Predictors of Psychological Morbidity in Parents of Children with Intellectual Disabilities

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Abstract

Objective: This study examined predictors of excess psychological morbidity in parents of children with intellectual disabilities.

Methods: Thirty two parents of children with intellectual disabilities and 29 parents of typically developing children completed the Hospital Depression and Anxiety Scale, and measures of social support, child problem behaviours, sleep quality, and perceived caregiver burden.

Results: Parents of children with intellectual disabilities registered high depression and anxiety scores and the majority met the criteria for possible clinical depression and/or anxiety. The strongest predictor of psychological morbidity was caregiver burden. Analyses of its component dimensions indicated that feelings of guilt held the greatest consequence for depression and anxiety.

Conclusions: Caregiver burden, in general, and its guilt component, in particular, predicted symptoms of depression and anxiety in parents of children with intellectual disabilities. Assisting such parents to resolve their feelings of guilt should benefit their psychological status.

Key words: Anxiety, Caregiving, Depression, Parents of Children with Intellectual Disability
Parents of children with intellectual disabilities frequently report symptoms of depression and anxiety (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Hastings et al., 2005; Yirmiya & Shaked, 2005). 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 generally been found to be inversely related to depression and anxiety in such parents (Gray & Holden, 1992; Weiss, 2002; White & Hastings, 2004), whereas the child’s problem behaviours are positively associated with these symptoms (Baker et al., 2003; Blacher & McIntyre, 2006). More recently, within the wider caregiving context, sleep quality and caregiver burden have been identified as significant predictors of psychological morbidity (Brummett et al., 2006; Magana, Ramirez Garcia, Hernandez, & Cortez, 2007; Meltzer & Mindell, 2006; Phipps, Dunavant, Lensing, & Rai, 2005; Thompson, Fan, Unutzer, & Katon, in press). These are factors amenable to psychological intervention (Carter, 2006; Ostwald, Hepburn, Caron, Burns, & Mantell, 1999). However, sleep quality and caregiving burden have rarely been examined as possible predictors of depression and anxiety in parents caring for children with intellectual disabilities.

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 caring for a child with intellectual disabilities. It has generally been found to minimize the impact of caregiving on parental distress in such parents; those with greater social support show better psychological adjustment (Gray & Holden, 1992; Dunn et al., 2001). 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 & McIntyre, 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) were associated with greater distress (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 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 Karine, Leproult Rachel, & Eve, 1999), and also to the increased prevalence of depression and anxiety in various caregiver groups (Brummett et al., 2006; 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 & Moore, in press). Further, one concern for parents of children with Down syndrome was that they were not getting enough sleep (Hedov, Anneren, & Wikblad, 2002). Despite being an issue for parents of children with intellectual disabilities, the impact of sleep quality on parental depression and anxiety has rarely been examined in this context.

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). In addition, a higher caregiver burden in parents of children 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 symptoms reported by parents caring for children with intellectual disabilities has yet to be examined.

The present study aimed to confirm the high levels of depression and anxiety in parents of children with intellectual disabilities using a case control design and then to explore the role of social support, child behaviour problems, sleep quality, and caregiver burden in the excess psychological morbidity observed in this group. The study was guided by the ABCX model (McGubbin & Patterson, 1983) which provides a framework for understanding the relationships between caregiving variables, available coping resources, and psychological outcomes. It was hypothesized: first, that parents of children with intellectual disabilities would report much higher levels of both depression and anxiety than parents of children who were typically developing; and second, that poorer social support and sleep quality, more problematic offspring behaviour, and higher perceived caregiver burden would be associated with their greater psychological morbidity.

**Methods**

*Participants and procedure*
Participants were 32 parents of children with intellectual disabilities and 29 parents of typically developing children. Parents of intellectual disabled children were recruited via invitation letters distributed by their respective associations and by adverts in local newspapers and syndrome newsletters, family support groups 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. Since the emotional reaction of parental caregivers is highly influenced by the diagnostic process (Graungaard & Skov, 2007), we aimed to avoid this particular event and focus on the parents stressful experiences of caring \textit{per se}. Thus, in keeping with existing research (Hastings, Daley, Burns, & Beck, 2006), intellectually disabled children had to be aged between 3 and 19 years and cared for at home during the school term. The majority of these parents self-reported caring for a child with Autism (66%); the remainder caring for a child with Downs syndrome (22%) and children with other syndromes (e.g. Cornelia de Lange) (12%). Controls were parents of typically developing children who were recruited via local schools, media campaigns and advertisements placed within University newspapers. The same age of child and domicile inclusion criteria applied.

One hundred and one parents contacted us about participating and 61 agreed to participate. Those who did not participate almost invariably cited geographical distance from the University, or an unwillingness to give blood or receive a vaccination as their reasons. It should be noted that the present cross-sectional data were derived from a longitudinal study of caregiving and immunity. Participants were administered a pack of questionnaires and had the option of completing the questionnaires at the University or at home, returning them in a prepaid envelope. The study was approved by the relevant Research Ethics Committees and all participants gave informed consent.

\textbf{Measures}

\textbf{Depression and anxiety}

Parental psychological morbidity was measured using the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983). 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 scale has been used in research with parents of children.
with intellectual disabilities (Hastings & Brown, 2002; Hastings et al., 2005). For the present sample, Cronbach’s $\alpha$ 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 sources of support available to them (e.g. ‘someone to help take care of my child’ and (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 used previously in intellectual disability research (White & Hastings, 2004). A high internal consistency (Cronbach’s $\alpha$ =.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 and four assessing problems behaviours. 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. 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 $\alpha = .88$.

Sleep quality
The 19-item Pittsburgh Sleep Quality Index (Buysse, Reynolds, Monk, Berman, & Kupfer, 1989) was used to assess sleep quality and disturbance. This index encompasses several dimensions of sleep from subjective sleep quality, sleep latency, to daytime dysfunction. Scores on items range from 0 (no difficulty) to 3 (severe difficulty). By summing component scores, a total sleep quality score is obtained that ranges from 0 (good sleep quality) to 21 (poor sleep quality). In the present study Cronbach’s $\alpha$ for the total scale was .86. The scale has also recently been used to assess sleep quality in caregiver research (Brummett et al., 2006).

Caregiver burden
As a measure of parental caregiver burden, an adapted version of the 22-item Caregiver Burden Index was used (Zarit et al., 1980). 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). High internal consistency (Cronbach’s $\alpha = .94$) was evident for the present sample. 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. This study examined both the overall scale score and scores on the three individual dimensions in order to elucidate possible future intervention strategies.

All of the above measures have good concurrent and/or criterion validity

**Statistical analyses**

Initial analyses of group differences were by Chi-square and univariate ANOVA and ANCOVA, with $\eta^2$ reported as a measure of effect size. These analyses were employed to test the first hypothesis. Subsequent analysis within the parents of children with intellectual disabilities was by regression. Linear regression was applied with continuous HADS depression and anxiety scores, and logistic regression was used when the dependent variable was binary. A binary variable for depression and anxiety pathology was formed using the established cut-off values of $\geq 8$ for possible caseness. This cut-off reliably identifies possible cases with a less than one percent false negative rate (Zigmond & Snaith, 1983). The regression analyses were used to test the second hypothesis.

**Results**

**Group differences in depression and anxiety**

Since the parents of children with Downs syndrome and other syndromes did not differ from the parents of children on the autistic spectrum on the outcome variables, these parents were treated
as a uniform group. The summary characteristics of the caregivers and controls are presented in Table 1. As can be seen, there are substantial differences between parental groups in depression and anxiety. In addition, although occupational status did not differ between the two parental groups, the parents of children with intellectual disabilities were slightly older, cared for older children, and were less likely to be currently employed outside the home. Accordingly, variations in depression and anxiety scores were re-examined with adjustment for these variables. The large differences in depression, $F(1, 54) = 29.04, p < .001, \eta^2 = .350$, and anxiety, $F(1, 54) = 33.08, p < .001, \eta^2 = .380$, scores remained.

[Insert Table 1 about here]

**Within group analyses**

Analyses now focused on whether social support, child behaviour problems, sleep quality, and caregiver burden accounted for this excess depression and anxiety among the cases. Child behaviour problems, $\beta = .34, t = 2.08, p = .04, R^2 = .13$, 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, $\beta = .64, t = 4.34, p < .001, R^2 = .41$, all separately predicted depression. However, in a model, in which all four of these variables were entered simultaneously, only 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 variation in depression scores among parents caring for intellectual disabled children. With regard to anxiety scores, 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, $\beta = .57, p = .004$, and the model accounted for 45% of the variation in anxiety scores. 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, $p = .013$, and anxiety, OR = 1.15, 95% CI = 1.00 – 1.32, $p = .019$.

**Caregiver burden**

In regression analyses, entering all three burden components: negative social and personal consequences, psychological burden, and guilt, it was guilt that emerged as the strongest predictor of both depression, $\beta = .35, p = .07$, and anxiety, $\beta = .49, p = .008$, scores. Of the four
items measuring guilt, responses to the item ‘Do you feel that you don’t have enough money to care for your child, in addition to the rest of your expenses?’ were significantly associated with both depression $\beta = .41, p = .03$ and anxiety scores, $\beta = .36, p = .03$. In addition, parents’ response to the item ‘Do you feel you could do a better job in caring for your child?’ significantly predicted anxiety, $\beta = .39, p = .02$.

**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; Yirmiya & Shaked, 2005). Almost two thirds of the parents of intellectually disabled children in the current study met the conventional criterion for possible clinical 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). 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-depressants, only one was using anxiolytic medication, and none were receiving formal cognitive behaviour therapy.

In line with previous research, poor social support and more problematic child behaviours were associated with increased psychological morbidity in parents caring for a child with an intellectual disability (Dunn et al., 2001; Gray & Holden, 1992; White & Hastings, 2004). Thus, our findings are consistent with the ABCX model (McGubbin & Patterson, 1983), which considers that child behaviours and social support are key factors in the etiology of parental psychological distress. Although, not previously studied in this context, poor sleep quality and a high caregiver burden were, as expected, associated with higher levels of both depression and anxiety. This extends results from other caregiving contexts (Brummett et al., 2006; Meltzer & Mindell, 2006; Vedhara et al., 2002; Wright, Tancredi, Yundt, & Larin, 2006). However, it is possible that whether or not an independent association emerges in studies between some of these variables and psychological morbidity depends on what has been included in the analyses. In competitive analyses in the current study, caregiving burden emerged as by far the strongest independent predictor of depression and anxiety.

Caregiver burden is a broad concept that has been shown to encompass three principal components: negative social and personal consequences; psychological burden; and guilt (Ankri
et al., 2005). It was the latter of these that proved to be the strongest predictor of psychological morbidity in parents caring for an intellectually disabled child. There is indirect evidence in favor of this contention. 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; Lenhard, Breitenbach, Ebert, Schindelhauer-Deutscher, & Henn, 2005).

The current study has a number of limitations. First, the analyses are cross-sectional. Accordingly, the high levels of psychological morbidity observed in parents caring for children with intellectual disabilities may be transitory. However, there is evidence that high levels of depression in this population persist over time (Dyson, 1993; Glidden & Schoolcraft, 2003). Further, in the present study, perceived stress scores were stable over a 6-month period1. 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 other published studies (Weiss, 2002). Finally, employment outside the home and age of caregiver and age of care recipient differentiated the groups. However, the main differences in psychological morbidity between caregivers and controls were still evident following adjustment for these variables.

In summary, relative to parents of typically developing children, parents caring for children with intellectual disabilities reported high levels of depression and anxiety; the majority of these parents met the established criteria for possible clinical depression and/or anxiety. The strongest and most consistent predictor of psychological morbidity was caregiver burden. Guilt was the component of burden that was most associated with depression and anxiety. In the context of bereavement, formally addressing guilt through psychological intervention has been reported to ameliorate symptoms of depression and anxiety (Nikcevic, Kuczmierczyk, & Nicolaides, 2007). Thus, assisting parents to resolve the feelings of guilt that are frequently a consequence of caring for an intellectually disabled child should yield similar dividends.

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1 As indicated, data are derived from a longitudinal study on stress and immunity in parents of children with intellectual disabilities; the Perceived Stress Scale was completed by parents at three time points: baseline, 1-month and 6-months.
Acknowledgements

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References


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

<table>
<thead>
<tr>
<th></th>
<th>Caregivers (N = 32)</th>
<th>Controls (N = 29)</th>
<th>Test of difference</th>
</tr>
</thead>
<tbody>
<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>23 (72%)</td>
<td>28 (96%)</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 age of main care recipient (SD) years</td>
<td>11.5 (3.35)</td>
<td>8.8 (4.23)</td>
<td>$F(1, 58) = 7.52$, $p = .008$</td>
</tr>
<tr>
<td>Mean depression score (SD)</td>
<td>8.6 (3.92)</td>
<td>3.2 (2.31)</td>
<td>$F(1, 59) = 41.64$, $p &lt; .001$</td>
</tr>
<tr>
<td>Mean anxiety score (SD)</td>
<td>11.0 (4.40)</td>
<td>5.0 (2.44)</td>
<td>$F(1, 59) = 43.12$, $p &lt; .001$</td>
</tr>
<tr>
<td>Depression score ≥ 8 (%)</td>
<td>20 (63%)</td>
<td>2 (7%)</td>
<td>$\chi^2(1) = 18.06$, $p &lt; .001$</td>
</tr>
<tr>
<td>Anxiety score ≥ 8 (%)</td>
<td>24 (75%)</td>
<td>3 (10%)</td>
<td>$\chi^2(1) = 23.22$, $p &lt; .001$</td>
</tr>
</tbody>
</table>