

Exploring The Challenges and Coping Strategies of Parents of Children with Autism

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Abstract

This qualitative study explores the unique challenges and coping strategies of parents of children with ASD. A sample of 7 parents (3 fathers, 4 mothers) was selected through purposive sampling and semi structured interviews were conducted with them. The collected data was transcribed and thematically analyzed using NVivo 14. The analysis revealed six major themes relating to the research questions. The findings highlight the various stressors faced by parents of children with ASD. They provide insights into the complex interplay of social, emotional, and psychological factors that influence the lives of these parents. Parents used a variety of coping strategies to cope with these challenges. The study also explores the perceived effectiveness and factors influencing the selection of coping strategies. It contributes to the field of psychology by offering useful insights into parental adaptation and resilience with respect to ASD

Keywords: Autism Spectrum Disorder, ASD, parenting challenges, parental coping, parental stress

1. Introduction

Autism Spectrum Disorder (ASD) refers to a neurodevelopmental disorder that is characterised by deficits in social interaction, restricted interests and repetitive behaviours (Vernhet et al., 2019). Recent estimates suggest that the prevalence of ASD in India ranges from 0.15%-1.01% (Vernal, 2021). This growing prevalence has drawn attention towards ASD and the challenges associated with it; for the diagnosed individuals as well as their families, particularly parents. While some studies have tried to explore the experiences of parents of children with ASD, there continues to be a large vacuum of such studies in an Indian context. This study tries to add to the body of literature by qualitatively studying the experiences of parents, especially with regard to the stressors faced by them and the coping strategies used.

Parents of children with ASD are likely to experience more stress than other parents (Vernhet et al., 2019; Al-Oran et al., 2022). This stress can be either due to the diagnosis itself or because of the special care, attention, and additional expenses that the child might require (Roxas et al., 2022). The deficits faced by the diagnosed children is often associated with a large number of difficulties in parents, like reduced parenting efficacy, heightened stress, and an increase in physical and mental health problems (Karst & Van Hecke, 2012). These highlight the impact that and ASD diagnosis can have on families. In fact, these parental effects can also negatively impact the diagnosed child and diminish the effectiveness of interventions (Karst & Van Hecke, 2012).

Coping strategies refer to cognitive and behavioral attempts to manage internal or external stressors (Vernhet et al., 2019). While the problems associated with ASD lead to heightened stress, parents are likely to adopt a variety of strategies to help them adjust with the parenting experience (Divan et al., 2012).

Therefore, a parent's ability to deal with these high stress levels is dependent upon the effectiveness of the coping mechanisms employed by them (Al-Oran et al., 2022).

The Transactional Model of Stress and Coping

The transactional model of stress and coping defines coping as “the process of managing demands (external or internal) that are appraised as taxing or exceeding the resources of the person” (Lazarus and Folkman, 1984; as cited in Lyons et al., 2009). It states that appraisal is a conscious and unconscious process by which individuals compare stressful stimuli to their perceived coping resources (Lim et al., 2023). The appraisal process involves the stimuli (what happens), how one deals with it, and how/what one thinks about the situation (Miodrag & Hodapp, 2011). This appraisal then determines the stress response.

Therefore, individuals employ coping mechanisms to restore functioning when they perceive that their resources have been exhausted by stressors (Pastor-Cerezuela et al., 2015). However, when these coping mechanisms fail to meet the demands, stress is most likely to occur (Pastor-Cerezuela et al., 2015). Lazarus and Folkman's theory of coping identifies two types of coping mechanisms that one might adopt: Problem focused and emotion focused coping (Miodrag & Hodapp, 2011). The former involves taking steps to do something about the problem, while the latter involves focusing on controlling one's emotions.

Resiliency Model of Family Stress, Adjustment, and Adaptation

This model has been widely used to study families at risk from a holistic perspective. It explains how families respond to stress and cope with it during and after crises. The resiliency model talks about the “adjustment phase”, wherein the diagnosis of a condition like ASD takes place (Luther et al., 2005). During this phase, the family's usual coping strategies might prove to be insufficient (Luther et al., 2005). Therefore, they may need crisis intervention. The “adaptation phase” comes after the adjustment phase. During this phase, the family tries to meet the diagnostic demands and needs of the child (Luther et al., 2005). Various protective factors can support the family during this phase. These could include personal factors like self efficacy and self esteem; family factors such as communication, problem solving, and extended family support; and community factors like informal social support, religious associations, and formal support from professionals (McCubbin et al., 1997, as cited in Luther et al., 2005). Therefore, this model provides a framework to understand how parents of children with ASD may respond to stressors and the factors that contribute towards adaptation over time.

Significance of the Study

Most interventions for ASD are usually evaluated in terms of the impact they have on the child, while ignoring the parental and familial factors (Karst & Van Hecke, 2012). By exploring both: the challenges faced by parents and the coping strategies used, the results of this study contribute to the broader fields of family psychology and ASD. The findings offer practical insights which will be useful to mental health practitioners, educators, policy makers etc.

2. Method

Objectives

1. To understand the stressors experienced by the parents of children with ASD
2. To study the coping mechanisms used by the parents
3. To study the perceived effectiveness of various coping strategies
4. To study the factors that influence the selection of coping strategies

Research design

A qualitative, phenomenological research design was adopted for this study

Participants

Seven parents of children with ASD formed the sample of this study. The sample included 3 fathers and 4 mothers. The demographics of the sample are given in Table 1 below.

Table 1 Socio-demographic details of the participants

Participant ID	Gender	Age	Child's Age
1	Female	39	10
2	Female	50	21
3	Male	48	20
4	Male	40	18
5	Female	37	6
6	Female	31	8
7	Male	33	11

Sample

Parents or primary caregivers of children diagnosed with ASD in Bangalore formed the population for the study. Purposive sampling was used to form a sample of 7 participants.

Inclusion criteria

1. The participant must be a parent or primary caregiver of a child with ASD
2. The child must have a formal diagnosis of ASD made by a qualified professional

Exclusion criteria

1. Parents living away from the diagnosed child
2. Participants with severe physical or cognitive impairments that might hinder with their ability to engage in interviews

Tools for the study

A semi-structured interview guide was formed for the purpose of collecting data. The questions were framed to be in line with the research questions. Thereafter, the interview guide was validated by experts from the fields of qualitative research and ASD.

Procedure

Parents or primary caregivers of children diagnosed with ASD in Bangalore were interviewed for the purpose of the study. Participants who met the sampling criteria were given detailed information about the purpose of the study, its procedure, risks, benefits, etc. Informed consent was taken from each participant before data collection. A semi-structured interview that was in line with the research questions and objectives was conducted. The collected data was transcribed and analysed using Thematic Analysis on NVivo 14. The emergent themes are presented in the next chapters.

Research ethics

Participation in the study was voluntary and the participants were informed about the objectives of the study before they gave their voluntary consent. Necessary information was collected in order to ensure their eligibility for participation. They were also informed that they were free to withdraw at any time and all the information gathered would be kept confidential. The collected data was analysed and reported with honesty and academic integrity.

3. Results

There were 6 key themes that emerged from analysing the data about the selfcare practices of counsellors. These are listed below in Table 2.

Adjustment and Acceptance

All of the parents stated that their child's diagnosis came as a "shock" to them. Describing the same, Respondent 5 said, "I think as parents, we were shocked, obviously very miserable. And it was basically like your world got turned upside down". However, there were various ways in which the respondents adjusted to the diagnosis after this initial shock. Emotional breakdowns, looking for causes, and self-blame were experienced by more than half of the respondents. Respondent 6 said, "I was blaming myself. I felt guilty. Was it because I had some problem that he inherited? Or was it because I let him watch too much TV? Or did he get hurt? I was questioning whether I was a good mother afterall".

All the parents interviewed said that they had very little or no knowledge about ASD before their child got diagnosed with it. Therefore, all of them began educating themselves and looking for treatment avenues. While some relied on online sources of information, 2 respondents enrolled themselves in ASD training and education programmes.

All of the respondents believed that acceptance of the child and their diagnosis was crucial. Speaking about the same, Respondent 1 said, "Because first step, I think, is the acceptance part of it. You need to accept that there is something the matter with your child. If you accept it, then you can think of at least reducing your mental stress and putting your kid to some sort of other activities and therapies". While some found it easy to accept, others resorted to denial before reaching an acceptance. However, all the parents eventually managed to adjust to and accept the situation,

Child's Behavioral and Developmental Challenges

Most of the major challenges related to the symptoms of ASD. These included lack of communication and eye contact, repetitive behaviours, need for routines, reaction to sensory stimuli etc. Aggression was a major behavioural challenge highlighted by Respondent 3, "He has sudden episodes of aggression. Pushing people and slapping is a major thing".

Parents highlighted that children would often throw tantrums or express discomfort if made to deviate from routines. Highlighting the same, Respondent 7 said, "You can plan everything down to the minute, and then something as simple as a change in routine can lead to a meltdown. If we usually take a certain route to school, but there's traffic and we have to take a detour, it can completely throw him off". Shifting between tasks and waiting for turns was another challenge that some respondents found hard to manage. Gross motor development, regression, and language were some of the developmental issues highlighted by the sample.

Emotional and Psychological stress

It is common for parents to experience a wide range of emotions like anxiety, guilt and frustration. Emotional burnout was commonly seen among the sample as a result of the constant demands of challenges. Apart from the daily challenges discussed above, one common major psychological stressor was worry about the child's future. This was mentioned by all the respondents. There was a general fear about the uncertainty of the child's future and support after the parents. Talking about the same, Respondent 5 said,

There is this fear that you have to plan for your child as though, you know you might, you might be taken away from this life tomorrow. That is the way you need to plan for it. You have to. Because more than with

a neurotypical child, a child on the spectrum needs a lot of planning and support from the parents side. So what will your child do?

Worry about the future, coupled with other stressors often led to emotional burnout among the parents. Respondents mentioned feeling “drained”, “exhausted”, “tired”, “on the edge”, “overwhelmed”, and “restless”.

Social isolation and Stigma

Lack of societal support and stigma can make parents feel alone and isolated. Respondents described feeling a sense of disconnection from their social groups. They often felt judged by friends, families, and society at large. Speaking about the same, Respondent 7 said.

Then there's the stigma. when we're out in public, and he has a meltdown, I can feel the stares and whispers. He looks like a “normal” child. So people often pass looks when his behaviour is not how they expect it to be. This judging from even relatives feels very bad sometimes. On top of that they even blame us only. The elders keep saying you should have done this and that etc.

Parents pointed out that this judgement and stress led to strained relationships and withdrawal from family and friends in many cases. Despite these social challenges, respondents also reported positive support from close friends and family, as mentioned in the following theme.

Coping Strategies

Parents use numerous approaches and strategies to manage the stress associated with raising a child diagnosed with ASD. This theme categorises them into 5 sub-themes: problem-focused (as given by Lazarus and Folkman), emotion-focused (as given by Lazarus and Folkman), social, avoidant, and religious or spiritual coping.

Problem-Focused Coping

This section focuses on the proactive measures taken by the parents to address the challenges associated with ASD. This included fixing routines, increasing knowledge about ASD, and finding professional help for the child and self. Respondent 1 highlighted the same while saying,

I prioritize routine because it helps us both feel grounded. I've also found that setting aside time for him is crucial. It helps him and avoids breakdowns. I am constantly reading up and meeting his therapist regularly to see what works best for us

Emotion-Focused Coping

This section focuses on how parents try to manage their emotional responses to stressful events. It included journaling, meditation, physical exercise, doing selfcare, and focusing on the positives. Respondent 6 said, *I've learned to be more flexible and to find joy in the little victories instead of just focusing on the challenges. I find it useful to focus on small wins, like when he uses a new word or plays with another child for a few minutes. Those moments help me keep going. My beliefs about self-care being important for effective parenting have shifted my mindset to prioritize these. That's why I try to maintain a balance between caring for him and caring for myself. I write out my feelings and exercise releases a lot of pent-up energy and stress, so those have been my go-tos.*

Social Support

6 out of 7 parents mentioned relying on their social networks for support. This included spending time with and talking to friends, family, and other parents of children with ASD. They mentioned that this support makes them feel heard, accepted and less alone. In many cases, the social networks also helped the parents in taking care of their child.

Avoidant Coping

Some parents spoke about coping by temporarily avoiding stressors. These included distancing themselves from the child, engaging in other work, and avoiding stressful social situations. While avoidant coping may provide short-term relief, most parents agreed that it was less helpful in the long run and often maladaptive.

Religious or Spiritual Coping

Many parents mentioned turning to their faith and spirituality to gain comfort and hope. They'd engage in religious practices, read scriptures, and try "remedies" suggested by religious practitioners. Talking about his experience, Respondent 4 said:

There are times when you want to rush about hunting for magic cures from all kinds of religious sources. I myself do a lot of prayers and chanting and meditation sometimes when I am scared. In fact I also used to think that maybe I have done something wrong and god is punishing us. I prayed a lot.

These religious and spiritual methods of coping helped the parents feel "resilient" and "hopeful".

Perceived Effectiveness of Coping Strategies

Parents mentioned that they tend to assess how various coping strategies suit them. This depends on their past experiences, needs of family, and the demands of the child. Respondent 1 said,

It depends on my emotional state and the situation at hand. Emotions also play a big role; if I'm feeling anxious or stressed, I know I need something more active, like exercise. I think it also impacts our other children, as I sometimes can't give them the attention they need when I'm focused on my son's needs. So I have to cope in a way that gives attention to both. And when I'm stressed, I tend to withdraw, which can frustrate my partner

Parents also mentioned that identifying the effectiveness of different strategies is often a "trial and error" process.

4. Interpretation of Findings

The main aim of this study was to explore the experiences of parents having children with ASD. It focused on the stressors faced by them and the coping strategies employed to deal with these stressors.

RQ1: What are the stressors faced by the parents of children with ASD?

Parents in the current study reported facing multiple stressors on a daily basis. Initial stressors faced upon getting to know about the diagnosis included denial, self-blame, guilt, shock, and breaking down. This initial response was in line with the "adjustment phase" of the resiliency model, wherein the diagnosis of ASD takes place. Most parents also tried to understand the causes and treatment options available for their child. Other studies have also found similar results: confusion, denial, decision-making doubt are likely to occur as a response to the diagnosis (Altiere & Kluge, 2009). These findings could be attributed to the misconceptions and lack of knowledge about ASD (Shilubane & Mazibuko, 2020). Parents highlighted that the initial stress tended to decrease with time due to acceptance and adaptation. The development of routines and increase in knowledge played a role in this process. The resiliency model also talks about this pattern of shifting from initial response to a crisis towards the making of profound changes in the "adaptation phase". As theorised, the parents built new coping strategies and resources in order to establish stability. There was an emergence of more deep and long term changes in order to cope, leading to greater adaptability and resilience.

The most commonly reported source of stress were the thoughts of the child's future. Every respondent expressed concern about their child's wellbeing and safety after their passing. Parents of high-functioning

children have previously reported that they were worried about the child's independence and safety in the future (Dabrowska & Pisula, 2010; Hill-Chapman, Herzog, & Madura, 2013; Ingersoll & Hambrick, 2011; Jones et al., 2013; as cited in Bonis, 2016). At the same time, parents of lower functioning children were worried about who would care for their child after them (Lutz et al., 2012 as cited in Bonis, 2016).

Challenging behaviours associated with ASD was reported as a major source of stress by all the respondents. Physical aggression, emotional aggression, tantrums, meltdowns, and inappropriate social behaviours were the most commonly reported stressors. Parental stress is worsened by the negative social stigma associated with diagnosis (Ladarola et al., 2017). This was also experienced by the respondents in the current study.

RQ2: What are the coping strategies used by the parents of children with ASD to manage challenges related to raising the child?

The findings highlight five major categories of coping strategies: problem focused coping (like finding treatment options and fixing routines), emotion focused coping (like journaling and self care), social support (from friends, family, and parent support groups), avoidant coping (temporarily distancing from the stressors), and spiritual or religious coping (turning to faith and spirituality for strength).

Each of these strategies played an important role in helping the parents adapt to the challenges associated with raising a child with ASD. Problem focused coping was the most common coping strategy observed in the sample, especially among fathers. Previous findings suggest that problem focused strategies are more likely to protect parental stress and enhance the quality of life (Vernhet et al., 2019).

Avoidant coping was used by some parents in the sample as a form of temporary relief. Previous studies suggest that avoidance strategies are often used after the announcement of an illness (Vernhet et al., 2019). The sample reported a reduction in the use of avoidant coping with time.

Social support from family, friends, and other parents was seen as an effective coping strategy by the sample. Studies have shown that social support may reduce stress by providing the emotional and practical support that is not present in formal services (Paynter et al., as cited in Pepperell et al., 2018). Some parents also involved in spiritual and religious practices as a means of coping. They believed that these practices gave them hope and strength (Luong et al., 2009).

RQ3: How do the parents of children with ASD perceive the effectiveness of different coping strategies?

The findings showed that problem-focused coping was seen as the most effective and widely used coping strategy. However, more mothers reported finding emotion-focused coping effective too. Fathers on the other hand, did not mention emotion-focused strategies at all. These findings are similar to those of previous studies which suggest that mothers are likely to use emotion-focused coping strategies more frequently, while fathers are more likely to use problem-focused coping strategies (Al-Oran et al., 2022). Previous findings suggest that an increased use of problem-focused coping led to better parent-child relations, while more emotion-focused coping led to poorer quality of life (Vernhet et al., 2019). Therefore, parents' perception of how the coping strategies impacted their quality of life could have influenced their perception of its overall effectiveness.

Social support can lead to better problem solving and quality of life, while reducing the feelings of isolation (Al-Kandari et al., 2017). One respondent reported a lack of support from his family and friends. The lack of such resources may impair parents' ability to adapt to stress and manage their responsibilities (Al-Kandari et al., 2017). Spiritual or religious coping was useful to those who engaged in it and believed in it. In many cases, belief in religion and spirituality has been found to increase one's confidence in

coping with the challenges related to raising a child with ASD (Vernhet et al., 2019). Such kind of coping can serve as a means of additional support and lead to increased well-being (Vernhet et al., 2019).

Avoidant coping was seen as being helpful by a few, but only for temporary relief. Similar to the respondents' experiences, avoidance has been found to be helpful in short-term coping (Heckman et al., 2004 as cited in Dardas & Ahmad, 2015). It can have an adverse effect on the mental health of individuals if used for a long time, especially while dealing with chronic stressors like raising a child with ASD (Holahan et al., 2004 as cited in Dardas & Ahmad, 2015).

RQ4: What are the factors affecting the selection of coping strategies?

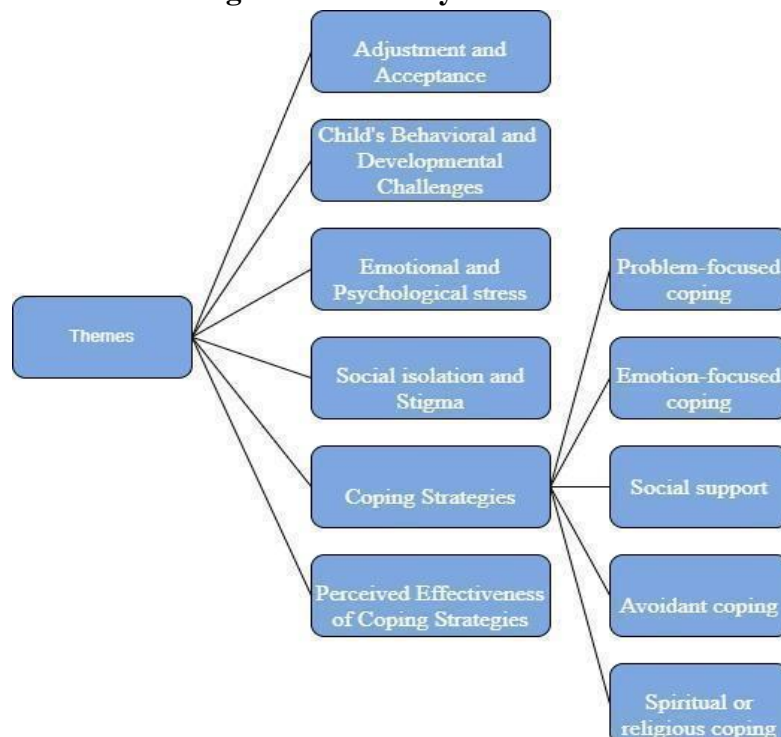
This study identified numerous factors that affected the selection of coping strategies. These included children's behaviour and symptoms, parental stress level, social support, family requirements, and financial resources. For instance, problem-focused coping strategies like fixing routines and therapeutic interventions, were used when the child's behaviour was more intense and unpredictable. Strategies like exercise and journaling were used on days when the parents felt emotionally burned out.

Parents also stated that their coping strategies often depended upon the wishes of their family members. For example, avoidance coping was not used when their partner expressed distaste for it. Moreover, the availability of supportive social groups led to an increased use of social coping. These findings align with the existing body of literature which suggests that parental and caregiver coping is influenced by a range of factors which include parental characteristics, child characteristics, and situational factors (Dabrowska & Pisula 2010; Gray 2006; Smith et al. 2008; Altieri & von Kluge 2009; as cited in (Lai & Oei, 2014).

5. Summary and Conclusion

This study aimed to explore the challenges faced by the parents of children diagnosed with Autism Spectrum Disorder (ASD) and the coping strategies used by them to deal with these challenges. A qualitative thematic analysis was conducted, which resulted in 6 major themes. These are illustrated in Figure 1.

Figure 1 Summary of Themes



The findings of this qualitative study provide insights into the complex interplay of social, emotional, and psychological factors that influence the lives of these parents. The findings reveal that parents face numerous challenges and stressors including denial, guilt, anxiety about the future, behavioural and developmental challenges with respect to the child. These are often compounded by isolation and societal stigma. Parents use various coping strategies to face these challenges. Problem focused approaches like fixing routines and seeking professional help are most commonly used and perceived to be most effective. Emotion focused strategies like journaling are often used alongside problem solving strategies. Social support was seen as a crucial component, with many parents relying on their social circles for emotional and practical support. Spiritual coping and avoidance coping were also reported by some parents. Avoidance was perceived to be ineffective in the long term. Moreover, parents highlighted multiple factors that influenced their selection of coping strategies: child's behaviour and symptoms, parental stress level, social support, family requirements, and financial resources.

The study highlights the need for increased awareness of the unique challenges faced by families of children with ASD. Community engagement via social support systems can help in alleviating isolation and societal stigma. These findings underline the importance of personalised and more accessible support systems for the families of children with ASD. The findings also show that most parents had very little to no knowledge about ASD prior to their diagnosis. Therefore, there is a need for greater awareness about the disorder and its symptoms. Culturally sensitive approaches may help in fostering a more inclusive support environment.

The study has some limitations. Firstly, the small sample may not have fully captured the diverse range of experiences among parents of children with ASD. Factors such as financial status, geographic location, and cultural background were not considered and analysed for their impact on the stressors and coping strategies. The study also does not account for the various severity levels of ASD.

Future research could address the limitations of this study by including a larger and more diverse sample. This will allow the researchers to explore a wider range of experiences and to analyse the differences that occur due to the diversity. Longitudinal studies may be done to understand the evolution of coping strategies over time.

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