transition to adulthood

Conclusion

Effective communication is the cornerstone of effective care. In children and adolescents, communication cannot be effective if it is not developmentally based. Successful communication

not only leads to the best outcome for the patient, but it also allows the care provider the privilege of more deeply knowing and connecting with the patients and parents with whom he or she works.

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Chapter 3

Talking with the Adolescent Patient

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Introduction

Adolescents see clinicians as valuable sources of health information and want to discuss personal matters with them. Unfortunately, however, clinicians do not always capitalize on opportunities to offer guidance to teens (Ham and Allen, 2012 ; Klein et al., 2001). Klein and Wilson (2002) found that among a nationally representative sample of U.S. teenagers, more than 50% wanted to discuss drugs, smoking, sexually transmitted infections (STIs) and healthy eating with their clinician, and although more than 70% reported engaging in at least one risky behavior, more than 60% of these teenagers did not discuss this with their medical provider. Further, Elliott and Larson (2004) found that 44% of adolescents in a non-urban setting forwent needed medical care. Reasons cited by adolescents for forgoing care included distrust of providers, embarrassment, privacy concerns and lack of knowledge about where to obtain needed services (e.g., mental health) or confidential care. While adolescents desire comprehensive care, a variety of studies report provider barriers to managing adolescent psychosocial issues and adhering to best practices (Fisher et al., 1996; Klein and Hutchinson, 2012; Sterling et al., 2012).

Provider comfort and competency providing appropriately confidential care are essential to adolescent disclosure and effective management of age appropriate health risks. (Fisher et al., 1996) While there is no substitute for a complete psychosocial interview, there are numerous preparatory elements that promote both adolescent and provider comfort, increase appointment efficiency, and foster a trusting and productive adolescent-provider relationship. These elements include understanding the adolescent's developmental and comprehension levels, being mindful of the interview pace and recognizing the need to establish trust with the parents as well as with the patient. There should be clear office policies about confidentiality of care (Ham and Allen, 2012; Klein and Hutchinson, 2012; Sasse et al., 2013). This Chapter will review each of these elements to enhance provider comfort and capability in efficiently and effectively caring for adolescents.

Creating an Adolescent-Friendly Environment

Confidentiality

The importance of confidentiality cannot be over-emphasized. It is the cornerstone of effective screening, accurate diagnosis and risk-reduction counseling (Ford et al., 2001, 2004; Ginsburg, Fork et al., 2002; Ham and Allen, 2012). The American Academy of Family Clinicians, American Academy of Pediatrics, Society of Adolescent Health and Medicine and the American College of Obstetricians and Gynecologists are examples of medical organizations that affirm the importance of confidential care for adolescents (American Academy of Family Physicians et al., 2004). Studies have demonstrated that assurance of confidentiality increases the number of adolescents willing to seek future healthcare and disclose sensitive information about sexuality, substance use and mental health (Ford et al., 1997; Ham and Allen, 2012). Although both the patient and parent should be informed about confidentiality policies early in the appointment, Purcell and colleagues

(1997) found that only 50% of clinicians discussed confidentiality with their patients and only 30% did so in front of the parent(s).

It is recommended that clinicians have a standard confidentiality statement they consistently present to patients and parents (See Figure 1). The statement should clearly state that confidentiality is qualified, not absolute. In situations in which the patient is being harmed, is at risk of being harmed by another or by him or herself, or is going to harm another, confidentiality can be breached. Adolescents recommend that medical providers be specific about what constitutes harm (e.g., physical, sexual and emotional abuse and suicidality) as well as what does not (e.g., STIs and contraception) (Ford et al., 2001). In most states, minors can consent for reproductive healthcare, including diagnosis and treatment of STIs and management of birth control; however, providers must be aware of state specific legally defined limits of confidentiality.

Figure 1. Sample Confidentiality Statement to Be Given to Patient and Parent

One of my goals as your doctor is to be a second person, in addition to a parent or family member, to whom you (the patient) can come for health advice. For this reason, starting with patients 12 years of age¹, I always spend some time with my² patients alone. What we talk about when we are alone is private, between us unless you are in danger. To me, danger is wanting to hurt or kill yourself, wanting to hurt or kill someone else, putting yourself at risk for harm or someone hurting or abusing you. If I am concerned about your safety, I will need to get others to help me make sure you are safe; I would tell you before I did this. Outside of these situations, our conversation is private. I strongly encourage teens and parents to be open with each other as this is very protective.

1. Substitute the age that works for you or your clinic.
2. If statement applies to a group of providers or to the office, substitute the appropriate term.

Each clinic or medical office should establish a written policy regarding confidentiality. Policies should address provider-patient interactions, test results notification, appointment scheduling and billing. To ensure consistent policy application, all staff should be familiar with and adhere to the policy with all patients at all adolescent visits (Akinbami et al., 2003; Ford et al., 2004). Providers must be aware of state specific legally defined limits of confidentiality.

It is important to consider parents' concerns when discussing confidentiality. Recent studies about parental beliefs reflect both apprehension about and appreciation for a confidential adolescent-provider relationship (Duncan et al., 2011; Sasse et al., 2013). Duncan et al. (2011) found that parents' leading concerns revolve around exclusion, specifically, not being informed by the adolescent or the provider about important health information. Parents also raised concerns that adolescents would not be honest with providers and that adolescents do not want time alone with providers. Clinicians should encourage openness and communication between parent and youth, to alleviate concerns about gaps in knowledge regarding treatment recommendations and adolescent concerns (Duncan et al., 2011; Ford et al., 2011). These parental concerns highlight the need for providers to guide parents toward appropriate and incremental adolescent emancipation. Parental hesitance allows providers the opportunity to discuss developing autonomy and the benefits of confidential care. See Table 1 for suggestions on managing parental hesitancy.

Several studies demonstrate that parents also understand the benefits of a confidential provider-adolescent relationship (Duncan et al., 2011; Sasse et al., 2013; Tebb et al., 2012). Duncan and coworkers (2011) reported that the majority of parents (71%) described confidential

care as an opportunity for their child to discuss sensitive matters. Most parents also were confident that the doctor would be attentive to their child’s point of view (63%), believed it was good practice for the teens to talk alone to their doctors (61%), identified time alone as an opportunity for youth to take responsibility for their health (57%) and saw confidential care as an acknowledgment of adolescents’ developing maturity (52%). Further, many parents are uncomfortable talking to their teens about sensitive topics, including sexuality, and appreciate provider assistance. Trust in the provider significantly impacts parental comfort with the confidential interview (Sasse et al., 2013; Tebb et al., 2012).

Table 1. Example Responses to Parental Concerns about Confidential Care

<p><u>Parental concern:</u> “We talk about everything.”</p> <p><u>Response:</u> “That is fantastic! We know that a close relationship between teens and parents helps teens make good health decisions.”</p>
<p><u>Parental concern:</u> “I’ve never left the room before.”</p> <p><u>Response:</u> “Parents are often surprised to be told it is time for their children to begin learning to work with a physician one-on-one. Even with close family relationships, teens can have questions they feel are embarrassing and would like to ask a physician. We always offer that opportunity.”</p>
<p><u>Parental concern:</u> “I’m not sure I am comfortable with this.”</p> <p><u>Response:</u> “We have the same goal, which is to take the best care of your child and help him (or her) make good health choices. We know that when teens get time alone with a physician, care is facilitated and improved, and we both want to help your teen make healthy choices.”</p> <p><u>More direct response if needed:</u> “Often when parents are reluctant to provide their son or daughter private time with a physician they have a specific concern. Do you have a specific concern?”</p>
<p><u>Parental concern:</u> “Can I speak to you outside”</p> <p><u>Response:</u> “Since your child is getting older, it is important that he (or she) is able to fully participate in his (or her) own healthcare. As your child’s physician, I will share whatever you tell me with your child, so I prefer to speak openly in the room.”</p> <p><u>Response if parents insist on speaking to you alone:</u> reiterate that you will share any conversation that impacts his or her health with the child. Listen to the parent and then tell the adolescent the content of the discussion.</p>

Provider and Clinic Characteristics

In a seminal study by Ginsburg and colleagues (1997), teens ranked 31 factors in order of importance in deciding to seek medical care; providers washing their hands and using clean instruments shared the top ranking with providers being honest. Adolescents also cited the desire for knowledgeable, respectful and experienced providers. Other key clinician qualities cited were reviewing confidentiality, treating all patients equally, being friendly and relating well to teenagers. These important interpersonal characteristics are interrelated, as youth felt they could trust provider confidentiality only if providers were honest and respectful. Discussing and maintaining confidentiality connotes respect and demonstrates trust (Ginsburg et al., 1997, Ginsburg, Forke et al., 2002). Provider continuity and competence and the provider having a good education were also considered important by adolescents (Britto et al., 2010; Ginsburg et al., 1997; Ginsburg,

Forke et al., 2002). When uncertain of the above characteristics, adolescents withhold information to protect themselves from breaches in confidentiality (Ginsburg et al., 1997).

Additional office-based ways to enhance the delivery of services to adolescents include having adolescent-only hours and adolescent specific exam rooms. Displaying a rainbow sticker in the room tells lesbian, gay, bisexual, transgender (LGBT) and gender-questioning teens that the office is an accepting and safe place (Ginsburg, Winn et al., 2002). Adolescent consultation room(s) should be stocked with health information (e.g., pamphlets and a list of recommended websites) addressing nutrition, sexual health, contraception, substance abuse, mental health and other culturally relevant topics (Burgis and Bacon, 2003). This discrete placement of health information serves two purposes. First, adolescents can privately obtain desired information they are unlikely to take from the more public waiting area, and second, this tacitly demonstrates a willingness to discuss sensitive topics such as those displayed in the handouts. See Table 2 for a summary of provider and office strategies to enhance adolescent care.

Table 2. Interventions to Promote Successful Adolescent Interviewing

<p>Clinician</p> <ul style="list-style-type: none"> Wash hands in front of the patient. Open any instruments or sterile packages in front of patient. Prominently display credentials and diplomas in the office. Reiterate confidentiality and its limits with the teen and parent at each visit. Always see the adolescent alone for at least part of every visit. Ask open-ended questions. Do not make assumptions about lifestyle or behaviors. Be friendly, sincere and honest with the patient and parent(s).
<p>Office</p> <ul style="list-style-type: none"> Post the office confidentiality policy in plain terms in the consultation rooms and waiting area. Instruct all staff members to be respectful and show genuine interest in caring for teens. Have health information available in the exam rooms so it can be taken privately. Display a rainbow sticker to demonstrate that lesbian, gay, bisexual, transgender or gender questioning youth are welcome and supported. Offer evening hours. Have adolescent-only clinic hours. Have an adolescent waiting area and adolescent exam room(s).

Preventive Health Screening Questionnaires

Questionnaires completed before the interview are an effective way to increase time efficiency and the quality of adolescent encounters (Gadomski et al., 2003; Klein et al., 2001). While a questionnaire is not a substitute for a face-to face interview, it can facilitate the collection of a comprehensive history, introduce sensitive topics that will be discussed in the interview and stimulate thinking by the parent and patient. Some individuals are also more comfortable revealing personal information in written format. Providing a written copy of the office confidentiality policy with the questionnaire can increase the yield from the instrument and

introduce the concept of confidentiality. Several screening tools are available. For example, the New York State Department of Health (2014) has a free, on-line screening questionnaire and provider guide, developed from The American Medical Association's (1997) Guidelines for Adolescent Preventive Services.

Conducting the Interview

Inviting the Parent out of the Room

Although pediatricians report concerns about parental objection as a significant barrier to providing confidential care, most parents understand that adolescents benefit from independent time with a clinician and will excuse themselves without objection (Fisher, 1996; Duncan et al., 2011; Sasse et al., 2013; Tebb et al., 2012). Mild initial parental resistance or hesitancy is usually easily managed by reiterating the merits of having a clinician that the adolescent can trust with personal health concerns (Wilkes and Anderson, 2000). Only rarely will a parent refuse to leave the examination room. This generally indicates a specific parental concern and is worrisome for underlying family dynamic problems (Ehrman and Matson, 1998). In these unusual cases, direct inquiry about reasons for parental apprehension is useful. Among families with whom providers have an established relationship, it is very helpful to discuss the routine inclusion of confidential time during upcoming adolescent visits as part of anticipatory guidance during earlier visits. A posted confidentiality policy (Figure 1.) including the age at which alone time with the physician will begin also promotes early awareness and reinforces private time with adolescents as standard practice.

After initial introductions and clarification of the confidentiality policy with the teen and parent (if present), it is helpful to briefly review how the appointment will proceed, first with the teen and parent in the room, followed by time with just the provider and adolescent, concluding with a reconvening of all participants and a summary of the visit. It is important to normalize this approach by mentioning that this pattern is followed with *all* adolescent patients at *all* visits. This is because concerns that may be too threatening to discuss with a parent present (e.g., STI or pregnancy) often present as more benign concerns, such as a sore throat or abdominal pain (Heyman and Adger, 2012). Teenagers with depression or in emotional distress rarely present to the primary care clinician with a psychosocial chief complaint; rather, they usually present with vague somatic complaints (Borowsky et al., 2003).

Many pediatricians are uncertain when to begin interviewing adolescents alone. Time alone with the clinician should coincide with the first physical or psychological signs of puberty, generally around 10 years of age in females and 11 years in males. It is best to err on the side of starting too early as pediatricians often underestimate the behavioral and psychosocial concerns their adolescent patients face (Wilson et al., 2004).

Occasionally a parent will request to speak to the provider away from the patient. In these situations it is important that the parent and adolescent be aware that any information that impacts the patient's health should not be kept confidential from the adolescent. Encouraging parents to discuss their concerns during the interview with the youth is often effective and opens a useful dialog between the parents and adolescent.

Provider Barriers

Data demonstrate that discomfort in assessing and managing adolescent psychosocial issues is a significant provider barrier to adolescent disclosure and results in inadequate screening for age appropriate health risks (Fisher et al., 1996; Klein and Hutchinson, 2012; Sterling et al., 2012). Clinicians identify several barriers to providing best practice adolescent care, including: concern

that parents will object; image as a *baby doctor*; lack of time; inadequate reimbursement for counseling services; inexperience and discomfort with specific medical conditions seen in adolescents; and lack of training (Fisher et al., 1996; Klein and Hutchinson, 2012; McKee et al., 2011; Sterling et al., 2012). Uncertainty with confidential management of serious health threats and concern about legal aspects of services for minors (e.g., substance abuse and contraception) are also reported (Klein and Hutchinson, 2012; Sterling et al., 2012). Sterling and colleagues' (2012) investigation of confidentiality and substance abuse found that primary care providers felt unprepared to diagnose and treat problems with alcohol and other drugs; specifically, 42% of pediatricians considered themselves unprepared to diagnose problems with alcohol. A provider's ability to build an effective and therapeutic relationship with the adolescent and diagnose and manage or refer these challenging conditions is enhanced by the use of standard screening tools such as HEADDDSS (Table 3) and CRAFFT (see below), as well as by developing a list of local community resources for families.

Table 3. Suggested Psychosocial Interview Questions in the HEADDDSS Format

Home
Who lives at home and how are things at home? Do you feel safe at home?
Education or employment
Tell me about school or work. Do you have any trouble at school or work? Does anyone bully you?
Activities
Tell me about your friends and what you do for fun. Do you have a best friend or a person to whom you can tell everything? Do you regularly attend any youth groups, church groups, or clubs?
Diet
Do you think you are too heavy, too thin or just right?
Depression
How would you describe yourself: happy, sad, in the middle? Do you talk to anyone about your feelings? Have you ever been so sad or angry that you thought about hurting or killing yourself? (Can also use the *PHQ-9 to screen for symptoms of depression (Kroenke et al., 2001)).
Drugs
Do any of your friends smoke or use alcohol or other drugs? Do you smoke? Do you use alcohol? Do you use drugs? (If any positive answers, can follow up with the CRAFFT screening tool below.)
Sexuality
Are you interested in or ever had a crush on someone? Are you interested in boys, girls or both? Have you ever messed around sexually with someone? Kissed? Touched? What questions or concerns do you have about sex and your body? <i>If sexually experienced:</i> How many sexual partners have you had? Were your partners male, female or both? What protection do you use against sexually transmitted infections (STIs)? Pregnancy? Have you ever had an STI? Have you or your partner ever been pregnant?
Table continued on next page

Safety and violence

Do you use safety equipment: bike or skateboard helmet, seat belts? Have you ever been beaten or physically abused? Has anyone ever touched you sexually in a way you did not want him or her to? Have you ever been in trouble with the law?
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CRAFFT is an acronym of the first letters of key words in six screening questions (Center for Adolescent Substance Abuse Research, 2009). The website recommends that the questions be asked exactly as written:

C: Have you ever ridden in a **CAR** driven by someone (including yourself) who was high or had been using alcohol or drugs?

R: Do you ever use alcohol or drugs to **RELAX**, feel better about yourself, or fit in?

A: Do you ever use alcohol or drugs while you are by yourself, **ALONE**?

F: Do you ever **FORGET** things you did while using alcohol or drugs?

F: Do your family or **FRIENDS** ever tell you that you should cut down on your drinking or drug use?

T: Have you gotten into **TROUBLE** while you were using alcohol or drugs?

Building Trust

Given the number of barriers perceived by adolescents and providers in coordinating optimal care, it is important to focus on strategies that can bridge these gaps, including building a trusting rapport. Providers should first introduce themselves to the adolescent and then have the teenager introduce any accompanying adults or friends. All questions and recommendations should first be addressed to the adolescent, emphasizing that he or she (not the parent) is the primary patient

When alone with the adolescent, it is helpful to begin with a positive comment about the patient's style, accomplishments or mood (Ehrman and Matson, 1998; Goldenring and Rosen, 2004). This segues into the HEADDDSS interview about social activities, school and current culture (Goldenring and Cohen, 1988; Goldenring and Rosen, 2004). The HEADDDSS interview is best conducted as a guided conversation, and Klein and colleagues (2014) provide an excellent review of the format. See Table 3 for sample HEADDDSS interview questions.

During this part of the visit a genuine interest and enjoyment in working with adolescents are easily conveyed and foster a therapeutic and trusting relationship (Schaeuble et al., 2010). If the adolescent is sending a clear message of anxiety or resistance, acknowledging this impression may quickly elicit the adolescent's primary concern (e.g., "I get the sense that you are a bit anxious about our visit."). It is important that the clinician be genuine, sincere, personal and respectful and clearly describe ways in which he or she can be helpful (Ham and Allen, 2012). Positive health choices should be acknowledged and encouraged. Avoid using slang terms (e.g., weed), as it will be clear to the adolescent this is not your typical manner of speaking, and the lack of authenticity can create distance. Be careful to avoid medical jargon; being clear and direct is a key characteristic of a successful encounter (Ham and Allen, 2011). If an adolescent uses an unfamiliar term, ask him what it means. Not only does this give the adolescent the opportunity to be an expert, but it also demonstrates interest and active listening. Resist the urge to fill silent pauses while an adolescent considers questions. If a patient begins to cry, do not try to stop him or her but rather be supportive and search for the root of the distress.

Active listening is important when developing a trusting and professional relationship. It can be demonstrated by non-verbal affirmations or brief paraphrasing of the patient's responses. It also helps the provider obtain the most accurate history. Maintain good eye contact and an open

body posture and limit writing or entering data into the computer as much as possible during the encounter. Collaboratively setting clear treatment goals is also important, as it supports the adolescent's desire for change. A nonjudgmental attitude, paired with open-ended questions, is essential for building the foundation for a productive, working relationship.

While building rapport with the patient is obviously essential, it is also important to do so with the parents. This usually is accomplished in the initial part of the interview, while collecting information about the current complaint, past medical history and family history. The adolescent should be asked all questions first, but be sure to inquire if the parent has any additional information or concerns and highlight the importance of parental involvement and input (Duncan et al., 2011; Sasse et al., 2013; Ford et al., 2011). The parents of an adolescent with a mood disorder or a substance abuse problem, for example, can offer essential insights into changes in behavior, including interactions with peers and scholastic achievement that the adolescent might be reticent to reveal. Reviewing past medical information and family history with the adolescent first, and then asking the parents to fill in any gaps, allows for more complete information and gives the patient the opportunity to hear this important information. Before asking the parents to leave the room, be sure to inquire if there are any other concerns they would like addressed.

Concluding the Visit

In keeping with confidentiality and reinforcing the provider's role as the patient's advocate, prior to inviting the parents back into the room, the clinician should review with the adolescent the concerns that arose, how these issues will be addressed, what will be kept confidential and what will be discussed with the family. If confidentiality must be compromised (e.g., in the event the adolescent reports a significant safety concern such as suicidal intent), the adolescent should be given the choice of whether he or she wants to tell the parent(s) or prefers that the clinician tell the parent(s). This allows more control for the adolescent, even in a situation in which confidentiality must be breached. This also provides good modeling for open communication and active listening within the family. When possible, the clinician should emphasize the importance of a close parent-child relationship, characterized by open communication and ongoing conversations about important health topics.

If there are risky behaviors that need not be revealed to a parent, the clinician should be open about his or her concerns and evaluate whether the patient is willing to try to manage these problems. Not uncommonly, what the provider sees as a problem (e.g., drug use), the adolescent sees as a solution to another problem (e.g., coping with anxiety). With this in mind, at the conclusion of the visit, prior to inviting the parent(s) back into the room, the clinician and patient should generate and prioritize a list of mutual concerns to be addressed. When the adolescent verbalizes changes he or she is motivated to try, the provider should assist the adolescent in trying to make these changes. Adolescents and parents should each receive a copy of the clinician's business card and be encouraged to call with any further questions.

Tailoring the Approach to the Adolescent's Developmental Level

The textbook, Neinstein's Adolescent Health Care (2008) provides an excellent review of adolescent development. It is critical to interviewing and counseling efficacy to be mindful of the different stages of adolescent development and tailor the approach accordingly.

In early adolescence (10-13 years), separation from parents and family begins, and there is increased importance placed on same-sex peer relationships. Nascent sexual feelings manifest as a preoccupation with physical changes and concerns about masturbation. *Crushes* are common, but romantic relationships are not. Adolescents in this age group, however, may initiate sexual activity and engage in sexual experimentation with same and opposite gender partners.

Concrete thinking necessitates that counseling focus on immediate benefits and advantages of healthy behaviors, rather than long term consequences. Simple and direct questions should be used and medical terms clearly defined

During middle adolescence (14-17 years), teens rely more on peers than on family for guidance and support. At this stage, adolescents have the ability to think abstractly and consider the consequences of their actions, although they do not do so consistently, and some adolescents are able to utilize abstract thinking more effectively than others. A sense of omnipotence and invincibility can lead to risk-taking behaviors, resulting in substance use, sexual activity, and criminal activities. Not surprisingly, middle adolescence is often the time of greatest family conflict. Romantic relationships are formed and are often characterized by brief, sequential, monogamous relationships. Questioning about dangerous behaviors and counseling with clear, reasoned recommendations are essential.

Late adolescents (18-21 years of age) places less importance on peer conformity. Romantic relationships focus more on mutual sharing and intimacy than experimentation. Older adolescents are knowledgeable about their sexual orientation, although they may struggle with self-acceptance if LGBT. It is easier to counsel late adolescents about health promotion and risk-prevention as they have increased capacity for abstract thought and are more able to understand the consequences of their actions; counseling can be more future oriented (Burgis and Bacon, 2003). A useful table of adolescent developmental milestones is available online (Spano, 2014).

Conclusion

Qualified confidentiality is the cornerstone of effective adolescent interviewing, and policies relating to confidentiality must be consistently applied. Attention must be paid to the patient's stage of development, and questions and counseling should be tailored to meet the adolescent's cognitive abilities, with the adolescent's motivation to change and personal goals in mind. When interviewing an adolescent, there are several simple office strategies that can be employed to promote trust, including clearly displaying diplomas, discrete placement of educational materials and posting information about office confidentiality policies in the waiting room. For clinicians, active listening, collaborative goal setting, carving out sufficient time for the adolescent interview, maintaining an open body stance, being clear and direct and being genuine and authentic are all important interpersonal factors that build trust and develop rapport. Most importantly, the provider must convey a sincere interest in the adolescent patient.

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Chapter 4.

Communicating in Difficult and High Stakes Situations

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Defining Difficult and High Stakes Conversations

For this chapter, a *difficult conversation* will be defined as a conversation about a topic that at least one participant is uncomfortable with or opposed to discussing. This discomfort or opposition may stem from a variety of problems, either singly or in combination: fear of the outcome of the conversation, unwillingness to acknowledge feelings about the issue at hand (anxiety, fear, frustration) or reluctance to reveal a lack of understanding of the topic. A difficult conversation should not be confused with a difficult patient or parent, in which case the personality, behavior or mannerisms of the individual pose a challenge, disrupt the dialogue or distract from the issue at hand.

The term *high stakes conversation* can have a variety of connotations, depending on the role played in the conversation. In a high stakes conversation there is major interest in the outcome of the conversation. In some circumstances, a high stakes conversation, like high stakes gambling, could be viewed as a conversation that is fraught with risk. In this chapter, a high stakes conversation will describe a discussion in which the content will be the basis for a major decision in a patient's life. Although all conversations between physicians and patients or their family members are important and warrant attention, care and sensitivity, only a minority would be viewed as difficult or high stakes.

In medicine, most high stakes conversations are difficult ones, even for the most experienced clinician. The outcome of every conversation is something of a mystery until the conversation is initiated, and such uncertainty can be a source of discomfort. Browning (2012) states, "Clinicians learn in their professional training, necessarily, to approach medical crises as routine events." However, he emphasizes that helping patients and families in difficult situations means joining them in the *non-routineness* of their experience and that clinicians strive to encounter each situation—and each conversation—with fresh eyes and a ready heart. Baldwin (2000) put it well when he wrote, "No one can possibly know what is about to happen: it is happening each time, for the first time, for the only time."

Patients' perceptions of events during medical encounters are based on actual occurrences but are subject to their interpretations. Framing the pertinent points of a clinical encounter occurs in real time *and also continues afterward*. The formation of the family's impression is largely the result of the comparison among perceived events, expectations (beliefs about the probability of an occurrence) and values (attitudes toward potential occurrences) (Kravitz, 2001). For example, consider the exchange in which a medical team must discuss with parents the suspicion that child abuse is the cause of their baby's illness or symptoms. This conversation brings up the need for state protection agency involvement and raises the question of removing the infant from the family. It also implies a judgment (purposefully or not) about their parenting skills and may initiate conflict between the parents as responsibility or blame for the abuse is considered. The lives of those family members will change after the clinicians share their concerns and answer the questions that follow. Parents' perceptions may include hearing accusation in the clinician's attempt at an explanation or failing to understand their explanation of how the child was injured.

It is common for parents in this situation to say, “The doctors never told us anything.” Their expectations may vary widely and will be influenced by past experiences with a state protection agency, with the healthcare system and with each other.

The Approach to a Difficult Conversation

Environment

Be considerate of the family’s right to have this conversation in private. Find a location with limited ambient noise and safe from surrounding clinical activities. The location should have ample room for all participants and should not be an area where you are likely to be disturbed. For example, using a staff break area is unlikely to afford privacy. Turn your pager and phone off or to silent. When possible, delegate responsibility for your pager and phone to a member of the medical team who will not be involved in the conversation.

When possible, try to separate the caretakers from the child so as to avoid distraction and promote a conversation that can focus on the issues. Identify a member of the medical staff or a child life specialist who can attend to the immediate needs of the child for the duration of the meeting. Children are sensitive to their parents’ emotions and will sense and react to adults’ distress, which can further escalate the emotional upset that may occur in high stakes conversations and create a distraction from or a barrier to a productive exchange of information.

Timing

Allot adequate time for the discussion. Do not attempt to squeeze it in between patients during morning rounds or into the few minutes before a conference or other activity. Be certain that the parents are not heading to work or have other time-sensitive obligations. It is important to remove time pressures on all participants in the discussion because urgency or distraction can connote impatience and insensitivity to the listener.

Pitfall: Unnecessary Urgency

When time is limited, it is best to focus on one or two primary messages, anticipating that the family will pose many questions that will occupy the time allotted for the discussion. Remember that the gravity of the message in a high stakes conversation often makes it difficult for the listener to absorb the message when hearing it for the first time. Expect to repeat major items. Prepare for the discussion by reviewing the pertinent points to be covered and identifying those concepts most likely to be confusing or upsetting to the patient or parents. The initial exchange should set the stage for further discussion as the child’s clinical course progresses. It is better to relay the salient information clearly, even if in less detail than desired, than to rush through a detailed explanation without providing time to address those details (Epting and Critchfield, 2006). A deluge of hurriedly delivered data can result in confusion for the family about the content of the message and the subsequent plan.

Content

High stakes conversations have the best chance of running smoothly when you prepare in advance. In a high stakes conversation, the family may not be surprised by the topic, yet hearing their suspicions confirmed by a physician can still be unsettling, which in turn can distract them from absorbing the content. Try to distill your message to two or three main points. When multiple subspecialists are involved in the discussion, confer about the main points and decide who will lead the conversation and who will deliver each point. For example, when talking with the parents of an infant who is a suspected victim of child abuse, important points would include:

- This baby has the following injuries: bruises on his face, two posterior rib fractures and a healing tibial fracture.
- The explanation provided (rough-housing with a 19-month-old brother) is not sufficient or plausible to explain these injuries.
- Out of concern for the baby's safety and protection (and his brother's), a child protection agency will be notified of the team's concern for physical abuse as the cause of his injuries.

Make no assumptions about the family's understanding of the medical situation. After introducing all participants in the discussion, begin by asking the family to explain what they know about their child's illness. Be direct, honest and precise.

Father: "Well, he's here because we were worried about the rash on his face, and then he had some little fractures on his x-rays, and everyone is treating us like we are scum of the earth, child abusers."

Physician: "I am really sorry to hear that you feel you and your wife are being treated poorly because of your son's injuries. It is never our intention to make families feel uncomfortable to be here."

Father "Yeah, we came here because we were worried about him, or else why would we bring him in to the emergency room?"

Physician: "Yes, we are worried about your son, too. What have you been told about why the doctors are worried?"

Father: "Because he has some fractures, which they said are going to get better and he's not even in a cast or anything."

Physician: "Yes, that's right, he has broken bones, and-"

Father: "No he just has fractures, and I'm not surprised because his brother doesn't know how to hold him."

Here is the first opportunity to clarify the situation for the family: the use of terminology such as fracture, though it seems clear to a medical provider, has created confusion about the severity of the child's injuries. A visual demonstration, such as sketch or review of the radiographs when explaining a skeletal injury or a diagram of how healthy compared to unhealthy bone marrow works when discussing leukemia is often helpful and gives the family something concrete to refer to in the discussion.

Physician: "I think that may be part of why you are feeling frustrated. His bones are broken – we use the word fracture to say that the bone is broken. Healthy little babies like your son shouldn't have any broken bones."

Father: "You mean his brother *broke* his ribs?"

Physician: "No, I don't think his brother could have done that. A 19-month-old-"

Father: "He's really strong."

Physician: "A 19-month-old is not strong enough or coordinated enough to break the bones inside a baby's body."

Father: "Yeah, well, he's a really strong kid and he's really clumsy with the baby."

Mother: "How many bones are broken instead of fractured?"

Physician: "Your son has 2 ribs that were recently broken and his shinbone was broken several weeks ago."

Mother: "Weeks ago?"

Physician: "That's right – he has new injuries and old ones so we are worried that he is not safe at home, because that is where the injuries happened. That is why you have heard people using the term child abuse."

Father: “So you’re saying we are child abusers because we brought our kid to your hospital for help with his rash?”

Physician: “I am glad that you brought up the rash. In fact, that wasn’t a rash at all. He had bruises on his cheek and on his jaw, and we know bruising only happens in healthy babies when their bodies are injured.”

Mother: “Is he healthy? What if he has some problem that makes him bruise easily? I bruise easily, so does our other son. Maybe he has a condition and you don’t know what you’re talking about.”

Physician: “You’re right. There are conditions that can look like child abuse that are really illnesses that can affect a baby his entire life. That’s why we have done all the blood work and scans and X-rays for him since he got here. What we have found is that your baby is completely healthy, except for his bruising and broken bones-”

Father: “So is he healthy or isn’t he? One doctor says one thing, then one says another thing! I can’t believe this!”

Physician: “I think that when you let me explain, you will have a better idea of the situation for your son. Here is the source of our concern: when there are injuries in a baby like the ones your son has, then we have to consider that someone hurt him and caused those injuries. And whenever we think a child has been hurt on purpose, we have to call our child protection agency to make sure the child stays safe.”

Pitfall: Self-editing

Beware extensive self-editing. Despite best efforts at clear communication, what reaches the listener may not produce understanding or compliance. When the actual consequences of a statement do not match the predicted consequences, we are likely to report that we said something different from what we intended and call our utterance an error. This is referred to as “self-editing” (Epting and Critchfield, 2006).

There is a risk to self-editing, particularly in the face of disbelieving or belligerent parents. For example, when faced with an outraged parent, there may be a tendency to use verbal modifiers, such as *sort of* or *likely* in an attempt to modify the parent’s dissatisfaction (Skinner, 1957). Doing so will dilute the message and add to the parent’s confusion. Consider if the last sentence in the above conversation had been, “So maybe something might have happened that could have been a problem for your baby, so the law says we have to call you in.” Self-edits cannot be undone, and under these circumstances will diminish a speaker’s clarity, credibility and effectiveness.

Pitfall: Disguised speech

Difficult or distasteful topics can tempt disguised speech. Skinner (1957) described covert speech as verbal mannerisms that occur when the speaker fears the negative response from the listener. The speaker engages in extensive editing of speech to disguise the undesirable content. For example, consider the term *non-accidental trauma*, or its even more evasive acronym, NAT, used to refer to a case of physical abuse. Defining a term by what it is not, rather than what it is, requires additional processing and awareness of the alternative types of trauma to understand the conclusion. If it is not an accident, then what is it? Imagine the absurdity of a scenario in which a neurosurgeon describing a brain tumor says, “We need to remove this non-infectious mass from your daughter’s frontal lobe.”

Delivery

Be direct. Acknowledge the feelings that the parents are having, whether they are worried that nurses are hiding a diagnosis of cancer or thinking that members of the team are saying the family is unfit. Families do deserve respectful treatment and open communication. Do not let

those legitimate grievances distract from the main points of your message. In the above conversation, you will note that the clinician did not make any qualifications or concessions such as, “Maybe, but I don’t think so.” to the father’s hypothesis that the brother injured the baby. That would have weakened the message and might have confused a non-abusing caretaker.

Be honest. Credibility is maintained by presenting consistent, reliable statements. This is simply the responsible practice of medicine across any type of conversation with patients, families and colleagues. You will notice that later in the example conversation above, the doctor explained that the baby’s rash was in fact facial bruising, and that facial bruising is not normal.

Acknowledge uncertainty if it exists. This is an extension of being honest in the conversation. What if the father had proposed that they have a 7-year-old son who babysits his brother? That raises numerous other child protection concerns, but also causes uncertainty about the source of the baby’s bruising and fractures. Also, be comfortable deferring to a subspecialist colleague in the discussion when you find yourself outside your knowledge base.

Do not retreat into medical jargon. Clinicians spend years in training to learn the necessary medical vocabulary. This vocabulary is detailed, specific, disease process oriented and highly unfamiliar to those outside of the medical sphere. It is reassuring to the clinician to use medical terminology because of its clarity regarding the physiology of the problem at hand. Unfortunately, that clarity is listener-specific and has no place in the overwhelming majority of family conversations (Korsch, 1968). Avoid medical and technical terms as much as possible and define those you must use. For example, during the course of a conversation about long term chemotherapeutic regimens, explain that a *Broviac* and a *Port-a-cath* are different types of devices that permit medicines to be given through a tube into the large veins near the heart rather than the small veins in the arm.

Response

This can be the most challenging part of the communication process because it is the most likely to be adversarial once the difficult topic has been broached. A *combat* mindset makes it challenging to reach shared goals—or at least shared understanding—as each side strives to *win* the perceived argument. In the above conversation, the father interrupted frequently with ill-tempered and tangential responses, but the physician did not confront the father about conversational manners with regard to the interruptions. Rather, the physician was firm toward the end of the conversation in communicating that the problem would not be dismissed.

Reinforce that the reason for the conversation is to move toward the best necessary care that can be provided for the child. This is true whether you are discussing the pros and cons of controversial chemotherapy, the use of obscene language by a parent or the need to involve a state protective agency in the family structure. The lack of mutually desirable options in achieving the best care is usually the root cause of the difficulty.

Pitfall: Mirroring

Do not escalate the volume, tone or scope of the conversation. Human interaction involves instinctive mirroring of the other participants in a conversation. When a parent raises his or her voice in outrage or disbelief, it is instinctive to match that volume to show that you are equally serious about your *side* of the discussion (Harolds, 2012). The effect is more likely to convey a desire to intimidate the parent or to ignore the parent’s statements rather than to convince him or her of your good intentions.

Pitfall: Condescension

In an effort to de-escalate a heated exchange, you may feel more comfortable slowing the

cadence of your speech (and thereby allowing fewer uttered self-edits) and lowering your tone. This can be effective *if done with care* but runs the risk of appearing condescending, particularly when paired with a comfortable retreat into medical jargon. When the clinician reverts to *medical speak* in an effort to be more precise in conveying needed information, parents may feel flustered that not only are they being misunderstood by members of the medical team but now they also are unable to understand them.

Re-acknowledgement

A high stakes conversation is likely to produce a strong emotional response in the parent(s). Acknowledge that the family is now in a frightening, saddening or even insulting situation as a result of the conversation. People want to have their feelings, ideas, concerns and dilemmas understood by others and feel isolated by a lack of understanding. An empathic communication lessens the sense of isolation (Platt and Keller, 1994). (See Chapter 1, *General Principles of Communicating with Pediatric Patients and Family Members*, section, *Empathy*.)

Conveying empathy is not well done with a canned phrase, such as, “I’m sorry if you feel offended, but we have to report this to CPS.” A less confrontational statement would be, “These situations can seem judgmental of you as parents. Please know that is not the intent of this process. The hospital takes this same action in every case of a baby with an unexplained injury in order to protect those hurt children who can’t protect themselves and to avoid another injury that could be even worse.”

Pitfall: Relating

It is natural to want to sympathize to defuse strong emotions: “I’m a dad too. I know what you are going through.” Unless you have had the looming concern that your child will be involuntarily removed from your home or an appropriate parallel to another difficult situation, you really do not know what a patient’s family member is experiencing. Even if you have had a similar experience, you still cannot know for certain exactly what the parent is feeling. Rather than smoothing ruffled feathers, such well-intentioned statements can be a trigger, causing the caretaker to lash out. Again, reframe: “Most parents in this situation would feel angry and hurt on top of being worried about their baby. You have every right to have your questions answered. Would you like to take a moment to think things through?” Except for situations in which you are threatened by a parent, make plans to return to re-address the difficult topic and follow through with these plans.

The need for difficult and high stakes conversations will persist throughout the course of one’s medical career. Clear and consistent information, delivered with a conscious effort to be sensitive to the family’s responses, provides the strongest foundation for developing an understanding of the issue at hand. Remind all parties involved that the overarching goal for all of us who care for children, whether professionally or personally, is each child’s optimal health and safety. Peabody (1927) wrote in the beginning of the twentieth century that one of the essential qualities of the clinician is interest in humanity, “... for the secret of the best care of the patient can be found in caring for the patient.”

Conclusion

When participating in a difficult or high stakes conversation, the most effective approach is to provide clear and consistent information, while being alert and sensitive to the family’s responses. Remind all parties involved that the overarching goal for healthcare providers and for the family is the child’s optimal health and safety. Couple this reminder with a sensitive, thoughtful and well-planned approach to the needs of the patient and his or her parents.

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Chapter 5

Patient Centered Communication and Decision Sharing

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The good physician treats the disease; the great physician treats the patient who has the disease. Sir William Osler.

Introduction

Patient-centered care is foundational to high quality healthcare delivery. The Institute of Medicine (2001) defines patient-centered care as “respecting and responding to patients’ wants, needs and preferences so that patients can make choices in their care that best fit their individual circumstances.” An important tool for physicians in the delivery of patient-centered care is patient-centered communication. Although a consensus definition of patient centered- communication does not currently exist, Epstein et al. (2005, 2007) identify outcomes and processes to describe it, including: eliciting, understanding and validating the patient’s perspective; understanding the patient within his or her own psychological and social context; reaching a shared understanding of the patient’s problem and treatment; and helping a patient share power by offering meaningful involvement in choices related to health. This chapter will provide an overview of patient-centered communication as it relates to routine healthcare. Guidelines and suggestions for communicating in specifically difficult situations are discussed in other chapters, including Chapter 4, *Communicating in Difficult and High Stakes Situations* and the chapters in Section 3, *Delivering and Discussing Bad News*.

Growing public dissatisfaction with the medical profession has led to significant changes in both physician training and educational research in communication. These changes include new communication curricula and defined competencies and milestones, along with a new understanding of the importance of relationship-centered care. Research suggests that patients have greater confidence and trust in physicians who practice patient-centered communication and a greater likelihood of accepting recommendations from them (Saha and Beach, 2011).

These findings have encouraged the development of communication practice guidelines by advisory boards and regulatory agencies. Empathic, patient-centered communication has been endorsed by the American Academy of Pediatrics (Levitown, 2008). In 2010, the Joint Commission (formerly the Joint Commission on Accreditation of Healthcare Organizations) released standard PC.02.01.21, which requires *effective communication with patients when providing care, treatment, and services*. Toward that end, the Interprofessional Education Collaborative Expert Panel (2011) has developed communication competencies specifically designed to foster a team approach using patient-centered communication.

Nurses represent the largest cohort of healthcare professionals in the United States. Patient-centered communication is in harmony with the domains of nursing and is promoted by that profession. For nurses, communication is a reciprocal process of sending and receiving verbal and non-verbal messages (Balzer-Riley, 1996). Nursing-specific concerns related to patient-centered communication include consistent messaging from the healthcare team, especially as it relates to the nurse’s role as the transmitter or translator of information between physicians and

patients (Slatore et al., 2012). Pediatric nurses are especially cognizant of their role as patient advocate and often see themselves as the last line of defense for children and their families when facing healthcare challenges or inequities (Paniker, 2013). (See Chapter 14, *Point of View: the Pediatric Nurse*.)

No consensus guidelines exist for the use of email or social media in patient-physician communication. Many physicians are hesitant to use email or texting due to patient privacy or Health Insurance Portability and Accountability Act (HIPAA) concerns. They also have concerns that the immediacy of these communication modalities may foster patient expectations for instantaneous communications that are both unrealistic and unsustainable. On the other hand, some physicians appreciate this rapid form of communication and value their patients' increased sense of access to their providers. While the U.S. Department of Health and Human Services (March, 2015) supports email communications with patients who have consented to receive unencrypted email, healthcare providers should familiarize themselves with institutional specific policies governing electronic communications.

The electronic medical record (EMR) is another resource that may enhance patient-centered communication by helping patients know more about their condition and increase their participation in their medical care. While most often viewed as a method of communication among healthcare providers, some physicians have employed methods to use the EMR to enhance communication during the clinical encounter. Essential to this practice is creating a physical space that positions the EMR screen so that it is visible to both the patient and physician (White and Danis, 2013). This is best achieved by facing the screen while sitting side by side with the patient. Explaining to the patient or parent that you will be typing notes and inviting him or her to correct any misrepresentations may enhance the encounter through increased patient collaboration.

Another strategy to enhance patient partnership is to invite the patient or parents to review longitudinal data for trends that reflect health behaviors (e.g., body weight or Hemoglobin A1C levels). Although controversial, some physicians invite their patients to enter a note into the EMR record as a method to increase active involvement (Charon, 2007). This practice can be limited by many factors, including language barriers, computer literacy and the need for unambiguous documentation associated with sensitive patient issues (e.g., substance abuse and morbid obesity). If in a hospital or other healthcare facility, this practice needs to be in accord with institutional policies and rules.

Essential Elements of Patient-centered Communication

Communicating with children and their parents is a crucial element of a successful medical encounter. Data indicate that effective communication with the family results in increased satisfaction and compliance, increased self-efficacy, decreased malpractice claims and, most importantly, improved patient outcomes (King and Hoppe, 2013; Weiner et al., 2013). Despite the increased emphasis on physician competency in communication during the past several years, patients report that many of their informational and emotional needs remain unmet during encounters with their physicians. In a study by Marvel et al. (1999), experienced physicians solicited the patient's complete agenda only 28% of the time. The increased emphasis on communication skills for physicians has resulted in several models for enhancing patient outcomes. One well established framework for communication skills is the Kalamazoo Consensus Statement, developed in 1999 (Makoul, 2001). Twenty-one medical education leaders and communication experts from the United States and Canada convened and identified seven evidence-based, essential elements of effective physician-patient communication: 1) build

the doctor-patient relationship; 2) open the discussion; 3) gather information; 4) understand the patient's perspective; 5) share information; 6) reach agreement on problems and plans; and 7) provide closure.

Research findings suggest that patients strongly desire to be partners in decisions about their own healthcare (Chewning et al., 2012). To enhance patient outcomes, medical care should also be responsive to patients' needs and perspectives. Thus there has been a shift in emphasis from physician-centered communication to patient-centered communication, with a goal of reaching a shared understanding of the patient's problem and its biopsychosocial impact in order to reach a mutually agreeable treatment plan that is in keeping with the patient's values. This approach emphasizes both the patient's disease and his or her illness experience (Smith, 2002). The Kalamazoo Consensus Statement outlines four key communication skills for building this type of therapeutic relationship with a patient or parent:

- Establish and maintain a personal connection with the patient
- Elicit the patient's perspective on his or her chief complaint
- Demonstrate empathy in response to patient cues
- Express a desire to work with the patient towards better health

Essential Elements of Communication from the Parents' Perspective

As stated above, patients and families should be empowered to express their healthcare expectations. In 1984, Beckman and Frankel published a landmark study that found the average length of time given patients to inform the physician of their concerns before the physician (primarily interns) interrupted was 18 seconds (Beckman and Frankel, 1984). A study with Board-certified family medicine physicians demonstrated an average of 23 seconds before interruption (Marvel et al., 1999). Remarkably, in this study, in one out of four visits, the patient's concern was not elicited; in addition a complete patient agenda was obtained less than one third of the time. Providers with a pre-set amount of time per visit may worry about allowing parents to set the agenda. However, patients who were allowed to finish stating their concerns averaged only 6 seconds more than those who were interrupted. Eliciting the full patient or family agenda decreases concerns at the closure of the visit, allowing more time to explore concerns in detail and gather important data. Marvel et al. (1999) state, "Using a simple opening solicitation, such as 'What concerns do you have?' then asking 'Anything else?' repeatedly until a complete agenda has been identified appears to take 6 seconds longer than interviews in which the patient's agenda is interrupted." It is important to plan the agenda with the patient in the context of time limitations and prioritize when necessary. "Let's make sure we talk about X and Y. It sounds as if you also want to make sure we cover Z. If we cannot get to the other concerns, let's plan to address these at your next visit."

Families like information explained in plain, non-medical language. Words that clinicians use in conversations with colleagues, including the most basic medical terms, may be unfamiliar to non-medically trained persons. Examples of non-medical terms to use include "keep track of" instead of "monitor" and "have for many years" instead of "chronic." The Centers for Disease Control and Prevention (2014) recommend that providers explain risk using numbers rather than words alone and provide absolute risk (e.g., 1 out of 50). Information should be limited to one to three key messages as it is easier to remember and patients are more likely to take action when information is given in small bits relevant to their needs. These key messages should be repeated often during the visit and reviewed at the close because people learn more effectively when they hear the information more than once. Patients and parents want providers to explore their thoughts (ideas, worries, feelings, expectations) about their problems and elicit their input about

the treatment plan. Both the parents' and the child's emotions should be solicited, acknowledged and explored. This concern is especially important for adolescent patients (See Chapter 3, *Talking with the Adolescent Patient*). A patient-centered approach regards the physician-parent relationship as a partnership and respects the parent's and child's active participation in decision making.

Sydney J Harris, an editor and columnist with the *Chicago Daily News*, is quoted as having said, "The two words information and communication are often used interchangeably, but they signify quite different things. Information is giving out, communication is getting through." (Brainy Quote, 2001) As active partners, patients and families should be encouraged to ask questions. Rather than asking, "Do you have any questions?" ask instead, "What questions do you have for me?" or "What is your first question?" Simple one word changes in a sentence can make a big difference in a patient's response. For example, asking, "Is there *something* else you want to address today?" was significantly more effective in soliciting patient concerns than "Is there *anything* else you want to address today?" (See Chapter 1, *General Principles of Communicating with Pediatric Patients and Family Members*, section, *The Words We Choose*.) Also, consider telling parents that it is all right to bring a friend to the office or clinic visit if they so desire.

In a doctor's office, parents have multiple responsibilities in addition to receiving information. Children do not stop acting like children when in the doctor's office, and thus parents need to continue to provide guidance and direction. For the worried or crying child, the parent must console and comfort. For the child who is uncooperative or just a little too curious, the parent must guide behavior in a desirable direction. For the child with questions, the parent needs to provide answers, and for the child who is bored, the parent must entertain. The more roles the parent has to balance at any one time, the more his or her attention is divided. The more a parent's attention is divided, the fewer internal resources are available for listening and understanding in-coming messages, resulting in missed or misunderstood information.

Routinely ask adolescents what concerns they have that have not been addressed. As participants in patient-centered communication and shared decision making, children and adolescents are partners with their parents in their own healthcare. When parents or teens ask questions or express a concern, be sure to address these concerns purposefully. As healthcare providers, we speak a foreign language, and it is our job to make sure that parents understand what has been said. Do not use the phrase, "Do you understand?" You are likely to get a "Yes" whether or not the individual understands. Instead, utilize the Teach-Back technique (Schillinger et al., 2003). This allows you to check for understanding and, if necessary, re-teach the information. This technique creates the opportunity for dialogue in which the physician provides information and then encourages the patient to respond and confirm understanding before adding any new information. We must ask the patient to explain or demonstrate understanding in a way that is not demeaning, for example, "What will you tell your spouse about what we discussed today?" It is important not to appear rushed, annoyed or bored during these efforts; your affect and body language should agree with your words. Asking patients to restate what they have been told is one of 11 top evidence-based patient safety practices (Wachter and McDonald, 2001).

Healthcare providers should assess parental satisfaction, either verbally or with questionnaires such as The Four Habits Patient Questionnaire or the Patient Perception of Patient-Centeredness Questionnaire (Rider and Nawotniak, 2010). All members of the team should practice reflection during and after actions related to communication skills. One option is to ask patients and parents, "How can I improve my skills in talking with you and your family?"

Essential Elements of Communication from the Child's or Adolescent's Perspective

Researchers analyzed video-recorded clinical encounters between pediatricians and their patients ages 2 to 14 and found that children were rarely given the opportunity to state the nature of the problems that brought them to the clinic (Stivers, 2001). The following statement, found on a bench in a teaching clinic, is a testament to the importance of talking to the child: "I think you should ask the patient what's wrong with him or her, not the parent. The parent is not sick. The kid is sick. He knows more of himself than anyone else understands. A patient. Thanks. Karen." (Kennell, as cited in Dixon and Stein, 2006) A 15-year-old adolescent, shares her perspective on being in the hospital and what patient-centered communication means to her in the YouTube video entitled "I am a patient – and I need to be heard!" (Gleason, 2001) These two examples illustrate the importance of the child's or adolescent's voice in the clinical encounter. Sydnor-Greenberg and Dokken (2001) interviewed children ages 4 to 17 years with both acute and chronic conditions to explore their preferences in the way healthcare providers communicate with them. These researchers categorized the children's responses into the following framework they call the CLEAR communication model:

Context – seeing the child as more than someone with a medical issue. Children wished their doctors would ask them about their school, friends and activities. Older adolescents suggested that providers ask more personal questions.

Listening – allowing children to speak without being interrupted and not making comments that demonstrate disapproval or surprise. Children did not want their fears trivialized even if they seemed like minor problems to the doctor or the parent. They also wanted to be supported and shown empathy for crying or getting angry during a painful procedure, instead of being made to feel foolish.

Empowerment – explaining in developmentally appropriate terms what is being done and why. Children, particularly those with chronic illnesses, want information conveyed directly to them. They do not want doctors to talk about them as if they were not in the room.

Advice and Reassurance – counseling on how to manage one's illness and reassurance, if appropriate, that the child is normal or is doing a good job managing his or her symptoms. This aspect was less important to the children than were context, listening and empowerment.

Best Practices for Patient-Centered Communication

King and Hoppe (2013) have synthesized the literature on best practices for patient-centered communication and created an amalgam of specific skills for all healthcare providers. These skills employ six functions of the medical interview and require eliciting the patient's story of illness while guiding the interview through a process of diagnostic reasoning. It also requires awareness that the ideas, feelings and values of both the patient and the physician influence the relationship. The remainder of this chapter uses these six functions of the medical interview as a framework for communication skills:

- Fostering the relationship
- Gathering information
- Sharing information
- Decision making
- Enabling disease- and treatment-related behavior
- Responding to emotions

Fostering the Relationship

A strong, therapeutic and effective relationship is essential to patient-centered communication. A patient-centered approach regards the physician-parent relationship as a partnership and respects the parent's and child's active participation in decision making. The fundamental communication task is to build this type of relationship starting at the beginning of the encounter. Amer and Fischer (2009) describe expectations from a parental perspective. Of the parents surveyed, 83% reported they would like the doctor to shake hands, 87% would like the physician to address them by name: 53% by last name, 13%, by first name and 21% by both first and last name. They did not want to be called "Mom" or "Dad." All of the parents wanted the physicians to introduce themselves, and most of the parents wanted the physicians to introduce themselves by their last names. When interviewing adolescents, pre-teenagers or grade school children, introduce yourself to the child first to make clear that he or she is the priority. You may then try having the child introduce the other people in the room. Table 1 lists other specific methods to establish rapport with children (Deering and Cody, 2002).

Table 1. Suggestions for Establishing and Maintaining Communication with Children and Adolescents

Establishing rapport
Show interest in the child or adolescent by talking about non-medical topics such as school, games and sports and asking about his or her interests. Mention things to show that you are familiar with the patient and family, as well as with their medical issues. A smile can go a long way in establishing rapport. A white coat can be intimidating and scary for a young child; consider not wearing a coat or wearing a coat of a different color.
Maintaining rapport
Be calm, gentle and respectful. Convey that you are not in a hurry: sit, assume an open, relaxed posture and do not look at your watch or the door. Use a normal tone of voice and rate of speech. Use developmentally appropriate language to share your thoughts and observations with the child (e.g., "It can be scary when you have to stay in the hospital and don't know when you will get to go home.").
Keeping the child in the conversation
Allow older children or adolescents to tell their own stories first and give them the last word in the conversation. For children who are initially hesitant in responding, ask them to tell you in their own words what is wrong after establishing the chief complaint from the parent. Allow children and adolescents to express their opinions and feelings. Facilitate this with questions. Do not jump to conclusions about or trivialize a child's or adolescent's perspective or concern. What may not seem like a problem to you may be an important issue for the child. When appropriate, allow choices during the interview and examination (e.g., "Would you like to sit on your mother's lap or on the table?" or "Which ear would you like me to look in first, the left or right one?")

Table continued on next page

Maintaining a supportive environment

For the child who may have difficulty understanding the spoken word (e.g., a child with autism or with a hearing deficiency), pictures of children participating in the various components of the exam can be extremely helpful and decrease anxiety. Do not allow other family members to speak unfavorably about the child or adolescent in your presence; this sets a poor example, embarrasses the child and undermines trust. Be careful of your own words, as they can be very powerful. Do not use words like fat or lazy. Share positive affirmations and celebrate successes with the child or adolescent (e.g., “I am so proud of your food choices.”).

Gathering information

As disease and illness are intertwined, the patient-centered clinical method seeks both a diagnosis and an understanding of the child’s and the parent’s experiences of illness. The pediatric interview encompasses the notion of the *dual patient*. The child and the parent are the patient, both as individuals and as an interactional unit. When gathering information, the healthcare provider should try to understand the patient’s and the parent’s goals in seeking care. “How were you hoping I could help you today?” Additionally, the provider should elicit a full description of the major reasons for the visit from both a biologic and psychosocial perspective. Patient-centered care includes exploring dimensions of illness (e.g., feelings, ideas, impact on the family’s function and expectations) as well as understanding the whole child (e.g., life history, family dynamics, social supports, culture, community and relationship with others integral to the child’s day-to-day life). In order to do this, the provider must elicit the patient’s full set of concerns through the use of open-ended questions.

In cross-cultural care, patient-centered communication can be facilitated using targeted questions developed by Kleinman and associates and described in the book, *Explanatory Model of Illness* (Hark and DeLisser, 2009). The intent of this communication is to elicit patients’ social, cultural and personal understanding of their illnesses and treatment goals. This information can clarify the patient’s values and priorities and help guide the physician in educating the patient. Questions that may be helpful are: “What do you think might be causing this problem?” or “What concerns you most about this problem?” Sometimes a more direct statement may be needed, such as, “I have families who tell me that when their child has these symptoms, they are most afraid that it may be cancer. Is that something you are worried about, or is there something else that you are concerned about?” Parents may have a hidden agenda for the clinical encounter. In a study of 370 office visits by Bass and Cohen (1982), 34% of parents expressed a fear not verbalized initially that appeared to worry them about a more serious condition than the provider would have anticipated based on the initially stated reason for the visit. If when asked about his or her concerns, a parent responded with a physical complaint, the researchers asked if there was anything special about the complaint (e.g., fever, cold or infection) that was causing concern. Once these concerns were expressed, the provider had an opportunity to put the symptom in perspective and act upon the concern(s). It also can be helpful to ask about what others in the family think might be causing the problem. In particular, asking about what a parent (or grandparent) who is not present thinks can be extremely helpful. Another targeted question to ask during the information gathering phase of the interview is, “What kind of treatment do you think you should receive?” Eliciting expectations at the beginning of the interview can help prepare the physician for partnering with the patient during decisions on management.

In patient-centered communication it is imperative that the provider elicit from the parents and from the child (when developmentally appropriate), their perspectives on the problem or illness. Children and adolescents may not be able to adequately express symptoms or emotions verbally. The use of drawings can be helpful in understanding how a problem or illness affects the child. Children can be asked to draw pictures of themselves or their families. Ask the child to explain what the different components of the drawing mean. When inquiring about drawings depicting family dynamics, ask the child and the parent what they think about the picture. Patient drawings have been used in a variety of situations and can be very insightful. Drawing allows a child to express his or her fears and can be used to assess how a child may be coping with a serious illness (Gallo, 2001). Other forms of artistic expression, such as poetry, narratives and videos created by the patient can be used to gain information. For example, a 9-year-old patient, rather than directly asking her orthopedic surgeon this very concerning question, gave the following note to her mother: “Ask him how my breasts are going to fit or grow with my brace? How am I going to wear a bra?” (Dixon and Stein, 2006).

Providers should spend at least as much time listening as talking. Start the conversation by letting the patient or family member talk to you and try not to interrupt the speaker’s narrative. Questions such as, “How has the illness affected your daily activities?” can provide context and perspective. The explanatory model of a parent or child may be different from the provider’s assumptions. Knowledge about and respect for the beliefs, attitudes and cultural lifestyle of children and their families can yield important information and enhance the therapeutic alliance. For example, when addressing the issue of encopresis in a school aged child, the provider needs to understand the issues associated with toileting practices during the school day. If a child is being bullied when he or she goes to the bathroom, this issue needs to be addressed before medical management can begin. The provider should explore the full effect of the illness on the child’s or adolescent’s life. For an obese adolescent male, weight loss may not be his main goal if he is the starting lineman for his high school football team. Adolescents should be interviewed separate from the parent to encourage autonomy and promote communication. Always give adolescents the opportunity to talk with you privately.

When eliciting perspectives from the patient or family, the provider should use active listening techniques, such as Invite, Listen and Summarize, which allow opinions and feelings to be heard and validate that the speaker has been understood (Boyle et al., 2005). (See Chapter 1, *General Principles of Communicating with Pediatric Patients and Family Members*, section, *The ILS Model*) By sensitively communicating with the child, the provider models for the parents the art of listening to and respecting the views of their children. The benefit of this process is not limited to the comprehension of statements and emotions. The child or adolescent is now primed to become an active participant in a behavior plan. Active listening helps providers avoid approaching already contentious situations through conflict and allows all participants to be a part of the discussion. Ideally, this approach impacts behaviors, particularly in the short term, and also affects a child’s or adolescent’s self-concept and self-esteem long term.

A simple and effective tool to facilitate patient-centered communication is a structured note pad. Farberg et al. (2013) created *Dear Doctor* notes that were designed to prompt patient questions. This low-cost tool includes sample questions and informational prompts to facilitate communication. The pre-printed form includes the following three questions: 1) What is the reason for my hospitalization? 2) What tests are planned for me today? and 3) What medications will I be on? Patients can also check the box, “I have a few more questions,” and write their own questions. Dear Doctor Notes prompt patients to ask questions very similar to the “Ask Me Three”

initiative by the National Patient Safety Foundation: 1) What is my main problem? 2) What do I need to do? 3) Why is it important for me to do this? (National Patient Safety Foundation, 2014). This simple tool improved patients' satisfaction with physician communication

Sharing Information

Approximately 25 million adults (8.7% of the U.S. population) have limited English proficiency (U.S. Census Bureau, 2011). However, half of all Americans may be at risk for medical misunderstandings, and this risk is increasing due to the increased use of written communication for instructions and the increased complexity of the healthcare system, including the burgeoning number of medications, treatments and tests available and the growing requirements for self-care.

The poet William Butler Yeats advised, "Think like a wise man but communicate in the language of the people." (William Butler Yeats Quotes, 2001) Other chapters in this book (Chapter 1, *General Principles of Communicating with Pediatric Patients and Family Members* and Chapter 27, *Using Communication to Improve Patient Adherence*) describe communication techniques that can maximize patient and parental understanding and adherence to therapy. While the provider should estimate the health literacy level of the parent and child, it is best to underestimate the literacy level, and it is a safe rule to talk to the family in language that the child, who is likely listening even if he or she does not appear to be, can understand. When communicating with a school aged child, it is important to know how he or she perceives the situation before explaining it. A simple question such as, "Why do you think you are here today?" may reveal surprising misconceptions. Healthcare providers should give uncomplicated explanations and instructions and pause after giving information to allow the child and family to absorb what they have been told. The clinician should frame the diagnosis and other relevant information in ways that reflect the patient's initial presentation of concerns. Explain the nature of the problem and the approach to diagnosis and treatment, including the rationale for tests and treatments. When parents or children ask questions or express concerns, address these directly. The Joint Commission report, *Advancing effective communication, cultural competence, and patient-and family-centered care: A roadmap for hospitals*, (2010) states that providers should identify the parent's preferred language for discussing healthcare issues. Children or adolescents should never be used as interpreters for parents, as this has the potential for miscommunication that may impact family dynamics as well as patient care. When using an interpreter, ask the person to comment on his or her interpretation of nonverbal elements, the fullness of the parent's or child's understanding and any culturally sensitive items. The 2001 Health Care Quality Survey of the Commonwealth Fund found that African Americans, Hispanics and other minorities reported higher rates of difficulties in communicating with their physicians (Collins et al., 2001). Communication issues can arise in race or culture discordant visits and may lead to lower satisfaction with the visit as well as poorer adherence to treatment plans (See Chapter 28, *Communicating across Cultural Differences*). Details regarding the family's preferred method of receiving information should be shared with all members of the healthcare team.

As healthcare providers who share information with patients and family, we should seek to understand their informational needs. Parental readiness to hear information is key. In a study to assess parental preferences in communicating about developmental delays, most parents preferred that the provider use non-alarmist wording, maintain optimism and acknowledge that the child's development might not be delayed (Sices et al., 2009). However, some parents favored a more direct, yet gentle, approach and emphasized the importance of not sugar-coating the information. The parents in this study recommended providing them with information

regarding what they could do, possible next steps for further evaluation and a plan to follow-up with the provider within a short time. Section 3 of this book outlines delivering and discussing bad news in detail. Time constraints, volume and complexity of information, unexpected or bad news and divided attention all may affect comprehension. Verbal discussion alone may not be enough. Methods such as audiovisual aids, written information and audio or video recordings can serve to reinforce verbal information. Family preferences regarding these types of additional communication methods should be sought. A study of women with breast cancer reported that despite all the informational resources available to providers, at follow-up, 66% of patients felt their informational needs had not been met (Luker et al., 1996)

Social media are changing how families interact with the healthcare system. Social media have become drivers to more patient-centered care by empowering families to seek out information, by providing support networks and by creating mechanisms for real time information and instantaneous feedback. A YouTube documentary entitled, “Health I.T. – Advancing Care, Empowering Patients” features a general practitioner who, rather than only seeing patients in the office, texts, sends instant messages and video chats with patients as much as possible. (Hopper, 2012). While families still appreciate contact with their providers by the established technology of the telephone, one study found that most patients with access to electronic mail want to communicate with their physicians via the Internet (Kleiner et al., 2002). Many patients feel that increased access to their healthcare providers by the Internet builds a closer relationship and stronger therapeutic bond with the healthcare team. Patient privacy and data security concerns, as well as institutional policies, should be addressed before social media are utilized to interact with patients and families.

Sharing Decision Making

Involving children and their parents in healthcare decisions can make significant and long-lasting differences in outcomes. Approaches to decision making span the spectrum from dictated by the physician (paternalistic) to completely determined by the patient or parent (consumerist model) (Greenfield, 2001). Between these two extremes is the patient-centered collaborative approach of shared decision making. Barry and Edgman-Levitan (2012) state that the most important attribute of patient-centered care is the active engagement of patients in the decision making process. A systematic review of 115 studies revealed that the majority of respondents preferred sharing decision roles in 50% of studies prior to the year 2000 and in 71% of studies from the years 2000 to 2011. (Chewning et al., 2011). Not all patients or parents want to be involved in decision making so providers need to establish or review each parent’s preference for his or her role in decision making. Conflict may exist between the parent(s) and the adolescent patient regarding the adolescent’s role in the decision making process or the adolescent’s values and preferences. (See Chapter 3. *Talking with the Adolescent Patient* and Chapter 6, *Ethical Considerations in Communicating with or about a Child*).

Sharing information also includes discussing options that are consistent with the child’s and family’s lifestyle, cultural values and beliefs. Questions such as “What matters to you?” will help elicit these preferences. In shared decision making, all parties share information. The clinician outlines treatment options and their risks and benefits in an unbiased way, while exploring the family’s understanding of these options. Providers need to respect alternative healing practices and faith based practices. Providers need to help the parents understand the importance of the family’s opinion in making decisions that will ultimately affect the child. It is vital that these discussions be focused on what is best for the child. Children, when involved in treatment decisions, should only be given choices that are acceptable to the parents and provider.

Sometimes, however, a child will make a choice that neither the parents nor the provider endorses (e.g., a youngster with diabetes who refuses dietary control). The provider and parent cannot accept this choice of action and should explain why and then work with the child, to direct him or her to a safer action plan.

Shared decision making is especially important in situations in which there is insufficient evidence or where there is no single, clearly best option. Decisions in such situations are sometimes called preference-sensitive decisions. When applicable, condition-specific decision aids that complement counseling, facilitate shared decision making and improve patient decision quality should be provided. Decision aids are tools that augment patient-parent-clinician communication to ensure that: all participants receive standardized information on the risks and benefits of medically reasonable options in plain language; preferences are elicited about important trade-offs among the various options; and the option that is selected is congruent with the family's preferences. Decision aids can be particularly beneficial for options involving technology, treatment of disorders of sexual development and treatment for attention deficit hyperactivity disorder. Examples of decision aids can be found at the websites of the James M. Anderson Center for Health Systems Excellence at Cincinnati Children's Hospital (1999) and of the Ottawa Hospital Research Institute (2014). Agreement should be reached among the patient, the parent and the provider, and a collaborative action plan should be outlined. Follow-up plans should then be discussed, as well as plans for dealing with unexpected outcomes.

Enabling Disease- and Treatment-related Behaviors

After a collaborative action plan has been developed, the provider should assess the child's and family's interest in and capacity for self-management, which includes assessing the patient's and parent's readiness to change health behaviors. The Transtheoretical model (aka Stages of Change Model) was first described in 1983 (Prochaska and DiClemente, 1983). In this model, the provider identifies where the patient and his or her parents are along a continuum of readiness to change behavior. To facilitate change, the provider should match counseling strategies to readiness. Readiness should be viewed as a fluctuating product of interpersonal interaction and not a static personality trait. One technique that is particularly effective for those who are in the precontemplative stage (i.e., not yet wanting to make a change) is the technique of motivational interviewing (Gold and Kokotailo, 2007). This method of effecting behavioral change is based on the foundation of collaboration, evocation and autonomy. The core communication strategies of motivational interviewing are: express empathy; develop a discrepancy (recognizing inconsistencies between current status or behavior of the patient (or parent) and goals and values); roll with resistance; and support self-efficacy (Gold and Kokotailo, 2007). Motivational Interviewing uses open-ended questions and reflective listening to facilitate a conversation about behavior change. Some specific techniques that can be helpful to motivate change are:

- Elicit-Provide-Elicit (aka Ask-Tell-Ask): ask the patient and parent what he or she knows about the behavior change, then ask for permission to provide information or advice and, finally, ask about their reactions to what was said.
- Decisional Balance: inquire about the positive and not so positive aspects of changing the specific behavior. If the patient is pre-contemplative, then ask about the pros and cons of not doing anything. Summarize the responses and open a dialogue to talk about the change. Strive for a commitment.
- Importance and Confidence Rulers: these are visual aids on a scale of 1-10 (least important or least confident to most important or most confident) by which the provider can gain an understanding of where to focus his or her efforts (importance or confidence).

- **FRAMES**: this is an acronym for: **F**eedback, **R**esponsibility (emphasize personal choice), **A**dvice (recommend change), **M**enu (present alternative strategies), **E**mpathy, **S**elf-Efficacy (reinforce hope and optimism) (Miller and Sanchez, 1994).
- **Behavior Change Plan**: this is a written document describing the changes the patient would like to make, specific objectives (realistic and measurable) needed to effect the change, and resources to help make the change and solutions to barriers. The plan does not have to be a commitment to do something; it can be a commitment to think about the issues, to talk with others or to get more information to help make a decision (Gold & Kokotailo, 2007).

The physician should provide advice on strategies for successful coping skills and assist the family in navigating the healthcare system. The family and physician should assist the child to optimize autonomy and self-management while building self-efficacy.

Responding to Emotions

Providers should facilitate and acknowledge the parent's or child's expression of emotional consequences of illness. Express empathy, sympathy and reassurance. Look for opportunities to use brief empathic comments such as, "You look really worried. Can you share what you are feeling?" School aged children tend to respond better to third person conversational prompts such as, "Some children are scared when they hear that they have to go to the hospital." Another helpful technique to help children reveal their feelings is to ask what they would wish for if granted three wishes. Once stated, a clear attempt should be made to explore feelings by identifying and labeling them. Clinicians should make comments clearly indicating acceptance and validation of these feelings (e.g., "I can see how that would worry you." or "I would feel the same way."). Assess psychological distress and provide help in dealing with emotions as necessary. Nonverbal behaviors that express great interest, concern and connection (e.g., eye contact, soothing tone of voice and open body orientation) should be displayed throughout the interaction. The NURSE mnemonic is useful for addressing emotions (Back et al., 2008).

Naming, labeling: "You sound sad."

Understanding, legitimizing: "I can understand your being upset. Most people would be."

Respecting, praising: "You have been very resourceful. That's great."

Supporting, establishing partnership: "I am here to help you however I can."

Explore: "How would you like us to proceed?"

Conclusion

Patient-centered communication is central to creating a healing relationship with patients and their families. This chapter provides the clinician with an overview of current recommendations, resources and practice tips for enhancing patient-centered communication. We endorse that all healthcare providers use patient-centered care and patient-centered communication so as to: include patients and their families in the patients' care and in decision making; enhance patient adherence; and improve patient outcomes. Ongoing research is needed to continue our understanding of the processes and outcomes of patient-centered communication as new technologies and healthcare delivery systems emerge.

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Chapter 6

Ethical Considerations in Communicating with or about a Child

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Overview

Pediatricians have a professional responsibility to effectively communicate with their patients and their patients' parents or legal guardians. The purpose of this chapter is to provide a practical, ethically justified and clinically comprehensive guide for pediatricians to consider when communicating with children and their parents or guardians. Appropriate verbal as well as non-verbal communication is absolutely essential in establishing and maintaining the physician-patient relationship. Documentation (electronic or written) reflective of that communication should be transcribed in a timely manner and be easily accessible.

Communicating Information

In past years the concept of appropriate communication consisted of a dyadic dialogue between the physician and the parent(s). Children, regardless of age, rarely were included or even asked to become involved in a conversation regarding their health or illness (Leikin, 1983). During the past 15 to 20 years, the involvement of children and adolescents in decision making and management of their healthcare issues has become more commonplace (Lantos, 2015). This form of triadic communication involving the physician, the parent(s), and the patient, however, has not always been ideal. (Garth et al., 2009).

In the past many parents believed that informing the child or adolescent of his or her disease, condition, prognosis or management was not in that patient's best interest. Even now, some parents hold this belief, and some professionals maintain that the decision of parents to withhold what they consider to be harmful information can be justified (Lantos, 1996). However, studies have shown that children often know and understand more than what others assume they know and understand and that they want to be informed with regard to their health status. (Committee on Bioethics, 1995; Levetown, 2008)

Ethical Framework

The healthcare of children is governed by two fundamental concepts of pediatric ethics: 1) the best interests of the child standard and 2) pediatric assent. Both concepts generate the ethical obligations of pediatricians and parents to the child who is a patient.

Best Interest of the Child Standard

The biomedical interests of a pediatric patient are identified on the basis of expert clinical judgment, which cannot be rendered by parents who are laypersons.

Pediatricians should exercise their professional integrity in making deliberative clinical judgments about the biomedical interests of their patients. They should first distinguish

technologically feasible from non-feasible clinical interventions. The pediatrician should then distinguish among the technologically feasible interventions those that are medically reasonable and beneficence-based. Is the technologically feasible intervention reliably expected to result in net clinical benefit for the patient? Clinical benefits to be assessed are prevention of mortality as well as prevention of both disease-related and iatrogenic morbidity, pain, distress, suffering, diminished functional status and reduced quality of life. The last item includes the patient's ability to engage in and derive satisfaction from the life tasks he or she values. By their very nature, quality-of-life considerations do not apply to infants or children whose neurologic condition precludes experiencing life tasks (i.e., children who have irreversibly lost the capacity to interact with the environment). It must be acknowledged, however, that it can be difficult to decide if a neurologically impaired child can interact; parents are often convinced that the child recognizes them and reacts although they are unable to demonstrate this convincingly to the medical provider. Also, this does not mean that these children are not entitled to ordinary medical and comfort care, even as decisions regarding interventions or withdrawal of life-sustaining measures are being considered.

When the evidence base for clinical judgment about the biomedical interests of the patient is strong, the pediatrician should be directive by making a recommendation. When the evidence base is weak, the pediatrician should be non-directive by offering, but not recommending, options from among medically reasonable alternatives. In such cases, shared decision making becomes the appropriate approach. (See Chapter 5, *Patient Centered Communication and Decision Sharing*.)

Pediatric Assent

The American Academy of Pediatrics (AAP) adopted the ethical concept of pediatric assent in 1995: "Patients should participate in decision making commensurate with their development; they should provide assent to care whenever possible. Parents and physicians should not exclude children and adolescents from decision making without persuasive reasons." (Committee on Bioethics, 1995) The AAP identified four elements of pediatric assent: 1) help the patient achieve a developmentally appropriate awareness of the nature of his or her condition; 2) tell the patient what to expect with treatment; 3) make a clinical assessment of the patient's understanding and the possible factors influencing how he or she is responding; and 4) solicit from the patient an expression of his or her willingness to accept the proposed care.

Older children, especially adolescents with chronic diseases, may be as capable as adults in exercising the capacities of decision making (e.g., absorbing, understanding and recalling information provided; assessing consequences in terms of one's values and beliefs; and explaining preferences on the basis of understanding). Ethically, the more adult-like the decision making capacity of the patient, the more prominent should be the patient's decision making role.

Not knowing their conditions or what efforts are being made in terms of appropriate correction or stabilization is not good for patients who have any capacity for understanding. Keeping them *in the dark* may increase anxiety and may decrease willingness to cooperate in care, especially if that care creates pain, distress or suffering. Also, modern pediatric care is delivered by teams of providers, not all of whom may be aware that the child is to be kept uninformed, or if aware, may be unwilling to participate in what they may quite reasonably judge to be a conspiracy of silence.

In addition, the child may learn about his or her condition through conversations with others or by simple deduction and have no biopsychosocial supports in place. This subterfuge is antithetical to the best interests of the child standard. Organizational policy therefore is crucial. In hospital settings, pediatricians should support the development and implementation of

organizational policy based on the AAP statement (Committee on Bioethics, 1995), avoiding a case-by-case approach and uncontrolled variation.

Complexities of Pediatric Assent

Within the 1995 AAP statement, the phrases "...whenever possible..." and "...should not exclude children and adolescents from decision making without persuasive reasons..." indicate an acknowledgement that establishing the best interest in terms of disclosure to a child can, in some cases, be complex. This complexity can be manifest in ethical challenges for individual providers and teams that, in turn, complicate communication with the patient and family. Addressing these challenges, particularly when the life and well-being of a child hangs in the balance, requires disciplined reasoning, as well as a clear understanding that a number of factors have the potential to impinge upon and unduly influence ethical reasoning.

These factors are rooted in good faith efforts of providers to respect parents, engage in shared decision making and demonstrate compassion for the substantial burdens families may face. Pediatricians understand that the parents are crucial supports for the patient and should remain partners in any treatment plan. Healthcare providers are concerned about provoking conflicts with parents that can disrupt trust and the therapeutic alliance essential to good patient care. The legal status of parents, rather than children, as decision makers also can make it difficult to draw the line as to where provider authority should over-ride parental wishes. Providers know that parents have to confront the continuing responsibility (and guilt, justified or not) with regard to decisions made and the outcomes for their child. Respect for the parents' role and a concern for the entire family can make it difficult for pediatricians to maintain a clear focus as to their primary responsibility (i.e., the child). A significant related factor that the pediatrician may also have to examine and manage carefully is a difference in his or her cultural beliefs from those of the patient's family.

General Principles of Communication with Patients and Families

Many disciplines within the field of medicine are crucial to pediatric care, but the family usually, and appropriately, sees the primary pediatrician as leader of the healthcare team. Although the amount and type of information communicated must be paced according to what the patient and family can absorb, it is important that the pediatrician provide clinically relevant information about diagnosis, prognosis and plan as early as possible.

Preparation

Before talking with the family, the provider should review all that is currently known about the patient's circumstances and then pause to reflect on the implications of the particular illness and treatment. Consider how the illness may have emerged, current symptoms, upcoming procedures and possible long-term effects. Imagine what it might be like from the patient's and family's perspectives. Depending on the amount of experience with particular situations and the degree of personal attachment the provider has developed with the patient and family, it is normal for providers to feel a mixture of emotions (e.g., sadness and fear) when a positive picture takes a turn for the worse. It helps to acknowledge these feelings in advance and to take time to process them (perhaps with the help of colleagues) and to reorient oneself to the purpose and importance of his or her professional role with the patient and family. It is appropriate for the provider to show the family that he or she cares, but patients and families need their providers to display a calm demeanor and the ability to lead them through threatening and often tragic circumstances.

Talking with Parents

In potentially difficult situations, such as when disclosing a very serious diagnosis, if possible,

the pediatrician should talk first with the parents, explaining the physician's role and that he or she will be talking with the child about the illness and the next steps in treatment. The physician should ask what the patient already knows, including what the parents have told him or her. It is important to know what is most challenging for the patient at this time (e.g., pain or fear) and how the patient, as well as the parents, is coping. If possible, an assessment of the social dynamics inside and outside the family should be ascertained. These factors could have an impact on decision making and coping abilities.

Parents should be told that providing the patient important information about his or her condition helps him or her to understand and cope with the situation and builds trust in both the team and the parents. Parents should be asked what information and support they believe the patient would want at this time. Even though the parents might not be correct in their assessment, it is important to know their perspective.

The pediatrician should explore and address all parental concerns about the upcoming discussion, addressing in particular terms parents are hesitant to use, e.g., "cancer". Parents are rarely resistant to disclosing information to their children if their concerns are understood and reasonably addressed by the pediatrician in an empathic yet firm manner, prospectively and over time. An effort should be made to ascertain what role the parents wish to play in explaining to the patient the diagnosis, prognosis and treatment plans. Reasonable parental preferences as to the manner of informing the patient should be taken into consideration.

Talking with the Patient

The pediatrician should introduce himself or herself and explain his or her role. The patient should know that the pediatrician is there to help him or her understand what is happening (e.g., why he or she is in the hospital) and what plan has been made to address the health problem. The physician should make an effort to establish a personal connection to the patient (e.g., common interests, likes and dislikes). The provider's body language should be receptive and non-threatening (e.g., sitting by the patient's bedside rather than standing; looking *at* rather than *down at* the patient). Patients should be asked to explain what they know about their conditions, what is being done and what concerns or questions they have.

It should not be assumed that the age of the patient is an indicator of cognitive ability or emotional coping capacity. During the interaction, the clinician should listen carefully to the quality of the patient's vocabulary and reasoning. Attention should be devoted to signs of anxiety and fear (e.g., lack of response to simple questions or tearfulness) indicating a possible level of distress that could impair the patient's willingness or ability to engage in a discussion or absorb relevant information. Should the patient appear to have difficulty understanding the information, the provider should acknowledge this and, if indicated, rephrase the information and reduce the speed and complexity of the communication.

Use of straight forward, simple explanations of diagnosis and treatment should be based upon a determination of the patient's vocabulary and reasoning ability. It can be helpful to ask the patient to explain his or her understanding of the illness. Reinforce what is correct and correct what is misunderstood. A shift to more concrete forms of communication (e.g., drawings) may be useful.

If patients are not interactive, it may be helpful to inform them that they can take an active role in the situation by asking questions and stating their preferences for what and how much information they want. Sometimes, however, children are not ready to process such information. If a patient somehow indicates that he or she is unable or unwilling to participate in

the discussion at the time, it is best to end the interaction on a cordial and supportive note. Plans for a follow-up visit should be made.

Case Scenarios: Potential Conflicts for the Healthcare Provider

Ethical Challenge Involving Physician and Child

Case 1: a 7-year-old child was diagnosed with viral myocarditis 3 months ago. Clinical and diagnostic studies reveal evidence of significant cardiomyopathy and potential end-stage cardiac disease.

Question 1: what is the ethical basis and scope of the pediatrician's professional responsibility in communicating some or all of this information to the child?

Answer: best interest of the child standard

Question 2: what rights should be extended to this child?

Answer: according to the concept of pediatric assent, the child has the right to be informed in a developmentally appropriate manner regarding the diagnosis, plan of treatment or non-treatment and prognosis.

Advice for Implementation

The following advice assumes that the patient and family are well known to the provider and that both the child and family have been informed about the diagnosis and treatment plan.

Talking with the Parents

Providers should be generally optimistic but also should be sure that the parents are aware that the chance of survival is significantly less than 100%. If parents are not informed of the potential for a life-threatening turn in the disease, they can justifiably feel misled and lose trust in the providers.

Talking with the Patient

By this time, the child should have been informed about the general diagnosis and the treatments to date. Given that current information suggests a high risk of mortality, it should be explained that the medications (treatments) so far are not doing the job. If other treatment options are available, those should be described (what would be entailed and how it might be beneficial). In general, discussion of the possibility of death with a child of this age should not be initiated by the provider until there is more definitive information. The child however is encouraged to ask any questions including questions about prognosis. If the child asks if he or she will die, the physician's response might be, "We don't know, but we hope that the medicines will work." The next steps in discussion should be determined by the child's concerns. Most children prefer to hear about what more can be done. If a child expresses concerns about death or the process of dying, the provider should explore these concerns openly and provide appropriate support. The physician's willingness to explore these concerns gives the strongest signal to the child that he or she will not face his or her fears alone.

Ethical Challenge Involving Physician and Adolescent

Case 2: patient is a 14-year-old adolescent with relapsing cancer who refuses a phase 1 trial of chemotherapy after standard therapeutic efforts have been unsuccessful. He expresses a desire to use alternative approaches to treatment.

Question 1: what is the limitation of adhering to the child's wishes?

Answer: if this patient prefers a reasonable alternative, then serious consideration should be given to the request. However, professional integrity limits the patient's preferences for treatment or non-treatment when those preferences are not compatible with the best interest of the patient, as determined by the physician.

Question 2: at what age and under what circumstances is a child legally eligible to give consent or refuse treatment?

Answer: in all cases, the pediatrician must conform to federal and state law as well to as organizational policy about the rights of minor children to give consent or refuse treatment. Assuming that this situation is occurring in a hospital or other organizational setting (not in the free-standing office of an oncologist or pediatrician), if the organizational policy is unclear or incomplete, the physician should consult with a risk management committee. In the case of phase 1 trials in which there is no guarantee of therapeutic effect, a child of any age should have the right to refuse participation. The parents' wishes in this matter should also be taken into consideration.

Advice for Implementation

Talking with the Parents

Explore parental interests and concerns about the patient's desires to pursue alternative treatments. If the alternative approaches present no significant health risks, then the task would be to help the parents understand and support the patient's choice. However, if the alternative approaches pose significant risk, then the task would be to engage the parents' help in explaining these risks to the patient and dissuading him or her from seeking this alternative.

Talking with the Patient

Explore the patients' reasoning for pursuing the particular alternative approaches and ensure that the basis of the preference is consistent with available scientific knowledge and evidence. If there is no significant risk posed by the request, then the provider should support the patient's choice. If there is a significant risk, then the physician is obligated to make an effort to convince the patient otherwise and to assist in pursuing a better alternative. If the patient's reasoning appears to be completely driven by fear or other emotional factors, referral to a mental health professional may be helpful.

Ethical Challenges between Physician and Parent(s)

Case 3: a 13-year-old girl, accompanied by her mother, is in the pediatrician's office for a pre-sports physical examination and overall check-up, as well as to receive recommended routine immunizations for her age. The mother relates that she wants her daughter to receive the meningococcal and Tdap vaccines, but not the human papillomavirus (HPV) vaccine.

Question: What course of action should a physician pursue when a parent refuses recommended preventive care for his or her child?

Answer: The best interests of the child standard in pediatrics ethically obligates parents to authorize clinical management that is reliably expected in deliberative clinical judgment to protect the life and health of the child. However, if preventative care is not necessary to immediately protect the life or health of the child (e.g., HPV vaccine), the law permits discretion to parents in such decisions. (See Chapter 33, *Working with Children and Families Who Refuse Treatment*)

Advice for Implementation

Providers should review the evidence base for the risk-benefits of the vaccine.

Talking with Parents

Explore the parent's reasons for declining the recommended vaccination and address any misconceptions (e.g., safety concerns) and present evidence for the benefits of the vaccine. Parents also may be reluctant because of the potential implications as to their child's future sexual activity. Having an open and nonjudgmental conversation about the parent's values and attitudes may allow the provider to acknowledge these views and to make a better case for the long-term benefits of vaccination. If the parent is still not convinced, additional information should be offered as to the efficacy and safety of the vaccine. An offer should be made to schedule a follow-up appointment to discuss the matter further.

Case 4: A 15-year-old girl from a middle-Eastern country is admitted to the hospital with abdominal distension and pain. Mother and grandparents have been with the patient, but the father remains overseas. Imaging studies and surgical exploration confirm the diagnosis of Stage IV non-Hodgkin lymphoma. The family does not want the patient told that she has cancer. Though the patient speaks no English, her facial expressions suggest that she knows that she has a serious condition but does not know the diagnosis.

Question: What are the physician's ethical and professional positions and responsibilities in informing the patient's family of the importance of revealing to the patient her true diagnosis and prognosis?

Answer: The ethical concept of pediatric assent creates an obligation for the pediatrician to inform the patient, in a developmentally appropriate way, about her diagnosis and treatment plan. On the basis of this concept, parents are ethically (but not necessarily legally) obligated to authorize and support this process.

Advice for Implementation

Providers should review what is known about the specific cultural practices and preferences of the family, bearing in mind that there is great diversity among and within cultures.

Talking with the Parents

Even though the parents may appear to have good proficiency in English, if English is not their native language, inclusion of a skilled translator should be included in family meetings so as to ensure understandable communication of complex information. The parents should be asked why they do not want the patient informed. The physician should convey to the parents the significant benefit of providing this information to the patient, the ethical obligation and the importance of forthright honesty. In addition, the potentially deleterious emotional or psychological effect on the patient if the information is not shared should be emphasized.

Family resistance to disclosure sometimes is a result of parents not knowing how to convey the information. If this is the issue, the physician can help to develop a plan of how to inform the patient or, in fact, serve as the spokesperson in delivering the information.

If the parent's approach remains unchanged over a reasonable period of time, consultation should be sought from the hospital ethics committee. Ultimately, the physician should inform the parent that he or she will take responsibility for informing the patient, but an effort also will be made to encourage the parents to offer their support.

Talking with the Patient

Assuming that the parent has made clear her objection to disclosure and the provider has decided to inform the patient, the key points to be made are: helping the patient develop an appropriate awareness of the nature of her condition; telling the patient what she can expect

regarding test results and treatment(s); and addressing her questions and concerns in an honest and forthright manner. It is important to prepare the translator in advance for the primary aims of the discussion with the patient.

Begin by ascertaining the patient's current understanding of her condition, what questions she has and her preferences for receiving information and for participating in decision making. Address any concerns or questions and then explain, in developmentally appropriate terms, the diagnosis and treatment plans. Depending on the medical status of the patient, and should time permit, it would be helpful to have these discussions over the course of several meetings, beginning with the most basic description of the illness and plan and then addressing questions as needed. Once the patient has absorbed this information, the prognosis should be addressed and plans made on how to manage fears and fulfill wishes.

Conclusion

When providing care for pediatric and adolescent patients and addressing family concerns, healthcare providers often encounter a number of ethical challenges. Among them may be dilemmas that arise in the effort to accommodate parental preferences as to the disclosure or non-disclosure of information or the sharing of alternative treatment plans with the patient. Communication with both patients and parents should be empathetic and considerate of the individual's emotional state as well as cultural and educational background. The clinician's first duty, however, is to the patient, keeping his or her best interest as the guiding principle. Ethical judgments and communications should remain consistent with the established ethical guidelines presented by the Committee on Bioethics American Academy of Pediatrics (1995).

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Section 2.

Point of View

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Chapter 7

Point of View: the Primary Care Pediatrician

Jan E. Drutz, MD

Overview

In addition to having a broad knowledge of pediatrics and optimal technical skills, the practicing pediatrician needs to be a strong and effective communicator, possessing among other notable qualities, those of humanism, sensitivity and empathy. The discipline of pediatrics, unlike most other medical specialties, requires that the clinician have the requisite ability and skill to communicate with infants, toddlers, young children, preadolescents, adolescents and, of course, adults—the patients' parents or legal guardians. Appropriate verbal as well as non-verbal communication is essential in establishing and maintaining the physician-patient relationship. Electronic or written documentation in support of important verbal patient-physician communication should be maintained.

The practice of medicine can be challenging and occasionally stressful. Clinicians must remain abreast of the current medical literature and be aware of newer approaches to patient care to optimally practice pediatrics. To that end, effective and efficient communication has become a significant part of the physician's responsibility (Leveton, 2008; AAP Committee on Bioethics, 2013). Explaining the diagnosis, management and potential risks and benefits of treatment and interventions to a patient or family member can be a daunting task.

Establishing Communication Begins Before You Enter the Exam Room

Think about creating the right impression and establishing appropriate rapport with the patient and family. This begins with a minimal amount of effort. Seek out the demographics available in the patient's medical record: the patient's first and last name, the mother's and father's last names (often they are different), the parents' marital status and the names of siblings, if any. Attempt to find out from the nurse or medical assistant if the child has a preferred first name and, if possible, make an effort to determine the family's ethnicity or cultural background.

Before entering the exam room, knock on the door and wait for a verbal response. Frequently, the patient or a sibling, whose head is at the level of the door knob, is standing just on the other side of the door. Should the door be opened by the physician before awaiting a response, the impact of the door hitting the child could leave a lasting but rather unfavorable impression. Additionally, especially for pre-adolescent and adolescent patients, waiting for a verbal response shows respect for the patient's privacy.

Initial Communication in the Exam Room

Upon entering the room, introductions should begin with the physician and then patient and parent providing their names. If others are in the room, the physician should learn their names and relationship to the patient. Whether the physician should make an effort to shake hands with everyone is somewhat dependent on the discernible comfort level of the individuals and on their cultural norms. Appropriately addressing the patient verbally or otherwise is primarily age dependent (see below).

Above all, avoid calling the mother "Mom" or the father "Dad". The same is true for grandparents. Parents are often offended by being addressed in these terms and may counter

by stating – “I am not your mother (or father).” Professionalism and appropriate decorum should be the standard when addressing family members.

Even though the physician may have washed his or her hands before entering the room, after introductions are concluded and some or all of the history is obtained, the physician should repeat the hand washing process, making it readily visible to patient and family. If the physician is using his or her own stethoscope, he or she should clean it with an alcohol swab before placing it on the skin of the patient. First impressions are lasting impressions.

Principles of Communication by Patient Age

(See Chapter 2, *Age Appropriate Communication and Developmental Issues.*)

Infants

Among experts in the field, there is general consensus that preverbal communication takes place beginning at a very young age (Yoon, 2008). When interacting with children in this age group, the exact age does make a difference. The physician should try to make some eye contact, smile frequently, speak softly and maintain a gentle touch. Most infants from birth to 8 or 9 months of age are relatively easy to examine. The older infant within this age group can be easily distracted and temporarily entertained by visually tracking an object held by the examiner or by verbal sounds or soft whistling. Before and just beyond a year of age, children often experience separation anxiety, and fear of strangers is readily evident. Even partial maintenance of rapport between the physician and this age child is difficult but is achievable with the aid and support of a parent or other adult. Such support is essential, especially in the effort to perform a meaningful physical examination.

Toddlers

A technique often used by pediatricians to enhance communication and interaction with patients in this age group is for the examiner to get down to eye level with the child. This may require sitting on the floor or even lying on the floor to gain the patient’s attention and generate some degree of comfort. While this approach is unlikely to result in the most optimal physical examination of the child, the physician is still able to observe the child’s limb and body movements, flexibility, motor skills, breathing pattern, reluctance or refusal to assume certain positions, eye movement and response to sound and voice.

Young Children

Verbal communication with children at the youngest end of this age range may prove difficult, depending on the child’s temperament and language development. For children 4 to 6 years of age, a sound approach is for the pediatrician to direct most of the visual contact and conversation to the child. Sitting on the examination table next to the patient and speaking directly to him or her is often effective in gaining the child’s trust. During some conversations, it is not unusual for a child to spontaneously divulge to the physician information considered more appropriate for personal family conversation. While this occasionally results in some embarrassment for the parent, the physician generally is able to maintain a professional verbal response and reaction, while suppressing the urge to laugh.

Older Children and Preadolescents

This age group is one in which conversation and communication between patient and physician are generally comfortable and open. The parent may accompany the child to the visitation, but the content of the verbal interchange is directed more to the child. Verbal input by the parent is highly important, but the pediatrician should make every effort to obtain the child’s

opinion and viewpoint as well. During routine health visits, the conversation generally focuses on the child's activities, school work, extracurricular achievements and peer group. It is appropriate, therefore, that the child be given the opportunity to provide this information. Ultimately, this empowers the child to express him or herself, instills a sense of being respected and helps to solidify the relationship between the pediatrician and the patient.

Adolescents

At times, physician communication with adolescents can be difficult or at least somewhat challenging. To initiate meaningful communication with patients in this age group, physicians should present a calm, respectful and non-threatening professional demeanor. Upon entering the patient's room (especially if it is the initial contact between the physician and the patient), it is best that the pediatrician introduce him or herself first to the patient and then to others present. Alternatively, the physician may choose to empower the patient by asking him or her to introduce the physician to others in the room.

It is essential that the physician obtain a developmentally appropriate psychosocial history from the adolescent patient. (See Chapter 3, *Talking with the Adolescent Patient*) A standard strategy for this purpose is the HEEADSSS questionnaire, variably standing for: Home; Education or Employment; Eating; Activities; Drugs or Depression; Suicidality; Sexuality; and Safety (Goldenring and Rosen, 2004).

During this time of remarkable growth and development, threats to adolescent health safety can arise, particularly related to physical and social exploration. Nearly all teenagers now have Internet access and most of them communicate with one another using mobile phones, especially for text messaging. The newest version of the HEEADSSS interviewing method can be used to evaluate how teenagers are coping with the pressures of daily living, especially in the context of electronic and social media (Klein et al., 2014).

The interview with the adolescent should be conducted in private unless the patient requests to have others present. It should be made clear that all information obtained and discussed will be held in strict confidence, to the extent allowed by law, by the physician unless the information indicates that the patient is in danger of harming him or herself or someone else. (See Chapter 3, *Talking with the Adolescent Patient*, section, *Confidentiality*.)

On occasion, the adolescent may present an attitude of indifference or reluctance to respond to the physician's questions or concerns. To counter this, the pediatrician may have to take an alternative approach, perhaps rephrasing the question and speaking in more non-specific or general terms. For example, instead of asking the patient, "Do you consume alcoholic beverages or take illicit drugs?" the pediatrician may make a statement that according to recent health reports, illicit drug ingestion and alcoholic consumption among teenagers is on the rise, leading to significant personal injury and potential harm to others. The physician may then ask, "Do you know of any of your friends who seem to be having a problem resisting the temptation to use any of these substances?"

For All Age Groups

When speaking to pediatric or adolescent patients or to adults, it is imperative to use language and terminology that is clearly understandable to them. Avoid the use of medical jargon and explanations that are neither clear nor familiar to the listener. The physician should know that he or she is not communicating successfully when the recipient has a blank stare, remains exceptionally quiet or has no questions. Even if some of the information provided was partially understood, it is helpful for the physician to ask the patient or family member to state what he or she heard with regard to the health problem, the possible diagnosis and the treatment plan.

Situations Requiring a Private Conversation between the Physician and the Child or Adolescent

Aside from an encounter with an adolescent, where a one-on-one conversation is almost always recommended, certain circumstances and events warrant a private conversation between the physician and patient, if age appropriate. Such circumstances may involve a suspicion of child or family member abuse or neglect, either physical or emotional, or an unusual comment made by the patient, necessitating more in-depth questioning. On rare occasions, a child or preadolescent may request to speak to the physician alone, asking for clarification of his or her illness, condition or treatment plan.

Communication as an Art Form

The art of communication requires not only verbal skills but also observational skills (e.g., interpreting body language). Among the cues to which attention should be given are: whether the parent or patient is maintaining or establishing eye contact; the individual's posture and facial expression; and the tone and pace of the individual's vocal communication. This includes non-verbal communication by facial expression and body language between patients and their parents.

Though often tempted to interrupt patients or parents when seeking information, the prudent physician may well heed the words of Christopher Morley: "There is only one rule for being a good talker—learn to listen." (Brainy quotes, 2001)

During a routine clinical visit, general conversational communication with patients and parents with regard to healthcare issues is relatively easy and non-stressful for the majority of pediatricians. For many practitioners, however, conversations involving the communication of difficult or sensitive information are stressful regardless of the number of times he or she has performed that task.

Comprehensive healthcare satisfaction surveys have reported that parental criticism focused on the lack of satisfactory communication with practitioners (Beckett et al., 2009; Street, 1991). This is especially true with regard to understanding the physician's findings and the treatment or management plan, as well as the patient's or family's recall of the information and instructions provided. A potential result of poor communication is failure of patient or parent compliance and adherence to treatment. One way to gauge understanding is to probe the patient (age appropriate) and parent for their understanding of the diagnosis and treatment plan. (See Chapter 5, *Patient Centered Communication and Decision Sharing*, section, *Probe for Understanding*.)

Cultural, Religious, and Ethnic Sensitivity

The cultural, religious and ethnic diversity of the United States population is changing rapidly. United States Census Bureau data (2000) predict that by the year 2020, 44.5% of American children from birth to 19 years of age will be in a racial or ethnic minority group. Most pediatricians practicing today are well aware of the population shift and have been encountering some of the discomforts of being unfamiliar with the broad diversity of languages, ethnic practices, religious beliefs and cultural differences in their patient populations (See Chapter 28, *Communicating across Cultural Differences*). The American Academy of Pediatrics Committee on Pediatric Workforce (2013) emphasizes the importance of "providing culturally effective pediatric care," and offers continuing educational activities to assist pediatricians in acquiring the necessary skills.

Language barriers can lead to a variety of problems. For the physician, this can result in an inaccurate history. For the patient, it can result in misunderstanding treatment directions, as well as deferring or missing scheduled medical office visits.

Another barrier to the provision of optimal pediatric medical care is the issue of poor health literacy, somewhat akin to having limited English language proficiency.

Access to Healthcare

Finally, it must be acknowledged that secure and continued access to the primary care provider is essential for a meaningful bond between the provider and the pediatric patient and family. The concept of a pediatric medical home implies continuous medical care, bringing together primary care, specialty services, emergency services and hospitals (Palfrey, 2009). Changing federal, state and local regulations and programs, the cost of healthcare insurance and fluctuating levels of financial assistance to those in need all threaten this access to care.

It is hard to predict where the future of healthcare is headed. Gawande (2012), in an online video entitled "How do we heal medicine?" described our medical systems as broken. He envisioned a future system where physician generalists and specialists work collaboratively to provide the best medical care possible for patients at the most reasonable cost possible. That certainly is our hope and our goal.

Conclusion

The pediatric clinician must have a strong knowledge base referable to the field of general pediatrics and an exceptional skill set in order to succeed as a practitioner. Strong effective communication skills are essential to help children of various ages, cultures, ethnicities and religions cope with their medical problems. Knowing when to suggest that a child or adolescent needs to be seen by the primary care provider alone rather than in the presence of the parent is one such important skill. The ultimate goal in the pediatrician-patient relationship is to create a true medical home for the patient.

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Chapter 8

Point of View: the Pediatric Oncologist

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Communicating a Cancer Diagnosis to Patients and Families

This chapter deals with delivering bad news, specifically a new diagnosis of cancer, to patients and families. Communicating bad news can be difficult for the provider or trainee. It is an uncomfortable task with many unknowns. How will the family react? How well will the patient and family understand the information? Will they be able to make the necessary decisions in the face of grief and distress? Careful listening and moments of silence are equally important to what one says during such discussions in which patients and parents are likely to be extremely uncomfortable and distressed. It is critically important to prepare for the meeting in which bad news will be delivered.

The “SPIKES” method, developed by Baile et al. (2000) provides a useful framework to prepare for the discussion. This tool includes six steps to prepare for delivering bad news:

Setting up the meeting: mental preparation (cognitive and emotional), location and arrangement of room, deciding who will participate

Perception: assessing the patient’s (if present) and family’s perceptions and understanding of the patient’s disease and condition

Invitation: assessing how the parents (or the patient and parents) would like the information provided, such as the level of detail and how ready are they to hear the diagnosis

Knowledge: providing knowledge and information

Emotions: assessing the family’s emotions and responses and validating these feelings

Summary: determining strategy, providing a plan for treatment and informing the family regarding the next step or follow-up

Keeping these steps in mind will provide a framework for each individual to develop his or her own style and comfort level with delivering bad news and assuring that the information is conveyed in a compassionate and understandable manner.

“Your Child has Cancer”

Hearing the news that their child has a life threatening illness, specifically cancer, can be devastating to parents. The “Day One Talk,” as described by Mack and Grier (2004), can impact the family’s adjustment to the new diagnosis of cancer. Many parents report not hearing or remembering much else after the word “cancer” was mentioned. A study of parents receiving a diagnosis of a life-threatening illness found that approximately one third of the parents understood or remembered less than 50% of the information communicated, and when the diagnosis elicited a “shock like reaction,” retention was even worse (Jedlicka-Kohler et al., 1996). Therefore it is important for these discussions to take place over several visits with the family when possible. Key information should be repeated at each visit.

Prior to meeting the patient and family, make sure to set aside adequate time for discussion and plan to minimize disruptions. Assure that the setting is appropriate, there are adequate chairs for everyone and all appropriate individuals are present. Consider including members of the team,

such as social workers, child life specialists, nurses and psychologists, to assist in delivering the news and help support the family. Allowing the parents to invite family or friends who can provide support is also important. Because patients have frequently met other healthcare providers prior to receiving the final diagnosis of cancer, it can be helpful to discuss with these providers what they have told the family and what services they believe the family may need to assist with processing the new diagnosis.

Upon first meeting the family it is important to clearly identify yourself and the role you will play in the child's care. After introductions, make an assessment of what the family currently understands, often by simply asking, "What have you been told so far?" Some families arrive on the oncology service having heard the presumed diagnosis. Others come to an oncologist or the Cancer Center without knowing why the referral was made and are wondering, "Does my child have cancer?" and "Is he (or she) going to die?" Learning what the family already knows will help frame the meeting and provide a place to start the conversation. Other important information to gather is the patient's and parents' personal and family experiences with cancer, both in adults and children. For many individuals these experiences will play a role in how they process the new diagnosis and will influence their expectations for cure and treatment side effects. For example, if they have just lost a relative to lung cancer, family members may focus on what a respiratory death looks like or they may focus on the stage of the cancer.

The diagnostic talk is often the beginning of the therapeutic relationship between the provider and the patient and family. It is important to reassure the family of your role in supporting them throughout the trajectory of the disease. This journey will lead to a cure for many patients. However, unfortunately, for some individuals the disease will prove to be incurable. Assuring the family that they will not be alone on this journey can be comforting and can provide a solid foundation for open dialogue related to goals of care throughout the treatment course. Open and honest communication, although it can be distressing for both the provider and family, is important for ensuring understanding of diagnosis and facilitating decision making at diagnosis and throughout the disease trajectory.

The Language of Cancer

A diagnosis of cancer will introduce the family to a brand new vocabulary that may be overwhelming. Terms such as *CBC*, *chemotherapy* and *central lines* will become very familiar over time but may start out as foreign terms that can instill fear. Whether the patient has leukemia, a brain tumor or a sarcoma, it is important for the family to understand that this is a diagnosis of cancer and words such as "malignancy", "tumor" or "mass" may not be clear to the family. It is best to avoid medical jargon when possible and use lay terminology if available. When available, provide the family with literature or links to websites that contain accurate information that is easy to read. Parent handbooks are an important resource for the family after the discussion.

Throughout the discussion, it is important to pause frequently and check in with the patient and parents to assess their level of understanding. Allowing time for questions throughout the discussion will guide the conversation and provide a good way to assess understanding based on the questions being asked. For many, the most pressing questions will be: "What caused this?" "What are the treatment options?" and "Will my child survive?"

Even if parents do not ask about the etiology of the child's cancer, it is crucial to explain that there was nothing they could have done to prevent the cancer and there was nothing that they did to cause the cancer. Often there is a level of parental guilt that is unfounded and complicates their grief over the new diagnosis, which can interfere with processing the information being provided.

Treating Cancer

Once the diagnosis of cancer has been made, the family will be anxious to learn about the treatment plan and its goals. Parents want to know if treatment will include frequent or prolonged hospitalizations and uncomfortable side effects. They want to know what effects these treatments will have on the child's school life and the family's home life. Treatment may involve standard chemotherapy, a clinical research study, surgical intervention, radiation or a combination of these modalities. It is important to review the details of the treatment options. Remember to inquire about any personal or family experiences with these treatment types, as this may set up potentially incorrect expectations about side effects that need to be addressed. Likely the family will have encountered someone who underwent treatment for cancer and may have misconceptions regarding the treatment or side effects. In addition to reviewing the side effects of the treatment, it is important to reassure the family about how the team will provide comfort and control of any symptoms incurred during therapy.

Treatment of cancer can cause significant changes in appearance, for example, hair loss from chemotherapy or disfigurement from surgery. Discussing these side effects can be particularly upsetting for families and patients. These side effects and the emotions they evoke sometimes are too easily dismissed by providers as the side effects are not life threatening and, in the case of hair loss, is reversible. However, at the time of diagnosis the thought of such changes may evoke significant distress for patients and parents.

Many physicians have difficulty discussing prognosis with patients, especially when the news is not good. Fear of upsetting patients and parents, taking away hope and provider discomfort are some of the common reasons providers avoid talking about *the numbers*. A study by Mack et al. (2006) revealed that the majority (87%) of parents surveyed wanted as much prognostic information as possible even if the news was upsetting. It is important to engage the family, so as to understand their desire for this information. Carefully explain what the prognostic data means and the limitations of the data.

Throughout the discussion, it is important to check in with the patient and family members frequently to assess their understanding or the need for a break. Periodically asking family members to explain their level of understanding can ensure that they understand the discussion. A multidisciplinary approach to diagnostic talks is extremely helpful. Social workers, child life specialists, nurses and psychologists can provide different ways of assessing psychosocial needs and providing emotional support.

In addition to providing information, it is important to allow space and silence in the conversation. Silence can be very uncomfortable for providers, especially if the patient or the family is very emotional, but it provides the family time to process information and to gather their thoughts and questions.

The Role of the Child in a New Diagnostic Talk

How do you explain a diagnosis of cancer to a child? This is a question frequently asked by parents of children of all ages. Age and maturity play important roles in the amount, detail and type of information that is shared with a child. Cultural norms also can affect what information parents are willing to share with the child. When available, child life specialists play a vital role in teaching patients and siblings about the disease at the time of diagnosis and as the prognosis changes.

An open discussion with the family about how the information will be given, how much information is to be provided and who will provide the information is important. Typically, information about the diagnosis is given to the parents first. This allows time for the parents to

process the information and sort out their emotions prior to discussions with the patient. Some parents may want to speak to their child on their own. In this situation, child life specialists can help provide language for parents to use to relay the information at an age appropriate level (See Chapter 15, *Point of View: the Child Life Specialist*). If parents do not feel comfortable disclosing the diagnosis, a member of the medical team can help deliver the news. This may be the physician, nurse practitioner or child life specialist. Age appropriate, plain and simple language should be used (e.g., bad cells).

For older children and adolescents, it may be appropriate for the child to be part of the initial family diagnostic talk. This can prevent the patient from feeling left out or that information was being withheld. Just as with parents, patients should be asked how much information they wish to receive and the level of detail. A child life specialist, if available, can be a vital member of these discussions, to provide clarification to the patient. Also, it is helpful for the child life specialist to have heard the information delivered to the family so as to provide better follow up.

Occasionally, parents may wish that a child not know he or she has a diagnosis of cancer, not hear the name of the cancer type or not know the seriousness of the prognosis. In this situation it is important to understand the parents' reasoning or fears behind this decision. It may be because of family experience with someone who had cancer. Cultural factors also may have a significant impact on what information parents want the child to receive. It is important to be culturally sensitive, but there should be discussion of the potential effects of non-disclosure. Especially for older children, when such information is withheld it can contribute to increased fear and anxiety in the patient. In addition, numerous individuals across many service lines will care for these patients, and some of these individuals will be unaware that the patient does not know the diagnosis. This can lead to a provider inadvertently revealing the diagnosis and increasing patient anxiety and mistrust of the parents and healthcare providers. Families should be aware that the child will be receiving treatment in a *Cancer Center*, which will most likely have signs designating this in the clinic and other hospital settings. In addition the patient will interact with other children in the hospital and clinic, children who may talk about their cancer diagnoses. Furthermore, cancer and its treatment can cause many physical symptoms such as weight loss or hair loss, which may be frightening for patients without an understanding of the diagnosis. In these situations it is important to negotiate the delivery of information with the parents, taking into account their beliefs and the necessity to allow patients to be informed about their condition. When discussing with parents how much information to provide to a patient, it is important to bear in mind that depending on the age and maturity of the patient, he or she may need to provide assent for treatment, depending on institutional guidelines (See Chapter 6, *Ethical Considerations in Communicating with or about a Child*). In this scenario the patient may need more diagnostic information in order to appropriately give assent. In many cases, the patient will know more than the parents assume.

Informing Siblings and Friends

It is important to consider the well being and understanding of not only the patient, but also the other members of the family. A new diagnosis of cancer often leaves siblings feeling scared, confused, left out or guilty. The child life specialist can play a vital role in helping the siblings as well as the patient. If the patient is old enough, he or she can play an active role in helping to teach brothers and sisters about the diagnosis and the treatment. Teaching tools learned from the child life specialist can be helpful in explaining a diagnosis of cancer to classmates at school. Often a child life specialist can accompany a patient to school or to the classroom to help

classmates understand and cope with the diagnosis, which can facilitate the patient's reintegration into school.

Addressing the Patient's Fears and Concerns

The patient with a new diagnosis of cancer will often have a great deal of anxiety. Just being in the hospital can cause fear and discomfort. Patient and family routines are disturbed, and observing family members who are upset can be distressing to the patient. These changes can cause anger, sadness and, in some individuals, even depression. For some, the diagnosis will result in significant changes in their current activities: athletes may be limited in their activities during treatment or possibly forever, school performance may be altered, and formerly favorite activities may no longer be possible. This loss of activity can lead to significant mourning in patients and should be acknowledged and addressed. The psychologist, social worker and child life specialist can all play a role in coping with these losses.

Conclusion

When delivering a diagnosis of cancer or any other distressing medical information, it is important to be prepared for the conversation. This preparation should include thinking about how the diagnosis should be disclosed, determining which team members and which family members should be included and the setting for the meeting. This discussion may need to occur over multiple conversations. Remember to engage other members of the team to provide support, not only to the patient, but also to siblings and extended family. Keeping these principles in mind can build a foundation of trust between the healthcare team and the family for the journey ahead.

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Chapter 9

Point of View: the Intensivist

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“The single biggest problem in communication is the illusion that it has taken place.” –
George Bernard Shaw

Introduction

The pediatric intensive care unit (PICU) presents a unique set of communication challenges to the physicians and staff taking care of patients. These units are high-stakes environments where a sense of urgency and pressure surrounds the care of critically ill patients. Patients and parents are often in unanticipated, life-or-death situations where circumstances change quickly. Intensive care units are loud and bright at all hours of the day and night. They are intimidating places: people constantly in motion; monitor screens full of unfamiliar symbols; and alarms going off repeatedly. While not disconcerting for the medical staff, these things can be terrifying for a patient or parent. The intensive care unit is invasive for the patient and parent with regard to such things as monitors, tubes, lines and procedures. There is rarely any privacy, and families often find themselves at their most vulnerable in front of complete strangers. The young child is frightened by the strangeness of the environment, the constant noise and lights, the intrusion of lines and monitoring devices and the pain and discomfort caused by his or her disease, as well as the pain and discomfort of procedures. Additionally, the older child is frightened by recognition of the serious and often life-threatening nature of his or her illness. Parents feel as if they have lost control of their most prized possession, their child.

Mcgraw et al. (2012) point out how important (and difficult) it is for parents of a child in the PICU to feel that they are providing love and care for their child, creating security and privacy for the family and exercising responsibility for what happens to the child. Physicians and other healthcare staff in the PICU should make every effort to assist parents in these roles, and one of the ways to assist is by communicating in a timely, understandable, sensitive and compassionate manner.

Devictor et al. (2008) note that most deaths in the pediatric intensive care unit occur after a decision to withhold or withdraw life-sustaining treatments. In addition to dealing with such decisions, parents are faced with complex questions regarding high-risk or experimental therapies with uncertain outcomes. Parents also often have to make decisions about family members at home. Should they leave the hospital to take care of things at home or stay at the bedside with their child? How should they explain what is happening to siblings or other family members?

General Guidelines for Conversations with Patients and Families in the PICU

Families under stress can be expected to have a difficult time processing and retaining information, particularly if it is complex. The intensivist, therefore, has the responsibility to communicate with both the patient (when developmentally appropriate) and the family in such a way that everyone involved can understand and retain as much of the information as possible. Some of the most important guidelines for a successful conversation are discussed below.

Honesty

It is imperative that the communication with patients and parents be honest and clear. Physicians are expected to deliver accurate information, no matter how bad the news may be. It is not uncommon to hear physicians make comments such as, “They aren’t ready to hear the prognosis.” or “If I tell them the truth, they will give up.” This is especially common when a patient is approaching death. Physicians often are afraid to use the words “death” and “dying” in conversations with families. Avoiding these words violates the trust that families and societies place in physicians to be honest and forthright with their knowledge. Being honest in conversations helps the patient and parents understand what is happening and helps them make appropriate plans.

Brevity

In these high-stakes situations, it is important that conversations be brief and targeted (See Chapter 4, *Communicating in Difficult and High Stakes Situations*). We try to keep initial conversations to less than 15 minutes if possible, as both patients and families tend to forget much of what is said after the first 5 to 10 minutes or after they are told of a new diagnosis, complication or deterioration in the patient’s condition. Lengthy conversations create opportunities for confusion, with important points being lost over time. In long conversations, the physician may begin to lose consistency of both content and language, potentially creating even more confusion for all parties involved.

Brevity includes concise content. The more concise the conversation, the more likely families will remember the important messages conveyed. Concise means giving essential information, free from elaboration and superfluous detail. The more words used, the greater the chance of confusion. It is easy for already overwhelmed patients or parents to get lost in lengthy conversations with unfamiliar vocabulary at a time when their focus is on their child and not on the person talking with them.

Repetition

Repetition is useful in physician-patient and physician-family conversations in the PICU. Families under stress have difficulty retaining information, particularly at the beginning of their PICU stay. Fear, anxiety and emotional distress can cause patients or parents to place more significance on individual words and expressions than on the contextual conversation (Haney, 1991). Patients and parents will not remember everything that you said, but they will remember how you said it, especially the amount of empathy with which the message was delivered (Luntz, 2007). Repetition helps clarify salient facts. Parents should be told the same diagnosis, with the same explanation and the same language as often as needed until they understand.

Consistency within the Team

A key factor in communication in an intensive care setting is consistency among members of the team designated to deliver important news. In a so-called *open unit*, many services or individual physicians can admit patients and assume primary responsibility for their care while the critical care service functions in a consultative capacity. In this situation, it is ideal for the primary service or physician to assume responsibility for updating the family. However, in a unit in which all patients are admitted to the critical care service (a *closed unit*), this service is responsible for updating the family. Parents are often quick to pick up on inconsistencies in the messages being conveyed, as well as in the expressive language used to convey the message. For example, if one service says that a patient’s condition is fatal, but another service says that the condition is *usually* fatal, parents will cling to the small glimmer of hope that they perceive one service is

providing. This can then be used by the parents to split the care team and create a negative relationship between providers and families that potentially can result in harm to the patient. Therefore, important changes in the patient's condition or changes in therapy are best communicated by the primary team or service so as to maintain consistency. Relying on the on-call team or other services to communicate non-emergent news can result in unnecessary variability.

Communicating with the Patient and Family during PICU Rounds

For the parents of a child in the PICU, the most informative events of the days are the visible changes in the child's condition and the family's interactions with the healthcare team. Organized team rounds mark a critically important time for the family because they have the formality of a hierarchical discussion, which ideally should take place in their presence. The family should play an active role in these rounds and be treated with the same respect as medical team members. Everyone must listen attentively and sensitively to what the parents are saying as they can recognize and point out subtle changes in the patient's behavior, provide a useful overview of preceding events and clarify facts surrounding a child's current state. *Listening* includes attention to non-verbal clues such as silence, eye contact and gaze. At the end of the presentation or discussion of the child's progress and situation, the family should be offered a separate time, one-on-one, with the responsible physician. The physician is well advised to give the family a tentative time of day when he or she will return to speak to family members directly. Families suffer a great deal of anxiety if they are not at the bedside when the physician returns. In the Texas Children's Hospital's PICU, scheduled rounds are held twice a day and at midnight. Midnight rounds are less formal but still afford an opportunity for the physician to communicate with the family.

The physician should consider the wellbeing of the family as a unit, as well as considering the distress felt by the patient and each family member. The physician should place the family's comfort ahead of his or her own. Some physicians are so worried about being wrong if a patient does less well than anticipated that they warn the parents of every possible complication, however remote, and of every possible undesirable outcome. This gives the physician a false sense of protection so that if the patient's condition deteriorates unexpectedly, he or she can say, "I told them in the beginning that this could happen." This, in effect, makes the family the inappropriate object of the physician's own insecurities. The physician should communicate to the family the most likely risk or complications within a reasonable degree of medical probability (Baxter, 1995). It is appropriate for the physician to say, "I think, based on my experience and the current medical information that... is the most likely outcome. If the situation changes, I will inform you immediately."

The clinician should present the plan of action for each of the patient's problems with appropriate concern and compassion and with language that is appropriate for the family's level of education. The use of adjectives to describe probability is discouraged because the implications of any particular word (e.g., substantial or mild) varies from person to person. For example, if a physician says, "There is a significant chance of recovery." one parent might interpret that as a 20% probability and another might interpret it as a 90% probability (Stein and Rodgers, 2009).

It is also important that, prior to formal rounds with the family, team members communicate with one another about the overall plan for the day. Disagreement on rounds can be distressing to the family as many are unfamiliar with the medical hierarchy and do not understand the roles of the various members of the team. This is particularly true with regard to complex medical procedures, diagnoses that remain uncertain or psychosocial factors that the family may not want

discussed in an open area. In an academic or teaching institution (such as Texas Children's Hospital), it is helpful to explain the structure of the team and the teaching component of rounds to the family as it could be worrisome for a patient or parent to hear a resident answer a question incorrectly without understanding that the resident is a learner as well as a care provider who is being taught and supervised (see below, Vicarious Liability).

Vicarious Liability

In a teaching hospital, medical students, residents and fellows are the responsibility of the supervising physician. What one of these learners says to a patient or parent could be interpreted as the opinion of the team or the attending physician. The supervising physician is potentially liable for errors of communication, as well as performance of duty errors, committed by the learner even if the supervising physician is not present at the time of the error (Baxter, 1995). This emphasizes the importance of frequent communication among members of the team prior to discussing plans with the family.

The PICU Family Meeting

Because of the intrusive nature of the PICU, when major discussions are held at the bedside they are frequently interrupted by activities of routine patient care, monitor alarms, questions from staff and a host of other disruptions. A scheduled family meeting away from the bedside facilitates effective communication and sends a message to the family that their child matters and you are willing to set time aside just for them to assure that they are informed. (See Table 1.)

One key point for a successful family meeting is ensuring no unnecessary interruptions. This means, if possible, that the physicians involved should hand off their phones or pagers to colleagues willing to cover for that period of time. Inviting all involved healthcare providers (e.g., nurses, social worker, chaplain) will provide the opportunity for sharing information and clarifying facts and the plan. An example of a benefit of this multidisciplinary meeting is that if a parent subsequently asks the bedside nurse a question that he or she did not feel comfortable asking the physician, the parent is likely to get a correct answer.

It is important, before multiple services sit down to discuss the patient with the family, that a meeting of the services be held to ensure all involved services are updated on the patient's condition and are in agreement with the treatment plan. Discovering different opinions regarding a patient's diagnosis or prognosis in front of the family can not only cause mistrust among the physicians, but also between the family and the physicians.

Table 1. Guidelines for a Formal Family Conference

Schedule the room in advance so that it is available, clean and ready at the appropriate time.
Ensure that there are enough chairs, tissues and any other necessary items in the room prior to the meeting time.
When the venue is secured, notify all participants by phone or email and confirm their participation or absence in advance of the meeting.
Invite all necessary care providers (surrogate decision makers, bedside nurses and occasionally, learners) but be aware that families may be intimidated by a large number of individuals in white coats or individuals with whom they are not familiar. Sometimes fewer is better.

Table continued on next page.

Prior to meeting with the family, the medical teams involved should discuss the case, determine who will lead the meeting and, if appropriate, discuss the goals and ideal outcome of the meeting. This is to ensure that all team members are united in the message so as not to confuse the family.

The family conference should not be viewed as the update for the day. The physician and other team members should still update the family per routine, with the family meeting being geared toward a specific problem, issue or outcome.

Conclusion

Communicating with families and patients in the PICU presents a unique set of challenges. The PICU is an intimidating environment that is frightening to both patients and parents. Young children are frightened by the strangeness of the environment and older children are frightened by their symptoms as well as by the monitoring and therapeutic interventions. Parents feel as if they have lost control of their most treasured possession, their child. It is imperative that physicians and staff keep these facts in mind as they provide care to the patient and do everything they can to alleviate the distress of patient and family. Communication that is honest, brief, concise, repetitive and consistent can provide the patient and family with a sense of security. Families may not be able to provide physical care to their child, but by keeping them informed in an empathetic and supportive manner, they will be able to provide the emotional support the child needs.

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Chapter 10

Point of View: the Pediatric Surgeon

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Surgery tends to be a unique and potentially life-changing event, often fraught with stress and anxiety. The pediatric surgeon is responsible not only for informing the family about the medical details of the diagnosis and procedure to be performed, but also for helping the patient and family cope with this unique experience. Open communication and trust form the backbone of the physician-patient relationship. Pediatric surgery is a field where this relationship can have a significant impact, not only for patient and family satisfaction, but also for medical outcomes.

Preoperative Communication

The preoperative consultation session is usually the first encounter between the patient and family and the pediatric surgeon. The significance of this encounter should not be underestimated, and the conduct of this initial evaluation and discussion needs to be adjusted to the circumstances, depending on a number of factors, such as the age of the child, the social situation of the family, the scope of the procedure, the urgency of the operation and the clinical status of the child. It is important during this encounter that the surgeon build trust with both the patient and the parents. Even though the consent is likely to be obtained from the parents, the patient should be acknowledged and, depending on age and developmental level, should be given an active role in the decision making process. (See Chapter 6, *Ethical Considerations in Communicating with or about a Child*, section, *Pediatric Assent*.)

General Principles of the Preoperative Consultation

The preoperative consultation should be conducted in an honest and candid manner and should include several key elements:

- Description of the normal anatomy and physiology, an explanation of the abnormal anatomy and a discussion of the disease in lay terms, easily understood by the patient and family.
- Discussion of the proposed therapy and details of the procedure. We have found that the use of diagrams and dividing the procedure into different numbered steps can help patients and their families better understand the details of complex procedures. The families can then take the diagram home and study it prior to surgery.
- Discussion of alternative treatment strategies including advantages and disadvantages. The surgeon should try to provide an unbiased assessment of the surgical and non-surgical treatments available and the rationale for the recommendation.
- Exploration of expectations for both the patient and family during and after the procedure. Even though this is sometimes ignored, it is one of the most crucial elements in preparing the patient and the family for surgery. Expectations should include aspects such as recovery time, amount of pain and how will it be controlled, lines and tubes, expected time to be spent in the intensive care unit versus the ward and need for further procedures.
- Discussion of the risks and benefits of the procedure.

The patient and family should be allowed to ask questions and actively participate in the decision process. However, the nuances of some of the most complex diseases (e.g., complex congenital heart disease) and therapeutic strategies (e.g., choice of chemotherapeutic agents) may be difficult for the family to comprehend. In these situations in particular, the surgeon may explain these nuances as much as possible but will undoubtedly play a more important role in the decision process than for simpler or elective cases. For example, it is not appropriate to expect a family to decide whether an extensive liver resection or a liver transplant is the best therapeutic strategy for a child with a large liver tumor. While it is ultimately the family's decision, it likely will depend more on the experience of the surgeon and the medical team, the intraoperative findings and the approach that the team believes would lead to a better long-term outcome for the patient.

When feasible, a structured program to prepare patients and families for surgery is desirable. Formalized programs for preoperative education have been successfully implemented to decrease the degree of anxiety and negative emotions experienced by children undergoing elective surgery (Justus et al., 2006; Murphy-Taylor, 1999; O'Shea et al., 2010). At Texas Children's Hospital, during the preoperative visit, the patient and family meet with a child life specialist who uses a combination of dolls, toys and other age-specific material to introduce the child and the family to the procedure and the basic expectations. (See Chapter 15, *Point of View: the Child Life Specialist*) Families also are provided with written material about the surgery, which they can review at leisure at home prior to the operation. A tour of the hospital facilities where the child will be admitted after surgery also helps ameliorate fears and anxiety related to the procedure.

Age-appropriate Communication

Rackley and Bostwick (2013) provide some guidelines for communication during the preoperative consultation depending on the age and life stage of the patient. (See also Chapter 2, *Age Appropriate Communication and Developmental Issues.*)

Infants and Toddlers

Even though most of the focus of the encounter will be centered on the parents, acknowledging and interacting with the child sends a reassuring message to the parents and can help make the patient feel at ease.

Preschool Children

Children at this stage tend to associate events with their own actions and can ascribe illnesses to punishment for their behavior. The surgeon should introduce him or herself first to the child and then to the parents, acknowledging the incipient autonomy of the child. Due to the prevalence of imaginative thinking at this stage, the surgeon should be very concrete when describing diagnoses and procedures. For example, telling a child with appendicitis that a small part of the intestine in her tummy is sick may be better than telling her that her appendix is ruptured and will need to come out.

Grade School Age Children

Children at this age are fascinated by the human body and enjoy engaging in some of the explanations regarding diagnoses and procedures. It is important for these children to have a good understanding of what to expect during and after the procedure. Honesty and respect are key components of this interaction. If the child finds out later that the experience differed significantly from what was explained to him or her, the child's trust in the physician and in the parents may be impaired.

Adolescents

This stage is especially challenging since teenagers tend to value their autonomy while at the same time they depend on their parents for major medical decisions. The best strategy to follow during the consultation is to address the patient primarily while including the parents as part of the discussion. Socialization, peer acceptance and body image are important concerns for this patient population. (See Chapter 3, *Talking with the Adolescent Patient*.)

Intraoperative Communication

The day of surgery is one of the most stressful days for the family of a child undergoing a procedure. Open communication can help dissipate the anxiety and at the same time slowly prepare the family for an optimal or suboptimal outcome. We have found that for long procedures that are progressing in a routine fashion, periodic updates by a member of the surgical team (usually by a nurse practitioner) every 1 or 1½ hours can be helpful. Similarly, keeping the family apprised of any major change in plans, significant complications (either life-threatening or not), or otherwise unexpected events, is key in maintaining an adequate open channel of communication. It is ideal that the surgeon personally provide this information to the family, unless the patient requires the surgeon's constant presence in the operating room.

Postoperative Communication

The most anxiety provoking moment for the parents is when the surgeon comes out of the operating room to inform them how the surgery went. In routine circumstances, when the procedure has gone well, it is important for the surgeon to present a calm and patient manner. The parents are looking for that first expression on the surgeon's face when he or she comes into view in the waiting room. A smile can go a long way in terms of conveying a positive message about the surgical outcome. Insist on having the parents sit in a private room away from the noise and activity of the surgical waiting room. This ensures that all questions are answered and no privacy violations occur.

Intraoperative findings and surgical outcome

This interaction can be as straightforward as a 3-minute conversation with brief surgical details showing that the case went as planned or a more in-depth discussion of surgical findings and potential impact on patient outcome. It is beneficial to have the postoperative discussion follow a format similar to what was discussed in the preoperative visit. The surgeon can refer back to the series of steps and diagrams presented at the preoperative visit and discuss each step according to what was detailed before and what actually happened in the operating room. The surgeon can then conclude with a discussion about prognosis and how what happened in the operating room can affect outcome.

Families with children undergoing very complex surgical procedures, such as operations for congenital heart conditions and cancer, often simplify the whole surgical experience down to, "Is the disease gone?" or "What survival can we expect now that surgery is completed?" It is best for the surgeon to have as many of these discussions as possible prior to surgery so that the expectations are clear. The post-operative discussion can then be based on the patient falling into one of the categories of outcome that had been discussed. For example:

Scenario #1: "The tumor was completely removed and this will improve Jennifer's chances for 5 year survival to 80-90%."

Scenario #2: "The tumor was removed, but microscopic examination of the tumor showed malignant cells up to the very edges of the specimen. With additional therapy, this will give a

survival rate of 50-60%.”

Scenario #3: “The tumor was too extensive to be adequately excised without causing harm to Jennifer; therefore survival will be the same as if surgery had not been done.”

It is much better to have discussions about prognosis prior to surgery, explaining the best and worst case scenarios, rather than waiting for the conclusion of surgery to start these discussions. Studies of Ogilvie (1990) and Murphy-Taylor (1999) have shown that good preoperative preparation and counseling from the surgeon to set expectations can reduce post-operative anxiety of the family and child.

Expectations

After the intraoperative course of each step has been discussed, the surgeon can discuss what the parent will see on their child when they enter recovery. The surgeon should discuss all of the tubes, wires, monitors and intravenous catheters they will see attached to the child and how long these will be in place. Parents tend to be most concerned about the endotracheal tube, the nasogastric tube, and the Foley catheter, so it is important to explain the parameters used to decide when these can come out. The surgeon should be very explicit about the post-operative pain management regimen and how much pain the patient will experience. It is very important to refer to the preoperative discussions of the anticipated pain level and the plan for pain control because parents inevitably return to this as their reference. Parents' expectations become very reasonable when the surgeon discusses post-operative pain in reference to what was discussed preoperatively.

Daily Rounds

In an academic hospital (such as Texas Children's), there often are multiple providers who care for the surgical patient, including residents and other trainees, as well as physician assistants, and nurse practitioners. The attending surgeon must make sure that discussions between trainees or midlevel providers and the patient or parents are limited to what the trainee or midlevel provider has discussed with the attending. A primary source of patient and family dissatisfaction in an academic hospital is the mixed messages conveyed to the family from multiple providers. A *united front message* conveyed from attending rounds with the team is ideal. In addition, the surgical team typically rounds very early in the morning, when the child and parent are asleep. This can lead to confusion by the family on the overall plan for the day, or alternatively, the family may feel that the surgical team is no longer interested in the care of the child.

Communication with the patient and family *must* occur daily. It is very important for the attending physician *not* to assume that the plan has been conveyed to the patient and parents because it is likely that the patient was seen very early in the morning. With the surgeon's busy schedule and early start times in the operating room, a phone call to the bedside can be critical to ensure that communication with the family occurs prior to physically seeing the patient in the afternoon. The surgeon should lay out a plan for the day on morning rounds with the patient and parents and have trainees or other team members follow up on this plan in the afternoon to check the progress.

It is wise to empower the child and parents to be involved with the treatment plan to facilitate early ambulation and deep breathing. Studies by Justus et al. (2006) and LaMontagne (2000) have shown that patient and parental involvement in the treatment plan can greatly increase parental self-confidence and decrease anxiety. When problems occur, such as post-operative fevers, infection or other surgical complications, the surgeon can refer back to the preoperative discussions to give a reference point about the complication that is occurring. The surgeon can

then discuss the treatment strategy for that symptom or complication. It is important to ensure that the patient and family feel that the problem is being addressed and not ignored.

A Bad Outcome

The most challenging situations occur when dealing with detrimental outcomes that cause morbidity to the patient or with events that lead to patient demise. It is imperative that potential bad outcomes be discussed during the preoperative visit. Expectations must be detailed and emphasized for complex surgeries with the potential for bad outcomes. These discussions are often uncomfortable for all parties and are sometimes avoided or overlooked. When these discussions are overlooked in the preoperative period, the surgeon will find it very difficult to deal with these situations postoperatively because the parents were not informed and their expectations were not realistic. Even for routine, low-risk surgeries, the discussion of *worst-case* scenario must take place. For a hernia operation, the surgeon must discuss the risk of damage to the spermatic cord, damage to the testicle and recurrence of the hernia. The anesthesiologist must talk about all the risks of general anesthesia for routine surgeries. For high-risk operations involving multiple steps and complex components, the possible morbidity and complications associated with each step of the surgery must be discussed. It is difficult for the surgeon to explain a complication of surgery that causes significant morbidity after it has happened if the family was not aware of the possibility of this complication.

General principles of delivering bad news should be followed, including provision of a private area without disturbances and provision of a gentle warning that bad news is coming (See Chapter 17, *Delivering and Discussing Bad news: General Principles*). Honesty and transparency are the best policies in these situations. Details regarding the patient's care that involve morbidity and potential mortality should be discussed as soon as they are detected, so that the parents remain informed of the patient's status and do not feel left out. This promotes a team approach between the surgeon and the family, both of whom want the best outcome for the patient. This also leads to better decision making when the best outcome is not achievable and the patient is deteriorating. In the situation where significant morbidity has the potential to lead to patient demise, it is best that this possibility be brought up in discussions from the outset of the declining status, rather than waiting until the patient's condition is spiraling down, and death is imminent. Families cope best when they can be with the critically ill patient during these dire situations. The surgeon must remember to constantly update the family on the patient's status and set realistic goals for and expectations of the patient's outcome. The surgeon also must remember to involve all consultants and team members in these discussions, so as to present a unified team approach in delivering the best care possible to the patient.

Conclusion

Open and honest communication between the surgeon and patient and between surgeon and family is extremely important in building trust as part of this unique physician-patient relationship. This in turn may lead to higher patient and family satisfaction, less anxiety and, ultimately, improved outcomes. The communication channels must be adjusted based on the patient's age, cognitive, and developmental level, diagnosis and procedure complexity, as well as individual characteristics of the family and the patient.

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Chapter 11

Point of View: the Pediatric Anesthesiologist

Laura Torres, MD

The typical daily workflow of the pediatric anesthesiologist is a non-stop *perioperative* process that includes preoperative, intraoperative and postoperative phases. After the conclusion of the first case of the day, the pediatric anesthesiologist may be simultaneously managing a patient in the recovery room as well as the next patient in the pre-operative area. At times, the anesthesiologist might be managing an individual patient in each of these phases, in three different locations. Given this challenging environment, the pre-operative phase may be the only time the pediatric anesthesiologist speaks directly with the family. However, the anesthesiologist must make time to engage the family in the post-operative phase to communicate unexpected events or other pertinent clinical information.

Effective Time for Communication versus Production Pressure

Despite time constraints, even for the first scheduled case, the anesthesiologist should strive to establish clear communication with the parents and the child to: evaluate the patient's readiness for surgery; discuss anesthesia management; create an environment in which the family is allowed an opportunity to ask questions; and obtain informed consent.

In a busy operating room (OR) suite, the first case assigned for a particular room might be as routine as a 10 month old infant with chronic otitis media for insertion of pressure equalizing tubes, as challenging as a 13-year-old girl with scoliosis for spinal instrumentation or as stressful as a 10-year-old child with head trauma, who is intubated and hemodynamically unstable, for emergency craniotomy. One can quickly appreciate the differences in the potential times needed for effective pre-operative communication in these three cases. The initial conversation between the anesthesiologist and the family will likely occur immediately before the patient's entrance to the OR—either directly or occasionally via telephone if the family is not physically present.

For the inpatient, there is a possibility that the communication between the patient and parents and the anesthesiologist can take place in a relatively quiet, private environment. This may not be the case in a high-intensity environment, such as a critical care unit. For the patient scheduled as an outpatient, the family more than likely has met the surgeon and may have spoken to a pre-operative nurse calling with questions and instructions, but they probably have not spoken to the anesthesiologist.

At Texas Children's Hospital, the outpatient undergoing spinal instrumentation would have been scheduled in the Pre-Anesthesia Screening Services (PASS) clinic in preparation for surgery. Like the Cincinnati Children's Hospital preoperative anesthesia screening and consultation clinic described by Varughese et al. (2013), the Texas Children's PASS clinic, staffed with nurse practitioners trained to perform preoperative evaluations and supervised by an anesthesiologist, allows for a dedicated time to fully evaluate and examine either complicated patients or patients having complex procedures. The clinic allows for additional consultation with pediatric specialists to optimize the patient's medical condition and reduce risk during anesthesia and surgery. Required or recommended additional studies are ordered during this visit, blood tests are drawn and imaging and cardiac studies are scheduled well in advance of surgery. All results are reviewed prior to surgery. Evaluating these selected patients potentially reduces delay

or cancellation on the day of surgery.

Healthy outpatients having *routine, minor* surgeries (e.g., insertion of pressure equalizing ear tubes) will usually undergo a preoperative evaluation just prior to entering the OR suite.

The child scheduled for emergent craniotomy is the most challenging of the three cases above. The urgency requires movement into the operating room suite as quickly as possible. The anesthesiologist will need to examine and evaluate the patient, discuss management with the parents and quickly obtain informed consent. This urgent, highly stressful situation still requires at least a brief time to address management concerns and obtain informed consent, with the expectation that a longer, uninterrupted conversation with the family will occur in the post-operative phase.

With technological advances in imaging and other diagnostic and therapeutic procedures, more patients are being scheduled for procedures in areas other than the OR. For example, some patients will have minimally invasive procedures in the interventional radiology suite rather than the OR. Regardless of whether the procedure is being performed in the OR or another site (e.g., post-anesthesia care unit (PACU), radiology suite, general inpatient unit or outpatient clinic), dedicated time is required to communicate well with the patient and family.

The Preoperative Consultation—Building Trust

For the anesthesiologist, the preoperative evaluation is essential for deciding whether or not to proceed with anesthesia and for deciding what additional issues need to be addressed before proceeding. For the parents (and patient if developmentally appropriate), this visit is their opportunity to provide information, learn about anesthesia care and discuss possible complications. Studies have shown that parents desire *comprehensive* information (Kain et al., 1997; Tait et al., 2011; Wisselo et al., 2004). Parents frequently are more concerned about their children's health than their own, and parents report less anxiety when they have received *comprehensive* rather than *minimal* information (Kain et al., 1997).

The questions asked by the anesthesiologist must focus on certain elements that help decide preparedness and guide management. The essential parts of a thorough anesthesia assessment and plan of care are listed below:

- Evaluation of the current medical or surgical diagnosis requiring the scheduled procedure
- Evaluation of current clinical condition, with emphasis on hydration, airway compromise, respiratory symptoms, cardiac hemodynamics, hematologic status, infection, mental status and risk for an allergic reaction
- Review of past medical history
- Review of prior procedures with sedation or anesthesia and noted complications
- Review of family history of anesthesia concerns
- Review of current and recent medications
- Review of allergies to medications, latex and foods
- Review of substance abuse if pertinent to care
- Review of fasting time
- Review of available consultants' progress notes and personal communication if necessary
- Review of pertinent laboratory data and imaging studies
- Performance of focused physical exam
- Evaluation of plan for additional analysis, imaging studies and other diagnostic tests to reduce clinical risk
- Formulation of a plan for pain management

- Formulation of a plan for patient separation from parents and family
- Formulation of a plan for patient disposition

The anesthesiologist should review whatever medical history is available. The electronic health record (EHR) often makes this possible before actually meeting the patient and parents. The EHR also provides contact information so the anesthesiologist, if he or she wishes, can communicate by telephone prior to the face-to-face interview.

Prior to initiating the conversation, the anesthesiologist should familiarize him or herself with the patient's basic information. Knowing the name of the child is the minimum relevant personal information you should have as you engage the child and parent(s). See Table 1.

Table 1. Minimal Exchange of Information in Pre-operative Visit

Know the patient's name, age and gender
Introduce yourself and your role
Show the patient and parent your badge; give them a business card if available
Arrange for an interpreter or translation service if needed

In an article about an interview technique that showed promise in improving satisfaction among adult patients in a preoperative clinic, DeMaria et al. (2011) studied the BATHE (Background, Affect, Trouble, Handling, Empathy) tool in the preanesthetic visit. Although this tool has not been studied in children in the preoperative setting, it seems to be a reasonable line of questioning for parents or older children. Using a tool like the BATHE technique can integrate the psychosocial stresses a patient or parent may be experiencing and complete the evaluation in a truly patient-centered way.

The salient points of the BATHE tool are listed below:

Background: identify the context of the visit. "Why are you here?"

Affect: allow patient to voice current feelings about impending surgery. "How do you feel about the coming surgery?"

Trouble: elicit what the patient or parent views as the most troubling aspects of the surgery; ask even if patient and parent have a positive attitude. "What about the surgery worries you the most?"

Handling: evaluate stressors the patient or parent may be experiencing; ask how they are coping with these stressors. "How are you handling that?"

Empathy: expressing empathy (See Chapter 1, *General Principles of Communicating with Pediatric Patients and Family Members*, section, *Empathy*), conveys a sense of concern and affirms the patient's feelings. "It's normal to be nervous about surgery. Let me explain what will happen on the day of your surgery."

Most of the anesthesia literature about communication in the preoperative setting has focused on the adult patient or parent, but more recently, the question of how much information a child desires is being addressed. Fortier et al. (2009) included 143 healthy, English speaking children (7 to 17 years old) undergoing elective, outpatient surgery in a study exploring what information children want to receive from the staff in the perioperative setting. They concluded that the majority of children desired *comprehensive* information about their surgery or procedure, pain and anesthesia, as well as information about potential complications. Younger children, compared to adolescents, wanted to know more about what the perioperative environment would look like. The authors recommend addressing the following questions with children prior to surgery. Pain: will the operation hurt; how bad will the pain be and how long will it last? Eating: when will I be

able to eat after the operation? Anesthesia: when I am asleep, will I feel anything; will I wake up during the operation? Discharge: when will I get to go home? Medical: will I be all right; will the problem come back?

For some children, the physical examination not only provides relevant clinical information, but also may provide an opportunity to establish rapport with the child and can help in assessing possible separation issues.

Informed Consent: Explaining the Plan and Risks

While the anesthesiologist is talking with the parents, the child, depending on his or her age and development, may appear not to be listening to the conversation, but be cautious when the details of the potential risks are explained. Hearing about serious risks and death can make any child nervous. The Fortier study identified a minority of children who did not want comprehensive information, and the anesthesiologist should be aware of this possibility. Ask the developmentally ready child or adolescent what he or she wants to know about the surgery or procedure (Fortier et al., 2009).

At Texas Children's the anesthesia informed consent form is separate from the surgery consent form. This Texas State-mandated form calls for information about the anesthesia plan and risks and requires an opportunity for patients and parents to ask questions. Only after they have had adequate time to learn, understand and agree, can they sign the consent form. The language on the Texas Children's form is not very technical but still requires appropriate explanation of the terminology used. While most hospitals offer additional consent forms in Spanish only, a translation service for a variety of languages is available at many children's hospitals, including Texas Children's.

Parents and patients are concerned about possible harm from anesthesia. In communicating risks, it is sometimes difficult to separate the risks of surgery from the risks of anesthesia. The use of separate consent forms (mandated in some states) allows the anesthesiologist to focus on possible side effects and potential adverse events from anesthesia. The actual wording of the Texas Children's anesthesia consent form makes reference to *serious* adverse events: respiratory and cardiac problems, nerve damage, cardiac arrest, paralysis and death. The section that parents, guardians and adult patients are asked to initial pertains to the planned technique. For instance, for general anesthesia, aside from the above, the possible adverse events included are: trauma (to vocal cords, teeth and eyes from airway management), intraoperative awareness, memory dysfunction and brain or organ damage.

While there are situations that are known to increase risk from anesthesia (emergency surgery, young age, acute illness), for the healthy child, brain damage and death are extremely rare. When parents ask, in reference to their otherwise healthy children, "What is the risk of my child dying from anesthesia?" a reasonable, and common, response is, "The risk of a healthy child dying as a result of anesthesia is less than the risk of death traveling in a car."

Separation and Induction of Anesthesia

A key element of the evaluation prior to surgery is to decide how a child will separate from the parent(s). Depending on the age, neurodevelopmental level, cognitive skill, degree of cooperation and anxiety of the child, the anesthesiologist can decide to administer an anxiolytic or to use non-pharmacologic interventions to help separate the child from the parent(s). Depending on the anesthetizing site environment and the comfort of the anesthesiologist, he or she might invite the parent into the suite and separate the parent and child *after* the induction period. Options for anxiolysis include: midazolam, dexmedetomidine and ketamine. Commonly used distraction

techniques include: electronic games, movies, music on smartphones or tablets, toys, bubbles, coloring books, stickers and story-telling. The anesthesiologist should continuously focus on the patient's behavior and adjust techniques, if necessary, on the way to the OR so as to promote a smooth induction period.

There are two common techniques for induction of anesthesia—inhalational and intravenous. An intravenous induction is usually performed when an indwelling intravenous catheter is already in place or when the patient's condition requires it, for instance, rapid sequence induction for a child with a risk of aspiration. An inhalational induction is commonly performed in the patient without an indwelling intravenous catheter or when the condition calls for it, for example, an anticipated difficult airway, even if the patient has an indwelling venous catheter.

Either technique requires the use of a facemask—either to administer supplemental oxygen prior to intravenous induction or to administer the inhalational anesthetics that will induce sleep. Acceptance of the face mask can be improved by adding a familiar scent (e.g., banana, strawberry, bubble gum or mint) and by continuously engaging the child with soothing talk and touch or encouraging distraction by providing music, a videogame or a movie. Focus should be on the child; all other distracting, unimportant talk and noise should cease.

Emergence from Anesthesia

Regardless of the duration and complexity of surgery, the anesthesiologist plans a safe, stable anesthetic that reduces side effects and complications and promotes a comfortable, pleasant awakening. While we often hear a child emerge from the anesthetic calmly asking, "Is it over?" emergence agitation remains a significant post-anesthetic issue that can interfere with the child's immediate recovery. Multiple factors have been cited: the child's temperament; the child's level of anxiety and whether or not specific anxiolytics had been administered; young age; specific inhalational agents; a short awakening time; and pain. Most of the time emergence agitation is brief and self-limited, but sometimes it lasts longer and requires pharmacologic intervention to calm the patient and reduce the risk of injury. Parents are always concerned about emergence agitation. We often hear a parent say, "This is not my child." The anesthesiologist should speak directly to the parents, explain that this is a well-recognized postanesthetic behavior and reassure them that it will resolve.

Adverse Events and Death

Even though every parent deserves direct communication from the anesthesiologist in the PACU, this is not always possible. However, the anesthesiologist must create time to talk to the parents to explain any adverse or unanticipated events, such as: unexpected reactions from the anesthetics; injury from positioning or airway manipulation; or medical errors.

If a child dies in the OR or PACU, coordinated communication with the parent(s) is critical. Coordination requires that the most senior anesthesiologist and surgeon speak with the family. While the surgeon is usually the one who initiates the discussion of events with the family, this author (LT) believes that it should be the physician who is most comfortable conveying the information. It is likely that the parents know (or at least have met) both the anesthesiologist and the surgeon. The lead physician should be identified prior to meeting the parents. Together, the surgeon and anesthesiologist should meet with the parents in a quiet, private room, with no interruptions. The lead physician begins by introducing him or herself as appropriate; while the parents will usually know the surgeon and anesthesiologist, in situations of emergency surgery this is not always the case. The lead physician then introduces and acknowledges everyone in the room. If at all possible, the surgeon and anesthesiologist should sit as they talk to the parents. In a frank and kind manner, the physician(s) should explain the events leading to the child's death.

The physician should anticipate questions such as, “Why did this happen?” “What caused it?” or “Whose fault was it?” It may not be possible to answer these questions until investigation into the event has taken place. If that is the case, the physicians should let the family know that they will share information as it is learned. Give the family time to ask questions and offer to escort them to see the body if they wish. If possible, contact them later to ask how they are doing.

In the case of an *unanticipated* adverse event or *unanticipated* patient death, the hospital’s risk management or legal department should be notified immediately and the situation discussed prior to meeting with the family. See Chapter 10. *Point of View: the Pediatric Surgeon*, section, *A Bad Outcome*, and Chapter 20. *When the Death of a Child Is Unexpected*.

Conclusion

Effective communication between the anesthesiologist and the patient and family is not only paramount to conducting a safe anesthetic experience but also is critical in establishing good rapport and alleviating stress. Improved patient outcomes have been reported with good perioperative communication and instruction. Communication must be clear and timely and delivered in a sensitive, compassionate manner to both the parent and the patient to assure a good experience.

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Chapter 12

Point of View: the Pain Management Team

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Introduction

Pain represents one of the more frustrating and intimidating symptoms for the healthcare provider. The intensity of pain cannot be measured objectively, and in infants, it is sometimes impossible even to determine if pain is present. The severity of pain varies considerably among patients with similar clinical conditions, and patients, especially pain-naïve or young patients, often have difficulty describing their pain. In older children, adolescents and adults, verbal self-reporting is the gold standard by which clinicians assess pain, but in pre-verbal and non-verbal pediatric patients, self-reporting is inapplicable for assessing and managing pain. A study by Nash (1974) documented that even older children in pain may have trouble talking with clinicians about their pain because pain itself hinders communication. To confound matters, parents introduce their own biases in their roles as historians and advocates. Healthcare providers also may introduce bias with regards to pain, for example, stating that a particular condition or procedure “should not be so painful.” The experience of pain is significantly influenced by factors such as the patient’s personal threshold for noxious stimuli, level of anxiety, anticipation of harm and trust or distrust in the medical environment and care providers. Both verbal and non-verbal communication integrates with the patient’s physiological and psychological experiences to either ameliorate or exaggerate the pain. Effective communication, therefore, provides the basis for effective pain management.

Attitudes of healthcare providers to pain have changed radically in the past few decades. As late as the 1980’s, it was believed that neonates did not perceive pain. That attitude has changed, and we now have several validated, behaviorally-based pain assessment tools and treatment protocols for newborns. Similarly, developmentally delayed children have historically received less pain medicine for a given condition when compared to their non-delayed cohorts because of the mistaken impression that these children had reduced pain perception. Communicating with patients and parents about pain is hindered if the practitioner is not open to the idea that the patient has the capacity to perceive pain, even if unable to verbalize it.

The composition of a pain team varies among hospitals and institutions. In some facilities, acute and chronic pain teams are independently staffed and organized, while in others, there is considerable overlap in staffing and operations. At Texas Children’s Hospital, these functions overlap considerably, with most acute pain physicians also seeing chronic pain patients in the outpatient setting. Ideally, the pain team should include pain physicians, nurses (including advanced practice nurses with interest and experience in managing pain), physical and occupational therapists and psychologists. Psychiatry consultants should be available to advise in cases of psychopathology or for patients requiring psychopharmacology.

Most (70-80%) of the Acute Pain Service efforts at Texas Children’s involve the management of acute perioperative pain; the remainder are consultations for hospitalized patients with medical pain. The Chronic Pain Service sees children with complex pain conditions (e.g., complex regional pain syndrome, Ehlers-Danlos syndrome, rare genetic disorders and prolonged or

complicated recovery from surgery) not adequately controlled by standard pediatric pain therapy. This service also follows children requiring chronic opiate therapy.

One of the goals of a pain service is to educate pediatric colleagues about effective pain management, maximizing the efficacy of standard pain medications, including oral opioids, non-opioid adjuvants and patient-controlled analgesic infusions. We strongly believe that pediatricians should be able to manage most acute pain situations as well as many chronic conditions. Communicating directly with the inpatient teams (residents, fellows and attending physicians) is part of our educational strategy, as are offers to speak to teams or services through organized conferences.

Preparing for Effective Communication

When preparing to meet with a family about acute or chronic pain, several principles guide our approach. In the in-patient setting, we do our best to find a way to sit down in the room to take the history because doing so sends a message about how important this issue is for our team. One person leads the discussion, and the other team members wait until the wrap-up phase to ask additional questions or add comments or suggestions. This strategy provides the patient and family with one person and one voice for their focus and helps keep the discussion on track. We do not interview children or parents during a meal, and we try very hard not to awaken them for our interview, believing that sleep in the hospital is hard-won and should not be interrupted. Our initial focus is on the child's pain experiences: has the child been hospitalized before; has the child had significant injuries or surgical procedures; has he or she ever had an intravenous line before? In this initial questioning, we gauge the child's experiences, so that we can help him or her compare this current experience with prior experiences, providing a context for the discussion. We also ask parents what words are used to describe pain in their family; this is particularly important for pre-school children who may have limited language skills. We find it helpful to ask about other family members' pain experiences because parents may have strong feelings for or against specific agents or techniques that we might be considering.

Whether to interview the child and parents together or separately is a complicated issue, and there are no hard and fast rules. While we usually address background questions to the parents, we always try to hear from the child first for a description of and details about his or her pain. Some children can not or will not describe their pain to us and immediately look to their parents. Nevertheless, we strive to obtain information first from the child and then seek clarification and details about the child's behavior and any family or social issues from the parents. Some parents immediately respond to questions posed to the child, answering for him or her. In these cases, we attempt to gently redirect the question to the child, encouraging him or her to speak first. "Mrs. Smith, let's see if Melanie can tell us about her pain first, and then we'll give you an opportunity to add details in just a few minutes." In the setting of chronic pain, particularly with school-age children, we gather the basic history with the child and parents together first, then interview the child and parents separately so as to get the richest possible sense of the child's experience. This strategy enables us to build a relationship with the child separate from the parents, assess the child's feelings and functioning and ascertain if family issues are impacting the pain. Separate interviews are especially important for chronic pain assessments.

Pain Assessment Tools

As hospitals have become more attentive to pain management, incorporating pain assessment as the *fifth vital sign*, there has been a dramatic increase in the use of pain scoring systems. While we appreciate the efforts to improve pain management, we recognize the limitations of these tools and their frequent misuse by patients and families, as well as by

physicians, nurses and other healthcare providers. For young children, the FACES rating scale predominates in most facilities (Tomlinson et al., 2010). This tool, using cartoon faces, is easy to present to a child over the age of 3 years; the child is supposed to match his or her feeling state with one of the cartoon faces. However, this scale is not neutral or unbiased, since the first hint of “unhappiness” occurs at a score of 6 out of 10. Experts in the pain field are also concerned that this scale measures the feeling state of *happiness or unhappiness* rather than *pain or distress*, and there are many reasons for a hospitalized child to be unhappy. Research has shown that about 60% of 6-year-old children are able to self-report pain using the FACES scale (Spagrud et al., 2003).

In older children, the tool most commonly used is the numeric rating of pain from 0 to 10. Correctly used, the patient indicates his or her level of pain on an unmarked 10 cm line, which is then measured with a ruler by the practitioner. This method has been validated (vonBayer, 2006). Instead however, this tool is commonly communicated to the patient verbally: “How is your pain today on a 0-10 scale, where 0 is no pain, and 10 is the worst pain imaginable?” Using the numeric scale in this manner has not been validated and has the potential to introduce considerable bias, particularly in the way worst pain imaginable is phrased. For the child with little to no prior pain experience, the current pain may be the worst imaginable, even if the pain is actually mild or well-controlled. We do employ these hospital-endorsed tools, but only as a small part of our pain assessment, depending more on behavioral scales such as the FLACC (Faces-Legs-Activity-Cry-Consolability) (Merkel et al., 1997) and on discussion with parents and staff regarding the patient’s activities and responses to pain therapy. We find that when multiple practitioners ask repetitively for the current pain score, the numbers seem to creep upward without other evidence of heightened pain, particularly for more anxious patients and parents. We find that reported pain scores rarely decrease in the acute inpatient setting, even when the child is ambulatory, on a regular diet and fully transitioned to oral or less intense pain therapy. In our experience, these limitations of pain scales are magnified in the chronic setting.

Managing Acute Pain

Acute pain is best defined as pain of sudden onset, usually resulting from an illness, trauma or surgery. For healthy children, the experience of severe pain may be completely novel, and may be accompanied by considerable anxiety. For postoperative pain, the pain may have been anticipated (e.g., after elective surgery), but the child’s expectation may have been for more or less pain than what he or she is experiencing. For other patients, the pain may be the result of a sudden trauma, the signaling symptom of a new illness or the reappearance of a chronic condition such as Crohn’s disease. Regardless of the origin of the acute pain, a thorough history and physical exam are the foundation for establishing a treatment plan. If age-appropriate, we ask the child directly about his or her pain. If a parent tries to speak for the child, we redirect him or her, explaining that we will solicit his or her input after we have heard directly from the patient. The importance of speaking directly to the child cannot be overstated. For optimal therapeutic benefit, children need to know that they are being listened to and are being heard by members of the care team.

Once the source and intensity of the pain are identified and understood, the clinician’s next task is to clearly and concisely communicate the plan for managing the pain. Parents and adolescents both reported decreased anxiety and better pain control when the management plan was described to them before initiation (Innis et al., 2004). In addition to describing the recommended medications and the route and frequency of administration, we also endorse the use of non-pharmacologic strategies for managing pain and its attendant anxiety. This may

include, depending on the situation: reassurance by parents; distraction by family interaction, games, texting and television, as well as by formal activities conducted by a child life specialist; appropriate body mechanics and mobilization; physical therapy, including heat-cold therapy and use of a transcutaneous electrical nerve stimulation (TENS) unit; therapeutic massage and acupuncture; and sleep hygiene.

Expectations should be outlined for both parent and child. If complete resolution of the pain is expected, then it is fair to say so. If, on the other hand, the pain is expected to be reduced but not completely eliminated anytime soon or by time of discharge, then this expectation should be stated clearly. With all the advertisements for a *Pain-Free Facility* promised by hospitals, parents frequently have unrealistic expectations about our ability to achieve a state of *no pain*, which, for example, may not be achievable when the patient has a recent, large surgical incision, major systemic inflammation or substantial traumatic injuries. We try to manage these expectations by saying something like:

“Our hope is that you will be mostly comfortable lying in bed, but you may notice more soreness when you turn over in bed or get up the first few times. We expect this to get better the more you are up and walking.”

In addition to describing the initial pain management strategy, it is important, when appropriate, to communicate to patient and parents the availability of medication for breakthrough pain and an outline of the next steps if the initial pain plan provides insufficient relief. We also communicate to parents the positive ways in which they can participate in the treatment plan, and conversely, how their own anxieties about the child’s condition are easily transmitted to the child. We encourage parents to serve as their child’s chief *cheerleader*, using whatever techniques (including reassurance, distraction, praise and encouragement) they have found works best for their child at times of increased pain, anxiety or distress. Research by Cohen et al. (2005) demonstrated that parental distraction was more effective than parental reassurance in the setting of procedural pain relief.

When acute pain from a chronic medical condition flares up, we begin by asking the patient what has worked for him or her in the past and whether or not he or she wants to start with that treatment for the current episode.

“What medications have you tried before this exacerbation? What has worked for you? Which medications do you think have *not* helped you? What would you like to try this time?”

Patients and parents appreciate having input into treatment decisions and rate the pain control better and are more likely to be compliant if given an opportunity to be involved in the plan.

Working with Chronic Pain Patients and their Families

Working with children with chronic pain and their families is more challenging than managing acute pain. Many of these patients have seen multiple physicians and tried all of the standard treatments with limited success although frequently the standard treatment was not prescribed or administered correctly. These patients and their parents are often sensitive to any verbal or nonverbal cues that suggest that the physician does not believe their story or does not accept their report of the intensity and impact of the pain. Some may assert from the beginning that nothing works except X, their drug of choice. This assertion generally gets the relationship off to a poor start, putting the physician in a defensive position. Sometimes, the patient has previously been accused by another physician as drug-seeking, making it even more difficult for the new physician to build a relationship with the patient or parents.

The primary objective in the initial patient encounter is two-fold: first, to collect, without judgment, a detailed narrative about how the pain began and what has been tried to alleviate it; and second, to gain a sense of the patient's prior experiences. We try to get the patient (if developmentally able) to tell his or her own story, starting at the beginning, interrupting only for prompts such as, "Tell me more about that." or "What happened after that?" The patient or parent may roll their eyes at this point, saying, "Didn't you read the records we sent?", or "Do we really have to go through the whole story again?" Replying, "I know this is hard for you, but I want to make sure that I don't miss anything." may help convey your attentiveness to the child's problem. Alternatively, showing that you already know something about their story by guiding the narrative may help: "If my memory is correct, this started with an auto accident about two years ago? Is that right? Tell me more about that."

We recommend expanding the focus beyond a discussion of the patient's pain to inquiries about commonly associated symptoms such as mood disturbance (e.g., anxiety, depression) and altered sleep patterns (e.g., insomnia). We also ask about relationships with family members, relationships with peers, romantic interests and suicidal ideation. We have found that asking open-ended questions, such as, "How has the pain changed things at home?" will yield more helpful information than direct questions, such as, "Does your pain cause you and your mom to fight?" Attempts to treat the patient's pain without addressing these associated symptoms will usually result in failure. Parents and other family members share the burden of the child's chronic suffering, and any encounter without seeking their input would be incomplete.

Given that in cases of chronic pain the disease causing the pain often cannot be cured or mitigated, and the only recourse is to manage the patient's symptoms, we often find ourselves reminding the patient that improved function and quality of life, not total relief of pain, is our goal. It helps to explain that pain control is not our only goal and that complete pain control in the setting of a chronic disease may not be possible despite our best efforts. Defining quality of life for the patient is the next step, and obviously, requires the child's input. From something as simple as being able to get out of bed, to returning to school or being able to run and play with friends, each child's goals should be clarified. The patient should be reminded at every opportunity that the focus is on quality of life and not simply pain control. If the patient or parent cannot understand or accept this, and if a pain management team or expert is not already involved, it would be wise to obtain such consultation. While our initial visits focus on listening intently and openly and establishing a trusting flow of communication, we structure subsequent visits to devote less time to discussion of the pain and more time to discussion of issues such as physical therapy, sleep and activity. Again, the goal is to move the focus from pain to quality of life.

Once goals to improve quality of life have been determined, the treatment plan should be proposed and discussed. It is generally a good idea to employ a multidisciplinary team approach for the patient with significant chronic pain that impacts his or her daily life and activities. The practitioner should outline the medications and adjuncts that will be prescribed to treat the pain and associated symptomatology and enlist the services of psychiatrists, physical therapists and others to help with rehabilitation. In addition, we recommend that all children with significant chronic pain be seen by a psychologist with experience and expertise working with children with chronic pain. We reassure families that the involvement of a psychologist does not imply psychiatric disease or factitious pain but rather that these professionals can be very helpful for both patients and their parents, to teach effective coping strategies and to provide parents with parenting strategies for the child living with chronic pain. If mood disturbances or suicidal ideation is present, we recommend consulting a child psychiatrist. Not all children need to be seen by

both psychologist and psychiatrist since most do not have serious, underlying psychiatric disease. We present our collaboration with mental health professionals as part of our *routine* care for children with chronic pain; this tends to reduce resistance to these referrals. The key concept in the discussion is to present the family with our recommendations, then pause to allow both the patient and parents to seek clarification, comment on the plan or suggest alternatives. In our experience, when patients have had a say in the treatment plan, they tend to be more diligent in its execution.

Modalities such as yoga, acupuncture, massage and hypnosis have been shown in some studies to play a helpful role in chronic pain management, particularly if the patients and parents are positively disposed to complementary therapies (Tsao et al., 2005; Yaster, 2010). Even if these therapies do not directly impact the pain itself, they may contribute to relaxation, anxiolysis, mood improvement, a higher level of activity and better body mechanics. We encourage parents to share with us any alternative or complementary treatments they have sought or are employing, maintaining a nonjudgmental approach to most of these untested therapies. Only when we believe the therapy may have serious adverse effects do we make specific recommendations against its use.

Two difficult groups of chronic pain patients deserve additional discussion as these patients may present themselves repeatedly to the primary care physician.

The Child with Chronic Pain, for which there Is No Specific Diagnosis

An especially challenging situation is posed by the child with debilitating, chronic pain for which there is no specific underlying diagnosis despite considerable work-up and visits to a number of primary care physicians and multiple specialists. These children and parents may be extremely difficult to work with as they focus on finding a diagnosis even though multiple laboratory and imaging investigations have been unrevealing. When families such as these present to us, we begin with our standard interview, inquiring about how the symptoms presented and developed over time. Then we explore the patient's and parents' concerns about what *might* be going on, what conditions they are afraid of and what the chronic pain means *to them*. From the patient, we may hear his or her fear that life will "always be like this", while the parents may still fear an unrecognized cancer. In the absence of new physical findings or laboratory data, we focus on the reassuring aspects of the workup (e.g., negative workup for cancer or osteomyelitis); discourage families from doctor-shopping; and develop a plan for chronic pain management that includes restoring function, resuming normal activities and avoiding pain-associated debilitation. Our experience has been that these parents are frequently mistrustful and have very strong opinions about treatments that they will and will not accept. They struggle with the ambiguity of not receiving a specific diagnosis and frequently present a lot of *research* that they have done on the Internet. These families require a great deal of reassurance and may best be referred to a pediatric pain specialist or pain team for multidisciplinary and comprehensive care.

Chronic Opioid Use

Another situation that deserves special note is the patient who is chronically taking or requesting opioids. Just as the use of chronic opioid therapy has increased in adult patients, we have also seen an increase in children, particularly adolescents, who believe that nothing will ameliorate their pain other than opioid medications. There are many issues for the clinician in managing children on chronic opioid therapy: assessing effectiveness; dealing with tolerance, abuse, or diversion; and recognizing the potential for accidental or suicidal overdose. In our experience, there are only a few children who should be maintained on chronic opioid therapy (e.g., a sickle cell patient with demonstrable joint destruction from avascular necrosis). Physicians

should be wary of the child or parent who constantly asks for refills of opioids initially administered for an acute condition. Most children who require chronic opioid therapy probably should be followed by a pediatric pain expert or team experienced in writing opioid contracts with patients, monitoring urine specimens and keeping track of the number of pills prescribed and administered.

Conclusion

Communicating effectively with patients and parents about acute and chronic pain requires the use of appropriate interviewing techniques and good listening skills. We acknowledge that the emotional meaning of pain creates a special burden of care for the practitioner and suggest that compassion, openness to discussion, a collaborative approach and the ability to deal with patient and parental frustrations are key skills for managing children in pain.

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Chapter 13.

Point of View: the Consultant

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Introduction

The pediatric consultant, often a subspecialist, frequently is called to assist in the care of children with complex, severe or confusing conditions. Pediatric subspecialty consultation has been shown to reduce the length of hospital stay and number of readmissions, reduce costs and result in improved quality of life and survival rates for children with complicated medical conditions (Albright et al., 2000; Chowdhury et al., 2007; Snow, 2005). However, accomplishing these goals requires coordinated communication among healthcare providers, patients and their family members.

Bates (1979) provides general statements about the importance of communication *between the medical consultant and the referring physician*, stating that the consultant should “render a report that informs without patronizing, educates without lecturing, directs without ordering, and solves the problem without making the referring physician appear to be stupid.” Additional literature exists about the role of the consultant in supporting the referring physician and effectively communicating recommendations for patient care (Gotlib et al., 2012; Sibert et al., 2002). However, little has been published on the important aspects of communication *between the consulting physician and the patient and family members* (Goldman et al., 1983; Goldman et al., 2009; Zambelt et al., 2007).

Typically, pediatric consultants are asked by referring physicians to:

- address a specific question or problem about a patient and the clinical course without maintaining a long term relationship with the patient or family members, or
- participate as members of a multidisciplinary team caring for a child with the expectation of an ongoing relationship and multiple opportunities for medical assessment and recommendations.

In either case, the pediatric consultant has an obligation to the child and parents to communicate the medical assessment and recommendations clearly and effectively and to provide opportunity for education and clarification of questions and concerns. Although the approach to communicating may differ slightly depending on the referring physician’s request, the general principles for communicating with the patient and family members are the same. The author (DLP) suggests a modification of Goldman’s “Ten commandments for effective consultation” and offers 5 strategies for effective communication *between the consulting physician and the pediatric patient and family members* (Goldman, 1983).

Five Communication Strategies for Consultants

1. Identify the question.
2. State your role.
3. Communicate clearly and succinctly.
4. Educate the patient, the family and, if necessary, the referring physician.
5. Make a plan for follow up.

Preparing for Effective Communication

Identify the Question

In both the inpatient and outpatient settings, the most important first step is to identify the question(s) being asked by the referring physician and his or her perception of what the patient and parents are looking for in the consultation. This information can guide the flow of the patient encounter and goes a long way in preventing potentially unhelpful assessments and recommendations. It also can reduce frustration for the parents, who usually are aware of the referring physician's reason for the consult and have certain expectations for the consultation visit.

For example, consider the patient who is referred for evaluation of recurrent febrile illnesses where the history suggests an expected number of common infections for the patient's age and no physical examination abnormalities are present. In this case, the consultant may be less likely to perform additional or extensive testing if he or she is aware that the referring physician desired only reassurance and education for the family than if the reason for the referral is thought to be to exclude immunodeficiency, even if unlikely. By spending time before the patient encounter investigating or discussing the referring physician's question(s) and his or her perception of the family members' expectations, the consultant can better address the concerns of all parties involved in the child's care.

In some instances, the referring physician's question differs from or is only one of many questions posed by the patient or parent during the consultation visit. For the patient in the above scenario, whose referring physician desires education and reassurance for the family, additional important questions to address may include, "Does my child have cancer?" or "What if this keeps happening?" Asking the parents at the start of the encounter, "What brings Johnny to our office today?" or "What concerns do you have about Johnny?" helps immediately identify additional concerns, provides awareness of the family's state of mind and allows an opportunity to address these issues during the visit.

Gather Data

Whenever feasible, review of the patient's history and records *prior to* the first encounter enables the consultant to formulate initial thoughts about the child's clinical problem. In the inpatient setting, where many healthcare institutions have transitioned to electronic medical records, review of data in preparation of the initial visit usually is accomplished quite easily. However, in the outpatient setting, obtaining records for review may require some advanced planning. Time should be allotted to accomplish this important task whenever possible.

Analyzing available information in advance of the encounter can facilitate the planning of an initial approach to the child and family. Additionally, in cases where a child has been seen by numerous physicians, advanced preparation and review of information also provides an opportunity to build trust during the initial visit when the parents realize that you, as the consultant, have put a significant amount of time and effort into their child's problem prior to meeting with them. Gathering data ahead of time also allows the consultant to identify and focus on key aspects of the case and allot appropriate time for education, questions and discussion of recommendations in a typically time-limited setting.

Communicating During the Initial Visit

Explain your role

In either the inpatient or outpatient setting, the consultant should introduce him or herself upon entering the room, preferably first to the patient (if age appropriate) and then to the family

members. “Hello, I am Dr. Smith, the cardiologist. It’s nice to meet you. Dr. Jones has asked me to evaluate your heart because he heard a murmur or special sound when he listened to your chest.” Inquire about what name the patient likes to be called and how the parents prefer to be addressed. Whenever feasible, sit down facing the child and parents, preferably in a triangular formation, to take the history. (See Chapter 1, *General Principles of Communicating with Pediatric Patients and Family Members*, section, *Starting the Conversation: Introductions and Opening*)

For adolescent patients, the consultant (like other physicians) can benefit from interviewing the child separately from the parents about relevant sensitive issues, such as sexual activity, school performance and participation in high risk behaviors. When explaining your role to the family, it can be helpful to tell them, “There are a few questions I need to ask Beth privately that can help me evaluate her heart. Can you please step into the hallway for a few minutes, where the nurse can make you comfortable, while I discuss these questions with Beth?” This directed approach to asking sensitive questions can convey the importance of the information to the family and the patient and usually results in the parent’s cooperation. In the uncommon situation where the parent refuses to leave or the child asks him or her not to go, relevant questions still should be asked but the child may refuse to answer or default to answers the parents would expect or want to hear. It is recommended to follow up in private with the adolescent on these questions if the opportunity arises in the future.

In stating your role to the patient and family, it is essential to describe your plans for communicating with other members of the medical team. In situations where the clinical problem is relatively straightforward, the pediatric consultant, typically with advanced permission from the referring physician, directly reports the recommendations for evaluation and management to the patient and family at the time of the initial visit. In such cases, it is important to inform the family that you also will be communicating with the referring physician, in person (preferably), by telephone or within the medical record.

In circumstances when the child’s illness is complicated and numerous providers are involved, the primary service or attending physician should coordinate communication with the family in order to decrease potentially mixed or confusing messages. In such instances, you as the consultant should inform the patient and parents that you will obtain the patient’s history, perform a physical examination, request appropriate additional studies and further review available data with the plan to discuss your recommendations with the primary team. Then, the primary service will discuss the finalized plan with the patient and parents. This use of a single *point of entry* (i.e., the primary physician responsible for communication) to the patient can be very effective in promoting optimal, effective communication by providing a consistent message to the family from providers with whom they are most familiar. Patients and their family members value this consistency, and this communication approach generates trust between the family and healthcare providers.

Communicate Succinctly

Communicating succinctly with patients and families helps maintain attention, simplifies the message and promotes retention of information shared. Patients and parents best remember what they are told first, so use this opportunity to make the message clear (Tate, 2010). Although communicating succinctly seems obviously beneficial and, in concept, simple to perform, many physicians find this task quite difficult.

Consider the patient mentioned previously being seen for a normal number of common infections for age. Here is an example of succinct communication: “Johnny is normal and has

had a normal number of infections for his age. Most children his age, like Johnny, have X number of infections per year, and we are not concerned as long as the child is growing well and has not required hospitalization.” This message is clear and gets the point across. However, many physicians in this type of clinical situation find it tempting to provide a *laundry list* of all the possible diagnoses for the chief complaint and then proceed to explain why the alternative diagnoses are unlikely, instead of focusing on why the actual diagnosis is correct. Many patients and families are anxious about needing to see a consultant and, therefore, may have difficulty maintaining attention due to fear or concerns. Reciting a long list of differential diagnoses is unhelpful, propagates anxiety and does not send a clear message.

Make Specific Recommendations Using Clear and Simple Language

Part of communicating succinctly involves making specific recommendations using clear and simple language. For example, when describing the procedure to correct pyloric stenosis, it is helpful to state, “We recommend an operation where we will make a very small opening through the skin over Abigail’s belly and then use a small instrument to loosen the stomach muscle that is too tight.” rather than, “We may consider performing a procedure to make an incision into the abdomen to perform a pyloromyotomy.” When it is not possible to make a clear recommendation without speaking first with the referring physician or other medical providers, the pediatric consultant should inform the family that further discussion among the medical team will determine the recommendations and plan.

Avoid Speculation

It is important to discuss the patient’s condition, its likely progression and the options for further evaluation and treatment with the patient and family at the time of the initial consultation, when feasible. In situations where identifying a well-defined diagnosis and management plan is not immediately possible, it is important to admit uncertainty and not to dwell on it or participate in unnecessary speculation (Tate, 2010). Dwelling on uncertainties to the point of speculating about future events can promote anxiety in the patient and family members and lead to lack of trust in the consulting physician. As the consultant, it is important to state the facts and findings known at the time of the initial visit. When discussing uncertainty, helpful approaches can include statements such as, “My recommendations for today include X, Y and Z. We need to gather data and continue to assess Philip’s course before being able to determine steps beyond this point. As soon as we have additional information, we will discuss the next steps with you.” Providing a clear, albeit tentative, plan of action, even in circumstances where the final diagnosis is not clear, provides patients and their families with comfort, trust and hope.

Educate

Whether during the first or fifteenth clinical visit, the consulting physician is poised to educate patients and families about their medical conditions. The following strategies are recommended for educating patients and parents.

Probe for Understanding

Probing for a patient’s understanding is an acquired skill and unfortunately is performed in a minority of clinical encounters (Tate, 2010). However, checking our patients’ and parents’ understanding is critical for a shared understanding of the clinical entity and recommended management plan. A “yes or no” question such as, “Have I made that clear?” is less useful than, “Can you share with me your understanding of our conversation today?” The former allows the patient to say “yes” even when uncertainty remains, and the latter provides an opportunity for the patient to recite what he understands and identifies areas of misunderstanding or uncertainty that

can be addressed. This approach is known as the *teach back method* of probing for patient understanding (Judson, 2013). Other questions that are helpful when using this method include, “What are you going to tell your family members about our plan for today?” and “Can you tell me what we have agreed upon for our plan?” These questions allow the patient to explain what he or she understands and provide the physician opportunity for further clarification of the diagnosis and management plan.

Encourage Questions

Encouraging questions not only enables shared decision making but can result in improved patient adherence and satisfaction. This result, in part, may be because patients are more likely to accept care that aligns with their values and preferences (Judson, 2013). Both the Agency for Healthcare Research and Quality (AHRQ) and The Joint Commission have ongoing campaigns to encourage patients to ask questions during their care. The AHRQ reminds patients that doctors *want their questions and that patients’ health depends on good communication. The AHRQ emphasizes that healthcare is a team effort. The Joint Commission encourages patients to participate in all decisions about their treatment and to speak up if they have questions.* This patient-centered approach to healthcare is supported in order to encourage more open dialogue that can lead to better outcomes.

Make a plan for follow up

The consultant’s relationship with the patient typically extends beyond a single clinical visit. Identifying a clear plan for follow up can improve patient compliance with recommendations and lead to improved care (Cohn, 2003). Depending on the complexity and urgency of the case, follow up may be arranged for the same day (more common in the inpatient setting), in a few days or in a week or more. Determining the plan for follow up with the patient and parents at the time of the initial consultation visit should include a discussion with the referring physician, who is coordinating the patient’s care.

Conclusion

The pediatric consultant often is a subspecialist who is asked by a referring physician to participate in the evaluation and management of a patient with a complex, severe or confusing condition. In order to promote optimal care of patients, consultants must communicate effectively with children and their family members, in addition to communicating with referring providers. Important communication strategies for the pediatric consultant include: identifying the clinical question; explaining the consultant’s role; communicating succinctly; educating the patient and family; and making plans for follow up. It is critical for pediatric consultants to communicate effectively with patients and parents in order to promote optimal patient compliance and outcomes.

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Chapter 14

Point of View: the Pediatric Nurse

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When considering how a nurse communicates with a pediatric patient, it is important to first discuss the differences between a nurse and other healthcare providers. Nursing training is quite different from that of other disciplines. In describing the role of the nurse, the International Council of Nurses (2010) states, “Nursing includes the promotion of health, prevention of illness, and the care of ill, disabled and dying people.” The Council cites advocacy as a key nursing role. One study asked nurses what functions they performed when acting as a patient and family advocate. The two most common responses were educating the patient and family and communicating with other members of the healthcare team (Hanks, 2010). The nurse is the voice of the patient and family members, who may not know exactly what to say. Whether the nurse works in an ambulatory setting, a hospital general inpatient unit or an intensive care unit, the key principles of nursing are the same.

Building Relationships

In pediatric nursing, one must consider the needs of the entire family unit as well as the needs of the patient. This requires building relationships with the patient and the family. When introducing yourself, it is important to explain your role in the care of the patient clearly and precisely. It is essential to develop rapport with the patient and parents quickly and display genuine interest in them, so as to earn trust. Learn preferred names and greetings and use them when interacting with the patient and family. A study by McCabe (2004) found that patients were reassured by and highly favored a personal approach. Rather than referring to the patient as *the baby* or *he* or *she*, refer to him or her by name, and when talking to the patient beyond infancy, address him or her by name. Take the same approach with parents: use the first name, or if the parent prefers more formality, use Mr. or Mrs. Smith rather than referring to her as Mom or him as Dad. There are many strategies to help those first interactions go well, including sharing a common interest and providing a quick laugh or sympathetic touch or gesture. Often the first impression can shape the future course of the relationship. It should not be hurried or dismissive. This first interaction builds the foundation for the relationship over the entire time that the nurse will care for this patient and family and therefore should be thoughtful and sincere.

Information Gathering

To build relationships and to truly advocate for the patient, the nurse needs to first become knowledgeable about the patient. The nurse should demonstrate knowledge about the underlying medical condition, while exhibiting genuine interest and a caring attitude. Review the medical record, obtain a full report and know the patient’s diagnosis and treatment plan before approaching the patient. Ask the patient and family member for additional clarification if needed but do not ask them to repeat the whole story that they likely have given numerous times already.

The pediatric nurse needs to examine all available sources of information. This baseline understanding is important before visiting with the patient and family for the first time. Being prepared greatly helps in building confidence and trust. If one is not prepared and knowledgeable,

the family's confidence may be lost immediately, and it may be difficult to reestablish trust. Be prepared for annoyed responses such as: "I've told his story to at least 5 other people today. Do you people not talk to one another?", "Didn't you read his chart?" or "Didn't Dr. Smith send his records?" Usually, this negative response can be avoided by not opening with the standard, "What brings you in today?" A better approach is to explain what you have reviewed or received through reports: "I read that your son was admitted for dehydration. Can you explain what you were most concerned about when you brought him in?" It is best to elicit the primary concerns in the context of global concerns. This will help keep the encounter focused, develop open communication and guide the nursing assessment.

Nursing Assessment

The nursing assessment is another opportunity to engage in active communication. Before starting an assessment, it is important to review all data and information already at hand, including past records, reports and other pertinent clinical data. This is invaluable in directing a more focused evaluation and assessment.

Physical Examination

The physical assessment should have an organized approach. Be gentle. Focus on specific areas based on the previous history and current problems. Every nurse has likely encountered the scenario where the mother pleads, "Please don't wake Johnny. I just got him to sleep after the doctor woke him up to listen to his chest." In some situations, it may be appropriate to wait and return after assessing other patients; in other cases, it may be necessary to explain to the mother the importance of a timely nursing assessment. The nurse is a 24/7 resource for the patient, and if subtle changes occur, she is likely to be the first person to notice. Being prepared and organized is especially important when caring for an infant or toddler who is unable to understand what you are doing. Once a young child becomes upset, it is very challenging to gather more findings for an assessment.

At the conclusion of the assessment, it is important to explain both positive and worrisome findings. This is an excellent opportunity to work on building a trusting relationship. Sit down. Take time after the assessment to address new findings and to address any questions the patient or family may have. A nurse-patient relationship focused solely on tasks devalues the role of the nurse. A task-focused approach can lead patients and parents to view nurses as *workers* rather than *professionals* (McCabe, 2004). Answers should be genuine and honest. If you do not know an answer or are unsure how to answer a question, admit this openly and either follow up with the correct answer or direct the family to the physician or whomever is appropriate in a timely manner. Providing contradictory information or misinforming the family can lead to mistrust and can undermine your efforts towards building a relationship. It also can lead to decreased confidence in nurses in general (Liljeroos et al., 2011). Be reassuring, yet honest, and explain assessment findings and link them to the plan of care.

Plan of Care

After the physical assessment is completed is an ideal time to discuss the nursing care plan and goals for the day, week and long-term. With proper communication, the parents or other caregivers can be your strongest asset in achieving these goals. The key is to involve them in the process of forming those goals and aligning interventions that meet the needs of both the family and the nurse. Involving the parents in the care of and plan for the patient will significantly improve your ability to meet the agreed upon goals. For example, in the case of a post-operative patient, the risk of a respiratory infection can be reduced greatly by proper pulmonary hygiene

(Hockenberry and Wilson, 2007). The patient and parent can be taught the importance of turning, coughing and deep breathing. Involving the parents in this and other therapies can increase their ability to confidently care for their child and diminish the time the nurse needs to spend on routine tasks, allowing her more time to focus on complex duties and patient education. However, the nurse must assess the parent's willingness and capability to perform each task.

Learning Assessment

In addition to physical assessments, the nurse also needs to assess the learning needs and learning style preferences of the patient and family. Parents of a newly diagnosed child often find it difficult to know what questions to ask. In these circumstances, it is important to assess what they know and how much they would like to know. Listening and exploring become a key part of communication in these situations (Jasmine, 2009). Nurses tend to over or underestimate the learning needs of the patient and family. Part of being an advocate is to assess these needs and tailor the education accordingly. During medical rounds, family members sometimes view the team, especially the physicians, as too hurried or too busy to answer their questions or address all their concerns. Patients and parents often are more comfortable asking a nurse questions they fear will appear unimportant or stupid (Liljeroos et al., 2011). One hospital introduced the following phrase for use by nursing providers: "What is the most important thing I can do for you today?" Patient education was a major theme expressed by patients and families (Cappabiaca, 2009). The nurse must create an atmosphere that is conducive to open communication and trust in order to ensure that families receive the necessary education. Discharge and the time leading up to discharge are often times of high anxiety for the patient and family. Patients report feeling ill prepared for and distressed about what to expect at home (Liljeroos et al., 2011). For complex medical conditions, patient and family education is a continual process throughout the entire hospitalization and should not be relegated to just before discharge.

The nurse has an important charge to assess and ensure appropriate learning in a manner that is best for the patient and family. It has been reported that 40% to 80% of information communicated to a patient is not comprehended or remembered (Kessels, 2003). *Teach-back*, a technique well studied in the literature (Tamura-Lis, 2013), can help the nurse assess what is understood by the patient and family. After giving new information to the patient and family, ask them to repeat, in their own words, what you told them. This provides an opportunity to clarify or re-teach the information in a different manner. This also can reveal uncertainties and misconceptions about the patient's progress and treatment plan, which the nurse will need to discuss with the healthcare team.

Nurses' Role in the Healthcare Team

A nurse's role in the care team varies in different settings. In an outpatient setting, such as a pediatric clinic, the nurse may coordinate a patient's visit from start to finish. For established patients with known conditions, the nurse may be the only provider seen at the appointment. In an inpatient setting, the nurse is part of a larger care team, which usually includes one or more physicians and may include advanced practice providers, nutritionists, social workers, and others. So, where does the nurse fit in?

At the center of a successful inpatient team is the nurse. On an inpatient unit, nurses are frequently the only members of the healthcare team that spend most of their day in contact with the patients and families, often spending the entire shift with just a few families (Panicker, 2013). The inpatient pediatric nurse must constantly be aware of the child's needs and the family's perception of the child's needs. For example, a mother calls the nurse into the room because her child, who is intubated, is moving around a great deal and appears to be in pain. The mother

verbalizes that she does not want the child to be in pain. After assessing the patient, the nurse determines that the child is uncomfortable and repositions the child using assistive devices. After repositioning, the child's heart rate decreases, his eyes close and he appears to be asleep again. Rather than walking away, the nurse should explain her assessment and actions to the mother. By providing reassurance and education, the nurse is helping the mother learn cues to assist her child and relieve her own anxiety.

Often, the nurse must share the patient's story. Other professionals spend fragmented time with the patient and often rely on the nurse to put the pieces together to form an overall picture of the patient's condition. The nurses' input in multidisciplinary rounds is crucial to providing the team the full picture. Without the nurse's presence and participation in rounds, the team sees only part of the child's current state. Benner (cited in Mattsson et al., 2013) states that nursing care involves the "care of the physical body, the psyche, and the psychosocial aspects." As discussed earlier, families can be intimidated by the multitude of caregivers that appears during rounds. Nurses should help pediatric patients and their families be more involved in rounds and have a voice during crucial discussions. Patients and families should be involved in rounds to the extent to which they are comfortable (Balik et al., 2011), and nurses should help ensure that pediatric patients and their families understand what they have been told and help them seek clarification, if needed. Effective team work by all members of the healthcare team is essential to providing quality care to patients and families. In a 2011 White Paper, the Institute for Healthcare Improvement stated, "Patients and families vary widely in their ability to assess the clinical components of care; however, they can assess how well care team members work together and communicate with one another." (Balik et al., 2011). When a team functions as a single unit, with a common goal of providing high quality care to patients and families, it is noticeable to those the team serves. High functioning healthcare teams recognize the importance of everyone's opinions and encourage active participation by all members. As a traditionally hierarchical system, healthcare sometimes downplays the opinions of nurses. Specialized education on closed loop communication and crisis resource management (aka *crew resource management*) is important for all members of the healthcare team and promotes respectful questioning of authority as needed for the good of the patient.

Communicating during Painful Procedures

One of the hardest things a pediatric nurse has to do is to tell a child she has to do something that will cause discomfort or hurt the child. Nurses are obligated to prepare children and families for painful procedures and ensure that appropriate measures are taken to decrease the severity of pain. When communicating about painful procedures with children, it is important for the nurse to be honest. If a nurse says, "Trust me, this won't hurt," and it does hurt, the child will no longer trust the nurse.

There are various techniques to communicate with children and adolescents about difficult or painful procedures. Preschoolers typically respond well to an explanation before and to distraction during a painful event (Perry et al., 2009). By taking time to assess the developmental age of the child and explaining the procedure in terms the child can comprehend, the nurse can have a significant impact on the patient's experience during the procedure as well as the child's response to future painful procedures. Young children may not understand the word "pain" but may understand "boo-boo." It is important to customize the communication to the child. (See Chapter 2, *Age Appropriate Communication and Developmental Issues* and Chapter 15, *Point of View: the Child Life Specialist*)

Pain Assessment

Using appropriate pain scales for children is extremely important. (See Chapter 12, *Point of View: the Pain Management Team*, section, *Pain Assessment Tools*.) Quantitative pain scales allow self reporting of the child's pain. While observed behaviors are important, the nurse should understand that each child reacts differently to pain and painful procedures. Although there are limitations to the accuracy of the Faces Pain Scale (See Chapter 12, *Point of View: the Pain Management Team*, section, *Pain Assessment Tools*), it generally can be used appropriately by children as young as three years, and by age four, most children can point to the area that hurts (Wong et al., 2002). Patients may not readily communicate about their pain, so it is vital for the nurse to assess pain routinely. Many painful procedures performed on children do not have established pain protocols, and such protocols, when established are not consistently followed. Unless a procedure is emergent, some form of pain control should be used. The nurse should act as an advocate for appropriate pain control. Nurses can choose from a variety of non-pharmacologic interventions to address painful procedures. Distraction, humor and relaxation are commonly used techniques for minimally invasive procedures such as injection of a vaccine.

Toddlers and preschool aged children do not understand the connection between painful procedures and treatment. Children at this age are generally most comfortable with their parents close by. The nurse can involve the parent by asking him or her to help hold the child close. This provides comfort to the child and parent and helps keep the child still although the nurse should not rely exclusively on the parents as they can be under a great deal of stress.

School aged children may be more verbal but still require observation of non-verbal clues to understand how they are dealing with pain. The school aged child may show pain by guarding the painful area, being irritable or displaying changes in his or her activity level (Children's Hospitals and Clinics of Minnesota, 2012). The nurse and family can help prepare the school aged child for potentially painful procedures by setting expectations, using distraction and helping the child with relaxation techniques such as deep breathing.

Once children reach adolescence, they worry about being embarrassed and strive for independence (Perry et al., 2009). Adolescents need to develop trust in their healthcare providers and need to be prompted to discuss their fears and concerns. Numerous pharmacologic interventions for pain management are available when appropriate. The nurse should consult the medical team with objective pain information and advocate for pharmacologic pain control as needed. Before addressing painful procedures with the child, it is often beneficial to discuss the procedure with the parents. Parents' behavior before and during painful procedures can influence the child's level of distress (Cline et al., 2006). Parents are most familiar with their child's past pain experiences and reactions and can provide valuable information to help the nurse manage the current painful situation or procedure. By empowering parents to advocate for their children, nurses break down barriers and build strong partnerships with families.

Boundaries

As described earlier in this chapter, building a solid relationship is important to meeting the needs of the patient and family. But where should this relationship stop? Whether it's a long hospitalization or an extended home health situation, families often have the same nurse with them for long periods of time. Some nurses and families find it difficult to differentiate between a professional and personal relationship. In the last decade, the explosion of social media has blurred this line even further. The American Nurses' Association (ANA) recognizes that the use of social media can be very beneficial to patients and families. In 2012, the ANA published *Guidelines for Using Electronic and Social Media: the Regulatory Perspective*, in which it states,

“Social media can be a very effective way of communicating in nursing, but guidelines for appropriate use by healthcare providers are essential.” The guideline further cautions nurses against crossing privacy and therapeutic lines.

Nurses communicate via social media (e.g., blogs, online video sites and forums) in ways that are very beneficial, including educating other health professionals and the public. A nurse’s social media communication is not problematic as long as the nurse remains cognizant of professional obligations to privacy, confidentiality and respect. There are potential, inadvertent breaches of patient confidentiality. Let us examine a hypothetical example. After a rough night at work, a nurse posts on her Facebook® page about the great teamwork that helped save the life of a heart transplant patient who was admitted that night. Even though she did not use specific identifiers, that nurse broke confidentiality. If that patient was the only heart transplant patient in the hospital that day, it would not be hard for someone to figure out about whom the nurse was talking. Another confidentiality breach would be accessing the organization’s electronic medical record without a valid reason. As another hypothetical example, a nurse cares for a patient in the intensive care unit for three weeks after a car accident. The patient improves and is transferred to the pediatric inpatient rehabilitation unit. The next day, the nurse checks the patient’s medical record to see how the patient is doing. This is a breach of privacy because the nurse is no longer caring for that patient. When a nurse is no longer actively involved in a patient’s care, he or she has no legitimate reason to access that patient’s medical record.

Appropriate policies and expectations must be in place to ensure that healthcare providers use technology and social media appropriately and do not cross boundaries. Maintaining professional nursing boundaries is an essential component of a healthy nurse-patient-family relationship. Because nurses spend so much time with patients and families, the nurse may be asked questions he or she is unable to answer or questions that make the nurse uncomfortable. Families of long-term patients often seek friendship and distraction. These factors can lead to distorted views of the nurse-family relationship. As another hypothetical example, a nurse had cared for a pediatric patient for more than four months, and the father asked for the nurse’s phone number. The nurse was unsure how to respond and gave her personal phone number to the father. Later, the father began texting the nurse messages that made her uncomfortable, and the nurse-family relationship was broken. Nurses must recognize that the nurse-patient-family relationship is professional, not personal. By respectfully declining inappropriate requests, the nurse can maintain professional boundaries and protect the nurse-family relationship, which ultimately benefits the patient. Nursing leadership should be contacted for questions or recommendations about these difficult situations, and the leadership should consider proactive training for nursing staff.

Conclusion

The pediatric nurse has a unique opportunity to make a substantial impact on pediatric patients and their families. Through advocacy and caring, along with utilizing good communication strategies, nurses can make a tremendous difference in the lives of those they touch. The communication techniques chosen by the pediatric nurse must be tailored to fit each individual situation. When collaborating with other members of the healthcare team, the nurse must be assertive, knowledgeable and respectful. When talking with pediatric patients, the nurse must speak and act in developmentally appropriate terms, so as to build trust and ensure understanding. While interacting with families, the nurse must be compassionate, realistic, honest and informative. To optimize the quality of patient care, nurses need to practice and share

communication techniques with one another and engage in lifelong learning to meet the needs of pediatric patients and families.

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Chapter 15

Point of View: the Child Life Specialist

Lauren Hollis, CCLS

What Is a Child life Specialist?

Child life specialists are trained professionals with expertise in helping children and their families overcome life's challenging events. With a strong background in family systems and child development, child life specialists promote effective coping through play, preparation, education and self-expression activities. They provide emotional support for families and encourage optimal development of children facing a broad range of challenging experiences, particularly those related to healthcare and hospitalization. Because they understand that a child's wellbeing depends on the support of the family, child life specialists provide information, support and guidance to parents, siblings and other family members. They also play a vital role in educating parents, administrators and the general public about the needs of children under stress (Child Life Council, 1998).

Helping a Child Cope with Hospitalization:

Rollins et al. (2005) note that a child's reaction to hospitalization is affected by his or her developmental age, the constellation of stressful events, the diagnoses, available support systems, coping skills and past medical experiences. Stresses in the hospital include, but are not limited to: loss of control; the perception of bodily injury; separation from family and friends; pain; a reduction in developmentally appropriate activities; and the unfamiliar hospital setting.

The term "coping" refers to what a person does and how he or she does it during a stressful situation to avoid, remove, minimize or *get through* it. (Gaynard et al., 1998). Children cope in different ways. For example, for some children crying during a procedure can be an effective coping technique as long as they are cooperative and follow commands. Crying also can be an effective way to express feelings during an emotional experience. According to Gaynard et al. (1998), effective coping can be linked with the concepts of mastery, competence and effectance (behavior that leads to the building of effective results). When children are able to effectively cope with stresses encountered in the hospital, they experience a sense of mastery or competence that can generalize to other potentially stressful situations. A child life specialist's main focus is to help minimize anxiety and increase positive coping.

A child's world revolves around play, and it can be a challenge to play in the hospital. It is important to remember that play is a universal language and is one way by which children communicate. Professionals need to work with children on their level. A child life specialist focuses on including therapeutic play, expressive activities, medical play and medical art to help normalize the hospital experience. Many children do not cope well in the hospital due to a variety of factors. These include: lack of knowledge about their diagnoses and procedures; lack of understanding about how the hospital works and how the staff functions; and lack of normalization opportunities. Brewer et al. (2006) stated, "Fear of separation, loss of control, unfamiliar routines, instruments, and environments were all sources of children's negative reactions." Therefore, providing developmentally appropriate preparations for surgery and procedures using pictures, medical equipment, role play and appropriate language describing what the patient will hear, feel,

taste, smell and touch can decrease a child's anxiety. In addition, providing opportunities for play and nonmedical conversations is important.

Building Trust: A Gateway to Communication

One of the core competencies that a child life specialist must possess is the ability to successfully build rapport with a pediatric patient and family and interact with the patient in an age appropriate manner. We cannot build rapport and trust if we cannot communicate effectively with a child. When working with pediatric patients, it is important that each team member understands how to successfully build rapport with the patients. The first aspect of building rapport is to get down to the child's level, physically. Standing over a child conveys the message that you are in charge and have power over the child. Getting down to the patient's level shows that you want to be an equal and engage with the child. Once you are engaged with the child, ask questions and do not assume you know the answers. For example, if a patient is crying, instead of saying, "I know you are scared." you could say "I see you are crying. Can you tell me why you are crying or how you are feeling right now?" Then make sure you validate the answer and feelings that the child expressed to you. It is important to remember that however the child feels is considered normal. Do not tell a child, "Don't be scared; it will be ok." It is appropriate for the child to be scared.

With pediatric patients, you cannot assume anything about their understanding of the hospitalization. Depending on developmental level and past experiences, the patient may have many misconceptions. It is important when building rapport, not to use words the patient may not understand. For example, telling a four year old child, "You are going to have an IV placed in your arm by the VAT (Vascular Access Team)." could be interpreted as, "You are going to have a plant (ivy) put in your arm by a bat." This misconception is due to a four year old child's magical thinking. Instead you could say, "You are going to have a small tube, like a straw, put in your arm so that you can get some water and medicine through the tube. A nurse is going to come into your room to put that straw in your arm." At that point a child life specialist can provide the patient with an opportunity for medical play to help familiarize the patient with the IV and associated medical equipment, as well as an opportunity to discuss and rehearse a coping plan.

Another component in successfully building rapport with a patient is to be honest and not make promises you cannot keep. If you tell a child, "I promise that your chest tube will be taken out by the end of the day." and it does not get removed for two more days, that child may have a difficult time trusting you again. And the child could generalize the lack of trust to all or most medical team members since a medical professional "lied" to her. Be open and honest about what is going to happen. You could say, "I hope that we can take out your chest tube today, but I can't make any promises. I know you are ready to get it out so we will take it out as soon as we are sure you don't need it anymore."

Consider the developmental age of the patient. Below is some basic information about developmental levels and how to build rapport with children in each age group.

6 to 12 months

At this age the child's primary source of stress is separation anxiety. Separation anxiety is anxiety and stress from being separated from the parent(s), with whom the infant has bonded. One way to build trust with infants in this age group is to allow parents to be present and hold the infant during examinations, conversations and when a stranger is present. Age appropriate distractions, such as bubbles and rattles, during interactions can be highly effective as well.

1 to 3 years

In this age group a primary source of stress during hospitalization is restriction of ambulation and access to areas to explore. Being limited in ability to ambulate and explore can cause regression in a child's psychomotor, behavioral and social skills. Allowing the child to explore during the hospitalization and even during examinations (e.g., playing with the stethoscope) can help reduce this anxiety. Find ways to encourage mobility outside of the child's hospital room if possible. Utilizing age appropriate activities such as giving the child stickers, blowing bubbles and playing with toys can be an effective way to build trust.

4 to 5 years

One of the preschool child's main sources of stress is magical thinking. Children believe they have the ability to wish things to happen (Rollins et al., 2005). Children at this age may view the hospital as a form of punishment, thinking that it is their fault that they are hospitalized. If children of this age are not given the opportunity for practice and development of psychomotor, behavioral and social skills, they may experience regression in these skills. Using developmentally appropriate language and explaining what you are going to do before you do it can help mitigate fears and eliminate misconceptions. Explaining why the patient is having a procedure or receiving medicine so as to clarify any misconceptions is very important. If a patient requires a procedure, it can be effective to perform the procedure in a room other than the child's hospital room (e.g., a treatment room). This helps to keep the child's hospital room a relatively safe place.

6 to 12 years

Much of the school-age child's stress in the hospital is centered on the lack of socialization and absence of a normal schedule. Contact with family and peers is very important. Implementing a schedule, including times when patients can interact with other patients their age (if appropriate) or communicate with their peers and families, is important.

13 to 19 years

Major sources of stress for the teenager are the need for privacy and independence and the need to find his or her identity. It is difficult for a patient to have privacy and independence and to establish his or her own sense of identity while in the hospital. A few ways to build rapport with the patient while meeting his or her needs are to: allow the teen to wear his or her own clothes (if appropriate); allow the teen to keep his or her door closed; and require personnel and visitors to knock before entering. In addition, encouraging patients to engage in normal activities that they like, such as journaling, playing video games, participating in arts and crafts and reading while in the hospital can help reduce stress and promote trust.

Examples of Words and Phrases to Avoid and Substitutes

Listed below are some examples of words and phrases to avoid, the implications of these words or expressions and suggestions for appropriate alternate wordage.

Physician: "We are going to give you some dye." This could imply "to die."

Suggestion: "We are going to give you some medicine in that tube (or straw) in your arm that will help us to be able to see your _____ more clearly."

Nurse: "I need you to collect some urine." This implies "you're in" to children.

Suggestion: "I need you to go "pee" (or the child's familiar term) "in this cup."

Physician: "I am going to put you to sleep." The child might have had a past experience with a pet being "put to sleep," and it never came back.

Suggestion: “I am going to give you a medicine that will help your body go to sleep. It is a different kind of sleep from the naps you take at home. When you wake up and the medicine wears off, you will be able to see your _____ (parent or caregiver).

Surgeon: “I am going to open you up during surgery.” or “I am going to cut it out.” This could imply pain or body mutilation to the child. Use concrete explanations.

Suggestion: “While you are sleeping, I am going to make a small (if it truly is going to be small) opening and take out the sick part of your tummy.”

Nurse: “We are going to do a dressing change.” A child might think he needs to change his clothes or that you are going to undress him.

Suggestion: “We are going to change your bandages for new ones.”

Pediatrics and Pain

Pain is subjective and very difficult to explain and measure because individuals learn the application of the word through different experiences in their life (Young, 2005). If you tell a child that something will not hurt and it does hurt, he or she may think you have lied intentionally. Instead, you could tell the patient what you are going to do. For example, instead of saying, “I am not going to hurt you.” you could say, “I am going to listen to your heart and touch your stomach.” This is telling the child exactly what you are going to do and does not give false expectations. Since pain is subjective and different for each person, it is better to use concrete words associated with the sensation that they may feel. For example, if a child is having an intravenous catheter placed, you could say, “Some children say it feels like a pinch, bee sting, ant bite or poke. You can tell me what it feels like to you.” According to Young (2005), “a child’s experience during painful medical procedures likely plays a significant role in shaping that individual’s pain response to future events.” Therefore, it is important to help children have a positive coping experience during medical procedures. Ways to help a child cope with a medical procedure include:

- Consulting a child life specialist in advance of the procedure
- Making sure the patient is provided developmentally appropriate preparation for the procedure
- Offering choices when choices are available
- Providing a calm environment with minimal background conversations
- Offering parental presence and support when available and appropriate
- Utilizing pain management techniques
- Using developmentally appropriate language throughout the procedure
- Provide items for distraction during the procedure, e.g., an *I Spy Book* (Marzollo and Wick, 1992-2012), a stress ball, an iPad, games and bubble blowing

Chronic pain is generally more of a challenge than acute pain, both to the patient and to the healthcare professional. Things that can help a patient with chronic pain include: distraction (e.g., arts and crafts, movies, video games, other games, books and puzzles); guided imagery; deep breathing techniques; squeezing a stress ball; massage; and self expressive activities. When a patient’s chronic pain cannot be completely alleviated by non-pharmacological measures, pain medication will be required. Helping the patient understand his or her pain and describe the pain and its intensity is a very important part of pain management. Many patients have a difficult time identifying their pain on a scale of 1-10 or 1-5 because each person’s perception of pain is different. For example, one child’s interpretation of a pain level of 10 could be being bitten by a shark, while another child’s interpretation is breaking his leg. It is important to find the pain measurement that works best for each individual patient. If you have a patient who is having a

difficult time using a numerical or faces scale, you could have him or her create a personal scale with his or her interpretations of pain. (See Chapter 12, *Point of View: the Pain Management Team*.)

End of Life: The Vital Role of Communication and Language

There are many variables that affect end-of-life conversations with families of pediatric patients. The most important, obviously, is whether or not the patient has already died, and if so, what were the circumstances of the death. Other important factors include: the social, cultural and religious support available to the bereaved; the strength of their attachment to the child; their coping behaviors; and their degree of ambivalence towards the situation.

When talking to families about end-of-life issues there are several aspects to consider. Before you start the conversation, find a quiet and safe place to talk. Be direct and honest about the patient's current health, the prognosis and the plans and options for end-of-life care. Usually the most difficult words for a healthcare professional to say and for the bereaved to hear are the words "death" and "dying". Yet these words are very important during end-of-life conversations. Family members may experience a number of feelings and emotions, and it is important for them to hear these words so as to start processing what is happening and not misinterpret the conversation. (See Chapter 19, *When the Death of a Child is Anticipated and Imminent*.) Other aspects include matching the affect of the family members and not being inappropriately cheerful or humorous. Know the child's name and use it. Be comfortable with silence and honor family wishes regarding privacy and visitors. Be available. Allow parents to express as much grief as they are feeling at the moment, expect different reactions from different people and encourage parents to be with the patient and with each other.

Below are some helpful things to tell families:

"I am sorry. I know this is a difficult time for you."

"What can I do to support you?" (Then do it.)

"Is there anyone I can call for you?"

"I know that nothing I can say will make this any easier or better for you."

Family members cannot always remember a lot of information during these situations, and it is often the small but useful things that you say that will help a family. Some phrases that families may *not* find helpful are:

"It was God's will."

"He is in a better place."

"Everything happens for a reason."

"Time will heal."

"You have to be strong for your ____ (wife, husband, other children)."

"The child would not have been normal anyway."

"At least she isn't in pain anymore." or "At least she lived a good life." (Beware the phrase, "at least"; it can be interpreted as implying that the death was not that bad because...)

These statements are not helpful because of the raw and intense emotional pain that a family goes through during the death of a child. The family loved the child and wanted the child alive and with them for as long as possible.

Parents often have a difficult time explaining the patient's prognosis or that the patient has died to siblings and other children in the family. A child life specialist can help the family provide an age appropriate explanation of death and dying, as well as an explanation of the illness. It is important to remember that children grieve differently than adults. Preschool age children will

often revert to playing after being told about a patient's death or poor prognosis. It can sometimes be hard for parents to understand why the sibling does not appear sad. This does not mean that the sibling is not sad; it is the child's way of processing and coping with the information. A teenager might become quiet and not want to remain at the bedside for a long period of time after the patient has died. These are all normal responses to grief. Davies wrote (cited in Rollins et al., 2005), "Siblings who are included at the time of death and in the rituals following the death are better able to reconcile the loss." A child life specialist can explain the spectrum of normal grief responses in children to the family in advance.

A child life specialist can offer memory making items and options, resources and encouragement of rituals during the time of grief and bereavement. For patients who are at the end of life and are alert and interactive, many of the rituals, memory making and legacy building activities and sibling support can be done with patient involvement. Some examples of memory making might include ink prints and molds of the patients' hands and feet, locks of their hair and pictures of the children and family members, either separately or together, for example, parents bathing the infant, holding the toddler or playing with the older child. These memories can be made by hospital personnel for the family or with the involvement of the family members. It is the family's option to have these memories and to participate in their creation. "What people who have experienced a loss believe, feel and do varies enormously from culture to culture." (Rollins et al., 2005). Some families have rituals that are very important during the bereavement process but do not encourage memory making. According to McGoldrick et al. (cited in Rollins et al., 2005), there is a series of questions to consider in making a plan to support parents and families during a time of bereavement:

- What are the prescribed rituals for handling the dying process, the dead body and the disposal of the body; what are the rituals to commemorate the loss?
- What are the family's beliefs about what happens after death?
- What are the family's beliefs about appropriate emotional expression and integration of a loss experience?
- Does the family have gender rules for handling a death?

Conclusion

The child life specialist is uniquely qualified to help the patient and family cope with the stresses of illness and hospitalization. Some of the principles of communication employed by the child life specialist, for example, talking in non-medical and age-appropriate language and avoiding words that can have unintended implications or be easily misunderstood by a child, can be used by all healthcare professionals. Other techniques, such as guided imagery and some methods of distraction, usually require the special training of the child life specialist. The support provided by a child life specialist can be especially helpful for patients undergoing procedures and for patients and families dealing with end-of-life issues.

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Chapter 16

Point of View: Team Approach to Communicating with Patients and Families in a Multidisciplinary Clinic

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A multidisciplinary approach to patient care has been a goal for effective and safe healthcare delivery for decades. The concept was introduced in the 1970s and proven effective in the 1980s, with continued evidence to suggest that patient care is safer when it is coordinated and collaborative (Mitchell and Crittenden , 2000; Yeager, 2005). When patient care involves complex or multiple chronic problems, it is difficult for one provider to meet all the needs of a patient and family. This is particularly true in high risk areas such as the intensive care unit, emergency department and operating room. Research shows that interdisciplinary care improves patient satisfaction, reduces errors (Kohn, 2000), improves clinical effectiveness and efficiency (Firth-Cozens, 2001) and improves the morale and job satisfaction of team members (Firth-Cozens, 2001). However, barriers to effective communication among team members are common. Typical barriers include: changing team structures; breakdowns in communication; insufficient time; and role ambiguity (Yeager, 2005). Overcoming these barriers is critical in order to deliver a consistent message to patients and families.

While we will use the pediatric multidisciplinary clinic as a model for this chapter, its importance in other settings, such as in-hospital, is recognized and appreciated.

Communication within the Team

When many professionals are involved in the care of a patient it is important to define a core group of individuals to take ownership of care coordination and communication. Depending on the clinical scenario, the core group is likely to include physicians, mid-level practitioners, nurses, social workers, therapists and medical assistants. By defining critical members of this core team, a consistent approach to patient care can be achieved. Additionally, by having diverse core teams, providers other than physicians are likely to have a greater sense of ownership in the wellbeing of patients. Members of this core team should be defined by their professional outlook and not necessarily by the individuals themselves. This allows some flexibility and fluidity to the team, as members frequently come and go. A cohesive team is one in which all members recognize the unique and valuable contribution each discipline offers to patient care.

Once a core team is established, leadership and direction must be provided. Leadership is often the role of the physician, in part because the physician is the driver of the care plan and also because patients and families have the expectation that their physician will be the team leader. Effective leadership defines the roles of members, promotes conflict resolution and encourages healthy communication (Yeager, 2005). However, an effective team is one that respects all members, understands shared as well as individual responsibilities and encourages members to use their unique skills and expertise when approaching patient care. This ultimately encourages open discussion and the free flow of information among team members.

Effective clinical care by a team relies on effective communication. This is best accomplished by having team members housed in the same building, to allow better integration and less fragmentation among members (Cook et al., 2001). This can be accomplished in other ways using modern technology. An electronic medical record allows easy pre-visit reviews of interim history and laboratory data and can promote consistency in care through clinical protocols and patient panel management. However, face-to-face communication is crucial, and regularly scheduled care coordination meetings are an excellent way to get all members of a team on the same page, especially when working with medically complex patients (Xyrichis and Lowton, 2008). By meeting regularly, goals and objectives for patient care can be established. Scheduled coordination meetings can also allow effective communication between inpatient and outpatient care teams. A core team can provide leadership and sharing of information to the multitude of providers a patient is likely to encounter across the hospital or clinic setting. Time is essential for this process to be effective and should be allocated appropriately for all team members. This can be a challenge, given the large patient loads in today's healthcare environment and the limited amount of time allotted to each patient. In order for team care to work, institutional support for adequate time is crucial (Fewster-Thuente and Velsor-Friedrich, 2008). The confidentiality of medical information is also something to consider when multiple providers are caring for the same patient. The chances of inadvertently disclosing confidential information to outsiders increases when a team discusses patient care in a non-secure area such as outside the patient's room. The team must take conscious precautions to protect private information when in the halls and work spaces of a clinic or hospital.

Communication between the Team and the Patient

Once fluid and effective communication is established within a team, optimal communication with families should ensue. Care coordination meetings allow providers a broader understanding of a patient's needs and a consistent message when speaking to the patient and family. Effective communication as a team requires a single point of entry. This is best done by having a person familiar to the family (such as a medical assistant) answer the phone and direct questions to the appropriate members of the team. Families appreciate this consistency and begin to trust and rely on the *front person* for information. This person should be an integral part of the team in order to be familiar with a patient's medical history and needs, thereby effectively handling everyday questions.

In a multidisciplinary clinic, many providers are likely to see a patient on the same day. Confusion ensues if the family detects conflicting information. Having a consistent message among team members is essential. Additionally, having clear role expectations and ensuring that individual team members focus on their area of expertise help to avoid unnecessary overlap and confusion.

Team care can also improve a patient's understanding of information given in the clinical setting. A study by Ley (1988) found that 7% to 47% of patients do not understand information given to them during typical clinical encounters. When all team members are involved in care coordination meetings, questions that arise after clinic visits can be addressed appropriately by fellow team members to strengthen and reinforce ideas or care plans previously discussed in clinic or in the inpatient setting. The more often a patient and parents have the opportunity to hear difficult or complex information, the better their understanding will be. Additionally, the advantage of a diverse team is the different techniques that are employed in relaying similar information. Multiple communication styles can be very advantageous when discussing nuanced information. The more a patient and parent(s) understand about the diagnosis, the more likely

they are to comply with recommendations. However, shifting to a team based system of care can be confusing for patients who are accustomed to a single physician providing all the information. We find that this is best handled by letting families know upfront which aspects of care will be addressed by which team members.

Team Communication in Pediatric Healthcare – Role of the Social Worker

Social workers are integral members of effective healthcare teams for several reasons. Social workers have expertise in communicating with patients and families and often serve as a bridge between other healthcare professionals and the family, helping to facilitate optimal communication. Social workers have advanced training in family systems and are able to assess family dynamics that contribute to challenges in implementing the healthcare team's recommendations. They also can identify and address problematic team dynamics and communication breakdowns among members of the healthcare team, as well as those that occur between the team and the family.

Inherent to the social work perspective is recognition that an individual's situation cannot be understood without also understanding the social context of that person. For a child, the most basic social context is his or her family. A social worker addresses the family's situation and needs, as well as the child's individual needs, because it is impossible to address the patient's needs without looking at the larger picture. This holistic approach may sometimes appear to be in conflict with the perspective of other medical professionals whose responsibility is to focus on the child's symptoms, disease process and treatment options. However, a holistic or family-centered-approach can complement rather than conflict with a disease-centered approach. The social worker may be aware of the financial, logistical and other psychosocial barriers that families face in trying to meet their children's needs. In the current era of family-centered care, this information can assist the team in developing a plan that meets the child's needs, while taking into account the family's strengths and challenges.

Social Worker as a Bridge

It is not uncommon for members of the healthcare team to use medical terminology or to talk with families at a level that is well above their understanding. Social workers are trained to continually check for understanding and to help translate the medical professionals' verbiage into a language that the families can understand. Within the team, it is essential for social workers and physicians to communicate clearly with each other and, as frequently as necessary, to ensure that they are on the same page and that the social worker has a full understanding of what has been relayed to the family so that there is no miscommunication. Social workers have the responsibility to check for their own understanding before communicating any medical information to families.

It is common for families to feel more comfortable talking to a social worker and asking questions that they might be embarrassed to ask their physician. Families are often reluctant to let physicians know that they do not understand something, or they may be reluctant to ask questions out of fear that they will be perceived as questioning the doctor's authority. Families may be more at ease with and less intimidated by a social worker, who is more likely to be perceived as an equal rather than as an authority figure. The social worker can then serve as a conduit for information between the healthcare team and the family, relaying patients' and families' questions to the appropriate team members.

Conversely, some families may have had negative experiences with a social worker in the past, particularly if they have been involved with the child protection system, and may be more likely to share information with another member of the team. In these cases, a family may convey

psychosocial concerns or stressors to another healthcare professional instead of to the social worker. It is important for other team members to communicate this information to the social worker for appropriate follow-up.

Social Work and Family Dynamics

As Fineberg (2010) notes, “Theoretical approaches and clinical skills applied by social workers make them logical leaders for practice and guidance in family-oriented communication and care.” Social workers are usually responsible for coordinating family meetings and patient care conferences, which provide a forum for the majority of the multidisciplinary team communications with the patient and family. During these meetings, the dynamics of the particular patient and family are often most evident. When a child becomes ill or has a chronic or disabling condition, this affects not only the child and his or her parents, but the family system as a whole. In turn, the reactions of individual family members can have a positive or negative impact on both the child and other family members. On the positive side, family members can be a strong source of support and comfort for one another. On the negative side, however, individual or family dysfunction can contribute to a child’s distress, as well as to the family’s ability to follow through with the child’s care plan.

When working with a family that is evidencing dysfunctional dynamics, it is essential for team members to agree in advance on a plan for communicating with the family members. They may need to be repeatedly redirected from their focus on their interpersonal problems to the child’s needs. Families that display signs of escalating internal conflict may need more assertive intervention, including removal from the patient care area if their conflict has the potential to upset the child or disturb other patients and families. Families may also engage in dysfunctional communication patterns, such as attempting to split the team, and team members must recognize these types of behaviors, discuss them and present a unified front to the family. The following is an example of this type of splitting:

Mother (to attending physician): “I don’t understand why you are telling me that Madison can’t go home until her dad comes in for training. Dr. Specialist said we’re doing great, and as long as I know how to do the trach care, I can show her dad once we’re home. Dr. Specialist really understands what our family is going through.”

The background for this scenario is that the mother has repeatedly challenged the attending physician and has either misunderstood or intentionally misrepresented information from the specialist. The physicians and other members of the team need to identify this type of behavior early in the episode of care, ensure that they are in accord and present a consistent message to the mother.

It is also important for the team to keep in mind that the overarching purpose of communication with the family is to address the child’s health needs and not to become enmeshed in the family’s broader problems. Similarly, the role of the medical social worker is not to conduct family therapy but to address the family’s immediate needs and to help resolve barriers to adhering to the child’s plan of care.

A major advantage of multidisciplinary team communication with families is that key members of the family and healthcare team are all present at the same time to hear the same information, clarify any areas of confusion and work together to formulate a plan. This type of communication is integral to effective family-centered care.

Social Work and Team Dynamics

Before a healthcare team can effectively communicate with a family, it is essential that the

team members have effective internal communication. In general, a team that communicates well functions well, and “Disharmony within a team is often manifested in communication difficulties.” (Foley, 1993). In order to establish effective team dynamics and team communication patterns, team members must have a good understanding of and respect for each other’s roles. Team members must also be aware and respectful of the differing perspectives of each discipline. For example, the social worker’s emphasis on patient and family self-determination may, at times, seem at odds with the more prescriptive approach of other members of the healthcare team.

Because the social worker is attuned to potentially dysfunctional *family* dynamics, he or she is often the first person to identify problematic *team* dynamics. Tensions and communication breakdowns within a team have been shown to contribute to decreased provider and patient satisfaction and are likely contributors to poor patient outcomes (Foley, 1993).

Coordinating Team Communication: a Clinical Nursing Perspective from a Multidisciplinary Clinic

Preparing for the Clinic Visit

Team communication is crucial for the success of a multidisciplinary clinic. One of the most important roles of a clinic nurse in facilitating effective communication is to help prepare the team for each clinic session. Prior to the scheduled visit, the nurse should review the patient’s chart to make note of any new laboratory or imaging results, emergency room documentation and primary care or subspecialty notes since the last visit to the multidisciplinary clinic. However, it is not always possible to capture complete information if the patient is seen by providers outside the organization or medical group. The nurse should also make note of the patient’s diagnoses, medications and other pertinent information documented by the medical team at the patient’s last visit.

In preparation for the patient’s visit, a pre-clinic team meeting should be held to discuss vital information the nurse has gathered since the patient’s previous visit. Although attendance at the meeting may vary, depending on the type of multidisciplinary clinic and provider availability, typical attendees include the nurse, clinic coordinator, social worker, dietician, physical therapist, occupational therapist, specialty physicians and individuals from other services provided in the clinic, as appropriate. This pre-clinic visit allows team members to re-orient themselves to the patient and family, review clinical concerns and develop a coordinated plan for the upcoming clinic visit. This coordinated planning results not only in an efficient clinic visit but also helps to reassure the patient and family that the team is knowledgeable about their care.

The Clinic Visit

Coordinating the multidisciplinary visit is often challenging, not only with regard to scheduling, but also in ensuring that patient confidentiality is protected. In order to protect patient privacy, the team should gather in a conference room and limit conversations about the patient to this room. In a busy multidisciplinary clinic, visual aids may help to optimize team communication. Using a dry erase board is one option. In the example below, the team uses the board to write the room number, patient name and the services that will see the patient during the clinic session. The team in the Texas Children’s Hospital Multidisciplinary Clinic uses an “X” to indicate that the patient is to be seen by a service and an “-O-” if the patient will not be seen by that service during clinic. The board can also be used to write notes about patients’ needs or the language they speak (Figure 1). When a member of the team is in the patient room, a magnetic disk can be placed by the patient’s name under the particular service to indicate who is in the room. To facilitate clinic flow, it is also helpful to have a clinic coordinator who can remain near the dry

erase board to enter updates and make sure the clinic runs smoothly. Visual aids and an identified *traffic controller* can help the team work together more efficiently and avoid mishaps or duplications of effort. The board is in the physician’s workroom where access is limited to authorized personnel.

Figure 1. Example of a Patient Services Board.

RM #	Patient		Pedi	NS	Uro	PM&R	Ortho	Nutr	SW	CLS	PT	
1	Johnny Smith			X	X	X	X	X	-O-	X	-O-	
4	Jenny Jones		X	X		X	-O-	X	X	X	-O-	Urine culture needed
5	Jesus Garcia	Sp	X	-O-	X	-O-	-O-		X	-O-	X	

 = Pediatrician

 = Urologist

 = Nutritionist

Sp = Speaks Spanish

During the multidisciplinary clinic session, the nurse should focus on carrying out physician orders, such as providing wound care, collecting specimens for the laboratory, completing laboratory requisitions and administering immunizations or other injections. A critical role of the nurse is to provide the patient and family members with education on a variety of topics. The nurse also needs to make sure that the team continues to communicate effectively regarding patients throughout the clinic session. Finally, the nurse needs to facilitate a smooth discharge by ensuring that the patient and family understand what took place during the visit, that all their questions have been answered adequately and that they understand the follow-up plans.

After the Visit

Team communication is important after the clinic session, and the nurse can serve as the liaison for all after visit follow-up requests. Phone calls are often needed to ensure that the family understood the information provided during clinic. The clinic nurse is often the first person to identify barriers to the family’s ability to understand and adhere to the care plan. When complex medical recommendations are necessary, parents may need additional support and guidance. Often, multiple phone calls will be needed as families can be overwhelmed by what may seem routine to the treatment team. The nurse is crucial in helping each patient achieve the best outcome, through ongoing support and education. In addition, relaying the family’s challenges back to the team will allow modification of the care plan as needed.

Between clinic visits, the nurse also serves as the patient’s primary connection to the physicians. The nurse needs to be skilled at phone triage since any given call could be an emergent situation. Can the patient be observed at home? Does he or she need to be seen by

the pediatrician or evaluated by a subspecialist? Does the patient need to go to the emergency department?

The nurse plays a vital role in the multidisciplinary clinic, as the facilitator for communication and ongoing patient education, as well as functioning as an intermediary between the family and the physicians.

Conclusion

While each member of a multidisciplinary clinic team has a unique perspective on team communication with children and families, the overarching concepts are common across disciplines. A team that communicates and functions well, with team members using their individual skills in mutually effective ways, makes patient care more proactive and more effective. Research has shown the many benefits of strong interdisciplinary teams: fewer and shorter delays in patient care; improved morale, increased job satisfaction and lower overall stress among employees; increased efficiency of staff; improved patient satisfaction; and enhanced clinical effectiveness with fewer errors (Yeager, 2005). Overall, teamwork, when implemented with appropriate delineation of individual roles, gives caregivers more control over their work environment and provides a safety net against clinical errors.

For teams to provide optimal patient care, all members must be able to communicate effectively both internally and with the patients and families they serve. Team members must be attuned to the potential challenges of team communication and must take care to deliver clear and consistent information to families. As a result, families whose children are cared for by multidisciplinary teams will reap the benefits of multiple professionals' expertise and support.

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Section 3.

Delivering Bad News

Section Editor: Antonio G Cabrera, MD

Chapter 17

Delivering and Discussing Bad News

Antonio G. Cabrera

Introduction

Bad news can be defined as information that does any of the following:

- Adversely affects a person's view of his or her present or future world
- Conveys a threat to a person's mental or physical well being
- Upsets an established lifestyle or limits a person's life choices
- Engenders a feeling of worry, fear, despair or hopelessness

Most of us have encountered clinical situations in which we were challenged to deliver bad news to patients and their family members. Receipt of such information can cause immediate or delayed changes in the individual's life and relationships to others, including the physician-patient relationship. These changes can be temporary or long-lasting. Bad news can engender a wide array of reactions from patients and parents, depending on the individual's life experiences, personality, emotional stability, culture, spiritual beliefs and worldview, as well as the available emotional and social support. Given the wide array of potential responses to receiving bad news, healthcare professionals often find it difficult to step back and take all these aspects into account.

Why Do Healthcare Providers Find It Difficult to Talk about Bad News?

One reason for difficulty in talking with patients about bad news, aside from the fact that bad news is *bad*, is that many healthcare professionals have had limited training in this regard. Insufficient training results in inadequate self-confidence. Even for clinicians with training and experience in delivering bad news, talking with patients about issues that will cause them distress and discomfort may similarly cause distress and discomfort in the clinician. The clinician may also experience feelings of anxiety, sorrow, guilt, and failure. A study by Ramirez et al. (1996) suggests that the discomfort felt by healthcare providers in delivering bad news does not diminish with time and experience. This study reported that dealing with patients' suffering was one of the top three factors given for burnout and psychiatric morbidity by oncologists and other physicians. The study also found that burnout was more prevalent among those consultants who felt insufficiently trained in communication skills (Buckman, 1992). Pediatrics poses special challenges. A survey of beginning residents in internal medicine, family medicine and pediatrics found that residents reported having received less training in, and feeling less prepared for, communicating with pediatric patients than adult patients, especially with regard to delivering bad news (Dubé et al., 2003).

We Do Not Want to Cause Pain

As physicians, nurses and other healthcare professionals, we have been trained to relieve pain and suffering and are hesitant to do anything that will cause pain or suffering. For this reason, we may find it difficult and challenging to deliver bad news.

We Do Not Want to Be Blamed

Healthcare providers tend to associate the success of a treatment with personal success. If the treatment is not successful, the provider may feel that he or she is not successful. And when

the clinical outcome or anticipated outcome is disappointing, the patient or family may blame the clinician rather than the disease.

We Are Uncomfortable Doing Things for which We Do Not Feel Well Prepared

Healthcare professionals function most comfortably when following guidelines, protocols, recommendations or validated empiric approaches. When it comes to conveying bad news, however, there is no clear, validated guideline to follow. There are numerous protocols (Table 1) which are generally believed to be helpful, but in a review of the literature, Paul et al. (2009) noted that less than 2% of publications in the arena of delivering bad news to cancer patients were rigorous intervention studies which addressed psychosocial outcomes for patients and concluded, "Current practice and training regarding breaking bad news cannot be regarded as evidence-based until further research is completed."

Studies querying physicians and other healthcare providers about their perceived ability to deliver bad news have shown that there is a low level of comfort and self efficacy when needing to deliver bad news (Ptacek and Eberhardt, 1996). In a review of the medical literature on communicating bad news published in 2004, Fallowfield and Jenkins concluded that although there were many studies and position papers on this topic, there was little evidence that this material had significantly affected the behavior of providers or satisfaction among patients (Fallowfield and Jenkins, 2004).

We Are Hesitant to Express Emotions

For many years, the image of the physician or nurse was one of imperturbable, unemotional, scientific calm, even in the face of horrendous human pain and suffering. Historically, surgeons amputated injured or gangrenous limbs without benefit of anesthesia, and nurses cared for wards of patients dying slowly of tuberculosis or quickly of cholera. In these horrific situations, showing emotions such as fear or loathing or even pity would be seen as weakness. Times have changed, but perhaps a collective subconscious still prevails to mute the clinician's expression of emotion.

Talking with patients or parents about death or other devastating news may cause us to confront our own emotions, and therefore we hesitate or feel uncomfortable. One of the reasons we might be unwilling to express emotions is our own fear of mortality. Maintaining an image of the unflappable clinician can be at odds with the need to communicate with compassion and can create a distance between the clinician and patient or family.

Including Children and Adolescents in the Discussion

Older children and adolescents are expected to be active participants in their own care, and discussing their health and illnesses with them reinforces this notion. The ethical principles of self-determination apply to children. (See Chapter 6, *Ethical Considerations in Communicating with or about a Child*). Involving children in their healthcare decisions shows respect for their capacities, enables them to provide input in their care decisions (especially in situations where there is not a single, clear best way to proceed) and will make them better decision-makers in the future. In circumstances in which there is disagreement between patients and their parents, the family, the family values, cultural preferences and roles, and cultural values should guide a respectful exchange with the family and the child. (Levetown, 2008).

Delivering and Discussing Bad News

A number of protocols provide a structured approach to delivering and discussing bad news (Baile et al., 2000; Rabow and McPhee, 1999). A comparison of four of these protocols is shown in Table No. 1. It is evident that these four protocols are remarkably similar albeit not identical. While the table only addresses *the patient*, in pediatrics, of course, we are usually communicating

with the parents as well, and in the case of an infant, only with the parents. In this chapter we will focus on the Six-steps approach suggested by Buckman et al. (1992).

Table 1. Comparison of Four Commonly Used Protocols for Delivering Bad News

Six-steps	SPIKES	BREAKS	ABCDE
Buckman, 1992	Baile et al., 2000	Narayanan et al., 2010	Vandekieft, 2001; Rabow and McPhee, 1999
Getting started	Set up for the interview	B ackground: review medical record R apport: set up space	A dvance preparation
Finding out how much the patient knows	P erception: access patient's knowledge and understanding	E xplore: determine what patient knows	
			B uild a therapeutic relationship
Finding out how much the patient wants to know	I nvitation: obtain patient's permission to proceed		
Sharing the information	K nowledge: share information	A nnounce: deliver warning and then the bad news	C ommunicate well
Responding to the patient's and parent's needs	E motions: recognize and respond to patient's emotions	K indling: recognize and respond to patient's emotions	D eal with patient and family E ncourage and validate emotions
Planning and following through	S ummarize and explain strategy and plan	S ummarize	

1. The Setting and Getting Started

Find a quiet and private place that will convey to the family the seriousness of and respect for the conversation to take place. If a private room is not available, close the curtains of the area you are in to provide a sense of privacy. Determine if the patient is to be present. It would be reasonable to apply the rules for pediatric assent when trying to decide if a child should be included in the initial conversation in which bad news is being discussed. Generally, it is safest to meet first with the parents and jointly determine how much the child should be told, how he or she should be told and by whom.

Be sure that you know the patient's and parents' names before starting. Families appreciate when healthcare providers have taken the time to learn individuals' names. Sitting down will avoid the perception of being in a rush (Johnson et al., 2008). Once in a room, introduce yourself and colleagues as necessary and ask the patient or parent to introduce anyone else present and explain what relationship they have with the patient. Introduce the subject: "I know you are all concerned about what's been happening. I am going to share the information we have with you and explain the situation. Please feel free to ask questions at anytime." Use effective listening techniques; let the family speak and then show that you have heard.

2. Determining How Much the Patient (if Present) or the Parent(s) Know

It is challenging to determine what a child knows or understands until he or she is at least 5 to 7 years of age. (See Chapter 2, *Age Appropriate Communication and Developmental Issues*.) The younger the child, the more the parents will be making the decisions, and, as such, they will be the primary recipients of the bad news. In a study of families with children with cancer at the end of life, Mask et al. (2005) reported parents gave higher ratings to physicians who gave

information about what to expect, communicated with care and sensitivity, communicated with the child when appropriate and prepared the parent for circumstances surrounding the child's death. This step is particularly important because it identifies the level of understanding of the family and the patient if present. The goal is to build upon their existing knowledge and to avoid assumptions about their understanding and preferences. During this step it is important to pay attention to both verbal and non-verbal clues in order to ascertain the emotional impact of the discussion. Specifically, look for signs of confusion, distress or anger to identifying potential areas for exploration during the conversation.

3. Finding out How Much the Patient or the Parents Want To Know

This is especially challenging in pediatrics. In conversations about bad news it is important to consult with parents about what and how much they want the child to know. As mentioned above, the pediatric patient is likely not to be included in the initial conversation. You may ask the parent(s): "If this condition turns out to be something very serious, how much do you want to know at this time? Do you want to know exactly what is going on? Some parents prefer that we discuss only the diagnosis and treatment plan. Others want to know the outlook, what we call the prognosis." Parents frequently feel they are losing control of their role as parents, unable to meet their responsibility to protect the child, failing to keep him and her from harm and unable to keep him or her from dying. They may feel that the medical team is usurping this role. These feelings can impact how much parents want to know about the diagnosis, treatments and prognosis.

When approaching patients and family about how much they want to know, one should consider their emotional and physical state. Parents who are sleep-deprived and exhausted may initially just want simple information. This is likely to change as the process of caring for the child continues. Frequent reassessment of how much the family wants to know is important and can avoid feelings of being left out or kept in the dark.

4. Sharing the information

Start by reviewing and acknowledging what the family already knows about the patient's illness and understands about the disease. This serves as the base upon which to build with subsequent information, a process known as aligning. After aligning, one can deliver and explain the medical details of the bad news. It is often helpful to start with a warning to prepare the family for what you are about to discuss. "I am afraid I do not have good news about Mary's tests".

One has to be mindful of how easily families are confused at a time such as this. Avoid medical jargon. Use lay language. If technical terms cannot be avoided, explain them in lay terms. Deliver information slowly, in small amounts. As you add information, check for understanding. "Has what we discussed so far made sense to you? What would you like me to go over?" It can be useful to ask the patient or parents to review what they have heard and to explain their understanding. Studies have demonstrated that the clarity and structure of this step can provide a safe framework and avoid misunderstandings (Gergis and Sanson, 1998).

Be careful of the words and phrases you use. Often it is not what you said but what the family heard that really matters. Certain words or phrases can easily convey an unintended message. For example, "Let's stop all heroic treatments." can be interpreted as the intention to provide less than optimal care. *Heroic* is an imprecise word. If you mean to say that the family needs to consider stopping all *painful and ineffective* treatments, then say it that way. Avoid the phrase, "There is nothing more we can do." It implies abandonment and continued suffering. Better to say, "There is nothing more that will stop the progression of the cancer. We need to concentrate on keeping Jerry as comfortable as possible." (Levetown, 2008)

5. Responding to the patient's and parents' feelings

Just as bad news itself varies, from disclosure of a chronic but usually not fatal disease (such as asthma or juvenile idiopathic arthritis), to a disease with a high probability of death (such as cystic fibrosis or acute lymphoblastic leukemia) to a diagnosis of certain death (inoperable brain tumor), so too do the reactions to any given bad news vary from stoical acceptance to depression.

When the bad news is that death is approaching, the reactions are invariably profound. In a classic treatise, Kübler-Ross (1997) described the five stages of facing death: denial, anger, bargaining, depression and acceptance. It is now felt that these are not really discrete, sequential steps but rather common reactions and that patients and their families move from one condition to another and can experience more than one at any given time. For example, a patient may be both angry and depressed at the same time.

When told of a fatal condition, children are especially likely to feel a sense of unfairness, given their short lifespan and the prospect of not living to fulfill their dreams. Caution should be exercised when attempting to reassure patients and their family members. Unjustified optimism and evasive forecasting of the prognosis will undermine the credibility of the healthcare provider. The challenge to the clinician (or social worker or chaplain) is to balance hope and reality. While there may be no hope of cure or remission, there can be hope for control of pain and other distressing symptoms and for comfort during the remaining time with loved ones.

6. Planning and following-through

After hearing bad news, the family will generally look to the physician for guidance. At this point, the physician should summarize the discussion, provide a clinical perspective, acknowledge the patient's and family's feelings, review their preferences and decide on a mutually acceptable plan. When there is no chance for a cure or remission, the care plan will focus on minimizing symptoms and maximizing the quality of life for the remaining time. It is important to decide on immediate and long-term goals and establish a therapeutic alliance with the family. In addition, the provider should make a plan or strategy and explain it to the family. While death may be certain, there are always uncertainties about when and how. Acknowledge these uncertainties and explain that you will work with the family as circumstances and their priorities change.

Make sure that the family knows who is in charge and how the team works. If the patient is not in the hospital, the family needs to know how to schedule the next visit and whom (and how) to contact for urgencies and emergencies.

Special Circumstances

Delivering News of a Child's Death in the Emergency Center

All too often, bad news in the emergency center (EC) is the news that the child has died, and frequently this is unexpected, for example, a well child fatally injured in an accident. If the parents are in the EC while the child is being resuscitated, they can be offered the opportunity to witness the process. This can help reassure them that everything possible had been done. When parents agree to witness resuscitation, they should be advised about what they would see, including a description of the process and the team members.

Delivering Bad News by Telephone

Sometimes parents are not present when a child dies in the hospital. Contacting the parent(s) by phone is especially challenging. The standard approach is to not tell them that the child is dead and to request that they come to the hospital immediately. Suggest that, if possible, somebody else should drive them to the hospital as they may be too upset to drive safely. (See Chapter 20, *When the Death of a Child Is Unexpected*, section, *Invitation*.)

Delivering Bad News in an Intensive Care Unit

Delivering bad news in an intensive care unit (ICU) poses special difficulties because the environment is so foreign and frightening for most patients and parents. Parental sources of distress for parents may include: seeing their child frightened, in pain or unresponsive; being surrounded by a maze of equipment, tubes and monitors; listening to constant beeps and intermittent alarms; recognition of the seriousness of the situation; and often an inability to communicate with the child (Miles, 1988). Conveying bad news in this setting requires intense sensitivity, compassion and tact. Trying to understand the patient's and parents' emotions and how they are coping or trying to cope is critical. The clinician needs to be supportive and non-judgmental regardless of how difficult the parents may be. Understanding what the parents are going through and how they are trying to handle a difficult situation can help the clinician maintain a nonjudgmental approach. Careful attention to the parents' needs will facilitate appropriate relationships between ICU staff and the parents of a child. (See Chapter 9, *Point of View: the Intensivist*.)

Operating room

When an unforeseen event occurs in the operating room, timely communication with the parents is essential. As parents wait for the child to come out from surgery, a nurse or member of the surgical staff should keep the family informed about unexpected events. After the operation is finished, the attending surgeon should directly address the family and provide a mechanistic explanation of the events during surgery. (See Chapter 10, *Point of View: the Pediatric Surgeon*, section, *A Bad Outcome*.)

Barrios et al. reported a study using simulation to evaluate surgical residents' comfort with and ability to deliver bad news related to a cholecystectomy. For half the residents the bad news was an incidental finding (unexpected cancer), and for the other half the bad news was an iatrogenic injury (laceration of the common bile duct). The authors found that, in general, surgical trainees were ill prepared to deliver bad news. Although (as would be expected) the residents felt more uncomfortable disclosing the iatrogenic injury than disclosing the incidental finding, when their performances were rated using a modified SPIKES protocol, there was no difference between the two groups (Barrios et al., 2008)

Documentation

Document the encounter in the medical record to facilitate consistency of information provided by the healthcare team. Include the family members present for the discussion, the conclusion of the discussion and special circumstances (e.g., who is permitted to know specific medical information) (Harrison and Walling, 2010).

Conclusion

Delivering and discussing bad news creates significant distress for patients and families, as well as for healthcare providers. Use of a guide such as the Six-steps protocol suggested by Buckman et al. (1992) will help ensure that the message is delivered in a sensitive, caring and supportive manner. A key concept is conveying that you are sincerely interested in the patient and family, including their feeling and concerns. Remaining engaged, asking questions to clarify the family's understanding and answering questions honestly are critical to establishing and maintaining trust at this difficult time.

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Chapter 18

Informing Pediatric Patients and Parents of the Diagnosis of a Chronic or Life-threatening Disease

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Introduction

Some of the most important and challenging communications that pediatric healthcare providers have with patients and families are those surrounding disclosure of the diagnosis of a life-threatening or major chronic disease. The initial conversation introduces the health challenge to the patient and family and gives the providers insight into the patient's and family's ability to work with the healthcare team and move forward in care. This discussion should be done in person. Clinicians have to assure that the family understands and accepts the diagnosis, gains knowledge and skills that are important to medical care decisions and self-management and develops a stable working relationship with the healthcare team. This chapter will highlight concepts related to planning and implementing these communications, as well as key factors influencing the patient's and family's responses and how to manage these responses.

Many chronic diseases have essentially no potential for fatality and do not require a team for management. For example, disorders such as nasal allergy, acquired lactose intolerance and mild eczema are usually managed by the primary care provider (PCP) and do not require a formal family conference to disclose the diagnosis. Informing patients and parents of these diagnoses should, of course, be done in a sensitive and supportive manner (See Chapter 1, *General Principles of Communicating with Pediatric Patients and Family Members*) but will not be addressed in this chapter.

Who Will Participate in the Diagnosis Discussion?

Management of most major, chronic diseases in children typically requires a team approach, and having core team members present during the diagnosis talk reduces unnecessary repetition for the family and assures that everyone on the core team is aware of what was presented and how the family reacted (Eiser, 1993). This must be balanced with the potential for families to feel overwhelmed or inhibited from sharing their feelings and concerns by a large group.

Often, discussion of the diagnosis is led by a physician specialist with whom the family has had little or no previous contact. Therefore it may be beneficial to involve the child's PCP in talking with the family before or during the discussion, if feasible and appropriate. However, if the diagnosis is based on state newborn screen results, new parents may not yet have established a relationship with their child's PCP. Also, depending upon the diagnosis, the PCP may have little current knowledge of the disease and may not feel competent giving the family information. Some families with children who have been symptomatic for a long time or families that are concerned that the PCP did not make a timely diagnosis may not want the PCP to participate in the discussion. This is an added challenge, as the child still needs a PCP, in which case the team will have to work with the family to either reconcile this concern or help them find a new PCP. It is important that the family not lose all trust in the medical profession.

As the meeting is planned, the team should help the parents decide whom they want to be at the meeting. It is ideal to have both parents present for the initial discussion, and if one of the parents is unavailable, a plan is needed to ensure that he or she is brought up to date about the child's diagnosis and plan. Ask about including extended family members in the initial discussion as well. Determine who lives in the household, who helps care for the child and who else is in the family's support system. Having more than one or two sets of ears listening can help reinforce what is being said and allow for more questions. It helps assure that others who will assist the family in care or provide support have a good understanding of the child's diagnosis, as they also may influence the parents' decision making (Lipstein et al., 2012). Other family or support persons can also be scheduled for training as needed.

Having young siblings in the room can be distracting and prevent the family from focusing on the message being conveyed. If siblings will be present, the child life specialist can provide them with activities or the parents might bring someone to babysit and keep them outside the clinic room. Sibling babysitting may not always be anticipated because test results often are not known before the visit. A quick assessment of the setting and who is present can allow for on the spot changes to help accommodate the patient and sibling(s). Otherwise, it is best to acknowledge the challenge and assure the parents that information can be reviewed again and another session can be planned, in which accommodations can be made for the children.

Involving the Child in the Diagnosis Discussion

If the patient is an infant or young child, then much or all of the discussion, naturally, will be with the parents. In some cases, the parents may not want the child to hear the diagnosis, and when possible this wish should be respected, and the initial discussion can take place without the child being present. Part of this conversation should include what is necessary and appropriate for the child to know, given the child's cognitive development and emotional state, and who will provide this information to the child. The child who is verbally, developmentally and cognitively capable should participate in his or her care and decision making.

The child's or adolescent's right to participate in decisions about his or her health can pose an ethical dilemma that cannot be ignored (Butz et al., 2007; Partridge, 2010). In fact, the child's own preferences may influence a parent's decision making, and it is important to ascertain what the child knows and thinks (Lipstein et al., 2012). Generally, parents should be advised that the child should be told about the disease to the extent that is appropriate for his or her cognitive and developmental levels, and the child's questions should be addressed in a direct and truthful manner. (See Chapter 6. *Ethical Considerations in Communicating with or about a Child*) Children often have more awareness than families wish to believe. So rather than try to hide the diagnosis and have the child imagine things that are not true, it is better to help the child understand and learn to deal with the diagnosis. It is important that the child know that others (both family members and the healthcare team) are ready to help (Coyne, 2008).

Child life specialists are a very important part of the team as they can help educate children in age appropriate ways. Some children may benefit from meeting privately with the child life specialist so as to be able to talk without parent interruption or fear that they will upset the parent with their questions. Some parents will want to know what the child life specialist is going to discuss with the child beforehand.

When and where to Have the Diagnosis Discussion

Several factors need to be considered in planning when and where the initial communication should occur. It is important to assure that parents are physically comfortable and that extraneous noise and other distractions are minimized. In the ambulatory setting, these initial diagnosis

discussions take more time than is usually allotted for a regular clinic visit. Ample time should be allowed, and the physician and team may want to schedule it at a separate time from the usual clinic visit. Patients and families should be informed that the visit may be lengthy. If a physical examination is needed, it is ideal to perform the exam in a clinic room and then move to a larger, more comfortable space if that option is available.

If the discussion will take place while the child is hospitalized, it is important to coordinate the time and place with all team members. If multiple specialists are involved, it may be appropriate to do some planning about who will lead the discussion and the order of speakers before the family enters the room. It also may be helpful to identify individuals (such as specialists) who will be there to address specific issues and then may need to leave after answering questions. This is particularly useful if a child has multiple problems. Sometimes the team will meet in the patient's hospital room, but this can be difficult as generally the room is relatively small, with few chairs. Infection control issues also can make this awkward. A conference room is usually a better option, especially for a large group (October et al., 2013). This also is helpful if the family would like to talk without the child present, or if the child is going to distract the parents. If the parents are uncomfortable leaving the child alone, try to arrange for someone to stay with the child.

Tailored Communication

No two patients or families are exactly alike so all diagnosis discussions should be customized for the individual patient or family. Matching the discussion to the needs of the patient and parents is an important step in building a partnership for care. In some cases, the life threatening nature of the condition will dictate how critical and timely it is to help the family move to a level of acceptance that permits family members to help the child and the team decide what is best for the child. In critical situations, the family may struggle with moving quickly from receiving a serious diagnosis to making decisions about the child's care. Acknowledging this and making a plan for how to continue the discussion will be valued, regardless of the child's outcome. For many families this will be the beginning of a journey in chronic disease care. A major goal of chronic disease management is empowering patients and parents to be responsible disease managers, who adhere to mutually developed treatment plans and monitor for clinical changes and response to therapy. If a family does not accept a diagnosis, a decision must be made as to whether therapy can proceed while allowing them to come around to acceptance or if their refusal to accept the diagnosis impacts their ability to consent to recommended care. Giving family members time to reflect on what they have been told and to formulate questions can be helpful. Set up another time to meet and ask if they would like anyone else to attend the meeting.

It is essential to establish rapport with the family from the beginning, and a few minutes of *small talk* can make it easier to initiate the discussion. Give the family an overview of what will happen during the visit and who will be talking with them. Introduce all team members present and explain their roles in the child's care. It is essential that family members understand that open and honest communication is an expectation on both sides. Start the discussion by validating that they may feel as if they are on an emotional rollercoaster and that this is normal. Set realistic expectations for the family and tell them it is okay if they feel they have shut down during the discussion. Chronic disease is complicated and learning about the disease will take time. Do not overwhelm families with too much information during the initial meeting. Tell them they will likely only remember part of the discussion and that is normal; tell them that team members will continue to review information with them as needed and will check back on their understanding. Assure them that there are no dumb questions and that all individuals learn at their own pace so they should not be embarrassed if they don't remember something or just need a break. Incorporating

social support behaviors to address parents' informational and emotional needs can facilitate therapeutic communication (Bradford et al., 2012). There are a number of nurturing support behaviors that can help families and that can assure them that they are cared for and valued. These behaviors include acknowledging emotions and providing encouraging messages to build confidence and self esteem.

Different approaches may be needed when talking with families in the ambulatory setting versus in the in-patient setting. For example, in the ambulatory setting, the child may be stable or asymptomatic, which is common in cases of a positive newborn screen. This can make it difficult for the parents to accept the diagnosis. For those who have seen symptoms for a long time, there is a certain level of relief, just to know why the child has been having so much trouble. On the inpatient side, the child typically is ill and symptomatic, and parents may be focused on a fast-acting therapy or a way to cure their child.

The clinician should plan how he or she will explain the condition and describe how the diagnosis was established. This may include: a review of how long the child has had symptoms; a discussion of how long it can take to recognize the disease and exclude other conditions; and an explanation of what signs and symptoms are most consistent with the diagnosis. If the diagnosis is a condition that can have complications, particularly ones that the child does not yet have (or may never have), decide how much information about this should be given in the first encounter. It is reasonable to mention that there are other complications that will be watched for but that this initial discussion will focus on the most common problems and those that are most relevant to the child at this time. Parents expect to be told something about the prognosis. One has to balance realism and hope in such discussions (Reder and Serwint, 2009) If there is no cure, state that explicitly, but if appropriate, talk about the hope that a cure will be found and the need to keep the child as well as possible in order to benefit from that possibility. Managing a chronic disease to achieve the best quality of life possible is the goal for many conditions. Talk about specific treatments that can be offered and review the benefits and risks and the time frame in which one would expect to see a response.

It is important to take clues from the parents and others during the discussion. Some parents become very quiet and have a *deer in the headlights* look, while others are engaging and want as much information as possible. Be aware of the family's emotional state and practice precautionary empathy. This requires that the provider elicit the patient's or parents' feelings about the diagnosis and offer acknowledgment regarding these emotions and suggestions for how to deal with them (Farrell et al., 2012; Tarini, 2012). Have tissues available and validate that it is all right to cry. Allow for moments of silence if that helps them compose themselves. Periodically pause and ask what clarifications are needed or what questions they have, rather than waiting until the end of the visit to do this. Body language and other nonverbal signs from the physician and team can be as important as the information being conveyed verbally. Ideally, the providers should be seated at eye level and in close proximity to the family. Each speaker should maintain eye contact with the family and not look around the room or at other team members. Sitting higher and farther away implies that the physician is not an equal partner with the family. Use simple, clear language and avoid medical jargon (Collins et al., 2013; Farrell and Christopher, 2013). Try to avoid technical terms. If it is necessary for the family to know a medical or technical term, explain it. Do not assume they know how the body works. Be creative in explaining the disease and how it affects the body by providing analogies, examples and visual aids. This will also help the family share the information with others.

Upon hearing the diagnosis of a chronic condition, parents may grieve for the psychological loss of their normal, healthy child (Goff et al., 2013). They may incorrectly attribute blame to themselves or to each other. Parents of children with chronic illness can have recurring grief in relation to their child's condition and various stages of the illness (George et al., 2006). Assure them that denial, anger, guilt, bargaining and feelings of depression are all common and part of the process of adjusting to a new reality. They will need to come to an acceptance and manage their fears, concerns and uncertainties. Assure them that the team will be there for them and will help in any way possible. It is important to let them know that the child's disease does not define who he or she is or who they are; it becomes part of who they are, but it does not define them. Some parents are eager for support from others (e.g., friends and relatives) while others prefer to keep things to themselves. What role each parent has in the relationship can be important to his or her degree of stress and reaction to the child's illness. Mothers tend to feel more responsible for care of their children and so may feel more overwhelmed than fathers (Eiser C, 1993). Help parents recognize that caring for a child with a chronic disease can cause stress among family members and that there are resources available if they need help.

Another challenge that occurs occasionally is a conflict between the family's religion, spirituality, world view or cultural beliefs and decisions about care (Hexem et al., 2011). The healthcare team has to balance respecting these beliefs and not compromising the child's health. (See Chapter 6, *Ethical Considerations in Communicating with or about a Child*) For example, a family may indicate that they expect prayer to heal the child. Prayer can be acknowledged for its potential benefits, while indicating that medical care needs to continue. At times, having the family's faith leader talk with the family and healthcare team can help dispel misunderstandings and show the parents how their faith can work together with medical care. Rarely, the healthcare team is forced to intervene legally on the child's behalf when the parent's beliefs lead them to refuse life-saving treatments (Hickey and Lyckholm, 2004). (See Chapter 33, *Dealing with Children and Families who Refuse Treatment*) Be clear that the child's health is your primary concern, without being judgmental about the family's beliefs.

Accessing and Managing other Sources of Information

Families differ in how they like to gather information. As the diagnosis discussion is being planned, parents should be advised where and how to look for information about their child's disease if they want to. Suggesting one or two reliable and accurate Internet sites will allow families to find information and resist the urge to surf the Internet that could lead them to inaccurate or outdated information. Encourage them to ask any questions they have about what they find on the Internet. Some families may identify complementary or alternative therapies, such as herbal supplements, that need to be discussed. Taking the name of the product or treatment and helping them find out about its risks, costs and benefits can be very helpful and reduce misunderstandings or conflict. When they find differences of opinion regarding care, help them understand why the healthcare team recommends the approach being proposed for their child. At the close of the diagnosis discussion, provide families with educational materials or resources. Have available different types and formats to match their preferred learning styles and needs.

Conclusion

Giving families a diagnosis of a chronic or life-threatening condition is a challenge and is best handled through an individualized approach, with careful planning, appropriate teamwork and effective communication. Consider the setting, decide who will take part in initial discussions and determine how much information needs to be covered. Help parents identify others who need to

be informed so that they can assist in the child's care and provide support. Discuss how to address the child's need to know what is happening and help the parents involve the child as much as is appropriate. Respect patients' and parents' differences in learning styles and beliefs. Recognize that all families need time to assimilate what they have learned and time to begin to cope with and manage their grief. Help family members become active partners with the child's healthcare team, to share in decision making, to manage barriers to care and to achieve the best quality of life possible for the child.

Establishing and maintaining effective communication and trust between the family and the medical team are essential to promote optimal outcomes in chronic disease management. For those facing a life-threatening illness, providing honest and clear information, acknowledging realistic uncertainty with respect to prognosis and offering support are obligations the healthcare team has to the child and family.

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Chapter 19

When the Death of a Child Is Anticipated and Imminent

Julienne Brackett, MD and Patricia Baxter, MD

The last hours and days before the death of a child are extremely difficult times for patients and their families. As a practitioner, it is vital to provide honest and complete information to help families make informed decisions and to prepare them for what to expect during these challenging days and hours. How this information is conveyed can have long lasting effects on the parents and siblings; incomplete or poorly delivered information can increase emotional distress (Contro et al., 2002).

No matter how much bad news a family has received during the child's illness, discussions surrounding the anticipated and imminent death of the child will be some of the most difficult and challenging conversations for patients and their families, as well as for the providers. Ideally, many of these conversations should be started before death of the child is imminent, thereby allowing family members time to process the information they are receiving about their child's illness and expected death. This also allows time to reflect on their wishes for the remaining time together and legacy building. Furthermore, this is not a one-time conversation, but rather a series of conversations that evolve as the child's condition changes and death approaches.

This chapter focuses on key issues to be addressed when the death of a child is anticipated, in order to help families make informed decisions about end-of-life care and to increase their comfort with the choices they make. The main focus of the chapter is on the imminent death of a child in the hospital, but many of the issues also are pertinent to the child dying at home or in an inpatient hospice facility.

Goals of Care

Once it is apparent that cure is no longer possible and that death is becoming more imminent, it is important to assess the family's goals of care frequently as these may change as the illness progresses and the child's symptom burden changes. This should include, but is not limited to: discussion of where the family would like end-of-life care to take place (e.g., home, hospital or free-standing hospice facility); symptomatic interventions to be made, including resuscitation; and funeral planning and consideration of autopsy.

Setting

One issue to address is where the child could potentially die, including the intensive care unit, hospital ward, inpatient hospice or at home, as well as issues associated with each setting. Often, the decision of the setting will be driven by the family's wishes for level of care; for example, some families may feel that every thing should be done to prolong life and may request an escalation of care. When discussing the preferred setting for end-of-life care, providers should ensure that parents feel that any decision they make will be respected by the team and that the family can change their minds at any time.

If the family wishes for the final days to be at home, community-based hospice services can provide medical and psychological support to the families, with the goal of allowing the patient to die comfortably at home. Home visits can reduce visits to the hospital or clinic for management of symptoms. However, it is important for families to have realistic expectations about hospice services. We have found that an informational visit with the potential hospice service prior to

discharge and prior to death being imminent helps establish a good relationship between the family and the hospice providers. While it is often assumed by healthcare providers that families will wish for the child to be cared for at home, not all families feel this way (Kassam et al., 2014). Many families do choose home for end-of-life care because it provides familiar, private surroundings, but for a number of families being at home is not the desired location for the child's death. Therefore, providers need to be aware of their own biases regarding the ideal location when having discussions about the desired setting for a child's death.

Since chronically ill patients often spend a significant amount of time in the hospital, as the child's death draws near, some families will be most comfortable surrounded by the medical team, including nurses, child life specialists, social workers and other support personnel, who are familiar to them. In the hospital, multiple interventions can be made, so it is important to establish with the family their goals of care for the admission and to re-address these goals as the child's condition changes.

Plan of care

Decisions to be made about the plan of care include: what, if any, disease-directed therapies will be continued; what symptomatic management will be continued or initiated; and what advanced directives do the patient or parent want with regard to possible resuscitative interventions? During these conversations, the provider should refrain from saying that there is nothing more to be done for the patient as the family needs to know that the medical team is not giving up on the child. A better statement would be, "There are no further treatments that can cure his disease." It is important to address the intent of future interventions and to be clear that none are expected to be curative. However, it should also be clearly explained that attention will be focused on symptom management and maximizing the quality of the child's remaining life.

Discussions about the plan of care need to focus on the family's goals for the child's care. As these goals are elucidated, the provider can offer insight into how different types of interventions can either help or hinder the patient and family in reaching these goals, as well as providing information about how realistic the goals are, given the child's disease trajectory (Feudtner, 2007). Including other members of the team (e.g., nurses, social workers, and psychologists) in these discussions can help families process the information and make necessary decisions.

Assuring comfort

When cure is no longer a possibility, it is the team's responsibility to reassure the patient and family that the team will continue to provide care and comfort for any symptoms. Pain and suffering at the end-of-life are primary concerns for many families. While pain is often the primary issue, other distressing symptoms such as fatigue, shortness of breath, nausea and constipation also should be addressed (Pritchard et al., 2008; Wolfe et al., 2000). A palliative care consult can often help the patient and parents identify and achieve their goals in symptom management. Detailed information regarding the expected progression of symptoms and management strategies can help ease concerns and help empower patients and parents to feel they have more control of the situation (Mack et al., 2006; Mack et al., 2007; Mack and Hinds, 2011). For patients who remain in the hospital, it is important to balance respect for the family's privacy and the need for continued reassessment of uncontrolled symptoms.

Resuscitation status

While discussions about resuscitative status can be very uncomfortable for healthcare providers, having these discussions in advance of an acute deterioration can help ensure that the patient's and family's wishes are followed. Research has shown that often these critical

conversations are delayed until death is imminent, likely in part due to provider discomfort (Hilden et al., 2001). Resuscitation directives (code status) should be addressed as part of discussions about the overall goals of care. (See Chapter 22, *Discussing DNR and Discontinuing Life Support*.) With advances in pediatric life-support, it is possible to offer a number of interventions that may prolong a child's life but often require transfer to the intensive care unit. Invasive support, such as intubation and mechanical ventilation, may prolong survival, but can limit the child's ability to interact with family and may limit the number of family members allowed at the bedside. Regarding code status, rather than reading off a list of interventions and asking parents to make difficult decisions for which they may feel unqualified, the physician should discuss overall goals of care with the patient (if appropriate) and family and offer recommendations based on those goals.

If a patient is in the hospital with death being imminent, it is critical for the entire care team to be clear on the plan to avoid undesired interventions if the parents are not at bedside during a critical event. For patients with a terminal diagnosis, resuscitative efforts may create difficult decisions at a subsequent time, for example, if the patient is intubated during the resuscitation and ventilatory support cannot be weaned down to allow extubation. In addition, resuscitative efforts will not cure the underlying terminal disease and can potentially prolong suffering for the child. At times, it is helpful to discuss a potential time frame for a trial of an intervention prior to escalating support, so that providers and families have plans for re-addressing the efficacy of the intervention in fulfilling the family's goals. An example of this would be intubating for respiratory distress thought to be due to an acute infection, with plans to re-evaluate if such support can not be weaned within a few days.

Education about what a cardiopulmonary resuscitation can look like may be necessary, as the only exposure many people have had to such an event is that depicted in the media (Baker, 2011). It can be helpful to explain that the outcome is often not the successful one portrayed on television, especially for chronically ill patients. Pointing out that, in the setting of a terminal illness, such efforts are unlikely to be successful, and if so, only temporarily, can help families develop more realistic expectations.

For patients who are at home when death is anticipated, having an out-of-hospital DNR (do not resuscitate) order can protect the patient from undesired interventions if emergency medical services are called to the home. These forms are necessary to allow the family to refuse resuscitation that the EMS providers otherwise legally have to provide when called to an emergency. Discussion of such DNR orders can be made easier by presenting them as providing options as parents will have the choice of presenting or not presenting them to EMS providers when they arrive at the home.

Including the Child

It is important to include the child in discussions surrounding end-of-life care, to the extent with which the child and the parents are comfortable. Age and developmental level of the child will often dictate the level to which the child participates in end-of-life decision making. Additionally, cultural issues can affect the degree to which the child is included in the discussions and what amount of information is provided to him or her. In some cultures, it may be unheard of for the child to be told the diagnosis or the prognosis (Evan and Cohen, 2011). It is important to be sensitive to these issues, and exploring the family's concerns about including the child may reveal ways in which the child can be provided with information that helps him or her better understand the situation and participate in decision making. (See Chapter 6, *Ethical Considerations in Communicating with or about a Child*)

Often, parents are conflicted as to how much information to give a child, and they fear that such discussions will be upsetting. In a study of bereaved parents, none of those who discussed death with the child expressed regret for having done so, but 27% of those who did not have these discussions later expressed wishing they had done so (Kreicbergs et al., 2004). Frequently, in our experience, the child knows more than the parents believe, and failing to have open conversations can lead to increased anxiety, misperceptions and feelings of isolation. Waechter (1971) studied 16 children with fatal diseases, only two of whom had discussed death with their parents. From the children's levels of anxiety, fantasy stories and responses to a set of pictures, Waechter concluded that the 14 children who had not discussed death with their parents were more aware of their conditions and prognosis than the parents believed.

Asking the child what questions or concerns he or she has provides the child, family and providers an opportunity to openly discuss these issues. Any misperceptions the child has can be clarified, and plans for addressing the concerns can be made. It is important to give the child time to consider what to ask or discuss, as well as the option not to discuss these issues. Reassess frequently for new questions or concerns as the disease progresses (Beale et al., 2005). Child life specialists can play a vital role in assisting clinicians and families with end-of-life discussions. Often, interactions with the child life specialist may reveal the child's fears, concerns and wishes, as well as those of the siblings.

To facilitate such conversations and help children express their wishes, there are a number of tools that can be used, such as *My Wishes*, which addresses the child's wishes for: how I want people to treat me; how comfortable I want to be; what I want my loved ones to know; and what I want my doctors and nurses to know (Central DuPage Hospital, 2006), or *Voicing My Choices*, which is a modification for adolescents (Wiener et al., 2012). These and other similar tools can be given to the family to work through and then reviewed as part of conversations to review the goals of care. We have found that when families are given one of these tools, they often wish they had received it earlier in the disease course.

Awaiting Death: the Vigil

When death is imminent, over the next few hours to days, many families will gather at the bedside awaiting death and often are troubled by the physical changes that can take place in the patient. Anticipatory guidance about what to expect can minimize anxiety and family discomfort. Reassurance should be provided that symptoms will be managed aggressively. For some families, it may be very difficult to stop close monitoring of vital signs or laboratory data, but such monitoring can increase anxiety because of monitors that are frequently alarming or because family members focus more on the numbers than on the condition of the child, which can sometimes be quite discrepant. Focusing conversations on the goals of care and how monitoring can achieve or interfere with these goals can be an important strategy for discussion of such issues (Feudtner, 2007; Wolfe, 2011).

Changes in respiratory status can be one of the more troubling signs of imminent death for families as the patient may have irregular or gasping respirations, with pooling of secretions causing rattling noises. Discussing such signs in advance of their onset and interventions that are available to minimize any potential discomfort can reduce anxiety (Pritchard et al., 2008; Wolfe, 2011). It is also important to explain that while these changes are difficult to watch, patients are likely not suffering (Wee and Hillier, 2008).

Hydration and nutrition are frequent concerns for many families when the child's appetite decreases at the end-of-life, with some families requesting continued intravenous fluids or parenteral nutrition. Educating families that nutritional and fluid needs are minimal when patients

are actively dying can minimize this concern. In some patients, the addition of intravenous fluids can exacerbate breathing difficulties and cause uncomfortable edema as renal function decreases. Discussing this in advance may help families understand that such interventions may cause more harm than good.

Although death is imminent, the process of dying can take hours to days. Therefore, self-care for the parents is a critical issue, as is care for other children in the family. Parents often need frequent encouragement to take at least short breaks from the patient's bedside, even if only to shower or to go for a walk. Providing reassurance that someone will closely watch the child and call the parent if there is any change may enable the parent to leave the bedside. This can also lessen the fear of the child *dying alone*.

“What if I’m not there?”

Families will often sit at the bedside for hours or days, unable to leave for fear of the child dying in their absence. The situation described by a parent below is not uncommon as it seems that some children wait until a family member is not present to die.

“I sat at her bed for hours, not able to sleep. I finally went to the bathroom, and then she was gone. It was like she knew I would fall apart if I watched her take her last breath.”

We have found that mentioning that this may happen can bring some comfort to a family member who is not present at the time of the death.

Preparing for the Death

Anticipatory guidance about what to expect at the time of death and for funeral planning can minimize anxiety and provide some sense of control in an otherwise uncontrollable situation. Although it is difficult for families to discuss, making funeral arrangements in advance or designating family members or friends who will help with this can reduce stress at the time of death. Some children and adolescents may want a role in planning what care they receive and how they want to be remembered in funeral services. Involvement in planning can provide patients, as well as the parents, some feeling of control over events, and they should be offered the opportunity to do so. Involving social workers, child life specialists and psychologists can help patients and families process their wishes for and thoughts about the death and prepare as much as possible.

In these discussions, autopsy and potential tissue donation should also ideally be brought up. Although most chronically ill children will not be eligible for organ donation, there may be tissue banks or research protocols that collect tissue for future studies which can allow families to feel that the child's death was not completely in vain, potentially helping advance treatment for future children. The autopsy process should also be explained, as there are often misconceptions about the appearance of the body after an autopsy. An autopsy may provide some explanation if there are lingering questions about disease progression or cause of death, and discussing the question of an autopsy prior to the death allows the family time to think about it. In addition, it is also helpful for the patient's primary physician to discuss it, rather than a physician who may only be covering at the time of death, as the primary provider will best know what issues an autopsy could address for a family. If an autopsy is agreed to or requested, the provider should explain to the family that results are frequently not available for many weeks and make a plan for how the results will be communicated to the family.

Finally, things that will or may occur at the time of death should be discussed with family members so they know what to expect, for example, that there will be an examination by a physician to confirm that the child is dead and the possibility of a last gasp or movement during

this exam. Although this will still be an upsetting time for the family, such anticipatory guidance can lessen anxiety and help families feel more prepared.

Conclusion

For all of the difficult conversations that are necessary when the death of a child is imminent, keeping a focus on the family's goals of care and hopes for the child's remaining days can provide a foundation for the decisions that are necessary as the disease progresses. By providing complete, honest information about the child's prognosis and expected trajectory, the healthcare team can, hopefully, lessen anxiety and distress during the dying process and after, as the family grieves the loss of the child.

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Chapter 20

When the Death of a Child Is Unexpected

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Background and Introduction

In the United States, a child under the age of 15 years dies every 20 minutes (Xu et al., 2007). Many of these deaths are unexpected and come as a shock to surviving family members. Deaths due to accidents and homicides are most often unpredictable and unanticipated.

For healthy children in normal circumstances, healthcare providers and parents go about their daily business with little thought of impending death even though, cognitively, they know that death is always a possibility. Motor vehicle accidents, pool drownings and the increasing prevalence of school shootings are some of the things that remind us that death in childhood, all too often, is unexpected and random.

Devastating, horrific, unimaginable—the list goes on when describing the unexpected loss of a child. The event overturns all that the parents have taken for granted, including things that they did not realize that they had taken for granted. As trauma is the leading cause of death in children beyond a year of age, this chapter will address the issue of unexpected death primarily from the point of view of the emergency provider. Not all unexpected deaths are in previously healthy children. For example, in children with chronic, severe, life threatening disease, the final life-ending event often is unexpected, and the principles discussed below apply. The role of the pediatrician in the weeks that follow the fatal event will be addressed towards the end of this chapter.

In general, families should be offered the opportunity to be present for any resuscitation efforts. A review of family presence during invasive procedures and resuscitation indicates that families want the option to be present, and when present, they report favorable experiences regardless of the outcome (Boudreaux et al., 2002). Therefore, in the event that cardiopulmonary resuscitation is being performed and efforts are deemed to be futile, if the family's arrival is known to be imminent, resuscitation efforts may be continued until the parents arrive.

The Conversation: Using the SPIKES Protocol

The SPIKES protocol described by Baile et al. (2000) offers six steps for delivering and discussing bad news. (See Chapter 17, *Delivering and Discussing Bad news: General Principles*.)

Setting up

A private room with tissues available and support staff nearby is preferred. Ensure that you will have enough time to spend with the family and turn off your phone or pager. If the resuscitation is ongoing, an attempt should be made to step away from the bedside with the parent(s) and sit so you can more easily communicate at eye level.

Care must be taken to identify the deceased child accurately and notify the correct family. An attempt should be made to elicit the relationships of all family members and identify any custody issues. It is very important to know the patient's name before starting the conversation. The importance of facing the parent(s) and making eye contact cannot be overstated. The ideal distance is one that is non-intrusive but permits the clinician to lean forward and touch the parent

or family member, when appropriate. Always address the family members by name and refer to the deceased by name. Use the preferred name for the child if known, for example, “Charlie” for Charles. Introduce all medical personnel involved in the conversation and explain their roles; identify all family members (or friends) present and clarify their relation to the patient.

A physician knowledgeable about events surrounding the death of the child should deliver the news. This is not always the most senior physician present. Sometimes another physician will have established a relationship with the family or will be more knowledgeable about the circumstances of the death. Notify the medical team, nurses, chaplains, child life specialist and social worker that the conversation will be taking place so they can be available and join the meeting if needed. It is important that these individuals be quickly available for additional support in case a family member has a severe grief reaction or experiences a syncopal event. If anyone displays threatening anger or aggression, security should be notified.

Perception

Assess the parent’s perception of the situation with an open-ended question, for example, “What have you been told about the situation thus far?” This allows for correction of any misinformation and the opportunity for information gathering as you may not have all the relevant data about the circumstances of the death. This also can help determine if the parent is engaging in denial or has unrealistic expectations about outcome. Begin by providing the information you have regarding the events that brought the child into your care. If a parent or family member asks if the child is dead, try to delay for a few moments by first disclosing the known background information, for example, “Johnny was walking home from school today when a truck struck him, knocking him to the ground.” If they ask again, confirm that the child is dead, “Yes, I am so sorry, but he has died.” If asked something about the circumstances that you do not know, acknowledge that and direct the family to the appropriate personnel, for example, the police.

Invitation

Invite the parents to have a conversation. Gather all family members who are present and, if feasible, wait for those who are expected to arrive imminently so as to avoid having to repeat this difficult conversation. Repeated disclosures can be taxing on the family as well as the staff. If asked to update a family member over the phone, it is best to say that the child is in your care (or in the emergency center) and is seriously ill or in critical condition and ask that he or she come to the hospital. However, do not dissimulate. If asked specifically if the child is dead, respond appropriately, “I am so sorry to have to tell you that he is dead.” If resuscitative efforts are ongoing, an appropriate response would be, “He is critically ill (or injured) and the team is attempting to resuscitate (or revive) him.”

A warning may be provided that the news to be shared is not positive, but it should *not* be a warning *shot* (Maynard, 1997). The bad news must be communicated, but a level of judgment is necessary in deciding when, how and how much bad news to give. In some circumstances, it may be possible and preferable to give the bad news in stages. For example if a resuscitation is ongoing, you might first let the parents know that their child has been in an accident, is very sick and is unable to breathe or that his or her heart is unable to pump blood on its own. This may provide the opportunity to field questions before proceeding to the more critical news that the resuscitation has been unsuccessful.

Some parents may want an opportunity to say goodbye to their child prior to cessation of resuscitation efforts, and having the conversation in stages allows the opportunity to explore the family’s preferences.

Knowledge

Use clear, simple and understandable language, with words that are not higher than a middle school level. Use nontechnical words such as “tube to give oxygen” instead of “intubated” and “pushing on the chest to make the heart pump” instead of “compressions.” Avoid excessive bluntness (e.g., “We have done all we can. Your child is dead.”), as it is likely to leave the parent isolated and later angry, with a tendency to blame the messenger of the bad news (Maynard, 1997). Give information in small pieces and check periodically for the caregivers’ understanding, pausing to answer their questions, while being compassionate and humanistic.

Avoid expressions such as, “There is nothing more to do.” or “There is nothing else we can do.” Replace them with more caring statements, such as, “I *wish* there were something more we could do.” or, “I wish things were different.” (Quill et al., 2001). Avoid euphemisms as they can be easily misunderstood. For example, saying, “Your child has passed on.” could be misinterpreted as meaning that he or she has been transferred to a different unit or different area of the hospital. Many advocate that this information should be definitive, with a *D* word— died, dead, or death. Avoid statements that minimize the tragedy, such as, “Your child is in a better place.” For the parents, the best place for the child would be here with the family, alive. Also avoid saying, “I know how you feel.” A parent will often argue that you cannot know how he or she feels. And indeed, even if you yourself have lost a child, you cannot know exactly what the parent is feeling at this moment. Additional helpful phrases can be found in Chapter 1. *General Principles of Communicating with Pediatric Patients and Family Members*, section, *A Repertoire of Rapid Responses*, subsection, *A Few Useful Phrases*.

Emotions

Individual family members’ responses vary greatly, from sadness and grief to anger. Observe family members for their emotional responses and acknowledge their shock and other emotions. Expressing your own emotion is acceptable, but take care not to break down, such that the family is consoling you. It may be appropriate to touch a parent’s knee, shoulder or back of the hand, and a parent may hug you, especially if he or she has no other support person present. Allow for catharsis and expression of emotions, while providing practical support for basic and comfort needs. Allow survivors to view, be with and touch the body. Make every attempt to provide emotional and psychological support to the family in a private setting.

Summarize

Summarizing at the end of the encounter is important to reiterate that the child is dead and if ongoing, the resuscitation will be stopped. At this time, the provider may issue an empathetic statement such as, “I am very sorry for your loss.” The next action item is to explain what is going to happen from here, for example, “You may have as much time as you need with your child. If you would like other family members or clergy to come here now we can assist you in contacting them at this time.” Notify the family members if you have plans to move the child, perhaps out of the resuscitation room to another location, and allow them to spend time with the child if desired. If the child will be moved to the morgue, explain the transfer process. Let the family know that both you and your staff will be available if questions arise. Asking, “What questions do you have?” is more likely to elicit a positive response than, “Do you have any questions?” Do not be surprised if you do not get a verbal response initially. Take care to have a staff member with the family at all times.

Important Considerations

Medical Legal Issues

If the cause of death is an accident, homicide or uncertain, care must be taken to ensure that the body is preserved for the medical examiner (ME). An estimated 1,570 children in the United States die each year as a result of abuse or neglect, with the greatest risk in the less than 1 year old population, and a death that at first appears accidental may actually be a homicide.

Defer to your institution policy in this matter, but, if allowed, swaddle the child in a clean sheet or blanket while taking care to preserve the original sheet used during the transportation and resuscitation of the child. Any materials or clothing transported with the child may be placed in the same collection bag. Do not remove any equipment used during the resuscitation from the body (e.g., airway tube, intravenous line, chest tube, EKG pads), and do not clean the patient. Unless directed to do otherwise by the ME, someone on the hospital staff or a law enforcement representative should be stationed in direct line of sight of the body at all times but at a distance that allows him or her to preserve evidence while providing privacy for the grieving family. Until released by the ME, the body and everything associated with the body before and after the child's death is considered evidence and must be preserved for the ME. Unless a crime has occurred in the emergency department (ED) proper, there is no need to cordon off the area, and the body may be moved from the resuscitation room to a quieter room if possible.

In most cases, family members should be allowed to touch or hold their child as long as the above tenets are maintained. Families should be allowed as much time as they need, provided they are not interfering with the ME or law enforcement investigations. If an altercation arises among family members or between family members and staff, hospital security should be notified and care be taken to protect the safety of all involved. In the cases where the cause of death may not be clear, for example, in a case of presumed sudden infant death syndrome, notify the family that the police may arrive, so that it will not add additional shock if they appear and question the parents. Additional time for grieving with the child is typically offered at the funeral home in a more private, less clinical setting. The ME's autopsy, if performed, does not interfere with the funeral home's ability to prepare the body for viewing if that is the family's preference.

When a hospitalized child dies unexpectedly, the tenets above apply. Thus, if allowed by hospital policy, tubes and lines may be removed and the body cleaned of blood, secretions, tape residue or emesis, so that the family can hold the child and take pictures without interference. Many families are grateful that they were able to see the baby's or child's face for the first time in days, after the tubes and tape were removed, providing special moments to kiss and embrace the child uninhibited by medical apparatus.

Preserving Memories

If available, a child life specialist can assist the healthcare team in preserving memories. This may consist of making hand or foot prints or molds, cutting off a lock of hair and, if the patient's appearance is appropriate, taking photos of the deceased. The child life specialist can help the family make a decision about whether or not it is appropriate for siblings to see the body and can be helpful in facilitating the difficult conversation with siblings in an age appropriate manner. The specialists can also assist in describing to the family anticipated reactions during the bereavement process.

Religion and Spirituality

Spirituality and religion offer an opportunity to understand illness and death and can be immensely helpful for families at this time. Many institutions have a chaplain or someone from

the spiritual care department available on call, and this person can be an invaluable resource. (See Chapter 29, *Communicating about Spirituality and other Worldviews*). In addition, some beliefs require that certain procedures or ceremonies be performed prior to or after the death. This can be teased out in the early conversation with the family regarding the critical nature of the child's condition, prior to cessation of resuscitative efforts. If asked to pray with the family, do so if you are comfortable.

Emotional Self-Help

Delivering the news of a child's death takes its toll on the healthcare provider as well as the family and care should be taken to acknowledge the emotional state of both yourself and your staff. The experience of delivering terrible news can be emotionally draining, and the emotional reaction of individual staff members will be framed by their own experiences and attitudes toward death. If there was a resuscitation attempt, it can be helpful to allow the medical team an opportunity to debrief after the event (Eberwein, 2006).

Organ Donation

Healthcare providers are frequently uncomfortable at the critical juncture where end-of-life care and organ donation interface. Yet organ donation offers a grieving family the opportunity to turn a personal tragedy into a gift of life. As healthcare professionals, we should strive to honor these gifts. The medical team should not discuss the issue of organ donation directly with the family. In compliance with federal regulations, a hospital notifies its local organ procurement organization (OPO) of every patient who has died or is nearing death. The hospital gives the OPO information about the deceased to confirm his or her potential to be a donor. If the patient is a potential candidate for donation, an OPO representative immediately goes to the hospital to seek consent from the next of kin. If consent is obtained, medical evaluation will continue, including obtaining the deceased child's complete medical and social history from the family. If this evaluation does not rule out donation, the OPO contacts the Organ Procurement and Transplantation Network (OPTN) to begin the search for matching recipients. Ischemia-resistant tissues such as cornea, bone, skin, tendon, fascia, cartilage, saphenous vein, and heart valves can be harvested from deceased emergency department patients up to 24 hours after death if the body is refrigerated within 4 hours after death.

The Primary Care Provider

The emergency center staff should contact the child's primary care provider (be it an individual practitioner, a group practice or a multidisciplinary team) at the time of the death. Receiving news of the death of a child in one's practice gives rise to many questions. Do I contact the family now, or do I wait? Should I inquire as to funeral arrangements? Should I attend the service? In a descriptive study evaluating people who had lost a spouse or child in a car crash, the most common helpful supports they found were provision of the opportunity to express emotions, demonstration of concern and presence of friends and healthcare providers (Lehman, 1987). If family members say they need space, then respect their wishes, but otherwise it may be best to err on the side of contact, by telephone, email, written note or card or attendance at the funeral or memorial service.

Conversely, in the Lehman study, the most unhelpful supports were: giving advice; encouraging recovery (e.g., "Life goes on. You need to get over this."); rude remarks or behavior; minimization of the loss or forced cheerfulness; and identification of feelings ("I know how you feel"). Many families value the continued acknowledgement of the deceased child as a family

member, for example, a mother of three children still considers herself a mother of three, even though one of her children has died.

Studies suggest that parents are likely to regularly reflect on their child's death, even many years after the event. For example, the Lehman study found that at 4 to 7 years after the traumatic death of a child, nearly 70% of the parents had spoken with someone about the loss of their child and 96% had thought about their child in the past month. It stands to reason that parents having experienced sudden loss may be preoccupied with thoughts about how the loss could have been avoided, and they may have difficulty coming to terms with the loss. If the parent of a deceased child is in your office with his or her other children, be aware that grieving is a continuous process and inquire as to how he or she or the family is doing.

Conclusion

The time around and following the unexpected death of a child is difficult and challenging for the child's family and for the healthcare providers involved. For the family, the death is a devastating loss. For the healthcare providers, it heightens their awareness of their own mortality. Delivering news of the unexpected death of a child is difficult, and use of a mnemonic protocol such as SPIKES allows a consistent approach so that key tenets are not overlooked. Demonstration of understanding and empathy by the providers will help the family grieve and are important support tools. Choose your words wisely, and don't be afraid to use a "D" word—death, dead or died.

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Chapter 21

After the Bad News: Talking with the Patient and Family

Teresa Duryea, MD

Background and Introduction

As clinicians, we are often faced with the difficult situation of providing care and support for patients and families after they have received bad news. The bad news varies in severity from an acute life-threatening illness with potential for recovery, to a newly diagnosed chronic condition that impacts the lifetime and quality of life of the patient, to a fatal event. The duration and trajectory of the illness is unique for each patient and family, as are their reactions to the news. Following the disclosure of bad news, conversations between healthcare providers and patients and families play an important role in fostering positive adjustments (Back et al., 2010). As healthcare providers, we not only listen to patients' stories but contribute to them by the way we communicate and support them through these difficult times. It is our task to help patients fully understand their diagnoses and face and deal with their new realities.

This chapter focuses on communication during the first hours or days after the receipt of bad news and is applicable to in-patient and out-patient settings. These communication skills continue to be used throughout the course of the illness and the recovery or bereavement period. In addition to providing medical information and therapeutic guidance, it is important that patient and family members be encouraged to talk about their concerns and feelings. Members of the healthcare team must be comfortable in recognizing and responding to these emotions. In order to help the patient and family navigate the continuum of the illness and treatment and adjustment to the outcome, we need to understand the patient's perspective and offer our expertise.

Important components for effective communication throughout this turbulent time include:

- Preparing for the encounter
- Exploring the patient's and parents' understanding of the illness and inquiring about their expectations
- Probing for preferences regarding how much information is wanted and with whom it should be shared
- Asking about symptoms and concerns
- Recognizing and responding to the emotional content of the patient's and parents' concerns
- Empathizing and acknowledging that the experience is difficult
- Setting goals and summarizing the plan.
- Offering hope.

Preparing for the Conversation

Find out as much as you can about the bad news. If you were not the one delivering the bad news and if you were not present during the delivery of the bad news, it is important to review the case thoroughly prior to seeing the patient. If it involves a disease with which you are not familiar, look up information about that disease if time permits. Unfortunately, sometimes you may be in a situation where patients and families are seeing you after a bad news diagnosis of which you were unaware or for which the etiology has not yet been determined. Although this is

uncomfortable and far from ideal, the experienced clinician can still offer support and a plan for follow up to discuss details of the illness as more information is received.

Exploring the Degree of Understanding of the Illness and Inquiring about the Expectations of the Patient and Family

Recognize that the significance of the bad news may not be understood initially by the patient or family. Although the words are heard, the meaning is not always fully grasped so it is imperative that the medical provider assess the patient's and family's understanding of the illness and what is to come. The use of open-ended questions, such as, "Tell me what you understand about your illness?" or "What have the doctors already told you?" will help elicit the degree of understanding of the illness and its severity. Then the clinician can center the discussion on patient-specific informational needs. Morris et al. (2012) identified five major themes to keep in mind when interviewing patients living with a serious illness: diagnosis and pathophysiology; illness history; prognosis; symptoms; and causality.

An analysis of autobiographical accounts of hearing bad news by Morse (2011) describes how patients and families cope. Morse noted that bad news is rarely given all at once. Often the concern for severity or chronicity of illness develops over time, and news is given in an incremental manner along the illness trajectory as diagnostic tests hone in on the problem. Therefore, it is imperative that the medical team continue to check in on the level of understanding and continue to clarify, verify, reframe and rephrase in language the patient and parents understand.

The developmental level of the patient impacts his or her understanding of the illness and impacts the coping mechanisms that will be used. (See Chapter 2, *Age Appropriate Communication and Developmental Issues*.) Infants can sense emotional changes in their parents and stress in the family, and they can experience separation anxiety. Preschool children do not yet have the ability to fully understand death or its permanence and may use magical thinking. School-aged children have moved into the concrete operational stage of development and have logical thinking. Teenagers have the capability for abstract thinking, allowing them to ponder the existential implications of death (Linebarger et al., 2009).

Comprehension and acceptance take time. Adjusting to living with a serious illness is a huge undertaking. Bad news is followed by a period of grieving for the loss of normalcy and grappling to accept reality. Often there is a somatic response in addition to the emotional response, and both need to be addressed. Patients report a wide variety of reactions to bad news; most experience the classic stages of grief described by Kubler-Ross (1969): shock and denial; pain and guilt; anger and bargaining; depression, reflection and loneliness; and acceptance and hope. It is currently recognized that these are not discrete, sequential stages. Stages overlap and individuals move back and forth between stages. Ongoing assessment of the level of understanding and the stage of acceptance is necessary to provide optimal patient-centered education and guidance. A clear understanding of the disease and prognosis is a crucial factor affecting the patient's and parents' coping skills.

Probing for Family Preferences Regarding How Much Information Should Be Given and with Whom It Should Be Shared

Communication needs to be responsive to the needs of the patient and parents and respectful of the family dynamic. The family needs sufficient information to understand and participate in medical decision making so practitioners must develop an understanding of how to share news, with whom to share it and how much detail is desired. Unique to pediatrics is the need to communicate with the patient in accordance with his or her developmental, verbal and cognitive

levels, in addition to communicating with parents and other family members. This duality of pediatric patient and responsible adults can give rise to ethical challenges, for example, when adult family members disagree, when the patient and parents have conflicting opinions regarding treatment or when parents request nondisclosure to the patient. (See Chapter 6, *Ethical Considerations in Communicating with or about a Child.*)

There is a moral and ethical obligation to discuss health and illness with the developmentally ready pediatric patient and an expectation that children will be active participants in their care. Satisfaction is greater and adherence to the care plan is enhanced when the child is treated as a partner. Practitioners should decide with parents or family members how to disclose health information to the patient (Levetown et al., 2008). Older children should have a significant role in decision making that grows over time. When disagreements arise, cultural and family values and roles that govern that dynamic should be respected whenever possible. An exception would be if this would cause harm to the patient.

Al-Mutair et al. (2013) conducted a structured literature review to better understand the needs of families of critically ill patients and found that assurance and timely, understandable information were ranked highest by family members. Yet these individuals often perceived their needs as being unmet. Intensive care rounds with family members resulted in improving this relationship as well as decreasing hostility and stress. Nurses, followed by doctors, were identified as the best staff to meet these needs.

Informed or shared decision making requires that patients and parents fully understand: the medical condition; the rationale for and results of tests; the risks and benefits of all available treatments; and expected outcomes, including long term consequences of the illness or therapies. Then they can make assessments according to their values. Although the ideal of informed decision making implies a need to communicate uncertainty to patients, this is problematic. Illness is unpredictable, best practice may not be clear and risk estimates have limited applicability at the individual level. Communicating uncertainty has the potential to overwhelm and confuse patients; some may respond by seeking information but others may exhibit avoidance, fear and impaired ability to make decisions (Politi et al., 2007). Healthcare providers should strive to offer just the right amount of accurate information in a timely and ongoing manner, while tailoring it to the specific needs of the patient and family. It is important that, as healthcare providers, we frequently reassess the need for more shared information throughout the course of the illness and include patients of all ages in a manner consistent with their developmental and verbal levels.

Asking about Symptoms and Concerns

Invitations to patients and parents to express their concerns are welcomed and increase the utility of the encounter, usually without lengthening it. The perception of interest, caring, warmth, respect and responsiveness are factors predictive of effective communication between clinicians and patients and parents (Levetown et al., 2008).

When parents are reluctant to speak openly with their children about illness or death, they should be counseled about the benefits of disclosure. Even very young children can recognize that something is wrong. Avoidance and denial of difficult information leaves the patient feeling abandoned. Sometimes patients will try to protect family members or feel guilty for the circumstances and hesitate to voice concerns or talk about their symptoms.

Frankel and Stein (2001) proposed The Four Habits model as a way to organize the clinical encounter: 1) invest in the beginning; 2) elicit the patient's perspective; 3) demonstrate empathy; 4) invest in the end. The goals of this model are to: establish rapport and build trust rapidly;

facilitate the effective exchange of information; demonstrate caring and concern; and increase the likelihood of adherence and positive health outcomes.

The most common patient concerns can be categorized into broad themes. Healthcare providers should attentively and genuinely address each of these concerns. Just as it is crucial to speak to each of these areas at the time of delivering bad news, it remains our duty to continue awareness of these concerns in our discussions with patients and families afterwards. One way to categorize these themes is as follows:

- **Communication:** disseminating accurate, timely and appropriate information and education about the long-term implications of illness
- **Comfort:** ensuring that physical discomforts are minimized and quality of life maximized
- **Support:** alleviating fears and anxiety by providing resources
- **Care coordination:** integrating services and seamless transitions
- **Respect:** valuing personal preferences and expressed needs
- **Family:** involving family and friends

Recognizing and Responding to the Emotional Content of Patient and Family Concerns

Realizing that you or a loved one has a debilitating or terminal illness is a life-changing, threatening and shocking event, even when there is some forewarning. Often, however, there is no forewarning, as in the case of a devastating acute illness or injury. Also, due to modern diagnostic technologies and routine screening, frequently diagnoses are made prior to the patient experiencing any problems, which makes the initial shock even greater. Discussions about life-limiting illness, interventions, complications and disability must occur early in the course of the ailment, which adds to the challenge for the healthcare provider (Back et al., 2010).

It is important to remember that emotions can derail cognitive understanding so recognizing and responding to emotion in an explicit and empathetic way is basic to providing optimal emotional and psychological support, as well as to effective communication regarding the medical plan of care. (See Chapter 1, *General Principles of Communicating with Pediatric Patients and Family Members*.) Rather than trying to fix the patient's emotional state, acknowledge it. Dealing with emotions can be challenging, especially in the setting of a busy office or clinic or in the context of rounding in the hospital. The **NURSE** acronym is one tool that can be helpful in these discussions (Smith, 2002).

- **Name the emotion:** "It sounds like you are frustrated... (e.g., or angry or sad)"
- **Show an Understanding of the emotion:** "It must be difficult..."
- **Respect the patient and praise his or her accomplishments:** "I am pleased that you have been able to..."
- **Offer Support:** "My associates and I will be here to help you..."
- **Explore the emotion.** "Tell me more about..."

Completing stages of planned therapy can be met with a variety of emotions that are largely dependent upon the success or failure of the treatment in modifying the disease. For example, a patient may feel anticipation for improvement, anxiety about moving forward, elation when milestones are achieved, fear about uncertainties such as potential treatment failure or future recurrence of disease and sadness or resentment when sequelae or disease progression occur. This highlights the importance of recognizing the emotions felt throughout the illness trajectory and not simply immediately after the receipt of bad news.

Studies have shown a wide variation in physicians' abilities to correctly judge emotions in their patients. Physicians who are more skilled at accurately decoding nonverbal behaviors, in addition to verbal cues and emotions expressed by patients, receive higher satisfaction ratings from patients. They are rated as being better listeners, more caring and more sensitive than other doctors. In addition, physicians who are more emotionally expressive in their nonverbal behaviors (e.g., facial expressiveness, eye contact, head nods, body posture and voice tone) are viewed more favorably by patients (Roter et al., 1997). These are skills that we should be mindful of developing and using in all patient encounters, but especially as we visit with patients after they have received bad news.

Parents and children are changed forever by bad news about themselves or a loved one. The constellation of the family and personal identity changes. It is important to recognize the influence of these changes on future family dynamics, as well on patient and family healthcare decisions. There is a lasting effect on the emotions of the healthy or surviving patient and family members as well. The demands placed upon family members who are living with patients with long-term disabilities or chronic or progressive diseases are substantial. We should be watchful for emotional content in all these scenarios. Lastly, since there is an emotional bond formed between patients, families, and providers, enhanced awareness of our own emotions can improve the clinical care we provide and increase our personal and professional satisfaction (Novack et al., 1997).

Empathizing and Acknowledging that the Experience Is Difficult

Every patient and family member has his or her own communication and coping style, which is influenced greatly by cultural and religious beliefs, in addition to personal experiences with illness and with death. This is true of the medical providers as well. The challenge is to be sensitive to these variations and to individualize one's empathetic comments appropriately for each encounter.

Cohen-Cole and Bird (1991) describe five types of empathetic responses that can be helpful:

- Reflection: expressly name an observed feeling or emotion, "It sounds as if this has really gotten you down." or "It looks to me that you are ..."
- Legitimization: normalize and express acceptance of the emotion, "I can understand why you feel ..."
- Support: offer ongoing support, "I want to help you deal with this."
- Partnership and joint problem solving, "Let's work together..."
- Respect: value personal choices and behaviors, "You are doing a great job with ..." or "I value your opinion ..."

(See Chapter 1, *General Principles of Communicating with Pediatric Patients and Family Members*, section, *Empathy*.)

Takemura et al. (2008) found reflection to be the strongest determinant of patient satisfaction, followed by legitimization. After voicing empathy for the situation, one strategy that may help patients move forward to see new possibilities is to ask permission to share your clinical experiences, "Would you like to hear how others have dealt with this issue?"

Set Goals and Summarize the Plan

The clinician can help patients and families cope with suffering and loss of control by selecting patient-centered, achievable goals. By focusing on goals that can be accomplished now, such as pain management or improved nutrition, patients regain some sense of control. It is helpful to

anticipate needs that may not be evident to patients and families, such as dealing with the school system or planning for an inclusive home healthcare package. For those who suffer from an unrecoverable diagnosis, acceptance can be realized through altering what is hoped for and by establishing new priorities.

Care goals should be developed in partnership with the patient and family, and they should be adapted as needed over time. The development of effective diagnostic and therapeutic strategies entails having a thorough understanding of the patient's illness story. Treatment goals should be discussed clearly and options explored. Aggressive symptom management should be routinely offered, alongside curative and disease-modifying treatments. Control of physical discomfort is basic to any plan. Remember to inquire about symptoms in addition to pain, for example, fatigue, insomnia, dyspnea, nausea and anorexia as these complaints must be managed effectively. Next treat anxiety and depression, which are common in patients with serious medical conditions, and handle other psychosocial issues causing distress (e.g., financial difficulties and family discord).

Goals that concentrate on emotional and spiritual needs are also important to the wellbeing of the patient and family. The overarching goal—to prevent and relieve suffering in order to support the best possible quality of life for the patient and family members—should always be at the forefront of shared decisions. Consistent and sustained communication with the patient and all care providers regarding each of these goals is fundamental.

It is frequently helpful for patients and families, in the aftermath of dealing with a new and difficult diagnosis, for the provider to summarize the treatment plan and concretely describe the next steps. Check for understanding and agreement and assess the patient's and parents' motivations and barriers to compliance. Empower their abilities and praise completion of therapy milestones. Provide written materials and refer to other resources to aid their understanding of the disease. Join with other allied health providers, including therapists (e.g., psychotherapists or physical therapists), social workers and case managers to assure that services are individualized, yet coordinated and easily accessible to patients. Assist families with understanding and navigating the complexities of the healthcare system. Offer support and provide links to community agencies for emotional, spiritual or psychological needs. Anticipate provisions required to make the necessary lifestyle changes mandated by the new diagnosis and facilitate access to these items.

Serious illness causes patients and families to confront anticipated losses as well as unexpected changes in roles. Often, family members faced with assuming the role of caregiver may be intimidated, angry or frightened, and they may feel incapable of performing the tasks required; sometimes they may even refuse. Patients often fear increasing dependence on others, feel vulnerable and helpless and worry about the toll their illness has on their loved ones. By encouraging open dialogue about these emotions and through creating small goals allowing for success, healthcare providers can help patients and families reach acceptance and competency in their new roles. Patients need encouragement and reassurance that they will continue to be a vital part of their families and social communities despite the new limitations they face.

For those patients with advancing or very serious illnesses, the care plan goals need to be constantly updated to focus on what time remains. Prognosis is paramount when considering the risks and burdens of alternative treatments in view of the patient's expectations and personal goals near the end of life. Information should be exchanged bidirectionally so that clinicians and patients can collaborate on the best course of action. Referral to a multidisciplinary palliative care

team or to a hospice program early in the course for those with a grave illness often is the best way to attend to all the needs of the patient and family members.

Offering Hope

The relationship between the clinician and the patient and family can be an important source of solace and security. Hopefulness can help sustain patients and families as they work through the turbulence of adapting to the reality of a major illness. Clinicians should promote hopefulness while remaining truthful and without endorsing unrealistic hope (Whitney et al., 2008). False hope can lead to ignoring risks or delaying preparation for the inevitable. Assure patients and their families that you will partner with them through this grueling process. You may facilitate conversations around what gives meaning and dignity to their life as a way to support hope. Give them time to accept revised hopes and dreams for their lives. When death is anticipated, open communication about what to expect can assist families through the process and facilitate constructive bereavement. (See Chapter 19, *When the Death of a Child is Anticipated and Imminent.*) Encouraging reconnection with important relationships, recognizing past accomplishments, celebrating memories and focusing on the legacy they will leave behind are ways to bring some joy to patients and families in closure.

Conclusion

The conversations that we, as healthcare providers, have with our patients and their families after the disclosure of bad news are crucial to helping them understand the diagnoses fully and to ensure the best outcome. To do this effectively, we must: be prepared; probe for understanding; appreciate family dynamics; address the patient's and parents' concerns; manage symptoms effectively; be responsive to the emotional needs of all family members; communicate empathy; set achievable goals; and offer hope. These important components of communication should guide us as we help our patients and families through difficult and often turbulent times.

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Chapter 22

Discussing DNR and Discontinuing Life Support

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Communicating with patients and parents about death and assisting family members through their child's process of dying are among the most difficult tasks required of pediatric healthcare providers. Both tasks require that the medical team contradict the usual expectations in pediatric care—to keep the child alive and, if possible, restore him or her to health. These conversations, therefore, should be preceded by careful thought and team discussion. We provide a set of guiding principles for: communicating with patients and parents about death and palliative care; helping patient and parents deal with the process of dying; and discussing the discontinuation of life-sustaining treatments.

Ethical Principles and Definitions

More than forty percent of children who die in hospitals do so after decisions are made to limit or discontinue life-sustaining treatments (Cantagrel et al., 2001), and end-of-life decisions are encountered frequently in the Pediatric Intensive Care Unit (PICU). The American Academy of Pediatrics (AAP) has defined *life-sustaining medical treatment* as “all interventions that may prolong the life of patients.” (Kohrman et al., 1994). This includes both invasive therapies, such as mechanical ventilation, cardiopulmonary resuscitation (CPR) and dialysis, as well as less invasive therapies, such as antibiotics, intravenous fluids, and nutrition via tube feeding. It is important to note the difference between discontinuation of life support through *withholding* and discontinuation by *withdrawing*. *Withholding* involves a prospective decision not to initiate a particular treatment (e.g., Do Not Resuscitate orders). *Withdrawing* involves stopping life-sustaining treatment that is ongoing (e.g., discontinuing a mechanical ventilator). Most medical, legal and ethical authorities in the United States and other Western countries do not usually differentiate between these terms and generally support the withholding and withdrawing of therapies when deemed to be of minimal or no benefit and a burden to the dying patient. Unless otherwise noted, we use the term *discontinuation* to connote both withdrawal and withholding. Importantly, some religions and cultures do differentiate between these terms and between discontinuing specific modes of treatment, such as mechanical ventilation, nutrition, hydration and antibiotics (Catholic Church, 2009; Steinberg, 2003). Such differences in ethical principles and definitions can create conflict between the patient or family and the medical team. The emphasis on autonomy and family decision making in most Western cultures also may directly conflict with some patients' cultural and spiritual beliefs. It is crucial that members of the care team be sensitive to these differences. The team should focus on common values, including relieving pain, limiting suffering, honoring spiritual beliefs and maintaining good communication between the medical team and the patient and family.

Lastly, decisions made on children's behalf by families and physicians should be grounded in the best interest standard for the child, which involves carefully balancing the ethical concepts of beneficence (offering and providing therapies based on the benefits they provide the patient) and non-maleficence (doing no harm by providing or withholding therapies). See Chapter 6, *Ethical Considerations in Communicating with or about a Child.*)

Being Comfortable with the Concept of Death

Before engaging in family meetings about end-of-life care, clinicians should consider their own feelings about death and dying. This includes insight into personal values, opinions and emotions, as well as the inherent fear of death. It is important that the healthcare provider acknowledge and address his or her feelings about death, so as not to project these onto patients and their families. Unease in discussing the process of dying or the discontinuation of life support treatments can lead a healthcare provider to avoid these difficult, but necessary, conversations and can lead him or her to unintentionally project false hope or present an unclear picture of the patient's poor prognosis (Curtis, 2004). Conversely, addressing their own emotions can help clinicians avoid these pitfalls, while achieving better job satisfaction. A review of 15 studies showed that a majority of bedside nurses experienced marked anxiety and stress in coping with the dying patient. Nurses who experienced higher levels of anxiety reported decreased satisfaction in caring for the dying patient. Short educational courses that encouraged nurses to reflect upon these emotions significantly improved satisfaction in caring for these patients (Peters et al., 2013). Death is a ubiquitous, emotional and complex subject, and these findings are unlikely to be limited to nurses. Consequently, it is crucial that all healthcare team members take time to address their inherent attitudes towards death and dying before they can adequately address these issues with patients and families.

Recognizing the Dying Patient

While death is a specific *event* in time, the act of dying is a *process* that can be difficult to identify, particularly in patients with whom clinicians have had a long-term relationship committed to healing. It is important to recognize the appropriate time to initiate discussion of end-of-life care, including hospice and limitation of life supporting treatments. Failure to engage families in these conversations in a timely manner can perpetuate false hope and a lack of emotional preparedness for both patients and families. In a study by Russ and Kaufman (2005) families of dying patients acknowledged feeling abandoned by the medical team when the team failed to prepare them for death, yet approached them about stopping life-sustaining therapies. Healthcare providers should be honest about when and how patients and families should begin the journey of facing the death of a loved one.

Setting the Stage

Once the need for end-of-life discussions has been established, it is important to consider the time, location and setting for these discussions. Conversations should occur in a quiet and comfortable location, free from interruptions and large enough to accommodate family and team members. Ask parents whether or not they wish to meet in the patient's presence. In many cases involving critically ill children, families prefer not to leave the bedside, even for short conversations. Conversely, other families will wish to have all medical conversations without the patient present (Barclay et al., 2007).

Team members should meet prior to inviting family members into the conversation. This helps ensure that all team members have the same information, address any internal concerns or conflicts and reach consensus regarding what will be discussed and offered during the family meeting. It is vital that all team members present the patient and family with a unified view. While ideally all team members should be present, including involved physicians, nurses, social workers, chaplains, child life specialists and any other staff with whom the patient and family have developed a relationship, it is important to discuss with the family, prior to the meeting, whom they would like present (Ptacek and Eberhardt, 1996). It is important to establish a safe environment

and supportive tone for these meetings. Physicians and other key team members should be seated with family members. This conveys to the family that team members are attentive and have dedicated time to discuss details of the patient's care. Begin by asking all individuals to introduce themselves and explain their roles in caring for, or their relation to, the patient. Then set the stage by clearly stating the meeting's purpose, who will lead the meeting and what will be discussed.

Delivering the Message

Key tenets to discussing withdrawing or withholding care are to be honest, address uncertainty and manage hope. The way difficult news is delivered greatly impacts how the information is received and processed. Start the conversation by asking the patient (if present) and family members what they understand about the diagnosis and prognosis. It is important to establish their level of understanding and tailor the conversation accordingly. Next, provide a brief summary of the patient's current condition and plan of care. Prior to delivering new and difficult information, it is useful to give a warning to prepare the patient and family and to lessen the shock of the difficult news. For example, one can preface the news with, "I am afraid I have bad news to share." or "Unfortunately, we have some very difficult things to discuss with you now." Knazik et al. (2003) describe a "psychic pain spike" in the minutes directly following difficult news where families are in shock and unable to process information or make decisions. Therefore, it is crucial to pause after delivering the initial bad news, to allow for absorption of information and grieving. This should be followed by expressions of empathy and compassion and the use of active listening. (See Chapter 17, *Delivering and Discussing Bad News: General Principles.*)

The tone of the conversation should be gentle and the pace deliberate, allowing time for pauses and questions. A strategic silence can be as important as the words used since it allows time for families to process and reflect before continuing. Family satisfaction has been shown to directly relate to the amount of time clinicians spent listening during family conferences (Curtis et al., 2002; McDonagh et al., 2004). Unfortunately, McDonagh et al. (2004), in an analysis of recorded family meetings in an adult intensive care unit, found that physicians spent approximately 70% of the time talking and only 30% listening.

The language used should be simple and straight-forward, employing lay terms to describe medical conditions and avoiding technical terms and medical jargon. Use of euphemisms in an attempt to avoid the use of the words *death* and *dying* only leads to confusion and uncertainty. It is natural for families to hold on to hope, thus, many families do not comprehend the gravity of the situation until the physician directly speaks words such as *dying*. Meert et al. (2008) interviewed 56 parents of children who died in the Pediatric ICU. Some parents felt that physicians often withheld information concerning the child's prognosis, "beat around the bush" and at times led them on in attempts to preserve optimism and reduce parent suffering. Despite the physicians' good intentions, parents experienced a sense of betrayal. In some cases, the false hope led to anger and mistrust. Generally, parents preferred that physicians provide complete information, in a candid, straightforward manner.

While honesty and directness are important, they must be joined with compassion, understanding and preservation of *realistic* hope. In a study evaluating surrogate caregivers of critically ill patients, 87% of family members wanted their physicians to openly discuss uncertain and poor prognoses. The family members believed that discussing prognostic uncertainty left room for *realistic* hope, increased their trust in the physician and signaled a need to prepare for bereavement (Evans et al., 2009). At times, families need guidance in redirecting their hope from

hope of a cure towards hope of controlling pain and discomfort, of honoring a patient's last wishes and providing the patient with a *good death*, as defined by the patient and family.

Make a Recommendation

After conveying the difficult news and supporting the patient and parents in their understanding and acceptance of the shift in focus from cure to comfort, move the discussion towards decision making and creating a new care plan. Begin by presenting all medically reasonable options. It is crucial that physicians do not leave this open-ended, placing the entire burden of such an excruciating decision upon a grieving family (Curtis, 2004). Families expect the care team to go beyond providing information and to guide them with a professional recommendation as to which route the team feels is best. In this regard, patients and families will differ in their need for guidance. The decision regarding limiting life-sustaining medical therapies and transitioning to a palliative focus should be a shared decision with the patient (when age appropriate), family and physician, modulated by the family's needs and the care team's guidance.

It is our experience that this shared decision can be reached and its burden eased once the patient's and parents' goals are identified, clearly verbalized and prioritized. When patients and parents are able to define their priorities, physicians can better direct them in making end-of-life decisions aligned with these priorities. The physician should ask the family to prioritize their goals and to help create a care plan. For example, families often express the importance of both keeping their child alive and avoiding prolongation of suffering. In such and similar situations, we often guide the family in a stepwise fashion, beginning with a conversation as follows:

We all would want Elaine to be cured and live with you for many years to come. Unfortunately, as we discussed, we cannot cure her cancer. Now we must make some difficult decisions that ideally no parent should have to make. (Pause) I'm going to ask you some difficult questions to help us understand your goals and priorities. This may help you make these decisions. What are your most important priorities for your child? If achieving your priority of keeping her alive would require compromising your priority of minimizing her pain, which would be more important?

Families often believe that opting to limit or discontinue life support would make them directly responsible for their child's death. Healthcare providers should dispel this belief to relieve families of this burden. Emphasize that life-sustaining measures, such as mechanical ventilation, cannot reverse the underlying disease process and discontinuing or limiting these therapies only allows for the natural and inevitable progression of the disease. Explain that discontinuation of life support often facilitates more effective palliative care and patient comfort (Curtis, 2004).

It may be necessary to introduce the concept of medical futility at this time. Explain that a therapy is futile if there is an exceedingly low likelihood, or no possibility, that it will result in a successful outcome. The definition of a successful outcome may depend on the patient's (when developmentally appropriate) and family's priorities. Any therapy that would not result in an outcome aligned with their goals should not be offered or should be discontinued (Curtis, 2004).

Individual members of the medical team or the family may have conflicting opinions regarding the best course of action. In these instances, consultation with institutional ethics committees can help resolve these differences and facilitate sound ethical decisions, in the patient's best interest.

Make a Plan and Set New Goals

Once the family (including the patient if developmentally appropriate) has decided to pursue palliative care, it is essential to establish a new care plan and set new goals. Utilize their priorities and goals to define limits and expectations, including how pain and discomfort will be managed,

whether nutrition will be continued and whether there will be limitation of tests, procedures and treatments. Families may prioritize prolongation of life, limited by the higher priority of comfort. In this case, intravenous antibiotic administration through an existing line would align with these priorities, whereas inserting a new intravenous line might not. In other situations the family may believe that any life-prolonging measures would only prolong their child's suffering. In this situation the discussion should focus on which interventions should be limited or discontinued.

Encouraging parents to set new care goals for their child can help shift the focus from curing disease to caring for the patient throughout the dying process. Additionally, it gives family members, including siblings, an opportunity to be involved in the patient's care in a way that expresses and honors their wishes. New goals should meet the family's spiritual needs. (See Chapter 29, *Communicating about Spirituality and other Worldviews*.) Child life specialists, social workers and chaplains are paramount to this discussion and are invaluable team members throughout this process. The location of this end-of-life care must also be addressed, and families should be given the option to pursue comfort care at home, as well as inpatient hospice care, if available.

Towards the end of each family meeting, the physician should summarize all conclusions and decisions and review the plan and the next steps. The meeting and its conclusions should be clearly documented in the patient's chart. Additionally, decisions should be entered in an advance directive signed by the patient or patient's guardian (usually the patient's parents). An *advance directive* is defined by the Patient Self Determination Act of 1990 as, "a written instruction, such as a living will or durable power of attorney for health care... relating to the provision of health care when the individual is incapacitated" (Patient Self Determination Act of 1990, 1990). The advance directive legally documents the patient's or surrogate's wishes and directs the actions of the medical team. Physicians should emphasize to patients and families that they can change their decisions at any time, and that the directive would be updated accordingly.

Do Not Resuscitate (DNR) Orders and Levels of Life Support

Do Not Resuscitate (DNR) orders are frequently addressed during end-of-life conversations. These orders limit resuscitative measures in the event of a cardiopulmonary arrest but do not define limitation of support in pre- or post-arrest states. Sanderson and colleagues (2013) evaluated how pediatric physicians and nurses viewed DNR orders, including how they were defined, discussed and implemented. Their study revealed substantial variability in how medical teams defined DNR orders. Additionally, the investigators found that while most healthcare providers believed DNR orders were intended to limit only cardiopulmonary resuscitation, these orders often lead to broader limitations of care. Therefore, the physician should clarify for the family the specificity of the DNR order and explain that it does not preclude continuation or initiation of other treatment modalities in non-arrest situations. Moreover, it is crucial that treatment preferences be clearly defined, rather than inferred, from a DNR order, so as to avoid misunderstandings.

Parents often evolve in their grieving and acceptance of their child's irreversible condition. Their stage of grief and changing priorities can result in hesitations or misgivings about limiting particular life-sustaining treatments. These often center on active withdrawal of treatments that could result in near-immediate death (e.g., disconnecting the patient from the ventilator), as well as active withdrawal or passive withholding of common care modalities such as nutrition, antibiotics or routine diagnostic studies. Limitation of support may be viewed as a spectrum, and goals and directives may shift in response to changes in the child's condition or the family's stage of grief. At one end of the spectrum, a family may opt to withhold resuscitation for cardiac arrest

(i.e., DNR) but proceed with all other treatments, including endotracheal intubation and ventilator support for respiratory arrest. At the other end, a family may decide upon the active withdrawal and passive withholding of all treatments except comfort measures. The medical team should expect to revisit end-of-life goals as the child's condition or the family's grieving evolves.

Meet Repeatedly and Be Available

It is important to encourage repeated conversations due to the complex and emotional nature of the information. In their study of physician-family meetings, Azoulay et al. (2000) found that 54% of family members had not understood basic components of the patient's diagnosis, prognosis or treatment by the meeting's conclusion. It is therefore helpful at the end of each meeting to set a future time to reconvene and address questions and possible changes in clinical status and care plan. In a qualitative study involving interviews of parents of deceased children, the communication issue mentioned most often was physician availability (Meert et al., 2008). Physicians should therefore provide contact information and be available between meetings for questions and additional follow up. This accessibility signals willingness to provide further support and results in greater family satisfaction.

Communication at the Time of Discontinuation of Life Support

The uncertainty surrounding the dying process is a significant stressor for patients and families. A majority of family members want to know details of the dying process, including what death will look like, how it will occur and when to expect it. Clinicians should be honest about the unknowns, particularly regarding the duration of the dying process. Assuring families that they will not be abandoned in this process provides comfort and eases acceptance of the unknown. Many families also ask about pain control, management of secretions and provision of nutrition, as well as details surrounding the removal of technological support. It should be pointed out that narcotics, though useful in controlling pain and discomfort, can suppress the respiratory drive. It should be emphasized that the intent of their use is not to hasten death but to control pain, discomfort and air hunger.

After life support measures are discontinued, it is essential to continue supporting families through the dying process and ensure that adequate comfort care is provided. Team members should frequently check if the family perceives any patient discomfort. At this time, clinicians should anticipate a variety of expressions of grief from family members. These vary between individuals and cultures and can include painful silence, loud crying and outbursts of anger towards the medical team. In extreme cases, a family member may develop physical symptoms including syncope or even symptoms of a myocardial infarction. Sometimes, family members need to be removed from the patient's bedside due to outbursts of anger or threatening behavior or to provide them with medical attention.

Respect Family Values, Goals and Culture

The death of a child is a complex and devastating experience, regardless of cultural differences. However, cultural differences can complicate communication between the medical team and the dying child or his family members. (See Chapter 28, *Communicating across Cultural Differences*). For example, familial cultural expectations can present an important caveat to the openness recommended in presenting the patient's poor prognosis. In some cultures, direct verbal communication of bad news is considered rude and insensitive. In other cultures the risks of truth-telling are seen to outweigh the benefits, and emphasis is placed on protecting the patient from distressing information and maintaining hope. Additionally, the actual words spoken carry different meanings among various cultures. In some cultures (e.g., Native American, Filipino, and

Bosnian) it is felt that talking openly about something bad may cause it to happen. For example, a commonly held Navajo belief is that negative words and thoughts about health become self-fulfilling (Barclay et al., 2007; Searight and Gafford, 2005). Accordingly, care providers may be expected to communicate bad news through non-verbal cues or other indirect means. For example, in talking to Navajo parents, rather than saying, "Wilson has an incurable cancer. There is nothing we can do to stop the cancer, but we can treat the pain and trouble breathing and keep him comfortable." one might say, "This type of cancer is not curable. In these cases, while we cannot stop the cancer, we can keep the patient comfortable." This is contrary to usual medical practice in the United States, where using the patient's name is strongly encouraged. These examples illustrate the importance of learning about families' cultural expectations before meeting with them (Barclay et al., 2007).

A study by Davies et al. (2008) found that approximately 40% of healthcare providers identified cultural differences as a frequent barrier to providing pediatric palliative care. Thibodeaux and Deatrck (2007) found that in contrast to Caucasian parents, the majority of Latino parents felt that every effort should be made to save the child, which led to a reduced acceptance and participation in palliative care. African-American individuals with strong Christian beliefs may resist the discontinuation of life-prolonging treatments because of a belief in and hope for miraculous interventions for their children (Sandoval, 2003). In these situations, families may regard discontinuing life-sustaining care as a violation of their beliefs. Such interpretation can lead to a preference for life-prolonging treatments over interventions designed to reduce suffering and provide comfort. Families may experience additional stress when there are language barriers between them and the medical teams. They may become frustrated with their inability to ask questions when translators are not immediately available, and they may feel (rightly or wrongly) that they are receiving incomplete information about their children's conditions (Wiener et al., 2013).

The preferred location for death also may differ between cultures. Whereas some families prefer that their children die in a hospital setting, surrounded by medical staff who can attend to their needs, others see this as undesirable. For instance, both Latino and Filipino families generally prefer that the child die at home (Mazanec and Tyler, 2003). Differences occur even within cultures, for example, some Chinese individuals believe that death in the home is a sign of bad luck whereas other Chinese fear that death in the hospital can result in loss of the deceased's soul.

It is important that the medical team recognize the need for cultural awareness and sensitivity. Bridging cultural differences may require support from ancillary team members, including interpreters, clergy and social workers, who may be especially equipped to address gaps in cultural understanding. When cultural differences result in conflict between families and the medical team, the hospital's bioethics committee may be helpful in resolving these conflicts.

Learn and Reflect

Conversations regarding the death of pediatric patients can be difficult and stressful for healthcare team members. Leading these conversations is a skill that can be cultivated through reflection. We recommend that this reflection occur, both individually and as a team, immediately after completing a family meeting. Individual team members should reflect upon and acknowledge personal feelings and emotions. Team reflection is critical in limiting the stress and emotional burdens carried by team members. Encourage open discussion and acceptance of opinions and emotions. Discuss what went well and suggestions for future conversations.

Conclusions

Guiding children and their families through the dying process and discussing withholding or withdrawing certain aspects of care can be challenging. We suggest a stepwise approach that begins and ends with the provider's self-reflection. Important steps include: preparing the medical team; setting the stage for the family meeting; preparing the family; presenting the bad news; assisting with setting goals and making a care plan. The process requires planning, introspection, empathy, compassion and strong communication skills. When done well, it can be very fulfilling and have a long-lasting positive impact on the child's family as well as members of the medical team.

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Chapter 23

End-of-Life Issues

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Introduction

In the developed world, death in childhood is relatively rare, especially beyond infancy. National mortality data from 2010 show that about 2.5 million people die each year in the United States. Of these, nearly 25,000 are children under 1 year of age, and another 10,000 are children ages 1 to 14 years (CDC, 2010). This relatively small number, given that the American Academy of Pediatrics reports that there are about 50,000 general pediatricians and another 27,000 pediatric subspecialists in the United States, means that many pediatricians have limited experience managing the care of dying children and thus may be uncomfortable with symptom management and with addressing psychosocial issues in the care of a dying child (Workforce COP, 2013). As with all other aspects of clinical medicine, providers' comfort with a topic increases with proficiency, and communication with the family of a dying child is a skill that can be learned and practiced. This chapter focuses on talking with the pediatric patient and parents when cure is impossible and death is approaching. Among the topics providers should be prepared to address are palliative care, hospice care and end-of-life care.

Palliative Care for Children with Prolonged, Chronic or Progressive Conditions

Palliative care is a family-centered, multidisciplinary effort that focuses on relieving suffering and maximizing quality of life in patients with serious illnesses. Palliative care is appropriate regardless of the expected outcome of the disease process and is complementary to other therapies, including aggressive attempts to cure the disease. Such care in the diagnostic and early management phase includes: establishing a trusting relationship with the child and family; attending to the effects of a life-threatening condition on family relationships and function; and treating symptoms and complications of disease to maximize functionality and quality of life. It is important to note that providers can and do provide primary elements of palliative care without consulting a palliative care specialist. When issues are complex, however, consultation can be helpful.

Delivery of quality palliative care involves a multidisciplinary team approach. Physicians, psychologists, advanced practice providers, nurses, social workers, physical and occupational therapists, child life specialists, chaplains and others play critical roles in the comprehensive approach to palliative care. In addition, these providers work across many different settings, including the office, hospital and intensive care unit, as well as in the home and community. Palliative care teams assist primary care providers and subspecialists in the management of children with complex and often life-threatening or life-limiting conditions through coordination of care and thorough, proactive communication with patient, family and providers. Palliative care activities include: evaluating the child's (when developmentally appropriate) and parents' understanding of the disease, treatment options and expected prognosis; identifying preferences for communication style and shared decision making regarding the child's care needs; establishing and communicating clear goals of care, including goals for the end of life as it

approaches; and assisting with pain and symptom management to maximize patient and family functioning and quality of life.

Various triggers may suggest the need for a palliative care approach over the course of an illness. For example, patients undergoing prolonged hospitalization, even if the ultimate outcome is expected to be good, may benefit from the multidisciplinary support and care coordination provided by a palliative care team. Similarly, a prolonged intensive care unit stay should lead to consideration of a palliative care consult. Changes in disease status also signal that palliative care support, either by the primary team or through a palliative care team consult, is warranted. At the time of an event such as recurrence of cancer or the need for increased technological support of a child with a complex medical condition, palliative care activities can help by focusing on expectations of further treatment with regard to overall prognosis, risk and burden to the child, and quality of life considerations for the child and family. Disagreements between the care team and family or among team members about goals of care or major treatment decisions, such as resuscitation status or the use of life-sustaining technologies, also may signal that palliative care support and consultation should be considered.

Hospice Care

Hospice care is a subset of palliative care focused on terminally ill patients. In the United States, hospice care generally takes place when death is anticipated within 6 months because Medicare and Medicaid Hospice Benefit requires physician certification that the patient's condition is likely to be fatal within that time period. In reality, the National Hospice and Palliative Care Organization (2013) reports that the median length of stay in hospice care in 2012 was 19 days. This short length of hospice care reveals the ongoing challenge of engaging palliative and hospice care earlier in the disease trajectory as opposed to the very last days of life. Conversely, if death has not occurred in the six month time frame, hospice providers may re-certify the child for benefits as long as the disease or condition continues to have a terminal prognosis and decline is documented. Since 2010, with the initiation of the Affordable Care Act, children (up to the age of 21) who are covered by Medicaid or the Children's Health Insurance Program (CHIP) have been able to receive concurrent treatment for their primary condition and community based hospice care (Keim-Malpass et al., 2013). This change in hospice eligibility for children has increased access to hospice and end-of-life care for children with complex medical conditions. A hospice or palliative care provider can assist in determining the appropriateness of the concurrent care benefit for a particular child.

End-of-life care refers to care during the time that a patient is approaching death in the next days to weeks. This period is generally evidenced by deterioration in the child's level of consciousness, breathing, nutritional intake and urine or stool output. Care is now focused on helping the family create memories and a legacy with the child, prepare for the death and address the child's symptoms to maximize comfort.

Child and Family Needs during Disease Progression

Anticipatory Guidance

Anticipatory guidance is a hallmark of pediatric care and requires a mutually trusting relationship between family members and their healthcare providers that promotes shared decision making based on knowledge of the child's condition, as well as the child's and family's values and preferences for care. Depending on the child's condition at diagnosis, hope for full recovery may be realistic, the prognosis and course of the illness may be uncertain or the illness may be expected to be inexorably fatal. In addition to variations in prognosis, disease trajectories also

may vary. For example, children may have many periods of severe illness with a return to baseline health between episodes, they may have a gradual decline with intermittent crises or they may have a relatively steady course with a sudden deterioration at the end. The pediatric provider should be able to guide the family through the illness regardless of anticipated trajectory.

Informational Needs

Parents of children with life-threatening, life-limiting or terminal conditions require clear, accurate information regarding: the child's diagnosis; medical, nursing and other interventions that may be appropriate; and the expected short and long term outcomes related to the particular child and situation. Children with complex conditions often have multiple medical providers, and communication among providers and between providers and parents can be inconsistent and confusing. It is important to designate a primary individual or group of providers who will coordinate information among the child's providers and take the lead in communicating this information to the family clearly and consistently, including information about differences in opinions among providers. Identifying a primary individual to coordinate communication through regular, supportive updates over the course of the child's illness and to clarify the patient's and parent's understanding allows children and families to make informed treatment decisions in a supportive setting.

Healthcare providers often fear taking away hope if they provide too much information regarding a poor prognosis for the child. Studies, however, have shown that patients want to receive prognostic information (Mack et al., 2006; Mack, 2007). Hope is an internal construct, unique to each person and as such cannot be taken away by medical personnel, although the content or object of hope may be affected by medical circumstances. Granek et al. (2013) suggest that parental hope is often expressed as a future-oriented desire for curing or controlling a disease process and maximizing the child's functionality and life-span but also can manifest as a present-oriented hope for comfort and relief from suffering and pain and for finding moments of joy and peace in day to day experiences, even when cure is no longer a realistic outcome. Mack et al. (2007) surveyed physicians and parents regarding the effect of communicating prognostic information on hope, trust and emotional distress. They found that when prognosis is poor, honest and compassionate communication by the provider can support hope and help parents deal with emotional distress.

Establishing Goals of Care

One desired outcome of anticipatory guidance during a child's disease progression is development of goals of care that guide providers and parents in medical decision making. When a child has an incurable disease, it is important to establish clear goals of care that focus on maximizing comfort and quality of life and minimizing non-beneficial, potentially harmful interventions. Changes in the child's condition should lead to discussions with the child and family about management options, risks and benefits, current level of function and comfort and quality of life. Goals of care may range from treating pain and other distressing symptoms and focusing on quality of life, to extending life as long as possible, even if it requires invasive technological interventions to do so.

Discussions of interventions, such as feeding tubes, respiratory support and cardiopulmonary resuscitation should be based on the child's overall condition, the expected benefit or outcome of interventions and the family's understanding of the child's disease process and prognosis. An important consideration in addressing goals of care close to the end of life is the distinction between *letting* or *allowing* a child to die by limiting interventions versus acknowledging that the disease has progressed towards an expected outcome of death and that further intervention will

only prolong suffering and the dying process. The former suggests that healthcare providers or parents could in some way stop the death from occurring, while the latter represents the reality that despite all available medical interventions, the disease is no longer responding and death is now the anticipated outcome.

Parents often make decisions based on their perception of the child's current level of activity and quality of life. Thus decisions regarding invasive intervention may need to change over time. Gentle and compassionate discussions regarding declines in the child's condition can help parents focus on interventions aimed at comfort and quality of life. Tools like "My Wishes" can be extremely helpful in allowing the child to voice his or her own preferences and goals of care (Pediatric My Wishes, 2013). Use of advance directives or written documentation of the family's and child's wishes is an important way to ensure that all providers, especially those who may be involved in an urgent setting and unfamiliar with the child, are aware of the overall goals for the child's care. (See Chapter 22, *Discussing DNR and Discontinuing Life Support*.)

Communicating Difficult Information

It is especially challenging for physicians to tell families and children that no further interventions are available to arrest or reverse the disease. This situation may trigger strong emotions in the physician, such as fear that the family will be angry or feelings of failure over his or her own performance. This conversation is never easy, but it can be made more manageable with some relatively straight forward steps. First, the physician should be well prepared and should refresh him or herself on the child's course of illness, treatments that have been attempted and their outcomes. He or she should be aware of potential additional interventions and be prepared to discuss why they are not appropriate for this child. If possible, the discussion should be arranged far enough in advance for the parents to identify other family members who should be present. Similarly, it may be helpful to have additional team members, such as social workers who have been involved with the family, attend the meeting. Depending on the age, maturity and prior involvement of the child in medical conversations, a decision should be made about whether to include the child in the initial discussion. If the plan is to speak first to the family without the child, arrangements should be made for someone to stay with the child while the parents are out of the room. A comfortable, private area such as a conference room should be provided for the meeting. Ideally, everyone's cell phone and pagers should be handed off or muted.

Family members (and patient, if present) should be asked for their assessment of the patient's current status. Any misunderstandings should be addressed and relevant new information provided. Goals of care should be revisited in view of the new circumstances. The crux of the conversation may be a change from the goal of cure or maximum life extension to a goal of quality time and maximum comfort.

It is important *not* to convey a message that *nothing more can be done*. Instead the physician should focus on the many things that *can be done* that are consistent with the new goals of care. These may range from specific treatments for particular symptoms to changes in priorities. For example, where adherence to a treatment regimen or schedule may once have been paramount, now allowing a child to take part in important social activities such as school or family events may become a higher priority.

Each family member will have a unique reaction to receiving information about a life-threatening disease. Reactions can range from overt expressions of anger, grief and denial to avoidance of further conversations or no overt response at all. Providers should be prepared for a range of reactions and should offer necessary support to family members as they process the information they have received. Simple statements indicating understanding of the difficult nature

of the information and normalizing the child and family's responses can help reduce the discomfort for both families and the healthcare team. Simple statements such as, "I'm sorry to have to give you this information." or "I understand that this is difficult to hear." indicate understanding of the difficult nature of the information. Similarly, one can normalize the child's and family's emotional reactions with a statement such as, "Many families feel overwhelmed when they first hear this information. Take your time and let me know when you are ready to continue."

If the child has not been included in the meeting, is it important to discuss how the child will be given the information. The family may hesitate to share such news from a desire to protect the child. Attempts to protect the child in this way, however, are likely to create feelings of fear, guilt and isolation in the child and to interfere with important work that the child and family can do to prepare for death, such as legacy building activities. The child life specialist can assist with explaining the situation to the child (and siblings) in honest, age-appropriate terms.

The initial delivery of such news should be viewed as a starting point, rather than as the end of the discussion. The family meeting should conclude with specific follow-up plans, including how the new information will be conveyed to the child and when the next meeting will be. These steps are critical to avoid patient and family feelings of abandonment.

Supportive Needs

Families need many types of support throughout the child's disease process and as the end of a child's life approaches. Some needs are obvious, for example, durable medical equipment such as a hospital bed or bedside commode at home. Other support needs may be more subtle, for example, enlisting a child life specialist to assist with age-appropriate education for siblings making hospital visits or seeing physical changes in the dying child. Social workers may provide critical help with financial problems or job-related issues, especially concerning work absences or family leave, as well as with complex issues such as obtaining permission for family members to travel from other countries to visit and support the family. Psychologists and chaplains can help families cope with emotional and spiritual distress. Each member of the multidisciplinary team contributes, although the specifics vary from family to family.

Approaching End-of-life

A child's journey toward end-of-life can be as long as decades to as little as hours. It is important that healthcare providers recognize the signs that indicate that the end of the child's life is near and assist parents in preparing for the impending death. For children who have lived with long term, progressive diseases, indications that they are reaching the end of life often include increased hospitalizations, worsening symptoms, need for more intensive care at home and decreased function and responsiveness. When the transition to end-of-life is gradual, involving hospice and palliative care providers early in the process has been shown to promote improved symptom control, decrease the use of non-beneficial interventions, decrease the frequency of intensive care admissions and increase time at home (Gans et al., 2012; Keele et al., 2013; Schmidt et al., 2013; Zhukovsky et al., 2009).

At the other end of the spectrum, some children experience rapid deterioration. If the family or healthcare providers are unprepared for the event, or if a situation that initially appeared reversible instead progresses, these children may approach end-of-life despite escalation of medical and technological interventions. Healthcare providers can assist parents in understanding the increasing likelihood of death by framing interventions in terms of time-limited trials to evaluate the response, while addressing sources of suffering from escalating interventions and providing a clear plan for maintaining comfort as the child progresses toward death (Doorenbos, 2012; Gupta, 2013; Madrigal, 2012).

Imminent Death

The period of *active dying* can last a short time or up to several weeks. There may be a gradual onset of increased sleep, decreased oral intake and overall disengagement from usual activities. Cognitive changes, irregular respirations, noisy breathing due to pooled secretions in the oropharynx (the so called death rattle) and mottling of the extremities generally portend death within hours to a few days as opposed to weeks. The provider should be able to recognize these signs in order to provide the family with anticipatory guidance about the child's final days.

Conclusion

Caring for children with incurable, fatal medical conditions involves skills beyond medical diagnosis and treatment of the condition. Healthcare providers must develop skill in managing disease progression, communicating with the patient and family and coordinating care, as well as proficiency in managing pain and symptoms associated with disease and treatment. Involving palliative care experts in the care of these dying children will not only provide support for the child and family but also will assist the healthcare providers involved in the child's care.

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Chapter 24

Disclosing an Adverse Event or Medical Error

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Introduction

When an unanticipated adverse event, such as a medical error, occurs, disclosure of the event to the patient and family is required ethically: as part of a professional obligation to the patient and family; to comply with regulatory requirements; and, depending on the state in which one practices, to be in compliance with statutory requirements. The inclusion of an apology with the disclosure of an adverse event in the healthcare setting is an area of active debate, which will be discussed further in this chapter. Internal reporting, such as through a facility's adverse event reporting system, is not addressed in this paper.

An analysis by Hickson and Pichert with the National Patient Safety Foundation (2007) states that when a healthcare injury occurs, the patient and the family are entitled to a prompt explanation of how the injury occurred and its short- and long- term effects. Furthermore, when an error contributed to the injury, the patient and the family should receive a truthful and compassionate explanation about the error and the remedies available to the patient. Finally, they should be informed that the factors involved in the injury will be investigated so that steps can be taken to reduce the likelihood of a similar injury to other patients.

Other national professional organizations also have addressed the issue of disclosing adverse events to patients and families. The American Medical Association (AMA) Code of Medical Ethics (1994) iterates that a physician has an ethical responsibility to deal with patients openly and honestly:

“Patients have a right to know their past and present medical status and to be free of any mistaken beliefs concerning their conditions. Situations occasionally occur in which a patient suffers significant medical complications that may have resulted from the physician's mistake or judgment. In these situations, the physician is ethically required to inform the patient of all the facts necessary to ensure understanding of what has occurred. Only through full disclosure is a patient able to make informed decisions regarding future medical care.”

The Joint Commission International Accreditation Standards for Hospitals' standard of care (2011) requires that patients and their families be informed about the outcomes of care, including unanticipated outcomes. The American Academy of Pediatrics' Professionalism in Pediatrics Statement of Principles requires “acceptance of responsibility for errors made, including the willingness to acknowledge and discuss errors and their consequences with the family and with peers, and collaborate in the search for systematic actions to prevent future harm.” (Committee on Bioethics, 2007)

Patient safety advocate groups continue to work to foster an understanding among healthcare providers that professional ethical responsibilities require disclosure of patient safety related issues to patients and their families. In the book, *After Harm*, Berlinger (2007) states, “There is basic intellectual agreement within the medical profession that telling patients the truth, including the truth about medical mistakes, constitutes a professional obligation for physicians.” For patient

safety advocates, the inclusion of an apology for a medical error during the disclosure of the adverse event is a significant factor.

Definitions

Medical Error

An act of commission (doing something wrong) or omission (failing to do the right thing) that leads to an undesirable outcome or significant potential for such an outcome (AHRQ, 2014a). For example, ordering a medication for a patient with a documented allergy to that medication would be an act of commission. Failing to prescribe a proven medication with major benefits for an eligible patient (e.g., heparin prophylaxis for venous thrombosis in a patient after undergoing hip replacement surgery) would represent an error of omission.

Near Miss

An event or situation that did not produce patient injury but only because of chance (AHRQ, 2014b). This good fortune might reflect robustness of the patient (e.g., a patient with penicillin allergy receives penicillin but has no reaction) or a fortuitous, timely intervention (e.g., a nurse realizes that a physician wrote an order for the wrong patient). This definition is identical to that for a *close call*.

Adverse Event

Any unanticipated, negative event that occurs during the care of a patient regardless of circumstance. Some are preventable, others are not readily avoidable. For example, when a patient who has never been on a medication has an idiosyncratic reaction to that medication, it is an adverse event, but not likely preventable. All medical errors are adverse events, but not all adverse events are medical errors.

Disclosure

Telling the patient and family about an adverse event is a disclosure. Disclosure typically includes a statement of recognition that an adverse event has occurred and an explanation of what is known about how the adverse event happened, how the effects will be managed and minimized and the actions that the physician and healthcare facility will take to prevent recurrences. Full disclosure of an adverse event that is also a medical error incorporates these elements, as well as an acknowledgement of responsibility and an apology by the physician or other appropriate healthcare provider (AHRQ, 2014c).

Apology

An apology is an expression of regret and compassion that an adverse event has occurred (Wojcieszak et al., 2008). For example, a physician might say, "I am sorry that your child had a reaction to the medication." or "I am sorry that your child has had pain as a result of his reaction to the medication." Avoid statements that criticize other care providers, such as, "I am sorry that the pharmacist provided the wrong medication to your child." An apology that accepts responsibility for an event ("I am sorry that I prescribed the wrong medication.") is admissible in some state courts, including Texas. Do not offer an apology accepting responsibility for an event before the investigation is completed. If the investigation indicates that an apology and accepting responsibility for the event is appropriate, contact your risk management office for guidance and support prior to offering the apology.

Background

How are physician's doing regarding disclosure?

For several decades medical educators have addressed how trainees respond to medical

errors, and specifically, if disclosure to patients and families occurred. In the early 1990s, Wu et al. (1991) surveyed 245 internal medicine residents and asked about learning from one's mistakes. They discovered that adverse events were common and that 90% of the adverse events reported resulted in serious adverse outcomes, with 31% of the patients dying. Fifty-four percent of the residents discussed the adverse events with their attending physicians, but only 24% informed the patient or family of the error. Exploring this issue with pediatricians working in an academic pediatric emergency department, Selbst et al. (1999) reviewed incident reports over a five year period. Thirty-three reports dealt with medication and intravenous fluid errors. Of these errors, 42% were disclosed to the families, 36% were documented in the incident report as having not been disclosed to the families and the remaining cases did not have sufficient documentation to determine if the family had been informed.

More recent data suggest that physicians and physicians-in-training are more aware of the expectation to disclose errors to patients and families. Kaldjian and colleagues (2008) surveyed 338 residents and faculty at several medical centers in 2004 and 2005 and found that 84% agreed that reporting errors improves the quality of care. Given a hypothetical case, 92% would report a medical error that caused major harm to a patient. However, 4% acknowledged not reporting a major error. Jericho and colleagues (2010) studied adverse event reports from 51 anesthesiology residents at a Chicago training program and tracked reporting behavior for 2 years prior to an educational intervention around reporting and for a year and 9 months after the intervention. When the residents were asked if near misses should be disclosed to patients, prior to the intervention 37% agreed or strongly agreed that such a disclosure should occur, whereas after the training, 61% agreed or strongly agreed. Gallagher and colleagues (2006) in a study of US and Canadian physicians found wide acceptance of the need to disclose adverse events but varying approaches to how explicit the physician should be with the patient and family about the details of a medical error. When asked to respond to medical error scenarios in a mailed survey, of the 2,637 physicians who responded, 56% would provide a partial disclosure where the adverse event is mentioned to the patient and family but not the presence of a medical error, 42% would provide complete disclosure to the patient and family, making an explicit statement about an error occurring; only 3% would not disclose the adverse event or error.

Finally, as a result of much more attention to patient safety since the publication of the two Institute of Medicine Reports, *To Err is Human* (1999) and *Crossing the Quality Chasm* (2001), state legislatures across the nation have addressed reporting and disclosure in a variety of ways. As of April 2008, according to the Agency for Healthcare Research and Quality, seven states had mandated the disclosure of unanticipated outcomes (AHRQc). The AMA's Advocacy Resource Center (2012) lists over 30 states that have apology laws in the form of a bill or statute. These apology laws provide some protection with regard to admissibility of an apology in a lawsuit. However, the statutes and the protection differ by state.

What are the barriers to disclosing adverse events?

The American Society for Healthcare Risk Management (ASHRM) (2003) characterizes barriers to disclosing adverse events to patients and families as either being rooted in personal beliefs or fears or based on perceptions of the legal process that may ensue after the disclosure is made.

Personal beliefs and fears include the following:

- Belief that:
 - Disclosure is unnecessary
 - Disclosure is a factual matter not a complex interpersonal conversation

Outcome is not related to action on the part of the discloser

Outcome would have potentially occurred without error

- Fear of:
 - Retribution from patient or family
 - Retribution from peers
 - Conducting disclosure conversation poorly, doing more harm than good
 - Having to handle emotions

In the legal realm, a number of questions arise in the minds of healthcare providers when they consider the need and value of disclosing an adverse event to a patient or family. Some of the questions that arise relate to:

- Legal protection for information during disclosure
- Legal protection for information in medical record
- Necessity for disclosure
- Benefit that disclosure might have during the legal proceeding other than the perception of honesty

What about malpractice and risk of being sued?

Perhaps underlying a significant portion of both personal issues and legal concerns is the very real possibility of liability and being involved in a malpractice lawsuit. In a study by the Kaiser Health News (2012), physicians consistently note that fear of being sued is one of their primary concerns. In a now classic work, Hickson et al. (1992) studied 368 closed cases involving families in Florida who experienced permanent injuries or deaths involving perinatal care from 1986 to 1989. Surveys were completed by 127 (35%) of the families. In this study, the reasons that families brought suits in these cases were:

- 33% advised by acquaintances
- 24% recognized a cover-up
- 24% needed money
- 23% perceived their child as having no future
- 20% received inadequate information
- 19% sought revenge or protection from future harm

The parents studied expressed significant dissatisfaction with physician-patient communication as evidenced by the following views expressed by respondents to the closed case perinatal malpractice study:

- 13% believed physicians would not listen
- 32% believed physicians would not talk openly
- 48% believed the physicians attempted to mislead them
- 70% expressed that physicians did not warn them about long-term neurodevelopmental problems to be expected in their child

Wu (1991; used with permission) cites an attorney who told him the following when asked about his observations about why patients bring law suits:

“In over 25 years of representing both physicians and patients, it became apparent that a large percentage of patient dissatisfaction was generated by physician attitude and denial, rather than the negligence itself.

In fact, my experience has been that close to half of the malpractice cases could have been avoided through disclosure or apology but instead were relegated to litigation. What the majority of patients really wanted was simply an honest explanation of what happened, and if appropriate, an apology.

Unfortunately when they were not only offered neither but were rejected as well, they felt doubly wronged and then sought legal counsel.”

What do patients and families do?

Witman et al. (1996) studied the responses of patients and families after a medical mistake occurred. The responses to questions about if they would continue seeing the physician involved with the mistake and if they would bring a suit varied with a number of factors, but the severity of the medical error was a significant differentiator (measured as minor, moderate or severe). Nearly all patients (98%) expected even minor errors to be acknowledged. Only 14% of patients would seek care from a different physician after a minor error, but 65% would change physicians after a severe error occurred. For both moderate and severe medical errors, patients were significantly more likely to consider bringing a suit against the physician if the physician failed to disclose the error. Specifically, 12% of patients would bring a lawsuit against the physician if they were informed, while 20% would sue if the physician did not disclose and the patient discovered the error by some other manner ($p < 0,001$).

Greenberg and colleagues (2010) conducted a study for the RAND Corporation on data from 2001 to 2005 in order to determine if a relationship existed between patient safety activities and malpractice claims. Using a sophisticated health service research design, counties in California were assessed for malpractice activity and patient safety initiatives. The authors recognize that the decision to bring a malpractice suit is complicated and depends on many factors. However, the intuitive relationship between improved patient safety performance and decreased malpractice activity, and the opposite tenet, that less patient safety work would be associated with more malpractice suits being filed, were confirmed in this study.

Models for Managing Communication during the Disclosure Process

Coaching is essential for the team or the lone professional who will disclose the adverse event. Serious adverse events, especially those due to medical error, are typically not common in any individual's professional's practice so relying upon recollection of important communication guidance from distant trainings is unlikely to lead to an optimal disclosure experience for either the patient and family or the professional(s) involved. Instead, supplementation of past training with customized, real-time coaching by colleagues who are current about best practices and who are skilled at disclosing difficult information, such as an adverse event, is generally viewed as the ideal way to manage the disclosure of adverse events to patients and families.

The disclosure of an adverse event should occur as soon as practicable after immediate healthcare needs are addressed. The focus of the discussion needs to remain on the patient and family and their clinical and emotional needs. Consistent with professional communication with patients and families, the disclosure conversation should be free of jargon. Avoid making excuses or being dismissive of the patient's or family's concerns. Guiding principles for disclosing adverse events require that:

- All caregivers have the patient's best interest in mind
- The physician is ultimately responsible for treatment decisions
- The physician and the organization are responsible for providing quality patient care
- Performance improvement and patient safety are continuous tasks

With these principles in mind, the professional(s) disclosing the adverse event should: explain the patient's current status; discuss only pertinent clinical facts; and explain the plan of action, the current prognosis and the updated plan of care. It is essential to be explicit that the physician (and the hospital or organization) has taken appropriate steps to reduce the risk of recurrence, including an internal review of the situation. If the cause is clear, it should be discussed. However, often the cause of the adverse event will not be clear at the time of the disclosure so it is incumbent on the professional(s) meeting with the family to state that the cause is unclear and to carefully avoid speculation. After a thorough investigation, the cause(s) of the event may be different from what was initially thought to be the cause(s). When the family is presented with the new or different causes, they may see the change as an effort to cover up the truth.

Nationally Recognized Models to Address Disclosure

There are various models of disclosure in use. The models below have garnered national attention. Laws regarding privilege vary from state to state. In order to make an informed decision regarding disclosure or use of a particular disclosure model, one should consider the specific statutes pertaining to privilege in the state in which one practices.

Extreme Honesty

Kraman and Hamm (1999) report on the Veteran's Administration (VA) Medical Center in Lexington, KY, which follows a risk management policy titled, *Extreme Honesty* that suggests *but does not prove* the financial superiority of a robust disclosure policy. In place since 1987, this policy has not caused an onslaught of litigation, and while in the top quartile for claims filed (i.e., comparatively large number of claims) compared to 35 other VAs, the Lexington VA is in the bottom quartile for payments (i.e., comparatively low dollar amount paid out for those claims).

This honest and forthright risk management approach is touted as putting the patient's interests first and is believed to be relatively inexpensive when compared to other approaches since Kraman and Hamm contend that it avoids the costs of lawsuit preparation, litigation and court judgments.

Open Disclosure with Offer

Boothman et al. (2012) describe the approach taken to adverse events at the University of Michigan Health System beginning in 2001. They describe a proactive, principle-based approach, built on a commitment to honesty and transparency and called "*open disclosure with offer.*" Three principles guided this new systematic approach to adverse events: compensate patients quickly and fairly when unreasonable medical care causes harm; if the care is deemed reasonable, support caregivers and the organization vigorously; reduce patient injuries by learning through patients' experiences and also reduce claims (by way of improved care).

Since the full implementation of this approach, the University of Michigan reports a steady reduction in the number of claims filed, reduction in defense costs, reduced time between claim reporting and resolution and reduced average settlements. The average monthly rate of new claims dropped from 7.03 to 4.52 claims per 100,000 patient encounters, and the average monthly rate of lawsuits decreased from 2.13 to 0.75 per 100,000 patient encounters.

Seven Pillars:

McDonald (2012) and Mayer (2013), along with the University of Illinois, Chicago (UIC), conducted a 3 million dollar AHRQ funded demonstration project to expand the Seven Pillars Program to 9 other Chicago area medical facilities and to evaluate its impact on liability activity. The Seven Pillars represent a comprehensive response to adverse events. The pillars are:

- 1) Reporting
- 2) Investigation
- 3) Communication
- 4) Apology with remediation (includes waiving of hospital and physician fees)
- 5) Process and performance improvement
- 6) Data tracking and analysis
- 7) Education around the entire process

The UIC reported that over a two year period, the Seven Pillars approach led to more than 2,000 incident reports and more than 100 investigations, resulting in approximately 200 specific improvements, 100 disclosure conversations and at least 20 full disclosures of inappropriate care that caused patient harm (Clancy, 2012). The AHRQ demonstration project that extends to 9 other medical centers has resulted in an 80% reduction in time to settle full disclosure cases and a 70% reduction in litigation-related costs, and UIC reported that no meritless suits were filed for at least 18 months. As a testament of success, in addition to the initial 9 hospitals, an additional 20 hospitals have joined the initiative even though they have received no funding.

A Practical Guide to Disclosure:

The American Society for Healthcare Risk Management (2003) characterizes various approaches to disclosing adverse events to patients and families. Each requires training and support from clinical colleagues, risk management professionals and legal counsel. Depending on one's institutional setting, more or less resources and supports may be available. But, with that said, models for adverse event disclosures can be summarized as:

- One person alone (aka, *the Lone Ranger* approach)
- Team oriented
 - Small group setting
 - Large group setting

Just-in-time coaching of the team or the lone professional who will disclose the adverse event is essential (Truog et al., 2011). As explained above, adverse events are not common in any one individual's practice so expert coaching at the time of discovery of the incident and before disclosure is essential. Prior to the disclosure conversation, the providers should consult with risk management and legal personnel. The provider who makes the disclosure will want to know what the organization's response to the adverse event will be from a financial perspective. Will the cost of care made necessary by the event be written off by the institution? Will future medical care required as a result of the event be covered? A disclosure of a medical error, with or without an apology, can lead to claims and litigation. Risk Management and legal personnel can provide assistance regarding a specific disclosure. Situations in which consultation prior to the first conversation is not possible are rare, but do occur. For example, a patient wakes up post-operatively and screams, "Why is the cast on my left foot?" Or a parent walks into the room just as the nurse completes administration of a medication that was supposed to have been discontinued because of an allergic reaction. In such cases, conversation should be limited to immediate care and assurance that the matter will be looked into and that the provider will return as soon as possible for a lengthier discussion.

Approaching disclosure

It would be difficult to overstate the importance of careful preparation for the disclosure conversation. Appropriate disclosure of an adverse event or medical error requires tailoring the

disclosure to the specific event. Although each disclosure is unique, there are some commonalities.

While the disclosure conversation generally should take place as soon as possible after the event, there is important work to do prior to the conversation. Before disclosure, one must determine what information is going to be communicated. We recommend planning what will be said, who will say it and how to say it. We do not recommend approaching the disclosure conversation with a written statement, but we do believe that the conversation will more likely be successful if the provider is prepared.

The provider should give consideration both to how the patient or family might respond and to how the provider him or herself might feel during the encounter. The conversation has the potential to be difficult for the provider.

Prior to the disclosure conversation, the provider needs to determine where the meeting will take place and who will be present at the meeting. It is important not to overwhelm the family with an army of people, but it is equally important that the individuals who need to be there are present. For example, in disclosing a medication error, one might consider having a pharmacist available to discuss the specific medication involved in the error.

Consideration to small details, such as having a sufficient number of chairs and having water and tissues available for the family, can help set the tone for the conversation. Allow sufficient time for the conversation.

Conducting the Disclosure

Begin the disclosure by introducing yourself and everyone else present on behalf of the providers. Ask the family to identify everyone with them. Do not begin the conversation until everyone in the room has been identified.

Some advocates recommend a gentle notice that bad news is coming prior to the disclosure. This is especially helpful if the bad news is unanticipated.

Clearly advise the patient and family of what happened in simple language, avoiding medical jargon. Do not speculate as to the causes of an event if they are unknown. Set out the next steps in the patient's care. If a decision was reached to provide some financial compensation, let the family know. Below is a sample beginning dialogue, assuming parents already know something untoward has happened:

“I am so sorry that this happened. We take all events like this very seriously, and we will be looking into how this happened very carefully. In the meantime, let me explain what we do know and what we have to do for Johnny at this time.”

While delivering the news, be attentive to and manage the patient's reactions. Allow time for the patient and family members to frame and ask questions, and answer all questions truthfully and factually. Before concluding the conversation, ask if anyone has other questions.

Closing the Disclosure

Disclosure is an on-going process, not a single conversation. Let the patient and family know what the follow up steps are and be sure that they are updated with new information on a timely basis. If there were any specific steps agreed upon, let the patient and family know as those steps are completed. Be sensitive to meet any agreed upon deadlines.

Based upon the conversation, consider what can be done to help the patient and family. The provider should also ensure that he or she is taking care of him or herself.

Conclusion

Disclosure of a medical error to the patient and family affected by the error is required ethically, as part of a professional obligation to the patient, pursuant to regulatory requirements, and, depending on the state in which one practices, by statutory requirements.

While it is ethically and professionally appropriate to disclose a medical error, offering an apology is the subject of a great deal of debate. There are arguments for and against offering an apology following a medical error. The decision regarding whether or not to apologize for a medical error should be made on a case-by-case basis following consultation with risk management and legal personnel.

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Section 4.

Other Specific Situations, Part I

Section Editor: Mark A Ward, MD

Chapter 25

Taking a Medical History and Communicating during the Physical Examination

Mark A Ward, MD

In taking histories, follow each line of thought; ask no leading questions; never suggest. Give the patient's own words in the complaint. Sir William Osler.

The general principles of communication discussed elsewhere in this book (Chapters 1, 2, 3, 5 and 7) apply to taking a medical history and communicating with the pediatric patient and parent during the physical examination and will not be reviewed here. Rather, this chapter will refer to specific sections in these and other chapters and build upon the principles discussed in them while reviewing and exploring issues and techniques especially germane to taking the medical history from and communicating with the pediatric patient and his or her parent during the physical examination.

Taking a Medical History

Importance of the Medical History

The clinician's first contact with a patient and family usually involves obtaining a medical history and performing a physical examination. The care and sensitivity with which this is done can set the stage for meaningful relationships between the clinician and the patient and between the clinician and the patient's family. First impressions are generally lasting.

Providing the medical history is an opportunity for the patient (if developmentally able) and parent to tell their stories. The history includes not only signs, symptoms and other medical information, it also includes the patient's and parent's concerns about and emotional reactions to the illness, as well as the impact of the illness on family life and family dynamics.

The history has long been considered the keystone of diagnosis, and despite the advent of an ever increasing number of diagnostic tests, it remains so. Peterson et al. (1992) reported that the history led to the diagnosis in 71% of new patients at a general internal medicine clinic, and Roshan and Rao (2000) in a similar study reported 79%. Thus, skill at obtaining a medical history is essential to effective patient care.

The Pediatric Challenge

Taking a pediatric history poses several special challenges. First, many pediatric patients are developmentally non-verbal or have limited communication skills, requiring that the history be obtained from a surrogate, usually the parent. Second, even when the child is verbal, the parent may try to monopolize the conversation. Third, the pediatric patient, depending on his or her developmental age may: have limited cognitive ability; engage in magical thinking; have difficulty in answering open-ended questions; and give answers he or she thinks the doctor or parent wants to hear.

Setup and Starting the Interview

Even before the conversation begins, communication can be facilitated by providing an appropriate setting. Ideally, this should be a quiet, private space with comfortable seating for the patient, family members and the clinician.

Be sure to know the patient's name before entering the room. Introduce yourself, identify all individuals present and ascertain how each would like to be addressed.

One of the keys to conducting an effective interview is to begin by establishing rapport. If the child is verbal and developmentally ready, address the first *icebreaker* to the child. Ask about the patient's interests or activities. Below are some examples of questions to start the conversation. Obviously, you need different questions for different ages and situations.

“Sam, how are things going at school? or “What sort of things do you like to do outside of school?”

“Debbie, what do you think about this weather we're having?” “Hot enough for you?” or “Cold enough for you?”

“Do you like baseball? What do you think about the Astros' latest winning streak?”

(See Chapter 1, *General Principles of Communicating with Pediatric Patients and Family Members*, section, *Starting the Conversation: Introductions and Opening*; and Chapter 7, *Point of View: The Primary Care Pediatrician*, sections, *Establishing Communication Begins Before You Enter the Exam Room* and *Initial Communication in the Exam Room*.)

Who Should Provide the History?

Whenever possible, and to the extent appropriate, the conversation should be child-centered. Management of the conversation at the extremes of the age spectrum is obvious—for the infant or non-verbal child, the history must come from the parent; for the older, verbal adolescent, most of the history should come from the patient. In between these extremes, deciding how much of the history is obtained from the child and how to elicit that information from the child is as much art as science. Involvement of the child is dependent on his or her age, development level, cognitive and verbal abilities, emotional state and willingness to participate. Beyond the infant and early toddler age, usually both patient and parent contribute to the history. (See Chapter 2, *Age Appropriate Communication and Developmental Issues*, and Chapter 3, *Talking with the Adolescent Patient*.)

Keeping a child engaged in the conversation can be a challenge. A review of 322 video-recorded community practice pediatric encounters found that whether or not children responded to questions by the physician was largely determined by how the question was posed. Children were more likely to answer if the physician had asked them social questions earlier in the visit and if the physician looked at them when asking the question. Children were also more likely to respond to yes-no questions than to open-ended questions (Stivers, 2012).

The Chief Complaint, List of Concerns and History of Present Illness

Identify the primary reason (aka the chief complaint) for the visit by starting with an open question such as, “What is the problem that brought you here today?” Let the patient (if developmentally appropriate) and parents complete their chief complaints and list of concerns without interruption. (See Chapter 5, *Patient Centered Communication and Decision Sharing*, sections, *Essential Elements of Communication from the Parents' Perspective*, and *Essential Elements of Communication from the Child's and Adolescent's Perspective*.)

After determining the chief complaint, it is generally useful, especially in an office visit, to determine what other concerns the patient or parent has. “What other concerns do you have?” or “Are there other problems you want to tell me about?” If there are a number of concerns or problems, especially if not all clearly related, it is useful to agree on which will and which will not be addressed at this visit. “So it sounds as if Charlie has been having diarrhea for almost a week.

His appetite is way down and you think he's lost some weight. He also has been having headaches on and off for a few months." (This is also a convenient time to summarize the presenting complaints.) "I think the decreased appetite and weight loss are related to his diarrhea, and we will address those issues today, but I think the headaches will have to wait for your next visit. Do you agree?"

Having ascertained the chief complaint and related concerns, the clinician can proceed to obtain the history of the present illness (HPI). Begin with open invitations (e.g., "Tell me more about..." or open questions ("How did you feel about that?"). Then proceed to directed questions as needed. "What did the vomitus look like? Was there any blood or dark material in it?"

One technique that works well for a chief complaint such as pain is the OPQRST mnemonic below.

Onset: "How long have you had the pain?" or "When did the pain start?"

Palliation and **P**rovocation: "What makes the pain better or worse?"

Quality: "What does the pain feel like?" or "Can you describe the pain?"

Region and **R**adiation: "Where is the pain?" or "Does the pain travel anywhere?"

Symptoms and **S**everity: "What other feelings or sensations do you get?" or "How bad is the pain?"

Timing: "What happened first?" "Then what happened?" "Is the pain continuous, repeating, or sporadic?"

With modification, this mnemonic can be used for other symptoms such as diarrhea and fatigue. (Nixon, 2013)

Although there are certain standard questions that the clinician will always ask (e.g., "When did this start?"), it is best to avoid a *series* of scripted questions, which tends to ignore the individuality of the patient or parent. Each question should be based on responses to previous questions and all other available information.

Sometime during the conversation, it may be helpful to ask the patient and parent what they think might be causing the problem. This is not always appropriate, for example, in the case of a child who has come in complaining, "I have the flu." or a child who cut his finger.

After completing the HPI, proceed to the past medical and surgical history, family history, social history and, finally, review of systems to be sure that you have not missed anything.

Interviewing Techniques

(See Chapter 1, *General Principles of Communicating with Pediatric Patients and Family Members*, sections, *Techniques to Facilitate Communication*, and *The Words We Choose*.)

Taking a pediatric medical history is much more complicated than simply asking the patient and parent to tell their stories. One needs to encourage and prompt the patient (or parent). At times one needs to direct the patient and help him or her maintain focus, and all too often, one needs to bring a meandering parent or patient back to the issue at hand.

Avoid leading questions. Instead of, "How nervous did you get when you had the palpitations?" ask, "How did you feel when you had the palpitations?"

When asking parents questions, remember that they are surrogates for the patient. Phrase the question in a way that they are likely to be able to answer accurately. For example, instead of, "When did Johnny's hip pain start?" ask, "When did you first notice Johnny was limping?" or "When did he first complain of pain?" because the parent may not know when the child's pain actually started.

Active listening

Active listening is a critical part of history taking. Focus on what the patient or parent is saying rather than on the next question to be asked. Listen for the meaning and feelings behind the words. The invite-listen-summarize (ILS) technique, (described in Chapter 1, *General Principles of Communicating with Pediatric Patients and Family Members*, section, *The ILS model*) is a useful way to probe for understanding.

Establish the meaning of the illness to the patient and family members. What are their concerns and what emotions are they experiencing? What is the impact of the illness on: family dynamics and the family's life-style; the child's ability to attend school and his or her performance in school; the parents' ability to go to work and work performance? A study with senior medical students on their pediatric rotation after having completed rotations in medicine and surgery found that they very often failed to elicit what the author called the patient's or parent's "hidden agenda," usually a non-organic issue such as a single-parent family, depressed mother or autocratic, rejecting father (Menahem, 1987).

Empathy

Empathetic comments by the provider encourage the patient or parent to go further and deeper into his or her story. An empathetic response is especially important when strong negative emotions such as anger, fear or sadness are involved. An empathetic response will help the patient or parent reveal feelings and concerns. Here is an example of an empathetic response: "It's hard to even imagine how difficult that must have been for you. Can you tell me how you felt when that happened?" (See Chapter 1, *General Principles of Communicating with Pediatric Patients and Family Members*, section, *Empathy*.)

Being empathetic does not necessitate more time. Ohm et al. (2013) consider history taking and empathetic communication as two important aspects in successful physician-patient interaction. They write, "Gathering important information from the patient's medical history is needed for effective clinical decision making while empathy is relevant for patient satisfaction." In a simulation study with senior medical students close to graduation and standardized patients, Ohm and coworkers found that students who were more empathetic obtained the same amount of information in the same amount of time as those who were less empathetic.

Working with the Poor Historian

Some parents seem to talk endlessly, wandering aimlessly around trivial details. To bring the parent back on track, Nguyen et al. (2013) suggest asking, "Would it be okay if I interrupt you to ask some specific questions?" For example, a parent rambles about the difficulties of managing a child with diarrhea. Acknowledging the difficulties (empathetic response) can help the parent accept a gentle nudge to change focus. Patients and parents want to be assured that they have been heard and understood.

Parent: It's so hard to keep up with his stooling. He goes through so many diapers. The other day I ran out of diapers and my husband wasn't home. I had to take Charles with me to the store to get more diapers and the store was crowded and there was a really long line. And some of the people looked at me because I know they could smell his poop. So much stooling. I feel like it's going on forever, like it will always be like this. I mean, I have three other kids and none of them ever had anything like this. All day he poops, six or seven times a day.

Physician: I can appreciate how difficult this has been for you and how stressful. (Empathetic response) Would it be okay if I interrupt you to ask some specific questions?"

At the other extreme, some patients, especially adolescents may be very quiet and non-communicative. While the clinician should be accepting of *periods* of silence (time for the patient or parent to gather his or her thoughts or muster the courage to talk about an emotional issue), prolonged silence is not productive. Below are a few suggestions for helping a non-communicative patient or parent:

- Acknowledge that it can be difficult to talk about certain issues or problems
- Explain why the discussion is important but that it is all right if the child is not ready to talk about it now
- Convey an attitude of patience; maintain a relaxed facial expression and body language
- Assuming that there will be follow-up visits, invite the patient (or parent) to write out his or her thoughts or questions for the next contact, at which time the individual can either read from the notes or give them to the physician
- Change your questioning to yes-no questions or questions with short answers: “How often does this bullying happen?” Or you can phrase the question as a choice between two or three (no more than three) options: “Would you say that this happens every day or less often than that?”
- Move the conversation to a less threatening topic

Communicating during the Physical Examination

The four points of a medical student's compass are inspection, palpation, percussion and auscultation. Sir William Osler.

Asking Permission

It is customary (and courteous) to ask permission before beginning the physical examination of the patient, and refusal by an adult patient is unusual. Refusal by a young child, however, is not that uncommon. If you ask a four-year-old child, “May I examine you now?” and the child says (or screams) no, you have boxed yourself into a corner. If the exam is necessary (and it usually is) you cannot abide by the child’s wishes. If you proceed to examine the child despite his refusal, then why did you ask in the first place? To the child, the fact that you asked permission implied that you would abide by his request; to the child, you lied. The result is time spent trying to convince the child to allow the exam. Unfortunately, all too often, he or she will not agree. For young children, especially those who are not cooperative, I suggest that instead of asking permission, say, “Now I have to examine you.” and pause, giving the child a chance to object. If he does object, you can try to reason with him, and if that fails, proceed without breaking any implied promise. For the older child or adolescent, asking permission is usually safe, but if you anticipate difficulty, it would be safer to use the “Now I have to...” technique.

Children (especially older children) can be extremely self-conscious of their bodies. A few seconds to acknowledge this and reassure the child that this is normal is time well spent. “Nicole, now I need to examine you. I know that sometimes patients feel embarrassed about this, but it is completely routine, and as a doctor, it’s something I’ve done thousands of times.”

Giving the Child Choices (Empowering)

To the extent possible, give the child some control of the examination. “Do you want me to look at your eyes or ears first?” “Do you want your mom to hold your hand while I examine your leg?” “Do you want me to take off the bandage or do you want to do it?”

Letting a toddler play with the stethoscope before you apply it to the chest, not only helps assure him or her that it’s not a threat but also gives the toddler some control over what is

happening.

Keeping the Child Informed

A running dialogue with the pediatric patient during the physical examination improves cooperation and helps allay anxiety. All of us want to know what is being done to our bodies during a medical procedure, and the physical exam is a procedure. Down to about age two years, the younger the child, the more the clinician needs to keep the child informed about what is being done and what will be done next. For a two- or three-year-old, it would be appropriate to say that you are now going to look in the other ear or listen to the child's chest. For the older child or adolescent, you would probably just put your stethoscope to the chest and say, "Take a deep breath."

A friendly smile, gentle touch and small talk can be helpful for children of all ages, and nonsensical jokes will make the examination less frightening for the young child: "Well, I didn't see any potatoes growing in your ear." or "I thought I heard some barking in there (after listening to the abdomen).

Children are generally both curious and concrete in their thinking. They will appreciate an explanation of what you are going to do and why. And explain what you find in developmentally appropriate language. If you detect an abnormality, consider if you should disclose it now or after the exam is finished. In either case, describe it in non-alarming terms. For a young, school age child you might say, "Nicole, when I felt your tummy I noticed that your liver was a bit bigger than usual. The liver is something in your tummy that helps your body use the food you eat. I would like to get some tests to see what's causing that." For an adolescent the following would be more appropriate: "Nicole, when I examined your abdomen I found that your liver was enlarged. I am not sure what the cause is. We will need to get some blood tests and probably an ultrasound examination of your liver. That's a painless test where they use sound waves to look inside your abdomen." This type of running commentary, when used during the examination of children, has been shown to be associated with a reduction in the prescription of unwarranted antibiotics (Mangione-Smith et al., 2003).

Conversing with the patient during the exam can distract the child and facilitate the exam. Communicating also maintains a sense of partnership between the clinician and the child. And finally, talking (and asking questions) as you are examining the child affords an opportunity to gather more information, both from the patient and the parent. Be alert to the fact that anything you say to the child will be heard by the parent and *vice versa*.

Dealing with Patient Distress

Of course, the best way to deal with a child's distress is to prevent it (to the extent possible). For the verbal child, giving the child choices and keeping the child informed (above) are helpful first steps. For the infant and young toddler, a soothing voice, gentle approach and soft touch can allay apprehension.

For any age patient, distraction can be effective in minimizing fear and distress: for the infant—a light or a brightly colored object, or even a stethoscope; for the older child—discussion, questions, jokes and puzzles. Distraction is useful not only for prevention but even when the patient is overtly upset.

It is important to be alert to subtle signs of distress before the infant starts to cry or the older child begins to resist. Whimpering is an obvious warning. A worried facial expression or the child's looking to the parent are more subtle forewarnings. Responses to these warnings include a slower approach, reassurance and asking the patient if he or she is worried about something. Having the parent hold the infant or hold the older child's hand can also be helpful.

If a child cries, don't tell him or her to stop. Crying is one way of coping. Reassure the child that you recognize that he or she is frightened (or in pain) and that you will be as gentle as possible. (See Chapter 15, *Point of View: the Child Life Specialist*, section, *Building Trust: A Gateway to Communication*.)

Dealing with Pain

Sometimes, parts of the physical exam will cause physical discomfort or pain, for example examining an inflamed oropharynx, palpating an enlarged, tender lymph node or pressing on a painful abdomen. It is important to tell the verbal child what you are going to do and why, acknowledge that it may cause some discomfort or pain and assure the child that you will be as careful and gentle as possible. Distraction may help, especially if the pain is not severe. Leaving examination of potentially painful areas to last should be self-evident. (See Chapter 15, *Point of View: the Child Life Specialist*, section, *Pediatrics and Pain*.)

Examining Private Areas

Examination of the genitalia (both genders) and the breasts (in girls) is frequently upsetting for the child or adolescent and poses a special challenge for the clinician.

There are few studies looking at the emotional aspects of a genital examination performed by a health professional. A study of 175 children (77% female and 23% male) undergoing "ano-genital" examination for suspected abuse found that only a minority (17.1%) experienced anxiety before the examination (Scribano et al., 2010). The authors do not provide data for male and female children separately but do state that there were no differences in endorsement of moderate to severe anxiety related to gender. In contrast, a study of 800 female high school children in Germany found that 60% recalled anxiety during their first gynecologic examination (Bodden-Heidrich et al., 2000). While the lower incidence of anxiety in the first study might be due to the inclusion of boys, it also might be hypothesized that the children being examined for suspected abuse were less anxious because, unfortunately, they were accustomed to having their genitalia *handled* by others.

Regarding the pediatric vaginal examination, Hein (1984) suggests, "The excuse that the patient would be too embarrassed to have a genital examination usually denotes reluctance on the part of the examiner rather than the patient." and recommends explaining the exam and the reasons for the exam, familiarizing the patient with any equipment that will be used and explaining what is being done during each step of the exam.

For the verbal child, permission should be obtained before examining this sensitive area. For the young child (generally less than 9 or 10 years of age) permission can be obtained indirectly by saying, "Now I need to examine your private area and make sure everything is okay there." pausing and proceeding if the child does not object. (See Asking Permission above.) For the preadolescent or adolescent, the request for permission should be direct: "Now I need to examine your genital area and make sure everything is normal. Is that all right?"

For a young child (boy or girl) it is good practice to mention to the child that this is a private area and only a parent or a doctor should be looking or touching the child there.

During the examination, talk to the patient and explain what you are doing. Be reassuring but honest: "I'm just going to take a look. It won't hurt." or "This may feel uncomfortable but shouldn't actually hurt." or, if the area is inflamed or you anticipate tenderness, "This will probably hurt a little, but I will be as careful and gentle as I can."

Concluding the Visit

The final part of the visit usually will include: the provider's summary of the findings; explanation of the findings and likely cause(s); and a plan for management and follow-up. (See Chapter 1, *General Principles of Communicating with Pediatric Patients and Family Members*, section, *Closing the Conversation*.) This should not be exclusively provider driven. The patient (if developmentally able) and parent should remain active participants in the discussion and share in the decision making. (See Chapter 5, *Patient Centered Communication and Decision Sharing*, section, *Sharing Decision Making*.)

At some point in the discussion, the provider will want to see what questions the patient and parent have. Avoid asking, "Do you have any questions?" Not only is it too easy for the patient or parent to say no, but it can be misconstrued as meaning that this is the end of the conversation, and parents may feel that the provider wants a negative answer. "What questions do you have?" is a much stronger invitation to ask questions.

Conclusion

Taking a pediatric history generally involves obtaining information from a surrogate (usually the parent) or from both the patient and the parent. For the developmentally ready patient, it is critical to engage him or her in the conversation. Communication with the child (as well as with the parent) during the physical examination is also important.

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Chapter 26

Patient- and Family-Centered Rounds

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Family-Centered Rounds (FCR) are defined as “interdisciplinary work rounds at the bedside of a hospitalized patient in which the patient and family share in control of the management plan as well as in the evaluation of the rounding process.” (Sisterhen et al., 2007) According to a survey conducted in 2007, FCR were the most common rounding practice of pediatric hospitalists (Mittal et al., 2010). The benefits of FCR are thought to include improved communication with the family, improved multidisciplinary and interdisciplinary communication, enhanced discharge planning and workflow and optimal health outcomes (Kleiber et al., 2006; Landry et al., 2007; Latta et al., 2008; Mittal et al., 2013; Muething et al., 2007; Rappaport et al., 2010). In teaching hospitals, educational benefits include the ability to role model for trainees and to observe the interaction of trainees with healthcare team members and families during FCR (Landry et al., 2007; Mittal et al., 2010; Muething et al., 2007). However, there continue to be concerns about both efficiency and teaching during FCR. Specifically, faculty members worry that the type of teaching done during FCR may undermine parental confidence in trainees (Kleiber, 2006), and trainees have mixed impressions about how parental presence during rounds impacts their education (Knoderer, 2009). They perceive decreased autonomy during FCR (Rappaport, 2010) and feel more comfortable asking questions away from the presence of the family (Landry et al., 2007; Rappaport et al., 2010). Faculty development is thought to be important in addressing the dual priorities of patient care and the education of trainees during FCR (Mitta et al., 2013; Rappaport et al., 2010). However, best practice in family-centered care encompasses family-centered rounds.

Family-Centered Care

The family-centered model of care recognizes family involvement as essential to quality, safety and optimal health outcomes. Families are not viewed as visitors but as experts on their children and as valuable partners in the plan of care (Griffin, 2006). The Institute for Patient- and Family-Centered Care (2013) outlines four core concepts that have become the national standard for family-centered care:

- **Dignity and Respect:** healthcare providers listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.
- **Information Sharing:** healthcare providers communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete and accurate information in order to effectively participate in care and decision making.
- **Participation:** patients and families are encouraged and supported in participating in care and decision making, at the levels they choose.
- **Collaboration:** patients and families are viewed as true partners in care. They are included on hospital-wide initiatives such as program development and evaluation, facility design and professional education, as well as in the delivery of care.

Family-Centered Rounds

A family's involvement in a child's medical care, or the lack of involvement, can significantly impact health outcomes. Parents are a constant in a child's life. They are able to recognize subtle changes and can provide valuable patient information (Muething et al., 2007; Sisterhen et al., 2007; Sodomka, 2006). Engaging parents through collaborative, family-centered rounds creates mutually beneficial partnerships. Family-centered rounding provides information sharing and learning opportunities for healthcare professionals, patients and families. Moreover, medical expertise, paired with mutual communication and with parental knowledge, can facilitate diagnosis and treatment, while reducing errors and unnecessary care (Sodomka, 2006).

Educating the patient and family about family-centered care, family-centered rounds and the importance of parental advocacy should begin on admission. Parents need to understand the concept and significance of family-centered rounds, and they should be encouraged to participate in their child's care to the extent to which they are comfortable. Educating families about the importance of confidentiality and their role in protecting patient privacy, particularly in open units, can further strengthen the healthcare professional-family partnership.

Hospitalization of a child is very stressful for families even when the hospitalization is for a minor illness or a simple procedure. Circumstances and emotions can fluctuate so it is important to inquire whether the family wants to participate in rounds each time rounds take place. Encourage parents who wish to participate to prepare questions and note concerns in advance. This provides them with a focused task and helps keep the healthcare team on schedule. Support parents who prefer not to be included in rounds by offering other opportunities to share information and decision making. Most parents will not feel uncomfortable if the physician does not have immediate, definite answers to all of their questions during rounds. If time does not allow for all questions to be answered fully, reassuring them that someone from the healthcare team will return later can alleviate stress and avoid calls to the physician.

Addressing parents as *Mom* or *Dad* can be perceived by parents as impersonal (Amer and Fischer, 2009; Duzy, 2008). If you do not know a family member's name, ask or address the individual with a standard courtesy salutation (e.g., Sir, Ma'am). There may be an exception to this in the neonatal setting where referring to new parents as *Mom* or *Dad* may reinforce the parental role and bond. If one chooses to use such a term in addressing a parent in the neonatal unit, it would be wise to ask permission: "Is it okay to call you Mom, now?" or "You are now a proud father. Is it all right if we call you Dad?" Avoid referring to the patient as *he* or *she* or *the baby*. Acknowledging the patient by addressing or referring to him or her by name, even if the child is nonverbal, conveys to the parents that their child is important and can help reduce anxiety.

Sitting (even briefly) during rounds and maintaining eye contact with the patient and parent(s) can help engage dialog and demonstrates commitment to the family. Asking parents to share their observations and suggestions reinforces the value of the family as a part of the child's healthcare team while fostering confidence and trust in the team.

Transparency and open information sharing with families should be standard practice, not optional. Parents want, and have a right to know, all information that pertains to their child's diagnosis and prognosis. They keenly perceive when information is guarded or withheld. Withholding information creates apprehension, eroding trust and confidence in the team and the hospital.

Including families on rounds and empowering them in the care of their hospitalized child reduces length of stay, increases parental confidence to care for the child at home following discharge and reduces the potential for readmission (Simmons, 2006).

Preparing for Family-Centered Rounds

Preparing the Family

Introduce the family to FCR on admission, either verbally or through brochures or videos. Critical elements are the definition, purpose and process of FCR and the time at which the family can expect the medical team for rounds. If the attending physician will perform a focused physical examination during FCR, add this information. Ask the patient (if developmentally appropriate) and the parents if they want to participate in FCR and whom to include, and then confirm before starting the rounds. If the family agrees to participate in FCR, before the rounds begin, ask the patient (if age appropriate) and parents to write down their questions or any observations they want to share. When the patient is being presented, encourage the family to correct errors in the history and to question any unclear medical terminology.

Preparing the Patient

Support the patient in understanding and participating in FCR. This will depend on the patient's developmental age, verbal ability and level of alertness (See Chapter 2, *Age Appropriate Communication and Developmental Issues*). Explain that a number of people will be in the room to discuss his or her care. The child life specialist is a useful resource who can prepare the patient for FCR and address follow-up questions that may arise.

Preparing the Nurse and other Clinicians

The bedside nurse has the most interaction with the family and patient and is an invaluable resource (See Chapter 14, *Point of View: the Pediatric Nurse*). The nurse is uniquely positioned to support the patient's and parents' participation, to assist them in formulating questions for the physician team and to share information about the patient's progress with them. Other clinicians (e.g., dietician or nutritionist, social worker, child life specialist) also can contribute and advocate for the family during FCR. Invite them to join and participate in the FCR, or if they are unable to join, solicit their input about the patient and family.

Conducting Family-Centered Rounds

The Team

Depending on the hospital, the unit and the circumstances, the rounding team will usually consist of at least an attending physician and, ideally, the patient's nurse. In a teaching hospital, such as Texas Children's Hospital, there are often one or more residents and medical or nursing students, and in some hospitals and some circumstances, a fellow as well. If the patient's nurse is not able to join rounds, the attending physician or a resident should get the nurse's input prior to entering the patient's room. After rounds, it may be necessary to meet with the nurse or other team members to update them.

Rounds

The team member (attending physician, fellow, resident or medical student) who has spent the most time with the patient or most recently seen the patient, should introduce the other team members to the patient and family as needed.

Optimal communication is at eye level. If the parent is standing, the team should stand. If the parent is seated, the team leader (and other members) should also sit if possible, maintaining level eye contact. Speak in a conversational manner, using lay terminology. Talk to the patient (when age appropriate) and parents during the history and talk to the family *and* team during the assessment and plan.

Elicit and allow time for questions and observations by the patient, family, nurse and other

team members. Clarify the discharge goals. If the physician on the inpatient team is not the patient's primary care provider, confirm with the family the name of the patient's primary care provider in order to facilitate co-management in the hospital (if appropriate) and to facilitate transition of care at discharge.

Roles of Individual Team Members during FCR

The attending physician should either lead the rounds or designate one of the other team members to do so. Often, as an educational strategy, a fellow, resident or student will be assigned this role. However, the attending physician maintains responsibility and must intervene as needed for optimal patient care.

A physician who is not presenting or leading the rounds can enter any orders decided on and repeat them to the team to confirm accuracy (closed loop communication). He or she or another unoccupied physician can initiate, update or complete any discharge paperwork. The medical student can be asked to look up laboratory and radiology results. If applicable, the resident should introduce the on-call resident to the family. If there are consults to be called, this should be done after exiting the room.

Senior physicians should act as role models for juniors and students, demonstrating how to engage and support the patient and family.

In a hospital without house staff or medical students, the attending physician will round with the bedside nurse or by him or herself. Under these circumstances, the lone physician will have to juggle these tasks and may need to hold order entry and other paperwork until after the visit.

Recommendations for Successful Family-Centered Rounds

Knock before entering the patient's room and inform the patient and parents that rounds will begin. Inquire whether the family would like to participate each time rounds take place. Where available, encourage families to use family-centered rounding tools. For example, at Texas Children's Hospital there are brochures that explain FCR for families and provide tips for family participants, and there are signage cards to post on the patient's door to indicate whether or not the family wishes to participate in FCR that day. As necessary, introduce members of the team to the family.

Include the patient's nurse in rounds and ask for her input, especially regarding assessment and plans. Other non-physician members of the healthcare team (e.g., care manager, discharge planner or child life specialist) who are present should be encouraged to participate, and their input and suggestions should be respected.

Be sure that parents and team members participate in the formation of treatment plans. Ask parents (and the patient when developmentally appropriate) to share their observations and thoughts, as well as their suggestions for the plan of care.

Ask permission from the patient and parents to conduct specific teaching activities such as a more comprehensive physical examination than would ordinarily be required. Sometimes the patient or parent can be utilized as a teacher. For example, the child can be asked to explain his or her understanding of and feelings about his or her illness. A parent can be asked to share his or her view of the medical system.

Encourage the patient and parents to speak-up and contribute to the discussion. Facilitate this by candidly sharing all information about diagnosis and prognosis with the family. Use language that helps establish rapport with the family and is void of acronyms and medical jargon. Avoid language or tone that might be perceived as patronizing. Ensure that parents understand the diagnosis, treatment plan and discharge goals, and provide ample opportunity for them to ask

questions. If family members have limited proficiency in English, request an interpreter to assist them.

Acknowledge uncertainty and help the family deal with it. Respect cultural diversity and incorporate unique family needs into rounds. Support families who wish to integrate innocuous cultural traditions or rituals in the patient’s plan of care.

There are special considerations for pre-adolescent and adolescent patients. (See Chapter 3, *Talking with the Adolescent Patient*.) When appropriate, ask them if they want to participate in FCR and who should be present. Adolescent age cutoffs and protected health topics vary by state; know your state laws. For other health topics, parents have a right to be present. If the teenager does not want a parent present for FCR, then efforts must be made to ensure good rapport with both the patient and family.

It is important to note that as the impact of family-centered care and the pivotal role of families in clinical decision making become more widespread, a systems approach is essential. Cohesive standards for family involvement are key. As families expect a consistent level of quality within each area of the hospital, they will equally expect to be included as integral members of their child’s healthcare team, regardless of the unit to which the child is admitted (particularly families of chronically ill children, who regularly frequent the hospital). Family-centered rounding models should best serve the needs of particular units while systematically incorporating the core principle of valuing family participation for optimal health outcomes.

Table 1 provides some sample phrasing to encourage family participation in rounds and decision making.

Table 1. Examples of Useful Phrasing to Facilitate Family Involvement in FCR

Goal	Examples of useful phrasing
General	Address patient and family members by name. Refer to patient by name regardless of age.
Empower family to edit the patient’s history	“I’m going to present Jerry’s story to the team. Please interrupt if I get something wrong or if there is something you want to add.”
Encourage family to talk about feelings and concerns about the illness and the care	“Mrs. Smith, we’d like to know how you and Jerry feel about his illness and the care so far.” “Jerry, I’m wondering what your major concerns are at this time.” “I’m wondering what concerns you all have at this time.”
Elicit family’s thoughts about diagnostic and therapeutic plans	“So, that’s our plan. How do you feel about that?” “What questions do you have about the plan?”
Encourage family to offer thoughts about goals	“I’ve explained the goals for this hospitalization as well as long term goals, as the team sees them. We would like to know your thoughts about these goals. Do you think they are realistic? Are there other goals we should address?”

Table continued on next page

Ask for family input when discussing discharge and post-hospital care	<p>“I know we’ve gone over a lot. Is this something you feel you will be able to do? What problems do you anticipate?”</p> <p>“What do I need to clarify or go over again?”</p> <p>“So we’ve reviewed the plans for Jerry’s care at home and for your follow-up with the surgeon. Do you think these plans are reasonable and doable? What problems do you foresee?”</p>
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Conclusion

Parental involvement in a child’s care during a hospitalization can have a major beneficial impact on the child’s ability to cope with the stresses of the illness and the hospitalization. Parents and healthcare professionals have different roles, responsibilities and expertise, but all have valuable knowledge to contribute to a child’s plan of care. Recognized as essential members of a child’s care team, parents can contribute to clinical observations and assessments. Providing family-centered care and including families in rounds demonstrate a commitment to quality, safety and the best possible pediatric care.

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Chapter 27

Using Communication to Improve Patient Adherence

Michael Speer, MD

Introduction

Patient adherence (previously referred to as *compliance*) to a medical regimen is the extent to which the patient's behavior coincides with the recommendations of the healthcare provider, with regard to medications prescribed or proposed life style modification. Adherence depends on multiple factors: the disease itself, the medications prescribed, the patient's understanding of his or her role in treatment, the physician's ability to communicate, and the environment (Falk, 2001; Matsui, 1997). In pediatrics there is one other element, the parents.

Because of the complex interaction of the above factors, adherence to medical recommendations is frequently poor, with long term regimens being more adversely affected than short term ones (Fotheringham and Sawyer, 1995; Litt et al., 1980; Matsui, 1997; Osterberg and Blaschke, 2005). Where treatment schedules are complex or require lifestyle changes, non-adherence may be more than 60% (Li et al., 2000). However, even in short term therapies, children are frequently given only a portion of the prescribed medicines. Mattar et al. (1975) reported that only 7.3% of patients demonstrated complete adherence and 53% took less than half of the medication. This is not a new phenomenon. Non-adherence dates from at least the 4th century BCE. In his *Decorum*, Hippocrates states that one should "keep watch also on the fault of patients which often make them lie about the taking of things prescribed." (Carrick, 2001).

The consequences of non-adherence are expensive and can be severe. Overall costs associated with medication non-adherence in the United States approach \$100 billion annually (Osterberg and Blaschke, 2005) and hospitalization costs account for as much as \$13.35 billion (Martin et al., 2005). Non-adherence to drug treatment can have a significant impact on prognosis. For example, pediatric patients with acute lymphatic leukemia or Hodgkin disease who were non-adherent to their prednisone regimen had a significantly higher rate of relapse (45%) compared to the adherent group (10%) (Festa et al., 1991). In pediatric renal transplant patients, non-adherence to immunosuppressive therapy leads to the need for more transplants, shorter transplant survival and increased mortality (Meyers et al., 1995).

Determinants of Non-Adherence

"Drugs don't work in patients who don't take them." – C. Everett Koop

Cognitive Factors

When too much information is presented, too little information may be assimilated. It is extremely difficult for the learner to determine what information is important and what is not, and recall is adversely affected (Ley, 1979; Selic et al., 2011). Ley and Spellman (1965) also determined that as much as 56% of instructions are forgotten shortly after leaving the physician's office even when high comprehension had been demonstrated immediately after clear instructions had been given. It has been shown repeatedly that forgetting to take or forgetting how to take medication is a major contributor to non-adherence (Brekke et al., 2004; Shemesh et al., 2004; Zaghoul and Goodfield, 2004). Health literacy, the "degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make

appropriate health decisions,” is frequently found lacking in such circumstances (Nielsen-Bohlman et al., 2004). Regarding understanding, 22% of adult Americans function at the basic level (understand information in short, common prose; read and understand simple documents; use quantitative information to solve simple, one-step problems), and 14% function below the basic level (locate easily identified information in short prose; follow written instructions in simple documents; use numbers to perform simple quantitative operations) (Kutner et al., 2006). Having low health literacy translates into an impaired ability to adhere through a lack of understanding. Williams et al. (1995) found that among patients at two public hospitals, 42% misunderstood directions for taking medications “on an empty stomach”, nearly 60% were unable to read and understand a consent form and 25% did not understand the scheduling of their next appointment. While language barriers contributed to these findings, lack of basic health literacy was the predominant barrier. Complex treatment plans compound the problem (Bauman et al., 2002; Tinkelman et al., 1980). Additionally, the lack of health literacy also influences patient health beliefs. Anarella et al. (2005) demonstrated that 40% of patients with asthma, in spite of receiving easy to understand information, continued to use daily inhaled corticosteroids only when they had symptoms. Further, 46% of the adults either smoked cigarettes or were exposed to smoke in the home, while 35% of the children continued to be exposed to smoke in the home. The use of medical jargon also contributes to patient misunderstanding (Barker et al., 2013; Cua and Kripalani, 2008; Sadeghi et al., 2013). Multi-syllable words, medical terminology and multiple compound sentences all play a role.

Non-cognitive Personal Factors

The relationship between provider and patient can be crucial to adherence to a recommended course of treatment. Poor relationships are frequently characterized by a lack of trust. This can manifest itself in a variety of ways, including forgetting to take medications (Atkins and Fallowfield, 2006). A number of patient belief systems may underlie this decision, including the desire of the patient to please his physician (Elliott et al., 2001; Iihara et al., 2008). This may lead patients to say what they believe their healthcare providers wants to hear (Osterberg and Blaschke, 2005). Other interpersonal beliefs and behaviors can also adversely impact adherence, for example: the patient’s perception that side effects make it not worth taking the medication; the patient’s lack of belief in the benefit of the treatment; and the patient’s lack of insight into the illness. Particularly important is the role of depression and other severe psychological conditions (DiMatteo et al., 2000; Williams, 2010). DiMatteo et al. (2000) found that compared with non-depressed patients, depressed patients have a 3 times higher risk of non-adherence with medical treatment recommendations. Young et al. (2001) found that these conditions commonly go untreated.

System Factors

Lastly, issues ordinarily beyond the control of the patient can adversely affect patient adherence. These include: the cost of medications (Osterberg and Blaschke, 2005; Ho et al., 2009) and office procedures (Winnick et al., 2005); limited access to healthcare (Stuart and Zacker, 1999); lack of transportation (Frogel et al., 2010); restricted formularies (Ridley and Axelsen, 2006; Wilson et al., 2005); and the use of generic medications (Kesselheim et al., 2013) where the patient and family are potentially faced with a different color and size of medication every time the prescription is refilled.

Measures of Adherence

“Most controversies would soon be ended, if those engaged in them would first accurately define their terms, and then adhere to their definitions.” – Tryon Edwards

While predictors indicating poor adherence may be useful, ascertaining true non-adherence is difficult. There is no gold standard for measurement, and all available methods are problematic (Matsui, 1997; Osterberg and Blaschke, 2005). For example, measures of adherence can differ from one another by as much as 37% (Milgrom et al., 1996). In this study, the median use of inhaled corticosteroids reported by asthmatic patients in their diaries was 95.4%, whereas the median actual use recorded electronically via the Medication Event Monitoring System (MEMS[®]) (bottle caps contain a microchip that records the date and time at which the bottles are opened) was 58.4%. It should be further noted that the median compliance with inhaled corticosteroids documented electronically was 13.7% for those who experienced exacerbations and 68.2% for those who did not. This particular study demonstrates the best and the worst methods for measuring adherence with self-reporting virtually always resulting in an over estimation of adherence.

Methods for measuring adherence to medications can be divided into direct and indirect methodologies.

There are basically two *direct methods*. The first is direct observation of the patient swallowing, inhaling or self-injecting the medicine. In some cases, a home healthcare provider will administer the injection. Rarely, the patient might be observed applying a patch, cream or ointment. Direct observation is accurate but requires a health provider's time. The second direct method is to measure the concentration of the medication, metabolite or biologic marker in blood or urine. This is expensive and may not reflect continuous adherence.

Indirect methods vary from patient reports (simple and inexpensive but prone to errors) to electronic monitors (usually accurate but expensive and may require downloads). Other indirect methods include information from a caregiver (not always accurate), a count of remaining pills (easily manipulated by the patient), and determining the number or frequency of prescription refills (not necessarily equal to consumption). The patient's clinical response (or lack thereof) may reflect adherence to medication but obviously is influenced by many other factors.

Improving Adherence

“Think like a wise man but communicate in the language of the people” – William Butler Yeats

Many different methods have been used in attempts to improve medication adherence, but few studies have examined whether health outcomes were also improved (Haynes, 2008). While there is a body of literature that indicates that simplifying both medication regimens and treatment options results in better adherence (Bangalore et al., 2007; Matsui, 1997; Osterberg and Blaschke, 2005), these results are found most often with short term courses of therapy (Finney et al., 1985; Lima et al., 1976). Complex strategies for improving adherence with long-term medication prescriptions are not very effective, despite the amount of effort and resources they can consume (Haynes et al., 2008). Macharia et al. (1992), using meta-analysis, showed that broken appointments can be reduced by: mail, telephone or physician reminders; orienting patients to the clinic; or contracting with patients. Simple maps showing the location of reference laboratories or consultants also may be helpful.

Enhanced communication as a tool to improve adherence has received mixed reviews (Berkman et al., 2011). Two relatively new techniques have come to the fore. Concordance, a state or condition of agreement or harmony, has been introduced into the adherence literature (Falk, 2001). As part of this technique, the doctor-patient interview moves from being doctor oriented to patient oriented. Some would term this motivational interviewing, but they are different (Possidente et al., 2004). In both instances, verbal and non-verbal communication take place, but key to motivational interviewing is the art of listening, which means the doctor is truly silent

and expresses non-verbal or minimal verbal empathy for the patient's words. While some clinicians are concerned that this approach will unduly lengthen the time of an office visit, this is not the case. Langewitz et al. (2002) demonstrated quite clearly that mean initial spontaneous talking time by the patient was one minute and 32 seconds, with a median of 59 seconds. Motivational interviewing builds upon the transtheoretical model for change (TMC) where patients or parents can be classified in one of five stages of readiness for change (Berger, 1997). This TMC stage appears to be a predictor of adherence to therapy. Both concordance and motivational interviewing implicitly or explicitly assume that the patient or parents are ready to change long standing beliefs or habits.

Throughout the above processes, the impact of health literacy and the concepts of adult learning play a prominent role. We would do well to remember Sir William Osler's admonition in 1892 regarding patient-doctor interaction (Falk, 2001), "The practice of medicine is an art, based on science." No matter what the literacy level, adult learners wish to learn the basics first. Also, healthcare providers should focus on the one to three key messages they want the patient to remember. Weiss (2003) and the National Patient Safety Foundation (2013) propose several steps to improve communication with patients:

- Slow your speech and spend a little additional time with the patient and family. Sit rather than stand. Listen rather than speak.
- Use plain, nonmedical language, e.g., high blood pressure rather than hypertension, heart doctor instead of cardiologist. Analogies (e.g. "A pipe that is partially clogged doesn't allow air or water to flow properly.") can be used to illustrate an obstructed airway or blood vessel. When using a translator, instruct him or her to stay with the ordinary words you use and not substitute medical terms.
- Use pictures as they enhance understanding and recall.
- Review and repeat key points. Consider simple handouts, written at or below the 6th grade level. In one study, the average grade level achieved by Medicaid enrollees was the 5th grade (Weiss, 2003). The average reading level of a high school graduate is 8th grade.
- Use teach-back or show-me techniques (Schillinger et al., 2003). Ask parents to demonstrate understanding. Avoid asking, "Do you understand?" Patients will frequently answer "yes" even if they understand nothing (Weiss, 2003). Examples of Teach-back include:

"What will you tell your husband about your baby's condition?"

"I want to be sure I explained everything clearly. Can you please explain it back to me so I can be sure that I did."

"Please show me how to place the feeding tube once again."

- The Ask Me 3[®] program was developed by the National Patient Safety Foundation and helps focus the patient or parent on the key issues regarding an episode of illness:

"What is my main problem?"

"What do I need to do?"

"Why is it important to me to do this?"

Weiss (2003) provides suggestions for preparing written materials for patients and families.

- General content: limit to a few key points—what the patient or parent needs to know
- Text: active voice; at or below 6th grade level; short words, sentences and paragraphs

- Font: at least 12 point, simple font such as Arial or Times New Roman; do not use all upper case
- Layout: avoid dense text, leave generous open spaces; simple illustrations as appropriate

Conclusion

Patient (or parent) adherence to a medical regimen is the extent to which the patient's behavior coincides with the recommendations of the healthcare provider. Consequences of non-adherence are expensive and can be severe. Determinants of non-adherence include cognitive and non-cognitive patient problems, as well as difficulties within the healthcare system. Effective communication geared to the patient's or parent's level of understanding is key to improving adherence. Techniques for improving communication (and thereby adherence) include: concordance, motivational interviewing, careful listening to the patient with attention to non-verbal as well as verbal signals, slow speech, avoidance of medical jargon, review and repeat of critical instructions and asking the patient to explain or demonstrate the instructions.

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Chapter 28

Communicating across Cultural Differences

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It is much more important to know what sort of a patient has a disease than what sort of a disease a patient has. Sir William Osler

Culture can be defined as integrated patterns of human behavior that include the language, thoughts, communications, actions, customs, beliefs, values and institutions of racial, ethnic, religious or social groups. An individual's identity with a cultural or social group is fluid, and providers should be aware that not all members of a group will follow all its beliefs or practices with regard to health, wellbeing or illness. In addition to culture, patients' health behavior and decisions are influenced by their degree of acculturation and socioeconomic and educational status.

Cross cultural communication occurs anytime a person from one racial, ethnic, religious or other cultural background communicates with an individual from a different background. Such interaction is common in the field of healthcare. Both healthcare providers and patients are diverse in a myriad of ways, from their worldviews to their sense of national identity (Grol-Prokopczyk, 2012). (See Chapter 29, *Communicating about Spirituality and other Worldviews.*) To communicate in a manner that respects these cultural differences, we, as healthcare providers, have to reflect on our own cultural identity and personal biases. Most medical personnel in the United States are oriented to the Western biomedical framework, which focuses on disease (although this is slowly changing), and which is quite different than Eastern or Traditional medicine, which views the illness as a reflection of the whole patient and not just the organic disease process. When we interpret a patient's behavior, emotional reaction or body language based on our own cultural background, we can easily misjudge the meaning of what we are seeing.

Healthcare providers want to deliver care that is inclusive, sensitive to the patient's and family's needs and that respects the values of their health beliefs and practices. In order to do this, we should learn about the most common minority cultures with which we interact. Every patient comes to the medical visit with a set of expectations for the manner in which the physician will ask about the symptoms, the amount of time he or she will take to listen to the patient's story and the degree to which he or she will negotiate treatment options (Groff, 2002). In this chapter, we examine the interplay of healthcare and culture in the office, the clinic and the hospital.

Health Beliefs

During the medical interview, we ask, in an organized fashion, questions to give us an idea of the patient's possible diagnoses, using our Western Medicine model. The patient, however, may be operating on her or his own health beliefs. For example:

Provider: What do you think made your daughter ill?

Parent: My daughter ate too much candy and that caused her to get empacho.

Provider: Empacho? Can you please tell me what that is?

Parent: You see my daughter ate candy at the party. She ate it again, the next day. She cried from the pain in her belly. She vomited many times. The empacho caused her intestines to stick together.

Provider: How do you treat empacho?

Parent: By massaging her tummy. But, this time it did not work, so I brought her to you.

In this case, the parent attributed the child's symptoms to *empacho* (em·pä·chō), a condition commonly believed among Latinos to be due to a blocked bowel caused by foods that are hard to digest. Cures for this ailment may consist of benign massage to the abdominal area, as in the case above, or various folk remedies that may contain substances such as greta, azarco or abeyalde that may have a high lead content (Jonas, 2005). This example illustrates the importance of knowing something of a culture's health beliefs and the importance of eliciting and providing information in a sensitive and nonjudgmental manner.

The negotiating that needs to occur is dependent on how strictly adherent the patient or parent is to his or her health beliefs (Flores et al., 2000). If a parent discloses that he or she is using a home remedy which contains (or potentially contains) a harmful substance, in addition to explaining the dangers of that substance, it would be helpful to ask, "How would you feel if you discontinued the use of the X?" or "What do you think would happen if you stopped the X?" This provides an opportunity for the parent to describe the possible negative effects of discontinuing the remedy or an opportunity for the parent to share a sense of relief that the practice in question can be stopped. Parents who have strict adherence to a practice will be less likely to acquiesce to a request to stop the practice.

It is helpful to explain that you want to learn about the family's concerns with regard to the visit. Ask if there is something else that worries the patient or parents. According to (Kleinman et al., 1978), one way to elicit a patient's health belief is to ask:

What do you think is causing your symptoms?

What have you done to get relief from your symptoms?

Whom would you like to be involved in the decision making for your (or your child's) treatment?

Religion

Patients and families very frequently have religious or spiritual beliefs that are different from those of their healthcare providers. Religion is usually defined as a system of beliefs or practices related to a sacred being or god. There is usually a set of doctrines or dogmas, as well as rules, rituals and observances, which may impact on the patient's health and acceptance of treatments. Respect for the family's religious beliefs may require flexibility in the choice of medications (e.g., avoiding liquid medications containing alcohol) or the timing of return visits or elective procedures that might conflict with a religious holiday.

Many hospitals provide a dedicated place for meditation or worship, and most can accommodate a family's dietary restrictions. In-hospital psychosocial support for a family in crisis because of a child's deteriorating condition or poor prognosis should include offering consultation with a chaplain or a leader of the family's faith or spiritual community.

I see that the information I gave you is very upsetting to you. I would like you to know that I can help you contact someone from your family or your faith or spiritual community. Is there someone I may call for you?

Or

I can understand that you were not expecting to receive this news, and it is a lot to process. Would it be helpful for me to ask our hospital chaplain to come for a visit?

Once the chaplain's consultation is complete, it is a good idea to follow up with a short conversation such as:

I saw that X came by to see you. How was your visit? Would you like me to notify our team that you want privacy when he (or she) comes again?

You may advise the parents that they have the option to request that all phone calls and interruptions be held during the time that the clergy is at the bedside. If you walk into a patient's room during a visit from a chaplain or a spiritual healer *who is performing a ritual*, it is always best to stay quiet until the process or prayer is over. To interrupt with, "I am sorry. When can I come back?" or "How long will you be here?" will likely be seen as disruptive and disrespectful.

Young children may sometimes wear a religious charm on a necklace or string around the neck. If the provider believes this poses a risk for strangulation, he or she should explain this concern to the parent(s) and ask if the jewelry has special meaning. If the parent says that the child needs to wear the jewelry for protection from further illness or the *evil eye*, you should gently explore options for wearing it around the wrist or placing it somewhere nearby where it would not pose a risk for strangulation or choking.

Occasionally, a patient's culture places a high value on the presence of and interaction with many family members. Some cultures have a patriarch who informs the family of appropriate decision making while in other cultures the value is on the entire extended family. The latter situation can result in an excessive number of visitors or a large number at the same time, interfering with the unit's function or the patient's rest or treatment. In some cases the parents are looking for assistance with crowd control; in other cases the parents may perceive the hospital policy as too restrictive. Review the patient's need for rest and the staff's needs in delivering treatments with the parents. Below is an example of how to discuss this issue.

Provider: Several people have come earlier today to visit with you and your child. I am sure that you appreciate all of their concerns and their support for you and your family. I want to make sure that you and they know that Joey must get enough rest each day.

Parent: Yes, they have all been wonderful.

Provider: I agree that it has been a wonderful experience for you. However, I am asking that we limit the number of visitors that come to the floor at one time since we have many patients who need to sleep during different times of the day.

Parent: I can't ask my friends from church to stay away. They are like family.

Provider: I am not asking that they stay away, but I am here to help you decide who comes and how they can take turns visiting, so that Joey gets the rest and care he needs. Our hospital has the following policy: visiting hours are from __ to __, and there should be no more than __ people visiting at one time. The lower age limit for children to visit is generally __. (Children's hospitals, including Texas Children's, typically have unrestricted visiting for parents and siblings, except in special care units.)

Studies suggest that religiosity may improve the physical and mental well being of patients (Taylor, 2001). It is thought that there are psychosocial benefits from religious activities and that the dynamics of the rituals, faith practices and support from the faith community help the patient understand and interpret his or her symptoms and cope with the diagnosis and prognosis.

Language

According to the 2011 US Census Bureau's American Survey Report, approximately 60 million

people (21% of the population) living in the United States (US) over the age of 5 years speak a language other than English in the home (Ryan, 2013). In fact, more than 300 different languages are spoken in this country. Since 1980, the largest increase has been in Spanish-speaking individuals, involving a total of more than 26 million people (Barrett et al., 2008).

Persons whose primary language is not English are often designated as having limited English proficiency (LEP). The quality of care received by those who encounter linguistic and cultural barriers is at risk (Barrett et al., 2008). Language differences between families and healthcare providers can create distrust, diminish adherence to therapy and lead to suboptimal outcomes.

One should never assume fluency, and when in doubt about the family's ability to understand English, it is important to corroborate information with a trained interpreter, particularly when major medical or social decisions are being made (Flores et al., 2000). If a trained interpreter is not physically available, many hospitals provide an interpretation service by telephone. The disadvantage of a phone interpreter (without video) is the loss of nonverbal signals between the interpreter and patient. For example, an interpreter may sense a patient's discomfort or relief through nonverbal cues, and the patient often sees the interpreter as a cultural broker rather than simply an expert in linguistics.

Here are some guidelines for effectively utilizing an interpreter:

- Place yourself side by side with the interpreter and face the parent and the patient.
- Do not leave the patient or parents out of the conversation. Speak directly to the patient or parent, pausing so the interpreter can translate what you have said.
- Talk in short sound bites. It is important to provide small amounts of information and wait for the interpreter to translate.

Ask the patient or parent to repeat the essential information given and clarify. Phrases such as, "I can see that you are happy to discuss your son's condition with someone who speaks Vietnamese. However, I would like you to tell me what you understood about the instructions that I just gave you." Pause and allow the interpreter to explain what is expected from the parent. Be patient and allow time for the translation to occur. (See Chapter 30, *Permission, Informed Consent and Preparation for a Procedure*, section, *Educating the Patient and Parents and Communicating Content*.)

When a language barrier exists, the healthcare provider will likely miss some cultural nuances if he or she has no knowledge of the family's culture and how it influences the roles of the patient, family and community in decision making. For example, if the provider enters the room and finds numerous family members present, it would be very helpful to know if the family is part of a culture in which communitarianism is highly valued. This can help the provider determine, in conjunction with the patient and parents, who are the important stakeholders who should remain in the room to discuss the medical issues (Grol-Prokopczyk).

When a language barrier is present, it is useful for the physician or other provider to ask him or herself some of the following questions:

- Do I give my patients time to tell their stories in their own words?
- Has the use of an interpreter become so time consuming that I forget to ask about pertinent social issues, including spiritual or religious preferences?
- Do I feel uncomfortable admitting that something was probably lost in the translation, since my patient continues to appear worried, upset or angry?
- Do I take the time to notice if family members hug or embrace one another?
- Do I notice who soothes the infant or consoles the irritable child or adolescent?

Research has demonstrated that healthcare discrepancies are common among culturally-diverse minority groups (Boykins and Carter, 2012). Because culture plays such an important role in provider-patient communication, health professionals must integrate patient values, beliefs and cultural and spiritual preferences in all interactions, in order to decrease or eliminate these discrepancies. The positive effects of successful interpersonal and cross-cultural healthcare communication with culturally-diverse populations include: greater access to and consumption of healthcare; better coordination of health services; improved quality of healthcare; better health outcomes; and better patient satisfaction.

Flores et al. (2000) provide some guidelines for helping the pediatric provider obtain truly informed consent when English proficiency is a problem. (See Chapter 30, *Permission, Informed Consent and Preparation for a Procedure*)

- Have a trained interpreter present and involved.
- Ask the patient or parent to repeat (through the interpreter if necessary) all essential information about the procedure.
- Have the consent document written in the patient’s or parents’ native language.
- Ask the patient or parents what cultural or personal beliefs they have relevant to the procedure.

Ethnicity and Race

A person’s race and ethnicity can have significant implications for healthcare delivery (Sondik et al., 2000). For example, the Healthy People 2010 report (2000) noted that in the United States HIV infection prevalence among Blacks is eight times that of Whites and twice that of Latinos. Racial or ethnic differences have also been reported to affect the safety and efficacy of at least 29 medications (Tate and Goldstein, 2004). This highlights the need for healthcare providers to be knowledgeable of the ethnopharmacology (aka pharmacogenetics) of the most common minorities with which they will be working.

The US Census Bureau (2012) uses the term, “Origin” to indicate nationality or country of birth and “Ancestry” to reflect peoples’ self-identification with their ethnic groups before their arrival to the U.S. (Table 1)

Table 1. Cultural Definitions (US Census Bureau, 2012)

Origin: heritage, nationality, lineage or country of birth of the person or his or her ancestors prior to arrival in the United States.
Ancestry: a person’s ethnic origin or descent, roots or heritage or place of birth before arrival in the United States.

A study by Cooper-Patrick et al. (1999) found that patients who look like and speak like their providers have higher levels of satisfaction with their visits than patients who do not share these features with their providers. Healthcare providers and patients of the same race or ethnic group are more likely to share the same or similar cultural beliefs, values and experiences, allowing for more effective communication.

Ethnic differences between healthcare providers and patients can result in barriers to effective communication (Kleinman et al., 1978; Mull, 1993). In a patient encounter where the provider appears different (due to dress, accent or personal grooming preferences), a patient with an intentional or unintentional bias may respond negatively to this provider. The family may ask to see a different provider next time, or they may be very specific and ask for a male or female provider, an older and more experienced individual or someone who is or is not of a certain racial,

ethnic or religious group. Similar bias can occur in the provider towards the patient. Unintentional racial or ethnic bias can result in stereotyping, which can affect symptom interpretation, prediction of patient behavior and medical decision making (Kaplan et al., 1995). Bias can also result in a change in the provider's tone of voice, body language and time spent in active listening.

It is imperative that, as healthcare providers, we be aware of any negative feelings toward a patient or family and not let these feelings interfere with appropriate medical care. Everyone has biases, but we are obligated to keep those biases out of the interaction so that each patient receives the care, compassion and education that all patients deserve, regardless of factors such as body habitus, skin color, body art, manner of dress, religious or spiritual identity, social status, sexual orientation, level of education or level of proficiency in English.

When working with patients of varying backgrounds and beliefs, it is helpful to reflect on questions such as: does a patient's race, ethnicity, level of education or socioeconomic status affect the care that you give that patient; how does the media portrayal of minorities affect your attitude towards these individuals; and how do you feel about care for someone with no English speaking skills? It also is helpful to reflect on your own identity: how does your ethnicity define who you are; with which racial or ethnic group(s) are you comfortable; and with which groups are you uncomfortable? Think about how you could change your communication techniques to prevent those biases from affecting your behavior towards certain groups or impacting patient care.

Mixed Ethnicity or Race

For many years, medical and nursing students were taught to report the race or ethnicity of the patient in the medical record. However, most of the time, the only criteria used were the name, physical appearance or accent of the patient. Currently, if the patient or parents are asked to self-identify during a hospital admission, that information is placed in the patient's medical record.

According to Udry and Hendrickson-Smith (2003), mixed-race adolescents are at a higher risk for health and behavioral problems than single-race youth. Despite findings suggesting that biracial or biethnic youth are especially vulnerable in terms of self-reported delinquency, school problems and poor self-regard, relatively few resources exist for understanding the unique needs of biracial youth and their families (Milan and Keiley, 2000). Additionally, the healthcare experiences reported by mixed-race families indicate concerns including a lack of respect by healthcare providers and staff, as well as a condescending attitude, a lack of knowledge about biracial health issues and inappropriate assumptions, primarily about the parent's educational level, socioeconomic status and living arrangements (Byrd, 2004). In order to provide high quality care to all children, providers need to develop trusting relationships with children and families in a supportive, culturally-competent environment (Division of Maternal Child Health Workforce Development, 2012). Patients and families may identify with multiple cultures, and surname and language spoken are not reliable indicators of the major culture for a racially blended family. Asking the patient and parents their preferred language at home and with friends will build trust.

Issues of Gender

Same Gender Parents

In the US 2010 Census, there were over 600,000 households with two same gender parents. These same gender parents raise approximately 115,000 children under the age of 18 years (Levine, 2013). There are a large number of children who are raised by single lesbian or gay parents. The estimate of children and teens raised by non-heterosexual parents is close to 2

million. The 2013 policy statement of the American Academy of Pediatrics affirms that the emotional and developmental well-being of children raised by gay and lesbian parents is equal to any other household whose parents offer security, social and emotional support and commitment to parenting (Levine, 2013).

In a typical scenario, a 15-year-old patient presents with two female parents. One parent introduces herself as, "Tricia's mom." It is best to turn to the other parent and say, "I am Dr. X, and you are?" Acknowledge both parents and verify their names in the medical record. You also can make a note as to which mother wants to be called for a change in an appointment and for laboratory results.

Children or teens who have gay or lesbian parents who have separated or divorced need to be supported in the same way as children of separated or divorced heterosexual couples. They need support to deal appropriately with the psychological losses that they experience, as well as with the myriad of legal, financial, social and mechanical issues engendered by the separation or divorce.

Another area of concern is inequality in health benefits for children of same sex partners. If a union between the two partners is not recognized by the state, the child may not qualify for certain healthcare coverage. Healthcare providers should be sensitive to families who request assistance in getting healthcare coverage for their children.

Gender Concordance and Discordance between Provider and Patient or Parent

Differences in communication styles between genders have been widely reported (Borisoff and Merrill, 1992; Pearson et al., 1991; Stewart et al., 1990). These differences are particularly notable when men and women listen. Men tend to listen for the bottom line, for some action to be taken and for decision making; women have a tendency to pay more attention to details in order to get the full picture (DeLange 1995). Women also use more eye contact and ask more questions in an effort to maintain the conversation; men use less eye contact and nod their heads.

Research has shown that another way of interpreting these differences is to consider communication between men and women as cross-cultural (DeLange 1995). Weisman (1986) studied concordance in the patient-provider dyad, i.e., patient and physician of the same gender versus opposite gender pairings, and how this related to patient satisfaction, healthcare service utilization and recidivism. Weisman's findings suggest that same-sex physician-patient pairings might be helpful where gender-specific conditions are the focus or where a long-term relationship between patient and provider is desirable, as in the case of a very sensitive condition or one requiring prolonged treatment for a chronic condition.

Sexual Minority Youths (Lesbian, Gay, Bisexual and Transgender Children)

Allen et al. (1998) report that gay, lesbian, bisexual and transgender (LGBT) adolescents have misunderstandings about their right to confidential care, fear of judgment by healthcare providers and concerns that their parents would be informed without their consent. Adolescents who are questioning their sexual orientation or who are LGBT are at a disproportionately high risk for depression, suicide and other mental health problems. Studies also indicate a lack of relevant health-related material and resources for the LGBT community, frustration trying to find useful information about sexual health and limited access to knowledgeable health professionals (Davis et al., 2009; Ryan, 2003; Silvestre, 2003). Therefore, it is very important for healthcare providers to identify this population and provide them with necessary support and guidance. Based on the results of a study of LGBT adolescents, Davis et al. (2009) recommend that healthcare providers, especially school health professionals, broaden their training to include ways to address risk

prevention and health promotion for LGBT youth. (See Chapter 3, *Talking with the Adolescent Patient*, section, *Provider and Clinic Characteristics*.)

According to Perrin and Kulkin (1996), more than a third of the 250 LGBT *parents* they surveyed in the US and Canada reported problems with primary pediatric care, clinics and hospitals. The main reasons given for their negative health experiences were exclusion of the non-biological parent, discrimination related to sexuality disclosure and deficiencies in health services. Because of the stigma associated with being LGBT, these parents are often ostracized by their communities. Thus, it is necessary for healthcare professionals to identify and confront personal and institutional bias and to educate themselves on issues involving sexuality and homophobia (Stein and Bonuck, 2001; Weber 2008). Awareness of one's attitudes and beliefs through self-examination is essential for good clinical practice (Horsman and Sheeran, 1995; Yoder et al., 1997). One recommendation is to provide LGBT parents with information about and referrals to similar groups in their community (Perrin and Kulkin, 1996; Rawsthorne, 2009). Implementing the family-centered care (FCC) model is an ideal way to provide care for all families, and especially with families who do not fit the stereotype of the nuclear, heterosexual family (Shields, 2010). (See Chapter 5, *Patient Centered Communication and Decision Sharing* and Chapter 26, *Patient- and Family-Centered Rounds*). The National Center for Family Professional Partnerships (2014) states: "Family-centered care assures the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship. Family-centered care is the standard of practice which results in high quality services."

Folk practices

The practice of traditional medicine that is rooted in the patient's culture is easily accessed by immigrant families. Often, they have brought with them the essential items for common remedies, or they may seek them in a neighborhood store with imported items from their native country. The store also may have information about persons in the community who are traditional healers or therapists. According to Ransford et al. (2010), many Latino immigrants rely on folk remedies which would be considered complementary and alternative medicines. Latinos commonly use herbs and medications brought from Central or South America or go to Mexico to purchase medicine or objects needed for cleansing, curing or treating an ailment. Many Latinos rely on the combination of prayer, traditional medicine and conventional medicine. It is important to recognize the parallel utilization of health practices and use this as an opportunity to engage the family in decision making.

Immigration and Culture

Recent immigration patterns reveal a predominance of immigrants from Latin America and Asia. Some states (California, Arizona, New Mexico and Texas) have a disproportionately higher number of Latino immigrants due to the proximity of their borders to Mexico. There are approximately 11 million undocumented immigrants in the United States. Even with the introduction of the Affordable Care Act, the children of these immigrants do not qualify for federal benefits. Parents have to learn how to navigate new systems for housing, shopping, school, healthcare and employment. They face many barriers to accessing healthcare: time lost from work and lost wages, a foreign language, lack of transportation and school policies regarding absences. For those families who miss appointments, it is important to recognize the psychosocial and financial stresses that may be involved. Below are examples of how to approach this problem in a culturally sensitive manner:

I understand that sometimes there are things that get in the way of making it to a clinic visit. Is there anything that I can do to help you keep your child's next appointment?
(If you are in a facility where a parking discount is available, offer to refer the family to the social worker or financial counselor.)

Some of my new patients find it difficult to understand the appointment system here in the US. May I help you understand our clinic's policies and the appointments?

I would like to introduce you to the person(s) who would be returning your call when you have a question.

Many undocumented immigrants live in the shadows and work at low-paying jobs. When their children are sick, they often have to balance missing work and a pay check (or even losing their job) with getting medical care for the child (Ransford et al., 2010). Even though their children (brought to this country illegally) have the opportunity to attend school, parents may hesitate to ask for help for fear of deportation. Children's adjustment to school is paramount to their wellbeing. Difficulty in learning in the new setting may be due to language or cultural barriers. A few patients will adjust poorly due to post-traumatic stress disorder from incidents that occurred at home or on the journey to the US. Families who come from rural areas of Mexico and Central America may have never received formal schooling.

In Texas (other states will have different policies), almost all undocumented, newly arrived immigrant and refugee Latino children are placed in public schools with bilingual education. Some children are placed one or two grades levels below their levels in their native schools. This can cause anxiety and lead to school avoidance or behavioral issues in the classroom and at home. It is important to evaluate the child's adjustment to school placement and his or her desire to excel and anxiety about failure. Many Latino children and teens will continue in bilingual education until the parents request a change to English-only instruction or until the school feels that the child has mastered reading and writing in English. The student will be expected to perform well in standardized school exams that are administered in Spanish. All public schools do not have the same resources, and immigrant students with special education needs benefit from a healthcare provider who is their advocate. Parents need to learn about their educational rights and school policies for testing and school placement. Parents should be encouraged to apply for health benefits for students who have a newly diagnosed medical condition or a chronic medical condition that may interfere with learning.

How to Interview a Newly Arrived Immigrant Family

Many recent immigrants have limited English proficiency so use an interpreter as needed. Pay special attention to body language. Is the patient or parent shifting about in his or her seat; is there nervous tapping of hands or feet or playing with hair?

If the family has entered illegally, parents will be concerned that they might be reported and deported. Assure the family that your conversation is strictly confidential and reassure the patient and parents that they are safe in the office, clinic or hospital. Explain that this conversation is important to you and will help determine the medical and healthcare needed.

Below are examples of questions to help assess a family's adjustment to this country:

I heard you say that you are new to our city. Tell me something about your arrival here. What went well? What didn't go as expected?

What do you miss the most about your home country (or city)?

How often do you talk with your family back home? I know that many families take advantage of video phone calls through the Internet. Are you connected to the Internet at home?

Since your arrival in Houston, has your child had a well child exam or check up? Have you had the opportunity to discuss with a doctor any concerns about his growth or other problems?

It is important to screen for symptoms of posttraumatic stress disorder (PTSD), since many undocumented families make enormous financial sacrifices to get to our country. The family's departure may have been abrupt and the journey filled with days or weeks with little food, long night walks with strangers and physical or sexual abuse by the smugglers.

Case example

A teenage boy had been separated from his mother since age 6, when his mother came to the United States to work and send money home to provide for her family. He had lived with his grandparents in their native country where he had attended school and had friends, some of whom were older. One day, one of his older friends was murdered. The patient developed difficulty breathing and sleeping. A few weeks later, he was smuggled into the U.S. In the U.S. he frequently got into trouble at school. He was having nightmares and anxiety attacks related to the murder of his friend. He agreed to attend counseling with a behavioral therapist who spoke his native language.

Some questions to ask:

I understand that this is your first school year here in Houston. How do you like your new school?

I heard you say that it is “dumb” to be placed in a lower grade than you were in last year. I know that schools will do that to give you time to learn to speak and read in English. Can you tell me about this?

Many of my patients who move to the United States find that there are things that they do not enjoy in school. What is your least favorite thing about your new school?

Some patients tell me that they feel sad or angry that they have moved so far from family and friends. Do you mind sharing your experience?

Conclusion

This chapter has reviewed ways to facilitate the provision of high quality, culturally sensitive healthcare to patients of varying racial and ethnic groups, educational and social levels and religious beliefs. All healthcare providers should develop the knowledge and skills necessary to communicate with families of different cultures, including those who have limited English proficiency and those who are not familiar with our Western healthcare system. To develop rapport with the families from culturally diverse backgrounds, one must: practice active listening; take the time and make the effort to understand the patient's and family's health beliefs; and explain the diagnosis and offer treatment in a manner that incorporates the cultural values of the patient and family. Reflection of one's own life experiences and biases, and on the positive and negative interactions with one's patients, will foster respect for different cultures and facilitate growth of professional communication skills.

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Chapter 29

Communicating about Spirituality and other Worldviews

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Background and Introduction

Although humanism, spirituality and religion are very different worldviews, they are also very similar in that they are tools used to answer questions of the shared human experience. These experiences define what it means to be human and are thought to shape the human spirit. Many writers throughout history have referred to the shared experiences of humanity. Commonly recognized themes include love, betrayal, guilt, a sense of right and wrong and questions of purpose, meaning, and suffering. The existence of these experiences is independent of gender, race, creed or culture, and only dependent on being human.

A profound communication occurs when people are able to connect through a shared human experience. Perhaps this connection is what Sir William Osler was referring to when he said, “The practice of medicine is an art, not a trade; a calling, not a business; a calling in which your heart will be exercised equally with your head.” (Osler et al., 2013). In the hospital setting, patients and families are likely to explore questions of purpose, meaning and suffering related to a diagnosis. The framework with which people explore these themes is called a worldview. Worldviews exist within a spectrum that includes humanism, spirituality and religion. Worldviews can be a source of common ground between the healthcare provider and the patient and parents, or they can be a source of conflict, resulting in compromise of the provider-patient relationship. Whatever the healthcare provider’s personal worldview, and whether or not it is compatible with the patient’s, the provider must recognize that the needs of the patient take precedence over his or her own. Spiritual and humanistic language is often the patient’s or parents’ way of communicating about what they hold sacred. They will also use this framework to give you insight into their fears and aspirations.

It should be recognized that people can hold virtually anything, anyone or any idea as sacred. The word “sacred” refers not only to the concept of God or a higher power, but to anything deemed so by the person considering it. Pargament (2013) suggests that something can be considered sacred if it has been assigned divine-like qualities, such as boundlessness or ultimacy. Commonly, people refer to God, nature, art, music, family members, wealth, or personal possessions as sacred. Who or what is sacred to an individual is a result of that individual’s worldview. For this reason, being sensitive to the patient’s worldview and developing the skills to communicate about the needs and concerns that arise from the patient’s worldview are paramount to the art of medicine.

Why address these issues?

The medical literature reflects a growing interest in the spirituality-medicine relationship, and a significant body of research demonstrates a benefit in those who have spiritual beliefs or practices (Gioiella et al., 1998; Levin, 1996; McCullough et al., 2000; Waldron-Perrine et al., 2011). Barnard and colleagues (1995) suggest that it is not always the specific theological content of a particular religion in these instances, but rather the experience of having one’s questions of meaning and hope taken seriously by a professional healthcare provider. Ehman (1999) found that patients would like their physicians to ask about their spiritual beliefs if they

become gravely ill. He found, not surprisingly, that 94% of people with religious beliefs wanted a physician to inquire about these beliefs. The surprising finding was that 45% of patients with no spiritual belief also agreed that physicians should ask about this issue.

The Association of American Medical Colleges tells us in its Medical School Objectives Projects Report (1999) of a changing attitude toward spirituality in medical practice. The expectation is that graduating medical students should: know how to elicit a spiritual history; understand that the spiritual dimension of people's lives is an avenue for compassionate care giving; and reflect on their own worldview and how it can be nurtured as part of their professional growth, promotion of their well being, and the basis of their calling as a physician. Many medical schools and medical training programs are integrating spirituality into their required curriculums (Barnett and Fortin, 2006; Nioaka et al., 2012; Pettus, 2002; Puchalski and Larson, 1998; Wear and Castellani, 2007). In addition, The Joint Commission (formerly the Joint Commission on Accreditation of Healthcare Organizations) now requires that a spiritual history be taken on all patients admitted to the hospital and suggests that taking a spiritual history demonstrates respect for the patient's and family's values, religion, and philosophy (Hodge, 2006). Developing the skills to meet these recommendations begins with a willingness to understand the patient's and family's worldviews.

Common Worldviews

Humanism

Humanism can be defined as a doctrine or way of life centered on human interest or values. Humanism stresses an individual's dignity and worth through reason and not through belief in a supernatural power or being. Patients and families with this worldview are likely to describe themselves as atheists, nonbelievers, secularists, naturalists, humanists or freethinkers. This worldview stems from the ideas of naturalism and materialism, the belief that all facts are physical facts and that all causes are physical causes (Humanists of Houston, 2013). This is a relatively new worldview, which became prominent sometime after the 17th century, when new strides in science, biology, and medicine were occurring. Prior to the era of modern science, people believed diseases were a curse from God and that many psychological ailments were caused by demons. One example of worldly understanding at that time included the idea of spontaneous generation, the appearance of living organisms from non-living matter. This concept was well accepted until Francesco Redi's famous experiment in the 17th century. Using uncovered and gauze-covered jars containing samples of raw meat, Redi proved that maggots came from flies not from spontaneous generation. Louis Pasteur, father of the Germ Theory, conducted experiments proving that bacteria did not spontaneously arise from inert substances. He also proved that illness was caused by microbes rather than punishment from God or demons (Gillen, 2008). Charles Darwin's 19th century book, *On the Origin of Species*, was and remains a significant influence supporting the ideas of naturalism. These and many other prominent scientists and freethinkers were instrumental (whether intended or not) in laying the foundation for the secular worldview of today. Many humanists are informed by science, inspired by art and motivated by compassion, and they are content to contemplate life's mysteries using these influences (Humanists of Houston, 2013). A recent Gallup poll suggests that 13% of the *world's* population identify themselves as atheist or agnostic, up from just 1% in 2005 (WIN-Gallop, 2012). Knowing that a patient or parent operates within a framework of humanism can be very helpful when talking to him or her about a life-threatening or other serious illness.

Spirituality and Religion

Religion and ideas of the transcendent have been prominent throughout recorded history. Although in recent times there has been a shift in thinking for some, most people still believe in a supernatural force that somehow relates to or watches over humanity. A Gallup poll in 2013 found that 90% of Americans believe in God or a universal spirit (Gallup, 2014). So it is certain that you will care for patients and families who embrace this worldview.

Spirituality and religion have some significant differences, and it is important to identify them. *Spirituality* is a very broad term and has been defined by Pargament as “a search for the sacred.” (Pargament, 2013). It is an internal experience, defined by the individual. Common descriptions by people trying to express their spirituality will include awe and wonder and mystery-sensing and value-sensing emotions. No two people will have the same view on spirituality, and it is important to validate a patient’s personal sense of spirituality. *Religion* on the other hand is a community oriented and outward experience. When asking people about their religion, you will likely hear them refer to doctrines, creeds, rituals and sacred texts. Religion, unlike spirituality, is defined by these specific doctrines, creeds and sacred texts. Some patients find it easier to talk about religion than spirituality, as religion is less ambiguous. In spite of the differences, there is a significant overlap between spirituality and religion that cannot be ignored. Hope, reflection, love and questions of purpose are a few of the things that reside in this area of overlap. So it is logical to view spirituality as a person’s personal expression of his or her search for the sacred while religion is the communal or shared expression of that search.

The worldviews of spirituality and religion can have far reaching implications for patients and their families. For instance, it is common for people to rely on religion for coping in times of stress. A study by Schuster et al. (2001) found that during the days following the 9/11 terrorist attacks, 90% of people who were asked said that they turned to prayer, religion or spiritual feelings to help them during that time. This is equally true when diagnoses or other stressors threaten a person’s personal health. In another study, 45% of patients said their religious beliefs would affect their decisions if they had a serious illness, and 94% of these felt that their physician should ask about their religious beliefs (Ehman, 1999). Additionally, discussions about spirituality can affect the patient’s and family’s satisfaction with end-of-life care. A study by Balboni and colleagues (2010) found that addressing patients’ spiritual concerns at the end-of-life resulted in a five-fold increase in receiving hospice care and decreased the likelihood of receiving aggressive end-of-life care by 72%. For these reasons, it is imperative that we be open to talking about issues of religion and spirituality in a way that is safe and nonjudgmental.

Assessing the Needs of the Patient

Before attempting to address issues of spirituality with patients and parents, it is important to understand their feelings about questions of purpose, meaning and suffering. There are several spiritual assessment tools that can help you more clearly identify their worldview.

The HOPE Questionnaire (Anandarajah and Hight, 2001) addresses four aspects of spirituality:

Hope

Organized religion

Personal spirituality and practices

Effects of this worldview on medical care.

The FICA Questionnaire, developed by Puchalski, is another commonly used tool for addressing spirituality (Puchalski and Romer, 2000).

Faith or belief: do you consider yourself spiritual or religious? What do you believe in that gives meaning to your life?

Importance and influence: what is important in your life? How have your beliefs influenced your behavior during this illness and how will these beliefs help you regain your health?

Community: are you part of a spiritual or religious community? Is there a person or group of people you love or who are very important to you?

Address: how would you like me to address these issues in your healthcare?

It is important to note that some people have never considered or identified their worldviews. Fowler (1981) suggests that children are not born with a mature faith but have stages of faith development that are in parallel to cognitive and psychosocial development. He suggests that in a safe and supportive environment, a person's faith will unfold and develop. Fowler has observed that life crises such as death, serious illness and other traumatic experiences may cause people to question the meaning and purpose of life. These crises may move the individual to the next step of faith development in order to effectively answer questions and resolve the crisis. If a patient or parent has never before experienced a serious life crisis, it is possible that he or she may have never considered these questions and may be struggling with them for the first time. This could result in feelings of helplessness and fear. An individual's worldview is fluid, and individuals may find themselves drawn to different ideas at different times in their life. It is important to remember this when communicating with patients with a life-threatening or chronic illness and to understand that the patients' worldviews may change as their diagnoses and prognoses progress.

Conclusion

As healthcare providers, we are called to restore the health of our patients. Health can be defined as the condition of being sound in body, mind, or *spirit*. So it is not only the desire of our patients, but also our duty as healthcare providers, that we be open and willing to engage in conversations that address the patient's worldview. The more a patient feels validated and understood, the stronger the patient-doctor relationship will become. A foundation of respect and validation when addressing what a patient holds most sacred can help lead the way to successful communication, resulting in optimal patient care.

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Chapter 30

Permission, Informed Consent and Preparation for a Procedure

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Introduction

Informed consent is an integral component of patient- and family-centered care (PFCC) and an accepted tenet of medical ethics and law (Committee on Bioethics, 1995). According to the Merriam-Webster dictionary (Merriam-Webster, 2014), to consent is “to give approval” and “to be in concord with an opinion”. Only patients legally and developmentally able to make decisions can give informed *consent*. Depending on their age, maturity and psychological state, children may be capable of giving their *assent*, which should also be obtained when applicable. For the purposes of this chapter, the term “informed consent” will encompass both informed *consent* and *assent*. (See Chapter 6, *Ethical Considerations in Communicating with or about a Child*.)

It is crucial for all healthcare providers to understand that informed consent is a process, not a form. Consent encompasses the understanding that all parties (patient, when appropriate, family and healthcare provider) are in agreement with the proposed intervention. The written paperwork is legal documentation that the intervention has been thoroughly explained and that the patient and parents understand and consent. The realization that informed consent is of vital significance has become more common in patient care, and an increase of awareness and implementation has become widespread among healthcare providers (Rozovsky, 1990; Schenker et al., 2007; Sloan et al., 1989).

Historical Perspective

The contemporary concept of consent first emerged in the case of *Schloendorff v. Society of New York Hospital* in 1914 (Sloan et al., 1989; Texas Constitution and Statutes, 2003). The patient consented to an examination under anesthesia but withheld consent for removal of any tumor. The surgeon removed a tumor thought to be malignant. The judge ruled that the procedure constituted medical battery. A case in the 1950s (*Salgo v. Stanford University Board of Trustees*) shifted information requirements from medical battery to negligence law (Sloan et al., 1989). After the case of *Natanson v. Kline* in 1960, the term “informed consent” entered the medical vocabulary (Texas Constitution and Statutes, 2003). Recognition of a moral commitment to respect the right of self-determination of patients first emerged at a high level of interest in the 1970s (Alton, 1977; Annas, 1976). The first published policy statement on informed consent by the American Academy of Pediatrics (AAP) appeared in 1976 (Committee on Bioethics, 1995).

As technology has advanced, medicine and surgery have become increasingly complex, and the doctor-patient relationship has become less personalized. Legal practice also has become technologically advanced and specialized, while at the same time there has been a growing tendency for societal mistrust in the medical profession. For some patients and attorneys,

medicine is now viewed as an industry with assets (Haight, 1990). Increasing numbers of lawsuits involving the informed consent process have been filed in recent decades, emphasizing the need to ensure that the risks, benefits and alternatives to the proposed treatment are discussed with the patient and parent (Alton, 1997; Annas, 1976; Gutheil et al., 1984; Haight, 1990; McCaughrin, 1979; Sloan et al., 1989).

Permission

Respecting and advocating for patient and parent autonomy are fundamental to establishing and maintaining a favorable relationship with the family. The AAP emphasizes that the experience, perspective and power of children are to be taken seriously (Committee on Bioethics, 1995). Healthcare provider paternalism is unacceptable and has been exchanged for a more equitable partnership among physicians, patients and parents.

Healthcare today is contractually based, at times written, but frequently assumed. Commonly, prior to a patient being seen by a healthcare provider, the patient or parent must sign a standard *consent to treat* document. Such documents tend to be generalized. In addition, there is an unspoken contract or expectation of healthcare. In fact, specific expectations are guided by personal and cultural beliefs and should be discussed candidly. Not all procedures (e.g., venipuncture or throat culture) require a signed, documented consent, but verbal consent should be obtained from the patient (when developmentally appropriate) and parent. As presented by the AAP, the following elements are considered to be necessary when obtaining informed consent (Lashley et al., 2000):

- Provision of information, including: an explanation, in understandable language, of the condition; the nature of the proposed diagnostic steps or treatment(s) and probability of their success; the existence and nature of the risks involved; and the existence, potential benefits and risks of recommended alternative treatments, including the choice of no treatment.
- Assessment of the patient's understanding of the above information.
- Assessment, if only tacit, of the capacity of the patient or surrogate to make the necessary decision(s)
- Assurance, insofar as is possible, that the patient has the freedom to choose without medical coercion or manipulation

Patient- and Family-Centered Care

The concept of patient- and family-centered care (PFCC) was introduced in 1969 and gained momentum in the 1980s, with the founding of the Picker Institute. The concept has been embraced by many American hospitals. The Institute for Patient- and Family-Centered Care (formerly the Picker Institute) defines this philosophy of medical care as: "an approach to the planning, delivery, and evaluation of healthcare that is grounded in mutually beneficial partnerships among healthcare providers, patients, and families." (Institute for Patient- and Family-Centered Care, 2010). When discussing a procedure, providers should be aware of providing information at a level the decision-maker can understand. Therefore, it is imperative that patients and parents have influence over the flow of information that is needed to make a decision (Taylor, 1999). Improved understanding of the procedure and potential risks and benefits leads to improved patient satisfaction. Conversely, poor communication (paternalistic or controlled by the provider) has a higher potential for a poor outcome and malpractice litigation (Institute for Patient- and Family-Centered Care, 2010).

Legal and Ethical considerations

Two key considerations to be discussed in this chapter are privacy and confidentiality. The

American Health Insurance Portability and Accountability Act (HIPAA) of 1996 solidified the requirement that all documentation, patient encounters and billing be handled according to a set of rules and standards. The privacy rule protects a patient's health information, i.e., how it is accessed, used and disclosed. In relation to informed consent, the patient and parent trust that all information discussed during the consenting process will not be disclosed to others unless authorized by the patient or guardian. While patients have a right to privacy, they also have a responsibility to disclose health information so that intelligent, inclusive decisions can be made. Although many of the issues pertaining to the ethics of informed consent in pediatric medicine are similar to those in adult medicine, several unique aspects of pediatric medical practice deserve a more thorough discussion (De Lourdes et al., 2003; Fulkerson et al., 2010). While parents have a legal right to give and withhold consent, healthcare providers have ethical duties to children and minor adolescents (Lashley et al., 2000). (See Chapter 6, *Ethical Considerations in Communicating with or about a Child.*) When parents fail to act in the best interests of their child or children, healthcare providers may need to seek the assistance of child protective services or the legal system to protect the rights of the child. Under such circumstances, the courts may appoint a guardian. The failure to act in the best interests of the child may be based on deeply held cultural or religious beliefs that are harmful (Texas Constitution and Statutes, 2003). An example is the reluctance of many Jehovah Witness families to allow blood transfusion for their minor children, even in life-threatening situations. According to the Committee on Bioethics of the American Academy of Pediatrics (1995), parents are not authorized to make decisions that can result in the death of a child. Physicians have a responsibility to advocate for the child and take steps to obtain consent to administer life-saving treatment; therefore, pediatric hospitals have established policies to address such issues.

The State of Texas Family Code, in Section 32.001 (Texas Constitution and Statutes, 2009) stipulates that informed consent can be given by someone other than a parent when a parent cannot be contacted and has not given notice to the contrary. Surrogates also must act in the best interests of the child. In fact, the common expression, "to act *in loco parentis*" (in place of the parent) has come to mean not only to act as a surrogate for the parent, but also, implicitly, to act with the devotion, motivation, and dedication of the parent, in the best interest of the child (Thompson, 1989). In emergency situations, to preserve life or limb, when a parent is not available, treatment should not be withheld.

Assent, or agreement, does not have a well-defined legal standing. Nevertheless, as children mature, their wishes and opinions become increasingly relevant as their cognitive understanding of consequences increases, and as adolescents mature, their opinions, their assent, and also their consent become ethically and practically, if not legally, required (Lashley, 2000).

As the child matures, the process of obtaining assent becomes indistinguishable from the process of obtaining fully informed consent, with the exception that written signature may not be required (Lashley, 2000). Emancipated minors are legally authorized to give informed consent, and healthcare providers have a duty to obtain informed consent from emancipated minors (Taylor, 1999). The criteria for emancipation vary by state, but typically include minors who are self-supporting, married, pregnant or parents, in the military service or declared emancipated by a court (Dickens and Cook, 2005; Thompson, 1989). Full or partial emancipation may be recognized legally on a state-by-state basis for the purpose of treatment of certain medical conditions.

Obtaining the assent of a minor is an important part of the practice of pediatric medicine and surgery (Lashley et al., 2000). It may be difficult to obtain cooperation if assent has not been

obtained in advance and if the physician does not continue to communicate with the minor during the course of the treatment. Assent is based on developmental age, not chronologic age. The AAP's position clearly describes important elements of assent: assessing developmental appropriateness, telling the patient what to expect and assessing the patient's understanding and willingness to accept the proposed care (Committee on Bioethics, 1995). While the assent of a minor is ethically and humanly desirable, it does not negate the requirement that the parent provide informed consent.

Refusal is a powerful manifestation of the ethical ideal of autonomy, and sometimes the only sense of worth and control available to the child. The tension between the autonomy of the minor and paternalism, even in the best of situations, is sometimes unavoidable. Three clinical actions to be avoided are deception, compulsion and alienation of the parents (Alton, 1977). In the face of an apparently irresolvable disagreement, parents should be offered every available assistance, including consultation and counseling by a social worker, child life specialist, priest or chaplain, pediatric psychologist or psychiatrist (Alton, 1977).

Medical practice is busy, and the delegation of obtaining informed consent may need to be considered provided such delegation does not conflict with the policies and procedures where the healthcare provider practices. However, it is essential to be aware that when a non-physician obtains the consent, it does not relieve the physician of his or her legal and ethical duty and liability (Boney, 1994; Ritter, 1990; Texas Medical Association, 2012). Nurse practitioners and physician assistants may obtain consent for procedures that they perform (e.g., lumbar puncture). One must remember that the informed consent process originates from the legal and ethical right of the patient to direct what happens to his or her body. It is therefore the ethical duty of the provider to involve the patient in his or her healthcare, and the responsible practitioner should disclose to the patient information necessary to enable the patient to evaluate a proposed medical or surgical procedure before acquiescing to it. In fact some hospitals are so concerned about this issue of delegation of informed consent, they will permit only the attending physician to obtain the patient's consent to a procedure and prohibit delegating informed consent to an assistant surgeon or house officer (Tovino, 2004). In general though, the attending physician may delegate responsibility for the informed consent process to another qualified physician but cannot delegate accountability.

Scope of Procedures Involving Specific Consent

During the informed consent process, not all medical and surgical procedures should be treated equally. Smaller, less invasive procedures, such as a bone marrow aspirate or lumbar puncture, are often explained in a short discussion and typically on a one-page form. More extensive and life-threatening procedures, such as an organ transplant or neurosurgery, require lengthy, in-depth discussion and often repeated visits with the patient and parents due to the amount of information involved, the long-term implications of the procedure and the complexity of the conversation. The obligatory legal paperwork referred to as the "consent" is also more extensive, frequently running many pages.

Educating the Patient and Parents and Communicating Content

Just as there are many learning styles and intellectual capabilities of patients and parents, the educational approach to the patient and family should be multifaceted and diverse. (See Table 1) Many novel interventions to increase comprehension have been described (Schenker, 2007), and they can be modified to fit individual patient populations. For example, prior to signing consent for a bone marrow transplant or solid organ transplant at Texas Children's Hospital, multiple modalities are utilized. Patients are presented with the information in one-on-one conversations spanning a minimum of one week by multiple team members, including the social

worker, child life worker and nurse coordinator. This process is augmented by center-developed books, foundation-developed pamphlets and recommended Internet websites. The Bone Marrow Transplant Team also has an hour-long introductory class for families, presented by a nurse practitioner or physician assistant. Furthermore, the National Marrow Donor Program has created a video, *Sam and the Marrow Monsters*, to educate children about bone marrow transplantation (Be the Match, 2011).

Language barriers have become increasingly prevalent and must be addressed respectfully. According to the 2010 U.S. census, approximately 13 million people were reported to speak English “not well” or “not at all,” introducing a challenge for obtaining adequate informed consent (Ryan, 2013). A study by Schenker et al. (2007) measured proper documentation of the informed consent process in limited English proficient (LEP) patients. Acceptable documentation included at least one of the following: documentation in the procedure note of a consent discussion in the patient’s language or through an interpreter; a consent form written in the patient’s primary language; or an interpreter’s signature on the consent form. Results indicated that English proficient patients were significantly more likely than LEP patients to have full documentation of informed consents ($p=0.003$). The authors recommended proper training of medical staff to encourage the use of interpreters and the use of informed consent forms in the patient’s primary language. There is an ethical and legal obligation that all patients receive the same quality of care, and this includes the informed consent process. Disparities related to a family’s language in informed consents are unacceptable and correctable (Schenker, 2007).

Table 1. Challenges to the Informed Consent Process and Suggested Solutions.

Challenge	Suggested dialogue
To assure that patient and family understand:	Do not ask, “Do you understand?” An affirmative answer is of little assurance. Suggest: “We have gone over a large amount of information. What would you like me to repeat or review?” or “Is there something that I have not made clear?” AND “Please tell me your understanding about X.” (choose at least one important point that was given to the patient or family for them to repeat back) “Can you explain it to me in your own words?”
To solicit questions:	Do not ask, “Do you have any questions?” It is too easy to say, “No.” Ask, “What questions do you have?”
To explore patient’s or parent’s feelings:	“I know this is a difficult time. Can you tell me about your thoughts and feelings about the procedure?”
To assure accuracy of translation:	Address only one point (or two closely related points) at a time. Instruct the interpreter, as much as possible, to translate the words you use and not to substitute medical terms.

Preparation for a Procedure

In PFCC, a multidisciplinary approach is necessary during the informed consent and procedure preparation processes. Basic concepts that should be discussed during the informed consent process include the diagnosis, recommended or proposed procedure, technical details of the procedure, indications for the procedure, probable outcomes and risks, goals, benefits and alternative modes of therapy (Alton, 1977; Rozovsky, 1990; Sloan et al., 1989). Other aspects of the consent process that are not commonly included on the consent form but are integral to the discussion include, but are not limited to, roles of each healthcare member, environment in which the intervention will take place, emotional aspects, physical aspects (including post-procedure items such as dressings and tubes) and potential family needs (e.g., overnight stays or financial concerns).

Effective communication throughout the consent process can be performed by multiple members of the team. Child life specialists, nurses and social workers are integral members who can provide pertinent information to help augment the educational process and facilitate complete understanding of the proposed procedure.

Finally, depending on the proposed procedure, the consent process needs to introduce post-procedure care. This care is inclusive of what to expect, when and where to follow up, with whom and why and when to call or return to hospital.

Novel Ideas for Improving the Informed Consent Process

Assessing the need for surgical intervention and completing the process of informed consent depend on a reliable measure of the expected surgical outcomes weighed against the risk of operative complications. Patients' or parents' perceptions of the success of a surgical procedure is dependent on both their expectations of the surgical outcome and their views of the risk and severity of potential operative complications.

A small pilot study was conducted at the Texas Children's Hospital Pediatric NeuroSpine Clinic to assess how perception of a surgical complication differs among surgeons, patients and caregivers. A survey of case vignettes describing a potential perioperative complication was administered to 14 pediatric spine neurosurgeons, 13 pediatric patients (ages 12 to 18 years) and 34 parents and other primary caregivers of pediatric patients (Fulkerson, 2010). Study findings revealed some similarities in the perceptions of complications among surgeons, patients and caregivers. Events leading to permanent neurological deficit, a return to the operating room and a prolonged hospital stay were consistently deemed to be complications. Pediatric spine neurosurgeons appeared just as or more critical than patients or caregivers in judging the severity of complications. Nonetheless, there is a need for clear communication about realistic surgical outcomes. Systematic and fair evaluation of perioperative complications is important for patient satisfaction and improvement in healthcare and the process of informed consent.

Conclusion

The informed consent process goes beyond the signing of a legal document. It serves as a communication center point among patients, parents, physicians and other members of the medical team. Informed consent is achieved when an individual understands his or her particular medical situation and the possible consequences of an action or inaction in light of acceptable and reasonable alternatives to that action or inaction. The information provided to patients and families about the condition or procedure and the associated risks is essential to this process. The process itself includes education of the patient and family in key aspects of the diagnosis,

disease severity and the proposed or planned procedure. A family-centered, multidisciplinary approach is helpful during the informed consent process and in preparing the patient and parents for surgery or another procedure.

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Chapter 31

Communicating with the Difficult Patient or Family

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Difficult patients, defined as those who do not assume the *patient role* expected by the healthcare professional, are encountered in every setting (Groves, 1978; Macdonald, 2003). The conflicts that arise in response to problematic interactions or negative experiences related to the delivery of medical care not only result in a breakdown in the physician-patient relationship but also contribute to worse medical outcomes, including non-compliance, decreased trust and satisfaction, worsening of presenting symptoms and higher 6-month utilization rates (Jackson and Kroenke, 1999; Lin et al., 1991).

With nearly 1 of 6 outpatient visits considered difficult by physicians, numerous studies have attempted to identify factors that contribute to the difficult encounter (Hahn et al., 1994; Hahn et al., 1996). Historically, patient characteristics, such as psychiatric illness (including substance abuse), functional impairment, healthcare overutilization, multiple and persistent somatic complaints, unmet expectations, dissatisfaction with medical care and threatening and abrasive personalities were felt to be the sole causes of difficult encounters (Hahn et al., 1994; Hahn et al., 1996; Hinchey and Jackson, 2011; Jackson and Kroenke, 1999). However, with increased recognition of the importance of patient-centered care and communication as integral components of quality, the responsibility for difficult encounters has shifted away from the patient alone and towards a shared, dyadic approach (Blackall and Green, 2012; Fiester, 2012). Both patient and physician characteristics, as well as environmental and situational factors, have been found to play major roles in the evolution of a difficult encounter or difficult physician-patient relationship. Although less well studied, physician characteristics associated with difficult encounters include younger age, female gender, less clinical experience, higher professional burnout and stress rates, and physician job dissatisfaction (An et al., 2009; Crutcher and Bass, 1980; Hinchey and Jackson, 2011; Krebs et al., 2006). Because the clinical encounter is a dynamic process, underlying patient and physician characteristics and behaviors can have a direct effect on verbal and non-verbal communication styles and can promote or alleviate interpersonal difficulty.

Managing Difficult Encounters

Once a difficult situation has been identified and significantly disrupted the provider-patient relationship, the physician or other team leader should call a short multidisciplinary meeting to discuss the situation. Eliciting staff feedback as to why and how this difficult encounter evolved is important in understanding the potential causes and triggers leading up to the conflict. It also gives the team leader the chance to reset potential staff biases and judgments regarding the patient or family. Labels, such as *difficult*, *hateful*, or *crazy*, tend to follow patients and family members throughout the medical care process and negatively affect the way they are approached and treated (Lin et al., 1991).

In order to ensure frequent and consistent communication with the family, a *point person* or *primary communicator* (usually the attending physician or team leader) should be identified. Although all team members should be encouraged to interact frequently and to communicate with the family, the point person is responsible for eliciting patient concerns and needs, helping

negotiate medical and service expectations and goals and actively pursuing and following up on all management and treatment plans. Mixed messages can be avoided by filtering all major communications through the point person. By reinforcing and modeling professional behavior and avoidance of labeling, the team leader promotes high quality and safe, patient-centered care.

Setting the scene

Prior to engaging the patient and family, the physician (or other healthcare provider) should mentally, emotionally, and physically prepare for a potentially stressful and emotionally-charged encounter. Preparation typically involves both external and internal factors. External preparation usually involves a thorough review of the patient's medical record, including previous clinical data, laboratory data, imaging studies, sub-specialty recommendations and events leading up to the difficult encounter. Being knowledgeable about the patient's previous and upcoming evaluation and treatment plan allows the physician to have a more meaningful conversation with the patient and parents when discussing the causes of discontent and potential solutions. Internal preparation, or mindfulness, involves assessing one's own thoughts and emotions surrounding the difficult encounter (Koekkoek et al., 2011). By preemptively acknowledging one's own personal biases and prejudices, the physician may be able to recognize and suppress potentially negative emotions in response to certain patient personalities, expectations or symptom profiles which may hinder the physician's ability to empathically or effectively communicate with the patient and family (Smith et al., 1999). Taking a few moments to collect one's thoughts and emotions is an effective technique to help de-escalate a natural, human response to a stressful situation (Beckman et al., 2012; Novak et al., 1997).

To ensure family privacy, the de-escalation and management of all difficult situations should occur in a quiet area or room, safe from extraneous distractions and interruptions. After silencing all pagers and phones and reminding staff of the need for privacy and limited interruptions, the physician should calmly approach and introduce him or herself to the patient and parents with a firm handshake and direct eye contact. Nonverbal gestures, such as sitting down, leaning forward and appearing relaxed and unrushed contribute to a meaningful and respectful interaction while reinforcing the physician's desire to find a collaborative, patient-centered solution to the difficult situation.

Conflict resolution

Many communication and conflict resolution techniques have been created to help physicians manage difficult and emotionally charged clinical encounters (Krasner et al., 2009; Pomm et al., 2004; Wasan et al., 2005). While highlighting the importance of empathic, patient-centered communication, most of these strategies focus on rebuilding and strengthening the physician-patient relationship. Communication skills, such as reflective listening, empathic validation, flexible negotiation and closure with planned follow-through will help defuse difficult encounters and help prevent future conflicts, as well (Laird-Fick et al., 2012; Lieberman and Stuart, 1999).

Reflective listening

During the de-escalation process, patients and family members should have the opportunity to privately communicate all of their emotions, frustrations, concerns and questions to the healthcare provider. This not only provides family members a chance to vent their feelings, but also highlights the way they perceived the events leading up to the difficult encounter. Because patients and family members can become highly emotional and labile during the venting process, it is important to remain open-minded and nonjudgmental while listening to their feelings and concerns. The provider should recognize his or her negative feelings and avoid voicing any

conflicting or argumentative remarks. This is difficult but necessary in order to maintain open lines of communication and ensure conflict resolution.

Reflective listening is a communication technique that attempts to reconstruct what the patient or parent is thinking and feeling and to relay this understanding back to him or her (Breuner and Moreno, 2011; Sykes and Javidnia, 2013). By actively listening and observing the individual's behavior and body language, the physician should be able to identify the underlying feelings that may be driving the cognitive and emotional response. Rather than simply paraphrasing, the physician should reflect back his or her understanding of the person's thoughts and emotions through facilitative responses such as: "Sounds like what you're telling me is..." "Seems like what is bothering you is..." or "Let's see if I have this right." Equally important, the use of nonverbal cues and behaviors, such as direct eye contact, pleasant and approachable facial expressions and posture, appropriately-timed nodding and eye-level positioning, allows the patient and family to see and feel that they have been heard, understood and respected (Coulehan et al., 2001). A physician's ability to listen reflectively during a difficult encounter can be challenging, particularly if strong emotions are involved, but it is a powerful tool for effective communication during all medical encounters.

Validation

Empathy and validation are equally important communication skills that are essential for developing mutual respect and trust. Similar to reflective listening, empathic validation acknowledges a patient's or parent's emotions or experiences, while also giving him or her the feeling of not being alone (Cannarella et al., 2013; Johnson et al., 2008). Although the physician may disagree with the patient's or parent's perspective or emotional response, the art of validation requires that the physician try to understand and appreciate the patient's or parent's emotions. (See Chapter 1, *General Principles of Communicating with Pediatric Patients and Family Members*, section, *Empathy*). Experiencing the same or similar experiences is not necessary to offer empathic validation, but being able to conjure up a feeling in another situation that has similar elements is important. For example, if a demanding and verbally aggressive parent discloses that his or her anger and frustration stem from past medical experiences involving the death of a child, most providers would be more empathetic and more understanding of those feelings. Although the physician may not have experienced the death of a child or loved one, he or she may be able to recall a situation and emotional response that allows him or her to connect with the emotion being described. Most feelings, including seemingly irrational ones, are logical, and are typically the result of current circumstances and past experiences. By verbalizing a willingness to acknowledge, understand and validate a patient's and family's points of view, the underlying source of those feelings may be disclosed and explored, and a more mutually respectful relationship strengthened.

An empathic and focused apology during the validation phase may also be valuable in regaining the family's trust and confidence. Rather than disclosing an admission of guilt or taking sole responsibility for the conflict, an apology can convey a desire to provide emotional support and an acknowledgement that the provider, healthcare team or organization regrets that the patient or parents have been distressed and that the provider, team or organization will learn from the difficult encounter (Haas et al., 2005; Petronio, 2013; Saitta and Hodge, 2012; Wilson and McCaffrey, 2005). When the clinician expresses regret and accountability for the events leading up to the difficult situation and resists blaming others or the system, patients and family members will likely feel a sense of satisfaction or closure (Hass et al., 2005).

Negotiation and closure

Once the family's perspective and feelings have been sought and understood, active problem solving can be implemented. During this time, physicians, patients (when developmentally and situationally appropriate) and family members should negotiate, agree on and set realistic and achievable expectations, goals and time frames. Many physicians believe that their medical management will be compromised in trying to satisfy or appease the difficult patient or family. However, studies demonstrate that most patients, rather than desiring technical excellence or specific testing or treatment, actually seek more interpersonal communication (e.g., more warmth and friendliness and a greater show of concern), a feeling of being heard and respected and an explanation of their diseases and their etiologies (Bertakis, 1977; Francis et al., 1969; Korsch et al., 1968). Often, the negotiation process is centered on communication rather than on medical management issues, which highlights the importance of patient-centered communication in creating a therapeutic and respectful relationship (Mangione-Smith et al., 1999). By framing the negotiation around mutual interests and keeping the discussion results oriented, the physician and family can engage in a respectful discussion that ultimately leads to solutions and plans with which both the physician and family are comfortable.

If common ground cannot be found or the patient or parents remain dissatisfied after multiple communications and service recovery attempts, then a mediator, such as a patient or family advocate, ethics consultant or risk management officer should be considered. An uninvolved, unbiased third party may be able to help mediate current and future conflicts, particularly those that are fraught with negative feelings of anger, frustration, anxiety or guilt.

Follow-up

Because unmet promises and repeated infringements may destroy the tenuous, hard-earned and newly regained trust and respect of the patient and family, the physician should take immediate action to ensure timely adherence to and completion of negotiated commitments. Anticipating both medical and non-medical (e.g., comfort items, nourishment or baby supplies) needs during the remainder of the visit or hospitalization will help recover current service failures and help prevent future conflicts. Additionally, following up with the family through scheduled inpatient or outpatient visits or phone calls will send the message that the individual provider or team truly cares about the family's satisfaction and well-being.

Physician self-care

Physicians should practice effective self-management, which includes acknowledging and accepting their own emotional responses to patients and attempting to ensure personal well-being. Because physicians who repeatedly experience encounters with difficult patients or families tend to feel less job satisfaction and more professional burnout, they should consider and seek support from a colleague, friend, support group or psychotherapist.

Additionally, eliciting feedback from colleagues and patients may be helpful in identifying and improving interpersonal communication skills, particularly if the physician is frequently involved in difficult situations and conflicts (Makoul et al., 2007). Although the Accreditation Council for Graduate Medical Education (ACGME) (2013) identifies interpersonal communication as a core competency (now referred to as milestones), most trainees learn how to communicate with patients and family members through mentored relationships or modeled behavior rather than through standardized, formal training. Identifying, improving upon and practicing empathic and other effective communication skills will not only strengthen the physician-patient relationship, improve medical outcomes, increase patient satisfaction and prevent future difficult encounters

but can also enhance job satisfaction, decrease stress and burnout and reduce medical malpractice and litigation (Boudreaux et al., 2004; Francis et al., 1969; Stelfox et al., 2005; Toma et al., 2009).

Scenarios

In order to summarize some key points when confronting a difficult situation, three scenarios are discussed below:

Case 1

Mary is a 12-year-old girl with chronic, recurrent abdominal pain and vomiting. Although Mary has undergone an extensive, medical workup and been seen by numerous pediatric neurologists and gastroenterologists, an underlying diagnosis for her symptoms has not been found. Because Mary has been seen (and admitted) so frequently in the emergency center, the inpatient team is usually notified of her arrival and impending hospitalization as soon as she is placed in a room.

Mary was just discharged from the hospital 1 week ago. The work-up was unrevealing and there were no further recommendations from her subspecialists. Mary is now readmitted, and her father, a high-profile, medical malpractice lawyer, continues to demand that further lab work and imaging be done to “figure out what’s going on.” When approached with the idea of a psychiatric or psychological evaluation, he aggressively reminds the medical team that he is a lawyer who “sues hospitals and doctors who don’t get it right.”

How would you approach and handle this case?

There are two main issues which make this case difficult: first, a patient with a chronic, undiagnosed illness who presents with recurrent symptoms that have been refractory to medical therapy; and second, a demanding parent with an underlying threat to sue. One obvious choice of action would be to placate the parent by ordering more tests and subspecialty consultations, but this decision typically leads to excessive medical spending, transfer of burden to another colleague and ongoing frustration and anger on the part of the parent. In this case, reflective listening and validation would be a more useful approach. By actively listening, understanding, empathizing, and validating the emotions and feelings driving Mary’s father and his constant demands, the physician can gain a fuller perspective and insight into Mary’s illness and the effects it probably has on her family and loved ones. Using statements such as “I can understand why you’re frustrated that we haven’t found a cause for Mary’s symptoms,” or, “I appreciate your advocating for your child, and we truly value you as an important member of our medical team,” or, “Like you, I want the best care for Mary, which is why I don’t think we need to repeat or order any more tests at this time.” will reassure the father that his thoughts and concerns are being heard and respected and that everyone is working collaboratively to help ease Mary’s symptoms and illness. Explain that your suggestion of a psychiatric consult does not mean that you think Mary’s symptoms are not real or that she has a psychiatric illness. Rather, such a consultation can shed light on how emotional issues may be impacting her illness and can help her deal with the stress of her illness. Offering frequent, brief outpatient visits will give the patient and parents a concrete time line for therapeutic interventions and clear evidence of support. Often, patients and family members like Mary’s father will require repeated validation of their frustration and anger, and it is important to remain empathic and persistent in validating their feelings without compromising your own principles in providing optimal medical care. If a therapeutic relationship cannot be re-established or threats of medical malpractice continue, soliciting the help of a third party such as patient advocacy and risk management can be helpful in negotiating current conflicts and future, medical decisions.

Case 2

Binita is an 18-month-old female with a history of leukemia who has been admitted to an academic, teaching hospital for fever and neutropenia. Because the parents do not want to “mess up her sleep schedule”, they expect all laboratory tests, radiographic studies and physician visits to be scheduled the same time every day and are refusing nighttime vital sign checks and non-antibiotic medication administration. Additionally, the parents refuse to have the child seen by “pretend doctors,” and expect that the attending physician will be available to them at any time of the day or night for any questions or concerns that may arise.

How would you approach and handle this case?

In managing this difficult situation, it is important for the physician to recognize that the parents are trying to exert some control over a situation that is mostly beyond their control (i.e., the child's illness and treatment). Recognizing that the parents' demands may be their way of maintaining self-integrity and control during a devastating illness will help the physician set limits on expectations and negotiate alternative solutions that both the family and medical team can agree upon and maintain. Although routine monitoring of vital signs, scheduling of laboratory and radiographic studies and timing of medications may be adjusted and planned according to the patient's sleep schedule, preventing fellows and residents from examining, evaluating and treating the child and the insistence that the attending physician be available 24/7 need to be discussed and negotiated. Focusing on and prioritizing the patient's health and safety will allow the physician and medical team to collaborate and revise expectations and care processes while maintaining a trusting and respectful relationship.

Case 3

After four hours of waiting, a young father and his two, active children are placed in a back room of the emergency center. Soon after they are placed in the room, the bedside nurse rushes up and tells the physician, “The dad in room 21 is really, really angry and is screaming and cursing at the children and staff members.” From the hallway, the father can be seen pacing and yelling while both children are screaming and crying in the room.

How would you approach and handle this case?

Assessing and understanding the cause and level of violence is very important for managing the angry and aggressive patient or family member. However, the amount of time available for de-escalation is often limited by the patient's or parent's current level of anger and the rapidity with which that level is rising (Kynes et al., 2013). If a patient's or family member's anger is escalating and he or she seems about to commit violence (but has not yet done so), an immediate verbal intervention designed to calm that individual should be implemented (Bell et al., 2000). After notifying security of the situation, an accompanied healthcare provider should enter the room calmly, introduce him or herself and sit down in a location that will not compromise his or her safe withdrawal if necessary (i.e., between the father and the door). Time and safety permitting, communication techniques, such as reflective listening, empathy and validation, will help to identify the underlying emotions driving the father's anger and potential violence. By negotiating and following up with the father, the conflict can be diffused and the patient medically evaluated and treated without further dispute. If, however, violent behavior is occurring or seems imminent, or if the father threatens the life of himself, staff members or other family members, security should be immediately called to the scene, and a systems-wide process implemented to protect all those involved in the conflict.

Conclusion

Healthcare providers, patients and family members are all adversely affected by difficult encounters. Through effective and empathic communication, most conflicts between the healthcare provider and a difficult patient or parent (defined as an individual who does not assume the *patient role* expected by the healthcare professional) can be resolved. The use of mindfulness, reflective listening, empathic validation, flexible negotiation, problem solving and frequent follow-ups are techniques which not only enhance interpersonal communication but also help prevent future conflicts.

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Chapter 32

Working with Children or Parents Who Refuse Treatment

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Background and Introduction

In the United States, parents have the authority to make decisions regarding their children's healthcare and treatment. As a result, parents may refuse treatment or preventive care for their children unless their refusal places the child at substantial risk of serious harm (Diekema, 2005). Appelbaum and Roth (1983) define treatment refusal as the "overt rejection by the patient, or his or her representative, of medication, surgery, investigative procedures or other components of hospital care recommended or ordered by the patient's physician." This definition can be expanded to include the refusal of treatment or preventive care in the outpatient setting. Healthcare providers must determine whether the parent understands the implications of such a decision and continue to provide medical care while focusing on the welfare of the patient (Diekema, 2005).

Parents who refuse medical treatment may do so for a variety of reasons. This chapter will discuss the reasons for parental refusal of treatment with a special emphasis on parental refusal to immunize. We will offer suggestions for working with parents who refuse treatment for their ill children as well as parents who refuse to allow their children to be immunized.

Reasons for Refusal of Treatment

Reasons for parents refusing treatment are broad and complex and include religious and cultural beliefs, lack of accurate medical information and poor provider-parent communication (Linnard-Palmer and Kools, 2004).

Refusal of Treatment for Religious Reasons

There are many churches in the U.S. whose doctrines promote prayer and other spiritual acts over conventional medical care. The two religious groups that consistently avoid conventional medicine are the Church of Christ, Scientist (aka Christian Scientists) and Jehovah's Witnesses (Grabenstein, 2013).

The First Church of Christ, Scientist, was founded in 1879 by Mary Baker Eddy. Eddy taught that disease is a manifestation of an underlying spiritual condition that needs healing which can be brought about through prayer and other spiritual means that are incompatible with conventional medical treatment (Grabenstein, 2013). While Christian Scientists typically refuse all medical assistance, they allow certain exceptions including dentistry and other basic medical procedures such as childbirth assistance and the setting of bones. Christian Scientists utilize practitioners who are not medically trained but rather assist believers in focused prayer and spiritual treatment (Talbot, 1983).

The Jehovah's Witnesses is a denomination within Christianity. This religious group was founded in the late 1870s and is organized through the Watch Tower Bible and Tract Society. Jehovah's Witnesses accept medical and surgical treatment and only refuse certain medical treatments, specifically transfusions of blood and its major fractions. This doctrine has evolved

so that today's Witnesses are taught that the use of certain blood components such as albumin, immune globulins and hemophiliac preparations are not expressly forbidden and should be a matter of personal choice (Dixon and Smalley, 1981).

Other Christian churches whose followers may refuse medical treatment in lieu of prayer include Followers of Christ, End Time Ministries, The Source, Faith Tabernacle, the Pentecostal Church, Evangelistic Healers, and the Church of the First Born (Linnard-Palmer and Kools, 2004).

Other religious groups may also refuse certain medical treatments due to dietary restrictions. For example, Hindus may refuse products that are beef-based and Muslims may refuse medicines that are perceived as addictive or that contain alcohol (Linnard-Palmer and Kools, 2004).

Refusal of Treatment Due to Non-Religious Reasons

A common reason for treatment refusal is poor parent-provider communication. Parents often make medical decisions for their children based on their own previous experiences. Negative experiences can tremendously impact parents' trust in the medical community and create undue fears. When these experiences are coupled with a lack of understanding of the recommended treatment, parents are very likely to refuse care (Kon, 2006).

Parents may refuse treatment for therapies they view as harmful and when they perceive that the potential adverse effects outweigh the potential benefits. For example, there are several documented cases of parents refusing cancer treatment due to concerns about the adverse effects of chemotherapy (Hord et al., 2006). Parents also may perceive conventional treatments as ineffective, or they may prefer to utilize a more holistic approach to care provided by complementary and alternative medical (CAM) practitioners. Loman (2003) found that 33% of parents reported utilizing CAM providers for their child, while Kemper et al. (2008) reported that 20% to 40% of healthy children and 50% of chronically ill children utilized a CAM provider in addition to a traditional healthcare provider. Furthermore, McCurdy et al. (2003) found that 47% of pediatric oncology patients reported use of CAM treatment following the cancer diagnosis. Parents who seek CAM care for their children do so for numerous reasons, including advice from family and friends, dissatisfaction with conventional medicine, fear of side effects from conventional therapies, lack of perceived effectiveness following conventional treatment, high treatment costs and the desire for more time and attention from their provider (Spigelblatt et al., 1994). Alternative medicine may appeal to patients or parents who desire more control over their medical care and who believe that a holistic, unconventional approach is more consistent with their worldview and values. Patients who reported previous unsatisfactory experiences with traditional healthcare providers as well as increased distrust of conventional medical systems were more likely to utilize CAM providers as their primary form of medical care (Astin, 1998).

Refusal of Immunizations

The development and initiation of childhood vaccines has significantly decreased the incidence of vaccine-preventable diseases in the U.S. Alarming increases in parental hesitation and refusal of vaccines potentially threaten these advances (Salmon et al., 2005). Pediatricians are now commonly faced with the challenge of interacting with parents who refuse vaccines for their children.

Approximately 26% of parents report delaying one or more vaccines, while 8% report refusing one or more vaccines and nearly 6% report both delaying and refusing a vaccine (Smith et al., 2011). Rates of vaccine refusal are measured through rates of nonmedical exemptions to school-required immunizations. Such rates have continually increased during the last two decades (Salmon et al., 2005). As of 2013, approximately 2% of children in the U.S. were exempt from school-required immunizations (Centers for Disease Control and Prevention, 2013). A study of

pediatricians found that 85% reported encountering a parent who refused at least one vaccine and 54% reported encountering a parent who refused all vaccines (Flanagan-Klygis et al., 2005). Parents who refuse vaccines for their children are more likely to be non-Hispanic white and older than parents who do not refuse vaccines. They also have higher average household incomes and higher education levels than parents who do not refuse vaccines (Gust et al., 2008; Smith et al., 2004). Unvaccinated children are more likely to have a mother who is at least 30 years of age or older and live in a household with at least four or more children (Gust et al., 2008; Smith et al., 2004). Parents of unvaccinated children are less likely to trust the information they receive from medical and public health authorities. They are more likely to have higher levels of trust in CAM professionals, have higher rates of utilization of CAM providers and are more likely to report that their child's primary care provider is a CAM professional (Salmon et al., 2005).

Parental reasons for immunization refusal include religious beliefs, concerns regarding injection pain and erroneous fears of vaccine safety, such as the belief that vaccines cause autism and other chronic medical conditions (Lyren and Leonard, 2006).

Implications of immunization refusal

It is well documented that children who are exempted from school-immunization requirements are at higher risk for contracting vaccine-preventable diseases. A study by Salmon et al. (1999) found that children with nonmedical exemptions were 35 times more likely to contract measles than children who were immunized. In addition, Feikin et al. (2000) found that children in Colorado with nonmedical exemptions were 22 times more likely to contract measles and nearly 6 times more likely to contract pertussis than children who were immunized. Moreover, immunization refusals have significant implications for outbreaks of vaccine-preventable diseases. A study by Atwell et al. (2013) found that a 2010 pertussis outbreak in California was, in part, due to increased rates of nonmedical vaccine exemptions.

Refusal of Immunizations Due to Religion

Religious concerns about vaccines date back to the days of Edward Jenner's smallpox vaccine in England. Many people believed that intentional exposure to disease was a violation of God's will and that vaccination was "un-Christian" because the vaccine came from an animal. In fact, in the U.S. in 1879 the Antivaccination Society was founded by several Boston clergymen and physicians (Hammond et al., 2013).

From the 1920's to the 1940's, the Watch Tower Society (responsible for leading Jehovah's Witnesses) prohibited immunization to the point of excommunication, however, this doctrine has evolved. The Society no longer prohibits immunization but rather has adopted a neutral stance on the issue. Today, refusal of immunizations due to religion is limited mainly to two groups: Christian Scientists and the Amish (Grabenstein, 2013).

Christian Scientists typically refuse all immunizations and the Church has a history of lobbying for religious exemptions to school-required vaccines. The Church's opposition to vaccines is consistent with their belief that disease is a result of a spiritual condition. Outbreaks of measles, diphtheria and polio have been reported among Christian Scientist communities after which some followers were more accepting of vaccines (Grabenstein, 2013).

The Amish are a denomination within Christianity. While Amish doctrine does not prohibit immunization, many Amish communities refuse vaccines. This is due to the social tradition of denying practices considered modern. Other reasons for refusal to immunize among the Amish include limited access to medical care, limited disease awareness and general vaccine concerns. Outbreaks of measles, pertussis, *Haemophilus influenzae* type b infection, polio, rubella, and

tetanus have all been reported in Amish communities, and believers are often more amenable to immunization during such outbreaks (Grabenstein, 2013).

While not directly related to a specific religious group, there are parents who refuse vaccines for ethical reasons related to the use of aborted cell lines, fetal tissue and blood and animal testing used during vaccine development and manufacturing (Salmon et al., 2005).

Refusal of Immunizations Due to Non-Religious Reasons

Parental refusal to immunize is often due to reasons other than religion, including fear of adverse reactions, concerns about safety and efficacy and disbelief of the risk and severity of vaccine-preventable disease. Moreover, many of these parents demonstrate a low level of trust in healthcare providers, public health authorities and the government (Wei et al., 2009; Smith et al., 2004).

Salmon et al. (2005) found that parents who refuse vaccines often do so because of: fear that the vaccines may cause harm; concern that vaccines will overload the child's immune system; or belief that healthcare providers give too many vaccines too soon. Salmon et al. (2005) also found that the more of these beliefs a parent held, the fewer vaccines the child received. Diekema (2005) reported that more than 20% of parents have significant concerns about vaccine safety and that these concerns have contributed to a decrease in the overall immunization rate among children.

The most common reason for parents refusing vaccines is concern about vaccine safety. In particular, many parents report concerns about the safety and necessity of the varicella and MMR vaccines. These parents do not perceive varicella, measles, mumps, or rubella as severe, nor do they perceive their children as being highly susceptible (Gust et al., 2008; Salmon et al., 2005).

Management

Healthcare providers play an important role in protecting vulnerable children from medical harm or neglect. Kamin (2012) says it is crucial that providers understand that a parent's greatest responsibility is to protect their child from harm. State laws and professional obligation require providers to report situations in which a child is at risk for serious harm (Orr et al., 2003).

Healthcare providers have a professional responsibility to provide care guided by the ethical principles of autonomy, beneficence and non-maleficence. Autonomy refers to a patient's right to determine the course of action most appropriate for him or her. Beneficence refers to the provider's responsibility to help others; non-maleficence refers to the provider's duty to do no harm. Parents and providers can work together under the guiding principle of beneficence by ensuring that the child's welfare is maintained (Fernbach, 2011).

The most important aspect of managing treatment refusal is achieving effective communication. Most parents have explicit reasons, often based on their past experiences, for refusing care. It is imperative that the provider listen carefully and respectfully to these concerns so as to understand why the parents have come to hold those beliefs and why they feel that they are acting in the child's best interest. After listening to the parents' concerns, the provider must consider the information received and come to his or her own understanding of the parents' perspective. Actively engaging the parents in open and bidirectional dialogue can avoid creating an antagonistic relationship and can increase the likelihood that the best result will be achieved for the patient. The assistance of a social worker or hospital chaplain can be invaluable in assisting with these critical conversations.

Methods to Improve Communications

The primary goal of communicating with parents who refuse treatment is to persuade them to

adopt the recommended treatment plan that the medical treatment team believes would be best for their child (Simpson et al., 2011).

Communication can be adversely affected by religious or cultural differences. Involving a healthcare provider from the family's cultural group may be beneficial (Jezewski, 1993). Utilizing a religious or cultural *broker* can also be of tremendous assistance (Orr et al., 2003). According to Jezewski (1993), cultural brokering is defined as "the act of bridging, linking or mediating between groups or persons of differing cultural backgrounds for the purpose of reducing conflict or producing change." While such a resource can be useful in educating the provider, it can be doubly useful by providing the parents with an objective perspective to the entire religious doctrine. For example, Catholics may cite a religious concern regarding the origin of certain vaccines such as varicella as they were derived from aborted fetal cell lines. However, the National Catholic Bioethics Center has stated that the individual and public health benefits outweigh the moral concerns about the origins of the vaccine (Hammond et al., 2013). In this example, a religious broker could provide this balanced perspective of the doctrine that allows the parents to comply with vaccination while remaining loyal to their overall religious beliefs (Orr et al., 2003).

Healthcare providers have a moral obligation to make medical recommendations that are in the best interests of the child, free from personal biases and beliefs. (See Chapter 6, *Ethical Considerations in Communicating with or about a Child*.) Providers should make every effort to use evidence-based recommendations when possible, but when safety and efficacy data do not exist, recommendations must be made on clinical judgment. While parents and providers usually share the common goals of ensuring patient safety, minimizing pain and harm and improving long-term health, parents may need reassurances that the provider also wants to avoid pain, suffering, and unnecessary medical interventions for their child.

After better understanding parental beliefs and re-directing the conversation to shared long-term goals, the provider is better able to pursue a successful management strategy. If possible, allow the parents time alone to process and discuss the information they received and develop a list of questions. The provider should make every effort to answer these questions as clearly and completely as possible, with the hope that once this is done the family will agree to the treatment recommendation of the medical team. The provider must remain flexible and be willing to negotiate a compromise which satisfies the parents while still meeting the child's medical needs (Simpson et al., 2011).

When Communication Fails

When parents refuse potentially life-saving treatment for their child and multiple efforts at communication have failed, a consultation by an ethics team (if available) is warranted. Most often the ethics team will help resolve communication issues and help find a reasonable solution that satisfies both the parents and the healthcare team and ultimately will be in the best interest of the child (Kon, 2006). While providers must respect the principle of parental and patient autonomy, the same principle of autonomy applies to healthcare providers. Kamin (2012) states that physicians should not be forced to provide care they think is wrong.

When the hospital ethics team is unable to resolve treatment issues, the provider and ethics team should contact the hospital's risk management department, which may request external judicial review. In these instances the court may appoint temporary custody of the child to a state governmental agency or local authority. Providers are advised against physically removing or detaining parents but are encouraged to contact law enforcement (Diekema et al., 2012). Of course, this is a last resort, when all efforts to reach a reasonable solution have failed. In the rare

instance where there may be an immediate threat to life, the medical team may provide care without judicial review. However, this should be done only when time taken for judicial review would result in death of the patient. As these actions may fall under legal scrutiny, the medical team should work closely with the risk management department to determine the best course of action (Kon, 2006). Historically, in life-threatening situations, the judicial system has ruled in favor of treatment over religious objections. The U.S. Supreme Court famously ruled in 1944 that “parents may be free to become martyrs themselves. But it does not follow they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion when they can make that choice for themselves.” (Antommaria and Weise, 2013)

Managing Patient and Parent Choices

When critical medical decision making involves a preadolescent or adolescent, it is possible that the child’s and parents’ wishes may conflict. Weir and Peters (1997) suggest that fourteen years is the age at which adolescents generally are competent to make their own healthcare decisions. The provider has three options in these instances. One option is to persuade the parents to respect and accept the child’s preferred treatment plan (Turkoski, 2005). A second option is for the child to seek an emancipated minor status which would allow the child to make his or her own medical decisions. A third option is to accept the decisions of the parents as they are the legal guardian for the child. If the parents’ and the patient’s wishes conflict, the provider must negotiate these complex options using the communication strategies previously discussed. The assistance of social workers, counselors and religious or cultural brokers may be helpful (Turkoski, 2005).

Managing Parents Who Refuse Immunizations

As the number of parents with vaccine-related concerns increases, providers are faced with the question of how to provide care to these children. Refusal to immunize is an ethically complex issue. Whereas refusal to accept treatment generally has consequences solely for the patient, refusal to immunize has potential consequences for the community.

Providers across the nation hold divergent views on how to manage vaccine refusal. Leib et al. (2011) found that more than 30% of physicians participating in their study asked families to leave their practices based on the parents’ refusal to have their children vaccinated. Proponents of dismissing patients whose parents refuse vaccines liken this refusal to a type of neglect. Physicians also may view parental refusal as an attempt to undermine the physician-patient relationship. Conversely, those who oppose dismissal argue that all pediatric patients deserve quality care (Lieb et al., 2011). When providers choose to continue a relationship with the family despite vaccination refusal, the patient may benefit from the opportunity to discuss vaccines in future appointments (Diekema et al., 2012).

Healthcare providers must partner with parents to ensure that the focus of vaccine related conversations is the well being of the child (Fernbach, 2011). When interacting with a parent who has vaccine concerns, it is important for the healthcare provider to listen and respect these concerns. When asked, parents will commonly cite concerns about side effects, risks, and the erroneous belief that vaccines contribute to the development of autism and other developmental disabilities (Lyren and Leonard, 2006). Discussion of the risks of vaccines is encouraged, and educational plans should be based on the unique needs of the parent and family. Healthcare providers may choose to utilize printed teaching tools, pamphlets, media sites, and other tools to illustrate the benefits and risks of immunizations (Leask et al., 2012). Although time consuming, it is imperative that the healthcare provider speak with the family to determine specific concerns

and to provide education to dispel myths and misinformation regarding vaccines. To this end, it is critical that providers remain up to date on immunization recommendations and issues surrounding vaccine safety so as to mitigate parental concerns and respond appropriately to questions (Schwartz and Caplan, 2011). Despite attempts at educating parents regarding vaccines and healthcare recommendations, families retain the legal right to decline or refuse treatment. When refusal occurs, healthcare providers should continue to discuss vaccines at future patient visits (Diekema, 2005).

Jacobsen et al. (2013) have suggested an approach for organizing these conversations with parents. Their approach utilizes the CASE acronym, which represents the following components: **C**orroborate, **A**bout me, **S**cience, **E**xplain and advise. After hearing the source of the parents' vaccine concerns, Jacobsen et al. (2013) suggest that the provider begin by offering a corroborative statement that acknowledges the source of the concerns without validating them. Following a corroborative statement, the provider introduces him or herself as a content expert, explaining that he or she has studied the question at hand and is able to provide evidence-based information. The provider should then bridge into discussing the scientific evidence related to the parent's medical concern. This conversation should culminate in the provider providing an evidence-based recommendation. For example, a parent may state his or her belief that the flu vaccine causes the flu. The provider may offer the following statements:

Corroborate: "Many of my patients tell me that they think the flu shot causes the flu."

About me: "I have studied CDC materials regarding the safety of the flu vaccine. I have also attended continuing medical education conferences regarding the influenza vaccine."

Science: "The flu vaccine cannot cause the flu. The flu shot contains only a very small piece of the dead virus that cannot cause an infection."

Explain and advise: "It's important for your child to get a flu vaccine today."

Poor communication may lead to refusal of vaccines and complaints regarding quality of care. Providers may believe that refusal stems from ignorance, but this should not dissuade them from discussing vaccine concerns with the parents, so as to gain an understanding of their concerns. (Leask et al., 2012).

Liability Concerns

Liability remains a concern for healthcare providers. Healthcare providers should maintain careful documentation of discussions with the family regarding healthcare options and risks associated with declination of vaccines. Providers may require that families sign a waiver if they decline vaccines (Diekema, 2005). Documenting parental refusal to immunize provides the added benefit of ensuring that the parents understand the implications of their decision (Schwartz and Caplan, 2011). The American Academy of Pediatrics refusal to vaccinate form (2013) is available on the Internet.

Dismissal

Increasing numbers of providers are choosing to terminate care when a parent refuses immunizations. Providers who choose to dismiss such patients often do so for many reasons including the desire to communicate to parents the significance of their decision and to reduce the number of unvaccinated children in their waiting rooms, which could pose a risk to other patients (Schwartz and Caplan, 2011). It is important to note that the American Academy of Pediatrics, American Medical Association, and the Centers for Disease Control and Prevention discourage providers from dismissing patients whose parents refuse to immunize (American Medical Association, 2007; Atkinson et al., 2012; Diekema, 2005). Evidence continues to

demonstrate that healthcare providers serve as the greatest influence over parents. Parents who change their minds after refusing a vaccine often report doing so because of conversations with the provider (Gust et al., 2008). Dismissing families who refuse vaccines prevents future opportunities for immunization education and poses a risk to the child for disrupted pediatric care. Moreover, these parents may turn to CAM providers who are more likely to promote vaccine refusal (Diekema, 2013).

Legal and ethical guidelines allow healthcare providers to withdraw from a provider-patient relationship so long as the withdrawal is done properly. If a healthcare provider chooses to terminate a physician-patient relationship, he or she must provide the family with ample time to select another provider for the child (Diekema, 2005).

Conclusion

Working with parents who refuse treatment or preventive care, including immunizations, for their children can be difficult. Reasons for parental refusal are complex and include fear, misinformation, poor parent-provider communication and religious or cultural beliefs. Healthcare providers continue to be an important source of information and must make every effort to negotiate with the parents while focusing on the health of the child.

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