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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 (Hastings, Kovshoff, Brown, Ward, Espinosa *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; White & Hastings, 2004), whereas the child's problem behaviours are positively associated with these symptoms (Blacher & McIntyre, 2006; White & Hastings, 2004)). More recently, within the wider caregiving context, sleep quality and caregiver burden have been identified as significant predictors of psychological morbidity (Brummett, Babyak, Segler, Vitaliano, Ballard *et al.*, 2006; Meltzer & Moore *in press;* 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.

 Sleep quality is an important aspect of well-being and is strongly related to overall quality of life (Zammit, Weiner, Damato, Sillup, & McMillan, 1999), and to the increased prevalence of depression and anxiety in various caregiver groups (Brummett et al., 2006; Flaskerud, Carter, & Lee, 2000). For example, parents caring for children with physical disabilities were characterized by both poor sleep quality and depression (Meltzer & Moore, *in press*). Another source of psychological morbidity in those caring for demanding others is perceived caregiver burden (Thompson, et al., *in press*; Maes, Broekman, Dosen & Nauts, 2003). 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 caring for children with intellectual disabilities has been related to a greater use of external health services (Maes et al., 2003).

 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 social support, child behaviour problems, sleep quality, and caregiver burden in the excess psychological morbidity observed in this group. 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***

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 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; 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 these parents self-reported caring for a child with Autism (66%); the remainder reported caring for 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.

***Procedures***

One hundred and one parents contacted us about participating and 61 agreed to participate. Participants were each given a pack of questionnaires to complete 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 scale has been used in research with parents of children with intellectual disabilities (Hastings et al., 2005). 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 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 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 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 α =.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 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).

**Caregiver burden**

As a measure of parental caregiver burden, an adapted version of the 22-item Caregiver Burden Index was used (Zarit, Reever, & Bach-Peterson, 1980). 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 α = .94) was evident for the present sample.

***Statistical analyses***

Initial analyses of group differences were by Chi-square and univariate ANOVA and ANCOVA, with η2 reported as a measure of effect size. 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 possible pathology was determined, yielding binary variables, using established cut-off values ≥ 8.

**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, the cases were treated as a uniform group. The summary characteristics of the cases and controls are presented in Table 1. As can be seen, there are substantial differences between parental groups in depression and anxiety. In addition, 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 were re-examined with adjustment for these variables. The large differences in depression, F (1, 54) = 29.04, *p* < .001, η2 = .350, and anxiety, F(1, 54) = 33.08, *p* < .001, η2 = .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,β = .34, t = 2.08, *p* = .04, R2 = .13, social support, β = -.40, t = 2.39, *p* = .02, R2 = .16, sleep quality, β = .56, t = 3.69, *p* = .001, R2 = .31, and caregiver burden, β = .64, t = 4.34, *p* <.001, R2 = .41, all separately predicted depression. However, in a model, in which all four of these variables were entered simultaneously, only social support, β = -.34, *p* = .02, and caregiver burden, β = .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, β = .50, t = 3.13, *p* = .004, R2 = .25, and caregiver burden, β = .66, t = 4.65, *p* <.001, R2 = .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, β = .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***

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 all three components, it was guilt that emerged as the strongest predictor of both depression, β = .35, *p* = .07, and anxiety, β = .49, *p* = .008, scores.

**Discussion**

The present study confirmed that parents caring for a child with an intellectual disability report substantial symptoms of depression and anxiety (Hastings et al., 2005; 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 (Hastings et al., 2005; Gray & Holden, 1992; White & Hastings, 2004). 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 (Meltzer & Mindell, *in press*; Thompson et al., *in press)*. 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 data 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 (Glidden & Schoolcraft, 2003). Further, in the present study, perceived stress scores were stable over a 6-month period[[1]](#footnote-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 (White and Hastings, 2004). 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 cases 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 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 for psychological morbidity.

**References**

Ankri, J., Andrieu, S., Beaufils, B., Grand, A., & Henrard, J. (2005). Beyond the global score of the Zarit Burden Interview: Useful dimensions for clinicians. *International Journal of Geriatric Psychiatry, 20*, 254-260.

Benderix, Y., Nordstrom, B., & Sivberg, B. (2006). Parents' experience of having a child with autism and learning disabilities living in a group home: A case study. *Autism, 10*, 629-641.

Brummett, B. H., Babyak, M. A., Segler, I. C., Vitaliano, P. P., Ballard, E. L., Gwyther, L. P., et al. (2006). Associations among perceptions of social support, negative affect, and quality of sleep in caregivers and noncaregivers. *Health Psychology, 25*, 220-225.

Buysse, D. J., Reynolds, C. F., 3rd, Monk, T. H., Berman, S. R., & Kupfer, D. J. (1989). The Pittsburgh Sleep Quality Index: A new instrument for psychiatric practice and research. *Psychiatry Research, 28*, 193-213.

Carter, P. A. (2006). A brief behavioral sleep intervention for family caregivers of persons with cancer. *Cancer Nursing, 29*, 95-103.

Dunst, C. J., Trivette, C. M., & Deal, A. G. (1988). Enabling and empowering families: Principles and guidelines for practice. *Cambridge, MA: Brookline Books.*

Flaskerud, J. H., Carter, P. A., & Lee, P. (2000). Distressing emotions in female caregivers of people with AIDS, age-related dementias, and advanced-stage cancers. *Perspectives in Psychiatric Care, 36*, 121-130.

Glidden, L. M., & Schoolcraft, S. A. (2003). Depression: Its trajectory and correlates in mothers rearing children with intellectual disability. *Journal of Intellectual Disability Research, 47*, 250-263.

Goodman, R. (1997). The strengths and difficulties questionnaire: A research note. *Journal of Child Psychology and Psychiatry, 38*, 581-586.

Gray, D. E., & Holden, W. J. (1992). Psycho-social well-being among the parents of children with autism. *Journal of Intellectual and Developmental Disability, Volume 18*, 83-93.

Hastings, R. P., Kovshoff, H., Brown, T., Ward, N. J., Espinosa, F. D., & Remington, B. (2005). Coping strategies in mothers and fathers of preschool and school-age children with autism. *Autism, 9*, 377-391.

Lenhard, W., Breitenbach, E., Ebert, H., Schindelhauer-Deutscher, H. J., & Henn, W. (2005). Psychological benefit of diagnostic certainty for mothers of children with disabilities: Lessons from Down syndrome. *American Journal of Medical Genetics Part A, 133A*, 170-175.

Maes, B., Broekman, T. G., Dosen, A., & Nauts, J. (2003). Caregiving burden of families looking after persons with intellectual disability and behavioural or psychiatric problems. *Journal of Intellectual Disability Research, 47*, 447-455.

Meltzer, L. J., & Moore, M. *(in press*). Sleep disruptions in parents of children and adolescents with chronic illnesses: Prevalence, causes, and consequences. *Journal of Pediatric Psychology*.

Nikcevic, A. V., Kuczmierczyk, A. R., & Nicolaides, K. H. (2007). The influence of medical and psychological interventions on women's distress after miscarriage. *Journal of Psychosomatic Research, 63*, 283-290.

Ostwald, S. K., Hepburn, K. W., Caron, W., Burns, T., & Mantell, R. (1999). Reducing caregiver burden: A randomized psychoeducational intervention for caregivers of persons with dementia. *Gerontologist, 39*, 299-309.

Phipps, S., Dunavant, M., Lensing, S., & Rai, S. N. (2005). Psychosocial predictors of distress in parents of children undergoing stem cell or bone marrow transplantation. *Journal of Pediatric Psychology, 30*, 139-153.

Shearn, J., & Todd, S. (2000). Maternal employment and family responsibilities: The perspectives of mothers of children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 13*, 109-131.

Thompson, A., Fan, M. Y., Unutzer, J., & Katon, W. (*in press*). One extra month of depression: The effects of caregiving on depression outcomes in the impact trial. *International Journal of Geriatric Psychiatry*.

White, N., & Hastings, R. P. (2004). Social and professional support for parents of adolescents with severe intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 17*, 181-190.

Yirmiya, N., & Shaked, M. (2005). Psychiatric disorders in parents of children with autism: A meta-analysis. *Journal of Child Psychology & Psychiatry, 46*, 69-83.

Zammit, G. K., Weiner, J., Damato, N., Sillup, G. P., & McMillan, C. A. (1999). Quality of life in people with insomnia. *Sleep, 22*, S379-385.

Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *Gerontologist, 20*, 649-655.

Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandavia, 67*, 361-370.

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

|  |  |  |
| --- | --- | --- |
|  Cases (N = 32) | Controls (N = 29) | Test of difference |
|  |
| Sex (Female) | 24 (75%) | 20 (69%) |  χ2 (1) = 0.06, *p* = .81 |
| Marital Status (Partnered) | 28 (88%) | 20 (70%) |  χ2 (1) = 2.11, *p* = .15 |
| Ethnicity (Caucasian) | 29 (91%) | 26 (90%) |  χ2 (1) = 0.00, *p* = 1.00 |
| Occupational status (Professional) | 15 (47%) | 16 (55%) |  χ2 (1) = 0.15, *p* = .70 |
| Currently employed outside the home  | 23 (72%) |  28 (100%) |  χ2 (1) = 7.19, *p* = .007 |
| Mean age (SD) years | 42.8 (5.78) |  39.9 (4.36) |  F (1,59) = 4.76, *p* = .03 |
| Mean age of main care recipient (SD) years | 11.5 (3.35) |  8.8 (4.23) |  F (1,58) = 7.52, *p* = .008 |
| Mean depression score (SD) | 8.6 (3.92) | 3.2 (2.31) | F (1,59) = 41.64, *p* <.001 |
| Mean anxiety score (SD)  | 11.0 (4.40) | 5.0 (2.44) | F (1,59) = 43.12, *p* <.001 |
| Depression score ≥ 8 (%) | 20 (63%) | 2 (7%) |  χ2 (1) = 18.06, *p* <.001 |
| Anxiety score ≥ 8 (%) | 24 (75%) |  3 (10%) |  χ2 (1) = 23.22, *p* <.001 |

1. Our 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. [↑](#footnote-ref-1)