Parenting Very Low Birth Weight Children at School Age: Maternal Stress and Coping

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Objective To compare severity and determinants of stress and coping in mothers of 8-year-old very low birth weight (VLBW) and term children varying in medical and developmental risk.

Study design Three groups of mothers/infants were prospectively compared in a longitudinal study from birth to 8 years (110 high-risk VLBW, 80 low-risk VLBW, and 112 term). Maternal psychological distress, coping, parenting/marital stress, child health, and family impact were measured in the children at age 8 years.

Results Mothers of VLBW children differed from term mothers, reporting less consensus with partners, more concern for their children's health, less parent–child conflict, and fewer years of education attained. Mothers of high-risk VLBW children experienced the greatest family and personal strains and used less denial and disengagement coping. The groups exhibited no differences in the sense of parenting competence, divorce rate, parenting/marital satisfaction, family cohesion, and psychological distress symptoms. Multiple birth, low socioeconomic status, and lower child IQ added to maternal stress.

Conclusions VLBW birth has long-term negative and positive impacts on maternal/family outcomes related to the infant's medical risk. *(J Pediatr 2007;151:463-9)*

Survival rates are increasing in the 59,000 very low birthweight (VLBW) and extremely low birthweight (ELBW) infants born annually.[1] Although a wide range of outcomes has been studied,[2-4] little attention has been paid to parental adaptation to VLBW birth beyond the neonatal period. Addressing the psychological impact of VLBW birth on parents is increasingly important, because parental involvement is now expected in decisions about life-sustaining treatment for critically ill infants.[5] Physicians need to be apprised of parental perspectives, because treatment decisions should be informed by facts.[6] In addition, the relationship of children's cognitive and behavioral outcomes to family stress[7,8] may be more salient for preterm, medically ill infants.[9] Understanding the nature, scope, and determinants of stress and coping in families of VLBW children can lead to interventions to reduce stress and improve child outcomes.

A convergent literature acknowledges the strong, immediate psychological distress of mothers of VLBW infants neonatally.[10,11] A longitudinal, controlled, prospective study of parenting VLBW infants found that the severity of medical risk, child's age, and developmental delay influenced maternal psychological distress and parenting stress during the 3 years after birth.[12] Three studies examined later parental experiences in families of VLBW children and found persistent negative maternal and family sequelae, but methodological flaws, including lack of prospective designs, low statistical power, and failure to control for confounding factors, led to conflicting findings.[13-15] None of these 3 studies recruited control families prospectively from birth, preventing longitudinal comparisons. They also did not screen for substance exposure; thus, adverse sequelae could

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ANOVA	Analysis of variance	GSI	General Severity Index
ANCOVA	Analysis of covariance	MANCOVA	Multivariate analysis of covariance
BPD	Bronchopulmonary dysplasia	MSPSS	Multidimensional Scale of Perceived Social Support
BSI	Brief Symptom Inventory		
CHQ	Child Health Questionnaire	PF50	Parent Form 50
DAS	Dyadic Adjustment Scale	PSI	Parenting Stress Index
ELBW	Extremely low birth weight	SES	Socioeconomic Status
FILE	Family Inventory of Life Events and Changes	VLBW	Very low birth weight
GEE	Generalized estimating equation	WISC-III	Wechsler Intelligence Scale for Children III

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be due to maternal drug or alcohol use rather than VLBW birth.[13-16] They also focused only on stress and did not address the role of coping.[17,18]

The present study improved the methodology through prospective recruitment of regionally representative VLBW cohorts and controls from birth; assessment of a wider range of outcomes, including coping; exclusion of drug/heavy alcohol-exposed children; and enrollment of an adequate sample size to allow evaluation of the moderating effects of socioeconomic status (SES). The conceptual model (Double ABCX Model of Family Adjustment)[9] views VLBW birth as a stressful life event that may negatively impact families across multiple biopsychosocial domains. This model is transactional and recognizes that stressors and resources may change over time. Race, SES, maternal education, and other stressful life events were considered confounding factors that did not differ among groups at birth. Multiple birth was also considered a confounding variable, and its effects were examined statistically. Based on our previous findings,[12] we hypothesized that the negative impact of VLBW birth would continue to school age and would be related to poorer child functional outcomes and risk status.

METHODS

Mothers were interviewed in a longitudinal study of the outcomes of infants with bronchopulmonary dysplasia (BPD), a chronic lung disease of prematurity,[19,20] and VLBW.[4,9,12,21] Children with VLBW admitted to all neonatal intensive care units in a Midwest region were prospectively enrolled between 1989 and 1991 at birth, with current follow-up at 8 years.

High-risk children with VLBW (high-risk VLBW; n = 110) had a diagnosis of BPD, birth weight <1500 g, supplementary oxygen requirement for more than 28 days, and radiographic evidence of chronic lung disease.[22] A partial stratification sampling approach[21] was adopted to enroll adequate numbers of subjects without socioeconomic disadvantage or severe neurologic risk, to assess the impact of social class and medical risk factors on outcomes. Infants with BPD free of neurologic problems other than grade I or II intraventricular hemorrhage and not socially disadvantaged (ie, Hollingshead classification IV or V)[23] were exhaustively recruited. The remainder were recruited by approaching the family of the next infant with BPD that could be accommodated in the schedule.

Low-risk children with VLBW (low-risk VLBW; n = 80) did not have BPD, weighed <1500 g at birth, and required oxygen supplementation for <25 days.

Term children (n = 112), recruited from neonatal nurseries, had no diagnosed medical illnesses or abnormalities at birth; were more than 36 weeks gestation, and, for singletons, weighed more than 2500 g at birth. Infants with major congenital malformations, drug or heavy alcohol exposure, maternal major psychiatric/physical illness as noted in the medical history, human immunodeficiency virus, or mental retardation, or who lived more than 2 hours driving distance from the study center, were excluded. Further details regarding recruitment and attrition have been reported previously.[4,9,12,21] Follow-up rates were 90% for the high-risk VLBW group, 90% for the low-risk VLBW group, and 80% for the term group.

Procedures

Mothers completed the following standardized, self-report measures at the 8-year visit. Several areas of stress were examined, assessing specific maternal psychological symptoms, stress related to parenting, family impact, marital stress, and child health concerns.

Stress Outcomes

The *Brief Symptom Inventory* (BSI)[24] measures psychiatric symptom patterns (eg, somatic complaints, obsessive-compulsive behavior, interpersonal sensitivity, depression, anxiety, phobic anxiety, paranoid ideation, hostility, psychosis) with consensually valid clinical significance. A summary score, the General Severity Index (GSI), measures overall psychological distress. Cutoff scores identify subjects whose symptoms reach severity levels higher than the 84th percentile compared with same-sex nonpatient norms.

The *Parenting Stress Index* (PSI)[25] assesses parental perceptions of the degree of stress related to dimensions of the parenting role. The parent domain measures 6 dimensions of stress: reinforcement of parent, depression, role restriction, sense of competence, social isolation, and spousal/partner support. Under the child domain, child characteristics of adaptability, acceptability, distractibility-hyperactivity, mood, and attachment and reinforcement to parent are rated.

The *Impact on Family Scale*[26] measures maternal perceptions of the child's impact on the family. Although this scale was designed to assess the impact of a child with a chronic illness/disability, statements were modified to apply to healthy children as well. The scale includes 1 factor assessing total impact and 1 set of items assessing financial impact. A mastery (coping) set was also retained from the original test.

The *Dyadic Adjustment Scale* (DAS),[27] a 32-item self-report measuring the quality of marital adjustment, yields an overall relationship adjustment score and 4 subscale scores: Consensus, Affection, Satisfaction, and Cohesion.

Questions from the *Child Health Questionnaire* (CHQ),[28] *Parent Form 50* (PF50) allows mothers to describe the child's physical health and limitations. Global Health provides a global parental health rating; Physical Health (6 questions) rates how health problems have limited specific activities in the last 4 weeks; Pain (2 questions) assesses the amount of pain that the child experienced in the last 4 weeks; and Your Child's Health (7 questions) assesses the child's health in general. In addition, questions 11 and 12 (Everyday Activities) rate restrictions on schoolwork and activities.

Coping Outcomes

The *COPE Questionnaire* of 60 items yields 15 subscales that assess 4 distinct, theoretically derived dimensions of coping in a 4-point Likert-type scale.[29,30] Factors include Adaptive Internal (Active, Planning, Suppression of Competing Activities), Adaptive External (Focus on and Venting of Emotion, Seeking Social Support for Emotional Reasons/for Instrumental Reasons), Avoidant (Behavioral Disengagement, Denial, Mental Disengagement), Acceptance (Positive Reinterpretation and Growth, Restraint), and Alcohol/Drug Use, Humor, and Turning to Religion.

Life Events

The *Family Inventory of Life Events and Changes* (FILE)[31] assesses family experience of stressful life changes in the previous year in 9 categories: intrafamily strains, marital strains, pregnancy and childbearing strains, finance/business strains, work-family transitions, illness, losses, transitions, and legal violations. At birth enrollment, FILE identified whether group differences in life stressors other than infant illness/prematurity could account for maternal psychological or parenting stress.

Social Support

The *Multidimensional Scale of Perceived Social Support* (MSPSS)[32] assesses perceived social support from family, friends, and significant other in 12 items on a 7-point Likert-type scale. At birth, families did not differ on these measures,[12] providing a baseline to assess changes in stressful life events.

At follow-up, all children were administered the *Wechsler Intelligence Scale for Children III* (WISC-III)[33] to obtain an IQ score. Demographic information was updated, including number of years of maternal education attained, number of children born, and marital status.

This study design was approved by the institutional review boards of the participating hospitals. Informed consent/assent was obtained from parents and children. A stipend of $100 was provided to each family.

Data Analyses

Before the analyses, positively skewed outcome variables were transformed with the natural logarithm function to achieve an approximately normal distribution. Negatively skewed outcome variables were log-transformed after reverse scoring (ie, $\log_e$ [(maximum $-$ x + 1)]. Means/standard deviations are reported from the original distribution, with transformations used in the analyses.

Group differences were assessed in terms of sample characteristics and the FILE using analysis of variance (ANOVA) and Kruskal-Wallis tests for continuous data and Pearson and Mantel-Haenszel χ^2 tests for categorical data. The original study design controlled for SES and maternal education, which are known to be related to various dimensions of stress at birth. Stressful life events and social supports were also examined, because we were interested in assessing the impact of VLBW birth apart from other life events. The groups did not differ in either dimension.[12] Multiple birth was controlled statistically when related to outcome.

To assess overall group differences, multivariate analysis of covariance (MANCOVA) was conducted on the outcome variables controlling for maternal education at 8 years, multiple birth, and total intrafamily strains, covariates related to birth group, and known to relate to the outcomes. To reduce chance findings, summary scores were evaluated first and followed with MANCOVA only if total composite score differences were significant at $P < .10$. For child health, generalized estimating equations (GEEs) were used. Follow-up analyses of covariance (ANCOVA) identified differences by birth group. In the event of a significant group effect, Tukey's multiple comparison technique assessed pairwise differences, controlling for the number of comparisons. Due to skewness, BSI scores were dichotomized using the clinical cutoff (t score > 63) and analyzed using logistic regressions.

A change in maternal educational level was calculated by deducting the number of years attained by each mother at birth from the number of years at the 8-year visit. T tests were used to determine the mean group difference. The interaction effect of birth group and SES was examined using ANOVA, with follow-up pairwise tests using a modified Bonferroni procedure. Because some mothers had multiple births, the Impact on Family Scale, CHQ, and PSI were assessed based on each child, whereas other variables were based on each mother. The power estimated under a general MANCOVA model, controlling for covariates, ranged from 84% to >99% to detect birth group effects, assuming a 2.5% significance level to account for multiple testing.

RESULTS

Sample Characteristics

Demographic and medical characteristics of the high-risk and low-risk VLBW groups at 8 years reflect the research design (Table). The high-risk VLBW children had lower birth weights, gestational ages, more neurologic and medical risk at birth, and lower IQ at 8 years compared with the low-risk VLBW and term children (Table). IQ scores were in the range of mental retardation (IQ < 70) for 19% of the high-risk VLBW children, 9% of the low-risk VLBW children, and <2% for the term children ($\chi^2 = 13.4$; $P < .001$). The groups did not differ in terms of sex, race, social class, or maternal marital status.

Educational Attainment

At birth, mothers in the 3 groups had not differed in achieved years of education, but at child age 8 years, the mothers of both high-risk and low-risk VLBW children had attained significantly fewer years of additional education than the mothers of term children (term, 14.2 $\pm$ 2 years; high-risk and low-risk VLBW, 13.5 $\pm$ 2 years; $t = 2.5$; $P < .01$). On average, educational level increased by 9.1 months in the

Table. Demographic and medical characteristics

	High-risk VLBW	Low-risk VLBW	Term	F/χ^2	P
Child	n = 94	n = 71	n = 97		
Birth weight (g)	946 (257)	1263 (174)	3451 (544)	1227	.0001*
Gestational age (weeks)	27 (2)	30 (2)	40 (1)	1236	.0001*
Sex (male)	51 (54)	31 (44)	46 (47)	1.9	.37
Full-scale IQ at 8 years	82.3 (19.7)	92.5 (16.1)	101.9 (15.0)	30.9	.0001*
Multiple birth, n (%)	16 (18)	17 (31)	6 (7)	14.8	.001†
Maternal	n = 88	n = 54	n = 89		
Race (African American), n (%)	42 (48)	29 (54)	41 (46)	.8	.66
Low social class, n (%)	47 (53)	34 (63)	54 (61)	1.6	.46
Married, n (%)	54 (61)	31 (57)	54 (61)	.2	.89
Years of education at birth	13.2 (2.1)	13.1 (2.1)	13.6 (2.5)	1.2	.31

Data are mean (standard deviation) unless specified otherwise.
*High-risk < low-risk < term ($P < .001$).
†Low-risk > term ($P < .02$).

mothers of term children and by 5.6 months in the mothers of high-risk and low-risk VLBW children ($t = 2.2$; $P < .03$).

Stressful Family Events During the Past Year

The total score of the FILE differed by birth group ($\chi^2 = 5.9$; degrees of freedom [df] = 2; $P < .052$), reflecting differences in the Intrafamily Strains subscale. Surprisingly, the mothers of both high-risk and low-risk VLBW children reported fewer family strains than the mothers of term children at 8 years (mean, 2.5 ± 2.8 for the high-risk VLBW group, 2.8 ± 2.6 for the low-risk VLBW group, and 3.5 ± 2.8 for the term group ($F = 7.5$; $P < .02$). The mothers of high-risk and low-risk VLBW children reported less parent–child conflict, and the mothers of high-risk VLBW children reported that their children were engaged in fewer outside activities and were less difficult to manage compared with the low-risk VLBW and term mothers. There was no significant difference in parental divorce rate in the 3 groups, with divorce reported in 14 (16%) families of high-risk VLBW children, 4 (7%) families of low-risk VLBW children, and 11 (12%) families of term children ($\chi^2 = 1.1$; $P < .33$).

Because in this study there were no differences among the 3 groups in maternal education or the incidence of stressful life events at birth, and because these factors had been considered confounding factors in the study design, they were controlled for in the remaining analyses.

Partner Relationship and Social Support

The MANCOVA was marginally significant ($F = 1.72$; $P < .09$). There were no differences on the DAS in Affection, Satisfaction, and Cohesion, but the mothers of both high-risk and low-risk VLBW children reported a lower level of Consensus With Partner/Spouse compared with the mothers of term children ($F = 5.26$; $P < .006$).

Perception of Child Health

Mothers perceived their child's health differently at school age related to the child's birth risk status. Only 66% of the mothers of high-risk VLBW children reported that their child was in excellent health, in contrast to 82.5% of the mothers of low-risk VLBW and term children (Figure 1). Likewise, the mothers of high-risk VLBW children described their children as being more limited in daily physical activities than term children, whereas the mothers of low-risk VLBW children did not. Nevertheless, the mothers of both high-risk and low-risk VLBW children were more likely to express concern for their child's health than were the mothers of term children. Limitations in everyday activities, pain, and family cohesion did not differ among the 3 groups.

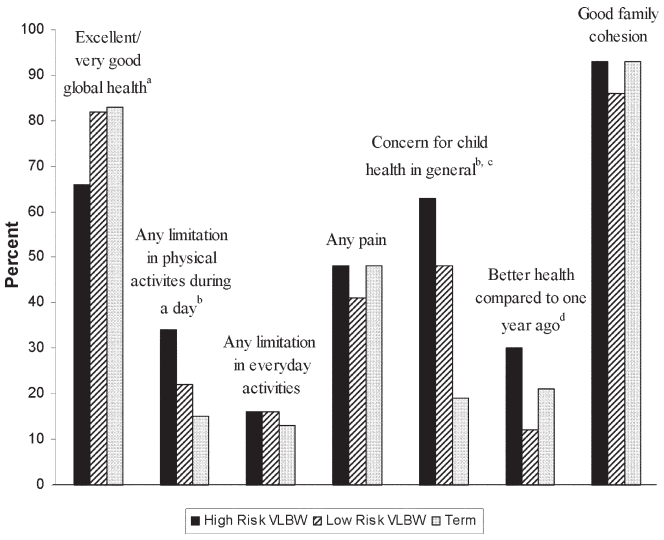

Figure 1. Child health by group risk status (GEE $\chi^2 = 49.5$; df = 14; $P < .0001$). [a]High-risk < term ($P = .007$); [b]high-risk > term ($P = < .002$); [c]low-risk > term ($P < .001$); [d]high-risk > low-risk ($P = .005$).

Psychological Distress

In contrast to earlier ages,[9,12] there were no differences on the Summary Score ($F = .61$; $P < .55$) or any subscale on the BSI.

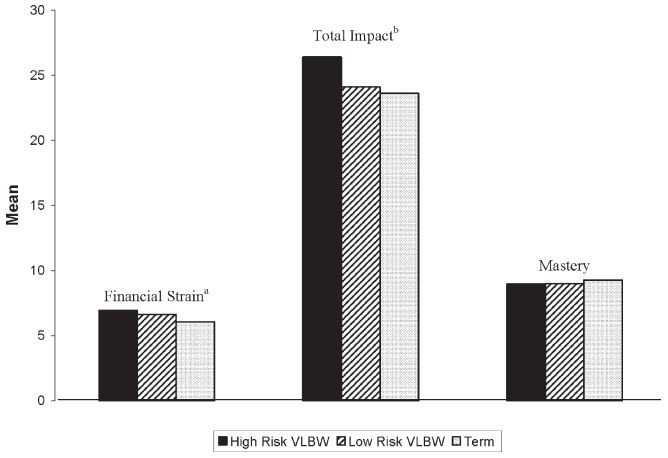

Figure 2. Mean scores on subscales within the Impact on Family Scale. MANCOVA adjusted for maternal education at 8 years, multiple birth, and total intrafamily strains subscale score, Wilks' $\lambda = .92$ ($F = 3.48$; df = 6, 500; $P < .003$). [a]High-risk > term ($P < .02$); [b]high-risk > low-risk ($P < .02$); [c]high-risk > term ($P < .02$).

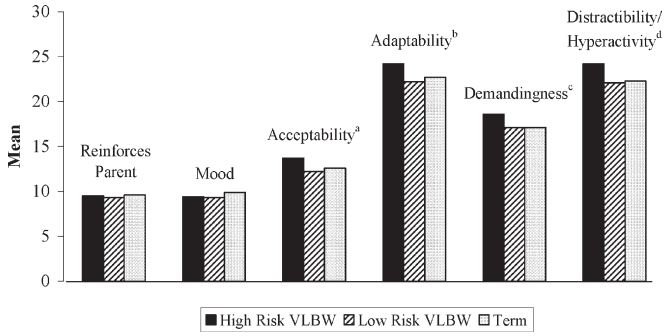

Figure 3. Mean scores on subscales in the Child Domain of the Parenting Stress Index (CDI). Mean CDI, 99.6 ± 19 for high-risk VLBW, 92.4 ± 27 for low-risk VLBW, 94.2 ± 21 for term ($F = 5.9$; $P < .003$). MANCOVA adjusted for maternal education at 8 years, multiple birth, and total intrafamily strains. CDI Wilks' $\lambda = .90$ ($F = 2.24$; df = 12,490; $P < .009$). [a]High-risk > low-risk ($P < .002$); [b]high-risk > low-risk ($P < .02$), high-risk > term ($P < .07$); [c]high-risk > low-risk ($P < .02$), high-risk > term ($P < .04$); [d]high-risk > low-risk ($P < .03$), high-risk > term ($P < .03$).

Impact On Family

Perceived family impact of the child differed by group (Figure 2). The mothers of high-risk VLBW children reported greater family and social impact, greater personal strain, and greater financial strain compared with the mothers of term children. Mastery scale scores did not differ.

Parenting Stress

Child Domain scores differed by group (Figure 3), reflecting that the mothers of high-risk VLBW children perceived their children to be more stressful, demanding, distractable, and hyperactive, and less acceptable and adaptable compared with the mothers of low-risk VLBW and term children. Parent Domain scores also differed among the 3 groups (mean, 112.5 ± 22, 106.7 ± 27, and 110.1 ± 23, respectively; $F = 3.1$; $P < .05$), indicating that the mothers of low-risk VLBW children had lower parenting stress than those of high-risk VLBW children, but neither group differed significantly from the term mothers.

Coping Mechanisms

The MANCOVA was marginally significant (Wilks' $\lambda = .94$ [$F = 1.85$; df = 8440; $P < .07$]). The mothers of high-risk VLBW children were less likely to use withdrawal/avoidant coping, including denial, mental disengagement, and behavioral disengagement than the mothers of term children (mean, 17.7 ± 3.85 vs 19.55 ± 5.00; $F = 5.3$; $P < .01$).

Moderating Effects of Social Class

SES did not differentially affect family stress relative to birth risk on any outcome. Social class was related to general family stress (total PSI Stress Score [$r = .15$; $P < .02$]), in that higher stress was related to lower social class, but the relationship did not differ by birth risk.

Other Factors Affecting Stress and Coping

In addition to high-risk VLBW, other factors were related to maternal stress and coping. Multiple birth was related to greater maternal social isolation ($\beta = .12$: $P < .05$). There were also trends toward greater negative family impact ($\beta = .12$; $P < .07$), lower feelings of mastery ($\beta = -.12$, $P < .08$), less child acceptability ($\beta = .11$; $P < .07$) and attachment ($\beta = .13$; $P < .06$), and to less use of humor ($\beta = -.11$; $P < .09$).

Lower IQ had low to moderate correlations with greater parenting stress in various areas, including less child acceptability ($r = .38$; $P < .001$), lower parent sense of competence ($r = -17$; $P < .01$), and greater role restriction and social isolation ($r = -.15$; $P < .05$). Financial and total family impacts also were related to lower child IQ ($r = -.20$, $-.30$, $P < .002$).

Higher maternal education was related to lower parenting stress in both the Child Domain ($\beta = -0.19$; $P < .003$) and the Parent Domain ($\beta = -0.18$; $P < .002$) of the PSI, as well as to all coping factors, including more active ($\beta = .25$, $P < .0002$), more adaptive ($\beta = .25$; $P < .0002$), less avoidant ($\beta = -.21$, $P < .0001$), and more acceptance ($\beta = .16$; $P < .02$) coping.

DISCUSSION

At child age 8 years, the pattern of maternal adaptation to VLBW birth was similar to that noted at the 3-year follow-up,[12] indicating significant stress in mothers of high-risk VLBW children but largely equivalent experiences between the mothers of low-risk VLBW children and those of term children. However, there were several areas in which the mothers of both high-risk and low-risk VLBW children differed from term mothers. The mothers of VLBW children did not advance in educational attainment at the same rate that mothers of term children did over the 8-year period, indicating a significant and long-lasting impact of the VLBW

birth. Both groups reported greater concern than mothers of term children for the health of their child, even though mothers of low-risk VLBW children perceived their child's health to be generally excellent. Surprisingly, although they also reported less parent-child conflict with their school-age children than mothers of term children, they reported less consensus in their marital/partner relationship.

As occurred at 3 years, at 8 years some effects of VLBW birth were found only for mothers of high-risk VLBW children, whose children at school age had lower IQ scores and higher rates of mental retardation. These mothers continued to report more negative family, social, and financial impacts and more personal strain from parenting compared with the mothers of low-risk VLBW and term children. As at 3 years,[12] mothers in the 3 groups did not differ in terms of psychological distress symptoms, divorce rate, perception of family cohesion, or sense of mastery in parenting. Although the findings of fewer intrafamily strains, such as parent-child and sibling conflict, were unexpected, they are consistent with our other findings of greater parental concern for their child's health, more child physical limitations, and fewer child activities outside the home, all of which may lead to increased parental monitoring and more child dependency and compliance, perhaps reducing or delaying some stressors of parenting school age children.

Earlier studies of this sample[17] revealed no differences in maternal use of coping strategies 2 years postpartum in the mothers of high-risk VLBW children, who at that time had greater psychological distress symptoms than the mothers of low-risk VLBW and term children.[12] At age 8 years, however, the mothers of high-risk VLBW children were less likely to use denial and mental disengagement in coping than the mothers of low-risk VLBW and term children, but no differences in maternal psychological symptoms were found among the 3 groups. Greater use of such avoidant coping has been associated with maternal psychological distress in mothers of VLBW and medically fragile children.[17,30,34] The findings from the present study may demonstrate a positive adaptation over time in the mothers of high-risk VLBW children. The decrease in clinical symptoms of depression and anxiety, which had been prominent at birth and 2 years postpartum, and the general similarity of psychological symptoms with the mothers of low-risk VLBW and term mothers at child age 8 years suggest that these mothers have adopted less avoidant coping strategies to manage the significant stressors (eg, greater care giving demands, higher financial burdens, and poorer child outcomes) associated with parenting.

Although these findings may be unexpected, other studies support such positive outcomes in mothers of high-risk VLBW infants.[14] In families with children with disabilities, mothers with greater caregiving demands also reported more personal growth and maturity.[35] Parenting a child with disability may provide mothers with more opportunities to deal successfully with challenges and increase feelings of efficacy. Alternatively, positive perceptions may be a mechanism for coping with the stressors of caring for a child with disabilities.[36] Keep in mind, however, that mothers may deny negative feelings because of social desirability bias.[37]

Multiple birth added to negative family impact and parenting stress. Mothers with multiple births felt more parenting stress and social isolation, consistent with previous studies.[37,38] This is the first prospective study to assess the impact of multiple births within a VLBW cohort. Because negative effects were not apparent in this cohort at earlier ages,[12] these findings indicate that the stressors for multiple birth families may increase with child age.

Higher maternal education was associated with lower stress, possibly through its association with greater use of coping mechanisms. In mothers of term children, higher maternal education has been found to enhance self-efficacy. Thus, lower maternal educational attainment, one outcome of VLBW birth, may be an additional mechanism by which VLBW birth contributes to parenting stress.

Finally, lower child IQ and SES predicted higher stress across all domains for all mothers. Although the effects of SES were not different by VLBW or risk status, these findings support the notion that SES is a risk factor for greater parenting stress for all families.

Limitations of the present study include an absence of data on fathers, who could not be reliably recruited despite attempts to do so. Thus, parental sex differences were not explored. In addition, measures of family impact were based on self-reports rather than objective measurement, and the interval between the 3-year and 8-year follow-ups did not allow us to make inferences about factors that may have altered maternal symptoms or coping strategies.

The increased survival rate of VLBW infants may be accompanied by important improvements in their medical care. However, survival of VLBW infants often results in child disability and family stress. Corresponding advances are needed to address maternal and family issues to ensure the long-term optimal outcome for VLBW infants and their families. Physicians and educators must be aware of burdens experienced by these families over time, so that appropriate advice and/or referrals can be provided to help ensure optimal family function and support for the long-term care of VLBW infants.

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