

Lived Parenting Experiences and Challenges of ASD Children

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ABSTRACT

Parenting a child with autism is a particularly challenging task in itself. The experiences and needs of individuals with autism are diverse and unique, requiring a nuanced understanding and tailored approaches to support and accommodate their specific needs. **AIM:** The primary objective of this research is to delve into the multifaceted experiences and challenges encountered by parents especially the father of children with autism. It seeks to understand their unique journeys, highlighting the emotional, social, and practical struggles they face while navigating the complexities of raising a child with autism. **Method:** Three couples were identified using purposive sampling from a hospital set up in Delhi. The data was gathered via semi-structured interviews and was thematically analysed. **Result:** The analysis of the findings was carried out about the delineated research questions, it was found that there were significant disparities in the parenting encounters, which can be attributed to the prevailing gender stereotypes in Indian culture. Furthermore, it was seen that a child's illness can have a substantial influence on the marital connection of couples. This relationship may either get stronger or weakened depending on the degree of perceived support, coping mechanisms, and participation exhibited by both partners. By focusing on these aspects, the research aspires to contribute to a deeper understanding of parental perspectives and inform the development of targeted support systems and interventions tailored to their needs

Autism is a complex childhood developmental disorder characterized by significant impairments in reciprocal social interaction; communication; and restricted, repetitive, and stereotypic patterns of behaviors, interests, and activities." Butcher et al. (2020). For the majority of children with autism, symptoms usually start in late infancy. Raising a child with autism is very challenging. Several studies have demonstrated that parents of children with developmental disabilities experience higher levels of stress than parents of children who are developing normally (Hodapp et al.,2003; Johnson et al.,2003). Nearly 40% of parents whose children have developmental delays have Parenting Stress Index scores above the 85th percentile, indicating a significant level of parenting stress, according to Webster et al. (2008). Autism Spectrum Disorder (ASD) is a neurodevelopmental condition marked by persistent challenges in social communication, interaction, and restricted, repetitive behaviors. Its prevalence has increased significantly over the past decade, affecting approximately 1 in 100 children globally, as reported by the World Health Organization (2023). The spectrum nature of autism means that its symptoms and severity vary widely among individuals, from mild difficulties in social interaction to profound communication deficits requiring lifelong support. This heterogeneity highlights the need for personalized, context-sensitive interventions and family-centred care approaches.

Unique Challenges of Parenting Children with Autism

Parenting a child with autism presents an intricate blend of joys and challenges. Early intervention has been shown to improve developmental outcomes for children with ASD; however, the journey is fraught with obstacles. Parents often describe initial feelings of shock, denial, and confusion following the diagnosis. The lack of awareness and availability of diagnostic services in many regions exacerbates this initial turmoil. For example, Sharma and Gupta (2022) explored Indian families' experiences and found that delayed diagnoses often stemmed from limited professional training, cultural taboos, and a tendency to dismiss early symptoms as behavioural quirks. Such delays increase parental stress, hinder timely intervention, and worsen outcomes.

Depending on the mental health condition and the family's stage of life, raising a child with autism might involve varying levels of stress. The real-world experiences of parents of autistic children worry about inclusion and education, challenges faced by the parents, and the experiences of siblings and their reactions have all been the subject of several psychological studies. Woodgate (2008) and Kourkoutas (2012) examined the perspectives of parents of autistic children using qualitative interviews. Based on these studies, the researchers concluded that parents find their child has autism suffer a range of negative emotions, such as shock, distress, terror, denial, depression, guilt, helplessness, and emotional emptiness." Even though the disorder manifests itself early, diagnosis is sometimes postponed because behavioral indicators are not recognized as serious issues and awareness of the condition is low. According to Woodgate's (2008) research, one of the biggest worries that families of autistic children have is the insensitivity and lack of knowledge displayed by those in the neighborhood, including neighbors, relatives, and acquaintances. When their child misbehaved, they claimed to frequently experience social shame and aggressive reactions in public areas.

The psychological toll of raising a child with autism has been well-documented. Research has consistently shown that parents of children with developmental disabilities experience higher stress levels compared to parents of neurotypical children. For instance, Ooi et al.'s (2019) meta-analysis revealed that maternal stress often peaked during early childhood, correlating strongly with the severity of the child's symptoms. Fathers' stress, while less frequently studied, has been linked to long-term concerns, such as their child's future independence and societal acceptance. This disparity in parental experiences underscores the importance of studying both maternal and paternal perspectives to develop comprehensive support systems.

Gender & Parenting of ASD Children

Mothers, traditionally the primary caregivers in many cultures, often bear the brunt of caregiving responsibilities. They are more likely to sacrifice career aspirations, social interactions, and personal goals to meet their child's needs. Divan et al. (2020) reported that Indian mothers frequently experience intense feelings of guilt and self-blame, compounded by societal expectations that position them as the sole nurturers. Fathers, in contrast, are often relegated to secondary roles in caregiving. This division of labour, though culturally ingrained, often limits fathers' emotional involvement and their ability to form deep connections with their child.

Collins (2018) explored the unique challenges faced by fathers, revealing that their initial reactions often include grief, guilt, and denial. However, many fathers also reported experiencing personal growth and resilience as they adapted to their child's needs. While some fathers adopted proactive coping strategies, such as seeking information or exploring therapies,

others displayed avoidant behaviours, choosing to detach emotionally through hobbies or excessive work commitments. The interplay between gendered roles and parenting dynamics is particularly evident in cultures like India, where traditional beliefs and patriarchal norms significantly influence familial roles. Pathappillil (2021), using in-depth interviews, examined the experiences of 11 Indian mothers having a child with autism. The study revealed that while motherhood is a fulfilling and rewarding experience for Indian mothers in general; mothering a child with autism is perceived as more of a challenge. Many mothers in the study indicated that a child with autism in Indian society is more likely to be looked down upon due to social comparison. The cultural beliefs and constricted mindset of Indians contribute to the stigma attached to any kind of abnormality including autism. The child is seen as a mistake or a burden on the family. It is the mother who is blamed for everything and she is made personally responsible for the child's behaviour. Other family members, including the father, take on a more distant and inactive role in the child's life. Pathappillil's (2021) study highlighted how societal judgments exacerbate mothers' isolation and emotional burdens, while fathers often face implicit pressure to focus solely on financial provision, distancing them from active caregiving.

In many societies, including India, autism is often misunderstood and stigmatized. Cultural beliefs, such as the notion of karma, which attributes disabilities to past-life actions, further alienate families and perpetuate feelings of shame. This stigma not only isolates parents but also deters them from seeking timely professional help. Divan et al. (2020) found that many parents delayed seeking interventions due to fear of social judgment, leading to missed opportunities for early support and skill development. The lack of societal awareness and insensitivity toward autism creates additional challenges for families. Parents often report feelings of embarrassment, frustration, and anger when confronted with judgmental attitudes or unkind remarks in public spaces. Woodgate et al. (2008) documented similar experiences among Canadian families, emphasizing that societal ignorance exacerbates the emotional toll on parents and diminishes their quality of life.

Parenting Stress and Coping Mechanisms

The stress of raising a child with autism extends beyond individual experiences, affecting overall family dynamics. Marital relationships, in particular, undergo significant transformations as couples navigate caregiving responsibilities. While some parents report strengthened bonds due to shared efforts and emotional support, others struggle with reduced intimacy and communication breakdowns. Martins et al. (2023) highlighted that fathers often rely heavily on their spouses for emotional support, with limited external networks, whereas mothers frequently seek solace in peer groups or professional counselling. Sibling relationships also warrant attention, as neurotypical siblings may experience feelings of neglect, jealousy, or guilt. Studies have shown that siblings often oscillate between protective instincts toward their autistic brother or sister and frustration over unequal parental attention. Addressing these dynamics through family counselling can mitigate potential conflicts and foster healthier relationships.

Despite the challenges, many parents demonstrate remarkable resilience and adaptability. Proactive coping strategies, such as gathering information, seeking professional guidance, and building supportive networks, have been linked to better mental health outcomes for parents. For example, Martins (2013) found that fathers who engaged in problem-focused coping reported greater satisfaction and a sense of control over their circumstances. Similarly, mothers who connected with peer support groups often described feelings of empowerment and reduced isolation. Religious beliefs and spirituality also play a significant role in coping for many families. Faith provides a framework for meaning-making, enabling parents to navigate their experiences with hope and perseverance. However, reliance on spirituality

should be complemented by practical interventions, such as therapy, to address the multifaceted nature of parenting stress.

The findings from recent research underscore the need for comprehensive, culturally sensitive support systems. Interventions must address both the immediate needs of the child and the long-term well-being of the family. Community awareness programs can play a pivotal role in reducing stigma, fostering acceptance, and encouraging families to seek help without fear of judgment. Schools and healthcare providers must also prioritize inclusive practices that accommodate the diverse needs of children with autism. Professional training for educators and clinicians can bridge knowledge gaps and ensure that children and their families receive appropriate support. Policy changes, such as increased funding for autism research and expanded access to diagnostic and intervention services, are crucial for creating an equitable support system. For instance, the introduction of government-funded parent training programs in countries like the UK and Australia has shown promise in empowering families and improving outcomes for children with autism.

Rationale of the Study

Autism, while a complex and multifaceted condition, presents opportunities for understanding human diversity and resilience. The study explores the experiences and challenges faced by parents of children with autism, with a specific focus on gendered parenting roles in an Indian context. Autism parenting often requires unique approaches due to the emotional, social, and practical complexities involved. The study's focus on fathers' narratives, often overlooked in existing literature, adds a novel perspective. Additionally, the research emphasizes cultural influences, societal stigma, and the impact of autism on family dynamics, contributing to the development of tailored support systems. The conventional function of the mother is well-known, and studies have been done on how maternal behavior affects early children. However, there is not much information available regarding the father's similar role and how it affects a child's growth. They always seem to play a supporting role to the mothers, for some reason. Paying attention to males and their experiences of fathering autistic children is as important. According to this theory, the current study attempts to close the gap in the literature by providing a voice to dads' viewpoints, which are frequently absent from it. Additionally, the study seeks to address the one-sidedness of the literature by addressing issues that are unique to mothers of autistic children. Another study suggested that additional research is required to evaluate the disparities between autistic adolescents' and parents' ideas of the future and to investigate strategies to assist families in pursuing common objectives of a healthy family environment (Kirby et al., 2022).

While the mental health professionals and scientific community have made significant progress in enhancing our understanding of this neurodevelopmental disorder, more research integrating parenting dynamics are required to fully elucidate the challenges as well as early identification of this disorder. Therefore, research in this area can contribute significantly and these findings are an important step in developing early recognition as well as prevention programmes.

Aim : To explore the lived parenting experiences and challenges of autistic children

Three research objectives were established for the current study. *First*, to investigate how both parents—especially fathers—involve themselves with their autistic children and what kind of participation, meaning-making, and problems they face. *Second*, to investigate the distinctions between fathers' and mothers' experiences. *Third*, to investigate how the couple's marriage is affected by the caregiving responsibilities of the autistic children.

Method

The research was situated within a qualitative design, utilizing an instrumental multiple case study approach to elucidate parental experiences and challenges of children with autism. Qualitative methods allow a researcher to understand a phenomenon through the meaning that an individual or group of individuals ascribes to it (Creswell, 2003). Meaning and significance of lived experiences is social and ebbs and flows through interaction with a human community. Qualitative methods provide the most adequate tools to address this need for understanding by obtaining data through capturing fathers experiences about the child with autism.

Participants

The participant pool consisted of six parents—three mothers and three fathers—of children diagnosed with varying degrees of autistic spectrum disorders from New Delhi. Participants were selected through purposive sampling, with recruitment supported by a well-regarded hospital in the region. The parental participants' ages ranged from 33 to 35 years, while their children, whose diagnoses were made between the ages of 2.0 and 2.5 years, were aged 3 to 5 years at the time of the study. Three couples were chosen for depth over breadth. Instead of generalizing data, the qualitative study examined parenting experiences in detail. Another reason is accessibility and sensitivity. Recruitment was difficult due to the sensitive topic and demanding caregiving needs. Many prospective participants declined. A smaller sample allowed researchers to focus on theme saturation and fully comprehend participants' perspectives.

Inclusion Criteria:

The study carefully selected participants to ensure the sample met the research objectives:

1. The child's diagnosis had to be verified and fall within the ages of 3–5 years to ensure uniformity in developmental stages.
2. This criterion facilitated accessibility for interviews and helped capture the unique experiences of parents navigating autism support systems in an urban Indian context.
3. This inclusion allowed the study to explore the dynamics between mothers and fathers, addressing a gap in literature that often overlooks fathers' roles.

Exclusion Criteria:

1. Single parents or non-active caregivers: Their experiences may differ significantly and would not align with the research aim of studying shared parenting dynamics.
2. Parents of children with other conditions: Autism-specific challenges were the focus, so unrelated diagnoses could confound the analysis.
3. Participants unwilling to consent or discuss sensitive issues: The study required open, detailed narratives to achieve meaningful insights.

Measures Taken for Semi-Structured Tool:

1. Design Approach: The tool was rooted in existing literature, focusing on areas such as parenting stress, coping mechanisms, and societal reactions to autism. It was designed to be open-ended, encouraging participants to share their stories in detail while remaining aligned with the research objectives.
2. Dimensions Covered: Emotional reactions to diagnosis, caregiving responsibilities, changes in marital dynamics, and experiences of societal stigma were key areas explored.

3. Pilot Testing: The tool was tested with a few parents outside the primary study. Their responses helped refine the phrasing and order of questions, ensuring they resonated with the participants.
4. Face and Content Validity: The questions were evaluated for their ability to address the intended research dimensions comprehensively and sensitively.
5. Iterative Refinements: Based on feedback, redundant or ambiguous questions were eliminated, and clarity was enhanced.

This process ensured the tool was culturally sensitive, ethically robust, and capable of eliciting nuanced narratives, crucial for thematic analysis.

Procedure

The interview schedule was first developed. Data was primarily collected through semi-structured qualitative interviews, employing the Zarit Burden Interview framework as the guiding structure. Each participant underwent an individual interview, with sessions lasting between forty-five minutes and one hour.

All interviews were audio recorded, and informed consent was secured prior to commencement. Participants were guaranteed confidentiality concerning their responses, and measures were taken to ensure data security; to maintain anonymity, all names were substituted with pseudonyms.

Transcriptions of the interview data were analyzed thematically, following the protocols outlined by Braun and Clarke (2006). An inductive thematic analysis was employed, facilitating the emergence of themes grounded in the data without imposing pre-existing theoretical frameworks. Interpretative efforts were made at both semantic and latent levels to derive a nuanced understanding of the data.

The recruitment process encountered challenges, as several potential participants declined due to time constraints or the sensitive nature of the subject matter. Significant difficulties arose, particularly with the paternal participants. During the interviews, mothers exhibited a higher level of expressiveness compared to fathers, who often struggled to provide detailed or emotionally nuanced responses. Despite prompting, paternal narratives tended to be concise, emotionally distant, and lacking in depth. Nonetheless, the analysis revealed a compelling framework of both convergent and divergent themes across the cases studied. The study employed purposive sampling to ensure participants met specific criteria related to the research objectives. A total of three couples were selected from a prominent hospital in New Delhi.

Results

The study employed a qualitative design, adopting an instrumental multiple case study approach to clarify parenting experiences and issues with children with autism. An inductive thematic analysis was utilized, allowing themes to emerge from the data without the influence of pre-existing theoretical frameworks. Interpretative efforts were conducted at both semantic and latent levels to develop a nuanced understanding of the data. To make sense of the story of each of the three couples, this section presents a brief case presentation of all three couples highlighting the relevant background information and presenting an overview of their relationship dynamics and parenting experiences.

Case 1: Zara and Zavan Ahmad

Seher Ahmad is 5 years and 6 months old girl who was born in Jammu and Kashmir. She was diagnosed with autism at the age of 3. Zara Ahmad (Seher's mother) is a 35 years old

school teacher by profession from Jammu and Kashmir, living in New Delhi from last 4 years with her husband and two children. She has been married to Zayan Ahmad Seher's father, for the last 6 years who is a medical doctor by profession. Her second child Hamid is 3 years old; he was conceived and born in Delhi. Initial period of her pregnancy with Seer was stressful as her relationship with her in-laws was disturbed. Also, due to her professional commitments, she couldn't give her daughter enough time in the early years. At that time, her parents were primarily taking care of the child. Zara and Zayan's relationship has seen frequent ups and downs, though it has substantially improved post their movement to Delhi. Off lately, Zara is having difficulties with her job as she is not being given leave extension and thus, is required to travel to Kashmir on a weekly basis. For their financial needs, family is primarily dependent on Zara's income as Zayan does not have a stable job. They also are supported financially from the families on both sides.

It is surprising that despite Zayan being a medical doctor, the awareness of the nature of autism in the couple was very limited to begin with. They also come from a background where there are not enough resources available for the treatment of the child. Zayan mentioned, *"In Jammu the awareness level is very low, particularly about these types of cases"*. This has forced a transition in their life where they have shifted their base from Jammu to Delhi. This transition has brought with it multiple changes, some positive and some negative. While their marital relationship has seen improvement due to non-interference from the extended family as Zara mentions, *"We bonded very well here only because we did get time"*. But, the professional life of Zayan has been compromised. The increased involvement of each other with the child and couple has been impactful as expressed by him *"we got involved with each other so much that it helped us together to handle the child"*. There are also challenges being faced by Zara as she has to keep on travelling back to Jammu every week. Hence, a lot of caregiving demands have been forced on Zavan and he probably feels burdened by them, he even mentioned *"when she (wife) is not around everything is done by me only, washroom to bathing and everything, feeding, clothing..."*. At an overall level, both parents are trying to deal with the situation.

Case 2: Jenny and Rahul Fernandez

Roy Fernandez is 4 years old, conceived and born in Delhi. He was diagnosed with autism at the age of a year and a half. Jenny Fernandez is a 33-year-old Human Resource Executive living in Delhi from last 4 years with her husband. She is on the verge of quitting her job due to extensive care giving demands. Her husband is Rahul Fernandez and they had a love cum arranged marriage. He is a 35 years old training executive by profession. He is a patient and down to earth person. Their married life is a satisfactory one.

Jenny and Rahul are representatives of urban modern parents who think through their parenting strategies well in advance. The diagnosis came as a shock to them as they were hoping for everything *'normal'*. Rahul reported the moment of the birth of his child as a *'priceless moment'* and articulated expectations of a *'smooth'* life afterwards which did not last for long. When enquired about reactions upon diagnoses, he reported, *"We never wanted to accept it, we were using our own ways of covering things"*. But, they have managed coming out from this initial shock very well and have now taken a very pro-active constructive approach to parenting. In this context Rahul proactively stated, *"So I feel okay, I don't feel ashamed and I don't take him as an autistic child"*. In order to meet the excessive care giving demands, they have made multiple changes in their personal and professional lives. Rahul is trying to balance his professional and personal life in order to be there for the child, while, Jenny is in the process of leaving her job. Although this decision of leaving her job is very difficult for her, she mentioned, *"So leaving my job, my career after a span of working in an organisation for good 8 years is a big change for me"*. When further probed about their relationship Rahul reported, that their married life has been good overall but as a couple, their intimacy has been compromised and they have not been able to *"spend time together"*. At an

overall level, their approach to parenting represents a balance of emotions, rationality and practicality.

Case 3: Neha and Gautam Das

Arun Das is 3 years and 6 months old; conceived and born in Delhi. He was diagnosed with autism at the age of 2. Neha Das is a 33 year old house wife originally from Kolkata has now moved to Delhi 3 years back after her husband's transfer. She has completed her education from School of Learning and Architecture. Instead for a full time job, presently she has opted for a part time job wherein she is required to report to the workplace only once in a week. She has been married to Gautam Das, a 34 years old manager by profession for the last 8 years. They are childhood friends and it was a love marriage. They both reported satisfaction with their marital relationship.

Neha and Gautam, it seems that have been thrown into a situation about which they are totally unaware, In one of Neha's narrative, she mentioned, "*I was shocked, I could not understand what happened, we had no idea about autism*". Since they had no idea about autism, initial period seemed manageable and they were hoping for quick and complete recovery. However, after realizing the true nature of the disorder, they are getting impatient as Neha mentioned, "*Gradually I'm realizing that it is very difficult*". Their unrealistic expectations about instant recovery of the child make them feel dejected. It seems that their outlook is more fatalistic wherein they do not take charge of their child's life and their excessive and exclusive reliance on experts represents that they are not enthusiastically making efforts to improve the child's condition. Post diagnosis, Neha has made significant changes in her life. She reported being career oriented from the very beginning but because of Gautam's transfer she left her job as a teacher in Kolkata and moved to Delhi. She changed her field and started Architecture course in Delhi. She wanted to work but post Arun's diagnoses; she has become homebound and started with a part time job. She feels dejected about the same, she mentioned, "*I was planning to take up job, but now I can't even think of it and I feel really sad about it*". Being the prime caregiver, she feels excessively burdened. As a parent. Gautam takes a secondary role, providing for mostly for the financial needs. As a couple, being childhood friends, they share a good chemistry and are supportive of each other. But, recently, the intimacy in their marital relationship has been compromised. Gautam expressed his concerns regarding the same and said. "*The time we used to devote to each other has been compromised, we used to go to theatres, concerts but now we have stopped everything*". It can be inferred from the table given below, comprising verbatims, code and themes emerged from the interview of the participants.

Verbatim	Code	Theme
<p>C1: "We bonded very well here only because we did get time"</p> <p>C2: "everything was normal and smooth in beginning days and to have a child was 'priceless moment'"</p> <p>C3: <i>I was shocked, I could not understand what happened, we had no idea about autism</i>".</p>	<p>Bonding,</p> <p>Quality time,</p> <p>emotional reactions</p>	<p>Initial parenting experiences</p>
<p>C1: "taking child to hospital for treatment made my entire routine different, and those changes were needed for my child".</p> <p>C2: "So leaving my job, my career after a span of working in an organisation for good 8 years is a big change for me".</p>	<p>Need of change,</p> <p>Availability of different routines,</p> <p>shifts in jobs</p>	<p>Changing Routines</p>

<p>C3: "I was planning to take up job, but now I can't even think of it and I feel really sad about it".</p>		
<p>C1: "In Jammu the awareness level is very low, particularly about these types of cases".</p> <p>C2: "We never wanted to accept it, we were using our own ways of covering thing"</p> <p>C3: Gradually I'm realizing that it is very difficult".</p>	<p>Limited knowledge, Lack of acceptance, Realization</p>	<p>Lack of Awareness</p>
<p>C1: "we got involved with each other so much that it helped us together to handle the child".</p> <p>C2: "wish to spend time together with my child and family together".</p> <p>C3: it's an opportunity given by the God to make me a better individual by being more involved with my child in his journey".</p>	<p>Help and Support Spending time together Opportunities for involving</p>	<p>Increased Involvement</p>
<p>C1: when she (wife) is not around everything is done by me only, washroom to bathing and everything, feeding, clothing...".</p> <p>C2: I have tried really hard to manage everything together, but with great support, excessive demands as place by my child can be managed with good parenting".</p> <p>C3: The time we used to devote to each other has been compromised, we used to go to theatres, concerts but now we have stopped everything".</p>	<p>Pressure, Hard experience, compromising time</p>	<p>Excessive Caregiving Demands</p>
<p>C1: " I don't understand why people look at autism as something that cannot be managed, it is so disheartening</p> <p>C2: So I feel okay, I don't feel ashamed and I don't take him as an autistic child".</p> <p>C3: "I feel as if I'm not living a normal life like any other family in this society".</p>	<p>Stressful, unashamed, coping, dissatisfaction</p>	<p>Discontent from Societal Reactions</p>

Table 1. Themes derived from the interview

Discussion

The experiences of every participant are unique in their own respective ways, yet, there are both convergences and divergences. This section aims at discussing the similarities and

differences across all the cases, particularly, with respect to the delineated research questions and three themes coded as Initial parenting experiences, changing routines and increased involvement.

The **first research objective** was to explore the involvement of the parents (particularly fathers) with the autistic children. The analysis in the previous section indicates that there is marked increase in the involvement of the parents with the child post diagnoses.

Initial parenting experiences : The nature of their involvement typically includes doing the activities recommended by the experts. Involvement of the fathers was observed at both functional level and emotional level. For instance, due to his wife's frequent travelling, Zayan's involvement with Seher includes taking her to the hospital, getting the treatment done, learn whatever she learns in the sessions, go back home and make her perform the activities that she has learnt. Almost everything is done by him including bathing and feeding. However, it seems that his parental role is driven more by responsibility rather than the emotional connect. He also feels burdened by the caregiving demands which are imposed on him because of the circumstances. When probed in this context he mentioned *“when she (wife) is not around everything is done by me only, washroom to bathing and everything, feeding, clothing...usually a male in Indian society does not do it very often”*. Zara has also made all necessary arrangements at the work and home front to be able to spend as much time as possible with her child that she could not do in the initial year. She reported feeling guilty over her absence and is now making up for it.

Coping has been reflected through these

Changing Routines : It was interesting to note that Rahul has devised interesting strategies to establish connect with Roy over something that they both enjoy i.e. music. He enthusiastically reported the fact that his son possesses a guitar and enjoys playing it just like him. It is clear from the analysis that he proactively takes responsibility and is enthusiastically engaged with the child. Also, he takes dealing with his son's condition as a learning opportunity as he reported that, *“it's an opportunity given by the God to make me a better individual by being more involved with my child in his journey”*. Jenny has also taken a major decision of quitting her job and being a full-time caregiver for her son despite being very career oriented and she is trying to take it constructively. This demonstrates her commitment to her child's well-being. As per Zayan as well, the changing routines were seen in his plight shared *“taking child to hospital for treatment made my entire routine different, and those changes were needed for my child”*.

Increased Involvement : Gautam's role primarily includes providing financially for the family and his involvement with Arun is rather limited as compared to other fathers in the study. He accepts that he does not get to spend much time with Arun because of his professional commitments; he still tries to make up for it whenever possible. His role in his child's caregiving is limited and he also did not explicitly express his concern over this issue. Neha's involvement with her son is absolute in the sense that she is single-handedly responsible for all his activities. She feels burdened with the same as there is no respite from these demands by the society and even stated, *“I feel as if I'm not living a normal life like any other family in this society”*.

In reference to the **second research question** that aimed at exploring the differences in the experiences of mothers and fathers, it can be said that although mothers and fathers share the experience of parenting, but, there exist qualitative differences in the way they understand and experience parenting. The two themes observed are **Lack of Awareness** and **Discontent from Societal Reactions**.

Both the parents expressed grief upon diagnosis, this confirms the previous research findings by Kourkoutas (2012) & Woodgate (2008) that reported the initial reactions of parents upon diagnoses include a range of negative emotions such as shock, distress, and denial. Fathers took a more practical and rational approach in dealing with the situation by deciding to take concrete steps for the treatment whereas mothers were more emotionally driven and experienced emotional breakdown. During the discussion, Zayan mentioned, *“When I got to*

know about this, straightaway decided to come to Delhi for the treatment.” Zara on the other hand stated, “We were very upset, listening that your child is autistic.” Jenny reported being broken. Rahul on the other hand reported being, “emotionally weakened” but immediately took the decision to start with the treatment. Both Rahul and Neha had no clue about Autism and hence they were confused. Mothers are also more actively seeking support from people around such as friends and other parents facing similar issues and derived strength from these relationships. In contrast to mothers, the support network for the fathers was limited to their spouses and parents. They are emotionally restrictive in sharing their concerns with others and hence did not seek support from others.

An exception to this trend is Rahul. He has an active group of friends who have helped him immensely over the years. **Lack of awareness** was apparent in all the cases irrespective of gender. This finding is also consistent with previous finding by Kourkoutas (2012) & Woodgate (2008) that despite of the early onset of the disorder, the diagnosis itself is often delayed as awareness is limited and the behavioural symptoms are dismissed as temporary problems which is further reinforced by the reassurances provided by family and significant others. It is quite clear from the analysis that the involvement of the fathers and mothers is in sync with the stereotypical roles prevalent in Indian society. Most of the times, the mothers are the primary caregivers and engage in more daily activities such as bathing; and feeding whereas fathers are primarily responsible for providing for the financial needs. A significant finding by Divan (2012) also found that often mothers are the primary caregivers; hence, they sacrifice their aspirations and become homebound. Even in the case of the most liberal couple who have claimed to share an egalitarian relationship, i.e. Rahul and Jenny, when it came to the choice of any one of them leaving the job despite both of them having the same professional standing, it was Jenny who quit her job. Although she exerted that, “I’m the mother or I’m the female and that it’s a patriarchal family where he should earn; it was nothing like that it was a mutual decision”.

Discontent From Societal Reactions: The experience of social dejection and marginalization was shared irrespective of gender. As it can be interpreted in the response shared by Zavan “ I don’t understand why people look at autism as something that cannot be managed, it is so disheartening ” and Rahul while reporting the incident at a telecommunication shop reported feeling, “embarrassment, anger, frustration” The negative impact of societal insensitivity on parents has also been confirmed in a study by Woodgate (2008) which concluded that one of the most significant concerns that families of children with autism face is insensitivity on part of the people around such as relatives, neighbours or acquaintances. All the participants shared the socially unpleasant experiences. Mothers got more emotionally affected by societal reactions, whereas fathers took a practical approach and believed that being patient would help them to deal with the situation in a positive manner.

The **third research objective** of the present study was to assess the impact of excessive caregiving demands on the marital relationship of the couple. This was also highlighted as one of the common theme observed in the experiences of the participants. In this regard, all the couples reported that the nature of their marital relationship has undergone considerable change post their child’s diagnoses with autism. It is difficult to classify this change as completely positive or negative, however. Here, it would be safe to say that all the couples reported that the **excessive caregiving demands** have taken a toll on the intimacy in their relationship. One of them, Rahul shared “ I have tried really hard to manage everything together, but with great support, excessive demands as place by my child can be managed with good parenting ”. This is in sync with the findings by Martins (2013), which also found that fathers reported that their relationship is adversely affected with their spouse. Though this experience has brought them together as a couple where they are extending their emotional support and love to each other to give the best possible environment to their child, yet, they are left with space where they can engage with each other like other couples do not have such responsibilities. It is interesting to note that while Gautam reported missing the exclusive time he would spend with his wife, the

intimacy between Zayan and Zara has truly developed only after their movement to Delhi which was primarily for treatment purposes.

As evident by the review, the experiences of mothers having excessive care giving demands is well documented and explored in the current literature, but, the experiences of fathers are often ignored and side-lined. Not only there are negligible studies focusing on the experiences of fathers, even the researches claiming to study the experiences of parents have very few fathers in the sample, most participants are mothers. Exceptions to this trend is a studies by Collins (2008) and Martins (2013) that examined the experiences of 15 fathers raising a child diagnosed with autism. The study revealed that the initial reactions of fathers range from sorrow and grief to guilt due to excessive demand of caring. Additional problems included, issues related to diagnosis and treatment, their dissatisfaction with mental health system and their apprehensions about the future of the child. However, their marital relationship provided strong support. The study also found that most fathers employed avoidant style coping where they chose to detach themselves mentally by playing video games, reading, or listening to music whereas some of the participants also reported having faith in "God" which provided a means of effective coping. Additionally, research by Martins (2013) Fathers articulated that within the negative experience, there was a sense of relief and meaningfulness. Although it had a negative impact on their social life and marital life. Fathers in the sample reported making use problem focused means of coping i.e. they coped by gathering additional information regarding their child's condition, as well as by exploring alternative treatment options. This mechanism has helped parents especially father in coping with the excessive care demands placed on them.

Conclusion

The present study aimed at exploring the experiences of parents with autistic children. The parents who participated in this study provided a wealth of valuable information about their experiences and struggles. The experiences of every participant are unique in their own respective ways. The significant themes common to all six participants that emerged from the analysis include: Initial parenting experiences; excessive caregiving demand; changing routines and increased involvement: lack of awareness; and discontent from societal reactions emerged as some common themes in all the cases. It not only uncovers the much-neglected concerns and voices of fathers, it also helps us gain insight into their parenting experience and coping strategies. This study also reinforces that much more familial and social support is required for parents with autistic children so that they are buffered from the stress and thus, can engage in better parenting which is crucial for the child with autism. Support is especially warranted after the diagnosis where the parents go through a period of emotional turmoil. The parents should also be counselled by experts in this phase so that they adopt constructive coping strategies and engage in a more pro-active approach to parenting.

This following limitations were observed. limited sample size (three couples) constrains the generalizability of its findings to the broader population. The research exclusively examines families from New Delhi, potentially neglecting the varied experiences throughout India. Fathers frequently offered less comprehensive responses, which may diminish the depth of paternal insights. The experiences of single caregivers were not investigated, potentially omitting valuable perspectives. The exploratory nature of the study and its restricted timeframe curtailed its depth and the incorporation of wider variables. By amplifying the voices of parents, particularly fathers, and addressing the cultural, societal, and systemic barriers they face, researchers and practitioners can contribute to a more inclusive and supportive environment. As awareness grows, it is essential to move beyond stereotypes and focus on the individual and collective strengths of families navigating the challenges of autism. Ultimately, a collaborative approach that integrates research and community engagement will pave the way for meaningful change.

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