

Chapter 8

Telling the Child: Ethics of the Involvement of Minors in Health Care Decision-Making and in Considering Parental Requests to Withhold Information from Their Child



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Abstract Truth-telling is a core value in medical ethics, and its importance has only grown in recent decades with the increased focus on patient-centered care. How and whether to inform children about aspects of their health care (and how/whether to include them in health care decision-making), however, is even more complex. In this chapter, using an example case, the authors describe some of the ethical underpinnings of truth-telling both in pediatrics and more generally, as well as important features of the disclosure of health care information to children. They then provide arguments both for and against withholding information from children when that is requested by parents, examining some common arguments made for each of these strategies in the literature and in clinical practice. After touching upon unique considerations regarding disclosure of different types of information to minors, the authors close by providing practical guidance on how clinicians can respond when parents explicitly request to not tell their child information about their health and/or health care.

Keywords Truth-telling · Consent · Assent · Decision-making · Disclosure · Pediatric ethics

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8.1 Introduction

Truth-telling is among the core ethical values in health care, but it has a particularly unique (and complex) role in pediatrics. In this chapter, we explore practical and ethical considerations in truth-telling in pediatric health care. First, we introduce a case to provide a foundation for these challenging, nuanced concepts. Next, we describe some of the ethical underpinnings of truth-telling in medicine, both generally and specifically in the care of children, followed by a description of some of the important features of information disclosure to children and of involving minors in health care decision-making. Then, we provide several arguments in support of withholding information from children if such is requested by parents, followed by several arguments against doing so. Finally, we conclude with practical guidance for clinicians when faced with a parent requesting to withhold information from their child, referring back to our case and providing concrete steps for those caring for children and their families.

8.2 Case Description

Billy is a 9-year-old, previously healthy boy who has just been diagnosed with leukemia (a cancer of the blood cells), which was diagnosed based on a screening blood test by his pediatrician. He is asymptomatic and feels very well. His health care team plans to run additional tests in the next few days, but Billy likely will require admission to the hospital to start his chemotherapy treatment course. His mother and father, who are both understandably distressed by the news of Billy's diagnosis, wish not to tell him that he has cancer. "He just got treated with antibiotics for an ear infection," they state. "Can we just tell him that he needs medicine for another infection? He won't understand what cancer is anyways, and telling him will just make him scared. What's the point of that?"

8.3 Ethical Underpinnings of Truth-Telling

Truth-telling ("veracity") is considered a core principle in modern medical ethics (Beauchamp and Childress 2009). In health care in general, as it relates to adult medicine, truth-telling typically refers to complete, comprehensive, and accurate provision of information about a patient's diagnosis, treatment option(s), and prognosis. Chapter 4 discuss the ethical theory that underpins the obligations of clinicians and parents to children receiving health care services, but several points about truth-telling and disclosure of information warrant mentioning here. First, the obligation to tell the truth to patients ultimately is grounded in the respect owed to them as persons (Beauchamp and Childress 2009; Jonsen et al. 2015). Even those who

cannot legally make their own decisions (e.g., those without capacity and/or minor children) deserve respect, including being told the truth. Further, individuals cannot make well-informed choices about their care without information about their options; this relates to the individual's ability to provide informed consent (or assent), but also more fundamentally to their autonomous right to control what is done to their body. Pediatric and adolescent assent are discussed in greater detail elsewhere in this text (See Chaps. 2 and 7), but for children, adolescents, and adults, informed decisions rely on the provision of adequate information. Truth-telling also is closely connected to other fundamental ethical principles, such as fidelity. The clinician-patient relationship implicitly assumes—and relies upon—truthful delivery of information by both the clinician and patient. Without this, one of the most fundamental aspects of health care can be endangered: trust. Finally, actively engaging patients in the decision-making process by providing them with information about their diagnosis, treatment options, and prognosis gives them the opportunity to take an active role in their treatment. This may potentially improve health care outcomes (a beneficence-based argument) (Lo 2009). That is not to say, however, that truth-telling is obligatory in all circumstances. Below, we will explore whether/when non-disclosure of information, limited disclosure, or even outright lying might be ethically justifiable.

It is also worth distinguishing between truth-telling as a legal entity versus an ethical one. Here, we will be focusing on ethical considerations around truth-telling. Lying is only rarely explicitly illegal in the health care setting (for example, when testifying under oath), but the threshold for criminality is a very different standard than that for ethical obligation/expectation (and certainly not to say that a physician who lied to a patient or parent might not be subject to civil action). Importantly, legal standards regarding decision-making for children, such as statutes addressing mature minors and emancipated minors, are complex and discussed elsewhere in this text. While comprehensive truthful disclosure has not always been considered ethically obligatory, most codes of medical ethics now advocate for the fundamental importance of telling the truth. The American Medical Association, for instance, had previously supported “therapeutic privilege” (American Medical Association 2017; Beauchamp and Childress 2009), which is the idea that a clinician can withhold information they feel would only harm a patient. However, they now state that, as long as a patient has capacity, “withholding information without the patient’s knowledge or consent is ethically unacceptable” (American Medical Association 2017, p. 31).

8.4 Ethical Underpinnings of Truth-Telling in Pediatrics

In many ways, the ethical underpinnings of truth-telling in pediatrics align with those in the adult health care setting. The American Academy of Pediatrics states that, for both children and adults, the informed consent process is grounded in the same fundamental ethical principles of beneficence, justice, and respect for autonomy (Katz and Webb 2016).

While there is significant overlap in ethical decision-making between pediatric and adult health care, there are also notable differences. One example is that, while adults with decisional capacity provide first-person informed consent for treatment, children have not yet developed the autonomy to do so. As described in greater detail in Chap. 7, in pediatrics, the informed consent process requires seeking the “informed permission” of the child’s parent(s). This is achieved through a process of shared decision-making between parents and the child’s clinician, ideally with assent from the child in accordance with their age, maturity, and developmental capacity (Katz and Webb 2016). This creates a trilateral clinical relationship structure which differs from that of the clinician-patient dyad that is typical in the adult population, lending added complexity to the pediatric health care encounter.

In addition, as described elsewhere in this text, children, by virtue of their age, are at varying stages of development and maturity. This, in part, informs the degree to which children can be substantively involved in decision-making, both in terms of providing assent (a concept that has evolved over time from absence of explicit dissent to one of active engagement) and more generally (Leikin 1983). In turn, this variation necessitates highly nuanced approaches to caring for them, and it can be challenging to discern how and to what extent children should be engaged in health care decisions that are being made by others on their behalf. There is wide agreement in bioethics, however, that, while clinicians and parents may weigh numerous factors when considering health care decisions for a child, the child’s interests must remain central (See also Chap. 4) (McCullough 2009). This being said, clinicians often must balance competing ethical obligations when caring for pediatric patients—those to the child (beneficence/nonmaleficence), to parents (autonomy/parental authority), and to clinicians themselves by not acting in ways which violate their own professional/personal integrity. When these ethical obligations come into conflict, it can be difficult to weigh them. In some circumstances, clinicians may determine that their obligations to the child outweigh those to parents (Diekema 2004).

8.5 Important Features of Information Disclosure in Pediatrics

There are several unique considerations around information disclosure in pediatrics. Perhaps most important are the child’s age and developmental capacity, which greatly inform the degree of detail and manner in which information will be shared. Preschool-aged children, for example, do not possess the maturity required to participate in health care decisions to the degree that older children do, such as typically developing adolescents. Even so, as noted above, all children, regardless of age or developmental capacity, are deserving of respect and generally should be afforded the opportunity to participate in their medical care to the extent possible, with guidance from skilled clinicians and input from parents. As described further in our practical

guidance below, the participation of multidisciplinary members of the health care team often are helpful in these discussions.

Historically, many parents have worried that disclosure of diagnostic or prognostic information would cause undue psychological or emotional distress to their child (Sisk, 2016). In our case scenario, Billy's parents cite this as their reason for not wanting him told about his leukemia diagnosis. It is important to keep in mind that the disclosure of health-related information to children does not necessarily need to be an "all or nothing" proposition. Approaches can be nuanced and tailored to best meet the needs of each individual child and family. In some situations, parents and clinicians might agree that particular aspects of diagnostic or prognostic information will be shared with the child and not others. Or, depending on the child's maturity, they might agree to let the child "take the lead" by providing information only in response to the child's queries.

Families' cultural, religious, or philosophical values also may influence their preferences for treatment decision-making, including information sharing (for further information on this topic, see also Chap. 2). Rosenberg and colleagues thoughtfully explored these issues, emphasizing the importance of eliciting and respecting cultural differences and working together with families to proceed in ways which respect their values while also respecting the child's developing autonomy (Rosenberg et al. 2017). The authors suggest language to help guide conversations with parents where a request for nondisclosure appears to be "culturally mediated." Of course, no culture or religion is monolithic in nature, and families from the same cultural or religious background may have different interpretations of what the culture or religion requires of them. It is also important to keep in mind that, while some societies such as the United States prize patient autonomy and parental authority, others are more communitarian in nature and may weigh more heavily the interests of the family as a whole, for example (See Chap. 12). Humility is important when working with families from varied sociocultural backgrounds and navigating differences between cultural norms. This includes norms around telling information to a child and, more generally, norms of an individual family. When these conflict with the values of the clinical team, treatment decision-making becomes even more complex (Rosenberg et al. 2017).

8.6 Arguments for Withholding Information from Children

Occasionally, parents will express interest in keeping information from their children for various reasons. Typically, this is not malicious in nature, but rather a well-intentioned attempt to protect children from harm. In our case, for example, Billy's parents state their concern that being told his cancer diagnosis will only scare Billy. Here, we explore several common arguments in support of withholding information from children when requested by parents. Importantly, we are only discussing here nondisclosure of information when such is explicitly requested by the minor's

parents/guardians, not due to the clinician's own prerogative. The latter is quite infrequent and beyond the scope of this discussion. We also do not intend here to argue that any of these reasons carries greatest valence, but only to familiarize readers with them.

8.6.1 *Harm Avoidance*

A common reason that parents might wish to withhold information from their child is to avoid hurting them. As in Billy's case, a parent may feel that telling their child about their diagnosis (or prognosis, or upcoming treatment, or other aspect of care) will cause them physical or psychological harm (Bluebond-Langner 1980). This rationale is not unlike that of clinicians who invoke therapeutic privilege to withhold information. Further, it is neither easy nor straightforward to provide complex, distressing information to a child in an age- and developmentally-appropriate fashion. Parents may report concern that the process of delivering the information itself may be harmful, whether due to an impact on trust or other aspect of the relationship with the child. Finally, sometimes information might be withheld in an attempt to protect others. Consider, for example, if Billy's mother wished to not tell Billy or others in their family about his diagnosis for fear of the impact that information would have on his elderly grandmother. Importantly, many parents understandably worry about information such as this harming their child while considering less the counterfactual—the potential harms from withholding the information (harms that we will discuss further below).

8.6.2 *"It's My Right"*

While there is significant sociocultural variability (as introduced above and described further below), many Western countries and cultures are quite individualistic. This is demonstrated, in part, by a Western focus on patient autonomy, and in pediatrics, on parental authority. Many parents feel strongly about their right and responsibility to care for their children as they best see fit, both regarding health care and more generally. As a result, it is common for parents to reference rights-based arguments for desiring to withhold information from their child (See also Chap. 11). Importantly, this typically is a well-intentioned desire, aimed at doing what they feel to be best for their child. Billy's father, for example, might consider it his paternal right (or even his paternal duty) to protect his son in the best way he knows how, even if the clinical team disagrees with his reasoning. Parental authority, however, is not absolute, as described throughout this text, so this right also is not absolute.

8.6.3 Sociocultural Considerations

Truth-telling practices in Western medicine have evolved greatly in recent decades, from a prior era of nondisclosure as standard to now, when nondisclosure is, as described above, only rarely ethically supported. Research demonstrates that shifts in favor of disclosure may have not been as significant in other areas of the world (including Asia and the Middle East, for example), (Rosenberg et al. 2017) and that disclosure practices in many cultures/communities vary. Parents may sometimes, as a result, request not to disclose information to their child based on their sociocultural beliefs (particularly if those differ from those of the clinical team). Interestingly, however, globalization and the near-universal access to information via the internet may have decreased variability in such practices across geographic and sociocultural lines. In Billy's case, it is conceivable that his cultural or religious background considers it unnecessary, or even inappropriate, to deliver news of a cancer diagnosis to a child, hence his parents' reticence. These sociocultural considerations are incredibly important, and further research is needed to fully understand how best to balance respecting sociocultural beliefs with optimally caring for—and informing—children.

8.6.4 Right to an Open Future

Joel Feinberg first described a child's right to an open future, arguing that children will one day be autonomous adults, so their future opportunities ("open future") should be limited as little as possible (Feinberg 1980). Chapter 3 of this text provides a more detailed discussion of the concept of a child's right to an open future, which is often referenced as a benchmark for how to make decisions for children who cannot do so themselves. In this setting, it could be argued that providing information might prevent a child from being able to "be a kid," much like how arguments have been made for withholding information from adult patients according to therapeutic privilege (American Medical Association 2017; Beauchamp and Childress 2009). Here, one could argue that telling Billy he has cancer would impose an unnecessary burden on him and risk taking away his opportunity to continue to live a free and happy childhood. That said, however, as discussed further below, in not providing this information, clinicians also limit certain future opportunities to the child (e.g., having a voice in treatment decisions, being involved in legacy-building activities, etc.).

8.7 Arguments Against Withholding Information from Children

In addition to arguments supporting a parent's request to withhold information from their child, there are important arguments in favor of disclosure of diagnostic, prognostic, and other health care information. Here, we provide several common considerations.

8.7.1 Deontological Versus Consequentialist Perspectives

There has been a growing trend in pediatrics in favor of disclosure of health-related information to children (Committee on Hospital Care 2012; Sisk et al. 2016). Theoretically, from a deontological perspective, most would argue that telling patients the truth is simply "the right thing to do." This rule-based ethic holds that the rightness or wrongness of an action is grounded in the action itself, regardless of the action's outcome (e.g., "it is always wrong to lie.") (Beauchamp and Childress 2009). Therefore, a strict deontologist would not be likely to honor Billy's parents' request to withhold his cancer diagnosis from him, because this would violate the rule of truth-telling and therefore be considered ethically unacceptable.

In contrast, a consequentialist approach evaluates an action's rightness or wrongness based upon its resulting consequences. In this view, withholding information from a child could be justified if doing so would further the child's interests in important ways, or achieve some 'good' outcome, such as protecting the child from harm. A consequentialist clinician might either honor or not honor Billy's parents request to withhold his cancer diagnosis from him, depending upon their assessment of the likely consequences. Billy's parents' request to withhold his diagnosis from him on the basis that this information would harm him reflects a consequentialist approach.

8.7.2 "It's the Child's Right"

In addition to the benefits discussed previously, engaging children in health care decisions through information disclosure supports their burgeoning autonomy. Most children ultimately will become future autonomous decision-makers. Withholding medical information from them in childhood could deprive them of important opportunities to develop skills for medical decision-making over time—skills they will need once they transition into adulthood and begin making their own health care decisions (American Medical Association 2017). For Billy, having the opportunity to know of his diagnosis and participate in his health care decision-making early on (via provision of assent or otherwise) may help improve the quality of the therapeutic relationship by fostering his trust in both his parents and providers. In addition,

allowing him to assent (or to dissent, if appropriate) to certain treatments conveys respect to him and also may reduce feelings of powerlessness about his condition by providing him as much control as is clinically reasonable. Demonstrating respect for the child and fostering trust early in the clinical relationship is important, and especially so when the child has a condition which will require frequent or long-term encounters with the health care system.

8.7.3 *Right to an Open Future*

When responding to parental requests for nondisclosure it is also important to consider the possible trade-offs associated with the decision. For example, if the request to withhold information is honored, are there opportunities that will be foreclosed to the child that might otherwise have been important to them? Though arguments (as above) can be made for *withholding* information in order to protect a child's open future (Feinberg 1980) (See also Chap. 3), arguments can also be made for *providing* that information to protect a child's right to an open future. For example, for children with incurable illness, withholding prognostic information could foreclose the opportunity to say goodbye to loved ones and friends, or to participate in legacy-making activities. Research examining the impact of legacy-making for children with serious illness has identified numerous benefits for both children and their family members, including giving ill children the chance to communicate about death and do and/or say something that will help them see that they will be remembered and providing a coping strategy for patients and families (Foster et al. 2012).

Billy is very early in his diagnosis. Hopefully he responds well to treatment, in which case legacy-making will not need to be a consideration in his care. However, for all options to remain open to him, he must be made aware (in an age- and developmentally-appropriate fashion) of his diagnosis and what choices he is empowered to make, especially given what might be at stake for him, and that he is the one who will have to bear both the benefits and burdens of treatment. As we have discussed, an open future argument could be made either in favor of or in favor against information disclosure. The best approach for an individual child is context-specific and will be dependent on a number of factors, such as the child's age and maturity level, the nature of the child's illness and their previous experience with it, patient and family dynamics and values, and sociocultural considerations.

8.7.4 *Children Often Are Already Aware*

Research also has shown that, particularly in the setting terminal illness, a child may already be aware of their poor prognosis but not "let on" out of a desire to protect their caregivers. Children and their caregivers may engage in a behavioral dynamic known as "mutual pretense," where all parties are aware of the child's poor prognosis, but

none acknowledges this openly (Sisk et al. 2016). As a result, attempts to withhold potentially harmful information actually may be based on a false premise—that the child is unaware of the information. It is certainly conceivable that in our case Billy already is aware that he has cancer (or at least that he has something other than “another infection”) such that withholding that information from him—no matter the rationale for doing so—cannot achieve the parents’ goal of harm avoidance. In fact, it is possible that harm could be compounded by nondisclosure if Billy already knows about his diagnosis or has sensed that caregivers are not being truthful with him. For example, it is possible that without disclosure of his diagnosis he could imagine that he is far sicker than he actually is, causing him the fear and anxiety that his parents are hoping to avoid. The very nature of mutual pretense, when this is present, makes it difficult to discern precisely how much a child understands about their medical condition. However, this warrants consideration for discussion with parents so that they can be best equipped to make health care decisions that they believe to be in their child’s best interest.

8.7.5 Trust

A final important consideration, as described further above, is that of trust. Trust is a fundamental component of health care; and withholding information—particularly if that information could later be discovered—runs the risk of irreparably harming the trilateral clinical relationship (Katz and Webb 2016). This is a particularly compelling argument, as once trust is broken, it can be very difficult to repair. In Billy’s case, it is conceivable that he would later learn the truth about his diagnosis, which could greatly harm his relationship both with his parents and the health care team and possibly have a negative impact on his willingness to engage in his care going forward.

8.8 Differences Based on Type of Information

Health care decisions rest on numerous types of information: diagnosis, prognosis, treatment options, potential treatment toxicities, etc. Parents may prefer not to disclose any or all of these information types to their minor children throughout the illness trajectory. The details and potential implications of non-disclosure vary somewhat with the type of information being withheld. Some pediatricians and ethicists might approach this case differently if Billy’s parents wished to withhold his new cancer diagnosis from him than they would if his parents wished not to tell him that, for example, his cancer had returned after multiple courses of treatment and he was now expected to die. It is important, when considering both how best to integrate a minor into their health care decision-making and whether/how to provide information to them, to attend to the type of information to be disclosed and the child’s place in their illness trajectory. As described by anthropologist Myra Bluebond-Langner

regarding her research with children with leukemia throughout the illness trajectory, it may well be that the greatest challenge “is not whether to tell, but how to tell, in a way that respects the children and all of their many, often conflicting needs” (Bluebond-Langner 1980, p. 235).

8.9 Practical Guidance for Navigating Parental Requests for Nondisclosure

Every patient is unique, as are the circumstances surrounding their care. As a result, all instances of parental requests for nondisclosure should be considered on a case-by-case basis to ensure that the unique considerations of the patient, their family, and their socio-clinical circumstances are adequately considered. Here, we provide some general practical guidance for considering these challenging situations, summarized in Table 8.1, alongside general guiding principles when considering truth-telling and information disclosure in this setting.

Table 8.1 Guiding principles for truth-telling and information disclosure with minors

Truth-telling is a core, but complex, ethical value in health care

- The obligation to tell the truth is grounded in the respect we have for the people (children or otherwise) to whom we are telling the truth. In pediatrics, truth-telling is nuanced due to the variability in age and developmental status of children. Parents occasionally wish to withhold the truth from their children, typically in an attempt to protect them or otherwise serve their children’s best interests

Arguments for withholding information from children

- Common arguments for withholding health care information from children include the avoidance of harm, rights-based arguments, sociocultural considerations, and arguments based in the child’s right to an open future

Arguments against withholding information from children

- Common arguments against withholding health care information from children include rights-based arguments, those based in the child’s right to an open future, the practical point that children often are already aware of the truth, and considerations related to supporting and maintaining trust

Practical guidance

- Information disclosure should be situation-dependent, taking into account factors related to the child, the parents, the information being disclosed, etc. Disclosure is not an all-or-nothing concept, and it may be personalized to the situation as needed
 - Clinicians should always clarify why parents are requesting that information be withheld from their child and inquire about parents’ values/beliefs/hesitancies. They can then help to correct any misunderstandings and engage in discussion about potential benefits of disclosure
 - When exploring how/whether to disclose information to a minor (particularly over the objections of a parent), it is important to maintain collaborative rapport with the parents while still maintaining one’s sense of professional integrity
 - Seek support and engagement of other members of the multidisciplinary health care team, particularly in the setting of conflict and/or uncertainty
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Ultimately, all things being equal, clinicians have a *prima facie* obligation to tell children the truth about their diagnosis, prognosis, and treatment in an age- and developmentally-appropriate manner, unless there is a compelling, morally relevant reason to do otherwise. The questions of how and when to do so can be tremendously challenging to resolve; optimal solutions will likely depend on a number of factors, described further below.

8.9.1 Explore Rationale for the Request for Nondisclosure

First, parents may have reasonable and ethically justifiable reasons for requesting that certain information be withheld from their child. Clinicians should seek to understand why parents are requesting to have information withheld. For example, as discussed earlier in this chapter, is the request based on a concern that the child will be harmed by the information? Or are there other factors at play, such as parental misunderstanding or cultural/religious values? As appropriate to the child's situation, parents should be made aware of the possible *benefits* of disclosure. These could include the potential for a child's increased buy-in to the treatment plan, improved quality of the therapeutic relationship with providers, and the opportunity to empower a child in his or her own health care (Hudson et al. 2019; Mack and Joffe 2014). Understanding the rationale behind a request to withhold the truth may help inform how best to proceed and whether involvement of additional staff and/or resources might be beneficial. Such queries may even lead to the parents changing their mind about withholding information from their child without needing further intervention. In Billy's case, the health care team should ask Billy's parents why they wish to withhold information about his cancer diagnosis. They should further ask about the parents' beliefs, values, and hesitations as a way to better understand their perspectives (and hesitations), and to serve as a foundation for further conversations.

8.9.2 Maintain Collaborative Rapport

Superseding parental refusals to disclose information to their child over the explicit objection of parents carries the possibility of eroding parents' trust in the clinical team or otherwise harming the clinician-parent-child relationship. Harming this relationship rarely if ever serves the best interest of the child and should be avoided if possible. Ideally, parents and the clinical team will come to consensus about not only what is told to the minor, but when and how. It is critical that clinicians strive to maintain the collaborative rapport with parents that is so fundamental to providing high quality pediatric health care. Building upon the initial questions aimed at understanding Billy's parents' perspectives, in this case, the health care team should continue to work with them, in hopes of finding a path forward that enables the delivery of age-

and developmentally-appropriate information to Billy in a fashion agreeable to his parents while maintaining the therapeutic alliance.

8.9.3 Uphold Professional Integrity

At the same time, the moral integrity of clinicians is an important consideration in this calculus and should be promoted and supported. Clinicians should not be expected to abdicate their own professional morals/responsibilities. For example, even if a parent wishes to wait to tell their child about the results of a new test, if the child explicitly asks the clinician, they should not be expected to lie in order to support the wishes of the parents. In such circumstances, a clinician might determine that a shift in favor of disclosure to the child is ethically justified. This may be based on various reasons, including the desire to respect the child's developing autonomy and/or to preserve the clinician's professional integrity. A "compromise approach" could be to inform parents who have requested that information be withheld that clinicians will not lie in response to a child's direct question. But that they will, at least for the time being, strive to calibrate responses narrowly, in proportion to the child's query, while continuing collaborative communication between clinicians and parents about how best to discuss these issues with the child going forward. Clarifying expectations a priori may help to minimize damage to the clinician-parent relationship if such a situation were to arise. It also aims to strike a challenging balance among the interests and perspectives of the parents, clinicians, and pediatric patient. Clearly, these are exceedingly challenging situations to navigate for health care providers and parents alike, especially when agreement cannot be reached in advance about how best to proceed. In this case, while working with Billy's parents to determine a mutually agreeable plan, the health care team members should be clear with the parents about their own professional obligations, including what they will (and will not) say to Billy in order to ensure mutual understanding and expectations.

8.9.4 Employ a Multidisciplinary Approach

Finally, it is generally advisable to involve other members of the health care team to optimize the skillset and expertise at navigating these challenging dilemmas. This also carries the benefit of dispersing moral responsibility for a potentially distressing decision among members of the health care team. There are many clinical scenarios in which utilizing a multidisciplinary team approach is beneficial; this can be especially true when parents and clinicians are unable to agree about whether health-related information should be disclosed to a child. As such, depending on the institutional resources available, involvement of other skilled clinicians, such as social workers and psychosocial clinicians, palliative care specialists, clinical ethicists, chaplains, child life specialists, communication and developmental specialists, and others, can

aid in decision-making. They also can provide additional support, as needed, to the child and parents, as well as to members of the primary clinical team. In addition, it can be helpful to seek consultation from community-based clinicians, such as primary care pediatricians, who may know the child and family longitudinally and be able to assist with communication and with insights regarding intrafamilial relational dynamics. Lastly, support and guidance from other institutional resources such as patient-family relations and legal services may also be beneficial. Such multidisciplinary collaboration can help support all involved stakeholders, provide alternative points of view, and supplement the expertise and skills of the clinicians tasked with navigating this challenging and distressing situation. In Billy's case, it is likely that the support of social work, psychosocial support, ethics, and/or Billy's primary care pediatrician could help the inpatient health care team as they proceed forward with Billy's parents.

8.10 Conclusion

Communication is a core component of modern health care, with the delivery of truthful, comprehensive, high-quality information at the core of compassionate communication. In pediatrics, the trilateral nature of the clinician-parent-child relationship makes this communication more complex, and sometimes more ethically fraught. Minors, though typically not legally empowered to make independent decisions about their health care, should generally be provided information in an age- and developmentally-appropriate fashion in a manner consistent with their parents' preferences. Occasionally, parents will request to withhold information from their child, typically wishing to do so in attempt to benefit (or protect from harm) their child. Such situations can be very challenging for clinicians, who should work to understand the parents' rationale for withholding the truth and then ideally work with a multidisciplinary team to find a disclosure plan that is amenable to both the parents and clinicians, while balancing competing ethical obligations. Though decisions about information disclosure in pediatrics are nuanced and should be considered on a case-by-case basis, these recommendations can help guide clinicians who are tasked with skillfully navigating these challenging circumstances.

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