

# Virtual Mentor

American Medical Association Journal of Ethics  
October 2008, Volume 10, Number 10: 673-676.

## OP-ED

### Medical Decision Making for the Marginally Viable Infant

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How should expectant parents react when they learn that the pregnancy will quickly end with the birth of an extremely premature infant? These fragile infants—at the margins of viability—demand extremes of life-sustaining care that often require months in the neonatal intensive care unit (NICU) connected to tubes in various orifices. And after this protracted period of time, what sort of guarantee do the parents have that the infant will be fine? Or, if we suspect that the infant will not be fine, what drives parents to sustain and endure such an intense level of anguish? What rights does the voiceless premature infant have? Does the medical team have the authority to override the medical decisions made by the parents?

#### Acquiring Good Clinical Facts

Neonatology involves life-and-death decision making, which should begin with accurate medical details [1]. Neonatology has witnessed substantial improvements in the equipment and care provided to the marginally viable infant. But, although currently available prenatal diagnostic equipment is excellent for most settings, major errors can arise in the accurate assessment of gestational age. Accurate gestational age is critical because the variation of 1 week in the determined age of an extremely premature infant (25 weeks instead of 24 weeks, for example) produces a far different set of prognostic implications. The initial complete examination at birth is the best way to assess gestational age accurately. In the early minutes to hours of the life of the marginally viable infant, much medical information becomes available and—typically—drives the decision-making process. At this point, predictions are made, outcomes are assessed, and a medical plan is put in place. It is not unusual for conflict to arise between a medical team and the parents at this juncture when future care is discussed in the context of medical futility. The discussion of medical futility should be framed using only the medical details and facts of the case. It should never be reduced to the notion of the value or quality of a premature baby's life.

Edmund Pellegrino offers the helpful triad of benefits, burdens, and efficacy in assessing medical futility [2]. In this analysis, Pellegrino considers not only the benefits and burdens of a particular treatment, but also the notion of how effective the treatment is in producing the desired results. Quite often, when physicians use these terms, they refer to the importance of benefits, burdens, and efficacy in a utilitarian way and, when speaking of withholding or withdrawing medical care from the marginally viable infant, they typically employ such data as (1) low probability of survival, (2) high probability of severe disability, and (3) high projected costs of medical care (neonatal and throughout) [3]. On the other hand, true medical futility

consists in a treatment plan that is not working in the infant's best interest or the infant's requiring increasingly aggressive treatment to stabilize his or her status.

### **The Best-Interest Standard**

In general, the best-interest standard is the ethical model for medical decision making for the marginally viable infant (and all young children). Decision making under best-interest standards requires the decision maker to use medical information (diagnosis, prognosis, and treatment options) objectively in deciding among various modes of treatment. In its purest form, the standard concerns nothing but the best interest of the patient [4]; preferences of the parents, health care team, and even of the patient (if he or she could express them) are not taken into consideration.

Practically speaking, such a strict standard is extremely difficult to implement because, to the degree that the infant will require significant future care, his or her best interest is inseparable from that of his or her family. Any chronically ill child places great demands upon the family, and decision making directly impacts family resources—time, money, and presence (being at the bedside and establishing a bond). Furthermore, the potential long-term support and care of the marginally viable infant after hospital discharge adds direct care services and financial costs [5]. Clearly the medical best interest is the highest ethical standard; there are times, however, when the best interest of the infant is not so clear. In these difficult situations, the preferences and best interest of the parents may be given more direct consideration in the decision-making process.

Parents and other individuals who advocate for continuing aggressive medical treatment of a marginally viable premature infant often point to notions such as (1) the sanctity of human life made in the image of God, (2) the inherent value of any human life (even if medically compromised), (3) the right, once born, to live a life, (4) future advances in medical science that may mitigate the infant's impairments, and (5) future blessings that continuation of the infant's life may confer. Some parents feel obligated to ask for aggressive medical treatment when an experienced neonatal team observes that providing it can be medically inappropriate and may even hold high risk of harm or pain accompanied by little likelihood of benefit. These parents may feel that the infant's life—no matter how short, or burdensome, or painful—is a life worthy to be lived. Some point to the possibility of medical breakthroughs and to the expectation of unknown (but expected) blessings as they care for their premature infant. Although physicians at the bedside may have difficulty understanding these parental feelings, they must, nonetheless, respect them as a parental privilege.

If the premature infant remains hospitalized for a prolonged period of time, the medical team may be able to suggest parameters which, if reached, would preclude further aggressive medical care. If the premature infant is safely discharged, a thorough discussion with the baby's primary care physician can be instrumental in establishing guidelines that grant both doctor and parents permission to choose not to readmit the infant should certain medical situations arise.

Decision-making authority for the marginally viable premature infant typically falls upon the birth parents (complications may arise if surrogate birth is involved), in large part due to the foundational presumption in our society that parents act in the best interest of their child. The American Academy of Pediatrics refers to this presumption of parental commitment to the child's best interest [6]. Nevertheless, parental decision-making authority is not an absolute right to be obeyed without question. It is possible that the medical decision reached by the parents vetoes treatment that the medical team considers reasonable and appropriate because it has substantial benefits, minimal burdens, and acceptable risks. If the standard of care supports the medical team's decision, then the treating physicians have the ethical and moral obligation to consider overriding parental refusal of treatment. This physician stance should only be taken when medical facts are reasonably certain, and the medical standard of care is easily ascertained.

Medical decision making for the marginally viable premature infant will always be difficult. The medical team should demand dependable medical facts, and the parents should similarly demand full and clear communication regarding these details. Health care professionals must demonstrate a strong bias in the support and preservation of survivable life. The parent, with recognized decision-making authority, and the physician, with professional knowledge and expertise, must work together in evaluating the developments and complications of the infant's medical progress and in making decisions in the infant's best interest. It is appropriate to grant the parent some decisional latitude in this process. Both parents and physicians must recognize that there are certain situations in which the physician's medical-ethical responsibility to the patient dictates overriding a parental request that is medically inappropriate in terms of either excessive or inadequate treatment.

## References

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**Acknowledgment**

The author wishes to thank Robert Orr, MD, for review of and assistance with this manuscript.

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