ISSN- 2349-7076

EduInspire-An International E-Journal
An International Peer Reviewed and Referred Journal (www.ctegujarat.org)
Council for Teacher Education Foundation (CTEF, Gujarat Chapter)
Patron: Prof. R. G. Kothari
Chief Editor: Prof. Jignesh B. Patel
Email:- Mo. 9429429550 ctefeduinspire@gmail.com

EduInspire

- An International Peer Reviewed and Refereed Journal

Patron
Prof. R. G. Kothari

Chief Editor
Prof. Jignesh B. Patel
Mo. 9429429550
drjigp@gmail.com
ctefeduinspire@gmail.com

VOL: XIII
ISSUE: I
JANUARY-2026

Council for Teacher Education Foundation

(CTEF, Gujarat Chapter)

ISSN- 2349-7076

EduInspire-An International E-Journal
An International Peer Reviewed and Referred Journal (www.ctegujarat.org)
Council for Teacher Education Foundation (CTEF, Gujarat Chapter)
Patron: Prof. R. G. Kothari
Chief Editor: Prof. Jignesh B. Patel
Email:- Mo. 9429429550 ctefeduinspire@gmail.com

The Caregiving Struggles and Mental Burden of Mothers of Children with Autism: A Phenomenological Study

Dr. Mukesh Kumar Chandrakar
Asst. Professor, Dept. of Education, Guru Ghasidas Central University, Bilaspur, C. G.

Dr. Ajay Samir Kujur
Asso. Professor, Dept. of Education, Guru Ghasidas Central University, Bilaspur, C. G.

Ms. Smita Sarkar
Research Assistant, ICSSR Project, Dept. of Education, Guru Ghasidas Central University, Bilaspur, C.G.

Abstract

A child diagnosed with Autism may represent a constant source of stress on the family unit, as not only the caregivers affected, but also siblings and relationships among family members. Parents of children with autism spectrum disorder (ASD) have valuable experiences of problems and other issues of their children. The present study aimed to obtain lived experiences of mothers during caregiving process using a qualitative approach to understand and explain mothers' problems. This study with a qualitative design was performed on thirty parents of children with ASD who were selected purposively. The study data were collected using semi-structured interviews, and interpretative phenomenological analysis was used to analyze the data.

Keywords: Autism Spectrum Disorder

Introduction

Autism Spectrum disorder is not like other mental disorders. The need, strength and challenges of autism are quite different from other mental disorders. Children with autism may find it difficult to adjust in different settings. Its appears in the first three years of life that significantly affects a person's ability to communicate, understand relationships and relate to others and is frequently associated with unusual or stereotypical rituals or behaviours (RPWD Act, 2016). There may be many factors responsible for making a child autistic including environmental, biologic and genetic factors but the exact causes for autism are not clear; there is nothing to prevent autism among newly born children. Individuals with ASD have difficulties interpreting their own and others reactions (such as desire, belief and knowledge) through mental states. There is also some other profound social deficits among individual with ASD including poor eye contact organizing and replying to others and not giving importance to others speech (Lind & Bowler, 2009), inattention (impaired joint attention in early childhood), and inappropriate perceptions which may behaviour in different activities of daily life. This is referred to as the triad of impairments and many individuals with autism have different ways of sensing their world. Autism results in qualitative impairments and the most confusing feature of autism is uneven skill development in the ASD children. According to the Individual with Disabilities Education Act (IDEA, 2000) "Autism is a development disabilities significantly affecting verbal and nonverbal communications and social interaction generally evident before age three that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped moments, resistance to environmental change or change in daily routines and unusual responses to sensory experiences". The major problems of children with Autism are Social behaviour and communication Impairment. Individuals with ASD have difficulties interpreting their own and others reactions (such as desire, belief and knowledge) through mental states. There are also some other profound social deficits among individual with ASD including poor eye contact, organizing and replying to others and not giving attention to others speech.

In an Indian family, caregiving is the primary and most important daily routine of a mother and is a challenging task. When a child is having autism or any type of disability, the role of caregiving is most challenging, difficult and stressful. Bronfenbrenner's Ecological Systems theory emphasizes that human development does not occur in isolation but is influenced by multiple, interconnected environmental layers (Bronfenbrenner, 1979). For mothers raising children with autism, this framework helps explain how their caregiving experiences are shaped by not only immediate family dynamics but also by schools, healthcare systems, workplace policies, and larger societal attitudes (Brown et al., 2020). Mothers of children with autism faces stressful situations like sense of loss and depression, less time for family and outing, loss of social support, personal sacrifice, changes in relationship with spouse, physical and emotional exhaustion. These challenges become grave when parents have less knowledge to tackle the problem facing by them as well as by their autistic children. It makes the mothers confused, sad, guilt, and sometimes led to depression. In addition, mothers felt a sense of loss of identity, and are forced to abandon their personal as well as professional ambitions. Moreover, the societal behaviour restrict mothers to participate in socio-cultural gatherings, thus led to social isolation, declining social support, and likely perpetuating stress (Altiere and Kulge, 2009). There is a limited research in India that has explored the mental agony of mothers of autistic children's Therefore, the current study was conducted to explore the mental agony of mothers in raising children with ASD.

Objectives

1. To explore the experiences of mothers in raising the children with ASD
2. To explore the mental agony faced by mothers in raising the children with ASD.

Methodology

To explore the experiences of mothers having autistic children, a qualitative explorative phenomenological approach was employed in the present study. In the present study, the lived experiences and the challenges faced by the mothers were explored by using Interpretative Phenomenological Analysis (IPA). The IPA approach is best suited for participant to articulate their live experiences in detail and helps for better understanding of the shared experiences of similar concerns feels and believes about their own world view (Smith, Larkin & Flowers, 2009). An in-depth semi structured interview was used to collect the internal mental turmoil and challenges of the mothers to understand what common feelings and experiences they lived with. The inclusion criteria mothers in this study were children having being diagnosed with ASD by a psychiatrist and having children aged between 3 and 18 years. The research objectives and processes were explained to the parents, and were ensured confidentiality terms regarding their personal information. Participation was voluntary, and the participants were allowed to withdraw from the research at any given time. A purposive sampling technique was used in this study which led to the inclusion of a diverse range of parents with different cultural, ethnic, and educational background. A total of 15 mothers were included in the present study.

Data Collection Procedure

Exploring the lived experiences of mothers in raising their ASD children, an in-depth face-to-face semi-structured interview was conducted following a series of questions. The objectives and conditions of the research were explained to the mothers, and those who were willing to participate were notified of the appropriate time and place decided by the mothers for the interview. An oral permission was sought to record the interview digitally and field notes were also obtained. The interview was conducted at their home and in the rehabilitation centres as per their convenience in Hindi language. Before conducting interview rapport was built with mothers by having daily interaction with them at rehabilitation centres. 30 days time was allotted for rapport building. Initially, general questions information (name, age, residence, religion, qualification, occupational status, socio-economic status, type of family etc.) were sought and then proceeded to ask questions related to raising their children. In order to ensure clarity and in-depth details, further probing questions were asked. Each interviews lasted between 30 to 45 minutes and sometimes in two seating. The verbal and non-verbal (gestural expressions) were also noted at the time of conducting interview.

These interviews gave the parents the chance to express in detail their personal experience of raising a child with autism. The interview started with a very broad question like "What was your reaction when you came to know that your child is autistic?", "How do you feel when your child doesn't respond to you when you teach him something"?, "What kind of problems do you face when you take care of your child"?, "How did your family members support you for taking care of your children"?, "Tell me about your overall experience as a parents raising a child with autism"? etc… To seek further information, some probing questions were asked during interview as and when the situation demands. The non-verbal expressions of mothers like voice modulation, weeping, choked throat, tearful eye were also noted down during interview.

Data Analysis

The IPA technique was used to analyse the transcribed data, to "give voice" to the participants essential life viewpoints (Larkin et al., 2006). Therefore, an in-depth inductive analysis was conducted to unveil mothers' unique experiences of raising the child with autism with detailed examination of their lived experiences with reference to the mental agony. The transcribed data were coded and analysed by the authors according the steps of IPA (Larkin & Flowers, 2009), which includes organizing, coding, integrating and interpreting the data (Flowers & Larkin, 2005). During review and analysis of data, the authors focused more on the subjective experiences of mothers. Initially, the author read and re-read the transcribed data several time to get familiar with the data to gain holistic understanding of mothers mental feeling and thoughts. However, during this phase the author recorded his observations and comments (Smith & Osborn, 2008).

At the second stage, line-by-line coding of the each transcribed data of mothers was conducted. The important words and statements helped to identify the themes of the each transcript and later on the cross narrative of the mothers' lived experience. The analysis of data was subsequently reviewed by another colleague and his insights and suggestions were incorporated in the analysis. After the analysis, the findings of the study were described with the relevant quotes/statements of the mothers which were the translated verbatim from Hindi into English to illuminate/highlight the lived narratives of the mothers.

Results

The analysis of the lived experiences of mothers in raising a child with autism revealed the mental agony of mothers which is the most prominent theme that emerged from the data. The result of the analysis is discussed below. The problem of mental agony was shared by all mothers when they were asked about the overall impact of raising their child. Almost all the mothers become tearful or choked throat while narrating their experiences. Few mothers started weeping and become speechless for some time. Mothers experienced overwhelming emotional reaction when they know that their child was identified as autistic; even not ready accept the child's diagnosis as they heard first time about autism. The daily care giving experiences revealed the mental agony of mothers are as under.

Acceptance Based Mental Agony:

1. The study found that children with autism in joint families spend more time with their family members and children in nuclear families with their mothers. One mother (M_2) reported that she has to take care of their child alone and due to which she face a lot of problems and always under stress. *"When we heard that my child has disability we couldn't believe and not ready to accept it. We thought that this is a simple problem and will be ok within few months. But at the end we accepted that out child has autism (Mother_03)".* Another mother (Mother_05) *reported that when we came to know that my child has autism, I was speechless for some time, mentally I felt exhausted and feel depressed".*
2. Almost all the parents reported the feeling of sense *'mentally tired and despair'* and find it difficult to handle the child and blamed herself for the autism of their child. One mother (Mother_8) reported that *"It was very discouraging in the beginning to see our child's behavior; I always think why this happened to our child only; but then we consoled ourselves and consulted doctors for treatment of our child".* Similarly, another mother (Mother_10) blamed herself and said that *"It's me who is responsible for my child; I think I have done some sin in my previous life because of which my child is autistic".*

Social Mental Agony

1. Mothers of autistic children not only faced mental agony related to acceptance of their child; also suffered the social-mental agony like social stigma, social isolation, fear of social judgment, and social ignorance. Most of the mothers indirectly experienced social stigma that resulted to remain at home and avoiding social gatherings. The reason of social stigma and isolation was due to of typical Indian stereotypes with respect to disability of any kind. One mother (M_15) stated that *"when we take our child to any social gatherings, people looks/stares to us as if we are from some other planet"*.
2. Another mother (M_9) reported that *"When many people looks at out child and feel pity, it becomes very embracing; people also try to avoid us..... It becomes very painful. Due to it we used to avoid attending social gatherings"*. This statement highlights the social stigma and exclusion of mothers. The excerpts also reflect the reaction of societal members that make mothers feel embraced and socially isolated.
3. Almost all the parents were of the opine that taking the child to public places like park, mall, market, hospital etc., they had to keep many things in mind like *"We have to watch him all the time so that he doesn't go anywhere or cause any vandalism; sometimes we have to take family members with us to take care of the children. Therefore, we have to think many times to take child into public places"*. A common observation of the mothers was to remain excluded many time from social functions is very harassing and exhausting.
4. Furthermore, several mothers described the feeling of embarrassing about their child's behavior in public places because they had to ensure that their *child shouldn't go anywhere, don't sabotage, harm own self. People believe that it is bad parenting.*

Mental Agony of Educating & Future

1. Mothers of autistic children reported constant worry and stress about the education of their children and their future prospect. Mothers were uncertain about the education of their child, their future livelihood; coping with the society for their living especially in the absence of parents becomes the source of constant mental stress and agony. The future-oriented concern of mother of a girl child was reported. Almost all the mothers had concern that *"their child should get well as soon as possible and may be able to do some employment in the future"* .

One mother (M_8) having both of her children autistic reported that *"both of my children have autism, so I am very worried about their future; As long as we are alive, it is fine, but I remain worried thinking about who will take care of these children after us"? "I see a very dark future for my child, I am very sad about the future of my child, sometimes I feel like to end myself and kill her too"* . Another mother *(M _7) reported that "I have a daughter, so I am more worried about her future, especially about his marriage"* . The above narrative reflect the existential worry and anticipatory grief and helpless of mothers in raising their child. It also reflects sense of fear and uncertain future after their parents' death and dependence of child on parental care.

2. A similar concern and mental stress were shared by almost all mothers about the education of their children especially due to unavailability of Government run Autistic school. They had to depend on private centres which were too costly for them. Mothers had to put in a lot of patience to teach the children. A mother (M_14) said that *"Initially when I teach my child something and he does not respond, we try to teach him again and again that becomes disheartening and irritating"*.
3. Several mothers shared that there is neither government facility was available for the education of autism children nor is there any separate government school available for autism children. All the parents depended on private schools for the education of their children. Few mothers' statements were - *"No government facilities are available for the education of children"; "There is no separate government school for the education of the children"; "We get children admitted in private special schools only for education; In these schools also all children with special needs are taught together"*. The parents used to be very worried, sad, frustrated and disappointed about the future and education of the child.

Discussion

The empirical findings of the present study highlights the severe mental agony of mothers experienced while raising children with Autism Spectrum Disorder (ASD). The mothers experienced and reported emotional distress stem from the daily life challenges allied with acceptance of diagnosis, social stigma, uncertain future of child and their educational concerns. These findings of the stud are allied with findings that parents particularly mothers faced heightened psychological distress as compared to the parents of naturally developing children (Hayes & Watson, 2013). The findings highlights that accepting the child's diagnosis was emotionally painful, and noticeable by denial of diagnosis, mental and grief. The mothers experienced emotional turmoil due to expectations and developmental delays. Gray (2006) highlighted that the process of acceptance of involves coping and emotional adjustment depending upon level of autism and social support. Social stigma was emerged as an important source of mental agony of mothers. Kumar & Singhal (2020) highlighted that in Indian socio-cultural context, mothers internalize blame for their child's condition leading to social withdrawal, feeling of shame, social isolation, and feeling of being judged. These findings align with Werner and Shulman's (2013) findings that social exclusion and stigmatization exacerbate parental distress and hinder their participation in community life. The present study also highlights parents concern about future their child, and their education that becomes the source of mental burden. Studies on autism highlighted that mothers often experience chronic anxiety during of caregiving, especially in the absence of adequate institutional or community support (Schieve et al., 2011). This future-oriented worry compounds the psychological strain and can lead to feelings of helplessness and depression (Phetrasuwan & Miles, 2009).

Conclusion

The present study provided useful insights into the mothers' experience of raising and caring a child with autism spectrum disorder. The findings of the current research revealed that mothers as well as family members having children with autism faces lot of mental agony that ranges from acceptance, social stigma, concern for future, and education. It was found that mothers taking care or raising the children and their behavior becomes the source of mental agony. Their social life has been affected and hesitates to participate in the social gathering. The social mindset of the people is not broad enough to accept the disability of the children. These issues had a lot of impact in their social as well as personal life.

Limitations

1. The study has been conducted only on 15 mothers of the autistic children. Therefore, it may not represent the entire population.
2. The study focused on the sensitive issues of the mothers, and the mothers might not have shared all of their opinions. Hence, their responses might be different.
3. The findings of the study may not be generalized as it is based on qualitative study with limited sample.

Recommendations

The study captures the experiences of mothers during caregiving process and focused on the mental agony of the mothers. Mothers reported various mental agonies related to acceptance of the child's diagnosis, agony related to society, child's education and future. Therefore, the findings suggest different aspects of caregiving of autistic children.

1. The present study highlights the urgent need of public awareness campaign for parents, teachers and members of the family on autism.
2. Special drive need to be organized in the society to accept the autistic child and treat like a normal child by community members.
3. The government need to create easy accessible support systems like school for autistic children, counseling of family members, specific policy for autistic children to mitigate the mental agony of mothers raising children with ASD.
4. A study need to be conduct on the geographical settings to address the limitation of the study.

Funding:

This article is based on a research project funded by ICSSR, New Delhi, India. We thanks the mothers who gave their precious time and share their experiences.

References:

Altiere, M. J., & von Kluge, S. (2009). *Searching for acceptance: Challenges encountered while raising a child with autism. Journal of Intellectual & Developmental Disability, 34*(2), 142–152. https://doi.org/10.1080/13668250902845202

Banach, M., Iudice, J., Conway, L., & Couse, L. (2010). Family support and empowerment: Post autism diagnosis support group for parents. *Social Work with Groups, 33*(1), 69–83. https://doi.org/10.1080/01609510903437383

Desai, M. U. (2012). *Caring in context: Parenting a child with an autism spectrum disorder in India* (Doctoral dissertation, Fordham University).

Edwards, B., Higgins, D. J., Gray, M., Zmijewski, N., & Kingston, M. (2008). *The nature and impact of caring for family members with a disability in Australia*. Australian Institute of Family Studies.

Gray, D. E. (2003). Gender and coping: The parents of children with high functioning autism. *Social Science & Medicine, 56*(3), 631–642. https://doi.org/10.1016/S0277-9536(02)00059-X

Gray, D. E. (2006). Coping over time: The parents of children with autism. *Journal of Intellectual Disability Research, 50*(12), 970–976. https://doi.org/10.1111/j.1365-2788.2006.00933.x

Hayes, S. A., & Watson, S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders, 43*(3), 629–642. https://doi.org/10.1007/s10803-012-1604-y

Heiman, T. (2002). Parents of children with disabilities: Resilience, coping, and future expectations. *Journal of Developmental and Physical Disabilities, 14*(2), 159–171. https://doi.org/10.1023/A:1015219514621

Kumar, R., & Singhal, N. (2020). Stigma and coping among parents of children with autism in India. *Journal of Autism and Developmental Disorders, 50*(2), 566–577. https://doi.org/10.1007/s10803-019-04288-0

Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology, 3*(2), 102–120. https://doi.org/10.1191/1478088706qp062oa

Papadopoulos, D. (2021). Mothers' experiences and challenges raising a child with autism spectrum disorder: A qualitative study. *Brain Sciences, 11*(3), 309. https://doi.org/10.3390/brainsci11030309

Phetrasuwan, S., & Miles, M. S. (2009). Parenting stress in mothers of children with autism spectrum disorders. *Journal for Specialists in Pediatric Nursing, 14*(3), 157–165. https://doi.org/10.1111/j.1744-6155.2009.00188.x

Reid, K., Flowers, P., & Larkin, M. (2005). Exploring lived experience. *The Psychologist, 18*(1), 20–23.

Sanders, J. L., & Morgan, S. (1997). Family stress and adjustment as perceived by parents of children with autism or Down syndrome: Implications for intervention. *Child and Family Behavior Therapy, 19*(4), 15–32. https://doi.org/10.1300/J019v19n04_02

Bassam, S. E. A., & Tork, H. M. M. (2019). Education program for mothers of children with autism spectrum disorder: Mothers and child outcomes. *American Journal of Nursing Research, 7*(6), 1046–1056. https://doi.org/10.12691/ajnr-7-6-19

Smith, J. A., Flowers, P., & Larkin, M. H. (2009). *Interpretative phenomenological analysis: Theory, method and research*. Sage.

Smith, J. A., & Osborn, M. (2008). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Doing social psychology research* (pp. 229–254).

Trute, B., Murphy, D. H., & Levine, K. (2007). Parental appraisal of the family impact of childhood developmental disability: Times of sadness and times of joy. *Journal of Intellectual and Developmental Disability, 32*(1), 1–9. https://doi.org/10.1080/13668250601146753

Tait, K. J., & Mundia, L. (2012). The impact of autism on Bruneian families. *International Journal of Special Education, 27*(1), 1–14.

Werner, S., & Shulman, C. (2013). Subjective well-being among family caregivers of individuals with developmental disabilities: The role of affiliate stigma and psychosocial moderating variables. *Research in Developmental Disabilities, 34*(11), 4103–4114. https://doi.org/10.1016/j.ridd.2013.08.029