



Behavior and well-being of extremely low birth weight teenagers in Iceland



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ABSTRACT

Background: Preterm children are at risk for behavioral and emotional problems.

Aims: To evaluate behavior and emotional well-being of extremely low birth weight (ELBW) teenagers born in Iceland in 1991–1995.

Methods: Participants, 30 of 35 ELBW survivors (25 girls, 5 boys, mean age 16.8 years), were interviewed, underwent medical examination and answered the Youth Self-Report for ages 11–18 (YSR) of the Achenbach System of Empirically Based Assessment (ASEBA). The ELBW parents answered the ASEBA Child Behavior Checklist for ages 6–18 and the Autism Spectrum Screening Questionnaire (ASSQ). A comparison group of 30 teenagers (23 girls, 7 boys, mean age 16.5 years) answered the YSR questionnaire and their parents answered the CBCL and ASSQ questionnaires.

Results: ELBW teenagers and parents report more behavior problems than the full term comparison teenagers and parents. They score significantly higher on the YSR and CBCL syndrome scales except for YSR and CBCL rule-breaking behavior and CBCL thought problems. The ELBW teenagers self-report on total competence, activities, social participation and academic performance was not significantly lower than the comparison teenagers. Parents of ELBW teenagers rated total competence, social participation and school performance of their children significantly lower than parents of comparison teenagers. The YSR Positive Qualities Scale was not significantly different between the two teenage groups. Two ELBW teenagers scored above cut-off points on the ASSQ questionnaire and none of the comparison teenagers. Bullying was reported by 20% of ELBW parents compared to none of the comparison group.

Conclusion: ELBW teenagers experience emotional, behavior and social challenges. The teenagers value their positive qualities, activities and academic performance similar to peers.

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1. Introduction

Improved neonatal intensive care, technical advances and devoted health care personnel have significantly increased survival rates of extremely low birth weight (ELBW) infants in the past 2–3 decades [1–5]. At the same time increased research interest in long term outcome has established firm evidence of multidimensional neurodevelopmental sequelae and impairments among the surviving children [6–9]. High risk of cognitive deficits has been identified in this vulnerable population as well as neurosensory impairments like cerebral palsy, blindness and deafness, and motor, behavioral and educational impairments [10–16]. Investigators have also reported subtle cognitive impairments in over 50% of very low birth weight (VLBW) and ELBW children [9,17], as well as impairments of visual-motor skills and impaired executive functioning, memory and adaptive functioning [12,18,19]. Many ELBW

schoolchildren have learning difficulties, especially in mathematics [10,11,19,20], and they have increased needs of special education compared to full term peers [9,11,20,21]. Even ELBW school-children without neurosensory or cognitive impairments have been found to have higher rates of learning disabilities than normal birth weight peers [10,19].

Reports on ELBW and VLBW adolescents and young adults born in the 1980s are not universal regarding academic and social difficulties [22–25]. Canadian ELBW teenagers reported lower scholastic and athletic skills and lower job and romantic competence than control peers [22]. Their parents reported more behavior and psychiatric problems than control parents with ELBW boys showing more problems than ELBW girls [22]. In another study ELBW teenagers evaluated their behavior similar to control teenagers whereas their parents reported significantly more emotional and attention problems [23]. In young adulthood high school graduation, secondary education and employment were similar among the ELBW and the normal birth weight control groups and there was not a significant difference between the two groups regarding independent living, marriage/cohabitation and parenthood [24]. In Ohio, USA fewer VLBW adults had graduated from

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high school and their cognitive and scholastic skills were significantly lower than among control subjects. However, when lifestyle and risk behavior were assessed, there was a positive difference with the VLBW young adults using less alcohol and tobacco than controls [25].

As for ELBW survivors of the 1990s, after the initiation of surfactant use, information has emerged on cognitive, behavioral and learning problems at school-age and in middle childhood [26–29]. The so called “preterm behavioral phenotype” characterized by inattention, anxiety and social difficulties was described among extremely preterm children born in the UK in 1995 [30] and early screening for cognitive and behavioral problems was recommended for increased risk of attention deficit and hyperactivity disorder (ADHD), emotional disorders and autism spectrum disorders [31]. In Ohio, USA, young ELBW adolescents born in 1992–1995 had lower scores on intelligence tests as well as tests of reading, mathematics and executive function when compared to normal birth weight peers [32]. According to self-report on health, functioning and well-being, the ELBW teenagers valued their satisfaction, comfort, resilience, achievement and disorders similar to normal birth weight peers and reported more risk avoidance [33]. However, being victims of bullying was reported more often among the ELBW teenagers and was associated with subnormal intelligence, functional limitations, anxiety and less risk avoidance [34].

In Iceland survival of ELBW children has been monitored for years and outcome in the 1990s and 2000s has been reported to be similar to other population based studies [35]. Results of a multidisciplinary national study at five years of age revealed that a quarter of the ELBW children was indistinguishable from healthy, normally developing same age peers born at term, two quarters had mild impairments and a quarter of the children had major neurological and/or developmental impairments [36]. Preschool developmental testing revealed cognitive deficits, poor sensory-motor skills and more behavior problems among the ELBW children when compared to full term peers, especially emotional, social and attention problems [37]. In adolescence a quarter of the teenagers in this cohort had disabilities and over 50% of them reported chronic health disorders and/or learning difficulties requiring special teaching [38]. In comparison to full term peers the ELBW teenagers reported lower quality of life with regard to physical and psychological well-being, moods and emotion and self-perception [39].

In this part of the study on ELBW teenagers we aimed to evaluate behavior, social adaptation and emotional well-being and compare them with those of full term peers. We expected the ELBW teenagers to experience behavior and social challenges. However, we hoped that support and special education throughout childhood and adolescence had enabled them to maintain a positive self-image and confidence.

2. Method

The study was part of a follow-up study on Icelandic ELBW teenagers, born in 1991–1995. According to the National Birth Registry a total of 102 infants, 58 (57%) girls and 44 (43%) boys, with birth weight 500–999 g were born in Iceland in the five year period, 67 live born and 35 stillborn. At five years of age 35 ELBW children (52%) were alive and participated in a multidisciplinary study on survival and developmental outcome. The proportion of girls in the cohort was unusually high (77%). Of the 35 ELBW survivors, 31 agreed to participate in the teenage study, 26 girls and five boys. One healthy, unimpaired teenage girl withdrew from the study and one teenage boy with major disabilities was unable to answer questionnaires, thus a total of 29 (83%) ELBW teenagers and 30 (85%) ELBW parents completed the study. Of the 29 ELBW teenagers able to respond, two had major disabilities and five had mild disabilities. Long term health problems requiring medical attention were reported by 17 (57%) of the 30 ELBW participants. Four ELBW teenagers from the national cohort, ages 17–19, did not consent to participate in the teenage study. Three of them attended school or were employed and one has major disabilities.

A group of 55 full term children had participated in the multidisciplinary study at five years of age in 1996–2001. The comparison children were recruited from the capital area, 1–3 children of the same age and gender for each ELBW child, with birthweight over 2700 g, born on the same day as the ELBW children, and had not undergone formal developmental testing prior to entry into the study. The comparison children had similar family background as the ELBW children regarding parental education and employment. Of the original comparison group of 55 children 37 agreed to participate in the teenage study. Seven did not complete the questionnaires, resulting in 30 (55%) comparison teenagers in the study, 23 girls and seven boys. None of the participating comparison teenagers had disabilities or reported long term health problems requiring medical intervention.

The study was conducted in the spring of 2010 when the ELBW teenagers were 14–19 years old (mean age 16.8 years) and the comparison teenagers were 14–18 years old (mean age 16.5 years). To evaluate behavior, social adaptation and emotional well-being the data was collected through standardized questionnaires, the Child Behavior Checklist (CBCL) for ages 6–18 and Youth Self-Report for ages 11–18 (YSR) of the Achenbach System of Empirically Based Assessment (ASEBA) [40] and the Autism Spectrum Screening Questionnaire (ASSQ) [41]. At the time of the study, three of the participating ELBW teenagers were 19 years old and nine were 18 years old, and thus above the CBCL and YSR questionnaires' age limit of 18 years and the ASSQ age limit of 17 years.

The CBCL and YSR forms were translated and published in Iceland in 2002–2004 and have been used in research and clinical work. The CBCL questionnaire consists of 113 questions and the YSR of 112 questions. The questions are rated 0 for not true, 1 for sometimes true and 2 for often true. Eight syndrome scales are constituted from the answers: anxious/depressed, withdrawn/depressed, somatic complaints, social problems, thought problems, attention problems, rule-breaking behavior and aggressive behavior. Three composite scales are computed: internalizing scale from anxious/depressed, withdrawn/depressed and somatic complaints, externalizing scale from rule-breaking behavior and aggressive behavior and total problem scale from all syndrome scores. The questionnaires also include seven questions on school, leisure and social activities that reflect parental and teenage description of general participation and competence. In a comparison study among 24 countries the mean total problem score ranged from 25.0 in Germany to 48.3 in Greece. Seventeen countries scored within one standard deviation (6.0) of the grand mean of 35.3 [42]. Iceland along with Germany, Finland and Norway scored more than one standard deviation below the grand mean [42].

In addition to the problem scales, scales referred to as 2007 scales can also be computed from the CBCL and/or YSR questionnaires. Two of them, Obsessive–Compulsive Problems (OCP) and Posttraumatic Stress Problems (PTSP) are computed from answers to 9 and 14 questions on the CBCL and YSR questionnaires. The third scale, Sluggish Cognitive Tempo (SCT), is computed from five factors from the CBCL or the Teachers' Report Form (TRF) and has been shown to be associated with the inattentive type of ADHD. The fourth factor, Positive Qualities (PQ) Scale, is computed from 14 YSR items: 6. I like animals; 15. I am pretty honest; 49. I can do certain things better than most kids; 59. I can be pretty friendly; 60. I like to try new things; 73. I can work well with my hands; 80. I stand up for my rights; 88. I enjoy being with people; 92. I like to make others laugh; 98. I like to help others; 106. I like to be fair to others; 107. I enjoy a good joke; 108. I like to take life easy; and 109. I try to help other people when I can [42]. The PQ scales have been calculated for several countries, showing low scores in Hong Kong, Korea and Japan and high scores in USA and Australia, possibly reflecting a difference in social pressure against appearing boastful [43].

The ASSQ questionnaire was designed for children and teenagers ages 6–17 and is answered by parents and/or teachers. It consists of 27 statements that are scored 0 points for “this does not apply”, 1 point for “this does sometimes apply” or 2 points for “this applies very

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