

Is the Best Interest Standard Good for Pediatrics?

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abstract

We argue that the “best interest standard” for surrogate decision-making is problematic for a number of reasons. First, reliance on the best interest standard is subjective. Second, it leads to behavior that is intolerant and polarizing. Third, appeals to the best interest standard are often vague and indeterminate. After all, cases are usually controversial precisely because reasonable people disagree about what is or is not in a child’s best interest. We then recommend that, instead of the best interest standard, parents should be held to a standard that we call the “not unreasonable” standard. By that standard, parents’ decisions would be respected unless they were deemed unreasonable. This recommendation would allow a greater range for parental discretion than the best interest standard. *Pediatrics* 2014;134:S121–S129

The “best interest standard” has been widely accepted as a benchmark for decisions made on behalf of others, both patients and loved ones. It is used to guide decisions in both law and medicine. It just seems like common sense. Referring to the best interest is taken to be as pleasing as apple pie, as wholesome as mother’s milk, and as salutary as chicken soup.

That said, we shall argue that invoking the best interest standard for surrogate decision-making is problematic. In what follows, we shall begin by briefly reviewing what is said in defense of the best interest standard and what is said in criticism of it. Using cases from pediatrics to illustrate our concerns, we shall then move on to raise several specific concerns. We argue that, at the very least, reliance on the best interest standard is subjective, and that it leads to behavior that is intolerant and polarizing. We also point out how appeals to the best interest standard can be vague, making it less useful than supporters presume that it is. Furthermore, we explain how using it as a point of reference can be misleading, egocentric, irrelevant, and unjust. We then turn to explaining why we cannot entirely abandon standards for assessing surrogate decisions and why pediatricians must accept responsibility for monitoring the decisions that parents or others who make decisions on behalf of children are allowed to make. Finally, we will put forward our own recommendation for evaluating surrogate decisions.

THE BEST INTEREST STANDARD IN THE BIOETHICS LITERATURE

Loretta M. Kopelman is well known as a vigorous defender of the best interest standard. As she points out, it is the “prevailing standard . . . in pediatrics as well as other professions” that has been widely embraced in the literature.^{1–11} Ideally, it involves selecting “the option that maximizes the person’s overall good and minimizes the person’s overall

risks of harm.”¹ In her most recent article she argues that upholding the best interest standard is required by the public’s trust in medicine as a profession. She maintains, as she has in the past, “that it is generally clear how this standard should be applied . . . and that it is a useful standard for making professional recommendations and decisions for those unable to decide for themselves about what is in their best interest.”¹ Kopelman sees best interest as an ideal, a threshold, and a constraint that most often produces consensus on what should be done. As she sees it, although disputes are rare, when they arise “disputes . . . are often solved by better communication.”¹ In other words, Kopelman takes the best interest standard to be the unproblematic touchstone for medical professionals and family members in making medical decisions on behalf of those who cannot decide for themselves.

Robert M. Veatch has been one of the most prominent critics of the best interest standard. His detailed criticism is articulated in his 1995 *Hastings Center Report* article, “Abandoning Informed Consent,”¹² in which he raises many of the objections that have been raised by others.^{13–16} He regards the best interest standard as having “achieved the status on an unquestioned platitude,” and he finds the standard to be “terribly implausible.”¹² In great detail he explicates the source of ambiguity and disagreement in the determination of what is in the patient’s best interest. He notes the possibility of conflicts between those who focus exclusively on health concerns and those who factor in other interests and goals. He elucidates different theories of the good, in his terms, hedonistic theories, desire-fulfillment theories, and objective list theories that could provide radically different conclusions about what is actually in a patient’s best interest. These possible differences in perspective lead Veatch

to conclude that “physicians are no better than the rest of us at guessing what counts as the medical good, how the medical good relates to the total good, and whether the patient’s total good should be promoted.”¹² In the end, he suggests that “to know what is good for this particular person,” decisions should be made by someone who shares deep values with the patient because this would allow the patient’s beliefs and values to govern the decision. In contrast with the best interest standard, Veatch calls his alternative standard the “reasonable interest standard.” As he describes it, this approach will tolerate any choice that is consonant with a patient’s values. Although Veatch does not explicitly discuss decisions on behalf of young children in that article, we may assume that he would count parents as those who share deep values with the pediatric patient. Thus, Veatch would find it acceptable for parents to make any choice that is consistent with the parents’ values and beliefs.

THE BEST INTEREST STANDARD IS SUBJECTIVE, INTOLERANT, AND POLARIZING

When we identify something as the best, we are picking out 1 thing. There is only 1 best apple pie at the state fair, 1 best student in the class, and 1 best picture of the year. That said, we know that there can be disagreement about which 1 in each category is the best. Different people value different things. Some like large chunks of apple in their pie; others prefer the apples to be sliced thinly. Some prefer thin crust, and others prefer a crumb topping. Some prefer their pie to be sweet with hints of cinnamon and nutmeg; others prefer an unadulterated tart apple taste. In other words, what we call “best” is subjective. Even when people agree on the factors that are most relevant to a specific judgment, they can prioritize them differently and, therefore, reach different conclusions about what is best.

Today we live in a pluralistic society. Inherent in that reality is the fact that the people we encounter have radically different views about what counts as good and widely divergent perspectives on what is best. When medical professionals adopt the view that they are the arbiters of what is best for a patient, it is certainly possible that other parties with an interest in a decision could see the situation differently. When doctors maintain that their professional responsibility requires them to advocate for what is best, they put themselves in the position of not being able to tolerate any deviations from their preferred course. When it's your duty to do what is best for the patient, anything else is a violation of duty and totally unacceptable. In this way, a commitment to the best interest of the patient may put health professionals at odds with each other or set the stage for conflict with a patient's family. Treating medical decisions from the perspective of the requirement to do what is in the best interest of the patient is intolerant of other people's values and perspectives. It polarizes the parties involved and leaves those with opposing views standing their ground with no room to compromise.

Aside from this structural problem of intolerance, the best interest standard doesn't work as well as people imagine it does. We invite you to consider some cases from our experience that illustrate a variety of ways in which the best interest standard may be found wanting. The distinct problems that we identify are instructive, even though these concerns share some measure of similarity.

CASE 1: VAGUE

The parents of 3 sons had a difficult choice to make. Their 11-year-old had leukemia and needed a bone marrow transplant. He also had sickle cell disease. They could use the better-matched son as the stem cell donor and minimize

the effects of graft versus host disease. They could also use the son who was a less perfect match. He did not have sickle cell disease, so a transplant that used his stem cells might also cure the sickle cell disease.

This case was brought to the attention of our ethics committee because the doctors involved violently disagreed about what was best for their patient. The bone marrow transplant team thought it was obvious that the best interest of the patient required a donation from the brother who did not have sickle cell disease. As they saw it, that option was best because it could cure both diseases at once. The pediatric oncology team was equally adamant that the best interest of the patient required using the better-matched brother as the donor. To them it was best to minimize the extent of the graft versus host disease.

Considering the case from the perspective of the best interest would require the decision-maker to determine which course was best and to impose that decision on everyone involved. Yet, both perspectives reflected a sincere concern for the patient and a genuine desire to do good. Invoking the best interest of the patient does not resolve the vagueness of the different considerations that would tend to make 1 course the clearly best choice. Sometimes all we can do is identify those options that would be unacceptable, leaving a set of choices with no clear and objective best.

In the end, the parents chose what they considered best. They decided not to go ahead with the transplant at all because they considered the burdens on their ill son to be too great and because they didn't want to impose burdens and risks on their other 2 sons.

The ethics committee found this option to be within the range of acceptable choices. As we saw it, there was no single best choice, just an array of relevant considerations. Any decision that took the most relevant factors into account

and avoided doing things that were clearly opposed to our patient's interests was an acceptable choice. In this case, there was no 1 best option, but at least 3 acceptable alternatives. Selecting 1 route among the 3 was a matter for the parents to decide. Our job was not to second-guess them but to offer them support for whichever path they took. Nonjudgmental regard, a professional responsibility of medicine, requires clinicians to recognize that people will have different values, and even when they share the same values, they may prioritize them differently. Respect for autonomy requires that we accept the priorities of our patients. And when family members are the appropriate decision-makers for patients who do not have decisional capacity, we should show respect for the choices that reflect their ordering of priorities even when we might order things differently, so long as their choices are not unreasonable.

CASE 2: MISLEADING

When Mrs Jones was pregnant with her sixth child, the fetus was found to have trisomy 18 with no significant life-threatening anomalies. Mrs Jones was determined to have the child and bring him up at home. She requests resuscitation, if needed, at delivery. She had been in touch with other parents of children with trisomy 18, and she was optimistic about her son's future.

When the child was born he did not require resuscitation. He clearly had many of the features of trisomy 18 including diminished neurologic functioning and an inability to handle secretions, necessitating frequent suctioning. He required feeding by nasogastric tube and a nasal cannula with oxygen and increased airway pressure to keep him comfortable.

After many weeks the neonatal team concluded that the child would not be able to go home any time in the near future and informed the mother that

he needed a tracheotomy and gastrostomy. She was told that these procedures were in his best interest. Mrs Jones was reluctant to agree with these measures. She was worried that something would go wrong.

It was never entirely clear that the recommendation was in the best interest of the child because he may not have needed the intervention if he stayed in the acute care setting for another month or 2. The statement may have been motivated by the team's interest in having him transferred to a longer-term care facility. Such institutions typically would not accept a child with a nasogastric tube and nasal cannula.

Often enough, medical professionals use the language of the patient's "best interest" to move family members to accept the decisions that they want the family to make. Psychologically and socially, it is extremely difficult for loving family members to refuse to accept interventions that are described as being in their loved one's best interest. Yet, when an intervention is described in those terms, it may be only 1 of several acceptable options or a course that actually is not best for the patient but best for others involved. In such circumstances, it is misleading to frame a treatment option as being in the patient's best interest.

In this case, it is not at all obvious which course would be best for the patient. When the child was evaluated shortly after birth, the team may have accepted a decision to withhold aggressive treatment and allow him to die. When a decision that would allow the child to die is acceptable, and a decision to treat aggressively is also acceptable, it is hard to justify a position that would rule out a course that falls somewhere in between.

CASE 3: EGOCENTRIC (CONSIDERING THE GOOD OF OTHERS)

Ella is a 2-month-old with several serious congenital anomalies. After an

extensive workup, the treating team of pediatricians concludes that features of her brain make it clear that if she survives she will have poor mental function. Furthermore, her only chance for survival is a small bowel transplant. The team explains to the parents that because of the low chance of success and the high risk of complications, the parents may opt for palliative care or have their infant listed for a transplant.

The parents do not want Ella to have a transplant. They explain that they will pray, and God will heal her.

The pediatric team was uncomfortable with the parents' choice to pray rather than to move ahead with the transplant. Prayer alone would not save Ella. The transplant team was willing to perform a small bowel transplant because it was the only treatment that had a chance of prolonging Ella's life. They thought a transplant was in her best interest.

No one was prepared to go to court for a judge's order to perform the transplant because, at the time, the procedure was too new and serious complications were likely enough to make it not entirely apparent that a transplant was in Ella's best interest. The frustration of the treating team, however, reflected how reluctant they were to deviate from the best interest standard.

In this case, the parents had very much wanted to have a child. The decision to forgo small bowel transplantation and allow their child with serious congenital anomalies to die was unspeakably difficult for them. Rather than having to say that they were choosing to let their daughter die, it was easier for them to live with their choice as a decision to pray rather than to move ahead with a transplant.

Forgoing transplantation was a reasonable decision under the circumstances. But the best interest standard requires attention to only the patient's

interests. In this case, the parents would live with the pain of the decision that they made. They would remember their daughter Ella, what they had chosen to do, and how she died. Caring medical professionals could see that the interests of the parents also deserved attention. Compassion required them to allow the parents to express their choice in their terms, not as sentencing their daughter to death, but as prayers for her recovery from her loving parents.

Typically, egoists are decried as selfish and reviled for failing to take others into account in their decisions. It is peculiar that when we regard those who cannot make decisions for themselves, we ascribe the perspective of the selfish egoist to them. We ask only, what is in the best interest of the patient? That means we refuse to consider the impact of the decision on others in determining what should be done.

Case 3 suggests that there are times when the interests of others may be as or more important than what is best for the patient. In such cases, adherence to the best interest standard could be the wrong thing to do. It would require the parents to accept the transplant, or to at least declare that they were refusing the procedure because they considered it best to allow their daughter to die. Pressuring the parents to accept the team's choice, or demanding that they put their decision in terms that the team found acceptable, both seem to be imposing demands that were simply cruel. A medical team who showed compassion for the difficult choice that the parents confronted should be willing to take the parents' pain into account, accept their language, and allow them to find some peace with their decision.

CASE 4: IRRELEVANT (CHOOSING THE WORSE OPTION)

Jose was a 3-month-old who was brought to the hospital after frequent vomiting and failure to thrive. He was found to

have a rare genetic anomaly that made it impossible for him to digest certain proteins. During his hospitalization, 1 particular formula was found to be tolerated somewhat.

The parents, a young couple from a rural Mexican village, had accepted all of the recommended treatments and tests. When they were finally given a fatal prognosis and offered palliative care, they wanted to take Jose home, feed him a regular baby formula, and treat him with Mexican medicine and prayer.

The pediatricians involved in Jose's care were appalled by what the parents wanted to do. As they saw it, restricting Jose's feeding to the special formula was in his best interest. Nevertheless, everyone agreed that Jose's condition was incompatible with life and that he would die soon regardless of what was done. This was not a case of a family refusing highly beneficial treatment: what we had to offer was not going to make much of a difference.

The parents wanted to take their son home and try other means to save their infant. Even if what they wanted to provide would be slightly worse than the medically recommended alternative, it wouldn't make much of a difference. The difference between the best form of feeding and what the parents wanted to try was therefore irrelevant. At the same time, the parents would likely have derived some measure of satisfaction from trying what might have been considered best in their culture. Because everyone agreed that the different approaches would not make much of a difference in what Jose experienced, all things considered, perhaps it was better to support the parents in their decision.

CASE 5: IRRELEVANT (TO CHOOSING THE BETTER OPTION)

Danny is a 35-week-gestation infant born to an 18-year-old single mother. Danny has an amniotic band syndrome

involving the placental membranes becoming entangled with the fetus early in development. He has a huge facial cleft that looks like an axe split his face into 2 parts. (Actually the umbilical cord was responsible.) There is no skull bone covering the brain over the top half of his head and, instead, there is placenta totally attached to the head. One eye is missing. He also has many limb anomalies, amputations from fusions with the placental membranes. His brain is very malformed. He breathes normally and can tolerate tube feeding.

We cannot know what his cerebral function will be, but it is extremely unlikely that Danny will have anywhere near normal mental function. The craniofacial service has been happy to try and reconstruct his face. (Clearly their best interest is in fixing this extremely rare defect.) His mother wants everything done to make him look closer to "normal." The father is supportive of that goal, as is the maternal grandmother. Everything that is done is "experimental" because there is no literature on how to proceed.

Danny has already had multiple surgeries to cover and protect his brain. He has a future of multiple surgeries, unbelievable handicaps, and questionable sentience.

Although physicians could argue about what is best for Danny, there is no clear and obvious answer to what is in Danny's best interest. Aside from his brain and his face, all of his other vital organs work well: his body is healthy. Danny currently has no life-threatening medical needs. It is also not clear that he himself will ever attain a level of sentience: without some degree of sentience, there are no interests. We could project interests on him, but that could go no further than conjecture.

Is Danny's mother's desire to improve his appearance and make him look more normal in his best interest? It would, perhaps, make it easier for others to

manage his care, which, in some sense, may be in his long-term best interest. Would doing less be better? After the initial surgeries to cover his brain, the subsequent procedures could involve discomfort if he was sentient. Is the best interest standard relevant at all in deciding how to proceed? Is there a good reason to exclude his mother's desire for improving her son's appearance as a relevant consideration?

CASE 6: JUSTICE (AVOIDING THE WORST OUTCOME)¹⁷

At 3:00 AM on a Saturday, the nurses in the NICU began to smell smoke. It seemed to be coming from the labor and delivery unit, 1 floor below the NICU. The fire alarm was activated. In accordance with institutional emergency planning guidelines, the neonatal attending announced that he was in charge and the full evacuation plan was put into effect. The attending directed that the least-ill infants (those without respiratory support who were in the NICU just to grow) would be evacuated first. They would be followed by the infants requiring oxygen, and then the critically ill infants.

As the smoke became thicker, it became obvious that the evacuation must occur quickly. A nurse demanded that her patient, a very sick 24-week premature infant who has been on the jet ventilator, nitric oxide, and vasopressors, be evacuated with the first group. The team had previously devoted incredible resources to save him. The nurse argued that it was in her patient's best interest for him to be evacuated immediately.

The nurse was certainly correct in claiming that evacuating her fragile patient in the first wave was in his best interest. Disaster evacuation plans, however, often comply with the well-accepted principles of medical triage. In drastic circumstances when it is presumed that all cannot be saved, avoiding the

worst outcome is taken to be the right course. We set aside all of those who have the least likelihood of surviving and who also require a great deal of medical attention so that more lives can be saved. In disasters, we consider a greater number of deaths to be the worst outcome, and we call policies that reflect the commitment to avoiding the worst outcome “just.”¹⁷

In less drastic circumstances, when it is expected that everyone will be saved, the circumstance of the ICU and the emergency department on ordinary days for instance, we treat those with urgent needs first in the expectation that those who can wait longer will not be permanently harmed by the wait. This approach is also called “just” even though it is not in the “best interest” of those whose care is delayed. Both disaster (wartime) triage and emergency department (peacetime) triage count as just because both policies conform to the Aristotelian formal principle of justice that requires treating similarly situated individuals alike.¹⁸ Furthermore, both triage policies are just because they reflect significant differences in the circumstances. Also, both policies express the priorities of an overlapping consensus of reasonable and rational people who consider the 2 sorts of situations.¹⁹ Neither policy upholds the best interest standard. Even Kopelman accepts that achieving the ideal of acting in the patient’s best interest should sometimes be set aside and that observing it “would not be an actual duty if . . . [it] was unfair or dangerous to others.”²¹

CASE 7: JUSTICE (ANTI-FREE-RIDER AND PROVISION OF A PUBLIC GOOD)

Tyler Smith’s primary care pediatrician has recommended a new vaccine to prevent a serious respiratory illness for his 4-year-old patient. Mr Smith, Tyler’s loving father, refuses to have his son vaccinated. The pediatrician explores Mr Smith’s reasons for refusing

the vaccines. As it turns out, he has no religious objections and he is not motivated by misleading articles or other false information. Instead, Mr Smith explains that in their community, almost everyone is already vaccinated. So, the low chance of Tyler contracting a disease does not justify vaccination given the small risk of significant harm associated with the vaccine. Mr Smith claims that he is acting in Tyler’s best interest.

The pediatrician reviews the literature and finds some anecdotal evidence of significant vaccine-related harm. She now worries that advocating for her patients to receive the vaccine is not in their best interest. She wonders whether she should continue to offer the vaccine to her patients.

Tyler may someday leave his vaccine-protected neighborhood, or some disease-infected individual from some other area might enter it and infect him. In our rapidly moving and transforming society, it is reasonable to assume that because of travel, the risks of forgoing some vaccination may be greater than what Mr Smith judges it to be.

But we could imagine circumstances to be somewhat different, so that it was in Tyler’s best interest to go without vaccination so long as the vast majority of children in his community received vaccination. In such a case, despite its being in his best interest to remain unvaccinated, it would still be wrong. As Paul Menzel and others have argued, refusing to do one’s fair share to contribute to a communally shared public good while accepting the benefits of others doing their part is being a free-rider and taking advantage of the generosity and good will of others.²⁰ It is treating them unjustly.

PEDIATRICIANS AND THE NOT UNREASONABLE STANDARD FOR SURROGATE DECISIONS: THE THREE-BOX APPROACH

Pediatricians who often treat patients who lack decisional capacity need some

guidance on what to advocate on behalf of their patients and how to respond to surrogate decisions. Medical professionals are neither required to decide what an ideal choice would be, as Kopelman suggests, nor are they required to accept any choice that someone who shares the patient’s deep values chooses, as Veatch suggests. Instead, they need a middle path that provides a clear justification for determining which goals of care are acceptable and whether a parent’s specific decision should be accepted or refused. In the preceding discussion, we have already explained why the best interest standard should not govern surrogate decisions. We shall now move on to explain why there should be some check on the decisions that parents make on behalf of their children.²¹

As we understand it, Veatch’s suggestion would allow parents to have all of the decision-making authority of adult patients who make the decisions on the basis of their own deep values. This approach would bind pediatricians to parents’ decisions so long as the parents themselves had decisional capacity. It amounts to treating a surrogate’s decisions just like the decisions of a competent patient. Yet, the difference between patient’s and surrogate’s decisions is significant.²² Pediatricians’ fiduciary responsibility as trusted guardians of their patients’ well-being gives them important responsibilities for assessing the appropriateness of surrogates and for determining when to allow surrogate choices to rule.

Here is how we understand that difference. Drawing on distinctions made by T.M. Scanlon, the reasons offered by an autonomous agent to explain a decision can come from 1 of “three concentric domains.”²³ Judgments can be based on reasons from the “central core,” the kinds of principles that people everywhere could not reasonably reject, for example, to avoid death, pain,

disability, loss of pleasure, and loss of freedom.²⁴ Judgments in the second domain reflect particular core reasons that reasonable people may give different priority. Judgments in the third domain reflect reasons that others may reject without being unreasonable. This third domain is significantly different from the other 2 because these judgment-determining reasons reflect an individual's personal commitments, moral standards, aesthetic values, or religious views, what Veatch has termed "deep values." These are reasons that other reasonable people may not share and have no reason to accept. For an adult who values them, they can support a judgment about whether a medical choice would be right or wrong and they can determine what should be done.

An adult patient who accepts a treatment because it is likely to preserve life (eg, appendectomy for a ruptured appendix) invokes a reason from the central core to support his judgment. But if more than 1 core reason could be relevant to the decision, a common enough circumstance, different individuals could evaluate and prioritize them differently. A patient who accepts an expensive treatment because it offers some small chance of prolonging life, although a significant likelihood of causing significant pain and disability, invokes core reasons to support his judgment. Another similarly situated patient could share the same core values but prioritize them differently and therefore refuse the life-extending treatment. These judgments would reflect the second domain of reasons. In situations in which a reasonable person rejects treatment that is likely to be effective and accepts the serious and likely consequences of foregoing treatment (eg, the patient who refuses an appendectomy for a ruptured appendix) because treatment would violate a religious commitment (eg, to reject surgical interventions) or because it would violate an aesthetic commitment

(eg, against disfigurement of the body), the conclusions are supported by reasons from the third domain of judgments that are idiosyncratic or shared only by some particular social or cultural group(s).

Physicians accept patient judgments from the first 2 domains because the supporting reasons are universal. Physicians find it difficult to accept patient judgments from the third domain precisely because the supporting reasons are not universal. Nevertheless, physicians who recognize the force of the moral requirement to respect autonomy abide by the treatment refusals of patients with decisional capacity even when they foresee the dire consequences (eg, the Christian Scientist who refuses surgery and is expected to die). When a patient refuses a treatment that promises great benefit and only relevantly minor burdens, the choice may trigger an evaluation of the patient's decisional capacity. Once the patient demonstrates understanding and an appreciation of the situation and provides reasons that support the judgment, however, physicians accept the patient's authority in refusing. At the same time, it is hard to imagine any acceptable reason that would be adequate for withholding a treatment that offered significant benefit for a child based solely on a surrogate's choice. If a previously competent adult had expressed her own views on refusing treatment under similar circumstances, withholding it would be consonant with her values or her advance directive. Young children, however, do not have their own "deep values." Even when pediatricians are confident of the parents' loving devotion, doctors should not accept their refusal of treatments that are likely to provide a child with a significant benefit because, without a justifying reason, that would be unreasonable. A refusal of treatment that entailed significant risks and a low likelihood of achieving benefits would be an entirely

different matter. In such cases, parents should be allowed to decide either way because neither choice would be unreasonable.

In a previous article, we explained this difference in authority to make surrogate decisions with what we called the three-box model.²² At 1 extreme is the box for the set of cases that are likely to have poor outcomes regardless of the interventions that are tried. In such cases, medical interventions prolong an agonizing dying process or create greater burdens than benefits. Physicians in such situations should and do encourage surrogates to withhold or discontinue treatment and to adopt a palliative mode of care because that approach would be humane and reasonable. At the opposite extreme is the box for the set of cases in which treatment promises a likely and significant medical benefit, whereas refusal of treatment is very likely to result in significant harm. In such cases, surrogates should not be allowed to refuse medical intervention because to do so would be unreasonable. Although patients with decisional capacity may refuse such treatment of themselves on the grounds of some "deep values," surrogates should not be allowed the authority to impose their own personal values on another at great detriment. Refusals in that extreme box are paradigmatically unreasonable. Absent some very personal and unusual consideration, they can only be justified by reasons from the outer domain of idiosyncratic (or group) reasons that other reasonable people may refuse to endorse. Although personal reasons are sufficient for guiding one's own life, they are not authoritative in surrogate decisions. Because physicians have a fiduciary responsibility to their patients, when a surrogate's choice would clearly subvert any universal treatment goal, the choice must be rejected. Pediatricians cannot accept a surrogate's personal reasons for

refusing significantly beneficial treatment when they determine that the choice violates universal values. Pediatricians must refuse to honor the refusal of treatment that is likely to provide significant benefit. Both medical decisions without significant consequences and decisions about treatments with uncertain outcomes can be sorted into the middle box. When nothing crucial turns on the decision or when reasonable people could accept or refuse the treatment option, medical teams should accept the decisions of surrogates. In these cases we recognize that core reasons can be prioritized in different ways; there is no obviously reasonable choice and no universal prioritization of reasons. Two further considerations incline us to allow surrogate discretion for decisions that are sorted into the middle box. First, because people derive some of their priorities from their own family or culture, decisions by surrogates are more likely to reflect patient values than decisions made by people who do not belong to the patient's (biological or social) family and culture. Second, because the surrogate is far more likely to bear the physical, financial, and moral burdens of the decision than the health professionals who can be expected to have only limited interaction with the patient, it is appropriate to leave the rights to effectively discharge the obligations with those who have the responsibility. As with patient decisions, once physicians determine that the decision belongs in the middle box, acceptable surrogates should be extended the presumption of reasonableness and allowed to make decisions that reflect

their values without physicians delving into their priorities or evaluating their reasons. In other words, if a surrogate decision is not unreasonable, it should be allowed to govern what is done.

CONCLUSIONS

Our not unreasonable standard can be effectively applied in a broad spectrum of challenging clinical cases that involve surrogate decision-making. According to our analysis, pediatricians should not be trying to determine the option that is in the best interest of the patient, but they do have important responsibilities in assessing parent choices and resisting some choices. For the most part, that responsibility involves sorting out whether the treatment belongs in the highly beneficial box or the optional middle box. When the clinicians involved determine that the refusal of treatment is unreasonable and belongs in the extreme box because it is likely to be highly beneficial, they should refuse to comply with the parents' choice to refuse the treatment. When time allows, they should bring the matter to the attention of an ethics committee or the courts.

When pediatricians determine that the course the parents choose is not unreasonable, the decisions should rest with parents who clearly care for their child. Whenever a decision is sorted into either the palliative or optional treatment box, the role of the pediatrician is to offer support for whichever course the parents choose for their child. To impose a pediatrician's personal view of which option is best would usurp the legitimate authority of parents.

In addition to its applicability in clinical situations, a variation on the three-box model can also be extended to the domain of research with children. In the research context, parents should be encouraged to enroll their children in studies that involve only minimal risk and promise to contribute to biomedical knowledge. For the most part, studies that would involve significant risks and burdens without offering a chance for similarly dramatic benefit should not be allowed to enroll children because they would be unreasonable. Enrollment in studies that are not unreasonable should be left to parental discretion.

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