## The Long Road Home

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# Understanding Neurodevelopmental Outcomes of Prematurity

Education Priorities for NICU Parents

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#### **ABSTRACT**

NICU nurses have an important role to play in many aspects of parent education. This article stresses the need for an increased focus on teaching parents about the central role that self-regulation will play in their infant's neurobehavioral development not only during the early infancy period but throughout all of childhood and adolescence. Suggestions are made about how to conceptualize the relation between cognition and emotions in humans and how to help parents understand that continued vigilance concerning potential problems in attention and self-regulation will be necessary.

KEY WORDS: neurobehavioral development, parent education, self-regulation

eaving the NICU is rightfully the major goal for both parents of premature infants and the medical staff that have been taking care of them. However, there are potential lingering effects from an early birth, and from the medical interventions that have been necessary to get the infant thus far. Specifically, premature birth is potentially disruptive to multiple aspects of neurodevelopment, especially when certain problems co-occur, like intraventricular hemorrhage, infection, or chronic lung disease. 1-3 Furthermore, some aspects of NICU care, like mechanical ventilation, supplemental oxygen, bright lights, noisy alarms, painful procedures, and use of medications like antibiotics and steroids, improve survival but may worsen long-term neurological outcomes.4-6 Similarly, routine caregiving procedures like diaper changes, endotracheal tube repositioning, and suctioning are linked to cerebral

hemodynamic circulatory changes that may impair appropriate neurodevelopment in premature infants.<sup>7</sup> Continued vigilance in observation and evaluation of the premature infant's health and well-being is important, and the nursing staff has a responsibility in helping parents be prepared.

In addition, the risk of neurodevelopmental problems is proportional with gestational age and birth weight (the earlier the infant was born and the smaller the infant, the greater chance that there will abnormal development). For example, in 1 meta-analytic review of the literature, 15% of infants with gestational ages between 22 and 27 weeks developed cerebral palsy, while only 6% of those born between 28 and 31 weeks, 0.7% of those born between 32 and 36 weeks, and 0.1% of those born full-term developed cerebral palsy.8 Similarly, gestational age and birth weight correlate significantly with scores on a wide range of intelligence tests of cognitive abilities in school-aged children.<sup>9,10</sup> But our predictive capacity about the outcomes for any given infant is limited, 11 and parents should be educated about the fact that problems may not emerge until later in development.

Thus, consistent and extended discussions about the premature infant's potential difficulty with neurobehavioral development, especially for the parents of smallest, sickest, and most immature infants are warranted. Parents are currently taught that premature infants are susceptible to respiratory tract infections and asthma and may need special formulas and strategies for the introduction of solid food to ensure

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that adequate nutrition and growth are maintained. Less is done to educate them about the NICU graduate's risks for the neurological problems that are related to low birth weight and gestational age. Just as the lungs and gastrointestinal system were not prepared for developing and functioning outside of the womb after premature birth, neither was the brain. 12

The majority of premature infants are seen for developmental follow-up assessments in the first year. In addition, intensive interventions that extend throughout the preschool years through participation in high-quality, center-based day care yield better performance on tests of cognitive ability during elementary school.<sup>13</sup> However, many neurodevelopmental issues will not become evident until school entry and beyond. Large numbers of the youngest and sickest premature infants may suffer moderate to significant negative neurodevelopmental outcomes like lower IQ scores, language delay and impairment, social and behavioral problems, school-related difficulties, and employment and relationship issues in adulthood. 10,14-22 Furthermore, for very low-birthweight infants (<2000 g), one study showed no significant sustained effects of preschool intervention at 18 years of age. 13,23

More education soon after a premature birth, and possibly adjusted as the infant does or does not have complications during their hospitalization,<sup>2</sup> could increase the chances that parents continue to request and access intervention services and adapt and adjust the home environment and their parenting behaviors to their child's needs. Parent education is especially important because many preemies are born into families who are already at risk for having difficulty providing optimal parenting due to factors like age, poverty, and lack of education.<sup>17</sup>

#### Understanding Development

Developmental change is normative, nonreversible, relatively stable, and sequential, and, most importantly, for NICU parents to understand, it involves not only growth but also maturation. Growth is change in size, for example, change in height or weight. Maturation is the change from an early form of an organism to its later forms through processes of internal and external physical and biochemical influences on structures and their functions. Critically, much of maturation is change in skills and abilities that involve aspects of learning, for example, change in motor coordination or communication based on experience. Each phase in a maturational process is built on past phases and is the basis for subsequent phases. However, just because one phase has been completed is not a guarantee that subsequent phases will be completed. At any point in the process, even a slightly unsuccessfully completed component may not contribute to a failure at that phase but might contribute to a failure at the next phase. For example, while the ability to crawl might be achieved, it may not successfully lead to walking, running, or athletic abilities. Similarly, while the infant may succeed in acquiring basic language skills, these skills may not lead to successful achievement in reading and writing and other academic abilities. This is why it is hard for us to predict exactly what kind of problems an individual child will have, even though we know that problems are likely in this population. While severe levels of disability are generally apparent in premature infants by 2 years of age, the presence or absence of mild to moderate levels of disability at 2 years is not well-predictive of neurodevelopmental issues later on.<sup>24</sup>

Parents may be prepared for "delayed" development in their premature infants, milestones that are reached at later ages but that are still successfully obtained. But the more complex concept of difficulty in successfully reaching some milestones, even though earlier ones have been met, because of disruptions in maturational pathways earlier in development may be harder to grasp. Importantly, preemies show more problems as the complexity of tasks increases<sup>25</sup>; thus, many problems will not show up until much later. Knowing the eventual level of performance across a wide variety of domains will not be possible until these children are well into adolescence and adulthood. Leaving the NICU is just the first step, and continued surveillance of the level of functioning of these children is necessary, so that appropriate interventions can be made.<sup>26</sup>

### NEUROBEHAVIORAL DEVELOPMENT AND SELF-REGULATION

One way to provide consistent and easily understandable information to help parents grasp the neurobehavioral problems that preemies may have is to focus on the concept of self-regulation. The third trimester of pregnancy and the early infancy period (sometimes called the "fourth trimester") are characterized by explosive developmental changes in the human brain. This is very unusual: postnatal cortical development, that is, development in the brain that is supposed to occur after birth and is 4 times longer in humans than that of other primates.<sup>27</sup> In addition to new brain cell production, this development involves interconnections between neurons being created, strengthened, and sometimes "pruned" through patterns of use and disuse that occur with experience and learning. These processes are what turn the smooth outer surface of the brain into a bumpy surface with deep crevices (the sulci and gyri). Many of these interconnections create intricate pathways between the lower "emotional" centers of the brain and the higher "cognitive" ones in the neocortex.<sup>28</sup>

Accurate and fast reciprocal communication between these brain areas is the underpinning for the

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ability to self-regulate and direct attention successfully on the kind of cognitive and social tasks in which humans engage. These include the ability to speak, to read and write, and to plan and organize complex information of the sort required for adequate schoolaged and adult social, academic, and career functioning. Importantly, they also include the capacity for curiosity, persistence, cooperative and satisfying relationships, and complex emotion understanding.

Self-regulation is the ability to coordinate and organize motor activity, levels of arousal, and attention, and is important for human learning, planning, decision making, performing complex sequential actions, and resisting temptation.<sup>29</sup> In addition, social interactions cannot flow smoothly between people unless they self-regulate their social behaviors and have the capacity for complex emotion understanding.<sup>30</sup> Hence, attention and emotional reactivity must be organized with the ability to self-monitor and correct errors when engaging in coordinated goal-directed activities of all types.<sup>31</sup>

Early research indicates an increased risk for attention-deficit/hyperactivity disorder (ADHD) in school-aged children who were born preterm. 9,32-34 The ADHD involves problems with the inhibition of impulsive reactions (emotional or movement) to stimulation, the ability to successfully prepare organized responses to environmental events, and the ease with which a person is able to incorporate feedback into his or her actions and coordinate information from multiple sources. Thus, ADHD taps significantly into self-regulation, attentional skills, and emotional reactivity, 29,35 and we should not be surprised to see that premature infants may be susceptible to this disorder. Research into how to treat ADHD needs to be integrated with preemie intervention strategies and will be discussed later.

For human infants, self-regulation is supported during infancy by caregivers. Caregivers help in the achievement and maintenance of calm, alert states during which the most learning occurs. The importance of successful self-regulation is firmly grounded in Heidi Al's synactive theory of developmental and individualized care for infants in the NICU (eg, Als, 1998/NIDCAP)<sup>36</sup> and in more recent discussions of the relation between the premature infant and their social and physical environment.<sup>37,38</sup> Nurses work hard to provide supportive neurodevelopmental care and help infants in the NICU to self-regulate.<sup>39</sup> Clustering of care, decreased and appropriately timed sensory stimulation, nonnutritive sucking, kangaroo care, and massage attempt to optimize the infant's physiology through enhanced regulation of certain heart rate rhythms and sleep/wake cycles, leading to increased levels of nutrition, good weight gain, and possibly better neurobehavioral development.<sup>40,41</sup>

Successful self-regulation is necessary for directing attention and engaging in coordinated action in

social, emotional, and cognitive functioning well beyond the neonatal, infancy, toddler, and preschool period, <sup>42,43</sup> and there is growing evidence that self-regulation is impaired in preemies. <sup>44-46</sup> Efforts and strategies to enhance self-regulation skills similar to those used in the NICU may need to be extended beyond the NICU in order to develop healthy family and peer relationships and for the achievement of educational goals and independent living skills. In the next section, typical problems of preemies as they get older, and suggestions for continuing the strategies used in the NICU, are presented.

#### Preemies as Infants and Toddlers

One of the major reasons that human infants are born in such an immature and dependent state compared with infants of many other animals is the need for specific social stimuli to promote sophisticated self-regulatory and attentional abilities.<sup>27,35</sup> In other words, certain types of experience are "expected" by the developing human brain. Unfortunately, preemies are less able to begin to learn the components of self-regulation that are rooted in early human social interactions.

Preemies spend more time in sleep and agitated states and frequently show aversive responses to many of the social stimuli directed to them even after they leave the NICU. Many preemies thrust out their hands and keep their eyes shut even when they are not fussing or sleeping. When their eyes are open, preemies frequently avert their gaze at times when term infants would be having increasingly extended bouts of mutual gaze with a caregiver.<sup>47</sup> In addition, when internal states are irritating or painful, like might be the case for infants experiencing reflux or breathing difficulties, the ability to successfully attend and learn from the external environment is impaired. These behaviors also interfere with the ability of caregivers to read the infant's emotional cues correctly and respond appropriately, quickly, and consistently to their needs.<sup>47–49</sup> The caregivers of preemies engage in less interactional synchrony and contingent responsiveness to fussiness and nondistress vocalizations, compared with their interactions with full-term infants.50

Parents may need additional support to learn to make sure that their infant is not overstimulated and to encourage quiet, awake, alert states in which mutual gaze and beginning contingent social interactions can occur. Parents can begin to gently "play" in face-to-face communication through singing, imitation of infant noises, and commenting on infant behaviors so that conversation is modeled. Repetition and routines of this kind are not boring for a child. 51,52 Gradually increasing the complexity of the speech directed at the child in multiple contexts, engaging in rhyming games and repeating and rephrasing infant vocalizations will build language skills. In all of these interactions, the establishment of

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mutual gaze, shared attention, and turn taking are especially important. If a child does not begin to successfully engage in these behaviors, intervention services should be sought.<sup>53</sup>

#### **Preschooler Preemies**

Over the course of the preschool and school years, children need to begin to utilize internal sources of self-regulation to support learning. As the preemie toddler turns into a preschooler, there might be continuing problems with sleeping and eating, difficulty self-soothing, and a generalized degree of hyperarousability. 45 These children may spend less time in free play, participate in less constructive and dramatic play, spend less time playing with or beside other children, and have fewer conversations with other children. They may have more negative interactions with teachers and be less compliant with the demands of adults by showing more "out-of-seat" behavior and impulsivity (eg, being worse at storytime and better at music time). With regard to speech, there may be persistent difficulty with coming to the point, frequent offtopic utterances, and difficulty with the abstract aspects of words, including age-appropriate humor.

Parents continue to play a critical role in helping their premature children develop better self-regulation skills across the preschool and school years.<sup>54</sup> First, the home should be childproofed to ensure that self-directed active exploration is safe. This will provide access to interesting things to which the child can begin to successfully direct his or her attention independently. In addition, children with selfregulation problems need more external supports for learning-more intermediate steps toward achieving goals with more immediate and frequent rewards, and more extensive use of verbal prompts and cues.<sup>55</sup> During social interactions, parents need to continue to show contingent, sensitive responses to child behavior. The child's ability to rely on consistent care and attention will foster self-control. Parents can also be aware of situations in which children are likely to have problems controlling their emotions and actions appropriately and be prepared to help the child.<sup>56</sup>

Parents also have an important role in engaging in times of shared attention to environmental stimuli in which the adult is not intrusive or demanding in the conversation or interaction.<sup>57</sup> The adult needs to make a special effort to take the child's perspective and be respectful and responsive to it. This will allow the child room to learn problem-solving skills and concentration abilities. The adult can provide appropriate choices in learning situations and support the child's choices. Critically, demonstrating the self-regulatory use of language by linking speech to behavior and sensory information will help the child begin to use language for communications both with others and with himself or herself through "self-talk" or private speech.<sup>55</sup> Telling stories, playing games with

opposites, and demonstrating prepositions will begin to develop the child's understanding of relations between objects, actions, and ideas using language.

"Self-talk" is an essential component of control of actions by thoughts and plans. The child should be encouraged to use words to express feelings and not simply act out on them. Learning chores, playing games with rules, and engaging in pretend play that includes role-playing (conforming one's behavior to make-believe situations) can also help children learn to think before acting. Aiding in the development of social skills with peers is also important, like encouraging sociodramatic and role-play, helping children be tactful and learn to share, and modeling other prosocial behaviors. The goal is to create children who are eager to participate positively in social interactions and the environment rather than needing a lot of directions or prodding to exert effortful control over impulses and negative behaviors. These are the skills that are the foundations of successful relationships with others and performance on school and other cognitive tasks.31,53,55,57

#### **School-age Preemies**

Difficulties with both physical and behavioral self-regulation may continue in the school-aged years and beyond, especially because so many more organized, self-directed attentional skills are going to be needed. 53,58 Children should be encouraged to engage in outdoor physical exercise, get adequate sleep, and eat well. Caregivers of school-aged preemies need to continue providing safety and love through environmental and social supports. In interactions, almost all of which should be viewed as learning situations, a balance between being overly directive, and encouraging problem solving and creativity should be achieved. Parents can talk about feelings and mental states to model empathy, teaching the use of words to plan and control behavior. 59

Paying attention also requires motivation. Having reasonable expectations for behavior and consistently discussing the rules and the consequences of infractions will be important to support good levels of motivation. For example, slowly increasing the time spent on difficult tasks like homework will make it easier for the child to build good study skills. Individual sports might be preferable over team sports to individualize motivational strategies.<sup>57</sup> Poor performance in school and lack of interest in school-based activities are another indication that parents should seek out intervention services, if they are not already being offered by educational personnel. Consistent strategies and goals for improving self-regulatory behaviors across school and home should be pursued.

#### IN CONCLUSION: TALKING TO PARENTS

Medical personnel in the NICU must constantly answer the question from parents "will she be OK?"

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What are parents asking? "Will she die?" is most probably what the question means in the early days after birth. But as the chances that the infant will die fall, the question may be asking whether the infant will develop normally or show handicaps. We must be careful to listen and respond appropriately to this second meaning in order to honestly portray the ramifications of prematurity. It is important to convey that negative neurodevelopmental outcomes are occurring in the absence of observable brain hemorrhages in the perinatal period or cerebral palsy in infancy and toddlerhood. What we are seeing is disruption of normal organizational processes of brain maturation after our initial assessments of neurological functioning. Successful achievement of basic skills in regulating sleep/wake cycles and nutritional intake and engaging in basic social interactions may not lead to the higher-level attentional abilities needed for complex planning and organizational skills. Parents need to be prepared for what is to follow so they can help professionals assess upcoming problems and address them.

It is of paramount importance that we begin to have meaningful and instructive conversations with parents about maturational problems and the underlying self-regulatory skills that may have been disrupted by premature birth. Premature infants have a right not only to physical health and well-being but also to neurobe-havioral health and well-being. <sup>60</sup> We want parents to work with professionals to provide support for curiosity and learning, positive family and peer relationships, successful academic achievement, and feelings of confidence and self-worth. NICU nurses have an important part to play in this education.

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