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The purpose of this autoethnography and interpretative phenomenological analysis (IPA) study was to gain a better understanding of the challenges faced by mothers of children with Autism spectrum disorder (ASD) in Saudi Arabia and the strategies they use to address these challenges. In addition, explore the feelings and meanings associated with these challenges and strategies. The study focused on Saudi mothers of children with ASD to align with my lived experience as a researcher and full member of this community. This study used my autoethnography writing as a mother of a child with ASD and online interviews with six Saudi mothers raising a child with ASD.

The study found that mothers and I faced a range of challenges, including dissatisfaction with the services provided to children with ASD, insufficient information, anger because lack of support, feeling lonely and isolated from society, and feelings of fear and worries. However, mothers and I also reported using various coping strategies, including spirituality, social media, and our own knowledge and self-learning are the key to our strength and success.

Keywords: ASD, challenge, strategy, family, Saudi Arabia, mothers

EXAMINING THE CHALLENGES AND STRATEGIES FOR MOTHERS OF CHILDREN WITH ASD IN SAUDI ARABIA THROUGH AN AUTOETHNOGRAPHY AND INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS

by

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TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER I: INTRODUCTION

My Story

I, Mashael, lived most of my life in Saudi Arabia, then recently moved to the United States to further my education. I am the mother of a 16-year-old child with Autism Spectrum Disorder (ASD). His pseudonym is Azoz; he is the second child in my family of three boys and one girl. My oldest son is 17, my third son is 11, and my daughter is six years old. I grew up in a large city in Saudi Arabia. After getting married I moved with my husband to a small city; it was the first time I had been separated from my birth family. After marriage, I lived with my husband and his siblings in their house. My mother-in-law and father-in-law died before our marriage. Azoz's birth was exceedingly difficult compared to his older brother. The birth did not leave physical problems but left me with psychological issues. I suffered from panic attacks for several months after birth, but I did not visit a psychiatrist for fear that people around me would believe I was suffering from insanity. After seven months, I found some information online for relieving psychological pain, such as exercising and eating healthy foods. I used this information and started to feel better.

Six months later, when Azoz was six years old, I noticed that my son was different from his older brother, as he did not respond to his name, did not use his eyes to communicate with those around him, and did not care about the presence of other children. When I talked to my husband, one of my family members, or my husband's family about what I observed about my son, no one listened to me. They said that what I was thinking of was just delusions, that every child was different, and that it was not correct to compare my son with his brother or any other child. In my opinion, this meant no one wanted to understand me. This made me feel frustrated and I preferred solitude and not talking to anyone about my concerns.

My first visit to the pediatrician took place when Azoz was 14 months old. I told the doctor about my fears and doubts, and that I felt my child was abnormal. I told him that he only says "Mama". The doctor looked at my son and gave him a pen. When my son held the pen, the doctor said “Look, your son responds, do not worry”. He also said, “If the child utters a word, he will utter the rest of the words; your son needs only time”. I was not convinced by the doctor’s words. I felt he did not have enough knowledge about my son's issue, so I started searching online for the reason for the appearance of these symptoms in my son. I did not know what ASD was. There was no awareness of this disorder at that time. Thus, I began to complete research online. I read about ASD and found that most of the characteristics of children with ASD applied to my son. I read about ASD online by writing my son’s characteristics in the Google search engine and found that most of the characteristics of children with ASD applied to my son.

I was shocked at the beginning, but I tried to be strong to help my child. I talked with my husband to start searching for a suitable doctor to help us diagnose our son's condition and start the appropriate treatment. However, I was surprised by my husband’s reaction. He refused to accept that his son had ASD. He asked me to hide the issue from the people around us. He told me that if the family knew that we have a child with a disability, they might seek divorce for fear of having other children with disabilities. A person with a disability may negatively affect the marriage prospects of the brothers and sisters as people might think that the disability was inherited. For years I remained silent about my son's condition due to the stigma of having a child with a disability and the fear of divorce. A woman's divorce may affect both the husband’s and wives’ families negatively. Thus, I was feeling stressed and fearful that someone would know about my son's condition.

In 2010, I got a scholarship to study in the United States (U.S.). My son was almost four years old at the time. I was incredibly happy, not only because I would achieve my dream and get my master's degree from a developed country, but because I read that the diagnostic and educational services for children with ASD in the U.S. were provided free and were of high quality. I traveled to U.S. and I did not tell anyone in Saudi Arabia that my son had ASD. When I arrived in the U.S., my husband and I took our son to the family doctor for a diagnosis, the family doctor referred us to an ASD doctor, and the ASD doctor did IQ tests and ASD tests and then told us that our child had ASD. After the diagnosis at age five, my son began receiving special education services at a public school.

I thought that after four years in the U.S., my son would become like a normal child when he returned to Saudi Arabia. After my scholarship ended, I was disappointed as my son was only slightly better. I realized that everyone would know my son had ASD because my son was now eight years old and still did not speak, nor could he perform simple tasks other children his age did, such as using the bathroom, changing his clothes, or even feeding himself. This time though, I felt that I was stronger and more knowledgeable about ASD, as I had earned a master's degree in special education and trained in American schools where there were all levels of disability among different ages of children with ASD. I felt that I would be able to help my son and help build community awareness of ASD in Saudi Arabia. In addition, my husband became more accepting of our son's situation and more aware of ASD through the information he was receiving from Azoz's teachers. He began looking for services that met Azoz's needs and helped him develop and adapt to society. He was also no longer afraid that anyone would know that Azoz had ASD, and this relieved our sense of tension, and we became supportive of each other for the sake of our son.

Unfortunately, when we returned to Saudi Arabia, I was shocked that those around me, instead of helping me, started to blame me and fabricate lies about my family and myself. They said that they searched my family history and found that ASD ran in my family. Some even described me as a bad person and that God had punished me with this child. This made me feel isolated.

At the beginning of 2014, after my return from the United States of America when my son was eight years old, I went to a public school that would provide services for children with ASD, but they refused to accept my son because he still could not use the bathroom independently. But I did not give up and went to the Education Department in my city and explained to them what happened. The workers in the education administration helped me and they contacted the school to accept my son.

In 2018, when Azoz was twelve years old, I received a scholarship from the university I work at to study for a doctorate in special education in the U.S. Now that my family and I live in the U.S., my son is receiving special education services in American schools. For example, my son receives occupational therapy and speech therapy services at school. He can now understand two- or three-word instructions while he used to only understand one-step directions: ‘sit-down’ and ‘stand-up’. He also learned some sign language, for example, he can now ask for ‘more’ using sign language. About three months ago, his teacher started teaching him to use the bathroom using visual supports. While he hasn't mastered toilet training, he's making progress.

Now my son lives with my immediate family and me (i.e., his siblings, my husband, and me). Living with my small family does not worry me because Azoz’s relationship with his siblings is good. They love him very much and accept his differences. In fact, they also help in his care, education, and share some educational games with him to teach him some skills.

However, when I return to Saudi our living situation may change since we plan to live in a separate house from my in-laws' house. Appendix F contains extracts from my autoethnography memoir that I chose to include because they relate to my dissertation findings but are not in my story.

I share this personal story to explain part of my motivation for pursuing this study. My interest in this study was shaped by my personal experiences and the desire to find strategies to help other Saudi mothers of children with ASD face the same challenges I faced. After reading several published studies, I found myself asking what were the challenges and experiences of these mothers? Where did they get the information they needed? How did they face these challenges? To answer these questions, I wanted to hear stories from Saudi mothers living in Saudi who had experience caring for a child with ASD.

Statement of the Problem

Over the past 15 years that I've lived with a child with ASD, I've learned many things about ASD. Among them, ASD is a term used for a group of neurodevelopmental disorders characterized by difficulties in social interaction, difficulties in language communication, and repetitive behaviors (American Psychiatric Association, 2013). Having a child with ASD leads parents to face many challenges that may have negative effects on marital relationships and/or sibling relationships (Papadopoulos, 2021). Also, families of children with ASD often experience feelings of anxiety and guilt, so they need support and help (Catalano et al., 2018).

ASD Knowledge and Supports in Western vs. Middle Eastern Countries

The social conception of children with disabilities remains a huge concern in many countries across the world today. Despite the sensitization and empowerment of individuals with disabilities both academically and economically, many families and societies have held conservative views about individuals with disabilities in their communities. According to Alkhalifah and Aldhalaan (2018), ASD is among the most widespread form of developmental disability with an increased prevalence from 1 per 10,000 individuals in the 1980s to about 1 per 68 persons in 2016 in the world. The ASD estimated prevalence is about 167,000 for any population estimated to have over 28 million people (Alkhalifah & Aldhalaan, 2018). Alenazi and colleagues (2020) state that the Gulf countries (Bahrain, Kuwait, Oman, Qatar, Saudi Arabia, and the United Arab Emirates) have an ASD prevalence of 29 per 1000 persons which is relatively lower compared to the U.S. The lower prevalence of ASD in Gulf countries is likely caused by limited awareness and research on ASD in the Gulf countries (Alenazi et al., 2020). ASD prevalence statistics in Saudi Arabia are not available and researchers believe this is related to the country's limited awareness and research (Alkhalifah & Aldhalaan 2018).

There is a wide range of research related to the challenges facing families of children with ASD in Western countries and how they overcame these challenges (Vernhet et al., 2019). However, there is limited research exploring the challenges facing Saudi families of children with ASD and how they overcame those (Balubaid et al., 2017). Further, the methods developed in Western countries to provide support for people with ASD have significantly improved the health and lives of individuals with ASD.

Over the years, the government of Saudi Arabia, through the education and health sectors, has established several interventions to support children with ASD (Alkhalifah et al, 2018). For instance, the government supports and help to fund different private institutions that provide care for children with ASD. The government also provides specialized education and has established several healthcare centers that specialize in the treatment of ASD. However, individuals with ASD still receive the majority of the care from their family members; thus, their parents face multiple challenges (Al rubiyea, 2010).

Rationale and Overview of this Study

The number of children diagnosed with ASD in Saudi Arabia is increasing, but research on the experiences and challenges faced by families of children with ASD in Saudi Arabia is lacking (Alqahtani, 2012). This study will first discuss the literature examining the challenges and strategies that parents with individuals with ASD face in Saudi Arabia. I will then describe the research study I completed that gave a voice to mothers of children with ASD in Saudi Arabia so that the experiences, challenges, and strategies can be better known and understood. Identifying the main challenges facing mothers with children with ASD in Saudi Arabia and exploring their current strategies to improve these challenges will help researchers and concerned individuals to improve the lives of families in the country. Further, I explored feelings and meanings. The inclusion of feelings and meanings in the study helped to provide a deeper understanding of the challenges faced by mothers of children with ASD in Saudi Arabia. By exploring the emotional and psychological impact of these challenges, the study can provide a more holistic view of the experiences of these mothers. This information also can be used to develop more effective strategies to improve the lives of families of children with ASD affected by the challenges they face. Additionally, by understanding the feelings and meanings associated with the challenges, researchers and stakeholders can better empathize with and support families of children with ASD affected by the challenges.

Brief Review of the Literature

Challenges for Parents of Children with ASD in the United States

Parents of children with ASD often face many problems due to diagnosis and care challenges. According to McAuliffe et al. (2017), a lot of energy and resources are used in caring for such children. Parents of children with ASD report increased anxiety and less energy when caring for a child with ASD. This may lead to family adjustment and communication issues because children with ASD could be antisocial and cannot communicate effectively. For example, Coleman1 et al. (2023) state that children with ASD may have embarrassing behaviors and mannerisms that humiliate parents and caregivers. In addition, some family members maybe distressed in handling these extremities with their children with ASD (Coleman1 et al., 2023). Other parents admit to being frustrated or depressed about their children's communication challenges, especially when they cannot respond appropriately to changing social phenomena. Coleman et al. (2023) further argue that some parents may feel guilty or confused, blaming themselves for believing they never did enough for their children. Some have worries about how their children will cope with life in the future, thus falling into depression.

Strategies for Parents of Children with ASD in the United States

Various interventions have helped parents of children with ASD in the U.S. to cope with the challenges described. According to Vernhet et al. (2019), parents of children with ASD used social support and self-controlling strategies to cope with the challenges. Notably, this was in the form of counseling to help them accept their children as they are and take care of them with effective interventions. Parents also described support groups as a coping strategy for parents of children with ASD to share experiences, resources, and encourage each other (Vernhet et al., 2019). Last, Coleman et al. (2023) state that the parents of children with ASD used emotional-focused strategies to cope with the challenges. For instance, they enrolled in parental counseling sessions to learn to control their emotions. Therefore, therapists helped in proposing solutions and therapy to the parents as a strategy.

Saudi Society Culture and ASD

Saudi culture and traditions may affect parents of children with ASD and increase the challenges they face in Saudi society. Some of the prevailing traditions in Saudi society are marriage traditions, tribal traditions, and Saudi wives being the primary caregivers.

Marriage Traditions. Within the Kingdom of Saudi Arabia (KSA), which practices arranged marriages, there is a tradition of permitting a male cousin to have the first choice to marry an eligible daughter within a family. If the relative chooses not to pursue that arrangement, the daughters' parents extend the search for a suitor to unrelated families. Al rubiyea (2010), who looked at the cultural traditions of marriage within Saudi society, concluded that one often finds marriage between relatives, and especially marriage between cousins, as an accepted practice. From a biological perspective, this is may highly problematic because such marriages have been proven to produce children with an array of health and psychological disorders (Al rubiyea, 2010).

Tribal Characteristics. Along with marriage, Al rubiyea (2010) also considered tribal characteristics in relation to challenges facing mothers and children with disabilities. In KSA most individuals belong to the originally nomadic Bedouin tribe population, from which tribes were organized. Alqahtani, (2012) considered how loyalty and trust informed decision-making for Bedouin families. The researcher found that Bedouin families are more likely to internally care for family members with disabilities instead of sending them to special institutes for their care. A downside of this decision-making, motivated by trust and loyalty, is that many family members do not have the knowledge or experience to provide appropriate care for individuals with disabilities which could result in delayed access to services or misguided support for the child with ASD. Additionally, it is within this context, that parents, especially the mother, who is the primary caregiver in Bedouin tribes, become frustrated by both the lack of knowledge and the absence of support services.

Saudi Wives are the Primary Caregivers. In addition to caring for their children, most Saudi mothers are also charged with caring for members of the extended family. Al rubiyea (2010) explains that the traditional Saudi family consists of a husband, wife, and children, as well as the parents' married children and grandchildren. In addition, this traditional model is grounded in cultural values that also require mutual support for older relatives such as the couple's parents. For example, in the Saudi culture, it is considered shameful to place an elderly parent in a nursing home. The family is also obliged to care for their divorced or widowed daughters and sisters. It is in this context that a cultural irony is present: although the Saudi culture mandates supporting people within the family unit, the family is often left without the resources needed to properly take care of those who are disabled because finances have to extend to such a large family unit. The Saudi mother of a child with ASD cannot sufficiently attend to that child because in big families, where the mother is caring for both the young and old, there is not enough money and resources to support the many members that reside in the home.

Superstition and Folk Beliefs. Because KSA is an Islamic country, religion influences every aspect of daily life, including familial culture. Like many religions, within Islam, there are superstitions and folk beliefs that take shape. Alqahtani (2012) explains that in addition to the official aspects of Islam, there are also a number of unofficial religious and cultural beliefs that contribute to the stress experienced by Saudi mothers of children with ASD. For example, there are many Muslim mothers that believe that black magic, or the “evil eye,” is the cause of their children being born with ASD (Alqahtani, 2012). Families who hold these superstitions often waste time, effort, and money in the treatment of black magic and the evil eye.

Public Communication: Mass and Social Media. AL-zaalah (2015) concluded that one the source of ASD information about ASD in Saudi society is mass media (e.g., Twitter and Facebook) written by people who are not specialists in the field of ASD. These outlets often provide incorrect information (Alqahtani, 2012; AL-zaalah, 2015) and increase the anxiety, fear, and stress of families and their children with ASD in Saudi Arabia. For example, AL-zaalah (2015) found that most of the study sample did not know if there is a medical treatment for ASD, while 21% of parents believed that there is a medical treatment to ASD, and about half of the sample thought that most children with ASD can be completely cured over time. In another study, Alqahtani (2012) found that many parents reported that they believed information they found online stating that some vaccines cause ASD (a widely held misbelief). The study also found that families predominantly relied on cultural and informal interventions, as opposed to medical and behavioral interventions, for their children’s treatment.

Advancing ASD Knowledge in KSA

Although the advancement is slow, there is still the development of better and more accurate diagnosis, education, and awareness of ASD in Saudi Arabia (Al-Towairqi, 2015). Most people outside of the Bedouin tribes are individuals who have migrated to KSA and live in larger urban cities. These families are referred to as “urban families” (Saad, 2019). Saad (2019) found that individuals with ASD whose families belong to the Bedouin tribes have lower literacy rates when compared to individuals with ASD whose families are urban. Bedouin tribe families raise their children with ASD and they prefer not to send their children to centers that specialize in

ASD therapy and care because the family members feel they can raise the child without help (Al rubiyea, 2010). Since urban families are more likely to send their individuals with ASD to centers that specialize in ASD it may explain why they have higher literacy rates and are provided better ASD-related services.

Education and ASD in Saudi Arabia

The educational services provided by the Saudi government are free for Saudi children with ASD. Most of these services are concentrated in the main cities which have a large population (Alamri, 2016). To provide support to families of children with ASD who cannot obtain free education services through governmental schools or centers, the Ministry of Education began to fund in-profit ASD centers. Parents are now able to enroll their children in-profit ASD centers (e.g., centers not run by the government), and the Ministry of Education is responsible for paying the fees (Alnemary, 2017; Aldhalaan, 2017). As an example, there are in-profit ASD schools that provide educational support and services such as speech and language therapy, occupational therapy, behavioral therapy, and social skills training.

Research Centers and ASD in Saudi Arabia

Saudi Arabia's three large research centers focusing on ASD are the King Salman Center for Disability Research (King Salman Center for Disability Research, 1992), King Saud University Autism Research and Treatment Center (ARTC) (King Saud University Autism Research and Treatment Center, 2010), and King Abdulaziz University's Center of Excellence for Autism Research (King Abdulaziz University's Center of Excellence for Autism Research, 2014). Research is carried out at these centers to find causes for ASD, prevention and treatments. In addition, these centers develop effective treatments for children with ASD and provide diagnostic and intervention services for individuals with ASD and their families. In Riyadh (the capital city of Saudi Arabia), there is also an ASD Society (ASD Society, 1991) that raises awareness about ASD and provides support to individuals with ASD and their families. These research centers and the ASD Society are funded and supported by the Saudi government.

It's important to note that in Saudi Arabia, all private schools, clinics, and in-profit ASD centers, are tightly controlled by the government and must abide by the government's laws and Saudi Arabia's cultural and religious values. This includes adhering to the government's regulations and standards for education and healthcare. The Saudi government takes a role in regulating private schools, clinics, and centers to ensure that they provide high-quality care that meets the needs of their patients and clients. For example, private schools in Saudi Arabia must follow the Ministry of Education's regulations for curriculum, teacher qualifications, and school facilities. Similarly, private clinics and centers must adhere to the Ministry of Health's healthcare and medical practice standards.

The Child with ASD Guardianship Law in Saudi Arabia

The child with ASD guardianship law in Saudi Arabia is based on Islamic Sharia law, which gives the father legal guardianship over his children (Alnemary, 2017). This means that all legal procedures related to the child with ASD are not completed without the father's consent. This includes any services, interventions, or obtaining the monthly salary for the child with ASD. Also, in cases of divorce, the father will typically be granted custody of the children unless he is deemed unfit by the court. However, in cases where the father is deceased or incapacitated, the mother can be appointed as the guardian (Alqahtani, 2012). It's important to note that while the law gives the father legal guardianship, it also places an obligation on him to provide for and protect his children.

Purpose of the Study and Research Questions

We know about ASD definitions, diagnoses, interventions, and education for children with ASD in Saudi Arabia, but little is known about the lived experiences of Saudi parents of children with ASD. The purpose of this autoethnography and interpretative phenomenological analysis (IPA) study is to gain a better understanding of the challenges faced by families of children with ASD in Saudi Arabia and the strategies to address these challenges. In addition, explore the feelings and meanings associated with these challenges and strategies.

The Saudi literature contains lived experiences of parents of children with ASD and the challenges that they faced (Khan, 2020), but limited research reports on strategies they used to overcome these challenges (Balubaid et al., 2017). This is a topic that parents and workers in the ASD field will greatly benefit from learning more about. A greater understanding of these issues will also be important as the upward trend in diagnosis continues. Parents need guidance from reliable formal and informal sources on ways to manage their lives so they can focus on their children's development. The following research questions will guide this study: (1a) How do Saudi mothers describe their experiences and feelings when raising a child that has ASD? (1b) How do these experiences and feelings shape the meanings the mothers create around raising a child with ASD? (2) What are the main challenges facing Saudi mothers of children with ASD? (3) What are the strategies they use to address these challenges?

In 2001, the Regulations of Special Education Programs and Institutes (RSEPI, Alnemary, 2017) law was established. This law is considered the first for Saudi students with disabilities. It includes rights for students with special needs and supports free and appropriate education for students with special needs. Based on this law, I would like to explore the following sub-research question: (1) How do challenges faced by mothers from the generation before the special education law differ from those of mothers after the law?

Theoretical Framework

Family Systems Theory

Family systems theory (FST) is a framework proposed by Murray Bowen, an American psychiatrist. The theory interrogates human behavior from a familial context and explores the intricate social system within a family unit (Johnson et al., 2016). Many therapists argue that this theory is critical in helping those with behavioral and psychosocial difficulties, including ASD and other behavioral disabilities. The theory is also crucial in explaining the factors around a child influencing behavioral development (Johnson et al., 2016). Traditionally, therapists believed that the relationship between a child and its caregiver, or mother, is a significant factor influencing child development. However, ever-emergent empirical trends and studies show that family members primarily influence child development.

From a family systems theory, the family provides an environment whereby children develop character. In addition, the family reinforces and allows children to learn ensuing behavior patterns (Jakimowicz et al., 2021). According to the FST, individual behaviors occur within family interaction sequences. From this theory, individual behavior and familial interaction have a nexus (Johnson et al., 2016). Therefore, therapists who practice under the FST framework (e.g., cognitive behavior therapist, early interventionist, and joint attention therapist) stress the importance of working with caregivers and family members (as opposed to directly working with the child) in order to support the child’s development (Johnson et al., 2016). Family systems theory includes four components: family characteristics, family interactions, family functions, and family life cycles. There are several family characteristics that the FST discusses as important components (Turnbull et al., 2011). Family characteristics are inputs into the family system. The family shares some characteristics such as family size, form, and cultural background.

Family Characteristics: Family Size and Form

The Census Bureau defines a family as two or more people living together and residing in the same dwelling. One of the members is the household and the others are related by blood, birth, marriage, or adoption (US Census Bureau, 2011; Turnbull et al., 2011). The number of children, parents, grandparents, uncles, and aunts living in one house determines the form and size of the family. If the family has a child with ASD, the impact of the child's disorder on the family varies according to the size of the family. For example, in large families, many people may help parents with housework and provide the specialized support and resources needed by the child with ASD. Saudi society is characterized by large families because, according to the traditions of some Saudi tribes, children live with their parents in the same house, even after marriage and having children. The Saudi wife is considered the primary caregiver in Saudi families, which may cause her stress if she has a child with ASD (Turnbull et al., 2011). Over time, the size and form of the family often change. The child with ASD may live with only one parent due to death or divorce or the child may live between his mother’s family and his father’s family after the divorce, which makes them adhere to different rules in two different families and live two different lifestyles. These different family dynamics might affect the child, especially since children with ASD typically strive when their routine is consistent (Turnbull et al., 2011). For example, Turnbull et al. (2011) found the change between the family dynamics might confuse the individual with ASD and cause them to get angry. On the other hand, the individual’s life between two different environments may cause stress on the parents themselves and makes it difficult for them to raise the child.

Family Characteristics: Cultural Background

Culture is the values and beliefs that influence the behavior of each family within their family, school, and community. Culture is shaped by several factors including language, gender, geography, religion, and experiences with a disability. Culture may change or evolve if there is a change in one of these factors. Researchers discussing FST explain that these factors are called sociocultural influences (Turnbull et al., 2011).

Culture impacts the child and their relationships with caregivers and the larger community. Furthermore, the effectiveness of available interventions and services, as well as the types of support received by the child and family may be affected by the family's culture and lifestyle. According to Turnbull (2001), the success of treatment plans and intervention tactics depends on how well they fit in with the family's culture and way of life.

Culture influences families of children with ASD and their relationship with professionals working with their children. For example, religious beliefs play a very large role in Saudi culture and have profound effects on parents raising children with ASD. Harmful and inaccurate religious beliefs can cause stress on parents while raising a child with ASD. For example, the participants in Alqahtani (2012) study indicated that because of the Saudi families’ religious beliefs, they believed that the child’s ASD was caused by an “evil eye and black magic” (p. 20). Thus, they did not access professional help or a diagnosis for years. On the other hand, parents of children with ASD reported that religion could be social support to reduce stress (Drogomyretska, et al., 2020), and the quality of religious social support affects the quality of parent-child relationships (Drogomyretska, et al., 2020). Bennett and colleagues (1995), in a study consisting of in-depth interviews with 12 parents of children with ASD, reported that prayer, church attendance, and religious summaries were identified as sources of social support that improved the relationship of parents of children with ASD. According to Balubaid et al. (2017) study, spirituality is one of the strategies that helped parents in Saudi to cope with challenges related to raising a child with ASD. For example, some Saudi parents in this study reported that prayer and reading the Qur'an make them feel comfortable and strong because they believe that God will help them and admit them to Heaven as a reward for their patience. This spirituality helps parents feel calm and relieves tension.

Family Interactions

In addition, the interaction system within the family is another component of the FST. It is important to realize that children with ASD do not live in isolation but rather interact, influence, and are influenced by their family members. Turnbull (2001) asserts that families are interdependent systems in which each member plays a unique role within the various subsystems. These subsystems can include parent-child relationships, sibling relationships, and marital relationships. Each subsystem within the family system has its own boundaries and communication patterns. Understanding the interactions within these subsystems is critical to understanding the overall functioning of the family and the impact of ASD on family members (Turnbull et al., 2011). Boundaries play a vital role in protecting the differentiation of subsystems. Boundaries in family systems refer to the boundaries and rules that define relationships and interactions between family members. Clear and healthy boundaries promote independence while maintaining a sense of togetherness and support within the family. Blurred boundaries can create challenges in communication, decision-making, and establishing appropriate roles within the family system (Turnbull et al., 2011).

Enmeshed family and disengaged units represent opposite ends of a continuum within the FST context. The enmeshed family system has blurred boundaries and intense emotional attachments. Individuals in these families may have difficulty defining their own identities and independence, making them stressed easily and affecting the family as a whole (Olson, et al., 2019). The disengaged family has strict and restricted boundaries. In these families, there is a lack of support and emotional connection between family members. Examining the continuum of enmeshed versus disengaged family units in the FST framework leads to a deeper understanding of the experiences of families affected by ASD. This knowledge can inform the development of support strategies that promote healthy boundaries, effective communication, and the overall well-being of the family.

Family Life Cycle

The family life cycle is also one of the FST components. The theory asserts that families go through different stages as their children grow older (Turnbull et al., 2011). These stages include early childhood, childhood, adolescence, and adulthood. At each stage, the family faces different challenges depending on the age of the child. Families must go through it to ensure successful adaptation and development (Turnbull et al., 2011). For example, in the early childhood stage, families face the challenge of discovering the disorder and searching for diagnostic services. As for the childhood stage, parents face the challenge of searching for available services and determining which one suits their child's needs. Throughout these stages, the theory emphasizes the importance of providing support to families and children by specialist ASD practitioners (Turnbull et al., 2011).

Family Function

The last component of FST is the family function. According to Turnbull (2001), the family's function is to meet the needs of each member. To meet these needs, the family performs some tasks such as providing affection, promoting self-esteem, addressing spiritual needs, managing the economy, providing daily care, facilitating socialization, and supporting education. In a family, each function contributes to the well-being of the entire unit. Each of these needs is interrelated, and if one isn't met, it may negatively affect the family and the child (Turnbull et al., 2011). For example, the mother who feels overwhelmed due to a large number of responsibilities may affect the provision of daily care and education for her child with ASD.

I used FST as a theoretical framework for this dissertation study because it addresses disability and family subsystems. In this chapter, I discussed the history of the framework and its uses. In the second chapter, the framework was used to code the published literature on the challenges facing Saudi parents of children with ASD and strategies parents used to cope with challenges. Further, I identified gaps in the literature that my dissertation explored. In the third chapter, the framework supported the data collection to explore the challenges faced by parents of children with ASD and the strategies they used to overcome these challenges. The qualitative interview also included questions to discuss the challenges in greater depth and created opportunities to understand mothers' feelings related to raising a child with ASD.

Positionality

I am married and a mother of four children, one of whom is a child with ASD. I worked as a lecturer for five years in the special education department at a Saudi university after I got a master's degree in special education from the United States. Part of my job was to supervise undergraduate students during their training in separate schools that included only children with

ASD. I conducted a dissertation on the challenges we face as Saudi mothers of children with ASD and how we overcame them to help other parents. This study may help describe some helpful resources and strategies available to Saudi children with ASD and their families. Additionally, my job as a lecturer at the university requires me to write and publish research that helps our voices (e.g., Saudi mothers of individuals with ASD) to be heard by stakeholders. I am also a member (not an administrator) of three WhatsApp support groups for Saudi parents of children with ASD. Through my experiences as a mother and as a specialist in the field of ASD, I share information about ASD and answer some questions of the participating parents, but in a very small way due to my preoccupation with my doctoral program and caring for my children.

When I joined the WhatsApp groups, I was not asked to introduce myself or my experiences in the field of ASD. Therefore, when I recruited participants from WhatsApp support groups, the mothers participating did so to their voluntary desire, and not because of my experience in the field of ASD. I introduced myself at the beginning of each interview, and I was objective and did not let my beliefs and experiences influence my interpretation of the data. As a Saudi mother raising a son with ASD for years and a specialist in the field of ASD, I can share my positive and successful experiences with mothers who may face the same challenges. I can also express the challenges I faced. This helped me to manage the conversation with the participants in a deeper way during the interviews.

Limitations of this Dissertation

One could argue that a limitation is my dual role as a participant and researcher. In addition to my knowledge of the beliefs and traditions of the participants' Saudi culture and the Islamic religion, I am considered a biased source as data collection and interpretations may be affected by my perceptions and beliefs (Creswell, 2000). It is important to take this into account in analyzing the data. To control this bias, I needed to constantly monitor my position as a researcher. I also remained objective and asked open-ended questions so that participants could provide their answers and express their life experiences caring for a child with ASD. I also recorded interviews, accurately transcribed interview data, and conducted members checks to address limitations (Creswell, 2013). On the other hand, the dual role may benefit greatly in this proposed dissertation, as it helped in obtaining valuable data that helps in exploring the living experiences and challenges of Saudi mothers of children with ASD, and thus learning from them that they are trying to find strategies to face the challenges (Creswell, 2000).

Delimitations

The delimitations of this dissertation include participants, their recruitment through WhatsApp only, and conducting interviews via Zoom. In this dissertation, I focused on mothers rather than fathers because mothers are mostly responsible for the daily care of children with disabilities in Saudi culture. Furthermore, since my plan was to recruit only mothers from ASD WhatsApp groups, the general population of parents raising children with ASD in Saudi Arabia may not be adequately represented by these participants. However, WhatsApp groups include a large number of mothers from different cities in Saudi Arabia, so I expected that there are diverse group of participants in the study. I conducted the interviews via Zoom because I am studying in the United States and it is difficult to travel to Saudi Arabia for face-to-face interviews. Face-to-face interviews help the researcher build a good relationship with the participants and help the participants to engage more (Creswell, 2000). Also, body language in face-to-face interviews helps the researcher to understand many meanings and feelings (Creswell, 2013). This dissertation included many sensitive topics that mothers felt more comfortable talking about via Zoom, especially since the camera was off for cultural and religious reasons. In Saudi culture, most mothers cover their faces so that men do not see them; thus, I did not ask mothers to turn on their cameras for the interviews.

Definition of Terms

Theoretical framework

The theoretical framework for this study is Family systems theory (FST). FST explains family units as complex systems in which family members interact and influence the behavior of other members of the family.

Autoethnography

One methodology used in this dissertation is autoethnography. It is a type of qualitative research that allows the writer to use self-reflection on his or her personal experiences and stories, and then link their personal autobiography with broader cultural, social, and political contexts (Wall, 2008).

Interpretative phenomenological analysis (IPA)

Another methodology used in this dissertation is a qualitative approach that provides rich and detailed information about participants' lived experiences. This approach helps explore the meanings and feelings of the participants' experiences.

Autism Spectrum Disorder (ASD)

Autism spectrum disorder (ASD) is a developmental disorder. These disorders are characterized by difficulties in social interaction, verbal and nonverbal communication, and repetitive behaviors (Diagnostic and Statistical Manual of Mental Disorders IV, text revision-DSM-IV TR, 2000).

Special Education

Instruction specially created to fulfill the educational needs of a qualified exceptional student, free of charge to the parents, including classroom instruction, extracurricular activities, instruction in a special school or residential setting, and instruction in other settings, such as the site of employment and training (IDEA, 2004).

Saudi Culture

The culture of Saudi Arabia has been greatly influenced by Arab and Islamic civilizations over the past several centuries. The society in Saudi Arabia is also distinguished by its preservation of religion, customs, and the concept of the family.

Challenges

The term challenge refers to a challenge or activity (physical or intellectual) that a person must undertake to overcome different types of difficulties.

Strategy

Strategy is an organized method that is followed in order to overcome difficulties according to the available financial capabilities and efforts.

Evil Eye

Evil eye is defined by a look of envy. Many cultures and religions believe in its ability to bring bad luck to the person to whom this gaze is directed. This term also refers to a force emanating from certain people that causes misfortune to others.

Black Magic

A black magic is a type of sorcery that brings bad luck and harm to others for personal gain without regard to how it will affect others.

Behavioral Modification Sessions

Behavioral modification sessions are a type of therapy that uses techniques based on the principles of learning theory to help individuals change specific behaviors. These sessions aim to replace negative or unwanted behaviors with positive ones by reinforcing desired behaviors and ignoring or punishing unwanted behaviors.

CHAPTER II: REVIEW OF THE LITERATURE

Due to the increased awareness and research in the US and other countries about ASD, we are more aware of what families and individuals with ASD are experiencing (Alkhalifah et al, 2018). However, there is limited research in Saudi Arabia that explores the experiences of families that are raising individuals with ASD.

Method

Inclusion Criteria

During the Fall of 2021, I did an initial search of literature related to families of children with ASD in Saudi Arabia using broad search criteria. I then completed another search in the Fall of 2022 to include articles that have been published since. In addition, I searched in the spring of 2023 and found no studies that met the inclusion criteria for this review. The following inclusion criteria were utilized when searching for articles to include in the review: (a) empirical, full-text, peer-reviewed articles, (b) included participants that were Saudi families of children with ASD, (c) conducted in Saudi Arabia or online with Saudi families who are lived in Saudi Arabia, (d) included challenges the Saudi families faced and/or strategies of overcome these challenges, and (e) published in English or Arabic (as these are the only languages I can read and understand). My criteria included articles published between 2001-2022. These inclusion dates were chosen because in 2001, the rights of children with ASD began to be established in Saudi Arabia under Law Number 224, the Regulations of Special Education Programs and Institutes (RSEPI; 224 Khan et al. 2020). I excluded any article that met one or more of these scenarios: (a) only abstracts, conference papers, seminars, or book chapters available, (b) published prior to 2001, (c) did not conduct with Saudi families, or (e) was not about challenges.

Procedures

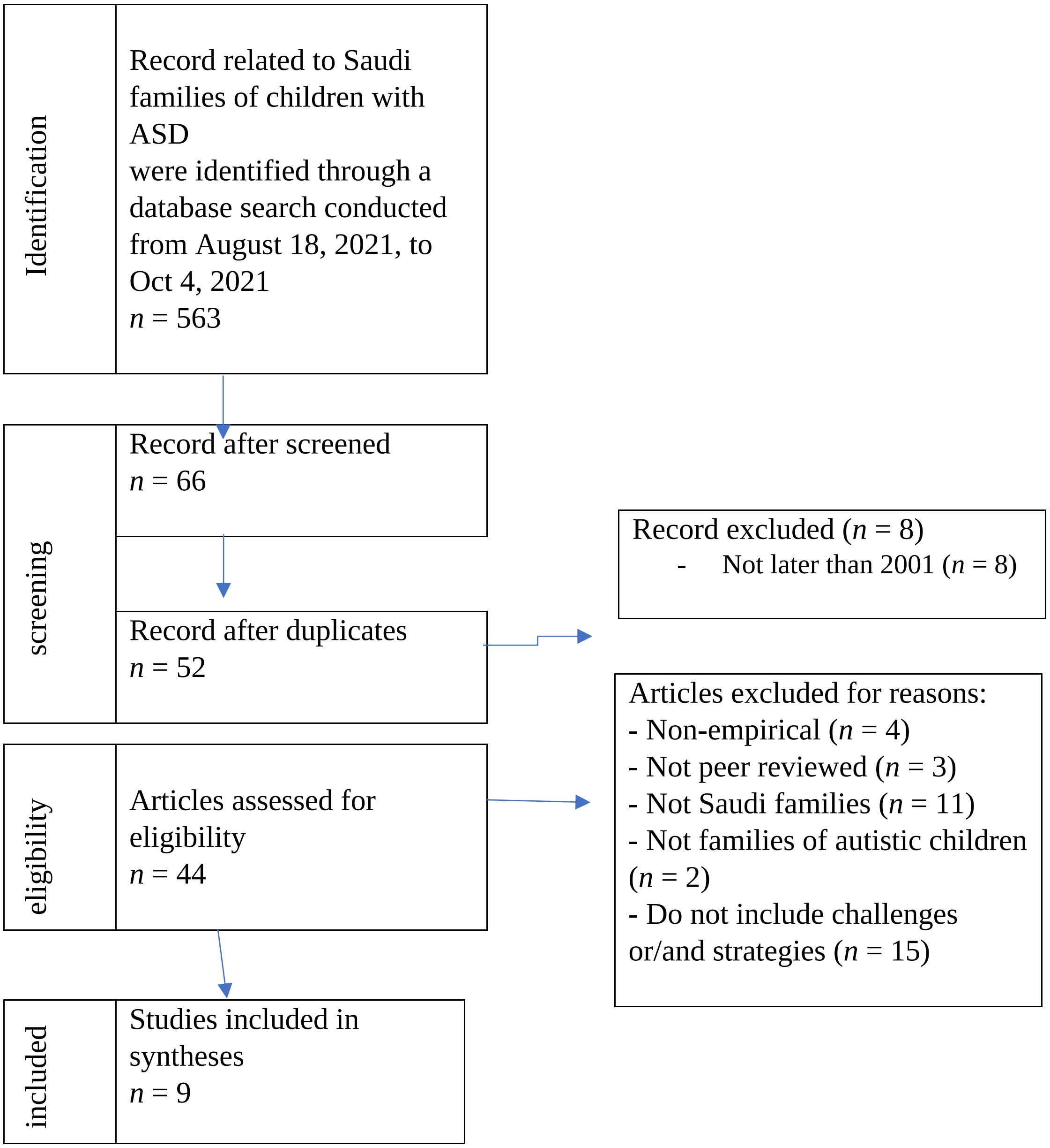
The identification of studies for this review went through four phases. I followed many of the procedures outlined in Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) methodology for reviews (Moher et al. 2015; Munn et al., 2018). First, after consulting a librarian regarding the search terms and my academic advisor, I searched the following databases: Science Direct, Education Source, PsycInfo, PsycInfo, and Education Source combined, Proquest Psychology, and Google Scholar. Search terms included “families of autistic children”, “parents of autistic children", “mothers of autistic children”. I also had the terms in various combinations such as “Autis* AND parents AND Saudi Arabia", "Autis* AND families AND Saudi Arabia, “Autis* AND mothers AND Saudi Arabia”. Second, I screened studies to identify studies that met the review criteria by reading the titles and abstracts. Third, I identified articles that met eligibility by reading the full text of articles to determine if they met the inclusion/exclusion criteria. Fourth, after identifying the studies that met eligibility through a full-text search, I searched the reference sections of the selected studies for additional relevant articles.

Initially, I found 563 studies, including empirical articles, book chapters, peer-review articles, conceptual and theoretical articles, and commentaries. Then, I screened these 563 studies by reading the titles and abstracts and I found 66 articles met the criteria for review. After removing the duplicates via Zotero, I read the full text of 52 articles. The 52 publications were assessed for eligibility using a yes/no indicator in a Google form that I created. The form was implemented to extract information from each manuscript identified in the database searches. I coded the 52 articles using the Google form to assess eligibility and to determine which articles were to be included/excluded from the analysis. I used the following codes to record information about the articles and determine eligibility: author(s), title, publication year, language, empirical, peer-review, conducted with the Saudi families of children with ASD, and includes challenges families faced and/or strategies to overcome challenges. During the screening process, 497 were excluded (see Figure 1 for a full description of the four-phase process). After the screening process was completed, there were a total of eight articles that met the inclusion/exclusion criteria. I then conducted a secondary search, which consisted of reviewing the reference section of my eight articles to determine if I could find more relevant articles. I found an additional five articles. However, I removed four articles based-on duplicates and read the full text of one article. During the reference list search, I found one more article to include. Thus, nine articles fit the inclusion criteria and were included in this literature review. I then followed the same procedure in Fall 2022 and found one new article to include.

Coding

Throughout my search of the literature, I coded the following variables from each article and kept track using a matrix. The following was coded on the matrix: authors' names, year of publication, journal, language the article was written in, purpose, methodology, measures, participants (male/father, or female/mother), participants' location, child information, and results in reference to challenges and strategies supported. The purpose of this matrix was to have a first glance at components I considered important for the systematization of my literature review. I coded the results related to the challenges and strategies by following the recommendations in the Saldana (2016) text. First, I read the ten reviewed articles and reported the main results in terms of challenges and strategies. I documented the exact codes presented in the articles (e.g., stress, anxiety, and depression). After reading all articles and analyzing the data into many and small codes, I transformed them into large and few themes by finding commonalities between codes, then collecting the same, similar, or close codes (presented in Table 1). For example, five articles (Alghamdi et al., 2022; Asi, 2016; Balubaid et al., 2017; Hemdi et al., 2017; Sahab, 2017) discussed about the small codes (stress, anxiety, fear, and depression) that I combined into the psychological problem theme presented in Table 1. Stress was spoken about in five articles (Alghamdi et al., 2022; Asi, 2016; Balubaid et al., 2017; Hemdi et al., 2017; Sahab, 2017), anxiety in two articles (Hemdi et al., 2017; Sahab, 2017), depression in three articles (Asi, 2016; Hemdi et al., 2017; Sahab, 2017), and Fear in one article (Balubaid et al., 2017)

Figure 1. Data Selection Criteria



Results

Journals

I explored the journal ranking, country of publication, and target audience of the journals that published the articles included in this review, as well as whether these journals were international or not. I found that the journal ranking (utilizing the SCImago Journal Rank [SJR] from the Scimago Journal & Country Rank, 2021) for the *Public Library of Science (PloS) One* journal is 2.7, while the SJR for the *Autism* journal is 2.3. The journal ranking for the remaining seven journals is less than one which is considered a low ranking compared to the first two journals. Also, I found that five of the journals targeted audience are professionals in education. Two journals targeted medical professionals, and two journals targeted professionals in the fields of engineering, science, and technology. Only one journal targeted people with ASD, their families, and ASD service providers. As for the results related to the country of publication, I found four journals published in the United States, two in the United Kingdom, one in Canada, and one in Saudi Arabia. All the journals were international except PloS One.

Methodology and Measures

The identified studies used different methodologies (e.g., semi-structured, qualitative interviews: $n = 3$, quantitative survey: $n = 5$, and mixed-method: open and closed-question survey: $n = 1$). The researchers in the reviewed studies developed the interview protocol in the three qualitative studies (Alqahtani, 2012; Balubaid et al., 2017; Hemdi et al., 2017) and developed surveys in four quantitative studies (Al Awaji et al., 2021; Alnemary et al., 2017); Asi, 2016; Khan et al., 2020) while they adapted surveys from a published source in one quantitative study (Alotaibi et al., 2016) and one in the mixed-method study (Sahab, 2017)

Different measures were used in the studies to report the validity and reliability of the studies. For content validity, the contents in two quantitative articles were reviewed and evaluated by professionals and experts in the field from different Saudi universities. For reliability, one of the two articles (Asi, 2016) used Test-Retest Reliability and the other one (Alotaibi et al, 2016) used reliability analysis in SPSS. In the qualitative interview articles (Alqahtani, 2012; Balubaid et al., 2017; Hemdi et al., 2017), the researchers consulted with experts as they were developing the interview questions. In one qualitative article (Hemdi et al., 2017) and one mixed method article by (Sahab, 2017) the transcripts of the interviews were sent to the participants for validation. The remaining five articles did not report information about the measures' reliability, validity, or trustworthiness. (See Table 1 for full information about each study)

Participants

Parents' Information

There were 856 participants included in the nine articles reviewed. However, many studies did not include demographic information about the participants (see Table 1 for full information about each study). For example, one study (Alqahtani, 2012) did not include the number or the demographic information of the participants. Three studies included the number of participants but did not include demographic information of the participants. Five studies included information about the gender of the participants, and the majority of the participants were female, the child's mother (fathers: n = 116, mothers: n = 409). Only two studies included information about participants' education level (e.g., high school graduate: n = 45, undergraduate degree: n = 42). Only one study (Alotaibi et al, 2016) included information about participants' monthly income (e.g., Less than $2,500: n = 48, $2,500 to $4,500: n = 28, more than $4,500: n =

4). According to the World Bank (2020), less than \$2,500 is equivalent to low income in Saudi Arabia between \$2,500 to \$4,500 is equivalent to middle income, and more than \$4,500 is equivalent to high income in Saudi Arabia. Two studies reported the participants' location (e.g., Riyadh city: *n* = 100, Jeddah city: *n* = 8). These two cities are considered major cities in Saudi Arabia.

Children Information

Six studies did not include demographic information about the children. Three studies included information about the age of the children. For example, the children’s age in Alnemary et al. (2017) were between three to 18 years, childrens’ ages were between two and six years in Alotaibi et al. (2016), while in Khan et al, (2020) the children’s age were between one to 12 years. Only two studies included information about the children’s gender for example, in Alnemary et al. (2017), there were 170 males (no females). While in Alotaibi et al. (2016) study, there were 49 males and 31 females. Only Alnemary et al. (2017) reported children’s additional diagnoses. For example, some children had ASD and additional diagnoses, e.g., attention-deficit/hyperactivity disorder (ADHD), intellectual disability, and cerebral palsy.

Table 1. Description of Reviewed Studies

First author and date	Methodology	Participants	Measures	Challenges faced by families	Strategies used to face challenges
Al Awaji et al (2021)	Quantitative closed-ended survey	*n* = 385 *Gender:* Male: *n* = 24 Female: *n* = 300	The researcher developed a survey with no reported validity & reliability statistics	Lack of educational services	N/A
Alnemary et al. (2017)	Quantitative-Closed-ended Survey	*n* =205 No demographic information	Researcher developed survey with no reported validity/ reliability statistics	Lack educational services	N/A
Alotaibi et al. (2016)	Quantitative Closed-ended Survey	*n* = 80 *Gender*: Male: *n* = 35	Researcher adopted from other surveys with reported validity/ reliability statistics	Lack of educational services	N/A

		Female: *n* = 45 *Educational level*: High school: *n* = 39 Undergraduate degree: *n* = 41 *Monthly income*: Less than 10,000 SR: *n* = 48 10,000 to 15,000 SR: *n* = 28 More than 15,000 SR: *n* = 4			
Alqahtani.	Qualitative Semi-	N/A	Researcher developed	Religious beliefs	-Diet intervention

(2012)	structured interview		protocol Trustworthiness information not provided		
Asi, K. (2016)	Quantitative closed-ended Survey	n =100 *Gender*: Male: n = 50 Female: n = 50 *location*: Riyadh (major city)	Researcher developed a survey with reported validity/ reliability	psychological problems	N/A
Balubaid et al. (2017)	Qualitative Semi-structured interviews, face to face	n = 8 *Gender*: mothers: n = 6 fathers: n =2 *Location*: Jeddah (major city)	Researcher developed interview protocol with no reported trustworthiness	psychological problems	Spirituality, social media, additional help

Hemdi et al. (2017)	Qualitative Semi-structured telephone interviews	*n* = 8 *Gender:* Male: *n* = 0 Female: *n* = 8 *Educational level*: High school: *n* = 6 Undergraduate degree: *n* = 2	Researcher developed protocol/ Trustworthiness information provided	Lack of understanding -Stigma - Lack of social support - lack of/unqualified diagnosis Psychological problems	N/A
Khan et al, (2020)	Quantitative closed-ended survey	*n* = 61	The researcher developed a survey with no reported validity & reliability statistics	- Lack of understanding	N/A

Sahab, L. (2017)	Mixed method open-ended and closed-ended survey	*n* = 9		The researcher adopted a survey with reported validity/ reliability	- Lack of understanding - Lack of social support - lack of/unqualified diagnosis Psychological problems	N/A

Challenges and Strategies

Themes began to emerge from the articles based on the challenges and strategies reported, so I began to create inductive codes based on what I found in the articles (Skjott et al, 2019). For the nine articles reviewed, I found that caregivers reported similar experiences regarding the challenges and strategies that they reported. The main challenges reported by Saudi families of children with ASD were lack of special educational services, lack of understanding, stigma, lack of social support, lack of/unqualified diagnosis, religious beliefs, and psychological problems. The strategies that they used to address these challenges were: spirituality, social media, additional help, and diet intervention. All the theme definitions and examples are listed in Table 2.

Challenges

I reviewed ten studies and I found that three of the articles (i.e., 33% of the articles) indicated that the **lack of special educational services** provided for children with ASD is the biggest challenge Saudi families face. For example, participants in the Alnemary et al. (2017) study reported that there is a lack of access to educational services, e.g., the educational services are in major cities only Dammam, Riyadh, and Jeddah. However, even in the major cities, there are few qualified centers with huge waiting lists. The participants in Alotaibi et al. (2016) mentioned there is a lack of early interventions and related services, there are unqualified professionals, and a lack of ASD service centers. The participants in Al Awaji et al (2021) reported that there is a lack of educational services (e.g., speech-language therapy services are limited) and accessing these services is challenging because there is no sufficient funding to pay for services.

The lack **of understanding of ASD** was reported in three studies (33%). For example, most families in the Khan et al.(2020) and Hemdi et al. (2017) studies were unaware of the possible causes and treatment of ASD because most of the helpful ASD resources are only written in English and most families speak and understand Arabic only. In the Saheb (2017) study participants reported that there is a lack of social understanding about ASD in Saudi society.

Some families in two studies (22%) also stated that they **lacked social support** from family and friends and considered this one of the difficulties they faced. For example, in Hemdi et al, (2017) and Saheb (2017) participants reported that in the Saudi culture mothers are considered to be the main care provider for the home and the children, while the fathers are responsible for providing the family's income. Thus, mothers need respite and time for themselves due to the constant burden of caregiving; however, it is difficult to find a reliable person for childcare.

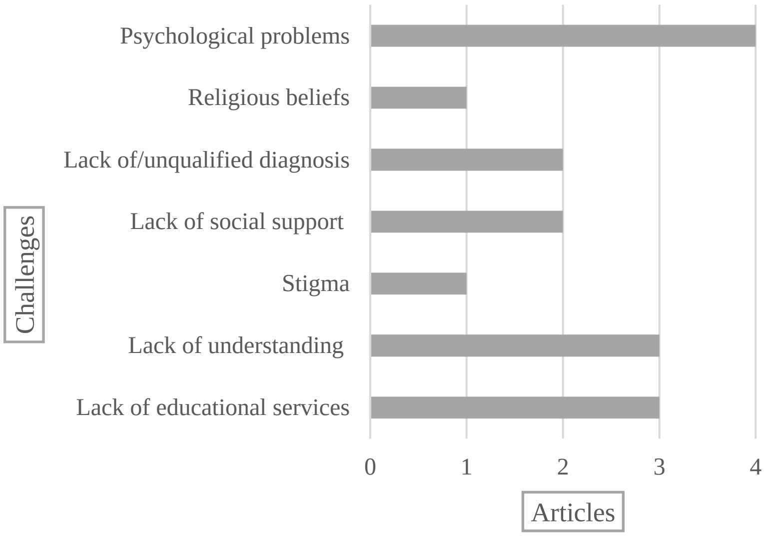
As indicated in two (22%) of the studies, there is **a lack of/unqualified diagnosis**. Parents in the Sahab (2017) and Hemdi et al. (2017) articles reported there are not enough professionals able to diagnose ASD and there is no clear diagnostic process to follow in hospitals and clinics. Most parents in these two studies reported that they sought a diagnosis for their children with ASD from psychiatrists, but each clinic used different measures and diagnostic tools. Further, some parents mentioned the lack of/unqualified diagnosis caused delays in early intervention (Hemdi et al., 2017).

In one article (11%, Alqahtani, 2012, p. 20) some parents indicated that because of the families' **religious beliefs**, they believed that the child's ASD was caused by an "evil eye and black magic". Thus, they did not access professional help and correct treatment.

In four of the articles (44%), parents expressed that they suffered from **psychological problems**. For example, participants in Asi, (2016) study suffered from depression for years because childcare with ASD requires great effort and financial requirements. In the Balubaid et al. (2017) study the parents are stressed because of their reduced ability to travel and the number of family visits which negatively affected their care for their children with ASD. Finally, families in the Sahab (2017) study suffered from anxiety due to their children’s sleeping disorders and lack of understanding of their well-being. Some participants in Hemdi et al. (2017) article also reported that caring for a child with ASD requires great effort from parents

Finally, one study (11%) indicated that **stigma** is one of the difficulties that Saudi families have faced. For example, some of the participants mentioned that people in public places look at their children with astonishment because of their different behavior. Some participants also mentioned that they hide their children's disabilities from friends and family because the disability may affect their sibling’s chances for marriage (Hemdi et al, 2017). See Figure 2 for the number of articles that address each challenge reported by Saudi parents of children with ASD.

Figure 2. Challenges Reported by Saudi Parents of Autistic Children



Strategies

Only two (22%) of the articles stated strategies that were helpful. For example, in the Balubaid et al. (2017) article, the parents cited **spirituality, social media, and additional help.** Spirituality, e.g., prayer and reading Quran, was the most important strategy to help the families. Most parents indicated that they believed Allah will help them and reduce their stress. When some parents joined social media groups, they reported the groups helped them to learn from others' experiences. Finally, some parents reported that receiving additional help (e.g., hiring teachers or maids to help educate and care for the child) reduced the stress. The other article (Alqahtani, 2012) that reported strategies indicated that one of the parents expressed that the Gluten-casein free **diet** helped to reduce hyperactivity and improve sleeping.

Table 2. Theme Definitions

Theme	Definition	Examples
Lack of educational services	Lack of system of integrated services provided to students to enhance their educational experience	The educational services are in major cities only, few qualified centers in the major cities with long waiting lists, lack of early interventions and related services, unqualified professionals, lack speech-language therapy services, and no sufficient funding to pay for services
Lack of understanding	Mis- or lack of understanding of the meaning of ASD and related services/resources that could be beneficial	Lack of information about ASD, unaware of the possible causes and treatment, most of the good resources available in English
Stigma	Feeling stigmatized because of a child's disability.	Isolating and not leaving the house with the child because people in public places are disturbed by his behavior, concealing the child's disability from family and friends because the child's disability is not accepted
Lack of social	The lack of assistance available from	Lack of assistance and support from the families and the friends (e.g., in

support	other people	the Saudi culture mothers 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), mothers need respite and time for themselves due to the constant burden of caregiving, difficult to find a reliable person for childcare
Lack of/unqualified diagnosis	Lack of the process and the tools of identifying and diagnosing ASD	Not enough professionals able to diagnose ASD, no clear diagnostic process to follow in hospitals and clinics, parents in Saudi Arabia seek a diagnosis for their children with from psychiatrists, but each clinic uses different measures and diagnostic tools, parents get a different diagnosis for their children each time.
Religious beliefs	Belief in a religion's central articles of faith	**A** prevailing religious belief that the cause of ASD is the evil eye or black magic, which delays intervention and treatment
Psychological problems	**A** mental health disorder is characterized by feelings of depression, anxiety, or fear that are strong	Families of autistic children suffer from depression, anxiety, or stress due to sleeping disorders, lack of understanding of their well-being and the need for help, lack of their own time, lack of support and assistance from

		their families and friends, childcare requires a great effort and financial requirements, and may reduce the ability to travel and the number of family visits which could lead to psychological problems
Spirituality	Religious rituals, prayer, meditation, belief in a sublime power or a feeling of comfort and peace	Saudi people are Muslim which means they believe Allah helps them to face challenges, prayer provides them with comfort and strength, belief that the autistic child is a gift and the way to Heaven
Social media	Interactive technology that facilitates the sharing of ideas and information through the building of virtual networks and communities	Joining social media groups to discuss the problems and resources with professional people or with people who had similar experiences
Additional Help	Receive extra assistance from other	Hiring teachers or maids to help educate and care for the child
Diet	Following a special course of food either to lose weight or for medical reasons	Gluten-casein free diet

Limitations in the Studies Reviewed

Parents' Information

Many studies did not report information on participants. However, for those that did, the mothers in the studies were the main reporters (Al Awaji et al., 2021; Alotaibi et al, 2016; Asi, 2016; Balubaid et al., 2017; Hemdi et al., 2017), possibly because mothers in Saudi Arabia are usually the caregivers. Similar to previous research, mothers typically spend most of their time with their children with ASD, making them more aware of the challenges when compared to the fathers (Hemdi et al. 2017). Typically, fathers spend their time outside the home to earn an income and they don't spend time with their children (Hemdi et al. 2017). Thus, this is likely why the fathers' input was lacking in this review studies.

The studies reviewed also did not include participants from villages or rural areas, or participants with differing educational and socio-economic levels. Two of the studies reported the participants' locations (Asi, 2016; Balubaid et al., 2017). In these two studies, the researchers reported that the participants were located in Riyadh and Jeddah cities, which are considered two major cities in Saudi Arabia where services are more available due to a large population. Many studies did not report on the level of education, or the socio-economic level of the families participating in the reviewed studies. The only study that did report the level of education and the socio-economic level, the Alotaibi et al. (2016) study, included participants that were educated and from a low socio-economic level (The World Bank, 2020). Thus, future research needs to explore the experiences of mothers and fathers located in differing locations, with differing educational, and socio-economic levels.

Children's Information

Many studies did not provide demographic information on children. Only (Alotaibi et al, 2016; Alnemary et al., 2017; Khan et al, 2020) studies reported the ages of the children which ranged from one to 18 years old. Future research needs to report the age of the child because the age of the child may influence the challenges faced by parents. Parents of children over the age of 13 may suffer and face more challenges than parents of children under the age of 13 because the education system in Saudi Arabia does not accept children over the age of 13 in public schools (Alshahrani, 2021). Therefore, this forces families to send their children to neighboring countries to complete their education, which may cause a financial burden. There are some families with low incomes who cannot send their children or even pay for the services available for a fee. Therefore, families with teenage children may face differing challenges related to the limited services available for their child to be able to complete high school, attend college, or learn skills needed for a career that will help them learn to be self-reliant (Alshahrani, 2021).

Among the studies that reported the gender of the children (Alotaibi et al, 2016; Alnemary et al., 2017), the number of males in the studies was more than the number of females. This is likely because the reported prevalence of ASD is higher among males than females in Saudi Arabia (Al-Zahrani et al., 2013), as it is globally. However, this may be due to under-diagnosis among females (Ferri et al, 2018) Future research should report the gender of the child because the families of female children with ASD may face additional challenges than the families of male children with ASD. Saudi Arabia is a Muslim country and one of its laws is that women do not mix with men in public places (e.g., women typically visit women doctors, and males with male doctors). However, most health services are provided by males, so families of female children with ASD find it difficult to obtain services because of the lack of female doctors qualified to treat and diagnose ASD (Alshaigi, 2020). For example, in the Alkhalifah et al. (2018) study, a parent reported that the culture of Saudi Arabia always mandated the segregation of men and women (e.g., in banking, and health) and those women should cover their faces in front of men, as face-to-face contact between men and women are prohibited. Under culture, these rules make communication between the sexes a sensitive issue. In some cases, families do not allow their daughters with ASD to receive services from men even if they are necessary. Most of the health workers in Saudi Arabia are men; thus, this increases the challenges for parents of females with ASD (Alkhalifah et al., 2018).

All articles in this review did not report whether the children with ASD had other additional disabilities, except for Alnemary et al. (2017) study. This study reported that most children have other disorders and disabilities in addition to having ASD, which increased the severity of their disability. The severity and multiple additional disabilities may affect the challenges faced by families of ASD children in Saudi Arabia. For example, most parents in Alnemary et al. (2017) study reported that it was difficult to find inclusive schools that would accept their children with “severe ASD” (p. 11). These parents want their children to learn with and from others who do not have a disability because this may reduce the parents' sense of stigma and that their child is different from his or her typical peers. Future research should report on the severity of the disability and on whether the child with ASD has multiple disabilities because the child with multiple disabilities may financially burden the family more because the child needs multiple services to meet the needs of each type of disability.

Methodology Limitations

In this review five articles were surveys. According to Johnson, et al. (2020) to meet the standards related to survey methodology, researchers should report at least one type of the following reliability types: test-retest, interobserver, intraobserver, alternate form, or internal consistency. In addition, researchers should report at least one type of the following validity type: face, content, concurrent, convergent, divergent/discriminant, or construct. However, only two of the five quantitative articles reported reliability and validity (Alotaibi et al, 2016; Asi, 2016). For example, for reliability, Asi (2016) used test-retest reliability and Alotaibi et al. (2016) calculated a reliability analysis. Also in these two articles, the validity of the instruments was measured. Professionals from the King Saud University, Department of Special Education reviewed the content to ensure validity in the Alotaibi et al. (2016) study. In the Asi (2016) study, the content was reviewed and evaluated by ten reviewers specialized in special education, psychology, and measurement and evaluation from different Saudi universities.

Three articles were qualitative in nature and used interviews. When creating interview protocols, researchers should consult with experts as they were developing the interview questions or pilot the questions. When analyzing interviews, researchers report data on trustworthiness by analyst triangulation, peer examination, or member check (Cypress, 2017). Two qualitative articles reported trustworthiness. For example, in Sahab et al. (2017) and Hemdi et al. (2017), the transcripts of the interviews were sent to the participants for validation and member checking.

Overall, five articles did not report trustworthiness, validity, and reliability which affects the quality of the data presented. Providing reliability, validity, and trustworthiness in qualitative and quantitative research is very important and is one of the criteria for assessing its quality. Reliability, validity, and trustworthiness in research are essential to ensure that data are sound replicable, and that the results are accurate. Validity and reliability are prerequisites to assure the integrity and quality of a measurement instrument.

The important findings that are related to the journals where the reviewed articles were published are that most of these journals had a low journal ranking (SJR score). The lower journal ranking may affect the quality of the article’s methodology. Also, I found that the reviewed articles are published in journals targeting different disciplines. Targeting differing disciplines/audiences is recommended because it allows the information presented in the article to reach a broader audience beyond those interested in the field of ASD.

Review Limitations

The current review focused on searching in English databases, so only articles written in English were reviewed, and relevant results published in Arabic in Arabic databases were not reviewed because while in the US, I could not access Arabic databases However, I made an effort to perform a comprehensive search of English databases to obtain relevant literature. Relevant work may also have been excluded by my inclusion criteria, e.g., only peer-reviewed papers were included. However, I reviewed ten studies that provided valuable information that helped answer literature review questions while ensuring rigor and scientific quality. Further, the current review only focused on parents of children with ASD and the experiences of other family members who may be primarily involved in the child's care may have been overlooked. However, in Saudi, most children with ASD are cared for by their parents (mostly their mothers). In the future, reviewing literature exploring siblings and extended family members can be explored. Also, the time range was not very wide. Articles published from 2001 onwards were reviewed, the year Saudi Arabia's special education rights and laws were established. However, very few studies on this topic are published before 2001.

Research Gap

The findings indicate that the majority of the reviewed articles were in agreement that the primary challenges that families of children with ASD in Saudi indicated included a lack of educational services and psychological problems. However, only two articles included strategies that the families cited as helpful for raising a child with ASD in Saudi. Thus, this dissertation study hopes to fill the gaps in the literature presented by exploring strategies and understanding families' experiences in greater detail.

Main Challenges Reported

Psychological Problems

The participants in the Balubaid et al. (2017), Asi (2016), Hemdi et al. (2017), and Sahab (2017) studies reported that one of the biggest challenges facing families of children with ASD is the psychological problems that affect one of the parents due to caring for the child with ASD. The psychological problems included depression, stress, fear, and anxiety. These psychological problems affect the parents' ability to care for their children, especially since there is a lack of psychological support services for parents. For example, most participants in Balubaid et al. (2017) study reported that having a child with ASD reduced their ability to travel and their family visits. Some participants in Asi (2016) and Hemdi et al. (2017) articles also reported that caring for a child with ASD requires great effort which reduces their private time when they need to rest or practice their hobbies. Failure to meet psychological needs may lead to psychological problems affecting the raising of the child.

Educational services

The participants in the Alnemary et al. (2017), Alotaibi et al. (2016), and Al Awaji et al. (2021) studies report there is a lack of educational services. For example, most participants in the

Alnemary et al. (2017) study found it difficult to access educational services for their children with ASD because educational services are only in the main Saudi cities with a long waiting list. Some participants also reported that some professionals working in these centers are not qualified, and some center does not provide occupational therapy and speech therapy services. On the other hand, some of the participants in Alnemary et al. (2017) study reported that there is a lack of early intervention services and related services. If these services are available, they are not provided for free.

Lack of understanding

The participants in the Hemdi et al. (2017), Sahab (2017), and Khan et al. (2020) studies reported that lack of understanding of ASD, its causes, and ways to support people with ASD is one of the challenges faced by families of children with ASD in Saudi Arabia. For example, participants in the Hemdi et al. (2017) and Khan et al. (2020) studies reported that they do not have information about ASD, its possible causes, or ways of treatment. Most of the helpful resources are only available in English.

Lack of social support

The participants in Hemdi et al. (2017) and Sahab (2017) reported that lack of social support and assistance is one of the challenges that they face. For example, in the Hemdi et al. (2017) study all mothers reported that the biggest challenge they face is the lack of help from family and friends. They mentioned that they are fully responsible for taking care of their children because fathers often spend their time outside the home. In addition, in the Sahab (2017) study, parents reported that there is a lack of social support groups. They need to communicate with professionals in the field of ASD or with families of other children with ASD to exchange experiences that support them, at least morally.

Lack of/unqualified diagnosis

The participants in Hemdi et al. (2017) and Sahab (2017) reported that lack of/unqualified diagnosis is one of the challenges that they face. For example, in these two studies, most participants reported that there were not enough professionals able to diagnose ASD. Further, there is no clear diagnostic process to follow in hospitals and clinics.

Stigma

The participants in Hemdi et al. (2017) reported that the stigma associated with having a child with ASD is considered one of the challenges that they face. For example, some of the participants mentioned that people in public places look at their children with astonishment because of their different behavior. Some participants also mentioned that they hide their children's disabilities from friends and family because the disability may affect their sibling’s chances for marriage.

Religious beliefs

The participants in Alqahtani (2012) study reported that religious beliefs are one of the challenges that they faced. For example, some participants in this study indicated that because of the families’ religious beliefs, they believed that the child’s ASD was caused by an “evil eye and black magic” (p. 20). Thus, they did not access professional help or a diagnosis for years.

Main Strategies Reported

Spirituality

The participants in Balubaid et al. (2017) study reported that spirituality is one of the strategies that helped them to cope with challenges related to raising a child with ASD. For example, some parents in this study reported that prayer and reading the Qur’an make them feel comfortable and strong because they believe that God will help them and admit them to Heaven as a reward for their patience, which will relieve tension.

Social media

The participants in Balubaid et al. (2017) study reported that social media is one of the strategies that helped them to face challenges. Some parents in this study reported that joining social media groups to discuss problems and resources with professional people or with people who had similar experiences helps them to reduce their stress. These groups helped them to become aware of the services and treatment provided to their children too.

Additional Help

The participants in Balubaid et al. (2017) study reported that getting additional help from others is one of the strategies. Some participants in this study reported that taking care of their children with ASD takes a lot of their time which makes them stressed. Therefore, help and support from other individuals is an important strategy to help them reduce stress. Some of the participants in this study mentioned that they hired a private teacher or helpers (e.g., maids) to help the parents.

Diet

One participant in Alqahtani. (2012) study reported that using a special diet for their children is one of the strategies that helped. For example, the participant in this study reported that she believed the casein- and gluten-free diet is one of the strategies that helped children reduce inappropriate behaviors associated with ASD. The diet helped reduce aggressive behavior, hyperactivity, and self-injury, and it also helped improve sleep. The participant believes that casein and gluten found in wheat, milk, and their derivatives are the cause of sleep disturbances and aggressive behavior.

Implications for Research

Families of children with ASD in Saudi Arabia face multiple challenges in caring for their children due to a lack of educational services, lack of understanding, stigma, lack of social support, lack of/unqualified diagnosis, religious beliefs, and psychological problems. This review did not report a lot of strategies. The ones that were useful to face the challenges are spirituality, social media, additional help, and diet. This review contributes to the Saudi literature related to raising children with ASD and the challenges facing their families. Based on the results of this review, I will focus my dissertation on exploring strategies to address the challenges faced by families of children with ASD in Saudi Arabia. I will also explore the families' feelings surrounding their experiences raising a child with ASD.

CHAPTER III: METHODOLOGY

Research Design

As described in the previous chapter, my research questions are: (1a) How do Saudi mothers describe their experiences and feelings when raising a child that has ASD?; (1b) How do these experiences and feelings shape the meanings the mothers create around raising a child with ASD?; (2) What are the main challenges facing Saudi mothers of children with ASD?; and (3) What are the strategies they use to address these challenges? I also explored the sub-research question: How do challenges faced by mothers from the generation before the special education law differ from those of mothers after the law?

To address my research questions, this study combined autoethnography and interpretative phenomenological analysis (IPA) framed in the IPA approach. I chose to use autoethnography methods to share my story of caring for my child with ASD, the challenges I faced during my journey, and how I overcame them. I also interviewed other Saudi mothers of children with ASD to develop an understanding of their lived experiences with facing this challenge and the strategies they used to address their challenges.

Autoethnography is a type of qualitative research that allows the writer to use self-reflection on his or her personal experiences and stories, and then link their personal autobiography with broader cultural, social, and political contexts (Wall, 2008). As a participant who met all the criteria for this study, I intended to include my own autoethnographic writing and data because I thought my participation in this study would be a valuable addition to the findings and give other participants an opportunity to hear stories from researchers who shared a similar situation, and who may not otherwise feel safe disclosing certain experiences. When a researcher conducts their own autoethnography and combines this information with data from other participants, it is recommended they collect their data prior to the interviews with another participant (McAuliffe, 2019). Therefore, I conducted my interviews and wrote my field notes about my feelings and thoughts in 07/03/2020, before completing the literature review and prior to conducting interviews with any other participants. I also conducted another autoethnography interview using the updated interview protocol to gain a deeper understanding of my feelings and experiences. I conducted my interview prior to the participant interviews to ensure that my responses weren't influenced by the participants' responses (McAuliffe, 2019). Further, when I remembered one of my experiences while interviewing the mothers, I did not change my autoethnography that I wrote before the interviews but added my new experience in a completely different way not to be affected by other mothers' thoughts and responses. For Example, when the myths about ASD in appeared as a theme, I remembered my experience when I believed that vaccinations caused ASD, which was different from the myths of other mothers, such as that ASD is a disease that can be cured or that ASD is a demon.

IPA is committed to the systematic exploration of personal experience (Tomkins, 2017). Using the IPA approach, I am exploring the lived experiences of Saudi mothers of children with ASD, their feelings associated, how they understand their situation as mothers of ASD, and how they draw meaning from that understanding. To seek meaning, IPA focuses on the feelings and memories of participants in order to get access to their inner lives. The participants’ narration of their real-life stories, in combination with the autoethnographic and IPA designs in this study, may illustrate important events when compared to other qualitative research designs.

Autoethnography and phenomenological approaches interface well with each other because there are common aspects between autoethnography and IPA. Both are exploratory, e.g., in both, the researcher (me) and the participants play an important role in the research because both are essential to data collection and analysis. Further, both autoethnography and IPA approaches search for meaning in the narrative. In both, the narrative is descriptive and intense, which gives a broader interpretation and more quality results (Maggs, 2000).

Maggs (2000) also argues that the use of a single approach (e.g., an autoethnographic approach) may leave the research incomplete. For example, the data do not speak for themselves; if we leave the data to speak for themselves without the help of my autoethnography interpretation, we shift the entire burden of interpretation from the researcher to the reader. By combining these methods, I can interpret the data collected from interviews with participants by supporting it with my own autoethnographic writing. Using more than one methodology can help to get a clearer picture of the social world and make for more adequate explanations (Maggs, 2000).

Although combining several data collection and analysis methods in one research study is common, combining the autoethnography and IPA approaches is an emerging area of methodology. Little has been written about combining the two methodological approaches. For example, to the best of my knowledge, there is only one study that combines autoethnography with IPA approaches (Shevack, 2014; used as a model to guide data collection and analysis decisions in the present study).

Data was collected first from my autoethnography writing, e.g., my experiences as a mother of a child with ASD. I reflected and recorded my experiences by 07/03/2020 (journal entries and memos). Second, data included from recorded online interviews that I conducted with six Saudi mothers of children with ASD. IPA aims to make an in-depth examination of particular phenomena, not to create a theory to generalize to the whole.

The combination of autoethnography and IPA gave in-depth and rich information about the participants' lived experiences. This research design and information helped answer the research questions of this dissertation and explored the experiences and feelings of Saudi mothers of children with ASD and the challenges we faced while raising our children and how we overcame them.

Participants

This study was reviewed and approved by the Ethics Committee of the University of North Carolina Greensboro in the US (IRB 21-0082) and the Ethics Committee of the Ministry of Education in Saudi Arabia (21677).

For the autoethnography, I included myself. According to Turpin et al. (1997), samples in IPA studies are usually small to allow detailed analysis of each individual case. There is no rule as to how many participants should be included. It generally depends on the depth of analysis of each case and the richness of individual cases. Thus, the mothers who participated in this study interviewed twice to reach data saturation to collect rich, in-depth data.

Recruitment for IPA

For the IPA, I recruited six Saudi mothers whose children had been diagnosed with ASD (and children who had an ASD and a co-diagnosis, e.g., ASD and intellectual disability). I recruited mothers by posting information about the study in a WhatsApp group for Saudi parents who had children with ASD (See Appendix C for recruitment script). There were three WhatsApp groups to support Saudi parents of children with ASD, which I joined seven years ago. The first group contains 852 participants, the second group includes 706, and the third group includes 564 participants. Participants in these groups are from all cities and villages of Saudi Arabia. My role in all groups is as a member, I am not an administrator of any of them. I share some information about ASD and answer some parents' questions rarely because I do not have enough time to participate. I have no friends in these groups and no one knows any information about me, such as my work or my experiences. Interested mothers sent a private message to me on WhatsApp expressing their willingness to participate.

Inclusion and Exclusion Criteria

Participants for both the autoethnography and IPA were identified based on the following criteria: (1) Parental role: Saudi mothers of a child with ASD; (2) Mothers' age: mothers' ages between 22 and 50; and (3) Children's age: Five to 29 years old.

Interviewing mothers of ages ranging from 22 to 50 enabled me to explore whether young mothers' experiences differ from those of older mothers. Also, choosing the age of children from five to 29 years old helped explore whether the experiences of mothers of younger children differ from those of mothers of adult children. For the autoethnography, I included myself because I met the inclusion criteria: I am a 44 year old Saudi mother of a 16-year-old child with ASD. He was born after special education law was established in Saudi Arabia.

I excluded non-Saudi mothers, Saudi mothers who have no children diagnosed with ASD, mothers of children with ASD who are under 22 or over 50 years old, and mothers of children with ASD whose age is not between five and 29. I excluded fathers because mothers are the primary caregivers and are mostly responsible for the daily care of children with disabilities in Saudi culture.

Participant Screening

I asked the mothers who responded to the WhatsApp invitation the parents screening questions to determine their parental role (e.g., mother), their age, and the child's age. I recruited from the second category (mothers' age) two mothers between the ages of 22 and 39 because their children with ASD were certainly born after special education law (RSEPI), and four mothers between the ages of 40 to 50 because it is highly likely that their children with ASD were born before the law. I found out the challenges faced by mothers from the generation before the law slightly differ from those of mothers after the law. Regarding the child's age category, I recruited two mothers of children born after the RSEPI law between the ages of 22 and 29. I explored whether the challenges faced by mothers of children with ASD who were born before the law slightly differed from the experiences of mothers of children who were born after the law and who benefited from the special education services enacted by the law.

Data Collection

My research questions 1, 2, and 3 were addressed by gathering autoethnography data and interview data from my participants. For the autoethnography part of my study, I recorded my experiences by writing journal entries and memoirs. For gathering information from other mothers, I conducted individual in-depth open-ended interviews (see Appendix A for the interview protocol). After selecting the participants, I arranged a suitable time with each participant for an online Zoom interview. They were not asked to turn on their camera, only the audio recording saved and analyzed. Before starting the interview, I provided information about myself, the purpose of the study, any anticipated positive results, and possible risks from the interview. Also, I informed them that their participation was voluntary, there was no cost to them and no payment to them for these interviews, I recorded the interviews, and all information was kept confidential. I obtained the participants’ verbal consent to these conditions (see Appendix B for the consent script).

I have a deep personal understanding of the phenomenon and can speak to the participants in this study in their native language of Arabic. Thus, I interviewed Saudi mothers of children with ASD in the Arabic language. Based on my pilot study, and consistent with IPA recommendations (Turpin et al., 1997), each interview took one to two hours. I also conducted one follow-up interview with each participant. Marshall and Rossman (2011) reported that three in-depth interviews per participant are appropriate in IPA studies, but that three interviews per participant may require a great deal of commitment on the part of the participants and they may not be able to successfully complete this. Therefore, Marshall and Rossman recommended that data saturation be the primary determinant of the number of interviews. This means continuing to conduct interviews until research results seem saturated, until ideas are repeated, and when no new information is forthcoming.

Interview Protocol

I have adopted the interview protocol for conversations with other ASD mothers from Gobrial (2018), my experiences writing my journal entries, and the pilot that I completed with two mothers. My supervisor and I examined, modified, and added questions to the protocol utilized by Gobrial (2018) to suit the purpose and place of my study. Then the revised interview protocol was shared with a professor who conducts qualitative research in the department of Human Development and Family Studies. The professor was asked to look at the interview questions to make sure that they are suitable for qualitative research and to start using them in conducting interviews. After discussing, we added questions and follow up questions to gain a deeper understanding of the mothers' experiences. I translated the questions into Arabic, which is the language in which I conducted the interviews since it is the first language in Saudi Arabia. After that, I sent the English interview questions to a Saudi doctoral student in UNCG Special Education Department to translate the questions into Arabic. I did this to compare the version I translated into Arabic with the version that the doctoral student translated to make sure the translation was accurate. Finally, the interview protocol was piloted with two Saudi mothers of children with ASD in my pilot study.

The interview questions are open-ended to give participants the opportunity to explain in depth the challenges they faced while raising a child with ASD and how they overcame these challenges. Aligning with the FST theoretical framework (Johnson et al., 2016), I believe that family members will have an impact on the mothers' experiences; thus, I asked for example, what is the reaction of family members when they learn that your child has ASD? Do they blame you for that? Do they support you and your child? In connection with family system theory (Algood, 2013) and previous literature (Balubaid et al.,2017), Saudi culture and religion are the external environmental factors that have a significant impact on the child and his family. Thus, I asked, for example, if there are widespread myths about ASD that influence their care for their children, or if there is pressure from friends and family to use medications or interventions to treat ASD?

The interview questions cover seven main sections, including the child's early life, the impact of ASD on the family, milestones in developing the diagnosis, the child's school, the child's behavior and mental health, the child's social life, and the mothers' life and mental health (additional questions and probes were added after the pilot study and explained in the following section, additions to the protocol based on the pilot). Throughout the seven sections, I also asked the mothers to describe their feelings associated with their experiences. For example, one of my questions is what is your reaction when you know that your child has ASD? Probe: What were your feelings?

The first section consists of 13 questions. The questions in this section focus on the early life of the child. Mothers were asked to share information about the child's birth, the child's order among his siblings, how old and what gender the child is, the first 12 months of the child’s life, diagnosis, the first signs of ASD and its severity, and the mothers' knowledge of ASD. The purpose of this section was to collect information about the child's characteristics and to determine mothers' awareness of ASD at the onset of diagnosis.

The second section consists of seven questions about the impact of ASD on the family. In this section, mothers were asked to discuss in depth their initial reactions when they were informed of the diagnosis, whether friends and relatives blamed them for having a child with ASD, and what was the reaction of the family and siblings to the diagnosis?

The third section contains ten questions about the diagnosis. The questions in the third section asked the mothers to share who discovered that the child was developing differently, and what were their feelings. I also asked how long the diagnosis process took, whether the mothers had to visit several professionals to find out the correct diagnosis and whether the doctor had conducted diagnostic tests. I asked mothers to share who directed them to the services that the child needed after the diagnosis, the extent of their satisfaction with these services, and the extent of the impact of the diagnosis on the family.

The fourth section consists of four questions about a child’s education. In this section I asked mothers to share the type of the child’s school (whether is it an inclusive school or a separate school for students with special needs), who made the child’s placement decision, and whether the teachers were qualified to work with children with ASD. I wanted to understand if mothers are generally satisfied with the educational services for their children.

The fifth section includes six questions all of which revolve around the child's behavior and mental health. I asked the mothers to share their child's aggressive behaviors, anger, and anxiety. I also asked about medicines and interventions to manage these behaviors, and if the medicines/interventions are costly and useful. The sixth section consists of four questions about the child's social life. I asked the mothers about relationships, friendships, and if the child participates in other activities, e.g., sports. I asked mothers to share their concerns about their child's sexual life.

The seventh section consists of seven questions about mothers, their social life, and their mental health. For example, do they have friends who support them? Do they feel anger or despair, and what do they do to overcome these feelings, if any? I asked mothers to share any pressures they face from family or friends to treat ASD and whether there are any prevalent myths about ASD in their communities that affect them. The purpose of this section is to access the unique individual stories that mothers want to share regarding their struggles and success with raising a child with ASD. Finally, I asked mothers to share any questions and ideas they may want to share that are not addressed in the protocol.

Similar to the methods described in McAuliffe (2019), I used my personal stories to get more information, especially regarding sensitive topics that the participant did not feel comfortable talking about. However, since I have the experience of raising a child with ASD in Saudi, I shared personal stories about my experiences. These personal stories encouraged mothers to talk about their own similar experiences for two reasons: (1) Participants felt that they were not alone in experiencing; and (2) They wanted to benefit others by mentioning their personal experiences (Annabelle et al., 2014). This method was utilized in this dissertation: Faten seemed hesitant to speak about her husband's family support for her and her child with ASD. I told her a personal story about my experiences of lack of support from people close to me. Afterward she felt comfortable and shared her experiences (see Appendix D for the personal story as an example).

Additions to the Protocol Based on Pilot Interviews

Purpose of Pilot Studies. A pilot study is a small version of a designed research study that is a trial of the study methods. The pilot study is conducted with a small group of participants similar to those who will be recruited later in the larger research study (Doody, 2015). In preparation for this dissertation research, I conducted a pilot study to help me examine the interview protocol, evaluate research methods, data collection and analysis procedures, and evaluate the significance of the proposed research. Pilot studies may not give conclusive results as Doody (2015) mentioned, but the one I conducted enabled me to anticipate potential problems in advance and to make necessary adjustments before they jeopardized the success of my dissertation. The purpose of my pilot study was to determine whether the interview questions would clearly identify the challenges faced by mothers of children with ASD in Saudi Arabia and how they overcame these challenges. I made some adjustments to the interview protocol based on the findings of my pilot study.

Procedures for the Pilot Study. Once the IRB was obtained, I conducted in-depth interviews with two Saudi mothers whose children were diagnosed with ASD. I did the interviews individually via Zoom. Each interview lasted from one to two hours. Interviews were recorded to ensure that participants' responses were accurately captured. After the end of each interview, I transcribed the interviews directly. I conducted follow-up interviews with each mother individually to discuss my findings.

Revisions to the Interview Protocol. My pilot study showed that the interview questions were sound and could be used in my dissertation. I heard about many challenges faced by Saudi mothers of children with ASD (e.g., ignorance, feelings of guilt, fear, anxiety, diminished social relationships, and lack of services), but I heard only about two strategies used by mothers to overcome these challenges (e.g., the distraction strategy and the strategy of accepting reality.) Thus, my pilot study drew my attention to the need to pay close attention to the strategies mothers have used to overcome the challenges they faced while raising a child with ASD. That is why I reviewed the protocol to include direct questions about the strategies. For example, in my pilot, I asked the mothers what they do when they feel upset. However, I did not receive detailed or specific information about the strategies that they used. Therefore, in my dissertation, I asked more detailed questions. I asked mothers to reflect upon strategies that are/were helpful for their children with ASD and strategies that are/were beneficial for the mothers' well-being.

To ask about children's strategies, first I asked the mothers to share the strategies or activities that were helpful for their child in general. When they did not provide specific and detailed information, I asked mothers to share a specific therapy, strategy, assistive device, or activity that made a significant difference in any aspect of their child with ASD and how they obtained or heard about it. To ask about mother strategies, I asked the mothers to share activities or strategies they used to relieve when they were stressed or worried about their child with ASD. When they did not speak about this in detail, I used probing questions, including: (1) the strategies used to solve problems that arose while raising a child with ASD, how they obtained the correct information to solve the problem, and the strategies used to relieve their and their children's stress while the problem occurred; and (2) the strategies used in the event of their dissatisfaction with health, community, and educational services.

To make sure I got the strategies mothers used to meet their challenges, I asked general closing questions about strategies. For example, I asked mothers to share one or two of their best experiences raising a child with ASD and why have these been the best. I also asked mothers to give advice to others who have just learned that they have a child with ASD. More details on strategies questions are in the interview protocol in Appendix A.

Follow-Up Interviews

I conducted one follow-up interview with each participant. Follow-up interviews helped me to talk with the participants about what was talked about in the first in-depth interviews to get new insights, clarify some questions, and share interpretations of the findings directly with the participants to get their reactions and enhance the trustworthiness of this study (Holter et al., 2019).

During the follow-up interviews, I presented my study findings to the participants as a visual image (see table 3 in appendix E). This strategy is considered a type of photo-elicitation interview (McAuliffe, 2019). I asked the mothers to think about the study themes and share their sights on whether the themes really represent their personal experiences, the challenges they faced in raising a child with ASD, and the strategies they used to overcome these challenges.

During the data analysis, I analyzed each transcript for each interview separately. Each transcript had themes representing the personal experiences of each mother, and, in the end, I collected similar themes for the final findings of my dissertation. To ensure confidentiality when explaining the findings to participants in the follow-up interview, I conducted a follow-up interview with each participant separately. I discussed and presented to each participant the findings of her interview only. When I shared everyone’s findings to encourage the other mothers to speak about an experience that they didn’t share in the first interview, I did not share any identifiable information (e.g., names or locations) to protect confidentiality.

Transcription and Translation

Transcription

After noting my experiences in autoethnography and collecting interview data from the participants, I made a backup copy of the recorded interviews in order to avoid the risk of damaged or lost content. After that, I transcribed the content of the recording tapes by hand into Arabic written text (due to the lack of reliable computer programs that convert Arabic language audio content into accurate written text). I transcribed all the interviews for this study verbatim, which meant that all pertinent details were included without leaving out any of the participant's speech. According to Maxwell (1992), leaving out some pertinent details would compromise the validity of the study, which is important for comprehending the interview. I reviewed the written content and compared it with the original content in the audio recording.

Translation

The participants in this study were Arabic speaking Saudi mothers of children with ASD; however, since this is a research study for a US Ph.D., the findings should be presented in English. Therefore, translations from Arabic to English should be provided for findings. In qualitative research, it is common practice to collect data in one language and present the findings in another, but this requires translators to be linguistically proficient in both languages and have knowledge of the culture of the participants under study (Regmi, 2010).

To do the translation, I used the forward translation method. Forward translation is the recruitment of two bilingual people who translate interview findings from Arabic into English (McDermott et al., 1994). Then, I compared each person's version to check for accuracy and equivalence and to find any differences between the two translated versions. For more accuracy, I did the backward translation, where the English findings were translated back into the language of the original findings (Arabic) by the two bilingual people (e.g., myself and the external reviewer) who were involved in the translation process.

There are different types of translation techniques used when translating the participants' words. In this study, I used literal translation and free translation. The literal translation is translating the text word by word without paying much attention to the meaning of the text in general. Therefore, in the literal translation, the meaning of the original text may be lost or changed, which may make it difficult for readers to understand the translated text. The literal translation preserves all the details and words of the participants without distortion, and the literal translation preserves the same syntax as the original text. The free translation does not translate the text word by word; it seeks to provide the best general meaning of the original text. When using the free translation, the translator may or may not follow the same structure as the original text, may omit many details, and may delete some of the participants’ words in order to preserve the content and natural language flow (Regmi, 2010). Therefore, I used both free and literal translation in translating the findings of the interviews in this study from Arabic into English to preserve the meaning and readability of the text, kept the details, and kept the participants’ words as best I could. I also went back to the original text when needed until reaching a level of satisfaction and clarity.

Data Analysis

The three major IPA and autoethnography guidelines for data analysis that Smith and Osborn (2004) initially established were: (1) “looking for themes in the first case”; (2) “connecting the themes”; and (3) “continuing the analysis with other cases” (p. 23). Jeong and Othman (2016) expanded on these guidelines and established a six-step IPA data analysis methodology that I followed and applied to my own autoethnography data first and then IPA data from interview participants: (1) Reading and making initial notes on the transcripts; (2) Developing emergent themes; (3) Looking for connections between emergent themes to develop themes and subthemes; (4) Producing table of themes for each transcript; (5) Repeating the first four steps for other participants; and finally (6) Looking for shared patterns across participants. By this stage themes and subthemes should become apparent and applicable to the majority of cases.

Reading and Making Initial Notes

I read and reread all transcripts throughout the initial phase of data analysis to allow for my complete involvement in the procedure. I read the transcripts while listening to the interview's audio recordings in an effort to be as "near" to the data as feasible (Pietkiewicz et al., 2012). With each reading, I commented on the transcript's margin with my initial thoughts. Since there are no restrictions on what can be commented on (Sparkes & Smith, 2014), any opinions, observations, or reflections regarding the participant's narratives were noted. In order to generate a more in-depth, interpretive analysis, it was crucial to go beyond simple description. Taking into consideration not only what was said, but how it was stated, I tried to understand the feeling and meaning of what was said. (Pietkiewicz et al., 2012). I read my data several times and started to create tentative labels for chunks of data, e.g., I began to use open coding. Open annotated coding makes it possible for participants to express themselves in their own unique ways rather than being dominated by preconceived ideas found in the literature (Williams et al., 2019).

Developing Emergent Themes

After reading the transcript several times and making notes on it, I went back to the beginning to record any codes or possible themes that had emerged. Emergent themes are a basic building block of inductive approaches (Creswell et al., 2000). I did not use the transcript itself to identify emerging themes because precise and thorough comments/notes were created in the previous stage. From my first note-taking, I saw the recurring themes that I translated later into succinct words (codes) that captured the essence of what I had learned from the transcript. These emergent themes were slightly more abstract than the initial notes, allowing for the creation of theoretical linkages, and I made sure that they are still rooted in the uniqueness of the participant's initial answer.

To develop these emergent themes, I used a mixed approach to coding which involved both inductive and deductive coding (Skjott, 2019). I first used inductive coding, meaning I analyzed the autoethnography and interview data without pre-defined codes. I developed codes based on what I found inside the data during the analyzing process (Williams, 2019). Inductive coding helped me analyze the open-ended interviews that I conducted in this dissertation, as I did not necessarily know the direction in which the conversation would go during the interview. For example, one conversation started with a discussion about depression due to caring for a child with ASD and it went on to include anxiety and fear, so I was able to use these codes as I progressed in my analysis.

Inductive coding derived from data is usually used when researchers want to explore new ideas or concepts or phenomena (Williams, 2019). Therefore, it helped me answer the questions of this thesis and explored the experiences, feelings, and challenges that Saudi mothers of children with ASD face while raising a child with ASD, in addition to exploring strategies to overcome these challenges. After completing the inductive analysis of my data to identify the themes, I used deductive coding (Skjott, 2019) to analyze the data based on the family system theory. Thus, I analyzed the data based on the three family characteristics described in FST (family size, form, and culture). I analyzed my data into those three predefined theory-based categories to complete the deductive coding.

The codes were developed during the analysis and I used codes already found in existing literature and theories. Still, I developed some codes while analyzing interviews I conducted with the mothers in my pilot study. Table 2 in Chapter 2 did partially serve as a code book in this dissertation when the emerging codes are similar to the themes found in the literature review. However, I have added questions to the interview protocol that are related to the revised research questions. For example, questions about strategies used to overcome challenges, and questions about the participants' ages and their children's ages were added to this dissertation.

Looking for Connections Between Emergent Themes

According to Smith and Osborn (2008), I looked for connections between emerging themes on a separate sheet of paper with the emerging themes recorded in chronological order, depending on the order they appeared in the transcript, and I searched for links between emergent themes based on conceptual similarity. When most of the themes were grouped together, I kept the themes that appeared as higher-order notions and had connections with one another. I dropped the themes that had insufficient supporting data: for example, fewer than three mothers (including me) discussed a certain theme. After grouping emergent themes, I went back to the transcript to make sure the connections of the themes with the raw data were accurate. By this point in the analysis, I might stray from the exact words of participants as per the interpretive analysis (Pietkiewicz et al., 2012), but I tried to make sure that I stayed close to the essence of the participant's words.

Producing a Table of Themes

The collated themes and sub-themes were then put into a table to provide a composite portrayal of experiences (Denovan &Macaskill, 2012). The table included a quote, feeling, and meaning next to each theme and I organized the sub-themes within their corresponding themes. By doing this, I preserved the voice of each participant's unique story and I helped the reader follow the analytical process as the data moved from the original source to the themes table. (The Table of Themes is included in Appendix E).

Repeating the First Four Steps for other Participants

After putting the themes/subthemes in a table for the first participant, I repeated the previous analysis process when analyzing the next transcript. The researchers may choose to use themes from the initial case to help with their subsequent analysis, according to earlier IPA literature (Smith et al., 1999), but recently have emphasized the importance of treating each case "on its own terms, to do justice to its own individuality" (Smith et al., 2009, p. 100). In this stage, it is possible that my analysis will be influenced by my findings from the previous participant’s transcript. However, I did my best to separately analyze each transcript.

Looking for Shared Patterns Across Participants

After repeating the previous analysis process to analysis each transcript, I created a final table of themes and sub-themes (included in Appendix E). I revisited the table of themes for each participant, reviewed them, made any required changes, and I re-read the original transcripts when necessary. Themes related to the research question were described. Smith and Osborn (2008) argued that themes should be chosen not only based on how frequently they appear in the data, but also on the depth and richness of the information that supports the theme. Although I was planning that a theme needed to be discussed by at least two participants (and I) to be labeled a theme, I chose the themes by how long phenomena were discussed and how much importance mothers gave them. This may create a risk of prioritizing those participants who were more articulate and verbose. I believe that for my dissertation this was not a problem because IPA methodology requires in-depth interviews with each participant of at least an hour, follow-up interviews, and probe questions which helped me to build a relationship with the participants. Thus, I built good relationships with the participants which encouraged all the participants to be more articulate and verbose (Creswell et al., 2000).

To conduct the analysis for exploring the differences in challenges faced by mothers of children with ASD who were born before and after the special education law in Saudi Arabia, I first identified themes in the transcripts related to the challenges faced by these mothers. I then highlighted each theme with a different color to make it easier to compare across the transcripts. By comparing the transcripts in this way, I could see if mothers of children born before and after the law faced similar or different challenges based on whether or not they had the same color-coded themes. If two transcripts had the same color for a particular theme, that would indicate that the mothers in both interviews faced a similar challenge related to that theme.

Seeking the Creation of Meaning

Meaning is fundamental in IPA, and the goal that the researcher seeks in IPA is to comprehend the intricacy and richness of those meanings. These meanings are not directly and clearly available. As a result, the researcher must engage in an interpretive relationship with the text and make an effort to capture the meanings provided by the participants in order to understand their social and mental environments (McAuliffe, 2019).

When analyzing the data in this study, I moved beyond superficial expressions or explicit meanings and focused on reading between the lines to reach the dimensions and implicit axioms.

As recommended by McAuliffe (2019), analyzing the participants' feelings helped me to reach the deeper meaning that the participants intended. For example, Amal, one of the women who took part in my pilot study, mentioned that raising a child with ASD made her feel nauseous. By analyzing what she feels when she says she feels nauseous, I realized the deeper meaning behind saying feeling nauseous, was that she suffers from stress, anxiety, fear, and guilt.

When analyzing IPA data, I engaged in double interpretation, which means: (1) my participants try to understand their world; and (2) I try to understand the participants trying to understand their world. As a result, the researcher is crucial to the analysis and interpretation of participant experiences.

Trustworthiness

Trustworthiness in qualitative research refers to the quality and rigor in conducting research and reporting data by ensuring credibility, dependability, and generalization (Le Roux, 2017). Trustworthiness in this study was achieved by utilizing member checking, peer debriefing, and an audit trail.

To enhance accuracy in qualitative research, Lincoln and Guba (1985) recommended member checking. This study used two ways of member checking. First, I sent the transcripts to the participants to check the accuracy of the transcription. I also conducted follow-up interviews with the mothers after analyzing the data. During the follow-up interview, I shared my study findings with the mothers and asked them to think about the study themes and share their insights on whether the themes truly represented their personal experiences to ensure that I had not misinterpreted what was said.

To complete peer debriefing, I followed the recommendations from Lincoln and Guba (1985). An Arabic colleague who is an expert in qualitative research agreed to complete peer debriefing. She read the Arabic interview transcripts and reviewed my analysis to check the compatibility in identifying themes and subthemes. The expert review and consensus were achieved by my colleague and me. After the consensus, I finalized the themes and subthemes. Lastly, throughout the data analysis process, I used an audit trail strategy that clearly described the steps I followed to manage threats to trustworthiness.

CHAPTER IV: RESULTS

Findings And Themes

Background and Demographics

In presenting my findings, all names other than my own are pseudonyms. My study included six mothers and myself. Our educational backgrounds ranged from elementary education to master's degrees. We lived in a variety of different places, including large cities and small towns. We were all married. Five children (including my son) were born pre-law and two children post-law. Three mothers work outside of the home, and three do not.

Mashael and Azoz

I am Mashael, 44 years old. I work as a lecturer at a Saudi University, though I am currently on a scholarship to obtain a doctorate from an American University in the Specialized Education Services Department. I have three sons and a daughter. All are in good health and do not have disabilities, except for my second son, Azoz, who is 16 years old. After Azoz's birth, I completed my master's and pursued a doctorate in special education, focused on ASD, to help my son. Azoz is a tall child, thin because he is selective with food. Azoz was born in 2006 . He was diagnosed with ASD when he was four years old. He was diagnosed with intellectual disability at 12 years by a specialized team at a school for children with ASD that he attended in the US when he moved with me to the US to obtain my doctorate. Azoz is non-verbal, has difficulty sleeping, and has difficulty changing routines. He is not toilet trained, as he completely depends on me to shower and prepare food, but he can get dressed and undressed by himself. He can feed himself food that can be eaten with fingers, but he cannot use a fork or knife. Azoz was born in Saudi Arabia and spent eight years there. Then he moved with me to the United States and spent seven years in the US. During these years, he received occupational and physical therapy and educational services. Azoz does not take any kind of prescription medicine. He takes over-the-counter remedies, such as melatonin, to alleviate his sleep problems. To learn more about my son and me, and our family, please refer to Chapter I where I discuss my personal story.

Zain and Tee

Zain is 38 years old. She worked as a teaching assistant in the Department of Biochemistry at a Saudi university. The university where she works sent her to Australia to complete her master's and doctoral degrees. She could not complete her postgraduate studies because of her son's health condition, and the university where she currently works transferred her to administrative work. During her pregnancy, Zain did not experience any health issues. However, she was sad and tense because she had the scholarship to study abroad during her pregnancy, and it was challenging to adapt to a new country away from family and friends. By reading and from her experience as a mother of a child with ASD, Zain has much knowledge about special education and ASD. She lives in one of the major cities of Saudi Arabia with her husband and only son. Her child with ASD is her only child because she believes she will be required to devote much time and effort to raising and educating him. Since the birth of her son, Zain has been suffering from depression, and she continues to take antidepressants under a physician's supervision.

Tee is a nine-year-old boy born with a congenital defect: a cleft palate and deformities in the jaw and speech organs. Because of the cleft palate, milk leaked from his milk bottle into his lung and caused pneumonia. He underwent an operation in the first year of his life and was fed through a tube extended to his stomach for two years which caused a delay in pronouncing words. Tee has communication disorders, Attention-Deficit Hyperactivity Disorder (ADHD), and struggles to make friends. When Tee was three, he was diagnosed with communication disorders and underwent speech therapy sessions for one year. As a result of these sessions, Tee began to speak, but he could not use the words properly or express himself or what he wanted. He only expressed hunger, pain, fear, and all feelings by crying. Tee was diagnosed with ASD at the age of five. As a result, Tee began receiving occupational and physical therapy and intensive speech therapy sessions. Still, during those sessions, the specialists noticed Tee's hyperactivity and advised him to take medication. During these sessions and after taking the medication, Tee became less hyperactive, more focused, and able to express himself better. Tee enjoys swimming, reading, and watching TV. Currently, Tee is in the third grade in a private inclusive elementary school at no cost to the family because the Saudi Ministry of Education pays for the annual fees. The Ministry of Education pays annual fees as support for families whose children could not access free education.

Hala and Hamad

Hala is 34 years old. She earned a master's degree in Network Engineering from a major American university. Despite several job offers; she refuses to take up employment because she wants to devote herself to caring for her son with ASD. Her son with ASD lives with her in one of Saudi Arabia's largest cities, along with two daughters, one of whom is 15 and the other 11 years old. Hala's 11-year-old daughter has attention deficit hyperactivity disorder (ADHD). Hala's husband works in another city and spends only weekends with his wife and children, so Hala takes on the role of mother and father and takes care of her son with ASD on her own. Hala has suffered from anxiety since her son was diagnosed with ASD. Hala is passionate about learning about ASD and would like to contribute to any research that aims to enrich the knowledge about children with ASD and their families.

Hamad is eight years old. His siblings include two sisters. Hamad is the third and last child in the family. He was diagnosed with ASD and ADHD at one year and eight months old. He spent ten days in intensive care following his birth due to water entering his lungs during delivery. In his first year of life, Hamad seemed to be developing in a typical manner. When he was fourteen months old, he had inflammation of the seventh facial nerve, which left half of his face paralyzed. Then he became extremely nervous and lost the ability to speak. Currently, Hamad does not have any difficulties with eye contact, speech, communication, or language. Hamad has good cognitive abilities, but he has some repetitive behaviors (e.g., playing certain games repeatedly), behavioral issues (e.g., hitting, stubbornness), and severe sensory issues (e.g., being sensitive to loud noises). Hamad loves physical games like running and tickling. He attends an inclusive public school in the morning and receives occupational and speech therapy in the evening at a private ASD center. Hamad does not take any prescription medication.

Safi and Taleen

Safi is 45 years old and lives in one of the small cities in Saudi Arabia, with her husband and three children, two daughters and a son. One of Safi's daughters has ASD and the rest of her children are healthy. They help Safi take care of her daughter with ASD. Safi's family has a maid who Safi has trained to support children with ASD. In the morning, Safi works as a social worker in an elementary school and in the evening as a volunteer in a charitable organization that supports people with disabilities. This association offers free workshops for the association employees on ASD, its causes, symptoms, and how to support a child with ASD. After learning that her daughter had ASD, Safi decided not to have more children so she could devote herself fully to caring for her. Safi is keen to attend behavior modification and speech therapy sessions provided by the ASD profit center for her daughter. Safi applies the sessions with her daughter at home in front of the maid to teach her to apply the sessions in case the mother is busy.

Taleen is 15 years old. She is the third and last child in her family. She was diagnosed with ASD and ADHD when she was eighteen months old. She started receiving 30-minute behavior modification sessions twice weekly because she was very young, not yet two years old. She does all daily tasks independently, without assistance. Taleen does not exhibit repetitive behavior or difficulties with eye contact. While Taleen can say words like ‘hungry’ and ‘bored’, she cannot make long sentences like her peers and has trouble pronouncing some letters. She has some aggressive behaviors, such as biting her hand if she gets angry, but she does not harm others and does not like to play with children. She is not picky about food and loves healthy food but has a peanut and soy allergy. She does not take prescription medication. Although Taleen is fifteen years old, the school placed Taleen in fifth grade at an inclusive school, but she is in a self-contained classroom. Swimming is one of Taleen's favorite physical activities.

Faten and Fadi

Faten is 50 years old. She lives in the Saudi large city, with her five children, her husband, and her husband's parents. She has two daughters and three sons, one with ASD and the others are healthy. The husband is an engineer who moves between Saudi Arabian cities, thus, he is at home in the weekends. Faten is responsible for all household duties, including school and hospital appointments, cooking, and cleaning. Her husband's parents are older and also need support, so Faten takes them to doctor appointments and provides them with food and medicine. Faten worked as a physics teacher in high school, but her husband asked her to leave her job to devote herself to caring for their child with ASD. She knows much about ASD but sought out specialized services or therapies because her husband refuses many interventions that could benefit her son. Faten has depression and receives behavioral therapy.

Fadi, a 20-year-old boy, is the third among his siblings. He experienced a lack of oxygen during his birth, so he has epilepsy and very slow motor development. From the age of 11 days, Fadi started visiting the doctor every month for an EEG and CT scan, and he started receiving physical therapy at one year and two months because he was not meeting large motor developmental milestones; e.g., he did not sit, and did not walk. Fadi was diagnosed with ASD at the age of five years. He does not have verbal communication, does not feel pain, and is not trained in using the bathroom. He is very calm and non-aggressive. He did not receive any educational services until he reached the age of 12 years, after which he joined a for- profit ASD center. However, he attended for only one semester because his father could not afford to continue to pay the center's costs. Fadi takes epilepsy prescription medications that negatively affect his balance while walking, which led to a recent fall and a collarbone fracture.

Farah and Abadi

Farah is 45 years old. She lives in a small city in Saudi Arabia, with nine children (six daughters and three sons), her husband, and two adopted children. Her oldest child, 25 years old, was diagnosed with Asperger syndrome and works as an engineer in an oil company in Saudi Arabia. Her middle daughter, 22 years old, has ADHD and works as a translator at the Saudi Ministry of Interior. Her youngest son is 17 years old and has ASD. Farah's family has a maid who does all the housework, so Farah devotes her time to caring for her son with ASD and her older husband, who has diabetes. Farah finished elementary school. Her experiences with her children and reading books about ADHD helped her learn about ASD and ADHD. Farah enjoys reading and has an extensive library of books in special education. She suffers from depression and undergoes behavioral therapy.

Abadi is a 17-year-old. He is the last of nine brothers in his family. When Abadi was two years and eight months old, he began to lose the ability to speak, memorize and focus. He had problems with visual and verbal communication, in addition to displaying stereotypical behaviors such as hand flapping. Abadi was diagnosed with ASD and ADHD when he was three years old. After the diagnosis, Abadi received speech therapy sessions that enabled him to regain his ability to pronounce some of the words he had lost. He now asks for what he wants and expresses his feelings in simple sentences. Abadi is self-reliant in all daily skills (e.g., toileting, cooking) and has no aggressive behaviors. He is picky about food and has sensory issues (e.g., fear of loud sounds and lights). To treat some sensory problems, Abadi received 20 auditory integration sessions. He currently attends a public segregated school for children with ASD and intellectual disabilities. Abadi takes prescription medication for depression, social phobia, obsessive-compulsive disorder, and some nutritional supplements (e.g., omega-3, vitamins B and D). Abadi loves handicrafts, for example, making bracelets and necklaces from beads and selling them to friends and relatives.

Mai and Mazen

Mai is 50 years old. Mai lives in one of the major cities in Saudi Arabia, with her husband and four children (three sons and a daughter), all of whom are healthy, except for her third son, who has ASD. Mai's husband works as a naval officer and spends most of his days at sea, so Mai is fully responsible for caring for her son with ASD. Mai obtained a university degree majoring in English and worked as an administrator in a school for five years, after which she had to leave work to care for her son due to her husband's busy work schedule. Mai has cancer. In addition to taking medication to treat her cancer, Mai is undergoing chemotherapy.

Mazen is 29 years old. He is third among his four siblings. Since birth, Mazen has been suffering from epilepsy. He still takes prescription medication to control the condition. Mazen attended school for students without disabilities until the fifth grade, but the school suspended him because he was hyperactive and slow to learn. As ASD and ADHD were unknown conditions at the time, Mazen was left without education until he was diagnosed with ASD and ADHD at 17 years. After that, Mazen joined the ASD center in Jordan for only five months but his parents withdrew him because the center was costly. Mazen can read and write, has an excellent visual memory, and is self-reliant in daily skills. Still, he has aggressive behaviors such as hitting and some stereotypical behaviors and echolalia. Mazen loves painting, handicrafts, and sculpture. He participated in many art exhibitions and has won many awards.

Findings

After interviewing these mothers and exploring my own autoethnography, I began to uncover similar themes that addressed my research questions. The main research questions in my study are: (1a) How do Saudi mothers describe their experiences and feelings when raising a child that has ASD?; (1b) How do these experiences and feelings shape the meanings the mothers create around raising a child with ASD?; (2) What are the main challenges facing Saudi mothers of children with ASD?; and (3) What are the strategies they use to address these challenges? A sub-research question is: How do challenges faced by mothers from the generation before the special education law differ from those of mothers after the law?

This section includes themes identified from the analysis of the interview transcripts and my autoethnography data. The participants and I have a history of challenges and different individual circumstances while raising a child with ASD. This history and circumstances have affected our thoughts, feelings, views, how we overcame these challenges, and the way in which we make meaning from these experiences. We also discussed different coping strategies (e.g., spirituality, social media, our own knowledge and self-learning are the key to our strength and success.

To address my first research question, I will first discuss the challenges faced by myself and the mothers which are represented by the following main themes: (1) Dissatisfaction with the services provided to children with ASD; (2) Insufficient information about ASD; (3) Blame, pity, and nonacceptance of children with ASD from others hurt mothers' feelings, contributing to them feeling lonely and isolated from society; (4) Feelings of anger at family, friends, and social support provided for mothers of children with ASD; and (5) Feelings of fear and worries.

In response to my second research question, I will describe the strategies that mothers and I used to overcome the challenges we faced while raising our children, which include the following themes: (1) spirituality, (2) social media, (3) our own knowledge and self-learning as the key to our strength and success.

To address the secondary research questions related to exploring the challenges faced by mothers whose children with ASD were born before or after the establishment of the ASD law in Saudi Arabia, I found slight differences in the following themes: (1) Dissatisfaction with the services provided to children with ASD; (2) Insufficient information about ASD; (3) Feeling lonely and isolated from society; (4) Anger because lack of support; and (5) Feelings of fear and worries.

Consistent with IPA methodology (Tomkins, 2017), I will discuss the experiences, feelings, and meaning associated with each theme. Table 3 (in Appendix E) describes the findings related to the first and second research questions.

Challenges

Dissatisfaction with the Services Provided to Children with ASD

One of the challenges the mothers and I faced in this study was dissatisfaction with educational and diagnostic services. This theme includes two sub-themes: (1) Dissatisfaction with educational services; and (2) Dissatisfaction with diagnostic services.

Dissatisfaction with Educational Services. In this study, most of the mothers and I reported our dissatisfaction with the educational services provided to our children with ASD in some inclusive schools. For example, Safi experienced inadequate support and resources for her daughter with ASD in the inclusive school. Safi said the school day for her daughter with ASD is short and insufficient to teach her the necessary academic skills. Also, excluding her daughter from the morning line and listening to the morning speech due to a lack of monitoring by special education teachers isolates her daughter from students without disabilities. From Safi's view, this means the lack of monitoring by special education teachers during the morning line shows a lack of commitment to inclusion and a failure to provide adequate support for children with ASD in her daughter's school. This indicates that Safi believes that there should be consistent and clear rules for inclusion for all so that teachers know their duties and rights and what must be done for inclusion to succeed.

> However, I am not satisfied with the duration of the school day, as it is very short, starting from 7:00 am until 11:00 am. Four hours a day is insufficient to teach children with ASD academic skills. In addition, the school prevents students with ASD from

> attending the morning assembly and listening to the morning speech on the pretext that the number of teachers assigned to monitor the morning assembly is insufficient to monitor all students with ASD. All the special education teachers working in the school were supposed to observe the students with ASD in the morning assembly, not just some of them. Special education teachers receive additional salaries to teach and supervise children with ASD and must fully perform their work. (Safi)

Additionally, the experience described by Hala is that she observed in one inclusive school a wall separating students with ASD from students without disabilities in the same class, with only a small hole for them to see the board. This experience made Hala feel dissatisfied with the way children with ASD are integrated with children without disabilities in that school; this led Hala to hide her son's ASD and enroll him in a school for students without disabilities. This means for Hala, the school was practicing a wrong way of inclusion that promotes discrimination and bullying towards students with ASD.

> Also, I would like to say that before I enrolled my son in a school for typical students and hid my son's ASD, I visited one of the inclusive schools. I saw a wall between students with ASD and typical students in the same class. There is a hole in this wall so the students with ASD can see the board. The wrong method of inclusion that I saw has a kind of discrimination and bullying is that prompted me to hide my son's ASD. (Hala)

Faten also described in her experience that her son did not feel comfortable in one inclusive school because the teachers were not qualified to deal with children with ASD and did not have sufficient experience in special education. In addition, the classrooms were not adequately prepared, and the students spent most of their time sitting around a table without any useful or engaging activities. Therefore, Faten felt dissatisfied with the services provided to her child in that inclusive school. For her, this means that it is necessary to have qualified, trained teachers who can effectively support the needs of students with ASD in inclusive settings. Further, there is a need for appropriate preparation and activities to engage and benefit all students.

> My son's center asked me to transfer him to inclusive schools because the conditions for inclusion with typical children apply to him. Unfortunately, my son felt uncomfortable in inclusion school and behaved like crazy. I feel dissatisfied with this inclusive school either, as the teachers were not qualified to deal with children with ASD. Children spend most of their school day gathered around a circular table without any activities that benefit or entertain them. Teachers allow children with ASD to integrate with typical children during recess and Art class. Still, the Art teachers of typical students objected to the inclusion and said that children with ASD distract typical children. Teachers need training and supervision. (Faten)

Dissatisfaction with Diagnostic Services. Interview data showed that some mothers and I expressed dissatisfaction with the diagnostic services provided to our children with ASD. Mothers and I stated that obtaining an official diagnosis was a long, complicated, and confusing process due to a lack of specialists conducting the diagnosis and the absence of clear and specific tools and tests that diagnostic professionals should follow. According to Safi’s experience, she moved between Saudi cities to get her daughter diagnosed. She visited a pediatrician and a professor specializing in speech and communication, but neither conducted an official test to diagnose Safi's daughter. They told her that Taleen was “normal” because she could assemble a puzzle and blow bubbles. Having experienced this, Safi felt dissatisfied with the diagnosis results. From Safi’s view, this means that while Saudi Arabia provides good medical services to children with ASD; she would appreciate the availability of specialists in diagnosis so that the mother and child may save time and conduct early intervention rather than moving between pediatricians, psychiatrists, or ASD professors to find a diagnosis. Safi described her journey with the diagnosis:

> I took my daughter to pediatricians and professors in the field of ASD in several cities. And they all said that my daughter was normal without running any formal tests. Some of them did a bubble test. When my daughter blew bubbles, they told me she was normal because a child with ASD could not master this skill. I was unsatisfied with this diagnosis because I noticed my daughter was not normal and had hyperactivity. After that, I took my daughter to a professor specializing in speech and working after his retirement from academic work in an ASD center. He gave my daughter a puzzle, and my daughter was able to put them together correctly. So, the doctor said my daughter is fine because a child with ASD can only do this after intensive training. I was upset and not convinced of this diagnosis, so I went to a professor specializing in psychology who worked in a profit center. She ran some tests and asked me some questions, which I do not remember well now, and then she said that my daughter has ASD. (Safi)

Faten also reported feeling frustrated and confused during her journey with her son's diagnosis. She felt the diagnosis results were misleading because, during her experience, she got two different diagnoses from two pediatricians, one of whom told her that her son had ASD. The other told her that her son has epilepsy and physical disability only. Both doctors did not run any formal tests. This means, for Faten, having clear and scientifically based diagnostic tools and tests should be considered by the Ministry of Health. She said in detail:

> My son was diagnosed with ASD at the age of five. Unfortunately, this delay was due to my son's doctor, who had followed up with him since birth. He told me that my son only suffers from epilepsy and physical disability. But fortunately, after I had a child with a disability, I read about disabilities and disorders. I noticed that my child had ASD traits, such as losing the ability to communicate verbally and visually. During one of my visits to a pediatrician, I told him what I noticed in my child. It was his opinion that if he had these characteristics, he would have ASD without a formal diagnosis, tests, or even a referral to someone who specializes in ASD. I was worried and scared because the doctor didn't do any tests and relied on my words. This is frustrating. I think to facilitate diagnosis, the Ministry of Health needs to provide clinics with clear guidelines throughout the diagnosis process. (Faten)

In my autoethnography writing, I mentioned that the pediatrician did not run any formal tests or use diagnostic tools when I visited him to diagnose my son. This made me feel dissatisfied with the outcome of the diagnosis and I searched for another doctor to conduct the diagnosis. This means to me that the pediatrician is not qualified to make the diagnosis because I expected him to conduct an IQ test at least or refer me to a specialized doctor. From my point of view, the diagnosis must be conducted by a specialized doctor who uses diagnostic tools based on scientific principles in order to avoid a wrong diagnosis or a late diagnosis that affects the type and timing of early intervention.

> My first visit to the pediatrician took place when Azoz was 14 months old. I told the doctor about my fears and doubts, and that I felt my child was abnormal. I told him that he only says "Mama". The doctor looked at my son and gave him a pen. When my son held the pen, the doctor said “Look, your son responds, do not worry”. He also said that

> “if the child utters a word, he will utter the rest of the words; your son needs only time”. I was not convinced by the doctor’s words. I felt he did not have enough knowledge about my son's issue. (Mashael)

Insufficient Information.

One of the challenges mothers and I faced in raising a child with ASD was insufficient accurate information about ASD, making it easy for us to believe the widespread myths about ASD. This theme includes two subthemes: (1) insufficient information about ASD; and (2) insufficient accurate information leads to a belief in myths.

Insufficient Information about ASD. Most of the mothers and I in this study reported that we did not have sufficient information about ASD, its possible causes, and treatment methods options. For example, in Zain's experience, she said she was unaware of the characteristics of a child with ASD, which influenced her thinking then and led her to think that her son's delayed speech was normal because he did not have brothers. As a result, she was late in diagnosing him and obtaining early intervention, so she felt sad. This means, from Zain's view, that although she gained some knowledge about ASD through her experience, she believes that if the research centers enrich ASD research, this will benefit families and professionals.

> I heard the term ASD, but I don't know what the characteristics of children with ASD are or what ASD means exactly. My family and friends said that my son's delay is normal because he has no siblings to communicate with, and he lived at the beginning of his childhood in a country that does not speak Arabic. My heart is heavy. We need more studies about ASD. (Zain)

Further, Hala mentioned that the insufficient information about ASD led her to search for information on the Internet, which was misleading and inaccurate. This experience affected her thinking then and led her belief that her child with ASD would not improve except with behavior modification sessions by specialists and certain tools. This made her feel despair because she was not qualified and her home was not equipped to conduct these sessions. This means, from Hala’s view, that she had more knowledge about ASD now through her experience in raising her son. However, she still wants to have the correct information from reliable sources available to everyone in Arabic.

> When my son was diagnosed with ASD, I was not well informed about ASD. I learned from the internet that a child with ASD would not develop except through individual sessions to modify behavior using educational games with different characteristics from regular games. My feelings of fear, despair, and pressure increased because I am not a specialist, and I do not know how to conduct these sessions, but I have learned from living for years with a child with ASD that he learns from every situation he faces. (Hala)

It was also a challenge for me to find sufficient information about ASD. I felt frustrated and sad then because I couldn't understand why my son had different traits from his peers. This means because of my insufficient information about ASD at the time, my son could not receive an early diagnosis and treatment.

> I started searching online for the reason for the appearance of these symptoms in my son. I did not know what ASD was. There was no awareness of this disorder at that time. Unfortunately, my lack of awareness interfered with my son getting a diagnosis and early intervention. This made me feel sad and frustrated. I read about ASD and found that most of the characteristics of children with ASD applied to my son. I read about ASD online by writing my son’s characteristics in the Google search engine and found that most of the characteristics of children with ASD applied to my son. (Mashael)

Insufficient Information Led to a Belief in Myths. Some mothers and I in this study reported that insufficient information about ASD led us to believe or follow myths that negatively affect us. The data include many descriptions of such. For example, Farah, through her experience and her insufficient information about ASD, it was easy for her to believe in the myth that there was a demon that entered her son’s body while taking a shower. This means that this myth affected Farah and her son negatively, so she spent years wasting her time and money searching for a cure to expel this demon and delayed early intervention behavior modification sessions that would have benefited her son. So, she felt sad because of these lost years.

> I gave my newborn son a shower in the bathroom two days after he was born instead of bathing him in the bedroom, as is standard among Saudi mothers - newborns should not bathe in the bathroom. As a result of the shower I gave him in the bathroom, my family says that he became possessed by Satan. I felt sad because 50 percent of what they say is correct. After all, when I read the Qur’an to him, I feel he is affected. And there are those in the family who say he was envied because he was so beautiful. I wished my husband sought a man who can treat envy and expel Satan from my son's body by reading the Qur’an. (Farah)

Zain also stated that she believed in the myth that marriage between relatives is the cause of ASD. She felt guilt and sadness because she may be the cause of her son's ASD because she married her cousin. This means Zain was greatly affected by this myth and she is still confused about whether she should continue in her marriage or divorce her husband so as not to have more children.

> Consanguineous marriage is the cause of my son's ASD, and I have to get divorced so that I don't have more children with ASD. If I had known before I got married that

> consanguineous marriage could cause ASD, I would have refused to marry my cousin. (Zain)

From Hala's experience, she also mentioned that she believed the myth that ASD is a disease that can be cured, which made her feel stressed because she wanted to help her son recover from ASD as soon as possible. This means from Hala's view, she believes she harmed her child through her attempts to correct him, and he developed undesirable behaviors.

> Based on the information I learned that ASD is a disease that can be cured, I wanted to get my son out of the circle of ASD, so I was pressuring him to do the right behavior like normal children until, unfortunately, he had behavioral problems such as beating and stubbornness because of my wrong way of dealing with ASD. (Hala)

I also believed the myth that vaccinations were the cause of ASD and stopped giving my son the necessary vaccinations. I felt guilty for putting my son at risk without reliable data to support the theory that vaccines cause ASD. This means that insufficient information about the cause of ASD and depriving the children of vaccinations may expose the child to serious diseases such as polio and measles that may lead to death.

> Initially, I stopped giving my son vaccinations because I assumed the vaccine he was given at birth had caused his ASD. But after conducting my own research and consulting medical professionals, I felt guilty since vaccines are safe and necessary for my child. (Mashael)

Anger because of Lack of Support

One of the challenges mothers and I faced in raising a child with ASD was feelings of anger at family, friends, and individuals providing social support (e.g., doctors, teachers, social workers, ASD specialties) for mothers of children with ASD. This theme includes sub-themes which are: (1) lack of family support; and (2) lack of specialists and social support.

Lack of Family Support. Some mothers and I in this study reported not receiving financial, moral, or psychological support from our husbands or families when raising our children with ASD. To explain her experiences raising a child with ASD, Faten shared that her husband refused to support her financially. Her husband stopped paying the annual fees for the ASD center where her child studies on the pretext that the cost was high. However, she explained that he is “well off” and can pay. This experience made her feel alone. This means that Faten expected her husband to provide her with financial support for her child's education and psychological services. These services would help her find her own time to relax and not worry about caring for her child with ASD.

> I took my son to an ASD center with 23 years of experience diagnosing all disabilities. They diagnosed him with ASD. They said he needs sessions to modify behavior and communication and physical and occupational therapy, which costs 12 thousand riyals per semester. My husband refused to pay because the cost was high. However, he can pay, as he is well off. I felt that I was spinning in a circle on my own. I still feel like I'm fighting alone. My husband needs to support and help me register my son in any school that provides ASD services. While it is important to me that my child goes to school to learn, I also need to find time for myself. (Faten)

Farah also reported that her husband and family did not assist her. She was responsible for everything in the house, including school and hospital appointments and daily housework. No one helped her. She felt tired as if she was in a marathon during her experience of raising a child with ASD. For Farah, this meant she did not have time to educate her child. Farah believes that her husband needs to support her by enrolling her son in an ASD center or hiring a maid to help the mother with the housework until Farah finds time to educate the child.

> My son did not go to school until he was nine years old. Before he entered school, I could not teach him anything myself. I only used to feed him, change his clothes, and bathe him because I did not have time to teach him. I am a mother and responsible for everything in the house, including school and hospital appointments and daily housework such as cooking and cleaning. I have no one to help me. I care for my husband's mother, who lives with us, as she is old and incapacitated. I provide her with food and medicine for her, and I take her to the doctor regularly. So, I didn't find time to teach my child because I felt tired as if I were in a marathon. I expected my husband to at least hire a maid. I feel sad about my son because he did not receive early interventions at home or school. After that, I convinced his father to register him in an ASD center because he had grown up and had not learned anything, even daily life skills. Indeed, he was registered, but the fees were costly, so he completed only one semester. After that, his father suspended him from school, although he seemed to be improving and looking at me and pointing at his body parts. (Farah)

Mai mentioned that although she knows what she needs to do to help her son, her husband does not support her, and rejects many interventions that could help her son without providing rational reasons. Mai states that her husband does not know anything about her son. This experience made her feel restricted. This means Mai expects her husband to support her and her son psychologically and morally and provide love and care for their son with ASD. Mai believes psychological support and love will help her son improve his condition. For example, the father needs to allow educational interventions to help him learn, take him for a walk, ask about him, and care when he is sick.

> I know a lot about ASD, but I feel restricted, like a thirsty person who has water in front of him and cannot drink. My husband rejects many interventions that could benefit my son without giving me rational reasons. My husband does not know anything about my son, whether he is sick or not, and he only sees him by chance. Even when I get busy with my son, he says, "me first, then your children." I obey my husband because I fear he will divorce me, which is unacceptable to my family. But I hope my husband feels more about my son, for example, taking him for a walk on the sand and making him feel love and tenderness. Still, I know this is impossible for my husband to do it. (Mai)

I faced the same challenge in the early years of caring for my son. I felt so sad that my husband did not support me and denied that our son had ASD for years. For me, this means that a lack of awareness or understanding of ASD leads to denial by family members and delays the search for appropriate treatment and support.

> I talked with my husband to start searching for a suitable doctor to help us diagnose our son's condition and start the appropriate treatment. However, I was sad and surprised by my husband’s reaction. He refused to accept that his son had ASD. He asked me to hide the issue from his family and everyone around us. (Mashael)

Lack of Specialists and Social Support. In this study, the mothers and I reported not receiving adequate support from specialists in the ASD field. For example, Faten said from her experience, the father is the child's guardian and no services are provided to the child without the father's consent (Alnemary, 2017). Therefore, may the child be deprived of the free government services available to the child with ASD if the father is busy or does not cooperate with completing the legal procedures to obtain the service. Because of this experience, Faten felt despair.

> I really feel despair, frustration, and anger because I see my son in front of me and I know what to do for his treatment, but I cannot. My husband does not help me either financially or morally. I couldn't even get my son's monthly salary that the government provides for children with ASD without my husband's consent. My son did not get these free services due to his father's lack of cooperation. (Faten)

From Hala's own experience, Hala said that when her son was diagnosed with ASD, she did not receive any support from community members such as doctors, teachers, social workers, or ASD specialists. Hala felt frustrated and angry because of this experience. For Hala, this meant she needed psychological and emotional support from a psychologist following a diagnosis. Moreover, she needed information about ASD, treatment options, and services for children with ASD and their families, as well as how to find these resources. In order to guide the mothers and other family members, Hala explained that there should be reliable guides and manuals written in Arabic that are easy to understand for non-specialists in ASD.

> When my son was diagnosed with ASD, I did not find anyone telling me where to go to treat my son or what to do, and there was no one to support me. I felt frustrated and angry then. I took information about ASD from the internet, whether wrong or true. It was not a reliable source, and some parents sent me some information about ASD, but I do not know how true it is or what is the source of this information. We need Arabic sources that we can understand. (Hala)

In addition, Zain indicated her experience when her child was diagnosed with ASD; she did not receive any support from doctors or specialists in the field of ASD. Nobody told her what she should do to obtain the services available for children with ASD. Also, there were no counseling services to calm her down, educate her and prepare her for the challenges she would face while raising a child with ASD or how she could overcome these challenges. This experience made her feel angry and alone. This meant for Zain that when a mother of a child with ASD received the news that her child had ASD, she needed support and awareness from the specialists. In Zain's view, it would be helpful if the specialists considered the existence of ASD organizations that aim to provide mental and emotional support to mothers of children with ASD by providing counseling services to advise and guide families on what to do after their children are diagnosed with ASD.

> Honestly, I felt angry at the specialists when my son was diagnosed with ASD; I did not find anyone to talk with to direct me on what to do and what I will face. There was no support for mothers whose children were diagnosed with ASD to guide them. I felt alone until I joined WhatsApp groups a year ago after I had overcome many difficult experiences on my own. (Zain)

I also expressed the lack of support from professionals in my autoethnography by saying that professionals failed to take our concerns seriously, leaving us feeling frustrated and hopeless. This means specialists in the ASD field should, in my opinion, spend more time listening to and understanding our concerns since we are the ones who live with the child and know him well. "It is frustrating when you're trying to find the right diagnosis and treatment for your child, but the doctors and specialists you visit don't really listen to you or take your concerns into consideration.” (Mashael)

Feel lonely and Isolated from Society

Some mothers and I faced loneliness and isolation from society due to others blaming the mothers and I for the ASD diagnosis, pitying us, and not accepting our children with ASD. This theme includes sub-themes which are: (1) blame from others; (2) pity; and (3) others not accepting our children.

Blame from Others. In this study, some mothers and I reported that we suffer from loneliness and isolation from society because others blame us for being the cause of ASD in our children. From Mai's experience, she withdrew from society, and now she does not even visit her family because her father believes that ASD occurs because of how the child is treated. Her father blames her as the cause of her son's ASD, for her wrong upbringing, her excessive pampering of her child, and her meeting all his needs. Due to her experience, Mai feels very upset and her father hurts her feelings. This means for Mai that when society blames her for her child's ASD, she feels oppressed since society does not understand what causes it.

> I do not visit my family much since my son was diagnosed with autism. My father , although he specializes in medicine, says that ASD is a behavioral problem that arises because of the way the child is raised. He blames me for my dealings with my son and says I spoil him too much, so he shows ASD behaviors. I am very upset and I feel he hurts my feelings. I tried to convince him that I was not the reason, but he insisted that my upbringing was the reason. This is a great injustice. (Mai)

Also, Zain commented on her experience that she withdrew from family visits because some of her relatives stated that her marriage to one of her relatives was the reason why she had a child with ASD and that continuing in this marriage could increase the birth of many children with ASD. As a result, she felt nervous after this experience and did not want to meet them again. From Zain's view, this means that society is unaware of the causes of ASD, so some people manage their fears of the unknown by blaming her. She believes that when relatives attach the cause of disability to a person's actions, they will feel confident that if they or their children do not do the same thing as that individual did, the disability will not touch them.

> When I meet my family members, I feel nervous because they blame me for my son's ASD because I married my relative, and extending this marriage and having more children will be unfair to them. I feel that I do not want to meet them. Society is unaware of ASD and afraid of the unknown. (Zain)

I faced the same challenge. People around me blamed me for my son's ASD. This blaming made me feel isolated and unwilling to attend family meetings or visit relatives. This, from my view, is unfair, inaccurate, and indicates a lack of awareness of ASD and its causes. To help my son and me, I expected people around me to provide support, compassion, and understanding, rather than blame me.

> I was shocked that those around me, instead of helping me, started to blame me and fabricate lies about my family and myself. They said that they searched my family history and found that ASD ran in my family. This is unfair. (Mashael)

Pity. Some mothers and I in this study reported that we became lonely and isolated from society due to annoying and painful pity for our children and us. For example, Zain mentioned her experience of avoiding social events because people looked upon her child with pity. People believe that they are helping her and making her feel sympathy. However, she dislikes this feeling of pity and the hurtful feeling it evokes, so she isolates herself from other people. Because of this experience, Zain felt pained by the looks of pity. This means that Zain wants respect from society, not pity. From Zain's point of view, pity does not mean to her that people are kind. Because some people show you pity to give them the right to ask embarrassing questions of you or your child or provide you with advice.

> Also, my social relations were affected, so I no longer visit friends or family because of the looks of sympathy and pity for my son's situation. People embarrass me with questions like, why does your son do this? What does he feel? Other questions of this kind bother me and I do not have an answer for them. I feel that the looks of pity hurt me so much. People around us do not understand that we need respect, not pity. (Zain)

Moreover, Hala spoke about her experiences of becoming isolated and not participating in social events because some of her relatives pitied her son and treated him differently from typical children. This experience made her feel hurt. For Hala, this means that some relatives pity her son because they are not aware of ASD and see that her son is crazy, cannot improve or develop, or is less than his peers. From Hala's view, her relatives should educate themselves on how to treat her son as any other child who can achieve and succeed and not only focus on his weaknesses. She wants him to be prepared for the outside community, which is unlikely to treat him differently.

> I no longer participate in social events. When some relatives asked me why I didn't work after I made an effort to get a master's degree, I didn't tell them that my son has ASD and I wanted to take care of him instead of working. I don't want them to look at my son with looks of pity that might make me feel hurt. Some relatives who know that my son has ASD pity my son and me because they do not have enough awareness about ASD and see my son as insane and that it is not possible for him to improve or develop or he is less than his peers. They deal with him on the basis that he is less sometimes. For example, if my son is with their children, they tell their children not to let him wait for his turn to

> play and make him the first because he is different. I asked them not to treat him on the basis that he did not understand and not to pity him because they would annoy him more than help him. If we treat him in a particular way, how will he adapt to a society that may not treat him as different? (Hala)

Safi experienced suffering from isolation as well. She does not visit friends and family or go out with them on a picnic because people pity her daughter and treat her differently. This experience hurt Safi's feelings and she felt sad. From Safi's view, this means that people need awareness campaigns about ASD and how to socially interact with children with ASD and their families. In addition, families of children with ASD need counseling services to educate them about responding to unwanted pity.

> I have friends and I go out with them sometimes in public parks and I take my daughter, but I am bothered by the feeling of pity from some friends, for example, when my daughter takes candy from the hands of one of their children and I return it to the child, I find the mother telling her child to give my daughter candy because she is different, or telling her child that my daughter does not understand and you do. They think they are helping me so that my daughter doesn't start crying or hurting herself but they hurt our feelings. Therefore, isolation has improved because society and we need awareness about ASD and pity. (Safi)

Throughout my autoethnography, I mentioned that my family also felt sorry for my son. The looks of pity make me feel sad because they mean that they see my child differently and helplessly. They don't see the whole picture. Yes, my child has ASD, but he also has strengths. ASD is just one part of his identity.

> I don't like taking my son to visit my family. Although I know that they pity him because they love him, the looks of pity make me feel painful. I wish people could see the joy my child brings to our lives instead of feeling sorry for us. We do have challenges, but we also have a lot of love and laughter in our house. (Mashael)

Others Not Accepting our Children. Most of the mothers in this study and I reported that society does not accept the behavior or the disability of our children with ASD, which isolated us from society for example, one of Hala's experiences was when one of the mothers of another child abused and beat her son with ASD after her son hit another child. This experience caused Hala to isolate herself and her son from society since people did not accept his behavior. This experience made Hala cry and feel sad and angry at society for several days. From Hala's view, this means that people are not properly educated about ASD, and public lectures or materials that are easy to read are necessary for raising awareness about how to socially interact with children with ASD and accept them.

> Society and many people still do not accept children with ASD behavior. For example, I was in a mall one day with my children, and my son saw a train and wanted to ride it. The train was a few steps away from me and I was watching my son with my eyes. Still, suddenly he saw a baby with his mother sleeping in his carriage and my son hit him, and the baby started crying. Hence, the mother hit my son and pulled him by his hair. I know my son was wrong, but the mother reacted aggressively and started screaming at my son and me so that all the passersby gathered and looked at us and tried to calm the mother down. And I told the mother that my son has ASD, but she said that this does not matter and that he deserves punishment for what he did. Honestly, I cried and felt sad and angry for several days because I was shocked by the mother's reaction, as she did not

> understand and accept my son's behavior, which was caused by ASD and was not poor parenting. I am still thinking about how to act if the situation repeats itself. Honestly, I isolated myself because I am afraid and do not want to take my son to public places, although he has the right to go outside and play like other children. People need to be educated, for example, through lectures or reading. (Hala)

Safi also mentioned that she had the same experience. Her family did not accept her daughter's hyperactivity, which made her isolate from them. This experience made Safi feel sad and alone. This means for Safi that society is unaware of children with ASD and their behavior, so it does not accept them. From the mother's perspective, society's lack of acceptance of children with ASD behavior may lead to children's social isolation, which decreases their ability to communicate with others. According to Safi, awareness of ASD should begin during the school years so society becomes more aware of it.

> Honestly, I consider support is accepting my daughter and her behavior, but unfortunately, no one accepts her behavior, especially when she was younger and had severe hyperactivity. Although she has improved. I feel sad and alone when I see my family not accept my daughter's behavior, so I isolated myself. I do not meet with family or friends because I cannot leave my daughter at home alone, and at the same time, I know they do not want me to bring her with me, so I do not visit relatives. People are not aware of children with ASD and their behavior, so it does not accept them, which affects the children socially. I believe that educating society should start from schools. (Safi)

Similarly, Farah's experience describes the same suffering. Her family does not accept her child's behavior and describes him as “insane”. This experience made Farah feel upset and she decided not to take her son to visit her family. To Farah, this means that society does not understand the behavior of children with ASD, so it does not accept them as children. Farah explained that it would be helpful if people are taught about ASD in the school curriculum so that society would be aware and understand cases of ASD that might appear in public places instead of calling them “madness”.

> No one accepts my son because they do not know what ASD is. I visited my sister one day, and my son destroyed some grass in their garden, so her husband got angry and said, “Do not let this madman destroy the plants of our garden.” I felt upset and promised myself that I would not take my son to visit anybody. It is my personal belief that if ASD were taught in schools, society would not think of autism as madness. (Farah)

In my autoethnography writing, I also reflected that I felt fear and isolated when my husband asked me to hide our son's disability from his family because they might ask him to divorce me because the presence of a disabled child might affect his siblings' marriage opportunities. This means to me that people do not understand ASD and its causes. It also means how the fear of negative social consequences, such as divorce or rejection from others, can prevent mothers from openly discussing or seeking help for their child's disability.

> My husband told me that if his family knew that he had a child with a disability, they might seek divorce for fear of having other children with disabilities. A person with a disability would negatively affect the marriage prospects of his brothers and sisters, as people might think that the disability was inherited, so no one would want to marry them. For years I remained silent about my son's condition due to fear of divorce. (Mashael)

Feelings of Fear and Worries

In this study, the mothers and I experienced feelings of fear due to family and friend pressure and worries when thinking about the future. This theme includes sub-themes which are: (1) pressure from family and friends; and (2) worries about the child's future**.**

Pressure from Family and Friends. Most mothers and I in this study reported constant pressure from friends or relatives to quit jobs, divorce, or use unsafe treatments. For example, Zain experienced pressure from her relatives to divorce because “consanguineous marriage is the cause of ASD”. This experience made her feel worried because she thinks about what will happen to her son after the divorce. As far as Zain is concerned, this means that the claim that inbreeding is the cause of ASD has not been supported by any studies, and therefore it is not based on evidence. Wherefore, to avoid affecting her child with ASD, who requires a stable marital relationship, a safe environment, and a loving, supportive father, she does not wish to leave her husband.

> Some relatives are pressuring me to ask for a divorce from my husband. They say that consanguineous marriage is the cause of my son’s ASD. But I feel worried about how I will leave my husband while we love each other and our marital relationship is stable, and what will be my son's fate after the divorce? This pressure is not supported by reliable evidence. (Zain)

In addition, Farah described how she experienced pressure from her husband to use unsafe treatments for her son with ASD. These treatment benefits are not scientifically proven for children with ASD. After this experience, Farah felt guilty because her son felt severe pain during treatment, and the treatment wasn't effective. From Farah's view, this means the stakeholders should stop entities and persons who provide treatment that is not scientifically proven to benefit children with ASD. There is an exploitation of the need for families of children with ASD to treat their children.

> My husband pressured me to take my son to an elderly woman who claims that she treats ASD and offers folk remedies. When I went to her, I asked her, do you treat children with ASD? She said yes. If the child with ASD does not speak, this means that he has blood collected in the palate. I need to remove the blood with my finger to help the child talk. I visited her five times but did not see a noticeable improvement in my son. I lost money, effort, and hurt my son for nothing. I was very sad for my son, as he bled from his mouth for several days and became afraid and did not want to eat. I felt guilty. In my opinion, ASD has become a business. I hope that these practices will end. Our children are being harmed and there are no scientific and reliable studies behind it. (Farah)

It was also Faten's experience that her husband pressured her to quit her job to devote herself to raising their son with ASD. This experience made Faten feel worried about her financial future. This pressure does not mean to Faten that her husband is wrong, but rather that he is busy with his work. Suppose there were free and official centers specializing in ASD that would train maids to deal with children with ASD and help parents in caring for children with ASD. In that case, this may give parents an opportunity to practice their daily practical and social lives.

> My husband pressured me to leave my high school physics teacher job to devote myself to caring for our son with ASD. My husband promised me that I would return to my work, complete my master's degree, and he would help me in the raising of our son, but he was unable to fulfill his promises. I regret losing my job, which made me feel very sad and worried about my future. From my point of view, I do not blame my husband, and I

> know that he cannot help me take care of our son because my husband is an engineer and he moves between Saudi cities constantly. I believe if there had been training for maids as a service provided to families of children with ASD, my husband would not have pressured me to leave my job. (Faten)

I faced the challenge of my father pressing me to give camel milk to my son because it was supposed to cure ASD, but I felt afraid and hesitant because it is not scientifically proven to work. To me, this means, as mothers of children with ASD; I think we always do our best to provide our children with the best care possible, even if that means trying new things. Some treatments and interventions, however, may harm children with ASD instead of benefiting them. As there is no scientific evidence supporting the use of camel milk to treat ASD, it may cause digestive problems (Al-Dabbas, 2015), so it is important to research, read, and consult specialists before offering any treatment to the child.

> My father pressured me to give my son camel milk, but I hesitated and felt afraid to use it. I don't think camel milk is a miracle cure for ASD, so I prefer to stick to treatments that have been proven through scientific research. (Mashael)

Worries about the Child's Future. In this study, the mothers and I reported that one of the challenges we face is worrying and thinking about our children's future. Mai experiences fear of death due to cancer at its terminal stage. Mai feels worried about her son after she dies or becomes elderly, wondering who will care for him afterward. This experience of Mai means establishing centers to shelter children with ASD after the death of their parents or their advanced age is a great idea. These centers should be well-equipped to take care of the children.

> I have cancer in its final stages, so I think about my son's future a lot and I feel fear and worry about him. I even started collecting all his monthly salaries that the government

> gives him as support for children with ASD in his own account in the bank to help him hire at least a maid for him in the future if I die. I hope he will be able to live independently and not be a burden to anyone. I hope there are centers for permanent residents to care for children with autism if their parents get old or die. (Mai)

Additionally, Zain's experience expresses her feelings of fear and worry about her son's future sexuality. From Zain's view, this means there needs to be free or nominally priced workshops and courses to educate mothers of children with ASD about their children's sexuality.

> I feel very worried about my son's future regarding sexuality, as I am afraid of harassment. The mothers of children with ASD and I need more information through courses and workshops on sexual education for adolescents with ASD. (Zain)

Strategies

Our Own Knowledge and Self-learning are the Key to our Strength and Success

Mothers and I in this study reported that self-learning about ASD was one of the strategies that helped us overcome the challenges we faced when raising a child with ASD. For example, Hala expressed her experience, saying that learning the techniques of behavior modification, such as reinforcement from her son's teacher, helped her reduce unwanted behaviors in her child, such as running away from home. Hala felt happy, accomplished, and relieved because through the behavioral intervention plan and the use of reinforcers, she successfully modified her son's behaviors that worried her. From Hala's view, she believes that the success of reinforcers and behavior modification techniques in general in changing unwanted behavior means that children with ASD can improve through appropriate support and intervention, but to prevent the child from getting accustomed to them, do not overuse them. Hala encourages other parents to self-learn by seek resources and support from ASD professionals because she believes that the disappearance of unwanted behaviors in children with ASD helps reduce parents' anxiety, stress, and fear of behaviors that may endanger their children.

> I was suffering from some wrong behaviors, such as my son running away from home. These behaviors bothered me and made me very tired because I could not leave my son for fear that he would run away from home, so I asked for a meeting with his teacher to discuss the matter. We came up with a plan to modify this behavior by using symbolic reinforcement, where my son gets a star when he refrains from the wrong behavior. If he collects a certain number of stars, he is rewarded by playing with one of his toys at home, which is in front of his eyes, but far from his hand. He gets it if he does not do the behavior. Indeed, this strategy succeeded in modifying many of the wrong behaviors he was doing at home or school by changing the reward each time. After the success of this strategy, I felt accomplished and very happy, and I had less fear of my son escaping. In general, I became less nervous because I knew at least one strategy to modify the wrong behaviors of my son that might harm him. Still, I felt that my son did not want to do any work without the reinforcers and not all reinforcers satisfy him. He wants material reinforcements every time he performs good behavior. So, I decided to use reinforcers on behaviors that need immediate intervention to stop them, such as self-harm or running away from home. Honestly, my view of ASD changed after I learned how to apply behavior modification techniques. I became sure that a child with ASD can improve and coexist with society without others seeing him as different. Therefore, I advise any mother not to hesitate to ask her child's teacher and specialists in autism at school about how to deal with an autistic child because they have much to help us. (Hala)

Safi also reported how her experience and self-learning of other evidence-based interventions (e.g., a picture exchange communications system (PECS) and Treatment and Education of Autistic and related Communications Handicapped Children (TEACCH) through workshops helped her teach her daughter to communicate and express her desires and feelings. Safi felt happy when her daughter could communicate and pronounce the words because she could then attend the schools of students without disabilities. From Safi's view, the success of these strategies means that support for children with ASD is important. Communication supports can reduce their anger that arises from their inability to express their feelings and needs. Safi also believes that teaching a child with ASD communication skills reduces the mother's tension and helps her meet her child's needs comfortably. It also gives the mother more time for herself because it reduces the child's dependence on her. Therefore, Safi advises mothers to constantly follow charities' websites to register for the workshops they offer at nominal prices. Safi thinks it would be great if the specialists in ASD give free workshops to mothers of children with ASD to teach them how to communicate with them.

> I used the PECS system to teach my daughter to communicate and express her wants and feelings. I also used TEACCH to create a routine daily schedule. I learned all this while working in the Association for Children with Special Needs. Also, this association offers workshops at nominal prices to non-employees. My house was full of pictures everywhere. I wanted my home to be an environment that helps visual children like my daughter learn. I did this because my daughter is in one of the inclusive schools, in which the classrooms are not prepared for visual children, such as children with ASD. I gradually removed the pictures when my daughter learned and generalized the skills. The PECS system helped my daughter to pronounce. I pronounced the word according to the

> picture she gave me to help her link the picture to the name. It was stressful, especially in the past time before the development of technology. It was challenging to get pictures, but I was so happy to teach my daughter, so I did my best to provide them. I believe teaching my daughter communication skills positively impacted me by strengthening my-child bond, reducing stress, and increasing her independence. So, I hope there are free workshops. (Safi)

In my autoethnography, I mentioned a similar strategy which is to acquire knowledge and experience in the field of special education, specifically ASD, by obtaining a master's degree and completing training in teaching children with ASD in American schools. As a result of this knowledge, I felt stronger and more confident about my abilities to help my son and make a difference in society by raising awareness of ASD. This means that knowledge about ASD and strategies for interacting with children with ASD can play an important role in helping children with ASD and their families thrive. As a result of gaining knowledge and experience, mothers will feel empowered to advocate for their children and make a positive contribution to their community.

> This time though, I felt that I was stronger and more knowledgeable about ASD, as I had earned a master's degree in special education and trained in American schools where there were all levels of disability among different ages of children with ASD. I felt that I would be able to help my son and help build community awareness of ASD. (Mashael)

Spirituality

Some mothers in this study reported that spirituality, such as gratitude, prayer, and reading the Qur'an helped them overcome some of the challenges they faced. For example, Hala expressed how her experience of practicing gratitude for God's blessings upon her when she was sad or desperate helped her feel at ease. In Hala's view, this means that gratitude for God's blessings positively affects an individual's perspective toward ASD. For example, when parents of children with ASD practice gratitude for God's blessings, they are more likely to focus on the positive aspects of their children, such as their unique strengths and abilities. This can lead to greater acceptance by parents of their children, relieving stress and anxiety and improving quality of life.

> When I feel sad and hopeless, I practice the worship of gratitude for Allah's blessings. I always remind myself that there are serious diseases that have no cure, but my son is learning and developing, and he does not have a serious disease that he pains from. He will improve with intensive training. We do not suffer from poverty, hunger, or wars. I feel comfortable when I remind myself of the blessings of Allah upon me. (Hala)

From Faten's experience, she mentioned that when she feels anxious or sad, she prays to Allah and reads the Qur’an to deal with those emotions. This means Faten trusts that Allah will help her raise her child with ASD. She believes that for being patient while raising her child, Allah will reward her by letting her enter heaven. As a result, Faten's connection with Allah is therefore strengthened. She prays, reads the Qur'an, and draws closer to Allah to feel comfortable and safe and that Allah is with her and will not let her down.

> I pray and read the Qur'an whenever I am in despair and anxiety to find relief. I believe Allah loves me because when Allah gave me an autistic child, He knew I could raise him and that I would be rewarded for my patience by entering paradise. (Faten)

Moreover, I mentioned in my autoethnography how spirituality, specifically prayer and reading the Qur'an, helped me overcome the challenges I faced when raising my son. As a result of prayer, reading the Qur’an, reflecting on its meanings, and how Allah is with us, I felt reassured and comfortable. This means that having faith in Allah gives us a positive view of our role as mothers, enables us to continue advocating for our children's needs, and provides us with the flexibility to continue to care for our children with love and devotion.

> Praying and reading the Qur’an has been essential to my self-care and reducing stress. It gives me inner peace and strength to continue advocating for my son. The Qur’an has taught me the importance of patience and perseverance in caring for my son. It reminds me that Allah is always with us and will never abandon us. I learned from the Qur’an to appreciate my son's unique qualities and strengths. I see my son as a gift from Allah, and I am grateful for the opportunity to be his mother. (Mashael)

Social Media

Some mothers in this study reported that joining social media groups helped them overcome some challenges they faced while raising a child with ASD. For example, Zain described her experience joining WhatsApp groups as useful and helped her identify useful resources about ASD and the services available for children with ASD and their families. Zain felt strong after this experience. This means to Zain that the WhatsApp groups made her able to defend her son's rights**.**

> WhatsApp groups helped me learn about inclusive schools and the best private ASD centers that offer behavioral modification sessions, occupational therapy, or communication services. Also, I learned the benefits that the country provides free of charge services to children with ASD and how I can obtain them, such as the monthly salary and discount cards for recreational games. These media groups also helped me know about some easy books that do not need specialists in the ASD field to understand. These books contain situations from reality and the correct behavior the mother should

> take if she were in the same problem as the "Teach me How to Communicate book.” When I learned all this information, I felt empowered. (Zain)

Mai also described her experience with social media as providing her with psychological support because she feels that she is not alone in her struggles, as many others have the same challenges. This means, for Mai, that social media is a place for sharing information about ASD. It is also a safe and supportive environment where mothers can share their experiences and feelings with others who understand what they are going through. It is Mai's belief that social media can be an effective tool for advocating for better resources, financing, and policies to support children with ASD and their families. In Mai's opinion, all mothers can easily join social media groups by using search engines to find information about how to join them.

> Social media such as WhatsApp, Facebook, Twitter, and Instagram support me psychologically, as I feel I am not alone. In addition to that, I benefit a lot from the experiences and information of mothers, and I share my experiences that may be useful to others who go through the same problem comfortably and safely. In some of the groups in which I participate, some decision-makers and stakeholders can help our voices be heard to obtain our rights and the rights of our children. I got information about these groups on social media from Google. (Mai)

Using social media has also been a valuable tool for me in overcoming the challenges of raising my son. The experience of using social media has been for me an experience of connection, support, and empowerment. I felt that social media provided a safe and supportive environment where I could share my successes and struggles with others who had similar experiences. After obtaining the findings of this study by recruiting mothers from WhatsApp, this also means that social media can be a platform to make our voices heard, and it can be an effective way to make a change.

> Using social media like WhatsApp and Twitter has been a lifeline for me in connecting with other moms who understand what I'm going through. I feel social media is a safe space to share successes and struggles with others. By communicating with other mothers through WhatsApp, I've been able to get a wealth of information and resources about ASD I wouldn't have discovered otherwise. I learned about my son's rights, such as his monthly salary, discounts for travel tickets, and paying fees for profit centers. It was also a way to make our voices heard. (Mashael)

Challenges Before and After the ASD Law

The results of this study indicate that there were slight differences found between the challenges faced by mothers whose children with ASD were born before or after the establishment of the ASD law in Saudi Arabia. Both groups of mothers reported similar challenges related to dissatisfaction with the services provided to children with ASD, anger because lack of support, feeling lonely and isolated from society, and feelings of fear and worries. For example, Faten, who is the mother of a child born before the law, and Hala, who is the mother of a child born after the law, both of them reported the same challenge, which is **dissatisfaction with the educational services** provided to their children in inclusive schools.

Hala mentioned that she observed in one school a wall separating students with ASD from students without disabilities in the same class, with only a small hole to see the board. This experience made Hala feel dissatisfied with the way children with ASD are integrated with children without disabilities in the same class.

> Also, I would like to say that before I enrolled my son in a school for typical students and hid my son's ASD, I visited one of the inclusive schools. I saw a wall between students with ASD and typical students in the same class. There is a hole in this wall so the students with ASD can see the board. The wrong method of inclusion that I saw has a kind of discrimination and bullying is that prompted me to hide my son's ASD. (Hala)

Faten also described her son did not feel comfortable in the inclusive school because the teachers were not qualified to deal with children with ASD and did not have sufficient experience in special education. In addition, the classrooms were not adequately prepared, and the students spent most of their time sitting around a table without any useful or engaging activities.

> My son's center asked me to transfer him to inclusive schools because the conditions for inclusion with typical children apply to him. Unfortunately, my son felt uncomfortable in inclusion school and behaved like crazy. I feel dissatisfied with this inclusive school either, as the teachers were not qualified to deal with children with ASD. Children spend most of their school day gathered around a circular table without any activities that benefit or entertain them. Teachers allow children with ASD to integrate with typical children during recess and Art class. Still, the Art teachers of typical students objected to the inclusion and said that children with ASD distract typical children. Teachers need training and supervision. (Faten)

Also, Faten, who is the mother of a child born before the law, and Safi, who is the mother of a child born after the law, both reported the same challenge, which is **dissatisfaction with the diagnosis services.** For example, Safi said she moved between Saudi cities to get her daughter diagnosed. She visited a pediatrician and a professor specializing in speech and communication, but neither conducted an official test to diagnose Safi's daughter. They told her her daughter was normal because she could assemble the puzzle and blow bubbles.

> I took my daughter to pediatricians and professors in the field of ASD in several cities and they all said that my daughter was normal without running any formal tests. Some of them did a bubble test. When my daughter blew bubbles, they told me she was normal because a child with ASD could not master this skill. I was unsatisfied with this diagnosis because I noticed my daughter was not normal and had hyperactivity. After that, I took my daughter to a professor specializing in speech and working after his retirement from academic work in an ASD center. He gave my daughter a puzzle, and my daughter was able to put them together correctly. So, the doctor said my daughter is fine because a child with ASD can only do this after intensive training. I was upset and not convinced of this diagnosis, so I went to a professor specializing in psychology who worked in a profit center. She ran some tests and asked me some questions, which I do not remember well now, and then she said that my daughter has ASD. (Safi)

Faten also reported feeling frustrated and confused during her journey with her son's diagnosis. She felt the diagnosis results were misleading because, during her experience, she got two different diagnoses from two pediatricians, one of whom told her that her son had ASD. The other told her that her son has epilepsy and physical disability only. Both doctors did not run any formal tests.

> My son was diagnosed with ASD at the age of five. Unfortunately, this delay was due to my son's doctor, who had followed up with him since birth. He told me that my son only suffers from epilepsy and physical disability. But fortunately, after I had a child with a disability, I read about disabilities and disorders. I noticed that my child had ASD traits,

> such as losing the ability to communicate verbally and visually. During one of my visits to a pediatrician, I told him what I noticed in my child. It was his opinion that if he had these characteristics, he had ASD without a formal diagnosis, tests, or even a referral to someone who specializes in ASD. I was worried and scared because the doctor didn't do any tests and relied on my words. This is frustrating. I think to facilitate diagnosis, the Ministry of Health needs to provide clinics with clear guidelines throughout the diagnosis process. (Faten)

Also, Mai, who is the mother of a child born before the law, and Farah, who is the mother of a child born after the law, both of them reported the same challenge, which is a **lack of support from the family**. For example, Farah said her husband and family did not assist her. She was responsible for everything in the house, including school and hospital appointments and daily housework. No one helped her.

> My son did not go to school until he was nine years old. Before he entered school, I could not teach him anything myself. I only used to feed him, change his clothes, and bathe him because I did not have time to teach him. I am a mother and responsible for everything in the house, including school and hospital appointments and daily housework such as cooking and cleaning. I have no one to help me. I care for my husband's mother, who lives with us, as she is old and incapacitated. I provide her with food and medicine for her, and I take her to the doctor regularly. So, I didn't find time to teach my child because I felt tired as if I were in a marathon. I expected my husband to at least hire a maid. I feel sad about my son because he did not receive early interventions at home or school. After that, I convinced his father to register him in an ASD center because he had grown up and had not learned anything, even daily life skills. Indeed, he was registered, but the fees

> were costly, so he completed only one semester. After that, his father suspended him from school, although he seemed to be improving and looking at me and pointing at his body parts. (Farah)

Mai mentioned although she knows what she needs to do to help her son, her husband does not support her and rejects many interventions that could help her son without providing rational reasons. Her husband does not know anything about her son.

> I know a lot about ASD, but I feel restricted, like a thirsty person who has water in front of him and cannot drink. My husband rejects many interventions that could benefit my son without giving me rational reasons. My husband does not know anything about my son, whether he is sick or not, and he only sees him by chance. Even when I get busy with my son, he says, " me first, then your children." I obey my husband because I fear he will divorce me, which is unacceptable to my family. But I hope my husband feels more about my son, for example, taking him for a walk on the sand and making him feel love and tenderness. Still, I know this is impossible for my husband to do it. (Mai)

Also, Faten, who is the mother of a child born before the law, and Hala, who is the mother of a child born after the law, both reported the same challenge, which is a **lack of specialists and social support.** For example**,** Faten said from her experience, the father is the child's guardian, and no services are provided to the child without the father's consent. Therefore, the child is deprived of the free government services provided to the child with ASD if the father is busy or does not cooperate with completing the legal procedures to obtain the service.

> I really feel despair, frustration, and anger because I see my son in front of me and I know what to do for his treatment, but I cannot. My husband does not help me either financially or morally. I couldn't even get my son's monthly salary that the government

> provides for children with ASD without my husband's consent. My son did not get these free services due to his father's lack of cooperation. (Faten)

From Hala's own experience, Hala said that when her son was diagnosed with ASD, she did not receive any support from community members such as doctors, teachers, social workers, or ASD specialists.

> When my son was diagnosed with ASD, I did not find anyone telling me where to go to treat my son or what to do, and there was no one to support me. I felt frustrated and angry then. I took information about ASD from the internet, whether wrong or true. It was not a reliable source, and some parents sent me some information about ASD, but I do not know how true it is or what is the source of this information. (Hala)

Also, Mai, who is the mother of a child born before the law, and Zain, who is the mother of a child born after the law, both reported the same challenge, which is **blame from others.** For example, Mai withdrew from society, and now she does not even visit her family because her father believes that ASD occurs because of how the child is treated. Her father blames her she is the cause of her son's ASD for her wrong upbringing, her excessive pampering of her child, and her meeting all his needs.

> I do not visit my family much since my son was diagnosed with ASD. My father, although he specializes in medicine, says that ASD is a behavioral problem that arises because of the way the child is raised. He blames me for my dealings with my son and says I spoil him too much, so he shows ASD behaviors. I am very upset and I feel he hurts my feelings. I tried to convince him that I was not the reason, but he insisted that my upbringing was the reason. This is a great injustice. (Mai)

Also, Zain commented that she withdrew from family visits because some of her relatives blamed her that her marriage to one of her relatives was the reason why she had a child with ASD and that continued marriage could increase the birth of many children with ASD.

> When I meet my family members, I feel nervous because they blame me for my son's ASD because I married my relative, and extending this marriage and having more children will be unfair to them. I feel that I do not want to meet them. People is unaware of ASD and afraid of the unknown. (Zain)

Also, Faten, who is the mother of a child born before the law, and Farah, who is the mother of a child born after the law, both reported the same challenge, which is **pressure from family and friends**. For example, Farah described how she experienced pressure from her husband to use unsafe treatments for her son with ASD. These treatment benefits are not scientifically proven for children with ASD.

> My husband pressured me to take my son to an elderly woman who claims that she treats ASD and offers folk remedies. When I went to her, I asked her, do you treat children with ASD? She said yes. If the child with ASD does not speak, this means that he has blood collected in the palate. I need to remove the blood with my finger to help the child talk. I visited her five times but did not see a noticeable improvement in my son. I lost money, effort, and hurt my son for nothing. I was very sad for my son, as he bled from his mouth for several days and became afraid and did not want to eat. I felt guilty. In my opinion, ASD has become a business. I hope that these practices will end. Our children are being harmed and there are no scientific and reliable studies behind it. (Farah)

It was also Faten's experience that her husband pressured her to quit her job to devote herself to raising their son with ASD.

> My husband pressured on me to leave my high school physics teacher job to devote myself to caring for our son with ASD. My husband promised me that I would return to my work, complete my master's degree, and he would help me in the raising of our son, but he was unable to fulfill his promises. I regret losing my job, which made me feel very sad and worried about my future. From my point of view, I do not blame my husband, and I know that he cannot help me take care of our son because my husband is an engineer and he moves between Saudi cities constantly. I believe if there had been training for maids as a service provided to families of children with ASD, my husband would not have pressured me to leave my job. (Faten)

Also, Mai, who is the mother of a child born before the law, and Zain, who is the mother of a child born after the law, both reported the same challenge, which is **worry about their child's future.** For example, Mai feels worried about her son after she dies or becomes elderly, wondering who will care for him afterward.

> I have cancer in its final stages, so I think about my son's future a lot and I feel fear and worry about him. I even started collecting all his monthly salaries that the government gives him as support for children with ASD in his own account in the bank to help him hire at least a maid for him in the future if I die. I hope he will be able to live independently and not be a burden to anyone. I hope there are centers for permanent residents to care for children with autism if their parents get old or die. (Mai)

Additionally, Zain’s experience expresses her feelings of fear and worry about her son's future sexuality.

> I feel very worried about my son's future regarding sexuality, as I am afraid of harassment. The mothers of children with ASD and I need more information through courses and workshops on sexual education for adolescents with ASD. (Zain)

Findings Related to Family System Theory

In this dissertation, the mothers and I reported our experiences while raising a child with ASD and the challenges and benefits we experienced due to a variety of family characteristics explained in the Family System Theory. These characteristics include the size, form, and culture of the family (see Table 3 in Appendix G).

Size

In this study, mothers and I reported that large families are sometimes not beneficial and do not help with caretaking. For example, Farah feels sad, alone, and exhausted due to the large size of Farah’s family because she is responsible for everything in the house. She is responsible for caring for her children, husband, in-laws, and two adopted children. Since she is responsible for many caretaking roles, Farah does not have time to complete a task that is important to her, i.e., educating her child. Farah thinks that the father needs to enroll her child in an ASD center or hire a maid to help.

> I am a mother and responsible for everything in the house, including school and hospital appointments and daily housework such as cooking and cleaning. I have no one to help me. I care for my husband's mother, who lives with us, as she is old and incapacitated. I provide her with food and medicine for her, and I take her to the doctor regularly. So, I didn't find time to teach my child because I felt tired as if I were in a marathon. I expected my husband to at least hire a maid. I feel sad about my son because he did not receive early interventions at home or school. After that, I convinced his father to register

> him in an ASD center because he had grown up and had not learned anything, even daily life skills. Indeed, he was registered, but the fees were costly, so he completed only one semester. After that, his father suspended him from school, although he seemed to be improving and looking at me and pointing at his body parts. (Farah)

When I lived in Saudi, I also felt alone like Farah. We lived with my husband’s family and I had to hide my son’s diagnosis. However, my family size has shifted since I moved to the United States. Thus, in contrast to Farah’s experiences and feelings, I now feel comfortable and reassured about my son's future among his siblings. I have a small family; however, I share caretaking responsibilities with my husband and Azoz’s siblings. My family loves him, accepts his different behavior, and helps me with his care and education. For me, this means having my husband and siblings who love and accept the child with ASD can create a supportive and inclusive environment.

> Now my son lives with my immediate family and me (i.e., his siblings, my husband, and me). Living with my small family does not worry me because Azoz’s relationship with his siblings is good. They love him very much and accept his differences. In fact, they also help in his care, education, and share some educational games with him to teach him some skills. This is reducing my worries about my son’s future. (Mashael)

Form

The mothers and I emphasized that the form of the family and the presence of the parents together affect the care of the child with ASD positively, while the father's absence may negatively affect the mother and child. For example, Mai shared her experience, saying that since her husband works in another city and visits her and her children on some weekends, the father does not care for his son with ASD and does not provide him with the love and emotional support that the child needs. For Mai, this means that when emotional support and psychological stability are not provided by the father, the mother feels alone. Mai is obedient to her husband’s requests and cannot discuss the harm her husband's absence will have on her son because she fears divorce. In Mai’s case, the fear of divorce may lead to her feeling stressed, making it difficult for her to care for and focus on her child.

> My husband works in another city we meet him some weekends only, my husband does not know anything about my son, whether he is sick or not, and he only sees him by chance. Even when I get busy with my son, he says, "Me first, then your children." I obey my husband because I fear he will divorce me, which is unacceptable to my family. But I hope that my husband feels more about my son, for example, taking him for a walk on the sand and making him feel love and tenderness, but I know this is impossible for my husband to do it. (Mai)

Hala feels worried because her husband lives and works in another city and is not present in her male child’s life. This means, from Hala's view, that her child with ASD needs special guidance and support to enhance his social skills and develop his ability to communicate and interact with other males.

> My husband works in another city and he visits us on some weekends. So, I take my son everywhere with me. As you know, in Saudi society, there is a society for females and a society for males. I am worried because I want my son to get used to the society of males and learn from his father the skills necessary to adapt to the society of males. This is very difficult with the absence of his father. (Hala)

I also stated in my autoethnography that having both parents in a child's life is essential, and I expressed my pleasure that my husband now accepts my son's condition and helps me raise him. This means for me, the father's involvement in supporting and advocating for a child with ASD is important. We are both actively engaged in raising our son; thus, I feel this leads to enhanced emotional well-being, a stronger support system, and increased opportunities for Azoz’s development and success.

> My husband became more accepting of our son's situation and more aware of ASD through the information he was receiving from Azoz's teachers. He began looking for services that met Azoz's needs and helped him develop and adapt to society. He was also no longer afraid that anyone would know that Azoz had ASD, and this relieved our sense of tension, and we became supportive of each other for the sake of our son. I felt happy and I would be able to help my son. (Mashael)

Culture

In this study, the mothers and I reported that some beliefs affected us and delayed early diagnosis and intervention for our children with ASD. For example, from Faten’s experiences, the father is the child's guardian and no services are provided to the child without the father's consent (Alnemary, 2017). Therefore, the child cannot receive the free government services available to the child with ASD if the father is busy or does not cooperate with completing the legal procedures to obtain the service. Because of this experience, Faten felt despair.

> I really feel despair, frustration, and anger because I see my son in front of me and I know what to do for his treatment but I cannot. My husband does not help me either financially or morally. I couldn't even get my son's monthly salary that the government provides for children with ASD without my husband's consent. My son did not get these free services due to his father's lack of cooperation. (Faten)

Farah also held certain religious beliefs, e.g., ASD is a demon or an evil eye that can be removed by reading the Qur'an. Farah felt sad because this negatively affected her and her family. E.g., Farah spent years wasting her time and money searching for how to expel this demon. This means for her; she delayed early intervention and behavior modification sessions that would have benefited her son.

> I gave my newborn son a shower in the bathroom two days after he was born instead of bathing him in the bedroom, as is standard among mothers - newborns should not bathe in the bathroom. As a result of the shower I gave him in the bathroom, my family says that he became possessed by Satan. I felt sad because 50 percent of what they say is correct. After all, when I read the Qur’an to him, I feel he is affected. And there are those in the family who say he was envied because he was so beautiful. I wished my husband sought a man who can treat envy and expel Satan from my son's body by reading the Qur’an. (Farah)

My autoethnography explains that certain beliefs, such as the presence of a child with a disability, may affect the chances of the husband's siblings getting married. Due to the possibility of divorce, I concealed my son's disability. This meant that my fear of negative social consequences, such as divorce or rejection from others, prevented me from discussing or seeking help publicly about my son's disability. Also, I felt fear and stress because my married life could end at any moment.

> A person with a disability would negatively affect the marriage prospects of my husbands’ brothers and sisters, as people might think that the disability was inherited, so no one would want to marry them. For years I remained silent about my son's condition due to fear of divorce. (Mashael)

CHAPTER V: DISCUSSION

Overall Results

The results of this study indicate that the mothers of children with ASD and I face similar challenges related to five themes. The first theme, dissatisfaction with some services provided. The second theme found in the data discussed insufficient accurate information about ASD which makes it easy for us to believe in myths and delay diagnosis and intervention. The third theme included anger because of lack of support. Some mothers and I reported not receiving financial, moral, or psychological support from the husbands, families, community members, or specialists in the ASD field. The fourth theme included loneliness and social isolation due to others' blame, pity, and non-acceptance of the children with ASD. The family was enmeshed- the family member was overbearing in their pressure to quit jobs, divorce, or use unsafe treatments. Further, the mothers and I in the study felt guilty and worried about the impact of these pressures on our children's well-being.

The study found three themes related to the strategies that the mothers and I used to overcome the challenges faced while raising a child with ASD. The first theme included self-learning and gaining knowledge about ASD through specialists or workshops. This has resulted in less stress and anxiety for mothers and me and improved our children's quality of life. The second theme included spirituality. An example of this was seen when mothers spoke about the practice of gratitude, which has helped mothers maintain a positive attitude and acceptance of their children's disabilities. The last theme discovered included joining social media groups. These provided a support network for mothers and me to locate resources and services for our children with ASD.

The study also found slight differences between the challenges faced by mothers whose children with ASD were born before or after the establishment of the ASD law in Saudi Arabia (2001, Regulations of Special Education Programs and Institutes). Both groups of mothers and me reported similar challenges related to dissatisfaction with the services provided to children with ASD, insufficient information about ASD, anger because of lack of support, blame from others, pity, family not accepting our children, and feelings of fear and worries. Both groups of mothers and me, for example, worry about the future of our children. But mothers of children with ASD who were born before the law are concerned about who will take care of their children after the mother is old or passes away, while mothers of children born before the law and I worry about child's sexual lives and the child’s education.

Overall, this dissertation study found many new themes that have not yet been explored in the literature discussing experiences of mothers that have children with ASD living in Saudi Arabia. I will discuss how the study findings compare to limited research and discuss the implications for research, policy, and practice.

Dissatisfaction with the Services Provided to Children with ASD

In this study, mothers and I expressed dissatisfaction with the approach some schools took to integrate children with ASD with children without disabilities. Some school failures to implement inclusion and to provide satisfactory educational support for children with ASD in inclusion schools include: the school day is too short to teach academic skills; the child is excluded and isolated from some activities with students without disabilities; the classrooms aren't well equipped; and the teachers aren't qualified to teach students with ASD. From the mothers’ (and my) perspective, these examples and experiences mean that some schools are not committed to inclusion and this may encourage discrimination. These findings are consistent with the study done by Alotaibi et al. (2016), which found that the professionals working with students with ASD in some schools were not qualified and that the classes were not well-equipped. In addition, most participants in the Alnemary et al. (2017) study also found it difficult to access some educational services for their children with ASD because most of educational services were only in the main cities that are densely populated, namely Riyadh, Dammam, and Jeddah.

In this study, mothers of children with ASD and I also expressed dissatisfaction with some diagnostic services as a challenge we faced. A number of reasons contribute to our dissatisfaction with some diagnostic services, including: the absence of standardized diagnostic guidelines in some clinics and the lack of trained specialists who can conduct a diagnosis. This may result in misdiagnosis or delayed diagnosis of the disorder. This in turn delays the early interventions and support services that are necessary for improving the performance of children with ASD. Mothers reports of dissatisfaction with the diagnostic services is a challenge in line with the findings of Hemdi et al. (2017) and Sahab (2017). In both of these studies, most parents reported insufficient professionals able to diagnose ASD. Furthermore, some hospitals and clinics do not have a clear diagnostic process for ASD. ASD is usually diagnosed by child psychiatrists; however, diagnosis and measurement tools vary from clinic to clinic (Alquhtani, 2012).

Insufficient Information

In this study, one of the challenges is the mothers' feelings (and mine) of despair and sadness when raising a child with ASD in a society where there is insufficient information about ASD. By turning to the Internet and relying on misleading, erroneous, and unreliable information about ASD and its possible causes, the diagnosis of ASD is delayed, which delays early intervention. These mothers' experiences (and mine) mean despite the challenges the mothers and I face, our experiences show our willingness to learn and meet the needs of our children. Through our experiences, we have gained valuable knowledge about ASD and effective intervention strategies. Still, we also recognize the importance of ongoing research to provide reliable information to support mothers and me in improving our children's lives. In comparison to previous studies examining the challenges faced by mothers of children with ASD in Saudi Arabia, Hemdi et al. (2017) and Khan et al. (2020) findings are similar. These studies reported that a lack of understanding of ASD, its causes, and ways to support people with ASD is one of the challenges faced by families of children with ASD in Saudi Arabia. For example, parents in the Hemdi et al. (2017) and Khan et al. (2020) studies reported that they do not have information about ASD, its possible causes, or ways of treatment. Some parents reported that psychiatrists tell them that their child has ASD after diagnosis without giving them enough information about the disorder, which makes parents resort to online resources to educate themselves. Still, most of the helpful resources are only available in English (Hemdi et al. 2017).

Some mothers and I in this study believed in widespread myths (e.g., ASD is a disease that can be cured, consanguineous marriages cause ASD, ASD is caused by vaccinations, and ASD is a demon) as a result of our insufficient information about ASD. The mothers and I felt sad and guilty because these beliefs caused us to waste time and money on ineffective treatments. This means belief in myths negatively affected mothers and me and our children and prevented us from obtaining effective early intervention and behavior modification. In comparison to previous studies about the challenges faced by mothers of children with ASD in Saudi Arabia, this study's findings are in line with the findings of Alqahtani (2012). According to Alqahtani's (2012) study, misinformation available online may contribute to beliefs in myths.

There is information available for parents of children with ASD on the Internet in Arabic, but it does not come from reliable scientific sources. For example, Twitter and Facebook accounts of non-specialists publish information that has not been verified by scientific studies. There is a lot of agreement between the findings of this dissertation and those of the existing literature, such as Lin (2008) and Hebert (2014). The study of Lin (2008) found that parents of children with ASD always sought treatment because they did not know what ASD was, so they sought treatment constantly. According to Hebert's (2014) study, parents reported that their lack of knowledge about ASD and their belief in false and fixed beliefs about its causes delayed diagnosis and early interventions, resulting in their children's unsatisfactory development.

Anger Because of Lack of Support

This study found that mothers and I felt angry because we were not provided with financial and psychological support by our husbands and families when raising children with ASD. Bringing up a child with ASD presents many challenges, and a lack of support or assistance from husbands or family can make it even more difficult and prevent a mother from taking time to relax or care for her child. The mothers (and I) discussed that financial, moral, and psychological support is essential for the mother's well-being and the child's progress. Therefore, it is important that mothers of children with ASD get the support they need to provide the best care for their children. This theme is also represented in previous literature. For example, in the Hemdi et al. (2017) study, all mothers reported that their biggest challenge was the lack of help from family and friends. The mothers mentioned that they were fully responsible for caring for their children because fathers often spent their time outside the home working or enjoy with their friends.

Mothers in this study and I also felt frustrated and angry because when our children were diagnosed with ASD, we did not receive support from our community members (e.g., doctors, teachers, social workers, or ASD specialists). This means mothers and I were not provided with resources to help us understand ASD and were not provided with access to treatment options and services for our children with ASD. In the absence of this support, parents may receive inaccurate information about ASD services and treatments which may harm their children and delay early intervention. There is a good deal of agreement between this study and previous studies regarding the challenges mothers of children with ASD face. For example, in the Sahab (2017) study, parents reported that there was a lack of social support groups. Parents considered this deficiency one of the challenges they faced. They needed to communicate with professionals in the field of ASD or with families of other children with ASD to exchange experiences that supported them.

Feeling Lonely and Isolated from Society

One of the challenges the mothers and I faced in this study was blaming the mothers and me for causing our children's ASD. The mothers and I stated that the phrase, "ASD is caused by the mother", is one of the misconceptions associated with ASD which was developed due to a lack of awareness about ASD and its causes. This means that mothers who are blamed for their children's ASD are more likely to experience challenges and isolation from society because they believe that people treat them unfairly, hurts their feelings, and makes them feel guilty. Furthermore, blaming not only increases mothers' isolation but also prevents them from seeking the social and emotional support they need to thrive in their community. Blaming may further discourage mothers from seeking early intervention, behavioral therapy, or other support services. When comparing the results of this study with the existing literature, the results of this study agree with the study of Sabitri et al. (2021). In the study by Sabitri et al. (2021), some mothers reported that their families and other people blamed them for their children's ASDs because of dietary negligence during pregnancy and coddling their children too much.

One challenge mothers and I also faced in this study was pity from our families and friends. Others' pity did not help mothers and me; rather, it made us isolate and withdraw from social events and family gatherings to avoid this pity, which made us feel hurt and upset. This means that others' pity for children with ASD is the result of a misunderstanding of ASD and children’s abilities. In the mothers’ and in my view, by pitying children with ASD, other people emphasize children's shortcomings instead of their strengths and imply that they cannot achieve and succeed the way other children without ASD can. There have been no similar findings in previous research regarding the challenges faced by Saudi mothers of children with ASD that can be compared with the results of this study. In fact, there is a contradiction between the findings of this study and the existing literature. For example, parents of children with ASD in Yaacob's (2021) study reported that they were not disturbed by pity from others. Instead, they feel relieved because when friends and families feel sorry for their children with ASD, they will be able to provide them with a lot of emotional and social support. Additionally, some parents said they ask their children without disabilities to pity their children with ASD.

In this study, the mothers and I reported feeling lonely and isolated due to people not accepting the disability and the behaviors of our children with ASD. For the mothers (and myself), we felt people did not accept the disability and the behaviors of children with ASD because it doesn't understand ASD and its associated behaviors. Both the child and family can be adversely affected by society's lack of acceptance of the child's behavior and child’s disability. For example, it can be emotionally upsetting for parents because they may feel that their community does not support them. Children with ASD are also likely to have reduced communication skills and difficulty making friends, which can negatively affect their mental health and self-esteem. In comparison to the existing literature, this study's results agree with the findings of Hauser (2001), which found that behavioral problems of children with ASD are among the most pressing issues and challenges facing their parents. Many parents feel isolated because their friends, family, and society do not understand and do not accept their children's behavior.

Feelings of Fear and Worries

A number of mothers and I in this study reported being under constant pressure from friends and relatives. For example, working mothers were pressured to leave work and dedicate themselves to raising their children with ASD, mothers in a consanguineous marriage were pressured to divorce because some believed that consanguineous marriages caused ASD, or mothers were pressured to use unsafe treatment for their children. These pressures are very stressful and challenging for mothers of children with ASD. In addition, these pressures adversely affect both parents and children, such as mothers feeling anxious about their financial futures and how their children's lives will be after divorce or leaving their jobs. In addition, these pressures make mothers and I feel guilty about using treatments and interventions that are not scientifically proven effective and may harm our children. These pressures can be explained and attributed to two reasons: (1) the lack of understanding of relatives and friends of the causes of ASD; and (2) the exploitation of merchants of the need of mothers to find treatments or interventions that help improve their children's condition. This study's findings contradict those in the existing literature. This can be seen, for instance, in Nealy et al. 's (2012) study. Authors found that parents of children with ASD in the US are under pressure to leave work, but not to devote themselves to caring for a child with ASD but rather to seek another job with a higher income to meet their children's needs.

One of the mothers' challenges in this study was the worry about our children's future. There are two reasons why mothers are concerned about the future of their children: one is the worry about who will take care of them after their parents die or become old. A second issue is their children's sexual lives because ASD can make them vulnerable to harassment because they may not be able to comprehend social signals and boundaries. This means that mothers' worry is exacerbated by the fact that children with ASD often require lifelong specialized care and support, which can be difficult to find. Compared to existing literature, this study's results are in line with the findings of a study (Cox et al., 2015) that reported that parents of children with ASD recorded a higher level of worry and stress due to fear of death compared to parents of children without disabilities.

Our own Knowledge and Self-learning are the Key to our Strength and Success

In this study, self-learning of evidence-based interventions is one of the effective and successful strategies mothers and I have used to overcome the challenges we faced while raising a child with ASD. The study showcased examples of evidence-based interventions learned through workshops and consulting with specialists, including: (1) behavior modification techniques (e.g., reinforcement) to reduce unwanted behaviors in a child with ASD; and (2) a system of communication using pictures (e.g., PECS and TEACCH) that helps children with ASD to communicate with those around them and reduce their anger and frustration due to their inability to express their feelings and needs. This means that the success of evidence-based interventions leads to feelings of happiness and fulfillment, stronger parent-child bonds, and improved quality of life for both the child and the parents. It also proves that the child with ASD is able to learn if we use appropriate intervention, which in turn reduces parental worry and fear associated with raising a child with ASD. According to the literature review presented in Chapter II, there has been very limited previous research exploring the strategies Saudi mothers of ASD children used. In fact, there was only one article that discussed diet, social media, additional help, and prayer as strategies. However, when compared to existing literature exploring parents in the US, this study's findings agree. For example, the findings of Kuhaneck et al. (2010), which explored parents' experiences in the US, reported the importance of obtaining knowledge about ASD, and it confirmed that "knowledge is power" (p. 6). For example, parents reported that they had knowledge of state and federal laws and the resources and services available to their children with ASD. Further, their knowledge was the key to being a successful advocate for their children. Also, this study indicated that educating oneself about ASD improved self-efficacy and thereby allowed a mother to feel more in control, more confident in the parenting role, and less stressed.

Spirituality

Spirituality, such as gratitude, prayer, and reading the Qur'an, was one of the strategies that helped mothers of children with ASD in this study and I feel comfort, strength, and a sense of hope during difficult times. This means that the practice of gratitude by focusing on the positive aspects of the child with ASD (e.g., the child's progress and development) helps the child's acceptance, relieves maternal worry, and improves the child's and mother's quality of life. In addition, praying and drawing closer to Allah increases mothers' and my confidence that Allah will help us in difficult times and reward us for our patience and perseverance. Previous research has also found similar findings about the strategies Saudi mothers of children with ASD used to overcome challenges. According to Balubaid et al. (2017), spirituality was one of the strategies parents used to deal with the challenges associated with raising a child with ASD. For example, some parents in Balubaid et al. (2017) study said that prayer and reading the Qur'an made them feel comfortable and strong because they believed Allah would help them and reward them for their patience. In Saudi, religion is very impactful; thus, it is unsurprising that the mothers spoke about it. In contrast, the US is not as religious. Therefore, compared to the existing literature, the findings of this study differ from those in Kuhaneck et al's. (2010) study. In the Kuhaneck et al. (2010) study, the parents in the US reported belonging to a religious sect but did not describe religion as a coping strategy.

Social Media

Joining social media groups has many benefits that help overcome some of the challenges mothers face while raising a child with ASD. These benefits include exchanging information and gaining psychological support. Mothers and I reported using social media to exchange information with specialists and other parents. This information can educate mothers about ASD, services available to families, and their children's rights. As a result of this information, mothers and I may feel stronger and better equipped to defend our children's rights. Mothers can gain psychological support from social media because it provides a safe, supportive environment where they can express their feelings and experiences with others who have similar feelings and experiences. This means social media is a powerful advocacy tool that can help improve the resources and policies available to children with ASD and their families. Previously, similar findings were found about Saudi mothers overcoming challenges for their children with ASD. In Balubaid et al.'s (2017) study, parents reported that social media groups helped them reduce their stress by discussing issues and resources with specialists and other parents who shared similar experiences. In addition, they learned some effective activities for improving their children's educational skills and reducing inappropriate behaviors.

Challenges Before and After the RSEPI Law

There was a slight difference in this study between the challenges faced by mothers whose children were born before the RSEPI law and the challenges faced by mothers whose children were born after the law. For example, mothers of children born before the law and after the law all face the challenge of worrying about their children's future. Still, mothers whose children were born before the law are concerned about the future of their children regarding who will take care of their children after the mothers are old or dead, while mothers whose children were born after the law are concerned about the sexual life of their children. This means that mothers whose children were born before the law, their children had grown and past their teens and may have realized sexual boundaries. The child's sexual life may be one of the challenges faced by mothers whose children were born before the law, but they were able to overcome it and they are not worried about it for their children in the future. When comparing this finding with the findings of previous literature, I was not able to find any studies exploring the differences between the challenges faced by mothers whose children were born before and after the implementation of the special education law in Saudi Arabia.

Findings and Family Systems Theory

The findings of this study are highly related to the family systems theory, which holds that families are interconnected systems that affect and are affected by their members and the external environment (Turnbull et al., 2011). The challenges faced by the mothers and me in raising children with ASD in Saudi Arabia reflect the impact of the external environment on family dynamics and functioning. The dissatisfaction with the services provided, insufficient accurate information about ASD, and a lack of support from family and specialists are examples of external factors that influence the family system's functioning. These challenges can cause stress and affect the well-being of family members, especially mothers who are often the primary caregivers for children with ASD in Saudi Arabia. These challenges can cause difficulties in communication and relationships among other members of the family, especially the mother and father. The study also identified coping strategies used by mothers and me to overcome these challenges. Self-learning and gaining knowledge about ASD, spirituality, and joining social media groups are examples of how mothers and I use external resources to overcome the challenges we face. These strategies reflect the interdependence between the family system and the external environment, as mothers and I use external resources such as spirituality to improve the functioning of the family system. This is related to FST, since FST emphasizes the interconnectedness of individuals within a family system, as well as the influence of external factors, including culture and religion (Turnbull et al., 2011).

The slight differences between the challenges faced by mothers whose children with ASD were born before or after the establishment of the special education law in Saudi Arabia highlight the impact of external factors on family functioning. The establishment of the law has improved access to services and resources for families of children with ASD, but it has not eliminated all the challenges faced by these families. For example, mothers of children with ASD who were born before or after the law face challenges related to the future care of their children, reflecting the impact of external factors on family dynamics and functioning over time.

The findings of this dissertation shed light on the effects of some inputs such as the three family characteristics (size, form, and culture) as it relates to FST (Turnbull, et al., 2011). Because most Saudi individuals share a common culture and religious believes, characteristics around family size and form are directly related to and enmeshed in the cultural characteristics. Thus, it is impossible to speak about size and form without discussing cultural characteristics. For example, according to FST, large families are sometimes helpful in supporting mothers because many people may help parents with housework and provide the specialized support and resources needed by the child with ASD (Turnbull, et al., 2011). However, the findings of this study contradict this notion and indicate that large families may not always be beneficial and may negatively affect family functions. This dissertation reveals that some mothers in large families experience a heavy burden and feeling of exhaustion because they are responsible for everything at home. In Saudi, it is common to have large family units living in one household and it is the mother's responsibility to care for the husband, children, and elderly (e.g., father and mother-in-laws) (Sahab, 2017). Therefore, when a mother must care for all the family members without support from others, a larger family size can become overwhelming and stressful. FST asserts that the family's function is to meet the needs of each member but when the mother is stressed and unable to meet her own needs, this can affect other members of the family as a whole (Turnbull, et al., 2011). Therefore, in Saudi when mothers have to care for large family units and their children with ASD, this may affect their function of meeting the care and education needs of their children with ASD. So, there is a need for inputs and support (e.g., maids) to rebalance the family system and create a more supportive environment for the mother and her child.

The findings of this dissertation also confirmed that having a subsystem of siblings who love and accept a child with ASD in a small family size plays a crucial role in creating a supportive environment for mothers and children with ASD. This finding indicates that the family interactions and quality of relationships within the family may be more important than the size of the family. This is consistent with FST, which emphasizes the importance of support and acceptance within the family unit (Turnbull, et al., 2011). This highlights the importance of fostering positive family interactions and sibling relationships and involving siblings in caregiving regardless of family size.

According to the findings of this study, family form and the presence of both parents have a significant impact on the lives of both children with ASD and their mothers. The absence of the father and weak relationships with his children also have negative effects on the mother and her children. For example, in the Saudi culture, there is a separate society for males and a separate society for females, and often the fathers help their sons fit into the male society. Thus, when a father has limited family interactions in their son's life, they have limited capacity to enhance the child's social skills, develop his communication, and support him to interact with other males. A male child (especially a child with ASD who finds social interactions difficult) needs a male role model to learn skills needed to live in the male society. Moreover, mothers usually respond to their husbands' requests and do not express their concerns about the negative impact of the father's absence on the child for fear of divorce. Divorce leads to social rejection; thus, the fear of divorce can cause a mother to feel stressed, making it difficult for her to care for and focus on her child which affects the family function negatively. Children with ASD need a supportive and safe environment that helps them improve. The father plays an essential role in family interactions and provides support and psychological stability to the child and the mother. These findings are consistent with FST, which emphasizes the importance of family form and the active involvement of both parents in supporting children with ASD (Turnbull, et al., 2011).

Mothers in this study reported that there are some inputs as beliefs may negatively affect the mothers' experiences and early diagnosis, intervention, and support for their children with

ASD. For example, belief that ASD is a demon, and the pressure to hide the ASD diagnosis led the mothers and me to delay getting our children help and free services provided by the Saudi government. This is consistent with the theory of the family system, which emphasizes that the culture of the family affects the support and services that the child and the family receive. The success of treatment and intervention plans depends on how well they fit the family's culture and lifestyle.

These dissertation findings relate directly to the importance of family interactions, specifically the continuum of enmeshed vs. disengaged family units (Turnbull, et al., 2011). The findings of this dissertation suggest that mothers in large families, or those who care for their children in the absence of their husbands, report feeling alone, burdened, and overwhelmed. Thus, mothers often feel as if their family units are disengaged in daily caretaking tasks yet enmeshed at other times.

In enmeshed families, the boundaries between family members become blurred and the demands of the family unit can overwhelm a person's individual needs (Olson, et al, 2019).). In the enmeshed families of Saudi society, the cultural expectations demand that the responsibility and caregiving tasks often fall heavily on the mother. Thus, the mother feels alone when their husbands are disengaged in daily tasks and caretaking for their children with ASD and other members of the household. When one family member is not fully involved or present, it can upset the balance and functioning of the entire family system. The father's absence can add stress and burden to the mother, limiting her ability to focus on the needs of the child. Further, since some mothers feel that their husbands are disengaged, they expressed being the only ones who can support their children since their husbands don’t understand their child’s ASD needs. In contrast, in my autoethnography, I shared that a good marital relationship, when both parents are actively involved and share decision-making, fosters an ideal balance between enmeshed and disengagement. My husband and I have healthy clear boundaries and so share a sense of cooperation, shared responsibilities, and emotional support within our family subsystem. Further, having siblings actively interact in the care and education of the child with ASD indicates a more balanced family dynamic. These families show greater individual autonomy and the participation of different family members in caregiving (Turnbull, et al., 2011). This contributes to a sense of comfort and reassurance for the mother and creates a supportive and safe environment for the child.

Limitations of the Study

A limitation of this study is the social desirability bias. Some mothers may have been reluctant to report negative experiences or feelings about raising a child with ASD, especially when it came to talking about their families, friends. This may affect the quality and depth of data collected. However, this study got in-depth data by providing privacy to the mothers and creating a safe and reliable analytical environment. Recruiting mothers only from WhatsApp groups is still seen as a limitation. There are some mothers of children with ASD who are not interested in joining WhatsApp groups, or who live in villages with limited access to the Internet. Thus, the participants included reflected privilege due to their family’s occupation, income, and digital access.

In addition, there is a limitation regarding the characteristics of the participating mothers. The majority of mothers in this dissertation held higher education degrees, and all were knowledgeable about ASD. They were dedicated to learning more and participating in conducting research related to ASD in Saudi Arabia. Their educational degree and knowledge of ASD may have influenced their experiences and perspectives, and this may limit the representation of mothers with less educational backgrounds. For example, one of the mothers declined to participate because of her lack of higher education and knowledge about ASD. However, I made an effort and included at least one mother with no higher education who had only completed elementary school. This is done by encouraging mothers and emphasizing the importance of their individual views and experiences in achieving the goals of my dissertation. Overall, I was able to recruit a somewhat diverse population of mothers by age, location, job, and educational backgrounds. However, in the future, researchers should explore the experiences of mothers who have less knowledge about ASD.

Implications for Research, Practice, and Policy in KSA

In this section, I will discuss the implications for practice, policy, and research at the national level in Saudi Arabia, and make recommendations for Saudi ministries of education and health, universities, research centers, and ASD professionals. By implementing these recommendations, policy, practice, and research in Saudi Arabia can be improved to better support individuals with ASD and their families.

Practice

In this subsection, I will discuss the implications for practice in using standardized diagnostic tools, such as the DSM and ADOS, to improve early intervention and accurate diagnosis of ASD.

Mothers in this study stated diagnosis was a challenge; therefore, the Education and Health Ministries in Saudi Arabia could work together to standardize diagnostic tools and identify children with ASD early. For example, the Diagnostic and Statistical Manual of Mental Disorders (DSM) is the standardized diagnostic tool for diagnosing ASD and other disorders in the US (American Psychiatric Association, 2013). It is used by trained specialists to ensure standardized diagnosis (Gulati, 2019). Further, the Autism Diagnostic Observation Schedule (Lord, et al.,2012) is also used. Autism diagnostic observation schedule, second edition (ADOS-2) manual (Part I): Modules 1-4. Western Psychological Services), or another highly effective diagnostic tool, could be used as an assessment that aligns with the Diagnostic and Statistical Manual of Mental Disorders (DSM). The use of standardized assessments that align with the DSM can help make accurate diagnoses and develop effective treatment plans for individuals with ASD (Gotham et al., 2012). In addition, the Saudi Education and Health Ministries can also benefit from the Centers for Disease Control and Prevention (CDC) (Centers for Disease Control and Prevention, 1946), a national public health agency in the United States. Information and resources regarding ASD diagnosis can be found on the CDC's website (Centers for Disease Control and Prevention, 1946), including guidance on developmental screening and diagnostic tools for Arabic speakers. Practitioners could translate these resources and information about ASD and publish them on WhatsApp, where they are easily accessible and shareable with others quickly. Practitioners can reach a wider audience and ensure that important information about ASD and available support services are accessible to all families. Further, special education teachers can obtain training certificates approved by the Ministry of Education in order to be able to provide workshops to educate mothers (and other family members) about ASD.

Policy

In this study, mothers reported that they had difficulties accessing information and knowledge that would have enabled them to understand the needs of children with ASD better because most information was available only in English or other languages. The information provided in Arabic was not from reliable sources. Therefore, ASD associations and universities could also translate reliable sources into Arabic and provide these to parents and service providers in the community. The CDC website (Centers for Disease Control and Prevention, 1946) provides information and resources related to ASD, including prevalence estimates, screening tools, and evidence-based interventions. The information is available in many languages, including Arabic, and some could be translated by ASD associations, universities, or practitioners.

Although the government provides free public education services for children with disabilities (and ASD), and a monthly stipend (Aldhalaan, 2017), the mothers in this study (and other studies (Alnemary, 2017) reported that some schools are not equipped and have unqualified teachers. The ministry of education could encourage more professionals to specialize in ASD care (e.g., psychiatrists, counselors, social workers, teachers, physical therapists, occupational therapists, and speech therapists). Further, ASD specialists in Saudi Arabia also need continuous training to ensure they are provided appropriate instruction and are using effective evidence-based practices. For example, in the US we have a number of programs to help educators get free training. Here is an example from NC for teachers: https://www.dpi.nc.gov/educators/recruitment-support/educator-compensation/teacher-loan-forgiveness#:~:text=Most%20teachers%20who%20participate%20in,for%20as%20much%20as%20%2417%2C500. The ministry of education could do this by a public campaign and incentives for teachers to get trained.

Research

Although I reviewed several studies included in Chapter II that provided insight into the challenges faced by mothers of children with ASD in Saudi Arabia (e.g., Alnemary, 2017; Alotaibi, 2016), none of these studies explored the differences between the challenges faced by mothers whose children were born before and after the implementation of the special education law in Saudi Arabia. It is important to note that the studies reviewed did not include information about the parents' ages. They only included information about the children's ages. The children in the studies reviewed were between one and 18 years, meaning they were born after the law was applied. Therefore, future research should explore the differences in challenges faced by mothers of children with ASD in different age groups, including children born before and after the implementation of the special education law. This can help policymakers and researchers understand how the law affects the lives of families of children with ASD in Saudi Arabia and identify areas for improvement in the support services provided to these families.

Parents often report that the challenges they face are too stressful and they would like strategies to overcome them (Khan et al., 2020). These challenges affect many areas of their health, psychological, economic, and social life. The findings of this dissertation and the findings of only one of the studies reviewed in Chapter II (Balubaid, 2017) explored some strategies that may help parents of children with ASD overcome the challenges they face while raising their children. Therefore, future research should focus on finding more strategies to address the challenges facing families of children with ASD. These strategies significantly improve the quality of life for children and their families. With these strategies, raising children with ASD can be transformed into a positive and enjoyable experience for the whole family (Al-Kandari et al., 2017). In addition, strategies can help families to adapt to a new situation by fostering a more positive family environment.

Future researchers can benefit from the innovative methodology used in this dissertation, e.g., the combination of autoethnography and IPA. This combination may help researchers gain deeper insights by integrating multiple perspectives on the study phenomena. However, it is essential for future researchers to be aware of the potential challenges and biases that may arise when using this innovative methodology. As stated earlier, one could argue that a limitation using autoethnography and IPA is the dual role of the participant also being the researcher, e.g., this could cause the researcher to be a bias in data collection and interpretations (Creswell, 2000). In order to minimize this bias, researchers need to clearly define the analytical processes used in autoethnography and IPA to maintain the trustworthiness of research findings. To minimize the challenges that arise when using this innovative methodology, researchers should write the autoethnography before conducting any interviews with the participants and before even conducting a literature review so that the autoethnography is not influenced by the participants' experiences (McAuliffe, 2019). However, when the researcher remembers a new experience while interviewing the participants, it should not change the autoethnography but add the new experience in a completely different way from the participants' experiences.

To address the limitations of this dissertation related to the characteristics of the participating mothers, future research should aim to expand the circle of participants and make an effort to reach mothers (and other family members) who lack higher education degrees or feel less familiar with ASD. The researchers also need to provide a supportive environment that encourages these mothers to participate and contribute to the research. Researchers should also include mothers from villages with limited access to the Internet to ensure a comprehensive understanding of the experiences of all mothers raising children with ASD in Saudi Arabia. Research on fathers’ and siblings' perspectives and their experiences with children with ASD is also needed. As this dissertation focused on the experiences of mothers, it is also necessary to expand the scope to include fathers and siblings since this will provide a deeper understanding of the family and its impact on the well-being of the mother and her child with ASD.

Future research should also more deeply explore the components of FST and related family inputs/outputs to identify the challenges mothers face in families with varying sizes, forms, and cultural backgrounds so that strategies and support services can be developed to provide better support to families of children with ASD in Saudi Arabia. While this dissertation did analyze the mothers' (and my) cultural beliefs, more research should also be conducted on the cultural background of the Saudi family since religious beliefs and cultural traditions are important factors that influence the experiences of families raising children with ASD. Understanding the impact of cultural factors on the challenges these families face can help in developing support services for Saudi families and their children with ASD. The family interactions and continuum of enmeshed vs. disengaged family units can also be explored at a deeper level.

Conclusion

This study explored mothers' experiences raising children with ASD in Saudi Arabia and how they dealt with the challenges associated with raising a child with ASD. The study found that mothers faced a range of challenges, including dissatisfaction with the services provided to children with ASD, insufficient information, anger because of lack of support, feeling lonely and isolated from society, and feelings of fear and worries. However, mothers also reported using various coping strategies, including spirituality, social media, and our own knowledge and self-learning as the key to our strength and success.

The significance of this study's findings lies in its exploration of the unique experiences and coping strategies of mothers who raise children with ASD in Saudi Arabia that haven't been discussed broadly in previous studies. The findings also have important implications for clinical practice. Healthcare professionals should consider offering support to mothers of children with

ASD, and supporting other caregivers who could support mothers (e.g., fathers, other relatives, and maids). In addition, policymakers and service providers should recognize the challenges faced by mothers of children with ASD and work to provide accessible and supportive services to these families. Furthermore, future research should continue to explore strategies for addressing the challenges faced by mothers and families with ASD and increasing awareness about ASD. The parent's and the child's quality of life is impacted by these strategies and awareness about ASD (Al-Kandari et al., 2017).

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APPENDIX A: INTERVIEW QUESTIONS PROTOCOL

Qualitative interview guides are subject to modification based on emerging results.

Screening questions will not change.

Screening Questions:

a. Hello …. Are you the parent of a child with autism? (Yes, No). If Yes, continue the screening. If No, find a way to politely end the interview.
b. What is your age? (if between 22 and 50 YES or NO). If Yes, continue the interview. If No, find a way to politely end the interview.
c. Do you live in a rural area or village OR did you move from a village to the city for your child's treatment? YES or NO. If YES to any one of these, then continue the interview. If NO to both, then find a way to politely end the interview.
d. How old is your child who has autism - is he or she of school age between age 5 to age 29 year? If YES, continue the interview. If NO, then find a way to politely end the interview.
e. Are you willing to record your voice in the interview? If YES, continue the interview. If NO, then find a way to politely end the interview.

Drafted Individual In-Depth Interview Questions

Q1. Could you tell me about the early life of your child?

Can you tell me about your child's first life, starting from:

- Is this your first child? If no, which child is this: second, third …. ?
- Is this your only child with autism, or do any of your other children also have autism? If your other children also have autism, let us only discuss your first child with autism for now.
- His or her birth, was it normal, did you notice anything atypical about your child?
- When was your child born?
- How old is the child now?
- What is the sex of the child?
- Can you tell me about the first 12 months of your child's life?

- Diagnosis, how did you know that your child has autism and what are the first signs?
- How old was your son or daughter at that time?
- Before your child's diagnosis, had you ever heard about autism or know anything about it?
- At the beginning of the problem (diagnosis) - Was anyone at your side standing / helping you? How did that make you feel? PROBE: If yes how? If no do you think why
- What are the features of your child's autism? Can s/he speak / understand language? Are there any communication challenges? What about with narrow interests? What about repetitive behaviors?
- What do you think is the level of severity of your child's autism?

Q2. The impact of the ASD

- What is your reaction when you know that your child has autism? Probe: What were your feelings?
- What is your understanding of the causes and nature of autism? Has anyone blamed you for "causing" the disease? How did that make you feel?
- What was the reaction of the husband? Who knew the first news? Does this impact your marriage relationship?
- And the reaction of family and friends? Probe: How did that make you feel?
- How many times do the grandmother and grandfather visit you? (Or are you visiting them? do they support you?) Please tell me
- What about siblings of the child? How have they been affected by the child's behaviors and diagnosis? Were the influences negative or positive, and how did you deal with them? Can you give an example?
- Are there activities you enjoy doing with your child? What are they? How often do you get to do them?
- Are there any aspects that you find especially challenging?

Q3. The milestones of diagnosis development

- When and how did you discover that something is not normal in your child? Probes: What did you notice? How did that make you feel?

- Did you/spouse notice that something was not typical in your child and seek a medical opinion? Or was it another family member or a friend? Or, did a medical professional, teacher, or other professional suggest it to you?
- When you sought a medical opinion, were you taken seriously at first? Or did you have to advocate for your child? How did that make you feel?
- How long did the diagnostic process take (e.g. same day, spread over some days or weeks, or longer)? Did you have to visit multiple professionals before diagnosis? Do you know the names of any tests conducted on your child? Were you given a written report?
- Were you connected with therapeutic and supportive services? Did you have to do this on your own or did you have professional guidance? What difficulties did you face connecting with services?
- What kinds of therapeutic and support services have you tried (Please be as detailed as you can)? Are they affordable, accessible, and acceptable to you? Are they effective? How long have you tried these methods? Are they for children or family or both?
- How old was your child at that time?
- How old are you?
- When you knew that your child has autism ... where did you go and what happened? What were your feelings at that time? Have your feelings changed now?
- Did this diagnosis have an impact on you and the family? Probe: How did you conclude that?

Q4. School

- Tell me about the school. Does your child go to school for students with intellectual disability, when did he or she start?
- Does your child attend a mainstream school, or special education classes within a mainstream school? How was this decision determined? How do the teachers work with him/her? How do other children interact with your child?
- How many children are in class? ProbeS: Do you think this number affects the quality of teaching? How?
- What training do the teachers have and what approach do they follow?
- Has this school been helpful to you as a parent/family and to your child?

Q5. Behavior and mental health

- Have you noticed any aggressive behavior by your child or is inappropriate?
- Does your child suffer from anxiety, anger, or a psychological problem .... Is there any medical intervention ... any change? How was the change?
- Does your child feel moments of happiness and joy? Probe: Can you give me an example?
- What therapies and interventions are available to your child? Have they been helpful or effective? To what extent? Is the cost affordable for you? Any barriers to accessing the treatments or therapies?
- What therapies and interventions are available to you/your family? Have they been helpful or effective? To what extent? Is the cost affordable for you? Any barriers to accessing the treatments or therapies?
- What are your aspirations for your child's future? What influences your thinking about this?

Q6. Social life

- Does he or she have friends?
- Have you ever had a party for him or her?
- What are the main issues for now?
- Has he or she become mature? If your child is physically mature, do you have concerns about his or her sexuality?
- Does he or she do some activities and sports?

Q7. What about you then?

- Do you have friends? If yes, are your friends supportive of you? If not why?
- During these years did you feel despair? If yes, why? What other feelings did you have? Please explain more about those?
- How did it affect you? Did you encounter a problem where you felt that you were desperate or angry?
- Is the reason a lack of experience or a sense of inefficiency?
- What do you do when you feel upset

- Have you taken any treatment for yourself?
- Is there a moment of joy or a time when you felt happy? Why? Probe: Why does that moment stand out in your memory?
- Have you been pressed to take up unscientific or unhelpful treatments to “cure” your child? Can you tell me about those?
- Are there any popular myths and misconceptions about autism in Saudi society? Probe: what are they?

Q8 Questions about the strategies that parents used to overcome the challenges they faced while raising a child with autism

- Is there a therapy that has made a big difference in any aspect of your child with ASD? What is it? And how?
- How does your child communicate with you? Are there specific strategies or devices that helped improve communication? Is it free or expensive, and if it is expensive for you, how did you overcome this problem? If it is free how do you get it? How you know about it?
- What activities does your child like? How did these activities help improve your child's shortcomings?
- What activities or strategies do you do to relieve when you are stressed or worried about your child with autism?
- If a problem arises when raising your child with autism, how do you solve it? Where do you go to find information and resources that may help you solve the problem?
- Do you have social support, for example, community activities, social support groups, financial support from the government, and how do the social support you receive affect you and your family? What was useful and what was not? Did you face any problems when participating in any of social support? And how did you manage to overcome it, if any?
- Can you describe the support you receive from your husband or family, if any? How did it affect your life and the life of your child?
- What support services does the school/district offer for your child? How satisfied are you with these services? What are the alternative solutions that you have taken if you are not

satisfied with any of the services provided? What support options are provided to you personally by your child's school or school district? Did you benefit from any of these options, if any? How satisfied are you with these options? If you are not satisfied, why? What did you do if you were not satisfied?

- Can you share one or two of your best experiences as a parent of a child with autism? Why were the experiments successful?
- What advice would you give to others who have just learned they have a child with autism?

Q 8. Is there anything else you would like to talk about or tell me?

Thank you for your time. If you have any questions, you can contact me at any time. I may contact you again for a follow-up interview. After my study is complete, I look forward to sharing my findings with you.

APPENDIX B: ORAL CONSENT FORM

Hello, my name is Mashael Aljuaid. I am a graduate student at the University of North Carolina in the Specialized Education Services Department. I am conducting research on the challenges the mothers of children with ASD face in Saudi Arabia, and I am inviting you to participate because you are a mother of a child with ASD.

The purpose of this research study is to further identify the challenges and needs that Saudi mothers of children with autism face and describe some helpful resources and strategies available to Saudi children with ASD and their mothers.

As part of my study, I will ask you to participate in in-depth, individual interviews via Zoom about the challenges you face as a mother of a child with ASD in Saudi Arabia due to the culture, religion, awareness, and services available, and what psychological and social support or strategies that helped them overcome these challenges. The interview will take about an hour and will be followed by further interviews as needed at another time that may last from 30 to 60 minutes. There is no cost to you and no payment to you for these interviews.

There is no expected risk for you to assist me in this study. But there is a possibility that some interview questions may make you uncomfortable or upset. If so, please let me know. You do not have to answer these questions if you do not want to, and you are entitled to withdraw at any moment from the study. Remember your participation is voluntary. If you feel distressed during the interview, I encourage you to contact your healthcare professional for support.

You also need to understand that all the information I receive, including your name and any other information, will be completely confidential and will be kept in Box, which is a secure electronic file storage system protected by a password.

I will not identify you or use any information that makes it possible for anyone to know you in my dissertation, any presentation, or written reports about this study. If appropriate for you, I may wish to use direct quotes from you, but your name will not be used.

I would like to make an audio recording of our discussion so that I can have an accurate record of the information that you provide to me. Also, I will transcribe that recording by a paid service and will keep the transcripts confidential and securely in my possession protected by a password. For the accuracy of the transcription, two other research colleagues and I will review the transcripts and I will de-identify the transcripts before my colleagues assist me.

Your participation will be of great value in helping me to complete this research project, the results of which can greatly improve the quality of services provided to children with ASD in Saudi Arabia and facilitate access to them, and it may also reveal useful strategies to overcome these challenges.

If you have any additional questions related to this research or your participation in it, please feel free to contact me, my supervisor, or the university research office at any time. My name is Mashael Aljuaid and you can contact me at: (phone number 336-540-4495 /email mgaljuai@uncg.edu). My supervisor is Dr. Heather Coleman and she can be contacted at: (phone number 757-524-220 /email hmcolem2@uncg.edu). The University of North Carolina Research Office can be contacted at: (phone number 919 962-0130 / email endeavors@unc.edu).

Do you have any questions about this research? Do you agree to participate? May I audio record your consent and our discussion? If yes, please state your name, and say “Yes I consent to participate and be recorded as described.”

APPENDIX C: PARTICIPANT RECRUITMENT SCRIPT

Hello, my name is Mashael Aljuaid. I am a graduate student at the University of North Carolina Greensboro in the Specialized Education Services Department. I am conducting a study on the challenges the mothers of children with ASD face in Saudi Arabia and how they face or overcome them. I also have a child with ASD, and I think we may face similar issues. I would love the opportunity to talk with you about my research study. The findings from this study will improve the quality of services and support available for mothers and children.

I am inviting you to participate in my study if you are (i) a mother of a child with ASD (ii) who lives in one of the Saudi, (iii) your age is between 22 and 50 years, and (iv) your child's age is between 5 to 29 years. If you are willing to participate, I will conduct an in-depth, individual, and unpaid interview via Zoom with you about the challenges you face as a mother of children with ASD in Saudi Arabia due to the culture, religion, awareness, and services available, and what psychological and social support or strategies that helped you overcome these challenges.

If you are interested in participating, please send me a private message on WhatsApp and I will be in touch with you.

APPENDIX D: PERSONAL STORY: AN EXAMPLE FROM MY PILOT STUDY

I want to tell you that there are some relatives when they knew that my son has ASD, started blaming me and fabricating lies about my family and me. They said that they researched my family history and found that ASD was inherited in my family. They said I was the cause of ASD in my son, if I continued in this marriage, I would have children with ASD. There are some people around me who described me as a bad person, and Allah punished me with this child. I did not receive support from the people around me.

APPENDIX E: TABLE OF THEMES AND EVIDENCE

Theme	Definition	Quotes	Experience	Feelings	Meaning	Comparison of challenges before and after the law
Challenges						
Dissatisfaction with the services provided to children with ASD.	**Definition:** The existence of educational and diagnostic services for children with ASD, but they are insufficient.	**Educational Services:** “I am not satisfied with the duration of the school day, as it is very short, starting from 7:00 am until 11:00 am. Four hours a day is insufficient to teach children with ASD academic skills. In addition, the school prevents students with ASD from attending the morning assembly and listening to the morning speech on the pretext that the	Safi **experienced** inadequate support and resources for her daughter with ASD in one inclusive school.	Safi **feels** dissatisfied	From Safi's view, this **means** a lack of commitment to inclusion	Both reported dissatisfaction with the educational services. But **Before the law:** teachers were not qualified and classrooms were not adequately prepared, **After the law:** dissatisfied with how children with ASD are integrated with children without disabilities in the same class.

number of teachers assigned to monitor the morning assembly is insufficient to monitor all students with ASD. All the special education teachers working in the school were supposed to observe the students with ASD in the morning assembly, not just some of them. Special education teachers receive additional salaries to teach and supervise children with ASD and must fully perform their work. (Safi)			
“Also, I would like to say that before I enrolled my son in a school for typical	**Experience** Dissatisfaction with some	Hala **feels** dissatisfied with the way children with ASD are	This **means** for Hala, a wrong method of inclusion

students and hid my son's ASD, I visited one of the inclusive schools. I saw a wall between students with ASD and typical students in the same class. There is a hole in this wall so the students with ASD can see the board. The wrong method of inclusion that I saw has a kind of discrimination and bullying is that prompted me to hide my son's ASD. (Hala)	educational services	integrated with typical children in the same class	promotes discrimination
“My son's center asked me to transfer him to inclusive schools because the conditions for inclusion with typical children apply to him. Unfortunately, my	**Experience** Dissatisfaction with some educational services	Faten **felt** dissatisfied	**Means** the importance of having qualified, trained teachers who can effectively support the needs of students with

son felt uncomfortable in inclusion school and behaved like crazy. I feel dissatisfied with this inclusive school either, as the teachers were not qualified to deal with children with ASD. Children spend most of their school day gathered around a circular table without any activities that benefit or entertain them. Teachers allow children with ASD to integrate with typical children during recess and Art class. Still, the Art teachers of typical students objected to the inclusion and said that children with ASD distract	ASD in inclusive settings and the need for appropriate preparation and activities to engage and benefit all students

typical children. Teachers need training and supervision. (Faten)				
Diagnosis Services: “I took my daughter to pediatricians and professors in the field of ASD in several cities. And they all said that my daughter was normal without running any formal tests. Some of them did a bubble test. When my daughter blew bubbles, they told me she was normal because a child with ASD could not master this skill. I was unsatisfied with this diagnosis because I noticed	**Experience** Dissatisfied with the diagnosis results	**Feeling:** Dissatisfied	**Meaning:** Saudi Arabia provides good medical services to children with ASD; she would appreciate the availability of specialists in diagnosis .	Both groups reported dissatisfaction with the diagnosis services/doctors did not conduct official diagnosis testes

my daughter was not normal and had hyperactivity. After that, I took my daughter to a professor specializing in speech and working after his retirement from academic work in an ASD center. He gave my daughter a puzzle, and my daughter was able to put them together correctly. So, the doctor said my daughter is fine because a child with ASD can only do this after intensive training. I was upset and not convinced of this diagnosis, so I went to a professor specializing in psychology who worked in a profit center. She ran some tests and

asked me some questions, which I do not remember well now, and then she said that my daughter has ASD. (Safi)			
“My son was diagnosed with ASD at the age of five. Unfortunately, this delay was due to my son's doctor, who had followed up with him since birth. He told me that my son only suffers from epilepsy and physical disability. But fortunately, after I had a child with a disability, I read about disabilities and disorders. I noticed that my child had ASD traits, such as losing the ability	**Experience**: she got two different diagnoses from two pediatricians. Both doctors did not run any formal tests	**Feeling:** frustrated and confused	**Meaning**: having clear and scientifically based diagnostic tools and tests should be considered

to communicate verbally and visually. During one of my visits to a pediatrician, I told him what I noticed in my child. It was his opinion that if he had these characteristics, he had ASD without a formal diagnosis, tests, or even a referral to someone who specializes in ASD. I was worried and scared because the doctor didn't do any tests and relied on my words. This is frustrating. I think to facilitate diagnosis, the Ministry of Health needs to provide clinics with clear guidelines throughout the diagnosis process.

		(Faten)			
Insufficient Information.	**Definition**: mis- or lack of ASD information.	**Insufficient Information Led to a Belief in Myths:** I gave my newborn son a shower in the bathroom two days after he was born instead of bathing him in the bedroom, as is standard among Saudi mothers - newborns should not bathe in the bathroom. As a result of the shower I gave him in the bathroom, my family says that he became possessed by Satan. I felt sad because 50 percent of what they say is correct. After all,	**Experiences**: easy to believe in the myth	**Feeling:** sad.	**Meaning:** myth affected Farah and her son negatively, so she spent years wasting her time and money searching for a cure

when I read the Qur’an to him, I feel he is affected. And there are those in the family who say he was envied because he was so beautiful. I wished my husband sought a man who can treat envy and expel Satan from my son's body by reading the Qur’an. (Farah)			
“Consanguineous marriage is the cause of my son's ASD, and I have to get divorced so that I don't have more children with ASD. If I had known before I got married that consanguineous marriage could cause ASD, I would have	**Experiences:** Believed the myth that the cause of ASD is the marriage of relatives.	**Feeling:** guilt and sadness.	**Meaning:** Zain was affected too much by this myth and she is still confused about whether she should continue to marry or divorce so as not to have more children.

refused to marry my cousin” Zain			
“Based on the information I learned that ASD is a disease that can be cured, I wanted to get my son out of the circle of ASD, so I was pressuring him to do the right behavior like normal children until, unfortunately, he had behavioral problems such as beating and stubbornness because of my wrong way of dealing with ASD.” Hala	**Experiences:** Believing the myth that ASD is a disease that can be cured.	**Feeling:** stressed.	**Meaning:** she harmed her child and he developed undesirable behaviors instead of treating him.
Insufficient Information about ASD:			

"I heard the term ASD, but I don't know what the characteristics of children with ASD are or what ASD means exactly. My family and friends said that my son's delay is normal because he has no siblings to communicate with, and he lived at the beginning of his childhood in a country that does not speak Arabic. My heart is heavy. We need more studies about ASD. (Zain)	**Experience**, was unaware of the characteristics of a child with ASD, which influenced her thinking then and led her to think that her son's delayed speech was normal because he did not have brothers. As a result, she was late in diagnosing him and obtaining early intervention,	**Feeling:** sad.	**Meaning:** She hops research centers enrich ASD research to benefit families and professionals.
"When my son was diagnosed with ASD, I was not well informed about ASD. I learned from the internet that a child with ASD	**Experiences:** Insufficient information about ASD led to search for information on the Internet, which was	**Feeling:** despair.	**Meaning:** she has more about ASD now through her experience in raising her son. However, she still wants to have the

		would not develop except through individual sessions to modify behavior using educational games with different characteristics from regular games. My feelings of fear, despair, and pressure increased because I am not a specialist, and I do not know how to conduct these sessions, but I have learned from living for years with a child with ASD that he learns from every situation he faces. (Hala)	misleading and inaccurate. This experience affected her thinking then and led to her belief that her child with ASD would not improve except with behavior modification sessions by specialists and certain tools.		correct information from reliable sources available to everyone in Arabic.	
Feel lonely and isolated from society.	Mothers of children with ASD avoid social events to hide their children	**Blame from others:** “I do not visit my family much since my son was	**Experience**: The mother withdrew from society, and now she does not even visit her family because	**Feeling**: upset	**Meaning:** when people blames her for causing her child's ASD; she thinks it oppresses her since it lacks	**Both** groups reported that they face the same challenge, which is being isolated

from society for several reasons, including looks of pity from others, others blaming the mother for being the cause of ASD, or people not accepting their children's behavior.	diagnosed with autism. My father, although he specializes in medicine, says that ASD is a behavioral problem that arises because of the way the child is raised. He blames me for my dealings with my son and says I spoil him too much, so he shows ASD behaviors. I am very upset and I feel he hurts my feelings. I tried to convince him that I was not the reason, but he insisted that my upbringing was the reason. This is a great injustice." Mai	her father believes that ASD occurs because of the way the child is treated. Her father blames her she is the cause of her son's ASD for her wrong upbringing, her excessive pampering of her child, and her meeting all his needs.		an understanding of the causes of ASD.	from society because people blames them for being the cause of ASD.
	"When I meet my family members, I feel nervous	E**xperience**: isolation and	**Feeling:** nervous, I feel that I do not	**Meaning:** people are unaware of the	

because they blame me for my son's autism because I married my relative, and extending this marriage and having more children will be unfair to them. I feel that I do not want to meet them. People unaware of ASD and afraid of the unknown." Zain	withdrawal from family visits because some of her relatives blame her that her marriage to one of her relatives is the reason for having a child with ASD, and that continuing to marry may increase the birth of many children with ASD.	want to meet them.	causes of ASD, So, some people blame the mother to managing their fears of the unknown, in the sense that when they attach the cause of disability to a person, they will feel confident that if they or their children do not do the same thing as that individual did, the disability will not touch them.
Pity: “Also, my social relations were affected, so I no longer visit friends or family because of the looks of sympathy and pity for my son's situation. People embarrass me with questions	**Experience:** she avoided social events because society looked upon her child with pity. People believe that they are helping her and making her feel sympathy. However, she dislikes this	**Feeling:** looks of pity hurt me so much.	**Meaning:** the mother wants respect from people, not pity. From a mother's point of view, pity does not mean to her that people are kind. Because some people show you pity to give them the right to

like, why does your son do this? What does he feel? Other questions of this kind bother me and I do not have an answer for them. I feel that the looks of pity hurt me so much. People around us do not understand that we need respect, not pity. (Zain)	feeling of pity and the hurtful feeling it evokes, so she isolates herself from other people.		ask embarrassing questions of you or your child or provide you with advice.
“I no longer participate in social events. When some relatives asked me why I didn't work after I made an effort to get a master's degree, I didn't tell them that my son has ASD and I wanted to take care of him instead of working. I don't want them to look	**Experience**: The mother became isolated and stopped participating in social events because some of her relatives pitied her son and treated him differently from typical children.	**Feeling:** I don't want them to look at my son with looks of pity that might make me **feel** hurt.	**Meaning**: that some relatives pity her son because they do not have sufficient awareness of ASD

at my son with looks of pity that might make me feel hurt. Some relatives who know that my son has ASD pity my son and me because they do not have enough awareness about ASD and see my son as insane and that it is not possible for him to improve or develop or he is less than his peers. They deal with him on the basis that he is less sometimes. For example, if my son is with their children, they tell their children not to let him wait for his turn to play and make him the first because he is different. I asked them not to treat him on the basis

that he did not understand and not to pity him because they would annoy him more than help him. If we treat him in a particular way, how will he adapt to a society that may not treat him as different? (Hala)			
“I have friends and I go out with them sometimes in public parks and I take my daughter, but I am bothered by the feeling of pity from some friends, for example, when my daughter takes candy from the hands of one of their children and I return it to the child, I find the mother telling her child to give my	**Experience:** The mother suffers from isolation. She does not visit friends and family or go out with them on a picnic because people pity her daughter and treat her differently.	**Feeling**: I am bothered by the feeling of pity from some friends.	**Meaning:** people need awareness campaigns about autism and how to deal with children with ASD and their families, just as families of children with ASD need counseling services to educate them about how to respond to unwanted pity.

daughter candy because she is different, or telling her child that my daughter does not understand and you do. They think they are helping me so that my daughter doesn't start crying or hurting herself but they hurt our feelings. Therefore, isolation has improved because society and we need awareness about ASD and pity. (Safi)			
Others are not accepting our children.: “Society and many people still do not accept children with	**Experience**: The mother suffers from the lack of acceptance by people of the	**Feeling**: sad and angry	**Meaning**: people are not properly educated about ASD and the need for public lectures

ASD behavior. For example, I was in a mall one day with my children, and my son saw a train and wanted to ride it. The train was a few steps away from me and I was watching my son with my eyes. Still, suddenly he saw a baby with his mother sleeping in his carriage and my son hit him, and the baby started crying. Hence, the mother hit my son and pulled him by his hair. I know my son was wrong, but the mother reacted aggressively and started screaming at my son and me so that all the passersby gathered and looked at us and tried to calm the	behavior of her child with ASD, which made her isolate herself from society.		or materials that are easy to read is necessary for raising awareness about how to deal with children with ASD and accept them.

mother down. And I told the mother that my son has ASD, but she said that this does not matter and that he deserves punishment for what he did. Honestly, I cried and felt sad and angry for several days because I was shocked by the mother's reaction, as she did not understand and accept my son's behavior, which was caused by ASD and was not poor parenting. I am still thinking about how to act if the situation repeats itself. Honestly, I isolated myself because I am afraid and do not want to take my son to public

places, although he has the right to go outside and play like other children. People needs to educate, for example, through lectures or reading. (Hala)			
Honestly, I consider support is accepting my daughter and her behavior, but unfortunately, no one accepts her behavior, especially when she was younger and had severe hyperactivity. Although she has improved. I feel sad and alone when I see my family not accept my daughter's behavior, so I isolated myself. I do not meet with family or friends because I cannot	E**xperience**: The mother suffers from the lack of acceptance by society of the behavior of her child with ASD, which made her isolate herself from society.	**Feeling:** sad and alone.	**Meaning:** society is unaware of children with ASD and their behavior, so it does not accept them. From the mother's perspective, society's lack of acceptance of children with ASD behavior may lead to children's social isolation, which decreases their ability to communicate with others. ASD should be started educated during the school years,

leave my daughter at home alone, and at the same time, I know they do not want me to bring her with me, so I do not visit relatives. people are not aware of children with ASD and their behavior, so it does not accept them, which affects the children socially. I believe that educating society should start from schools. (Safi)			according to the mother, so society becomes more aware of it.
“No one accepts my son because they do not know what ASD is. I visited my sister one day, and my son destroyed some grass in their garden, so her husband got angry and said, “Do not let this	E**xperience**: The mother suffers from the lack of acceptance by society of the behavior of her child with ASD, which made her isolate herself from society.	**Feeling:** upset.	**Meaning**: society does not understand the behavior of children with ASD, so it does not accept them as children. It would be helpful if people are taught about ASD in the

		madman destroy the plants of our garden.” I felt upset and promised myself that I would not take my son to visit anybody. It is my personal belief that if ASD were taught in schools, society would not think of autism as madness. (Farah)			school curriculum.	
Anger because of lack of support	**Definition:** The lack of assistance available from other people or society.	**Lack of family support:** “I took my son to an ASD center with 23 years of experience diagnosing all disabilities. They diagnosed him with ASD. They said he needs sessions to modify behavior and communication and physical and	**The mother's experience**: husband refuses to support her financially.	**I felt** alone.	**This means** that the mother expected the husband to provide her with financial support for her child's education as well as psychological support to help her find her own time to relax and not worry about caring for her child with ASD.	**Both** groups reported a lack of support from the family, but before law: the husband does not support and rejects interventions. After law: the husband and family do not assist and the mother is responsible for

occupational therapy, which costs 12 thousand riyals per semester. My husband refused to pay because the cost was high. However, he can pay, as he is well off. I felt that I was spinning in a circle on my own. I still feel like I'm fighting alone. My husband needs to support and help me register my son in any school that provides ASD services. While it is important to me that my child goes to school to learn, I also need to find time for myself. (Faten)

everything in the house.

“My son did not go to school until he was nine years old. Before he entered school, I could not teach him anything myself. I only used to feed him, change his clothes, and bathe him because I did not have time to teach him. I am a mother and responsible for everything in the house, including school and hospital appointments and daily housework such as cooking and cleaning. I have no one to help me. I care for my husband's mother, who lives with us, as she is old and incapacitated. I provide her with food and medicine for her,	**Experience**: She is responsible for everything in the house.No one helps her.	**Feeling:** tired	**Meaning:** the mother does not have time to educate her child. The mother thinks that the father needs to enroll the child in an ASD center or hire a maid to help the mother with the housework until the mother finds time to educate the child.

and I take her to the doctor regularly. So, I didn't find time to teach my child because I felt tired as if I were in a marathon. I expected my husband to at least hire a maid. I feel sad about my son because he did not receive early interventions at home or school. After that, I convinced his father to register him in an ASD center because he had grown up and had not learned anything, even daily life skills. Indeed, he was registered, but the fees were costly, so he completed only one semester. After that, his father suspended him from school,

although he
seemed to be
improving and
looking at me and
pointing at his
body parts.
(Farah)

Feelings of fear, guilt, and worries	**Definition:** Friends or relatives pressure mothers of children with ASD to leave their jobs and devote themselves to raising the child with ASD or leave their husbands if they are relatives because this is the cause of ASD. These pressures make mothers feel guilty, which increases fears and worries.	**Pressure from family and friends:** “Some relatives are pressuring me to ask for a divorce from my husband. They say that consanguineous marriage is the cause of my son’s ASD. But I feel worried about how I will leave my husband while we love each other and our marital relationship is stable, and what will be my son's fate after the divorce? This pressure is not supported by reliable evidence.” Zain	E**xperience**: Relatives pressure to divorce because consanguineous marriage is the cause of ASD.	***Feeling***: *worry.*	**Meaning:** pressure from relatives to divorce due to consanguineous marriage is not based on evidence, and there has been no study that confirms this claim. To avoid affecting her child with ASD, who requires a stable marital relationship, a safe environment, and a loving, supportive father, she does not wish to leave her husband.	**Both** groups faced pressure from family and friends. But before the law: pressure to quit job to raise the child, and after the law: pressuring to use unsafe treatments for the child with ASD.

“My husband pressured me to take my son to an elderly woman who claims that she treats ASD and offers folk remedies. When I went to her, I asked her, do you treat children with ASD? She said yes. If the child with ASD does not speak, this means that he has blood collected in the palate. I need to remove the blood with my finger to help the child talk. I visited her five times but did not see a noticeable improvement in my son. I lost money, effort, and hurt my son for nothing, I was very sad for my son, as he bled from his mouth for several days	**Experience**: The mother was pressured by her husband to use unsafe treatments for her son with ASD. These treatments benefit are not scientifically proven for children with ASD.	**Feeling:** guilty.	**Meaning:** stakeholders should stop entities and persons who provide treatment that is not scientifically proven to benefit children with ASD. There is an exploitation of the need for families of children with ASD to treat their children.

and became afraid and did not want to eat. I felt guilty. In my opinion, ASD has become a business. I hope that these practices will end. Our children are being harmed and there is no scientific and reliable studies behind it.” Farah			
My husband pressured me to leave my high school physics teacher job to devote myself to caring for our son with ASD. My husband promised me that I would return to my work, complete my master's degree, and he would help me in the raising of our son, but he was	**Experience:** The mother expressed pressure from her husband to leave her job and devote herself to raising her son with ASD.	**Feeling**: I regret losing my job, which made me feel very sad and worried about my future.	**Meaning:** This pressure does not mean to the mother that her husband is wrong, but rather that he is busy in his work. If there were free and official centers specializing in ASD that would train maids to deal with children with autism and help parents in caring

unable to fulfill his promises. I regret losing my job, which made me feel very sad and worried about my future. From my point of view, I do not blame my husband, and I know that he cannot help me take care of our son because my husband is an engineer and he moves between Saudi cities constantly. I believe If there had been training for maids as a service provided to families of children with ASD, my husband would not have pressured me to leave my job.”
Faten

for children with autism, this may give parents an opportunity to practice their daily practical and social lives.

Worries about the child’s future: “I have cancer in its final stages, so I think about my son's future a lot and I feel fear and worry about him. I even started collecting all his monthly salaries that the government gives him as support for children with ASD in his own account in the bank to help him hire at least a maid for him in the future if I died. I hope he will be able to live independently and not be a burden to anyone. I hope there are centers for permanent residence to care for children with autism if their	**Experience**: fear and worry for her son in the future after she dies or becomes elderly	**Feeling:** fear and worry.	**Meaning:** establishing centers to shelter children with autism after the death of their parents or their advanced age. These centers should be well-equipped to take care of them.	**Both** groups reported worrying about the child's future but before the law: they worried about who would take care of the child after the mother died or became old. And after the law worried about the child's sexuality.

		parents get old or die.” Mai			
		“I feel very worried about my son's future regarding sexuality, as I am afraid of harassment. The mothers of children with ASD and I need more information through courses and workshops on sexual education for adolescents with ASD.” Zain	**Experience**: fear and worry about son's future regarding sexuality.	**Feeling:** worry.	**Meaning:** needs to be free or nominally priced workshops and courses to educate mothers of children with ASD about their children’s ASD.
Strategies Reported:					
Spirituality	**Definition:** Spirituality is religious rituals, prayer, meditation, belief in a sublime power or a feeling of comfort and peace and child is	**Gratitude for Allah's blessings:** “When I feel sad and hopeless, I practice the worship of gratitude for	**Experience:** of practicing gratitude for God's blessings upon her when she was sad or desperate helped her **feel** at ease.	**Feeling:** comfortable	**Meaning:** gratitude for God's blessings positively affects an individual's perspective toward ASD. For example, when

a gift and the way to Heaven. This reduces stress, depression, and anxiety.	Allah's blessings. I always remind myself that there are serious diseases that have no cure, but my son is learning and developing, and he does not have a serious disease that he pains from. He will improve with intensive training. We do not suffer from poverty, hunger, or wars. I feel comfortable when I remind myself of the blessings of Allah upon me.” Hala			parents of children with ASD practice gratitude for God's blessings, they are more likely to focus on the positive aspects of their children, such as their unique strengths and abilities. This can lead to greater acceptance by parents of their children, relieving stress and anxiety and improving quality of life.
	“I pray and read the Qur'an whenever I am in despair and anxiety in order to find relief. I believe Allah loves me because when Allah gave	**Experience**: prays to Allah and reads the Quran to deal with those emotions.	**Feeling:** comfortable and safe and that Allah is with her and will not let her down.	**Meaning:** Faten trusts that Allah will help her raise her child with ASD and that for being patient while raising her child, he will reward her by

		me an autistic child, He knew I could raise him and that I would be rewarded for my patience by entering paradise.” Faten			letting her enter heaven.
Social media.	**Definition:** Interactive technology that facilitates the sharing of ideas and information through the building of virtual networks and communities.	“WhatsApp groups helped me learn about inclusive schools and the best private ASD centers that offer behavioral modification sessions, occupational therapy, or communication services. Also, I learned the benefits that the country provides free of charge to children with ASD and how I can obtain them, such as the monthly salary	**Experience**: Zain described her experience joining WhatsApp groups as useful and helped her identify useful resources about ASD and the services available for children with ASD and their families.	**Feeling**: strong after this experience.	**Meaning:** This means to Zain that the WhatsApp groups made her able to defend her son's rights.

and discount cards for recreational games. These media groups also helped me know about some easy books that do not need specialists in the ASD field to understand. These books contain situations from reality and what is the correct behavior that the mother should take if she were in the same problem as "Teach me How to Communicate book". Zain			
“Social media such as WhatsApp, Facebook, Twitter, and Instagram support me psychologically,	**Experience:** Mai described her experience with social media as providing her with psychological support.	**Feeling:** she is not alone in her struggles, as many others have the same challenges.	**Meaning**: social media is a place for sharing information about ASD. It is also a safe and supportive environment where mothers

as I feel I am not alone. In addition to that, I benefit a lot from the experiences and information of mothers, and I share my experiences that may be useful to others who go through the same problem comfortably and safely. In some of the groups in which I participate, some decision-makers and stakeholders can help our voices be heard to obtain our rights and the rights of our children. I got information about these groups on social media from Google.” Mai	can share their experiences and feelings with others who understand. It is Mai's belief that social media can be an effective tool for advocating better resources, financing, and policies to support children with ASD and their families. In May's opinion, all mothers can easily join social media groups by using search engines to find information about how to join them.

Our own knowledge and self-learning are the key to our strength and success.	Our own knowledge and self-learning about evidence-based interventions are indeed the keys to our strength and success.	**Learning about behavior modification techniques from ASD teachers:** **Reinforcers** "I was suffering from some wrong behaviors such as my son turning on and off the lights constantly and running away from home. These behaviors bothered me and made me very tired because I could not leave my son for fear that he would run away from home, so I asked for a meeting with his teacher to discuss the matter, and we came up with a plan to modify this behavior by using symbolic reinforcement,	Hala expressed her **experience**, saying that learning the techniques of behavior modification, such as reinforcement from her son's teacher, helped her reduce unwanted behaviors in her child, such as running away from home.	Hala **felt** happy, accomplished, and relieved	From Hala's view, she believes that the success of reinforcers and behavior modification techniques in general in changing unwanted behavior **means** that children with ASD can improve through appropriate support and intervention, but without overusing them so that the child does not get used to them. Hala encourages other parents to self-learning by

where my son gets a star when he refrains from the wrong behavior, and if he collects a certain number of stars, he is rewarded by playing one of his toys at home, which is in front of his eyes, but far from his hand. He gets it if he does not do the behavior. Indeed, this strategy succeeded in modifying many of the wrong behaviors that he was doing, whether at home or at school by changing the reward each time. After the success of this strategy, I felt accomplished and very happy, and I had less fear of my son escaping. In

seeking resources and support from ASD professionals because she believes that the disappearance of unwanted behaviors in children with ASD helps reduce parents' anxiety and stress.

general. I became less nervous because I knew at least a strategy to modify the wrong behaviors of my son that might harm him. Still, I felt that my son did not want to do any work without the reinforcers and not any reinforcers satisfies him. He wants material reinforcements every time he performs good behavior. So I decided to use reinforcers on behaviors that need immediate intervention to stop them, such as self-harm or running away from home. Honestly, my view of ASD changed after I learned how to apply behavior

modification techniques, and I became sure that a child with ASD can improve and coexist with society without others seeing him as different. Therefore, I advise any mother not to hesitate to ask her child's teacher and specialists in autism at school about how to deal with an autistic child because they have a lot to help us.” Hala			
Learning PECS and TEACCH systems from workshops:			
“I used the PECS system to teach my daughter to communicate and express her wants and feelings. I also used TEACCH to	Safi also reported how her **experience** and self-learning of PECS and TEACCH (systems that use pictures to teach	Safi **felt** happy.	From Safi's view, the success of this strategy **means** that support for children with ASD is important to reduce their anger behavior

create a routine daily schedule. I learned all this while working in the Association for Children with Special Needs. My house was full of pictures everywhere. I wanted my home to be an environment that helps visual children like my daughter learn. I did this because my daughter is in one inclusive schools, in which, the classrooms are not prepared for visual children, such as children with ASD. When my daughter learned and generalized the skills, I gradually got rid of the pictures. The PECS system helped my daughter to	communication) through workshops helped her teach her daughter to communicate and express her desires and feelings.		arising from their inability to express their feelings and needs. Safi also believes that teaching a child with ASD communication skills reduces the mother's tension and helps her meet her child's needs comfortably. It also gives the mother more time for herself because it reduces the child's dependence on her. Therefore, Safi advises mothers to constantly follow charities' websites to register for the workshops they offer at nominal prices. Safi thinks It would be great if the government gave free workshops to

pronounce. I pronounced the word according to the picture she gave me to help her link the picture to the name. It was stressful, especially in the past time before the development of technology. It was challenging to get pictures, but I was so happy to teach my daughter so I did my best to provide them.” Safi

mothers of children with ASD to teach them how to communicate with them.

APPENDIX F: EXTRACT FROM MY AUTOETHNOGRAPHY MEMOIR

Initially, I stopped giving my son vaccinations because I assumed the vaccine he was given at birth had caused his ASD. But after conducting my own research and consulting medical professionals, I felt guilty since vaccines are safe and necessary for my child.

I don't like taking my son to visit my family. Although I know that they pity him because they love him, the looks of pity make me feel painful. I wish people could see the joy my child brings to our lives instead of feeling sorry for us. We do have challenges, but we also have a lot of love and laughter in our house.

My father pressured me to give my son camel milk, but I hesitated and felt afraid to use it. I don’t think camel milk is a miracle cure for ASD, so I prefer to stick to treatments that have been proven through scientific research.

APPENDIX G: FINDINGS RELATED TO FAMILY SYSTEM THEORY

Characteristics	Participant Quote	Feeling	Meaning
Size	I am a mother and responsible for everything in the house, including school and hospital appointments and daily housework such as cooking and cleaning. I have no one to help me. I care for my husband's mother, who lives with us, as she is old and incapacitated. I provide her with food and medicine for her, and I take her to the doctor regularly. So, I didn't find time to teach my child because I felt tired as if I were in a marathon. I expected my husband to at least hire a maid. I feel sad about my son because he did not receive early interventions at home or school. After that, I convinced his father to register him in an ASD center because he had grown up and had not learned anything, even daily life skills. Indeed, he was registered, but the fees were costly, so he completed only one semester. After that, his father suspended him from school, although he seemed to be improving and looking at me and pointing at his body parts." Farah	Alone, and exhausted	Because the size of Farah's family is large and the mother is responsible for everything in the house, the mother does not have time to complete a task that is important to her, i.e., educating her child. Farah thinks that the father needs to enroll her child in an ASD center or hire a maid to help
	"Now my son lives with my immediate family and me (i.e., his siblings, my husband, and me). Living with my small family does not worry me because Aroz's relationship with his siblings is good. They love him very much and accept his differences. In fact, they also help in his care, education, and share some educational	Comfortable	For me, this means having siblings who love and accept the child with ASD can create a supportive and inclusive environment, even if the family size is small

	games with him to teach him some skills. this is reducing my worries about my son’s future" Mashael		
Form	“My husband works in another city we meet him some weekends only, my husband does not know anything about my son, whether he is sick or not, and he only sees him by chance. Even when I get busy with my son, he says, "Me first, then your children." I obey my husband because I fear he will divorce me, which is unacceptable to my family. But I hope that my husband feels more about my son, for example, taking him for a walk on the sand and making him feel love and tenderness, but I know this is impossible for my husband to do it.” Mai	Alone, fear	For Mai, this means that when emotional support and psychological stability are not provided by the father, the mother feels alone. Mothers are typically obedient to their husbands’ requests because they fear divorce. In Mai’s case, the fear of divorce may lead to her feeling stressed, making it difficult for her to care for and focus on her child.
	"My husband works in another city and he visits us on some weekends. So, I take my son everywhere with me. As you know, in Saudi society, there is a society for females and a society for males. I am worried because I want my son to get used to the society of males and learn from his father the skills necessary to adapt to the society of males. This is very difficult with the absence of his father." Hala	Worried	For Hala, when her husband is not present in her male child’s life, she feels that her child will need special guidance and support to enhance his social skills and develop his ability to communicate and interact with other males.
	“My husband became more accepting of our son's situation and more aware of ASD through the information he was receiving from Azoz's teachers. He began looking for services that met Azoz's needs and helped him develop and adapt to society. He was also	Happy	This means for me the father's involvement in supporting and advocating for a child with ASD is important. We are both actively engaged in raising our son; thus, I feel this leads to enhanced emotional well-being, a stronger support system, and increased

	no longer afraid that anyone would know that Azoz had ASD, and this relieved our sense of tension, and we became supportive of each other for the sake of our son. I felt happy and I would be able to help my son” Mashael		opportunities for the child's development and success
Culture			
	I gave my newborn son a shower in the bathroom two days after he was born instead of bathing him in the bedroom, as is standard among Saudi mothers - newborns should not bathe in the bathroom. As a result of the shower I gave him in the bathroom, my family says that he became possessed by Satan. I felt sad because 50 percent of what they say is correct. After all, when I read the Qur’an to him, I feel he is affected. And there are those in the family who say he was envied because he was so beautiful. I wished my husband sought a man who can treat envy and expel Satan from my son's body by reading the Qur’an.” Farah	Sad	For Farah, means that some beliefs, such as ASD is a demon or an evil eye, can be removed by reading the Qur’an. This negatively affects her and her family, e.g., Farah spent years wasting her time and money searching for how to expel this demon. She delayed early intervention and behavior modification sessions that would have benefited her son.
	“My husband told me that if his family knew that he had a child with a disability, they might seek divorce for fear of having other children with disabilities. A person with a disability would negatively affect the marriage prospects of his brothers and sisters, as people might think that the disability was inherited, so no one would want to marry them. For years I remained silent about my son's condition due to fear of divorce. that	Fear and isolated	This means that I hide my son's disability because I was worried about a divorce. This meant that my fear of negative social consequences, such as divorce or rejection from others, prevented me from discussing or seeking help with my son's disability.

someone would know about my son's condition."
Mashael