



EXPERIENCES OF MOTHERS IN DEALING WITH STIGMA RELATED TO THEIR CHILDREN WITH AUTISM SPECTRUM DISORDER IN THE SAUDI CONTEXT

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Abstract

It remains unknown to what extent mothers of children with Autism Spectrum Disorder (ASD) are stigmatized. Children with ASD require special care to increase their attention and master the necessary motor and behavioural skills. In most society, particularly Middle East and Africa, mothers are largely the care providers for children while their partners concentrate on financial provision. Therefore, mothers experience a lot of challenges and stigma from some partners, family members, and the society. This qualitative phenomenological research examined the experiences of 15 mothers regarding the stigma associated with their children autism in Jeddah, Saudi Arabia. The research examined mothers' beliefs about the positive and negative roles that culture, education, and health institutions play in this regard. Five broad themes emerged from the analysis: mothers' concerns; reactions to the child's diagnosis; difficulties obtaining an ASD diagnosis; difficulty accessing resources; and cultural stigma (people's reactions). The researcher explored the themes and challenges of ASD through literature review and field Research (interviews). Findings showed the need to change structural and societal approaches toward ASD to share the burden among all stakeholders alleviating pressure on mothers.

Keywords: children with ASD, cultural stigma, mothers' stigmatization, mothers experience, society positive roles, society negative roles

Introduction

Autism Spectrum Disorder (ASD) and the issue of stigma in the context of the Kingdom of Saudi Arabia (KSA) is an area of interest because of knowledge and research gaps. In Saudi Arabia, people with ASD are still stigmatized, as are people with other disabilities. This research explored how mothers of children with ASD in Saudi Arabia perceive the stigma they encounter following their child's diagnosis of ASD. ASD stigmatization affects all parents, family members, and society; however, mothers bear a greater burden because of their connection and constant care for the child from birth; hence, their experience is different. Furthermore, mothers are preferred as the participants because the scope of the research, time limit, and financial constraints cannot allow an exhaustive exploration of all the family members. Thus, mothers are the best representation of the ASD problem in a family setting. In KSA and some parts of the developing world, ASD is considered unacceptable and stigmatized because people view disability as an abnormality (Brosnan & Gavin, 2021). It is also viewed stereotypically, with people holding entrenched opinions about ASD.

ASD is a series of developmental stages characterized by disorders in three areas: repetitive behavioural patterns in communication, problems with social interaction, and activities and interests (Harrop & Kasari, 2015). It is characterized by difficulties using communication for social purposes, an inability to adapt communication output to the context, difficulty following

traditional conversational rules, and problems understanding implicit language as defined by a series of states (APA, 2013). In other words, ASD is associated with verbal and non-verbal social communication deficits and challenges in adhering to communication norms and forming and maintaining relationships (Bonis, 2016). The condition affects individuals' abilities to engage in social and academic activities. Restricted and repetitive behaviour and issues with social communication are the two core problems associated with ASD. The chief issue with repetitive and restrictive behaviour is that it is difficult to establish when to intervene because it is impossible to determine why such behaviours develop or their underlying mechanisms and management.

Parents of children with ASD often experience high levels of stress. Research by Bonis (2016) revealed a connection between parental stress and ASD. The results showed that parents of children with ASD suffer from high levels of stress and depression compared to parents of children without disabilities. This stress is attributable to the challenges that parents experience when trying to understand their children's behaviour and communication challenges. Compared with other parents, parents of children diagnosed with ASD are more likely to experience depression, confusion, and denial after their child's diagnosis of autism (Bashir et al., 2014; Bonis, 2016; Brei et al., 2015; DePape & Lindsay, 2015). Bonis (2016) outlined the challenges parents encounter when accessing ASD services. High-stress levels make it difficult for parents to care for their children adequately, and parents report increased financial burdens, marital problems, and stigma. Bonis (2016) explained that parents need access to stress management support groups and educational programmes to help them manage their emotions. Existing studies have concentrated on the stigma parents with ASD children undergo. However, the role of parenting differs in KSA; thus, it is relevant to explore mothers' experiences because of inconclusive findings, research, and knowledge gaps.

Purpose

The research aimed to find opinions and perspectives on mothers' stigmatization because of their children with ASD in KSA, particularly in the Jeddah area. They were completing this research with a complete knowledge gap about mothers' experiences and dealing with ASD-associated stigma.

Research Questions (RQ)

RQ is essential for guiding and narrowing research content to the project's purpose and most significant aspects. The following RQs were applicable.

1. How do mothers with ASD children deal with the stigmatization of the condition in KSA?
2. How does the culture propagate mothers' stigmatization because of their ASD children?
3. How has education affected attitudes to and awareness of their children's conditions?

Research Justification

In a patriarchal society, men earn more money than women, even in families where both parents work. Furthermore, women are expected to continue to play a traditional role at home, even if they are also active members of the workforce. In a relationship where both parents work, the woman will be responsible for caring for the children and ensuring that the husband's needs are met. She thus needs to balance two full-time jobs. For her, family responsibility is more important than anything else. In such a society, women must take care of their children

and meet their needs. The man provides help and support, but he does not have to actively monitor the needs of children, including those with ASD.

An examination of the Saudi context clearly shows that mothers feel guiltier and fear that their children may be stigmatized because of their ASD diagnosis. In a culture where many mothers struggle with the social stigma associated with the birth of a child with special needs, much work still needs to be done to examine institutions and their role in reducing the stigma experienced by these mothers. By examining mothers' experiences of stigmatization, this research; therefore, sheds light on how cultural issues shape the experiences of mothers, as well as the institutional role that various institutions play in helping mothers to cope with the problems associated with this stigmatization of children who have been diagnosed with ASD.

Literature Review

A large and growing body of literature has examined the stress experienced by parents when raising children with ASD. Researchers agree that parents of children with ASD exhibit higher stress levels than other parents (Bonis, 2016; Brei et al., 2015; DePape & Lindsay, 2015; Miranda et al., 2015). Some studies have found that parents of children diagnosed with ASD experience high-stress levels. Raising children with autism is more taxing for parents than parenting a child without disabilities, as children with autism have a wide range of learning and developmental issues (Kinnear et al., 2016). Parents who experience physical and psychological stress are likely to find it challenging to prepare meals, help children with their homework, and fulfil their responsibilities, thus leading to parent-child conflicts (Kinnear et al., 2016). Researchers assert that disagreement between children and parents promotes the development of stressful situations in parents raising children with ASD.

Such tension can harm parenting, managing tantrums, and marital relationships. Parents need access to classes that teach them how to manage their stress to help them cope with their children with ASD. According to Bonis (2016), the importance of support groups for parents of children with ASD. Early diagnosis of ASD makes it easier to access the services and support groups that can improve the quality of life for children with ASD and their families. According to Bartholomew (2016), stigma is a Greek term initially referring to a mark cut or burned into the skin. Since the precise meaning of specific terms may vary from one society to another, the term stigma has a variety of definitions and interpretations. Commonly, however, it refers to a belief or an attitude that leads individuals to reject, fear, or avoid those they deem different (Liamputtong, 2013; Link & Phelan, 2011). Generally, a stigma is not a pre-existing characteristic but rather a linguistic affiliation that allows attributes to be associated with a particular stereotype.

Society tends to divide people into groups based on the characteristics they share. According to Link and Phelan (2001), stigma has four related components: those who decide and tend to label human variations; associating labelled individuals with particular detrimental characteristics; placing adversely labelled individuals or groups in discrete and isolated groupings from the non-stigmatized; and labelled individuals experiencing a loss of status. Identity can include professional roles, physical activities, and the self, and anything that changes one of these identities is considered a negative social stigma (Cronin & Mandich, 2015). There is also a stigma associated with people diagnosed with ASD, as some parents are apprehensive about how other people, especially the general public, perceive their child's health (Kinnear et al., 2016). In this regard, parents of children diagnosed with ASD may develop low self-esteem due to their child's condition.

Parents of children with high-functioning ASD must cope with the demands of raising a child with a disability and the social consequences of the disability (Bonis, 2016). According to Gray (2002), having ASD does not mean a lower IQ or poor verbal skills and does not nec-

essarily involve schooling away from mainstream settings. However, children with ASD have difficulty forming and maintaining relationships and have uneven intellectual and cognitive functioning. One of the leading causes of the difficulty children with ASD face in social relations is that they are stigmatized by society. Numerous researchers agree that parents of children with disabilities experience stigma because their children are stigmatized (Bonis, 2016; Brei et al., 2015; DePape & Lindsay, 2015; Kinnear et al., 2016). Parents of children with ASD often have limited options for reducing the adverse reactions of society toward their children. Many studies have explored the stigma experienced by parents on social occasions or in the presence of their children (Bonis, 2016; Brei et al., 2015; DePape & Lindsay, 2015; Miranda et al., 2015). Parents of children with ASD face the same stigma as people with ASD.

Gray (2002) examined the difference between felt and staged stigma. Parents experience feelings of shame and embarrassment when they believe that others are criticizing them. On the other hand, when people avoid their parents, children face stigma. Gray found that many parents experience stigma and that parents experiencing stigma were less likely to have experienced it in the past. There was a significant spike in parents experiencing enacted stigma right after their child exhibited behaviour associated with ASD, and many children with ASD have been bullied or mistreated. However, the author found that both felt and enacted stigma exists and considerably affects parents. One of the findings was that mothers experience high levels of stigma compared to fathers and that the level of the presenting symptoms of ASD affected the level of stigma experienced by parents. Those whose children were more violent or aggressive experienced enacted stigma, unlike the parents whose children were passive. Evidence suggests that parents of children with ASD experience stigma associated with their child's diagnosis. While there have been some improvements in understanding stigma, these have not been explored in depth. Interviews by Gray (2002) indicate that most parents attribute stigma to different manifestations of similar negative experiences.

Research Context

While most people in Saudi Arabia know ASD is a neurological disorder, there is considerable confusion about its causes. Because the Saudi Arabian government and the Department of Special Education provide special education services, it is essential to promote awareness of this disorder widely. Awareness will ensure that more students with ASD receive tailored educational support and that their mothers receive the help they require (Alzaalah et al., 2015). In a research study on the relationship between autism and cultural context in the Saudi community, Alqahtani (2012) found that parents attributed the causes of their children's ASD to medical, psychological, and cultural factors. The suggested medical causes of autism include problems during pregnancy, vaccinations, and vitamin deficiencies. It has also been suggested that psychological problems associated with early childhood trauma due to the death of one or both parents may cause ASD. Some parents believe that the evil eye and black magic have led their children to develop ASD.

A survey of 367 Saudi citizens by Alman et al. (2017) found that most Saudis have heard of ASD and have some knowledge of it. Their findings indicate that the Saudi community pays little attention to the organic causes of this disorder because they believe it is simply a psychiatric problem. Many people believe that there are religious explanations for pregnancy complications that result in ASD. Most people believe that children with ASD can overcome this condition with appropriate intervention. There is a 6% chance that a child will be diagnosed with ASD in Saudi Arabia. Of these children, ASD is diagnosed in 42 out of every 1,000 boys and 189 out of every 1,000 girls. Most children in Saudi Arabia with ASD are diagnosed before age five (Alzaalah et al., 2015). There is a connection between ASD and the parents' age, with older parents being more likely to have a child with ASD. A child psychiatrist diagnoses speech

delay in children. In addition to behavioural and pharmacological therapies, speech interventions are among the most widely used therapeutic interventions in treating children with ASD in Saudi Arabia (Alzaalah et al., 2015).

Whatever the cause of ASD, parents, especially mothers, have often been burdened with guilty feelings associated with their children's disorders, fearing they were the ones who had contributed to their children's diagnosis of ASD. Despite disagreement about the causes of ASD, the most common interventions used by parents to treat autism are cultural or informal, such as reading Quran verses or seeking help from religious healers. Treating the source of symptoms rather than the symptoms themselves is often preferred (Alqahtani, 2012). Alqahtani (2012) found that no parents reported using essential therapies focusing on behavioural, educational, or developmental interventions. Zeina et al. (2014) reiterate that fear of cultural stigma related to disability means that some mothers remain reluctant to seek help for their children with ASD. Some researchers have commented on the situation of women in the KSA, noting their status as caregivers and frequent lack of paid employment (Basaffar et al., 2016). It is essential to recognize the inequalities within the country and the importance of fixed gender roles for both men and women domestically.

Research Methodology

General Background

This research explored the experiences of individual mothers whose children had been diagnosed with ASD and were stigmatized in a Saudi context. The research focuses on the challenges associated with ASD in a patriarchal society, where mothers are the primary caregivers of children diagnosed with ASD. A phenomenological approach was used to understand the data collected during interviews with Saudi mothers whose children were diagnosed with ASD. The phenomenological approach focused on highlighting individual participants' experiences of specific phenomena. The use of a phenomenological approach was appropriate because this research focused on how mothers experience stigma directed toward their children with ASD. Rather than focusing on what these mothers experience, the phenomenological approach focuses on how their experience matters and highlights their unique experiences (Vagle, 2014). The methods are designed so that the results are trustworthy and can contribute to understanding how the Saudi cultural context affects mothers' experiences of stigma as a result of having children with ASD.

Sample Selection

The researcher recruited 15 mothers in Jeddah, Saudi Arabia, with children diagnosed with ASD. In patriarchal societies such as Saudi Arabia, women are more likely to have family responsibilities than to be in paid employment (Basaffar et al., 2016). Because of their role as caregivers, mothers are more likely to experience stigma related to their child's condition. For example, children with ASD may yell in public, ignoring the impact of their actions on the people around them.

The participants were selected based on the following criteria: mothers of children with ASD; in the age range of 22-42 years; and children in the age range of five to 12. The mothers were recruited after the university's Institutional Review Board permitted the use of human subjects. After the administration had approved the research, details were sent to three different groups on WhatsApp, and only individuals who met the criteria were invited to participate. Communication was used to clarify the risks and benefits of the research to parents. After a series of interactions, a group meeting was planned to explain the project's specific details to

potential participants and provide them with details regarding the meeting's time, venue, and agenda. After the potential participants had been confirmed, the research team contacted them to arrange individual interviews. Individual contact was made to determine participants' schedules and to make arrangements to meet them on a one-on-one basis to conduct the interviews.

The demographic data for 15 mothers is shown in Table 1.

Table 1
Demographic Data of Mothers and Their Children Diagnosed with Autism

Participant	Mother's Age	Level of Education	Occupation	Gender of the child	Age of the Child
Mother 1	33 years	High school	Kindergarten Teacher	Boy	6 years
Mother 2	26 years	High school	Stay at home mother	Boy	5 years
Mother 3	26 years	Bachelor's degree in art	Elementary Teacher	Boy	7 years
Mother 4	24 years	Bachelor's degree in Arabic language	Stay at home mother	Boy	5 years
Mother 5	42 years	Bachelor's degree in science	High school Lab-teacher	Boy	10 years
Mother 6	25 years	Bachelor's degree in history	Stay at home mother	Boy	6 years
Mother 7	27 years	Bachelor's degree religious studies	Elementary Teacher	Boy	5 years
Mother 8	30 years	High school	Hairdresser	Boy	7 years
Mother 9	31 years	Bachelor's degree in art	High school teacher	Girl	8 years
Mother 10	29 years	Master's degree in accounting	Bank manager	Boy	7 years
Mother 11	22 years	Senior in history	Undergraduate student	Girl	6 years
Mother 12	38 years	Bachelor's degree in physics	Middle School teacher	Boy	8 years
Mother 13	41 years	High school	Stay at home mother	Boy	12 years
Mother 14	35 years	Bachelor's degree in science	High school teacher	Boy	10 years
Mother 15	23 years	Bachelor's degree in maths	Elementary teacher	Boy	7 years

A representation of the relationships between the themes and subthemes of the data is presented in Figure 1 below.

Instrument and Procedures

The researcher adopted interviews as the preferred instrument for data collection because they give in-depth information to help generate concepts and themes. Interviewees give their opinions and experiences, which are required for exploring the problem under investigation. Before the start of the interviews, the participants gave their consent to participate in the interview and for it to be recorded. The interviews were held in a local café to ensure the participants' comfort and lasted between 25 and 45 minutes. To ensure the accuracy of their responses, interviews with participants were audio-recorded. After each interview was completed, notes were taken, and the interviews were carefully transcribed as quickly as possible, using additional memos while the information was fresh.

Data Analysis

A phenomenological approach was used to analyse data from interviews with mothers in a Saudi context who have a child with ASD to understand their experiences and highlight the stigma experienced by these women. The analysis was completed using van Kaam's phenomenological data analysis method, which includes listing and preliminary grouping or levelling, reduction and elimination, analysis of invariant components, clustering, and theming (Sumskis & Moxham, 2017). The steps are followed by finalizing the invariant components and themes through the application and constructing a structural description of the personal experience for each co-researcher according to the individual structure description of each co-researcher (Sumskis & Moxham, 2017). Furthermore, it entails imagining changes to construct an individual structural description of the experience and then constructing a textural-structural description of the meanings and essences of the experience, incorporating the invariant constituents and themes for each participant (Sumskis & Moxham, 2017). Finally, from the individual textural-structural descriptions, a composite description of the meanings and essences of the experience was developed, representing the group as a whole.

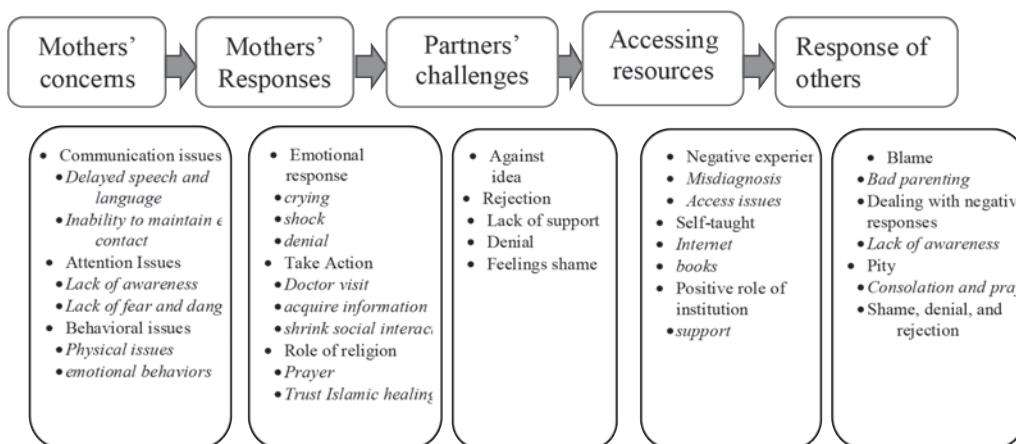
Researchers are careful in conducting their analysis when transcribing, organizing, and interpreting data. This research, in addition to the steps listed above, relied on the methods of epoché, phenomenological restoration, imaginary variation, and synthesis to collect and organize the emerging themes. A rigorous method of data analysis known as the analyst triangulation method was used to ensure the reliability and validity of this research. The co-reader was an education professor trained in quantitative and qualitative methods. Throughout the data analysis, parallel analysis was conducted, and the researchers met regularly to discuss the interpretation and understanding of the results.

Co-readers worked together to ensure that vocabulary was used accurately to describe the experiences of the mothers studied. When analysing the data, the transcriptions and translations were carefully examined, with attention given to unique phrases that explain how participants experienced particular phenomena (Creswell, 2016). The mothers' data were analysed using a modification of the van Kaam method for the analysis of phenomenological data. The process of data levelling was carried out through a review of the mothers' verbatim interview records. Epoché was used during the subsequent reading and reflections, respectively. The remaining list became the horizon for the mothers' experience of stigma. The immutable components from the mothers' data were organized from each transcript and clustered into new thematic groups. Some repetitive and distracting wording and irrelevant data were eliminated.

Research Results

Interview findings were opinions expressed in different patterns and phrases depending on the level of education and interpretation of the questions. Therefore, thematic analysis of the common responses led to five themes with respective subthemes. Figure 1 presents the themes and subthemes.

Figure 1
Invariant Constituents Organized by Theme and Subtheme



The five themes included: mothers' concerns, mothers' responses, partners' challenges, accessing resources, and the responses of others. Table 2 provides a list of the five themes and mothers' descriptions of their lived experiences that are represented by each theme.

Table 2
Themes and Descriptions of Saudi Mothers' Lived Experiences Related to Stigma Associated with having Children Diagnosed with Autism

Theme	Description
Mothers' Concerns	<ul style="list-style-type: none"> Delayed speech Not communicating Crying No eye contact Excessive movement Lack of focus Lack of fear
Mothers' Responses	<ul style="list-style-type: none"> Beating himself Not scared of anything Short attention span Not interacting with others Bad temper Spinning in circles Not responding to his/her name
Partners' challenges	<ul style="list-style-type: none"> Isolation Depressing/Helpless Attending conferences Searching for information Meeting different doctors Joined a group Defending their child Shrinking social interactions Relying on Allah
Accessing resources	<ul style="list-style-type: none"> Against idea Rejection Lack of support Denial Feelings shame
Response of others	<ul style="list-style-type: none"> Blame <ul style="list-style-type: none"> Bad parenting Dealing with negative responses <ul style="list-style-type: none"> Lack of awareness Pity <ul style="list-style-type: none"> Consolation and prayer Shame, denial, and rejection

Partners' Challenges	Against idea Rejection/ Feeling shame	Lack of support Denial
Accessing Resources	Negative experiences Lack of reliable resources Limited resources Expensive	Misdiagnosis Book and internet Educational games Support/Providing guidance
Responses of Others	Blaming the mother Bad parenting Dealing with disrespect Negative responses Rejection	Lack of awareness Responding with pity Prayers and soft words Feeling ashamed Denial

The 15 mothers in Saudi Arabia described their experiences of stigma directed toward their children with ASD. Their experiences are described in the following sections and are organized by categories from the themes that emerged from the data.

In presenting the findings, it is essential to describe the coding used. To facilitate the horizontalization of mothers' statements in the interview transcripts, M1 indicates statements from mother number 1. The number next to the "M" indicates the numbered horizon in the transcripts. When a statement made by M1-1 is presented, it indicates the horizon's location in the interview with the mother. The M1-1 statement, therefore, indicates that the statement was made by mother number 1 and was the first horizon gleaned from her interview. This numbering system was used with all the mothers. This system makes it easier for others to examine the transcripts and verify the claims made.

The mothers reported that some individuals attributed their children's erratic behaviour to poor parenting, and when the mothers were blamed, they often felt guilty. Their children were sometimes disrespected when people called them retarded, or weird or accused them of being disrespectful of social norms. Mothers indicated that many individuals offered prayers to help their families deal with challenges. Although one of the mothers did not face difficult situations where she was blamed or disrespected, she was mainly "unhappy with the feeling of pity that others directed" (M4-33) at her.

The negative responses of some fathers also contributed to the stigma. Some mothers found dealing with their husbands' denial of their children's conditions challenging. Mother 10 explained, "My husband completely refused to let me take him to any centres or even diagnoses him" (M10-19). Additionally, some fathers ignored their responsibilities regarding caring for their children, even though they needed significant support. The shame that some mothers experienced also contributed to isolation. The mothers often attributed their experiences to the lack of others' awareness.

The findings show that mothers encountered shock, sadness, and denial when dealing with their children's condition. Mother 8 explained, "my husband and I became extremely sad and cried when we figured out that he has autism. We were shocked because he is our first child." (M8-6). Many mothers experienced stress when dealing with their children's diagnosis, consistent with the experiences reported in the literature. Additionally, the research found that parents of children with ASD experienced depression, confusion, and denial. However, when mothers started seeking help for their children, their initial negative responses changed. The mothers reported that until there is greater awareness of this condition, they would continue experiencing stigma by association.

Mothers were primarily concerned about their children's communication skills, inattention, and behavioural issues. Of the 15 mothers interviewed, 12 were concerned about their children's poor communication and non-verbal communication skills. For example, mother 1 argued that she was primarily concerned with "delayed speech and language" (M1-6). Other

mothers were concerned about their children's lack of attention since this could put them in danger. Mother 2 described this point clearly when she explained that her child seemed as if "he was not aware of things around him as if he did not hear them. He was not even aware of danger" (M2-2). Seven of the 15 mothers interviewed were concerned that their children's inability to develop proper behaviour impedes their social and emotional development. Mother 5 asserted that she was concerned because her son would "strangely move his head, spinning fast, and engage in excessive movement" (M5-2).

The mothers indicated that they used the Internet to help them learn about and cope with their children's diagnoses. Mother 10 emphasized this when she said, "I read a lot of articles from Google, and I watched a lot of videos on YouTube about this disorder." (M10-7). The Internet allowed them to learn more about their children's condition and connect with virtual friends dealing with the same issue. The findings indicate that some mothers relied on their faith to help cope with their children's diagnosis and as a means of healing. Faith also guided them to behave appropriately regarding their children's diagnosis. Their reliance on Allah stemmed from believing their faith could help provide the needed answers. Mother 12 emphasized that "the effect of trusting God is a miracle. I believe in leaving it to God and trusting him and praying. Keeping that connection with God is the solution." (M12-41). This finding supports Alqahtani's (2012) finding that the most common interventions used by parents to treat ASD were cultural and other informal interventions, such as reading Quranic verses (p. 19).

Some mothers reported having had negative experiences with specialized institutions. They reported that the diagnoses they received were confusing and ultimately inaccurate, which led them to lose trust in some institutions. Additionally, after consulting various institutions and specialists, there were problems with contradictory diagnoses, which mothers attributed to a lack of standard regulations and guidelines. Mother 4 clarified this point when she stated, "I went to hospitals to get him checked, and I went to centres for a diagnosis. However, I received different contradicting diagnoses." (M4-11).

Some mothers also had issues with access, having been rejected for services due to the institutions' lack of preparedness to accommodate children with disabilities. Mother 3 explained how she did not have access to many public institutions, and they did not accept her child due to his condition. She stated, "Many public schools do not accept his condition because they are not qualified to have any child with disabilities." (M3-16).

The findings indicate that institutions supported mothers. Through the centres, some mothers established contact with other women who provided advice and shared their experiences. Additionally, some institutions provided informative workshops and lectures, teaching mothers more about their children's condition. Specialists in the centres also provided mothers with exceptional guidance on essential resources. Mother 15 explained, "I received some guidance from the specialized centres, and after that, my husband and I decided that these centres would benefit our child." (M15-22).

Medical and learning institutions helped mothers find people to talk to about their children's condition. Many mothers praised their doctors, indicating that they guided them to explore different beneficial resources. The connections mothers established with other women were productive. The knowledge that mothers gained was often helpful in a culture where individuals often misunderstood the condition. Mother 15 explained, "I went to all the workshops, shared my experiences with other mothers, and tried to learn from their experiences. I got to meet many parents who have a child with a disability. Honestly, I learned a lot from these workshops and lectures." (M5-20). Mothers with this new knowledge could explain their children's conditions to questioning family members who often blamed them for the erratic behaviours of their children. Not only did the centres provide initial guidance, but some continue to provide long-term helpful support to some mothers.

Discussion

The findings provided insights into how mothers react to the social stigma directed at them when their children are diagnosed with ASD. It also presents the social, cultural, and perceived roles of specialized agencies in Saudi Arabia, as well as the experiences and concerns of the Saudi people. The data were collected and analysed from different age groups of mothers to offer a complete picture of their experiences. The research was open to all mothers, regardless of their children's gender or severity of their condition, as long as their children were between the ages of five and 12 since gender and the severity of ASD was not the focus of this research.

The process of imagining various possibilities was used to make sense of anything not explicitly stated by the participants. By engaging in imaginative variation, the researcher moves beyond the facts to arrive at different possible underlying meanings behind participant stories (Messick, 1995). After listening, translating, reading, and rereading these mothers' stories, such a process facilitated the attempt to break down the data into different themes and sub-themes. The researcher must try to understand what the person is saying and then figure out their hidden meaning, a creative process accomplished through variation. None of the mothers used the term "stigma" to describe the reactions they faced. However, their isolation was motivated by the denials spoken of by some and the embarrassment brought about by the condition. The tendency to seek evacuation was understood as a form of stigma. After carefully analysing the transcripts from each interview, five major themes were identified and validated; these described individual mothers' experiences of the stigma directed toward their children.

The results of this research collaborated with previous researchers' findings; hence, it is viable and can be replicated with the same outcome. The differences in mothers' stigmatization were associated with many external factors and implications. This outcome confirms what earlier researchers had indicated. According to Mash and Wolfe (2010), the reactions of parents and the impact of their child's diagnosis vary depending on their work environment, family setting, and level of education. Educated people may react to societal challenges differently. Cultural, economic, and social experiences are changed by education (Mash & Wolfe, 2010). In this research, mothers responded differently regarding the stigma associated with having a child with ASD in the Saudi context. Therefore, the influence of mothers' professions and education was considered in this research to provide insight into how mothers managed the challenges they faced due to their children's conditions. Another objective of the research was to examine how education affected attitudes to and awareness of their children's conditions.

Research findings showed that many mothers depend on doctors' diagnosis to know the condition of their ASD children. Unfortunately, fewer mothers seek doctor services or consultation earlier enough. This delayed medical consultation leaves many mothers and families unaware of their children's conditions and continue to experience stigmatization associated with the condition. This realization conforms to what earlier researchers had discovered. According to Alzaalah et al. (2015), most people in KSA consider children with ASD are more of a curse, not a medical condition; thus, they seek spiritual interventions. Awareness of this condition will help mothers attain tailored intervention and reduce mother's stigmatization (Alzaalah et al., 2015). Alman et al.'s (2017) study showed that many are aware of the condition but pay little attention because they consider it a psychiatric problem.

Research findings showed that support systems mothers have had are helpful in reducing stigmatization. They will help to demystify and debunk misconceptions linked to ASD stigmatization and foster better intervention strategies. The stigmatization is associated with negative responses mothers get from their husbands, family members, and the community. They all agree that dealing with negative vibes from their loved ones make it harder to handle the situation better. Apart from the stigmatization, mothers were affected by delayed communication capability, inattention, and behavioural challenges of their children. As much

as they tried to rely on religious beliefs and sought spiritual healing, they came to understand that ASD is a medical condition that requires healthcare intervention, and they are exonerated from blame and guilt. They should seek support system and continue to engage with various stakeholders to abolish stigmatization through awareness and sensitization campaigns.

Conclusions and Implications

This research found that many mothers had negative attitudes toward their children's condition and felt overwhelming sadness when they found their child had ASD. Although learning more about the disability helped many people feel comfortable, many still struggled with the social stigma. While many people have found that specialized institutions can be helpful in understanding and dealing with children with ASD, much more needs to be done to increase public understanding and empathy toward those with ASD. The mothers' experiences show that much needs to be done to improve the quality of services for people with ASD in Saudi Arabia. The lack of a clear policy structure about who can diagnose autism and how that diagnosis should be made makes it difficult for mothers of children with ASD to obtain an appropriate diagnosis. Many mothers said that some of the public facilities they visited offered very little support, which can be a problem for people with disabilities, for example, the availability of skilled workers.

In the context of Saudi Arabia, policymakers should be encouraged to establish clear guidelines to ensure correct diagnosis for people with disabilities, using standards similar to those used in other countries. The mothers' experiences in this research suggest that those making the diagnosis did not have the necessary skills and were not specialists. Some mothers had to rely on their family doctor to diagnose their children. These findings support strong recommendations that institutions must take this matter seriously and make many structural changes to provide the services these children and their families need. A key policy priority should therefore be to accommodate all people with disabilities and provide them with long-term care, including those diagnosed with ASD in Saudi Arabia. The implication is that the research increase awareness of the need for institutional and cultural changes to alleviate mothers from stigmatization due to ASD children. ASD is a public and societal health burden that all stakeholders must address.

Declaration of Interest

The authors declare no competing interest.

References

- Almana, Y., Alghamdi, A., & Laila, A. A. (2017). Autism knowledge among the public in Saudi Arabia. *International Journal of Academic Scientific Research*, 5(1), 198-206. <https://www.ijasrjournal.org/wp-content/uploads/2017/03/MS52XX-17.pdf>
- Alqahtani, M. (2012). Understanding autism in Saudi Arabia: A qualitative analysis of the community and cultural context. *Journal of Pediatric Neurology*, 10(1), 15-22. <https://doi.org/10.3233/JPN-2012-0527>
- Alzaalah, M. A., Alasmari, A. H., Almalki, H. H., Ashehri, N. M., & Almoalwi, N. M. (2015). Characteristics of autism spectrum disorder among Saudi children and its impact on their families. *The Medical Journal of Cairo University*, 83(2), 239-244. <https://www.medicaljournalofcairouniversity.net/images/pdf/2015/December/34.pdf>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th Ed.). American Psychiatric Publishing.

- Bartholomew, E. L. K. (2016). *Planning health promotion programs: An intervention mapping approach*. Jossey-Bass & Pfeiffer Imprints, Wiley.
- Basaffar, A. A., Niehm, L. S., & Bosselman, R. (2018). Saudi Arabian women in entrepreneurship: Challenges, opportunities, and potential. *Journal of Developmental Entrepreneurship*, 23(02), Article 1850013. <https://doi.org/10.1142/S1084946718500139>
- Bashir, A., Bashir, U., Lone, A., & Ahmad, Z. (2014). Challenges faced by families of autistic children. *International Journal of Interdisciplinary Research and Innovations*, 2(1), 64-68. <http://ikefoundationforautism.org/e-library/Challenges%20Faced%20by%20families%20of%20Autistic%20Children-153.pdf>
- Bonis, S. (2016). Stress and parents of children with autism: A review of literature. *Issues in Mental Health Nursing*, 37(3), 153-163. <https://doi.org/10.3109/01612840.2015.1116030>
- Brei, N., Schwarz, G., & Klein-Tasman, B. (2015). Predictors of parenting stress in children referred for an autism spectrum disorder diagnostic evaluation. *Journal of Developmental and Physical Disabilities*, 27(5), 617-635. <https://doi.org/10.1007/s10882-015-9439-z>
- Brosnan, M., & Gavin, J. (2021). The impact of stigma, autism label and wording on the perceived desirability of the online dating profiles of men on the autism spectrum. *Journal of Autism and Developmental Disorders*, 1-9. <https://doi.org/10.1007/s10803-020-04830-8>
- Creswell, J. W., & Poth, C. N. (2016). *Qualitative inquiry and research design: Choosing among five approaches*. Sage publications.
- Cronin, A., & Mandich, M. B. (2015). *Human development and performance throughout the life span*. Cengage Learning.
- DePape, A. M., & Lindsay, S. (2015). Parents' experiences of caring for a child with autism spectrum disorder. *Qualitative Health Research*, 25(4), 569-583. <https://doi.org/10.1177/1049732314552455>
- Gray, D. (2002). Everybody just freezes, Everybody is just embarrassed: Felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health & Illness*, 24(6), 734-749. <https://doi.org/10.1111/1467-9566.00316>
- Harrop, C., & Kasari, C. (2015). *Learning when to treat repetitive behaviors in autism*. Spectrum. <https://spectrumnews.org/opinion/viewpoint/learning-when-to-treat-repetitive-behaviors-in-autism>
- Kinnear, S. H., Link, B. G., Ballan, M. S., & Fischbach, R. L. (2016). Understanding the experience of stigma for parents of children with autism spectrum disorder and the role stigma plays in families' lives. *Journal of Autism and Developmental Disorders*, 46(3), 942-953. <https://doi.org/10.1007/s10803-015-2637-9>
- Liamputtong, P. (2013). *Stigma, discrimination and living with HIV/AIDS: A cross-cultural perspective*. Springer.
- Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, 27(1), 363-385. <https://doi.org/10.1146/annurev.soc.27.1.363>
- Mash, E., & Wolfe, D. (2010). *Abnormal child psychology* (4th Ed.). Wadsworth.
- Messick, S. (1995). Validity of psychological assessment: Validation of inferences from persons' responses and performances as scientific inquiry into score meaning. *American Psychologist*, 50(9), 741-749. <https://doi.org/10.1037/0003-066X.50.9.741>
- Miranda, A., Tárraga, R., Fernández, M. I., Colomer, C., & Pastor, G. (2015). Parenting stress in families of children with autism spectrum disorder and ADHD. *Exceptional Children*, 82(1), 81-95. <https://doi.org/10.1177/0014402915585479>
- Sumskis, S., & Moxham, L. J. (2017). The use of van Kaam's psychophenomenological method to interpret the meaning of resilience in the experiences of people with schizophrenia. *Nurse Researcher (2014+)*, 25(3), 8-13. <https://doi.org/10.7748/nr.2017.e1514>
- Vagle, M. D. (2014). *Crafting phenomenological research*. Left Coast Press.
- van Manen, M. (1990). *Researching lived experiences: Human science for an action sensitive pedagogy*. Routledge.
- Zeina, R. M., Al-Ayadhi, L., & Bashir, S. (2014). Autism spectrum disorder: Main problem waiting for solution in Kingdom of Saudi Arabia. *International Scholarly and Scientific Research & Innovation*, 8(8), 526-529. <https://doi.org/10.5281/zenodo.1095971>

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