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ETHICS CASE

Minors' Right to Know and Therapeutic Privilege

Commentary by Cristie M. Cole, JD, and Eric Kodish, MD

“Why do I feel so bad, doctor?”

Dr. Marion's heart broke as she looked at the adorable 9-year-old girl who asked the question. Jill had been diagnosed with acute lymphocytic leukemia almost 5 months earlier, and Dr. Marion had quickly grown attached to the young girl. When Dr. Marion first started caring for Jill, it appeared that she was responding to treatment quite well. But over the past several weeks, Jill was in the hospital more often—the combined result of frequent infection and the toxic agents needed to treat her leukemia.

Throughout Jill's treatment course, her parents had insisted she not be told about her diagnosis. A friend at school had died from cancer, and the loss had affected Jill profoundly. For months afterward, Jill had not wanted to go back to school and refused to sleep in her own room, preferring to be close to her parents. Not long after Jill seemed to be recovering from the most intense effects of her schoolmate's death, she was diagnosed with leukemia. Her parents feared that telling her she had leukemia would compromise her emotional health and well-being. They asked Dr. Marion and others involved in Jill's care to refrain from disclosing her diagnosis to her.

Dr. Marion—and the rest of the medical staff—had thus far respected their wish, but felt strongly that Jill was mature enough to understand her condition and that she deserved to know what was going on, given that her leukemia might be life-limiting. Once, when her parents were not around, Jill asked what was wrong with her, and Dr. Marion offered an explanation that did not mention cancer but focused on side effects of medications. Now, Jill was asking again.

Commentary

Jill's parents are not alone. Families are generally concerned that knowledge of a life-threatening diagnosis will harm the patient's psychological and physiological well-being [1-5]. In the past, physicians routinely withheld medical information from a patient if they believed the information would harm the patient's overall health, justified by what is known as “therapeutic privilege” [1-3, 6, 7]. While not exclusive to pediatrics, the ethical dilemmas raised by nondisclosure requests are complicated further when made by a parent of a minor patient [8-11]. Dr. Marion and her team must grapple with reconciling their obligations to Jill with Jill's parents' authority to make decisions on behalf of their 9-year-old child [10].

Pediatric Decision Making: Reconciling Parental Authority, Physician Obligations, and a Child's Developing Autonomy

Informed consent is a cornerstone of patient-centered medical decision making. Rooted in respect for patient autonomy, it focuses on the process as much as on consent itself [8, 9, 12-15]. The goal is to elucidate the patient's values and preferences, given the decision and surrounding circumstances [8-11, 13]. Even for most adults lacking capacity, a surrogate strives to make decisions based on the adult patient's previously expressed preferences in accordance with the standard of substituted judgment [16].

In pediatrics, informed consent is at best an imperfect fit [8-10, 15]. Generally, a pediatric patient is not and never has been legally competent to make medical decisions. Until the child reaches 18, legal authority is vested in the patient's parents to determine what is in their child's best interest. Unlike decisions made by an adult's surrogate decision maker, such decisions cannot be based on the child's previously expressed values and beliefs, and so are based on the parents' values and beliefs [8, 9, 15, 16]. Instead of seeking informed consent, then, the American Academy of Pediatrics advises physicians to obtain "parental permission" and, when developmentally appropriate, *assent* (willingness to undergo the proposed treatment) from the young patient. Reframing informed consent as parental permission plus assent respects parental authority and recognizes its limitations. While substantial discretion is afforded to parents in child rearing, the interests of the child and the interests and obligations of the physician, state, and society at large act as limitations. Conflicts are rare, but, when they do arise, the interests and obligations of the stakeholders should be carefully weighed in light of the moral considerations and contextual factors [8-10].

In cases of nondisclosure requests from parents, the child's emerging autonomy and the physicians' obligation to provide appropriate treatment to the young patient must be balanced against parental authority [5, 10]. Of primary importance when thinking about medical decision making is the obligation to foster the child's capacity to make medical decisions [8, 9, 17]. This does not require treating the child as a fully autonomous decision maker [8, 9]. Rather, as a young patient matures, his or her role in medical decision making should also evolve. The physician and parents have an obligation to enable the young patient's participation in accordance with the patient's cognitive and emotional capacity [8, 9, 17]. The process of assent embodies this obligation because it allows the child to take a more active role in decision making once he or she has sufficiently matured. Like informed consent, assent seeks to elucidate the child's willingness to undergo the proposed medical intervention in a developmentally appropriate manner [8, 9]. Out of respect for the person, a broader concept than respect for autonomy, assent (or dissent) should only be sought if the child's expressed preference will be seriously considered [1, 8, 9]. If it will not, then this should be clearly communicated to the child [8, 9].

While each child should be assessed based on his or her own capabilities, a 9-year-old such as Jill generally has sufficient capacity to assent to at least some medical

interventions [8]. Regardless, some information about the medical condition and treatment should be provided in a developmentally appropriate manner for even the youngest patients [8, 9]. Disclosure fosters not only the patient's decision-making capacity but also trust in the clinician from an early age [5, 8-10, 18].

Therapeutic Privilege and a Minor's Right to Know (or Not Know)

Patient autonomy was not always a defining value in medical ethics [2-4, 7]. As late as the 1970s, paternalism was the cornerstone of the physician-patient relationship and reflected a general belief that the physician's fiduciary obligation to act in the patient's best interest was of paramount importance [2-4, 7, 19]. The physician was the primary decision maker and not required to solicit or consider the patient's preferences [2-4, 7]. Therapeutic privilege embodies this fiduciary duty by protecting the patient from information the physician deems to be potentially harmful and that the patient does not have an overriding interest in [2-4, 7]. The American Medical Association itself endorsed the practice in its 1847 *Code of Medical Ethics*, stating that a physician has "a sacred duty...to avoid all things which have a tendency to discourage the patient and depress his spirits" [20].

In contemporary medical practice, paternalism has given way to patient autonomy and the corresponding values of bodily dignity and self-determination [3, 19]. Medical decision making is a partnership between the physician and the patient. The physician is obligated to disclose information that the patient needs to meaningfully participate in and make decisions regarding medical care [3, 7, 12]. While pediatric patients are not generally treated as fully autonomous decision makers, the young patient's developing autonomy warrants respect [1]. The same values upon which informed consent is founded also support a physician's obligation to engage children in medical decision making proportionate to their cognitive and emotional development [5, 8, 9, 17]. Consistent with this shift in philosophical priorities, the American Medical Association's *Code of Medical Ethics* now states that "it is a fundamental ethical requirement that a physician should at all times deal honestly and openly with patients. Patients have a right to know their past and present status and to be free of any mistaken beliefs concerning their *conditions*" [13].

Under some circumstances, respect for patient autonomy can paradoxically support withholding medical information. If a patient expresses a desire not to know all or some medical information, then the physician should respect that decision and withhold that information [21, 22]. This is distinguished from therapeutic privilege because the physician is acting in accordance with the patient's preferences rather than on his or her own judgment [21]. The patient's religious or cultural beliefs may indicate preferences, but they should not be attributed to the patient without corroborating them with him or her [22-25]. The physician should offer the truth, speaking in general terms about categories of information to avoid mistakenly revealing information while also soliciting the patient's preferences [21].

Exercising therapeutic privilege also risks undermining trust in the physician-patient relationship. One risk of nondisclosure is the patient's discovering the withheld

information from another source [2, 5, 10]. A family member or another clinical team member could mistakenly reveal the withheld information. The patient could also find the information on his or her own, whether through medical records, the Internet, or accidentally hearing a voicemail. If a patient discovers that the physician intentionally withheld information, trust is compromised, which could prove detrimental to the patient's care [2, 3, 10, 26].

Clinical Realities of Nondisclosure: Problems and Unintended Harms

Yet, some parents and even physicians are tempted to withhold a life-threatening diagnosis from pediatric patients [26-28]. Not disclosing a diagnosis, though, is fraught with its own obstacles and harms [1, 5, 10]. More often than not, the child is aware of the hushed whispers and discussions among grown-ups and can ascertain that a secret exists that is not to be discussed [29-31]. The child may know to some degree what that secret is, whether he or she knows the specific disease, the severity of the illness, or that he or she is dying from the disease [5, 29-32]. In the context of the terminally ill child, this is often called "mutual pretense"—all parties including the child know the child is dying but act as if he or she were not [31, 32].

Research shows that withholding information may result in the child's imagining a worse scenario or at least a much different scenario [5, 27]. Without understanding why he or she feels bad, the child may begin to ascertain his or her own explanation for secrecy, including that the illness or treatment is a form of punishment [5]. Research shows that children not aware of their diagnosis do not experience any less distress and anxiety than those who are told about their life-threatening illness [6, 29], and in some cases may actually experience *more* [6, 33]. Openness, by contrast, appears to contribute to good long-term adjustment [27, 33]. Practically speaking, not understanding a diagnosis may also prevent compliance with treatment recommendations, particularly in older children [26, 33].

Nondisclosure also raises the question of how to respond to inquiries from patients about their condition, just as Jill asked Dr. Marion. Several strategies may be used to evade questions, including providing contingent answers, narrow answers, non-answers, or questions [28]. These strategies, however, do not directly resolve the underlying moral dilemma, i.e., reconciling parental authority in pediatric decision making with the physician's obligation to be honest with the young patient.

Conclusion

The desire to protect Jill from knowledge of her own mortality is understandable, particularly given her experience with the death of her friend. This experience, her age, her developmental status, and the impact this information may have on her health should all be factors influencing how and even when the diagnosis is disclosed. These factors do not however justify withholding the diagnosis from Jill indefinitely. Ultimately, Jill's developing autonomy and Dr. Marion's obligations to Jill outweigh Jill's parents' desire to protect her from the knowledge of her life-threatening illness. In discussions with Jill's parents, Dr. Marion should be careful not to appear to be seeking parental permission for diagnostic disclosure. Rather, she

should clearly communicate that the diagnosis will be disclosed within a finite period of time [11]. Allowing Jill's parents some control in choreographing how the disclosure takes place may help facilitate acceptance of disclosure and demonstrates respect for Jill's relationship with her parents. Dr. Marion could offer three options: (1) Jill's parents tell Jill alone; (2) Dr. Marion tells Jill alone; or (3) Dr. Marion and Jill's parents tell Jill together. Explaining that diagnostic disclosure is a process and that prognosis may be treated separately may also help Jill's parents accept diagnostic disclosure.

Lying to Jill is not an option. If Jill asks a direct question, then Dr. Marion has an obligation to answer it honestly and in a developmentally appropriate manner. She should clearly convey this obligation to Jill's parents. Even absent Jill's questions, Dr. Marion at the very least has an obligation to offer 9-year-old Jill the truth and assess whether Jill wants to know about her diagnosis and if so, how much she wants to know.

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