

Assessment of the burden of caregiving among parents of children with Autism Spectrum Disorder attending Child Autism Center in Sulaimani city

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Background: A growing body of evidence suggests that parent's caregivers of a child affected with autism spectrum disorder experience high rate of anxiety, stress and poorer overall well-being. Autism spectrum disorder is a lifelong neurodevelopmental disability that includes deficits in social, communication and repetitive behaviors.

Objective: To assess the type and severity levels of caregiving burden as perceived by parents of children with autism spectrum disorder.

Methods: A quantitative design descriptive was used to conduct this study. A non-probability, purposive sample size of (40) parents (24mothers and 16fathers) assuming the role of caregivers of (40) children with autism spectrum disorder attending Sulaimani Child Autistic Center. A questionnaire was developed including the Montgomery family caregivers burden scale to measure parent's burden. An interview method (face to face technique) was used to collect data from parent's participants. A pilot study was carried out on a purposive sample of (eight) parents and their (eight) autistic children were select from Sulaimani Child Autistic Center. The Pearson coefficient correlation (r-test) was used to find out the correlation between the test and retest, in which the result of reliability was 0.89 which is significant at p-value < 0.05 level, this result means the questionnaire is

acceptable and reliable measure for the assessment of study variables. The statistical analysis was performed by statistical package of social science spss-22.

Results: The children with autism spectrum disorder mostly male, mean age 7.5 years and first child ranking in the family. The mother caregivers mostly housewife and mean age 36.8 years. And father mostly governmental employed and mean age 43.9 years. The parent's experience high severity level of objective burden (3.37 ± 1.18) and moderate level of stress burden (2.37 ± 1.30) and demand burden (2.28 ± 1.22), no statistically significant difference between total burden scale of caregiving in regard to parents socio-demographic characteristics ($P > 0.05$)

Conclusion: The parent's caregivers of children with autism spectrum disorder experiencing high severity level of objective burden of caregiving was mainly related to decrease time for their personal and social life, and moderate level of subjective stress burden was related to anxiety, worry and nervousness.

Keywords: Autism spectrum disorder, children burden, parent, caregiving. Subjective, objective burden.

Introduction:

Autism spectrum disorder (ASD) is a childhood neurodevelopmental disorder characterized by deficits in social interaction, communication and restricts repetitive patterns of behavior, interests and activities (Almandil et al., 2019; Zaky & Behav, 2017). A child with ASD may show unusual interests and behaviors and may have problem with sleeping and eating.(Crane, Chester, Goddard, Henry, & Hill, 2016; Daljeet, 2019). The manifestation of the autism spectrum disorder (ASD) symptoms may range from mild to severe and varying from individual to individual(Association, 2013; Cohen et al., 2015). Recent research has clearly specified the importance of early identification since early intensive treatment is associated with better long term outcome (Bhuiyan, Hossain, Islam, & Sciences, 2018)

A single etiology for ASD has yet to be unattached (Catalano, Holloway, Mpofu, & health, 2018). The causes of ASD are multiple etiologies which included parentally induced autism, brain injury/ anomalies. And both environmental genetic factors are crucial for the development of ASD (Baxter et al., 2015; Crane et al., 2016).

Caring for children with ASD is challenging for parents as caregivers and they may face difficulties (Özgür, Aksu, & Eser, 2018). In dealing with the unusual behaviors of their children , caring and teaching them of the basic life skills, interaction, protecting them from danger and preparing for their transition to adolescence and adulthood due to this multidimensional requirement of caregiving, the parent's may experience stress, misconception, guilt feeling and self-blame regarding child's condition (Islam, 2018; Pandey & Sharma, 2018).

The personal suffering of parents is a consequence of the illness of a family termed "burden" (Idstad, Ask, & Tambs, 2010). The burden on parent's caregivers concerning the children with ASD is described as a disorder resulting from dealing with physical dependence and mental incapacity of the child, which need attention and care (Al-Farsi et al., 2013; Morley et al., 2012). The parents by assuming the role of caregiver were responsible for the welfare and care of the dependent child and they may subjected to stress, depression and anxiety (Misquiatti, Brito, Ferreira, & Assumpção Júnior, 2015) Approximately 85% of children with ASD presents with cognitive and adaptive limitation that limit their ability to live independently, that they will need some assistance from their parents for the duration of their lives (Karst, Van Hecke, & review, 2012).

Commonly, the literature describes three types of burden. (1) Objective burden, (2) subjective demand burden and (3) subjective stress burden (Magliano et al., 2005). The objective burden refers to multitude of practical problems including disturbed family relationship, constraint in social, leisure and work activity and

financial difficulties (Al-Dujaili & Al-Mossawy, 2017). The subjective burden refer to the psychological reactions by caregivers including loss of hope and the parenting stress described as the experience of distress that derived from the demands that parent implies to the ASD child (baxter et al, 2015)

Objectives: This is study aimed to assess the severity levels of the burden caregiving among parents of children with ASD, which includes objective burden, subjective demand burden and subjective stress burden

Methods: A total of convenience sample size of (40) children with ASD and (40) parents caregivers who were attending with their children to the sulaimani autism center of Kurdistan Region, Iraq during the period of data collection start from November 2018 to March 2019. A questionnaire was developed including four part child's socio-demographical characteristics, parents (father & mother) socio-demographical characteristics, and parent's burden of caregiving was based on Montgomery family burden intervention.

Result: The results of this study shown that have half of the children of the ASD are in the age group (4-7) years old, the other half are in the age group 8-11 years old, and the mean age is 7.5 SD \pm 1.96. Most of the children 80% are males, 35% of them are first child ranking of their family, all of them not attending mainstream schooling (Table 1). More than half of them (57.5%) are diagnosed in age three years old and 25% of them diagnosed at two years old (table 2) In regard to the characteristics of the mother (n=24), the appear that the higher percentage (41.7%) of the mothers are in the age group 35-39 years old and the mean age 36.8,SD \pm 5.25 years. Concerning educational status 50% of the mothers have secondary school and (8.33%) illiterate. The majority of the mother's housewives, and their economic status barely sufficient (75%) (Table3).

In regard to the fathers characteristics the results appear that (50%) in the age group 41-45 years old, and mean of age 43.9 SD \pm 3.71 years. More than half (56.25%) of the father have primary school graduate, 62.5% are governmental employed, and 6.25% are retired. The majority of fathers their economic status barely sufficient (81.25%) (Table4).

The results appear that are statistical significant differences between the mean score of objective burden, subjective demand burden, subjective stress burden ($P < 0.05$). The result indicate that objective burden rated high in severity level ($X=3.24SD\pm 1.18$) while subjective demand burden ($X=2.28SD\pm 1.22$), and subjective stress burden($X=2.37 SD\pm 1.30$) rated in moderate level of severity according to the standard scoring of Montgomery family caregiving burden scale.

Discussion:

The result of this study suggested that parents of children with ASD experience more level of objective burden than subjective stress burden and subjective demand burden. Parents perceived that caregiving contributes to the conditions determines in the personal life. Similarly, the result of a study carried out in Nepal (pandy and sharma, 2018) and another study conducted in Nigeria (Al farsi et al, 2013).

Also misquiatti et al (2015) conformed the finding of this study and reported that consequences and limitation of personal life of the parents caregivers comprises many situations, which may cause changes and impact on personal life such as reduce time available, affected health, and this necessities of changing in many habits in order to support the needs of their children with ASD.

In this study parents experience moderate level of subjective stress burden and subjective demand burden of caregiving, these results inconsistent with study carried out in Saudi Arabia which found that parent's caregivers of children with ASD have high incidence of stress burden such as anxiety and worry due to the burden posed by challenging child's care demands. (AL Mansour et al 2013). However the finding of this study was in agreement with the result of (misquitte et al 2018) who found that the parents of the children with ASD were not significant in overload index ant their levels of demand burden moderately overload.

Conclusion:

The study concluded that the parents of children with ASD are significantly experiencing more objective burden of caregiving mainly related to decrease time for their personal and social life. The parents providing ongoing care to their child affected by ASD are found experiencing moderate level of subjective stress burden which was mainly related to psychological distress. And subjective demand burden of caregiving was also moderate; this resulted mainly from the child's manipulation behaviors and the child demand over and above what is needed.

It is recommended that it is useful to identify the areas that are affected by the burden of caregiving process among parents of children with ASD to help in developing interventions focusing on the needs of the parents and their children.

Table (1) children with ASD characteristics (n=40)

Variable	Frequency	%
Age group		
4-7 years	20	50
8-11 years	20	50
Mean± SD 7.5±1.96		
Gender		
Male	32	80
Female	8	20
Child ranking		
1 st	14	35
2 nd	7	17.5
3 rd	9	22.5
4 th	4	10.0
≥ 5 th	6	15.0
schooling		
mainstream School	0	0
non-school	40	100

Table (2) Distribution of the ASD children according to Child's age at medical diagnosis by years:

Child's age at medical diagnosis by years	No.	%
Child's age at medical diagnosis by years		
2	10	25
3	23	57.5
4	4	10
5	2	5
6	1	2.5
Total	40	100

Table (3): Distribution of the socio demographic characteristics of the mothers of children with ASD (n=24)

Mother's socio demographic characteristic		Frequency	%
Age group	30-34 years	8	33.3
	35-39 years	10	41.7
	40-44 years	3	12.5
	≥ 45 years	3	12.5
	Mean ±SD 36.8±5.25		
Educational levels	Illiterate	2	8.33
	Primary school	5	20.84
	Secondary school	12	50
	Institute graduate	2	8.33
	College graduate	3	12.5
	Other	0	0
Occupational status	Governmental Employed	5	20.84
	Self-employed	1	4.16
	House wife	18	75
	Student	0	0
	Retired	0	0
Economic status	Sufficient	4	16.67
	Barely sufficient	18	75
	Insufficient	2	8.33

Table (4): Distribution of the socio demographic characteristics of the fathers of children with ASD (n=16)

Father's socio demographic characteristics		Frequency	%
Age group	36-40 years	3	18.75
	41-45 years	8	50
	46-50 years	5	31.25
	Mean ±SD 43.9±3.71		

Educational levels	Illiterate	0	0
	Primary school	9	56.25
	Secondary school	2	12.5
	Institute graduate	4	25
	College graduate	1	6.25
Occupation	Governmental Employed	10	62.5
	Self-employed	5	31.25
	Student	0	0
	Retired	1	6.25
Economic status	Sufficient	3	18.75
	Barely sufficient	13	81.25
	Insufficient	0	0

Table (5): Differences of the parent's total levels of severity related to the types of burden by mean, standard deviation and F-test.

No.	Type of burden	Mean	SD	Severity levels
1.	Objectives burden	3.24	1.18	high
2.	Subjective demand-burden	2.28	1.22	Moderate
3.	Subjective stress-burden	2.37	1.30	Moderate
	F-test	22.56		Significant
	P-value	0.047		

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