

# Communicating About Prognosis: Ethical Responsibilities of Pediatricians and Parents

## abstract

Clinicians are sometimes reluctant to discuss prognosis with parents of children with life-threatening illness, usually because they worry about the emotional impact of this information. However, parents often want this prognostic information because it underpins informed decision-making, especially near the end of life. In addition, despite understandable clinician concerns about its emotional impact, prognostic disclosure can actually support hope and peace of mind among parents struggling to live with a child's illness. Children, too, may need to understand what is ahead to manage uncertainty and make plans for the ways their remaining life will be lived. In this article, we describe the ethical issues involved in disclosure of prognostic information to parents and children with life-threatening illness and offer practical guidance for these conversations. *Pediatrics* 2014;133:S24–S30

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## Prologue

*The parents sit across from us in the small conference room. They had brought their 9-year-old daughter, whom we will call Amy, into the oncology clinic for a routine follow-up visit, including surveillance imaging, as she concluded her long course of chemotherapy. The radiologist had paged us (the pediatric oncology team) from the imaging suite; the news was not good. The tumor was back, and the cancer had spread. In a moment, we knew that any reasonable chance of a cure was gone. We felt sick at heart. Now we must talk to these parents, tell them what the imaging had revealed, start to formulate a plan, figure out a way to help them cope, keep going, and not lose hope. But what should we say, to them and then to Amy?*

Clinicians have long struggled with communicating difficult news, especially about a poor prognosis or incurable illness, because they worry about how these conversations affect patients and their families.<sup>1–3</sup> Honest discussions about prognosis, however, offer a variety of benefits, particularly in allowing patients to recognize what is ahead and to make thoughtful plans for care.<sup>4,5</sup> Furthermore, data do not support the contention that, on balance, honest discussion of prognosis is harmful for either adult patients or for children and parents.

In this article, we consider communication about prognosis in the context of the patient–clinician relationship. We believe that communication about such difficult issues illuminates the obligations of physicians to their patients. In addition, communication about prognosis takes on special resonance in pediatric settings, in which relationships are typically triangular, involving a clinician, the child, and the parents. Physicians hold obligations to both the child (ie, their patient) and to the child's parents. Parents, in turn, have obligations to their children. As fiduciaries for their children, parents may have special obligations to hear even the most difficult news and make thoughtful decisions on their child's behalf. The

triangular nature of the clinician–parent–child relationship in pediatrics invokes considerations that are unique to this context.

## CLINICIANS' CONCERNS ABOUT COMMUNICATING PROGNOSTIC INFORMATION

Clinicians who advocate for non-disclosure of prognostic information often emphasize concerns about the patient's welfare, including a belief that bad news may cause psychological harm.<sup>1,2,6–12</sup> We worry that prognostic information will cause patients emotional distress<sup>1–3</sup> and take away hope.<sup>1,13–18</sup> In addition, some clinicians fear that discussing a poor prognosis will create a prophecy that is either inaccurate or, perhaps worse, destined to be fulfilled by a now-hopeless patient<sup>19</sup>; patients who recognize a terminal illness will “give up.”

Clinicians may also avoid prognosis communication because they believe that patients do not want to know what is ahead.<sup>8,20</sup> This concern may be heightened when patients are of minority racial or ethnic backgrounds, given evidence that such patients may be less likely to want prognostic information,<sup>21</sup> even though preferences for prognostic disclosure within racial and ethnic groups are highly variable and not simply culturally determined.<sup>21–25</sup>

Finally, clinicians recognize correctly that prognostication is difficult. We often do not know how long the patient may live or even whether he or she will survive the illness. Yet we sometimes respond to this uncertainty by discussing prognosis in vague<sup>2</sup> or overly optimistic terms,<sup>10,19</sup> waiting for patients to ask for prognostic information,<sup>1</sup> avoiding discussion of prognosis unless the patient is insistent,<sup>2,19</sup> and focusing conversation on treatment rather than on outcomes.<sup>2,19</sup>

## BENEFITS OF PROGNOSIS COMMUNICATION: WHAT IS THE EVIDENCE?

### Research in the Adult Setting

A growing body of evidence among adult patients, especially those with cancer, demonstrates that prognosis communication has important benefits. Among them is informed end-of-life decision-making. Weeks et al<sup>24</sup> found that adult patients with metastatic cancer who have unrealistic expectations about the length of life ahead are more likely to choose aggressive, life-prolonging therapy, whereas those who recognize a poor prognosis tend to prefer palliative measures. Similarly, adults with advanced cancer who report having discussed end-of-life care with a physician are less likely to use mechanical ventilation, resuscitation, or care in the ICU at the end of life and are more likely to enroll in hospice care. Less aggressive care, in turn, is associated with a better quality of life near death.<sup>25</sup> Other research has found that treatment preferences depend on the likelihood of possible outcomes,<sup>26,27</sup> as well as a clear understanding of the burdens of therapy.<sup>26,28</sup> Patients who recognize the possibility of poor outcomes in conjunction with significant burdens of therapies are less likely to pursue aggressive care at the end of life. Taken together, this research suggests that patients who are aware of the likely outcome of their illness and its treatment are best equipped to make thoughtful decisions regarding care. This finding is particularly salient for patients with life-threatening illnesses, whose goals for care often hinge on an understanding of what is possible. A patient with incurable cancer, for example, may not reasonably be able to prioritize quality of life and time at home over trying 1 more treatment regimen unless he or she understands that treatment will not be curative.

Of note, although previous work suggests that patients who understand

a poor prognosis often prefer to avoid aggressive end-of-life care,<sup>24</sup> the argument for communicating about prognosis should not presuppose that all patients who know they are dying will want palliative care. In fact, patients who recognize a poor prognosis are more likely to receive the care they want (whether intensive life-prolonging care or care focused on symptoms) at the end of life.<sup>29</sup> Conversations about prognosis thus support patient autonomy and value-driven decision-making, not just 1 kind of care.

Despite the distressing nature of prognostic information, several lines of evidence suggest that communicating about a poor prognosis and making plans for end-of-life care do not cause lasting emotional harm and may in fact have psychological benefits. Wright et al,<sup>25</sup> for example, found that patients with advanced cancer who reported discussing end-of-life care planning with their physician had no higher rates of depression or worry than patients who had not had such discussions and that their caregivers had lower rates of depression in the bereavement period. In a separate study, patients with advanced cancer remained hopeful about the future even after being told they had no possibility of cure.<sup>30,31</sup> Similarly, patients with advanced breast cancer felt more satisfied and less anxious when provided with explicit prognostic information rather than general information, especially when this information was accompanied by reassurance of nonabandonment.<sup>32</sup>

Additional literature affirms the possibility that physician honesty, even regarding difficult news, can help patients to feel more hopeful. For example, Hagerty et al<sup>33</sup> surveyed adult patients who had metastatic cancer about physician behaviors they considered to be hope-giving. They found that patients experienced more hope when physicians engaged in realistic communication about

prognosis; in contrast, use of euphemisms or avoidance of honest disclosure of bad news made patients feel more hopeless. Similarly, a study of surrogate decision-makers for patients receiving mechanical ventilation revealed that 93% of surrogates considered avoidance of discussions about prognosis to be an unacceptable way to maintain hope.<sup>34</sup>

Others have reported that uncertainty about one's medical situation can result in a diminished sense of hope<sup>35</sup>; this research argues for the therapeutic power of information, even if it represents bad news. Adult patients with end-stage renal disease, for example, felt more empowered about their own medical decisions and more hopeful when they received prognostic information. However, because many patients in this study relied on physicians to initiate these discussions, hope was threatened when discussions did not take place because patients feared the worst.<sup>36</sup> Work by Wright et al,<sup>25</sup> which documented better coping after death among family members of patients who had end-of-life discussions, also suggests that the emotional impact of prognosis communication evolves over time. Thus, the immediate distress of learning about a poor prognosis may start patients and family members on a trajectory of integration and acceptance of the news. Ultimately, this research raises the question as to whether, as the patient's illness progresses, well-informed patients and families may have better psychological outcomes than those who are unprepared for the likely course of events.

### Research in the Pediatric Setting

Thus far, we have focused on research among adult patients who are making decisions about their own care. Evidence suggests that many of the same issues are at work among parent decision-makers. For example, most parents of

children who have cancer say they want to know their child's prognosis because knowing this information helps them make the best possible decisions about their child's care.<sup>37</sup> In addition, in a survey of bereaved parents of children with cancer, those who recognized a poor prognosis sooner during the child's illness had earlier discussions about hospice care, and their children experienced earlier institution of do-not-resuscitate orders and decreased use of cancer-directed therapy at the end of life,<sup>38</sup> echoing work in adults that argues for the role of prognostic knowledge in informed decision-making.

In addition, in the pediatric cancer setting, prognostic disclosure has not been found to be associated with higher rates of parental distress.<sup>37</sup> Rather, honest communication about prognosis is associated with greater parental peace of mind<sup>39</sup> and trust in the physician.<sup>40</sup> In 1 study, parents who received more complete prognostic information were more likely to report that physician communication made them feel hopeful, even if the child's prognosis was poor. These findings may be counterintuitive to physicians who describe prognosis communication in viscerally physical terms, such as "hitting them over the head" or "beating it into them."<sup>3</sup> However, honest and supportive conversation about prognosis may actually relieve distress and support hope, even if the news is difficult.

As we have noted, uncertainty about the future can be distressing. In a parallel situation, much like physicians who instinctively withhold bad news from parents, parents themselves are sometimes reluctant to disclose diagnoses and prognostic information to their children for fear of causing distress. A common argument for direct communication with children and adolescents, however, is that not knowing can be more difficult than knowing, because uncertainty gives reign to one's worst fears. When talking about prognosis

with parents, the same principles may hold. Parents of children with cancer who feel poorly informed about the child's prognosis experience more distress than those who feel well informed,<sup>37</sup> suggesting again that knowledge is less painful than the alternative.

Acknowledgment of a poor prognosis may allow patients and parents to formulate alternative hopes by focusing on outcomes that are possible. Feudtner<sup>41</sup> has noted that hope is broad and multifaceted, and that individuals experience many different hopes simultaneously. Parents may, for example, hope at once for a long life for their child, for a meaningful life, for limited suffering, and for the child's experience of love within a family. Parents may even hold seemingly contradictory hopes, such as hope that the illness will be cured and hope that death will not involve suffering. Instead of experiencing these wishes as conflicting or as evidence that the parent "doesn't get it," Feudtner suggests that clinicians explore the many things parents are hoping for, giving time to a full spectrum of hopes, as avenues toward hearing what matters to the parent and toward thinking about what can be achieved. This technique, which involves asking parents what they are hoping for, and then continuing with, "and what else are you hoping for," offers clinicians and parents the opportunity to share thoughts about the child's future in a deeper way and to create a shared vision for that future which can serve as a compass for decision-making as the child's illness unfolds.

Although nondisclosure of prognostic information seems to contradict the wishes of many patients, it is important to remember that refraining from prognosis communication may stem from physicians' compassionate inclinations.<sup>1</sup> Every clinician knows the look of pain and sadness that often comes from such a conversation, and

physicians understandably want to shield patients and their families from this experience. In many areas of medicine, the compassionate inclination helps us to uphold the fiduciary nature of the patient–physician relationship. For prognosis communication, however, human emotion creates an apparent conflict between 1 aspect of patient interests (ie, supporting decisional autonomy) and another (ie, doing no harm).

Despite evidence that knowing a poor prognosis may be less distressing than living with uncertainty about the future, the reality is that receiving bad news is distressing. We cannot hold these conversations without provoking sadness and anger. But even if the anguish such conversations create is profound, the clinician's role should not center on protecting patients from bad news. Instead, Harris and DeAngelis<sup>42</sup> suggest that a physician's presence is an important source of hope in times of suffering. Thus, the clinician may have a meaningful role to play in the development and maintenance of hope, which can emanate from a caring, human connection between the patient and clinician. Rather than protecting patients and parents from a painful but unavoidable reality, clinicians can aim to be with patients and families through their difficult times.

### PROGNOSIS COMMUNICATION AND THE PARENT'S ROLE

Until this point, we have largely balanced 2 major issues when considering communication about prognosis; on 1 hand, prognosis communication offers the opportunity for informed decision-making, whereas on the other, there are potential emotional consequences of learning about a poor prognosis. For adult patients, the benefits and consequences of prognosis communication are both experienced by the patient. In contrast, in pediatrics, these issues

are often separate; children are likely to experience the benefit of more informed parental decision-making, and parents generally experience the emotional consequence (or benefit) of knowledge of what is ahead. (Older children and adolescents may also benefit from knowledge and not just from informed parents; we address the issue of discussing prognosis with pediatric patients later in the article.) Thus, in pediatrics, in which the interests of the child are paramount, the balance of considerations may shift toward disclosure, even at the cost of potential emotional burdens for parents.

Of course, the experiences and needs of individual families are varied and complex. Children often experience negative consequences of parental distress, and children may not be fully insulated from parental sadness in this situation. Furthermore, and importantly, some children may themselves wish to know what is ahead and, in requesting such information, open themselves up to painful knowledge about the future. At the other end of the spectrum, some children do not wish to hear such information and often will manage to avoid hearing the news even if the information is presented to them directly. In such cases, the parents must be committed to listening to medical information and making thoughtful decisions on the child's behalf. Just as physicians are fiduciaries to their patients, parents hold a similar role for their children, with similar obligations to act in the child's best interests. Withholding bad news from parents neither upholds physicians' obligations to patients nor parents' obligations to their children. Instead, doing so favors the presumed needs of the parent (to avoid difficult information) over the needs of the child (to have an informed decision-maker acting as a fiduciary on his or her behalf).

An apparent paradox emerges in the disconnect between most physicians'

common assumptions that parents should be somehow shielded from bad news to protect them and studies documenting that knowing about prognosis, even when it is poor, offers parents greater hope and peace of mind. Why would parents, when better informed about bad prognostic news, do better? One possibility is that this information helps to reinforce the role that parents play in their children's lives. By asking parents to hold such information and make thoughtful decisions, we reinforce the deep sense of purpose parents may feel in helping the child through this time. Ultimately, the parent cannot be protected from the course of the child's illness because it will unfold regardless of whether we talk about it. But we can help parents by reminding them that they will be able to undertake what is for many the most important role of their lives, and that we will be there with them to help guide them through it.

### ADDRESSING AND MANAGING PROGNOSTIC UNCERTAINTY

Even though some arguments for prognosis communication may seem clear, the reality is that even clinicians who wish to have these conversations are faced with complex decisions, such as when to initiate these discussions and how to deal with medical uncertainty. Previous research has found that communication tends to happen late; for example, among adult patients with metastatic cancer, conversations took place a median of 1 month before death.<sup>43</sup> In this study, although most patients did ultimately have discussions about end-of-life care with a physician before death, conversations tended to happen during acute inpatient hospitalizations near death, rather than close to diagnosis when the incurable nature of the cancer was first known or during times of relative medical stability when care decisions might be made more

thoughtfully. Although most patients were able to talk about their wishes for end-of-life care before death, the timing mattered; patients who had earlier discussions were less likely to receive aggressive measures at the end of life and more likely to receive hospice care.<sup>44</sup> Thus, physicians of patients facing death may do well to start discussing this possibility early rather than at a later moment of crisis.

It is important to acknowledge that while researchers can look retrospectively at the timing of such conversations relative to death, clinicians are faced with making these decisions prospectively, when the timing of death, and sometimes even whether death due to the current illness will occur, cannot be known with certainty. Previous work in the adult setting suggests that physicians are more likely to avoid discussing prognosis or to convey overly optimistic prognostic information when there is considerable prognostic uncertainty.<sup>9,45</sup> In the pediatric setting, in which life-limiting illnesses are diverse and often have long, waxing and waning courses, pediatricians' opinions about the optimal timing of referrals to palliative care vary widely,<sup>46</sup> potentially fostering divergent practices in discussing prognosis. Many pediatricians also consider themselves inexperienced with communication about end-of-life care,<sup>47</sup> which may lead to delays in conversations about prognosis and care preferences.

With this challenge, however, comes an opportunity; physicians who face considerable prognostic uncertainty can begin conversations by using language that is open to multiple possible outcomes long before acute deteriorations necessitate urgent decision-making. Some related guidance comes from a technique for conversations about end-of-life care planning proposed by Back et al<sup>13</sup> as well as others. This advice focuses on times when the physi-

cian is aware that an adult patient's illness is terminal, but the patient is unable fully to accept the terminal prognosis or to engage in end-of-life care planning. Back et al have thus proposed that physicians allow patients to "hope for the best and prepare for the worst" as 1 way to support emotional and cognitive dissonance about a terminal illness. Physicians might first ask, for example, "As you think about what is ahead, can you tell me more about what you are hoping for?" After giving time to hearing and understanding the patient's hopes, the physician might then ask, "Would it be helpful to talk about your concerns if things don't go as we hope?" In holding a hypothetical conversation framed around patients' hopes and wishes for the best and worst possible situations, physicians allow patients to make concrete decisions about how they would want the end of their life to unfold without being forced to accept that future as inevitable. Patients may then, for example, have the opportunity to express a wish to die at home or without invasive interventions if the worst should happen but simultaneously retain hope that things may be different.

This guidance, although originally intended for conversations with adult patients who have difficulty accepting a terminal prognosis, may also serve as a framework for situations in which a child's outcome is uncertain. Clinicians can begin conversations about the future, focused on hopes and worries, early in the course of illness, even if the actual course of the child's illness is not clear. As with other conversations about prognosis, it can be helpful to start by asking parents what they believe is ahead for their child. What are they expecting? What are they hoping for? (And, as suggested by Feudtner,<sup>41</sup> what else are they hoping for? And what else?) What are they most

worried about? Finally, would it be helpful to hear more about what may be ahead?

For parents who wish for information about the future, if the future is uncertain, clinicians can honestly say that “no one knows for certain what is ahead for your child.” But, if this conversation is occurring, it is likely because there are real concerns that the course will be difficult. Thus, the clinician can also say, “Although I don’t know for certain what is ahead, I’m worried. Many children in this situation don’t survive, although they can have many good years of life before that time comes.” The words will depend on the situation, but the use of the words “I’m worried” conveys a message: this is a serious conversation; things may be difficult; I care about you and your child; and because of that, we need to work together so that things go as you wish. In beginning these conversations early, clinicians can start to learn about what is most important to families, without the pressure of urgent decision-making. Families, too, can begin to consider and understand their own wishes, so that they can continue to reflect on them as the child’s illness evolves.

### WHERE DO CHILDREN COME INTO THESE CONVERSATIONS?

Throughout this article, we have focused on communicating with parents, who often have primary responsibility for hearing information about prog-

nosis and making good decisions on their child’s behalf. But children, and especially adolescents, may need to hear about the future themselves, so that they too can manage uncertainty and develop realistic priorities for their lives, including their medical care, going forward.<sup>48</sup>

Although communicating with children and communicating with adults involve similar skills, 1 important difference is that adults may be able to have these conversations on the clinician’s schedule, such as in a planned family meeting. Children, however, may need to talk on their own time frame. As with adults, conversations with children should center on attentive presence and listening. Clinicians must be particularly attentive to signs that the child has concerns or a need for more information, and to signs of emotion. When these signs arise, the clinician can simply follow them: “Is there something you are worried about? Can you tell me more about that?” Even when children do not raise questions themselves, the clinician can raise the same questions with children that they use with the parents: “What are you expecting may be ahead? What are you worried about? What are you hoping for? What else are you hoping for?”

Like their parents, children often wish to protect their families from difficult conversations about the future. But whereas parents can find opportunities to hold these conversations without the

**TABLE 1** Seven Reasons to Have Honest Prognostic Conversations

Most parents want to have information about prognosis
Prognosis communication builds a trusting relationship between the clinician, parent, and child
Communication about prognosis respects and reinforces the parent’s role as a fiduciary and caregiver for the child in difficult times
Honest conversations about prognosis enable patients and families to make thoughtful decisions about care and other important life plans
Communication about prognosis is associated with greater hope and peace of mind
Prognosis communication reduces uncertainty, which may be more distressing than the reality
Honest conversation about prognosis opens up the opportunity for discussions about hopes, worries, and values, all of which help to guide the care to come

child (eg, in conversation with the clinician outside the child’s room), children may not have such opportunities unless we consciously provide them. Thus, just as we do for parents, we need to give time to children’s expectations, hopes, and worries.

Returning to the opening vignette, all that we have discussed here will not diminish the sadness and pain, and perhaps anger or despair, that will permeate the conversation with the parents. Confronting life-threatening pediatric illness is always hard. Nevertheless, the clinicians should know about and be guided by the body of evidence regarding the benefits of providing clear, accurate, and forthright prognostic information in a compassionate manner both to parents and, in an age-appropriate manner, to children themselves (Table 1).

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