

Understanding the Lived Experiences of Mothers of Children with Autism Spectrum Disorder: A Qualitative Phenomenological Study

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Abstract

Raising a child with Autism Spectrum Disorder (ASD) presents unique emotional and social challenges for mothers. This study aimed to explore the lived experiences of mothers of children with ASD through a qualitative phenomenological approach. Semi-structured interviews were conducted with mothers whose children were referred to rehabilitation centers in Tabriz, Iran. Data were analyzed using Colaizzi's seven-step method. The findings revealed five major themes: emotional turbulence, social isolation, adaptation and coping mechanisms, family relationship dynamics, and hope for the future. These mothers described both emotional struggles and personal growth, emphasizing resilience and the need for social and psychological support. Understanding their experiences can help professionals design effective family-centered interventions that promote psychological well-being and coping capacity among mothers of children with ASD.

Keywords: Autism Spectrum Disorder, Mothers, Lived Experience, Phenomenology, Qualitative Study

Introduction

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental condition characterized by persistent difficulties in communication, social interaction, and restricted or repetitive patterns of behavior. The prevalence of ASD has increased significantly over the past two decades, leading to growing attention to the challenges faced by families and caregivers of affected children. Among these caregivers, mothers often bear the greatest emotional and practical burden, as they are typically the primary individuals responsible for their child's care and therapeutic follow-up.

Raising a child with ASD is not merely a medical or developmental challenge—it profoundly influences the psychological well-being, identity, and social relationships of mothers. Numerous studies have documented that mothers of children with ASD experience elevated levels of stress, anxiety, and depression compared to mothers of typically developing children. They also encounter stigma, social isolation, and limited access to professional and community support. These factors can create a cycle of emotional exhaustion and reduced quality of life, which in turn may affect their ability to engage in effective parenting and self-care.

Despite this, many mothers demonstrate remarkable resilience, developing adaptive coping mechanisms and finding new meaning through their caregiving experiences. The process of adaptation often involves emotional adjustment, redefinition of family roles,

reliance on faith and spirituality, and seeking informal networks of understanding. Exploring these lived experiences provides valuable insights for psychologists, counselors, and policymakers who aim to design culturally sensitive, family-centered interventions.

In Iran, as in many societies with strong familial and cultural ties, the experience of raising a child with ASD occurs within a distinct sociocultural framework. Mothers may face societal misunderstanding, limited public awareness, and insufficient specialized resources, all of which compound their emotional struggles. However, the collectivist culture may also offer unique forms of social and spiritual support that shape mothers' coping strategies in meaningful ways.

Given these considerations, the present study aims to explore and understand the lived experiences of mothers of children diagnosed with Autism Spectrum Disorder in Tabriz, Iran. Using a phenomenological approach, this research seeks to uncover the essence and meaning of their daily experiences — encompassing emotional, social, and coping dimensions — to inform more empathetic and effective clinical and educational practices

Methodology

This study adopted a qualitative phenomenological research design to gain an in-depth understanding of the lived experiences of mothers raising children with Autism Spectrum Disorder (ASD). The phenomenological approach was chosen because it allows researchers to explore the meanings and essence of human experiences as perceived by the participants themselves.

Participants and Sampling:

The participants consisted of ten mothers of children diagnosed with ASD who were referred to rehabilitation centers in Tabriz, Iran. A purposive sampling technique was employed to ensure that participants had direct and rich experiences related to the phenomenon under study. Inclusion criteria included having a child formally diagnosed with ASD, willingness to participate, and ability to express experiences clearly.

Data Collection:

Data were collected through in-depth semi-structured interviews. Each interview lasted approximately 45 to 60 minutes and was conducted in a quiet and private setting to ensure comfort and confidentiality. The interviews included open-ended questions such as "Can you describe your experience of living with a child with autism?" and "What challenges have you faced as a mother?" All interviews were audio-recorded with participants' consent and transcribed verbatim for analysis.

Data Analysis:

The transcribed data were analyzed using Colaizzi's (1978) seven-step method. This method involves reading all participants' descriptions, extracting significant statements, formulating meanings, clustering these meanings into themes, and integrating the results into an exhaustive description of the phenomenon. To enhance credibility, member checking was conducted by returning the interpreted data to participants for validation.

Ethical Considerations:

The study was approved by the Ethics Committee of Tabriz University of Medical Sciences. Informed consent was obtained from all participants before data collection.

Anonymity and confidentiality were strictly maintained throughout the study, and participants were assured that their responses would be used solely for research purposes

Results

Data analysis revealed five overarching themes that encapsulate the lived experiences of mothers raising children with Autism Spectrum Disorder (ASD): **(1) Emotional turbulence, (2) Social isolation, (3) Adaptation and coping mechanisms, (4) Family relationship dynamics, and (5) Hope for the future.**

1. Emotional Turbulence:

Nearly all participants described the diagnosis of ASD as a shocking and emotionally overwhelming experience. Mothers reported feelings of fear, guilt, anxiety, and helplessness, particularly during the early stages of diagnosis. Many expressed that their emotional distress was intensified by uncertainty about their child's future and societal misconceptions about autism.

2. Social Isolation:

Participants frequently referred to withdrawal from social interactions due to stigma, misunderstanding, and lack of acceptance by others. Mothers shared that they often avoided public gatherings to protect their children from negative judgments or unsolicited comments. This social isolation, in turn, deepened their sense of loneliness and reduced access to emotional support networks.

3. Adaptation and Coping Mechanisms:

Despite the emotional strain, most mothers demonstrated remarkable adaptability over time. They reported using coping strategies such as seeking spiritual comfort, reframing challenges as opportunities for growth, and

developing problem-solving routines in daily caregiving. The presence of supportive family members and professionals played a crucial role in facilitating this adaptation process.

4. Family Relationship Dynamics:

Raising a child with ASD affected family functioning and interpersonal relationships. Some mothers mentioned that their marital relationships were strained due to increased caregiving responsibilities and stress, while others reported strengthened emotional bonds as both parents collaborated to support their child. Sibling relationships were also influenced, with some children displaying jealousy and others developing a sense of empathy and responsibility.

5. Hope for the Future:

Although the mothers' journeys were marked by distress, their narratives revealed resilience and a profound sense of meaning. Many expressed hope for their children's gradual improvement through therapy and education, as well as optimism about growing societal awareness and acceptance. This theme reflected an evolving sense of empowerment and personal transformation among participants.

Overall, the analysis illustrates that these mothers experience a complex interplay of emotional pain, personal growth, and resilience. Their lived experiences highlight the urgent need for enhanced social support, accessible mental health services, and culturally sensitive interventions.

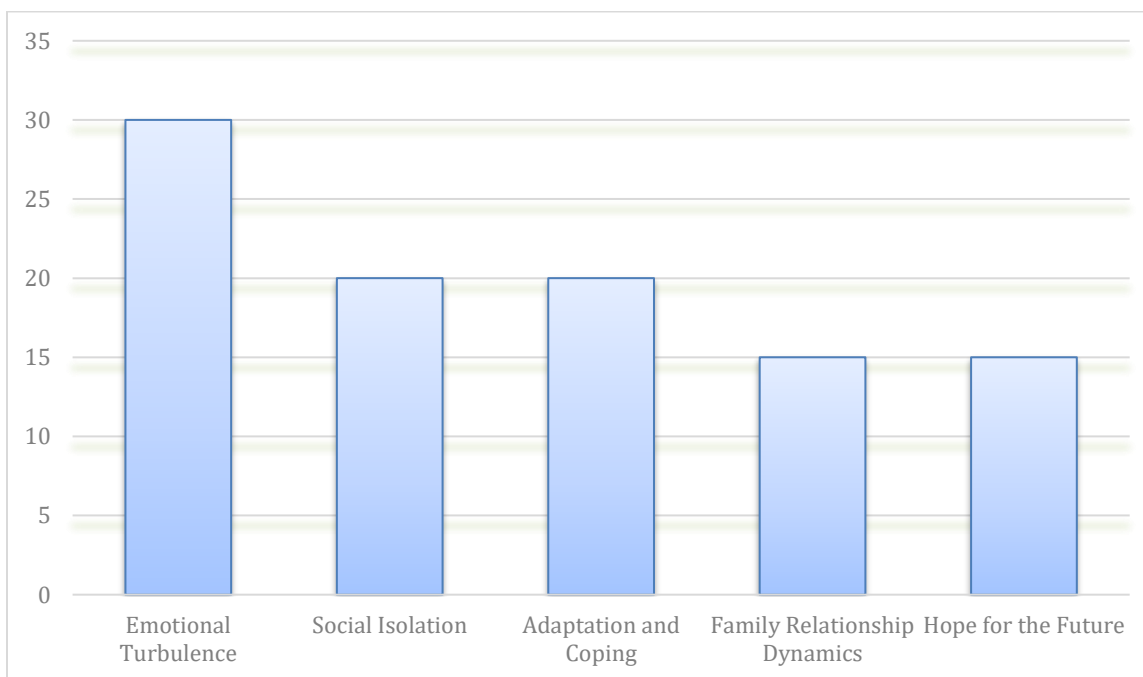


Figure (1). Distribution of Main Themes Among Participants

Table 1. Demographic Characteristics of Participants

Variable	Category	Frequency (n=10)
Age	30–45 years	6
Education	High school or higher	8
Marital Status	Married	10
Employment	Homemaker	7

Table 2. Main Themes and Subthemes Identified in the Study

Main Themes	Subthemes
Emotional Turbulence	Fear, guilt, anxiety
Social Isolation	Reduced social participation, stigma
Adaptation and Coping	Acceptance, spiritual reliance, problem-solving
Family Relationship Dynamics	Changes in marital and sibling relationships
Hope for the Future	Optimism, meaning-making

Discussion

The findings of this study align with global research emphasizing the emotional strain and resilience of mothers raising children with ASD. The mothers' narratives revealed a dual experience of suffering and personal growth. Cultural values and spiritual beliefs played a significant role in shaping coping strategies. Consistent with prior studies, the results suggest that interventions should incorporate emotional support, parental education, and social inclusion programs to reduce stigma and enhance well-being.

Conclusion

This phenomenological study provides insight into the multifaceted experiences of mothers caring for children with ASD. Findings underscore the necessity for family-centered support systems and culturally sensitive interventions aimed at promoting mothers' psychological resilience and social well-being.

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