

Ethical considerations at the threshold of viability

Recommendations for the care of extremely premature infants should acknowledge that well-informed, competent parents are the best surrogate decision-makers for their babies.

ABSTRACT: Advances in the field of neonatology over the past 50 years have allowed us to treat smaller and more premature babies. When managing these babies, we need to address a number of ethical issues at the threshold of viability. Canadian society has generally accepted well-informed, competent parents as the best surrogate decision-makers for their not-yet-competent children, and expected parents to act in the best interests of their children. However, the “best interest” standard presents certain difficulties because of the subjective nature of judgments involved, and because there is a great deal of medical uncertainty when evaluating risks for the individual baby. Research has established that doctors in the delivery room are inaccurate when identifying which extremely premature babies will survive and which will die, and which will have disabilities and which will not. Because of the degree of medical uncertainty, the latitude for parental decision making ought to be very broad and the parents’ role must be appreciated in the development of guidelines for managing newborns delivered at the threshold of viability.

Neonatology is a relatively young field of endeavor that has witnessed increasing development and technical complexity over the past 50 years. One area of particular importance involves the treatment of smaller and more premature babies. Neonatologists have realized the potential concerns related to outcome for these children and incorporated neonatal follow-up in evaluating treatment modalities. This provides an opportunity to compare local outcomes with other neonatal centres, particularly centres with similar referral patterns. With this opportunity comes an attendant responsibility to regularly re-evaluate local practice in light of available outcome data, and to provide recommendations for the management of extremely premature infants.

We know that in BC survival rates range from 6% at 22 weeks of gestational age to 81% at 25 weeks (see accompanying article beginning on page 498). Though it is important to consider such population-based survival statistics, for the woman in premature labor, these percentages have a somewhat circumscribed utility. For the individual baby survival is not a percentage, it is a binary consideration: the baby will either survive or

die. Similarly, while the risk of a neurodevelopmental disability in a population is clear, there is a great deal of uncertainty about this risk for an individual baby. In the neonatal period, we do not know whether there will be a disability, or what the functional significance of any disability will be. Since there is even greater uncertainty before birth, consideration of ethical issues is essential in the development of guidelines for the management of newborns delivered at the threshold of viability.

Issues

There are several complex ethical issues to consider when developing guidelines such as those seen in the accompanying article.

To begin with, medical ethics assigns primacy to respect for person. In adult medicine this equates to respect for informed autonomous choice. In pediatrics this involves considering the best interests of the child, for which we depend on third-party

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authorization. Canadian society has generally accepted well-informed, competent parents as the best surrogate decision-makers for their not-yet-competent children.^{1,2} Nested within surrogate decision making is an assessment of what is in the best interests of another person. This is closely tied to an evaluation of quality of life, which requires a value judgment—one that is inevitably informed by the decision-maker's worldview, life experiences, and religious and cultural beliefs.

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In general we respect parental decision-making authority and see parents as well situated to appreciate what would be best for their children. On occasion the courts have ruled that a parent has not met the “best interest” standard, but these occasions involving abuse or neglect are rare, and medical recommendations are not helpful when they are based on exceptional circumstances. As well as recognizing that exceptional circumstances should be dealt with as such, we must recognize that equally competent people can make totally different decisions based on personal values, and that different decisions can be equally valid. Aside from this lack of uniformity in decision making, there are limits placed on parental decision-making

authority at the threshold of viability.^{3,4} In a recent study, researchers reported that a significant number of Canadian neonatologists would either try to convince parents to choose resuscitation or would resuscitate babies at the threshold of viability, even against parental informed choice.³ Therefore, another variable encountered in pediatrics is the prominent, if not paternalistic, role of the physician in evaluating “best interest” in decision making. Though there is an air of objectivity to the term “best interest,”

chance” to justify intensive care? Singh and colleagues demonstrated how inaccurate doctors are in the delivery room when it comes to identifying which extremely premature babies will survive and which will die, and which will have disabilities and which will not.⁴

Given the lack of uniformity in decision making and the inherent medical uncertainty when treating newborns at the threshold of viability, where are the limits to parental decision-making authority?

Approaches

To circumvent the problematic terrain of “best interest,” Diekema has proposed the “harm principle.”⁷ Diekema suggests that parental decision-making authority should be overridden when the decision places the child at significant risk of serious preventable harm, and that this principle can be used to determine the need for legal intervention.

Rhodes and Holzman⁸ have proposed the “not unreasonable” standard for surrogate decision making, based on three potential options:⁸

- The first option would apply to situations where intensive care treatment is best for the baby, and it would be “unreasonable” not to provide intensive care.
- The second option would apply to situations where aggressive treatment is not best for the baby, and it would be “unreasonable” to provide intensive care.
- The third option would be where the outcome is uncertain, and it would be “not unreasonable” to either provide or withhold intensive care; in this situation decisions should be accorded to the considered opinion of the parents.

The persisting difficulty is in clarifying the boundaries for Rhodes and Holzman's options. In order to impose

in fact these assessments of what is best for the child have subjective and objective components,⁵ and are not purely objective for physicians because of personal biases about neurodevelopmental outcome and personal experience.⁶

When the standard procedure is to resuscitate and provide intensive care, parental refusal of medical treatment pushes the health care team not to act. However, the more common scenario is when parents push the health care team to do “everything.” If there is no chance of survival, or a very small chance of survival and no chance of intact survival, it would not be reasonable to impose the burdens of intensive care. However, how much of a chance would be a “reasonable

resuscitation and intensive care treatment against parental wishes, thereby limiting parental decision-making authority, how certain must the health care team be that treatment will result in survival with a “good” quality of life? Most authors would agree that treatment is warranted if the success rate is very high and the risk of significant complications minimal.⁷ And in order to limit treatment when parents request full intensive care, how certain must the health care team be that there will be harm imposed and no physiological benefit of resuscitation and intensive care treatment?

Schneiderman and colleagues suggest that intensive care treatment is not warranted in situations where aggressive treatment is thought to be futile (defined as treatment failure in the last 100 similar patients).⁹ However, the degree of medical uncertainty when dealing with infants at the threshold of viability means the latitude for parental decision making ought to be very broad. Moreover, we must remember that parents will deal with the consequences of the decision emotionally, physically, and financially. We must also give serious consideration to proportionality in the provision of services for a child if intensive care is imposed against parental wishes. If full intensive care treatment is imposed in order to satisfy the “best interest” standard, then based on the principle of justice (fairness) the system that imposes such treatment must also provide adequate long-term assistance for the child and the family if there are long-term disabling conditions from the treatment imposed. There would not be the same degree of responsibility to a family choosing aggressive intensive care treatment, aside from an equitable portion of societal goods, including social, educational, and health care benefits.

Summary

Although the “best interest” standard is generally promoted in pediatrics, it is difficult to rely upon for decision making because subjective components, including the subjective nature of quality-of-life assessments and religious considerations, are unique to the individual or family involved. The “best interest” standard is also difficult to apply because of medical uncertainty and difficulty in evaluating risks and benefits for the individual baby at the threshold of viability. Moreover, the manner in which reasonable people make decisions varies. Therefore, since the “right” decision is unknown and the process of decision making is variable, we need to honor parental decision-making authority as well as any legal requirements. There are some limits to parental decision-making authority based on *primum non nocere* to ensure that parents do not make unreasonable decisions for their children. However, this is limited to situations where there is evidence of a clear benefit or a significant risk of serious preventable harm, in which case legal intervention might be considered. Aside from these rare circumstances, well-informed, competent parents are the best surrogate decision-makers for their babies, and this fact must be appreciated in the development of guidelines for managing newborns delivered at the threshold of viability.

Competing interests

None declared.

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