

Assessing the issues of Children's parents with autism spectrum disorders in Al-Najaf City

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Abstract- Autistic spectrum disorder (ASD) is a new unique disorder. It has qualitative impairments on child and many impacts extend to all family members and his community.

A cross-sectional study was included (80) parents had child with ASD enrolled in centers for ASD caring in Al-Najaf City. The study aimed to assess the parents issues, as well as, to find any significant relationship among severity of ASD and demographic characteristic of parents, child and impacts them.

Purposive sample used to select parents to participate in study according residence in Al-Najaf Province, enrolled their child in centers for autism and have at least one biological parents as a guardian on him.

A tool of study contain two main parts. First part included question related to demographic characteristics of parents and their child. Second part related to impacts on parents. As well as information about informants and copy from CARS scale to detect severity of ASD by staff of autism centers.

The results revealed (46.3%) of both the mothers and fathers shared to answer the questionnaire together and more (76%) of parents have good information about ASD and readiness to receive more information about it. More than (78%) of children have moderate to severe ASD. There is significant relation among severity of ASD, types of treatment used with child and degree of impacts on parents, but no significance between severity of ASD and parents health status.

The study concluded ASD have more impacts on parents when severity of it increased, closeness between parents increased after diagnosing their child with it. So it is recommended to establish special multidisciplinary plan among Ministries of Health, Education and Iraqi Ministry of Labor and Social Affairs to support and reduce the parents and their child impacts.

Index Terms- Assessing, Issues, Parent, Autism spectrum disorder.

I. INTRODUCTION

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INTRODUCTION

Autism spectrum disorder (ASD) is of the neurodevelopmental disorders, which onset during the developmental period and can be diagnosed before the child enters grade school and lasts throughout a person's life" (Jorgensen, 2008). When a child diagnosed with ASD in first time their parent feel sad, stress, depression, anxiety and denial (Chimeh et al., 2008). Solomon et al. (2004) mentioned the parents stress increases about their children and affected on their performance and health. In recent years, there are vast improvement in diagnostic criteria of ASD, social services, psycho-educational services (Bryson and Smith ,1998), heightened attention public in ASD (Howlin, 2005) and active roles for parents in treatment their children (Marcus et al., 2005). Early diagnosis for a child are poses many benefits for a child and their parents due to receive them for best services and more than a child late diagnosed with ASD (Attwood, 2007) and can established experiences the naturalistic educational for a child (Baker-Ericzén et al., 2005). Although early diagnosis of a child with ASD, parents might need counseling or other services support to alleviate emotional distress and stress (Hutton & Caron, 2005). ASD is characterized by impairments of personal, social, academic, or occupational functioning and has intellectual disabilities (intellectual developmental disorders) or without intellectual disabilities (DSM-5, 2013).

ASD includes autistic disorder, Asperger's syndrome, pervasive developmental disorder not otherwise specified (PDD-NOS) (Gurney et al., 2006), childhood disintegrative disorder and Rett's syndrome according the new definition of ASD in the DSM-5, published in 2013.WHO is define ASD as "a range of conditions characterized by some degree of impaired social behavior, communication and language and a narrow range of interests and activities that are both unique to the individual and carried out repetitively" (www.who.int, in April 2017).

Estimate a prevalence of ASD in about 10-20 per 10,000 persons (Semple& Smyth, 2013) or in the United States estimate a prevalence of ASD about 1 per 68 according to report of Centers for Disease Control and Prevention (CDC) published in 2014, ,but in Iraq does not have official statistical for incidence of ASD.

Many of parents find difficulties to access services because the lack of information concerned of procedures to reach services and policy (Divan et al., 2012).The requirements of parents with children of ASD are different according to their level of education, gender and age of their children (Derguyet al., 2015), but there was no influence to the types of parents' occupation (Papageorgiou&Kalyva, 2010). Some studies revealed the parents faced problems when they needed to getinformation about their children's disorder and appropriate support by professionals (Papageorgiou and Kalyva, 2010) and Some of parents are ready to participate in activities and training programs of ASD management.Mostof ASD programsmanagement are poor to collaboration and coordination between professionals and parents (Ahmadi et al., 2011; Derguyet al., 2015). So that most mothers and fathers seek about alterations to restore parental confidence, share tips and experiences (Papageorgiou&Kalyva, 2010), they used effectively communication with their family and friends (Ahmadi et al., 2011).

There are large numbers of therapeutic options available now to improve functioning of children with ASD, so in study of Green et al., (2006) mentioned the survey of Autism Organization Worldwide Internet of 552 parents reported used at least one from 108 treatments of 111 listed for ASD (Brown, 2010).ASD has a permanent impacts not only on a child, but also on his family members (Gau et al., 2012). Parents often are not able to deal with the secondary symptoms of ASD such as eating problems, sleeping, stereotypies and behavioral disorders (Humphreys et al., 2014). Also a child may suffering from lack in social reciprocity, hinder learning, intelligence deficit and emotional sharing. Other dimensions to impact of ASD are related in social, financial, professional domains, physical and mental health of parents may deteriorate and experience of stress, anxiety, depression... etc. (Divan et al., 2012). On the other hand, ASD child and their parents are in more need to services and support from normally children or with other disorders (Kogan et al., 2005-2006).ASD disorder may lead to the social isolation to parents because of avoidance of stigma and had limited amount of time spent outside the family (Divan et al., 2012; Gray, 2001), as well as, effects on parents' health in physical, mental, emotional and in other life domains like in social relationship (in community, work or in home).Other issues related in parents have a child with ASD such as some problems related to effect ASD on a marital status, family impact and changes in family

relationship, environment, communication and function (Derguy et al., 2015; Gau et al.; 2012),also number of hours spent (time) to care for a child and hours of work, the relationship with friends and community may altered in numerous trends, difficulties of family to access and getting support to their needs were related to ASD (Derguy et al., 2015), difficulties in access of services and traveling to treatment, money expenditure on services, care and treatment, stress and anxiety about future of his/her child and family (Brown , 2010); these impacts may be less with medical home (Kogan et al., 2005-2006).Weakness in provision of services system will increase the challenges on parents in economical and medical spheres which result negatively reflect on family members in general and child's disorder specifically (Derguy et al., 2015).

To reduce these impacts on parents, family and child by assist child to do daily living skills and courage parents to depend on formal and informal sources of supports (Hartely& Schultz, 2015).

This study is first research will which study the issues of parents who have children with ASD in Al-Najaf province. The researchers will study ASD for many reasons: Modern disorder and high prevalence and continuous increased numbers not only in Iraq, but in the world (CDC, 2014). Also, the parents of children with ASD are important part of community who have enough services and supports such as other diseases and disorders like heart centers, DM centers, institutes of mental retardation, deafness institutes,...etc. So that the study will aim to explore and identify the important issues of parents with children ASD and also, to identifythe relationship between severity of ASD and the issues of parents who have a child with ASD and their demographic characteristics.

Methodology

A cross-sectional study was included parents who had child with ASD enrolled in centers for ASD caring in the Holy Al-Najaf province.Instrument of study had two main parts in addition to a very important paragraph related to informant of the questionnaire because this tool used to self-reported by informant. Part one related with demographic characteristics of father, mother and their child who had ASD. Part two is related with the impacts of ASD on parents from Brown study (2010).

Sample Size and Sampling Technique

Size of sample was included (80) parents had child with ASD. The parents were selected by a purposive sample technique which have criteria of study such as should live in or inclusion with Al-Najaf province boundaries, have a child with ASD age's between 3 to 12 years and enrolled in center of autism. The data collectedfrom28th Mars to 20th April 2017.

Statistical Analysis

By using computer software SPSS v.17 and Microsoft Office Excel (2010) to analysis data and determine whether the study will achieve their goals or not. The researchers checked data void of mistakes and missing, then used computer software to analyze and extract the results.

Results and Discussion

The value of Cronbach's Alpha for impact on parent scale in current study equal 0.896 acceptable in scientific research.

The dominant of informants are both fathers and mothers were shared to answer the questions of study tool (37), as shown in figure (1). Age of majority fathers and mothers who joined in the study between 31-50 years; range of fathers age between (22-64) years, with mean (38.39 ± 7.975) . While the range of mothers age between (20-62) years, with mean (33.36 ± 7.150) (table 2). Al-Najaf province occupies first rank in marriage rate in early age among other provinces (CSO, 2007a, 2007b; NCPP, 2012). This reflects the nature and traditions of Iraqi society in marriage of girls in early age (under 18 years). So that, (53.8%) of parents married from kindred and (96.3%) of them were still married although had a child with ASD; majority parents (95%) had (1-5) children, although (65%) of them had a child with ASD in order he is the first or second among his siblings. This is a good indicator for ASD which is not effective on relationship between them or reproduction status. It may be considered as a positive gain from ASD to strength and closeness of family (Hastings et al., 2002), as shown in table (1).

Majority of parents lived in urban region of Al-Najaf City (97.5%) because most them prefer to live in close places to their work and this fact confirm the reported of NCPP in (2012) more than (70%) of dwelling population in Al-Najaf located in urban area. Most parents worked as civil servant (46.3%) with limited income and most of their wives worked as house wives (75%) who are a free to work in his home only (table 2) and reported moderately sufficient of income (43.8%) (table 1).

On the other hand, (60.66%) of fathers and (65.08%) of mothers had information about dealing with ASD from more than one source of information; that indicator for increased awareness of parents about ASD and readiness to receive information about their child state.

The range of children's age between (3- 12) years and (51.3%) of children's age between (7- 10) years, with mean (6.83 ± 2.215) , but range of children age was diagnosed with ASD (2-8) years and (63.75%) of them diagnosed with it in age (≤ 3) years, with mean (3.29 ± 1.245) . Most children had moderately severity of ASD (46.3%; mean = $2.11 \pm .729$). These results revealed the nature of centers to age accepted for children and awareness of parents to their child symptoms (table 3).

The majority of children enrolled in institutes with ASD were male (77.5%). This reflects the fact that males are more vulnerable to ASD than female (table 3)(Semple & Smyth, 2013). Most parents who reported their children did not have any other health problems with ASD (51.3%). About (57.5%) of parents used both medications psycho-pharmacotherapy and other psychological therapies to treat their children and residual ratio used only psychological therapies in institutes without medications (table 3) which may be due to parents who had limited income.

Degree of inmate relationship between parents after diagnosing their child with ASD were one of important issues. About (75%) of parents reported that they had a good relationship and their relation not effected with ASD diagnosing for their child because the majority of them were married from kindred (53.8%, table 1) or parents may become closer after it. This point is confirmed by the study of MacMullin et al. (2011), but (10%) from them the relationship became bad after their

child being diagnosed and (15%) became moderately after it (table 1). The reasons may be due to the impacts of ASD on their income, work, time, changing in environment of family and their functions (Hartley et al., 2010; Derguy et al., 2015). In context the changed of health status for parents after diagnosing their child with ASD were (51.3%) of fathers and (43.8%) of mothers who reported they did not have any health problems because of ASD (table 2). It may be due to the experiences of parents in life and ability to adaptation with it or most them their ages were between 31-50 years (table 2).

Majority of parents reported no change in hours of work after diagnosing their child with ASD which may cause most them worked as a civil servant in general sector of Iraq (table 2). The system of time work in Iraq fixed and does not change to the personal or familial status or does not have other source to get financial support such as government support or from civil agencies, but (28.8%) of fathers and (7.5%) of mothers change their time of work which may be due to work in a free job, day laborer, jobless, retired or house wife (in state of mothers) (table 2). In other hand, (78.8%) of fathers and (67.5%) of mothers reported change in hours spent outside of home for not work because they need to care their child's ASD or other family members or to avoid shyness and stigma from ASD (Divan et al., 2012; Gray, 2001).

The scale of impacts on parents revealed (53.8%) of parents experienced of high degree of impacts with M.S (2.475), because their child suffered from severe to moderate ASD which were more than (78%) of (childrentable (4)).

There is no significant relationship between severity of ASD and degree of inmate relationship after diagnosing their child with ASD which may be for previous causes mentioned in above. Also, no significance relationship between the parents age and the severity of ASD (p-value for fathers and mothers $> .05$), as shown in table (5) because the parents age was not one causes of incidence ASD in their child. Also, no significance among the severity of ASD and the change of hours work, hours spent outside of home and their health status (.319-.522 $> .05$, table (5)).

Whereas the relationship between the severity of ASD and demographic characteristics for child such as age of child or age of child when diagnosed with ASD and if the child had other health problems there was no significance (.121-.926 $> .05$) which may be due to most children diagnosed in early years of life (≤ 3 years old, table (3)), but the researchers found significant relationship between the types of treatment used with child and severity of ASD (.033 $< .05$) which may be due to the child is needs to more treatments when severity of it increased. Also, it was found high significance between the severity of ASD and degree of impacts on parents (.002 $< .05$, table (5)) which may be due to the impacts on parents increased when severity of ASD intense on their child.

Conclusions and Recommendations

The researchers concluded to importance of coordination among ministries of Health, Education and Labor and Social Affairs in Iraq to construct new system services to the parents and their child who has ASD.

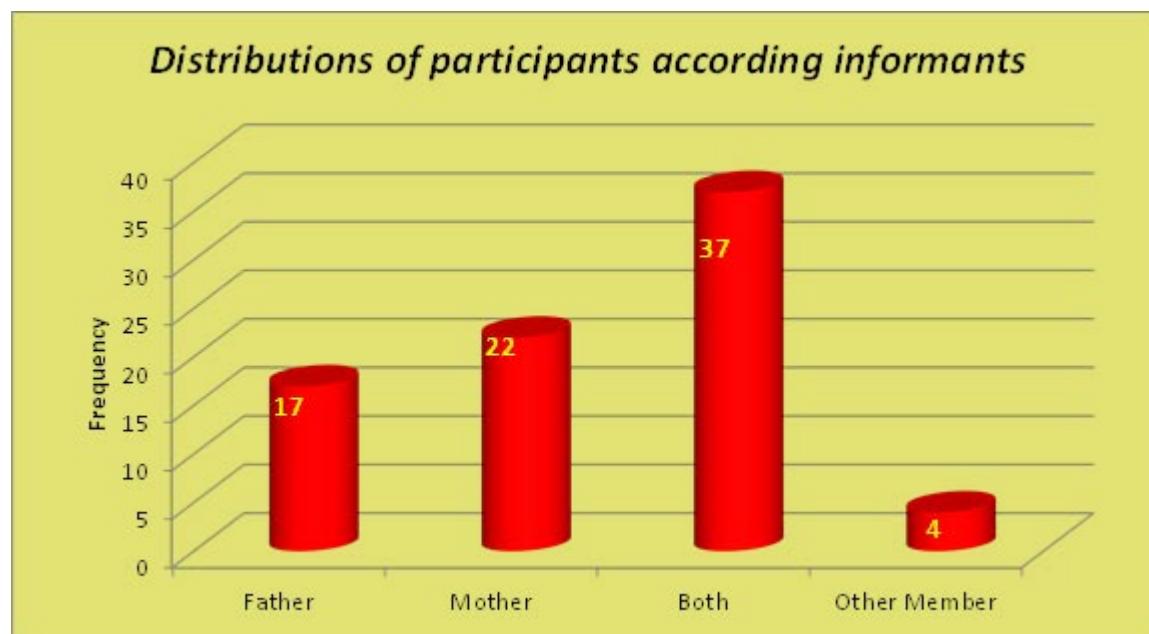


Figure 1. distributions of participants according informants

Table 1. Socio-economic status for parents' child with ASD

		N = 80	
		Frequency	Percent
Residence	Urban	78	97.5
	Rural	2	2.5
Income	Sufficient	28	35.0
	Moderately Sufficient	35	43.8
	Insufficient	17	21.2
Marital status	Married	77	96.3
	Widowed	1	1.2
	Separated	2	2.5
Degree of relation	Kindred	43	53.8
	Strangers	37	46.2
Number of children	≥2	39	48.8
	3 - 5	37	46.2
	More than 5	4	5.0
Degree of inmate relation after diagnosis their child with ASD	Good	60	75.0
	Moderate	12	15.0
	Bad	8	10.0
Total		80	100.0

Table 2. Demographic characteristics for fathers and mothers who had child with ASD

		Fathers (N=80)		Mothers (N=80)	
		Frequency	Percent	Frequency	Percent
Age	≤ 30	15	18.8	31	38.8
	31 - 50	62	77.5	48	60.0
	More than 50	3	3.8	1	1.2
Job	Civil Servant	37	46.3	19	23.8

	Retired	2	2.5	0	0
	Clerk Private Sector	6	7.5	1	1.2
	Free Job	20	25.0	0	0
	Day Laborer	6	7.5	0	0
	Jobless	3	3.8	0	0
	Student	1	1.2	0	0
	Housewife	0	0	60	75.0
	Other	5	6.2	0	0
Level education	Illiterate	4	5.0	4	5.0
	Able to Read And Write	2	2.5	3	3.8
	Primary School Graduate	13	16.3	11	13.8
	Intermediate Graduate	6	7.5	21	26.3
	Preparatory Graduate	9	11.2	12	15.0
	Institute Graduate	14	17.5	10	12.5
	College Graduate	26	32.5	15	18.6
	Post Graduate	6	7.5	4	5.0
Has information about dealing with ASD	Not has information	19	23.8	17	21.3
	Has information	61	76.2	63	78.7
Changed health status	Psychiatric Problems	17	21.2	24	30.0
	Physical Problems	16	20.0	12	15.0
	Psychiatric and Physical Problems	6	7.5	9	11.2
	Not have other health Problems	41	51.3	35	43.8
Changed hours of work	Changed	23	28.7	6	7.5
	Unchanged	57	71.3	74	92.5
Changed hours spent out of home	Changed	63	78.8	54	67.5
	Unchanged	17	21.2	26	32.5
Total		80	100.0	80	100.0

Table 3. Demographic characteristics of children with ASD

		N = 80	
		Frequency	Percent
Order between siblings	First	36	45.0
	Second	16	20.0
	Third	11	13.7
	Forth	11	13.7
	Fifth	3	3.8
	Sixth	2	2.5
	Eighth	1	1.3
Gender	Male	62	77.5
	Female	18	22.5
Age	≤ 6	35	43.7
	7 - 10	41	51.3
	More than 10	4	5.0

Age diagnosing with ASD	≤ 3	51	63.75
	4 - 6	27	33.75
	More than 6	2	2.5
Severity of ASD	Mild	17	21.2
	Moderate	37	46.3
	Severe	26	32.5
Types of treatments used	Without Medications	34	42.5
	Both Medications and without Medications	46	57.5
Other health problems of child	Psychiatric Problems	8	10.0
	Physical Problems	23	28.7
	Psychiatric and Physical Problems	8	10.0
	Not have other health Problems	41	51.3
Total		80	100.0

Table 4. Degree of impacts on parents' child with ASD

Degree of impacts	N = 80		M.S	Assessment
	Frequency	Percent		
Low	5	6.2	2.475	Severe
	32	40.0		
	43	53.8		
Total	80	100.0		

Cut off point (0.66), **M.S** (mean of scores), **Mild** (mean of score 1-1.66), **Moderate** (mean of score 1.67-2.33), **Severe** (mean of score equal or more than 2.34)

Table 5. Relationship among severity of ASD and Demographic characteristics of parents, their children and impacts on parents

	Demographic Data	Rating	Severity of ASD			Chi-Square			Sig.
			Mild	Moderate	Severe	χ^2	df	P-value	
Parents	Income	Sufficient	7	15	6	5.66	4	.226	NS
		Moderately sufficient	7	12	16				
		Insufficient	3	10	4				
	Degree of inmate relationship after diagnosis their child with ASD	Good	15	26	19	2.9	4	.575	NS
		Moderate	2	6	4				
		Bad	0	5	3				
Fathers	Age	≤ 30	4	6	5	.819	4	.936	NS
		31 - 50	12	30	20				
		More than 50	1	1	1				
	Changed hours of work	Changed hours of father work after diagnosed child's ASD	7	9	7	1.68	2	.432	NS
		Unchanged hours of father work after diagnosed child's ASD	10	28	19				
	Changed hours spent out of home	Changed father's hours spent out of home after diagnosed child's ASD	15	27	21	1.72	2	.424	NS
		Unchanged father's hours spent out of home	2	10	5				

		after diagnosed child's ASD						
Mothers	Health status	Psychiatric problems	1	11	5	5.17	6	.522 NS
		Physical problems	5	5	6			
		Psychiatric and physical problems	1	3	2			
		Father was not have problems	10	18	13			
Mothers	Age	≤ 30	6	15	10	3.81	4	.433 NS
		31 - 50	10	22	16			
		More than 50	1	0	0			
	Changed hours of work	Changed hours of mother work after diagnosed child's ASD	2	1	3	2.284	2	.319 NS
		Unchanged hours of mother work after diagnosed child's ASD	15	36	23			

Continues table 5.

	Demographic Data	Rating	Severity of ASD			Chi-Square			Sig.
			Mild	Moderate	Severe	χ^2	df	P-value	
Mothers	Changed hours spent out of home	Changed mother's hours spent out of home after diagnosed child's ASD	13	22	19	2.08	2	.353 NS	NS
		Unchanged mother's hours spent out of home after diagnosed child's ASD	4	15	7				
	Health status	Psychiatric problems	4	10	10	6.9	6	.331 NS	NS
		Physical problems	5	5	2				
		Psychiatric and physical problems	2	6	1				
		Mother was not have problems	6	16	13				
Child	Age	≤ 6	7	17	11	.890	4	.926 NS	NS
		7 - 10	9	19	13				
		More than 10	1	1	2				
	Child age diagnosing with ASD	≤ 3	9	29	13	7.292	4	.121 NS	NS
		4 - 6	7	8	12				
		More than 6	1	0	1				
	Other health problems of child	Psychiatric problems	0	3	5	6.664	6	.353 NS	NS
		Physical problems	4	12	7				
		Psychiatric and physical problems	3	4	1				
		Child was not have problems	10	18	13				
	Types of treatments used with child	Without medications	9	10	15	6.84*	2	.033* S	S
		Both medications and without medications	8	27	11				
Impacts	Degree of impacts on parents	Low	2	2	1	16.82	4	.002* HS	HS
		Moderate	12	16	4				
		High	3	19	21				

HS: Highly significant, S: significant, NS: non-significant, P-Value: probability value, df: degree of freedom, χ^2 : chi-square observation

Majority of parents are ready to participate in special programs and accepted a new knowledge about ASD or how to care and deal with their child. Also parents need more help and necessary support from governmental and private foundations. Al-Najaf City does not have governmental centers specialized in diagnosing, caring and treating of autism. Most drugs (medications) of ASD are expensive price and not available in governmental hospitals and in psychiatric units, too. Almost all schools in Al-Najaf were not have special class for mild cases of ASD or teachers have experience to deal with ASD.

Finally, there is significant relationship among the severity of ASD on child and parents impacts, types of treatments used with a child. Also, when parents have knowledge, sufficient income and high level of education, the severity of ASD may be insignificant on them.

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