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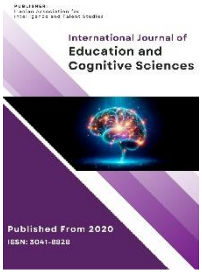

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Phenomenology of Mothers' Lived Experiences of Raising Children with Autism and Study of the Legal Status of Social Protections for Mothers of Certain Children

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ABSTRACT

Purpose: This study aimed to explore the lived experiences of mothers raising daughters with autism spectrum disorder (ASD).
Methods and Materials: A qualitative research design based on descriptive-interpretive phenomenology was employed. Twelve mothers of autistic daughters were purposefully selected from occupational therapy centers in Bandar Abbas. Data were collected through in-depth semi-structured interviews, each lasting between 45 to 70 minutes. Interviews were audio-recorded, transcribed verbatim, and analyzed thematically to identify recurring patterns and core experiential themes. Ethical protocols, including informed consent and confidentiality, were rigorously observed throughout the research process.
Findings: Analysis revealed five major themes: (1) the burden of ongoing and challenging caregiving, (2) conflicting emotional experiences, (3) search for social support, (4) redefinition of motherhood, and (5) persistent anxiety about the child's future. Mothers described caregiving as physically exhausting and emotionally draining, with frequent episodes of unpredictability and public misunderstanding. Emotional experiences ranged from guilt and despair to deep love and spiritual acceptance. Social isolation and stigma were recurrent, though even minimal instances of support were found to be deeply impactful. Mothers reported significant transformations in how they understood and enacted their maternal roles, shifting from normative expectations to more flexible and emotionally attuned identities. A common and profound concern was the uncertainty surrounding their daughters' futures in the absence of sustained social and institutional care.
Conclusion:. Interventions must address not only the needs of autistic children but also the emotional, informational, and structural support required by their mothers. Policy and practice should prioritize culturally sensitive, gender-informed caregiving frameworks to improve maternal well-being and caregiving outcomes.

Keywords: *Autism Spectrum Disorder; Mothers; Lived Experience; Phenomenology; Caregiving Burden; Emotional Resilience; Social Support; Cultural Context; Bandar Abbas; Maternal Identity.*

1. Introduction

The lived experiences of mothers raising children with autism spectrum disorder (ASD) have received growing scholarly attention in recent years, highlighting the profound and multidimensional challenges these women encounter. Although autism is a neurodevelopmental condition characterized by difficulties in communication, social interaction, and restricted behaviors, the manifestation and management of these traits are not merely clinical concerns—they deeply impact familial dynamics, particularly the experiences of mothers who are often the primary caregivers (García-Molina & Cortés-Calvo, 2025; Smith et al., 2023). As autism care increasingly shifts toward community- and family-based interventions, the voices and narratives of mothers become central to understanding the broader implications of autism on psychological well-being, caregiving burden, identity formation, and systemic barriers to support (Benson, 2023; Ramos-Serrano, 2025; Silva et al., 2024).

Despite advances in diagnostic tools and therapeutic services, mothers of autistic children often confront a constellation of emotional, social, and cultural obstacles. Many report overwhelming feelings of guilt, helplessness, and confusion during and after the diagnostic process, which can be exacerbated by societal stigma, lack of professional guidance, and misconceptions about autism (Upoma et al., 2020; White & Talpade, 2024; Zamani et al., 2022). These emotional responses are not static but evolve over time, as mothers develop personal coping mechanisms and renegotiate their maternal identities in response to their child's unique needs (Curtis & Izett, 2025; Dugdale et al., 2021). The meaning-making processes that emerge from this renegotiation are central to phenomenological inquiry, which seeks to explore lived experience in its situated, embodied, and subjective form (Acharya & Sharma, 2021).

The intersection of maternal roles and autism caregiving is particularly critical in non-Western and resource-limited contexts. While much of the literature on autism has emerged from high-income countries, studies in low- and middle-income settings underscore the compounding effects of poverty, limited access to services, and cultural narratives that may reinforce blame or denial (Alhammashi et al., 2024; Ebadi et al., 2021). In such environments, mothers often become de facto case managers, educators, therapists, and advocates for their children, all while grappling with their own emotional resilience and social isolation (Magalhães et al., 2021; Wah et al., 2024). This study, grounded in the lived experiences of mothers in Bandar Abbas, Iran, seeks to contribute to this growing body of literature by exploring how mothers of autistic daughters navigate caregiving within a specific cultural and geographic context.

Phenomenological research provides a particularly suitable methodology for this inquiry. By focusing on lived experience as it appears to consciousness, phenomenology bypasses the abstract generalizations of quantitative research in favor of exploring the subjective, embodied realities of participants (Acharya & Sharma, 2021; Curtis & Izett, 2025). In the context of autism caregiving, this approach enables a richer understanding of how mothers interpret, endure, and give meaning to their experiences. For example, studies have shown that mothers often endure a persistent state of hyper-vigilance due to the unpredictability of their child's behaviors, which can lead to chronic stress and physical exhaustion (Gobrial & Shoeib, 2022; Greenlee et al., 2023). This caregiving burden is not merely a function of behavior management but encompasses emotional labor, the navigation of bureaucratic systems, and the social-emotional toll of constant advocacy (Bragina et al., 2021; Rabba et al., 2024).

One of the most compelling aspects of mothers' experiences is the emotional ambivalence they often report—oscillating between deep love, pride, and connection with their child, and frustration, sorrow, and burnout. Dugdale et al. (2021) describe this paradox as a defining feature of motherhood in the context of autism, noting the "intense love and connection" that can coexist with profound emotional fatigue (Dugdale et al., 2021). This emotional complexity was similarly highlighted in recent research by Ramos-Serrano (2025), who noted that many autistic mothers described themselves as "havens" for their children, positioning their maternal role as both a sanctuary and a site of tension (Ramos-Serrano, 2025). Such experiences underscore the fluid and dynamic nature of emotional responses, further emphasizing the value of a phenomenological lens in understanding maternal narratives.

The process of identity reconstruction is another critical theme. As mothers confront societal norms of "ideal motherhood," they often undergo a reevaluation of their self-worth and maternal competence (Benson, 2023; Silva et al., 2024). Bragina et al. (2021) argue that mothers of children with autism frequently redefine the meaning of motherhood in ways that transcend normative developmental milestones—shifting from a focus on academic or social success to a more present-centered, relationship-based understanding of maternal fulfillment (Bragina et al., 2021). This identity transformation often involves relinquishing past expectations and embracing a new model of motherhood anchored in acceptance, advocacy, and love. For many, this process is emotionally taxing but also a site of profound growth and resilience (García-Molina & Cortés-Calvo, 2025; Palser et al., 2021).

Crucially, the search for social support—or the lack thereof—remains a central axis of experience for many mothers. Studies consistently report that insufficient institutional support, judgmental attitudes from extended family, and inadequate school engagement exacerbate feelings of isolation and helplessness among mothers (Rabba et al., 2024; Smith et al., 2023). In a comparative study, Wah et al. (2024) found that stress levels among mothers of autistic children were inversely related to perceived self-efficacy and availability of support systems, highlighting the importance of relational resources in promoting maternal well-being (Wah et al., 2024). Yet, as Liang (2022) notes, the voices of mothers—especially from marginalized communities—are frequently absent or underrepresented in public discourse, further contributing to their invisibility and psychological burden (Liang, 2022).

The psychological impact of raising a child with autism is not limited to stress and anxiety; it also encompasses issues such as emotional regulation, depression, and cognitive overload (El-Bouhali-Abdellaoui et al., 2024; Gobrial & Shoeib, 2022). Some mothers may internalize responsibility for their child's diagnosis, leading to heightened self-blame and parental guilt, particularly in the absence of reliable information about autism's etiology (Mohammadi et al., 2023; Upoma et al., 2020). In contrast, other studies suggest that spiritual beliefs and cultural frameworks can serve as protective factors, helping mothers to reframe their experiences in a more empowering or redemptive light (Greenlee et al., 2023; White & Talpade, 2024).

Moreover, mothers' concerns are not restricted to the present but extend deeply into the future. Anxiety about long-term caregiving, the child's future independence, education, employment, and even death of the caregiver are recurrent and often debilitating fears (Alhammashi et al., 2024; Northrup et al., 2024). Oppenheim et al. (2025) note that these anticipatory anxieties influence not only maternal mental health but also parenting behaviors, as mothers attempt to prepare their children for an uncertain future in often unsupportive environments (Oppenheim et al., 2025). These long-term concerns highlight the need for robust policies that address care continuity, disability rights, and transitional support for autistic individuals and their families (Lampi & Jaswal, 2022).

It is also important to note that much of the global autism literature has historically focused on boys, despite growing recognition that autistic girls may present differently and face unique challenges in diagnosis and support (Gu et al., 2024). The specific experiences of mothers raising autistic daughters remain underexplored, even though these experiences may involve distinct stressors—such as concerns about puberty, gender-based expectations, and social safety (El-Bouhali-Abdellaoui et al., 2024). Research by Curtis and Izett (2025) has emphasized the need to examine maternal experiences through gendered lenses, particularly for girls with profiles such as pathological demand avoidance (PDA), which further complicate caregiving dynamics (Curtis & Izett, 2025).

In summary, the complex interplay of emotional, cultural, relational, and institutional factors makes the maternal experience in autism caregiving a compelling subject of inquiry. This study builds upon a diverse and interdisciplinary body of research to examine the lived experiences of mothers of autistic daughters in Bandar Abbas.

2. Methods and Materials

The present study was designed with the aim of deeply exploring the lived experiences of mothers of children with autism. Accordingly, a qualitative approach based on a phenomenological framework was selected as the methodological foundation. This section seeks to provide a transparent and systematic account of the research method, including the sample, sampling procedure, and data collection tools, thereby acquainting the reader with the structured process that led to a profound understanding of these experiences. The choice of this approach and related tools is rooted not only in the theoretical foundations of phenomenology but also aligned with the realities of daily life experienced by mothers in the local context of Bandar Abbas.

Phenomenology, as an approach that seeks to describe and interpret human experiences in terms of how they appear in consciousness, was applied in this study. This method, inspired by the ideas of Husserl and Heidegger, aims to represent lived experience without external preconceptions and within its natural context. Here, the objective was not causal explanation or variable measurement, but rather the

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comprehension of the deep and multilayered meanings that mothers construct when confronting their child's autism. To achieve this goal, the study employed a descriptive-interpretive phenomenological method, which combines the detailed description of experiences (in the Husserlian style) with attention to their existential context (in the Heideggerian style). This methodological choice enabled the researcher to delve into both the depth of individual perceptions and the sociocultural context of the experience.

The study population consisted of mothers of girls with autism who were attending occupational therapy centers in Bandar Abbas. This group was selected not only due to the study's focus on maternal experiences but also because of the unique challenges that girls with autism may present compared to boys—such as delayed diagnosis or gendered cultural expectations (Gould, 2017). From this population, a sample of 12 mothers was selected. This number, determined based on the criterion of theoretical saturation, allowed the researcher to capture a sufficient range of experiences while maintaining analytical depth. Inclusion criteria were: having a daughter formally diagnosed with autism (based on DSM-5 criteria), at least two years of experience living with this condition, and willingness to participate in an interview. The participating mothers had a mean age of 34 years (range: 28 to 42 years) and diverse educational levels (from middle school to doctoral degrees), which enriched the data quality.

Sampling was conducted purposively—a common method in qualitative research for selecting individuals with rich and relevant experiences regarding the phenomenon under study. In this context, purposive sampling meant selecting mothers capable of providing deep insights into life with a child with autism. To do this, a list of eligible mothers was first compiled with the help of occupational therapy centers in Bandar Abbas. Then, through initial phone contact, the researcher explained the study objectives and obtained their informed consent. This process was conducted meticulously to ensure that participants not only had the necessary experience but were also emotionally and psychologically ready to express themselves freely. After conducting ten interviews, data saturation indicators began to emerge, but two additional interviews were conducted to ensure comprehensiveness.

The primary data collection tool in this study was the semi-structured interview, selected due to its flexibility and effectiveness in exploring personal experiences. Unlike closed-ended questionnaires, this type of interview allows the researcher to begin with open-ended questions and, based on the participants' responses, ask follow-up questions that delve deeper. The interview guide was designed within a phenomenological framework and included questions such as: "What is your daily life like with your child?", "How do you feel when facing her needs?", and "How has this experience influenced your understanding of yourself?" These questions were crafted to both facilitate the description of experience and elicit the underlying meanings.

Each interview was conducted in person and in a calm environment (usually at home or at the therapy center, based on the mother's preference) and lasted between 45 and 70 minutes. Before the start of each session, a written consent form was signed, and mothers were assured that their identities would remain confidential. All interviews were audio recorded, and the researcher simultaneously took notes on non-verbal observations such as body language or tone of voice, which were later incorporated into data analysis. To adhere to ethical standards, after each interview, participants were given the opportunity to discuss their feelings, helping to mitigate any potential emotional burden.

3. Findings and Results

The participants in this study can be divided into two categories: employed mothers and stay-at-home mothers. Below, the characteristics of their age, education, occupation, marital status, and number of children are presented.

Table 1

Demographic Characteristics

No.	Age	Education	Occupation	Marital Status	Number of Children
1	41	PhD	University Faculty	Married	1
2	36	Bachelor's Degree	Accountant	Married	2
3	42	Bachelor's Degree	Housewife	Married	1
4	28	High School Diploma	Housewife	Divorced	1
5	30	Middle School	Housewife	Widowed	2
6	30	High School Diploma	Hairdresser	Divorced	1
7	42	Master's Degree	Office Employee	Married	2

8	33	High School Diploma	Housewife	Married	2
9	31	Bachelor's Degree	Office Employee	Divorced	1
10	30	High School Diploma	Housewife	Married	3
11	38	High School Diploma	Domestic Worker	Divorced	3
12	29	Master's Degree	Housewife	Married	2

The current study, conducted with a phenomenological approach to explore the lived experiences of mothers of daughters with autism in Bandar Abbas, revealed a set of main themes that illustrate the interwoven challenges, emotions, and efforts of these mothers in coping with the realities of their daily lives. These findings, derived from detailed analysis of semi-structured interviews with 12 mothers, not only reflect the depth of their personal experiences but also highlight the socio-cultural context of those experiences. The key themes include: the burden of ongoing and challenging caregiving, conflicting emotions, search for social support, redefinition of motherhood, and concerns about the future—each elaborated below in a systematic manner.

The Burden of Ongoing and Challenging Caregiving

One of the most prominent themes emerging from the data was the relentless challenges that mothers face in caring for their autistic children both inside and outside the home. These challenges, commonly referred to in the literature as *caregiving burden* (Green, 2007), here emerged as tangible and daily experiences. Mothers spoke of difficulties arising from repetitive behaviors, communication problems, impulsive and sudden actions, and the specific needs of their children. For instance, Mother 5 shared, *"I never know what might trigger a scream from my daughter when we step outside—what she might hear or see. Sometimes she's calm in the same place one day, and completely different the next. I can't plan everything ahead to reduce her reactions. Life is full of stress, and I'm always bracing for something to explode."* Similarly, Mother 7 said, *"In a house with an autistic child, we always expect anxiety at any moment. It's like a battlefield; suddenly everything collapses, and I don't even know how to manage it."* These narratives not only illustrate the severity of the challenges but also emphasize their unpredictability and omnipresence in both private and public spaces.

These difficulties were further exacerbated by the local context of Bandar Abbas, characterized by limited therapeutic and educational resources and a hot climate most of the year. Mothers often complained about the shortage of autism specialists, limited choice of treatment centers, and the concentration of occupational and speech therapy clinics in the city center, far from their homes. Mother 7 said, *"The constant commute through heavy city traffic wears me out, especially under the unbearable heat. After I take my daughter to her therapy sessions, I'm too exhausted to do anything else, but I have no choice."* These conditions added to their physical and mental burden and underscored the impact of the local environment on their lived experience. Nevertheless, some mothers tried to compensate for these gaps through personal initiatives—such as learning simple techniques from the internet or therapists or using online therapy services—demonstrating noteworthy resilience.

Conflicting Emotions

The second main theme was the complex and sometimes contradictory range of emotions experienced by mothers. These emotions ranged from exhaustion and despair to deep love and fleeting moments of joy, a spectrum also noted in previous phenomenological studies (Woodgate et al., 2008). Mother 2, with a trembling voice, said, *"Some days I just want to cry, but then I see a tiny smile on her face and feel like I own the world."* Mother 1 shared, *"Sometimes I complain to God about my situation, and other times I submit to His will and tell myself maybe He saw something in me that made Him choose me for this child."* This emotional fluctuation highlights the dynamic nature of life with autism—never static but constantly shifting.

Feelings of guilt and self-blame were also prevalent. Some, like Mother 12, held themselves largely responsible for their child's condition: *"Maybe if I had been more careful during pregnancy or in the first two years, this wouldn't have happened."* Similarly, Mother 4 said, *"If I had watched my diet during pregnancy, avoided vaccinations, or not left her in front of the TV, maybe she wouldn't be like this. I suffer from guilt every day."* These thoughts, often rooted in limited public awareness or inadequate information about autism's causes, increased psychological pressure. Employed mothers particularly expressed guilt over the time spent away from their children. Mother 1 said, *"Maybe if I had quit my job and focused only on being a mother, things would be different. What good is my salary if I'm not emotionally content?"* However, moments of acceptance and satisfaction also emerged. Mother 11 stated, *"I stopped denying and complaining. I've accepted this as my fate and try to enjoy the good moments and endure the tough ones."* This shift from denial to acceptance marked an internal transformation that contributed to their identity reconstruction.

Search for Social Support

The third theme involved the mothers' efforts to seek social support and the barriers they encountered. Support—from family, friends, or institutions—is recognized as a key factor in reducing caregiving stress (Lutz et al., 2012). However, mothers in this study frequently mentioned the lack of such support. Mother 5 explained, *"My family thinks I've read a few psychology books and now I'm labeling my daughter, but they don't realize how serious and complicated it really is."* This dismissive attitude, often compounded by social stigma, heightened their sense of isolation and left them to face challenges alone.

On the other hand, some mothers pointed to the value of even limited support. Mother 3 shared, *"A therapist at the center taught me how to calm her down. That meant a lot to me."* Mother 6 recounted, *"I was in a large shopping center and after going through a lot to shop, when we got to the checkout line, the cashier asked others to let me go first and requested staff to bag my items and carry them to my car. That really made my day."* Likewise, Mother 10 said, *"Sometimes one of my sisters takes my daughter to her house for a while, and I get a chance to rest or shop—I feel like I can be a better mother then."* These examples show that even small gestures—professional guidance, brief childcare, or public empathy—can significantly impact these mothers' experiences. Still, the lack of formal support structures like counseling groups or government services in Bandar Abbas was repeatedly emphasized, underscoring the need for policy attention at the local level.

Redefinition of Motherhood

The fourth theme, perhaps the deepest layer of these mothers' lived experiences, was the redefinition of maternal identity in light of autism. Raising a child whose needs deviate from typical expectations compelled these mothers to rethink their roles and the meaning of motherhood. Mother 12 reflected, *"I used to think being a mom meant watching my child study, but now I know it means just being with her, however she is."* Similarly, Mother 7 said, *"I used to compare myself with other moms and felt left behind. I thought it was so unfair—I couldn't even dream normal dreams for my child. But gradually I accepted that being a mother means loving your child with all their traits. Now I just compare myself to who I was yesterday to see if I've become a better mom."* This shift in perspective—known in phenomenological literature as *meaning-making*—revealed these mothers' capacity to find purpose amid adversity.

This redefinition often came with resilience. Through everyday experiences, mothers not only adapted to their circumstances but also discovered previously unknown strengths. Mother 8 stated, *"I never thought I was this strong, but now I know I am."* This transformation, supported by the cultural emphasis on traditional maternal roles in Bandar Abbas, enabled them to construct a new identity centered on care and endurance. Above all, this theme highlighted the inner strength of these women in the face of hardship.

Concerns About the Future

The fifth theme—likely a common core across the lived experience of mothers of autistic children—was persistent concern about their children's future, both near and far. Much of this worry centered on how their child would navigate life events like marriage, childbirth, and independent living in the mother's absence, as well as physiological changes such as puberty and menstruation, age-specific milestones like entering school (mainstream or special), and the social labeling that may follow a failed school readiness assessment. This constant internal monologue compelled mothers to develop innovative coping techniques that helped them manage their child's needs without being paralyzed by fear, while also maintaining their own mental well-being.

Mother 4 tearfully said, *"I always wonder what will happen to my daughter after I'm gone—if she gets her period at school or on the street, if other kids mock her, if she gets married and her husband can't understand her, or if I die suddenly and she's left alone in the house."* Mother 7 added, *"I'm constantly torn between worry and trust in God. Sometimes I even think of registering a trusted person as a godmother or godfather, just to have peace of mind. I wish there were a government program where I could open a dedicated account for my autistic daughter and be assured that after our death, the state would care for her."* This future-oriented concern reflects a deep uncertainty about their child's fate and suggests that mothers have already begun contemplating and proposing tangible solutions.

This future anxiety manifested in two opposing ways for mothers in Bandar Abbas: on one hand, proximity to extended family and traditional caregiving norms gave them some reassurance; on the other hand, the lack of specialized institutions and care centers intensified fears about what might happen if family support were unavailable. Altogether, these concerns offered a multidimensional and at times paradoxical understanding of autism's impact on the daily and existential realities of mothers raising daughters on the spectrum.

4. Discussion and Conclusion

The aim of this phenomenological study was to explore the lived experiences of mothers raising daughters with autism spectrum disorder (ASD) in the socio-cultural context of Bandar Abbas. The analysis of semi-structured interviews with 12 mothers revealed five interrelated and deeply embedded themes: (1) the burden of ongoing and challenging caregiving, (2) conflicting emotions, (3) search for social support, (4) redefinition of motherhood, and (5) concern for the child's future. These findings offer significant insight into the psychological, social, and cultural dynamics that shape maternal experiences and identities in relation to autism caregiving.

The first theme—the burden of continuous and challenging caregiving—highlighted the intense and unrelenting nature of mothers' daily responsibilities. Participants consistently described high levels of stress caused by the unpredictability of their children's behavior, such as sensory sensitivities, repetitive behaviors, and emotional dysregulation. These challenges extended to both home and public spaces, creating a state of constant alertness. This finding aligns with previous research emphasizing the physical and emotional toll of caregiving on mothers of autistic children, especially in environments where support systems are lacking (Alhammashi et al., 2024; Greenlee et al., 2023). Wah et al. (2024) demonstrated that caregiving stress is strongly associated with a decline in quality of life when not accompanied by high levels of maternal self-efficacy and accessible external resources (Wah et al., 2024). The Bandar Abbas context further complicates these burdens due to the scarcity of therapeutic services and environmental stressors such as high temperatures and transportation difficulties, compounding the challenges highlighted in broader literature (Zamani et al., 2022).

The second key theme—conflicting and paradoxical emotions—captured the emotional volatility mothers experienced in their caregiving journey. Feelings of joy and deep love were interspersed with exhaustion, guilt, grief, and helplessness. These emotions were dynamic and complex rather than static. Similar emotional dualities were documented by Dugdale et al. (2021), who identified "intense connection and love" alongside psychological fatigue among autistic mothers (Dugdale et al., 2021). Ramos-Serrano (2025) also noted that Spanish autistic mothers experienced themselves as "havens" for their children—an identity marked by affection but also the burden of constant responsibility (Ramos-Serrano, 2025). Guilt and self-blame, especially among working mothers or those who lacked knowledge during pregnancy or early childhood, were recurring themes. These findings echo those of Upoma et al. (2020), who described similar maternal narratives in Bangladesh, where guilt was linked to perceived failure in fulfilling maternal expectations (Upoma et al., 2020). The current study confirms that cultural and spiritual worldviews, including religious acceptance and surrender to divine will, serve as both coping mechanisms and meaning-making frameworks for some mothers (White & Talpade, 2024).

The third emergent theme was the search for social support, which revealed not only the mothers' unmet needs but also their experiences with judgment, stigma, and marginalization. Many mothers reported limited support from family or society and described interactions marked by misunderstanding or outright denial of their child's condition. The lack of public awareness and the persistence of stigmatizing narratives often exacerbated their isolation. These findings are consistent with studies by Rabba et al. (2024) and Smith et al. (2023), which documented the struggles of mothers in navigating school systems and social environments that viewed them as "the problem" or failed to accommodate their children's needs (Rabba et al., 2024; Smith et al., 2023). Nonetheless, mothers also cited isolated moments of compassion and empathy—from therapists, retail workers, or family members—which had disproportionately positive effects on their emotional well-being. These episodes underscore the transformative potential of even small acts of kindness, as also emphasized by Benson (2023), who argued that recognition and validation of maternal labor can counterbalance experiences of neuronormative marginalization (Benson, 2023).

The fourth and perhaps most profound theme was the redefinition of motherhood. Mothers in this study described a transformative shift in their perceptions of what it means to be a "good" mother. Many let go of conventional expectations related to academic achievement or normative development and embraced a more inclusive and relational understanding of motherhood, grounded in presence, patience, and unconditional love. This evolution of maternal identity is consistent with findings by Bragina et al. (2021), who noted that mothers of children with ASD often redefine their parental role based on emotional connection and individualized care rather than societal benchmarks (Bragina et al., 2021). Similar narratives were observed by Silva et al. (2024), who highlighted how the emotional and physical overload borne by autistic mothers necessitated an ongoing reevaluation of selfhood and caregiving (Silva et al., 2024). Additionally, this internal redefinition was often intertwined with cultural values, particularly in a society like Bandar Abbas where traditional maternal roles are emphasized and reinforced through family and religious structures (Magalhães et al., 2021).

The final theme—concern for the future—revealed deep-seated anxieties that extended beyond the present moment. Mothers expressed intense fears about the long-term well-being of their daughters, particularly in areas such as puberty, marriage, safety, and independent living after the mothers' death. These concerns were intensified by the lack of institutional guarantees for the long-term care of autistic individuals. Similar concerns have been identified across diverse cultural contexts. Oppenheim et al. (2025) showed that parental anxiety regarding future social interactions and support systems significantly influences how parents approach early development (Oppenheim et al., 2025). Northrup et al. (2024) further emphasized how early emotional dysregulation in children at high risk for autism prompts parents to adopt anticipatory caregiving strategies that prioritize long-term adaptability (Northrup et al., 2024). The fact that some mothers in this study proposed structured solutions—such as legal guardianship or governmental financial plans—demonstrates their readiness to actively engage in planning, despite systemic limitations. Such proactive thinking is rarely captured in autism research and should inform future policy frameworks.

Another noteworthy aspect of this study is its gender-specific focus. Most autism research has centered on boys, thereby marginalizing the experiences of autistic girls and their caregivers (Gu et al., 2024). Yet, as highlighted by El-Bouhali-Abdellaoui et al. (2024), gender moderates both parental stress and child outcomes, suggesting that mothers of autistic daughters face unique emotional and logistical challenges (El-Bouhali-Abdellaoui et al., 2024). These challenges include delayed diagnosis, higher levels of social masking, and concerns about social vulnerability during adolescence. Curtis and Izett (2025) have also noted that mothers of autistic girls with profiles such as Pathological Demand Avoidance experience heightened stress due to behavioral unpredictability and poor fit within traditional intervention models (Curtis & Izett, 2025). This study contributes to this underexplored area by foregrounding the voices of mothers navigating female-specific expressions of autism.

Moreover, this research supports the findings of Palser et al. (2021), who suggested that autistic individuals often show reduced differentiation of bodily emotions, a factor that may increase the caregiving complexity for mothers who must constantly interpret non-verbal cues (Palser et al., 2021). Similarly, Mohammadi et al. (2023) found that emotion recognition training significantly improved autistic children's responses, indirectly alleviating maternal stress by enhancing communication channels (Mohammadi et al., 2023). These studies support the conclusion that targeted interventions not only benefit autistic children but also play a significant role in reshaping maternal experience.

In synthesis, the present study affirms the multi-layered and context-sensitive nature of caregiving among mothers of autistic daughters. The findings reinforce the importance of viewing autism not as an isolated developmental disorder but as a condition embedded in social, cultural, and emotional matrices. By capturing the complexity of maternal experiences—from caregiving stress and emotional ambivalence to identity transformation and future-oriented anxiety—this research contributes to a more holistic understanding of autism as lived reality. It also underscores the critical need for culturally responsive, gender-informed, and family-centered support systems.

While the findings offer important insights, this study is not without limitations. The sample size was small and limited to mothers residing in Bandar Abbas, which may constrain the transferability of results to other regions or cultural settings. Additionally, the participants were exclusively mothers of daughters with ASD; the absence of paternal perspectives or experiences related to boys with autism limits the scope of the inquiry. Language and cultural norms may have also influenced how openly participants expressed certain emotions, particularly those involving guilt, spiritual beliefs, or stigma.

Future research should expand this line of inquiry by including more diverse participant groups, such as fathers, siblings, or extended caregivers. Comparative studies across different Iranian cities or between rural and urban settings could shed light on regional disparities in autism care and social perception. Furthermore, longitudinal research could track how maternal perceptions and coping mechanisms evolve over time. Given the gendered focus of this study, future work should continue to explore how caregiving experiences differ based on the gender of the autistic child, especially during critical transitions like puberty, education, or marriage.

Practitioners and policymakers should prioritize developing accessible support infrastructures for mothers of autistic children, especially in underserved regions like Bandar Abbas. This includes expanding the availability of occupational and speech therapy centers, creating peer support groups for parents, and promoting public education to reduce stigma. Mental health services tailored to the emotional needs of mothers should be integrated into autism intervention programs. Finally, social policy should ensure long-term care and protection mechanisms for autistic individuals, especially those without family support in adulthood.

Authors' Contributions

All authors significantly contributed to this study.

Declaration

In order to correct and improve the academic writing of our paper, we have used the language model ChatGPT.

Transparency Statement

Data are available for research purposes upon reasonable request to the corresponding author.

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Declaration of Interest

The authors report no conflict of interest.

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Ethical Considerations

In this study, to observe ethical considerations, participants were informed about the goals and importance of the research before the start of the interview and participated in the research with informed consent.

References

Acharya, S., & Sharma, K. (2021). Lived Experiences of Mothers Raising Children With Autism in Chitwan District, Nepal. *Autism Research and Treatment*, *2021*, 1-12. https://doi.org/10.1155/2021/6614490

Alhammashi, A. N. A., Yousefi, Z., Radhi, A. J., & Khayatan, F. (2024). Predicting the Emotional Social Adjustment of Children With Autism Based on Mother-Child Anxiety and the Adaptability of Maternal Parenting. *PWJ*, *5*(2), 4-10. https://doi.org/10.61838/kman.pwj.5.2.2

Benson, K. J. (2023). Perplexing Presentations: Compulsory Neuronormativity and Cognitive Marginalisation in Social Work Practice With Autistic Mothers of Autistic Children. *The British Journal of Social Work*, *53*(3), 1445-1464. https://doi.org/10.1093/bjsw/bcac229

Bragina, E. A., Belozerova, L. A., & Prokofyeva, M. V. (2021). Attitude Towards a Child and the Family Role of Mothers of Children With Autistic Spectrum Disorders and Children With Speech Disorders. *Vektor Nauki Tol Yattinskogo Gosudarstvennogo Universiteta Seriya Pedagogika I Psihologiya*(2), 39-45. https://doi.org/10.18323/2221-5662-2021-2-39-45

Curtis, S. J., & Izett, E. (2025). The Experience of Mothers of Autistic Children With a Pathological Demand Avoidance Profile: An Interpretative Phenomenological Analysis. *Discover Mental Health*, *5*(1). https://doi.org/10.1007/s44192-025-00127-3

Dugdale, A.-S., Thompson, A. R., Leedham, A., Beail, N., & Freeth, M. (2021). Intense Connection and Love: The Experiences of Autistic Mothers. *Autism*, *25*(7), 1973-1984. https://doi.org/10.1177/13623613211005987

Ebadi, M., Mardani-Hamooleh, M., Seyedfatemi, N., Ghaljeh, M., & Haghani, S. H. (2021). Effects of Written Emotional Disclosure on the Stress of Mothers of Children With Autism. *Iran Journal of Nursing*, *34*(131), 19-30. https://doi.org/10.52547/ijn.34.131.19

El-Bouhali-Abdellaoui, F., Voltas, N., Morales-Hidalgo, P., & Canals, J. (2024). Examining the Relationship Between Parental Broader Autism Phenotype Traits, Offspring Autism, and Parental Mental Health. *Autism Research*, *18*(2), 387-401. https://doi.org/10.1002/aur.3295

García-Molina, I., & Cortés-Calvo, M. (2025). "Until I Had My Son, I Did Not Realise That These Characteristics Could Be Due to Autism": Motherhood and Family Experiences of Spanish Autistic Mothers. *Autism in Adulthood*, *7*(3), 303-311. https://doi.org/10.1089/aut.2023.0013

Gobrial, E., & Shoeib, A. (2022). Relative Contribution of Anxiety, Depression and Difficulties in Emotional Regulation in Forecasting Emotional Sensitivity of Autistic Children's Mothers. *Social Sciences*, *12*(1), 17. https://doi.org/10.3390/socsci12010017

Greenlee, J. L., Hickey, E., Stelter, C. R., Huynh, T., & Hartley, S. L. (2023). Profiles of the Parenting Experience in Families of Autistic Children. *Autism*, *27*(7), 1919-1932. https://doi.org/10.1177/13623613221147399

Gu, J., Li, T., & Dong, H. (2024). Maternal Autistic Traits and Anxiety in Children With Typical Development in Chinese Families: A Moderated Mediation Model of Mothers' Negative Emotional Expressions and Child Gender. *Frontiers in psychology*, *15*. https://doi.org/10.3389/fpsyg.2024.1264173

Lampi, A. J., & Jaswal, V. K. (2022). Parenting an Autistic Child Is Not Associated With the Amount of Facial Emotion Information Needed to Perceive Happiness or Sadness From Faces. *Collabra Psychology*, *8*(1). https://doi.org/10.1525/collabra.33136

Liang, B. (2022). Divided Communities and Absent Voices: The Search for Autistic BIPOC Parent Blogs. *Studies in Social Justice*, *16*(2), 447-469. https://doi.org/10.26522/ssj.v16i2.3407

Magalhães, J. M., Rodrigues, T. A., Neta, M. M. R., Carolinne Kilcia Carvalho Sena, D., Kayo Henrique Jardel Feitosa, S., & Emília Ângela Lo Schiavo, A. (2021). Experiences of Family Members of Children Diagnosed With Autism Spectrum Disorder. *Revista Gaúcha De Enfermagem*, *42*. https://doi.org/10.1590/1983-1447.2021.20200437

Mohammadi, F., Khazaei, S., Bashirian, S., Barati, M., Mirzaie, F., Rezaei, M., Jenabi, E., Cheraghi, F., & Moradi, V. (2023). Recognition of Facial Emotions Training in Autistic Children - Clinical Trial Study. *Romanian Journal of Pediatrics*, *72*(3), 133-141. https://doi.org/10.37897/rjp.2023.3.4

Northrup, J. B., Cortez, K. B., Mazefsky, C. A., & Iverson, J. M. (2024). Expression and Co-Regulation of Negative Emotion in 18-Month-Olds at Increased Likelihood for Autism With Diverse Developmental Outcomes. *Autism*, *28*(10), 2534-2548. https://doi.org/10.1177/13623613241233664

Oppenheim, D., Mottes-Peleg, M., Dolev, S., & Yirmiya, N. (2025). Play Interactions of Autistic Preschoolers With Their Mothers and Fathers Without Toys Yield More Positive Interactions Than Play With Toys. *Autism*. https://doi.org/10.1177/13623613251329975

Palser, E. R., Galvez-Pol, A., Palmer, C. E., Hannah, R., Fotopoulou, A., Pellicano, E., & Kilner, J. M. (2021). Reduced Differentiation of Emotion-Associated Bodily Sensations in Autism. *Autism*, *25*(5), 1321-1334. https://doi.org/10.1177/1362361320987950

Rabba, A. S., Smith, J., Hall, G., Alexander, V., Batty, K., Datta, P., Goodall, E., Heyworth, M., Lamb, S., Lawson, W., Lilley, R., Reid, K., Syeda, N., & Pellicano, E. (2024). 'I'm Sick of Being the Problem': Autistic Mothers' Experiences of Interacting With Schools for Their Autistic Children. *Autism*, *29*(4), 1034-1046. https://doi.org/10.1177/13623613241297223

Ramos-Serrano, L. (2025). "I Am Their Haven": Mothering Experiences of Spanish Autistic Mothers. *Neurodiversity*, *3*. https://doi.org/10.1177/27546330251349375

Silva, B. L. d., Camilozi, J. L. D., Franco, A. G., & Morais, R. C. N. (2024). I Am an Autistic Mother With an Autistic Child": Documentary Analysis of Family Overload. *Revista De Gestão Social E Ambiental*, *18*(8), e08516. https://doi.org/10.24857/rgsa.v18n8-179

Smith, J., Rabba, A. S., Ali, A., Datta, P., Dresens, E., Faragaab, N., Hall, G., Heyworth, M., Ige, K., Lawson, W., Lilley, R., Syeda, N., & Pellicano, E. (2023). 'Somali Parents Feel Like They're on the Outer': Somali Mothers' Experiences of Parent–teacher Relationships for Their Autistic Children. *Autism*, *27*(6), 1777-1789. https://doi.org/10.1177/13623613221146077

Upoma, T. F., Moonajilin, M. S., Rahman, M. E., & Ferdous, M. Z. (2020). Mothers Initial Challenges Having Children With Autism Spectrum Disorders in Bangladesh. *Bangladesh Journal of Medical Science*, *19*(2), 268-272. https://doi.org/10.3329/bjms.v19i2.45006

Wah, Y. B., Nasir, N. N. M., Hadrawi, M. F., Kamaruddin, A. A., Jannoo, Z., & Afthanorhan, A. (2024). Effects of Stress and Self-Efficacy on Quality of Life of Mothers With Autistic Children: Covariance-Based Structural Equation Modeling (CB-SEM) Approach. *Belitung Nursing Journal*, *10*(2), 201-208. https://doi.org/10.33546/bnj.3096

White, A., & Talpade, M. (2024). Exploration of Experiences of Parents Raising Children on the Autism Spectrum. *International Journal of Arts Humanities & Social Science*, *05*(06), 9-13. https://doi.org/10.56734/ijahss.v5n6a2

Zamani, P., Khoramshahi, H., Khosravi, N., & Hesam, S. (2022). Comparison of Quality of Life, Anxiety, and Satisfaction With Rehabilitation Services Among Mothers of Children With Autism Spectrum Disorders and Those Without Autistic Children in Ahvaz-Iran. *Medical Journal of Tabriz University of Medical Sciences*, *44*(5), 438-448. https://doi.org/10.34172/mj.2022.047