

Predictors of care-giver stress in families of preschool-aged children with developmental disabilities

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Abstract

Background: This study examined the predictors, mediators and moderators of parent stress in families of preschool-aged children with developmental disability.

Method: One hundred and five mothers of preschool-aged children with developmental disability completed assessment measures addressing the key variables.

Results: Analyses demonstrated that the difficulty parents experienced in completing specific care-giving tasks, behaviour problems during these care-giving tasks, and level of child disability, respectively, were significant predictors of level of parent stress. In addition, parents' cognitive appraisal of care-giving responsibilities had a mediating effect on the relationship between the child's level of disability and parent stress. Mothers' level of social support had a moderating effect on the relationship between key independent variables and level of parent stress.

Conclusions: Difficulty of care-giving tasks, difficult child behaviour during care-giving tasks, and level of child disability are the primary factors which contribute to parent stress. Implications of these findings for future research and clinical practice are outlined.

Introduction

It is generally accepted that caring for a child who has a developmental disability can involve significant and prolonged periods of time and energy, completion of physically demanding and unpleasant tasks, and frequent disruption to family routines and activities (Seltzer & Heller 1997; Shultz & Quittner 1998). As a result of these increased care-giving demands, it seems reasonable to assume that parents of children with developmental disability are at increased risk for high levels of personal stress. When a parent feels overwhelmed by the stress associated with caring for their child with a disability, there can be negative implications for the child, the parent and the family as a whole. For example, heightened parent stress is associated with coercive parent-child interactions (Moes & Frea 2000; Bor *et al.* 2002), predicts dropout from parent training interventions (Andra & Thomas 1998; Sanders *et al.* 2000; Schreibman 2000), and is linked with parental depression (Gray 2002; Vitaliano *et al.* 2003). In addition, high levels of stress can negatively influence a parent's interaction with other family members and increase the risk of family maladjustment (Turnbull & Ruef 1996).

Research findings, however, are inconsistent. Some studies support the occurrence of increased parent stress and maladjustment in these families (Featherstone 1981; Friedrich & Friedrich 1981; Krahn 1993; McDonald *et al.* 1996; Blacher *et al.* 1997),

while others show significant variability in parents' responses to the demands of care-giving. Several studies report no differences in level of parent stress or maladjustment between families of children with developmental disability and those who do not have a child with developmental disability (Kazak 1987; Bristol *et al.* 1988; Dyson 1991).

A range of variables may contribute to parent stress associated with care-giving. These include the difficulty of completing care-giving tasks (Gallagher *et al.* 1983; Leyser *et al.* 1996; McDonald *et al.* 1996), the time involved in completing tasks (Erickson & Upshur 1989; Quittner *et al.* 1992; Quittner *et al.* 1998), the presence of difficult child behaviour during tasks (Floyd & Gallagher 1997; Hastings 2002; Hastings & Brown 2002; Saloviita *et al.* 2003) and the level of a child's disability (Beckman 1991; Haveman *et al.* 1997).

Children with developmental disabilities are often dependent upon parents to meet their needs. Parents may therefore find care-giving tasks more burdensome, and as a consequence experience higher levels of stress. Variation in parent stress associated with care-giving may relate to the heterogeneity of childhood disability, and the fact that individual children present with a unique profile of skills, behaviours and challenges for parents. This means that there is significant variation in the specific care-giving tasks undertaken by families in relation to the four contributing factors of task difficulty, time involved in tasks, difficult child behaviour and level of child disability.

Alternatively, variation in parent stress may be explained by the way parents cope with their care-giving role. In the present context, stress is described as the ongoing relationship between a person and environmental factors (Lazarus & Folkman 1984). It refers to the emotion experienced when a situation is perceived as threatening or demanding, and when the person does not have an adequate coping response. In relation to parents of children who have developmental disabilities, any of the numerous tasks associated with care-giving may potentially be perceived as threatening or demanding. Stress is also influenced by the coping processes of cognitive appraisal, coping strategies and coping resources. Cognitive appraisal is defined as a person's subjective interpretation of events in terms of threat, challenge and controllability (Lazarus & Folkman 1984). In relation to parents of children with developmental disability, interpretation of their care-giving role and how they perceive and appraise specific care-giving tasks, child behaviour and their child's level of disability may directly influence level of parent stress. If care-giving is appraised as outside their control or highly threatening, then parents may experience high levels of stress irrespective of actual tasks or demands. The importance of cognitive appraisal in explaining the relationship between specific care-giving factors and parental stress has been widely demonstrated (Frey *et al.* 1989; Grant & Whittell 2000; Hastings & Johnson 2001; Hastings & Brown 2002; Heiman 2002). Given the demonstrated importance of cognitive appraisal, it is reasonable to hypothesize that appraisal may have a direct causative or mediating relationship between care-giving factors and parent stress. The processes of coping strategies (Frey *et al.* 1989; Sloper & Turner 1993; Judge 1998) and coping resources (Suarez & Baker 1997; Judge 1998; Goode *et al.* 1999) have also been identified as impacting on parent stress. According to Lazarus & Folkman (1984), coping strategies reflect a person's cognitive and behavioural efforts to manage a stressful event, and coping resources as what is available (e.g. social supports) to assist a person with achieving positive outcomes. In the literature pertaining to care-giving and developmental disability, the use of problem-focused coping strategies (Judge 1998) and high levels of support from spouse, family, friends and external agencies (Goode *et al.* 1999) have been demonstrated to be associated with lower levels of parent stress. There is also evidence to suggest that coping strategies and coping resources can moderate or buffer the impact of care-giving factors on parent stress (Suarez & Baker 1997). Figure 1 shows the model used to conceptualize factors which contribute to parent stress.

Although numerous studies have investigated the relationship between parent stress and care-giving factors such as the difficulty of tasks, time involved in tasks, child behaviour and level of child disability, and coping processes of cognitive appraisal, coping strategies and coping resources, these have typically examined isolated or smaller subsets of these variables, or they have included other variables of interest. In addition, few studies have systematically utilized findings to guide the development of intervention programmes for parents. The present study investigated the extent to which the variables of difficulty of care-giving tasks, time involved in care-giving tasks, difficult child behaviour during care-giving tasks and level of child disability predicted level of parent stress in families of children with developmental disability. In addition, the mediating effects of cognitive appraisal of care-giving responsibilities, and moderating effects of positive coping strategies and social supports (e.g. family/friend/external) were examined. The aim was to identify key factors influencing parent stress associated with care-giving tasks and incorporate these into an intervention programme.

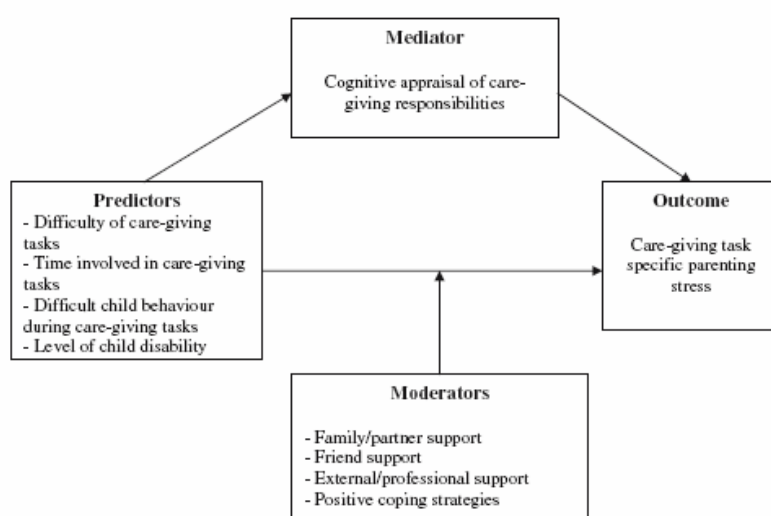


Figure 1 Model of factors contributing to parent stress associated with care-giving tasks.

Method

Participants

Participants consisted of 105 families with a preschool-aged child (<6 years) with developmental disability from the geographical catchment area of South-east Queensland, Australia. Eligibility criteria for the study were that (1) the child was receiving early intervention services because of identified developmental disability; (2) the child presented with developmental disability or was 'at risk' because of a diagnosed condition; and (3) the child had not yet commenced primary school education. Recruitment was on a voluntary basis, and 100% response rate was attained for those families who expressed interest in the study.

Demographic characteristics for the 105 families are summarized in Table 1. The majority of parents were married or in a defacto relationship (84%), had a high education level (36% of mothers and 43% of fathers having completed some tertiary education) and a high employment rate (95% of fathers and 41% of mothers). The majority of children were male (70%). Diagnoses included autism spectrum disorder (23.8%), Down's syndrome (23.8%), chromosomal abnormality other than Down's syndrome (8.6%) and cerebral palsy (6.7%). Level of disability ranged from mild (45%) to moderate (30%) and severe (8%). Seventeen per cent of children were within the borderline or average range, and these consisted of the younger children who were deemed 'at risk' because of a diagnosed condition (e.g. Down's syndrome).

Measures

Demographic information

A family background checklist (Plant & Sanders 1999) was used to obtain demographic information. The first section of this checklist provides demographic information pertaining to the child with developmental disability. The second section provides family details such as parents' name, age, marital status, educational level, employment status and family income. In addition, names, gender and ages of other family members is included.

Table 1 Characteristics of respondents and their families (n = 105)

| Variable | Mean | SD | Range |
|---------------------------------|---------------------|---------------------|-------|
| Child's age (month) | 49.71 | 15.33 | 12-81 |
| Mother's age (year) | 35.24 | 5.30 | 25-47 |
| Fathers' age (year) | 38.31 | 5.39 | 26-50 |
| Children in family | 2.53 | 1.19 | 1-7 |
| | % (n) | | |
| Child's gender | | | |
| Male | 70.5 (74) | | |
| Female | 29.5 (31) | | |
| Child disability | | | |
| Down's syndrome | 23.8 (25) | | |
| Other chromosomal abnormality | 8.6 (9) | | |
| Cerebral palsy | 6.7 (7) | | |
| Autism spectrum disorder | 23.8 (25) | | |
| Undiagnosed developmental delay | 23.8 (25) | | |
| Other | 13.3 (14) | | |
| Siblings | | | |
| No | 15.2 (16) | | |
| Yes | 84.8 (89) | | |
| Marital status - parents | | | |
| Married | 74.3 (78) | | |
| Defacto | 9.5 (10) | | |
| Separated/divorced | 13.3 (14) | | |
| Never married | 2.9 (3) | | |
| Family Income (per annum) | | | |
| Less than \$2001 | 1.9 (2) | | |
| \$2001-12 000 | 1.0 (1) | | |
| \$12 001-25 000 | 19.0 (20) | | |
| \$25 001-35 000 | 16.2 (17) | | |
| \$35 001-50 000 | 21.0 (22) | | |
| \$50 001-70 000 | 17.1 (18) | | |
| More than \$70 000 | 19.0 (20) | | |
| Don't know | 4.8 (5) | | |
| | Mother % (n) | Father % (n) | |
| Educational level | | | |
| Primary | 1.0 (1) | 3.5 (3) | |
| Secondary Year 10 | 33.3 (35) | 32.6 (28) | |
| Secondary Year 12 | 17.1 (18) | 17.4 (15) | |
| Trade | 12.4 (13) | 3.5 (3) | |
| Tertiary | 36.2 (38) | 43.0 (37) | |
| Employment | | | |
| Home | 59.0 (62) | 5.7 (5) | |
| Professional | 9.5 (10) | 23.9 (21) | |
| Teaching | 7.5 (8) | 1.1 (1) | |
| Administration | 6.7 (7) | 4.5 (4) | |
| Technical/trade | 4.8 (5) | 40.9 (36) | |
| Sales | 1.0 (1) | 4.5 (4) | |
| Student | 1.9 (2) | 1.1 (1) | |
| Health/medical | 6.7 (7) | 3.4 (3) | |
| Self-employed | 1.0 (1) | 3.4 (3) | |
| Business/management | 0.0 (0) | 7.9 (7) | |
| Military | 0.0 (0) | 1.1 (1) | |
| Unskilled | 1.9 (2) | 2.5 (20) | |

Stressfulness of care-giving tasks

The most stressful care-giving tasks were identified by providing respondents with a checklist outlining 22 different tasks. This checklist was specifically designed for use in the present study, as no existing measure could be identified. The checklist was developed by examining the topography of a typical day for parents and identifying common tasks that parents undertake in their daily routine. Once the preliminary list was established, it was reviewed by a panel of clinicians and parents, and then compared with relevant literature on developmental disability and typical development which pertained to high-risk parenting tasks (Dadds *et al.* 1987; Harris & McHale 1989; Sanders & Plant 1989). As a result of this process, the measure was perceived as a valid index of care-giving tasks undertaken by parents.

Respondents selected the five most stressful tasks from the list, and gave these a rank order from 5 (the most stressful task of all) to 1 (the fifth most stressful task). Scores for each care-giving task were then summed to attain a total score for each task.

Care-giving task specific parenting stress

Parent stress associated with care-giving tasks was assessed by respondents indicating how stressful they find completing tasks associated with eight identified care-giving areas. These areas were based on the work of Shearn & Todd (1997), and included: (1) direct care tasks such as bathing, feeding, dressing, toileting; (2) in-home therapy which involves the completion of special activities recommended by medical practitioners, therapists and teachers; (3) attendance at medical appointments, therapy sessions and educational programmes; (4) supervision of the child's activities and whereabouts; (5) involvement in leisure and play activities; (6) education and information about child disability; (7) advocating for services; and (8) managing child behaviour.

Respondents rated level of stress for each of the eight areas using a 7-point Likert scale which ranged from 1 (not stressful at all) to 7 (extremely stressful). Ratings for each of the eight care-giving areas were summed, and a total score calculated. The higher the score, the more stress associated with care-giving tasks. The measure had good internal consistency ($r = 0.82$).

Difficulty of care-giving tasks

Difficulty of care-giving tasks was measured by respondents rating how difficult they find completing care-giving tasks in eight different care-giving areas. These care-giving areas are the same as those used to assess parent stress. Respondents rated task difficulty on a 7-point Likert scale which ranged from 1 (not difficult at all) to 7 (extremely difficult). Ratings for each of the eight care-giving areas were summed, and a total score calculated. Higher scores indicate more difficulty associated with completion of care-giving tasks. Internal consistency was good ($r = 0.85$).

Time involved in care-giving tasks

Time involved in completing care-giving tasks was assessed by respondents indicating whether they spend more or less time completing tasks with their developmentally disabled child than they would with a child without developmental disability. Care-giving tasks are grouped into eight care-giving areas similar to those used for assessing parent stress. Respondents rated their time involved in the tasks on a 7-point Likert scale which ranged from 1 (significantly less time) to 7 (significantly more time). Ratings for each of the eight care-giving areas are summed, and a total score calculated. Scores of 32 and above suggest respondents spend more time involved in tasks with their

developmentally disabled child as compared with a child without developmental disability. The measure had good internal consistency ($r = 0.83$).

Difficult child behaviour during care-giving tasks

To assess frequency of difficult child behaviour when completing care-giving tasks, respondents were required to rate how often their child engaged in difficult child behaviour in seven different care-giving areas. These areas were the same as those used to assess parent stress, with the exception of managing child behaviour which was removed. Respondents used a 7-point Likert scale to rate frequency of difficult child behaviour in these seven care-giving areas, and this ranged from 1 (never) to 7 (always). Ratings for each of the seven care-giving areas were summed, and a total score calculated. Higher scores are indicative of higher frequency of problematic behaviour. Internal consistency was adequate ($r = 0.78$). Concurrent validity ($r = 0.82$) was demonstrated using a different sample, by comparing scores on this measure with an observable measure of negative child behaviour based on the Revised Family Observation Scale (Sanders *et al.* 1996).

To attain a more global measure of child problem behaviour, respondents were also required to complete the Developmental Behaviour Checklist (Einfeld & Tonge 1995). This measures behavioural and emotional disturbance in children and adolescents with developmental disabilities. Respondents are required to rate the presence or absence of specific behaviours according to a three point scale (0 = not true, 1 = somewhat or sometimes true, 3 = very true or often true). The scale provides a score for Total Problem Behaviour, as well as scores for six sub-scales – Disruptive, Self-absorbed, Language Deviance, Anxiety-relating, Autistic-relating and Anti-social. Reliability studies have revealed adequate inter-rater agreement (0.75–0.80) and test-retest (0.83) for both the total score and individual sub-scales. Internal consistency has been shown to be 0.98. Content, construct and concurrent validity studies have also been conducted with satisfactory results.

Level of child disability

The child's level of disability was determined using the Vineland Adaptive Behaviour Scale – Survey Form (Sparrow *et al.* 1984). This measures adaptive behaviour in children and adolescents from birth to 18 years. The scale is completed via a semi-structured interview. Items are scored on a three point rating scale (0 = No never, 1 = Sometimes or partially, 2 = Yes usually). The scale provides standard scores (mean = 100, SD = 15), percentile ranks, stanines, adaptive levels and age equivalents for an overall Adaptive Behaviour Composite, as well as scores for four domains – Communication, Daily Living Skills, Socialization, and Motor Skills. Adaptive Behaviour Composite reliability coefficients for children aged 5 years and under show internal consistency from 0.96 to 0.98, test-retest reliability from 0.89 to 0.90, and inter-rater agreement of 0.74. Content, construct and criterion validity are also adequately demonstrated. The scale is widely used in clinical, educational and research settings.

Cognitive appraisal of care-giving responsibilities

Parents' appraisal of the care-giving role was assessed using 17 appraisal items which are an adaptation of the revised Ways of Coping Checklist as used by Vitaliano *et al.* (1985). Respondents indicate on a seven point scale (from 1 = do not agree at all to 7 = strongly agree) their agreement or disagreement with statements related to a stressful life event. In the present study, caring for a child with a developmental disability was identified as the stressful life event. Examples include, 'caring for my child with a disability is something I can't accept' or 'caring for my child with a disability will always be a problem in my life'. Ratings are summed across the 17 statements to

provide a total appraisal score, with higher scores suggesting more negative appraisal of caring for a child with developmental disability. Internal consistency was good ($r = 0.87$).

Social support and care-giving

Three measures of social support were obtained – family/partner support, friend support and external/professional support. Respondents were asked to rate how much support they receive from family/partner, friends and service providers in carrying out tasks in eight different care-giving areas on a 7-point Likert scale. These areas are the same as used to assess parent stress. Ratings for each of the eight care-giving areas are summed, and a total score calculated for family/partner support, friend support and formal support. Internal consistency for each scale was good ($r = 0.93$ family/partner support; $r = 0.88$ friend support; $r = 0.85$ formal support).

Positive coping strategies

Coping strategies were assessed using the Ways of Coping Questionnaire – Revised (Folkman & Lazarus 1988). This checklist is designed to measure the coping processes (thoughts and actions) an individual uses to cope with a stressful event. In the current study, the stressful event was caring for a child with a developmental disability. Respondents indicate the frequency with which they use a particular strategy on a 4-point Likert scale (0 = Not used, 1 = Used somewhat, 2 = Used quite a lot, 3 = Used a great deal). Eight coping types – confrontative coping, distancing, self-controlling, seeking social support, accepting responsibility, escape-avoidance, planful problem solving, positive re-appraisal – are identified from factor analysis; and raw and relative scores are derived for each coping type. Internal consistency reliabilities are adequate (0.78–0.86) and are higher than the alphas reported for most other measures of coping processes. Test-retest reliability studies have not been conducted as coping processes are variable over time and depend on the event. Content and construct validity have been adequately demonstrated.

Procedure

Information was distributed to families via government early intervention services, and families then self-referred to the study. When participants were accepted into the study, a combined information sheet and consent form, copies of the questionnaires and instructions for completion were mailed to families. When completed questionnaires were returned, parents were contacted and the Vineland Adaptive Behaviour Scale – Survey Edition (Sparrow *et al.* 1984) was completed via a semi-structured telephone interview. A multi-informant approach was adopted and in two parent families both parents were asked to complete the questionnaires. If questionnaires had not been returned within 4 weeks, project staff contacted the family to encourage a prompt return and to enquire if assistance was required with completing the questionnaires.

Results

Preliminary analyses

The total sample consisted of data from mothers ($n = 105$) and fathers ($n = 34$). Primary analyses were conducted on mothers' data only because of the small sample size for fathers. Regression analyses were undertaken to determine whether specific demographic variables (child gender, child age, marital status, family income, maternal education) significantly contributed to the outcome variable of perceived stress. None of

these variables were found to be significant predictors of perceived stress and therefore their effects were not controlled for in subsequent analysis.

In addition, the sample was divided into two groups according to child's age (<4 years and >4 years), and analysis revealed no significant differences for either predictor or outcome variables. Bivariate correlations for all variables used in the analyses are outlined in Table 4 and these revealed no evidence of multi-collinearity.

Descriptive analyses

Table 2 summarizes information about the care-giving tasks that parents identify as most stressful. This shows that the most stressful tasks for mothers were helping and supervising at mealtimes, cleaning up after their child, settling their child at bedtime, helping and supervising with toileting and advocating to professionals on behalf of their child. Helping and supervising at mealtimes which attained the highest total score (total score = 174) clearly exceeded other tasks, with a 34-point difference between this task and cleaning up after their child which was ranked second (total score = 140).

Table 2 Perceived stressfulness of specific care-giving tasks

| Task | Mothers (n = 105) | | | Fathers (n = 34) | | |
|---|-------------------|-------------|-------------------------|------------------|-------------|-------------------------|
| | Rank | Total score | Most stressful item (%) | Rank | Total score | Most stressful item (%) |
| Helping and supervising at mealtimes | 1 | 174 | 18.1 | 2 | 55 | 14.7 |
| Cleaning up after child | 2 | 140 | 5.7 | 1 | 72 | 14.7 |
| Settling child at bedtime | 3 | 132 | 10.5 | 4 | 41 | 8.8 |
| Helping and supervising with toileting | 4 | 129 | 12.4 | 3 | 54 | 14.7 |
| Advocating on behalf of child | 5 | 122 | 10.5 | 9 | 22 | 5.9 |
| Helping and supervising with dressing | 6 | 97 | 1.9 | 13 | 18 | 0.0 |
| Doing therapy and educational activities | 7 | 88 | 6.7 | 14 | 17 | 0.0 |
| Transporting to appointments | 8 | 78 | 6.7 | 20 | 3 | 0.0 |
| Attending medical and therapy appointments | 9 | 77 | 5.7 | 7 | 22 | 5.9 |
| Helping and supervising with bathtime | 10 | 54 | 2.9 | 6 | 30 | 2.9 |
| Reading information relating to child or disability | 11 | 54 | 1.9 | 12 | 19 | 5.9 |
| Getting child ready for bed | 12 | 54 | 1.9 | 10 | 21 | 0.0 |
| Giving medication to child | 13 | 50 | 1.9 | 5 | 36 | 8.8 |
| Providing other medical procedures | 14 | 46 | 1.9 | 16 | 15 | 0.0 |
| Helping and supervising teeth cleaning | 15 | 43 | 0.0 | 11 | 19 | 5.9 |
| Filling out forms relating to child | 16 | 41 | 1.9 | 8 | 22 | 5.9 |
| Preparing resources and activities | 17 | 40 | 1.9 | 18 | 9 | 0.0 |
| Playing with child – out of home | 18 | 39 | 2.9 | 15 | 15 | 5.9 |
| Attending meetings | 19 | 38 | 1.9 | 17 | 9 | 0.0 |
| Playing with child – at home | 20 | 31 | 0.0 | 19 | 8 | 0.0 |
| Preparing special meals for child | 21 | 30 | 1.9 | 21 | 3 | 0.0 |
| Going to seminars or workshops | 22 | 17 | 0.0 | 22 | 0 | 0.0 |

Descriptive statistics for mothers' scores on all variables used in the analyses are shown in Table 3. Scores for the Vineland Adaptive Behaviour Composite (mean = 58.10, SD = 13.65) suggest the average level of child disability within the low mild range of functioning. In addition, mean Developmental Behaviour Checklist (DBC) Total Problem Behaviour scores (mean = 50.68, SD = 27.33) are slightly above the clinical cut-off of 46 regarded as indicative of behaviour disorder (Einfeld & Tonge 1995). Scores for level of parent stress associated with care-giving tasks and difficulty of care-giving tasks which have the same possible minimum and maximum scores are comparable (mean of 28.35 and 26.13, respectively). In addition, scores for difficult child behaviour during care-giving tasks is comparable (mean = 26.30, SD = 8.37). Mean time involved in care-giving tasks is higher; however, this is expected because of

the scale used where a rating of 4 or above is required in each care-giving area to indicate more time involved in tasks that an average child.

Cognitive appraisal of care-giving responsibility scores (mean = 54.39, SD = 19.60) are reasonably low, suggesting generally positive appraisals related to having a child with developmental disability. These scores have a possible range from 17 to 119 with higher scores indicating more negative appraisal towards the child. Scores for partner/family support (mean = 28.77, SD = 13.62) and external/professional support (mean = 24.23, SD = 11.31) are comparatively higher than average scores for friend support (mean = 12.49, SD = 6.85). Scores for use of positive coping strategies (mean = 26.10, SD = 10.01) have a possible range from 0 to 57, and the identified mean does not support either high or low use of positive coping strategies.

Table 3 Means and SD for predictor, mediating, moderating and outcome variables

| Variables | Mean | SD |
|---|-------|-------|
| Level of parent stress | 28.35 | 9.84 |
| Cognitive appraisal of care-giving responsibilities | 54.39 | 19.60 |
| Difficulty of care-giving tasks | 26.13 | 10.83 |
| Time involved in care-giving tasks | 42.83 | 9.97 |
| Difficult child behaviour during care-giving tasks | 26.30 | 8.37 |
| Level of child disability (VABS) | 58.10 | 13.65 |
| DBC total problem behaviour | 50.68 | 27.33 |
| Partner/family support | 28.77 | 13.62 |
| Friend support | 12.49 | 6.85 |
| External/professional support | 24.23 | 11.31 |
| Positive coping strategies | 26.10 | 10.01 |

VABS, Vineland Adaptive Behaviour Scale; DBC, Developmental Behaviour Checklist.

Correlations between variables

The relationships between variables used in the analysis were investigated using Pearson product-moment correlations, and these are summarized in Table 4. Level of parent stress associated with care-giving tasks correlated significantly with all five predictor variables (difficulty of care-giving tasks, time involved in care-giving tasks, difficult child behaviour during care-giving tasks, level of child disability and DBC total problem behaviour). There were strong positive correlations between level of parent stress associated with care-giving tasks and the variables of difficulty of care-giving tasks ($r = 0.87$, $n = 101$, $P < 0.01$) and difficult child behaviour during care-giving tasks ($r = 0.66$, $n = 103$, $P < 0.01$) indicating that those parents who reported higher stress associated with care-giving also reported care-giving tasks to be more difficult and associated with higher frequencies of difficult child behaviour when completing tasks. Moderate positive relationships were found between level of parent stress associated with care-giving and the variables of time involved in care-giving tasks ($r = 0.35$, $n = 102$, $P < 0.01$) and DBC total problem behaviour ($r = 0.48$, $n = 103$, $P < 0.01$). Level of child disability was also significantly associated with parent stress ($r = -0.24$, $n = 100$, $P < 0.05$); however, this relationship was weaker and inverse, indicating that parents report slightly higher levels of stress if their child's disability is more pronounced. Cognitive appraisal of care-giving responsibilities which was identified as a potential mediating variable showed a significant relationship with the dependent variable of level of parent stress ($r = 0.66$, $n = 102$, $P < 0.01$) and predictor variables of difficulty of care-giving tasks ($r = 0.56$, $n = 100$, $P < 0.01$) and difficult child behaviour during care-giving tasks ($r = 0.59$, $n = 102$, $P < 0.01$). Relationships with time involved

in care-giving tasks ($r = 0.21, n = 101, P < 0.05$) and DBC total problem behaviour ($r = 0.35, n = 102, P < 0.01$) were significant but weaker. Cognitive appraisal of care-giving responsibility scores did not relate to level of child disability. Variables identified as potential moderators between the level of parent stress and the predictor variables (difficulty of care-giving tasks, time involved in care-giving tasks, difficult child behaviour during care-giving tasks, level of child disability, DBC total problem behaviour) revealed significant inverse relationships between partner/ family support and level of parent stress ($r = -0.23, n = 103, P < 0.05$) and difficulty of care-giving tasks ($r = -0.27, n = 101, P < 0.01$), indicating that lower levels of partner/family support are associated with higher levels of parent stress and more difficulty associated with completing care-giving tasks. These relationships, however, are quite weak. There were no significant correlations between other variables.

Table 4 Correlations between predictor, mediating, moderating and outcome variables

| Measure | Measure | | | | | | | | | | | |
|--|---------|--------|---------|--------|--------|--------|-------|------|-------|------|------|--|
| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | |
| 1. Level of parent stress | 1.00 | | | | | | | | | | | |
| 2. Cognitive appraisal of care-giving responsibilities | 0.66** | 1.00 | | | | | | | | | | |
| 3. Difficulty of care-giving tasks | 0.87** | 0.56** | 1.00 | | | | | | | | | |
| 4. Time involved in care-giving tasks | 0.35** | 0.21* | 0.40** | 1.00 | | | | | | | | |
| 5. Difficult child behaviour during care-giving tasks | 0.66** | 0.59** | 0.65** | 0.32** | 1.00 | | | | | | | |
| 6. Level of child disability (VABS) | -0.24* | -0.19 | -0.18 | -0.15 | -0.16 | 1.00 | | | | | | |
| 7. DBC total problem behaviour | 0.48** | 0.35** | 0.47** | 0.21* | 0.55** | -0.25* | 1.00 | | | | | |
| 8. Partner/family support | -0.23* | -0.05 | -0.27** | 0.00 | -0.04 | 0.19 | -0.03 | 1.00 | | | | |
| 9. Friend support | -0.08 | -0.13 | -0.03 | 0.01 | -0.04 | 0.14 | -0.09 | 0.06 | 1.00 | | | |
| 10. External/professional support | -0.10 | -0.09 | -0.13 | 0.07 | -0.04 | -0.03 | -0.03 | 0.03 | 0.21* | 1.00 | | |
| 11. Positive coping strategies | -0.10 | -0.06 | -0.13 | 0.08 | 0.01 | -0.02 | -0.11 | 0.05 | 0.15 | 0.13 | 1.00 | |

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

VABS, Vineland Adaptive Behaviour Scale; DBC, Developmental Behaviour Checklist.

Differences between high and low parent stress

A median split was conducted to divide the sample into two groups according to level of parent stress (low vs. high). An independent samples *t*-test was conducted to compare the groups across variables. Results of this analysis are outlined in Table 5. They show significant differences between the groups for difficulty of care-giving tasks, difficult child behaviour during care-giving tasks, level of child disability, DBC total problem behaviour, cognitive appraisal of care-giving responsibilities, and positive coping strategies were all in the expected direction. Specifically, mothers in the high stress group appraised their care-giving role more negatively, perceived care-giving tasks as more difficult and complex, experienced more difficult child behaviour during care-giving and reported higher levels of total problem behaviour. In addition, mothers in the high stress group had children with a lower level of functioning.

Table 5 Comparison of parents with high and low care-giving stress

| Variables | Low stress (n = 53) | | High stress (n = 52) | | SD |
|---|------------------------|-------|-------------------------|-------|---------|
| | Mean | SD | Mean | t | |
| Cognitive appraisal of care-giving responsibilities | 44.60 | 15.41 | 64.36 | 18.44 | -5.96** |
| Difficulty of care-giving tasks | 20.04 | 7.31 | 32.35 | 10.34 | -7.06** |
| Time involved in care-giving tasks | 42.07 | 10.76 | 43.62 | 9.13 | -0.80 |
| Difficult child behaviour during care-giving tasks | 22.18 | 7.78 | 30.49 | 6.76 | -5.84** |
| Level of child disability (VABS) | 60.83 | 13.87 | 55.14 | 12.91 | 2.14* |
| DBC total problem behaviour | 39.42 | 24.98 | 62.15 | 24.91 | -4.67** |
| Partner/family support | 30.92 | 14.74 | 26.58 | 12.12 | 1.65 |
| Friend support | 12.84 | 7.46 | 12.13 | 6.22 | 0.52 |
| External/professional support | 25.13 | 11.68 | 23.31 | 10.96 | 0.83 |
| Positive coping strategies | 25.49 | 10.94 | 26.65 | 9.03 | -0.59 |

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

VABS, Vineland Adaptive Behaviour Scale; DBC, Developmental Behaviour Checklist.

Test of mediating effects

Hierarchical regression procedures were used to examine the mediating effect of mothers' cognitive appraisal of their care-giving responsibilities on the relationship between the predictor variables (difficulty of care-giving tasks, time involved in care-giving tasks, difficult child behaviour during care-giving tasks, level of child disability, DBC total problem behaviour) and the outcome variable (level of parent stress). First, scores for difficulty of care-giving tasks, time involved in care-giving tasks, difficult child behaviour during care-giving tasks, level of child disability and DBC total problem behaviour were entered into the regression as predictors. In order to test for mediation, cognitive appraisal scores were entered into the analysis as the second step. Results of this analysis are summarized in Table 6. This shows that the predictor variables accounted for a significant amount of variance (71%), and that the variables of difficulty of care-giving tasks (57%), difficult child behaviour during care-giving tasks (35%) and level of child disability (13%) make unique and statistically significant contributions towards predicting parent stress. The addition of the mediator variable (cognitive appraisal of care-giving responsibilities) resulted in a significant increment (3%) in variance explained by the model, with associated reductions in the variance explained by individual predictor variables (difficulty of care-giving tasks - 51%, difficult child behaviour during care-giving tasks - 25%, level of child disability - 2%). However, the unique contribution of difficulty of care-giving tasks and difficult child behaviour during care-giving tasks continued to be significant, and therefore there was no evidence to support that cognitive appraisal of care-giving responsibilities has a mediating effect between these two predictor variables and level of parent stress. If cognitive appraisal mediated the effect of the predictor variables on level of parent stress, then the initial significant independent contribution of the predictor variables on the outcome variable would reduce and be no longer significant once cognitive appraisal scores were entered (Baron & Kenny 1986).

Table 6 Hierarchical regression – summary of mediator effects on mothers' level of care-giving stress

| Variable | R ² | R ² change | F | B | Beta | t |
|---|----------------|-----------------------|----------|-------|-------|---------|
| Step 1 | 0.71 | 0.71*** | 46.58*** | | | |
| Difficulty of care-giving tasks | | | | 0.51 | 0.57 | 7.71*** |
| Time involved in care-giving tasks | | | | -0.03 | -0.03 | -0.50 |
| Difficult child behaviour during care-giving tasks | | | | 0.42 | 0.35 | 4.54*** |
| Level of child disability (VABS) | | | | -1.3 | -0.13 | -2.22* |
| DBC total problem behaviour | | | | 0.01 | 0.03 | 0.38 |
| Step 2 | 0.74 | 0.03** | 45.43*** | | | |
| Difficulty of care-giving tasks | | | | 0.46 | 0.51 | 7.14*** |
| Time involved in care-giving tasks | | | | -0.04 | -0.04 | -0.65 |
| Difficult child behaviour during care-giving tasks | | | | 0.30 | 0.25 | 3.15** |
| Level of child disability (VABS) | | | | -1.1 | -0.11 | -1.96 |
| DBC total problem behaviour | | | | 0.01 | 0.02 | 0.29 |
| Cognitive appraisal of care-giving responsibilities | | | | 0.12 | 0.24 | 3.49** |

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

VABS, Vineland Adaptive Behaviour Scale; DBC, Developmental Behaviour Checklist.

In comparison, the contribution of level of child disability is reduced to non-significance, suggesting that cognitive appraisal plays a mediating role between level of child disability and parent stress. The model as a whole was significant $F_{6,94} = 45.43$, $P < 0.001$; and although there was no evidence to support mediation, difficulty of care-giving tasks (51%), difficult child behaviour during care-giving tasks (25%) and cognitive appraisal of care-giving responsibilities (24%) all make unique and statistically significant contributions towards predicting level of parent stress. Individual regression analyses were also conducted by entering predictor variables separately rather than as a block. These analyses revealed similar results in relation to the mediating effect of cognitive appraisal of care-giving responsibilities on level of parent stress.

Test of moderating effects

Evidence for the moderating effect of partner/family support, friend support, external/professional support and positive coping strategies on the relationship between the predictor variables (difficulty of care-giving tasks, time involved in care-giving tasks, difficult child behaviour during care-giving tasks, level of child disability, DBC total problem behaviour) and the outcome variable (level of parent stress) was examined using hierarchical regression procedures. A total of 20 separate analyses (5 predictor variables \times 4 moderator variables) were conducted. For each analysis, a predictor variable was entered as the first step, followed by one of the moderating variables as the second step. In the third step of each regression, an interaction term for the predictor variable and the moderator variable was entered. In line with recommendations, centred scores (Aiken & West 1991) were utilized to eliminate multi-collinearity effects between the predictor variable, moderator variable and the interaction term.

Evidence for moderating effects occurred if the interaction term explained a significant proportion of the variance beyond that accounted for by the main effects of the two contributing variables (Baron & Kenny 1986). Significant results arising from these regression analyses are summarized in Table 7, and this shows that significant moderator effects are found in only three of the 20 analyses. As a moderator variable, partner/family support buffered the effects of level of child disability on parent stress. In this analysis, the model is significant $F_{1,97} = 6.17$, $P < 0.01$, and accounted for 16% of the variance. Level of child disability made a significant contribution to this variance, and the interaction term (level of child disability \times family/partner support) resulted in a significant increment (6%) and accounted for 25% of the variance. There was no evidence that partner/family support had a moderating effect on the predictor variables

of difficulty of care-giving tasks, time involved in care-giving tasks, difficult child behaviour during care-giving tasks, or DBC total problem behaviour. As a moderator variable, friend support buffered the effects of difficult child behaviour during care-giving tasks on level of parent stress. This model was significant $F_{1,100} = 27.88$, $P < 0.001$, and accounted for a significant amount of variance (46%). Difficult child behaviour during care-giving tasks contributes significantly to this variance (65%), and the interaction between difficult child behaviour and friend support results in a significant increase in variance explained (3%) and accounts for 17% of the variance. Friend support did not have a moderating role in other predictor variables – difficulty of care-giving tasks, time involved in care-giving tasks, level of child disability, or DBC total problem behaviour. Finally, as a moderator variable, external/professional support buffered the effects of DBC total problem behaviour on level of parent stress. The model accounts for 28% of the variance and is significant as a whole $F_{1,100} = 12.93$, $P < 0.001$. DBC total problem behaviour makes a unique contribution to the variance (47%), and the interaction term explains an additional 4% of the variance and overall accounts for 21% of the variance.

Table 7 Hierarchical regression – summary of moderator effects on mothers' level of care-giving stress

| Variable | R ² | R ² change | F | B | Beta | t |
|--|----------------|-----------------------|----------|-------|-------|---------|
| Moderator: family/partner support | 0.16 | 0.06** | 6.17** | | | |
| Level of child disability (VABS) | | | | -0.28 | -0.24 | -2.52* |
| Family/partner support | | | | -0.13 | -0.18 | -1.92 |
| Level of child disability × family/partner support | | | | -0.18 | -0.25 | -2.66** |
| Moderator: friend support | 0.46 | 0.03* | 27.88*** | | | |
| Difficult child behaviour during care-giving tasks | | | | 0.68 | 0.65 | 8.77*** |
| Friend support | | | | -0.01 | -0.01 | -0.03 |
| Difficult behaviour × friend support | | | | -0.20 | -0.17 | -2.17* |
| Moderator: external/professional support | 0.28 | 0.04* | 12.93*** | | | |
| DBC total problem behaviour | | | | 1.95 | 0.47 | 5.44*** |
| External/professional support | | | | -0.07 | -0.08 | -0.90 |
| DBC × external/professional support | | | | -0.62 | -0.21 | -2.39* |

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

VABS, Vineland Adaptive Behaviour Scale; DBC, Developmental Behaviour Checklist.

Discussion

The current study explored the factors that impact upon the level of parent stress associated with caring for a preschool-aged child with developmental disability. The results confirmed that more difficult care-giving tasks and the presence of child behaviour problems when completing care-giving tasks were the most significant contributors to the level of parent stress. In addition, to a lesser degree, higher levels of stress were reported in parents of children with more severe disabilities. These findings are consistent with previous studies which suggest that difficulty of care-giving tasks (McDonald *et al.* 1996), difficult child behaviour during care-giving tasks (Hastings & Brown 2002) and level of child disability (Haveman *et al.* 1997) are associated with parent stress. However, while it is often reported that difficult child behaviour is the major contributor to parent stress, the present study suggests that although difficult child behaviour is an important factor, difficulty of care-giving task is the best predictor of level of parent stress. This finding highlights the need for further research to explore what specific aspects of individual care-giving tasks are difficult for parents. Contextual factors such as lack of experience with care-giving tasks, time of day care-giving tasks are completed, complexity of tasks and unpleasantness of tasks are potentially areas which require investigation. In the present study, parents identified helping and supervising their child at mealtimes, cleaning up after their child, settling their child at bedtime, helping and supervising their child with toileting and advocating on behalf of their child as the five most stressful care-giving tasks. Based on current findings, it

seems reasonable to deduce that these specific tasks may be more difficult for parents, that children may be more likely to engage in difficult behaviours when these tasks are being completed, and that they are more readily influenced by level of child disability. There was no evidence that time involved in care-giving tasks or overall problem child behaviour was associated with level of parent stress.

There was no evidence that cognitive appraisal of care-giving responsibilities has a mediating relationship between difficulty of care-giving tasks or difficult child behaviour during care-giving tasks and level of parent stress. However, although level of child disability is a significant but weaker predictor of parent stress, analysis supports a mediator relationship between cognitive appraisal and level of child disability. This means that parents' cognitive appraisal of their child's level of disability directly influences level of stress. Parents of children with more severe disabilities are more likely to perceive care-giving responsibilities in a negative way, and perceive the tasks associated with caring for their child as beyond their control. This directly results in heightened levels of parent stress. Similar findings are reported by Hastings & Johnson (2001) who found that parents of children with more severe features of autism are more pessimistic. Regardless of the inconsistent findings related to the mediating role of cognitive appraisal in this study, it is an important variable in its own right; and results suggest that cognitive appraisal of care-giving responsibilities is a significant independent predictor of level of parent stress. This is consistent with previous research findings which emphasize the importance of the relationship between cognitive appraisal and parent stress, through either main mediator or moderator effects (Frey *et al.* 1989; Grant & Whittell 2000; Hastings & Johnson 2001).

The present study did not identify large numbers of interaction effects between key variables included in the analysis. In addition, where significant interaction effects were found, there was no pattern or consistency in the findings. Partner/family support tended to influence the effects of level of child disability on parent stress, support from friends buffered the effects of difficult child behaviour during tasks on parent stress, and high levels of support from external agencies or professionals influenced parent stress associated with overall levels of child problem behaviour. While it was anticipated that a greater number of interaction effects would be identified, the finding does not mean that social supports do not have an important role in assisting families to cope with stress associated with care-giving. Rather, the results are consistent with previous studies which demonstrate that parents' experiences of stress differ considerably across families (Dyson 1991; Goode *et al.* 1999), and that this is likely influenced by individual circumstances.

There are certain methodological issues that require consideration in interpreting findings of the present study. First, results are based on data provided by mothers ($n = 105$) of children with developmental disability. While fathers' participation in the study was requested, only a small number ($n = 34$) completed assessment measures, and therefore analysis of data was not conducted. It would be useful for future research to replicate the study with both mothers and fathers as participants, and to compare mothers' and fathers' scores across key variables related to stress, coping and care-giving. Second, findings of the present study may be limited in their generalizability to other samples and to other studies. In the present study, participation was voluntary and based on self-referrals. Demographic information indicates the sample consisted of predominantly two-parent families where parents had relatively high educational level and socio-economic status. In addition, mean age of parents was over 35 years. It cannot be assumed that results would be similar if the sample consisted of younger parents or one-parent families with lower educational and socio-economic backgrounds. Third, this study relied on parent self-report data and did not use any objective or independent assessment of variables. While it is difficult to attain independent measures of many of the constructs (e.g. stress, appraisal) used in the study, it may have been

interesting to request completion of assessment measures by significant others (e.g. extended family members, friends, child's teacher) in relation to their perception of the stress and coping of the parent. Finally, while the study examined several important factors which impact upon parent stress, there are likely other variables which also have the potential to contribute to stress. These may include parenting knowledge and ability, cultural and ethnic factors, family economic status, family composition and sibling relationships to name a few. Examination of all these variables is beyond the scope of the present study.

Results identified difficulty of care-giving tasks, difficult child behaviour during care-giving tasks, and level of child disability as the primary factors which contribute to level of parent stress. Although the hypotheses in relation to mediator and moderator variables were not fully supported, the findings confirm the important role of cognitive appraisal and social support and their impact upon level of parent stress. This study has added to existing research in that it systematically addressed a number of key variables related to parent care-giving and stress. Furthermore, the findings can be readily utilized to guide the development of intervention programmes for families of children with developmental disabilities.

Specifically, based on current findings parent programmes need to incorporate training in strategies to reduce difficult child behaviour, specific routines for dealing with difficult care-giving tasks, stress reduction techniques, suggestions for enhancing partner/family/friend supports, guidelines for developing quality supports from external agencies and professionals, use of positive coping strategies and cognitive behavioural techniques to promote positive appraisals of the care-giving role.

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