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USING A NEW ANALYSIS OF THE BEST INTERESTS
STANDARD TO ADDRESS CULTURAL DISPUTES:
WHOSE DATA, WHICH VALUES?

ABSTRACT: Clinicians sometimes disagree about how much to honor surrogates' deeply held cultural values or traditions when they differ from those of the host country. Such a controversy arose when parents requested a cultural accommodation to let their infant die by withdrawing life saving care. While both the parents and clinicians claimed to be using the Best Interests Standard to decide what to do, they were at an impasse. This standard is analyzed into three necessary and jointly sufficient conditions and used to resolve the question of how much to accommodate cultural preferences and how to treat this infant. The extreme versions of absolutism and relativism are rejected. Properly understood, the Best Interests Standard can serve as a powerful tool in settling disputes about how to make good decisions for those who cannot decide for themselves.

KEY WORDS: ethics, best interests, law, neonatal intensive care unit, culture, resource allocation, incompetent, premature infant

THE CASE

A graduate student from India was completing studies in the U.S. and had planned to return home soon with his pregnant wife.¹ She developed vaginal bleeding and uterine contractions and was taken to a hospital where she delivered an extremely premature male infant, Baby S. He weighed 900 grams (two pounds) and was estimated to be 26 weeks gestation, three months early. The infant was immediately intubated and resuscitated, and was then transferred to a Neonatal Intensive Care Unit (NICU). Clinicians provided standard treatments, including ventilator support, and the infant's condition stabilized. On the sixth day, he had uncontrollable seizures and was poorly responsive; a head ultrasound showed that Baby S had a large right-sided intraventricular hemorrhage with moderate ventricular enlargement and an associated parenchymal hemorrhage. In discussing the baby's condition with his parents, the neonatologist estimated that he had a 70% chance of surviving. Clinicians judged

that if Baby S lived, he might have developmental or neurological problems as a result of the brain hemorrhage. Their best assessment using literature from tertiary hospitals was that 1/3 of surviving infants are completely normal, 1/3 have mild to moderate problems such as learning disorders, and 1/3 have severe or profound disabilities such as mental retardation and/or severe cerebral palsy.

After receiving this information, the parents requested withdrawal of life-support. The neonatologists disagreed because Baby S's prognosis seemed reasonably good, especially when compared to other babies in their NICU. Normally, if such a dispute cannot be resolved, clinicians should turn to the courts. Courts can decide if children are at risk in the parents' care, take temporary or permanent custody of the child, and authorize the treatments it deems appropriate.² Yet this case never went to the courts. Some physicians, nurses, and social workers were persuaded that an exception should be made in this case and continuing life support would be the wrong course of action for Baby S. The parents were polite, concerned, articulate, and firm in presenting their view that maximal treatment was not in their son's best interest, not in the family's best interest, and that it was unfair to use the host country's outcome data and traditions to decide what treatment was appropriate.

First, Baby S's parents held that life-saving treatment was not in their son's best interest. Even if he lived to return to India, they said, their son would not receive optimal treatment there unless the family requested and paid in advance for such treatment, something they were unable and unwilling to do. Infants born at such early gestational ages who survive often require re-hospitalization in the first year for such conditions as pulmonary and other infections, hernia repair, and treatment of retinopathy of prematurity. In India, they argued, he would most likely not be able to receive treatment for such medical problems and might die after enduring the discomfort of procedures done to prolong his life in the U.S. Of great concern to his parents was that if he survived, he would have a significant chance of obvious disabilities and this would result in a terrible existence for him. They claimed that in India persons with obvious disabilities typically face a life of scorn, deprivation, and ridicule. Both the severity and impact of his disabilities would therefore be much worse in India than in the U.S, they argued.

Second, the parents maintained that it was harmful and unfair to impose U.S. values, guidelines, traditions, resources, or practice

standards because they were about to return to India. In India, public resources are not provided to treat such premature infants, so Baby S would not receive intensive or rehabilitative care unless the family paid for it. Because he probably would not receive rehabilitative services in India, the ultimate severity of his disabilities would be greater than if he lived in the U.S. They stated that it was therefore wrong to use U.S. outcome statistics as they would not represent the outcomes for infants living in India.

Third, the family claimed that maximal life-saving treatment for Baby S was not in the family's best interest. If Baby S survived to return home he would likely have disabilities. Disabled children, they claimed, bring shame upon their parents and other relations because in their culture abnormalities are viewed as punishment for the family's sins.

In deciding whether to accommodate the parents' wishes, a series of conferences occurred that included physicians from India. They confirmed, with regret, that the parents' views about disabled persons were widespread in India and that there would be few resources available to treat such infants unless families paid for such care.

Most of the debate was mired in competing intuitions among clinicians, nurses, and social workers about what was best for this infant. While the controversy continued, Baby S received maximal treatment.³ We will argue that careful attention to the meaning and use of the Best Interests Standard offers insight about what should be done. After discussing this standard in the next section, we apply it to the problem of when to honor parental requests that are grounded in a cultural tradition different from those of the host country.

THE BEST INTERESTS STANDARD

The Best Interests Standard is a widely-recognized guidance principle for decision makers to use in making choices for children and other persons who lack decision-making capacity.⁴ It is an "umbrella concept" because it is used in different ways, yet it unites under one standard different meanings and uses about how to make good or at least acceptable choices for those unable to choose for themselves.⁵ It is sometimes used to express ideals or goals about what is best such as, "Every child should have good dental care." In contrast, it is sometimes used to make practical decisions for individuals, usually in

less than optimal circumstances. These practical decisions include moral, medical, or legal choices which do not necessarily require “the best” but good and reasonable options.⁶

In what follows we apply a new analysis of the Best Interests Standard which is intended to reflect how it is used in many medical, moral, social, and legal frameworks, although, as we shall point out, the context affects how these features are interpreted. This standard has “subjective” features in the sense that it is shaped by the values, views, and perceptions of decision-makers. Some parents may choose to have their dying infants maximally treated and want to pursue every opportunity for experimental therapies to save their lives, while others seek comfort care for them.

The Best Interests Standard, however, also has “objective” features in the sense that guardians’ choices must be “good enough” and certainly not endanger children. What is “good enough” and “endangerment” is judged in terms of what is compatible with sound logical, medical, and scientific views, arguments, and what honors justifiable duties. Some parents may sincerely believe it is best for their imperiled infant to be discharged from the hospital and taken to a faith healing ceremony even though he is responding to life-saving interventions. If it can be shown on objective grounds that the parents would be endangering their child, their preferences should be challenged. From a legal and social perspective, parents have the liberty to check themselves out of a hospital to go to a faith healing ceremony if they like; but once the Best Interests Standard took hold, parents could no longer make such decisions for their children as they did for themselves. What a parent believes about an intervention does not substitute for evidence and the courts will turn to such sources as science and medicine to help establish what options are acceptable. Moreover, even if their views are good enough from a legal perspective, they may be far from optimal from a moral or medical point of view.⁷

In the next sections, we use the troubling case of Baby S to show that this analysis of the Best Interests Standard offers helpful guidance about how to resolve difficult cases. This standard, we will argue, is clear and no more open to abuse than other guidance principles. Well-established children’s rights and justified moral, medical, social or legal judgments help clarify what constitutes acceptable thresholds of care and give this standard clout for making important decisions. (In some cases, of course, the threshold can be

modified when new information or resources become available.) It is also a misunderstanding to suppose that the Best Interests Standard requires decision-makers seeking practical solutions to do what is ideal, ignore the interests of everyone else, or set aside all allocation or triage policies. It would be a self-defeating and incoherent standard if it required everyone to have “the best.” Our analysis of the Best Interests Standard reflects its practical uses, including when employed in moral, professional, or legal circumstances.⁸ For example, it is compatible with legal definitions of the Best Interests Standard in terms of a reasonable person standard.⁹

We have argued elsewhere that the Best Interests Standard when used as a practical guide should be analyzed in terms of three necessary and jointly sufficient features:¹⁰

- (1) First, decision makers should use the best available information to assess the incompetent or incapacitated person’s immediate and long-term interests and set as their *prima facie* duty that option (or from among those options) that maximizes the person’s overall or long term benefits and minimizes burdens.
- (2) Second, decision-makers should make choices for the incompetent or incapacitated person that must at least meet a minimum threshold of acceptable care; what is at least good enough is usually judged in relation to what reasonable and informed persons of good will regard to be acceptable were they in the person’s circumstances.
- (3) Third, decision makers should make choices compatible with duties to incompetent or incapacitated individuals (those unable to make decisions for themselves).

In what follows we will argue that attending to these three features of the Best Interests Standard offers insights about how much to accommodate cultural preferences and what to do in the case of Baby S.

Assessing Potential Benefits and Risks

The first necessary condition of the Best Interests Standard (see above) concerns picking good options when assessing potential benefits and risks on behalf of people who cannot decide for themselves. When we agree about what information is relevant and how to rank the potential benefits and risks (including their nature, probability, and

magnitude) it is relatively easy to use this condition. If a child would endure discomfort from an intervention for a short time and then thrive, it is obvious that he should be treated.

The outcome for premature infants is determined by the combined effects of their potential, parental commitment, and resources. Some clinicians agreed with the parents that we should not use data from U.S. infants for Baby S and consequently that his prognosis should not be set at a 1/3 chance he will be normal, a 1/3 chance he will have only minor disabilities and a 1/3 chance of severe disabilities. This is a "U.S. prognosis" framed by U.S. practices and resources. These clinicians estimated if Baby S returned to India, the probability for Baby S's survival would be at less than 70% by one year of age, and the magnitude of his disabilities would likely be much worse than predicted because he would not receive adequate rehabilitative care. Those taking this line were persuaded that it was not in Baby S's best interest to have maximal life-saving treatments in the U.S. when they saw a much worse prognosis after the family returned to India. They agreed with the parents in favoring comfort care and honoring doctors' long-established duties to prevent unnecessary suffering. Some worried that treating Baby S over the parents' objections amounted to "cultural imperialism."

Yet others argued that the prognosis was too good to deny Baby S maximal treatments. Even if he has obvious disabilities, his parents would probably become attached to him. They might decide to prolong their stay or even immigrate to the U.S. to find better resources and support for him. Alternatively, they might agree to allow the child to be adopted. Importantly, people with disabilities generally find life worth living despite cultural attitudes and most people would probably want to have their lives prolonged given these odds.

No consensus was reached about how to understand or rank potential benefits and risks. The Best Interests Standard, however, consists of more than this first condition. Two other necessary conditions exist offering more guidance about whose data and values to use in ranking these potential benefits and risks in disputed cases.

Setting an Acceptable Threshold

The second necessary condition (see above) acknowledges that parents sometimes make different choices in deciding what is best for their children, but it requires decision-makers to select options at

least meeting a minimum threshold of acceptable care. From a legal perspective, as noted, parents are permitted to decide what is best for their children unless they endanger them. Reasonable and informed persons of good will, such as legislators and judges, have set these thresholds by deciding when wards are endangered in their guardians' care.¹¹ A choice is judged "good enough" in relation to what reasonable and informed persons of good will would regard to be acceptable were they in the person's circumstances. But acceptable for what? An acceptable threshold in one circumstance may not be in others. For example, a gap exists between endangerment and an optimal choice, so what is good enough legally may be morally problematic. Moreover, to some degree the threshold is culture specific with, for example, wealthier nations setting a higher threshold for medical treatment, shelter, education, or other basic care.

Nonetheless, letting Baby S die when he has such a good chance of being normal or mildly disabled, would constitute the use of an entirely different legal and professional threshold from what is usual in the U.S. Failing to provide Baby S maximal treatment when it does not meet U.S. standards of care poses a threat to our own hard-won and important moral, professional, and legal consensus about how to treat children (and incapacitated adults). Thus even if there is a dispute about how to balance potential benefits and risks (the first necessary condition), we can conclude that Baby S ought to be treated over the parents' objections if failing to provide such treatment falls below the threshold of acceptable care (the second necessary condition). However, some might respond, as the parents of Baby S and some clinicians did, that it is unfair to use the U.S. threshold of acceptable care. This raises issues about rights and duties or the third necessary condition of the Best Interests Standard.

Honoring Rights and Duties

The third necessary condition (see above) requires decision makers to make choices for incompetent or incapacitated individuals that are compatible with more general duties to them. The Best Interest Standard does not stand alone in its meaning and use but is tied to a web of established duties to persons who cannot decide for themselves.¹²

The parents argued that it was unfair to impose U.S. cultural values and practice standards because they differed from those in

India. This reasoning is flawed. Justice systems, including allocation schemes, apply to some target group, in this case residents of a particular country. Different nations often allocate resources differently, with some spending proportionally more on medical care and others more on housing, police, education or the military. It is unfair, however, to treat similarly situated individuals *within* the target group differently. This is a *necessary or formal* requirement of all just systems.

Allocation schemes also have *contingent features* about 1) how much there is of something to allocate, 2) to whom it will be allocated, and 3) the criteria and values to use in making the allocation to similarly situated persons. These features are called “contingent” because they can justifiably change, and frequently do. For example, in World War II when penicillin was a scarce resource, there was broad agreement it should all go to treat the troops. This allocation scheme changed when the war ended and penicillin became more plentiful. Different contingent features result in different allocation schemes and this need not mean that one plan is unjust or unethical. The U.S. and Indian health care systems are different because they use different values, resources and criteria and this affects who has just claims in each system. (There are, of course important issues about the unfairness of wealthy countries ignoring the needs of poor countries.) Moreover, while countries may have different levels of health care available for citizens, that is not true for premature infants in the U.S. and, additionally, Baby S is a citizen of the U.S. because he was born here.

The argument that it is unfair to use U.S. standards in treating Baby S, then, is untenable. Moreover, it would be unfair to treat Baby S as the parents request since it would be entirely different from the treatment of others in his U.S. target group. It would violate medical practice standards to deny him life saving care and fail to offer him equal protection. Making an exception for Baby S so far from what is acceptable violates the formal requirement of just allocation schemes to treat all similarly situated individuals in a target group similarly. It threatens hard-won rights for persons lacking decision-making capacity. Treatment for Baby S is obligatory because resources are available to care for such babies and if other parents refused to consent to life-saving treatment, then a court order would ordinarily be obtained.

For the Best Interests Standard to be more than a vague nod to the duty of beneficence, it must be seen in its moral, professional, social,

and legal frameworks which include established rights for and duties to people. A test of a moral judgment is that one is willing to generalize one's decision to everyone similarly situated. Consider how making an exception about Baby S might, if generalized, erode carefully constructed policies. Suppose that clinicians could predict with equal or better accuracy than that claimed about outcomes for Baby S, that babies going into certain impoverished homes lacking heat, air conditioning, or even running water in the U.S. will also have a different prognosis than other children. The reasoning used by those arguing for a different standard for Baby S could also be used for "justifying" different standards for these infants of poor parents based upon their social circumstances. "Why bother subjecting them to painful interventions," they might say, "if they cannot thrive?" The Indian parents' request when generalized, then, opens the door to accommodation too widely and is clearly wrong. This approach would erode civil and moral rights and promote the crudest sort of consequentialist balancing of people's interests.

Thus even if there is disagreement about how to rank potential benefits and hazards for this infant (the first condition) and about which threshold of acceptable care to use (the second necessary condition) we can still turn to established duties to and rights of people (the third necessary condition) to decide what to do. We now want to anticipate and address some possible criticisms.

CULTURAL IMPERIALISM?

Some may object that our recommendation to use our own standards and practices when the parents' requests are so far from what is normally acceptable in treating imperiled infants is a form of cultural imperialism. We do not believe that this is correct.¹³ International organizations such as the United Nations place respect for human rights as a higher value than respect for cultural diversity. For example, a recent policy, called, "The Universal Declaration on Bioethics and Human Rights" released on October 19, 2005, recommends in its Article 12, ranking respect for rights as a higher value than honoring pluralism and cultural diversity.¹⁴ We see life-saving treatment in this case as a right since such care would be considered obligatory for other infants in his target group and hence such care would be a higher value than accommodating cultural diversity.

This ranking of human rights ahead of cultural diversity and pluralism limits cultural accommodation. We defend the view that we should accommodate other cultural practices in our culture unless or until they threaten justifiable values in our own society. This stance, as noted, entails the rejection of both ethical absolutism and extreme ethical relativism.¹⁵

INTERESTS OF OTHERS?

Some have criticized the Best Interests Standard for focusing too narrowly on the interests of the single individual as if it said, "Forget about everyone else." We have argued that this is a misconception since the Best Interests Standard does not require all other interests to be set aside, whether it is used in moral, medical, legal or other contexts. For example, legally, how much consideration to give incompetent persons is up to the guardians unless their choices fall below thresholds of acceptable care. Medically, clinicians have to consider the available resources and needs of many patients in deciding the best option for a particular patient.

Stopping maximal life-saving treatments, according to this family, was in their best interests since having a child with obvious disabilities would bring them shame and financial, emotional and social problems. The family maintained that the infants' disabilities would be viewed by others as punishment for the parents' sins or those of other relatives.

The family's comments reflect a view we have elsewhere called the *punishment theory of disease*.¹⁶ It is the view that being bad or doing bad things can directly cause disease, and when it does, blame should be placed on those who get sick or those who are related to the person who gets sick. The association between disease and blame is ancient and has been used throughout history to account for epidemics and illnesses.¹⁷

There are religious and secular versions.¹⁸ In religious versions of the punishment theory of disease, illness is allegedly inflicted on a wrongdoer or someone closely related to the wrongdoer (such as his infant), in order to punish the wrongdoer for his offense, to give him a chance for rehabilitation, to warn him to become more virtuous, to demonstrate that the bad perish and the good thrive, or to show some cosmic order requires punishment.¹⁹ The secular, non-religious versions of the punishment theory of disease regard illness and

disease to be the results of punishing effects of irresponsible behavior, bad habits, or weakness of will (such as smokers getting lung cancer).

Both the religious and secular versions fail as general accounts of why people get sick.²⁰ The religious versions fail since many good people die before many evil people. As HIV/AIDS sweeps through continents, it is implausible to suppose that survivors are better people than those who die (including infants). Moreover, it explains the obscure with the more obscure. To explain why people get sick, this theory appeals to the intentions of a deity or supernatural being. Our disagreement over how to settle controversies about divine intentions (such as whose side God is on in a war) undermines this view. Such appeals to divine intentions are not only unhelpful but harden people's hearts to rational discussion (since they "know" what God intends).

The secular, non-religious versions of the punishment theory of disease also fail.²¹ First, taking disease or illness to be the result of the punishing effects of irresponsible behavior, bad habits, or weakness of will, is also unsuccessful in offering a general account of why people get sick. For example, Baby S and other infants have never behaved badly, yet get sick. Moreover, some diseases and anomalies result from pollutants or genetic factors unrelated to what their people have done.

The punishment theory of disease is irrational, albeit ubiquitous. Its power may be related to primitive human psychological defense mechanisms (such as the belief that if one leads a good life, that one will not suffer terrible diseases). Seeing sick people or their families as "innocent" or "guilty" is not only irrational but dangerous. It is a perilous view we should resist, not the least of reasons being that we need to unite to fight the AIDS epidemic, show compassion and cooperation, and share resources.²² Thus, although deeply engrained in many cultures including our own, the punishment theory of disease is untenable from a moral, logical and scientific vantage. It should not be used to make an exception for the live-saving care of Baby S.

EXTREME ETHICAL RELATIVISM OR ABSOLUTISM?

Some objected that too little attention was paid to cultural differences between the family and clinicians. Culture describes a group's shared attitudes, social practices, or beliefs or their common ethnic, racial, or religious character. Most of us belong to multiple cultures associated

with such things as our religion, work, race, geography, language, and ancestors' nationalities. Our cultures, however, are neither uniform nor entirely distinct entities. For example, clinicians from India we talked to acknowledged that these parents' views about disabled persons are widespread yet disagreed with them. Moreover, the disputes about Baby S continued because the U.S. doctors, nurses, and social workers disagreed among themselves about whether or not to honor the parents' request.

We reject both extreme relativism and absolutism.²³ Extreme absolutism holds that values are *never* culturally determined but grounded in some epistemological or faith tradition. This view is harshly criticized for failing to justify its foundational claims of certainty and for failing to take into account circumstances, resources, cultural values and beliefs, and duties and obligations within communities.²⁴

Extreme relativism maintains that all values are *always and entirely* culturally determined and that criticisms from outside the culture lack moral authority.²⁵ Among the difficulties with this view is that it relies upon the vague concept of a "culture." Given your professional, political, religious, social, sports, and other associations, how would you count up how many cultures you are in? And if you could, would it be plausible to suppose you agree with everyone in each of them? Moreover, how many people belong to your composite "culture" by having exactly the same mix of groups and associations as you? Thus "culture" is an elastic notion that does not provide a firm footing to make exceptions to people's rights to have life-saving care. In addition, if this view were true it would be impossible for people from different cultures to have genuine moral discussions. Yet as this case about Baby S illustrates, there was at least some understanding and negotiation about moral issues among people from different cultures.

Some propose the relativist view "when in Rome, do as the Romans do," but what would that mean in this case? Since the family was living in the U.S., it would apparently entail the implausible view that we should *never* accommodate cultures. Moreover, this maxim suggests a categorical universal standard, so it is inconsistent with the view that there are none.

Many discussions exist about the implausibility of the extreme versions of both relativism and absolutism.²⁶ Rejecting them means we can and should communicate, negotiate, and assess the quality of

reasons we and others give for considering accommodations across cultural divides, including how to rank benefits and burdens. In rejecting both the extreme versions of relativism and absolutism, we are committed to trying to find common ground for decisions among people from different cultures. Finding common ground often takes sensitivity, communication, perseverance, and a willingness to explore each other's cultures, views, and practices.

CONCLUSION

The Best Interests Standard is a complex guidance principle that may be used differently depending upon the context including in moral, medical or legal frameworks. It was introduced to challenge the view that children and incompetent persons were the property of their guardians. In its practical uses, it requires that a good and reasonable choice be selected from the available options. It is a misunderstanding to think it is a vague instruction to do whatever you happen to think is best. It is also a mistake to think it requires everyone to have "the best" since this would be incoherent or self-defeating. This standard has both subjective features (in the sense of reflecting to some degree the values, views and perceptions of decision-makers) and objective features (in the sense of requiring that guardians' choices are good enough or cannot endanger children as assessed by sound logical, medical and scientific views, arguments, and conclusions). Moreover, this standard is used in different situations differently. For example, what is acceptable from a legal perspective because a child is not endangered may differ from a moral vantage about what is the best available option.

This analysis shows that we can resolve disputes by using the Best Interests Standard even if there is a controversy, as there was in the case of Baby S, about how to understand and rank potential benefits and risks. Denying Baby S maximal life-saving care would not be in his best interest because he has a good prognosis compared to other infants in the NICU. Parental assertions that discontinuing life support would be best for their family rests on prejudicial attitudes to disabled persons and on irrational views that disease is punishment for sin. Their allegations that it is unfair to use the U.S. standards of care were also rejected since Baby S should be treated as other similarly situated infants in the target group for the allocation schema. Countries can justifiably have different allocation schemes, given

their resources and values. But this baby is a U.S. citizen, living on U.S. soil and in the U.S. target group, so if resources are available, it would be unfair not to provide Baby S the same care given to other similarly situated children. Making exceptions so far removed from established practices threatens the standard itself. We have argued that clinicians should seek to accommodate other cultural values and preferences up to the point where doing so undermine our own morally justified and important practices. Moreover, we found each of the parents' reasons for discontinuing life-support treatments for their son to be problematic. If the policies supporting the rights and welfare of children and other incompetent persons are morally justifiable, then we should not undercut them by making exceptions far removed from their carefully established thresholds.

In this paper we apply a new analysis of the Best Interests Standard and show how it may be used in deciding what should be done in a very troubling clinical problem. The Best Interests Standard in its practical use was analyzed into three necessary and jointly sufficient conditions: it requires decision makers first assess potential benefits and risks, second set an acceptable threshold for treatment, and third honor the rights of and duties to patients. All three conditions must be met for a treatment choice to be compatible with the Best Interests Standard. The disputes over this case continued long after it was resolved by nature. Baby S's condition worsened, everyone agreed that comfort care should be provided, and he died.²⁷ His parents returned to India.

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We would like to acknowledge that this discussion was based on an actual case where the attending physician was Dr. William Meetze. He initiated discussions about the ethical questions involved.

NOTES

¹ Although many features were changed to protect the parent's identities we could not change the country from which they came.

² H.D. Krause, *Family Law in a Nutshell*, 2nd edition (St. Paul: West Publishing Co., 1986).

³ The male infant was born at approximately 26 weeks gestation and had respiratory distress syndrome requiring support with a ventilator. Initial chest X-ray was consistent with severe respiratory distress syndrome and there was pulmonary

interstitial emphysema on subsequent films. He received intratracheal surfactant but had minimal improvement. He had hypotension that was unresponsive to fluids and pressors, and he was started on hydrocortisone. During the course of his hospitalization he also received medical therapy with indomethacin for a patent ductus arteriosus, and a of vancomycin for sepsis with coagulase negative staphylococcus. Subsequently the infant developed a tension pneumothorax and had an acute deterioration in respiratory status requiring high frequency ventilation. On day six the infant developed seizures and was poorly responsive. A head ultrasound showed a right sided intraventricular hemorrhage with an associated parenchymal hemorrhage. A repeat head ultrasound done on day 13 showed extension of the intraventricular hemorrhage, ventriculomegaly, and a large area of cerebral parenchymal infarction. The anterior fontanel was now bulging and the head circumference had increased by one centimeter. The infant's respiratory status had not improved. A neurology consultant's view at that time was that the infant would most likely have severe disabilities if he survived. The neonatologists' judgment then was that there was a 100% chance of moderate to severe physical disability and an 80% chance of severe mental disability; survival now seemed improbable. The parents' request to discontinue life support was then honored and the infant died quickly.

⁴ For example, The United Nation's Office of the High Commission for Human Rights. Convention on the Rights of the Child writes: "Article 3: In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration." Adopted and opened for signature, ratification and accession by General Assembly resolution 44/25 of 20 November 1989 entry into force 2 September 1990, in accordance with article 49, <http://www.unhchr.ch/html/menu3/b/k2crc.htm>. (Accessed 1/23/07). In addition, recently, the Maryland Appellate Court wrote: "We have long stressed that the "best interests of the child" is the overriding concern of this Court in matters relating to children...." *Grimes v. Kennedy Krieger Institute, Inc.* 782 A.2d 807 at 852–3 (Md. 2001). Many important policies also recommend using the Best Interests Standard to make decisions for persons lacking decision making capacity including the Institute of Medicine in setting research policy for children. Institute of Medicine of the National Academics, *Ethical Conduct of Clinical Research Involving Children* (Washington D. C.: The National Academies Press, 2004) and the President's Council on Bioethics, *Taking Care: Ethical Caregiving in Our Aging Society* (Washington D.C.: NBAC HHS, 2005). Support for the Best Interest Standard may also be found in the following sources: American Academy of Pediatrics, Committee on Bioethics, "Guidelines on Foregoing Life-Sustaining Medical Treatment," *Pediatrics* 93 (1994): 532–536; American Academy of Pediatrics, Committee on Fetus and Newborn, "The Initiation or Withdrawal of Treatment for High-Risk Newborns," *Pediatrics* 96 (1995): 362–364; American Academy of Pediatrics, Committee on Bioethics, "Ethics and the Care of Critically Ill Infants and Children," *Pediatrics* 98, no. 1 (1996): 149–153; A.E. Buchanan and D.W. Brock, *Deciding for Others: The Ethics of Surrogate Decision-Making* (New York: Cambridge University Press, 1989); L.M. Kopelman, "Are the 21-Year-Old Baby Doe Rules Misunderstood or Mistaken," *Pediatrics*, 115, no. 3 (2005a): 797–802; L.M. Kopelman, "Rejecting the 'Baby Doe' Regulations and Defending a 'Negative' Analysis of the Best Interests' Standard," *Journal of Medicine and Philosophy* 30 (2005b): 331–352.

⁵ There are disputes about what the Best Interests Standard means and to some degree this analysis is reformative.

⁶ Some critics charge the Best Interests Standard is vague, open to abuse, or guides decision makers to do whatever they happen to think is best. Yet if we look at why it developed and how it is used, its meaning is clear (although there may be times it is hard to apply). For example some critics have defined the Best Interests Standard as requiring decision makers to do what is ideal and then argued the Best Interests Standard is unknowable, unattainable or self-defeating; others argue that it is too narrowly focused on the incompetent or incapacitated person's interests. In these cases the Best Interests Standard is analyzed in ways that are unrelated to how it is used and then criticized for being unusable. For a detailed response to criticisms of the Best Interests Standard see Kopelman, L. M. "The Best Interests Standard as Threshold, Ideal, and Standard of Reasonableness," *Journal of Medicine and Philosophy* 22, no. 3 (1997): 271–289; Kopelman, "Rejecting 'Baby Doe' Regulations"; and L.M. Kopelman, "The Best Interests Standard for Incompetent or Incapacitated Persons of All Ages," *The Journal of Law, Medicine and Ethics* 35, no. 1 (2007): 187–196.

⁷ This is discussed in more detail in L.M. Kopelman, "Using the Best Interests Standard to Decide Whether to Test Children For Untreatable, Late-Onset Genetic Diseases." *Journal of Medicine and Philosophy* 32, no. 4 (2007): 375–394.

⁸ For a more detailed discussion of this see LM Kopelman, 1997 cited at note 6; Kopelman, 2005b cited at n. 4; Kopelman 2007 cited at 6; Kopelman, 2007 cited at n.7.

⁹ For example, the President's Council offers the following analysis: "Best interest: a legal standard of caregiving for incompetent patients, defined by the courts in terms of what a "reasonable person" would decide in the same situation. A consideration of best interests generally attempts to weigh the burdens and benefits of treatment to the patient in his present condition, when no clear preferences of the patient can be determined" (President's Council 2005, p. 231). Hafemeister and Hannaford write that in judicial opinions the "...'best interest' incorporates what a reasonable person in the patient's position would want" T.E. Hafemeister and P.L. Hannaford, *Resolving Disputes for Life-Sustaining Treatment* (Williamsburg: National Center for State Courts, 1996), 19n.

¹⁰ Kopelman, "Rejecting 'Baby Doe' Regulations"; Kopelman, "Best Interests Standards" ; L.M. Kopelman, "Using the Best Interests Standard to Decide Whether to Test Children For Untreatable, Late-Onset Genetic Diseases," *Journal of Medicine and Philosophy* 32, no. 4 (2007): 375–394.

¹¹ Kraus, *Family Law*.

¹² Kopelman, cited at n. 4; Kopelman cited at 6; Kopelman cited at n. 7.

¹³ The norms we are invoking are not those of the U.S. alone. See, for example, the U.K.'s Nuffield Council on Bioethics, "Critical Care Decisions in Fetal and Neonatal Medicine: Ethical Issues," (2006). http://www.nuffieldbioethics.org/fileLibrary/pdf/CCD_web_version_8_November.pdf Accessed April 30, 2007. This council recommends babies born after 25 weeks gestation, should normally be provided intensive care, unless the parents and the doctors agree that there is no

hope of survival or the level of suffering outweighs the baby's interest in continuing to live.

¹⁴ International Bioethics Committee, United Nations Education, Scientific and Cultural Organization, "Universal Declaration on Bioethics and Human Rights" 2005 http://portal.unesco.org/en/ev.php-URL_ID=31058&URL_DO=DO_TOPIC&URL_SECTION=201.html. Access on November 13, 2007.

¹⁵ As we discuss below, decisions whether to make accommodations in difficult cases such as this, should involve considerable discussions, negotiations, and assessment of the quality of reasons given.

¹⁶ L.M. Kopelman, "The Punishment Concept of Disease," in *AIDS: Ethics and Public Policy*, eds. C. Pierce and D. Van De Veer (Belmont, CA: Wadsworth Publishing Co., 1988), pp. 49–55; L.M. Kopelman, "If HIV/AIDS is Punishment, Who is Bad?" *The Journal of Medicine and Philosophy* 27, no. 2 (2002): 231–243.

¹⁷ H.E. Sigerist, *History of Medicine*. (New York: Oxford University Press, Vol. 1, 1955), pp. 180ff, 442ff and Vol. II, pp. 298ff; *ibid.*

¹⁸ Kopelman "The Punishment Concept of Disease" cited in note 16.

¹⁹ *Ibid.*

²⁰ *Ibid.*

²¹ *Ibid.*

²² *Ibid.*

²³ There are many versions of relativism and absolutism. We criticize only the extreme forms of each.

²⁴ There are other less extreme versions of absolutism and relativism. Some absolutists make more modest assertions that some claims are certain, but that they must be interpreted. Moreover, some versions of relativism are not even controversial—such as saying we do as a matter of fact have differences. Extreme ethical relativism was once popular among many anthropologists but has been challenged from many sides. For a fuller discussion of these criticisms see E. Sober, *Core Questions in Philosophy* (New York: Macmillan Publishing Co, 1990); R. Macklin, *Against Relativism: Cultural Diversity and the Search for Ethical Universals in Medicine* (New York: Oxford University Press, 1999). L.M. Kopelman, "Female Circumcision/Genital Mutilation and Ethical Relativism," *Second Opinion* 20, no. 2 (1994): 55–71; L.M. Kopelman, "Female Circumcision and Genital Mutilation," in *Encyclopedia of Applied Ethics* 2 (1998), pp. 249–259; L.M. Kopelman, "Circumcision, Female Update," *Encyclopedia of Bioethics*, 3rd Edition, Stephen G. Post, Editor in Chief, (MacMillan Reference USA 2004), pp. 417–420. For defenses of extreme ethical relativism see: N. Scheper-Hughes, "Virgin Territory: The Male Discovery of the Clitoris," *Medical Anthropology Quarterly* 5, no.1 (1991): 25–28; F. Ginsberg, "What Do Women Want? Feminist Anthropology Confronts Clitoridectomy," *Medical Anthropology Quarterly* 5, no.1 (1991): 17–19; and R. Shweder, "Ethical Relativism: Is There a Defensible Version?" *Ethos* 18 (1990): 205–218.

²⁵ Sober, *Core Questions*; Macklin, *Against Relativism*; Kopelman, "Female Circumcision."

²⁶ *Ibid.*

²⁷ See note 3.

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