

Prognostic Disclosures to Children: A Historical Perspective

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AMA – American Medical Association

ICC – Initial Consent Conversation

US – United States

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Dr. Sisk conceptualized and designed this review study, drafted the initial manuscript, and approved the final manuscript as submitted.

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Abstract:

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. Prior to 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 four 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 four 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.

Introduction:

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 US, but also because diagnosis and prognosis of cancer prior to the 1970s were largely synonymous – a death sentence. We follow this history to 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.

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 (AMA) Code of Ethics in 1847 stated: “A physician should not be forward to make gloomy prognostications 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 wellbeing 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 prior.¹³ This trend toward open, partnership-based communication has persisted. According

to current AMA 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} Prior to this time, most child mortality was attributable to 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 Due to 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 three 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 one 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 four 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 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 upon 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, “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 four 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. Out 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 (e.g. relief of uncertainty, opportunities to express fears). Additionally, there was a shift in the view of the child from a passive recipient of actions (e.g. 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 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’.”⁵⁴ In 2015, the average 5-year

survival rate for pediatric cancer reached 80%.⁵⁵ 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.”⁶² 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. For example, age and developmental level provide rough estimates of a child’s understanding of his/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."⁶²

Furthermore, individual children may have different preferences pertaining to communication. Research prior to 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 while 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.^{52,62} 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.⁶²

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.^{62,77,78} 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 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 impacted by the family's cultural and religious background.⁷⁹(Table 5) Additionally, family communication is largely affected by parental preferences. While parents generally want to be fully informed⁶⁶, some prefer to protect their children by withholding negative prognostic information from them.^{48,80,52,81,82} These parents are attempting to fulfill an integral role as caregiver – protecting and caring for their children.^{62,83} In a recent qualitative study of 18 Romanian parents of children with cancer, parents reported three 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.^{16,24,27,39,62,78,89} 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.”⁶² 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.^{52,62} One proposed approach to such conflicts is “shuttle diplomacy”, where physicians serve as an arbitrator between parents and children, trying to hear all voices and find a middle ground for communication and decision-making.⁶²

Clinician Considerations

Prognostic disclosure to a seriously ill child is an intensely demanding responsibility⁹¹, 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 cancer patients and their families.⁹³ This lack of guidance likely contributes to the anxiety many clinicians feel when having disclosure conversations. In one study, 55% of pediatric oncologists sometimes or always had anxiety prior to 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 over 90% perceived

this to be a very important skill.⁹⁵ In another study, over 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 consummate 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 also 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 impacts the patient’s adjustment, wellbeing, 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

Conclusion

Over the last 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 one question, healthcare 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, should communication differ depending on the illness?

Perhaps most importantly, 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, parent’s 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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