

What are the Sources of Stress in Parents of a Child with Autism? A Qualitative Study

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Abstract: Backgrounds: Autism is a neuro-developmental disability that creates stress on the parents of a child with autism. This study was aimed to examine the sources of stress in parents of a child living with autism in Addis Ababa, Ethiopia. **Method:** Through purposive/convenience sampling, 12 parents were selected and interviewed. The interviews were transcribed and analyzed using thematic data analysis. **Result:** The identified sources of stress were: (a) Stresses during the Diagnosis, (b) Stresses from a Busy Day-to-Day Routine, (c) Stresses from Managing the Behavior of a Child with Autism, and (d) Stresses about the Future. **Implications:** The existing system in Ethiopia has to proactively/actively work to address the stress and other concerns of the parents.

1. Introduction

ASD is a multi dimensional, neurodevelopmental disability affecting social interactions and communication skills (American Psychiatric Association, 2013). The impact of having a child with an ASD potentially affects parents in several ways, including increased parental stress (Meadan, Halle, & Ebata, 2010), feelings of anxiety and depression (Factor, Swain, & Scarpa, 2018). Accordingly, stress was emerged as one of the psychological burdens of raising a child with ASD. Some parents also go through periods of disbelief, deep sadness, and self-blame whereas others experience helplessness, feelings of inadequacy, anger, shock, and guilt (Gupta & Singhal, 2005, p. 64). “Parents of children diagnosed with autism often experience greater amounts of anxiety and stress than parents of Typically Developing (TD) children or parents of children with other types of developmental delays” (Dumas, Wolf, Fisman, & Culligan, 1991; Plant & Sanders, 2007 as cited in Plumb, 2011, p. 1).

Deater-Deckard (1998) concisely defined parental stress as “the aversive psychological reaction to the demands of being a parent” (p. 315). Parenting stress occurs when one’s perceived resources or the ability of a parent is low compared to one’s perceived demands of parenting, often resulting in negative psychological reactions (Deater-Deckard, 1998). As a challenge to the parent, autism ranks among the most stressful childhood developmental disabilities. Problems with communication, emotional expression, and antisocial behaviors all combine to place tremendous stress on the families of children with autism (Gray, 2006). In a survey of 219 parents of children with autism, Sharpley and Bitsika (1997), found that more than 80% reported sometimes being “stretched beyond their limits,” with mothers reporting higher stress levels than fathers. They stated that the three most stressful factors are (a) concern over the permanency of the condition; (b) poor acceptance of autistic behaviors by society; and (c) very low levels of social support received by parents. On the other hand, the Autism Society (2011) categorized factors that put families in stressful situations into five categories: “Child’s inability to express his/her own need, taking child diagnosed with autism out of the community, the concern of child’s future welfare, parents’ financial aspect and feelings of grief” (Hartmann, 2012, p. 8). Thus, parents of children with ASD report elevated parental stress (Brobst, Clopton, & Hendrick, 2009).

Hastings, Daley, Burns, and Beck (2006) examined predictors of maternal stress in a sample of 75 mothers of children with autism and other intellectual disabilities aged 3-19 years. Although 56% of the mothers of children with other intellectual disabilities reported clinically elevated stress levels, 75% of the mothers of children with ASD were above the clinical cut-off point (Hastings, 2008). Thus, this figure indicates that mothers of children with ASD experience clinical levels of stress more often and of a higher intensity than mothers of children with other disabilities. Similarly, a meta-analysis of studies specifically comparing stress in parents of children with ASD to stress in parents of typically developing children demonstrated that the effect size for both was large, 1.58 and .64, respectively (Hayes & Watson, 2013). Along with research demonstrating that the majority of parents of a child with autism, estimated between approximately 66% (Tomanik, Harris, & Hawkins, 2004) to 70% (Derguy, M’Bailara, Michel, Roux, & Bouvard, 2016), report significantly elevated stress levels, is concerning.

The child’s state is the primary factor behind anxiety and stress among parents. Fleischmann (2005) identified the most difficult problems that parents mention as poor language skills, inappropriate and embarrassing public behavior, disruption and destruction in the home, violence and aggression, inappropriate sexual expression, and obsessions with eating and toileting. Higher levels of autism symptomatology are associated with higher reported parental stress (Hastings & Johnson, 2001). Parents of children with high-functioning autism report significantly higher levels of stress and lower levels of adaptive coping and resources than parents of children with typical development (Lee et al., 2009). The more severe the child’s symptoms, the greater degree of parental stress (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001).

Parents of children with developmental disabilities experience higher levels of stress than parents of typically developing children (Davis & Carter, 2008; Pisula & Kossakowska, 2010).

The feelings of loss of personal control, absence of spousal support, informal and professional support are found to be the major source of stress for parents of children with autism. Other important factors associated with parental stress in families of children with autism include adjustments to the reality of the child's condition, housing, and finance. Families with aggressive and violent children experience a high level of stress in the presence of few resources for treatment or residential placement to deal with the situation (Gupta & Singhal, 2005, p. 63).

Daily stress has been associated with negative mood states (e.g., anxiety and depression) among parents of children with ASD (Pottie & Ingram, 2008). Negative outcomes extend beyond mental-health concerns (e.g., anxiety and depression) to more general quality-of-life issues, such as parenting competence and limiting the enjoyment that comes from the positive aspects of parenting (Hastings & Johnson, 2001; Rodrigue, Morgan, B., & Geffken, 1990; Tomanik et al., 2004). The negative impact of stress can also have far-reaching effects on areas outside of the caregiving role for parents of children with ASD, including marital satisfaction, family adaptability, the functioning of siblings, and social isolation (Sanders & Morgan, 1997). In addition to external factors, such as financial costs, the time burden of seeking intervention, and restrictions placed on social activities, could also contribute to parental stress (Lollar, 2008). Therefore, parents raising young children with ASD are more likely to experience high parental stress and burden, which are associated with a plethora of negative child and family variables. This high level of stress must be addressed due to its potential negative impact on parents and child development.

2. Methods

Participants. The study participants are selected based on their ability to clarify and deepen understanding of cases, events or actions, and rich knowledge of the research issue to provide a good insight. This study used a non-probability sampling method, specifically purposive sampling based on eligibility criteria, to identify cases that fit particular criteria and who will provide in-depth information about the research issue (Creswell, 2014). Then, for this study, 12 (twelve) in-depth interviews with parents of a child with autism were conducted. The results are reported through the themes that are emerged from the data.

3. Result

Parental Stress. The participants expressed that they experienced a high level of stress and disturbance due to the burdens associated with raising a child with ASD. The majority of study participants experienced stress, deep sadness, worry, and grief in caring for a child with autism. Accordingly, Belay described his experience by saying:

The psychological impact of caring for an autistic child is vital. Emotionally and physically, my wife and I have experienced stress and we were in a burn-out due to caring for our child with autism. I am more physically tired, I became exhausted very quickly. When I am at work, it is difficult for me to focus and function efficiently, as my body feels tired more than before. My wife was always worried about our [autistic] son. She feels frustrated, distress, and gets offended easily.

The parents also reported stress during their day-to-day lives and in thinking about the future. Therefore, the identified sources of stress were explained in four themes: stress during diagnosis, stress from the busy day-to-day routine, stresses from managing the behavior of the child, and stress about the future.

Theme 1: Stress during the Diagnosis

Most of the participants experienced a high level of stress during the diagnosis of their children with autism, which began from the time they first knew about their children's health status. Before acceptance, the participants went through denial, shock, and grief. They expressed the moment of learning the diagnosis as the most heartbreaking incident in their lives. One participant (Ruhama) remembers it as follows:

When the doctor told me that my daughter is autistic, I had no clue about what autism was. After he explained it to me, I did not want to accept that my only child is autistic. I felt that the whole world, even God, has turned his back on me. I was so stressed that I closed my door and stopped my relationship with everyone for a week.

Parents gave different explanations for their first emotional reactions. Meron mentioned it as: *"It was the most painful thing I have experienced, she is my only daughter, and knowing she is autistic was devastating. Everything was blocked for me; I cried a lot that day."* All participants conveyed that although they are less stressed than at the time of diagnosis, they still experience stress when

they think about having a child living with a disability and about the caregiving responsibility. Belay once again described the stress that emerged from thinking about having a disabled child:

I am adapted to this life but it does not mean that I am okay with it. It has a stress. I am jealous of parents who have 'normal' kids that would go to the toilet by themselves.

Regarding the initial reaction of the parents, the participants mentioned the incidence of autism as a major life stressor and that they experienced shock, confusion, denial, and self-blaming. Some parents in this study also related the cause of autism with the cultural attitudes of associating the illness with their prior wrongdoings (sins), evil spirits, and punishment by the divine or supernatural power.

Theme 2: Stress from a Busy Day-to-Day Routine (Schedule)

Respondents confirmed that nurturing children with ASD is challenging and extremely demanding. The daily schedules for most of the respondents entailed feeding, getting their children dressed for school, taking them to school, going to work, picking up their children from school, and taking them to their various medical treatments. Parents reported that their daily activities were very routine and scheduled. In this regard, Dawit expressed his situation as:

...My life is busy, tedious, and hectic but organized. From the time he is awake to his bedtime, he is the main focus, as I hope that he is safe and well taken care of. It makes you busy and very scheduled. If I did not follow the schedule, my child could not function. That caused more stress. I can say, every day except for the weekends (where my child will not go to the centers), I have to follow the very busy daily routine.

I left almost everything else. Sometimes, I spend the whole day busy without a rest running around my child to control him (especially on the weekends where he didn't go to the center) if he is having a bad day and meltdowns. I am paying a lot of sacrifices and it is really a great burden (Martha).

Some mothers illustrated another aspect of the challenge related to their children with autism, whereby they could not pay proper attention to their husband and the remaining children without disabilities. They have been urged to give more time to take care of their children with autism. Martha told the researchers how hard it is to have a child with autism because it takes a huge amount of time to care for the child, which makes it difficult to have time for herself, her husband and the two typically developing children. As she explains:

He requires most of my time. I give a mammoth amount of my time to my son. As a mother, you have a lot of responsibilities, and it makes the burden of being a mother even more difficult. Generally, I have no time to myself, to attend social events, and I feel very busy. Let alone caring for myself, I don't think I have given proper care for my husband and the two other children without disabilities as I plan everything around my autistic child.

The participants had a strong fear that due to their strange behavior, their children with autism might have been abused by home servants and even the siblings at home and members of the local communities including their peers without disabilities. Among the study participants, two mothers were forced to leave their jobs and stay at home to take care of their respective child with autism. Generally, a majority of the participants were required to protect their children with autism, which forced them to have tight schedules and go through hectic life being overburdened by extra responsibilities and duties they needed to carry out for the sake of the safety of their child with autism. The participants further depicted a situation in which they were always in a state of stress and fear due to the inability of their children with autism to respond properly to their environments. Furthermore, participants found daily activities cumbersome, indicating that the effect on their day-to-day life, as everything has to be on a schedule and routine. Although the day-to-day experiences were challenging, the participants became more involved in their children's lives and gave due emphasis to their roles as primary caregivers.

Theme 3: Stress from Managing the Behavior of a Child with Autism

The most challenging aspect associated with ASD was when their child became upset, sometimes leading to violent behavior. Unpredictable behavior is especially challenging for parents and threatens their ability to function well in a consistent mode. Abera said, "My child has difficulty in following instructions consistently. ...if she thinks that she has a better option, she doesn't remember and is guided by it." Most of the parents shared that managing their children's behaviors can often be challenging and stressful. For example, Zahara explained the volatile behavior and quick temper:

Her unpredictable behavior is I can say challenging for me. I feel frustrated when I told her to do something and she does the opposite. ...Though it occurs once in a blue moon, the difficult behavior of my child is she'd get very angry, screams, shout, and slams the door. ...She is smart but when she has a meltdown, it's overwhelming for her and me. She become almost frighteningly angry very quickly, which is weird and you couldn't manage easily.

Meron said her daughter would get exceedingly frustrated especially when she gets upset, which would make her think and feel bad. She described the distressing incidents:

When my child thinks things are done against her interest or feels threatened, she would be-upset and respond by screaming, banging against windows or walls, hurting her arms, biting herself, disturbing, throwing everything around her. Sometimes, she would be punching, kicking, and bailing up with me. It would be a nightmare that feels bad.

Dealing with the anger or inflexibility of the children was stressful for some parents and challenged their patience and relationships. Meseret portrayed:

Yeah, he is facing a big meltdown. He is quite polite, he has got quite an engaging personality but if he was aroused and starts to have a meltdown, he will lash out by yelling, hurting, and biting himself. He would also break things, throw things, hit, punch, and kick even other children in the center. That is appalling for us [as a parent], something that can challenge your patience, and rarely I even hit him, out of grievance and anger.

...My child does not consider my need. Occasionally, he might ask the same question repeatedly while I want to talk to my friend or want to see an interesting movie; he asks very simple questions that he knows the answers to; he just wanted it again and again for not less than 20 or 30 minutes. Then I found it demanding and run out of patience in these kinds of situations (Martha).

After analyzing the narratives, it became evident that the parents described their children almost having a dual nature and character. They can be upset either after a long or short calm down. Participants reported that their child's mood changes can be accompanied by physically aggressive behaviors, including pushing, hitting, kicking, or throwing items. Therefore, their child's self-regulation problems, both in and outside of the home, caused considerable stress and worry in conjunction with significant management challenges for parents during these occasions.

Theme 4: Stress about the Future

The parents viewed and described the future as challenging and stressful. The participants shared unpleasant thoughts in the back of their minds about the future regarding their children and themselves. Both are reviewed separately as, *stress about the future of a child with autism (i.e., concern about the child's future) and stress about the future of the parents.*

i. Stress about the future of a Child with Autism: The parents worry about the future of their children in terms of who cares for their children when they can no longer be available for them, and what the future holds for their children appeared to be a major cause of concern. For example, Aster worries about what the child is going to face in the future and how his life would turn out if something bad happened to her because most of the things that the child needs are tied to her.

My child's future is the main thing that worries and stresses me a lot. What concerns me about the future of my child is who takes care of my child if I will die or something happens to me? Because if bad things happen to me, I thought how my son would be? I am the one who understands his behavior; he needs me to wear clothes, eat, toileting, socialization, and depends on me for survival basics in general. ...Sadly, [with tears in her eyes], I wish if he dies either before me. I think this is weird, but due to his situation, I don't want him to suffer. I don't think he will have someone to help and manage him like me...

ii. Stress about the future of the Parents: Some of the participants were stressed about their well-being and ability to deal with their children in the future. Zahara expressed her distress about herself that stems from caring for the child, her future ability to care for her child, and thinking about the future of her child:

As my child grew up, the burden of caring for her is making me thinner and thinner; I am looking old more than my age, and my friends, due to the distress. Because I gave everything to my child and I don't take care of myself and my lifestyle. ... her survival depends on me, and if unexpected life events such as death or serious health problem could hamper me from providing proper care, who would take care of my daughter?—is the question that stresses me a lot. Of course, I am asking and praying to my God to give me full health until I see the end of her life.

Generally, stress experienced by parents of children with autism in different spheres of life seems to be a major psychological challenge. On the contrary, three participants stated that they are very hopeful and that they fear nothing when they think about the future. These parents mentioned that believing in God, looking at the behavior, and seeing the changes in their children have made them feel better and hopeful about the future of their children. Although most of the participants discussed their fear about their child's future, Meseret (a mother) talks about the future in a very optimistic way: *"I don't think I have to worry much. Who created him in the first place? God and I do not doubt that he is going to live a better life. I think he is going to be okay. He is friendly and he can live with anybody. ...If he can work and support himself that is enough for me."* Abigail also stated, *"I don't fear the future and nothing worries me, our God who created him knows and has the way for him. I hope that one day he will survive on his own as everybody does."*

4. Discussion: Parenting a child with ASD is a journey that begins with initial concerns of parents that something may not be "quite right" with their child. The parent receives a diagnosis for their child, begins a marathon of visits to professionals, and navigates through services and supports to obtain the most appropriate intervention for their child. Once initial treatments are started, future worries continue to arise as the child's developmental trajectory changes and unfolds over time. Parental stress in this population is higher than in parents of typically developing children (Hastings et al., 2006). Thus, the findings of this study are consistent with previous studies (Dumas et al., 1991; Hastings & Johnson, 2001; Koegel et al., 1992; Konstantareas & Papageorgiou, 2006; Lyons, Leon, Roecker, & Dunleavy, 2010; Pisula & Kossakowska, 2010; Soltanifar et al., 2015) that indicated parents of children diagnosed with ASD experience high levels of stress.

As mentioned above, the parents described the stress and emotional disturbance they experienced. In their meta-synthesis of 14 studies on the lived experiences of parenting children with autism (Cocoran, Berry, and Hill, 2015) also reported: "Caring for a child with ASD is an emotionally taxing experience and parents reported intense negative emotions" (p. 358). Autism compels parents to endure additional roles and tasks. This is because of the behavioral problems the child with autism displayed (like physical aggression, damaging properties, and uncertainty) and the effect of the disorder (lack of self-care, inability to work, and social isolation) on the child creates a new and additional role for the parents. Parents become burdened by providing more care than what is needed for a typically developing child of that age (Knudson & Coyle, 2002).

Many of the studies of parental stress in families with ASD attribute the high levels of stress to the behavioral challenges that are often inherent to ASD (Sharpley & Bitsika, 1997). Similarly, studies by Tomanik et al. (2004) have attributed the increased stress to behavioral characteristics associated with ASD and severity of symptoms (Konstantareas & Papageorgiou, 2006). The severity of autism symptoms was also found to affect parenting stress among parents of children with ASD (Lai, Goh, Oei, & Sung, 2015; Lyons et al., 2010). Using a comparison group (parents of children with typical development) in a Singaporean sample, Lai and colleagues (2015) were able to show that parents of children with ASD (who were found to have more experience of difficult child behavior) had higher levels of parenting stress.

Stress during Diagnosis: The participants experienced shock, denial, grief, and sadness upon hearing the diagnosis of their child with autism. Heiman (2002) claimed for parents, this is the most difficult and shocking experience to find out that there is a problem with their child. Tsao, Davenport, and Schmiege (2012) further state that the two opposing experiences of a family, which are the joyous experience of having a newborn baby and the painful experience of learning within few years that the child is disabled creates a high level of stress on the parents.

Stress during day-to-day lives: According to the finding of this study, within the caregiving responsibilities, managing the behaviors of their children with autism daily is challenging. Chee et al. (2008) claimed that parents' stress was situational and related directly to their role as a parent and their interactions with the child.

Lo (1994) investigated the care-taking responsibilities of parents and categorized their family life in four groups based on the age of the individuals with autism: infancy to early childhood, early childhood to late childhood, adolescence, and adulthood. This study indicated that the care-taking role of parents is present throughout the life of the child with autism where it is higher in the first stage; gets lower in the second stage, and increases in the third and fourth stages. Although the current research did not compare the magnitude of the challenge of the caregiving role at different developmental stages as the above research did, findings concur with the presence of stress in caring for the children. Therefore, the findings of this research and the above literature show that even after parents accepted the fact that their child is autistic, the continuous care they must provide their children, mainly managing the children's behaviors and responding to their needs, is stressful for parents.

Stress from Managing the Behavior of a Child with Autism: Managing the behavior of the child with autism, which is the major care-taking role of the participants, was found to be stressful for the participants of this study. Dzubay (2011) supports this finding

by saying that a child's behavior related to having autism causes the greatest amount of anxiety and distress for parents. This is also substantiated by the study by Altieri (2006) who found that the combination of difficult emotional and physical behavior displayed by the child with autism creates a high level of stress for the entire family. Ritche (2008) further argues that it is no surprise that the caregiver of a child with autism may become distressed and begins grieving due to the lack of the child's ability to securely attach to them. Therefore, the finding of the current and above studies showed that parents are prone to stress because of the behavior of their children with autism.

The bizarre responses by children with autism's to various aspects of the environment, their pervasive lack of responsiveness to other people, resistance to change, peculiar interests, attachment to odd objects, resistance to a minor change in the environment, repetitive, peculiar hand/motor movements, unstable mood, unexplainable crying, laughing without unidentifiable cause, under/over responsiveness to sensory stimuli, such as light pain and sound, and when children behave in these unusual ways, dealing with even one of these behaviors is difficult and magnified the combination of many of these behaviors (Altieri, 2006; Dzubay, 2011; Knudson & Coyle, 2002; Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011). The daily caregiving process associated with managing the behavioral problems and the nature of ASD is also psychologically damaging for caregivers. Schaaf et al. (2011) indicated that parents have to re-arrange their daily routines to accommodate their child with autism as the child is unpredictable and often unable to regulate their behavior.

Stress about the future: The findings of the current study indicate that parents experience stress about the future of their children and their own future as well. Most of the time parents are the primary caregivers of a child. They are the ones who provide their child with autism with exceptional care no matter how distressful and frustrating the process is. They are the ones who can tolerate their children for lifelong treatment. So, the thoughts and worries about who is going to care for their child in their absence constantly bother parents. Heiman (2002) examined what aspects of the future worries parents and found that financial and physical independence, education, and how the children would manage themselves were primary concerns. Thus, parents felt overwhelmed due to the inability of the child to be independent, the vulnerability of the child, the inability of the child to properly deal with psychosexual issues during adolescence, and the possibility of regression of the problem. This is consistent with other studies (e.g., Bayat, 2007; Gray, 2006; Murphy & Tierney, 2007), whereby parents of children with autism felt great psychological distress due to worry about the child's level of independence and being a burden later in life, their inability to maintain relationships as well as worry about what would happen to their child if they became ill and could no longer take care of them. These findings are similar to reports from other parents around the world including participants from the U.S. (Bayat, 2007), Australia (Farrugia, 2009), China (McCabe, 2008), Taiwan (Shyu, Tsai & Tsai, 2010), Ghana (Anthony, 2009), and Kenya (Gona et al., 2016).

Generally, the parents were not only concerned about the future of their autistic child's, but also had even more concerns about their own future. "The looming thought is these parents will never be independent of their autistic child" (Koegel et al., 1992, cited in Glass, 2001, p. 124). This is a very powerful statement used by the author that affects most if not all parents of autistic children. Upon determining the leading source of anxiety and stress for parents of ASD, Koegel et al. (1992) affirmed the long-term burden of parenting a child with autism. The issue of separation becomes particularly critical (Lo, 1994). This could be at least in part since their child would be a burden to them later in life or lack of established residential settings to provide support for individuals (adults) on the spectrum (Parish-Morris, 2019).

5. Conclusion: The study describes the sources of stress in parents of a child with autism in Addis Ababa, Ethiopia. The burden of caring for a child with ASD was strenuous for parents. Findings indicated that initially parents had no or little knowledge about autism and parents were overwhelmed with the concern over the future life and career of their children with autism upon the detection of their child's autism. Thus, parents raising children with ASD are leading a complex life partially due to the stress emanating from the daily hectic schedule and extra responsibilities and duties to manage their children's difficult behavior and functional limitations. As a result, some parents may not pay proper attention to themselves, their life partners and other children without disabilities.

6. Recommendations: Parents of children with ASD were surrounded by the challenges that came along with the diagnosis of their children with autism. In making things complex, lack of government intervention and services were also posed additional responsibility on parents and families of children with ASD. Hence, unless some immediate and feasible measures are taken, the stress, miseries and bitter sentiments of these parents remain unsolved and further trigger them to serious psychosocial and financial turbulences.

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