

Disability and Shame Special Issue Forum: Research Article

Dealing with Shame: Saudi Mothers' Responses to Their Children's Diagnosis of Autism Spectrum Disorder

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Abstract: Autism is a disorder affecting individuals' academic, communication, and social development. The findings of this qualitative study report 15 Saudi mothers' responses to their children's diagnosis of autism spectrum disorder and provide insights into mothers' experiences and responses to stigma in the context of the Kingdom of Saudi Arabia.

Keywords: Autism Spectrum Disorder; Stigma; Mothers' Perceptions

Introduction

Individuals diagnosed with autism spectrum disorder (ASD) have difficulties when communicating and often show repetitive interests and behaviors. Therefore, mothers of children with this condition have encountered many problems when raising them. How ASD manifests depends on the chronological age and developmental level of the children. Symptoms of ASD include delayed toilet training, temper tantrums, self-injurious behavior, aggression, impulsivity, and hyperactivity (Duarte, Bordin, Yazigi, & Mooney, 2005). On the other hand, mothers of children diagnosed with ASD are more likely to experience depression, higher pessimism about their children's future, and reduced quality of life (Cappe, Wolff, Bobet, & Adrien, 2011; Johnson, Frenn, Feetham, & Simpson, 2011). According to previous research, it is evident that parents of infants diagnosed with ASD experience more parenting stress relative to other individuals (Hayes & Watson, 2013), indicating that having children with ASD can strongly impact the health and well-being of parents. Consequently, the degree of parental stress is proportional to the severity of children's behaviors and symptoms of autism (Davis & Carter, 2008; Ingersoll & Hambrick, 2011; Lyons, Leon, Phelps, & Dunleavy, 2010). When children manifest poor behavior and severe symptoms, their parents subsequently experience higher parental stress.

Furthermore, parents of children diagnosed with ASD often feel shame. For example, they may experience disapproval and criticism from neighbors as they are perceived as being unable to control their children (Gray, 1993; Mak & Kwok, 2010). Due to this stigma, children diagnosed with ASD are perceived as behaving inappropriately of their own volition. As a result, many individuals think that parents are to be blamed for using ineffective parenting styles when raising their children (Fernandez & Arcia, 2004). Consequently, mothers might feel they are not utilizing appropriate interventions or treatments, specifically when their friends advise them about various other treatments or interventions they should use

(Miller, Schreck, Mulick, & Butter, 2012). Additionally, mothers may blame themselves for not being able to help their children develop properly (Kuhn & Carter, 2006). They might even blame themselves for being the reason for their children's diagnosis. Therefore, these experiences of self-blame, shame, and guilt are the major causes of anxiety, depression, and parenting stress (Cappe et al., 2011; Mak & Kwok, 2010).

The shame, blame, and stigma experienced by individuals with disabilities and their families are reflected in the moral and medical models of disability where fault is attributed to the individual or his/her family and not to society (Olkin, 2002). Olkin (2002) proposes in the moral model of disability, that disability "is a defect caused by moral lapse of sins, failure of faith, evil, test of faith...brings shame to the person with the disability and his or her family" (p. 133). The moral model results in individuals "being ostracized from family and community, having profound shame, having to hide disability symptoms or the person with a disability" (Olkin, 2007, p. 6).

Review of the Literature

This study examined mothers' responses to the cultural stigma associated with their children's diagnosis of autism and the role institutions play. Individual interviews with mothers allowed for an examination of these women's experiences navigating issues of stigma related to autism in the Kingdom of Saudi Arabia (KSA). Goffman's (1963) theory of stigma as a theoretical framework underpinning this research review and stigma is examined in relation to culture, paying particular attention to the role that the Saudi culture plays in the lives of mothers whose children have been diagnosed with autism.

Culture

Culture plays a role in shaping the way individuals see, think, and understand the world. It comprises "a dynamic yet stable set of goals, beliefs, and attitudes shared by a group of people" (Gurung, 2006, p. 172) and even though some beliefs are fluid, "the general level of culture stays stable because individuals change together" (Gurung, 2006, p. 4).

As members of a community, the lives of individuals with ASD are generally determined by the culture in which they are immersed. Families and communities do the best they can to help individuals with ASD function as productive members of society and live as normally as possible, guided by their cultural beliefs and level of understanding. The beliefs held by members of a community regarding the potential and treatment of individuals with autism differ from one culture to another and can change over time (Ravindran & Myers, 2012). Culture influences key aspects of the diagnosis and treatment process, and affects the likelihood that individuals seek help, what treatments to use, available resources, and the relationships between families and professionals. Daley (2002) suggests treatment approaches that work and are culturally accepted in the West may not be the same approaches accepted and used to treat individuals with ASD in other parts of the world. For instance, in the West, known causes of autism are increasingly attributed to science and various treatments that are available which include behavioral, cognitive, pharmaceutical, sensory, relational, vitamins,

and diet therapy. However, in other cultures, the causes of autism might be regarded as “‘Karma,’ ‘Allah’s will,’ or ‘the will of God’” and may be treated with non-scientific remedies such as acupuncture and/or herbal medicine (Ravindran & Myers, 2012, p. 311).

ASD and Stigma

Within the scientific community, autism is viewed as a disorder marked by abnormal social skills stemming from an incurable medical condition (Martin, 2012). Over the years, the negative stigmatization and social perceptions associated with ASD have grown due to the individualized nature of the syndrome and a lack of understanding of the symptoms (Martin, 2012). Historically, one of the most common social challenges faced by individuals with autism is a feeling of isolation as they grow older, due to increased segregation and rejection from peers, combined with an increase in self-awareness (Martin, 2012). An individual’s level of isolation is dependent on key factors such as environment, personality, and intensity of impairment, all being impacted by the level of stigmatization received from others in the surrounding environment. Isolation and rejection are further exacerbated by the fact that the social behaviors of individuals with autism are perceived as different from the norm, or deviant. As such, since the behaviors of those with autism do not meet the expectations of what is appropriate, they are often ignored and avoided by the normative groups.

Goffman’s Theory of Stigma

Goffman’s (1963) framework is useful for examining Saudi mother’s perceptions of their experiences with stigma associated with their children’s autism. Particularly when discussing the societal stigma associated with having certain characteristics, Goffman sheds light on how communities stigmatize individuals that display certain traits that are deemed undesirable. This is true for individuals with autism in Saudi Arabia, where the culture still stigmatizes such individuals.

In *Stigma: Notes on the Management of Spoiled Identity*, Goffman (1963) describes the different types of stigma and how they impact the identity of those who are labeled undesirable by society. Goffman refers to those who are not forced to live under a perceived stigma, or “do not depart negatively from the particular expressions at issue” as “normals” (p. 5). This perspective is in line with how society views individuals who have been stigmatized, as well as, behaving the opposite of how normal society should act, despite how damaging these thought processes are to the relationships between the stigmatized and the general population.

Goffman (1963) identifies three separate forms of social stigma that are essential to conceptualizing how stigma impacts members of a society, whether individuals are, or may be perceived through this ever-present lens. The first form of social stigma involves physical abnormalities that are referred to with harsh, unsympathetic words. Goffman writes these “abominations of the body -- the various physical deformities” are enveloped with harsh judgment and are prevalent despite the physical differences occurring without the person’s will or desire (p. 4).

The second form of social stigma is associated with characteristics or behavioral traits that bring negative connotations despite often being no direct connection between the trait and the negative association. Often, these traits are:

Blemishes of individual character perceived as weak will, domineering, or unnatural passions, treacherous and rigid beliefs, and dishonesty, these being inferred from a known record of, for example, mental disorder, imprisonment, addiction, alcoholism, homosexuality, unemployment, suicidal attempts, and radical political behavior (Goffman, 1963, p. 5).

As seen in this quotation and thousands of other representations of people who express certain traits associated with the stigma, each action or trait can trigger a far worse reaction and behavior in turn.

The last form of social stigma is tribal stigma which is associated with linking different identities and people of a larger group into a singular category. It is created by combining individuals of a specific race, religion, nation, or some form of community into one single group or person, rather than a group of unique individuals. The individualistic needs and components of each person in the stigmatized community are immediately erased and those in the broader outside community are unable to sympathize with those stigmatized. Outsiders, on the other hand, relieve themselves from any responsibility by disassociating themselves from those in the stigmatized community. Therefore, dehumanizing and apathetic responses towards the community become easier and much more frequent (Goffman, 1963).

Goffman (1963) reinforces this statement by continuing to describe what he calls the stigma-theory which allows the community to continuously dehumanize someone with any stigmas and justifies whatever negative issues/perceptions in regard to the stigmatized individuals, as well as, continues to “break the claim that his other attributes have on us” (p. 5). Goffman notes that any other claim or connection that the stigmatized persons have with the general population is put aside in comparison to the overriding stigma, whether from physical, behavioral, or group stereotypes of the stigma.

In the case of autism, social stigma arises from misconceptions, stereotypes, and ignorance of the disorder and those living with it. One can attribute this stigma towards individuals with autism to the fact that research on how to best diagnose and work with autism disorder has only begun to surface relatively recently. Despite research addressing stereotypes, stigmas have unfortunately continued.

Stigmas associated with autism are often based on the three types of stigmas as noted by Goffman (1963), with some stigmas related to how an individual with autism should look, but even more so, the perceived behavioral traits of someone with autism, and the assumed identity grouping of the community of individuals with autism. Educators are often seen as abandoning the needs of children with autism by grouping them as a separate and distinct category from what Goffman would have referred to as normal children. In this way, some

educators may excuse themselves from learning and helping children simply because of stereotypes based on the assumed behaviors that an individual with autism is expected to display. In response, the general population fails children by perpetuating the common stereotypes and resultant stigma in the classroom when a child with autism arrives.

More recently, Bos, Pryor, Reeder, and Stutterheim (2013) highlighted Goffman's contribution concerning stigma. Bos et al. (2013) and Olkin (2002) reiterate that stigma was originally conceived as a physical mark to identify immoral people, but over time, the definition incorporated behavior resulting in social disapproval. According to the authors, stigma varies across social contexts, and from a psychological perspective, stigma serves several functions, which include exploiting and domineering people, enforcing social norms, and avoiding diseases. Additionally, the authors discuss the theoretical views of the concept of stigma and further classify four additional types of stigma, which are public stigma, self-stigma, stigma by association, and structural stigma (Bos et al., 2013), and defined in the next section.

Bos et al. (2013) highlights the interrelationships between the types of stigma. First, public stigma arises from the cognitive representations that are perceived against people with a particularly stigmatized condition, especially if it is fatal or severely disabling. An example of public stigma is the assumptions and the representations a culture has for certain individuals. For example, different cultures have different representations for individuals with a physical impairment based on what they can and can't do. Self-stigma, on the other hand, results from the existence of public stigma, since people experiencing stigma understand the social devaluation attached to their condition. An individual who experiences stigma is likely to associate negative attitudes of others directed at them with their condition. Next, stigma by association affects individuals who have an association with stigmatized people. Mothers of individuals with stigma can experience this type of stigma as well as other relatives of the stigmatized individual. Finally, structural stigma presents the ways in which the society perpetuates a stigmatized condition. Society can perpetuate the feeling of stigma by continuing to associate labels with the condition.

Goffman's (1963) work is crucial for its ability to provide a framework through which stigma could be understood based on its characteristics and causes. Using this framework to understand stigma in a KSA context helps to make sense of mothers' experiences, by highlighting not only the cause of the stigma but how it operates within society.

The Saudi Context

According to Alqahtani (2012), most parents whose children have been diagnosed with ASD argue that cultural, medical, and psychological factors are the main causes of autism. The medical factors perceived to cause autism include vaccination, examination during pregnancy, and vitamin deficiency. Additionally, the cultural factors perceived to cause autism include black magic and the evil eye. Finally, perceived psychological factors are due to the trauma of experiencing the death of parents and associated with causing autism.

Despite the existence of sufficient evidence showing the causes of autism spectrum disorder, parents blame themselves for their children's condition (Alqahtani, 2012). Since parents do not have adequate information about the causes of autism, they use interventions such as consulting religious leaders and reading Qur'an verses (Alqahtani, 2012). They prefer these treatments because they believe they heal the symptoms of autism. The findings of the study show that no parents used essential therapies focused on developmental, educational, and behavioral interventions (Alqahtani, 2012). Furthermore, it was found that some parents fear seeking help for their children due to the cultural stigma associated with disabilities (Alqahtani, 2012; Zeina, Al-Ayadhi, & Bashir, 2014).

Some individuals applaud women in the KSA for doing a commendable job as caregivers despite the lack of paying jobs (Basaffar, Niehm, & Bosselman, 2016). However, it is crucial to recognize that in Saudi Arabia, women and men play clearly distinct gender roles in the society. As a male-dominated community, men are perceived as the providers for the family while women perform traditional roles even when they are part of the labor force. Similarly, in homes where both parents are working, women are expected to meet the needs of their husbands and take care of their children. This means women have to balance their family and work life in order to be able to satisfy the needs of their children. The men may provide support and help, but they do not play active roles in overseeing the needs of children, including those who require special attention.

The findings are clear that parents in the KSA fear their children will be humiliated due to their autism diagnosis. Children with autism require special attention from parents or caregivers. Therefore, institutions have a responsibility and role to lessen the effects of social stigma that mothers of children with ASD experience. The findings of the current study bring to light the cultural issues associated with raising children with autism and the roles played by institutions in addressing issues of stigma.

Method

This study examined mothers' experiences with stigma associated with their children diagnosed with ASD in the KSA. Using Goffman's (1963) theory of stigma as a theoretical framework, 15 interviews were conducted with mothers in the KSA whose children were diagnosed with autism spectrum disorder. A phenomenological approach was used to explore these mothers' individual, personal experiences, examining the similarities while highlighting the uniqueness of their individual experiences. It allowed a better understanding of their experiences by providing access to their unique perspectives (Creswell, 2007; Marshall & Rossman, 1999; McCaslin & Scott, 2003; Wertz et al., 2011).

A phenomenological approach works from the belief that "there is an essence or essences to shared experience" (Patton, 2015, p. 116). Phenomenologists are interested in shedding light on what individuals experience and more importantly how they experience it. Through its focus on individual experiences, a phenomenological approach works to validate these experiences. In addition, van Manen (1990) posits that a phenomenological approach

should strive for collecting stories about the experiences of individuals and validating those experiences. While it allows for capturing the individual experiences and addressing their uniqueness, a phenomenological approach is described as “the study of the shared meaning of the experience of a phenomenon for several individuals” (McCaslin & Scott, 2003, p. 449). Due to a focus on shared experience, commonalities between the mothers were examined while remaining faithful to the uniqueness of their experiences.

The participants involved in this study included 15 mothers between 22 and 43 years old. They provided information about their experiences with stigma associated with raising children diagnosed with ASD. The study did not focus on the severity of the children’s condition or gender. It included all mothers with children between the ages of 5–12. The mothers provided unique responses to their experiences of stigma. Mash and Wolfe (2010) indicated parents’ reactions depend on their level of education, family setting, and work environment. Parents’ level of education may impact individuals’ reactions to the problems they face based on various forms of social, economic, and cultural stress (Mash & Wolfe, 2010).

Data Collection

Before conducting interviews, mothers involved in the study provided informed consent. The setting for each of the 25–45 minute individual interviews was a local coffee shop. They were audio recorded to ensure accurate capturing of participants' responses. At the end of each interview, a summary of the interview was written, and transcriptions of interviews were created along with additional investigator memos.

Results

The investigation focused on the challenges associated with autism in a male-controlled society, specifically on mothers as they assume the role of primary caretaker for their children diagnosed with autism. Mothers’ responses were organized into themes/sub-themes for the following purposes. First, it represents the association of themes/subthemes. Second, it provides clear insights into mothers’ responses to the important issues that arose in the conversations. Third, it highlights the different issues that mothers chose to emphasize, struggled with, or found useful in their journey of trying to provide the proper services for their children. Finally, others reading this article are able to examine the responses on their own and evaluate the approach followed in analyzing the data.

For the case of data presentation, a numbering system was used. M1 was used to represent the response of mother number 1 as found in the transcript. M1-1 was used to refer to a comment’s position in the conversation containing mother number 1. For example, M1-1 means that mother number 1 provided the comment as the first response in the interview transcript. The numbering system was applied for all the participants. This system allowed easy examination of the transcripts and verification of the conclusions drawn from mothers’ responses.

Mothers' Responses

The findings represent mothers' responses to their children's situation which are represented in Figure 1. First, the initial emotional responses mothers displayed in reaction to their children's condition are highlighted. Next, following their initial responses, mothers decided to take action to learn about their children's situations, and in addition to the positive steps they took, some relied on their faith to help them cope with the challenges they were facing. The findings conclude with an examination of mothers' perceptions of the negative effects of their children's autism on their social milieu.

Figure 1. Visual Representation of the Components of Mothers' Responses to Shame.

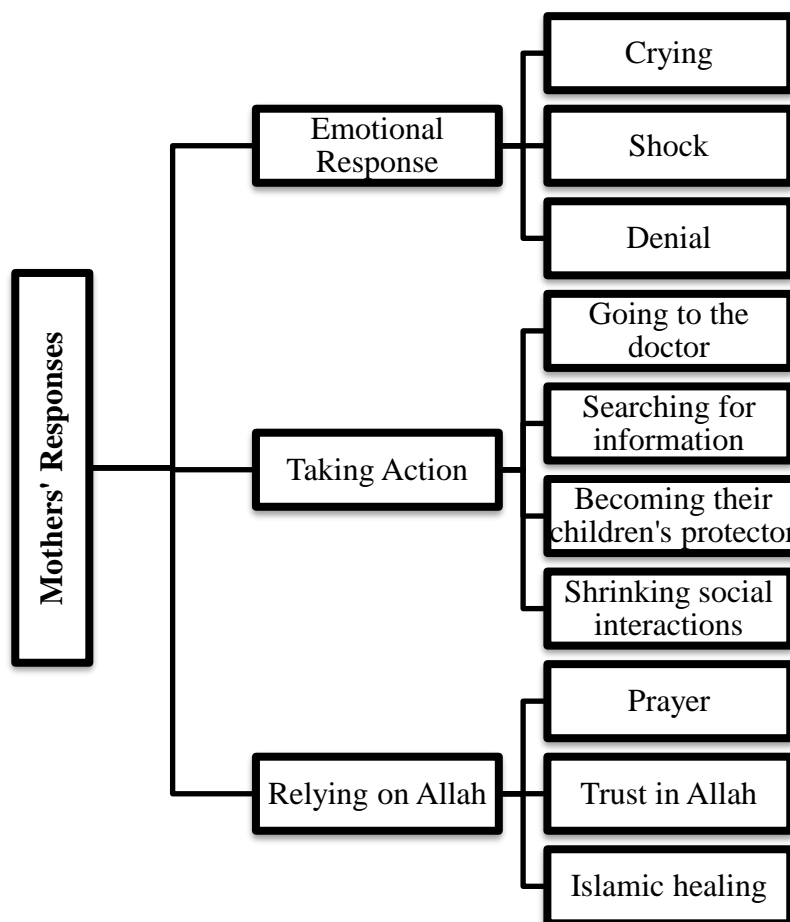


Image Description: Figure 1 provides a representation of the components of mothers' responses to shame. Their responses are divided into three major areas: Emotional Response, Taking Action, and Relying on Allah. Initial emotional responses mentioned by mothers included crying, shock, and denial. After their initial emotional response, some mothers described actions they took or experienced in response to their children's diagnosis. Such actions included going to the doctors, searching for information, becoming their children's protectors, and experiencing shrinking social interactions. Finally, for those mothers who reported relying on Allah, they responded with prayer, put their trust in Allah, or relied on Islamic healing.

Most mothers interviewed noticed the challenges their children were facing at an early age. Nine of the 15 mothers interviewed, received a diagnosis of autism for their children between the ages of 1 and 2 years old. Of the 15 mothers, four learned of their children's condition when they were 3 years old. One of the mothers reported she learned of her child's condition when the child was 1 year old. Of the 15, only one mother learned of her child's condition at a later age, after the child was 6 years old.

Mothers' emotional responses

The mothers reacted differently to their children's diagnosis. Their initial responses reflected the emotional difficulty associated with receiving a diagnosis. Most of the mothers (M1, 3, 4, 5, 6, 8, 9, 10, 11, 12, 13, and 14) agreed about the emotional challenges they faced shortly after their child's diagnosis. Their responses ranged from surprise to crying. Mother 3 reported that an overwhelming feeling of sadness overcame her. Mother 4 indicated she was in a state of disbelief. She said, "at first, of course, I was in shock, denial, and crying. I tried to deny it in every way possible" (M4-5). She could not do anything to stop the feeling and claimed that "the issue physically drained his father and me" (M4-6).

For some, however, they felt a sense of isolation. Mother 5 asserted that she was in shock and responded with "crying and isolation from everybody for several days. I became hot tempered and cried a lot" (M5-7). Some took this on themselves as Mother 5 explained that she "was in denial and stopped eating and drinking. My brain completely stopped thinking" (M5-8). However, she was not the only one who experienced this feeling. Mother 8 explained, "My husband and I got extremely sad and cried when we figured out that our child has autism. We were definitely shocked because he is our first child" (M8-6).

Isolation sometimes resulted in mothers trying to cover up the issue. Mother 9 said that she and her husband "got scared and did not tell anyone about her disorder" (M9-6). While this was a big problem for the parents, some had a harder time than others. Mother 12 made this point when she described the difficulty her husband had with accepting their child's diagnosis. She indicated, "I was so confused and couldn't believe that my son has autism. My husband and I had a tough time accepting it. I can't forget what my husband said: he can't [be] autistic, he can write, talk, and read. My son cannot be autistic! He is a normal child!" (M12-6). For some, the feelings took longer to deal with. Mother 14 explained that it took her "three months to get rid of that feeling. I felt extremely sad for his situation" (M14-7).

Taking action

Despite initial difficulty in dealing with the diagnosis, eventually some mothers were driven to take positive steps to help their children (M2, 3, 4, 6, 7, 9, 10, 11, 13, 14, and 15). Mother 2 reported, "I tried to take care of him more and visited specialists and experts including counselors and a private tutor specialized in these cases. I also followed up with hospitals and took him to rehabilitation sessions and massage therapy for exercising the affected muscles" (M2-6). This desire to seek help was echoed by others. Mother 7 posited that she "tried to search and read. I wrote the symptoms on the Internet to know what is wrong with him because I had no knowledge about ASD and its symptoms. I asked a counselor. I

visited an otolaryngologist. I attended educational workshops. I gained awareness and I learned about autism and autistic mood and thinking” (M7-6). Not only did mothers seek diagnosis, but some often went beyond that to learn more about their children’s conditions. Mother 10 emphasized this when she said, “I read a lot of articles from Google and I watched a lot of videos on YouTube about this disorder” (M10-7). Some invested money in acquiring more help. Mother 11 indicated that she “asked some speech specialists for some assistance to help my daughter talk” (M11-9).

These mothers also assumed the role of protector for their children. However, sometimes, they became overprotective. Mother 2 said, “I prefer to always be with him when we get out. I don’t like taking him with me to other people’s houses. When I do, I would be close to him the whole time because he does not defend himself” (M2-34).

Being overprotective was often designed to ensure the child’s feelings were not hurt by others. Mother 9 argued that she tried to be with her daughter to “avoid having others hurt her feelings” (M9-38). These protective mothers often worked to stop others from hurting their children. Mother 9 made this point when she described, “a year after my daughter’s diagnosis, I became stronger and I was able to confront them and stop them from making any negative comments because I did not want my daughter to get affected or hate her life when she grows up” (M9-41). Mother 15 agreed that she stopped anyone who tried to mock her child. This strength translated into trying to learn more about others. Mother 3 explained that after becoming overprotective, she felt “much better than before because I learned a lot about his disorder. I also tried to let my friends/relatives to understand/learn about my child’s condition” (M3-39). Mother 15 made the same point when she said, “I learned a lot about his condition, and I want the best for him. I tried to talk to his friends and told them about his disorder” (M15-21). These mothers were not only strong in advocating and standing up for their children, but they also worked hard to learn about the condition and educate others around them.

A shrinking social circle

Some mothers had to deal with a shrinking social circle that resulted from their children’s condition. Six of the 15 mothers (M1, 2, 5, 6, 8, and 9) reported issues with their shrinking social circles. Mother 1 explained that she was unhappy with some of the comments made by people in her circle, which led her to isolate herself. She posited, “I isolated myself and only relied on educated people who supported positively because at first, I swear to Allah, I got really tired of comments made by some people” (M1-42). Mother 5 responded in a similar manner to people in her circle who stigmatized her child. She explained, “I isolated myself and I stayed with my son and I ignored them, and I celebrated my success alone” (M5-47). This type of criticism led many to stay home and keep their children away from the rest of the family. Mother 9 made this point most clearly when she indicated, “sometimes I don’t like to take her with me to any parties or special occasions to avoid criticism and blame or mocking looks that might lead my daughter to have more complications” (M9-29). Mothers’ shrinking social circles were a result of the misconceptions of others and justified by a desire

to protect their children from others' judgmental looks and harsh remarks.

Relying on Allah: Role of religion

Despite the difficulty of their situations, many mothers found comfort in their faith. Mothers 1, 5, 6, and 12 emphasized the role their faith played in helping them become more comfortable with their children's diagnoses. Some reported their faith helped them accept their child's condition. Mother 1 explained, "The first and best resource is Allah's blessing and praying for him only. I was content with what Allah has chosen for me. It made me pleased with my child and I saw improvement. Thanks to Allah" (M1-37). For her, this reliance on Allah "helped and guided/showed me how to behave so I isolated myself indirectly and I felt comfortable" (M1-41). Furthermore, she went on to explain the role the Qur'an can play in helping heal autism. "I ask you and other brothers and sisters who dedicated themselves for this cause to pay attention to my viewpoint/opinion. I think autism can be healed through [the] Qur'an and it is related to satanic/demonic forces. And I have proof for that" (M1-56). For Mother 1, her reliance on Islamic healing helped her child tremendously. She claimed:

To be honest with you, I relied on Islamic healing, and I would recite three times a day and give them honey and ground black seeds and holy water. And the result was my older son improved [by] 80% (M1-58).

Similar to Mother 1, Mother 5 explained that her reliance on Allah made things easier after the initial challenges. She explained, "even his father abandoned him and refused to pay attention, but Allah with his mercy made things easy" (M5-9). Mother 6 found the same comfort in her submission to Allah, relying on prayer to help her child, viewing the condition as "a test from Allah" (M6-37). Because it was perceived as a test, the solution was in trusting God. Mother 12 emphasized that "the effect of trusting God is a miracle. I believe in leaving it to God and to trust him and to pray. Keeping that connection with God is the solution" (M12-41).

Consistent with the reliance on faith was the cultural belief that autism may be a result of an evil eye. Mother 11 explained that members of her family told her that this might be an evil eye. She explained, "two of my sisters-in-law told me that my daughter has an evil eye because she is so beautiful. They told me there are several ways to get rid of it: reading [the] Qur'an and taking her to a Sheikh" (M11-19).

Recommendations

Mothers in this study experienced social stigma similar to that proposed by Goffman (1963) and reiterated by Bos and colleagues (2013) and Olkin (2002). Others in their social circles blamed the mothers or their children for behaviors that deviated from what was perceived as society's norms. Mothers responded in a variety of ways that allowed them to cope with and in some cases, actively confront the stigma they and their children were experiencing.

This study's findings provide many implications for practice and demonstrate the importance of utilizing and making the most of the mothers' experiences. As the primary caregivers, mothers know more about their children than anyone else. While some specialists tend to ignore mothers' input and experiences, it is clear that a clear diagnosis and the determination of appropriate services should be responsive to mothers' wishes, to ensure services are culturally appropriate and sensitive to families' unique needs.

To overcome the problem of excluding mothers or having them feel as if they cannot bring their children into the community—for fear of stigmatization or negative reactions from others—specialists and other concerned individuals should develop individualized self-management systems to help children develop appropriate social behaviors. Self-management systems are not only useful for helping individuals with disabilities achieve certain behavioral goals but are also inclusive of the parents.

There are four stages when introducing a self-management plan. First, the collaborative team discusses diverse activities for effective and efficient implementation of a plan. The team should include teachers, specialists, and parents who identify and develop target behaviors they want to enhance or curb (Busick & Neitzel, 2009). One way to accomplish this is through goal setting. Goal setting involves coming up with a target for changing behavior (Schulze, 2016) and enables children with ASD to motivate themselves in addressing specific deficits in their abilities related to organizing, planning, and executive functioning.

Next, the self-management system must be effectively introduced to the learner. In this scenario, students should understand vital elements of the system, for instance, they should demonstrate the target behaviors and determine if key aspects of the behavior have taken place or not. The learner is engaged in recording the occurrence or lack of target behaviors. Students should effectively manage the reinforcements related to the achievement of identified goals (Busick & Neitzel, 2009). In this stage, students are encouraged to internalize the steps of the system in their own words to check for understanding. Using a self-instruction strategy is one way to measure comprehension which requires the child to verbalize the steps of a given task to be completed (Schulze, 2016). Self-statements prompt the child to promote a positive behavioral change and gives a student with ASD the ability to perform tasks independently.

The third stage in the process is implementation. Teachers provide the necessary materials for learners to utilize the self-management system as well as enable them to acquire necessary materials independently. Additionally, practitioners may provide different cues such as visual aids and verbal cues as well as teaching them how to self-record target behaviors. Teachers then educate learners on how to acquire access to earned reinforcements (Busick & Neitzel, 2009).

Finally, the fourth stage is to allow students to work independently and measure their development. Practitioners employ periodic check-ups to determine whether the learners are

consistent in self-recording and reinforcement. The next step is for teachers to gradually heighten specified criteria for success while also assessing the success of the students (Busick & Neitzel, 2009).

Another means of measuring outcomes is through self-charting, which empowers students to determine how effective they are in achieving their target goals. Self-charting works hand in hand with goal setting and self-monitoring to increase students' time on activities, academic performance, and accuracy. Furthermore, this strategy enables children with ASD to monitor their progress in behavioral change (Schulze, 2016).

The utility of this strategy lies in its collaborative nature (Busick & Neitzel, 2009). Teachers, parents, and education specialists work together to design plans that help learners achieve individualized behavioral goals, and this collaboration should take mothers' concerns into account. Although all of these steps are used in a school setting, mothers can and should participate in their implementation, learn how to introduce these strategies, and implement them on their own.

Peer support is also required to help both peers and individuals with ASD work in an environment that is inclusive. Studies have shown that peer supports consistently demonstrate increased levels of tolerance, awareness, and acceptance of differences (Bellini, Peters, Benner, & Hopf, 2007; Harper, Symon, & Frea, 2008; Kamps et al., 1992; Kohler, Greteman, Raschke, & Highnam, 2007). Similar support could be provided to family members. Researchers have shown that:

Family therapists are well-suited to help parents stay connected to each other as they create a "new normal." However, family therapists need updated information about autism, and they need to understand how family therapy can help parents of children with autism. Because having a child with autism affects multiple domains of family life...family therapists can utilize an integrative approach with parents, enabling them to flexibly work with the domains of action, meaning, and emotion (Solomon & Chung, 2012, p. 250).

It is also apparent that some mothers deal not only with stigma, but also other cultural beliefs that may inhibit their willingness to trust modern scientific approaches to disability. For specialists who work in this type of environment, the effort that is required is doubled, due to the fact that they must not only help mothers, but also be able to understand the underlying causes behind their fears and lack of trust. As some of these mothers demonstrate, belief in the supernatural as a cause of disability has led some of them to seek traditional methods for dealing with their children's conditions. Professionals should be aware of the need to adapt and to be flexible when working with individuals from different cultural backgrounds. As future specialists are trained, they must be aware of cultural differences. This also includes dealing with people from the same culture, as this study shows, it is important to remember that individuals' responses to disability vary depending on many factors. Al-Aoufi, Al-Zyoud, and Shaminan (2012) eloquently articulated this concern when they argued that:

Despite the fact that Muslims share the same beliefs and principles, people's attitudes and understanding regarding these concepts, and their reactions to individuals with a disability, may vary depending on the intensity of a person's faith, as well as their socio-economic status, level of education, awareness and, more importantly, their cultural context (p. 205).

Such an awareness is necessary in a world that has become incredibly interconnected and diverse in its makeup.

Clearly, much needs to be done to help increase awareness and acceptance of disability. On the institutional level, especially in schools, teachers need to receive proper training to increase their readiness to provide support for students with special needs, including those with ASD. Curricular activities ought to be redesigned to take these needs into account.

Finally, on a societal level, the adoption of a social model of disability is needed which "locates the disablement in the environment and society" (Olkin, 2002, p. 132), as opposed to the moral or medical models which place blame on the individual. One way to support this paradigm change is through the media which can play an instrumental role in helping increase awareness of different impairments, including autism spectrum disorder, and how society and the environment create disabling conditions. This could be achieved through educational programs that teach others about impairments and the subsequent disabling conditions. It also imperative to explore, "the mutual contribution television and disability studies can make to one another, focusing on the role of television and visual media in raising awareness and challenging gaps in understanding" of disabling conditions that are frequently stigmatized (Heward, Palfreman-Kay, & Innes, 2015, p. 229).

Conclusion

As noted above, many of these mothers had negative perceptions of their children's conditions and felt overwhelming sadness upon discovering that their children had ASD. Although these experiences and attitudes improved upon learning more about the disability, many still struggled with the cultural stigma that exists. And while many have found specialized institutions useful, much is needed to help improve people's awareness regarding impairments in an attempt to help the public be more understanding of individuals with ASD and more empathetic toward their experiences. Focusing on developing the knowledge and understanding of members of society in order to impact the present culture, only then might it be possible to address society's perceptions of impairments and eliminate the associated stigma experienced by individuals with impairments and those who love and support them.

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