Predictors of Psychological Morbidity in Parents of Children with Intellectual Disabilities

Stephen Gallagher,1 MSC, Anna C. Phillips,1 PHD, Christopher Oliver,2 PHD, and Douglas Carroll,1 PHD
1School of Sport and Exercise Sciences and 2School of Psychology, University of Birmingham

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 behaviors, 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.
of the stress hormone, cortisol (Spiegel, Leproult, & 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, 2008). Further, one concern for parents of children with Downs 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 (Cybul, 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 behavior 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 behavior, 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 (caregivers) and 29 parents of normally developing children (controls). 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 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 normally 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.

Measures
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 HADS has good concurrent validity
assess sleep quality and disturbance. This index (Reynolds, Monk, Berman, & Kupfer, 1989) was used to obtain sleep quality in the present sample. 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). This index has been shown to distinguish between “good sleepers,” “poor sleepers,” and “sleeping disorder patients” over an 18-month period (Buysse et al., 1989). Global and component scores of the scale were also found to correlate with a sleep diary, actigraphy, and depression scores (Grandner, Kripke, Yoon, & Youngstedt, 2006). Further, sensitivity and specificity rates to the clinical diagnosis of insomnia were 93% and 100%, respectively, for a PSQI Global Score of >8, and 83% and 100% for a diagnosis of insomnia based exclusively on PSQI-derived sleep variable data (Fichtenberg, Putnam, Mann, Zafonte, & Millard, 2001).

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).

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”) on a 5-point Likert scale ranging from 1, never, to 5, quite often. The reliability and validity of the scale were established in a study of 121 parents of children with intellectual disabilities. Coefficient $\alpha$, computed from the average correlation among the scale items was .87 (Dunst et al., 1988). Criterion validity of the scale was examined in terms of covariation between factor scores, total scale score, and a number of parent and family outcome measures (Trivette and Dunst, 1985) including family well-being (McCubbin, Comeau, & Harkins, 1981). This scale has been used previously in intellectual disability research (White & Hastings, 2004). A high internal consistency (Cronbach’s $\alpha = .89$) was evident for the present sample.

Child’s Problem Behavior
The 25-item Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997), was used to screen for child behavior problems. The scale has five subscales, with one assessing prosocial behavior and four assessing problem behaviors. Parents are asked to rate whether a behavior is true (1), somewhat true (0), or certainly true (2) of their child with higher scores indicating more problem behaviors. It has good concurrent validity with scores derived from the SDQ being highly correlated with scores on the Rutter (Rutter, 1967) and Child Behavior Checklist (CBCL) (Achenbach, 1991) questionnaires (Goodman and Scott, 1999). Further, the SDQ has also been found to discriminate satisfactorily between young people attending a mental health clinic and those in the community (Goodman Melzer & Bailey, 1998). For the purposes of our analyses only the problem behavior 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). This index has been shown to distinguish between “good sleepers,” “poor sleepers,” and “sleeping disorder patients” over an 18-month period (Buysse et al., 1989). Global and component scores of the scale were also found to correlate with a sleep diary, actigraphy, and depression scores (Grandner, Kripke, Yoon, & Youngstedt, 2006). Further, sensitivity and specificity rates to the clinical diagnosis of insomnia were 93% and 100%, respectively, for a PSQI Global Score of >8, and 83% and 100% for a diagnosis of insomnia based exclusively on PSQI-derived sleep variable data (Fichtenberg, Putnam, Mann, Zafonte, & Millard, 2001).

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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). The items, derived from clinical and research experience with dementia caregivers, have content validity estimated by correlating the total score with a single global rating of burden ($r = .71$) and it takes into account common areas of concern such as health, finances, social life, and interpersonal relations (Zarit and Zarit, 1990). It has also been found to have high internal consistency (Cronbach’s $\alpha = .88$ and .91), and good test–retest reliability $\alpha = .71$ (Gallagher, Rappaport, Benedict, Lovett, & Silven, 1985; Hebert, Bravo, & Previle, 2000). 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.

Statistical Analyses

Initial analyses of group differences were by chi-squared 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 ≥8 for possible caseness. This cut-off reliably identifies possible cases with a less than one percent false negative rate (Zigmond & Snith, 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 caregiving parents were treated as a uniform group. The summary characteristics of the caregivers and controls are presented in Table I. 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.

Within-Group Analyses

Analyses now focused on whether social support, child behavior problems, sleep quality, and caregiver burden accounted for this excess depression and anxiety among the caregivers. Child behavior 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, odds ratio (OR) = 1.33, 95% confidence interval (CI) = 1.04–1.69, $p = .013$, and anxiety, OR = 1.15, 95% CI = 1.00–1.32, $p = .019$. These linear and logistic regression models were reexamined adjusting for the age of the child; the outcomes remained the same.

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

<table>
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<th>Table I. Demographics, Anxiety, and Depression Levels for Caregivers of Children with Intellectual Disabilities (Caregivers) vs. Caregivers of Normally Developing Children (Controls)</th>
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<td>Occupational status (Professional)</td>
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<td>Depression score ≥8 (%)</td>
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\[ R^2 = 0.380, \quad F(2, 59) = 11.5, \quad p < .001, \quad \chi^2 (1) = 0.00, \quad p = 1.00, \quad \chi^2 (1) = 2.11, \quad p = 0.15, \quad \chi^2 (1) = 0.00, \quad p = 0.15, \quad \chi^2 (1) = 7.19, \quad p = 0.007, \quad \chi^2 (1) = 1.33, \quad 95\% \text{ CI} = 1.00–1.32, \quad p = 0.019. \]
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 cut-off >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 antidepressants, only one was using anxiolytic medication, and none were receiving formal
cognitive behavior therapy.

In line with previous research, poor social support and
more problematic child behaviors 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 behaviors 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 period.1 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, Kuczmierniczky, & 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.

1As 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.
Acknowledgments

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Conflicts of interest: None declared.

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