

## Very Preterm Birth Influences Parental Mental Health and Family Outcomes Seven Years after Birth

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**Objective** To evaluate the long-term influence of very preterm birth on parental mental health, family functioning, and parenting stress at age 2 and 7 years.

**Study design** Participants were 183 children born very preterm (<30 weeks gestation; n = 148 families) and 69 term-born children (n = 66 families). When children were age 7 years, parents were assessed based on the Hospital Anxiety and Depression Scale, the Family Assessment Device, the Parenting Stress Index, and the Social Support Questionnaire. Similar measures were evaluated at age 2 years.

**Results** When the children were age 7 years, parents of the very preterm-born children were more likely to report moderate to severe anxiety symptoms ( $P = .03$ ), higher levels of depression symptoms ( $P = .03$ ), poorer family functioning ( $P < .05$ ), and higher levels of parenting stress ( $P < .001$ ) compared with parents of the children born at term. Group differences in parenting stress and family functioning persisted after adjustment for social risk and child neurodevelopmental disability. There was strong evidence of a relationship between family functioning and parent-related stress at age 2 and 7 years ( $P < .001$ ), but little evidence that parental mental health problems at 2 years were predictive of anxiety ( $P = .15$ ) or depression ( $P = .28$ ) at 7 years for parents of very preterm children.

**Conclusion** These findings demonstrate that very preterm birth has a negative influence on parent and family functioning at 7 years after birth, which for some families is consistent with their functioning at 2 years. These results have implications for the support required by parents of very preterm children. (*J Pediatr* 2014;164:515-21).

Very preterm birth consistently increases the risk for impairments in neurosensory, physical, social-emotional, and academic functioning later in life.<sup>1-4</sup> Research on the ongoing influence of very preterm birth on parents and the family is mixed, and comparisons between studies are difficult owing to differences in selection criteria and era of birth. Parenting, and more generally the family environment, have a strong influence on child development,<sup>5</sup> and parental mental health problems are linked with poorer outcomes for children,<sup>6</sup> including those born preterm.<sup>7-9</sup>

Previous studies have reported higher levels of parental distress, stress, and depression and anxiety; greater family burden; and poorer family functioning in parents of very preterm or very low birth weight (VLBW; <1500 g) children compared with parents of term born/normal birth weight ( $\geq 2500$  g) children in infancy and early childhood,<sup>9-16</sup> although not all studies found evidence of group differences across all areas of family outcome.<sup>16,17</sup> Few previous studies have examined parent and family outcomes after early childhood. Two studies of parental mental health in families with VLBW or extremely low birth weight (ELBW; birth weight <1000 g) children have reported little evidence of group differences in psychological distress at school age or early adulthood,<sup>18,19</sup> although 1 of these studies found that having a child with bronchopulmonary dysplasia had a negative impact on the family.<sup>19</sup> In 1 study, mothers of ELBW adolescents reported that their child's health influences their own emotional health and marriage (both negatively and positively), and was a major factor in marriage breakdown.<sup>20</sup> In contrast, other studies found little evidence that preterm or ELBW/VLBW birth influences parenting stress or family functioning during adolescence<sup>21,22</sup> or family functioning in early adulthood.<sup>18</sup>

Overall, having a very preterm or ELBW/VLBW child appears to influence parental mental health, stress, and family functioning during early childhood. Although the strength of the relationship diminishes after this time, few previous studies have followed families after early childhood or have included cohorts of very preterm children containing many children born at <28 weeks gestational age who would not have survived in earlier eras.

In the present study, we evaluated the longer-term influence of very preterm birth on the family. We predicted that poorer parent and family outcomes for those with very preterm children would be seen at 7 years after birth compared

ELBW	Extremely low birth weight
FAD	Family Assessment Device
FSIQ	Full-Scale IQ
HADS	Hospital Anxiety and Depression Scale
PSI	Parenting Stress Index
SSQ6	Social Support Questionnaire, short form
VLBW	Very low birth weight

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with families with term-born children. Importantly, these outcomes were examined taking into account the influence of social, medical, and developmental factors, given that these factors are likely to contribute to parent and family outcomes.<sup>23,24</sup>

A final aim of the study was to examine the relationships between 2-year and 7-year parent and family outcomes. We expected to see continuity over time, so that parents and families in distress at 2 years were more likely to be experiencing stress at 7 years.

## Methods

Participants were families from the Victorian Infant Brain Studies cohort, which included 224 infants born at <30 weeks gestational age or with a birth weight <1250 g at the Royal Women's Hospital in Melbourne between 2001 and 2003 (very preterm group). A comparison group of 77 full-term children (born at >36 weeks' gestation) were recruited at birth from the Royal Women's Hospital maternity wards between 2001 and 2003 (n = 46) or at age 2 years from maternal-child health centers in 2004 (n = 31), both in Melbourne, Australia. Outcomes at age 2 and 5 years have been reported elsewhere.<sup>9,16,25</sup> At age 7 years, corrected for prematurity, families were contacted, and questionnaires eliciting information on parent and family functioning were completed while the children completed a neuropsychological and developmental assessment. This longitudinal study was approved by the Human Research Ethics Committees of the Royal Women's Hospital and the Royal Children's Hospital, and informed written consent was obtained from parents of all children.

At age 2 years, the total score from the General Health Questionnaire<sup>26</sup> was used to assess parental mental health problems. The General Health Questionnaire is a 28-item parent report measure assessing symptoms of mental health problems in 4 areas: cognitive symptoms of depression, anxiety symptoms, somatic symptoms, and social dysfunction. The overall score served as a marker of mental health problems owing to the overlap in symptoms among the 4 areas that relate to different psychiatric diagnoses. Higher overall scores represent greater symptom severity (range for total score, 0-84), and a score of  $\geq 24$  was considered to indicate clinically significant symptoms of mental health problems.<sup>27</sup>

At age 7 years, parental symptoms of anxiety and depression were measured using the Hospital Anxiety and Depression Scale (HADS).<sup>28</sup> The HADS has 2 subscales, anxiety (7 items), and depression (7 items). Items are scored on a 4-point scale (ranging from 0, not at all to 3, most) and then summed to generate total scale scores. Scores were classified as follows: 0-7, normal; 8-10, mild; 11-15, moderate; or 16-21, severe anxiety/depression. For the present study, scores in the moderate to severe range (11-21) were classified as "clinically significant." There is evidence suggesting that the HADS performs well in assessing the severity of anxiety and depression in both primary care patients and the general population.<sup>29</sup>

Social support was measured using the short form of the Social Support Questionnaire (SSQ6).<sup>30</sup> The SSQ6 assesses parents' perceived availability of and satisfaction with their social support on 6 items, and has 2 scales: social support number (sum of the number of people listed for each item divided by 6; range, 0-9) and social support satisfaction (sum of satisfaction score for each item divided by 6; range, 1-6). Higher scores represent a higher number of social supports and greater satisfaction with social support. The SSQ6 has acceptable test-retest and internal reliability.<sup>30</sup>

The Parenting Stress Index (PSI), long form,<sup>31</sup> was completed by parents at 7 years and provided a measure of stress associated with parenting. Only the total parent-related stress index of this scale was completed at 2 years, and the total parent, total child, and overall scales were calculated at 7 years. The PSI provides scores for overall level of parenting stress, total parent-related stress (ie, stress from personal distress, parent-child interaction, and child's behavioral characteristics), and total child-related stress (ie, stress related to child qualities that make it more difficult for parents to fulfill their parenting role). These scores are generated from 14 individual subscales (eg, child adaptability, child mood, parent competence, parent isolation). Parents indicate the degree of agreement/disagreement to statements using a 5-point Likert scale. Higher scores indicate more stress, with score ranges of 131-320 for overall total stress, 69-188 for total parent-related stress, and 50-145 for total child-related stress. The PSI has been found to have acceptable test-retest reliability and construct validity.<sup>31</sup>

Family functioning was assessed using the Family Assessment Device (FAD)<sup>32</sup> at both time points (2 and 7 years). The FAD has 7 domains: problem solving, communication, roles, affective responsiveness, affective involvement, behavioral control, and general functioning. Parents completed this 60-item questionnaire by indicating their level of agreement or disagreement on a 4-point Likert scale for each item. The sum of scores divided by the number of items answered provides a score ranging from 1 (lower scores representing healthy family functioning) to 4 (higher scores representing unhealthy family functioning) for each domain. The FAD has acceptable reliability and concurrent and discriminant validity.<sup>32,33</sup>

Additional data on family variables and neurodevelopment disability were also collected at 7 years. Familial social risk was calculated from a composite measure assessing 6 social risk factors (family structure, education of primary caregiver, occupation and employment status of primary income earner, language spoken at home, and maternal age at birth), as used previously.<sup>9,16</sup> Each domain was scored on a 3-point scale from 0 (lowest risk) to 2 (highest risk), and the scores were summed to give a total score of 0-12.

Finally, neurodevelopmental disability was defined as having at least 1 child (in the case of twins and triplets) with a score <70 on the Full-Scale IQ (FSIQ) of the Wechsler Abbreviated Scale of Intelligence,<sup>34</sup> severe cerebral palsy (ie, not walking), blindness (visual acuity worse than 20/200 in the better eye), or significant hearing loss (requiring a hearing aid or worse).<sup>35</sup>

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