

What Are We Measuring as Outcome? Looking Beyond Neurodevelopmental Impairment

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KEYWORDS

- Neonatal follow-up • Outcome measures • Neurodevelopmental impairment (NDI)
- Quality of life • NICU survivors • Very preterm infants

KEY POINTS

- Categorization of neurodevelopmental impairments allows quantification of severe problematic outcomes in early childhood but these may not reflect later more subtle, functional outcomes.
- More prevalent, less severe, neurobehavioral dysfunctions are often not identified in early childhood but are important predictors of later academic achievement and social outcomes.
- Extremely preterm and other high-risk neonatal intensive care unit graduates are at risk for lifelong health needs that are often underappreciated.
- Postnatal influences, including psychosocial factors, are important for resilience and quality-of-life outcomes for extreme preterms.

The primary outcomes of neonatal intensive care have generally been presented as rates of survival and neurodevelopmental impairment (NDI).¹ This approach provides a rather complex outcome that varies with regard to categorical cutoffs. Levels of impairment are defined based on thresholds of cognition, motor performance, and neurosensory function. Moderate to severe NDI, which includes major disabilities (intelligence quotient [IQ]/developmental quotient [DQ] <70, cerebral palsy [CP], or neurosensory [vision, hearing] impairments) have been reported for approximately

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20% to 25% of extremely preterm infants, based on follow-up evaluations at 2 years of age.² However, there are important outcomes that go beyond discharge and short-term morbidity/mortality endpoints. In fact, these should be considered the first of many endpoint outcome measurements.³

Understanding the risk for NDI in preterm survivors is important for public health decisions and as a metric for research initiatives designed to improve outcomes. However, recent criticisms challenge the assumptions on which this follow-up model is based.^{4,5} More specifically, preschool developmental testing has limited value in predicting later cognitive performance. There are many other important variables that need to be identified so as to understand implications of NDI in terms of functional outcomes and quality of life (QoL). It is also important to recognize other, perhaps less severe, but significant dysfunctions that become apparent at older ages in NICU survivors. In this article, we briefly review limitations of early developmental testing of NDI, discuss other important areas of evaluation needed to better understand functional outcomes, and highlight medical outcomes that have ramifications on QoL. The focus is on outcomes of infants born prematurely, but many of these issues are also relevant to term gestation survivors following a difficult neonatal intensive care unit (NICU) course.⁶⁻⁸

EARLY DEVELOPMENTAL TESTING FOR NEURODEVELOPMENTAL IMPAIRMENT

Two-year follow-up data, including assessments in cognitive, motor, and neurosensory domains, have traditionally been considered “long-term outcomes” for neonatal studies, although that view is changing.³ Findings in each of these areas have been used to define NDI as “mild,” “moderate,” or “severe,” based on preset thresholds. Although a composite score may produce greater power than individual components,¹ there are concerns about overinterpretation of findings using this model. A “severe” finding in any of the domains would categorize the child as having “severe NDI” even with “normal” findings in the other areas; for example, a child with diplegia that interferes with ambulation would be classified as having severe NDI even if cognition is normal.⁹ With regard to cognitive and motor function, the National Institute of Child Health and Human Development Neonatal Research Network has defined scores of less than 70 as severe and scores in the 70 to 84 range as moderate NDI.¹⁰ The components of NDI are often interrelated: grossly one-half of those with CP have cognitive impairment, and sensory disabilities are associated with CP as well. Moreover, it is easier to assess whether an infant or young child has CP than it is to measure DQ in a severely impaired child because motor and speech impairments interfere with cognitive testing.¹¹

The Bayley Scales are often used for infant assessments with categorization of findings based on reference standards. The Bayley was introduced as a developmental testing tool in 1969 and several versions have subsequently been introduced. Currently, the Bayley Scales of Infant and Toddler Development (Bayley III)¹² is used, particularly the cognitive, language (receptive, expressive), and motor (gross, fine) subscales. Although the DQ is often thought of as a measure of cognition, it is not, as only precursors of cognitive function are being tested. Predicting cognitive outcomes at school age from these early assessments has been called a “conundrum.”¹³ Changes to the Bayley Scales items and format over time (Bayley II compared with Bayley III), as well as alterations to the reference standards, have made longitudinal comparisons challenging.¹⁴ In comparison studies the Cognitive Composite has been reported to be 6 to 10 points higher with the Bayley III compared to the Bayley II Mental Developmental Index (MDI).^{12,15} These issues are particularly of concern

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