Maternal Psychological Distress and Parenting Stress After the Birth of a Very Low-Birth-Weight Infant

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V ERY LOW-BIRTH-WEIGHT (VLBW; <1500 g) birth has become an increasingly common occurrence because of medical advances in neonatal intensive care and management of high-risk pregnancy. Approximately 50 000 VLBW births occur annually in the United States.[1] Significant improvements have occurred in survival rates of small preterm infants, especially those of extremely low birth weight (ie, <1000 g). However, follow-up studies of survivors have documented higher rates of neurodevelopmental impairment, including motor, visual, and hearing disabilities; mental retardation; attention disorders; and learning disabilities at school age in comparison with term infants.[2-6] Increased rates of disability among survivors have engendered debate about the ethics and justification of intensive care for the most immature infants.[7] Although the birth of an infant with VLBW poses a considerable challenge to parents, there is little information detailing how they adapt to this experience and subsequent caregiving demands.

Context Few studies document how parents adapt to the experience of a very low-birth-weight (VLBW; <1500 g) birth despite societal concerns about the ethics and justification of intensive care for these infants.

Objective To determine the degree and type of stress experienced over time by mothers whose infants vary in degree of prematurity and medical and developmental risk.

Design Longitudinal prospective follow-up study of a cohort of mothers of high- and low-risk VLBW and term infants from birth to 3 years.

Setting All level III neonatal intensive care units from a large midwestern metropolitan region.

Participants Mothers and infants prospectively and consecutively enrolled in a longitudinal study between 1989 and 1991. High-risk VLBW infants were diagnosed as having bronchopulmonary dysplasia, and comparison groups were low-risk VLBW infants without bronchopulmonary dysplasia and term infants (>36 weeks, >2500 g).

Main Outcome Measures Standardized, normative self-report measures of maternal psychological distress, parenting stress, family impact, and life stressors.

Results Mothers of VLBW infants (high risk, n = 122; low risk, n = 84) had more psychological distress than mothers of term infants (n=123) at 1 month (13% vs 1%; P = .003). At 2 years, mothers of low-risk VLBW infants did not differ from term mothers, while mothers of high-risk infants continued to report psychological distress. By 3 years, mothers of high-risk VLBW children did not differ from mothers of term children in distress symptoms, while parenting stress remained greater. Severity of maternal depression was related to lower child developmental outcomes in both VLBW groups.

Conclusions The impact of VLBW birth varies with child medical risk status, age, and developmental outcome. Follow-up programs should incorporate psychological screening and support services for mothers of VLBW infants in the immediate postnatal period, with monitoring of mothers of high-risk VLBW infants.

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Mothers of preterm infants experience more severe levels of psychological distress in the neonatal period than mothers of full-term infants,[8,9] with depression and anxiety notable at the time of hospital discharge,[8-11] but there have been few controlled studies beyond this period. In studies of healthy term infants, maternal depression has been

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linked to negative effects on child cognitive, emotional, and behavioral development.[12-14] Early maternal depression or other psychological distress symptoms may have differential effects on preterm infants.[15,16] The relationship of maternal mental health to parenting behavior is important to investigate prospectively in preterm populations because maternal psychological status has been found to correlate with childhood emotional and mental well-being at school age in low-birth-weight and preterm children.[4]

Parenting strains may also be exacerbated for mothers of preterm infants.[8,17] Greater caregiver burdens in parents of preterm infants have been related to the severity of neonatal medical complications that make daily parenting tasks more time-consuming and difficult,[18] although not all findings are consistent. In a Canadian survey[19] of parents of young preschool children with VLBW, even those parents whose children with VLBW had cognitive delays reported no greater personal, family, or financial strains than parents of term children, while parents of normally developing children with VLBW actually reported less negative family and personal impact than the reference group of parents of healthy term children.

However, such cross-sectional studies may obscure the effects of age-related parenting strains, which can affect maternal mental health. Also, few prior studies on the family impact of VLBW birth have included controlled comparison groups, which are important because psychosocial sequelae may be related to other factors associated with VLBW birth, such as low socioeconomic status,[20] maternal substance abuse,[21] multiple birth, or other life stressors.[22]

We longitudinally followed up mothers of prospectively recruited cohorts of high- and low-risk infants with VLBW and a comparison cohort of term infants until 3 years of age, measuring maternal psychological distress, perception of parenting stress, family impact, and concurrent life stressors at multiple age points.

METHODS

Mothers were interviewed as part of a longitudinal study of the outcomes of infants with bronchopulmonary dysplasia (BPD) and VLBW.[23] Infants with VLBW admitted to the neonatal intensive care units of hospitals in the Cleveland, Ohio, region were eligible for the study and were prospectively and consecutively enrolled between 1989 and 1991 at birth.

High-risk infants with VLBW were defined as those with all of the following: (1) diagnosis of BPD, (2) birth weight of less than 1500 g, (3) supplementary oxygen requirement for more than 28 days because of lung immaturity at birth, and (4) radiographic evidence of chronic lung disease.[24,25] A partial stratification sampling strategy was adopted to enroll adequate numbers of subjects without socioeconomic disadvantage or severe neurologic risk so the impact of social class and medical risk factors on outcome could be investigated. Infants diagnosed as having BPD who were free of neurologic problems other than grade I or II intraventricular hemorrhage and who were not socially disadvantaged (ie, Hollingshead classification IV or V)[26] were exhaustively recruited. The remainder was recruited by approaching the family of the next available infant with BPD who could be accommodated in the follow-up schedule. Parents of infants with BPD were approached by a research assistant in the hospital as soon as possible after the diagnosis of BPD was made by the attending neonatologist. Parents were informed that the longitudinal study was investigating the outcomes and family stressors associated with BPD and VLBW.

Low-risk infants with VLBW did not have a diagnosis of BPD, were preterm, weighed less than 1500 g at birth, and required oxygen supplementation for less than 14 days. For each infant with BPD, the next available comparison infant with VLBW and without BPD who was of the same race and socioeconomic status and born during the same period was recruited.

As a control group, term infants were recruited from the neonatal nurseries.

Term infants had no diagnosed medical illnesses or abnormalities at birth, were more than 36 weeks' gestational age, and, for singleton births, weighed more than 2500 g at birth. Information about the study and return-addressed postcards were provided to all mothers in the term nurseries. For each infant with BPD enrolled, the next eligible term infant equivalent in race and socioeconomic status with a returned postcard indicating parental willingness to participate was recruited.

For all groups, infants with major congenital malformations or drug exposure or whose mothers had major psychiatric or physical illness, human immunodeficiency virus, or mental retardation or who lived more than 2 hours' driving distance were excluded. Other details of recruitment and information regarding attrition and medical risk status have been previously reported.[23] More than 91% of survivors recruited were seen for at least 1 follow-up visit. Follow-up rates at each age ranged from 83% to 89% for the high-risk VLBW group, 64% to 88% for the low-risk VLBW group, and 85% to 90% for the term group.

Procedures

Mothers completed the following standardized self-report measures at 1, 8, and 12 months and 2 and 3 years (ages corrected for prematurity).

1. The Brief Symptom Inventory (BSI)[27] measures 9 psychiatric symptom patterns (somatic complaints, obsessive-compulsive behavior, interpersonal sensitivity, depression, anxiety, phobic anxiety, paranoid ideation, hostility, and psychoticism) that possess consensually valid clinical significance.[28] A summary score, the General Severity Index (GSI), measures overall psychological distress. Cutoff scores identify subjects whose symptoms reach severity levels suggestive of the need for clinical intervention, ie, higher than the 84th percentile (moderate) or higher than the 98th percentile (severe) compared with same-sex nonpatient norms.

2. The Parenting Stress Index (PSI)[29] assesses parental perceptions of the degree

of stress related to dimensions of the parenting role. The parent domain measures 6 dimensions of stress, ie, reinforcement of parent, depression, role restriction, sense of competence, social isolation, and spousal/boyfriend support. Under the child domain, child characteristics of adaptability, acceptability, distractibility-hyperactivity, mood, attachment, and reinforcement to parent are rated. Normative data from the PSI were derived from 534 families of children aged 1 month to 19 years seen in a pediatric setting. The PSI has acceptable reliability and demonstrated validity in studies of parents of sick children.[30,31]

3. The Impact on Family Scale,[32] given at 2 and 3 years, measures maternal perceptions of the child's impact on the family. Designed to assess the impact of a child with a disability, statements were modified to also apply to healthy children. The scale assesses financial and personal strains; disruption of family, social and sibling relations; and mastery (coping) abilities in 5 subscales that can be summed to a total score. Prior studies have demonstrated the reliability and validity of the scale.[18,19,32,33]

4. The Family Inventory of Life Events and Changes (FILE)[34] assesses the family's experience of a variety of life changes during the previous year. It documents the occurrence or nonoccurrence of family life changes conceptualized as stressful in 9 categories: intrafamily strains, marital strains, pregnancy and childbearing strains, finance/business strains, work-family transitions, illness, losses, transitions, and family legal violations. The FILE served to determine whether group differences in life stressors, other than infant illness and prematurity, could account for maternal psychological, parenting, or family strains.

At 8 months and each subsequent visit, all infants were administered the Bayley Scales of Infant Development.[35,36] Results from the mental scale yield the Mental Development Index (MDI), a standard score reflecting overall cognitive development.

This study was approved by the institutional review boards of the hospitals that participated and written informed consent was obtained for all subjects.

Data Analyses

For cases in which distributions were significantly skewed, scores were normalized using logarithm (x + 1) transformations prior to data analysis. Group differences and changes over time for the BSI, PSI, and FILE were examined using a mixed-models approach with restricted maximum likelihood estimation procedures. PROC from SAS, Version 6.12, was used.[37]

For the Impact on Family Scale, repeated-measures analyses of variance were used. Incidence of clinically significant symptoms of moderate or severe general distress, depression, and other symptoms from the BSI were also compared by group for each point.

Spearman rank-order correlations were computed to assess the relationship of severity of maternal psychological symptoms with child outcome (Bayley MDI) at each point.

RESULTS
Sample Characteristics

As reported previously,[23] high-risk infants with VLBW had lower birth weight and gestational age, with more neurologic and medical risk factors and significantly lower standard scores on the Bayley mental scale than low-risk infants with VLBW and term infants (**TABLE**). Bayley standard scores were in the mentally retarded range (<70) for 18% to 21% of the high-risk VLBW group at each age, 6% to 11% of the low-risk VLBW group, and less than 5% of the term group (F score >13.1 for all; $P<.001$ for all), supporting the validity of the classification of risk status.

Groups did not differ in race, social class, sex, or maternal educational or marital status. There was a higher percentage of multiple births and a larger family size at 3 years in the low-risk VLBW group than in the other 2 groups.

Maternal Psychological Distress

During the 3-year study, mothers of high-risk infants with VLBW reported higher levels of psychological distress than mothers of low-risk infants with VLBW and term infants, especially depression, anxiety, and obsessive-compulsive behaviors, but the severity of these symptoms varied over time (**FIGURE 1**).

At infant age of 1 month, the mean scores of mothers of high-risk infants with VLBW were higher on dimensions of general psychological distress, anxiety, depression, and obsessive-compulsive behaviors than those of mothers of term infants, while those of mothers of low-risk infants with VLBW

Table. Demographic and Medical Characteristics*

	High-Risk VLBW (n = 122)	Low-Risk VLBW (n = 84)	Term (n = 123)	F Statistic	P Value
Birth weight, g	956 (248)	1252 (178)	3451 (526)	1633	<.001†
Gestational age, wk	27 (2)	30 (2)	40 (1)	1416	<.001†
Social class‡	3.5 (1)	3.6 (1)	3.6 (1)	0.7	.71
Total oxygen, d	106 (149)	5 (5)	0 (0)	44.5	<.001§‖
Race, white, %	55	48	51	1.1	.58
Sex, male, %	52	43	50	1.9	.39
Multiple birth, %	21	43	10	31.5	<.001¶
Bayley Mental Development Index at age 3 y	84 (24)	90 (16)	96 (12)	11.2	<.001†
Maternal marital status, % married	56	60	54	0.5	.80
Maternal education, y	13.1 (2)	13.3 (2)	13.3 (2)	0.11	.88
Parity	2.0 (1)	2.3 (1)	. . .	1.6#	.11
Family size at 3 y	2.3 (1)	3.0 (1)	2.3 (1)	4.4	.02¶

*VLBW indicates very low birth weight; ellipses, data not applicable. Data are mean (SD) unless otherwise indicated.
†High risk < low risk < term; $P<.05$.
‡Defined by Hollingshead classification.[26]
§High risk and low risk > term; $P<.05$.
‖Data were derived using the Wilcoxon test.
¶Low risk > high risk and term; $P<.05$.
#Data were derived using the t statistic.

were halfway between mothers of high-risk and term infants, supporting the notion that higher levels of child risk were related to severity of maternal psychological distress. Nine percent of mothers of both high- and low-risk infants with VLBW reported severe symptoms (ie, >98th percentile for female norms) of depression (χ^2 = 5.6; P = .02) and 13% of mothers of both high- and low-risk infants reported severe symptoms of overall distress compared with 1% of term mothers (χ^2 = 8.8; P = .003). Less severe but clinically significant symptoms of general distress were reported by 32% of mothers of high-risk and 29% of mothers of low-risk infants with VLBW in con-

trast with 17% of mothers of term infants. Mothers of both groups of infants with VLBW were also more likely to experience moderately elevated symptoms in the domains of obsessive-compulsive behavior (39% high risk vs 27% low risk vs 15% term; χ^2 = 10.9; P<.001) and anxiety (26% high risk vs 23% low risk vs 7% term; χ^2 = 9.5; P = .002).

By infant ages of 8 and 12 months, there were no differences among groups and all scores were within normative ranges, with the exception that more mothers of high-risk infants with VLBW continued to have clinically significant symptoms of anxiety at 8 months (20%

high risk vs 4% low risk vs 6% term; χ^2 = 7.7; P = .02).

However, at 2 years, mothers of high-risk infants with VLBW were more likely to report symptoms of moderate but clinically significant depression than mothers of low-risk infants with VLBW (24% high risk vs 0% low risk vs 10% term; Fisher exact test, P = .006) as well as clinically higher levels of general distress than mothers of term infants (24% high risk vs 0% low risk vs 13% term; Fisher exact test, P = .03). By 3 years, there were no differences among the 3 groups of mothers in clinical incidence of psychological distress symptoms.

Parenting Stress

The PSI child domain score indicated significantly higher stress for mothers of high-risk infants with VLBW compared with mothers of term infants at 1 and 3 years, reflecting that they perceived their children as more distractible, hyperactive, and demanding than did mothers of term infants (**FIGURE 2**). However, high-risk children with VLBW were not perceived as less acceptable, less attached, or less reinforcing than low-risk children with VLBW or term children. Mothers of low-risk children with

Figure 1. Mean Scores on Brief Symptom Inventory Subscales of GSI, Depression, Anxiety, and Obsessive-Compulsive Behavior
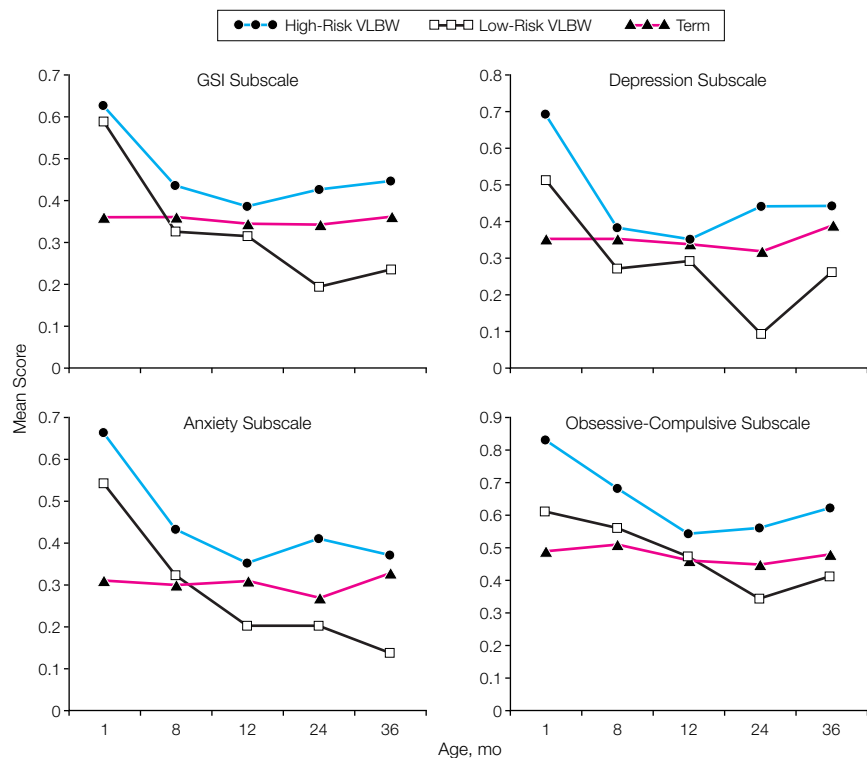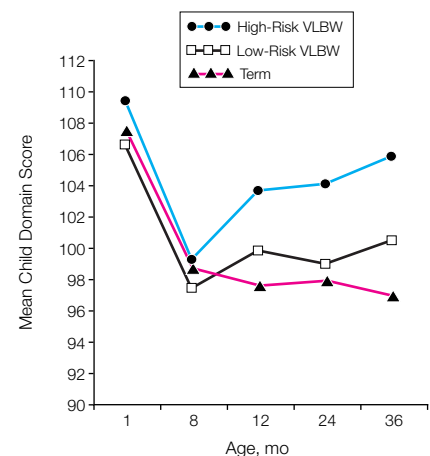

GSI indicates General Severity Index. All scores had significant group effects (P<.001) and group-by-time interactions (P = .05). High-risk very-low-birth-weight (VLBW) scores differed significantly over time from low-risk VLBW and term scores in post hoc comparisons. For GSI scores, at birth, high risk are higher than term (t = 2.7; P = .007); at 2 years, high risk are higher than low risk (t = 2.4; P = .02) and high risk are higher than term (t = 1.9; P = .06); and at 3 years, high risk are higher than low risk (t = 2.6; P = .01) and high risk are higher than term (t = 1.7; P = .10). For depression scores, at birth, high risk are higher than term (t = 2.5; P = .01); at 2 years, high risk are higher than low risk (t = 2.4; P = .02); and at 3 years, high risk are higher than low risk (t = 1.7; P = .09). For anxiety, at birth, high risk are higher than term (t = 3.5; P<.001); at 8 months, high risk are higher than term (t = 1.9; P = .05); at 12 months, high risk are higher than low risk (t = 1.9; P = .06); at 2 years, high risk are higher than term (t = 1.9; P = .06); and at 3 years, high risk are higher than low risk (t = 2.2; P = .03). For obsessive-compulsive scores, at birth, high risk are higher than term (t = 3.2; P = .002); at 2 years, high risk are higher than low risk (t = 2.2; P = .03) and high risk are higher than term (t = 1.8; P = .08); and at 3 years, high risk are higher than low risk (t = 2.5; P = .01) and high risk are higher than term (t = 2.1; P = .03).

Figure 2. Mean Scores on the Parenting Stress Index Child Domain Scale

There was an overall group effect (F = 3094; P<.001) with a group-by-time interaction (F = 3.9; P = .008). High-risk very-low-birth-weight (VLBW) scores differed significantly over time from term scores (t = 2.1; P = .03) in post hoc comparisons.

VLBW did not perceive their children as more stressful than did mothers of term children on any dimension.

The PSI parent domain scores did not differ among mothers at any time. Mothers of high- and low-risk infants with VLBW experienced levels of partner or spousal support and general support equivalent to mothers of term infants, as well as equivalent feelings of parenting competence.

Family Impact

More family stress was experienced by mothers of high- and low-risk infants with VLBW compared with mothers of term infants at 2 years (**FIGURE 3**). At 2 years, mothers of both high- and low-

risk infants with VLBW reported greater financial stress than mothers of term infants, but only mothers of high-risk infants with VLBW reported greater family stress, more personal strain, and higher overall stress. There were no differences in coping mastery among the 3 groups of mothers, indicating that all mothers endorsed similar positive feelings of accomplishment related to parenting. By 3 years, however, the stressors experienced by mothers of low-risk infants with VLBW had diminished to levels similar to mothers of term infants on all dimensions, while mothers of high-risk infants with VLBW continued to report greater financial, family, personal, and total stress scores.

Life Stressors

The number of infant illness and pregnancy stressors differed over time for families with high- and low-risk infants with VLBW or term infants, indicating that the classification of high and low medical risk was valid (**FIGURE 4**). There were more pregnancy stressors for the families of high-risk infants neonatally compared with families who had term infants, indicating that they reported more experiences of a difficult pregnancy in the previous year. By 3 years, however, there were more pregnancy stressors reported in the families of term infants

compared with families with high-risk infants, indicating more experiences with pregnancy in the prior year, either through birth, adoption, abortion, or a difficult pregnancy. Families did not differ on financial stressors, life transitions, losses, or legal or work-related events in the year prior to infant birth or during the course of the study that might influence maternal distress symptoms independent of VLBW birth.
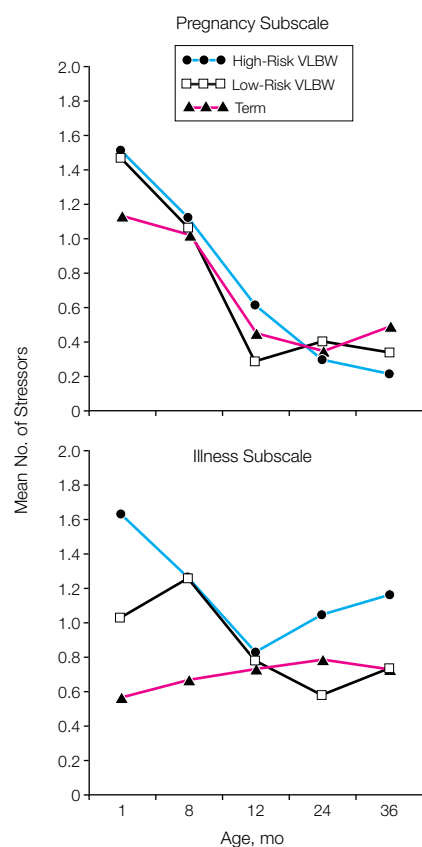
Multiple VLBW Births

When the same comparisons of stressors and distress symptoms experienced by mothers of high- and low-risk infants with VLBW were analyzed for mothers whose infants with VLBW were multiple births, the findings were similar. There was no evidence for greater maternal stress on any of the dimensions measured based on multiple-birth status. Moreover, the lowest levels of stress after the neonatal period were experienced by the low-risk VLBW group, which had greater parity, more multiple births, and greater family size, suggesting that high-risk status was a more important factor in maternal distress.

Relationship of Maternal Depression and Child Outcome

Correlations were examined between concurrent maternal depression scores

**Figure 3.** Mean Number of Stressors in the Family Inventory of Life Events

VLBW indicates very low birth weight. There were significant effects for the subscale of illness for group (F = 99.1; P = .04) and for the group-by-time interaction (F = 2.78; P<.05). For the pregnancy subscale, there was also a significant group-by-time interaction (F = 11.0; P<.001).

Figure 4. Mean Scores on Subscales Within the Impact on Family Scale
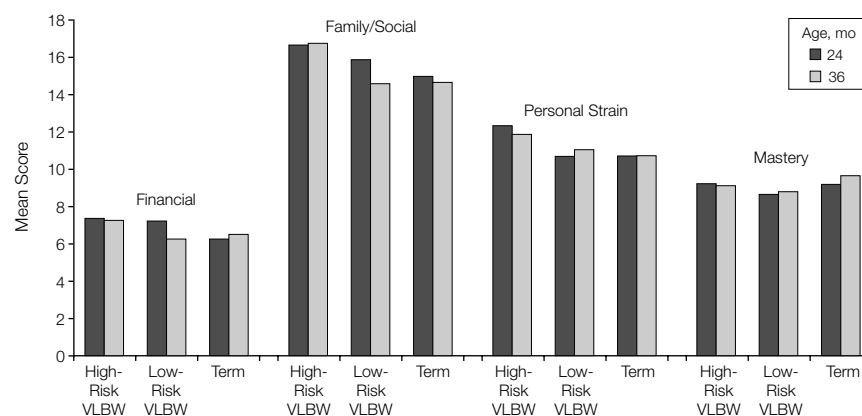
VLBW indicates very low birth weight. There was an overall group effect (P<.05) for the family/social (F = 4.4; P = .04) and personal (F = 4.2; P = .04) strain subscales and a trend for the financial subscale (F = 3.0; P = .09). There was a group-by-time interaction effect (P<.05) for the family/social (F = 4.0; P = .05) and financial (F = 3.5; P = .07) subscales.

on the BSI and Bayley MDI scores at each age for the VLBW and term groups. Significant negative relationships between severity of maternal depression and child mental outcomes were found within the VLBW group, with correlations of −0.31, −0.27, −0.22, and −0.33 (*P*<.05 for all) at 8, 12, 24, and 36 months, respectively. For the term group, in which only a few children functioned at below-normal levels, there were no significant relationships between severity of maternal depression and child mental functioning, with correlations of −0.10, −0.15, −0.11, and 0.10 for the same ages.

COMMENT

The results of this longitudinal study indicate that the psychosocial impact of VLBW birth varies dependent on the medical risk status, age, and developmental outcome of the infant. In terms of maternal mental health symptoms, mothers of both high- and low-risk infants with VLBW had similar initial responses, with elevated levels of psychological distress neonatally, but had few differences from mothers of term infants by 8 and 12 months. During the neonatal period, symptoms of depression, anxiety, and obsessive-compulsive behaviors, including difficulty concentrating and making decisions, were prominent.

A surprising finding was that mothers of low-risk infants with VLBW were similar after the neonatal period to mothers of term infants on all measures and, by 3 years, had the lowest levels of distress. Because low-risk infants with VLBW performed within normative ranges at follow-up and because maternal distress was related to poorer child outcome, it is possible that these mothers' relatively low distress levels were due to maternal relief after an initial period of fear and anxiety.

Mothers of high-risk infants with VLBW, in contrast, had a more complicated course, with more symptoms of distress at 2 years, more negative family impact at 2 and 3 years, and more parenting strains and illness stressors at 3 years. Yet, by 3 years, their reported psychological distress was not different from term mothers and parenting satisfaction was similar, except that

mothers of high-risk infants with VLBW regarded their children as more demanding. These mothers' positive feelings of mastery were also equivalent to those reported by mothers of term infants and mothers of low-risk infants with VLBW.

The recurrence of elevated symptoms of distress for mothers of high-risk infants with VLBW at 2 years may reflect the opposite of the process that occurred for mothers of low-risk infants with VLBW. By 2 years, infant developmental scores are predictive of later outcomes, and many mothers of high-risk infants with VLBW must relinquish their hopes for their children to "catch up" to term infants developmentally, with accompanying symptoms of psychological distress. The finding that these symptoms for mothers of high-risk infants with VLBW are not different from those of term mothers by 3 years suggests some psychological adaptation despite continued maternal acknowledgment of greater family and parenting stressors. At 3 years, mothers of term infants reported experiencing more pregnancy-related events in the prior year than mothers of high-risk infants with VLBW. This finding suggests that parents of high-risk infants with VLBW may wait longer to try to have more children.

The current findings confirm results from smaller cross-sectional studies of significant psychological distress[8-10] in postpartum mothers of infants with VLBW, as well as positive family adaptation and parenting satisfaction, even for mothers of high-risk infants with VLBW by 3 years.[18]

In contrast with prior studies, our cohort was regional, prospectively recruited, and followed up longitudinally. Furthermore, the cohort included a racially and socioeconomically diverse sample in which important confounding factors were controlled and multiple dimensions of parenting stress and mental health were assessed. Thus, the bias of hospital-based selection was avoided and assessment of age-related changes in stress could be accurately evaluated. In particular, life event stressors other than those associated with VLBW birth did not differ among the groups in the year prior to or at birth.

However, our findings may not generalize to fathers of infants with VLBW, who may experience different parenting stressors. Another limitation is the reliance on parental perceptions of family impact rather than direct measurement of family and maternal functioning. Subjective reports of well-being, however, are an important measure of life satisfaction. Finally, the small sample of multiple births may have precluded detection of differences for that group.

These findings have implications for health care policy, given some concerns that the increased survival of very small infants with VLBW and neurodevelopmental disabilities may lead to intolerable family burden.[38,39] Symptoms of psychological distress, satisfaction with parenting, attachment to their children, and positive feelings of coping and mastery in mothers of high- and low-risk infants with VLBW were not different from those reported by mothers of term children by 3 years, even in the group with the highest rate of severe disabilities. These positive findings are congruent with other studies that found satisfactory quality of life self-reported by teenage survivors of VLBW[40] and positive attitudes toward saving high-risk infants with VLBW in parents of children who had VLBW births.[41]

These findings further suggest that current VLBW follow-up programs might benefit from the addition of psychological and family services into traditional neurodevelopmental assessment programs, particularly in the neonatal period and at infant age of 2 years. Despite the overall positive adaptation of mothers by 3 years, 10% of mothers of infants with VLBW reported severe symptoms of psychological distress neonatally—5-fold the rate for term mothers—while almost one third of mothers of infants with VLBW had clinically meaningful levels of depression and anxiety. For mothers of high-risk infants with VLBW, significant symptoms recurred at infant age of 2 years. The neonatal period affords an opportunity to identify mothers who are most at risk with standardized, simple screening techniques.[27] Such identification and refer-

ral for treatment may prevent the development of more severe symptoms, which can interfere with effective parenting,[13,16] while the provision of social supports may also effectively buffer distress.[9,42,43]

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