Long-term Family Outcomes for Children With Very Low Birth Weights

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Objective: To examine long-term outcomes in families of children with very low birth weights (<1500 g) in relation to the extent of low birth weight and neonatal medical risk.

Design: Concurrent/cohort prospective study.

Setting: Regional follow-up program.

Participants: Families of 60 children of school age with birth weights less than 750 g, 55 with birth weights between 750 and 1499 g, and 49 normal birth weight full-term controls.

Main Outcome Measures: Parent ratings of psychological distress, family function, and child-related stress.

Results: Families with children with birth weights less than 750 g experienced greater stress than did families of controls (born at full term), and families who were sociodemographically advantaged experienced greater stress than did those who were disadvantaged. Higher neonatal medical risk also predicted a more negative impact on the family, but only in advantaged families. Regression analyses suggested that adverse family outcomes were mediated by ongoing problems in child functioning.

Conclusions: Families of children with birth weights less than 750 g experience more long-term adversity than families of full-term children. Family sequelae are also present for children with very low birth weight at high neonatal medical risk. Ongoing child health and behavior problems may be the major source of these sequelae, and sociodemographic status is an important consideration in identifying family adversity. Although many families appear unaffected, results support the need to monitor family outcomes and develop interventions for both the child and family.


Previous research has demonstrated that families of infants and young children with very low birth weights (VLBW) (<1500 g) experience more distress and burden than do families of children born at full term at a normal weight. We know little, however, about the later adjustment of families of children with VLBW. Our study is among the first to document that family sequelae extend into the school-age years and to investigate predictors of these sequelae. The findings also clarify sources of family adversity and indicate a need for family intervention.

The birth of an infant with VLBW (<1500 g) is a stressful event for many families, especially in cases involving extreme prematurity, neonatal medical complications, and long hospitalizations. Parents of infants and young children with VLBW report more symptoms of depression and experience greater child-related stress than do mothers of full-term children. Early parenting behaviors and attachment of the infant to the caretaker are also adversely affected.

The negative impact of children with VLBW on their families, although diminishing after the neonatal period, persists into early childhood. However, we are aware of no published reports of family outcomes for older children with VLBW. It is unclear if family sequelae are intransigent or dissipate as the child grows older. Even if family problems related to early separation from the child or to stress associated with neonatal complications resolve with time, children with VLBW are at risk for a variety of problems in health, behavior, and development. Research on children with VLBW and on children who have other chronic conditions indicates that child health and developmental problems have adverse effects on families. Because these problems continue to be present in children with VLBW during the school-age years, one would expect persistent family sequelae.

The primary goal of this study was to test the hypothesis that family outcomes would be more negative for children of school age with VLBW than for those born at full term at a normal weight. In view of the greater health, developmental, and family morbidity associated with more extreme degrees of preterm birth and neonatal medical risk, we anticipated that family sequelae would be more marked for...
PATIENTS AND METHODS

POPULATION

The sample consisted of children and parents participating in an ongoing longitudinal study of the consequences of birth weights less than 750 g in older children. The participants were first recruited when the children had a mean age of 7 years. The sample included 68 children with birth weights less than 750 g, 65 with birth weights between 750 and 1499 g, and 61 controls born at full term. The group that had birth weights less than 750 g constituted 93% of the 73 surviving children born in this weight range who were treated at neonatal intensive care units in region V of Ohio between July 1, 1982, and December 31, 1986. The 2 comparison groups were formed by selecting matches for each child with a birth weight less than 750 g. The birth weight match in the 750 to 1499 g group was the next-born child in this birth weight range delivered at the same hospital and of the same sex and race. The full-term match was a randomly selected classmate of the same age within 3 months, and of the same sex and race. Failure to recruit comparison children for some of the children with birth weights less than 750 g was the result of refusals, difficulties in matching out-of-town participants, and missed appointments. Comparison of the 3 original groups did not reveal differences in age, sex, or sociodemographic factors.

The family assessments considered in this report were obtained at a second assessment conducted when the children had a mean age of 11 years. We were unable to follow up with 30 of the original families due to moves out of the region (4 cases), inability to locate families (7 cases), and disinterest or lack of follow-through by families (19 cases). Maternal education and children's cognitive ability were lower for those who dropped out of the study than for those who remained in the study, but these 2 groups of children did not differ in gestational age, neonatal complications, or rates of neurosensory disorders.

Table 1 presents neonatal and sociodemographic characteristics for the 3 groups of children (mean age, 11 years). Neonatal medical status was assessed in terms of rates of individual complications and of high overall neonatal risk, as defined by a score greater than 3 on the Neonatal Risk Index. Measures of sociodemographic status included the Hollingshead Four Factor Index and the Social Disadvantage Index. The SDI has been previously validated as a predictor of child outcomes and is defined as a composite of maternal education (< high school = 1; = high school = 0), paternal marital status (unmarried = 1; married = 0), and minority status (minority = 1; nonminority = 0). For this study, families were classified on the basis of the SDI as advantaged (SDI = 0 or 1) or disadvantaged (SDI > 1).

As expected, the less than 750 g group had a lower mean birth weight and gestational age, longer hospitalizations, and higher rates of individual neonatal complications and overall neonatal medical risk than the 750 to 1499 g group. Proportionally, more children in the less than 750 g group had high neonatal medical risk than those in the 750 to 1499 g group. The groups did not differ in age, sex, race, or the Hollingshead Four Factor Index, but did differ in maternal educational status and in the proportion of disadvantaged families.

Fifteen children had neurosensory disorders, including cerebral palsy or a visual or sensorineural hearing impairment. Visual impairment was defined as corrected acuity in at least 1 eye of less than 20/100. These disorders were found in 11 children from the less than 750 g group (4 with cerebral palsy, 4 with visual impairment, 2 with sensorineural hearing impairment, and 1 with cerebral palsy and visual impairment) and 4 from the 750 to 1499 g group (2 with cerebral palsy, 1 with sensorineural hearing impairment, and 1 with cerebral palsy and hearing impairment).

ASSESSMENT PROCEDURES

Although child testing was comprehensive, only results from parent interviews and parent-based child behavior ratings were considered in this study. Respondents included mothers (86.6%), fathers (4.9%), grandparents (6.7%), and foster parents (1.8%). Institutional review board approval and informed consent from families was obtained prior to participation.

Family outcomes were assessed by administering several self-report scales to parents. The Brief Symptom Inventory (BSI) was given to assess parent psychiatric symptoms; the Competence and Attachment scales of the

RESULTS

EFFECTS OF BIRTH WEIGHT GROUP AND SOCIODEMOGRAPHIC STATUS

Table 2 presents results from analyses of the effects of birth weight group and sociodemographic status on the

children with birth weights less than 750 g than for those with birth weights between 750 and 1499 g. We also expected more adverse outcomes for families with children who have VLBW and a higher neonatal medical risk.

Based on previous research, we anticipated that outcomes would be poorer in families at greater social disadvantage. We also examined the possibility that the influences of low birth weight or neonatal medical risk on family outcomes differed according to sociodemographic status. If families at greater social disadvantage are less able to cope with parenting demands and child needs than families from more advantaged backgrounds, negative effects of children with VLBW on their families may be heightened by social disadvantage. Alternatively, stresses related to raising a child with VLBW may have a smaller relative impact on families facing other hardships than on more advantaged families.

Evidence for both types of moderating effects can be found in research on the relationship between family social status and child outcomes. Associations between birth weight or neonatal medical risk and family outcomes may be mediated by concurrent problems in the child's functional health, as broadly defined by the presence of a neurosensory disorder or a problem in child behavior or adaptive functioning.
Results from logistic analysis showed a higher rate of the 750 to 1499 g group and 14 (32%) of the full-term group pertained to the need for child supervision, acceptance of the child by peers and the child’s self-esteem, the effects of child problems on family routines, and the child’s future.

To further assess the parent’s perception of child-related family stress, we administered the Family Burden Interview. This procedure was modeled after a similar assessment used in a study of family outcomes in children with traumatic brain injury.30 The latter study documented the reliability of the procedure, and validity was substantiated by associations of interview results with both injury severity and the IOF-G. In the modification employed in this study, the interviewer first asked parents if their children had any medical, developmental-learning, school, or emotional-behavioral problems. Parents who identified a problem were then asked about the nature of their concerns for the child and family. For each concern, parents rated the level of associated stress on a 0 to 4 scale (not stressful to extremely stressful). When parents endorsed multiple child problems, they identified the ones associated with stress. The overall burden on this measure was assessed in terms of the presence or absence of any child-related stress.

To provide a more encompassing assessment of family sequelae, we also classified families as having adverse or nonadverse outcomes. Adverse outcomes were identified by: (1) a T score greater than 70 on either the General Severity Index of the BSI or on 2 BSI subscales; (2) a score above the 95th percentile on either of the 2 Parenting Stress Index scales; (3) the presence of significant family dysfunction, as indicated by a score of greater than 2.17 on the McMaster Family Assessment Devise General Functioning scale31;(4) an IOF-G Total Negative Impact score greater than 2 SDs above the mean for the full-term group; or (5) report of high stress (ratings >2) on the Family Burden Interview.

Measures used to assess the child’s functional health included the Child Behavior Checklist,32 a parent-based rating of child behavior problems, and the Vineland Adaptive Behavior Scales.33 a parent interview procedure for assessing behavioral development and adaptive functioning. Children with functional health problems were those with a Child Behavior Checklist Total Problem score greater than 63, a Vineland Adaptive Behavior Composite score less than 70, and/or a neurosensory disorder as defined above.

DATA ANALYSIS

Given our interest in relating predictor variables to both continuous and dichotomous measures of outcome, data analysis was conducted using hierarchical multiple regression. Linear regression was used in analysis of continuous outcomes, and logistic regression in analysis of the dichotomous measures. Birth weight group was defined in the models by dummy variables representing contrasts between each of the VLBW groups and the full-term group. Children with VLBW were classified as at low or high neonatal risk based on their scores on the Neonatal Risk Index (0–3=low risk, 4–8=high risk). Sociodemographic status was classified as advantaged or disadvantaged.

In the first series of analyses, we compared models that included the 2 birth weight group contrasts and sociodemographic status with models that included these factors plus their interactions. If the interaction terms did not add to the prediction of a given family outcome, models without the interaction terms were used to test the effects of birth weight and sociodemographic status. Only data for the 2 VLBW groups combined were considered in the second series of analyses. These analyses paralleled those just described, with low vs high neonatal medical risk substituted for the birth weight group contrasts. The third series of analyses examined the possibility that concurrent child health problems mediated any relationships of family outcomes with birth weight or neonatal medical risk. As required in tests of mediating relationships,4 we first tested associations between the latter factors and the presence of child problems. We then carried out hierarchical regressions to determine if the child problems factor was related to family outcomes, and if relationships of either birth weight or neonatal medical risk to family outcomes were reduced when this factor was included as a predictor. The α level for significance was P<.05 for all analyses.

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verse family outcome, compared with 19 (36%) from the 750 to 1499 g group and 12 (27%) from the full-term group ($\chi^2=6.24; P<.05$). Logistic regression showed that the rate of adverse family outcomes was higher in the less than 750 g group than in the full-term group (OR=2.75; CI, 1.19-6.38; $P<.05$).

**EFFECTS OF LOW VS HIGH NEONATAL MEDICAL RISK AND SOCIODEMOGRAPHIC STATUS FOR THE VLBW GROUPS COMBINED**

Table 3 presents findings from analyses of the effects of neonatal medical risk (VLBW groups combined) and sociodemographic status on the continuous measures of family outcome. The results indicate that differences between the neonatal risk groups on the IOF-G were dependent on sociodemographic status. According to simple effects tests, there was a more negative impact on families for the high-risk group, but only in advantaged families. As in the previous analyses, outcomes were poorer for disadvantaged than for advantaged families on several of the measures. Logistic regression analysis also revealed a higher rate of adverse family outcomes for children with VLBW at high vs low neonatal medical risk (OR=2.27; CI, 1.00-5.13; $P<.05$).
MEDIATING EFFECTS OF CONCURRENT CHILD HEALTH PROBLEMS

Concurrent problems in functional health were identified in 32 children (53%) in the less than 750 g group, 12 children in the 750 to 1499 g group (22%), and 4 full-term controls (8%) ($\chi^2 = 28.52; P < .001$). These problems were identified in 25 children with VLBW (60%) in the high neonatal medical risk group and 17 (27%) in the low-risk group ($\chi^2 = 11.52; P = .001$). In logistic analysis that controlled for the effects of sociodemographic status, only the difference between the less than 750 g group and full-term group was significant (OR = 12.96; CI, 4.13-40.68; $P < .001$). Adjusting for sociodemographic status, the rate of child problems was also higher in children with VLBW at high relative to low neonatal medical risk (OR = 4.09; CI, 1.76-9.49; $P = .001$).

Results from the hierarchical regression analyses presented in Table 4 reveal that the presence of child problems was associated with several of the family outcomes, even after taking into account birth weight group contrasts and sociodemographic status. In each of these instances, family outcomes were poorer for children with problems than for children without problems. As evidence for a mediating effect of child problems, the effects of the birth weight group contrasts were diminished by inclusion of the child problems factor as a predictor.

The presence of child health problems was also associated with higher rates of child-related stress on the Family Burden Interview and adverse family outcomes. Furthermore, the effects of the less than 750 g group vs full-term group contrasts were no longer significant with the child problems factor included as a predictor. Similar results were obtained in analyses involving comparisons of children with VLBW at high vs low neonatal medical risk. None of the birth weight contrasts or high vs low neonatal risk group effects remained significant when families of children with these problems were excluded from analysis.

COMMENT

Compared with parents of full-term controls, parents of children with birth weights less than 750 g reported lower perceptions of parenting competence, more difficulties

Table 3. Summary of Findings From Comparisons of VLBW Children at Low vs High Neonatal Medical Risk on Continuous Measures of Family Outcome

<table>
<thead>
<tr>
<th>Outcome Measure</th>
<th>Low Neonatal Risk</th>
<th>High Neonatal Risk</th>
<th>Regression Results</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>ADV (n = 35)</td>
<td>DIS (n = 30)</td>
<td>ADV (n = 30)</td>
</tr>
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<td></td>
<td></td>
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<tr>
<td>Brief Symptom Inventory, General Severity Index</td>
<td>50.87 (8.24)</td>
<td>57.33 (10.92)</td>
<td>47.43 (8.97)</td>
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<tr>
<td>Parenting Stress Index</td>
<td>30.66 (6.39)</td>
<td>30.75 (4.00)</td>
<td>29.18 (5.58)</td>
</tr>
<tr>
<td>Attachment T score</td>
<td>12.99 (3.71)</td>
<td>13.75 (2.60)</td>
<td>12.40 (3.66)</td>
</tr>
<tr>
<td>Family Assessment Device, General Functioning Scale</td>
<td>1.76 (0.36)</td>
<td>1.77 (0.31)</td>
<td>1.67 (0.36)</td>
</tr>
<tr>
<td>Impact on Family Scale, Total Negative Impact raw score</td>
<td>29.21 (8.61)</td>
<td>27.58 (3.32)</td>
<td>23.31 (4.62)</td>
</tr>
</tbody>
</table>

*Data are given as mean (SD) unless otherwise indicated. VLBW indicates very low birth weight; ADV, sociodemographic advantage; DIS, sociodemographic disadvantage; SDS, sociodemographic status; and NMR, neonatal medical risk (high vs low). Sample sizes are for all VLBW children in sample. Sample sizes are slightly reduced due to failure of some families to complete all procedures. For all measures, higher scores reflect poorer family outcomes.
†P < .01.
‡P < .05.

Table 4. Results of Hierarchical Regressions Relating Sociodemographic Status (Advantaged vs Disadvantaged), Birth Weight Group (<750 g vs Full-Term, 750-1499 g vs Full-Term), and Concurrent Child Health Problems (Present, Absent) to Continuous Measures of Family Outcome

<table>
<thead>
<tr>
<th>Measure</th>
<th>Unstandardized β (SE)</th>
<th>Model 1</th>
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<th>Model 2</th>
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<tr>
<td></td>
<td>Unstandardized β (SE)</td>
<td>R²</td>
<td></td>
<td>Unstandardized β (SE)</td>
<td>R²</td>
<td></td>
<td>Unstandardized β (SE)</td>
<td>R²</td>
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<td>SDS</td>
<td>R²</td>
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<td>R²</td>
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<tr>
<td>BSI, General Severity Index</td>
<td>4.17 (1.56)†</td>
<td>0.24 (1.80)</td>
<td>0.61 (1.87)</td>
<td>0.05</td>
<td>3.93 (1.54)†</td>
<td>−1.49 (1.94)</td>
<td>0.12 (1.86)</td>
<td>3.83 (1.75)†</td>
<td>0.03‡</td>
</tr>
<tr>
<td>Parenting Stress Index</td>
<td>1.02 (0.94)†</td>
<td>2.23 (1.09)†</td>
<td>1.95 (1.14)</td>
<td>0.04</td>
<td>0.75 (0.90)</td>
<td>0.35 (1.13)</td>
<td>1.40 (1.09)</td>
<td>4.27 (1.02)†</td>
<td>0.10†</td>
</tr>
<tr>
<td>Attachment T score</td>
<td>1.53 (0.56)†</td>
<td>1.39 (0.65)†</td>
<td>1.11 (0.67)</td>
<td>0.08</td>
<td>1.41 (0.54)†</td>
<td>0.54 (0.69)</td>
<td>0.87 (0.66)</td>
<td>1.87 (0.62)†</td>
<td>0.05†</td>
</tr>
<tr>
<td>FAD, General Functioning Scale, raw score</td>
<td>0.12 (0.07)</td>
<td>0.00 (0.78)</td>
<td>0.00 (0.08)</td>
<td>0.02</td>
<td>0.12 (0.07)</td>
<td>0.00 (0.09)</td>
<td>0.00 (0.08)</td>
<td>0.04 (0.08)</td>
<td>0.00</td>
</tr>
<tr>
<td>IOF-G, Total Negative Impact, raw score</td>
<td>2.13 (0.92)‡</td>
<td>2.51 (1.07)‡</td>
<td>0.22 (1.10)</td>
<td>0.07</td>
<td>1.83 (0.87)‡</td>
<td>0.58 (1.10)</td>
<td>−0.34 (1.05)</td>
<td>4.38 (0.99)†</td>
<td>0.10†</td>
</tr>
</tbody>
</table>

*Data are given as mean (SD) unless otherwise indicated. SDS indicates sociodemographic status; CHP, child health problem; BSI, Brief Symptom Inventory; FAD, Family Assessment Device; and IOF-G, Impact on Family-General Scale.
†P < .01.
‡P < .05.
related to child attachment, a more negative impact of the child’s health on the family, and higher rates of both child-related family stress and adverse family outcomes. These differences were found even when adjusting for the effects of sociodemographic status. The results are consistent with previous reports of negative family outcomes in young children with VLBW, and suggest that family sequelae persist into the school-age years.

Family sequelae were also related to the extent of neonatal medical risk within the VLBW groups. Specifically, parents of children with VLBW at high neonatal medical risk reported more adverse outcomes than did parents of children at low risk. The latter findings, which are in keeping with studies of family outcomes in younger children with VLBW, suggest that family sequelae are most likely for the least mature and most medically compromised infants.

Further support for a gradient of family sequelae was provided by the absence of significant differences in outcome between the 750 to 1499 g group and full-term group and by the fact that rates of adverse family outcomes for the 750 to 1499 g group fell between those for the less than 750 g group and full-term controls. Because several children in the 750 to 1499 g group were at high neonatal medical risk, we interpret the lack of differences between the 750 to 1499 g group and full-term group as reflecting the lower overall biological risk in this group relative to the less than 750 g group. Thus, families of some children in the 750 to 1499 g group may be adversely affected, but sequelae in this group may be less pervasive and more difficult to detect than in families of children whose birth weights were less than 750 g.

Our findings also confirm the importance of considering sociodemographic status in evaluating family sequelae. Several outcomes were poorer in sociodemographically disadvantaged families than in more advantaged families. In addition to the direct effects of sociodemographic status on family outcomes, this factor moderated the association between neonatal medical risk and the negative impact of the child’s health on families as measured by the IOF-G. The negative effect of high versus low neonatal medical risk on this outcome was evident only in the advantaged families. This same pattern of findings has been observed in studies of child outcomes of low birth weight, and suggests that impact of children with VLBW on families may have been obscured by other family stressors.

Despite persisting family sequelae, nonadverse outcomes were common even in the less than 750 g group and in the subset of children with VLBW at high neonatal medical risk. Moreover, group differences were not observed for measures of parent psychiatric symptoms or family functioning. These results parallel findings from past studies showing that most families adjust successfully or that problems in these areas were to be expected. Sources of family stress included concerns about both the children (self-esteem, acceptance by peers, the future) and their impact on family members (need for child supervision, altered family routines). These concerns are similar to those identified in studies of children with other chronic conditions, and they illustrate the special challenges faced by the families of some children with VLBW.

The most likely reason for the negative effects of VLBW or high neonatal medical risk on families is that parents were burdened by birth-related problems in the child’s health and development. A further possibility is that, although parent distress during the neonatal period may have resolved, this distress had longstanding effects on the family and its relationship with the child. These effects, in turn, may have led to family adversity. Family stresses and dysfunction may also have had negative influences on the child’s psychosocial development, thus contributing to negative bidirectional relationships between family and child outcomes. Thus, both environmental factors and the child’s neurodevelopmental impairments may explain long-term family sequelae.

Study limitations include reliance on parent self-report and assessment of only 1 family member. Direct observation of the family environment and family interactions, together with outcome data for other family members, would have provided a more comprehensive assessment of outcome. The disproportionate attrition from our original sample of families of lower sociodemographic status, which mirrors a trend seen in other long-term follow-up studies, also raises questions about the generalizability of our findings. Finally, only a small amount of the variability in family outcomes was accounted for by birth weight, neonatal medical risk, and sociodemographic status. Families are undoubtedly influenced by many factors that were not considered in our analyses. Despite these weaknesses, the less than 750 g group is 1 of the largest regional cohorts to be assessed at school age. The attrition rate was relatively low and sociodemographic status was taken into account in analysis.
More research is needed to explore longer-term family adversity and the interrelationships of child and family outcomes. Follow-up of our sample of children with VLBW has not demonstrated decreases in child morbidity with time.14,18 Stresses on families, therefore, are not likely to diminish with age and may even increase as progressively greater demands are made on children’s cognitive skills and independent functioning.43 Other avenues for future research are to examine prospectively the nature of the parent-burden and parent-child relationships in greater detail, and to identify family characteristics that moderate risks for poor family outcomes.10,14 For example, the risks for family sequelae may be lessened when friend- or spouse-support is high or when families have access to counseling resources. Conversely, risks may be heightened in single-parent households or in families with non-child–related stresses.5,9,35

The enduring adversity experienced by some families of children with VLBW supports the need for careful monitoring of family outcomes and for services aimed at improving family support systems and the family environment.3,34,35 Given the relationship between ongoing functional health problems and family adversity, assisting parents in managing child behavior and promoting the child’s development may be a critical component of family interventions.

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REFERENCES