Case narrative

Amanda is a bright, active 12-year-old, who has been experiencing some shortness of breath and taking naps after school, something she has never done even as a toddler. After fainting during a track and field meet, her physician ordered a number of tests and diagnosed Amanda with dilated cardiomyopathy. Amanda’s father died of a drug overdose before she was born. Amanda’s mother, Lynn, hoping to protect Amanda from knowledge of her father’s lifestyle, has told her that he died of a sudden heart attack. She is raising Amanda on her own, without family or community to support her.

At the time of Amanda’s diagnosis, her pediatric cardiologist advises Lynn that Amanda will likely need a heart transplant. He suggests that the pediatric cardiology fellow, advance practice nurse, and child life specialist meet with Amanda and her mother to explain Amanda’s condition, the medication she will have to take, and the likely need for surgery, in a developmentally appropriate way.

Lynn comes to the meeting without Amanda. She agrees that Amanda will have to be told that she needs to take medication, but requests that the explicit diagnosis and need for surgery not be disclosed. She insists that she knows her daughter will become depressed and “lose her right to a childhood,” worrying constantly that she is about to die of a heart attack as she believes her father did.

Introduction

The parents of a child or adolescent who has a serious illness are faced with many treatment decisions. Their parenting philosophy and values may be challenged in unfamiliar ways, forcing them to reflect on the nature of their relationship with their child and their responsibilities as parents. Health care professionals who care for children may also have their personal and professional values challenged and may experience conflicting responsibilities to their patients and their patients’ parents. The health care team must decide how much information to share with a child, both at the child’s initial diagnosis, and again throughout the course of her illness and treatment as new information becomes available. Parents and clinicians may hold different views about the nature of their obligations in this context. Two ethical principles that may help guide their thinking are fidelity and truthfulness.

Ethical principles: fidelity and truthfulness

Fidelity requires that we act towards others in such a way that we fulfill the commitments made and the promises implicit in the relationship we have with them. In medicine, this includes placing the patient’s interests ahead of others’ interests, including those of members of the patient’s family, society, and oneself (Beauchamp & Childress, 2009). In pediatrics, however, the intertwined interests of the child and family often require health practitioners and parents to collaborate when determining what care is likely to be best for the child.

It is not unreasonable for parents to desire to protect their child from potentially distressing information, and, as in Amanda’s case, to ask that the child not be told their explicit diagnosis. Ideally, disclosure of medical information should be guided by the principle of fidelity, but should also be appropriate to the patients’ developmental capacities and independence. Decisions for younger children will be made for them by their parents (or guardians) in collaboration with...
the health care team; treatment decisions for older children and adolescents will more actively involve them. As minor patients increase in maturity and decision-making capacity, they should be allowed a greater role in making medical decisions, while their parents’ role transitions from one of decision-making to one of support.

On first consideration it may seem obvious that physicians should be truthful with their patients and that to do otherwise would be inconsistent with values that are core to the patient–physician relationship. However, to say that one must be truthful with patients is not as straightforward as it seems. Philosophically, the notion of “truth” is the subject of considerable debate (Simmons, 2006). In health care, at minimum, we might say that being truthful means not providing inaccurate information to a patient with the intention to deceive. We might then consider questions regarding the disclosure of information, such as, how much information is enough? What format is appropriate? When is the “right” time to disclose? The answers to each of these questions will vary from case to case, especially in pediatrics where the child’s or adolescent’s developmental stage, emotional state and desire for knowledge, and the parents’ views about how the child is likely to cope, are all relevant considerations.

Health care professionals who practice in Western settings value effective communication and truth-telling, as reflected in professional codes of ethics and the doctrine of informed consent. Interestingly, these values have not always been seen as essential to the practice of medicine. Until the mid twentieth century, most physicians believed that dismal diagnoses and prognoses should not be disclosed to patients, at least not by the physician (Katz, 1984). Some parents today, especially those from non-Western or ethnically diverse backgrounds, hold a similar view and see the decision about what information to provide children and adolescents as rightfully belonging to parents, not health care professionals (Valle, 2001; Gupta et al., 2008; Hurwitz Swota, 2008).

Pediatric associations have established standards through the development of position and policy statements stressing the importance of communicating effectively and honestly with children, while acknowledging that this may require negotiation with parents (British Medical Association, 2001; Canadian Paediatric Society Bioethics Committee, 2004; Levetown & AAP Committee on Bioethics, 2008). These guidance documents acknowledge the fact that parents may have deeply held beliefs that may be grounded in personal, religious, or cultural values that may influence their views about the disclosure of medical information to their children. In general, these beliefs should be respected. If there is concern about the child or adolescent being harmed in some way due to a decision to withhold information, those concerns should be raised with the parents in a way that focuses attention on the child’s or adolescent’s needs.

Requests from parents to withhold or limit information to their children should be explored with them, and discussions should include the following considerations:

- Children like Amanda have serious, lifelong health problems. They will maintain relationships with their pediatric teams until they transition to the adult system, and will require specialized care throughout their lives. The adult system presumes that the patient is the primary decision-maker and thus entitled to available information about their health condition and treatment alternatives. An important part of preparing adolescents for this transition is recognizing and supporting their role in their own health care, including decision-making about treatment.

- Health care providers can respect children and adolescents as persons by acting consistently and honestly to fulfill their commitment to these patients. There is some research to suggest that many children and adolescents want to be told the truth and to participate in decisions about their care (Ellis & Leventhal, 1993; Lyon et al., 2004; Wolfe, 2004).

- Caregivers who communicate openly and provide forthright opportunities for children and adolescents to discuss their illness may help reduce their patients’ anxiety and improve coping, consistent with duties of beneficence and nonmaleficence (Turkoski, 2003; Beale et al., 2005; Goldie et al., 2005; Kouyoumdjian et al., 2005).

- Providing children and adolescents with developmentally appropriate information about their condition and treatment supports their ability and, in some cases, their right to participate in decision-making. In legal jurisdictions where there is no explicit age of consent (e.g., Ontario, Canada) the capacity to make specific treatment decisions triggers the right to do so, which also creates an obligation to ensure that legal decision-makers (in some cases the child or adolescent) are
fully informed about their health condition and details of treatment options.

- Many professional codes of ethics consider good communication and the provision of information to be an ethical duty.

On the other hand, there may be reasons to honor parents’ requests to withhold information from their child or adolescent. These might include the following:

- Caregivers should respect the moral and legal authority and role of parents. For example, a Canadian Supreme Court decision, R.B. v. Children’s Aid Society of Metropolitan Toronto (1995), supported parents’ rights to make decisions about issues affecting their children:
  
  … the common law has always, in the absence of demonstrated neglect or unsuitability, presumed that parents should make all significant choices affecting their children, and has afforded them a general liberty to do as they choose … our society is far from having repudiated the privileged role parents exercise in the upbringing of their children. This role translates into a protected sphere of parental decision-making which is rooted in the presumption that parents should make important decisions affecting their children both because parents are more likely to appreciate the best interests of their children and because the state is ill-equipped to make such decisions itself.

- While health care professionals have an independent duty to guard the interests of the child-patient, parents are usually higher standing in decisions by virtue of their personal knowledge of the child and the values by which the family lives. The consequences of decisions made are also more likely to be borne by parents than medical caretakers.

- Sometimes there exists an unspoken agreement between parents and their children to avoid speaking about distressing things. Such “mutual pretense” may serve as a coping mechanism for some patients and families (Bluebond-Langner, 1978).

- To respect parents’ wishes is consistent with the philosophy of Family Centered Care, prevalent in pediatric health care institutions (Committee on Hospital Care, 2003). This philosophy recognizes the important role parents play in caring for their children, and acknowledges the significance of families’ values in this context.

Amanda’s mother, Lynn, has acted in the past to protect her daughter from distressing information and now wishes to prevent Amanda from learning the seriousness of her medical condition, the true cause of her father’s death, and the fact that she has lied to Amanda about her father’s death. Exploring these issues with Lynn may reveal that she places a higher value on beneficence than truth-telling, and that she sees her actions as protective of her daughter and consistent with her own role as a parent.

Even if Amanda’s caregivers are willing to limit the information she is given about her condition and treatment, however, the physical and social environment where health care is provided makes doing so difficult or even impossible. Most attempts to keep “secrets” from patients are unsuccessful. The body language and whispering of adults combined with physician’s visits, laboratory or radiologic investigations, and hospital stays that are not adequately explained lead patients, including children, to realize that something is wrong. Their imagined fears may be worse than the truth. Adolescents may find consent forms or health literature that was provided to their parents or in the waiting room that provide clues to their illness. Clinic waiting rooms, hospital play rooms, and disease-specific camps and fundraisers create opportunities for children and families to meet others who are going through similar experiences with whom they may talk. Finally, many children and adolescents use the Internet to research their health conditions. The ability to restrict and filter information that children and adolescents receive may be limited by such practicalities, and parents’ wishes to protect through secrecy may not be realistically supportable in the current environment.

While Amanda’s case focuses on a parent wishing to withhold information from a child who is likely to survive and do well with treatment, clinicians who care for children with life-threatening illnesses may be asked by parents to not disclose to the child when the illness has entered its terminal phase. Practically, it may be easier to carry this off if dying children are cared for at home. Changes in the care plan, such as shifting care from aggressive treatment given in the hospital to comfort measures at home, will not go unnoticed, however, and some studies suggest that, contrary to protecting children from harm in these situations, they often are well aware that they are seriously ill or dying, and their fears and anxieties may escalate if they don’t have an opportunity to discuss them (Wolfe et al., 2002).

**Ethics in practice**

There are a number of issues that teams such as Amanda’s should assess and discuss when faced with a
parent's request to limit or withhold information from her child or adolescent.

Is the child or adolescent likely to experience harm if information is withheld from him or her? Team members may be uncomfortable with parents' request to limit or withhold information, yet they may be reluctant to override a parent's request at the risk of compromising the parent–provider relationship. If harm to the patient is likely, however, there is less justification for honoring the request. For example, the child might develop anxiety and depression when her questions and concerns about her health go unanswered. Children and adolescents in these situations should be carefully monitored.

Some children who are seriously ill, and from whom information is withheld, may have greater anxiety than those who are able to ask questions about their condition and treatment (Turkoski, 2003; Beale et al., 2005; Goldie et al., 2005; Kouyoumdjian et al., 2005). Additionally, if there is a good chance that attempts to withhold information will fail and inadvertent disclosure occurs, this may seriously harm the child or adolescent's ability to trust her parents or the physicians in the future. Careful and sensitively planned disclosure may not eliminate this harm, but may reduce it.

Involving the multidisciplinary team. It is important that members of the multidisciplinary team participate in discussions about whether or not the team will try to limit the information that is intentionally disclosed to the child and if so, for how long. Some members spend a great deal of time with children (e.g., nurses providing bedside care and rehabilitation specialists). Children may ask these team members questions or demonstrate signs that they are confused or anxious about their condition and treatment. It is not fair to expect health care professionals to lie to their patients and doing so requires them to constantly scan the environment for risks of inadvertent disclosure.

Negotiating a plan. Teams should enter discussions with parents prepared to listen to their concerns, discuss practical and ethical reasons why secrecy may not be a realistic option, and explain their experience with other children or adolescents and their families. One model that has been developed in the context of HIV involves “partial truth-telling,” i.e., gradual, developmentally appropriate disclosure. Younger children are given basic explanations about their health condition and treatment; however, the actual diagnosis and the words “HIV” or “AIDS” are not used. As the child develops and begins to indicate a desire for information, further disclosure is planned and carried out together with families (increasing their sense of control). This strategy could be negotiated and used effectively when parents wish to withhold information from children with other conditions as well (Salter-Goldie et al., 2007).

Seeking ethics consultation. Where there is significant ethical uncertainty or conflict among team members including seemingly intractable conflict between the team and the family, pediatricians are advised to seek ethics consultation, either through an ethics committee or an ethics consultant, bioethicist, or clinical ethicist. While the roles and functions of committees and consultants may vary, they will assist clinicians in identifying and analyzing ethical issues, supporting teams and families through the facilitation of challenging negotiations, and providing information about relevant ethical norms, law, and policy considerations.

Amanda: working towards a resolution

The pediatric cardiology fellow, advance practice nurse, and child life specialist were expecting to meet with Amanda and her mother, Lynn, to begin information disclosure and education with Amanda so that her treatment might proceed and plans be set in place for a work-up towards a heart transplant. They were unprepared for her mother's request that Amanda not be given explicit information about her condition or the need for transplant. They listened to Lynn's explanation, and explained to her that her request would have to be discussed with the multidisciplinary team and the responsible physician. A follow-up appointment with Lynn was made.

Prior to this follow-up meeting, a multidisciplinary case conference was held, which included professionals from the many services who would be providing care to Amanda; the hospital bioethicist was also invited to attend. Some individuals raised concerns about the challenges of providing coordinated and complex care while constantly guarding what they said to the patient – to many this felt ethically equivalent to lying. Some were more willing to compromise than others, and after a thorough discussion over several meetings facilitated by the bioethicist, the health care team reached an agreement that the pediatric cardiologist, fellow and advance practice nurse would meet with Lynn to discuss her concerns as well as those of the team. The team's goal for the meeting was to engage Amanda's mother in a time-limited plan to identify information that
would be necessary for Amanda in order to proceed with treatment, to collaborate on the most compassionate and developmentally suitable way of disclosing this information, and to decide how disclosure would occur. The team agreed to compromise, with two exceptions—they would not intentionally lie to Amanda, and they would monitor her psychological and emotional condition. If they had good reason to believe that limiting information was causing her anxiety and distress they would offer opportunities for her to raise questions and concerns with members of the team. Amanda’s mother, although initially angry and reluctant to compromise, appreciated that the team respected her concerns and agreed to work together to plan staged disclosure to Amanda so that treatment could begin.

Acknowledgment
Michelle Greenwood, LLB assisted with legal research.

References

Further reading
Case narrative: medical misadventure and the case of Chloe

Chloe is a 3-month-old infant who was brought to the emergency department by her parents after developing a fever. Over the past 18 hours, she has become increasingly fussy and refused to nurse. While Chloe was being weighed in the triage room, her parents inquired about her weight in pounds, a number quickly provided by flicking a switch on the scale that changed the reading from metric (5.4 kilograms) to English (12 pounds) units. The nursing team was about to change shift and a nurse who was recording the weight heard Chloe's weight as 12 pounds and recorded this number on the triage chart. This weight was then entered as the kilogram dose calculation weight in Chloe's electronic medical record by a medical technician. During her evaluation, Chloe appeared ill, and displayed signs of moderate dehydration. Her laboratory findings were consistent with a urinary tract infection and she was admitted for intravenous antibiotic treatment with ampicillin and gentamicin; these drugs were ordered via the computerized provider order entry system, the doses calculated based on the infant's recorded weight. During the order entry, several message boxes appeared on the computer screen providing hospital announcements. Additionally, a warning box appeared questioning the doses of both antibiotics as excessive given the age of the patient. The provider in the emergency department, who had been on-duty for 14 hours at that point, was distracted and clicked all the dialogue boxes closed, permitting the order to be signed. The ampicillin was infused while Chloe was in the emergency department; the gentamicin dose arrived at her bedside just before she was transported to her acute care inpatient room. The emergency department nurse connected the gentamicin syringe to Chloe's IV pump, and the acute care nurse activated the pump upon arrival at Chloe's room. Over the next 12 hours, Chloe's urine output did not normalize despite appropriate fluid resuscitation efforts. While evaluating her low urine output, she was weighed again and this new weight was recorded in her nursing notes. During change of nursing shift, Chloe's nurse reviewed her charting notes and recognized that the weight being used for the medications was over twice the correct weight and realized that the two antibiotics were overdosed. Chloe's nurse then called the on-call hospitalist to report the two medication errors. Because gentamicin can cause kidney and hearing damage, the level of Chloe's gentamicin level was checked and was found to be markedly elevated at 25 mcg/ml. Her serum creatinine had increased from 0.8 on admission to 3.5 mg/dl, suggestive of rapidly worsening kidney function.

Chloe's care team is now faced with an entirely new problem in her care. They must decide how to respond to this change in her renal function, if and how to tell Chloe's parents about what happened, how to report this event to the relevant hospital operations leadership, and what to do with their own deeply unsettling feelings that they may have just participated in a sequence of events that harmed one of their patients.

Discussion of issues

Among the most fundamental of ethical precepts in medicine is the principle of primum non nocere, “first do no harm.” When Chloe's care team became aware of her medication overdose and consequent kidney injury, they began to grapple with vexing ethical challenges. What exactly is a medical error? How do they balance principles of beneficence, justice, truth-telling, and informed consent? How does each team member’s perception of authority gradients influence their response to Chloe's medication errors? If Chloe were
an older child, would we tell her, and if so, how? Who benefits from disclosing – or concealing – the medication error? Could disclosure also be harmful to some of the parties involved? Who takes responsibility for disclosing this error given the complexity of the events that ultimately led to her medication toxicity (Wu et al., 1997; Surbone et al., 2007; Shannon et al., 2009)?

A wide spectrum of investigations over the past two decades has demonstrated the alarming frequency and toll of medical errors in terms that are both economic (lost productivity, lost actual and potential income, increased length of hospitalizations, additional procedures and testing) and human (impact on individual and public trust of health care, reduced longevity and even mortality). Despite this public and academic attention to medical errors, there remains a lack of consensus regarding a clear definition of medical error. The Institute of Medicine, in the groundbreaking 2000 publication *To Err Is Human: Building a Safer Health System*, framed medical error as the “failure of a planned action to be completed as intended or the use of a wrong plan to achieve an aim.” An adverse event, “harm that is the result of the process of healthcare rather than the patient’s underlying disease,” is distinctly different from a medical error and refers to a specific outcome rather than a breakdown in the process of care. Many medical errors are resolved before reaching a patient and thus cause no physical harm. Furthermore, many adverse events are not anticipated yet do not arise out of medical errors. Chloe’s renal failure, and potential ototoxicity from the gentamicin overdose, appears to be an adverse event resulting from a complex medical error. When Chloe’s nurse alerted the care team of the error no one yet understood the cause, or the range of care providers involved in the error (Gallagher & Lucas, 2005; Espin et al., 2006).

Multiple failures within Chloe’s care ultimately led to her medication overdose. Errors that occur in complex systems are often not the result of a single failure; rather they are the result of a misfortunate alignment of latent errors. The first step in mitigating these process vulnerabilities is to admit that they exist. Chloe’s team could justify disclosure based on their duty to fulfill a responsibility to institutional improvement by reporting this error to the hospital. At the time these errors were recognized her attending physician had only partial information about what happened and why, and none of Chloe’s providers were certain of their own responsibility, if any, in causing these events. Nevertheless, by disclosing the initial basic facts of her overdose to Chloe’s parents, her team is effectively fostering a culture of accountability, open communication, and transparency (Shapiro, 2008; Gallagher, 2009).

Chloe’s team could justify disclosure within the context of justice by adhering to standards of professionalism. The Joint Commission for Accreditation of Hospital Organizations (JCAHO) Standard R1.2.90 articulates that patients and families be informed about “unanticipated outcomes” of provided care. The National Quality Forum Safe Practice #4 describes specific mechanisms to support medical error disclosure, emphasizing transparency as a core value. The American Medical Association Code of Ethics E-8.12 on professionalism (issued in 1981 and reaffirmed in 1994 and 2005) defined medical error disclosure as a “fundamental ethical requirement,” further admonishing physicians to refrain from allowing fear of legal repercussions to interfere with error disclosure.

Chloe’s care team members could consider disclosing the medication error within the context of informed consent. Chloe’s parents need to know and understand the current status of her health in order to make fully informed decisions regarding her additional care. Their only opportunity to fully participate in informed consent is for them to comprehend the details that led to her injury. Furthermore, withholding information germane to Chloe’s health care would only be interpreted as dishonesty in the eyes of her parents. Such obfuscation undermines her care team’s fiduciary relationship to Chloe and her parents, further disabling her parents’ ability to accept and trust any proposed care (Gallagher et al., 2003).

Chloe’s care team might be motivated to disclose the error out of a desire to repair her parents’ trust in both the team and in health care in general. In this context, they may perceive disclosure as an ethical imperative of truth-telling. While societal, cultural, and religious paradigms promote the general concept of truth-telling, Chloe’s care team may wrestle with just exactly how much, to whom, and for what purpose do they tell the truth. Their concerns appear to be validated based on data from surveyed physicians who report skepticism that disclosure has benefits for the patient; these surveys describe concerns that disclosure may be further injurious to a patient and that non-disclosure may represent patient-centered care (Gallagher, 2009).

Chloe’s care team may view truth-telling as an avenue to empower her parents to better participate in medical decision-making, fostering family-centered
care. However, telling Chloe herself (if she were an older child) presents additional, unexplored challenges. While the tenets of assent in pediatrics promote fostering a partnership between medical care teams, parents, and the child, truth-telling to a child may only undermine this partnership. Truth-telling depends upon both the accuracy of information and the candor with which it is communicated. How much truth can be relayed when an error is first reported can be further complicated as the initial impressions of the cause of a medical error are often inaccurate. Sufficient ambiguity may also exist in the early stages of a potential error discovery that care team members are unable to disaggregate an adverse event from a naturally deteriorating clinical scenario. Chloe's team had only a few simple facts about the error available to them when the medication overdose was discovered. She received over twice the appropriate dose of two antibiotics, the weight recorded in her electronic medical record was not correct, and her renal function had worsened since being admitted to the hospital. Her care team understandably pondered the etiology of her clinical condition, wondering if nature, their care, or both were responsible. What data might guide this team as they contemplated telling Chloe's parents about the error (Lantos, 1996)?

Research over the past decade with adult patients has demonstrated that virtually all want to be told about serious medical errors and most even want to be told about minor errors. Parents maintain very similar expectations regarding errors that occur with the care of their children. When told about a medical error, patients and parents want to hear an explicit statement that an error occurred, what happened and why, as well as any consequences for their child's continued health care. People harmed by an error want to know that their suffering was not in vain and thus want to know how recurrences of the error will be prevented. The majority of patients also want to hear an empathetic apology recognizing the harm that they have experienced. Chloe's team sympathized with these apparently simple directives. However, they acknowledged that fulfilling these expectations might create tension between serving Chloe's needs and protecting themselves from legal and disciplinary repercussions (Gallagher et al., 2003; Loren et al., 2008; Matlow et al., 2010).

Potent inter-professional issues of loyalty, fidelity, and trust can be present when an error arises out of the complex interplay between personnel, clinical processes, technology, and organizational factors within a clinical setting. How does a physician disclose an error when that physician may not have been directly involved, or not involved at all in that error? How does a team decide who will lead a disclosure conversation and how can team members remain confident that they will not be unduly implicated during a disclosure conversation? Some team members providing bedside care to a child may have knowledge of an error before a family has been told, creating extreme moral distress of the kind Chloe's nurse is experiencing. Indeed, team members may not all agree that an error occurred. The authority gradients present within a multidisciplinary care team can add additional challenges to successfully resolving these dilemmas. Chloe's attending physician wanted to be forthright as soon as possible with this family; however, she was uncertain of the proportional roles that the weight and drug overdoses played in Chloe's clinical condition. Chloe's parents might never know that these errors occurred; should they be told? Considering the answers to these questions elusive,
Chloe's attending physician approached the hospital's risk manager and patient safety director, asking specifically about whether the lack of parental knowledge of the weight and dosage errors should influence the decision to reveal any details of the potential causes of her clinical condition. Both administrators recommended that the parents be told about the weight and dosage errors, specifically counseling Chloe's attending physician to relay only the basic facts along with a commitment to share additional details about the error as they become better understood (Shannon et al., 2009).

Exploring the conflicts of interest posed by the disclosure of a medical error provides insights into the nuances of truth-telling and loyalty in this setting. Disclosing a medical error places tension between a family's desire for knowledge about what happened during their child's medical care and a physician or hospital's interest for self-preservation. Contemporary developments in the relationship between risk managers and physicians may serve as an effective illustration of the changing frame of loyalties within health care settings. Historically, risk managers have been perceived as protectors of a hospital's financial interests and have counseled physicians to refrain from disclosing errors. Recently, risk managers have assumed a more proactive role in protecting the hospital and advancing the paradigm of patient safety, by encouraging adverse event reporting and disclosure of medical errors. Indeed, present experience with medical error disclosure suggests that contrary to the classical paradigm of “do no harm to the organization” (e.g., do not tell patients about any errors), open and honest communication about unanticipated outcomes may actually lead to safer health care systems and greater patient trust in those organizations (Loren et al., 2010).

Chloe's attending physician prepared for the initial disclosure to the family, attentive to her internal tension between feeling compassion and fearing that Chloe's parents might wish to find culpability within her words. She wondered if a genuine apology might be self-sacrificial. The interaction between medical error disclosure, apology, and litigation is complex. Exactly why some patients seek legal counsel against a physician is not well understood. Indeed, some authors contend that greater error disclosure could increase the rate of litigation surrounding medical errors as more patients learn about the errors that occur in their care. Other authors argue that genuine and compassionate communication can diminish both the motivation for legal redress and the enthusiasm for an attorney to pursue a case (Lazare, 2006; Studdert et al., 2007).

Perhaps the greatest challenge faced by everyone involved in Chloe's care was the anxiety and ambivalence they felt surrounding the unfamiliar terrain of disclosing errors and the unforeseeable outcomes that could follow the initial disclosure conversation. Who was benefiting from this disclosure? Disclosing this error allowed her parents to openly admit that they had been hurt in a human enterprise. For Chloe's care team, and the hospital, disclosure began the process of forgiving and self-reconciliation that appears to be strongly desired by health care workers who have been involved in causing a medical error. Disclosing in pediatrics may be further complicated by the possibility that we may not know that harm occurred for a prolonged period. If Chloe's renal or auditory injuries are lifelong, who will tell her how it happened, and how should that disclosure be staged over time? Indeed, what role do parents play in the disclosure to the child, and how do we address their own potential sense of guilt arising out of their belief that they may not have adequately protected their child?

The errors that occurred in Chloe's care may have caused permanent injury as well as transient but life-threatening harm, fulfilling the Institute of Medicine's characterization of a serious medical error; her care team ultimately acknowledged little uncertainty that these events deserved disclosure. Had these events unfolded somewhat differently, had the infusion of potentially allergenic medication stopped early enough to prevent an overdose, might the obligation to disclose the error be diminished? Indeed, might some medical errors be trivial enough – causing no harm at all – to obviate the need, or expectations, for disclosure? Considering a threshold for disclosure suggests that a boundary around transparency of institutional operations can be established, and justified in the eyes of parents.

Framing the decision to disclose based on the perception of harm alone is admittedly subjective and appears to only partially account for when parents desire to be told about errors that occur in the care of their children. In one study, nearly all (98%) parents expected to be told about a harmless medical error (child received an intravenous dose of an allergenic medication but experienced no symptoms) and a majority (80%) wanted to be told about a near miss (infusion of potentially allergenic medication stopped before the dose reached the child). Indeed, almost half (41%) of the parents endorsed disclosing the near
miss to the child. Parents may view disclosure as a professional and institutional prima facie obligation for truth-telling, viewing their role as a partner in the medical care team and thus expecting to learn about process failures even if they were harmless (Matlow et al., 2010).

However, revealing every procedural misadventure also has the potential to imperil parental trust of the care team. Benevolent deception – therapeutic privilege – may be one strategy care team members employ in an effort to protect parents from a litany of clinically harmless system defects – mistimed blood tests, mislabeled samples, incorrectly infused crystalloid solutions, et cetera. Aware of the alarming frequency of near misses, parents might read the hospital’s marquee through the eyes of Dante’s words, “All hope abandon, ye who enter here!” While care team members may be genuinely motivated by sensitivity to parents’ emotional turmoil, such deception if detected can only raise parental doubt, erode trust, and undermine the therapeutic alliance. While deception may not be morally equivalent to lying, the person being deceived is rarely likely to discriminate between the two. Reversing our role with the parent could endow us with sufficient perspective to recognize benevolent deception as only self-serving. Transparency – accessibility and opportunity for scrutiny – therefore may be the institutional realization of the concept of role-reversal (Bok, 1999).

**Effective disclosure of errors**

Fundamental first steps to effective error disclosure are grounded in empathic, honest, and genuine communication. Although every harmful medical error is accompanied by unique circumstances, a growing body of research offers the following framework for fulfilling patient and family expectations of disclosure:

1. Attend to caring for the patient immediately, and seek out additional clinical support when appropriate (acknowledging an error may leave care team members shaken enough to impair their clinical judgment).
2. As soon as possible, familiarize yourself with your institution’s error disclosure procedures. You may be directed to establish contact with a representative from your organization’s office of risk management or patient safety.
3. Begin to clarify as many of the facts as possible and avoid speculation about what led to the error. Rarely are all the details available when an error is first recognized.

4. Carefully plan the initial disclosure conversation. Consider who will be present, who will lead the conversation, and how questions will be answered. Consider who might take notes for the family during the meeting.
5. When meeting with the family, assess what they know already; fill in gaps by providing basic information about the error. Describe how, and if known, why it happened and how you will manage the medical consequences of the error. Call the error what it is, an error.
6. Extend an apology that acknowledges the suffering of the child and family.
7. Describe how the error will be investigated; demonstrate a commitment to preventing recurrences of the error.
8. Offer ongoing psychological support for the family and child. Heed any request for transferring care to another provider or facility.

These conversations are multiple and can be exhausting experiences for all involved (Wu et al., 1997; Gallagher & Lucas, 2005).

**Resolution of case**

Within minutes of learning about the medication error, Chloe’s attending physician set in motion both the disclosure and event discovery process. The nursing unit director and nursing shift administrator were both notified, ensuring that emotional support services were made available to Chloe’s nursing team. Chloe’s attending physician called the director of patient safety and the hospital’s office of risk management, and she subsequently received guidance on crafting an initial disclosure conversation with Chloe’s parents. The risk manager’s counseling regarding an apology was based on her awareness of the specific state legislative codes that surround a statement of apology as well as the potential legal ramifications that may arise from the individual words offered to Chloe’s parents.

Within an hour of learning about the error, the attending physician, the unit charge nurse, and a member of the family services support team met with Chloe’s parents, first inquiring about what they understood about her clinical condition and then describing the medication error. Her parents were shocked; one parent was outraged, “How could such an obvious mistake be allowed to happen?” The other parent expressed guilt: “I can’t believe I let her down, I’ve been with her ever since we got here.” Their immediate questions
were answered factually, candidly, and compassionately: “Will she survive?” “What happens next?” “You tell me you are going to investigate this, how can we be confident that it won’t happen again before your investigation is finished?” “What will happen to the people who gave her these overdoses?” What few details were known about how the error occurred were offered (an incorrect weight in the electronic medical record, two antibiotics were provided at just over twice the appropriate dose). The attending physician and nurse both acknowledged the raw emotions of Chloe’s parents, “We take this very seriously, we are so very sorry for what happened, for Chloe’s suffering and for the anguish we have created for you.”

Her parents were informed about the next steps necessary to appropriately manage the effects of her medication overdose, including consultation with a nephrology subspecialist and additional laboratory, ultrasound, and oto-acoustic testing. They were reassured that these services would be provided at the hospital’s expense.

Within one week, a team consisting of members from each clinical service area who were directly involved in this medication error convened to review the timeline of events and to perform a root cause analysis (RCA) of the error. Their investigation identified issues related to six discrete factors: human, equipment, process and policy, communication and access to information, patient-specific, and staffing or individual competencies. From their investigation, three specific operations changes were designed that would prevent Chloe’s medication error sequence from occurring again.

With guidance from the hospital’s risk manager, patient safety leader, and chief medical officer, Chloe’s attending physician and the nurse manager from her medical unit reviewed the RCA findings and process revisions with her parents. Still visibly shaken, Chloe’s parents expressed a mixture of disappointment, anger, and appreciation for her care team’s “consistent transparency about what happened.” “First do no harm” may be emerging into “First, acknowledge all harm.”

References


Introduction

“Non-therapeutic” interventions are those performed or requested for reasons other than medically indicated need. Examples in the ethics literature include leg-lengthening surgery for children with achondroplastic dwarfism, or appearance-normalizing surgery for children with craniofacial abnormalities that have no functional significance (Parens, 2006). This chapter focuses on childhood male circumcision that is not medically indicated. While there are relevant differences among these cases, they demonstrate that requests for non-therapeutic interventions in children combine several complex issues for pediatric ethics: the rights and vulnerabilities of children; the boundaries of parental prerogatives; and the difficulty of defining a procedure’s benefits based on social, cultural, or religious considerations. Physicians asked to perform non-therapeutic interventions on children must assess whether acceding to these requests is medically appropriate and ethically permissible.

Case narrative

During an annual check-up, the parents of a 7-year-old boy asked the pediatrician to recommend someone to circumcise their son. Having just examined the child, the pediatrician could identify no clinical indication for circumcision, and questioned the parents about why they wanted the procedure performed. They explained that their son was born in the UK, where newborns are not routinely circumcised because the National Health Service only funds circumcisions done for medical indications. Upon moving to the United States, the parents decided that they wanted their son circumcised in adherence with their culture and what they presumed was local custom. They believed that circumcision was the standard medical practice in the United States and that their son would feel less conspicuous among his peers.

The pediatrician was uncomfortable with the request. In her experience, circumcisions were usually performed on newborns by the delivering obstetrician at the request of their parent(s); boys the age of this patient were typically not circumcised without a medical indication. The pediatrician was concerned that, even for newborns, the procedure did not usually have any medical benefits, and in this patient, would cause unnecessary pain and pose other risks as well. She also wanted to be sensitive to the patient’s family and their values. She called a urologist colleague to discuss the case.

Summary of ethical issues

Physicians have a responsibility to promote the interests of their patients while avoiding unnecessary harms. Deciding what is in a child’s interests can be difficult when a procedure poses medical risks and its benefits are not based purely on medical indications, but on social, cultural, religious and/or parental beliefs. Physicians can generally assume that parents will act in their children’s best interests, and parents have considerable ethical and legal authority over children’s upbringing, including medical decisions. Still, there are limits to parental authority, and children who have sufficient maturity and understanding can often voice their own opinions regarding the medical procedures they undergo. Requests for non-therapeutic interventions require physicians to balance these considerations in assessing whether it is ethically supportable to perform these procedures.
Section 1: Core issues in clinical pediatric ethics

Background on circumcision

History

The precise origin of male circumcision is unknown. Throughout history and across cultures it has been considered an important practice for reasons of religion, custom, and health. The oldest pictorial evidence of circumcision is found on an Egyptian tomb dating back circa 2400 BCE. Circumcision was accorded honor by ancient Egyptians as a religious and social practice, and may have signified cleanliness for a culture attentive to health and hygiene (Gollaher, 2000, pp. 1–6).

Among the major religions, circumcision continues to be practiced by people of Jewish and Muslim faiths. In Judaism, circumcision embodies the covenant between God and Abraham: the Torah states that God promised, “I will make of you a great nation,” and in exchange Abraham and his male descendants would circumcise themselves. The bris (from the Hebrew word for “covenant”) takes place on the eighth day of an infant boy’s life; traditionally a mohel (a person trained to do circumcisions) performs the procedure. Circumcision marks the child’s entrance into the Jewish community (Gollaher, 2000, pp. 6–29).

Though the Qur’an is silent about circumcision, its importance in Islam is drawn from the hadith, the sayings of the prophet Muhammad that ground much of Islamic law and practice. Muhammad reportedly prescribed cutting the foreskin as a fitrah, a means of cleanliness indicating a man’s moral and mental health. Muslim clerics have never agreed on the best age to circumcise. However, males reaching puberty uncircumcised must undergo the procedure before participating in acts of worship. As Islam has spread to different continents and absorbed different cutting rituals, the act of circumcision has taken many forms (Gollaher, 2000, pp. 44–52). Beyond religion, social scientists have found extensive variations of circumcision in tribes throughout the world, and proposed that it indicated social or sexual maturity or admission into that tribal community. Attempts to interpret its meaning throughout history and across cultures have not been successful (Gollaher, 2000, pp. 53–59).

In the United States and the United Kingdom, circumcision arose as a medical intervention in the latter half of the nineteenth century, based on assertions that it was effective treatment for a variety of disorders such as epilepsy, other neurologic disorders, or even hernias. Medical reports later claimed that circumcision would also benefit healthy males. None of these “medical studies” were scientifically sound; nevertheless, doctors began to advocate that male circumcision be adopted as a routine prophylactic measure. Historical claims that circumcision curtailed masturbation and improved sanitation may also have helped make circumcision more acceptable during this period (Gollaher, 2000, pp. 73–92, 100–106). Misceptions about circumcision continued to be reported into the mid-1900s, and neonatal circumcision became commonplace in the United States and United Kingdom. By the mid twentieth century, some physicians began to question the supposed benefits of infant circumcision and to scrutinize its burdens. The UK National Health Service stopped paying for circumcision in the 1950s, and currently only funds circumcision to treat a small number of conditions. The American Academy of Pediatrics (AAP) evaluated the available evidence and officially concluded in 1971 that there was no medical basis for routine circumcision. Nevertheless, circumcision remains common in the United States: in 1999, 65.3% of all male newborns born in hospitals were circumcised (Gollaher, 2000; CDC, 2010).

Medical risks and benefits

Some of the medical indications initially reported for circumcision were and remain legitimate today: to relieve severe phimosis, to correct paraphimosis, or to remove foreskin on which a tumor or other lesion has grown and which cannot be otherwise treated. The latter are rarely found in children, and phimosis and paraphimosis can be prevented by good hygiene and proper care of the foreskin (AAP, 1999, 2010).

Epidemiological studies have demonstrated some modest benefit to circumcision, such as a decreased incidence of urinary tract infection in circumcised versus uncircumcised boys, mostly in the first years of life. The conclusion that these studies support circumcision, however, has been subject to criticism, particularly because a large number of boys would have to undergo routine circumcision to avert a small number of potential infections. International studies have documented that circumcision can reduce a man’s risk of acquiring human immunodeficiency virus (HIV), though the results and potential benefits may not be generalizable to populations with a lower risk of HIV infection than
found in those studies’ samples. Prevention of penile cancer is another proposed benefit, but most studies indicate that its incidence is very low, and it remains extremely rare in countries where circumcision is not done but where adequate hygiene is practiced (AAP, 1999; CDC, 2008).

The burdens of circumcision include the pain and the potential complications that accompany the procedure. Preventing the pain associated with the procedure may require a penile nerve block in newborns and mild analgesics afterward. General anesthesia is necessary when older children are circumcised and this adds risk for the child. The true incidence of complications after newborn circumcision is unknown, though reports suggest that the rate in developed countries ranges between 0.2% and 0.6%. The most frequent complication is bleeding, seen in ~0.1% of circumcisions. The need for transfusions is rare since most complications can be addressed with local measures. Infection is the second most common complication. Other complications are less common but more serious: reported cases include sepsis and surgical problems such as buried penis, urethral fistula, amputation of a portion of the glans penis, and penile necrosis. Though most of these risks are reported for newborns, many of the complications are similar in older boys. A potential harm that may be recognized later in life is diminished sexual sensation (historically considered a “benefit”). While some studies and anecdotal evidence support this claim, others do not show any significant, measurable changes in sensitivity or sexual satisfaction post-circumcision (AAP, 1999; CDC, 2008).

Ethical principles for non-therapeutic interventions

Two debates surround circumcision: (1) whether circumcision of newborns should be routine, and (2) whether non-therapeutic circumcision should be performed at all. Though both raise many of the same issues, whether circumcision should be routinely implemented for preventive purposes is also a question of public health practice and ethics (Hodges et al., 2002). This chapter focuses on the obligations that physicians must balance when they are asked to perform an apparent non-therapeutic intervention: to promote the child’s interests, to respect parents making medical decisions for their children, and to respect children themselves as patients.

Physician obligations and promoting children’s interests

Physicians are ethically bound to promote their patients’ welfare under the principle of beneficence, and to minimize risks or burdens under the principle of nonmaleficence. Physicians thus recommend treatments that they judge as presenting the best balance of risks and benefits, and are not professionally obligated to provide interventions that they judge to offer little or no benefit and which may pose more than nominal risk. In pediatrics, this obligation is intensified by the inherent vulnerability of children, who cannot protect their own interests (Beauchamp & Childress, 2009). When the risks of a procedure are justified by a clear medical benefit, the physician’s course of action is clear. For example, choosing circumcision to treat severe phimosis unresponsive to conservative management would not be ethically controversial.

For some procedures, such as circumcision, the balance of the medical risks and benefits remains uncertain. In 1999, an AAP Task Force concluded that there was potential medical benefit to circumcision, but not enough to recommend its routine performance. The AAP reaffirmed this statement in 2005, and others who have examined the evidence have reached similar conclusions (Benatar & Benatar, 2003; Diekema, 2009). The British Medical Association (BMA) similarly states that there is an “absence of unambiguously clear and consistent medical data on the implications of non-therapeutic circumcision” (2006). On the other hand, the procedure may have benefits that are not medical, but may be personally significant to the patient and/or his parents. Whether a child has undergone circumcision may determine whether he is considered to have fulfilled a covenant consistent with his family’s religious beliefs or whether he can more freely participate in the religious or broader cultural life of his community.

When parents ask a physician to perform a procedure where the balance of medical risks and benefits is unclear and potential non-medical benefits are intangible, it may be difficult to determine whether acceding to the request is ethically permissible. The obligation to promote a child’s well-being may be viewed by some as prohibiting physicians from performing procedures which are not shown to have clear physiological benefit. However, this interpretation may ignore other features of children’s lives that may contribute to their welfare, benefits which are psychosocial in nature. Reasonable
persons may disagree on how these benefits and harms should be weighed against each other regarding circumcision (Diekema, 2009).

Respecting children and parents in pediatric decision-making

The principle of respect for autonomy establishes that competent patients may make medical decisions based on their personal values, and these decisions are entitled to physicians’ respect (Beauchamp & Childress, 2009). Pediatric patients challenge this framework because they are still developing as autonomous individuals, and may lack the decisional capacity to participate in the consent process. Additionally, the law may not consider pediatric patients competent to give valid informed consent (AAP, 1995).

Because most children generally lack capacity, parents are ethically and legally presumed to have the authority to make decisions for them. (“Parents” in this discussion also includes legal guardians.) This presumption acknowledges that because most parents care about their children, they may be in the best position to make decisions promoting their health and general well-being. This presumption is also justified by the parental interest in raising children according to their own personal values – such as those based in religion or culture – and transmitting those values to their children (Diekema, 2004). Physicians respect parents’ role in decision-making by obtaining their informed permission to perform procedures (AAP, 1995). However, parental decisions are subject to limits. The boundaries of parental authority are clearest when parents refuse a safe, effective, and available treatment that may save a child’s life. In these situations, physicians, as well as the state, are ethically justified in intervening regardless of whether the parents’ choices are based on personal or religious conviction (Diekema, 2004).

Even when children are not yet fully autonomous, they are still entitled to respect as persons. Children should be able to participate along with parents in decision-making to the extent their capacity permits; as such, physicians should engage these children by obtaining their assent or their dissent. As children mature and are able to understand and rationally evaluate the information necessary to make medical decisions, the weight given to their input should correspondingly increase, even when they may not agree with their parents or physicians (AAP, 1995). In addition, ethics and law have sometimes recognized that children’s future ability to make autonomous decisions should be protected (Diekema, 2009, p. 254), especially when parental decisions would foreclose those choices entirely (Davis, 1997, pp. 9–10). Part of the objection to circumcising children when they are young is that it removes the opportunity for them to make the decision for themselves based on values they may later develop (Geisheker, 2010).

Balancing ethical considerations for non-therapeutic interventions

Ethical dilemmas may arise when it is unclear how physicians should balance their obligations to patients. In the adult world, bioethics has tended to prioritize respect for competent patients’ choices over promoting their medical interests. Thus, adults can undergo procedures that are considered potentially medically harmful, provided they are competent and give informed consent. Balancing these interests is less clear in pediatrics because children are not autonomous individuals and may not have the capacity to voice their own interests. Physicians and parents must therefore make decisions on a child’s behalf, based on what each judges to be in the child’s best interest.

In the absence of clear medical benefit, some have interpreted the obligation to promote children’s well-being as prohibiting physicians from performing circumcision when there is no medical indication (Fox & Thomson, 2005). Some would prioritize respect for children by arguing that a child’s future autonomous choice regarding circumcision should be preserved, rather than permitting him to be circumcised while he is unable to fully consent. These positions often complement each other, and are also supported by pointing to circumcision’s dubious history in medicine, and by claims of a child’s right to bodily integrity (Geisheker, 2010). In addition, some compare male circumcision to female circumcision and call for more scrutiny of its acceptance based on religion and health. On the one hand, similarities between male circumcision and less physically damaging forms of female circumcision are also acknowledged by commentators who would not prohibit male circumcision, though they would argue that consistency may require challenging currently accepted views of both. On the other hand, this comparison may ignore relevant differences between the two: some forms of female circumcision are clearly more harmful than
standard male circumcision, and further, male circumcision may present potential health benefits for certain at-risk populations (Benatar & Benatar, 2003; Abu-Sahlieh, 2006).

For some, the medical uncertainty and the historical significance surrounding circumcision argue for leaving the decision to the discretion of properly informed parents (AAP, 1999; BMA, 2006). This position does not always mean that physicians are deferring to parental authority, or abrogating their duty to promote the child’s interest. Rather, it recognizes that there may be non-medical benefits motivating the request for circumcision, including those based in social, religious, or cultural tradition; parents do not necessarily ignore medical risks and benefits in their assessment, but they may give equal weight to personally significant factors which matter for their child’s well-being (Benatar & Benatar, 2003; Diekema, 2009). In acknowledgment of the respect due to the child’s future autonomous choice, some would also ask whether the decision to circumcise could be postponed, to the extent that the delay would not affect any non-medical benefits of the procedure and would give the child time to mature (Diekema, 2009).

As children mature and develop the capacity to make decisions, the dilemma of determining interests on their behalf may resolve itself. When they cannot make decisions for themselves, ethical and practical considerations must guide physician decisions.

**Practical summary**

Physicians who are asked to perform a non-therapeutic intervention must assess the request to determine whether it would be medically and ethically appropriate to do so. Physicians should engage the parents and, when appropriate, the child in a thorough discussion regarding the procedure.

**Assessing requests**

1. **Physicians have no ethical obligation to perform procedures they do not believe to be medically indicated or beneficial to the patient.**

   For some procedures, reasonable physicians may disagree on how to interpret the evidence regarding risks and benefits. A physician who does not believe that the medical risks of the procedure sufficiently balance the benefits can refuse to perform the procedure. However, physicians should be sensitive that they are not merely imposing their personal values on the patient and the patient’s family. As with all legally available medical services, parents may choose to seek the procedure elsewhere.

2. **If the balance of medical risks and benefits – including non-medical benefits – is uncertain, it is ethically permissible for a physician to perform the requested procedure.**

   Because a child’s well-being may not depend on medical factors alone, physicians may take into account personally significant benefits, such as those based in religion or culture, in determining the child’s best interest. Physicians may wish to consult others whose insight may assist in evaluating the requested procedures (e.g., religious figures, other physicians faced with similar requests, ethics committees).

3. **If the non-medical benefits of the procedure would not accrue until a later time, then the physician should attempt to persuade the family to delay the procedure.**

   The non-medical benefits of a requested procedure are less compelling when they will not affect the child until a later age. In that case, the procedure should be delayed in order to give the child more time to develop the capacity to more fully participate in decision-making.

**Decision-making process**

As part of respecting children and their parents, a physician who accepts a request to perform a non-therapeutic procedure should obtain the parents’ informed permission and, when appropriate, the child’s assent.

1. **Physicians should ensure that parents are fully informed about the procedure before obtaining their permission.**

   Parents should be informed of the procedure’s short-term and long-term risks and lack of clinical benefit when not done for medical purposes. Properly informed parents, with the guidance of physicians, should be able to weigh the procedure’s risks and benefits for themselves. The nature of the procedure may require the permission of both parents.

2. **Physicians should involve the child in the decision process to the extent that the child can participate.**

   Assent includes giving children information about medical procedures they will undergo, even
when they would not be able to refuse. Children who can express a considered opinion about circumcision should be part of determining their own best interest. If a child consistently refuses the procedure, the physician should not perform the procedure against the child’s wishes.

Case resolution

The pediatrician and the urologist should inform the parents that their son’s circumcision is not medically necessary, and further, that there is no consensus in the medical community that circumcision would be medically beneficial to their son. The physicians should also describe the various burdens of the procedure, including risks of general anesthesia for a 7-year-old to undergo the procedure, and the required recovery from the surgery. The physicians should discuss with the parents the benefits they hope their son will gain from the procedure. This may prompt the parents to more carefully weigh those benefits with the risks discussed. This may also reveal whether it is possible to delay the procedure until the son is older and can possibly make decisions regarding the procedure for himself. The circumcision should not be performed unless there is agreement between the parents regarding the decision to circumcise their son.

The physicians should also discuss circumcision with the son, and explore how he feels about the procedure and the reasons his parents are requesting it. If the son is ambivalent or refuses, the physicians may take the son’s wishes into account, as it may be difficult or dangerous for the son to be circumcised even with the parents’ permission. If the physicians are truly uncomfortable with providing the procedure, they should decline the request.

Conclusion

While this chapter has focused on circumcision, “non-therapeutic” interventions include a broad range of procedures. Circumcision brings to mind religious and cultural reasons for the requests, but in some circumstances parents may be motivated by other personal reasons – the belief that a procedure may afford their child an important psychosocial benefit and the wish to place their child in the best possible position to succeed in life, or the belief that a procedure may spare their child from some traumatic psychosocial harm and the desire to lessen the burdens their child already bears. The issues in these cases are made more difficult by the uncertainty surrounding most of these procedures. Though physicians and parents may want to act in the children’s best interests, deciding on children’s behalf is always a complicated task.

References


