Health, Wealth, Social Integration, and Sexuality of Extremely Low-Birth-Weight Prematurely Born Adults in the Fourth Decade of Life

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**IMPORTANCE** Although it has been previously reported that the transition of extremely low-birth-weight survivors (≤1000 g) in their mid-20s was similar to that of normal-birth-weight controls (>2500g), there was uncertainty as to whether this positive pattern would persist.

**OBJECTIVE** To compare the social functioning of low-birth-weight prematurely born adults aged 29 to 36 years with that of normal-birth-weight term controls.

**DESIGN, SETTING, AND PARTICIPANTS** A population-based longitudinal cohort study was conducted in Ontario, Canada, between March 14, 2011, and August 13, 2013, among 100 of 165 low-birth-weight survivors (60.6%) prematurely born between January 1, 1977, and December 31, 1982, and 89 of 144 sociodemographically matched normal-birth-weight term controls (61.8%) recruited at age 8 years. Neurologic impairments were present in 20 premature participants (20.0%).

**EXPOSURES** Extremely low birth weight.

**MAIN OUTCOMES AND MEASURES** Information on health, educational level, employment, social integration, sexuality, and reproduction was obtained through standardized questionnaires completed by the participants.

**RESULTS** Participants included 100 (39 males) extremely low-birth-weight survivors and 89 (33 males) normal-birth-weight term controls. The groups did not differ in the highest educational level achieved or in family and partner relationships. However, a lower proportion of premature adults was employed (odds ratio [OR], 0.37; 95% CI, 0.15 to 0.93) and fewer were employed full time (OR, 0.49; 95% CI, 0.24 to 0.98). The premature group had a mean total personal income of $20 000 less than controls, and more required social assistance (OR, 4.16; 95% CI, 1.13 to 15.33). Compared with the control group, more members of the premature group remained single (OR, 1.95; 95% CI, 1.08 to 3.50), had never had sexual intercourse (OR, 11.30; 95% CI, 2.56 to 49.91), did not have children (OR, 0.52; 95% CI, 0.27 to 0.99), reported more chronic health conditions (β, 1.54; 95% CI, 0.79 to 2.30), had lower self-esteem (β, 8.40; 95% CI, 1.68 to 15.12), and were less likely to have current drug abuse or dependence (OR, 0.29; 95% CI, 0.90 to 0.92) or lifetime alcohol abuse or dependence (OR, 0.30; 95% CI, 0.15 to 0.59). A higher proportion of premature adults without neurosensory impairments identified themselves as nonheterosexual (OR, 4.87; 95% CI, 1.01 to 23.69). After exclusion of individuals with neurosensory impairments, differences in employment, social assistance, marital status, and reproduction were no longer significant.

**CONCLUSIONS AND RELEVANCE** In the fourth decade of life, extremely low-birth-weight survivors achieved similar educational levels and family and partner relationships, and reported fewer risky behaviors compared with controls. However, they had lower levels of employment, income, and self-esteem, and fewer were married and had children. It is therefore essential that these individuals receive necessary support and continued monitoring throughout life.
Lifestyle, Social Integration, and Sexuality of ELBW Adults

Original Investigation Research

The first generation of extremely low-birth-weight (ELBW, <1000 g) premature infants born after the introduction of neonatal intensive care has survived into the fourth decade of life. Several international studies on the young adult outcomes of very premature infants have been published in the last decade from Canada,1–5 the United States,6,7 England,8 Sweden,9 Norway,10 the Netherlands,11 Denmark,12 Finland,13 and Australia.14 These reports reveal that these individuals have poorer educational5,8–11 and employment outcomes,6,11 fewer leave the parental home,13 and more experience delays in the onset of sexual activity,6,8,11,13,15 marriage or cohabitation,7,13,15 and reproduction.16–18 In addition, a higher prevalence of chronic physical4,7,14 and mental health issues5,19–22 have been noted, although risk-taking behaviors appear to be less common.6,8,11

In previous assessments of this Canadian ELBW cohort of young adults aged 22 to 26 years, no differences were reported in educational attainment; employment; living arrangements; marriage or cohabitation; and peer, partner, and family relationships; as well as in self-reported quality of life, compared with the normal-birth-weight (NBW, >37 weeks and >2500 g) control group.3 Consistent with other studies, previously reported findings with this cohort showed that fewer ELBW individuals were sexually active, and a lower proportion indulged in risk-taking behaviors.5,6,8,11,13,23 These general findings pertained to all participants, both with and without neurosensory impairments (NSIs).

The question remains, though, whether as these ELBW individuals mature, will they have employment opportunities, earn suitable wages, have fulfilling family and sexual relationships, and/or integrate well into society? It is also not clear if they will continue to have more chronic health problems that might affect their adult functioning. This study explores these issues, including possible sex differences and the effect of NSIs, in the only prospective longitudinal cohort, to our knowledge, of ELBW infants and NBW term controls followed into their fourth decade of life.

Methods

Participants
Extremely low-birth-weight participants, weighing between 501 and 1000 g at birth, were recruited to a population-based study of all individuals born from January 1, 1977, to December 31, 1982, in central-west Ontario, Canada.24 They have been followed up longitudinally since birth, and their outcomes have been reported in multiple domains at ages 3, 5, and 8 years,25 at adolescence,26 and at young adulthood.2

The NBW term group was recruited at age 8 years from local schools, and matched for sex, age, and social class.25 The subsequent follow-up protocol for the NBW cohort was identical to that of the ELBW cohort. Both groups, now aged 29 to 36 years, were the primary respondents for all questionnaires, completed on a visit to McMaster Children’s Hospital, between March 14, 2011, and August 13, 2013. Ethics approval was obtained from the Hamilton Health Sciences Research Ethics Board, and written informed consent was obtained from all participants.

Measures and Sources of Data

Demographics
Information on educational level, employment, income, marital status, number of children, and current living arrangements was obtained using standardized questionnaires, derived from the Ontario Child Health Study.27

Relationships
Information regarding current involvement in romantic relationships was obtained through a self-administered questionnaire,28 complemented by additional questions from the Ontario Child Health Study27 regarding the respondent’s relationship history. For those currently in a relationship, participants rated their satisfaction with their partner using the Relationship Assessment Scale.29 Family functioning (specific to their current cohabiting family members) was measured using the General Functioning subscale of the McMaster Family Assessment Device.30 Information on sexual activity and sexual orientation was derived from the Starfield Teen Health Profile.31 A Finnish study questionnaire on reproduction was modified, but not validated.32

Subjective Well-being
Social support was measured using the Young Adult Social Support Index,33 which reflects 5 aspects of social support: emotional, esteem, network, appraisal, and altruism. Participants rated their loneliness on the Revised UCLA Loneliness Scale34 and rated their self-esteem using the Coopersmith Self-Esteem Inventory.35

Risk-Taking Behaviors
Information on current and lifetime alcohol and substance misuse was obtained via the Mini International Neuropsychiatric Interview, a structured psychiatric interview conducted by trained interviewers who were naive to participant group status.22,36 Participants also answered questions from the Young Adult Self-Report questionnaire37 about contact with police and whether they had ever been convicted of a crime.
Within the ELBW cohort, those who participated at age 29 to 36 years were more likely to be female (odds ratio [OR], 2.44; 95% CI, 1.23-4.83) and have a higher parental socioeconomic status at the 8-year visit (M difference, 0.52; 95% CI, 0.22-0.81) than those lost to attrition. However, they did not differ by birth weight or gestational age.

NBW Cohort

At age 29 to 36 years, 89 of 144 of those recruited at age 8 years (61.8%) were assessed. Of these, 1 woman with NSIs subsequently died. The NBW participants were also more likely to be female (OR, 2.44; 95% CI, 1.23-4.83). At the current visit, the 2 groups did not differ by participant sex or age.

Participant Attirion

Of the 282 potential ELBW and NBW participants from young adulthood, we were unable to contact 73 individuals (ELBW, 38; NBW, 35), 13 declined participation (ELBW, 5; NBW, 8), 2 were deceased (ELBW, 1; NBW, 1), and 5 ELBW participants were unable to be tested owing to severe neurologic and/or cognitive deficits (eFigure in the Supplement). Among the nonparticipants, 20 ELBW individuals and 2 NBW individuals had NSIs.

Education, Employment, Income, and Housing

There were no differences in the total number of years or in the highest educational level completed to date (Table 2). In comparison with the NBW group, the ELBW group had significantly lower rates of any employment in the last year (78 of 97 [80.4%] vs 78 of 85 [91.8%]) and fewer were employed full time (48 of 78 [61.5%] vs 59 of 77 [76.6%]); women in the ELBW cohort were less likely to work full time than were women in the NBW cohort (OR, 0.42; 95% CI, 0.18-0.99). There were marked differences between the groups in personal annual income and total household income, with those in the ELBW cohort earning a mean of $20 000 (Canadian dollars) less per year than those in the NBW cohort. In addition, a higher proportion of ELBW survivors were receiving social assistance (12 of 87 [13.8%] vs 3 of 81 [3.7%]), which was significant only for ELBW men vs NBW men (OR, 1.19; 95% CI, 1.02-1.39). Nevertheless, similar to the NBW group, more than one-third of the ELBW cohort owned their own home, while 8 of 96 individuals in the ELBW cohort (8.3%) and 2 of 84 individuals in the NBW cohort (2.4%) were in subsidized housing. The proportion of those in the ELBW cohort vs those in the NBW cohort with special living arrangements (7 of 98 [7.1%] vs 1 [1.1%]) did not reach statistical significance.

Results

Participant Characteristics

ELBW Cohort

A total of 179 of 397 (45.1%) ELBW infants survived to hospital discharge; 13 children died after discharge. One ELBW child with NSIs subsequently died in young adulthood. At age 29 to 36 years, 100 of 165 eligible survivors (60.6%) were assessed (Table 1). Mean (SD) birth weight for the ELBW cohort was 834.90 (132.74) g and mean (SD) gestational age was 27.13 (2.42) weeks; 25 participants (25.0%) were born at less than 26 weeks’ gestation and 29 (29.0%) were small for gestational age. Neurosensory impairments were present in 20 of the participants (20.0%).

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In terms of their sexual orientation, although a higher proportion of the ELBW cohort identified themselves as nonheterosexual (9 of 96 [9.4%] vs 2 of 86 [2.3%]), statistical significance was achieved only when participants with NSIs were excluded (Table 3). Of the 9 nonheterosexual ELBW participants, 6 identified as bisexual (5 women and 1 man), 1 as lesbian, and 2 as questioning their sexual orientation (1 man and 1 woman). Two women in the NBW cohort (2.2%) identified themselves as nonheterosexual (1 as bisexual and 1 as questioning her sexual orientation).

Significantly more ELBW survivors had never experienced sexual intercourse compared with the NBW cohort (20 of 97 [20.6%] vs 2 [2.2%]) (Table 3). Men in the ELBW cohort were 9.93-fold (95% CI, 1.19-82.25) more likely to have never experienced sexual intercourse than were men in the NBW cohort (9 of 38 [23.7%] vs 1 of 33 [3.0%]), while women in the ELBW cohort were 12.60-fold (95% CI, 1.57-101.23) more likely than women in the NBW cohort (11 of 59 [18.6%] vs 1 of 56 [1.8%]). The mean (SD) age at first sexual intercourse was also higher for those in the ELBW cohort than those in the NBW co-
Table 4. Social Integration and Risk-Taking Behaviors

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>ELBW Cohort (n = 100)</th>
<th>NBW Cohort (n = 89)</th>
<th>OR (95% CI) or β (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Entire Sample</td>
<td>Excluding Participants With NSIs</td>
<td></td>
</tr>
<tr>
<td>Social relationships, mean (SD)*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relationship with partner</td>
<td>13.10 (5.04)</td>
<td>12.59 (4.73)</td>
<td>β, 0.13 (−1.68 to 1.94)</td>
</tr>
<tr>
<td>Family functioning</td>
<td>40.44 (6.76)</td>
<td>41.13 (6.11)</td>
<td>β, −0.53 (−2.66 to 1.60)</td>
</tr>
<tr>
<td>Loneliness</td>
<td>34.59 (11.61)</td>
<td>31.11 (10.43)</td>
<td>β, 3.16 (−0.17 to 6.44)</td>
</tr>
<tr>
<td>Self-esteem</td>
<td>29.16 (24.44)</td>
<td>20.45 (20.31)</td>
<td>β, 8.40 (1.68 to 15.12)</td>
</tr>
<tr>
<td>Social support index</td>
<td>102.03 (24.90)</td>
<td>108.64 (24.43)</td>
<td>β, −5.43 (−12.75 to 1.88)</td>
</tr>
<tr>
<td>Risk-taking behaviors, No. (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Current alcohol abuse or dependence</td>
<td>10/81 (12.3)</td>
<td>16/83 (19.3)</td>
<td>OR, 0.59 (0.25 to 1.39)</td>
</tr>
<tr>
<td>Lifetime alcohol abuse or dependence</td>
<td>17/81 (21.0)</td>
<td>40/85 (47.1)</td>
<td>OR, 0.30 (0.15 to 0.59)</td>
</tr>
<tr>
<td>Current drug abuse or dependence</td>
<td>4/81 (4.9)</td>
<td>13/85 (15.3)</td>
<td>OR, 0.29 (0.80 to 0.92)</td>
</tr>
<tr>
<td>Lifetime drug abuse or dependence</td>
<td>13/81 (16.0)</td>
<td>21/84 (25.0)</td>
<td>OR, 0.57 (0.27 to 1.24)</td>
</tr>
<tr>
<td>Contact with police</td>
<td>7 (7.0)</td>
<td>9/88 (10.2)</td>
<td>OR, 0.66 (0.24 to 1.86)</td>
</tr>
<tr>
<td>Convicted or incarcerated</td>
<td>4 (4.0)</td>
<td>7/88 (8.0)</td>
<td>OR, 0.49 (0.14 to 1.72)</td>
</tr>
<tr>
<td>Used protection during sex</td>
<td>65/79 (82.3)</td>
<td>69/87 (79.3)</td>
<td>OR, 1.21 (0.56 to 2.63)</td>
</tr>
</tbody>
</table>

Abbreviations: ELBW, extremely low-birth-weight; NBW, normal-birth-weight; NSI, neurosensory impairment; OR, odds ratio.

* Higher scores indicate poorer relationship with partner, better family functioning, higher loneliness, poorer self-esteem, and more social support.

Lifestyle, Social Integration, and Sexuality of ELBW Adults

Table 4. Social Integration and Risk-Taking Behaviors

hert (19.7 [4.0] vs 18.4 [3.3] years); there were no differences between sexes for this outcome.

A significantly lower proportion of the ELBW cohort had children vs the NBW cohort (20 [20.0%] vs 29 [32.6%]) (Table 3). Women in the ELBW cohort were less likely than women in the NBW cohort to have children (OR, 0.44; 95% CI, 0.11-0.81) less likely among women in the ELBW cohort than women in the NBW cohort. Current drug abuse or dependence was significantly lower among women in the ELBW cohort than women in the NBW cohort.

Current drug abuse or dependence was significantly lower among the ELBW than NBW participants. Men in the ELBW cohort reported lower levels of abuse or dependence than did men in the NBW cohort (OR, 0.19; 95% CI, 0.04-0.97), while there were no differences between the women in the ELBW and NBW cohorts. There were no differences in lifetime substance abuse or dependence. Rates of contact with the police and being convicted of a crime or incarcerated were similar between the cohorts.

Reproductive Problems

There were no differences in the proportion of participants in the ELBW and NBW cohorts with self-reported fertility problems (Table in the Supplement). Women in the ELBW cohort did not have a higher incidence than those in the NBW cohort of menstrual irregularities or endometriosis. Significantly fewer women in the ELBW cohort had ever been pregnant (23 of 60 [38.3%] vs 32 of 52 [61.5%]), there were no differences in the rates of miscarriages (8 of 23 [34.8%] vs 6 of 32 [18.8%]) or births at less than 37 weeks’ gestation (4 of 23 [17.4%] vs 3 of 32 [9.4%]) compared with women in the NBW cohort.

Social Integration and Risk-Taking Behaviors

There were no differences between the groups in relationship functioning with their partners, family functioning, loneliness, or social support (Table 4). However, the ELBW group had significantly poorer self-esteem, which did not differ by sex.

Although there were no differences in current alcohol abuse or dependence between the ELBW and NBW groups, lifetime alcohol abuse or dependence was significantly lower among both ELBW men and women, both with and without NSIs. Lifetime alcohol abuse or dependence was 0.24-fold (95% CI, 0.08-0.70) less likely among men in the ELBW cohort than men in the NBW cohort, and 0.30-fold (95% CI, 0.11-0.81) less likely among women in the ELBW cohort than women in the NBW cohort.

Chronic Health Conditions and Medication Use

Participants in the ELBW cohort self-reported significantly more chronic health conditions than did those in the NBW cohort (mean [SD], 3.29 [3.1] vs 1.71 [1.8]) (Table 5). Visual problems were significantly more common in the ELBW cohort: 64 of 87 participants in the ELBW cohort (73.6%) required contact lenses or prescription glasses vs 38 of 81 participants in the NBW cohort (46.9%), with women in the ELBW cohort having a higher rate than those in the NBW cohort (OR, 3.44; 95% CI, 1.51-7.81). Significantly more participants in the ELBW cohort had undergone eye surgery, mainly for strabismus (11 [11.0%]) and retinal detachment (6 [6.0%]). Those in the ELBW cohort, both with and without NSIs, reported a significantly higher prevalence of learning disabilities (28 of 99 [28.3%] vs 2 [2.2%]), which were higher among men in the ELBW cohort than men in the NBW cohort (OR, 6.32; 95% CI, 1.29-31.05). Incidence of mental illness was higher in the ELBW cohort than the NBW cohort (20 [20.0%] vs 6 [6.7%]); this incidence was higher among women in the ELBW cohort than women in the NBW cohort (OR, 4.62; 95% CI, 1.44-14.83). Participants in the ELBW...
cohort had a higher prevalence of coordination problems vs those in the NBW cohort (16 of 99 [16.2%] vs 1 [1.1%]), which was higher in women in the ELBW cohort than women in the NBW cohort (OR, 10.78; 95% CI, 1.33-87.25). Those in the ELBW cohort had a higher rate of medication use on a regular basis than those in the NBW cohort (55 of 99 [55.6%] vs 32 of 88 [36.4%]), which was higher among women in the ELBW cohort than women in the NBW cohort (OR, 2.23; 95% CI, 1.05-4.77). Overall, the rate of long-term health conditions was significantly higher among the ELBW cohort than the NBW cohort (24 of 98 [24.5%] vs 11 of 88 [12.5%]), but there were no reported limitations in daily activities due to these conditions.

Exclusion of Individuals With NSIs
After excluding individuals with NSIs, there were no significant differences in rates of any employment, rates of full-time employment, receipt of social assistance, dating and marital status, mean age at first sexual intercourse, proportion who had children, and current drug abuse or dependence. However, statistically significant associations remained in personal and total household income, lower self-esteem, ever-experiencing sexual intercourse, lifetime alcohol abuse or dependence, learning disability, mental illness, problems with coordination, visual impairment, sinusitis, medication use, wearing glasses or contact lenses, and chronic health conditions.

Discussion
This is the first comprehensive report, to our knowledge, of the health and social status of a longitudinally followed cohort of ELBW adults into the fourth decade of life. The ELBW group showed no differences in family and partner relationships vs the NBW cohort and continued to have a lower rate of risk-taking behaviors than did the NBW group. Although the groups did not differ in their educational levels, the ELBW cohort had lower rates of employment and personal income, and a higher proportion received social assistance. Fewer participants in the ELBW group were dating, married, or cohabiting, and a significant proportion had never experi-

Table 5. Chronic Health Conditions and Medication Use

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>ELBW Cohort (n = 100)</th>
<th>NBW Cohort (n = 89)</th>
<th>Entire Sample</th>
<th>Excluding Participants With NSIs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic health conditions, mean (SD)</td>
<td>3.29 (3.12)</td>
<td>1.71 (1.83)</td>
<td>β, 1.34 (0.79 to 2.30)</td>
<td>β, 1.44 (0.65 to 2.23)</td>
</tr>
<tr>
<td>Wear glasses or contact lenses</td>
<td>64/87 (73.6%)</td>
<td>38/81 (46.9%)</td>
<td>OR, 3.15 (1.65 to 6.01)</td>
<td>OR, 3.92 (1.91 to 8.07)</td>
</tr>
<tr>
<td>Had eye surgery</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>For strabismans</td>
<td>11 (11.0)</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vision correction laser surgery</td>
<td>1 (1.0)</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Retinal detachment laser surgery</td>
<td>6 (6.0)</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>4 (4.0)</td>
<td>2 (2.2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>78 (78.0)</td>
<td>87 (97.8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Learning disability</td>
<td>28/99 (28.3%)</td>
<td>2 (2.2)</td>
<td>OR, 17.16 (3.95 to 74.49)</td>
<td>OR, 17.87 (4.05 to 78.75)</td>
</tr>
<tr>
<td>Mental illness</td>
<td>20 (20.0)</td>
<td>6 (6.7)</td>
<td>OR, 3.46 (1.32 to 9.06)</td>
<td>OR, 3.73 (1.39 to 10.01)</td>
</tr>
<tr>
<td>Any difficulty with coordination or clumsiness</td>
<td>16/99 (16.2%)</td>
<td>1 (1.1)</td>
<td>OR, 16.96 (2.20 to 130.78)</td>
<td>OR, 11.31 (1.40 to 91.45)</td>
</tr>
<tr>
<td>Problems seeing</td>
<td>35/98 (64.3%)</td>
<td>12 (13.5)</td>
<td>OR, 3.57 (1.71 to 7.44)</td>
<td>OR, 2.97 (1.37 to 6.42)</td>
</tr>
<tr>
<td>Problems hearing</td>
<td>11 (11.0)</td>
<td>3 (3.4)</td>
<td>OR, 3.54 (0.96 to 13.14)</td>
<td>OR, 3.19 (0.82 to 12.45)</td>
</tr>
<tr>
<td>Limitations in use of hands or fingers</td>
<td>10 (10.0)</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hypertension</td>
<td>5 (5.0)</td>
<td>3 (3.4)</td>
<td>OR, 1.51 (0.35 to 6.50)</td>
<td>OR, 1.51 (0.33 to 6.96)</td>
</tr>
<tr>
<td>Migraines</td>
<td>24 (24.0)</td>
<td>18 (20.2)</td>
<td>OR, 1.25 (0.62 to 2.49)</td>
<td>OR, 1.50 (0.73 to 3.05)</td>
</tr>
<tr>
<td>Diabetes mellitus</td>
<td>4 (4.0)</td>
<td>2 (2.2)</td>
<td>OR, 1.81 (0.32 to 10.14)</td>
<td>OR, 2.29 (0.41 to 12.85)</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>5 (5.0)</td>
<td>1/88 (1.1)</td>
<td>OR, 4.58 (0.53 to 39.97)</td>
<td>OR, 3.39 (0.35 to 33.27)</td>
</tr>
<tr>
<td>Bronchitis</td>
<td>5 (5.0)</td>
<td>1 (1.1)</td>
<td>OR, 4.63 (0.53 to 40.42)</td>
<td>OR, 3.43 (0.35 to 33.65)</td>
</tr>
<tr>
<td>Asthma</td>
<td>20 (20.0)</td>
<td>12 (13.5)</td>
<td>OR, 1.60 (0.74 to 3.50)</td>
<td>OR, 1.73 (0.77 to 3.89)</td>
</tr>
<tr>
<td>Sinusitis</td>
<td>8/99 (8.1)</td>
<td>1 (1.1)</td>
<td>OR, 7.74 (0.95 to 63.14)</td>
<td>OR, 8.56 (1.03 to 71.16)</td>
</tr>
<tr>
<td>Heart conditions</td>
<td>5 (5.0)</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Long-term health conditions</td>
<td>24/98 (24.5%)</td>
<td>11/88 (12.5%)</td>
<td>OR, 2.27 (1.04 to 4.96)</td>
<td>OR, 1.67 (0.72 to 3.89)</td>
</tr>
<tr>
<td>Limited in any way in carrying out normal daily activities because of any health conditions or problems</td>
<td>17 (17.0)</td>
<td>7 (7.9)</td>
<td>OR, 2.40 (0.95 to 6.09)</td>
<td>OR, 1.87 (0.69 to 5.08)</td>
</tr>
<tr>
<td>Takes medication on a regular basis</td>
<td>55/99 (55.6)</td>
<td>32/88 (36.4)</td>
<td>OR, 2.19 (1.22 to 3.94)</td>
<td>OR, 2.44 (1.31 to 4.55)</td>
</tr>
</tbody>
</table>

Abbreviations: ELBW, extremely low-birth-weight; NBW, normal-birth-weight; NSI, neurosensory impairment; OR, odds ratio.

*Data are presented as number (percentage) of participants unless otherwise indicated.

bCannot provide point estimate because no NBW participants reported the condition.
enced sexual intercourse. Although they did not report more reproductive problems, fewer participants in the ELBW cohort had children. In addition, chronic health problems and medication use were more frequent among the members of the ELBW cohort. Unlike the data reported in some studies, the data in our study are based on all participants, including those with NSIs.

The trajectory exhibited in our longitudinal study appears to be that during early childhood the ELBW group presented with delayed milestones and 46 of 166 individuals (27.7%) had NSIs.

As they grew older, they faced further challenges with learning and behavioral issues that persisted into adolescence. However, they did show relative improvements in their health status and reported similar levels of self-esteem and quality of life compared with their peers. In their early 20s, contrary to our hypothesis, the members of the ELBW cohort did remarkably well in most variables of successful transition. Based on this finding, the future of these former children should be considered from a lifespan perspective.

What is the explanation of this downward trend seen at the current assessment? First, it may be that in the last report at young adulthood, the participants had just started this transition, and therefore the differences were less apparent. Second, many social and economic factors may have contributed to this delayed transition. Despite pursuing a higher education, today's young adults face a labor market in which fewer are employed full time and jobs are scarce. Consequently, they may live in the parental home for a longer time and postpone marriage and parenthood. Obviously, these factors also apply to the NBW group. However, the high proportion among the ELBW cohort with NSIs accounted for many differences between the groups. After exclusion of those with NSI, only differences in employment, income, lower rates of sexual intercourse, self-esteem, and lifetime alcohol abuse or dependence remained significant.

An unexpected finding was that, after exclusion of those with an NSI, a higher proportion of the ELBW cohort self-identified as bisexual or homosexual compared with the NBW group. By and large, there was consistency in the reported sexual orientation at young adulthood (ELBW, 12 of 141 [8.5%] vs NBW, 3 of 133 [2.3%]; P = .23) and at the current age, except for 1 member of the ELBW cohort and 1 member of the NBW cohort who changed their status between the 2 follow-up periods. However, it is unclear why there is a preponderance of nonheterosexual women in both follow-up periods and in both groups. To our knowledge, there is no such information available from other premature cohorts.

The first 2003 Canadian Community Health Survey on sexual orientation of more than 135,000 individuals aged 18 to 59 years revealed that 1.0% considered themselves to be homosexual and 0.7% considered themselves to be bisexual. The homosexuality rate of 1.3% among men was about twice that of women (0.7%). However, a slightly higher proportion of women than men identified as bisexual (0.9% vs 0.6%). The corresponding figures from a 2013 US National Survey reported that 1.6% of adults identified as gay or lesbian and 0.7% as bisexual. Similar to this study, these surveys also relied on self-report. We recognize that survey respondents may not feel comfortable disclosing their sexual orientation for fear of stigma and discrimination. Nevertheless, we have a comparison NBW group that was surveyed at the same time, using the same methods. The incidence of nonheterosexuals is much higher in our ELBW cohort relative to both our NBW group and the Canadian and US population-based data. Pooled data from other premature cohorts, when available, would help confirm whether this is a true association, or whether it is within the range of measurement error.

The rate of chronic health conditions, particularly visual impairments, was higher in the ELBW cohort than the NBW cohort. This finding may be a reflection of the lack of treatment in the era before cryotherapy; participants in the ELBW cohort also had a high prevalence of retinal detachment. Women in both groups reported more health problems than did men. Although our preterm adults had lower pregnancy rates, we did not observe an increase in infertility, miscarriages, or premature births. However, we recognize that our sample size is rather small for such analyses.

Overall, the majority of extremely premature adults are living independently and contributing well to society. Women in the ELBW cohort are more compromised than men in employment, dating, marriage, and chronic health conditions.

This 4-decade longitudinal follow-up study of former ELBW infants is not without limitations. In our previous reports, compliance was very high, but new family and employment pressures may have contributed to the lower rates at this visit. The sample size is thus smaller and may have contributed to the large variance in some findings. A higher proportion of women than men participated, and the parental socioeconomic status at age 8 years was also higher. Nevertheless, the groups were balanced on most key variables, and the follow-up rate of over 60% into their 30s is still acceptable relative to other studies.

Conclusions

It is difficult to predict what the future will hold for these ELBW adults as they reach middle age in terms of their employment, income, family and partner relationships, and quality of life. In addition, concerns have been expressed about their mental and physical health, as well as reproduction and cardiometabolic problems. It is therefore essential that these individuals receive necessary support and continued monitoring. Survival of very premature infants has now doubled, and so in absolute numbers, there are significantly more survivors. Such studies, and others on newer cohorts in the post-surfactant era, should be conducted throughout the life course of these individuals to obtain a better understanding of the most pressing issues, and to develop effective intervention strategies.
Lifestyle, Social Integration, and Sexuality of ELBW Adults

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Study supervision: Saigal, Van Lieshout, Schmidt, Morrison.

Critical revision of the manuscript for important intellectual content: All authors.

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