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The Spectrum of Behavioral Outcomes after Extreme Prematurity: Regulatory, Attention, Social, and Adaptive Dimensions

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Advances in obstetrics and neonatology have increased the survival rates of premature infants with very preterm (<32 weeks) and extremely preterm (<28 weeks) gestations. However, survivors have a high frequency of challenges in academic and social skills. There has been an increased emphasis on examination of outcomes beyond survival rates and rates of neurosensory disabilities at ages 18 to 24 months (eg, cerebral palsy, blindness, deafness, global development delay). One of the key strategies for understanding pathways of risk and resilience is to examine behavioral, social–emotional, and adaptive competencies. The purpose of this paper is to apply the International Classification of Functioning framework to a spectrum of behavioral outcomes after extreme prematurity, describe useful tools for measuring behavioral, social, and adaptive competencies, as well as review model outcome studies before middle childhood. Thus, we can use current information to begin to understand pathways underlying behavioral health, well-being, and social competence.

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Long-term neuronsensory disability and adverse health outcomes of very low birth weight (VLBW, <1500 g) and very premature (VP, <32 weeks gestation) infants have been well documented during the past two decades.[1] Although advances in obstetrics and neonatology throughout the 1980s and 1990s have increased the survival rates of infants with extreme prematurity (EP, <28 weeks gestation) and extremely low birth weight (ELBW, <1000 g) status, there has not been a decrease in rates of major neurodevelopmental disabilities, such as cerebral palsy and serious intellectual disability (IQ <55).[2,3] In addition, high rates of more subtle disability impact on regulatory, attention, social, and adaptive skills.

The long-term behavioral, social, and adaptive well-being of children receiving life-saving neonatal intensive care has become a source of concern. Increased long-term survival creates increased opportunities for these children to be compared with peers in mainstream education, examine their social skills in the community, and understand the precursor of behavioral competencies required for independent living.

In this chapter, we will review the behavioral, social, and adaptive competencies of children who survived VLBW and ELBW status. Although the majority of past literature has used birth weight classifications, especially in the United States, we will also describe survivors using VP and EP gestational age classifications whenever possible. We will also examine how environmental effects (eg, family life, human capital, and neighborhood/community supports) interact with medical factors in promoting resiliency in preschool years and in middle childhood.

The ICF Model

In the 1970s, it was assumed that the majority of VLBW and ELBW survivors would have neurodevelopmental disability or challenges in emotional, behavioral, or adaptive competencies continuing throughout childhood. Too often size at birth and degree of prematurity were assumed to be predictive factors for all aspects of a child's physical and emotional

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health later in life. However, increasing evidence demonstrates that the continuum of developmental and behavioral competencies does not depend on a single determinant, but many interacting components of health status, home environment, developmental status, social stressors, and, in particular, family and community supports. We should also keep in mind that these elements also influence one another, and the combination of these interactions affects the overall well-being of the child. To better understand the complex pathways of child development, behavioral health, and well-being, a variety of models and frameworks have been developed.[4] Of these, the International Classification of Functioning (ICF) model illustrates health and disability through components covering Body Function, Body Structure, Activities, and Participation.[5]

Body function refers to the physiological functions of body systems (such as breathing, growth, and digestion), as well as psychological functions (such as regulating behavior, attending, remembering, and thinking). Body structures are anatomical parts of the body, such as organs and limbs, as well as structures of the nervous, sensory, and musculoskeletal systems. Activities are tasks, including learning, communicating, walking, carrying, feeding, dressing, toileting, bathing, reading, calculating, writing, interacting with peers, and solving a problem. Participation means involvement in community life, such as friendships, education, chores, recreational, religious, civic, and social activities (eg, scouts, 4H). The ICF Model also includes contextual factors in a child's life and highlights environmental and personal factors. Environmental facilitators include policy, social, and physical factors, such as mentors, positive social attitudes, and legal protections. Environmental barriers include negative attitudes of others, nonaccessible transportation, and discriminatory practices. Personal factors include age, gender, interests, and sense of self-efficacy. Figure 1 shows how the ICF model can be applied to a 5-year-old boy with attention and learning challenges, and how different components of everyday life influence one another. In this model, one can highlight how an asthma care plan and multimodal management strategies for attention deficit hyperactivity disorder (ADHD) are essential for academic success.

Table 1 provides several additional scenarios for children of different ages and medical background risks with respect to regulatory, behavioral, and social challenges. Note that these facilitators and challenges do not stem from a child's physical health alone, but also from their developmental status and social environment, including family life, caregiver's work status, caregiver's attitude, presence of sibling(s), and community resources.

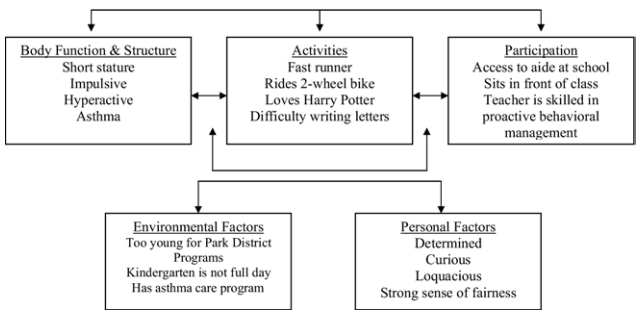

Figure 1 ICF Model. A 5-year-old with ADHD after 900-g birth weight and 27 weeks gestation.

Behavioral, Attention, Social, and Adaptive Outcomes of Premature and Low Birth Weight Children

Each year in the United States, there are approximately 60,000 children born after VP gestation and with VLBW status. In the past 25 years, the field of medicine has seen a growing body of research documenting the complex pathways underlying adverse outcomes in physical, developmental, emotional, and behavioral health. In the early stages of these outcome studies, much of the attention was focused on major neurodevelopmental disorders, such as cerebral palsy, blindness, deafness, and severe intellectual disability (ie, intelligence scores measured by standard tests of more than 3 standard deviations below the mean). However, the perspective of concerns regarding behavioral and psychological health in these children has shifted in recent years as more health care professionals have begun to consider a broader range of outcomes and concepts.[6-8] Several meta-analyses of case-control studies between 1980 and 1990 found that school-aged children who were born VP or with VLBW exhibited both internalizing disorders (eg, anxiety and social withdrawal) as well as externalizing problems (eg, ADHD, oppositional and disruptive behavioral disorders) compared with term peers. Children who survived VLBW and ELBW born between 1990 and 2000 were also found to be prone to inattention, hyperactivitiy, and social skill difficulties.[9]

Four major domains of psychological development in preterm infants are relevant to understanding outcomes and include: (1) intellectual development (eg, cognitive, linguistic); (2) behavioral and emotional status (eg, temperament, regulatory problems); (3) social functioning (ie, ability to form and maintain social relationships with peers and adults); and (4) adaptive (eg, educational and community self-sufficiency). Several research studies suggest that VP and EP school-age surviviors are at risk for a spectrum of behavioral, social, and learning disorders compared with peers born with normal birth weight.[8,10-13]

Intellectual

There is a dose response curve between degree of prematurity/low birth weight and suboptimal cognitive outcomes, even in the absence of severe physical or mental impairment.[13-16] VLBW and ELBW infants are especially vulnerable to specific learning disorders, impaired executive function, nonverbal learning disorders, and poor academic achievement.[8,13,16,17] In their study of school-aged children who were ELBW infants, Anderson and Doyle found that 1 in 5 of their preterm cohorts had repeated a grade in elementary