

Prognostic Disclosures to Children: A Historical Perspective

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Prognostic disclosure to children has perpetually challenged clinicians and parents. In this article, we review the historical literature on prognostic disclosure to children in the United States using cancer as an illness model. Before 1948, there was virtually no literature focused on prognostic disclosure to children. As articles began to be published in the 1950s and 1960s, many clinicians and researchers initially recommended a “protective” approach to disclosure, where children were shielded from the harms of bad news. We identified 4 main arguments in the literature at this time supporting this “protective” approach. By the late 1960s, however, a growing number of clinicians and researchers were recommending a more “open” approach, where children were included in discussions of diagnosis, which at the time was often synonymous with a terminal prognosis. Four different arguments in the literature were used at this time supporting this “open” approach. Then, by the late 1980s, the recommended approach to prognostic disclosure in pediatrics shifted largely from “never tell” to “always tell.” In recent years, however, there has been a growing appreciation for the complexity of prognostic disclosure in pediatrics. Current understanding of pediatric disclosure does not lead to simple “black-and-white” recommendations for disclosure practices. As with most difficult questions, we are left to balance competing factors on a case-by-case basis. We highlight 4 categories of current considerations related to prognostic disclosure in pediatrics, and we offer several approaches to prognostic disclosure for clinicians who care for these young patients and their families.

Prognostic disclosure to children has perpetually challenged clinicians and parents. In this article, we review the history of prognostic disclosure to children using cancer as an illness model. We chose this focus because a majority of historical disclosure literature focused on cancer care in the United States but also because diagnosis and prognosis of cancer before the 1970s were largely synonymous: a death sentence. We follow this history to the present day, highlighting the complexity of prognostic disclosure in pediatrics and offering guidance to clinicians.

The lessons we highlight provide important insights that can inform communication in other childhood illnesses.

A BRIEF HISTORY OF TRUTH-TELLING IN AMERICAN MEDICINE: STARTING WITH DIAGNOSTIC DISCLOSURE

American medicine has a long history of withholding information to shield patients from the harms of bad news.¹ The first American Medical Association Code of Ethics in 1847 stated: “A physician should not be forward to make gloomy prognostications

abstract



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because they savour of empiricism....

For the physician should be the minister of hope and comfort to the sick.”² Given that cancer was essentially terminal, this approach was likely rooted in both concern for the patient’s well-being and the physician’s personal discomfort. The code further stated: “The life of a sick person can be shortened not only by the acts, but also by the words or the manner of a physician.”² This guarded approach persisted for the next century.³⁻⁵ As recently as 1961, a survey found that 90% of physicians preferred not to disclose cancer diagnoses to their adult patients.⁶

During the 1960s and 1970s, professional and social factors led to major changes in the conception of the physician-patient relationship.⁷⁻⁹ Modern bioethics and the patients’ rights movement affirmed patients’ autonomy and authority to make personal medical decisions. Simultaneously, cancer treatments were improving, creating a divide between diagnosis and prognosis. Soon, clinicians began calling for more open communication with patients, even if the prognosis was terminal.¹⁰⁻¹² By 1979, a landmark study showed that 97% of physicians preferred disclosing cancer diagnoses, a complete reversal from 18 years earlier.¹³ This trend toward open, partnership-based communication has persisted. According to current American Medical Association standards: “The patient has the right to receive information from physicians and to discuss the benefits, risks, and costs of appropriate treatment alternatives.”¹⁴

COMMUNICATION IN PEDIATRICS: “PROTECTIVE APPROACH”

Despite this long history in adult medicine, little attention was paid to disclosure in pediatrics until the 1950s.¹⁵⁻¹⁷ Before this time, most child mortality was attributable to

TABLE 1 Nagy’s 3 Stages of Recognition of Death (1948)¹⁵

Stage	Age	Description
First stage	3–5 y old	Death is departure, a separation, temporary
Second stage	5–9 y old	Death is personified, considered a person, outside of us, not universal
Third stage	≥9 y	Death is a process that takes place in us, and results in the dissolution of bodily life

tuberculosis and acute infections. Cancer became a relatively greater cause of mortality in children as death tolls from infections decreased in response to antibiotics, nutrition, vaccination, and improved hygiene.^{18,19} Suddenly, clinicians had the dilemma of communicating with these young patients about a disease from which “no child has ever been cured.”¹⁸ Because of the absence of data or training and the inherent difficulty of the subject, many felt unprepared.^{16,20-29}

The first publications on children’s understanding of death came from the psychological literature.^{15,21} Nagy published a seminal article in 1948 proposing 3 stages of a child’s recognition of death, based on interviews and observations of children (Table 1).¹⁵ According to Nagy, children older than 9 years understood death similarly to adults; younger children did not have a realistic conception of death. As the question of disclosure trickled into the pediatric literature, several authors interpreted Nagy’s study to mean that young children were unable to recognize, fear, or feel anxious about death.^{19,20,25} Therefore, it was widely assumed that young children should be excluded from discussions about their illness. As 1 article noted, “Obviously the confused and conflicting views about what or how much to tell the adult patient about his mortal illness do not apply here.... A child does not press for a complete account of his disease, and gentle reassurance about getting better soon should suffice.”¹⁹ For older

children, most pediatric^{17,22-24,30} and psychological^{26,31,32} literature from the 1960s supported a protective approach that shielded children from the harms of bad news. “[The] view of children as vulnerable and hypersensitive combined with the ancient medical doctrine that truth could kill to provide justification for medical lying to children.”³³

Review of this early literature shows 4 main arguments against disclosing a cancer diagnosis to children (Table 2). Some authors feared potential inaccuracies in diagnosis.²⁶ Others worried that disclosure could harm children.^{17,23,26,30,32} One article suggested that disclosure of terminal cancer might even push some patients toward suicide.³⁰ Concealing this “harmful truth” sometimes required elaborate explanations:

Anemia and “tired blood” are concepts of leukemia that can be explained on the basis of insufficient red cells, so that the child is tired and pale.... Ways of treating the disease are known, and the child will be well again. It should be explained that anemia in children is unusual and can be quite serious, to account for the parental distress and the necessity for continued clinic visits.³⁴

Many authors also noted that children seldom asked for information.^{24,26,32,34} Some interpreted this as a lack of interest; others saw this as an effective means of coping. “By open discussion, this excellent defense mechanism is destroyed and the patient made to face his certain death.”³⁴ Lastly, authors cited the effect of disclosure on family interactions as a concern, particularly “the effect this revelation may have on relationships with

TABLE 2 Arguments Against Disclosure of Terminal Diagnosis/Prognosis to Children (1950s–1970s)

Potential inaccuracy of diagnosis/prognosis	"[W]ithout an accurate diagnosis, it is cruel to arouse anxieties unnecessarily." ²⁶
Truth could be harmful to children	"[I]f a child were aware of or suspected the significance of his illness (that is, his impending death), the accompanying anxiety would be highly upsetting to him and would become a concern for the staff." ⁵²
Sick children did not want information; or children were repressing awareness to cope with anxiety	"[C]hildren observed by us rarely manifested an overt concern about death... Our suspicion is that this does not reflect an awareness but rather represents an attempt at repression psychologically of the anxiety concerning death." ²⁶
Disclosure could upset family structure	"We are concerned about the effect this revelation may have on relationships with parents, brothers and sisters, other relatives, and playmates and classmates." ²³

TABLE 3 Arguments for Disclosure of Terminal Diagnosis to Children (1960s–1980s)

Children already know they are ill or dying	"The fatally ill child of 6 to 10 years appears to be aware of the seriousness of his illness, even though he may not yet be capable of talking about his awareness in adult terms." ³⁵
Great effort is required to maintain pretense; the façade usually falls apart	"[C]hildren inevitably sense what is happening to them or in their family, even when a deliberate attempt is made to shield them from tragic, frightening or complicated affairs." ²⁴
Children's silence may result from lack of secure, open communication environment	"Is the child who does not verbalize concern really unconcerned, or only afraid to speak?" ²⁷
Honest and safe communication environment offers support to dying children	"In order to help a child cope with the problems of serious illness, it is necessary to develop an environment in which he feels perfectly safe to ask any question, and completely confident of receiving an honest answer." ³⁹

parents, brothers and sisters, other relatives, and playmates and classmates."²³ The family unit was the main source of support for the ill child, and they worried that open disclosure would make interactions more difficult.

Although this literature on disclosure to terminally ill children was growing, it was primarily based on opinion and observational data, with little more to support conclusions than intuition. No attempts were made to look for subtle expressions of death anxiety. Empirical, controlled studies were not commonplace until the mid-1970s, nearly 20 years after the first articles on disclosure to children were published.^{35–38} One article stated in 1973 that "few or no objectively based data have been gathered from the younger child himself on what he knows about his illness or what his psychological reactions are to it. Worse still, unsupported positions and opinions have been stated as objective fact."³⁵ Despite a growing appreciation for the complexity of caring for dying children, "This whole field of the child's fear of death is full

of contradictions and the absence of empirical knowledge."³⁸

COMMUNICATION IN PEDIATRICS: TRANSITION TO AN "OPEN APPROACH"

By the late-1960s, there was growing opposition to this "protective" approach, with 4 main arguments supporting an "open" approach (Table 3). First, several authors contended that children were often already aware of their reality.^{16,24,27,39–41} For example, in 1969, Binger et al interviewed bereaved parents of 23 deceased leukemia patients. Of 14 parents who withheld information to protect their children, "11 of these children indicated their sense of impending death."⁴⁰ In this same study, Binger commented that "the loneliest of all were those who were aware of their diagnosis but at the same time recognized that their parents did not wish them to know.... No one was left to whom the child could openly express his feelings of sadness, fear or anxiety." The work of John Spinetta, a prominent psychologist in behavioral and psychological research in childhood cancer, further refuted the previously

held concept that children were unaware and uninterested in the reality of their terminal illness.^{35,36,42}

Second, authors noted that some parents and clinicians expended great effort to maintain a façade of normalcy.^{22,34} This sometimes led to unabashed lying: "We recently had a 13 year old boy with lymphosarcoma who had a frozen pelvis and a functioning colostomy. He had been told that he had a draining abscess from a ruptured appendix.... We never intended for him to know otherwise."³⁰ However, these efforts at concealment often failed as children became aware of their reality, and when parents and clinicians put such great effort into maintaining this pretense, there was little energy left to develop a meaningful and supportive relationship with the suffering patient.

Third, with the growing acknowledgment that children were aware of their diagnosis (and inherent prognosis), authors began suggesting that children with cancer were afraid to ask questions or discuss their disease because there was

not an open environment to support such communication.^{16,27,39,41} “If he is passive, it may be only a reflection of how freely the environment encourages him to express his concerns.”³⁹ This lack of openness could have been related to the clinician’s concern for protecting young patients; however, many authors suggested that clinicians and parents were actually protecting themselves by withholding the truth.^{24,25,27,39,40,43} “Those who take refuge behind the classical ploy, ‘He didn’t ask, so I didn’t tell him,’ are often trying to avoid their own anxiety about death and dying.”⁴³

Finally, as the psychological and clinical literature on disclosure in pediatrics trended away from opinion-based articles and toward more objective studies in the 1970s and 1980s, emerging research supported the idea that an honest and safe communication environment was helpful to dying children.^{37,44-47} In the ensuing decades, this growing body of evidence and clinical guidelines continued to support transparent communication with severely ill children.⁴⁸⁻⁵¹ The harms of disclosing distressing information were now being balanced against benefits of disclosure (eg, relief of uncertainty, opportunities to express fears). Additionally, there was a shift in the view of the child from a passive recipient of actions (eg medical care, instructions, commands, silence) to an active agent able to interpret the behavior of others and forge a line of behavior based on those interpretations.⁵²

This movement toward open communication with children has persisted to the present day, as “practice evolved from one of secrecy to one that advocates presenting accurate information to a child in developmentally meaningful terms.”⁵³ The answer to the question of disclosure to children seemed to be an emphatic “yes.” However, as this movement toward open

communication was growing, treatments were improving, and prognosis was becoming more variable. As such, the question of disclosure to children was shifting focus from diagnosis to prognosis, injecting new complexity into the debate.

TO TELL OR NOT TO TELL: GROWING APPRECIATION OF COMPLEXITY

By the 1980s, this historical pendulum was swinging from “don’t tell” to “always tell.” However, this question is now being reconsidered with a growing appreciation for the true complexity of prognostic disclosure to children, leading to a renewed questioning of how and when it is appropriate to disclose. Current understanding of pediatric disclosure does not lead to simple “black-and-white” recommendations for disclosure. As with most difficult questions, we need to balance competing factors on a case-by-case basis. In the following sections, we discuss current considerations that affect prognostic disclosure to children, and propose approaches that can aid clinicians in this process (Table 4).

Hope and Prognosis

Continued improvement of cancer treatments has increasingly separated diagnosis from prognosis, further complicating the approach to communication in pediatric oncology. As early as 1967, Green commented that “equating the diagnosis with the prognosis of death due to disease is no longer possible.”²⁴ Children were surviving 3 years by the 1970s,³¹ and 5 years in the 1980s with “a growing number experienc[ing] a longer term remission and perhaps ‘cure.’”⁶¹ In 2015, the average 5-year survival rate for pediatric cancer reached 80%.⁶² As survival rates improved, it became more difficult to predict the outcome for any individual patient.

Improved outcomes have given families more reason to hope for a cure, and clinicians have long felt a responsibility to sustain this hope.^{63,64} Historically, this drive to sustain hope led many physicians to withhold negative information from children. However, there is a growing understanding that hope is broad and multifaceted, and individuals experience many different hopes simultaneously, not just hope for a cure.⁶⁵ As Feudtner questioned, “What happens if we shift away from the monolithic vision of hope and toward the proposition that hope in the big sense is actually composed of multiple hopes in the smaller sense?”⁶⁵

Recent studies also suggest that hope is resilient. Bluebond-Langner et al noted that “Children with chronic, life-threatening illnesses hold out hope and for a very long time believe, sometimes until within days and weeks of death, that there are things that can be done to make them better.”⁶⁰ Furthermore, Mack et al found that prognostic disclosure does not inhibit parental hope⁶⁶ and can actually support hope “even when the prognosis is poor.”⁶⁷ However, studies continue to demonstrate reluctance to discuss poor prognoses with adult patients and parents (and presumably children also), especially in the setting of uncertainty. As Mack and Joffe recently noted, “we sometimes respond to this uncertainty by discussing prognosis in vague or overly optimistic terms, waiting for patients to ask for prognostic information, avoiding discussions of prognosis unless the patient is insistent, and focusing conversation on treatment rather than on outcomes.”⁶⁸

Individual Patient Considerations

Prognostic disclosure to children has also been complicated by the realization that each patient is unique, and generalizations must be adapted to the individual patient.

TABLE 4 Considerations and Suggested Approaches for Prognostic Disclosure to Children

Considerations	Recommended Approach
Hope and prognosis	
Growing divide between diagnosis and prognosis	Ask parents and patients about their hopes; encourage them to identify several hopes by asking, "What else?" Notably, continued hope for a cure does not equate to denial or lack of understanding of terminal prognosis.
Role of hope in disclosure	Avoid repeatedly reinforcing negative information to parents, when it may be more beneficial to address their hopes, fears, perceived duties, and expectations.
Therapeutic misconception and misestimation with focus on clinical trials	Ask parents what they see as the benefit of a clinical trial.
Distinction between realistic and unrealistic expectations of patients and parents	
Individual patient considerations	Reassure the patient that he or she is safe to ask any question and, when appropriate, provide opportunities for the patient to have discussions without parents present
Unique needs of individual patients	Use open-ended questions, such as, "Tell me what you know about what is making you sick."
Patient's age, developmental level, and illness experience	Listen for cues that the patient wants more or less information, and reflect these cues to the patient. For example, "It sounds like you might have some questions about your illness." Or "Would you feel comfortable telling me what worries you most?"
Awareness of patient's communication cues	Ask patients how they prefer to communicate (eg, receive information from parents vs medical team; preference for written materials, pictures, videos). Recognize that younger children often communicate nonverbally through play, and this may be the most comfortable way for them to interact. Several therapeutic tools exist to help assess what the child understands and open conversations (eg, <i>My Wishes</i> , ⁵⁴ <i>This Is My World</i> , ⁵⁵ <i>Shop Talk</i> , ^{56,57} and <i>Hear My Voice</i> ⁵⁸).
Family considerations	Ask parents how decisions are made in their family and about their preferences for prognostic disclosure.
Cultural beliefs of family	Ask parents what they think their child may know or understand. Offer an example of ways in which children signal their awareness.
Communication style of family (how decisions are generally made)	Provide parents with guidance on how to broach the subject of prognosis with their child.
Challenge of balancing parents' desires and patient's communication needs	When parents oppose disclosure to their children, use "shuttle diplomacy." ^{59, 60} This diplomatic approach allows all parties to have their voice heard and provides an avenue to deeper understanding of parental beliefs, understanding, and fears.
Children and parents may change over time	Revisit parental preferences for communication throughout treatment. Reinforce parent's sense of being a "good parent."
Clinician considerations	Strive to create a private, quiet, and safe communication atmosphere without prodding the patient into a discussion they are not ready to have.
Manner of telling (who tells, what they say, how it is shared, etc)	Listen to the parents and the child so they can help to guide these sensitive discussions.
Considering the purpose of telling	Take a "team" approach to communication, with openness, eg, to disclosure coming from parents, physician, psychosocial clinician, or a beloved nurse.
Clinicians' potential lack of training and comfort with difficult discussions	
Importance of support and self-care for clinicians who must repeatedly share difficult news with children	

For example, age and developmental level provide rough estimates of a child's understanding of his or her illness, but a patient's unique illness experience may be even more important. Bluebond-Langner et al found that children participating in a cancer camp "engaged in informal discussion about cancer and its treatment, and that information on a variety of topics, ranging from medical procedures to prognosis, was

exchanged."⁶⁹ At the end of the camp, they found a significant increase in children's knowledge about cancer and its treatment, regardless of age. Thus, "Age is not necessarily predictive of what children know.... Children's experience with their illnesses plays a major role in their understanding."⁶⁰

Furthermore, individual children may have different preferences pertaining

to communication. Research before the 2000s focused primarily on preferences of parents, but the few studies that focused on children showed a wide range of preferences for information and involvement in decision-making.⁷⁰⁻⁷² Studies also showed that physicians and parents often misinterpreted the child's fears and level of understanding.^{71,73} For example, physicians reported "significantly more patient fear,

lack of understanding, discomfort, dissatisfaction with choice, and preoccupation with illness than was reported by the patients.”⁷³ Recent studies have shown that most adolescents are able to interpret prognostic disclosure and prefer involvement in end-of-life decision-making.^{68,74–76} However, these studies also show that some children are uncomfortable with such open communication. For example, Jacobs et al showed that although 75% of adolescents thought it appropriate to discuss end-of-life decisions, 12% were not comfortable discussing death.⁷⁶ As noted by Mack and Joffe, “some children may themselves wish to know what is ahead.... 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.”⁶⁸ Conversely, some children may avoid these discussions because they wish to protect their parents, and therefore may need private space apart from family to raise their concerns.^{52,60} Lastly, children can change over time, and may “demonstrate different understandings and present different views to different individuals on different occasions” at different points in their illness.⁶⁰

Clinicians face the difficult task of determining where their patients fall on this spectrum at any given time. To support these children’s needs, authors have encouraged clinicians to seek out and interpret patients’ communication cues and preferred communication style.^{60,77,78} For example, Bluebond-Langner noted that we “should take our cues from the child, to tell the child what he or she wants to know, on his or her terms.”⁷⁷ Responding to these cues, clinicians can indicate their openness to these discussions and provide children with opportunities to engage (or not), opening doors to future conversations. These fleeting

TABLE 5 Effects of Culture and Religion on Prognostic Disclosure

Nondisclosure to children is considered acceptable in many cultures. ⁸⁵
For example, Chinese, Korean, and Russian American families may often withhold challenging information from children to preserve hope, fearing that loss of hope will affect survival. ^{86–88}
In many cultures, “family” can include extended family as well as community members.
Providers ought to respect individual religious, cultural, and family values and practices while preserving the integrity of the parent-child relationship.
When cultural traditions conflict with ethical standards of medical practice, clinicians should first strive to better understand the family’s thoughts and beliefs.
Clinicians should never stereotype families or patients based on their perceived cultural beliefs. Rather, clinicians should simply ask families about their individual preferences.

opportunities should not be ignored. However, there is little empirical evidence showing how to best seek out these cues or how to ensure the clinician is not projecting personal biases onto the patient’s silence. This area requires further study.

Family Considerations

Just as every patient is unique, each family has a unique system of communication. This style of communication can be influenced by the family’s cultural and religious background⁷⁹ (Table 5). Additionally, family communication is largely affected by parental preferences. Although parents generally want to be fully informed,⁶⁶ some prefer to protect their children by withholding negative prognostic information from them.^{48,52,80–82} These parents are attempting to fulfill an integral role as caregiver: protecting and caring for their children.^{60,83} In a recent qualitative study of 18 Romanian parents of children with cancer, parents reported 3 factors that contributed to restricted communication with their child: information overload and emotional turmoil, lack of knowledge and skills for disclosing the diagnosis, and assumptions about burdening the child when discussing cancer.⁸² To fully understand parental behavior, clinicians should give attention to “the reason and emotion they bring to decision-making and their children’s care, their unique responsibilities as parents, and what they learn throughout the illness.”⁸⁴

Since studies began supporting open communication with pediatric patients, authors have recognized the importance of having agreement and cooperation from parents.^{16,24,27,39,60,78,89} They argued that parents know their children best, and they will be responsible for providing emotional comfort and guidance to the child after disclosure. Furthermore, “family and other social interactions are often central to a child’s understanding of his or her experience and any policy that is blind to the social characteristics of children will not serve them well.”⁸⁹ As such, parents have become central in the decision of whether to disclose prognosis to children by managing “the exchange of information between healthcare professionals and the ill child.”⁸⁰ This executive parental role causes some children to feel constrained in their understanding of their illness and decision-making, especially adolescents.⁹⁰ As Mack and Joffe point out, “whereas parents can find opportunities to hold these conversations without the child... children may not have such opportunities unless we consciously provide them.”⁶⁸

However, clinicians and parents are not all-powerful gatekeepers of information. Many children with terminal cancer realize that they are dying even if not told. When parents withhold prognostic information, the child’s growing awareness sometimes occurs in the setting of mutual pretense, where parent and child are both aware of

the prognosis but neither openly acknowledges this to the other.⁵² Parents and children who practice mutual pretense typically do it in some contexts, but not others, which can confuse and frustrate the clinician. In some families, this “can become the dominant mode of interaction between parents and ill children, especially as the disease progresses and a child’s condition deteriorates.”⁶⁰ Some view mutual pretense as potentially harmful to children who are left without anyone to confide in and subsequently must cope in emotional isolation.⁴⁰ However, others note that this mode of interaction can be foundational to the child-parent relationship in certain families, and should be respected as such.^{52,60} One proposed approach to such conflicts is “shuttle diplomacy,” in which physicians serve as an arbitrator between parents and children, trying to hear all voices and find a middle ground for communication and decision-making.⁶⁰

Clinician Considerations

Prognostic disclosure to a seriously ill child is an intensely demanding responsibility,⁹¹ yet there is little evidence to guide clinicians, “particularly in helping them balance children’s and parents’ communication needs.”⁹² A Cochrane review found few studies and limited evidence to support interventions to improve communication with pediatric patients with cancer and their families.⁹³ This lack of guidance likely contributes to the anxiety many clinicians feel when having disclosure conversations. In 1 study, 55% of pediatric oncologists sometimes or always had anxiety before disclosing bad news. Of these physicians, 82% cited “how the family/patient would react” as most worrisome.⁹⁴ This anxiety may underlie the tendency to “limit or carefully tailor the information they give to patients.”⁶⁷

There is also a lack of education and support for trainees. In a recent study, only 27% of residents felt confident about disclosing bad news to parents of seriously ill children, although >90% perceived this to be a very important skill.⁹⁵ In another study, more than half of a cohort of residents reported never having observed the disclosure of bad news about a child or adolescent.⁹⁶ As a result of insufficient training, Hilden et al found that clinicians have “a strikingly high reliance on trial and error in learning to care for dying children.”⁹⁷ Interestingly, a recent study suggested that lack of training can also lead to overconfidence in some clinicians, despite employing communication practices that are not congruent with expert recommendations.⁹⁸ For clinicians to adapt to the increasing complexities of communication in medicine, there must be an infrastructure of evidence and education to mirror this complexity.

Additionally, clinicians need emotional support for themselves. The process of providing difficult news is emotionally taxing, and teaching medical providers coping strategies and self-care is paramount to help them manage the stress of dealing with death.⁹⁹ Institutions should strive to create a healthy atmosphere for medical teams through personal, professional, and organizational support.^{100,101}

Poor communication can increase the suffering of patients and families, while undermining the processes of decision-making and informed consent. For example, a recent study observed physicians during the initial consent conversation (ICC) for enrollment in phase I trials with parents and children. In this study, “Physicians failed to mention no treatment and/or palliative care as options in 68% of ICCs and that the disease was incurable in 85% of ICCs.”¹⁰² Effective and appropriate communication is the bedrock of the

clinician-patient-parent relationship. It affects the patient’s adjustment, well-being, and decision-making process. As Mack and Grier noted, “Although seldom emphasized in medical school, conversation is a major, and sometimes the only, way for physicians to alleviate suffering.”¹⁰³

CONCLUSIONS

Over the past 60 years, communication of prognosis to children has undergone dramatic changes. In the 1950s, most clinicians recommended a protective approach that shielded patients from the harms of bad news. As more objective evidence accumulated in the 1970s, clinicians largely called for more open and direct prognostic communication with children. This preference for an open approach has largely persisted until today, but there is a growing appreciation of the complexities of prognostic disclosure to children. Instead of answering 1 question, health care providers must answer many questions and adapt the answers to the individual clinical scenario: who should tell, what should be told, how should it be told, when to tell, how much do patients and parents understand, what is the responsibility of the clinician, and whether communication should differ depending on the illness,

Perhaps most important, clinicians must answer the question, “What are we trying to accomplish with prognostic disclosure?” Is knowing in and of itself important? Or is the utilization of knowledge by patients what matters? How do we provide the greatest benefit for our patients while doing the least harm? As a first principle, pediatric patients should be given the choice to initiate such conversations in a safe and open atmosphere. Children should know they will not be lied to, but neither will they be forced into disclosure discussions. Clinicians should be

trained to identify a child's cues, to engage in such conversations if they occur, but not to prod or force such discussions. Striving for openness in and of itself, regardless of the individual factors for an individual family, may be detrimental. Rather, clinicians should respect that every patient and parent has unique needs, and these needs may present differently over time and depending on the context.

Lastly, research on prognostic disclosure is still lacking. We need a larger base of empirical studies to inform best practices. Future studies should prospectively explore how prognostic disclosure conversations evolve over time from the child's, parents', and clinician's perspective. Furthermore, studies should seek to elucidate how prognosis is disclosed in practice and how it affects all of the family, including the patient as well as healthy siblings. Ideally, this stronger evidence base will inform new interventions that can improve communication and bolster the clinician-parent-patient relationship.

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ABBREVIATION

ICC: initial consent conversation

REFERENCES

- Sisk B, Frankel R, Kodish E, Isaacson JH. The truth about truth-telling in American medicine: a brief history. *Perm J*. 2016;20(3):215–219
- Code of Ethics of the American Medical Association. 1847. Available at: <https://collections.nlm.nih.gov/bookviewer?PID=nlm:nlmuid-63310420R-bk>. Accessed April 8, 2016
- Mapes CC. Shall patients be informed that they have cancer or syphilis? *N York Med J*. 1898;5:560–562
- Sutro T. Do professional ethics require a physician to disclose to his patient an unfavorable prognosis. *Med Times*. 1915;43:115–117
- Fitts WT Jr, Ravdin IS. What Philadelphia physicians tell patients with cancer. *J Am Med Assoc*. 1953;153(10):901–904
- Oken D. What to tell cancer patients. A study of medical attitudes. *JAMA*. 1961;175:1120–1128
- Cassell EJ. *The Nature of Suffering and the Goals of Medicine*. 2nd ed. New York, NY: Oxford University Press; 2004
- Starr P. *The Social Transformation of American Medicine*. York, NY: Basic Books; 1982
- Lyndon Johnson's "Great Society." Available at: www.ushistory.org/us/56e.asp. Accessed September 21, 2015
- Nahum LH. To tell the truth. *Conn Med*. 1963;27:443–445
- Snyman HW. Should the doctor tell? *S Afr Cancer Bull*. 1974;18(4):130–134
- Kubler-Ross EMD. *Death and Dying*. New York, NY: Macmillan; 1969
- Novack DH, Plumer R, Smith RL, Ochitill H, Morrow GR, Bennett JM. Changes in physicians' attitudes toward telling the cancer patient. *JAMA*. 1979;241(9):897–900
- AMA's Code of Medical Ethics. Available at: www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics.page? Accessed September 21, 2015
- Nagy M. The child's theories concerning death. *J Genet Psychol*. 1948;73(First Half):3–27
- Friedman SB, Chodoff P, Mason JW, Hamburg DA. Behavioral observations on parents anticipating the death of a child. *Pediatrics*. 1963;32:610–625
- Blom GE. The reactions of hospitalized children to illness. *Pediatrics*. 1958;22(3):590–600
- Walker EA Jr. Management of the child with a fatal disease. *Clin Pediatr (Phila)*. 1964;3:418–427
- Death in childhood. *Can Med Assoc J*. 1968;98(20):967–969
- Alvarez WC. Care of the dying. *J Am Med Assoc*. 1952;150(2):86–91
- Natterson JM, Knudson AG Jr. Observations concerning fear of death in fatally ill children and their mothers. *Psychosom Med*. 1960;22:456–465
- Lourie R. The pediatrician and the handling of terminal illness. *Pediatrics*. 1963;32(4):477–479
- Agranoff JH, Mauer AM. What should the child with leukemia be told? *Am J Dis Child* 1960. 1965;110:231
- Green M. Care of the dying child. *Pediatrics*. 1967;40(suppl 3):492–497
- Yudkin S. Children and death. *Lancet*. 1967;1(7480):37–41
- Richmond JB, Waisman HA. Psychologic aspects of management of children with malignant diseases. *AMA Am J Dis Child*. 1955;89(1):42–47
- Karon M, Vernick J. An approach to the emotional support of fatally ill children. *Clin Pediatr (Phila)*. 1968;7(5):274–280
- Morrissey J. A note on interviews with children facing imminent death. *Soc Casework*. 1963;44(6):343–345
- Nitschke R, Meyer WH, Sexauer CL, Parkhurst JB, Foster P, Huszti H. Care of terminally ill children with cancer. *Med Pediatr Oncol*. 2000;34(4):268–270
- Lourie RS, Hatleberg J, Guin GH, Leikin SL. Panel discussion: what to tell the parents of a child with cancer. *Clin Proc Child Hosp Dist Columbia*. 1961;17:91–99
- Share L. Family communication in the crisis of a child's fatal illness: a literature review and analysis. *Omega*. 1972;3:187–201
- Morrissey J. Children's adaptation to fatal illness. *Soc Work*. 1963;8(4):81–88
- Pernick MS. Childhood death and medical ethics: an historical perspective on truth-telling in pediatrics. *Prog Clin Biol Res*. 1983;139:173–188
- Evans AE, Edin S. If a child must die. *N Engl J Med*. 1968;278(3):138–142. 10.1056/NEJM196801182780304

35. Spinetta JJ, Rigler D, Karon M. Anxiety in the dying child. *Pediatrics*. 1973;52(6):841–845
36. Spinetta JJ. The dying child's awareness of death: a review. *Psychol Bull*. 1974;81(4):256–260
37. Slavin LA, O'Malley JE, Koocher GP, Foster DJ. Communication of the cancer diagnosis to pediatric patients: impact on long-term adjustment. *Am J Psychiatry*. 1982;139(2):179–183
38. Mitchell NL, Schulman KR. The child and the fear of death. *J Natl Med Assoc*. 1981;73(10):963–967
39. Vernick J, Karon M. Who's afraid of death on a leukemia ward? *Am J Dis Child*. 1965;109(109):393–397
40. Binger CM, Ablin AR, Feuerstein RC, Kushner JH, Zoger S, Mikkelsen C. Childhood leukemia. Emotional impact on patient and family. *N Engl J Med*. 1969;280(8):414–418
41. Waechter EH. Children's awareness of fatal illness. *Am J Nurs*. 1971;7(6):1168–1172
42. Spinetta J. Adjustment in children with cancer. *J Pediatr Psychol*. 1977;2(2):49–51
43. Karon M. The physician and the adolescent with cancer. *Pediatr Clin North Am*. 1973;20(4):965–973
44. Jamison RN, Lewis S, Burish TG. Psychological impact of cancer on adolescents: self-image, locus of control, perception of illness and knowledge of cancer. *J Chronic Dis*. 1986;39(8):609–617
45. Nitschke R, Humphrey GB, Sexauer CL, Catron B, Wunder S, Jay S. Therapeutic choices made by patients with end-stage cancer. *J Pediatr*. 1982;101(3):471–476
46. Warren G. Discussion summary: truth telling in pediatrics. *Prog Clin Biol Res*. 1983;139:195–196
47. Pantell RH, Stewart TJ, Dias JK, Wells P, Ross AW. Physician communication with children and parents. *Pediatrics*. 1982;70(3):396–402
48. Claffin CJ, Barbarin OA. Does "telling" less protect more? Relationships among age, information disclosure, and what children with cancer see and feel. *J Pediatr Psychol*. 1991;16(2):169–191
49. Kreicbergs U, Valdimarsdóttir U, Onelöv E, Henter J-I, Steineck G. Talking about death with children who have severe malignant disease. *N Engl J Med*. 2004;351(12):1175–1186
50. Masera G, Chesler MA, Jankovic M, et al. SIOP Working Committee on Psychosocial Issues in Pediatric Oncology: guidelines for communication of the diagnosis. *Med Pediatr Oncol*. 1997;28(5):382–385
51. Committee on Bioethics, American Academy of Pediatrics. Informed consent, parental permission, and assent in pediatric practice. *Pediatrics*. 1995;95(2):314–317
52. Bluebond-Langner M. *The Private Worlds of Dying Children*. Princeton, NJ: Princeton University Press; 1978
53. Wiener L, Mellins CA, Marhefka S, Battles HB. Disclosure of an HIV diagnosis to children: history, current research, and future directions. *J Dev Behav Pediatr*. 2007;28(2):155–166
54. Aging with Dignity. *My Wishes*. Tallahassee, FL: Aging with Dignity; 2015
55. Zadeh S, Wiener L. *This is My World*, 2nd ed. Bethesda, MD: National Institutes of Mental Health; 2011
56. Wiener L, Battles H, Mamalian C, Zadeh S. ShopTalk: a pilot study of the feasibility and utility of a therapeutic board game for youth living with cancer. *Support Care Cancer*. 2011;19(7):1049–1054
57. National Cancer Institute. Shop Talk. Available at: <https://ccr.cancer.gov/Pediatric-Oncology-Branch/psychosocial/education>. Accessed April 12, 2016
58. Alberta Health Services. Hear my voice. Available at: http://rotaryflamshouse.ca/pdfs/Hear_My_Voice_Cards.pdf. Accessed April 12, 2016
59. Bluebond-Langner M, DeCicco A, Belasco J. Involving children with life-shortening illnesses in decisions about participation in clinical research: a proposal for shuttle diplomacy and negotiation. In: Kodish E, ed. *Ethics and Research with Children: A Case-Based Approach*. Oxford, New York: Oxford University Press; 2005:323–345
60. Bluebond-Langner M, Belasco JB, DeMesquita Wander M. "I want to live, until I don't want to live anymore": involving children with life-threatening and life-shortening illnesses in decision making about care and treatment. *Nurs Clin North Am*. 2010;45(3):329–343
61. Chesler MA, Paris J, Barbarin OA. "Telling" the child with cancer: parental choices to share information with ill children. *J Pediatr Psychol*. 1986;11(4):497–516
62. What are the key statistics for childhood cancer? January 2015. Available at: www.cancer.org/cancer/cancerinchildren/detailedguide/cancer-in-children-key-statistics. Accessed January 5, 2016
63. Kodish E, Post SG. Oncology and hope. *J Clin Oncol*. 1995;13(7):1817
64. Delvecchio Good MJ, Good BJ, Schaffer C, Lind SE. American oncology and the discourse on hope. *Cult Med Psychiatry*. 1990;14(1):59–79
65. Feudtner C. The breadth of hopes. *N Engl J Med*. 2009;361(24):2306–2307
66. Mack JW, Wolfe J, Grier HE, Cleary PD, Weeks JC. Communication about prognosis between parents and physicians of children with cancer: parent preferences and the impact of prognostic information. *J Clin Oncol*. 2006;24(33):5265–5270
67. Mack JW, Wolfe J, Cook EF, Grier HE, Cleary PD, Weeks JC. Hope and prognostic disclosure. *J Clin Oncol*. 2007;25(35):5636–5642
68. Mack JW, Joffe S. Communicating about prognosis: ethical responsibilities of pediatricians and parents. *Pediatrics*. 2014;133(suppl 1):S24–S30
69. Bluebond-Langner M, Perkel D, Goertzel T, Nelson K, McGeary J. Children's knowledge of cancer and its treatment: impact of an oncology camp experience. *J Pediatr*. 1990;116(2):207–213
70. Levenson PM, Pfefferbaum BJ, Copeland DR, Silberberg Y. Information preferences of cancer patients ages 11–20 years. *J Adolesc Health Care*. 1982;3(1):9–13
71. Pfefferbaum B. Communication with pediatric cancer patients. *Am J Psychiatry*. 1982;139(6):844–845

72. Ellis R, Leventhal B. Information needs and decision-making preferences of children with cancer. *Psychooncology*. 1993;2(4):277–284
73. Pfefferbaum B, Levenson PM, van Eys J. Comparison of physician and patient perceptions of communications issues. *South Med J*. 1982;75(9):1080–1083
74. Hinds PS, Drew D, Oakes LL, et al. End-of-life care preferences of pediatric patients with cancer. *J Clin Oncol*. 2005;23(36):9146–9154
75. Wiener L, Zadeh S, Battles H, et al. Allowing adolescents and young adults to plan their end-of-life care. *Pediatrics*. 2012;130(5):897–905
76. Jacobs S, Perez J, Cheng YI, Sill A, Wang J, Lyon ME. Adolescent end of life preferences and congruence with their parents' preferences: results of a survey of adolescents with cancer. *Pediatr Blood Cancer*. 2015;62(4):710–714
77. Bluebond-Langner M. Worlds of dying children and their well siblings. *Death Stud*. 1989;13(1):1–16
78. Leikin SL. An ethical issue in pediatric cancer care: nondisclosure of a fatal prognosis. *Pediatr Ann*. 1981;10(10):37–41, 44–45
79. Wiener L, McConnell DG, Latella L, Ludi E. Cultural and religious considerations in pediatric palliative care. *Palliat Support Care*. 2013;11(1):47–67
80. Clarke S-A, Davies H, Jenney M, Glaser A, Eiser C. Parental communication and children's behaviour following diagnosis of childhood leukaemia. *Psychooncology*. 2005;14(4):274–281
81. Whittam EH. Terminal care of the dying child. Psychosocial implications of care. *Cancer*. 1993;71(suppl 10):3450–3462
82. Badarau DO, Wangmo T, Ruhe KM, et al. Parents' challenges and physicians' tasks in disclosing cancer to children. a qualitative interview study and reflections on professional duties in pediatric oncology. *Pediatr Blood Cancer*. 2015;62(12):2177–2182
83. Matsuoka M, Narama M. Parents' thoughts and perceptions on hearing that their child has incurable cancer. *J Palliat Med*. 2012;15(3):340–346
84. Bluebond-Langner M, Belasco JB, Goldman A, Belasco C. Understanding parents' approaches to care and treatment of children with cancer when standard therapy has failed. *J Clin Oncol*. 2007;25(17):2414–2419
85. Elwyn TS, Fetters MD, Gorenflo W, Tsuda T. Cancer disclosure in Japan: historical comparisons, current practices. *Soc Sci Med*. 1998;46(9):1151–1163
86. Brolley G, Tu A, Wong E; Patient and Family Education Services at the University of Washington Medical Center. Culture clues: communicating with your Chinese patient. 2007. Available at: <http://depts.washington.edu/pfes/CultureClues.htm>
87. Song S, Ahn P; Patient and Family Education Services at the University of Washington Medical Center. Culture clues: Communicating with your Korean patient. 2007. Available at: <http://depts.washington.edu/pfes/CultureClues.htm>
88. Patient and Family Education Services at the University of Washington Medical Center. Culture clues: communicating with your Russian patient. 2007. Available at: <http://depts.washington.edu/pfes/CultureClues.htm>
89. Kon AA. Assent in pediatric research. *Pediatrics*. 2006;117(5):1806–1810 doi: 10.1542/peds.2005-2926
90. Young B, Dixon-Woods M, Windridge KC, Heney D. Managing communication with young people who have a potentially life threatening chronic illness: qualitative study of patients and parents. *BMJ*. 2003;326(7384):305
91. Stenmarker M, Hallberg U, Palmérus K, Márky I. Being a messenger of life-threatening conditions: experiences of pediatric oncologists. *Pediatr Blood Cancer*. 2010;55(3):478–484
92. Young B, Ward J, Salmon P, Gravenhorst K, Hill J, Eden T. Parents' experiences of their children's presence in discussions with physicians about Leukemia. *Pediatrics*. 2011;127(5). Available at: www.pediatrics.org/cgi/content/full/127/5/e1230
93. Ranmal R, Prictor M, Scott JT. Interventions for improving communication with children and adolescents about their cancer. *Cochrane Database Syst Rev*. 2008;(4):CD002969 doi:10.1002/14651858.CD002969.pub2
94. Johnston DL, Appleby W. Pediatric oncologists opinions on breaking bad news. *Pediatr Blood Cancer*. 2011;56(3):506
95. Rider EA, Volkan K, Hafler JP. Pediatric residents' perceptions of communication competencies: Implications for teaching. *Med Teach*. 2008;30(7):e208–e217
96. Dubé CE, LaMonica A, Boyle W, Fuller B, Burkholder GJ. Self-assessment of communication skills preparedness: adult versus pediatric skills. *Ambul Pediatr*. 2003;3(3):137–141
97. Hilden JM, Emanuel EJ, Fairclough DL, et al. Attitudes and practices among pediatric oncologists regarding end-of-life care: results of the 1998 American Society of Clinical Oncology survey. *J Clin Oncol*. 2001;19(1):205–212
98. Sanderson A, Hall AM, Wolfe J. Advance care discussions: pediatric clinician preparedness and practices. *J Pain Symptom Manage*. 2016;51(3):520–528
99. Williams CM, Wilson CC, Olsen CH. Dying, death, and medical education: student voices. *J Palliat Med*. 2005;8(2):372–381
100. Meadors P, Lamson A. Compassion fatigue and secondary traumatization: provider self care on intensive care units for children. *J Pediatr Health Care*. 2008;22(1):24–34
101. Abrams AN, Muriel AC, Wiener L. *Pediatric Psychosocial Oncology: Textbook for Multidisciplinary Care*. Cham, Switzerland: Springer International Publishing; 2016
102. Miller VA, Cousino M, Leek AC, Kodish ED. Hope and persuasion by physicians during informed consent. *J Clin Oncol*. 2014;32(29):3229–3235
103. Mack JW, Grier HE. The Day One Talk. *J Clin Oncol*. 2004;22(3):563–566

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