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Experiences and perceptions of parents raising children autism

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Abstract

The prevalence of autism spectrum disorder (ASD) in general and autism in particular is on rise globally and the need for evidence-based intervention and care for children with autism has grown, too. However, evidence on autism is scanty in developing countries including Ethiopia. With the aim to help fill the gap and paucity in research into the issue, the main purpose of this study is to explore, better understand, and document the experiences and perceptions of parents of children with autism. To this end, we used qualitative survey to collect data from a convenient sample of parents raising a child with autism. The data collected were subjected to qualitative analysis that yielded several themes and subthemes including late diagnosis, parents' reactions to diagnosis, sources of information during and after diagnosis, differing reactions to having a child with autism from siblings, extended family members and the larger community, attribution of autism to several causes by the community, lack of recognition and open discussion of autism and lack of appropriated public educational and health care services for children with autism and their parents. The themes and subthemes identified were discussed in light of existing literature and implications for practice were drawn.

Keywords: ASD, autism, children with autism, raising children with autism

Introduction

Autism is a complex neurodevelopmental disorder with a wide range of differences among individuals having the disorder that affects a range of individuals' functioning. It is one of the five subtypes of pervasive developmental disorders encompassed by autism spectrum disorder (ASD). The five pervasive developmental disorders included under ASD umbrella are autism, Asperger's syndrome (AS), childhood disintegrative disorder, pervasive developmental disorder-not otherwise specified and Rett Syndrome (Christensen, Braun, Baio, & *et al.*, 2018; Kalash & Olson, 2012) ^[9, 20]. Autism as a developmental disability is diagnosed based on three areas of disorder as defined by the American Psychiatric Association (APA) in the DSM-IV such as qualitative impairment in social interaction, qualitative impairment in communication and restricted, repetitive and stereotyped patterns of behaviors, interests and activities (APA, 2013) ^[2]. No distinction is made between ASD and autism in general public (Ooi, Ong, Jacob, & Khan, 2016) ^[25] and they are used interchangeably in some literature (e.g., Glazzard & Overall, 2012) ^[14].

Autism is not widely known among the larger public in Ethiopia. To the best knowledge of the authors of this research, it does not have clear expression in local languages widely spoken in Ethiopia. Media, academicians, practitioners and parents of children with autism simply call it autism.

Globally, the prevalence of ASD in general and autism in particular is on rise (Glazzard & Overall, 2012; Ruparelia, *et al.*, 2016) ^[14, 27] with one in 88-100 children have been diagnosed with ASD (CDC, 2013; Glazzard & Overall, 2012) ^[14]. Although ASD occurs both in boys and girls, it is more common among boys than girls (Christensen, *et al.*, 2018) ^[9]. ASD also occurs in all racial, ethnic and socioeconomic groups though its prevalence is likely to vary across groups (Hewitt, *et al.*, 2013) ^[19]. Its cause is not yet clearly understood but it is generally thought that autism is caused by a mixture of genetic and environmental factors (Hewitt, *et al.*, 2013) ^[19]. Studies show that people, including parents of children with autism, erroneously attribute autism to several genetic and environmental factors including parental weakness (Altiere & von Kluge, 2009) ^[4].

Currently, there is no medical test such as a blood test, brain scan or other neurochemical test to diagnose ASD in general and autism in particular (Hewitt, *et al.*, 2013) ^[19]. For this reason, professionals rely on comprehensive psychological and behavioral evaluations such

as clinical observations, parent-reported developmental and health histories, psychological testing, and speech and language assessment (Hewitt, *et al.*, 2013) ^[19] making the identification and diagnosis of autism difficult for professionals and for parents as well.

Parenting is a challenging yet a rewarding undertaking. Parenting a child with autism is much more challenging and taxing. Parenting and caring for a child with autism is not a limited time duty and responsibility as with a typical child. It is a lifelong journey that begins with the diagnosis process or even before that. Studies show that parents and caregivers of children with autism face a multitude of multilayered challenges that extend from personal emotional well-being to community participations and relations. At a personal level, raising and caring for a child with autism jeopardize parents' and caregivers' emotional-wellbeing. For instance, parents who care for children with autism are more stressed, anxious, and depressed than parents who raise typical children (Fewster & Gurayah, 2015; Gomes, Lima, Bueno, Araujo, & Souza, 2015; Helen, 2016;) ^[13, 16, 18]. In particular, mothers of children with autism face multiple stressors that put their emotional well-being at-risk (Omar, Ahmad & Basiouny, 2018) ^[24]. At interpersonal level, raising children with autism interferes with family dynamics endangering the relations and interactions between and among family members (Bashir, Bashir, Lone & Ahmad, 2014; Begum & Mamin, 2019; Devan, Vajaratkar, Strik-Lievers & Patel, 2012) ^[7, 8, 12] leading to family dysfunctions such as conflict and divorce. At community level, children with autism and their families, particularly mothers, most often face explicit and implicit discriminations and stigma (Agyekum, 2018; Gobrial, 2018; Grasu, 2015; Oprea & Stan, 2012) ^[3, 15, 17, 26] that may stem from wrong societal beliefs about autism and negative attitudes toward children with autism and their families.

Handling the diagnosis of autism is one of the most difficult challenges for the whole family in general and for parents in particular though their reactions to it differ greatly (Glazzard & Overall, 2012) ^[14]. The journey of the diagnosis of autism is not only a long but also it is an ambiguous process and thus presents unique challenges and stressors to the families of children with autism (Altiere & von Kluge, 2009; Kocabiyik & Fazlıoğlu, 2018) ^[4, 21].

Unquestionably, early diagnosis and intervention are important factors for positive functional outcomes in children diagnosed with autism for efficaciousness of an intervention is highly dependent on the timing of diagnosis and intervention. Therefore, early detection and identification of children with autism is crucial for early intervention and helping the children reach their developmental potential (Marlow, Servili, & Tamlinson, 2019) ^[22]. In fact, 18 months is an ideal age for autism check (Glazzard & Overall, 2012) ^[14] though delay in diagnosis and then in treatment is not uncommon even in developed countries (Kalash & Olson, 2012) ^[20]. Delay in identification and diagnosis of children with autism is particularly common in Africa (Ruparelia, *et al.*, 2016) ^[27] and autism is not well recognized as a public health problem in Sub-Saharan Africa for that matter (Abubakar, Ssewanyana, & Newton, 2016) ^[1]. Mostly due to lack of adequate awareness among the public and health care personnel, small number of specialists diagnosing and managing children with autism and lack of validated tools of screening children suspected for autism, most children with

autism in Africa are either not diagnosed or diagnosed too late (Ruparelia, *et al.*, 2016) ^[27]. Overall, Antezana *et al.* (Antezana, Scarpa, Valdespino, Albright, & Richey, 2017) ^[5] concluded that screening, diagnosis and intervention of children with ASD is surrounded with various barriers particularly in rural areas.

Diagnosis of autism is stressful to parents and other family members in one way or the other and most parents react to it negatively. In other words, upon learning the result of their children's diagnosis of autism, most parents have mostly negative emotional responses such as shock, despair, anger, resentment, denial, sadness, unhappiness, helplessness, feelings of loss and devastations and confusion among others (Altiere & von Kluge, 2019; Ooi, *et al.*, 2016) ^[4, 25] that stem from dealing with the diagnosis and associated symptoms (Gomes, *et al.*, 2014) ^[28] and are exacerbated by lack of appropriate debriefing following diagnosis (Ruparelia, *et al.*, 2016) ^[27] and poor access to health care services and social support (Gomes, *et al.*, 2014) ^[28]. Even after diagnosis, parents particularly mothers of children with autism continue to face challenges such as economic and financial burden (Obaigwa & Cloete, 2019) ^[23], lack of access to adequate health and educational services for their children (Gobrial, 2018; Grasu, 2015; Kalash & Olson, 2012; Obaigwa & Cloete, 2019) ^[15, 17, 20, 23] and lack of information and social support (Altiere & von Kluge, 2009; Helen, 2016; Gomes, *et al.*, 2014; Grasu, 2015; Kalash & Olson, 2012) ^[4, 18, 28, 17, 20]; studies persistently show that families of children with autism do not get sufficient social support from people around including their family members in their endeavors and struggles to help their children (Glazzard & Overall, 2012; Helen, 2016; Kalash & Olson 2012; Obaigwa & Cloete, 2019) ^[14, 18, 20, 23] which exacerbates the stress that having a child with autism has already posed to them. Moreover, social stigmatization and marginalization of children with autism and their families that might have originated from lack of awareness and understanding of autism on part of the larger public further complicates raising children with autism which is demanding and challenging in itself. Overall, parents of children with autism are required to deal with all direct and indirect demands and challenges that having a child with autism brings with it (Autism Speaks, 2018) ^[6].

Emerging research revealed that autism in general and parental experiences of raising children with autism in particular has become a topic of concern and interest. While issues related to autism including parenting of children with autism have been extensively researched internationally, autism and auxiliary issues including raising and caring for children with autism have received no or little research attention in developing countries (Desai, Divan, Wertz & Patel, 2012) ^[11]. In fact, Africa is lagging behind in autism research and evidence base is too scanty to support autism intervention and treatment in Africa (Abubakar, *et al.*, 2016) ^[1] and research on ASD in the continent is concentrated in South Africa and Nigeria. Generally speaking, paucity of research and low professional knowledge and understanding in issues pertaining to ASD in Africa in general and Sub-Saharan Africa in particular is outstanding. With the aim to help fill the gap and paucity in research into the issue, the main purpose of this study is to explore, better understand, and document the experiences and perceptions of parents of children with autism. By so doing, we aim to lay foundation for evidence-based intervention and tailored health care and

educational services for children with autism and their families in Ethiopia and beyond.

In order to achieve the purposes put forth, this research sought to answer the following research questions:

1. How do parents deal with having and raising a child with autism?
2. What are the experiences and perceptions of parents of children with autism in their journey of raising children with autism? How are they impacted by having and raising children with autism?
3. What information and supports are available to these parents?
4. How do siblings, close relatives, friends and the community around react to having and raising a child with autism?
5. How is autism perceived and understood by the

society? What about its cause?

Methods and Materials

Research Design

We employed a qualitative research design to examine the experiences and perceptions of parents who raise a child with autism. Using a phenomenological approach and design, the authors explored, uncovered, and gained a better understanding of the unique experiences and perceptions of parents of children with autism in their journey of raising their children.

Participants

Table 1. Below summarizes key characteristics of the participants of this study along with sex and ages of children with autism cared for.

Table 1: Key characteristics of the study participants

No	Relationship to the child	Respondent's sex	Respondent's Age	Respondent's level of education	Child's sex	Child's age
P01	Mother	F	40	College Diploma	F	9
P02	Mother	F	48	Bachelor degree	M	18
P03	Mother	F	38	Bachelor degree	M	6
P04	Father	M	33	Bachelor degree	M	8
P05	Mother	F	32	Primary	F	-
P06	Mother	F	45	Bachelor degree	F	13
P07	Mother	F	36	College Diploma	M	11
P08	Mother	F	40	Secondary	M	12
P09	Mother	F	48	Secondary	F	22
P10	Mother	F	38	Secondary	F	20
P11	Father	M	52	Secondary	F	12
P12	Mother	F	27	Master's degree	M	4
P13	Father	M	48	Secondary	M	14
P14	Mother	F	46	Some tertiary	F	15
P15	Mother	F	67	College education	M	43
P16	Mother	F	48	Bachelor degree	F	13
P17	Mother	F	60	Secondary	M	22
P18	Mother	F	-	Primary	M	14
P19	Mother	F	38	Secondary	M	13
P20	Father	M	58	College Diploma	M	18
P21	Mother	F	38	secondary	M	13

Twenty-one respondents completed the qualitative survey dispatched. Vast majority (about 80%) of the participants were mothers who were caring for their child with autism. Age of the participant parents ranged between 27 and 67 years (Mean Age = 44.00 years; Standard Deviation = 10.02 years). Ages of children with autism cared for ranged between 4 and 43 years (Mean Age = 15.00 years; Standard Deviation = 8.17 years). Majority (about 62%) of the children with autism cared for were boys. About half (50%) of the participant parents had college diploma or better. About 40% of them had some secondary education and the remaining participants (About 10%) had some primary education.

Instrument and procedure of data collection

Based on a thorough literature review, we developed a qualitative survey questionnaire that contained some twenty questions including the questions that were used to capture demographic characteristics of both parents and children with autism. We used highly open-ended questions that asked the participants to provide written accounts of their lived experiences and perceptions of raising a child with autism. The open-ended questions used revolved mostly around diagnosis of autism, availability of sustainable

information and support to parents and their children with autism and impacts of having a child with autism on parents. The questionnaire was initially written in English by the first author, translated into Amharic by the second author and then reviewed by the first author. Eventually, the questionnaire was administered in Amharic to help participants understand the questions presented to them properly and provide rich and accurate data.

The questionnaires were dispatched to a convenient sample of parents through the Joy Autism Center. Joy Autism Center is one of the very few local non-government organizations based in Addis Ababa that provides integrated health care and educational services to children with autism and their parents. The participants were allowed to take questionnaires home with them and asked to drop the questionnaires at the center throughout the week to allow them enough time and provide as much response to each open question as they could. Only parents of children with autism enrolled at the center's school, who can read and write, participated in this study. Overall, 26 questionnaires were dispatched and 21 collected back leading to a response rate of about 81%.

Ethical considerations

In the first place, permission to conduct the study was

sought from Joy Autism Center before participants were contacted. Participation in this study was completely voluntary and oral consent was obtained from the respondents. The purpose of this research was explained to the respondents in the questionnaire and orally as well. Participants were assured that the information they provide would be kept confidential.

Data Analysis

Analysis of the data collected was guided by the research questions stated and findings were organized around main questions presented to the participants through the questionnaire. Responses given by each participant to each question were read and reread carefully and translated into English. Where possible, similar responses were counted and described in percentages or figures. Overall, data were analyzed thematically using the questions in the questionnaire as preset themes and then supported by quotes and excerpts from selected responses provided.

Findings

Diagnosis

One of the questions posed to the participants through the qualitative survey revolved around initial identification and diagnosis of children with autism. Careful analysis of their responses to this question yielded three subthemes pertaining to diagnosis: Age at first diagnosis, parents' initial reaction to the diagnosis, and appropriateness of the age at which diagnosis was received.

Age at first diagnosis

Participants were asked about the age at which their child received first diagnosis. Almost all of them (95%) reported diagnoses between 2 and 6 years of age. Only one mother reported that her child received first diagnosis very early at four months of age. In addition to age at first diagnosis, participants were asked to elaborate on what signaled them to seek the diagnosis and the process they had gone through. They mentioned different reasons as to why they sought help including lag in growth, delay or regress in language and communication, lack of age-appropriate concentration and communication, hyperactivity, bizarre and unusual behaviors, self-isolation, self-talk, physical sluggishness, etc. Delay or regress in language and communication was frequently cited by the parents as a reason as to why they started the process of the diagnosis as illustrated by the excerpts below:

Until one year and seven months, she used to say 'baba'; she used to say 'Chao' when going to sleep; she used to call all family members by their names in a baby language; she used to pretend on a cellphone. All of sudden, she stopped talking and all what she used to do; once upon a day, she began to cry out of nothing; this continued for a month especially during night; we were then scared and took her to a doctor; this was how we could come to know that she's autism. (A 40-year old mother).

His growth was slow compared to my first child; he couldn't start walking on time; he couldn't talk and he lacked concentration (A 48-year old mother).

He showed delay in walking and talking; so, we took him to a physician (A 38 year old mother).

At the age of two years, she's non-verbal; she used to show unusual behaviors mainly hyperactivity (A 45-year old mother).

He showed odd behaviors compared to children of his age in our neighborhood; he also showed delay in language; he remained aloof and failed to make friends; attachment with a single item or toy; repetitive behaviors and actions and repetition of certain words. As a result of these, we were prompted to visit a physician (A 36-year old mother).

Since she couldn't talk even at the age of four years, we took her to a neurologist; the neurologist told us that she's ok but directed us to a psychiatrist; there, we were told that she had no problem but they referred us to Joy Center where she was diagnosed with autism and could enroll for schooling (a 52 year old mother).

My child never talked; he's aloof; he has got a certain problem in his legs; I then consulted a friend who advised me to visit a physician; I then visited a pediatrician; the pediatrician referred me to a neurologist who eventually told me my child is autistic (A 27 year old mother).

My son A. has suddenly started to display strange behaviors after three years of age; he cries when a certain home furniture is moved from its place; he began to talk alone; he's extraordinarily hyperactive; after sometime when the symptoms became apparent, we took him to a physician; this is how we could learn he has got this problem (A 48 year old father).

Since her older sister was totally disabled, we were observing this one's growth closely. Overtime, we could observe that her growth deviates from normal growth. We then took her to different hospitals. At first, it was suspected that she has got ear problem and even hydrogen drop has been poured into her ears with no changes; eventually, she has undergone CT scan and we were told that she's autistic (A 46 year old mother).

Appropriateness of the age at which the diagnosis was received

More than a third (about 38%) of the parents studied felt that the diagnosis was not received at appropriate age and should have been done earlier.

A mother who seemed to recognize the importance of early diagnosis and intervention regrettably stated that:

I am of the opinion that the diagnosis was not received at appropriate age. Based on my current understanding, I feel that if the diagnosis was received earlier, a lot of damages would have been avoided or at least reduced. For instance, she could have talked; she could have been enrolled in mainstream schools which might have helped her improve a lot (A 46 year old mother).

Another young mother added that "I think it was a little bit late; I was a little bit late to take him to a physician; his delay in talking was taken as normal for it is said boys talk late compared to girls" (A 27 year old mother).

A middle aged mother who thought she lacked knowledge of autism expressed that "she didn't receive it at appropriate age; since I didn't know about autism, I feel that I didn't take her to a physician at the right age" (A 48year old mother).

A sixty year old mother echoed similar view: "We began the process too late; this was because of the fact that we didn't have knowledge of autism at that time" (A 60 year old mother).

Three mothers expressed their regret of late diagnosis of their children as follows:

It was not received at the right age; it should have been received earlier; I visited several hospitals and no one told

that he has got autism (A 38 year old mother). It would have been better had it been received earlier; hoping that things would get better overtime, we delayed it until the age of four years (A 38 year old mother). If I would have been able to know his problem earlier in infancy, he could have been cured through medication (A 40 year old mother).

Almost all participants who reported that the diagnosis was not received at the right age attributed the delay in diagnosis to lack of knowledge and awareness about autism on part of the parents. One participant stated that lack of competent professionals in the country is a challenge to parents, however. One more participant attributed late diagnosis of her child to irresponsiveness to her child's symptoms as "Hoping that things would get better overtime, we delayed it until the age of four years" (A 38 year old mother).

On the other hand, about a third (about 33%) of the participants felt that the diagnosis was received at the right age as epitomized by the excerpts below:

As soon as I observed he has got a certain problem, I promptly endeavored to get help from a physician (A 67 year old mother).

She received the diagnosis at the right age. But, she couldn't enroll in appropriate special education until the age of seven years. She was entrusted to mainstream school until the age of seven (A 45 year old mother).

I believe that he received the diagnosis at appropriate age; but, I feel, since he is my first child, I might have lacked parenting experience and skills; once we have known that he has a got a problem, it took us longer to believe and accept the problem and seek help [intervention] accordingly (A 36-year old mother).

Once we have observed changes in his behaviors, we have taken him to a physician for diagnosis; so, there's no problem in this regard (A 38 year old mother).

Parents' initial reaction to the diagnosis

Parents' initially reacted to their child's diagnosis with autism in two different ways. About a third of the participants (about 33%) reported feelings of disbelief, denial, helplessness, despair, complete shock, sadness, self-blame, worrisome, heartbroken and anger as illustrated by the following excerpts from their responses to the qualitative survey:

Both of us (I and her father) were heartbroken and lost hope by the incident. We were hoping to see the recovery of our first daughter at that time; on top of that we were sorrowful of our youngest daughter's cardiac problem. It was really difficult for us to believe and accept the result of the diagnosis (A 46 year old mother).

When the physician told us that the result of the diagnosis was not good, I was terrified and I cried a lot. (A 48 year old mother).

We refused to accept the result saying that this couldn't happen to us. It was difficult to believe and accept the result for us. We were shocked, upset and cried. I isolated myself from people around me. I blamed myself for what happened (A 36 year old mother).

My first reaction was a complete shock; when I realized that it is incurable and its cause unknown anyways, it was difficult; I asked myself what I should do; what should be done. I was preoccupied with endless questions; I was distressed but, at the end I accepted it believing that it's from God (A 48 year old mother).

Sadness because I had no idea about autism at that time; for

some time, I was distressed and it was very difficult for me (A 38 year old mother).

Some parents were indifferent to their child's result of diagnosis may be due to lack of knowledge about autism or else they were not fully informed and even misinformed about the result of the diagnosis.

We were not disturbed by the result of the diagnosis; we were at ease and we began to ask and read about autism and its cause (A 52 year old father).

Since I didn't have any knowledge of autism at that time, I felt nothing; it was my first time to hear about autism. I was indifferent about my child's being autistic for I lacked knowledge of autism and I thought it's curable (A 27-year old mother).

We had no idea about the disease [autism]; we asked what it is and whether or not it has medication and treatment (A 58 year old father).

They told us she has got autism but we didn't understand what it's (A 40 year old mother).

At the beginning, they told us the child has special IQ; they didn't tell us he's got autism (A 48 year old father).

Information and support is of paramount importance to parents and caregivers of children with autism throughout the journey of caring for children with autism. As such, we posed some questions that asked the parents the extent to which they have been offered information and support during and after diagnosis process. Three subthemes emerged from their responses to these questions: Availability of information and support during the diagnosis process, availability of additional information and support after diagnosis, and additional sources of information and support.

Availability of information and support during the diagnosis process

Vast majority of the participants (about 76%) have reported having been offered some sort of information and support at the time of the diagnosis by the professionals making the diagnosis.

Yes, we were offered some sort of information. We knew nothing about autism before; the professional who made the diagnosis has given some information about autism which has helped us in some way (A 38 year old mother).

The physician who diagnosed our child has provided my husband with good explanation and information; he/she has then directed us to concerned center; the center has confirmed the diagnosis and enrolled our child to their school; the center has helped us and our family to know a lot of things about autism that we never knew before (A 46 year mother).

The physician told us that our child has got autism and then referred us to Joy Center (A 45 year old mother).

The physician told us that the child's diagnosis result shows that the child has got autism; she/he went on advising us that the child can improve if he has happen to get adequate care and support (A 52 year old father).

Yes, we were given advisement; the doctor told us the child needs close follow-up and support; she/he then has given information about and directed us to an autism center (A 48 year old mother).

On the other hand, few participants (about 20%) reported not having been offered with information and support at the time of the diagnosis by the professional making the diagnosis. For instance, one father witnessed that "neither

information nor support was offered; and even the information offered was confusing” (A 48 year old father).

Availability of additional information and support after diagnosis: Most parents (about 52%) reported having been offered information and support after the initial diagnosis mainly from their doctors and autism centers as illustrated by the quotes below:

Yes, we were given; Joy Center is keeping us informed about autism. (A 38 year old mother).

Yes, Joy Center is supporting us through its educational and behavioral intervention programs (A 46 year old mother).

The doctor explained to me my child needs special care; he/she advised me to google to get additional information regarding autism and directed me to Joy Center (A 27 year old mother).

Yes, we joined Nia Foundation where we are getting support and information (A 60 year old mother).

She is enrolled at Nia Foundation School where we get educational service and other supports (A 40 year old mother).

After initial diagnosis, she joined Joy Center where she is receiving special education and extensive support; and we have seen tangible improvement (A 52 year old father).

We took her to Joy Center when she was three; there, she’s received additional diagnosis confirming the previous diagnosis; but, due to lack of place, she’s put on waiting list until the age seven without proper educational service (A 45 year old mother).

Additional sources of information and support

More than two-third (about 70%) of the parents reported having received information and support from other additional sources of information and support. Sources of information and support often listed by parents who reported having received information and support from other additional sources of information and support include, Joy autism center, parents of children with autism, school, other family members, books, media, friends, internet, and social media among others. Surprisingly, health facilities and professionals were not reported by a single participant as an additional source of information and support for families who are caring for children with autism implicating that developmental disorders in general and autism in particular is not mainstreamed into maternal and child health and care subsector.

Impact of caring for child with autism on caregiver’s relationships

More than a third (about 38%) of the participants felt that their relationships with other people around them (spouse, other children, other family members and close friends) suffer due to the time devoted to caring for their child with autism. Some participants (about 29%), however, felt that their relationships with other people around them (spouse, other children, other family members and close friends) do not suffer due to the time devoted to caring for their child with autism. Those parents who felt that their relationships with other people around them suffer due to the time devoted to caring for their child with autism mentioned different ways as to how their relationships are affected:

People around me accuse me of pampering and spoiling her; they push me to beat her; they blame me for all her misbehaviors; they don’t understand me and my child; as a

result of this, sometimes our relationships go wrong (A 48 year old mother).

I devote all my time and attention to her; as a result, other family members don’t get the time and attention they deserve (A 45 year old mother).

When you try to devote all your time to properly care for your child with autism, your family might be at risk; your marriage might be at risk; other children are forgotten (A mother with 14 years old boy with autism).

We don’t have time to socialize and to properly care for our other children; we don’t quality time for ourselves and we don’t care for ourselves (A 46 year old mother).

They always tell me that she disturbs and misbehaves when I am around; but, I don’t hear them; I don’t allow anyone to touch her; I am highly permissive when it comes to her. All around me object me saying that it’s me who spoiled her; they are not understanding and annoys me a lot (A 48 year old mother).

Siblings’ reaction to having a child with autism

Three parents reported that their child with autism has no sibs. Nine out of 18 parents felt that their other children were not okay with their child with autism. Five parents said that their other children were sad with their child with autism. One mother said her other children “feel bad deep inside”; they always ask what should be done”. Another mother remarked that “they used to fear and stigmatize him; but, now they are good with him; they love him; they play with him; they include him in their play”. Another mother of 22 year old girl with autism added that “They feel inferiority; they are ashamed of her; but, not to dismay me they remain silent they feel bad inside; they don’t want to take responsibility about her; they seem to think as if I am the only responsible person to care for he”.

On the other hand, seven parents expressed that their other children have a loving and caring relationship with their child with autism as the quotes hereunder demonstrate:

“They feel nothing bad rather, they are always curious to know why their sister is the way she’s; they care for her” (A52 year old father).

He is their youngest brother; they know that he needs special care and support; they love him very much; they are not disappointed at or ashamed of him because he is autistic; they call him our special brother for that matter; they introduce him to their friends confidently (A 38 year old mother).

My other children feel nothing; they try hard to care for her; now days, she is seen as a special one; she has become the beauty of our home; we all enjoy her talks, dances and her everything (A 48 year old mother).

His sister loves him very much; she offers him a lot of love, care and support (A 67 year old mother).

Reaction of extended family to a child with autism

The reactions of extended family differed greatly. Six parents reported that their extended families ‘sympathize’ with their child with autism. Five parents reported a positive reaction from their extended family members. They described the reactions from extended family with one or more of the following qualities: helpful, understanding, loving, supportive, and encouraging. Four parents reported a negative reaction from their extended family members. They described the reactions from extended family with one or more of the following qualities: blameful, unhelpful, and

avoiding. For instance, a 48 year old mother expressed the negative reactions from extended family as “They try to blame us for the incident; they think that it is inherited; those from my side blame it on her father; those from her father’s side blame it on me; they point fingers to each other”. Another mother added that “they point their finger at us; they stigmatize us as if we are part of the problem”.

Two parents reported extended family as indifferent- neither understanding nor helpful. Yet, two parents were of the opinion that the reaction of extended family depends on their level of knowledge and understanding. They felt that extended family members who have some knowledge of autism are understanding and helpful but those who don’t have knowledge about autism are judgmental or indifferent.

Reaction of community members to a child with autism

As with extended family reaction, community reaction seemed to be mixed, some positive and favorable, some negative and unfavorable and yet others ambivalent. Seven parents reported mixed feelings about the community members’ reactions to their child with autism. Specifically, they felt that while some community members are understanding and helpful and others are avoiding and indifferent as exemplified by the excerpts from their responses given below:

It’s difficult to say the community has enough understanding of autism, but there are some community members who have some understanding of it and who try to help at times (A 38 year old mother).

There are some community members who have unfavorable attitude towards children with autism and their parents; there are also some who try to understand our situation; they try to comfort and encourage us; even there are some people who advise us to try some traditional and religious healings (A 48 year old mother).

Most of the community members don’t understand autism including its name; they confuse autism with mental retardation; Although they don’t understand it, most people are helpful; they sympathize with us and try to help us; for instance, in public transportation they give us a way; they leave seats for us; they advise us to try holy water, prayer, witch doctors, etc. from good faith (A 46 year old mother).

Our community’s understanding of autism was very poor; but, now they have begun to understand though not enough (A 58 year old father).

People differ in their attitude toward children with autism; some are helpful and others are not helpful (A 40 year old mother).

Six parents reported that their community is compassionate but they don’t know how to help. For example, one mother expressed that “most community members feel sorrow upon coming across our children with autism”. Another mother added that “they compassionately ask to know about the problem”.

Two parents reported that their community is not understanding but rather judgmental as witnessed by the quotes:

“They see my child with autism as if he is a unique and weird creature” ((A 40 year old mother).

“They see us as a needy, loser, and helpless; they give us lip service.” (A 36 year old mother).

One participant complimented her neighbors as “my neighbors love my child with autism very much; they are happy with her way of talking and other manners.”(A 48 year old mother).

Recognition of and open discussion about autism

More than half (about 57%) of the participants felt that autism is not recognized and openly discussed in their culture at all. For instance, a 48 year old father of 14 year old boy with autism expressed that “autism is not known at all; in Ethiopian culture, let alone open discussion about autism, its name is not known at all”. Another mother of 15 year old girl with autism who believed that parents of children with autism should play their part in awaking their community stated that “our culture doesn’t allow us to openly and boldly discuss about autism; most of us are not understanding but rather we tend to be judgmental; so, we need to defy the culture and use our children with autism to teach our community to open door for open discussions about autism wherever we go.”. A 33 year old father of 8 year old boy with autism added that “no open discussion about autism and I feel that extensive educational program needs to be put in place to open up open discussion about autism”.

A 36 year old mother of 11 year old girl with autism had to say that “autism is not recognized at all; the word autism is not known for that matter; children with autism are not different from normal ones in their appearance; so, they are misperceived and misunderstood as a rude, disobedient, spoiled and ill parented children; I suppose we need to do a lot to create better awareness in the larger public...”. A 52 year old father of 12 year old girl with autism, a 38 year old mother of 13 year old girl with autism and a 45 year old mother of 13 year old girl with autism all echoed that “autism is not widely known and openly discussed in their culture and wished that the wider community has adequate awareness about autism”.

On the other hand, four participants (about a fifth) reported that autism is being recognized and openly discussed in the wider community to some extent as illustrated by these quotes:

To some extent, people discuss about autism; people are open to know about autism now than before. (A 38 year old mother).

Some public agencies make discussions about autism at times; I hope, there will be more discussions and solutions for the problem in the future. (A 40 year old mother).

There are some discussions but not enough given the size of the problem (A 40 year old mother).

Two more parents responded that they are unsure of the extent to which autism is recognized and openly discussed in their culture. One participant, however, felt that autism is getting due attention and credited Nia Foundation for the progress as “currently, autism is being given a special attention and Nia Foundation’s unreserved effort is a key for the change” (A 48 year old mother).

Community’s thought of the causes of autism

Majority of the participants (about 57%) reported that in their culture the community associates autism with different causes such as devil, evil spirit, evil eye, curse, God’s order, God’s chastisement, sinfulness, heredity, and witchcraft as exemplified by the witnesses below:

Based on their culture, level of knowledge and faith, people attribute autism to several causes. As to me, it comes from God’s order and will. (A 45 year old mother).

Most people associate autism with sinfulness but I don’t believe; the so called educated members of the society attribute autism to inorganic foods, polluted air, vaccination

and mostly to medical errors(A 46 year old mother).

Most people think that autism is caused by evil spirit. (A 48 year old mother).

The society attributes autism to many things; I used to attribute autism to devil or evil eye and so did the society. Believing that autism is caused by devil or evil eye, I used to take my child with autism to holy water. Now, I understood that autism is not caused by devil or evil eye (A 38 year old mother).

Some think it is caused by curse; others think it's inherited from parents and fore parents; no universal thoughts regarding the causes of autism in our society (A 48 year old father).

It is said autism is inherited and transmitted genetically or caused by curse but I don't believe so. (A 27 year old mother).

People associate autism to wrong belief and curse but I don't believe this is true. (A 33 year old father).

People think autism is caused by devil, evil spirit, etc. They often advise me to take my child with autism to holy water. But, I don't agree totally. (A 36 year old mother).

It's said God's punishment for our sins but I don't believe so. (A 38 year old mother).

People think that autism is caused by curse, devil's work, etc. but, we don't believe so since we have got sound understanding about autism. (A 52 year old father).

More than a third (about 38%) of the participants reported they don't know or unsure of what the society thinks about the cause (s) autism.

Independent functioning of children with autism as an adult

Most parents (about 76%) seemed to be pessimistic about their autistic child's independent functioning as an adult without ongoing care as summarized in the quotes below:

Children with autism require lifelong care to function in a society (A 45 year old mother).

I don't believe that children with autism will function independently as adults because they need lifetime support and supervision they can easily be deceived, attacked, and mistreated by others anytime and anywhere (A 46 year old mother).

I don't believe so because their mental development is slow and limited to do so. (A 48 year old mother).

I don't believe that he would function independently in the future; he needs someone's support throughout his lifetime (A mother of 14 year old child with autism).

Two parents seemed to be highly optimistic about their child's independent functioning as an adult. For example, a mother expressed her optimism about her autistic child's future independence as "yes I feel so because I see promising changes in other children with autism; that made me believe so; and I don't lose hope in God's help". A 33 year old father of a child with autism echoed similar optimism in his child's independent functioning and progress as "I fully believe that he would function independently in the future due to the fact that he is getting extensive care, support and close supervision in his early age and we hope that he will improve very well". Yet, two parents seemed to be ambivalent. A 48 year old father remarked that "That depends on the level and difficulty of the problem and the intensity of care and support offered to them". A 67 year old mother of 43 year old son with autism held the view that children with autism who received

intensive care, support and training starting early in life are likely to lead independent life in adulthood with minimum support and supervision.

Access to public education and health care services

Almost all of the participants (about 95%) mourned total lack of access to public education and care services for their children with autism. Regarding this, a 36 year old mother of an 11 year old boy with autism remarked that "we don't have access to public school for our children; there is neither public nor private school that is meant for or that accommodates children with autism; to my knowledge, there are only two NGO based schools that offer education and care services to children with autism and their parents". A 52 year old father of a 12 year old girl with autism also said that "I tried some two public schools but I withdrew my child for they didn't have enough qualified teachers and suitable teaching spaces; in addition, the schools' communities don't have adequate knowledge of and awareness about children with autism". A 46 year old mother of a 15 year old girl with autism explained the reasons why public schools cannot accommodate children with autism as "the public schools around including the so called special needs schools don't have well qualified teachers; they enroll only few students; they even don't care for and support those enrolled properly; they don't have sufficient teaching-learning materials, teaching aids and classroom and school environment suitable for children with autism; above all, their school communities have no idea about children with autism". Overall, all participants, except one mother who said her child is in a public school, reported that their children with autism were getting education and care services from two NGO run schools for children with autism-Joy Center for Autism and Nia Foundation. Almost all parents participated in this study worried about the future of their children and felt that total lack of public health care and educational services for children with autism jeopardized their children's health, development, and learning and their own health. Eventually, participants called for more actions from all stakeholders including the government and collaborations among them to meet the education and care service needs and demands of children with autism and their parents.

Discussion

In this study, we aimed to explore, better understand, and document the experiences and perceptions of parents of children with autism in Ethiopia. To this end, we collected the data required for this study from 21 parents of children with autism using qualitative survey questionnaire. From the data generated, we observed key findings that revolve around several themes and subthemes.

It was observed that diagnosis of children with autism is of profound importance issue in the journey of raising children with autism. As part of this key theme, the present study found out that majority of the children with autism underwent their first diagnosis somewhat late with almost all of the parents (95%) reporting diagnoses between two and six years of age. In addition, more than a third of the participants of this research felt that the diagnosis was not received at appropriate age and they attributed this mostly to lack of knowledge and awareness of autism on part of the parents. These findings are consistent with literature on the diagnosis of autism. In line with this finding, previous

studies consistently show that delay in identification and diagnosis of children with autism is a big obstacle and challenge for parents who raise children with autism (e.g., Kalash & Olson, 2012) ^[20]. In this regard, Marlow *et al.* (2019) ^[22] have stressed that early detection and identification of children with autism is most vital for early intervention and helping children reach their potential. In fact, Glazzard and Overall (2012) ^[14] claimed 18 months as a right age for detection and identification of diagnosis. In consistent with previous studies, this study found that more than a third of the parents studied reacted to the diagnosis of their children negatively entailing feelings of disbelief, denial, helplessness, despair, complete shock, sadness, self-blame, worrisome, heartbroken and anger. For example, in line with our finding, Ooi and colleagues (Ooi, *et al.*, 2016) ^[25] in their meta-analytic review concluded that most parents had mostly negative responses such as shock, despair, and devastation upon receiving their children's diagnosis result. Altieri and von Kluge (2009) ^[4] and Oprea and Stan (2012) ^[26] all reported similar findings. In contrast to previous studies, however, some parents in this research were indifferent to their children's diagnosis result and this might have been due to their lack of knowledge about autism. In fact, Glazzard and Overall (2012) ^[14] concluded that not all parents react negatively to their children's autism diagnosis. Information and support is of profound importance for parents raising children with autism across the journey. In this regard, this research found mixed findings. While most and majority of the participants reported having received adequate information and support during and after diagnosis, respectively, from the professionals making the diagnosis, some participants mourned lack of adequate information and support during and after diagnosis. In addition, organizations working with autism, parents of children with autism, school, other family members, books, media, friends, internet, and social media were reported to have been additional sources of information and support for most parents studied. These findings are partially consistent with the findings of previous studies. In contrast to our findings, lack of adequate information and support from professionals making the diagnosis during and after diagnosis is almost a trend across studies and meta-analytic reviews (e.g., Abubakar, *et al.*, 2016; Glazzard & Overall, 2012; Grasu, 2015; Helen, 2016; Kalash & Olson, 2012) ^[11, 14, 17, 18, 20]. On the other hand, consistent with our findings many prior studies found that parents of children with autism are important source of information and support for each other (Glazzard & Overall, 2012) ^[14]. In addition, books, media, friends, internet, and social media were reported by many studies as valuable sources of information for parents of children with autism (Glazzard & Overall, 2012) ^[14].

Raising and caring for a child with autism affects caregiver's social relations in one way or the other mostly due to the time they devote to their children with autism. In this study, we observed that more than a third of the parents in this study felt that their relationships with the people around them suffered due to the time they spend for caring for their children with autism. This finding converges well with findings of prior research. Literature consistently shows that raising a child with autism is a 24 hour seven-day task (Altieri & Von Kluge, 2009) ^[4] which denies primary caregivers-most often mothers - the time to meet other family and social commitments which in turn tightens

and jeopardizes their family and social relations ((Divan, *et al.*, 2012; Helen, 2016) ^[11, 18]).

We found that having and caring for a child with autism elicits differing reactions from family members and the larger community. While majority of the participants felt that their other children were not good with the child with autism, some felt that their other children were fairly good with the child with autism they care for. This is in line with the existant literature in that siblings of children with autism react to their sisters or brothers with autism in different ways (Autism Speaks, 2018). As with the reaction from siblings and consistent with literature, extended family members react to children with autism positively and favorably, negatively and unfavorably or indifferently (e.g., Kocabiyik & Fazlıoğlu, 2018; Obaigwa & Cloete, 2019; Oprea & Stan, 2012) ^[21, 23, 26]. As with extended family reaction, community's reaction to children with autism and their parents seemed to be mixed, some positive and favorable (Understanding and helpful), some negative and unfavorable (Blameful and judgmental) and yet others ambivalent (Having mixed feelings). In convergence with this, literature shows that most parents of children with autism feel judged, stigmatized and discriminated against by some community members (e.g., Agyekum, 2018; Gobrial, 2018; Grasu, 2015; Helen, 2016; Kalash & Olson, 2012; Oprea & Stan, 2012; Ruparelia, *et al.*, 2016) ^[3, 15, 17, 18, 20, 26, 27] but some others feel understood and supported by community members, neighborhoods, friends and relatives (Kocabiyik & Fazlıoğlu, 2018) ^[21].

As regards recognition and open discussion of autism, while majority of the parents we studied felt that autism is not recognized and publicly discussed in their culture, few were of the opinion that it is being recognized and openly discussed. This finding converges with prior literature. For instance, Chu, *et al.* (2018) ^[10], Grasu (2015) ^[17] and Ruparelia, *et al.* (2016) ^[27] concluded that due to lack of knowledge, awareness and information among the larger public ASD is not widely recognized and discussed publicly in developing countries making raising children with autism very challenging. Regarding the causes of autism, we found that autism was wrongly attributed to different causes such as devil, evil spirit, evil eye, curse, God's chastisement, sinfulness, heredity, and witchcraft among others and this consistent with literature reviewed. The cause of autism is not clearly known but literature shows that people, including parents of children with autism, erroneously attribute autism to several genetic and environmental factors including parental weakness (Altieri & von Kluge, 2009) ^[4]. Finally, almost all parents studied lamented total lack of public education and health care services for their children with autism and for themselves and most of them were highly hesitant of their children's independent functioning as adults in the face of such grave lack of education and health care services. Similar to our observation, many studies reported grave lack of educational and health care services for children with autism particularly in developing countries. For example, Gobrial (2018) ^[15] has observed that lack of educational and health care services is one of the key factors that make caring for a child with autism challenging. Similarly, Grasu's sample (Grasu, 2015) ^[17] disclosed lack of inclusive mainstream schools and schooling. In their study of 14 African countries, Ruparelia, *et al.*, (2016) ^[27] have also documented serious lack of health care services for children with ASD and their families. Gomes and

colleagues' meta-analytic review in Brazil (Gomes, *et al.*, 2015) [16] revealed that poor access to health services and social support is one of the challenges that families of children with ASD in Brazil face. Overall, total lack or low level of access to public services such as education and health services is a common experience of parents of children with autism in developing countries. And such lack of public services not only overloads care givers of children with autism but it also compromises children's overall development to their potential.

Limitations and direction for future research

This research has some limitations that need to be pointed out. In the first place, this research is based on small convenient sample which might have compromised the general liability of the findings of this research beyond the current context. Second, it is based on self-reported data. Third, the data used for research came from parents of children with autism from Addis Ababa who are supposed to be better off in terms of education and access to information. Hence, the findings of this research may not represent and reflect the situations of parents of children with autism in Ethiopia. In order to better inform the intervention and care for children with autism in Ethiopia and beyond, more and more population-based and contextualized research is required. Future research would benefit broad and rigorous data that would come from multiple sources through multiple techniques of data collection.

Conclusion and implications

The current research derived some themes and subthemes that revolve around the experiences and perceptions of parents raising children with autism. By so doing, it shed an important light on the situations of parents raising children with autism albeit the afore-mentioned limitations. Based on the findings of this research, some practical implications were drawn.

Rigorous community awareness systems should be put in place. It is evident from this narrow research that lack of awareness and knowledge about autism among the larger community and other stakeholders is rife. When the larger community and other stakeholders such as families, teachers and health professionals are knowledgeable and well-informed about autism, its identification, diagnosis and intervention is less likely to be cumbersome. Therefore, well thought community awareness system about autism and other developmental disorders should be integrated into the general public health education and promotion scheme.

Screening and diagnosis of developmental disorders including autism should be part and parcel of mainstream maternal and child health care. Our data showed lack of systemized autism screening and diagnosis which led to late diagnosis and intervention of children with autism and other developmental disorders. Hence, in resource constrained countries such as Ethiopia, mainstreaming the screening and diagnosis of autism and other developmental disorders is a cost-effective and viable strategy for early detection, diagnosis and intervention of developmental disorders including autism. Since autism manifests itself as early as 18 months of age, children can be screened and diagnosed for autism and other developmental orders during healthy child visits and routine vaccination schedules if screening and diagnosis of developmental disorders is mainstreamed

into maternal and child health care provisions.

Delivery of practicable inclusive education needs to be ensured. Lack of public educational services that practically meet and accommodate the educational needs of children with autism and their parents is lamented by almost all the parents studied. Therefore, in order to meet the growing needs of public educational services that accommodate the unique needs of children with developmental disorders including children with autism and to ensure their right to quality education, education and school systems must be organized in the manner they can deliver practical inclusive education.

Health care system that is responsive to children with developmental disorders is desirable. As with education, health care service that is responsive to children with autism and their parents is lacking even in the capital city where health care service provision is supposed to be better. To meet the health care needs and demands of children with developmental disorders in general and children with autism in particular, treatment and referral of children with developmental disorders needs to be integrated into maternal and child health care units at all levels of health care systems. In addition, coordinated effort is required to capacitate health care professionals so that they would be able to meet the unique health care needs of children with all sorts of developmental disorders and their families.

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Contributions

Walga, TK: Conceived the research idea; wrote and reviewed the qualitative survey; carried out data analysis and wrote the manuscript

Tibebu Yohannes: Translated the qualitative survey into Amharic; facilitated data collection; collected the data; reviewed the manuscript

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