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Persisting Behavior Problems in Extremely Low Birth Weight Adolescents

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Abstract

Objective—To describe behavior problems in extremely low birth weight (ELBW, <1000 g) adolescents born 1992–1995 based on parent ratings and adolescent self-ratings at age 14 years and examine changes in parent ratings from ages 8 to 14 years.

Method—Parent ratings of behavior problems and adolescent self-ratings were obtained for 169 ELBW adolescents (mean birth weight 815 g, gestational age 26 weeks) and 115 normal birth weight (NBW) controls at 14 years. Parent ratings of behavior at age 8 years were also available. Behavior outcomes were assessed using symptom severity scores and rates of scores above DSM-IV symptom cut-offs for clinical disorder.

Results—The ELBW group had higher symptom severity scores on parent ratings at age 14 years than NBW controls for inattentive attention deficit hyperactivity disorder (ADHD), anxiety, and social problems (all p 's < 0.01). Rates of parent ratings meeting DSM-IV symptom criteria for inattentive ADHD were also higher for the ELBW group (12% vs. 1%, p < 0.01). In contrast, the ELBW group had lower symptom severity scores on self-ratings than controls for several scales. Group differences in parent ratings decreased over time for ADHD, especially among females, but were stable for anxiety and social problems.

Conclusions—ELBW adolescents continue to have behavior problems similar to those evident at a younger age, but these problems are not evident in behavioral self-ratings. The findings suggest that parent ratings provide contrasting perspectives on behavior problems in ELBW youth and support the need to identify and treat these problems early in childhood.

INTRODUCTION

Premature infants have survived at an ever-increasing rate for the last 20 years, although the rates of neonatal mortality have leveled off since 2000.¹ Reports of the long term sequelae of prematurity and low birth weight include higher rates of chronic health and

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neurodevelopmental problems as compared to normal birth weight (NBW) controls. Higher rates of psychiatric disorders relative to NBW peers are also well documented and comprise a wide range of behavior problems.^{2–5} However, the most frequently identified problems are symptoms of the inattentive subtype attention deficit hyperactivity disorder (ADHD), internalizing disorders (e.g., anxiety, worry, and depression), and social difficulties, referred to collectively as the “preterm behavioral phenotype.”³ The phenotype is further characterized by less frequent symptoms of externalizing disorders (e.g., oppositional behavior, conduct disorder) and the hyperactive-impulsive subtype of ADHD.^{3,6–9}

Behavior problems in preterm or low-birth-weight children and adolescents are typically based on parent symptom ratings rather than on youth self-report. Most studies that have included youth self-ratings indicate either similar or lower self-ratings of problems preterm adolescents or those born at low birth weight compared to NBW controls.^{10–14} However, in one investigation of adolescents born at gestational age (GA) <29 weeks, the preterm group reported more emotional problems (e.g., fears, worries) but less delinquency and no group differences in hyperactivity or peer problems.⁸ Another study found higher self-ratings of depressive symptoms in adolescents with GA <26 weeks but did not assess self-ratings of other symptoms.⁷ Further research examining both parent behavior ratings and youth self-ratings is justified by the possibility that youth may not fully share emotional or behavior problems with their parents, particularly with advancing age.¹¹ Youth self-reports may provide information about behavioral outcomes that is not available in parent report. Moreover, because parent ratings and youth self-ratings represent different perspectives on youth behavior problems, surveying the views of both parties offers a fuller picture of outcomes.^{10,11}

Cross-sectional studies reveal similar behavior problems in child and adolescent samples of preterm or low birth weight youth, suggesting that these symptoms are evident early in childhood and persist throughout the school-age years.^{5–7,10–12,15–17} Past studies have examined behavior outcomes from childhood to adolescence,^{9,17,18} but to our knowledge only two studies directly compared these youth to NBW controls in behavioral change from childhood to adolescence using the same or comparable ratings across follow-up. Hall and Wolke¹⁹ followed very preterm (GA <32 weeks) and full-term groups from ages 6 to 12–13 years. Latent growth modeling classified a larger proportion of the preterm compared to full-term children into a high-stable pattern of emotional problems over time. A second study examined changes in rates of elevated parent and teacher ratings of internalizing, externalizing, and attention problems in low birth weight (<2500 g) children compared to NBW controls at 6, 11, and 17 years,²⁰ with results again documenting stable group differences over time.

As part of a longitudinal study of extremely low birth weight (ELBW, <1000 g) children born 1992 through 1995 in Cleveland, Ohio we previously described parent reports of behavioral sequelae at age 8 years in this cohort compared to NBW term born controls. The ELBW children had a higher rate of ADHD, and increased symptoms of anxiety and autism spectrum disorder.²¹ The primary objective of the present study was to describe the behavioral outcomes of this cohort at age 14 years compared to the NBW controls using both parent ratings and adolescent self-ratings of behavior problems. Secondary objectives

were to compare the parent and self-ratings and examine the stability of parent ratings from 8 to 14 years of age. Ratings were based on symptoms listed in the Diagnostic and Statistical Manual of Mental Disorders: 4th Edition (DSM-IV), allowing us to determine if findings from past studies using other behavior questionnaires, such as the Child Behavior Checklist (CBCL), would be replicated on DSM-IV-based scales. Because item content was the same for the parent and self-ratings and across the two ages, we were also able to compare parent ratings to adolescent self-ratings and to assess age-related changes in parent ratings.

METHODS

Description of Population

Extremely Low Birth Weight (ELBW) Group—The population included adolescent survivors of a cohort of 344 ELBW children admitted to the neonatal intensive care unit at Rainbow Babies and Children's Hospital, Cleveland, Ohio during 1992 through 1995. Thirteen children including 10 with major malformations, two with AIDS and one with Tuberous Sclerosis were excluded. Two hundred and thirty eight (72%) of the remaining 331 children survived of whom 219 (92%) were followed to 8 years and 181 (76%) to 14 years of age. Twelve of these 181 adolescents were excluded from the 14 year analyses due missing questionnaires of three parents and nine adolescents, leaving 169 with both parent ratings and adolescent self-ratings of behavior at age 14 years. These 12 adolescents were similar to those included in the analyses in birth weight, GA, sex of the child and maternal social class as defined by the mean of the sample z scores of median family income according to the 2000 census tract of the family's residence and years of education reported by the mother (zSES).²² However, the excluded subset had a lower proportion of African American youth [2 (17%) vs. 106 (63%), $p=.004$] and proportionally more neurosensory impairments [6 (50%) vs. 25 (15%), $p<0.01$] and subnormal IQ [9 (75%) vs. 23 (14%), $p<0.001$] (procedures described below). Of the surviving 238 children, the 169 adolescent participants (71% of the survivors) did not differ from the 69 non-participants in ethnicity, birth weight, or GA but included significantly fewer boys [63 (37%) vs. 38 (55%), $p<.05$].

Normal Birth Weight (NBW) Comparison Group—A NBW child born at term (GA >36 weeks by parent report) was recruited at age 8 years by random selection of a child from the same school as the ELBW child who was within 3 months of age and of the same race and sex. Matches were selected for 176 ELBW children. At age 14 years, questionnaires from both the parent and adolescent were available for 115 (65%) youth in the NBW group. They did not differ from the 61 children not followed at age 14 years in zSES, ethnicity, sex of the child or rates of subnormal IQ at 8 years.

Measures and Variables

The primary outcome measures of behavior at age 14 years were the Adolescent Symptom Inventory-4 (ASI-4) completed by the caregivers and the Youth's Inventory-4 (YI-4) completed by the adolescents.^{23,24} The primary caregiver was the biologic or adoptive mother for 134 (79%) adolescents in the ELBW group and 101 (88%) NBW controls ($p=0.062$). The questionnaires screen for behavioral, emotional and cognitive symptoms of DSM-IV defined disorders. They take 10 to 15 minutes to complete. Examiners supervised

completion of the ratings to determine if participants could read and understand the questions. Questions were read to participants with limited reading skills but those judged incapable of understanding questions or task demands were excluded from the study. The primary caregiver had completed the Child Symptom Inventory (CSI-4) at age 8 years.²⁵ Items pertaining to autism spectrum disorder were not examined at age 14 years as the ASI-4 does not include items pertaining to this condition.

The symptom categories considered in comparing the ELBW and NBW groups at age 14 were those in common with the parent and adolescent versions of these inventories, including inattentive, hyperactive/impulsive and combined types of ADHD, oppositional defiant disorder (ODD), conduct disorder, generalized anxiety disorder, major depressive disorder, social phobia disorder (anxiety in social situations), separation anxiety disorder, specific phobia (fears of specific objects or situations), vocal and motor tics, schizoid personality disorder, bipolar disorder and schizophrenia. A smaller set of symptom categories was selected in comparing parent to adolescent ratings at 14 years and parent ratings from 8 to 14 years, including the three types of ADHD, ODD, conduct disorder, generalized anxiety disorder, major depressive disorder, social phobia disorder and separation anxiety disorder. The rationale was our interest in focusing on behavior problems more commonly reported in ELBW samples. Questions concerning substance abuse from the category of drug use disorder included items related to smoking of marijuana, using alcohol or other illegal drugs, or getting into trouble because of these activities, but excluded cigarette smoking.

Results from both parent and youth questionnaires were scored in two ways: symptom severity scores and symptom count scores. Symptom severity scores are the sum of item ratings for a particular symptom category (i.e. within a set of items pertaining to a specific behavioral disorder and include 0 (never), 1 (sometimes), 2 (often), and 3 (very often). The symptom count scores within each symptom category are the sum of symptoms reported as often (2) or very often (3). When the symptom count scores within a specific category equaled or exceeded the criterion cut-off score for a given DSM-IV disorder, the child was defined as having met DSM-IV criteria for the disorder. However the parent and youth questionnaires provide symptoms and not diagnoses; symptom counts meeting DSM-IV cut-offs are used only as a means for screening youth in need of further clinical evaluation. Furthermore the agreement between the symptom severity scores (dimensional model) and screening cut off scores (categorical model) is low and it is possible for a child to have a high symptom severity score and yet not meet DSM-IV criteria for a disorder.²³

Scale reliabilities for the ASI-4 and YI-4 as measured by Cronbach's alpha were high for our sample. For the ASI-4 reliabilities were 0.93 for the inattentive type of ADHD, 0.88 for the hyperactive type of ADHD, 0.93 for the combined type of ADHD and 0.76 for generalized anxiety disorder; and for the YI-4 reliabilities were 0.81 for the inattentive type of ADHD, 0.77 for hyperactive ADHD, 0.86 for combined ADHD and 0.85 for generalized anxiety disorder. Based on research by the developers of these inventories, test-retest reliability coefficients for the CSI-4 exceed .65 for most diagnostic categories.²³⁻²⁶ Concurrent validity of the CSI-4 is documented by correlations of symptom severity scores with corresponding symptom counts or scaled scores on the Diagnostic Interview for

Children and Adolescents-Parent Version (DICA-P, $r's=.39-.69$) and CBCL ($r's=.49-.81$).²⁶ ASI-4 severity scores are also significantly correlated with corresponding CBCL scales ($r's=.41-.80$).²³ Adolescent self-ratings on the YI-4 are only modestly related to parent ratings on the AIS-4 ($r's=.21-.43$), though self-ratings on several scales of the YI-4 accord well with corresponding ratings on the Youth Self Report (e.g., $r=.72$ for depression symptoms, $r=.59$ for oppositional behavior) and Children's Depression Inventory ($r=.85$).²⁴ However, the associations of CSI-4 ratings meeting the DSM-IV cut-offs with corresponding DICA-P diagnoses, although significant, are only modest ($kappa's=.27-.61$) and the validity of the YI-4 is low for disruptive behavior disorders.^{24,26}

Data were also collected on family sociodemographic characteristics and other sample descriptors. At 8 years, the subjects underwent a complete physical and neurologic evaluation.²¹ At age 14 years, a short form of the Wechsler Abbreviated Scale of Intelligence (WASI) short form comprised of the Vocabulary and Matrix Reasoning subtests was administered to assess IQ²⁷ and parents was asked to if their adolescent was enrolled in an Individualized Educational Program (IEP) at school. Subnormal IQ was defined as an IQ score <70 and neurosensory impairment as cerebral palsy, blindness or deafness. The study protocol was approved by the Institutional Review Board of University Hospitals Case Medical Center. Written informed consent was obtained from the parents, with assent also obtained from older youth.

Statistical Analysis

Descriptive analysis of group differences (ELBW vs. NBW) were conducted using student *t* tests for continuous variables and chi-square for dichotomous variables. Analyses examining the effect of group and adjusting for zSES, ethnicity, and sex were conducted using linear regression for continuous outcomes and logistic regression for binary outcomes. Group differences in logistic regression are described in terms of the adjusted odds ratio and its 95% confidence interval [AOR (CI)]. To investigate the effects of reporter and age, repeated measures models accounting for correlations between parent and adolescent or within subject and adjusting for covariates were fit using mixed models for continuous outcomes and generalized estimating equations logistic regression (GEE)²⁸ for binary outcomes. Each group was examined separately to better characterize the repeated effects. For these analyses, reporter differences were tested using mixed models or GEE and adjusting for sex, and age differences were examined using paired *t*-tests or McNemar tests. Mixed model analysis was also conducted on symptoms severity scores for the total sample to determine if group differences varied by reporter or age and to explore moderating effects of sex. Significance was defined as $p<.05$ and effect size (ES) as the group difference in adjusted means divided by the SD of the NBW group.

RESULTS

Comparison of Demographic, Birth and 14 Year Neurodevelopmental Outcomes (Table 1)

The ELBW adolescents and NBW controls were of similar age at the time of testing and did not differ significantly in maternal sociodemographic descriptors with the exception that the biologic mothers of the ELBW adolescents were older than those of the controls. Twenty

five ELBW adolescents had neurosensory impairments, including 21 with cerebral palsy. Compared with the NBW controls, ELBW adolescents had significantly higher rates of subnormal IQ and IEPs at 14 years ($p's < .05$).

Parent Report of 14 Year Adolescent Behavioral Outcomes (Table 2)

Parents of ELBW adolescents reported significantly higher symptom severity scores than parents of NBW controls for the inattentive and combined types of ADHD, generalized anxiety disorder and social phobia, with small to moderate ES's. Parent ratings failed to reveal a significant difference in the symptom severity scores for substance use disorder [mean (SD) = 0.04 (0.29) for ELBW group vs. 0.10 (0.48) for NBW group, $p=0.193$]. The only significant differences in counts meeting DSM-IV cut-offs were higher rates for the ELBW group compared to NBW group for inattentive ADHD (12% vs. 1%) and specific phobia (25% vs. 12%).

The groups did not differ significantly in numbers of disorders as defined by scale counts meeting DSM-IV cut-offs, with a mean (SD) of 0.33 (0.86) disorders for the ELBW compared to 0.16 (0.51) disorders for the NBW controls, $p=0.197$. Analysis also failed to reveal a significant group difference in the rate of one or more disorders [29 (17%) of ELBW adolescents versus 14 (12%) of NBW controls, $p=0.250$]. However, 10 (6%) ELBW adolescents met criteria for three disorders or more as compared to one NBW control (1%), $p=0.031$. The results were similar when the 25 adolescents with neurosensory impairment were excluded.

Consistent with other literature,^{3,10,19} for the combined sample male sex was associated with higher symptom severity scores for all three types of ADHD; female sex with separation anxiety; and lower zSES with the hyperactive and combined types of ADHD, ODD, and bipolar disorder (all $p's < .05$). Analysis failed to reveal significant sex x group interactions.

Adolescent Self Report of 14 Year Behavioral Outcomes (Table 3)

ELBW adolescents reported lower symptom severity scores on all measures than their NBW peers. Differences were significant for the hyperactive and combined types of ADHD, ODD and bipolar disorder, with generally small effect sizes. The symptom severity scores for substance use disorder were also lower for the ELBW group than for NBW controls, with respective means (SDs) of 0.12 (0.50) and 0.31 (0.73), $p<0.05$. The ELBW adolescents also reported lower rates of symptom counts meeting cut-offs for DSM-IV disorders, although the only significant difference was for ODD. The results were similar when the adolescents with neurosensory problems were excluded, with the exception that the neurosensory normal ELBW adolescents also reported significantly lower symptom severity scores than their NBW peers for inattentive ADHD and conduct disorder. Similar to findings from a previous study,¹¹ female sex for the combined sample was associated with higher self-reported symptom severity scores generalized anxiety disorder, major depressive disorder, and ODD (all $p's < .05$), but there were no significant sex x group interactions.

The groups did not differ significantly in rates of disorders as defined by scales on which self-reported counts met DSM-IV symptom criteria, with a mean (SD) of 0.49 (1.03) disorders for ELBW adolescents compared to 0.56 (1.03) for NBW controls, $p=0.267$. Group comparisons in rates of one or more disorder [53 (31%) ELBW adolescents vs. 40 (35%) NBW controls, $p=0.546$] and of three or more disorder [7 (4%) ELBW adolescents vs. 4 (3%) NBW controls, $p=0.776$] also failed to reveal significant differences. Findings were similar in analyses that excluded youth with neurosensory impairment.

Comparison of Parent and Adolescent Reports at Age 14 Years

In analysis of the ELBW group, adolescents reported higher symptom severity scores than their parents for hyperactive ADHD, Beta (95% confidence interval) [β (CI)] = 2.20 (1.37, 3.03), $p<.001$, combined ADHD, β (CI) = 1.72 (0.11, 3.32), $p=.036$, ODD, β (CI) = 1.40 (0.65, 2.15), $p<.001$, generalized anxiety disorder, β (CI) = 2.13 (1.38, 2.88), $p<.001$, major depressive disorder, β (CI) = 5.40 (4.72, 6.09), $p<.001$, social phobia disorder, β (CI) = 0.35 (0.10, 0.60), $p=.006$, and separation anxiety disorder, β (CI) = 0.32 (0.02, 0.63), $p=.036$. Compared to parents, adolescents reported lower rates of symptom counts at or above the DSM-IV cut-off for inattentive ADHD, AOR (CI) = 0.23 (0.09, 0.56), $p=.001$, and conduct disorder, AOR (CI) = 0.24 (0.06, 0.99), $p=.048$, but higher rates for generalized anxiety disorder, AOR (CI) = 3.88 (1.28, 11.75), $p=.017$, and social phobia disorder, AOR (CI) = 11.61 (4.04, 33.34), $p<.001$.

Within the NBW group adolescents reported higher symptom severity scores than their parents for inattentive ADHD, β (CI) = 2.56 (1.67, 3.45), $p<.001$, hyperactive ADHD, β (CI) = 4.17 (3.35, 4.99), $p<.001$, combined ADHD, β (CI) = 6.73 (5.29, 8.17), $p<.001$, ODD, β (CI) = 2.79 (1.94, 3.63), $p<.001$, generalized anxiety disorder, β (CI) = 3.35 (2.57, 4.13), $p<.001$, major depressive disorder, β (CI) = 6.47 (5.82, 7.13), $p<.001$, social phobia disorder, β (CI) = 0.50 (0.25, 0.74), $p=.001$, and separation anxiety disorder, β (CI) = 0.27 (0.01, 0.54), $p=.040$. Compared to parents, adolescents reported lower rates of symptom counts at or above the DSM-IV cut-off for conduct disorder, AOR (CI) = 0.17 (0.04, 0.79), $p=.020$, but higher rates for ODD, AOR (CI) = 7.08 (2.10, 23.88), $p=.002$, and generalized anxiety disorder, AOR (CI) = 7.48 (1.20, 46.57), $p=.030$.

Results from analysis of the total sample were similar to those reported above. Main effects were found for reporter, indicating higher ratings by adolescents in both groups compared to their parents for social phobia ($p<.001$) and separation anxiety disorder ($p=.006$). These findings complemented those from analysis of each group separately by revealing significant group x reporter interactions for inattentive ADHD ($p<.001$), hyperactive ADHD ($p<.001$), combined ADHD ($p=.002$), ODD ($p=.017$), and generalized anxiety disorder ($p=.032$). Consistent with results presented in Tables 2 and 3, on parent ratings the ELBW group had significantly higher symptom severity scores than the NBW group for inattentive ADHD (ES=0.38), combined ADHD (ES=0.34), and generalized anxiety disorder (ES=0.32), whereas on adolescent ratings the ELBW group had significantly lower scores than the NBW group for hyperactive ADHD (ES=0.28), combined ADHD (ES=0.28), and ODD (ES=0.43). A similar group x reporter interaction (suggesting higher ratings for the ELBW group on parent report only) was found for major depressive disorder ($p=.033$) but was not

accompanied by significant group differences on either parent or adolescent ratings. Sex x reporter interactions for all three types of ADHD, ODD, and generalized anxiety disorder indicated that differences between parent and adolescent ratings were larger for females than males across both groups.

Intraclass correlation coefficients (ICCs) between parent and adolescent symptom severity scores across disorders, although uniformly low, were significant ($p < .05$) for the ELBW group for inattentive ADHD, combined ADHD, ODD, conduct disorder, social phobia, and separation anxiety (range=.18-.28), and for NBW controls for inattentive ADHD, ODD, conduct disorder, social phobia, and separation anxiety (range=.20-.39).

Comparison of Parent Reports of ELBW and NBW Youth at Age 8 Versus Age 14 Years (Tables 4a and 4b)

In analysis of the ELBW group, parents reported significantly lower symptom severity scores at age 14 years compared to 8 years for all measures with the exception of conduct disorder and generalized anxiety disorder. Parents of the NBW controls reported significantly lower symptom severity scores at age 14 years for hyperactive and combined ADHD, major depressive disorder, social phobia disorder, and separation anxiety disorder. There were no differences between age 8 and 14 years for either group in rates of youth meeting DSM-IV cutoff criteria for disorders, with the exception of a lower rate of social phobia disorder in the ELBW group at 14 compared to 8 years (2% vs. 8%).

Analysis of the total sample revealed higher ratings across the two assessments for the ELBW group compared to NBW controls for generalized anxiety disorder ($p < .001$, $ES = 0.43$) and social phobia disorder ($p = .006$, $ES = 0.29$). A group x age interaction was also found for hyperactive ADHD ($p = .025$), with simple effects indicating a significant group difference only at 8 years. Similar group x age interactions were evident for ODD ($p = .029$) and conduct disorder ($p = .046$) but were not accompanied by significant simple effects of group at either age. Additional effects included group x age x sex interactions for inattentive ADHD ($p = .040$) and combined ADHD ($p = .019$). Follow-up tests indicated larger decreases in group differences in scores over time for females than males, though symptom ratings for both scales were significant or trended toward significance for both sexes at both ages. For inattentive ADHD, ES 's for females declined from 0.77 at 8 years to 0.36 at 14 years but only from 0.45 to 0.41 for males. Similarly, for combined ADHD, ES 's for females declined from 0.68 at 8 years to 0.28 at 14 years but only from 0.45 to 0.43 for males.

DISCUSSION

Consistent with the behavioral phenotype reported by other investigators,³ ELBW adolescents had more parent-reported symptoms of inattentive ADHD, anxiety and social problems than their NBW peers. As in previous studies the pattern of group differences was similar when excluding ELBW adolescents with neurosensory impairment.^{5,7,10} The lack of group differences in parents ratings of symptoms of hyperactive ADHD and externalizing problems, such as ODD and conduct disorder, confirms past findings and suggests that inattentiveness in ELBW youth are not accompanied by the co-morbidities observed in children with developmental ADHD.^{3,7-9}

Rates of symptom severity scores at or above clinical cut-offs on parent ratings were generally low and did not discriminate the two groups, suggesting that group differences were primarily within the subclinical range. Two exceptions to this included the higher rates for ELBW youth compared to controls for inattentive ADHD (12% vs. 1%) and multiple disorders (6% vs. 1%), results similar to those reported in a study of extremely preterm children using parent interviews.⁹ A further exception was the higher rate of parent-reported specific phobias in the ELBW group (25% vs. 12%). Questions about fears have been embedded in the ratings of emotional problems administered in some previous studies but to our knowledge have not been examined in isolation.^{9,19} This group difference highlights situational fears as a special area of concern for ELBW youth.

As observed in previous research,^{8,10–14} adverse behavioral outcomes for the ELBW group relative to controls were found only on parent ratings and not on adolescent self-ratings. In fact, self-ratings revealed lower symptom severity scores for ELBW adolescents relative to NBW controls for hyperactive and combined ADHD, ODD, conduct disorder, and substance abuse. The ELBW group also had a lower rate of self-reported symptom counts that met the DSM-IV cut-off for ODD than NBW controls. The findings are consistent with previous research suggesting that ELBW youth have a good self-image despite their deficits in cognitive, academic, and daily functioning.²⁹ This same positive outlook of ELBW youth is likely reflected in similarities between them and their NBW peers in self-ratings of self-esteem, global self-worth, and quality of life.^{5,8,13,30–33} Self-ratings of substance use also confirms past evidence for lower risk-taking in ELBW youth and young adults.^{33,34}

Potential reasons for the lack of evidence from self-ratings of adverse behavioral outcomes in ELBW adolescents include their denial of problems, health-related adjustments in expectations, or lack of objectivity or insight due to cognitive limitations.^{10,11,13,14,35} Parental perceptions of the vulnerability of ELBW youth also may have contributed to more negative parent ratings, although this possibly seems unlikely in view of data showing that parent ratings accord with those of teachers and with youth interviews.^{8,12} Qualitative research on adolescent self-perceptions may provide more insight into the basis of these reporter differences.¹⁴

The weak associations between self and parent behavior ratings observed in both the ELBW and NBW groups are characteristic of findings from community and clinic samples.^{11,23,35–38} In further agreement with past research, self-ratings were higher than parent ratings for several disorders and for both groups, suggesting adolescent activities or emotions of which parents are unaware or a tendency for adolescents to be less optimistic about their well-being than their parents.^{10,37–39}

Repeated measures analysis of parent symptom ratings of their children at 8 and 14 years revealed stable group differences across age in symptom severity scores for generalized anxiety disorder and social phobia disorder, though rates of the latter disorder decreased slightly within the ELBW group. Group differences also diminished over time for symptoms of inattentive, hyperactive and combined ADHD. Reduced symptoms of inattentive ADHD in the ELBW group relative to controls were not accompanied by a decreased rate of this disorder over time, suggesting only subclinical changes in symptoms. More pronounced

decreases in symptoms of inattentive and combined ADHD with age for females than males accord with other evidence for sex differences in outcomes and with young adult follow-up data indicating persisting elevations in symptoms of ADHD in VLBW young adult males but not females.^{5,19,40} Other studies, however, have failed to reveal sex differences in behavioral outcomes.^{7,10,12,15}

The development of compensatory neural systems supporting attention⁴¹ provides one potential explanation for the reduction in symptoms of attention deficits. Alternatively, a lessening of inattention relative to NBW age peers may reflect the later emergence of attentional capacity in ELBW youth; or problems may remain but be manifest in more subtle ways or only under higher demand conditions, such as on tasks that are more cognitively challenging or tap complex organizational skills. Whatever the basis of the age-related changes, they imply that some of the behavioral problems associated with extreme prematurity become less obvious to parents during adolescence and thus support a limited form of functional normalization.

One limitation of the study is the failure to obtain teacher reports or to administer interview-based diagnostic evaluations. A second weakness is the need to exclude data from a small subset of adolescents who were unable to complete the ratings. Third, the cut-offs applied to identify youth meeting symptom criteria for DSM-IV disorders do not accord closely formal psychiatric diagnoses based on comprehensive data-based evaluations.²⁶ These cut-offs may have limited validity in relation to clinically meaningful disorders and are specific to disorders as defined by DSM-IV. Finally, caution is advised in generalizing findings to other populations with different sociodemographic and neonatal characteristics. The study nevertheless has several strengths, including: (a) administration of the same behavior ratings of DSM-IV symptoms over time and across informants, (b) comparisons of ELBW adolescents to NBW controls in terms of both symptom severity and rates of elevated symptom counts, (c) control for background factors in making group comparisons, and (d) examination of moderating effects of sex. The findings from this study are among the first to show that ratings of DSM-IV symptoms reveal behavioral outcomes similar to those previously documented in the literature using other measures and that symptom elevations fall largely at subclinical levels.

In summary, results confirm the persistence into adolescence of increased symptoms of inattentive ADHD, anxiety, and social problems for ELBW youth compared to NBW controls. Higher symptom severity scores in the ELBW group relative to NBW controls were evident only on parent report and not on self-report. Comparison of parent symptom ratings at 14 years to earlier ratings at 8 years revealed stable elevations in symptoms of generalized anxiety disorder and social phobia disorder in ELBW youth relative to NBW controls but less prominent symptoms of ADHD. The higher parent reported symptom severity scores for ELBW adolescents compared to controls may be attributed to adverse effects of prematurity on early experiences, parent-child relationships or ELBW-related brain abnormalities, such as deficiencies in white matter integrity, connectivity in brain networks supporting behavior self-regulation, or modulation of the stress response.^{9,42–47}

Further research is needed to assess rates and types of psychiatric problems using other informants such as teachers and more rigorous clinical interview methods and to identify risk factors related to variability in these outcomes. The tendency for adolescents to under-report their symptoms relative to NBW controls documents the greater utility of parent over self-ratings in recognizing adolescent disorders. However, the low association between parent and adolescent ratings, along with the findings from this study showing group differences in substance use only on self-report, point to the benefits of obtaining both self- and parent reports.^{10,14,36–39} The persistence of behavior problems across childhood and their associations with difficulties in learning, daily functioning, and educational and vocational attainments underscores the importance of early identification and treatment.^{7–9,19,20,48} Evidence that ELBW adolescents are at risk for increasing symptoms of internalizing disorders and other mental health problems in young adulthood also justifies efforts to extend follow-up to later ages.^{3,18,49,50}

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Table 1

Sample description: maternal demographic risk factors, perinatal data and 14 year outcomes

Characteristic	Extremely Low Birth Weight (ELBW) N=169	Normal Birth Weight (NBW) n=115
Maternal & Family Demographic Data		
Mean age in years for biological mothers $\pm$ SD	43 $\pm$ 6	41 $\pm$ 7 ^a
Married, n (%)	75 (44%)	63 (55%)
Maternal education:		
<High school, n (%)	13 (8%)	12 (10%)
High school, n (%)	53 (31%)	22 (19%)
>High school, n (%)	103 (61%)	81 (70%)
Ethnicity:		
White, n (%)	63 (37%)	39 (34%)
Black, n (%)	106 (63%)	76 (66%)
Mean percent below poverty level $\pm$ SD	13 $\pm$ 11	15 $\pm$ 13
Mean family income $\pm$ SD	44 $\pm$ 20	40 $\pm$ 19
Perinatal Data		
Birth weight in gm $\pm$ SD	815 $\pm$ 122	3260 $\pm$ 524 ^c
Gestational age in weeks $\pm$ SD	26.4 $\pm$ 2	37
Female sex, n (%)	106 (63%)	73 (64%)
Multiple birth, n (%)	27 (16%)	0 ^c
Adolescent/Child Characteristics		
Mean age (years) at 14 year assessment $\pm$ SD	14.7 $\pm$ 0.7	14.8 $\pm$ 0.8
Mean age (years) at 8 year assessment $\pm$ SD	8.6 $\pm$ 0.6	9.2 $\pm$ 0.8
Neurosensory impairment, n (%)	25 (15%)	0 ^c
IQ <70 on short form of WASI at 14 years, n (%)	23 (14%)	4 (4%) ^b
IEP at age 14 years, n (%)	76 (45%)	11 (10%) ^c

Note: Unless otherwise stated, family demographic data are for primary caregivers, which were biologic or adoptive mothers of 134 (79%) ELBW adolescents and 101 (88%) NBW controls. High school education includes GED and white ethnicity includes 1 Asian ELBW mother. The mean percent of families below the poverty level and mean family income in 1000's of dollars was based on 2000 Census tract data for the neighborhood in which the families lived. Neurosensory impairment in the ELBW group includes 21 children with cerebral palsy, 1 with bilateral blindness and 3 with deafness requiring a hearing aid.

Abbreviations: WASI: Wechsler Abbreviated Scale of Intelligence; IEP: Individual Education Plan at school.

^a $p < 0.05$,

^b $p < 0.01$,

^c $p < 0.001$

Table 2

Parent report of symptom severity scores and DSM-IV symptom cut-off scores

Disorder/Symptom	Symptom Severity Scores			Cut-Off Scores		
	ELBW n=169	NBW n=115	Effect Size	ELBW n=169	NBW n=115	OR (95% CI)
ADHD						
Inattentive	7.93±6.08	5.84±4.42	0.47 ^b	20 (11.8%)	1 (0.9%)	15.4 (2.0, 116.4) ^b
Hyperactive	3.52±4.52	2.70±3.25	0.25	4 (2.4%)	0	NA
Combined	11.44±9.50	8.53±6.65	0.44 ^b	4 (2.4%)	0	NA
Oppositional Defiant Disorder	3.97±4.32	4.37±3.65	-0.11	11 (6.5%)	3 (3%)	2.6 (0.7, 9.7)
Conduct Disorder	0.99±1.75	1.40±2.70	-0.16	8 (4.7%)	11 (9.6%)	0.5 (0.2, 1.3)
Generalized Anxiety Disorder [•]	3.62±3.11	2.65±2.85	0.34 ^b	3 (1.8%)	1 (0.9%)	2.1 (0.2, 20.1) [*]
Major Depressive Disorder ^{••}	1.46±2.06	1.25±1.82	0.12	1 (0.6%)	0 (0%)	NA
Social Phobia	0.93±1.16	0.58±0.91	0.38 ^b	4 (2.4%)	0 (0%)	NA
Separation Anxiety Disorder	0.73±1.29	0.52±1.15	0.18	0 (0%)	0 (0%)	NA
Specific Phobia	-	-	-	42 (25%)	14 (12%)	2.4 (1.2, 4.7) ^b
Motor Tics	-	-	-	8 (5%)	8 (7%)	0.7 (0.2, 1.9)
Vocal Tics	-	-	-	17 (10%)	7 (6%)	1.8 (0.7, 4.7)
Schizoid Personality Disorder	1.1±1.4	0.8±1.2	0.25	6 (4%)	2 (2%)	2.1 (0.4, 10.5) [*]
Bipolar Disorder	2.4±3.1	2.5±3.1	0.01	0 (0%)	0 (0%)	NA
Schizophrenia	0.6±1.2	0.7±0.9	0.29	2 (1.2%)	0 (0%)	NA

Note: Unless otherwise indicated, analysis adjusted for sociodemographic status, race and sex. Higher scores indicate greater behavior problems. Effect sizes were calculated as the adjusted mean difference between the ELBW and NBW scores divided by the SD of the NBW group.

Abbreviations: ELBW = extremely low birth weight; NBW = normal birth weight; OR (95% CI) = odds ratio (95% confidence interval); ADHD: attention deficit hyperactivity disorder; NA: not applicable--statistic cannot be estimated due to empty cells.

a $p<0.001$
b $p<0.01$
c $p<0.05$

* Unadjusted OR computed because of small cell size.

Categorical (yes/no) variable, includes only one question.

- 3 symptoms;
- 5 symptoms.

Table 3

Child report of symptom severity scores and DSM-IV symptom cut-off scores

Disorder or Symptom	Symptom Severity Scores			Cut-Off Scores		
	ELBW n=169	NBW n=115	Effect Size	ELBW n=169	NBW n=115	OR (95% CI)
ADHD:						
Inattentive	7.44±4.15	8.39±4.04	-0.23	5 (3%)	6 (5%)	0.6 (0.2, 1.9)*
Hyperactive	5.72±3.9	6.86±4.40 ^a	-0.25	4 (2%)	3 (3%)	0.9 (0.2, 4.1)*
Combined	13.16±7.23	15.26±7.38 ^a	-0.27	1 (0.6%)	3 (3%)	0.2 (0.0, 2.2)*
Oppositional Defiant Disorder	5.37±3.80	7.15±4.27 ^c	-0.4	10 (6%)	18 (16%)	0.4 (0.2, 0.8) ^b
Conduct Disorder	1.00±1.85	1.44±2.01	-0.2	2 (1%)	2 (2%)	0.7 (0.1, 5.0)
Generalized Anxiety Disorder [•]	5.74±4.43	6.00±4.21	-0.05	11 (7%)	7 (6%)	1.2 (0.4, 3.2)
Major Depressive Disorder ^{••}	6.86±4.46	7.72±3.78	-0.21	1 (0.6%)	0 (0%)	NA
Social Phobia Disorder	1.27±1.44	1.07±1.33	0.16	37 (22%)	20 (17%)	1.4 (0.8, 2.6)
Separation Anxiety Disorder	1.05±1.79	0.79±1.42	0.20	3 (2%)	0 (0%)	NA
Specific Phobia	-	-	-	37 (22%)	23 (20%)	1.2 (0.7, 2.2)
Motor Tics	-	-	-	11 (7%)	15 (13%)	0.5 (0.2, 1.1)
Vocal Tics	-	-	-	9 (8%)	8 (5%)	0.6 (0.2, 1.1)
Schizoid Personality Disorder	1.0±1.5	1.3±1.1	-0.22	5 (3%)	1 (1%)	3.8 (0.4, 33.7)
Bipolar Disorder	9.0±3.8	10.6±3.8 ^a	-0.44	4 (2%)	8 (7%)	0.3 (0.1, 1.1)
Schizophrenia	1.9±2.6	2.1±2.2	-0.07	2 (1%)	2 (2%)	0.7 (0.1, 5.2)

Note: Unless otherwise indicated, analysis adjusted for sociodemographic status, race and sex. Higher scores indicate greater behavior problems. Effect sizes were calculated as the adjusted mean difference between the ELBW and NBW scores divided by the SD of the NBW group.

Abbreviations: ELBW = extremely low birth weight; NBW = normal birth weight; OR (95% CI) = odds ratio (95% confidence interval); ADHD: attention deficit hyperactivity disorder; NA: not applicable--statistic cannot be estimated due to empty cells.

a $p<0.001$
b $p<0.01$
c $p<0.05$

* Unadjusted OR computed because of small cell size.

Categorical (yes/no) variable, includes only one question.

- 3 symptoms;
- 5 symptoms.

Table 4a

Parent report at age 8 compared to 14 years, extremely low birth weight (ELBW) group (n=169)

DISORDER	SYMPTOM SEVERITY SCORES			CUT-OFF SCORES		
	8 YEARS	14 YEARS	MEAN DIFFERENCE (95%CI)	p	8 YEARS	14 YEARS
ADHD[#]						
Inattentive	9.46±5.78	7.93±6.08	1.50 (0.65, 2.34)	<0.001	18 (11%)	20 (12%)
Hyperactive	6.75±4.97	3.52±4.52	3.24 (2.57, 3.91)	<0.001	5 (3%)	4 (2%)
Combined	16.8±9.54	11.45±9.50	4.67 (3.44, 5.91)	<0.001	5 (3%)	4 (2%)
Oppositional Defiant Disorder	5.13±3.89	3.97±4.32	1.16 (0.48, 1.84)	<0.001	10 (6%)	11 (7%)
Conduct Disorder	1.10±1.75	0.99±1.76	0.11 (-0.20, 0.42)	0.483	17 (10%)	8 (5%)
Generalized Anxiety Disorder [•]	3.56±3.10	3.62±3.11	-0.06 (-0.51, 0.39)	0.794	6 (4%)	3 (2%)
Major Depressive Disorder ^{••}	10.13±1.60	1.46±2.06	8.67 (8.28, 9.06)	<0.001	3 (2%)	1 (0.6%)
Social Phobia Disorder	1.82±2.01	0.93±1.16	0.89 (0.58, 1.20)	<0.001	14 (8%)	4 (2%)
Separation Anxiety Disorder	1.89±2.70	0.73±1.29	1.16 (0.78, 1.55)	<0.001	7 (4%)	0 (0%)

Note: Symptom severity scores analyzed using paired t-tests and rates of scores at or above cut-off by McNemar tests.

Abbreviations: ADHD = attention deficit hyperactivity disorder; NA = not applicable--statistic cannot be estimated due to empty cell.

[#] n reduced by 1 or 2 depending on subscale due to missing data at age 8 years.

[•] 3 symptoms;

^{••} 5 symptoms.

Table 4b

Parent report at age 8 compared to 14 years, normal birth weight (NBW) group (n=115)

Disorder	SYMPTOM SEVERITY SCORES			CUT-OFF SCORES			
	8 YEARS	14 YEARS	MEAN DIFFERENCE (95%CI)	p	8 YEARS	14 YEARS	p
ADHD [#]							
Inattentive	5.85±4.21	5.84±4.42	0.02 (-0.67, 0.71)	0.960	1 (1%)	1 (1%)	1.000
Hyperactive	4.79±4.28	2.70±3.25	2.10 (1.38, 2.81)	<0.00	1 (1%)	0 (0%)	>0.99
Combined	10.64±7.86	8.53±6.66	2.11 (0.96, 3.28)	0.004	1 (1%)	0 (0%)	>0.99
Oppositional Defiant Disorder	4.40±3.75	4.37±3.65	0.03 (-0.69, 0.76)	0.927	6 (5%)	3 (3%)	0.257
Conduct Disorder	0.98±1.97	1.42±2.70	-0.44 (-0.90, 0.03)	0.067	9 (8%)	11 (10%)	0.617
Generalized Anxiety Disorder [•]	2.43±2.03	2.65±2.85	-0.23 (-0.76, 0.31)	0.401	0 (0%)	1 (0.9%)	>0.99
Major Depressive Disorder ^{••}	10.19±1.54	1.25±1.82	8.94 (8.55, 9.34)	<0.001	0 (0%)	0 (0%)	NA
Social Phobia Disorder	1.40±1.56	0.58±0.91	0.82 (0.52, 1.12)	<0.001	2 (2%)	0 (0%)	0.5
Separation Anxiety Disorder	1.49±2.12	0.52±1.15	0.97 (0.61, 1.33)	<0.001	2 (2%)	0 (0%)	0.5

Note: Symptom severity scores analyzed using paired t-tests and rates of scores at or above cut-off by McNemar tests.

Abbreviations: ADHD = attention deficit hyperactivity disorder; NA = not applicable--statistic cannot be estimated due to empty cell.

[#] n reduced by 1 or 2 depending on subscale due to missing data at age 8 years.

• 3 symptoms;

•• 5 symptoms.