



Lived Experiences of Iranian Parents of Children with Autism Spectrum Disorder: A Systematic Review

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(Received 06 Oct 2022; accepted 11 Dec 2022)

Abstract

Background: Autism is a lifelong condition that seriously affects many aspects of children's and families' lives. The experience attained by living with a child with autism can be a valuable source of information to provide support and satisfactory services to children with autism and their families. We aimed to investigate the lived experiences of Iranian parents of children with autism.

Methods: The search was conducted in PubMed, Web of Science, Embase, Google Scholar, CINAHL, PsychInfo, SID, and Magiran until Nov 2021. Two reviewers screened the articles, applied inclusion criteria, critically evaluated articles using the Critical Appraisal Skills Program (CASP), and extracted study details according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist. Thematic synthesis was used to analyze included studies.

Results: From 2772 articles in the initial search, sixteen studies entered the final analysis. Four themes emerged, including treatment-related lived experience, individual lived experience, social lived experience, and occupational lived experience. Iranian parents of children with autism are confronted with negative experiences, including inaccurate diagnostic processes, lack of adequate support at the diagnosis time, low-quality treatment, psychological problems, and concern about the child's future. Also, Parent's experiences showed family problems, stigma, and problems with doing occupations.

Conclusion: Practitioners, policy-makers, and regulatory organizations should urgently consider issues mentioned in the parents' experiences to provide proper healthcare services for children with autism and their families.

Keywords: Autism; Parents; Qualitative; Systematic review



Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder with a sharp increase in prevalence in the last two decades (1). Social, behavioral, cognitive, and sensory problems associated with ASD disrupt the lives of children and their parents and cause various physical, psychological, and social problems for their parents and families (2-4).

The parents' experiences of children with ASD have been studied in different countries, especially in Western countries. These studies were conducted in different countries based on the assumption that culture can affect parents' experiences (5). It also has because each country has its specific structure in providing healthcare, educational, and social services (4). Findings from these studies showed the similarities as well as differences between the experiences of parents of children with ASD in different countries and cultures. Search for an accurate diagnosis, time-consuming referral processes, leaving the job, conflicts in marital relationships, and stigma are common negative experiences of parents of children with ASD reported in studies from different countries (4-8). However, some studies reported the greatest discrepancies compared to international findings, such as different parental coping strategies reported by the parent of children with ASD in Eastern European countries that showed these parents used less avoidance-oriented strategies (9). Also, parents in Arab countries are confronted with more financial problems related to caring for a child with ASD and have more limited access to health, education, and social services compared to US parents (10).

Family-centered healthcare services that meet and support the needs of the entire family have ensured the well-being and quality of life in families of children with ASD (11). The experience gained by living with a child with autism can be a valuable source of information, so service providers should hear parents' voices (12). Incorporating the child's, parent's, and family's needs in interventions will promote well-being and family life

satisfaction (13). In other words, people's lived experiences are most valuable in planning preventive, treatment, and educational programs (14).

Attention to the lived experiences of parents of children with ASD in studies conducted in Iran has increased in recent years; this study aimed to investigate the lived experiences of Iranian parents with children with ASD.

Methods

Search Strategy

A comprehensive search was conducted in PubMed, Web of Science, Embase, Google Scholar, CINAHL, PsychInfo, and Scopus. Moreover, we searched SID and Magiran for articles in the Persian language. Searches in these databases was conducted from their inception until 1 November 2021. An initial search was carried out in PubMed using five concepts derived from the research question: (Autism OR autistic OR "autism spectrum disorder" OR "autistic disorder") AND (child) AND (Parent OR mother OR father OR caregiver OR family OR families) AND ("lived experience" OR "personal experience" OR experience OR perception OR perspective OR attitude OR feeling) AND ("qualitative research" OR "qualitative study" OR qualitative OR "mixed method" OR phenomenology OR "grounded theory" OR ethnography OR interview OR narration OR "focus group") AND (Iran). Keywords and combinations were further refined to optimize the search results from each database.

Study Selection and Eligibility

Two reviewers (EJ and EH) independently screened the records and applied inclusion criteria for them. These criteria included: (a) peer-reviewed articles, (b) articles in Persian or English language, (c) primary studies that use qualitative methods, (d) mixed-method studies in which qualitative information about parents of children

with autism is separately expressed and can be extracted, (e) studies conducted on Iranian parents residing in Iran. Any disagreement was resolved by discussion and consensus between two reviewers (EJ and EH) and another author of this article (corresponding author).

Quality Appraisal

Using the Critical Appraisal Skills Program (CASP) (15), two reviewers (EJ and EH) independently evaluated qualitative studies meeting the selection criteria.

Data Extraction

Two reviewers (EJ and EH) used the PRISMA checklist to extract details and descriptive data for each study (16). Information extracted from the articles includes the author's name, publication year, sample characteristics, methodologies, contexts, and themes (Table 1).

Data Synthesis

Our approach for thematic synthesis in this study was Thomas and Harden's approach (17). Initially, one author (EJ) used MAXQDA software to code and organize line-by-line data from the "Results" or "Findings" and "Discussion" sections of each study. This process was iterative; when a new code was recognized, the author reviewed previous studies' findings and recoded them as

appropriate. The author could make connections between studies and translate concepts through this process. Finally, the author reviewed the coded data line by line for consistency. Codes grouping and developing descriptive themes were conducted through discussion with other authors. Authors then go beyond the findings of these primary studies and develop analytical themes.

Protocol and Registration

The protocol of this study has been registered with PROSPERO (registration number: CRD42021285494; available at https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42021285494).

Results

Search Results

The total search results were 2772 articles. After excluding duplicates and screening titles and abstracts, 29 potentially eligible articles were identified. Twelve articles were excluded because (a) Not existed separate data for parents of children with ASD, (b) Participants were not parents, and (c) Not match to aims of our research. Finally, 17 articles were included for the quality appraisal (Fig. 1).

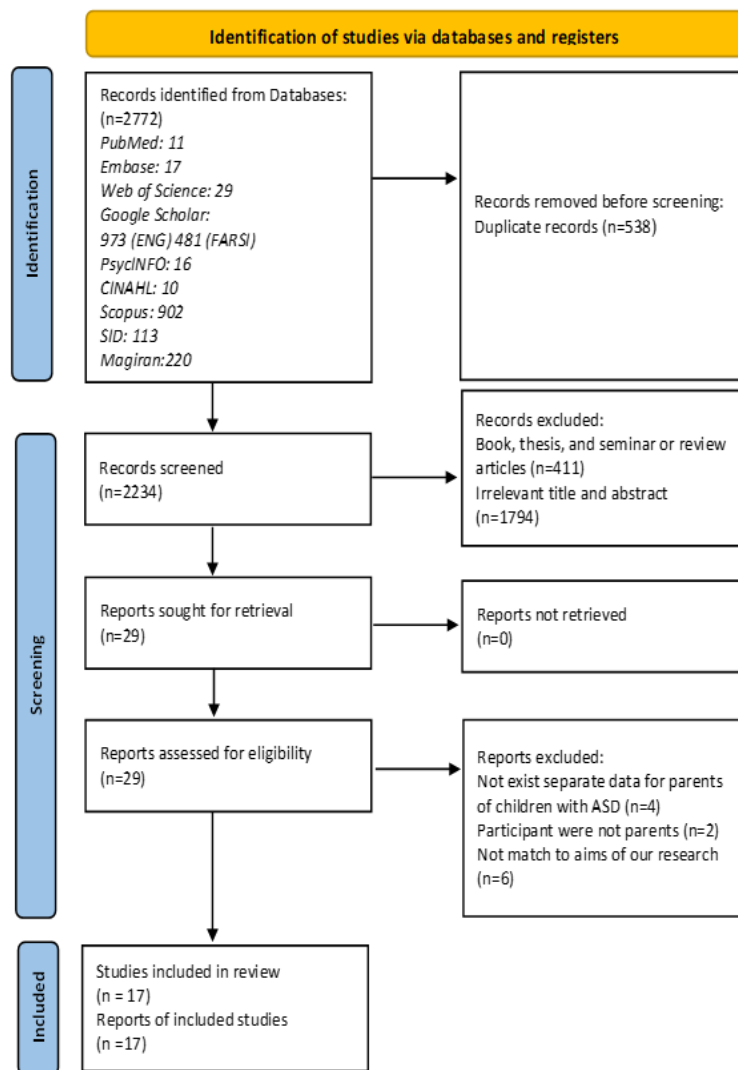


Fig. 1: PRISMA (2020) flow diagram for the study selection process

Quality Appraisal Results

Fifteen studies were of high quality, and all received ‘yes’ answers for 8 to 10 of the CASP checklist questions. Two articles (20 and article titled “The impact on Iranian mothers and fathers who have children with an autism spectrum disorder” by Samadi and McConkey) received lower scores than the other. So, the authors discussed these two articles. One of them (reference no. 20) was preserved because of its' highly relevant and valuable information and acceptable methodology. Another study was dropped due to

serious methodological issues. The CASP score for each study is presented in Table 1.

Characteristics of Included Studies

Sixteen articles entered the final analysis phase. These studies were conducted between 2008 and 2021 (75% for the last four years). In all studies, 306 people participated, 74% were mothers, and 26% were fathers. Also, in seven studies (44%, 14, 20, 22, 25, 26, 29, 31), participants were only mothers. Nine studies (56%, 14, 18, 19, 20, 22, 24, 26, 28, 29) were conducted in Tehran (Iran’s capital) (Table 1).

Table 1: Characteristics of selected studies

Author (Yr-Ref)	City	Methods <i>Participant characteristics</i> <i>Study design</i> <i>Data gathering</i> <i>Data analysis</i>	Key findings/themes	CASP score
Zarafshan (2019) (14)	Tehran	<ul style="list-style-type: none"> • N=10 10 mothers Parents' mean age: 36.3 (24-46) Children's mean age: 91.7 months 5 boys; 5 girls • Qualitative • Semi-structured interview • Framework approach 	<p>Based on parents' perspectives, several barriers exist in provided health and social services in Iran, including four domains:</p> <ul style="list-style-type: none"> • Early diagnosis • Service use and availability • Impact on the family • Supports 	8
Samadi (2020) (18)	Tehran	<ul style="list-style-type: none"> • N=43 27 mothers; 16 fathers Children mean age: 8.2 years (3-17) • Mixed-method • Interview • Thematic analysis 	<p>Iranian parents had their special justification regarding their experience with ASD, including about:</p> <ul style="list-style-type: none"> • The way that parents describe their child's problem • First signs which made parents concerned about their child • Change in parental expectations after the diagnosis 	9
Khougar (2019) (19)	Tehran	<ul style="list-style-type: none"> • N=13 9 mothers; 4 fathers Parents' mean age: 39 (29-63) Children's mean age: 8.5 years (5-12) 11 boys; 2 girls • Qualitative • Semi-structured interview • Thematic analysis 	<p>Challenges caused by ASD are categorized into five main themes:</p> <ul style="list-style-type: none"> • Diagnosis process • Parents' everyday problems • Family's presence in the community • Support services • Financial problems 	8
Chimeh (2008) (20)	Tehran	<ul style="list-style-type: none"> • N=13 13 mothers • Phenomenological • interview • Content analysis 	<p>Parents experienced problems such as:</p> <ul style="list-style-type: none"> • Denial, anger, and depression at the diagnosing time • Lack of proper support from the diagnostician • Labeling the child • Social relations restriction 	6
Shahrokhi (2021) (21)	Tabriz	<ul style="list-style-type: none"> • N=32 12 mothers; 20 fathers Parents' mean age: 39.5 Children's mean age: 7.5 years 	<p>There are several challenges in the implementation of autism screening programs and providing healthcare services in Iran:</p> <ul style="list-style-type: none"> • Shortcoming of ASD screening tools • Weakness of the health system 	9

Abazari (2017) (22)	Tehran	<p>25 boys; 7 girls</p> <ul style="list-style-type: none"> • Qualitative • Interview & focus group • Content analysis <p>N=10 10 mothers Parents' mean age: 33</p> <ul style="list-style-type: none"> • Mixed-method • Semi-structured interview • Content analysis 	<ul style="list-style-type: none"> • Lack of coordination among the ASD service providers • Social and ethical issues • Lack of universal screening program <p>Five factors influence expressed emotion by mothers:</p> <ul style="list-style-type: none"> • Being worried about others' comment • Being worried about children future • Just paying attention to child's needs and ignoring their own and other family member's needs • Comparing their child with other children • Blaming and criticizing the child 	8
Mohammadi (2018) (23)	Shiraz	<ul style="list-style-type: none"> • N=11 <p>8 mothers; 3 fathers Parents' mean age: 38.78 (18-51) 7 boys; 4 girls</p> <ul style="list-style-type: none"> • Qualitative • Interview & focus group • Content analysis 	<p>"empowering" the parents of children with autism can be defined as "adapting to the present situation to gain self-efficacy." Adapting to their situation can be gained through:</p> <ul style="list-style-type: none"> • Acceptance of the child's disorder • Patience • Participation of other family members in child-care • Social supports • Spiritual connection 	7
Aarabi (2021) (24)	Tehran	<ul style="list-style-type: none"> • N=13 <p>12 mothers; 1 father Children mean age: 3-15</p> <ul style="list-style-type: none"> • Qualitative • Semi-structured interview • Content analysis 	<p>Parents' experiences showed that there are some challenges in using rehabilitation services in Iran:</p> <ul style="list-style-type: none"> • Lack of the systematic support • Lack of commitment to observing professional ethics • Neglecting the rehabilitation structures and policies • Lack of comprehensive ASD diagnostic and rehabilitation protocols • Inadequate knowledge and attitude • Lack of feasible access to services 	9
Faraji-Khiavi (2021) (25)	Ahvaz	<ul style="list-style-type: none"> • N=14 <p>Parents' mean age: 20-40</p> <ul style="list-style-type: none"> • Phenomenological • Semi-structured interview • Colaizzi's seven-step method 	<p>The experiences of families raising children with autism reflect on the two main themes:</p> <ul style="list-style-type: none"> • Family-related problems • Education and treatment problems 	8
Ramezanloo (2020) (26)	Tehran	<ul style="list-style-type: none"> • N=8 <p>8 mothers Parents' mean age: 44.62 (40-50)</p> <ul style="list-style-type: none"> • Phenomenological • Semi-structured interview • Colaizzi seven steps method 	<p>The lived experience of mothers can be classified into three categories:</p> <ul style="list-style-type: none"> • Contradictory feelings in mothers • Low psychological capital • Restrictions on social support networks 	9

Khara (2020) (27)	Tabriz	<ul style="list-style-type: none"> • N=23 15 mothers; 8 fathers Parents' mean age: 34.2 Children's mean age: 6.8 years 19 boys; 4 girls • Qualitative • Semi-structured interview • Content analysis 	<p>Needs expressed by parents include:</p> <ul style="list-style-type: none"> • Information needs • Service and care needs • Supportive needs • Financial needs 	9
Samadi (2011) (28)	Tehran	<ul style="list-style-type: none"> • N=43 27 mothers; 16 fathers Children mean age: 8.2 years (3-17) 32 boys; 11 girls • Qualitative • Interview • Thematic analysis 	<p>Several issues should be noticed:</p> <ul style="list-style-type: none"> • Lack of parental understanding about autism • Parents' reactions to the diagnostic process • The dearth of available information • Dissatisfaction with the professional services • Lack of support from their families 	8
Ebadi (2021) (29)	Tehran	<ul style="list-style-type: none"> • N=27 27 mothers Parents' mean age: 29-52 Children mean age: 7-12 years • Qualitative • Semi-structured interview • Content analysis 	<p>Mothers living under psychosocial pressure caused by stressors such as:</p> <ul style="list-style-type: none"> • Psychological concerns and suffering • Sociocultural challenges 	10
Mohammadi (2018) (30)	Shiraz	<ul style="list-style-type: none"> • N=20 12 mothers; 8 fathers Parents' mean age: 38.52 (18-51) • Qualitative • Interview & focus group • Content analysis 	<p>Parental competence among parents of children with autism is defined as "Excellence in care," including:</p> <ul style="list-style-type: none"> • Achieve excellence and self-confidence in child-care • Ability to restore family stability 	9
Heydari (2015) (31)	Mashhad	<ul style="list-style-type: none"> • N=18 18 mothers Parents' mean age: 34.83 (24-48) Children mean age: 4-11 14 boys; 4 girls • Phenomenological • Semi-structured interview • Interpretative method 	<p>Parents' lives can be described under a phenomenon of "spiritual journey" that consists of three components:</p> <ul style="list-style-type: none"> • Descent: wondering between what is and what will be • Connecting to deity: reflection on the failure in her struggle • Ascent: helping her child is becoming all of the mother's life 	9
Ganjeh (2020) (32)	Arak Ahvaz	<ul style="list-style-type: none"> • N=8 5 mothers; 3 fathers Parents' mean age: 33 Children mean age: 6 years • Qualitative • Semi-structured interview • Content analysis 	<p>Parental concerns about children's future are explained around the three axes of main categories:</p> <ul style="list-style-type: none"> • Self-sufficiency and independency in life • Transition to adolescence • Child education and learning 	9

Thematic Synthesis Findings

Four major themes were identified in the results: (a) treatment-related lived experience, (b) individual lived experience, (c) social lived experience, and (d) occupational lived experience.

See the summary of thematic synthesis results in Fig. 2 and the frequency of themes and subthemes in Fig. 3.

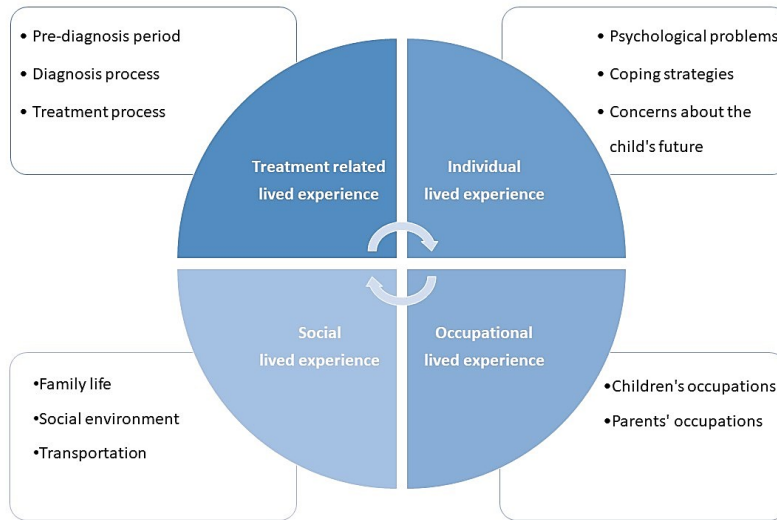


Fig. 2: Summary of thematic synthesis findings

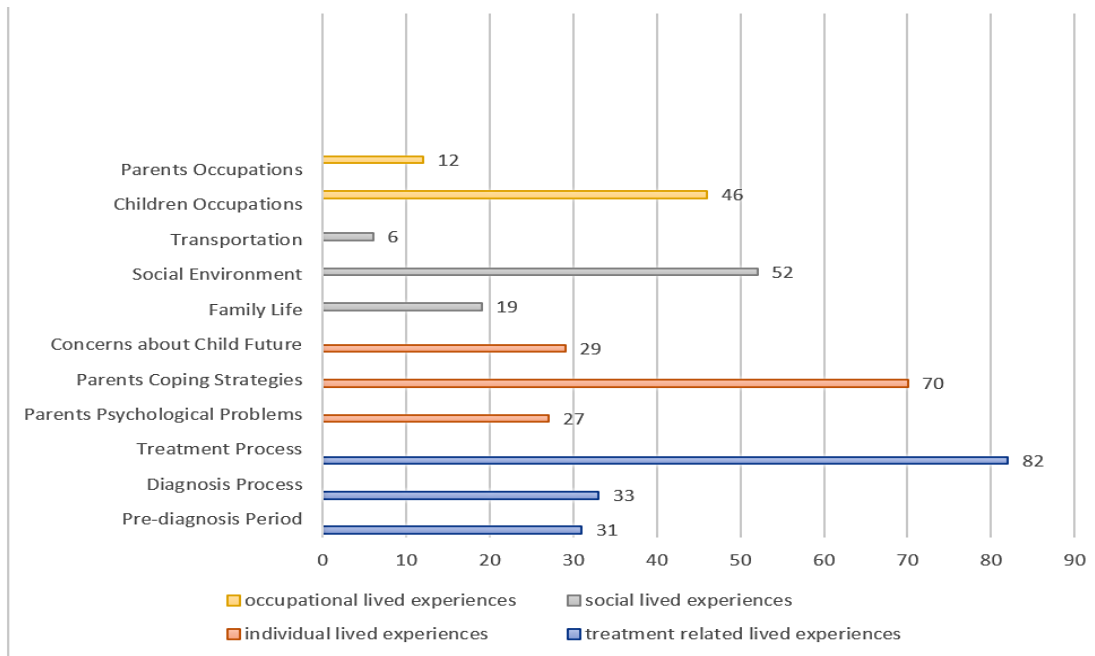


Fig. 3: Themes and subthemes frequency

Theme 1: Treatment-Related Lived Experience

Treating children with ASD was the most often noticed aspect of parents' experiences across the

studies. Except for one study, other included studies in the review reported information on this theme. We discuss below the three sub-themes:

pre-diagnosis period, diagnosis process, and treatment process.

Pre-diagnosis Period

In the pre-diagnosis period, symptoms such as speech delay, communication problems, regression, restlessness, and inability to play with toys attract parents' attention. In the face of such symptoms, some parents are confused, and some seek to find information and understand the cause of the child's abnormal growth. However, some share these issues with their relatives. Relatives usually try to make the child's problem seem normal or deny the child's problem (14, 18, 19).

Diagnosis Process

Iranian parents of children with ASD face serious challenges from the beginning diagnosis process. Due to the lack of specific references for diagnosis, parents are confused and have been referred to various specialists to diagnose the child's prob-

lem. Some specialists have used numerous expensive tests such as brain scans for diagnosis. Some others have made quick diagnoses without an accurate assessment, have not used a specific test or protocol for diagnosis, and finally have different opinions about the child's problem. Also, parents have stated that they did not give sufficient explanation and necessary support from the diagnostician (14, 19, 20-22).

Treatment Process

Parents face many challenges by going through the diagnosis stage and entering the treatment process, as presented in Fig. 4. Moreover, the parents were not satisfied with the services provided in the healthcare centers and stated that these services have low quality. There are several reasons for parents' dissatisfaction with healthcare services presented in Fig. 4 (23-27).

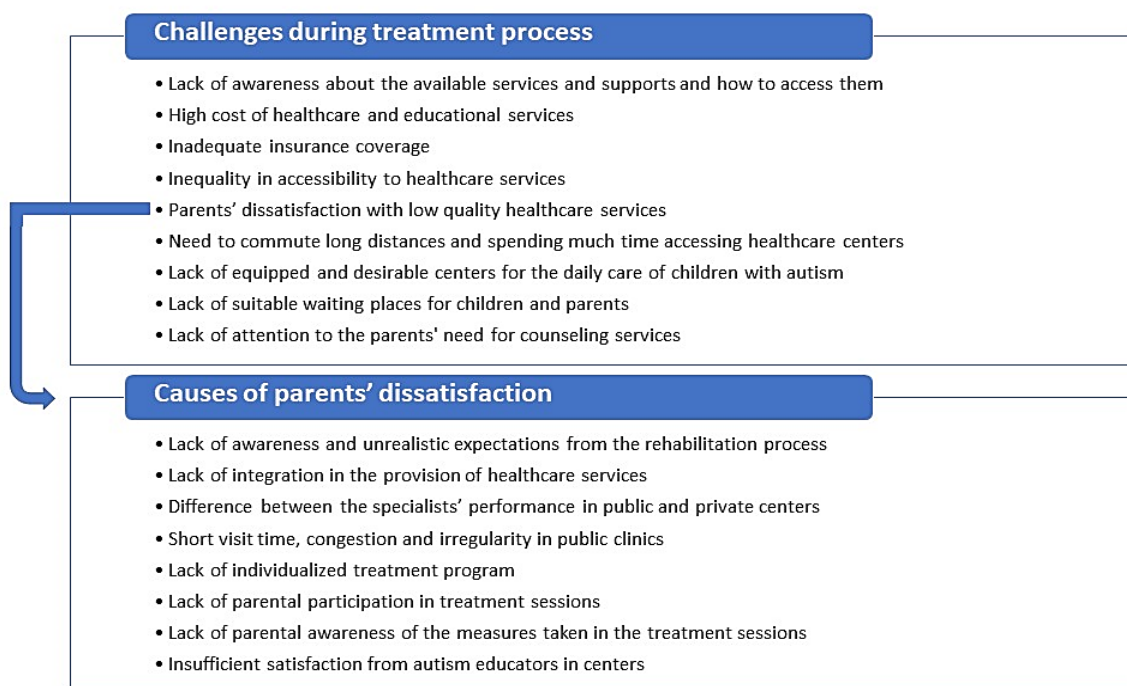


Fig. 4: Challenges and causes of parent's dissatisfaction during the treatment process

Theme 2: Individual Lived Experience

This theme developed based on the thirteen studies' findings. We categorized the results into three

subthemes: parents' psychological problems, coping strategies, and concerns about the child's future.

Parents' Psychological Problems

Iranian parents of children with ASD experience depression at various stages, including after diagnosis, after realizing that the disorder is incurable, and after ineffective treatment measures. Anxiety is another psychological problem expressed by parents (20, 22, 25, 26, 28, 29).

Parents' Coping Strategies

At the beginning of a child's problem diagnosis, parents often have difficulty accepting the child's problem and feel unable to help the child improve. After a while, parents accept the child's condition, take the necessary medical measures for the child, and often gain the ability to understand and manage the child's condition over time (20, 23, 26, 28-31).

Guilt feeling, self-blame, blaming others, rumination, submission, controlling emotions and feelings, seeking information, and turning to religion (Religious coping strategies) are the other coping strategies reported in Iranian parents (20, 22, 23, 26, 28-31).

Concerns About the Child's Future

Parents of children with ASD repeatedly spoke about their concerns about the child's future. Concerns about caring for the child after their death, puberty, future job, ability to live independently, education, and marriage were the frequently reported concerns of parents (14, 20, 22, 26, 27, 29, 32).

Theme 3: Social Lived Experience

The social lived experiences of Iranian parents of children with ASD were described in twelve studies. Challenges are presented in the three sub-themes: family life, social environment, and transportation.

Family Life

Autism affects many aspects of family life as the most basic social unit. "Healthy children in the

family" and "couples' relationships" are affected by a child with autism and related issues based on the experience of Iranian parents (14, 20, 22, 23, 27, 29).

Social Environment

Public misbehavior in society causes parents of children with autism to experience different types of stigmas. Isolation, feelings of shame, and pity are other consequences of inappropriate behaviors in society toward these children and their families (14, 19, 20, 22, 25, 27, 29).

Transportation

Parents of children with autism have described transportation as a barrier to community presence for themselves and their children. The unfit public transportation system, and not accepting a child with autism without a companion in transport vehicles are some issues mentioned by parents (19, 20, 25-27).

Theme 4: Occupational Lived Experience

In eight studies, we found content related to children and parent occupations. All the cases mentioned in this field have dealt with the limiting factors and the adverse effects of autism disorder on children and parents' occupations.

Children's Occupations

Parents' experience indicates that children with ASD experience occupational challenges mainly in activities of daily living (ADL), sleep, leisure, and education (14, 19, 23, 25, 29, 32). The field of education has received more attention from former researchers and parents. In this field, we can mention the challenges related to the educational system, teachers, transportation, and parents' attitudes (Fig. 5).

Parent's Occupations

Parents of children with ASD have expressed limitations in the occupational areas of sleep, work, and leisure (14, 19, 22, 26, 29).

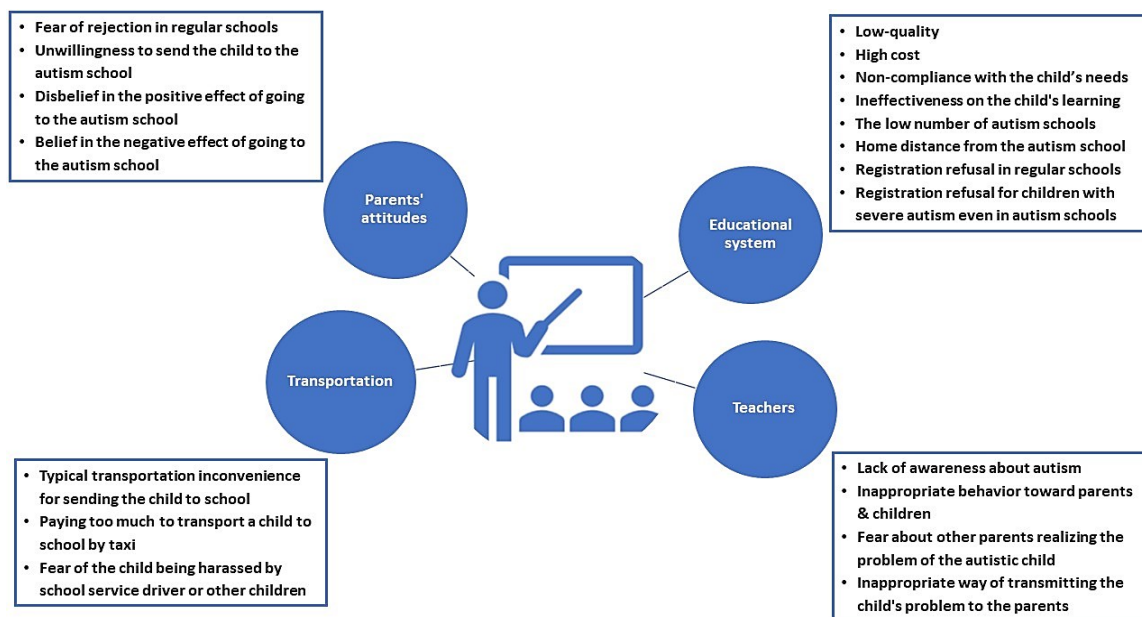


Fig. 5: Challenges related to the occupation of education

Discussion

This study aimed to investigate lived experiences of Iranian parents of children with ASD. Through the thematic synthesis of qualitative studies, we found that Iranian parents of children with autism are confronted with challenges, including inaccurate diagnostic processes, lack of adequate support at the diagnosis time, low-quality treatment, psychological problems, concern about the child's ability to future independent living, family problems, stigma, isolation, and problems with doing occupations for parents and children.

Treatment-related lived experiences of Iranian parents of children with ASD showed the various challenges in their journey from the pre-diagnosis period to the treatment process. In the pre-diagnosis period, normalization of the child's problems or deny it by relatives causes a delay in the specialized follow-up of the child's problem and early intervention. Studies in Western countries have not reported similar ones, but studies by Desai et al have reported similar experiences about Indian parents (4, 8, 33). After parents decide to pursue their child's problem professional-

ly, Iranian parents do not have access to a specific reference for counseling and diagnosis. So, Iranian parents face misdiagnoses and late diagnoses that are also reported in studies conducted in other countries (34, 35). Lack of timely and correct diagnosis delays the child's treatment process and reduces the effectiveness of the interventions (14, 19, 21). Non-supportive diagnosis is another noteworthy point in the Iranian parents' experiences. Similar experiences have been reported in studies conducted in European countries and New Zealand (7, 36, 37). Post-diagnostic support strongly predicts parental satisfaction with the overall diagnostic process and facilitates parents' adjustment to their child's diagnosis (38).

The findings of this study about the treatment process are consistent with previous studies stating services accessibility, expensive treatments, and limited funding or insurance coverage as issues in the treatment pathway of children with autism (11). Also, like Turkish parents in the Yassibaş study, Iranian parents were not satisfied with the quality of services provided in the medical, rehabilitation, and educational centers (33). Service providers in public and private centers

can increase the quality of services by providing qualified specialists from different fields in their centers, proper client management, providing appropriate equipment and space, paying attention to the parent's counseling needs, and continuous training of therapists and educators and monitoring their performance (14, 24, 25, 27).

As individual lived experiences, Iranian parents of children with ASD experience psychological problems, show various coping strategies and have concerns about their child's future. Depression and anxiety experienced by Iranian parents of children with autism at various stages of life. In a systematic review and meta-analysis, Schnabel et al reported a high prevalence of psychological disorders in parents of children with ASD, especially depression and anxiety (39). Additionally, in our study, we observed active coping strategies, including information seeking, maintaining a positive mindset, and demonstrating a fighting spirit which findings align with previous research in this field (5). Also, we found negative coping strategies in Iranian parents, such as self-blame, blaming others, and rumination. Furthermore, we found religious coping strategies in Iranian parents. Inclination to religion as a coping strategy is not unique to Iranian or Muslim parents. Parents in Eastern and Western countries consider their child's disorder as God's will, blessing, or trial, which helps them accept their child's condition (5). Religion positively impacts mental health, well-being, and coping outcomes (40). Our findings also show that religious tendencies positively affect most parents in accepting their child's conditions, having a better mood, and helping their child progress. Moreover, as in studies conducted in the US, Turkey, and Asian countries, Iranian parents have concerns about their child's future. Existing evidence shows that parents of children with ASD living all over the world have two important common concerns, including child independent living and employment, that should be addressed (4, 5, 33). Families of Iranian children with autism experience challenges at different levels of their social life. At the family level, autism affects "Healthy children in the family" and "couples' relation-

ships". Caring responsibilities stress, ignoring needs, always being the second person in the family, and loss of parental and social network support can affect the emotional and mental health of siblings of children with autism (41, 42). Also, previous studies suggested less time spent with the spouse, the mother's intense involvement in the child's treatment programs, the husband's refusal to come home, and the mother's less expressive emotions toward their spouse as reasons for the couple's disputes (41, 43). Moreover, public misbehavior in society causes Iranian parents of children with ASD to experience stigma, Isolation, feelings of shame, and judgment. These results are consistent with another study in the US (4). We should address stigmatization and help families for post-traumatic growth. In the process of post-traumatic growth, social support is one of the most important factors in helping families of children with disabilities to accept their condition, reduce their stress, and enhance their ability to fight and grow (33). Additionally, Iranian parents have described transportation as a barrier to community presence. High dependence of people with ASD on their families for transportation cause immobility and the need to allocate significant time and money to their families (44, 45).

The experience of Iranian parents of children with ASD indicates that these children experience challenges in the occupational areas, mainly in ADL (feeding, toileting, grooming), sleep, leisure, and education. Similar difficulties were reported in the experiences of Indian parents of children with ASD; based on Indian parents' experience, eating was the hardest thing to do, followed by toileting, brushing, dressing, and bathing (46). Additionally, sleep disturbances can decrease the performance of children with autism in social communication, daily life, and learning (47). Addressing these issues can increase the independent living of children and the quality of life in families (3). Also, it was inferred from the Iranian parents' opinions that environmental factors (educational system, teachers, transportation, and parents' attitudes) most disrupt the education of children with ASD. Similarly, environmental fac-

tors were the main obstacle to the participation in leisure activities for these children. Other qualitative studies also showed that environmental factors (physical, attitudinal and social environment) could restrict or enhance the participation of children with ASD and their families in leisure activities (48-49). It is essential to notice parents' experiences, go beyond "child with autism" and pay more attention to the environmental factors in our research and practice.

Iranian parents have expressed limitations in their occupational areas of sleep, work, and leisure. Sleep problems can affect the daily functioning of parents of children with autism and are associated with higher mental and physical health problems, especially anxiety (50). Regarding work, the mother leaving the job to meet the child's needs and the need for more father work were mentioned by Iranian parents. Having a child with autism is a significant risk factor affecting parents' employment status and families' income (51). Iranian parents of children with ASD have also reported eliminating leisure activities. Several studies have shown that mothers of children with disabilities spend more time caring for their children and may also be responsible for housekeeping and work, resulting in reduced participation in leisure activities that are optional (11). Lack of participation in leisure activities leads to occupational imbalance and reduced satisfaction (52).

Limitations

Studies included in this review are mother-focused studies conducted in metropolitan areas in Iran. So, should be cautious when applying these findings as the experiences of parents of children with ASD.

Conclusion

There are important and main issues that parents of children with ASD confront with them. Practitioners, policy-makers, and regulatory organizations should consider issues mentioned in the parents' experiences to provide proper healthcare

services for children with autism and their families. Facilitating and clarifying the diagnosis process, using accurate diagnostic procedures, conveying the diagnosis to parents in a professional and empathetic manner, guiding parents to start early intervention, providing integrated treatment interventions performed by trained professionals, providing mental health care services for parents and paying attention to the needs of these people in adolescence and adulthood can create more suitable conditions for children with ASD and their parents. Also, according to the experiences of Iranian parents of children with autism, environmental factors play an important role in limiting the occupational performance of children and families that should be considered.

For future research, we recommend that researchers go beyond mothers and consider the experience of fathers, siblings, teachers, and healthcare providers to provide proper services for these children and their families. Also, researchers can examine caregivers' experiences for other age groups of people with ASD, including adolescents and adults. Moreover, we suggest researchers go beyond focusing on the child's characteristics (e.g., sensory abnormalities) and investigate these children's occupational experiences by emphasizing the environment's role.

Journalism Ethics considerations

The authors have entirely observed ethical issues (including plagiarism, double publication or submission, fabrication or falsification, etc.)

Acknowledgements

We have not received any financial support from any agencies for this study.

Conflict of interest

The authors declare that they have no conflicts of interest.

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