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ORIGINAL ARTICLE

Experiences of Mothers of Children with Autism Spectrum Disorders in Addis Ababa

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Abstract

The purpose of this study was to examine the experiences of mothers whose children have been diagnosed with autism spectrum disorders (ASDs) in Addis Ababa, Ethiopia. A set of in-depth interviews were conducted with four mothers of children with ASD through purposive sampling technique. The interviews with the mothers were recorded, transcribed and analyzed under thematic analysis. The results containing two themes indicated that mothers' knowledge of ASD and the difficulties that mothers of children with ASD face. The result showed that three of the four mothers who took part in the assessment admitted that they had no prior knowledge of ASD. Besides, all mothers often experienced feelings of exhaustion due to their incapacity to understand the child's development, along with anxiety and fear about the possibility that something was wrong with the child. The results of this study also demonstrated that stigma, marital discord, and financial limitations were among the difficulties faced by mothers of children with ASD. Implications for future research and interventions that aim to increase knowledge about ASD and improve the lives of children and mothers are discussed.

Keywords: Autism spectrum disorders, challenges, experiences

Introduction

Autism spectrum disorder (ASD) is the term used to describe a group of early-onset, lifelong developmental disorders. They are categorized by deficits in two domains: limited, repetitive behavior or interest and social communication (APA, 2018). Affected children make up one in every 160 children worldwide (WHO, 2019). In the United States, the prevalence of autism has increased dramatically, with 1 in 36 children receiving a diagnosis in 2023, up from 1 in 69 in 2012 (Harris, 2023). No population-based prevalence or early intervention studies of autism have been conducted in Africa to-date due to various obstacles like a lack of diagnostic facilities, but there is no reason to believe that rates of

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autism will be any lower than elsewhere (Franz et al., 2017).

There is, presently, no precise official data on the prevalence of ASD in Ethiopia; however, 530,000 children may have autism and related developmental disorders, according to estimates from the Nia foundation (2015). The number of parents and families that are responsible for providing care for children with autism is increasing due to the high number of diagnoses. This is a concerning figure that needs to be addressed immediately by a number of social groups. According to Dirbsa (2013), the majority of Ethiopian communities have little to no awareness of autism. Commonly, ASD and other developmental disorders are blamed on demonic spirits. As a result, autism has an impact on the parents in many different ways as well as the children.

A plethora studies indicate that mothers of children with disabilities are especially susceptible to stress (WHO, 2019; Gobrial, 2018; DePape & Lindsay, 2016). For instance, high levels of suffering are reported by up to 70% of mothers and 40% of fathers of children with disabilities (Turner & Alborz, 2003). In addition, research on children with disabilities and general psychological literature indicate that family functioning and parental stress have a variety of effects on children's cognitive, behavioral, and social development.

While there are many other developmental disorders that cause parents to grieve continuously, autism is distinct in a number of ways (Paster, et al., 2009). Unlike many other developmental disorders such as intellectual disability, deafness, blindness, or aphasia, autism spectrum disorder, currently, lacks a definitive biological marker. Without a conclusive diagnostic test, both diagnosis and prognosis remain uncertain, making it difficult for parents to fully acknowledge their child's condition. Moreover, ASD is defined by present difficulties in social interaction challenges in forming relationships, expressing affection, and understanding social cues that can prevent parents from experiencing some of the most rewarding aspects of parenthood. As a result, ASD is widely regarded as one of the most complex and demanding developmental disorders parents may face (Hodis et al., 2025).

When an ASD diagnosis is made for a child, mothers face challenges on the relationship of the family since the daily activities must be changed as the child with ASD require more parental attention. When parents learn that their child has autism, they often experience a wide range of emotions. Each family responds differently to the diagnosis and develops its own approach to supporting their child's future. Just like the autism spectrum itself, every family's journey is unique. Benson (2018) noted that parents' reactions to hearing their child had an assessment ranged from 52% feeling relieved to 43% feeling grieving and loss, 29% feeling shocked or surprised, and 10% feeling guilty. Having an explanation for their child's symptoms often relieves parents, but it does not lessen the stress that comes with raising a child with autism. After the initial diagnosis, parents often experience difficult situations pertaining to their child's behavior, acclimating to this new lifestyle

and obtaining the family's required services.
According to Oprea and Stan (2012), mothers of autistic children may encounter a variety of difficulties, particularly in less developed areas where resources are scarce and awareness is lacking. Given that mothers are the primary caregivers and play a central role in their children's daily lives, the complexities of ASD can have a profound impact on families raising children with ASD (Farzana, 2017). The difficulties mothers of children with ASD face are also discussed by Papageorgiou and Kalyva (2010). These difficulties include poor communication, avoiding or rejecting their children, a lack of awareness from relatives and society, a restricted interaction with others, parental differences, and economic shortcomings.

Regarding with the Ethiopian context, local research conducted by Zeleke et al. (2018) revealed that over 80% of ASD cases in Ethiopia are stigmatized by society. In addition, mothers may find it difficult and overwhelming to care for their child with ASD because there are insufficient resources specifically tailored to their child's needs. This is because there are insufficient resources available for children with disabilities as a whole and children with ASD in particular. Due to the incredibly restricted provision of services for these children, kids with ASD and their parents may suffer scarce health, social care, mental health facilities, rehabilitation, a dearth of special needs education, and limited access to equitable opportunities (Benson, 2018).

Overall, several research has been done on parents' experiences raising kids with ASD (Depape & Lindsay, 2015). Nonetheless, the majority of these studies were conducted in developed, Western nations (Tekola et al., 2023). Despite the fact that Ethiopia is thought to have a sizable number of ASD cases, relatively little research has been done in that field (Genet, 2013). According to WHO (2019), a major barrier to the development of effective provision plans for parents who have children with ASD in undeveloped nations is the paucity of research on the effects of raising ASD children on parents. Investigating the experiences of mothers whose children have been diagnosed with ASD is therefore crucial.

Methods

Setting

This qualitative case study was conducted at the Nehemia Autism Center (NAC), one of the two autism centers in Addis Ababa, which is a non-governmental and non-profit organization founded in 2011. The qualitative case study approach was chosen to gain an in-depth understanding of complex, context-specific experiences, allowing for a rich and detailed exploration of mothers' perspectives and lived realities. The center's primary services for kids with ASD include education and behavioral therapy. Additionally, it offers parents psycho-social support to help them enhance their children's social and academic development.

Participants

NAC was used to identify participants for the purposes of this study. Through this organization, the researcher was able to get in touch with the mothers because they work with families and children who have ASD. Four mothers who had children enrolled in NAC were chosen for the study and expressed their willingness to take part. As shown in Table 1, the ages of the participants vary from 32 to 49. Of the four participants, two have completed their education below the fifth grade; one has a first degree, and the other has a diploma. Among the participants, one is married, two are divorced, and one is single. The participants held various jobs, including secretary, teacher, and housemother.

Table 1. Background Information of Interviewees

Name (code)	Age	Education level	Relationship	Occupation	Marital Status
P1	39	4th grade complete	Mother	House Mother	Divorced
P2	43	2nd grade complete	Mother	House Mother	Married
P3	49	Diploma	Mother	Secretary	Divorced
P4	32	Degree	Mother	Teacher	Single

Data Collection

For the purpose of gathering data, an in-depth interview guide was employed. It is divided into two sections: the first one covers the participants' demographics, and the second one evaluates the experiences of mothers in raising children with ASD, and the challenges of having a child with ASD. The interviews were conducted in the center in Amharic language and translated into English language by language teachers at the University of Gondar. The researchers completed the transcription, coding, and theme identification steps before beginning the data analysis. To help the researcher become immersed in the data and identify any explanatory signs from the participant reports, the data were read and reviewed again. Thematic analysis was utilized in this study.

Ethical Issue

The study strictly adhered to ethical principles and approval from the University of Gondar, College of Education Critical Review and Evaluation Committee (CREC). Informed consent was obtained from all participants after providing them with comprehensive information about the study's purpose, procedures, and potential risks and benefits. To ensure confidentiality, all identified information was removed.

Results

This section deals with the analysis of study results. Hence, from the parents' narratives, the researchers discerned two major themes regarding mothers' experiences in raising children with ASD. The first theme focuses on mothers' knowledge of ASD, their awareness of developmental delays, and their responses to the diagnosis. The second theme highlights the various difficulties faced by these mothers, including financial strain, marital discord, and the psycho-social impact of raising a child with ASD.

Mothers' awareness about autism

This theme focuses on mothers' awareness of and recognition of ASD, as well as how they respond to developmental delays in their kids and how they respond when an ASD diagnosis is made. "Mother awareness" and "reaction to developmental delay and reaction to diagnosis" were its two sub-themes. I asked the mothers to explain their knowledge and information about autism in order to understand their understanding of the condition. Prior to their children receiving an autism diagnosis, all mother respondents (P1, P2, and P3), with the exception of P4, stated that they had never heard of autism. However, P4 was somewhat aware of ASDs. P2 clarified this notion by saying, "I had no idea what ASDs were. I had not heard anything about it until the problem arrived at my house. I had never seen children with ASDs, neither in my hometown nor in Addis Ababa. I'm still not sure about the cause and nature of the problem." It can be inferred from this mother's explanation that she does not know enough about ASDs and is still confused about the disability.

P 3 also explained, "The doctor informed me that he had recognized my child's autism, and I was not feeling well at the time because I was crying because I was unaware of autism at the time." P4, on the other hand, revealed that she had only heard a little about autism from television.

From the above discussion, it can be concluded that mothers of autistic children lack information and knowledge about the symptoms of autism. The finding indicated that participants' lack of awareness about autism has an impact on the child's treatment as early as possible.

Mothers' reaction to diagnosis of autism

Mothers were asked to explain their initial reactions when they learned the results of their children's diagnoses in order to learn more about them. Two of the four mothers expressed sadness as a result of the diagnosis outcome. The other two mothers, on the other hand, reported that they initially did not out rightly accept the diagnosis result. Most of the parents reported that they had concerns about their child's development at a very early age. Only one mother reported that she was not aware of delays in her child's development.

Here is what P3 reported:

> Even if I did not recognize the developmental delay of my child. It was difficult to learn that my child had ASDs. I was confused and stunned after receiving a couple of diagnoses at Yekatit 12 Hospital. The reality of the diagnosis was so overwhelming that I couldn't accept any of the doctor's suggestions. I was initially depressed and perplexed. I wished I could go to a different hospital or doctor who would tell me something different. I went into God's argument. "What did I do wrong?" I enquired.

When participant number 3 learned that her son had autism, her initial reaction was denial. She expressed great concern about visiting another hospital to confirm the assessment results during the diagnosis briefing session.

P4 also discussed how she initially became aware that their child's development was different. She became aware of the delay in speech and social interaction milestones. To put it in her words:

> I was in denial in the beginning. I began to doubt myself as the months and years passed and my child turned four without oral communication. Furthermore, I began to compare my child's development to that of other children, and he was clearly behind. At the age of four, he was unable to communicate with his peers. That is why I convinced myself that doing something was preferable to denying and doing nothing. However, I had not anticipated ASDs. I educated myself after the diagnosis by googling. I questioned what I had done to deserve such a punishment for my son.

P1 also discussed the difficulties in explaining their child's situation to others and referred to the diagnosis as a solution, explaining that:

> When I recognized the developmental lag of my child, I have tried to get my child treated at medical facilities. In addition, I went to "Entoto Mariyam" for holy water treatment. I was shocked to learn that my child had autism when I heard the assessment results. I had no idea anything about it. NAC accepted my child with the help of God.

The findings revealed that mothers frequently become concerned about their children's development delays before professionals become aware of the signs and make a diagnosis of autism. Furthermore, mothers reported that it was difficult and distressing to not understand their child's behavior and to not know what was wrong with the child.

Dimensions of Challenges

The complex and varied character of the parents' social and familial ties is reflected in this theme. Narratives from parents indicate that while social relationships may be negatively impacted by stigma and a lack of understanding from others, not all parents experienced a total and permanent withdrawal from family and social interactions. The parents were either maintaining their social lives and family relationships in spite of challenging circumstances, or they were putting their obligations and relationships on hold (hoping to resume them later when their circumstances permit). This was dependent on their current situation.

Psycho- Social Impact

Concerning the psychological well-being of mothers who have children with ASDs, mothers were interviewed to explain their situation. The participants reported that their social, psychological, and emotional lives had been impacted by their autism diagnosis. The level of participation in social life varies from person to person. The majority of respondents stated that it was impossible to participate in social activities. Three of the four participants mentioned losing their social lives as a result of having an autistic child. The reasons given included a lack of time, their children's behavior, and people's failure to understand the disorder. P2 states it as follows:

> I deal with a lot of social influences because I have an autistic child. For example, I am unable to attend various social occasions such as weddings. Since she requires my care, I am constantly preoccupied with caring for my baby. Her behavior makes it difficult to leave her alone. That is why I have stopped participating in any social activities in order to spend more time with my autistic child. Overall, I was socially isolated.

As P2 explained above, the psycho-social impact of autism on her manifests as social isolation, embarrassment, and fear of appearing in public. Furthermore, her daughter's behavior is extremely difficult for her.

P1 also reported that:

> In terms of psycho-social impact, I am unable to socialize with my neighbors and relatives because I am afraid of not being the topic of their conversation. I'm always suspicious that they're talking about my autistic child, and I don't want to get any closer or socialize with them. This made me anxious and demanding.

Similar reflection has also be reported by P4 saying:

> Having an autistic child is not as simple as it may appear. It has an impact on my daily routine because my autistic child is very dependent on the activities, he participates in. As his mother, I am supposed to help him feed himself, dress him, give him a shower, and so forth, which takes up a lot of my time. It's hard enough when his behaviors are out of control when we're at home, behind closed doors. But it's too difficult for me to see how people are staring at him and me in public. I've been going to work a lot lately.

Marital Discord

According to the demographic information gathered from the interviews, two of the four mothers were divorced. Autism was cited as a major factor in the breakdown of both divorced participants' marriages. In response to the question asking respondents to explain how autism affects their marriage, both of these women provided details about what happened after their divorces. P2 says:

> My husband loved me both before and after I gave birth to my child. He adored my child as well. After learning that his child has autism, he realized that autism cannot be cured. Every night he got drunk and started a fight. I wouldn't know how to handle it after two years of being together in this way. Finally, we split up.

P3 further supports the notion as follows:

> As a wife, I may require my husband's attention. However, my husband hid himself from me by changing locations, and I always felt completely alone. He can't accept that he has a child who has a problem. And I'm always complaining about my husband's absence.

P1 also face similar experience in such regard; and thus spoke, "Unfortunately, unlike me, my husband did not want to take on any parental responsibilities. He has not offered me any assistance. At home, I felt the loneliest, which really bothered me."

P2, on the other hand, reported that her husband was supportive: "My husband started providing care after learning that our child has autism. He is a great advocate for me. Because we are responsible parents, we are beginning to find solutions."

According to the mothers' interview response cited above, dealing with their husbands presented considerable difficulties for them. Since their children had special needs, all of the mothers went through difficult times in their marriages and eventually divorced. Another factor that contributed to couples' lack of communication was the influence of the extended family.

Financial Pressures

With regards to the question like how having children with ASD affects their financial situation, the mothers responded that they greatly face financial stress. . They noted that in situations of appropriate concern for their children, there are additional expenses affecting the family's economic well-being. Concerns about financial burdens posed by autism include skyrocketing food, clothing, and transportation costs.

Here is what P1 had to say, "I have already mentioned that I'm a teacher. Spending a lot of money on treatment makes things very painful for me. Furthermore, it is extremely difficult to manage the costs of living, which is one of my challenges in addition to the others."P2 also reported, "I am not employed. I'm staying with my autistic child. In terms of finances, it is extremely difficult. Because I am always waiting for my husband's hand. "Raising an autistic child has many demands that must be met; the majority of which are needs rather than wants. The majority of participants stated that they were unable to work and had to stay at home to care for the child with ASD, putting a significant financial strain on the mother and the rest of the family. Growing future fear and a dearth of supports for individuals with autism are two further variables that add to mothers' financial stress. In addition, worries about what would happen to their kids in the event that their parents' advanced age prevented them from caring for them at home, as well as the possibility of getting hurt during a child's violent outbursts.

Overall, it was clear from the study's findings that mothers are significantly impacted by ASD. According to the literature review, because their child has ASD, parents of ASD-affected children may find it difficult to carry out every day practices and might need to make individual costs in order to equilibrium a family life, spousal relationships, and work obligations.

Discussion

The main purpose of the current study was illuminating the experience of mothers who bring their ASD children to Nehmia Autism Center. Mothers' accounts in this study were largely dominated by their ignorance of ASD. Three of the four mothers who took part in the assessment admitted that they had no prior knowledge of ASD. This outcome was directly linked to the discrimination and stigma that mothers with ASD experienced. However, one mother was somewhat knowledgeable about ASD prior to her child's diagnosis.

The current study's findings are in line with those of Tekola et al. (2023), who claimed that our communities lack knowledge about autism and other conditions linked to ASD. When a condition is diagnosed, many parents are unaware of it, which creates anxiety and raises a lot of questions. The problem is made worse by society's lack of awareness and comprehension of ASD, which makes things more difficult for parents.

In addition, the participants talked about how tired they were from not being able to understand the child's development, and how nervous and afraid they were that something might be wrong with the child. The answers above make it quite evident that the mothers had no knowledge or education regarding ASDs. Children seemed to be experiencing regression and/or developmental delays. Since the symptoms and indicators were there and the reason for the delay was questioned, many of the mothers expressed concern. Consequently, mothers are greatly impacted by their lack of experience and understanding of autism spectrum disorder. The results of the present study are also in line with earlier research (Tekola et al. 2020; de Leeue et al. 2020), which demonstrated that parents of children with ASD observed a delay or lag in their child's development at an early age.

According to Hodis et al. (2025), parents of children with ASD experience significant stress during the early years of their child's development. The study highlights that this stress intensifies when parents first recognize that something may be wrong with their child. This realization often emerges as their child's developmental challenges become more noticeable in comparison to typically developing peers. As parents begin seeking treatment and an accurate diagnosis, the level of stress they experience tends to increase over time. In a similar vein, the results of this study indicate that mothers may find the time leading up to a diagnosis especially challenging as they try to understand their child's behavior. The participants often experienced feelings of exhaustion due to their incapacity to understand the child's development, along with anxiety and fear about the possibility that something was wrong with the child.

Numerous studies showed that mothers who have children with ASD experienced anxiety, depression, and denial as their first reactions to receiving the diagnosis (Cohrs & Leslie, 2017; Osborne & Reed, 2008; Chamak et al., 2011). The results of this study are consistent with those of the previous one because two of the participants in this study said they felt depressed and overwhelmed after learning their kids had ASD. The other two moms refused to accept the assessment results and, in spite of the difficulties brought on by the drawn-out diagnosis procedure, tried to assess their children in other hospitals.

The results of this study demonstrated that stigma, marital discord, and financial limitations were among the difficulties faced by mothers of children with ASD. Mothers with ASD children stated that they are the primary targets of discrimination and social stigma, and they have very weak social ties to other societal groups. Consequently, this causes them to feel alone and lonely. In a similar vein, Reed and Osborne (2012) noted that parents would sooner isolate themselves than deal with the aggravation of bringing their child out in public because they are terrified of their behavior and actions. Hodis et al. (2025) added that it was challenging for society to accept a child who had autism. Parents who have children who behave inappropriately are subjected to social stigma and embarrassment because of the low chance of societal acceptance.

As was mentioned in the previous discussion, mothers of children with ASDs often felt overwhelmed and alone in society. Additionally, a lot of the participants deal with behavioral issues on a daily basis, which can be very discouraging for mothers, in general and single mothers, in particular. Because they had children with ASD, two of the mothers in this study divorced. Given the information above, it is clear that one of the main ways autisms affect mothers is by making marriages more difficult for them. For mothers of children with ASDs, finding child care can be challenging, which makes it challenging for them to go out together.

Opera and Stan (2012) supports this conclusion by noting that a number of mothers also brought up the subject of marital discord. In a developing society, a woman is supposed to have total authority over her offspring. Total control suggests that the mother should take care of her child’s everyday needs, including dressing, feeding, using the restroom, helping with schoolwork, and so forth. It is believed that a mother’s duty to raise her children well is to create polite, competent, and successful members of society. Conversely, a respondent expressed that her marriage has become stronger as a result of both of them sharing the responsibility of raising their child.

Having a child with ASD has a wide range of consequences, according to all of the mothers in this study. Full-time employment is extremely difficult for mothers to maintain; loss of full-time employment can have a negative impact on the family’s finances. Because caring for a child with ASD demands additional time and attention. Furthermore, these families face public transportation issues as a result of the center’s location, not to mention the lengthy ups and downs they must endure to get transportation. As a result, they are concerned about transportation. The current study’s findings are in line with those of Reddy et al. (2019) who documented the high household costs and financial strain faced by parents of ASD children.

Conclusion

In conclusion, the study highlights the major challenges mothers face in raising children with ASD at Nehmia Autism Center, including limited awareness, emotional distress, social stigma, marital strain, and financial hardship. While some showed resilience by seeking support, the findings emphasize the need for early awareness, community acceptance, and targeted support systems to improve both caregiver and child well-being.

Implications for future research and practice

The current study showed that mothers of children with ASD faced a variety of worrisome situations. Additional studies are required to focus on the challenges faced by fathers and siblings in raising an autistic child in low-income households. Further studies are also required to examine the effects of different family system types and aspects as well as the varied experiences of siblings in various cultural families. Programs aimed at reducing stigma and discrimination against mothers or raising awareness of ASD among mothers and the community at large should take these nuanced understandings into consideration.

This study was conducted in Addis Ababa, which may not accurately represent the lived experience of mothers in rural areas and other urban regions of Ethiopia. Given the country's cultural diversity, additional research outside of Addis Ababa may produce different findings. Furthermore, the study focused on mothers of children with ASD, thereby excluding the perspectives of other key family members. Considering the limited body of research on ASD in Ethiopia, further studies are essential to improve the well-being of children with ASD and their families.

Declaration of conflicting interests

Regarding the research, writing, and/or publication of this article, the authors have stated that they have no potential conflicts of interest.

Ethical Approval

The college review and ethics committee of the University of Gondar granted ethical approval for the study. In addition, every participant gave their informed consent.

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