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Original Article

Anxiety and Depression in Parents of Children and Adolescents with Intellectual Disability

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Abstract

Background: Parents of the children and adolescents with intellectual disability (ID) are prone to psychological distress than as compared to parents of normally developing children and adolescents. Various biopsychosocial factors affect the perception and manifestation of this stress and influences difference in quality and severity in psychological outcomes. When a couple faces stress of caregiving as a unit, it is worthwhile to know and assess distribution pattern amongst the primary care giver and the other parent. **Aim:** The aim of the study is to evaluate the proportional distribution of depression and anxiety in primary care giver and the other parent in parents of children and adolescents with ID. **Materials and Methods:** Using a Cross-sectional observational study design, 99 parents (99 fathers and 98 mothers) of 99 children and adolescents (up to 18 yrs of age) with Intellectual Disability were assessed for Depressive and Anxiety symptoms using Hospital Anxiety and Depression Scale (HADS). Comparison of proportional distribution of psychiatric morbidity among fathers and mothers (primary care giver) was done using 2 independent sample proportion tests. **Results:** The mothers were found to be the primary care givers. 35.4% of fathers and 66.3% of mothers had significant depressive symptoms. 57.6% of fathers and 91.8% of mothers had significant anxiety symptoms. In 33 couples, fathers did not report anxiety or depressive symptoms but corresponding 27 mothers reported significant anxiety or depressive symptoms or both. In rest of the couples in whom fathers reported anxiety and/or depressive symptoms, the corresponding mothers also reported. In six couples where mothers did not report anxiety or depression, the fathers also did not report any anxiety or depressive symptoms. **Conclusion:** Depressive and Anxiety symptoms are very prevalent in parents of children with ID. Their proportion is significantly high in primary care giver (mother) as comparedto corresponding other parent (father). There is unequal distribution of anxiety and depression in these parents with a skew towards mother.

Keywords: Anxiety, depression, distribution, intellectual disability, parents

Introduction

The prevalence of intellectual disability (ID) globally is around 1%–3%.[1] In India, studies over the past six decades have found the prevalence to be around 2%.[2] Caregivers of the affected children experience psychological, social, and financial distress, more than other family members as well as parents of intellectually sound children.[3-5] Increase in severity of ID is associated with higher levels of stress in parents, lower family support, and poorer family atmosphere.[6] The caregiver's exposure to this long-standing stress adds to the occupational, financial, or personal stress levels and can precipitate psychiatric morbidities.[7] This can be further exaggerated by the presence of problem behaviors of these children.[8] Parents may internalize features of depression, anxiety, and somatic complaints or externalize with excessive irritability, quarrelsome behavior, and verbal and physical aggression, which is more than parenting stress associated with child behavior problems.[9,10]

An Indian study found that 94% of mothers and 66.7% of fathers of children and adolescents with ID to have either anxiety or depressive symptoms, or both.[11] However, other Indian studies show the prevalence of depression in mothers of children with ID up to 85%.[12-14] Regarding affected fathers, 44% had anxiety, depression, and somatic complaints.[15]

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The strongest predictors of the mental health of fathers were children's behavior problems, daily stress arising out of the father's own needs, burden of child care, and low level of parenthood satisfaction. Affected parents' interaction with their disabled children has a profound impact on the therapeutic progress of the child.[15]

Due to various biopsychological and environmental factors, individuals perceive and manifest stress differently. However, when a couple undergoes caregiver stress as a unit, it is worthwhile to know and assess the difference in their psychological outcomes. It may also provide insight into the magnitude of psychological morbidity and its distribution pattern among couples. It may further help in effectively crafting and delivering the psychological interventions as per caregiving role and might increase the overall impact of the targeted measures.

Studies to date have evaluated the burden of care, stress, and psychological morbidity among parents of children and adolescents with ID, either together or separately.[4,16-21] However, studies have not evaluated and compared the proportional distribution of the morbidity among the primary caregiver and the other partner.

This study was, therefore, undertaken with the aim to determine the distribution of depression and anxiety among primary caregiver and the other parent in parents of children and adolescents with ID.

Materials and Methods

The study was conducted in the psychiatry unit of a tertiary care hospital in Maharashtra. The cross-sectional observational study design was followed. The study population comprised of parents of children and adolescents below the age of 18 years, with ID (intelligence quotient [IQ] below 70), attending the outpatient department for IQ assessment of their children and/ or disability certification for ID. They were living with these children and adolescents for more than a year. Parents with preexisting chronic medical/psychiatric illnesses before the birth of the affected child were excluded from the study. Those parents giving care and support to any other family member having ID, chronic medical or psychiatric illness were also excluded from the study. Using a mean anxiety score of 11.0 and standard deviation (SD) of 4.40 and mean depression score of 8.6 (Hospital Anxiety and Depression Scale [HADS]) and SD of 3.92 from a previous study, a sample size of 80 and 61 was calculated, respectively.[22] The sample size of 80, being larger was chosen. The study population was recruited using non-probability purposive sampling. Informed consent was taken from the parents who met the inclusion and exclusion criteria. Information regarding psychosocial correlates was gathered using a sociodemographic pro forma. Psychological morbidity was assessed using HADS.[23]

The HADS is a valid scale in assessing the symptom severity and domains of anxiety and depression in psychiatric, primary care patients, and the general population.[23,24] A subscore of 8 or more in a respective subset is a definitive indicator of anxiety or depression. Both English and the validated Hindi version of the scale were used. The sensitivity and specificity for both HADS-Anxiety subscale and HADS-Depression subscale is 0.80.[23] The reliability (Cronbach's α) of HADS is 0.80–0.93 for the anxiety and 0.81–0.90 for the depression subscales. A significant correlation with both anxiety and depression subscales supports the validity of the instrument.[24]

Family support was assessed by asking if anybody immediate or extended family was staying with the parents for taking care of or to help them in taking care of their intellectually disabled children and adolescents. Family support was construed as being present, if the answer was "Yes;" and not present if the answer was "No."

IBM® SPSS® Statistical Package for the Social Sciences (Version 25) was used for statistical analysis. Qualitative data were expressed using frequency and percentage (%) and quantitative data variables were expressed using mean and SD. The Chi-square test and Fisher's exact test were used to find the association between anxiety and depression of caregivers with various qualitative data variables. The power of the study was adjusted at 80% and $P < 0.05$ was considered significant. A comparison of proportional distribution of psychiatric morbidity among fathers with mothers (primary caregiver) was done using two independent sample proportion tests.

Ethics clearance was taken from the Institutional Ethical Committee, Armed Forces Medical College, Pune, vide Reference IEC/Oct/2017 dated October 12, 2017, and data were collected from October 2017 to October 2019 in accordance with the Declaration of Helsinki 1975, revised in 2000.

Results

About 69.7% of the children and adolescents with ID were males. About 46.5% were in the age group of 6–10 years.

Table 1: Sociodemographic details of children and adolescents with intellectual disability

	Number of children and adolescents with ID, *n* (%)
Age group (years)	
≤5	20 (20.2)
6-10	46 (46.5)
11-15	27 (27.3)
>15	6 (6.1)
Gender	
Male	69.7 (69)
Female	30.3 (30)
MR level	
Mild	43 (43.4)
Moderate	40 (40.4)
Severe	13 (13.1)
Profound	3 (3.0)

ID: Intellectual disability, MR: Mental retardation

Forty-three percent of children and adolescents had mild level of ID, and 40% had moderate level of ID. About 53.6% had various behavioral comorbidities, and 32.3% had various medical comorbidities [Table 1].

The parents represented nearly all regions of India. About 80.8% of fathers and 67.7% of mothers were in the age group of 31–40 years, respectively. About 77.8% of fathers and 82.8% of mothers were educated up to 12th and 19.2% of fathers and 12.1% of mothers were graduates. All the fathers were employed industrial workers. All the mothers were homemakers. Mothers were the primary caregivers in all these cases and the quantum of time spent by the mother with these children and adolescents was much more than that of the father. Only 17.2% of the parents have family support in the form of instrumental support from family members or relatives. Hence, the term primary caregiver has been used interchangeably with the mother. The single most important causes of psychological stress in these parents were outcome of the illness and worries about the care of these children in the future after their own demise. About 62.63% had reported to psychiatry outpatient department for IQ assessment of their children and 37.37% for disability certification for ID [Table 2].

On evaluation of depressive symptoms by HADS-Depression subscale, 27.3% of fathers and 32.7% of mothers had scores suggestive of mild level of depression (score 8 ≤11), 6.1% of fathers and 25.5% of mothers had scores suggestive of moderate level of depression (score 12 ≤14), and 2% of fathers and 8.2% of mothers had scores suggestive of severe level of depression (score 15 ≤21). On the evaluation of anxiety in these parents by HADS-Anxiety subscale, 37.4% of fathers and 39.8% of mothers had scores suggestive of mild level of anxiety (score 8 ≤11), 19.2% of fathers and 44.9% of mothers had scores suggestive of moderate level of anxiety (score 12 ≤14), and 1% of fathers and 7.1% of mothers had scores suggestive of severe level of anxiety (score 15 ≤21). These results showed that as compared to fathers almost twice the number of mothers had higher scores on both anxiety and depressive symptoms subscale of HADS [Table 3] and these results were statistically significant ($P < 0.05$) [Table 4]. Parents with moderate-to-severe scores were referred to the adult psychiatry unit for further evaluation and management by psychiatrist.

On the evaluation of family support, only 17% of the parents had family support from close family members or extended family in taking care of their intellectually disabled children.

Table 5 shows that 33.3% of fathers and 6.1% of mothers had neither anxiety nor depression. About 26.3% of fathers had both anxiety and depression and 64.3% of mothers had both anxiety and depression. Hence, around two-thirds of mothers had both anxiety and depression which is more than double the number of fathers with both anxiety and depression.

Table 6 shows that out of 33 couples in whom fathers did not report anxiety or depression, 27 mothers reported significant anxiety or depression or both. Similarly, couples in whom fathers had anxiety and/or depression, the corresponding mothers also had anxiety and/or depression.

Table 7 shows that in six couples in whom mothers did not report anxiety or depression, the fathers also did not report any anxiety or depression. Similarly, out of 63 mothers who had

Table 2: Sociodemographic details of parents of children and adolescents with mental retardation

	Father	Mother
Age group of parents		
≤30	9 (9.1)	27 (27.2)
31-40	80 (80.8)	67 (67.7)
>40	10 (10.1)	5 (5.1)
Total	99 (100.0)	99 (100)
Education level of parents		
Up to 10th standard	47 (47.5)	51 (51.5)
Up to 12th standard	30 (30.3)	31 (31.3)
Up to graduate	19 (19.2)	12 (12.1)
Postgraduate	3 (3.0)	5 (5.1)
Total	99	99 (100.0)

Table 3: Scores of fathers and mothers on Hospital Anxiety and Depression Scale-Depression and Anxiety subscale

	Father, *n* (%)	Mother, *n* (%)
Depression		
No depression	64.6	33.7
Mild	27.3	32.7
Moderate	6.1	25.5
Severe	2.0	8.2
Total	99	98
Anxiety		
No anxiety	42 (42.4)	8 (8.2)
Mild	37 (37.4)	39 (39.8)
Moderate	19 (19.2)	44 (44.9)
Severe	1 (1)	7 (7.1)
Total	99 (100)	98 (100)

*Mild: 8-10, moderate: 11-14, severe: 15-21

Table 4: Evaluation of the difference between the scores of fathers and mothers on HADS Depression and Anxiety subscale

Parents	Depression		Total	*P*
	Present	Absent		
Father	35	64	99	0.0001
Mother	65	33	98	
Total	100	97	197	
Parents	**Anxiety**		**Total**	***P***
	Present	**Absent**		
Father	57	42	99	0.0001
Mother	90	8	98	
Total	147	50	197	

**P*<0.05 (significant) Chi-square test used

reported both anxiety and/or depression, only 52 corresponding fathers had anxiety and/or depression.

Discussion

This study was assessed the distribution of anxiety and depression among parents of children and adolescents with ID. Earlier studies have found anxiety, depression, or both, being the most common psychological morbidities among these parents, significant enough to warrant mental health support and services.[25,26]

About 35.4% of fathers and 66.3% of mothers had depressive symptoms (above cutoff score of 7). These results are comparable with some previous studies,[13,19,22] and higher than found in other studies.[27-30]

About 57.6% of fathers and 91.8% of mothers had anxiety symptoms (above cutoff score of 7). These results are comparable with some previous studies,[13,19,22,27] and higher than found in other studies.[28-30]

It was further found that a significantly higher proportion of mothers were having anxiety, depression, or both when compared to the corresponding group of fathers. Further, around one-third of mothers and two-third of fathers were free of significant anxiety or depressive symptoms, which in other way is a dissonant finding when parents are deemed to be a functional unit in caregiving.

This study found that the burden of care for children in our study population was shouldered predominantly by the mother, being the primary caregiver and evidently had more caregiver stress and its psychological manifestations. The caregiving stress is present even if the child is developing normally but caregivers can cope with it. However, in chronic disabilities like ID, the enhanced psychosocial cum caregiving burden can lead to significant psychiatric morbidity.

It is hypothesized that the difference in proportionate distribution of anxiety and depression in parents may be due to:

a. Mothers were the primary caregivers who with minimal family support (17%) spent maximum time at home with the affected children and were fully committed to caregiving. Most societies and mothers hold them responsible for any birth defects or arrested state of mind in the children
b. All fathers were full-time employed and shared less time in caregiving. Furthermore, societal and cultural norms in India expect fathers to behave as emotionally strong individuals, shouldering family responsibilities without explicit display of distress.

However, further studies in the future will be needed to support these hypotheses.

The strengths of this study are that this study is the first of its type which gives us an insight into the disproportionate manifestation

Table 5: Comparison of parents with above threshold scores on Hospital Anxiety and Depression Scale-Depression and Anxiety subscales

Presentation	Father, *n* (%)	Mother, *n* (%)
No anxiety or depression	33 (33.3)	6 (6.1)
Depression	9 (9.1)	2 (2.0)
Anxiety	31 (31.3)	27 (27.6)
Both anxiety and depression	26 (26.3)	63 (64.3)
Total	99 (100.0)	98 (100.0)

Table 6: Comparison of fathers with mothers (primary caregiver) based on proportional distribution of anxiety and/or depression

Father (*n*)	Mother			
	No anxiety depression	Only depression	Only anxiety	Both anxiety and depression
No anxiety depression (33)	6	0	16	11
Only depression (9)	0	2	0	7
Only anxiety (31)	0	0	11	20
Both anxiety and depression (26)	0	0	0	25
Total (99)	6	2	27	63

Test used-2 independent sample proportion test, $P<0.001$

Table 7: Comparison of mothers (primary caregiver) with fathers based on proportional distribution of anxiety and/or depression

Mother (*n*)	Father			
	No anxiety depression	Depression	Anxiety	Both anxiety and depression
No anxiety depression (6)	6	0	0	0
Depression (2)	0	2	0	0
Anxiety (27)	16	0	11	0
Both anxiety and depression (63)	11	7	20	25
Total (98)	33	9	31	25

Test used - 2 independent sample proportion test, $P<0.001$

of depression and anxiety in mothers of children and adolescents with ID when compared with fathers. A structured, reliable, and widely accepted scale (HADS) was used in this study. A larger sample size with variegated job profile could have increased the external validity of the study. The fathers in our study population were predominantly government employees, whose responses to interviewer as well as marking of responses on questionnaire, might have been influenced by its impact on their career, job, and benefits. Furthermore, the presence of a comparable control group could have compared the distribution of the psychological morbidity of these parents with parents of normally developing children and adolescents.

Conclusion

Depression and anxiety are prevalent in parents of children and adolescents with ID. Their presence is significantly high in mothers as compared to fathers. This unequal distribution of anxiety and depression with a skew toward the mother (primary caregiver), warrants necessitous consideration during the evaluation and management of children and adolescents with ID. It is recommended that specific support groups targeting these parents along with a special focus on mothers be established at community level to improve the existing support for caregivers. Furthermore, specific community outreach activities may be devised and integrated into the existing mental health programs to increase awareness among the affected parents.

Further research with a larger sample size and with more rigorous statistical methods may be conducted which may include detailed information on child's disease and disability, behavioral and medical comorbidities, the control group of parents of normally developing children and adolescents, personality profile of parents, and characteristics and quality of the social support available.

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Conflicts of interest

There are no conflicts of interest.

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