

## Ethical issues in pediatrics

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### Objectives

- Identify ethical difficulties in the role of parental decision-making.
- Discuss pediatric assent and the ability to consent for themselves.
- Recognize the difficulty with applying the “best interest” standard for some children.

### Case 1

Tommy, 3, sustained a traumatic brain injury (TBI) from a motor vehicle accident. Two weeks into his ICU stay, physicians presented Tommy’s parents with the option to forgo life-sustaining treatments (FLST). After a few days of reflecting and discussing the issue, they agreed that stopping the ventilator was best, but by that time there was a new ICU physician who, after review of Tommy’s condition, did not think that FLST was warranted. With more intensive therapy, Tommy was able to breathe without the vent, and he was moved to the rehabilitation unit. Because of his TBI, however, he continued to be fed through a tube. Neurological scans indicated problems with the basal ganglia, and Tommy’s parents suggested that Tommy’s condition was not in his best interest and asked the palliative care physician about the possibility of stopping feeds. At the same time, the physical and occupational therapists working with Tommy, as well as nurses and social workers from the PICU who came to visit him in rehab, believed they saw slight but noticeable improvements in his cognitive status – possibly tracking, smiling, and reacting to some stimuli. The entire unit, as well as these PICU staff members, is concerned about the ethics of what the parents are suggesting.

### Case 2

Yasmine is a 2-month-old whose parents have brought her to her first appointment with her pediatrician, Dr. Jones. Her parents have been told by their church pastor that some vaccines violate religious tenets and after doing some research online, they also have decided that the medical risk is too high, especially since the chance of her getting any of these diseases is so low. Dr. Jones explains that the risks have been misstated on the internet and even in medical journals, and that there is a real risk to Yasmine should they not get her immunized. Further, the “herd immunity” that offers any protection to Yasmine should she not get immunized is, itself,

compromised whenever a child does not get her shots. Yasmine's parents explain that they have read some very convincing articles, and that medicine can't promise she won't become autistic or come down with some immune deficiency. That, for them, is too high a price to pay for their "precious little angel."

### Case 3

Anna, 14, has been living with acute lymphoblastic leukemia (ALL) for 3 years. She has recently been admitted into the Children's Hospital after complaining of fatigue and lethargy. This is her third extended admission and by all accounts, this time will lead to her death. Her parents decide not to begin any treatment for her ALL and ask the medical staff not to tell her that her ALL has returned nor about the dire prognosis.

## Introduction

Concerns about the ethical care of children have been central to modern bioethics since its inception over 40 years ago. Key milestones in pediatric bioethics include the controversy over the Willowbrook hepatitis experiments in the 1960s, acknowledgment of the importance of "assent" for adolescents by the National Commission in the 1970s, and the Baby Doe regulations about the treatment of neonates in the 1980s. Nevertheless, development of bioethical reasoning during the first 30 years was heavily focused on issues surrounding adults with decisional capacity and the principle of respect for autonomy. In fact, most of the ground-breaking judicial opinions about end-of-life decisions focus on protecting the rights of adults to make autonomous decisions about their care (Menikoff, 2002).

Many healthcare ethics committees (HECs) operate in an environment primarily geared towards the care of adult patients, and the ethics education of many HEC members is adult based as well. Along with the chapter on neonatal issues, this chapter focuses on unique considerations in pediatric ethics, considerations that can differ, subtly though importantly, from adult-care ethics.

## Children as "little adults": where medical ethics fails

It may sound trivial, but it is no small matter to recognize that children are not just adults in miniature. Yet, for many years, that is how the medical profession used to treat children. One clear example of this is the deplorable lack of pediatric-tested medications. This is due, in part, to our interest in protecting children from harm, but it stems just as much from the belief that the dosage used on adults could simply be reduced for children.

Even with the long history of ethical concerns regarding pediatric care, medical ethics has suffered from its own version of this fallacy. The powerful hold on medical ethics of the principle of respect for autonomy is a testament to the adult-centered emphasis of medical ethics – a principle that fails to apply to children. Consider the case of Tommy (Case 1), who lies in a hospital after a severe TBI and is unable to speak for himself. Clearly, someone else must make his healthcare decisions. Given only the fact that Tommy has a TBI and cannot speak for himself; Tommy could be 3 or 30 years old; he could be in an adult ICU or in a pediatric rehabilitation facility.

But something morally substantive changes when we think about Tommy's age. If he were 30, when we turn to another person to make decisions for him, we are looking for someone

**Table 15.1.** Adults vs. pediatric – differing ethical presumptions

Adult-care ethical presumptions	Pediatric-care ethical presumptions
<ul style="list-style-type: none"> <li>◦ Presumption of patient autonomy               <ul style="list-style-type: none"> <li>• Presumption of maturity/ownership of values</li> <li>• Presumption of full accountability                   <ul style="list-style-type: none"> <li>• Ethically: Presumption of obligation to respect</li> </ul> </li> </ul> </li> <li>◦ Presumption of <i>family insight</i> into the patient's values               <ul style="list-style-type: none"> <li>• Greater potential for conflict between respecting autonomy and providing "benefit"</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>◦ Presumption of patient incapacity               <ul style="list-style-type: none"> <li>• Presumption of patient immaturity/innocence</li> <li>• Presumption of developmental accountability                   <ul style="list-style-type: none"> <li>• Ethically: Presumption of need to protect</li> </ul> </li> </ul> </li> <li>◦ Presumption of parental authority over their child's values-development</li> <li>◦ Greater potential for conflict between parental authority and avoiding harm</li> </ul>

to act as his "surrogate" or "proxy" (see Chapter 9). We do so in order to attempt to bring Tommy's voice into a conversation where he, in fact, cannot speak. We ask of this surrogate that s/he try to respond the way Tommy would respond if he could do so himself – to *make decisions based on his values and interests, extending his autonomy as far as it can be stretched.*

If Tommy is 3, however, his decision-maker is not tasked with the same responsibilities. Whereas Tommy the 30-year-old presumably would have had decisional capacity before his TBI, and as such, would be presumed to own the values that he believed in and acted upon at that time in his life, for Tommy the 3-year-old, no such presumption of capacity, of values ownership, exists. Thus, in the younger Tommy's case we turn not to a reasonable surrogate, but to someone with "authority" to make decisions for him – typically parents. They are not expected to speak in Tommy's voice but to address his "best interests." These facts about the basic presumptions regarding minors and the responsibilities that follow from them create a different moral space when making pediatric decisions. (Table 15.1 puts some of this into perspective.)

## The role of parents

Pediatric care typically contains an element in the decision-making process not seen as often in adult-care situations – i.e., the default need to look towards someone other than the patient for consent. Legally, this default assumption of parental decision-making is often phrased as a parental *right* to make decisions,<sup>1</sup> but ethically, it might be better characterized as parental *responsibility*. While rights can be exercised as desired, responsibilities have a stronger moral claim on those who have them. Parents, it is believed, should try to make good decisions for their children. They should demonstrate that they are responsible as parents.

The basic presumption in favor of parental decision-making is legally supported by medical consent. It is accepted within our society that parents are typically the primary persons to make decisions for their children because the role of parenting requires protecting and raising children. Parents have more invested in their own children than others do; they

<sup>1</sup> *Nota bene:* the parental right (or authority) to make decisions should not be confused with the oft-used but mistaken concept of "parental autonomy" (cf. Ross, 1998). Given that "autonomy" is the concept of "self-determination," the only sense that a phrase "parental autonomy" can make is if we are talking about parents making decisions about *themselves as parents*. Parents making decisions about their children are not exercising "autonomy" but "authority."

typically know their own children better than others; and they should want what is best for them. Moreover, it is through familial bonds that many values are imparted and children develop significant aspects of their moral characters. Also, the values families hold are typically imparted to children, and thus, children develop much of their moral characters through familial bonds (Nelson & Nelson, 1995).

Traditionally, to act responsibly, a parent is expected to make decisions for his/her child based on what is in the child's "best interest" (Buchanan & Brock, 1990; Kopelman, 1997), yet what this means might vary greatly. In addition, since most children have underdetermined interests, save for avoiding harm, some argue that "best interest" is a less appropriate standard than the "harm principle" (Diekema, 2004). Whatever the conceptual framework used in making decisions, however, parental *responsibility* remains a focus of moral evaluation of parental *actions* toward their children, with the central focus remaining on what is best for the child.

*Of course, not all parents are (capable of being) responsible. Some do not have the welfare of their children at heart, and others may simply not be in a position (physically, mentally, economically, etc.) to act responsibly. Again, these are the exceptions, not the rule, but as exceptions they pose ethical challenges to the healthcare of children.*

## A two-pronged moral concern when deciding for children

Medical decisions regarding children pose at least two concerns:

1. Who is best able to determine what should be done?
2. What criteria should be used to determine what should be done, and are there limits to the use of these criteria?

### Who decides?

We have already stated that the ethical and legal presumption is that parents are the legitimate decision-makers, but it is not clear that this should always be the case. On the one hand, some medical decisions are complex, some patient conditions are tragic, and some family situations are difficult. Parents may not understand what is needed and why; some parents may be struggling with emotions and grief; some parents may have conflicts of interest (whether money or time or other). On the other hand, physicians have experience concerning certain conditions and would seemingly be impartial to adjudicate the well-being of the child.

A most tragic and stark case where these issues collide is with severely impaired infants (see Chapter 14). Whether genetic, congenital, or postnatal, severe impairment in very young children is devastating to parents and tragic to medical personnel. Making the best decisions for these children is not easy. Is living with the suffering of a severe impairment better than allowing the child to die? Is death ever better than life? Does prognosis matter concerning *how long the child might live, how severe the impairment, how troubling the care?* What if parents wish to keep a child with no higher brain functioning alive? What if parents wish to cease life-sustaining treatment for a child with cerebral palsy? Should physicians ever have the right to refuse to implement or continue a treatment request by the parents? Must they treat children whenever they foresee the possibility of the child having some (even if diminished) cognitive function? In all these questions, the tensions between who should decide and the limits of decision-making are evident.

Further, some children are older, more experienced, highly intelligent and thoughtful, and thus, the decisions being made might best be made by them. Though children are not just “little adults,” they are developing into adults, and their decisional abilities develop as well. As persons, whether little or big, they deserve to be respected. The American Academy of Pediatrics has suggested that providers consider developmental maturity when working with pediatric patients (AAP, 1995). One recommendation is that, roughly speaking, young children into their early school-aged years should be informed about what is happening to them to the extent they can understand; those who are between mid-school-age into early teen years should not only get information, but also be allowed to *assent* (not consent – the legally recognized agreement); and finally into the teenage years, serious consideration should be given to allowing the child to consent to, and even to dissent from, the proposed therapy for him/herself. Further, in most states, minors become emancipated by virtue of the fact that they get married.<sup>2</sup> Unlike the latter exemption (marriage), the former exception (developmental maturity in teenagers) offers little clarity. Yet, the latter condition tells us nothing about the child’s ability to reason through difficult decisions, unless the presumption is that anyone who marries is capable of this kind of reasoning – a dubious assumption, at best. In fact, the latter exception is much more common in state laws. Either way, the unstated rule seems to be, “act/think like an adult; be treated like an adult.”

## What decisions are allowed?

Even when we determine who is (are) the best person(s) to make decisions in pediatric cases, we often remain concerned about the decisions themselves. We might all agree that the parents of a 1-year-old are the correct decision-makers, and yet we might be highly dubious of their decision to withhold childhood immunizations. In order to delimit properly the focus and range of medical decisions about minors, two kinds of standards have been proposed: the “best interests” standard and the “harm” principle.

The best interest standard requires decision-making to aim at care that is in the best interests of the patient (Buchanan & Brock, 1990). It is an aspirational standard; it aims at achieving some positive goal. But, even so, it is not without its detractors. While the best interest standard sounds appealing, it is not clear how “best interests” are to be determined. In Case 2 above, the physician believes strongly in vaccination for children. To her, this is an important health protection for both the child and the community. The parents, however, disagree, possibly fearing poor medical outcomes or following a religious injunction against immunizations. *Which path, in fact, leads to Yasmine’s best interest?*

In adult care, a question of what is in a patient’s best interest starts by looking to the patient him/herself. An ethically acceptable, participatory process of medical decision-making typically means that the patient’s own values and interest determine what is “best” for him/her (Hester, 2001). As we have said, however, pediatric patient care differs importantly in this regard. Especially young children cannot be said to have enough experience to express their own interests. And, even as they get older, how good are children at weighing short- and long-term considerations? Further, since children are highly dependent on their families, familial interests might need to be part of a reasonable consideration of the “best interests” of an individual child – with burdens of care for children being carried not only by the patient but by the family/caregivers as well (Ross, 1998).

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<sup>2</sup> Or a court grants emancipation.

The best interest standard, then, can founder at precisely those moments when we try to rely on it for guidance. Parents are tasked with pursuing the “best interests” of their child, but so are healthcare professionals. When these parties differ in their conceptions of what is best, the best interest standard is not so much the solution as the problem.

Troubles with applying the best interest standard have led some to suggest a threshold standard: the harm principle (see Diekema, 2004). Of course, medical care should be guided by trying to do what is best for the patient, but often it is precisely a debate of what constitutes “beneficence” in a given case that constitutes ethical conflicts in pediatric care. Since parents have presumptive authority over their children’s care, the use of the harm principle, then, attempts to locate parental decision-making parameters in order to help define not what parents should be trying to achieve when they make decisions but, instead, when others should step in to take decision-making away from parents. So, in particular, the question is not, “what is best for this child?” but “how can we identify when decisions exceed parental authority?” *Since the state intervenes only under conditions of medical neglect or abuse, the harm principle explains that only those decisions that can be deemed harmful would be ruled out – that is, would require state intervention.* The harm principle, then, is based primarily on an ethic of protection, not on one of respecting the interests of the child.

### **So which is it? “best interest” or “harm principle”**

Ethically, then, we are left to ask what is the best ethical approach to pediatric decision-making: pursue the ideal of the best interest standard or be guided primarily by the harm principle? The answer is “both.”

Especially when HECs are confronted with difficult pediatric cases that raise the question of what is best for this patient, it is important to pursue carefully what the medical, personal, familial, cultural, and legal facts and interests are. Determining what interests are at play is no small task, but the aspiration to provide “best” care for this patient requires a thorough *understanding of what interests are relevant in determining what is “best”* (Hester, 2001). Parental authority has its limits, no doubt, and it is not the case that whatever parents say is “best” is, in fact, best for the child. The best interest standard is intended therefore, not simply to do what parents say is best, but also to propel our development *and recommendations* of medically appropriate options in light of the interests at play for this particular child’s care (Kopelman, 1997).

At the same time, however, there are limits of the authority of the healthcare professionals, the HEC, and the state, for that matter. We must acknowledge that parental authority has fairly broad scope, and given that no one of us has the hold on “truth,” and that the story of his/her medical care is not the sum total of any patient’s life story, it may be necessary to allow parental decision-making to hold sway even when doubts remain about whether those decisions are, in fact, best for the child. Here, then, is the place of the harm principle, setting a threshold for harm below which we cannot allow parents to go. Above that threshold, however, the most we can do ethically is attempt to persuade parents, giving reasons why we think a given path is best.

### **Older children and teens: issues with developing capacity**

One of the more challenging aspects of pediatric care is that most children grow and develop, physically, intellectually, and emotionally. Ethical considerations must change in accordance with these developments. As children mature, they become more accountable for their

decision-making, which means that others must wrestle with the degree of ownership of children's interests and values, including the extent to which any particular child should participate in healthcare decisions that affect him/her. The 6-year-old who refuses a shot for tetanus after stepping on a rusty nail will most likely get the shot regardless, but the same is not the case for the 16-year-old who refuses to get a contraceptive shot because her mother wants to protect her from getting pregnant.

In light of developmental considerations, the mature minor doctrine has been proposed as an ethical and legal concept that attempts to speak to the concern that even children (typically teenagers) may be capable of making their own healthcare decisions. The doctrine can be put thus:

**Mature minor doctrine:** Any minor who is capable of understanding his/her treatment options, is experienced enough to weigh the consequences to him/her of those options, and is mature enough to cope with the information, deliberation, and outcomes should have authority to make the decision at hand.

Legally, the doctrine has limited statutory coverage – primarily applying to teenage females regarding sexual health and pregnancy, all teens regarding sexually transmitted diseases and drug/alcohol abuse, and teens who are incarcerated (cf. Guttmacher Institute, 2011). Outside these narrow categories, only a few states recognize mature minors in statute. Beyond statute, however, the legal concept does have common law support in some jurisdictions.

Ethically, the doctrine attempts to recognize the developing autonomy and moral agency of minors. Such recognition seems warranted, since the actions proposed will directly affect him/her. In Case 3, Anna's parents attempt to protect her from the harm that might follow from the news of relapse. However, at 14, with multiple admissions, her personal knowledge and experience with her disease is possibly quite robust. Excluding her from this information, and the decisions that follow from it, ignores or devalues her own experience and maturity *with this disease*. In cases like this, the doctrine has intuitive appeal, but some applications of the doctrine may not meet with ready favor.

*What if Anna's case was a bit different – instead of ALL, Anna has Hodgkin's and has been given one round of chemotherapy? Even though successful remission occurs 80 percent of the time after several rounds of chemo, after this first round, Anna and her parents reassess her condition, and she decides that she does not want to undergo further chemotherapy. In fact, she wants to try some alternative, homeopathic treatment options. Anna is a bright girl, capable of making careful decisions, and she states clearly that she understands the possible consequences; she is just unconvinced that the chemo is healing her and the websites of other Hodgkin's patients have convinced her and her parents to try another method.*

In this case, vigorous debate might ensue with regard to whether child protective services should be called in. But in this latter scenario, surely Anna is not somehow less mature than in the original case. Rather, the underlying reason for any objection to Anna declining treatment may be the simple fact that we do not agree with her choice. There may be several reasons for this. For one, treatment efficacy may prove so high that some might claim not providing it constitutes medical neglect. Further, some might argue that the consequences of non-treatment are of such "high stakes" that Anna simply must be protected from the significant harm that could follow. Whatever our initial reactions to such a case, even careful reflection may lead to reasonable differences (see Ross *et al.*, 2008). Such considerations are challenging, but they require more than simply emotive reaction or intuition; they demand reflection, discussion, and principled determinations, for such cases are not simply about the current patient, but can set precedent within the institution.

## Conclusion

It is important to recognize not only the physiological but also the ethical differences between adult and pediatric care. Pediatrics creates a different moral space in which patients, families, and practitioners operate, and this difference is characterized by a powerful ethic of protection, the importance and scope of parental authority, and the developing maturity, and thus participation, of the patients themselves. HECs in hospitals with both adult and pediatric patients, or in pediatric-only facilities, would do well regularly to work on targeted education in the arena of pediatric ethics in order to keep the subtle but important moral differences in mind for when cases arise or policies need crafting or review.

## Discussion questions

1. *Conceptual*: What are the limits of parental authority? Ought we expand the extent to which we respect teenage decision-making?
2. *Pragmatic*: In what ways is parental authority respected within your institution and HEC? Is too much deference paid to parental decisions?
3. *Strategic*: In what ways can your HEC better prepare for pediatric cases and policies in your institution? Is “best interest” or “harm” the operative principle followed in pediatric cases?

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