



Health-Related Quality of Life Trajectories of Extremely Low Birth Weight Survivors into Adulthood

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Objectives To compare the health-related quality of life (HRQL) trajectories of a regional cohort of extremely low birth weight (ELBW, <1000 g) survivors (births from 1977 to 1982) and a group of normal birth weight (NBW) controls, at 3 ages: 12-16 years, 22-26 years, and 29-36 years, spanning over 20 years. We hypothesized that the HRQL of the ELBW cohort would be significantly compromised compared with their NBW peers, and that neurosensory impairments (NSI) would have an additional negative effect.

Study design We used the Health Utilities Index Mark 3, in which health status was self-assessed and utility scores were derived from community preferences; multilevel modeling was used to delineate trajectories of HRQL among ELBW survivors with (n = 37) and without NSI (n = 116), and NBW controls (n = 137).

Results Adjusting for participant sex and socioeconomic status at age 8 years, ELBW survivors with NSI had consistently lower HRQL compared with both ELBW survivors without NSI and NBW controls, from adolescence through to adulthood ($\beta = -0.264$; $P < .001$). ELBW survivors without NSI also had significantly lower HRQL compared with NBW controls ($\beta = -0.092$; $P < .01$). At all ages, differences seen in the Health Utilities Index Mark 3 scores between ELBW participants and NBW controls were clinically important, though there was no differential rate of decline between the 2 groups.

Conclusions ELBW survivors manifest meaningfully poorer HRQL from their early teens through their mid-30s. Individuals with NSI appear to represent a distinct group of ELBW survivors with substantially lower HRQL at all ages. Information on HRQL can be helpful in prioritizing research and intervention strategies. (*J Pediatr* 2016;179:68-73).

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Children born very prematurely are at increased risk for physical, motor, cognitive, psychosocial, and behavioral problems.¹⁻³ To provide a holistic picture of the health and well-being of these individuals,⁴ researchers have begun to report on the quality of life of premature survivors.⁵⁻¹³ Health-related quality of life (HRQL) reflects the impact of multidimensional health and illness variables on the individual's subjective psychological and social perceptions.^{4,14,15}

The Health Utilities Index Mark 3 (HUI3) measures functional status and HRQL using indirect preferences derived from community samples.¹⁴⁻¹⁶ The HUI3 is widely used in clinical and population health surveys, and performs particularly well in capturing HRQL and the life impact of disease.¹⁷ Moreover, guidelines from the US^{18,19} and Canada²⁰ have recommended the use of community preferences for the economic evaluation of health care services.^{21,22}

The HUI3 has been used to examine HRQL in extremely low birth weight (ELBW) survivors and normal birth weight (NBW) controls at adolescence and adulthood, with some studies reporting similar HRQL,^{5,6,13} and others have found lower scores among preterm individuals.⁹⁻¹² The current literature exhibits methodological limitations that restrict our understanding of the HRQL of adult survivors born at ELBW. These limitations include analyses that are cross-sectional in nature^{5,6}; studies that lack a NBW comparison group^{9,11}; and failure to adjust for relevant confounding factors, such as neurosensory impairment (NSI).^{6,9,23} They are also limited by substantial sample attrition⁹ and the implementation of less than robust approaches to missing data.^{9,11,23}

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ELBW	Extremely low birth weight
HRQL	Health-related quality of life
HUI3	Health Utilities Index Mark 3
NBW	Normal birth weight
NSI	Neurosensory impairments

The aims of this study were to prospectively examine HRQL using the HUI3 in a sample of ELBW survivors, stratified by the presence or absence of NSI, and matched NBW controls across 3 ages: adolescence (12-16 years); young adulthood (22-26 years); and adulthood (29-36 years). We hypothesized that ELBW survivors would have significantly compromised HRQL compared with their NBW counterparts; that NSI would have an additional negative effect on HRQL; and based on the literature,^{8,11,24} that there would be a divergent decline in HRQL trajectories, with the ELBW group differentially worsening over time.

Methods

A total of 179 ELBW survivors (birth weight 501-1000 g), born to residents of central-west Ontario (Canada) from 1977 to 1982, and followed longitudinally from birth were eligible for the study.²⁵ ELBW survivors were classified as to whether they had NSI (cerebral palsy, blindness, deafness, and microcephaly) diagnosed at 3 years of age by a developmental pediatrician. At 8 years of age,²⁶ 145 NBW same age term controls (>2500 g) were recruited from a random list provided by the school board, and matched with the ELBW survivors on sex, age, and socioeconomic status. HRQL was measured at 3 ages (12-16; 22-26; and 29-36 years), and the assessment protocol was similar for both groups. Assessments were completed at McMaster Children's Hospital.

At adolescence (12-16 years of age) and young adulthood (22-26 years of age), trained professional interviewers who were unaware of birth weight status, interviewed the participants to determine their health status using questionnaires from the HUI2/3 system.^{14,15} At adulthood (29-36 years of age), the participants self-completed the HUI3 questionnaire. For the purposes of this study, only HUI3 data are analyzed at each visit. Written informed consent was obtained from each respondent. The Hamilton Health Sciences Research Ethics Board approved the study.

HRQL

The HUI3, a comprehensive, multi-attribute, generic scale, was used to measure HRQL.¹⁵ The HUI3 health states are 8-element vectors, with 5-6 levels per attribute: vision, hearing, speech, ambulation, dexterity, emotion, cognition, and pain. We used the preexisting preference scores obtained by standard gamble measurements from a random sample of the general population parents in Hamilton, Ontario.^{14,15} A multiplicative multi-attribute utility algorithm synthesized the descriptive health information into a single, global utility score on an interval scale, which ranges from -0.36 (for the worst state), through to 0.00 (dead), and 1.00 (perfect health).¹⁵ Empirical studies have pointed to 0.03-0.05 as the minimal clinically important difference for the HUI3.¹⁶ There is considerable evidence supporting the validity and reliability of the HUI3,¹⁶ and it has a strong track record of use among samples of ELBW survivors.^{5,6,9-12,17}

Covariates

Several sociodemographic characteristics were measured in this cohort including sex, age, marital status, race, immigrant status, maternal education, and parental socioeconomic status (based on the Hollingshead Index²⁷) at 8 years of age. These characteristics were considered as potential covariates in the multi-level model of HUI3 trajectories.

Statistical Analyses

Across-group HUI3 scores were compared using analysis of variance at each measurement occasion. Pairwise group contrasts, when appropriate, were examined using the post hoc Scheffé procedure. Multilevel modeling was used to delineate trajectories of HRQL among ELBW survivors with and without NSI and NBW controls.²⁸ The model used patient age as the measure of time, and participant sex and socioeconomic status were included to provide unbiased estimates of the effect of birth weight status on HRQL. In an effort to generate a parsimonious model and because of the high correlation between family structure, parental education, and socioeconomic status, ($r = 0.60$), only family socioeconomic status was included in the multilevel model. Variables were grand mean centered at the final assessment (adulthood) to improve the interpretation of results and provide a more informative intercept. Both the model intercept and slope were specified as random effects. Full-information maximum likelihood was used to account for missing data in the multilevel model and participants with at least one HUI3 score were modeled.^{29,30} Hypothesis tests were 2-sided at $\alpha = 0.05$ and 95% CIs were computed. Data were analyzed using SAS 9.2 (SAS Institute Inc, Cary, North Carolina).

Results

The point of inception of the HUI studies was at adolescence, and the sample characteristics stratified by birth weight status and presence of NSI are shown in **Table I** (available at www.jpeds.com). They refer to the number of individuals who provided at least 1 HUI3 score at any given time. There were 116 ELBW survivors without NSI (ELBW-NSI), 37 ELBW with NSI (NSI = 24.2%), and 137 NBW controls (2 with NSI = 1.5%). Although the NBW controls were age- and sex-matched when the ELBW survivors were 8 years of age, there was a small difference in the age distribution between groups at the adolescent assessment; ELBW survivors without NSI were 6 months younger (13.9 vs 14.5; $P = .001$) than NBW controls. No other sociodemographic group differences were found; however, pairwise contrasts showed that ELBW survivors without NSI had longer gestational age compared with those with NSI (27.4 vs 26.2 weeks; $P = .001$).

Of the 290 ELBW and NBW participants, 27 had missing HUI3 scores at the adolescent assessment, 16 had missing scores at the young adult assessment, and 113 had missing scores at the adult assessment. There was no evidence of differential attrition between ELBW survivors and NBW controls. Missing data was not associated with birth weight status (OR 1.03; 95% CI 0.65, 1.64) when comparing participants with complete HUI3 scores ($n = 126$) to those with at least 1 missing HUI3

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