

# Mothers' lived experiences of autistic adults' challenges, community support gaps, and pathways to independence – A phenomenological study

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## ABSTRACT

**Aim:** To investigate the obstacles encountered by Saudi mothers with adult autistic children in promoting autonomy and meaningful relationships. Additionally, it aimed to assess the available community resources and assistance for these mothers, as well as gather their recommendations for enhancing support systems.

**Materials and Methods:** A phenomenological study design was used among 17 autistic mothers who were conveniently selected. The Focus group discussion guide included four open-ended questions to define mothers' challenges, as well as their coping and adaptation strategies for autistic adults' independent lives.

**Results:** The thematic analysis highlighted six main themes and their subthemes. The subjects' response themes started with autism detection among children and went behind challenges and adaptation and coping mechanisms to create an independent living approach for autistic adults.

**Conclusions:** Mothers emphasized the need for comprehensive support systems, including early intervention, specialized resources, and trained caregiver. In addition, community engagement, acceptance and comprehensive family support are crucial.

**KEY WORDS:** phenomenological, navigation, mothers, independent live, autistic, community services, support system

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## INTRODUCTION

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition characterized by difficulties in social interaction, communication, and repetitive behaviors [1]. Globally, ASD affects approximately 1 in 100 children, with its prevalence steadily rising, emphasizing the need for improved support systems [2]. However, as autistic individuals transition into adulthood, they encounter significant challenges, including limited access to healthcare, vocational training, and opportunities for social integration [3]. Early intervention services are often discontinued in adulthood, creating a critical gap that negatively impacts the quality of life for autistic adults and their families [4].

In Saudi Arabia, ASD prevalence is estimated at 1 in 146 children, yet there remains a significant shortage of services, particularly for adults [5]. Saudi mothers of autistic adults face unique challenges due to cultural barriers, social stigma, and a lack of specialized adult services [6,7]. Societal perceptions of autism contribute to stigma and social isolation, reducing awareness and

acceptance [8]. This fear of stigma further deters families from seeking necessary support, exacerbating existing service gaps [9].

Currently, autism-related services in Saudi Arabia predominantly focus on children, with limited provisions for adults. Compared to Western nations, community-based support systems for autistic adults remain underdeveloped. Expanding vocational training, life skills programs, and social integration initiatives could significantly improve independent living and overall well-being for autistic adults and their families [10].

Disparities in community services exist between urban and rural regions in Saudi Arabia, making it difficult for many families to access adequate support [11,12]. Despite government efforts to enhance autism services through funding and specialized centers, these initiatives remain insufficient and require further expansion [13]. Non-governmental organizations (NGOs) play a crucial role in supporting autistic individuals and their families [14].

## AIM

To investigate the obstacles encountered by Saudi mothers with adult autistic children in promoting autonomy and meaningful relationships. Additionally, it aimed to assess the available community resources and assistance for these mothers, as well as gather their recommendations for enhancing support systems.

## SPECIFIC OBJECTIVES

- 1 Exploring the obstacles encountered by Saudi mothers of adult autistic individuals in fostering independence and meaningful relationships.
2. Assess the availability and adequacy of community support services in helping these mothers achieve their aims of maintaining fulfilling relationships and a normal lifestyle.
3. Explore and examine recommendations for enhancing services to support autistic adults in achieving independent living and marriage.

## MATERIALS AND METHODS

### SIGNIFICANCE OF THE STUDY

This study addresses critical gaps in supporting autistic adults in Saudi Arabia by focusing on improving health-care services, policies, and societal attitudes toward autism. It identifies unmet needs in community services, providing valuable insights to guide effective interventions [15]. The research highlights the experiences of mothers, empowering them to strengthen support networks and advocacy efforts [16]. Additionally, it offers actionable recommendations for policymakers and service providers to enhance support for autistic adults and their families [17].

By focusing on Saudi Arabia, the study contributes to the limited research on autism in non-Western contexts, offering culturally relevant perspectives on these challenges [18]. Its emphasis on promoting independent living underscores the need for programs that foster autonomy and improve the quality of life for autistic adults [19].

### STUDY DESIGN

A descriptive phenomenological study design was used to explore the lived experiences of participants. This approach seeks to describe a phenomenon from the perspective of those who have directly experienced it, emphasizing both the nature of the experience and how it was encountered. This method offers deeper insights into the challenges and positive aspects faced

by individuals, contributing to a more comprehensive understanding of their experiences [20].

### STUDY AREA/SETTING

The study was conducted at the Comprehensive Rehabilitation Center in Jazan, a government-affiliated institution that provides services to individuals with multiple disabilities across various age groups. Situated along the southern Red Sea coast near Yemen, the center focuses on delivering care, rehabilitation, and empowerment programs to individuals with special needs, with the aim of enhancing their independence and overall well-being [21].

### STUDY PARTICIPANTS AND SAMPLE SIZE

A nonprobability convenient sampling technique was used to recruit 17 mothers and caregivers of autistic adults, with each focus group consisting of 5 to 8 participants.

### INCLUSION CRITERIA

Participants, including both mothers and caregivers, were selected based on having at least one year of experience caring for autistic adults. A non-probability convenient sampling technique was used. Inclusion criteria included being an adult (male or female), displaying a cooperative attitude, and agreeing to participate in the study.

### DATA COLLECTION METHODS

The research employed a focus group discussion guide (FGG) to gather the information required for the study. Researchers have developed the FGG to obtain qualitative data after examining recent literature. The guide aimed to investigate participants' views on the capabilities and constraints of adult individuals with autism spectrum disorder (ASD), assess its influence on developing autonomy and fulfilling relationships, and identify participants' recommendations and requirements to assist ASD adults in achieving their objectives and leading normal lives with satisfactory relationships. FGG comprises the following stages:

### PHASE I

Introductory stage: During this phase, the researchers present themselves (name, profession), clarify the study's objectives, and ensure data confidentiality. They enquired about the participants' personal details (age,

autism discovery time, duration of caring for autistic adults, occupation, marital status, educational background, and specialization).

**PHASE II**

Engagement stage (icebreaker queries). These questions were designed to help participants feel at ease in the discussion and freely express their opinions, such as their knowledge of ASD symptoms and diagnoses, their feelings about managing ASD, and the health services and resources available to them.

**PHASE III**

Exploration stage (Core questions) which addresses the primary issues the researcher aimed to cover in the FGDs session, including Examining ASD abilities and limitations regarding developing an independent life and satisfactory relationships. Participants’ perspectives on the challenges faced by adults’ individuals and their impact on independent living and satisfactory relationships. Investigating the challenges encountered by caregivers and adults with autism in achieving satisfactory relationships and independent life skills. Assessing participants’ coping strategies and suggestions for reducing challenges.

**PHASE IV**

Concluding stage (final question): Do you have any additional comments.

**DATA COLLECTION PROCEDURE**

Researchers conducted three virtual focus group discussions (FGDs) via Zoom with 5-8 family members of autistic adults, following approval from KAIMRC and the IRB. A mock session was held beforehand to refine the focus group guide. Participants were recruited from a rehabilitation center, and informed of the study’s purpose, and confidentiality was ensured through identification numbers. Each Zoom session, lasting 1.5 to 2 hours, included introductions, ice-breaking, and open-ended questions. Discussions continued until data saturation was achieved, and all sessions were audio-recorded with consent. Exit questions and participant acknowledgments concluded each session.

**DATA MANAGEMENT AND ANALYSIS PLAN**

After data collection, all audiotaped sessions were transcribed verbatim to ensure the exact words and phrases

expressed by participants were captured. Transcripts were thoroughly proofread and compared against the audio recordings to ensure accuracy. Sensitive information, such as accidental mentions of names, was replaced with participant IDs to maintain confidentiality.

The data was organized and analyzed by clustering findings and relevant quotations into overarching themes, which served as the main headings for the results. To ensure the trustworthiness and quality of the qualitative data, several strategies were used, including triangulation, member checking, peer debriefing, inquiry audits, and the use of thick descriptions.

**ETHICAL CONSIDERATIONS**

Informed consent for the study was obtained through formal approval from the research unit at the College of Nursing, KAIMRC, and the IRB (NRJ22J/048/02). A letter of approval and a brief explanation of the study’s purpose and procedures were provided to the relevant setting. Participants were informed that their participation was voluntary and that they could withdraw at any time without any negative consequences. The Principal Investigator (PI) ensured secure storage of both hard and electronic data on MNGHA premises, with access restricted to the research team. Throughout the study, anonymity, confidentiality, and privacy were upheld. Participants received the informed consent form electronically and provided consent by agreeing to participate, after which they were invited to join focus group discussions.

**RESULTS**

Table 1 shows maternal sociodemographic characteristics that a substantial portion (64.7%) were aged 30 years or above, with the majority possessing a university degree (58.8%) and not engaged in employment (70.6%). A large percentage (82.4%) were married, while 29.4% indicated consanguineous unions with their spouses. The age at autism diagnosis in their offspring was fairly evenly distributed among ages 2, 3, and 4 years. Regarding adult sociodemographic data, 57.1% were below 30 years of age and a significant majority (71.4%) reported no parental consanguinity. These observations suggest a pattern wherein mothers of autistic children tend to be older, highly educated, and predominantly unemployed, with a notable incidence of consanguinity, which could be significant for the genetic aspects of autism studies.

Fig.1. illustrates these six primary themes. The initial theme, autism detection in children, encompasses several subthemes: early identification and typical

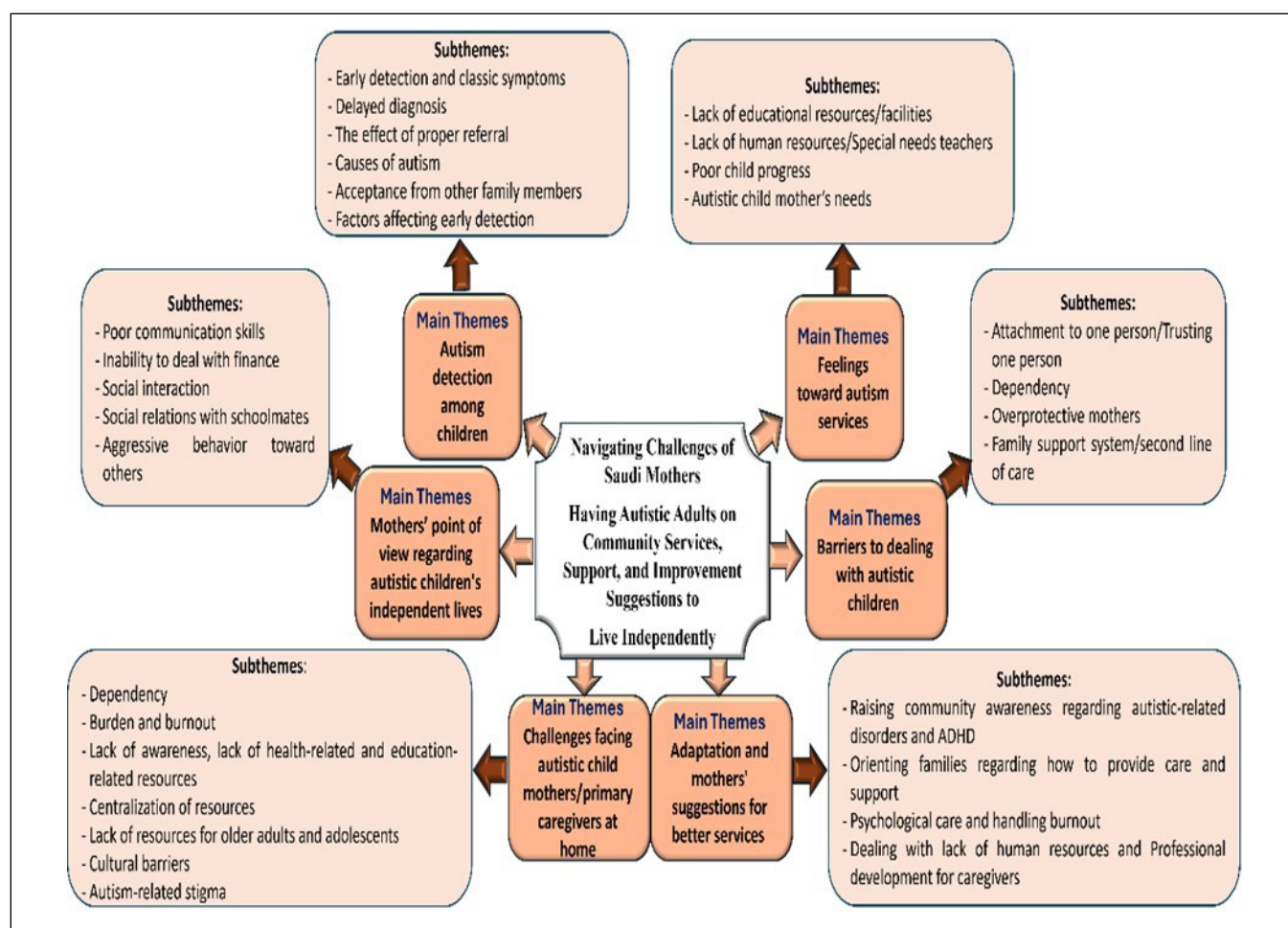
**Table 1.** Distribution of studied sample according to their demographic data (N=17)

| <b>Variables</b>                                      | <b>No.</b> | <b>%</b> |
|---|------------|----------|
| <b>Mother's sociodemographic data</b>                 |            |          |
| <b>no.17</b>  |            |          |
| <b>Age (Years)</b>                                    |            |          |
| Less than 30  | 6          | 35.3     |
| 30 and more   | 11         | 64.7     |
| <b>Educational level</b>                              |            |          |
| Middle  | 3          | 17.6     |
| High  | 4          | 23.5     |
| University  | 10         | 58.8     |
| <b>Occupation</b>                                     |            |          |
| Working   | 5          | 29.4     |
| Non-working   | 12         | 70.6     |
| <b>Marital status</b>                                 |            |          |
| Married   | 14         | 82.4     |
| Widow   | 3          | 17.6     |
| <b>Husband consanguinity</b>                          |            |          |
| Yes   | 5          | 29.4     |
| No  | 12         | 70.6     |
| <b>Age of the child's diagnosis of autism (Years)</b> |            |          |
| 2   | 5          | 29.4     |
| 3   | 6          | 35.3     |
| 4   | 6          | 35.3     |
| <b>Adult sociodemographic data</b>                    |            |          |
| <b>no.7</b>   |            |          |
| <b>Age</b>  |            |          |
| Less than 30  | 4          | 57.1     |
| 30 and more   | 3          | 42.9     |
| <b>Mother/Father consanguinity</b>                    |            |          |
| Yes   | 2          | 28.6     |
| No  | 5          | 71.4     |

Source: compiled by the authors of this study

symptoms, delayed diagnosis, impact of appropriate referral, autism causes, acceptance from other family members, and factors influencing early detection. The second theme, perceptions of autism service, includes subthemes such as insufficient educational resources and facilities, shortage of human resources and special needs educators, limited child progress, and the requirements of mothers with autistic children. The third theme addressed barriers in managing children with autism, highlighting subthemes such as attachment to a single individual, dependency, overprotective mothers, and family support systems as secondary care providers. The fourth theme explored mothers' perspectives on autistic children's independent living, featuring subthemes such as poor communication abilities, financial management difficulties, social engagement, relationships with classmates, and aggressive

behavior towards others. The fifth theme examined the challenges faced by mothers or primary caregivers of autistic children at home, including subthemes of dependency, burden and exhaustion, lack of awareness, insufficient health and education-related resources, centralization of resources, inadequate provisions for older adults and adolescents, cultural obstacles, and autism-related stigma. The final theme, as depicted in figure (1), focused on adaptation and mothers' recommendations for improved services, presenting subthemes such as increasing community awareness about autism-related disorders and ADHD, guiding families on care and support provision, emphasizing the importance of workshop materials, highlighting the significance of psychological care and burnout management, and addressing the shortage of human resources and professional development for caregiver



**Fig. 1.** Focus group discussion thematic analysis navigating challenges of Saudi mothers having autistic adults

Picture taken by the authors

### Theme 1: Autism detection among children

This theme includes subthemes such as early detection and classical symptoms, delayed diagnosis, the impact of proper referral, causes of autism, family acceptance, and factors influencing early detection.

#### A: Early detection and classical symptoms

##### A1: Age of discovery

Most mothers noticed abnormal symptoms in their children between the ages of 2 to 3 years, often recognizing developmental deviations compared to other children, relatives, or neighbors. Participants 1, 3, 7, and 15 stated, "I detect autism at age 2 to 3 years, actually I can't remember," and "Detected at 2.5 years."

##### A2: Early indicators

Some mothers identified early signs of autism in their children, including delayed speech, lack of responsiveness, non-verbal communication, and poor eye contact. Participants 2 and 3 mentioned, "The child stopped talking after 18 months even minor words" and "The child responds by shouting." Participants 1 and 3 noted, "When I am talking to him, he doesn't look at me and has poor eye-to-eye contact."

##### A3: Misdiagnosis

Some mothers reported that their children were misdiagnosed, initially being believed to have hearing problems or mental disturbances. For example, Participant 1 mentioned, "My relatives have told me that my child is crazy or psychologically disturbed; I didn't believe them at first, but now I'm starting to wonder if it's true." Others were misdiagnosed with ADHD, as noted by Participants 5 and 6. This highlights the challenges in accurately diagnosing autism.

##### A4: Repetitive and stereotyped behavior

Some mothers reported that their children are mostly isolated or withdrawn, and preferring to be alone. As mentioned by participants (8, 9, and 10), "My kids mostly sit at the same place in front of the TV, he mostly isolated, introverted didn't hear other words or neglect them,"

##### A5: Head banging

Some mothers reported that their child exhibited head-banging behavior. As stated by participants (1 and 3), "I noticed that he moved his head and flopped it backward," and "he pushed himself into the floor and hit his head."

#### A6: Risk perception

Some mothers reported that their children were unaware of dangers and threats, requiring constant supervision to prevent harm. As stated by participants (4 and 11), "My child can't differentiate between hazardous substances; they need continuous observation, they can hurt themselves."

#### A7: Impaired verbal communication

Some mothers reported that their children neglected them, did not use verbal communication, and failed to understand their words. As stated by participants (10 and 13), "He didn't understand me when I tried to speak to him."

#### A8: Agitation and Biting and hurting others

Some mothers reported that their children displayed aggressive behavior, moved quickly and frequently, and engaged in non-purposeful body movements, they bite and hurt their siblings. As stated by participants (2,4,11 and 13), "My son kept moving and they never stopped, do non-purposeful body movement, she responds by biting."

#### A9: attach to one clothes.

Some mothers reported that their children were closely attached to specific clothing and refused to wear anything else. As stated by participants (2 and 3), "I noticed that my kid is attached to certain clothing and refuses to wear anything else."

#### A10: Oversensitivity to sound

Some mothers reported their children are oversensitive to high-pitched sounds, becoming aggressive. As stated by participants (10 and 15), "I noticed that my child is oversensitive to sound and becomes aggressive in response to high-pitched sounds."

#### A11: Delayed gross motor and language development.

Some mothers observed a delay in their child's gross motor skills and language development, particularly when compared to an older sibling. As stated by Participants (1,3,17 and 18), "When I compare my autistic child with her oldest sister, I noticed that they didn't go on the same track.", "she uses very limited words and can't proceed in communication."

#### A12: Lack of orientation to place/settings

Some mothers noticed that their children would wander and feel lost if left alone. As stated by participants (1 and 3), "I can't leave my daughter alone anywhere, she can't tell others about their home or location."

#### A13: Hand flapping

Hand flapping was reported by some mothers, as stated by Participants 1 and 4, "My child continuously does hand flapping, especially with high loud sounds."

#### A14: Detached from reality.

Some mothers believe their child hears external sounds that detach them from reality. As stated by participants (10 and 16), "I observed that my child didn't

concentrate, and he might hear other sounds that make him not aware."

#### **B: Delayed diagnosis**

Autism diagnosis was confirmed for some mothers when their children were 4–9 years old, initially misdiagnosed as mentally retarded before identifying autism. As stated by participants (1,3,5 and 17), "I have a problem with the delay of autism diagnosis, which leads to a lack of proper treatment."

#### **C: Effect of proper referral**

Some mothers reported significant benefits from proper referral and management. As stated by participants (1 and 13), "I become so excited after proper referral to the correct agency. My daughter behaves near to normal."

#### **D: Causes of autism**

D1: Lack of awareness of autism causes

Some mothers believe that high temperature might be a cause of autism. As stated by Participants 1, 7, and 13, "I remembered that my child got a high temperature at 6 months, then was diagnosed with autism at age 2 years. I believe that the high temperature was the cause. I didn't know why my kids get autism."

D2: Genetic predisposition and autism

Some mothers believed that familial tendencies and genetic factors might contribute to autism, while others disagreed. As stated by participants (3 and 9), "Consanguinity plays an important role from my point of view,," "No, I disagreed. There is no association between consanguinity and autism."

#### **E: Acceptance from other family members**

There is a discrepancy in family response and acceptance of autistic children. First-degree relatives, especially females, tend to be more cooperative and accepting than others. As stated by participants (2, 3, and 17), "I noticed that close family members, as sisters, are more accepting and helpful and caring than others or other relatives."

#### **F: Factors affecting early detection**

Mother's prior experience with other siblings affects early detection. As stated by participants (1, 2, 3, and 13), "From my experience, I noticed early that my autistic child is deviated from normal, compared my child with her sisters and sons."

#### **Theme 2: Feeling toward autism services**

The second theme presents the following subthemes: lack of educational resources/facilities, lack of human resources/Special needs teachers, poor child progress, and autistic child mother's needs.

#### **A: Lack of Educational Resources/Facilities**

Some mothers face challenges due to the lack of specialized educational resources for autistic children. As stated by participants (1 and 3), "The problem is the

lack of facilities to teach my autistic child in a specialized school."

#### **B: Lack of Human Resources/Special Needs Teachers**

Most mothers highlighted the need for special needs teachers, as regular teachers often lack the necessary experience. Participants 2, 4, 7, 9, and 14 "Having specialized support in classrooms to improve integration and ensure better care for autistic students".

#### **C: Poor Child Progress**

Some mothers are dissatisfied with their children's slow progress, believing it could improve with better-qualified care. Participants (10 and 13) mentioned, "The progress of my child is accepted, but it is very slow, he does not have a special needs teacher,"

#### **D: Autistic Child Mother's Needs**

Mothers highlighted two main sources of care: specialized centers with satisfactory services and general hospitals with unsatisfactory services. Participants 14 and 15 stated, "Health services are very limited" and "I go to hospitals for a speech therapist not available at schools."

### **Theme 3: Barriers to dealing with autistic children.**

The third theme shows the following subthemes: attachment to one person/Trusting one person, dependency, overprotective mothers, and family support system/second line of care.

#### **A: Attachment to One Person/Trusting One Person**

Many mothers reported that their children are closely bonded to them and reject care from others. As stated by participants (1, 2, 3, 4, 5, and 17), "My child mainly refuses any care provided by others."

#### **B: Dependency**

Specialized centers and teachers keep children independent. As mentioned by participants (1 and 3), "Most of the time my child is dependent, which puts extra load on me. Dependency decreases if they receive care from specialized centers and teachers."

#### **C: Overprotective Mothers**

Some mothers exhibit overprotective behavior, fearing their children might hurt themselves. Participants 14 and 17 stated, "I am trying to encourage my child to have self-care activities and be independent," and "No, I have to protect my child, they may hurt themselves."

#### **D: Family Support System/Second Line of Care**

Most mothers agreed on the importance of preparing a second line of care. As mentioned by Participants 1, 2, 7, 9, 10, and 14, "The main concern is to prepare a second care provider," and "Family support is important for future life."

### **Theme 4: Mothers' point of view regarding autistic children independent life**

The fourth theme presents the following subthemes: poor communication skills, inability to deal with finance,

social interaction, social relations with schoolmates, and aggressive behavior toward others.

#### **A: Poor Communication Skills**

Many mothers believe that poor communication skills limit their autistic children's independence and affect their chances of marriage. Participants 1, 2, and 15 stated, "I don't think my daughter can marry; she can't communicate well."

#### **B: Inability to Deal with Finance**

Some mothers worry that autistic individuals cannot handle finances, making marriage difficult. As stated by participants (5 and 7), "Financial skills needed for marriage. I can't believe my child can handle it, so it's difficult to get married."

#### **C: Social Interaction**

Poor social interaction skills were cited as a key factor in mothers' decisions about marriage. As mentioned by participants (1 and 3), "An autistic person with poor social interaction skills can't be married at all."

#### **D: Social Relations with Schoolmates**

Mothers noted that their children have limited social interactions with schoolmates. Participants (1, 2, 5, 9, and 11) shared, "I noticed that my child has a limited number of friends, and he lacks social interaction, so I can't accept the idea of his marriage."

#### **E: Aggressive Behavior Toward Others**

Aggressive behavior was a concern, making it difficult for autistic individuals to find marriage partners. As Participants 1 and 3 mentioned, "My child is aggressive, no family would accept this marriage," and "In our culture, autistic are considered mad and can't be married."

### **Theme 5: Challenges facing autistic child mothers/primary caregivers at home.**

The fifth theme portrays the following subthemes: dependency, burden and burnout, lack of awareness, lack of health-related and education-related resources, centralization of resources, lack of resources for older adults and adolescents, cultural barriers, and autism-related stigma.

#### **Dependency**

Most mothers felt overwhelmed expressing that they had no support and had to handle all aspects of care alone. Participants 7, 8, 9, 10, and 13 shared, "No one can help me, I am alone. My child is fully dependent and needs me all the time."

#### **Burden and burnout**

Many mothers felt powerless and emotionally drained, struggling to cope with the challenges of caregiving for their autistic children. Participants 1 and 3 stated, "I am human, and I can't tolerate it. I feel frustrated, I have no power."



### ***Lack of awareness***

Many mothers highlighted the lack of understanding about managing autism, which makes their situation difficult. As participants 7 and 13 stated, "If I don't know what autism is or how to manage it, I can't provide proper care. Lack of awareness prevents effective management."

### ***Lack of health-related and education-related resources***

Most mothers agreed that access to healthcare and educational facilities is crucial for managing autism. They stressed the need for specialized centers and schools to alleviate their burden. Participants 2, 4, 5, 6, 7, and 11 mentioned, "If we had adequate specialized hospitals and centers, we wouldn't feel unsupported."

### ***Centralization of resources***

The unequal distribution of resources, with many services concentrated in larger cities, posed a major challenge for mothers in remote areas, making it difficult to access essential care. Participants (1 and 3) highlighted this issue, noting that resources are unevenly spread, leaving smaller, rural areas underserved.

### ***Lack of resources for older adults and adolescents***

The shortage of services for older adolescents was a concern, leading to discontinuity in care. Participants (10, 11, 12, and 13) mentioned, "Most centers only offer services until the age of 10 or 12. There are no schools that provide integration, so we often must place our kids in general schools, which leads to setbacks."

### ***Cultural barriers***

Cultural factors, such as gender-specific services, were mentioned as a challenge affecting care. As participants (11 and 13) pointed out, "Services available for girls at schools are different from those for boys, especially when the care provider is of the opposite sex."

### ***Autism-related stigma***

The stigma around autism contributed to psychological challenges. They expressed feeling isolated and unsupported. As participants (11 and 13) explained, "When I knew autism diagnosis, I was shocked. I didn't know how to face the community, and I hid it to avoid their negative reactions and comments."

### **Theme 6: Adaptation and mothers' suggestions for better services**

The last and sixth theme presents the following subthemes: raising community awareness regarding autistic-related disorders and ADHD, orienting families regarding how to provide care and support, and workshop materials are important, psychological care and handling burnout are important, and dealing with lack of human resources and Professional development for caregivers.

### ***Raising community awareness regarding autistic-related disorders and adhd***

Some mothers emphasized the need for increased community awareness about autism and ADHD. An informed community could offer better help and support. Participants (8 and 13) shared, "An aware community can provide help and support us. They can push toward better care."

### ***Orienting families regarding how to provide care and support, workshop materials***

Many mothers highlighted the importance of educating and training families to properly care for their autistic children. Participants (10, 11, 12, 13, and 14) stated, "Trained and skillful family members can provide better care."

### ***Psychological care and handling burnout are important***

Psychological stress and burnout were common issues for mothers. Most of them reported that access to psychological support could help alleviate frustration and reduce negative thoughts. As participants (8, 9, 10, 11, 12, and 14) stated, "If I found psychological support, it may protect me from frustration and decrease my negative thoughts."

### ***Dealing with lack of human resources and professional development for caregivers***

The shortage of trained and qualified staff in healthcare and educational facilities was a key issue for mothers, with many calling for increased government support to hire qualified professionals. As shared by Participant (1), "I have a question: why do we have a lack of trained and qualified teams? The government must support us and hire a qualified team."

## **DISCUSSION**

This study explores how mothers detect autism in their children, focusing on early signs, challenges, and misdiagnoses. Mothers commonly notice symptoms such as developmental delays, lack of verbal communication, poor eye contact, and unusual social responses around 2–3 years of age, which align with existing research on early autism indicators [22,23]. Early detection enables timely interventions and access to support services that address developmental delays associated with autism spectrum disorder (ASD) [24]. However, diagnostic challenges arise due to symptom overlap with conditions such as hearing impairments, ADHD, and intellectual disabilities, often leading to misdiagnoses. This results in delays in receiving appropriate care and causes frustration for families [25,26].

The study highlights the challenges mothers face in detecting autism in their children, including delayed diagnoses, varied beliefs about autism, and the emo-



tional impact of caregiving. Misdiagnoses, such as ADHD or hearing impairments, can contribute to delays in obtaining an accurate diagnosis and appropriate interventions [25,26]. The psychological burden on mothers is significant, marked by worry, uncertainty, and frustration, particularly when dealing with societal stigma or diagnostic challenges. Adequate support is essential to help mothers navigate these difficulties and promote their child's development [27]. Timely, accurate diagnosis and early intervention are crucial for improving outcomes for children with autism [24].

Family dynamics, particularly support from female relatives, play a crucial role in helping mothers cope with autism. Prior experiences with siblings allow mothers to recognize early developmental signs [28]. Misconceptions about autism, stemming from genetic and environmental factors, further emphasize the need for increased community awareness [22].

The second theme provides insight into mothers' perspectives and experiences regarding available autism services and resources. The study highlights significant challenges mothers face in accessing and utilizing support services for their children with ASD, including limited specialized educational resources and a lack of trained special needs teachers, which impact academic progress [29,30]. Mothers expressed dissatisfaction with the care their children receive, particularly concerning behavioral issues, highlighting the need for tailored interventions to promote optimal development [31]. Furthermore, they emphasized the importance of integrated healthcare services, such as speech therapy and behavioral interventions, but many face obstacles in accessing coordinated care across different settings. Effective collaboration between healthcare providers, educators, and families is crucial for achieving positive outcomes [32].

In conclusion, improving the accessibility and quality of autism services—through specialized education, integrated healthcare support, and trained professionals—is essential. Collaboration among policymakers, educators, healthcare providers, and community stakeholders is necessary to provide holistic and sustained support for individuals with autism and their families.

The third theme examines the challenges mothers face in caring for children with autism, including attachment, dependency, overprotectiveness, and the need for support. Children with autism often form strong attachments to their mothers, making it difficult for them to accept care from others, thereby limiting access to external support services [33]. Dependency on mothers is another significant issue, as children who lack exposure to specialized centers and trained educators rely heavily on them. Structured interventions

and educational programs are necessary to promote independence and reduce caregiving burdens [34].

Mothers adopt varying approaches to fostering independence, with some prioritizing autonomy while others emphasize safety, creating challenges in balancing these needs [35]. Additionally, strong support networks, including emotional support and respite care, are crucial for both the child and the family [36]. Addressing these challenges requires comprehensive interventions, such as tailored support services, caregiver training, and community involvement, to ensure effective care for children with autism and their families.

The fourth theme focuses on mothers' concerns about their autistic children's future independence, particularly in marriage and relationships. Many mothers worry about their children's limited communication skills, which hinder social interactions and romantic relationships [37]. They also express concerns about their children's financial literacy and decision-making abilities, questioning their capacity to handle marriage responsibilities [38]. These concerns highlight the need for targeted interventions aimed at improving communication, life skills, and social competence to foster greater independence.

Mothers emphasized the importance of social interactions in marriage, noting struggles with understanding social cues and forming meaningful relationships [39]. Limited social engagement often reflects their children's potential for future relationships, and mothers fear this could impact social competence and suitability for marriage [40]. Additionally, concerns about aggressive behavior and impulsivity were raised, as these traits challenge stable and harmonious relationships [40].

In conclusion, these findings underscore the multifaceted cognitive, social, and behavioral factors influencing mothers' perspectives on their autistic children's potential for independence and meaningful relationships. Addressing these concerns requires holistic support, including targeted interventions aimed at enhancing communication, emotional regulation, and social skills for individuals with ASD.

The fifth theme highlights the challenges mothers face in caring for children with autism, including emotional strain, isolation, and practical caregiving burdens. Many mothers feel overwhelmed by the sole responsibility of caregiving, leading to exhaustion and burnout. The lack of adequate support, such as respite care, exacerbates their struggles [37].

Mothers often experience gaps in their knowledge about autism and management strategies, limiting their access to effective care [38]. The shortage of healthcare and educational resources, particularly in rural areas, poses additional barriers to quality care [39]. Long-term

stability is further challenged by limited resources for older adolescents, discontinuity in care, and a lack of integrated services. Cultural norms and stigmatization also impact access to care, necessitating culturally sensitive approaches.

Addressing these challenges requires a holistic approach that includes culturally tailored support, equitable resource distribution, and collaboration across healthcare, education, and community sectors to improve caregiver well-being and ensure sustainable care for children with autism.

The sixth theme highlights the need for improvements in services for individuals with ASD and ADHD, as suggested by mothers. Key recommendations include raising community awareness to foster understanding and acceptance, providing educational workshops to equip families with essential caregiving skills, offering psychological support to manage caregiver stress, and addressing human resource challenges by enhancing recruitment and professional development opportunities in healthcare settings. Mothers' recommendations for improving care require a collective effort across healthcare, education, and community sectors. By focusing on awareness, family engagement, psychological support, and professional development, these suggestions aim to better support individuals with ASD and ADHD, along with their families.

## CONCLUSIONS

To summarize, this study underscores the myriad challenges encountered by mothers caring for adults with autism. The principal concerns include obstacles to early identification, obtaining suitable support services, and promoting autonomy. Mothers stressed the

importance of comprehensive assistance frameworks, encompassing early intervention programs, specialized resources, and skilled caregivers. Moreover, it is vital to address the mental health of caregivers through support services such as therapy and respite care. Bolstering family support networks and encouraging community acceptance can help reduce the burden on caregivers and enhance the quality of life of both individuals with autism and their families.

## RECOMMENDATIONS

The findings suggest several key recommendations:

1. Enhance awareness and training for healthcare professionals to ensure early detection and intervention for autism and ADHD.
2. Build integrated support systems that offer access to specialized education, therapy, and healthcare services tailored to individuals with autism throughout their lives.
3. Provide psychological support, counseling, and respite care to caregivers, especially mothers, to reduce burnout and strengthen coping mechanisms.
4. Promote community awareness and acceptance of autism through workshops, support groups, and inclusive activities to reduce stigma.
5. Invest in professional development programs to enhance the skills of caregivers and healthcare providers in delivering effective, holistic care.





## DATA AVAILABILITY STATEMENT

All data included in article/supp. material/referenced in the article. Further data will be available from the corresponding author upon reasonable request.

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## CONFLICT OF INTEREST







The Authors declare no conflict of interest




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