
High Risk Infants: Thirty Years of Intensive Care

by Cheryl Hall Harris

For centuries, infants born prematurely or with a variety of congenital conditions had little hope for survival. The advancement of newborn intensive care during the past thirty years, clinical expertise, and technologic advances have changed outcomes and enabled such infants to live. This paper describes these developments in the clinical care of high risk infants and their mothers, along with the ethical considerations and issues that accompany them.

The past thirty years of newborn intensive care have been characterized by significant advances in technical capabilities in the diagnosis and treatment of diseases and congenital conditions of newborns. As the technology increased, attention focused on attending ethical issues. This article surveys the newborn intensive care over the past thirty years and reviews some of these ethical issues that arose over that time. Much of the applied technology developed as a consequence of scientific study, often without discussions about whether or not technology ought to be applied. Reflection on the history of newborn intensive care will hopefully lead to ongoing dialogue in the ethical aspects of future technologic excursions.

History

For more than fifty years, clinicians have been interested in hyaline membrane disease or respiratory distress syndrome, a disease common among premature infants. Avery and Oppenheimer (1960) compared autopsy findings of liveborn, premature infants with hyaline membrane disease born at the Johns Hopkins Hospital from 1944-48 and 1954-58. Shortly after the article was published, the subspecialty of neonatology began to develop as a research discipline (Usher 1961). As physician scientists' knowledge increased, they began providing primary care to their subjects. Subsequent innovations designed to treat complications of infants born at risk have resulted in our modern newborn intensive care

units staffed by highly skilled health care professionals and multidisciplinary teams that provide the complex care these infants require to live.

The birth of a president's son in 1963 brought the state of neonatal care into sharp focus. That August, Jacqueline Kennedy gave birth to a premature infant born by Caesarean section. Patrick Bouvier Kennedy weighed four pounds ten-and-a-half ounces. Shortly after birth, the infant was transferred to Boston Children's Hospital Medical Center for further treatment. The president's press secretary released a statement that attending physicians described the infant as having "idiopathic respiratory distress syndrome," but indicated that the baby was not on the danger list (Blair 1963).

Shortly after the baby's arrival at the hospital, he was placed in a high-pressure oxygen chamber, designed to force more oxygen into his lungs. This experimental treatment had been developed for infants who required surgery for heart conditions, and the primary researcher, Dr. William Bernhard, clinical professor of surgery at the Harvard Medical School, served on the team caring for the Kennedy baby. The thirty-one-foot steel

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chamber enabled a medical team to work inside with a patient. Dr. Bernhard conducted a series of some 500 animal experiments to determine the pressure chamber's safety and efficacy before using it on humans. The pressure inside the chamber was usually kept at 44 to 55 pounds per square inch. (Normal atmospheric pressure at sea level is 14.7 pounds per square inch.) Initially, the baby's condition seemed to improve after he was exposed to the unusual treatment (Blair 1963). Patrick Kennedy died on August 9, 1963.

Although other research teams had been experimenting with hyperbaric chambers used for infants with respiratory distress syndrome (Hutchison 1962; Hutchison 1963; Pattle 1962; Cochran 1965), the usual treatment did not employ this apparatus. Typically, infants were placed into incubators (also called Isolettes) for warmth; given fluids through an IV or umbilical artery catheter; and the oxygen and carbon dioxide levels in their blood streams were analyzed. Correction of acid-base imbalances was also common treatment at the time (Warley 1962). At Royal Victoria Hospital, Usher studied 150 infants over a course of four years (1961). He described classical symptoms of the syndrome, and then noted the essentials of good management of these neonates. Treatment included positive pressure ventilation following birth and administration of oxygen. Antibiotics were given only to infants with signs of infection. Keeping infants warm was also important. Usher recommended intravenous fluids when the infant was first born and gastric tube feedings "when the baby shows signs of spontaneous activity and begins to withstand handling well" (535).

Because much of the research into effective therapies for small premature infants occurred in university hospital settings, the cost of care was often supported by grants and charitable contributions. In the late 1960s the costs exceeded \$100 per day, with an average hospital stay of three to four weeks. Also at that time, most insurance companies did not cover hospitalization costs until the infants were fourteen to thirty days of age (Harris 1970). The justice implications of pro-

viding care for all infants, regardless of ability to pay, meant that infants of impoverished parents received identical care to those who could afford to pay for newborn intensive care.

In the late 1960s, respirators were used only when all other avenues of treatment had proven ineffective. By early 1970, three-pound babies were surviving, blood gas monitoring was routine, and ventilators were used in early treatment rather than as a "last ditch" attempt to keep the baby alive. Many of the advances in equipment, such as cardiopulmonary monitors, occurred as the space program developed. As machines were designed to monitor astronauts' vital signs, the technology was brought to medical centers. The primary force behind the application of technology and staffing resources for newborn intensive care was driven by caregivers' desire to provide beneficent care, and to avoid doing harm, to the best of their ability.

The care required of tiny newborns in intensive care units is exacting and challenging, both by health care professional and parents. During the 1960s, nurseries routinely excluded parents from entering the unit in order to reduce the number of people in the Newborn Intensive Care Unit (NICU) and thereby decrease the risk of infection. However, a group of Stanford researchers experimented with permitting mothers to have physical contact with their infants while a control group experienced the usual separation of three to twelve weeks (Barnett et al., 1970). The study concluded that "the presence of mothers in the nursery did not increase the risk or occurrence of infection," and resulted in encouraging such physical contact: "The nurse should encourage the parents to visit their infant as often as possible, and when the infant is almost ready for discharge, the nurse should make sure the parents have many opportunities to handle and care for their infant" (Harris 1971).

The 1970s marked the establishment of regional newborn intensive care centers which provided care for high risk infants. In an effort to improve care by placing infants with the most experienced staff and sophisticated equipment available, neo-

natal transport services were developed. Usher (1970) noted that a number of specialized nurseries had been in operation with full-time staff and equipment for five to ten years. He also described the dismay of those involved to learn at a 1969 conference that these newborn facilities did not seem to reduce neonatal mortality. Because the focus on providing intensive care to the infant had not significantly decreased the newborn death rate, Usher concluded that developing intensive care techniques prior to and surrounding birth by providing high risk mothers with care in a perinatal center might address this problem. Therefore, he suggested the establishment of *perinatal centers* where high risk mothers would be delivered, and their infants could receive intensive care to reduce mortality rates and decrease the incidence of complications with long-term implications for the infants who were treated (202). Later the field of perinatology provided intensive therapy for mothers and infants who met high-risk criteria (Nesbitt 1974). High risk women included those who had a history of spontaneous abortions, who were having problems in a current pregnancy, who were extremely young or older than forty years of age (Harris 1971).

In the 1970s, several ethical issues involving clinical decision making in the NICU received considerable attention. Duff and Campbell (1973) reported that of 299 consecutive deaths that occurred in the Yale-New Haven Hospital special care nursery, 43 were infants who had had treatment withheld. In that group, 15 had multiple anomalies and the rest had life-threatening conditions. In all 43 cases, their parents and physicians made the decision to reject further treatment after concluding that the "prognosis for a meaningful life was extremely poor or hopeless." (Duff and Campbell 1973). Other nurseries had faced similar issues, with staff and parents making similar decisions, but Duff and Campbell were the first to describe their agonizing deliberations and raise the ethical questions to facilitate further discussion.

In May 1974 a multidisciplinary group of clinicians and other professionals convened a confer-

ence to explore the most troublesome ethical issues faced in the practice of newborn intensive care (Jonsen 1975). Discussion called attention to questions of resuscitation and maintenance of small, asphyxiated pre-term infants who required prolonged assisted ventilation, and the issue of withdrawing life support from an infant diagnosed as having a poor prognosis for intact survival. Quality-of-life issues for infants and burdens imposed on families focused discussion on the "locus of decision-making authority and dealing with tensions that accompany the exercise of authority." Questions were also raised about allocation of scarce resources within the NICU to infants with better prognoses. An anthropologist asserted that by focusing so much attention on the provision of neonatal intensive care diverted staff, equipment, and monetary resources away from other types of health care for children who

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were born healthy but developed problems later (Jonsen 1975).

In 1976 Duff and Campbell revisited the issues of caring for severely handicapped or dying infants. They presented their interpretation of two primary philosophies of care, the first "disease-oriented . . . which implies that life itself is all that matters; that death represents the ultimate in human and medical failure, something to be avoided at all costs." The second philosophy, which they describe as "person-oriented . . . considers that the quality of life should be the primary concern" (487). Within that framework, they explored the conflicts among the family and the physicians. Given that parents must bear the consequences

of decisions for infants, they promoted involving parents as critical to the process.

The 1980s were dominated by events surrounding several Baby Doe cases that brought the issue of nontreatment of infants with disabilities into the forefront of medical and societal discussions. The use of aggressive treatment for infants born with congenital anomalies sparked debate over possible discrimination on the basis of handicap, with resultant congressional action. The conflicts over Baby Doe regulations led to the development of infant bioethics committees to review individual cases, as well as to a proliferation of articles and projects reviewing issues surrounding newborn intensive care.

By the late 1980s, perinatal intensive care had evolved into a specialized discipline wherein advanced technology was applied routinely throughout pregnancy and delivery. Frequently, decisions were made to resuscitate every neonate, regardless of the stage of pregnancy (gestational age) or the baby's size. Those involved in neonatal care began to question the assumption that initiation of intensive care was always warranted and the ethical and economic ramifications, given the results.

Hack and Fanaroff (1986) reviewed a study of 42 live-born infants with birth weights below 750 grams (1 pound 6 ounces) with a mean gestational age of 24 weeks who all received aggressive intensive care between 1982 and 1985. In the perinatal setting, they noted that endotracheal intubation and respiratory support had been applied to progressively smaller and less mature infants. No specific policy development led to this circumstance, but they recognized that the practice had evolved over the three-year period reviewed. Twenty percent of these 42 infants survived. The mean length of hospital stay was 137 days with a mean cost of care calculated to be \$158,000. Since nearly one-third of all of the survivors had serious chronic developmental disabilities, the authors questioned the enormous medical, financial and social costs that would be associated with these infants throughout their lives (664).

Hack and Fanaroff (1989) looked at a group of 129 infants with birth weights less than 750 grams born between July 1985 and June 1988. The mean length of hospitalization for these infants was 149 days. Their survival rate was tabulated at 18 percent, and their morbidity (neurodevelopmental

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and other physical problems) were similar to the infants studied in the earlier sample. Specific morbidity included lung disease that made the infants dependent on additional oxygen for 28 days or longer, hemorrhages into the brain, visual impairment, and severe intestinal problems (necrotizing enterocolitis). Their conclusions following the review of the data suggest "the outlook is extremely poor for infants below 24 weeks of gestation or birth weights below 600 grams" (1643). Another researcher concluded that "Whether the occasional child who is born at 23 or 24 weeks' gestation and does well justifies the considerable mortality and morbidity of the majority is a question that should be discussed by parents, health care providers, and society" (Allen, et al. 1993).

In response to these and other studies, Young (1990) applied ethical principles of distributive justice and nonmaleficence in considering the treatment of very low birth weight infants. With the mandate to do no harm, physicians face a dilemma in the application of the highly developed technology at their disposal, especially when that technology may save an infant who will then be severely impaired throughout his life. Allocating scarce resources is also problematic when the care for a critically-ill infant may cost up to half a mil-

lion dollars and result in infants whose level of functioning, should they survive, will possibly be extremely compromised.

Conclusions

Society has come to expect that neonatal care will include the latest and best of medical technology. Media reports do not balance stories of "miracle babies" with the many premature infants who do not survive, or with those who live but with a 30 percent chance of being severely developmentally delayed. Society, then, expects that all babies can be saved intact. Stahlman (1990) asks, "What if maximal efforts result in survival but at enormous financial cost to parents, to hospitals, and to society, and at an incalculable cost in pain, grief and frustration, with the survival of a severely handicapped child? Must we press on so that we can achieve the 20 percent potentially good outcome, as we share the pain of the 80 percent death or disability?" (167)

In an era of shrinking resources, our society must face the difficulty of allocating scarce resources. As Daniel Callahan and Norman Daniels have raised issues of rationing intensive care for the elderly, our society must critically review the routine application of highly sophisticated technology to extremely premature infants with low birth weight.

Although the development of ethics committees brings collective wisdom of a diverse group of individuals to review decisions, both Duff (1987) and Stahlman (1990) suggest this trend may not be the best way to engage in difficult decision making presented by dilemmas in the NICU. Those health care providers and parents who are closely involved with the newborn may be best equipped to deal with the ethical dilemmas described as "multifaceted, complex, and gut-wrenching for parents and care-givers alike" (Stahlman 1990 169). Duff (1987) asserts, "I believe firmly that 'close-up ethics' will guide us to the most humane decisions appropriate for each individual set of difficult problems."

Stahlman (1990) raises other areas for consideration, such as the questions about new tech-

nologies developed without carefully controlled clinical trials; or the ethics involved in the "depersonalization of newborn intensive care by high technology" that has decreased the sense of humanity associated with this care in the early days. "Primary care nurses have taken over many of the past responsibilities of physicians, and machines have taken over many of the responsibilities of the nurses," Stahlman asserts. This loss of personal contact with parents in some units has caused an unfavorable impact on the quality of care.

One way to address this concern is to encourage NICU nurses to increase their involvement in ethical discussions. Neonatal nurses spend hours at the infants' bedsides every day. Through their constant monitoring and care activities, nurses develop special knowledge about the infants' conditions, and have the most contact with the parents. NICU nurses implement the decisions made by physicians and parents, but have often had no input into the decision-making process. Elizondo (1991) surveyed neonatal nurses to determine their level of involvement in discussions of ethical issues. She found that 91 percent held informal conversations with physicians, and 62 percent participated in case management conferences with physicians but that none of them belonged to either a nursing ethics committee or hospital-wide ethics committee. Considering that nurses "may have insights into the situation that the medical staff may overlook," Elizondo (1991) urges neonatal nurses to become involved to improve care for the high-risk family.

Finally, as an experienced neonatologist, Stahlman considers the future of this field. She expresses concern over the latest developments with health care delivery systems that pay only for care at specified hospitals in their system, whether or not they have intensive care facilities to provide necessary critical care in those cases where it is undeniably appropriate. From an economic perspective, a hospital may view the regional high-risk care center as a competitor for the patient care dollar, appropriate referrals may not occur. This leads to ethical dilemmas for health

care personnel in the non-regional hospital who are unable to provide the care they know their patients deserve.

In conclusion, if we should learn anything from the history of the development of newborn intensive care, it is that as we continue to employ a "we can do that" mentality in embracing new technology, we need time for reflection about "ought we to do that?" Such reflections could prove beneficial in this and other health care settings that rely heavily on technology.

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