

The University of Chicago
Graduate School of Business
Center for Health Administration Studies (CHAS)
1101 East 58th Street, Walker 111
Chicago, Illinois 60637
(312) 702-7104

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EDEM EKWO, M.D.* and CAROL GOSSELINK, PH.D.**
Associate Professor*
Research Associate**
Department of Pediatrics
LaRabida--University of Chicago Institute

"Births, Deaths and Chronic Disabilities Among Low-Birthweight Infant Survivors"

for

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3:30 - 5:00 p.m.

The Effect of Technology: Postneonatal Death and Chronic
Disabilities Among Low Birthweight Infant Survivors

by

Edem E. Ekwo, M.P.H., M.D.

and

Carol A. Gosselink, Ph.D.

La Rabida Children's Hospital and Research Center
University of Chicago

An estimated 10 to 20 percent of infants and children less than 20 years of age have chronic disorders that interfere with normal functioning, physical activities, growth, and development (1-3). A vast majority of chronic childhood disorders result from inherited and familial diseases, congenital defects, and physical trauma. Low birthweight (LBW) also accounts for a proportion of chronic disabilities in childhood. However, the exact attributable risk is unknown since LBW and premature infants often have associated inherited and familial diseases.

In the last fifteen years most LBW infants have been admitted to neonatal intensive care units (NICUs), where high technological care is given. Birthweight-specific survival among LBW infants has improved remarkably since the introduction of NICUs (4-6). Concerns remain, however, about whether the number of disabled infants and children among NICUs survivors has increased.

The paper addresses three issues:

- i) what are the effects of increased survival of LBW newborns on postneonatal mortality.
- ii) what are the chances of long-term disabilities among LBW infant survivors.
- iii) what are the limits to technological applications in the NICUs.

It is generally accepted that the introduction of NICUs has resulted in increased survival among very low birthweight (VLBW) infants weighing ≤ 1500 grams (4-6). Data derived from several nurseries (7) and from defined populations (8-13) have amply demonstrated this decrease in mortality rate. In 1985 infants with birthweights between 1001 and 1500 grams had a 95.0% chance of surviving and those with 751 to 1000 gram birthweights had a 70.0% chance. Pooled data from NICUs in the United States show that mortality rates for infants born in such units and weighing < 1000 grams declined from 93.9% during 1961-65 to 55.0% for the 1981-85 time period. The trend is even more dramatic for the 1001 to 1500 grams birthweight infants where the mortality rate of 51.8% in 1961-65 dropped to 9.9% in 1981-85. Because these are pooled data from nurseries with different follow-up and reporting rates, caution should be exercised in interpreting the results. However, similar results have been obtained in most of the industrialized nations (14). Unfortunately, survival among infants from 500 to 800 grams has been less promising (15-20). Between 20.0% and 44.0% of these infants survived until they were discharged from the nursery.

Population-based studies from the United States, Canada, and the United Kingdom likewise show a significant drop in neonatal and early neonatal deaths following the introduction of NICUS that served the entire population. The important question that then must be considered is what effect the increased survival of LBW infants has on subsequent morbidity and mortality rates of these infants.

Mortality data is often expressed as early neonatal death occurring within the first 6 days, late neonatal death between 7 and 28 days of life, or as mortality at discharge from the hospital. By the 1950s two-thirds of all infant death occurred in the neonatal period. Between 1965 and 1980 infant mortality in the United States decreased by 47.0%, primarily due to increased survival of LBW infants (21-22). The postneonatal mortality rate decreased only moderately overall. Given the enormous resources required to maintain life among many of the VLBW and LBW survivors and the vast social impact of postneonatal deaths on parents, trends in postneonatal deaths must be examined carefully, although studies investigating these infant deaths are limited.

Data from defined populations and from follow-up studies of NICU discharges indicate that an increasing number of LBW infants die postneonatally. In Upstate New York postneonatal death of 4.5% of infants weighing 500 to 1000 grams at birth during 1977-1979 was three times higher than that of 1.0% occurring between 1968 and 1970. Similarly, 4.9% of infants weighing 1001-1500 grams at birth died postneonatally during 1968-1970 compared with 13.8% during 1977-1979, more than a two-fold increase. Smaller increases in postneonatal deaths were observed at all birthweights less than 2500 grams (23).

Studies from Georgia (24) also showed an increase in the percentage of postneonatal death from 2.4% for the 500 to 999 gram birthweight infants born in 1974-75 to 7.4% among infants born in 1980-81. During the same period the percentage of postneonatal deaths among the 1000-1499 gram birthweight group increased from 9.0% to 12.0%, and for the 1500-to-1999-gram birthweight infants from 20.5% to 32.2%.

The most complete information on postneonatal mortality is derived from the Robert Wood Johnson Foundation regionalized perinatal care projects in 8 geographically-defined populations in the United States (25). Neonatal mortality decreased by 9.3% between 1976 to 1978/1979 for infants weighing <2500 grams, and 17.9% overall for all infant birthweight. During the entire study period postneonatal mortality for infants weighing less than 2500 grams actually increased by 20.0%. The increase was highest for infants <1500 grams (47.5%) and lowest (4.1%) among infants with birthweights of 2001-2500 grams. Though total

postneonatal mortality decreased by 2.8%, this rosy picture resulted from an 8.5% decrease in postneonatal mortality for infants weighing more than 2500 grams. Thus an examination of the total population-based infant mortality rates may mask serious shifts in the distribution of mortality in time and within birthweights. Generally, postneonatal mortality rates among LBW infant survivors are 10 to 15 times that of normal birthweight infants; the reason for this excess mortality is not yet well understood.

Morbidity Rates

Concerns have been expressed about the possibility that some NICU survivors may be seriously impaired infants who otherwise might have died. The rate of handicapping conditions, particularly neurodevelopmental handicaps, among LBW infant survivors dropped steadily from the mid 1940s until the mid 1960s, and remained relatively stable through 1977, when 14% of survivors or 6 to 8% of all livebirth infants experienced some degree of handicap (26). From the mid 1970s, the highest increase in survival has occurred among infants weighing 1501 to 2500 grams at birth (27), while increased survival among infants weighing less than 1000 grams has been more modest. Therefore, a greater proportion of these infants of very small birthweight may experience handicapping conditions.

The criteria used to classify morbidity has varied among medical centers. Assessment of morbidity is also affected by the relationship between mortality and morbidity, which is little understood. Further, most studies of morbidity are based on infants managed at specific hospitals, and assessment of morbidity has been restricted to neurologic and developmental outcomes. Other factors that may affect morbidity rates include the use of different measures of outcome and population characteristics such as the rate of high risk pregnancy, number of survivors, and the distribution of birthweight among survivors. Differences in definition of abnormalities, in diagnostic categories, in the age of follow-up at which outcomes are measured, and the type of measurements used to assess morbidity abound in the literature. Also a large percentage of survivors, particularly in the 1000-to-1500-grams group, are lost to follow-up. Yet most of these lost subjects are considered normal, further introducing bias. Keeping these reservations in mind, studies have examined three facets of chronic disabilities in LBW infant survivors: a) the rate of hospitalization or physician office visits, b) the type and degree of handicaps present, and c) measures of school or intellectual and motor functions.

Chronic disabilities affecting LBW infants include: a) lung disease resulting from bronchopulmonary diseases in

infancy, b) cerebral palsy associated with birth injury and intraventricular hemorrhage, c) retinopathy of prematurity resulting in blindness and cicatricial sequelae such as myopia, strabismus and retinal detachment, d) congenital malformations, and e) learning disabilities. The percentage of infant survivors with serious handicaps increase with reduction in birthweight. At two years of age, an average of 26% of ≤ 800 grams birthweight survivors have serious handicap compared to 10.0% among 1000-1500 gram birthweight infants. There are wide variations in the proportion of serious handicap in survivors from different centers. However, the proportion of infants within each birthweight group with serious handicap has not changed significantly since the mid-sixties (7, 28). Since more infants now survive, however, the absolute number of infants survivors with serious handicap has increased. Using the 1984 birth rate and assuming all LBW infants are admitted to NICUs, it has been estimated that there would be a net increase in 15,000 normal LBW survivors and 2,200 LBW survivors with serious handicap per year. A large number of infants with retinopathy of prematurity now survive. Based on 1979 birth rates, an estimated 81 infants of 1000-1500 grams birthweight, and 465 of ≤ 1500 grams birthweight would be blind. Another 2,100 infants would suffer from cicatricial sequelae, including myopia, strabismus, blindness and possible late retinal detachment. These figures must be balanced against the majority of LBW survivors who presumably are normal (29).

Infants survivors also have a higher risk of rehospitalization in the first year of life. The percentage of infants who had one or more hospitalizations was 38.2% for the ≤ 1500 grams birthweight group, 21.0% for those with 1501 to 2000 grams birthweight, and 16.0% for the 2001-2500 birth class (30). Thus the VLBW infants had at least 4 times the chance of being hospitalized compared with normal weight infants. Moreover, 34.7% of these VLBW infants, as compared with 16.5% of normal birthweight infants, were hospitalized more than once during their first year of life. VLBW infants had an average of 16.2 days in the hospital, compared with 7.8 days for normal weight infants. In a similar study in Liverpool, England, 53.0% of infants weighing between 630 and 1500 grams at birth were hospitalized compared to 10.0% of control term birth infants in their first year of life (31).

A third area of concern is the school performance of LBW infants. Several studies have examined the neuropsychologic performance of LBW infants at 1 to 3 years of age. Some of these studies have been overly optimistic in classifying 67.0% to 87.0% of these infants as normal, whereas others have found only 40.0% to 53.0% to be normal. A review of the literature suggests that the classification of neuropsychologic impairment is very confusing and for

consistency I have employed the previously developed criteria (7). Severe handicap is defined as any of the following: developmental quotient (I.Q.) less than 70, cerebral palsy, major seizure disorder, blindness and severe hearing impairment; moderate handicap as I.Q. of 70-80; and mild handicaps as behavioral problem, learning disorder, language disorder. I have limited the review to reports of school-age children. Though most of the studies are not comparable because of differential rates of ascertainment, varied testing instruments, and differences in exclusion criteria, reasonable conclusions can still be drawn. Between 32.0% and 56.0% of all LBW infants have moderate to severe problems at school age; only about 27.9% of controls have similar problems (32-34). On tests of intellectual functions and reading abilities children who were LBW infants generally score significantly lower than control children who were of normal birthweight.

In conclusion, the use of technology in NICUs has been very successful in saving a large number of infants who would otherwise have died. In that sense NICUs have been effective. Nonetheless, more seriously impaired infants now survive than before. The incidence of LBW infants is much higher among blacks (12.5 per 1000 live births) compared with whites (5.7 per 1000 live births). VLBW infants are born to blacks at a rate of 2.4 per 1000 live births, as compared with 0.9 for whites (35). Many parents giving birth to LBW infants are single, unemployed, and belong to the lower socioeconomic class (36). Thus, it should be expected that at least in the United States a large proportion of severely affected VLBW and LBW survivors will come from disadvantaged families. Such adverse distribution could tax the health care and social systems to the limits, not to mention the burden imposed on the families involved. It is therefore essential to monitor closely the morbidity and mortality rates and consequences of LBW infant survivors.

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