
Chapter 5

Access to Neonatal Intensive Care

Access to Neonatal Intensive Care

INTRODUCTION

The concept behind regional perinatal care is a coordinated, cooperative system of physicians and hospitals in which maternity patients and their newborns at high risk are identified early and the optimal techniques of obstetrics and pediatrics are appropriately applied (34). Numerous studies document the higher survival rates for very low birthweight infants born in Level III hospitals versus those born elsewhere within the same geographic area. Table 14 summarizes these reports and lists, for comparative purposes, neonatal mortality rates for several geographic regions and for the United States as a whole. In those population-based studies that identify place of birth by

hospital type, the survival rates for very low birthweight infants born in perinatal centers are significantly better than for those born in either Level I or Level II hospitals. ¹ In New York City, for example, Paneth and his colleagues concluded that in 1978 preterm and low birthweight infants born

¹The single exception was a 1978 study in Iowa which found higher survival rates in small Level I hospitals than in Level III hospitals for very low birthweight infants. Since this was after the regionalized system was in place, a likely explanation is that physicians working in the smallest hospitals referred the highest risk obstetric cases to the perinatal center (66). Moreover, a followup study showed the survival advantage in small Level I hospitals disappeared after 1978. Babies born in the Level III center were most likely to survive (67).

Table 14.— Regional Neonatal Mortality Rates^a for Very Low Birthweight Infants, 1976-81

Reference ^b	Year of birth	Population	Birthweight (grams)		
			< 1000 ^c	1001-1500 ^c	< 1500
Saigal (139) ^d	1976-78	Hamilton-Wentworth County, Ontario	617	122	343
Paneth (119)	1976-78	New York City	—	—	529 ⁱ
		Level III	—	—	487 ^e
Vogt (175)	1977	Southern California	628 ^f	241	371 ⁱ
Hein (66)	1978	Iowa	—	—	470
		Level III	—	—	440
Goldenberg (54)	1976-80	Alabama	663	212	—
		Level III	497	118	—
Cordero (35)	1977-79	Franklin County, Ohio	—	—	580 ^g
		Level III	—	—	470 ⁱ
Gortmaker (59)	1978-79	3 States Louisiana,	521 ^h	185	—
		Tennessee, Washington	484 ^h	139	—
		Level III	—	—	—
Shapiro (151)	1978-79	8 geographic areas	—	—	439
Saigal (140) ^d	1977-80	McMasters Health Region	541	—	—
		Level III	462	—	—
Kitchen (81) ^d	1979-80	Victoria, Australia	744	—	—
		Level III	710	—	—
Newns (14)	1979-81	West Midlands, England	713	276	417
		Level III	522	175	267
Buehler (26)	1980-81	Georgia	642	161	—
U.S. Department of Health and Human Services (172) ^h	1980	U.S.A.	648	187	431

^aDeaths per 1,000 live births

^bSee references in the back of this case study for full citations

^cSome studies reported birthweight categories as 500-999 and 1000-1499g

^dDeaths reported to hospital discharge

^eIncludes 501- to 1250-g infants

^fBirthweight Categories 701 to 1000 and 701 to 1500 g

^gIncludes 750- to 1000-g infants

^hRates for singleton births

SOURCE Off Ice of Technology Assessment, 1987



Photo credit: Yale University and March of Dimes Birth Defects Foundation

Identifying high-risk pregnancies and appropriately referring mothers to perinatal centers is key to regionalization.

outside Level III centers had a 24 percent higher risk of dying (120). During the same time period, Gortmaker and associates studied birth and death certificates in four States and found that black infants with birthweights between 1000 and 1500 grams were more than twice as likely to die during the neonatal period if they were born in a rural hospital instead of in a perinatal center (59).²

One component of regionalization is the efficient transfer of sick newborns from their hospital of birth to facilities capable of providing sophisticated critical care. But even a well-functioning infant transfer system cannot erase the mortality differences across hospital levels. In the New York City study, deaths were assigned to hospital of birth to assess the effect of interhospital transport on neonatal mortality. Despite the transfer of 48 percent of the low birthweight infants from the Level I hospitals to Level III units, the neonatal death rates were significantly higher in Level I hospitals (119). Thirty percent of all neonatal deaths in the study population occurred in the first 4 hours of life. These early deaths cannot be influenced by infant transport and point to difficulties in the resuscitation and immediate neonatal

management of low birthweight infants in the more poorly equipped and staffed hospitals.

The advantages and disadvantages of neonatal versus antenatal (maternal) transfer continue to be argued in the medical literature. Some studies find no significant differences in mortality (17,103) and others report advantages for those infants referred prior to delivery (64,89), but all the institutional studies report only on the infants who reach the intensive care unit. The newborns selected for transfer introduce bias into these studies. On the one hand, the sickest and most premature neonates may die at referring hospitals before transport can be arranged, and transfers could therefore be more viable than their cohort. On the other hand, preterm infants without morbidity are probably cared for at their hospital of birth rather than being transferred. Moreover, transported infants may suffer inadequate temperature maintenance or delays in the initiation of mechanical ventilation before their admittance to the neonatal intensive care unit (NICU), leading to a relatively sicker group of transferred babies (81).

Several population-based studies support maternal over neonatal transport. In Hamilton-Wentworth County in Ontario, researchers estimate that the pre-delivery transfer of selected pregnant women to the regional center accounted for 28 percent of the improvement in survival among the very low birthweight babies born after the introduction of neonatal intensive care (157). In the British Mersey Region in 1980, neonatal survival was significantly better for those very low birthweight infants who were transferred prior to birth than for infants who were not transferred or were transferred after delivery (93). Moreover, the difference between the survival rate for those infants transferred before delivery and those infants born to mothers who had booked at the perinatal center was not significant. And in the State of Victoria, Australia in 1979 and 1980, both survival and outcome were better for tertiary center births than for those born elsewhere (81). The Australian study, which examined only infants with birthweights under 1000 grams, found a significantly higher prevalence of severe functional handicaps in the outborn children than in either the inborn or the antenatal transfer

²This was the most disadvantageous differential in survival reported in the study, and it should be noted that overall survival among black infants was greater than among white infants at the same level of hospital care (59).

groups. Several other institutional studies also report an increased incidence of intraventricular hemorrhage or respiratory distress syndrome in infants transported neonatally as compared with inborn infants, implying these infants were not

adequately stabilized at birth (**31,89,103**). Although the birth of a premature infant cannot always be anticipated, there is ample evidence that, ideally, pregnant women at high risk should be transferred to a perinatal center prior to delivery.

LEVEL II HOSPITALS

Besides questioning the efficacy of relying on neonatal transport from Level I hospitals, the population-based study in New York City also raises doubts about the effectiveness of neonatal intensive care in Level II facilities. The study showed that while there was a survival advantage for low birthweight babies in a Level II hospital over a Level I hospital during the first 4 hours of life, that advantage disappeared by 28 days. Improvements in neonatal mortality rates from 1976 to 1978 were statistically significant only for infants born in Level III units. The researchers concluded that intrapartum management and postnatal stabilization were performed well in Level II hospitals, but that the management of later complications of low birthweight such as respiratory failure was less expertly handled (119).

Paneth and his colleagues blamed the virtual absence of infant transfers from Level II units to Level III facilities for the discouraging mortality rates (**120**). Support for these views comes from the State Division of Health Services in North Carolina. Their study of perinatal mortality rates from 1969 to 1979 for very low birthweight infants in North Carolina found that by 1979 the Level II centers had higher mortality rates than either of the other two hospital levels (117). This study also concluded that Level II hospitals seldom referred infants or maternity patients. The author urged greater participation in a coordinated referral system.

One reason Level II hospitals might not refer high-risk mothers and infants to nearby Level III hospitals is competition. A major way that hospitals compete for patients is through the scope and quality of services. Childbirth is often a family's first contact with hospitalization. Transfer of mother or child to a nearby Level III hospital could jeopardize the family's continuing relation-

ship with the Level II institution. Particularly in urban settings, where competition among hospitals is keenest, Level II facilities may be reluctant to refer to Level III units (128).

Since the New York City and North Carolina studies, there has been a nationwide movement to upgrade the capabilities of Level II units (144). Conversely, some Level II hospitals have terminated their specialized neonatal intensive care services. In New York City, for example, the number of facilities offering Level II nursery services declined from the study period high of 20 to only 14 in 1982 (65,120). Moreover, the extent to which there is a problem may well be related to the region of the country. For example, a Level II nursery in Georgia, which published its experience for 1976 to 1978, referred 62 percent of its newborns with birthweights under 1500 grams to a Level III facility (76). The Level II facility unit considered that its capabilities included the care of moderately ill newborns weighing 1500 grams or more and convalescing neonates who had been returned from the Level III facility.

The guidelines published by the Committee on Perinatal Health in 1977 and reiterated jointly by the major professional associations in 1983 specifically list gestation of less than 34 weeks or birthweight of less than 2000 grams as indications for transfer from Level II units to Level III units (4,34). But the American Academy of Pediatrics acknowledged the wide range of functional capabilities existing within the definition of a Level II unit in a 1980 statement by its Committee on Fetus and Newborn (3). Some units provide care only slightly more complex than Level I nurseries, while others have capabilities approaching Level III centers. The referring practices of these centers may vary just as widely. And while the Committee on Fetus and Newborn clearly states

that it is undesirable for Level II units to provide neonatal cardiology and surgery services, no mention is made of referring practices for low birth-weight infants beyond the requirement for ongoing

liaison and consultation with a Level III center. Each Level II unit is urged to assess its own capabilities for delivering care in terms of personnel and facilities.

CONCENTRATION OF BIRTHS IN LEVEL III HOSPITALS

Although regionalization is often given credit for many of the improvements in perinatal outcome over the last decade, little is known about the extent to which high risk mothers and infants are actually redistributed to the appropriate levels of care. Several groups have reported comparisons of areas that did or did not have a regionalized program. In 1975, the Robert Wood Johnson Foundation funded eight sites to promote coordi-

nated systems of perinatal care for entire geographically defined regions, comprising about 6 percent of the births in the United States. An evaluation compared mortality rates both before and after regionalization and in program and comparison regions. Neonatal mortality rates declined in both types of regions, but no greater reduction was noted for the program-funded regional network. The investigators concluded that regionalization had become widespread and extended into the comparison areas without the encouragement of specific funding (100). Likewise, Siegel and colleagues looked at two comparable areas in North Carolina (one funded to develop a perinatal system) and reached much the same conclusions as the Robert Wood Johnson Foundation researchers (155). However, a third program launched in 1979 specifically to improve perinatal health care (including high-risk maternal referrals to Level III centers) in 10 rural areas with histories of high infant mortality did show sharp declines in neonatal mortality rates while rates in control areas did not change (58).

The Robert Wood Johnson Foundation evaluation also studied the extent to which high-risk births occurred in tertiary care centers. By 1979, almost 60 percent of all very low weight births in the demonstration areas were delivered in perinatal centers, compared with only 36 percent at the beginning of the decade. Similar changes occurred in the comparison areas, although the percentage of very low weight births in the Level III units was lower than in the demonstration areas (100). Those results, along with the results of other studies examining the concentration of very low weight births in Level III units, are shown in table 15. All the studies demonstrated a shift in the site of delivery over time, with high-risk deliveries increasingly moved to the perinatal centers. Such changes indicate that with regionalization some antenatal assessment of risk is



*Photo credit: Kay Chernush, photographer,
Children's Hospital National Medical Center, Washington, DC*

Time is crucial in the transport of very sick newborns.

occurring and that the management of high-risk pregnancies is being transferred to the Level III units before delivery.

But table 15 shows there is wide variation among areas in the extent to which infants of very low birthweight are born in Level III hospitals. The largest area, the Robert Wood Johnson Foundation regions representing 6 percent of all births nationally, shows the highest concentration of very low weight births in tertiary centers. Iowa, a rural State, shows one of the lowest concentrations. However because of low population density and distance considerations, a single Level III center serves the entire State, and Iowa is considered to be successfully regionalized (66).

The degree to which access to Level III services varies within regions among different subgroups in the population is difficult to determine. Gortmaker and colleagues examined racial and urban/rural differences in four States. (See table 15.) The lowest concentration of very low weight

births in Level III centers occurred among whites in Louisiana and Ohio; 23 percent of white very low birthweight infants were born in regional centers in these States. Black infants, in general, had better access to specialized services. In Tennessee more than 50 percent of the black very low birthweight infants were born in perinatal centers. Residents of rural areas were always less likely than their urban counterparts to be born in Level III units, but again, black rural infants were more likely than white rural infants to be born in specialized centers (59).

These data on the concentration of very low weight births in Level III centers do not fully describe the extent to which sick newborns actually receive services in Level III units. The contribution of infant transport systems to increased access cannot be assessed. However, the wide variation among geographic areas in the concentration of high-risk births points to inequities in the availability of neonatal intensive care.

Table 15.—Concentration of Births of Infants Weighing Less Than 1500 Grams in Level III Hospitals

Reference ^a	Year of birth	Population	Births in Level III hospitals	
			< 1500 grams (percent)	All births (percent)
Hein (66)	1978	Iowa	23	7
Nugent (17)	1979	North Carolina	47	
McCormick (100)	1978-79	8 Robert Wood Johnson Foundation geographic areas	59	43
		Comparison Areas	47	31
Gortmaker (59)	1978-79	LA: white, urban	27	
		black, urban	59	
		white, rural	14	
		black, rural	31	
		Ohio: white, urban	26	
		black, urban	35	
		white, rural	13	
		black, rural	11	
		TN: white, urban	40	
		black, urban	67	
		white, rural	38	
		black, rural	45	
		WA: white, urban	42	
		white, rural	44	
Goldenberg (53)	1980	Alabama	56	32
Lobb (93)	1980	Mersey, Great Britain	28	
Information Service Center (72)	1984	Maryland	54	31

^aSee references in the back of this case study for full citations

BARRIERS TO MATERNAL AND NEONATAL TRANSPORT

Level III hospitals may refuse admission for a neonatal transfer for a number of reasons. The lack of available beds is the reason proffered in most instances. Although the average occupancy nationwide in Level III units is only 73 percent, occupancy in some intensive care nurseries does consistently approach 100 percent. (See ch. 2.) It is also likely that a few hospitals use the excuse of full occupancy to turn away infants whose care would not be adequately reimbursed. As discussed in chapter 2, neonatal intensive care is one of the most costly services provided by hospitals and entails some of the longest lengths of stay. Uninsured infants may be deemed undesirable admissions by some hospitals. Moreover, because Medicaid is often considered a poor payer which does not fully reimburse a hospital's costs, even Medicaid coverage may not ensure entry. (See ch. 4.)

There is no legal requirement that forces hospitals to admit every child, regardless of ability to pay. Depending on when a neonatal intensive care service was started, the need for such services may have been analyzed by health planners under State certificate-of-need legislation. However, once a certificate-of-need is granted, the State has no ongoing authority over how services are operated. The Joint Commission on Accreditation of Hospitals, which reviews the operations of hospitals and lists staffing, equipment and procedural guidelines for neonatal intensive care units, does not address issues of access to treatment (75). Some hospitals are legally required to provide a certain amount of charity care to indigent individuals if they received Federal funds for hospital construction and renovation under the Hill-Burton Act of 1946. Currently, about 4,200 hospitals in the United States are still fulfilling their Hill-Burton obligations (182).

Likewise, hospitals are not required to preadmit high-risk pregnant women for their deliveries, even if the hospital serves as the designated perinatal center for the region. In fact, most hospitals have policies requiring advance payment in full for deliveries if the maternity patients do not have insurance. However, in March 1986 the Consolidated Omnibus Budget Reconciliation Act was passed, and it prohibits any Medicare-par-

ticipating hospital from refusing to treat or from transferring any woman already in labor (50).

The same financial incentives operate for physicians. Obstetricians and pediatricians may be leery of accepting non-paying or partial-pay patients. Survey data show that obstetricians lag behind other specialties in the extent to which they accept Medicaid patients. The average Medicaid reimbursement rate for obstetrical care is at least one-third lower than the average private fee, and the gap between the two amounts is widening over time (170).

On the other hand, obstetricians with paying maternity patients may not want to refer high-risk cases to the perinatal center and risk losing their fees. Many of the Level III hospitals are university-affiliated with closed medical staffs; non-faculty physicians are not allowed admitting privileges.

The escalation in recent years of malpractice actions, especially against obstetricians, has probably had a side effect of improving access to perinatal services for high-risk women. Concerns about possible malpractice litigation would encourage community obstetricians to refer high-risk maternity cases to regional centers. Obstetricians might particularly employ such "defensive medicine" tactics for low-income high-risk women because the physicians have poor financial incentives to keep their patients.

Finally, the perceptions of physicians about neonatal mortality and outcome affect access to neonatal intensive care. Several studies show that physicians substantially underestimate the potential survival of low birthweight infants (56,185). The obstetrician's understanding of prognosis in turn influences his or her management of premature labors, such as the decisions to utilize electronic fetal monitoring, to perform cesarean sections for fetal distress, or to transfer mother and baby prior to delivery to a Level III facility (56). These early management decisions may determine whether the newborn infant actually survives.

A survey of obstetrical residency programs in 1981 found that at less than 28 weeks gestational

age there is still considerable variation among hospitals in how labor and delivery are managed. Based on the survey, about one-half of university training programs consistently performed cesarean sections for fetal distress at 27 weeks gestational age and one-third of the nonuniversity residency programs routinely performed cesarean

deliveries under these conditions. (The average birthweight for a 27-week infant is between **950** and 1000 grams.) This study points to a lack of consensus among obstetricians on how aggressively labor and delivery should be managed between **25** and 28 weeks gestational age (55).

THE TINIEST BABIES

Once a low birthweight infant is in a Level III hospital, through birth or transfer, access to neonatal intensive care is almost assured. In practice, the almost universally followed approach in the NICU today is to initiate aggressive treatment for all infants at birth (160,165). Broad latitude has traditionally been given to doctors and parents involved in making the difficult decisions about treatment for premature or sick neonates. But in part in reaction to the so-called "Baby Doe" rules, pediatricians, anxious about their legal liability, are increasingly treating virtually all newborns, including extremely premature infants with very low birthweights. Although the rules **came** about in response to several "Baby Doe" cases involving selective nontreatment for infants with Down's syndrome, spina bifida cystica, and other congenital anomalies, the primary controversy in the medical community revolves around the tiniest infants who are born at the threshold of viability.⁵

The Department of Health and Human Services (DHHS) issued a "Notice to Health Care Providers" in May 1982 informing hospital administrators that, under Section 504 of the Rehabilitation Act of 1973, they risked losing Federal funds if treatment or nourishment was withheld from handicapped infants. The so-called "Baby Doe" rules were promulgated **in interim regulations** by DHHS the following March and in final regulations in January 1984. Facilities were required to post notices in nurseries and provide access to medical records for Federal investigators. Although the Supreme Court ruled in 1986 that the 1973 Rehabilitation Act could not be used to

justify the regulations because there was no evidence that hospitals denied care to babies solely because of handicap, Congress had in the meantime passed legislation dealing with medical neglect in the 1984 amendments to the Child Abuse Prevention and Treatment Act (Public Law 98-457) (181). These amendments define medical neglect in the treatment of disabled infants as child abuse and give the oversight responsibility for implementing the law to the States' child-abuse agencies (**164**). Both the American Academy of Pediatrics, which vehemently opposed the initial Baby Doe regulations, and Right to Life groups, which supported them, participated in reaching compromise language. Regulations implementing this legislation went into effect in June 1985.

The new regulations permit "reasonable medical judgment" to be used in making decisions about the care of disabled newborns and explicitly lists three exceptions when withholding medical treatment (other than appropriate nutrition, hydration, or medication) is not "medical neglect" (106,164). The exceptions deal with situations where treatment would merely prolong dying or would be "virtually futile" in terms of the survival of the infant and, under these circumstances, the treatment itself would be inhumane.

The regulations also encourage hospitals to set up Infant Care Review Committees. A **1985** survey by the American Academy of Pediatrics of hospitals with NICUs found that nearly 66 percent had an ethics body, up from 56 percent the previous year. However, the survey also found that slightly more than half of the committees had considered no cases during the previous year (1). Apparently, Baby Doe cases are relatively rare with most conflicts resolved by parents and health professionals (181),

⁵Most experts believe that there is an anatomical threshold of fetal development (especially for lung and kidney development) at about 23 to 24 weeks before which time fetal survival is not possible even with modern techniques (148).

Although the Baby Doe rules have raised public debate on the issue, their legal impact on treatment decisions for extremely premature infants is unclear (90). Aside from the limited clout of the new regulations (withholding Federal dollars from the State child protection service agency), the language is ambiguous and open to interpretation. In the case of extremely low birthweight infants, “reasonable medical judgment” is divided on whether it is “virtually futile” to offer treatment. The guidelines accompanying the regulations admit that “virtually futile” does not mean absolute certainty and that the prospect of death need not be imminent (106). If most physicians understand the law this way, a minimal effect on treatment decisions might be expected. On the other hand, in today’s malpractice-wary climate, physicians may react by treating aggressively all but the most clearly hopeless cases so as to avoid any possibility of liability for medical neglect (105).

In practice, physicians often employ guidelines for treatment based on their own observations of prognosis. Under such informal policies, infants who are born weighing less than 500 grams are not resuscitated in most hospitals. In some institutions, this boundary on treatment might extend

to babies under 600 grams or even under 750 grams. Of course gestational age and the condition of the infant are also taken into consideration. Without the application of sophisticated life-extending technologies, like respirators, these infants are almost certain to die. Although, as discussed, the Baby Doe regulations do not force evaluation of such policies, many neonatologists cite the Federal rule as a primary reason for the aggressive treatment of smaller and smaller neonates. At least one published report blames the intrusion of the Baby Doe regulations into the NICU for the unnecessary and costly treatment of conjoined twins when there was no hope for survival **(150)**.

Practicing defensive medicine is a negative incentive for most physicians, and it should be noted that the same neonatologists who mention legal considerations also point to the now many publicized successes with extremely tiny babies. The normal outcome for some of these infants encourages imitation. More importantly, it is impossible during the first weeks of life, even with today’s most sophisticated technology like ultrasound brain scans, to predict accurately an infant’s eventual outcome (21,163).