Expert analysis is indispensable, especially in medical decision making, because it helps both physicians and patients in making rational decisions. In fact, medical expertise is the very reason people seek health care from physicians and health care institutions. Expertise becomes dangerous, however, when it is associated with coercive power. In the case of decision making for severely impaired newborn infants, using predetermined algorithms or calculations to override parental decisions or to bypass parental judgment entirely is disrespectful of parental authority, potentially weakens the fabric of family relationships, and may be an unwarranted intrusion into family life.

Wilkinson’s (2011) thoughtful proposal of the Threshold View in his paper “A Life Worth Giving? The Threshold for Permissible Withdrawal of Life Support From Disabled Newborn Infants” uses quality-of-life analysis as a means to guide decisions to withhold or withdraw life-sustaining treatment from a severely impaired newborn infant. The main problem with his proposal is that he seems to intend that the decision the analysis generates be coercively imposed on uninformed or objecting parents, when it could be used instead as a tool supporting parents in their decision-making process.

SURROGATE DECISION MAKING FOR CHILDREN

Individuals have a right to refuse medical treatment—this is well established in both law and ethics. As human beings, newborns have such a right but are incapable of exercising it, so the right must be exercised for them by a surrogate decision maker. Who is the rightful surrogate when treatment decisions must be made for severely compromised newborns? Newborns have no preferences, desires, or chosen values, so the surrogate must use a standard other than substituted judgment in choosing among therapeutic options. Although several standards are available (Diekema 2004; Rhodes and Holzman 2004), the best interest of the child is the most widely used standard. As Wilkinson suggests, a quality-of-life calculation may be a suitable factor in determining an infant’s best interest. Parents have special knowledge of the culture and value system in which the child would be raised, so they are in the best position to make judgments about quality of life in the context of the environment in which the child would be living, including the needs and interests of other children in the family (Ross 1998). The traditions and laws of most countries, including the United States, recognize parents as the proper surrogate decision makers for their own children, under the presumption that they more than anyone else have the best interests of the child at heart and understand better than anyone else the conditions under which the child will be raised to maturity (Dare 2009). Given this widely recognized parental authority, who, if anyone, has the authority to bypass parents or to overrule their decisions to withhold or withdraw a life-supporting intervention?

The best interest standard is generally interpreted by health care providers as medical best interest, but, as Wilkinson recognizes, it is in reality far more complex than suggested by that narrow view. It comprises many other personal factors. For example, if I were making decisions for myself in a situation of irreversible critical illness, I could authoritatively demand that life support be withdrawn in order to avoid the large expense of continuing a life that for me is no longer worth living, thus avoiding unwanted impoverishment of my family. A child does not emerge as an atom in a vacuum, but is born into a family and the communities in which the child’s parents live, which include immediate and extended family, religious, business, or professional groups, and an assortment of political/legal jurisdictions. Parents understand and experience the child’s world in ways no expert can. Just as individual adults are best situated to determine which courses of action are best for themselves, so they are well situated to determine the best course of action for their children (albeit within limitations).

Because parents are the proper surrogate decision makers for their children, physicians and hospital administrators lack the authority to overrule parental choices. In the case of severely impaired newborns, they must either honor the parents’ decisions, try to persuade parents to adopt their conflicting points of view, or challenge what they view as an inadequate parental choice in the courts.

In constructing his proposal, Wilkinson defines a life worth living as “A life in which future benefits for the individual outweigh the burdens. There is positive net future well-being.” He defines a life not worth living as “A life in which future burdens for the individual outweigh benefits. There is negative net future well-being.” He clearly

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1. This phrase has an unfortunate resemblance to the term “Lebensunwertes Leben”—life unworthy of life—used in 1930s and 1940s Europe as a label justifying unmistakably malevolent acts against individuals and groups. Perhaps a less provocative term could be found.

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intends that an individual infant’s future quality of life be measured by some sort of expert-determined standards of what constitutes benefit and harm.

How does one find or create a standard for measuring benefit and harm as they relate to quality of life determinations? Statistical data on morbidity and mortality alone are not adequate, for reasons noted earlier. There can be no universal standard, as benefit and harm must be related to an individual’s life situation; that is, what constitutes benefit and harm is agent-relative and cannot be determined by others, no matter their levels of expertise (Rasmussen and Den Uyl 2005, 134–138). There can be no single standard for measuring quality of life, for people have moral and other commitments that arise from fundamentally different worldviews (Engelhardt 2010). Although infants have no personal values or preferences, those they will eventually have are undoubtedly more closely related to those of their families than to those of larger communities; indeed, the larger the community, the more weakly its standards would relate to those of the child’s world—the weakest relation would be to a national or international standard such as the United Nations Convention on the Rights of the Child (United Nations 1989/1990; Cherry 2010).

THE LOCUS OF AUTHORITY TO OVERRIDE PARENTAL JUDGMENT

In the worst cases of parental malfeasance, who or what entity has the authority to override parents’ judgment (Cherry 2010)? Wilkinson never makes clear whom he has in mind. Rather, he uses a generic “we” throughout his paper: for example, “In what circumstances should we permit parents and doctors to allow an impaired newborn infant to die?” At one point, he suggests that the authority to override resides in the vague notion of society: “For parents and doctors to be obliged to preserve the life of the infant, or for society to overrule parents’ right to decide, the infant’s life must be more than one barely worth living.” The lack or imprecision of discussion about the locus of decision-making authority is a critical omission.

Parental authority to make decisions about medical treatment of their children is not absolute; nevertheless, it is incumbent upon physicians, before they take any action, to inform parents about therapeutic options, including withholding or withdrawing treatment, and the likely consequences of each option. If a physician believes that a particular course of action is in the child’s best interest, after presenting all the relevant options, the physician could, and, if he or she feels strongly, should, attempt to persuade the parents of his or her point of view. If the parents choose not to allow a therapeutic intervention to take place in opposition to the physician’s efforts at persuasion, the physician has no authority to override their decision. Health care insti-

stutions should have a mechanism in place for addressing and resolving disputes between caregivers and patients or their surrogates; in the United States, most hospitals have such a policy. If the disagreement on treatment decisions continues throughout the process, the option of last resort should be to bring the matter to a court of competent jurisdiction for adjudication. Courts of law, like physicians and hospitals, struggle with issues of decision making for children, but they at least provide a forum in which arguments can be presented, evaluated, and finally decided. The courts generally (and correctly, in my view) have a high threshold for countermanding parental decisions.

CONCLUSION

Wilkinson’s proposal of the Threshold View would be a useful tool for helping a family to think through the options open to them in deciding on treatment for life-threatening conditions in newborn infants. Expert quality-of-life analysis, while potentially helpful to the parents, should not be used by physicians or hospital administrators to bypass or overrule the judgment of parents without an appropriate process of deliberation, negotiation, and adjudication. ■

REFERENCES


