Is a Premature Infant Ever an “ex” or “Former” Preemie?

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Opinion

Is a premature infant ever an “ex” or “former” preemie? I say, no. Moreover, I feel strongly it is time to stop referring to premature infants in this manner. In 1995, Badgwell affirmed the following: “remember that the premature infant is defined as being less than 37 weeks gestational age; therefore, an “ex-preemie” by definition has now reached greater than 37 weeks conceptual age” [1]. This type of designation may have made it easier for the medical profession to determine when a neonate was closer to term, thus popularizing its use. However, the terminology has morphed in use and is no longer helpful in recognizing the life changing events that may impact the life course of premature infants.

In medical documentation, discharge planning meetings, pediatric offices, and conversations between medical professionals, the dialogue is about the “ex” preemie. Here is one example, which is probably the most egregious I have ever seen: an infant born at 23 weeks and 3 days gestation (23 3/7) was referred to in the medical record as “this ex-preemie” on day one of life. Former preemie? Seriously! This infant is still a premature neonate at 23 4/7 days, and, based on research, development and overall functioning will be impacted for years to come, a lifetime of years to come.

What we know about the long-term developmental outcomes of premature infants ought to inform our conversations with medical students, pediatric residents, parents, pediatricians, educators, medical professionals and others providing services and supports to children who were born prematurely. Recognizing the developmental complication, that is the intellectual, academic and behavioral consequences, of prematurity can improve the short and long-term outcomes and life course of those born prematurely.

In the United States, approximately ten percent of all births are preterm and the rate of preterm births continues to rise. We are experiencing the increased survival of the smallest and of the sickest infants. The prevalence of major neonatal morbidities such as periventricular leukomalacia (PVL), bronchopulmonary dysplasia (BPD), retinopathy of prematurity (ROP), necrotizing enterocolitis (NEC), is relatively unchanged, despite ever evolving and less invasive medical strategies [2]. Premature infants, especially those who were extremely premature (less than 28 weeks gestation) are at substantial risk for poor neurodevelopmental outcomes and significant lifelong disabilities. There is growing evidence that proposes that gestational age (GA) may be conceptualized as a continuum in which births prior to 28 weeks gestation represent the severe end of a spectrum of developmental adversity and health outcomes. Early preterm births pose the greatest challenge to neonatal medicine and to education, health and social services and supports [3].

Abnormal brain development may be the result of oxygen deprivation, intraventricular hemorrhage, periventricular leukomalacia, or other brain insult. Approximately fifty percent of preterm infants experience academic and behavioral consequences of an early birth. An infant born with a birth weight (BW) less than 1,500 grams or 3.3 pounds has an 11.6 percent increased risk of being diagnosed with intellectual disabilities [4]. Children born prematurely experience difficulties in learning, understanding language and in reading comprehension. They experience difficulties with visual perceptual abilities, graphomotor skills, visual memory, complex language and abstract reasoning which often results in grade retention and special education services.

Individuals born prematurely are also at risk for attentional difficulties and hyperactivity. Research indicates that there is a two to six percent increase in infants with a BW between 1,000 grams and 1,500 grams being diagnosed with Attention Deficit Hyperactivity Disorder (ADHD). Overall, children with ADHD
are 3.1 times more likely to have been born with a BW less than 2,500 grams. Additionally, premature infants are at-risk for social-behavioral communication dysfunction and psychiatric disorders in adolescence and adulthood [5].

Adverse developmental outcomes can lead to difficulties in social, employment and health realms in adults who were born prematurely, which could lead to continued economic and social difficulties. Premature infants are more likely to repeat one or more grades, more likely to require special education services, and more likely to leave school early. Seventy-four to eighty-two percent graduate from high school and only thirty to thirty-two percent matriculate to college. As adolescents and adults, premature individuals do not perceive themselves as different from their peers behaviorally or emotionally; yet, they rate themselves lower in scholastic, athletic, romantic and job competency measures [5].

We have improved the major morbidities of prematurity but now have a population of those suffering from a “hidden disability”. This population is easily misdiagnosed as functioning on the autism spectrum with higher positive screens seen in children with lower gestational ages at birth. A number of studies have reported reduced social interactions and risk-taking behaviors in very premature and very low birth weight adolescents and higher introversion, autistic features and neuroticism that may reinforce some of the social difficulties in this population [3]. Premature children do look differently from children on the autism spectrum both behaviorally and medically.

It is incumbent upon the medical profession to stop using the term “ex” or “former” preemie in order to promote family and educator understanding of possible neurodevelopmental outcomes as these premature infants grow and learn. Research of preterm populations shows improved short-term outcomes for infants who received developmental care including: increased growth; decreased pulmonary support; decreased incidence of respiratory disease; and, improved neuro developmental outcomes [6]. But why stop here? Parents who hear “this ex-preemie” in daily rounds often assume that their child’s prematurity has resolved just as their ROP or NEC has resolved prior to discharge. Reinforcement of their “ex preemie” status by the pediatricians further confuses the parent who is urged to continue receiving services from medical and developmental follow-up programs.

The complications do not end when the neonate is discharged from the neonatal intensive care unit (NICU). Those born prematurely never outgrow the effects of their environment and early experiences on their central nervous system (CNS) maturation. They may accommodate and have minimal overt difficulties, but you cannot fully erase how an atypical environment influenced neurologic system development. It is time to change our terminology.

References