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Influence of child's autism on relationships: A phenomenological study among maternal caregivers in Kerala

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Abstract---Background: Although the world has been witnessing a steady increase in the autism population, there is a paucity of research on the maternal experiences of caregiving a child with autism. Aim: The rationale of this study is to explore the maternal experiences of children with autism in Kerala, India. Materials and Methods: Ten mothers of children with autism were interviewed and the transcripts were analyzed using interpretative phenomenological analysis. Findings: Two superordinate themes were identified in the analysis: a) deteriorating marriage, and b) deteriorating social relations. Mothers in the study were affected by their child's autism, as it reflected on their personal, marital and social aspects of life. Mothers had conspicuous marital strain due to the increasing demands of caregiving and child's autism influenced their family planning decision-making. Mothers were blamed for their child's autism and discriminative and judgmental behaviours from the public restricted their social participation. The findings provide an understanding of the maternal experiences in raising a child with autism in Kerala. Conclusion: These findings can be useful for researchers, healthcare providers and policy makers to provide support and address the issues faced by the mothers in raising children with autism.

Keywords---autism, Kerala, maternal caregivers, phenomenology, relationships.

Introduction

Autism is an umbrella term associated with a wide array of neurodevelopmental disorders characterised by the presence of repetitive behaviours and interests. With deficits in social communication and interaction, it restricts one's ability to establish and maintain social relationships. As an invisible disability defined by the lack of physical markers (Oduyemi *et al.*, 2021), autism can result in stigmatising reactions from the society. The number of people affected with autism are increasing globally (Bougeard *et al.*, 2021), supporting the claim of an autism epidemic (Chiarotti & Venerosi, 2020) and evidence corroborates that it could be more likely due to the increased reporting and application of diagnosis (Russell *et al.*, 2021), and the growing awareness and societal recognition among people towards autism (Underwood *et al.*, 2021). Worldwide, about one in 100 children has autism (WHO, 2022; Zeidan *et al.* 2022), with at least three times as many males diagnosed as females (Loomes *et al.* 2017). Estimates of autism prevalence suggest rates of around 1% in the general population (Chiarotti & Venerosi, 2020; Fombonne *et al.*, 2021; Lyall *et al.*, 2021) and at least 1.5% in developed countries (Lyall *et al.* 2017). In India, it is estimated that there are about 1.7 to 2 million people with autism in India (Mahapatra *et al.*, 2019). In Kerala, a cross-sectional community survey conducted among toddlers aged between 16 and 24 months showed a prevalence rate of 5.5% (T.S. *et al.*, 2018). A community-based survey in a semi-urban area in Central Kerala reported a prevalence of 23.3 per 10,000 in the age group of 1-30 years (Poovathinal, 2016). Various studies have indicated that caregivers of children with autism are at higher risk of psychological distress, decreased well-being (Torbet *et al.*, 2019), and increased stress and difficulties (Anderson *et al.*, 2020). Parenting a child with autism in itself is a challenging process due to the behavioural concerns, difficulties in access to specialised care, and lack of community acceptance (Shattnawi *et al.*, 2020). Parents of children with autism have poorer family functioning (Zhou *et al.*, 2019; Walton, 2018; Pisula & Porebowicz-Dorsmann, 2017; Zaidman-Zait *et al.*, 2017), lower leisure satisfaction (Walton, 2018; Kim *et al.*, 2018) and less family life satisfaction (Walton, 2018). Their perceptions and experiences of stigma are varied with child's autism behaviours and symptom severity (Liao *et al.*, 2019) and they have increased stress and difficulties compared with parents of typically developing children (Anderson *et al.*, 2020).

Mothers of children with autism exhibit high levels of anxiety and depressive symptoms (Zhou *et al.*, 2019) and experience the sense of burden, distress, and vulnerability (Papadopoulos, 2021). The feelings of hopelessness, negative expectations of the future and loss of motivation in association with the future are significantly higher among them (Hemati Alamdarloo & Majidi, 2020). In Kerala, women are the primary caregivers of their children and Keralite homes focus on child management, often becoming a custodial space centred on caregiving (Sarrett, 2015). Among maternal caregivers of children with autism in Kerala, perceived stress and caregiving burden are the highest and the factors associated with their higher perceived stress include child's lower age, child being the first-born, presence of other comorbidities, lower socio-economic status, higher maternal education and being in a joint family. Their quality of life is also low and is influenced by child's functional impairment, higher care burden, and lack of social support (Thomas, Venkateswaran, & Alexander, 2020). High stress among

maternal caregivers in Kerala is significantly associated with low spousal support, having a completely dependent child, and low acceptance levels. Unlike mothers with high spousal support, mothers with low spousal support were likely to have a low level of acceptance and difficulty in interacting with others (Jose, Sundaram, & Varma, 2021).

As mothers are often the main caregivers of a child with autism, they have useful insights into the experiences of parenting children with autism (Anderson *et al.*, 2020) and thus, the study is aimed to understand the lived experiences of the maternal caregivers in Kerala on child's autism and its influence on marital and social relations. The study is unique as it also looks into the influence of autism on the family planning along with other attributes. Although there are studies on the issues of maternal caregivers of children with autism, not many studies have been made so far exploring the lived experiences of maternal caregivers of children with autism in Kerala. The current study, therefore, is intended to answer the question, "What are the lived experiences of maternal caregivers on raising a child with autism?"

Methods

Research Participants

The participants in the study were mothers who are the primary caregivers of their children clinically diagnosed with autism from Ernakulam district, Kerala. These mothers were all married and lived with their spouses. Ten participants whose children were clinically diagnosed with autism were conveniently recruited from Autism Club of Ernakulam chapter, as the small sample size facilitates the micro-level reading of the participants' accounts (Smith & Osborn, 2014). A small, select and homogenous convenience sample was recruited as it helps with understanding a particular context. The names of the participants have been changed to pseudonyms to protect their privacy.

Demographics

All of the participants belonged to Ernakulam district, Kerala, living in urban or semi-urban regions of Ernakulam. Eight lived in urban areas while two lived in semi-urban areas. The mothers were aged between 36 and 47 years ($M_{age} = 41.1$ years). Their religious affiliation, educational, and occupational status are illustrated in Table I. These ten mothers had one child each diagnosed with autism (eight boys, two girls) who were between the ages of 6 and 17 years ($M_{age} = 13$ years; see Table I).

Design

Interpretative Phenomenological Analysis (IPA) has been employed to get insights into the mothers' lived experiences. It is best suited to a data collection method which invites participants to offer a "rich, detailed, first-person account of their experiences" (Smith *et al.*, 2009). It is idiographic in its commitment to examining the detailed experience of each case in turn, prior to the move to more general claims (Smith & Osborn, 2014).

Thus, the study has made use of Interpretative Phenomenological Analysis (IPA) in order to explore the lived experiences of mothers to understand how they think their child's autism diagnosis has affected their marital and social relations. IPA is advantageous in this study because of the meticulous attention it gives in understanding the participants and enabling them to recount their experiences to the fullest (Smith & Osborn, 2014).

Procedure

Recruitment Strategy

Authors sought the help of Autism Club of Ernakulam Chapter to get a list of names of mothers, whose children were clinically diagnosed with autism. Those mothers who would be willing to participate in the study were conveniently selected and were further contacted to conduct the interview in a place preferred by them.

Interview Guide Development

A semi-structured interview guide was developed by the researchers for the purpose of qualitative data collection (see Table II). The tool was developed after going through extensive literature review, especially on studies regarding the lived experiences of mothers of children with autism employing IPA method. The questions were later modified from the suggestions of the participants. The questions in the interview guide were about the respondents' experiences on the changes in marital relationship following child's autism diagnosis and the societal responses to being a mother of child with autism. This study is a part of pilot study done for the doctoral research.

Interview Process

The participants were interviewed face-to-face using semi-structured interview guide to include their diverse lived experiences. Semi-structured, one-to-one interview is used as it has been the preferred method for data collection in an IPA study (Reid, Flowers & Larkin, 2005). This use of semi-structured interviews was preferred over structured interviews in an effort not to lead participants, and to ensure that the researcher will be "speaking with" rather than "speaking for" participants (Fielding, 2004). The use of semi-structured interviewing ensured rich material for qualitative analysis (Dilley, 2004). Interviews lasted between 30 to 60 minutes. Intention of the study was explained to each participant and confidentiality was maintained. Participants signed an informed consent form, regarding the nature of the study and they were interviewed in their vernacular language. All the interviews were audiotaped with the prior consent of the participants and interviews were conducted in places where participants preferred, ensuring their privacy.

Data Analysis

The interviews were conducted in the vernacular language (Malayalam) and they were audio-taped. Participants used both languages in their conversations and

the authors manually transcribed the interviews verbatim and subsequently analysed in English for the purpose of IPA. This was an attempt to reduce the suggested 'subtle alterations' in meaning suggested by Pugh and Vetrere (2009, p. 313), which would arguably be detrimental, particularly in the context of an IPA study. Authors deleted those details which could reveal the identity of participants to ensure anonymity.

Each participant's analysis was conducted separately to ensure that engagement with the data began at the earliest transcription stage, before full group analysis took place. The semantic content and the language use were explored. Connections across themes were identified before the next participant account was approached and themes that emerged from the previous case were bracketed. Once all accounts had been analysed, patterns across accounts were investigated and superordinate themes were created that captured the shared experiences of the participants. Several quotes were chosen and presented as they were the voices of the mothers.

Results

The emerging themes from the interview transcripts were identified and a cluster of such combined themes were formed. These clusters were given a name and they represented the superordinate theme. A few superordinate themes were articulated from the transcripts. Interview transcript of the first participant was analysed to generate themes and was kept aside. Similarly, all other transcripts were analysed *de novo* and the repeating patterns were identified throughout all the transcripts, taking into consideration the convergence and divergence in the data. Thus, two superordinate themes were identified in the study. The two themes formed in the study were *deteriorating marriage* and *deteriorating social relations*. (Table III)

Theme I: Deteriorating Marriage

Marital Strain upon Child's Diagnosis:

Diagnosis becomes a crucial point in the lives of the mothers where their journey as a full-time caregiver commences. Marital friction as a result of child's autism diagnosis was evident among all of the respondents in the form of disagreements, fights and difficulties. Living with the conviction that their lives are to be spent for taking care of their child with autism, these mothers had no time for their spouses due to which they had to go through a rough phase in their marriage. Venting out anger at their spouse was an alternative found by few mothers which could prove to be disruptive for their marital relationship. Lack of attention towards the spouses due to the increased caregiving demands and prioritising their child over anything resulted in considerable strain in their relationship. Few mothers were remorseful about the lack of time to invest in their marital relationship. Below are the excerpts:

"I do give priority to my child and his likes, not to that of my husband. If some of his actions hurt my son, I would get upset. And that reflects in my behaviour towards him"- Respondent I (DP)

I feel down when I cannot do certain things that I love as I have to be with my child always. That frustrates me. So, I get angry with my husband.”- Respondent VII (SA)

“I resigned from my job owing to the pressures of taking care of my kid. I devote my whole time for him which means I have less time for my husband. We don’t get to spend some quality time together”- Respondent IX (AU)

“My husband must be feeling bad due to lack of attention from my part. He wants to have meaningful conversations with me but there is no time for that.”- Respondent X (SN)

Lack of time to interact with each other and difficulty in accepting child’s autism negatively affected the quality of marital relationship. Disagreements over lack of communication and not having time to think about themselves deteriorated their marital lives.

“We don’t sit and talk. Who has time for that? When he comes home, he is glued to the phone and I’m into looking after the child always. We do make a lot of adjustments, all the time.”- Respondent III (CG)

“Marital strain is a part of life. It goes on. I don’t even have time to breathe. I’ve a son to take care of, who is dependent on me.”- Respondent VI (SU)

“Fights and other issues are going on. We are not happy with the way our life has been going.”- Respondent IV (MA)

Autism takes a toll on family planning

As caregiving became the priority, mothers found it hard to consider the possibility of another kid in their lives. Six out of ten respondents were of the opinion that child’s autism influenced their family planning decisions. For few, they were so preoccupied with their child that they didn’t think about having another kid. There were others who felt trapped in their own preconceived notions of autism and others’ opinions about caregiving such that it took a toll on their family life and influenced their family planning decisions.

“We were too occupied with him. We were busy arranging things for him. Years passed and we didn’t even get time to think of another child.”- Respondent II (UA)

“Few people told me that my child became autistic because I conceived him at the age of 30. Even I too thought so. I was scared to even think of another pregnancy”- Respondent III (CG)

“We were busy with his therapies and all that. So, I didn’t consider the possibility of another child in our life or consult doctor regarding that.”- Respondent VII (SA)

There were also cases where the family members prevented the respondents from planning on another child mainly due to the former’s health concerns over the baby to be born. Shockingly enough, there were even health personnel who restricted mothers from having another kid due to the elder child’s autism.

“Even my mother told me not to have another kid as nobody was there to take care of my autistic son other than me. My siblings and in-laws said the same. Gynaecologist too discouraged me. I personally also know few cases where gynaecologists discouraged parents from planning for another kid when the elder one is autistic.”- Respondent IV (MA)

There were also mothers who thought it was selfish to give birth to another kid hoping that he or she would take care of the child with autism. For them, their entire lives were about taking care of their child with autism.

"I have to give all my focus on her and if another child is born, there is no guarantee that he/she will also take care of my daughter. It would be a very selfish reason to give birth to another kid just for the sake of that." - Respondent VIII (CA)

Theme II: Deteriorating social relations

Blame placed upon the mothers:

One concerning issue faced by these mothers was the blame placed upon them by the stereotypical society, owing to the lack of knowledge regarding autism. Seven respondents opined that they were being blamed for their child's disability. Mothers were labelled as bad parents by the people who attributed child's autism to mother's lack of parenting skills.

"People had given me this bad parenting tag and I have heard a lot about people saying that. They blame me for bad parenting or say that autism is hereditary." - Respondent I (DP)

"People had blamed me and told me it was because of me that he became autistic. Even now, people say that." - Respondent IV (MA)

"People used to question me. They don't know what autism is. We do feel sad then." - Respondent X (SN)

Public Spaces aren't autism-friendly

The places in the city do not seem to be autism-friendly as going by the words of these mothers. An alarming problem for these mothers was not having a safe place to take their child along with them. Public stares concerned them and explaining their child's condition to every other person was traumatic for them. Lack of tolerance from the public frightened the mothers who were apprehensive about taking their child out.

"There are no autism-friendly places. People stare at and blame us for taking child along with us." - Respondent I (DP)

"People have expressed their disinterest in taking him to public places. They stare at my kid, probably because he is different from rest of the kids." - Respondent IX (AU)

"My son doesn't behave normal if he visits a place for the first time. Some people can't tolerate that. I am sad when people stare at him. They don't talk to him. They just stare at him. So, I feel reserved to take him to public places." - Respondent IV (MA)

As pinpointed by the respondent CA, malls in the city were not autism friendly and the loud environment could be problematic to the children. As a result, the mothers were apprehensive about going to malls along with their child. They were worried of the public responses upon the strange behaviours of the child.

"In most of the malls, they use speakers and heavy noise emanates that makes it difficult for my kid. It causes disturbance at times. I don't think we have autism-friendly public spaces here."- Respondent VIII (CA)

"I have a fear that my son would behave strangely. Sometimes he laughs hysterically. I do fear people's reaction on his antics."- Respondent III (CG)

Judgemental and Discriminative Behaviours

Respondent CG had faced discrimination at her workplace as none of the colleagues used to inform her about the events in the workplace as they believed she couldn't attend those as her child was autistic. Sympathy and avoidance that people showed towards her was something which let her down.

"I work with a Self-Help Group. My colleagues won't inform me about any functions happening there. They say it is because I won't be able to attend as my child is disabled. People isolate and avoid us. They sympathise. We're adjusting to it."- Respondent III (CG)

For respondent MA, people had openly expressed their disinterest in her tagging the child along to family functions and public places.

"People have told me not to take him to public places, for family functions and all."- Respondent IV (MA)

For respondents SA and TY, it was the judgemental behaviours from the public that added to their woes. Unsolicited advices and reprimands from the society made the situation worse for these mothers. This points to the lack of autism awareness among public and shows how mothers are being suffered due to the ignorance of the people.

"The staff in supermarkets get angry at my son's behaviour and scold him. They do not know that he is autistic. He looks very normal."- Respondent VII (SA)

"Sometimes people behave differently when they get to know that the child is autistic."- Respondent V (TY)

Respondent CA opined that there was a stigma around autism and people felt entitled to interfere with their privacy and shower them with advices once they found the child to be autistic. As far as she was concerned, her financial and educational status helped her in gaining societal acceptance which might not be the same for the underprivileged.

"There is a social stigma around autism. Once when we went to a restaurant, my daughter started screaming. And the people's reactions were very mean. So far, my husband and I are financially and educationally in a better position and we have more acceptance in society compared to those who aren't. It really happens."- Respondent VIII (CA)

Discussion

This study made use of interpretative phenomenological analysis to understand the nuanced, lived experiences of the maternal caregivers of children with autism in Kerala using semi-structured interview guide. The study included the maternal

perceptions on how child's diagnosis affected their relationship with spouse and with society at large. Participants in the study included mothers of children with autism from semi-urban and urban areas with different religious affiliations and socio-economic backgrounds. The maternal perceptions on autism affected the nature of relationship with their spouse and their interactions with society. A number of key findings were observed. First, the increased demands of caregiving made it difficult for the mothers to spend time with their spouse, affecting their marital life. It also had an influence on their family planning. Second, the stereotypical nature of society and the unwarranted behaviours from the public restricted the social participation of these mothers. Two superordinate themes were developed in the study, namely *deteriorating marriage* and *deteriorating social relations*. The current study contributes to the existing body of knowledge about sociology of caregiving and sociology of autism.

The first theme to have emerged from the study was about the changes in the relationship that the participants share with their spouse post child's autism diagnosis. Two subordinate themes emerged under this theme, namely- 'marital strain upon child's diagnosis' and 'autism takes a toll on family planning'. As mothers devote their full time towards the caregiving, they find less time to spend with their spouses. They prioritise the needs of their child with autism and are more attached to their child than to their spouse. This is similar to the study findings of Hartley *et al.* (2011) which indicated that mothers felt closer to their child with autism than to the fathers. Absence of communication with the spouse due to the increased caregiving demands along with the lack of acceptance of child's autism makes the marital relationship vulnerable. This is in congruence with the findings of Gau *et al.* (2012) which reports that mothers of children with autism perceived less marital satisfaction and that of Hoseinnejad *et al.* (2020) which points to a possible relationship between the autism disorders of children and their parents' marital satisfaction and happiness. The conspicuous changes in the marital relationship have an influence on their family planning. Few of these mothers were discouraged by health professionals from conceiving. This points to the lack of autism awareness among the professionals as is given by Crane *et al.* (2018), Mitchell & Holdt (2014) in their study.

The second theme to have emerged from the study was about the relations that these mothers have with the society. Stereotypes and insensitive nature of the public and their lack of knowledge on autism have negatively affected them. They are blamed for their child's autism and are labelled as bad parents. This is similar to the findings of Fox *et al.* (2017) and Hussein *et al.* (2019). Absence of autism-friendly public places is another predicament faced by mothers. They are welcomed by unwarranted stares and intolerance from the public which traumatises them. Mothers have faced discrimination from workplace and judgemental behaviours from the family and public alike due to their child's autism. This is similar to the study findings of Salleh *et al.* (2020) and Acharya & Sharma (2021) which report that mothers experience blame, judgement and avoidance from others due to their child's behaviours.

Conclusion

The study throws light on the lived experiences of the maternal caregivers in raising a child with autism and its influence on their marital and social relations. The autism diagnosis has a crucial role in the way the mothers interacted with their spouses and the larger society. Public ignorance on autism can obstruct the social participation of the mothers and make them reclusive. Further study in the form of a survey can help understand the very many issues faced by the maternal caregivers.

Implications

The study findings would aid policymakers to effectively address the issues of the caregivers by implementing policies for them. This study also points to the importance of parent support groups and family therapies for the mental and social well-being of the caregivers and the need for autism awareness and sensitisation programmes aimed for the public. This could also assist town and city planners towards creating autism-friendly public spaces. The study would prove to be helpful for the future researchers as a baseline for further research.

Limitations

Though the study has its own strengths, it is not free from limitations. The study is qualitative in nature thus invalidating the generalisability. Also, the study is about the mothers from a particular geographical context and carrying out a study from various geographical areas can enrich it further. Additionally, maternal perspective is only explored in the study. Further studies can be conducted from paternal perspective to understand their share of issues in raising a child with autism. Moreover, this study is about the experiences of mothers on the changes in their marital relationship and other social relationships due to child's diagnosis and data has been collected from mothers whose children's autism diagnosis occurred years ago as that would effectively help in understanding the study attributes better. A study among mothers soon after their child's autism diagnosis can take us to their unique, harrowing experiences of caregiving which is also not explored in the study.

Conflict of Interest

The authors declare no potential conflicts of interest with respect to research, authorship and/or publication of this article.

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Data Availability Statement

The audio data and transcripts are confidential in nature and are accessible to researchers only.

Informed consent form

Informed consent form was given to the participants that had to be signed by them before data was collected from them. The form entailed the voluntary nature of the study and the psychological risks involved.

Ethical Approval

The study has been scrutinized and approved by Bharathiar University Human Ethics Committee (BUHEC/041/2021).

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Table I. Participants' demographics

Participant	Age	Religion	Level of Education	Occupational Status	Gender of Child with Autism	Age of Child with Autism	Age of Child's Autism Diagnosis
DP	41	Christian	Graduate	Resigned*	Male	14	2
UA	39	Hindu	Higher Secondary	Nil	Male	17	2
CG	46	Christian	Higher Secondary	Employed	Male	14	3
MA	46	Hindu	Post Graduate	Nil	Male	17	4
TY	47	Christian	Graduate	Resigned*	Male	16	2.5
SU	44	Hindu	Graduate	Employed	Male	17	3
SA	40	Christian	Graduate	Resigned*	Male	13	3
CA	36	Christian	Graduate	Resigned*	Female	7	2
AU	36	Christian	Graduate	Resigned*	Male	6	1.5
SN	36	Christian	Post Graduate	Employed	Female	9	2.5

*The mothers who resigned from their jobs did so to take care of their child with autism. Pseudonyms are given to the respondents to ensure confidentiality.

Table II. Interview Guide*

1. What do you think and feel about your marital relationship as mother of a child with autism?
2. How do you think your child's autism diagnosis has affected the relationship that you have with your spouse?
3. Please tell me briefly if it has influenced your family planning.
4. Could you explain your perceptions on how society treats you since child's autism diagnosis?
5. How do you think it has affected your relations with the larger society?
6. Is there anything else that you would like to comment on that I haven't asked you about?

*(only includes the main themes discussed with the participants and does not include the various prompts used.)

Table III. Themes and Sub-themes

Themes	Sub-themes
Deteriorating marriage	• Marital strain upon child's diagnosis • Autism takes a toll on family planning
Deteriorating social relations	• Blame placed upon mothers • Public spaces aren't autism-

	friendly • Judgemental and discriminative behaviours
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