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Original Article

Paediatrics Section

Knowledge, Awareness and Attitude of Parents towards their Children with Autism at a Tertiary Care Hospital, Saudi Arabia: A Cross-sectional Study

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ABSTRACT

Introduction: Autism Spectrum Disorder (ASD) is a lifelong hereditary neurodevelopmental disorder characterised by a lack of social communication and restricted and repetitive behaviours. The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) classified symptoms of autism into two domains: the social communication and interaction domain. However, studies on autism in Saudi Arabia are still insufficient. Therefore, awareness and knowledge about autism can facilitate early detection and treatment, resulting in better outcomes.

Aim: To evaluate parents' knowledge, awareness, and attitude towards their autistic children in a tertiary care hospital in Saudi Arabia.

Materials and Methods: This hospital-based cross-sectional study was conducted at Baljurashi Mental Health Hospital, AL-Baha region, Saudi Arabia, from January 2023 to November 2023. A total of 69 parents with autistic children who attended the outpatient clinic at Baljurashi Mental Health Hospital were included in the study. A questionnaire was administered among parents to assess their knowledge, awareness, and attitude regarding autism. Data was statistically analysed using descriptive statistics and the Chi-square test.

Results: The age of the parents ranged from 16 to over 50 years, with 47 (68.1%) being males and 22 (31.9%) being females. Almost 29 (42.0%) of the parents were postgraduates, and 21 (30.4%) had a university-level education. About 24 (34.8%) of the participants believed that consanguineous marriage increases the risk of autism, 19 (27.5%) believed that some vaccines increase the risk of autism, and 39 (56.5%) knew that autism is associated with learning disabilities. Three-quarters of the participants, 54 (78.3%), stated that autism was known to them, 50 (72.5%) thought that an autistic child could be affected by a normal child, and 53 (76.8%) had good knowledge about autism.

Conclusion: The study showed that the majority of parents had good knowledge about autism disorder. The findings reflect the positive impact of focused training initiatives and public awareness efforts aimed at improving parents' knowledge, awareness, and attitude toward autism.

Keywords: Neurodevelopmental disorder, Public awareness, Repetitive behaviour

INTRODUCTION

A neurodevelopmental disorder known as ASD can typically be identified around the age of two [1]. It encompasses pervasive developmental disorders, Asperger syndrome, and autistic disorder. There is a significant correlation between autism and the genetic condition known as fragile X syndrome, and autism is more commonly seen in males and children born prematurely [1,2]. Repetitive behaviour, delayed language development, poor name recognition, and communication difficulties are all indicative of autism. The DSM-5 [3] categorises symptoms of autism into two domains: the social communication and interaction domain, involving deficits in verbal and non-verbal communication, and the repetitive behaviour domain. For a formal ASD diagnosis, children must exhibit at least three symptoms in the social communication and interaction domain, and two symptoms in the repetitive behaviour domain. Recent data in the United States suggests that one in 68 children receive a diagnosis of autism [4].

In a study by Vivanti G et al., it was found that early interventions significantly improved the cognitive, linguistic, and social-emotional functioning of children with ASD, highlighting the benefits of early ASD diagnosis. Early identification of ASD leads to early interventions that have been shown to enhance developmental outcomes for children with ASD [5]. Grzadzinski R et al., reported that parents who received an early diagnosis of their child's ASD experienced lower levels of stress and anxiety [6]. As a result, these parents were more likely to access the services and support needed for their child, contributing to reduced parental stress and improved family functioning.

Since the 1960s, there has been a steady increase in the number of children diagnosed with autism [7,8]. This increase is believed to be due to improved diagnostic methods, broader diagnostic criteria, reduced stigmatisation of the condition, and increased awareness among health professionals and families [8]. A similar study conducted in the Aseer area of Saudi Arabia found that most parents had poor knowledge about autism [9]. Furthermore, the present study was the first of its kind in AL-Baha region of Saudi Arabia, where parents of diagnosed autism cases attending the outpatient clinic at Baljurashi Mental Health Hospital, the largest health facility caring for autism patients, were interviewed. Therefore, good knowledge, awareness, and attitude towards autism can facilitate early detection and enable early treatment, leading to improved outcomes.

Hence, the present study was conducted to explore the general concept of autism and evaluate parents' perspectives and attitudes towards their children with autism.

MATERIALS AND METHODS

A cross-sectional study was conducted in Baljurashi city, Al-Baha region, Saudi Arabia, from January 2023 to November 2023. The study adhered to ethical principles and was conducted in accordance with the Ethics and Research Committee approval of the College of Medicine of Al-Baha University {EC/PEA/BU-FM/2022/17}. Informed consent was obtained from the study participants prior to the commencement of the study.

Inclusion criteria: All parents above 16-year-old, along with their children diagnosed with autism by a doctor and who attended the outpatient clinic at Baljurashi Mental Health Hospital, which is the largest hospital in the region for the care of children with autism, were included in the study.

Exclusion criteria: Subjects who refused to participate or had an incomplete questionnaire were excluded from the study.

Sample size: A total of 69 parents out of 73 participants answered the survey, representing a response rate of 95%. These 69 participants were enrolled in the present study through convenient sampling.

Data collection: Following a thorough assessment of the literature, the authors developed and adjusted a 26-item questionnaire [10-12]. To make sure Arab mothers could comprehend it, the questionnaire was also translated into Arabic. Initially, the questionnaire's simplicity, clarity, and reliability were assessed in a pilot study including 13 parents who were not included in the sample. Suspicious components were removed, and the questionnaire underwent additional revisions considering the results of the pilot research analysis. Among these changes was the wording used, which was more understandable and clearer. To ensure the validity of the questionnaire, two experts authorised it. There were three sections to the study questionnaire. For each of the three questionnaire sections, interviews with all participants were conducted in a timely manner. The participants' socio-demographic information (age, education, marital status, and whether they had a child with autism) was the main topic of the first section. There were two parts of 13 questions in the second section. The participants' knowledge of autism risk factors was evaluated in the first portion, and their understanding of behavioural management of autism was evaluated in the second. Seven items about attitudes toward children with autism made up the third section of the questionnaire. The choices for answering were "Yes," "No," and "Not sure." When there were two possible answers to a question, one point was awarded for a correct response, and zero points were awarded for a "Not sure" or erroneous response. Twelve was the highest possible score. The American Psychiatric Association Diagnostic and Statistical Manual for Mental Disorders' guiding principles served as the base for the concerns about the risk factors of autism or autism as a disorder [3].

Knowledge Score

Participants' Knowledge Score: Parents' knowledge was evaluated using the knowledge scoring system, which was adapted from an earlier study [13]. Examining parents' awareness of autism, consanguinity in marriage, immunisations, and certain foods as risk factors for autism were among the parameters evaluated to assess their level of understanding. Options for behavioural control of autism, like social integration and enrolling children with autism in a standard school, were also taken into consideration. This also included evaluating the parents' understanding of the effects of autism, including learning impairments and the IQ of children with autism. An accurate response received a score of 1, whilst an inaccurate response received a score of 0. Two groups of parents were identified based on their total knowledge: those who scored 60% or above for good knowledge, and those who scored lower than 60%, for poor knowledge [13].

STATISTICAL ANALYSIS

After the data were coded, they were imported into Statistical Package for the Social Sciences (SPSS) version 25.0. Descriptive statistics, such as frequencies, percentages, means, and standard deviations, were used to analyse the data that were gathered. The associations between the variables were investigated, and any significant differences between the variables were tested, using the Chi-square and t-test.

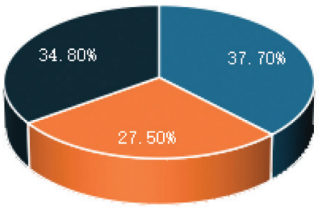
RESULTS

A total of 69 parents participated. The parents' ages ranged from 16 to above 50 years. Of these, 47 (68.1%) were males and 22 (31.9%) were females. Nearly 29 (42.0%) of the parents had postgraduate education, and 21 (30.4%) had a university level education. [Table/Fig-1] summarises the socio-demographic characteristics of the study participants.

Variables		n (%)
Age (years)	16-18	5 (7.2)
	19-30	5 (7.2)
	31-40	20 (29.0)
	41-50	27 (39.1)
	More than 50	12 (17.4)
Sex	Male	47 (68.1)
	Female	22 (31.9)
Marital status	Widow	6 (8.7)
	Married	56 (81.2)
	Divorced	7 (10.1)
Educational level	Primary education	4 (5.8)
	Intermediate education	8 (11.6)
	Higher secondary education	7 (10.1)
	University education	21 (30.4)
	Postgraduate education	29 (42.0)
Do you have an autistic child?	Yes	56 (81.2)
	No	13 (18.8)
Do you have previous experience with autistic children?	Yes	18 (26.1)
	No	48 (69.6)
	Not sure	3 (4.3)

[Table/Fig-1]: Socio-demographic data of parents (N=69).

Regarding the knowledge of participants about autism and its relation to consanguineous marriage, 19 participants (27.5%) believed that there is no link between consanguinity and autism [Table/Fig-2].

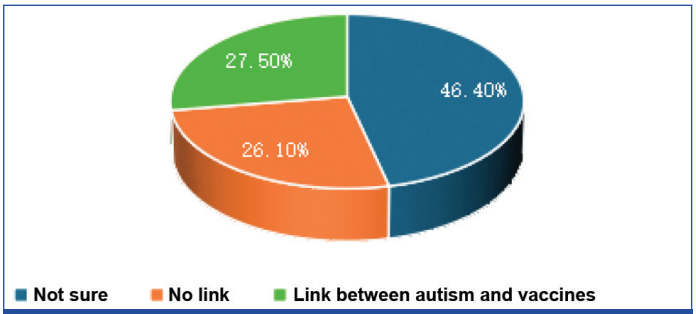


[Table/Fig-2]: Link between autism and consanguinity marriage.

Regarding autism and its relationship to vaccines, 19 participants (27.5%) believed that some vaccines increase the risk of autism, while 18 (26.1%) did not think so [Table/Fig-3].

[Table/Fig-4] represents the results of parents' awareness regarding the behavioural management of autism. When asking the parents about the possibility of admitting children with autism into a regular educational program and whether they can benefit from this integration, it was found that 43 (62.3%) of parents said it is possible, and 49 (71.0%) of them said they could benefit from this admission. On the other hand,

the majority of participants, 58 (84.1%), believed that social interaction for autistic patients had a positive impact on their health.



[Table/Fig-3]: Link between autism and vaccines.

Variables		n (%)
Is it possible to merge autism patients into a normal educational programme?	Yes	43 (62.3)
	No	16 (23.2)
	Not sure	10 (14.5)
Do autism patients get benefits from merging them in a normal educational programme?	Yes	49 (71.0)
	No	5 (7.2)
	Not sure	15 (21.7)
Does social mixing for autism patients have a positive impact on their health?	Yes	58 (84.1)
	No	4 (5.8)
	Not sure	7 (10.1)
Is a normal child affected by the behaviour of an autistic child?	Yes	22 (31.9)
	No	29 (42.0)
	Not sure	18 (26.1)
Do you think that an autistic child can be affected by a normal child?	Yes	50 (72.5)
	No	9 (13.0)
	Not sure	10 (14.5)

[Table/Fig-4]: Awareness of parents regarding behavioural management of autism (N=69).

Three-quarters of the participants, 54 (78.3%), stated that they were aware of Autism. More than half of the participants, 39 (56.5%), mentioned that autism disorder is associated with learning disabilities and that the IQ of an autistic child was low (20 participants, 28.9%), while 23 (33.3%) said that their IQ is good. Other parameters of participants' knowledge were presented in [Table/Fig-5].

Variables		n (%)
Autism is known to me	Yes	54 (78.3)
	No	9 (13.0)
	Not sure	6 (8.7)
Do you think the autism child has a distinguishable appearance like as in down syndrome?	Yes	14 (20.3)
	No	34 (49.3)
	Not sure	21 (30.4)
Do you think that the autism disorder is associated with learning disabilities?	Yes	39 (56.5)
	No	13 (18.8)
	Not sure	17 (24.6)
Does some types of food cause autism?	Yes	7 (10.1)
	No	31 (44.9)
	Not sure	31 (44.9)
Is there any effective treatment for autism?	Yes	6 (8.7)
	No	32 (46.4)
	Not sure	31 (44.9)
What is the IQ in autism patients?	Low	20 (28.9)
	Good	23 (33.3)
	Very good	14 (20.3)
	Excellent	12 (17.4)

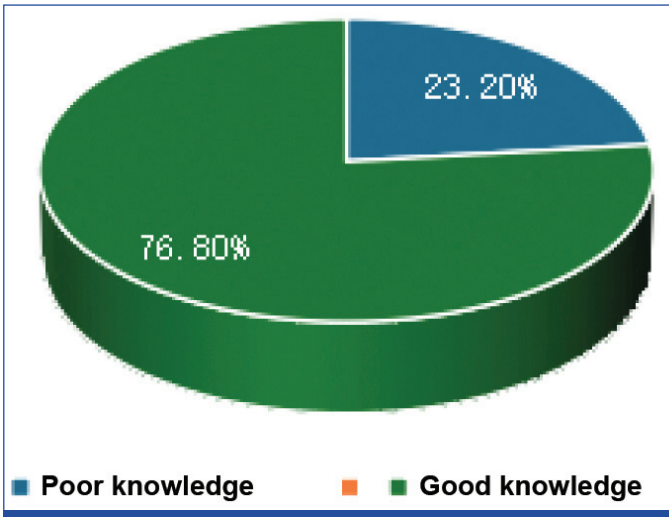
[Table/Fig-5]: Knowledge of parents regarding autism (N=69).

When assessing the behaviour and attitude of children with autism regarding their ability to dress themselves, prepare food, get married, drive a car, and obtain employment, it was found that 60.8%, 26.1%, 30.4%, 10.1%, and 33.2% said yes they can, respectively. Meanwhile, 27.5%, 67.3%, 30.4%, 10.1%, and 34.8% said no, respectively. These results are presented in [Table/Fig-6].

Variables		n (%)
Do you think that autistic children can dress themselves?	Yes	42 (60.8)
	No	19 (27.5)
	Not sure	8 (11.6)
Do you think that autistic child can prepare food for themselves?	Yes	18 (26.1)
	No	44 (67.3)
	Not sure	7 (10.1)
Do you think that autistic children can marry and build a family?	Yes	21 (30.4)
	No	24 (34.8)
	Not sure	24 (34.8)
Do you think that autistic children can drive a car?	Yes	7 (10.1)
	No	52 (75.3)
	Not sure	10 (14.5)
Do you think that autistic children can be employed?	Yes	23 (33.2)
	No	24 (34.8)
	Not sure	22 (31.9)
Do you think that autistic patients should have health services which are different from others?	Yes	60 (87)
	No	5 (7.2)
	Not sure	4 (5.8)
Do you have appropriate information about the availability of autism centres?	Yes	26 (37.7)
	No	26 (37.7)
	Not sure	17 (24.6)

[Table/Fig-6]: Parents awareness regarding child's attitude with autism (N=69).

Overall, the majority of participants, 53 (76.8%), have good knowledge about autism [Table/Fig-7]. This reflects a job well done by those responsible for raising awareness and providing counseling services for the community in Baljurashi city, Al-Baha region, Saudi Arabia.



[Table/Fig-7]: Overall parents knowledge regarding autism.

DISCUSSION

Present study sheds light on various aspects concerning the knowledge, awareness, and attitudes of the participating population regarding autism disorder. These aspects include consanguinity, vaccines, educational level, social interaction, specific characteristics, and treatment possibilities for autism disorder. Present study findings indicate that 34.8% of the participants believe there was an association between autism disorder and consanguinity among parents. This belief is supported by the current body of research [14].

A study conducted in Aseer, Saudi Arabia, found that 50.9% of parents expressed their opinion that genetics plays an important role in the cause of autism [9]. However, susceptibility to autism disorder is influenced by genetic factors; siblings of individuals with ASD have a higher diagnostic rate than the general population, and there is significantly greater, if not perfect, agreement between autism diagnoses in monozygotic twins [15,16].

In present study, it was found that 27.5% of the respondents believed in the effect of vaccines in increasing the risk of autism, while 26.1% do not think so, and only 46.4% were not sure about this relationship. This reflects a persistent and common myth that has circulated in various communities, including Saudi society. In a previous study, "26.6% of parents agreed that vaccines can potentially cause autism, and 18.6% believed that they can also cause learning difficulties" [17]. It is not surprising to find such beliefs in other parts of the world [18]. Another study on the Measles, Mumps and Rubella (MMR) vaccine and autism clearly revealed that the MMR vaccine does not increase a child's risk of developing autism, does not cause autism in children who are vulnerable to it, and is not linked to a clustering of cases of autism following immunisation [19]. This undoubtedly necessitates educational efforts within society, including public campaigns and raising awareness among community leaders.

The study showed a high awareness of the causative relationship between specific types of food and autism disorder. Only 10.1% had this incorrect belief, while 44.9% were aware that ASD has nothing to do with any specific type of food, and 44.9% were unsure. As reviewed by Oken E and Bellinger DC, most studies examining maternal fish intake and child neurodevelopmental outcomes have indicated that higher maternal fish consumption is associated with higher child development scores [20]. The one study to date that specifically looked at the relationship between maternal fish intake and ASD did not find any relationship [21].

The inclusion of students with autism and other challenges in general education classrooms alongside their typically developing classmates has become more common in recent years [22]. Interestingly, there is a notable positive attitude towards admitting children with autism into regular educational programs, with 62.3% of the sample supporting this idea, while only 23.2% had a contrary opinion about the possibility of including children with autism in normal educational programs. This result is very encouraging and aligns with the inclusivity movement in education and current educational policies in Saudi Arabia [23].

Another related result concerns the benefits that autistic children can gain from inclusion. Present study found that 71.0% gave positive responses to this, in contrast to the small percentage (7.2%) that claimed no benefit from this inclusion. Researchers have documented that students with disabilities, including those with autism, display higher levels of engagement and social interaction compared to their counterparts in separate placements. They have larger friendship networks, give and receive higher levels of social support, have more advanced individualised education plan goals, and have more advanced goals for their development [24,25].

Present study also revealed that a significant percentage of participants (78.3%) declared that they have knowledge about autism, which was consistent with a study conducted in Karachi, Pakistan, showing that 75% of the population had heard of autism [26]. Only 20.3% of the participants were unaware that autistic children have a distinguishable appearance, as in Down syndrome, while 49.3% were aware that autistic children do not have a distinguishable appearance. Regarding the presence of effective treatment for autism, 8.7% responded positively, while 46.4% denied the existence of any effective treatment for ASD. The remaining 44.9% expressed hesitation and lack of information.

According to the results of a clinical experiment by Ghanizadeh A and Moghimi-Sarani E [27], the combination of acetylcysteine and risperidone reduced irritability in autistic children but had no effect on the primary symptoms of the disorder. Similarly, a systematic review of drugs commonly used to treat autism revealed that while these drugs are frequently utilised, their efficacy is not well demonstrated [28].

Regarding the correlation between autism disorder and learning disabilities, 56.5% of the participants showed awareness of the scientifically proven relationship between these two issues. This was similar to a study conducted in the Aseer Region, Southwestern Saudi Arabia, where 64.2% of the respondents stated that learning disabilities are one of the main symptoms of autism [9].

Another aspect of knowledge and awareness about autism disorder was the IQ level in autistic patients. In present study, 28.9% believed that the IQ is low in autistic patients, 33.3% thought that autistic patients have a normal IQ, 20.3% believed it was very good, and 17.4% believed that autistic patients have an excellent IQ. When considering the last two percentages, a significant portion of the participants held the common misconception about high IQ in autistic patients, which aligns with the media's portrayal of savants who possess extraordinary talents. This finding contrasts with a study in Saudi Arabia cited above, where 69.6% believed that most children with autism have special talents [9].

Although well-known examples of special or savant abilities exist, they are relatively infrequent and occur in only one out of every 200 individuals with autism [29]. In present study, participants' knowledge about patients with autism disorder were assessed regarding specific abilities such as dressing, preparing food, getting married, driving, and working. The responses were as follows: 60.8% believed autistic patients can dress themselves, 26.1% believed they could prepare food, 30.4% believed they could get married, 10.1% believed they could drive a car, and 33.2% believed they could work. These results show non homogeneous responses. A study conducted at The Children's Hospital of Philadelphia, United States of America (USA), revealed that individuals with ASD who obtained a permit and were eligible for a driving license, the vast majority (89.7%) obtained a license within two years [30]. On the other hand, only 21% of people with disabilities, including autism, are employed. Nearly 60% of people with autism in the United States (US) are employed after receiving Vocational Rehabilitation (VR) services [31].

Overall, the awareness of this sample of the Saudi population revealed good knowledge at 76.8% and only 23.2% had poor knowledge, reflecting the efforts made in education and awareness-raising in the general population. This contrasts with a study conducted in the Aseer area, Saudi Arabia, which found that 85.5% had poor knowledge about autism [9].

Limitation(s)

Certain limitations were encountered in present study due to convenient sampling. As this study was conducted only in Baljurashi city, Al-Baha region, a clear estimate of the awareness about autism in the entire Saudi population cannot be generalised.

CONCLUSION(S)

The present study concluded that most of the participants had good knowledge about ASD. The study reflects the positive impact of focused training initiatives and public awareness efforts aimed at improving parents' knowledge, awareness, and attitudes towards autism. Alongside strong cultural beliefs and practices, the study highlights the importance of healthcare providers having appropriate knowledge and attitudes towards creating a supportive environment for children with autism among parents in Saudi Arabia. It is recommended that having good knowledge, awareness, and a positive attitude toward autism is crucial in facilitating early and accurate diagnosis, which significantly influences outcomes and behavioural development in children. Therefore, if parents recognise

symptoms of autism in their child, such as a lack of eye contact or responsiveness to verbal cues, they should seek early medical help.

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