A Study of Depression among Caregivers of Individuals with Intellectual Disability – A cross sectional study

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ABSTRACT

Background and Objectives: Caregivers of children with intellectually disability experiences high level of emotional, financial and physical stress. The aim of this study is to assess the risk of depression among caregivers of individuals with intellectually disability.

Methods: A cross sectional study was done on caregivers of intellectually disabled individuals who has attended Psychiatry outpatient, Department of Government Medical College. 60 patients diagnosed with ID were included by systematic random sampling method. Objective data was collected in a special proforma. Patient health questionnaire (PHQ-9) was used to assess risk of depression among caregivers of Individuals with Intellectually Disabled. MS Excel sheet and SPSS were used for data entering and statistical analysis.

Results: On PHQ-9 scale, 71.7% of caregivers had depression out of which, 26.6% shows minimal symptoms of depression, 20% had mild depression, while 13.4% had moderately severe depression and 11.6% had major severe depression while 28.3% of caregivers had no depression. Depression was more common in females (36.6%) than males (35%).

Conclusion: The prevalence of depression among caregivers of Individual with intellectually disabled was higher in this study. The risk of depression was higher in female caregivers as compared to male caregivers.

Keywords: Depression, caregivers, intellectual disability, mental retardation.

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INTRODUCTION

Intellectual disability is a disability that occurs before age 18. People with this disability experience significant limitations in two main areas: intellectual functioning and adaptive behaviour. These limitations are expressed in person's conceptual, social and practical everyday living skills [1]. According to ICD-10, Intellectual disability can be classified into four classes on the basis of intelligent quotient (IQ) i.e. mild IQ 50-70, moderate IQ 35-50, severe IQ 20-35, profound IQ below 20. A number of people with intellectual disability are mildly affected, making the disability difficult to recognize without visual cues. In intellectual disability there is a significantly sub-average mental development from birth or early childhood. It is substantial limitations in age appropriate intellectual functioning and adaptive behaviour and it is a lifelong condition. These children are slow in reaching developmental milestones later than the normal children. Intellectual disability affects about 2–3% of people, 75–90% of the affected people have an intellectual

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disability [2]. In intellectual disability there is marked impairment in communication, academic and social skills due to which the child is more dependent on care giver than normal child. The parents of children with intellectual disabilities experience chronic stress. It is also seen that having a child with intellectual disabilities affects not only the parents, but also siblings and the relationships among the family members [3]. Stress experienced by the caregivers of disabled child is influenced by several factors such as child's age, gender, degree of disability and also social class, economic status and family coping strategies like acceptance of the child's diagnosis and perception of stigma associated with the disorder [4]. Becoming a caregiver of disabled child introduces an additional role, and therefore will require some rearrangement of priorities, and redirection of energy [5]. Therefore, the caregiver should monitor changes in person's mental condition, including becoming unhappy, depressed, confused, or otherwise not as healthy as they have been. In all this monitoring it is caregiver's duty to inform to doctor if anything unusual happens [6]. Various studies across the globe have already focused on the relation between evidence of psychological distress in caregivers of disabled children [7-9]. A study done in Kenya on caregivers of children with intellectual disability shows that majority (79%) of caregivers were at risk of depression [10]. Freidrich et al studied the sample of 112 mothers of intellectual disabilities with developmental delay had noticed that depression among mothers had been increased from time one to two [11]. However, there is little data in developing countries like India on this topic [12]. Therefore, the aim of this study is to assess prevalence of depression in caregivers of ID children, to study clinical profile of ID, and the relation between demographic variables and depression in the caregivers of the intellectually disabled children.

METHODOLOGY

This cross-sectional study was conducted at department of psychiatry of Dr Shankarrao Chavan Government Medical college Nanded which is located in eastern Maharashtra. Caregivers of the persons with intellectually disabled attended out-patient department of psychiatry for either certification or treatment of behavioural problems who met inclusion criteria were screened. Patients of any age, diagnosed intellectually disabled according to DSM-5 and whose caregivers willing to sign an informed consent were included in study. The caregivers who participated in the study were explained the nature of study and were assured of confidentiality.

A sample of 60 patients were selected for the study. The enrolled participants were subjected to a sociodemographic details to collect data on gender, age, family income, type of family, religion, residence, education and occupation. Patients who included in this study were subjected to IQ assessments by clinical psychologist.

Inclusion Criteria

- > Caregivers of more than 18 years of age who were willing to participate in the study
- Caregivers of intellectually disabled patients
- Confirmed diagnosis of ID according to DSM-5 criteria.
- ➤ Both male and female caregivers were included in the study

Exclusion Criteria

- Caregivers with preexisting psychiatric illness
- ➤ History of sever medical or surgical illness
- Caregivers who were not willing to participate

The caregivers were administered Patient Health Questionnaire (PHQ 9) [13]. PHQ 9 was used to determine depression status in caregivers. The PHQ 9 was designed for use in medical and clinical settings. PHQ9 uses a four-point Likert scale (0= not at all, 1= several days, 2= more than half the days, 3= nearly every day) to gauge responses to questions asking about the respondents emotional/mental health over the last 2 week period. It is suitable for use in screening for depression among parents of children with severe disabilities [14].

Scores on the PHQ 9 can range from 0-27; scores between 0 and 4 indicate no depression, 5-9 indicate minimal symptoms, 10-14 indicate mild depression, 15-19 indicate moderately severe depression, and score ≥20 indicate severe depression [13]. Reliability and validity studies of PHQ9 indicate that PHQ9 has sound psychometric properties it has high internal consistency. Study of two different patient populations and 6000 participations has shown Cronbach's alpha of 0.86 and 0.89. Test-retest reliability of PHQ9 has high correlation at r=0.84, discriminant validity of PHQ9 was established by ROC analysis that produced an area under the curve of 0.95 when diagnosing depression [13]. It has high sensitivity and specificity [13]. Since Marathi version of the original Patient health questionnaire was not available. It was translated in Marathi language. The selection of questions was done from the translated version. It was translated in such a way that the meaning of translated question should be same as the meaning of the questions in English. The selected words for framing questions were very familiar to Marathi language. It was again translated back to English to compare the original. Translations were done by doctor who were bilingual. The data collected was tabulated in an excel spreadsheet and subjected to statistical analysis.

RESULTS

In this study, 60 intellectually disabled children and their care givers were included. Considering sociodemographic variables of intellectually disabled children, 51.7% were males and 48.3% females. Most of the children in this study belonged to the age group of 1-18 years (51.7%) and 71.1% were from nuclear family and 28.3% from joint family background. Seventy percent of the children were from rural area and 76.7% children were Hindu followed by 20% Muslim by religion. Sixteen percent children had mild ID, 41% moderate ID, 36% severe ID, 5% had profound ID. (Table 1)

Table 1: Association between Socio-demographic characteristic factors of patients and degree of disability of patients

Social demo	graphic		Degree of	Disability			
characteristi	cs	Mild	Madagata	Carrana	Profound	Total	χ^2
		Mild	Moderate	Severe			(p value)
		n=10	n=25	n=22	n=03		
6 1	3.6.1	(16.7)	(41.7)	(36.7)	(5.0)	21 (51 7)	2.550
Gender	Male	6 (10.0)	12 (20.0)	10 (16.7)	3 (5.0)	31 (51.7)	3.559
	Female	4 (6.7)	13 (21.7)	12 (20.0)	0 (0.0)	29 (48.3)	(0.313**)
Age	<18	4 (6.7)	11 (18.3)	13 (21.7)	03 (5.0)	31 (51.7)	
	18-50	6 (10.0)	13 (21.7)	9 (15.0)	0 (0.0)	28 (46.7)	5.629
	>50	0 (0.0)	1 (10.0)	0 (0.0)	0 (0.0)	1 (1.7)	(0.466**)
Family	<5000	5 (8.3)	6 (10.0)	1 (1.7)	9 (15.0)	21 (35.0)	
Income	5000-20000	4 (6.7)	18 (30.0)	2 (3.3)	12 (20.0)	36 (60.0)	7.054
	20000-45000	1 (1.7)	1 (1.7)	0 (0.0)	0 (0.0)	2 (3.3)	(0.631**)
	>45000	0 (0.0)	0 (0.0)	0 (0.0)	1 (1.7)	1 (1.7)	•
Type of	Joint	4 (6.7)	7 (11.7)	5 (8.3)	1 (1.7)	17 (28.3)	1.049
Family	Nuclear	6 (10.0)	18 (30.0)	17 (28.3)	2 (3.3)	43 (71.7)	(0.789**)
Religion	Buddhist	0 (0.0)	1 (1.7)	1 (1.7)	0 (0.0 %)	2 (3.3)	6.416
	Hindu	8 (13.3)	16 (26.7)	20 (33.3)	2 (3.3)	46 (76.7)	(0.378**)
	Muslim	2 (3.3)	08 (13.3)	1 (1.7)	1 (1.7)	12 (20.0)	!
Residence	Rural	7 (11.7)	16 (26.7)	17 (28.3)	2 (3.3)	42 (70.0)	0.999
	Urban	3 (5.0)	9 (15.0)	1 (1.7)	5 (8.3)	18 (30.0)	(0.802**)

In our study, most of the caregivers were males (53.3%) than females (46.7%). Seventy percent caregivers were in 26-50 years age group followed by twenty one percent from more than 50 years. Considering family background of caregivers, the majority of caregivers were from nuclear family(71.7%) background and the families whose earning capacities was in between 5000-20000/month were 60%, while 35% families had

less than 5000/ month income. Moreover, caregivers from rural background (70%) form the major group than urban background (30%). On religion basis, 76.7% of caregivers were Hindu by religion (Table 2).

Table 2: Association between Social demographic factors of caregivers and degree of depression

Socio-demographic		Degree of Depression						2
characteristi	CS	No	Minimal	Mild	Moderately	Major	Total	χ^2
		Depression	Symptoms		Severe	Severe		(p value)
Gender	Male	11 (18.3)	8 (13.3)	7 (11.7)	4 (6.7)	2 (3.3)	32 (53.3)	2.836
	Female	6 (10)	8 (13.3)	5 (8.3)	4 (6.7)	5 (8.3)	28 (46.7)	(0.587**)
Age	≤25	1 (1.7)	2 (3.3)	0 (0.0)	0 (0.0)	1 (1.7)	4 (6.7)	
	26-50	15 (25.0)	9 (15.0)	7 (11.7)	7 (11.7)	5 (8.3)	43 (71.7)	9.869
	>50	1 (1.7)	5 (8.3)	5 (8.3)	1 (1.7)	1 (1.7)	13 (21.7)	(0.274**)
Family	<5000	5 (8.3)	6 (10.0)	3 (5.0)	4 (6.7)	3 (5.0)	21 (35.0)	
Income	5000-20000	11 (18.3)	9 (15.0)	8 (13.3)	4 (6.7)	4 (6.7)	36 (60.0)	'
	20000-45000	0 (0.0)	1 (1.7)	1 (1.7)	0 (0.0)	0 (0.0)	2 (3.3)	6.397
	>45000	1 (1.7)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	1 (1.7)	(0.895**)
Type of	Joint	5 (8.3)	7 (11.7)	1 (1.7)	1 (1.7)	3 (5.0)	17 (28.3)	5.961
Family	Nuclear	12 (20.0)	9 (15.0)	11 (18.3)	7 (11.7)	4 (6.7)	43 (71.7)	(0.202**)
Religion	Buddhist	0 (0.0)	1 (1.7)	1 (1.7)	0 (0.0)	0 (0.0)	2 (3.3)	
	Hindu	15 (25.0)	12 (20.0)	9 (15.0)	7 (11.7)	3 (5.0)	46 (76.7)	9.557
	Muslim	2 (3.3)	3 (5.0)	2 (3.3)	1 (1.7)	4 (6.7)	12 (20.0)	(0.297**)
Residence	Rural	12 (20.0)	11 (18.3)	8 (13.3)	8 (13.3)	3 (5.0)	42 (70.0)	5.963
	Urban	5 (8.3)	5 (8.3)	4 (6.7)	0 (0.0)	4 (6.7)	18 (30.0)	(0.202**)

Majority of caregivers were illiterate (36.7%), while 20% educated up to primary level, 16.7% studied up to SSC level. By occupation, forty one percent of caregivers were labour, 25% were farmer. (Table 3)

On PHQ-9 scale, 71.7% of caregivers had depression out of which, 26.6% shows minimal symptoms of depression, 20% had mild depression, while 13.4% had moderately severe depression and 11.6% had major severe depression while 28.3% of caregivers had no depression. Depression was more common in females (36.6%) than males (35%) in our study. Caregivers whose age in between 26-50 years experienced more depressive features (46.7%) than other age groups. Depression found more in caregivers whose family income in between 5000-20000/month (41.7%). Caregivers from nuclear families (51.7%) had more depression than joint families (20%).

A significant association was found between caregiver's depression and degree of intellectual disability of their children (p value=0.044). The depression was highest among caregivers of children with moderate disability (41.7%) followed by severe disability (36.7%). (Table.4) A significant association was found between associated disability of ID Individuals and caregivers depression (p = 0.14).

DISCUSSION

The study was carried out in the out-patient Department of Psychiatry, Dr S.C. Govt. Medical College and hospital. Caregivers, who come to psychiatry department for certification or treatment for behavioural problems of their intellectually disabled child, were recruited after informed consent. In our study, 60 intellectually disabled children and their care givers were included. Among intellectually disabled children majority were males. Sixteen percent children had mild ID, 41% moderate ID, 36% severe ID, 5% had profound ID. Most of the intellectually disabled children were deprived of schooling because of degree of disability they had.

Table 3: Association between education and occupation of caregivers and degree of depression

		Degree of Depression						
	demographic acteristics	No Depressio n	Minimal Symptoms	Mild	Moderately Severe	Major Severe	Total	χ² (p value)
Education	Illiterate	4 (6.7)	7 (11.7)	3 (5.0)	4 (6.7)	4 (6.7)	22 (36.7)	
of the	Primary	3 (5.0)	3 (5.0)	2 (3.3)	4 (6.7)	0 (0.0)	12 (20.0)	•
Parent	Secondary	1 (1.7)	2 (3.3)	1 (1.7)	0 (0.0)	3 (5.0)	7 (11.7)	•
	SSC	5 (8.3)	1 (1.7)	4 (6.7)	0 (0.0)	0 (0.0)	10 (16.7)	31.805
	HSC	1 (1.7)	1 (1.7)	1 (1.7)	0 (0.0)	0 (0.0)	3 (5.0)	(0.132**)
	Graduate	3 (5.0)	2 (3.3)	0 (0.0)	0 (0.0)	0 (0.0)	5 (8.3)	-
	Post Graduate	0 (0.0)	0 (0.0)	1 (1.7)	0 (0.0)	0 (0.0)	1 (1.7)	•
	House Wife	2 (3.3)	1 (1.7)	4 (6.7)	1 (1.7)	1 (1.7)	9 (15.0)	
	Driver	1 (1.7)	0 (0.0)	1 (1.7)	0 (0.0)	0 (0.0)	2 (3.3)	•
	Farmer	6 (10.0)	4 (6.7)	1 (1.7)	3 (5.0)	1 (1.7)	15 (25.0)	•
	Labour	4 (6.7)	10 (16.7)	4 (6.7)	3 (5.0)	4 (6.7)	25 (41.7)	36.697
	Private Job	1 (1.7)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	1 (1.7)	(0.620**)
Occupation	Retired Teacher	1 (1.7)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	1 (1.7)	•
of Parent	Saloon	0 (0.0)	1 (1.7)	0 (0.0)	0 (0.0)	0 (0.0)	1 (1.7)	•
	Self employed	1 (1.7)	0 (0.0)	1 (1.7)	1 (1.7)	0 (0.0)	3 (5.0)	•
	Shopkeeper	0 (0.0)	0 (0.0)	1 (1.7)	0 (0.0)	0 (0.0)	1 (1.7)	•
	Tailor	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	1 (1.7)	1 (1.7)	•
	Welder	1 (1.7)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	1 (1.7)	•

Table 4: Association between Degree of Severity of ID and Depression

PHQ-9 Score		Degree of	Total	χ^2		
	Mild	Moderate	Severe	Profound		(p value)
No Depression	3	6	7	1	17	
(<5)	(5.0%)	(10.0%)	(11.7%)	(1.7%)	(28.3%)	
Minimal Symptoms	2	7	7	0	16	_
(5-9)	(3.3%)	(11.7%)	(11.7%)	(0.0%)	(26.7%)	
Minor Depression, Mild	5	5	2	0	12	_
(10-14)	(8.3%)	(8.3%)	(3.3%)	(0.0%)	(20.0%)	
Major Depression,	0	3	5	0	8	21.434
Moderately Severe	(0.0%)	(5.0%)	(8.3%)	(0.0%)	(13.3%)	(0.0445
(15-19)						(p=0.044*
Major Depression, Severe	0	4	1	2	7	
(>20)	(0.0%)	(6.7%)	(1.7%)	(3.3%)	(11.7%)	
Total	10	25	22	3	60	
	(16.7%)	(41.7%)	(36.7%)	(5.0%)	(100%)	

Most of the caregivers were unaware of the educational facilities available for their children and this could be another reason due to which these children are deprived of schooling. Hence every mental health professional should make them aware about facilities like special education in special schools.

In our study, 71.7% of caregivers of intellectually disabled children were at risk of depression as derived from PHQ9 score, this finding is consistent with other studies [10-11, 15-16]. In one study [16], 85% of the mothers of the mentally retarded suffer from depression. Moreover, Solomon study noted 72.1% of caregivers of were at risk of depression [17]. The depression seen in Indian studies is more than the studies done around the world15. Having a child with intellectual disability, a family faces many challenges such as psychological distress, interactive family issues, disturbed schedules and additional expenses, which can create financial burden on family and there requires a reorientation and re-evaluation of family goals, responsibilities and relationships [18-20]. Those caregivers of ID children who were diagnosed as having depression they needed mental health services and support. Finding predicting factors of depression among caregivers of intellectually disabled child may help in identifying those caregivers who need special care by mental health professional to reduce their risk of psychological distress.

In our study sample, depression was more common in female caregivers (36.6%0) than male caregivers. This finding is in consistent with previous studies [10,20]. As in Indian culture the female have high social responsibilities and they are the primary care takers of their children. Within that context, in nuclear families, stress and care demands are expected to be strongest for females [20-21]. Accordingly, females are more vulnerable to the psychological distress associated with child's behavioural problems [22]. Researchers have noticed [23] that 22% of female visited doctor concerning about their psychological problems are due to their children. From the observations and results it can be concluded that, there is direct correlation between degrees of disability in intellectually disabled child with level of depression in caregivers. The levels of depression were more in caregivers whose ID child had moderate to severe disability. This was statistically found significant. Similar findings have been shown in previous studies [20,24]. As the severity of disability in ID child increases, the child may face impairments in different areas of adaptive functioning like self-care, academic, home living, use of community resources etc. and within that context, the more special care requires from caregivers that leads to additional burden on caregivers which may result in psychological distress.

In our study, the maximum number of caregivers is from the age group of 26-50 years. This finding is in consistent with a study [24] in which they found maximum number of caregivers were from the age group of 36-50 years. In our study this age group had more risk of depression than other age group. This may be due to, the caregivers in younger age group could have more worries about their intellectually disabled child's future and this may predispose them to depression. From observations it can be concluded that, caregivers from nuclear family background had higher levels of risk of depression as compared to caregivers from joint family background. In joint family there are other family members who can help to take care of ID child but in nuclear family the burden of care of ID child remain on alone which may attribute to psychological distress among caregivers from nuclear family background. Moreover, the risk of depression was higher among the illiterate and primarily educated caregivers from the study sample.

Limitations

- Small sample size
- This study is hospital based conducted in single locality, so that bias may have occurred in selection of sample population hence, it would be difficult to ascertain if the risk of depression of caregivers would be the same or different from other localities.

CONCLUSION

The prevalence of depression among caregivers of children with intellectually disabled was higher in this study. The risk of depression was higher in female caregivers as compared to male caregivers. Therefore, there is need to develop support system to prevent the risk of depression in the caregivers of intellectually disabled children.

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