

## ORIGINAL ARTICLE

## Parental stress in families of 2 year old extremely low birthweight infants

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**Objective:** To compare the parental stress in the families of 2 year old extremely low birthweight (ELBW) infants with that in control families, and to compare the stress of mothers with that of fathers.

**Methods:** The study population included all parents of ELBW infants (birth weight < 1000 g and gestational age at least 22 gestational weeks) born between 1 January 1996 and 31 December 1997 in Helsinki University Hospital and followed at the hospital's neuropaediatric department. The parents of full term, healthy infants born subsequent to each ELBW infant were eligible for the control group. The Swedish Parenthood Stress Questionnaire (SPSQ) translated into Finnish was completed by parents during the neurological assessment visit at 2 years of age.

**Results:** No significant differences were found in total SPSQ or subscale scores when mothers of ELBW infants were compared with control mothers. Nor did the scores of fathers of ELBW infants differ from the scores of control fathers. However, in the comparison of all mothers with all fathers, several differences were found: mothers indicated significantly more distress than fathers with respect to role restriction, incompetence, and spouse relationship problems, and fathers indicated significantly more distress on the social isolation subscale.

**Conclusion:** The study shows that, although the birth of an ELBW infant is a stressful event for parents, most parents seem to have recovered well by the time the child has reached the age of 2. In both control families and those of ELBW infants, the overall stress of mothers seemed to be higher than that of fathers.

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○wing to advances in perinatal and neonatal care, the survival of prematurely born infants, especially those with extremely low birth weight (< 1000 g), has improved significantly during the last few decades.<sup>1–4</sup> In spite of the improved survival, the percentage of extremely low birth weight (ELBW) infants with adverse neurological outcome has remained constant, resulting in a growing number of disabled children.<sup>5–6</sup> The birth of an ELBW infant is considered a stressful event for the parents.<sup>7–9</sup> Neonatal intensive care may be frightening, with worries about the infant's survival and disability.<sup>9–11</sup> Parents may also feel confused because of the changed parenting role during the long hospital stay.<sup>10</sup> After discharge from hospital, during the first few years, the daily care of an ELBW infant is more time consuming and laborious, with feeding difficulties, special nourishment requirements, and medication. Uncertainties about the future may continue after the neonatal period, as the child grows and confronts new problems: in addition to common sensory-neural disabilities, ELBW infants have a high risk of slight delays in motor and verbal development, behavioural and emotional problems, and minor learning disabilities.<sup>12</sup>

In this study, we aimed to compare parental stress in families of ELBW infants with that in control families, and also to compare the stress experience of mothers with that of fathers when the infants had reached 2 years of corrected age. All infants in the patient group needed prolonged intensive care postnatally and close developmental follow up after the discharge. Our hypothesis was that parents of ELBW infants would still, two years after the initial intensive care period, feel more stress and have more difficulties in relationships with their child, spouse, and friends than parents of full term infants.

## SUBJECTS AND METHODS

## Study population and controls

Of the 109 liveborn infants born in Helsinki University Hospital from 1 January 1996 to 31 December 1997, 86 (79%) were alive at the age corresponding to 40 gestational weeks, and 78 infants from 74 families (four twin pairs) were seen in the same hospital at the corrected age of 24 months. Of the remaining eight infants, two had died and six families lived outside the Helsinki region. Four families were not eligible for the study because of language or recruitment problems. The entire study group consisted of families of 74 ELBW infants. The infants in the study population form a subgroup in a national cohort, which was followed until the corrected age of two years.<sup>13–14</sup>

The control group consisted of 75 families of full term infants born after each ELBW infant in the same hospital (in 1996 the subsequent infant, in 1997 two subsequent children). The inclusion criteria for control infants were: gestational age  $\geq$  37 weeks, no need for medical care during the first three days, native language of the family Finnish, Swedish, or English.

A national ELBW infant register, established in 1996, included the background information of the ELBW infants and their controls. This information was cross checked with the national birth register<sup>15–16</sup> (table 1).

Infants with birth weight below  $-2$  SD according to Finnish intrauterine growth charts were classified as small for gestational age.<sup>17</sup> Gestational age was estimated on the basis of ultrasound examination before the end of 20 gestational weeks (96% of the ELBW infants and 89% of the control

**Abbreviations:** ELBW, extremely low birthweight; SPSQ, Swedish Parenthood Stress Questionnaire

**Table 1** Baseline characteristics of the extremely low birthweight (ELBW) infants and their controls

	ELBW infants (n=70*)	Controls (n=75)	p Value
Mother's mean age (years)	32.2	32.0	0.820
Upper social classes 1–2	45 (64)	62 (83)	0.012
Lower social classes 3–4	25 (36)	13 (17)	0.012
Mother's smoking	12 (17)	9 (12)	0.379
Primiparity	41 (58)	26 (35)	0.004
Average number of children in family	0.67	0.88	0.164
Response rate of mothers	56 (80)	66 (88)	0.137
Response rate of fathers	23 (33)	38 (51)	0.039
Birth weight (g)	780 (447–995)	3671 (2530–5250)	<0.001
Gestational age (weeks)	27.1 (23.7–32.6)	39.9 (37.3–42.1)	<0.001
Assessment age (years)	2.24 (2.12–2.56)	2.22 (1.91–2.73)	0.524
Male	37 (50)	39 (52)	0.807
SGA	35 (47)	1 (1)	<0.001
Multiple pregnancy infants	16 (22)	2 (3)	<0.001
Bayley scores <70	1 (1)	0	0.497
Blindness at the age of 2 years	0	0	
Cerebral palsy at the age of 2 years	3 (4)	0	0.245

Values are either number (%) or mean (range).  
\*n=74 for infant parameters (birth weight, etc).  
SGA, Small for gestational age.

infants) or on the last menstrual period. Standard diagnostic criteria were used for blindness.<sup>18</sup> Cerebral palsy was defined at the age of 18 months as a non-progressive motor impairment with brisk tendon reflexes, positive Babinski's sign, and persistent primitive reflexes. Allocation of social class was based on mother's education or occupation, and four classes were used.<sup>19</sup> In the analysis, the upper two and lower two classes were combined.

## Methods

At the age of 24 months corrected for gestational age, a neurological examination and developmental age assessment with Bayley Infant Scale 2nd edition<sup>20</sup> were performed on ELBW infants at the neuropaediatric department of Helsinki University Hospital. During the visit the parents of ELBW infants were invited to join the study and to fill in the Swedish Parenthood Stress Questionnaire (SPSQ)<sup>21–22</sup> translated into Finnish. The SPSQ is based on parts of the Parent Domain of the American Parenting Stress Index.<sup>23</sup>

Control families were invited to join the study by letter and, after parental consent, the child was assessed at the age of 2 years with the same developmental methods as the ELBW children. A total of 75 families (60%) out of 126 invited were studied, and all accompanying parents completed the questionnaire during the visit. The control families who agreed to participate did not differ from those who did not with regard to mother's age, social class, mother's smoking habits, mean number of previously born children in the family, children's sex, mean birth weight, and gestational age, and number of multiple pregnancy infants.

The SPSQ contains 34 items divided into five subscales designated incompetence, role restriction, social isolation, spouse relationship problems, and health problems. Each item is scored on a Leikert scale from 1 to 5, the highest score indicating problems or difficulties in a particular area of the parent-child relationship.<sup>22</sup> Mean scores were calculated for each subscale and for the whole SPSQ. The test method was standardised and validated in Sweden,<sup>21–22–24</sup> where the culture and social structure closely resemble those in Finland. The internal consistency of the translated inquiry form was tested by calculating Cronbach's  $\alpha$  coefficients for all subscales and the total SPSQ score (table 2). All coefficients except one were above 0.65, showing that satisfactory internal consistency in most subscales had been achieved.

All statistical analysis was performed using the SPSS program. Pearson's  $\chi^2$  test, Fisher's exact test, and Student's *t*

**Table 2** Reliability coefficients (Cronbach's  $\alpha$  based on average interitem correlation) for the total SPSQ and the subscale scores in parents of premature infants (ELBW group) and parents of control infants (control group)

	$\alpha$ coefficients	
	ELBW group (n=79)	Control group (n=104)
Total SPSQ score	0.89	0.86
Incompetence	0.86	0.80
Role restriction	0.78	0.77
Social isolation	0.70	0.67
Spouse relationship problems	0.81	0.75
Health problems	0.55	0.69

SPSQ, Swedish Parenthood Stress Questionnaire.

test were used as appropriate to distinguish differences between the groups.  $p < 0.05$  was considered significant.

## RESULTS

The response rate for mothers was acceptable and that for fathers was low in both groups. No differences were found in any of the stress subscales between the mothers of ELBW infants and the control mothers, nor did the subscale or total SPSQ scores differ between the fathers of ELBW infants and the control fathers (table 3).

In the families of ELBW infants, the scores of the mothers did not differ significantly from those of the fathers, whereas the control mothers had higher scores than the control fathers on the role restriction subscale ( $p = 0.021$ ) (table 4). The control mothers seemed also to experience more distress on the incompetence subscale, and the control fathers on the social isolation subscale, but neither of the differences reached full significance ( $p = 0.059$  and  $p = 0.052$  respectively; table 4). As the mothers and fathers in the two groups did not seem to differ from each other, the comparisons were made between all mothers and all fathers; several significant differences were found. In the subscales of incompetence (2.20 *v* 1.95;  $p = 0.011$ ), role restriction (3.37 *v* 3.04;  $p = 0.008$ ), and spouse relationship (2.39 *v* 2.10;  $p = 0.018$ ), mothers had higher scores than fathers, and fathers scored higher than

**Table 3** Comparison of SPSQ total and subscale scores between parents of extremely low birthweight infants (ELBWI) and controls

	N	Total SPSQ scores	Subscales				
			Incompetence	Role restriction	Social isolation	Spouse relationship	Health problems
ELBWI mothers	56	2.41 (0.57)	2.19 (0.70)	3.32 (0.76)	1.97 (0.62)	2.46 (1.00)	2.10 (0.77)
Control mothers	66	2.43 (0.48)	2.20 (0.64)	3.41 (0.73)	1.91 (0.62)	2.32 (0.93)	2.34 (0.88)
p Value		0.852	0.933	0.473	0.591	0.446	0.120
ELBWI fathers	23	2.25 (0.51)	1.90 (0.62)	3.03 (0.84)	2.12 (0.66)	2.10 (0.67)	2.29 (0.67)
Control fathers	38	2.27 (0.40)	1.98 (0.44)	3.05 (0.79)	2.15 (0.54)	2.10 (0.60)	2.20 (0.72)
p Value		0.866	0.582	0.920	0.836	0.979	0.606

Values are mean (SD).

SPSQ, Swedish Parenthood Stress Questionnaire.

**Table 4** Comparison of SPSQ total and subscale scores between mothers and fathers

	N	Total SPSQ scores	Subscales				
			Incompetence	Role restriction	Social isolation	Spouse relationship	Health problems
ELBWI mothers	56	2.41 (0.57)	2.19 (0.70)	3.32 (0.76)	1.97 (0.62)	2.46 (1.00)	2.10 (0.77)
ELBWI fathers	23	2.25 (0.51)	1.90 (0.62)	3.03 (0.84)	2.12 (0.66)	2.10 (0.67)	2.29 (0.67)
p Value		0.259	0.081	0.146	0.361	0.074	0.307
Control mothers	66	2.43 (0.48)	2.20 (0.64)	3.41 (0.73)	1.91 (0.62)	2.32 (0.93)	2.34 (0.88)
Control fathers	38	2.27 (0.40)	1.98 (0.44)	3.05 (0.79)	2.15 (0.54)	2.10 (0.60)	2.20 (0.72)
p Value		0.099	0.059	0.021	0.052	0.142	0.395

Values are mean (SD).

SPSQ, Swedish Parenthood Stress Questionnaire; ELBWI, extremely low birthweight infants.

mothers on the social isolation subscale (2.14 *v* 1.94; *p* = 0.040). The health problem scores did not differ between the groups (2.23 *v* 2.23; *p* = 0.991).

## DISCUSSION

Only a few validated methods have been used to measure the stress of parenting. The Parenting Stress Index (PSI) designed by Abidin<sup>23</sup> has been used in different study populations<sup>25–27</sup> and has been considered a reliable method for measuring parental stress. The Swedish instrument, SPSQ, influenced by the PSI, has been validated and standardised,<sup>21, 22</sup> and proved sensitive and stable in finding differences in parenting problems in certain risk populations.<sup>24</sup> In our study population, the internal consistency of the full scale and five subscales was acceptable and comparable to the Swedish validation samples.<sup>22</sup>

In our ELBW infants and control group, the mothers differed significantly from each other in several background characteristics. The average social class of control mothers was higher than that of mothers of the ELBW infants. The social class distribution was based on the mother's education or occupation, factors that may have an effect on stress experienced according to previous studies, in which higher maternal education has been associated with lower parental distress.<sup>8, 24</sup> If social class had any influence on our study results, it would have caused more pronounced differences between SPSQ scores, but no difference was found. The primiparity rate was higher in families of ELBW infants, but no significant difference was found between the average number of children in families.

Lower mean birth weight, gestational age, higher incidence of multiple birth infants, and also higher incidence of various disabilities were closely related to reasons for and consequences of extreme prematurity and assumed to be different in the groups. The children's average age at the time of assessment did not differ between the groups.

Stjernqvist, in her study from Sweden, found no relation between permanent neurological injury and strong reactions in family members during the first year of life.<sup>7</sup> Parallel results have been reported by Lee *et al.*,<sup>28</sup> but the opposite was found by Singer *et al.*<sup>29</sup> and Cronin *et al.*<sup>8</sup> Recent studies have also shown that parents of ELBW infants usually graded the harm caused by the functional disability of their child less than did health care professionals,<sup>30, 31</sup> and most parents supported life saving interventions in all infants at the limit of viability regardless of the outcome.<sup>28, 31</sup> In the present study population, apparent impairments were rare (*n* = 5): no infant was blind, only one infant had mental Bayley scores below 70, three had diagnosed cerebral palsy, and two an obvious delay in speech development requiring speech therapy.<sup>14</sup> However, with so few severely disabled infants, we could not investigate the effect of apparent handicaps on parental distress.

Many studies confirm that mothers experience more distress than fathers about their premature infant during the initial period and the prolonged hospital stay and also later after discharge.<sup>8–11</sup> In the Swedish study, in which parenting stress was measured in parents seeking specialised medical assistance for their young child, fathers had lower total and four subscale scores in SPSQ than mothers.<sup>24</sup> Only on the social isolation scale were the scores similar in mothers and fathers. In our study, the total stress of mothers was higher, although not significantly so. They also showed greater distress on the subscales of incompetence, role restriction, and spouse relationship problems, and fathers on the social isolation subscale, whereas the health problem scores did not differ between the groups. When parents were divided into groups depending on whether their baby was premature or a control, the patterns were similar, but, because the groups were smaller, some of the differences were no longer significant. Perhaps fathers who accompanied their child to hospital and participated in the study felt a greater responsibility for their child than average fathers and thus may have had reduced opportunities for social activities. The results may

also refer to traditional role differentiation in which fathers seem to fulfil their main duties outside the home.

Postnatal depression is shown to be greater in mothers of preterm infants.<sup>29–32</sup> In this study, the exact number of mothers with a diagnosis of postnatal depression is not known in either of the groups, but according to previous studies the birth of an ELBW infant is considered to be a crisis for both parents.<sup>7</sup> However, our results show that after 2 years, most parents, at least, had coped well with the situation and recovered, appearing not to have any greater stress than parents of full term infants of the same age. Although this finding contradicts the results of some previous investigations,<sup>7–8</sup> similar findings have also been reported.<sup>28–33</sup>

The importance of parenting stress has been realised over the last few decades. In several studies, parental distress was found to be related to the delay in the infant's cognitive and neurological development.<sup>29–34–35</sup> Parental support and intervention programmes have been shown to reduce maternal distress and probably promote the infant's development.<sup>36–37</sup> In our study population, the parents of an ELBW infant seemed to have recovered well from the initial shock, but the group of severe handicapped infants in our study population was too small to allow detection of possible problems in that special group. As psychosocial factors seem to play an important role in the neurological development of ELBW infants, reducing or increasing the effects of the perinatal and neonatal medical risk factors, the well being of the parents must be considered an important challenge to modern neonatal and paediatric care.

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