KNOWLEDGE ASSESSMENT AMONG AUTISTIC CHILDREN'S PARENTS REGARDING AUTISM SPECTRUM DISORDER

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Abstract

Background: Autism Spectrum Disorder (ASD) is a neuro-developmental disorder this involves difficulties in social communication and interaction as well as unusual patterns of interest and behavior.Aim: This study aimed to assess knowledgeof autistic children's parents about ASD. Design:A descriptive design was utilized in currentstudy that carried out atthree governmental hospitalslocated in Dakahlia and Port Said Governorates.Convenient sampleof 68 parents whose children have ASDincluded in the study.Tools:A structured interview sheet was used to assess socio-demographic characteristics of the studied parents and parent's knowledge about ASD. Results: The majority of studied parents know symptoms of ASD. More than half of parents were had no knowledge about red flags of ASD.Less than two thirds of studied parents reported the relation between aggressive behaviors and ASD. Moreover, less than two thirds of them reported that children diagnosed with ASD have special skills.Additionally, more than half of studied parents reported that psychological treatment to be the best. Conclusion: There was avariation regarding parents' knowledge about ASD. Recommendations: Enhance parents' knowledge regarding ASD
Keywords:autistic children, autism spectrum disorder, Parents' Knowledge.

Introduction

Autism spectrum disorder (ASD) is a pervasive developmental disorder in which the core impairments influence the children's development(Center for Disease Control and Prevention, 2018). Moreover; autistic children show a clear impairment in communication skills and social interaction. This is associated with the nature of autism, which is characterized by delays in the development of social, kinetic, and psychological skills; especially in acquiring communication skills with family and friends, self-care, forming social relationships, and visual communication. In addition to underdeveloped social skills when playing with other children, forming friendships, group integration, and increased repetitive behavioral patterns (Abdel Hamid, 2020).

The exact cause of ASD is unknown. While there are many risk factors make the prevalence of ASD increasing globally; the genetic factors are an important possible source of causation which may include parent's age at the time of conception, maternal illness during pregnancy, and birth complications. However, these factors do not cause autism on their own; ASD is typically caused by a combination of

environmental factors and risk genes that influence the early stages of brain development(World Health Organization, 2019).

On the other hand, the essential characteristics of ASD are; persistent impairment in reciprocal social communication and social interaction (criterion A), and restricted, repetitive patterns of behavior, interests or activities (criterion B). These symptoms are present from early childhood and result in limitation or impairment of everyday functioning (criterion C and D). The stage at which functional impairment becomes obvious will vary according to characteristics of the child and his or her environment. Manifestations of the disorder will also vary greatly depending on the level of the autistic condition, developmental level, and chronological age (American Psychiatric Association, 2013).

Furthermore, parents sometimes cannot recognize early symptoms. In fact, the behavior of children younger than two years may not certify for a diagnosis, as it is very difficult to evaluate their verbal communication. Social interactions are usually built from the family environment and develop as the child moves into unfamiliar social environments. Consequently, it may be difficult to notice impairments in social interactions before children are exposed to a different social setup(Jagan & Sathiyaseelan, 2016).

The core diagnostic features of ASD are impaired social interaction and communication skills in addition to restricted, repetitive interests and behaviors (American Psychiatric Association, 2013). However, individuals with ASD frequently experience a range of other emotional and behavioral problems that are generally referred to as "problem behaviors" which may also be referred to as externalizing behaviors; include self-injurious behavior (SIB), aggression toward others, temper tantrums, and non-compliance , these behaviors are typically difficult to get better and make daily living particularly challenging but persistence and escalation of these behaviors may lead families to seek psychological and/ or psychiatric services(Zaidman-Zait et al., 2014).

Early intervention programs have been evolving from different models such as behavioral interventions, developmental interventions and cognitive-behavioral interventions. Each program is based on a different model and has its unique strategies for children who enter in the programs in early ages to achieve the best outcomes(Corsello, 2005). Moreover,early intervention strategies improve cognitive ability, adaptive behavior, receptive and expressive language, communication skills, social competence, and daily living skills and prevent the side effects caused by early deficits, which will more negatively interfere with later development, creating a series of problems, in the psychological and neurological development(Marchi, 2015).

Significance of the Study:The Autism and Developmental Disabilities Monitoring (ADDM) Network and the Center for Disease Control and Prevention estimate that ASD has been a growing public health concern with a prevalence rate of 1 in 59 children affected with a higher incidence in males in the United States (Baio et al., 2018). Related to epidemiology of ASD in Egypt, there has been few numbers of researches focused on autism with no documented research about

epidemiology among Egyptian children(Elbahaaey, Elkholy, Tobar, & El-Boraie, 2016).So, the current study aimed to assess autistic children's parents'knowledge about ASD.

Subjects and Method

I - Technical design: -

Research design

Descriptive research deign was used to conduct this study.

Settings

This study was carried out at three governmental hospitals which provide behavioral therapy for children with ASD affiliated to Mansoura, Talkha and Port Said Cities. **First:** The child psychiatric outpatient clinics at Psychiatry Department- Mansoura University Hospital, children clinics are available on Saturday, Monday, and Wednesday. **Second:** The child psychiatric outpatient clinics at Demera Mental Health Hospital that affiliated to Talkha City. The children and adolescents' clinics are available on Sunday, Tuesday, and Thursday from each week. **Third:** The child psychiatric outpatient clinics at Port Said Psychiatric Health Hospital that is affiliated to Port Said City. The child clinic that is available on Sunday and Tuesday from each week. Three clinics available in the morning shift from 8 AM to 1 PM. All these clinics specialized for determining diagnosis and treatment by psychiatrist and psychiatric nurse while psychometric tests and psychotherapeutic interventions specialized for children and adolescent was conducted by psychologists in the outpatient hall.

Subjects

A convenience sample of all parents (n= 68) having children with ASD who are attending the previously mentioned settings during 6 months, who are willing to participate in the study.

Tool

Data were collected through using of the following tool:

A structured interview sheet for parents

It was developed by the researcher in Arabic language after reviewing the related literature. It comprised of two parts as follows:

Part (1): Concerned with socio-demographic characteristics of the studied parents and their autistic childrensuch as age, sex, and level of education.

Part (2): Concerned with parent's knowledge about ASD, which composed of 17 multiple choices questions to cover these items; parent's knowledge level, sources of knowledge, symptoms and red flags, and management of ASD.

II - Operational design:

1 –Preparatory phase

This phase included a review of past and current related literature and studies, using available appropriate books, periodicals, magazines, and articles to develop the study tools.

2 - Exploratory phase:

a)Pilot study: -

A pilot study was carried out on a total of 10% of the total subject's sizeaccording to the criteria of selection before starting the data collection to test the tool applicability, to estimate the time needed to apply the study tool and to detect the required modification.

b)Filed work:

- Data collection extended over a period of six months period from first of March 2019 to the end of September 2019.
- Every parent was interviewed individually by the researcher to collect the necessary data, interview will be for 30 min

between 10 am to 12 pm, 3days weekly. The researcher will fill the questionnaire sheet by himself.

III - Administrative design.
Ethical considerations

An official approval was obtained from the research ethical committeeof Mansoura Faculty of nursing to conduct the study. Permissions to conduct the study were obtained from the heads of the previously mentioned settings after explaining the purpose of the study. An approval was obtained from each participant (parent) before the start of the study after the explanation of the purpose of the study and the researcher emphasized that the study causes no physiological or psychological harm to the parents and their autistic children. Privacy and confidentiality of the collected data were assured throughout the whole study phases. Moreover, any participant (parent) has the right to withdraw from the study at any time without any responsibility.

Statistical design

Data were analyzed with SPSS version 24. The normality of data was first tested with one-sample Kolmogorov-Smirnov test. Qualitative data were described using number and percent.

Results

Table (1): Number and percentage distribution of studied parents according to their sociodemographic characteristics (n= 68)

Sociodemographic characteristics		Number	Percent
Parent's age			
20: <25		13	19.1
25: <30		31	45.6
30: <35		17	25
35: ≤40		7	10.3
Gender			
Male		26	38.2
Female		42	61.8
Residence			
Rural		20	29.4
Urban		48	70.6
Marital status			
Married		53	77.9
Widowed		15	22.1
Father Occupation			
Have no work		16	23.5
Working father		52	76.5
Mother occupation			
Housewife		49	72.1
Working mother		19	27.9
Number of children in the family			
One		31	45.6
Two		29	42.6
Three		8	11.8

Table (2): Number and percentage distribution of studied children according to their sociodemographic characteristics (n= 68)

Sociodemographic characteristics		Number	Percent
Child's age			
4: < 5		36	52.9
5: ≤ 6		15	22.1
> 6		17	25.0
Gender			
Boys		62	91.2
Girls		6	8.8
Birth order			
First		42	61.8
Second		21	30.9
Third		5	7.4
Time since diagnosis			
less 1 year		37	54.4
1:<3		31	45.6
Family history for ASD			
No		62	91.2
Yes		6	8.8

Table (3): Number and percentage distribution of studied parents according to their general knowledge about ASD (n= 68)

Items	Number	Percent
Parent's general knowledge about ASD		
Knowmore	7	10.3
Knowlittle	44	64.7
Donot know	17	25.0
Parent's sources of knowledge about ASD		
Internet	60	88.2
Scientific related lectures	8	11.8
Parent's previous dealing with autistic child		
Yes	16	23.5
No	52	76.5
Support the integration of an autistic child with the normal child in school		
Yes	46	67.6
No	12	17.6
do not know	10	14.7
Society awareness about dealing with autistic child		
Yes	15	22.1
May be	23	33.8
No	30	44.1

Table (4): Number and percentage distribution of studied parents according to their general knowledge about symptoms of ASD (n= 68)

Items	Number	Percent
Parent's knowledge about symptoms of ASD		
Yes	56	82.4
No	12	17.6
Parent's knowledge about red flags of ASD		
Yes	21	30.9
No	39	57.4
do not know	8	11.8
There is arelation between autism and aggressive behaviors		
Yes	43	63.2
No	17	25.0
do not know	8	11.8
The autistic children have special skills		
Yes	42	61.8
No	16	23.5
do not know	10	14.7

Table (5): Number and percentage distribution of studied parents according to their general knowledge about management of ASD (n= 68)

| Items	Number	Percent
The causes of autism are psychological		
Yes	30	44.1
do not know	38	55.9
No	0	0
Thereare programs to develop autistic children skills appropriately		
Yes	9	13.2
No	45	66.2
do not know	14	20.6
The programs achieved its goals for autistic children		
No	46	67.6
do not know	22	32.4
Yes	0	0
Best treatment for autism disorder		
Psychological treatment	36	52.9
Pharmacological treatment	11	16.2
Need more knowledge	10	14.7
Do not know	11	16.2
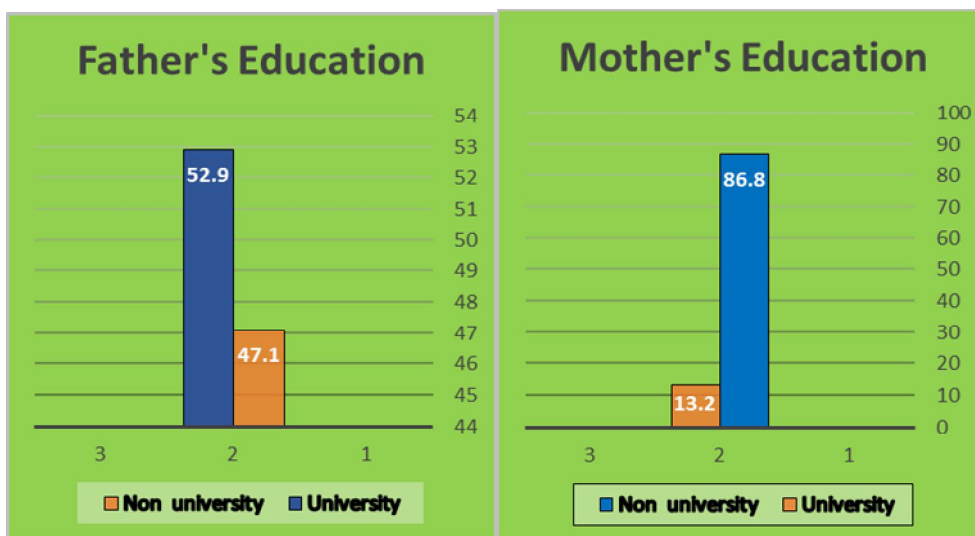
Figure (1); Distribution of the studied parents according to their educational level

Table (1) revealed that 45.6% of studied parents were in the age group from 25 to ≤ 30 years of age. In relation to gender, 61.8% were females and 70.6% were living in urban area. Concerning marital status, 77.9% were married. According to occupation, it was evident that 76.5% of fathers were working, while 72.1% of mothers were housewives. Finally, this table showed that 45.6% of the families were had only one child.

Table (2) demonstrated that 52.9% of children were in the age group from 4 to less than 5 years old. In relation to gender, 91.2% of studied children were boys. Concerning the birth order, it was found that 61.8% of children were the first child. According to time since diagnosis, 54.4% of studied children were diagnosed since less than one year ago. As regards family history of ASD, 91.2% of studied parents had no family history for ASD.

Table (3) showed that 64.7% of studied parents had little knowledge

about ASD. Concerning parents' sources of knowledge about ASD, 88.2% using internet as a source of their knowledge. However, 76.5% of studied parents had no previous experience for dealing with autistic children. In relation to parent's opinion for integration of autistic children in school, 67.6% support this integration. In addition, 44.1% of studied parents reported that the society in not aware of dealing with autistic children.

Table (4) showed that 82.4% of studied parents know symptoms of ASD. Concerning parents' knowledge about red flags of ASD, 57.4% were had no knowledge about it. However, 63.2% of studied parents reported the relation between aggressive behaviors and ASD. In addition, 61.8% of studied parents reported that autistic children have special skills.

Table (5) illustrated that, 44.1% of studied parents reported that ASD had a psychological cause. Concerning availability of programs that develop autistic children skills, 66.2% of studied

parents reported that there were no available programs. Moreover, 67.6% of parents reported that, programs available for autistic children do not achieve their goals. In relation to parent's opinion for the best treatment for autistic children, 52.9% of studied parents reported that psychological treatment to be the best.

Figure (1) illustrated that 52.9% of fathers were had university education, while 86.8% of mothers were had non university education.

Discussion

Autism spectrum disorders (ASD) represent a group of neurodevelopmental disorders characterized by impaired reciprocal socialization and communication, often accompanied by stereotyped ritualistic behavior. Till now, there is no clear explanation for the dramatic worldwide increase in the incidence of ASD during the last two decades. It is suggested that some environmental factors besides a genetic predisposition lead to thisdisorder. In addition, ASD is known to be associated with other psychiatric comorbidities(Elbahaaey et al., 2016). There are no specific biological investigations or tests to diagnose ASD, but there are special evaluations for diagnosis of ASD such as speech and language assessment, psychological and psychiatric evaluation, EEG, neuroimaging positron emission tomography scan, and chromosomal analysis if indicated. Moreover, diagnosis of ASD is typically made during childhood, based on comprehensive behavioral evaluations by specialists in child psychiatry or psychology or by those in behavioral and developmental pediatrics (Basavanthappa, 2015; Moura, Fulco, & Albuquerque, 2018).

Regarding the birth order of studied children, the current study showed that the high percentage of children were the first child (table 2); this result goes in the same line with the result ofElwardany, Ibrahim, Askar, and Bayomi(2013) who showed in their study that carried out in Assiut city, that less than half of studied autistic children are first birth order among the siblings. From the researcher's point of view, the first child faces the less experienced parents in rearing and teaching him the social communication skills, as well as in detecting and seeking medical help.

The current study revealed that, less than two thirds of the studied parents have poor knowledge scores about ASD. Moreover, the majority of them use internet and the media as their sources of knowledge about autism (table 3). These results goes in the same line withAnwar, Tahir, Nusrat, and Khan(2018) in their study about "knowledge, awareness, and perceptions regarding autism among parents", which conducted in Karachi, Pakistan and reported that poor knowledge scores about autism, with a mean score of 5.59 in the section concerning correct opinions about autism. Also, they reported that the media was the most popular source of knowledge among parents.

From the researcher's point of view; these results can be interpreted as the media is considered as an easy source of knowledge,which it is available by different means as mobile, computers and television but the most of this information is not scientifically based, and consists mainly of websites or articles written by the general public which leads to poor correct knowledge about autism. Furthermore, more than half of the study subjects were mothers and the majority of them had non

university education which may affect their interpretation of autism information.

Additionally, the study results in (table 3) showed that more than two thirds of parents support the integration of autistic children in schools; these results are in contrast withMutabbakani and Callinan (2020) in their study about "mothers' perspectives on the inclusion of young autistic children", which conducted in Kuwait and revealed that none of the study mothers support the inclusion of autistic children.

Current study was clearly showed that less than half of studied parents reported that the causes of autism are psychological causes (table 5); these results are incongruence with Samadi(2020)who reported in his study about "parental beliefs and feelings about autism spectrum disorder", which conducted in Iran that Iranian parents mentioned different factors for autism occurrence, but maternal factors during the pregnancy such as maternal stress, fears, and delivery problems, were the dominant factors for autism.

Concerning the treatment of ASD, (table 5) revealed that more than half of studied parents reported that the psychological treatment is the best treatment options for their autistic children. This result was in disagreement with Alqahtani (2015) who reported in his study about "understanding autism in Saudi Arabia: a qualitative analysis of the community and cultural context", that parents of children with ASD in KSA often choose informal intervention and treatments such as diet intervention containing gluten-casein-free as a treatment option for their autistic children. However, this study result goes in the same line with Hemdi and Daley(2017) who reported in their study

about "The needs of mothers of children with ASD in the Kingdom of Saudi Arabia (KSA): a qualitative study", that parents prefer to seek behavioral and educational interventions as a treatment option for their autistic children.

Conclusion

Based on the finding of the current study, it was concluded that, there was a variation in the knowledgeof the parents about autism spectrum disorder. The majority of parents use internet as the source of their knowledge about ASD.

Recommendations

In the light of the findings of the current study, the following recommendations are suggested:

- Preparing awareness programs for parents about the autism spectrum disorders in children to improve their knowledge related diagnosis and management.
- Expand public awareness through mass and social media about the importance of early diagnosis and early intervention of autism in order to minimize dependence and enhance functioning for autistic children.
- Periodical survey (at first years of development) for early detection of any child risk for autism who complains from deficits in language and communication skills and have stereotyped or repetitive movements to provide early intervention to enhance children functioning.
- Develop an updated tool to assess autism related to changes in DSM-5 and adapted to our culture.

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