

Services for children with autism in the Kingdom of Saudi Arabia

Autism

1–11

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Abstract

Little information is available about autism spectrum disorder services in the Kingdom of Saudi Arabia. A sample of 205 parents completed an online survey about the use of autism spectrum disorder services for their children. The results revealed that on average, children began services by 3.3 years. Most parents reported utilizing non-medical treatments followed by biomedical treatments and cultural and religious treatment. The age at the initiation of services and the type of treatments used differed by parent's income, educational attainment, the extent of knowledge about autism spectrum disorders, and geographic location. Some child characteristics also influenced the use of services. The disparities in service utilization in Saudi Arabia point to the need to develop policy and interventions that can mitigate the paucity of services for children with autism spectrum disorders. More research is needed to better understand service use and the decision-making processes that underlie treatment selection by parents of children with autism spectrum disorders in the Kingdom of Saudi Arabia.

Keywords

autism, disability, parents, Saudi Arabia, services, treatments

Introduction

Accessing services and identifying empirically validated treatments for individuals with autism spectrum disorders (ASD) can be challenging tasks for their parents (Hess et al., 2008; Thomas et al., 2007). These tasks can be far more difficult for parents of children with ASD in the Arab world countries (Elsabbagh et al., 2012; Taha and Hussein, 2014). In the Kingdom of Saudi Arabia (KSA), tremendous efforts to advance ASD services and research have been made. These include collaborating with prestigious universities' research centers and service providers (Center for Autism Research, 2014), offering scholarships to graduate and medical students along with postdoctoral fellows interested in basic and clinical research (Ministry of Education, 2015), and recently approving to cover the cost of private schools (King Salman Center for Disability Research, 2014). Yet, current ASD services are limited with little information about them.

The population of KSA is over 28 million, and the prevalence of ASD is one per 167 (Aljarallah et al., 2007), suggesting that the total number of individuals with ASD is over 167,000. No data about the confirmed cases of ASD in the KSA are available, and anecdotal data suggest that

many children with ASD have not been identified yet. Recent documents from the Ministry of Education indicate that of all students served under the education system ($N=5,137,839$; aged 5–18 years), 925 are male students with ASD (Ministry of Education, 2012) and 437 are female students with ASD (Ministry of Education, 2015).

The majority of children with ASD in the KSA with access to services receive them in private schools (Zahrani, 2013), where the family mostly pays the cost for these services. Some families travel either to neighboring countries (e.g. Jordan, Egypt, Kuwait, Bahrain, Qatar, and United Arab Emirates) and/or overseas (e.g. United Kingdom and

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United States of America) seeking services for their children with ASD. While some families pay for their travel expenses, others may receive governmental funding. The KSA government funds 800 children with disabilities, including 10% with ASD, to receive special education services and/or respite care in Jordan (Saudi Arabian Cultural Mission in Jordan, 2013). There are no available data about other Saudi children with ASD in other countries.

Existing studies conducted in Western countries such as United States (Irvin et al., 2012; Thomas et al., 2007) and Canada (Lake et al., 2014) indicate that numerous factors can potentially influence the use of ASD services. First, family characteristics can predict who receives ASD services. For example, parents' culture and knowledge of ASD may affect the way they perceive autism and seek treatments for their child. Ravindran and Myers (2012) reported that parents in Western countries (e.g. the United States) believe that ASD is at least partly caused by biological and/or environmental factors. They tend to have positive expectations (i.e. improvement or even recovery from ASD) and mostly choose medical treatments and behavioral interventions. However, parents in developing countries (e.g. Pakistan) understand the child's disability from a fatalistic perspective and they have low expectations about ASD interventions. Other family-related factors such as geographical locations, income, family composition, and parents' level of education affect the use of ASD services. Children of families who lived in nonmetropolitan areas had limited access to major treatment approaches such as Applied Behavior Analysis (ABA), Floor Time, and the Early Start Denver Model, and to summer camp or respite care (Thomas et al., 2007). High-income parents accessed occupational therapy (OT) and ABA more frequently than low-income parents (Irvin et al., 2012). Children who lived with their biological fathers received more services than their counterparts who did not live with their biological fathers, and children of parents with higher educational attainment used special diets and vitamin therapy and received an increased number of services (Patten et al., 2012).

Second, differences in intervention use are also related to the child characteristics. The severity of ASD symptoms was associated with an earlier initiation of ASD treatments (Patten et al., 2012), the utilization of the Picture Exchange Communication Systems (PECS) outside the school setting (Thomas et al., 2007), and an increased dose of in-school OT (Irvin et al., 2012). Other clinical variables such as aggression (Lake et al., 2014), gastrointestinal problems, sleep problems, and comorbidity (Coury et al., 2012) predicted the use of psychotropic medications. In addition, age was positively associated with the use of more psychotropic medications and partial hospitalizations (Cidav et al., 2013; Coury et al., 2012), along with individualized and school services (Siller et al., 2013). Furthermore, the child's gender impacted ASD service use. Compared to

girls, boys with ASD were found to receive more intensive individualized services (Siller et al., 2013) and use of psychotropic medications (Mandell et al., 2008).

Third, the characteristics of ASD services can also contribute to the provision of such services. Studies showed that children with ASD receive a wide range of treatments (Bowker et al., 2011), and the use of treatments from one category (i.e. behavioral) was associated with the use of other treatments (i.e. biomedical; Lake et al., 2014). Increased use of ASD services (Mandell et al., 2008) and psychiatric visits (Spencer et al., 2013) predicted the use of psychotropic medications.

While previous studies have contributed to the knowledge base on the relationship between family, child, and services characteristics and ASD service use in Western countries, there is little to no information about the influence of such factors on the ASD service use in the rest of the world, and particularly in the Arab world.

This study is the first step to address this gap in the literature by examining factors influencing the use of ASD services in the KSA. The research questions were as follows: (1) what is the average age at treatment initiation in the KSA; (2) what services children with ASD receive in the KSA; and Finally (3) what child, family, and service characteristics are associated with use of ASD services in the KSA.

Method

Data source and sampling

Due to the lack of accurate statistics or centralized country and/or province services for children with ASD in the KSA, a convenience sampling method was used. Data were collected via an online survey from April to June 2014. Nearly 60% of the population of the KSA uses the internet (Internet Live Stats, 2014), suggesting that this data collection method is appropriate. Local parent support groups and colleagues assisted with the recruitment process.

Survey development and content

The survey was developed on the basis of previous studies that examined factors associated with the use of ASD services. The survey included the following sections.

Information about the family. This section was to provide information about the family including parents' age and educational levels, existence of consanguinity, family's composition, and geographical location. We asked about consanguinity because it is frequent in the KSA households (Tadmouri et al., 2009). The family's geographical location was assigned to one of three groups: major city or non-major city or out of the KSA. The major cities included the cities with the largest populations in each of the main

regions of the KSA: Central, Eastern, and Western (Central Department of Statistics and Information, 2004). Those cities are Riyadh, Jeddah, and Damman. Other cities are considered non-major cities and other countries are considered out of the KSA.

Information about the child. This section asked parents to provide information about their child, including the child's gender and age, the presence of autism red flags, and the age at ASD diagnosis. Parents also reported the services that the child received, age of treatment initiation, the number and type of treatments received, the city and educational placement of treatments, and the treatments' cost.

The services list was adapted from a previous study that included 111 treatments (Green et al., 2006). Cultural and religious interventions were added because they are commonly used by parents of children with ASD in the KSA (Alqahtani, 2012). The final list was reduced to 29 treatments after pilot testing, as described below. For organizational purposes, these treatments were grouped into three categories: (1) non-medical or NMD interventions such as ABA, speech therapy (ST), OT, sensory integration therapy, auditory integration therapy, play therapy, animal therapy, music therapy, augmentative and alternative communication, art therapy, special day classroom, segregated classroom, and partial mainstreaming; (2) biomedical or BMD interventions such as vitamins and supplements, medications, special diets, craniosacral therapy, chelation therapy, hyperbaric oxygen therapy, and iridology; and (3) cultural and religious or CR interventions, including reciting Quran, honey diet, religious/traditional healers, camel milk intake, goat milk intake, and herbs and homeopathic treatments.

For each treatment option, parents were asked to indicate whether (a) they were currently using the treatment, (b) had used it in the past, or (c) never used it. Additional spaces were provided for parents to add additional treatments and make comments.

Of note, all children with ASD who attend public or private schools in the KSA receive services in special education classrooms, otherwise known as Special Day Class. There is no traditional mainstreaming (partial inclusion in general education classrooms) or full inclusion. However, some schools implement a practice (i.e. partial mainstreaming) to encourage students with disabilities and non-disabled peers to participate together in extracurricular activities. Also, in public schools, services are funded by the government, whereas in private school, families pay for services.

Additional measures. The last section of the survey comprised two measures. First, the Parental Concerns Questionnaire (McGrew, et al., 2007), which included 13 items for the parents to indicate their opinion (using a four-point scale: 1=*no problem*, 2=*mild problem*, 3=*moderate*

problem, and 4=*severe problem*) about the extent to which each core and behavioral symptom of autism has been a problem for their child. The score of this scale ranged from a minimum value of 13 (mild symptoms) to 52 (severe symptoms). Second, the Autism Knowledge Questionnaire (Schwartz and Drager, 2008) was used. It included 20 items to assess parents' knowledge about etiology, diagnosis, and specific features of ASD. Parents responded to the items using a four-point Likert-type scale: 1=*Strongly agree*, 2=*Agree*, 3=*Disagree*, and 4=*Strongly disagree*. Despite their adequate psychometric properties, both measures were factor-analyzed in this study. The 13 items of the Parental Concerns Questionnaire appeared to underlie one factor, while 12 out of the 20 items of the Autism Knowledge Questionnaire were found to represent four factors. These factors included Criteria Necessary for Diagnosis, Descriptive Features, Cognitive Features, and Social Communication Features.

Translation and pilot testing

Three independent Saudi graduate students in the field of Special Education translated the survey into Arabic using the forward-translation method (Hambleton and Kanjee, 1995). Translators worked individually to translate the survey and then met to discuss their translations and created one Arabic version. Subsequently, the survey was pilot-tested with six parents of children with ASD, aged 4–18 years, in the KSA. After completing the survey, each parent met with the first author (F.M.A) to review and comment on the content and readability. All feedback was considered to finalize the survey. The institutional review board (IRB) of the University of California, Los Angeles approved the study and use of these data (IRB#13-001853).

Survey distribution

Following the pilot testing, a Google™ search was conducted to identify autism parent support groups in the KSA. The search terms were *autism*, *parent support groups*, and *Saudi Arabia*. Next, websites and/or social networking sites of relevant parent support groups were visited to locate the email address of the contact person(s) (e.g. the head of the parents support group or secretary). Those individuals were sent an email information message about the survey. This message included a brief description of the survey along with the IRB approval, a URL to the survey, and request to post the survey's link on their social networking sites. In addition, the email message was sent to colleagues from different regions in the KSA who had contact with families of children with ASD in the KSA. Once the link was distributed, it remained opened for a 3-month period (April to June 2014).

To increase the response rate, approximately every other week, a reminder email message was sent to the

parents support groups and our colleagues to share in their networking sites again. The reminder email included the survey link with a statement thanking those who had completed the survey and encouraging the rest to complete it before the deadline.

The initial page of the survey included background information that described the purpose of the survey, a statement of informed consent, and the estimated time to complete the survey (i.e. 30 min) along with instructions for completing the survey. Participants were asked to complete the survey for their child with ASD. Participants were given the opportunity to enter a drawing in which 100 people won gift cards of US\$10 each.

Study variables

Outcomes. The outcomes of interest were the average age of treatment initiation and the number of services received in each treatment type. The age of treatment initiation was the parent-reported age when the child started to receive ASD treatments. Treatments were grouped according to the three previously mentioned categories and the total number of services was calculated by adding the number of currently and previously used treatments in each category.

Predictors. The primary predictors were identified from a review of literature on factors associated with the use of ASD services (Cidav et al., 2013; Coury et al., 2012; Irvin et al., 2012; Mandell et al., 2008; Patten et al., 2012; Ravindran and Myers, 2012; Siller et al., 2013; Thomas et al., 2007). These predictors were the characteristics of the child (i.e. age, gender, age at ASD diagnosis, severity of ASD symptoms, and comorbidity) and the characteristics of the family (i.e. parents' income, educational attainments, and knowledge of autism; and family's composition and geographical locations). Service use predictors included the number of services received in each treatment type (i.e. non-medical, biomedical, and cultural and religious interventions) and locations where they were provided (i.e. in a major city, in non-major city, outside the city of residence, and outside the KSA).

Analysis

Descriptive statistics were calculated to provide an overview of the demographic and clinical characteristics of the children with ASD and their parents. To determine the association between these factors and our four outcome variables, linear regression analysis was undertaken. Each predictor was entered into a univariate model with each outcome variable to calculate its unadjusted regression coefficients with associated 95% confidence intervals (CIs). Next, predictors that were found to be significant at level of $\alpha=0.05$ were introduced together into a multivariate model. The multivariate model was developed

through backward elimination to identify which combination of predictors explained each outcome variable. Initially, all variables were included in the model, but those that caused the smallest reduction in the R^2 were removed. This process continued until there were no variables that could be removed without significantly decreasing the variance.

Results

Number of submissions

A total of 238 parents/caregivers completed the survey during the 3-month data collection period. Data screening identified 33 surveys that needed to be excluded: either the child's age was over 21 years or the child's family was not in Saudi and did not reside in the KSA. Thus, the results reported next are based on our final sample of 205 surveys.

Sample characteristics

Parents. The majority of respondents (73%) were between 24 and 44 years old at the time of the survey and most of them were fathers (61%), followed by mothers (34%) and other family members (5%). The sample was geographically diverse; 52% of respondents resided in a major city, 46% resided in other cities in the KSA, and 2% of the sample consisted of Saudi families not currently residing in the KSA. The distribution of the sample across cities of residence was consistent with the existing statistics in the KSA (Central Department of Statistics and Information, 2004). Nearly 50% of the participating parents completed a 4-year college degree or higher. This educational level exceeded the one of the population of the KSA (i.e. 15%; Central Department of Statistics and Information, 2013). Over 40% of the families had an annual household income at or below the sufficiency line in Saudi Arabia. The sufficiency line refers to the income necessary to meet a family or an individual's basic needs without public support, including housing, childcare, food, health care, transportations, and entertainment in the KSA: this is US\$28,480 (Al-Damigh, 2014). Consistent with research in the KSA (Tadmouri et al., 2009), more than one-third of the sample (36%) had a history of consanguinity. Regarding the Autism Knowledge Questionnaire, parents scored the highest on the subscale of Criteria Necessary for Diagnosis ($M=8.6$; standard deviation (SD)=2.1) and Descriptive Features ($M=8.6$; $SD=2.5$), followed by Social Communication Features ($M=7.4$; $SD=2.3$) and Cognitive Features ($M=4.8$; $SD=1.9$).

Children. The mean age of children was 8 ($SD=3.5$; 26% aged <6; 64% aged 6–13; and 10% aged >14) years. Consistent with epidemiological findings (Elsabbagh et al., 2012), the ratio of affected males to females was

4.9:1. A high level of comorbidity was observed across the sample, with 65% of children having additional diagnose(s). In this study, attention deficit/hyperactivity disorder (ADHD) was the most frequently reported disorder among children with ASD (53%), followed by intellectual disability (ID; 8%), epilepsy, and cerebral palsy (2%, each). The Parental Concerns Questionnaire's average score was 34.9 ($SD=6.9$), suggesting that most children were at the severe end of the autism spectrum (McGrew et al., 2007).

Use of ASD services

Table 1 presents the characteristics of the sample. The average age at treatment initiation was 3.3 years ($SD=1.2$). The majority of the children (94%) had received at least one non-medical treatment ($M=5.2$; $SD=2.4$), followed by biomedical treatments (88%; $M=3.0$; $SD=1.4$) and cultural and religious treatments (84%; $M=2.3$; $SD=1.3$; see Appendix 1 for details). The majority of children received their current treatments at private schools (42%) and home (45%), while only 14% received services at public schools. Nearly 80% of the families paid for early intervention services and the current treatments. Families traveled outside their cities of residence to another city and/or country to receive early intervention services (29%) and/or additional ASD treatments (40%).

Factors associated with the use of ASD services

Age at treatment initiation. Table 2 presents the regression analysis predicting age at treatment initiation from clinical and demographic variables. After the backward elimination regression, a significant model emerged that predicted the age at treatment initiation ($F(3, 191)=66.55$, $p < 0.001$). The model explained 50% of the variance in the age at treatment initiation as it had an adjusted R^2 of 0.50. Three predictors remained in the final model. The unstandardized coefficients will be reported, as the raw units are generally familiar. A 1-year increase in the child's age was associated with an age of starting treatments occurring a 0.09 year later (95% CI: 0.05 to 0.13). A 1-year increase in the age of diagnosis of ASD was associated with an age of starting treatments occurring a 0.70 year later (95% CI: 0.56 to 0.83). Being a mother with a BA degree (or higher) was associated with a 0.35-year earlier age at starting treatments when compared to a mother with lower educational attainment (95% CI: -0.60 to -0.10).

Number of non-medical or NMD interventions. Table 3 illustrates the regression analysis results predicting the number of NMD interventions. Following the backward elimination regression, a significant model emerged that predicted the number of NMD treatments ($F(6, 186)=9.18$, $p < 0.001$). With an adjusted R^2 of 0.20, the model explained 20% of the variance in the number of NMD

Table 1. Sample characteristics ($N=205$).

Variable	<i>n</i>	%	<i>M</i> (<i>SD</i>)
<i>Child</i>			
Male	170	83	
Age (years)	–	–	8.0 (3.5)
3–5	53	26	
6–9	109	53	
10–13	23	11	
14–18	20	10	
Saudi citizen	184	90	
Noticing ASD red flags	131	64	
Severity of ASD symptoms	–	–	34.9 (6.9)
Age at diagnosis	–	–	2.9 (1.0)
<i>Comorbidity</i>			
ADHD	109	53	
Intellectual disability	16	8	
Epilepsy	3	2	
Cerebral palsy	3	2	
Age of treatments initiation	–	–	3.3 (1.2)
Families paid for the early intervention	123	60	
Families paid for current treatments	158	77	
<i>Number of interventions</i>			
Non-medical	193	94	5.2 (2.4)
Biomedical	181	88	3.0 (1.4)
Cultural and religious	172	84	2.3 (1.3)
Received at least one intervention outside the city of residence	83	40	
Received at least one intervention out KSA	33	16	
<i>Current educational placement</i>			
Private school	100	49	
Home	48	23	
Hospital/clinic	80	39	
Public school	19	9	
<i>Family</i>			
<i>Household composition</i>			
Two-parent household	168	82	
Extended-family household	33	16	
Single-parent household	4	2	
<i>Maternal educational attainment and age</i>			
<High school	26	12	
High school degree	47	23	
Some college credits	24	12	
College degree	94	46	
≥Graduate degree	14	7	
≤24 years	12	6	
25–34 years	100	49	
35–44 years	75	37	
≥45 years	18	8	
<i>Paternal educational attainment and age</i>			
<High school	24	12	
High school degree	50	24	
Some college credits	34	17	
College degree	70	34	

(Continued)

Table 1. (Continued)

Variable	<i>n</i>	%	<i>M</i> (<i>SD</i>)
≥Graduate degree	26	12	
25–34 years	47	23	
35–44 years	96	47	
45–54 years	45	22	
55–64 years	9	5	
≥65 years	7	3	
Annual household income			
Below the SL	81	39.5	
From SL to 100% above	81	39.5	
100% above	43	21	
Residence			
Major city	106	51	
Other city	94	47	
Out of KSA	5	2	
Parents' knowledge about autism			
Criteria Necessary for Diagnosis	–	–	8.6 (2.1)
Cognitive Features	–	–	4.8 (1.9)
Descriptive Features	–	–	8.6 (2.5)
Social Communication Features	–	–	7.4 (2.3)

SL: sufficiency line.

treatments. Five predictors remained in the final model. A 1-year increase in the child's age was associated with a 0.13-unit increase in the number of NMD treatments (95% CI: 0.04 to 0.22). Receiving at least one treatment in a different country was associated with a 1.34 increase in the number of NMD treatments compared to children who received treatments only in the KSA (95% CI: 0.50 to 2.20). Each unit increase in the number of the biomedical treatments was associated with a 0.24 increase in the number of NMD treatments (95% CI: 0.04 to 0.44). Having a household income below the sufficiency line was associated with a 0.84 decrease in the number of NMD compared to those who have a household income above the sufficiency line (95% CI: –1.50 to –0.21). Being a resident of a major city was associated with a 0.81 increase in the number of NMD treatments compared to residents of other cities (95% CI: –0.20 to 1.42).

Number of biomedical or BMD interventions. Table 4 shows the regression analysis results predicting the number of BMD interventions. A significant model emerged that predicted the number of BMD treatments ($F(9, 171)=9.35$, $p < 0.001$) after the backward elimination regression. The model had an adjusted R^2 of 0.29, meaning it explained 29% of the variance in the number of BMD treatments. Nine predictors remained in the final model. A 1-year increase in the child's age was associated with a 0.07-unit increase in the number of BMD treatments (95% CI: 0.01 to 0.13). Odd play in the first 2 years of life was associated with a 0.40 increase in the number of BMD treatments when compared to children who did not engage in odd play

in the first 2 years of life (95% CI: 0.02 to 0.77). Received at least one intervention in different country was associated with a 0.62 increase in the number of BMD treatments compared to children who received treatments only in the KSA (95% CI: 0.04 to 1.21). Intervention received only at the city of residence was associated with a 0.46 decrease in the number of BMD treatments compared to children who received treatments outside the city of residence (95% CI: –0.88 to –0.03). Each unit increase in the number of non-medical treatments was associated with a 0.09 increase in the number of BMD treatments (95% CI: 0.01 to 0.16), while each unit increase in the number of cultural and religious treatments was associated with a 0.14 increase in the number of BMD treatments (95% CI: 0.01 to 0.27). Being a father with a high school diploma or lower was associated with a 0.47 decrease in the number of BMD treatments when compared to those of a father with higher educational level (95% CI: –0.90 to –0.04). Each unit increase in the Knowledge of Criteria Necessary for Diagnosis' scale was associated with a 0.11 increase in the number of BMD treatments (95% CI: 0.02 to 0.30), while each unit increase in the Knowledge of Social Communication Features' scale was associated with a 0.12 decrease in the number of BMD treatments (95% CI: –0.20 to –0.04).

Number of cultural and religious or CR interventions. Table 5 presents the regression analysis results predicting the number of CR interventions. After the backward elimination regression, a significant model emerged that predicted the number of CR treatments ($F(2, 169)=4.73$, $p=0.010$). The model had an adjusted R^2 of 0.04, meaning it explained 4% of the variance in the number of CR treatments. Two predictors remained in the final model. Being a mother without a college degree was associated with a 0.72 increase in the number of CR treatments when compared to the number of CR treatments received by mothers with higher educational level (95% CI: 0.13 to 1.13). Each unit increase in the Knowledge of Social Communication Features' scale was associated with a 0.08 decrease in the number of CR treatments (95% CI: –0.16 to –0.01).

Discussion

The purpose of this study was to examine the use of ASD services in the KSA and factors affecting it. A total of 205 parents of children who received ASD services completed an online survey. This study reflected the experiences using ASD services of this particular group of parents with Internet access.

First, the mean age at treatment initiation was 3.3 years compared to 2.2 years in the United States (Patten et al., 2012), suggesting that many children in the KSA did not receive early intervention services before the age of 3 years. This might be due to the special education law in the KSA. The Regulations of Special Education Programs

Table 2. Adjusted regression analysis of child, family, and service characteristics to predict the age of treatment initiation (N=205).

Variable	B	β	95% CI for B
Child age	0.09**	0.25	(0.05 to 0.13)
Age at ASD diagnosis	0.70**	0.55	(0.56 to 0.83)
Maternal education (BA+)	-0.35*	-0.14	(-0.60 to -0.10)

B: unstandardized beta coefficient; β : standardized beta coefficient, CI: confidence interval.

* $p < 0.05$; ** $p < 0.01$.

Table 3. Adjusted regression analysis of child, family, and service characteristics to predict the number of non-medical interventions (N=193).

Variable	B	β	95% CI for B
Child age	0.13*	0.19	(0.04 to 0.22)
Received at least one interventions in different country	1.34*	0.43	(0.50 to 2.20)
Number of biomedical interventions	0.24*	0.16	(0.04 to 0.44)
Maternal age (≥ 45 years)	1.02	0.12	(-0.07 to 2.10)
Income below the SL	-0.84*	-0.17	(-1.50 to -0.21)
Residence (major city)	0.81*	0.17	(0.20 to 1.42)

B: unstandardized beta coefficient; β : standardized beta coefficient; CI: confidence interval.

* $p < 0.05$.

Table 4. Adjusted regression analysis of child, family, and service characteristics to predict the number of biomedical interventions (N=181).

Variable	B	β	95% CI for B
Child age	0.07*	0.17	(0.01 to 0.13)
Odd play in the first 2 years of life	0.40*	0.13	(0.02 to 0.77)
Received at least one intervention in different country	0.62*	0.16	(0.04 to 1.21)
Received intervention only at the city of residence	-0.46*	-0.16	(-0.88 to -0.03)
Number of non-medical interventions	0.09*	0.15	(0.01 to 0.16)
Number of cultural and religious interventions	0.14*	0.14	(0.01 to 0.27)
Paternal education (high school)	-0.47*	-0.14	(-0.90 to -0.04)
Knowledge of Criteria Necessary for Diagnosis	0.11*	0.15	(0.02 to 0.20)
Knowledge of Social Communication Features	-0.12*	-0.19	(-0.20 to -0.04)

B: unstandardized beta coefficient; β : standardized beta coefficient; CI: confidence interval.

* $p < 0.01$.

Table 5. Adjusted regression analysis of child, family, and service characteristics to predict the number of cultural and religious interventions (N=172).

Variable	B	β	95% CI for B
Maternal education (without a college degree)	0.72*	0.18	(0.13 to 1.13)
Knowledge of Social Communication Features	-0.08*	-0.15	(-0.16 to -0.01)

B: unstandardized beta coefficient; β : standardized beta coefficient, CI: confidence interval.

* $p < 0.05$.

and Institutes of Saudi Arabia (RSEPI) do not specify the age of eligible children nor the type of early intervention services they should receive (Alquraini, 2013). However, this study revealed a relatively young age of treatment initiation when contrasted to anecdotal data. This result might be attributed to the study sample's characteristics. Children

were young and had moderate to severe symptoms; in addition, their parents were highly educated and likely to be advocates for their child. Another key finding from this study suggests that ASD services in public sectors are insufficient in the KSA. The majority of children received services in private agencies or schools and their families

paid for those services. While consistent with existing data (Ministry of Education, 2012; Zahrani, 2013), such finding is somewhat surprising given that the public education and health care are free in the KSA. Finally, ASD services in non-major cities were limited. Families from those cities traveled to major cities and/or outside the KSA to receive ASD services, suggesting that ASD services vary across cities. Overall, despite the study limitations related to sampling, results indicate that there is a paucity of services for children with ASD in the KSA.

Family characteristics

Differences in service use were related to some family characteristics. First, income and parental education were associated with receiving ASD services. Being a mother with a college degree was associated with an earlier age of treatment initiation, while being a family of household income at or below the sufficiency line was associated with a decrease in the number of non-medical treatments. These relationships are in line with prior research from Western countries that shows that higher income and education predicted the use of OT and ABA (Irvin et al., 2012) along with intensive individualized intervention programs (Siller et al., 2013), while low parental education attainment was associated with limited access to care (Thomas et al., 2007). In addition, being a father with a high school diploma was associated with a decrease in the number of biomedical treatments. This association is also consistent with existing literature that indicates that the likelihood of using special diets or vitamin therapies increased for children of parents with higher educational attainment (Patten et al., 2012). This association might have been influenced by a third mediating variable (i.e. cost of biomedical treatments). Specifically, these parents may have limited income, so they have refrained from using treatments that may cause additional financial burden. Finally, being a mother without a college degree was associated with an increase in the number of cultural and religious treatments. This group of mothers may not be familiar with interventions that were rigorously examined in research studies and may rely on religious beliefs and healers to make medical and educational decisions.

Second, the family's geographical location influenced the use of ASD services. Namely, being a resident of a major city resulted in using more non-medical interventions compared to those who reside in other cities. This is consistent with existing research from Western countries showing that children with ASD who resided in nonmetropolitan areas had limited access to care (Thomas et al., 2007). It is possible that there is a disparity in provision of ASD services across the KSA cities, as most children with disabilities reside in major cities (Central Department of Statistics and Information, 2004).

Finally, an increase in score in the parents' knowledge of Criteria Necessary for Diagnosis was associated with an

increase in the number of biomedical interventions, while an increase in the score in the parents' knowledge of Social Communication Features was associated with a decrease in the numbers of biomedical and cultural and religious interventions. The relationship between parents' knowledge of the Criteria Necessary for Diagnosis and the increased number of biomedical treatments might be attributed to methodological limitations. The Autism Knowledge Questionnaire assesses parents' knowledge about the etiology, diagnosis, and specific features of ASD, all of which might not be necessary to guide treatment selection decisions. However, it is noteworthy that parents' knowledge of Social Communication Features was associated with decreased numbers of biomedical and cultural and religious interventions, most of which lack empirical support. Parents who are familiar with the social and communications deficits of their children with ASD may also select interventions that directly target communication and language, such as the non-medical interventions. These findings shed light to the potential influence of some parental knowledge of ASD on the use of ASD services in the KSA.

Child characteristics

Some child characteristics also influenced the utilization of ASD services. For example, age at treatment initiation, number of non-medical interventions, and number of biomedical interventions increased with age. These findings are consistent with recent research from Western countries showing that age was associated with using more psychotropic medications and partial hospitalizations (Cidav et al., 2013; Coury et al., 2012) along with individualized services and school services (Siller et al., 2013). Because of the awareness of ASD and the availability of services have improved over time, younger children with ASD are diagnosed and receiving services earlier compared to their older counterparts. However, in the KSA, there is a lack of early intervention services, and older children, rather than younger, are eligible to access available interventions. The increase in the number of biomedical interventions with age might be explained by the fact that older children with ASD are likely to exhibit severe symptoms as they received their ASD diagnoses when the awareness in the KSA was limited (i.e. those with mild-moderate ASD symptoms might have been under-diagnosed), and their parents used biomedical treatments to address their unique needs.

In addition, odd play was associated with an increase in the number of biomedical interventions. This is in accordance with the current research from Western countries showing that children's clinical symptoms such as aggression (Lake et al., 2014), gastrointestinal problems, sleep problems, and comorbidity (Coury et al., 2012) predicted the use of psychotropic medications. One would expect that children with no functional play may fall at the more

severely impaired end of the spectrum and as such, they are more likely to use psychotropic medications.

However, other child characteristics such as gender and severity were not predictive of the use of ASD services. These findings contradicted recent investigations (Mandell et al., 2008; Patten et al., 2012; Siller et al., 2013). The lack of associations between these factors and the use of the ASD services might be attributed to the characteristics of our sample as the majority of children were males with severe symptoms. The limited variability of the sample might not offer sufficient power to detect these potential associations. What might also have contributed to such findings is the lack of data on intervention dosages.

Service characteristics

Service characteristics also influenced the use of ASD interventions in this study. First, positive associations were found between the number of biomedical treatments and the number of non-medical treatments. Similarly, some studies in Western countries showed that using more ASD services predicted the use of medical interventions such as psychotropic medications (Mandell et al., 2008), while others indicated that the use of treatments from one category was associated with use of treatments from another one (Lake et al., 2014). In our study, non-medical and cultural and religious interventions were also associated with the number of biomedical treatments. It is possible that parents who were dissatisfied with the quality of services provided to their child tended to utilize other available treatments. Of note, most parents accessed both non-medical and biomedical interventions simultaneously, in line with evidence supporting their effectiveness when used concurrently (Lake et al., 2014). In contrast, the number of cultural and religious treatments was related to the number of biomedical treatments, suggesting that some families relied on interventions without strong empirical support.

Second, receiving treatments outside the KSA resulted in increase in the number of non-medical and biomedical treatments, while receiving treatments only at the city of residence resulted in decrease in the number of biomedical treatments. These findings are consistent with existing research from Western countries showing that children with ASD who resided in nonmetropolitan areas had limited access to care (Thomas et al., 2007) and those who had more psychiatric visit used more of psychotropic medications (Spencer et al., 2013). It is possible that parents travel to different cities/counties to receive biomedical treatments because of the inadequate ASD services in the KSA, especially in non-major cities. Alternatively, they may have been dissatisfied with the quality of available services. Finally, an increase in the age of diagnosis of ASD was associated with an increase in the age of treatment initiation. Clearly, receiving the ASD diagnosis opens the gate to obtain ASD-related treatments.

This study is subject to important limitations related to the used sampling methods. The sample was not representative of the KSA population and results from this study should be interpreted with caution. Parents' educational attainments were substantially high for Saudi Arabia. This group of parents may have a higher than average knowledge about autism, sophistication about autism services, and the ability to advocate for their children. Also, the children in our sample were young and with moderate to severe symptoms, suggesting an earlier than average age of treatments initiation and higher use of ASD interventions. Furthermore, the sampling method used in this study prevented the participation of parents of children with ASD who are not connected to parents support groups and those who do not have access to the Internet. Thus, we have no information about this group of families.

Second, our survey included questions about the number of interventions used, but no questions about the dosage of such treatments. Although factors associated with the number of treatments used are in line with the existing literature, our outcome measures and the number of intervention types in each category may over- or under-estimate the intensity of these treatments. Future studies should gather information about the intensity of ASD treatments received by children in order to provide a better picture about the use and effectiveness of ASD treatments in the KSA.

Third, the Autism Knowledge Questionnaire used in this study only assesses parents' knowledge about the etiology, diagnosis, and specific features of ASD, information that may not be relevant to parents when seeking services and advocating for their children. Finally, this study's findings were based on parents' report about events that have happened in the past. As such, inaccurate reporting might have biased our findings. However, despite these limitations, this study provides important information and is a first step in examining the use of ASD services in the KSA and factors affecting it.

Conclusion

This is the first study to examine the factors associated with the use of ASD services in the KSA. With its limited design, this study found that children with ASD have limited access to services in the KSA and such finding underscores the importance of reforming the special education law in the KSA (i.e. RSEPI) to specify the age of eligible children and the type of services they should receive. In addition, disparities in treatment use associated with residence speak to the need to utilize innovative methods (Alnemary et al., 2015) that can address barriers to services for children with ASD. Moreover, the utilization of a variety of interventions, most of which lack empirical support, underlines the importance of developing parent-friendly best practice guidelines to support parents in choosing treatments to use

with their children. As such, these parents may refrain from utilizing controversial and unsupported treatments, resulting in time, energy, and fund savings. Future investigations that include different data collection methods with more representative samples are needed to provide policy makers and services providers with recommendations to enhance current and prospective ASD services in the KSA. Future studies should also examine the dosage of the treatments, and the therapeutic and medical effects.

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References

- Al-Damigh S (2014) Line of sufficiency in the Kingdom of Saudi Arabia. *Report, King Khalid Foundation, Kingdom of Saudi Arabia*, June.
- Al-Haddan A (2013) The Saudi Arabian Cultural Mission in Jordan organizes a meeting for the directors of special education service provider and Princess *Samira Al-Faisal Alriyadh*. Available at: <http://www.alriyadh.com/886386> (accessed August 2016).
- Aljarallah A, Alwaznah T, Alnasari S, et al. (2007) A study of autism and developmental disorders in Saudi children. *Report, King Abdulaziz City for Science and Technology, Kingdom of Saudi Arabia*.
- Alnemary FM, Wallace M, Symon JG, et al. (2015) Using international videoconferencing to provide staff training on functional behavioral assessment. *Behavioral Interventions*. Epub ahead of print 21 January 2015. DOI: 10.1002/bin.1403.
- Alqahtani M (2012) Understanding autism in Saudi Arabia: a qualitative analysis of the community and cultural context. *Journal of Pediatric Neurology* 10(1): 15–22.
- Alquraini T (2013) Legislative rules for students with disabilities in the United States and Saudi Arabia: a comparative study. *International Interdisciplinary Journal of Education* 2(6): 601–614.
- Bowker A, D'Angelo NM, Hicks R, et al. (2011) Treatments for autism: parental choices and perceptions of change. *Journal of Autism and Developmental Disorders* 41(10): 1373–1382.
- Center for Autism Research (2014) Projects. Available at: <http://cfar.kfshrc.edu.sa/ProgramsArabic.aspx> (accessed 15 June 2014).
- Central Department of Statistics and Information (2004) Disabilities (region). Available at: <http://www.cdsi.gov.sa> (accessed January 2014).
- Central Department of Statistics and Information (2013) Population (15 years and over) by age group and educational status: 1434 H/2013 D. Available at: <http://www.cdsi.gov.sa> (accessed January 2014).
- Cidav Z, Lawer L, Marcus S, et al. (2013) Age-related variation in health service use and associated expenditures among children with autism. *Journal of Autism and Developmental Disorders* 43(4): 924–931.
- Coury DL, Anagnostou E, Manning-Courtney P, et al. (2012) Use of psychotropic medication in children and adolescents with autism spectrum disorders. *Pediatrics* 130(2): 69–76.
- Elsabbagh M, Divan G, Koh Y, et al. (2012) Global prevalence of autism and other pervasive developmental disorders. *Autism Research* 5(3): 160–179.
- Green VA, Pituch KA, Itchon J, et al. (2007) Internet survey of treatments used by parents of children with autism. *Research in Developmental Disabilities* 27(1): 70–84.
- Hambleton RK and Kanjee A (1995) Increasing the validity of cross-cultural assessments: use of improved methods for test adaptations. *European Journal of Psychological Assessment* 11(3): 147–157.
- Hess K, Morrier M, Heflin L, et al. (2008) Autism treatment survey: services received by children with autism spectrum disorders in public school classrooms. *Journal of Autism and Developmental Disorders* 38(5): 961–971.
- Internet Live Stats (2014) Internet use by country. Available at: <http://www.internetlivestats.com/internet-users-by-country/> (accessed 28 January 2016).
- Irvin DW, McBee M, Boyd BA, et al. (2012) Child and family factors associated with the use of services for preschoolers with autism spectrum disorder. *Research in Autism Spectrum Disorders* 6(1): 565–572.
- King Salman Center for Disability Research (2014) The fourth international conference on disabilities and rehabilitation: recommendations. Available at: <http://www.icdr.org.sa> (accessed 28 November 2014).
- Lake JK, Weiss JA, Dergal J, et al. (2014) Child, parent, and service predictors of psychotropic polypharmacy among adolescents and young adults with an autism spectrum disorder. *Journal of Child and Adolescent Psychopharmacology* 24(9): 486–493.
- McGrew S, Malow BA, Henderson L, et al. (2007) Developmental and behavioral questionnaire for autism spectrum disorders. *Pediatric Neurology* 37(2): 108–116.
- Mandell D, Morales K, Marcus K, et al. (2008) Psychotropic medication use among medicaid-enrolled children with autism spectrum disorders. *Pediatrics* 121: 441–448.
- Ministry of Education (2012) Statistics of special education programs (Males Division). Unpublished report.
- Ministry of Education (2015) King Abdullah scholarship program. Available at: <http://www.mohe.gov.sa/en/aboutus/Institutions/Pages/Emission-of-the-outer.aspx> (accessed 10 June 2014).

- Patten E, Baranek GT, Watson LR, et al. (2012) Child and family characteristics influencing intervention choices in autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities* 28(3): 138–146.
- Ravindran N and Myers B (2012) Cultural influences on perceptions of health, illness, and disability: a review and focus on autism. *Journal of Child and Family Studies* 21(2): 311–319.
- Schwartz H and Drager K (2008) Training and knowledge in autism among speech-language pathologists: a survey. *Language, Speech, and Hearing Services in Schools* 39(1): 66–77.
- Siller M, Reyes N, Hotez E, et al. (2013) Longitudinal change in the use of services in autism spectrum disorder: understanding the role of child characteristics, family demographics, and parent cognitions. *Autism* 18(4): 433–446.
- Spencer D, Marshall J, Post B, et al. (2013) Psychotropic medication use and polypharmacy in children with autism spectrum disorders. *Pediatrics* (132): 833–840.
- Tadmouri GO, Nair P, Obeid T, et al. (2009) Consanguinity and reproductive health among Arabs. *Reproductive Health* 6(1): 17.
- Taha GR and Hussein H (2014) *Autism Spectrum Disorders in Developing Countries: Lessons from the Arab World Comprehensive Guide to Autism*. New York: Springer, pp. 2509–2531.
- Thomas K, Ellis A, McLaurin C, et al. (2007) Access to care for autism-related services. *Journal of Autism and Developmental Disorders* 37(10): 1902–1912.
- Zahrani A (2013) Prevalence and clinical characteristics of autism spectrum disorders in school-age children in Taif-KSA. *International Journal of Medical Science and Public Health* 2(3): 578–582.

Appendix I. Rank order of interventions in terms of percentage of parents reporting use ($N = 205$).

No.	Intervention name	Rank order of all categories	Percentage	
			Currently using	Used in the past
<i>Non-medical</i>				
1	Applied behavior analysis	1	58	23
2	Speech therapy	2	53	22
3	Augmentative and alternative communication	5	38	16
4	Occupational therapy	6	34	20
5	Play therapy	7	38	14
6	Segregated classrooms	8	31	17
7	Sensory integrative therapy	12	26	9
8	Special day class	14	12	17
9	Art therapy	15	20	8
10	Partial-mainstreaming	21	10	6
11	Auditory integration therapy (AIT)	22	0	13
12	Music therapy	24	2	5
13	Animal therapy	25	4	2
<i>Biomedical</i>				
1	Vitamin and supplement therapy	3	46	23
2	Risperdal, Ritalin, or Prozac	9	20	25
3	Special diet	10	22	23
4	Anti-fungal medication (Diflucan, Nystatin)	17	8	13
5	Craniosacral therapy	18	10	10
6	Chelation therapy	20	9	8
7	Hyperbaric oxygen therapy	23	1	11
8	Iridology	27	1	2
9	Secretin	28	1	1
10	Magnet	29	0	2
<i>Cultural and religious</i>				
1	Reciting Quran	4	23	45
2	Honey	11	22	21
3	Visiting traditional/religious healer	13	5	28
4	Camel milk	16	10	16
5	Herbs and homeopathic treatments	19	4	14
6	Goat milk	26	2	4