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Reactions of Parents to the Diagnosis of Autism in Addis Ababa, Ethiopia

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Abstract

Autism is a neuro-developmental disorder that causes impairments in multiple areas of development including social interaction, communication, and behavior. In Ethiopia, around 600,000 individuals are living with autism. Developmental disorders such as autism are sometimes regarded as an evil-spirit or as a punishment from the supernatural/divine power in this country. The level of awareness, acceptance, and support for Autism Spectrum Disorder (ASD) in Ethiopia is very low. Joy and Nehemiah Autism Centers are the only two centers providing support for children with autism and their parents. The main objective of this study was to examine the reactions of parents to the diagnosis of autism in Addis Ababa, Ethiopia. To achieve this objective, nonrandom purposive sampling was used to select parents of children with ASD. Twelve parents were recruited from the two institutions with the help of managers of the centers. Data were collected by semi-structured interview guides. Interviews were transcribed and analyzed using thematic analysis. The identified reactions of parents to the diagnosis of autism were: stress, shock, denial, and feelings of guilt, blame, sorrow, and grief. Only a few participants relieved by the fact that their confusion was over and knowing their challenge had a name, autism. Overall, the negative feelings and reactions were dominant, but a few parents who felt relieved perhaps reframed their minds early on to thinking towards helping and providing care to their children. As a result, parents need to be cared for in order to provide for the needs of their children at the moment of diagnosis and throughout the entire process of caring for individuals with ASD.

Keywords: 1. Autism, 2. Parents, 3. Reactions, 4. Diagnosis, 5. Child with ASD

Introduction

ASD is a severe neurological developmental disorder, beginning in early childhood, in which an individual has varying degrees of deficiency in social interactions and communication as well as behavioral routines (American Psychiatric Association, 2013). The prevalence of autism has considerably risen and one in 68 children or 1.5% of all children in the US was diagnosed with ASD (Center for Disease Control and Prevention, 2014). Autism has steadily increased in reported prevalence over the past decade (Maenner et al., 2020), leading to growing pressure on professionals and systems to provide a timely and accurate diagnosis (Makino, Hartman, King, Wong & Penner, 2021).

Today, there is no reliable biological marker for ASD. Diagnosis of ASD is based on behavioral observation, parental interview, developmental history, and clinical impression (Dawson & Murias, 2009). Medical and developmental history is taken through discussion with parents. This information is combined with the other assessments to provide an overall picture. Professionals diagnose autism through the presence or absence of certain behaviors, characteristic symptoms, and developmental delays. The criteria were outlined in the DSM-IV and DSM-V and the International Classification of Diseases/ICD-10 (World Health Organization, 2004). Although not within the scope of this paper, it is noted that, there are other additional screenings and diagnostic tools available to clinicians screening children for ASD.

Reaching a diagnosis of autism is not a simple process (Ponde, Matos & Oliveira, 2017). Parents' search for help is marked by a period of uncertainty and questions prior to receiving confirmation of the diagnosis (Onzi & Gomes, 2015). Delaying the diagnosis and valuable interventions for children with ASD until school age can be extremely detrimental to the children and their parents. Searching for answers to their questions, ascertaining the diagnosis, and obtaining appropriate treatment are daunting challenges for most parents and can cause financial, social, and emotional difficulties that negatively affect the entire family (Hock, Timm, & Ramisch, 2012; Karst & Van Hecke, 2012; Neely-Barnes, Hall, Roberts, & Graff, 2011).

Receiving a diagnosis of ASD in a child constitutes a relevant event in parents' lives and in the life of a family (Howlin & Moore, 1997). When the diagnostic process comes to a close and a family is finally told their child has ASD or is autistic, parents have a variety of reactions, both positive and negative (Abbott, Bernard, & Forge, 2013; Mansell & Morris, 2004). For parents and caregivers, the diagnosis or evaluation process creates a learning session to acquire advice from the professionals. On the contrary, diagnostic periods are challenging due to unexpected reactions of families. The reaction of families to the diagnosis varies from individual to individual. The parents experience a range of reactions to the diagnosis of autism from extreme shock, grief, or denial to relief. Negative and positive (relief) feelings are the common mixture experienced by parents (Ozonoff, Dawson, & Mcpartland, 2002). Upon hearing their child's diagnosis, a study by Banach, Iudice, Conway, and Couse (2010) found that 52% felt relieved, 43% felt grief and loss, 29% felt shocked or surprised, and 10% felt self-blame.

This diagnosis can produce strong emotions and stress (Mansell & Morris, 2004) but also can help families to learn about their child's weaknesses, strengths, and access to helpful resources (Moh & Magiati, 2012). Some parents express that their relief is because they finally know what is going on with their child and can move forward (Midence & O'Neill, 1999). Many parents note that the diagnosis helped them gain acceptance and understanding of their child's behaviors (Mansell & Morris, 2004; Midence & O'Neill, 1999). In addition to positive emotional reactions, many parents expressed negative emotions as a result of receiving the diagnosis. Mansell and Morris (2004) found that 73% of parents reported worrying more about their child's future as a result of the evaluation. Parents also commonly describe feeling "shocked" or "in shock" after the diagnosis was given (Abbott et al., 2013; Mansell & Morris, 2004; Nissenbaum, Tollefson, & Reese, 2002).

Similarly, parents also expressed that they left somewhat confused about the diagnosis or uncertain about what to tell others about the diagnosis (Abbott et al., 2013; Mansell & Morris, 2004). Several parents felt that they came away with very little information about autism and had to get it from other sources (Mansell & Morris, 2004). Parents in two UK studies identified post-diagnostic support (including information, follow-up, and direction) to be a top research priority in the coming years, and many felt frustrated with leaving the feedback session feeling directionless, without necessary supports (Crane et al., 2018; Pellicano, Dinsmore, & Charman, 2014). Thus, parents often express feeling devastated, upset and hopeless about their child's diagnosis (Abbott et al., 2013; Midence & O'Neill, 1999; Nissenbaum et al., 2002). Consequently, the diagnosis can also lead families to despair about their child's future and leave them unsure of how to proceed (Mansell & Morris, 2004). Professionals are also challenged by making ASD diagnoses which identified barriers to conducting ASD diagnostic assessments including inadequate training, challenges on how to disclose the diagnosis to families, and concerns about how to help families navigate through resources in a fragmented system (Jacobs, Steyaert, Dierickx, & Hens, 2018; Penner, Anagnostou, & Ungar, 2018). According to Siegel (1996), diagnostic debriefing is necessary for some parents to assure the fit between the observations of unusual child behavior and the real entity.

Parents often cite that receiving the diagnosis was a turning point in their lives (Howlin & Moore, 1997). The goal of diagnostic assessment is not only to clarify the diagnosis but also to help the caregivers and child understand the diagnosis and direct the family to appropriate supports (Abbott et al. 2013; Zwaigenbaum and Penner, 2018). The diagnosis should help them find information, access services, gain understanding and acceptance, and receive support (Moh & Magiati, 2012).

The parents' functioning and their reaction to the situation of having a child with ASD need to be evaluated as part of the diagnosis communication, taking into consideration that this process will differ from region to region, in the different countries (Reed & Osborne, 2012). Increasingly research focuses on interventions and treatment of children diagnosed with ASD. Few studies have examined parents' experience during the diagnosis process for children with ASD in Ethiopia. In this respect, the objective of the present study was to examine how parents react to the diagnosis of autism in their children. Interventions to support these parents require knowledge of their emotional state to plan and implement programs adapted to their real needs.

1. **Method:** The study aimed to investigate the reactions of parents to the diagnosis of autism in Addis Ababa, Ethiopia. Purposive sampling was used to select 12 parents of children diagnosed with ASD from two centers, namely, Joy and Nehemiah autism centers. Parents were recruited via schools or centers that offer placement for children with ASD, and via teachers, therapists, and coordinators of the centers. In addition, six key informants were recruited from the two centers. The data were collected using semi-structured in-depth interview guides and key informant interview guides. A pilot study was conducted and minor adjustments were made to the interview guides. Finally, interviews were transcribed and analyzed using thematic analysis.

2. Results: Parents Reactions to the Diagnosis of Autism

Theme 1: "I was shocked and felt lost" (Roman)

Participants of the study reacted to the diagnosis of autism in a variety of ways. The diagnosis processes for the majority of the parents were very long, labyrinthine, and complicated procedures. The majority of the parents demonstrated a range of emotions immediately following the diagnosis, of which the salient feelings and reactions were shock, confusion, denial, despair, and sorrow, feelings of blame and guilt, and being overwhelmed by the news. However, other parents reacted with feelings of relief and described it as a learning session to start a new chapter in their life's journey.

Most parents spoke about the time they heard the diagnosis as a very shocking, despairing, and disturbing experience. Upon hearing the diagnosis, Zahara did not want to believe what she heard about her child and reacted with shock, confrontation, denial, and outcry. She articulates [with saddened and lower tone of voice]:

> *… It was a hard time when I heard that my son had been diagnosed with autism, [clearing tears from eyes], I did not want to believe, I confronted the doctor because I know other children with [low functioning] autism and that is not how they behave. I just wasn't prepared to accept it. I was in a denial for a while. I knew what autism was in general, but I didn't know its types.*
>
> *… Really, I was shocked and felt lost when we received the diagnosis, I felt like a person who had lost everything… especially after browsing the internet about autism, I stayed home the whole day and I was just in tears literally for the first two days. I'm crying, wondering how I am going to get through this. Why me? What did I do wrong? I couldn't stop crying and it was a devastating experience* (Roman).

When the diagnosis was formally confirmed by the physician, Martha (a mother), described how she felt and reacted by saying,

> *I was shocked very much... When I first heard that my son was suffering from a disorder that would last for the rest of his life, I have out–cried a lot. I was very disturbed and didn't even know what to say. The shock and the pain are something you can't explain in words… Especially if it is something you never heard in life, autism, happening to your child, I mean it is hard. I can't tell and express how exactly I felt. I was sick for the whole night, thinking about the incurability of the disorder and the future life of my child.*

The initial reactions of Aster to the diagnosis of her son with autism included stress, feelings of blame, and guilt. She asserted:

> *When they [the medical professionals] tell you, it comes as a bit of a blow, oh my God! I was just a wreck; because we knew nothing about it, you know, you think the worst, like what am I going to do? How do I care for him within our limited resources? It generally blows your mind. As a result, I felt stressed and cried a lot for some time…what makes me feel bad is I took the blame and guilt to myself. You know, during my pregnancy, I worried a lot because of the bad relationship between my husband and me. He used to be a drunker, alcoholic (which he has stopped after our child's diagnosis). He drinks almost every day, we run out of money very early each month, I would cry, stressed a lot and I don't provide appropriate care for myself and the child in my womb (I don't eat well and take good rest). Thinking about my stress and lack of good care during the pregnancy, I feel guilty and blame myself. I thought I would not have a child with autism or it might not happen if I would take good care. … I was distraught, heartbroken, and it was like the worst feeling…*

A key informant from Nehemia Autism Center also stated,

> *…Upon the diagnosis, some feel blame and guilt, shock or denial. …One key factor for the negative reactions might be due to a low level of awareness and the prevailing belief that it is a result of God's punishment for one's wrongdoings, which may in turn, result in a feeling of self-blame, guilt, and stigma. Only very few (those who were fed up with the diagnostic process or*

> *suspicious of the disorder) accept and endeavor to learn how to live with the challenge and help their children.*

Theme 2: We felt relieved! (**Belay**)

In contrast to the other participants who felt great concern about their child's condition, a few were relieved to get the diagnosis, knowing what was wrong with their child after an infuriating process. Belay, a father, stated,

> *When we found out what was wrong with Daniel, we (as a parent), felt relieved. Now things were clear. Before the diagnosis, we faced obvious, more pronounced and great impact to know what was wrong with our child. We have been at different medical centers; none of them came up with a diagnosis of autism. As we didn't get a response from the medical aspect, we visited numerous religious places for holy water treatment. In all our effort after a long period, numerous ups and downs, a physician at a private medical hospital diagnosed our son with autism. Then, we felt relieved, our child is autistic; he is a child who needed to be disciplined, exceptionally cared, and needs to access a special school.*

Meseret, a mother sharing a similar experience, also felt a bit of relief on receiving her son's diagnosis.

> *When Yafet was finally diagnosed, I felt a bit relieved because whatever my son was going through had a name. I had known what is wrong with my son, and I knew what I was dealing with. I decided not to give away my feelings; all I cared about was how I was going to help my son, what I could do for him because I have spent and drained a lot to know the problem [autism]. Then, started working on how to handle and help him. I made things up in this way.*

3. Discussion: The participants were asked questions on how they felt, responded, or reacted when they noticed their child's autism. It is argued that when parents heard the news for the first time that their children are autistic, they enter into shock, uncertainty, anger, denial, and guilt (Hong, Seltzer, & Greenberg, 2008). According to Durban et al.'s (2012) study in the Philippines, the majority (65.12%) of the parents were stressed and overwhelmed upon learning of their child's disability. The authors further elaborated that parents expressed being shocked, sad, and fearful of their child's fate especially if the child with developmental delay would outlive them. In this qualitative study, the parents described their reactions to diagnoses of autism, and it was found that almost all the participants displayed a range of emotions including despair, sadness, shock, confusion, sorrow, grief, and feelings of loss. This is very similar to reports from participants living in the U.S. (Bayat, 2007; Myers, Mackintosh, & Goin-Kochel, 2009), France (Chamak, Bonniau, Oudaya, & Ehrenberg, 2011), China (McCabe, 2008), Iran (Samadi, McConkey, & Kelly, 2012), Turkey (Bilgin & Kucuk, 2010), and South Africa (Badu, 2015) that found parents to have feelings of despair, sadness, or being overwhelmed upon first hearing of their children's diagnosis, along with a period of grief associated with those feelings. On the other hand, a couple of parents reported a feeling of relief upon learning of their child's diagnosis, which is similar to respondents in the United Kingdom (Russell & Norwich, 2012) and France (Chamak et al., 2011).

4. Conclusions: The study describes the parents' reactions to diagnosis for parents of a child with autism based on a sample from Joy and Nehemia Autism Centers in Addis Ababa, Ethiopia.

Findings indicated that initially parents had no or little knowledge about autism and reacted with feelings of relief, shock, denial, loss, grief and sadness, and frustration. Parents were also overwhelmed with the concern over the future life and career of their children with autism upon the detection of their child's autism.

5. Recommendations: 1) the findings underscored the need to design policies that address the comprehensive burdens of ASD at a national level. Thus, federal policymakers must understand and determine the most appropriate programs and intervention services for all individuals with autism and their families. 2) Universities, research institutions, and concerned government institutions should encourage researchers and academicians to carry out research in the area of autism and produce policy recommendations to improve the lives of autistic children and their families in demonstrating the exact implications of autism on economic, social and psychological issues at the household, community and country level. 3) Considering the heterogeneity of Ethiopia, conducting a study in other parts of the country is highly recommended. Further research on parents raising a child with autism residing out of Addis Ababa may provide diverse findings. Overall, considering the inadequacy of studies of ASD in Ethiopia, additional research on the situation of individuals and families impacted by ASD in Ethiopia would contribute to the literature and possibly inform practices leading to improved outcomes for this population.

Limitations of the study: The small sample size and geographical context limit transferability to the broader population. All information was collected from the parents by self-report.

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