

Parenting Very Low Birth Weight Children from Birth to Adolescence

Largely because of improvements in medical technologies, more low birth weight infants are surviving and living into adulthood. However, many of these children and youth have long term functional disabilities that have raised concerns about how best to care for low birth weight children. In addition to understanding the effects of low birth weight on children themselves, researchers are increasingly investigating the effects of low birth weight on parenting and parental well-being.

Very low birth weight (VLBW) refers to infants who are born weighing less than 1500 grams. These births are becoming increasingly common because of advances in neonatal care and the ability to manage high risk pregnancies. More than 63,000 very low birth weight children are born each year in the United States.ⁱ There has been intense scholarly interest in the outcomes for these children. Research has demonstrated that they have higher rates of disabilities and impairment, including neurodevelopmental impairments, learning disabilities, mental retardation and attention disorders.^{ii, iii, iv, v}

There has been considerably less research on the impact of VLBW on families, especially as children get older. In fact, there are only a small number of studies of parental outcomes of VLBW children beyond the immediate postpartum period, and therefore little information on the longitudinal trajectory of parental coping and stress or on

factors contributing to stress over time.^{vi} Understanding parents' experiences is important for parental and child well-being. While it is known that the birth of a VLBW infant presents challenges for families, less is understood about exactly how parents adapt to these challenges. For example, it is known that children's behavioral and cognitive outcomes are associated with factors influenced by low birth weight such as family stress, financial burden, maternal psychological well-being and maternal coping strategies. Mothers whose children are born VLBW experience more psychological distress, particularly depression and anxiety, than mothers whose infants are born at full-term.^{vii} Additionally, parenting may be affected by low birth weight because the strains of parenting are exacerbated for parents of VLBW infants.^{viii}

More research is necessary to understand how parenting, parental stress and coping change over time, as well as how maternal psychological distress, and its effects on parenting, may affect children's health and well-being. Very few studies address the longitudinal impact of low birth weight on parental stress and coping. Researchers from Case Western Reserve University are working to address this gap. Dr. Lynn Singer and colleagues have conducted the first prospective, controlled study to investigate the relationship between maternal stress and parenting a low birth weight child from birth to adolescence.

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METHODS

For this longitudinal study, mothers of very low birth weight infants were interviewed at seven different points in time beginning when the child was one month old and ending when the child was age fourteen. Both high and low risk VLBW children were recruited for this study to allow for comparison. High risk children were those who had a diagnosis of bronchopulmonary dysplasia (BPD), weighed less than 1500 grams at birth, required oxygen supplementation for more than 28 days because of lung immaturity at birth, and showed evidence of chronic lung disease. Low risk VLBW children were those who did not have a diagnosis of BPD, required less than 25 days of oxygen supplementation, and weighed less than 1500 grams at birth. Each high risk child was matched with a low risk VLBW child who was similar in terms of age, race and socioeconomic status. For additional comparison, infants who were carried to term and not VLBW were also recruited. A total of 315 children participated: 113 high risk VLBW, 80 low risk VLBW and 122 term.

At each of the seven visits, mothers completed the *Parenting Stress Index*, which is an instrument that measures parents' perceptions of stresses associated with being a parent. In addition, an *Impact on*

Family Scale was used to understand the effects on the family of caring for a child with a chronic illness or disability. Other instruments measured mothers' social support, social isolation, coping and vocabulary IQ. Children were administered developmental and IQ assessments at each of the visits.

RESULTS

The results of this first study of the long-term effects of VLBW on parenting and parental well-being indicate that giving birth to a very low birth weight infant affects mothers in a number of areas, and that these effects change over time as the child develops to adolescence.

Maternal Education

The research demonstrated that mothers who had term infants increased their educational attainment at a faster rate than mothers who had VLBW children such that, by the time the children had reached 14 years of age, mothers of term infants had achieved more years (14.28 vs. 13.65, $p < .035$) of education than had VLBW mothers. This finding is important because educational level is associated with other benefits such as higher socioeconomic status and self esteem.

Financial Impact

Mothers of high risk VLBW children reported experiencing higher levels of financial strain than mothers in the other two groups. These mothers reported both higher negative financial impact and a greater negative effect on the family in general than did mothers with low risk VLBW children.

Social Support

Interestingly, social support was shown to buffer these effects. Mothers with high risk VLBW children who reported high levels of social support did not differ in terms of negative impact from mothers in the low risk or term groups. Mothers of high risk VLBW children who had low levels of social support reported more negative strain than other mothers.

Maternal Stress

When asked about the stress of parenting a child, mothers of high risk VLBW children reported higher levels of stress, especially until age three. As children got older, these differences decreased until they were no different from mothers of term children.

Some factors were related to maternal stress. For example, socioeconomic status was negatively associated with maternal stress levels. While most mothers reported a decrease in stress as children got older, mothers with low socioeconomic status did not experience this reduction. Additionally, lower levels of social support and certain coping styles, specifically mental disengagement, were also associated with higher maternal stress, while higher IQ scores and social support were associated with mothers reporting having greater control over their situations.

Interestingly, the stress of mothers with term children increased over time, while that of mothers of low risk VLBW children decreased. This may be because VLBW children tend to be more avoidant of risk in adolescence and less likely to engage in conflict with their parents than term children. Indeed, mothers of low risk VLBW children did not have worse outcomes than term mothers in any area except educational attainment, and by adolescence, low risk VLBW mothers reported less stress than term mothers.

Maternal Coping

Greater feelings of positive mastery, the coping strategies used by mothers to deal with stress associated with parenting, were found to be associated with higher maternal IQ and social support. They were also found to change over time. From birth until the child reached three years of age, mothers did not show differences in the coping methods used. However, as children got older, mothers of high risk VLBW children showed less use of avoidant coping mechanisms, such as denial or mental disengagement, which provide distance from the reality of the situation. These changes in the use of coping strategies suggest that mothers were adapting to parenting stress. The authors also suggest that parents of VLBW children, who have pressing medical and caregiving needs, were simply unable to avoid the reality of their children's situation through such coping strategies as denial.

Additionally, positive mastery was found to be higher among mothers of VLBW children at 14 years of age compared to mothers of children who were born at term. Of note, this difference seems to be related to higher feelings of stress among term mothers, and an associated decrease in feelings of positive mastery as children get older which was not observed in mothers of high or low risk VLBW children.

CONCLUSIONS

This study provides important insights into the effects of having a VLBW child on maternal stress and parenting. In particular, it demonstrates that parental stress is affected by a range of factors and varies with the child's developmental age. This research is an important contribution to our understanding of the effects of VLBW on children and families. It illustrates the challenges that families of VLBW children face while also demonstrating that the majority of parents are able to adapt to the challenges of parenting a VLBW child.

IMPLICATIONS FOR POLICY AND PRACTICE

The longitudinal research of Dr. Singer and colleagues has important implications for policy and practice related to low birth weight infants and their families. There has been much concern about the increase in low birth weight, the outcomes for these children and the challenges they present to families.

The research results show that VLBW birth has significant and enduring effects on maternal educational attainment. However, particularly among those with low risk VLBW children, maternal psychological outcomes were not worse than for those whose children were full-term, particularly over time and for those with strong social support networks. Furthermore, findings show that financial stress and the total stressful impact of the child on the family decreased over time for all mothers but remained greater for mothers of high risk VLBW children especially when they experienced low levels of social support. While many parents do adapt to parenting a VLBW child, there are certain periods when parenting stress is particularly high. For example, immediately after birth

and through the first three years seem to be particularly vulnerable times for parents.

These results suggest some areas for improving programs to support families of VLBW children. In addition to traditional neurodevelopmental programs, family and psychological programming may assist parents with VLBW children to deal with the stresses of parenting, particularly when children are young. Resources to help families build social support could also be beneficial. This research can be used to provide a better understanding of the challenges these families face at different developmental periods. It will also be important to educate health care providers about the role of coping mechanisms and social supports in modifying stress. This knowledge could be beneficial to pediatricians and school staff who come into contact with these families on a regular basis. For example, with this knowledge, pediatricians, school teachers, or counselors who monitor the outcomes of VLBW children might also be able to refer parents to needed programs and supports.

Parenting stress is a particularly important issue, not only for its effects on the well-being of parents, but also for its implications for child outcomes. More research is needed into the best ways to support parents and to help them develop adaptive coping mechanisms during the critical times identified by Dr. Singer and colleagues. In addition, while Dr. Singer's research provides insight into the stresses and challenges for mothers, more research should explore the specific challenges of fathers. Follow-up in late adolescence is also warranted.

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For more information, please see the papers listed below.

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