

Parenting a Child with Autism: Shared Experiences and Unique Realities

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The present study touches upon the confluence of two sensitive topics i.e. disability and parenting. The objective of the present research is to explore the experiences of the parents (particularly fathers) of children with autism. Three couples were identified using the purposive sampling from the hospital setup in Delhi. The data was gathered using the semi-structured interviews and was subjected to thematic analysis. The discussion of results was carried out in reference to the delineated research questions. It was also found that there were stark differences in the parenting experiences of mothers which can be understood in reference to the stereotypical gender roles prevalent in the Indian society. It also emerged that there was a significant impact of child's condition on the marital relationship of the couples where the relationship can either get strengthened or compromised depending upon the support available, coping strategies adopted and engagement levels of both the spouses. The findings of the research have further been discussed and related to the previous researches in this area.

Keywords: parenting, autism, inclusion, lived reality, disability

Introduction

International Classification of Functioning, Disability & Health/ICF, (WHO, 2001) defines disability as “an umbrella term for all or any of the following components- Impairments: problems in body function or structure; activity limitations: difficulties in executing any activities; participation restrictions: problems an individual may experience in involvement in life situations”. Over a billion people are estimated to live with some form of disability, which corresponds to about 15% of the world's population. Furthermore, the rates of disability are increasing in part due to ageing populations and an increase in chronic health conditions. According to census of India 2011, the percentage of disabled to total population of India is 2.21%. However, if we look at the census figures of other developed and developing nations closely, for instance, the census figures of Australia says 18.5% people have disability, USA 12.1 %, Sri Lanka 7%, Pakistan- 2.65%, it can be assumed that 2.21 % in India is a huge underestimation. It would defy the logic to think that India is the sole exception for the lower figures. The reasons for such underestimation could be numerous, for example limited categories for enumeration of disabled people, lack of sensitivity on the part of trainers on the issue of disability, inability on the part of disabled population to report about their disability as there still continues a lot of stigma regarding any disability especially in rural areas.

One of the forms of mental disability is autism. “Autism is a complex childhood developmental disorder characterized by significant impairments in reciprocal social interaction; communication; and restricted, repetitive, and stereotypic patterns of behaviours, interests, and activities.” (Butcher, Carson, & Mineka, 2007, p. 575). Autism is the third most common developmental disorder five times more prevalent in boys than girls. Typically the onset of symptoms for most children with autism occurs during late infancy.

Parenting a child with autism is a particularly challenging task in itself. A number of studies have demonstrated that parents of children with developmental disabilities experience higher levels of stress than parents of typically developing children (e.g. Hodapp et al., 2003; Johnson et al., 2003). Webster et al. (2008) found that the scores in the Parenting Stress Index were above 85th percentile in over 40% of parents of children with developmental delay, indicating significant parenting stress. The stress of raising a child with autism varies across the family's life cycle and with the extent of the child's disability. Various studies in the discipline of psychology have explored the lived experiences of parents with autistic children, issues regarding schooling and inclusion, challenges faced by the parents, experiences of siblings and their reactions.

Woodgate (2008) and Kourkoutas (2012), studied the experiences of parents with autistic

children using the qualitative interviews. Based on these studies, both the researchers concluded that the initial feelings of parents upon diagnoses of the child with autism includes a range of negative emotions such as shock, distress, terror, denial, depression, guilt, helplessness and emotional emptiness. 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. Woodgate (2008) also found that one of the most significant concerns that families of children with autism face is the lack of awareness and insensitivity on part of the people around such as relatives, neighbours or acquaintances. They reported facing repeated embarrassment in social settings and hostile reactions in public spaces when their child behaved inappropriately.

One of the significant researches in Indian context on this topic has been carried out by Divan et al. (2012). They investigated the experiences of parents with autistic children using phenomenological approach with a sample of 12 parents. The study concluded that with diagnosis of autism, parents, especially mothers, embark on a difficult journey. The intensive care giving places excessive demands on parents, which in turn can lead to negative emotional reactions, increased stress levels and a sense of isolation. The care giving process negatively affects the professional, social and interpersonal aspect of parent's lives. Often mothers are the primary caregivers; hence, they sacrifice their aspirations and literally become homebound.

Pathappillil (2011), 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 dominant belief of Indians in the notion of '*karma*', that action of past life will determine the present life's successes, failures and illnesses further worsens the condition of the child. Severe physical or mental illness is perceived as punishment for past wrongdoings of the individual's previous lives. Due to lack of awareness and social stigma, mothers are resistant to accept the problems of the child and are reluctant to seek professional help. 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.

As evident by the review, the experiences of mothers 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 and lack of acceptance. 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 is contradictory to Collin's research.

The traditional role of mother is familiar, and the influence of maternal behaviour on young children is also well researched. Knowledge, however, of the comparable role of the father and their influences on child's development is relatively limited. Somehow their role is always considered secondary to the mother's role. It is equally significant to focus on men and their experiences of fathering a child with autism.

In accordance with this idea, the present study aims to give voice to perspectives of fathers which are often missing in the current literature and also aims to bridge the gap in the existing literature which is one sided and raises concerns only encountered by mothers of autistic children.

For the purpose of present research three research objectives and questions were delineated. First, to explore the involvement of both parents (particularly fathers) with autistic children with respect to the nature of involvement, meaning making and challenges experienced by them. Second, to explore the differences in the experiences of mothers and fathers. Third, to explore the impact of care giving demands of the child with autism on the marital relationship of the couple.

Method

The study was situated in the paradigm of qualitative research. In order to develop an in-depth understanding of the experiences of parents, the design chosen for the present study was instrumental multiple case study analysis. As a method of data collection in the present inquiry, semi-structured qualitative interview has been used. All participants were interviewed individually and each interview session lasted for about forty-five minutes to an hour. The interview sessions were audio-taped. Before starting the interview sessions, informed consent was taken from all participants. The participants were assured of the confidentiality and careful handling of the data. In order to ensure the confidentiality, the names of all participants were changed to pseudonyms. Data collected from interviews in the form of transcripts was subjected to thematic analysis as suggested by Braun and Clarke (2006). In the present study, the method of inductive thematic analysis has been employed to let the themes emerge from all possible theoretical perspectives. To gain a comprehensive understanding of the data at both implicit and explicit level, the themes derived are interpreted at semantic and latent level.

A total of six parents, three mothers and three fathers of children with varying degrees of autistic disorders coming from New Delhi were selected as participants. The participants were chosen using purposive sampling. The participants were contacted through a prominent hospital in New Delhi. The parents ranged in age from 33 to 35 years. The children with autism ranged in age from 3 to 5 years, with age of initial diagnosis ranging from 2.0 to 2.5 years.

Many participants were approached some declined due to their taxing schedules and many refused due to the sensitivity of the topic itself. The process of data collection was the most challenging, especially in case of fathers. During the interactions with participants, mothers were more expressive than

the fathers. It was extremely difficult to obtain detailed and accurate information from fathers as their verbal and emotional expression was limited. Despite extensive probing, their narratives were brief, emotionally distant and lacked elaboration. Yet, the analysis revealed an interesting pattern of both similarities and dissimilarities across cases.

Results and Discussion

Section 1

To make sense of the story of each of the three couples, this section presents a brief case analysis of all three couples highlighting the relevant background information and presenting an overview of their relationship dynamics and parenting experiences:

Case 1: Zara and Zayan 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 Seher 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 didn't get time"*. But, the professional life of Zayan has been compromised. There are also challenges being faced by Zara as she has to keep on travelling back to Jammu on a weekly basis. Hence, a lot of care giving demands have been forced on Zayan 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 the 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”.

Section 2

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.

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. 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 care giving 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.

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 learning opportunity as he reported that, *“it’s an opportunity given by the God to make me a better individual”*. Jenny has also taken a major decision of quitting her job and being a full-time care giver 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. 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 care giving 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 and even stated, *“I feel as if I’m not living a normal life”*.

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 care giver and engage in more daily based activities such as bathing; 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 literally 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”*.

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. Both the parents expressed grief upon diagnoses, 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, 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, I straightaway decided to come to Delhi for the treatment”*. Zara on the other hand stated, *“We were*

very upset, listening that your child is a..." Jenny reported being 'broken'. Rahul on the other hand reported being, "emotionally weakened" but immediately took a decision of starting with the treatment. Both Rahul and Neha had no clue about Autism and hence they were confused. Mothers are also more actively seeking the 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. Also, the experience of social dejection and marginalization was shared irrespective of gender. 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 intensive care giving demands on the marital relationship of the couple. 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 care giving demands have taken a toll on the intimacy in their relationship. 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 have brought them together as a couple where they are extending their emotional support and love to each other in order to give 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 the treatment purposes.

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 analysis include: Initial parenting experiences; excessive care giving demand; changing routines and increased involvement; lack of awareness; discontent from societal reactions emerged as some common themes in all the cases. Though the present enquiry was exploratory and had a specific scope, yet it has significant implications. 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 diagnoses 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 more proactive approach to parenting.

Based on the literature review and current findings, some suggestions for the future research emerged. Firstly, since the present study included limited participants due to time constraints, researchers need to direct more studies towards experiences of fathers of children with special needs with varied backgrounds and socio-economic strata. Additionally, since the awareness about autism is lacking at every level and leads to significant problems for parents, there may be an action-based research carried out to address this issue. And lastly

researchers should investigate the efficacy of the specific coping strategies employed by the parents through determining the perceived impact of different coping strategies on parental psychological well-being and functioning.

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