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Psychological Wellbeing among Parents of Children with Autism Spectrum Disorder

Original Research Article

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Psychological Wellbeing among Parents of Children with Autism Spectrum Disorder in Najaf Province

Abstract:

Parents of children with Autism Spectrum Disorder (ASD) reported more negative impact and poor psychological wellbeing. They appear to be at great risk for depression, stress, anxiety and distress; and many parents have managed to overcome the constant challenge by using their patience and take the consequences to adapt well in the face of adversity. The researcher highlights the family role to find themselves dealing with additional challenges to cope and accept modification, and minimizing the impact of ASD on parents by helping them to adjust their expectation to their children. A descriptive cross-sectional study was to determine the burden of ASD on the parents and to identify the level of psychological wellbeing in dealing with the impact of raising a child with ASD. The present study aimed to identify the level of severity of ASD for children, and also, to assess psychological wellbeing among parents of children with ASD, and to find out the relationship between psychological wellbeing with severity of autistic children and with parents and child characteristics.

A non-probability purposive sample of (152) children with ASD and (152) parents at AL-Najaf province. The results of the study revealed that parents of children with ASD experienced moderate level of psychological wellbeing; there were significant differences between the level of psychological wellbeing among parents and childhood autism rating scale, whereas there is a significant difference between psychological wellbeing and some of socio-demographic characteristics of Child's parents (gender and monthly income and General Health Questionnaire GHQ). The current study recommends providing family support for families with autistic children, especially a psychological one, and educational about clinical behaviors of ASD for early detection and Family to Family Education Programs to the existing services in community mental health programs.

Keywords: Psychological Wellbeing, Parents of Children, Autism Spectrum Disorder

Introduction

Autism spectrum disorder is characterized by persistent deficits in social communication and social interaction across multiple contexts, including deficits in social reciprocity, nonverbal communicative behaviors used for social interaction, and skills in developing, maintaining, and understanding relations (APA, 2013). Several ways in which parenting a child with ASD is different from parenting a child without ASD. Children with ASD often require additional primary care as well as more specialized and long-term medical care. Functional limitations may necessitate structural or technical modifications in the physical home environment.

A study by the ASD funded by the Centers for Disease Control and Prevention CDC determined the prevalence of ASD in the United States to be about 11.3 per 1,000 (1 in 88) children (Baio, 2012).

Weiss (2002) mentions that the experience of parents of children with ASD (developmental disabilities) can be positive (e.g., joyful and happy feelings) or negative (e.g., stress, burden, sorrow, physical exhaustion etc.) or a combination of both, depending on the severity of cases.

Therefore, the researcher highlights the family role to find themselves dealing with additional challenges to cope and accept modification, and minimizing the impact of ASD on parents by helping them to adjust their expectation to their children.

ASD occurs about 4.5 times more often in boys than in girls. Onset of the disorder occurs in early childhood, and in most cases, it runs a chronic course, with symptoms persisting into adulthood (Townsend 2015).

Estimated prevalence of ASD increased from 2011 to 2014 following changes in developmental disabilities questions in the National Health Interview Survey (NHIS), according to recent findings (Zablotsky, 2015).

The Study Hypothesis is ASDs children have an effect on the psychological health of parents; they may experience additional psychological and social burdens.

Objectives of the Study:

The present study aimed to identify the level of severity of ASD for children, and also, to assess psychological wellbeing among parents of children with ASD, and to find out the relation between psychological wellbeing with severity of ASD found in children, and to find out the relation between psychological wellbeing with child characteristics such as gender, age, number of children in family, sequence, child's schooling, autistic children in family, child's age at diagnosis and treatment place; also, with parent characteristics such as Child's Parent, age, occupation, educational level, family crowding index, SES scale, marital status, income, residency area, participation in trainings of ASD.

Methodology:

By using a descriptive design, a cross-sectional study was carried out with analytic utility. A self-administered questionnaire composed of two parts, each part is consisting of three domains were used, the first part (ASD children) included three domains inquiry regarding sociodemographic and clinical characteristic of autistic children and Childhood Autism Rating Scale CARS (15 questions), and the second part (parents of children) included two domains inquiry regarding socio-demographic characteristics and General Health Questionnaire GHQ (12 questions) scale. The study has been conducted on the children with ASD and their parents' at Imam Hussein Autism Center and Psychiatric Private Clinics and AL-Hakeem General Hospital/Psychiatric Department located in Najaf city/ Iraq.

Sample size was calculated according to the standard equation cross-sectional studies was used, (Naing, Winn and Rusli, 2006; Hajian-Tilaki, 2011; Charan and Biswas, 2013). A non-probability purposive (medical diagnosed as autistic child only) sample of (170) children with ASD and (170) parents' inpatients and outpatients, were selected from AL-Hakeem General Hospital/ Psychiatric Department was (32) sample and Psychiatric Private Clinics was (49) sample and from Imam Hussein Autism Center (IHAC) was (89) sample at AL-Najaf city. The data collection process has been performed from March 25, 2016 to July. Sixth, 2016.

Finally, only (152) questionnaires were acceptable for analysis due to missing or incomplete data, because some paper of questionnaire is lacking. The data were collected through the utilization of the developed questionnaire and by means of self-reported technique (paper and pencil) with the subjects who were included in the present study, by using the Arabic version of the questionnaire, because, the parents are read and write by Arabic language and then gather in one place and the purpose of the study was explained to them; verbal consent to participation was obtained and the parents answer the questionnaire at the same time for all those subjects who were included in the present study and the rate of response to the survey about 76% . A pilot study was conducted on (20) autistic children who were attending whole AL-Najaf province. The pilot study aimed to determine the following: clarity and content adequacy of the assessment tool and time required for data collection. The data collection process has been performed from March 25th, 2016 to July. 6th, 2016.

By using statistical package for social sciences (SPSS), version 20. All the scale variables were normally distributed with small Skewness and Kurtosis in some variables. Appropriate statistical tests were used accordingly, P.value ≤ 0.05 considered significant difference or relation, the statistics (Frequencies (F), Percentages (%), Means (x), Standard Deviations (SD), Mean of Score, Reliability Coefficients, Chi-square-test, Anova test and Simple Linear Regression Analysis).

Results:

A. Autistic children:



Figure (1) Distribution of Autistic Children According to their Gender

This figure show Majority of child's parent was (75.7%) mother and (14.3%) was father.

Table (1)	Distribution of the Participants' Overall Level of Severity Related to Children
	with ASD through the Total Scores

Level of ASD	(N = 1	.52)
	F.	%
Mild/ Moderate ASD	70	46.1
Severe ASD	82	53.9
Total	152	100.0

Majority of child's age was (50%) aged (7-10) years old. Majority of age of child at diagnosis (67.1 %) was Less Than 3 years. (90.1 %) treatment place of children were private, the level of severity ASD of children (53.9%) were severe ASD [Table 1].

B. Parents of Autistic children:

Table (2)	Distribution of the Parents by their Socio-Demographic Characteristics through
	Frequency and Percentage

No	No. Variables	Crouns	(n = 152)		
110.		Groups	F.	%	
	Who is the child's parent?	- Father	37	24.3	
1.		- Mother	115	75.7	
		Total	152	100	
	Parent's Age	- (18 - 24) years	9	5.9	
2.		- (25 - 31) years	44	28.9	
		- (32 - 38) years	64	42.1	

		- (39 - 45) years	26	17.1
		- 46 & Above	9	5.9
		Total	152	100
		- Illiterate	6	3.9
		- Literate (read & write)	6	3.9
		- Graduate of Primary School	33	21.7
3.	Level of Education	- Graduate of Intermediate School	32	21.1
5.	Level of Education	- Graduate of Secondary School	10	6.6
		- Graduate of High Education (Institute, University,)	65	42.8
		Total	152	100
		- Low S.E.S	50	32.9
4	Level of Socio-Economic Status	- Moderate S.E.S	64	42.1
4.		- High S.E.S	38	25.0
		Total	152	100
	Marital Status	- Married	146	96.1
		- Divorced	2	1.3
5.		- Widow	2	1.3
5.		- Separated	1	0.7
		- Partner	1	0.7
		Total	152	100
	Residency Area (Housing)	- Urban	147	96.7
6.		- Rural	5	3.3
		Total	152	100
		- Not Once	96	63.2
	Participation in Trainings	- Once	32	21.1
7.	Participation in Trainings	- Twice	15	9.9
	about ASD	- Three or More	9	5.9
		Total	152	100

Majority of child's parent was (**75.7**%) mother and (14.3%) was father. Majority of parent's age was (42.1%) aged (32-38) years old, (42.8%) were graduate of high education, (42.1%) participants of moderate S.E.S, (96.1%) were married. Nearly half of the participants had a Level of Socio-Economic Status is high (44.1%), (96.7%) participants of urban residents, more half of the participants have participation in trainings about ASD (63.2 %) are not once [Table 2].

Table (3) Prevalent of the Psychological Well-being among Parents of Children with ASD.

Psychological well-being	(N = 152)			
G.H.Q	F.	%		
No Psychological Distress	114	75.0		
Psychological Distress	38	25.0		
Total	152	100.0		

By Chi-square Test

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According to the overall evaluation of participants' psychological distress GHQ (75%) was no psychological distress (psychological well-being), and only 38 (25%) have psychological distress [Table 3].

Level of Psychological wellbeing	(n = 152)			
Level of 1 Sychological webbeing	F.	%		
No Distress	7	4.6		
Mild Distress	46	30.3		
Moderate Distress	76	50.0		
Severe Distress	23	15.1		
Total	152	100.0		

Table (4) Distribution of the Participant Level of Psychological wellbeing among Parents

By Anova Test

According to the overall evaluation of participants' levels of psychological distress (50%) was moderate psychological distress by anova Test [Table 4].

No statistically significant association was found between the overall psychological wellbeing score of parents with socio-demographic and clinical characteristics for child parent, (P> 0.05), except significant correlation with severity of ASD (P=0.03) and child's parent (P=0.004) parent's Level of Socio-Economic Status (P=0.002) [Table 5, 6, 7].

Table (5) Association between the Levels of Psychological wellbeing of Parents and Severity of ASD

Variables	Groups		roups (G.H.Q)					p-value C.S.
			No	Mild	Moderate	Severe	(N=152)	
	- Mild to	F.	6	24	34	6	70	
Autism Spectrum	Moderate	%	3.9%	15.8%	22.4%	3.9%	46.1%	D 0.02
Disorders (ASD)	- Severe	F.	1	22	42	17	82	P = 0.03
		%	0.7%	14.5%	27.6%	11.2%	53.9%	S
Total		F.	7	46	76	23	152	
		%	4.6%	30.3%	50.0%	15.1%	100.0%	

Table (6) Association between the Levels of Psychological wellbeing of Parents and Child's Parent

	Groups		Psycho	logical D	Total	p-value		
Variables			No	Mild	Moderate	Severe	(N=152)	C.S.
	- Father	F.	3	10	19	5	37	P= 0.004
Who is the		%	2.0%	6.6%	12.5%	3.3%	24.3%	
Child's Parent?	- Mother	F.	3	36	56	18	115	
		%	2.0%	23.7%	36.8%	11.8%	75.7%	H.S.
		F.	7	46	76	23	152	
	Total	%	4.6%	30.3%	50.0%	15.1%	100.0%	

Table (7) Association between the Levels of Psychological wellbeing of Parents and Monthly Income

	Level		Psycho	logical	Distress (Total	p-value	
Variables			No	Mild	Moderate	Severe	(N=152)	C.S.
	Low	F.	0	4	10	7	21	
	- Low	%	0.0%	2.6%	6.6%	4.6%	13.8%	
Level of Socio-	- Moderate	F.	3	16	35	10	64	
Economic Status		%	2.0%	10.5%	23.0%	6.6%	42.1%	P= 0.002
	- High	F.	4	26	31	6	67	S
		%	2.6%	17.1%	20.4%	3.9%	44.1%	
Total		F.	7	46	76	23	152	
100	11	%	4.6%	30.3%	50.0%	15.1%	100.0%	

Discussion of the results:

The present study included a group of (152) child (152) parent, all the children in this study were diagnosed in early childhood with ASD; however, they showed impairment related

to their 'autism features'. Almost all individuals included in the present study still meet clinical DSM-V and CARS diagnostic criteria for ASD.

Majority of autistic children are males (80.3 %) and (19.7 %) are females [Figure 1], this result reflects the higher prevalence of ASD in males compared with females. The findings of this study were supported by the study of AL-Ayadhi & Halepoto, (2011); Mandell, et al., (2002); (APA, 2000), and Bromely et al. (2004), who reports that the majority of the study subjects were males (80 %), also this result is consistent with Benjak et al., (2009).

Therefore, the males are more often diagnosed with ASD than females and the sex ratio of males to females with ASD is approximately 4:1. This evidence has predicted that psychological wellbeing associated with Autistic children of males will be highly perceived with children and their parents.

The analysis of the current study indicated that the majority of the severity of ASD more than half of the parents perceived that their children have average to high severity of autistic clinical features (53.9 %) were severe ASD [Table 1]. This result is consistent with Nikmat, et al. (2008) who revealed that more than half of the parents perceived that their child has average to high severity of autistic symptoms. Of the 52 subjects, 29 (55.8%) subjects perceived that their child's symptoms were within the severe level of ASD.

The majority of the gender (75.7 %) was Mother (females) of the completely sample, [Table 2]. This result comes along with Nikmat, et al. (2008) who revealed that the majority of the gender of parents with autistic children (65.4%) subjects were female (mother). Very few up-to-date research projects have compared the psychological wellbeing of mothers and fathers.

Concerning the parent age, the dominant age group of the study sample (42.1 %) is within (32-38) years old and the mean of age group were (25-31) years old [Table 2], this finding is supported by Nikmat, et al., (2008) who showed that the finding (53.8%) falling within (31-40) years old, is major of age group for parents of autistic children.

In relation to the subjects' levels of education, the results show that the majority of the study sample is high level of education (42.8%) [Table 2]. This result comes along with Rhoades, et al., (2007) who pointed out that (64%) of parents with autistic children were at college degree. In addition, Hamlyn et al. (2007) revealed that most of the autistic children parents were at college level (55.75). Allik, et al. (2006) stated that (64.5%) of mothers with autistic children were at high school-education.

[Table 2] shows that the majority of the subjects' marital status (96.1%) are married. This result comes in consistent along with our culture; where both males and female tend to marry early. This result is consistent with Yuen & Wai (2003), who found that (90%) of the parents with autistic children were married. Suggestion of the present finding is that the normal structure

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of families in our country is composed of father, mother, and their children and all are living together. So the effect of autistic children is on interrelation of family.

The result of the data analysis showed that the majority of the monthly income of parents (44.1%) were sufficient (high level) [Table 2], this finding agrees with Nikmat, et al; Montes and Halterman, (2008) who reported that (50%) of the sample were of a high level of household of monthly income.

The study results reveal that the differences of the observed percentages for general mental health that the majority of the GHQ (75 %) were of no psychological distress whereas the minority of them (25 %) were psychological distress [Table 3].

This result agrees with Tobing & Glenwick (2002) whose results indicate that the general mental health is mostly affected among the parents of children with ASD.

Further, the findings were consistent with Keller, et al. (2004) whose findings reveal that (90.4%) of parents with autistic children have highly significant burden and stress, and (53.8%) of the parents showed clinical disturbance in psychological wellbeing.

This result indicated that parents of children with ASD suffer from a rate of psychological co-morbidity with anxiety, increasing the disability associated with this disorder.

Parents of children with ASD frequently experience a higher amount of psychological wellbeing due to providing care to these children [Table 4]. Even though many researchers have studied children with ASD and their impact on parent's well-being (Harris, 2003).

The researcher has also shown that worries about the future are very common in mothers of children with ASD.

Heiman (2002) stated that when children were young, parents worry about whether they will be bullied at school or whether they will have any friend. As their children grow older, parents' concerns tum toward prospects for independent living, employment opportunities, potential romantic relation.

From our point of view, mothers of a child with ASD are highly burdened and more likely to report poor or fair mental health than mothers in the general populations. Tobing and Glenwick (2002) stated that most parents of children with ASD suffer a great deal of psychological burden; there are several reasons why the burden of those parenting children with ASD is so high. According to the study of Lainhart (1999) parents of autistic children had an increased rate of developing psychiatric disorder such as depression; this increased risk may be directly related to the burden of living with caring for an ASD children. Kogan et al., (2006) elucidate that parent of a child with ASD suffered from feeling of isolation and depression.

In conclusion, the study finds that stress as one psychological distress is higher than other emotional disturbance aspects (anxiety and depression) among parents with autistic children. The possible explanation regarding the high level of stress in parents could be that ASD is a pervasive developmental disorder so autistic children have more severe form of disability. Moreover, children with ASD display features such as impulsivity, hyperactivity, irritability, and aggressiveness, which are characterized by unpredictability and volatility. The researcher suggests that the experience of psychological wellbeing is related to how the individual perceives the stressful event and whether coping strategies can be used effectively to manage stress positive adaptation lower the stress.

Concerning child's age at diagnosis, the results show that there is no significant relation between the psychological wellbeing and child's age at diagnosis. These results are consistent with Stuart (2009) who mentioned that autism occupies extreme pathologies in terms of its severity, duration and impact on the family. So hopefully, early detection and diagnosis of infants and children at risk will enable treatments to be designed and implemented to alter the course of early behavior and brain development.

For this reason, no child and no family go untouched by the diagnosis parents' reactions to the diagnosis of ASD in their children ranged from initial relief that they finally know what is wrong with the child, to a complex and continuous process of grief over the loss of a "normal" child. The researcher elucidates this result as; the family's ability to remain healthy and cope with such adversity contributes to their resilience.

The results showed that the parent with ASD children have highly significant relation between psychological wellbeing of parents and severity of ASD children [Table 5]. The findings of this study were consistent with that of Nagaraju & Wilson, (2013); Nikmat, et al. (2008) and Sarkova, et al. (2006) who reported that the severity of ASD children mostly effected on their parents' regard to psychological wellbeing in future.

This result is agrees with Cadman, et al., (2012) who state that parent burden was high in both groups, but it was significantly higher in the ASD group. As for as gender is concerned the results show that there is a significant relation between the parent gender with psychological wellbeing of parent [Table 6].

The results indicated that there were no significant differences between female's parents experiencing higher level of psychological wellbeing than male's parents. This result revealed that there was significant relation between psychological wellbeing s among parents of ASD children with respect to Monthly Income [Table 7]. The result of the current study agrees with Zablotsky et al., (2015) who showed that there was significant relation between burden of autism and monthly income.

The researcher suggests that those parents with an ASD children were more likely to be in substantially lower-income households, and to have costly educational expenses. Therefore, the household income was decreased in families with ASD children, because of the parental trainings and education and healthcare services for ASD and was positively associated with family income.

This finding shows that there was a highly significant relation between psychological wellbeing s among parents of ASD children with respect to general mental health [Table 7]. This finding was consistent with Keller, et al., (2004) who found that there were parents with autistic children have highly significant psychological wellbeing and showed clinical disturbance in psychological situation. Therefore, the researcher called for further comprehensive study to explore their psychological distress, and proper program should be applied to help them managing their emotional disturbance, anxiety and stress. In this study also, the results revealed that mothers report greater impact on psychological wellbeing compared to fathers.

This finding is supported by earlier findings of Abbeduto, et al., (2004) who reported that mothers of youths with Down syndrome were less pessimistic about their children's future and reported greater reciprocated closeness with their child than do mothers of the youths with ASD.

Therefore, the researcher called for further comprehensive study to explore their psychological distress, and proper program should be applied to help them managing their emotional disturbance, anxiety and stress.

Conclusions and Recommendations (directions and implications):

A. Conclusions

According to the discussion and interpretation of the study findings, the researcher has drawn the following conclusion: The study depicts that the majority of autistic children are males, their age ranged between (7-10) years and they are diagnosed at age less than (3) years. They are treated by medications and behavioral therapy at governmental and private place. About (42.1 %) of parents were age (32 - 38) years old, and more than half of parents' children were young females (mothers) is the majority of the sample and most of the parents' lives together, with high level of education; they suffer from barely sufficient income, while approximately half of them are Moderate socioeconomic status. Parents of ASD children are impacted by psychological distress about (25%) of them. Parents of autistic children are impacted by psychological wellbeing at moderate level approximately half of them.

Most socio-demographic characteristics of autistic children have no impact on parents, psychological wellbeing except the severity of ASD children (CARS). All socio-demographic characteristics of parents have no impact on parents, psychological wellbeing except the parent's gender and the monthly income.

B. Recommendations

The study recommends: 1) appropriate and enough information regarding ASD are needed and very necessary to provide among parents of ASD children to rectify their perception and dealing with autistic children. Standard indicators should be adopted to assess child development for early recognition and diagnosis of ASD in all the primary care centers. As one of the most important aspects of burden, is financial one; supported employed programs and lifelong financial help should be planned not only for the autistic children but also for the families.

2) Counseling units can be established in the primary care centers for coordinating their services to the autistic child and their family.

Future researches to build up is also a 3) recommended program to reduce the family psychological distress of autistic children and call for further comprehensive study to explore their burden and stress, and proper program should be applied to help them managing their burden.

4) Parents to parents Education Program should be established for family members who provide care for parents with ASD children to support those who face courtesy psychological problems by presenting knowledge about ASD and treatments, teaching problem solving and communication skills and providing coping skills. It must have Press and Media played a major role in terms of providing parents with adequate information to deal with children with ASD to reduce the burdens of caring.

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