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Parenting Stress and Childhood Impairment

As neonatal intensive care has evolved, mortality and serious morbidity in survivors were the initial concerns and remain issues still today for those children born at borderline viability.¹ It was also recognized that children who survive without major morbidities still have a wide variety of high frequency but less-severe impairments of cognitive, behavioral, and motor function.² More recently, we have become equally concerned that simply measuring performance against normative data or comparison children born at term may give a fallacious view of outcome that is unnecessarily over-pessimistic. Recent studies have concerned outcomes for children and their families in functional terms that reflect the impact that these impairments have on day-to-day life. This in turn may affect our own perceptions of these conditions.

There is little doubt that taking home a child who has been through the whole panoply of neonatal intensive care after very preterm delivery is a daunting task, even to well-adapted mothers. The stress may be enhanced when there is evolving disability and will persist when there is serious childhood impairment. In this issue of *The Journal*, 2 groups report studies of parenting stress and wellbeing in children with or at high risk of childhood impairment and their families.

Majnemer et al report a study of the factors that determine quality of life in school age children with cerebral palsy.³ The risk of this condition is often used to guide intensive care decisions, and thus it is valuable to detail what impact the associated disability has on the child or family and which factors determine the extent of this impact. This group of children was thought to be representative of a complete population of children with cerebral palsy from the case list of 1 pediatric neurologist (and comprised a high proportion of

preterm children), but the associated motor deficit was classed as mild (GMFCS level 1) in nearly half the children, half were attending mainstream school, and only 28% had IQ scores >2 SD below the mean. This is far from the commonly held outcome when a diagnosis of cerebral palsy is first broached with parents. The questionnaires used give a broad view of function in a wide range of dimensions for child and family. In particular, physical wellbeing might be easily predicted from the degree of limitation of activity (and is reassuringly well assessed with the simple gross motor function classification system), but psychosocial wellbeing was more dependent on associated behavioral problems, an area which might be amenable to modification and thus enhance quality of life.

Notable among the measures that they report is the observation that parenting stress was high in nearly half of the families. Alongside this paper is a report from a longitudinal study of maternal stress and coping for families after very low birthweight (VLBW) infants are born from Singer et al.⁴ They observed 3 groups of children from birth: "high risk" VLBW children with chronic lung disease, "low risk" VLBW children, and term comparators. This is an important study because it charts the evolution of family environment from birth. It presents a mixed picture—mothers of VLBW children reported fewer family strains than the comparator group and less parent-child conflict, but perceived more concern for their child's health state and more

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VLBW Very low birthweight

personal strain. The study was somewhat confounded by the additional stress of having multiple birth and the increase in parenting stress associated with a low IQ in the child, which was more common in the VLBW group and more so in the “high risk” group. The authors do not tell us how many of these children had cerebral palsy. Furthermore, the mothers of the “high-risk” VLBW children had made positive adaptation from the earlier assessment at 2 years postpartum.

We have recently attempted to support maternal coping strategies and relieve maternal stress in families with very preterm babies by using a targeted nurse-led intervention during the neonatal stay and during the period of transition to home. Sadly, and despite a moderately intensive intervention, we were unable to demonstrate significant benefit in parenting stress at 3 months post-term age.⁵ The stresses and stressors are maximal in the periods closest to birth when uncertainty is greatest, particularly as the parent adapts to the child’s homecoming, but are easily measurable at 3 years out, as Singer et al have shown.⁶ In this period, however, they demonstrated that adaptive mechanisms came into play; although stress scores remained high, coping strategies improved. In middle childhood, this period of adaptation continues.

Although a range of interventions are targeted at maternal stress during the period of intensive care, it is often difficult to know whether they produce lasting benefits after the period of intervention. It is clear that further studies are necessary to define what makes a good support strategy after preterm birth. A systematic review of studies that attempted to influence maternal sensitivity and attachment has arrived at the counter-intuitive conclusion that relatively infrequent in-

terventions commencing later in the first year seem to be more effective than earlier, more intense interventions.⁷

We still have a lot to learn about the key goal of relieving parenting stress—this could be 1 route by which we might enhance the outcome of this vulnerable group of children—but it is also clear from these papers that disability and non-optimal childhood outcomes, which are an ever present feature of outcome after very preterm birth, are important determinants of parenting stress despite the impressive adaptation that occurs during early childhood.

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