

Virtual Mentor

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Clinical Case

Disagreement over Resuscitation

Commentary by John M. Lorenz, MD

After trying for 4 years to have a child, Jane Craft and her husband, George, were thrilled when Jane became pregnant. The couple considered Jasmine a “miracle baby.” Just after her first birthday, Jasmine fell down the stairs of the family’s third-floor apartment and suffered serious head trauma. The injury, coupled with prolonged hypoxemia following the fall, left Jasmine with severe mental and physical handicaps—she was unable to walk or speak coherently, suffered from seizures, and lost her vision. Jane and George coped with this sudden, devastating situation as best they could, but caring for Jasmine was a hardship. George, a bank teller, began to work extra shifts to help pay for the medical bills. Jane left gainful employment so she could provide 24-hour care for Jasmine.

A year after Jasmine’s accident, Jane found that she was pregnant again. This time the pregnancy was not a uniformly joyous event; both Jane and George worried about how they would manage, financially and emotionally, having another child. With the help of George’s health insurance coverage, Jane was able to have routine visits with her obstetrician-gynecologist, Dr. Hearsh. Melanie Hearsh, who had overseen Jane’s first pregnancy and had become quite close to the Craft family, understood Jane’s concerns and had been thorough in monitoring this pregnancy.

Twenty-four weeks into her pregnancy, Jane felt a dull, aching pain in her stomach and lower back that quickly progressed to contractions. She called George at work and together they went by ambulance to the hospital. Terbutaline therapy was started immediately in an attempt to stop the contractions, but Jane soon developed severe hypotension, and therapy was discontinued. When Dr. Hearsh arrived at the hospital she had a chance to speak with the couple. She stated that, since Jane’s membranes had ruptured, it would be dangerous to continue trying to stall labor. She spoke at length with the Crafts about the prognosis for children born at 24 weeks; many of the possible outcomes reminded the Crafts of the limitations that Jasmine faced on a daily basis. The couple told Dr. Hearsh that unless the baby was born “alive and vigorous,” they did not want him to be resuscitated.

Jane was given oxytocin to induce labor, and Dr. Hearsh oversaw the birth of a 652-gram, cyanotic boy with a weak, slow heartbeat and an extremely slow respiratory rate. His Apgar score at 1 minute was 4. Dr. Hearsh was mindful of the Crafts’ wishes, but, as she stood there over the infant, she believed that it would be morally wrong to let him

die. She quickly intubated the baby and sent him to NICU, while informing George about the baby's status. He became both distraught and enraged. Half-crying, he demanded to know why the child had been resuscitated and requested that the breathing tube be removed immediately. When Dr. Heath went to check on Baby Craft, his Apgar scores had improved to a 6. Though he had moderately diminished reflexes, he seemed to Dr. Heath to be doing as well as other infants she had delivered at 24 weeks.

Commentary

Dr. Heath believed she was morally obligated to resuscitate Baby Boy Craft over the wishes of his parents. The Crafts, however, believed their decision to withhold resuscitation was morally acceptable. Assuming that both Dr. Heath and the Crafts employed a rational decision-making process and followed their consciences, how could they have reached such different conclusions? Was only 1 of these 2 alternatives morally acceptable or could both be? Ethical theory is a system of principles that provides a structured approach to moral reasoning and, thereby, directs and justifies decisions about what actions are morally acceptable. Was either Dr. Heath's or the Crafts' application of the relevant ethical principles flawed? Did the parties accept the same principles, but prioritize them differently? Moral dilemmas arise when ethical principles come into conflict and no decision is consistent with all the relevant principles; in such cases, the decision reached is the one that is most consistent with the principle(s) highly valued by the decision maker.

Relevant Ethical Principles

In searching for a "best" alternative, it is helpful to identify the ethical principles relevant to the decision about whether to withhold or withdraw neonatal intensive care. These are (1) beneficence/nonmaleficence, (2) the best interest standard for surrogate decision making, (3) sanctity of life, and (4) parental autonomy.

Beneficence/nonmaleficence. Health care professionals have a duty to minimize harms such as pain, suffering, disability, and death due to injury or disease and to promote well-being. The good to be promoted is health. Fulfillment of this duty requires judgments about the benefits and risks of various treatment options. In this case, the benefits and risks of intensive care must be weighed against the benefits and risks of providing comfort care.

Best interest standard. Surrogates responsible for making health care choices for patients who have never attained decision-making capacity should base those decisions on the best interests of the patient. Opinions vary about whether this principle is absolute or whether the interests of others are relevant to the decision-making process. *The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research* interpreted this principle strictly, completely excluding consideration of the interests of others in judging best interests of newborns.

As in all surrogate decision making, the surrogate is obligated to try to evaluate the benefits and burdens from the infant's own perspective....This is a very strict standard in

that it excludes consideration of the negative effects of the impaired child's life on other persons, including parents, siblings, and society [1].

This position is based on the vulnerability of the ill to potential discrimination or even exploitation, especially those who have lost or never achieved capacity for decision making.

Another widely held view, however, is that the circumstances of surrogate decision making are too complex to dismiss consideration of the interests of the family out of hand [2-5]. It is argued that to be part of the family in the fullest sense is to be morally bound to make decisions that consider the consequences for all concerned, not merely ourselves. In other words, it is irresponsible to completely exclude the interests of those to whom we are close. Following this line of reasoning, family interests should not be excluded from medical decisions made on behalf of persons who have lost or never had capacity to consider their family members. This view recognizes that the vulnerable require special protection and argues that their interests should be duly considered, but not necessarily exclusively served.

Sanctity of life. There is an almost-universal belief that human life has intrinsic value and ought to be preserved. One extreme of this principle holds that *biological* human life has intrinsic value and ought to be preserved. According to this belief, the *quality* of that biological life has no bearing on its value. Another sanctity-of-life view holds that only life of some minimum quality to the person ought to be preserved [6, 7]. In general, however, there is no consensus on what constitutes the “minimum quality of life” that ought to be preserved.

Parental autonomy. Parents are the legitimate surrogate decision makers for their minor children and are granted broad discretion in making informed decisions about the health care of those children, including the declining, continuing, limiting, or discontinuing treatment, whether life sustaining or not. The right of parents to make health decisions follows from the importance of natural love and affection in optimizing one's child's quality of life, as well as from the disproportionate responsibility for the consequences of these decisions that parents ultimately bear. It is argued that the less support the community is willing and able to provide the family in dealing with the consequences of unwelcome decisions, the broader the discretion parents should have. However, this discretion is not without bounds. Physicians caring for infants and children are charged to be advocates for their patients' best interests. Only in the unusual circumstance that a family's decision clearly conflicts with the best interests of the infant or child, however, does the physician have an obligation to override that decision. On first consideration it may seem that death always conflicts with patients' best interests. This, however, depends upon whether only the *patient's* interest is thought to be relevant to the health care decision and whether *quality* of life is of any relevance to the decision to forgo life-sustaining interventions.

Having reviewed the ethical principles most applicable to decision making for Baby Boy Craft, we can consider how differences in the Crafts' and Dr Hearth's values might account for the discrepancy in the conclusions reached by each and whether either or

both were in accord with wider community standards. In their application of the best interest standard, the Crafts have clearly considered their family as well as their son in their decision to conditionally withhold resuscitation. One possible explanation for the lack of agreement between their decision and Dr Hearth's, therefore, is that Dr Hearth believes that withholding resuscitation clearly conflicts with the best interests of the newborn, given his prognosis, and she may believe that only his interests should be considered. It is also possible that she accepts that interests of the family are relevant to the decision but believes that the Crafts have not given adequate weight to their son's interests.

It is likely that the Crafts considered their son's potential quality of life in light of their experience with their severely disabled daughter. This experience may well have permitted them to evaluate their son's prospective quality of life realistically, should he survive with major disabilities. Dr Hearth, on the other hand, may believe that quality of life has no role in this decision—that biologic life is sacred in and of itself and should be preserved whenever possible. Or she may have a different notion than the Crafts of what level of quality mandates an attempt to preserve a life and therefore may believe that Baby Craft's chance of surviving with this minimally acceptable quality of life is too great to justify withholding resuscitation.

Finally, Dr Hearth may believe that the Crafts could not possibly have the information necessary to make an informed decision prior to the birth of their son because information about his condition at birth was required to make an informed decision. Although case law in Texas would support this view [8], the Texas decision is highly controversial [7, 9-11]. Moreover, state law is applicable only in the state where it is passed.

Community Standards

So, was only 1 of these 2 alternatives morally acceptable or could both be? The larger community also has a role in this determination. Morality deals with things that ought or ought not to be done because of their deep social importance in the ways they affect the interest of other persons. Morality consists of social norms of behavior. In a pluralistic society, social norms often prescribe a *range* of behaviors that are morally acceptable in order to accommodate the range of legitimate values held by members of the community—or rather the various communities, professional, faith-based, political, and others. Thus, it is the larger community, not individuals alone, that determines the *bounds* of morally acceptable choices that are consistent with the relevant ethical principles. The fact that the parental choice may be inconsistent with the physician's values does not alone justify denying the parents an option that is among the range of values that are morally acceptable to the community.

If deciding to forgo resuscitation of newborns at 24 weeks of gestation is not within the range of choices considered morally acceptable by the community, then Dr Hearth is not only justified in intervening, she has a duty to do so. In this situation she also has an obligation to inform the parents of this duty when they express their wish to withhold resuscitation. If, on the other hand, withholding resuscitation is within the range of options morally acceptable in the community, Dr Hearth would have no right to impose

her personal values on the Crafts. Rather, her role in the decision-making process is to inform the family of the risk and benefits of all options and then use her medical knowledge, expertise, and experience to guide the family through decision making based on the family's value system [12]. (It would be prudent for Dr Hearth to involve a neonatologist in this counseling as recommended by the American College of Obstetricians and Gynecologists: "A multidisciplinary approach may be helpful in ensuring that information provided is consistent and represents a range of concerns and areas of clinical care" [13].)

This systematic approach requires that parental values be attained and that direct decisions about what choice is in the best interests of their infant be made. It is important to note, however, that Dr Hearth cannot be compelled to act against her own conscience. If she cannot, in good conscience, comply with the decision made by the Crafts based on their values, then she may choose not to participate further in the care of Mrs Craft. In that case, Dr Hearth has a duty to transfer care to an obstetrician who can, in good conscience, comply with parental wishes. If a pediatrician or neonatologist were expected to be involved in Baby Boy Craft's care in the delivery room, it would also be important to know whether he or she would be willing to comply with the Crafts' wishes. Delaying the induction of labor may have allowed time to acquire the relevant information and, if necessary, transfer of care to have been accomplished.

Whether Dr Hearth's action was justified, then, depends on whether a parental decision to forgo resuscitation of a 24-week newborn based on the best information available prenatally is among the range of morally acceptable options in the community or not. As a member of a moral community, do you think Dr Hearth's action was justified? Do you think the Crafts' decision was morally acceptable?

Notes and References

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