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The Journey from Diagnosis to Services for Parents
of Children with Autism Spectrum Disorder
in Saudi Arabia

A dissertation submitted in partial satisfaction of
the requirements for the degree of Doctor of Philosophy
in Special Education

by

Fahad Alnemary

2017

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ABSTRACT OF THE DISSERTATION

The Journey from Diagnosis to Services for Parents
of Children with Autism Spectrum Disorder
in Saudi Arabia

by

Fahad Alnemary

Doctor of Philosophy in Special Education

University of California, Los Angeles, 2017

Professor Connie L. Kasari, Co-Chair

Professor Lois A. Weinberg, Co-Chair

Awareness of autism spectrum disorder (ASD) is relatively new in Saudi Arabia and systematic information about existing services is lacking. A convenience sample of 293 parents of children with ASD completed an online survey about their experiences and opinions attaining the ASD diagnosis for their children as well as the use of early intervention services in Saudi Arabia. The results revealed that the median age of the child when parents first noted atypicalities was 2.0 years. The median of the delays that parents experienced before they sought professionals help and to attain the diagnosis for their child were 0.3 years and 0.5 years, respectively. Just over one of third of parents were satisfied with the overall diagnostic process. Satisfaction was linked with higher perceived collaboration with professionals, higher perceived helpfulness of received information, higher perceived helpfulness of post-diagnosis support, lower household income, and

shorter delay to attaining the diagnosis for those who live in a major city. The median age of treatment initiation was 3.8 years. More than 16% of children received no early intervention (ASD interventions prior school age) and more than a half of those who accessed such services received 3 to 6 hours per week. Earlier age of treatment initiation was associated with earlier age of diagnosis, earlier age when parents first sought professionals help, lower severity of child ASD symptoms, residing in a major city, and younger child's age. Higher number of early intervention hours received per week was only associated to higher household income, rather than with child characteristics. Findings provide a valuable picture of an important group of families affected by ASD in Saudi Arabia, pointing the need to increasing ASD awareness and mandating early identification and intervention services in Saudi Arabia. National efforts for conducting research are needed to better understand and manage the access and use of diagnostic and therapeutic ASD services.

The dissertation of Fahad Alnemary is approved.

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Presentations

- **Alnemary, F.**, Alnemary, F. Factor Analysis of the Parental Concerns Questionnaire in Children with Autism Spectrum Disorder (poster). International Meeting for Autism Research (IMFAR) (May 2017).
- **Alnemary, F.**, Alnemary, F. Trends in Autism Research Funding in the Arab World (poster). International Meeting for Autism Research (IMFAR) (May 2017).
- **Alnemary, F.**, & Hernandez, A. Factor Structure and Psychometric Properties of an Arabic Version of the Autism Knowledge Questionnaire (poster). International Meeting for Autism Research (IMFAR) (May 2016).
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- M. Habash, F. Alnemary & **F. Alnemary**. An Investigation into the Effectiveness of an Arabic AAC Solution for Minimally Verbal Children with Autism. International Meeting for Autism Research (IMFAR) (May 2016).
- Alnemary, F., Gharapetian, L., Wallace, M., Yassine, J., **Alnemary, F.** Application of Pyramidal Training Model on the Implementation of Trial-based Functional Analysis (presentation). The 41st Annual Convention of the Association for Behavior Analysis International (May 2015), San Antonio, Texas.
- **Alnemary, F.**, Aldhalaan H. & Alnemary. Factors Associated with the Utilization of Autism Spectrum Disorders Services in the Kingdom of Saudi Arabia (presentation). The International Meeting for Autism Research (IMFAR) (May 2015), Salt Lake City, Utah.
- Simon-Cerejido, G., **Alnemary, F.**, Alnemary, F. Valera, I., Castro, J., Esparza, I., & Seward, M. Using a single subject design to develop evidence-based language facilitation lessons for early intervention classrooms: PLATICAR and child verbalizations (poster). California Speech-Language-Hearing Association Annual State Convention (March 2015), Long Beach, California.
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Refereed Contributions

- **Alnemary, F.**, Aldhalaan H., Alnemary, F., et al. (2017). Services for Children with Autism Spectrum Disorders in the Kingdom of Saudi Arabia. *Autism*, 21(5), 592-602.
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- Bahadur D, Aljobeir A, AlMashmoom I, Alshammari N, Aldhalaan H, Alnemary F, **Alnemary F.** (Under review). *Autism Awareness in Saudi Arabia*.
- **Alnemary F.**, Alnemary F, and Aldhalaan H, et al. (Under review). Factors associated with age of diagnosis among children with autism: An exploratory survey of parents in Saudi Arabia.

CHAPTER 1

Introduction

Awareness of autism spectrum disorder (ASD) is relatively new in Saudi Arabia and the government has made substantial efforts to advance ASD services. However, available ASD services are still scant. ASD early developmental screening and diagnostic evaluations occur in an unstructured system and many of healthcare professionals have little to no formal training in ASD (Helmy, 2017). In addition, with a prevalence of one per 167 (Aljarallah, et al., 2007), it is likely that the total number of the affected individuals under the age of 16 exceeds 448,000. However, only a small portion of these individuals have access to care through the Ministry of Education and the Ministry of Labor and Social Development, the two governmental agencies that coordinate public services for individuals with disabilities. For example, a total of 1778 students are receiving special education services in public schools across all regions in the country (Ministry of Education, 2016). Many children with ASD receive special education, respite care, and rehabilitation services from providers that are affiliated with the Ministry of Labor and Social Development (Ministry of Labor and Social Development, 2014). These providers also serve individuals with other special needs. The total number of children with ASD that are served by these providers is not available. Some children with ASD may receive services either in neighboring countries (e.g., Jordan, Egypt, United Arab Emirates) or in Western countries (e.g., United Kingdom and United States). While some families pay for their travel expenses, many others receive governmental support. Anecdotal data suggest nearly 800 individuals with disabilities, including those with ASD, receive governmental funding to receive special education services and/or respite care in Jordan and Egypt.

The limited understating and management of ASD in Saudi Arabia have been driven in part by the significant scarcity of research evidence. Few studies have examined some aspect of the use of ASD diagnostic and therapeutic services in Saudi Arabia. In a study that compared 20 Saudi children with ASD in Saudi Arabia to 28 Egyptian children, the age at which parents expressed concern about their child's development was younger for Saudi children; however, Saudi children were diagnosed later than their Egyptian counterparts (Hussein, Taha, & Almanasef, 2011). Another study of 324 families of children with ASD from three major cities (i.e., Riyadh, Jeddah, and Dammam) indicated that most of the children were diagnosed before the age of five years (78%). The percentages of children who were diagnosed before five years old were similar across cities, but Dammam had the highest percentage of children diagnosed at 10 years old or later (Murshid, 2011). More recently, 205 Saudi parents of children with ASD reported on their use of ASD diagnostic and therapeutic services of their children with ASD, age 3 – 18 years old (Alnemary, et al., 2017; Alnemary, et al, under review). Findings indicated that many parents traveled and/or paid to receive diagnostic and therapeutic services; the median age at diagnosis was 3.0 years and earlier diagnosis was associated with residing outside Saudi Arabia at the time of the survey's completion as well as their child not responding to his name in the first two years. Having no comorbidity, parents' concern about challenging behavior in the first two years, and the child's age were associated with later diagnosis. In addition, the age of intervention initiation was by 3.3 years and most parents reported utilizing a variety of interventions, some of which lack empirical support such as vitamin and supplement therapy, reciting Quran, special diet, honey, visiting traditional/religious healer, and camel malik. Most services were received in private clinics or schools and families paid for such services. Age of the initiation of intervention and total number of treatments used differed by child, family, and services variables. These include

parent's income, educational attainment, the extent of knowledge about ASD, geographic location, child age, and treatment type.

Findings from this recent work suggest that many children did not receive early intervention services, underscoring the importance of reforming the special education law in Saudi Arabia (i.e., Education Programs and Institutes of Saudi Arabia) to mandate early intervention services. Also, the association between treatment use and residence speaks to the need of utilizing available technology (e.g., video-conferencing) as a services delivery approach while the use of a variety of interventions with no empirical support underscores the importance of developing parent-friendly best practice guidelines to support parents in choosing treatments for their children.

Despite previous efforts to offer important insights into the use of ASD diagnostic and therapeutic services in Saudi Arabia, there is a lack of comprehensive description about parents' experiences attaining the ASD for their children. Systematic information about the use of early intervention services is also limited. Examining the use of diagnostic and early intervention services can provide useful information about the understanding and management of ASD. In order to have a better understanding of Saudi parents' use of assessment and treatment, the barriers and helpers must also be contextualized in terms of culture, religion and language. Therefore, the purpose of this study is to bridge this gap by exploring parents' experiences and opinions attaining the ASD for their children as well as to examine the use of early intervention services in Saudi Arabia.

CHAPTER 2

Review of Literature

Parents' Experiences and Opinion Attaining ASD Diagnosis

The early diagnosis of an ASD is a major step to receiving services as early as possible (Mandell, Listerud, Levy, & Pinto-Martin, 2002). Despite debate as to the specifics of such services, there is a growing consensus that these services could substantially minimize the impact of ASD, on the child, family, and society (Buescher, Cidav, Knapp, & Mandell, 2014; Jacobson & Mulick, 2000; Jarbrink & Knapp, 2001). Although some symptoms of ASD are present early in life (Goin-Kochel, Mackintosh, & Myers, 2006), many children with ASD are not diagnosed until later in life (Goin-Kochel et al., 2006; Rosenberg et al., 2009). Previous research reports significant differences in parents' experiences from the time they are first concerned to the time their child is diagnosed with an ASD (Crane, Chester, Goddard, Henry, & Hill, 2015; Howlin & Moore, 1997). Such experiences can potentially affect parents' satisfaction with the diagnostic process. For example, higher levels of parents' satisfaction with diagnostic process was linked to receiving a formal diagnosis at a young age, a shorter length of time between initial concerns being noted and the final diagnosis being received, receiving a clear diagnostic label from professionals (Howlin and Moore, 1997), higher satisfaction with the information provided at diagnosis, higher satisfaction with the manner of the diagnosing professional (Moh & Magiati, 2011), and higher satisfaction with post-diagnostic support (Crane, et al., 2015). Parents' experience with the ASD diagnostic process for their child may impact their levels of acceptance and levels of stress (Woolley et al., 1989). Obtaining a detailed picture of parents' experience attaining ASD is important to inform the decisions of governmental agencies in relation to funding of services and training of professionals.

Use of Early Intervention

Difficulties in identifying and accessing services have been reported by parents of children with ASD (Siklos & Kerns, 2006). For example, recent research revealed that more than 20% of children did not receive early intervention services (intervention for children with ASD aged 7 or younger) in some developed European countries (Salomone, et al., 2015). Difficulties in accessing early intervention might be attributed to the shortage in the number of services providers (Elsabbagh et al., 2012; Suppo & Floyd, 2012). However, family characteristics can also affect the use of and access to ASD services. Previous research in Western countries suggest that parental educational level was a significant predictor of receiving an early diagnosis (Mandell et al., 2009) and accessing services (Liptak et al., 2008); residing in nonmetropolitan areas was linked to 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); and high-income parents accessed occupational therapy (OT) and ABA more frequently than lower income parents (Irvin et al. 2012).

Differences in access to and use of early intervention services are also related to the child's characteristics. Researchers have found that the severity of ASD symptoms was associated with an earlier initiation of ASD treatments (Patten, Baranek, Watson, & Schultz, 2013) and the utilization of the Picture Exchange Communication Systems (PECS) In addition, the child's age was positively associated with the use of more partial hospitalizations (Coury et al. 2012) and individualized services and school services (Siller et al., 2013). Furthermore, the child's gender impacted ASD service use such as compared to girls, boys with ASD were found to receive more intensive individualized services (Siller et al., 2013).

Systematic information about parents' experiences and opinions in attaining the ASD diagnosis for their children as well as the use of early intervention services is available in many Western countries (Durkin, et al., 2015). However, this research is lacking in many other countries, including Saudi Arabia. Examining the use of ASD diagnostic and therapeutic services can provide useful information for increasing awareness and improving services.

The Current Study

The overall purpose of this study was to explore parents' experiences and opinion attaining the diagnosis of ASD for their children as well as to examine the use of early intervention services in Saudi Arabia. Specifically, this study was conducted to address four primary aims. The first aim was to describe parents' experiences attaining the ASD diagnosis for their children. It was hypothesized that parents would notice atypicalities with their child's development in a range of areas in the first two years of life, seek professional help before the second birthday of their child, and attain the ASD diagnosis when their children between the age of three and four years old. The second aim was to examine factors that may be associated with parents' satisfaction with the diagnostic process. It was hypothesized that parents' experiences to attain an ASD diagnosis for their child would be associated with their satisfaction with the experience with more positive attitudes associated with shorter time taken to receive the diagnosis, younger age of diagnosis, not having to travel to attain diagnosis, receiving the diagnosis at first consultation, sensitive and knowledgeable diagnosing professionals, perceived helpfulness of information received, perceived collaborative relationship with professionals, and perceived helpfulness of post-diagnosis support. The third aim was to describe the use of early intervention services, including the delay from diagnosis to accessing services, age of treatment initiation, and dosage of early intervention. It was hypothesized that many children would start receiving services between the age of three and four

years old as well as a wide ranging of dosage of early intervention services would be reported. The fourth aim was to identify factors that may delay the age of treatment initiation and reduce use of early intervention services. It was hypothesized that the child's severity of symptoms, a higher maternal educational attainment, living in a major city, and having a higher household income, an earlier age of the child when parents first sought help, and an earlier age at diagnosis would be associated with an earlier age of treatment initiation and more use of early intervention.

CHAPTER 3

Method

Data Source

Due to the lack of accurate statistics for children with ASD in Saudi Arabia, a sample of convenience was drawn for this study. Survey data were collected as part of an effort to examine the quality of care for individuals with ASD in Saudi Arabia, using an online platform (Qualtrics[®]) from February 22 through May 31, 2017. Participants were recruited through an email that was sent by the Department of Special Education in the Ministry of Education to all school districts in the country (N = 46). The message included a brief description of the survey along with its URL, and a request to share the survey's link with schools that serve students with ASD within that district. As a follow up, the same message was shared with supervisors of schools serving students with ASD. In addition, another link to the survey was made available on the Twitter account of the Center for Autism Research, King Faisal Specialist Hospital & Research Center, Riyadh, Saudi Arabia. Participants were asked to complete the survey for their oldest child with ASD.

Survey Description

The survey included 34 questions that were designed to examine the parents' experiences regarding the quality and quantity of services and supports they received from the time when their concerns about their child's development first were noted through the attainment of the ASD diagnosis to accessing early intervention services. The survey took an average of 40 minutes to complete. Questions about clinical and sociodemographic characteristics were also included. The survey was developed based on previous studies as well as anecdotal reports from clinical experts and families in Saudi Arabia; it was translated into Arabic by independent translators following

the guidelines of the forward-translation (Hambleton & Kanjee, 1995); it was pilot-tested with three Saudi parents of children with ASD and then modified for content and readability.

Study Variables

Aim 1. To address the first aim, parents reported their experiences attaining an ASD diagnosis for their child by answering a series of questions, that were adapted from the work of Crane et al. (2015). These questions asked about the: (1) child's age when the parents started to be concerned, (2) nature of the initial concern noted, (3) child's age when the parents first sought help, (4) professionals seen at the first consultation, (5) outcomes of the first consultation, (6) child's age when receiving the formal diagnosis, (7) support services offered post diagnosis, (8) perceptions of information given at diagnosis, (10) perceptions of professionals' manner during diagnosis, (10) perceptions of post-diagnosis support, and (11) satisfaction with the diagnostic process.

Aim 2. For the second aim, the dependent variable is satisfaction with the diagnostic process. This was measured with a dichotomous variable that grouped parents who responded to "I am satisfied overall with the diagnostic process" with "strongly disagree" or "disagree" or "neither" versus "agree" or "strongly agree".

Independent variables of satisfaction with the diagnostic process were grouped into one block that was entered into the equation. These variables included: time taken to receive the diagnosis, age at diagnosis, traveling to attain the diagnosis, receiving the diagnosis at the first consultation, diagnosing professionals, perceived helpfulness of information received, perceived collaborative relationship with professionals, and perceived helpfulness of post-diagnosis support. The time taken to receive the diagnosis was calculated by subtracting the age of the child when parents first sought help from child's age of diagnosis. Traveling to attain the diagnosis was

determined based on whether the family lived at the time of the survey completion in the city where their child was diagnosed. I collapsed the variable into two categories: “traveled” when the family lived in a city that is different from the one that their child was diagnosed in while “did not travel” when the family lives in the same city that their child was diagnosed in. Receiving the diagnosis in the first consultation was measured with a dichotomous variable that grouped parents who responded to “what happened during the first consultation” with “diagnosis given” versus “referred to another professional” or “asked to take child for further tests” or “told there was no problem” or “come back if problems persisted or “Other (e.g., different diagnosis was given)”. Perceived helpfulness of information received, perceived collaborative relationship with professionals, and perceived helpfulness of post-diagnosis support were measured with dichotomous variables that grouped parents who responded to “I am satisfied with the quality of information given at diagnosis”, “I am satisfied with the manner of the professional during the diagnosis process”, and “I am satisfied with the support that was offered post-diagnosis”, respectively, with “strongly disagree” or “disagree” or “neither” versus “agree” or “strongly agree”.

To control for background characteristics, clinical and demographic variables were included into the same block. They include child’s age and gender, comorbidity, severity of symptoms, maternal educational levels, family’s geographical location, and household income. Comorbidity was measured with a dichotomous variable that grouped parents who responded to “ASD is frequently accompanied by other physical and mental health conditions, does your child have a diagnosis of another condition?” with “no” versus “intellectual disability” or “attention-deficit/hyperactivity disorders” or “depression” or “epilepsy” or “other”. Severity of symptoms is a composite variable combining parent responses to the Parental Concerns Questionnaire (PCQ),

a measure for parents that assesses the extent to which each of several core and behavioral symptom of ASD has been a problem for their child (McGrew, et al., 2007). The PCQ consists of 13 items (e.g., “my child does not use words, has difficulty initiating conversations,” “my child completes routines always in the same manner,” and “my child does not fall asleep easily, wakes often”) with reporting options of “strongly disagree,” “disagree,” “agree,” and “strongly agree.” The PCQ has adequate psychometric properties and its factor structure has been examined previously in children with ASD in Saudi Arabia (Alnemary et al., 2017). The PCQ ranged from a minimum value of 13 (strongly disagreeing that each of the core and behavioral symptoms of ASD has been a problem for their child) to 52 (strongly agreeing that each one has been a problem). The family’s geographical location was assigned to one of two groups: major city or non-major city. The major cities include the cities with the largest populations in each of the main regions in Saudi Arabia: Central, Eastern, and Western (Central Authority for Statistic, 2016). These cities are Riyadh, Jeddah, and Dammam. Other cities were considered non-major cities. Income was coded based on the sufficiency line in Saudi Arabia (\$28, 564; Al-Damigh, 2014), which is the amount of income that a family requires to meet its needs without public’s support. These needs include housing, childcare, food, health care, transportations, and entertainment. I collapsed the variable into 3 categories: below sufficiency line, from sufficiency line to 100% above, and >100% above sufficiency line.

Aim 3. To address the third aim, parents answered two questions to reported on their use of early intervention services. These questions asked about age of treatment initiation and dosage of early intervention. The delay from diagnosis to services was also included. It was calculated by subtracting child’s age of diagnosis from child’s age of treatment initiation.

Aim 4. For the fourth aim, age of treatment initiation and dosage of early intervention were the two dependent variables. Age of treatment initiation was measured with a continuous variable that is the answer of parents to the question “At what age, did your child start receiving behavioral services at home or school?”. The use of early intervention was measured with a continuous variable that is the answer of parents to the question “If your child took part in, or is taking part in, Early Intervention therapy (ASD interventions prior school age), how many hours are/were completed in an average week?”.

Independent variables for age of treatment initiation and dosage of early intervention were grouped into one block that was entered into the equation. These variables included child’s severity of symptoms, parental educational attainment, family geographical location, and/or family household income. Child’s age and gender, age when parent sought help, and age of diagnosis were included into the same block to control for these variables. Also, for the use of early intervention, I controlled for age of treatment initiation. I did not impute missing data. A copy of the survey is available in Appendix A.

Statistical Analyses

Descriptive information was calculated for the entire sample (numbers and percentages for count data and means and standard deviations for continuous variables). Cross-tabulations were used to calculate numbers and percentages of satisfaction with the diagnostic process for all levels of each categorical variable. Continuous variables (e.g., child’s age, duration of the diagnostic process, age of diagnosis) were categorized to do the cross-tabulations calculations. The mean with standard deviations and median with associated range of age of treatment initiation and dosage of early intervention were calculated for all levels of each categorical variable. The distribution of the age of treatment initiation and dosage of early intervention were examined using Kolmogorov-

Smirnov and Shapiro-Wilks tests; deviations from normality were found for the dosage of early intervention but were of relatively small magnitude. Cross-tabulations were also used to calculate numbers and percentages of receiving early intervention services for all levels of each categorical variable

Logistic regression. Logistic regressions on satisfaction with the diagnostic process was conducted, adjusting for clinical and demographic characteristics and families' report of experiences attaining the ASD diagnosis for their child. The duration of the diagnostic process, child's age, age at diagnosis, and severity of symptoms were entered as continuous variables. Forced entry method was used as it surpasses other methods in theory testing; resisting influence of random variation in the data; and most importantly, providing replicable results if the model is replicated (Filed, 2013). Based on the bivariate relationships presented in Table 3, several interactions were tested. They included: (1) duration of the diagnostic process with major city, income, and traveling to attain diagnosis; and (2) receiving diagnosis at the first consultation with income and major city. Each of the interaction was tested in the original model individually due to the small sample size. Only the coefficient associated with the interaction of major city with duration of diagnostic process was statistically significant; thus, it was kept in the final model.

To assess the final model, first, I examined the standardized residuals to isolate points for which the model fits poorly while I used Cook's distance statistics to isolate points that exert an undue influence on the model (Filed, 2013). Five cases have been identified as possible outliers as they have absolute values above three and such cases have been inspected and their data seem to be legitimate. Cook's distance statistic indicated three potential influential cases as their values were above one. I ran the analysis with and without these outliers and obtained very similar results, thus these cases were included in the final model. In addition, multicollinearity was examined

using the tolerance and the variance inflation factor (VIF). None of the predictors has a tolerance value that is greater than .10 or a VIF value is less than three.

Linear regression. Linear regression analysis was undertaken to characterize the relationship between parents' experiences attaining ASD diagnosis variables and each of the continuous outcomes variables: age of treatment initiation and dosage of early intervention. For both outcomes, a number of interactions were tested whose potential importance was indicated by the bivariate relationships presented in Table 6 and Table 8, respectively. For age of treatment initiation, the interactions included: (1) child's age when parents sought professional help with severity of symptoms and maternal educational levels; and (2) major city with household income and age of diagnosis. The coefficients associated with these interactions were not statistically significant thus they were removed from the final model. Similarly, for dosage of early intervention, the following interactions were tested: major city with maternal educational levels and age of treatment initiation. The coefficients associated with these interactions were removed from the final model, as they were not statistically significant.

For both models (age of treatment initiation and dosage of early intervention), multicollinearity was tested; tolerance values are greater than .10 and a VIF values are less than three. In addition, regression assumptions were examined; histograms and normal probability plots of residuals looked like normal distribution; and the graph of the residual versus fitted plot shows dots have no pattern and the variance of the residuals are homogeneous across levels of the predicted values, suggesting that both homogeneity of variance and linearity are not violated. Moreover, three cases have been identified as possible outliers for the age of treatment initiation, as their standardized residuals' absolute values that are above three; such cases have been inspected

and their data seem to be legitimate. Cook's distance statistic shows that all cases for both outcomes have values are below one, suggesting no potential influential cases.

The use of these data for this study was approved by institutional review board of the University of California Los Angeles and the Center of Research and Studies, Ministry of Education, Saudi Arabia.

Number of Submissions

A total of 375 surveys were opened during the 4-months data collection period; 133 were accessed through the link that was shared with the Ministry of Education and 242 through the link that was shared in the Twitter account of the Center for Autism Research; and 82 surveys contained few data and were excluded from the sample. Therefore, the final sample included 293 surveys; 38% of children that were receiving services at schools affiliated with the Ministry of Education (response rate = 6.2%); 45% of children that were receiving services at schools affiliated with the Ministry of Labor and Social Development; 3% of children that were receiving services in private schools or at home; 3% of children that were receiving services in a different county (e.g., Jordan, Kuwait, Bahrain, United States); and 11% of children with no services at the time their parents completed the survey.

Sample Characteristics

Tables 1 provides descriptive information of the sample. Most respondents were between 31 and 40 years old at the time of the survey and 56% were mothers. Fairly higher maternal educational attainment was observed in this study, with 57% with a four-year college degree or post-graduate degree, exceeding the general population by 27% (i.e., 15%; General Authority for Statistics, 2017). Thirty-six percent of the families had an annual household income below the sufficiency line and 61% resided in major cities. The median age of children was 7.5 years, and

ranged from 3 to 18 years (30% < 6 years; 47% aged 6 - 9; 13% 10-13 years; 10% 14 - 18 years). The ratio of affected males to females was four to one, consistent with epidemiologic findings. The majority of parents (91%) rated their children as having moderate to severe symptoms (median = 35; range = 16 - 52). Fairly high levels of comorbidity were observed across the sample, with 60% of children having one or more additional diagnoses. Comorbid disorders included ADHD (45%), intellectual disability (16%), epilepsy (6%), and other (7%).

CHAPTER 4

Results

Parents' Experiences and Opinions Attaining ASD Diagnosis

Table 2 provides descriptive information on parents' experiences attaining ASD diagnosis. Parents first noted atypicalities with their child's development in a range of areas, but mostly related to impairments in language development and socialization. The median child age when parents started have concern was 2.0 years, and ranged from 0.0 to 5.8 years. Most parents noted atypicalities before their child was 2 years (49%) or between 2 and 3 years (46%).

The median amount of delay that parents experienced before they sought professionals help was 0.3 years, and ranged from 0.0 to 6.0 years; over 29% parents waited for a year or more. Child's median age when parents first sought help was 2.3 years, and ranged from 0.0 to 7.3 years. For 25% of parents, seeking help was before their children were 2 years old. A range of professionals was seen at this first consultation, mostly a Psychiatrist (36%) or Pediatrician (23%). For 44% of parents, the outcome of the first consultation was receiving the ASD diagnosis; however, when the diagnosis was not given, parents were mostly referred to another professional (22%).

The median amount of delay between the parent initially contacting a health professional and the child receiving a formal diagnosis was 0.5 years, and ranged from 0.0 to 8.0 years. Over a third (34%) of parents waited for a year or more to receive the formal diagnosis. The median age of receiving the formal diagnosis was 3.0 years, and ranged from 1.5 to 8.0 years. Although a small proportion were diagnosed before their second birthday (9%), most children were diagnosed between the age of 2 and 3 years old (61%) or when they were 4 years or older (30%). About one third of children (32%) were diagnosed outside their city of residence, including 10% outside the

country. The diagnosis tended to be given by psychiatrists (40%), psychologists (20%) or teams of professionals (14%). Other diagnosticians included pediatricians, neurologists and other professionals.

Post-diagnosis, 62% of parents received a written report, 56% were referred to service providers, and 46% were provided with informational support (e.g., parents support group, funding/charitable organizations). However, 21% of parents received no offers of help or assistance during or after the diagnostic process. Over a third of the parents (39%) perceived information given during diagnostic process as helpful, 44% perceived the relationship with the professionals as collaborative, and 16% perceived post-diagnosis support as helpful. However, only one third (34%) of parents were satisfied with the overall diagnostic process.

Satisfaction with Diagnostic Process and Associated Factors

Results of bivariate analyses for satisfaction with diagnostic process are presented in Table 3. Most parents who were satisfied with the diagnostic process perceived post-diagnosis support as helpful (85%), perceived information given at diagnosis as helpful (67%), and perceived relationship with professionals during diagnosis as collaborative (66%), sought help when their child was 4 years of age or older (47%); and their children reportedly had moderate symptoms (51%), were currently between the age of 14 and 18 years old (48%), were diagnosed by a team of professionals (47%), were typically diagnosed before the age of 2 years (42%), with no comorbid conditions (40%), and lived in houses with income below the sufficiency line (43%) often in a major city (39%), and mothers had at most a high school diploma (40%).

Multivariate logistic regression on satisfaction with the diagnostic process revealed a similar pattern to the bivariate analyses, and these data are presented in Table 4. The model's χ^2 statistics was significant ($p < .001$). The Hosmer and Lemeshow was not significant ($p = 0.735$),

indicating a well-fitting logistic regression model. Nagelkerke's R^2 was 0.58 and Cox & Snell's R^2 was 0.42, which is an indication that some relevant variables have not been included in the model. Adjusting for clinical and demographic characteristics and families' report of experiences attaining the ASD diagnosis for their child, perceiving relationship with professionals as collaborative increases the odds of satisfaction seven fold (OR: 7.51 [95% CI: 3.38–16.67]). Perceiving post-diagnosis support (OR: 6.94 [95% CI: 2.19 –21.96]) and information given at diagnosis (OR: 5.14 [95% CI: 2.33 11.31]) as helpful had similarly sized ORs. Compared to being in households with income that is 100% above the sufficiency line, being in a household below the sufficiency line (OR: 3.66 [95% CI: 1.16–11.45]) or from the sufficiency line to 100% above (OR: 3.93 [95% CI: 1.39–11.12]) was associated with higher odds of satisfaction. For those who live in major cities, an additional year in the time taken to receive the diagnosis lowered the odds of satisfaction by 61% compared to those living in non-major cities (OR: 0.39 [95% CI: 0.16–0.95]).

Use of Early Intervention Services

Tables 5 provides descriptive information on the use of early intervention services. The median age of treatment initiation was 3.8 years, and ranged from 0.5 to 8.0 years. For 47 % of children, they started services after their fourth birthday. Over a third of the parents reported that their children started receiving services before or at the time of receiving the formal ASD diagnosis. For those who waited, the median of delay for receiving services was 1.0 years, and ranged from 0.3 to 6.5 years. Over 16% of parents reported that their children did not receive early intervention (ASD interventions prior to school age). Most of these parents (40%) sought professional help when their children were 4 years or older and/or lived with in a family where maternal education level was below high school (41%). On the other hand, most parents that

accessed early intervention services reported that their children received 3 to 6 hours per week (43%), followed by 2 hours or less (23%), and 22 hours per week (9%). The majority of these parents were those who rated their children at the mild end of the spectrum (96%), were from families where the highest degree earned by the mother was a graduate degree or higher (95%), and lived in homes with a household income greater than 100% of the sufficiency line (95%). The median of use of early intervention was 4.5 hours per weekly, and ranged from 1.0 to 22.0 hours per week.

Age of Treatment initiation and Associated Factors

Results of bivariate analyses for age of treatment initiation are presented in Table 6. Various groups of children started treatment earlier compare to their counterparts. These include male children, those between the age of 3-5 years old, those with mild symptoms, those without comorbid conditions, those of mothers with a graduate degree, those who live in a major city, those from families with a household income greater than 100% of the sufficiency line, those whose parents who sought professional help during the first two years of life, and/or those who were diagnosed before the age of 2 years old.

Table 7 provides the results of the multivariate linear regression predicting age of treatment initiation. Using a forced entry method of multiple regression, a significant model emerged that predicted overall satisfaction with age of treatment initiation ($F(13, 274) = 19.80, p < 0.001$). Of the independent variables hypothesized to predict age at treatment initiation, five were significant at alpha level <0.05 : child's age, severity of symptoms, city of residence, age when parents first sought help, and age at diagnosis. The model had an adjusted R^2 of 0.46, meaning it explained 46% of the variance regarding the age of treatment initiation, an indication that some relevant variables have not been included in the model. Adjusting for other variables, each year

increase in a child's age was associated with a 0.06-year increase in the age of treatment initiation (95% CI: 0.02– 0.10). An additional score in the severity measure had the same coefficient (95% CI: 0.03– 0.07). Being a resident of a major city was associated with a 0.45-year earlier age of treatment initiation when compared to residents of non- major cities (95% CI: –0.76 – –0.14). Starting treatment occurred 0.46 years and 0.44 years later for each year of a child's age when parents sought professionals help (95% CI: 0.28– 0.63) and when diagnosis was received (95% CI: 0.30– 0.58), respectively.

Dosage of Early Intervention and Associated Factors

Table 7 provides the results of the bivariate analyses for dosage of early intervention treatment. The median hours of early intervention per week was consistent across all levels of each family and child characteristics, except it was higher for children of mothers who completed some collages credits (Median = 6.5; Range = 1.0 – 22.0).

Table 8 provides the results of the multivariate linear regression predicting weekly hours of early intervention. Using a forced entry method of multiple regression, a significant model emerged that predicted weekly hours of early intervention ($F(14, 226) = 2.02, p = < 0.007$). Of the independent variables, the associations of being from a family that has a household income below the sufficiency line and being from the sufficiency line to 100% above were found to be significant at alpha level < 0.05 . The model explained 6% of the variance regarding the age at treatment initiation. This indicate that several relevant variables have not been included in the model. Controlling for other variables, being from a family that has a household income below the sufficiency line or from sufficiency line to 100% above was associated with receiving 4.6 (95% CI: –7.04– –2.22) and 3.8 (95% CI: –5.98– –1.62) fewer hours, respectively, when compared to those of a family that has household income greater than 100% above sufficiency line.

CHAPTER 5

Discussion

The purpose of this study was to examine the journey from diagnosis to services for parents of children with ASD in Saudi Arabia. This includes describing parents' experience accessing diagnostic and therapeutic services for their children, and examining factors associated with satisfaction with the diagnostic process, age of treatment initiation, and dosage of early intervention. By surveying 293 parents who experienced ASD diagnostic and therapeutic services for their children (typically within the past 6 years), this study provides a valuable picture of an important group of families affected by ASD in Saudi Arabia.

A major finding in this study was that the median age of the children was 2 years when parents reported noticing signs of developmental delay and differences; for over a half of children, it was after their second birthday. This is slightly late compared to parents of children with ASD from other countries, who were able to first report warning signs when their children were 1.6 year (Guinchat, et al., 2012). It is possible that this group of parents could have recognized the warning signs of ASD at an earlier age given the severity of symptoms of their children, but may not have due to cultural differences noted in other studies of delayed recognition in the United States (Mandell, Listerud, Levy, & Pino-Martin, 2002). Efforts to increase parents' knowledge and understanding of child development, including early signs of ASD, could potentially benefit them in understanding what to expect and how to provide what their children need during early childhood. As such, parents would seek screening services if noticing atypicalities in their children, paving the way for early diagnosis and intervention at the earliest point possible.

In this study, parents waited more than 7 months to start contacting a health professional and nearly 10 months to receive the ASD formal diagnosis, suggesting that many parents

experienced a delay of 17 months. The duration of this delay is less than half of what parents experienced in the United Kingdom (Crane, et al., 2015). Similarly, the age of diagnosis in this study is low compared to what has been reported from research in other countries (Daniels & Mandell, 2014). These findings can be attributed to the potential bias generated from the sampling method in this study. The majority of children were rated with moderate or severe symptoms. It is reasonable for this group of children to receive the ASD diagnosis earlier than those who are more intellectually able. It is important to investigate and address the experiences of parents of children with mild symptoms, as they may experience even longer and more frustrating diagnostic delays (Crane, et al., 2015).

This study also corroborates findings from recent research in Western countries. Specifically, a study of four countries in Southeast Europe revealed that ASD diagnoses were most commonly assigned by psychiatrists (51%) and only over a tenth by teams of professionals (15%). Also, it was found that nearly one-third of families from these countries traveled over 100 km or outside the country to receive the ASD diagnosis (Daniels, et al., 2017). These findings are consistent with the results of this current study. The particular diagnostician and traveling associated with attaining an ASD diagnosis in these two studies suggest diagnostic services in these countries and Saudi Arabia are somewhat comparable and they require improvement. With the booming access to internet and portable devices, the use of telemedicine to provide ASD diagnostic services has great potential to address these issues. It would increase access to specialized multi-disciplinary teams as well as minimize the burden associated with traveling (Boisvert, Lang, Andrianopoulos, & Boscardin, 2010).

More findings from this study point to the need to improve diagnostic services in Saudi Arabia. That is, 21% of parents received no offers of help or assistance after the diagnostic process.

While 62% received a written report of their child's diagnosis, only 16% perceived post-diagnostic supports as helpful. Although satisfaction with the overall diagnostic process differs by several variables, the variables with the most predictive power were parents' perception of the quality of information given at diagnosis, perception of the manner of the professionals during the diagnosis, and perception of post-diagnosis supports. A major step towards increasing parental satisfaction with the overall diagnostic process would be ensuring that diagnosticians have the necessary skills to provide parents with sufficient information at diagnosis as well as to direct them to the support they need upon receiving the ASD diagnosis.

It is also important to mention the two other factors that are associated with the overall diagnostic process. First, compared to those with lower household income, having a household income that is 100% above the sufficiency line was linked to less satisfaction. This finding diverges from previous research in Western countries (Hidalgo, McIntyre, & McWhirter, 2015; Goin-Kochel et al., 2006). Second, for those who live in major cities, an additional year in the time taken to receive the diagnosis was linked to lower odds compared to parents' living in non-major cities. It is possible that parents in these two groups might have had higher expectations for the diagnostic process given their income and geographical location.

Clearly, many findings from this study suggest that more needs to be done to improve early intervention services in Saudi Arabia. For example, the median age of treatment initiation is 3.8 years; nearly half of children started receiving services at age 4 years or after; more than one half (54%) waited one year, after diagnosis, to receive services; 16% did not receive early interventions services (ASD intervention prior to school age); for 72% of those who did, the median dosage of early intervention was 7.7 hours per week. These findings suggest many children may miss early learning opportunities, which are critical in minimizing the impact of ASD, or if they do receive

services these services are at a fairly low dose. These findings are consistent with the educational system policies in Saudi Arabia; typically, children begin primary school when they reach 6 years. Mandating early identification and intervention services is important step to addressing the significant needs of young children with ASD (Aldabas, 2015; Alnemary, et al., 2017; Alquraini, 2011).

Some factors associated with age of treatment initiation and use of early interventions is in line with findings from previous research in Western countries. First, this study revealed that an increase in the child's age of diagnosis was associated with an increase in age at treatment initiation, suggesting that receiving an ASD diagnosis is critical to accessing services (Mandell, et al., 2002). In addition, the finding that being a resident of a major city resulted in an earlier age of treatment initiation in this study is consistent with previous work showing that access to care is limited for families living in nonmetropolitan cities (Thomas et al., 2007). Moreover, the association between income and the greater use of early intervention services in this study is consistent with previous work in Saudi Arabia showing that children of income below sufficiency line received fewer non-medical interventions (e.g., applied behavior analysis, speech therapy, occupational therapy) than those from families with income above the sufficiency line (Alnemary, et al., 2017). Such politics result parents having to pay for early intervention services. As mentioned previously, these services must be offered freely to minimize the impact of ASD on the child, the family, and the society.

The child's age was also associated with the age at treatment initiation. This finding may reflect the recent governmental efforts to increase awareness of ASD and improve services in Saudi Arabia, resulting in that younger children with ASD are accessing services earlier compared to their older counterparts. In addition, in this study, the child's age when parents first sought

professional help was associated with age at treatment initiation, suggesting that parents who are competent in accessing diagnostic services are also competent in accessing therapeutic services. Surprisingly, however, the age of services initiation was positively associated with the child's severity of symptoms. In other word, children who had mild symptoms started receiving services earlier compared to those with more sever symptoms.

It is likely that parents of children with severe symptoms face challenges accessing services, as it is not clear whether they can receive services from schools affiliated with the Ministry of Education (which tend to serve children with mild symptoms) or from daily care and rehabilitations centers affiliated with the Ministry of Labor and Social Development (which usually serve children with moderate to severe symptoms). Making this clearer would potentially reduce the delay that parents' experience when attempting to access ASD services for their children.

Strengths and Limitations

This is the first study to examine parents' experiences using diagnostic and early intervention services for their child with ASD in Saudi Arabia. Results offer important insights to policy makers and advocates who are attempting to understand parents' journey from diagnosis to services.

This study also has three major limitations that are noteworthy. First, the sample was not representative of families of children with ASD. The mothers' educational attainment observed in this study was higher than that of the general population of Saudi Arabia. Families of lower material educational attainments may have a lower than average knowledge about ASD and sophistication about ASD services. Also, children in this study had moderate to severe symptoms. Families of children with mild symptoms may have different experiences accessing and using ASD

diagnostic and early intervention services. Moreover, the sample was missing parents with no access to the Internet. It is possible that this risk is minimal due to the increased use of the portable devices and smartphones, as existing evidence indicates that about 83.87% of Saudi households have access to the Internet (85.45% of the same-family users) (Central Authority for Statistic, 2016). Second, despite being comprehensive, the survey would have improved our understanding about parents' experiences attaining the ASD diagnosis and using early intervention services for their children by including questions about other related factors. For example, including parental stress during the diagnosis process as a factor into the model to predict satisfaction with the diagnostic process might have improved its predictive power (Moh & Magiati, 2102). Similarly, information about the type of intervention used, the reason of using such interventions, and barriers to access would explained the variability in the child's age at treatment initiation and number of weekly hours of early intervention received (Salomone, at al., 2016). Third, findings in this study were based on parents' report. As such, inaccurate reporting might have biased our findings. Despite these limitations, this study provides a valuable picture of an important group of families affected by ASD in Saudi Arabia.

Future Directions

Further research that includes a nationally representative sample is needed to confirm these finding as well as clarify how services that assess children who might have ASD are structured and organized. More research also is needed to gain a better understanding about the type and quality of early intervention services and factors affecting them, since these relationships have not been explored among parents of children with ASD in Saudi Arabia.

Conclusion

Findings cannot be used to make inferences to the general population of children with ASD; however, they provide a valuable picture of an important group of families affected by ASD in Saudi Arabia. They point to the need to increase ASD awareness and mandate early identification and intervention services in Saudi Arabia. National efforts to do conducting research is needed to better understand and manage the access and use of diagnostic and therapeutic ASD services.

LIST OF TABLES

Table 1.

Sample Characteristics

	<i>n</i>	%	Mean (SD)	Median (Range)
Gander (Male)	236	81		
Age			8.2 (4.0)	7.5 (3 – 18)
3-5 Years	88	30		
6-9 Years	138	47		
10-13 Years	38	13		
14-18 Years	30	10		
Severity of Symptoms			35.3 (6.7)	35.0 (16.0 – 52.0)
31 – 26 (Mild)	25	9		
27 – 39 (Moderate)	37	13		
40 – 52 (Sever)	232	79		
Comorbidity				
None	118	40		
Attention-Deficit/Hyperactivity Disorder	133	45		
Intellectual Disability	47	16		
Epilepsy	17	6		
Others	22	7		
Maternal Educational Attainment				
< High School	36	12		
High School	72	25		
Some College Credits	20	7		
College Degree	144	49		
≥ Graduate Degree	22	8		

Annual Household Income				
Below Sufficiency Line	95	32		
From Sufficiency Line to 100% Above	124	42		
>100% Above Sufficiency Line	75	26		
Residence				
Major City	179	61		
Non-Major City	113	39		

Table 2.

Parents Experiences Attaining ASD Diagnosis

	<i>n</i>	%	Mean (SD)	Median (Range)
Child's Age When Parents Became Concerned			1.9 (1.0)	2.0 (0.0 – 5.8)
< 2 Year	143	49		
Between 2 and 3 Years	135	46		
≥ 4 Years	15	5		
Nature of Initial Concern				
Delay in Starting to Talk	225	77		
Eye Contact	145	50		
Dose not Respond to Name	194	66		
Delay in Other Milestones (e.g. Walking)	42	14		
Social Development	130	44		
Rituals/Obsessions/Dislike of Change/Object Attachments	70	24		
Failure to Develop Normal Pretend Play	94	32		
Behavior Problems	73	25		
Medical problems (e.g. Epilepsy)	20	7		
Schooling	12	4		
Sensory Sensitivity	40	14		
Sleep Problems	65	22		
Time Taken to Seek Help			0.6 (0.9)	0.3 (0.0 – 6.0)
< 1 Year	200	71		
≥ 1 Year	82	29		
Age When Parents Sought Professionals Help			2.5 (1.1)	2.3 (0.0 – 7.3)
< 2 Years	72	25		

Between 2 and 3 Years	186	63		
≥ 4 Years	34	12		
Professionals Seen at First Consultation				
General Practitioner	6	2		
Pediatrician	68	23		
Speech and language therapist	13	4		
Psychiatrist	105	36		
Psychologist	40	14		
Neurologist	36	12		
Others	40	13		
Outcome of First Consultation				
Diagnosis was Given	130	44		
Referred to Another Professional	65	22		
Told There was no Problem	24	8		
Come back if Problems Persisted	15	5		
Other (e.g. different diagnosis given)	59	20		
Time Taken to Get Diagnosed			0.8 (1.1)	0.5 (0.0 – 8.0)
< 1 Years	183	63		
≥ 1 Years	99	34		
Child's Age at Diagnosis			3.3 (1.1)	3.0 (1.5 – 8.0)
< 2 Years	26	9		
Between 2 and 3 Years	180	61		
≥ 4 Years	87	30		
Traveled Outside City of Residence	93	32		
Traveled Outside Saudi Arabia	28	10		
Diagnostician				
Pediatrician	13	4		

Psychiatrist	117	40		
Psychologist	59	20		
Neurologist	29	10		
Team of Professionals	41	14		
Others	34	12		
Support Services				
Report	182	62		
Referral	165	56		
Informational	136	46		
No Support	60	21		
Perceived Information Received as Helpful	115	39		
Perceived Relationship with Professionals as Collaborative	129	44		
Perceived Post-Diagnosis Support as Helpful	47	16		
Satisfaction with Diagnostic Process	105	34		

Table 3.

Satisfaction with Diagnostic Process by Variables of Interest

	<i>n</i>	%
Gander		
Male	85	36
Female	20	36
Age		
3-5 Years	26	30
6-9 Years	54	39
10-13 Years	11	29
14-18 Years	14	48
Severity of Symptoms		
31 – 26 (Mild)	7	28
27 – 39 (Moderate)	19	51
40 – 52 (Sever)	79	34
Comorbidity		
Yes	59	33
No	47	40
Respondent		
Mother	63	38
Father	39	33
Maternal Educational Attainment		
< High School	12	33
High School	28	40
Some College Credits	5	25
College Degree	54	38
≥ Graduate Degree	6	29

Annual Household Income		
Below Sufficiency Line	41	43
From Sufficiency Line to 100% Above	44	36
>100% Above Sufficiency Line	20	27
Residence		
Major City	70	39
Non-Major City	35	31
When Parents Sought Professionals Help		
< 2 Years	24	33
Between 2 and 3 Years	65	35
≥ 4 Years	16	47
Time Taken to Get Diagnosed		
< 1 Year	68	37
≥ 1 Year	33	33
Age of Diagnosis		
< 2 Years	11	42
Between 2 and 3 Years	64	36
≥ 4 Years	30	35
Received Diagnosis at First Consultation		
Yes	51	39
No	55	34
Diagnosed Outside City of Residence		
Yes	30	32
No	75	38
Diagnostician		
Pediatrician	5	39
Psychiatrist	40	34

Psychologist	20	34
Neurologist	11	38
Team of Professionals	20	49
Others	9	27
Perceived Helpfulness of Information Given at Diagnosis		
Yes	77	67
No	28	16
Perceived Collaborative Relationship with Professionals		
Yes	85	66
No	20	12
Perceived Helpfulness of Post-Diagnosis Support		
Yes	40	85
No	65	26

Table 4.

Logistic Regression Predicting Overall Satisfaction with Diagnostic Process

Variable	B	S.E.	95% CI for Odds Ratio		
			Lower	Odds Ratio	Upper
Gender (Male)	.401	.457	.610	1.493	3.658
Age (In Years)	.038	.052	.937	1.039	1.151
Severity	-.047	.031	.898	.954	1.014
Comorbidity	.156	.398	.536	1.169	2.549
Respondent (Father)	.203	.392	.568	1.225	2.644
Maternal Educational Attainment					
(< High School)	-.735	.938	.076	.480	3.016
(High School)	-.375	.774	.151	.688	3.132
(Some College Credits)	-1.311	.986	.039	.269	1.861
(College Degree)	-.118	.705	.223	.888	3.538
Annual Household Income					
(Below Sufficiency Line)	1.297 *	.582	1.169	3.660	11.457
(From Sufficiency Line to 100% Above)	1.370 **	.530	1.393	3.937	11.126
City of Residence (Major)	.964	.588	.829	2.622	8.295
Age at Diagnosis (in years)	-.002	.188	.690	.998	1.444
Time Taken to Get Diagnosed (in years)	.576	.413	.792	1.779	3.996
Interactions of Duration of the Diagnostic Process with City of Residence (Major)	-.936 *	.450	.162	.392	.947
Diagnosed Outside City of Residence	.020	.451	.422	1.020	2.467
Receiving Diagnosis at the First Consultation	-.140	.383	.410	.869	1.841
Diagnostician					
(Psychiatrist)	.524	1.045	.218	1.688	13.078

(Psychologist)	.567	1.100	.204	1.764	15.245
(Neurologist)	1.101	1.147	.318	3.006	28.450
(Team of Professionals)	1.314	1.126	.409	3.720	33.833
(Others)	-.062	1.142	.100	.939	8.809
Perceived Helpfulness of Information Received	1.636 ***	.403	2.331	5.135	11.313
Perceived Collaborative Relationship with Professionals	2.016 ***	.407	3.383	7.511	16.676
Perceived Helpfulness of Post-Diagnosis Support	1.937 ***	.588	2.193	6.940	21.964

Note. Model $\chi^2(25) = 146.07, p < .001$.

Hosmer and Lemeshow $\chi^2(8) = 5.212, p < .735$.

$R^2 = .42$ (Cox & Snell), $.58$ (Nagelkerke). The reference group consists of female children without comorbid condition whose mothers responded to the survey, those of mother with graduate degrees, those who live in a non-major city with household income 100% above the sufficiency line, and those diagnosed by a pediatrician in their city of residence.

(* $p < .05$, ** $p < .01$, *** $p < .001$).

Table 5.

Use of Early Intervention Services

	<i>n</i>	%	Mean (SD)	Median (Rang)
Treatment Initiation				
Before Diagnosis	44	15		
At Diagnosis	67	23		
After Diagnosis	182	62		
Time Taken to Treatment Initiation			1.3 (1.2)	1.0 (0.3 – 6.5)
< 1 Years	83	46		
1 to 2 Years	75	41		
≥ 3 Years	24	13		
Age of Treatment Initiation			3.9 (1.7)	3.8 (0.5 – 8.0)
< 2 Years	23	8		
2 Years	49	17		
3 Years	83	28		
4 Years	51	17		
5 Years	43	15		
6 Years	14	5		
≥ 7 Years	30	10		
Number of Early Intervention Hours per Week			7.7 (6.9)	4.5 (1.0 – 22.0)
No Early Intervention	47	16		
≥ 2	55	19		
3 to 6	105	36		
7 to 10	18	6		
11 to 14	15	5		
15 to 18	12	4		
19 to 21	18	6		

$22 \leq$	21	7		
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Table 6

Age of Treatment Initiation in Years by Variables of Interest

	Mean (SD)	Median (Rang)
Gander		
Male	3.8 (1.7)	3.5 (0.5 – 8.0)
Female	4.4 (1.9)	4.3 (0.5 – 8.0)
Age		
3-5 years	3.0 (1.2)	3.0 (0.5 – 7.0)
6-9 years	4.3 (1.7)	4.0 (0.5 – 8.0)
10-13 years	4.4 (1.8)	4.1 (2.0 – 8.0)
14-18 years	4.1 (2.1)	4.0 (0.5 – 8.0)
Severity of Symptoms		
31 – 26 (Mild)	3.3 (1.3)	3.0 (1.5 – 6.8)
27 – 39 (Moderate)	4.0 (1.4)	3.5 (1.8 – 7.0)
40 – 52 (Sever)	4.0 (1.8)	3.8 (0.5 – 8.0)
Comorbidity		
Yes	3.9 (1.8)	3.8 (0.5 – 8.0)
No	3.9 (1.6)	3.5 (1.3 – 8.0)
Maternal Educational Attainment		
< High School	4.8 (2.2)	4.5 (0.8 – 8.0)
High School	4.0 (1.7)	3.8 (0.5 – 8.0)
Some College Credits	3.8 (1.9)	3.8 (0.5 – 8.0)
College Degree	3.8 (1.5)	3.5 (0.5 – 8.0)
≥ Graduate Degree	3.2 (1.6)	2.8 (0.5 – 7.0)
Annual Household Income		
Below Sufficiency Line	4.4 (1.8)	4.0 (0.5 – 8.0)
From Sufficiency Line to 100% Above	3.9 (1.7)	3.8 (0.5 – 8.0)

>100% Above	3.5 (1.5)	3.3 (0.5 – 8.0)
City of Residence		
Major City	3.8 (1.7)	3.5 (0.5 – 8.0)
Non-Major City	4.1 (1.8)	4.0 (0.5 – 8.0)
When Parents Sought Professionals Help		
< 2 Years	2.9 (1.6)	2.5 (0.5 – 8.0)
Between 2 and 3 Years	2.9 (1.5)	3.5 (0.5 – 8.0)
≥ 4 Years	6.0 (1.5)	6.0 (3.8 – 8.0)
Age of Diagnosis		
< 2 Years	2.3 (1.5)	2.0 (0.5 – 7.0)
Between 2 and 3 Years	3.4 (1.3)	3.3 (0.5 – 8.0)
≥ 4 Years	5.4 (1.5)	5.0 (1.8 – 8.0)

Table 7.

Linear Regression Predicting Age of Treatment Initiation in Years.

Variables	B	SE B	β	95% CI	
				Lower	Upper
Gender (Male)	-.328	.194	-.076	-.709	.053
Age (In Years)	.055 **	.020	.127	.015	.095
Severity	.050 ***	.012	.194	.027	.073
Comorbidity	-.048	.156	-.014	-.355	.259
Maternal Educational Attainment					
(< High School)	.270	.382	.051	-.481	1.021
(High School)	.036	.335	.009	-.624	.696
(Some College Credits)	-.158	.418	-.023	-.980	.665
(College Degree)	-.099	.307	-.029	-.704	.506
Annual Household Income					
(Below Sufficiency Line)	.181	.214	.049	-.240	.602
(From Sufficiency Line to 100% Above)	.132	.197	.038	-.257	.520
City of Residence (Major)	-.454 **	.157	-.129	-.764	-.145
When Parents Sought Professional Help	.460 ***	.087	.297	.289	.631
Age of Diagnosis	.444 ***	.073	.349	.301	.588

Note. Adjusted $R^2 = .46$. $F(13, 274) = 19.80$, $p < 0.001$ (* $p < .05$, ** $p < .01$, *** $p < .001$). The reference group consists of female children without comorbid condition, of mothers with graduate degrees, and who live in non-major cities with household income 100% above the sufficiency line.

Table 8.

Dosage of Early Intervention in Hours per Week by Variables of Interest

	<i>n</i>	%	Mean (SD)	Median (Rang)
Gander				
Male	198	85	7.8 (6.9)	4.5 (1.0 – 22.0)
Female	46	81	7.3 (7.4)	4.5 (1.0 – 22.0)
Age				
3-5 Years	79	91	7.7 (7.0)	4.5 (1.0 – 22.0)
6-9 Years	112	82	7.5 (6.8)	4.5 (1.0 – 22.0)
10-13 Years	30	79	8.0 (7.2)	4.5 (1.0 – 22.0)
14-18 Years	23	79	8.0 (7.9)	4.5 (1.0 – 22.0)
Severity of Symptoms				
31 – 26 (Mild)	24	96	9.0 (8.0)	4.5 (1.0 – 22.0)
27 – 39 (Moderate)	31	84	9.1 (7.9)	4.5 (1.0 – 22.0)
40 – 52 (Sever)	189	83	7.4 (6.7)	4.5 (1.0 – 22.0)
Comorbidity				
Yes	145	83	7.2 (6.7)	4.5 (1.0 – 22.0)
No	99	85	8.5 (7.3)	4.5 (1.0 – 22.0)
Maternal Educational Attainment				
< High School	21	60	7.3 (7.4)	4.5 (1.0 – 22.0)
High School	58	81	6.6 (5.5)	4.5 (1.0 – 22.0)
Some College Credits	14	70	10.0 (7.7)	6.5 (1.0 – 22.0)
College Degree	131	92	7.9 (7.3)	4.5 (1.0 – 22.0)
≥ Graduate Degree	20	95	9.1 (7.8)	4.5 (1.0 – 22.0)
Annual Household Income				
Below Sufficiency Line	73	78	7.1 (5.7)	4.5 (1.0 – 22.0)
From Sufficiency Line to 100% Above	100	81	7.9 (7.2)	4.5 (1.0 – 22.0)

>100% Above Sufficiency Line	71	96	7.7 (6.8)	4.5(1.0 – 22.0)
City of Residence				
Major City	159	89	7.5 (76.9)	4.5 (1.0 – 22.0)
Non-Major City	83	76	8.2 (7.3)	4.5 (1.0 – 22.0)
When Parents Sought Professionals Help				
< 2 Years	66	92	7.1 (7.0)	4.5 (0.0 – 22.0)
Between 2 and 3 Years	157	85	7.9 (7.2)	4.5 (1.0 – 22.0)
≥ 4 Years	20	59	7.7 (7.0)	4.5 (1.0 – 22.0)
Age of Diagnosis				
< 2 Years	24	92	8.0 (8.0)	4.5 (1.0 – 22.0)
Between 2 and 3 Years	159	89	8.3 (7.0)	4.5 (1.0 – 22.0)
≥ 4 Years	61	70	6.3 (6.3)	4.5 (1.0 – 22.0)
Age of Treatment Initiation				
< 2 Years	21	91	7.1 (7.0)	4.5 (1.0 – 22.0)
Between 2 and 3 Years	125	95	7.9 (7.2)	4.5 (1.0 – 22.0)
≥ 4 Years	98	72	7.7 (7.0)	4.5 (1.0 – 22.0)

Table 9.

Linear Regression Predicting Dosage of Early Intervention in Hours per Week

Variables	B	SE B	β	95% CI	
				Lower	Upper
Gender (Male)	.184	1.178	.010	-2.136	2.505
Age (In Years)	.019	.122	.011	-.222	.260
Severity	-.078	.071	-.071	-.218	.063
Comorbidity	-.749	.962	-.051	-2.645	1.147
Maternal Educational Attainment					
(< High School)	-.214	2.274	-.009	-4.695	4.267
(High School)	-.403	1.882	-.025	-4.111	3.305
(Some College Credits)	2.844	2.508	.092	-2.098	7.785
(College Degree)	.084	1.695	.006	-3.256	3.424
Annual Household Income					
(Below Sufficiency Line)	-4.632 ***	1.223	-.303	-7.042	-2.222
(From Sufficiency Line to 100% Above)	-3.795 ***	1.106	-.267	-5.976	-1.615
City of Residence (Major)	-.749	.962	-.051	-2.645	1.147
When Parents Sought Professionals Help	.380	.591	.050	-.785	1.546
Age of Diagnosis	-.744	.464	-.133	-1.659	.170
Age of Treatment Initiation	.390	.391	.084	-.381	1.161

Note. Adjusted $R^2 = .06$. ($F(14, 226) = 2.09$, $p < 0.001$ (* $p < .05$, ** $p < .01$, *** $p < .001$). The

reference group consists of female children without comorbid conditions, of mother with graduate degrees, and who live in non-major cities with a household income 100% above the sufficiency line.

APPENDIX A

استبيان رحلة الأهتمام بالأطفال المشخصين بأضطرابات طيف التوحد من التشخيص الى العلاج في المملكة العربية السعودية الجزء الأول

1. بعض الأسر لديها أكثر من طفل مشخص بالتوحد. كم لديك من طفل مشخص بالتوحد؟
 - طفل واحد
 - طفلان
 - ثلاثة أطفال
 - أربعة أطفال
 - خمس أطفال أو أكثر
2. سوف اكمل هذا الاستبيان عن طفلي المعني بهذه الدراسة
 - أوافق
3. اسم مدرسة التي يدرس بها طفلك _____
4. عمر طفلك _____
5. الجنس
 - ذكر
 - أنثى

6. أجب على العبارات التالية بما يتناسب مع قدرات طفلك الحالية

لا أوافق بشدة	لا أوافق	أوافق	أوافق بشدة	طفلي لا يستخدم الكلمات أو يجد صعوبة في المبادرة بالحديث مع الآخرين
لا أوافق بشدة	لا أوافق	أوافق	أوافق بشدة	طفلي يكمل الروتين دائما بنفس الطريقة
لا أوافق بشدة	لا أوافق	أوافق	أوافق بشدة	طفلي يقلق في الأماكن الجديدة أو المزدحمة
لا أوافق بشدة	لا أوافق	أوافق	أوافق بشدة	طفلي يتحسس من الأضواء، الأصوات، الملامس
لا أوافق بشدة	لا أوافق	أوافق	أوافق بشدة	طفلي لا ينام بسهولة أو نومه متقطع
لا أوافق بشدة	لا أوافق	أوافق	أوافق بشدة	طفلي يضرب أو يعض الآخرين
لا أوافق بشدة	لا أوافق	أوافق	أوافق بشدة	طفلي يتحرك أو يجري أو يقفز بشكل مستمر
لا أوافق بشدة	لا أوافق	أوافق	أوافق بشدة	طفلي يواجه صعوبة في الإنتهاء من المهام الموكلة إليه
لا أوافق بشدة	لا أوافق	أوافق	أوافق بشدة	طفلي يتغير مزاجه/عواطفه بشكل مفاجئ
لا أوافق بشدة	لا أوافق	أوافق	أوافق بشدة	طفلي يأكل أنواع محددة من الطعام
لا أوافق بشدة	لا أوافق	أوافق	أوافق بشدة	طفلي يفضل أن يكون بمفرده أو لديه عدد قليل من الأصدقاء
لا أوافق بشدة	لا أوافق	أوافق	أوافق بشدة	طفلي يهز جسمه أو يرفرف يديه
لا أوافق بشدة	لا أوافق	أوافق	أوافق بشدة	طفلي يضرب أو يقرص أو يعض نفسه

7. ما هي صلة القرابة؟

- أب
- أم
- أخرى (وضح من فضلك)

- كم عمرك؟ _____
- ما هي أعلى درجة علمية لك؟
- a. مرحلة الابتدائية
- b. مرحلة متوسطة
- c. مرحلة ثانوية
- d. دبلوم
- e. بكالوريوس
- f. دراسات عليا

8. مدينة سكن الاسرة _____

9. أعلى درجة علمية للأم

- أمية /غير متعلمة
- مرحلة الابتدائية
- مرحلة متوسطة
- مرحلة ثانوية
- دبلوم
- بكالوريوس
- دراسات عليا

10. عمر الأم؟ _____

11. وظيفة الأم

- لا تعمل
- تعمل بشكل جزئي
- تعمل بشكل كامل) ما هو مسمى الوظيفة
- أخرى (وضح)

12. أعلى درجة علمية للأب

- أمية /غير متعلمة
- مرحلة الابتدائية
- مرحلة متوسطة
- مرحلة ثانوية
- دبلوم
- بكالوريوس
- دراسات عليا

13. عمر الأب؟ _____

14. وظيفة الأب

- لا يعمل
- يعمل بشكل جزئي
- يعمل بشكل كامل

• أخرى (وضح من فضلك) _____

15. ما هي الحالة الاجتماعية لوالدي الطفل؟

- متزوجان
- مطلقان
- أحدهما متوفي

16. هل هناك صلة قرابة بين الأم و الأب؟

- نعم، أقارب من الدرجة الأولى
- نعم، أقارب من الدرجة الثانية
- نعم، أقارب من الدرجة الثالثة
- لا ليس هناك صلة قرابة بين الأم و الأب

17. ما هو مجموع دخل الأسرة الشهري؟

المقصود هنا ليس بالمرتب الشهري، لكن يشمل كل مصادر الدخل المتوفرة، مثل: مجموع المرتب الشهري للوالدين، الأرباح من عمل خاص، الضمان الاجتماعي، نفقة دعم الأطفال، وغيره

- ٤،٩٩٩ ريال سعودي أو أقل
- ما بين ٥٠٠٠ الى ٨٩٩٩ ريال سعودي
- ما بين ٩٠٠٠ الى ١٣٩٩٩ ريال سعودي
- ما بين ١٤٠٠٠ الى ١٧٩٩٩ ريال سعودي
- ما بين ١٨٠٠٠ الى ٢١٩٩٩ ريال سعودي
- ما بين ٢٢٠٠٠ الى ٢٥٩٩٩ ريال سعودي
- ٢٦٠٠٠ ريال سعودي أو أكثر

18. كم كان عمر طفلك عندما بدأت تشعر بالقلق تجاه نموه؟ _____

19. ما هي الأمور التي جعلتك تقلق على طفلك في تلك المرحلة؟

- تأخر في الكلام
- عدم وجود أو محدودية التواصل بصري
- عدم الإستجابة عند مناداته باسمه
- تأخر في المشي
- السلوكيات النمطية وعدم الرغبة في تغيير الروتين أو التعلق بالأشياء
- المشكلات السلوكية
- الأداء الدراسي
- مشكلات صحية
- المشكلات الحسية
- مشكلات النوم
- عدم الاهتمام بالآخرين
- يلعب بطريقة غريبة) مثل: يضع المكعبات بطريقة مستقيمة، يدور عجلة السيارة)
- أخرى (وضح من فضلك) _____

20. كان عمر طفلك عندما بدأت في البحث عن مختص للكشف عليه؟ _____

21. ما هو اختصاص الشخص الذي فحص طفلك تلك المرة؟

- طبيب الأسرة
- طبيب الأطفال
- طبيبي نفسي للأطفال
- أخصائي نفسي
- طبيب أعصاب
- معلم/ة
- ممرض/ة
- أخصائي/ة اجتماعي/ة
- لست متأكد أو لا أعرف
- أخرى (وضح من فضلك) _____

22. مالذي حدث؟

- تم تشخيص طفلي
- التحويل إلى مختص آخر
- عمل فحوصات و اختبارات
- تم إخباري بأن طفلي لا يوجد لديه أي مشكلة
- أخبروني بأن أعود إليهم إذا لم تتحسن حالة طفلي
- أخرى (وضح من فضلك) _____

23. بماذا تم تشخيص طفلك في تلك المرة؟

- التوحد
- اسبرجر
- اضطرابات طيف التوحد
- اضطراب نمائي غير محدد
- اضطراب في اللغة
- تأخر في النمو
- أخرى (وضح من فضلك)

24. بعد ملاحظة النمو الغير الطبيعي للطفل تذهب الأسرة الي طبيب (أو فريق من المختصين) ليتم الكشف على الطفل و من ثم تشخيصه بالتوحد. لكن هناك أسر لا تحصل على تشخيص التوحد لظفهم الا بعد زيارة أكثر من طبيب أو فريق. كم طبيباً أو فريقاً زرت حتى حصل طفلك على تشخيص التوحد؟

- تم تشخيص طفلي بالتوحد بعد زيارة أول مختص أو فريق
- تم تشخيص طفلي بالتوحد مباشرة بعد زيارة ثاني مختص أو فريق
- تم تشخيص طفلي بالتوحد مباشرة بعد زيارة ثالث مختص أو فريق
- تم تشخيص بالتوحد مباشرة بعد زيارة رابع مختص أو فريق
- تم تشخيص طفلي بالتوحد مباشرة بعد زيارة خامس مختص أو فريق
- اضطررت إلى أن أزور أكثر من خمس مختصين إلى أن تم تشخيص طفلي بالتوحد
- أخرى

25. ما هو التشخيص الرسمي الحالي لطفلك؟

- التوحد
- اسبرجر
- طيف التوحد
- اضطراب نمائي غير محدد
- متلازمة ريتز
- أخرى (وضح)

26. كم كان عمر الطفل حينما تم تشخيصه؟

27. ما هي المساعدات الي قدمها لك المختص أو فريق المختصين الذي شخص طفلك بعد الانتهاء من عملية التشخيص؟

حصلت على تقرير يبين مستوى أداء طفلي بما فيها جوانب القوة و جوانب الضعف و يشمل توصيات بالخدمات التي يحتاجها طفلي	نعم	لا	لست متأكد
تم تحويلي لمدرسة تدرب أو تدرس الأطفال المشخصين بالتوحد، أو تم تحويل لطبيب أو مستشفى، أو حصلت على قائمة بالمركز التي تقدم خدمات	نعم	لا	لست متأكد

لست متأكد	لا	نعم	تم تحويل لجهة تقدم معلومات لأسر أطفال ذوي التوحد مثل مجموعات الدعم الأسر، تم تحويلي لجهة تقدم دعم مادي، حصلت على منشورات أو كتب بها معلومات عن التوحد
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28. هل هناك مساعدات أخرى قدمت لك بعد الانتهاء من عملية التشخيص؟

- نعم (وضح من فضلك) _____
- لا

29. ما هو اختصاص الشخص الذي قام بتشخيص طفلك؟

- طبيب أطفال
- طبيب نفسي للأطفال
- أخصائي نفسي
- طبيب أعصاب
- معلمة
- ممرضة
- أخصائي/ة اجتماعي/ة
- لست متأكد أو لا أعرف
- فريق من المختصين
- أخرى (وضح) _____

30. أجب على العبارات التالية بما تراه مناسب

أوافق بشدة	أوافق	محايد	لا أوافق	لا أوافق بشدة	أنا راض عن المعلومات التي تم تقديمها لي خلال عملية التشخيص
أوافق بشدة	أوافق	محايد	لا أوافق	لا أوافق بشدة	أنا راض عن طريقة تعامل المختصين خلال عملية التشخيص
أوافق بشدة	أوافق	محايد	لا أوافق	لا أوافق بشدة	أنا راض عن الدعم الذي قدم لي بعد عملية التشخيص
أوافق بشدة	أوافق	محايد	لا أوافق	لا أوافق بشدة	أنت راض عن عملية التشخيص بشكل عام

31. قد يصاحب تشخيص التوحد التشخيص باضطرابات أخرى .هل تم تشخيص طفلك بأي اضطراب أخرى؟يمكن اختيار أكثر من إجابة

- لا يتم تشخيص طفلي بأي مرض أو اضطراب أخرى
- نعم، الصرع
- نعم، تم تشخيصه باعاقة ذهنية/عقلية
- نعم، تم تشخيصه اضطراب نقص الانتباه وفرط الحركة
- نعم، تم تشخيصه باكتئاب
- نعم، تم تشخيصه لدية الوسواس القهري
- نعم، تم تشخيصه لدية الفصام
- نعم، تم تشخيصه بمتلازمة فراجيل أكس
- نعم، تم تشخيصه باضطرابات أخرى (وضح من فضلك) _____

32. في أي مدينة تم تشخيص طفلك؟ _____

33. كم كان عمر طفلك عندما بدأ بالحصول على خدمات التدخل المبكر؟ (خدمات التدخل المبكر هي التدخلات التدريبية أو التدريسية الخاصة بالتوحد قبل سن المدرسة 7 سنوات يمكن الحصول على هذه الخدمات في المدرسة/المركز أو في المنزل)

- عمر طفلي عندما بدأ في الحصول على الخدمات _____

34. إذا حصل (أو يحصل) طفلك على خدمات التدخل المبكر (التدخلات التدريبية أو التدريسية الخاصة بالتوحد قبل سن المدرسة 7 سنوات)، كم هو عدد ساعات تلك الخدمات في الأسبوع؟ _____

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