

Depression in mothers and fathers of children with intellectual disability

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Abstract

Parental depression was assessed using the Beck Depression Inventory (BDI) in 216 families with children with autism and/or intellectual disability (ID), and in 214 control families. Mothers with children with autism had higher depression scores (mean = 11.8) than mothers of children with ID without autism (mean = 9.2), who in turn, had higher depression scores than fathers of children with autism (mean = 6.2), fathers of children with ID without autism (mean = 5.0), and control mothers (mean = 5.0) and fathers (mean = 4.1). Forty-five per cent of mothers with children with ID without autism and 50% of mothers with children with autism had elevated depression scores (BDI > 9), compared to 15–21% in the other groups. Single mothers of children with disabilities were found to be more vulnerable to severe depression than mothers living with a partner.

Keywords children, depression, fathers, mothers, intellectual disabilities (ID)

Introduction

Several studies have found that parents of children with intellectual disability (ID) report higher levels of child-related stress than parents of normally developing children (i.e. Kazak & Marvin 1984; Hanson & Hanline 1990; Beckman 1991; Dumas *et al.* 1991; Reddon *et al.* 1992; Dyson 1997; Sanders & Morgan 1997; Browne & Bramston 1998; Hoare *et al.* 1998; Warfield *et al.* 1999). It has often been assumed that the extra stress of caring for a child with disabilities places parents at risk of suffering from depression. The main aim of the present study was to investigate the prevalence and severity of parental depression in families with children with disabilities, as compared with a group of control families.

Most studies investigating the mental health of parents with children with disabilities have found higher scores for maternal depression compared to norms or to control groups (i.e. Breslau *et al.* 1982; Fisman *et al.* 1989; Harris & McHale 1989; Dumas *et al.* 1991; Blacher & Lopez 1997; Hoare *et al.* 1998; Veisson 1999). However, some studies involving the parents of children with Downs syndrome (DS) have not found differences in depression scores (Van Riper *et al.* 1992; Scott *et al.* 1997). Maternal reports of depression have usually been generalized to parental depression, and the very few

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studies that have included fathers have usually found normal depression scores or reduced symptoms of depression in fathers of children with disabilities than in mothers (Bristol *et al.* 1988; Fisman *et al.* 1989; Wolf *et al.* 1989; Dumas *et al.* 1991; Gray & Holden 1992; Veisson 1999). Studies of parents with children with disabilities suggest that 35–53% of mothers with children with disabilities pass cut-off scores for depression (Bristol *et al.* 1988; Carpiniello *et al.* 1995; Blacher *et al.* 1997; Hoare *et al.* 1998; Veisson 1999). However, many of these studies rely on small samples which still makes inferences about the prevalence of depression uncertain. Depending on how depression is defined and assessed, lifetime prevalence rates for diagnosable depressive disorders in large population studies range from 2.6% to 12.7% in men, and 7% to 21% in women (Clarke & Beck 1999).

Even though the prevalence of parental depression varies between studies, it is clear that most parents of children with disabilities do not suffer from depression. Differences in child characteristics have been shown to be related to the prevalence of parental depression (Gowen *et al.* 1989; Wolf *et al.* 1989; Ryde-Brandt 1990; Dumas *et al.* 1991; Gray & Holden 1992; Ireys & Silver 1996; Sanders & Morgan 1997; Hoare *et al.* 1998). Several studies dividing families into groups based on the child's diagnosis have found that parents of autistic children report higher stress and more adjustment problems than parents of children with DS (Ryde-Brandt 1990; Dumas *et al.* 1991; Sanders & Morgan 1997). Few studies have reported the relation between family characteristics, such as socio-economic or marital status, and parental depression in families with children with ID. For example, single parents have been excluded from several studies (Bristol *et al.* 1988; Harris & McHale 1989; Beckman 1991). Blacher & Lopez (1997) found single mothers to have more depressive symptoms, whereas Hoare *et al.* (1998) did not find parental depression to be related to either marital or socio-economic status. Breslau *et al.* (1982) found that depression scores declined as education and income levels rose.

The aim of the present study was to investigate the prevalence and severity of parental depression in families of children with ID and in control families. The following hypotheses were tested:

- 1 Mothers of children with autism have higher depression scores than mothers of children with ID without autism, who in turn, have higher depression scores than control mothers. Fathers of children with autism have higher depression scores than fathers of children with ID without autism, who in turn, have higher depression scores than control fathers.
- 2 Elevated Beck Depression Inventory (BDI) scores (BDI > 9) are more common in mothers of children with autism than in mothers of children with ID without autism, who in turn, have more elevated depression scores than control mothers. Elevated depression scores are more common in fathers of children with autism than in fathers of children with ID without autism, who in turn, have more elevated depression scores than control fathers.
- 3 Mothers have higher depression scores than fathers both in families with children with ID and in control families.
- 4 Lower socio-economic status is related to higher parental depression scores both in families with children with ID and in control families.
- 5 Elevated depression scores are more common in single-parent families than in two-parent families, both in families with children with disabilities and in control families.

Subjects and methods

Participants and procedure

Families of children with ID, ranging from the newly born to 16 years of age, living in urban and rural communities in the south-west of Sweden, were recruited from community-based programmes providing services to families of children with disabilities. Families are automatically referred to these programmes from the maternity hospital or from well-baby clinics (which serve almost 100% of the infants and toddlers in Sweden) when difficulties/disabilities are discovered. Children and families are protected by professional confidentiality, and could not be contacted in person for research purposes. A total of 691 introductory letters were sent out to all families enrolled in the programmes in the selected area who had children with a primary diagnosis of ID and/or autism. In this two-step

recruitment procedure, 288 parents mailed back answer-cards with their name and address, indicating that they wanted more information about the study. After two reminders, the second together with a new survey, 216 families (207 mothers and 167 fathers) returned completed surveys in prepaid envelopes. Based on the medical provider's categorization, the children were divided into two diagnostic groups. There were 151 children with a primary diagnosis of ID without autism and 65 children with a primary diagnosis of autism. The children with autism also had ID.

The control group was comprised of the families of 496 randomly selected children living in the same geographical area who had the same age and gender distribution as the study group. The randomization was carried out at the National Office of Statistics. Surveys were mailed to parents together with introductory letters explaining the selection procedure and the purpose of the study. After two reminders, the second together with a new survey, 214 families (204 mothers and 185 fathers) returned completed surveys in prepaid envelopes.

The groups had similar demographic characteristics (Table 1), but there was a larger proportion of single-parent families in the two ID groups compared to the control families [$\chi^2_{(2, n=430)}=6.7$, $P<0.05$].

Three differently coloured booklets were mailed to the families, all in the same envelope. One con-

cerned the family characteristics, and was completed by either one of the parents or both together. The other two booklets concerned the parents' individual well-being, one was directed to the mother and one directed to the father. Parents were instructed to respond to the questions regarding their mental health independently of each other. Completion of the survey took between 30 and 45 min. Data were analysed using the SPSS for Windows, Release 8.0.2 (1998), computer program. An alpha level of $\alpha=0.05$ was used for all statistical tests.

Measures

The Swedish version of the BDI (Beck *et al.* 1979; Beck & Steer 1996) was used to measure depression. This widely used instrument consists of 21 symptoms or attitudes commonly seen in patients suffering from depression (e.g. sadness, negative self-concept, sleep and appetite disturbances). The symptoms are rated from '0' to '3' in intensity. The internal consistency for non-psychiatric subjects has yielded a mean coefficient α of 0.81, and the mean correlation of BDI with clinical ratings on the Hamilton Psychiatric Rating Scale for Depression has been found to be 0.74 (Beck *et al.* 1988). Kendall *et al.* (1987) suggested caution with regard to the use of the term depression from a single-administration BDI classification and recommend that the term depression should only be used when

Table 1 Demographic variables in the three groups of families

Demographic variable	Family group		
	Children with ID without autism	Children with autism	Controls
Single parents [% (n)]	17 (25)	23 (15)	11 (23)
Male gender of child [% (n)]	60 (90)	72 (47)	63 (153)
Child's age (years; mean $\pm$ SD)	7.4 $\pm$ 4.2	9.8 $\pm$ 2.5	8.4 $\pm$ 2.2
Number of children in family (mean $\pm$ SD)	2.3 $\pm$ 0.9	2.2 $\pm$ 0.8	2.4 $\pm$ 0.9
Socio-economic status (mean $\pm$ SD)*	35.6 $\pm$ 14	36 $\pm$ 12.3	37 $\pm$ 11.8
Fathers' years of schooling (mean $\pm$ SD)	11.9 $\pm$ 2.5	12.0 $\pm$ 2.4	12.2 $\pm$ 2.2
Mothers' years of schooling (mean $\pm$ SD)	11.9 $\pm$ 2.4	12.1 $\pm$ 2.5	12.3 $\pm$ 2.2

*Hollingshead Four-Factor Index of Social Position (Hollingshead 1975; Broberg 1992).

individuals score above 20 on the BDI. The following cut-off points of depressive symptomatology were used when interpreting the results in the present study (Kendall *et al.* 1987): the range of scores from 0 to 9 indicate no depression, 10–20 dysphoria and over 20 depression. Depression scores above 9 are referred to as elevated depression scores. In large samples, the mean BDI score usually falls between 4 and 6, with women usually scoring two points higher than men (Kendall *et al.* 1987; Beck *et al.* 1988). Cronbach's α for internal consistency in the present study was 0.90.

Socio-economic status was assessed using the Hollingshead Four-Factor Index of Social Position (HFFISP; Hollingshead 1975; Broberg 1992). This is an index of the families' socio-economic status based on the number of years that the mothers and fathers spent in education and the status of their profession, which, typically, is also linked to income. The type and size of housing, measured as either an apartment or own house and the total number of rooms, was also used as measures of socio-economic status. Single parenthood was defined as the presence of a single adult in the family regardless of whether the parent was divorced, never married or widowed. If two adults lived in the family, the family was considered to be a two-parent family, even if the other adult was not the biological parent of the child.

Results

As Table 2 shows, the first hypothesis was supported for mothers. Since marital status was thought to influence depression, the number of adults in the family was entered as a covariant in an analysis of covariance (ANCOVA). Mothers with children with autism had higher depression scores than mothers of children with ID without autism, who in turn, had higher depression scores than control mothers in the corrected model [$F_{(3, 410)} = 17.4$, $P < 0.01$]. No difference in depression scores was found for fathers.

The second hypothesis was supported. Table 3 shows that elevated depression scores ($BDI > 9$) are more common in mothers of children with autism than in mothers of children with ID without autism, who in turn, have more elevated depression scores than control mothers [$\chi^2_{(4, n=411)} = 46$, $P < 0.01$]. This difference persisted even when single mothers were excluded. Elevated depression scores are more common in fathers of children with autism than in control fathers [$\chi^2_{(4, n=352)} = 11$, $P < 0.05$].

Hypothesis 3 was also supported. Mothers of children with disabilities had higher depression scores than fathers of children with disabilities [$t_{(366)} = 5.9$, $P < 0.01$]. The control mothers also had higher depression scores than control fathers

Table 2 Beck Depression Inventory (BDI) scores for parents of children with intellectual disability (ID) without autism, parents of children with autism and control parents. The BDI scores are also shown in relation to the number of adults in the family

	Family group											
	Children with ID without autism				Children with autism				Controls			
	Mothers		Fathers		Mothers		Fathers		Mothers		Fathers	
	Number	Mean	Number	Mean	Number	Mean	Number	Mean	Number	Mean	Number	Mean
Single parent	22	11	5	8.8	14	12.2	3	2.7	17	5.5	10	4.8
Two parents	122	8.9	115	4.9	48	12	44	6.4	187	5.1	175	4.1
All families	145	9.2	120	5	62	11.8	47	6.2	204	5.2	185	4.1

Table 3 Beck Depression Inventory (BDI) classifications (Kendall *et al.* 1987) among parents of children with intellectual disability (ID) without autism, parents of children with autism and control parents

BDI classification	Family group											
	Children with ID without autism						Children with autism					
	Mothers			Fathers			Mothers			Fathers		
	Number	Percentage		Number	Percentage		Number	Percentage		Number	Percentage	
No depression (BDI < 10)	80	55	99	82	31	50	37	79	170	83	158	85
Dysphoria (BDI = 10–20)	53	37	19	16	21	34	7	15	27	13	27	15
Depression (BDI > 20)	12	8	2	2	10	16	3	6	7	4	1	0

$[t_{(387)} = 1.9, P < 0.05]$. In several families in both groups, both parents had elevated depression scores. The correlation between mothers' and fathers' depression scores in two-parent families was $r = 0.29$ ($P < 0.01$) in the control families and $r = 0.36$ ($P < 0.01$) in families with children with disabilities. In 47% of the families with children with disabilities, at least one parent had elevated depression scores ($BDI > 9$), compared to 24% in the control families [$\chi^2_{(2, n=430)} = 24.6, P < 0.01$].

Hypothesis 4 was partly supported. Socio-economic status as measured by the HFFISP had no relation to depression scores in mothers and fathers with children with disabilities or in the control fathers. However, there was a negative correlation between the BDI scores and the HFFISP score in control mothers ($r = -0.163, P < 0.05$). Control mothers owing their own house reported less depression than those living in apartments [$\chi^2_{(2, n=204)} = 10, P < 0.005$], although the type of housing was not related to depression in any other group. More spacious housing was associated with lower depression scores in fathers of children with disabilities [$F_{(7, 165)} = 21, P < 0.05$], although the standard of housing was not associated with depression in any other group.

Hypothesis 5 was also partly supported. Marital status did not affect the number of mothers with children with disabilities who had elevated depression scores, but single mothers were found to have more highly elevated depression scores than mothers living with a partner. Out of the single mothers with children with ID, 28% (10) had dysphoria ($BDI = 10-20$) and 22% (8) suffered from depression ($BDI > 20$). Out of the mothers in two-parent families 37% (64) had dysphoria ($BDI = 10-20$) and 8% (14) suffered from depression [$\chi^2_{(2, n=207)} = 6.4, P < 0.05$]. Marital status had no relation to depression scores in control mothers or fathers in either of the groups.

Discussion

The BDI with its well-evaluated psychometric qualities was used to investigate the prevalence and severity of parental depression in a large sample of both mothers and fathers of children with disabilities and in a control group. As anticipated, mothers

of children with autism experienced more distress than mothers of children with ID without autism, who in turn, experienced more distress than fathers of children with disabilities and control parents.

In the light of the present study and from the results of previous research, it can be concluded that mothers of children with disabilities are at a markedly increased risk of suffering from psychological distress and depression. The finding that mothers of children with autism had higher depression scores than mothers of children with ID without autism is consistent with previous research (Ryde-Brandt 1990; Dumas *et al.* 1991; Sanders & Morgan 1997). Autism is a disorder that, in addition to ID, involves severe behavioural disturbances and a lack of social competence and responsiveness, factors all of which have been shown to increase parental stress (Cameron *et al.* 1991; Hodapp *et al.* 1997). High stress caused by the difficult behaviour of a child in combination with restrictions in personal life may be some of the factors that contribute to a higher risk of depression in mothers of children with autism. The higher depression scores in both groups of mothers with children with disabilities are a result of both slightly elevated depression scores (dysphoria) in many mothers and extremely high depression scores (depression) in over one-tenth of all the mothers. It is important to identify and offer appropriate psychiatric support for parents who are depressed ($\text{BDI} > 20$) since this is a serious condition not only for the parent, but also for the rest of the family (Blacher & Lopez 1997).

Consistent with previous studies, fathers of children with disabilities showed normal depression scores (Bristol *et al.* 1988; Fisman *et al.* 1989; Wolf *et al.* 1989; Dumas *et al.* 1991; Gray & Holden 1992; Veisson 1999). Why then are mothers of children with disabilities at an increased risk of depression while their spouses are not? It is possible that the consistent finding of mothers experiencing more distress than fathers is caused by the fact that mothers take on a larger part of the extra care and practical work that the child with disabilities requires (Bristol *et al.* 1988; Moes *et al.* 1992). They more often give up their job and feel unable to pursue their own interests (Breslau *et al.* 1982). The mother's self-competence may also be more related to the parenting role than father's, and therefore,

mothers may be more vulnerable when stress and difficulties arise in the parenting domain. It may also be that fathers show their distress in other ways than depression, which would suggest that we should include other measures of psychological health than depression in future studies.

Socio-economic status was not consistently related to parental depression in families with children with ID. This supports Blacher *et al.*'s (1997) idea that socio-economic status may not serve as a buffer against depression in the presence of specific stressors such as ID. The fact that free services are available to all families may further decrease the impact of socio-economic status in parents in Sweden. Most parents also received a monthly financial grant to compensate for expenses and reduced income caused by care-taking demands which may decrease extreme stress and financial strain in families from the lowest socio-economic group.

Single mothers with children with disabilities were more vulnerable to severe depression than mothers living with a partner, which supports the findings by Blacher & Lopez (1997). This, along with the fact that poorer family functioning is associated with higher stress and depression in families with children with disabilities (Wyngaarden Krauss 1993; Dyson 1997; Sanders & Morgan 1997), supports the suggestion that support for marital and cohabitational relationships, and the prevention of domestic discord may be some of the best ways to promote parental mental health in families with children with disabilities (Fisman *et al.* 1989; Hanson & Hanlin 1990; Beckman 1991; Sloper 1999).

Why would parents of children with ID experience more depression than parents of normally developing children? Cognitive theories of depression (Clarke & Beck 1999) acknowledge that stressors play an important role in both the onset and the course of the depressive disorder. However, most individuals do not develop a depressive disorder when faced with difficult and stressful life experiences. The meaning the individual attaches to a stressful event will determine its impact on the individual. If a life-event or stressor threatens or intrudes upon personal issues or concerns that are central to the individual's self-perception, then a depressive response may be elicited. The experience

of parenting a child with ID increases the risk of provoking feelings of loss (i.e. of the perfect or dreamed of child, and of one's personal freedom), helplessness (i.e. experiencing high stress, not being able to change the situation and not being able to get the help one needs) and failure (i.e. having a child with difficult behaviour and not being able to pursue one's personal goals in life). Pre-existing dysfunctional schemas can make some parents particularly sensitive to these feelings, especially if they do not have an adequate activation of compensating positive schemas. Since parenting a child with ID is likely to provoke these feelings more often, there is greater risk of the repeated activation of the dysfunctional depressive schemas, which could explain why most studies find more depressive symptoms in mothers of children with ID than in parents of normally developing children. Parents of children with ID probably do not have more dysfunctional schemas than other parents prior to the birth of the child, but dysfunctional schemas that remain inactivated in parents of normally developing children have greater possibility to be activated in parents of children with ID.

The match between a stressful event and a dysfunctional schema may not be the only reason for depression in parents of children with ID. It seems reasonable to assume that some parents of children with ID would have been depressed even in the absence of their child because of their own biological or emotional vulnerabilities. For others, there exists a cognitive vulnerability that is triggered by having a child with ID. In the absence of a child with ID, these dysfunctional schemas could have been activated by some other stressor, or could have remained unactivated. The third group of parents experience so much stress in their lives that their positive compensating structures are not sufficient to resist repeated feelings of helplessness and depression in spite of a robust cognitive set-up. To learn more about these possible psychological differences between depressed parents of children with ID, we need studies that focus on mental health prior to the birth of the child, the history of depression in the family, the severity and duration of the depression, and the circumstances surrounding the onset of depression, as well as qualitative descriptions and analyses of thoughts and feelings elicited in parents in different situations.

The strengths of the present sample are that: (1) it is large; (2) the authors know that all families with known ID in the area received the information and had the chance to participate in the study; and (3) they can and do describe the different steps and drop-outs during the process. Out of the families with children with ID who volunteered to participate, 75% mailed back complete surveys, which was 31% of the total population. Forty-three per cent of the control families completed their surveys. Even though the present authors found no other way to conduct the sample, the non-compliance rate still raises questions about the representativeness of the samples. The distribution of socioeconomic status (SES) scores is in accordance with other studies in the same area (Sorbring 2001) and the proportion of single-parent families in the control group (11%) was similar to that found in the 1990 census. Even though the samples may be representative of the general population, there may still be a risk of psychological differences between those who sent back the surveys and those who did not. The higher depression scores in parents of children with ID may indicate that parents with children with disabilities who were depressed were more inclined to answer the survey, perhaps in the hope that this would lead to a better understanding and better support for families with children with disabilities. However, parents with depressive symptoms, with an accompanying lack of energy, in the control group did not have this motivation, and therefore, may be more inclined not to mail back the survey than control parents without depressive symptoms. This would lead to an over-report of depression in the study group and an under-report in the control group. The BDI scores for the control mothers and fathers were in accordance with those found in other large samples (Kendall *et al.* 1987). The BDI scores for mothers and fathers and the prevalence of mothers with elevated depression scores fall within the previously reported figures (Bristol *et al.* 1988; Dumas 1991; Carpiniello *et al.* 1995; Hoare *et al.* 1998; Veisson 1999). Thus, the correspondence with previous research indicates that the samples are reliable.

The present study relies on one single administration of the BDI. Future studies should preferably use repeated measures and structured diagnostic interviews to increase knowledge about the stability

and severity of depression in parents of children with ID.

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