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In their own words: Life at adulthood after very premature birth

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ARTICLE INFO

Keywords:
Extremely premature infants
Adulthood
Quality of life
Personal perspectives
Narrative medicine

ABSTRACT

Very premature infants born in the last century following the early days of post-neonatal intensive care have demonstrated an array of physical, emotional, and mental health problems as they approach their third and fourth decades. These outcomes have been well documented by several international investigators. However, there is a paucity of information on the personal perspectives of these individuals with regard to their own quality of life, their hopes and their fears. This article will focus on the objective information from the published literature and how it differs from the personal perspectives of former very premature infants.

A large body of literature exists on the medical and mental health outcomes of very premature infants at adulthood, both from longitudinal cohort studies[1–18] and from National Databases.[19–22] Most studies suggest that a significant proportion of former premature infants have made a reasonably successful transition into adulthood, although some differences do exist when compared to normal birth weight (NBW) peers.

However, to date, hardly any studies have reported on the personal "existential" perspectives of former premature infants. Although there is objective data on their health, achievements, and social integration, no studies have sought to find out how these former preemies feel about their life, family and partner relationships, work satisfaction, and their hopes and fears for the future. In other words, we have not considered asking former preemies, who are now adults, "how has prematurity affected your life?" or "how do you see your future unfold?" Obviously, the key question is, whose perspectives are important? It is clear that from the perspectives of health professionals and for quality assurance, that objective measurements are most important.[23] However, from the perspectives of former premature individuals, their feelings about their own life and their future should be paramount. In this chapter both perspectives will be presented.

Outcome of very premature infants at adulthood

The majority of longitudinal studies on adult outcomes have emanated from Europe, Canada, the United States, and Australia. These cohort studies were conducted on very low birth weight survivors from the late 1970s and early 1990s, and include a broad range of outcomes such as physical and mental health, education, employment, peer, partner and sexual relationships, and marriage and childbirth.[1–18] Recently, studies from the Scandinavian countries.[19–22] have examined adult outcomes on a broader gestational age range up to term, using data from their national databases. These national studies link data from birth to adulthood, and have the advantage of a very large sample size, lower costs, and fewer losses to follow-up.

Disclosure: Dr. Saigal is the author of the book, "Preemie Voices." This chapter is based partly on the book (publisher, Friesen Press, Vancouver, BC, Canada, 2014).

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http://dx.doi.org/10.1053/j.semperi.2016.09.010
0146-0005/

Most studies in the literature have reported poorer educational attainment in terms of graduation from high school and enrollment in post-secondary education,[1–3,7] although some report no differences.[4] European national studies report a gestational age gradient,[19,20] with fewer premature participants having completed University education.[19] Unemployment rates vary at young adulthood, and depend on whether they were enrolled in post-secondary education or had neurological impairments.[1,4] Lower gestational age was associated with a lower income, with more receiving social security benefits.[19]

Reports also vary in terms of the social lives of VLBW participants, with some reporting similar rates to the NBW group,[2] whereas the others report that the premature groups are less likely to live independently,[2,9] engage less in sexual activity,[1,5,7–10] have fewer sexual partners,[9] and have lower rates of pregnancy and childbirth.[1,5,8,9,20,24–26] There is also a suggestion of a higher rate of premature births among female participants.[24]

Of concern are the higher rates of internalizing problems, such as depression, withdrawal, and anxiety disorders that seem to peak at adulthood.[11–16] In addition, there are differences in the temperament and personality of VLBW adults, including higher conscientiousness and agreeableness, and lower sociability and extraversion.[17,18] These characteristics of cautiousness and low extraversion may account for the lower incidence of risk-taking behaviors that have been reported consistently in all studies.[1,2,5,8,22]

The McMaster Canadian cohort of extremely low birth weight (ELBW) has been followed on two occasions at adulthood (19–25 years and 29–36 years).[4,5] These infants, with birth weights of 1000 g and below, were born between 1977 and 1982 in a geographically defined region of central-west Ontario.[27] The regional survival in that era was 46%, and 166 ELBW infants survived to young adulthood (19–25 years). The comparison group was comprised of 149 normal birth weight (NBW) children recruited at age 8 years.

At the first assessment at young adulthood, there were no differences between the groups in the proportions of those who had completed high school, were living independently, were employed, had married/cohabited, and had children.[4] A higher proportion of ELBW women reported internalizing problems.[12]

At their latest assessment into their thirties (29–36 years), however, the ELBW group showed a divergence from the NBW participants in several areas.[5] Although there were no differences in the highest educational level achieved, a lower proportion of the ELBW group were employed, fewer had full-time employment, their household income was approximately $20,000 lower, and more required social assistance. For the first time in the longitudinal follow-up of this cohort, the ELBW group reported lower self-esteem; however, they had similar success in family and partner relationships, and exhibited lower risk-taking behaviors. They were also more likely to be single, never having experienced sexual intercourse, and a lower proportion had children. After exclusion of ELBW with impairments, differences in employment, social assistance, marital status, and having children were no longer significant. In terms of their mental health, ELBW adults had higher odds of having generalized anxiety disorders, social phobias, and inattentive subtype of attention deficit anxiety disorders.[13] Although the above findings may collectively appear to be negative, a significant majority of ELBW adults were functioning members of society, despite the presence of impairments in one-fifth of the survivors.

Quality of life

The above section has provided us with objective data at adulthood. However, there has been a shift in our thinking in the last three decades. We now believe that measures of disease status alone are insufficient to capture the personal burden of illness and life satisfaction. Other factors that impact on the quality of life (QL) such as physical and functional limitations, pain, inability to assume personal and family responsibilities, and the consequent financial burden must also be considered.[28]

We first obtained the self-reported health-related quality of life (HRQL) of this cohort when they were adolescents, using the standard gamble technique.[29] Our hypothesis was that the ELBW group would have a substantially lower quality of life than their NBW counterparts. We showed that although the mean HRQL score was lower than that of the NBW group, we were impressed with the fairly high HRQL scores provided by the ELBW group, despite the fact that one-quarter of them had impairments (0.87 vs. 0.93, on a scale of 0–1; where 1.0 indicates “perfect health,” and zero is equivalent to “dead”). When we repeated the HRQL at young adulthood, we again anticipated that the HRQL of ELBW would be lower, as they were now in the “real world,” and no longer under the protective umbrella of their parents. However, this time there were no differences between the HRQL scores of the two cohorts (0.85 vs. 0.88).[30] It should be noted that these scores represent all participants, including parental proxy responses for those with severe impairments. Also, interestingly at both ages, there were no differences in the scores between those with and without impairments.

So what have we learned from these QL studies? It appears that despite physical challenges, the premature adolescents and young adult participants, valued their life highly, and nearly equivalently to those of the NBW cohort. So, while it may be surprising that the ELBW rate their HRQL high, the more intriguing question is why the NBW participants who do not have any impairments, do not rate their HRQL much higher? It is quite likely that individuals with impairments find satisfaction in overcoming their challenges and cherish their lives in ways that the able-bodied may find hard to comprehend.

The term “disability paradox,” coined by Albrecht and Devlieger,[31] has been used to describe the situation in which individuals report a high quality of life despite impairments or chronic illnesses. Several studies have now shown that when the personal perceptions are elicited from patients, they are often discordant with the objective measures as rated by health professionals,[32] or as viewed by society. Individuals with impairments argue that it is not the disability itself that results in their dissatisfaction, but the lack of opportunities and attitudes of society toward their functional challenges.[33]