Stressors and Coping Strategies among Parents of Children with Autism Spectrum Disorder in Ethiopia

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Abstract

This study investigated the stressors that parents of children with autism spectrum disorder (PCASD) experienced and the coping strategies they employed to manage it. Following phenomenological design, focused group discussion (FGD) was employed to collect data. Sixteen parents were drawn using purposive sampling participated. Thematic analysis of the data revealed that challenges related to personal development and building friendship, finding schools for children with autism spectrum disorders (CASD), CASD being non-verbal, and the extent of care and safety the CASD need as major stressors for parents. Mothers of CASD experienced more stress compared to their fathers. PCASD used emotion-focused coping strategies. Implications are highlighted against policy formulations and implementation initiatives.

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Introduction

Autism spectrum disorder (ASD) is a developmental disability resulting predominantly from differences in the brain. The complete etiology of ASD is not known yet. According to Emad, Fatimah, and Yazan (2019), autism spectrum disorder (ASD) is one of the most confusing disorders for which no cure has been found. ASD is a disorder that is usually observed in children at an early age, affecting various developmental processes and outcomes. Children with ASD typically show an imbalance in their social interaction, repeat certain behavioral patterns, and have challenges in verbal and nonverbal communication with others. Over the past few decades, its prevalence showed an ascending trend that triggered researchers across the globe to investigate into ASD comprehensively, that is, its etiology, symptomatology, comorbidity, diagnosis, prognosis and interventions.

Each child with ASD is unique. Parents, siblings, teachers, neighbors or anyone else who has contacted a child with ASD encounters challenges. One of the difficulties could be stress, as many of the children with ASD do not communicate verbally and socialize less due to the nature of the disability.

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Any situation considered to be stress provoking is called a stressor. A study conducted by Style and Cavanaugh (cited in Muhammad, 2011) revealed that expectations, self-fulfillment, student-teacher relation, self-understanding, conflicting values, professional constraints, personal (in)competence, ego needs could be the sources of stress. Ali (2014) indicated that the presence of a child with disability in a family is one of the stressors regardless of the severity of the disability.

A lot has been written about the stressors in the lives of parents of children with disabilities, and many of them have focused on understanding the types, causes and the effects of stressors. Studies that aimed to understand the implications of stress for family intervention and even understanding maze ways for different stressors and coping strategies in different cultural settings are lacking. The different cultural components including pattern of beliefs, values and commitments can shape individuals' behaviors For example, Matson et al. (2017) say that cultural differences impact parental attitudes and behaviors, affecting several parent-child domains, including parental stress and styles.

Parents who face stressors in life due to rearing a child with ASD usually try to use some kind of coping strategy. For Ben-zur (2009), coping is the process of managing taxing circumstances, expending effort to solve personal and interpersonal problems, and seeking to master, minimize, reduce, or tolerate stress or conflicts. Appropriate management of coping strategy can help parents to counter balance stressors, and parents can be more effective if they get support from others. Supports from family members, neighbors and other significant members of society play a very important role for children with ASD (CASD). Despite wrong understanding about the causes, course, and consequences of disabilities, family members are one of the sources of support to parents of children with autism spectrum disorder (PCASD) who experience stress. Of course, the misconception and negative attitude, almost in every corner of the country (Ethiopia) towards people with disabilities has led many parents to hide their children with disabilities including children with ASD at home. Along this line, Weldeab (2006) stated that misconceptions and unfavorable attitudes towards disabilities and persons with disabilities result in continued stigmatization even in the few schools where students with disabilities are included. Research notes different stress coping strategies used by parents. For example, Weiten and Lloyd (2008) suggested appraisal-focused coping strategies through changing mindset, or a revision of thoughts already experienced such as denial. Another one is problem-focused coping strategies where the focus is through modifying the behavior of the person such as learning how to tackle stress and understand its sources. Emotion-focused coping strategies could be used through alteration of one's emotions to tolerate or eliminate the stress such as distraction, meditation, and relaxation techniques.

Ethiopia is a multicultural and multilingual country (Abiy, 2017). It is also the second populated country in Africa next to Nigeria. According to WHO's (2011) world report of disability, 17.6% of the population of Ethiopia has disability. However, to the knowledge of the researchers of the current study, most of disability related studies conducted in Ethiopia have focused on visible disabilities, specifically on people with sensory and orthopedic impairments. Studies on people with neuro-development disorders are less common. To the knowledge of the researchers, only a few studies on the stress of PCASD and the coping strategies that they adopt have been conducted and published within the context of Ethiopia. The current study, hence, aimed at investigating the major stressors, and coping strategies that PCASD use in Ethiopia.

There are varieties of stressors surrounding PCASD, and the nature of the stressors vary across contexts. Unlike developed counties where services are available for CASD and their parents, PCASD in Ethiopia face several challenges. A gap in terms of knowledge and understanding about ASD, finding school for their child with ASD, neighbors' discrimination and prejudice originated from misconceptions about disability and others escalate the stress level of parents. African Child Policy Forum (2011) described that the knowledge level of the society towards disability seem to be minimal in Ethiopia. Only a few children with disabilities receive education; many adults with disabilities are unemployed and possess obsolete historical beliefs about the cause and nature of disability.

In Ethiopia, family comprises the largest group of caregivers due to a combination of factors such as lack of residential services and the prevailing societal beliefs that influence families to keep their children with disability hidden and protected at home. Misconceptions and unfavorable attitudes towards disabilities and persons with disabilities result in continued stigmatization (Tirussew, 2005).

This implies that PCASD, are exposed to stressors due to having a child with disability. So far, few studies have investigated into the experiences of parents taking care of their CASD in developing countries. And there is a scarcity of studies that could fit into the context of the African countries. World Health Organization (2011) has also reported that interventions targeting ASD in developing countries face many challenges, most notably the poor treatment of the cases due to the presence of many comorbidities and the lack of adequate number of centers and trained staff to deal with disorders. Moreover, there are limited practical support programs to PCASD and their family in Africa. According to the World Health Organization's (2011) report of disability, one of the main obstacles that hinder the establishment of efficient support programs for PCASD in African countries is the lack of research studies that can inform about the impacts of raising these children by their parents.

Ethiopia is one of the low-income developing countries in Africa that has huge gap in the support provision for CASD and their families. Even though there are a large number of CASD, they are left unsupported formally by the government. Further, researches on the lives of the PCASD in general and the stressors operating upon them and the way they handle their stress in particular are almost negligible here, leaving a huge research gap in this research context According to Mahlet (2016), in Ethiopia, parents who have a CASD face a lot of stressors due to their low socioeconomic status, poor household conditions, and uncertainties about their child's future condition in employment and social activities. Abera, Robbins, and Tesfaye (2015) also indicated that PCASD in Ethiopia are left unsupported. Leaving the issue unstudied in Ethiopia may lead this Country to under-serve or ill serve CASD and PCASD which can be in gross violation of the human rights enshrined in the constitution of Ethiopia and in other relevant provisions in various legal obligations of the Country.

Having that all in mind, this study attempted to answer the following research questions: (1) what are the common stressors experienced by parents of children with autism spectrum disorder? (2) What coping strategies do PCASD employ to deal with their stress related to having a CASD?

Methods

This study employed phenomenological research design to inquire into the stressors experienced and the coping strategies that PCASD used to deal with their stress. The design was considered the most suitable one because it helps to understand human experiences common to group of people (Creswell, 2013).

The study was conducted in three schools (Kokebetsebah, Yekatit 23 Primary School, and Champions Academy) and three centers for CASD (Nehemia autism center, Joy autism center and Bright autism center). All the schools and centers were located in Addis Ababa and Hawassa cities of Ethiopia.

Participants of the study were selected following purposive sampling procedure from the three centers mentioned above. Two of the three schools were public funded, and the third school and the three centers for CASD were privately owned. Sixteen purposively selected PCASD (8 from Addis Ababa and 8 from Hawassa) participated in the FGDs conducted in the two cities. The parents' engagement in the schools and centers for CASD and their commitments to support CASD were the criteria used for the inclusion of them in the pool of respondents. Either parent (a mother or a father) of a particular CASD was included in the FGD and as many more as possible were invited.

Utmost care was taken to collect credible, authentic, and transferable, data because the trustworthiness and dependability of the study rely on the quality of data. Questions in the FGD were framed in a way to help parents to talk about the different stressors that they experienced and the coping strategies they employed to deal with their stress pertaining to their CASD. For the sake of triangulation, questions of the same concept were asked in different ways. Stressors emerging from family members, marriage partner, neighbors, service providing organizations and community at large were areas of discussion during FGD.

The FGD guide was tested with two purposively selected PCASD, and it was commented by two special needs educators. Two FGDs were held for 75 minutes on average in each city. Amharic (official language in Ethiopia) was used for the discussion. Before interpreting the data, audio recordings of the FGD from each research setting was translated to English language and transcribed into word texts immediately after the discussions. The transcripts were categorized into emerging themes and codes. Data categorization was done under each theme and sub-theme of stressors of PCASD, and the coping strategies they employed to manage their stress. Finally, the data under each theme and sub-theme were interpreted and analyzed using thematic analysis and ideas from the related literature.

None of the PCASD were forced to take part in the FGDs. Informed consent was signed. For the sake of anonymity identifying information of the participants were not collected. Moreover, the data gathered from the participants was kept strictly confidential. Participants were also given the option of withdrawing from the study at any stage without any conditions.

Results

The different stressors PCASD faced and the coping strategies they have employed were identified and presented in this section. Four fathers and 12 mothers have participated in the FGDs. Each parent was coded with an acronym and number as PCASDA1 (parent of a child with ASD from Addis Ababa) and PCASDH1 (parent of a child with ASD from Hawassa). The results pertaining to stressors and coping strategies, are presented below. For stressors, four themes, namely personal development and friendship of CASD, care and safety of CASD, causes of the disability, and life of PCASD (social, economic, job, health) were identified as major stress dimensions/themes with sub-themes emerging under each dimension. For coping strategies, two themes, namely emotion-focused and problem-focused coping strategies were identified and each theme had sub-themes as well.

Stressors

Personal Development and Friendship of CASD

Participants reported their worry about their children's difficulty in comprehensive personal development and building friendship with other children. This according to the parents has aggravated their stress. The following stressors (sub-themes) were repeatedly mentioned by PCASD.

Non-verbalism

Most children's difficulty to use verbal language appropriate for their age made PCASD to worry a lot. One of the parents said, "My child is 11, she nods her head very frequently and I get very much stressed thinking that her unusual behavior persists when she gets older" (PCASDH2).

In addition to that, more than half of the parents mentioned about abuse in different ways. Many CASD cannot report if they are physically or verbally abused since many of them are non-verbal and in case they try to tell parents in some way, parents hardly understand them. One of the mothers (PCASDH8) reported that, she caught her house assistant (maid) physically abusing her CASD and the house assistant finally confessed that she had been doing that for three years. Another mother (PCASDA1) reported that verbal abuse is very common that she does not send her child out to play with kids in the neighborhood.

Building Friendship

More than half of the mothers participated in the discussion reported that they play both parenthood and friendship role with their CASD because very limited people at home and neighborhoods approach them and even so most approach the children as support providers not as friends**.** Fathers also in agreed with this observation of mothers. Moreover, some of the parents indicated that CASD do not tell their feelings (what they like and do not like) except screaming which contributed negatively in the process of friendship building for the CASD. One of the parents was quoted saying:

> I have a boy who is 19, cannot express what he likes or dislikes. For example, for some time, I do not know that he has a sexual feeling (drive) until something had happened. That is, we were once walking together and he looked at a girl in the village, stretched out his hands, screaming unusually and I noticed that the girl had made him horny. I could not help him because I have been experiencing for long that the society including girls like the one my child stretched his hands think CASD have mental illness. The very day he showed his sexual desire, I saw semen in his underwear. (PCASDA7)

The parents reported that their stress gets elevated when they think about the failure of their CASD to develop friendship and/or to maintain it (if already there) and their inability to express feelings to parents, siblings or someone else.

Dependency

Almost all the parents reported that their CASD are dependent on them or someone else in the family, and cannot manage themselves though they grew older. This means, there is no point in time that they can stop nursing their CASD. Therefore, parents think that they must avail themselves full time for their CASD unless s/he is sent to care centers. For example, one of the mothers said:

> I don’t let my child stay away from me. She is 12 and [you know], once I let her free while we were in a city train from Gotera to a bus station we stopped by. She was next to a man sitting at the corner of the train and started laughing at him. He did not know that she had ASD and just slapped her on the face. That was the day I cried most and decided not to let her be alone anymore. (PCASDA4)

Considering this and similar incidents and pattern of life, PCASD expressed that their level of stress gets worsened.

Care and Safety of CASD

Taking care of a CASD and constantly worrying about them was reported by many of the parents as a stress elevating factor and they have also reported that their children do not tell them if they are abused. From this theme, the following sub themes got emerged:

Fear of CASD Acquiring Additional Disability

Parents reported that they were afraid of trying to make CASD independent and letting them try life alone because this may result in additional disability for the child. Almost all parents said that taking care of CASD after school and in weekends give them hard time because they need full time care so as to prevent them from acquiring additional disability. Therefore, constant fear for their children not to acquire additional disability elevates their level of stress. A mother and founder of one of the centers for CASD in Hawassa reported that:

> I am with my 7 years old child 24/7. Two years back, my CASD was playing with a toy sitting on a couch and I told my husband to look after him for a while because I had a business for an hour. When I got back, my child was taken to a hospital because he climbed up to the top of a cupboard, found a gentian violet we kept for first aid medical treatment, and drank it. This happened because of my husband's carelessness. Fortunately, he survived. He could have additional disability. Constant worrying for my child with ASD elevates my stress. (PCASDH3)

Failure to Remember Residential Addresses

Parents reported that their CASD easily get loss of their surroundings and do not know residential addresses. A mother (PCASDH6) reported:

> It was in the eve of one of the national holidays and I had a plan to go to the local market to buy some food stuffs. I had told my other typically developing children to look after their brother with ASD. When I got back, my child was not home. He got lost. I reported to police, tried to find him anywhere we thought he could go. Until 6:30 PM. there was no clue. I was crying and finally the manager of autism care center where he gets day support called and told me that my child was at the center. Because it was an eve, no one except the security guard was at the center. My child is non-verbal and could not tell residential address or telephone number to the center's security guard. Finally, the security guard found us through the center's manager. This incident astonished me a lot and always worries me about losing him at any point in time. This elevates my stress level very much.

Many other parents such as PCASDH6, PCASDH1, PCASDH8, PCASDH2, PCASDA1, PCASDA7 and PCASDA6 also shared the same concern.

Causes of the Disability

The understanding PCASD have about the cause of ASD varies. For instance, some of them associate the cause with something related to the genetic makeup of the father or the mother. Others associated it with God's displeasure on what the parents did earlier in their lives and they believe that it was a time to pay back. Others associated the cause with poor maternal care during pregnancy and poor medical care during delivery. Whatever be the perceived cause, PCASD experienced elevated level of stress thinking and rethinking about the causes. Based on the different causes reported by PCASD, curse and complications during delivery were the two sub-themes emerged.

Curse as a Cause of ASD

Among the PCASD who participated in FGD, an older father explained that he was cursed for so many misdeeds he committed in life and now he believes that he has a CASD to pay back for his misdeeds. He said:

> I am 75 years old and my wife is 69. I know I am cursed by my late father. God is making me pay back with my only child who is 19 and having ASD. Thinking that I cannot fix all the hard times that I had given to my father, I worry a lot and get stressed. I am very hopeless about my CASD. Sometimes, I beg God to end my life so that I don't see my child suffering from autism. Other times, I think the decision I have made to have a child was my biggest mistake. I always regret about it. That is why I get stressed every minute I see my child struggling in life. (PCASDA8)

Perinatal Care as a Cause of ASD

Inadequate or improper perinatal care was generally considered as a cause for ASD. For example, a mother reported that she was informed by her midwife that she was pregnant with twins and she did not know the exact date of delivery. She said that in one of the days she had a pain on her belly; she started experiencing her baby pushing down and no midwife appeared on time. With the absence of midwife support, the mother kept pushing down hard and finally one of the twins survived and was diagnosed with ASD later. She said:

> The unusual push I experienced during delivery made my child who survived have ASD as I am informed by a physician who diagnosed my child with ASD. I always regret the push that caused ASD to my child. Whenever I think the moment, my stress gets high. (PCASDH7)

Life of PCASD (social, economic, job, health)

More than half of the participants were single mothers. They have reported that one way or another their husbands left them after having a CASD. Many challenges were reported in relation to their living situation. All the study participants stated that life gets tough for having a CASD. Every life aspect and action of their CASD call for their attention. Moreover, mothers claimed that they experienced more stress than fathers. Mothers attributed their elevated stress to the expectation of the society that mothers are given the role to rear children at home and fathers are expected to win daily bread for the household. Based on the general discussion under a theme 'Life of parents', the following sub-themes has been drawn.

Fear of Death

Many of the parents reported their wish to live longer and fear death because they believed that nobody will be there to take care of their child if they die. A father said:

> My wife and I are very old now. My CASD is 17. We cannot afford to take him to good hospitals to get medical treatment. Neighbors do not welcome him to get into their house or play with their kids. They think he has got some kind of contagious disease. Having this in mind, the question 'what would happen if we die?' is one of the biggest worries we encounter every day. I am afraid of dying and if I die, I know my child will die soon because I know nobody cares for my child including the government. As a result of over stress due to the uncertain future of our CASD, his mother is under medical treatment for high blood pressure. Anyway, we are afraid of death. (PCASDH4)

Unemployment and Financial Constraints

Among the parents, all the mothers, except the founder of support center for CASD in Hawassa, reported that they were unemployed and financially weak. A mother (PCASDA4) stated that she gets very much stressed thinking about what to feed and clothe her 14-year-old CASD and other typically developing children. Another mother also said:

> I have a bachelor's degree with good cumulative grade point average, but unemployed because I must take care of my CASD. I have two extra rooms in my house, and I rent them to earn money. Sometimes, I face a serious financial problem. Buying hygiene-related materials for my CASD who cannot control her bladder is not affordable and makes me cry. I cannot get employed because I have nobody to trust and keep my CASD with. Hence, my stress challenges me a lot due to financial constraints. (PCASDH2)

Societal Reaction and Social Life

PCASD reported that the burden they have due to raising their CASD prevents them from involving in different local support and relationship gatherings like "Equb", "Idir" and "Mahber" - social networking schemes in the Ethiopia communities that help people ease their financial burden, funerals ceremonies, and religious practices, respectively. If someone is not involved in any of these gatherings, villagers exclude him/her from different informal groups. However, PCASD do not get involved in these social gatherings because they must take care of their CASD at home and moreover they are afraid of the stigma that may be expressed by the villagers towards their CASD. Therefore, feeling of exclusion is reported as one of the stressors that escalate their level of stress.

Coping Strategies

The PCASD reported two parental stress coping strategies: emotion-focused coping strategies and problem-focused coping strategies.

Emotion Focused Coping Strategies

Most of the coping strategies parents reported under this theme were short lived and helped them only to wipe out their temporary fear and frustration. Based on the discussions, the following sub-themes have been drawn.

Sleeping

Less than half of the parents said that they sleep (sometimes take a nap) when they fail to handle their stress. A mother reported that she preferred to sleep to pass the moment when sometimes things get out of control due to the child's behavior making sure that her child is also sleeping beside her.

Crying

More than half of parents, particularly mothers, mentioned that crying is one of the best stress busting strategies they used. They believed that crying for a while gave them a relief from stress. Other mothers said that they cry at home while they get much stressed and they also cry in churches where they believed God could give them a solution.

Visiting Spiritual Places

About half of the parents expected miracles from God to make their child free from ASD. As a result, many of them reported they frequently went to churches and mosques, begged religious men to pray for them so that their child becomes 'normal'. One of the parents expressed:

> When I get much stressed about my child's case, I start to think why God has given me this? I pose this question for myself: "Is God testing my commitment and faith on him? Is God checking me how faithful I am?" Then I start to be strong and prepare myself for the worst. I start to be faithful to the almighty God. Ultimately, I start to cool down and come back to the usual life routines and I know God will make a miracle in the life of my child with ASD. (PCASDH3)

Attempting Suicide

Only very few of PCASD reported an attempt of suicide. A mother said:

> … My sister's boyfriend, who had a plan to marry her, found out that her sister (me) has a child with ASD, and canceled the marriage plan because he was afraid of making marriage union with a family having someone with ASD. This was the time I decided to commit suicide. I prepared everything and hanged myself in the bedroom. Fortunately, my husband showed up and saved me. (PCASDA2)

Corporal Punishment and Chaining the Child with ASD

Only few parents reported practice of corporal punishment. A father who uses a stick as a means of teaching good manner to his CASD reported that he found corporal punishment effective and said:

> Sometimes, I tie the leg of my CASD with a leg of relatively bigger chair at home using galvanized iron chain so that we can be sure that he will not mess up us with the hating neighbors. (PCASDH5)

A mother also used tying the child as a strategy using a thicker and longer sleeve like cotton cloth. She said:

> I don't own a house. I live in a small rented house. Because of the nature of my child, the landlords don't let me live longer than three months in their house. My child screams, doesn't sleep longer at night so that the light needs to be kept on whole night, my child also frequently bangs and nods head. All these disturb neighbors who share wall with my house. After experiencing so many 'leave my house' warnings from landlords, I thought of tying up my child with long and soft piece of cloth. I kept my bed at the center of the room and put my child with ASD on so that he can't bang on the wall. I tie him around his waist and the other end of cloth will be tied with the bed so that he can't move out of the bed. To lower his screaming, I pile up three pillows in front of him so that while he bangs and screams, the sound gets muted by the pillows. (PCASDH1)

Overlooking the Child's Action and Retreating

Parents reported strategies such as just ignoring the child's actions, telling oneself and hoping that the child will come out of the disorder. Thinking that the child's disorder is less serious than his/her death will help PCASD take what is happening in the child as easy as possible, and staying away from home for a while to cool down. For instance, a father (PCASDH5) reported that he sometimes self-locks himself in a room and listens to religious songs when he gets much stressed.

Problem-focused Coping Strategies

The parents also used coping strategies that targeted solving the problem they faced due to having a child with ASD and managing their stress to optimal level. They have discussed many strategies, and the following sub-themes have been drawn from the major theme of problem focused coping strategies.

Taking More Care of the Child

More than half of the parents reported that they enhanced their care for their children as a coping strategy. A mother (PCASDH7) said she takes the maximum care possible as a coping strategy to manage her stress.

Trying to Understand the Nature of the CASD

PCASD reported that consultations and discussions among spouses, care givers, and professionals working in the centers of CASD helped them a lot to manage their stress. Few parents reported that they try to understand the nature of their CASD to deal with their elevated level of stress. One of the parents said:

> After my child was diagnosed with ASD, I have tried to read books and articles about ASD. Therefore, I understand the nature of my CASD and that helped me to handle my stress to an extent. Even if something very annoying happens, I think that happens as he gets older. (PCASDH3)

Discussion

Stressors of PCASD

The contents, tone, and the emotions that the PCASD expressed to explain their stress and the local situations that they are in in the FGDs clearly signified that they experience higher level of stress. Studies also show that PCASD experience higher levels of stress than parents of typically developing children (PTDC) (Eisenhower, Baker, & Blacher, 2005), or than parents of children with other disorders and medical conditions including Down syndrome, intellectual disability, fragile X syndrome, cystic fibrosis, cerebral palsy and developmental delay (Hayes & Watson, 2013). Approximately 2/3 of mothers of young children with autism experience clinically significant levels of child-related stress (Tomanik, Harris, & Hawkins, 2004). PCASD participated in the current study also reported many other stress elevating factors related to their CASD personal development, care and safety, belief/ understanding about causes of the disability, and life status of the parents themselves.

PCASD expressed various stressors operating upon them. One of the stressors that PCASD reported is in terms of personal development deficits of their CASD. That is, the challenge of their children being unable to verbally communicate with others. Indeed, their worries in this regard align with the findings of various studies. For example, Kasari et al. (2014) reported that more than 70% of children diagnosed with ASD were non-verbal. The importance of verbal communication for personal development is very crucial because as it is common everywhere, parents in Ethiopia also teach cultural norms and values to their children predominantly through verbal communication such as storytelling and retelling, paying respect to elders, etc. But CASD having verbal skill deficits put their parents under stress. The situation is further complicated by the non-availability of professionals in the area of speech therapy for CASD in Ethiopia.

Parents also reported other stress elevating factors that hindered the personal development of their children with ASD: the challenge to build friendship with others, and being lifetime dependent on others. It is a natural reality that building friendship and maintaining it is an easy task for typically developing children. However, it is very hard for CASD. Initiating and keeping conversations, taking part in play activities, understanding body language, taking-andgiving turns for smooth flow of conversation, and solving disagreements are some of the unwritten rules for maintaining and sustaining friendship. However, CASD can hardly practice these rules. Consequently, their social interaction becomes so weak, and they fail to maintain any friendship. This cause parents to experience higher level of stress. Sedgewick, Hill, and Pellicano (2018) associated higher level of stress of parents not only with their children's disability but also with their gender. For instance, some parents who have daughters with ASD are afraid that their children could be sexually and physically abused. Holroyd and McArthur (1976) also reported that, apart from a feeling of overburdened, the parents' pessimistic view of the future of their CASD and the children's total dependence on the parents or family members raise their level of stress drastically. In addition, in the Ethiopian context, the level of public awareness about the nature of ASD adversely affects the stress level of PCASD because unlike other visible type of disabilities, ASD is less emphasized in national policy documents and mass media.

With regard to a relationship between the level of parental stress and demographic variables such as age of the child and the number of children parents have, a mother explained that her biggest worry is the discrepancy she observes between her child's increasing age and the immature behavior or unusual behavior. Similarly, a father having a 19-year-old child with ASD, explained the same worries. Both parents got worried due to the discrepancy of expected behavior with the age of their children. Therefore, it is possible to say that the age increment of the CASD raises the level of stress of PCASD if the child could not act according to the age-appropriate behavioral norms. These parents do not see promising future for their CASD. Along this line, Milačić (2008) also reported that the age of the CASD has an influence on parental stress levels in that parents of CASD feel a higher degree of stress as their children get older. For instance, a father had no idea that his 19 year old child could have sexual desire until he once got embarrassed by looking at his child's unexplained sex drive to an unknown girl. He reported that his child's behavior caused him much stress.

Despite their typically profound delayed development, CASD sexually mature at normal age, and the combination of their sexual drive and the inability to express it in socially appropriate ways make many parents face awkward situations. Some children publicly masturbate from an early age, but this behavior is especially disturbing when the child is an adolescent (Gray, 1994). Studies also show the difference on the level of stress between parents having CASD at different ages. For instance, Tripathi (2015) reported that, parents whose CASD were in adolescent group reported high level of stress than those in pre-adolescence age group.

Moreover, some of the parents reported that their CASD's typically developing siblings support them to take care of their brother or sister with ASD and that helps them reduce their stress. This is supported by a study by Warfield et al. (1999) who found mothers' lower level of stress when they get support from family members.

With regard to difference on level of parental stress of fathers and mothers of CASD, mothers reported that they take more pain of stress than fathers. Interestingly, this was confirmed by fathers who participated in the present study. A study by Tehee, Honan, and Hevey (2009) also reported that mothers experienced more stress than fathers. Care and safety of their CASD was another factor causing higher level of stress of PCASD. Under this, parents reported their fear for their CASD acquiring additional disability, being abused, and not understanding the surrounding. These fears of parents seem reasonable, and in relation to this finding Ventola, Lei, Paisley, Lebowitz, and Silverman (2017) reported that parents have experienced higher stress due to their children with ASD's lack of safety consciousness.

Causes of ASD itself were another source of stress for parents. Curse and poor perinatal care of mothers were frequently reported as a cause for ASD among parents and that indirectly causes their stress. A case study by Rahman, Bairagi, Kumar, and Sultana (2017) also reported similar results: taking curse as a cause for ASD among PCASD. This can have wrong implication for support provision to CASD. Because it is a belief system that inhibits parents not to put any effort for change as they think it is something that cannot be changed with efforts. Similarly, poor perinatal care and service for pregnant mothers may have implications to work with maternal care providing organizations including health centers that maximum care during delivery may contribute for lower prevalence of ASD.

Moreover, PCASD discussed stress enhancing social, economic, and job-related stressors as rising in their life. Fear of death, challenges related to a lifelong nursing of a CASD, unemployment and financial constraints, negative social reaction and seclusive social life were some of the many stress elevating factors parents mentioned. However, in Ethiopian context both fathers and mothers vocalized their fear of death thinking that no one will be there for their CASD after their death.

Parents experienced stress as they were worried about the need of committing their whole life taking care of a child with ASD. This is because unlike TDC, CASD requires full time support and care. A similar finding is reported by Lina et al. (2018) where a mother reported that, "*After my child with ASD was born, I don't have any time for myself. From the moment he gets up until bedtime, I have to watch him all day"*. The parents of CASD in this study context shoulder more burdens because there is no publicly funded organization to support them in some ways like in terms of free medication, rehabilitation, free meal service, and hygiene equipment. Since the government of Ethiopia has no specific service delivery either to CASD or PCASD, parents are expected to cover their bills.

Stress Coping Strategies

Any conscious effort by an individual to manage or overcome a stressful event is known as coping (Holahan & Moos, 1987). Lazarus and Folkman (1984) categorize coping strategies as problem-focused coping strategy (PFCS) and emotion-focused coping strategy (EFCS).

With regards to PFCSs, parents of CASD demonstrated a knowledge gap regarding the meaning of PFCSs, even though they unknowingly used some of them, such as taking more care for the child for extra support, making an effort to understand the nature of the CASD, and attempting to create situations to discuss with family members, marriage partners, professionals, and practitioners in order to support the child in leading an effective life. There was no disparity between genders of the parents in utilizing PFCSs. Previous research, such as that of Hamilton and Fagot (1988), supports the conclusion that gender has no impact on the use of certain coping methods. Ghobari, Motamedi, and Zare (2017) likewise found no difference in the use of PFCs between fathers and mothers.

Similar findings suggested that taking more care and discussions with other supporting bodies such as family members and professionals can help a lot to cope with the stress that parents face. For instance, Heiman (2002) found out that parents' resilience strategy brought long lasting positive effect to support CASD though discussion with family members and professionals as well as with the provision of more care. Drawing from this understanding, popularization of PFCS through various psycho-educative methods among PCASD by different agencies and/or organization can go a long way in mitigating the stress of PCASD.

On the other hand, the results of the current study indicated that PCASD used EFCS in stressful situations related to raising their CASD. As it is presented in the results section, PCASD reported the use of different EFCS such as sleeping, crying, visiting spiritual places and praying, contemplating or attempting to commit suicide (though it must not be taken as a strategy at all), corporal punishment and chaining the child with galvanized chains, overlooking the case and retreating for a while (distancing or escaping). A study by Davis and Carter (2008) indicated that, problems related to sleep is common for mothers of CASD who experienced higher level of stress. In the current study, half of the participants reported that, they prefer to sleep when they get stressed. In support of this finding, Upamanyu (1997) explored the stress management techniques used by women in India. He found that sleep, relaxation, exercise, time management, diet and yoga were the common ways adopted to cope with stress by women. There are also significant numbers of findings that reported that parents do not sleep well because their CASD have sleeping problem. For instance, Goodlin-Jones, Tang, Liu, and Anders (2008) reported that a number of CASD have sleeping problems, such as excessively short sleep time, trouble falling asleep, waking up multiple times at night, problems getting out of bed in the morning and drowsiness during the day.

In a qualitative study, Atasoy and Sevim (2018) reported that parents of children with disability cry a lot regardless of their 'easily happy' personal characteristics before the diagnosis of their child with disability. The current study also found out that crying is one of the emotion focused coping strategies PCASD used. The reason to cry in the parents' context of the current study varies from one parent to the other. PCASD also used prayer as EFCS regardless of the differences of the religious sects they belong to. According to Pargament, Smith, Koenig, and Perez (1998), prayer aims to get spiritual support, increasing spiritual connection, asking religious forgiveness, and collaborative religious coping. A decreasing level of stress is the ultimate result parents expect from it. Individuals using prayer as a coping strategy tend to have both improved perceived mental and physical health, as well as improved objectively measured health outcomes (Faigin & Pargament, 2008). Scholars have found out that prayers improved the parents' belief in God, the greater the belief in God, the more the parents were able to focus on the important things in their life (Al-Kandari et al., 2017; Beighton & Wills, 2017; Ekas, Whitman & Shivers, 2009).

Regarding attempting suicide, there is suicide ideation among PCASD. The cause is beyond the issue of having a CASD. However, it is also reported that, despite the availability of evidence for the relationship between stress-coping strategies and suicidal attempt, how the coping strategies relate to suicidal attempt is still unclear.

PCASD also reported that they use corporal punishment and facial or verbal reminders to manage the behavior of their CASD as one of coping strategies. Communication is one of the challenges CASD experience. They cannot tell their feelings and needs as typically developing children do. Certain activities that CASD are engaged in seriously disappoint parents. As a result, PCASD in the current study also reported that, they used corporal punishment and gestural or verbal reminders as a coping strategy. In similar studies, parents also reported using physical punishment and reminders in response to problem behavior, spanking, and denying rights of having playing items or other privileges as among the types of punishments used to manage problem behaviors (Armstrong, DeLoatche, Preece, & Agazzi, 2015). Other studies also reported alternative strategies to manage problem behavior of CASD such as providing verbal explanations and social stories (Beer, Ward, & Moar, 2013). They gave verbal reprimands in response to problem behavior (e.g., saying “don’t”, “stop”) (Blair, Lee, Cho, & Dunlap,2011).

In the current study, a new way to manage the behavior of a CASD was reported by one of the mothers. She reported that she ties her CASD with the bed using cotton fabric. That is reported as a very individualistic and the only solution that the mother had in order to cope with the situation, according to the mother. In order to retain a rented single roomed house in spite of all the banging and screaming nature of her child with ASD, she said that she had to tie him up in a bed located at the center of the room and far from the walls. She said that she had used piled up pillows to mute his high-pitched voice in order to significantly reduce, if not completely stop, his screaming noticed by neighbors while he bangs and screams.

As it is reported earlier, some parents said they overlook the challenges their child has and pretend that nothing special has happened. Of course, the very reason behind using EFCS is that the stressors exceeded the ability of the person to control it. That is why some PCASD in the current study preferred to employ overlooking the case of their CASD in order to get a temporary relief. Some PCASD who participated in the study reported self-talking that nothing in life is perfect. Everything happening in life has negative and positive faces. They reported that focusing on the positive and appreciating a very little improvement the child is making helped them deal with their stress. PCASD also preferred to think that reality is contextual; the reality of ASD that PCASD have may not be the same as the reality that PTDC make.

In the current study, PCASD also reported distancing as means of coping strategy. Staying away and withdrawn from a CASD for a while is used as one of the strategies to get relief from the stress. A study by Vidyasagar and Koshy (2010) found out that mothers of CASD have used distancing or avoidance as an emotion-focused coping strategy more often than mothers of ‘normal’ children.

Generally speaking, PCASD who have participated in the study used more EFCSs compared to PFCSs because the majority of the participants confessed that with all lacks of training on managing CASD and lack of professional supports, it is very likely for parents, particularly single mothers, to take any ways out to get relief regardless of considering the coping strategy is emotion focused or problem focused. Neither fathers nor mothers showed knowledge-based intention to use specific coping strategy based on their gender. However, more EFCSs were reported as a coping mechanism by mothers.

Conclusions and Recommendations

The current study sheds light on stressors, and coping strategies among PCASD in Ethiopia. Some of the stressors experienced and coping strategies employed are similar to the ones experienced and employed by parents elsewhere and some-other experiences are typical to Ethiopia. Parents' stressors related to their CASD include stressors related to CASD's personal development challenges and failure to build friendship, being non-verbal, finding schools for their CASD, the scarcity of care and service provisions that the children with autism spectrum disorder require, uncertainty about the cause of the disability and fate of their CASD after their death. The higher level of stress negatively affects the life of PCASD as well as their CASD.

With regard to coping strategies, PCASD use predominantly use EFCS compared to PFCSs and mothers tend to use EFCS more than fathers. PCASD are not aware of the type of coping strategies that they use and also their efficacy in helping them handling their stress effectively.

Based on the results obtained and conclusions made, the following implications are drawn. Ethiopia is a signatory of different international policy documents, conventions, proclamations and guidelines such as UNCRPD, SDGs, etc. It has also developed many local policies and directives related to the rights and support of children with disabilities such as Ethiopian Education Development Roadmap, SNE/IE strategy, Inclusive Education 10 year's Master plan for Ethiopia etc. However, the majority of locally developed policies do not consider the challenges parents are facing particularly parents of children with neurological disorders such as ASD. The finding of the current study can contribute to the development of locally relevant policies pertinent to CASD Therefore; policy makers should consider establishing scientifically proven and contextually effective support system for PCASD to reduce the effect of stressors on PCASD.

The PCASD indicated that they have been struggling with many challenges such as finding inclusive school for their CASD due to the condition that their child has. Therefore, it is recommended that the Federal Ministry of Education Ethiopia in collaboration with other key stakeholders (Federal Ministry of Women and Social Affairs, Ethiopia and Federal Ministry of Health, Ethiopia) to work at all levels of schools to make schools accessible and inclusive for CASD and establish public funded learning and health intervention centers for CASD and their parents.

Parents get more stressed as they get older. They get more stressed not merely because they are getting older but they do not trust the whole support system in the society as responsive as the parents' expectations regarding the care and support for their CASD. Therefore, the Ministry of Education, the Ministry of Women and Social Affairs, and the Ministry of Health need to establish a trustworthy support system for CASD so that the level of stress PCASD experience can be reduced or eliminated.

PCASD reported that earning less is the cause for higher level of stress. The government can introduce certain financial support systems to the PCASD as this can relieve them from the burden of mending their existence while taking care of their CASD. A work from home provision may also be thought of for PCASD because this can help them work at their convenience and pace. Further, detailed researches are to be initiated to consider the Ethiopian context in terms of income and its effect on the level of stress of PCASD.

It is recommended for the Ethiopian government, Ethiopian Special Needs Education Professionals Association (ESNEPA), Non-governmental Organizations (national and international) and DPOs to scale up and shape the purpose of different social groups available in Ethiopian context such as ‘Equb’, ‘Edir’ and ‘Mahiber’ for supporting PCASD. Finally, the Ethiopian government, Ethiopian Special Needs Education Professionals Association, NGOs (national and international) and organizations of persons with disabilities may educate the public and PCASD on the cause, course, and consequences of ASD so that the stigma, prejudice, and discrimination is reduced. Further, this move will support PCASD to resort to more of PFCS to deal with their stress.

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