

---

# Reducing Suffering and Ensuring Beneficial Outcomes for Neonates: An Ethical Perspective

by Dennis Brodeur

---

*Although health treatment regulations exist for protecting infants from unnecessary suffering, the ethical dilemmas created by some births have not been successfully resolved. A reconfiguring of neonatal medicine, with more carefully designed studies, greater uniformity about treatment and greater attention to the impact of treatment outcomes may be the solution.*

Infants born at very young gestational age, or with very low birth weight, or those who suffer from severe congenital or genetic anomalies are among the most vulnerable patient populations. In the 1980s, regulations were issued and infant care review committees were established to protect these children from unnecessary suffering, harm, or neglect and to provide guidelines for appropriate medical treatment.

While some of these regulations may have helped, the ethical quandaries created by the birth of these infants have not been successfully resolved. The therapeutic and diagnostic capabilities of neonatal medicine continue to advance though there is no consensus on many of the ethical, medical, and legal issues concerning the treatment or non-treatment of neonates. The ethical obligation of physicians, families, and hospitals as well as society's commitment to rescue every neonate regardless of medical condition, gestational age, or birth weight remains controversial.

In addition, the outcomes of medical interventions may or may not have been beneficial to children. For example, Indiana Baby Doe, born with Down Syndrome, and Angela Lakeburg, a conjoined twin, are both dead. Some people would argue that no harm was done to Baby Doe by not feeding him, while others contend that the greatest harm was done by allowing him to die rather than surgically correcting his esophageal fistula. Some argue that Angela Lakeburg underwent excruciating suffering and pain through the months

of treatment prior to her death, while others believe that her separation from her sister, with whom she shared a heart, and her ensuing months of life could only be viewed positively. Baby Jane Doe of Long Island, New York, now known as Keri Lynn, is an affectionate ten-year-old attending a school for the developmentally disabled and has seemingly benefited from her parents initial decision to treat her medically rather than surgically. Some question whether she continues to suffer from continuing medical interventions and because she deviates from whatever "normal" is in other ten-year-old children.

The fact that these debates continue indicates the ambiguity of individuals, the medical community, and society regarding the causes of suffering or harm, or conversely what treatment or non-treatment is in the best interest of a child.

## **Ethical Assumptions in Treatment**

In *Selective Non-Treatment of Handicapped Newborns*, Robert Weir identifies five distinct types of arguments that ethicists use to discuss the treatment or non-treatment of neonates (Weir 1984). These include a belief that all non-dying neonates should be treated regardless of the severity of their anomalies. A second argument encourages terminating the lives of selected non-persons, in the sense that some children have so many medical difficulties that they have no claim to continued

---

*Dennis Brodeur, STB, MA, PhD, is senior vice president of SSM Health Care System, St. Louis, Missouri.*

treatment. A third option relies on parental discretion to treat or not to treat on the basis that parents must live with the consequences of these choices and, therefore, should be the primary decision makers. A fourth option raises questions of quality of life projections and would allow non-treatment in cases where it is highly likely that a child could not live a meaningful existence, where meaningful existence usually implies the ability to interrelate with one's environment and one's social world. The final criteria used by some ethicists is to make judgments solely in the best interest of the child. Rather than asking questions of quality, these ethicists ask questions about the projected burden of continued existence to the child who is treated and kept alive.

As noted, there is not clear consensus among ethicists, lawyers, and the medical community about which criteria to use in making decisions about treatment or non-treatment of neonates. Federal regulations and some state laws encourage the treatment of all non-dying neonates. Parental discretion remains a fundamental concern for many interested in keeping outside forces away from the deliberation process. However, disagreement continues about parental decision-making rights, evidenced by the impending court case against Dr. Messenger for a decision not to treat his child, born with severe neurological damage, and the decision of Mr. and Mrs. Nguyen to be aggressive in the treatment of their child, born with multiple anomalies, whom the medical community felt should not be treated.<sup>1,2</sup>

With no foreseeable consensus and with medical and ethical dilemmas continuing to arise, what questions need to be asked to ensure that treatment or non-treatment results in benefit for the infant and that suffering is not prolonged? At least four areas suggest themselves for consideration: the value of life and treatment decision, the continuum of benefits, long-term outcomes, and the complex of social relationships involved.

### **The Value of Life and Treatment Decisions**

Some ethical arguments about treatment or non-treatment of neonates connect respect for the

value of an infant's life with aggressive treatment. For example, when the most aggressive treatment was not done for Keri Lynn, questions were raised about the moral propriety of her parents' decisions. When Dr. Messenger stopped treatment, it raised questions about criminal actions and disrespect for the sanctity of life. When the Nguyens decided that a severely affected child must be treated with surgical interventions, ventilator assistance, hemodialysis, and a possible kidney transplant, it is assumed that this is a statement of pro-life respect for a child and, therefore, all treatments should be provided regardless of cost.

The result of this connection is that anyone who is not aggressively treated is perceived to be neglected, demeaned, or allowed to die too early. The questions not raised are whether or not aggressive medical treatments for severely compromised infants don't increase suffering in the immediate future, and in the long term if the treatment only prolongs life but doesn't enable individuals to pursue activities of daily living.

Because society has difficulty with death, particularly with the death of young life, the connection between valuing life and treatment comes naturally. The fact that sometimes respect for life may be furthered more by allowing death to occur is not fully considered unless death seems imminent. Rather than alleviating suffering by treatment, treatment can continue suffering or even increase it in both the short term and long term.

Not treating seriously compromised neonates is problematic when non-treatment and resulting death are unwarranted. The criteria necessary to distinguish appropriate non-treatment from medically indicated treatment is not clearly established. What is clear is that respecting the value of life by always treating is not necessarily ethical, in the child's best interest, or certain to avoid unnecessary pain and suffering.

### **The Continuum of Benefit**

If aggressive treatment of neonates is not always a sign of respect for the value of life, then one has to consider the continuum of benefits known or unknown in the treatment of the seriously com-

promised neonate. The benefits of continued treatment will only be recognized when one is more assured of the outcomes of therapeutic interventions once initiated. This requires greater honesty about the unknown outcomes of therapeutic care and a greater willingness to confront decisions to cease treatment when certain outcomes have not been established.<sup>3</sup> Ceasing treatment, however, is one of the most difficult things to do in the neonatal intensive care unit.

Underlying this concern is honesty in the description of the experimental or non-experimental nature of the interventions offered. Over time, it is apparent that certain children greatly benefit from intensive care interventions. Children born with insufficient lung capacity and cardiac insufficiency later in the gestational period benefit from respiratory assistance, cardiac surgery, or other types of aggressive care. This becomes less certain as children are born earlier in a pregnancy or suffer from multiple congenital and genetic anomalies. For example, it may be relatively clear that a child born with insufficient lung capacity at 32 weeks greatly benefits from NICU care, but a child at 24, 25, or 26 weeks of gestation is less likely to benefit from this treatment. The fact that some infants survive intervention at this early stage of life, does not automatically translate into all children benefiting from this treatment unless one assumes that all children must be treated to have some statistically significant beneficial outcomes for a few.

In this regard, neonatal intensive care may in some circumstances be experimental. While experimental medicine is certainly critical to the increasing capacity of neonatologists and others to better treat infants, some of these interventions do not conform to a pattern of well-designed experimental medicine. As a result, some children are treated simply because they are born and alive and the technology exists to attempt intervention even when other medical, physiological, or therapeutic factors may indicate that treatment should not continue. Sometimes this treatment continues in the guise that information gathered from the treatment of one child may be beneficial for the

treatment of others. While in certain circumstances this may be true, well-designed experimental protocols generally require the aggregation of information across a wide cohort of subjects in order to prove the value of the medical intervention. Neonatal medicine, by its very nature, sometimes allows continued experimental treatment even when this information is not gathered in sufficient number to justify continued practices.

This raises the difficult question of futility. Futility in adult medicine is poorly defined and the subject of debate. Futility in the treatment of a seriously compromised newborn becomes more complicated if for no other reason than life seems so young and precious. Additional difficulties arise because the benefit or detriment of the therapeutic intervention may not be known for years. Subsequently, how a child responds to medical intervention neurologically, educationally, or emotionally may not be evident for years. Tracking the progress of these children, measuring the outcomes, and knowing what interventions were successful is more difficult.

The nature of experimental medicine in neonatology raises questions about how appropriate decision makers weigh the possible benefits or burdens of continued treatment. Here parents and the medical community may be most at odds. A family may judge that prolonged NICU care and aggressive treatment may not be in the best interest of their child or of other family members and, therefore, may not wish to take the long-shot, therapeutic approach. Neonatologists, nurses, and other caregivers more accustomed to the NICU and to some successes in treatment protocols, may see this refusal of treatment as abandonment or neglect of the sacredness of human life. Since these conflicts are often unresolved in favor of the medical community, cases like the Messengers' arise.

The ethical resolution of these difficulties may come in allowing parents or surrogates to make decisions even if in some circumstances these decisions result in the death of a child who might have otherwise lived an impaired and medically difficult short life. On the other hand, parents may

make decisions for non-treatment based upon a desire not to have a child with deformities, such as Down Syndrome. Difficult lines will continue to be established to protect the vulnerable child from these types of decisions even when they are totally understandable from the parents' perspective. Clearly, in this realm of experimental and non-experimental neonatal care clear lines are difficult to draw, regulations are unlikely to resolve pressing dilemmas, and better processes for decision making and alternatives for care of a child saved by neonatal medicine must be discovered.

### **Long-Term Outcomes**

Some recent studies<sup>4</sup> address the long-term outcomes of early interventions in compromised newborns. One study looked at the early intervention of low-birth weight premature infants through five years of age, while a second study examined school age outcomes in children with birth weights under 750 grams. The study that reviewed early intervention, low birth weight, premature infants through five-years of age studied children less than 2,000 grams or greater than 2,000 grams. By today's standards, these children are relatively healthy compared to children who are frequently aggressively cared for when their birth weight is under 750 grams. This study was not focused solely on the intervention of the neonatal intensive care unit but looked at the type of medical care children received in home visits through three years of age, as well as in center-based schooling from one to three years of age. While these children did fairly well, their age and the lack of other complicating genetic or congenital anomalies is not necessarily generalizable to the rest of the neonatal population.

The second study with school age outcomes in children born under 750 grams is less promising. The conclusion of this study noted that those children under 750 grams who survived represented a subgroup of very low birth weight children who were at high risk for neurobehavioral dysfunctions, poor school performance, and continued medical problems.

Today, other centers are experimenting with

caregiving by nurses who trained in individualized developmental care of a child. After admission to a NICU, support systems are put in place for both nurses and parents to enhance the child's care and improve medical outcomes. However, while medical success may be measured by lung capacity, a lack of infection, the ability to be removed from ventilator assistance, and a quick transfer of the child to a home setting, we don't know the long-term implications of this care. Again, this becomes more obvious in lower birth weight children and children with severe congenital or genetic anomalies.

These cases are significantly different from Baby Doe in Indiana, Baby Jane Doe in New York, the Lakeburg twins, or other children of national prominence. The vast majority of neonates will either benefit or be burdened by the outcomes of the use of today's technology. In the absence of clear long-term outcomes, one can at least ask about whether or not aggressive medical intervention is necessary, desirable, or ethical. Distinguishing the children who may benefit from those who will not is difficult and raises questions about the experimental or non-experimental nature of the interventions offered. This suggests that the mandate to treat all non-dying neonates is insufficient. Greater distinctions are necessary, requiring more sophisticated medical indications to determine when treatment is appropriate in order to avoid inflicting unnecessary suffering or harm on the child. This, again, returns to the focus of decision making: who has power to make decisions, and whose values in those decisions should be respected.

The above comments are not to suggest that children with serious medical problems are to be shunned or not treated. Instead, they propose that not all of these children should automatically be treated simply because this is the protocol or *modus operandi* of the health care community. Both treatment and non-treatment in the absence of long-term outcomes can increase suffering. The desire to alleviate or eliminate suffering from this group of patients simply cannot result in uniform treatment and non-treatment protocols. After

more than twenty years of increased neonatal intensive care unit development, these questions still appear a long way from resolution.

### **The Social Setting**

One of the problems of trying to reduce suffering in the neonatal population comes from a still unresolved complex of social rather than medical relationships. Whatever may or may not be medically indicated by state of the art technology for the appropriate treatment of a seriously compromised neonate is evaluated differently, depending upon the social community looking at the issue.

Families may be the first and most important social unit to examine in this matter. In most pregnancies, wanted or not, parents have a deep and abiding desire for a healthy child and have dreams and hopes for that child's birth, childhood life, and adult accomplishments. News that a child has a particular congenital or genetic anomaly, or the onset of premature labor, or other medical complications dash these dreams. As a result, one confronts not only the medical dilemmas of treating the child but a series of spiritual, emotional, and familial responses to the needs of the newborn. This cuts both ways.

On one hand, parents, as in the recent case of Baby K in Virginia, can decide that all aggressive measures should be taken to save their anencephalic child even though medical opinion is generally that these children should be allowed to die and not be aggressively supported. On the other hand, parents of a child such as Baby Doe in Bloomington, Indiana, may decide not to intervene to correct problems that would allow the child to take food, based upon an unwillingness to raise a child with Down syndrome. These two cases represent two ends of a spectrum. One can find defenders of treatment or non-treatment in each case. Children at both ends of the spectrum may suffer from the decisions made. It is troubling, however, that no uniform process exists to deal with these cases in family settings or in the medical community. The courts seem inadequate in both settings.

Families are not alone, however. In the medical community it is not unusual for people in the NICU, for example, to disagree about whether to continue or discontinue treatment. These decisions are not based solely on medical facts. In some circumstances, they are based upon long-term relationships with a seriously compromised child, the acceptance or rejection of the response of family members to a child's care and needs, or the implications of economic and social cost. These are legitimate and understandable care giver emotions involved in these treatment cases. Whether children benefit or suffer from these unresolved medical processes remains a question.

Finally, there are serious ramifications from a social setting apart from either the family or the medical community. On one hand, as was probably most evidenced in the Baby Jane Doe case in New York, individuals who were neither a part of the medical community nor the family may take it upon themselves to intervene legally or by whatever other means to save the life of a child. On the other hand, society seems unwilling to expend its dollars to care for a child beyond the medical treatment in the hospital setting. Subsequently, medical needs that follow hospital discharge, some that accompany families for the life

---

***Both nontreatment and treatment in the absence of understandable long-term outcomes can increase suffering.***

---

of a child, are denied. The wonders of technology have saved the child, only to have him or her suffer at the hands of a society unwilling to provide the resources necessary to care for the child. Notions of preserving life and alleviating suffering in neonates are clouded by such ambiguity in any social commitment to support children in their future years. Again, this raises questions about the appropriate decision makers. If parents are not allowed to make decisions to discontinue treatment but are saddled with the economic costs of caring for neurologically devastated and educa-

tionally deprived children for years because society doesn't shoulder this responsibility, why aren't parents allowed to be the final decision makers? If there is no financial support for the needs of children once they go home, why should the medical or legal community be able to trump parental decisions, even if those decisions do not seem to be in the best interest of some children?

These are difficult questions without an easy answer. What seems to be clear is that a decision to treat or not treat is not necessarily in a child's best interest, does not necessarily alleviate suffering for the child or for his or her larger social group, and may not be the best ethical response.

### Conclusions

Following the political, medical, and ethical hoopla of Baby Doe, Baby Jane Doe, to the recent cases of the Lakeburg twins and the Messenger baby, there is still no clear answer as to how to treat children of very low birth weight or those suffering from severe congenital or genetic anomalies. Progress has been made but tough ethical questions remain. Perhaps all society can do is recognize that it will continue to live in moral ambiguity, an uncomfortable place to be. It is not resolved by the assertion of parental rights, legal statutes, or medical prerogative. Rather, it is a place of increasing struggle over key human values for one of the most vulnerable populations. Moral ambiguity is uncomfortable, but it may be the only place to stand in the moral debate.

What is needed is a reconfiguring of neonatal medicine. Carefully designed studies for children need to be established. Greater uniformity about treatment for children with certain medical complications needs to be ascertained. Departures from these solidly designed experimental protocols need to be well-documented. Studies need to be aggregated to affirm that treatment does enhance the well-being of children rather than increase or continue suffering. We need to design better processes to deal with parental anguish in these decisions; and those who reflect on the ethi-

cal dimensions of this care need to focus not only on the underlying philosophical or religious argumentation, but also on the impact of outcomes.

### Endnotes

1. Baby Messenger was born at twenty-five weeks gestation and weighed under two pounds. He was considered at risk for severe neurological damage due to a lack of oxygen and was given a minimal chance to survive. Dr. and Mrs. Messenger decided not to pursue any aggressive treatment with their child, born by Caesarean section. Despite their stated wishes, the Messenger baby was intubated and put on a ventilator. Dr. Messenger removed his child from the ventilator without the permission of the child's neonatologist.

2. The Nguyen child was born in Spokane, Washington, with multiple anomalies. While each anomaly taken separately might be treated, such as kidney failure, the anomalies taken together present a bleak picture. Physicians at Sacred Heart Hospital in Spokane refused aggressive treatment and suggested to the parents that their baby be allowed to die. A group of physicians based in a Portland, Oregon, hospital decided that this was disrespectful to the Nguyen baby's life. As a result, they accepted the transfer of the child and are aggressively treating the baby, believing that these children, regardless of how bleak the outcome might be, should receive all treatments.

3. Also see Evans, Martyn. 1994. "Conflicts of Interest in Research on Children." *Cambridge Quarterly of Healthcare Ethics* 3 (4): 549-559

4. See for example Hack, Taylor, Klein, Eiben, Schatschneider, and Mercuri-Minich. 1994. "School Age Outcomes in Children with Birth Weights Under 750 Grams." *New England Journal of Medicine* 331(12): 753-759; and Brooks-Gunn, McCarton, Casey, McCormick, Bauer, Bernbaum, Tyson, Swanson, Bennett, Scott, Tonascia, Meinert. 1994. "Early Intervention in Low-Birth-Weight Premature Infants." *Journal of the American Medical Association* 272(16): 1257-1262.

### References

Allen, M., P. Donohue, and A. Dusman. 1993. "The Limit of Viability—Neonatal Outcome of Infants Born at 22-25 Weeks' Gestation." *New England Journal of Medicine* 329 (22):1597-1600.

Weir, Robert. 1984. *Selective Non-Treatment of Handicapped Newborns*. New York: Oxford University Press: 143-187.