
The Lived Experience of Mothers with an Autistic Child in Addis Ababa: A Phenomenological Study

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Received: 02 August 2019; Accepted 23 March 2021

Abstract: This study is aimed at describing the essence of the lived experience of mothers with autistic children. Identifying contexts or situations that influence the experience of mothers for having an autistic child was also assessed. A qualitative research approach through the application of phenomenological approach was employed. The social constructivist paradigm was applied in exploring and documenting lived experiences of mothers. Three mothers with autistic children were purposively approached and ethical principles were followed during data collection. An in-depth and semi-structured interview was conducted with mothers that lasted from 20 to 40 minutes. The data analysis conducted revealed that having an autistic child has an impact on mothers in many ways including quitting a job, having limited social interaction, mood swings, and at times frustration. Misconceptions and a low level of societal understanding of autistic children and their associated mothers were also highlighted as the second theme cluster of the study. Mothers indicated public transport and mainstream schools as the most difficult places to deal with autistic children. Mothers also indicated challenges concerning getting the diagnosis, treatment, and support services for their children. Praying, consuming alcohol, crying, and accepting the case as a gift from God were identified as coping mechanisms by mothers to deal with challenges and stressful situations emanating from being a mother of an autistic child.

Keywords: *Lived experience; Autism; Phenomenological; Qualitative; Mothers; Autistic children*

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Background and Purpose

According to American Psychiatric Association (APA), autism is described as neuro-developmental disorders which emerge during early childhood. This neurodevelopmental disorder has an impact on a person's ability to socially relate to and interact with others. Social interaction and nonverbal communication, and restricted, repetitive movements, behaviors, and interests were indicated as diagnostic criteria for Autism Spectrum Disorder (ASD) by APA and the Center for Disease Control and Prevention (CDC). This suggests that People with ASD communicate, interact, behave, and learn in different ways (APA; Lindsay et al. 2013, 2014). Effects emanating from ASD and the severity of symptoms differ from person to person (APA). This is explained by the word 'Spectrum' in ASD which individuals can experience mild to severe symptoms in cognition, learning, and sensory processes (Bello-Mojeed et al., 2014). Depending on the severity of the effect, people with ASD can be gifted or severely challenged. Due to this, according to the CDC, the level of assistance that people with ASD require greatly varies from person to person. Children with ASD share some common characteristics concerning social interaction, communication difficulties (delay or lack of language development), and repetitive activities. Another scholar Jordan (1997) has summarized the impairments associated with ASD as social impairment, communication impairment, and flexibility impairment.

Currently, ASD has received a lot of attention worldwide. In 2008 the World Health Organization (WHO) designated the second day of April each year as "World Autism Awareness Day". Although ASD has attracted universal attention, according to Bello-Mojeed et al. (2014), identification and diagnosis of ASD are premature in the African context.

Concerning perceived causes of ASD, a single factor was not identified as a cause in various literature reviewed; there could be many causes (ADDMN, 2016). In the scientific world, generally, environmental and genetic factors are used to explain the causes of ASD (CDC). According

to CDC, the early incidence of ASD in the family may lead to having the case in newborns. Some medicines could also be associated with the development of ASD if taken during pregnancy. Age of mothers is also a factor, according to the same source; children born to older mothers have the risk of being autistic.

Quite a large number of people also give attention to the non-scientific perceived causes of ASD. Various researches conducted to assess the attitude of caregivers and other parts of the general public towards ASD, particularly in Africa, suggest the existence of misconceptions about perceived causes of ASD. Divine intervention and traditional forces were used to explain the possible causes of ASD. Curses, enemies, devil action, or God's punishment were also used to explain perceived causes of ASD and other intellectual disabilities (Tilahun et al., 2016).

Beyond these speculations on the possible causes, there are no commonly agreed and scientifically proven causes of ASD but scholars and health practitioners identify the case by attending to some common signs and symptoms.

The great majority of research on ASD has been conducted in developed countries, which suggests the need for conducting the same in developing countries like Ethiopia. Even prevalence rates are not well documented and used for policy inputs and for designing interventions in developing countries like Ethiopia. Burton (2016) has indicated the presence of as many as 500,000 children living with ASD in Ethiopia, which might not be realistic as the exact figure is not known. Tilahun et al. (2016) puts this number as high as 600,000 and these children are denied access to services they need due to lack of awareness on the general public.

Scholars have highlighted various challenges that hamper the effort to improve the lives of autistic people in Ethiopia. Lack of awareness about the disorder in the general public as well as among health professionals is one to mention (Burton, 2016; Tekola et al., 2016). Other challenges

pinpointed by Burton (2016) were stigma and discrimination to autistic people, high rate of underdiagnosis, lack of trained specialists, lack of care and support, and few schools to teach children with ASD. Concerning the shortage of trained specialists, Ethiopia has close to 60 psychiatrists who are supposed to handle autistic and other neurodevelopmental disorders.

Even though ASD-related researches conducted in the Ethiopian context are very limited, they were found to be informative in documenting the challenges and misconceptions of the disorder. Concerning exploring and documenting lived experiences of mothers/caregivers with an autistic child, little attention was given in past researches. The following study was conducted to identify and describe lived experiences of mothers/caregivers with an autistic child with the main purpose of identifying the essence of their experience towards having an autistic child. It has explored and presented the textural (what have you experienced in terms of having an autistic child?) and structural (what contexts or situations have typically influenced or affected your experience of having an autistic child?) descriptions related to the phenomenon, having an autistic child as a mother/caregiver.

Methods

Design

A qualitative research design was used through the application of a phenomenological approach which helped to explore the lived experience of mothers/caregivers with an autistic child. Through the use of phenomenological study, detailed data was gathered to understand the lived experience of mothers on the phenomenon, which is having an autistic child. The social constructivist paradigm was applied to explore and document lived experience of mothers as meaning is believed to be created through human interaction with the phenomenon (Creswell, 2007). So, this study considered two paradigms to inform its epistemological stances, phenomenology and social constructivist.

In the effort to get a deep understanding of the phenomenon, the researcher put aside past knowledge and early experience about the phenomenon. This helped to take a fresh perspective of participants' responses to the phenomenon. To this end, the study employed transcendental phenomenology.

Sample

A purposeful sampling method was used for the selection of participants of the study. Three mothers with autistic children¹ were approached for the study, as they fitted the purpose of the phenomenon under discussion. Two mothers were approached from Kokebe Tsibah Primary School and one mother from Nehmia Autism Centre for in-depth interviews to explore and document their lived experience about the phenomenon and these mothers were identified in consultation with school management and center officials. The following table presents demographic characteristics of the mothers and their associated autistic children:

Table 1. Participant Overview

Code	Mothers/caregivers Information:				Child's gender, & current age
	Gender	Age	Occupation	Relationship with the child	
Mother 1	Female	36	Working at Nehmia Autism Centre	Mother	Boy, 12
Mother 2	Female	38	Not working	Aunt ²	Boy, 19
Mother 3	Female	42	Not working	Mother	Boy, 10

¹ They were diagnosed positive for ASD at Public Hospitals like Yekatit 12 and their mothers submitted medical examination results to the sampled school and autism center for enrollment purposes.

² She is the one responsible for his care and support, the child is not receiving support from his biological parents for undisclosed reasons.

Data Collection

Before the actual data collection, institutional approval was obtained from Kokebe Tsibah School and Nehmia Autism Centre. Besides, participants provided their consent verbally to take part in the study. The purpose of the study, their anonymity, limits of confidentiality, and their right to withdraw from the study at any time was explained to the study participants in advance. Convenient time and location were also arranged for the interview.

An in-depth and semi-structured interview procedure was primarily applied to obtain descriptions of the experience of sampled mothers with an autistic child. The interviews were conducted face-to-face by the researcher who had many years of experience in data collection and conducting research. The researcher has fostered rapport with the study participants at the beginning of the interview through discussion of general issues which helped in getting detailed responses on their lived experiences. Moreover, probing, reflections, paraphrasing was applied to detail responses of mothers on the phenomenon. Interviews were audio-recorded and transcribed verbatim for data analysis and theme clustering. After the end of planned interviews, the researcher held a conversation with mothers, particularly with Mother 2, on neutral topics and handled emotional disturbances created due to the discussion on experiences of having an autistic child.

Study Setting

The study was conducted at Kokebe Tsibah school and Nehmia Autism Centre. Kokebe Tsibah is a public school with pre-primary, primary, and secondary school levels while Nehmia Autism Centre is a private organization mainly established as a center for children with ASD and has trained professionals. Both parents from Kokebe Tsibah stay at the school waiting for their children until the end of school time sitting idle while the respondent from Nehmia Autism Centre is an employee at the center and she is engaged in taking care of children with ASD. The

children at the center displayed some of the attributes characterizing ASD like challenges in communication and social interaction, repetitive activities, etc.

Data Analysis

As indicated by Creswell (2007), the audio recorded interviews were transcribed verbatim which was followed by examining their responses line-by-line to highlight key statements about the lived experiences of mothers with autistic children. Key statements helped to get a general sense of their lived experience about the phenomenon. To identify this key statement, the researcher immersed in the data both the transcribed and the recorded interviews. Through the horizontalization process, significant statements, sentences, or quotes that help to understand participants' experiences about the phenomenon were identified. Finally, the researcher developed formulated meanings based on the significant statements which in turn were compiled and themes were developed that helped to explain the structure and essence of the experience of mothers with autistic children. This whole process involved a frequent review of codes, categories, and themes to get the essence of the phenomenon. Through this process, the researcher was able to write a rich and exhaustive description of the lived experience of mothers with autistic children.

Results

The data analysis from a total of 95 significant statements resulted in 16 formulated meanings and 4 clustered themes on the lived experience of mothers with autistic children. The four clustered themes, which have their corresponding subthemes, were (a) societal misconceptions and low level of understanding about autistic mothers and their children, (b) impact on the Social life of mothers, (c) diagnostics and services, and (d) coping mechanisms. The following is a detailed description of each theme.

Misconceptions and Low Level of Societal Understanding About the Case

The second cluster theme, misconceptions and low level of societal understanding about the case, includes issues related to misunderstanding autistic children, stigma and discrimination, and misconceptions about perceived causes of autism. Mothers who took part in the study indicated societal lack of awareness in understanding autism in general and autistic children in particular. Due to this, mothers and autistic children experienced misconceptions and maltreatments in social places like public transport and mainstream schools. Public transport is identified as the most difficult place to deal, for mothers, while together with their autistic children. Mother 3 described her experience that public transport is *the most challenging place to be together with my baby*. Mother 2 and 3 described their experience as follows:

On public transport, some people are not kind and cooperative with my baby. One day in a taxi, when I asked a guy for cooperation to shift his seat so that I could sit together with my baby, he said 'I don't care. Immediately after the incident, he shifted to another seat when requested by another lady which was alone. (Mother 2)

Particularly, public transport is the most challenging place to be with an autistic child. People won't easily understand the situation of the baby as he [her baby] may not be willing to share seats and some people get annoyed by the situation (Mother 3)

Mainstream/regular schools were also identified as places where mothers and their children get discriminated against due to unusual behaviors emanating from the neurodevelopmental disorder of autistic children. Mainstream schools were not willing to keep the autistic children once they identify that they have some unusual and unique

behaviors from the rest of the group. All mothers who took part in this study indicated they initially enrolled their children in mainstream schools but were expelled after schools identified the situation. Mother 2 and 3 spoke about their experience as follows:

He [her autistic child] was enrolled in a private mainstream school and a teacher from the school once said to me that it is better to herd cattle than taking care of my baby. I was very annoyed and emotional and wanted to fight with her (Mother 2)

His [autistic child] grandmother was a teacher and took him to the school where she was working at that time and she quarreled with her colleagues due to the way others treated her grandchild. Then he dropped out of school and stayed home for one year (Mother 3)

Mother 3 indicated that she took her autistic child to another close-by school, but it ended up the same which he dropped out again and stayed at home as the school was not willing for his stay after they identified for unusual behaviors displayed.

The existence of societal misconception on perceived causes of autism is reported by mothers. Moreover, the situation was impeded by the prevalence of a low level of awareness by society. People have no awareness about the case, its associated behavior, and remedial actions that could be taken to alleviate the challenges of autistic children and their mothers. Mothers described their experience on this as follows:

When we go out of home, he [autistic child] hits neighbors' doors and people say something negative about him. Even when we go out for a walk, as he is not able to walk and also screams, people express their sympathy, and the way they show their sympathy is frustrating. This is due to a lack of awareness about the case in the community (Mother 1)

When I walk together with him [her child], my baby laughed which is a behavior he usually shows, and a person passing by thought my baby was laughing at him. He then confronted me to fight and hit my baby. I explained to the person about the situation of my baby which he apologized for the incident. So, mothers need to be patient when having an autistic child (Mother 2).

When people encounter him in social places, they try to show their sympathy in a way that doesn't give comfort to him as well as to me. I try to explain his situation that he is a gift of God (Mother 3)

Lived experiences from mothers suggest supernatural force as perceived causes of autism by society. People tend to relate autism and other similar intellectual disabilities to curses, spirit possession, or sinful acts of parents. Mother 1 shared her experience that 'people relate it [having autism] to spirit possession or too sinful acts of parents'. Mother 3 spoke about how people perceive the possible cause of autism by stating *some people consider the case as a 'curse, something related to evil possession or due to bad worshipping of parents.*

Since parents expect stigma and discrimination from the community for having an autistic child, they sometimes perceive normal people's actions and activities negatively. Mother 2 has indicated the incidence of the following phenomenon:

Socially, we have a lot of challenges and some of the challenges are mere perceptions that I create in my mind. One day a guy passing by near to us [with her autistic child] laughed and I get angry and wanted to fight with him assuming that he laughed at my baby. The passer explained that he didn't even notice them and he laughed out of thinking something funny which then I asked for an apology and agreed with him.

Impact on social life

Participants of the study identified various impacts of having an autistic child in their life. These challenges were related to their social interaction, job, mood, and level of self-esteem. Due to the nature of their children, all mothers who took part in this study described their experience of having limited social interaction. The situation of having an autistic child is demanding much of their time, as they have to look after their child. In this regard, the following responses attest to the time demand of having an autistic child on parents and its impact on their social life:

I have limited social interaction, for example, I don't go to grieving places, wedding ceremonies as it is difficult to leave such kinds of babies at home for housemaids and attend social occasions. This kind of baby (autistic children) needs close monitoring. So, it is not possible to go to social occasions together with my husband (Mother 1)

He is always together with me during day and night times, and we have reached a stage where it is impossible to separate and I have sacrificed my life for him and I don't have friends now and have also very limited social life and social interaction due to this situation. (Mother 2)

If he is not at school, he will stay at home and not be allowed to go out of the home to play. If he wants to go out for play, someone has to accompany him for close follow-up as he eats dirty things from the surrounding. (Mother 3)

Mother 1 spoke about her limited social interaction due to the nature of her baby and expressed it as follows: *in social life, I was the only one with an autistic child in my neighbor and he was unique among them; he was not playing like other babies, he was at home, he produces some*

unusual sounds, and he hits doors. So, we keep him at home and we have limited social interaction.

Since the nature and behavior of autistic children require close follow-up, mothers were forced to quit their job. Mother 2 has no intention of joining a job and has been jobless so far due to the time demand and the need for close follow-up of an autistic child which she is responsible for providing care and support. Mother 3 described her situation as follows: *I quitted my job as I have no one who could take care of him in my absence, just sacrificed my job for him and I spent my time with him at home as well as at school.*

Mother 3 indicated her effort not to quit her job by employing a housemaid which indicated that *they (housemaids) won't be happy to look after the baby and they quit working at my home too early after identifying he has some unusual behavior.*

Mood swings and frustrations were experienced by mothers with autistic children. Mothers indicated experience of mood variation quite often which largely depends on the situation of their children. For example, Mother 2 noted: *when he (her autistic child) is happy, I will be happy and when he is distressed, I will have the same feeling of stress. So, I have an unpredictable mood which depends highly on his situation.*

Some incidences and situations were noted as frustrating by mothers with autistic children. These frustrations have emanated from the absence of societal support, societal misconceptions about the case, worrying about the future life of their children, and lack of improvement on autistic children after they enrolled in schools. Besides, knowing that the case cannot be cured has identified as a source of frustration on mothers. Mothers described their experience of visiting different places like private clinics, government hospitals, and religious healing services like holy water. In this regard, Mother 1 and 2 discussed their experience as:

We [with her husband] felt bad when we heard that there is no treatment to cure the baby of autism and we have passed through challenging times in life (Mother 1)

I feel concerned about his health status and took him to holy water and also went to places like private clinics and government hospitals for treatment. At that time what remained was going to the sky, otherwise, we visited a lot of hospitals and religious places (Mother 2).

The same mother (2) spoke about her experience of frustration as *I am the only one who is assisting him, I feel worried and frustrated when thinking about his future that what will happen if I die*

Diagnosis, Treatment, and Services

Interviews conducted with mothers suggest the existence of late diagnosis for autistic children. The sampled mothers indicated their children received the medical diagnosis after they were already four years old. Mothers have indicated they observed some unusual behaviors and activities by their children like not able to walk, crying, constipation, communication challenge, hitting oneself, feeling irritated, etc. Mothers taught these unusual behaviors and activities would improve through time, and were not attentive in seeking medical advice from professionals. For example, Mother 2 noted that *He [her baby] has some unusual behavior as he hits himself; he was not able to communicate his needs when hungry or thirsty and started to ask me why this baby was unique from others.*

Due to the hope envisaged by parents that things will be improved through time, children of the three mothers were enrolled in mainstream schools, where the reactions of the school community towards their children served as an alarm for looking for advice from health professionals. Mother 2 stated that *so, it was discovered at school that*

he has some unique and unusual behavior and then went to medical diagnosis. Mother 3 said my baby went to regular school without noticing that he was autistic, and it was after he was 4 that we went to get a medical diagnosis

According to the mothers, mainstream schools were characterized as inattentive to the unique behaviors and activities of autistic children. So, children were expelled from mainstream schools due to their behavior which was considered as not normal by the school community. As indicated above in the 'misconceptions' theme, mainstream schools were indicated not to be responsive to autistic children and they were places where these children got stigmatized for their behavior.

To get treatment for their children, parents commonly sought advice from health professionals and attended religious-based treatments like 'Holy Water.' Mother 3 visited four different health institutions to make sure that her baby was not misdiagnosed. She also took him for holy water treatment at various places. She said, *for diagnosis (of her baby), first I went to the private clinic then to Yekatit 12 Hospital then to two other private medical centers and found out that I should treat my baby at home on my own.*

Concerning support services for autistic children and their parents/caregivers, respondents indicated the unavailability of adequate institutions and professionals in the area. Mothers were not aware of behaviors associated with autistic children and had no idea how to manage them. It was through experience that mothers learned about the behavior of autistic children, their likes and dislikes, situations that affect their mood, food preference, toilet practice, etc. Lack of mother support group was raised as one factor for poor service in the area. Mother 1 and 3 indicated their experience as follows:

I have no idea that I should give selected foods to the autistic child to prevent and minimize constipation. I understood about this lately and began to limit the food types that I provided for my baby. (Mother 1)

I haven't received any training on managing autistic children and on other issues like toilet practice and how to live together with autistic children. Practice taught me a lot of lessons in rearing autistic children. It was from practice that I was able to identify foods that were appropriate to my baby, and also able to identify situations that annoyed him (Mother 3)

Mother 1, whose child is attending school at Nehemia Autism Centre, described some positive changes observed on her childlike his ability to eliminate feces properly through popo training, and being able to walk which was impossible before. The other two mothers, whose children were enrolled at Kokebe Tsibah School, indicated their relief for enrolling their children as they were not able to afford in enrolling them at private autism centers in Addis Ababa. The two mothers suggested the need for improved service and support for their children and the school was indicated as not inviting them to closely work with them.

The school has at least helped me in enrolling my child, but there is no improvement so far and he is not at least able to write his name and residence address (Mother 2)

We are not working with the school in any way, what I do is to bring my kid to school and wait sitting there until the end of daily schooling time (Mother 3)

Mothers have employed various coping mechanisms to deal with the challenges and difficulties of having an autistic child which the following section presents details of the fourth cluster theme.

Coping Mechanisms

As indicated in the presentation of the above three cluster themes, mothers and their autistic children are facing a challenge due to lack of awareness about the case, societal misconceptions about autistic cases, poor service provision for unmet needs, and stigma and discrimination. To deal with these challenges, mothers indicated the use of various coping mechanisms which include praying, consuming alcohol, crying, etc. Praying has been described as one of the coping mechanisms to deal with the frustrations of having an autistic child. Mother 1 discussed her experience saying *I use prayer as a coping mechanism to deal with frustrations related to having an autistic child, we are Christians and God has helped us a lot*. Mothers acknowledge the use and power of prayer in controlling one's emotions in social settings where people maltreat them or their autistic children. Mother 2 also acknowledges the use of prayer to cope with the challenges of having an autistic child. Besides, consuming alcohol was also used as a coping strategy with the situation which she described as follows: *As a coping mechanism, I pray to God to be patient with frustrating situations and also drank a lot to forget things. I usually grumble to God why he gave me this kind of challenge in my life*.

Mothers often indicated the value of being patient in social settings when one has an autistic child. Little is known about ASD in general and associated behaviors of autistic children in particular in the general public and this lead to misunderstanding and conflict between parents and other community members. It is for this reason that mothers insisted on the need for patience as a coping mechanism for parents with autistic children.

Accepting the situation as a 'gift of God' is also mentioned as a coping strategy by mothers who took part in the study. Mothers indicated their resistance to accept the case as soon as the diagnosis results of their child were known. It is through time that they accepted the case and

adjusted to living and deal with the situation. Mother 1 stated her lived experience as:

As a mother, what I advise others is to accept the situation, which is difficult at the initial stages. It is also not good to keep autistic children at home but rather to take them to this kind of center and seek advice from professionals. Early diagnosis is also good for early intervention which will be more effective on *popo* training, self-feeding, etc. All this depends on accepting the situation.

Mothers seem to fight the societal misconceptions about perceived causes of autism which were related to spirit possession, curse, or evil acts of parents and get relief by accepting the case as God's gift. Experience from Mother 1 supports this idea which she described her child as 'he is a gift from God and we need to accept the situation and act accordingly. Similar narratives were described by Mother 2 and Mother 3:

Finally, after all these (visiting health facilities and religious places like holy water) efforts to get treatment for him, you have to convince yourself and accept the situation as a gift of God but not something related to evil acts or bad worshiping of parents (Mother 2)

We went to various specialists, to holy water, but there is no change in his health condition. Then decided to accept that he (her child) is the gift of God and extend our love and affection to him (her child) (Mother 3)

Crying was also noted as one coping mechanism of mothers in dealing with the challenges of having an autistic child. Even though not frequent, mothers acknowledged the use of fighting as one coping strategy to deal with challenges in public places and social gatherings. This is indicated in the theme clusters discussed above.

Discussion

The major findings of this study on the lived experience of mothers with autistic children signify the existence of prevalent impacts on the social life of mothers as well as autistic children. In this study, mothers with autistic children were found to have limited social interaction and quitted jobs or have no intention to look for a job to closely follow up their autistic children. Mood swings and frustrations were also reported by mothers as other impacts emanated due to having an autistic child. These results share findings of the study conducted by Taha and Hussien (2014) which identified various economic impacts of autism in Arab Countries. This economic cost placed enormous burdens on families which included lost employment time and cost, increased stress, disruption of family life, and reduced time with other family members

Mothers have also indicated the presence of misconceptions on perceived causes of autism which largely community relates it to spirit possession, sinful acts of parents, and a curse. This substantiates previous findings which acknowledged a lack of awareness about the disorder in the general public as well as among health professionals as challenges hampering the effort made to improve the lives of autistic people in Ethiopia (Burton, 2016; Tekola et al., 2016). Misconception on perceived causes of mental health disorders (autism included) is reported by MoH (2012) as a serious challenge of the existing situation in Ethiopia. Spirit possession, bewitchment, or evil eyes were common examples used to explain supernatural causes of mental illness. This was supported by a study conducted by Tilahu et al. (2016), in which 102 caregivers from three mental health clinics took part in the assessment. As to the cause of autism/intellectual disability, the sampled caregivers have provided possible reasons from biomedical perspectives (like head injury, birth complications, epilepsy, family history) and supernatural reasons (spirit possession, punishment from God, Evil eye, or 'buda', sinful act). Moreover, the study conducted by Tekola et al (2016) has also indicated the existence of misconceptions on perceived causes of autism and common explanations were a punishment from God, curse,

or devil's possession. The same findings were reported by Bello-Mojeed et al. (2014) and Abdullahi (nd) which reported that children with ASD, which presumed resulted possibly from wrongdoings by parents, were considered as defective in African culture. Witchcraft, demonic affliction, and evil spirits were mentioned to explain supernatural causes of ASD. According to Cornett (nd), this kind of misconception towards autism has primarily emanated from a lack of awareness.

Informants of this study also indicated incidences of stigma and discrimination towards autistic children, which were commonly observed on public transport, social gatherings, and at mainstream schools. In this regard, Burton (2016) identified stigma and discrimination towards autistic people as a challenge in the Ethiopian context.

The late diagnosis was also identified as a challenge that has an impact on early intervention for autistic children. Tekola et al. (2016) indicated that children sampled from government clinics were usually diagnosed from 4 to 7 years old which is consistent with the finding of this study. Bello-Mojeed has related cultural influence as one possible reason for commonly observed late identification of ASD cases in Africa in general. Other reasons mentioned included inadequately trained personnel and inadequate healthcare facilities in Africa which is in good agreement with this study in the Ethiopian context.

Findings in the present study are consistent with the findings of Tekola et al. (2016) and Tilahun et al. (2016) in which the level of support for autistic children and their parents was indicated as poor due to few available institutions and professionals. To this end, autistic children and their parents were facing practical challenges like getting a diagnosis, accessing appropriate education, and enrollment at mainstream schools. Ethiopia has quite a few centers that attend to the unmet needs of autistic children, which are mainly in main cities. Supporting this claim, Waganesh et al. (2018) indicated that autistic children in Ethiopia were underserved for reasons like shortage of trained specialists, the low number of health facilities, and inadequate family support programs.

To cope with challenges emanating from having an autistic child, mothers used various mechanisms like praying, consuming alcohol, crying, accepting their children as God's gift, etc. No mother has indicated their effort for task-focused reactions to deal with the stressful situation of having an autistic child but rather focused on a psychological effort to accept the situation as God's gift which helped them to manage stressful situations and associated emotions. The study conducted by Pepperell et al. (2018) detailed two kinds of strategies that help to manage stressful situations and associated emotions which are problem-focused and emotion-focused coping strategies. Strategies that help to solve or change the problem were identified as problem-based coping while those strategies which help to reduce feelings of distress were indicated as emotion-based coping strategies. The study indicated that mothers mostly applied emotion-focused strategies like drinking alcohol, eating, watching TV, crying, talking, venting as opposed to problem-focused strategies which are consistent with the findings of the present study.

Limitations and Future Research

Only three mothers took part in this study and this sample size may not be representative of other mothers with autistic children. Besides, only mothers were interviewed in this study, which the finding is limited to the lived experiences of mothers and suggests the need to conduct further research on lived experiences of fathers with an autistic child. Mothers who took part in this study accidentally found out to have autistic sons, which their lived experiences could have been different if mothers with autistic girls were included. Further studies need to explore the experiences of mothers having autistic girls to expand on the findings of this study.

Conclusion

In this particular study, the lived experience of mothers with autistic children was associated with challenges like limited social interaction, no intention of having a job, and mood swings. Deep-rooted misconceptions about ASD and other similar neurodevelopmental disorders were indicated in this study. People often relate the disorder to spirit possession, sinful acts of parents, or as a curse. Societal lack of awareness about the disorder and its associated behaviors displayed by autistic children has often presented as a difficult challenge to deal with for mothers. Public transport services were indicated as the most difficult place where mothers and their autistic children were maltreated and misunderstood. Praying, consuming alcohol, crying, and accepting the case as God's gift was some of the coping strategies employed by mothers in dealing with stressful situations and accompanying emotions for having an autistic child. The level of existing support services for autistic children and their parents was indicated to be very poor. Based on the findings of this study, building awareness of ASD and its associated behaviors observed on autistic children could help to enhance societal support in this regard. Besides, establishing a mother support group and strengthening support services could help in addressing the unmet needs of autistic children and their parents with parameters like health, social, education, and economic. Closely working with mainstream schools could also help in the early identification of ASD and other neuro-developmental disorders.

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