

## Psychological Distress in Parents of Autistic Children in Baghdad City

الكرب النفسي عند أولياء أمور الأطفال المصابين بالتوحد في مدينة بغداد

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### المستخلص:

**الهدف:** تهدف الدراسة إلى: (١) تقييم الكرب النفسي لدى أولياء أمور الأطفال المصابين بالتوحد، (٢) تحديد العلاقة بين الكرب النفسي والخصائص الاجتماعية والديموغرافية للوالدين مثل (العمر، الحالة الاجتماعية، العلاقة مع الطفل، المستوى التعليمي والدخل الشهري) و (٣) تحديد العلاقة بين الكرب النفسي وبعض الخصائص الاجتماعية والديموغرافية للأطفال مثل (الجنس، العمر، تسلسل الطفل و عدد الأطفال في العائلة).

**المنهجية:** دراسة وصفية تحليلية أجريت من ١٢ ديسمبر ٢٠١١ إلى ١ مايو ٢٠١٢ على عينة عرضية (غير الاحتمالية) شملت ١٢٠ من الوالدين (الأب والأم) والذين لديهم أطفال مصابين بالتوحد ويرسلون أطفالهم إلى مراكز الرعاية في بغداد. تم جمع البيانات من خلال استخدام الاستبانة وإجراء الملى الذاتي للاستبانة. وتتألف الاستبانة من ثلاثة أجزاء: 'الخصائص الاجتماعية والديموغرافية للوالدين، الخصائص الاجتماعية والديموغرافية للأطفال، ومقياس كرب الوالدين. تم تحديد صلاحية محتوى الاستبانة من خلال فريق الخبراء وتم تحديد الاتساق الداخلي للأداة من خلال الدراسة التجريبية وحساب معامل ارتباط ألفا (٠.٨٣). وقد تم تحليل البيانات من خلال تطبيق النهج الإحصائي الوصفي والاستدلالي باستخدام الحزمة الإحصائية للعلوم الاجتماعية (SPSS) النسخة ١٦.٠.

**النتائج:** كشفت النتائج أن معظم العينة من أمهات في علاقة زوجية طبيعية وتقع فئاتهن العمرية من ٢٦-٣٥ سنة، تخرجن من المعهد أو الكلية ويعشن في أسر صغيرة مع دخل شهري يكاد يكفي. وكان معظم الأطفال هم بكر في الأسرة تتراوح أعمارهم من ٣-٧ سنوات ومعظم الأسر لديها ١-٣ أطفال / أسرة. آباء وأمهات التوحد يعانون من مستوى معتدل من كرب الوالدين. هناك علاقة سلبية قوية بين أعمار الوالدين مع نوع الأسرة، وهناك علاقة معتدلة بين المتغيرات الأخرى. هناك علاقة إيجابية بين كرب الوالدين، جنس الطفل وتسلسل الطفل وليس هناك أي علاقة مع المتغيرات الأخرى.

**التوصيات:** أوصت الدراسة بتوفير المعرفة الكافية للآباء والأمهات حول كيفية التعامل مع طفلهم من خلال الدورات والكتيبات، مع التركيز على استراتيجيات التأقلم لكرب الوالدين مع الأطفال المصابين بالتوحد مع الأخذ بنظر الاعتبار من قبل وسائل الإعلام لتقليل الكرب النفسي وضرورة إجراء المزيد من الدراسات المسحية لتشمل جميع أنحاء البلاد.

### Abstract

**Objectives:** The study aims to: (1) assess psychological distress in parents of autistic children, (2) identify the relationship between psychological distress and parents' socio-demographic characteristics such as (age, marital status, relationship with child, educational level and monthly income) and (3) identify the relationship between parent's distress and some of children' socio-demographic characteristics such as (gender, age, birth order and mean number of children).

**Methodology:** A descriptive-analytical study that was carried out from December 12<sup>th</sup>, 2011 to May 1<sup>st</sup>, 2012. on a purposive (non- probability) sample of 120 parents (father and mother) who have children with autism and send their children to the delayed care centers in Baghdad. Data were collected through the use of the constructed questionnaire and the process of the self-administrative report. The questionnaire was consisted of three parts: parents' socio-demographic characteristics, autistic children' socio-demographic, and parenting stress scale. Content validity of the instrument was determined through the use of panel experts and the internal consistency of the instrument was determined through the pilot study and the computation of Alpha Correlation Coefficient ( $r = 0.83$ ). Data were analyzed through the application of descriptive and inferential statistical approaches by using Statistical Package for Social Science (SPSS) version 16.0.

**Results:** The findings revealed that most of sample were mothers in normal marital status who fall in the age group 26-35 years old graduated from institute or college and living in nuclear families with barely sufficient monthly income. Most of the children were firstborn male fall in the age group of 3-7 years and most of families have 1-3 children/family. Parents of autistic children are experiencing moderate level of parenting distress. There is strong negative relationship between parents' ages with family type and there is moderate relationship among other variables. There is positive relationship between parenting stress, child's gender and birth order and there is no relationship with other variables.

**Recommendations:** The study recommended providing adequate knowledge for parents about how to deal with their child through sessions and brochure; focusing on coping strategies for parents with autistic child should be taken in consideration by media to decrease distress and further studies should be conducted as survey to include all over the country.

**Keywords:** Psychological Distress, Parents, Autism.

## Introduction

One of the major neurodevelopmental disorder is autism which affect children at the age of three years old and characterized by significant impairment in social interaction and communication and unusual, stereotyped behaviors<sup>(1)</sup>.

Mainly parents of children with disabilities or chronic health problems suffer from psychological stress. There is indication, however, that parents of children on the autism spectrum are more prone to psychological distress<sup>(2)</sup>. A number of studies have specifically associated the troublesome behaviors of children with the autism spectrum to high levels of parental stress<sup>(3)</sup>.

Parenting a child with autism may pose additional stressors related to the child's challenges in communicating, difficult behaviors, social isolation, difficulties in self-care, and lack of community understanding<sup>(4)</sup>.

Children with autism often engage in unusual behaviors, have heightened sensory and transition difficulties<sup>(5)</sup>. Presented the unique stresses and challenges familial in parenting a child with autism, maintaining a positive sense of parenting capability may be extremely difficult<sup>(5)</sup>. Too much parents are not advised through the complicated process of coming to terms with their child's diagnosis<sup>(6)</sup>.

Children with autism have often been considered strains on family life, despite the challenging face by parents of autistic child, some parents are able to cope remarkably well, while other are conservable difficulty in dealing with these challenging<sup>(7)</sup>.

The parenting stress of having an autistic child affects the psychological wellbeing as well as functioning of the parents<sup>(8)</sup>. Therefore, the researcher interested in exploring the parenting distress in parents of children with autism and to find out the relationship between parenting a child with autism and distress indicators according to some of related characteristics of the parents and their children.

### Objectives of the study

The study aims to: (1) assess psychological distress in parents of autistic children, (2) identify the relationship between that distress and parents' socio-demographic characteristics such as (age, marital status, relationship with child, educational level and monthly income) and (3) identify the relationship between parent's stress and some of children' socio-demographic characteristics such as

(gender, age, birth order and number of children in the family).

### Methodology

A descriptive-analytic study was carried out in order to achieve the earlier stated objectives. The study was initiated in December 12<sup>th</sup>, 2011 and finished on the 1<sup>st</sup> of May, 2012. A purposive (non- probability) sample of 120 parents (father and mother) who have autistic children. and send their children to the delayed care centers in Baghdad which are: Rami Institute for Autism, Al-Rahma Institute for Autism and Child Central Teaching Hospital.

Self administrative questionnaire was constructed by the investigator for the present study through the review of available literature and related previous studies scale (Berry & Jones, 1995). The constructed questionnaire consisted of three parts: the first part include the socio-demographic characteristics of parents; the second part is related to the socio-demographic characteristics of autistic children; and the third part includes 19 items of Parenting Stress Scale. These items were rated to five levels of likert scale and scored as follows: strongly agree (5), agree (4), neutral (3), disagree (2), strongly disagree (1). The level of psychological distress was calculated as three level and scored as follows: low with cutoff point (19-44); moderate with cutoff point (45-69); and high with cutoff point (70-95).

Relevancy, and adequacy of the questionnaire were done by using of panel experts (four experts from college of nursing, three of them were specialized in psychiatric mental health nursing, and one was specialized in community health nursing) to determine the content validity of the instrument in order to achieve the present study's objectives.

The internal consistency of the instrument was determined through the pilot study and the computation of Alpha Correlation Coefficient (Cronbach's Alpha). The result of the reliability was ( $r = 0.83$ ) and such an estimation was statistically adequate which means that the questionnaire had adequate level of internal consistency and equivalence measurability.

The data were collected through the utilization of the self administrative questionnaire as a mean of data collection; the data were collected through the utilization of structured interviewing of the subjects after being willing to answer the questionnaire and participate in the study. Filling the questionnaire takes approximately 15 – 20 minutes.

Statistical analyses were conducted by using statistical package for social science (SPSS) version 16.0. Data analysis was employed through the application of descriptive and inferential statistical approaches which were performed

through the computation of the following: frequencies, percentage, means of scores, standard deviation, alpha correlation coefficient and Pearson correlation coefficient.

## Results

**Table 1. Parents' Socio-demographic Characteristics**

No.	Variable	F	%
1	<b>Age (years)</b>		
	≤ 25	16	13.3
	26 – 35	57	47.5
	36 ≤	47	39.2
	<b>Total</b>	<b>120</b>	<b>100</b>
2	<b>Relationship with child</b>		
	Father	58	48.3
	Mother	62	51.7
	<b>Total</b>	<b>120</b>	<b>100</b>
3	<b>Marital status</b>		
	Married	87	72.5
	Divorced	12	10
	Widowed	16	13.3
	Separated	5	4.2
	<b>Total</b>	<b>120</b>	<b>100</b>
4	<b>Level of education</b>		
	Read & write	2	1.7
	Primary	1	0.8
	Intermediate	17	14.2
	Secondary	38	31.7
	College or Institute	54	45
	Postgraduate	8	6.7
	<b>Total</b>	<b>120</b>	<b>100</b>
5	<b>Monthly income</b>		
	Sufficient	36	30
	Barely sufficient	54	45
	Insufficient	30	25
	<b>Total</b>	<b>120</b>	<b>100</b>
6	<b>Family type</b>		
	Nuclear	65	54.2
	Extended	55	45.8
	<b>Total</b>	<b>120</b>	<b>100</b>

**No: Number, F: Frequency, %: Percentage**

The findings of revealed that most of sample were mothers of autistic children (51.7%) fall in the age group 26-35 years old (47.5%) who were married (72.5%). Most of the sample graduated from institute or college (45%) and living in nuclear families (54.2%) with barely sufficient monthly income (45%). (Table 1)

**Table 2. Characteristics of Autistic Children**

No.	Variable	F	%
1	<b>Gender</b>		
	Male	63	52.4
	Female	57	47.5
	<b>Total</b>	<b>120</b>	<b>100</b>
2	<b>Age (year)</b>		
	< 3	31	25.8
	3 – 7	77	64.2
	8 ≤	12	10
	<b>Total</b>	<b>120</b>	<b>100</b>
3	<b>Birth's order</b>		
	First	55	45.8
	Second	30	25
	Third	18	15
	Fourth	7	5.8
	Fifth	10	8.3
	<b>Total</b>	<b>120</b>	<b>100</b>
4	<b>Number of children/family</b>		
	1 – 3	79	65.8
	4 ≤	41	34.2
	<b>Total</b>	<b>120</b>	<b>100</b>

No: Number, F: Frequency, %: Percentage

The characteristics of autistic children revealed that most of the children were male ( 52.5%) with age group of 3-7 years (64.2%), the firstborn (45.8%) children in the family consisted of 1 – 3 children (65.8).

**Table 3. Levels of Psychological Distress in Parents**

Psychological Distress	F	%	M.S	S.D
<b>Level</b>				
Low	5	4.2	2.20	0.50
Moderate	86	71.7		
High	29	24.2		
<b>Total</b>	<b>120</b>	<b>100</b>		

F: Frequency, %: Percentage, M.S: Mean of score, S.D: Standard deviation

The analysis of findings indicated that parents have moderate level of psychological distress related to their parenting of an autistic children (71.7%).

**Table 4. Distribution of Psychological Stress Related to its Items of Responses**

No	Item	Strongly agree	Agree	Not sure	Disagree	Strongly disagree	M.S	Severity
1	I am unhappy in my role as a parent of autistic child	29	36	27	19	9	3.48	M
2	There is something I would do for my autistic child if it was necessary	42	<b>65</b>	10	2	1	4.24	H
3	Caring for my autistic child sometimes takes more time and energy than I have to give	19	<b>69</b>	22	10	0	3.81	M
4	I sometimes worry whether I am doing enough for my autistic child	21	<b>63</b>	27	8	1	3.79	M
5	I don't feel close to my autistic child	1	21	19	<b>69</b>	10	2.45	M
6	I don't enjoy spending time with my autistic child	1	<b>36</b>	30	32	21	2.70	M
7	My autistic child is an unimportant source of affection for me	1	16	33	<b>46</b>	24	2.37	M
8	Having child with autism give me less certain and pessimistic view for the future	7	<b>40</b>	29	29	15	2.96	M
9	The major source of stress in my life is my autistic child	27	<b>49</b>	17	23	4	3.60	M
10	Having child with autism leaves little time and flexibility in my life	19	<b>59</b>	27	13	2	3.67	M
11	Having child with autism has been a financial burden	<b>70</b>	32	9	7	2	4.34	H
12	It is difficult to balance different responsibilities because of my autistic child	17	<b>61</b>	29	13	0	3.69	M
13	The behavior of my autistic child is often stressful to me	19	<b>63</b>	23	14	1	3.71	M
14	Because of my autistic child, I might decide not to have another child	11	10	23	<b>54</b>	22	2.45	M
15	I feel overwhelmed by the responsibility of being a parent of autistic child	26	<b>61</b>	17	11	5	3.77	M
16	Having autistic child has meant having too few choices and too little control over my life	9	33	<b>46</b>	32	0	3.16	M
17	I am unsatisfied as a parent of autistic child	5	19	33	<b>55</b>	8	2.65	M
18	I find my autistic child not enjoyable	8	36	25	<b>38</b>	13	2.90	M
19	Having autistic child has caused more problems than I expected in my relationship with my spouse	23	30	<b>33</b>	25	9	3.27	M

**M.S: Mean of Score, M: Moderate, H: High**

This table shows the mean of score which indicate that parents of autistic child experiencing moderate stress among all items except of item 2 and 11 which indicate high parent's psychological stress.

**Table 5. Correlation Between Parent's Psychological Distress and their Socio-demographic Characteristics**

Correlation	Age	Relation	Marital status	Level of Education	Monthly income	Family type	Distress
Age	1.000						
Relation	- 0.370**	1.000					
Marital status	0.250**	0.010	1.000				
Educational level	- 0.125	- 0.198*	- 0.202*	1.000			
Household income	- 0.190*	0.205*	0.231*	- 0.329**	1.000		
Family type	- 0.549**	0.120	- 0.039	0.236**	0.266**	1.000	
Stress	- 0.021	0.350**	- 0.036	- 0.147	0.094	0.169	1.000

\*\* Correlation is significant at the 0.01 level (2-tailed)

\* Correlation is significant at the 0.05 level (2-tailed)

This table depicted that there is a strong negative relationship between ages with family type and there is moderate relationship among other variables. The results of this table show also that there is no relationship between stress with (age, marital status and household income) (p-value= 0.005).

**Table 6. Correlation Between Parent's Psychological Stress and Their Children' Socio-demographic Characteristics**

Correlation	Child's gender	Child's age	Birth order	Mean Numbers of Children	Stress
Child's gender	1.000				
Child's age	0.087	1.000			
Birth order	0.022	0.207*	1.000		
Mean Numbers of Children	-0.193*	0.198*	0.608**	1.000	
Stress	0.042	0.133	0.143	0.132	1.000

\*\* Correlation is significant at the 0.01 level (2-tailed)

\* Correlation is significant at the 0.05 level (2-tailed)

The findings of this table indicated that there is positive relationship between parent's psychological stress, child's gender and birth order and there is no relationship with other variables (p-value= 0.005).

## Discussion

The analysis of findings revealed that most of sample were married mothers of autistic children, fall in the age group 26-35 years old, graduated from institute or college and living in nuclear families with barely sufficient monthly income (Table 1). These finding indicated that parenting of autistic children to be present into mothers' responsibility more than fathers, these mothers are responsible for taking care of their children and keeping on the rehabilitation programs for them. The sense of responsibility by the mothers may be expounded by their knowledge which indicated by the findings. The finding indicated also the majority of families were nuclear with barely sufficient income, this could be clarified that some families are going to be separated from the main family and due to that they may have socio-economic difficulties. A study presented supportive evidence to this result that found Rodrigue and his associates <sup>(9)</sup> who reported that 74% of parents were mothers and 77.5% of them married with 40% of parent have postgraduate degree. Additional support was found by Peishi Wang and his colleagues <sup>(10)</sup> who find that 59.2% of parents was mothers with fear enough household income.

In table (2), the characteristics of autistic children revealed that most of the children were male. Such finding could be explained by the incidence ratio of autism which reflect that the incidence rate of autism is higher in males than female because of genetic differences. A study presented supportive evidence to this result that found Brugha <sup>(11)</sup> it has been known of his survey that the cases of autism is high in males than females. The distribution of autistic children according to their age (table 2) indicated that the majority of them were fall in the age group of 3-7 years. The finding was slightly different from the results of Scott and his associates <sup>(12)</sup> who found that most of autistic children were fall in the age group of 5-11 years old. The table (2) shows also that autistic children were firstborn children in their families. Such finding may be related to several factors. In the largest study of its kind, the researchers have found that the risk of autism increases for firstborn children and children of older parents, they suggested that different factors may related but they didn't

confirmed the main factor<sup>(13)</sup>. The mean numbers of children in the family (table 2) shown that most of families have 1-3 children/family. This finding may interpreted that they are new families and they worrying about having more children to avoid their socio-economic difficulties. The finding was marginally unique in relation to the results of Bayat's<sup>(14)</sup> that reviewed the family size consisted of four or more children.

It has been known out of the finding in the table (3) that parents of autistic children are experiencing moderate level of parenting stress. It is clear of such finding that families associated with autistic children facing the emotional and psychological burdens of autistic disorder due to its nature; the children with autism usually associated with behavioral and interpersonal relationship problem which make it difficulty to deal with these children. Many studies have reviewed the impact of autism on the families and parenting stress experienced by these families. The finding was slightly dissimilar from the results of Wang and his colleagues who reported high level of stress associated with mothers of autistic children. A study presented unsupportive evidence to this result that found Rodrigue and his colleagues <sup>(9)</sup> which mentioned in their study that 50% of parents have low level of stress.

Table (4) shows the mean of score which indicate that parents of autistic child experiencing moderate stress among all items except of item 2 and 11 which indicate high parenting stress. This reflect that doing something necessary and financial burden are the major source of parenting stress. Parents are trying to provide any necessary thing for their children which made them better and also they see that having autistic child is considered a financial burden on the family. A study presented supportive evidence to this result that found Davis & Carter <sup>(15)</sup>; Wulffaert and his associates <sup>(16)</sup>.

The result in table (5) revealed that there is strong negative relationship between parents' ages with family type and there is moderate relationship among other variables. This indicates that younger parents tolerating more burden due to responsibility and efforts provided for creating new family. The findings indicated also that there is no relationship between parents' stress with their (age, marital status, and educational level). This considers an important indicator about these variables to be not affected by stress. A survey presented

supportive evidence to this result that found Intelligence Agency <sup>(17)</sup> which described the moderate relationship between stress with house income and family type.

Table (5) indicated that there is positive relationship between parent's stress, child's gender and birth order and there is no relationship with other variables. Such finding depicted the researcher's hypothesis. It has known out of the previous studies the relationship between gender and birth order in which both affect parenting stress because there is difference in parenting a boy or a girl at the same time the birth order, usually firstborn associated with more parenting difficulties and so on. A study presented supportive evidence to this result that found Hoffman <sup>(18)</sup> who found the presence of positive relationship between parenting stress and children characteristics.

#### Recommendations:

1. Providing adequate knowledge for parents about how to deal with their child through sessions and brochure.
2. Focusing on coping strategies for parents with autistic child should be taken in consideration by media to decrease stress and further studies should be conducted as survey to include all over the country.

#### References

- (1) Higgins DJ, Bailey SR, Pearce JC, Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder, *Autism*, 2005, Vol. 9, pp. 125– 137
- (2) Gallagher, S. & Whiteley, J., The Association Between Stress and Physical Health in Parents Caring for Children with Intellectual Disabilities is Moderated by Children's Challenging Behaviours, *J Health Psychol.*, 2013, Vol. 18, No. 9, p. 1220.
- (3) Anderson, C, Relieving Parental Stress and Depression: How Helping Parents Helps Children, Kennedy Krieger Institute, 2010.
- (4) Weiss MJ, Hardiness and social support as predictors of stress in mothers of typical children, children with autism, and children with mental retardation, *Autism*, 2002, Vol. 6, pp. 115– 130.
- (5) Autism and Parenting Stress, Parenting a child with autism is an extraordinary challenge, Bright Tots information on child development, available at [www.brighttots.com](http://www.brighttots.com), accessed on May, 2013.
- (6) American Psychiatric Association: Diagnostic and Statistical Manual of Mental Disorders, 4th, text revision (*DSM-IV-TR*), 2000.
- (7) Centers for Disease Control and Prevention, Parental report of diagnosed autism in children aged 4–7 years, *United States*, 2003–2004.
- (8) Wati Nikmat, A., Ahmed, A., Laioon, N. & Razali, S., Stress and Psychological Wellbeing Among Parents of Children with Autism Spectrum Disorder, *ASEAN Journal of Psychiatry*, 2008, Vol. 9., No. 2, p. 65.
- (9) Rodrigue J, Morgan S & Geffken G, Families of autistic children: Psychological functioning of mothers, *Journal of Clinical Child Psychology*, 1990, Vol. 19, No. 4, pp. 371–379.
- (10) Wang P, Michaels C & Day M, Stresses and Coping Strategies of Chinese Families with Children with Autism and Other Developmental Disabilities, *J Autism Dev Disord*, 2011, Vol. 41, pp. 783–795
- (11) Brugha, T , McManus S, Smith J, Scott F , Meltzer H, Purdon S, & others, Validating two survey methods for identifying cases of autism spectrum disorder among adults in the community, *Psychol Med* , 2011, Vol. 29, pp.1-10.
- (12) Scott F, Baron-Cohen S, Bolton P, and Brayne C, Brief Report: Prevalence of Autism Spectrum Conditions in Children Aged 5 – 11 Years in Cambridgeshire, UK, *Autism Research Centre*, University of Cambridge, 2002.
- (13) Rust S, UW researcher finds link between age, birth order and autism available at <http://www.jsonline.com>, access by February, 2012.
- (14) Bayat M, Evidence of resilience in families of children with autism, *Journal of Intellectual Disability Research*, 2007, Vol. 51, No. 9, pp. 702–714.
- (15) Davis N & Carter A, Parenting Stress in Mothers and Fathers of Toddlers with Autism Spectrum Disorders: Associations with Child Characteristics, *J Autism Dev Disord*, 2008, Vol. 38, pp. 1278–1291.



- (16) Wulffaert J, & Scholte E, Dijkxhoorn Y, Bergman J, Ravenswaaij-Arts S & Berckelaer-Onnes I, Parenting Stress in CHARGE Syndrome and the Relationship with Child Characteristics, *J Dev Phys Disabil*, 2009, Vol. 21, 301–313.
- (17) Central Intelligence Agency, *Maternal Stress and Infant Mortality - Psychological Science*, 2009.
- (18) Hoffman C, Sweeney D., Lopez-Wagner M, Children with autism: Sleep problems and mothers' stress, *Focus on Autism and Other Developmental Disabilities*, 2008, Vol. 23, No. 3, pp. 155-165.

