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Navigating challenges and emotional responses: a qualitative study of Iranian parents' experiences in the Autism Diagnosis process and beyond

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Abstract

Background Autism spectrum disorder (ASD) is a complex neurodevelopmental condition posing significant emotional and practical challenges for families, particularly during the diagnostic process. Limited research has explored how parents in non-Western contexts interpret and emotionally navigate this experience. This study investigated Iranian parents' beliefs, meaning-making processes, and emotional trajectories during and after the ASD diagnostic journey, aiming to identify culturally shaped patterns and implications for family-centered care.

Methods In 2024, a qualitative study was conducted in Yazd, Iran, using conventional content analysis guided by Graneheim and Lundman's framework. Twelve parents of children with ASD (aged≤6 years) were recruited via purposive sampling with maximum variation from "Tolou-e-Mehr" and "Baqa" Autism Centers, the only Welfare Organization-supervised diagnostic and rehabilitation centers in Yazd at the time. In-depth, semi-structured, face-to-face interviews with individual participants were conducted until data saturation was reached. Data were analyzed using MAXQDA version 18, and rigor was ensured through Lincoln and Guba's trustworthiness criteria. The findings were reported in accordance with the 32-item COREQ checklist.

Results Three categories and one overarching theme emerged from the analysis. The overarching theme, *"The Parental Journey Through Autism Diagnosis Amid Uncertainty and Progressive Adaptation,"* captures parents' evolving experiences across the diagnostic pathway. The three categories included: (1) Diagnostic Process Challenges; (2) Emotional Trajectory of Parents During Diagnosis; and (3) The phases of Parental Response, from initial symptom recognition through post-diagnostic adaptation. A key contribution of this study is the identification of a culturally grounded predominant trajectory encompassing seven key phases of parental responses across and beyond the autism diagnostic journey: symptom recognition, denial and shock, anger and frustration, bargaining and resistance to medical advice and treatment, emotional distress/depression, social isolation, and acceptance/adaptation. Granular participant-level analysis revealed that while parents demonstrated an overarching chronological progression toward adaptation without backwards regression, individual trajectories were dynamic and flexible, with parents selectively navigating or bypassing intermediate phases. This trajectory incorporates culturally specific elements, including resistance to medical recommendations through religious practices and

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stigma-related isolation that extends to broader family networks. Parents also reported diagnostic delays, inconsistent assessments, and fragmented service pathways that intensified emotional burden.

Conclusions It seems this study provides novel insight into the culturally shaped emotional processes Iranian parents undergo during ASD diagnosis and beyond, highlighting how systemic challenges intersect with personal coping responses. Findings underscore the need for timely diagnosis, coordinated family-centered services, and culturally sensitive psychosocial support to help parents navigate their dynamic diagnostic pathways.

Trial registration Not applicable.

Keywords Autism spectrum disorder · Diagnostic process · Parental experience · Qualitative research

Background

Autism spectrum disorder (ASD) is a complex neurodevelopmental condition characterized by persistent challenges in social interaction, communication, and restricted, repetitive behaviors. Globally [1], the prevalence of ASD is estimated at approximately 1 in 100 children [2]. In Iran, limited epidemiological studies report a prevalence ranging from 0.6% to 1.0%, with an upward trend attributed to increased awareness and improved diagnostic tools [3]. However, in addition to these emerging trends, the broader sociocultural and structural landscape of Iran plays a critical role in shaping families' experiences. Pervasive social stigma surrounding developmental disorders, strong family expectations, and cultural beliefs that may associate disability with family shame all contribute to hesitancy in seeking early assessment [4, 5]. These challenges are compounded by systemic constraints, including shortages of trained specialists, limited diagnostic centers, and fragmented care coordination, which together delay access to appropriate services [4–6].

Only a few specialized diagnostic and rehabilitation centers—such as "Tolou-e-Mehr" and "Baqa" Autism Centers in Yazd—operate under the Welfare Organization's supervision, and many families must navigate lengthy waiting lists and inconsistent referral pathways [4]. The absence of comprehensive psychosocial support systems, such as structured psychological counseling services or parent support groups, further intensifies the emotional burden on caregivers. These contextual factors highlight the importance of understanding how Iranian parents experience and interpret the complex process of seeking an ASD diagnosis for their child [6].

Early ASD diagnosis, typically between 18 and 24 months of age, is crucial for accessing evidence-based interventions during key developmental periods and improving developmental outcomes [7]. Nevertheless, recognizing early symptoms and obtaining a formal diagnosis can be a confusing and emotionally demanding process for many families 8]. Previous studies in Iran have shown that parents often experience considerable emotional distress, uncertainty, and concern when confronting a child's autism diagnosis, reflecting the unique psychological and social pressures surrounding ASD in Iranian families [9, 10].

Despite these insights, little is known about how Iranian parents navigate the temporal diagnostic journey itself—from the initial recognition of symptoms to receiving a formal diagnosis and adapting post-diagnosis—and how their emotional and behavioral responses evolve throughout this process [10, 11]. While qualitative studies from Western contexts, such as those by Kim et al. (2021) and Crane et al. (2020), have highlighted parental frustrations with fragmented diagnostic systems [12, 13], few studies have explored these experiences in Middle Eastern settings using qualitative content analysis [14]. Evidence from other Asian countries, such as India and China, also points to diagnostic delays and stigma-related distress (15, 16), yet the culturally embedded emotional trajectories that parents experience during this diagnostic process remain insufficiently examined.

Also, despite these contributions, existing research has rarely examined the diagnostic journey as a dynamic process in which parents' emotional responses evolve through diverse and personalized pathways of seeking, receiving, and adapting to an autism diagnosis within the specific sociocultural context of Iran [10, 11, 14].

From the perspective of coping theory, parents' emotional responses are expected to evolve as they reappraise the stressor (Lazarus–Folkman coping theory) [15]. Yet, no study has mapped this process during the autism

diagnostic journey in Iran, based on the authors' literature review. Similarly, family systems theory would predict that the diagnosis affects family roles and relationships (Bowen family systems theory) [16], but the specific ways Iranian families experience this reverberation remain unexplored. While our study was not prospectively designed around these theories, they offer a coherent conceptual backdrop against which the emergent subcategories can be interpreted and contextualized post hoc.

Therefore, this study seeks to address these gaps by employing qualitative content analysis to explore how Iranian parents interpret, navigate, and emotionally respond to the ASD diagnostic journey. By examining both the procedural aspects and the evolving sequence of emotional reactions, the study aims to generate culturally grounded insights that can inform more responsive diagnostic protocols, psychosocial interventions, and policy frameworks tailored to families navigating ASD in non-Western contexts.

Methods

Design and setting

This qualitative study was conducted in 2024 in Yazd, Iran, using a conventional content analysis approach [17]. The interviews were originally conducted as part of the qualitative phase of a broader mixed-methods project examining prenatal psychosocial risk factors perceived to be associated with autism spectrum disorder (ASD).

The present study constitutes a secondary, independent qualitative analysis of the same interview dataset used in our previous publication [4], but addresses a distinct and non-overlapping research question. While the earlier analysis focused specifically on prenatal psychosocial experiences perceived by parents and professionals to be linked to ASD, the current study explores parents' narratives concerning their emotional reactions and adaptive processes following their child's initial symptom recognition of autism through post-diagnostic adaptation—dimensions that were entirely beyond the scope of the initial analysis.

Importantly, the previous study [4] employed a combined coding framework in which interviews with parents ($n=12$) and professionals ($n=10$) were analyzed together, with codes organized thematically without distinguishing between respondent groups. In contrast, the present study (a) focuses exclusively on parent interviews, (b) re-examines only those segments of the parent interview transcripts that were not coded or analyzed in the prior study, and (c) develops a new, independent coding structure tailored to the emotional and adaptive trajectory during and after diagnosis. Thus, although the same interview dataset was used, the segments analyzed in the present study were not previously coded or interpreted in the earlier publication, and therefore, no analytical overlap exists between the two studies.

Twelve parents of children diagnosed with ASD were recruited through purposive sampling with maximum sample variation from the "Tolou-e-Mehr" and "Baqa" Autism Centers, the only officially recognized diagnostic and rehabilitation centers under the Welfare Organization's supervision in Yazd at the time of data collection. In-depth, semi-structured interviews were conducted until data saturation was achieved. After the 10th interview, no new open codes emerged, and the subsequent two interviews yielded no additional codes, meaning Unit, categories, or conceptual insights. In such a way that the extracted codes comprehensively described all dimensions of a category. Also, data saturation was monitored continuously during the coding process [18].

The conventional content analysis approach was chosen because it allows researchers to derive theme)s(directly from the data without imposing preconceived theoretical assumptions, making it suitable for exploring parents' experiences in the culturally specific context of Iran and enabling the identification of organic and unexpected patterns [17].

Furthermore, open-ended, semi-structured interviews were used instead of structured interviews to provide greater flexibility in exploring participants' experiences in depth, allowing for rich, individualized responses based on their natural narratives, which aligns with the exploratory nature of qualitative research.

Participants and sampling

Twelve Iranian parents of children (aged ≤ 6 years) diagnosed with autism spectrum disorder (ASD) were selected using purposive sampling with maximum variation in age, gender, education, and occupation. This approach aimed to enhance the transferability and confirmability of the findings. Inclusion criteria were: (1) having a child formally diagnosed with ASD according to DSM-5 criteria (American Psychiatric Association, 2013) [19]; (2) the child's age at diagnosis being six years or younger; (3) willingness to participate and share personal experiences; and (4) fluency in Persian. Parents with severe psychiatric conditions or cognitive impairments were excluded. In families where both parents met the criteria, the primary caregiver was selected.

The decision to include only parents of children under six years old was informed by two methodological considerations. First, limiting the child's age to under six ensured that a relatively short time had elapsed since the diagnosis, thereby reducing the likelihood of substantial narrative reconstruction and retrospective reinterpretation of events [20]. In qualitative studies exploring experiences, minimizing temporal distance from the phenomenon of interest strengthens credibility by capturing participants' experiences closer to the actual event [20].

Second, restricting the age range increased the likelihood that the child's diagnosis had been formally established and clinically confirmed. Diagnostic conclusions in much younger children, especially during very early developmental stages, may still be provisional [21]. Consequently, this inclusion criterion ensured that all participants had recently navigated a confirmed diagnostic process, consistent with the study's aim of exploring parents' emotional and adaptive responses during and after the diagnostic journey [22].

Data collection tool and technique

Data were gathered from March to May 2024 through face-to-face, in-depth semi-structured interviews conducted at referral autism care centers in Yazd ("Tolou-e-Mehr and Baqa"). The interview protocol for this study was developed based on a comprehensive literature review and expert input from specialists in child psychiatry, psychology, speech therapy, and occupational therapy. Designed to collect rich, descriptive narratives, the semi-structured format provided flexibility to explore parents' experiences during the autism diagnostic process in depth. Sample questions included:

- "How and when was your child diagnosed with autism?"
- "Can you describe the moment you first suspected something unusual?"
- "What difficulties did you encounter during the diagnostic process?"
- "How did you feel when you received the diagnosis?"

To elicit more detailed and reflective responses, probing questions such as "Could you share more about what that moment felt like?" or "What specific challenges stood out to you?" were used strategically during the interviews. These probes encouraged participants to elaborate on their experiences, feelings, and perceptions, ensuring a deeper understanding of their narratives.

Each interview lasted approximately 40 to 60 min and was conducted in a quiet room at the autism centers to facilitate open dialogue. The first author, who was not involved in the diagnostic process, conducted the interviews to minimize interviewer bias. Data collection continued until data saturation was achieved. All interviews were audio-recorded with participants' informed consent and complemented by simultaneous field notes that documented nonverbal cues, including facial expressions, tone, gestures, and emotional intensity. These additional observations supported data triangulation, strengthening the reliability and contextual richness of the findings [22].

Data analysis

Data were analyzed using a conventional content analysis approach, guided by the strategies outlined by Graneheim and Lundman (2004) [23]. Initially, all interviews were transcribed verbatim and thoroughly reviewed multiple times to develop a comprehensive understanding of the content. We extracted text segments relevant to parents' experiences during the ASD diagnostic process and compiled them into a single document. These segments were then condensed into meaning units, which are presented in Table 2. Each meaning unit was abstracted and assigned descriptive codes to capture its essence. Codes were subsequently organized into categories and subcategories based on their similarities and differences, reflecting the core content of the data.

Coding followed an inductive open-coding approach grounded directly in participants' experiences and language throughout the entire analytic process. Analytic memos and reflexive notes documented interpretive decisions and evolving ideas throughout the process [22, 24].

Although the coding process was fully inductive and no priori theoretical framework guided theme generation, coping theory and family systems theory [15, 16] were incorporated only after the core categories and the main theme had been established. These theories were used as interpretive lenses to contextualize and deepen understanding of emergent parental experiences, consistent with a post-hoc interpretive approach rather than a theory-driven analytic design.

Two members of the research team independently coded the interview transcripts. To evaluate analytical dependability prior to consensus discussions, initial inter-coder percentage agreement was calculated across three analytical levels: open codes (82–87%), subcategories (86–92%), and main categories (89–94%). Following independent coding, the two primary coders met in iterative reflexivity sessions to resolve discrepancies and harmonize interpretations. Persistent coding disagreements—which were limited to less than 10% of the total extracted codes and were distributed across four of the twelve interviews (33.3%)—were adjudicated by a third senior qualitative researcher (the supervising author) to achieve final consensus (100%). MAXQDA version 18 [25] was utilized to facilitate systematic data management and code organization.

Trustworthiness

To ensure methodological rigor, the criteria proposed by Lincoln and Guba (1998) for qualitative research—credibility, transferability, dependability, and confirmability—were applied throughout the study [23].

- **Credibility**: Credibility was enhanced through several strategies. The researcher engaged deeply with the data by repeatedly listening to and reviewing the interview transcripts. After each interview was analyzed, participants were contacted again to review the researcher's interpretations and confirm or modify them (member checking). Interviews were conducted in a quiet and private environment to allow participants to freely express their experiences. In addition, the characteristics of participants and the context of data collection were documented in detail before each interview. To further strengthen credibility, peer debriefing was conducted in which another member of the research team reviewed the interpretations and provided feedback on the accuracy of the researcher's understanding of the parents' interviews.

- **Confirmability**: To minimize researcher bias and ensure objectivity, an audit trail of coding decisions and reflexive notes was maintained throughout the study. Coding dependability was established through independent dual-coding and third-party adjudication for discrepant segments as detailed in the data analysis section. Furthermore, preliminary categories and latent themes were systematically reviewed and confirmed through iterative team discussions among all authors, ensuring that interpretations were grounded directly in the participants' empirical accounts.

- **Transferability**: Transferability was supported by providing detailed descriptions of the study context, participants' characteristics, and the procedures used for data collection and analysis. Rich descriptions and representative quotations from participants were included to allow readers to evaluate the applicability of the findings to other contexts or populations.

- **Dependability**: Dependability was addressed by maintaining a clear and systematic coding process during data analysis. All steps of the research process were carefully documented, allowing the analytical decisions to be traceable. The researcher also attempted to bracket personal assumptions and avoid imposing prior beliefs during data collection and analysis. Furthermore, the study reporting followed the 32-item Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist to ensure transparency and methodological consistency.

Reflexivity

The primary researcher (first author) had a background in health sciences and qualitative research. She had no prior relationship with any of the participants, and she had no personal experience of having a child with autism spectrum disorder. However, she was aware that her academic interests in parental stress and caregiving challenges could shape her sensitivity to certain emotional categories in the data. Rather than attempting to eliminate this positionality, she acknowledged it as part of the knowledge production process and sought to manage its potential influence transparently [26].

Several strategies were used to minimize potential bias:

1. Bracketing: Before data collection, the first author wrote a reflexive memo documenting her prior assumptions about parents' emotional responses to autism diagnosis (e.g., expecting high levels of distress, guilt, and stigma). These assumptions were reviewed during team discussions and set aside during coding [26].
2. Reflexive field notes: After each interview, the first author recorded notes about her own emotional responses, any unexpected reactions from participants, and how her position might have influenced the interaction. A total of 12 field notes were maintained (one per interview) [26].
3. Collaborative analysis: All coding decisions were reviewed by the second author. Discrepancies were discussed in weekly team meetings. A third researcher (supervising author) was consulted when consensus could not be reached, which involved fewer than 10% of the total codes [26].
4. Peer debriefing: An experienced qualitative researcher not involved in the study reviewed a subset of transcripts (3 out of 12, representing 25%) and the corresponding coding scheme. Feedback from this debriefing was used to refine category definitions [26].

These strategies enhanced the transparency, credibility, and dependability of the study's findings. The reporting of reflexivity follows the COREQ (Consolidated criteria for Reporting Qualitative research) guidelines [27].

Ethical consideration

This study was approved by the Ethics Committee of Shahid Sadoughi University of Medical Sciences, Yazd, Iran (Ethical approval code: IR.SSU.SPH.REC.1400.227). The qualitative interviews were conducted as part of a broader mixed-methods doctoral research project.

It should be noted that the same interview dataset has also been used in a separate publication [4] examining prenatal psychosocial experiences. However, the present study reports a distinct analysis with a different focus (post-diagnosis emotional reactions), a different unit of analysis (parents only, whereas the previous study combined parents and professionals), and different portions of transcripts (only previously unanalyzed sections describing emotional responses to diagnosis). A completely new coding process was conducted from scratch

without reference to prior codes. Therefore, the findings presented here were not analyzed or reported in the previous study, and there is no duplication of results [4].

All participants were adult parents of children with ASD, and no minors (individuals under 16 years) were included as participants. Written informed consent was obtained from all participants in accordance with the principles of the Declaration of Helsinki, ensuring voluntary participation and confidentiality.

Participants were fully informed about the study's purpose, procedures, and their right to withdraw from the study at any time without consequences. All identifying information was removed from the transcripts to protect participants' privacy. Names were replaced with numerical codes, and only these codes were used during data analysis and in the presentation of the findings to ensure anonymity.

Results

The study included parents with diverse demographic backgrounds, the details of which are summarized in Table 1. Conventional content analysis of the interview data yielded one overarching theme: "The Parental Journey Through Autism Diagnosis Amid Uncertainty and Progressive Adaptation", three categories, and 16 sub-categories that illuminate the experiences of parents navigating the diagnostic journey of autism spectrum disorder (ASD) in their children (Table 2). The categories are: [1] Diagnostic Process Challenges [2], Emotional Trajectory of Parents During Diagnosis, and [3] The phases of Parental Response from initial symptom recognition through post-diagnostic adaptation. Each category encompasses several subcategories, supported by illustrative excerpts from participants' narratives.

The analysis revealed recurring patterns in parental accounts, often influenced by limited access to specialized services in Yazd, Iran, and cultural factors such as family expectations and societal perceptions of disability. These patterns highlight the multifaceted barriers and emotional burdens faced by families, with many parents describing a prolonged and iterative process marked by uncertainty and adaptation.

Table 1 Demographic description of informants and their children with ASD ($n = 12$)

Participant ID	Parent Age (y)	Parent Sex	Parent Education	Parent Employment	Marital Status	Child Age (y)	Child Sex	ASD Severity	Number of children with ASD in each interviewed family	Total number of children in the interviewed family
P1	28	Female	Academic	Home duties	Married	4	Male	Moderate	1	1
P2	36	Female	Academic	Home duties	Married	3	Male	Moderate	1	3
P3	29	Female	Academic	Home duties	Married	5	Male	Severe	1	1
P4	42	Male	12th grade	Retired	Married	6	Male	Severe	1	4
P5	37	Male	Academic	Bank clerk	Married	3	Male	Mild	1	1
P6	32	Female	12th grade	Home duties	Married	6	Male	Moderate	1	1
P7	42	Female	Academic	Tailor	Married	4	Male	Moderate	2	3
P8	32	Female	Academic	Home duties	Married	5	Male	Moderate	2	2
P9	36	Male	Academic	Teacher	Married	3	Male	Moderate	1	1
P10	33	Female	Academic	Nurse	Married	4	Male	Moderate	1	1
P11	31	Female	Academic	Technician	Married	5	Female	Mild	1	1
P12	38	Female	Academic	Home duties	Married	4	Female	Mild	1	2

Note: Child denotes the child with ASD from the interviewed family. y = years; n = number; ASD = Autism Spectrum Disorder

Table 2 Theme, categories, sub-categories, codes, meaning units, and examples of quotes from the analysis of parents' experiences in the ASD diagnostic process

Theme	Categories	Sub-categories	Codes	Meaning units	Raw quotes (Example)
The Parental Journey Through Autism Diagnosis Amid Uncertainty and Progressive Adaptation	**Diagnostic Process Challenges**	Delayed Diagnosis	Late diagnosis, missed early intervention, prolonged uncertainty.	Parents experienced long delays in receiving a clear diagnosis despite repeated consultations.	"We went from one clinic to another for months, but no one gave us a clear answer." (P6)
		Inconsistent Expert Opinions	Different diagnoses from specialists, confusion from multiple opinions	Parents received contradictory diagnostic opinions, creating confusion and mistrust.	"One doctor said ADHD, another mentioned autism. We didn't know which one to believe." (P3)
		Fluctuating Diagnostic Conclusions	Conflicting conclusions, unclear diagnostic outcomes	The diagnostic label kept changing, increasing parental uncertainty.	"Each visit came with a new conclusion, and nothing was definitive." (P9)
		Overlap with Other Comorbidities	Misdiagnosis with ADHD, developmental delay, and ineffective treatments	ASD symptoms were mistaken for other conditions, delaying intervention.	"They treated him for speech delay for a whole year before autism was even considered." (P11)
	Emotional Trajectory of Parents During Diagnosis	Ambiguity and Confusion	Unclear causes, lack of understanding	Parents struggled to understand their child's behaviors and searched for explanations.	"We kept wondering what was wrong and why our child acted differently." (P2)
		Contradictory Emotions and Emotional Fluctuations	Hopefulness vs. despair, emotional instability	Parents fluctuated between hope and hopelessness.	"Some days I thought everything would be okay, and other days I felt completely hopeless." (P7)
		Difficulties in Social Interactions	Social stigma, avoiding social situations, and hiding the child	Families withdrew from social gatherings to avoid judgment.	"I stopped going to family gatherings because people kept asking hurtful questions." (P4)
		Disruption of Daily Life	Time-consuming therapies, caregiving burden, and daily life interruptions	Therapy schedules and caregiving responsibilities disrupted daily routines.	"Our whole routine changed because most of our time went into therapy sessions." (P10)
		The Meaning of Autism for Parents	Negative perceptions, hardship, and distress	Autism was initially perceived as a major crisis and the end of hopes for the child	"At first, autism felt like the end of all the dreams we had for our child." (P1)
	The phases of Parental Response from initial symptom recognition through post-diagnostic adaptation	1. Recognizing the Child's Symptoms	Identifying abnormal behaviors, early recognition	Parents noticed early developmental signs that led to concern and seeking help	"I realized he didn't respond to his name and avoided eye contact." (P8)
		2. Denial and Shock	Emotional numbness, shock, disbelief at diagnosis	Parents initially rejected or struggled to accept the reality of the diagnosis.	"When the doctor said autism, I felt completely numb." (P5)
		3. Anger and Frustration	Frustration with the diagnostic process, lack of clarity	Parents felt anger due to unclear explanations.	"I was angry because no one explained things clearly." (P8)
		4. Bargaining and Resistance to Medical Advice and Treatment	Initial disbelief, rejecting medical advice	Parents initially refused medical recommendations; some turned to religious practices instead of seeking further medical help.	"At first we didn't accept the diagnosis and rejected some of the advice….We focused on Quran sessions and prayers instead of going back to the doctor" (P3)
		5. Emotional Reactions and Depression	Feelings of hopelessness, suicidal thoughts, and emotional breakdown	Diagnosis triggered severe emotional suffering for some parents.	"There were days I felt so hopeless I didn't know how to continue." (P12)
		6. Social Isolation	Withdrawal from social circles, cutting off from family and friends	Families isolated themselves due to stigma, judgment, and emotional exhaustion	"We gradually stopped meeting even close relatives." (P6)
		7. Efforts to Accept and Adapt	Gradual acceptance, coping mechanisms, and seeking improvement for the child	Parents slowly moved toward acceptance and child-focused adaptation.	"Over time we tried to accept the situation and focus on helping him grow." (P9)

Main theme: the parental journey through autism diagnosis amid uncertainty and progressive adaptation

First category. Diagnostic process challenges

Parents described facing multiple barriers during the diagnostic journey, including confusion, misdiagnoses, and delays in receiving a definitive diagnosis. This category captures the systemic and interpersonal obstacles that prolonged the process, often exacerbating parental stress and delaying access to interventions. The subcategories reflect a cascade of challenges, where initial delays led to inconsistent opinions and overlapping diagnoses, creating a cycle of frustration and repeated consultations.

Delayed diagnosis

Numerous parents ($n=11$) reported significant delays in obtaining a formal ASD diagnosis, which typically spanned from initial symptom recognition to confirmation, lasting several months to years. These delays were attributed to limited availability of diagnostic centers in Yazd, reliance on general practitioners for initial referrals, and a lack of awareness about ASD symptoms among primary care providers. Parents emphasized how these postponements resulted in missed opportunities for early intervention, heightened emotional distress, and increased financial burdens from repeated visits. "*If I had known from the beginning it was autism*, *I would have taken my child to a center earlier and saved us stress and lost time*" (Participant 3).

Another parent highlighted the emotional toll: "*We waited for months for an appointment*, *and during that time*, *my child's behavior worsened*, *leaving us feeling helpless and isolated*" (Participant 7). This subcategory underscores how delays not only affected the child's progress but also strained family dynamics, with parents often juggling work and caregiving responsibilities amid uncertainty.

Inconsistent expert opinions

Contradictory assessments by different professionals—psychiatrists, psychologists, and neurologists—amplified parental frustration and eroded trust in the healthcare system ($n=10$). Parents recounted consulting multiple specialists, sometimes traveling to larger cities like Tehran, only to receive varying interpretations of their child's symptoms. This inconsistency stemmed from differences in diagnostic criteria application and limited interdisciplinary collaboration.

> *"None of the doctors gave a clear cause… I visited neurologists, psychiatrists, and even doctors in Tehran, but no one could give me a definitive answer" (Participant 5). Another parent described the confusion: "One specialist said it was just a speech delay, another mentioned possible neurological issues, but nothing aligned, making us question everything"* (Participant 11). *Such discrepancies often led to repeated testing and emotional exhaustion, particularly for mothers who were primary caregivers, as seen in demographic patterns from* Table 1*, where most female participants reported higher involvement in seeking care.*

Fluctuating diagnostic conclusions

Many parents ($n=9$) noted that diagnoses varied significantly over time and between professionals, resulting in uncertainty and a sense of instability. Initial provisional diagnoses would shift upon follow-up, influenced by evolving child behaviors or new assessments, leaving parents in a state of limbo. "*Every professional had a different opinion. There was no certainty*" (Participant 2).

For example, one parent shared: "*At first*, *it was labeled as a mild delay*, *but later it became autism with comorbidities*, *and we had to start over with therapies*" (Participant 8). This fluctuation was particularly pronounced in

families with limited educational resources (as per Table 1), who struggled to navigate conflicting information without adequate guidance.

Overlap autism with other comorbidities

Several cases ($n=6$) involved overlapping symptoms with other conditions, such as attention deficit hyperactivity disorder (ADHD) or developmental delays, further complicating the diagnostic process and leading to initial misdiagnoses. Parents described ineffective treatments prescribed for presumed comorbidities, which delayed ASD-specific interventions. "*One said it was hyperactivity*, *another said developmental delay… nothing helped*, *and my child got worse*" (Participant 9). Another account illustrated the diagnostic maze: "*We treated ADHD first*, *but the symptoms persisted*, *and only after seeing a third specialist did autism emerge as the core issue*" (Participant 4). This subcategory highlights how symptom overlap, combined with limited diagnostic tools in local centers, prolonged the journey and intensified parental doubt.

Second category emotional trajectory of parents during diagnosis

Parents experienced a sequence of emotional responses in their journey toward understanding and accepting the diagnosis. These reactions appeared to follow a recurring emotional cycle, intertwined with daily life disruptions and cultural pressures. The diagnostic journey elicited a range of emotional responses from parents, characterized by feelings of confusion, distress, and helplessn**ess**. Five subcategories were identified, revealing how emotions evolved dynamically, often amplifying one another in a non-linear fashion.

Ambiguity and confusion

Many parents ($n=8$) struggled to understand the cause of their child's condition, leading to confusion and cognitive dissonance. This ambiguity arose from unclear explanations by professionals and a lack of accessible information on ASD in Persian resources. "We couldn't figure out the cause of the illness." (Participant 5). "*I saw that my child didn't respond to his name being called*, *but I didn't recognize it as a disease*" (Participant 1). Parents described persistent questioning: "*Why our child? Was it something we did during pregnancy or genetics? No one could explain*" (Participant 10).

Contradictory emotions and emotional fluctuations

Parents often experienced fluctuating emotions ($n=3$), ranging from hopefulness to despair.

"It's been two years, and it's been very stressful… It's exhausting and overwhelming." (Participant 6).

One parent elaborated: "*One day I'd feel hopeful after a good therapy session*, *but the next*, *despair would hit when symptoms returned*" (Participant 12).

Difficulties in social interactions

Parents frequently experienced severe social friction and embarrassment ($n=4$) due to unpredictable child behaviors in public settings and the lack of community awareness regarding ASD. This often led to feelings of scrutiny, judgment, and eventual social withdrawal. As one mother explained:

> *"Whenever we went to family gatherings or public places, my child would scream or cover his ears. Relatives would stare at us with judgmental looks, whispering that we had failed to discipline him properly. It became so humiliating and exhausting that we gradually cut off ties with our relatives and stopped going out altogether."* (Participant 8).

Disruption of daily life

The demands of caregiving and therapy led to significant disruptions in daily life, particularly for mothers ($n=4$). "The classes and therapies take up so much time." (Participant 6). Parents reported altered routines: "Work, household chores, and sibling care all suffered; it felt like our whole life revolved around appointments." (Participant 5).

The meaning of autism for parents

Some parents expressed (n = 7) extreme emotional distress related to the diagnosis, perceiving ASD as a profound hardship that redefined family identity. *"... Sometimes, I just wish he wasn't here. Life would be so much easier*" (Participant 9). Another reflected: "Autism meant endless worry and loss of dreams for our child's future" (Participant 3).

Third category. The phases of parental response from initial symptom recognition through post-diagnostic adaptation

The parental journey following initial symptom recognition through post-diagnostic adaptation was characterized by a multi-phase, dynamic trajectory progressing from initial symptom recognition to gradual adaptation and acceptance. Rather than representing a rigid, universal linear sequence through which every parent uniformly progressed, this trajectory reflects a composite, dynamic, and often recursive pathway. While the overarching temporal flow typically moved from initial awareness to emotional turmoil and eventual coping, participants exhibited individualized pathways: some parents bypassed specific phases, experienced overlapping reactions, or oscillated recursively between phases depending on personal resilience, spiritual beliefs, and family dynamics. Table 3 summarizes the individual-level pathways across the 12 participants, detailing which phases were endorsed and their chronological progression within individual narratives. Also, Fig. 1 presents the predominant temporal flow of these phases; as detailed in Table 3, individual participants traversed this trajectory in

Table 3 Individual participant trajectories and reported phases across the diagnostic journey ($N=12$)

Participant	S1: Symptom recognition	S2: Denial & shock	S3: Anger & frustration	S4: Bargaining & resistance to medical advice and treatment	S5: Emotional distress / depression	S6: Social isolation	S7: Acceptance & adaptation	Individual trajectory pattern
P1	✓ (1)	✓ (2)	—	✓ (3)	✓ (4)	—	✓ (5)	S1 → S2 → S4 → S5 → S7
P2	✓ (1)	✓ (2)	✓ (3)	—	✓ (4)	✓ (5)	✓ (6)	S1 → S2 → S3 → S5 → S6 → S7
P3	✓ (1)	✓ (2)	✓ (3)	✓ (4)	✓ (5)	—	✓ (6)	S1 → S2 → S3 → S4 → S5 → S7
P4	✓ (1)	✓ (2)	✓ (3)	—	✓ (4)	—	✓ (5)	S1 → S2 → S3 → S5 → S7
P5	✓ (1)	—	✓ (2)	✓ (3)	—	✓ (4)	✓ (5)	S1 → S3 → S4 → S6 → S7
P6	✓ (1)	✓ (2)	—	✓ (3)	✓ (4)	—	✓ (5)	S1 → S2 → S4 → S5 → S7
P7	✓ (1)	✓ (2)	✓ (3)	✓ (4)	✓ (5)	✓ (6)	✓ (7)	S1 → S2 → S3 → S4 → S5 → S6 → S7 (Full sequence)
P8	✓ (1)	✓ (2)	—	✓ (3)	—	✓ (4)	✓ (5)	S1 → S2 → S4 → S6 → S7
P9	✓ (1)	✓ (2)	✓ (3)	—	✓ (4)	—	✓ (5)	S1 → S2 → S3 → S5 → S7
P10	✓ (1)	—	✓ (2)	✓ (3)	✓ (4)	—	✓ (5)	S1 → S3 → S4 → S5 → S7
P11	✓ (1)	✓ (2)	—	—	✓ (3)	✓ (4)	—	S1 → S2 → S5 → S6 (Ongoing adaptation)
P12	✓ (1)	✓ (2)	—	✓ (3)	✓ (4)	—	✓ (5)	S1 → S2 → S4 → S5 → S7
Total (n)	**12**	**10**	**7**	**8**	**9**	**5**	**11**	*Numbers in parentheses indicate chronological sequence reported in narrative.*

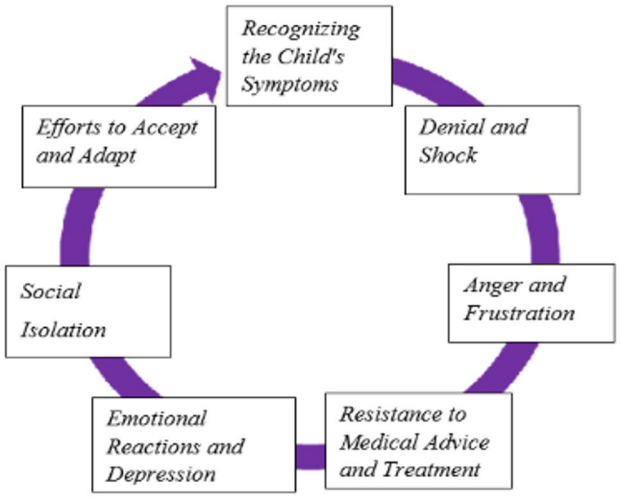


Fig. 1 The phases of Parental Response, from initial symptom recognition through post-diagnostic adaptation. *NOTE:The circular arrangement depicts the predominant temporal flow of phases identified across participants' narratives, not a fixed or invariant sequence. Individual pathways varied considerably (see Table 3): some parents bypassed specific phases, experienced overlapping reactions, or oscillated recursively between phases (e.g., returning from adaptation to anger or isolation). The trajectory should therefore be interpreted as a composite, culturally grounded mapping of the collective experience rather than a prescriptive, stage-by-stage progression that every family uniformly follows*

heterogeneous ways, with phases being skipped, merged, or revisited. Across the entire dataset, seven distinct phases were identified:

Phase 1: recognizing the child's symptoms

Parents typically begin noticing unusual behaviors in their children at a young age, often before or during early childhood ($n = 12$). "*I noticed my child's abnormal behavior when he was one year old*" (Participant 1). This recognition often started subtly, like delayed milestones, prompting initial concern without full awareness.

Phase 2: denial and shock

The diagnosis often induced shock and disbelief ($n = 10$), with many parents initially unable to accept the reality of the situation. "*When we first received the diagnosis, I was completely shocked. It felt like something unknown had suddenly attacked our lives*" (Participant 3). Shock manifested as emotional numbness, delaying engagement with services.

Phase 3: anger and frustration

After the initial shock, many parents expressed anger and frustration ($n = 7$), particularly due to the perceived lack of support and clarity. " *We were really angry about it after finally understanding what had happened*" (Participant 4). Anger targeted the system or fate, fueling advocacy efforts.

Phase 4: bargaining and resistance to medical advice and treatment

Resistance to treatment and medical advice was common ($n=8$) during this phase, with some parents doubting the accuracy of the diagnosis. "At first, I resisted. I thought the specialists were wrong." (Participant 6). This phase involved seeking second opinions and delaying interventions.

Parents even sought prayer, vows, and spiritual interpretations in hopes of improving their child's condition, and they resisted or refrained from following the therapist's recommendations. According to one parent, *"My spouse said that if we sacrifice a sheep, the child will get better and there will be no need for a therapist "* (Participant 1).

Religious and spiritual beliefs also supported some parents during the later process of adaptation. For some participants ($n=3$), spiritual interpretations of their child's condition provided a framework for meaning-making and acceptance, helping them reinterpret the diagnosis in a less self-blaming and more manageable way. For example, one of Fathers said: " Maybe God has loved me to give me this child. He wants to reward me in this world and the next world if I keep and raise this child. I can accept and continue this situation better."

Phase 5: emotional reactions and depression

As parents processed the diagnosis, feelings of hopelessness, depression, and even suicidal thoughts emerged ($n=9$). "*I sometimes wish my child didn't exist… it would be easier*" (Participant 4). Suicidal thoughts were mentioned by some, highlighting severe distress.

Phase 6: social isolation

Fear of judgment and stigma led to social isolation ($n=5$), with many parents cutting off contact with extended family and friends. "*We've completely cut off from everyone because of this child*" (Participant 8). This withdrawal protected families but increased loneliness.

Phase 7: efforts to accept and adapt

Over time, parents began to accept the diagnosis and adapt ($n=11$) their lives accordingly, seeking to improve their child's condition. "*We've accepted it… It's a kind of growth and progress*" (Participant 12). Adaptation involved seeking support and focusing on the child's improvement.

Discussion

This study aimed to explore the experiences of parents during the diagnostic process of autism spectrum disorder (ASD) in their children aged six years and under. The analysis identified three main categories: [1] Challenges in the diagnostic pathway [2], Emotional experiences during the diagnostic process, and [3] The trajectory of parental response from denial to acceptance. Each is discussed below, followed by an integrative conclusion.

Diagnostic process challenges

Parents encountered numerous obstacles, including delays in referrals, inconsistencies among health professionals, and a lack of clear guidance. These challenges align with findings from earlier studies [13, 28, 29]; however, in this context, they were exacerbated by the limited local diagnostic resources and less coordinated services in semi-urban areas like Yazd. Unlike settings with well-established early intervention pathways, participants here described navigating a fragmented healthcare system, often relying on informal networks and personal initiative.

This aligns with findings from other Middle Eastern and Asian contexts [30], where systemic barriers such as limited access to specialists and fragmented care exacerbate diagnostic delays, as seen in Saudi Arabia [31] and India [32]. This difference underscores the structural inequities in access to ASD diagnosis and care, and disparities in service utilization.

Adding a theoretical perspective, these systemic barriers are also consistent with principles of Family Systems Theory, which posits that disruptions in one part of a service or familial system reverberate across the entire family unit [16]. In our study, fragmented diagnostic pathways and inconsistent communication from professionals appeared to strain familial functioning, decision-making, and emotional stability, reinforcing the systemic nature of the challenges reported by parents.

Parental emotional trajectory during diagnostic process

The emotional journey was marked by confusion, anxiety, sadness, and isolation, consistent with qualitative studies in various cultural contexts [33, 34]. However, in our study, stigma emerged as a dominant intensifier of these emotions. Parents described feelings of shame and fear of social judgment, which sometimes contributed to social withdrawal. Similar emotional reactions have been reported globally; however, cultural interpretations of disability and the availability of social and psychosocial support may influence how these experiences are expressed and managed across contexts. For instance, Samadi et al. [10] found that Iranian parents often experience heightened emotional distress due to cultural stigma associating disability with family shame, while Furrukh et al. [35] reported similar patterns of social isolation among Pakistani mothers due to societal misconceptions or lack of social support about ASD. The interplay between high stigma and low psychosocial support appears to amplify parental emotional distress in traditional communities.

Our findings also build upon and extend previous qualitative literature on ASD in Iran, such as the work by Khougar et al. (2019) [36]. While Khougar and colleagues explored the broad sociological phenomenon of 'social suffering' among Iranian parents—highlighting diagnostic confusion, inconsistent professional opinions, and public unawareness—the present study advances this knowledge in several key ways. Rather than capturing static themes of suffering, our study delineates a dynamic, a seven-phase composite trajectory that maps how Iranian parents process the diagnostic journey from initial symptom recognition to ultimate adaptation. Furthermore, our findings unpack culture-specific mechanisms embedded within this trajectory, such as religious and spiritual bargaining (e.g., vows, sacrificial offerings, and spiritual interpretations) as well as active resistance to early therapeutic recommendations—nuances that were not explicitly conceptualized as developmental stages in earlier Iranian studies [10, 36].

The role of religion and spirituality in parents' coping appeared to be multidimensional rather than uniformly facilitating or obstructive. During the earlier phase of bargaining and resistance to medical advice and treatment, some parents described religious practices, such as vows or sacrificial rituals, as attempts to negotiate with or make sense of the diagnosis, which in some cases was associated with delayed engagement with professional treatment. However, participants' narratives also suggested that religious and spiritual beliefs could serve a different function during later adaptation. For some parents, spiritual interpretations of the child's condition provided a framework for meaning-making and acceptance, helping them reinterpret the diagnosis and sustain their capacity to cope with long-term caregiving. Thus, spirituality may function differently across the trajectory: initially as a form of bargaining or resistance for some parents, and later as a source of meaning and acceptance for others. Importantly, these patterns should not be interpreted as a universal or sequential progression experienced by all parents, but rather as context-dependent coping responses that varied across individual trajectories.

These emotional patterns also resonate with the appraisal component of Coping Theory, where parents' interpretations of ambiguous information, uncertainty, and stigma shape the intensity and direction of their emotional responses [15]. In this context, limited information and cultural stigma appeared to amplify negative appraisals, contributing to heightened stress reactions.

The phases of Parental Response from initial symptom recognition through post-diagnostic adaptation

A notable finding of this study is the culturally contextualized trajectory parents navigated after the diagnosis (Table 3 and Fig. 1). While classical models of grief and adaptation—such as Kübler-Ross's framework [37]—often depict emotional transitions in chronic conditions [38], our findings capture how this process unfolds within the Iranian socio-cultural milieu. Rather than a strictly uniform or linear march, parents' journeys were dynamic, iterative, and recursive, characterized by initial symptom recognition, denial and shock, anger, culturally grounded resistance and bargaining, resistance to medical advice and Treatment, intense emotional distress/depression, social withdrawal, and eventual adaptation.

Importantly, our individual-level analysis (Table 3) demonstrates that while the overarching arc progresses from distress toward adaptation, not every parent traversed all seven phases linearly. For instance, resistance to medical advice (phase 4) was heavily intertwined with spiritual interpretations and vows (e.g., seeking alternative religious healing or sacrifices), while social isolation (phase 6) emerged primarily in response to profound external social stigma. This demonstrates that parental adaptation in this setting is a fluid, culturally responsive process rather than a static sequential continuum.

However, it extends these by highlighting culture-specific responses such as resistance to medical advice and social withdrawal due to stigma, elements less emphasized in Western models. This finding resonates with Zhou et al. (2022) (16), who noted culturally driven coping mechanisms among Chinese parents, such as initial denial followed by community-based adaptation, and Alsehemi et al. (2022), who identified spiritual questioning as a prominent response among Saudi parents [39]. This culturally grounded perspective offers a more contextualized understanding of how Iranian parents emotionally process an autism diagnosis, contributing to the discourse on family adaptation in similar cultural settings [9].

Furthermore, content analysis revealed that this seven-phase composite framework serves not as a rigid temporal model, but as a dynamic heuristic that aligns with the stress and coping framework [40], as parents' emotional and behavioral responses reflect processes of appraisal, coping, and adaptation to the stress of an ASD diagnosis [41]. This alignment appears to strengthen the validity of our findings, as it situates the parental response within an established theoretical model.

From a theoretical standpoint, this conceptual model reflects both individual coping processes and broader family dynamics. Consistent with Coping Theory, parents moved through phases of appraisal, emotional regulation, and adaptive problem-solving as they navigated the diagnosis. At the same time, elements of Family Systems Theory were evident in how parental responses were shaped by intra-family dynamics, social expectations, and the ripple effects of diagnostic uncertainty on marital, parental, and extended-family interactions [15, 16]. This dual-lens interpretation offers a more comprehensive understanding of how families in culturally traditional settings respond to an ASD diagnosis.

Limitations

While this study provides valuable insights into the experiences of Iranian parents during the ASD diagnostic process, several limitations should be acknowledged. First, the sample was recruited via purposive sampling from two autism centers in Yazd, Iran, which may limit the transferability of findings to other regions or populations with different socioeconomic or cultural backgrounds. However, maximum variation in participant demographics (age, gender, education, and occupation) was pursued to enhance diversity, and data saturation was achieved to ensure comprehensive coverage of the theme and categories.

Second, the reliance on self-reported interviews introduces the potential limitations inherent in narrative reconstruction, as parents reflected on past experiences. To mitigate this, interviews were conducted soon after diagnosis (aged 6 years or younger), and trustworthiness was ensured through member checking and peer debriefing.

Third, although both mothers and fathers were recruited, the sample had an unequal gender distribution (nine mothers vs. three fathers). In the Iranian socio-cultural context, primary caregiving and daily accompaniment of children to therapeutic sessions predominantly fall upon mothers, which naturally facilitated their greater availability and willingness to participate. However, paternal coping styles, emotional processing (such as internalizing distress or cognitive avoidance), and social isolation mechanisms may differ substantially from maternal experiences. Therefore, the emotional trajectory and challenges documented here predominantly reflect the maternal narrative, and findings should be generalized to fathers with caution. Future research specifically exploring paternal emotional processing and gender-specific coping trajectories in autism caregiving is necessary.

Fourth, the qualitative nature of the study and its small sample size ($n = 12$) preclude statistical generalizability; however, the in-depth narratives align with Lincoln and Guba's criteria for rigor, providing a rich, contextualized understanding.

Fifth, while our findings offer a detailed trajectory of parental experiences, the retrospective design focuses on participants' narrative reconstructions of their diagnostic journey. As such, these findings reflect the parents' subjective framing of their past experiences rather than a real-time observation of emotional transitions. Consequently, while our seven-phase framework provides a robust heuristic for understanding these journeys, future research employing longitudinal designs could further illuminate the fluid, experiential dynamics of these transitions as they unfold over time.

Suggestions for future studies

Future research could expand on the findings of this qualitative study in several important ways. First, quantitative studies are needed to examine the prevalence, determinants, and predictors of parental stress, diagnostic delays, and service navigation challenges among families of children with ASD in different regions of Iran. Additionally, mixed-methods research could help triangulate qualitative insights with measurable outcomes, providing a richer understanding of parents' experiences during the diagnostic process. Also, future research should enlarge the sample and specifically target parents of younger children (aged < 4 years) closer to the time of symptom emergence and initial diagnosis to mitigate probable narrative reconstruction.

Longitudinal studies are also recommended to track changes in parental coping, service access, and child developmental outcomes over time. Further research should evaluate the feasibility and effectiveness of culturally adapted parent-support programs and community-based interventions, particularly in semi-urban and underserved areas. Finally, comparative studies across diverse sociocultural contexts within Iran may help identify structural and cultural factors influencing diagnostic pathways and family support needs.

Conclusion

Overall, the findings highlight several emotional and practical challenges experienced by Iranian parents during the ASD diagnostic process, pointing to areas where diagnostic practices and family support may benefit from further attention in similar sociocultural contexts.

A particularly pivotal contribution of this study is the identification of a culturally grounded, multi-phase pattern of parental emotional and behavioral responses, ranging from initial recognition of symptoms to denial, anger, spiritual questioning, resistance to medical advice, depression, social withdrawal, and eventual adjustment and acceptance. This sequential yet sometimes recursive pattern highlights the profound psychological burden parents face and the influence of cultural stigma, limited resources, and family support on their coping processes.

This category has important theoretical and clinical implications. While partially consistent with established grief and coping models, it extends them by illuminating culturally specific reactions such as resistance to diagnosis and stigma-driven social withdrawal. These findings emphasize the need for systematic mental-health

screening for parents, particularly mothers, and the development of structured, culturally sensitive counseling interventions following diagnosis.

The results suggest the potential value of developing culturally sensitive family support approaches and improving professional awareness of parental experiences during the diagnostic journey. In particular, the findings indicate that structured educational initiatives for healthcare professionals—such as child psychiatrists, psychologists, and pediatricians—focusing on communication skills, cultural competence, and clearer diagnostic pathways may help reduce parental confusion and uncertainty. Although causal inference is not feasible given the qualitative nature of this study, the findings may nonetheless offer sparks and initial insights that can illuminate future prospective quantitative research.

In addition, participants' accounts of delayed diagnosis and fragmented services highlight the possible benefits of improving access to specialized diagnostic services, particularly in semi-urban areas such as Yazd. Future research and health policy evaluations could further explore strategies for strengthening diagnostic pathways and service coordination.

Finally, given the emotional distress and social isolation reported by many parents, the development of community-based support initiatives, including parent support groups and counseling services, may represent a potentially valuable avenue for supporting families coping with ASD. However, further research is needed to evaluate the feasibility and effectiveness of such interventions within the Iranian cultural and healthcare context.

Abbreviations

ASD Autism Spectrum Disorder
ADHD Attention Deficit Hyperactivity Disorder

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Author contributions Fatemeh Doost Mohammadi (FDM) conceptualized and designed the study, conducted interviews, performed data analysis, and drafted the initial manuscript. Tahmineh Farajkhoda (TF) contributed to the study design, supervised data collection, and assisted in drafting and revising the manuscript. Mohammad Hassan Lotfi (MHL) conceptualized the study, supervised the research process, and was a major contributor to writing and revising the manuscript. Ali Dehghani (AD) participated in data analysis and interpretation and provided critical revisions to the manuscript. Hossein Fallahzadeh (HF) contributed to data analysis and interpretation and provided critical revisions to the manuscript. Tahereh Sadeghiyeh (TS) conducted interviews and contributed to the interpretation of qualitative findings. All authors (FDM, TF, MHL, AD, HF, TS) reviewed and approved the final manuscript.

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Data availability No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate This study was approved by the Ethics Committee of the School of Public Health, Shahid Sadoughi University of Medical Sciences, Yazd, Iran (Approval ID: IR.SSU.SPH.REC.1400.227). All participants were adult parents of children with ASD, and no minors (individuals under 16 years) were included as participants. Informed written consent to participate was obtained from all adult participants in accordance with the principles of the Declaration of Helsinki, ensuring confidentiality and voluntary participation.

Consent for publication Written informed consent for publication was obtained from all participants (parents of children with autism spectrum disorder) involved in this study. No person's identifiable data, such as names, images, or videos, is included in the manuscript. The consent forms are available from the corresponding author upon request.

Competing interests The authors declare no competing interests.

Declaration regarding the use of artificial intelligence (AI) during manuscript preparation.

AI tools were used only to assist with language editing, grammar, clarity, and formatting of the manuscript. No AI tool was used to collect or analyze qualitative data, generate codes or themes, interpret participants' accounts, or determine the study findings and conclusions. The authors remain fully responsible for the accuracy, originality, interpretation, and final content of the manuscript.

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References

1. World Health Organization. (2020). Autism spectrum disorders: Fact sheet. https://www.who.int/news-room/fact-sheets/detail/autism-spectr-disorders. [Last accessed: July 2025].
2. Chiarotti F, Venerosi A. Epidemiology of Autism Spectrum Disorders: A Review of Worldwide Prevalence Estimates Since 2014. Brain Sci. 2020;10(274):1–21. https://doi.org/10.3390/brainsci10050274.
3. Salari N, Rasoulpoor S, Rasoulpoor S, Shohaimi S, Mohammadi M. The global prevalence of autism spectrum disorder: a comprehensive systematic review and meta-analysis. Ital J Pediatr. 2022; 48: 112. https://doi.org/10.1186/s13052-022-01310-w.
4. Lotfi MH, Farajkhoda T, Doost-Mohammadi F, Dehghani A, Fallahzadeh H, Sadeghiyeh T. Parental and professional perspectives on prenatal psychosocial experiences perceived to be linked to autism spectrum disorder: a qualitative content analysis study. BMC Psychiatry. 2026;26(336):1–12. https://doi.org/10.1186/s12888-026-07872-x.
5. Ebadi M, Samadi SA, Mardani-Hamooleh M, Seyedfatemi N. Living under psychosocial pressure: Perception of mothers of children with autism spectrum disorders. J Child Adolesc Psychiatric Nurs. 2021;1–7. https://doi.org/10.1111/jcap.12310.
6. Ahmadi A, Sharifi E, Azizi Zalani H, Bolouk SH, Amrai K. The needs of iranian families of children with autism spectrum disorder, cross-cultural study. Procedia - Social Behav Sci. 2011;15(2011):321–6. https://doi.org/10.1016/j.sbspro.2011.03.094.
7. Hof Mvan, 't, Tisseur CH, Berckelear Onnes Ivan, Nieuwenhuyzen Avan, Daniels M, Deen A. Age at autism spectrum disorder diagnosis: A systematic review and meta-analysis from 2012 to 2019. Autism. 2020;0(0):1–12. https://doi.org/10.1177/1362361320971107.
8. Zwaigenbaum L, Bauman ML, Choueiri R, Kasari C, Carter A, Granpeesheh D, et al. Interventions for autism spectrum disorder in children under 3 years: a review. Pediatrics. 2014;134(3):147–52. https://doi.org/10.1542/peds.2014-3667E.
9. Younesi SJ. Understanding the experiences of parents in raising children with autism: A qualitative study. Iran Rehabilitation J. 2024;22(1):23–34.
10. Samadi SA. Parental Beliefs and Feelings about Autism Spectrum Disorder in Iran. Int J Environ Res Public Health. 2020;17:828. https://doi.org/10.3390/ijerph17030828.
11. Ghanadzadea M, Waltzb M, Ragi T. The intervention priorities of parents of children with autism spectrum disorders in Iran. Res Autism Spectr Disorders. 2018;55:14–28. https://doi.org/10.1016/j.rasd.2018.08.002.
12. Kim J, Kim H, Park S, Yoo J, Gelegjamts S. Mediating effects of family functioning on the relationship between care burden and family quality of life of caregivers of children with intellectual disabilities in Mongolia. J Appl Res Intellect Disabil. 2020;00:1–9. https://doi.org/10.1111/jar.12814.
13. Crane L, Chester JW, Goddard L, Henry LA, Hill EL. Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. Autism. 2016;20(2):153–62. https://doi.org/10.1177/1362361315573636.
14. Keenan M, Dillenburger K, Doherty A, Byrne§ T, Gallagher S. The Experiences of Parents During Diagnosis and Forward Planning for Children with Autism Spectrum Disorder. J Appl Res Intellect Disabil. 2010;23:390–7. https://doi.org/10.1111/j.1468-3148.2010.00555.x.
15. Lazarus RS, Folkman S. Stress, appraisal, and coping. New York: Springer Publishing Company; 1984. p. 444.

16. Thompson HM, Stevenson A, Cooley E, Cooley W. Family-based approach to the child welfare system: an integration of Bowen family theory concepts. J Family Social Work. 2019;21:1540–4072. https://doi.org/10.1080/10522158.2019.158477.
17. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. Qual Health Res. 2005;15(9):1277–88. https://doi.org/10.1177/1049732305276687.
18. Hennink MM, Kaiser BN, Marconi VC. Code saturation versus meaning saturation: how many interviews are enough? Qual Health Res. 2017;27(4):591–608. https://doi.org/10.1177/1049732316665344.
19. Centers for Disease Control and Prevention. (2025, April 18). Clinical testing and diagnosis for autism spectrum disorder. https://www.cdc.gov/autism/hcp/diagnosis/index.html. [Last accessed: May 2026].
20. Ellott J. Using Narrative in Social Research: Qualitative and Quantitative Approaches. London: SAGE; 2005.
21. Benedetto L, Cucinotta F, Maggio R, Germanò E, De Raco R, Alquino A. One-Year Follow-Up Diagnostic Stability of Autism Spectrum Disorder Diagnosis in a Clinical Sample of Children and Toddlers. Brain Sci. 2021;11(37):1–15. https://doi.org/10.3390/brainsci11010037
22. Creswell JW, Poth CN. Qualitative inquiry and research design: Choosing among five approaches (4th ed). Sage; 2018.
23. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: Concepts, procedures, and measures to achieve trustworthiness. Nurse Educ Today. 2004;24(2):105–12. https://doi.org/10.1016/j.nedt.2003.10.001
24. Lincoln YS, Guba EG. Naturalistic inquiry. Sage; 1985.
25. Guetterman TC, James TG. A software feature for mixed methods analysis: The MAXQDA Interactive Quote Matrix. Methods Psychol. 2023;8:100116. https://doi.org/10.1016/j.metip.2023.100116.
26. Elyssa BM, Luke S, Luke M. A Call for Radical Reflexivity in Counseling Qualitative Research. Counselor Educ Superv. 2021;60:164–72. https://doi.org/10.1002/ceas.12201.
27. Buus N, Perron A. The quality of quality criteria: Replicating the development of The Consolidated Criteria for Reporting Qualitative Research (COREQ). International Journal of Nursing Studies. 2019 (pre-proof). https://doi.org/10.1016/j.ijnurstu.2019.103452
28. Carlsson E, Miniscalco C, Kadesjö B, Laakso K. Negotiating knowledge: Parents' experience of the neuropsychiatric diagnostic process for children with autism. Int J Lang Communication Disorders. 2016;51(3):328–38. https://doi.org/10.1111/1460-6984.12206.
29. Makino A, Hartman L, King G, Ying Wong P, Penner M. Parent Experiences of Autism Spectrum Disorder Diagnosis: A Scoping Review. Rev J Autism Dev Disorders. 2021;8:267–84. https://doi.org/10.1007/s40489-021-00237-y.
30. Divan G, Vajaratkar V, Desai MU, Strik-Lievers L, Patel V. Challenges, coping strategies, and unmet needs of families with a child with autism spectrum disorder in Goa, India. Autism Res. 2012;5(3):190–200. https://doi.org/10.1002/aur.
31. Alnemary FM, Aldhalaan HM, Simon-Cereijido G, Alnemary FM. Services for children with autism in the Kingdom of Saudi Arabia. Autism. 2016;25:1–11. https://doi.org/10.1177/1362361316664868.
32. Bhavnani S, Lockwood Estrin G, Arora1 R, Kumar D, Kakra M, Vajaratkar V. I was Confused… and Still am Barriers Impacting the Help-Seeking Pathway for an Autism Diagnosis in Urban North India: A Mixed Methods Study. J Autism Dev Disord. 2021;21:1–15. https://doi.org/10.1007/s10803-021-05047-z.
33. Bonis S. Stress and parents of children with autism: A review of literature. Issues Ment Health Nurs. 2016;37:153–63. https://doi.org/10.3109/01612840.2015.1116030.
34. Romney J, Austin K, Fife T, Sander S, Snyder D. Stress Experienced and Meaning-Making of Couples with Children with Autism Spectrum Disorder: A Phenomenological Study. Am J Family Therapy. 2020;2(20):1–21. https://doi.org/10.1080/01926187.2020.1813654.
35. Furrukh J, Anjum G. Coping with autism spectrum disorder (ASD) in Pakistan: A phenomenology of mothers who have children with ASD. Cogent Psychol. 2020;7(1):1728108. https://doi.org/10.1080/23311908.2020.1728108.
36. Khougar A, Asgharnejad Farid AA, Ranjbar H, Lotfi M, Hakim Shoushtari M. Lived Experience of the Social Suffering of the Parents with Autism Spectrum Disorder (ASD) Child. Social Welf Q. 2019;19(72):243–82. https://doi.org/10.29252/refahj.19.72.243.
37. On Death and Dying. Kubler - Ross. Elisabeth: New York: The Macmillan Co.; 1969. p. 260.
38. Dutta O, Tan-Ho G, Ying Choo P, Hau Yan Ho A. Lived experience of a child's chronic illness and death: A qualitative systematic review of the parental bereavement trajectory. Death Stud. 2018;14(4):1–16. https://doi.org/10.1080/07481187.2018.1503621.
39. Alsehemi MA, Abousaadah MM, Sairafi RA, Jan MM. The impact of autism spectrum disorder on parents in Arab countries: A systematic literature review. Front Psychol. 2022;13:955442. https://doi.org/10.3389/fpsyg.2022.955442.
40. Rabba AS, Dissanayake C, Barbaro J. Parents' experiences of an early autism diagnosis: Insights into their needs. Res Autism Spectr Disorders. 2019;66:101415. https://doi.org/10.1016/j.rasd.2019.101415.
41. Boshoff K, Gibbs D, Phillips RL, Wiles L, Porter L. A meta-synthesis of how parents of children with autism describe their experience of advocating for their children during the process of diagnosis. Health Soc Care Commun. 2019;27(4):143–57. https://doi.org/10.1111/hsc.12691.
42 Desai MU, Divan G, Wertz FJ, Patel V. The discovery of autism: Indian parents' experiences of caring for their child with an autism spectrum disorder. Transcult Psychiatry. 2021;49(3–4):613–37. https://doi.org/10.1177/1363461512447139

43 Zhou T, Chen H, Zhang X. A qualitative study on the experience of stigma for Chinese parents of children with autism spectrum disorder. Sci Rep. 2022;12:19750. https://doi.org/10.1038/s41598-022-23978-0

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