Parenting stress in mothers and fathers of a child with a hemiparesis: sources of stress, intervening factors and long-term expressions of stress

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Abstract

Background In a substantial minority of children with a hemiparesis, motor impairments are accompanied by behavioural problems. This combination confronts parents with several persistent, frequently intense, sources of stress. At the same time, it is likely to reduce the effectiveness of psychosocial resources, such as feelings of competence, which would normally buffer the impact of the stressors.

Aim To investigate the association between motor and behavioural problems in children with a hemiparesis and symptoms of stress in their parents, with particular attention to psychosocial factors which may mediate between the child's problems and parents' symptoms of stress.

Method Questionnaires assessing the medical, functional and behaviour problems of the child, and the parents' experience of stress were completed by the mothers and fathers of 108 children with a hemiparesis who were members of the Association for the Motor Handicapped in the Netherlands.

Results Both parents reported (extremely) high levels of long-term stress significantly more frequently than parents in a normative sample. Indices of long-term stress were associated with the child's behavioural problems and, less strongly, with dysfunctionality in daily life. However, behavioural problems and dysfunctionality also reduced parents' feelings of competence and social support. A mediation analysis showed that feelings of incompetence and social isolation mediated between the child's problems and the parents' symptoms of stress. Fathers and mothers did not differ in level of reported stress, or in the associations between the child's problems and degree of experienced stress.

Conclusion Both parents of a child with a hemiparesis experience high levels of stress, which are strongly associated with feelings of incompetence and social isolation. This suggests that one focus of intervention should be the alleviation of parenting stress with particular attention to increasing perceived competence in the parenting role and reducing feelings of social isolation.

Keywords

fathers and mothers,
hemiparesis, parenting
stress

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Introduction

Many studies have found that parents of children with disabilities report higher levels of stress than parents of typically developing children (Manuel 2001; Smith *et al.* 2001; Esdaile & Greenwood 2003). Parenting stress has a negative effect on the parents' well-being, and may also impair their ability to respond constructively to their child's needs (Deater-Deckard 2005). When parents of a child with a disability experience persistently high levels of stress, the child's development is threatened not only by the disability, but also by the heightened levels of stress their parents experience. This makes it particularly important to identify signs of stress in parents of children with a disability, and to understand their association with characteristics of both child and parents. The goal of this study was to investigate parenting stress in a particularly vulnerable group, the mothers and fathers of a child with a hemiparesis.

A hemiparesis is a disorder in the control of muscle activity on one side of the body secondary to a non-progressive defect in the developing brain (Goodman & Yude 2000). Gross motor functions such as balance and the co-ordination of movements involving both sides of the body are impaired. Independent movements of the fingers of the affected hand are also impaired, leading to difficulty grasping and manipulating objects (Beckung & Hagberg 2002). The movement limitations lead to limitations in everyday activities. While 97% of children with a hemiparesis learn to walk independently, more advanced skills such as running and jumping remain difficult (Gorter *et al.* 2004). While activities requiring only one hand can be carried out by the unaffected hand, activities requiring the co-ordination of precise movements of both hands, for example, fastening buttons, remain particularly difficult (Beckung & Hagberg 2002). Depending on the degree and location of the brain damage, cognition, vision and hearing may also be impaired. Behavioural problems are also frequent. In a minority of children, they are serious enough to warrant a psychiatric classification (Goodman & Yude 2000). All parents must cope with the minor irritations and inconveniences that accompany the daily functioning of a family, and the cumulative effect of such irritations is an established source of parenting stress (Crnic & Low 2002). When motor and behavioural problems complicate routine activities of daily life, the stresses associated with minor irritations and inconveniences are likely to accumulate particularly rapidly.

A search of PsychINFO and MEDLINE databases using the terms 'hemiparesis', 'hemiplegia', 'parents' and 'stress' yielded no studies of stress in parents of children with a hemiparesis. However, three studies found higher levels of stress in mothers

of pre-schoolers with cerebral palsy (CP), the broad group of non-progressive motor impairments of which hemiparesis is one example, than in mothers of typically developing pre-schoolers (Wanamaker & Glenwick 1998; Mobarak *et al.* 2000; Britner *et al.* 2003). Further, higher levels of depression and distress, and poorer mental and physical health, characteristics indicative of stress, have been reported in parents of older children with CP (Wallander *et al.* 1989; Wiegner & Donders 2000; Manuel 2001; Brehaut *et al.* 2004). However, CP covers a range of disabilities of varying severity. At the moment, little is known about aspects of parenting stress which may be specific to families of a child with a hemiparesis.

The stress process

The stress process model developed by de Brock *et al.* (1992/2006) provides a useful theoretical framework for analysing parenting stress. Like the researchers from whose work their model is derived (Gottlieb 1983; Cohen & Wills 1985), de Brock and colleagues see parenting stress as the final phase of a complex, dynamic process. Stress occurs when a situation is appraised as demanding, but no appropriate response is available. Stressful situations elicit negative affect and may initiate the complex chain of neuroendocrine events that constitute the stress response. When multiple sources of stress persist over long periods, short-term expressions of stress may give rise to more enduring expressions of stress.

Individual parents differ in how well they are able to manage the short-term physiological and psychological impact of the feelings of irritation, concern and uncertainty that accompany parenting. Several characteristics have been shown to influence the risk that potentially stressful situations will actually lead to enduring expressions of stress. Such characteristics – referred to as buffers – influence the probability that difficult situations will be appraised as stressful, and when appraised as stressful, will actually lead to more permanent expressions of stress. Buffers may be more strongly associated with enduring expressions of stress than the potential stressor(s) themselves. The stress process model suggests that, to understand parenting stress, we must first identify the sources of stress, and next investigate how they are associated both with parental characteristics which may act as buffers, and with more permanent expressions of parenting stress.

Sources of stress

The child's motor disability and its impact on daily functioning are potential sources of stress (Manuel 2001). Many self-care activities take longer to learn, and when mastered, require more

time and effort from the child, and from family members (Gorter *et al.* 2004). Their child's delayed motor development makes extra demands on the parents, and may cause feelings of anxiety and helplessness (Wanamaker & Glenwick 1998). Further, the parents in this study reported clinically significant levels of externalizing and internalizing behaviour and extreme difficulty in social interaction in 25%, 36% and 41% of the children, respectively (Bouma & Butcher 2005). When behavioural problems accompany a motor disability, they may be even more strongly associated with parenting stress than the severity of the disability or its impact on daily functioning (Mobarak *et al.* 2000; Smith *et al.* 2001; Baker *et al.* 2003). Clearly, parents of a child with a hemiparesis must cope with not just one, but several persisting sources of stress.

Intervening factors or buffers

Two dynamic psychosocial resources which have been shown to be important buffers against parenting stress and which are likely to be threatened by the demands of raising a child with a hemiparesis are perceived competence in the parenting role (Coleman & Karraker 1998; Raikes & Thompson 2005) and perceived social support (Cohen & Wills 1985; Crnic & Low 2002; Skok *et al.* 2006). Parental competence refers to the parents' perceptions of their ability to care for their child, and to foster his/her ongoing development (Coleman & Karraker 1998). High levels of perceived competence are thought to reduce the tendency to appraise situations as problematic, and to increase confidence that situations appraised as problematic can be managed (Raikes & Thompson 2005). Low levels are thought to have the opposite effect. Feelings of incompetence are often reported by parents of children with physical disabilities (Wanamaker & Glenwick 1998) and behavioural problems (Hastings 2002).

A supportive relationship between the parents (Kersh *et al.* 2006), and the availability of support from a broader network of family and friends have also been found to act as buffers (Crnic & Low 2002). Close social contacts provide emotional support and collective experience in the management of difficult situations (Cohen & Wills 1985). When such support is available, fewer situations are likely to be considered stressful, and managing situations considered stressful is likely to be easier (Skok *et al.* 2006). The extra demands made by the child's motor difficulty reduce the parents' opportunities for social contact (Britner *et al.* 2003). When such opportunities exist, parents may face lack of understanding of the extra demands placed on them by their child, and of his/her frequently inappropriate behaviour (Skok *et al.* 2006). Further, the child's demands may affect the relationship between the parents (Kersh *et al.* 2006).

Enduring expressions of stress

Mobility and self-care skills in children with a hemiparesis improve as they grow older (Gorter *et al.* 2004). However, more complex skills remain difficult. The nature of behavioural problems is likely to change as the child grows older. However, higher frequencies of behavioural problems have been found at all ages in children with CP (McDermott *et al.* 1996). As their child progresses through the different developmental stages the demands on the parents are likely to change constantly, but not to decrease (Rentinck *et al.* 2007). When sources of stress are persistent, their short-term physiological and psychological impact may develop into long lasting symptoms of stress, including reduced mental and physical well-being and a more problematic relationship with the child. This is particularly likely when parental characteristics which buffer the short-term impact of potential stressors are less effective (Crnic & Low 2002), as seems to be the case for parents of a child with a hemiparesis.

This analysis suggests that parents of a child with a hemiparesis run a higher risk of developing long-lasting symptoms of parenting stress. As little is known about levels of stress in this group of parents, the first goal of this study was to investigate whether they indeed report higher levels of parenting stress.

The second goal was to determine whether factors known to mediate between the short-term impact of potential stressors and enduring symptoms of stress play a similar role in parents of a child with a hemiparesis. We were most interested in the role of perceived competence and social support, resources which are particularly threatened by the demands of raising a child with a hemiparesis, and may therefore be appropriate targets for intervention programmes. We expected that child characteristics likely to disrupt family functioning would be positively associated with enduring symptoms of stress, and negatively associated with parental characteristics which buffer against the development of enduring symptoms of stress. Further, we expected that when the association between child characteristics and buffering characteristics was taken into account, the association between child characteristics and enduring symptoms of stress would decrease in strength.

Differences between mothers and fathers

Most investigations of parenting stress have focused on the mother. The few comparisons of parenting stress in mothers and fathers have produced inconsistent results. Some find no differences in the degree of stress reported (Wanamaker & Glenwick 1998). Others find mothers report more stress

(Esdaile & Greenwood 2003). Yet others find differences only in some of the associations between parental stress and its precursors (Deater-Deckard & Scarr, 1996; McBride and colleagues 2002). There are theoretical and empirical reasons for expecting mothers and fathers to differ in the level or symptoms of stress associated with parenting a child with a hemiparesis. First, even when stressors are comparable, the biological reactions to those stressors may differ in males and females (Uhart *et al.* 2006). Second, in families with atypically developing children, where the day-to-day running of the house demands extra time and energy, and medical costs are high, the division of roles may be sharper than in families with typically developing children (Kazak & Marvin 1984). This may increase the caregiver's isolation and simultaneously reduce the experiences of competence and opportunities for social interaction provided by a career outside the home.

The final goals of this study were therefore to determine whether mothers and fathers reported different levels of stress, and whether the associations among symptoms of stress, child characteristics and parental characteristics known to buffer stress were different in mothers and fathers.

Method

Participants

Participants were 107 mothers and 95 fathers of a child with a hemiparesis aged between 1.75 and 14 years. Invitations to participate were sent to 177 families who were members of the Association for the Motor Handicapped in the Netherlands (BOSK). Eighty percent, 142 families, agreed to participate. Completed questionnaires over their child's disability and behaviour were returned by 132 families. Completed questionnaires on parental stress were returned by 108 families, a response rate of 61.5%. Children with complete parental data did not differ on any characteristic investigated from children with incomplete parental data. Of these families, 105 consisted of two parents. In 96 families, both parents completed questionnaires on parental stress. In 12 families, only the mother returned the questionnaire. In one other family, only the father returned the questionnaire. Six families consisted of mother living alone. Mothers ranged in age from 27 to 49 years of age ($M = 39$; $SD = 4.6$). Fathers ranged in age from 28 to 55 years of age ($M = 41$; $SD = 5.3$). All children had been diagnosed with a hemiparesis. Twenty-one had additional handicaps including sensory loss or articulation problems (6), mental retardation (9) and epilepsy (6). The children ranged in age from 1.75 to

14.75 years ($M = 7.5$ years; $SD = 3.3$ years). The ratio of boys to girls was 64 : 44.

The study was approved by the Ethics Committee of the Psychology Department.

Procedure

Participating families received two packets of questionnaires through the post. The first packet included three questionnaires assessing the severity of the hemiparesis, the child's dysfunctionality in everyday activities, and behaviour problems. Demographic information on the parents was also collected. Most questionnaires (91%) were completed by the mother. A further 7% were completed by the father, the remaining 2% by both parents. When the first packet was returned, the second packet, consisting of two sets of three questionnaires designed to assess the family climate, coping styles and parental stress, was sent. Mothers and fathers were requested each to complete a set of questionnaires. Completed questionnaires could be returned at no cost to the family in a pre-addressed envelope. Parents who did not return the questionnaires were reminded once by post.

Instruments

Child measures

To assess dysfunctionality in everyday activities, parents were asked to indicate, on a 4-point scale ('not at all' to 'slightly' to 'moderately' to 'severely'), how difficult their child found each of five global activities. The activities selected covered three key areas of everyday functioning – mobility, self-care, social functioning – (Vermeer & Lankhorst 1997; Ostensj *et al.* 2003), which even the youngest children could be expected to (be beginning to) carry out independently, for example, feeding him/herself, moving around, playing. To assess severity of movement impairment, parents indicated the extent to which movement in each of the child's limbs was impaired on 4-point scales ('not at all' to 'slightly' to 'moderately' to 'severely').

Both measures were developed for this investigation. The appropriateness of the items was determined in a pilot study with parents of six children with a hemiparesis ranging in age from 3 to 18 years. Initial convergent validity for both measures was indicated by their moderate, positive correlations ($r = 0.36$, $P < 0.000$). The internal consistency of the measure for dysfunctionality was good (Cronbach's $\alpha = 0.82$).

The Dutch version of the Child Behavioural Check List (CBCL, Verhulst *et al.* 1996; Achenbach & Rescorla 2001) was

used to assess behavioural problems. The CBCL is a screening instrument with well-established validity in distinguishing between children with and without behavioural problems, according to parental report. Parents indicated, on a 3-point scale ('never or rarely' to 'often' to 'all the time'), how well the behaviour described in an item applies to their child. The total behaviour problems score was used in this analysis.

Parental measures

The Nijmeegse Ouderlijke Stress Index (NOSI: de Brock *et al.* 1992/2006) was used to measure both the extent to which parents experience parenting of their handicapped child as stressful, and parental characteristics which act as buffers between stress-eliciting characteristics of the child and the parent's experience of stress. The NOSI is a revised and extended version of Abidin's (1983) Parenting Stress Index (PSI), an instrument frequently used in investigations of stress within families (Crnic & Low 2002; Esdaile & Greenwood 2003). The NOSI includes the 13 scales of the original PSI, and the life events scale. However, items less relevant to the Dutch situation were replaced by more relevant items, and new items were added to extend the age range to approximately 14 years. In this investigation, we used only the seven subscales which comprise the parent domain. Three subscales measure psychosocial resources thought to act as buffers between the short-term impact of stressors and the development of long-term symptoms of stress. Social Isolation assesses perceived social support, Dissatisfaction with Partner assesses dissatisfaction with the relationship with the partner, and Incompetence assesses perceived incompetence in the parenting role. Four subscales measure long-term symptoms of stress. Role restriction assesses feelings of being limited by the needs and demands of the child, Health problems assesses the presence of minor physical complaints, Depression assesses despondency and lack of vitality, and Attachment Problems assesses the parents' perception of the quality of their relationship with their child. Parents indicate agreement with each statement on a 4-point Likert scale ranging from strongly disagree to strongly agree. The combination of measures of intervening factors and long-term symptoms of stress in a single instrument makes the NOSI particularly suited for the investigation of associations between these variables.

Reliability and validity of NOSI are rated as good by the Dutch Committee for Tests and Test Research (Evers *et al.* 2000). Internal consistency for these participants was adequate to good (Cronbach's alpha range 0.71–0.83) for all but Attachment problems (Cronbach's alpha 0.62 for mothers and 0.53 for fathers).

Analysis

The data were analysed using SPSS for Windows (version 11).

For purposes of interpretation, the scores on NOSI subscales are assigned to one of seven categories ranging from extremely low to extremely high. To determine whether significantly elevated levels of stress were reported more frequently by parents of children with a hemiparesis than parents in the normative sample, the lowest five categories, corresponding to scores <85%, were considered to indicate average levels of stress while the categories high (85% ≤ score <95%) or extremely high (≥95%) were considered to indicate significantly elevated levels of stress. χ^2 -tests were used to compare the distributions of the three categories in the participants and the normative sample.

Following Baron and Kenny (1986), a series of multiple linear regressions was used to determine whether hypothesized mediators mediated between potentially stressful child characteristics and parental stress. First, associations between child characteristics and hypothesized mediators were examined. Second, associations between child characteristics and measures of stress were examined. Third, child characteristics and hypothesized mediators were included in a single regression for each measure of stress. Parent's education may also act as a buffer and was therefore included in all regression models. Further, as the dynamics of the stress process may differ at different stages of the child's development, the age of the child was included in all regression models.

Preacher and Hayes' (2008) procedure was used to test whether the effects of stressors were significantly reduced by controlling for the hypothesized mediators. Preacher and Hayes divide the *total* effect of an independent variable on a dependent variable into a *direct* effect and an *indirect* effect via one or more mediators. Their procedure tests the significance of the *indirect* effect, that is, of the difference between the *total* effect and the *direct* effect. The indirect effects of several mediators on the same dependent variable can be tested in a single model, allowing the unique indirect effect of each mediator to be estimated. For each measure of stress, a separate mediation analysis was carried out for each child characteristic with which it was significantly associated in the regression analysis. All hypothesized mediators found to be significantly associated with both the child characteristic and the measure of stress were included in the same mediation analysis.

To investigate whether associations between stressors, mediators and symptoms of stress were similar for mothers and fathers, parental role (father/mother) was included in all

Table 1. Correlations among child and parent characteristics included in the regression analysis

Fathers (<i>n</i> = 97)	Mothers (<i>n</i> = 107)											
	1	2	3	4	5	6	7	8	9	10	11	12
1. Age child	–	0.15	–0.19	0.22*	0.05	–0.00	–0.21*	–0.18	0.07	–0.15	–0.16	0.07
2. Movement impairment	0.13	–	0.38***	0.00	0.02	–0.07	–0.07	–0.05	–0.02	–0.09	–0.05	–0.01
3. Dysfunctionality	–0.21*	0.35***	–	0.24*	–0.20*	0.26*	0.24*	0.11	0.20	0.27**	0.25*	0.29**
4. Behaviour problems	0.16	0.02	0.23*	–	–0.15	0.32**	0.22*	0.13	0.24*	0.24*	0.19	0.39**
5. Education parent	–0.03	–0.11	–0.19*	–0.25**	–	0.01	–0.03	0.06	–0.09	–0.11	–0.05	–0.11
6. Incompetence	0.04	–0.05	0.20*	0.46***	–0.09	0.46**	0.65***	0.45***	0.75***	0.57***	0.57***	0.65***
7. Social isolation	–0.11	–0.02	0.17	0.28**	0.09	0.41***	0.52***	0.61***	0.63***	0.61***	0.71***	0.42***
8. Dissatisfaction partner	–0.15	–0.09	0.14	0.28**	–0.07	0.44***	0.64***	0.64***	0.48***	0.38***	0.48***	0.36***
9. Depression	–0.02	–0.05	0.13	0.34***	–0.12	0.81***	0.43***	0.45***	0.34***	0.56***	0.51***	0.54***
10. Health problems	–0.10	–0.11	0.11	0.31**	0.06	0.56***	0.54***	0.47***	0.52***	0.30**	0.59***	0.31**
11. Role restriction	–0.13	–0.10	0.14	0.34***	–0.11	0.47***	0.57***	0.56***	0.49***	0.56***	0.37***	0.35***
12. Attachment problems	0.02	0.02	0.26**	0.43***	–0.11	0.56***	0.31**	0.34***	0.43***	0.32**	0.34***	0.52***

* $P < 0.05$; ** $P < 0.01$; *** $P < 0.001$.

Correlations for mothers are shown above the diagonal, correlations for fathers below the diagonal, and correlations between mothers and fathers are shown in bold along the diagonal. Presence of an additional disability was excluded as it was a categorical variable ($n = 214$).

models. Subscale scores for fathers and mothers in the NOSI standardization sample differ systematically: mothers report higher mean levels of all symptoms of enduring stress and mediators (de Brock *et al.* 1992/2006). To eliminate these differences in, Z-scores derived from the norm tables for mothers and fathers were used in the analyses.

To check that the data met the assumptions of linearity, homoscedasticity and normality of residuals, the plots of the standardized residuals against the standardized predicted values, and the P–P plot of the residuals were inspected for each multiple regression model tested.

Results

Correlations between stressors, psychosocial resources and measures of enduring stress

Behaviour problems and dysfunctionality in everyday activities were significantly, positively associated with both hypothesized mediators and measures of stress (See Table 1). The hypothesized mediators were also significantly, positively associated with measures of stress. The size of the correlations showed that the subscales Depression and Incompetence provided overlapping rather than unique information on both mothers and fathers ($r = 0.81$ and $r = 0.75$, respectively). For fathers, the subscales Role restriction and Social isolation also overlapped ($r = 0.79$). The hypothesized mediators were interrelated, as were the measures of stress. However, there was no overlap across mediators or measures of stress.

Psychosocial resources and enduring symptoms of stress in the parents

A χ^2 -analysis showed that both mothers and fathers were over-represented in the categories high and extremely high on all hypothesized mediators and symptoms of stress (See Table 2). The expected frequency for high and extremely high scores was 16%. The observed frequencies ranged from 30% for Attachment problems and Role restriction to 36% for Social isolation in the mothers, and from 27% for Role restriction to 37% for Health problems in the fathers.

Mothers' and fathers' scores did not differ on any of the subscales measuring mediators or symptoms of stress (See Table 2).

The mediation analysis

First, the associations between child characteristics and hypothesized mediators were tested. Parental role and education and the child's age were entered first, followed by the indices for severity of the disability, and Behavioural problems score. Behavioural problems were positively associated with all mediators (See Table 3). Dysfunctionality in daily life activities was positively associated with Incompetence and Social isolation. Unexpectedly, the severity of the motor impairment was negatively associated with Incompetence. Although significant, these associations were all small.

Next, the associations between child characteristics and the measures of stress were tested. Again Behavioural problems were significantly positively associated with all measures

Table 2. Comparison of the scores on the NOSI (Nijmeegse Ouderlijke Stress Index) subscales of parents of a child with a hemiparesis and parents in the normative sample group

	Fathers			Mothers			Father vs. mother
	Expected	Observed	Observed vs. expected	Expected	Observed	Observed vs. expected	
Enduring symptoms of stress			χ^2 (d.f.)			χ^2 (d.f.)	χ^2 (d.f.)
Depression	84%: 11%: 5%	73%:17%: 10%	27.89 (2)***	84%: 11%: 5%	68%: 17%: 5%	9.45 (2)**	1.01 (2)
Health problems	84%: 11%: 5%	64%:23%: 14%	59.89 (2)***	84%: 11%: 5%	68%: 11%: 21%*	30.38 (2)***	6.10 (2)
Role restriction	84%: 11%: 5%	73%: 6%: 21%	52.98 (2)***	84%: 11%: 5%	70%: 10%: 20%	10.90 (2)**	3.77 (2)
Attachment problems	84%: 11%: 5%	76%: 21%: 3%	19.75 (2)***	84%: 11%: 5%	70%: 24%: 6%	9.55 (2)**	1.30 (2)
Psychosocial resources							
Incompetence	84%: 11%: 5%	75%:13%: 12%	32.34 (2)***	84%: 11%: 5%	67%: 17%: 6%	11.59 (2)**	1.75 (2)
Social isolation	84%: 11%: 5%	74%: 18%: 8%	43.18 (2)***	84%: 11%: 5%	64%: 23%: 13%	6.90 (2)*	2.80 (2)
Dissatisfaction partner	84%: 11%: 5%	75%: 21%: 4%	6.61 (2)*	84%: 11%: 5%	77%: 13%: 10%	9.19 (2)**	4.55 (2)

* $P < 0.05$; ** $P < 0.01$; *** $P < 0.001$.

Distribution of scores of both groups of parents of a child with a hemiparesis over the categories normal, high and extremely high: frequencies expected on the basis of the normative group: 84%: 11%: 5% ($n = 214$).

Table 3. Summary of hierarchical regression analyses for characteristics of the child predicting parental characteristics hypothesized to act as mediators ($n = 214$)

Variable	Incompetence			Social isolation			Dissatisfaction partner		
	B	SE B	β	B	SE B	β	B	SE B	β
Parental role	0.32	0.15	0.14*	0.26	0.16	0.11	0.18	0.16	0.08
Parental education	0.07	0.07	0.06	0.13	0.08	0.11	0.05	0.08	0.05
Age child	0.02	0.03	0.04	-0.05	0.03	-0.12	-0.21	0.22	-0.15
Movement impairment	-0.10	0.05	-0.14*	-0.06	0.05	-0.08	-0.06	0.03	-0.08
Additional handicap	-0.18	0.21	-0.06	-0.24	0.22	-0.08	-0.05	0.05	-0.07
Dysfunctionality	0.08	0.03	0.22**	0.06	0.03	0.17*	0.03	0.03	0.08
Behaviour problems	0.04	0.01	0.36***	0.03	0.01	0.27***	0.03	0.01	0.24**

* $P < 0.05$; ** $P < 0.01$; *** $P < 0.001$.

$R^2 = 0.22$ for Incompetence; $R^2 = 0.15$ for Social isolation; $R^2 = 0.11$ for Dissatisfaction with partner.

(See Table 4, Step 1). Dysfunctionality was significantly positively associated with Health problems and Attachment problems. Again, although significant, these associations were all small.

In the third step, the hypothesized mediators were added to the model. Incompetence was highly significantly associated with Depression, Health Problems and Role restriction, and significantly associated with Attachment problems (See Table 4, Step 2). Social Isolation was highly significantly associated with Health problems and Role restriction and significantly associated with Depression. Dissatisfaction with partner was significantly associated with Role restriction. Associations ranged in size from moderate to large.

With the inclusion of the hypothesized mediators, the contribution of Behavioural problems and Dysfunctionality to all measures of stress decreased substantially. Only the association between Behavioural problems and Attachment problems remained significant.

The multiple mediation analysis showed that the decrease in the *total* effect of Behavioural problems on all measures of stress reflected a significant *indirect* effect of one or more of the hypothesized mediators. The *indirect* effect via Incompetence was significant for all measures of stress (See Table 5). The *indirect* effect via Social isolation was significant for Depression, Health problems and Role restriction. The contrasts showed that Incompetence had a stronger effect on Depression than Isolation. No other differences in effect size were found. The decrease in the *total* effect of Dysfunctionality on Health problems and Attachment problems reflected a significant *indirect* effect of Incompetence (See Table 6). Dissatisfaction with partner showed no significant *indirect* effects in the analyses.

Discussion

The mothers and fathers in this study reported high or extremely high levels of all expressions of enduring stress one

Table 4. Summary of Hierarchical Regression Analyses for child characteristics and enduring symptoms of parenting stress, before (Step 1) and after (Step 2) parental characteristics hypothesized to mediate between stressful events and the development of enduring symptoms of parenting stress are included in the regression equation ($n = 214$)

Variable	Depression			Health problems			Role restriction			Attachment problems		
	B	SE B	β	B	SE B	β	B	SE B	β	B	SE B	β
Step 1												
Parental role	0.21	0.15	0.09	0.16	0.19	0.06	0.09	0.16	0.04	0.17	0.14	0.08
Parental education	-0.04	0.08	-0.03	0.08	0.09	0.06	0.01	0.08	0.01	-0.00	0.07	-0.01
Age child	0.02	0.03	0.05	-0.05	0.04	-0.11	-0.08	0.03	-0.20*	0.02	0.03	0.05
Movement impairment	-0.06	0.05	-0.10	-0.11	0.06	-0.14	-0.07	0.05	-0.12	-0.06	0.05	-0.09
Additional handicap	-0.21	0.21	-0.07	-0.10	0.26	-0.03	0.39	0.22	0.13	-0.05	0.20	-0.02
Dysfunctionality	0.05	0.03	0.15**	0.07	0.04	0.16*	0.05	0.03	0.12	0.08	0.03	0.23**
Behaviour problems	0.03	0.01	0.26**	0.04	0.01	0.29***	0.03	0.01	0.26***	0.04	0.01	0.35***
Step 2												
Parental role	-0.06	0.10	-0.03	-0.09	0.15	-0.03	-0.12	0.12	-0.05	0.01	0.12	0.01
Parental education	-0.10	0.05	-0.10	-0.00	0.07	-0.00	-0.06	0.06	-0.06	-0.04	0.06	-0.04
Age child	0.02	0.02	0.05	-0.04	0.03	-0.08	-0.05	0.02	-0.14	0.02	0.02	-0.04
Movement impairment	0.02	0.03	0.02	-0.05	0.05	-0.06	-0.02	0.04	-0.03	-0.01	0.04	-0.02
Additional handicap	-0.04	0.14	-0.01	0.09	0.21	0.03	0.57	0.17	0.19	0.06	0.17	0.02
Dysfunctionality	-0.01	0.02	-0.04	0.01	0.03	0.02	-0.00	0.02	-0.01	0.04	0.02	0.12
Behaviour problems	-0.01	0.01	-0.05	0.01	0.01	0.05	0.00	0.01	0.03	0.02	0.01	0.17*
Incompetence	0.68	0.05	0.70***	0.42	0.08	0.35***	0.22	0.01	0.22**	0.43	0.01	0.46***
Social isolation	0.13	0.06	0.14*	0.39	0.09	0.34***	0.41	0.07	0.41**	0.00	0.07	0.01
Dissatisfaction partner	0.10	0.06	0.10	0.05	0.09	0.04	0.17	0.07	0.16*	0.01	0.07	0.10

* $P < 0.05$; ** $P < 0.01$; *** $P < 0.001$.Step 1: $R^2 = 0.12$ for Depression; $R^2 = 0.14$ for Health problems; $R^2 = 0.14$ for Role restriction; $R^2 = 0.22$ for Attachment problems. Step 2: $\Delta R^2 = 0.53$ for Depression; $\Delta R^2 = 0.30$ for Health problems; $\Delta R^2 = 0.36$ for Role Restriction; $\Delta R^2 = 0.20$ for Attachment problems.**Table 5.** Mediation of the effect of behaviour problems on depression, health problems, role restriction and attachment problems through incompetence, social isolation and marital dissatisfaction ($n = 214$)

Indirect Effects	Depression			Health problems			Role restriction			Attachment problems		
	effect	SE	95% CI	B	SE	95% CI	B	SE	95% CI	B	SE	95% CI
Incompetence	0.028	0.006	0.018–0.040*	0.017	0.005	0.010–0.030*	0.009	0.003	0.003–0.016*	0.019	0.004	0.012–0.030*
Social isolation	0.004	0.002	0.001–0.008*	0.011	0.004	0.004–0.021*	0.010	0.004	0.003–0.016*			
Dissatisfaction partner							0.004	0.002	0.005–0.009*			
Total	0.033	0.006	0.020–0.044*	0.028	0.007	0.016–0.043*	0.022	0.006	0.011–0.033*	0.019	0.004	0.012–0.030*
Contrasts												
Incompetence vs. isolation	0.024	0.006	0.014–0.036*	0.006	0.006	-0.005–0.021	-0.002	0.005	-0.012–0.007			
Incompetence vs. dissatisfaction							0.005	0.004	-0.003–0.013			
Isolation vs. dissatisfaction							0.006	0.004	-0.001–0.017			

* $P < 0.05$.

and a half to two times as frequently as parents in the normative sample. The extra demands of raising a child with a hemiparesis clearly take their toll on the parents' physical and mental well-being, and on their relationship with their child.

Potentially stressful characteristics of the child were significantly associated with parenting stress. Behavioural problems showed the strongest association, contributing to elevated scores on all measures of enduring stress. Difficulty carrying out everyday activities contributed significantly to elevated scores on Health and Attachment problems. Neither the severity of the

movement impairment nor the presence of an additional disability was associated with any symptom of stress. As with other studies of parents of children with physical disabilities, stress in these parents was less strongly associated with the severity of the disability than with its impact on daily functioning (Mobarak *et al.* 2000; Smith *et al.* 2001; Baker *et al.* 2003).

However, behavioural problems and difficulty carrying out everyday activities were also significantly negatively associated with parental characteristics which act as buffers against the development of long-term expressions of stress. Feelings of

Indirect Effects	Health problems			Attachment problems		
	B	SE	95% CI	B	SE	95% CI
Incompetence	0.022	0.011	0.004–0.052*	0.025	0.012	0.005–0.053*
Social isolation	0.024	0.012	0.004–0.052*			
Dissatisfaction partner						
Total	0.046	0.020	0.010–0.087*	0.022	0.012	0.005–0.053*
Contrasts						
Incompetence vs. Isolation	0.002	0.012	–0.027–0.023			

* $P < 0.05$.

Table 6. Mediation of the effect of dysfunctionality in everyday activities on health and attachment problems through incompetence and social isolation

incompetence, social isolation and dissatisfaction with the relationship with the partner were all higher in parents who reported that their child showed more behavioural problems. Feelings of incompetence and social isolation were also higher in parents who reported that their child needed more help with everyday activities. Including these parental characteristics in the regression decreased the strength of all associations between child characteristics and symptoms of enduring stress. Only the association between the child's behavioural problems and the parent's attachment problems remained significant. A mediation analysis showed that the associations between potentially stressful child characteristics and depression, health and attachment problems were mediated by feelings of incompetence in the parental role, social isolation and to a lesser extent, dissatisfaction with the partner. Including in these variables in the model produced a substantial, highly significant increase in explained variability, showing that, as hypothesized, high levels of stress were strongly associated with low levels of characteristics that act to buffer the short-term impact of sources of stress.

Perceived incompetence in the parenting role predicted all measures of stress and mediated all associations between the child's problems and the parents' experience of stress. Although its particularly strong effect on Depression undoubtedly reflected the overlap between the two measures, it also showed strong effects on other aspects of stress where no overlap was found. Feelings of being highly incompetent were reported by significantly more parents in this group than in the normative sample. Doubts about their competence as parents have been found in mothers raising children with chronic illnesses (Maltby *et al.* 2003) and under other conditions likely to make high demands on parenting skills, such as poverty (Coleman & Karraker 1998; Raikes & Thompson 2005). Lower levels of perceived competence have been found to be associated with higher levels of stress (Raikes & Thompson 2005). Perceptions of one's own competence may be especially vulnerable in parents raising children under difficult conditions. One factor eroding feelings of competence in the parents studied here was the

extra demands made by their child's motor and behavioural problems. However, the associations between the child's problems and parents' feelings of incompetence, though significant, were small. The Incompetence scale of the NOSI taps parents' feelings of being ashamed of their inadequacy as parents. Parents' feelings of incompetence may then have been less strongly associated with child's problems than the feelings of shame the problems elicited.

Feelings of social isolation showed strong associations with the parents' feelings of depression, ill health and of being limited by the needs of their child, and mediated between the behavioural problems of the child and these expressions of stress. These findings are consistent with the literature on parenting stress in both typically and atypically developing children (Crnic & Low 2002; Skok *et al.* 2006). While having a child with a disability limits parents' opportunities for social contact, the associations between the child's problems and parents' feelings of isolation were small. This suggests that feelings of isolation may have been less strongly associated with the extra demands on the time resulting from their child's problems than was the feeling of distance they created between parents and their family and friends.

Unexpectedly, dissatisfaction with the partner played a significant mediating role only between the behavioural problems of the child, and the parents' feelings of being limited by the needs of their child.

Differences between fathers and mothers

Mothers scored higher than fathers on all NOSI subscales. However, subscale scores of mothers in the norm group were also higher than those of fathers, suggesting that mothers and fathers differ in their tendency report the feelings tapped by the NOSI. When the differences in response tendencies were controlled, mothers and fathers did not differ in levels of stress or of psychosocial resources hypothesized to act as mediators or in the associations among child characteristics, mediators and symptoms of stress. Differences between mothers and fathers in

susceptibility to stress have been explained in terms of the different social roles of the partners and the likelihood of more traditional role divisions in families with a disabled child (Kazak & Marvin 1984). The absence of such differences in this group of Dutch parents may then reflect cultural differences, for example, in attitudes towards careers and in social welfare systems.

Limitations of the study

These findings must be considered within the context of the limitations of the study. First, while the number of participants was unusually high and had the advantage of not being associated with a particular medical or rehabilitation centre, all participants were members of the BOSK. Second, only 61% of the families invited provided complete data on both child and parents. How representative these children and their parents are of the broader population parents of a child with a hemiparesis is unclear. Further, all measures used were self-report measures, which, although they have the advantage of tapping the respondent's perception of their own and their children's characteristics, are not always consistent with more objective measures (Esdaile & Greenwood 2003). Also, the parents assessed their own and their child's characteristics, raising the possibility of a confound. Finally, because this study was cross-sectional, the direction of the associations is unclear.

Implications for intervention

Within these limitations, the study shows a need for stress management in programmes for parents of children with a hemiparesis. The finding that feelings of incompetence and isolation were most strongly associated with behavioural problems suggests that support systems should be broadened to include the management of behavioural as well as movement problems. The small size of the association between parents' feelings of incompetence and isolation and their child's problems suggest that support programmes should go further than equipping the parents to deal with difficult behaviour to address the feelings of shame and distance from family and friends that were so much more prevalent in these parents than in parents in the normative sample. Finally, programmes need to be directed at both parents. Although their tendency to report fewer problems may suggest that fathers experience fewer symptoms of enduring stress, comparison with the normative sample showed that fathers of a child with a hemiparesis also experience higher levels of stress.

Key messages

- Although a hemiparesis is defined in terms of motor dysfunction, stress in parents of a child with a hemiparesis is more closely associated with the behavioural problems which frequently accompany the motor dysfunction than with the motor dysfunction itself.
- Stress in the parents of a child with a hemiparesis is associated with the child's behavioural and motor problems *indirectly* through the feelings of (in)competence in the parental role and social isolation to which these problems contribute.
- When the tendency of fathers to report lower levels of parenting stress is taken into account, levels of parenting stress reported by fathers and mothers of a child with a hemiparesis do not differ.
- Parents of a child with a hemiparesis require assistance in managing not only their child's motor dysfunction but also the behavioural problems that frequently accompany the motor dysfunction.
- Assistance in managing behavioural problems should focus both on the problems themselves and on their impact on parents' feelings of (in)competence and social isolation.

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