Agency for Healthcare Research and Quality

Evidence Report/Technology Assessment

Number 70

Criteria for Determining Disability in Infants and Children: Low Birth Weight

Summary

Overview

The Social Security Administration (SSA) of the Department of Health and Human Services requested that the Agency for Healthcare Research and Quality (AHRQ), through its Evidence-based Practice Center (EPC) program, produce an evidence report to determine whether specific factors or a combination of factors alone or in addition to birth weight predict significant developmental disability in former premature infants and whether premature infants with such factors have long-term developmental disabilities. This evidence report is prepared to assist the SSA in updating its *Listing of Impairments*, and revising its disability policy, as may be appropriate. This report does not provide or suggest a new listing of impairments.

This report examines the evidence that Very Low Birth Weight (VLBW) in infants (birth weight <1,500 grams) with or without other conditions is associated with long-term disabling outcomes. The primary outcomes of interest included in this report are cerebral palsy (CP), mental retardation (MR), hearing/speech/language/behavioral impairments, visual impairments, adverse pulmonary function, and disrupted growth.

The category of VLBW infants was chosen because it is well recognized to represent a population of infants, primarily premature infants, at increased risk for acute and chronic impairments related to their immaturity. VLBW is often divided into subcategories of lower birth weights, such as less than 1,250, less than 1,000, and less than 750 grams, to facilitate analyses of infants within different birth weight strata. Extremely Low Birth Weight (ELBW) infants are often defined as infants with birth weight less than 1000 grams, although this definition may vary among studies by as much as 250 grams in either direction. In general, the lower the birth weight, the greater the degree of immaturity, and the greater the risk for serious complications.

Birth weight, however, is not a perfect measure of immaturity since some infants may have birth weights that are disproportionately large or small for their gestational age. Many studies appropriately and preferably use gestational age as the marker of prematurity. Similar to birth weight, gestational age categories of premature infants often include groupings of premature infants less than 32 weeks gestation, less than 30 weeks gestation, less than 28 weeks gestation; or less than 26 weeks gestation. Less than 32 weeks gestational age is considered by some authorities as "very premature" and less than 28 weeks gestational age as "extremely premature."

Premature birth is an important public health problem due to the number of premature births each year, the serious acute complications of prematurity, and the long-term sequelae directly related to the vulnerability of VLBW infants. Among the four million births in the United States during the year 2000, about 58,000 (1.4%) were VLBW (<1,500 grams). Although VLBW is a relatively small proportion of total births in the USA, this category of infants accounts for the highest neonatal mortality and greatest morbidity among newborns. The long-term complications result in significantly increased tangible and intangible lifelong costs to the family and society for medical care as well as for ongoing ancillary health and educational services.

Advances in neonatal/perinatal medicine have improved the survival and the quality of survival

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of premature infants. Despite advances in medical care, infants born prematurely experience a disruption in the normal process of growth and development. The degree of disruption in the growth and development of each organ system is a reflection of the degree of immaturity and physiologic derangement. Survival is inversely proportional to the degree of prematurity. Recent evidence indicates that approximately 95 percent of infants with birth weights between 1,251 and 1,500 grams survive in contrast to approximately 75 percent of infants with birth weight less than 1,250 grams. For any adverse sequela associated with premature birth, the incidence as well as the severity of the complication is inversely proportional to the gestational age. For instance, 12 percent of infants with birth weight between 1,251 and 1,500 grams survived with at least one major morbidity in contrast to 53 percent with birth weight 501 to 1,250 grams.

Surviving premature infants often sustain multi-organ system complications that may persist beyond the first few years of life and frequently result in permanent impairments. Examples include major neurodevelopmental impairments, such as CP, MR, deafness and disorders of speech/language/communication; perception, attention, behavior and learning disorders; blindness or other visual impairments; chronic lung disease; and growth retardation. Complications of even a single organ system may have a profound impact upon other organ systems. Biomedical determinants of disability in premature infants are often compounded by adverse determinants of social and psychological adaptation of these vulnerable children and their families.

Reporting the Evidence

Key questions of interest

This review addresses the following key questions of interest to SSA.

For infants with birth weight <1,200 grams and for infants with birth weights between 1,200 grams and 1,500 grams:

1. What factors or combination of factors alone or in addition to birth weight will predict significant developmental impairment in former premature infants?
2. Are such infants developmentally impaired at 1 year, 2 years, or beyond?

In order to identify the functional or physical outcomes related to disability and the elements that predicted them, we sought evidence that a specific factor was significantly associated with a specific disability (e.g., very low birth weight infants with bronchopulmonary dysplasia [BPD] have lower receptive language scores; or the degree of immaturity influences the risk of CP and neurodevelopmental disability in VLBW infants). We looked for evidence of association of VLBW with six outcome conditions:

- CP and neurological impairments
- Abnormal cognitive development and MR
- Speech/language delay, hearing loss, behavioral disorders, and learning disabilities
- Visual impairment (with or without other conditions)
- Pulmonary impairment (with or without other conditions)
- Growth impairment

Methods

A systematic literature search was performed for journal articles with original data. English language studies were identified primarily through MEDLINE® searches conducted between October 2000 and February 2001. We performed an updated search in September 2001 and again in January 2002. Supplemental searches were also performed in ERIC, PsychINFO, HealthSTAR and E<BASE. Additional studies were identified from reference lists, review and primary articles, and from domain experts and reviewers.

Disability is not a specific medical condition that can be readily searched for. Thus we had to look at many studies with related concepts (i.e., medically definable impairments that are related to disability) to identify potentially relevant studies. Therefore, we developed a comprehensive list of predictors and outcomes by organ system and those that are associated with VLBW infants. The predictor and outcomes then formed the basis of literature search terms.

We focused the literature review primarily on premature infants born weighing less than 1,500 grams, including all subcategories of birth weights (e.g., less than 1,250 grams, less than 1,000 grams, and less than 750 grams). We also incorporated literature that included infants with birth weight less than 1,500 grams within a larger premature cohort and literature on infants whose prematurity was defined by gestational age, since many studies use gestational age and not birth weight criteria.

We reviewed retrospective and prospective studies reporting impairments in infants or children who weighed 2,000 grams or less, whose gestational age was 35 weeks or less, or whose birth weight or gestational age were below these thresholds. Longitudinal data for a minimum of 6 months was preferred.

We identified and screened 16,614 abstracts from the literature searches. These abstracts covered 13 categories: central nervous system (2,930 abstracts), opthalmology (398), audiology (80), pulmonary (1,833), nutrition and growth (2,533), medication (dexamethasone) (183), perinatal factors (875), illness acuity (56), infectious diseases (2,378), gastrointestinal (477), bone/osteomalacia (10), health care (466), and immune disorder (921). Approximately 1,693 potentially relevant articles were retrieved after screening the abstracts.

The very large number of articles precluded all of them from being incorporated into the evidence report. We used the following method to reduce the articles to a feasible number and include the most relevant. We screened in articles that met the minimum inclusion criteria for LBW, reported one or more relevant clinical outcomes, had a followup duration greater than or equal to 6 months, a study size greater than 10, and enrolled patients born after 1980. We then established a hierarchy of studies based on study size and birth year of the infants. Studies with birth years from 1990 onward were given preference, followed by studies with birth years between 1985 and 1989, and then studies before 1985. Within each birth year cohort, studies with more than 100 infants were selected first, followed by studies with 50 to 100 infants and less than 50 infants. Using this classification hierarchy, we worked through the most relevant (recent) and strongest (largest study size) studies in succession before older and smaller studies, until a complement of 178 articles were reviewed.

We report the evidence organized by the six outcome conditions listed under the key questions. We summarized the evidence in three complementary forms. The evidence tables provide detailed information about the features of study design and results of all the studies reviewed. A narrative and a tabular summary of the strength and quality of the evidence of each study are provided for each outcome condition. The summary tables describe the strength of the evidence according to four dimensions: study size, applicability of the study population, association of the factor of interest with impairments, and the methodological quality of the study.

Findings

Evidence that VLBW With or Without Other Conditions is Associated With Cerebral Palsy (CP) and Neurologic Disability

The literature overwhelmingly supports evidence that the risk of CP and major neurologic disability is increased among VLBW infants compared to full-term infants. The literature is consistent in demonstrating that risk of CP, major neurosensory and/or neurologic disability is inversely proportional to the degree of immaturity whether measured by gestational age or by birth weight. The recently reported incidence of CP is currently stable compared to the 1980s (7-10 percent VLBW infants; 7-17 percent ELBW infants) or modestly decreased despite improved survival of extremely immature infants. This suggests that recent advances in neonatal care have had either no or modest effect on further reduction in the incidence of CP. Several studies demonstrated that the risk of major neurosensory or neurologic disability may range from 12-50 percent among VLBW and ELBW infants. Despite the stable risk of CP, the risk of disability, due primarily to visual disabilities, has increased since the 1980s. Differences among studies regarding the incidence of CP, neurologic, and neurosensory disability may be accounted for by differences in the criteria for neurologic/neurosensory disability, the era of study, the degree of immaturity, and other characteristics or risk factors of the patient population, neonatal care practices, as well as length and completeness of followup.

Several articles in this review provide compelling evidence that cerebral white matter damage (WMD), as manifested by periventricular leukomalacia (PVL) (such as echodensities and echolucencies), ventriculomegaly, posthemorrhagic cerebral infarct, and severe intracranial hemorrhage are among the strongest predictors of CP and other neurologic disabilities in VLBW infants. Visual and ocular abnormalities are often associated with neurodevelopmental abnormalities in VLBW infants with cerebral white matter damage. The degree of visual impairment correlates with the degree of neurodevelopmental impairment.

Increasing evidence indicates that antenatal events contribute to the etiology and sequence of events leading to neurologic impairment and CP in VLBW infants. Antenatal inflammation, chorioamnionitis, subclinical infection, fetal hypoxia/acidosis, and premature rupture of membranes (which may be related to antenatal inflammation and infection) and abruption appear to play an important role via stimulating a fetal inflammatory response that injures the immature cerebral white matter.

Several studies documented that prolonged mechanical ventilation and BPD are associated with increased adverse neurodevelopmental outcome in premature infants compared to infants without BPD or prolonged mechanical ventilation. In addition, there is increasing evidence that the use of postnatal systemic glucocorticoid therapy (specifically, dexamethasone) for the prevention or treatment of neonatal chronic lung disease may have an adverse effect on long-term neurologic development and increase the risk of CP. The evidence supports that BPD and systemic dexamethasone each may be separate factors influencing the risk of CP and neurologic impairment in VLBW infants.

Studies also illustrate that VLBW infants with parenting, social, and environmental risk factors are at increased risk for neurodevelopmental disabilities. The relationship between biological-medical risk factors and parenting-psychosocial risk factors on subsequent neurodevelopmental outcome is complex. The interaction of these factors may have synergistic effects on an infant's outcome.

Evidence that VLBW With or Without Other Conditions is Associated With Abnormal Cognitive Development and Mental Retardation (MR)

The evidence demonstrates that children who were born VLBW have significantly higher rates of cognitive abnormality in early childhood and a several-fold increased prevalence of IQ <70 as adults compared with children or adults who were born normal birth weight at term. Given current rates of birth and

VLBW in the USA, these results suggest that there may be more than 3,500 new cases of MR in the United States each year in former VLBW infants. There is evidence that even children who were apparently "well" VLBW infants during their neonatal course are also at significantly greater risk for both moderate and severe delay compared to larger-birth-weight groups.

Among children born as ELBW infants, the prevalence of MR is even higher than in VLBW infants, who are larger than ELBW infants. Approximately 40 percent of ELBW survivors have Bayley Mental Development Index (MDI) <70, half of ELBW survivors have at least one significant neurodevelopmental impairment, and 20-35 percent of ELBW survivors have two or more impairments. Evidence suggests that the incidence of MR in ELBW infants is not changing with time, despite recent increases in survival rates in this birth weight category. Our search methods identified evidence that birth weight is a useful factor in identifying VLBW infants at especially high risk for MR. However, once the range of birth weight and gestational age are narrowed to the most immature infants, and stronger predictors of neurodevelopmental outcome are taken into consideration, the evidence that birth weight or gestational age is useful in identifying VLBW infants at high risk for MR was mixed.

Intraventricular hemorrhage (IVH), particularly severe (i.e., grade III or IV) IVH, PVL, and ventriculomegaly are also among the strongest independent predictors of cognitive impairment and MR in VLBW and ELBW infants. Infants with a combined outcome IVH ≥ grade III or PVL are more than twice as likely to have Bayley MDI <70 as those without these findings, after adjusting for the effect of other clinical factors.

Recent studies strongly document a significant independent relationship between BPD and abnormal neurodevelopment in both VLBW and ELBW infants. This effect of BPD on long term outcome is independent from the many co-morbid conditions commonly seen concurrently in VLBW infants, such as intraventricular hemorrhage, posthemorrhagic hydrocephalus and periventicular leukomalacia. Evidence strongly indicates that postnatal systemic steroid therapy (dexamethasone) for the amelioration or prevention of BPD is an independent determinant of abnormal cognitive development in ELBW infants after adjusting for clinical factors and associated with almost two-fold increased risk of Bayley MDI <70.

Our search methods identified many strong studies documenting a significant independent association between parenting-pychosocial risk factors and cognitive development in VLBW infants even after accounting for the effects of intraventricular hemorrhage and chronic lung disease. Methods used to measure social risk are numerous, however, and the identified evidence in the literature is not always sufficient to distinguish the independent effects of various commonly examined elements of social risk, such as race, economic status, or level of maternal education. The quality of parent-infant interactions may play an important role in cognitive development of VLBW infants. The variability among studies with respect to the association of parenting-pyschosocial risk and cognitive outcome may be accounted for by differences among studies with respect to population characteristics, sample size, age of assessment, ascertainment of other potential confounding factors, accuracy of methods/measures used to determine social risk, parenting risk, and other socioeconomic markers.

The identified evidence suggests that race may be an independent predictor of cognitive development in VLBW infants with black race among the social risk factors associated with an approximately 50 percent increased risk of subnormal Bayley MDI.

The level of maternal education was identified as a significant independent predictor of abnormal cognitive development in VLBW and ELBW infants. One methodologically strong study found that maternal education less than high school graduate level increased risk of Bayley MDI <70 almost two-fold.

The identified evidence suggests that gender may be a significant independent predictor of MR among ELBW infants, but this relationship may be less significant in larger birth weight categories.

Evidence suggests that illness severity scoring systems may be useful in identifying infants at risk for MR. Durations of various therapies such as mechanical ventilation, intravenous nutrition, etc. are markers of illness severity and may be tested as independent predictors of outcome.

The evidence identified by our search methods was equivocal regarding the utility of antepartum and intrapartum factors as independent predictors of MR. Strong studies suggested that specific antepartum factors (e.g., use of antenatal steroids, maternal hypertension, route of delivery, or inborn versus outborn) do not provide a useful contribution to prediction of MR in ELBW infants after accounting for other clinical factors.

The identified evidence regarding intrauterine growth retardation/small for gestational age (IUGR/SGA) as an independent risk factor for MR was equivocal. One study documented worse cognitive development in children who were SGA VLBW infants compared with appropriate gestational age (AGA) VLBW infants. Other studies that found that SGA ELBW infants were not at increased risk for cognitive delay compared with their AGA peers after adjusting for other clinical factors.

Our methods located no studies examining the relationship between necrotizing enterocolitis (NEC) and subsequent cognitive development in VLBW infants.

Our search methods identified studies that examined the relationship between sepsis or meningitis and subsequent cognitive development in VLBW infants. Two studies found that neither sepsis nor meningitis was associated with cognitive outcome in ELBW infants after adjusting for other clinical factors.

Evidence that VLBW is Associated With Speech/Language Delay, Hearing Loss, Behavioral Disorders, and Learning Disabilities

VLBW infants are at high risk for developing cognitive, neuromotor, and neurosensory disabilities including blindness and hearing loss. These disabilities in turn may lead to other disabilities in speech and language, behavior problems, and learning disabilities affecting school performance. All of the above problems have been identified in disproportionate numbers in the VLBW infants.

The studies provided strong evidence of increased incidence of speech and language delays in VLBW and extremely premature infants, and identified clinical factors associated with the increased incidence. One study emphasized higher prevalence of functional limitations in most language domains with children who were born ELBW. Children who were ELBW have a higher utilization rate of speech therapists and require more educational and health care services. Across all measures of short-term memory and language outcomes, preschool children who were born preterm performed at a lower level than children who were full-term counterparts. These deficits were independent of the general IQ.

In overall communication skills, children who had BPD as preterm neonates scored significantly lower than the other comparison non-BPD groups. Even after controlling for lower IQ, children who were VLBW infants with BPD have lower receptive language scores.

Data on the incidence of hearing loss in ELBW infants is conflicting. Four excellent, recent studies report higher incidence ranging from 9 to 14 percent and nine studies report rates (~1-2 percent) similar to their full-term controls. This variability may be due to differences in testing methods.

There is good evidence that VLBW infants have increased attention problems and more passive temperament. Intracranial lesions, CP, impaired cognition, and urban socioeconomic setting was associated with the increased incidence.

Available evidence suggests that VLBW and ELBW infants are at higher risk for developing learning disabilities and have difficulty in school. Studies of school learning problems at 6 years may be too early and may miss children with less grossly obvious difficulties.

One study provided evidence that even seemingly "healthy" premature infants may have later sequelae needing special assistance. The well-preterm group, compared to full-term controls, had significantly higher than expected incidence of minimal brain dysfunction including attention deficit disorder, learning disabilities, language impairment, mild neurologic impairment, and general school concerns. In fact, only 25 percent had no concerns by grade 5 compared to 57 percent in term controls. The mother's perception of their infants' competence was a sensitive marker for disabilities.

Evidence that VLBW With or Without Other Conditions is Associated With Visual Disability

The evidence identified by this review clearly demonstrates that children born as VLBW, with or without retinopathy of prematurity (ROP), are at significantly increased risk of visual impairments and disability compared to children born full term. The risk of visual disability in VLBW infants varies inversely with gestational age. The risk of having any ophthalmic morbidity (e.g., significant reduction in visual acuity tests or presence of strabismus, myopia, color vision defect, or visual field defect) is two-fold greater in children born VLBW infants and five-fold greater in children born ELBW compared to children born at term. Ophthalmic morbidity (i.e., greatest reduction in visual acuity or incidence of strabismus, myopia, etc.) is highest in eyes with severe (Stage 3 or 4) ROP. No or regressed mild ROP, by itself, has no major important long-term effect on visual acuity, although children born prematurely with no or regressed mild ROP may have statistically significantly reduced visual acuities compared with full-term controls.

The risk of blindness is higher in ELBW infants compared to normal birth weight controls and is inversely related to birth weight or gestational age. The reported incidence of blindness in ELBW infants, the population at greatest risk for visual disability, ranges from 1 to 4 percent in most studies identified in this review.

Retinal ablation with cryotherapy or laser therapy for severe (i.e., threshold) ROP significantly reduces the incidence of blindness and unfavorable outcome, especially in Zone 2 threshold eyes. Despite this benefit, infants successfully treated with cryotherapy still had an unacceptably high risk of unfavorable functional outcome (44.4 percent of treated eyes). Unfavorable outcome was particularly true in eyes with Zone 1 (posterior pole) threshold ROP regardless of whether or not the eye received cryotherapy (i.e., poor outcome in 75 percent of Zone 1 treated eyes and 92 percent of not treated eyes). Unfavorable outcome of successfully treated eyes is most likely a reflection of the severity of the underlying retinal injury and of the disruption in normal growth and development of the retina. Retinal ablative therapy (cryotherapy or laser therapy) for threshold ROP is cost effective therapy that can improve the quality of life. Laser therapy can reduce the risk and/or severity of myopia, which is a major complication of premature infants, especially in premature infants with severe ROP. Any reduction in myopia is important in terms of long-term visual benefit.

A 10-year followup of premature infants with threshold ROP revealed that the rate of retinal detachment among control (no cryotherapy) threshold eyes increased at 5.5 years (38.6 percent) and again at 10 years of age (41.4 percent), after having been "stable" during the first 3 years of followup. The rate of retinal detachment remained stable in treated eyes (22.0 percent). Eyes with severe ROP and not treated, have smaller visual fields compared to eyes that never had ROP. Eyes treated with cryotherapy had a further reduction in the visual fields. At the 10-year outcome, treated and control threshold eyes are equally likely to have 20/40 visual acuity, but this is the minority of threshold eyes.

VLBW infants are also at increased risk for non-retinal ophthalmic diseases. Cortical visual impairment is visual impairment due to central nervous system (CNS) damage. Causes of cortical visual impairment in VLBW infants include hypoxic-ischemic-hemorrhagic and /or inflammatory injury (antenatal, perinatal, or postnatal) which may be manifested in the neonatal period as periventricular leukomalacia, ventriculomegaly, intracranial hemorrhage, and posthemorrhagic hydrocephalus. Neuroimaging of VLBW infants via cranial ultrasonography, cranial tomography, and magnetic resonance imaging (MRI) techniques has provided strong evidence that central nervous system injury, especially periventricular leukomalacia, is associated with visual disability and other neurodevelopmental abnormalities, including motor and perceptual abnormalities. The strong association of visual impairment with the extent of MRI evidence of cerebral white matter damage and the concomitant occurrence of neurodevelopmental disability in premature infants is well documented.

One study demonstrated that even healthy preterm children with no detectable neurodevelopmental problems on screening examinations, have evidence of visual-motor disabilities when these functions are specifically tested.

There is long-standing evidence that the risk and degree of myopia increases with the degree of prematurity, degree of ROP severity, and with central nervous system injury. Myopia is the most common ophthalmic sequela of premature infants and requires optical correction. Other adverse ophthalmic outcomes, such as astigmatism and anisometropia, were highly correlated with severe myopia. Studies clearly illustrate the significant and independent contributions of prematurity, ROP, and central nervous system injury in the development of visual disability in terms of myopia and strabismus.

There is a strong positive association between the occurrence of strabismus and the degree of prematurity, the severity of ROP, abnormal cranial ultrasounds, and neurodevelopmental abnormality, especially CP. The presence of strabismus and nystagmus implies a central nervous system component or insult, which may or may not be independent of ROP. The ocular misalignments may result from CNS injury and/or as a direct result of retinal disease (e.g., ROP) and its treatment. Strabismus may continue to increase in frequency through second year. Among children with Grade III or IV IVH, 100 percent had strabismus (esotropia).

Ophthalmic examinations revealed that premature infants with BPD and no detectable severe neonatal neurological abnormalities and no ROP > Stage 2 had greater incidence of strabismus and high refractive error and poorer recognition acuity compared to premature infants with hyaline membrane disease but no BPD and healthy preterm infants. Extremely premature infants treated with systemic dexamethasone therapy for BPD had significantly higher rates of blindness in addition to significantly higher rates of CP and lower intelligence quotients. Extreme prematurity, brain injury, ROP, BPD, and glucocorticoid therapy individually and/or collectively have an impact on visual disability.

Children who had ROP are at even greater risk for long-term ophthalmic sequelae in terms of anatomic and functional problems, and thus need close ophthalmic evaluation and interventions. The frequency of procedures to correct visual disability increases with severity of ROP. Long-term costs of both extreme prematurity and ROP include not only the initial ablative therapy for ROP and individual/family/societal loss due to vision impairment and blindness, but ongoing costs of caring for eye problems in children who were VLBW. Expenses include doctor's office visits, time lost from work, eyeglasses, surgery, and special education.

Evidence that VLBW With or Without Other Conditions is Associated With Pulmonary Disability

The studies reviewed indicate that VLBW infants with bronchopulmonary dysplasia (BPD) are at increased risk for long-term pulmonary disability. The greater the severity of BPD, the greater the association with long-term pulmonary impairment and need for re-hospitalization. Children who were VLBW infants who had no BPD have comparable pulmonary outcome to children who were born full term. Children who were VLBW with more severe BPD may have persistent lung disease during young childhood and continuing through to their adolescent, and young adult years. Findings in five studies indicate that BPD at 36 weeks corrected gestational age is predictive of longer-term pulmonary disability through at least 1-2 years of age.

Preterm children with BPD have an increase in multiple measures of pulmonary disability. The most frequently described consequences of pulmonary disability are increased respiratory symptoms and respiratory illnesses, the need for respiratory medications, and re-admission to the hospital for other medical and surgical reasons. Respiratory illnesses frequently documented in children who had BPD include chronic lung disease, recurrent bronchitis and pneumonia, increased airway responsiveness and asthma. Asthma or

bronchial responsiveness actually appears to be increased in VLBW premature children who did or did not have BDP.

Rehospitalization of former VLBW infants is unfortunately a common event especially during the first 2 years of life and is even higher among VLBW infants with BPD. Most hospitalizations are for respiratory conditions or failure to thrive.

Evidence that VLBW With or Without Other Conditions is Associated With Growth Impairment

VLBW infants, with or without other conditions, are at high risk for poor growth during the first years of life due to acute neonatal illnesses, developmental delays, and chronic illnesses (e.g., BPD, gastroesophageal reflux, short-gut syndrome). Understandably, the degree of prematurity and severity of the illness/hospital course have great impact and influence growth. Attaining appropriate growth and nutrition in VLBW infants continues to be a challenge during the initial hospitalization and after discharge from the neonatal unit. Long-term studies demonstrated definitive problems with postnatal growth. There is evidence that the weight and height of VLBW infants is significantly behind that of normal birth weight infants through 14 years of age, although the differences become less over time.

It is well documented that VLBW infants with BPD are smaller and have difficulty gaining weight while in the neonatal intensive care unit. Recurrent illness and pulmonary exacerbations of BPD, increased metabolic needs and inadequate nutrient intakes all contribute to compromise growth in VLBW infants with BPD. BPD infants with home oxygen therapy had a three-fold increase in rehospitalization for failure to thrive. The primary reasons for failure to thrive in the BPD patients were related to poor feeding and gastroesophageal reflux.

Future Research

We propose two prospective health service research opportunities. The first proposal, "Evaluation of the Application Process of SSA VLBW Disability Criteria," involves documentation of baseline risk factor data on all VLBW infants born within participating regions, following surviving VLBW infants over pre-specified time with respect to pre-specified disabilities, documenting the proportion of VLBW who come to the attention of SSA, relative to the entire regional cohort of VLBW infants, and identifying barriers to referring infants to SSA. This research proposal would help SSA assess the application of SSA VLBW Disability Criteria. This would, in turn, provide greater insight into reasons for successful programmatic implementation and impediments of applying the criteria. It would provide insight regarding the effectiveness of identifying high-risk VLBW infants.

The second proposal, "Determining the Appropriateness of the New VLBW Disability Criteria" proposed by SSA based on the evidence of this report, is a natural next step linked to the first research concept. The combination of these two concepts affords the SSA the ability to know if the process and the criteria are achieving the objectives established by the SSA.

Refinement of predictors of disability or identification of new predictors, and development of a robust, well-designed, and carefully validated predictive models to be used at the time of hospital discharge could create a "profile" of a VLBW infant at risk for specific disabilities. A series of models predictive of longer-term outcome could be developed and validated to incorporate new factors and information noted during specified times of followup. Refinement of risk factors invites a systematic, collaborative effort to develop a series of predictive models using large regional cohorts of VLBW infants, followed by validation of the model in an independent group.

Availability of the Full Report

The full evidence report from which this summary was taken was prepared for the Agency for Healthcare Research and Quality (AHRQ) by Tufts New England Medical Center Evidence-base Practice Center (EPC), Boston, MA, under Contract No. 290-97-0019. It is expected to be available in the winter 2003. At that time, printed copies maybe obtained free of charge from the AHRQ Publications Clearinghouse by calling 800-358-9295. Requesters should ask for Evidence Report/Technology Assessment No. 70, *Criteria for Determining Disability in Infants and Children: Low Birth Weight*. In addition, Internet users will be able to access the report and this summary online through AHRQ's Web site at www.ahrq.gov.

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