

Stress among the caregivers of mentally disabled children visiting a rehabilitation centre in Chennai, Tamil Nadu – A cross-sectional study



Aarthi Ramachandran^{a,*,**}, Navya Vyas^b, Dan Isaac Pothiyil^c

^a Master of Public Health, Department of Health Policy, Prasanna School of Public Health, Manipal Academy of Higher Education, Postal Address: 1/294, Periyar Street, Injambakkam, Chennai, 600115, Tamil Nadu, India

^b Department of Health Policy, Prasanna School of Public Health (PSPH), Manipal Academy of Higher Education, Manipal, 576104, Karnataka, India

^c Manipal College of Health Professions, Manipal Academy of Higher Education, Manipal, 576104, Karnataka, India

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ABSTRACT

Caregiving is a complex health care activity, from an informal family level activity; it is becoming a major part of health care. In India, family members are mostly caregivers for persons with mental disabilities. The present study assessed the stress among the caregivers of mentally disabled children (Autistic Spectrum Disorder, Intellectual Disability, and Attention Deficit Hyperactivity Disorder) and found the association between stress and selected socio-demographic variables. This was an institutional based cross-sectional study with a duration of six months, i.e. from January 2019 to June 2019. This study was conducted among the caregivers availing services (therapies and follow-ups) at the National Institute for Empowerment of Persons with Multiple Disabilities, Chennai, Tamil Nadu. The level of stress was assessed using the Kingston Caregiver Stress Scale. This study was conducted with time-bound complete enumeration method, by which data from 101 participants were collected. The results of this study showed that 64.3% of the caregivers had the severe level of stress, 21.7% of the caregivers had a moderate level of stress and 13.8% of the caregivers had mild stress. Hence, it can be concluded that caregiver's stress is an important element to determine the burden and the unexplained psychological pressure a caregiver holds onto.

1. Introduction

Mentally disabled children have combined characteristics such as a lack of intellectual potential, mental capacities that lag behind those of the peers, slow to learn and many such; hence the presence and attention of a caregiver are mandatory throughout their lifetime. The degree of disability in terms of mental health tends to increase with significant effect on the human rights, health, economic consequences globally. In India, 84% of the caregivers are women and more than 96% of them are of working age.² A huge quantity of physical and mental health is required to maintain equilibrium among their self-necessities and the needs of their children.³ Children with Autistic Spectrum Disorder (ASDs), Attention Deficit Hyperactivity Disorder (ADHDs) and Intellectual Disabilities (IDs) are dependent on their caregivers henceforth they are deprived of their social life. The caregivers are usually tired, stressed and stay frustrated or isolated from the family members. Caregiving can also be challenging. They help the mentally disabled children with everyday activities such as eating, dressing, bathing/toileting activities, going out for therapies/doctors and taking

medications. They usually get no support or less support for the limitless work they do, but they are very essential for empowering the standard of living of the mentally disabled. Factors like family, occupation, economic status; age and gender influence the caregiver's stress.⁵

Caregiving stress does not occur only with taking care of the children with needs, it is accompanied with other household and family pressure. They have difficulties in managing stress. These care related stress along with other personal elements will have an effect on the caretaker's welfare and health, influence major relationships in their lives and even result in economic pressure. Caregivers who invest a lot of resources such as time, energy, money and care for the children with mental disability experiences the highest degree of burden. Research has shown that caregivers experiencing stress are at high risk of utilizing dysfunctional methods to handle their child's difficulties. Others characteristics such as the number of members in the family, age and gender of the caregiver, the educational qualification of the caregivers and the economic status of the caregiver were all related to the degree of caregiver stress.⁴ In India, very often, the responsibilities of caring

* Corresponding author.

E-mail address: ammuaarthi.ar@gmail.com (A. Ramachandran).

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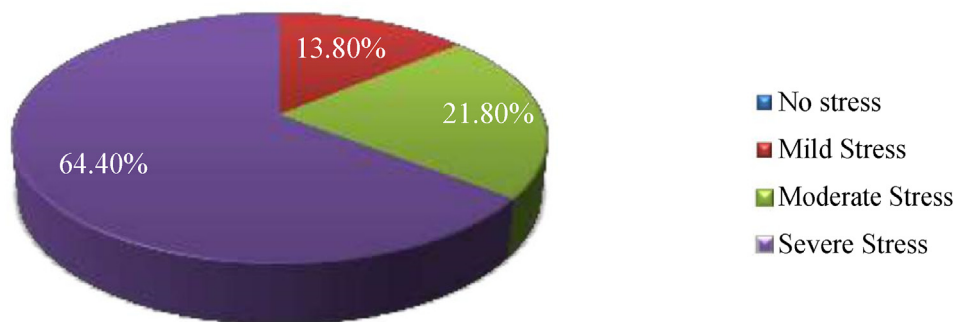


Fig. 1. Level of stress among the caregivers (n = 101).

Results: Fig. 1 represents the results of the first objective of the study. Statistical package for social science (SPSS: version 15) was used for data analysis.

for a person with mental disabilities rely on women of the house. According to a recent research by “The World Bank”, most of the responsibilities of caregiving were among the women between the age group 25–54 years. Usually, the caregivers have to forego jobs that could otherwise have brought in desperately needed wages, in addition to the mental strain that accompanies caregiving. In Indian families, mothers are mostly the caregivers of any type of disabilities or chronic illness, and they tend to have more stress. Fathers and even other family members get agitated from depressive signs, but comparatively lesser than that of mothers.⁶

In this study, caregivers of children with three major mental disabilities i.e., Autistic Spectrum Disorder, Intellectual Disabilities and Attention Deficit Hyperactivity Disorder, have been included to assess their stress and find their association with socio-demographic variables.⁷ The common difficulty they face raising a child are impaired memory, less attention, the problem with making decisions, solving problems, difficulties with finding words and weak civic behavior. The difficulties faced by caregiver of a child with mental disabilities like ASD, ID and ADHD are very high. This study was initiated in order to address the stress among the caregivers of mentally disabled children (Autistic Spectrum Disorder, Attention Deficit Hyperactivity Disorder and Intellectual Disabilities) and the socio-demographic factors associated with stress.

2. Method

Sample: The data were collected from 101 caregivers of children with mental disabilities. The place of data collection was the National Institute for Empowerment of Persons with Multiple Disabilities in Chennai, Tamil Nadu.

2.1. Inclusion criteria

Caregivers of Mentally disabled children within the age range of 4–17 years.

Primary caretakers of the differently abled children.

2.2. Exclusion criteria

Caregivers who have not provided care for the last 12 months.

Tools Used: In this study, Kingston Caregiver Stress Scale was used to assess the stress among the caregivers. This scale was developed by the Kingston Scales Institute. The scale consisted of the following domains: Caregiving Issues, Family Issues, Financial Issues. Using this five point rating scale, where 1 indicates no stress and 5 indicates extreme stress, indicate the extend of frustration or stress the caregivers feel surrounding the above mentioned issues. The socioeconomic status of the caregivers was collected as per the Income Certificate issued by the government of Tamil Nadu. Statistical Package for the Social Sciences (SPSS) version 16 was used for statistical analysis. Based on the

diagnosis done at the National Institute for Empowerment of Persons with Multiple Disabilities and the Disability Card issued by the Government of India, the children are classified as ASD, ADHD or ID.

Procedure: This was a cross-sectional study from January 2019 to June 2019. Data were collected from 101 caregivers of mentally disabled children. Participants were recruited from the National Institute for Empowerment of Persons with Multiple Disabilities who were availing service and therapies. Participants fulfilling the inclusion criteria were selected for the study. Informed consent was taken from the participants after explaining about the purpose and procedures of the study.

3. Results

The results of this current study showed that 64.3% of the caregivers had severe level of stress, 21.7% of the caregivers had a moderate level of stress and 13.8% of the caregivers had mild stress (Fig. 1). The association of level of stress among the caregivers was statistically significant with the economic status with a p-value of 0.015, with the type of family with a p-value of 0.045 and with the gender of the caregiver with a p-value of 0.004 (Table 1).

4. Discussion

Caregiver stress is one of the useful indicators to assess the burden among the caregivers who are the primary caretakers of the mentally disabled children. More than 66% of the caregivers belong to the age group 35 years and below, among these caregivers, 65.7% had severe stress level, 23.9% had moderate level of stress and 10.4% had mild stress level (Table 1). Among all the participants, 93% of the caregivers were mothers and they tend to have more stress than other caregivers (Table 1). Similarly a study conducted in 2009 matches with the results of this present study; it has been found that mothers of children with mental disabilities like ASD tend to have issues related to the mental welfare in adaptability among family and cohesion.³ There were statistical significance between the level of stress and social-demographic variables. Caregivers who had lower and middle economic status had more stress than others. There is a similarity among the findings of this present study and a study conducted by Oyeleke Ajiboye Isaac et al., which had highlighted that the career and economic status both predict welfare of the family caretakers the disabled children.⁸ Female caregivers had more stress than male. Caregivers living in a nuclear family had more stress than those who live in a joint family. In contrary to the results of this present study, the findings of a similar study conducted by Abirami P, with the objectives to assess the caregiver burden and its association with disabilities and demographic variables, has found that 89% of the caregivers had moderate stress and they were significant association with demographic variables such as sex, education, occupation, income and relationship with the child.⁵

Table 1
Factors associated with Level of Stress and Socio-demographic details of the Caregivers (n = 101).

Socio-demographic Variables:		Level of stress n (%)			P - value
		Mild Stress	Moderate Stress	Severe Stress	
Age(Caregivers)	≥ 35 years (67)	7(10.4)	16(23.9)	44(65.7)	0.345
	≤ 36 years (34)	7(20.6)	6(17.6)	21(61.8)	
Type of mentally disabled children	ASD(41)	5(12.2)	8(19.5)	28(68.3)	0.757
	ID(37)	4(10.8)	9(24.3)	24(64.9)	
	ADHD (23)	5(21.7)	5(21.7)	13(56.6)	
Age(Child)	4–6 years (39)	4(10.4)	9(23.1)	26(66.7)	0.520
	7–11 years (38)	5(13.2)	9(23.6)	24(63.2)	
	12–14 years	4(33.3)	1(8.3)	7(58.4)	
	15–17 years	1(8.3)	3(25.0)	8(66.7)	
Gender of the Caregiver:	Male	0(0.0)	3(100.0)	0(0.0)	0.004
	Female (98)	14(14.3)	19(19.4)	65(66.3)	
Type of Caregiver	Mother (94)	13(13.8)	19(20.2)	62(66)	0.354
	Others	1(14.2)	3(42.9)	3(42.9)	
	Others	1(14.2)	3(42.9)	3(42.9)	
Educational Qualification	Graduate (47)	9(19.1)	13(27.7)	25(53.2)	0.414
	Intermediate/diploma	0(0.0)	1(50.0)	1(50.0)	
	High school	1(6.2)	4(25.0)	11(68.8)	
	Middle school	1(10.0)	2(20.0)	7(70.0)	
	Primary school (26)	3(11.5)	2(7.7)	21(80.8)	
Marital Status	Married (98)	14(14.3)	22(22.4)	62(63.3)	0.425
	Others	0(0)	0(0)	3(100)	
	Others	0(0)	0(0)	3(100)	
Family type	Nuclear family (77)	7(9.1)	18(23.4)	52(67.5)	0.045
	Joint family (24)	7(29.2)	4(16.7)	13(54.1)	
Economic Status	Low (36)	1(2.8)	4(11.1)	31(86.1)	0.015
	Middle (56)	11(19.6)	15(26.8)	30(53.6)	
	High	2(22.2)	3(33.3)	4(44.5)	

Result: Table 1 represents the results of the second objective of the study.

5. Conclusion

This study shows that the majority of the caregivers had severe stress and no participant were without stress (Fig. 1). The level of stress among the caregivers was statistically significant with socio-demographic variables such as type of family, gender of the caregiver and economic status (Table 1). Caregivers offers a massive array of emotional, nursing, social, financial and other services to the mentally disabled children. They tend to limit the time for their personal. The results of this study showed that the majority of the caregivers had severe level of stress and no caregivers were found to be without stress. The level of stress and socio-demographic variables such as gender of the caregivers, type of family and economic status were statistically significant. The level of stress increases with a decrease in the economic status of the caregivers. It was observed that most of the caregivers had stressed over lack of family support apart from financial issues. Though the level of stress is high among the caregivers living in a nuclear family, they still prefer to live in a nuclear family in order to avoid sympathy and discrimination that usually arises in a joint family.

Hence, it can be concluded that caregiver's stress is an important element to determine the burden and the unexplained psychological pressure a caregiver holds on to. The family members and the spouse, especially, have to understand the trauma any female goes through while taking care of a mentally disabled child and emotionally support them. There is a need to develop systems of skills, support and supervision to caregivers in providing care to the individuals with mental disability. This can minimize the stress of caregiving and maximize the positive feelings of caregivers.

Declaration of competing interest

None.

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