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Original Investigation

Psychological Burden among Caregivers of Children with Autism Spectrum Disorder at Special Schools

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ABSTRACT

INTRODUCTION: The alarming increase in the prevalence of autism has cause not only an increase in the number of cases of autism but also increased need for better awareness and understanding of the condition and its management for them who are in direct daily contact with someone with autism. The support for caregivers of autism spectrum disorder children is highly needed to minimize their experienced burden. The objective of this study was to assess the psychological burden among caregivers of children with autism spectrum disorder. **MATERIALS AND METHODS:** Quantitative non-experimental descriptive research design was adopted for the study. The data was collected from 70 samples with the Modified Zariet Burden Interview Scale. Collection of data was entered into Ms-excel and was analyzed and interpreted using SPSS Software. **RESULTS:** The present study revealed that majority (56%) sample has mild to moderate burden, (24%) has little or no burden, (19%) has moderate to severe burden and the least (1%) has severe burden. The demographic variables such as educational level, monthly income, training received regarding care of the child were directly associated with psychological burden of the caregivers. **CONCLUSIONS:** The study concluded that assessing the burden level of caregiver can help them to reduce their burden through proper counselling.

Keywords: Autism, caregivers, psychological burdens, special schools.

INTRODUCTION

Autism Spectrum Disorder (ASD) is a complex group of neuro-developmental disorders characterized by triad of impairments in communication skills, social skills and repetitive behaviour which is seen during early childhood primarily from 18 months to 30 months of age [1]. Raising a child with ASD puts tremendous strain on the parents and caregivers due to increased responsibility and social stigma. The stress of caring for a child with autism can affect the psychological and emotional well being of parents [2]. The Indian Scale for the Assessment of Autism (ISAA) was developed by the National Institute for Mentally Handicapped (NIMH) in India for diagnosing and measuring the severity of autism. The support for caregivers of autism spectrum disorder children is highly needed to minimize their experienced burden. There is death of availability of scientific literature's among the caregivers of children with autism spectrum disorder at school level. Appropriate and enough information regarding ASD are needed and very necessary to provide among caregivers of ASD children to rectify their perception and dealing with autistic children and counseling units can be established [2]. Support can be given by awareness about the misconception and social stigma about the autism and disabilities in community and make the caregivers aware about the services available for their children and to utilize it. Therefore, the objective of this study was to assess the psychological burden among caregivers of children with autism spectrum disorder. There is a need to investigate how caregiver's life is affected while providing care to affected child with autism and also to develop comprehensive health care strategies that not only target the persons diagnosed with autism, but cares for and supports to all caregivers. The alarming increase in the prevalence of autism has cause not only an increase in the number of cases of autism but also increased need for better awareness and understanding of the condition and its management for them who are in direct daily contact with someone with autism [3].

MATERIALS AND METHODS

Study design and setting

A non-experimental cross- sectional descriptive research design was used to conduct this research. The study was conducted in three selected special schools at Hyderabad. The selected schools were National Institute for the Empowerment of Persons with Intellectual Disabilities (NIEPID) at Secunderabad, Ananya Learning Center, Kondapur and Child Guidance Clinic, Madhapur, Hyderabad, India.

Participants, sample size and sampling technique

A total of 70 caregivers were included in this study. Caregivers were family members of children with autism spectrum disorder, and providing direct care to the children's daily living and other activities. Purposive sampling technique was used to select caregivers in this study. Caregivers who were available at the time of data collection and who was willing to participate in this study were included. Caregivers of children with any other intellectual problems such as mental retardation or cerebral palsy were excluded.

Table-1: Interpretation of caregiver's burden

Caregiver's burden	Interpretation
0-20 score	No burden
21-40 score	Mild to moderate burden
41-60 score	Moderate to severe burden
61-88 score	Severe burden

Data collection procedure and study variables

Modified Zariet Burden interview technique was used to gather the information. It is composed of 22 items that reflect how a person feels when they are taking care of their child. The scale was modified as "your relative"" into "your child" in all the 22 statements. The scale includes 5 categories of responses (never, rarely, sometimes, quite frequently, nearly always, rated 0 to 4 respectively).

The total score ranges from 0 to 88. A total score was calculated by the sum of all the item scores and high scores indicate a higher level of burden. Scores were interpreted as 0-20: no burden, 21-40: mild to moderate burden, 41- 60: moderate to severe burden and 61- 88 severe burden according to Modified Zarit Burden Interview Scale [4].

Socio-demographic details including gender, age, relationship with the child, occupation, marital status, family monthly income, distance between the home and school, number of hours spent with the child for care per day, training received regarding care of the child were also included.

Statistical analysis and data management

Data were entered into Microsoft excel and was transferred to SPSS version 18 for analysis. Frequencies and percentages were used to present the demographic variables. Responses of psychological burden was measured using Zariet Burden Scale and Chi-square was used to assess the association between demographic variables and burden level. p-values less than 0.05 were considered as significant.

Ethical considerations

An ethical clearance letter was obtained from institutional review committee of Apollo College of Nursing, Hyderabad, India before the commencement of this study. Also, written consent was obtained from the participants prior to the study explaining the purpose of study.

RESULTS

The table 2 shows that majority of the caregivers were female and mother. The caregivers were graduated but still unemployed. Most of them were married and continuously spending more than 15 hours but they have not received any training to take care of autistic child.

Table-3| Level of psychological burden

Psychological Burden	**Percentage**
Little or no burden	24.0
Mild to moderate burden	56.0
Moderate to severe burden	19.0
Sever burden	1.0

The above table 3 shows that majority of the respondents experienced mild to moderate Psychological burden and only few respondents have experienced severe psychological burden.

Item analysis for psychological burden with modified Zarit burden interview scale is described in Table 4.

Table 5 shows the association between psychological burden among caregivers of child and demographic variables of the caregivers. Among the nine demographic variables, only educational level (chi square value= 8.07; p<0.000), and monthly income (chi square value=8.41; p=0.020) were associated with psychological burden. However, training received regarding care of the child (chi square= 0.577; p=0.749) and the other socio-demographic characteristics were not found statistically significant at p ≤ 0.05.

DISCUSSION

The present study has shown that among the 70 participants, majority of them were female caregivers, caregivers were mother and married caregivers as compared to male. A similar type of study conducted among 51 participants at Thammasat University Hospital 14 were male and 37 were female, 35 were caregiver mother, 10 were father and others 5, 31 were married, 17 single and 3 divorced was reported by Lerthattasilp and Chunsuwan [5]. The possibility is that the Stress-coping theories propose that women are more likely to be exposed to care-giving stress, and are likely to perceive, report and cope with these stress differently from men.

Table-2| Distribution of demographic variables

Demographic characteristics	**Number**	**Percentage**
Gender		
Male	11	16.0
Female	59	84.0
Age		
18-24 Years	1	1.4
25-31 Years	18	25.7
32-38 Years	31	44.3
39 & above	20	28.6
Relationship with the child		
Mother	56	80.0
Father	8	11.4
Sibling	1	1.4
Relatives	5	7.1
Educational Level		
Primary Education	3	4.0
Secondary Education	2	3.0
Higher Education	5	7.0
Graduate	60	86.0
Occupation		
Unemployed	39	55.7
Employed	22	31.4
Self employed	9	12.9
Marital Status		
Married	65	92.9
Single	1	1.4
Divorced	1	1.4
Widow	3	4.3
Family Monthly Income		
5001-10000	3	4.2
10001-15000	2	2.9
15001 & above	65	92.9
Hours spend with child		
5-10 hours	22	31.0
10-15 hours	20	29.0
15 & above	28	40.0
Number of training received		
Not even once	46	65.7
Once	16	22.9
Twice	4	5.7
Three or above	4	5.7

Table -4 | Item analysis of psychological burden with modified Zarit burden interview scale

Item in questionnaire	Never	Rarely	Sometimes	Quite frequently	Nearly always
	%	%	%	%	%
Asks for more help than needed	17.1	22.9	32.9	14.3	12.9
Don't have enough time for self.	31.4	31.4	25.7	7.1	4.3
Stress of caring the child & responsibilities for family	22.9	11.4	37.1	22.9	5.7
Embarrassed over the child‟s behavior.	34.3	24.3	32.9	7.1	1.4
Irritated when you are around the child.	40.0	31.4	27.1	1.4	0.1
Affects relationship with other family members.	45.7	20.0	28.6	2.9	2.9
Afraid what future holds of child.	19.6	15.7	17.1	24.3	24.3
Child is dependent on you.	12.9	15.7	38.6	14.3	18.6
Strain when you are around the child	28.6	30.0	37.1	1.4	2.9
Health has suffered due to involvement with the child	42.9	27.1	24.3	4.3	1.4
Don't have personal time as you like.	35.7	31.4	30.0	1.4	1.4
Social life has suffered.	34.3	21.4	18.6	21.4	4.3
Uncomfortable with friends.	37.1	22.9	31.4	7.1	1.4
Child seems dependent only on you.	18.6	35.7	28.6	7.1	10.0
Don't have enough money to take care of child	67.1	18.6	7.1	1.4	5.7
Will not be able to care longer for the child	51.4	25.7	20.0	1.4	1.4
Lost control of life since the child's illness	38.6	32.9	20.0	2.9	5.7
Want to leave the care of the child to someone else	55.7	28.6	12.9	1.4	1.4
Feel uncertain about the child	28.6	27.1	30.0	5.7	8.6
Should be caring more	7.1	2.9	20.0	35.7	34.3
Could do a better job in caring	11.4	7.1	24.3	35.7	21.4
Overall, how burdened do you feel	25.7	32.9	25.7	11.4	4.3

Table-5 | Association of psychological burden among caregivers of children with selected demographic variables

Demographic variables	Category	No burden	Mild to moderate	Moderate to severe	Severe burden	p-value
Gender	Male	3	8	0	0	
	Female	14	31	13	1	
Age	≤31 years	1	14	4	0	0.093
	32-38 years	8	15	8	0	
	≥39 years	8	10	1	1	
Relationship with the child	Mother	11	31	13	1	0.104
	Father/siblings	3	6	0	0	
	Relatives	3	2	0	0	
Educational level	Higher Secondary & less	3	2	4	1	0.0176
	Graduation & above	14	37	9	0	
Occupation	Employed	6	11	4	1	0.868
	Unemployed	8	23	8	0	
	Self employed	3	5	1	0	
Marital status	Married	14	39	11	1	0.116
	Single*	3	1	2	0	
Family monthly income	≤15,000	0	1	4	0	0.003
	>15,001	17	38	9	1	
Hours spent with the child for care per day	5-10 hrs.	7	12	3	0	0.236
	10-15 hrs.	6	12	2	0	
	16 hrs. and above	4	15	8	1	
Received training regarding care of child	Yes	7	13	3	1	0.749
	No	10	26	10	0	

Majority of females as caregivers might be due to belief that females are inherently more caring and encouraged to fulfill social roles traditionally associated with caring and nurturing.

All over the world women are the predominant providers of informal care for family members with chronic medical conditions or disabilities, including the elderly and adults with mental illnesses. It has been suggested that there are several societal and cultural demands on women to adopt the role of a family-caregiver. In Asia, a study from Taiwan showed that 60 percent of mothers of autistic children had severe depression when assessed by Center for Epidemiologic Studies Depression Symptomatology Scale (CES-D) [6]. The present study also reveals that majority 56% sample has mild to moderate burden, 24% has little or no burden, 19% has moderate to severe burden and the least 1% has severe burden. In a related study, on depression prevalence was 5.9% with respect to caregiver burden, 45.1% of the participants reported little or no burden, and 45.1% reported mild to moderate burden. Only 7.8% and 2.0% experienced moderate to severe and severe burdens, respectively [5]. And [7] also reported that older caregivers experienced more severe burden, worse physical health, and fewer adaptive skills. This may be due to high levels of patient's behavior problems, early onset of autism, low functioning patients, inadequate social support that caregivers received, caregivers suffering from illness or disability. Major findings of item analysis of Psychological burden with Modified Zarit Burden Interview Scale reveals that majority 70% of the sample felt quite frequently and nearly always that they should be caring more whereas nearly half of the sample that is 48.3% felt quite frequently and nearly always afraid what future holds for the children and 57% felt they could do a better job in caring. Almost 28.6% felt stress of caring for the child and responsibilities for the family, 32.9% felt child is dependent on them and 25.7% felt their social life had been suffered. Surprisingly, 67.1% never felt they don't have enough money to take care of the child and also 55.7% never want to leave the care o the child to someone else. About one - third of the sample 31.4% never felt they don't have enough time for self, 34.3% felt embarrassed over the child's behaviour, 35.7% never felt don't have personal time as they like, 38.6% never felt that they lost control over life since the child's illness. In the line with this study, Saeed et al. [8] among 157 caregivers of autistic children at Aseer Region, Saudi Arabia revealed that social component of burden was the most common among participants 89.2%, followed by physical 61.8%, financial 60.5% and lastly the psychological 56.1%. These problems could be more associated with some personal characteristics of caregivers and management of autistic children should include the provision of support to caregivers socially, physically, psychologically and also financially, with special concern regarding those with risk of experiencing certain types of burden. Consequently, it seems essential to provide health education for caregivers of autistic children to raise their awareness and knowledge regarding autism management. The present study also reveals that there is significant association between selected demographic variables such as educational level, monthly income, training received regarding care of the child with psychological burden among caregivers of children at $P \leq 0.05$ whereas, the demographic variables such as gender, age, relationship with the child, occupation, marital status, number of hours spent with the child were not associated with the psychological burden among caregivers of children at $P \leq 0.05$. The findings of Dhafer AA revealed that there was a significant difference between the level of psycho social burden among caregivers and social-demographic variables of caregivers [9]. Nevertheless, Al-Dujaili and Al-Mossawy [10] reported no statistically significant association between the overall psycho-social burden score of caregivers with caregivers' social-demographic characteristics. It is understandable to discover that older caregivers for children with special needs may have less coping abilities than younger ones.

This finding indicates the higher need to provide more support to caregivers of autistic children, especially older ones. The sample size was small and limited to selected special schools of Hyderabad only and cannot be generalized to overall India.

CONCLUSIONS

The present study concludes that 56 % caregivers had mild to moderate burden. The 80% caregivers were mother among which 85.7% were graduated and above but 55.7% were unemployed due to child diagnosed with autism. The study concluded that assessing the burden level of caregiver can help them to reduce their burden through proper counselling and providing support for families, especially a psychological one, and education about clinical behavior, early detection and family to family education programs to the existing services in community mental health programs. Health professionals should a play a major role in terms of providing caregivers with adequate information to deal with the children with ASD through media, press and local communication. Furthermore, new descriptive studies on awareness of autism spectrum disorder in Rural areas is recommended in future.

ADDITIONAL INFORMATION AND DECLARATIONS

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Data Availability: Data will be available upon request to corresponding authors after valid reason.

REFERENCES

1. Sagar VKJ. , Research on autism spectrum disorders in India. Journal of Psycho Med.2011; 12(1):69-72.
2. Juneja M, Sairam S. Autism Spectrum Disorder- An Indian Perspective (PDF). SMG Group. Available from http://www.smgebooks.com/autism/chapters/AUT-18-12.pdf
3. Dhafer AJ AI Mossawy, Araft H AI Dujaili. Psychosocial Burden among Caregivers of Children with Autism Spectrum Disorder in Najaf Provinance. International Journal of Curr Res Aca Rev. 2017; 5(4): 122-143.
4. Pandey S, Sharma C. Perceived Burden in Caregivers of Children with Autism Spectrum Disorder. J Nepal Health Res Council. 2018;16(39): 184-9
5. Lerthattasilp T, Charernboon T, et al. Depression and burden among caregivers of children with autistic spectrum disorder. Journal of Medical Association of Thailand. 2015; 98 (Suppl.2): S45-S52.
6. Lin Y, Orsmond L G. Maternal well-being and lifespan issues of autism in Taiwanese families of adolescents and adults with autism spectrum disorders. The 18th Asian conference on mental retardation, 18-23 NovemberTaipei, Taiwan. 2007: 618-28.
7. Anh MTL. Factors related to burden among caregivers of children with autism in Vietnam. A Thesis Submitted in Partial Fulfillment of the requirement for the Master Degree of Nursing Science International Program. Faculty of Nursing Burapha University, 2015.
8. Saeed FA, S.B.F.M., A.B.F.M. Experienced Burden by Caregivers of Autistic Children. Med J Cairo Univ. 2018; 86(3) 1523-1528.
9. Ameen Almossawy, Dhafer. (2017). Psychosocial Burden among Caregivers of Children with Autism Spectrum Disorders in Najaf Province, Iraq. International Journal of Current Research and Academic Review. (2017) 5:122-134.
10. Al-dujaili AH and Al-mossawy DAJ. Psychosocial burden among caregivers of children with autism spectrum disorder in Najaf Province. Current Pediatric Research. 2017; Volume 21(I).