Burden on Caregivers of Children with Autism Spectrum Disorder in El-Beheira Governorate

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Abstract

Background: Caregiver of Children with Autism Spectrum (ASD) are experienced high level of stressors and burden   due to lack of information related to ASD, lack of health service, lack of social support and financial problems which increase the caregiver burden. **The aim of this study** was to assess the burden experienced by caregivers of child with autism spectrum disorder in El-Beheira Governorate. **Research design:** a descriptive research design was used. **Settings:** This study was carried out at all governmental intellectual schools in El-beheira governorate and private centers for autism coping and rehabilitation in El-Beheira governorate. **Subjects:** this study was carried out on all caregivers of children with ASD at the previous mentioned setting were included into the study (110 caregiver) at 2019-2020 academic years. **Data collection tools:** data were collected using three tools: **Tool (I):** Stressors of caregiver having Children with Autism Interview Schedule. **Tool (II):** Caregiver burden scale. **Tool (III):** caregivers Adjustment pattern Adapted to modify their child behaviour. **Results:** The majority of the caregivers 90.8% were the mothers of the autistic child, about 75.2% had high level of physical and psychological stressors. About 46.6% of them had high level of social stressors, about (80%) of them had high level of marital stressors and about 100% of caregivers had high level of financial stressors. Also, about (97.3%) of them had high level of burden with mean percent score 83.75%. about (76.4%) of the caregiver had moderate level of adjustment. **Conclusion:** the study concluded that majority of the studied caregivers had high level of burden, they were vulnerable to   health hazards as the majority of them had high level of physical and psychological burden because they the only provider of care for the autistic child and ignoring their health. Moreover, the majority of them were suffering from financial problems, as the cost of treatment of autism spectrum disorder is very high and endless rehabilitation process. **Recommendations:** Conduct health education campaigns in rural & urban areas about early sign and symptoms of ASD and benefits that result from early identification of sign and symptoms of ASD. Early case finding & screening of early sign and symptoms of autism spectrum disorder cases. Encourage small projects and provide opportunity for housewives to increase their income to help them in expensive treatment and the lifelong process of coping with autism

Keywords: Autism spectrum Disorder, caregiver, stressors, burden, adjustment

Introduction

Autism Spectrum disorder is a lifelong disorder and one of the most devastating and least understood mental disorders of childhood that affect children in the family and make their lives more difficult. Children with autism need careful attention all the time *(Cohrs et al., 2017).* Parents or the caregivers play an important role in supporting their children with autism. They take a primary role in delivering the intervention and in decision-making process. In addition, facing difficulties and unique daily stressors associated with their autistic children *(Al shekaili et al., 2019).*

In recent decades, the number of diagnosed cases of ASD has increased at a profound rate. It is unclear whether the incidence of autism has increased, or the rise in

numbers is due to a greater awareness of autism, and improvement in the accuracy of the diagnosis. The Centers for Disease Control and Prevention (CDC) estimated that 1.5% of children from UN member states (one in 68) had autism, as of 2014, a 30% rise over 2012. The new estimate represents a 15 percent increase in prevalence nationally to 1 in 59 children, and 1 in 54 children at 2020 also boys are four times more likely affected than girls to have it *(Center for Disease Control and Prevention, 2020.*

Autism affects all ethnic and socioeconomic groups. The definitive causes and risk factors for developing ASD are not clear. Researches indicate that genetics are involved in the vast majority of cases about 10%-20% cases related to Genetics. Other factors include environmental, nutritional, and immunological, also per-and post-natal predisposing factors play a role in pathophysiology of ASD *(Anne BA et al., 2020)*. Early detection of ASD is critical as early intervention leads to significant improvement in intellectual capability and behavioral performance of children with ASD *(Yousef AM et al., 2021)*

Caring for children with ASD is challenging, as these Children require a lot of time and energy. In addition, the caregivers face difficulties in dealing with the unusual behaviors of their child. They must teach their children basic life skills, protecting them from danger, improve their child capability of independency and teach them the way to communicate with others and preparing for their transition into adulthood *(Jenaro C et al., 2020)*

Caregiver burden is "a complex response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience"*(Kunkle R et al., 2020*) Due to this multidimensional requirement of caregiving, caregivers experience stress, misconceptions, feeling of guilt and self-blame regarding child's disorder. In addition, Caregivers face the daily challenge of trying to understand their child needs. Additionally, searching for new treatments, resources, and medical providers is stressful for the caregivers *(El Monshed AH et al., 2021)*.

Early detection of ASD is critical as early intervention leads to significant improvement in the intellectual capability and behavioral performance of children with ASD. One of the obstacles that face caregivers with autistic children is the social stigma, which affected by lack of knowledge and understanding of ASD, lack of special education and behavioral treatment, lack of governmental facilities, lack of trained staff and nurses *(Gabra RH et al.,2021)*.

Community health nurse should provide support and educates the autistic child, management of challenging behavior of the autistic child, counseling stress, reduce care burden and creating stability in the family, provide counseling about available rehabilitation services ,educational services and other social services for children with autism . In addition, direct the family to behavioral services specialists in autism. *(Pinto-Martin JA., et al 2005).*

Significance of the study:

Autism spectrum disorder is a universal problem. It places an enormous burden on the autistic child and on their caregivers. Raising public awareness about ASD has a positive influence on autistic children and their caregivers *(Arafa A et al., 2022).* Child with disability may require parents and their caregivers to seek educational and recreational accommodations to ensure that their child has equal opportunities with those children without a disability *Al-Dujaili AH et al., 2017.*

Aims of the study

The current study aimed to

Assess the burden experienced by caregivers of child with autism spectrum disorder in El-Beheira Governorate.

Research Question:

1 - What are burden perceived by caregivers of child with Autism Spectrum Disorder in El-Beheira governorate?

2 - How caregivers of child with Autism Spectrum Disorder adjust with their child in El-Beheira governorate?

MATERIALS AND METHOD

Materials:

Study Design:

A descriptive research design was used to carry out this study.

Setting:

The study was conducted at all governmental intellectual schools (Damanhour, Kafr El-dawar, Koum-hamada, El-mahmoudya, Etay El-baroud, Shubra-kheit intellectual schools) and private centers for autism coping and rehabilitation in El-Beheira governorate.

Subjects:

The subjects of this study was all caregivers with autistic children (father, mother, both of them, stepfather, stepmother, grandfather, grandmother) previously selected from the previous mentioned settings for conducting this study, who have Child with autism spectrum disorder only without other disorders and Caregivers willing to participate in the study.

Tools of the study:

Three tools were used to collect the required data

Tool I: Stressors of caregiver having Children with Autism Interview Schedule:

This tool was developed by the researchers after reviewing the recent literature review. This tool includes the following three parts:

Part I: Data related to the child: such as age, sex, and child order, age of diagnosis with Autism, other medical problems, level of child communication ,delayed or abnormal language ,pre occupation with repetitive , stereotyped behavior or, aggressive and challenging behavior of the child such as, harmful to himself or to others

Part II: caregivers' socio demographic data: such as age, family size, care giver relation to autistic child, level of education, and occupation, residence family income, parent's kinship, other siblings with ASD consanguinity.

Part III: Stressors of caregiver having child with autism: It consists of 38 items and measures six domains. **1-Physical stressors experienced by caregivers of autistic children: -** It consist of three items: Exhaustion from frequently waking up at night to check the child's status and satisfy his/her needs, sleeping disturbance, exhaustion and fatigue.**2-Psychological stressors**: consist of nine items as Feeling that day is heavy and long, guilt feeling, anger and nervousness, worry and fear without cause, sadness and want to cry, anhedonia. **3-Social stressors:** consist of nine items as Siblings' sadness because of their brother /sister suffering, siblings' sadness due to lack of visits and social relations, siblings' jealousy owing to extra care provided to the sick child .**4 Financial and community resources-related stressors:** It consists of four items as high cost of regular follow-up, high cost of medication, lack of resources and information that help in child's status .**5-Marital stressors:** it consists of six items bad relationship with husband, husband is not sympathetic, husband does not help in caring for the child. Moreover, mothers were blamed for child' status by husband .**6-Management-related stressors:** consist of seven items as repetition of the child admission to hospital, being with the child during medical examination and diagnostic tests. Additionally, unsatisfactory results of child's diagnostic tests, lack of nurse's interest in giving opportunity to express feeling. The score of stressors was transformed into categories as the following: (1) Low level of stressors; for those who had score% of less than 50% of the maximum score. (2) Moderate level of stressors; for those who had score% from 50 to less than 75% of the maximum score. (3) High level of stressors; for those who had score% of at least 75% of the maximum score.

Tool II: Caregiver burden scale: It consists of 22 items that reflect how a person feels when they were taking care of child with autism spectrum disorder. It includes the following items such as. Child asks for more help than he/she needs, no time for themselves, conflict between caring of child and responsibilities of family, embarrassed over your child's behavior, angry when present around your child's ,child's currently affects relationships with other family members .The scale for first twenty-one questions includes five categories of responses. (Never, Rarely, Sometimes, quite frequently, nearly always) rated 0 to 4, respectively). However, the last question i.e. Question number 22 include five response categories (not at all, a little, moderately, quite a bit, extremely) rated 0 to 4, respectively, the term "your relative" in Zarit Burden Interview was replaced by "your child" . The total score range from 0 to 88. A total score calculated by the sum of all the item scores and high scores indicate a higher level of burden. The level of burden was categorized according to the scores obtained by the caregivers and included: Little or no burden (zero – 21), Mild to moderate burden (21 – 40), Moderate to severe burden (41 – 60), (Severe burden (61 – 88). **Tool (III): caregivers Adjustment pattern scale Adapted to modify their child behavior.** . It was designed to measure parent functioning and adjustment to various types of physical, emotional, and social stressor. It consists of 20 statements includes; Telling stop to child as soon as I notice them misbehaving, when child does not do what they are told to do, i give in and do it myself, ignoring child's minor misbehavior deliberately, rewarding the child or fun activity for behaving well, following through with consequence (e.g take away a toy) when child misbehave, sending child to time-out (sit alone in quite place) when they misbehave The items of the scale were written in a four-point Likert scale as not at all (0) , sometime (1) good part of time (2), and most of time (3). Scores on the response scales will be reversed, summed and scaled to range from zero to 100. Score % = (the observed score/the maximum score) ×100. Low pattern of adjustment: for those who had score <50% of the maximum score. Moderate pattern of adjustment: for those who had score from 50 to <75% of the maximum score. High pattern of

adjustment: for those who had score ≥75 percentage of the maximum score

Methods:

The study was implemented according to the following steps:

Administrative process:

- An official letter from the Dean of faculty of Nursing, Damanhour University. It was directed to the head of central agency for public mobilization and statistics in Cairo governorate to obtain approval to collect necessary data from educational directorate in El-Beheira governorate. Obtain its cooperation for collecting necessary information about children with autism spectrum disorder in El-Beheira governorate to obtain approval for collecting the necessary data from the previously mentioned study setting to obtain their permission for conducting the study after explanation of research purpose.

- An Official letter was directed from educational directorate to the director of the selected schools and private centers in El-Beheira governorate.

Validity and reliability of study tools:

-Development of the tool (I) was done by the researcher based on extensive review of recent and relevant literature.

- Tool (II) was adopted and translated into Arabic.

- Tool (III) was adapted and translated into Arabic.

- Tools II, III were tested for content validity by a jury of 5 experts in community health nursing at Faculty of nursing, Damanhour University.

-The tools were revised, reconstructed, and made ready for use. The recommended modifications were done, and the final form was prepared after proving valid.

- Tools were checked for their reliability by test technique Cronbach' Alpha the results as

follows: tool (I) was 0.831, tool (II) was 0.850 and, tool (III) was 0.852.

Pilot study

- Was conducted on 10 caregivers having children with autism spectrum disorder from the previously mentioned settings (and they were included again to the selected sample). It was conducted to ascertain the relevance and content validity identify obstacle that might interfere with the process of data collection, and estimate the time needed to complete the tool. No modification was done after pilot study.

Collection of data:

- The data was collected individually by interviewing every caregiver of autistic children fulfilling the inclusion criteria attended with their children to intellectual schools in El-Beheira governorate. After a brief explanation of the purpose and the nature of the research.

- Establishment of trust relationship with caregivers of autistic children was the first step done before data collection.

- Each interview took approximately from 20-40 minutes.

- Data was collected over a period of 6 months (from September 2021 to March 2022).

Data processing and analysis:

The collected data was revised, categorized, coded, computerized, tabulated and analyzed using statistical package for social sciences (SPSS) version 18. The following statistical measures were used: analysis of categorical data cross tabulation with percentages were used to explore relationships between variables. Appropriate tests such as arithmetic mean, Pearson Correlation and Chi-square at 0.05 level of significance were used, Pearson chi-square test (p) is a statistical test applied for categorical data to determine weather data were significantly different from what was expected. ANOVA test (t) were used to test the significance of the results and to test association between more than two groups are to be compared.

Ethical considerations

- Ethical approval was obtained from ethical committee at faculty of nursing Damanhour University.
- Written consent from subjects was obtained.
- Securing the subject's informed written consent.
- Keeping subjects' privacy, right to withdrawal at any times as well as assuring confidentiality of their data.

Results:

Table (1) Distribution of the basic characteristic of autistic children:

This table shows the basic characteristics of the autistic children in which more than two thirds (68.2%) of them aged from eight to less than 14 years, while about one third (31.8%) of the autistic children aged from 6 to less than 8 with the mean of 9.92 ± 1.71 With respect to the sex of the autistic child. It can be observed that about more than two- thirds (68.2%) of the autistic children were male. Regarding the place of residence of the autistic children, majority (86%) of them were from rural area.

Table (2): Distribution of the studied caregivers of autistic children according to their basic characteristics:

It was observed from the table that, mothers were the caregivers in the majority (91.8%) of the studied sample .The age of caregivers, it was clear from the table that exactly half (50%) of studied caregivers aged more than 40 years. While less than half (40.9%) of studied sample their age ranged from 35 to less than 40 year. Level of education of studied caregivers of autistic children, nearly three quarters (73.6%) of them had secondary education, although (10%) of the studied caregiver had university education, about (11.8%) of them can read and write, only (4.6%) of studied caregiver were illiterate. Respectively to the caregiver's occupation , nearly three quarters (76.4%) of the caregivers were housewives/not works, about (8.2%) had professional job, also about (6.4%) of them had skillful job. The table also shows that, the majority of studied caregiver's (87.3%) stated that, their income wasn't enough, while only (12.7%) of them stated enough. In relation to the caregiver's

perspective about availability of autism health services, the table shows that, the majority (87.3%) of studied caregiver stated that it was moderately available, and who stated that it wasn't available more than one tenth (12.7%) of them.

Figure (1) Distribution of the studied caregivers according to their mean percent score of stressors domains. It represents the distribution of the studied caregivers' according to their mean percent score of stressors domain .It was observed from the figure that the highest mean percent of stressors domains was related to financial community stressors (98.58%) ,followed by Psychological stressors (81.41%) and physical stressors (81.33%) . However, the lowest mean percent score observed with social stressors. Moreover, the figure shows that the total percent score related to stressors domains was (80.52%).

Table (3) Relationship between the studied caregivers' levels of stressors and the caregivers' basic characteristics:

The table showed that about (69.3%) from caregivers who had high level of stressors was among mothers of the autistic children. A statistically significant difference was observed (X2=21.208, p= 0.000) between level of caregiver stressors and who was the caregiver of the child. Additionally the table clarified that about (100.0%) from the caregivers who aged 25 years had high level of caregiver's stressors. In relation to caregiver's education about (84.6%) from caregivers who had high level of caregivers stressors was among those can read and write. As regard to caregivers' occupation, the table showed that about (66.7%) from the caregivers had high level of stressors was among those who had no work.

Moreover, the table clarified that about (67.7%) from caregivers had high level of stressors was among those who had not enough income. A statistically significant difference was observed (X2=7.848, p= 0.020) between level of caregivers stressors and caregivers' income. Regarding to caregivers perspective about availability of autism health services the table revealed that, about (85.7%) from caregivers had high level of stressors was among those who reported unavailable autism health services

Table (4) Distribution of the studied caregivers according to the level and mean score of their burden:

The table represents that the majority (97.3%) of studied caregivers had high level of burden, while less than three percent (2.7%) of them had moderate level of burden with mean score (73.70±7.562) and their mean percent score equal (83.75%). **Table (5)** Relationship between the studied caregivers' mean score of burden and the caregivers' basic characteristics:

The table portrays that there was a statistically significant difference was observed between mean score of caregivers burden and who is the caregiver of the child (F=12.486, p= 0.000), in which the mean score of caregiver burden increased among mothers (74.56±6.064). Additionally, there was a statistically significant difference was observed between mean score of caregivers burden and the age of caregivers (F=3.213, p= 0.026), the mean score of caregivers burden increased among caregivers aged from 25 to less than 30 years (83.50±2.121).

Although there was no statistically significant difference was observed between mean score of caregivers burden and the caregivers education (F=1.437, p= 0.236), but the mean score of caregivers burden increased among illiterate caregivers (80.00±3.317). Moreover, the tables shows that there was a statistically significant difference was observed between mean score of caregivers burden and the caregivers occupation (F=5.233, p= 0.002). However, the mean score of caregivers burden increased among caregivers had not work (74.13±6.267).

Regarding to mean score of caregivers burden and caregivers income there was no statistically significant difference was observed between (t=0.198, p= 0.657) .While the mean score of caregivers burden increased among care givers stated that their income not enough(73.82±6.698). The table also shows that there was a statistically significant difference was observed between mean score of caregivers burden and caregivers perspective about availability of autism health services) (t=9.169, p= 0.003), the mean score of caregivers burden increased among caregivers stated that, autism health services not available (79.21±6.518).

Table (6) Distribution of the studied caregivers according to the level and mean score of their adjustment: The table demonstrates that more than three quarters of caregivers (76.4%) recorded that they have moderate level of adjustment, while nearly one quarter (23.6%) of

them had high level of adjustment with mean score equal (35.68±6.888), and mean percent score present was (59.47%). **Table (7)** Relationship between the studied caregivers' mean score of adjustment and the caregivers' basic characteristics:

The table clarifies that there was no statistically significant difference was observed between mean score of caregivers adjustment and caregivers of the child (f=1.199, p=0.305). Whoever the mean score of caregiver's adjustment is highest among mothers (35.98±6.91. A statistically significant difference was observed between mean score of caregivers adjustment and caregivers age (f=6.836, p=0.000). While the mean score of caregivers adjustment increased among those age 25 years to less than 30 years (52.00±1.414). The table represents that there was no statistically significant difference was observed between mean score of caregiver's adjustment and caregiver's education, caregiver's occupation, caregiver's income(f =1.398, p=0.248),(f= 0.959, p =0.415),(t =0.720, p =.378). A statistically significant difference was observed between mean

score of caregivers adjustment and caregivers perspective about availability of autism health services (t=20.524, p=0.000) .However, the mean score of caregivers adjustment increased among those stated not available autism health services (42.86±7.735).

Table (8).Correlation Matrix between the studied caregivers' stressors, burden and adjustment:

The table represents that there was a statistically significant Correlation was observed between caregivers stress and caregivers burden(r=0.694, p= 0.000). It is clear from the table that there was a statistically significant Correlation was observed between caregivers stress and caregivers adjustment(r=0.493, p=0.000). Finally the table shows that there was a statistically significant Correlation was observed between caregivers burden and caregivers adjustment (r=0.638, p=0.000).

Table (1): Distribution of the basic characteristic of autistic children (n=110).

Autistic Children's characteristics		Total N=110	
		No.	%
Age (years)			
▪ 6-		10	9.1
▪ 8-		25	22.7
▪ 10		63	57.3
▪ 12-<14		12	10.9
Min- Max 6.0-13.0	Mean ± SD 9.92 ± 1.71		
Sex			
▪ Male		75	68.2
▪ Female		35	31.8
Place of birth			
▪ Rural		86	78.2
▪ Urban		24	21.8
Birth order			
▪ First		46	41.8
▪ Second		31	28.2
▪ Third		25	22.7
▪ Fourth and more		8	7.3
Presence of sibling			
▪ No		9	8.2
▪ Yes #		101	91.8
- Brothers		76	75.2
- Sisters		25	16.6

Table (2): Distribution of the studied caregivers of autistic children according to their basic characteristics (n=110).

Items	Total N=110	
	No.	%
Caregiver of the child		
▪ Father	7	6.4
▪ Mother	101	91.8
▪ Grandmother	2	1.8
Caregiver's age (years)		
▪ 25-	2	1.8
▪ 30-	8	7.3
▪ 35-	45	40.9
▪ ≥40	55	50.0
Caregiver's education		
▪ Illiterate	5	4.6
▪ Read and write	13	11.8
▪ secondary education	81	73.6
▪ University education	11	10.0
Caregiver's occupation		
▪ Professional job	9	8.2
▪ Skillful/literal job	7	6.4
▪ Free business	10	9.1
▪ No work/ retirement	84	76.4
Caregiver's income		
▪ Enough	14	12.7
▪ Not enough	96	87.3
Caregiver's perspective about availability of autism health services		
▪ Not available	14	12.7
▪ Moderately available	96	87.3

Figure (1): Distribution of the studied caregivers according to their mean　　percent score of stressors domains .
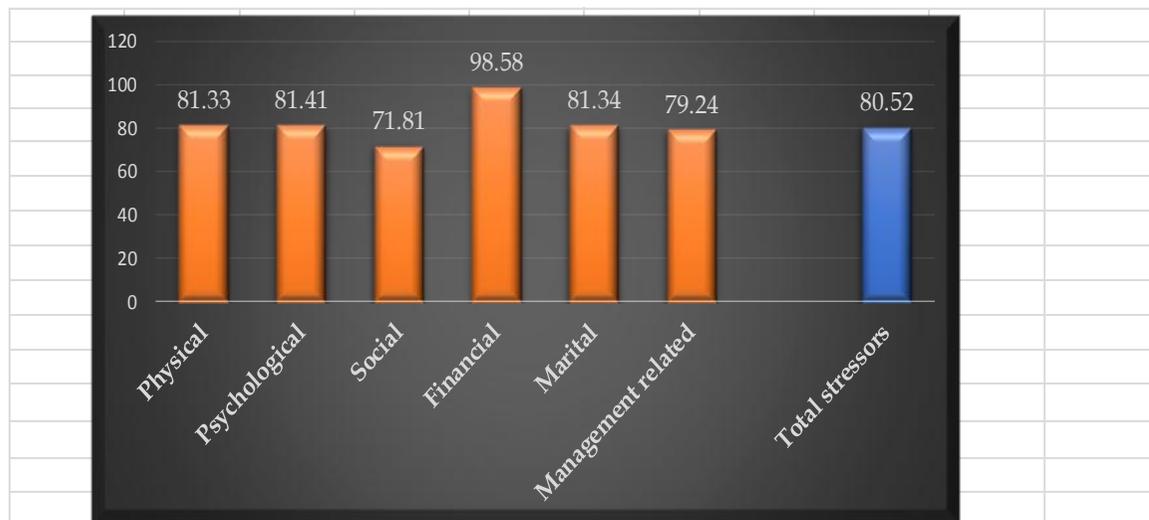
Table (3): Relationship between the studied caregivers' levels of stressors and the caregivers' basic characteristics (n=110).

Items	Level of Caregiver's Stressors						Total N=110		Test of significance
	Low (N= 1)		Moderate (N= 37)		High (N= 72)				
	No.	%	No.	%	No.	%	No.	%	
Caregiver of the child									
▪ Father	1	14.3	5	71.4	1	14.3	7	6.4	**X²=21.208**
▪ Mother	0	0.0	31	30.7	70	**69.3**	101	91.8	**p= 0.000***
▪ Grandmother	0	0.0	1	50.0	1	50.0	2	1.8	
Caregiver's age (years)									
▪ 25-	0	0.0	0	0.0	2	**100.0**	2	1.8	X²=2.153
▪ 30-	0	0.0	3	37.5	5	62.5	8	7.3	p= 0.905
▪ 35-	0	0.0	16	35.6	29	64.4	45	40.9	
▪ ≥40	1	1.8	18	32.7	36	65.5	55	50.0	
Caregiver's education									
▪ Illiterate	0	0.0	1	20.0	4	80.0	5	4.5	X²=12.034
▪ Read and write	0	0.0	2	15.4	11	**84.6**	13	11.8	p= 0.061
▪ Intermediate education	0	0.0	30	37.0	51	63.0	81	73.6	
▪ University education	1	9.1	4	36.4	6	54.6	11	10.0	
Caregiver's occupation									
▪ Working	1	3.8	9	34.6	16	61.5	26	23.6	X²=3.320
▪ No work/ retirement	0	0.0	28	33.3	56	**66.7**	84	76.4	p= 0.190
Caregiver's income									
▪ Enough	1	7.1	6	42.9	7	50.0	14	12.7	**X²=7.848**
▪ Not enough	0	0.0	31	32.3	65	**67.7**	96	87.3	**p= 0.020***
Caregiver's perspective about availability of autism health services									
▪ Not available	0	0.0	2	14.3	12	**85.7**	14	12.7	X²=2.938
▪ Moderately available	1	1.0	35	36.5	60	62.5	96	87.3	p= 0.230

X² Chi Square Test   * statistically significant at p ≤ 0.05

Table (4) : Distribution of the studied caregivers according to the level and mean score of their burden (n= 110).

Items	Low		Moderate		High	
	No.	%	No.	%	No.	%
▪ **Levels of Caregiver's Burden**	0	0.0	3	2.7	107	97.3
▪ Min - Max			34.0-88.0			
▪ **Mean ± SD**			73.70±7.562			
▪ **Mean Percent Score**			83.75%			

Table (5) :Relationship between the studied caregivers' mean score of burden and the caregivers' basic characteristics(n= 110).

Items	Mean Score of Caregivers' burden Mean ±S.D	Test of Significance
Who is the caregiver of the child		
▪ Father	61.14±15.14	**F=12.486**
▪ Mother	**74.56±6.064**	**P= 0.000***
▪ Grandmother	74.00±1.414	
Caregiver's age (years)		
▪ 25-	**83.50±2.121**	**F=3.213**
▪ 30-	77.38±5.854	**P= 0.026***
▪ 35-	74.76±5.721	
▪ ≥40	71.95±8.638	
Caregiver's education		
▪ Illiterate	**80.00±3.317**	F=1.437
▪ Read and write	74.15±7.128	P= 0.236
▪ secondary education	73.49±6.539	
▪ University education	71.82±13.84	
Caregiver's occupation		
▪ Working	63.57±6.882	**F=5.233**
▪ No work/ retirement	**74.13±6.267**	**p= 0.002***
Caregiver's income		
▪ Enough	72.86±12.28	t=0.198
▪ Not enough	**73.82±6.698**	P= 0.657
Caregiver's perspective about availability of autism health services		
▪ Not available	**79.21±6.518**	**t=9.169**
▪ Moderately available	72.90±7.393	**P= 0.003***

F ANOVA Test   t Student T test   ***** statistically significant at p ≤ 0.05

Table (6): Distribution of the studied caregivers according to the level and mean score of their adjustment (n . 110).

Items	Low		Moderate		High	
	No.	%	No.	%	No.	%
▪ **Levels of Caregiver's Adjustment**	0	0.0	84	76.4	26	23.6
▪ **Min - Max**			24.0-54.0			
▪ **Mean ± SD**			35.68±6.888			
▪ **Mean Percent Score**			59.47%			

Table (7) Relationship between the studied caregivers' mean score of adjustment and the caregivers' basic characteristics.(n .110).

F ANOVA Test   t Student T test   * statistically significant at p ≤ 0.05

Items	Mean Score of Caregivers' Adjustment Mean ±S.D	Test of Significance
Caregiver of the child		
▪ Father	32.00±4.041	F=1.199
▪ Mother	**35.98±6.914**	P= 0.305
▪ Grandmother	33.50±13.43	
Caregiver's age (years)		
▪ 25-	**52.00±1.414**	**F=6.836**
▪ 30-	40.00±7.892	**P= 0.000***
▪ 35-	36.18±6.132	
▪ ≥40	34.05±6.442	
Caregiver's education		
▪ Illiterate	**40.80±12.15**	F=1.398
▪ Read and write	35.31±7.181	P= 0.248
▪ secondary education	35.16±6.703	
▪ University education	37.64±4.130	
Caregiver's occupation		
▪ Working	35.53±4.457	F=0.959
▪ No work/ retirement	**35.64±7.275**	P= 0.415
Caregiver's income		
▪ Enough	**37.14±4.504**	t=0.720
▪ Not enough	35.47±7.163	P= 0.398
Caregiver's perspective about availability of autism health services		
▪ Not available	**42.86±7.735**	**t=20.524**
▪ Moderately available	34.64±6.129	**P= 0.000***

Table (8) : Correlation Matrix between the studied caregivers' stressors, burden and adjustment.

		Caregivers' stress	Caregivers' burden
Caregivers' stress	r		
	P		
Caregivers' burden	r	**0.694**	
	P	**0.000***	
Caregivers' adjustment	r	**0.493**	**0.638**
	P	**0.000***	**0.000***

r= Pearson Correlation   * Correlation is significant at p ≤ 0.05
r ≥0.9 very high correlation   r 0.7-<0.9 high correlation   r 0.5-<0.7 moderate correlation   r < 0.5 low correlation

Discussion

The current study revealed that, the majority of caregivers were mothers. This finding as in line with a lot of studies revealed same results, as *(El Monshed et al, 2020 ;Al-Nazly E K et al ,2019; Lerthttasilp T et al ,2015)* Mothers of autistic children spend more time and effort on daily duties to meet the high care demands, as well, managing ASD challenging behavior. In contrary, the finding of

study done in Egypt by *Mansour E, 2021* found that, just over half of Egyptian caregivers of autistic children were men and almost half of them were women.

In the current study, autism health services were limited as reported by the caregivers. These findings were congruent with studies conducted by *Papoudi D et al, 2020 ; Gobrial E et al., 2019, Farg A et al, 2018* reported that, the majority of caregivers emphasized that, services were extremely

limited, or that they were only available in private clinics and caregivers are required to pay themselves for specific treatments offered in private clinics especially caregivers with low socioeconomic status have limited access to healthcare services. Also, the current study clarified that, majority of caregivers' income was not enough. This result was in agreement with studies done in Kenya *by Masaba BB et al, 2021 ;Al Masa'deh MM et al 2021; Papadopoulos D 2021* who revealed that, more than three quarters of caregivers had insufficient income.

The findings of the current study showed that, about three quarters of caregivers had secondary education .While about one tenth of them had university education. This result in harmony with studies as *Al-Malki NS ,2021; El-Awady et al, 2019 ;pandey S & Sharma C 2018* revealed that, nearly half of caregivers had secondary education . In the other hand this findings disagreed with study done in Iraq by *Al –Dujaili AH et al, 2017* which portrayed that, less than half of study sample had high level of education.

The current study revealed that more than three quarters of studied caregivers with autistic children had high level of physical stressors. This results agreed with *Mohammad F et al 2022 ,Shattnawi et al, 2021 , and Ezzat O et al, 2017* which revealed that more than two thirds from caregivers had high level of physical stressors .

The current study proves that nearly half of the studied sample had high level of social stressors. This result consistent with studies carried out by *Al Qahtani F et al ,2018 , Lotfy OM et al ,2018)   and DePape D et al, 2014* ,which indicates that more than two thirds from caregivers with ASD children felt socially isolated as they didn't engage in social activities and kept their ASD children at home . Despite the current findings indicated social stigma among caregivers of children with ASD. In contrast with these findings a study done by *Sidig E A et al ,2022* study done in Egypt by *Gobrial E 2015* showed positive societal attitudes towards children with ASD in Egypt and in Sudan.

The findings of the current study proved that all the caregivers had high level of financial stressors. These finding in harmony with studies done by *Adib NA et al ,2019 ; Al Shalakani M et al ,2019)⁾ ; Gobrial E et al ,2018 ;Al-Farsi et al ,2016* and *Ou JJ et al ,2015* which revealed that ,the majority of studied samples had financial problems.

The present study clarified that, caregivers with autistic children diagnosed with ASD after age 6   had a significant effect on caregivers' level of stressors, which increased respectively with age at diagnosis with ASD. This result confirmed by study done by *Rodriguez et al, 2019 and Rayan et al., 2016* which indicted that level of caregivers stressors increased when autistic children diagnosed with ASD from 10 years to 13 years.

The findings of the current study clarified that, majority of caregiver had high level of burden, this result agreed *with Christina N et el, 2021;Al Shahrani MS et al ,2021 and Picardi A et al ,2018* which revealed that more than three quarters from mothers with autistic children experienced high level of burden , due to long-term challenges associated with ASD and child care demands .

The present study results proved that , caregiver burden had a significant association with the caregivers' occupation , housewives caregivers had insufficient income which increase their level of burden, this result agreed with *Lamba et al ,2022 and   Ibrahim N et al ,2020* which revealed that, more than three quarters were from caregivers who had high level of burden were housewives with insufficient income . In contrast with *Christina N et al, 202*1 revealed that more than three quarters of caregivers were working.

The findings of the current study proved that, level of caregivers burden had a significant association with availability of autism health services, caregivers experienced high level of burden due lack of needed services .This result agreed with *Prata J et al ,2019 ;Gobrial E et al., 2019 ,and Rayan A et al ,2016* revealed the same result.

The current study revealed that, more than three quarters of studied caregiver had moderate level of adjustment with mean percent score (59.47%), this result agreed with *Shattnawi KK et al ,2021 and Achour et al ,2016* which revealed that nearly half from studied samples had moderate level of adjustment . On the other hand, study carried out by *Cetinbakis G et al, 2020 and Akram B et al, 2019* indicated that more than three quarters from studied caregivers had low level of adjustment.

The results of present study revealed that advanced age of caregivers especially mothers experienced moderate level of adjustment. Moreover, once the caregiver understand the child condition, support from extended family and child with ASD received available health and educational services the caregivers develop adjustment skills to have new perspective in their lives. This result consistent with study done in Saudi Arabia by *Khusaifan S et al, 2022,* also*, Iadarola et al, 2019 and Mostafa MH, 2019* revealed that, mothers aged from 35 to 45 with autistic child had moderate level of adjustment, as well as, caregivers were trying to educate and empower themselves to help their children and implementing coping strategies at home. Additionally, the extended family showed empathy and provide positive social support towards their family member with ASD, help and support to care for the child With ASD.

The result of current study demonstrated that, caregiver burden had a significant correlation with caregivers' stress and caregivers' adjustment. Caregivers experienced high level of stressor with moderate level of adjustment had high level of burden. This result in line with study done in Bangladesh by *Naheed A et al, 2019;* also *Cloete et al ,2015* revealed that, caregivers of autistic children encountered high level of stress and high level of burden had to manage their burden to overcome the constant challenges and adapt with their life.

The results of current study revealed that, level of burden experienced by studied caregivers had a significant association with stressors they facing through their journey with their children with ASD ; about more than two thirds of caregivers who had high level of stressors, had high level of burden. Moreover, more than half of caregivers who had high level of stressors had moderate level of adjustment. This finding agreed with many studies as *Shattanwi KK et al,2022 ; Selvakumar N et al ,2020 ; Khusaifan S et al ,2020 and study in Egypt by Omar T et al,2017* reported that caregivers experienced high level of stressors and burden can adapt and adjust with their live moderately, especially in Muslims society, they consider a sick child is a gift from God, and they should accept their destiny and the new life with ASD.

In contrary for this result a study done in turkey by *Cetinbakis G et al, 2020 and Kartini I et al, 2017* revealed that, caregivers had high level of burden with low level of adjustment ,this difference between results may be due to difference in religious and socio cultural difference between regions.

Conclusion

Based on the findings of the present study, it could be concluded that:

- The majority (91.8%) of studied caregivers were mothers, (100.0%) from caregiver had high level of financial stressors .Nearly three quarters (74.6%) of them had high level of physical and psychological stressors. Thus (97.3%) from caregivers had high level of burden with mean percent score (83.75%).Moreover, (76.4) from caregivers had moderate level of adjustment. High correlation (r = 0.694).between caregiver stressors and caregivers burden, also high correlation (r = 0.638) between level of caregivers burden and their level of adjustment. Furthermore, there were number of factors which play a significant role such as age of the child at diagnosis with ASD, age of the caregivers, level of caregivers education, caregivers financial status , place of residence, availability of autism health services, presence of other family member with ASD and social support services..

Recommendations

Based on the current study findings the following recommendations are proposed:

1.Conduct health education campaigns in rural & urban areas about early sign and symptoms of ASD and benefits that result from early identification of sign and symptoms of ASD.

2.Early case finding & screening of early sign and symptoms of autism spectrum disorder cases.

3.Assign trained health care providers to provide continuous care for the autistic child, and help the caregivers to cope with the child's condition.

4.Develop guidelines for nurse's role with autistic child and with their caregivers in primary health care settings.

5.Encourage small projects and provide opportunity for housewives to increase their income to help them in expensive treatment and the lifelong process of coping with autism.

6.Provide opportunities for disadvantaged and less educated women to empower themselves, by developing & implementing progress that increase their access microfinance and informal education.

7.Caregiver's education programs through media and press should be developed for mothers of children with ASD to help those who experience high levels of stress and burden by presenting knowledge about ASD treatment and training on adaptive coping methods and teaching communication and problem solving.

Ethical approval and consent to participate

The Ethics Committee of the Faculty of Nursing, Damanhour University approved this study.

Consent for publication

Informed consent has been obtained from all the participants.

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Conflict of interest

The authors declare no conflict of interest or otherwise.

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