

Parenting a Child with Autism: The Lived Experiences

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ABSTRACT

Even though we have considerable amount of research focusing on the parents of children with Autism, majority of these studies have primarily attempted to explore the stress and burden that these parents experience. There are very few attempts towards capturing the specific experiences of parents who have children with autism. The present study explored the socio-psychological realities of parents with children having ASD to gain insight into the lived experiences of these parents. The Zarit Burden interview was administered on 20 parents of children with ASD. A ZBI cut-off score that was 40 (moderate to severe burden) helped identifying 10 caregivers with high caregiving burden. A semi structured interview was further conducted to get a detailed account of the experiences of these parents. Qualitative analysis revealed major themes such as an inherent loss of control, fear of the future, shrinking self and emotional transformations. Although parents found the battle challenging, there were also signs of strengths they gained in the course of parenting child with ASD. Findings from this study may be helpful in developing programs to address life qualities of these parents.

Keywords: ASD: autism spectrum disorder, lived experiences, parenting, challenges.

Raising a child is indeed the most challenging task that parents encounter. The challenges get further intensified if the child suffers from some kind of disability. It is a well-known fact that caring for a disabled child leads to higher level of stress in comparison to of a typically developing child (Dyson, 1997). These parents experience significant stress and face challenges in parenting often accompanied by great sadness, fear, worry regarding disabled child and even disbelief they are really disabled. The parents face significant stress arising from factors like financial burden due to the expenses of medications, therapy, counseling, rehabilitation and physiotherapy, occupational therapy, social and emotional development and schooling, changes in routine and the emotional stress from dealing with typically developing siblings. Parenting a child with developmental disorder may even impact family and have negative consequences on the parents. Because of the behaviour of the disabled child parents may even withdraw

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themselves from social interactions. Problems such as absence of language and behavioural difficulties lead to increased stress levels (Bristol, 1984; Pisula, 2007). Regulatory problems such as eating, sleeping and emotion regulation) which is highly prevalent in young children with ASD (Degangi, et al., 2000; Dominick, et al., 2007) negatively affects these parents. The continual care provided to the disabled individuals can be extremely burdensome for the parents leading to mental health issues, depression, anger and stress, reduced well-being and poor life-satisfaction.

When considering disabilities as a challenge to the parents, autism must rank among the most stressful of childhood developmental disabilities. Marked by problems with communication, emotional expression and maladaptive behaviours, autism is one of the neurodevelopmental disabilities. The Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV) explains autism under the umbrella term ASD to club Autistic disorder, Asperger's Syndrome, and pervasive developmental disorder (Sharpe & Baker, 2007; National Collaborating Centre for Mental Health, 2013).

Parenting a child with Autism Spectrum Disorder can lead to significant stress, it is often accompanied by various challenges. According to various researchers (Olsson and Hwang 2001; Cohrs and Leslie 2017; Hayes and Watson 2013; Abbeduto et al. 2004), mental health issues and stress seem to be more prevalent in parents of children with autism than to parents of children with other developmental disability.

Anybody who has ever tried to curb a three-year-old child's temper tantrums precisely knows how stressful it is to deal with small children and when Autism Spectrum Disorder is added to the mix, the parental stress increases significantly. Studies have found that depending on the intensity of the disability and resources available for coping there have been a few parents who have tried contemplating of death for themselves or for the child. For instance, in Bangalore, India there has been a case where the mother dragged her nine-year-old autistic daughter to the roof and threw her over the edge resulting in death of the child (August 30, 2017). In another case in England a depressed mother who was struggling with severely autistic daughter drowned herself, the day after her autistic daughter was denied residential care (September, 2015). These cases throw light on the extreme levels of stress families of children with autism experience and are pushed to the limits that lead to such negative outcomes.

Researchers have found that parents of children with autism spectrum disorder experience increased levels of financial, emotional and physical stress (Byrne & Cunningham, Singh et al., 1990). The work life of parents of children with ASD gets adversely affected (Barrett et al. 2012).

It has also been found that those with weaker educational backgrounds have greater financial problems leading to increased levels of subjective caregiver burden (Barak-Levy & Atzaba-Poria, 2013). This is because raising an autistic child is three times costlier as compared to raising a typically developing child due to therapy costs and high intervention (Sawyer et al., 2009; Ludlow et al., 2011 Sharpe & Baker, 2007).

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There are further multiple problems with feelings of stress, anxiety and depression particularly when the realization of the child's disability is recent. Bringing up a child with a disability is a difficult task that carries the burden of constant care, supervision, financial strain, pressure on marital and sibling relationships and isolation (CBC News Report, September 2009). Therefore, parents of the autistic children have been viewed as being at high risk for a variety of family life problems and emotional difficulties.

AUTISM IN THE INDIAN CONTEXT

People with disability of any kind are perceived in a different light in the Indian context since time immemorial. The ancient Indian scripture, Atharva-Veda, mentions that mental illness may result from divine curses. Disability is perceived as a curse from the gods or a sign of bad omen excluding them from major spaces of society. Stories were built around the birth of children born with disabilities linking them with fearsome animals with distorted human features. They are perceived as weaker beings and often called by negative names like “*Vikshipt*” “*pagal*”, “*moordh*”, etc. Still we note a tendency of people to associate disability with some kind of personal weakness or flaw. Even now it is perceived to be a consequence of some curse or spirit possession.

India is home to almost 10 million people with autism and the disability has shown a tremendous increase over the past few years. (Uttam, 2012). Despite such an alarming statistics and tremendous increase of ASD in India, there is still lack of awareness regarding the disability among people. While there is a growing body of literature which has explored the impact of other developmental disabilities on Indian families, there is comparatively little work which has explored the impact of ASD on parents of children with ASD. Study by (Daley & Sigman, 2002) is the only contribution which highlights that despite a sound understanding of ASD in the Indian specialist biomedical professional Indian parents delayed in seeking help because of societal taboos linked with disability.

It is to be noted that the goal of healthy and holistic development of ASD children cannot be achieved if parents experiences stress or anxiety. Parents, both as individuals in their own rights and as caregivers who can maximize the potential of an autistic child, need special attention. Despite the recognition that it is only when the parents are competent and satisfied with their life, they can provide effective care to the child with ASD, little is known about the experiences of parents raising a child with ASD.

In the light of the above understandings, the present study would endeavour to fill this gap with special reference to the in the Indian context. It attempts to examine how parents of children with ASD comprehend and interpret their own selves and lives as they pave their ways through the challenges and threats posed by autism.

Thus, present study aims to explore the parent's account of their practical care giving experience. This study aims to explore socio-psychological realities of parents with children suffering from ASD.

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The specific research questions addressed in this study include:

- 1) What characterizes the day-to-day-living for parents having a child with autism?
- 2) How do they understand their roles as parents of these children?
- 3) What strengths and weakness esareinherent in parental practices?

Participants consisted of 20 parents of children with Autism Spectrum Disorder whose child was of age group 3-10years. This age group was taken because over the years, the parents get used to the stressors and learn various coping mechanism however, at this age, the diagnosis is fresh, and parents are still in the process of acceptance of the disorder and some are even on denial. Along with the process of acceptance, these parents have to face new stressors and lack awareness and special parenting skills required to raise an autistic child which makes them go through anxiety, depression, social withdrawal, embarrassment and anger. The mean age of the child with ASD was 5.8 years old. The mean number of children in each family was 1.5. The percentage of children with mild autism was: 35%; moderate autism: 55% and severe autism: 10%. Out of 20 participants 95% were married and 5% were divorced/separated; 75% (15) of the participants were mothers of children with ASD whereas, 25% (5) were fathers parenting children with ASD. The mean age of the parents of children with ASD was 35.55 years.

The sample was purposive as only those parents of children with autism were to be included. In addition, there was resistance on the part of the parents in participating in the study. Parents were selected based on the degree of severity of autism using The Zarit Burden Interview. Only the parents with moderate to severe and severe autism were included in the study. The study was done on parents from Delhi and Dehradun (India). The sample was identified through these organizations and schools based in these two cities.

Procedure

Data was collected from 20 parents of children with Autism Spectrum Disorder having kids between the age group of 3-10 years old. Semi structured interview was prepared using open ended questions that focused on the various issues encountered by the parents of children with Autism while parenting these kids. The questions were prepared both in Hindi and English and were standardized. Pilot study was carried out on four parents of children with ASD in which The Zarit Burden Interview was administered on the subjects followed 16 item semi-structured interview.

The Zarit Burden Interview was administered on 20 parents of children with ASD. This 22-item questionnaire was used to measures the level of burden faced by these parents. The questionnaire yielded a score which gave the level of burden: 0-21 little or no burden; 21-40 mild to moderate burden; 41-60 moderate to severe burden:60-88 severe burden. From these 20 parents on whom The Zarit Burden Interview was administered, 10 of them were further interviews using a semi-structured interview. Parents who scored above 40 (moderate burden) were interviewed further to get a deeper insight of the various challenges faced while parenting a child with ASD. Therefore, the data was collected using a mixed approach, using both quantitative and qualitative method of data collection. The data collected was then further interpreted.

RESULTS AND DISCUSSION

Autism manifests not just in developmental delays but in striking deviations in development. It is suggested (Seltzer, Krauss, Orsmond and Bestal) that it affects the overall psychological health of the concerned families. In order to ensure healthy development of the child, it is important to ascertain that primary caregivers need to be in a positive psychological state. It is believed that although research evidence supports parents of children with autism face variety of challenges and stressors, there is hardly any work focusing on parental perceptions and experiences. The present study attempts to explore how parents experience their roles. More specifically it attempts to explore the social psychological context of these parents by largely focusing on meaning they assigned to being parents of children with ASD. The study was conducted in two steps as already mentioned. The first of which involved the identification of parents with moderate to severe burden and severe burden using the Zarit Burden Interview. Forty five percent of the parents were in the category of moderate to severe burden and other forty five percent of the parents experienced severe burden. Thus, showing that the majority of the parents having a child with ASD experience significant burden and stress. The parents so identified were further interviewed to gain an insight into the lives and experiences using a semi structured interview. The data so obtained was put to qualitative analysis and several dominant themes related to the experiences of parents were identified. Parents though varied the severity of intensity of experience, more or less reflected certain themes in their narratives that were common to majority of them. In the section that follows some of the dominant themes and sub themes are described.

One of the most important themes identified in the course of analysis was an inherent sense of loss of control over the child. Majority of them found the maladaptive behaviours to be challenging and stressful to handle. As these individuals are likely to lack desirable social behaviour and reflect stereotypical behaviours it becomes extremely difficult for caregivers to manage. It was reflected in the responses of the participants for instance participant 1 stated:

“He behaves aggressively and stubbornly, pacing back and forth especially behaving like that in public which is quite an embarrassment. When we go to someone’s house, he would pick some decorative or any other items of the house and throw it as a part of his aggressive response and this gets very embarrassing for us and so we do not socialize or even go out of the house for this reason.”

Similarly, participant 5 stated “*He is very stubborn, will throw things not understanding its valuable which leads to great loss at times. His aggression is a big problem*”

Thus, majority of them reported a sense of helplessness with regards to controlling their behaviour. Such an experience often led to conscious avoidance from social interactions for instance, Participant 3:

“*I cannot have my friends at home because he cannot bear people at home and this leads to shouting and all that aggression*”

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Parents of children with ASD report feelings of lack of control and anxiety over the child's conduct. For instance, in the studies done by Ludlow et al (2011); Lecavaller et al., (2006) it was found that individuals with ASD often display difficult behaviours that aggravate the caregiver burden. The difficult behaviours mostly included aggression which mostly resulted from changes in routine or from socializing or from sensory difficulties. Konstantareas (1989) suggests, behaviours of autistic individuals include being aggressive toward themselves or others and self-abusive behaviour is the best predictor of stress for parents. These challenging behaviours also included tantrums, mood swings, repetitive behaviours, self-injurious behaviours. These behaviours were viewed as highly challenging by the parents, unpredictable, out of control leading to feelings of embarrassment in public. Therefore, many parents spoke about challenging behaviours as a major cause of stress and these results were found to be mirroring studies of the current literature.

Parents described the desire to see their children as fully functioning, normal children. There was a constant comparison made by the parents with other children is exemplified by the following: Participant 5:

"I see my friend's children narrating poems, stories, and at times this makes me feel that why I do not have a child like them, I feel disheartened."

There was also a strong wish to see their children gaining certain degree of independence as they grow older, for instance one of the participant 3 responded:

"I see kids doing all their work by themselves, they are very independent whereas, he is not. He is entirely dependent upon him."

Overall, a well-behaved, independent and socially active child was the image they seem to have been carrying in their mind. India being a collectivistic culture, not being socially involved is seen as a major limitation.

Another major theme that was identified from the narratives was fears and worries related to the future. The parents were highly fearful and expressed future related anxiety, they were scared of not just what the future held for their child but also about who would look after their child later. For instance, Participant 6:

"The future really makes me worried, who is going to take care of her when I will not be there or if something happens to me."

Such future related anxiety among the parents indicates a sense of helplessness and this was viewed as highly stressful by the parents leading to anxiety. As the children were dependent on their parents for majority of the needs and activities, the parents displayed feelings of helplessness and future related anxiety as they were worried as to who would provide care to their children if they died as Participant 1:

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“I have started thinking a lot especially about the future. What will happen, how will things work for him, how will he manage everything by himself. So, I have started to think a lot about the future possibilities.”

This thought was found to be impacting the emotional wellbeing of the parents resulting in significant stress. The self of the parents got remarkably impacted from the experiences of taking care of these children. Parents felt as though they were permanently losing pieces of their selves both in context of family and other close relationships. Parents spoke about the emotional impact that having a child with ASD had on them as parents and family. Majority of the participants spoke about increased stress in their marital relationship due to parenting a child with ASD as they were unable to give enough time to each other. Participants even complaint about lack of communication with their partners due to time constraint and high burden of care giving thereby leading to increased stress in their marital relationship. For instance, Participant 1 reported:

“My wife and I do not spend time with each other as much as we used to and maybe it is because of this lack of communication that at times we even have arguments and most of the time it is for no reason. And that is why I feel we should try and spend more time alone, but this cannot really happen because of our child.”

Because of the heavy burden of parenting, they cannot enjoy leisure time. These findings were found to be consisted with studies that reported reduced intimacy among (Fishman and Wolf 1991) that lead to the damaging effects on marital relations which were in the form of divorce or spouse completely separating themselves from the family. Similarly, Blair et al., (1996); Rodrigue, Morgan, &Geffken, (1990) suggests, presence of such children can lead to increased stress in the marital relationship and decreased marital satisfaction. However, not all the parents reported negative impact on their marital relationship. Some even reported that their partners were very supportive and that they have become closer as a couple. It is the string communication between the parents which was found to be the key of the strengthened marital relationship.

The accounts obtained also reflect that eighty percent of the subjects had more than one child and sixty of them stated their inability to give enough time to the other typically developing child due to high demands from the child with ASD. They also stated how their typically developing child developed the feelings of jealousy because of not being able to receive enough time and attention from the parents. Participant 6 reported:

“There have been times when my daughter feels neglected and even fights with me for being partial towards the younger one and spending all my time with the younger one, so she feels neglected. I try giving her time too, but the younger one needs so much of attention that I cannot strike a balance between both the kids.”

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The parents were unable to strike a balance between both the kids and this was viewed as highly stressful by the parents. The parents had feelings of guilt and helplessness as they were unable to give enough time to the other child/ children. These findings suggest, parents helplessness and inability to strike a balance between the autistic kid and the typically developing child. These findings are in accordance with the study by DeMyer (1979) which compared siblings of autistic children with that of typically developing ones. It was found that generally children belonging to autistic group experience sense of neglect. Similar findings are also reported in other studies too (McHale, Sloan, and Simeonsson 1986) it was found that many children felt that they have do not receive the same amount of attention from their parents as compared to their disabled sibling and called it an unfair treatment.

Most of the parents stated that their child was subjected to judgement from the society and how people called their children with names like “mad, dumb, useless, burden, abnormal possessed” and other such inhumane terms like Participant 4 stated:

“There have been people who have called my child mad and even possessed. She even asked me to take her for exorcism”.

These parents expressed how the society lacks the awareness about the condition of their child and how these judgments from the society led to social withdrawal among the parents. However, social withdrawal was not just a result of society’s perception towards the child but also resulted from challenging behaviours of the child, time constraints, increased burden.

FINDINGS AND SUGGESTION

Findings suggest that parenting a child with ASD can lead to shrinking of the self by impacting the family life, social life and leading to emotional transformation. The parents spoke in detail about how caring for a child with ASD has impacted their social life. Seventy percent of the subjects spoke about how they were unable to socialize due to their child and reported social withdrawal. Most of the parents avoided socializing as their child was uncomfortable with it and socializing mostly resulted in aggressive behaviours and tantrums further leading to embarrassment. Participant 6 stated:

“I do not socialize or talk to anyone, so I am not even in touch with my friends or relatives. I am so engrossed with my child that I do not have the time nor the will for anything else.”

These results were found to be mirroring the results of the studies already been done, for instance, according to Gray (1993) that identified parent’s withdrawal from the social world due to the conduct of the child (1993). Similarly, Tomanik and colleagues (2004) suggested that mothers of autistic children experienced increased anxiety due to adjustment problems that children display. The irritable behaviour, difficulties to communicate and social withdrawal affects the caregiver’s ability to live independently and function normally in society.

Parenting a child with ASD was also found to impact the social life of the parents but

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was also found to be impacting their family lives and close relations. Therefore, from the above results it can be concluded that parenting a child with ASD not just impacts the social life of the parents in terms of social withdrawal but also impacts the family life as it affects the marital relationships as the parents or the couple is not able to give enough time to each other resulting in communication gap further leading to marital issues. It also has an impact on typically developing siblings as the parents are unable to strike balance between the kids and are unable to pay enough attention and give time to the typically developing child which leads to feelings of jealousy, complaints, arguments in the family thereby, impacting the entire family which was viewed as very challenging by the subjects. Parenting a child with ASD does not just impact the social and family life of the parents but also impacted the emotional wellbeing of the parents. Parents reported that they felt changes in themselves psychologically. For instance, Participant 7 reported:

“I have started feeling exhausted all the time, I feel stressed. I have developed anxiety issues only after my child’s diagnosis and I am on pills for anxiety.”

Findings suggest that parents felt how their set of responsibilities after having their child had increased and felt burdened which had led to significant stress among the parents. Parenting is a challenging task which is accompanied with many responsibilities however, the responsibilities increase and aggravate manifold when the child has ASD due to high demands of the child. This was found to lead to feelings of burden among the parents. Parents also reported emotional changes in themselves due to this burden, they reported being cranky, having feelings of being exhausted, being stressed and dealing with anxiety and even depression as a result of burden resulted from parenting a child with ASD. This was found to be consistent with a study done by Sawyer et al., (2010); Stuart & McGrew, (2009) which identified increased aggressive behaviours and anxiety and relatively mental health problems as compared to other parents. Therefore, from this it can be concluded, that parenting a child with ASD has found to impact the emotional wellbeing of parents due to increased burden of parenting, feelings of incompleteness, desire for a typically developing child, hopes and fears about the future of the child, increased financial implications and other such factors that accompany while parenting a child with ASD.

Parenting a child with ASD is not just accompanied with psycho-emotional implications but is also found to have financial implications. Parents spoke about the financial burden experienced by them caused due to parenting a child with ASD and meeting expenses to fulfill the child’s needs and demands, medications, speech therapies, special education and other such expenses. They further mentioned how caregiving has impacted their work life. Most of the parents expressed this financial burden as challenging and taxing leading to significant stress. Caregiving impacted their work and work life. Because the child is dependent upon them and needs the caregiver’s attention all the time, the parents found it difficult to strike a balance between work and caregiving which further led to financial losses. This indicates how parents felt a sense of loss of control over their own life. This was found to be consistent with the study by Gray, (1994); Montes & Halterman, (2008) which indicated

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that parents experience declines in career related growth and further lead to increased stress. This loss of control over one's life and financial implications were viewed as major stressors by the parents.

The accounts revealed the parents' recognition of possibility of positive outcomes of all their efforts in future. Majority of them were somewhat hopeful that they would along with support from professionals, succeed in developing the full potential of the child. Participant 5 stated:

"There is a ray of hope that all the therapies and medications would work so that our child becomes compatible with the society."

Parents also displayed a great degree of patience in their child rearing practices. They reported of a relatively more intense and active participation in the child's life. Findings also suggest increased inclination towards spirituality by the parents as a means of coping mechanism. For instance, Participant 5 stated:

"When I am stressed I read Sukhmani sahib (holy book of Sikhs) or play with my kids"

Studies link spiritual practices to positive psychological health and physical health (Hill & Pargament, 2008). India is a highly spiritually oriented country and consistent with this, findings suggested that parents relied on devoting time to god or spiritual activities or even meditation to overcome the stressful situations. Studies suggest that religious coping is found to be associated with lower depression, increased quality of life, and relieves anxiety (Pargament, 2002).

From the above discussion it can be concluded that parenting a child with Autism Spectrum Disorder is accompanied with various stressors, challenges like feelings of loss of control over one's life, desire for a typically developing child, feelings of incompleteness, future related anxiety, disturbed marital, family and social life, social withdrawal, judgement from the society, dealing with the difficult behaviours of the child and so on. These challenges have found to have implications on the emotional wellbeing of the parents leading to feelings of stress, fatigue, anxiety, irritability, mood swings and even depression. However, effective coping strategy like meditation, exercise, acceptance, breathing exercises, progressive relaxation and so on may help parents of children ASD to deal with daily stressors, experiences and challenges while maintaining their well-being. A strong inclination towards spirituality was also found among the parents and was used as a coping mechanism to deal with the stressors.

CONCLUSION

Parenting is an inherently difficult task but when the child has a disability, it becomes challenging. The present study suggests that parents with Autism Spectrum Disorder may face unique stresses. Challenges like financial burden, feelings of loss of control over one's life, desire for a typically developing child, feelings of incompleteness, future related anxiety, disturbed marital, family and social life, social withdrawal, judgement from the society, dealing with the difficult behaviours of the child have found to have implications on the

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emotional wellbeing of the parents leading to feelings of stress, fatigue, anxiety, irritability, mood swings and even depression. The findings also suggested a strong inclination of the parents of children with ASD towards spirituality which was used as a coping mechanism.

Parents described their experiences as a journey, with acceptance as a turning point where the frustration gets somewhat replaced by patience and calmness. Social acceptance and independence for their children are the goals parents want to achieve. It is only through the expression of frustration and anger and support by health care and social care professional, parents maybe be able to overcome the challenges experienced.

Since presence of an autistic child in family remarkably affects them at personal and emotional levels, we need to turn our attention to ways of combating these issues. The first step perhaps should be building awareness related to ASD which can further help to remove stigma and discrimination. The findings from the present study can be used to inform and guide programs concerned with improvement of quality of life of parents. Psychologists can contribute effective intervention programs to address the cognitive and emotional needs of these parents.

However, the results obtained from the study cannot be generalized as these results are based on data collected from a small population of 10 families belonging to varied socio-economic status. The sample under represents the other stakeholders like grandparents who have a significant especially in a collectivistic culture like India. Further studies are required to confirm and expand on these findings with a focus on specific stressors that adversely impacts the parents of children with ASD.

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Parenting a Child with Autism: The Lived Experiences

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Conflict of Interest

There is no conflict of interest.

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