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## **Communicating With Children and Families: From Everyday Interactions to Skill in Conveying Distressing Information**

Marcia Levetown and the Committee on Bioethics

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## TECHNICAL REPORT

# Communicating With Children and Families: From Everyday Interactions to Skill in Conveying Distressing Information

Marcia Levettown, MD, and the Committee on Bioethics

## ABSTRACT

Health care communication is a skill that is critical to safe and effective medical practice; it can and must be taught. Communication skill influences patient disclosure, treatment adherence and outcome, adaptation to illness, and bereavement. This article provides a review of the evidence regarding clinical communication in the pediatric setting, covering the spectrum from outpatient primary care consultation to death notification, and provides practical suggestions to improve communication with patients and families, enabling more effective, efficient, and empathic pediatric health care.

## INTRODUCTION/OVERVIEW

Health care communication is a critical, but generally neglected, component of pediatric and pediatric subspecialty practice and training and is a skill that can and must be taught.<sup>1-13</sup> The practicing clinician's ability to communicate openly and with compassion is essential for effective and efficient routine health care; this ability becomes a vital lifeline for parents and children confronted with life-altering and sometimes life-ending conditions.<sup>13-16</sup> The purpose of this report is to provide research-based and practical guidance to enable effective communication with pediatric patients and their families in a number of common settings and situations. Although child abuse, sexuality, divorce, and many other situations are not individually addressed, the principles and approaches discussed apply equally to these situations.

Communication is the most common "procedure" in medicine. Health care communication is different from normal social discourse, because intimate and very private issues are often discussed. These include hopes and fears, developmental concerns, sexuality, and mental health disorders. Painful issues, such as abuse, school failure, drug use, and terminal illness, are also discussed. Communication is the foundation of the therapeutic relationship; it is the basis of fiduciary and ethical obligations of physicians to patients and their families. Effective health care communication is an essential tool for accurate diagnosis<sup>17-19</sup> and for the development of a successful treatment plan,<sup>20-23</sup> correlating with improved patient knowledge,<sup>15,24</sup> functional status,<sup>25,26</sup> adherence to the agreed-on treatment regimen,<sup>20,21,27-32</sup> improved psychological and behavioral outcomes,<sup>15,33-36</sup> and even reduced surgical morbidity.<sup>3,4,37</sup> In the case of distressing news, skillful communication can enable a family to adapt better to a challenging situation,<sup>12,38,39</sup> including a child's unanticipated impairments.<sup>40-43</sup> Poor communication, on the other hand, can prompt lifelong anger<sup>31,42,44-48</sup> and regret,<sup>14,40</sup> can result in compromised outcomes for the patient and family, and can have medicolegal consequences for the practitioner.<sup>49</sup>

## WHAT IS COMMUNICATION?

Effective communication is responsive to the needs of the whole patient and family dynamic; it is essential to patient-centered and family centered care, the basic building block of the medical home concept ([www.medicalhomeinfo.org](http://www.medicalhomeinfo.org)) endorsed by the American Academy of Pediatrics (AAP) as a cornerstone of care.<sup>50</sup>

Taking time to build rapport and understand the child and family builds trust, leading to increased reporting of the actual reason for the visit.<sup>51,52</sup> Clearly, improved communication will enhance patient outcomes and satisfaction.<sup>4</sup> There are 3 elements of physician-parent-child communication<sup>53</sup>:

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The guidance in this report does not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

### Key Words

patient-doctor communication, medical education, patient-centered and family centered care, medical home, health care outcomes, breaking bad news, death notification, assent, empathy, treatment adherence

### Abbreviations

AAP—American Academy of Pediatrics  
AACH—American Academy on Communication in Healthcare  
ED—emergency department

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- Informativeness: quantity and quality of health information provided by the physician;
- Interpersonal sensitivity: affective behaviors that reflect the doctor's attention to, and interest in, the parents' and child's feelings and concerns; and
- Partnership building: the extent to which the physician invites the parents (and child) to state their concerns, perspectives, and suggestions during the consultation.

There are 2 types of patient needs to be addressed during the medical interview: cognitive (serving the need to know and understand) and affective (serving the emotional need to feel known and understood). Thus, physicians are expected to have task-related behavior and relational behavior. The first involves asking questions and providing information. The latter includes reflecting feelings and showing respect, concern, and compassion, often by nonverbal means, such as gestures, posture, and eye contact, as well as the use of silence to allow for the processing of emotional responses and the formulation of questions. (An example of a reflective response is, "When you say you don't think you can manage this, what is the hardest thing about Chad's illness for you and your family?") Parent satisfaction with quality of care is substantially influenced by the interpersonal skills of the practitioner, particularly in the case of anxious parents.<sup>53,54</sup>

### MEDICAL EDUCATION AND COMMUNICATION

Despite the essential nature of communication in health care, there is little programmatic or curricular emphasis on building interpersonal skills in pediatric service or training. Instead, a preponderance of time is spent on facts and procedures, with minimal attention to feelings, relationships, and continuity of care.<sup>12,34,47,54-60</sup> The AAP, in its policy statement "The New Morbidity Revisited: A Renewed Commitment to the Psychosocial Aspects of Pediatric Care," states that "there is a need to better learn how to elicit information, including using a narrative interview approach, allowing the child, adolescent, and parents to tell their stories," and "there is a need to communicate empathy."<sup>3</sup> The AAP suggests that the teaching of these skills involves supervised practice, feedback, and mentoring.

There is a long history of concern among holistic medical educators and philosophers regarding the loss of empathy related to current medical education methods and role models.<sup>61-66</sup> This concern has led to attempts to measure empathy and to reinforce it during medical education.<sup>67-69</sup> It has been demonstrated in preliminary studies that empathy not only can be extinguished by training but also can be amplified and taught. Empathy affects quality of care and patient satisfaction; physicians who are empathetic have been shown to elicit patient concerns more accurately and address needs more effectively, often enhancing cost efficiency.<sup>70-76</sup>

Unfortunately, studies over the last 15 years do not indicate a trend toward improvement in this area. Despite requirements and recommendations of the

American Council for Graduate Medical Education,<sup>77</sup> the Future of Pediatric Education II Task Force,<sup>2</sup> and the long-standing dedication to the child, family, and psychosocial environment by the AAP as manifested in numerous policies and published goals,<sup>3,4,50,78-84</sup> the "informal" or "hidden curriculum" (that which is taught by observing the daily behavior of health care professionals, both good and bad)<sup>85</sup> continues to disproportionately reward "hard" data collection while downplaying the role of the psychosocial, existential, and interpersonal concerns and needs of the patient and family. Such a training emphasis does not enhance the ability of the physician to fully meet the needs of our patients and their families.<sup>86</sup>

### The Current Situation

Health care communication is currently learned primarily through trial and error.<sup>1</sup> This may be attributable, in part, to a dearth of skilled mentors. A large national survey published in 2003 indicates that medical school faculty members may, themselves, need communication skills training.<sup>87</sup> Nonphysician mentors who are trained communicators, such as child life therapists,<sup>88</sup> child psychologists (as an example, see Sourkes<sup>89</sup>), and members of the American Academy on Communication in Health Care (AACH [[www.aachonline.org](http://www.aachonline.org)]), can help practicing physicians and medical school faculty develop these skills.<sup>55</sup> In the inpatient setting, social workers, advanced practice nurses, psychologists, and chaplains can assist in the provision and modeling of effective communication with children and their families,<sup>90-93</sup> but the practice of depending on numerous caregivers to communicate poses a risk of families being exposed to conflicting information and opinions, often provoking anxiety and confusion. True interdisciplinary teamwork and collaboration can prevent this complication.<sup>43</sup> Regardless of the help available, however, the physician must always play a significant role in the communication process.

### Communication Needs

Patients and families expect more accessible information than is commonly provided in virtually every health care setting.<sup>12,31,58,94-98</sup> It is estimated that 35% to 70% of medicolegal actions result from poor delivery of information, failure to understand patient and family perspectives, failure to solicit and incorporate patients' values into the plan of care, and perceptions of desertion.<sup>49,99-104</sup>

Psychosocial and practical/family issues are often overlooked.<sup>52</sup> Closed interviewing techniques, such as asking yes or no questions, may be used by clinicians to control the duration of the interview. Families perceive this style as indicative of a lack of interpersonal interest, sometimes resulting in a reluctance to reveal the true reason for seeking consultation; potential results are treatment failure and poor health outcomes.<sup>56,105-107</sup> Invitations by physicians to the child and family to contribute and to express concerns are nearly always welcomed by parents and do not increase the duration, but do increase the utility, of the encounter.<sup>49,108</sup> Formal

**TABLE 1 Physician "Competencies" for Health Care Communication**

1.	Develop a partnership with the patient
2.	Establish or review the patient's preferences for information
3.	Establish or review the patient's preferences for his or her role in decision making
4.	Ascertain and respond to the patient's ideas, concerns, and expectations
5.	Identify choices (including those suggested by the patient) and evaluate research in relation to the individual patient
6.	Present information and assist the patient to reflect on the impact of alternate decisions with regard to his or her lifestyle and values
7.	Negotiate a decision with the patient
8.	Agree on an action plan and complete arrangements for follow-up

communication training is helpful in developing this skill.<sup>6,35,72,109–116</sup>

### Communication Competencies for Physicians

One group identified 8 physician "competencies" that enable "informed shared decision-making" to take place<sup>117</sup> (see Table 1). These competencies, behaviors, and protocols will also result in patient-centered and family-centered interviews, which are key elements in the construction of a medical home.

According to these investigators, such an interview can be accomplished in 10 minutes with adult patients. The triadic nature of pediatric patient interactions would, as always, require more time. The child's preferences and values should be solicited in addition to that of the parents. Sharing of information and responsibility for decision-making must be negotiated.

### Effective Methodologies for Teaching Communication Skills

High proportions of physicians at all levels of practice are willing to reveal their discomfort with communication, particularly involving unwelcome information that is likely to upset parents.<sup>118</sup> In response to residents' requests and parents' complaints, Northwestern University's pediatric residency program developed a communication course<sup>9</sup> designed according to the articulated needs of the learners. Provided during the middle of the first year of pediatric residency, training addressed "breaking bad news" and "difficult families." Scenarios were designed with input from the residents. Teaching tools included didactic sessions, interactive discussion, parent-panel discussions (including children who had survived life-threatening illness and bereaved parents), paired role play, and discussion. Although well received, the effect was difficult to evaluate because of the low number of participants.

Use of simulated patients, observation of role models, attendance at camps, support groups, and home visits are also useful in developing a patient-centered and family-centered perspective, resulting in more effective communication skills.

A teaching program for "breaking bad news" in the emergency department (ED) setting using simulated patients and video feedback demonstrated improvement in skills after 2 sessions on the basis of a checklist of desired behaviors, simulated patient feedback, and improved confidence of trainees.<sup>6</sup> A study of a 1-day workshop

using scenarios relevant to the PICU also demonstrated statistically significant improvements.<sup>10</sup> Simulated or "standardized patient" programs are, however, expensive.

Other investigators have found measurable success improving communication by using immediate video feedback alone.<sup>7</sup> One innovative program designed for undergraduate medical students used two 2-hour sessions in both inpatient and outpatient settings, interviews with parents, and play with child patients to enable students to better understand family perspectives about communication.<sup>113</sup> Progressive experiences included a small-group discussion about the difficulties of breaking bad news, a video role model followed by a parent panel, and finally, time to meet the child patient. The training was favorably received by student, parent, and patient participants. After the experience, some students reported a profound effect on their attention to the patient and his or her supporters; 18 months after the seminar, 1 student noted he still "keenly felt the influence of his eyes being opened to the myopic view of the medical fraternity" in health care communication.

Another communication workshop to teach pediatric residents how to tell parents about a child's lifelong disability was developed by a parent support group and a pediatrician.<sup>119</sup> In this workshop, the psychosocial dynamics of the interchange are defined/identified, and facilitative behaviors are described. The resident chooses a skill in which he or she feels most deficient and works specifically to improve it in a role-play exercise. The workshop concludes with a debriefing and a review of the interview tape with the parent.

There are several communication skills teaching aids available. The Initiative for Pediatric Palliative Care ([www.ipcweb.org](http://www.ipcweb.org)) has communication modules, including videotapes for difficult conversations. The AACH has 3- to 5-day intensive training sessions on communication, generally focused on adult patient scenarios, which include videotaped feedback, self-critique, and peer critique. In addition, the AACH provides Web-based, multimedia interactive modules on communication and relational topics ([www.aachonline.org](http://www.aachonline.org)). A list of tips, techniques, and resources can also be found in other publications.<sup>120,121</sup>

Unfortunately, efforts to elevate health care communication, empathy, patient-centered and family-centered care as core competencies within the educational process and professional practice have, thus far, failed. Despite the overwhelming evidence of the benefit to patients, physicians, and society, effective communication is not rewarded by academic promotion or financial compensation. In fact, increased attention to communication can be costly to the practitioner in the short term because of inadequate payment for time spent discussing treatment plans and otherwise counseling families. The willingness of students, mentors, and practitioners to exert the time and effort to learn and practice effective and compassionate communication is undoubtedly influenced by these factors. Long-term benefits, such as improved patient outcome and satisfaction, decreased

risk, and greater professional satisfaction, may be harder to quantify and appreciate.

### Practitioners' Needs

Practicing physicians' self-assessment of skill level in breaking bad news is often inaccurate and overly self-flattering.<sup>1,122</sup> Practice alone clearly does not result in improved communication skills. When self-assessed skill in this critical area is inadequate, some physicians avoid the discomfort by not engaging in difficult conversations. Less dramatically, given the widespread dissatisfaction with communication, it is clear that most practitioners would benefit from objective assessment of their current communication skills followed by targeted training, regardless of seniority.

### Need for Research on Communication Education and Practice

If communication skill training is to be recommended throughout medical training and for continuing education, it is important to understand what techniques are most efficacious, time-efficient, and cost-efficient to achieve the goal of more consistently achieving effective, empathetic, and culturally appropriate communication that meets the needs identified by patients and parents. What timing during the course of education is most likely to result in durable change? Which communication techniques best prevent the anger and dismay that too often lead to suboptimal patient outcomes or malpractice litigation? Finally, what changes in institutional culture or reimbursement mechanisms will reinforce good communication throughout the career of the practitioner? Research on these topics should be a priority, given the central importance of communication in medicine.

## CLINICAL PRACTICE ISSUES

### Communication With Parents: Ensuring Effective Communication

Factors predictive of effective communication between physicians and patients/parents are the perception of interest, caring, warmth, and responsiveness.<sup>123-125</sup> Parents' most frequent criticisms of health care practice concern relationships with practitioners<sup>53</sup>; these relationships have a dramatic effect on parental satisfaction, recall of instructions and, not surprisingly, treatment adherence.<sup>126,127</sup> Greater trust and a better relationship with the physician have more of an effect on patient recall and satisfaction than written instructions or even the amount of time spent.<sup>128</sup>

#### *Causes of Dissatisfaction*

Even with very detailed explanations, parents who feel they are not treated with respect or who have unrecognized or unaddressed fears feel unhappy about the amount of information provided. For instance, being asked to consent to a new aspect of a procedure while standing in the hall the night before surgery caught 1 parent by surprise, coloring her overall satisfaction and perception of the sufficiency of information.<sup>54</sup> Facilitators of improved communication include clear demon-

**TABLE 2 Recommended Communication Behaviors for Procedural Interventions**

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Find a private setting for discussion and decision making
Use language the family can understand
Use visual aids (drawings, models, and radiographs)
Pace the information, providing it in a logical sequence; be prepared to patiently repeat information and answer questions
Recognize emotional distress
Discuss indications, risks, benefits, and all reasonable alternatives (including not doing the procedure at all) and the associated risks and benefits
Discuss specific tubes and drains immediately before surgery
Personalize the information rather than giving it as a rote speech (eg, use the child's name)
Avoid last-minute surprises when feasible
Ask parents and the child (when appropriate) to repeat what they understood in their own words, and clarify information and plans as needed

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Data were adapted from Lashley et al.<sup>54</sup>

strations of empathy and respect. See Table 2 for additional recommendations.

#### *Audiotapes as Communication Aids*

Several articles support the use of audiotapes to allow parents to repeatedly listen to the information, allowing it to soak in, and importantly, enabling dissemination of accurate information to others who could not be present.<sup>129-135</sup> Parents frequently consult others in making health care decisions for their children, ranging from extended family members to other practitioners, other parents, religious leaders, and tribal elders. One study found that tapes made during outpatient encounters were listened to by parents nearly universally; grandparents listened to them more than half the time (52.8%), 70% were listened to more than once, and one third of parents made a copy to keep for themselves. The tapes were found to be helpful >99% of the time.<sup>129</sup> Physician fears of the use of such tapes in medicolegal actions are understandable but, thus far, unfounded. In fact, the tapes often reveal that much more information was shared than either party realized, suggesting that the tapes may even be protective.<sup>136</sup>

#### *What Parents Want to Know: Surgical Procedures and Chronic Conditions*

Patients undergoing surgery and their parents often want answers to seemingly "minor" questions.<sup>137</sup> The expected duration of the surgery, the amount of hair to be removed, the location and length of the incision and bandages, location and purpose of intravenous lines and other assorted tubes, and the child's likely appearance after the procedure are sources of concern that, although routine for practitioners, should be prospectively addressed.<sup>54</sup>

Parents consistently state that they need more and clearer information about their children's health status, particularly in the setting of chronic or terminal illness.<sup>50,94,138-142</sup> Parents of chronically ill children want more information about the child's condition, its treatment, and its long-term implications;<sup>94,142-144</sup> they want

that information to be shared with them as soon as it is known.<sup>42</sup>

Parents want advice about their child's behavior and development, genetic implications of the child's condition, and social contact with families in similar situations.<sup>39,142</sup> They would like someone, preferably the physician, to provide oversight of the long-term care plan, including an opportunity for advance care planning and execution of advance directives.<sup>143,145</sup> They want their views and concerns factored into the care plan and to be treated like partners (and often experts) in their child's care.<sup>5,53,54,94,137,142,143</sup> They need affirmation of their efforts and assistance with and recognition of the need to preserve family solidarity and support, including social support, child care, education, and professional services;<sup>94,140,143,146</sup> in some studies, parents report assistance with family and social support as their greatest unmet need.<sup>94,142,143</sup> One proposed solution is to have an annual meeting of the family and physician to discuss the "big picture."<sup>94</sup> In short, parents of chronically ill children want a "medical home" as envisioned by the AAP. When appropriate information is not provided and this style of communication and relationship does not occur, the bitterness can linger for years.<sup>12-14,32,41,42</sup> Physicians who are empathic, well informed, and honest are a source of strength for parents, particularly those struggling to adapt to a difficult situation.

### **Intraprofessional Communication**

Particularly for children living with chronic health conditions, communication between primary care practitioner and specialist is critical for effective and efficient care.<sup>50,147-152</sup> A recent study<sup>153</sup> indicates that pediatric practitioners agree about the importance of such communication but have difficulty putting it into practice. Specific recommendations include timely, systematic information transfer from generalist to specialist at the time of referral, after consultation, and during follow-up visits. A toolkit with practical recommendations and reimbursement strategies can be found at [www.medicalhomeinfo.org/tools/toolkits.html](http://www.medicalhomeinfo.org/tools/toolkits.html). In addition, recognition of the medical home concept and a plan for comanagement and communication should be in place.<sup>50,147,153</sup>

### **Telemedicine**

In the setting of rural health care and limited numbers of pediatric specialists, communication and medical care may be provided via video and audio conferencing. Even in the case of psychiatric illness<sup>154</sup> and chronic illness requiring multispecialty input,<sup>155,156</sup> parents and caregivers found this means of communication nearly as efficacious as in-person communication, particularly when combined with less frequent face-to-face consultations.<sup>155,156</sup> Another application of telemedicine is to provide frequent updates and secure communication for parents and extended families and other practitioners when a child is receiving care in the ICU.<sup>157</sup>

### **Communication With the Child Patient: Ethical, Relational, Developmental, and Cultural Considerations**

#### *Moral, Ethical, and Developmental Obligation to Include Children in Communication About Their Health*

There is a moral and ethical obligation to discuss health and illness with the child patient, which is supported by a number of United Kingdom,<sup>158,159</sup> Canadian,<sup>160,161</sup> and US<sup>162,163</sup> laws, policies, and court decisions (eg, *Bellotti vs Baird*, 443 US 622 [1979]<sup>164</sup>), indicating an expectation that children will be active participants in their care.<sup>165-167</sup> The principle of self-determination applies to children and adults.<sup>158,168-172</sup> Involving children in communication about their health and in decisions regarding their health care shows respect for their capacities, will enhance their skill in the process of making future health decisions, and enables their essential input into decisions where there is no "right answer" other than the 1 that best meets the needs of the individual child and family.<sup>167,169,173,174</sup> Older children and adolescents should have a significant role in such cases. When the patient and family disagree, the cultural and family values, roles, and structure that have always governed the relationship should be treated with due respect.

#### *Communication as a Developmental, Relational, and Cultural Process*

At its core, child health decision making is family-centered decision making.<sup>173</sup> Parents and children themselves are more satisfied and adherence to the treatment regimen is enhanced when the child is addressed in information gathering and in the creation of the treatment plan.<sup>5,78,169,175</sup> However, parents want to be involved in the decision regarding how their children are informed about their health conditions.<sup>150</sup> It is, therefore, important to understand the preexisting parent-child relationship, the family's cultural and idiosyncratic values,<sup>176-178</sup> and the developmental needs of the child, including the desire to participate in his or her own care plan.<sup>178</sup> Simultaneously, determination of the parents' perspectives on providing information to the child is imperative. It is important for parents to understand that research demonstrates improved adherence to the plan and resultant health outcomes when the child is treated as a partner. (For 2 recent reviews of the literature, see *Tates and Meeuwesen*<sup>175</sup> and *Rushforth*.<sup>168</sup>) Pediatric health care quality will improve if the child is recognized to have his or her own individual cognitive and emotional needs, is taken seriously, and is considered to be intelligent, capable, and cooperative.<sup>5,137,150,168-170,173,175</sup> Parents and practitioners should decide together whether the child will be present at the informational consultations, whether parents would prefer to tell the child themselves or have another person tell the child, and whether the informing interview will occur with or without the parents present. A recent literature review indicates that children 7 years and older are more accurate than their parents in providing health data that predicts future health outcomes, although they are worse at providing past medical histories.<sup>179</sup> Thus, significant attention to the child's input should be routine

**TABLE 3 Strategies to Engage Children in the Outpatient Setting**

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Speak with the child; not at or to him or her
Speak in a private setting
Determine whom the child would like to be present (younger children will generally prefer parents to be present; children who have been abused by family members may need privacy to facilitate disclosure; most adolescents prefer privacy)
Begin with a nonthreatening topic
Listen actively
Pay attention to body language and tone of voice
Use drawings, games, or other creative communication tools
Elicit fears and concerns by reference to self or a third party
Ask the child what he or she would do with 3 wishes or a magic wand

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Data were adapted from Lask.<sup>180</sup>

practice. Assisting the child to achieve gradually increased capacity to take responsibility for the maintenance of health and the treatment of illness is a crucial task, specific to pediatric physicians and practitioners.<sup>5,168,169</sup> See Table 3 for helpful strategies to accomplish this goal.

Despite these seemingly simple and cost-effective techniques, recent studies indicate that children are generally passive recipients of medical care, with little opportunity to express their concerns and virtually no attempt to engage them in the creation or implementation of a feasible care plan.<sup>150,181</sup> In 1 study, children 8 to 15 years of age who had cancer perceived that they “occupy a marginal position in consultations . . . their priorities were of little interest to medicine.”<sup>150</sup>

#### *Enabling Effective Child Participation*

In the past, children of any age were rarely consulted about their own health concerns. In current Western culture, children are highly valued, yet attention to their autonomous needs, especially when the child is not yet an adolescent, remains challenging.<sup>137,150,168,169,173</sup> There are many reasons to include children as active partners in their own health care; however, this rarely happens.<sup>170</sup> Some attribute this situation to the dearth of tools to clarify children’s conceptualization of health and illness, to assess their capacity for decision-making, to effectively share information with children, and to assess the outcome of shared decision making on the child patient.<sup>169</sup>

Children can be coached to effectively assume the role of a health partner. One study<sup>5</sup> used brief videos, age-appropriate workbooks, and a short (1- to 2-minute) role-play for the child subjects. Simultaneously, the physician and parents were educated on the importance of the child’s participation. The goal was to enable children to raise concerns, ask questions, note information, and participate in the creation and troubleshooting of potential problems with the care plan. Coached children preferred an active role in their care and reported better rapport with the physician, recalling significantly greater amounts of information about their medication regimen than controls (77% vs 47%, respectively). Physicians can encourage the parent to coach the child to be an effective advocate for his or her own health.

The importance of the child possessing effective health communication skills becomes evident when trying to assess and treat a child’s subjective symptom, including pain. In the absence of the child’s input, it is difficult to understand the nature and severity of the pain; thus, it is nearly impossible to relieve the discomfort effectively and safely. It is well known that the use of patient-controlled analgesia assists with the resolution of pain beyond the dose of medication. The message that the child knows his pain, is in control of his therapy, and is trusted is a powerful therapeutic intervention.<sup>182</sup> Children as young as 4 years of age have used patient-controlled anesthesia effectively.<sup>183</sup>

In many cases, parents mistakenly think that not informing the child is best. Some professionals argue that paternalistic decisions (primarily on the part of the family) to withhold “harmful” information from the child can be justified.<sup>184</sup> This position is not supported in the literature that examines the child’s preference for information.<sup>5,150,167–169,181,185–188</sup> One of the most striking was Bluebond-Langner’s<sup>189</sup> landmark study of terminally ill children, indicating that children as young as 3 years of age were aware of their diagnosis and prognosis without ever having been told by an adult. She found that adult avoidance of disclosure and denial of difficult information led the child to feel abandoned and unloved. At the same time, the child’s response is often to “protect” the “unaware” adults, despite great personal cost; this situation is called mutual pretense and it hurts both parties.<sup>189</sup> By using whatever information they have, children will continually try to make sense of their situations. An incomplete ability to understand does not justify a lack of discussion with a child who desires involvement in his or her care and decision making.

Children often understand more than has been assumed;<sup>168,185</sup> increased experience with information they can understand creates a stable framework on which to add new information, promoting the integration of increasingly complex pieces of information.<sup>169</sup> Children need to have usable information, to be given choices (including their desired level of involvement), and to be asked their opinion, even when their decision will not be determinative.<sup>165</sup> Enhanced understanding provides a sense of control, which in turn mitigates fear, reducing the harms associated with illness and injury. Moreover, if the child is asking about the condition, he or she often already knows something is wrong and is checking to see whom to trust. Children who do not ask should be given the opportunity to receive information, but if they refuse it, information should never be forced on them.

Parents are also apparently harmed in the aftermath of nondisclosure to their children. A study of bereaved parents in Sweden indicates that all those who spoke openly with their children had no regrets, whereas 27% of those who did not speak to their children about dying not only regretted their decision but also suffered from an increased incidence of depression and anxiety as a result.<sup>190</sup> Thus, counseling parents about the benefits of disclosure should be invoked when they are reluctant to speak with their child about illness or death.

## Adolescents' Roles in Health Care Communication and Decisional Authority

If adolescents are to be given authority for their health care decisions, they must receive thorough, developmentally appropriate, understandable information,<sup>165</sup> to enable an understanding of the condition, what to expect with various tests and treatments, the range of acceptable and practical alternative care plans, and likely outcomes of each option.<sup>191</sup> Only then can adolescents fully participate as partners in their health care.

Because the ability to comprehend and decide is fluid and variable within and between individuals, the assent given by an informed child or adolescent who can weigh the pros and cons of the proposed intervention should be given progressively greater weight compared with parental permission.<sup>165</sup> However, the child's choice and parents' choices may be discordant. Expecting children to adhere to adult priorities and preferences may be illogical; Ladd and Forman<sup>192</sup> argue that adults' priorities clearly change over the trajectory of adulthood. Thus, if no value set is static, the adolescent's seemingly trivial or superficial judgments may be just as legitimate as any other. They argue that total paternalism toward adolescents' decisions undermines respect for the emerging, autonomous adults they will become and the emotional investment they have in their current values. The values with which adolescents judge their options are applied to an adolescent who holds those values, not to an adult with divergent values. This tolerant model of decision making addresses potentially harmful decisions by giving weight to the adolescent's decision, with the proxy taking the role of educator, discussant, challenger, and shared decision maker.<sup>193</sup> Overriding the adolescent's decision should be undertaken with great trepidation, using the same criteria as are used to override an adult's choice.<sup>192</sup>

### *Adolescents and Forgoing "Life-Prolonging" Treatments*

Children who have undergone treatments for a condition know the burdens of therapy more intimately than the adults trying to help them. Although they may not appreciate all the hoped-for benefits, their input into treatment decisions is clearly critical for a legitimate weighing of the benefit-burden calculus.<sup>186,193-196</sup> When adolescents are able to appreciate the hoped-for benefits, they then also have the capacity to make full-fledged decisions regarding whether to forgo medical interventions. Decisions to forgo life-prolonging treatments made by adolescents have been upheld in courts of law. Landmark cases are described by Traugott and Alpers.<sup>173</sup> Ridgway<sup>197</sup> found that when physicians oppose these decisions, the courts generally decide for the professionals, prompting a caution to physicians to carefully weigh the likely burdens and benefits before going to court to force treatment.

### *Adolescent Decision Making: Legal and Ethical Issues*

By US law, adolescents younger than 18 years (19 years in Nebraska and 21 years in Michigan)<sup>198</sup> cannot make decisions about their health without their parents' per-

mission with some exceptions, notably emancipated minor status. Emancipated minors are persons younger than 18 years who live independent of their parents, who have taken on the responsibilities of an adult, including financial independence, parenthood, or military service, or who are emancipated by court order.<sup>199</sup> Most states recognize "mature minors" by criteria strikingly similar to emancipated minor status.<sup>200</sup> However, both the age of the patient and the conditions vary somewhat from state to state. Adolescents who are neither emancipated nor mature minors are allowed by some state statutes to give legally binding consent for treatments for limited reasons (examples include testing and treatment for sexually transmitted infections, including HIV infection; drug or alcohol abuse; family planning; blood donation; and mental health care) without parental notification.<sup>201</sup>

## Cultural Considerations

Minority and non-English-speaking families often have cultural expectations and nuanced understandings of language that, if not understood and attended to, can substantially interfere with effective medical care and may lead to a decrease in health status for their children.<sup>176</sup> The AAP endorses the responsibility of the practitioner to be aware of and to accommodate the needs of such families.<sup>178</sup> At issue are concerns regarding who gets information, who makes decisions, amount of eye contact, forthrightness, and the need for indirect discussion. It is a good idea to be aware of the general cultural norms and taboos of the dominant subcultures attending the practice. Although there are guidelines for what is "culturally competent,"<sup>178,203</sup> none describes any individual family. Rather than assuming that a family will identify itself a certain way or follow cultural "norms," it is generally safer to ask family members about the etiquette for communicating with them. "How should I give your family medical information about Mary?" "With whom do I share information?" "Who makes decisions?" "Are there topics that should not be directly discussed in your family?" Offering to wait until the relevant persons arrive is culturally respectful.

Members of subcultures that are typically passive with authority figures, who are fearful in medical situations, who make decisions that favor the group over the individual, or who have generally low educational levels may have special needs. These needs may include repeated invitations to ask questions, use of long silences during discussions, accommodation of large groups for information dissemination and health-planning discussions, extra time to consult with others when decisions are to be made, and written summaries or tapes of conversations to facilitate understanding through sharing information with others,<sup>129,177</sup> particularly if there is limited English language proficiency. See Table 4 for suggested prompts to elicit culturally related health beliefs, concerns, and practices.

## Use of Translators

The availability of trained translators is required by the Joint Commission.<sup>205</sup> Medicaid partially pays for transla-



**TABLE 4** Prompts to Elicit Medically Relevant, Culturally Important Information

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What concerns prompted you to bring your child (use the child's name) for health care?

What behaviors and symptoms are of greatest concern to you?

What do you think caused this problem?

How do you think the illness affects your child?

What have you tried to do to make the illness better? Have you tried any traditional remedies?

Are there any specific dietary, religious, or cultural practices that need to be accommodated?

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Data were adapted from De Trill and Kovalcik.<sup>204</sup>

tion services.<sup>206</sup> Well-trained translators are often aware of cultural norms in addition to their language proficiency. Effective use of translators includes the establishment of a framework for collaboration; before the consultation begins, acknowledge the potential for and the desire to prevent cultural missteps. "I may ask you to say some things that you think are not culturally acceptable. If that happens, please let me know and guide me to more appropriately approach these topics." Use of untrained translators, such as bilingual children or other family members who are trying to absorb information and transmit it while emotionally upset, is inappropriate. Nonprofessional hospital employees are also a common source of "translation." Their knowledge of the English language is often limited, their educational levels, even in their own country, may be low, and they too will be assaulted emotionally with confidential and difficult information. There is rarely a debriefing opportunity for these kinds of volunteers in the aftermath of the discussion. Use of untrained translators is, therefore also, an unacceptable option.

### Bad News

Bad news can be defined as "pertaining to situations where there is a feeling of no hope, a threat to a person's mental or physical well-being, a risk of upsetting an established lifestyle, or where a message is given that conveys to an individual fewer choices in his or her life."<sup>207</sup> An alternate definition is that bad news is information that "results in a cognitive, behavioral, or emotional deficit that persists for some time."<sup>46</sup> Recognition that much of health care communication is actually bad news will improve attention to its delivery. As an example, although the diagnosis of neurofibromatosis type 1 may not seem to the practitioner to be bad news, the variability of the outcome and the lack of predictability of the disease make this diagnosis very difficult for parents.<sup>13</sup>

Similarly, the need for unanticipated blood tests for a needle-phobic child or the disruption of an unexpected overnight hospital stay, the need to take medications for the rest of one's life for a chronic condition, and many other common occurrences are bad news for families. Greater attention to the empathic delivery of bad news will result in improved skills when the stakes escalate, as in terminal conditions. Communication skills will be well honed and practitioner fear and guilt will not pre-

dominate when a bereaved parent states "I remember every aspect of what was said and how it was said when the doctor told me that my daughter had cancer."<sup>208</sup>

Pediatric oncologists have significant-to-profound discomfort in discussing prognosis, particularly the impending death of their patients.<sup>1</sup> Bereaved parents of trauma victims<sup>12</sup> have reported being told of the death in the hallway, waiting room, or other public area, implying a lack of training of emergency and surgery personnel. When information is delivered poorly, parents perceive a lack of empathy and respect, and memories of this experience may be etched in the minds of the survivors for the remainder of their lives, compounding and prolonging the grieving process.<sup>14</sup> Given the risks of such permanent damage, there is a moral imperative to ensure that preparation for the effective and empathetic disclosure of bad news is routinely integrated into pediatric training.

### Good Ways to Give Bad News

Most of the advice about breaking bad news in general applies to the ICU, ED, and delivery room settings and to the disclosure of terminal illness. The main difference is the time frame and the intensity of emotion, although even parents of chronically ill children who have survived many previous hospitalizations will also often be shocked (and frequently unbelieving) that the child will not recover this time ("We've been told that before, and he is still here").

Many clinicians believe there is no good way to give bad news. However, research with parents whose children had a wide range of diagnoses provides consistent guidance.<sup>15,24,32-35,40-42,46,47,92,209-213</sup> See Table 5 for suggestions for breaking bad news with skill and empathy.

When hearing bad news, parents value a physician who clearly demonstrates a caring attitude and who allows them to talk and to express their emotions.<sup>47</sup> One effective opening to the conversation is to ask, "What do you already know about what is happening to (patient's name)?" Once their ideas are elicited, misperceptions should be corrected. Asking whether they know someone else with this diagnosis or situation and inquiring about their associated experience can be helpful. The latter question assists the physician to be aware of the family's fears and expectations. Pointing out how the child's situation is similar to or different from the previous experience helps parents to better understand the child's likely course.

Parental dissatisfaction with the process of breaking bad news is common. Use of a protocol for breaking bad news can substantially improve the experience.<sup>41</sup> Comprehensive guides for breaking bad news are available.<sup>40</sup> Although needing to inform parents of a chronic, incurable diagnosis may challenge a physician's feelings of competency, parents are most attentive to the affective relationship of their informant, rather than the ability of the informer to "fix it." Parents are able to distinguish the difference between the delivery of the news and the news itself.<sup>32</sup>

One US study in the 1980s<sup>209</sup> found that parents of children with cancer, when hearing the initial diagnosis,

**TABLE 5** Suggestions for “Breaking Bad News” With Skill and Empathy

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Do not disclose bad news over the telephone
Use trained translators as needed
Avoid telling a lone parent without his or her spouse and/or a preferred support person present
Enable the parents to touch the deceased child before or during the interview
Hold or touch the child with obvious care
Recognize that parents are primarily responsible for their child
Show caring, compassion, and a sense of connection to the patient and the family
Pace the discussion to the parents’ emotional state; do not overwhelm them with information
Do not use jargon
Elicit parents’ ideas of the cause of the problem; ensure they do not blame themselves or others
Name the illness and write it down for the parents
Ask the parents to use their own words to explain what you have just told them to confirm effective transmission of information
Address the implications for the child’s future
Acknowledge their emotions and be prepared for tears and a need for time; it is helpful to bring a social worker and/or chaplain to the meeting
Be willing to show your own emotion; aloofness or detachment is offensive
Give parents time to be alone to absorb the information, react, and formulate additional questions
Be able to recommend relevant community-based resources
Provide contacts with other willing families with a similarly affected child
Provide a follow-up plan and make an appointment for the next conversation

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Data were adapted from Krahn et al,<sup>15</sup> Fallowfield,<sup>35</sup> Nursey et al,<sup>42</sup> Heller and Solomon,<sup>125</sup> and Woolley et al.<sup>214</sup>

desire less information at that time, preferring an emphasis on establishing trust with new caregivers. Parents’ trust of advice is built by acknowledging the grief, anxiety, and fear the family is experiencing and inviting them to share their feelings and ask questions. Gradually sharing additional illness and treatment information, supplemented by written or taped materials, and providing a means to contact the physician when additional questions arise, is also greatly appreciated.<sup>32</sup> Many parents now are asking for e-mail contact and, in some instances, this is a reimbursable service.<sup>215</sup>

When parents (predictably) become upset during the informing interview, acknowledge their grief and fear by waiting until their attention turns back to the discussion, then state (for instance):

“I can see you were not expecting this.” (Silence)

“You seem quite upset; I would be, too. (Silence.) Do you know anyone who has had this illness? (Silence.) How did things go for them?”

Facial tissues are essential equipment. Parents want hopeful and positive things said about their child, and an opportunity to touch or hold the child, particularly newborn infants or children from whom they have been separated during a transport. They need recognition by the physician of the child’s unique value as an individual first and as an ill or injured person second.<sup>15</sup> Speaking of the child as if he or she “is” the diagnosis is hurtful.

As time progresses, parents also appreciate emotional support and affirmation of their efforts and ability to care

for the child. “Your child is lucky to have you for parents! I can’t imagine anyone doing a better job than you two!” Harsh or judgmental statements about the child, the parents, or their behaviors are unhelpful.

### Communication in the ICU and ED

#### *Bad News in the ED*

In the ED, parents often arrive separately from the child. If they are available by telephone, let them know the child is seriously ill/injured, but do not disclose death over the telephone unless the parent is insistent. Suggest they come in as soon as possible and bring their spouse and a close friend with them. Ask them to be careful and to consider letting someone else drive, because they are at an increased risk of having an accident because of their appropriately upset emotional state.

If a child is undergoing resuscitation when the parents arrive at the ED, it may be appropriate to offer the parents the opportunity to be with the child.<sup>216–222</sup> The majority of families offered this option accept and feel much better knowing that “everything was done” and that they were there in the child’s last moments of life.<sup>223–228</sup> Parents should know they do not have to go into the resuscitation area if they choose not to; affirmation should be provided indicating that loving and good parents decide either way. If the parents choose to be present, a staff member should be assigned as a dedicated escort. This individual should tell them what they will see and let them know they can leave at any time. Parents should be informed that they will be asked to leave if they interfere with the team’s function or seem to be harmed by being there. When in the room, the escort explains the role of each person present, what is being done, then affirms that, despite all that is going on, this is still their child (use the child’s name) and that he or she may be able to hear the parent. The escort can suggest the parents touch and speak to the child, assuring him or her of the family’s love.

An even more challenging task is to inform families of trauma victims that their previously healthy child is dead.<sup>229</sup> Jurkovich et al<sup>12</sup> studied the experiences of bereaved families of child and adult trauma victims. The findings and recommendations were consistent with those for ICU patients. The most important attributes of the communication, from the parents’ perspectives, are the attitude of the informer, clarity of the message, privacy of the conversation, and the ability of the informer to accurately answer parents’ questions. Many parents recounted positive experiences, primarily of having caring hospital and prehospital staff. Physicians garnered most of the negative comments. Rank and attire were of minimal concern to these families.

After greeting the parents and escorting them to a private area, have someone who has directly participated in the care of their child speak with them. Sit down and bring tissues. Begin by asking what they know so far. Ask when they saw the child last and what he or she was doing at that time. Explain any factual details that are known about what happened at the scene and what has been done so far in the resuscitation. There are

**TABLE 6 Family Centered Communication and Support in the ICU**

Early (within 24–48 hours of admission) and frequent communication
Indication that the health care team cares for the child as an individual
Practitioners trained in meeting facilitation and conflict management
The use of open-ended questions and reflective explanation
Hopeful but honest and clear communication; acknowledgment of uncertainty
Discussion of likely and hoped-for outcomes
Use of numeric terms when describing probabilities; use of drawings and models
Provide timeframes for improvement and future discussion
Participation of families in clinical bedside rounds, caregiving for their child and ability to stay with their child during invasive procedures
Listen to and involve the nurse, chaplain, and social worker in the information loop
Open visitation, including sibling and pet visitation
Consistent caregivers; if this is not possible, ensure consistency of the message
Prompt informing of parents of transitions, such as a change of location, condition, treatment plan, assignment of attending physician or residents
Shared decision making rather than autonomy; encourage the parents to involve their family, friends, and medical home pediatrician to help them to understand information and make decisions
Written, audiotaped, and computerized education for families (see <a href="http://www.icu-usa.com">www.icu-usa.com</a> )
Discussion and support of coping mechanisms, including religious and spiritual values
Initiation of palliative care at the time of admission

Data were adapted from Todres et al,<sup>16</sup> Davidson et al,<sup>228</sup> Robinson et al,<sup>231</sup> and Todres.<sup>232</sup>

2 choices at this point; the first is immediate notification of the death, offering to escort the parents into the room to be with the body, and explaining what was done and that the child's injuries were too severe to survive but reassuring them that everything that could have been done to save the child's life was done.<sup>92</sup> Alternatively, there can be a staged disclosure, initially telling them that the child is very severely injured and at risk of dying, but that everything possible to save him is still being done. Tell them you are going to check on the rescue team's progress, leaving a team member in the room with them; make sure the rescue area is cleaned up and that the child's body is presentable. Leave some of the tubes in place to demonstrate the efforts that were made to save the child's life. Call the chaplain and the social worker if they are not on the scene.<sup>230</sup> Then, go back and inform the parents of the child's death a few minutes later. In the case of sudden, unexpected, and overwhelming illness or death, parents will likely be shocked, highly emotional, angry, and suspicious. This reaction, although difficult to endure as the perceived target of their animosity, is certainly understandable. A parent might blurt:

"But I put Juanita on the school bus this morning. She can't be dead!"

Offer to take parents in to see their child, and ensure a member of the resuscitation team is available to provide the specifics of what was done and to answer any questions. If feasible, move the body and the family to a private area to maximize privacy and minimize disruption; allow families to have some private time with the body. Ensure an appropriate environment, including a rocking chair, support persons from the family, and a limited number of members of the care team, if desired

**TABLE 7 Coping Strategies of Parents of Critically Ill and Injured Children<sup>16</sup>**

Focus on the positive (hope)
Minimize the significance of the information
Preoccupation with medical details
Support from family, friends, and clergy
Religious faith
Hostility, depression, irritability

by the family. Do not rush them. Experience indicates that 2 to 3 hours is the maximum time most families want to remain with the body; 15 to 20 minutes is more common.<sup>93</sup>

#### *Communication in the NICU and PICU*

Communication within an NICU or PICU generally involves bad news in a very foreign environment, virtually always with large numbers of unfamiliar health care professionals. Guidelines have been promulgated to suggest important ways to support families of ICU patients.<sup>228</sup> See Table 6 for suggestions with regard to communication.

Understanding how parents cope with bad news may prevent some judgmental conclusions and may assist ICU caregivers to be effective communicators with families. See Table 7 for a list of coping mechanisms, both adaptive and maladaptive, of parents with critically ill children.

The stakes involved in having a child in the ICU and the constant uncertainty make negative reactions understandable.<sup>16</sup> Parental sources of stress include seeing their child in pain, frightened, or sad, and the inability to communicate with the child.<sup>233</sup> Increased attention to the fulfillment of parental needs can improve relations between parents and ICU staff.

#### **Special Communication Considerations in Terminal Illness**

No communication is more difficult than telling a parent that his or her child will die. However, in many instances, painful as it is, parents may be hoping doctors will do just that. Parental recognition that one's child is suffering, disproportionate to the likelihood of benefit, is extremely distressing. However, it is a rare parent who will challenge the physician who continues to hold out hope for "cure" or prolonged life. Parents and adult patients expect physicians to recognize and discuss the need to change the goals of care. In 1 study, 45% of parents of critically ill children thought it may be time to stop attempts to treat the illness before the physician brought it up, but none broached the topic.<sup>234</sup> Many physicians, however, wait until they perceive the family or patient is "ready," leading to additional emotional and physical suffering, including a prolonged dying process. Mixed messages from multiple consultants, particularly in the ICU setting, can be extremely confusing and upsetting for families, often leading to poor decision making as the parents (understandably) hold on to the most hopeful messages. Having a clear captain of the care team, one who is evaluating the situation as a whole,

particularly as death nears, is extremely helpful in preventing such problems.

### Bad News in the Delivery Room

Despite increasing accuracy and availability of prenatal diagnosis, a pediatrician can be confronted in the delivery room by a child who is too immature to survive or who has anomalies that are incompatible with life; attempts at resuscitation would be inappropriate in these situations.<sup>235</sup> When prematurity is the problem, the parent is generally already aware of this. Introducing oneself and providing “a warning shot” may be helpful.

“I am Dr. \_\_\_\_\_ and I am the pediatrician who was called by your physician to care for your infant. My team and I have experience doing everything possible to help premature newborns. Based on your history and our examination, it seems, unfortunately, that your daughter was born too early to survive for very long, no matter what we do. (Pause) I am sorry. I really wish it were different. At this point, we are ensuring her warmth and comfort. (Pause) Does she have a name? Would you like to spend some time with her and hold her?”

Point out the infant’s normal features. Important things not to say at his time include asking when the mother noted her premature labor or asking about factors that may have triggered premature delivery. Blaming is unhelpful and unnecessary; avoidance of a recurrence can be accomplished at a future time when the information can be seen as helpful and can be absorbed.

For the near-term child with lethal anomalies, the diagnosis has typically been made before delivery. In this case, it can be helpful for pediatricians to ask parents what they know and provide confirmation of what they see. Goals of care should have already been established; in some settings, a prenatal hospice program may have been set up and available for support during the delivery.<sup>236</sup> If not, or if the diagnosis is unexpected, a “warning shot” is needed, followed by empathic and clear disclosure. Hovering and whispering about the infant only adds to the panic and confusion.

“I am Dr. \_\_\_\_ and I was asked to help care for your son. He has beautiful hands! And he also appears to have some unusual characteristics. Did you or your obstetrician have any concerns or suspicions that something may have been different about your baby before his birth?”

If the prognosis or diagnosis is not clear, the infant will likely be brought to the NICU for additional evaluation and management.<sup>235</sup> An explanation of what will be done, how long it will take, when the parents can visit, and when more will be known is important. If the child has a clearly lethal anomaly (eg, anencephaly), the child should not be separated from the parents unless that is their preference, and the process of palliative care should begin immediately. Pointing out the normal features of the child and ensuring the parents do not blame themselves for the anomalies are important therapeutic interventions. Asking whether parents wish to bathe or dress their child or have siblings hold their child helps families accept the newborn. If the infant is alive, attend to its comfort with warm blankets and maternal skin

contact, if desired. Suggest making a hand mold or print, cutting a lock of hair, or taking photographs. Offer to call a chaplain or the parents’ own clergy, if they prefer, to assist them to explore meaning and to help with any rituals.<sup>231</sup> Give them time to be with the infant or the body in a private place for as long as they desire. Offer help to call friends or family if they choose. Ensure bereavement follow-up.

In the NICU and PICU, parents are often asked to participate in the decision-making process regarding the use of “life-prolonging” measures. Little research addresses effective and compassionate ways to communicate about stopping critical care interventions and changing goals of care, although much research documents dissatisfaction with current methods. The usual way of addressing the failure of medical therapy can be very problematic and may generate thoughts or conclusions that are unintended but potentially devastating. Table 8 presents common medical statements, how they may be perceived, and suggests alternatives.

### INFORMED CONSENT, COMMUNICATING RISKS, AND BENEFITS OF RESEARCH

Sometimes, when conventional treatment has failed, clinical trials are available. Although parents often state their motives to enroll their child in research are altruism and/or the desire to learn more about their child’s disease, it is interesting to note that, when they are in an outpatient setting and less rushed to make a decision, participation rates in clinical trials are lower than in inpatient settings.<sup>237</sup> It is clearly difficult to achieve truly informed consent for medical care or procedures, let alone clinical research, when death is likely; strong emotions govern such situations. The need to explain complex constructs of risks and benefits, randomization, physiology, and often, pharmacology to lay people is daunting. Nevertheless, there is still an obligation to make a valiant effort to obtain truly informed consent. Too often there is a problem of therapeutic misperception, representing that the purpose of the research is to treat the patient rather than benefit future patients.<sup>238</sup> Indeed, therapeutic misperception may sometimes even be fostered by investigators. However, a recent analysis of cancer trials found that there were “insufficient data to conclude” that enrollment in clinical trials resulted in improved outcomes.<sup>239</sup> According to the Institute of Medicine Committee on Clinical Research Involving Children,<sup>240</sup> consent, permission, and assent should be viewed as a process of communication, encouraging questions at the initiation and throughout treatment to assess understanding and ensure lack of coercion in ongoing participation. These recommendations are based in part on 2 other important, recent reports on research ethics.<sup>241,242</sup>

A study of consent for childhood leukemia trials found that not providing information, and lack of understanding of information presented, hampered the achievement of informed consent.<sup>243</sup> For instance, randomization was not mentioned in 17% of cases, and parents did not understand it 50% of the time, despite efforts to explain the concept. Similarly, 18% of parents

**TABLE 8 Methods of Communicating Sensitive Health Care Information and Perceptions of Communication**

Usual Method of Communicating Message	How the Usual Communication May Be Perceived	Alternative Method of Communicating Message
"Do you want us to do CPR?"	"CPR would work if you would allow us to do it"	"Tell me what you know about" CPR. "CPR is most helpful for patients who are relatively healthy, and even then, only 1 of 3 patients survive. Many of Lisa's organs are not working. As you know, she is getting dialysis to clean her blood like her kidneys would have, a breathing machine for her lungs, and medicine to keep her blood pressure up. If her heart were to stop, it would not be because there is a problem with her heart (it is fine), but it would be because she is dying. All of our hearts stop when we die. So pumping on her heart, or "doing CPR" will not make her better. On the other hand, while I would recommend not doing CPR, I am not recommending stopping any other treatment she is receiving at this time. There is still a chance that she may get better. Let's hope for the best, but also plan for the worst. We will need to keep a close watch on her and keep you up to date on how she is doing. Do you have any questions?" "Let's talk again later today so I can update you. Is there anyone else I need to talk to?"
"Let's stop heroic treatment"	"We will provide less than optimal care" (What is heroic about performing invasive, painful, costly, nonbeneficial care?)	"At this time, I think the most heroic thing we can do is to understand how sick Jamal is and stop treatments that are not working for him. I think we should do all we can to ensure his comfort and yours, make sure there are no missed opportunities, and ensure we properly celebrate his life. I will follow your lead on this. Some ideas that have helped other families include getting him home with help for you if you wish, or you may choose to have his friends and your family come here instead and have a party; you can bring his clothes so that he will look like himself, bring in his music or a photo album and relive some of your best memories of him, make a mold of his hand so that you will always have his hand to hold, or anything else that would be a proper celebration of his life."
"Let's stop aggressive treatment"	"We will not be attentive to his needs, including symptom distress and need for comfort"	"We will do all we can to ensure he is as comfortable as possible."
"Aeisha has failed the treatment"	"The patient is the cause of the problem"	"We have tried all the proven treatments and even some experimental ones for Aiesha. Unfortunately, we did not get the results we had hoped for. I wish it were different!"
"We are recommending withdrawal of care for Marisa"	"We are going to abandon her and you"	"Marisa is too ill to get better. We need to refocus our efforts on making the most of the time she has left."
"There is nothing more we can do for Adam"	"We will allow him to suffer, we do not care about him, we only care about fighting the disease"	"We need to change the goals of our care for Adam. At this point we clearly cannot cure him, but that does not mean we can't help him and your family."
"Johnny is not strong enough to keep going"	"Johnny is weak"	"Johnny is a strong boy and he has fought hard with us to beat his disease. Unfortunately, as much as we wish we could, we cannot cure Johnny. At this point, we are hurting him rather than helping, giving him side effects, and keeping him from being at home or taking a trip, or whatever he really wants to do with the time he has left."
"We will make it so Thuy does not suffer"	"We are going to kill Thuy."	"We will do everything we can to make Thuy comfortable."
"We need to stop active treatment for Dwayne"	"We will not take care of him at all"	"The goal of curing Dwayne's disease, despite the best efforts of a lot of smart and hard-working people, is no longer possible. We are so sorry and wish that that were different! I have cared for many children who are as sick as your son. It is very hard on all of us, especially you, his parents and family when the treatments do not work as we had hoped. Many parents like you have agreed to stop efforts to cure when they are not working, as difficult as that is. Would you like me to put you in touch with some of the other parents who have been through this too?"
"Do you want us to stop Bobby's treatment?"	"You are the final arbiter of your child's death"	"Bobby is lucky to have such excellent, loving and selfless parents. I know this is hard; we will get through it together. I am glad you agree with our recommendations to change the goals of care to better meet Bobby's needs. I will let my team know what we have decided."
"I am glad you agree. Will you sign Juan's do-not-resuscitate order?"	"You are signing his death warrant"	"There is no surgery, no medicine, and all the love you clearly feel for Juan will not make him better, he is just too sick. I wish it were different." (Silence) "I will change his orders to make sure he only gets tests and treatments that can help him now."

CPR indicates cardiopulmonary resuscitation.

**TABLE 9** Suggestions to Improve Communication About Clinical Trials

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Ensure the presence of a nurse
Read the consent document with the parents, explicitly soliciting questions and allocating sufficient time to answer them
Provide time to process the information, including taking the consent document home overnight
Provide written and video explanations
Provide information in the family's native language when possible
Provide names and contact information for practitioners who can offer independent, competent second opinions
Conduct a daily education conference to allow information to be incrementally processed

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Data were adapted from Kodish et al.<sup>244</sup>

lacked understanding of the right to refuse to participate (attempted explanation, 97%) and 20% did not understand the right to withdraw from the study at any time (attempted explanation, 72%).<sup>243</sup> In another study, parents did not understand the existence or details of treatment alternatives.<sup>244</sup> Health literacy is a problem for much of the adult US population, not just parents.<sup>245,246</sup>

Children being offered the opportunity to participate in clinical research trials must be asked their opinion and must give permission to proceed. In fact, the requirement for affirmative child assent is codified in the Current Federal Regulations.<sup>247–249</sup> The opportunity to provide assent implies the ability to dissent as well; dissent must be taken seriously but is not considered to be determinative, when rendered by the child, if the trial holds realistic promise for a beneficial outcome. These concerns and needs must be anticipated as routine and accommodated. Clinical investigators need explicit training regarding how to obtain truly informed consent.<sup>244</sup> Suggestions to help improve communication about clinical trials are in Table 9.

In the setting of research with a potentially terminally ill child, emotions run high. Parental and clinician ability to judge the situation on the objective merits of the alternatives, within the framework of long-held values, is severely challenged and rarely accomplished. An altruistic child may prefer to continue on to benefit others, regardless of his or her own outcome.<sup>195</sup> These children are ideal candidates for research. However, others want desperately to control their destinies and to enjoy the time remaining. Parents' need to sustain life, often at all costs, can blind them to the child's need to enjoy it. It is the clinician's obligation to ensure that the risks and benefits are communicated in an unbiased way, while giving recommendations based on disclosed priorities and experience. Decisions should incorporate the views of the child, parents, and other caregivers who know the child well. Additional research is desperately needed to ensure a process that enables truly informed consent.<sup>240</sup>

### Presenting Palliative Care as a Viable Alternative to Research Participation

At such vulnerable times, parents are often told that the "only" alternative to enrollment in experimental therapies is "doing nothing," an alternative that is never at-

tractive and is also never true. Each treatment option should be evaluated based on the likely (not just hoped for) outcomes in this individual child's case, given his or her illness history and comorbidities, and the known and possible burdens and complications, including pain, isolation, fatigue, and missed opportunities. The merits and burdens of pursuing palliative goals of care without further attempts to reverse the disease versus experimental or "innovative" (uncontrolled research) treatment must be clearly explained to ensure that a choice is truly being offered.

Palliative care can be provided concurrently with life-extending measures<sup>81,228</sup> or can be the sole focus of care. Palliative care is intensive care, addressing the whole child within the context of self, family, and community. Palliative care attends to spiritual, physical, emotional, and social needs of the patient while also addressing the needs of parents, siblings, and others affected by the child's illness and ultimate death. Palliative care can facilitate an excellent quality of living in the face of a short life expectancy, ensuring that the child and his or her family live fully, despite being in the shadow of inevitable death.<sup>14,81,121,250</sup> Children can even live longer than expected when effective palliative care is offered because of renewed hope and relief of symptoms that are too often ignored in other treatment paradigms.

### Postmortem Communication

Parents are generally supported by family, friends, the community-based medical home pediatrician, and their congregational clergy after the death.<sup>93</sup> However, they often feel cut off from the people with whom they developed an intense bond in the hospital; the last people to assist them to care for their child, the people who guided their initial acknowledgment of their child's death.<sup>234</sup> Even small tokens of continued concern have a huge effect on families. In a study of bereaved survivors of adult patients, a condolence card, signed by direct care providers and mailed 2 weeks after the death, had a profound impact.<sup>251</sup> Ninety-four percent of the recipients still had the card in an easily accessible place 1 year later. One woman whose husband died in the ED stated that the card helped her cope with his unanticipated death, because "at least I know he died among caring people." There is published guidance for physicians about how to write a condolence card,<sup>252</sup> but even a signature will suffice.

Sometimes, especially when practitioners have become extremely close to the patient, attending the memorial or funeral service may be appropriate. This act serves to let the family know that the concern and attachment they perceived were real; it may also allow some healing for the practitioner, who otherwise may "burn out" from the emotional exhaustion of the investment in children who die and their families. Giving oneself permission to love and let go is important, and societal rituals may assist in the resolution of the professionals' grief as well. Families are generally overcome with appreciation when the physician attends the memorial or funeral and can be resentful when they do

not.<sup>125</sup> The AAP endorses an active role for the pediatrician in providing bereavement care.<sup>82</sup>

### Autopsies as Communication Opportunities

Particularly if an autopsy is performed, it is advisable to have a postmortem conference with the parents (and sometimes siblings as well) approximately 6 to 8 weeks after the death.<sup>93,253–255</sup> As parents reflect on the whirlwind events of their final days with their child, numerous questions arise. They need a vehicle to have these questions answered efficiently. If an autopsy is performed and there is no opportunity to hear and discuss the results, parents may become suspicious that the medical establishment was “experimenting” on their child.<sup>92,93</sup> Moreover, parents may have requested the autopsy to assist in family planning or to determine the need to do screening procedures on close relatives; thus, they may be awaiting the results anxiously. An in-person meeting allows the treating physician to answer all the family’s questions, translate the autopsy findings into understandable lay language, and importantly, to check on the well-being of the parents and siblings. The family and the staff appreciate coordination of the timing of this meeting so all important members of the care team can attend. Long-term follow-up may include an annual card on the child’s birthday or anniversary of the death, invitation to annual memorial services at the hospital, or other locally appropriate options.

### MEDICAL ERROR DISCLOSURE

Medical errors are increasingly in the public eye. Communication about medical errors is 1 of the most challenging aspects of health care,<sup>256</sup> yet parents exhort caregivers to be forthright and timely in revealing the mishap.<sup>104</sup> Training on how to approach patients and families about the occurrence of a medical error can increase family and patient satisfaction regarding these situations and can substantially decrease the medical malpractice payouts related to such occurrences. (Multiple case studies are available at [www.sorryworks.net](http://www.sorryworks.net).)

### PHYSICIAN SELF-CARE

Medicine is a challenging and rewarding profession. It requires lifelong learning, not only from books, journals, and courses, but also from attention to interactions with patients and families. Physicians have a difficult job; the responsibility to communicate effectively and efficiently to clarify the diagnosis, consider psychosocial and existential concerns, respect family and other supporters’ needs, and to come to an agreed-on plan of care is substantial and can be overwhelming. Allowing time between patients and debriefing conversations with staff, increased physician education on communication, and improved payment for counseling time can help.

### SUMMARY

Effective, empathic communication is an essential skill for physicians caring for pediatric patients and their families. It can lead to improved outcomes for children, their families, and physicians themselves. Communication de-

serves a place at center stage for pediatric education, practice, and research.

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# Communicating With Children and Families: From Everyday Interactions to Skill in Conveying Distressing Information

Marcia Levetown and the Committee on Bioethics

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