Health Status of Extremely Low-Birth-Weight Children at 8 Years of Age

Child and Parent Perspective

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Objectives: To compare the self-reported health of extremely low-birth-weight (ELBW; <1 kg) preterm children with that of normal-birth-weight (NBW) control children and the children's perspective with that of their parents.

Design: We administered questionnaires to the ELBW and NBW children and their parents from March 1, 2000, through February 2003.

Setting: A children's hospital.

Participants: Two hundred two ELBW children and 176 NBW children aged 8 years of similar sociodemographic status.

Main Exposure: Birth weight of less than 1 kg.


Results: There was poor agreement between the parent and child ratings of health for the ELBW and NBW cohorts. The ELBW children rated their health as similar to that of NBW children. In contrast, parents of ELBW children reported significantly poorer health for their children than parents of NBW controls, including poorer satisfaction with health, comfort, and achievement and less risk avoidance.

Conclusions: There is poor agreement between child and parent reports of health. At 8 years of age, ELBW children rate their health as similar to that of NBW controls. Their parents, however, report significantly poorer health. Both perspectives need to be considered when making health care decisions.

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Reports of the long-term outcomes of children with extremely low birth weight (ELBW) and gestational age have focused on assessments of neurodevelopmental outcomes and behavior. The few studies of health status during the school years have been based mainly on parental proxy report. These have indicated that preterm children have a poorer health status than full-term control children, including poorer performance in physical, emotional, and social functioning. However, parental proxy reports provide an incomplete view of children's health because parents may be unaware of their children's internal feelings of health and well-being. To date, the only information on the self-perception of the health of preterm children pertains to adolescents. There have been no studies at earlier ages despite evidence that children as young as 7 to 8 years understand health concepts, are able to provide reliable responses to a health survey, and accurately respond to a 4-week recall period for symptoms or behaviors.

As part of a longitudinal study, we sought to examine the self-reported health experiences at age 8 years of ELBW (<1 kg) children compared with those of normal birth weight (NBW) controls and to compare the children's perceptions with those of their parents. For this purpose we used the Child Health and Illness Profile–Child Edition (CHIP-CE), a multidimensional instrument with child self-report and parent proxy forms. The CHIP-CE includes a broad set of measures that assesses satisfaction with one's health and self, symptoms and limitations due to illness, psychosocial resiliencies, avoidance of risk behaviors, and achievement in school and with friends. We hypothesized that the children's perception of their health would be more positive than that of their parents and that their perceptions of health would be determined by biological risk as evidenced by ELBW status and by sociodemographic risk factors, with both having a negative effect on health.
ELBW COHORT

The study population included 344 ELBW children admitted to the Neonatal Intensive Care Unit at Rainbow Babies and Children's Hospital from January 1, 1992, through December 31, 1995. Thirteen children (10 with major congenital malformations, 2 with AIDS, and 1 with tuberous sclerosis) were excluded. Of the remaining 331 children, 238 (71.9%) survived, of whom 219 (92.0%) were followed up to 8 years of age.15,22 Seventeen ELBW children did not complete the CHIP-CE questionnaire (15 were unable to comprehend the questions and 2 completed only 1 domain). These children had a mean (SD) IQ of 49 (11); 10 had cerebral palsy; and 1 was autistic.23 The present report thus includes 202 ELBW children and their parents who responded to the CHIP-CE questionnaire. The 202 participants had significantly (P < .05) lower rates of cerebral palsy (21 of 202 [10.4%] vs 10 of 17 [58.8%]) and subnormal (<85) IQ scores (67 [33.3%] vs 17 [100.0%]) and few boys (77 [38.1%] vs 12 [70.6%]) than the 17 nonparticipants but did not differ in caregiver education (26 [12.9%] vs 0 had less than a high school education) or race (123 [60.9%] vs 6 [35.3%] black).

COMPARISON GROUP OF NBW CHILDREN

A control group of NBW children (gestational age, >36 weeks by parent report) was recruited at 8 years of age by randomly selecting a child from a list of children in the same school as the ELBW child who was within 3 months of age and of the same race and sex as the ELBW child. Controls were recruited for 176 (87.1%) of the ELBW children, all of whom responded to the CHIP-CE questionnaire.15

MEASURES AND VARIABLES

The primary caregiver, usually the mother, and the child were interviewed, and the child underwent physical and neurological examinations and psychometric testing, including the Mental Processing Composite of the Kaufman Assessment Battery for Children to measure cognitive function.25 The results have been reported elsewhere.15-19

The primary outcome measure of this report, the CHIP-CE, measures the health of children from 6 to 11 years of age from the perspectives of the child and parent. It includes reports of feelings, symptoms, well-being, health-related behaviors, problem behavior, school performance, and connectedness with family and peers.20,21 It uses the same conceptual framework of the adolescent self-report instrument, the CHIP–Adolescent Edition.24 Most of the items assess frequency or degree, typically during the preceding 4 weeks, using 5 response options (scored 1-5). Scores from each of the 45 questions are used to calculate 5 domains of health, with higher scores indicating better health. The domains include satisfaction (with health and self) with 9 items, comfort (physical and emotional symptoms and limitations in activity) with 12 items, resilience (behaviors that enhance health, including family involvement) with 8 items, risk avoidance (of behaviors that pose a risk to health) with 8 items, and achievement (developmentally appropriate role functioning in school and with peers) with 8 items. The domains are scored as item-level averages. Seventy percent of items need to be completed to be calculated; otherwise the scale score is considered missing. The parent and child reports have been validated and shown to be predictors of children’s use of health care services.12,13,20,21,23,26 They have been used to assess the health-related quality of life of children with attention-deficit/hyperactivity disorder20,24 and to examine the relationship of social class gradients to health in childhood.25

The Child Report Form of the CHIP-CE includes the 45 questions or items illustrated by a cartoon-type race-, age-, and gender-neutral character that anchors the ends of each set of 5 Likert-type graduated response circles, with the smallest circle indicating the least amount or never and the largest circle most or all the time (Figure). The Child Report Form has good domain internal consistency reliability (ranging from 0.70 to 0.82) and test-retest reliability (ranging from 0.63 to 0.66).20,26 The questionnaire was administered by research assistants unaware whether children were part of the ELBW or NBW cohort and took up to 20 minutes to complete. The research assistants usually helped children read the questions and explained the response format. After looking at the illustrations, children marked an “X” in the circle corresponding to their rating.
The Parent Report Form of the CHIP-CE has the same 45 items included in the Child Report Form. It also includes 12 subdomains (31 additional items) and a disorders section with acute and chronic conditions and psychosocial problems. These results are not included in the present report. It takes about 20 minutes to complete. Domain reliability is high with internal consistency of 0.79 to 0.88 (Cronbach’s alpha coefficient) and retest reliability of 0.71 to 0.85.21 The Parent Report Form was administered to primary caregivers of the children. Four caregivers (2 in the ELBW and 2 in the NBW cohorts) responded to less than 70% of the items in a specific domain, which was thus considered missing.

The study protocol was approved by the institutional review board of University Hospitals of Cleveland, and informed consent was obtained from parents.

STATISTICAL ANALYSIS

Univariate comparisons between the ELBW and NBW groups were made using the t tests for continuous variables and the χ² test or Fisher exact test for discrete variables. Multiple linear regression analyses were used to compare the domain scores of the ELBW and NBW Child and Parent Report Forms, adjusting for socioeconomic status (SES), sex, and race. Because the child’s cognitive function may affect understanding of and response to the CHIP-CE questionnaire, in separate analyses we examined the effect of a child’s IQ on his or her self-report. With the available sample size of 202 ELBW and 176 NBW children, the study has 80% power to detect a mean difference of 0.29 SDs, using 2-sided tests at the .05 significance level. Agreement between the parent and child domain scores was examined via paired-sample t tests and intraclass correlation coefficients. In secondary analyses, we compared the outcomes of the ELBW and NBW children who were free of neurosensory impairments.

As in our previous reports, the measure of SES was defined as the mean of the sample z scores of maternal education and median family income according to the 2000 census tract of the family’s residence.15 These serve as a proxy for a range of family and environmental factors. Race/ethnicity was considered a social construct and self-identified by parents from a list of racial/ethnic categories used for federal reporting.

### RESULTS

The ELBW and NBW children did not differ significantly in their mothers’ sociodemographic background (Table 1). The ELBW children were studied at a significantly younger postnatal age than the NBW controls (mean [SD] age, 8.7 [0.7] vs 9.2 [0.8] years; P < .001) because the NBW children could be recruited only after the ELBW child had been enrolled. Among the ELBW children, 12.4% had neurosensory impairments. They also had significantly higher rates of subnormal IQ scores and asthma requiring medication.15,16

### COMPARISON OF THE CHILD-REPORTED CHIP-CE DOMAIN MEAN SCORES BETWEEN ELBW AND NBW COHORTS

According to child self-report, ELBW children did not differ significantly from the NBW controls in any of the domains of health (Table 2). The results were similar after excluding the 25 neurosensory-impaired ELBW children. In multivariable analyses, higher SES was significantly associated with more comfort (β = 0.15; 95% confidence interval [CI], 0.06-0.24) and better achievement (0.10; 0.02-0.19); black race with less comfort (−0.38; −0.54 to −0.21) and risk avoidance (−0.26; −0.42 to −0.10); and male sex with less risk avoidance (−0.21; −0.35 to −0.07). In separate analyses, higher child IQ score (Mental Processing Composite, >84) was significantly associated with more comfort (β = 0.24; 95% CI, 0.07-0.42) and risk avoidance (0.22; 0.06-0.39). In analyses that considered the age of the child, age was not associated with any of the outcomes (data not shown).

### Table 1. Maternal Demographic Risk Factors, Perinatal Data, and 8-Year Outcomes

<table>
<thead>
<tr>
<th>Cohort</th>
<th>ELBW (n=202)</th>
<th>NBW (n=176)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maternal demographic data</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age, mean (SD), y</td>
<td>37 (7)</td>
<td>35 (8)</td>
</tr>
<tr>
<td>Married</td>
<td>102 (50.5)</td>
<td>87 (49.4)</td>
</tr>
<tr>
<td>Educational level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; High school</td>
<td>26 (12.9)</td>
<td>22 (12.5)</td>
</tr>
<tr>
<td>High school</td>
<td>54 (26.7)</td>
<td>44 (25.0)</td>
</tr>
<tr>
<td>&gt; High school</td>
<td>122 (60.4)</td>
<td>110 (62.5)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>79 (39.1)</td>
<td>58 (33.0)</td>
</tr>
<tr>
<td>Black</td>
<td>123 (60.9)</td>
<td>118 (67.0)</td>
</tr>
<tr>
<td>Below poverty level, mean (SD), %</td>
<td>18 (16)</td>
<td>20 (17)</td>
</tr>
<tr>
<td>Annual family income, mean (SD), $</td>
<td>39.9 (21)</td>
<td>36.8 (21)</td>
</tr>
<tr>
<td>Perinatal data</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Birth weight, mean (SD), g</td>
<td>809 (125)</td>
<td>3300 (513)</td>
</tr>
<tr>
<td>Gestational age, mean (SD), wk</td>
<td>26.4 (2.0)</td>
<td>37 (2.0)</td>
</tr>
<tr>
<td>Female sex</td>
<td>125 (61.9)</td>
<td>111 (63.1)</td>
</tr>
<tr>
<td>Multiple birth</td>
<td>35 (17.3)</td>
<td>0</td>
</tr>
<tr>
<td>8-y outcomes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neurosensory impairment</td>
<td>25 (12.4)</td>
<td>0</td>
</tr>
<tr>
<td>IQ score &lt; 85</td>
<td>67 (33.3)</td>
<td>25 (14.2)</td>
</tr>
<tr>
<td>Asthma requiring medication</td>
<td>43 (21.3)</td>
<td>15 (8.5)</td>
</tr>
</tbody>
</table>

Abbreviations: ELBW, extremely low birth weight; NBW, normal birth weight.

a Unless otherwise indicated, data are expressed as number (percentage) of participants.

b Unless otherwise stated, refers to primary caregiver, which for 183 of the ELBW cohort (90.6%) and 157 of the NBW cohort (89.2%) was the biological or adoptive mother.

c Includes biological and adoptive mothers only (16 ELBW and 4 NBW children were adopted).

d Includes 1 Asian ELBW and 2 Asian NBW mothers.
e Indicates mean percentage of families below the poverty level according to the 2000 US Census Bureau.
f Indicates mean of the sample z scores of maternal education and median family income according to the 2000 US Census tract.
g Includes cerebral palsy (n=21), deafness requiring hearing aids (n=3), and blindness (n=1).
h One ELBW child did not have an IQ score.
i P < .001.
j P < .01.

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Parents of ELBW children reported significantly less satisfaction with health and comfort for their children compared with parents of NBW children (Table 2). They also reported poorer achievement and less risk avoidance. Resilience did not differ between groups. The results were similar after excluding the neurosensory-impaired ELBW children. There were no sex differences in any of these comparisons.

In the multivariable analyses, higher SES was significantly associated with better health in all the domains of health, including satisfaction (β, 0.11; 95% CI, 0.05-0.18), comfort (0.16; 0.10-0.22), resilience (0.13; 0.07-0.18), risk avoidance (0.18; 0.11-0.25), and achievement (0.24; 0.16-0.32). Male sex was associated with less risk avoidance (β, −0.24; 95% CI, −0.35 to −0.13) and black race with less resilience (−0.15; −0.26 to −0.06) and risk avoidance (−0.14; −0.26 to −0.02).

**COMMENT**

We sought to examine the health status of ELBW children at 8 years of age from the perspective of the children and their parents. Our results reveal very little agreement between the self-reports of the children and the proxy reports of their parents, with children reporting less comfort and resilience than their parents but better achievement. Despite higher rates of asthma and cognitive and neurosensory impairments, the 8-year-old ELBW children view their health and well-being as similar to those of NBW controls. Parents of the ELBW children report significantly poorer health for their children than parents of NBW children, specifically poorer satisfaction with health, comfort, and achievement and less risk avoidance. Most of the findings were similar when ELBW children with neurosensory impairments were excluded.

This is, to our knowledge, the first report of the self-assessed health and well-being of preterm children born at extremely low birth weight (ELBW) and preterm controls born at normal birth weight (NBW), over an 8-year period. The findings may be of interest to clinicians and researchers interested in assessing the health of preterm children and their parents.
fore adolescence. Previous information has relied on parents acting as proxies for their children, with findings similar to our parent reports. The self-reports of our ELBW children are in agreement with studies of adolescent preterm children, which indicate very little difference between the children’s perceptions of their health and that of NBW controls.

Our findings of poor agreement between parents and their 8-year-old ELBW children concerning their health are similar to results obtained in the study of the original CHIL-CE normative sample of children in which parent-child reports were poorly to modestly correlated. Poor parent-child agreement has also been documented in other normative populations using a variety of questionnaires, including the European KIDSCREEN-52 questionnaire. Among British children, the highest agreement between parents and children pertained to visible and diagnosed conditions and the lowest agreement to emotional symptoms such as sadness and anxiety. Stronger correlations between parent and child reports ranging from 0.44 to 0.61 were found among Dutch children.

Upton et al reviewed the 1996-2006 literature and concluded that parents of healthy children tended to report higher health-related quality of life for their children than did the children themselves, whereas the assessments of parents of children with chronic illness were lower than those of their children. Our findings of poorer parent-reported satisfaction with health and achievement for their ELBW children than the child self-reports are in agreement with these findings. Ingerski et al also found that parents of children with chronic conditions reported poorer physical, emotional, and social functioning but, in contrast to our findings, better school functioning than their children. Achenbach et al reported low parent-child correlations (0.22) for behavioral ratings, with children reporting more internal and subjective symptoms and adults reporting more objective behavioral symptoms. In contrast, Saigal et al reported agreement between parents and their adolescent children, with the only differences pertaining to sensation and cognition.

Many factors influence response to questionnaires. Parent reports may be influenced by their level of education and sociodemographic status as well as by their own health, their child caregiving burden, and the child’s health status. Children’s reports are influenced by their age, gender, health, and cognitive level as well as by their social experience. Our study population was restricted to ELBW children capable of responding to the CHIL-CE questionnaire, thus excluding severely impaired children. Parents may have reported even poorer satisfaction with health and achievement for their ELBW children had such children been included.

The predominant effect of SES on the health status of children has been well described. We used a composite of maternal education and family income as a measure of SES and found a significant effect of SES on parent and child reports of most of the health measures, with higher SES associated with better health. Starfield et al similarly reported significant social class differences in parent-reported domains of health, with the exception of satisfaction; contrary to our findings, though, the effects of SES were not significant according to the child report. However, a significant effect of maternal education on the self-reported health of European children has been reported, supporting our findings of an effect of SES on child-reported health status.

We found a significant association of black race with less comfort and risk avoidance. Poorer health status has been reported among black low-birth-weight children. Cultural differences in responding to questionnaires, rather than poverty, may play a role in our population because the racial differences were evident even after adjusting for SES in the multivariable analyses. Sex differences were also apparent in our population, which might be related to gender differences in responding to questionnaires.

Limitations of the study include that the children were born in the early to middle 1990s, a period of increased survival but also of increased neonatal morbidity that has decreased since the year 2000. The findings thus might not reflect current outcomes. Ours is a predominantly urban population and might not be representative of other regions.

This is, to our knowledge, the first report of the school-age health of preterm children before adolescence who have survived since the 1990s. Strengths of the study include our measure of health status, the CHIL-CE, which provides a comprehensive, multidimensional assessment of health. Although different, the perspectives of the children and their parents present equally valid perceptions of the functioning and well-being of the child, with each providing complementary information. Parents and children may use different standards to appraise health and well-being. Furthermore, parents may not be aware of subjective symptoms among their children, such as sadness, loneliness, and anxiety. This is evident in our population, in which the children reported less comfort (including emotional comfort) and less resilience (including family involvement) than their parents. The child’s perspective is thus important when making health decisions and for identifying such aspects of their emotional and social lives that parents may not be aware of and that may possibly be improved with interventions. The parents’ perspective also has importance because parents control most aspects of the child’s life, including their referral to and use of health care resources. Furthermore, parent and child reports of health and well-being predict current and future health care needs and use of services and are increasingly viewed as primary and secondary end points of health care.

In conclusion, the findings of this study stress the importance of considering the self-perception of the health status of preterm children when assessing them with any educational and social difficulties they may have. Longitudinal follow-up of this cohort will be important to examine possible changes in parent and child perception of health that may become evident during adolescence.

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Author Contributions: Dr Hack had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis. Study concept and design: Hack, Forrest, Taylor, and Drotar. Acquisition of data: Hack, Drotar, and Andreias. Analysis and interpretation of data: Hack, Forrest, Schluchter, Taylor, Drotar, Holmbeck, and Andreias. Drafting of the manuscript: Hack. Critical revision of the manuscript for important intellectual content: Hack, Forrest, Schluchter, Taylor, Drotar, Holmbeck, and Andreias. Statistical analysis: Hack, Schluchter, Drotar, Holmbeck, and Andreias. Obtained funding: Hack and Taylor. Administrative, technical, and material support: Hack, Forrest, and Andreias. Study supervision: Hack and Taylor.

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REFERENCES