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Psychosocial Burden among Caregivers of Children with Autism Spectrum Disorders in Najaf Province, Iraq

Dhafer Ameen.J. Al-Mossawy^{1*} and Arafat H. Al-Dujaili²

¹Assistant Lecturer, University of Kufa, Faculty of Nursing, Psychiatric Mental Health Nursing Branch, Al-Najaf Al-Ashraf, Iraq

²Assistant Prof., University of Kufa, Faculty of Medicine, Psychiatry Branch, Al-Najaf Al-Ashraf, Iraq

*Corresponding author

Abstract

Caregivers of children with ASD reported more negative impact and poor psychological wellbeing. They appear to be at great risk for depression, stress, anxiety and distress; and many caregivers have managed to overcome the constant challenge by using their patience and take the consequences to adapt well in the face of adversity. The researcher highlights the family role to find themselves dealing with additional challenges to cope and accept modification, and minimizing the impact of ASD on caregivers by helping them to adjust their expectation to their children. A descriptive cross-sectional study was to determine the burden of ASD on the caregivers and to identify the level of psychosocial burden in dealing with the impact of raising a child with ASD. A non-probability purposive sample of (152) children with ASD and (152) caregivers at AL-Najaf province. The results of the study revealed that caregivers of children with ASD experienced moderate level of psychosocial burden; there were significant differences between the level of psychosocial burden among caregivers and childhood autism rating scale, whereas there is a significant difference between psychosocial burden and some of socio-demographic characteristics of Child's caregivers (gender and monthly income and GHQ). The current study recommends providing family support for families with autistic children, especially a psychological one, and educational about clinical behaviors of ASD for early detection and Family to Family Education Programs to the existing services in community mental health programs.

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Caregivers of Children,
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Introduction

Autism spectrum disorder is characterized by persistent deficits in social communication and social interaction across multiple contexts, including deficits in social reciprocity, nonverbal communicative behaviors used for social interaction, and skills in developing, maintaining, and understanding relations (APA, 2013).

Several ways in which parenting a child with ASD is different from parenting a child without ASD. Children with ASD often require additional primary care as well as more specialized and long-term medical care. Functional limitations may necessitate structural or technical modifications in the physical home environment.

A child's disability may require parents to seek educational and recreational accommodations to ensure that the child has opportunities that are equal to those of a child without a disability. Finally, as the child ages, specialized rehabilitation programs may be necessary to ensure a positive transition to adulthood. While there are numerous programs and organizations to provide parents of children with disabilities with social and financial support, navigating and coordinating these benefit programs can be a challenge. Overall, caregivers of a child with ASD may encounter a unique set of challenges, that not faced by caregivers of a child without ASD (Reichman *et al.*, 2008).

A study by the ASD funded by the Centers for Disease Control and Prevention CDC determined the prevalence of ASD in the United States to be about 11.3 per 1,000 (1 in 88) children (CDC, 2012).

Weiss (2002) mentions that the experience of caregivers of children with ASD (developmental disabilities) can be positive (e.g., joyful and happy feelings) or negative (e.g., stress, burden, sorrow, physical exhaustion etc.) or a combination of both, depending on the severity of cases.

Therefore, the researcher highlights the family role to find themselves dealing with additional challenges to cope and accept modification, and minimizing the impact of ASD on caregivers by helping them to adjust their expectation to their children.

ASD occurs about 4.5 times more often in boys than in girls. Onset of the disorder occurs in early childhood, and in most cases, it runs a chronic course, with symptoms persisting into adulthood (Townsend 2015; Kaplan, 2010). Estimated prevalence of ASD increased from 2011 to 2014 following changes in developmental disabilities questions in the National Health Interview Survey (NHIS), according to recent findings (Zablotsky, 2015).

The Study Hypothesis is ASDs children have an effect on the psychological health of caregivers; they may experience additional psychological and social burdens.

Objectives of the Study

The present study aimed to identify the level of severity of ASD for children, and also, to assess general mental health and psychosocial burden among caregivers of children with ASD, and to find out the relation between psychosocial burden with general mental health and

severity of ASD found in children, and to find out the relation between psychosocial burden with child characteristics such as gender, age, number of children in family, sequence, child's schooling, autistic children in family, child's age at diagnosis and treatment place; also, with caregiver characteristics such as Child's Caregiver, age, occupation, educational level, family crowding index, SES scale, marital status, income, residency area, participation in trainings of ASD.

Methodology

By using a descriptive design, a cross-sectional study was carried out with analytic utility. A self-administered questionnaire composed of two parts, each part is consisting of three domains were used, the first part (ASD children) included three domains inquiry regarding socio-demographic and clinical characteristic of autistic children and Childhood Autism Rating Scale CARS (15 questions), and the second part (caregivers of children) included three domains inquiry regarding socio-demographic characteristics and General Health Questionnaire GHQ (12 questions) scale and Zarit Burden Interview ZBI (22 questions). The study has been conducted on the children with ASD and their caregivers' at Imam Hussein Autism Center and Psychiatric Private Clinics and AL-Hakeem General Hospital/Psychiatric Department located in Najaf city/ Iraq.

Sample Size and Sampling Technique

Sample size was calculated according to the standard equation cross-sectional studies was used, (Naing, Winn and Rusli, 2006; Hajian-Tilaki, 2011; Charan and Biswas, 2013). A non-probability purposive (medical diagnosed as autistic child only) sample of (170) children with ASD and (170) caregivers' inpatients and outpatients, were selected from AL-Hakeem General Hospital/ Psychiatric Department was (32) sample and Psychiatric Private Clinics was (49) sample and from Imam Hussein Autism Center (IHAC) was (89) sample at AL-Najaf city. The data collection process has been performed from March 25th, 2016 to July. 6th, 2016. Finally, only (152) questionnaires were acceptable for analysis due to missing or incomplete data, because some paper of questionnaire is lacking. The data were collected through the utilization of the developed questionnaire and by means of self-reported technique (paper and pencil) with the subjects who were included in the present study, by using the Arabic version of the questionnaire, because, the caregivers are read and write by Arabic language and then gather in one place and the

purpose of the study was explained to them; verbal consent to participation was obtained and the caregivers answer the questionnaire at the same time for all those subjects who were included in the present study and the rate of response to the survey about 76%. A pilot study was conducted on (20) autistic children who were attending whole AL-Najaf province. The pilot study aimed to determine the following: clarity and content adequacy of the assessment tool and time required for data collection. The data collection process has been performed from March 25th, 2016 to July. 6th, 2016.

Statistical Analysis

By using statistical package for social sciences (SPSS), version 20. All the scale variables were normally distributed with small Skewness and Kurtosis in some variables. Appropriate statistical tests were used accordingly, $P.value \leq 0.05$ considered significant difference or relation, the statistics (Frequencies (F), Percentages (%), Means (\bar{x}), Standard Deviations (SD), Mean of Score, Reliability Coefficients, Chi-square-test, and Simple Linear Regression Analysis).

Criteria for Including the Sample

The caregivers of children with ASD were selected according to the following criteria: All children are diagnosed by psychiatrists with ASD, both sexes (male and female), all caregivers are from Al-Najaf city and Arabic Nationality, the ages of the all caregivers were 18 years old and more, caregiver of children diagnosed as psychiatric patient for at least six months, caregivers who provide care directly and attached to child with ASD about 16 hours.

Criteria for Excluding from the Sample

The study excluded the following: Respondent who did not fill the questionnaire completely, caregivers of children with ASD under 18 years old, caregivers who are free from systemic diseases, caregivers who are free from clinical psychiatric disorders especially depression.

Limitations of the Study

This study faces some limitations during its process:

1. There are many safety and security burdens.
2. The study sample is distributed in wide geographical area.
3. Some caregivers are refused participate in the study.

4. Lack of literature and previous studies relative to the psychosocial burden among caregivers of children toward ASD.
5. Due to caregivers' feeling about their children, some difficulties are experienced through data collection.
6. Small sample size, due to the time of implementation of this study.
7. This study need more time, to cover a lot of caregivers and autistic children.
8. Caregivers feel hopeless when they are asked about their child due to the lack of information toward child situation.
9. Much time needed to some caregivers due to their low education to clarify and explain the questionnaire for them.

Results and Discussion

Autistic children

Males represented 80.3% of the studied group[Figure 1]. Majority of child's age was (50%) aged (7-10) years old. Majority of age of child at diagnosis (67.1 %) was Less Than 3 years. (90.1 %) treatment place of children were private, the level of severity ASD of children (53.9%) were severe ASD[Table 1].

Caregivers of Autistic children

Majority of child's caregiver was (74.3%) mother. Majority of caregiver's age was (42.1%) aged (32-38) years old, (42.8%) were graduate of high education,(42.1%) participants of moderate S.E.S, (96.1%)were married. Nearly half of the participants had a monthly income of sufficient (44.1%), (96.7%) participants of urban residents, more half of the participants have participation in trainings about ASD (63.2 %) are not once[Table 2].According to the overall evaluation of participants' psychological distress GHQ (75%) was no psychological distress (psychological well-being), and only 38 (25%) have psychological distress [Table 3].Half of the participants (50 %) have a moderate burden level of psychosocial burden (ZBI) [Table 4].

No statistically significant association was found between the overall psychosocial burden score of caregivers with socio-demographic and clinical characteristics for child caregiver, ($P > 0.05$), except significant correlation with severity of ASD ($P = 0.03$) and child's caregiver ($P = 0.004$) caregiver's monthly

income ($P=0.002$), and psychological distress of caregiver ($P=0.000$) [Table 5,6,7,8].

Regarding, psychological distress, majority of the caregivers, (75%), had a no psychological distress, the mean score for this scale was (1.12) [Table 9].

The present study included a group of (152) child (152) caregiver, all the children in this study were diagnosed in early childhood with ASD; however, they showed impairment related to their 'autism features'. Almost all individuals included in the present study still meet clinical DSM-V and CARS diagnostic criteria for ASD.

Majority of autistic children are males (80.3 %) and (19.7 %) are females [Figure 1], this result reflects the higher prevalence of ASD in males compared with females. The findings of this study were supported by the study of AL-Ayadhi & Halepoto, (2011); Mandell, *et al.*, (2002); (APA, 2000), and Bromely *et al.* (2004), who reports that the majority of the study subjects were males (80 %), also this result is consistent with Benjak *et al.*, (2009).

Therefore, the males are more often diagnosed with ASD than females and the sex ratio of males to females with ASD is approximately 4:1. This evidence has predicted that psychosocial burden associated with Autistic children of males will be highly perceived with children and their caregivers.

The analysis of the current study indicated that the majority of the severity of ASD more than half of the caregivers perceived that their children have average to high severity of autistic clinical features (53.9 %) were severe ASD [Table 1]. This result is consistent with Nikmat, *et al.* (2008) who revealed that more than half of the parents perceived that their child has average to high severity of autistic symptoms. Of the 52 subjects, 29 (55.8%) subjects perceived that their child's symptoms were within the severe level of ASD.

According to the documents of Ministry of Planning, the number of all children (< 18) years within the boundaries of Najaf Province was (18563) child for (2016) year (Ministry of Planning, 2016). This study indicated that the children diagnosed with ASD (number of study sample) were (152) autistic child; therefore, the prevalence rates of autistic children in Najaf City may be approximately 1 per 122 (7 per 1000 – 66 per 10,000) (0.0081 %) or even higher. However, there are some autistic children at Najaf city don't we have assessment

document about their pathological status. Anyway, the most recent studies suggest that the overall rate of ASD may be as high as 40 to 60 per 10,000 (Bertrand *et al.*, Chakrabarti & Fombonne, 2001).

The majority of the gender (74 %) was Mother (females) of the completely sample, [Table2]. This result comes along with Nikmat, *et al.* (2008) who revealed that the majority of the gender of parents with autistic children (65.4%) subjects were female (mother). Very few up-to-date research projects have compared the psychosocial burden of mothers and fathers.

Concerning the caregiver age, the dominant age group of the study sample (42.1 %) is within (32-38) years old and the mean of age group were (25-31) years old [Table 2], this finding is supported by Nikmat, *et al.*, (2008) who showed that the finding (53.8%) falling within (31-40) years old, is major of age group for caregivers of autistic children.

In relation to the subjects' levels of education, the results show that the majority of the study sample is high level of education (42.8%) [Table 2]. This result comes along with Rhoades, Scarpa and Salley, (2007) who pointed out that (64%) of caregivers with autistic children were at college degree. In addition, Hamlyn *et al.* (2007) revealed that most of the autistic children caregivers were at college level (55.75). Allik, *et al.* (2006) stated that (64.5%) of mothers with autistic children were at high school-education.

[Table 2] shows that the majority of the subjects' marital status (96.1%) are married. This result comes in consistent along with our culture; where both males and female tend to marry early. This result is consistent with Yuen & Wai (2003), who found that (90%) of the caregivers with autistic children were married. Suggestion of the present finding is that the normal structure of families in our country is composed of father, mother, and their children and all are living together. So the effect of autistic children is on interrelation of family.

The result of the data analysis showed that the majority of the monthly income of caregivers (44.1%) were sufficient (high level) [Table 2], this finding agrees with Nikmat, *et al.*; Montes and Halterman, (2008) who reported that (50%) of the sample were of a high level of household of monthly income.

The study results reveal that the differences of the observed percentages for general mental health that the

majority of the GHQ (75 %) were of no psychological distress whereas the minority of them (25 %) were psychological distress [Table 3].

This result agrees with Tobing & Glenwick (2002) whose results indicate that the general mental health is mostly affected among the caregivers of children with ASD.

Further, the findings were consistent with Keller, *et al.* (2004) whose findings reveal that (90.4%) of caregivers with autistic children have highly significant burden and stress, and (53.8%) of the caregivers showed clinical disturbance in psychological wellbeing.

This result indicated that caregivers of children with ASD suffer from a rate of psychological co-morbidity with anxiety, increasing the disability associated with this disorder.

Caregivers of children with ASD frequently experience a higher amount of psychosocial burden due to providing care to these children [Table 4]. Even though many researchers have studied children with ASD and their impact on caregiver's well-being (Harris, 2003).

The researcher has also shown that worries about the future are very common in mothers of children with ASD.

Heiman (2002) stated that when children were young, caregivers worry about whether they will be bullied at school or whether they will have any friend. As their children grow older, parents' concerns turn toward prospects for independent living, employment opportunities, potential romantic relation.

From our point of view, mothers of a child with ASD are highly burdened and more likely to report poor or fair mental health than mothers in the general populations. Tobing and Glenwick (2002) stated that most caregivers of children with ASD suffer a great deal of psychological burden; there are several reasons why the burden of those parenting children with ASD is so high. According to the study of Lainhart (1999) caregivers of autistic children had an increased rate of developing psychiatric disorder such as depression; this increased risk may be directly related to the burden of living with caring for an ASD children. Kogan *et al.*, (2006) elucidate that caregiver of a child with ASD suffered from feeling of isolation and depression.

In conclusion, the study finds that stress as one psychological burden is higher than other emotional burden aspects (anxiety and depression) among caregivers with autistic children. The possible explanation regarding the high level of stress in caregivers could be that ASD is a pervasive developmental disorder so autistic children have more severe form of disability. Moreover, children with ASD display features such as impulsivity, hyperactivity, irritability, and aggressiveness, which are characterized by unpredictability and volatility. The researcher suggests that the experience of psychosocial burden is related to how the individual perceives the stressful event and whether coping strategies can be used effectively to manage stress positive adaptation lower the stress.

Concerning child's age at diagnosis, the results show that there is no significant relation between the psychosocial burden and child's age at diagnosis. These results are consistent with Stuart (2009) who mentioned that autism occupies extreme pathologies in terms of its severity, duration and impact on the family. So hopefully, early detection and diagnosis of infants and children at risk will enable treatments to be designed and implemented to alter the course of early behavior and brain development.

For this reason, no child and no family go untouched by the diagnosis caregivers' reactions to the diagnosis of ASD in their children ranged from initial relief that they finally know what is wrong with the child, to a complex and continuous process of grief over the loss of a "normal" child. The researcher elucidates this result as; the family's ability to remain healthy and cope with such adversity contributes to their resilience.

The results showed that the caregiver with ASD children have highly significant relation between psychosocial burden of caregivers and severity of ASD children [Table 5]. The findings of this study were consistent with that of Nagaraju & Wilson, (2013); Nikmat, *et al.* (2008) and Sarkova, *et al.* (2006) who reported that the severity of ASD children mostly effected on their caregivers' regard to psychosocial burden in future.

This result is agrees with Cadman, *et al.*, (2012) who state that caregiver burden was high in both groups, but it was significantly higher in the ASD group. As for as gender is concerned the results show that there is a significant relation between the caregiver gender with psychosocial burden of caregiver [Table 6].

The results indicated that there were no significant differences between female's caregiver experiencing higher level of psychosocial burden than male's caregivers. This result revealed that there was significant relation between psychosocial burdens among caregivers of ASD children with respect to Monthly Income [Table 7]. The result of the current study agrees with Zablotsky *et al.*, (2015) who showed that there was significant relation between burden of autism and monthly income.

The researcher suggests that those caregivers with an ASD children were more likely to be in substantially lower-income households, and to have costly educational expenses. Therefore, the household income was decreased in families with ASD children, because of the parental trainings and education and healthcare services for ASD and was positively associated with family income.

This finding shows that there was a highly significant relation between psychosocial burdens among caregivers of ASD children with respect to general mental health [Table 7]. This finding was consistent with Keller, *et al.*, (2004) who found that there were caregivers with autistic children have highly significant psychosocial burden and showed clinical disturbance in psychological well being. Therefore, the researcher called for further comprehensive study to explore their psychological distress, and proper program should be applied to help them managing their emotional disturbance, anxiety and stress. In this study also, the results revealed that mothers report greater impact on psychological wellbeing compared to fathers.

This finding is supported by earlier findings of Abbeduto, *et al.*, (2004) who reported that mothers of youths with Down syndrome were less pessimistic about their children's future and reported greater reciprocated closeness with their child than do mothers of the youths with ASD.

This finding shows that there was a highly significant relation between psychosocial burdens among caregivers of ASD children with respect to general mental health (psychological distress) [Table 8].

This finding was consistent with Keller, *et al.* (2004) who found that there were caregivers with autistic children have highly significant psychosocial burden and showed clinical disturbance in psychological wellbeing. These results confirm the earlier findings, which report

that caregivers of children with disabilities have more psychological distress than caregivers of children without disabilities.

In addition, this result comes along with Nikmat, *et al.* (2008) who showed that there are mothers of ASD children significantly greater depression, greater social isolation and a lower level of marital intimacy when compared to mothers of normal children or mothers of Down's syndrome children.

Therefore, the researcher called for further comprehensive study to explore their psychological distress, and proper program should be applied to help them managing their emotional disturbance, anxiety and stress.

Conclusions and Recommendations (directions and implications)

According to the discussion and interpretation of the study findings, the researcher has drawn the following conclusion: The study depicts that the majority of autistic children are males, their age ranged between (7-10) years and they are diagnosed at age less than (3) years. They are treated by medications and behavioral therapy at governmental and private place. About (42.1 %) of caregivers were age (32 - 38) years old, and more than half of caregivers' children were young females (mothers) is the majority of the sample and most of the caregivers' lives together, with high level of education; they suffer from barely sufficient income, while approximately half of them are Moderate socioeconomic status. Caregivers of ASD children are impacted by psychological distress about (25%) of them. Caregivers of autistic children are impacted by psychosocial burden at moderate level approximately half of them. Most socio-demographic characteristics of autistic children have no impact on caregivers, psychosocial burden except the severity of ASD children (CARS). All socio-demographic characteristics of caregivers have no impact on caregivers, psychosocial burden except the caregiver's gender and the monthly income. The researcher recommends is 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. Standard indicators should be adopted to assess child development for early recognition and diagnosis of ASD in all the primary care centers.

Table.1 Distribution of the Participants' Overall Level of Severity Related to Children with ASD through the Total Scores

Level of ASD	(N = 152)	
	F.	%
Mild/ Moderate ASD	70	46.1
Severe ASD	82	53.9
Total	152	100.0

Table.2 Distribution of the Caregivers by their Socio-Demographic Characteristics through Frequency and Percentage

No.	Variables	Groups	(n = 152)	
			F.	%
1.	Who is the child's caregiver?	- Father	37	24.3
		- Mother	113	74.3
		- Sister	1	0.7
		- Other Relatives	1	0.7
		Total	152	100
2.	Caregiver's Age	- (18 - 24) years	9	5.9
		- (25 - 31) years	44	28.9
		- (32 - 38) years	64	42.1
		- (39 - 45) years	26	17.1
		- 46 & Above	9	5.9
		Total	152	100
3.	Level of Education	- Illiterate	6	3.9
		- Literate (read & write)	6	3.9
		- Graduate of Primary School	33	21.7
		- Graduate of Intermediate School	32	21.1
		- Graduate of Secondary School	10	6.6
		- Graduate of High Education (Institute, University,)	65	42.8
Total	152	100		
4.	Level of Socio-Economic Status	- Low S.E.S	50	32.9
		- Moderate S.E.S	64	42.1
		- High S.E.S	38	25.0
		Total	152	100
5.	Marital Status	- Married	146	96.1
		- Divorced	2	1.3
		- Widow	2	1.3
		- Separated	1	0.7
		- Partner	1	0.7
		Total	152	100
6.	Do you enough monthly income for family needs	- Insufficient	21	13.8
		- Barely sufficient	64	42.1
		- Sufficient	67	44.1
		Total	152	100
7.	Residency Area (Housing)	- Urban	147	96.7
		- Rural	5	3.3
		Total	152	100
8.	Participation in Trainings about ASD	- Not Once	96	63.2
		- Once	32	21.1
		- Twice	15	9.9
		- Three or More	9	5.9
		Total	152	100

Table.3 Prevalent of the Psychological Well-being among Caregivers of Children with ASD

Psychological well-being G.H.Q	(N = 152)	
	F.	%
No Psychological Distress	114	75.0
Psychological Distress	38	25.0
Total	152	100.0

Table.4 Distribution of the Participant Level of Psychosocial Burden among Caregivers

Level of Psychosocial Burden	(n = 152)	
	F.	%
No Burden	7	4.6
Mild Burden	46	30.3
Moderate Burden	76	50.0
Severe Burden	23	15.1
Total	152	100.0

Table.5 Association between the Levels of Psychosocial Burden of Caregivers and Severity of ASD

Variables	Groups		Psychosocial Burden (Z.B.I)				Total (N=152)	p-value C.S.
			No Burden	Mild Burden	Moderate Burden	Severe Burden		
Autism Spectrum Disorders(ASD)	- Mild to Moderate	F.	6	24	34	6	70	P= 0.03 S
		%	3.9%	15.8%	22.4%	3.9%	46.1%	
	- Severe	F.	1	22	42	17	82	
		%	0.7%	14.5%	27.6%	11.2%	53.9%	
Total	F.		7	46	76	23	152	
	%		4.6%	30.3%	50.0%	15.1%	100.0%	

Table.6 Association between the Levels of Psychosocial Burden of Caregivers and Child's Caregiver

Variables	Groups		Psychosocial Burden (Z.B.I)				Total (N=152)	p-value C.S.	
			No Burden	Mild Burden	Moderate Burden	Severe Burden			
Who is the Child's Caregiver?	- Father	F.	3	10	19	5	37	P= 0.004 H.S.	
		%	2.0%	6.6%	12.5%	3.3%	24.3%		
	- Mother	F.	3	36	56	18	113		
		%	2.0%	23.7%	36.8%	11.8%	74.3%		
	- Sister	F.	0	0	1	0	1		
		%	0.0%	0.0%	0.7%	0.0%	0.7%		
	- Grandmother	F.	1	0	0	0	1		
		%	0.7%	0.0%	0.0%	0.0%	0.7%		
	Total	F.		7	46	76	23		152
		%		4.6%	30.3%	50.0%	15.1%		100.0%

Table.7 Association between the Levels of Psychosocial Burden of Caregivers and Monthly Income

Variables	Groups		Psychosocial Burden (Z.B.I)				Total (N=152)	p-value C.S.
			No Burden	Mild Burden	Moderate Burden	Severe Burden		
Do you enough Monthly Income for family needs	- Insufficient	F.	0	4	10	7	21	P= 0.002 S
		%	0.0%	2.6%	6.6%	4.6%	13.8%	
	- Barely sufficient	F.	3	16	35	10	64	
		%	2.0%	10.5%	23.0%	6.6%	42.1%	
	- Sufficient	F.	4	26	31	6	67	
		%	2.6%	17.1%	20.4%	3.9%	44.1%	
Total		F.	7	46	76	23	152	
		%	4.6%	30.3%	50.0%	15.1%	100.0%	

Table.8 Association between the Levels of Psychosocial Burden of Caregivers and General Mental Health

Variables	Groups		Psychosocial Burden (Z.B.I)				Total (N=152)	p-value C.S.
			No Burden	Mild Burden	Moderate Burden	Severe Burden		
Psychological Distress	- Not affected	F.	7	45	56	6	114	P= 0.000 H. S.
		%	4.6%	29.6%	36.8%	3.9%	75.0%	
	-Affected	F.	0	1	20	17	38	
		%	0.0%	0.7%	13.2%	11.2%	25.0%	
Total		F.	7	46	76	23	152	
		%	4.6%	30.3%	50.0%	15.1%	100.0%	

Fig.1 Distribution of Autistic Children According to their Gender

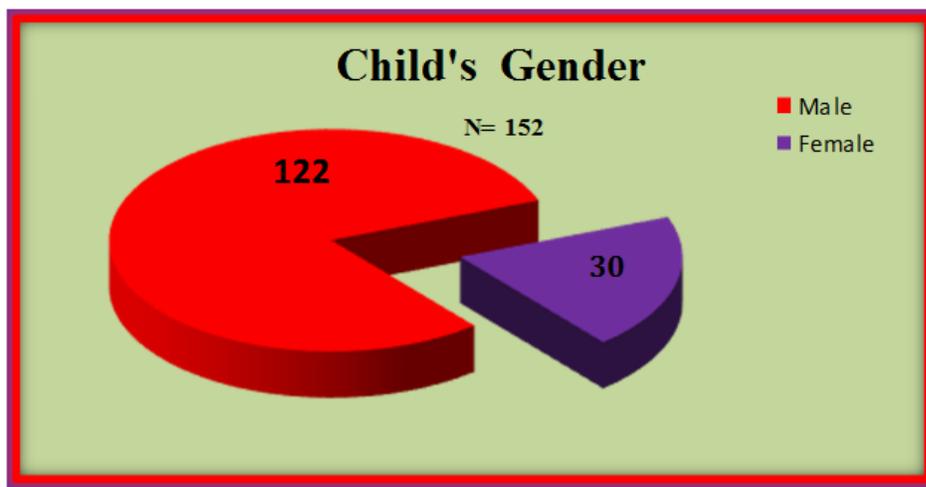


Table.9 level of General Mental Health for Caregivers of Children with ASD

No.	Items	Ratings	(N = 152)		M.	S.D.
			F.	%		
1.	Been able to concentrate on what you're doing?	- Better than usual	14	9.2	1.24	0.728
		- Same as usual	99	65.1		
		- Less than usual	27	17.8		
		- Much less than usual	12	7.9		
		Total	152	100		
2.	Lost much sleep over worry?	- Not at all	34	22.4	1.26	0.924
		- No more than usual	61	40.1		
		- Rather more than usual	41	27.0		
		- Much more than usual	16	10.5		
		Total	152	100		
3.	Felt you were playing a useful part in things?	- More than usual	29	19.1	0.96	0.608
		- Same as usual	102	67.1		
		- Less than usual	19	12.5		
		- Much less than usual	2	1.3		
		Total	152	100		
4.	Felt capable of making decisions about things?	- More than usual	21	13.8	1.15	0.753
		- Same as usual	99	65.1		
		- Less than usual	20	13.2		
		- Much less than usual	12	7.9		
		Total	152	100		
5.	Felt constantly under strain?	- Not at all	20	13.2	1.82	1.030
		- No more than usual	36	23.7		
		- Rather more than usual	47	30.9		
		- Much more than usual	49	32.2		
		Total	152	100		
6.	Felt you couldn't overcome your difficulties?	- Not at all	47	30.9	1.14	0.935
		- No more than usual	47	30.9		
		- Rather more than usual	48	31.6		
		- Much more than usual	10	6.6		
		Total	152	100		
7.	Been able to enjoy your normal day-to-day activities?	- More than usual	8	5.3	1.49	.780
		- Same as usual	81	53.3		
		- Less than usual	44	28.9		
		- Much less than usual	19	12.5		
		Total	152	100		
8.	Been able to face up to your problems?	- More than usual	19	12.5	1.18	.732
		- Same as usual	96	63.2		
		- Less than usual	27	17.8		
		- Much less than usual	10	6.6		
		Total	152	100		
9.	Been feeling unhappy and	- Not at all	47	30.9	1.20	1.080

	depressed?	- No more than usual	57	37.5		
		- Rather more than usual	19	12.5		
		- Much more than usual	29	19.1		
		Total	152	100		
10.	Been losing confidence in yourself?	- Not at all	87	57.2	0.66	0.885
		- No more than usual	37	24.3		
		- Rather more than usual	21	13.8		
		- Much more than usual	7	4.6		
		Total	152	100		
11.	Been thinking of yourself as a worthless person?	- Not at all	111	73.0	0.39	0.719
		- No more than usual	26	17.1		
		- Rather more than usual	12	7.9		
		- Much more than usual	3	2.0		
		Total	152	100		
12.	Been feeling reasonably happy, all things considered?	- Not at all	34	22.4	0.93	0.642
		- No more than usual	98	64.5		
		- Rather more than usual	17	11.2		
		- Much more than usual	3	2.0		
		Total	152	100		
Average					1.12	

Table.10 Stepwise Regression for Predicting the Effect of ASDs on Psychological Health of Caregivers

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	Beta	Std. Error	Beta		
(Constant)	1.337	.136	-	9.830	.000
Autism Spectrum Disorders	.268	.078	.270	3.434	.001
Adjusted R. Square = .067 F= 11.789 P-value= .001					

*Dependent variables: Psychosocial Burden

Table.11 Pearson Correlation Coefficient among Different Study Scales (measures)

Scales	Correlation	Autism Spectrum Disorders (CARS)	Psychological Well-being (GHQ)	Psychosocial Burden (ZBI)
Autism Spectrum Disorders	Pearson Correlation	1	.287**	.270**
Psychological Well-being	Pearson Correlation	.287**	1	.504**
Psychosocial Burden	Pearson Correlation	.270**	.504**	1
**. Correlation is significant at the 0.05 level (1-tailed).				
*. Correlation is not-significant at the 0.05 level (1-tailed).				
N = 152				

This table reveals the Pearson correlation among all the studied scales, the results show that there was a significant relationship between all the studied scales at p-value ≤ 0.05 .

Socio-Economic Status Scale (SES)

Items	scores	Descriptions
Occupation	25	High professional and managerial job as a doctor, director of business, land owners
	20	Lower professional, skilled and semiskilled workers as school teacher, clerical workers, owner of small business, military men, or policemen
	10	Unskilled workers as laborers, farmers, casual worker, unemployed, and retired
Level of education	0	Illiterate
	4	Read and write
	7	Graduate of primary school
	10	Graduate of intermediate school
	20	Graduate of secondary school
	25	High education
Crowding index	25	Less than one
	20	1 – 1.5
	10	2 – 2.5
	7	3 – 3.5
	0	4 and above
Property	25	Owns a house, with or without car and all of household assets
	20	House is rented, with or without car and has most of the household assets
	10	House is shared with other family, no car and some of the household assets

As one of the most important aspects of burden, is financial one; supported employed programs and lifelong financial help should be planned not only for the autistic children but also for the families.

Counseling units can be established in the primary care centers for coordinating their services to the autistic child and their family. Future researches to build up is also a recommended program to reduce the family burden of autistic children and call for further comprehensive study to explore their burden and stress, and proper program should be applied to help them managing their burden.

Caregivers to caregivers Education Program should be established for family members who provide care for caregivers with ASD children to support those who face courtesy burden by presenting knowledge about ASD and treatments, teaching problem solving and communication skills and providing coping skills. It must have Press and Media played a major role in terms of

providing caregivers with adequate information to deal with children with ASD to reduce the burdens of caring.

References

Abbeduto, L., Seltzer, M.M, Shattuck, P.T., Krauss, M. W., Orsmand, G.I., and Murphy, M. Psychological wellbeing and coping of mothers of youths with autism, Down Syndrome, or Fragile X Syndrome. American Journal on Mental Retardation, 2004; 109, 237-254.

AL-Ayadhi Laila Y. and Halepoto Dost M., (2011), General Characteristics of Children with Autism Spectrum Disorder at Autism Research and Treatment Center, King Saud University, KSA, International Conference on Medical, Biological and Pharmaceutical Sciences (ICMBPS'2011) Pattaya Dec. 2011, p.p. (483-486).

Allik, H. (2006) *Asperger syndrome and high-functioning autism in school-age children: the children's sleep and behaviour, and aspects of their.* Karolinska Institutet, Stockholm, Sweden, pp. 29-31.

- American Psychiatric Association (APA), Diagnostic and Statistical Manual of Mental Disorders DSM-5, 2013, 5th Edition, p.p. (501-504).
- Benjak T., Vuletic G., and Simetin I.; Comparative Study on Self-Perceived Health of Parents of Children with Autism Spectrum Disorders and Parents of non-Disabled Children in Croatia, *Croat Medical Journal*, 2009; 50(4): pp 403-409.
- Bertrand J, Mars A, Boyle C, Bove F, Yeargin-Allsopp M, Decoufle P: Prevalence of autism in a United States population: the Brick Township, New Jersey, investigation. *Pediatrics* 2001, p.p. (108,1155-1161).
- Bromley J., Hare D., Davison K., & Emerson E.; Mothers supporting Children with Autistic Spectrum Disorders, Sage Publications and The National Autistic Society, 2004; 8(4): pp. 409-423.
- Cadman, T., Eklund, H., Howley, D., Hayward, H., Clarke, H., Findon, J., Xenitidis, K., Murphy, D., Asherson, P. and Glaser, K. (2012) 'Caregiver burden as people with autism spectrum disorder and attention-deficit/hyperactivity disorder transition into adolescence and adulthood in the United Kingdom', *Journal of the American Academy of Child and Adolescent Psychiatry*. Elsevier Inc., 51(9), pp. 879–888. doi: 10.1016/j.jaac.2012.06.017.
- Charan, J. and Biswas, T. (2013) 'How to Calculate Sample Size for Different Study Designs in Medical Research?', *Indian Journal of Psychological Medicine*. India: Medknow Publications & Media Pvt Ltd, 35(2), pp. 121–126. doi: 10.4103/0253-7176.116232.
- Hajian-Tilaki, K. (2011) 'Sample size estimation in epidemiologic studies', *Caspian Journal of Internal Medicine*, 2(4), pp. 289–298.
- Harris S. & Glasberg B.; Siblings of Children with Autism: A guide for families. Bethesda, MD: Woodpine Press. 2003;(2nd ED); pp.16-160.
- Heiman T.; Parents of Children with Disabilities: Resilience, Coping, and Future Expectations. *Journal of Developmental and Physical Disabilities*, 2002; 14(2): pp 159-171.
- Kaplan and Sadock's, *Synopsis of Psychiatry Behavioral Sciences-Clinical Psychiatry*, 2010, 10th Ed, pp (332-342).
- Keller, D. and Sterling A. H. Maternal and paternal stress in families with school-aged children with disabilities. *American Journal of Orthopsychiatry*. 2004; 74(3):337-348.
- Lainhart D.; Psychiatric Problems in Individuals with Autism, Their Primary Caregiver and Siblings, *International Review of Psychiatry*, 1999; 11(4): pp. 278-298.
- Mandell David S., D.Sc., Listerud John, D.M., Levy Susan E., D.M., And Pinto-Martin Jennifer A., (2002), Race Differences in the Age at Diagnosis Among Medicaid-Eligible Children With Autism, *Journal of the American Academy of Child & Adolescent Psychiatry* • Dec. 2002, 41(12): p.p.(1448-1450),
- Montes G, & Halterman S.; Association of Childhood Autism Spectrum Disorders and Loss of Family Income. *Pediatrics*. 2008a; 121(4): pp. 6-821.
- Naing, L., Winn, T. and Rusli, B. N. (2006) 'Practical Issues in Calculating the Sample Size for Prevalence Studies', *Archives of Orofacial Sciences*, 1(Ci), pp. 9–14.
- Nikmat A. W., Ahmad Mahadir, Oon Ng Lai, & Razali Salmi, (2008), Stress and psychological wellbeing among parents of children with autism spectrum disorder, *ASEAN Journal of Psychiatry* 2008;9 (2):64-72.
- Rhoades, R. A., Scarpa, A. and Salley, B. (2007) 'The importance of physician knowledge of autism spectrum disorder: results of a parent survey', *BMC Pediatrics*, 7(1), p. 37. doi: 10.1186/1471-2431-7-37.
- Stuart M. & John H.; Caregiver Burden after receiving a diagnosis of an Autism Spectrum Disorder, *Autism*, 2009; 3(1):87-97.
- Tobing, L. E., Glenwick, D. S. (2002). Relation of the Childhood Autism Rating Scale–Parent Version to diagnosis, stress, and age. *Research in Developmental Disabilities*, p.p. (23, 3, 211–223).
- Townsend Mary C., *Essentials of Psychiatric Mental Health Nursing*, (2015), F. A. Davis Company, 8th Edition, p.p. (651-656).
- Yuen c., and Wai C.; Quality of Life of Parents who Have Children with Disabilities, *Hong Kong Journal of Occupational Therapy*, 2003; 13: pp. 19-24.
- Zablotsky, Benjamin, *et al.* "Estimated Prevalence of Autism and Other Developmental Disabilities Following Questionnaire Changes in the 2014 National Health Interview Survey." *National health statistics reports* 87 (2015): 1-20.

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