

The Gender Dimensions of Parenting a Child with Autism: A Phenomenological Study in Addis Ababa

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Abstract

Parenting a child with autism is a unique experience that presents considerably higher levels of parenting challenges and psychological distress. This study was conducted in Addis Ababa to understand parents' experience of parenting children with autism and analyse such phenomenon from a gender perspective. Seven parents, two of whom were fathers, who sent their children to Nehemiah and Ryan Autism centres were purposively selected to participate in the study. Another parent was included through snowballing. Data were gathered through in-depth interviews using semi-structured questions. The findings of the study revealed that parents had gone through a series of emotional upheavals and distress before accepting their children's situations. They encountered multifaceted problems related to lack of understanding on the part of their communities, lack of facilities that suit the needs of their children with autism, lack of time for their personal and professional lives, and lack of finance to meet the unique needs of their children. Mothers experienced a greater caregiving burden compared to fathers, and sacrificed in the various dimensions of their lives.

Keywords: Autism, child, parenting, gender, phenomenology

1. Introduction

Autism is a group of neurodevelopmental disorders, collectively called Autism Spectrum Disorders (ASD). The spectrum of symptoms and levels of impairment fall into social impairment, communication problems, and repetitive and stereotyped behaviours (Park *et al.* 2016; Wiggins *et al.* 2015), and they vary from child to child. Some children are mildly impaired by the symptoms; but others live with severe disability (NIMH 2011; Crespi 2016; Ooi *et al.* 2016).

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Children with autism have trouble expressing themselves either in words or through gestures, facial expressions, and touch. They may also have repetitive, stereotyped body movements such as hand flapping, making unintelligible sounds and saying repetitive phrases. They are also attentive to routines and have difficulty adjusting to unfamiliar surroundings or changes in routine (Park *et al.* 2016).

According to CDC (2014), the prevalence of ASD in the USA is about 1.5%, and the incidence is almost 5 times more common among boys than among girls. Studies conducted in Asia, Europe, and North America reported a prevalence rate of approximately 1% (CDC 2016). A prevalence of 2.6% was reported in South Korea (Kim *et al.* 2011). This disorder is seen among all racial, ethnic, and socioeconomic groups (CDC 2014).

In Ethiopia, information on the prevalence of autism is scanty. However, it is estimated that about 530,000 children in Ethiopia live with autism and other developmental disorders (Cleopatra 2018). Low level of awareness about autism in Ethiopia has made parents unable to speak about their children openly and seek support services. Parents experience guilt about their child's condition, and feel personally responsible, or believe that the symptoms of autism are related to curse and evil eye, rather than the manifestation of a neurobiological condition (Ephrem 2005; Merhawit 2017).

Parenting a child with autism is accompanied by significantly higher levels of parenting challenges and psychological distress (Pottie *et al.* 2009). Parents of children with autism experience more parenting stress and lower levels of wellbeing than parents of children with no disorder or parents of children with other disabilities (Kamei 2013). Stressful nature of autistic symptoms, associated behavioural problems, and the lack of public understanding and tolerance for the behaviours of children with autism, among others, account for the poorer wellbeing of parents of children with autism (Gray and Holden 1992).

Having a child with autism may have adverse effects on family life including, among others, marital relationships, sibling relationships and

adjustment, as well as normal family routines (Greeff and Walt 2010; Merhawit 2017). Families face extreme difficulties in dealing with challenging behaviours, teaching their child to communicate, training her/him in basic life skills, guarding the child from danger, and preparing him/her for adult life (Bashir et al. 2014). In addition, the severity and duration of the child's disorder, a very low intellectual capacity on some children, lack of congruity with the community norms, bizarre forms of communication and behaviour, and enduring disruptive or disorganized behaviours might induce acute or chronic stress to the parents, which, in turn, leads to dysfunctional parenting (Kourkoutas *et al.* 2012; Ooi 2016).

Many parents experience periods of disbelief, deep sadness and depression and self-blame and guilt, whereas others experience helplessness, feelings of inadequacy, anger, shock and guilt (Gupta and Singhal 2005; Pisula and Porebowicz-Dorsmann 2017). Concerns over the permanency of their child's condition, poor acceptance of autistic behaviours by society and other family members, and low levels of social support received from others contribute to parental distress (Prince 2007). Chronic sorrow and a sense of failure are emotional states that are often reported by parents of children with autism (Kourkoutas *et al.* 2012).

Difference in the experience of mothers and fathers in raising a child with autism mainly results from respective biological and socially constructed roles of fathers and mothers. Mothers are the primary care givers of their children as a result of their reproductive roles in a family. However, when they have a child with a disability, in this case autism, their reproductive role will be extended to meet the special demands of the child and have to stay home with their child with autism (van Tongerloo *et al.* 2015; Merhawit 2017; Pisula and Porebowicz-Dorsmann 2017). This and other additional burdens mothers carry to care for their child are not recognized and are taken for granted. Most fathers usually spend less time with their child with autism and do not use the same level of energy as the mothers (Jardine 2008). Moreover, mothers take the blame for not delivering a child that meets extended families' and society's expectations of a perfect child (Peters and Jackson 2008).

In Ethiopia, autism has been studied from a public health perspective (Dejene Tilahun *et al.* 2017; Bethelehem *et al.* 2019). Studies on the social aspect of autism are scanty, especially issues with regards to parenting a child with autism and the role gender plays to define this relationship have not received attention. The aim of this study was, therefore, to introduce gender as an important dimension in the study of parenting a child with autism. By making gender the centre of analysis, the study attempted to identify the respective parental roles of fathers and mothers in caring and raising a child with autism, and explore the respective challenges they faced.

2. Methods

2.1. Description of the Study Areas

The study was conducted on mothers and fathers whose children with autism were registered and enrolled in Nehemiah and Ryan Autism Centres in Addis Ababa. One parent came outside of these centres through snowballing. Nehemiah Centre for Autism, found around Megenagna area, was established in August 2010, by a mother of a child with autism, who was unable to send her child to a school or to the only centre due to lack of space. The Centre now works to create access to education and skills for children with autism and related disabilities, to help them grow as confident adults and become productive members of the society (Nehemiah Autism Centre Founder, personal communication). During the study, the Centre gave school-based intervention services to 40 children, while 140 children were on waiting list. The second one, Ryan Autism Centre, located in a small compound in Nifas-Silk Lafto Sub-city, was established in 2013 by a father of a child with autism with the intention of giving care and basic intervention services for children with autism. It started operation in September 2014. At the time of the study, Ryan Autism Centre had enrolled 25 children.

2.2. Research Design and Sampling Technique

The study used a qualitative phenomenological exploratory research design to look into the lived experiences of parents of children with autism, and to listen to their voices while they narrate their untold stories. The phenomenological approach is used to understand individuals' common or

shared experiences of a phenomenon, in this case, parenting a child with autism (Giorgi 1997; Creswell 2007).

The study participants included six mothers and two fathers of children with autism. Except one, the rest of the children were registered and enrolled for the academic year 2014/15 in the two centres. Of the 18 parents who were asked to participate in the study, only nine volunteered. Two withdrew after confirming, and another parent was included through snowballing. Both mothers and fathers of children with autism were asked to give their respective views and discuss their experiences of parenting a child with autism from a gender perspective. However, due to their unavailability because of work, only two fathers volunteered to participate in the study.

Purposive sampling technique was adopted for this study, because it was deemed to be appropriate to conduct a qualitative research with an in-depth phenomenological approach on information-rich cases. Phenomenological approach requires that all participants share similar experiences (Glass 2001). In this case, the eight participants were purposively selected, with the criteria of being parents of a child with autism, being the caregivers of the child, and sending their children to the autism centres for the academic year 2014/15. Those who consented to participate in the study were included in the study.

The primary sources of data for this study were parents of children with autism. Research reports and available publications served as sources of secondary data.

2.3. Data Collection and Analysis

Data were collected mainly through in-depth interviews, and observations were made, especially when an interview was conducted at a participant's home. Open-ended questions were used to elicit responses from the interviewees.

Interviews were transcribed, and in order to become familiar with the data, transcripts were read and re-read thoroughly. Relevant segments of data were coded. Clusters of meanings from the coded statements were

developed into themes. Understanding and perceptions about autism; parents' roles in caring; discovery, acceptance and meaning; and challenges in raising a child with autism were the major themes discerned. The clustered themes and meanings were used to develop the textual descriptions of the experience. Structural implications of the textural description were provided by writing a description of the context or setting that influenced how the participants experienced the phenomenon. This led to the construction of an overall description of the meaning and essence of the experience using an integration of textural descriptions, and structural descriptions. Finally, examples from the participants' verbatim statements were included to allow consensual validation of the text.

2.4. Ethical Considerations

Participants were first contacted by the Centres, and following their willingness to participate in the study, they were given information regarding the objectives of the study and were provided with a free choice to consent to participate or decline to participate in the study. They were informed of their rights to withdraw from the study at any time. Their right to confidentiality, anonymity and privacy was observed throughout the study and pseudonyms were used in the report. Interviewees have given verbal informed consent, which was tape-recorded along with the interviews.

3. Results and Discussion

3.1. Participant Profiles

The number of mothers who participated in the study was higher than that of fathers since more mothers were responsible in accompanying their children to and from the centre and were, thus, available for interviews. The fathers were not around as much, because most were fully engaged in work. All of the participants were married, lived with their spouses and were directly involved in child raising. They fell in the age category of 39 and 42 years, and came from diverse religious background. Each of them had one child with autism. In terms of education, three have completed grade 12, and another three have gone beyond. Most of the parents were either self-employed or not employed (Table 1).

Table 1. Background Information on Participants

Pseudonym	Sex	Age	Religion	Total No. of Children	Children with Autism	Educational Status	Employment Status
Hiwot	F	42	Protestant	4	1	Grade 12	Not employed
Neima	F	42	Muslim	2	1	12+2	Not employed
Birtukan	F	42	Orthodox	3	1	Grade 10	(Part-time) Employed
Teiba	F	40	Muslim	3	1	Grade 12	Not employed
Kidist	F	37	Protestant	3	1	Grade 12	Self-employed
Mesfin	M	49	Protestant	4	1	B.A Degree	Self-employed
Ahmed	M	45	Muslim	2	1	Diploma	Self-employed
Hirut	F	39	Protestant	4	1	Grade 12	Employed

3.2. Understanding and Perceptions about Autism

Parents' perception of what society thinks about autism could be grouped under the following themes: as a price for parents' sin, as a sickness, as living in one's own world, and as living with stigma and pity.

According to Kamei (2013), the experiences and perceptions of parents concerning their children with disabilities are considerably influenced by social and cultural factors. Each culture has its own explanations as to why some babies are born with disabilities, how these children are to be treated, and what responsibilities and roles are expected of family members (Lamorey 2002). Religious beliefs, especially play an important role in shaping cultural attitudes toward disabilities, individuals with disabilities and how individuals perceive the world around themselves (Kamei 2013).

Respondents described their community as religious, and viewed matters from religious perspective. Conditions like autism were considered as God's punishment for a vice made by parents. Kidist, a mother of a child with autism, retorted the following.

There is no awareness about autism in our country. The society does not understand the situation of our children and the circumstances we live in. Most people believe that it is a curse or an evil spirit, or that we are paying a price for our sin.

Ahmed, a father, added, “*They think it is an evil spirit or a curse that passes through generations*”.

The connections between sin and suffering are pervasive themes in religious texts. Illnesses and disorders, such as autism, are depicted as sin, as something that should be healed, but not accepted (Schumm and Stoltzfus 2007). Findings of this study confirmed the existence of a belief in the society that autism was a result of parents’ sin.

Understandings about autism are now changing. Currently, it is understood as a neurological syndrome, and autistic symptoms are recognized as the final pathway with which the brain expresses a great variety of lesions and malfunctions of the infant central nervous system (Glass 2001). Although modern medicine classifies autism as not an illness, but as a special condition of the mind, the communities, in which the study participants lived, viewed it otherwise. In this regard, Hiwot, a mother, said:

They [people] think my child is sick; and they are afraid that it is contagious and want to keep their children away from my son. As a mother, I know that it is not contagious. But, I do not try to convince them. I feel so hurt when I see people point their fingers at my child; I just accept it and move on. All I care about is my child’s wellbeing.

According to Ecker (2010), however, there is still the perception of autism in western and Asian cultures as an incurable, disabling illness which limits individuals’ abilities in many aspects of their daily lives. In South Korea, for example, many people recognize autism as a cognitive disease of the individual and a disease of the family (Ecker 2010). Mesfin, one of the fathers, concurred with this idea as follows:

They think it is a sickness that resulted from some wrong we did during pregnancy. Some people think that it is caused by taking the wrong medications, while others think that it is because of substance abuse like drinking alcohol during pregnancy. But we know that this is not the case; at least, I know that my wife did not do any of these things. But there is nothing we can do to change their thinking except explaining that this is not a disease or a sickness that has to do with our negligence or mistakes.

Currently, at least in the scientific world, an increased understanding has encouraged a transition from perceiving those with autism as mentally ill or dangerous people to viewing them as special-needs individuals. It is now generally understood that autism is not a medical issue that can be cured. Rather, it is a disorder marked by the display of certain social characteristics (Martin 2013).

Most of our respondents described autism as a condition that made children isolate themselves from the rest of the world to live in their own. Teiba, a mother, said,

I do not know its medical definition; but, what I know is that children with autism are isolated from the rest of the world; they do not care about the things you say. For example, when my son does something wrong, and I tell him not to do that, he will do it again right away. This is because he does not follow my instructions. Especially, those children with autism, who have problems with verbal communication, suffer the most since they cannot say what they want or what they do not want. These are the children that may be abused by domestic workers as they are not able to communicate with their parents.

Hiwot, another mother, agreed with Teiba in the following terms: *“As far as I know, autism is a condition that makes children live in their own world, who choose their solitude.”* According to Ecker (2010), extreme feelings of isolation exist among individuals with autism extending from childhood to adulthood, with many individuals reporting increased feelings of isolation due to increased self-awareness as they grow older.

Parents also reported that having a child with autism meant being isolated because the society lacked understanding of what autism was and what caring for a child with autism required. Woodgate et al. (2008) concurs with the ideas that despite the challenging nature of autism, parents believe that their suffering is not recognized by others around them, and that they feel they are invisible to others. They also believe that society places less value on the lives of the children with autism and that those children are stigmatized, a situation which adds to their feeling of isolation. Hirut, a mother, described this state-of-being in as follows:

The society thinks less of me and my child; they always give me sad looks. They treat my entire family as if we are different. They feel sorry for us and it is really disturbing to be seen that way. I keep myself within my family circle as much as I can, because I do not feel like I belong in these people's circle anymore.

Stigma is not only experienced by parents of children with autism, but also, to a greater extent, by the children with autism themselves, whether or not they understand the condition. According to Martin (2013), stigmatization of those with developmental disabilities has always been common, as it is human nature to judge those who are noticeably different, with severity of this judgment and stigmatization typically increasing with the severity of the condition. The perception of Birtukan, a mother, about what her neighbours think of her son can be explained by this note:

Other children point their fingers at my son saying, 'There he is! There he is!'. They see him as a different creature or some crazy kid. They are afraid of playing with him. Even if they are not, there is no way that their families allow them to play with him. It is very painful to see my son sitting alone for most of the day.

Another reaction the society had towards children with autism and their parents was pity. As opposed to being stigmatized, being pitied does not have a negative element to it. However, this does not make it immune from inflicting a feeling of discomfort on the victims. Kidist, a mother, said:

My neighbours are very good people; they really feel sorry for me. They want to help me by covering my social duties, and they understand that I might not be able to fulfil my social duties because of my child's condition. They are very kind to me. However, they take their sympathy too far and make me feel that I am less able than others, and someone who should be pitied because of her child's condition.

3.3. Respective Roles of Parents in Taking Care of a Child with Autism

In the attempt to identify the respective parental roles of fathers and mothers in caring for and raising a child with autism, parents were asked to describe a typical day in taking care of their children with autism: what their roles as a mother/father are, and in what ways they compare their roles with those of

their spouses, and whether they think roles vary between spouses and how. Findings indicated two themes: autistic-child-driven life routines and the relative burden on the mother.

Most of the respondents testified that their days revolved around their children, especially after learning that they had autism. According to Woodgate et al. (2008), parents of children with autism entertained a feeling of “*missing a ‘normal’ way of life*”, because many aspects of their lives were affected by their child who needed demanding care due to autism. Hiwot, a mother, described her typical day in taking care of her child in the following way:

The moment I wake up in the morning, I think of my day with my son. I plan my days around him. I plan my day from the moment of getting up and preparing breakfast to bringing him back home from the autism centre. Once I prepare his food, I take him to the centre and go back home to do other domestic chores for my family and then come back here [the centre] to pick him at the end of the day.

Kidist added to this by saying:

Because I am the only one who knows my son’s needs, I am responsible for his care: bathing, dressing and feeding him, and putting him to bed. Being a mother is really difficult in the morning because that is when I struggle to wake up all my three children, dress, feed and make them ready for school. Imagine my life when one of them has autism!

All parents agreed that their lives were driven by the needs of their children with autism. It is true that the arrival of a child in a family changes the life led by the parents before. However, having a child with autism multiplies the effect. Mesfin, a father, strongly believed that the life of both mothers and fathers was driven by the needs of a child with autism. He described his typical day in taking care of his child as follows:

At home, we share household responsibilities equally. Every morning, my wife brings our son to the autism centre, while I go to work. But, in the afternoon, I come straight to the centre from work, to pick him up. I do not visit my friends neither do I go out for a drink like other fathers do. I do not even have the luxury of

working till the end of the day because the centre closes before 5 p.m.

When asked to compare their respective roles as a mother/father of a child with autism with those of their spouse, most respondents confirmed that they shared household responsibilities with their spouse. Hiwot, a mother, indicated this by saying:

We share our responsibilities equally. We know that both of us are responsible as parents. Except the fact that he is the breadwinner and has to work outside of the house, we both have roles in the care of our child. I think these roles are different because as I am a housewife, I spend most of my time with my son. Moreover, as a mother, I am closer to my child than his father is.

In line with this, Woodgate et al. (2008) stated that it was not uncommon for the mothers to assume the primary responsibility for the care of their child since fathers considered caring as an additional task to their traditional role of bread winning. Gupta and Singhal (2005) also argue that the brunt of caring for a child with autism fall predominantly upon the mother, who may, as a result, experience low parenting competence, less marital satisfaction, less family adaptability and significant levels of chronic stress and fatigue. Birtukan, a mother, emphasized on her role as the primary care giver of her child with autism, while still acknowledging that her husband helped a lot:

He helps me a great deal. He looks after the child when I am away from home for my part-time job or for a social duty. He helps me when our child encounters difficulty sleeping at nights. Our son beats himself until he bleeds so he has to be watched out all the time and it is his father who does most of that. But, still our roles are different, because I am closer to my child than his father is.

Most of the parents thought that they were in this journey of raising a child with autism together. However, fathers admitted that it was the mothers who bore much of the burden. Mesfin, a father, testified:

Even though we share household responsibilities between us, the burden still lies on the mother because mothers are closer to their children and having a child with autism will also be another

reason to keep the child closer to his mom. My wife used to work, but she stopped working after we found out that our son has autism. Between the two of us, she is the one who gave up her job and stays home for the child, not me, because I am the father and a man.

The difficulty to manage a child with autism puts a burden on mothers. The following challenges were mentioned by the parents:

... going to work or any other places leaving my child at home; because other people, be it his father or his siblings, would not have the patience as much as I do. (Birtukan)

...keeping him calm and happy; because he can easily get irritated and it would take us long to be able to calm him down. This is the most difficult part. (Teiba)

...not being able to communicate with your child; hence, not being able to make him understand what is good or bad for him, so that he does not easily hurt himself. (Kidist)

The participants also indicated that the most difficult times are when their children are sick. Excerpts:

...when he is sick, because I cannot tell which part of his body is aching. (Hirut)

...when he is sick; because they [children with autism] do not have the ability to speak and tell that they are sick. (Hiwot)

Raising a child with autism places more burden on mothers, which could be the result of the traditional female gender role which places the greatest burden of child raising on mothers and, therefore, attributes more responsibility to them for the child's behaviour, especially when the child is with some disability (Kaniel and Siman-Tov 2011). Kidist, a mother, believes that, no matter how modern a society can be, mothering is a life-time commitment. According to her, mothers work relentlessly to take care of their children with autism, while fathers still enjoy a relatively normal life. When she was asked to compare her roles as a mother of a child with autism with that of her spouse, she replied:

It is not even comparable. The burden lies on me [the mother]. I heard that some men are good at giving a hand at home; but, in my case, I bear the total burden. For instance, the difference in our days begins early in the morning; I wake up at 6:00 a.m. and he wakes up at 7:15. I take care of myself and my children, while he takes care of only himself.

This finding conforms with what has been found by Tehee *et al.* (2009) that when compared with fathers, mothers of children with autism tend to feel more involved in their children's everyday lives, a situation which makes mothers experience a greater care-giving burden compared to the fathers.

3.4. Meanings attributed by parents to their experience of parenting a child with autism

Following a phenomenological approach, this study sought to understand what meanings the participants give to the phenomenon they experience (Cresswell 2007). The process of discovering that their children have autism, the age and the circumstances under which they came to know about it, their reaction at the time, and meanings given by them to their experience of parenting a child with autism, are discussed under the themes that follow from here:

3.4.1. *It is autism!*

According to Jardine (2008) key points in the process of raising a child with autism include making sense of their child's symptoms, knowing their child's diagnosis and the emotional experiences following the discovery. The participants of this study were asked to elaborate on these. Teiba, a mother, when asked how she found out that her child had autism, answered:

Before finding out that our child has autism, we used to send him to a regular school. At the school, the teachers wrote on his books, did the classwork and homework for him, and he always scored good. So, we thought our child was learning well; we had no idea that our child was different and that he did not understand any of the things written on his books. They kept us in the dark about our child's condition. ... After a while, he changed school and one of the teachers at the new school told me that my child had a different condition and that he should be sent to a different school

where children like him attended. His father and myself did not understand what she was trying to say; so, we took him to a hospital and learned that he was autistic...

Many parents, too, saw and sensed that their children were different, but did not take any measure until it was very late, very obvious or triggered by something. Kidist, a mother, remembered her experience this way:

I used to compare him with my elder son and I always thought that he was different. I started to see some symptoms after he was one year and two months old. He used to have sleeping problems and a severe constipation. People gave me explanations such as 'it could be because you gave birth to another baby without adequate spacing and maybe he is not getting enough attention'. One day, I saw him eating his faeces. Then, I knew that something was wrong. I went to my children's doctor and said to him 'look, I know you do not believe me when I tell you there is something wrong with this kid'. But the doctor said he was healthy, and he even criticized me for calling bad omen. So, I went back home in vain.

...He preferred to be alone so I used to leave him to play alone. He used to pile everything up. When I brought this to my husband's attention, he used to reject it saying 'maybe it's just his way of playing'.

One day I was watching TV with my youngest son and, in the middle of a show, there came an advertisement by Save the Children which talked something about autism. One child was shown in the TV while piling up things and hitting the wall with the back of his head. I was so shocked and cried, 'Beyesus Sim!' [In the name of Jesus!]. I knew, right there and then, that my child had autism, although I had no idea what it was. Then I told my husband to read about autism. When he asked me why I needed it, I said our son had this thing called autism. He said 'ok' and he read about it. Afterwards, he called me back and said 'go, go, go' and when I asked 'where?', he said 'go to the doctor right away! Our child has all the symptoms of this thing they call autism!' Then we went to the Doctor and confirmed that our child has autism.

For most parents, inability of the child to learn to talk at the appropriate age triggers the need for medical diagnosis. Learning to talk is one of the most important milestones in a child's development. According to Retaskie (2015), parents realize, for the first time that there is something different about their child's development, by the child's delay in reaching certain milestones. One important milestone that they notice is a delay in speech. Most children begin talking around age one and say short phrases by age two (Retaskie 2015). All of the parents in this study noted that their children did not hit this milestone. Hiwot described her experiences this way:

We did not know our son had autism; we even sent him to a regular school. However, he was not able to talk for a very long time and they told me he also had behavioural problems, and they suggested that we took him to a hospital. After that we discovered that he has autism.

The age of the children at the time of discovery that they had autism ranges from two to seven years. Most parents recalled this period to be the most difficult time of their lives. According to Jardine (2008), the child's diagnosis with autism is a defining moment in the lives of the parents and one which many of them always remember with great clarity.

After learning that their child has autism, parents go through some serious emotional upheavals including depression, sadness, self-blame, grief, and finally acceptance (van Tongerloo, et al. 2015). The following section looks into the journey parents took to come to terms with their children's autism.

3.4.2. It is God's will

The most repeatedly used expression by parents while talking about the meanings they gave to their child's autism, and their reactions immediately after the diagnosis and how they handled it is 'It is God's will'. Extracts from Neima, a mother:

Parenting a child with autism is not a good experience; it is not a good life to live. But since it is Allah's will, we have to accept it. I wish I had a healthy child, but it is not Allah's will. It is very difficult to raise a child with autism; it is totally different from the experience of raising a typical child. However, in order to bear the burden, the first step in our journey should be accepting it as

Allah's will, then He will give us the strength to do whatever is necessary; He helps us carry on.

Parents were repeatedly heard talking about acceptance. Jardine (2008) argues that acceptance is an important part of the parents' experience that facilitates their ability to cope with a child's autism. For Hiwot, a mother, accepting her child's autism was mixed with hope leading to the belief that he would change. She said:

I have accepted my child's autism with a full heart, because God does not give me such a child without a purpose or by mistake. He gave him to me, because he knows that I am capable of handling it; he knows I can be a good mother for the child. I accept it with the hope that he will change for the better in the future, God will show it to me!

Meanwhile, for some of the parents in this study acceptance was not just about being able to accept autism, but also to deal with and adjust to the things that come along with autism. For some, it is something that comes and goes. Mesfin, a father, described his feelings in the following terms:

Being a parent of a child with autism has both positive and negative implications for me. Sometimes I accept it as God's will, but, at times, I say why does this have to happen to me? What would be the fate of my child? Thinking about the future is the most depressing part for me. When your expectation of a perfect child is crashed, it could be very depressing. But again, I say to myself, "If it is God's will, there is nothing that we cannot handle! God only gives us what we can bear!"

Jardine (2008) resolved that acceptance of their child's autism is something which clearly took time for parents. Participants of this study all agreed that the passage of time helped.

3.4.3. A special child to a special heart

In spite of the conventional belief and understanding that all parents of a child with autism feel troubled about their experience of parenting such a child, some parents admitted that they saw their child not as a burden but rather as a blessing. This is what Kidist, a mother, said about her child:

I think God gives children with autism to women who are kind-hearted; some women are not sensitive when it comes to children; but I and other mothers who have children with autism, share one common trait and that is having a very soft heart for children. And I think God knows what is best for these children. That is why He chose us. '*Enquanim yene lij hone!*'- [Good that he is my child!] Because he loves me unconditionally, he comes and kisses me unexpectedly. When my other children come and kiss me, I know that they want something in return, be it a candy or cake, but with him, this is not the case; he just does it regardless! He is special to me. I think about him every second of my day. I know that I have a special son! And I love him with all the love in my heart.

Hiwot also shared Kidist's feeling in these terms:

To be honest, I do not see my child's condition as the society sees it. I mean I do not have to see it the way everyone sees it, right? ... The way I see it, I have a special son and I am thankful to God regardless of what everybody else thinks of our situation. I accept it with the hope that God would help him improve. The way I see it, God would not have given me such a child if he thinks that I do not have the capacity and the heart to raise him with the utmost love and care. I have devoted my life and my time for my child. I love him with all my heart and I know I am chosen to be a mother for this child, because I have the heart to bear it.

This is in conformity with what was reported by Ecker (2010) about Pakistani and Bangladeshi Muslims who believed that a child with autism was a pure and innocent gift from Allah. According to Jegatheesan *et al.* (2010), parents believed that Allah chose them to be the parents of a child with autism because of their love, hard work, dignity, and ability to nurture. Allah was believed to help the families gain a deeper understanding of having a child with autism, and thus autism brought them closer to their religion.

Caring for a child with a disability could be a gratifying experience for some parents (Kyung and You 2009; Ooi et al. 2016). For example, some mothers of children with disabilities experience a sense of satisfaction and pride when they master medical techniques necessary to maintain their children's health. Also, mothers who have children with disabilities sometimes

experience a broadening of their identities because of a newfound sense of responsibility for others (Kyung and You 2009).

Parents explained the different types of support they received from their families and neighbours. Some also accepted their children's autism as being a chosen parent. Despite all these, however, parents of children with autism explained the challenges in their journey of parenting as presented in the next section.

3.5. Challenges faced by parents of a child with autism

Having a child with autism affects every member of the family in diverse ways. Parents must focus on helping their child with autism, which may put strains on their marriage, other children, work, finances, personal relationships and responsibilities (Baba 2014). In relation to this, parents were requested to discuss in what ways they thought their being a mother/father of a child with autism affected their personal, social, marital, familial, financial, and professional lives; whether they thought parenting a child with autism was a challenging experience; and, if so, the sources of these challenges; the circumstances in which being a mother/father of a child with autism became difficult; the most difficult part about parenting a child with autism; and what, if any, they would change about the experience of parenting a child with autism. The themes that emerged in relation to these issues were: *“Where did my normal life go?”*; *“For better or for worse”*; *“The cost of autism”*, and *“We need help”*.

3.5.1. Where did my normal life go?

In the study of Woodgate et al. (2008), parents described their experience of raising a child with autism with an expression, “living in a world of our own”. Similarly, in the current study, parents felt that they carried all the responsibilities alone, with no assistance in all aspects of their daily lives; but, especially with respect to dealing with the challenges of parenting and caring for a child with autism.

Regrettably, the life parents used to lead before the diagnosis of their child as autistic changed forever; they felt that they no more had a personal and social life. For example, Kidist said:

Having a child with autism is like being possessed; every aspect of your life will be changed and controlled by your child's autism. It is funny how you become a completely different person. The angle from which you look at life would forever change. Even your prayer changes. I used to hear mothers say, *'Dear God, please take me before you take my children'*; but, now when it comes to Baby [her child with autism], I say to God, *'who would take care of my child, if you take me first?'*

Parents' attempt to be there for their children with autism in every aspect of their lives, whether that pushes them to abandon their personal and social lives. According to Woodgate et al. (2008), parents become super-parents to be able to protect their child with autism from a world that does not support them. They are forced to completely focus on every dimension of their child's life by developing a sense of heightened watchfulness and preparedness for action. This desire to become a super-parent obliges parents to abandon their own lives to make their children's lives easier. In this regard, Neima, a mother, said:

I cannot go anywhere if my child is at home; I have to either take him along wherever I go or I should wait for a day that his dad would be at home. Because no one else would take care of my son the way I do. I know what and when he wants to eat; I know when he is disturbed and wants some peace, I know how to protect him from hurting himself and comfort him when he cries. I live for my son. Sure, it somehow takes away my personal life, but I do not complain, since I have already accepted it. It is great that he is alive.

Specifically, talking about their social lives, parents explained that it was next to being non-existent. Woodgate et al. (2008) and Ooi (2016) stressed that the challenges posed by autism placed parents in a situation in which they lost pieces of their life; their social life being one. According to Teiba, her child's autism changed her social life completely:

Being a mother of a child with autism totally changed my life. As a woman, I am expected to attend so many occasions and social events. But now I am forced to cut out these activities from my life, because there would be no one to care for my child the way I do.

The other parents also shared the view that having a child with autism has put a toll on their social life. Regarding this, Birtukan, a mother, said, “*I have abandoned almost every aspect of my social life: I do not visit sick people, nor do I go to mourn a dead or attend weddings. My social life is completely gone*”. Mesfin, a father, also mentioned, “*Now, I do not have any friends except my wife and children*”. Another mother, Kidist, also explained that she would not be able to relax and enjoy social events leaving her child at home, since she would worry that he would do something and hurt himself.

3.5.2. For better or for worse?

Parents experience a variety of challenges that can jeopardize their relationships and question their wedding vows, by which they commit themselves to be there for their partner for better or for worse. Parents who have children with autism face additional stressors that arise from the condition of their children, which put their marital commitments to test. They are often challenged with finding adequate time for both their children and their partner. Children with disabilities are more likely to see their parents’ divorce than other children are (Brobst *et al.* 2009). According to Olson (2010), parents of children with Autism Spectrum Disorder (ASD) report more symptoms of anxiety and marital dissatisfaction than parents of children with other types of disabilities. This could begin with the ‘blame game’ in which parents go back and forth blaming each other for things that they may have done to cause their child’s autism (Olson 2010).

Brobst *et al.* (2009) further found that parents of children diagnosed with autism reported significantly lower relationship satisfaction than parents of children without developmental disabilities, and that respect for partner was a significant predictor of relationship satisfaction. In the present study, however, the marriages of the participants did not seem to be negatively affected by their children’s autism. The following quotes from mothers confirm this.

Glory to the Lord, our marriage is not at all affected by our son’s autism. I do not have problems with my husband that has to do with our child. (Kidist)

Alhamdulillah... My son's autism does not affect my marriage. Since he is our flesh we accept everything. (Neima)

Both my husband and I are involved in taking care of our son, and thus, his condition does not affect our marriage. (Teiba)

This concurs with the observation by Hartley et al. (2012) in which three fourths of the marriages of the parents of children with an ASD in their sample remained intact, indicating that most marriages survived despite having a child with an ASD. A similar contention is also shared by Ooi et al (2016), in that in many of the cases they reviewed, most marriages remained intact and or strengthened further.

Mesfin and Ahmed (fathers), explained that minor arguments in the process of caring for the child might arise, which did not lead to serious consequences. Excerpts:

While I want to make him stop displaying his repetitive acts, my wife tells me not to bother him. We do not have serious problems, but from time to time some issues may arise that will lead to arguments. (Mesfin)

Because we do not know what he wants, what I assume he wants might differ from what his mother assumes, and at times this could be a ground for arguments (Ahmed).

One of the participants of this study, however, reported that her marriage was at risk as a result of her child's condition. Birtukan, a mother, said:

My husband is saying that he can no more handle the stress and the depression caused by our son's autism. He always threatens to leave us. He complains that he can no longer withstand the pain that he feels when he sees our son hurting himself and his siblings. I know that my marriage is in danger. I feel so helpless.

Another very important part of a couple's relationship is the relationship they have with their family members. As confirmed by Meron (2006), families having children with autism tended to have lower self-esteem as their children's disability could bring not only sorrow and worry but it also could be a blow to their confidence. For Teiba, the source of her familial

problem does not arise from family members or siblings, but rather from the domestic workers who are also part of the family:

Our family understands our child's conditions and they love him; we do not have a problem in that regard. However, it is very difficult to keep house maids for long. Because they get easily irritated with my child's behaviour. They take his misdeeds as misbehaviour and hit him when we are not around. So, most of the time, I have to stay home and take care of my son.

Ahmed, a father, also narrated how he shares Teiba's distress:

My son breaks things at home and this could be very irritating to the maids. At times, they may hit him so hard and we would not have any information about it since he cannot communicate.

3.6. The Cost of Autism

The cost of autism comes in many forms. In relation to finance, strains placed on parents as additional expenses incurred for the care of the child and potentially missed opportunities, such as employment, are two of the impacts. With this in mind, respondents were asked to explain changes that occurred as a result of parenting a child with autism.

Contrary to expectations, not all respondents felt financial burden due to having a child with autism. However, most (five out of eight) of the participants agreed that they had financial strains caused by their children's autism. For Teiba, for example, it was the medical expenses that outweighed the rest:

My son does not communicate how he feels when he is sick. So it is difficult to take care of him at home; we always take him to hospital whenever we think he is sick. We buy medications as prescribed by the doctor' but, he refuses to take them and he could splash the syrups. It is always a waste to try to give him medicine...and that could get very expensive.

For Kidist, the cost is her child's extra demands. Extracts:

He has a few more demands than my other children do because of his conditions like wanting special foods and toys. For example, if I am preparing meat for my other children, I should prepare fish for him. If I have to give them macaroni, I have to look for a

substitute for him and so on. Also, he breaks several household items. And all these entail financial burdens.

Another concern that comes with having a child with autism is the possibility of reduced family income. If both parents used to work, they may decide that it would be better for the child if one of them stays to care for the child. The consequence is depending on one source of income as opposed to two (Olson 2010; Ooi et al. 2016). This assertion is also true for the participants of this study. Here is a quote from Mesfin.

My wife used to work before we found out that our child had autism. But now, since she is not working, we have to depend on only my income for our expenses. So, experiencing some financial problems is inevitable.

Most of the other parents shared this experience. *“I used to have a small business of my own, but I had to quit it in order to be able to take care of my son”*, Hiwot indicated. Neima also said, *“I cannot work; because there is no one else to take care of my child”*. There was a situation where a father did less work than before. Ahmed explained that he did not work as much as he did before. He further indicated that the income the family used to earn from renting out an extra house had stopped since he and his wife converted the house to a centre for children with autism. *“Currently, I cover most of my expenses from my savings”*, said Ahmed regarding the loss of income.

3.7. We Need Help

Parents underlined that, apart from the challenges they bore on the personal, social, marital, familial, professional, and financial aspects of their lives, they also encountered problems in accessing facilities and services to address the needs of children with autism.

In relation to facilities, transportation was highlighted. Mesfin, a father, faced challenges of *“...transporting my child from home to the centre, and from the centre back home, because he could be difficult to manage, at times, and he might disturb other people”*. Most parents also stressed on the need to avail facilities such as autism centres, transportation services and priorities in health care services. Ahmed said:

We know that there are vast lands inside government schools. It would have been great if, at least, 500m² could be devoted to establishing autism sections in each of the public schools. ... Also, it is very difficult to transport these children from place-to-place because of their behaviour. If public schools that are found in each sub-city have such centres, it would be convenient for families who have children with autism.

The following quote from Kidist conforms to Ahmed's:

I wish their rights as citizens to be able to access education could be protected. I wish there were some arrangements that would give priorities to address their needs in clinics and health centres and transport services....

Availing recreational facilities for children with autism was also mentioned by the parents. Scarcity of facilities that address the needs of children with autism was mentioned as a challenge by other researchers as well (Ooi et al. 2016; van Tongerlo 2015). Despite the absence of these facilities, parents were still struggling with their children's conditions in their own ways.

4. Conclusion and Recommendations

The study explored the experiences of parents in raising their children with autism. The data revealed the existence of lack of awareness about autism on the part of society, and the attribution of autism to sickness, curse, punishment for parents' misdeeds, and negligence during pregnancy. Due to this lack of awareness, families feel alone and the children isolated. Sometimes, parents, especially mothers, are pitied on, which creates discomfort. This is compounded by lack of support provided to children with autism and parents such as necessary services and facilities.

Most mothers had to quit work to take care of their child with autism, cut on their social lives, and put aside their personal interests. They thought that only they understood the needs and concerns of their children with autism and thus, in many cases, took the care work single-handedly and diligently. This burden of care in the absence of information, sufficient health care services, appropriate interventions, and facilities, put mothers under a lot of pressure and stress.

In order to address problems related to parenting a child with autism and reduce social stigma, efforts need to be made to educate the public about autism through media and awareness-creation events about autism. Supportive services, such as public autism centres, transportation services and different intervention programs for both parents and children with autism, need to be made available. Since mothers disproportionately bear the burden of raising a child with autism, fathers need to be encouraged to share proportional responsibilities for the care of their child with autism. Organizations need to consider creating part-time job opportunities for mothers of children with autism to enable them fit in their caring tasks along with their employment. This, in addition to giving them respite from the stressful care of their child with autism, earns them income contributing to family wellbeing, which feeds into community wellbeing and development. Creating access to education and training for children with autism and providing opportunities for employment will help them to become independent, thereby reducing the burden on society.

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