

The Initiation or Withdrawal of Treatment for High-Risk Newborns

Committee on Fetus and Newborn

As medical technology has advanced, outcomes for high-risk newborns have greatly improved. With advanced technology such as assisted ventilation, it is now possible to keep some terminal, severely ill, or extremely premature infants alive for long periods of time. The result of such treatment is that dying may be prolonged or that the infant will survive with profound neurologic or other debilitating problems.¹ The medical treatment of infants should be based on what is in their best interest. However, because the infant's "best interest" is not always clear, parents and health care givers are often faced with difficult treatment decisions when faced with the situation of a severely ill, extremely premature, or terminally ill infant.

The Treatment Dilemma

If intensive treatment uniformly resulted in saving infants at risk, it would be the obvious choice for all severely ill infants. This outcome, of course, does not always occur. If intensive treatment is not provided to very ill infants, most of them will die, but some may survive with significant neurodevelopmental disability, in part because specific treatments were withheld. The following dilemma therefore exists: intensive treatment of all severely ill infants sometimes results in prolongation of dying or occasionally iatrogenic illness; nonintensive treatment results in increased mortality and unnecessary morbidity. The overall outcomes of either approach are disappointing.

Strategy for Care

A reasonably acceptable approach to this dilemma is an individualized prognostic strategy.^{2,3} In this setting, care is provided for the individual infant at the appropriate level based on the expected outcome at the time care is initiated. In this strategy, the infant is constantly reevaluated, and the prognosis is reassessed based on the best available information in conjunction with the physician's best medical judgment. This approach places significant responsibility on the physician and health care team to evaluate the infant accurately and continuously. The family of the infant must be kept informed of the infant's current status and prognosis. They must be involved in major decisions that ultimately could alter the infant's outcome.⁴ For this approach to be successful, one

physician should be designated as the spokesperson for the health care team and should discuss treatment options with the family. When the health care team is unable to agree on a treatment strategy, the physician, serving as the team leader, should attempt to resolve existing differences by using an independent medical consultant or reference data, or by consulting with the hospital bioethics committee. When there is more than one valid approach to care, the physician should present these options to the family for their consideration and opinion.

The physician spokesperson must be sensitive to the parents' concerns and desires, which are often based on a complex combination of values and influences derived from their cultural, religious, educational, and ethnic backgrounds.^{3,4} Physicians are ethically and legally obligated to provide appropriate care for the infant based on current medical information and infant assessment. Parents are encouraged to take an active role in the decision-making process. Decisions to continue, stop, or alter care must not be based on the financial status of the parents or the financial interests of the physicians, the hospital, or the insurance carrier or other third-party payer.

The rights of parents in decision making must be respected. However, physicians should not be forced to undertreat or overtreat an infant if, in their best medical judgment, the treatment is not in compliance with the standard of care for that infant. When there is a conflict or disagreement between the recommendations of the physician and the desires of the infant's parents, one option is to consult with the hospital bioethics committee. Another option is for the physician and family to seek another physician willing to provide care for the infant in the manner desired by the family. This disagreement between the physician and the family may result in the involvement of the court. In that case, the physician should continue to serve as an advocate for the infant.

In all of these considerations, there is no distinction between initiation or withdrawal of life-sustaining treatment.

RECOMMENDATIONS

1. Ongoing evaluation of the condition and prognosis of the infant is essential, and the physician as the spokesperson for the health care team must convey this information accurately and openly to the parents of the infant.

The recommendations in this statement do not indicate an exclusive course of treatment or procedure to be followed. Variations, taking into account individual circumstances, may be appropriate.
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2. Parents should be active participants in the decision-making process concerning the treatment of severely ill infants.
3. Humane care must be provided to all infants, including those from whom specific treatment is being withheld. Parents should be encouraged to participate in the care of their infant as much as they wish.
4. If the viability of the infant is unknown, or if the curative value of the treatment is uncertain, the decision to initiate or continue treatment should be based only on the benefit to the infant that might be derived from such action. It is inappropriate for life-prolonging treatment to be continued when the condition is incompatible with life or when the treatment is judged to be futile.

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