# **Relation between Care Burden, Depression and Suicide Risk among Family Caregivers of Children with Autism Spectrum Disorder**

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### Abstract

Background: Autism spectrum disorder (ASD) is among the greatest tough circumstances for family caregivers to intervene with and give attention. The situation described above results in burden, depression, in addition to suicide risk among the caregivers. Aim: This study was created with the intention of assessing the relation between care burden, depression and suicide risk among family caregivers of children with ASD. Research design: A descriptive correlational research design was applied. Sample: A purposive sample of 60 family caregivers of children with ASD were selected from Minia Hospital for Mental Health and Addiction Treatment's children and adolescent outpatient clinic in Minia governorate. Tools: Sociodemographic questionnaire including (Data related to family caregivers & data related to the child), Zarit Caregiver Burden Interview, Beck Depression Inventory BDI-II and Frequency of Suicidal Ideation Inventory were utilized. **Results:** The mean age of family caregivers is  $37.4\pm7.4$ , about 61.7% of respondents are mothers and most of autistic children (81.7) are boys. 75% of studied family caregivers suffer from moderate to severe level of burden, more than half of the sample have moderate depression, also, moderate and high frequency of suicidal ideation among the participants are represented by 11.7 & 6.7% respectively. Conclusion: A significant positive correlation between family caregivers' burden with both depression and frequency of suicide ideation is found as well as a strong significant positive correlation is indicated between depression and frequency of suicide ideation among samples studied. Recommendations: Develop comprehensive support systems to better assist family caregivers in reducing burdens, managing their multifaceted responsibilities and well understanding of all risk factors that can lead to depression and suicide.

Keywords: Autism spectrum disorder, Care burden, Depression, Family caregivers, Suicide risk Introduction

The Diagnostic and Statistical Manual (DSM-5)of the American Psychiatric Association is currently in its fifth version offers a precise definition and standardized criteria for autism spectrum disorder (ASD) diagnosing. The disorder is a condition affecting neurological development in which abnormal sensory responses that set it apart from other disorders, limited and repetitive and behaviors. interests and socialcommunication deficits. Individuals with ASD may exhibit difficulty establishing or reacting to interactions with people, difficulty using gestures or keeping eye contact, repetitive motor movements, difficulty transitioning from one activity to another, difficulty switching between activities, or excessively intense focus on a particular interest. The diagnosis might not be made until much later, even if these characteristics may be recognized in the early stages of development (American Psychiatric Association APA, 2013).

"Autism spectrum disorder" (ASD) refers to a collection of neurodevelopmental diseases that are typified by limited/repetitive behavior ongoing and interest, early onset and impairment in social interaction, and communication (David, 2021 and Warrier et al., 2020). Though no clear clinical nor behavioral indicators for ASD have been found in children younger than a year, the autism diagnosis is often verified between 18 and 24 months. when its symptoms may be differentiated from those of other developmental problems (Okoye et al., 2023).

ASD is brought on by a confluence of environmental and hereditary variables, while the precise reasons and risk factors included are yet unknown. ASD is thought to affect three to six out of every 1,000 children under the age of sixteen worldwide, with males being four times

more likely to have it. According to the Ministry of Social Solidarity, 800,000 Egyptian youngsters were expected to have autism in 2017. Signs of this mental illness are present in one out of every 160 children (Masr, 2017). Autism affects all ethnic and socioeconomic groups. Research indicate that 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. Early detection of ASD is critical as early intervention significantly improves intellectual capability and behavioral performance of children with ASD (Yousef et al., 2021).

Because autism is a chronic and diverse disorder with a wide range of potential cooccurring illnesses, caring for children with an ASD diagnosis can be risque (Alibekova et al., 2022). Families raising a child diagnosed ASD face difficulties because of the child's inadequate socialization and communication skills. insufficient self-care capacity in everyday life and social hurdles including a lack of additional support resources and insufficient school system services to meet needs (Ho et al., 2018). Parents of autistic children are always looking for assistance from various sources and professionals to meet their requirements because of children's the condition's complexity and the dearth of evidence-based treatment choices (An et al., 2020 and Srinivasan et al., 2021).

A family caregiver is someone who has an extremely strong emotional bond with those receiving care; those persons possibly are a relatives of the affected individual and are typically near people who help and look after without expecting payment or reward (Toledano-Toledano & Dominguez-Guedea 2019). The primary caregiver for people with ASD is their family. Most persons who care for those with ASD are women, especially moms. The study on caregivers has also uncovered that women report more burdens and have poorer mental health than males (Herrero, et al., 2024).

Caregivers of relatives with ASD who require support and care because of concurrent diseases and autistic symptoms face two distinct problems. Firstly, the challenges such ASD caregivers encounter while trying to get training, education, and medical care for their autistic family members, secondly, social, financial, and also emotional challenges the family members expertise while administering care for patients with ASD, where burden and mental health play crucial parts (Appah et al., **2024**). Caregivers are responsible for providing care, as is well known. However, the numerous restrictions of people with ASD mav necessitate exhaustive, ongoing care, requiring the caregivers to devote a significant amount of spare time to caring for such children. Family caregivers' physical and emotional health will be forced to bear a disproportionately heavier burden as a result. (Zohari Anboohi et al., 2023). So, families that have a child with ASD face a significant emotional, financial, and physical care burden (Metwally et al., 2023).

Autism spectrum disorder is a universal problem. It places an enormous burden on the autistic child and on their caregivers (Ragab et al., 2023). Caregivers of ASD child defiantly bear a heavy caregiving burden. Research on families with ASD has identified comorbidity, lack of social support, degree of disability, length of disease, and symptom severity as key predictors of family burden. (Marsack-Topolewski et al., 2021). The load or stress that a person who provides care for a family member diagnosed with chronic illness is being pointed to as "care burden." As reported by Ezzat et al., (2017). Complicated reactions to the financial, psychological, physical, and social challenges faced by those providing care is known as a caregiver burden (Kunkle et al., 2020). Because of the multifaceted nature of caregiving, family caregivers face regular struggles of trying to understand their sick child's needs. Also, searching for new treatments, resources, and medical providers is stressful for the caregivers (El Monshed et al., 2021).

Around five percent of the population are suffering from depression, ranking it among the most prevalent mental health issues (World Health Organization WHO, 2023). Also, it contributes significantly to the global disease burden and is a major contributing factor leading towards disability globally. Sadness, impatience, an extreme feeling guilty, a sense of worthlessness or emptiness, feeling despair over the future, loss of interest, or even suicide are characteristics of depression, which differs from normal mood swings. (Xia et al., 2023). Likewise, a significant number of parental autism caregivers withstand anxiety and depression (Warreman et al., 2023).

Because of the high demand for care and the scarcity of resources, caregivers for people with ASD are susceptible to mental health troubles, especially depression. Compared to parents of typical children, parents of children with ASD are 2.77 times more probable to face a depression diagnosis. (Cohrs & Leslie, 2017). In addition, Padden & James (2017) provide evidence that the most frequent mental health issues the caregivers of autism children reported were depression symptoms. Family caregivers' depression sometimes includes major depressive disorder (MDD), which is the prevalent mental disorder marked by persistent hopelessness or sadness feelings and a decline in enthusiasm in once-enjoyed tasks. However, it's possible that caregivers exhibit behavioral, psychological, and physical signs of depression that fail to fit the criteria for major depression (MDD), like feelings of inadequacy or guilt, difficulty concentrating, indecision, fatigue, and changes regarding dietary habits or weight. (APA, 2013).

Taking into account, the term "suicidal ideation" describes the thinking, and planning, about suicide. Experts have proposed adding suicidal behavior as a condition with a distinct diagnosis in the (DSM-5) due to the growing prevalence and severity of the suicide problem (Oliogu & Ruocco, 2024). Every year, more than 700,000 people lose their lives to suicide, not including the number of suicides attempts that probably happen but are not documented (WHO, 2021).

According to research, women are more likely to suffer from mild to moderate psychological distress as well as the negative impacts of the caregiving burden, this in turn may lead them towards suicidal ideation (Akram et al., 2019). Mothers of children with certain needs may experience feelings of depression and anxiety because of an apparent burden and the absence of support from others, which may further contribute to suicidal thoughts. (Joling et al., 2018).

# Significance of the study:

ASD has become much increasingly common over the last two decades; according to a 2018 Centers for Disease Control and Prevention (CDC) report, about one out of every fifty-nine children have ASD. That percentage has been raised to be one out of forty-four children globally in 2020, and males are four times as likely than girls to be impacted (CDC, 2020). The determined autism prevalence has been raised obviously over the past 20 years, from 0.48 to 3.13 percent, according to the most recent statistics from both the United States and Europe (Micai et al., 2021). Even yet, ASD is commonly misdiagnosed or underdiagnosed in Egypt (Alallawi et al., 2020), existing research were suggesting that ASD is a prevalent disorder in it. Some recent research displayed that the prevalence of ASD varies greatly, ranging from 5.4/1000 to 33.6%. (Yousef et al., 2021).

High prevalence of burden faced by the caregivers of children with ASD was reported in Egyptian recent research which illustrated that 97.3 percent of the participants has the average percent score of 83.75%, indicating a significant level of burden (Ragab et al., 2023). Caregivers with severe burden significantly had higher depression (Gabra et al., 2021). A significant positive relationship between care burden and suicidal ideation is documented in study findings achieved by Akram et al., (2019) which revealed that burden of care positively affected suicidal ideation. Besides, Liu et al., (2020) proved that having a high risk of depression, ASD family caregivers are more likely to experience exhaustion, poorer care quality, motivational decline, and even suicidal thoughts and actions.

Burden in family caregivers of children with ASD is among the most important and public obstacles which negatively affect an individual's mental health issue that represented in many troubles as stress, anxiety, disturbed quality of life, depression symptoms or disorder, and suicidal behavior. Moreover, there is minimal, or no concern on the health of family caregivers of ASD children and the risk for suicidal thoughts in textbooks. Research in Egypt was restricted to confined regions, and with a restricted sample size: thus, the current study planned to investigate relation between care burden, depression and suicide risk among those members who look after children with autism spectrum disorder (ASD) in their families.

## Aim of the Study

The aim of the current study is to assess the relation between care burden, depression and suicide risk among family caregivers of children with autism spectrum disorder.

## **Research** questions

- 1- What are the levels of care burden, depression and suicide risk among those who care for children with ASD in their families?
- 2- Is there a relation between care burden, depression and suicide risk among those who care for children with ASD in their families?

## **Patients and Method**

## **Research Design:**

A descriptive correlational research design was applied to reach the aim of the current study.

## Setting:

The research study was executed at "Minia Hospital for Mental Health and Addiction Treatment's children and adolescent outpatient clinic" which is connected to the Ministry of Health and in the city of New Minia, Upper Egypt. The outpatient clinic received cases from nine a.m. to two p.m. on Monday and Wednesday. It covers all nine regions of the Minia governorate.

## Study subjects:

A purposive sample of 60 family caregivers who look after youngers with ASD was selected from the previously mentioned settings for getting involved in this study and met the inclusion criteria. The sample size is determined according to **Issac and Michael** (1995) formula as (N=  $n \times 30 / 100$ ). Total annual attendance of children with ASD in 2023 to outpatient clinic of "Minia Hospital for Mental Health and Addiction Treatment" was 167 children.

### Inclusion criteria:

- Family caregivers over 18 years of age caring for a child diagnosed with ASD only without other disorders.
- Children with ASD aged from 6 to 12 years with illness duration not less than one year.
- Family caregivers who are enthusiastic about taking part in the study.

### **Data Collection Tools:**

Information was gathered using the following instruments:

### **Tool I: Sociodemographic questionnaire:**

The sociodemographic questionnaire was divided into two parts:

### Part 1: Data related to family caregivers:

This part was comprised of questions on the following variables: age, relation of the caregiver to child, residence, education levels, marital status, work status, monthly income, and another child with disability in family.

### Part 2: Data related to the child:

This part covered characteristics of children as: age, gender, child order and onset of disorder.

# Tool II: Zarit Caregiver Burden Interview (ZBI):

Zarit et al., (1980) developed the Zarit Caregiver Burden Interview (ZBI) in an English language and Arabic version was done by researchers. It evaluates how social life, socioeconomic status, the caregiver-disabled connection, and psychological well-being all affect. Five response possibilities on a Likerttype scale, in which points are: never: 0, seldom: 1, occasionally: 2, often: 3, and almost often: 4 points is used to evaluate the 22 items on this self-administered test. Greater caregiver burden is indicated by higher ratings. Sufficient evidence of validity and reliability has been documented in various languages and nations. The level of caregiver burden shown on the **ZBI** is little or no burden is represented by a score of 0-20, mild to moderate burden by a score of 21-40, moderate to severe burden by a score of 41-60, and severe burden by a score of 61-88.

## Tool III: Beck Depression Inventory BDI-II:

The Beck Depression Inventory (BDI), an individual rating tool with 21 items, is used to evaluate the aspects and hallmarks of depression. The BDI assesses suicidal thoughts, mood, despair, a sense of failure, self-dissatisfaction, guilt, punishment, self-dislike, self-accusation, impatience, social disengagement, body image, work-related challenges. sleeplessness. exhaustion, appetite, weight loss, loss of libido and obsession with the body through individual questions. The score was between 0 and 3 points. A high level of depression is indicated by an elevated score. For instance, scores between 0 and 9 represent minor depression, 10 to 18 suggest mild depression, 19 to 29 reflect moderate depression, and 30 to 63 signify severe depression. 3 (Beck, et al., 1996).

## Tool IV: Frequency of Suicidal Ideation Inventory (FSII):

This tool was adopted by Chang & Chang (2016) who established the FSII, or Frequency of Suicidal Ideation Inventory. The frequency of suicidal thoughts during the previous 12 months was evaluated with five items using a 5-point rating, with 1 denoting never and 5 representing nearly daily. Higher scores signify a higher frequency of suicidal thoughts. The total score goes from 5 to 25. A total item score has summed includes scores ranging from 5 to 25, where higher numbers indicate a higher frequency of suicidal thoughts. The overall scores are categorized as low suicidal ideation frequency when the score was ranged as 5-14; moderate suicidal ideation frequency considered when the score was 15-19 and finally, high suicidal ideation frequency counted when the score was 20-25.

# Validity and Reliability

A panel of five specialists from Psychiatric and Mental Health Nursing domain assessed the study tools' content validity. The statements were comprehensiveness, reviewed for item sequencing, clarity, relevance, format, and applicability. The content of the tools was valid and pertinent to the research aim based on the opinion of all jury members. The researchers employed the test-retest approach to measure internal consistency to ascertain the research tools' reliability. The Cronbach's alpha-coefficient test had been used to contrast repeated test responses. Internal consistency of ZBI, BDI-II and FSII was estimated through the application of Cronbach's alpha coefficients test and resulted in values of 0.89, 0.90, and 0.89 respectively, that mean excellent reliability.

## Procedures

To choose the best instruments for measuring the study variables, it was necessary to review the existing and previous relevant literature utilizing recent publications on the different facets of the research, journals, and online resources which help get a clear picture of the topic and familiarize alongside the research problem. Data were collected through interviewing studied family caregivers at outpatient clinic for two days a week (Monday and Wednesday from nine am to two pm.) over a period of six months from December 2023 to May 2024. During these meetings before giving out the pre developed study questionnaires, the researchers introduced themselves to each of the study sample, after that gave an introduction, went over the aim of the study, and the tools' items. Participants who could read and write selffilled out the tools, however the researchers completed the forms for the caregivers who couldn't after asking them. The duration taken filling out the study substances differed from 25 to 35 minutes, depending on the necessary explanation with each respondent.

# **Pilot Study**

As a means of assessing study's tools regarding their clarity, applicability, and duration required to complete them, a pilot study was performed on exactly 10% (6 participants) of entire sample size. The sample chosen for the pilot study was involved in the main study since the assessment tools were left unchanged.

# Ethical considerations

Following official permission by the ethical committee of Minia University's Faculty of Nursing was obtained (Code No.; REC2023119), the director of Minia Hospital for Mental Health and Addiction Treatment in New Minia City provided an official approval for data collecting. A consent form was signed by each study participant. In this step, the objective, nature and methods of the study were clarified, and official permission was obtained. Family caregivers were being told that their involvement in the research was entirely optional; the researcher also notified the participants regarding their possibility to leave the study whenever they want. The coding of the data ensured confidentiality and anonymity.

## Limitations of the Study

The study may be limited for several reasons. Firstly, absence of specific or noiseless area for meeting studied family caregivers for collecting data, Thus, the researcher encountered numerous disruptions. and obstacles, which lead to frequent repetition. Also, this study did not assess certain factors such as family caregivers' medical illnesses, coping skills, and perceived social support all of which might have an impact care burden. Finally, as nearly two thirds of the caregivers in current research were mothers of children with ASD, the findings might not apply to other family relatives who provide care.

## **Statistical Analysis**

The computer statistical package for social science SPSS for Windows version 20.0 (SPSS, Chicago, IL) was used for all demanded statistical analyses. Continuous data was distributed normally and expressed by mean  $\pm$  standard deviation (SD), while categorical data was represented as numbers and percentiles. The correlation coefficient test was applied to check for correlations between two continuous data variables, and the chi-square test (or Fisher's exact test, if applicable) was used to compare variables with categorical data. In addition, the study questionnaires' internal consistency (reliability) test was calculated. At p<0.05, statistical significance was established.

## Results

**Table (1):** Shows that the mean age of family caregivers is  $37.4\pm7.4$  and that (55%) of them belong to an age group average of 30 to less than 40 years. About 61.7% of respondents are mothers; 63.3% are residents at rural areas; more than half (51.7%) of participants have moderate level of education. In addition, 91.7% of the sample are married; 60.0% of them are working, and only (13.3%) of studied caregivers have another child with disability in their family.

**Table (2):** Reveals that the mean age of children is  $8.3\pm1.9$ , while, most of them (81.7)

are boys. Regarding child order, 60% of the autistic children are the first in ranking among brothers and sisters, and 55.0% have the disorder between the periods of 3 to less than six years.

**Figure (1)**: Illustrates that 20% of the studied family caregivers have a severe level of burden, followed by 75% of them suffers from moderate to severe level of burden, while the remaining percent (5.0%) of participants have mild to moderate burden.

**Figure (2):** Clarifies depression levels among studied family caregivers. It is observed from the findings that 53.3% of the sample have an average level of depression, and 13.3% of them have a severe level of depression.

**Figure (3):** It is noted from this figure that most of the studied sample (81.7%) have low frequency of suicidal ideation, while moderate and high frequency of suicidal ideation among the participants are represented by 11.7 & 6.7% respectively.

**Table (3):** The results present a high positive significant correlation between family caregivers burden with both of depression and frequency of suicide ideation (r= 0.723, p =0.001\*\*& r= 0.570, p=0.001\*\*) respectively, as well as a strong positive significant correlation is indicated between depression and frequency of suicide ideation among studied sample (r= 0.745, at p=0.001\*\*).

**Table (4)**: As shown in this table, the result reports a statistically significant relation between care burden levels and caregivers' age, educational level, monthly income and another child with disability in family, as regard child characteristics, the finding states a significant association between caregivers' burden levels and both of children number and child order. In addition, the highest percent (66.7%) of severe burden is presented among mothers of children with autism spectrum disorders than fathers.

Table (5): From this table, it is found that the most significant factors which affecting suicide ideation frequency scores of studied family caregivers are the presence of another child with disability in family and Zarit burden score while the highest significant factor is Beck depression inventory score.

Table (1): Frequency distribution of family caregivers relating to their sociodemographic data (n=60).

Sociodemographic data	No.	%					
Age (Years)							
20 < 30	8	13.3					
30 < 40	33	55.0					
40 years and more	19	31.7					
Mean ± SD	<b>37.4±7.</b> 4						
Relation of caregiver to child							
Mother	37	61.7					
Father	23	38.3					
Grandparents	0	0.0					
Other relatives	0	0.0					
Residence							
Urban	22	36.7					
Rural	38	63.3					
Educational levels							
Not read or write	3	5.0					
Moderate education	31	51.7					
University or Higher	26	43.3					
Marital status							
Married	55	91.7					
Divorced	2	3.3					
Widow	3	5.0					
Working status							
Working	36	60.0					
Not working	24	40.0					
Monthly income							
Enough	6	10.0					
Not enough	54	90.0					
Another child with disability							
Yes	8	13.3					
No	52	86.7					

**Table (2):** Frequency distribution of children characteristics (n= 60).

children characteristics	No.	%
Child age (Years)		
6 - < 9	38	63.3
9 - 12	22	36.7
Mean ±SD	8.3±1.9	
Child gender		
Boy	49	81.7
Girl	11	18.3
Child order		
First child	36	60.0
Second child	12	20.0
Third child	11	18.3
Fourth or more	1	1.7
Onset of illness		
1-<3	26	43.3
3 - < 6	33	55.0
6 or more	1	1.7



Figure (1): Burden levels among studied family caregivers (n=60).









 Table (3): Correlation between Zarit burden scale, Beck Depression Inventory, and Frequency of Suicide Ideation Inventory among studied family caregivers (n=60)

	Zarit burden scale		Beck Inventory	Depression	Frequency of Suicide Ideation Inventory		
	r	р	r	р	r	р	
Zarit burden scale	1		0.723	<0.001**	0.570	0.001**	
Beck Depression Inventory	_		1		0.745	0.001**	
Frequency of Suicide Ideation	_		_		1		
Inventory	_		_				

Table	(4):	Association	between	sociodemographic	data	of	the	caregivers	and	children
	chai	acteristics wit	h Zarit bu	rden scale ( $n = 60$ )						

	Zarit burden scale								
Caregivers	Mild to moderate burden		Moderate to severe burden		Severe burden		Chi – square / fisher's exact test		
	n	%	n	%	n	%	X <sup>2</sup>	Р	
Age (Years)									
20 - 30	2	66.7	3	6.7	3	25.0			
31-40	1	33.3	27	60.0	5	41.7			
More than 40	0	0.0	15	33.3	4	33.3	<u>10.973</u>	0.027 <sup>*</sup>	
Relation of caregiver to child									
Mother	3	100.0	26	57.8	8	66.7			
Father	0	0.0	19	42.2	4	33.3	2.280	0.320	
Residence	2		10	40.0	2	167			
Urban	2	66.7	18	40.0	2	16.7	2 4 4 5	0.170	
Rural	1	33.3	27	60.0	10	83.3	3.445	0.179	
Educational level	1	22.2	2	4.4	0	0.0			
Not read or write	1	33.3	2	4.4	0	0.0			
Moderate education	0	0.0	22	48.9	2	75.0	0.740	0.045*	
Merital status		00.7	21	40.7		23.0	<u>9./49</u>	0.045	
Married	3	100.0	12	03.3	10	83.3			
Divorced	0	0.0	42	25.5	10	83			
Widow	0	0.0	2	2.2 1 1	1	83	1 738	0.784	
Working status	0	0.0		<u> </u>	1	0.5	1.750	0.704	
Working	1	333	30	66.7	5	417			
Not working	2	66.7	15	33.3	7	58.3	3 403	0.182	
Monthly income		0017			,	0010	000	0.1102	
Enough	2	66.7	3	6.7	1	8.3			
Not enough	1	33.3	42	93.3	11	91.7	11.296	$0.004^{*}$	
Another child with disability									
Yes	0	0.0	3	6.7	5	41.7			
No	3	100.0	42	93.3	7	58.3	10.529	<mark>0.005*</mark>	
Child					_		_		
Child age (Years)									
6-8	3	100.0	28	62.2	7	58.3			
9-12	0	0.0	17	37.8	5	41.7	1.890	0.389	
Child gender									
Boy	2	66.7	39	86.7	8	66.7			
Girl	1	33.3	6	13.3	4	33.3	3.006	0.223	
Child order		· · · <b>-</b>	•						
First child	2	66.7	30	66.7	4	33.3			
Second child	1	33.3	10	22.2	1	8.3			
I hird child	0	0.0	4	8.9	1	58.3	16 510	0.011*	
Pourun or more	0	0.0	1	2.2	0	0.0	16.518	0.011	
	2	100.0	10	40.0	5	41.7			
1 - 2 = 5	3	100.0	18	40.0	5	41./			
5 - <i>/</i> 0	0	0.0	27	0.0	0	50.0 8 2	0 255	0.002	
0 01 more	0	0.0	0	0.0	1	0.3	0.200	0.085	

	Unstand	ardized	Standardized			
Items	Coeff	icients	Coefficients	t	Sig.	
	В	Std. Error	Beta			
(Constant)	8.368	3.379		2.467	0.013*	
Caregivers						
Age	0.017	0.114	0.020	0.153	0.879	
Residence	0.249	0.174	0.211	1.427	0.160	
Educational level	0.238	0.135	0.244	1.760	0.085	
Marital status	0.083	0.153	0.068	0.542	0.590	
Working status	0.762	0.576	0.115	1.324	0.191	
Monthly income	0.085	0.232	0.045	0.366	0.716	
Relation of caregiver to child	0.058	0.204	0.050	0.285	0.777	
Another child with disability	2.350	0.938	0.246	2.506	<mark>0.015*</mark>	
Child						
Child age	0.095	0.187	0.081	0.509	0.613	
Child gender	0.050	0.200	0.034	0.249	0.805	
Child order	0.779	0.393	0.201	1.981	0.053	
Onset of illness	0.081	0.179	0.075	0.450	0.655	
Zarit burden scale	3.549	1.881	0.712	3.100	<mark>0.041*</mark>	
Beck Depression Inventory	1.110	0.204	0.486	5.438	<0.001**	

 Table (5): Linear regression analysis of factors affecting suicide ideation frequency among studied family caregivers (n=60)

### **Discussion:**

The current study's aim was to estimate the relation between care burden, depression and suicide risk among family caregivers of children with autism spectrum disorder (ASD).

Regarding levels of care burden, the findings of the current study claimed that one fifth of studied family caregivers had a severe level of burden, and three quarters of them suffer from moderate to severe burden. This study finding might be attributed to long-term challenges associated with ASD and child care demands. Behavioral problems, difficulties in accessing health services, caregiver's level of education, and training for their children have been one that was most extensively shared negative experiences of caregiver stress and burden. Also, social, financial, and emotional obstacles the caregivers experience may be other critical factors that affect the problem of care burden. Other predictors include a deficit of community awareness, lack of training programs, therapies as well as other endeavors that deal with approaches and assets the family caregivers use to minimize burden and deal with autistic children. Mohamad & Rosdi (2018) added another indicator of caregiver burden containing the degree of ASD symptoms, caregiver parenting abilities, lesser

reported social support, and medical comorbidity among caregivers.

The current study's outcome matches recent findings: within research the research respondents, little over half of the caregivers experienced high level of care burden, with the majority experiencing mild burden (Chua et Another previous study of al., 2023). AlShahrani & Algashmari (2021) indicated that more than three quarters of mothers with autistic children experienced a high level of burden. А similar study assumed bv Ardhanaari et al., (2020) who found a rise in the caregiver burden that affected by the seriousness of autism.

Concerning depression levels of studied family caregivers, it was observed from the findings that slightly over one-half of the participants had an average level of depression, and about thirteen percent of them had severe depression. This result could be attributed to the height levels of children's behavior problems, early onset, low functioning of autism, and insufficient social assistance that caregivers obtained. Also, a significant fact was discovered when parents who perceived their children as a heavy burden and hard to handle were more associated with poor mental health, which resulted in an elevation of depression rate among family caregivers. This result is nearly congruent with those of Xia et al., (2023) who evidenced that, among family caregivers' sample, mothers were more susceptible to depression than fathers, and grandmothers reported higher rate of depression than grandfathers. Another recent supported study was carried out by Warreman et al., (2023) which proved that those who cared for someone with autism had a higher prevalence of depressive illnesses than those who did not. Similarly, Scherer et al., (2019) corporate that depressive symptoms are more prevalent among parents of autistic children than in control group. Also, Alibekova et al., (2022) stated that much greater levels of stress and depression were claimed by parents of children with ASD.

As regard family caregivers' suicidal ideation frequency, it is noted from this outcome that moderate and high frequency of suicidal ideation among the participants are represented by 11.7 & 6.7% respectively. This might be explained by different factors as ongoing demands of caregiving, including managing challenging behaviors and navigating complex healthcare systems, can lead to chronic stress. Another rationale is social isolation that caregivers experience, intensive nature of their responsibilities, limiting social interaction and support networks. Moreover, financial strain can place a significant burden on families, witnessing child's struggles and feeling helpless can take an emotional toll on caregivers, leading to feeling of despair and hopelessness, these associated factors are contributing to the developing of suicidal ideation among caregivers. This outcome is corroborated by a recent survey conducted by Newell et al., (2023) who published that about 10% of parents of autistic children experiencing suicidal thoughts. This prevalence is notably higher than in parents of typically developing children.

The current findings exhibited a highly positive significant correlation between family caregivers' burden with both of depression, and frequency of suicide ideation as well as a strong positive significant correlation was found between depression and suicidal ideation frequency among studied sample. This could be a result of significant factors as taking care of a child with ASD has varying effects on family caregivers bringing attention to how intricate family dynamics may be in these situations. Usually, primary caregivers are mothers, they experience elevated stress resulting from extensive dav-to-dav participation in caregiving responsibilities and the trouble in maintaining a balance between professional, marital and familial harmony. Moreover, the most widely predictors encompass ASD manifestations' intensity, financial circumstances, perceived social support levels, and caregivers' medical comorbidity, all of which contribute to a higher burden level which in turn trigger symptoms of depression and increase risk for suicide. In alignment with this perspective, a supported study of Akram et al., (2019) who documented a positive relationship between burden of care and suicidal ideation, also, the author proved that the care burden positively affected suicidal ideation. In addition, Rankin et al., (2022) discovered a positive correlation between caregiver burden and depressive symptoms.

The current findings showed an analysis of statistically significant association between burden levels with caregiver care characteristics and child-related factors: caregivers' age, educational level, monthly income, and the presence of another child with a disability in the family. Furthermore, the child's traits, including the child order, also play a big part in the perceived burden. The results highlighted several critical aspects and cleared offer insights into the key variables influencing caregiver burden. Firstly, caregiver characteristics; age, the data show a significant association between the caregiver's age and the level of burden experienced. A supported recent literature. indicating that older caregivers may experience greater stress due to potential physical limitations and reduced energy levels compared to younger caregivers (Ferguson et al., 2024). However, these findings disagreed with those of Jia et al., (2023) who documented that younger family caregivers often face greater stress and burden due to balancing caregiving with other life responsibilities. On the other hand, the highest percent (66.7%) of severe burden is presented more in women than in fathers have children with autism spectrum disorders. This outcome could be explained by the significant evident

that mothers; typically, the primary family caregivers who experience unusual stress resulting from intense involvement in daily caregiving tasks and activities, mothers also face struggle with balancing their professional and other multiple responsibilities. In line with this study findings, a recent study was carried out by **Mohammad et al.**, (2022) claimed that the care burden score reported by mothers of children with autism was  $2.57 \pm 64.74$ .

As regards educational level; family caregivers with university or higher education reported a lower proportion of severe burden compared to those with no formal education or moderate education. This is related to the fact that educated caregivers have better coping strategies and resources, which can mitigate care burden. This finding was nearly corroborated by Pandey & Sharma (2018) who reported that higher levels of education were associated with lower burden levels. Regarding monthly Income: a significant association between monthly income and caregiver burden was discovered in the present finding, this could be related to the fact that caregivers with inadequate income reported a much higher proportion of severe burden. Financial strain is a well-documented stressors for caregivers, impacting their ability to access necessary resources and support (Johnson et al., 2023; Roth et al., 2023). The current results proved statistically significant relation between care burden levels with the present of another child with a disability in the family, this outcome might be related to an evident that the presence of another child with a disability can exacerbate caregiver burden due to the compounded demands on the caregiver's time and resources (Lee et al., 2024). This finding suggests that caregivers in such situations may experience increased stress and challenges compared to those with only one child with a disability. Additionally, the order of children can influence the caregiver's responsibilities and stress levels, caregivers of children who are not the firstborn might face additional challenges or expectations, which could contribute to a higher burden (Johnson & Chen, 2024).

It was found that the crucial determinants which affecting suicide ideation frequency of studied family caregivers are the presence of another child with disability in family and Zarit burden score while the highest significant factor is Beck depression inventory score. These findings could be interpreted as depression is a key factor in predicting suicide ideation and underscores the well-established link between depression and suicidal thoughts. Also, family caregivers of ASD often experience high levels of emotional stress due to their demanding roles, which can exacerbate feelings of hopelessness and despair that triggering depression and elevate suicide risk. The present study outcome is supported by Van Heeringen & Mann (2014) who highlighted that depressive disorders are a robust predictor of suicide ideation and attempts. The same author emphasized that higher levels of depressive symptoms significantly elevate the risk of suicide ideation among family caregivers.

The fact of having another child with a disability in the family also significantly affects suicide ideation frequency. This result might be explained by Maridal et al., (2021) who evidenced that caregiving for multiple children with disabilities can intensify stress and fatigue, potentially leading to higher levels of psychological distress. In addition, The responsibilities multiple and emotional challenges of managing care for more than one child with special needs may contribute to feelings of inadequacy increased and hopelessness, which are exacerbating their risk of depressive symptoms and suicidal thoughts. The Zarit Burden Scale score's significance in predicting suicide ideation reflects the critical role of perceived caregiving burden. A supported study by Hsu et al. (2017) corroborated that higher caregiver burden was associated with increased suicidal thoughts and symptoms of depression among caregivers.

# **Conclusion:**

The research outcomes proved that the majority of the studied family caregivers have moderate to severe level of burden, as well as moderate and sever depression were observed and suicide risk was evidenced. Also, a significant positive correlation between the studied sample' burden with both of depression and frequency of suicide ideation was found, similarly, a strong significant positive

correlation is indicated between depression and frequency of suicide ideation among studied subjects. The burden of care among family caregivers of ASD children triggers depression and causes them to develop suicidal thoughts.

## **Recommendations:**

The study' recommendations include:

- Develop a comprehensive (psychological, social, and economic) support systems to better assist family caregivers in reducing burden, managing their multifaceted responsibilities and well understanding of all risk factors that can lead to depression and suicide.
- Encourage supportive interventions aimed at immediate burden detection and handling is crucial for the caregiver's health and, more significantly, for the child's disorder prognosis.
- Create Future research with larger sample sizes and diverse populations to determine how common mental health conditions are among family caregivers and help in developing more effective support strategies.

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