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REVIEW ARTICLE

Prevalence of psychological distress among parents of children with autism in Al-Diwaneyah province/Iraq

Noor Abdulmahdi Alrabeeah[1], Abdulzahra Al-Khafaji[2]

[1]Al_Diwaniyah Teaching Hospital/ Psychiatry Department, Al-Diywaniyah, Iraq

[2]M.B.Ch.B.,F.I.C.M.S.(psych)/ Consultant Psychiatrist, Al-Diywaniyah, Iraq
*Corresponding author: E-mail: dr.nooralrabeeah@gmail.com

Abstract:

Background: Families suffer from a lot of psychological pressure in accepting their child's illness, especially if the disorders are affecting their mental and psychological development, such as autistic spectrum disorder.

Aim: The study aimed to evaluate the extent of psychological distress among parents of children with autistic disorder and its association with the socio-demographic characteristics of their children with autism.

Material and Method: A descriptive analytical study conducted during the period from January 15, 2023, to December 1, 2023, on a sample of voluntary participants consisting of 120 parents in Al-Diwaniyah Teaching Hospital. Data were collected through the use of a constructed questionnaire and the General Health Questionnaire (GHQ28).

Results: parents of children with autism suffer from psychological distress. The results indicated that the factors increasing psychological distress include being in the age group of 26 to 35 years, being divorced or widowed, experiencing a difficult economic situation, and being unemployed. The distress was more severe if the affected child was male. Psychological distress among parents was also significantly associated with attention deficit hyperactivity.

Conclusion: The study indicated that autism is associated with stress among parents and caregivers of affected children. The additional requirements and care that a child with autism needs lead to an increased risk of psychological distress, depression, and anxiety among the child's family or caregiver.

Keywords: Psychological disorders, distress, parents, children, autism spectrum, caregiver.

Introduction

Autistic spectrum disorder (ASD) is a lifelong neurodevelopmental disorder diagnosed by several behavioral features (1). According to the Diagnostic and Statistical Manual of Mental Disorders, fifth edition, DSM-5, the core clinical characteristic of ASD is a deficit in two areas of functioning, «social communication and social interaction,» in addition to stereotyped behaviors, interests, or activities (2). These symptoms are present in a child›s early developmental life but are not fully apparent until social demands are more than the child›s limited capacities (3).

Autism is associated with more burden and stress for parents (4) compared with parents of children with other disabilities. The demands placed on parents caring for a child with autism are associated with a higher overall incidence of parental stress, depression, and anxiety, which adversely affects family functioning and marital relationships (5, 6).

According to the WHO factsheet 2017 entitled "Autism Spectrum Disorders," the disease forces significant economic and emotional burdens not only on the patients but also on their families and caregivers (7). Mothers of children with autism have to face severe disabilities presented in their children and endure the emotional, financial, and social burden of their children›s condition. They are more susceptible to social isolation and 'burnout syndrome,' and they are more likely to suffer from depression and anxiety (8).

There are many factors that contribute to psychological stress in parents of autistic children, such as the deficit in the autistic child's verbal and nonverbal communication skills, impairment of socialization skills, poor ability to manage daily routines, and other barriers such as inappropriate school system services to address the needs of the child, and lack of other support resources will impose more burden on families raising a child with ASD (9). Parenting an autistic child is challenging because of the heterogeneous and chronic nature of the disorder and a wide range of possible co-occurring conditions (10). Because of the absence of evidence-based treatment options, parents of autistic children are in a continuous search for services from different sources and specialists to address and provide for the needs of their children (11). Also, the source of stress may be

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due to exhausted emotional relationships, necessarily limited family social or pleasurable activities and unachieved career ambitions, reduced chances for social and leisure pursuits, difficulties in meeting the treatment demands and appointments, educational disadvantages, and the ongoing difficulty in coming to terms with the disability (12).

Method

Study area and period:

A descriptive study was conducted from 15th January 2023 until 1st December 2023 (10 months) in the psychiatry consultation clinic in Al-Diwaniyah Teaching Hospital.

Population:

The sample consists of 120 parents, aged between 18 and more than 45 years; they have children diagnosed with Autism Spectrum Disorder (ASD) who already meet the DSM-5 criteria of autism.

Data collection:

The parents who were chosen to participate in the study gave their verbal consent. Each parent was interviewed separately using a structured interview that covered the socio-demographic characteristics of parents and their children. The demographic questionnaire included information about age, sex, educational level, and employment details of the parents and sociodemographic and clinical information of their autistic children.

In addition to that, the parents› psychological status assessment was conducted using the General Health Questionnaire (GHQ 28-item version; Goldberg, 1979) (56). The GHQ 28 version was utilized in this study. The questionnaire has 4 subclasses:

1) Somatic symptoms (items 1–7)
2) Anxiety and insomnia (items 8–14)
3) Social dysfunction (items 15–21)
4) Severe depression (items 22–28)

Inclusion criteria:

1. Both genders (fathers and mothers)
2. All parents of children with autism who consented to take part in the study.
3. Absence of further general medical conditions or another mental
illness.
4. Parents who lived inside the Al-Diwaneyah government who are Iraqi nationals.

Exclusion criteria:

1. Individuals who were uncooperative
2. People whose kids were diagnosed with other mental illnesses (e.g., learning disability, mental retardation)
3. Illiterate parents who cannot read the questionnaire.

Ethical consideration:

The Iraqi Board of Psychiatry ethical and scientific committee thoroughly debated and accepted the research proposal. Before beginning the data gathering process, the health authority›s verbal agreement was obtained. Verbal agreement was obtained from each parent.

Statistical analysis:

Using a personal laptop, the acquired data were entered into Microsoft Excel and imported for statistical analysis. The findings were sorted and tabulated statistically. Tables and graphs with descriptive statistics, such as data frequencies and percentages, were displayed. Data were analyzed using SPSS (statistical package for social science, version 26; Chicago, USA, IBM). The data were presented as numbers and percentages. The chi-square test was used. P-value was considered significant when < or = 0.05.

Result

The frequency distribution of parents according to psychological status is shown in figure 3.1. GHQ of < 24 was reported in 45 (37.5%) of cases, whereas GHQ of >

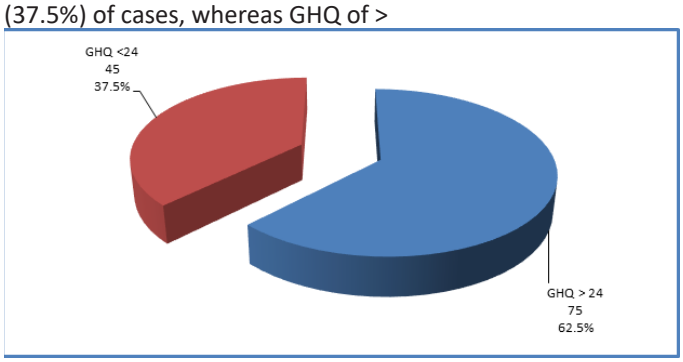

Figure 3.1: Pie chart showing the frequency distribution of parents according to psychological status

The association between parents' psychological status and their socio-demographic characteristics is shown in table 3.1. Distress was significantly associated with the age interval of 26 to 35 ($p < 0.001$), with divorced and widowed status ($p = 0.035$), with no postgraduate education level ($p = 0.017$), with barely sufficient and insufficient economic status ($p < 0.001$), with unemployment ($p = 0.001$), and with single parenthood ($p = 0.002$).

Parents characteristics	Parents Psychological Status		p
	Distress Present n = 75	Distress Absent n = 45	
1) Age of parents			
< 25	5 (6.7 %)	1 (2.2 %)	0.279 C NS
26-35	62 (82.7 %)	15 (33.3 %)	< 0.001 C ***
36-45	8 (10.7 %)	27 (60.0 %)	< 0.001 C ***
>45	0 (0.0 %)	2 (4.4 %)	0.066 C NS
2) Gender of participating parents			
Male	20 (26.7 %)	15 (33.3 %)	0.437 C NS
Female	55 (73.3 %)	30 (66.7 %)	0.437 C NS
3) Marital state			
Married	61 (81.3 %)	45 (100.0 %)	0.002 C **
Divorced	7 (9.3 %)	0 (0.0 %)	0.035 C *
Widowed	7 (9.3 %)	0 (0.0 %)	0.035 C *
4) Education			
Illiterate	1 (1.3 %)	0 (0.0 %)	0.437 C NS
Primary School	5 (6.7 %)	2 (4.4 %)	0.615 C NS
Secondary school	19 (25.3%)	7 (15.6 %)	0.208 C NS
College	49 (65.3 %)	31 (68.9 %)	0.689 C NS
Postgraduate	1 (1.3 %)	5 (11.1 %)	0.017 C *
5) Finance			

Sufficient	14 (18.7 %)	40 (88.9 %)	< 0.001 C ***
Barely sufficient	25 (33.3 %)	5 (11.1 %)	0.006 C **
Insufficient	36 (48.0 %)	0 (0.0 %)	< 0.001 C ***
6) Residence			
Rural	16 (21.3 %)	13 (28.9 %)	0.349 C NS
Urban	59 (78.7 %)	32 (71.1 %)	0.349 C NS
7) Employment			
Unemployed	44 (58.7 %)	12 (26.7 %)	0.001 C ***
Government employee	20 (26.7 %)	27 (60.0 %)	< 0.001 C ***
Private section employee	11 (14.7%)	6 (13.3 %)	0.839 C NS
8) Family type			
Nuclear	55 (73.3 %)	26 (57.8 %)	0.078 C NS
Extended	6 (8.0 %)	19 (42.2 %)	0.001 C ***
Single parent	14 (18.7 %)	0 (0.0 %)	0.002 C **

Table 3.1: The association between Parents Psychological Status and their socio-demographic characteristics

The association between parents' psychological status and children's socio-demographic characteristics is shown in table 3.2. With respect to age, distress was significantly associated with age interval 2-5 years ($p < 0.001$). With respect to gender, distress was significantly associated with male sex ($p = 0.001$). Regarding autism severity, distress was significantly associated with moderate and severe disease ($p = 0.011$ and $p < 0.001$, respectively). Distress was also significantly associated with co-occurrence of ADHD ($p < 0.001$). Distress was also significantly associated with short duration since the disorder was diagnosed for less than 1 year ($p < 0.001$). Distress was, in addition, significantly associated with lack of autism-related .(services ($p = 0.036$

Child Characteristics	Parents Psychological Status		p
	Distress present n = 75	Distress absent n = 45	
1) Age			
< 2 years	1 (1.3 %)	0 (0.0 %)	0.437 C NS
2 - 5 years	60 (80.0 %)	18 (40.0 %)	< 0.001 C ***
> 5 years	14 (18.7 %)	27 (60.0 %)	< 0.001 C ***
2) Gender			
Male	54 (72.0 %)	22 (48.9 %)	0.011 C *
Female	21 (28.0 %)	23 (51.1 %)	0.011 C *
3) Autism Severity			
Mild	3 (4.0 %)	37 (82.2 %)	< 0.001 C ***
Moderate	30 (40.0 %)	8 (17.8 %)	0.011 C *
Severe	42 (56.0 %)	0 (0.0 %)	< 0.001 C ***
4) Co-occurrence of ADHD			
Yes	56 (74.7 %)	2 (4.4 %)	< 0.001 C ***
No	19 (25.3 %)	43 (95.6 %)	< 0.001 C ***
5) Duration since diagnosis			
< 1 year	41 (54.7 %)	7 (15.6 %)	< 0.001 C ***
3-5 year	26 (34.7 %)	16 (35.6 %)	0.921 C NS
> 3 years	8 (10.7 %)	22 (48.9 %)	< 0.001 C ***
6) Available services			
No services	38 (50.7 %)	14 (31.1 %)	0.036 C *
Public institute	10 (13.3 %)	5 (11.1 %)	0.722 C NS
Private institute	27 (36.0 %)	26 (57.8 %)	0.020 C *

Table 3.2: The association between parents psychological status and children socio-demographic characteristics

Discussion

This study shows that parents of children with autism were more susceptible to negative psychological outcomes. About 62.5% of participating parents suffer from psychological disorders, which can be attributed to the many difficulties faced by these parents when caring for their child with autism. This result is higher than that reported among parents of children with autism in some other Arab countries, like Saudi Arabia and .(Qatar (13

Surprisingly, the parent's gender was not shown to be a significant predictor of psychological discomfort experienced by the parents in this study. Research carried out in Saudi Arabia yielded similar results (3). Mothers and fathers reported equal stress levels, according to another study done in the United States published by the American Psychological Association. This could be a sign of societal changes in middle-class households, where fathers are now more accountable for .(providing their children with direct care and nurture (14

The GHQ-28 subclasses mean depression and somatic symptom scores were significantly higher among mothers compared with fathers. On the other hand, the mean anxiety scores were higher in fathers than mothers. The higher scores of mothers' depression and somatic symptoms could be explained by the difference of responsibilities assigned to each parent when caring for their child. Mothers of children with autism have limitations on their own time and independence, may experience low self-esteem due to their perception of themselves as having "failed" in their job as parents, and report feeling depressed, irate, tired, and tense. These findings concur .(with those of other foreign study projects (15

The sociodemographic characteristics of parents enrolled in the study showed a higher incidence of psychological distress in the age group between 26 and 35 years. Parents in this age group start to pursue their dreams and try to achieve goals such as building a house, starting a project, pursuing a higher educational degree, or traveling; but having an autistic child is considered an obstacle and disappointment, which could prevent parents from achieving such goals. This finding is supported by a study done in Malaysia, which showed that participants falling within the 25 to 31 age range (53.8%) have .(more distress than other age groups (16

This study showed less distress among married participants and a higher level of distress among widowed and divorced participants. This can be explained in many aspects, such as marriage being a known protective factor and a good prognostic factor against depression and distress. In addition to that,

having a supportive spouse who is willing to help with rearing an autistic child will result in a better psychological outcome for both parents. In contrast, being a widowed or divorced parent who has to deal with an autistic child without emotional, financial, or physical help could be devastating. Other research has revealed similar results, demonstrating that over 50% of divorced mothers report feeling less able to enjoy life as a result .(of the difficulties involved in having an ASD child (17

Concerning educational level, the study showed no significance to all educational levels except for postgraduate parents, who have less stress than other parents, possibly due to better understanding of the nature of their child's disorder, better financial situation, and ability to achieve their goal concerning higher education, or it may be due to the small study sample of postgraduate parents (5%). Other studies showed no effect of education on the psychological state of parents who have .children with ASD

This study showed a substantial relationship between the psychological wellness of parents of children with ASD and their monthly income. Parents with sufficient finances showed less depression and anxiety. The researcher suggests that those parents were more likely to be able to provide treatment and training for their autistic children and can afford costly educational programs. In other studies, the household income was insufficient in families with ASD children and adversely associated with parents' mental health due to feelings of .(incompetence and guilt (18

In this study, residence showed non-significance in both rural and urban families, which is incongruent with other internationally available studies. This revealed more depression in families living in rural areas because of difficulty in accessing health care services for autistic children. Especially in mothers living in rural areas compared to mothers living in urban areas .((19

The employment status of participants in our study, mostly consisting of mothers, was associated with lower levels of stress. The study has found that maternal employment positively affects mood, feelings of accomplishment, and a positive sense of self-esteem. Our findings provided evidence that mothers' employment is a protective factor for mothers of children with ASD by empowering their social network, as suggested by other .(study findings (20

Worthy of mention, a correlation was discovered between the number of family members and psychological suffering. When there is an increase in the number of people living in the same house, the parental distress will be less. This may be explained as extended family-type functions as a source of inter-family support; it is well known that the family members, especially grandparents, do help each other in Iraq, and the family members are intimately bonded to one another, and providing care is a typical social norm. Larger families were not found in this study to be significantly related to higher scores of depression or anxiety; the same has been documented by .(other studies (21

The results about the relation between parent's psychological distress and autistic child sociodemographic data showed significance to the child's age, duration since diagnosis, and severity of autism disorder, which is supported by other studies .((22

Both severity of autism and comorbidity with ADHD showed adverse significance on parental psychological state. The high severity of autism and its combination with ADHD made parents more gloomy about their children's future. Additionally, these children exhibit traits that are indicative of instability and unpredictability, such as impulsivity, hyperactivity, irritability, and aggression, which make it harder for their parents to rear .them

The study showed that parents are more frustrated when their children are in the 2- to 5-year-old age group and are less frustrated when children are older. This can be attributed to the fact that parents worry about whether they will be able to go to school soon or whether they will have friends or speak normally. As their children grow older, parents' worries turn toward possibilities of independent living and self-care and doing daily tasks, which will improve as the child grows older. This is supported by other studies where older children were not found to be significantly related to higher scores of .(depression or anxiety in their parents (23

Duration of diagnosis was shown to affect the mental state of participating parents, as less than one year since diagnosis was associated with higher stress and more than 3 years was associated with less stress. This can be explained by the fact that parents managed to develop coping strategies to deal with their child's behavior and developed a better understanding about their condition. This viewpoint is supported by research where it was mentioned that parents of newly diagnosed children with ASD have negative perceptions about their child and the child's negative impact on the parent's quality of life. Family adaptation to a disabled child is not a single event but a .(lifelong process (24

Both the gender of the child and the availability of services such as treatment and training have an effect on caring parents. The study showed more parental psychological disorder associated with a male child than a female child, which can be attributed to the fact that male children are more precious than female children in our community. In addition to that, family, especially mothers, will face more societal criticism and blame for an affected male child than a female. Such results are similar to results of a study done in Baghdad/Iraq, where the gender of the child influences the parents' psychological state because .(there is a difference in parenting a boy or a girl (25

Treatment and training for children with ASD can lead to developmental gains in cognitive ability, communication skills, and reduced ASD symptoms. The primary goal of ASD intervention is improving child outcomes, but it also impacts parents' mental state and improves family functioning. Results of this study showed a positive impact of the availability of autism-focused services on parents' psychological well-being. These findings are supported by similar findings in research conducted in the United States that showed that there is a transactional relationship between parent well-being and child intervention outcomes, with each mutually influencing the .(other (26

Recommendations:

When managing a child with ASD, it is essential to evaluate the mental health of the parents, particularly mothers, in order to decide the next course of action. Research has demonstrated that having a child with a chronic disease or experiencing significant levels of life stress are risk factors for poor health

.outcomes for both parents

In order to provide the best possible care for the child and to give parents sufficient information about how to interact with their child through sessions and brochures, it is crucial to call the attention of medical professionals working with children .diagnosed with ASD to the mental health of the parents

It is advised to offer certain family-supporting activities, particularly for women, in order to improve family coping mechanisms and to develop coping mechanisms that parents .of children with autism may use to reduce stress

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