

The Needs of Mothers of Children with Autism Spectrum Disorder (ASD) in the Kingdom of Saudi Arabia (KSA): A Qualitative Study

Alyaa Hemdi^{1,2,3} ; David Daley^{1,3,4}

¹Division of Psychiatry & Applied Psychology, School of Medicine, University of Nottingham, UK

²Special Education department, Institute of Educational Graduate Studies, King Abdulaziz University, Saudi Arabia.

³Institute of Mental Health, University of Nottingham, UK

⁴Theme lead for Neurodevelopmental Disorders, NIHR MindTech Healthcare Technology Cooperative, Institute of Mental Health, University of Nottingham, UK.

Abstract: The purpose of this qualitative study was to explore the unmet needs and experiences of mothers of ASD children in The Kingdom of Saudi Arabia (KSA). This study employed telephone interviews with eight Saudi mothers raising a child with autism. Questions from a researcher-developed interview guide elicited responses about challenges and unmet needs. Results indicated that the majority of respondents felt they had low to no knowledge of ASD prior to and after their child's diagnosis. Six themes were identified: i) Mothers' identification of their lack of information about their children with ASD, ii) Mother's perceptions about their mental and physical well-being, iii) Mothers' recognition of their constant challenges raising children with ASD, iv) Suggestions to increase public awareness about ASD, v) Mothers' identification of their training needs, and vi) Mothers' perceptions of their children's educational needs. Respondents insisted that cultural issues such as lack of transportation and fathers' involvement did add to their burden. This study recommended that professionals and academics in KSA should take into consideration the unmet needs of mothers of ASD children when designing interventions and services for children with ASD to ensure they are tailored to the cultural context and needs of mothers.

Keywords: Autism Spectrum Disorder, ASD, Kingdom of Saudi Arabia, Mothers, Needs.

Introduction

Autism spectrum disorder (ASD) is a term used for a group of neurodevelopmental disorders that are characterised by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviours [1]. Autism statistics from the U.S. *Centre for Disease Control and Prevention* (CDC) identify around 1 in 68 American children as having ASD [2]. According to the latest statistics from the King Abdulaziz City for Science and Technology, the prevalence rate of ASD among children in the Kingdom of Saudi Arabia (KSA) is one in every 180 [3].

Research has revealed that raising a child with ASD is a unique challenge for parents due to the nature of the disorder [4]. There is a lack of clarity about the most effective treatment options for ASD [5]. Uncertainty about the causes of ASD also adds to the challenges facing parents of children with autism [6]. Each person with ASD is unique and has different demands. Each of the behaviours associated with ASD may range from mild to severe. There is no biological or medical test for ASD; a diagnosis is only made through a thorough evaluation by a team of professionals.

Families with autistic children face many challenges because of the care demands and behavioural problems associated with the disorder. Having a child with autism in the family may have adverse affects on various domains of family life including marital relationship, sibling relationships and family routines [7].

In their study about ASD in developing countries, Samadi and McConkey [8] argue that research about parenting children with ASD “has been limited largely to families in Western countries” and that “research is needed to identify the particular needs of families in non-western countries” (p. 1). There is a gap in the literature on studies exploring the needs of mothers of children with ASD in KSA. Therefore, the goal of this study was to identify the unmet needs of mothers of children recently diagnosed with ASD in KSA. A multitude of information is available in the literature with regards to parenting experiences of mothers of children with ASD, mostly based on American and European samples. However, little is known about these experiences for mothers of children newly diagnosed with ASD in KSA. This study would thus not be similar to theses from other parts of the world due to the unique characteristics of each community. In Iran, for example, limited number of materials are published in Persian language for parents of children with ASD [8]. Therefore, parents in Iran receive information about ASD through other parents due to their “inability, or limited ability, in English Language: which makes international sources of information inaccessible for them” [8].

The traditional role of Saudi mothers involves taking complete care of their children, while the fathers take care of providing financial support for their families. Therefore, most fathers have an inactive role in the care of their children with ASD. This may enhance the care burden for mothers. As no current evidence is available to inform research about the unmet needs and issues of Saudi mothers parenting their children with ASD, it was important to explore these needs within the cultural context of KSA.

1.1 Objectives

The main objective of this study was to identify what mothers of children with ASD in KSA want and need to be able to support their children.

The second objective of this study was to examine the perspectives of mothers of children with ASD in KSA regarding the optimal support and services they expect to be provided following the diagnosis of their children.

Methods

2.1 Study Design

A qualitative design was identified as the most appropriate way to meet the research aim of exploring the unmet needs of mothers of children with ASD in KSA. This study utilised semi-structured telephone interviews with eight mothers of children with ASD in KSA. The interview schedule was designed using open-ended questions to give the participants the opportunity to explain their needs and difficulties dealing with their children following the diagnosis. The interview schedule covered four main areas including: participants’ experiences of having a child diagnosed with ASD; their unmet needs as mothers of children with ASD in KSA; their child’s behaviours and how they cope with it; and their concerns and hope for the future of their children. Interviews were conducted in Arabic, the mother tongue language of people in KSA. The first author is bilingual in both Arabic and English.

2.2 Data Collection

With the approval of the Faculty of Medicine Ethics committee at the University of Nottingham in the UK and the approval of the Ethics committee at King Abdulaziz University in KSA, study information sheets and consent forms were distributed by the collaborating ASD organisation to all mothers of children recently diagnosed with ASD (within a year) and whose children were still in the waiting list to be accepted into day care services. Those mothers who consented to participate in the study were asked to sign the consent forms. Once consent forms were collected, the researcher arranged a convenient time with each mother to be interviewed about their experiences of parenting their children with ASD and their unmet needs and concerns following their children’s diagnosis. Seven interviews were digitally recorded with the agreement of the respondents. However, one of the participants requested that her interview not be recorded, and therefore extensive notes were taken

during that interview. It is very common in studies conducted in Arab countries and within female communities in particular that participants do not accept the use of technology including recorders during interviews [9]. Each interview lasted approximately 30 minutes. The researcher transcribed all the transcripts into Arabic and sent copies to participants to ensure the accuracy of transcription. All except two mothers responded that the researcher had accurately interpreted what they had said.

2.3 Participants

A purposeful sampling method was employed by the researcher to select the participants on the basis of "what cases they can learn the most from" [10]. It was thought that interviewing mothers whose children had just been diagnosed with ASD would help elicit the required information.

The term *data saturation* refers to the criteria widely used in qualitative research for assessing the suitability of the sample size to address the study's aims. According to Strauss and Corbin [11], data saturation refers to the point when no new or relevant data seems to emerge regarding a theme. Data saturation was achieved in this study after six interviews, after which no new themes or subthemes emerged. Participants were recruited through a local voluntary support organisation that provides a variety of support services for families of children with ASD as well as educational services for the children.

Interviews were conducted with eight mothers who agreed to participate in the study. The demographic characteristics of the interviewed mothers are presented in

Table . All mothers in this sample were married and their educational levels vary from less than high school to bachelor degree with the majority of them being high school graduates. The mothers' mean age was (M=28.5) years, with their child's mean age being (M= 42.75) months. Only two mothers in this sample were employed (25%

Table 1. Demographic Characteristics of Participants

Participant's ID	Age (years)	Child's age (months)	Number of children	Educational level	Working status	Interview length (minutes)
P1	28	36	2	High school	No	25.53
P2	33	48	2	Bachelor	Yes	29.50
P3	23	40	3	High school	No	22.07
P4	29	36	3	High school	No	39.27
P5	35	48	2	High school	Yes	20.28
P6	29	48	4	Less than high school	No	47.57
P7	26	36	2	High school	No	23.41
P8	25	50	2	High school	No	33.38

2.4 Data Analysis

The method used to analyse the data collected in this study's interviews was *thematic analysis*. It "involves the search for and identification of common threads that extends throughout an entire interview or set of interviews" [12]. The analysis followed the six stages to thematic analysis proposed by [13].

The researcher used an inductive analysis approach to code relevant data and to identify emergent themes and subthemes. The interviews were transcribed verbatim and then transcripts were re-read several times after which the preliminary codes were assigned to the data. The codes, which were assigned to segments of data with similar ideas, were refined in order to better depict the data. These codes eventually become categories that helped in the identification of the various themes and subthemes, which was then used to report the results of the qualitative study [14]. Moreover, once themes and subthemes were established, a codebook was developed to describe each theme according to the guidelines by Boyatzis [15]. Participants were given an identification number based on the order in which they were interviewed so that, for example, the participant interviewed first, received the ID P1. Long extracts from the data were used under the description of each theme and subtheme. The interview length varied between approximately 20 minutes and 47 minutes, with a mean interview length of approximately 30.12 minutes. To enhance the credibility of the data, the consistency of the themes' identification between the researchers were explored. Two interview scripts were back translated into English and given to the second author to identify themes and subthemes using the codebook and a discussion with the researcher. The extent of agreement between the researchers was calculated using a percentage agreement index formula (agreements divided by agreements plus disagreements and multiplied by 100). The percentage agreement between the two coders was established at 87.5%, indicating that the themes were consistent and reliable to a recommended standard.

2.5 Trustworthiness

Trustworthiness in qualitative research refers to the quality and rigor in conducting research and reporting data through ensuring credibility, dependability, and transferability [16]. Credibility was ensured in this study through different procedures. First, the researcher spent intensive periods of time engaging with the data before conducting data analysis, which led to a clear understanding of the participants' opinions and answers. Second, negative cases were identified when creating the codebook which allows the readers to get a hint of the differences between what belongs to the theme and what does not. Third, transcripts of the interviews were sent to the participants for validation to ensure that the researcher did not misinterpret what was said, a criteria termed by Lincoln and Guba [17] as *member check*. Fourth, a reflexive statement about the role of the researcher in the study has been described in detail. Fifth, *analyst triangulation* as a method of ensuring credibility was employed in this study as two English versions of the interview transcripts were read in details by the second author to check for the accuracy of the assigned codes, themes, and subthemes. Finally, the credibility of the findings in this study was checked through *peer examination*, in which a volunteer medical student, who was bilingual in Arabic and English, voluntarily read two transcripts in Arabic to check for the consistency of the identification of themes and subthemes between him and the researcher. He was able to identify all the main themes in both transcripts; however, he could not clearly identify some subthemes in one of the transcripts. The percentage agreement between the researcher and the medical student was established at 81.25%, indicating that the themes were consistent and reliable to a recommended standard.

Dependability refers to the extent that a given study can be replicated to attain similar results [10]. The first author of this study digitally-recorded seven interviews. She then carefully transcribed them and when reporting the findings, included extracts from the participants' replies to verify the themes and subthemes.

2.6 Reflexive Statement

The first author is a female postgraduate student who has completed her undergraduate education in KSA followed by a postgraduate (Master) in Canada. She is married and a mother of two children. Prior to starting her PhD, she was working as an academic lecturer for two years and part of her job involved

supervising graduate students during their training at autism organisations. The researcher introduced herself to the participants at the beginning of the interview. The researcher tried to be objective and not let any of her feelings affect her interpretation of the data. It should be noted that being a mother and living in the same country (KSA) could have impacted the participants to talk freely about their needs and challenges raising their children with ASD.

Findings

Six broad themes emerged from the interviews, along with subthemes (Table).

Table 2. Themes and subthemes

Themes	Subthemes
Mothers' identification of their lack of information about their children with ASD)) Insufficient information about ASD Inconsistent diagnosis for children with ASD
Mother's perceptions about their mental and physical well-being)) Understanding their well-being and the need for help Wanting their own time
Mothers' recognition of their constant challenges raising children with ASD)) Lack of support and assistance The stigma associated with having a child with ASD
Suggestions to increase public awareness about ASD	
Mothers' identification of their training needs)) Managing behaviour problems Removing barriers to engagement
Mothers' perceptions of their children's educational needs)) Need for ASD organisations with quality services The inclusion of children with ASD in general classroom education

3.1 Mothers' Identification of their Lack of Information about Children with ASD

This theme captured mothers' expressing their lack of information about ASD and its causes, diagnostic process, and treatment options.

3.1.1 Insufficient information about ASD

Mothers felt that they lacked sufficient information about ASD and its aetiology and that they needed to understand the disorder. P2 described that "a mother needs someone to explain to her what is ASD, how does ASD affect her child and her relationship with him, she needs to know what she can do to be able to communicate with him, it is never enough to tell the mother that her child is autistic, nobody ever told me what ASD is all about". All the mothers in this study indicated that they did not understand the meaning of ASD and that they were not aware of the possible causes and treatment options. Some of them thought that it was a curable disease and not a permanent developmental disability. Five of the participants indicated that their children did not suffer from ASD but rather according to P3 "a touch of autism".

Mothers described relying on searching the Internet and learning from other mothers' experiences to find out about treatment options for children with ASD, physicians who diagnosed their children, and how to deal with their children. P1, who was looking for treatment options for her son after his diagnosis, noted that "when I was searching the net, I was not able to find scientific information as most of the stuff there were regular things, I mean unclear and non-scientific information about ASD". Some mothers mentioned that they felt that seeking information about ASD from other mothers who have children with

ASD did give them a better understanding of their children's conditions and how to deal with difficulties related to its symptoms. P3 noted

I did not have enough time to attend training and I did not want to put my child in special care because his case is mild and it was only a few behaviours that I needed to modify at the time, therefore, I decided to learn from other mothers' previous experiences and I followed all their advice blindly. (P3)

3.1.2 Inconsistent diagnosis for children with ASD

The participants in this study highlighted their feelings of confusion during the process of their children's diagnosis. They expressed that the journey to receive an official diagnosis for their child's condition was misleading as they received multiple diagnosis of their children's conditions. P2 said that

I received three different diagnoses for my child. One doctor told me that he has mild autism, another doctor told me that he has moderate autism, and a third doctor told me that he only has mental retardation and therefore I decided to take him to X hospital and I told them that we have three different diagnoses for the child and they evaluated him and we are waiting for their report. (P2)

3.2 Mother's Perceptions about their Mental and Physical Well-being

This theme captured the participant's thoughts about their unmet mental and physical needs, which according to them need to be addressed by government and professionals in the field.

3.2.1 Understanding their well-being and the need for help

Participants in this study acknowledged their poor psychological well-being after the diagnosis of their children. They felt that the diagnosis of their children had cause the majority of them to be depressed, stressed, and anxious most of the time. When the mother receives the news that her child has ASD, she needs psychological and emotional support, which means she needs a Psychiatrist or a social worker to help her calm down and tell her not to have fear and that having that child is not the end of this world. (P2)

Mothers also expressed their need for counselling services. They explained how they needed somebody to listen to them and give them advice. P4 discussed that "It's very good to find someone who asks about you. We have many problems here and many problems related to the children being harassed, but no one knows and no one cares. It's good to ask and care about us".

3.2.2 Wanting their own time

All the participants felt that they wanted their own time when they can relax and not worry about taking care of their children with ASD. P7 noted "my situation is really difficult as I am a full time student and I only come back home in the evening, I need time to relax". Mothers discussed that although some private organisations are starting to provide full day care for children with ASD, however, they insisted that "they are costly" (P2). P5 mentioned that she needs "time to socialize and go to parties", which was not possible according to her as nobody will be there to take care of her child.

3.3 Mothers' Identification of their Training Needs

This theme explained mothers' opinions about the need for training that they felt was necessary for them as mothers of children with ASD.

3.3.1 Managing behaviour problems

All the mothers in this study expressed their need for training to help them manage their children's behaviour problems. P1 mentioned "there was a time when my son used to hit me very badly that sometime I want to cry, now he is better but I noticed that he is starting to hit his younger sister and I need a solution".

3.3.2 Removing barriers to engagement

Mothers described that they felt many issues had prevented them from participating in training. The high cost of workshops is one issue expressed by mothers that prevent them from attending the necessary training. Another issue is transportation difficulties as mothers had to find a male who would take them to attend the training. P4 noted that transportation is one of the major obstacles preventing her from attending training because "my husbands' work is so far and it took him two hours to go to his work and other two hours to come back. This means 18 hours outside the home". Therefore, most of the participants preferred to undergo training using the android application called WhatsApp.

3.4 Mothers' Perceptions of their Children's Educational Needs

All the mothers in this study have acknowledged the importance of education and training for their children with ASD. This theme reflected the mothers' opinions about the educational needs of their children.

3.4.1 The need of ASD organisations with quality services

Mothers felt that it is extremely essential for their children to be placed in ASD organisations that provide quality services. According to them, the long waiting lists and shortage of qualified staff at these organisations have prevented their children from receiving the interventions necessary for their development and skills' acquisition. P1 said that we wanted our son to join the autism organisation but they told us to come after Hajj [one month] but when we went back after Hajj they told us that they are overbooked and you can leave your name and number and if there is a space we will call you and since then we were waiting and I do not know where to go or which organisation. (P1)

Mothers felt that there is a shortage of qualified ASD staff within nurseries in the country and that day care settings rarely have qualified professionals who know how to deal with children with ASD. P6 stated that My eldest son went to school but the teacher didn't continue with him. She told us that she teaches the whole class and can't show him everything separately. So the best place for him to learn is XXX autism Centre. (P6)

3.4.2 The inclusion of children with ASD in the general classroom education

Mothers felt that it is a necessity to include their children with ASD in the regular classroom as some of the children have mild ASD symptoms and would be able to perform well in the regular class with the assistance of the teachers. P1 mentioned that "I want my child to learn and join the regular classroom; I knew he is not normal but he is smart and can understand things so why would they not give him the chance".

3.5 Mothers' Recognition of their Constant Challenges Raising their Children with ASD

This theme highlighted mothers' concession of their constant demands and challenges raising their children with ASD.

3.5.1 Lack of support and assistance

All the mothers in this study repeatedly cited the lack of assistance as one of their biggest concerns. They reported that they are the parent responsible for daily childcare of their children with ASD, while fathers work outside the homes to earn income. They insisted that even when fathers were at home, they rarely looked after their children. P4 described her life It is like I was living alone in a separate world that has only me and my son. Even my husband, I was living away from him. He usually leaves me at home and goes to visit his relatives and friends and only comes back home to sleep. I'm lonely with my son. No one with is with us. (P4)

Mothers also mentioned their need for a maid to look after their children so that they can find time to do other things. Some mothers insisted on the importance of having a maid who is specifically trained to take care of children with ASD. P1 noted that

I wanted a nurse or a maid who understands my son and has a strong background with these matters [ASD symptoms] because I have another daughter who needs my attention and needs me to stay with her. Nobody else knows how to take care of him, even his father does not know about him, I wish I could have a maid or a nurse. (P1)

3.5.2 The stigma associated with having a child with ASD

Mothers expressed that they felt stigmatised as a result of their children's disability. According to some mothers, it was very hard going outside the home with their children because people in public places are annoyed by their children's behaviour. Therefore, mothers reported being isolated as a result of having a child with ASD. Moreover, some mothers indicated that they did hide their children's disability from family and friends because according to P3 "I did not accept having a child with ASD from the beginning and I was really annoyed so I decided that nobody will know except me and my husband and when people ask me why my child is not normal I tell them that he has a touch of autism and not full autism".

3.6 Suggestions to Increase Public Awareness about ASD

This theme focused on mothers' suggestions regarding the importance of increasing society's awareness about ASD. Some mothers highlighted the importance of public lectures about ASD as well as the provision of easy to read materials and manuals to educate the public about ASD and how to deal with children with ASD. P3 explained that "the mother is shocked by the news of having ASD child and there is nobody to advise her, especially as not all people know about ASD, therefore, I wish there was more information available for mothers such as guides and manuals". Moreover, one mother noted that it is essential to teach children in regular classrooms about ASD and its symptoms so that the public becomes more aware about autism and the people affected by it. P6 explained that Autism should be taught in schools' curriculums and there should be subjects on these cases so that the whole community, schools, hospitals and people, knows about it. The same way people study English and computer in schools, they should study these cases so that when they grow up and see these cases in malls or streets, they don't call them crazy. Mothers and fathers feel ashamed and don't go out more often; consequently children get isolated because of low social communication. P6

Discussion

This study explored the unmet needs of mothers of children with ASD in KSA. The findings of this study revealed many of these mothers' needs which were reflected in the six main themes and 10 subthemes (Table 2). Mothers' identification of their lack of information about ASD aetiology, causes, symptoms, and treatment options is one of the major concerns for all the mothers in this study. The same finding was found by [18-20] who acknowledged the need for clear information about the nature of ASD for parents of children with ASD for. The diagnosis process of children with ASD was reported by mothers to be lengthy and complicated, with no clear diagnostic process to follow in hospitals and clinics. Most parents in KSA seek diagnosis for their children with ASD from psychiatrists, but each clinic uses different measures and diagnostic tools and there is no clear guidelines for clinics to follow during the diagnosis process, therefore, parents usually get different diagnosis for their children with ASD when they seek a second opinion, such as mental retardation, pervasive developmental disorder, and mild or severe autism. This finding is consistent with the findings of other studies in which parents reported the diagnostic process to be complicated and confusing for parents of children with ASD [21, 22].

There is a wealth of information available online for parents of children with ASD. However, most of the available information is in Arabic, not scientifically based, and consists mainly of websites or articles written by the general public. The findings of this study revealed that mothers in KSA rely on information on the Internet to help understand their children and deal with their problem behaviours. Thus, it is an important for autism related service providers and academics in the field to publish useful information based on evidenced research [23]. This study also revealed that mothers are looking for treatment and cures for their children as a result of their lack of sufficient information about ASD. They did not realise that ASD is an incurable neurodevelopment disability. Weiss, Fiske [24] observed that "this understandable desire for a 'cure' leaves many vulnerable and susceptible to the appeal of treatments that are based solely on hearsay, anecdotal evidence, and biased report" (p.33). The same finding was replicated by Lin, Tsai [25] who found that parents of children with ASD are always looking for cure for their children. The findings of this study revealed that many mothers in KSA get information and support from other mothers of children with ASD.

Contrary to the findings of this study, Alqahtani [26] found that parents of children with ASD in KSA often choose informal intervention and treatments such as diet intervention containing gluten-casein-free, however, this study revealed that parents do not usually rely on informal treatment as it is expensive and not reliable and they instead prefer to seek behavioural and educational interventions.

Another major concern for mothers in the findings of this study was their perceptions about their own mental and physical well-being, which includes their need for psychiatric intervention, counselling, and full time child care to help them relax and have their own time. Many mothers insisted on their needs for psychiatric treatment after the diagnosis of their children. According to Gupta and Singhal [27], parents experience periods of depression and self-blame, which makes it necessary for them to get psychiatric intervention. Mothers in KSA do not usually get referrals for psychiatric or counselling therapy after the diagnosis of their children. Only those mothers who can afford to pay for private clinics would be able to access such service. This study also highlighted the mothers' needs for training in dealing with their children's behaviour problems as one of the major complaints was their uncertainty about how to deal with their children's behaviours in different situations. This is consistent with the findings of the review by McConachie and Diggle [28], in which parent trainings for parents of children with ASD were found to enhance parents' communication skills with their children and also their knowledge about their children's behaviour.

The mothers' perceptions about their children's educational needs, is a major concern discussed by the participants in this study. This is in contrast to what Alqahtani [26] found that parents of children with ASD in KSA were not concerned about the educational and behavioural interventions for their children. Speech therapy is the most valued form of therapy for Saudi mothers [26]. According to the mothers in this study, this is because they noticed improvements in their children's language through therapy, and the lack of language development is one of the first signs a mother usually notices in her toddler who eventually gets an ASD diagnosis. Some autism organisations in KSA provide speech therapy sessions for children with ASD on an outer clinic basis so that even children who are in the waiting list can start speech therapy sessions soon after their diagnosis. This study highlighted the unavailability of qualified professionals who works in ASD organisations. In accordance with this study, Alqahtani [26] found that parents of children with ASD in KSA did suffer from trying to find full time organisations for their children as well as shortage of well-trained people who works in these organisations.

Mothers' recognition of their lack of assistance and support is another major finding of this study. Mothers of children with ASD in KSA suffer from the heavy load of care giving for their children, as they are considered to be the main care provider for the home and the children as well, while the fathers are responsible for providing the family's income. This is consistent with Bilgin and Kucuk [29] according to which "maternal roles include more responsibility of a child with disability than paternal roles" (p2). Altieri and von Kluge [30] highlighted the lack of support from surrounding family to parents of children with ASD. This study also found that mothers of children with ASD felt that they were not receiving support from their family and some of the families blamed the mothers for having more children. Mothers in this study reported their need for respite and a time for themselves due to the constant burden of care giving. They insisted that it is difficult to find a reliable person to look after their children and many mothers wished they could have a maid or nurse trained to help them in the care of their children. House maids are very common in Saudi culture [26], however, these days, it has become expensive to have a house maid due to new policies established by the Ministry of Labour and a consequent increase in salaries. Therefore, it is not affordable for each family to have a maid. Gray [31] explained that "Because of social stigma, there is a lot of discrimination not only of the autistic child but also of the family as a whole" (p3). This study also suggests that more materials should be designed and made available to the public in KSA about the nature of ASD and how to deal with children with ASD.

4.1 Limitations of this Study

First, it is important to acknowledge that the interviews were conducted with only a small sample of Saudi mothers of children with ASD, all from one voluntary organisation in the country. Therefore, the findings may be unique and only representative of this region. However, the sample number is usually small in qualitative studies as the main aim is to gain more in depth insights from the target population about the studied topic.

Conclusion

Mothers of children with ASD in KSA face multiple challenges and difficulties caring for their children due to the demands of the child with ASD and the cultural issues related to their surroundings and social life. This study contributed to the literature on parenting children with ASD in the Saudi culture as well as to Saudi literature about the unmet needs of mothers of children recently diagnosed with ASD. The findings of this study will help professionals address the main issues facing mothers. Academics might use the findings of this study to help in the design of a parenting intervention that can take into consideration the mothers' needs.

References

- [1] American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders: Dsm-5*. 2013: Amer Psychiatric Pub Incorporated.
- [2] Centres for Disease Control and Prevention, *CDC estimates 1 in 68 children has been identified with Autism Spectrum Disorder* 2014.
- [3] Salman, S., *A study revealing the prevalence rate of autism in Saudi Arabia*, in *Asharq Al-Awsat news* 2011.
- [4] McCubbin, H.I. and J.M. Patterson, *The Family Stress Process*. Marriage & Family Review, 1983. **6**(1-2): p. 7-37.
- [5] Howlin, P., *Practitioner review: psychological and educational treatments for autism*. Journal of child psychology and psychiatry, and allied disciplines 1998. **39**(3): p. 307-22.
- [6] Dale, E., A. Jahoda, and F. Knott, *Mothers' attributions following their child's diagnosis of autistic spectrum disorder: exploring links with maternal levels of stress, depression and expectations about their child's future*. Autism, 2006. **10**(5): p. 463-79.
- [7] Greeff, P.A. and K.-J. Walt, *Resilience in Families with an Autistic Child*. Education and Training in Autism and Developmental Disabilities, 2010. **45**(3): p. 347-355.
- [8] Samadi, S.A. and R. McConkey, *Autism in developing countries: lessons from iran*. Autism research and treatment, 2011. **2011**: p. 145359-145359.
- [9] Opdenakker, R., *Advantages and Disadvantages of Four Interview Techniques in Qualitative Research*. Forum Qualitative Social Research, 2006. **7**(4).
- [10] Patton, M.Q., *Qualitative Research & Evaluation Methods*. 2002: SAGE Publications.
- [11] Strauss, A. and J. Corbin, *Basics of qualitative research: Techniques and procedures for developing grounded theory, 2nd ed.* 1998, Thousand Oaks, CA, US: Sage Publications, Inc. xiii, 312.
- [12] Field, P.A. and J.M. Morse, *Nursing Research: The Application of Qualitative Approaches*. 1985: Croom Helm.
- [13] Braun, V. and V. Clarke, *Using thematic analysis in psychology*. Qualitative Research in Psychology, 2006. **3**(2): p. 77-101.
- [14] Pope, C., S. Ziebland, and N. Mays, *Analysing qualitative data*. BMJ, 2000. **320**(7227): p. 114-116.
- [15] Boyatzis, R.E., *Transforming Qualitative Information: Thematic Analysis and Code Development*. 1998: SAGE Publications.
- [16] Miles, M.B. and A.M. Huberman, *Qualitative Data Analysis: An Expanded Sourcebook*. 1994: SAGE Publications.
- [17] Lincoln, Y.S. and E.G. Guba, *Judging the quality of case study reports*. The qualitative researcher's companion, 2002: p. 205-215.
- [18] Kapp, L. and O. Brown, *Resilience in Families Adapting to Autism Spectrum Disorder*. Journal of Psychology in Africa, 2011. **21**(3): p. 459-463.
- [19] Kuhaneck, H.M., et al., *A Qualitative Study of Coping in Mothers of Children with an Autism Spectrum Disorder*. Physical & Occupational Therapy In Pediatrics 2010. **30**(4): p. 340-350.
- [20] O'Brien, M., *Ambiguous Loss in Families of Children With Autism Spectrum Disorders**. Family Relations, 2007. **56**(2): p. 135-146.
- [21] Hutton, A.M. and S.L. Caron, *Experiences of Families With Children With Autism in Rural New England*. Focus on Autism and Other Developmental Disabilities, 2005. **20**(3): p. 180-189.
- [22] Osborne, L.A. and P. Reed, *Parents' perceptions of communication with professionals during the diagnosis of autism*. Autism, 2008. **12**(3): p. 309-24.
- [23] Elder, J.H. and T. D'Alessandro, *Supporting families of children with autism spectrum disorders: questions parents ask and what nurses need to know*. Pediatr Nurs, 2009. **35**(4): p. 240-5, 253.
- [24] Weiss, M.J., K. Fiske, and S. Ferraioli, *2 - Evidence-Based Practice for Autism Spectrum Disorders*, in *Clinical Assessment and Intervention for Autism Spectrum Disorders*, J.L. Matson, Editor. 2008, Academic Press: San Diego. p. 33-63.
- [25] Lin, C.R., Y.F. Tsai, and H.L. Chang, *Coping mechanisms of parents of children recently diagnosed with autism in Taiwan: a qualitative study*. Journal of clinical nursing 2008. **17**(20): p. 2733-40.
- [26] Alqahtani, M.M., *Understanding Autism in Saudi Arabia: A Qualitative Analysis of the Community and Cultural Context*. Journal of Pediatric Neurology, 2012. **10**.
- [27] Gupta, A. and N. Singhal, *Psychosocial support for families of children with Autism*. Asia Pacific Disability Rehabilitation Journal, 2005. **16**(2).
- [28] McConachie, H. and T. Diggle, *Parent implemented early intervention for young children with autism spectrum disorder: a systematic review*. Journal of Evaluation in Clinical Practice, 2007. **13**(1): p. 120-129.
- [29] Bilgin, H. and L. Kucuk, *Raising an autistic child: perspectives from Turkish mothers*. Journal of child and adolescent psychiatric nursing : official publication of the Association of Child and Adolescent Psychiatric Nurses, Inc, 2010. **23**(2): p. 92-9.
- [30] Altieri, M.J. and S. von Kluge, *Searching for acceptance: Challenges encountered while raising a child with autism*. Journal of Intellectual and Developmental Disability, 2009. **34**(2): p. 142-152.
- [31] Gray, D., *Coping over time: The parents of children with autism*. Journal of Intellectual Disability Research, 2006. **50**(12): p. 970-976.

