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Evaluation of Mothers' Knowledge about Autism: Saudi Arabia

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تقييم مدى معرفة الأمهات بالتوحد: دراسة على المجتمع السعودي

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ABSTRACT

Autism is an advanced neurogenic disease condition with specific neurodevelopmental characteristics and deficiency in social relations and interaction, as well as limited rhythmic and stereotyped patterns of actions that habitually arise in the toddler stage of life. Mothers of children with autism were found to have greater levels of childcare-associated stress. This study aims to determine mothers' general knowledge of autism. A cross-sectional study was conducted among the mothers of autistic children in Al Hsa, Saudi Arabia, between 20 September and 20 December, 2019. The study included 63 mothers of autistic children. A 29-items questionnaire was created following a wide-ranging literature review. A pilot study was conducted on 20 mothers to assess the simplicity and understanding of the questionnaire. The data indicated that more than two thirds, i.e. 44(69.8%) of all respondents had a low level of or insufficient knowledge about autism, 19(30.2%) had a medium level, while none had a high level of knowledge. The results showed that the mother's job, the child's age, and the child order variables were important predictors, and the value was statistically significant at ($\alpha = 0.05$) for the mothers' knowledge level. It could be concluded that Al Hsa's mothers' children with autism lack the perception and knowledge of the signs and symptoms. Mothers were also found to need awareness programs for diagnosis and treatment approaches.

المخلص

التوحد مرض وراثي عصبي، يتميز بصفات نمو عصبي خاصة، ونقص في العلاقات الاجتماعية والتفاعل، وأنماط محدودة من الإيقاعات والقوالب النمطية للأطفال التي تنشأ في مرحلة الطفولة. ولدى أمهات الأطفال المصابين بالتوحد مستويات ضغوط أعلى من أمهات الأطفال الطبيعيين. هدفت هذه الدراسة إلى تحديد مدى معرفة الأم باضطراب التوحد. تم إجراء دراسة مستعرضة بين أمهات الأطفال المصابين بالتوحد في الأحساء، المملكة العربية السعودية، في الفترة من 20 سبتمبر إلى 20 ديسمبر 2019 بمشاركة 63 من أمهات الأطفال المصابين بالتوحد. تم إعداد استبانة مكونة من 29 نقطة بعد مراجعة أدبية واسعة النطاق. أجرى الباحثون دراسة تجريبية على 20 أمًا لتقييم بساطة وسهولة فهم الاستبانة. أظهرت النتائج أن أكثر من ثلثي العينة 44 (69.8%) من الأمهات المستجيبات كانت لديهن معرفة منخفضة أو غير كافية بمرض التوحد، و19 (30.2%) لديهن مستوى متوسط من المعرفة، وصفر في المئة لديهن مستوى عالٍ من المعرفة. وأشارت النتائج إلى أن متغيرات الأم، وعمر الطفل، وترتيب الطفل في الأسرة، لها علاقة دالة بمدى معرفة الأم عن المرض، وهذه القيمة ذات دلالة إحصائية عند مستوى ($\alpha = 0.05$) لمستوى معرفة الأمهات بمرض التوحد. وبناء على هذه النتائج تم استنتاج أن أمهات المرضى بمنطقة الأحساء لديهن نقص في المعرفة حول التوحد وعلاماته وأعراضه وطرق التشخيص والعلاج، الأمر الذي يستلزم توعيتهن بتلك الأمور.

1. Introduction

Autism spectrum disorder (ASD) is a child-development disability that alters social, communication, and behavioural tasks. Often there is nothing that distinguishes autistic people from others; however, people living with ASD usually communicate, interact, and learn to act differently from other people (Autism Research Institute, 2019). ASD also defines disorders categorised by behavioural, communication, and language difficulties, as well as low levels of interest and unique repetitive behaviours that appear in the child (WHO, 2019).

The learning, thinking, and problem-solving skills of autistic people range from talented to having severe special needs. Sometimes autistic people require the support of their family members to perform their daily routine work, while others require less support (CDC, 2019).

ASD is a condition with neurodevelopmental characteristics and deficiency in social relations and interaction, as well as limited, rhythmic and stereotyped patterns of actions that habitually arise in the toddler stage of life, from three to five years, and continue life-long (American Psychiatric Association, 2000; Levy S, 2010; National Institute of Neurological Disorders and Stroke, 2020). In general, an autistic child always has repetitive and restricted behaviours (Boyd, 2012). The demands of persons with ASDs are massive and include behaviour therapies, psychological care, extraordinary schooling, and supported engagement (Ganz, 2007).

The Centres for Disease Control and Prevention (CDC), 2020 report shows that the prevalence of children diagnosed with ASD by the age

of eight is now 1 in 54. The earlier rate, in 2018, was 1 in 59. An increase in ASD prevalence is visible (CDC, 2020). Care givers for autistic children were found to have a low level of knowledge about the disease (Almana, 2017). In another study, the teachers had a low to moderate knowledge level about ASD (Hendricks, 2007).

ASD is recognised as one of the pervasive developmental disorders (PDDs), which include of disorders such as autistic disorder, Asperger's syndrome, and pervasive developmental disorder (National Institute of Mental Health, 2011; de Giambattista, 2019). There is variability in the pattern and severity of symptoms and in the timing of diagnosis (CDC, 2012). The risk of autism among boys is four times higher than in girls. The frequency of diagnosis of the disease has increased recently, and it has appeared among different races and different economic and social groups (Murshid, 2014).

It can be said that ASD is the most advanced neurogenic disease that includes both genetic and environmental factors (Hallmayer, 2011; Bozzi, 2018). Families with autistic children use family routines to offer consistency and a form of support engagement for their family members. Mothers undertake the most important role in organising tasks in the family routines. ASD impacts the wellness of the whole family (McAuliffe, 2019; Kiami, 2017).

Being a mother is a complicated task. Being the mother of a child with autism is a further challenging task. Researchers have realised that mothers of children with autism have greater levels of childcare-associated tension (Estes, 2009). Parents of children with ASD experience a complex range of stressors, such as child behaviours and community and services barriers (Bluth, 2013).

Due to the stress of having autistic children, parents find it difficult to

maintain positivity. Parents' feelings relate to their competence to be good parents to their children, and their view of themselves as such is associated with their physical and psychological wellbeing (Kuhn, 2006).

This research aimed to determine the mothers' general knowledge of the signs, symptoms, and the treatment of ASD among mothers of autistic children.

2. Materials and Methods

A cross-sectional study was carried out among the mothers of children with ASD children in Al Ahsa region, Saudi Arabia, from 20 September 2019 to 20 December 2019, to assess the knowledge of signs and symptoms, and the awareness of treatment approaches among mothers of autistic children. The researchers used this convenient sample because it was available, and the centre is the largest in the region for the care of children with autism.

Ethical approval was obtained from the Itqan Day Care Centre. Written approval was acquired prior to study participation from the mothers through informed consent. Sixty-three mothers out of 75 participants answered the survey, representing a response rate of 84%. The study conformed to the ethical principles of the research and ethical committee of the College of Applied Medical Sciences of King Faisal University.

Eligible study participants included mothers between the age of 18–60 years old who have children with ASD. Mothers who have a medical-related career were excluded from the study because of their medical knowledge about ASD.

A 29-items questionnaire was created by the researchers after a wide-ranging literature review. This was also modified from similar studies. Additionally, the questionnaire was translated into the Arabic language to allow Arab mothers to understand the questionnaire. The pilot study was initially conducted using 20 mothers (not from the sample) to assess the simplicity and understanding of the questionnaire and to ensure its reliability. The questionable elements were excluded, and the questionnaire was further modified based on the findings of the analysis of the trial run; these modifications included the use of clearer and more comprehensible vocabulary. Two experts approved the questionnaire to confirm its validity.

The study questionnaire contained three parts. The first part was about the sociodemographic aspects of the participant (age, qualification, career, and number of children of the participant mother). The second part involved 22 questions that were subdivided into two sections. The first section assessed the participants' knowledge about child development, and the second section measured the participants' knowledge and awareness about ASD. A three-point Likert scale was given that consisted of the following choices with which to answer the questions: 'agree', 'disagree', and 'I don't know'. The questions that had two potential replies were awarded one point for the accurate answer and zero points for the wrong or uncertain 'I don't know' reply. The questions about the collective symptoms of a patient, or autism as a disease, were built on the principles of the *American Psychiatric Association Diagnostic and Statistical Manual for Mental Disorders, Fourth Edition*.

Generally, the questionnaire consisted of 22 questions. If the respondent completed the questions accurately, 22 counting points were awarded. Respondents who achieved a knowledge score higher than or equal to 18 (85%) were judged to be of a high-ranking level, while scores between 13 and 18 (60–< 85%) were considered to be of a medium level. A score was considered to be of a low level if it was less than 13 (< 60%). The questionnaires that had not been fully completed were excluded.

The data were recorded and interpreted using the Statistical Package for Social Sciences (SPSS version 23.0).

3. Results

As shown in Table (1), 35 mothers out of 63 (55.6%) were aged between 26–30 years. The participants varied as to educational qualifications with secondary school 28 (44.4%) being the most common. Among all of the respondents 51(81%) were employed. Forty-one (65.1%) of the participants had a male child with ASD, while 28(44.4%) had a first child with ASD. Furthermore, ten (15.9%) respondents had more than one child with ASD.

Table 1: Mothers' Demographic Data

		N=63
Mother's age	<=25	3(4.8%)
	26-30	35(55.6%)
	>30	25(39.7%)
Mother's education	Primary school	6(9.5%)
	Intermediate school	14(22.2%)
	Secondary school	28(44.4%)
	College	15(23.8%)
Mother's job	Housewife	10(15.9%)
	Current student	2(3.2%)
	Employed	51(81%)
Child age	Range	(3-11)
	Mean ± SD	7.1±2.3
Child gender	Male	41(65.1%)
	Female	22(34.9%)
Child order	1st	28(44.4%)
	2nd	9(14.3%)
	3rd	2(3.2%)
	4th or more	24(38.1%)
Sibling	No	53(84.1%)
	Yes	10(15.9%)

Table (2) illustrates the mothers' knowledge level. The results showed that the knowledge range related to typical child development was from (0–2) out of 2, and the mean was 1.1±0.5.

In relation to the knowledge about ASD, the range was from (0–14) out of 20, and the mean was 9±3.7.

With regard to the total knowledge score, the range was from (0–16) out of 22, and the mean was 10.2±3.8.

Table 2: Mothers' Knowledge Score about ASD

		N=63
Typical child development	Range	(0-2/2)
	Mean ± SD	1.1±0.5
Autism spectrum disorder	Range	(0-14/20)
	Mean ± SD	9±3.7
Total knowledge score	Range	(0-16/22)
	Mean ± SD	10.2±3.8

Figure 1. Mothers Degree of knowledge about ASD

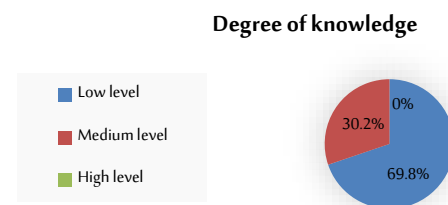


Figure (1) illustrates that 44 (69.8%) of all the respondents had a low or insufficient level of knowledge about ASD and 19 (30.2%) had a medium level of knowledge. None of the respondents (0%) exhibited a high level of knowledge.

Table 3 presents the results of the correlations between the demographic data and total knowledge score. The results suggest that the mother's job, the child's age, and the child order variables are generally important predictors; child age and child order are positively correlated with knowledge about ASD, and this value is statistically significant at the significance level of ($\alpha = 0.05$). On the other hand, no significant differences were observed in the mothers' age and education level when correlating with knowledge about ASD.

Table 3: Correlations between demographic data and total knowledge score

	Total knowledge score	
	R	P value
Mother's age	-0.099	0.438
Mother's education	0.111	0.385
Mother's job	-0.276	0.029*
Child age	0.304	0.016*
Child order	-0.475	<0.001*

Spearman's rho correlation, Pearson's correlation, *: Significant level at P value <0.05

4. Discussion

ASD is certainly one of the most challenging child-development syndromes to recognise due to the wide variety of symptoms that disturbs the child's behaviour. Children with ASD are physically healthy and have developed as their peers, but their performance profile is unequal due to a series of symptoms that may affect the child's daily life (Cridland, 2015).

The study showed that none of the participants had a high-level knowledge score. A mean score of 10.2 ± 3.8 out of 22 was seen for all the sections. The insufficient knowledge showed by the participants was in agreement with previous studies. A research study performed in Pakistan among kindergarten teachers found that only 50% were able to recognise the physical characteristics of the disease (Liu, 2016). Another study in China found that only 17% of day-care-centre teachers could answer more than 50% of the items about autism correctly (Ayub et al., 2017).

Furthermore, Anwer et al (2018) found that a mean score of 5.59 out of 14 was observed with regard to accurate information about autism. Another survey by Deeb (2016) revealed inconsistent findings related to the influence of career on the capability to distinguish signs and symptoms of autism in children. The level of education of the caregiver had no impact on their behaviours with children with autistic characteristics.

Another study supports the idea that there is a lack of awareness about autism disorder and its consequences in caregivers. Many family members discussed their affected adolescent's difficulties in recognising degrees of emotion, especially anger, expressed by others. Social isolation, as a product of a low-level of knowledge, was reported by the majority of adolescents and their families (Saccà, 2019).

In another study, it was found that lack of understanding and acceptance of ASD manifestations was a common characteristic in mothers of children with ASD (Opreaa and Stanb, 2012).

The results suggest that a mother's job, the child's age and the child order variables are generally important predictors, and are correlated with knowledge about ASD. It is noteworthy that a mother's job negatively affects this knowledge, perhaps because of the time spent being employed rather than being a housewife. (Philip, 2010). Another study carried out by Koydemir (2009) reported many career problems with mothers who had a child with ASD. In a similar vein, the study of Grant and Ramcharan (2001) revealed that mothers of a child with ASD may finish or postpone their career. Parish and Cloud (2006) reported that many mothers suffered from work problems that were related to having a child with ASD; this gave the impression of the time problems of mothers with a child having ASD.

Child age and child order correlated with knowledge about ASD. These factors are generally important predictors as they affect the mothers' knowledge due to them having experience of the disorder. Also, as a result of difficulty in diagnosing autism before three years, almost all children are diagnosed when they are just before school age. Many studies have mentioned that the second child has a higher chance of having ASD than the first child (Khudhair, 2018).

5. Conclusion

Childhood autism is characterised by a serious and wide deficiency in numerous areas of individual development; it requires massive care and increased dependency on the parents. The main conclusion developed from our study is that there is a lack of perception and inadequate knowledge about autism in mothers. Mothers of children with ASD lack not only knowledge about the signs and symptoms of ASD but also knowledge about the diagnosis and therapeutic approaches of this condition.

Biographies

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Dr Mousa is an assistant professor of nursing. She started her career in Minia, Egypt, where she obtained her Master's and Ph.D. degrees, and taught for 13 years. She specialises in obstetrics and gynaecology nursing. Her research areas of interest are maternity nursing, and women's and adolescents' health; additionally, she assists mothers of children with special needs. ORCID ID: <https://orcid.org/0000-0003-4163-3413>

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Miss. Alkhars is about to receive a Bachelor's degree in Nursing. Her area of interest is emergency nursing, and her future goal is to get a Master's degree in this area. She spends part of her time as a BLS trainer for the public. She works on raising awareness of chronic diseases in Saudi Arabia. She aims to enhance her potential and expertise in this research area by participation in research activities. Her future plan is to be a highly qualified lecturer in an academic nursing department. Her most prominent characteristic is her willingness to learn; she is a life-long learner.

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Mr. Alkishi's research areas of interest are family medicine and medical specialties that are devoted to general health care for people of all ages. He has clinical experience in many areas of medicine. He aims to participate in designing strategies to improve primary health care centres' service in Saudi Arabia. He is interested in life-long education and training. He is renowned for being a hard worker, an excellent leader, and a good team member. ORCID ID: <https://orcid.org/0000-0001-8882-7157>

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Mr. Alnazzal was involved in a few outside activities related to community services. His research areas of interest are psychiatry and psychological fields: mental health and behavioural disorders. He has obtained clinical experience in this area under the supervision of experts. His future goals are to be an excellent psychiatrist by training in a well-known centre, and conducting informative research that may aid clinical practice. He is a member of several groups that serve public awareness. ORCID ID: <https://orcid.org/0000-0001-9165-260X>

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Mr. Alkhars received a high school degree in Al Ahsa, Saudi Arabia, and he is about to receive an MBBS degree in the same town. His research area of interest is internal medicine. He has multiple publications that have served clinical practice in various medical specialties. He has a long record of participation in public health and health promotion. His future goal is to enhance his potential in this research area. He is known to be very willing to learn and ambitious. ORCID ID: <https://orcid.org/0000-0001-8882-7157>

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