



BURDEN OF CAREGIVING AND LIFE SATISFACTION AMONG THE CAREGIVERS OF CHILDREN WITH AUTISM SPECTRUM DISORDER

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ABSTRACT

OBJECTIVE: To examine the predictive relationship between burden of caregiving and life satisfaction among the caregivers of children with Autism Spectrum Disorder (ASD) from different cities of Panjab, Pakistan.

METHODS: This correlational study was conducted from January - June 2019, on 71 caregivers of ASD patients from different cities of Punjab province, registered with different autism treatment centers, Lahore- Pakistan. Informed consent was taken from caregivers, selected through purposive sampling technique. Caregiver burden scale by Zarit Burden Scale was used to measure family burden while Satisfaction with Life Scale by Diener ED, was used to measure life satisfaction among the care givers.

RESULTS: Out of 71 caregivers of children with ASD, 55 (77.5%) were females and 16 (22.5%) were males. Caregivers ranged in age from 20-55 years and majority (n=33/71: 46.5%) were from 31-40 years age group. Forty-seven (66.2%) caregivers belonged to joint family. Majority (36/71, 50.7%) of caregivers had 1-3 children and 24 (33.8%) caregivers had 4-6 children. Zarit Burden Scale has a high reliability ($\alpha=.84$) and Life Satisfaction Scale has satisfactory reliability ($\alpha=.74$) for current sample. The findings of the study revealed significant negative relationship between burden of caregiving and life satisfaction ($r=-0.33$, $p<0.05$). Regression analysis predicted family burden to be negatively associated with life satisfaction $\alpha=-0.17$, $p<0.05$. The results reported significant effect of levels of burden on life satisfaction ($R^2=0.11$, $p<0.05$).

CONCLUSION: Caregiver burden negatively predicts the life satisfaction indicating that caregivers who experience more burden are less satisfied with life.

KEY WORDS: Burden of caregiving (Non-MeSH); Life satisfaction (Non-MeSH); Zarit Burden Scale (Non-MeSH); Satisfaction with Life Scale (Non-MeSH); Autism Spectrum Disorder (MeSH).

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INTRODUCTION

Autistic children face difficulties in communication, poor in self-help skills, have limited interests and strong adherence to routine tasks. The caregivers perceive many difficulties and pressures while taking care of autistic children and these adversities include physical strain, psychological distress, emotional exhaustion, and socioeconomic turmoil. Hence, they become greatly dependent upon the people who are responsible for their care and support and this

feeling of being constantly responsible for someone with disability becomes a tiresome process. These difficulties aggravate when the demands of caregiving outweigh the available financial resources.¹ Financial strain involved in the upbringing of children with autism is far more as compared to the average / typical / normal children.² Moreover, parents had to take leave from their works or have limited professional choices owing to their duties for autistic children. More often such problems end up into mental, social and physical hazards for the parents.³

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Families having children with developmental disabilities experience more negative psychological outcomes than families with average / typical / normal children.⁴ Families experience additional financial burdens, more restrictions in social activities, and heightened parental stress. As a group, parents of children with autism seem to experience even more stress than parents of children with other disabilities.⁵ A quasi-experimental study investigated the worth of life and individual load on caretakers (86 female caregivers) of ASD children and found that the care providers of autistic children reported greater strain and deficit in life as compared to experimental group (36 caregivers).

Another important aspect is the life satisfaction of caregivers of autistic children. Life satisfaction is "an overall assessment of feelings and attitudes about one's life at a particular point in time ranging from negative to positive". It is one of three major indicators of well-being: life satisfaction, positive affect and negative affect.⁷ Satisfaction with life is also defined as "desire to change one's life; satisfaction with past; satisfaction with future; and significant other's views of one's life".⁸ Life satisfaction is a universal concept which indicates a positive approach towards the life in general.⁹ Healthier and happier persons focus less on adversities the life brings to them. Such people are not only friendly but they also play an important role in promoting a happier and healthier life which in turn raises the levels of satisfaction among the individuals.¹¹ Life satisfaction effects the individual in two ways: (a) Micro-social life domains, i.e., living conditions,

TABLE I: DEMOGRAPHIC CHARACTERISTICS OF CASRE GIVERS (N=71)

Parameters		Frequency	Percentage
Gender	Female	55	77.5
	Male	16	22.5
Age (years)	20-30	19	26.8
	31-40	33	46.5
	41-50	15	21.1
	51-55	4	5.6
Family system	Joint	47	66.2
	Nuclear	24	33.8
Socio economic status	Low	23	32.4
	Middle	27	38.0
	High	21	29.6
Marital status	Single (key relatives)	11	15.5
	Married	54	76.1
	Divorced	6	8.5
No of children	Nil	11	15.5
	1-3	36	50.7
	4-6	24	33.8

including features such as work-related conditions, subjective health conditions, marital status, financial household status. (b) Macro-social life domains, i.e., Societal conditions, including aspects such as government performance, political democracy, welfare growth and economic equality.

Various determinants of life satisfaction were observed among the caregivers of children with developmental disabilities in South Korea. The objective was to explore those factors that are linked with life satisfaction in the caregivers through the data taken from 390 caregivers. It was reported that age of both the child and the care provider have negative impact on the life satisfaction of the caregivers of children with autism spectrum disorder (ASD). Whereas, levels of child's disability and the socioeconomic status of the family was positively correlated with caregivers life satisfaction. At the same time life satisfaction decreases with increased strain related to caregiving

and finances but duration of caregiving didn't show any particular effect upon life satisfaction.¹²

ASD is a life long disability and caregivers of these children equip themselves with strategies to face the related pressures accordingly. The rationale behind the study was to predict how burden of caregiving influence the life satisfaction of parents/caregivers who are going through the lifelong struggle with children suffering from ASD. The objective of the study was to investigate the relationship between burden of caregiving and life satisfaction among the caregivers of children with ASD and to find out the predictive influence of caregivers' burden on their life satisfaction among the caregivers of children with ASD.

METHODS

The correlational survey research was conducted from January-June 2019 on caregivers of ASD patients who were

TABLE II: DESCRIPTIVE STATISTICS AND ALPHA COEFFICIENTS OF CAREGIVER BURDEN SCALE AND LIFE SATISFACTION SCALE (N=71)

Scale	k	M	SD	α [#]
Zarit Burden Scale	22	41.81	12.734	.84
Life Satisfaction Scale	5	22.50	6.31	.74

#: Cronbach's alpha

registered with different autism treatment centres, Lahore, Pakistan. Study was approved by the departmental board of studies and university's board of ethics review committee of Government College University Lahore, Lahore, Pakistan with certificate number GCU/IIB/787.

Inclusion criteria for participants was caregivers, having a child diagnosed with ASD, with education level of graduation. Exclusion criteria for this study was caregivers of children with developmental (learning, intellect) delays and disorders.

Seventy one caregivers from different cities of Punjab of children with ASD were selected through purposive sampling technique. More often, the sample size for clinical research is always smaller than general community sample. Out of 71 caregivers, 55 (77.5%) were females and 16 (22.5%) were males. The number of male participants was smaller because Pakistani males reported less involvement with the child in the care giving process.¹¹ Informed consent was taken from all caregivers of ASD before enrolling in the study.

This study was specific to the area of clinical psychology. Hence findings are applicable only to caregivers of ASD. For the current study two questionnaires used were caregiver burden scales and satisfaction with life scale.

Zarit Burden scale (ZBI) was developed in 1980 by Zarit. It is the most widely used instrument for assessing the burden experienced by the caregivers.¹² It is a 29-item scale with 5-point Likert rating ranging from 0 to 4. It consists of five subscales including, Burden in the relationship (1, 8, 11, 14, 18, 20), Emotional well-being (2, 4, 5, 9, 10, 21, 22), Social and family life (3, 6, 12, 13), Finances (15), and Loss of control over one's life (7, 16, 17, 19). It has a good internal reliability (Cronbach alpha coefficient of 0.92).¹³ The internal consistency of the scale for the present study was (α=0.88).

Satisfaction with Life Scale (SWLS) It is a 5-item scale designed to measure global cognitive judgments of one's life satisfaction.¹⁴ Participants indicate how much they agree or disagree with each

TABLE III: INTER-CORRELATION AMONG STUDY VARIABLES (N=71)

S.No	Source	1	2	3	4	5	6	7
1.	Burden caregiver	--	-0.33*	0.75**	0.90**	0.80**	0.52**	0.78**
2.	Life satisfaction		--	-0.20	-0.31*	-0.17	-0.13	-0.36*
3.	Burden in relationship			--	0.61**	0.58**	0.23*	0.44**
4.	Emotional well-being				--	0.64**	0.50**	0.60**
5.	Social and family life					--	0.23*	0.51**
6.	Finance							0.38*
7.	Loss of control							--

*p<0.05, **p<0.01

of the 5 items using a 7-point scale that ranges from 7 strongly agree to 1 strongly disagree. It has a good internal reliability (Cronbach alpha coefficient ranges from $\alpha=0.84$ to 0.96). The internal consistency of the scale for the present study was $\alpha=0.74$. In the present study, research ethics were maintained throughout the research. First of all, permission for using the scales was taken from the respective authors through email correspondence. Permission was obtained from the respective heads of the institutes of children with ASD. Verbal consent of the participants was also taken and it was clarified that their participation in the study was voluntary and that information to be kept confidential and it was assured that their participation will not cause any harm or damage to caregivers and children with ASD them.

Data of current study was analyzed by using software SPSS 21. Correlational analysis was done to see the relationship between life satisfaction and family burden among the caregivers. Analysis of variance was conducted to see the difference in life satisfaction with different levels of burden among the caregivers as well as the differences between socioeconomic status, gender and family system with family burden and life satisfaction were explored.

Regression analysis was run to predict the role of family burden over the life satisfaction among the caregivers.

RESULTS

Out of 71 caregivers of children with ASD, 55 (77.5%) were females and 16 (22.5%) were males. Caregivers were ranging in age from 20 to 55 years. Most of the caregivers (n=33; 46.5%) were from age group 31-40 year and 19 (26.8%) were from 20-30 years of age. Forty seven (66.2%) caregivers belonged to joint family. Majority (36/71, 50.7%) of caregivers had 1-3 children (Table I).

Table II indicates that Zarit Burden Scale has a high reliability ($\alpha=.84$) and life satisfaction scale has satisfactory reliability ($\alpha=.74$) for current sample. It means that questionnaires used in the current sample were reliable.

Table III demonstrated that there is a negative relationship among caregiver burden and life satisfaction ($r=-.33$). Moreover, caregivers who reported higher burden were found higher in terms of burden in relationship ($r=.75$) and lower in terms of emotional well-being ($r=.90$), social and family life ($r=.80$), loss of control ($r=.78$) and finance ($r=.52$).

Table IV indicate that high burden of

care predicts poor life satisfaction among caregivers ($\alpha=-0.17, p<.05$). $R^2=0.11$ shows that burden of care explains 11% variance in life satisfaction among caregivers.

DISCUSSION

The present study was designed to examine the relationship of burden of caregiving and life satisfaction among the caregivers of children with ASD. The findings of the study revealed significant negative relationship between burden of caregiving and life satisfaction. Regression analysis predicted family burden to be negatively associated with life satisfaction.

First hypothesis stated that there would be a significant relationship in family burden and life satisfaction among the caregivers of children with ASD. The results of the study also supported the first hypothesis and showed negative correlation between burden and life satisfaction among the caregivers of children with ASD. The caregivers who experienced more burden of care were poorly satisfied with their lives. Same results were reported in a previous correlational study on life satisfaction, caregiver burden and caregiver self-efficacy.¹⁶ Results indicated that caregivers' burden decreased their life satisfaction. Moreover, caregivers who reported higher burden were found higher in terms of burden in relationship ($r=.75$) and lower in terms of emotional well-being ($r=.90$), social and family life ($r=.80$), loss of control ($r=.78$) and finance ($r=.52$).

Second hypothesis states that family burden is likely to predict life satisfaction. In the second hypothesis, results of the study proposed that burden of caregiving will negatively

TABLE IV: BURDEN OF CAREGIVING AS PREDICTOR OF LIFE SATISFACTION (N=71)

Predictors	B
Constant	29.91
Burden of Caregiver	-0.17*
R	0.33
R ²	0.11
F	8.60

*p<.05; Note= only significant results are reported.

predict life satisfaction. The present study also reported that burden is negatively predicting the life satisfaction among caregivers so they experience burden more and are not satisfied with their lives. No previous literature was found in this concern showing direct prediction between the study variables but a related research reported socio-demographic characteristics and care-related stressors among caregivers of children with developmental disabilities (CDD) predict their life satisfaction.¹² Similar results were reported in a research conducted on mentally disabled children and risk factors of the family. Results indicated that level of burden differ significantly in life satisfaction of the individuals.¹⁷ Looking beyond families of individuals with ASD, several studies of caregivers of individuals with intellectual disabilities also reported an association between caregiver burden and life satisfaction.¹⁸

In present study, the phenomena of family burden and life satisfaction among the caregivers of autistic children was explored quantitatively. In future, qualitative study needs to be carried out to explore the experiences of caregivers specifically mothers about burden of caregiving and life satisfaction. Due to shortage of time, the sample size couldn't be increased and was restricted to one city only which has reduced the opportunity for the generalization of the study. The results can be generalized in future by increasing sample size and collecting data from different major cities of Pakistan. Moreover, the present study included educated caregivers as the mode of data collection was questionnaire. In future studies, data can be collected by conducting structured interviews. The present study focused only on two variables which were family burden and life satisfaction. Future researchers can study the role of optimism and personality related variables as correlates of burden of caregiver.

CONCLUSION

Caregivers especially mothers of children with autism spectrum disorder experienced higher burden of care and were less satisfied with their lives. Caregiver burden was a significant

predictor of poor life satisfaction among caregivers.

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AUTHOR'S CONTRIBUTION

Following authors have made substantial contributions to the manuscript as under:

SK: Conception and study design, acquisition of data, drafting the manuscript, critical review, approval of final version to be published

IB & NA: Acquisition of data, analysis and interpretation of data, drafting the manuscript, approval of final version to be published

Authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

CONFLICT OF INTEREST

Authors declared no conflict of interest

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