International Journal of Environmental Sciences
ISSN: 2229-7359
Vol. 11 No. 8s, 2025
https://theaspd.com/index.php

EXPLORING THE COMPLEX ROLES AND CHALLENGES OF CAREGIVERS SUPPORTING CHILDREN WITH AUTISM SPECTRUM DISORDER: A QUALITATIVE STUDY

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Abstract
Background: Caregivers of children with autism spectrum disorder (ASD) face a unique and demanding set of responsibilities, often underrecognized in both clinical and social contexts. This study aims to explore the complex roles and challenges experienced by these caregivers within a low-resource setting. **Methods:** A qualitative phenomenological design was employed, involving in-depth semi-structured interviews with 20 primary caregivers of children diagnosed with ASD, recruited from autism care centers in Chennai, India. Data were analyzed thematically using Braun and Clarke's six-step framework. **Results:** Thematic analysis revealed five major themes: multifaceted parenting roles, emotional and psychological strain, social stigma and isolation, systemic and resource constraints, and coping and resilience strategies. Caregivers assumed multiple roles—ranging from therapist to advocate—while grappling with emotional exhaustion, financial burden, and lack of formal support. Despite these challenges, many relied on informal support systems, religious faith, and structured routines to manage their caregiving responsibilities. **Conclusion:** The study highlights the need for integrated support services and culturally relevant policies that address both the practical and emotional needs of caregivers. Strengthening caregiver-focused interventions can enhance not only caregiver well-being but also outcomes for children with ASD.
Keywords: Autism Spectrum Disorder, caregivers, qualitative study, caregiver burden, role complexity, coping strategies, thematic analysis

INTRODUCTION

Caregivers of children with Autism Spectrum Disorder (ASD) face a myriad of complex roles and challenges that significantly impact their well-being and family dynamics. Numerous studies have explored the multifaceted nature of caregiving in this context, focusing on the emotional, physical, and social challenges faced by these individuals. One significant aspect of the caregiving experience relates to the psychological distress often reported by caregivers. Silva et al. highlight that during the COVID-19 pandemic, caregivers experienced considerable psychological strain, underscoring the need for targeted mental health support (Silva et al., 2024). This mental stress can be exacerbated by the distinctive behavioral challenges presented by children with autism, such as communication difficulties and behavioral problems that are often more pronounced than those experienced by typically developing children or those with learning disabilities (Dira et al., 2024; Tathgur & Kang, 2021). This can lead to increased family stress levels, as caregivers are not only tasked with daily management but also with navigating their child's unique needs within potentially

dysfunctional support systems Paula et al., 2020) Mire et al., 2021). Moreover, research illustrates that caregivers often experience significant burdens due to the lack of awareness and support within their communities. In many cases, caregivers report feeling stigmatized or unsupported when seeking professional help, which can inhibit timely access to necessary services. Studies indicate that caregivers in low-income settings face barriers to service access, leading to feelings of isolation and increased stress (Heys et al., 2016; Vohra et al., 2013). Additionally, the chronic nature of caregiving stress is associated with poorer mental health outcomes, ultimately affecting caregivers' overall quality of life (Wilson et al., 2023).The role of social support structures is also crucial in the caregiving landscape. Social work within educational environments has been identified as essential in facilitating social integration for children with ASD and promoting communication between families and educational professionals to enhance support networks (Đào, 2023). Furthermore, caregivers' experiences differ significantly across cultural contexts, as evidenced by studies in places like India and Brazil, where local cultural perceptions of autism can influence caregivers' experiences and the nature of support available to them (Estrin et al., 2023; Paula et al., 2020). The interpersonal dynamics of caregiving reveal not only the stressful components but also the resilience that caregivers often exhibit amidst these challenges (Ilias et al., 2018).The ongoing caregiving journey is intricately connected to the child's developmental trajectory. Increased severity of ASD symptoms is correlated with heightened stress levels in caregivers, leading to a vicious cycle of emotional strain, which can impact their overall ability to provide effective care (Pandey & Sharma, 2018). Furthermore, the lack of effective behavioral interventions and support services exacerbates the difficulties caregivers face in managing complex behaviors associated with autism (Lai & Oei, 2014).

MATERIALS AND METHODS

Research Design

A qualitative, phenomenological research design was adopted to explore the lived experiences of primary caregivers of children diagnosed with autism spectrum disorder (ASD). This approach was appropriate to capture in-depth emotional, psychological, and contextual nuances of caregiving.

Study Setting and Participants

The study was conducted in three urban autism care and rehabilitation centers located in Chennai, Tamil Nadu, India. A purposive sampling technique was employed to select 20 primary caregivers (15 mothers and 5 fathers) of children aged between 3 to 12 years diagnosed with ASD. Participants were included based on the following criteria:

- Minimum of one year of caregiving experience
- Willingness to participate and share personal experiences
- Ability to communicate in Tamil or English

Caregivers with psychiatric illnesses or cognitive impairments were excluded.

Data Collection Procedure

Data were collected between January and March 2025 using in-depth, semi-structured interviews. An interview guide with open-ended questions was developed and validated by three experts in pediatric psychology and qualitative research. Questions focused on emotional impact, caregiving roles, support systems, and coping strategies.Each interview lasted approximately 45–60 minutes and was conducted in a private setting to ensure confidentiality. All interviews were audio-recorded with prior written informed consent from the participants. Field notes were taken to capture non-verbal cues and contextual factors.

Ethical Considerations

The study was approved by the Institutional Ethics Committee. All participants provided informed consent and were assured of their confidentiality, anonymity, and the voluntary nature of participation. No incentives were offered.

RESULT

Thematic analysis of interviews with 20 caregivers of children with Autism Spectrum Disorder (ASD) revealed five major themes reflecting the complex roles and multidimensional challenges they experience. Each theme is illustrated with direct quotations from participants to ensure authenticity and depth.

Multifaceted Parenting Roles

Caregivers described assuming a wide array of roles beyond traditional parenting, often without training or guidance. "I'm not just his mother—I'm also his speech therapist, behavioral coach, and sometimes his doctor." (Participant 4)"I monitor everything: diet, behavior, therapy. It's like I'm running a small clinic at home." (Participant 11) "My day starts with preparing his food as per the nutritionist, then online therapy, and then homework. There's barely time to breathe." (Participant 7)They emphasized the need to adapt daily routines to accommodate therapy schedules, reinforce learning goals, and manage behavioral challenges—all while balancing domestic and employment responsibilities. This multiplicity of roles caused significant mental and physical strain but was viewed as essential to the child's progress.

Emotional and Psychological Strain

Nearly all caregivers reported high levels of emotional burden, including chronic stress, fear, guilt, and anxiety. This emotional strain was often silent and self-managed."Sometimes I cry in the bathroom so he doesn't see me. I can't show him I'm weak." (Participant 13)."I never relax. Even at night, I keep checking if he's sleeping okay or having sensory issues." (Participant 2.)"What will happen to him when I'm gone? This fear doesn't let me sleep." (Participant 10).The constant vigilance required to manage meltdowns and anticipate triggers contributed to psychological fatigue. Many also voiced a deep fear about their child's long-term future and who would care for them in their absence.

Social Isolation and Stigma

Caregivers frequently felt alienated in public and private spaces due to lack of awareness and empathy around ASD."We stopped going to family functions. People look at us with pity or confusion." (Participant 8)."They say it's because I didn't take care properly during pregnancy… it's heartbreaking." (Participant 15)."I prefer staying at home. Outside, I feel like everyone is watching us." (Participant 3).Mothers in particular shared experiences of being blamed for their child's condition, especially within extended families and conservative communities. Social withdrawal became a self-imposed protective mechanism to avoid judgment and emotional pain.

3.4 Systemic and Resource Constraints

Financial stress emerged as a major challenge, with therapy, specialized schooling, and healthcare costs placing a heavy burden on families."We are middle-class, but therapy charges like ₹800 per hour are killing us." (Participant 5) "I had to take leave from work just to sit in line for assessment at a government hospital. They don't treat us seriously." (Participant 1). "Each therapist gives different advice. Schools don't want to take him. We are left to figure it out on our own." (Participant 17). Caregivers reported long waiting times, poor service quality at government centers, and the need to travel long distances to access even basic support. There was also widespread dissatisfaction with the lack of coordinated care or educational integration for children with ASD.

Coping and Resilience Strategies

Despite overwhelming responsibilities, caregivers adopted various strategies to cope and maintain hope. Religious faith, acceptance, and support from other caregivers were common buffers."Every day I say a prayer and tell myself: I am doing my best." (Participant 14). "Talking to other mothers gives me strength. They understand what I go through." (Participant 6). "He needs routine, and I do too—it helps reduce surprises and meltdowns." (Participant 12). Several participants relied on informal networks like WhatsApp groups and parent support forums to share experiences and find encouragement. Establishing structured routines was also reported as essential to maintaining stability at home.

Table 1: Categories and Themes Extracted from the Qualitative Data on Complex Roles of Caregivers Supporting Children with Autism Spectrum Disorder

First-Order Concepts (Participant Narratives)	Second-Order Themes	Aggregate Dimensions
"I teach him everything—basic tasks, speech, behavior."	Acting as Home-Based Educator	**Multifaceted Parenting Roles**
"I coordinate his therapy, school, and medical appointments."	Serving as Case Manager	
"I observe and track his behavior daily for therapists."	Informal Data Collector	
"I have to explain his condition to every new teacher or doctor."	Advocacy and Information Mediator	**Advocate and Liaison Role**
"I educate relatives and neighbors about autism."	Community Awareness Facilitator	
"I manage his meltdowns and emotions around the clock."	Emotional Regulator and Behavior Manager	**Emotional and Behavioral Management**
"When he falls sick, I do the nursing."	Performing Basic Healthcare Functions	**Health and Safety Caregiver**
"I research diets, routines, and therapy methods online."	Knowledge Seeker and Decision Maker	**Therapeutic and Wellness Manager**
"It's my job to keep things structured at home, like therapy does."	Routine Enforcer and Structure Creator	
"I act strong for him, even when I'm breaking inside."	Emotional Anchor and Role Model	**Invisible Emotional Labor**

Table 2: Categories and Themes Extracted from the Qualitative Data on Challenges of Caregivers Supporting Children with Autism Spectrum Disorder

First-Order Concepts (Caregiver Quotes)	Second-Order Themes	Aggregate Dimensions
"It's like I'm doing everything—teacher, nurse, psychologist."	Multiple Role Burden	**Role Overload and Complexity**
"There's no time left for myself anymore."	Lack of Personal Time or Self-Care	
"People avoid us in social events."	Social Withdrawal and Rejection	**Social Isolation and Stigma**
"My in-laws blame me for his condition."	Cultural Stigma and Blame	

"I'm constantly worried about what will happen when I'm gone."	Anxiety About the Future	**Emotional and Psychological Distress**
"I'm always exhausted but can't show it in front of my child."	Emotional Suppression and Fatigue	
"Every therapy session costs a lot, we can't afford all of them."	Financial Strain	**Resource and Systemic Barriers**
"We are on waitlists for months—nothing is available nearby."	Limited Access to Specialized Services	
"No one explains what we're supposed to do after diagnosis."	Lack of Guidance or Professional Support	
"Only my faith keeps me going."	Dependence on Faith and Religion	**Coping Under Strain**
"I joined a WhatsApp group—it's the only place I feel understood."	Reliance on Informal Support Networks	

DISCUSSION

The findings of the study reveal significant insights into the complex roles and challenges faced by caregivers of children with Autism Spectrum Disorder (ASD). Specifically, caregivers undertake diverse roles which include acting as therapists, educators, health managers, and advocates, often without the formal training or adequate support that would enable them to manage their responsibilities effectively. This multiplicity of roles is frequently tied to considerable emotional and psychological strain, reflecting the chronic stress, anxiety, and fears regarding their child's future experienced by many caregivers Carbone et al. (2024)(Alnazly & Abojedi, 2019; Rodriguez et al., 2019). The emotional toll on caregivers is underscored by research indicating that higher parenting stress is associated with lower family resilience and poorer mental health outcomes (Khanna et al., 2010; . Caregivers' experiences of emotional distress can be exacerbated by social stigma and isolation, with many reporting feelings of judgment from relatives and exclusion from social gatherings (Pandey & Sharma, 2018). Indeed, stigma related to autism can significantly affect caregivers' self-esteem and social presence, leading to increased feelings of isolation and despair Poorkhorshidi et al., 2022). The financial burden of care, alongside limited access to specialized services, represents another considerable challenge, particularly in resource-constrained settings where families may rely heavily on public systems that are often underfunded and overburdened (Pillay et al., 2024; Aslam et al., 2022). This financial strain can diminish caregivers' quality of life and increase their stress, leading to a cyclical problem where stress further complicates caregiving responsibilities (Alnazly & Abojedi, 2019; Poorkhorshidi et al., 2022). Despite these numerous challenges, many caregivers demonstrate remarkable resilience. Research has shown that coping mechanisms such as maintaining faith, forming peer support networks, and establishing structured daily routines significantly contribute to their ability to manage stress (Lien et al., 2020). This adaptability is crucial, as it aids caregivers in performing their various roles and fortifies their emotional well-being (Zheng et al., 2024). Studies suggest that enhanced social support can improve caregivers' mental health-related quality of life, emphasizing the importance of establishing supportive communities for caregivers (Khanna et al., 2010; Jiu & Rungreangkulkij, 2019).The study's findings underline the urgent need for comprehensive support systems that address not only the emotional and psychological needs of caregivers but also the systemic barriers they face. Investing in targeted training programs for caregivers, providing greater access to mental health resources, and fostering societal understanding of autism can contribute to alleviating the burdens of caregiving. Policymakers must recognize these dynamics and work to create integrated support structures that acknowledge the vital roles that caregivers play in the lives of children with autism while also

recognizing their individual needs and experiences. In conclusion, the study encapsulates the intricate interplay between the multifaceted roles of caregivers for children with ASD and the emotional, social, and financial challenges they encounter. As research continues to highlight these issues, it becomes increasingly evident that without robust support systems and societal awareness, caregivers will continue to bear an onerous burden that can adversely affect their well-being and that of their children.

CONCLUSION

This study highlights the multifaceted roles and significant challenges faced by caregivers of children with Autism Spectrum Disorder. Caregivers shoulder emotional, social, and financial burdens while navigating inadequate support systems and societal stigma. Despite these hardships, they exhibit resilience through adaptive coping strategies. The findings underscore the urgent need for integrated, culturally sensitive support programs and policies that prioritize caregiver well-being alongside child-centered interventions.

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