Stress and Ameliorating Factors among Families with a Seriously Ill or Disabled Child

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Abstract

Research suggests families with a chronically ill or disabled child are subject to higher levels of stress than families with typically developing children. Family resources have been found to buffer parental stress, and there is some evidence that several factors relating to the illness of the child may also have an impact on parent stress levels. The current study examined the relationships between parenting stress, parenting style, family resources (family income mother's education, number of children in the family), and illness factors (ill child behaviour, care time required) in families with a chronically ill or disabled child. Participants were 77 parents (69 mothers, 8 fathers) of children with a chronic illness or disability and 77 of their well children (37 boys, 30 girls). Parents rated their level of stress and their ill child's behaviour, as well as providing child illness and demographic information. A well child in the family rated parenting style. Results suggested parents were exceptionally stressed compared to norms. High parent stress was associated with difficult ill child behaviour and high care demands for ill child. Additionally, parents with 'difficult' ill children and whose parenting styles were characterised by high behavioural control were particularly stressed. Implications for managing parental stress are discussed.

Keywords: *Parent stress; Chronic illness; Siblings; Parenting style; Child Adjustment; Family Factors.*

Introduction

Family life cycle research suggests that the most stressful times for families are those years when there are dependent children, especially pre-schoolers (Carter & McGoldrick, 2005). But the effort required by parents during those years is tempered by the knowledge that the children are growing toward independence and maturity and that their dependency is a passing phase in development. For families with a chronically ill or disabled child, outcomes are less clear, and potentially less optimistic. There are possibilities that the child will be dependent for many years longer, even for the whole of his/her life. Indeed, lifespan itself may be jeopardised, leaving the parents with the possibility that no parent wants to experience – being pre-deceased by their child.

Existing research on the level of stress in families with ill children is equivocal, some studies showing stress levels comparable with families of typically developing children, most indicating higher levels (Nereo, Fee & Hinton, 2003). It seems likely that there are a range of factors which can buffer the potentially distressing effects of child illness/disability, and that such family resources and/or child characteristics are more or less present in resilient and vulnerable families. General family resources, such as income, family type and parental education are obvious ones to examine, given that these resources are related to many family and child outcomes in families with and without ill children (e.g., Smith, Oliver & Innocenti, 2001; Williams et al., 2002). Social support too is related to coping with adversity in general (Schreurs & de Ridder, 1997) and, in the case of families with ill children, to both child outcomes and family stress, at least in some studies (Varni, Katz, Colegrove & Dolgin, 1993; von Weiss et al., 2002).

Of particular interest are variables relating to illness severity. In a previous study we demonstrated that adjustment outcomes for well siblings in families with an ill or developmentally delayed child were more strongly related to the ill child's behaviour problems than the seriousness of the illness/disability (Rayner & Moore, 2006). The question of whether parental stress is also more strongly related to behavioural problems than to illness severity in their children is one we examine in the current study. There is some research to suggest this might be the case. For example, Smith, Oliver and Innocenti (2001) showed that impairments in developmentally disabled children's social skills predicted parental stress to a greater extent than other aspects of child functioning including motor, cognitive and communication skills. Mobarak, Khan, Munir, Zaman and McConachie (2000), in a study of parents of children with cerebral palsy, found that the strongest predictor of maternal stress was child behaviour problems rather than illness severity per se. In this study, we used 'care time required' as assessed by parents as a way to operationalise the difficult-to-assess concept of illness severity.

Another key focus in the examination of family stress and resilience in the current study was parenting style. Woolfson and Grant (2006) for example, acknowledging that bringing up a child with a

developmental disability is associated with increased parental stress, suggest that parenting style could influence these negative outcomes. Parenting style has been conceptualized in a range of different ways, one of the most popular being the authoritative, authoritarian, indulgent/permissive and neglectful categorization. In this model, authoritative parenting, characterized by high levels of both warmth/ responsiveness and limit setting (behavioural control), has been associated with positive child outcomes by a number of researchers (e.g., Baumrind, 1991; Jackson & Goossens, 2006; Steinberg, Mounts, Lamborn & Dornbush, 1991). Woolfson and Grant (2006) examined relationships between parenting approaches and stress in 53 parents of children with developmental disabilities across two age groups, 3 to 5 years and 9 to 11 years. These parents were compared with 60 parents of normally developing children. Results showed that parents of older developmentally delayed children used authoritative parenting less than parents of younger developmentally delayed children, while the opposite developmental pattern was seen for typically developing children. Multivariate analysis of variance showed a significant group-by-parenting style interaction on parental distress. The authors suggested that parenting style may moderate the stressful effects on parents of bringing up a developmentally delayed child. Authoritative parenting, though 'recommended' by some experts on child development (e.g., Baumrind, 1991) may be highly stressful for parents with developmentally delayed children to implement, resulting in a decrease in its use across the two age groups. The child's high level of neediness, continuing for longer than is the norm for typically developing children, may make it difficult for parents to sustain either their responsiveness to the child, their limit setting, or both. They may resort to parenting styles that are less high maintenance/idealistic, as the difficulties of family life with a disabled child continue to impinge. Whether same effects are evident for parents of chronically ill children has not yet been established.

Our overall aim was to examine families with an ill or disabled child who were more or less stressed, to ascertain what kinds of factors make a difference. We examined the family stresses associated with caring for a seriously ill or disabled child, from the point of view of parental daily hassles. There is evidence to suggest that an individual's appraisal of minor daily stresses influences well-being (e.g, Lazarus & Folkman, 1994). The stresses of daily hassles may be particularly applicable to the task of parenting, especially the parenting of young children or children with special needs (Crnic & Greenberg, 1990; Nereo, Fee & Hinton, 2003). Minor daily hassles have been found to exert a cumulative effect on parental stress over time, which present a greater risk to children's adjustment than single stressful events. A three year study of parental stress in 125 mothers and their children found cumulative parenting stress affects parenting behaviour and puts pressure on the parent child relationship, placing the children at increased risk of poor adjustment outcomes (Crnic, Gaze & Hoffman, 2005). Parenting of young or needy offspring requires high levels of vigilance, comprises many routine tasks, and has the potential for many minor irritations and annoyances as well as major tensions such as those which can be associated with medical treatment and children experiencing pain. The Parenting Daily Hassles Scale (Cnic & Greenberg, 1990) measures routine minor stressors associated with parenting, and is used as the measure of parent stress levels in the current study.

The current study examined the relationships between parenting stress (parenting daily hassles), parenting style, family resources (family income mother's education, number of children in the family), and illness factors (ill child behaviour, care time required) in families with a chronically ill or disabled child. It was expected that (a) these parents would report high levels of stress, (b) stress would be more strongly related to ill child behaviour than to care time required for the ill child (illness severity), (c) parenting stress would be associated with family resources, specifically lower family income, lower maternal education and more children in the family, and (d) there would be an interaction between parenting style and ill child behaviour on parenting stress, with greater stress associated with more 'difficult' ill children whose parents use more authoritative styles of parenting.

Method

Participants

Informants in this study were parents of a chronically ill or disabled child, and one of the well children in each family. Parent participants comprised 69 mothers and 8 fathers (77 parents) of children with a chronic illness or disability, who also had at least one well child. The well children (37 boys and 40 girls) were aged between 7 and 19 years (M = 11.7 years, sd =2.5 years). The parents were aged between 30 and 52 years (M = 36 years, sd = 5.3 years). Most of the parents were well educated with 46% holding a tertiary qualification and 35% having completed secondary education or holding a trade or a technical qualification. Family size ranged from 2 to 9 children (M = 3, sd = 2). Ninety one percent of families had both parents living at home. Family income was generally high with 56% having an income of more than $55,000 per annum.

The children with a chronic illness or disability (n = 77) did not participate directly in the research, but were a key aspect of the study. There were 28 females and 49 males, ranging in age from 2-23 years (M = 9.9, sd = 3.7), all living within the family and dependent on family care. All the illness and disabilities were chronic (long term) and serious (life threatening and/ or requiring continuous monitoring and care). A wide

range of illness and disabilities were present in the families and in many cases more than one aspect of the child's functioning was affected and several, sometimes many, diagnoses were described. Detail about the nature and severity of the illnesses and disabilities are described in the results section but include cystic fibrosis, diabetes, asthma, epilepsy, cerebral palsy, Duchene's muscular dystrophy, cancer, Autism spectrum disorders, Rett syndrome, Wolf Hirschhorn syndrome, Prader-Willi syndrome and Down syndrome.

Procedure

Participants were recruited by engaging a variety of organizations which serviced the needs of families with ill or disabled children. Participating organizations either contacted their clients to explain the study and request volunteers, mailed out information about the project, or advertised in newsletters or on websites. In the latter situations, potential participants could then contact the researchers directly, or indicate to their organization that they were prepared to be involved and provide a phone number to the researcher. Child friendly flyers, developed in conjunction with Association for Children with a Disability, were provided to organizations to distribute to families.

The first author contacted each family and arranged participation either by personal visit or mail. Personal visits occurred in all cases where the well child to be assessed was younger than 10 years (N=21), so that the researcher could spend time explaining the questionnaire to the child and assisting with reading the items and recording the responses if necessary. For older participating well children and their families, the questionnaires were mailed out (N=56). In these cases, telephone support for filling out the questionnaires was available from the researcher if required. Parents were asked to complete their questionnaires in a room separate to the child, and to respect the confidentiality of the child's responses by not reading the completed questionnaires. Participants were assured of confidentiality and that none of their individual details would be identifiable, only group data would be reported.

With respect to response rates, 33 chronic illness or disability organisations were approached to recruit participants. A total of 17 (52%) agreed to participate in recruiting participants for the study. Four of these organisations agreed to personally invite participants through the organisation support workers. This was the most effective method of recruitment through organisations, with 28 families recruited. Thirteen organisations agreed to advertise the project either in newsletters, via the organisation website or by making the project flyers available to families. Three families were recruited using this method. All 79 Victorian special developmental schools listed on the Victorian Department of Education and Training website were approached. Thirteen participated in the project (16%) by advertising the project to parents in the school newsletter. A total of 24 families responded, of these 20 returned completed forms. A further 24 families contacted the researcher directly via email or phone and did not indicate how they were informed about the project. Three families were personally known to the researcher and two families were informed by friends who had already participated. Overall, from the sources for which data was available it is possible to say that of the 99 families who agreed to respond, 77 actually returned completed questionnaires (78%).

Measures

Parents completed measures of their stress levels and scales relating to the behaviour of their ill child. They also provided information on family structure and ill child care requirements. The participant well child in the family completed a scale assessing parenting style. These measures are described below.

Parenting Daily Hassles Scale: Parent stress was measured by the Parenting Daily Hassles Scale (PDHS) (Crnic & Greenberg, 1990). The PDHS was designed to measure the routine minor stressors associated with parenting based on the theoretical premise that daily hassles are a more significant predictor of stress than significant life events. The PDHS indicates how intensely the parent is affected by twenty hassles relating to parenting that routinely occur in families with young children. Examples of the items include "Continually cleaning up messes of toys or food"; "Being nagged, wined at or complained to"; "Difficulties in getting privacy like in the bathroom".

Parents were asked to consider each event and rate the frequency (how often it has happened) and intensity (how much of a hassle it felt) over the past few weeks. The intensity items were rated on a 5 point scale where 1 = "*no hassle*"; 2 = "*small hassle*", 3 = "*medium hassle*", 4 = "*large hassle*", 5 = "*extreme hassle*". Possible total scores ranged from 20 to 100 with high scores indicating higher impact of daily hassles, that is, higher levels of stress. The frequency items were rated on a 5-point scale ranging from 0 = "*never*", 1 = "*rarely*", 2= "*sometimes*", 3 = "*a lot*" and 4 = "*constantly*". Possible total scores ranged from 0 to 80 with high scores indicating frequent occurrence of hassles, or frequent stress. Internal consistency alphas for the frequency scale range from .80-.89 and for the intensity scale range from .89-.93 (Crnic & Greenberg, 1990). For this study the Cronbach α for the frequency scale was .87, and for the intensity scale was .89. The scales were highly correlated ($r = 0.84$, $p < 0.001$). For this reason, only Daily Hassles Frequency was used in subsequent analyses, with the exception of the descriptive analysis indicating levels of stress experienced.

Child Behaviour Checklist: Parents completed the Child Behaviour Checklist (CBCL: Achenbach & Rescorla, 2001) in relation to the children in the family

who were study participants. The CBCL is a measure of behavioural maladjustment designed to be completed by a parent about their child aged 6 years to young adulthood. The parent rates the degree to which 113 items describe their child, on three point scales (not true to very often true). Scores are added to form two subscales: Internalising Problem Behaviour (anxious/ depressed, withdrawn/ depressed, somatic complaints) and Externalising Problem Behaviour (rule breaking, aggression). Norms specific for age and gender are available from the manual (Achenbach & Rescorla, 2001). In this study, the Cronbach α was .89 for Internalising and .91 for Externalising Behaviour. As well as using the continuous variable scales in analyses, ill child acting out behaviour was divided into two categories ("difficult" and "easy") by dividing the ill child Externalising scale at the median to produce two groups for some subsequent analyses.

Family resources: Measures included family income (6 categories ranging from "up to $15,000/year" to "$55,000 and above", mother's education (7 categories ranging from "primary education only" to "post graduate qualification"), and number of children in the family.

Illness severity: Level of severity of the illness or disability of the ill child was assessed by the variable 'care time required' (4 categories ranging from "less than one hour/day" to "continuous care") and hours of respite care utilised per week.

Parenting Styles Questionnaire: Well children participants in the study completed a slightly modified version of the Parenting Style Questionnaire (PSQ; Lamborn et al., 1991), adapted to the reading age of the children in the study and standardizing the response options where possible (modifications available from the first author). The PSQ is based the model of parenting style originally proposed by Baumrind (1971) and further developed by Maccoby and Martin (1983). The PSQ consists of 26 items asking children to relate the questions to the parent(s) with whom they live.

Children rated 18 statements about their parent(s) on 4 point Likert scales ranging from "*strongly agree*" to "*strongly disagree*". The two subscales represented by these items are: warm involvement (the degree to which the child perceives their parent as loving, responsive and involved) and psychological autonomy granting (the extent to which the child perceives parents as democratic and non-coercive in their discipline). The third subscale comprises a further eight items assessing behavioural control (extent of parental monitoring and supervision). Children rate how late they are allowed to stay out at night on a 7-point scale (separately for weekends and week nights). They also rate how much they perceive that their parents TRY to know and how much they DO know about where the children go at night, what they do in their free time, and where they are most afternoons after school (on 3-point rating scales – *"don't try", "try a little", "try a lot"* and *"don't know", "know a little", "know a lot").* Alpha reliability coefficients for the subscales have been reported at .72 for warm involvement, .82 for psychological autonomy granting, and .71 for behavioural control (Steinberg, Darling & Fletcher, 1995). In this study, α was 0.71, 0.60 and 0.37, respectively. The unacceptably low alpha for the behavioural control scale meant that it must be interpreted with caution when used as a continuous variable; however it was considered adequately valid to use as a categorical variable differentiating parents rated "high" and "low" on the dimension by their children. (For example, as might be expected due to gender role socialization, parents were rated as more behaviourally controlling with their daughters than their sons, Chi square (1) = 4.76, $p < 0.05$).

Steinberg provides two methods of forming categories of parenting style from scores on the PSQ. The first method (Steinberg et al., 1994) uses only the warm involvement and behavioural control scales, and divides scores on each at their medians to form four groups: authoritarian (low warm involvement, high behavioural control), authoritative (high on both subscales), neglectful (low on both subscales), and indulgent (high warm involvement, low behavioural control). In the second method, degree of authoritativeness is measured. All three subscales are divided at their respective medians (Steinberg, 1992). Parents in the "high" category on all subscales are categorised as most authoritative (score 3), two high scores are categorised as moderately authoritative (score 2), one as somewhat authoritative (score 1) and zero as not at all authoritative (score 0). Both methods were used in the current study; the former to analyse interactions between ill child behaviour and parenting style on parent stress (using ANOVA), the latter as a continuous measure for regressions predicting parental stress.

Results

Table 1: Frequency and Intensity of Daily Hassles of Parents with an Ill/Disabled Child

Hassle (item shortened)	Hassle happens a lot or constantly (frequency) %	Hassle rated large or extreme (intensity) %
Continually cleaning up kids' messes	79.2	29.9
Being nagged, whined at, or complained to	50.7	36.4
Mealtime difficulties	48.1	28.6
The kids don't listen, won't do as asked	48.1	39.5
Babysitters hard to find	48.1	35.6
Kids' schedules interfere with meeting other needs	28.6	9.3
Sibling fights require a "referee"	39.0	28.9
Kids demand you entertain them.	27.3	7.8
Kids resist bedtime	24.7	14.5
Kids constantly under foot	17.2	10.7
Need to keep constant eye on them	57.2	29.3
Kids interrupt adult conversations	41.0	21.1
Having to change plans because of child need.	32.5	25.0
Kids get dirty several times a day requiring changes of clothes	19.5	14.3
Difficulty getting privacy	42.9	18.2
Kids hard to manage in public	29.9	26.0
Difficulties in getting kids ready, leaving on time.	28.6	24.7
Difficulties in leaving kids for a night out or at school or day care.	16.9	18.7
Kids' difficulties with friends	23.4	14.5
Having to run extra errands to meet kids' needs	29.9	10.4
Mean (SD), N=77, current study, families with ill/disabled child	62.8 (11.2)	50.1 (13.3)
Mean (SD), Crnic & Greenberg (1990), N=74, families with 5-year olds	37.3 (6.9)	41.8 (12.2)
t (149)	16.20*	14.51*

Note: * $p < 0.01$

Level of parenting stress: Data in Table 1 show most frequent hassles to be ones concerned with order and surveillance, these being: "*continually cleaning up kids' messes of toys or food"* and "*the need to keep a constant eye on where the kids are and what they're doing*". The most intense ones were different, relating more to bad behaviour on the part of the children: "*the kids don't listen, won't do what they are asked without being nagged*" and "*being nagged, whined at, or complained to".*

When total scores on Daily Hassles Frequency and Daily Hassles Intensity were compared with data from a study of 74 families with 5-year olds (Crnic & Greenberg, 1990), parents in the current study were significantly more stressed in terms of both measures (Table 1). (Note that this analysis required a recoding of the rating scale used in the current study for Daily Hassles Frequency (but not for Daily Hassles Intensity), so that it matched the scoring system used in the Crnic and Greenberg study).

Predictors of parenting stress Regressions were performed to examine the major predictors of parental stress from a set of variables including ill child factors representing the child's behaviour and illness severity (externalising, internalising, amount of care required), parenting style (degree of authoritativeness, Steinberg, 1992 method) and general family factors (family income, maternal education, number of children in the family). Correlations between variables are shown in Table 2, and the regression results in Table 3.

Table 2: Inter-correlations between variables

	2	3	4	5	6	7	8
1	.07	-.11	.31**	.42**	.28*	.09	-.06
2		.07	.19	.00	.09	-.10	.06
3			-.20	-.07	-.20	.04	. 38**
4				.36**	.02	.00	-.04
5					.16	.10	-.11
6						-.01	-.36**
7							.05

Notes: ** $p < 0.01$; * $p < 0.05$; 1= daily hassles frequency, 2 = authoritativeness, 3 = family income, 4= ill child internalising, 5= ill child externalising, 6= care time required, 7 = number of children in the family, 8 = mother's education.

None of the potential predictors were correlated at > 0.6, limiting the possibility of multicolinearity. Daily Hassles Frequency was significantly associated with ill child internalising, ill child externalising and care time required, but there was no significant linear association between stress and the other variables.

Table 3:Regression predicting Daily Hassles Frequency

Variable	Beta weight
Mother education	.06
Number of children	.03
Family income	-.07
Ill child internalising	.05
Ill child externalising	.33**
Care time required	.25*
Authoritativeness	.07
F(7, 65)	2.85**
R^2	.235

Note: *p < 0.05; **p < 0.01

The regression predicting Daily Hassles Frequency was significant with 23.5 % of the variance accounted for. There were two independent predictors, Ill Child Externalising and care time required. Greater parental stress was associated with more externalising (or difficult behaviour) on the part of the ill child, and more care required for the ill child.

Parent stress and parenting style A three-way analysis of variance was conducted with parental daily hassles frequency as the dependent variable, and parenting style (high and low behavioural control; high and low warm involvement) and ill child behaviour (high vs. low externalising) as the independent variables. The aim was to test for a possible interaction between parenting style and ill child behaviour on parent stress. There was a significant main effect for ill child behaviour on daily hassles ($F(1,69) = 17.98$, $p < 0.001$). Parents of 'difficult' (high externalising) ill children were more stressed than parents whose ill children were less likely to externalise (mean Daily Hassles Frequency: low externalising = 58.8, high externalising = 67.1).

There were no significant main effects of behavioural control or warm involvement, but a significant interaction between warm involvement and behavioural control ($F(1,69) = 7.00$, $p = 0.01$). Authoritarian parents were significantly more stressed (mean daily hassles score = 66.83) than authoritative (60.00), indulgent (62.05) and neglectful (60.42) parents. Also, there was a significant interaction between behavioural control and ill child externalising ($F(1,69) = 4.38$, $p < 0.05$). Parents with styles incorporating higher levels of behavioural control (authoritarian, authoritative) were similarly stressed to low behavioural control parents (indulgent, neglectful) if their children were 'easy', but relatively much more stressed if their children were difficult (Table 4). The combination of this interaction and the previous one was reflected in the particularly high score on daily hassles frequency for authoritarian parents trying to raise an ill child who was a high externaliser, or "difficult" (see bolded means in Tables 4 & 5). Conversely, the behaviour of the ill child did not appear to impact much on the stress experienced by indulgent parents. Table 5 shows the means for the different parenting styles, differentiated by 'easy' or 'difficult' ill child, on the daily hassles measure.

Table 4: Effects of Behavioural Controlling Parenting Style and Ill Child Behaviour on Parental Stress

	Daily Hassles Frequency	
	Easy child	Difficult child
Low behavioural control	59.0 (7.9)	63.6 (8.5)
High behavioural control	58.7 (11.2)	**71.2** (12.8)

Table 5: Means of Daily Hassles Frequency and Intensity by Parenting Style and Ill Child Externalising

Parenting style	Daily Hassles Frequency	
	Easy child	Difficult child
Authoritative	51.2	65.5
Authoritarian	61.2	**76.2**
Indulgent	61.8	62.3
Neglectful	55.4	64.9

Discussion

These are an exceptionally stressed group of parents, much more so than parents of 5-year olds although the children in this sample ranged from 7 to 19 years. The addition of an ill or disabled child to a family, not surprisingly, adds a significant burden to family stress. This burden may arise because of dealing with the ill child's special needs and all that entails, but it is also manifest through a perceived increase in the frequency and intensity of stress associated with everyday living. Coping with children's difficult behaviour and seemingly constant demands, as well as trying to manage what often appears to be the chaos of family life, looms large for the adult members of these families. Not only the ill child in the family, but the well children also, are likely to be affected by these stress levels. Both the correlations and regression beta

weights (Tables 2 and 3) suggested stronger relationships between ill child behaviour and parental stress than between care time required for the ill child and parent stress.

Previous research has found associations between high levels of parental stress and poor child adjustment outcomes such as behaviour problems, poor social competence (Creasey & Reese, 1996; Crnic & Greenberg, 1990) and poorer child wellbeing (Crnic & Low, 2002). Parenting stress is more closely related to child behaviour outcomes than other forms of stress experienced by parents such as work stress or stress in the martial relationship, presumably because it occurs closer to parent child interactions (Deater-Deckard, Smith, Ivy, & Petril, 2005). Pett , Vaughncole and Wampold (1994) found stressed mothers reported higher numbers of problem behaviours in their children than non stressed mothers. Using observations as well as parent ratings to assess child behaviour problems, Crnic, Gaze and Hoffman (2005) found high stress in parents related to increased child negativity, and accounted for 15 percent of the variance in child behaviour problems. Similarly, in a study of 211 parents and their adolescent children, Compas, Howell, Phares, Williams and Ledoux (2003) found higher levels of parental stress related to increased levels of psychological symptoms in children. While other studies have found higher levels of parental resources (income, education, small families) reduce parent stress, these relationships were not evident in the current sample, possibly because of its homogeneity with respect to these variables. Most families in the sample were relatively affluent, well educated and had only a small number of children.

The analysis of variance assessing the relationships between parenting style and parenting stress showed that at least one aspect of family context is important, that being the behaviour of the ill child. Parental styles high on behavioural control were associated with particularly high parent stress. This was exacerbated if the parenting style was authoritarian (that is, there was also low warm involvement) and if the ill child was classified as high on difficult (externalising) behaviours (Tables 4 and 5). In a study such as this there is no way of knowing the direction of cause and effect of these variables. On the one hand, high family stress may lead to increased attempts at behavioural control of the well children. Parents in more stressed families (child illness more severe, ill child badly behaved, limited energies to express warmth) may be trying to bring order into the chaos through being stricter and more controlling, at least with the well child over whom they may feel they have more influence. On the other hand, parents with a tendency toward parenting styles characterised by behavioural control may add to their felt stress through trying to enact this perceived responsibility. Those parents with a higher need to maintain control over their children's behaviours may be more stressed because this type of parenting is inherently more difficult than allowing children looser limits. So-called neglectful and indulgent parents in a sense have less to do because they do not feel the need to be so vigilant about behavioural standards. In families which already have to deal with managing an ill child, adding the responsibility of high supervision of the well children magnifies parental stress. Probably, there is a two way relationship between perceived parental stress and attempts at behavioural control. More stress may lead to tighter controls being implemented, which in turn may create more family conflict, which in turn increases stress. It is also possible that authoritarian parents are linked to higher stress only because the same endogenous factors that cause them to be authoritarian also cause them to perceive their environment as more stressful than is normal.

Previous research has linked high parent stress with more controlling parent behaviour. Parents with higher levels of stress tend to use more authoritarian approaches to parenting and be more negative and less involved in their interactions with their children (Belsky et al., 1995, Bolger et al., 1989; Crnic & Low, 2002; Deater-Deckard & Scarr, 1996; Deater-Deckard, 1998; Pett et al., 1994). High parental stress also results in less parent-child pleasure and more parent-child conflict (Crnic et al., 2005).

These data are not presented as necessarily an argument to promote a more laissez-faire family environment for families with an ill or disabled child. However, parents under this much stress need help, not only in the form of respite from the care of their ill child, but also in the development of strategies to maintain family cohesion. One example is the recruitment of benign adults from outside the family who can assist in the nurture of the well children in the family, for example through mentor programs or through engaging them in structured activities. Sibling programs of this nature are only just beginning in Australia, for example the Very Special Kids Big Brother/Big Sister program.

In summary, families with a child with a chronic illness or disability are highly stressed, not only from the many pressures relating to the illness, prognosis and treatment but also from the ill child's difficult behaviour. The high levels of parent stress are likely to have detrimental effects on both parents and children. Use of more controlling techniques in an attempt to manage the ill child's difficult behaviour may create further problems for parents by increasing stress levels further. Assistance to families can be directed at helping parents reduce stress and providing more effective ways to manage ill child behaviour problems.

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Research Profiles

Meredith Rayner is a psychologist who has recently submitted her PhD exploring resilience in siblings of children with a chronic illness or disability. Her area of interest is family psychology, in particular childhood resilience and aspects of parenting. She currently works in an applied research role at the Parenting Research Centre and prior to that worked as an organisational psychologist in private industry for 7 years.

Susan Moore is a research professor at Swinburne University. Her major areas of interest are adolescence, sexuality and coping with illness.