

Autism Spectrum Disorder (ASD): a review of the literature with specific focus on Autism in Saudi Arabia

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Abstract: This study provides a review of the literature on Autism Spectrum Disorder (ASD) that includes descriptions of the characteristics of children and youth with ASD, the prevalence of the disorder, the challenges that families face when they have a child with ASD, and the instructional needs of children and youth with ASD. Include available US and Saudi Arabia studies/literature/research, contrasting both in terms of where the field of ASD is currently, and identifying where there are gaps in our knowledge and research that should be addressed.

Keywords: Autism, ASD, Saudi Arabia, literature review.

1. INTRODUCTION

Autism spectrum disorder (ASD) has received increased attention from physicians, researchers, parents, and educational specialists in recent years. One reason for this is the growth in ASD diagnoses. The Centers for Disease Control and Prevention (CDC) (2014) estimated that roughly 1 in 68 children in the United States have ASD. Because of the primary common skill deficits and developmental learning difficulties associated with ASD it is considered a complex developmental disorder. Hetzroni and Tannous (2004) have shown that these children have difficulty developing language and communication skills. Deficits in joint attention skills are also common in children with ASD. Many children with ASD are not able to make eye contact with others even when asking for something they need (Tsao & Odom, 2006). Moreover, children with ASD have difficulty with many adaptive behaviors, such as being safe, getting dressed, and using the toilet.

Tsao and Odom (2006) noted that children with ASD have difficulty developing and maintaining social relationships. These difficulties in social competence result from other deficits and difficulties such as language development and joint attention. Bass and Mulick (2007) found that the difficulties children with ASD have with social competence and joint attention lead to problems in social play skills. Social play skills are significant in improving children's social and cognitive skills. Deficits in social play skills can affect communication, imagination, and ongoing social interactions.

These social skill difficulties may be addressed with early, intensive, interventions (Strain & Danko, 1995). One type of these interventions is technology-based treatment. According to the National Autism Center (2009), technology-based treatment is considered as an established treatment with effective and beneficial effects when used with children with ASD. Technology-based treatment includes computer-based technology, where specific software is used on a computer, laptop, tablet, or smartphone. Teachers are more frequently using computers with students with ASD as an instructional tool (Bosseler & Massaro, 2003).

According to a study by Yaw et al. (2011), computer-based instruction increased motivation and decreased problem behaviors in children with ASD when compared to personal instruction. Such assistive technologies offer promise for improving the communication and social skills of children with ASD (Reichle, 2011). Lightweight and portable electronic devices (e.g. tablets and smartphones) are easier for students with autism to use throughout the day, at home, and in

school (Sennott & Bowker, 2009). These portable devices utilize many computer software programs, applications, and designs.

Children with ASD are not treated in a vacuum. It is critically important when considering any intervention we involve families, and parents in particular. Orsmond and Seltzer (2007) found that families and siblings with a child with ASD encounter greater challenges than families with other kinds of special needs children. Rao and Beidel (2009) added that the behavior, communication, and social problems of a child with ASD can create stress for the entire family. "In fact, the delayed and/or atypical ways in which young children with autism interact with parents, peers, and siblings represent one of the defining characteristics of autism" (Strain & Danko, 1995, p. 2). As a result, children tend to spend less time with a sibling with ASD. According to Orsmond and Seltzer (2007), "past research has shown that siblings of young children with ASD spend less time with and have a less close relationship with their brother or sister than do siblings of children with DS [Down Syndrome]" (p. 693). Parents can help their children with ASD overcome stress and develop good relationships with family members. This can be done if parents are included in the child's ASD interventions and treatments.

2. LITERATURE REVIEW

This section considers the prevalence of ASD and addresses definitions, diagnostic features, types, and causes of autism. It also examines the instructional needs of students with ASD and the challenges faced by their families. Finally, the prevalence of autism in Saudi Arabia and gaps in the research on autism in Saudi Arabia are discussed.

Prevalence of Autism Spectrum Disorder (ASD)

The number of children with autism spectrum disorder (ASD) grew by approximately 173% over the past decade (Sansosti & Powell-Smith, 2008). In fact, ASD is the fastest growing developmental disability category in the United States (Zager, 2005, p. 162). One reason for this growth is the increased awareness of ASD in parents, teachers, and others. In addition, the diagnosis of ASD has become more accurate and children are being diagnosed earlier. Finally, autism spectrum is now better defined (Downs & Downs, 2010; Sansosti & Powell-Smith, 2008; Zager, 2005). Globally, one in every 120 children is diagnosed with ASD (Elsabbagh, Divan, Koh, Kim, Kauchali, Marcín, & Fombonne, 2012). Several studies have observed that autism occurs in a 4:1 male to female ratio (Murshid, 2011; Al-Gadani, El-Ansary, Attas, & Al-Ayadhi, 2009). However, no difference has been observed in the rate of autism prevalence reported among a specific race, socioeconomic status, or education level of parents (Murshid, 2011, p. 1627). In fact, autism disorder is found in all ethnic, racial, and socioeconomic groups (Matthews, Booth, Taylor, & Martin, 2011; Al-Faiz, 2006).

Autism and Autism Spectrum Disorder (ASD)

Autism is a developmental disorder that is first observed very early in life and affects the development of essential behaviors and skills, such as communication, imagination, social interaction, and relationship development (National Research Council, 2001). Symptoms usually manifest by the age of three (Al-Wakeel, Al-Ghanim, Al-Zeer, & Al-Nafjan, 2014; Al-Salehi, Al-Hifthy, & Ghaziuddin, 2009; Murshid, 2011). "Autism is best characterized as a spectrum of disorders that vary in severity of symptoms, age of onset, and associations with other disorders (e.g., mental retardation, specific language delay, epilepsy)" (National Research Council, 2001, p. 11). Moreover, the manifestation of various characteristics can change over time in one or many individuals. Although social deficits are common in children with autism, these children do not necessarily share specific, common, social deficits (National Research Council, 2001). "A child with autism looks physically just like any other child but has distinctive behavior patterns. For example, these children may enjoy rocking or spinning either themselves or other objects and may be happy repeating the same activity for a long period of time" (Allothman, 2001, p. 1).

Contributions by Leo Kanner, Hans Asperger, and Michael Rutter have shaped the current clinical conception of autism. Kanner Syndrome or classical autism is "the prototypical ASD, representing the PDD [Pervasive Developmental Disorder] subtype that involves the most severe social-communicative impairments and the greatest number and range of clinical characteristics" (Zager, 2005, p. 6). Kanner Syndrome's essential features "are most closely captured" by the Diagnostic and Statistical Manual (DSM-IV) and International Classification of Disease (ICD-10) (Zager, 2005, p. 6). In 1943, Leo Kanner described a unique neurodevelopmental problem that follows changes in the routines, environment, and close relationships of people with autism. Kanner termed this early infantile autism. In his description of this

neurodevelopmental problem, Kanner included many secondary characteristics such as repetitive behaviors, language and speech abnormalities, unusual sensitivities, and abnormal cognitive development (Zager, 2005; Alothman, 2001).

In 1944, Hans Asperger, a German Viennese physician, described four children with significant social impairments. These children had some linguistic skills and strong problem-solving skills. Asperger's study, published only in German originally, was known to few professionals in the field before the 1980s.

Autism was considered a psychotic condition and many children with autism were diagnosed with childhood schizophrenia prior to publication of the Diagnostic and Statistical Manual-third edition (DSM-III) in 1980. The DSM-III used diagnostic criteria that reflected Kanner's original criteria (Zager, 2005). Later, the term pervasive developmental disorders (PDD) was introduced as an umbrella term for autism and other disorders with similar social impairments while varying in repetitive behaviors and manifestation of communication delay (National Research Council, 2001). This diagnostic term includes Asperger's, autistic disorder, and pervasive developmental disorder-not otherwise specified (PDD-NOS), according to the fourth edition of DSM (DSM-IV). "Collectively, these disorders are referred to as autism spectrum disorder (ASD)" (Bertrand, Mars, Boyle, Bove, Yeargin-Allsopp, & Decoufle, 2001, p. 1155; Zager, 2005, p. 7). For the remainder of this paper, the terms autism and ASD will be used interchangeably. There are three major categories of ASD, "(a) qualitative impairments in social interaction; (b) communication impairments; and (c) restricted, repetitive, stereotyped behavior, interests, and activities" (Zager, 2005, p. 7; Alothman, 2001).

Causes of Autism Spectrum Disorder (ASD)

The cause of autism spectrum disorder (ASD) is unknown (Al-Ayadhi, 2005; El-Ansary, & Al-Ayadhi, 2012; Alothman, 2001; Murshid, 2011), however, a number of theories have been put forward. Al-Ayadhi (2005) suggested that autism could result from genetic, neural, and immune factors, which are still under investigation. Other studies have linked autism to both environmental and genetic factors (El-Ansary & Al-Ayadhi, 2012; Murshid, 2011). "Genetic factors such as a family history of speech delay, learning disability, or other developmental disorder have also come to the forefront as possible correlates to autism" (Alothman, 2001; p. 13). However, no specific gene has been identified as the cause of autism (Alothman, 2001; p. 13).

Types of Autism Spectrum Disorder (ASD)

Alothman (2001) described several types of autism:

1. "Pervasive Developmental Disorder-Not Otherwise Specified (commonly referred to as atypical autism). The diagnosis of PDD-NOS is made when a child does not meet the criteria for a specific diagnosis, but has severe and pervasive impairment in specified behaviors.
2. Asperger's Disorder. A disorder characterized by impaired interactions, restricted interests and activities, no clinically significant delay in language, and testing at average to above average intelligence (Autism Society of America, 1999; Attwood, 2000).
3. Rett's Disorder. A progressive disorder which, to date, has occurred only in girls, and includes a period of normal development followed by a loss of previously acquired skills, and a loss of purposeful use of the hand replaced with repetitive hand movements beginning at one to four years of age.
4. Childhood Disintegrative Disorder. This disorder is characterized by normal development for at least the first two years, with a subsequent significant loss of previously acquired skills" (p. 12-13).

Some children with autism may manifest symptoms of one type of autism's types. On the other hand, some children with autism may show symptoms of more than one type of autism's types. Moreover, while some of these types depend on the gender, such as Rett, some of these types are common more than others (Alothman, 2001).

Diagnostic features. Diagnosing autism spectrum disorder (ASD) is difficult due to the complexity and variability of autism characteristics and symptoms. For example, the degree of associated cognitive impairment varies. Another difficulty is the wide range of associated developmental disabilities such as cognitive, mental retardation, learning disabilities, and other behavioral deficits. However, autism can be identified or distinguished from other disabilities by looking to "the presence of a distinctive impairment in the nature and quality of social and communicative development"

(Zager, 2005, p. 1). The most common feature of help in diagnosing ASD is the deficit in producing spoken language (Bosseler & Massaro, 2003).

Classification of children with ASD. Children with autism spectrum disorder (ASD) can be classified as high-functioning autism or Asperger Syndrome (HFA/AS), or lower-functioning children with autism. Children with high-functioning autism have difficulties with social skills, such as listening and responding to teachers or others, requesting information from others, interacting with others when playing with them, making eye contact, and starting and maintaining conversations (Sansosti & Powell-Smith, 2008). On the other hand, children with Asperger Syndrome (AS) have intelligence quotients (IQ) and expressive language similar to that of typically developing children (Myles, 2005). In fact, autism symptoms range from severe impairment to mild delay (Haimour & Obaidat, 2013).

Characteristics and Instructional Needs of Students with ASD

For students with autism spectrum disorder (ASD), education should include academic learning as well as instruction in social, language, adaptive, and communication skills and techniques to reduce distracting behaviors. Because no two students with ASD are alike, instructional programs should be advised by and based on each student's IEP (Individual Educational Plan) (Silverberg, 2014, p. 129). Students with ASD often have difficulty completing scheduled tasks independently (even though many of these students have strong cognitive skills) because they struggle with memorization, planning, and organization (Gentry, Wallace, Kvarfordt, & Lynch, 2010). In fact, the most important characteristics of children with autism are:

1. "Failing to develop social relationships.
2. Failing to develop communicative language.
3. Difficulty in social communication.
4. Slow development or lack of physical, social, and learning skills" (Allothman, 2001, p. 11).

Communication skills needs. According to the National Research Council (NRC) (2001), two major communication deficits are found in students with autism spectrum disorder (ASD), the lack of joint attention skills, and an inability to use symbols. Joint attention is the ability to coordinate attention between objects and people. The NRC also points out that students with autism usually fail to point to others, get another student's attention, or share emotional moments with others. Also, according to NRC, 2011, the second communication deficit is that students with ASD have difficulties with symbol use of conventional meaning of word or gestures. Education that includes support for social, language, adaptive, and communication skills can help students with ASD complete educational tasks independently and improve personal responsibility. In addition, educational goals for students with ASD should be established based on their deficits (e.g., nonverbal communication, language development, and cognitive disability) (National Research Council, 2001).

Social skills needs. Students with autism spectrum disorder (ASD) may have many social deficits. Zager (2005) observed that the central deficit of students with ASD is an inability to develop and maintain relationships with others. In fact, students with ASD encounter difficulties when they need to respond to others or interpret their own needs effectively in their social world. Instead of learning from their own social experiences, as typically developing students do, students with ASD need direct social skills instruction.

Behavioral skills needs. These students may have many behavioral deficits. Zager (2005) reported that inappropriate and atypical behaviors, reactions, and perceptions are common in students with ASD. They are often hypersensitive to visual, auditory, tactile, and olfactory stimuli (Zager, 2005; Murshid, 2011; Al-Faiz, 2006). For instance, when students with ASD are exposed to even low intensity sound or light, they may become uncomfortable, agitated, or distressed. Students with ASD are usually dislike changes in daily routines (Zager, 2005; Allothman, 2001, Al-Faiz, 2006). This can result in students experiencing social difficulties. In addition, students with ASD produce repetitive stereotyped behaviors, such as head shaking, hand flapping, and jumping. However, it is important to note that there is no common behavioral symptom across all students with autism, as they represent a range of characteristics along a mild to severe continuum.

Academic skills needs. Students with autism spectrum disorder (ASD) vary in their academic abilities. There are students with ASD who have severe cognitive impairment. They learn academic skills by using many of traditional categories,

such as functional academic, self-help skills, language development, and others. On the other hand, there are students with ASD who are HFA/AS and they need to have modifications in the curriculum and instruction process that meets their specific needs (Zager, 2005).

Challenges of Families of Children with ASD

Families of children with autism spectrum disorder (ASD) encounter many challenges and often frustrating experiences (Bayat, 2007; Hoogsteen & Woodgate, 2013). Dyches, Wilder, Sudweeks, Obiakor, and Algozzine (2004) noted “these difficulties may be greater among children with autism than among those with other developmental disabilities” (p. 211-212). Parents of a child with autism encounter challenges both at home and in the community (DePape & Lindsay, 2014). Children with autism frequently have associated problems such as functional speech and cognitive disabilities. Together, these coexisting disabilities can be overwhelming for the families of autistic children.

Dyches, Wilder, Sudweeks, Obiakor, and Algozzine (2004) pointed out the difficulties parents experience in teaching basic life skills (e.g., communication, staying safe, preparing for adulthood). Parents find the challenging behaviors of an autistic child stressful and endless (Ludlow, Skelly, & Rohleder, 2011; Diggle & McConachie, 2009; Guthrie, Swineford, Nottke, & Wetherby, 2013). These behaviors affect the family’s sense of wellbeing and ability to cope. These families face social and educational challenges as well. Parents have reported that the most difficult challenges in raising a child with autism are often found in the social sphere. Many feel socially isolated due to their child’s behavioral problems, others’ judgments of their parenting, and the stigma of having a child with autism (Ludlow et al., 2011; Matthews, Booth, Taylor, & Martin, 2011; Dababnah & Parish, 2013). Parents have reported that “educational and social service supports are not efficient and that they are forced to rely largely on support from within the family or from friends” for help with their child with autism (Ludlow et al., 2011, p. 719). Alothman (2001) asserted that to overcome the educational challenges of students with autism, effective interventions for behavioral problems must first be found.

One of the first challenges parents of children with autism face is finding support for assessment and diagnosis. The second begins when parents seek services and interventions for their child. They start to think about the type of interventions required for their child. They begin considering their role in the intervention process. These challenges put pressure on their relationships with their other children, at work, on financial resources, and with the child with autism (Lee, Harrington, Louie, & Newschaffer, 2008; Dababnah & Parish, 2013). Identifying these challenges helps professionals understand how best to deliver appropriate interventions and services (Lee et al., 2008).

Another challenge for these families is a lack of environmental support (Ludlow, Skelly, & Rohleder, 2011). Parents have difficulty communicating with their children with autism and other difficulties like self-care challenges (Matthews, Booth, Taylor, & Martin, 2011). Depression and other medical, emotional, and psychological challenges are experienced by these parents. (Matthews, Booth, Taylor, & Martin, 2011; Rao & Beidel, 2009; Greeff & Walt, 2010; Dababnah & Parish, 2013).

Family function can be affected. (Rao & Beidel, 2009). Having a child with autism affects family routines and puts stress on the personal time of the parents. Sometimes, these stresses lead to divorce (Greeff & Walt, 2010). Overall, parents of children with autism have more work-family difficulties than do typical parents (Matthews, Booth, Taylor, & Martin, 2011). Parents of a child with autism are at “higher risk of experiencing a host of negative outcomes” (Matthews, Booth, Taylor, & Martin, 2011, p. 626; Alothman, 2001; Dababnah & Parish, 2013).

Siblings of children with autism have mixed impact. Some are positively affected and have increased positive self-concept, while others have more behavioral problems and depression (Rao & Beidel, 2009).

Several studies pointed out that “parents of children with ASD not only report increased levels of stress compared to parents of children without disabilities, but also report more stress compared to parents of children with some other type of disability or chronic illnesses” (Matthews, Booth, Taylor, & Martin, 2011, p. 627). Altieri & Kluge (2009) found that “a child with autism presents unique challenges and stressors for the family because of the ambiguity of diagnosis, the severity and duration of the disorder, and problems with the child’s lack of adherence to social norms” (p. 83). Parental stress can affect the success of early interventions (Osborne, McHugh, Saunders, & Reed, 2008). These parents need support and help from others to overcome the challenges of caring for a child with autism (Hall & Graff, 2011). It is important to point out that a number of studies found that mothers were generally more stressed than fathers of children with autism (Ludlow, Skelly, & Rohleder, 2011; Hall & Graff, 2011).

To conclude, Neely, Amatea, Echevarria-Doan, and Tannen (2012) wrote:

“the concerns families face during their child’s infancy and early childhood include the following: (a) identifying that the child has a problem and gaining a clear diagnosis, (b) coping with family members’ emotional reactions to the disorder, (c) helping families make treatment decisions, and (d) developing a support system. We then describe three additional circumstances families often face when their child with ASD enters a formal school setting. These include (a) creating new routines and roles, (b) developing relationships with new service providers, and (c) advocating for appropriate services” (p. 214).

Studies of parents of children with autism have primarily been done in urban areas. Little is known about the challenges that rural parents of children with autism experience in parenting their children (Hoogsteen & Woodgate, 2013). Mandell, Novak, & Zubritsky (2005) found that in urban areas children with autism were diagnosed earlier than in rural communities. Finally, these challenges vary depending on the needs and characteristics of each child and each family.

Autism and Saudi Arabia

Saudi Arabia is a developing, Middle Eastern country on the Asian continent. The population of Saudi Arabia is approximately 29 million people; most of them are under 21 years of age (Alqahtani, 2012). Saudi Arabia is bordered by Yemen in the south; Kuwait, Iraq, and Jordan to the north; the Red Sea in the west; and Oman, United Arab Emirates, Qatar, and the Arabian Gulf to the east. Islam is the dominant religion. The country occupies most of the Arabian Peninsula, is home to the world’s largest sand desert, and possesses more oil than any other country. In fact, the main driver of the Saudi Arabian economy is oil. The Saudi Arabian Ministry of Education was established in 1953 and education is free. Special education began soon after. According to Al-Faiz (2006) “the commencement of special education in Saudi Arabia was initiated in the 1960s, and developed in stages parallel to those in the United States” (p. 2). In addition, education in Saudi Arabia is considered a fundamental right of people with special needs, not a privilege, as stated in the Royal Decree of the Rights of Individuals with Disabilities (RDRID) (Alquraini, 2011; Alothman, 2001; Alqahtani, 2012; Al-Faiz, 2006).

Autism has become more prevalent throughout the world over the past decade due to increased awareness, better diagnostic criteria, and other factors (Al-Gadani, El-Ansary, Attas, & Al-Ayadhi, 2009). Autism cases are increasing in Saudi Arabia as well (Al-Salehi, Al-Hifthy, & Ghaziuddin, 2009; Alqahtani, 2012). For every 120 of the world’s children, one is diagnosed with autism according to Elsabbagh, Divan, Koh, Kim, Kauchali, Marcín, & Fombonne (2012). However, around the world, there is a great conflict between the amount and quality of provided services and the number of children who need them. This discrepancy is widest in developing countries (Elsabbagh et al. 2012). It is estimated that eighteen in every 10,000 people in Saudi Arabia have been diagnosed with autism (El-Ansary, & Al-Ayadhi, 2012; Murshid, 2011). Yet, only 925 students with autism in Saudi Arabia (ages 5 to 18) are receiving services through the educational system (Ministry of Education, 2012). The prevalence of autism in Saudi Arabia is slightly higher than in other developing countries. It was estimated (method is unknown) that 42,500 individuals have autism in 2002, while many individuals with autism remain undiagnosed (Halepoto & Al-Ayadhi, 2014; Murshid, 2005; Yazbak, 2004; Murshid, 2011; Alqahtani, 2012; Al-Yafee1, Al-Ayadhi, Haq, & El-Ansary, 2011; Al-Salehi, Al-Hifthy, & Ghaziuddin, 2009; Al-Wakeel, Al-Ghanim, Al-Zeer, & Al-Nafjan, 2014). Most reports on the prevalence of autism were introduced by the Saudi Autistic Society, established in 2003. These reports were distributed in flyers and brochures (Murshid, 2005). Unlike the US, few reports have been done on the prevalence of autism in the Middle East and Saudi Arabia (Dababnah & Parish, 2013; Al-Salehi, Al-Hifthy, & Ghaziuddin, 2009). In Saudi Arabia, the rate of autism is higher in males than females (Hussein, Taha, & Almanasef, 2011) with a ratio of 4:1, comparable to that of the United States (Murshid, 2011).

The literature review of autism in the Middle East, particularly Saudi Arabia, indicated that little is known about autism in this region and only a few studies have been done on the subject (Al-Faiz, 2006; Al-Salehi, Al-Hifthy, & Ghaziuddin, 2009; Al-Salehi & Ghaziuddin, 2009; Hussein, Taha, & Almanasef, 2011). Most studies in the Middle East and Saudi Arabia have been based in the western industrialized countries, such as the United States (Al-Salehi, Al-Hifthy, & Ghaziuddin, 2009). Previous research has focused on inclusion or special educational services for students with autism in Saudi Arabia. Al-Faiz (2006) pointed out that “it is important to conduct research to help improve the overall knowledge in Saudi Arabia about autism and its educational needs” (p. 5). Publications addressing autism in the Arab world, including Saudi Arabia, are “under-represented” (Al-Salehi & Ghaziuddin, 2009, p. 227; Hussein et al., 2011). Most

autism research in Saudi Arabia has been in medical and clinical fields. For instance, one study of 49 patients in Saudi Arabia found that “females were older than males at the time of referral” (Hussein et al., 2011, p. 2). Little research has been done on increasing the awareness of autism among professionals in developing countries (Al-Salehi, Al-Hifthy, & Ghaziuddin, 2009). Another gap in the literature is in the beliefs of Saudi Arabian parents regarding autism. Finally, there is a need for research to identify the gaps between the autism knowledge of professionals and parents in Saudi Arabia (Alqahtani, 2012).

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