

Walking in their shoes: exploring the lived experiences of mothers of autistic children

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ABSTRACT

There has been a dramatic increase in Autism Spectrum Disorder (ASD) around the globe. A growing body of research has sought to characterize the different presentations of ASD among boys and girls. However, very limited number of Indian studies have focused on mothers of children with ASD. As mothers are the major caregivers of the autistic children, deeper understanding is needed to understand the life experiences of Indian mothers with ASD children. According to the American Psychiatric Association Diagnostic and Statistical Manual, Fifth Revision (DSM-5), the current diagnostic criteria for ASD include deficits in: (a) social interaction and nonverbal communication; and (b) restricted, repetitive movements, behaviours and interests. The lifelong nature of autism has deep implications on parents of children with the disorder, resulting in a wide range of challenges. This is because parents, especially mothers, are generally the primary caregiver of children with autism. Very limited number of Indian studies address the daily challenges faced by mothers of children diagnosed with Autism Spectrum Disorder. The purpose of this research is to gather in-depth information and understanding of mothers who have autistic children. Their perception and difficulties in raising a child with autism and to critically look at areas where future research might need to focus. To conceptualize the recorded experiences; primarily the feminist standpoint epistemology (that focuses on building knowledge and empowerment through women's lived experience) has been taken into consideration. A pre generated interview questionnaire has been used while conducting the interviews. To analyse the mothers' narratives, thematic content analysis method has been used. The thematic content analysis of the qualitative data identified five core categories: resources, care load distribution, me time and mental health, autism: subjective understanding of mothers, blame and mothering. The results of this study offer valuable insight into the lived experiences of mothers of children with autism and need for further course of action to empower them.

Keywords: *Autism, Blame, Autistic Children, Qualitative Study*

Autism Spectrum Disorder (ASD) is a developmental disorder involving abnormal communication, repetitive and restrictive interests and impaired social functioning. Studies have shown that it can have a profound impact on the individual as well as family life. In

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Received: February 19, 2020; Revision Received: March 23, 2020; Accepted: March 31, 2020

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India, little research has sought to examine parents' indigenous viewpoints of their children diagnosed with ASD. The available literature has suggested that children with ASD often do present families with considerable challenges requiring external support (Kishore & Basu, 2011; Krishnamurthy, 2008). According to the American Psychiatric Association Diagnostic and Statistical Manual, Fifth Revision (DSM-5), the current diagnostic criteria for ASD include deficits in: (a) social interaction and nonverbal communication; and (b) restricted, repetitive movements, behaviours and interests. Parents realize either that their child does not respond to parental cues of affection or communication or that the child does not show affection or speak. The child's behavior may also become abnormal or disruptive. The lifelong nature of autism has deep implications on parents of children with the disorder, resulting in a wide range of challenges. This is because parents, especially mothers, are generally the primary caregiver of children with autism. The daily challenges of caring for the child are endless and affect multiple aspects of the child's care as well as the mother's mental health, quality of life and ability to manage the needs of the child along with needs of the family members.

With the aim of exploring mothers' subjective experiences of having a child diagnosed with autism, a qualitative study has been designed that explores mother's experiences around current stressors and factors that help them to cope. We attempt to report here on the observations of the study, focusing on the daily experiences of mothers, and what challenges they face, as well as what helps mothers to cope with challenges and stresses. Kleinman (1977) suggested that "ideal" cross-cultural studies begin with "local phenomenological descriptions" (1977, p. 4). Instead of presupposing the nature of psychopathology from a culturally distant perspective, local descriptions are required to provide an understanding of it in cultural contexts. Knowledge of local perspectives has helped strengthen community-based care and improve outcomes for individuals experiencing significant psychological distress (e.g., Chatterjee et al., 2008). The extant literature provides some knowledge of the influence of Indian cultural beliefs and social norms on the local responses to ASD. However, more information is needed on parents' indigenous viewpoints, prior to theoretical conceptualizations like symptoms and diagnosis. The phenomenological approach has been utilized in order to freshly access and concretely describe the mothers' lived experiences of their child with sensitivity to local context and meaning.

Theoretical Framework

In the present study, feminist standpoint epistemology has been taken into consideration to conceptualize the narratives of mothers of autistic children. As the basic purpose of the feminist standpoint epistemology is to empathetically understand and build new knowledge from women's real-life experience. Social scientists are of the view that it is an alternative way of thinking that would be developed by women for women, with the goal of granting, visualizing authentic expression and representation to women's lives. According to feminist standpoint scholar Patricia Hill Collins (1990), when making knowledge claims about women, we must always remember that it is women's concrete experience that provides the ultimate criterion for credibility of these knowledge claims. The next step of feminist standpoint is its application for improving the condition of women and creating social change. The basic assumption of this theoretical component conceptually fits into the qualitative phenomenological research design of the present study.

REVIEW OF LITERATURE

It is well established that mothers of children with developmental and psychiatric difficulties are at risk for experiencing greater distress than mothers of typically developing children

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(Baker, Blacher, Crnic, & Edelbrock, 2002; Dumas, Wolf, Fisman, & Culligan, 1991; Hauser-Cram et al., 2001; Hodapp, Ricci, Ly, & Fidler, 2003; Johnston et al., 2003; Rodrigue, Morgan, & Geffken, 1990). Research suggests that the challenges of caring for a child with autism can result in pronounced psychological distress for parents (Davis & Carter, 2008; Ekas & Whitman, 2010; Hastings, 2008), reflected not only in the impact of diagnosis, but as well as in the specific and on-going psychosocial, developmental and behaviour challenges in the process (Eisenhower, Baker & Blacher, 2005). Ekas and Whitman (2010) indicate that greater severity of ASD symptoms is directly related to increased maternal stress. For example, children with ASD can have interrupted sleep routines, such as waking earlier than a normally developing child, which is likely to contribute to fatigue for mothers (Glazzard & Overall, 2012). There is the acknowledgment of potential loss of self and family image and livelihood, which implies a unique parenting experience with different expectations, hopes and dreams for the child and family (Woodgate, Ateah & Secco, 2008) to what they had anticipated.

METHODOLOGY

The present qualitative study aims to gather in-depth information and understanding of four mothers who have autistic children. Their perception and difficulties in raising a child with autism and to critically look at areas where future research might need to focus. The participants of the present study were 4 mothers of children who were diagnosed with autism spectrum disorders (ASD), with their age ranging from 25 to 45 years old. Purposive sampling technique (a kind of non-probability sampling technique), through which samples were collected from the Learning Clinic, Bhubaneswar. In the current study, a set of pre-generated interview questionnaire was used for data collection. These questions were divided into seven categories and covered the following; General and demographic profile, family composition, work, care work and child care, disability or child specific questions, stress, emotional well-being and coping, access to information and services used.

In the interviews, mothers were asked questions aimed at their particular experiences, and these questions revealed important insights for what it was like to care for a child with autism, how to cope with having a child with a disability, and how mothers thought of themselves and their children. Without the experience of our interview, it was likely that most of these women may not have had a chance to articulate their struggles and stories to anyone other than their closest confidants—as a rule, they are too busy to “dwell” on their difficulties and must instead put their energies toward their children. I chose to conduct in-depth interviews because of the potential to get at individual experience and not to make generalizations about mothers of children with autism. Because part of the purpose of in-depth interviews was to reach for a deeper quality of the interviews, rather than securing a large breadth of information, I limited the number of interviews to four sessions, the lengths of which ranged from one to two hours. The current study strictly follows the Ethical Code of Conduct by National Academy of Psychology, 2010.

RESULTS

The resulting data identified five core thematic categories: resources, care load distribution, me time and mental health, autism: subjective understanding of mothers, blame and mothering. However, it was important to understand how one thematic category affects another.

The first thematic category, resources, was used to describe details about financial and social capital and how the amount of resources available to Indian mothers facilitated or hindered

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their access to services, support, and information. To a great extent social and economic class statuses of these women and their families affected their abilities to advocate on the behalf of and obtain quality treatments for their children with autism. While three out of the four mothers (Case A, B, and D), had relatively high monetary and social capital; Case C, on the other hand, did not. The disparity between Case C's access to services, information, and treatments and the other mothers was quite significant. This does not infer, however, that there was no variation among the four mothers with higher access to resources. It was revealed in the current study that high paying and/or flexible jobs, part of the resource's category, provided families with the ability to acquire and access services which were unavailable to those with lower incomes.

The second thematic category, care load distribution, was used to describe mothers, basically the primary caregivers, who were doing a disproportionate share of caring for children with special needs. These claims were backed by the narratives from the interviews. All mothers performed a large majority of the care work demanded by their children with autism. Support from fathers, wherever it came, was not enough for the workload of mothers. When asked about the amount of time mothers usually spend taking care of their children, they unanimously responded by saying that most of their time was spent after their child by accompanying them to therapy sessions. The fear that someone might abuse their child was also very indicative in their narratives. The mothers also pointed out that their children needed unlimited care and attention.

The third thematic category, me time and mental health, focused on the massive amount of care work performed by these mothers affected their mental health and well-being and the amount of time they had for themselves, for their personal care and career. It also affected their relationship with their spouse. Feeling of sadness, helplessness, hopelessness, lowered self-confidence was also observed. Repeated somatic complaints has also been pointed out by the mothers. Research has shown that "mothers of children with ASD experience significantly higher levels of stress and lower levels of psychological well-being than mothers of children without ASD. Dale and colleagues (2006) explored mothers' understanding and attributions made about their child's diagnosis, and found that most mothers had multiple, complex attributions as to the causes of their child's diagnosis. From the beginning of the diagnosis of their child's autism, mothers described emotional struggle in accepting and depression. Two mothers clearly described regarding their reaction to their children's initial diagnosis. Case B related her feelings of hopelessness, frustration, the search for why me after first finding out about diagnosis: "When she was first diagnosed... I burst into tears with helplessness. It took me eleven months for me to say to the outside world, 'My daughter is autistic,' without sobbing my eyes out."

Mothers also expressed deep concern regarding the dependency of their children for care. Mothers always were worried with the thought that how their children would be able to cope when they were no longer alive. A mother explains: as he gets older, I do worry kind of what things will hold for him. When you're a little child, people are understanding of you, but as you get older people, you know, perhaps won't be [pause] and, in years to come, when I'm gone or [his father is] gone who will protect him? (Case D)

The fourth thematic category was mothers' subjective understanding of autism. One aspect of these interviews was the degree to which mothers would voluntarily share with me extensive details about their children's experiences and struggles with autism. They invested a majority of their energy and time toward caring for these children, for their training and improvement.

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The amount of time that all of the mothers spent discussing each of their autistic child's journeys revealed not only the degree to which they make their children a priority, but also how much of their identities, their lives were comprised of thinking about, and planning for these children. Some mothers also pointed out regarding their internal peace and satisfaction in making someone else aware about autism and helping mothers of other disabled children to cope with the challenges.

The fifth thematic category was the issue of blame and mothering. During our interviews, most of the mothers said that they have been blamed directly for causing their children's conditions. But while they have not been blamed directly, the ways in which the mothers spoke about their experiences caring for their children suggests that they have felt pressure and judgment from outside world. It was not surprising to hear Case B, for example, say: "I have never felt blamed that my daughter's condition is my fault." But in our discussion about caring for the child, she expressed feeling pressure. She expressed about the pressure to be a good mother and how motherhood is something women are pressured." Case B invoked the gendered ideals that were imposed upon many women and in turn revealed the extent of the effects of gendered socialization. Self-blame and self-imposed pressure were a common theme throughout the narratives. The pressure on mothers to produce healthy, "functional," and so-called normal children was really high. Two of the four mothers had left careers in order to care for their children. Case A said that she left her career because balancing the care load and a career got to be too much and she felt she had to focus on her daughters. She expressed that "the pressure to do care work for children was on women." And the pressure put on mothers, in case of A, could operate in ways that made mothers feel guilty for not leaving work, to provide better care for her children.

DISCUSSION

The study revealed that the mothers' experience of raising children with autism is a challenging journey that could be conceived into various phases. One is characterized by the mothers' attempt to find a diagnosis that begins with an intuitive ability to sense a deviated characteristic of their children. Another more difficult challenges were confrontation with the diagnosis, confusion, blaming experience, treatment seeking, challenges of schooling (rejection of normal schools and non-availability of special schools) etc. While dealing with the challenges mothers go through an intensely emotional and stressful experience of raising an autistic child which results in deep depression and poor mental health. The findings of the study reflect that parental distress began in the pre-diagnostic phase when mothers noticed developmental delays in their children in comparison with children of their child's similar age group. Participants became worried when the child did not develop speech, aloofness toward normal behavioural patterns and when the situation became difficult to manage. The situation where the participants did not know what was wrong and could not get clear answers from health practitioners led the parents to feel frustrated and unsupported. Although described as normal reactions to a diagnosis of a pervasive developmental problem like autism, the findings strongly suggest that early interventions are crucial, not only for the affected child, but also for parents, in order to prevent a potentially destructive build-up of anger which may lead to depression or possible abuse of the child. Parental conflict has also been observed due to demanding care work and lack of personal time. When asked about the most difficult challenges with which they were confronted, the participants reported that they were highly dissatisfied with the state of the current available educational facilities for children with autism. The mothers emphasized their metamorphosis that their motherhood journey with a child with autism has brought.

CONCLUSION

The findings in the present study highlighted the unique experiences and issues that mothers faced in caring for a child with autism. Scarcity of Indian studies in the area has been observed. More research work needs to be done in regional cultural context regarding difficulties of mothers. Continuous review of changing experience of mothers of autistic children needs to be documented. The interventions or therapies that autistic children require puts parents not belonging from affluent families in both financial and psychological strain; as it restricted mothers to stop their career and work outside for caring the child. No doubt, caring for a child with a disability is a difficult economic task. Past researchers have described caregivers' frustrations with time constraints, costs of interventions, and employment restrictions (Gray, 2002; Jabrink, Fombonne, & Knapp, 2003). Mothers in this study also pointed out society's lack of knowledge regarding autism. A clearer understanding of autism by informal and formal supports was necessary for improved support. School authorities' refusal to accept the autistic children in regular schools and lack of availability of special schools puts mothers in tremendous psychological pressure, thereby increasing serious anxiety about their children's future. Our findings confirm that caregivers of children with autism have anxiety about their child's future (Gray, 2002). Regular somatic complaints, low self-esteem, anxiety and depression of mothers needs serious attention from academicians, policy makers and community members to extend a support system to empower mothers of autistic children.

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Acknowledgements

The author appreciates all those who participated in the study and helped to facilitate the research process.

Conflict of Interest

The author declared no conflict of interest.

How to cite this article: S Behura & S Panigrahi (2020). Walking in their shoes: exploring the lived experiences of mothers of autistic children. *International Journal of Indian Psychology*, 8(1), 1023-1029. DIP:18.01.129/20200801, DOI:10.25215/0801.129