

The Public Reactions and Social Stigma faced by Parents of a Child with Autism in Addis Ababa, Ethiopia: A Qualitative Study

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Abstract: This study aimed to examine the public reactions and social stigma faced by parents of a child living with autism in Addis Ababa, Ethiopia. A convenience sample of 12 parents was interviewed. Both positive and negative public reactions were identified: rejection/avoidance, blaming looks, rumors, fisting, pointing fingers, staring, and non-verbal cues as indicators of stigma were reported. Hence, professionals and the concerned bodies should work to raise the awareness of the society in this regard.

Keywords: Autism, Parents, Publics reactions, Stigma

1. Introduction

Autism is a developmental disorder characterized by difficulties with social interactions, social communications and an unusually restricted range of behaviors and interests (Agyekum, 2018). Autism is a common developmental disability which occurs in one of 116 children over the world (WHO, 2013). The autism spectrum disorder (ASD) affects the cognitive and social capabilities in diagnosed children as well as their families (Alshaigi et al., 2019). Families caring for a child with autism experience several social challenges. Based on families' reports, Gray's (1994) study indicated that society, in general, is resistant to accept children with autism. The low level of probability to get acceptance from society exposes parents to social stigma and embarrassment associated with inappropriate behavior displayed by their children (Altiere, 2006, p. 15). Extended family members may also show rejection of autistic children or detach themselves from the family. Schall (2000) explained that relatives of parents with a child diagnosed with autism might be cold, distant, and unhelpful.

Public area attendance is another issue that affects the social life of parents living with a child diagnosed with autism. Since families have a fear of their children's behavior, parents prefer to isolate themselves instead of facing the frustration of taking their child out in public (DeMyer, 1979 as cited in Altieri, 2006, p. 15). Gray (1993) indicated that parents, most commonly mothers and extended family members, experienced severe socializing problems and frequent social rejection. Findings from the follow-up research also indicate that the majority of parents experienced stigma with mothers more likely to experience it than fathers (Gray, 2002, p. 221).

Stigma: Erving Goffman, a widely cited scholar in the field, defined stigma as "the situation of the individual who is disqualified from full social acceptance" (1963, p. 9). Hence, there is an understanding that a particular individual's or group's unique traits have been evaluated and deemed to be discredited by mainstream society (Goffman, 1963). The stigma associated with ASD is significant and enveloping. As a result, Kinnear, Link, Ballan, and Fischbach (2016) suggest the need for research into the parents of children with ASD to further understand the components and impact of stigma on their lives.

Parents of children with autism experience stigma from the outside world. They often find that the public's reaction to them is stereotypical and negative (Gray, 2002). Gray (2002) further explained that the parents of autistic children frequently encounter hostile or insensitive reactions (such as slur, frowning, unusual staring, and fisting) from the public when their children behave inappropriately. This problem may be exacerbated by the contrast between the children's appearance, which shows no signs of disability, and their behavior, which is perceived as abnormal and strange.

Parents reported that they received criticism from strangers when they were out in public (Farrugia, 2009; Gray, 2002). According to parents' reports, strangers thought their children were acting out and should be disciplined (Farrugia, 2009). Parents conveyed diverse reactions with regards to the judgment of strangers. In certain cases, parents decided to ignore such strangers, whereas other parents confronted strangers and/or educate them about the nature of ASD (Gray, 2002).

Generally, according to Goffman (1963), stigma deeply discredits an individual from a whole person into a tainted, discounted one. Gray and Holden (1992) demonstrated that stigma is linked to decreased wellbeing via increased levels of stress, particularly in

social interactions. In supporting this view, Swanepoel (2003) stated that families of autistic children lose friends or isolate themselves because of the public's criticism and inappropriate behavior of the autistic child in public places. As a result, Wachtel and Carter (2008) argue that when a child is diagnosed with ASD, parents experience a range of feelings and a set of challenges that impact their psychological and social wellbeing.

2. Method: The participants were selected through a convenience sampling. Data were collected from 12 individuals who were participated in the study via in-depth interview guide. The data were transcribed and analyzed through thematic data analysis method.

3. Result: Reactions from the Public and Social Stigma. In their daily lives with their children on the spectrum, participants faced negative reactions of various people including neighbors and the general public. The participants reported differing views on the reactions and comments from society. Accordingly, Yared, a father, reported sympathy and love from neighbors and community members:

...Everybody is sympathetic toward my son. People around me, especially, my neighbors love him and they take good care of him when his mother and I were not around. We are lucky to have these kinds of neighbors. ...you know people around me know my son's condition even if they don't have detailed information and knowledge about the disorder. They are showing countless sympathy for our son and encourage us when they see little progress on our child that motivates us to provide more care and treatment for our child.

However, most have talked about negative reactions and perceptions of society and how that bothers and distresses them. The lack of understanding from the public or the way people react when they see their children and judgments gave them a hard time and makes them feel sad. As Meron describes:

Autism is not well understood by the public in this country. Society mostly perceives these [autistic] children as being raised (socialized) in a bad manner. Mostly, I see people's eyes on us, feel judging us, I mean, everybody stares at her or stares at us. I did feel nobody seems to understand why she displays such unique behavior and what I am going all the way through because she doesn't seem disabled. I get angry when a person tells me what I should be doing to make her behave well. ...people thought he was just a boy socialized in a bad way, not knowing he is autistic is what makes them judge and think that way. As a passerby, while individuals occasionally see his tantrums, aggressiveness, and screams, they would come to me and tell me how to make him a calm and unspoiled child. ...when I tell them he is autistic, they suck on lips for me, which makes me feel bad (Martha).

The community is not aware of children with autism or other mental illnesses. They consider them as the children with a bad omen, having a curse or being punished for a prior sin. It is distressing for parents like us. I am a protestant married to a non-believer; my sister told me that some of my relatives thought as if it is the result of punishment from God for this sin. It makes me feel sad. ...the other thing is when you move with your child in public places, the way people react and stare at you just makes you feel different and pity. I wish people had the awareness and saw it as an ordinary incident. I hope they can just see them [autistic children] like a typical child (Aster).

Social Stigma: Another key theme identified as a social challenge for parents of a child with an ASD was indeed 'social stigma.' These stigmas as mentioned by parents come from friends, neighbors, relatives, and the general public. Even though the extent and source of stigma varies, the parents reported rejection/avoidance, blaming looks, rumors, fisting, pointing fingers, staring, and non-verbal cues as indicators of stigma. Rejection is one way that the parents feel stigmatized and discriminated against. The parents have observed rejection of their children and of other family members. This rejection is manifested in different forms such as by not responding well when they need assistance especially when the child disturbs, not coming to their home, lack of interest to invite them home, and by pushing away (distancing) the child or parents. For example, Zahara feels rejections from her friends and describes the situation as:

I have noticed my friends are becoming fewer and fewer, I have lost friends on the way. When you ask them, their reason was 'I don't think you have time to chat and spend with us.'
...I have also observed some of my relatives especially from my partner's side would not have good eye contact with me, thinking as if I am the cause and reason. Because of the history of mental health problems in my family (you know, my uncle has a mental health problem) (Meseret).

Though half of the participants mentioned that their neighbors are sympathetic towards them, two parents spoke of how neighbors' lack of understanding stigmatizes their child:

Some neighbors didn't want their children to play with him as if his condition is a communicable illness (Belay).

Some people won't let their children come to your house; they don't want their children to mix with my son thinking he is possessed by evil. So they want to stay away from you as much as they can. It was an embarrassing experience... (Martha).

Some experience stigmatization that often placed the parent in a position of 'blame' without considering their reality. In this regard, Aster spoke about the stigmatization in the form of 'pointed fingers, blaming looks, and staring' whenever she is going out in public with her autistic child:

When you go out in public places, you may come across pointing fingers, unusual staring, or a blaming look. They see me as the woman with a badly behaved child, as if it is my fault, or they see my son as naughty, without knowing that he is challenged, which makes me feel bad and these are the sort of social challenges that I am facing.

The participants' explanation of why people stigmatize and discriminate against them was lack of awareness from the community such as associating the illness with evil, thinking that the children are aggressive, and considering the behavior as deliberate. Parents also mentioned that there was a situation in which people relate it with parental sin and as if it is the result of God's punishment. However, three parents did not face stigma for various reasons including having their own house with a separate fence, their children's behavior was not aggressive, or they have supportive neighbors and understandings relatives.

4. Discussion: The participants also discussed how society views their children's developmental disorders and the reactions of the community. The way the community reacts towards children with developmental disorders had a big impact on the participants. Reactions of pity, feeling sorry, and sucking one's lips had the effect of creating sadness and discomfort in the parents. This reaction might be because of a lack of awareness interacted with different cultural and religious explanations (Malik, 2011) and high misconceptions and assumptions about developmental disorders (Bashir et al., 2014) which created the stigma in the community (Tilahun et al., 2016).

The findings were two types. Some reported sympathy and love from neighbors and community members towards their children similar to Murphy and Tierney (2007) who reported sympathy was extended to the parents of children with autism from different members of society. However, other parents talked about how lack of understanding from the public gave them a hard time and how being negatively evaluated by people around made them feel judged and stigmatized over time.

The current finding that clarified participants complained about the lack of understanding of autism from the society and the unsympathetic comments from the general public made them feel being negatively evaluated, judged and isolated by people around them was consistent with previous studies (Aadil et al., 2014; Hoogsteen & Woodgate, 2013; Mann, 2013; Nyoni & Serpell, 2012). Moreover, others (Bakare et al., 2009; Bello-Mojeed, Bakare & Munir, 2013) not only found a very low level of knowledge and awareness about ASD among the general population, but a low level of understanding among even health care workers leading to the negative attitudes, avoidance, rejection, as well as negative comments. This stigma and discrimination according to the authors are manifested in rejection and embarrassment which is expressed by rumors, taunting, side talk, and nonverbal cues. This is consistent with the WHO (2003) publication on Mental Health that argued, stigma and discrimination are manifested by "stereotype, fear, embarrassment, anger and rejection, avoidance and denial of the most common basic human rights" (p. 13).

Most of the participants of the study spoke of stigma that is consistent with the findings of Gray (2002) in Australia, and Mak and Kwok (2010) in China. The most common examples of stigma by association reported by parents in this study included being avoided, glared at, blamed, disregarded, and given unsolicited advice. Farrugia's (2009) study also revealed unfriendly looks and staring.

Associating the illness with the supernatural power and lack of understanding of the illness are mentioned as factors that make parents vulnerable to social stigma. Lack of knowledge and a widespread belief that associates mental illness or developmental disorder with supernatural power make millions of families struggle with its social consequences (Alem, Jacobsson, Araya, Kebede, & Kullgren, 1999; Shibrei et al., 2003). Considering the child as lazy, and foolish; viewing the behavior as deliberate and rude; and negative labeling such as dependent and helpless, thoughtless, dangerous, and unpredictable are reasons that parents face stigma (Seltzer et al., 1995; Shibrei et al., 2003). Similarly, a study by Getnet (2013) found that attitudes towards people with a developmental disability and their families in Ethiopia are still characterized by stereotypes and prejudice, based on traditionally held views that link disability with punishment and curses.

The experience of stigma and the feelings it provoked in participants could be related to the proximal processes in Bronfenbrenner's (1986) ecological system theory. Participants were concerned about stigma and other people's perceptions of ASD. Stigma could influence the relationships that some participants had with family members, occurring at the level of the microsystem and the mesosystem (in their relationships with professionals and significant others). Lilley (2012) also identified the presence of stigma at a macro-systemic (communal) level, which was manifested in the form of lack of understanding and negative comments which make the participants feel judged (if it is rooted in a culture's overarching beliefs and values).

5. Conclusion: Most of the parents were not aware of autism before the diagnosis. This limited knowledge and information reflected a lack of awareness about autism in the community. The limited understanding and wrong perception of the causes of autism within society also created additional social burdens. Parents of children with autism experience negative responses from the community in the form of isolation and social stigma. Due to traditionally held beliefs about their children's disability, the parents felt underrated by society as well as their relatives threatening their psychosocial well-being. Therefore, they are isolated, blamed and their participation in social life is limited by virtue of having and caring for a child with autism.

6. Implications: The larger community at the country level can be addressed through wide-ranging media coverage about autism. The media can also play an important role in educating the community for the social acceptance of children with autism and their families by increasing the understanding of ASD. Thus, effective coordination among autism centers, schools, Media, and families to enhance the level of awareness, and to promote social inclusion and supports in schools, neighborhoods, and public places.

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Reference

Aadil, B., Unjum, B., Afifa, L., & Zahoor, A. (2014). Challenges faced by families of autistic children. *International Journal of Interdisciplinary Research and Innovations*, 2(1), 64–68.

Agyekum, H. (2018). Challenges of parents with autistic children in Ghana. *Brain Disorder and Therapy*, 7(4), 1-4. doi: 10.4172/2168-975X.1000248.

Alem, A., Jacobsson, L., Araya, M., Kebede, D., & Kullgren, G. (1999). How are mental disorders seen and where is help sought in a rural Ethiopian community? A key informant study in Butajira, Ethiopia. *Acta Psychiatrica Scandinavica*, 100 (Suppl. 397), 40–47.

Alshaigi K., Albraheem, R., Alsaleem, K., Zakaria, M., Jobeir, A., & Aldhalaan, H., (2019). Stigmatization among parents of autism spectrum disorder children in Riyadh, Saudi Arabia. *International Journal of Pediatrics and Adolescent Medicine*. <https://doi.org/10.1016/j.ijpam.2019.06.003>.

Altieri, J. (2006). *Family functioning and coping behaviors in parents of children with autism*. Unpublished manuscript. Eastern Michigan University. Retrieved May 28, 2019, from <http://www.commons.emich.edu/cgi/viewcontent.cgi?article=1053&context=theses>.

Bakare, M., Agomoh, O., Eaton, J., Onwukwe, U., Onyeama, M., Okonkwo, O., Igwe, N., Orovighwo, O., & Aguocha, M. (2009). Knowledge about childhood autism and opinion among healthcare workers on availability of facilities and law caring for the needs and rights of children with childhood autism and other developmental disorders in Nigeria. *BMC Pediatrics*, 9(3), 1-12.

Bashir, A., Bashir, U., Lone, A., & Ahmed, Z. (2014). Challenges faced by families of autistic children. *Journal of Interdisciplinary Research and Innovation*, 2(1), 64-68.

Bello-Mojeed, A., Bakare, M., & Munir, K. (2013). *Identification of Autism Spectrum Disorders (ASD) in Africa: Need for shifting research and public health focus*. Berlin, Heidelberg: Springer-Verlag.

Bronfenbrenner, U. (1986). Ecology of the family as a context for human development: Research perspectives. *Developmental Psychology*, 22(6), 723-742.

Farrugia, D. (2009). Exploring stigma: Medical knowledge and the stigmatization of parents of children diagnosed with autism spectrum disorder. *Sociology of Health and Illness*, 31(7), 1011-1027.

- Getnet, D. (2013). *Autism and Alzheimer's disease in Ethiopia: A present glance*. International conference on psychology of Autism and Alzheimer disease. Accessed April 03, 2019, from <http://www.omicsgroup.com/conferences/psychology-autism-alzheimers-2013>.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. New York: Touchstone.
- Gray, E. (1993). Perceptions of stigma: The parents of autistic children. *Sociology of Health and Illness*, 15(1), 102-120.
- Gray, E. (1994). Coping with autism: Stresses and strategies. *Sociology of Health and Illness*, 16(3), 275-300.
- Gray, E. (2002). Ten years on: A longitudinal study of families of children with autism. *Journal of Intellectual and Developmental Disability*, 27(3), 215-222.
- Gray, E., & Holden, J. (1992). Psycho-social well-being among parents of children with autism. *Australia and New Zealand Journal of Developmental Disabilities*, 18(2), 83-93.
- Hoogsteen, L., & Woodgate, L. (2013). Centering autism within the family: A qualitative approach to autism and the family. *Journal of Pediatric Nursing*, 28(2), 135-140.
- Kinnear, S., Link, B., Ballan, M., & Fischbach, R. (2016). Understanding the experience of stigma for parents of children with autism spectrum disorder and the role stigma plays in families' lives. *Journal of Autism and Developmental Disorders*, 46(3), 942-953.
- Lilley, R. (2012). It's an absolute nightmare: Maternal experiences of enrolling children diagnosed with autism in primary school in Sydney, Australia. *Disability and Society*, 28(4), 514-526.
- Mak, W., & Kwok, T. (2010). Internalization of stigma for parents of children with autism spectrum disorder in Hong Kong. *Social Science and Medicine*, 70(12), 2045-2051.
- Malik, A. (2011). *Beliefs and attitudes towards intellectual disability: with in the UK Pakistani community as perceived by key community members*. Doctoral Thesis, UCL (University College London). Retrieved April, 13, 2021, from <http://www.ucl.ac.uk>.
- Mann, A. (2013). *The experiences of mothers of children with autism in Jamaica: An exploratory study of their journey*. University of South Florida. Graduate Theses and Dissertations. Retrieved on June 15, 2019, from <http://scholarcommons.usf.edu/etd/4722>.
- Murphy, T., & Tierney, T. (2007). *Parents of children with autistic spectrum disorders (ASD): A survey of information needs*. Report to the National Council for Special Education Research Initiative. Accessed August 27, 2018, from http://ncse.ie/wpcontent/uploads/2014/10/Parents_of_children_with_ASD.pdf.
- Nyoni, J., & Serpell, R. (2012). *The impact on parents of raising a young child with autism: A phenomenological study of parents in Lusaka, Zambia*. Lusaka: International Disability Research Center.
- Schall, C. (2000). Family perspectives on raising a child with autism. *Journal of Child and Family Studies*, 9(4), 409-423.
- Seltzer, M., Greenberg, S., & Krauss, W. (1995). A comparison of coping strategies of aging mothers of adults with mental illness and mental retardation. *Psychology and Aging*, 10(1), 64-75.
- Shibre, T., Negash, A., Kullgren, G., Kebede, D., Alem, A., Fekadu, A., Medhin, G., & Jacobsson, L. (2003). Schizophrenia: Illness impact on family members in a traditional society of rural Ethiopia. *Journal of Social Psychiatry and Epidemiology*, 38(1), 27-34.
- Swanepoel, Y. (2003). *Primary caregivers' experience of raising a child with autism: A phenomenological perspective*. Edinburgh: Rhodes University.
- Tilahun, D., Hanlon, C., Fekadu, A., Tekola, B., Baheretibeb, Y., & Hoekstra, A. (2016). Stigma, explanatory models and unmet needs of caregivers of children with developmental disorders in a low-income African country: A cross-sectional facility-based survey. *BMC Health Services Research*, 16(1), 1-12.

Wachtel, K., & Carter, A. (2008). Reaction to diagnosis and parenting styles among mothers of young children with ASDs. *Autism, 12*(5), 575-594.

WHO/World Health Organization. (2003). *Investing in mental health*. Geneva, Switzerland: Author.

World Health Organization. (2013). *Autism spectrum disorders and other developmental disorders: From raising awareness to building capacity*. Geneva, Switzerland: Author.