

Original Article**Study of Anxiety and Depression in Caregivers of Intellectually Disabled Children**

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ABSTRACT

Background: Intellectual disability is a permanent condition unlike many other diseases. It is a highly disabling condition. Study once, this is an attempt to study negative impact on caregivers to help and manage this problem in the best possible way.

Aims & Objective: To find prevalence, influence of various socio-demographic variables and its clinical correlation with anxiety and depression in caregivers of intellectually disabled children.

Material & Methodology: The study was conducted at the Outpatient Department (OPD) Of Psychiatry, G.G.Govt. Hospital, Jamnagar, Gujarat. The caregivers who came with their intellectually disabled child for certification were recruited. Using specially designed semi-structured socio-demographic and clinical data sheet, information was collected about intellectually disabled children and their caregivers. Parents fulfilling inclusion and exclusion criteria consenting for the study were selected and Zung's self rating anxiety and depression scale was used.

Results: Prevalence of anxiety was 57% and depression was 63%. Earning status and Type of family has been significantly associated with high anxiety score and other socio-demographic variables i.e. Gender, Religion, Education and marital status were not associated with high anxiety score among caregivers. Out of all socio-demographic variables only age of caregiver was significantly associated with high depression score.

Conclusion: Study shows high anxiety score and depression score among caregivers of intellectually disabled children.

Key words: Caregivers, Intellectually Disabled, Zung's self rating scale, Anxiety score, Depression

INTRODUCTION

Intellectual disability is a disabling condition. It is generally considered that 2% of the Indian population constitutes persons with intellectually disabled. In India, prevalence of intellectually disabled varies from 0.22 to 32.7 per thousand populations [1,2]. Intellectually disabled is defined as a significantly sub-average general intellectual functioning, resulting or associated with concurrent impairment in adaptive behaviour and is manifested during the developmental period [3].

There can be no doubt that intellectual gifts have been distributed on a continuum for as long as mankind has walked the earth. Yet, through the ages, understanding and treatment of persons with intellectually disabled has moved like a pendulum

between extremes. At one extreme, persons with intellectually disabled have been exalted, considered "les enfants du Bon Dieu" (children of the Good God). The word "cretin" (congenital hypothyroidism), was used previously, for intellectually disabled children, takes its origin from Christian or Christ-like, even as its modern definition includes descriptors such as stupid, vulgar, and insensitive. To this day, society wrestles with the exact nature of such persons. Caring of an intellectually disabled child is a challenge and parents or other caregivers are always at increase risk of anxiety and depression. Age, economical condition, and social background are important factors affecting the overall mental health of caregiver.

MATERIAL AND METHODS

Study was conducted at the Department of psychiatry, M. P. Shah Government Medical College and Guru

Gobind Singh Government Hospital, Jamnagar, Gujarat. Relatives of the Patients with intellectually disabled attended psychiatry OPD for either certification or treatment of behavioural abnormalities were screened. Simple random sampling was done. Those who met inclusion criteria for the study were enrolled in this study. Written informed consent was obtained from the patient's care-givers before including in the study by explaining nature of the study, about the procedure, its purpose and being assured of confidentiality of the information.

Hypothesis

Our hypothesis is that depression and anxiety score are more prevalent among the caregivers of intellectually disabled children compared to normal population.

Inclusion Criteria

- Age from 20 to 80 years.
- Caregivers of intellectually disabled patients.
- Confirmed diagnosis of intellectually disabled according to DSM IV-TR criteria.
- Both male and female caregivers were included in study.

Exclusion Criteria

- Caregivers with Axis-I diagnosis of any other mental disorder.
- Caregivers of less than 20 years or more than 80 years of age.
- Relevant history of any significant and/or unstable cardiovascular, respiratory, neurologic, renal, hepatic disease and other organic condition.
- Caregivers who were uncooperative and unwilling to participate.

Zung's self rating depression scale (Zung SDS)

The Zung's SDS was designed for assessing depression in whose patients with a primary diagnosis of depressive disorder. Total 20 items of the scale address each of the four common characteristics of depression: the pervasive effect, the physiological equivalents, other disturbances, and psychomotor activities. Ten items are worded positively and ten items are worded negatively. Each item is scored on a scale of 1 to 4 (a little of the time - most of the time) with reverse scaling for the negatively worded items. This yields an overall score of 20 to 80 and a converted SDS Index score of 0.25 to 1.00 [4, 5]. Since, Gujarati and Hindi translated version of the original Zung's anxiety and depression scales were

not available, it was translated in local languages. The item selection was done from the translated version of the scale with the help of supervisor. The item translated were selected on the basis of that meaning of translation should be same as the meaning of the original English item and its language is such that the words are familiar in day to day language of the region. Translated version was again translated to English language for comparison with original. Translation and back translation was done to Hindi and Gujarati was done by consultants who were bilingual. Data was collected from Psychiatry OPD. Caregivers of intellectually disabled patients screened as per inclusion and exclusion criteria. They were explained purpose of study and after taking written informed consent, "Research tools" were administered.

Statistical test: Frequency, Percentages, Means and Standard Deviation & Chi-square test

OBSERVATIONS

Table 1: Socio-demographic variables of Caregivers of Intellectually Disabled Children

	No. (%) (n=100)
Age (yrs)	
21-35	21 (21%)
36-50	38 (38%)
51-65	29 (29%)
66-80	12 (12%)
Gender	
Male	42 (42%)
Female	58 (58%)
Religion	
Hindu	81 (81%)
Muslim	19 (19%)
Education	
Illiterate	13 (13%)
Primary	58 (58%)
Secondary	21 (21%)
Graduate	07 (7%)
Post-graduate	01 (01%)
Marital status	
Single	15 (15%)
Married	69 (69%)
Divorced	07 (07%)
Separated	09 (09%)
Earning status	
Earning	52 (52%)
Non-earning	48 (48%)
Type of family	
Nuclear	67 (67%)
Joint	33 (33%)

Table 2: Association between various Socio-demographic variables and high anxiety score in Caregivers

	No. of caregivers (n=100)	Caregiver with high Anxiety Score No. (%)	Chi-square value	P value
Age				
21-35	21	18 (85.71)	4.016	0.25
36-50	38	24 (63.15)		
51-65	29	11 (37.93)		
66-80	12	04 (33.33)		
Gender				
Male	42	21 (50.00)	0.216	0.64
Female	58	36 (62.07)		
Religion				
Hindu	81	43 (53.07)	0.383	0.53
Muslim	19	14 (73.68)		
Education				
Illiterate	13	09 (69.23)	0.754	0.94
Primary	58	32 (55.17)		
Secondary	21	10 (47.62)		
Graduate	7	05 (71.43)		
Post-graduate	1	01 (100)		
Marital status				
Single	15	10 (66.67)	0.499	0.91
Married	69	40 (57.97)		
Divorced	7	03(42.86)		
Separated	9	04 (44.44)		
Earning status				
Earning	52	17(32.69)	6.37	0.01
Non-earning	48	40 (83.33)		
Type of family				
Nuclear	67	50 (74.63)	7.15	0.007
Joint	33	07(21.21)		

The study was conducted in 100 care-givers and out of them thirty-eight (38%) caregivers were in 36-50 years age group followed by twenty-nine (29%) caregivers between ages 51-65 years. Out of 38 of caregivers from age group 36-50 years, 24 (63.16%) had high Zung's anxiety score and 31 (81.58%) had high Zung's depressive score. This ratio was somewhat higher in 21-35 years age group for both anxiety score and depressive score i.e. 18 (85.71%) and 20 (95.24%) respectively. These differences in age and anxiety score is not statistically significant ($p>0.05$) while age and depression score is statistically significant ($p<0.05$). Association between earning status and type of family found to be statistically significant while it was not found

significant between other variables i.e. Gender, Religion, Education and Marital status.

Table 3: Association between various Socio-demographic variables and Low anxiety score in Caregivers

	No. of caregivers (n=100)	Caregiver with high Depression Score No. (%)	Chi-square value	P value
Age (yrs)				
21-35	21	20 (95.24)	9.2	0.02
36-50	38	31 (81.58)		
51-65	29	10 (34.48)		
66-80	12	02 (16.67)		
Gender				
Male	42	27 (64.29)	0.003	0.95
Female	58	36 (62.07)		
Religion				
Hindu	81	53(65.43)	0.089	0.76
Muslim	19	10 (52.63)		
Education				
Illiterate	13	11 (84.62)	1.47	0.83
Primary	58	36 (60.34)		
Secondary	21	13 (61.90)		
Graduate	7	03 (42.86)		
Post-graduate	1	00 (00.00)		
Marital status				
Single	15	8 (53.33)	0.349	0.95
Married	69	44(63.77)		
Divorced	7	04 (57.14)		
Separated	9	07(77.78)		
Earning status				
Earning	52	41 (78.85)	2.19	0.13
Non-earning	48	22 (45.43)		
Type of family				
Nuclear	67	42 (62.69)	0.16	0.89
Joint	33	21 (63.64)		

Association between all socio-demographic variables except Age i.e. Gender, Religion, Education, Marital status, Earning status & Type of family with high depression score does not found statistically significant ($p>0.05$).

DISCUSSION

The study was carried out in the Out Patient Department of Psychiatry, M.P. Shah Govt. Medical College and Guru Gobind Singh hospital and caregivers who come to psychiatry department for certification or treatment for behavioural problems of

their intellectual disabled child, were recruited after written informed consent.

Socio-demographic characteristics

Results of our study are similar to the findings of Njeri Mbugua et al (2011), which suggest that maximum numbers of care-givers are from the age group of 35-50 years [7]. Our study matches with the study of Okewole et al (2011), which suggest that gender of the care-giver has no significant correlation with High Zung's anxiety score levels. It means that care-givers may develop anxiety regardless of their age group and all age group are equally vulnerable [9].

Care-givers of intellectually disabled children have significant depressive score. Caldwell et al (2008) found that age has significant correlation with high depressive score; they found that younger care-givers are more affected with anxiety initially and later on they develop more depressive symptoms compared to older care-givers because they have more worries and anxiety about the future of their intellectually disabled child. Though elder care-givers also, may be worried but they may have significantly abundant coping skills. This correlates well with our study that age is significantly related with developing high depressive scores while caring for an intellectually disabled child [8], while there is no statistical correlation found in our study between anxiety and age group. In our study, from observation and results it can be concluded that gender of care-giver hasn't any significant correlation with High Zung's anxiety and depression score. It also means that either male or female care-givers can develop High Zung's anxiety and depression score while caring for their intellectually disabled child. Majmudar et al (2005), found that male and female caregiver have significantly high Zung's anxiety score, as with our finding using Zung's self rating scale [10]. This finding is consistent with the study of Okewale et al (2011), suggesting that caregivers regardless of their gender are equally affected while caring for disabled child, but study of Njeri Mbugua et al (2011) suggests that female caregivers are more affected than male caregiver while caring for their intellectually disabled child [7,9]. Here the ratio of female care givers seems to be quite high due to their more involvement in caring intellectually disabled child. As the female have high social responsibilities & more concern about their care recipients. In one study, Emerson et al(2004) found that 22% of women visited doctor concerning about their psychological complains are due to their children [11].

From observations and results it can be concluded that both Hindu and Muslim care-givers are equally affected while caring for their disabled child. Majmudar et al (2005) have noted that religion has not much correlation while caring for their intellectually disabled child, which is similar finding with our research study. But large sample size is required to give any critical comment on this, as we did not measure the pre-morbid personality trait while assessing the caregiver and as the sample size is 100, further conclusion and comments regarding correlation between religion and high anxiety and depression score, is difficult to evaluate [10].

High Zung's anxiety and depression scores is equal or somewhat higher among illiterate and primarily educated care givers due to concomitant low financial condition, poor socio economical background, less ability to capture the opportunity and available resources. But educated care-givers are not exceptions, and they regardless of their higher education, also develop more worries, anxiety and consequently more Zung's high anxiety and depression score Which is a similar finding with the study by Charnsil et al (2010) and Ladik et al (2008), that regardless of their educational status, care-givers may develop anxiety [12,13] however, in a study by Yildirim et al (2010), it was found that caregivers who had less educational status and who were illiterate have high depressive score, and they need some intervention [14] but in our study we have not found any significant correlation, this may be due to hospital based study and may be due to less sample size.

It can be concluded that any caregiver regardless of their marital status develops more anxiety and depressive symptoms while caring for their intellectually disabled child. Our study matches with the study of Okewale et al (2011) and Hoarse et al (1998) which also shows that marital status does not have any significant correlation with High Zung's anxiety score and regardless of marital status, caregivers of any marital status are equally affected, but Osslon et al (2011), shows that divorced, separated caregivers are more commonly affected than married caregiver [9, 15, 16]. It may be due to additional stress of caring their intellectually disabled child alone without any moral support of spouse. And no any significant correlation has found between high depression score and marital status, depressive symptoms are equal among divorced and separated compared to married care givers. Though married care givers are not exceptions from getting High

Zung's depression score while caring their disabled child. Here, married care givers may get depressed due to social stigma of having disabled child in family, while divorced and separated caregiver may be depressed due to burden of caring alone; without the help of spouse, and more economical responsibilities, to cope up with their daily expenses. Our finding is consistent with Hoarse et al (1998) where marital status had not significant correlation with High Zung's depression score while caring for their intellectually disabled child. Also, A.Okewale et al (2011) suggest that depressive symptoms can be seen in all caregivers taking care of their intellectually disabled child, regardless of their marital status [9,15].

Employment has very high correlation with High Zung's anxiety score, Which is highly indicative that unemployed or non-earning caregiver has significantly more Zung's anxiety score while caring their intellectually disabled child and this finding is consistent with findings of studies by Bradshaw et al (1978), Brita et al (1990) and Kumar et al (2001) that care-giver develops more anxiety when daily expenses does not cover their basic daily needs. But in contrast to this no any statistical significant correlation is found between high Zung's depressive score and employment, A.Okewale et al (2011) had similar findings as our study [9] In contrast, Chou et al (2010) and Olsson et al (2011) found that depression is more common among nonearning and unemployed caregivers [4,5].

Care-givers residing in nuclear family have very high Zung's anxiety score level in compare to caregiver of joint family. This may be due to other members, in joint family, who also simultaneously taking care of intellectually disabled child, so burden to care alone, as in joint family is somewhat less in compare to nuclear family and so is Zung's anxiety score level. It shows that Indian tradition and culture of residing in joint family is very protective and caregivers of nuclear family have high psychiatric co-morbidities as compared with caregivers of joint family, but there is no any significant statistical correlation found between family type and high Zung's depression score [1].

Limitations of our study

- Small sample size
- As it is cross-sectional study and follow up of study participants were not done, consistency of results can't be obtained.
- This is a hospital based study, so that bias may have occurred in selection of sample

population and so results obtained may not be applied to universe.

- High degree of resistant was found, due to procedure of informed consent.
- Different levels of personality traits have not been taken into consideration, which also influences on perception of anxiety and depression.

REFERENCES

1. Madhavan, T., Kalyan, M., Naidu, S., Peshawaria, R. & Narayan, J. Intellectually disabled - A manual for psychologists. Secunderabad: NIMH. ;1989
2. Shalini. In: Madhavan T, Kalyan M, Naidu S, Peshwaria R, Narayan J. Intellectually disabled: A Manual for Psychologists. Andhra Pradesh, India: National Institute for the Mentally Handicapped (Under the Ministry of Social Justice and Empowerment, Government of India);1982.
3. American Association of Mental Deficiency. In intellectually disabled, a manual for psychologists, Secunderabad, India: National Institute for mentally handicapped; 1983.
4. Zung WWK. Self rating scale for depression. Arch Gen Psychiatry 1965;12:63-70.
5. Zung, W.W. Sajatovic, M & Ramirez, L.F. Zung depression scale[SDS], ECDEU version. Rating scales in mental health, 2nd ed. Hudson OH;2003.p.112-5.
6. Zung WWK. A rating instrument for anxiety. Psychosomatics. 1971; XII:371-379. Reprinted with permission from Psychosomatics, ©1971. American Psychiatric Association.
7. Margaret Njeri Mbugua, MaryW. Kuria, and David M. Ndeti. The Prevalence of Depression among Family Caregivers of Children with Intellectual Disability in a Rural Setting in Kenya. International Journal of Family Medicine 2011; 54-63.
8. Caldwell J. Health and access to health care of female family caregivers of adults with developmental disabilities. Journal of Disability Policy Studies2008;19:68-79.
9. Okewole, M.U.Dada, O.Ogunl, M Bello-Mojeed, T.Usoh. Prevalence and correlates of psychiatric morbidity among caregivers of children and adolescents with neuropsychiatric disorders in Nigeria. African Journal of psychiatry 2011;14:306-09.
10. Mita Majumdar, Yvonne Da Silva Pereira, John Fernandes. Stress And Anxiety in Parents of Intellectually disabled children. Indian J Psychiatry 2005;47:144-7.
11. Emerson E, Robertson J, Wood J. Levels of psychological distress experienced by family carers of children and adolescents with intellectual disabilities in an urban conurbation. Journal of Applied Research in Intellectual Disabilities 2004;17:77-84.

12. Chawanun Chamsil, Narumol Bathia. Prevalence of Depressive Disorders among Caregivers of Children with Autism in Thailand. *Asean Journal of Psychiatry* 2010;11:1-11.
13. Ladin K. Risk of late-life depression across 10 European Union countries: deconstructing the education effect. *J Aging Health* 2008;20:653-70.
14. Hatice Yildirim Sari; Zümürüt Başbakkal. Depression among caregivers of children and adults with an intellectual disability in Turkey. *International Journal of Nursing Practice* 2010;16:248-54.
15. Hoare P., Harris M., Jackson P. & Kerley S. A community survey of children with severe intellectual disability and their families: psychological adjustment, carer distress and the effect of respite care. *Journal of Intellectual Disability Research* 1998;42:218-27.
16. M. B. Olsson & C. P. Hwang; Depression in mothers and fathers of children with intellectual disability. *J Intellect Disabil Res* 2001;45:535-43.
17. Kumar I, Akhtar S. Rate of anxiety in mothers of intellectually disabled children. *Indian J Psychiatry* 2001;43:27.

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