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Self-Perceived Health, Functioning and Well-Being of Very Low Birth Weight Infants at Age 20 Years

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Abstract

Objective—To examine the self-perceived health of very low birth weight (VLBW; <1.5 kg) infants during young adulthood.

Study design—The population included 241 VLBW and 232 normal birth weight (NBW) controls who completed the Child Health and Illness Profile: Adolescent Edition (CHIP-AE) at 20 years of age. The CHIP-AE includes six domains: Satisfaction, Comfort, Resilience, Achievement, Risk Avoidance, and Disorders, and 13 profiles that characterize patterns of health. Results were compared between VLBW and NBW subjects adjusting for sex and sociodemographic status.

Results—VLBW subjects did not differ from NBW controls in the domains of Satisfaction or Comfort but reported less Resilience (effect size [ES] -0.19 , $P < .05$), specifically in physical activity and family involvement. They reported better Achievement, specifically in work performance (ES 0.28 , $P < .05$), more Risk Avoidance (ES 0.43 , $P < .001$), and significantly more long-term medical, surgical, and psychosocial disorders. Similar proportions of VLBW and NBW subjects reported Excellent (15% vs 11%), Average (27% vs 34%), and Poor (12% vs 13%) profiles of health.

Conclusions—VLBW subjects report similar health, well-being, and functioning compared with NBW controls and greater risk avoidance. However, we are concerned that their lesser resilience may prove detrimental to their future adult health.

Reports of the young adult outcomes of very low birth weight children (VLBW; <1.5 kg) who were the initial survivors of neonatal intensive care have included educational achievement and various aspects of health and behavior.^{1–4} The reports of health outcomes have, with few exceptions,^{2,3} pertained to specific biological markers of health such as neurosensory impairments and other chronic conditions.^{1,3,5–7} There has been very little prior research on the overall impact of VLBW on young adults' self-perceived health, functioning, and well-being.^{2,3} This broader concept of self-assessed health has been termed "health-related quality of life," which is widely considered to be an important outcome of medical interventions, because it constitutes the individual's own experiences and evaluations of health.

As part of a longitudinal study of the outcomes of a cohort of VLBW young adults born during the years 1977 through 1979, we previously reported on outcomes at 20 years of age, including

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specific chronic conditions and types of risk-taking behavior,¹ growth attainment,⁵ blood pressure,⁶ and psychopathology.⁸ These categorical outcomes do not, however, describe the influence of very low birth weight on health defined by the World Health Organization (WHO) as a “state of physical, mental and social well-being and not just the absence of disease or infirmity.”⁹

To more fully describe the health experiences of VLBW children as compared with normal birth weight (NBW) controls at 20 years of age, we used the Child Health and Illness Profile: Adolescent Edition (CHIP-AE) a multidimensional self-report instrument that is based on a framework of health-related quality of life that includes satisfaction with health and self, comfort feelings, psychosocial resiliencies, risk behaviors, and achievement in academic and work settings. The CHIP-AE also includes biological markers of medical health and psychosocial disorders.^{10,11} We hypothesized that the self-perceived health-related quality of life of our population would be determined both by biological risk, as evidenced by birth weight status (VLBW vs NBW) and by sociodemographic factors.

METHODS

Very Low Birth Weight Group

A population of 490 VLBW children were admitted to Rainbow Babies and Children’s Hospital (Cleveland, Ohio) between 1977 and 1979 of whom 312 (64%) survived to 20 years of age. The original young adult study population studied at 20 years of age included 242 VLBW participants.¹ One additional subject with cerebral palsy did not participate. Two hundred and forty-one subjects (116 men and 125 women) completed the CHIP-AE. They constitute 77% of the surviving birth cohort. A description of maternal sociodemographic status at the time of birth and infant birth data was previously published¹ and is summarized in Table I. The young adult study participants did not differ significantly from those not studied in terms of the sociodemographic characteristics of their mothers at the time of their birth, in mean birth weight, gestational age, and rates of neonatal problems, or in IQ at 8 years of age.^{1,12}

Normal Birth Weight Control Group

The original control group included 366 NBW children born at term gestation in 1977, 1978, or 1979, who were selected by means of a population sampling procedure when they were 8 years of age.¹² Three controls died between 8 and 20 years of age. Of the remaining 363 controls, 130 were not studied at 20 years of age. The 20-year control population thus included 233 participants of whom 232 (108 men and 124 women) completed the CHIP-AE questionnaire and are the subjects of the present study. They constitute 64% of the cohort that was recruited at 8 years of age. The controls who participated at 20 years of age had significantly higher mean IQ scores at 8 years of age than those who did not participate (105 ± 16 vs 93 ± 15 , $P < .001$). Fewer of their mothers were unmarried (36% vs 61%), fewer had less than high school education (11% vs 27%) at the child’s 8th year, and fewer were black (55% vs 76%), $P < .001$ for all comparisons.

Measures and Variables

The CHIP-AE is a self-report instrument that includes 107 items related to perceived health, functioning, and well-being and 46 disease- or injury-specific questions.^{10,11} Twenty subdomains are organized into six conceptually based domains: (1) “Satisfaction,” with items concerning self-worth and overall satisfaction with one’s health; (2) “Comfort,” includes physically and emotionally experienced body sensations and feelings, and limitations in activity due to illness; (3) “Resilience” includes states and behaviors that promote psychosocial adaptability to stressors, including social problem solving, physical activity, home safety, and family involvement such as family support and the amount of time and activities done as a

family; (4) “Achievement” includes academic performance in school such as achieving the honor role or failing a grade, and work performance includes work attendance, getting to work on time, and getting the work done; (5) “Risk Avoidance” includes avoidance of individual risks, negative behaviors that may disrupt social development and subsequent health, and influences from peers who are involved in risky behaviors; and, (6) “Disorders” include biomedically defined states of ill health, injuries, and impairments (Table II; available at www.jpeds.com). (Additional information on the CHIP-AE is available at <http://www.chip.jhu.edu>)

The CHIP-AE was developed for use with adolescents and was empirically tested with youth up to 18 years of age. However, its conceptual basis and item content with minor modification are developmentally appropriate for young adults. The most common recall period is the past 4 weeks. Seventy percent of items had to be completed for domain and subdomain scores to be calculated. Higher scores indicate better health and well-being with the exception of the Disorders domain, which indicate poorer health. All the domains have internal consistency reliability >0.80 and one week test–retest reliability >0.60 . Construct validity has been documented by showing that the instrument has moderate to high correlations with other measures that assess single domains of health and by demonstrating that it can discriminate “well” respondents from those with “illness” as characterized by acute and chronic disorders¹³ as well as chronic conditions such as asthma.¹⁴

Because health, functioning, and well-being compose multiple concepts, no single variable fully captures a person’s current status. To examine these concepts integrated at the level of the person, we used the CHIP-AE profile-types, which characterize persons according to their patterns of health and well-being scores.^{15,16} The conceptual and statistical approaches for constructing the profile-types have been published.^{15,16} Each profile-type represents current health and well-being as well as states that have implications for future health. The profile-types provide a 13 type mutually exclusive taxonomy of health at the individual level. Categories represent a hierarchical spectrum of health and well-being, from persons with excellent health to those with multiple health needs.

The profile-types are based on the distribution of scores on four domains: Satisfaction, Comfort, Risk Avoidance, and Resilience. We used the NBW group to determine the 25th and 75th percentiles for each domain. To characterize each subject’s score as above the 75th percentile, between the 25th and 75th percentile, or below the 25th percentile the scores of each of the four domains were trichotomized into poor health (lowest quartile), average health (two middle quartiles), and excellent health (top quartile). The 13 mutually exclusive profile-types are: Profile 1: Excellent Health with excellent health on three or four domains and no domains of poor health; Profile 2: Good Health—at least average health on all domains, with excellent health on no more than two domains; Profiles 3 to 6 include the four profiles Dissatisfied, Discomfort, Low Resilience, and High Risks in which each have poor health in their specific domains; and Profiles 7 to 12 in which health is poor in each possible combination of two domains: Dissatisfied/high discomfort, Dissatisfied/low resilience, Dissatisfied/high risks, Discomfort/low resilience, Discomfort/high risks and Low resilience/high risks; and Profile 13: the worst health profile type, which includes poor health on three or four domains. The profile-types have the expected relations to sociodemographic characteristics, family structures, school achievement, medical disorders, and psychiatric disorders¹⁶ and have been used to examine incarcerated youth¹⁷ and the effects of social class on health of populations with chronic illnesses.¹⁸

The young adults completed the questionnaire either at the research facility (48%) or during an assessment in the home, with the exception of three VLBW and two NBW subjects who lived out of state and mailed their responses. The questionnaires were completed via self-

administration, with the exception of 5% of subjects who had difficulty in reading where the questionnaires were administered orally.

The study was approved by the Institutional Review Board of University Hospitals of Cleveland, and all of the participants provided written informed consent to participate in the study.

Statistical Analyses

Univariate comparisons between the VLBW and NBW groups were made with the use of the Student's *t* test for continuous variables and the χ^2 test or Fisher's exact test for discrete variables. Domain and subdomain scores of the CHIP-AE of the VLBW and NBW subjects were compared and effect sizes calculated as the mean differences between the VLBW and NBW scores adjusted for sociodemographic status and sex divided by the SD of the NBW group. The effect size expresses the magnitude of the effect in SD units, which facilitates comparisons across domains and subdomains. Because of the known effects of sociodemographic factors and sex on health and behavioral outcomes, we controlled for these factors in the analyses. A composite score representing the mother's sociodemographic status, which we have previously used, was calculated by assigning one point for each of the following factors: unmarried status, black race, and less than high school education.^{1,12} Black race was included as it is associated with poverty in our inner city Cleveland population. The composite score ranged from 0 to 3. Sociodemographic descriptors at the time of the children's birth were available only for the VLBW subjects. We thus used the mother's marital and educational status at the time the child was 8 years of age for all analyses. These maternal social status indicators were considered to span the period of childhood and to be more relevant than the mother's social status at 20 years. Because of the possible effects of neurosensory impairment and/or subnormal IQ on health and behavior, and of possible reporting bias, in separate analyses, we also examined the outcomes of subjects who did not have neurosensory impairments and/or a subnormal (<70) IQ.

RESULTS

Sociodemographic Status, 20-Year IQ, and Neurodevelopmental Status of the Very Low Birth Weight and Normal Birth Weight Participants

More mothers of the VLBW participants than mothers of the NBW controls had not completed high school when the children were 8 years of age. However, the VLBW and control groups did not differ in maternal marital status, race, or in the composite sociodemographic risk score.¹ At 8 years of age, the VLBW participants had significantly higher rates of neurosensory impairment and subnormal IQ than NBW subjects¹² (Table I), findings that persisted at 20 years of age.¹ The neurosensory impairments in the VLBW population, of whom 2 had more than one impairment, included cerebral palsy in 14, shunt-dependent hydrocephalus in 5, uni- or bilateral blindness in 4, and deafness in 3 subjects. One NBW subject required a hearing aid for deafness.

Comparison of Mean Scores of the CHIP-AE Domains and Subdomains between VLBW and NBW Subjects (Table III)

The VLBW subjects did not differ significantly from the NBW controls in the CHIP-AE domains of Satisfaction or Comfort; however, they reported significantly less Resilience (effect size [ES] -0.19 , $P < .05$), specifically at the subdomain level of Physical Activity and Family Involvement. VLBW subjects also reported significantly more Risk Avoidance (ES 0.43 , $P < .001$) with significant differences in all three of the Risk Avoidance subdomains. These included Individual Risks such as drug, alcohol abuse, and sexual activity; Threats to Achievement such as delinquent and violent behavior; and Influences of Peers who abuse drugs or alcohol or who

are sexually active. The VLBW subjects reported better Achievement than the NBW subjects specifically because of significantly higher scores at the subdomain level of Work Performance.

There were no overall differences in the Disorders domain, but at the subdomain level VLBW subjects reported significantly more Long-term Medical and Surgical Disorders and Psychosocial Disorders but fewer Acute Minor Disorders than the NBW subjects. In general, the differences between the VLBW and NBW subjects were greater for females than for males (Table IV; available at www.jpeds.com).

The results were similar when we excluded the 34 VLBW and 3 NBW subjects who had either a subnormal IQ and/or neurosensory impairment, with the exception that the differences in Long-term Medical and Surgical Disorders and Psychosocial Disorders were no longer significant and the differences in family involvement now only bordered on significant ($P = .062$).

In multivariate regression analyses that included birth weight status (VLBW vs NBW), sex, and sociodemographic status, higher sociodemographic status was significantly associated with higher scores (ie, better functioning) in the domains of Resilience ($P < .001$), Risk Avoidance ($P < .05$), and Achievement ($P < .001$) but not with the domains of Satisfaction, Comfort, or Disorders. At the subdomain level, higher sociodemographic status was significantly associated with better physical activity, home safety and health, family involvement, social problem-solving, academic and work performance, and fewer threats to achievement. Sociodemographic status was negatively associated with acute major disorders and recurrent disorders but was not associated with long-term medical, surgical, or psychosocial conditions.

Comparison of Profiles of Health

The distributions of the 13 health profile-types are shown in Table V. Three VLBW and one NBW subject had at least one missing domain and could not be assigned to a profile-type. The proportions of VLBW and NBW subjects at the excellent/average health and poor health extremes of the profile-type distribution were similar. However, the VLBW subjects were more likely to be in one of the four profile-types with one domain of poor health (Types 3 to 6, 32% vs 25%), whereas NBW subjects were more likely to be in one of the six profile-types with two domains of poor health (Types 7 to 12, 18% vs 14%). In other words, the NBW distribution of the CHIP-AE profile-types was shifted toward the poorer health of the spectrum, suggesting better overall self-perceived health for VLBW subjects compared with NBW counterparts. The results were similar after excluding the VLBW and NBW subjects who had either neurosensory impairments and/or a subnormal IQ. Higher social risk (ie, lower sociodemographic status) was not significantly associated with the excellent/average profiles or with the poor health profile types after adjusting for VLBW status and sex.

DISCUSSION

We sought to examine the health, functioning, and well-being of VLBW infants at 20 years of age to obtain an individual personal assessment of the health-related aspects of their lives. VLBW subjects, as compared with NBW controls, reported similar outcomes in terms of their satisfaction with health and self, and in the levels of physically and emotionally experienced symptoms. On the other hand, the VLBW subjects reported better risk avoidance but poorer psychosocial resilience than their NBW counterparts.

At 8 years of age VLBW participants of this longitudinal study had significantly more health problems than the NBW controls including respiratory ailments, persistent neuromuscular

disorders, and the need for surgery to alleviate these conditions.¹⁹ Our results indicate that the VLBW subjects may have adapted to their functional limitations by 20 years of age and that, from an individual perspective, VLBW status has no influence on young adult satisfaction with health, subjective well-being, or health perceptions, despite the persistence of neurosensory impairments and their associated long-term medical, surgical, and psychosocial problems. These findings are in agreement with other reports of late adolescent and young adult outcomes including health status as measured with the SF-36 self-report questionnaire,³ self-esteem,^{3, 20} and quality of life.²⁻⁴ Some differences have however been noted for VLBW young adults who have severe neurosensory or physical handicaps.^{2,4} Our findings also agree with studies of children with chronic illness and intellectual and physical disabilities that report similar rates of satisfaction with health and/or self-esteem to that of controls,²¹⁻²³ as well as a successful transition to adulthood.²⁴ Gortmaker examined the relationship between having a chronic physical health condition during adolescence and subsequent transition to adulthood in a nationally representative sample and found no difference in self-esteem and only a slightly higher risk of problems in early adulthood related to educational attainment and work performance. These problems were mainly influenced by socioeconomic and demographic factors.²⁴ The many factors that may affect health status and well-being include quality of health care, cultural and sociodemographic factors, educational enrichment and vocational training, individual personality characteristics, and the ability to compensate by using aids to prevent disability or taking advantage of alternative abilities. The WHO International Classification of Functioning, Disability and Health takes account of social and environmental influences on an individual's health and well-being, but we do not have detailed information in this regard.²⁵

Our findings may be partly explained by different perceptions of health and reporting bias. The greater differences between VLBW and NBW women, than between VLBW and NBW men, in the domains of Resilience, Achievement, and Risk Avoidance (Table IV) may be because of sex differences in responding to questionnaires, especially those related to health and risk behaviors. However, the CHIP-AE items do not have any known differential item functioning by sex that argues against this explanation.²⁶ Preterm subjects may also respond differently to questionnaires than term NBW subjects. In a recent study of the self-reported personality of 18- to 19-year-old preterm subjects born <33 weeks gestation compared with term controls, Allin et al reported that the preterm subjects had a significant increase in "lie scores" defined as a tendency to simulate and to give false answers to appear more socially acceptable.²⁷ It has also been suggested that persons with intellectual disabilities tend to compensate in a way that causes them to deny their disability and maintain their feeling of satisfaction and well-being through various processes of adaptation.²⁸

We previously reported that this cohort of VLBW subjects reported lower rates of alcohol and marijuana use than the NBW subjects.¹ The present findings of overall increased risk avoidance, including individual risks, threats to achievement, and influences from delinquent peers among the VLBW subjects are also in agreement with other reports of lesser risk-taking among preterm and VLBW adolescents and young adults^{3,4} and with Allin et al's finding of decreased extroversion, including a decrease in sensation seeking and early sexual activity.²⁷ These findings are in contrast to those of population studies of adolescents and young adults with chronic conditions where the rates of risk-taking behaviors tend to be similar or higher than those of controls.²⁹ We have previously suggested that the increased risk-taking among preterm subjects could be related to increased parental monitoring.¹ It is of interest that in the CHIP-AE subdomain of Home Safety and Health, VLBW subjects reported significantly fewer guns in the home and greater curfew on school nights during adolescence, factors that could have contributed to the lesser risk-taking (data not shown). It has also been suggested that the lesser risk-taking may be related to decreased peer relationships and opportunities to participate in risk-taking experiences.³⁰ This is supported by a national self-report study of Canadian

children attending public schools that found that although children with physical disabilities had as many friends as those without physical disabilities, they participated in fewer out-of-school social activities and thus did not fully share in the activities of their peers.³¹ In our study, the increased risk avoidance was evident even in subjects who did not have neurosensory impairments and were presumably free of physical disabilities. The fact that the differences in risk avoidance were greater for VLBW women than men may partly be explained by the increase in internalizing behaviors, including anxious, withdrawn, and depressed symptoms that we have reported among these women.⁸ These symptoms may inhibit the development of risk-taking behavior.³²

Resilience as defined in the CHIP-AE pertains to psychosocial states and health behaviors likely to reduce subsequent illness or injury or be protective. They include physical activity, home safety and health, family involvement, and problem solving. Although there is some overlap, this definition of resilience differs from that used in the psychology literature that refers to how children overcome adversity to achieve good developmental outcomes.³³ The lower resilience among our VLBW subjects, even among those who had no neurosensory impairments, was most evident in the subdomains of Physical Activity and Family Involvement. Adolescents with chronic illness have similarly reported less than adequate family relationships including doing less things with their family.³⁴ Decreased family connectedness has also been reported for adolescents with mobility impairments and learning and emotional disabilities.²⁹

Sociodemographic status both during childhood and adulthood has a significant effect on adult self-rated health status.³⁵ Its effect on self-reported health during mid/late adolescence and early adulthood is however less consistent.³⁶ This may explain the fact that, in our 20-year-old population, sociodemographic status was not associated with the CHIP-AE domains of Satisfaction, Comfort, or Disorders. The significant relationship between higher sociodemographic status and greater Resilience, and lesser Risk-taking and Achievement in our population are, however, in agreement with the findings of others.³⁷ Starfield et al used the CHIP-AE to examine the effects of gradients of parental social class, based on parental education and occupation, on the self-reported health of a normative population of 11- to 17-year-old adolescents.¹⁸ Similar to our results they found a significant association between the social class gradients and the domains of Resilience and Risk-avoidance. However, in contrast to our findings they also found a significant association with Satisfaction with Health and with the Excellent/average health profiles and a negative association with the Worst health profile. The discrepancies between our and Starfield's results may possibly be explained by differences in the populations studied, age of the subjects, and how social class was measured.

Limitations of our study include those inherent in using a self-report health measure, especially among subjects with a lower mean IQ.¹ Questionnaires concerning physical activities have however been found to be fairly reliable.³⁸ In our population the lower alcohol use reported by the VLBW subjects was confirmed by parent report.¹ The CHIP-AE was developed and validated for use among adolescents 11 to 17 years of age.¹⁰ The only modification we made to the questionnaire related to a few specific questions about school activities, which we rephrased as when they were in school. The rates of Excellent and Average profiles of health for our NBW cohort were similar to those of Riley et al (45% vs 43%) as were the other categories of the 13 profile-types.¹⁵ Because neonatal survival and morbidity have changed since 1977–1979, when our cohort was born, the nature of the adult chronic sequelae of prematurity may also have changed. Our results may thus not apply to current survivors, although they will be highly relevant to the increasing numbers of preterm children currently reaching late adolescence and young adulthood.

The strengths of the study include our measure of health status, the CHIP-AE, which provides a comprehensive, multidimensional, noncategorical assessment of health status and health-related quality of life based on the WHO's broader concept of health.⁹ In addition, the profile-types reflect underlying patterns of current physical, mental, and social health that express different needs for health services and are likely to be related to future adult health. Results of the longitudinal 1958 British Birth Cohort Study indicate that social differences in health at 23 years of age persist to 33 years of age, and that although self-reported health ratings at 23 years of age predicted health at 33 years of age, when there was a change, it tended to be a decline in health.³⁹ Although the increased risk-avoidance behaviors of the VLBW subjects may prove beneficial in the long run, we are concerned about the lower resilience with regard to health behaviors including lesser physical activity, which together with the increase in mean systolic blood pressure and poorer pulmonary function reported among VLBW young adults^{6,7} may prove detrimental to future health. It will thus be important to ensure optimal medical care as these survivors of neonatal intensive care enter mature adulthood.⁴⁰

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References

1. Hack M, Flannery D, Schluchter M, Cartar L, Borawski E, Klein N. Young adult outcomes of very low birth weight children (VLBW, <1.5 kg). *N Engl J Med* 2002;346:149–57. [PubMed: 11796848]
2. Saigal S, Stoskopf B, Pinelli J, Streiner D, Hoult L, Panet N, et al. Self-perceived health-related quality of life of former extremely low birth weight infants at adulthood. *Pediatrics* 2006;118:1140–8. [PubMed: 16951009]
3. Cooke RWI. Health, lifestyle, and quality of life for young adults born very preterm. *Arch Dis Child* 2004;89:201–6. [PubMed: 14977689]
4. Dinesen SJ, Greisen G. Quality of life in young adults with very low birth weight. *Arch Dis Child Fetal Neonatal Ed* 2001;85:F165–F169. [PubMed: 11668156]
5. Hack, M.; Schluchter, M.; Cartar, L.; Rahman, M.; Cuttler, L.; Borawski, E. Growth of very low birth weight infants to 20 years; *Pediatrics*. 2003. p. e30-e38. Available at: <http://www.pediatrics.org/cgi/content/full/112/1/e30>
6. Hack M, Schluchter M, Cartar L, Rahman M. Blood pressure among very low birth weight (<1.5 kg) young adults. *Pediatr Res* 2005;58:677–84. [PubMed: 16192252]
7. Halvorsen T, Skadberg BT, Eide GE, Roksund OD, Carlsen KH, Bakke P. Pulmonary outcome in adolescents of extreme preterm birth: a regional cohort study. *Acta Pædiatr* 2004;93:1294–1300.
8. Hack M, Youngstrom EA, Cartar L, Schluchter M, Taylor HG, Flannery D, et al. Behavioral outcomes and evidence of psychopathology among very low birth weight infants at age 20 years. *Pediatrics* 2004;114:932–40. [PubMed: 15466087]
9. World Health Organization. Constitution of the World Health Organization. New York: World Health Organization; 1947.
10. Starfield B, Bergner M, Ensminger M, Riley A, Ryan S, Green B, et al. Adolescent health status measurement: development of the child health and illness profile. *Pediatrics* 1993;91:430–5. [PubMed: 8424023]
11. Starfield B, Riley AW, Green BF, Ensminger ME, Ryan SA, Kelleher K, et al. The Adolescent Child Health and Illness Profile: a population-based measure of health. *Med Care* 1995;33:553–66. [PubMed: 7739277]
12. Hack M, Breslau N, Aram D, Weissman B, Klein N, Borawski-Clark E. The effect of very low birth weight and social risk on neurocognitive abilities at school age. *J Dev Behav Pediatr* 1992;13:412–420. [PubMed: 1469109]
13. Starfield B, Forrest CB, Ryan SA, Riley AW, Ensminger ME, Green BF. Health status of well vs. ill adolescents. *Arch Pediatr Adolesc Med* 1996;150:1249–56. [PubMed: 8953996]

14. Forrest, CB.; Starfield, B.; Riley, AW.; Kang, M. The impact of asthma on the health status of adolescents; *Pediatrics*. 1997. p. e1-e7. Available at: <http://www.pediatrics.org/cgi/content/full/99/2/e1>
15. Riley AW, Green BF, Forrest CB, Starfield B, Kang M, Ensminger ME. A taxonomy of adolescent health: development of the adolescent health profile-types. *Med Care* 1998;36:1228–36. [PubMed: 9708594]
16. Riley AW, Green BF, Forrest CB, Starfield B, Green B, Kang M, et al. Reliability and validity of the adolescent health profile-types. *Med Care* 1998;36:1237–48. [PubMed: 9708595]
17. Forrest CB, Tambor E, Riley AW, Ensminger ME, Starfield B. The health profile of incarcerated male youths. *Pediatrics* 2000;105:286–91. [PubMed: 10617737]
18. Starfield B, Riley AW, Witt WP, Robertson J. Social class gradients in health during adolescence. *J Epidemiol Community Health* 2002;56:354–61. [PubMed: 11964432]
19. Hack M, Weissman B, Breslau N, Klein N, Borawski-Clark E, Fanaroff AA. Health of very low birthweight children during their first 8 years. *J Pediatr* 1993;122:887–92. [PubMed: 8501564]
20. Tideman E, Ley D, Bjerre K, Forslund M. Longitudinal follow-up of children born preterm: somatic and mental health, self esteem and quality of life at age 19. *Early Hum Dev* 2001;61:97–110. [PubMed: 11223272]
21. Arnold P, Chapman M. Self-esteem, aspirations and expectations of adolescents with physical disability. *Dev Med Child Neurol* 1992;34:97–102. [PubMed: 1531135]
22. Ireys HT, Gross SS, Werthamer-Larsson LA, Kolodner KB. Self-esteem of young adults with chronic health conditions: appraising the effects of perceived impact. *J Dev Behav Pediatr* 1994;15:409–15. [PubMed: 7884011]
23. Pless IB, Cripps HA, Davies JM, Wadsworth ME. Chronic physical illness in childhood: psychological and social effects in adolescence and adult life. *Dev Med Child Neurol* 1989;31:746–55. [PubMed: 2599268]
24. Gortmaker SL, Perrin JM, Weitzman M, Homer CJ, Sobol AM. An unexpected success story: transition to adulthood in youth with chronic physical health conditions. *J Res Adolesc* 1993;3:317–36.
25. World Health Organization. *International Classification of Functioning, Disability and Health*. Geneva: World Health Organization; 2001.
26. Starfield, B.; Riley, AW.; Green, BF.; Ensminger, ME.; Forrest, CB.; Robertson, J., et al. *Manual for The Child Health and Illness Profile: Adolescent Edition (CHIP-AE)*. Baltimore: John Hopkins University; 2000.
27. Allin M, Rooney M, Cuddy M, Wyatt J, Walshe M, Rifkin L, et al. Personality in young adults who were born preterm. *Pediatrics* 2006;117:309–10. [PubMed: 16452348]
28. White-Koning M. Subjective quality of life in children with intellectual impairment: how can they be assessed? *Dev Med Child Neurol* 2005;57:281–5. [PubMed: 15832552]
29. Blum RW, Kelly A, Ireland M. Health-risk behaviors and protective factors among adolescents with mobility impairments and learning and emotional disabilities. *J Adolesc Health* 2001;28:481–90.
30. Harrison H. Letter to the Editor. *NEJM* 2002;347:141. [PubMed: 12110746]
31. Stevens SE, Steele CA, Jutal JW, Kalnins IV, Bortolussi JA, Biggar WD. Adolescents with physical disabilities: some psychosocial aspects of health. *J Adolesc Health* 1996;19:157–164.
32. Masten AS, Roisman GI, Long JD, Burt KB, Obradovic J, Riley JR, et al. Developmental cascades: linking academic achievement and externalizing and internalizing symptoms over 20 years. *Dev Psychology* 2005;41:733–46.
33. Masten AS, Coatsworth JD. The development of competence in favorable and unfavorable environments. *Am Psychologist* 1998;53:205–20.
34. Orr DP, Weller SC, Satterwhite B, Pless IB. Psychosocial implications of chronic illness in adolescence. *J Pediatr* 1984;104:152–7. [PubMed: 6690661]
35. Laaksonen M, Rahkonen O, Martikainen P, Lahelma E. Socioeconomic position and self-related health: the contribution of childhood socioeconomic circumstances, adult socioeconomic status, and material resources. *Am J Public Health* 2005;95:1403–9. [PubMed: 16006419]

36. Glendinning A, Love JG, Hendry LB, Shucksmith J. Adolescence and health inequalities: extensions to MacIntyre and West. *Soc Sci Med* 1992;35:679–87. [PubMed: 1439918]
37. Lowry R, Kann L, Collins JL, Kolbe LJ. The effect of socioeconomic status on chronic disease risk behaviors among US adolescents. *JAMA* 1996;276:792–7. [PubMed: 8769588]
38. Aaron DJ, Kriska AM, Dearwater SR, Cauley JA, Metz KF, LaPorte RE. Reproducibility and validity of an epidemiologic questionnaire to assess past year physical activity in adolescents. *Am J Epidemiol* 1995;142:191–201. [PubMed: 7598119]
39. Manor O, Mathews S, Power C. Self rated health and limiting longstanding illness: inter-relationships with morbidity in early adulthood. *Int J Epidemiol* 2001;30:600–7. [PubMed: 11416091]
40. Freed GL, Hudson EJ. Transitioning children with chronic diseases to adult care: current knowledge, practices, and directions. *J Pediatr* 2006;148:824–7. [PubMed: 16769396]

Glossary

CHIP-AE	Child Health and Illness Profile: Adolescent Edition
NBW	Normal birth weight
VLBW	Very low birth weight
ES	Effect size
WHO	World Health Organization

Table I
Maternal sociodemographic status at 8 years of follow-up and birth data for very low birth weight (VLBW) and normal birth weight (NBW) participants

	VLBW (n = 241)	NBW (n = 232)
Maternal factors [*]		
Unmarried	100 (41%)	84 (36%)
Education [†]		
< High school	40 (17%)	25 (11%)
High school	132 (55%)	117 (50%)
> High school	69 (29%)	90 (39%)
Black race	132 (55%)	127 (55%)
Composite sociodemographic score [‡]		
0	79 (33%)	90 (39%)
1	73 (30%)	66 (28%)
2	70 (29%)	59 (25%)
3	19 (8%)	17 (7%)
Birth data		
Birth weight (mean g ± SD)	1180 ± 219	3279 ± 584
Gestational age (mean wk ± SD)	29.7 ± 3	≥37 ^{//}
Female sex	125 (52%)	124 (54%)
Multiple birth [§]	32 (13%)	4 (2%)
8-Year outcomes		
Neurosensory impairment	24 (10%)	1 (0.4%)
IQ <70	15 (6%)	3 (1%)
Asthma	19 (8%)	13 (6%)

^{*}The maternal status at the time the participant was 8 years old. Maternal characteristics refer to participant's primary caretaker, who was an adoptive mother in five VLBW and three NBW children, a foster mother in one VLBW, and a grandparent in three VLBW children.

[†] $P = .03$ for the comparison between groups.

[‡]In the calculation of this composite score, one point was assigned for each of the following factors: unmarried status, black race, and less than a high school education.

[§]Data are for participants with a living twin or, in one case, two living triplets.

^{//}Specific information on gestational age was not available for the NBW group.

Table II

Description of CHIP-AE domains and subdomains

Domain and subdomains	Description	Examples of questions
I. Satisfaction:	Perceived level of health and well-being	
1. Satisfaction with health	Overall perceptions of and beliefs about one's health	Full of energy
2. Self-esteem	Self-concept	Like being the way I am
II. Comfort:	Specific physical and emotional sensations/feelings that interfere with comfort	
1. Physical comfort	Physical feelings and symptoms	Days free of pain
2. Emotional comfort	Emotional feelings and symptoms	Days had trouble falling asleep
3. Physical activity	Restrictions in age-appropriate activities and limitations in mobility	Days had trouble walking
III. Resilience:	States and behaviors known to protect persons from subsequent illness or injury	
1. Physical activity	Involvement in a variety of activities related to fitness	Days played hard enough to sweat
2. Home safety and health	Aspects of the home that reduce/increase likelihood of harm	Such as smoke detectors
3. Family involvement	The amount and type of activities done as a family and family support available	Days family spent time with you
4. Social problem solving	Active approaches to solving a hypothetical problem	Try to see good side
IV. Achievement:	Evaluation of one's own developmentally appropriate role performance	
1. Academic performance	Perceived school accomplishments	Received a school award or prize
2. Work performance	Perceived work accomplishments	Days not at work on time
V. Risks:	States/behaviors that are known to heighten likelihood of subsequent illness or injury	
1. Individual risks	Activities that threaten individual development	Last time smoked cigarettes
2. Threats to achievement	Negative behaviors that threaten to disrupt social development	Last time carried a weapon
3. Peer influences	Involvement with peers who engage in risky behaviors	Number of friends who smoke marijuana
VI. Disorders:	Diagnostic entities including conditions, injuries, and impairments	
1. Acute minor disorders	eg, colds, tonsillitis, sprains, etc.	In past 12 months
2. Acute major disorders	eg, pneumonia, broken bones, hepatitis, etc.	} Ever had problems? If so, in past 12 months?
3. Recurrent disorders	eg, ear infections, asthma, allergies, etc.	
4. Long-term medical disorders	eg, arthritis, diabetes, epilepsy, etc.	
5. Long-term surgical disorders	eg, scoliosis, vision problems, hearing problems, etc.	
6. Psychosocial disorders	eg, speech problems, eating problem, learning disability	

Table III

Domain and subdomain scale scores and effect sizes for differences in these scores for very low birth weight (VLBW) compared with normal birth weight (NBW) 20-year-old subjects

Domain and subdomain scales	VLBW (n = 241) Mean ± SD	NBW (n = 232) Mean ± SD	Effect size *
Satisfaction	3.30 ± .54	3.29 ± .49	0.03
Satisfaction with health	3.17 ± .60	3.14 ± .54	0.04
Self-esteem	3.43 ± .63	3.43 ± .57	0.01
Comfort	4.44 ± .41	4.42 ± .38	0.03
Physical comfort	4.39 ± .44	4.36 ± .39	0.09
Emotional comfort	4.30 ± .59	4.29 ± .57	0.02
Physical limitations	4.61 ± .48	4.63 ± .50	-0.04
Resilience	3.21 ± .45	3.31 ± .47	-0.19 [‡]
Physical activity	2.35 ± .91	2.58 ± .97	-0.24 [§]
Home safety and health	3.61 ± .45	3.63 ± .53	-0.01
Family involvement	3.85 ± .88	4.03 ± .78	-0.21 [‡]
Social problem-solving	3.03 ± .51	2.99 ± .55	0.08
Achievement	3.43 ± .56	3.31 ± .62	0.23
Academic performance [†]	2.60 ± .72	2.60 ± .77	0.04
Work performance	4.20 ± .72	4.00 ± .80	0.28 [‡]
Risk avoidance	3.80 ± .52	3.60 ± .49	0.433
Individual risks	3.97 ± .90	3.71 ± .80	0.34 [§]
Threats to achievement	4.51 ± .46	4.39 ± .51	0.26 [§]
Peer influences	2.92 ± .63	2.69 ± .54	0.433
Disorders	1.36 ± .23	1.33 ± .19	0.13
Acute minor	1.64 ± .41	1.74 ± .40	-0.27 [§]
Acute major	1.14 ± .29	1.14 ± .24	-0.02
Recurrent	1.45 ± .43	1.42 ± .37	0.08
Long-term medical	1.10 ± .23	1.06 ± .18	0.22 [‡]
Long-term surgical	1.56 ± .61	1.45 ± .57	0.20 [‡]
Psychosocial	1.30 ± .57	1.21 ± .43	0.22 [‡]

Higher scores indicate better health except for the subdomains of the Disorders domain.

There were no significant birth weight by sex interactions.

* Adjusted for sociodemographic status and sex. Effect sizes were calculated as the adjusted mean difference between the VLBW and NBW scores divided by the SD of the NBW group. Effect sizes translate changes in health status into standardized units. For the first five domains (which are scored as higher = better), a minus sign preceding the effect size indicates a negative effect on health (ie, poorer health status) for the VLBW group. For the Disorders domain, the minus sign indicates a positive effect on health for the VLBW group.

[†] When in high school.

[‡] $P < .05$.

[§] $P < .01$.

// $P < .001$.

Table IV
Sex-specific domain and subdomain scale scores and effect sizes for differences in these scores for very low birth weight (VLBW) compared with normal birth weight (NBW) 20-year-old subjects

Domain and subdomain scales	Males			Females		
	VLBW (n = 116) Mean ± SD	NBW (n = 108) Mean ± SD	Effect size*	VLBW (n = 125) Mean ± SD	NBW (n = 124) Mean ± SD	Effect size*
Satisfaction						
Satisfaction with health	3.42 ± .48	3.33 ± .48	0.22	3.18 ± .58	3.25 ± .49	-0.13
Self-esteem	3.35 ± .56	3.24 ± .52	0.22	3.00 ± .60	3.06 ± .55	-0.11
Comfort	3.51 ± .57	3.42 ± .57	0.17	3.37 ± .68	3.44 ± .57	-0.12
Physical comfort	4.51 ± .36	4.50 ± .30	0.04	4.36 ± .44	4.36 ± .43	0.02
Emotional comfort	4.47 ± .39	4.43 ± .33	0.11	4.32 ± .47	4.29 ± .43	0.07
Physical limitations	4.41 ± .55	4.40 ± .48	0.03	4.20 ± .61	4.19 ± .62	0.02
Resilience	4.67 ± .47	4.68 ± .42	-0.03	4.57 ± .49	4.59 ± .56	-0.04
Physical activity	3.26 ± .43	3.33 ± .47	-0.11	3.15 ± .46	3.28 ± .47	-0.26 [‡]
Home safety and health	2.60 ± .94	2.84 ± .88	-0.25	2.11 ± .82	2.36 ± .98	-0.25 [‡]
Family involvement	3.57 ± .47	3.58 ± .59	-0.01	3.65 ± .42	3.67 ± .48	30.03
Social problem-solving	3.85 ± .81	4.01 ± .85	30.16	3.85 ± .94	4.04 ± .73	30.22
Achievement	3.05 ± .49	2.92 ± .58	0.24	3.00 ± .54	3.05 ± .53	30.07
Academic performance [†]	3.29 ± .56	3.23 ± .61	0.11	3.56 ± .54	3.37 ± .62	0.33 [‡]
Work performance	2.33 ± .67	2.38 ± .78	30.03	2.76 ± .71	2.70 ± .76	0.10
Risk avoidance	4.11 ± .73	3.96 ± .86	0.17	4.31 ± .68	4.04 ± .73	0.40 [‡]
Individual risks	3.68 ± .51	3.52 ± .49	0.34 [‡]	3.91 ± .50	3.67 ± .48	0.513
Threats to achievement	3.82 ± .84	3.64 ± .84	0.22	4.10 ± .94	3.77 ± .75	0.45 [§]
Peer influences	4.38 ± .49	4.28 ± .54	0.19	4.64 ± .40	4.49 ± .46	0.35 [§]
Disorders	2.87 ± .62	2.63 ± .49	0.49 [§]	2.97 ± .64	2.74 ± .57	0.39 [§]
Acute minor	1.38 ± .25	1.34 ± .20	0.18	1.35 ± .21	1.33 ± .19	0.08
Acute major	1.69 ± .43	1.78 ± .43	30.20	1.59 ± .39	1.71 ± .38	30.33 [‡]
Recurrent	1.19 ± .33	1.16 ± .26	0.08	1.10 ± .24	1.13 ± .23	30.12
Long-term medical	1.42 ± .43	1.40 ± .37	0.03	1.48 ± .43	1.43 ± .37	0.13
Long-term surgical	1.07 ± .21	1.06 ± .17	0.11	1.12 ± .24	1.06 ± .18	0.30 [‡]
Psychosocial	1.61 ± .68	1.41 ± .53	0.38 [‡]	1.51 ± .54	1.48 ± .59	0.06
	1.31 ± .58	1.25 ± .47	0.11	1.30 ± .56	1.17 ± .40	0.32 [‡]

Higher scores indicate better health except for the subdomains of the Disorders domain. There were no significant birth weight by sex interactions.

* Adjusted for sociodemographic status and sex. Effect sizes were calculated as the adjusted mean difference between the VLBW and NBW scores divided by the SD of the NBW group. Effect sizes translate changes in health status into standardized units. For the first five domains (which are scored as higher = better), a minus sign preceding the effect size indicates a negative effect on health (ie, poorer health status) for the VLBW group. For the Disorders domain, the minus sign indicates a positive effect on health for the VLBW group.

[†] When in high school.

[‡] $P < .05$.

[§] $P < .01$.

// $P < .001$.

Table V

Comparison of the 13 profile-types for very low birth weight (VLBW) compared with normal birth weight (NBW) 20-year-old subjects *

	Criteria	VLBW (n = 238)	NBW (n = 231)
1) Excellent health	Excellent health on 3 or 4 domains, with no domains of poor health	36 (15%)	25 (11%)
2) Average health	At least average health on all domains, with excellent health on no more than 2 domains	66 (27%)	79 (34%)
3) Dissatisfied	Poor health only on Satisfaction	18 (8%)	16 (7%)
4) Discomfort	Poor health only on Discomfort	16 (7%)	11 (5%)
5) Low resilience	Poor health only on Resilience	32 (13%)	13 (6%)
6) High risk	Poor health only on Risks	9 (4%)	17 (7%)
7) Dissatisfied/discomfort	Poor health on Satisfaction and Discomfort	8 (3%)	14 (6%)
8) Dissatisfied/low resilience	Poor health on Satisfaction and Resilience	12 (5%)	4 (2%)
9) Dissatisfied/high risk	Poor health on Satisfaction and Risks	1 (0.4%)	3 (1%)
10) Discomfort/low resilience	Poor health on Discomfort and Resilience	3 (1%)	5 (2%)
11) Discomfort/high risk	Poor health on Discomfort and Risks	6 (3%)	6 (3%)
12) Low resilience/high risk	Poor health on Resilience and Risks	3 (1%)	9 (4%)
13) Worst health	Poor health on 3 or 4 domains	28 (12%)	29 (13%)

* Three VLBW and one NBW subjects had at least one missing domain.