


Challenges of the Caregivers in Managing a Child with Autism Spectrum Disorder—A Qualitative Analysis

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ABSTRACT

Background: Autism spectrum disorder (ASD) is a complex neurological condition resulting in impaired social interaction and difficulty in understanding verbal and nonverbal communication. Caring for children with ASDs is challenging for both children and their caregivers. The child suffering from ASD starts to show the developmental outcome during early 2.5–3 years and continues thereafter till the child turns to an adult. Many caregivers face severe financial crises, high out-of-pocket healthcare expenses, and unemployment. Previous studies have reported a plethora of psychosocial problems affecting caregivers of children with ASD, ranging from stress, depression, anxiety, restrictions of activities, strain in marital relationships, and diminished physical health.

Objective: This article aims to explore the concerns of the caregivers of children suffering from ASD. Aggregate themes were prepared based upon Corley and Gioia's method of data structuring.

Methods: After development and validation of an interview schedule, verbatim of

seven caregivers of children with ASD were imported on the Atlas.ti version 8. Initial coding and final coding were followed by extracting the aggregate themes. Lincoln and Guba's framework was used to assess the quality criteria as a part of qualitative analysis.

Results: Caregivers face various challenges while caring for a child with ASD, with a negative impact on physical health, psychological well-being, societal reactions, and financial balance. Caregivers reported concerns related to service availability for ASD, poorly coping with the diagnostics, and disease processes.

Conclusions: Caregivers undergo a lot of problems while taking care of a child with ASD. Health professionals must have an understanding of these problems and must provide the education and information for a better management. Furthermore, the findings of this study have policy implications for the health authorities for providing better health services to children diagnosed with ASD.

Keywords: Autism spectrum disorders, caregivers concerns, Lincoln and Guba's framework, coding, aggregate themes

Key Messages: Children suffering from autistic spectrum disorder show a plethora of symptoms, mainly repetitive and agitated behavior and persistent deficiencies in communication. Caregivers of these children face various challenges related to personal relationships, professional strata, financial balances, and, most importantly, lack of service availability and management process. Since caregivers are the first point of contact for these children, understanding their psychological well-being is a priority.

“**D**evelopmental disorder” or “developmental disability” means a severe, chronic disability of the child that is an attribute to a mental or physical impairment, or combination of both. Among other developmental disorders, incidence of autistic spectrum disorder is increasing globally.¹ Autism spectrum disorder (ASD) is characterized by the persistent deficits in social communication along with social interaction. Caring for the children suffering with autistic spectrum disorder is challenging and affects the life of the caregivers. Psychological distress,

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depression, anxiety, and other mental or physical health problems are the common symptoms that the caregivers face while caring for a child with autistic spectrum disorder. In order to manage the intellectual inabilities and communicational deficits of children with autistic spectrum disorder, majority of the caregivers face financial issues during the course of treatment. General experiences of the caregivers of child with autistic spectrum disorders can be either positive or negative or combination of both. Since caregivers are the first point of contact for the children, it is necessary to maintain positivity and self-confidence among them for a reformed care.² As caregivers' appraisal of child's development is a key component in terms of pediatric evaluation, this article aimed to garner explorative insight of caregivers' perspectives. More specifically, a qualitative method was used to delineate the major concerns faced by the caregivers while caring for a child with autistic spectrum disorder. Meeting the high care demands of affected children requires much time, effort, and patience. This often results in psychological distress, depression, anxiety, and other mental or physical health problems among the caregivers. As per the research evidences, the management process if started in early ages of 2.5–3 years has significantly better outcome as compared to a late start. The main purpose of the present study is to explore the concerns of the caregivers while taking care of a child with autistic spectrum disorder in terms of comprehensive rearing and social involvement. Previous available literature have stated about the fact that the caregivers of the autistic children are often seen burdened with challenges and concerns related to socialization, financial crisis, behavioral changes, and career advancements.³ The present study explores the caregivers' concerns and the challenges faced while upbringing a child with ASD.

Materials and Methods

To explore the caregivers' concerns in managing a child with ASD, a qualitative narrative research design was used, which included oral detailed verbatim records of the caregivers. The study was approved by the Ethics Review Board of the institution, and informed consent was taken from all the subjects.

The participants' actual experiences were collected with the help of a semistructured interview schedule. The interview guide was prepared by including questions about birth history, age of diagnosis of ASD, treatment strategies, family balance and couple adjustments, support from friends, relatives, and neighbors, and the child's overall behavior. Caregivers were also asked how they were managing repetitive behavior of the child, interpersonal relationships, workplace environment adjustment with seniors and colleagues, treatment effectiveness, hope toward future, and behavioral therapies for early management.

Contact information of the subjects was taken from a clinic for children with ASD in New Delhi, India. In-depth interviews were conducted on seven caregivers. The sample size was decided based on data saturation; the data collection was stopped when no new information was being received. The average time taken for each caregiver's interview was 45 minutes, and data were collected from December 2019 to March 2020.

Verbatims of the caregivers were documented and transcribed. The transcribed data were analyzed using ATLAS.ti version 8 software.⁴ Corley and Gioia method was used for analyzing the qualitative data; first-order and second-order coding were done, and final aggregate themes were developed.⁵ Lincoln and Guba's framework was used to assess the rigor and trustworthiness of the qualitative data in terms of credibility, dependability, confirmability, and transferability.⁶ Data credibility was ensured through prolonged engagement with the client (45 minutes of interview session). The researchers reflected upon their own thoughts before conducting study and bracketed their own thoughts and feelings in order to decrease the researchers' reflexivity. Data dependability was assured by preparing comprehensive thick notes of verbatim of the caregivers (documentation and member checking (caregivers were given feedback regarding the interview interpretations). Furthermore, peer-reviewing was conducted where peer reviewers verified each phase of the study and coded and developed the themes along with researchers. Codes and themes were finalized if an intercoders agreement was reached.

Qualitative Content Expert Validation

After data collection and management, the set of codes and themes were initially prepared from the researcher's theoretical notes. Furthermore, three experts were identified from the related field for content validation of the same. After necessary changes and inclusions, themes were finalized based upon expert validation and opinion.

Results

Seven caregivers were interviewed. About four out of seven parents of the autistic children were graduates. The majority, that is, six out of seven fathers of the autistic children were employed in private jobs, whereas four out of seven mothers were self-employed. Six out of seven study subjects had weekly follow-ups for the management process and five children were diagnosed with an ASD since birth.

In-depth data were collected on mainly two aspects: the impact of caring for a child with ASD and the concerns of the caregivers for the child with ASD. Five themes each in both the areas emerged after reading, rereading, and categorization of data. The description of categories and themes has been presented in **Tables 1** and **2**.

Impact on Caregivers

Negative Impact on Personal Relationships and Responsibilities

The caregivers reported experiencing disputes with the spouse, resulting in strained couple relationships. The couples also reported that, due to the lack of understanding about the general signs of the child with ASD in the starting years, they experienced anxiety, resulting in occasional fights and aggression toward each other. Two caregivers also expressed the inability of their other family members to understand the problems related to the abnormal behavior of the child.

P2: "All I used to do was shout on my wife or mother when we were not able to get any idea what my child needed due to which he was showing aggressive behavior."

TABLE 1.

Categories and Themes Extracted from the Qualitative Data on Impact of Having a Child with Autism Spectrum Disorder (ASD) (Corley and Gioia Data Structuring)

First-Order Coding	Second-Order Coding	Final Themes
<ol style="list-style-type: none"> 1. Strained couple relationships 2. Occasional disputes with the spouse 3. Neglect of the next child 	Impact on personal relationships	Negative impact on personal relationships and responsibilities
<ol style="list-style-type: none"> 1. Financial burden due to management of the child 2. Job irregularity 3. Inability to balance professional and personal lives 	Effect on the job and financial balance	Financial impact
<ol style="list-style-type: none"> 1. Frustration with societal reaction(e.g., autism in girl child) 2. The inability of the family to understand the signs of ASD in the child 3. The inability of neighbors to understand a child with ASD 4. Support from friends and relatives 5. Misconceptions and myths regarding the disease 	Lack of support from family, friends, and neighbors	Societal reactions toward a child with ASD
<ol style="list-style-type: none"> 1. Concern about nonavailability of treatment for ASD 2. Nonavailability of specialized autistic school 	Lack in healthcare and schooling services for autistic children	Lack of service availability
<ol style="list-style-type: none"> 1. Immediate reaction to disease by caregivers 2. Behavioral modification through positive reinforcement 3. Pleased with child's improvement 4. Gratitude toward teachers and therapists 	Immediate reaction toward autism diagnosis Satisfied with treatment and child's improvement	Coping with diagnosis and disease process

TABLE 2.

Categories and Themes Extracted from the Qualitative Data on Caregivers' Concerns About Child with Autism Spectrum Disorder (ASD)

First-Order Coding	Second-Order Coding	Final Theme
<ol style="list-style-type: none"> 1. At-birth complications 	Complications during birth	Birth complications
<ol style="list-style-type: none"> 1. Delay in milestones 2. Poor gait and imbalanced posture 3. Concerned about speech delay 4. The inability of the child to perform activities of daily living 	Milestones delay	Developmental delay
<ol style="list-style-type: none"> 1. Aggressive behavior 2. Self-hurt 3. Repetitive behavior 	Impaired behavior	Inappropriate behavior
<ol style="list-style-type: none"> 1. Impaired socialization 2. Inability of the child to develop interpersonal relationships 	Impaired communication and socialization	Impaired socialization and communication
<ol style="list-style-type: none"> 1. Concern about the likelihood of sexual abuse of girl child 2. Concern about bodily changes in the child 3. Waiting for child's independence and normalization 4. Feeling of helplessness 	Specific concerns about girl child with ASD Concern about the independence of the child.	Concern for the future and safety of the child

At times my wife used to cry, and everything was upside down."

P5: *"Due to our daughter's condition, sometimes both of us yell at each other without any known cause, and many a time this ends up in serious emotional issues."*

P6: *"We (parents of the child) fight like anything because we used to think that it was our incapability that our child was not able to behave normally as others. Even my parents used to blame my wife for our child." "Life was just impossible with all this."*

Financial Impact

Due to the need for specialized treatment and schooling, the caregivers reported suffering from financial issues. Absenteeism at the workplace and frequent leaves needed for the child's treatment resulted in loss of pay, which adversely affected the financial condition and sometimes affected the child's treatment plans. Sometimes, one of the caregivers (parents) had to leave the job as they had to accompany the child for treatment sessions in autistic clinic and school. So, the loss of job of one family member, who was otherwise an earning member, further resulted in a financial burden. Furthermore, the caregivers also reported that the cost of specialized treatment of one child often resulted in neglect and inability to provide the necessary facilities to other children, which further added the stress and guilt among the caregivers.

P1: *"My wife had to leave her job, and sometimes I had to go on leave without pay, thus affecting our financial balance."*

P3: *"I am usually left with less than half of my salary every month. Living in a metropolitan city is very tough with less earnings."*

P7: *"We usually balance our financial demands by always cutting down the majority of my daughter's demands and our personal family visits."*

P6: *"My colleagues just felt pity for me due to my child. I had to be on leave every third day due to ongoing therapies. That way, I am on leave without pay many days a month."*

P4: *"I don't usually go for my business, so finances and budgets came down like anything."*

Societal Reactions Toward the Child with ASD

The caregivers reported negative reactions and lack of support not only from the family members and relatives but also from friends and neighbors. Furthermore, the caregivers expressed concern regarding unempathetic behavior by family members, friends, and neighbors. Instead of providing hope and positivity, they showed pity toward the caregivers and the child. Relatives negatively commented on having a child with ASD and considered it a burden on the caregivers and the family. One caregiver reported about the beliefs and myths expressed by neighbors and relatives, such as past-life sins resulting in a child with ASD.

P2: *“Our relatives are not so good in terms that they always need to say something negative about our girl child. They say, “She is a girl. Who’ll marry her? How long will you wait for her marriage when she is grown up?” and many more things I don’t want to state. But we all don’t want to go into these rubbish talks because we have seen her improving day by day, and I hope that she will be an independent girl soon.”*

P4: *“Soon after my daughter was diagnosed with ASD, my daughter and I were sent to my parents’ home as my in-laws and my husband thought it was due to my negligence that my daughter got the illness.”*

P6: *“Even our relatives used to support our parents and say that he is not a normal child.”*

P7: *“I mean it was so bad that my friends used to laugh at my child and even we parents were unable to understand in starting years.”*

P1: *Our relatives used to say, “Your son is so because you have sinned in your past life.”*

Lack of Service Availability

The caregivers complained of the unavailability of treatment and school services for children with ASD. In addition to the unavailability of specialized treatment centers for managing ASD, there is also a lack of an efficient teaching support system for managing the

child’s developmental issues. Due to the unavailability of treatment, the caregivers had to change their place of residence in order to get access to better healthcare facilities for the child.

P1: *“Due to nonavailability of treatment in our home town, in 2017 we planned to shift to the capital city for his treatment and studies.”*

P2: *“It’s sad and disheartening that no medical facility or clinic is actually managing children with ASD in smaller cities as clinics in metropolitan cities do.”*

P4: *No specialized schools for autistic children. Rather, clinics in my home city asked us to admit our child in a school for mentally retarded children rather than for children with ASD. Do you think my child is mentally retarded?”*

Coping with Diagnosis and Disease Process

Almost all caregivers had an instant reaction of shock and denial when their child was diagnosed with an ASD. But an improved health and behavioral condition of the child, with professional support from the staff in autistic clinics and schools, resulted in better coping among the caregivers.

P1: *“After continuous treatment, our child has changed. Now, he shares his things with his sister and is comfortable playing with her.”*

P2: *“With doctors’ hope and help, we happened to manage our child slowly and steadily, and now at least the child can write 1–10 and tries to balance herself but with support, which was not possible without their management and treatment.”*

P4: *“All credit goes to his teachers and therapists who had such patience that now he can understand our points, not much, but, yes, to a certain extent.”*

Caregivers’ Concerns About Child with ASD

Birth Complications

Almost all caregivers reported incidences of birth complications of their child as the cause for autism, such as the absence

of cry immediately after birth, cord around the neck, respiratory distress syndrome, apnea of prematurity, and neonatal seizures.

P1: *“She had blue lips and nails at the time of birth, which might have affected her brain function.”*

P3: *“My son did not cry for 20 minutes after birth.”*

P5: *“At the time of birth, my daughter had a weak cry.”*

P4: *“At the time of birth, our daughter had the cord around the neck, so was taken up for cesarean section.”*

P7: *“He had seizures in the hospital itself after birth and was unresponsive for four weeks.”*

Developmental Delay

Caregivers reported that the indications of autism in their children were lack of maintaining eye contact at 4–6 months of age, lack of responding to an external stimulus, delayed speech, and the inability to sit and stand at an appropriate age. Another symptom reported was unexplained cry for 15–20 minutes at about 2–3 months of age.

P2: *“Our daughter does not like making friends; rather, she was comfortable with me only. No one else she wanted to talk with. At 6 months, she never made eye contact with anyone while cuddling or giggling. When we made her sit with support, she could not balance her lower body with the upper.”*

P4: *“Around 8 months, our daughter did not even smile when we made her do so. We would not understand what word she wrote. If we asked her to speak what she wrote, she would say something else.”*

P5: *“She was not able to even sit without support. At around 8 months, she didn’t even start speaking maa, paa, daa, etc. We were extremely tense thinking about it, and finally, we thought of consulting a psychologist.”*

Inappropriate Behavior

Caregivers reported major concern about inappropriate behaviors, such as repetitive and aggressive behavior, which sometimes resulted in self-harm. Caregivers felt stressed and anxious due to

this behavior of the child. They further shared that the children often used to become aggressive when they were stopped from doing what they wanted to do at a particular moment. Furthermore, continuous nodding of head and twitching of fingers, banging the head on the table, and tearing the books were some other behavioral symptoms that concerned the caregivers.

P3: *"If the teacher repeatedly asked him something, he would tear his books and bang his hand on the table."*

P4: *"Behaviorwise, she was irritated and got aggressive very early if someone stops her from doing what she wanted. She liked playing with switches, and we stopped her every time, which ultimately ended up in agitation."*

P6: *"He used to shout when we give some belongings of one child to another. He used to shout and throw things. If we say "Don't do it," he would continuously say "no, no, no," with drooling. He would get tired but won't stop. This was very common every other day."*

P7: *"She usually got aggressive when any toy she liked was taken by other children."*

P7: *"She used to get aggressive very easily, and sometimes she hurt herself in aggression. Also, she had a habit of spinning her hands whenever she wanted something and will not stop until she was tired."*

Impaired Socialization and Communication

Caregivers reported that their children like to play and sit alone in the classroom or playing rooms. They often get aggressive if their things or belongings are shared with someone else. They also had impaired interpersonal relationships due to a lack of communication and socialization.

P2: *"She was not much responsive in her school. She liked to play on her own and usually was not comfortable with some other children around. In school, she used to sit alone, always looking down at desk or books. She didn't like to be social."*

P2: *"She was not comfortable sitting and playing with her co-mates and friends. She enjoyed playing and writing alone and did not share her things even with her sister."*

P5: *"Our son never communicated with his friends and family and always used to play on his own."*

Concern for the Future and Safety of the Child

Caregivers reported concern about their children's independence and future well-being. Moreover, the caregivers of a girl with ASD were concerned about the likelihood of sexual abuse and managing bodily changes and puberty. They expressed their helplessness and reported feeling extreme stress whenever they thought of the future of their child.

P5: *"I am very much worried about her for the stage when she will attain puberty. I pray that till then, at least she gains that sense of dealing with her periods. I am also concerned that my daughter should always be accompanied by my parents or me since I am very worried about her safety as she is prone to sexual abuse."*

P2: *"I am really worried about my child as she is a girl."*

Discussion

This study revealed the multifold impact on caregivers while caring for a child with ASD. The major issues shared were strained relationships due to the stress and burden of caring for the child. Consistent with this finding, previous studies have also reported poor interpersonal relationship between parents and with other family members due to the burden of caring for the child.⁷ Often, small issues end up in unmanageable fights due to the stress and negativity due to the child's disease. A research study carried out by Hill and Zuckerman in 2006 supported the evidence that about 47% of the parents deny about being their child to be autistic. This results in the delay in accessing intervention and management of ASD.

Previous studies have reported that parents of children with ASD experience heightened stress, overburden, and a sense of self-blame.⁸ Since caregivers are continuously experiencing stress,

and they are overburdened while caring the child with ASD, their quality of life is extremely affected. The present study points toward the importance of mental health professional's involvement in helping the caregivers manage the child's symptoms, which can help lower their stress level. Caregivers' involvement in caring for a child with ASD requires patience and willpower to go through the challenges related to speech, behavioral, and communicational issues. In order to balance the multidimensional needs of the child with ASD, it is necessary for the healthcare professionals to understand the caregivers' concerns related to the management of their child.⁹

Caregivers reported the financial loss due to the costs of health services and frequent nonattending of office and business by the parents. Similar concerns were reported by Bent et al. in 2020 who found that financial issue was the major concern of the caregivers, as managing the disease process and special educational facilities are costlier than normal schooling. Caregivers usually face absenteeism at job, and, most importantly, they report an inability to manage personal and professional lives. Another study reported that mothers of children and adolescents with ASD spend a significant part of their time caring for the children as compared to the mothers of normal children. This can have a direct impact on finances, as the mothers often lose their jobs due to absenteeism or they voluntarily leave the job due to the responsibilities and burden of care of the child.¹⁰

Caregivers reported the stress and concern due to the negative attitude of family, friends, and the general public toward a child with ASD. They also reported experiencing various concerns related to lack of support from society and family members. Also, associating the disease occurrence with past-life sins is still prevalent in Indian society, as shared by the caregivers in this study. Similar findings have been reported by previous studies which found that knowledge of the general public and family about ASD is directly associated with attitude. It is recommended to improve the public's knowledge regarding ASDs to decrease the stigma related to this disorder.¹¹ Consistent with the previous literature,³ another major challenge reported by

caregivers in our study was the unavailability of facilities and services for children with ASD. Lack of specialized care centers in the place they live resulting in shifting the stay to an area with management facilities and training specializations is very common. This further aggravates the financial conditions due to higher costs of living in addition to the cost of treatment.²

Apart from this, the caregivers reported that children with ASD expressed their aggression due to environmental or behavioral stimuli had impaired socialization, delayed milestones, and, most importantly, inability to perform normal activities. It is of utmost importance to strengthen the healthcare facilities to manage the early signs.¹² For helping the caregivers cope with their child's illness, there is a need for specialized facilities to treat and manage these conditions.

Conclusion

The major concerns of the caregivers were delayed milestones, high costs of treatment, and nonavailability of healthcare services and special schools for children with ASD. Our findings have strong policy implications and point toward the need for availability and strengthening of healthcare services for ASD in the public sector. Furthermore, education of the general population on the signs and symptoms of ASD is also needed, not only for early diagnosis but also for better acceptability of these children in society. India needs to go a long way in managing these disorders, and healthcare professionals need to shoulder the responsibility of making this

world better for these children and their caregivers.

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