Research Paper





Perception of Burden and Stress Among Mothers of Autistic Children in Pakistani Cultural Background

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Citation Mumtaz N, Fatima T, Saqulain G. Perception of Burden and Stress Among Mothers of Autistic Children in Pakistani Cultural Background. Iranian Rehabilitation Journal. 2022; 20(1):43-52. http://dx.doi.org/10.32598/irj.20.1.1335.5





Article info:

Received: 30 Aug 2021 Accepted: 27 Sep 2021 Available Online: 01 Jun 2022

Keywords:

Autism Spectrum Disorder, Caregiver burden, Parental stress scale

ABSTRACT

Objectives: The study aimed to explore the perceived burden and stress among mothers of autistic children.

Methods: This cross-sectional study was conducted at Riphah International University over 4 months, from October 2020 to January 2021. The samples were recruited using non-probability convenience sampling and comprised 84 mothers (23-60 years old) of children aged 3-16 years with Autism Spectrum Disorder (ASD) from different special education centers in Lahore. A demographic questionnaire, Parental Stress Scale (PSS), and Zarit burden interview (ZBI) were used to collect the study data, which were analyzed in SPSS v. 22 software.

Results: Forty-five Mothers (53.6%) suffered from moderate to severe burden with a high Mean±SD ZBI (41.75±10.62) and Parental Stress Scale (PSS) scores (48.67±8.04). Also, there is a significant positive correlation between the two scores (r=0.585, P=0.000). A significant association was noted between the mother's stress and the severity of autism (P=0.006) and the child's medication (P=0.008), also between the mother's burden and the child's age (P=0.019).

Discussion: According to the current study's findings, mothers of children with ASD perceived a high level of burden and stress. The association was seen with factors of children's age, severity level, and child medication.

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Highlights

- Mothers of children with ASD perceive moderate to severe burden and stress.
- Mothers' stress is significantly associated with the severity of autism in children and their medications.
- Mothers' burden is significantly associated with a children's age.

Plain Language Summary

Parenting a child with ASD is challenging and demanding for the caregivers, with the struggle of never-ending parenting and a probable source of burden and stress. In the Pakistani cultural background, where women are primarily involved in caregiving, studying the stress and burden posed by rearing an autistic child is of immense importance. This study explored the perceived burden and stress among mothers of autistic children. This cross-sectional study was conducted on 85 mothers (23-60 years old) of autistic children (aged 3-16 years), using the parental stress scale and Zarit burden interview. Results revealed moderate to severe burden and stress among most mothers. Association of mother's stress with severity of autism (P=0.006) and child's medication (P=0.008), as well as an association of mother's burden with child's age (P=0.019), was noted.

1. Introduction

arenting is a God-gifted phenomenon. It is characterized by a feeling of belongingness in rearing a child and lasts till adulthood. However, in the case of a child with developmental disabilities, there is no end to parenting, which is challenging and characterized by burden and stress [1]. This situation is the case when rearing an autistic child [2]. In 1989, Pearlin et al. added the concept of caregivers' burden in their model "Pearlin Stress Process Model," which demonstrates how the care becomes a burden over time [3]. In 1980, Zarit et al. developed a self-report measure, "caregivers burden inventory," to assess the burden of caregivers [4].

Stress is a widespread phenomenon in Behavioral Health Sciences that can be explained in three stages, starting from circumstances that are likely to confuse and un-stabilize. As a result, a person is being subjected to different risks, and finally, the interaction between risky conditions and a person's response to this pressure [5]. The perceived stress, on the other hand, depends on the person, i.e., how he or she takes it, feels it, and eventually caters to it, along with the personality types, resources of coping, and support that can make a difference. The perception of stress also depends on a person's social and ethnic characteristics and religious values, varying from culture to culture [6]. The role of culture is redefining and shaping family, professional, and community understanding of developmental disabilities and management. The cultural aspect of disability cannot be undermined [7].

In the Pakistani cultural background, women are primary caregivers as mothers, wives, and adult daughters. They are predominantly involved in caregiving while putting their health and well-being on the back foot, thus creating a vicious cycle that leads to a lot of anxiety and depression [8]. The factors contributing to the development of stress followed by burden depend on multiple elements, including family, personal, financial as well as sociocultural issues [9]. Based on the evidence, parents of differently-abled children and especially those with autism, perceive a high level of stress compared to parents of typically developing children [10].

Autism Spectrum Disorder (ASD) is a pervasive neurodevelopmental disorder that includes autism, Asperger, Rett, childhood disintegrative, and other developmental disorders. ASD occurs with varying degrees of severity, affecting three significant areas of life, i.e., communication skills, social skills, and interaction, and repetitive, stereotypical patterns of behavior and activities that affect daily functioning from early childhood. However, its etiology is still unknown [11].

Autism has increased worldwide like an epidemic, with a prevalence of 1 in 54; however, the prevalence varies quite significantly across different areas [12]. A local study conducted in special education schools in Lahore, Pakistan, revealed a prevalence of 6.31% [13], with a higher prevalence of boys [14]. There are misconceptions regarding autism [15], and significantly less awareness among medical professionals compared to allied

medical professionals regarding autism in Pakistan has also emerged as a concern [16].

Considering a high prevalence rate, lack of awareness, misconceptions, and cross-cultural differences, this study investigated the perceived burden and stress among mothers of autistic children. This study will help understand the stress and burden among mothers of autistic children. The study findings can provide guidance, raise awareness, help better management by medical and allied health clinicians and ultimately improve the quality of life of primary caregivers of these children. The limited research on the mental health of the population residing in Islamic countries with varied cultural implications has led to addressing this gap in literature [17]. The culture shapes family, professional, and community understanding of developmental disabilities and their treatments. The cultural aspect of disability cannot be undermined [7]. Pakistan, an Islamic republic and developing economy with a majority of the Muslim population, dwells with certain cultural elements like discouraging birth control, keeping special children at home, considering them as God's gift, or vice versa. Hence, increasing financial constraints on the already struggling economic plight of the families is further aggravated due to the caring of a special child.

2. Materials and Methods

This cross-sectional study with a sample of 84 mothers of autistic children (selected by non-probability convenience sampling) was conducted at special education setups in Lahore (COMPASS, Rahein, Turning Point, Rising Sun Institute for Special Children, Lahore Autism Centre, Impact, Amin Maktab, Step Ahead autism Centre, and Autism Institute), over a period 4 months from October 1, 2020, to January 31, 2021. The sample included 23-60 years old mothers of autistic children. The autistic children belonged to both genders and were aged between 3 and 16 years. The lower limit of 3 years was taken because the age of autism diagnosis is usually 24 to 36 months. These children had mild to severe autism, with verbal and non-verbal communication skills. Mothers of children with comorbid conditions like epilepsy and those with other physical and mental illnesses were excluded from the study since this could increase the burden and stress on the mothers. The sample size of 87 was calculated, taking the prevalence proportion as 6 [12]. A basic demographic sheet, Parental Stress Scale (PSS), and zarit burden interview (ZBI) [4] were administered for data collection. Three cases with incomplete data were excluded from the study leaving behind a sample of 84, which was our study sample.

PSS [18] is a self-report tool developed by Judy Berry and Warren Jones in 1995 and consists of 18 statements regarding parents' feelings and perceptions of being a parent, positive and negative feelings and perceptions. It is scored on a 5-point Likert scale (1-5) from 1=strongly disagree to 5=strongly agree. PSS total score ranges from 18 to 90; lower scores indicate a lower level of parental stress, and authors have reported good test and retest reliability and validity for this scale.

The Zarit burden Interview [4] was developed in 1980 by Zarit et al. and is used to measure the burden consisting of 22 items that depict how the person feels about taking care of another person. It is scored on a 5-point Likert scale (0-4) from 0=never to 4=nearly always. A score range of 61-88 indicates severe burden, 41-60 moderate to severe burden, 21=40 mild to moderate burden, and <20 no or minimal burden. It has been reported to be a valid and reliable tool with the Cronbach α value of 0.93 and test-retest reliability being 0.89 [19].

The study was initiated after obtaining ethical approval of the research from Riphah International University vide registration number REC/RCRS/20/3019 dated August 1, 2020, and obtaining mothers' consent for inclusion in the study. The questionnaires were applied through special education teachers.

The collected data were tabulated in Microsoft Excel and statistically analyzed using SPSS v. 22 software. Mean±SD were calculated for ZBI and PSS scores. Oneway ANOVA was used to see any association with sociodemographic variables, and further results were compared and discussed with national and international literature.

3. Results

The present study with a sample of 84 mothers of autistic children revealed the predominance of moderate to severe burden in 45 mothers (53.6%); however, 3 mothers (3.6%) reported no burden (Figure 1). Results revealed a high ZBI Mean±SD score (41.75±10.62) and PSS Mean±SD score (48.67±8.04) with a significant positive correlation between ZBI score and PSS score (r=.585, P=0.000) (Table 1).

Table 2 presents that 40 mothers (47.6%) were 30-40 years old and well-educated, with 29 mothers (34.5%) being graduates and only 13(15.5%) being single parents. Also, 69 mothers (82.1%) belonged to the middle class. However, 49 mothers (58.3%) were not working, and only 12(14.3%) were taking medications for stress.

Table 1. The Pearson Correlation Matrix for Zarit Burden Interview and Parental Stress Scale Score

Tool		Score	Mean±SD	Zarit Burden Interview	Parental Stress Scale
	Zarit burden inventory score		41.75+10.62	1	0.585**
	Zant burden inventory score				0.000
	Parental stress scale		49 67 19 04	0.585**	1
	Parental stress scale		48.67+8.04	0.000	

^{**} Correlation is significant at the 0.01 level (2-tailed).

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Gender distribution showed that most children were boys, with 61(72.6%) and 23(27.4%) being girls. Also, 44 children (52.4%) were 3-9 years old, and 40 (47.6%) were 10-16 years old (Table 3). Most children, i.e., 42 children (50%), had moderate autism and 14(16.7%) had the least severe autism. Also, 57 children (67.9%) were not taking any therapy at home, and 51(60.7%) were not on any medication.

Table 2 presents that ZBI and PSS mean scores did not show significant association with variables related to mothers of autistic children like age, marital status, education, employment status, socioeconomic status, availability of physical help and support, number of children, presence of another child with a disability and even if mother was on medication related to stress.

Regarding child's characteristics, ZBI had a significant (P=0.019) association with age, and a higher Mean±SD ZBI score (44.58±9.74) was seen in the 10-16 years age group compared to 3-9 years (39.18±10.84) (Table 3).

Significant association (P=0.006) was noted between Mean±SD scores of PSS with the severity of autism with the highest score (54.14±5.92) with severe autism. A significant association (P=0.008) of PSS Mean±SD scores were noted between the medication status of a child and a higher score (51.55±6.08) in mothers whose children were taking medications. However, ZBI and PSS did not reveal any significant association with the child's gender, birth order, type of communication, and whether a child receives therapy at home or not. No significant association of PSS was noted with age, and an insignificant association of Caregiver Burden (CGB) was noted with the severity of autism and the child's medication status.

4. Discussion

Parenting a child with ASD is very challenging and distressing; hence this study investigated the perceived burden and stress among mothers of autistic children. The present study revealed that mothers of children with ASD perceived high levels of burden and stress as mea-

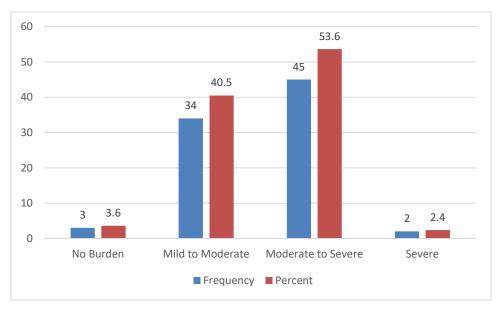


Figure 1. Severity of Caregiver Burden (n=84)

Table 2. Mother Characteristics VS Zarit Burden Interview and Parental Stress Scale Association, t-test and ANOVA statistics (cross tabulation)

Mother's Characteristics		(50)	Zarit Burden	Zarit Burden Interview		Parental Stress Scale	
Variables	Group	No.(%)	Mean±SD	F/t, P	Mean±SD	F/t, P	
	≤30	22(26.2)	40.36±10.95	0.481 0.620	47.18±10.47		
Age (y)	31–40	40(47.6)	42.93±11.26		48.48±7.55	0.957 0.388	
	>40	22(26.2)	41.00±9.23		50.50±5.85		
Cocial status	Single	13(15.5)	43.31±9.60	0.573	49.77±7.14	0.594	
Social status	Co-parent	71(84.5)	41.46±10.84	0.568	48.46±8.23	0.562	
	Middle	2(2.4)	39.00±5.66		53.00±.00		
	Matric	1(1.2)	31.00±00		44.00±00		
Education	Intermediate	5(6)	41.60±10.11	1.387 0.246	45.20±8.32	0.837 0.506	
	Graduated	29(34.5)	45.17±9.47		50.28±8.79		
	Post-graduated	47(56)	40.00±11.23		47.96±7.67		
5	Nonworking	49(58.3)	43.02±9.75	1.302	49.69±8.29	1.393	
Employment	Working	35(41.7)	39.97±11.64	0.196	47.23±7.56	0.167	
	Lower class	3(3.6)	33.00±9.17		42.33±7.64		
Socioeconomic status	Middle class	69(82.1)	42.19±10.77	1.085 0.343	49.41±8.18	1.924 0.153	
	High class	12(14.3)	41.42±9.85		46.00±6.41		
Physical help and	No	48(57.1)	40.56±10.37	-1.186	48.71±8.98	0.055	
support	Yes	36(42.9)	43.33±10.89	0.239	48.61±6.71	0.957	
		1(52)	41.10±9.96		47.50±8.62		
Number of		2(21)	41.24±11.86	0.723	50.76±6.96	0.989	
children		3(10)	46.40±11.78	0.541	50.00±6.77	0.402	
		5(1)	40.00±00		52.00±00		
Other child	Yes	84(95.2)	41.67±10.47	-0.288	48.35±8.00	-1.63	
disability	No	4(4.8)	43.25±15.17	0.774	55.00±6.98	0.107	
If mother is on	No	71(84.5)	41.34±10.64	-1.105	48.45±8.42	-0.779	
any medication for stress	Yes	13(15.5)	45.00±10.47	0.272	50.42±5.52	0.438	

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sured by ZBI and PSS, with a significant positive correlation between ZBI and PSS scores (r=0.585, P=0.000). Forty-five mothers (53.6%) reported moderate to severe burden, while only 3 mothers (3.5%) reported no burden. The findings are supported by Padden et al. [20], Sabih and Sajid [21], and Ishtaiq et al. [2], reporting a signifi-

cant level of stress in parents of ASD children. Firdouset al. [22] also recounted more stress in parents of children with intellectual disabilities than mothers of hearing-impaired children.

Table 3. Child Characteristics VS Zarit Burden Interview and Parental Stress Scale Association, t-test and ANOVA statistics (cross tabulation)

Child Characteristics		(20)	Zarit Burden	Zarit Burden Interview		Parental Stress Scale	
Variables	Group (N=84)	No.(%)	Mean±SD	t/F, P	Mean±SD	t/F, P	
Ago (v)	3-9	44(52.4)	39.18±10.84	5.708	47.50±9.10	1.968	
Age (y)	10-16	40(47.6)	44.58±9.74	0.019	49.95±6.56	0.164	
Gender	Girl	23(27.4)	42.65±11.02	0.476	48.48±7.85	-0.131	
Gender	Воу	61(72.6)	41.41±10.54	0.635	48.74±8.17	0.896	
	First	49(58.3)	43.00±9.35		49.20±8.60		
Birth order	Second	23(27.4)	41.17±11.83	0.827 0.483	47.65±7.70	0.264	
Birtirorder	Third	11(13.1)	37.55±13.45		48.09±6.79	0.851	
	Fifth	1(1.2)	40.00±00		52.00±00		
	Mild	28(33.3)	40.14±10.53		45.86±8.76		
Severity	Moderate	42(50)	42.57±10.15	0.475 0.624	48.71±7.32	5.483 0.006	
	Severe	14(16.7)	42.50±12.53		54.14±5.92		
Type of communications	Verbal	41(48.8)	43.12±10.84	1.346	48.37±8.23	-0.315	
Type of communications	Non-verbal	42(50)	40.02±10.12	0.182	48.93±8.03	0.753	
If child taking therapy at	No	57(67.9)	41.96±9.98	0.268	48.96±7.72	0.492	
home	Yes	27(32.1)	41.30±12.05	0.789	48.04±8.80	0.624	
If child taking any	No	51(60.7)	40.22±11.29	-1.6663	46.80±8.64	-2.741	
medication	Yes	33(39.3)	44.12±9.16	0.1	51.55±6.08	0.008	

Regarding mothers' characteristics, most mothers belonged to the middle class, 30-40 years old, well educated, but non-working. Their ZBI and PSS mean scores had no significant association with variables of age, marital status, education, employment status, socioeconomic status, availability of physical help and support, number of children, presence of another child with a disability, and even taking medications for stress. However, divorced and widowed mothers scored higher on ZBI and PSS than coparenting mothers. This finding agrees with previous studies like McAuliffe et al. [23] and Dyches et al. [24].

No significant association between working status was noted with ZBI and PSS, though non-working women scored higher on ZBI and PSS than working mothers. These findings are specific to our Pakistani culture, where women are primary caregivers as mothers, wives, and adult daughters and are predominantly involved in caregiving while putting their health and well-being on the back foot, thus creating a vicious cycle that leads to a lot of anxiety and depression [7], and so are at higher risk of stress and burden compared to working mothers.

Also, in the current study, no significant association was found between physical help and support with ZBI and PSS, which is in contrast to Lei and Kantor [25], who concluded in their study that social support has a positive impact on the Quality of Life (Qol) of caregivers of children with ASD. While Llias et al., in a systematic review, reported a lack of support and six other factors in South Asia resulting in parental stress, including financial constraints [26]. In contrast, higher parental stress was noted in the middle class, followed by the higher class in the current study. The other factors reported causing parental stress are the severity of autism, financial constraints,

perception, and understanding of parents, worries for the child's future and anxiety, and religious beliefs [26].

Characteristics of autistic children revealed that most were boys (72.6%) with higher ZBI scores in mothers of female children; also, there is a significant association of ZBI and PSS scores noted with the gender of the child. In an Irish study, Fowler and O'Connor [27] reported that parents of girls with ASD face a higher stress level along with social similar stigmatization is commonly seen in Pakistan and the brunt is born the mothers. In a local study, Sabih F. found that parents of female-child with ASD experience more stress than parents of male children [21].

About 52.4% of mothers in the current study had 3-9 years old children, while 47.6% had 10-16 years old children, and a higher mean ZBI score was seen in the mothers of the 10-16 year age group. Similarly, Devi et al. [28] reported a positive correlation between stress and the burden of caregiving and the child's age. In contrast, no significant association of stress with age was noted, though the PSS score was higher for mothers having the 10-16 years old group.

There was no association of ZBI and PSS with birth order, type of communication, child's receiving therapy at home, and child's medication status. Though no significant association of Caregiver Burden (CGB) was noted with the severity of autism, the level of impairment increases parental stress. In our study, most children had moderate autism (50%), with the least having severe autism (16.7%) showing a significant association of stress with the severity of autism. Similarly, studies by Llias et al. [26] and Batool and Khurshid [29] revealed a correlation between autism severity and parental stress. Hence, children's problematic behavior and sensory issues increase the level of impairment, resulting in stress in parenting [30].

In the current study, 67.9% of children who did not take any therapy at home and their mothers had a higher burden and stress. Literature also reveals that ASD children who receive home therapy show improved behavioral results, thus reducing anxiety, stress, and depression in mothers [31].

In the current study, a significant association of PSS mean scores was noted with the medication status of the child. So higher scores were seen in mothers whose children were taking medications. This finding might be because many side effects do occur after taking medicines.

Hence healthcare staff should educate mothers about medications and their side effects [32].

Study Limitations

This study was conducted in one region of Pakistan, and hence the results cannot be generalized.

5. Conclusion

Mothers of children with ASD perceived a high level of burden and stress because they are primary caregivers as per the cultural norm. Also, an association was noted between mothers' stress with child's age, the severity level of ASD, and child's medication.

Ethical Considerations

Compliance with ethical guidelines

The study was approved by Research Ethics Committee of Riphah International University, Pakistan (Code: REC/RCRS/20/2019).

Funding

This research did not receive any grant from funding agencies in the public, commercial, or non-profit sectors.

Authors' contributions

Conceptualization, writing -review & editing: Nazia Mumtaz; Methodology, resources & data curation: Tanveer Fatima; Formal Analysis & writing-original draft preparation: Ghulam Saqulain; Supervision: Ghulam Saqulain.

Conflict of interest

The authors declared no conflict of interest.

Acknowledgments

The article is part of the MS thesis in Speech-Language Pathology by Tanveer Fatima

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