



Noninitiation or Withdrawal of Intensive Care for High-Risk Newborns

Committee on Fetus and Newborn

Organizational Principles to Guide and Define the Child Health Care System and/or Improve the Health of All Children

ABSTRACT

Advances in medical technology have led to dilemmas in initiation and withdrawal of intensive care of newborn infants with a very poor prognosis. Physicians and parents together must make difficult decisions guided by their understanding of the child's best interest. The foundation for these decisions consists of several key elements: (1) direct and open communication between the health care team and the parents of the child with regard to the medical status, prognosis, and treatment options; (2) inclusion of the parents as active participants in the decision process; (3) continuation of comfort care even when intensive care is not being provided; and (4) treatment decisions that are guided primarily by the best interest of the child.

INTRODUCTION

As medical technology has advanced, outcomes for high-risk newborn infants have greatly improved. With advanced technology, such as assisted ventilation, it is now possible to keep some terminally or severely ill or extremely preterm infants alive for long periods of time. The result of such treatment is that dying may be prolonged or the infant may survive with profound neurologic or other debilitating problems.¹⁻³ The treatment of infants should be based on what is perceived to be in their best interest. Parents and health care professionals often confront difficult treatment decisions when faced with the care of a severely ill, extremely preterm, or terminally ill infant, in part because the effects of treatment decisions on the infant's outcome are not always predictable. In these circumstances, there is no ethical distinction between noninitiation and withdrawal of life-sustaining treatment.

THE TREATMENT DILEMMA

If intensive treatment uniformly resulted in survival with an acceptable quality of life for 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, perhaps in part because specific treatments were withheld. The following dilemma, therefore, exists: intensive treatment of all severely ill infants may result in prolongation of dying accompanied by significant discomfort for the infant or in survival with unacceptable quality of life; on the other hand, nonintensive treatment may result in increased mortality and morbidity. Either approach risks undesired and unpredictable results.

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Key Words

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STRATEGY FOR CARE

For infants with poor prognosis, decisions about treatment should be made jointly by the health care team and the infant's family on the basis of the infant's physiologic maturity; the infant's medical condition, including any serious birth defects or medical complications; and the probabilities of death and severe disability based on the best available data.⁴

The types of decisions can be divided into 3 categories on the basis of prognosis⁵:

1. When early death is very likely and survival would be accompanied by high risk of unacceptably severe morbidity, intensive care is not indicated.
2. When survival is likely and risk of unacceptably severe morbidity is low, intensive care is indicated.
3. There may be cases that fall within these first 2 categories in which the prognosis is uncertain but likely to be very poor and survival may be associated with a diminished quality of life for the child; in these cases, parental desires should determine the treatment approach.

Whenever possible, discussion between the physician and parents should begin before the birth of a child with anticipated poor prognosis.⁶ The obstetric care provider and the health care professional who will care for the infant after birth should collaborate in communicating with the expecting parents before the birth of the child. Such dialogue helps to ensure that appropriate care is provided for the individual infant on the basis of the infant's condition and prognosis at the time of birth. Sometimes, as when the woman is in active labor, it may seem that there is inadequate time for such a discussion. Nevertheless, it is essential that the meeting be conducted promptly and with great empathy. Follow-up meetings can take place if the situation changes over subsequent hours and days. Despite efforts to the contrary, an infant with a poor prognosis is sometimes born quickly, before the physicians can converse with the parents about the plan for treatment of the infant after birth. In such cases, the physician must use his or her judgment on behalf of the infant in deciding whether to initiate resuscitation of the infant until the parents can be involved in the decision. In making these decisions, the physician should err on the side of resuscitating the infant if the appropriate course is uncertain.

Once intensive care is initiated, the infant is continuously reevaluated, and the prognosis is reassessed on the basis of 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 benefits to and burdens on the infant with continuing intensive care. The family of the infant must be kept fully informed of the infant's evolving status and prognosis. The physician

and family must be involved together in major decisions that ultimately could alter the infant's outcome.⁷ Unless circumstances dictate otherwise, one physician should be designated as the spokesperson for the health care team and should discuss treatment options with the family and communicate decisions to the full health care team. When there is more than one valid approach to treatment, the physician should present these options to the family for their consideration and opinion. 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 consulting with the hospital bioethics committee.

The physician spokesperson must recognize that the parents' view of their child's status and the treatment choices is influenced by how the information is presented by the physician.⁸ This recognition imposes a special obligation on the physician to present prognostic information in a frank and balanced way without coercion. 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, social, and ethnic backgrounds. The physician's role is to present the treatment options to the parents and provide guidance as needed. The parents' role is to participate actively in the decision-making process. Decisions to continue, limit, or stop intensive care must be based only on the best interest of the infant and not on the financial status of the parents or the financial interests of the physicians, the hospital, or any third-party payer.

The important role of the parents in decision-making must be respected. However, the physician's first responsibility is to the patient. The physician is not obligated to provide inappropriate treatment or to withhold beneficial treatment at the request of the parents. Treatment that is harmful, of no benefit, or futile and merely prolonging dying should be considered inappropriate. The physician must ensure that the chosen treatment, in his or her best medical judgment, is consistent with the best interest of the infant.

When there is conflict or disagreement between the recommendations of the physician and the desires of the infant's parents, continued discussion will often lead to agreement. If the disagreement continues, one option is to consult with the hospital bioethics committee. Another option is for the physician and family to seek another physician who is 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 system. If this occurs, the physician should continue to serve as an advocate for the infant. Involvement of the court system is adversarial by nature and should be considered the last possible choice in resolution, to be used only in the case

of irreconcilable differences of opinion, and it should be avoidable in nearly all cases.

RECOMMENDATIONS

1. Decisions about noninitiation or withdrawal of intensive care should be made by the health care team and the parents of a high-risk infant working together. This approach requires honest and open communication. Ongoing evaluation of the condition and prognosis of the high-risk 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.
2. Parents should be active participants in the decision-making process concerning the treatment of severely ill infants.
3. Compassionate basic care to ensure comfort must be provided to all infants, including those for whom intensive care is not being provided.
4. The decision to initiate or continue intensive care should be based only on the judgment that the infant will benefit from the intensive care. 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 harmful, of no benefit, or futile.

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