

ORIGINAL ARTICLE

Autism in Saudi Arabia, a challenge to Saudi families: a cross-sectional study

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ABSTRACT

Background: Autism spectrum disorder (ASD) is a mental condition, usually presented from early childhood; it is often observed and diagnosed within the first 3 years of the child's life. This study aims to evaluate the challenges that families are facing regarding raising a child with Autism in Saudi Arabia.

Methodology: An observational cross-sectional study was conducted in the eastern region of Saudi Arabia from December 2016 to February 2017 to assess the challenges faced by families of ASD children. This study involved all the families that have one or more autistic children between the ages of 1 and 12 years. The data were collected by using a self-administered questionnaire distributed electronically and in paper form among families with an autistic child with the help of autism centers. The data were analyzed by Statistical Package for the Social Sciences version 21.

Results: The questionnaire consisted of 31 questions, a total of 61 families participated in this study. Regarding the diagnosis, the majority of the sample was diagnosed with Autism at an early age. The prevalence of ASD in males was found higher than females. Public awareness was still very poor. Families were spending a lot of money even though the government's facilities were acceptable. The study found it to be challenging to raise an autistic child in the studied population,

Conclusion: The study found families with autistic children were suffering from many challenges, psychologically, socially, emotionally, and financially in the Saudi population.

Keywords: Autism, Saudi families, autism spectrum disorder, challenges, child.

Introduction

Autism spectrum disorder (ASD) is a biological-based neurodevelopmental disorder that is diagnosed in childhood and has many symptoms, some being more severe than others. ASD characterized by impairment in two major domains: Deficit in social communication and social interaction and restricted and also repetitive movements, behavior, interests, and activities [1]. The presence of these symptoms causes children with ASD to have a lot of challenges in forming new meaningful relationships. A child diagnosed with Autism has his way of communication either verbally, nonverbally, or a combination of both. There are common experiences among autistic children, including obsession, impairment of social relationships, cognitive impairment, and abnormalities in language [2-4]. Although the potential impact of ASD is significant, some autistic children attend conventional schools with normal intelligence quotient [5]. As a result of this communication style,

special education services need to be modified in accordance. Other children often think that autistic children are socially awkward. Over a short period, the number of cases diagnosed with ASD has been increased. Approximately 11 years ago, it ranged from five per 10,000 [6] to 60 per 10,000 [7]. A recent study conducted by Meadan [8] concluded that the Autism is affecting about 1/110 children and is growing to 17% of children per year [8]. In today's society, the prevalence

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of ASD is increasing, with males being affected 4.5 times higher than females [9]. The current prevalence in the United States is estimated at 1 in 91 children [10]. Recent epidemiological studies conducted in different regions of the world have indicated that at least one in every 100 people has some form of Autism [11]. In Arab Gulf countries, prevalence estimated between 1.4 and 29/10,000 [12]. Few studies published about the prevalence of Autism in the developing countries. Autism in Saudi Arabia is slightly higher than reported in the developed countries. In Saudi Arabia, the prevalence estimated that the number of confirmed cases of ASD was 42,500, and many remained undiagnosed [13]. Although the cause of Autism is unknown, there is growing evidence that a variety of disorders can cause Autism. However, exact pathophysiology is still unknown, and no disease markers for the diagnosis of Autism have been validated [14]. Early diagnosis of ASD could help the families to develop better-coping strategies for the classical behaviors of their child. With that said, we need to educate social workers about ASD as this diagnosis not only affects the individuals themselves, but also affects their families. It is a big challenge to have an autistic child. Not only to the family, but also it has an impact on society on the country. Autistic children are going to need special care because they have a lot of difficulties in their life. Also, they have many learning difficulties. They can't find the appropriate words to communicate with others. Even if they are talking with them, people won't be able to understand what they mean. These difficulties, in turn, will produce feelings of grief, stress, and confusion. Immediately, with no warning or preparation, the family has to transform and adapt to a new lifestyle [8]. The family will have to go to a lot of primary health care centers for ASD to help their child to overcome his obstacles, and they may need a lot of money for that. The siblings also are affected; they will have many difficulties to understand their brother. They won't be able to communicate or take care of him. The main aim of this study was to examine ASD and how it is impacting families. The study primarily focused on the challenges that parents faced in raising an autistic child. The goal of the study was to empower families who had children with ASD as well as providing educational support and further knowledge and understanding for social workers and other professionals working in this field.

Subject and Methods

This study was conducted from December 2016 to February 2017 in the eastern region of the kingdom of Saudi Arabia (KSA). The target population included all the families that have one or more autistic children between the age of 1 and 12 years.

Case identification

The present study is about the challenges that the families of an autistic child are facing, psychologically,

socially, emotionally, or financially. Autistic child's families were identified by going to the autism centers in the eastern region of KSA and asking them for the communication data of the families. We reached them either by social media or by meeting them in a particular place. The questionnaire was consisted of 31 questions, and it was distributed as two forms, an electronic form and a paper form. An agreement was included to take their consent.

Sampling

The data for this study was collected by a cross-sectional design. It can be defined as a type of observation that involves the analysis of data collected from a population, or a representative subset, at one specific point of time. We chose this way to collect the data because it is an observational study without any experiments or to use any medication or comparing with other groups. Also, it is not related to the past or the future; it is about the current time only.

Results

The coding was done in this study, categorizing the research into a limited number of categories. This analysis allowed the researchers to study the similarities and differences between families who are impacted by ASD through semi-structured interviews. Content analysis also enabled the researchers to identify the major themes presented in these families due to their personal experience with ASD. The participants of this current study were 61 families. We reached them either by social media or by meeting them in a particular place. The questionnaire was consisted of (31 questions), and it was distributed as two forms, an electronic form and a paper form. An agreement was included to take their consent. All the children with Autism were found to be between age 1 and 12 years, and the majority of them were diagnosed at an early age, i.e., 1-5 years (Figure 1). Regarding the prevalence, Autism was found to be higher in male children (73.8%) as compared to female children females (24.2%) of a sample population of 61 families (Figure 2). Having an autistic child will make the lifestyle difficult and facing many challenges within the family or society. About public awareness of the needs of individuals with Autism that 37.7% of the Children are causing an embarrassment to their families, while 63.9% of the families are suffering from the way that the society is dealing with their child (Table 1). Children with Autism need special attention and care from centers and schools. This study showed 31.1% of the families said that there is no autism center near their houses. Also, 72.1% of the families are living in an area where there is no private school for their Child (Table 2). Furthermore, 91.8% of the families have been spending a lot of money to help their Child. While 45.9% of the families evaluated the government facilities as acceptable, 29.5% evaluated it as bad (Figure 3). Public awareness of ASD is very essential for families and society by organizing

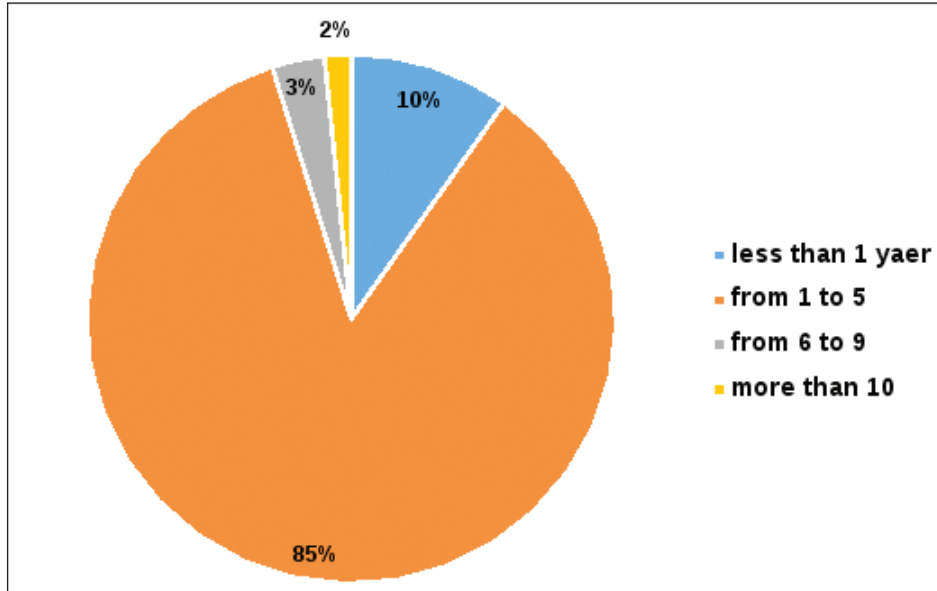


Figure 1. Age of the child when the family noticed that the child is autistic.

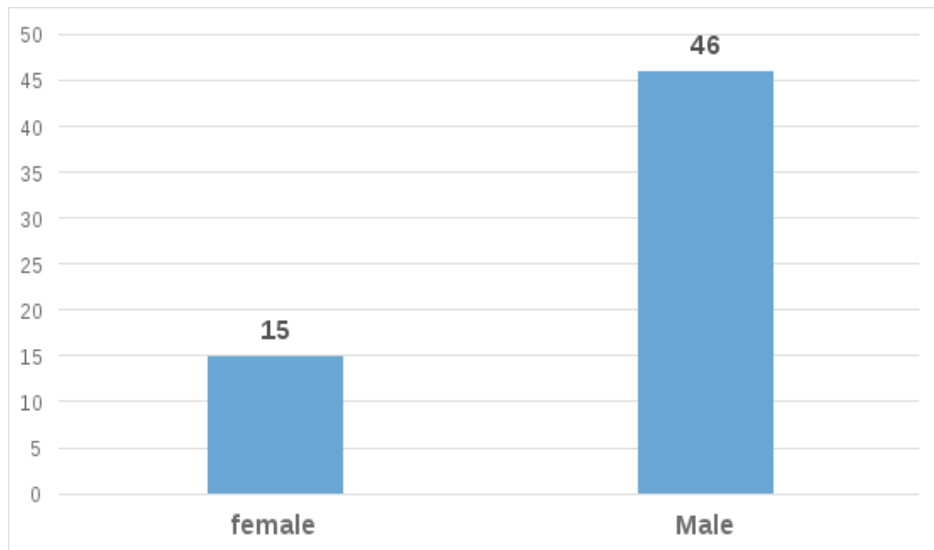


Figure 2. Number of children affected by Autism.

Table 1. Public awareness of ASD causing embarrassment to families with autistic child.

P-value	Suffering from society			Embarrassment to the family
	Yes	No	sometimes	
0.048	20(32.85)	3(4.9%)	15(24.6%)	No
	19(31.1%)	00	4(6.6%)	Yes
	39(63.9%)	3(4.9%)	19(31.1%)	Total

conferences, workshops, and sources of different languages. Regarding this point, the study showed 57.4% of the families went to some conferences to teach them about Autism, while 72.1% thinking that there aren't enough Arabic sources talking about Autism (Table 3).

Discussion

The current study aims to explore the challenges that families are facing with their autistic children. We observed several key findings. First, parents are facing

difficulties with the dealing of the society with their autistic child. Second, there is no near private autism center to most of the families, which makes it more difficult and challenging. Also, there are many findings, but these are the main ones. The result of the current study has shown that the overall prevalence of Autism in nursery schools and primary schools whose ages ranged from 1 to 12 years old. Regarding diagnosis, the majority of the sample was diagnosed with Autism at an early age of 1-5 years, which has a similar finding of the previous studies [15]. The present study revealed that the prevalence of ASD in males is higher than females, which is similar

to the findings of previous studies [9]. About public places, such places can be stressful and challenging for parents and individuals with Autism without appropriate support and public understanding and awareness of their particular needs. Parents of autistic children want to be allowed to go first and avoid queuing as it is known that waiting is difficult for children with Autism. Therefore, they have to be given the appropriate support by services in public places, for instance, by providing a special pass and hand stamp that allows them to go first in accessing any public services. The deep meaning of awareness about Autism is not only about understanding

Table 2. Availability of Autism centers and private schools near the families.

p-value	A private school near the family house		Autism center near the family house
	Yes	No	
0.008	1 (1.6%)	18 (29.5%)	No
	16 (26.2%)	26 (42.6%)	Yes
	17 (27.9%)	44 (72.1%)	Total

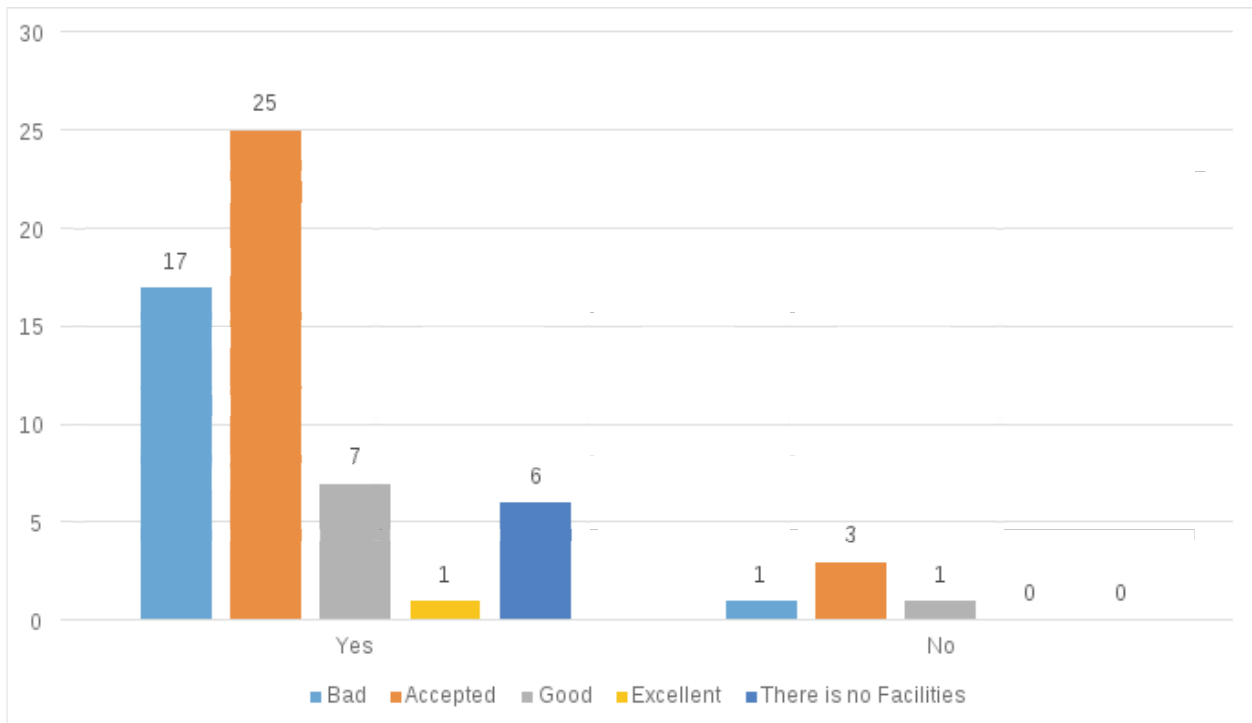


Figure 3. Governmental facilities to autistic children.

Table 3. Family members going to a conference in relation to their thoughts about if there are enough Arabic sources.

p-value	Thoughts about if there are enough Arabic sources to teach about Autism		A family member went to a conference about Autism
	Yes	No	
0.030	11 (18%)	15 (24.6%)	No
	6 (9.8%)	29 (47.5%)	Yes
	17 (27.9%)	44 (72.1%)	Total

its characteristics but also understanding its needs and accommodating them accordingly in the environment. Also, this study represents that most of the families have difficulties in accessing the information and knowledge that allow them to have a better understanding of their children's needs because the majority of information and sources are provided in English or different languages. Therefore, autism associations and universities have to perform their role in providing Arabic sources for parents and service providers in the community by translating guidance and advice for parents, in addition to ensuring that their training programs are up to date [16]. Even though the facilities of the government are acceptable, most of the families still spending a lot of money to help their child because the facilities do not fulfill their needs. For instance, parents have to teach their children in a private school because there are not adequate governmental schools. To receive follow-up advice and support, after diagnosis is the first right for individuals with Autism and their family members. They have to be guided to the most appropriate services available for them in the community. These services and support include the appropriate school for them, social services, support for family members, benefits, and support groups.

Conclusion

At the end of this research, we found that families with autistic children are suffering from many challenges, psychologically, socially, emotionally, and financially. They need more attention.

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List of Abbreviations

ASD Autism Spectrum Disorder
KSA Kingdom of Saudi Arabia

Conflict of interest

The authors declare that there is no conflict of interest regarding the publication of this article.

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Consent for publication

Informed consent was obtained from all the participants.

Ethical approval

Not provided.

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References

1. American Psychiatric Association. Autism spectrum disorder. In: Diagnostic and Statistical Manual of Mental Disorders. 5th ed. Arlington, VA: American Psychiatric Association; 2013. p. 50. <https://doi.org/10.1176/appi.books.9780890425596>
2. Lincoln AJ, Courchesne E, Kilman BA, Elmasian R, Allen M. A study of intellectual abilities in high-functioning people with Autism. *J Autism Dev Disord.* 1988;18(4):505–24. <https://doi.org/10.1007/BF02211870>
3. Szatmari P, Bartolucci G, Bremner R, Bond S, Rich S. A follow-up study of high-functioning autistic children. *J Autism Dev Disord.* 1989;19(2):213–25. <https://doi.org/10.1007/BF02211842>
4. Gray DE. Coping over time: the parents of children with Autism. *J Intellect Disability Res.* 2006;50(12):970–6. <https://doi.org/10.1111/j.1365-2788.2006.00933.x>
5. Johnson CP, Myers SM. Identification and evaluation of children with autism spectrum disorders. *Pediatrics.* 2007;120(5):1183–215. <https://doi.org/10.1542/peds.2007-2361>
6. American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 4th ed. text rev. Washington, DC: Author.
7. Altieri MJ, Von Kluge S. Family functioning and coping behaviors in parents of children with Autism. *J Child Fam Stud.* 2009;18(1):83. <https://doi.org/10.1007/s10826-008-9209-y>
8. Meadan H, Halle JW, Ebata AT. Families with children who have autism spectrum disorders: stress and support. *Except Child.* 2010;77(1):7–36. <https://doi.org/10.1177/001440291007700101>
9. Rice C, Centers for Disease Control and Prevention. Prevalence of autism spectrum disorders: Autism and developmental disabilities monitoring network, United States, 2006. *Morb Mortal Wly Rep.* 2009;58(S-10):1–20. Available from: <http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5810a1.htm>. <https://doi.org/10.1037/e562722010-001>
10. Kogan MD, Blumberg SJ, Schieve LA, Boyle CA, Perrin JM, Ghandour RM, et al. Prevalence of parent-reported diagnosis of autism spectrum disorder among children in the US, 2007. *Pediatrics.* 2009;124(5):1395–403. <https://doi.org/10.1542/peds.2009-1522>
11. Kim YS, Leventhal BL, Koh YJ, Fombonne E, Laska E, Lim EC, et al. Prevalence of autism spectrum disorders in a total population sample. *Am J Psychiatry.* 2011;168(9):904–12. <https://doi.org/10.1176/appi.ajp.2011.10101532>
12. Hayat AA, Meny AH, Salahuddin N, Alnemary FM, Ahuja KR, Azeem MW. Assessment of knowledge about childhood autism spectrum disorder among healthcare workers in Makkah-Saudi Arabia. *Pak J Med Sci.* 2019;35(4):951. <https://doi.org/10.12669/pjms.35.4.605>

13. Al-Salehi SM, Al-Hifthy EH, Ghaziuddin M. Autism in Saudi Arabia: presentation, clinical correlates and comorbidity. *Transcult Psychiatry*. 2009;46(2):340–7. <https://doi.org/10.1177/1363461509105823>
14. Trottier G, Srivastava L, Walker CD. Etiology of infantile Autism: a review of recent advances in genetic and neurobiological research. *J Psychiatry Neurosci*. 1999;24(2):103.
15. Rogers SJ. Diagnosis of Autism before the age of 3. In *International review of research in mental retardation*. Cambridge, MA: Academic Press; 2000. Vol. 23, pp. 1–31. [https://doi.org/10.1016/S0074-7750\(00\)80004-X](https://doi.org/10.1016/S0074-7750(00)80004-X)
16. Alotaibi F, Almalki N. Parents' Perceptions of Early Interventions and Related Services for Children with Autism Spectrum Disorder in Saudi Arabia. *International Education Studies*. 2016;9(10):128–40.