Chapter 1

Summary and Conclusions

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INTRODUCTION

Neonatal intensive care is defined by the American Academy of Pediatrics as the constant and continuous care of the critically ill newborn (2). Although modern, high-technology neonatal intensive care units (NICUs) are a relatively recent innovation, their widespread application has already played a major and definitive role in the improved survival of low birthweight and premature infants (25). Despite this success, ethical and economic concerns remain about this technology. Because of intensive care, some infants, who previously would have died, survive but with serious and permanent handicaps. The double-edged sword of technology, at ever-increasing costs, both saves and disables babies. This case study reviews the evidence on the effectiveness of neonatal intensive care and addresses a number of these related issues:

- What are the chances of serious handicap among surviving very low birthweight infants as mortality declines?
- What changes in technology and medical practices are and will affect the chances for survival and good developmental outcome?
- How are decisions made about treatment for extremely premature infants who are at the edge of viability?
- How much does neonatal intensive care cost? Who pays for treatment, and are there problems with reimbursement?
- Is there unequal access to neonatal intensive care? What are the barriers that may prevent entry for some babies?
- What are the long-term economic consequences of providing neonatal intensive care?

Scope of the Case Study

Up to half of all patients in neonatal intensive care are normal birthweight infants with congenital anomalies, pneumonia, or other problems. However, this case study limits discussion to low birthweight infants (<2500 grams) for several reasons. First, low birthweight infants, particularly

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those with birthweights below 1500 grams, are at the greatest risk for high mortality and morbidity. Moreover, outcomes are changing most rapidly for these infants, and new technologies currently under investigation hold promise for continuing improvements in the future. Second, there appears to be a shift in the patient population in neonatal intensive care, with increasing numbers of beds occupied by extremely low birthweight infants. Difficult ethical, social, and economic judgments are involved in the decision to treat these infants. Finally, because low birthweight and low socioeconomic status are associated, it is likely that public payment programs pay a substantial portion of the expense for neonatal intensive care.

Throughout this case study, the term "low birthweight infant" is used to refer to infants who weigh less than 2500 grams at birth.[1] "Very low birthweight infant" refers to infants with birthweights of less than 1500 grams, and "extremely low birthweight infant" describes infants who are born weighing less than 1000 grams. Gestational age is likely more important than birthweight in determining outcome, but the two are highly correlated. Birthweight is easier and more reliable to

[1]For ease of reference, 2500 grams is approximately 5 lb 5 oz; 1500 grams is about 3 lb 3 oz; and 1000 grams is about 2 lb 2 oz.

measure, and most of the medical literature and available data focus on birthweight alone. That bias is reflected in this review.

Under the regionalization concept first introduced in the mid-1970s, the most sophisticated neonatal intensive care is provided in so-called Level 111 hospitals. Level II hospitals also provide intensive care services but lack some of the components and expertise of Level III units, while Level I hospitals provide only normal newborn care. The extent to which high-risk mothers and infants are referred to and treated at the appropriate level of care is addressed in this study.

Organization of the Case Study

Findings and conclusions about the costs and effectiveness of neonatal intensive care are summarized in the remainder of chapter 1. Chapter 2 inventories the national supply of neonatal intensive care units and describes recent trends in use and costs. Chapter 3 reviews mortality and handicap rate: over time and discusses the outlook for the three clinical problems that account for a majority of the deaths and poor outcomes among very low birthweight infants (respiratory distress syndrome, intraventricular hemorrhage, and retinopathy of prematurity). Problems in financing neonatal intensive care, with special emphasis on Medicaid policies and expenditures, are reviewed in chapter 4. Then, findings of unequal mortality risks in different types of hospitals are reviewed, and possible inequities in access to neonatal intensive care are considered (ch. 5). Competitive and financial constraints on hospitals and physicians, as well as ethical considerations, are explored. Finally, chapter **6** analyzes the lifetime economic implications of neonatal intensive care for very low birthweight infants and for society.

SUMMARY

Supply, Use, and Costs

Between 150,000 **and 200,000 infants (4 to 6 percent of all newborns) are treated annually in** NICUs, **and at least one-half of them are low birthweight infants.** Confusion over which hospitals deliver the most intensive v. less specialized care complicates estimates of the supply of neonatal intensive care. Of a total of **534** combined Level II and Level 111 neonatal intensive care units in the country, about 420 of them offer very sophisticated Level III services. While many individual neonatal intensive care units are filled to overcapacity, there does not appear to be a shortage of NICUs or intensive care beds nationwide. In 1983, the occupancy rate for NICUs was 73 percent, comparable to the national occupancy rate for all hospital beds.

Neonatal intensive care for very low birthweight infants ranks among the most costly of all hospital admissions. Although the average hospital cost for low birthweight infants ranges from only **$12,000** to **$39,000,** the distribution of costs among patients in the neonatal nursery is highly skewed. A few infants incur truly extraordinary costs. About half of the variation in costs is explained by four risk factors: birthweight, survival to hospital discharge, use of assisted ventilation, and surgical intervention. **A primary predictor of cost is birthweight; costs increase as birthweight falls.** The average cost for a very low birthweight survivor is from **$31,000** to $71,000. The tiniest infants who survive, those with birthweights under **750** grams, have the longest average hospital stays, about **98** days, and the highest costs, averaging **$62,000** to **$150,000.** Hospitals report increasing numbers of these tiniest babies in their NICUs. (About 8,500 infants weighing less than 750 grams are born each year in the United States.)

Mortality and Morbidity

Neonatal intensive care, along with improved obstetrical practices, is in large part responsible for the remarkable decline in birthweight-specific neonatal mortality rates over the past 25 years. Neonatal mortality for infants with birthweights of 1000 to 1500 grams has fallen from more than 50 percent to only 10 percent. And whereas more than 90 percent of all infants weighing under 1000

grams died in *1960,* the neonatal mortality rate for this group now is about 50 percent. This achievement reflects improvements primarily in the 750- to 1000-gram birthweight group (more than two-thirds survive today), because mortality in the smallest and most premature infants, those under 750 grams, is still very high.

Even **among the most sophisticated neonatal intensive care centers, the risk of mortality for very low birthweight infants varies substantially.** In the mid-1980s for example, the mortality rates reported for the most vulnerable group, infants with birthweights under 750 grams, varied from 28 percent in one university-affiliated center, to **53** percent in another, and 74 percent in a third center. The success of some centers indicates that the technology of neonatal intensive care is changing very rapidly.

The rate of serious long-term disability increases with decreasing birthweight, but within each birthweight group, the proportion of NICU survivors who have serious handicaps has not changed significantly since the introduction of neonatal intensive care. Because many very sick newborns who previously would have died are now surviving, an increasing rate of handicap might have been expected. OTA **concludes that neonatal intensive care has contributed to improved long-term developmental outcomes for premature infants. The great decline in mortality among all subgroups of very low birthweight infants over the last 10 years, however, means there are now larger absolute numbers of both seriously handicapped and normal survivors.** For every 100 very low birthweight infants treated in today's NICUs, about **27** will die before hospital discharge, 16 will be seriously or moderately disabled, and 57 will be normal children, though some will develop mild learning disabilities.

The majority of deaths in the extremely low birthweight group are attributable to respiratory distress syndrome (RDS) or intraventricular hemorrhage. The incidence of both these clinical problems, -as well as the incidence of retinal disease, increases with progressively lower birthweights. About half of all very low birthweight infants have RDS, and one-third have brain hemorrhages. Infants with severe hemorrhage have both high mortality and, for those who survive, a high rate of later neurodevelopmental disability. Retinal disease, which is almost entirely restricted to very low birthweight infants, causes blindness in about 1 percent of infants with birthweights between 1000 and 1500 grams and in about 5 to 11 percent of infants with birthweights below 1000 grams.

RDS is the most common problem in the neonatal nursery, and assisted mechanical ventilation is usually essential to help babies in respiratory distress breathe. But the use of assisted ventilation is correlated with both intraventricular hemorrhage and the development of chronic lung disease. One-third of very low birthweight survivors have chronic lung disease at 1 month of age. A recent study showed that the way in which ventilator support is medically managed may be associated with outcome; some neonatal intensive care centers have significantly lower rates of chronic lung disease than others. **Changing and refining existing medical practices in NICUs could further decrease the mortality and poor outcomes associated with RDS and assisted ventilation.**

Moreover, it is possible that **several technologies could substantially prevent RDS in the future.** Steroid treatment, administered to women in preterm labor in order to accelerate fetal lung maturation, has been available for 16 years. Despite numerous studies confirming its efficacy, however, many obstetricians have concerns about specific indications for use, and steroid treatment has not been widely integrated into obstetrical practices. The other technology, administering exogenous pulmonary surfactant into the lungs of the newborn, is new, and the medical community is hopeful about its potential for treating lung deficiency. Controlled clinical trials conducted to date have demonstrated lowered risk of death and respiratory disease. It will be several more years before surfactant therapy is generally available for premature infants.

Financing

A study in children's hospitals (some of the most sophisticated Level III centers) found **that neonatal intensive care is the most costly category of service to provide, and that these hospitals suf-**

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fer their greatest financial losses from neonatal cases. In those hospitals studied, neonates represented only 8 percent of admissions but 21 percent of all patient days and 25 percent of the hospitals' costs.

As third-party payers, including Medicaid, increasingly move to prospective payment methods, concerns have been raised that diagnosis-related groups (DRGs) as currently constituted under Medicare do not adequately reimburse hospitals' costs in providing neonatal intensive care. As many as half of the admissions to NICUs are classified as outliers (cases with statistically unusual lengths of stay) under the current Medicare system. **Reform of the DRG system to reflect more accurately the true resource use of very low birthweight infants will help hospitals' finances, but hospitals may continue to experience revenue shortfalls for neonatal intensive care because of their inability in the future to shift costs as the proportion of charge-paying patients declines.**

Medicaid is generally considered a poor payer by hospitals. The method of reimbursement and the level of payment for neonatal intensive care varies by State. Likewise, the proportion of Medicaid admissions, and therefore Medicaid's importance as a payer, varies widely across institutions; overall, Medicaid recipients account for about a quarter of all NICU admissions. From the perspective of the Medicaid program, about 6 percent of all newborns whose deliveries are subsidized by Medicaid require neonatal intensive care, but this care is so expensive that it represents about *30* percent of all Medicaid expenditures for maternity care. Through recent legislative changes, any newborn whose mother met income requirements for Medicaid prior to delivery is assured of at least 60 days automatic Medicaid coverage. Financial coverage for other infants in the NICU who are not eligible for Medicaid is sometimes available through a variety of State and county payment programs for the indigent.

Access

The statistics on survival and outcome that are cited in this case study refer to infants who are treated in the regional perinatal centers (Level III hospitals). A number of studies document better survival rates for very low birthweight infants born in Level III hospitals than for those born elsewhere in the same geographic area. Moreover, several studies go further and indicate that **survival rates for very low birthweight infants born in Level III hospitals are significantly higher than for those infants born in either Level I or Level II hospitals, despite transfer of sick infants after birth.** Because deaths within a short time of birth cannot be influenced by infant transport, it may be that very low birthweight infants are not adequately resuscitated and stabilized at birth in Level I hospitals. Poorer survival rates in Level II hospitals were reported in only a few studies. The Level II hospitals with poorer survival rates rarely referred their very low birthweight patients to regional centers, and the researchers concluded that the intermediate units could not expertly manage the complications of low birthweight, such as respiratory failure.

Because little is known about whether high-risk mothers and infants are actually redistributed to the appropriate level of care, the observed gradient in mortality risk across hospital level could indicate possible inequities in the provision of neonatal intensive care. Although the contribution of infant transport cannot be assessed, one indication of access to intensive care is the extent to which high-risk deliveries are concentrated in Level III centers. All published reports indicate that although **high-risk deliveries have increasingly been moved to Level III centers over time, there is still wide variation among geographic areas.** Rural populations, as expected, clearly have less access to perinatal centers than urban populations, and one study showed better access to specialized care for black infants than for white infants.

Although the extent of a possible access problem cannot be determined from existing data sources, **hospitals may have financial incentives not to serve high-risk mothers and infants.** Hospitals have no legal obligation to admit these patients even if they are perinatal centers, and some hospitals suffer their greatest financial losses from neonatal cases. Medicaid coverage for very low birthweight infants does not guarantee admission, because Medicaid is generally considered a poor payer by hospitals. The same financial incentives operate for physicians with regard to nonpaying

or partial-pay patients. Obstetricians lag behind other specialties in the extent to which they accept Medicaid patients.

A more important barrier to treatment, however, is the unwillingness of many obstetricians to refer high-risk maternity cases to perinatal centers prior to delivery. **The perceptions of obstetricians, many of whom substantially underestimate the potential survival of extremely low birthweight infants, influence the management of high-risk pregnancies and premature labors, which, in turn, actually affects the survival of newborns. On the other hand, once a low birthweight infant, no matter how tiny and premature, is admitted to an NICU, aggressive treatment is almost always assured.** Neonatologists, in part in reaction to legal liability concerns raised by "Baby Doe" rules, are increasingly treating even the tiniest infants born at the threshold of viability. The probability of handicap cannot be determined at birth, and the normal outcome for a few of these infants encourages neonatologists to push for the unprecedented treatment of the lowest birthweight infants.

Cost-Effectiveness

The incremental cost of neonatal intensive care to produce a survivor in 1984 was $86,000 for infants with birthweights between 1000 and 1500 grams and $118,000 for infants with birthweights below 1000 grams. The long-term economic consequences of providing neonatal intensive care to very low birthweight infants were evaluated in a cost-effectiveness study performed by Canadian researchers. Projected over a lifetime, the introduction of neonatal intensive care costs **$4,460** per quality-adjusted life-year gained for infants with birthweights between 1000 and 1500 grams and $31,240 per quality-adjusted life-year gained for infants with birthweights under 1000 grams. **Thus, neonatal intensive care results in both increased survival and increased costs. Moreover, neonatal intensive care becomes more expensive as it is employed in increasingly marginal cases.** The worth of a life saved, however, is ultimately a value judgment involving ethical and social considerations. The results from cost-effectiveness studies alone cannot guide decisions regarding who should receive care.

CONCLUSIONS

This OTA case study corroborates earlier reports concluding that neonatal intensive care is an effective technology for the improved survival and long-term developmental outcome of very low birthweight infants. **In the 1980s, continued improvements in outcomes are shown in every very low birthweight subgroup, with the greatest statistical improvement, recently, in the 750- to 1000-gram birthweight group.**

The success of neonatal intensive care does carry a burden of increasing numbers of seriously handicapped children, As mortality **rates decline, there are larger absolute numbers of both handicapped and normal survivors.** If today's neonatal intensive care were provided for all very low birthweight infants, over 15,000 normal children who would have died in 1975 would be added to the Nation's population. Likewise, families and society would face an increase of about 2,200 seriously handicapped infants who would not have survived a decade ago, These individuals require outside resources and help throughout their lifetimes.

Neonatal intensive care is costly. While the average hospital cost for low birthweight infants is about **$620 per** day in the hospital, a few infants incur truly extraordinary costs. The cost to society increases as neonatal intensive care is provided to the very lowest birthweight infants, but it would be unethical and illegal categorically to deny treatment. So **far, technology cannot determine at birth which infants are doomed to severely handicapped lives.** Physicians, in *conjunc*tion with parents, have traditionally grappled with decisions about treatment for premature and sick newborns—and they must continue to do this.

The disturbing fact is that **an extremely premature baby's chances for survival and normal development are in large part determined by where the baby is born.** While moderately sized low birthweight infants do well in Level II units, there is a gradient in mortality risk across hospital level for very low birthweight infants. Although the birth of a premature infant cannot always be anticipated, there is ample evidence that a pregnant woman at high risk should be transferred to a Level III center prior to delivery. Very low birthweight infants should be transported to Level III hospitals as soon as they are stabilized.

The extent of a possible problem in access to neonatal intensive care is unknown. Regional organization may have proceeded further in neonatal care services than in any other aspect of medicine in this country. This regionalization has been accomplished, in almost all States, through the voluntary cooperation of hospitals, physicians, and maternal and child health officials. Moreover, the optimum concentration of high-risk births in Level III centers is unknown because of unavoidable hurdles to admission (e.g., access to services in rural areas will always lag behind availability in urban areas).

It does appear, however, that some **high-risk mothers and infants are not transferred to Level III hospitals for financial reasons. It also appears that some Level II hospitals are not appropriately transferring high-risk women and newborns because of a desire to offer competitively a full array of services even when those services do not meet the needs of the patients. And** most importantly, surveys show that **many obstetricians and pediatricians do not have a good understanding of the prognosis for extremely low birthweight infants;** they substantially underestimate the potential for survival and normal outcome. Their management of high-risk pregnancies and births reflects these misunderstandings.

These problems point to a **need to continue to push for further regionalization of perinatal services in the 1980s. Stronger guidance from professional associations and State health authorities may be necessary** in two areas. One is the formulation of clear recommendations on treatment and transfer policies for infants with particular problems and/or birthweights by level of *care.* Second is the exercise of leadership in informing obstetricians and pediatricians about current practices and outcomes in neonatal intensive care.

Even among Level III hospitals, there are substantial differences in mortality risk for very low birthweight infants. At present, there is only suggestive evidence that variations in medical practices within institutions may lead to these differences. Differences in the organization of NICUs, the methods of applying existing technologies, and the use or disuse of certain technologies may all play a part in the success of some centers. Clearly, the technology of neonatal intensive care is changing very rapidly. **The rate of diffusion of the latest and most effective techniques and knowledge—even among the 420 most sophisticated NICUs offering Level III services—may not be proceeding apace with developments.**

The problem of disseminating information to medical professionals and institutions is not unique to neonatal intensive care. The need to share information among professionals is ongoing in all arenas of medicine. Moreover, skepticism about new ideas and techniques is healthy in that the diffusion of technologies which are not efficacious is at least slowed. Further research in NICUs is definitely necessary to evaluate which medical practices are effectively helping very low birthweight infants. Nevertheless, the speed of technology diffusion in neonatal intensive care is critical because the lives and well-being of our smallest babies may hang in the balance.