RESEARCH

The possible relation between stigma, parent psychiatric symptoms, quality of life and the disease burden in families of children with autism spectrum disorder in Egypt: a multicentre study

Romany H. Gabra[1], Doaa F. Hashem[2] and Gellan K. Ahmed[1,3]*

Abstract

Background: Most autism spectrum disorder (ASD) interventions evaluated child outcomes and ignoring the role of parent and family factors on both the immediate- and long-term effects of therapy. The purpose of this study was to determine the relationship between stigma, parent mental health problems, and quality of life and burden in families of children with ASD in Egypt and its risk factors. Seventy parents of ASD children were recruited from two child intervention centers. Participants were divided into two groups based on burden scale: caregivers of moderate burden ($n = 27$) and caregivers of severe burden ($n = 43$). All parents were evaluated for demographic data, zarit Burden Interview, socioeconomic scale, symptom checklist–90 (SCL90), Explanatory Model Interview Catalogue Community Stigma Scale (EMIC-CSS), and the World Health Organization Quality of Life–BREF (WHOQOL-BREF).

Results: Half of the parents reported significant stigma, particularly caregivers with a severe burden. Caregivers with severe burden had more depression and about twice the frequency of sensitivity and somatization problems, lower QoL (20%) as compared with caregivers with moderate burden. Parents with ASD had many associate factors such as work, male autistic children and their caregiver, age of children and parents, the severity of the condition, and disease duration with burden, stigma, QoL, and mental health problems.

Conclusions: This study linked the interrelationships between increased burden and stigma, impaired quality of life, and parental mental health problems; the presence of one of these variables was found to increase the risk of other variables.

Keywords: Autism, Associated stigma, Burden problems, Quality of life, Psychological problems, Parent

Background

Autism spectrum disorder (ASD) is a chronic neurodevelopmental illness marked by communication difficulties and restricted social engagement as well as repetitive patterns of behavior, activity, or interest [1].

The worldwide prevalence of ASDs is between 1 and 2% worldwide [2, 3]. Families with an autistic child may face a variety of issues, such as reduced parenting efficacy, high stress rate, mental and physical health issues, severe financial problems, time constraints, sibling adjustment issues, reduced social support, and family conflict [4–7]. As compared with many other disorders, ASD may have a greater effect on the family [8]. As a result, raising autistic children in both developing and developed

*Correspondence: gillankaram@aun.edu.eg
[1] Department of Neurology and Psychiatry, Faculty of Medicine, Assiut University, Assiut, Egypt
Full list of author information is available at the end of the article

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countries can be challenging for parents and families [9, 10]. To provide professional interventions for ASD children, many obstacles must be overcome, particularly in developing countries, such as financial burden, childcare challenges, stigma, psychological issues, and poor family quality of life [4].

Furthermore, the burden of ASD in developing countries can be greater. Although high professional intervention services are standard in developed countries for children and their parents, they are broadly unreachable in developing countries, and only a small percentage of autistic children have access to them. [9, 10]. ASD Children, particularly those who do not receive professional intervention services, can have a significant impact on the well-being of their entire family [11]. Despite the high community and individual costs of ASDs, these disorders have received little attention in the global public health arena [12].

One of the obstacles that face parents of ASD children is the social stigma, which is affected by parents' beliefs, a lack of knowledge and understanding of ASD, a severe lack of special education and behavioral treatments, as well as a lack of trained staff and inadequate facilities [10]. Parents' beliefs about ASD will influence their interaction with specialists, how they see their children, their understanding of their roles and duties in their children's situation, and the kind of therapy they choose [13]. If professionals understand the parents' beliefs about ASD, they can provide more culturally appropriate support for individuals with ASD and their parents [14, 15]. According to previous research, the cultural background of parents influences their views on ASD. [14, 16]. Expectations and attitudes about ASD can affect parents' and families' functioning and psychological well-being [17]. As a result, it is necessary to compare parents' perceptions of ASD across cultures.

Many individuals with autism experience high levels of clinical anxiety, depression [18], and stress [19]. In the face of stress due to their children's emotional/behavioral difficulties, parents of autistic children need greater perceived social support [20]. It may be especially relevant to examine variables linked to parental engagement with ASD children, as these children require a great deal of care from their parents [21]. Improved parental mental health will improve parent engagement and effective interventions of ASD children.

Family and/or friend support [22], coping strategies used [23], caring demands [24], and child perceptions [25] have all been found to have a significant impact on parental quality of life (QoL). All previous studies have shown that parents of children with ASD had lower scores in one or more QoL dimension as compared with parents of typically developing children. Furthermore,

contradictory results demonstrated the relationship between ASD severity and the QoL of the parent. Two studies indicated a negative relationship [26, 27], while the other two studies reported no relationship [28, 29]. One study [30] reported that lower levels of QoL were associated more with mothers than fathers.

As a result, many studies are currently being conducted worldwide, particularly in developed countries, to investigate the stigma, burdens, QoL, and psychological problems experienced by autistic children's families. However, because of the influence of various variables such as demographic characteristics, socioeconomic status, culture, and clinical presentations, results of these variables differ from country to country. Because no previous studies have been conducted in Egypt, it is important to evaluate these variables to raise awareness about the issues surrounding autistic children and to improve the quality of our services and the outcomes of these children. As a result, the purpose of this study was to determine the relationship between stigma, parental mental health problems, QoL, and burden in families of children with ASD in Egypt and its risk factors.

Methods

From January 1, 2020, to April 1, 2020, a cross-sectional survey was conducted at two centers, to obtain data from families of different socioeconomic levels measured by Socioeconomic Scale [31] (15% of high level, 55% of middle level, 30% of low level): Assiut University's psychological and educational counseling center at the west of the Assiut city ($n=38$) and from a child and adolescent outpatient clinic in neurology and psychiatry department, Assiut Hospital University, at the east of the Assiut city ($n=32$). Parents of autistic children were included if their children were aged from 5 to 12 years with a clinical diagnosis of ASD based on the *Diagnostic and Statistical Manual of Mental Disorders*, fifth edition (DSM-5). We excluded parents of autistic children if the child had any medical or neurologic disease or had an intelligence quotient of less than 70.

The EPI info statistical package version 7 was used to calculate the sample size. The parameters used for determining the sample size were a proportion of 0.5, a confidence level of 95%, and a margin of error of 5%; thus, we calculated that a sample size of 31 was required. The final sample included 70 parents of autistic children. Each of the parents came from a different family. Thirty parents (42.9%) were fathers, and 40 parents were mothers (57.1%). The parents' average age was 35.32 years, and the children with ASD had an average age of 8.21 years. Almost half of the parents had completed 15 years of education (45.7%).

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After given a description of the study to eligible participants, they were asked to take part of study and provide written informed consent. All participants were asked to complete a comprehensive questionnaire to collect demographic information, followed by a clinical interview with doctors to assess their psychological problems and other scales. Furthermore, we divided the study groups into caregivers with a moderate burden ($n = 27$) and caregivers with a severe burden ($n = 43$).

Measures

Sociodemographic data about the parents: caregiver gender, caregiver age, number of education years, and work of caregivers.

Clinical data of child: child gender, child age, the child's disease severity, and the child's disease duration.

Socioeconomic scale [31]

When determining the social burden and socioeconomic classes, the Socioeconomic Scale is employed. It also includes four key variables: the father and mother's educational level, their occupation, the total family income, and their way of life.

Arabic version of the Zarit Burden Interview [32, 33]: This measure is a regularly used metric of caregiver burden. It is a 22-item self-report scale that measures the burden of the behavior and functioning of the caregivers in interpersonal relations, financial affairs, physical health, and social life. In the current study, the reliability and the validity of Zarit Burden Interview symptom checklist was assessed among a sample of the study ($n = 40$) using the Cronbach's alpha coefficient, which was 0.73, whereas for validity as assessed using the validity convergent with the depression scale, the correlation coefficient was 0.70.

Explanatory Model Interview Catalogue Community Stigma Scale (EMIC-CSS) [34]

This tool measures the attitudes and behavior of stigmatized persons perceived in 15 items. The EMIC-CSS addresses aspects of life that may be affected by stigma, such as concealment, avoidance, pity, shame, being made fun of (respect), and marriage (prospects). In the current study, the reliability and validity of the EMIC-CSS were evaluated in a study sample ($n = 40$) using the Cronbach's alpha coefficient, which was 0.72, whereas for the validity, as assessed by using the validity convergent with the depression scale, the correlation coefficient was 0.52.

Symptom checklist 90 (SCL90) [35]

This measure is a 90-item questionnaire used to assess mental health issues. Each item is rated on a scale of 0 to 4 based on how problematic the item is to the individual. The checklist is divided into nine subscales; however, in this study, we included only four subscales: depression, anxiety, interpersonal sensitivity, and somatization.

World Health Organization Quality of Life–BREF (WHOQOL-BREF)

This measure is used to obtain subjective perceptions of QoL [36]. The WHOQOL-BREF includes four domains of QoL: physical capacity (seven items), psychological well-being (six items), social relationship (four items), and environment (nine items). All items are scored on a five-point Likert scale, with higher scores indicating better QoL. In the current study, the reliability and the validity of QoL was assessed in a sample of the study ($n = 40$) using the Cronbach's alpha coefficient, which was 0.77, whereas for the validity, as assessed using the validity convergent with the depression scale, the correlation coefficient was -0.74.

Statistical analysis

SPSS has been used for statistical analysis (version 26). As descriptive statistics, frequencies and percentages were reported. To assess categorical variables, we used the Pearson chi-squared test. The evaluation of quantitative variables was conducted with an independent t test to detect a significant difference in means between two groups. To identify risk factors, we performed multivariate linear regression model. A p value of < 0.05 was considered statistically significant.

Results

Sociodemographic data of studied groups

We found a statistically significant difference in the age of caregivers, age of the child, severity of the child's disease, and duration of the child's disease among the studied groups ($P < 0.01$). Most participants were working mothers, had an age range of 30 to 35 years, and had 15 years of education. Also, most participants had a male autistic child, aged 5 to 8 years, with severe autism. Among the caregivers with a moderate burden, most were the father (51.9%), had 15 years of education (55.6%), had a child of 5 to 8 years of age (100%), and had a child diagnosed with autism between the ages of 2 and 5 years (92.6%) with moderate severity of disease (70.8%), whereas caregivers with severe burden consisted of a higher percentage of mothers (62.8%) with 11 years of education (41.9%), who had a child between 9 and 12 years of age (69.8%) who was diagnosed with autism between the ages of 6 and 9 years (76.7%)with severe autism (81.4%). We noted that

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Table 1 Demographic characteristics of the studied sample

Variables	Caregivers of moderate burden (N = 27)		Caregivers of severe burden (N = 43)		Total (N = 70)		P value
	N	%	N	%	N	%	
Gender of caregivers							
Father	14	51.9%	16	37.2%	30	42.9%	0.32
Mother	13	48.1%	27	62.8%	40	57.1%	
Age of caregivers							
30–35 years	20	74.1%	25	58.1%	45	64.3%	0.2
36–41 years	7	25.9%	18	41.9%	25	35.7%	
Mean ± SD	34.37 ± 2.7		35.88 ± 2.32		35.32 ± 2.65		0.01*
Numbers of years of education							
8 years	0	0%	2	4.7%	2	2.9%	0.22
11 years	8	29.6%	18	41.9%	26	37.1%	
15 years	15	55.6%	17	39.5%	32	45.7%	
17 years	4	14.8%	6	14%	10	14.3%	
Mean ± SD	14.11 ± 2.17		13.18 ± 2.49		13.44 ± 2.40		0.11
Work of caregivers							
Work	15	55.6%	29	67.4%	44	62.9%	0.32
No work	12	44.4%	14	32.6%	26	37.1%	
Gender of child							
Male	15	55.6%	22	51.2%	37	52.9%	0.72
Female	12	44.4%	21	48.8%	33	47.1%	
Age of child							
5–8 years	27	100%	13	30.2%	40	57.1%	0.000*
9–12 years	0	0%	30	69.8%	30	42.9%	
Mean ± SD	6.48 ± 1.34		9.30 ± 1.87		8.21 ± 2.17		0.000*
The severity of the disease for child							
Moderate	19	70.8%	8	18.6%	27	38.6%	0.000*
Severe	8	29.6%	35	81.4%	43	61.4%	
Duration of the disease for child							
2-5 years	25	92.6%	10	23.3%	35	50%	0.000*
6-9 years	2	7.4%	33	76.7%	35	50%	
Mean ± SD	3.48 ± 1.34		6.30 ± 1.87		5.21 ± 2.17		0.000*

Chi squared test * Significant *P* value < 0.05

both groups had no children with mild autistic severity (see the details given in Table 1).

Associated stigma, SCL90, and QoL

In Table 2, there was statistically significant difference in associative stigma, depression, anxiety, and QoL among the studied groups ($P < 0.001$). Half of the participants had high stigma. In addition, caregivers with moderate burden had a higher frequency of moderate stigma (51.9%), whereas caregivers with severe burden had higher proportion of high stigma (48.8%). We noted that the caregivers with moderate burden had no depression or anxiety, whereas one-third of the caregivers with severe burden had depression (32.6%) and anxiety (37.2%). The frequency of sensitivity and somatization problems was double that in the caregivers with severe burden as compared with the caregivers with moderate burden. About 20% of the caregivers with severe burden had low QoL, whereas the caregivers with moderate burden had no low QoL. Most parents in both groups had moderate QoL.

Identification of possible risk factors of burden scale, associated stigma, and QoL scale in parents of autistic children

Multiple risk factors that affected stigma scale, burden scale, and QoL were studied in the multivariate regression analysis, as shown in detail in Table 3.

Worked caregivers and male autistic children were less vulnerable for increased stigma and burden scale

Table 2 Associative stigma, SCL90, and Quality of life between Caregivers of children with moderate (*n*=27) and severe (*n*=43) autism

Variables	caregivers of moderate burden (*N*=27)		caregivers of severe burden (*N*=43)		Total (*N*=70)		*P* value
	N	%	*N*	%	*N*	%	
Associative stigma							
Low	11	40.7%	5	11.6%	16	22.9%	0.002*
Moderate	14	51.9%	17	39.5%	19	27.1%	
High	2	7.4%	21	48.8%	35	50%	
Depression							
Normal	27	100%	29	67.4%	56	80%	0.001*
Abnormal	0	0%	14	32.6%	14	20%	
Anxiety							
Normal	27	100%	27	62.8%	54	77.1%	0.000*
Abnormal	0	0%	16	37.2%	16	22.9%	
Sensitivity							
Normal	25	92.6%	35	81.4%	60	85.7%	0.2
Abnormal	2	7.4%	8	18.6%	10	14.3%	
Somatization							
Normal	21	77.8%	25	58.1%	46	65.7%	0.09
Abnormal	6	22.2%	18	41.9%	24	34.3%	
Quality of life							
Low	0	0%	9	20.9%	9	12.9%	0.000*
Moderate	15	55.6%	30	69.8%	45	64.3%	
High	12	44.4%	4	9.3%	16	22.9%	

Chi squared test * Significant *P* value < 0.05

scores, whereas sensitivity problems in parents of autistic children were an independent risk factor for increased stigma and burden scale scores. Severe autism in the child (*P*=0.001) was a significant risk factor for increased stigma, whereas male caregivers (*P*=0.005), increased duration of the child's disease (*P*<0.000), and increased QoL (*P*=0.02) were less likely to increase the burden scale score. We noticed that depression problems in parents of autistic children (*P*<0.000) was an independent risk factor for increased burden scale score.

With regard to QoL, increased caregiver age (*P*=0.01), anxiety problems (*P*=0.02), and increased total of burden scale score (*P*=0.02) were more vulnerable to impaired QoL (decrease total QoL score).

Identification of possible risk factors of parental mental health problems of autistic children

Table 4 shows that among caregivers of autistic children, worked caregivers (*P*=0.03) were at less risk for depression, whereas increased total score of associative burden (*P*<0.000) and parents with sensitivity problems (*P*<0.000) were more likely to experience depression.

Male caregivers (*P*=0.03) with increased age (*P*<0.000) and high QoL (*P*=0.02) were less vulnerable to anxiety, whereas parents with somatization and sensitivity problems and who had a child with severe autism (*P*<0.000) were at higher risk of anxiety problems.

Among parents of autistic children, male caregivers were at lower risk of sensitivity and somatization problems, whereas those with children who had severe autism and parents with anxiety problems were highly vulnerable to sensitivity and somatization problems.

Among parents of autistic children, those with depression (*P*<0.000) and somatization problems (*P*<0.000) and with a child with increased duration of autism (*P*=0.008) and total score of stigma (*P*=0.02) and burden (*P*=0.01) were at higher risk for sensitivity problems.

Increased parent age (*P*=0.04) was low risk for developing somatization problems, whereas the presence of sensitivity problems (*P*<0.000) in the parent was a high risk for developing somatization problems.

Discussion

This research included four factors (burden, associated stigma, parental mental health problems, and QoL). The purpose of this study was to determine the relation between stigma, parental mental health problems, and QoL and burden in families of children with ASD in

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Table 3 Multivariate generalised regression model of Total score of Associative Stigma, Total score of Burden Scale, and Total score of quality of life among studied group

Predictors	Total score of Associative Stigma		Total score of Burden Scale		Total score of quality of life	
	OR	*p* value	OR	*p* value	OR	*p* value
Gender of Caregivers #1						
Males	− 0.02	0.79	− 0.19	0.005*	− 0.12	0.22
Age of Caregivers	− 0.02	0.79	0.03	0.61	0.23	0.01*
Numbers of years of education	− 0.03	0.62	0.06	0.27	0.08	0.27
Work of Caregivers	− 0.18	0.02*	− 0.12	0.03*	− 0.12	0.12
Gender of child#2						
Males	− 0.36	0.000*	− 0.05	0.37	− 0.04	0.62
The severity of the disease for child#3						
Severe	1.42	0.001*	− 0.17	0.08	–	–
Duration of the disease for child	− 0.21	0.19	0.61	0.000*	0.18	0.27
Depression	1.26	0.12	1.45	0.000*	1.30	0.07
Anxiety	− 2.02	0.92	2.16	0.25	− 0.41	0.02*
Sensitivity	2.35	0.02*	− 2.29	0.01*	3.073	0.64
Somatization	0.008	0.94	0.01	0.83	0.061	0.56
Total score of Associative Stigma	–	–	− 0.13	0.17	− 0.22	0.09
Total score of Burden Scale	− 0.25	0.17	–	–	− 0.41	0.02*
Total score of quality of life	− 0.23	0.09	− 0.22	0.02*	–	–

Multivariate Linear Regression Model

[#] 1 female was reference group

[#] 2 female was reference group

[#] 3 Moderate group was reference group

[*] Significant *P* value < 0.05

Egypt and its risk factors. To the best of our knowledge, this is the first study in Egypt to assess these variables among ASD parents and their risk factors. The findings of this study could contribute to the knowledge regarding how to improve services in the clinical setting of any child psychiatry unit.

According to the findings, the final sample included 70 parents of autistic children. with regard to the burden scale, parents were divided into two groups: those with a moderate burden ($n = 27$) and those with a severe burden ($n = 43$). We found there was a lack of mild burden in ASD families, which might reflect problems in developing countries with pay public services for ASD children. Furthermore, there were no children with mild autism in this study because the parents were unfamiliar with the disease and how to detect and treat it. Caregivers who had a severe burden were more likely to be mothers with secondary education (11 years of education) and to have an autistic child with a severe degree and a long duration of symptoms, whereas caregivers with a moderate burden were more likely to be fathers with a high education (15 years of education) and to have an autistic child

with a moderate degree of autism and a short duration of symptoms.

A comparative literature review identified 14 studies published by Arab researchers on parents raising children with ASD between January 1, 2000, and December 31, 2016, and 55 studies published by American researchers. The review found that more financial problems were mentioned in Arab studies than in the United States (US) studies. Because of the much higher availability of publicly funded services in the US, it is significantly less of an issue for US families to bear the burden of paying for services than in Arab countries. Also, it found that Arab studies have revealed a lack of or limitations in health, educational, and/or social services for ASD children and their families [37]. Furthermore, a Previous study discovered that caring for a child with ASD costs families approximately 15% of their income per month [38]. Dababnah and Bulson highlighted that many families could not seek or retain services because of financial difficulties [39].

In this study, half of the participants reported significant stigma, particularly caregivers with a severe burden. Caregivers with a severe burden had lower QoL than

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Table 4 Multivariate generalised regression model for parent mental health problems of autistic children

Predictors	Depression		Anxiety		Sensitivity		Somatization	
	OR	*p* value	OR	*p* value	OR	*p* value	OR	*p* value
Gender of caregivers #1								
Males	0.14	0.053	0.13	0.03*	− 0.32	0.000*	− 0.38	0.001*
Age of Caregivers	0.14	0.057	0.25	0.000*	− 0.14	0.08	− 0.25	0.04*
Numbers of years of education	− 0.006	0.92	0.05	0.33	− 0.02	0.71	− 0.01	0.88
Work of Caregivers	0.13	0.03*	− 0.02	0.69	0.003	0.96	0.15	0.14
Gender of child #2								
Males	0.02	0.67	0.06	0.27	0.05	0.5	0.01	0.92
The severity of the disease for child #3								
Severe	− 1.06	0.54	1.31	0.000*	1.37	0.001*	1.37	0.03*
Duration of the disease for child	− 0.24	0.05	− 0.03	0.79	0.35	0.008*	− 0.01	0.88
Depression	−	−	− 2.04	0.68	2.49	0.000*	2.29	0.17
Anxiety	− 3.06	0.68			3.63	0.000*	3.96	0.000*
Somatization	1.1	0.17	1.27	0.000*	− 1.31	0.000*		
Sensitivity	2.41	0.000*	2.42	0.000*			− 2.72	0.000*
Total score of associative stigma	1.15	0.12	− 1.009	0.92	1.23	0.02*	2.012	0.94
Total score of Burden Scale	1.49	0.000*	1.14	0.25	− 1.38	0.01*	1.05	0.83
Total score of quality of life	− 0.17	0.07	− 0.19	0.02*	0.05	0.64	0.1	0.56

Multivariate Linear Regression Model

1female was reference group

2female was reference group

3Moderate group was reference group

*Significant *P* value < 0.05

did caregivers with a moderate burden. Many factors are associated with stigma and burden, such as worked caregivers, gender of the caregiver and their autistic children, duration of the disease, impaired QoL, and presence of parental mental health problems.

Werner and colleagues (2013) investigated the stigma of child caretakers with various mental illnesses, including autism. The findings revealed that good psychosocial resources had an essential influence on the experiences. The negative link between stigma and QoL among caregivers has been influenced by self-esteem, social support, and positive opinions [40]. Dehnaviet and colleagues (2011) highlighted the multilevel roles of social stigma on the mental health of mothers with children on the autistic spectrum. They discovered that mothers of autistic children struggled with associated stigma in different aspects of their lives. The degree of internalized stigma can predict 25% of the variations in maternal mental health [41].

According to a systematic review of stigma among ASD parents, parents of autistic children reported that stigma varied by both the behaviors of autism and the severity of symptoms, particularly for mothers. Furthermore, most parents stated that they were particularly vulnerable to stigma in school and community settings. Although

stigma experiences could vary among social cultures [42], parents from various cultures (West to East) have difficulty dealing with the stigma of having an autistic child [43].

With regard to the SCL9, caregivers with severe burden had greater depression and anxiety than caregivers with moderate burden. Moreover, caregivers with a severe burden had twice the frequency of sensitivity and somatization issues as did caregivers with a moderate burden. Parents with mental health problems were more vulnerable to psychosocial stressors, such as age and work of caregivers, gender of caregivers and their autistic children, increased burden and stigma, presence comorbid parental mental health problems, and impaired QoL.

An increase in mental health problems has been observed both before and after the birth of a child [44, 45]. From 21 of 55 studies by US researchers published from January 1, 2000, to December 31, 2016, a literary review reported that parental stress, depression, and/or anxiety related to caring for autistic child [37]. Furthermore, three studies [46–48] indicated that mothers have a greater likelihood of having mental health problems, but other studies have found no considerable differences in perception of ASD's psychological impact on fathers or mothers [49–51]. In the investigation of

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possible triggers of mental health problems, it was found that the genetic predisposing could account for the association between psychopathology in children and their parents, but a previous study using genetically sensitive designs showed that the environment plays a significant role in the transgenerational association of anxiety [52], depression [53], and conduct problems [54]. Environmental factors play a role in developing psychopathology, such as intense parenting challenges. These intense parenting challenges were related to parent and child age, as well as the parent's ability to express their feelings [19], challenging behavior in ASD children [55–57], family working [58], ASD severity [59], social support [60], and interpersonal strain on the parents' social network [61].

Caregivers with a severe burden had a lower QoL (20%) than did caregivers with a moderate burden. Multivariate logistic regression was conducted to detect possible independent predictors of QoL. The age of the caregivers, increased burden, and the presence of parental mental health problems such as anxiety would increase the risk of impaired QoL for families who have children with ASD.

Previous research has shown that parenting an autistic child has a detrimental effect on the QoL of parents [30, 49–51]. Although other studies found no differences in the QoL of mothers and fathers [50, 51], one study [30] reported that mothers had lower levels of QoL than fathers did.

This gender disparity in partner effects may be due to fathers' tendency to utilize inadequate coping mechanisms when raising their autistic children. Mothers of autistic children are more likely to use social support and problem-focused coping, while fathers are more likely to use distraction and avoidant coping, according to studies [62–64]. Furthermore, studies on the relationship between ASD severity and parent QoL have provided conflicting results, with two studies indicating a negative relationship [26, 27] and two indicating no relationship [28, 29].

Our study had some limitations, such as the relatively small sample size. We also recruited parents of autistic children who attended paid public centers, who are not representative of children under the age of 5 years or adults with ASD or mild severity of ASD. We did not include families with single parents, adopted families, or unmarried couples. Thus, we recommend that future studies include large sample sizes of ASD families in Egypt to verify our research results. Also, we participated in children from different centers that were evaluated their severity and diagnosed with autism by different psychometry scales. Finally, due to the survey's cross-sectional design, we were unable to investigate the causal relationship of variables. As a result, a longitudinal study is advised.

This study found that caregivers with a severe burden had a higher likelihood of severe symptoms of autism in the child, significant stigma, lower QoL, more depression and anxiety, and about twice the frequency of sensitivity and somatization problems than did caregivers with moderate burden. Regarding risk factors, worked caregivers, male autistic children and their caregiver, increased age of the child and parents, and increase duration of disease were protective factors from increased burden and stigma, impaired QoL, and parent with mental health problems in autistic families, whereas more severe autism was a risk factor for the presence of these variables in the child.

A few significant implications for practitioners have been discovered in this study, which might be used to support families of autistic children and assist in understanding the challenges they face in terms of improving QoL and reducing stigma, burden, and mental health problems of ASD parents. These challenges include health, financial well-being, assistance from disability-related services, spiritual and cultural beliefs, careers and job preparation, family relations, leisure, and pleasure of life [65]. For example, pointed out that practitioners might discover programs such as "parent night out" that help couples to develop connections by offering care for ASD-supported children through organizations [66]. In addition, Lee and colleagues (2009) indicated that financial well-being can be affected [29], which is a demographic characteristic over which practitioners have no influence; therefore, practitioners should be required to integrate this element to create intervention programs for parents, that is, to more specifically address caregiver needs [29]. Once again, it was concluded that these strategies could be used either to improve QoL or to cope with parental stressors or both to create intervention programs for the benefit of parents of children with ASD.

Conclusions

We found there was a lack of mild burden in ASD families, which might reflect problems in developing countries with pay public services for ASD children. Furthermore, there were no children with mild autism in this study because the parents were unfamiliar with the disease and how to detect and treat it. So, this is highlighting the need to offer free professional services, increase awareness of the disease, offer psychiatric help and support for parents, and improve the QoL for autistic children, especially in developing countries.

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Declarations

Ethics approval and consent to participate
The study received ethical approval from Assiut University, Faculty of Medicine's institutional review board (IRB). Parents signed an informed consent for study participation on behalf of their children. All procedures performed in this study were in accordance with the ethical standard of the institution and/or national research committee and with the 1964 Helsinki Declaration and its later amendments.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

Author details
[1]Department of Neurology and Psychiatry, Faculty of Medicine, Assiut University, Assiut, Egypt. [2]Faculty of Arts, Assiut University, Assiut, Egypt. [3]Department of Child & Adolescent Psychiatry, Institute of Psychiatry, Psychology & Neuroscience, King's College London, London SE5 8AF, UK.

References
1. American Psychiatric Association, American Psychiatric Association. Diagnostic and statistical manual of mental disorders: DSM-5. Arlington, VA; 2013.
2. Maenner MJ, Shaw KA, Baio J. Prevalence of autism spectrum disorder among children aged 8 years—autism and developmental disabilities monitoring network, 11 sites, United States, 2016. MMWR Surveill Summ. 2020;69(4):1.
3. Sun X, Allison C, Wei L, Matthews FE, Auyeung B, Wu YY, et al. Autism prevalence in China is comparable to Western prevalence. Molecular autism. 2019;10(1):1–19.
4. Wang H, Hu X, Han ZR. Parental stress, involvement, and family quality of life in mothers and fathers of children with autism spectrum disorder in mainland China: A dyadic analysis. Res Dev Disab. 2020;107:103791.
5. Meyer KA, Ingersoll B, Hambrick DZ. Factors influencing adjustment in siblings of children with autism spectrum disorders. Res Autism Spectr Disorders. 2011;5(4):1413–20.
6. Smith LE, Hong J, Seltzer MM, Greenberg JS, Almeida DM, Bishop SL. Daily experiences among mothers of adolescents and adults with autism spectrum disorder. J Autism Dev Disord. 2010;40(2):167–78.
7. Weiss JA, Wingsiong A, Lunsky Y. Defining crisis in families of individuals with autism spectrum disorders. Autism. 2014;18(8):985–95.
8. Dyches TT, Wilder LK, Sudweeks RR, Obiakor FE, Algozzine B. Multicultural issues in autism. J Autism Dev Disord. 2004;34(2):211–22.
9. Samadi SA, McConkey R. Autism in developing countries: Lessons from Iran. Autism research and treatment. 2011;2011
10. Uwaezuoke SN. Autism Spectrum Disorder in children: the disparities between the developed and developing countries. Autism Open Access. 2015;5(3):152.
11. Read N, Schofield A. Autism: are mental health services failing children and parents? Recent research suggests that many CAMHS need to improve. J Fam Health Care. 2010;20(4):120–5.
12. Kogan MD, Blumberg SJ, Schieve LA, Boyle CA, Perrin JM, Ghandour RM, et al. Prevalence of parent-reported diagnosis of autism spectrum disorder among children in the US, 2007. Pediatrics. 2009;124(5):1395–403.
13. Zuckerman KE, Lindly OJ, Sinche B. Parent beliefs about the causes of learning and developmental problems among children with autism spectrum disorder: Results from a national survey. Am J Intellect Dev Disabil. 2016;121(5):432–47.
14. Gona JK, Newton CR, Rimba K, Mapenzi R, Kihara M, Van de Vijver FJ, et al. Parents' and professionals' perceptions on causes and treatment options for autism spectrum disorders (ASD) in a multicultural context on the Kenyan coast. PLoS ONE. 2015;10(8):e0132729.
15. Harrington JW, Patrick PA, Edwards KS, Brand DA. Parental beliefs about autism: implications for the treating physician. Autism. 2006;10(5):452–62.
16. Mire SS, Gealy W, Kubiszyn T, Burridge AB, Goin-Kochel RP. Parent perceptions about autism spectrum disorder influence treatment choices. Focus Autism Other Dev Disabil. 2017;32(4):305–18.
17. Bayat M. Evidence of resilience in families of children with autism. J Intellect Disabil Res. 2007;51(9):702–14.
18. Bitsika V, Sharpley CF. Stress, anxiety and depression among parents of children with autism spectrum disorder. Aust J Guid Couns. 2004;14(2):151–61.
19. Duarte CS, Bordin IA, Yazigi L, Mooney J. Factors associated with stress in mothers of children with autism. Autism. 2005;9(4):416–27.
20. Zaidman-Zait A, Mirenda P, Duku E, Vaillancourt T, Smith IM, Szatmari P, et al. Impact of personal and social resources on parenting stress in mothers of children with autism spectrum disorder. Autism. 2016;21(2):155–66.
21. Karst JS, Van Hecke AV. Parent and family impact of autism spectrum disorders: a review and proposed model for intervention evaluation. Clin Child Fam Psychol Rev. 2012;15(3):247–77.
22. Benson PR, Kersh J. Marital quality and psychological adjustment among mothers of children with ASD: cross-sectional and longitudinal relationships. J Autism Dev Disord. 2011;41(12):1675–85.
23. Pottie CG, Ingram KM. Daily stress, coping, and well-being in parents of children with autism: a multilevel modeling approach. J Fam Psychol. 2008;22(6):855.
24. Hoefman R, Payakachat N, van Exel J, Kuhlthau K, Kovacs E, Pyne J, et al. Caring for a child with autism spectrum disorder and parents' quality of life: application of the CarerQol. J Autism Dev Disord. 2014;44(8):1933–45.
25. Lickenbrock DM, Ekas NV, Whitman TL. Feeling good, feeling bad: Influences of maternal perceptions of the child and marital adjustment on well-being in mothers of children with an autism spectrum disorder. J Autism Dev Disord. 2011;41(7):848–58.
26. Khanna R, Madhavan SS, Smith MJ, Patrick JH, Tworek C, Becker-Cottrill B. Assessment of health-related quality of life among primary caregivers of children with autism spectrum disorders. J Autism Dev Disord. 2011;41(9):1214–27.
27. Zablotsky B, Anderson C, Law P. The association between child autism symptomatology, maternal quality of life, and risk for depression. J Autism Dev Disord. 2013;43(8):1946–55.
28. Kuhlthau K, Payakachat N, Delahaye J, Hurson J, Pyne JM, Kovacs E, et al. Quality of life for parents of children with autism spectrum disorders. Res Autism Spectr Disorders. 2014;8(10):1339–50.
29. Lee GK, Lopata C, Volker MA, Thomeer ML, Nida RE, Toomey JA, et al. Health-related quality of life of parents of children with

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high-functioning autism spectrum disorders. Focus Autism Other Dev Disabil. 2009;24(4):227–39.

30. Obeid R, Daou N. The effects of coping style, social support, and behavioral problems on the well-being of mothers of children with autism spectrum disorders in Lebanon. Res Autism Spectr Disorders. 2015;10:59–70.

31. Abdel-Tawab MA, 2010. Socioeconomic scale for family, revised edition. M.D. thesis in educational basics, Faculty of Education, Assiut University, 3: 32–55. 2010.

32. Bachner YG. Preliminary assessment of the psychometric properties of the abridged Arabic version of the Zarit Burden Interview among caregivers of cancer patients. Eur J Oncol Nurs. 2013;17(5):657–60.

33. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. Gerontologist. 1980;20(6):649–55.

34. Weiss M. Explanatory Model Interview Catalogue (EMIC): Framework for comparative study of illness. Transcult Psychiatry. 1997;34(2):235–63.

35. Derogatis LR. SCL-90-R: Administration, scoring and procedures. Manual II for the R (evised) Version and Other Instruments of the Psychopathology Rating Scale Series. 1983

36. Skevington SM, Lotfy M, O'Connell KA. The World Health Organization's WHOQOL-BREF quality of life assessment: psychometric properties and results of the international field trial. A report from the WHOQOL group. Qual Life Res. 2004;13(2):299–310.

37. Al Khateeb JM, Kaczmarek L, Al Hadidi MS. Parents' perceptions of raising children with autism spectrum disorders in the United States and Arab countries: a comparative review. Autism. 2019;23(7):1645–54.

38. Al-Farsi YM, Waly MI, Al-Sharbati MM, Al-Shafaee M, Al-Farsi O, Al-Fahdi S, et al. Variation in socio-economic burden for caring of children with autism spectrum disorder in Oman: caregiver perspectives. J Autism Dev Disord. 2013;43(5):1214–21.

39. Dababnah S, Bulson K. "On the sidelines": access to autism-related services in the West Bank. J Autism Dev Disord. 2015;45(12):4124–34.

40. Werner S, Shulman C. Does type of disability make a difference in affiliate stigma among family caregivers of individuals with autism, intellectual disability or physical disability? J Intellect Disabil Res. 2015;59(3):272–83.

41. Dehnavi SR, Malekpour M, Faramarz S, Talebi H. The share of internalized stigma and autism quotient in predicting the mental health of mothers with autism children in Iran. Int J Busin Soc Sci. 2011;2:20.

42. Mak WW, Kwok YT. Internalization of stigma for parents of children with autism spectrum disorder in Hong Kong. Soc Sci Med. 2010;70(12):2045–51.

43. Liao X, Lei X, Li Y. Stigma among parents of children with autism: a literature review. Asian J Psychiatr. 2019;45:88–94.

44. Bolton P, Pickles A, Murphy M, Rutter M. Autism, affective and other psychiatric disorders: patterns of familial aggregation. Psychol Med. 1998;28(2):385–95.

45. Jokiranta E, Brown AS, Heinimaa M, Cheslack-Postava K, Suominen A, Sourander A. Parental psychiatric disorders and autism spectrum disorders. Psychiatry Res. 2013;207(3):203–11.

46. Kheir N, Ghoneim O, Sandridge AL, Al-Ismail M, Hayder S, Al-Rawi F. Quality of life of caregivers of children with autism in Qatar. Autism. 2012;16(3):293–8.

47. Al-Farsi OA, Al-Farsi YM, Al-Sharbati MM, Al-Adawi S. Stress, anxiety, and depression among parents of children with autism spectrum disorder in Oman: a case–control study. Neuropsychiatr Dis Treat. 2016;12:1943.

48. Fido A, Al Saad S. Psychological effects of parenting children with autism prospective study in Kuwait. 2013

49. Almansour MA, Alateeq MA, Alzahrani MK, Algeffari MA, Alhomaidan HT. Depression and anxiety among parents and caregivers of autistic spectral disorder children. Neurosciences. 2013;18(1):58–63.

50. Dardas LA, Ahmad MM. Predictors of quality of life for fathers and mothers of children with autistic disorder. Res Dev Disabil. 2014;35(6):1326–33.

51. Dardas LA, Ahmad MM. Quality of life among parents of children with autistic disorder: a sample from the Arab world. Res Dev Disabil. 2014;35(2):278–87.

52. Eley TC, McAdams TA, Rijsdijk FV, Lichtenstein P, Narusyte J, Reiss D, et al. The intergenerational transmission of anxiety: a children-of-twins study. Am J Psychiatry. 2015;172(7):630–7.

53. McAdams TA, Rijsdijk FV, Neiderhiser J, Narusyte J, Shaw DS, Natsuaki M, et al. The relationship between parental depressive symptoms and offspring psychopathology: evidence from a children-of-twins study and an adoption study. Psychol Med. 2015;45(12):2583–94.

54. D'Onofrio BM, Slutske WS, Turkheimer E, Emery RE, Harden KP, Heath AC, et al. Intergenerational transmission of childhood conduct problems: a Children of Twins Study. Arch Gen Psychiatry. 2007;64(7):820–9.

55. Hall HR, Graff JC. The relationships among adaptive behaviors of children with autism, family support, parenting stress, and coping. Issues Compr Pediatr Nurs. 2011;34(1):4–25.

56. Schaaf RC, Toth-Cohen S, Johnson SL, Outten G, Benevides TW. The everyday routines of families of children with autism: Examining the impact of sensory processing difficulties on the family. Autism. 2011;15(3):373–89.

57. Walsh CE, Mulder E, Tudor ME. Predictors of parent stress in a sample of children with ASD: Pain, problem behavior, and parental coping. Res Autism Spectr Disorders. 2013;7(2):256–64.

58. Johnson N, Frenn M, Feetham S, Simpson P. Autism spectrum disorder: parenting stress, family functioning and health-related quality of life. Fam Syst Health. 2011;29(3):232.

59. Lyons AM, Leon SC, Phelps CER, Dunleavy AM. The impact of child symptom severity on stress among parents of children with ASD: The moderating role of coping styles. J Child Fam Stud. 2010;19(4):516–24.

60. Tobing LE, Glenwick DS. Predictors and moderators of psychological distress in mothers of children with pervasive developmental disorders. J Fam Soc Work. 2007;10(4):1–22.

61. Benson PR. Network characteristics, perceived social support, and psychological adjustment in mothers of children with autism spectrum disorder. J Autism Dev Disord. 2012;42(12):2597–610.

62. Ang KQP, Loh PR. Mental Health and Coping in Parents of Children with Autism Spectrum Disorder (ASD) in Singapore: An Examination of Gender Role in Caring. J Autism Dev Disord. 2019;49(5):2129–45.

63. Dabrowska A, Pisula E. Parenting stress and coping styles in mothers and fathers of pre-school children with autism and Down syndrome. J Intellect Disabil Res. 2010;54(3):266–80.

64. Pozo P, Sarriá E, Brioso A. Family quality of life and psychological well-being in parents of children with autism spectrum disorders: a double ABCX model. J Intellect Disabil Res. 2014;58(5):442–58.

65. Hoffman L, Marquis J, Poston D, Summers JA, Turnbull A. Assessing Family Outcomes: Psychometric Evaluation of the Beach Center Family Quality of Life Scale. J Marriage Fam. 2006;68(4):1069–83.

66. Mancil GR, Boyd BA, Bedesem P. Parental stress and autism: are there useful coping strategies? Education and Training in Developmental Disabilities. 2009:523–37.

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