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Research Paper

Behind the Caregiving: A Qualitative Exploration of Lived Experiences of Mothers Navigating Through Daily Routines While Raising Children with Autism Spectrum Disorder

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ABSTRACT

Considered as a developmental disorder, ASD obstructs the daily functioning of a child. Its symptoms include, impaired social communication, a range of symptoms tied with intellectual disabilities and various mental health concerns as well. The current study focused on exploring the lived experiences of the mothers as they go through the daily routine with their children diagnosed with ASD. As the study opted for a qualitative approach, semi structured interview was utilised for data collection, wherein 11 open ended questions were asked to the participants. Once the interview transcripts were generated, they were analysed using the Interpretative Phenomenological Analysis (IPA). Through the analysis, sub themes and themes were generated. Four major themes that were generated are, ADLs considered easy, Difficult ADLs lead to a strenuous routine, Mental strain on the mother and unwell psychological well-being and developing their own coping techniques. The results indicated that bathing and dressing and grooming were considered as easy ADLs, whereas eating, assisting in communication, sleep routines and routine changes were difficult. Straining daily routine negatively affects psychological well-being. It was also seen that mothers often come up with their own strategies and methods to assist themselves in the daily routine which decreases the intensity of the hassles of their daily life to a certain level.

Keywords: *Developmental Disorder, Autism, Qualitative Approach, Interpretative Phenomenological Analysis*

Autism Spectrum Disorder (ASD) is characterised as a developmental disorder which hampers the various aspects of normal functioning of the child in their day-to-day life. It is referred to as a developmental disorder as the symptoms usually start to emerge during early years when the child is 2 or 3 years old. The symptoms of ASD are often diverse, and this diversity demands different needs and care for those who have it. The symptoms typically include impaired social communication, a range of symptoms tied with intellectual disabilities, various mental health concerns as well.

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The most widely recognised cause has been considered to be genetic. It is further considered that a person is more likely to be at risk of developing it, if it is shared by their sibling. Other causal factors are premature birth, harmful toxins, drugs, alcohol and harmful environmental factors. Still, it requires further complete knowledge in the area.

Children with autism often experience difficulties in following day to day routines. When there is a sudden change in the environment, something that is deviating from their usual one, they tend to get overwhelmed. These difficulties can stem from a variety of reasons. They are:
As autistic children navigate the world around them, a sense of predictability helps them in understanding it better. As soon as this element of predictability vanishes, they feel like losing their grasp or control over it. When there are sudden shifts in their surroundings, like strong smells, textures, it can be discomforting to them as it triggers the already persisting sensory issues. The autistic child might respond to sudden changes with impaired emotional regulation, which might manifest into meltdowns in them.

It can be easily comprehended that these routines are demanding and require high levels of attention and supervision from the caregivers. According to a study by Kavitharam T. R (2012), mothers are extremely stressed and anxious as they must multitask by taking care of the autistic child and the job duties as well. Even in the midst of strenuous routine and caretaking they are required to adhere to their social and professional roles. These straining routines can lead to impaired emotional regulation and financial setbacks as well.

Mothers are often the primary caregivers in the family and the entire burden of taking care of those with autism looms on their shoulders alone. They often experience emotional turmoil, financial setbacks while they themselves are busy taking care of the child. Their social engagement is significantly reduced as well. There is little to no social life as the autistic child's needs require constant supervision from day to night (Ray, Alphonsa, & Chandran, 2024).

This makes it very clear that taking care of and parenting a child with autism is a tough task. It is more challenging than parenting a normal child. On top of that, when there is lack of access to adequate services needed to cater them, it becomes more challenging. In societies where mental health is a hushed topic, the symptoms reported regarding autism are shaped by stigma and collective beliefs. Therefore, to curb this stigma from society's mind, it is important that we collectively contribute towards spreading awareness and acceptance in people. (Lockwood Estrin, Bhavnani, Arora, Gulati, & Divan, 2023)

METHODOLOGY

Aim of the study

The aim of the study was to understand the lived experiences of the mothers going through the strenuous routine with their children who have ASD, the toll on their psychological health and the methods that they come up with to ease the routine work.

Sample

The data was collected from the mothers coming to the B.M. Institute of Mental Health, Ahmedabad. A total of 9 parents were approached, but only 6 agreed upon sharing the information. So here, only those 6 parents are considered for the data analysis.

The children that were focused on for this study were the ones who did not have any comorbidity. The study utilized purposive sampling to make sure the relevant sample was chosen to address the research question accurately.

Inclusive criteria

The sample consisted of 6 mothers whose children had ASD diagnosed by a professional clinical psychologist and did not have comorbidity.

Exclusive criteria

- The children who are diagnosed with ASD and display comorbidity were not considered for the current study. Therefore, their mothers were not interviewed.
- The sample selection therefore was done carefully, keeping in mind the inclusion criteria and relevance to the research question.

Research questions

A total of 11 questions were formulated, ensuring the relevance to the research question. The questions were concerning the difficulties faced in assisting the child in ADLs, the coping techniques and personal struggles of the mothers.

Procedure

The current study opted for a qualitative approach. The data was collected through semi structured interviews as it allowed the interviewer to ask to follow up questions to the research participants.

Before the offline interview process was initiated, the researcher explained the purpose of the study, took their consent for recording the interviews and assured them of the confidentiality of their identities and responses. Moving forward, six participants were interviewed regarding their daily routine, the difficulties they face and their struggles and the methods they come up with in this process.

Rapport was established and 11 open-ended questions were included in the interview schedule so that the participants are given a comfortable space to discuss their experiences. After the interview conduction was completed, transcripts of the audio recordings of interviews were generated. Then the method of IPA was utilized to analyse the data and come up with codes and recurring sub themes. These sub themes were further grouped into themes. Four rounds of Thematic analysis were conducted for this purpose. Following this process helped in maintaining the depth and richness in the findings.

Date collection

The data was collected from B.M. Institute of Mental Health, Ahmedabad. It was collected through semi structured interviews as the study had a qualitative approach. The questions concerning the struggles of the daily routine and gaining in depth insight into the experiences of mothers were formulated by the researcher. Then the interview was taken and was recorded with prior consent of the participants. The semi structured format was beneficial for both the researcher and participants. It allowed the researcher to ask to follow up questions and ask to elaborate more on their experiences. The participants were able to answer freely and descriptively as well.

Analysis of the results

The 6 interviews recorded were transcribed into transcripts. As the IPA was utilized, the transcripts were reread to grasp the context. Then the codes were generated from each interview. From here, sub themes were generated from codes of 6 interviews. These sub themes were then later grouped into 4 major themes. Four rounds of analysis were conducted to generate themes which are described in the results and discussion section.

Ethical considerations

The participants were explained about the purpose of the study. The consent of the participants was taken prior to recording their interviews. The participants were also told that they can refuse to give their interviews if they feel uncomfortable at any point in time. These ethical considerations were followed to keep the study aligned with ethical standards by keeping in mind the rights of the participants.

RESULTS

Themes and sub themes

Themes	Sub themes
ADLs considered as easy	Bathing, dressing and grooming,
Difficult ADLs lead to a strenuous routine.	**Mealtimes** Picky eating behaviour, unable to feed themselves, mobile phone to distract **Communication** Must be assisted Must be supervised in greeting others **Sleep routine** Disturbed sleep Leads to lack of sleep for mother **Routine changes** Resistant behaviour, shows anger, irritation
Mental strain on the mother and unwell psychological well-being	Tension due to children not being at par level with others Sacrificed psychological health Stresses and tension a lot
Developing their own coping techniques	**Bathing** Take baths immediately Stop bathing for few days due to sensory issues and then resumes **Sleep routine** Manages the time to sleep Adjust the surroundings (make the room dark) **Overall** Lack of pampering and strict parenting

The common and recurring themes that were found during the analysis process are mentioned and described below in detail.

1. ADLs considered easy

The ADLs, that did not present that much difficulty to the mothers and were considered easy, were found to be bathing and dressing and grooming the child.

Bathing

Bathing an autistic child isn't that much of an issue for the mothers as the children typically enjoy their bathing time. Four mothers recounted that the child likes to play with water whenever they take them to a bath in the morning and likes to stay in it 24/7.

Although bathing activity remains easy compared to other ADL, there seems to be some issues as the autistic children sometimes show sensory issues. Some mothers also mentioned that their child has sensory issues in the head, therefore they do not like the touch of water on their head. One of the mothers reported that they face difficulties in applying soap and shampoo on the child's head due to this.

"He wants to stay in water for 24 hours... He just doesn't want water on his head. He doesn't even allow shampoo."

"Adhya loves to take a bath. She loves water... but she does this. She pulls my hand and takes me with her."

"Yes, she bathes peacefully.. she likes to bathe."

Dressing and grooming

Dressing and grooming the child doesn't present many difficulties. It was reported that children cooperate with them by moving their hands and legs and wearing the dress. It was also mentioned that they show some specific preferences in terms of clothing as well. So if their preferences and wishes are taken care of they'll happily cooperate, otherwise might showcase resistant behaviour. It was seen that mothers often comply with their requests. Certain difficulties were seen to arise due to sensory issues. It was also reported that the children who have sensory issues in their head, does not let them apply oil to their hair.

"No problem. He is very happy and ready…He can move his hands and legs. He has been doing this since he was small."

"He does everything."

2. Difficult ADLs leading to a strenuous routine

The following listed ADL are the ones which were seen as difficult. This adds the burden and strain on the mothers and makes their entire day seem like never ending. These ADLs are, Mealtimes, lack of communication, sleep routine and routine changes.

This theme highlights how strenuous the routine of the mother with an autistic child can become. When a mother is running all day after her child and monitoring them, it eventually becomes a long day. The sub themes under this theme are as follows:

- **Mealtimes**

Picky eating behaviour-

It was reported by that children often have strong fixations on particular foods and are resistant when changed. These strong preferences have to be taken care of so they do not get nutritional deficiencies. So it becomes difficult to plan everyday meals.

"Comparatively, he doesn't like liquid items…doesn't want to eat khichdi.

"When she doesn't like something, she refuses to eat it. She insists that she doesn't want to eat it."

"If she likes something, she eats it well. Otherwise, she doesn't eat it."

Unable to feed themselves-
The autistic children are unable to eat on their own, as they do not have that level of understanding nor the ability to do so. Due to these mothers said they have to feed them. One of the mothers reported that, as sometimes they tend to be hyperactive, unable to sit in one place and run around a lot, which means that the mothers have to run behind them and feed.
"He doesn't eat in one place?..No..I have to follow him around."
"She can't eat food with a spoon. I have to feed her khichdi."
"He does not eat by himself."

- **Communication**

Must be assisted and supervised in greeting others-
When it comes to meeting and greeting people or social communication generally, autistic children must be assisted as they themselves are unable to do so. While 2 mothers reported that their child greets people when asked to, other 2 mothers said that their child feels uncomfortable when taken to a new place. 1 mother reported that they must be shown around to make them familiar to the new place.
"I have to show him around. I have to tell him that there is an uncle. He will sit for 5–10 minutes…Then he will leave."
"If a stranger comes to your house...She'll just look at me. If I ask her to high-five me, she'll do it...Then she'll go back to her world."

- **Sleep routine**

Disturbed sleep leads to lack of sleep for mother-
A child's disturbed sleep means a lack of sleep for the mother. Four mothers reported that as the child wakes up in the night, they must stay awake with them for hours. The child might suddenly cry or even start laughing in the middle of the night. But on the other hand, it was reported that they do not face any major issues here. Having a full packed day, they are unable to get a sound sleep in the night, which might deter their functioning the next day.
"He wakes up at 3 in the morning…He starts laughing. He is disturbed in his sleep.", "I have to stay awake with him. It can be 2 hours or 3 hours at night.'
No, he wakes me up when I'm sleeping."

- **Routine changes**

Resistant behaviour, shows anger, irritation-
Several mothers reported that children show resistant behaviour, anger and irritation, if the routine changes. Children do not listen to their mothers when they try to discipline them. They are the ones to endure this while making sure that the child doesn't skip anything like mealtimes, bathing etc.
Above mentioned sub themes throw light on how this routine activity; its components drain the mothers. Their struggles are embedded in running after the child and monitoring them 24/7.
"She never listens to me. Now, she does this to me. I tell her not to hit me."
"He will get a little angry."

3. Mental strain on the mother and unwell psychological well-being

The sub themes under this theme specifically focus on the mental strain and pressure the mothers experience as they go through the routine.

Tension due to children not being at par level with others-

It was observed that mothers worry about their kids not being like other 'normal' kids. They also want their kids to showcase and achieve all the developmental milestones as the other children do. They often worry about when will they start understanding, when will they start speaking, etc. This constant worrying over the child can be distressing for them.

"Mentally, I am stressed. When will she speak well? When will she understand? I am stressed."

"If there is no command following, I have to assist him. That is a big issue. I have to get him to respond.", "Because he doesn't understand. He doesn't have much understanding. That is a big struggle."

"It's because of stress. Other kids are doing well. But we are behind. It's a little sad. It's stressful. We get tired of doing it.

Sacrificed psychological health-

While they are in the midst of prioritizing and taking care of their children, their own psychological health and emotional regulation is left far behind. The time and space required to think about themself has been long sacrificed.

Their life now revolves around their children. The daily routine is demanding as they must deal with the tantrums, emotional meltdown and anger of the child. This can result in feeling lonely and helpless in the process. They tend to ignore their self-care, social life as well.

"I have a lot of stress and anxiety. The doctors have told me that if I don't take care of myself, I will have to take antidepressants. But what can I do?"

"I sit alone and cry on the terrace."

4. Developing their own coping techniques

It was seen that mothers often come up with their own adaptive strategies to deal with the situation and guide their children throughout their routine. They prove to be helpful in taming down the complexity of the process. Mothers talked about various small methods that they utilize and they are described below.

- **Bathing**

Take a bath immediately: To avoid any hassle during bathing, one mother mentioned how she immediately takes her son for a bath. This makes sure that the child doesn't get a chance to throw tantrums or display moody behaviour.

"I have to do it early in the morning. So, I wake him up from his sleep and take him to take a bath immediately."

Stops bathing for few days due to sensory issues and then resumes: One of the mothers says as her son has sensory issues, she takes him for a bath only a few. She ensures there is a gap in the bathing days, so the difficulties that arise due to sensory issues don't have to be faced on a daily basis.

"I stop bathing him for a few days or stop washing his hair. Then he calms down and starts again."

- **Sleep routine**

Manages the time to sleep: It was mentioned that they adjust the sleep cycle of the child so as to ensure that when they go to sleep at night, they get a sound sleep. This involves avoiding any sleep episodes in the afternoon for the child. This will also make sure that mothers also get a sound sleep.

"When he was small… if he slept in the afternoon, he would sleep very late at night…would go to sleep at 3 or 4 in the night. After that, I decided not to put him to sleep in the afternoon. Now, he sleeps completely at night."

Adjusts the surroundings: They often make the room pitch dark during the nighttime. This darkness helps the child to understand that it is time to sleep and they can be put to sleep with ease.

"I have to make her sleep at night. I have to make the room dark, then she sleeps."

- **Less pampering and strict parenting**

It was noticed in the analysis process that mothers often showcase strict parenting style and do not pamper their children a lot. This is usually seen when the children throw tantrums, show anger and resistant behaviour. In these instances, instead of giving them what they want, they try to actively deal with their child.

"Now, I am strict with her. I tell her strictly not to do this, not to do that."

"I don't give him whatever he wants. I don't pamper him much."

CONCLUSION

Summary of findings

The current study tried to comprehend the lived experiences of the mothers as they go through strenuous routines everyday while raising with their autistic child. The study focused on the sample consisting of mothers residing in Ahmedabad, Gujarat.

It was found that bathing and dressing and grooming are considered to be easier Activities of Daily Living (ADL). The difficult ADLs were considered to be eating, assisting in communication, making the child fall asleep and routine changes. It was found that the day turns into a struggling one because the needs and demanding behaviour of the child is taxing on the mother.

It was also seen that there is an increase in mental strain on the mother which ultimately leads to unwell psychological well-being. Mothers are constantly surrounded by stress and anxiety as they are concerned about their children. In the process of restoring the physical and mental health of their child, it seems like they have lost theirs in the process.

Further, it was found that mothers often come up with their own strategies and methods to assist themselves in the daily routine. It makes the process a lot easier to follow and decreases the hassles of their daily life to a certain level.

Practical implications

1. Considering that certain ADLs are more challenging than the others for the mothers, the support given for those should be tailored according to the specific needs of the mothers to ease those ADLs.

2. The daily routine extracts a heavy toll on the psychological health of the mothers. This makes it necessary that there are appropriate mental health programs and interventions for caretakers.
3. The mothers often develop their own methods and strategies to deal with problems. These strategies can be incorporated into well-structured programs or workshops that guide the parents on how to effectively deal with kids. This can be helpful for inexperienced parents.
4. Community programs can be initiated to spread awareness about how difficult and straining a job of the caregiver can be. This will help in creating a community wherein a caregivers' sacrifice and hard work are acknowledged and respected.

Limitations

1. The study was conducted on a small sample.
2. The interview method was utilized for the data collection method. A mixed method consisting of both qualitative and quantitative approach would have resulted in more comprehensive findings.

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Conflict of Interest

The author(s) declared no conflict of interest.

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