Predictors of psychological morbidity in parents of children with intellectual disability.

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Abstract

Objective: This study investigated symptoms of depression and anxiety and their origins in parents caring for intellectually disabled children relative to parents of typically developing children.

Design: A cross-sectional case control study.

Methods: Thirty two parents of children with intellectual disabilities and twenty nine parents of typically developing children completed measures of anxiety and depression, social support, child problem behaviours, sleep quality and caregiver burden.

Results: The parents of children with intellectual disabilities registered much higher depression and anxiety scores on the Hospital Anxiety and Depression Scale and the majority met the established criteria for possible clinical depression and/or anxiety. Of the putative mediators measured, the strongest and most consistent predictor of group differences in distress, as well as individual variations in distress within the group of parents with intellectually disabled children, was caregiver burden. Analyses of its component dimensions indicated that the negative psychosocial consequences of caregiving were particularly predictive of depression, whereas guilt was the main associate of anxiety.

Conclusions: Symptoms of depression and anxiety are highly prevalent in parents of children with intellectual disabilities and different dimensions of caregiver burden predicted depression and anxiety. This suggests that, in developing interventions for this population, attention should be paid to the way in which parental distress presents itself as depression, anxiety, or both, in the individual caregiver.
**Key words:** Anxiety, caregiving, case control study, depression, parents of intellectual disabled children
Introduction

Parents of intellectually disabled children frequently report symptoms of depression and anxiety (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Eisenhower, Baker, & Blacher, 2005; Floyd & Gallagher, 1997; Hastings & Brown, 2002; Hastings et al., 2005a; Hastings et al., 2005b; Piven & Palmer, 1999; Sharpley, Bitsika, & Efremidis, 1997; Yirmiya & Shaked, 2005). In one UK study, for example, 59% of parents caring for a child with autism had scores on the General Health Questionnaire indicative of psychiatric caseness (Bromely, Hare, Davison, & Emerson, 2004). The cost of such psychological morbidity to the immediate family can be enormous. Poor parental mental health has been shown to have deleterious consequences for parenting role, offspring wellbeing, and marital relationships (Dyson, Edgar, & Crnic, 1989; Early Child Care Research Network, 1999; Fisman & Wolf, 1991; Kahn, Brant, & Whitaker, 2004; Pilowsky, Wickramaratne, Nomura, & Weissman, 2006). Distressed parents are more likely to separate and divorce (Pilowsky et al., 2006).

A number of factors have been considered to contribute to the high levels of psychological morbidity in parents of intellectually disabled children. Two key factors: the adequacy of social support and the extent of the child’s problem behaviours have been argued to account for much of the distress observed. Social support has long been regarded to mitigate distress (Bailey, Wolfe, & Wolfe, 1994; Dunn et al., 2001) and considerable research has been directed at its role in parents with an intellectually disabled child. Social support has generally been found to be inversely related to depression and anxiety in such parents (e.g. Gray and Holden, 1992; Hare, Pratt, Burton, Bromely & Emerson, 2004; McCallion, Janicki, & Kolomer, 2004; Weiss, 2002). The child's behavioural problems appear to be a major
source of psychological distress in parents of children with intellectual disabilities (Baker et al., 2003; Blacher & McIntrye, 2006; Floyd & Gallagher, 1997; Maes, Broekman, Dosen, & Nauts, 2003). Higher scores on the Aberrant Behaviour Checklist (Aman, Richmond, Stewart, Bell, & Kissel, 1987) subscales (e.g. lethargy, stereotypical behaviour, and hyperactivity) was associated with greater distress in these parents (Stores, Stores, Fellows, & Buckley, 1998). Further, the more challenging the behaviours that a child exhibits, the greater the recourse to mental health services by parents (Floyd & Gallagher, 1997).

Sleep quality and caregiver burden have been identified as significant predictors of psychological distress in other caregivers (e.g. caregivers for Alzheimer’s sufferers, and people with schizophrenia, and physically disabled children), but have rarely been examined in the context of parents caring for intellectually disabled children. However, one concern for parents of children with Downs syndrome was that they were not getting enough sleep (Hedov, Anneren, & Wikblad, 2002). Sleep quality is an important aspect of well-being and is strongly related to overall quality of life (Zammit, Weiner, Damato, Sillup, & McMillan, 1999), secretion of the stress hormone, cortisol (Spiegel, Leproult, & Van Cauter, 1999), and also to the increased prevalence of depression and anxiety in various caregiver groups (Brummett et al., 2006; Flaskerud, Carter & Lee, 2000; McCurry, Logsdon, Teri, & Vitiello, 2007; Wilcox & King, 1999). For example, parents caring for a child with a physical disability (cystic fibrosis and ventilator dependency) were characterized by both poor sleep quality and depression (Meltzer & Mindell, 2006).

Another source of psychological distress in those caring for demanding others is perceived caregiver burden (Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000;
Maes et al., 2003; Wade, Taylor, Drotar, Stancin, & Yeates, 1998). Perceived burden includes embarrassment, guilt, overload, feelings of entrapment, resentment, isolation from society, and loss of control (Zarit, Reever, & Bach-Peterson, 1980). In parents of children with intellectual disabilities, curtailed employment opportunities, a likely consequence of burden, were associated with feelings of isolation, lack of fulfillment, and low self-esteem (Shearn & Todd, 2000). Further, a higher caregiver burden in parents with intellectually disabilities has been related to a greater need by parents to use external health services (Maes et al., 2003). However, the role of caregiver burden in the high level of depression and anxiety symptoms reported by parents caring for intellectually disabled children has yet to be examined.

The present study aimed to confirm the high levels of psychological morbidity in parents of intellectually disabled children and explore a diverse range of likely sources of depression and anxiety using a case control design. The role of functional social support, child behaviour problems, sleep quality, and caregiver burden were examined. It was hypothesized: first, that parents’ of children with intellectual disabilities would report much higher levels of both depression and anxiety than parents of typically developing children; and second, that poorer social support and sleep quality, more problematic offspring behaviour, and higher perceived caregiver burdens would be associated with greater psychological morbidity.

**Methods**

**Participants**

Participants were 32 parents of children with intellectual disabilities and 29 parents of typically developing children. Cases, i.e. parents of intellectual disabled children, were recruited from syndrome specific family support groups, via invitation letters.
distributed by their respective associations and by advertising on syndrome newsletters and by word of mouth. Inclusion criteria for these parents were: caring for at least one child with Downs, Autism, Cornelia de Lange, or Smith-Magenis syndromes; the intellectually disabled child had to be aged between 3 and 19 years and cared for at home during the school term. The majority of parents reported caring for a child with Autism (66%); the remainder were parents of a child with Downs syndrome (22%) and children with other syndromes (e.g. Cornelia de Lange) (12%). Controls, i.e. parents of typically developing children, were recruited via local schools, media campaigns and advertisements placed within University newspapers. The same age of child and domicile inclusion criteria applied. Attempts were made to match the groups as closely as possible on age, sex, socioeconomic position, ethnicity, and marital status (See Table 1).

Measures

Depression and anxiety

Parental psychological morbidity was measured using the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983), a well-recognised and respected assessment tool. The scale contains 14 four-point items, from 0 (not present) to 3 (considerable), with seven assessing largely the anhedonic rather the somatic aspects of depression (e.g., ‘I have lost interest in my appearance’) and seven assessing anxiety (e.g., ‘I feel tense or wound up’). The item scores are added, giving sub-scale scores for depression and anxiety from zero to 21. The HADS has good concurrent validity (Bramley, Easton, Morley, & Snaith, 1988; Herrmann, 1997), performs well as a psychiatric screening device (Bjelland, Dahl, Haug, & Neckelmann, 2002;
Herrmann, 1997), and boasts good psychometric properties; for example, a Cronbach’s α, an index of internal reliability, of .90 for the depression items and .93 for the anxiety items has been reported (Moorey et al., 1991) with test-retest reliability coefficients as high as .85 for depression and .84 for anxiety (Herrmann, 1997). For the present sample, Cronbach’s α was .86 for both the depression and the anxiety subscales.

Social support

Social support was assessed using the 12-item Support Functions Scale (Dunst, Trivette, & Deal, 1988). Parents rate each source of support available to them including practical (e.g. ‘someone to help take care of my child’) and emotional (e.g. ‘someone to talk to about things that worry me’) support on a 5-point Likert scale ranging from 1, never, to 5, quite often. This scale has been shown to be reliable (Cronbach’s α = .86) and is used extensively in intellectual disability research (e.g. White & Hastings, 2004). A high internal consistency (Cronbach’s α = .89) was also evident for the present sample.

Child’s problem behaviour

The 25-item Strengths and Difficulties Questionnaire (Goodman, 1997), was used to screen for child behaviour problems. The scale has five subscales, with one assessing prosocial behaviour (e.g. ‘kind to younger children’) and four assessing problems behaviours; emotional symptoms (e.g. ‘often unhappy, downhearted or tearful’), conduct disorder (e.g. ‘often argumentative with adults’), hyperactivity (e.g. ‘easily distracted, concentration wonders’), and peer relationships (e.g. rather solitary, tends to play alone’). Parents are asked to rate whether a behaviour is true (1), somewhat true (0) or certainly true (2) of their child with higher scores indicating more
problem behaviours. Some items are reversed scored (e.g. generally obedient, usually does what adults request) so that a true (2) and certainly true (0). The scale has been shown to be reliable (Cronbach’s alpha = .76) and effective at identifying behavioural problems in children (Goodman & Scott, 1999). Further, it has been used extensively in research with intellectually disabled children (Beck, Hastings, Daley & Stephenson, 2004; Hastings, Daley, Burns, & Beck, 2006). For the purposes of our analyses only the problem behaviour total score was used and a satisfactory Cronbach's alpha was obtained in the present sample α =.88.

Sleep quality

The Pittsburgh Sleep Quality Index (Buysse, Reynolds, Monk, Berman, & Kupfer, 1989) is a 19-item self-report questionnaire that assesses sleep quality and disturbance. This index encompasses seven dimensions of sleep: subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleeping medications, and daytime dysfunction. Scores on items range from 0 (no difficulty) in a particular dimension to 3 (severe difficulty). For some items the 0 (not during the past month) to 3 (three or more times a week) scale captures frequency. Examples of items include ‘During the past year, how would you rate your sleeping quality overall?’ and ‘During the past year, how often have you had trouble staying awake while driving, eating meals, or engaging in social activity?’ By summing component scores, a total sleep quality score is obtained that ranges from 0 (good sleep quality) to 21 (poor sleep quality). This index has excellent has been shown to distinguished between ‘good sleepers’, ‘poor sleepers’ and ‘sleeping disorder patients’ over an 18-month period (Buysse et al., 1989). The sum of scores of the seven dimensions yields one global score. The total scale has acceptable internal consistency (Cronbach’s α =
.83) and good test-retest reliability (r = .85) (Buysse et al., 1989). In the present study Cronbach’s α for the total scale was .86. The scale has also recently been used to assess sleep quality in caregiver research (Brummett et al., 2006) including studies of parents of children with physical disabilities (Wright, Tancredi, Yundt, & Larin, 2006).

Caregiver burden

As a measure of parental caregiver burden, an adapted version of the 22-item Caregiver Burden Index was used (Zarit, Todd, Zarit, 1986). This index was designed to assess the stresses experienced by family caregivers of elderly and disabled persons. It can be administered as interview or questionnaire; we opted for the latter approach. Questions were amended replacing ‘your relative’ with ‘your child’. Examples of items include ‘Do you feel that because of the time you spend with your child that you don’t have enough time for yourself?’, ‘Are you afraid what the future holds for your child?’, and ‘Overall, how burdened do you feel in caring for your child?’. Responses range from never (0) to nearly always (4). It has been used extensively in caregiver research (Ukpong, 2006; Vedhara et al., 2002). High internal consistency (Cronbach’s α = .94) was evident for the present sample.

Procedure

From 101 contacts, 61 parents were recruited to the study and attended a session at the University where they provided informed consent. The purposes of the study were explained in detail and participants were given a pack of psychosocial questionnaires to complete. They had the option of completing the questionnaires on site or at home, returning in a prepaid envelope. The study was approved by the relevant Research Ethics Committees.
**Statistical analyses**

Initial analyses of group differences were by Chi-square and univariate ANOVA; in the latter, $\eta^2$ is reported as a measure of effect size. Subsequent, analyses were by regression, mainly testing hierarchical models. Linear regression was applied with continuous HADS depression and anxiety scores, and logistic regression was used when possible pathology was determined, yielding binary variables, using established cut-off values. For analysis involving the whole sample, parental group was always entered at step 1 as a dummy variable. Regression analyses were also applied within parental groups. Slight variations in degrees of freedom reflect occasional missing data for some variables.

**Results**

*Descriptive characteristics of parental groups*

Since the parents of children with Down’s syndrome did not differ from the other cases in terms of the outcome variables, parents of intellectually disabled children were treated as a uniform case group. The socio-demographic and summary childcare characteristics of the two parental groups are presented in Table 1. It is evident that the groups are reasonably well matched on most variables. There are two exceptions; parents of intellectually disabled children were slightly older on average and were less likely to be currently employed outside the home.

[Insert Table 1 about here]

*Group differences in depression and anxiety*

Parents caring for intellectually disabled children had much higher levels of depressive symptomatology than parents of typically developing children, $F(1, 59) =$
41.64, \( p < .001, \eta^2 = .414 \). They also had much higher anxiety scores, \( F(1, 59) = 43.12, \ p < .001, \eta^2 = .422 \). A cut-off of \( \geq 8 \) on the depression subscale of the HADS was used as an indicator of possible pathology (Zigmond & Snaith, 1983). Parents of intellectually disabled children were much more likely to reach this criterion than parents of typically developing children \( \chi^2 (1) = 18.06, \ p < .001 \). The same was true using the same recommended cut-off for anxiety \( \chi^2 (1) = 23.22, \ p < .001 \). Table 2 presents the summary data.

[Insert Table 2 about here]

*Group differences in social support, sleep quality, child problem and prosocial behaviours, and caregiver burden*

There were significant group differences for four all of these variables. Parents of intellectually disabled children reported poorer functional social support, \( F(1, 59) = 6.53, p = .01, \eta^2 = .100 \), and sleep quality, \( F(1, 59) = 24.46, p < .001, \eta^2 = .293 \), greater child behaviour problems, \( F(1, 57) = 85.00, p < .001, \eta^2 = .599 \), and higher caregiver burden, \( F(1, 57) = 40.93, p < .001, \eta^2 = .418 \). The descriptive statistics are presented in Table 3.

[Insert Table 3 about here]

*Contribution of potential mediator variables to group differences in depression and anxiety*

In hierarchical linear regression analysis, in which parental group was entered at step 1 and the potential mediators individually at step 2, child behaviour problems, \( \beta = .42, t = 2.28, p = .007, \Delta R^2 = .07 \), social support, \( \beta = -.26, t = 2.59, p = .01, \Delta R^2 = .06 \),
sleep quality, $\beta = .44$, $t = 4.17$, $p < .001$, $\Delta R^2 = .14$, and caregiving burden $\beta = .53$, $t = 4.58$, $p < .001$, $\Delta R^2 = .17$ were significant predictors of depressive symptomatology. In these analyses, $\beta$ for parental group was attenuated from .64 at step 1 to .56, .41, .32 and .31 at step 2, respectively. Accordingly, we tested for mediation in each case using the Goodman test (Goodman, 1960). In the case of child problem behaviours, sleep quality and caregiver burden, there was evidence of mediation, $z = 2.65$, $p = .007$, $z = 3.23$, $p = .001$, and $z = 3.65$, $p < .001$. Thus, it would seem that child behaviour problems, sleep quality and caregiver burden were not only associated with depression independently of parental group in these models, but they accounted, at least in part, for case/control group differences in depression. The outcome of the mediation analysis is presented in Figure 1.

A further hierarchical regression analysis was undertaken, in which at step 2, social support, child behaviour problems, sleep quality and caregiver burden were entered. In this analysis, the effect of parental group was no longer significant, $\beta = .16$, $p = .25$. However, both social support, $\beta = -.24$, $p = .009$, sleep quality, $\beta = .23$, $p = .04$, and caregiver burden, $\beta = .48$, $p = .001$ emerged as significant predictors of depressive symptomatology. In a final regression model, parental group was again entered at step 1. Age and work outside the home were entered at step 2 since they differentiated groups, and social support, child behaviour problems, sleep quality and caregiver burden entered at step 3. Again, only social support, $\beta = -.19$, $p = .03$, and caregiver burden, $\beta = .29$, $p = .04$ were associated with depressive symptomatology; there was no influence of parental group, $\beta = .10$, $p = .44$.

Similar analyses were undertaken with anxiety score as the dependent variable. In these analyses, problem behaviours, $\beta = .35$, $t = 2.28$, $p = .02$, $\Delta R^2 = .05$, sleep quality,
\(\beta = .38, t = 3.51, p = .001, \Delta R^2 = .10,\) and caregiver burden, \(\beta = .60, t = 5.77, p < .001, \Delta R^2 = .22,\) emerged as predictors of anxiety. In these analyses, \(\beta\) for parental group was attenuated from .66 at step 1 to .40, .45 and .29 at step 2, respectively.

Mediation analysis confirmed that child behaviour problems, \(z = 2.23, p = .02,\) sleep quality, \(z = 3.23, p = .001,\) and caregiver burden, \(z = 4.15, p < .001,\) were candidate mediators, at least in part, of the association between parental group and anxiety score. The mediation analysis is presented in Figure 2. In the model in which both child behaviour problems, sleep quality and caregiver burden were entered after parental group, only caregiver burden emerged as a significant predictor of anxiety, \(\beta = .52, p < .001.\) The same was true of the analysis that included age and work outside the home, \(\beta = .51, p = .001.\)

Sensitivity analysis using the HADS cut-off scores for possible pathology

In logistic regression models with parental group entered at step 1 and the potential mediators as step 2, a broadly analogous picture emerged. Child behaviour problems, \(\text{OR} = 1.16, 95\% \text{ CI} = 1.017 – 1.32, p = .02,\) sleep quality, \(\text{OR} = 1.50, 95\% \text{ CI} = 1.10 – 2.05, p = .01,\) and caregiver burden \(\text{OR} = 1.17, 95\% \text{ CI} = 1.06 – 1.28, p = .001,\) proved to be significant predictors of possible depression. In the sleep model, parental group remained a significant predictor of possible depressive pathology, \(\text{OR} = 10.36, 95\% \text{ CI} = 1.81 – 59.21, p = .009,\) but not for models on child behaviour problems, \(\text{OR} = 4.43, 95\% \text{ CI} = 5.41 – 32.28, p = .16,\) and burden, \(\text{OR} = 4.59, 95\% \text{ CI} = 0.65 – 32.47, p = .12.\) In the analysis in which child behaviour problems, sleep quality and caregiver burden were entered simultaneously, only the latter was associated with depression,
OR = 1.16, 95% CI = 1.04 – 1.31, p = .01. In this model, parental group did not significantly predict depression, OR = 4.62, 95% CI = 0.44 – 48.14, p = .20. The same outcomes were apparent with analyses of anxiety; child behaviours, OR = 1.17, 95% CI = 1.02 – 1.33, p = .02, sleep quality, OR = 1.41, 95% CI = 1.05 – 1.90, p = .02, and burden, OR = 1.18, 95% CI = 1.06 – 1.32, p = .003, were associated with possible pathology. Again, there was no effect of parental group on anxiety in these analyses.

*Within group analyses*

Linear regression analyses with each of the potential mediators entered separately as independent variables revealed no significant associations between social support, child behaviour problems, sleep quality, and caregiver burden and depressive symptomatology in the control group. However, for parents of intellectually disabled children, child behaviour problems, \( \beta = .34, t = 2.08, p = .04, R^2 = 13.3 \), social support, \( \beta = -.40, t = 2.39, p = .02, R^2 = .16 \), sleep quality, \( \beta = .56, t = 3.69, p = .001, R^2 = .31 \), and caregiver burden, \( \beta = .64, t = 4.34, p < .001, R^2 = .41 \), predicted depression. In a model, in which all three of these variables were entered simultaneously both social support, \( \beta = -.34, p = .02 \), and caregiver burden, \( \beta = .53, p = .009 \), were significant predictors of depressive symptomatology. This model accounted for 56% of the variance in HADS depression scores within the parents of intellectual disabled children.

In parallel analyses, only caregiver burden within the control group was associated with anxiety scores, \( \beta = .55, t = 3.16, p = .004, R^2 = .30 \). Within the case group, both sleep quality, \( \beta = .50, t = 3.13, p = .004, R^2 = .25 \), and caregiver burden, \( \beta = .66, t = 4.65, p < .001, R^2 = .44 \), predicted anxiety levels. In a model in which sleep quality and
caregiver burden were both entered, only the latter emerged as a significant predictor, \( \beta = .57, t = 3.15, p = .004 \); this model accounted for 45% of the variance in anxiety score among parents caring for a child with an intellectual disability.

In analyses using the criterion ≥ 8 for possible pathology, it was burden which again emerged as the single predictor of depression, OR = 1.33, 95% CI = 1.04 – 1.69, and anxiety, OR = 1.15, 95% CI = 1.00 – 1.32.

**Caregiver burden**

Previous principal component analysis of the caregiver burden index has uncovered three dimensions of burden: negative social and personal consequences, psychological burden, and guilt (Ankri, Andrieu, Beaufils, Grand, & Henrard, 2005). Examples of items loading on these factors are ‘Do you feel that your child currently affects your relationship with other family and friends in a negative way?’, ‘Do you feel strained when you are around your child?’, ‘Do you feel you could do a better job in caring for your child?’, respectively. In regression analyses, entering parental groups at step 1, and scores on three burden dimensions at step 2, negative social and personal consequences was a significant predictor of depressive symptomatology, \( \beta = .34, p = .03 \). Neither of the other two dimensions were significantly associated with depression score. In contrast, the same analysis applied to anxiety scores revealed that guilt was the only caregiver burden dimension to significantly predict anxiety levels, \( \beta = .28, p = .02 \).

**Discussion**

The present study confirmed that parents caring for a child with an intellectual disability report substantial symptoms of depression and anxiety (Dunn *et al* 2001;
Eisenhower et al., 2005; Glidden & Schoolcraft, 2003; Sharpley et al., 1997; Weiss, 2002; Yirmiya & Shaked, 2005). Almost two thirds of the parents of intellectually disabled children in the current study met the conventional criterion for possible depression, and three quarters for possible anxiety. Similar levels of caseness for depression on the HADS were observed in an earlier UK study, although lower estimates of anxiety were reported (White & Hastings, 2004). What is clear from our data and the results of other studies (Carroll, Phillips, Hunt, & Der, 2007; Herrmann, 1997) is that depression and anxiety are co-morbid conditions; in the present study symptoms of depression and anxiety were highly correlated among the parents of intellectually disabled children ($r = .64$). Very few of the parents of typically developing children met the criteria for possible pathology. The depression and anxiety scores for these parents were comparable to those found in recent non-clinical population studies in the UK (Carroll et al., 2007; Crawford, Henry, Crombie, & Taylor, 2001). Further, whereas none of the control parents met the criteria (HADS cutoff $> 11$) for definite depression or anxiety, a third and a half, respectively, of the parents caring for an intellectually disabled child did. In spite of this, none of these parents reported taking anti-depressives and only one was using anxiolytics. Other under-treated at risk populations have been identified previously (Lane, Carroll, Ring, Beevers, & Lip, 2001).

In terms of the potential pathways to distress, cases and controls differed on all four putative mediators. Parents of children with intellectual disabilities reported poorer functional social support and more problematic child repetitive behaviours, outcomes that resonate with the results of previous research (Dunn et al., 2001; Eisenhower et al., 2005; Gray & Holden, 1992; Stores et al., 1998; Weiss, 2002; White...
& Hastings, 2004). In the present study, they also reported poorer sleep quality and a much higher caregiver burden compared to controls. Although, not previously studied in this context, low sleep quality and demanding caregiver burden has been found for caregivers of children of physical disabilities, Alzheimer and multiple sclerosis sufferers, and cancer patients. (Meltzer & Mindell, 2006; Vedhara et al., 2002; Wilcox & King, 1999; Wright et al., 2006). However, in linear regression analyses, with parental group entered as a dummy variable, social support, sleep quality, and caregiver burden emerged as significant predictors of depression. Tests of mediation identified child problem behaviours, sleep quality and caregiver burden as candidate mediators. The same mediators emerged from analyses of anxiety scores. In parallel logistic regression analyses, with possible psychopathology status as the outcome, child behaviour problems, sleep quality and caregiver burden again proved to be key predictors of both depression and anxiety.

Analyses within the group of parents caring for intellectually disabled children implicated much the same variables in depression and anxiety. Sleep quality and caregiver burden were associated with depression and anxiety scores; additionally, social support was related to depression score. In analyses of possible pathological status, however, only caregiver burden predicted whether or not these parents were depressed or anxious. As expected, child problem behaviours were associated with depression and anxiety parents of children with intellectual disabilities (Blacher & McIntyre, 2006; Floyd & Gallagher, 1997; Hastings et al., 2005a; Hastings et al., 2005b). However, in competing analyses problem behaviours in the child were no longer significant in the prediction of depression or anxiety. It is likely that whether or not an association emerges between the extent of behaviour problems and parental
distress depends on what other variables have been included in the analyses. After all, there were large case control group differences in parents’ reports of their children’s behaviour problems in the present study. It is just that other variables better accounted for group differences in depression and anxiety and depression and anxiety *per se*. It is possible that children’s behaviour problems influence parental depression and anxiety largely through parents’ perceptions of the burden they impose. Behaviour problems and caregiver burden were highly correlated in the sample as a whole (*r* = .76).

Throughout our analyses, caregiver burden emerged as the most consistent and robust predictor of both symptomatology and possible pathology. Thus, burden would appear to be as potent a source of distress for parents of intellectually disabled children as it has been observed to be for other caregiver groups (Bibou-Nakou, Dikaiou, & Bairactaris, 1997; Clyburn *et al*., 2000; Wade *et al*., 1998; Vedhara *et al*., 2002).

Caregiver burden is a broad concept encompassing feelings of embarrassment and guilt, a sense of entrapment, resentment, and the experience of loss and isolation from society (Zarit *et al*., 1980). A recent principal components analysis distilled three dimensions of burden from the scale used in the current study: negative social and personal consequences, psychological burden, and guilt (Ankri, *et al*., 2005). The first of these proved to be the strongest predictor of depressive symptomatology in parents caring for an intellectually disabled child, whereas the last was the only significant predictor of anxiety scores. Thus, it would appear that symptoms of depression are manifest when parents feel that their social and personal lives are constrained and disrupted as a result of their caring role. There is indirect evidence in favour of this contention. Parents of children with Down’s syndrome and autism were found to experience more distress
when their social and work life was restricted as a result of their caring role (Hare, et al., 2004; Roach, Orsmond, & Barratt, 1999; Shearn & Todd, 2000). Similarly, parents of children with pervasive developmental disorders were found to have a poorer quality of life, compared to controls, when their social relationships were impaired (Mugno, Ruta, D'Arrigo, & Mazzone, 2007).

Originating in family stress research, the ambiguous loss theory (Boss, Caron, Horbal, & Mortimer, 1990) considers that many parents of children with autism experience a sense of ambiguous loss. Since caring in this context is neither stable nor predictable, parents struggle to manage and tolerate this burden of ambiguity. The identity loss, consequent on parents’ failure to separate their own identity from that of their child, results in distress. Ambiguity about roles and responsibilities has been found to contribute to depressive symptomatology in caregivers of dementia patients (Boss et al., 1990). More telling in the current context, identity ambiguity in parents of children with intellectual disabilities, but not the severity of autism spectrum disorder symptoms (e.g. communication, social interaction, and restricted/repetitive interests, was a significant predictor of depressive symptoms (O'Brien, 2007).

In contrast, guilt was most the potent dimension of caregiver burden to predict anxiety scores in these parents. This finding is broadly consistent with the results of previous studies. A number of studies have observed that the parents of children with intellectual disabilities who reported feelings of guilt also indicated that they lacked confidence in their parenting abilities and decision-making which, in turn, was associated with increased distress, including anxiety (Benderix, Nordstrom, & Sivberg, 2006; Hedov et al., 2002; Hilton, Hunt, & Petticrew, 2007; Lenhard, Breitenbach, Ebert, Schindelhauer-Deutscher, & Henn, 2005).
The current study has a number of limitations. First, the data are cross-sectional. Accordingly, the high levels of distress observed in those parents caring for intellectually disabled children may be transitory. However, there is evidence that the distress observed in this population persists over time (Dyson, 1993; Glidden & Schoolcraft, 2003). Second, our sample size might be regarded as small. Parents of intellectually disabled children are, for obvious reasons, notoriously difficult to recruit for research purposes and this study is of the same order of magnitude of many of the other published case control studies (Padeliadu, 1998; Roach et al., 1999; Weiss, 2002). Third, women outnumbered men, but this is hardly surprising since they predominate as primary caregivers. Importantly, the ratio of women to men was almost identical in the two parental groups. Finally, employment outside the home and age differentiated the groups. However, the main associations were still evident following adjustment for these variables.

In summary, relative to parents of typically developing children, parents caring for intellectually disabled children reported high levels of depression and anxiety symptoms. Further, the majority of these parents met the established criteria for possible clinical depression and/or anxiety. The strongest and most consistent predictor of group differences in distress, as well as individual variations in distress within the group of parents with intellectually disabled children, was caregiver burden. Analyses of its component dimensions indicated that the negative social and personal consequences of caregiving were associated with depression, whereas guilt was associated with anxiety. This suggests that psychosocial interventions for this population might be tailored depending on how the distress presents itself as depression, anxiety, or both, in the individual caregiver.
References


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Table 1. Demographic characteristics and child care responsibilities of parental groups

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<th>Cases (N = 32)</th>
<th>Controls (N = 29)</th>
<th>Test of difference</th>
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<tr>
<td>Sex (Female)</td>
<td>24 (75%)</td>
<td>20 (69%)</td>
<td>$\chi^2 (1) = 0.06, p = .81$</td>
</tr>
<tr>
<td>Marital Status (Partnered)</td>
<td>28 (88%)</td>
<td>20 (70%)</td>
<td>$\chi^2 (1) = 2.11, p = .15$</td>
</tr>
<tr>
<td>Ethnicity (Caucasian)</td>
<td>29 (91%)</td>
<td>26 (90%)</td>
<td>$\chi^2 (1) = 0.00, p = 1.00$</td>
</tr>
<tr>
<td>Occupational status (Professional)</td>
<td>15 (47%)</td>
<td>16 (55%)</td>
<td>$\chi^2 (1) = 0.15, p = .70$</td>
</tr>
<tr>
<td>Currently employed outside the home</td>
<td>22 (69%)</td>
<td>29 (100%)</td>
<td>$\chi^2 (1) = 7.19, p = .007$</td>
</tr>
<tr>
<td>Mean age (SD) years</td>
<td>42.8 (5.78)</td>
<td>39.9 (4.36)</td>
<td>$F (1,59) = 4.76, p = .03$</td>
</tr>
<tr>
<td>Mean body mass index (SD) kg/m$^2$</td>
<td>26.8 (4.27)</td>
<td>24.7 (4.10)</td>
<td>$F (1,56) = 3.80, p = .06$</td>
</tr>
<tr>
<td>Primary caregiver</td>
<td>25 (78%)</td>
<td>21 (72%)</td>
<td>$\chi^2 (1) = 0.05, p = .83$</td>
</tr>
<tr>
<td>Mean age of main care recipient (SD) years</td>
<td>11.2 (3.99)</td>
<td>8.9 (4.57)</td>
<td>$F (1,54) = 3.88, p = .06$</td>
</tr>
</tbody>
</table>
Table 2. Symptoms of depression and anxiety by parent group

<table>
<thead>
<tr>
<th></th>
<th>Cases (N = 32)</th>
<th>Control (N = 29)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean depression score (SD)</td>
<td>8.6 (3.92)</td>
<td>3.2 (2.31)</td>
</tr>
<tr>
<td>Mean anxiety score (SD)</td>
<td>11.0 (4.40)</td>
<td>5.0 (2.44)</td>
</tr>
<tr>
<td>Depression score ≥ 8 (%)</td>
<td>20 (63%)</td>
<td>2 (7%)</td>
</tr>
<tr>
<td>Anxiety score ≥ 8 (%)</td>
<td>24 (75%)</td>
<td>3 (10%)</td>
</tr>
</tbody>
</table>
Table 3. Social support, sleep quality, child problem behaviours, caregiving burden by parent group

<table>
<thead>
<tr>
<th></th>
<th>Cases (N = 32)</th>
<th>Control (N = 29)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean social support score (SD)</td>
<td>31.3 (9.76)</td>
<td>37.9 (10.37)</td>
</tr>
<tr>
<td>Mean sleep quality score (SD)</td>
<td>10.0 (2.48)</td>
<td>7.1 (2.09)</td>
</tr>
<tr>
<td>Mean child behaviour problem score (SD)</td>
<td>22.9 (5.88)</td>
<td>9.9 (4.89)</td>
</tr>
<tr>
<td>Mean caregiver burden score (SD)</td>
<td>44.0 (14.26)</td>
<td>22.9 (10.67)</td>
</tr>
</tbody>
</table>
Figure captions

Figure 1. Mediation analysis of the association between parental group and depressive symptomatology for child problem behaviours, sleep quality and caregiver burden: statistics are standardised regression coefficients

Figure 2. Mediation analysis of the association between parental group and anxiety scores for child problem behaviours, sleep quality and caregiver burden: statistics are standardised regression coefficients
Anxiety score

Parental groups

Anxiety score

Child behaviours

Parental groups

Sleep quality

Parental groups

Care burden

Parental groups

Anxiety score

Anxiety score

Anxiety score

Anxiety score