



# Exploring Challenges and Needs of Parents Providing Care to Children with Autism Spectrum Disorders: A Qualitative Study

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## Abstract

**Background:** The circumstances and needs of children with autism spectrum disorder (ASD) affect children and their families.

**Objectives:** This study aimed to explore the challenges and needs of parents caring for children with ASD.

**Methods:** An exploratory qualitative method and the conventional content analysis method were employed in the present study. Participants were 18 parents with children with ASD in Tehran who were recruited by the accessible sampling method. To collect data, semi-structured, face-to-face, and in-depth interviews were used. The interviews were audio-recorded and transcribed verbatim into Microsoft Word software. Qualitative analysis was performed using the content analysis approach.

**Results:** Parents had three main needs in caring for their children: (1) first, issues and problems related to diagnosis, treatment, and rehabilitation, including three categories (issues and problems of diagnosis and treatment, issues and problems of rehabilitation, and inadequate therapeutic support); (2) second, issues and problems related to parents, including four categories (parents' lack of knowledge and awareness about ASD, lack of life skills, daily problems of parenting, and familial & marital issues); and (3) third, financial, cultural, and social issues, including two categories (financial problems and social & cultural problems).

**Conclusions:** The needs and challenges mentioned by the parents of children with ASD highlighted the need for medical, educational, and counseling services and emotional and material support from the community and the government. Planning and implementing support programs enable parents to face problems strategically, which ultimately improves their quality of life.

**Keywords:** Autism Spectrum Disorder (ASD), Caring Parents, Challenges, Qualitative Research, Needs Assessment, Needs

## 1. Background

Autism spectrum disorders (ASD) are common neurodevelopmental disorders characterized by a triad of impairment in reciprocal social interactions, verbal and non-verbal communication deficits, and repetitive and stereotyped behaviors (1). This disorder is identified by changes in the development of the infant's brain during the first years of life, affecting a person's behavior and how she/he interacts and communicate with others (2). Studies show that ASD affects 1-1.5% of the population of the world (3). Developmental neurological disorders, such as ASD, cause many problems for the individual and the family. Studies show that parents of children with ASD are exposed to psychological and social problems (4). In fact, the birth of an ill child exposes families to unknown and unexpected issues (5). Day-to-day challenges faced by parents caring for

children with ASD are endless, and their behaviors create many problems for parents (6). Studies have shown that the daily life of families of children and adolescents with ASD revolves around their needs and problems in the family and society. Parents have a vital role in treating their child's disease and meeting his/her needs (5). The needs of the child cause chronic stress for parents, making them neglect other aspects of family life (7). In addition, the results of other studies indicate that raising children with ASD is more stressful and challenging for parents than raising normal children or children with other disabilities (8). Another concerning need of parents with an ASD child is access to health services. Parents face many obstacles and challenges in accessing health services (9). Access to information about the disorder, treatments, services, and the health care network can help these parents cope with the situation and the diagnosis (2). Although new and appro-

appropriate strategies are being planned in developed countries to provide health care services to fulfill the needs of children with ASD, developing countries face a rise in the incidence of ASD, where there is very inadequate information about the needs and problems of parents caring for children with autism (10). Therefore, identifying these challenges seems critical and necessary. On the other hand, any educational and rehabilitation intervention for children with ASD should be primarily tailored to the essential needs of their parents.

## 2. Objectives

Due to the lack of coherent and sufficient research in this field, the present study was conducted to explore the challenges and needs of parents caring for children with ASD.

## 3. Methods

This study employed an exploratory qualitative method and a conventional content analysis approach.

### 3.1. Study Environment and Population

In Iran, services to children with ASD and their families are provided by governmental rehabilitation centers such as clinics affiliated with medical universities, the Welfare Organization, and the Exceptional Education Organization. Other private and charitable centers also provide services to these children, such as the Iranian Autism Association. Participants were selected among the parents of children with autism who were referred to these centers.

Sampling was conducted by the Iranian Autism Association headquarters. Due to the nature of the association and the broad range of services and support provided to children and adults with ASD, either at a fair price or freely, numerous parents with various socioeconomic conditions and different educational levels choose the association to receive necessary services. Therefore, the sample selected would meet the maximum variety and diversity.

In this study, authors tried to include parents of different ages and from different social classes, in order to achieve acceptable variety, in the number of pregnancies and the gestational age of the birth of a child with autism. After preparing the sampling matrix, it was tried to have at least two people from each matrix in the sample.

### 3.2. Sampling

The study population included 18 parents of children with ASD. Sampling was done in a purposeful sampling

method to fulfill the principle of maximum diversity. Inclusion criteria for parents were at least one-year passing since their child was diagnosed with ASD and being literate.

### 3.3. Data Collection

In-depth, face-to-face semi-structured interviews were used to collect data to identify the needs and problems of parents of children with ASD from their own perspectives. Informed consent was obtained from the participants; then, the time and place of the interview were confirmed. The minimum interview time for each participant was 45 minutes, and the maximum time was 90 minutes. The interview was conducted in a calm environment where parents were free to express their needs. In the case of a telephone interview, verbal consent was obtained for participation in the study. After obtaining permission from the participants, their voices were recorded by a tape recorder.

### 3.4. Data Analysis

The conventional content analysis method was used to analyze the data. First, all interviews were recorded and transcribed verbatim. Data analysis was performed simultaneously with transcription. The recorded voices of the participants were typed in Microsoft Word software, and the typed texts were sent to participants via email to edit or confirm them. In addition, data coding and analysis were performed independently by two of the authors. Data from the interviews were extracted by content analysis to obtain codes, main themes, and sub-themes. The main themes and sub-themes were identified and reviewed by two authors.

For data analysis, Graneheim and Lundman's content analysis method (11) was used as follows: (1) the recorded voices of the participants were typed and read several times by researchers; (2) meaningful units and initial codes were identified; (3) main themes and sub-themes were named and defined; and (4) the reliability of the codes extracted and the main theme and sub-themes were tested.

To evaluate the reliability and validity of the data, four criteria were used: credibility, transferability, dependability, and confirmability. Credibility means that the explanation or interpretation of an experience is approved by the person who had experienced it. In this regard, each subject was referred to again to confirm his/her agreement with the researcher's perception of the material. Then vague statements were discussed and clarified to correct them in the case of contradiction with the participant's real experiences to finally ensure the agreement and approval

of the subjects. Regarding transferability and whether or not the results can be applied to other groups or cultures, participants with different experiences were recruited as much as possible. At the same time, the authors tried to provide more details about the participants, as well as accurate and purposeful explanations about their activities, and draw the path of this study to allow others to know the characteristics of the study population. To meet the criterion of dependability, the interviews continued to the point that individuals referred to similar concepts and interpretations when answering questions and explaining their experiences. Finally, the separation process was used for confirmability (i.e., leaving aside previous experiences as much as possible and having a new look at the phenomenon under study). The authors tried their assumptions and attitudes not to interfere with the data analysis process and to avoid any prejudice and bias on the subject before and after the interview.

### 3.5. Ethical Issues

This study received ethical approval (IR.USWR.REC.1399.041) from the Research Ethics Committee of the University of Rehabilitation Sciences and Social Health (previously named the University of Social Welfare and Rehabilitation Sciences). Thereafter, the authors were introduced to relevant places (the Iranian Autism Association and specialized clinics and care centers for autistic children) for recruiting and interviewing subjects. Participants were informed about the aims of the study and the confidentiality of the interviews.

## 4. Results

### 4.1. Demographic Characteristics of the Participants

Most of the participants in this study were female (66.6%). The age mean of the participants was  $35.4 \pm 7.25$  years; 38.6% of them had a bachelor's degree or higher education, and 68.4% had a lower than a bachelor's degree. Males and females comprised 13 (72.15%) and 5 (27.75%) of children with ASD, respectively. The age mean of children with ASD was  $7.92 \pm 7.8$  years. Parents' needs were classified into three main themes and nine sub-themes using MAXQDA v10 software.

### 4.2. The Needs of Parents of Children with ASD

The main themes, sub-themes, and concept codes are presented in [Table 1](#). Parents believed that to empower the families of children with ASD in Iran; some needs should be met as follows:

#### 4.2.1. Main Theme: Issues and Problems Related to Diagnosis, Treatment, and Rehabilitation

The theme of problems related to diagnosis, treatment, and rehabilitation included three categories: issues with the diagnosis and treatment, issues with the rehabilitation process, and an inadequate support system.

##### 4.2.1.1. Sub-theme 1: Problems with the Diagnosis and Treatment

One of the most important challenges for parents was the late diagnosis of the disorder. After observing the child's abnormal development, parents tried to find out the cause. They were initially confused about where to go and how to diagnose their child's problem. Most parents stated that due to the lack of diagnostic centers, especially in smaller cities, it took years for their child to be accurately diagnosed. They were referred to various clinicians and hospitals and undertook various expensive tests to finally diagnose their child with ASD. Parents were also annoyed by some physicians not giving them enough time to explain the disorder, its symptoms, and problems; hence, these issues caused discomfort and a lack of trust between parents and medical staff. One parent said, "One of the worst things that can happen to a family of a child with autism is that there is no one who can tell you for sure what's going on, and almost all families who see some weird behaviors in their child, who do not speak or anything else, don't know when to start and where to go" (participant 3). Another parent said about the costs of treatment and the fate of their child: "With this inflation and everything is overpriced, although we can afford things mediocly, we are bending our backs under the burden of costs, with the lack of support from organizations and institutions, which is decreasing every day, I do not know what will happen to these children" (participant 2). Other parents complained about the lack of a referral center for diagnosis and treatment: "There was no one to help me, to guide me, I did not know where to take Khashayar! - (participant's son) - I was confused" (participant 5). One parent also reported that "we sought to diagnose the problem way too long until we found out what the problem was. We went wherever we could. Everyone said something: Take him to a speech therapist! Take him to an audiologist! Take him to a neurologist! To everyone, we took him for three or four sessions, come and go, do this test and that test, spend money for this, for that..." (participant 17).

##### 4.2.1.2. Sub-theme 2: Inadequate Support and Treatment Systems

Parents complained about the lack of governmental support and financial support systems, as well as the high cost of rehabilitation. Apart from the major costs of rehabilitation related to occupational therapy and speech ther-

apy, parents complained about the lack of efficient insurance. Meanwhile, parents' lack of awareness about autism has led to more confusion, burnout, and helplessness because normal schools do not accept children with autism, and parents do not readily accept sending their children to special education schools. One parent said: "The most important issue is the financial issue, which is not supported by the government. They do not accept insurance, and insurance companies do not cover autism" (participant 10). Another parent said about the costs of treatment and daily care: "My child goes to occupational therapy, speech therapy, every 45 minutes it costs at least 80,000 Tomans (at the time of the study), three times a week, 12 times a month, count the diaper money in these years and see how much it might be. Maybe the money for a house was spent on the child" (participant 14). Another participant also complained about the lack of a governmental support system and the costs of treatment: "For a while, our situation got worse. We had to take him to private clinics. We paid a lot for the child, while insurance did not cover any medical expenses. I had to take my child to welfare (State Welfare Organization of Iran). I went and came dozens of times and was frustrated until I could see a psychiatrist examine my child. I protested, and they said: go and thank God, that's what you could get; there are some cases where even though their child is covered by welfare, they cannot receive any services" (participant 12).

#### 4.2.1.3. Sub-theme 3: Rehabilitation Issues and Problems

In general, parents were dissatisfied with the slow progress of their children's condition despite spending a lot of time and money. Several parents had unpleasant experiences with the medical staff's attitudes, treating them and their child unfairly, including having a bad tone when talking to parents, labeling, judging, and lack of empathy with parents. Several parents were upset by the therapist's physical aggression toward their child, to the point that several of them complained to the court.

One parent said, "Early on, I was sitting in the rehabilitation line and on a nerve strip so much that I, myself got back pain. In that hustle and bustle, we got sick too" (participant 14). "He went to the Prophet's school for two years. His environment was very bad, and he came home every day with his head bowed as if he had returned from the war", said one parent about the unsuitable atmosphere of the rehabilitation center (participant 16). Another participant complained about mistreatment by medical staff: "In clinics, occupational therapists beat children. Speech therapists do not work with children at all and only have their heads in their phones and talk to their colleagues. They also lie very much" (participant 6).

#### 4.2.2. Main Theme 2: Issues and Problems Related to Parents

The theme of issues and problems related to parents included four categories: parents' lack of knowledge and awareness about autism, lack of life skills, daily problems of parenting, and familial and marital problems.

##### 4.2.2.1. Sub-theme 1: Parents' Lack of Knowledge and Awareness About Autism

It seems that apart from difficulties in the diagnosis of autism due to the nature of this disorder, the parents of children with autism have difficulty realizing the differences between their children and other children. In general, in Iranian society, people are less informed about the symptoms and nature of this disorder. Unfortunately, after recognizing the child's differences and feeling the need to seek a doctor, families do not know what to do and where to go. Some admitted that after a while, they became more and more confused and desperate to visit a specialist. "Now, I know a little about this disorder. I only know that children with speech delay may be autistic", said one parent (participant 4). Another participant said, "However, I was not sure about this and did not research why my child was like this. Is the child autistic or what?" (participant 11).

Another parent said, "Despite being suspicious of some of my child's behaviors, I attributed them to his childish playfulness until one day when he knocked his head on a wall, I took him to the doctor. He wrote some tests. It was not normal. They said he had autism. I thought it was a temporary illness and it would get better" (participant 7).

##### 4.2.2.2. Sub-theme 2: Lack of Life Skills

Parents of children with autism seem not to have life skills, either intentionally or unintentionally. In the beginning, these parents tried to hide the issues related to their child's disorder from those around them. One of their solutions was to reduce communication with others, which would automatically aggravate the problem. The main reason for this is parents' feelings of shame and anxiety about the child's behavior in the social environment. One mother said, "When I meet relatives and friends, I am embarrassed by my child's behavior. Some acquaintances even link my child's behavior to my inability to raise my child" (participant 18). Another participant said: "I do not go to parties at all. I do not think this is a celebration for a family with a child with autism" (participant 13). "I hate going to parties because I'm afraid of being ridiculed by others behind my back, saying my child is sick. I cannot go anywhere except where it's important", said a parent (participant 8).

#### 4.2.2.3. Sub-theme 3: Daily Problems of Parenting

Children with autism have different and unique characteristics, including misbehaving, temper tantrums, disobedience, stubbornness, self-harm, long-term need to wear diapers, running away from treatments, and improper and inappropriate nutrition. Some parents seem to have difficulties managing and dealing with these special situations, and in some cases, they have been forced to pay a ransom or to physically deal with their child. Some parents lacked the proper knowledge and understanding of how to interact and communicate with their children in these situations and did not know how to meet the needs of these children, including the need to drain their child's energy. Some parents still compare their sick child to a healthy peer and do not know how to behave when their other children become jealous of the autistic child and how to respond to their needs properly to avoid more problems and prevent other children from thinking they are not as important as the sick child. "My son needs round-the-clock attention to be able to control his behavioral problems. You know, it's so frustrating to have to meet her needs every day", said one participant about her child's stress and behavioral problems. "Sometimes, I feel like I do not like this child enough" (participant 17). Another participant said about meeting her child's desires and managing behaviors: "I'm alone, I do not have a husband, and it is difficult when you have an autistic child. I do not know how to help him. I'm confused" (participant 10). Another participant said about how he treats the child and expects more from him: "Sometimes my husband gets angry with the child, and sometimes he wants to hit him because of some of his behaviors. He keeps expecting from the child. I'm tired" (participant 1). Finally, another participant complained about her child's communication problems: "Communicating with her is hard for me as her mother. Sometimes I feel I cannot stand this anymore. I always feel tired, and I run out of energy" (participant 11).

#### 4.2.2.4. Sub-theme 4: Familial and Marital Problems

It seems that among the most important problems faced by families with children with autism are familial and marital problems. These families need social, emotional, and psychological support from their spouses and others after the diagnosis of their child with autism. One of the participants said about her relationship with her husband: "My relationship with my husband has cooled. I filed for divorce because he never comes home, and even if he does, he stays home for 2 hours a day" (participant 9). Another participant said, "I always criticized my husband because he had a different view on the treatment of the child. We argued a lot, we shouted, and we just did not conclude. The condition of the child affected our intimate

life, and eventually, we divorced" (participant 7). Another parent also said about her husband's attitude and support: "Neither Pouya nor his father gives me any rights anymore. There is too much (should not) around me because if I force myself to make time for myself, I will be faced with their frowns. Because they think it's just my job and I should not do anything but take care of Pouya and the rest of them. I'm getting mental. I'm alone" (participant 1).

#### 4.2.3. Main Theme 3: Financial, Cultural, and Social Issues

The theme of issues related to parents included two sub-themes: social and cultural issues and financial issues.

##### 4.2.3.1. Sub-theme 1: Social and Cultural Issues

Another problem of parents was the incorrect culture of the society in dealing with the disorder. The presence of parents with children with autism in society is hampered by seeing the ignorance of others about the nature of the disease and inappropriate behaviors of those around them having different reactions and calling the child crazy after his/her unusual behaviors outdoors. One mother said, "People think these children are crazy or retarded and make fun of them. We cannot take her to the park, shop, etc. Even our relatives sometimes talk sarcastically and insult her" (participant 4). Another participant said: "People around me do not know what they are saying; they do not understand. My child is not normal, and he has a problem. Unfortunately, our children are not calm and may not remain calm in a park. They may go into a fight and push other children several times. There were several times when others argued with me and yelled at me that my child was impolite and blamed me for not knowing how to raise a child and keep him in" (participant 8). One parent also said: "People's glances or whispers are annoying. People do not say these children have autism; they say they're crazy. Sometimes, other children mock my child. We spend so much time on the child that there is no time left for ourselves. It even has affected our sex life" (participant 15).

##### 4.2.3.2. Sub-theme 2: Financial Issues

Among the main needs and problems of parents of children with autism are financial problems and limitations. These families are charged with different costs than normal families. The most important of these costs and financial burdens are expensive diagnostic, therapeutic, care, and rehabilitation procedures. "The cost of caring for a child with ASD is very high. Occupational therapy and speech therapy are not covered by any insurance. We even have problems with transportation", said one parent (participant 5). Another parent said: "The costs are high. We have to cut our other costs so that we can pay for our child's



treatment" (participant 3). Another parent noted, "To be honest, I cannot send her to a speech therapy class. I teach her at home myself" (participant 18).

## 5. Discussion

This study aimed to identify the needs of parents caring for children with ASD. Based on the results of this study, the needs of parents of children with ASD were classified into three main themes, nine sub-themes, and 76 codes. Examining the needs of parents of children with ASD showed that these families would face problems and challenges in the areas of diagnosis, treatment, and rehabilitation and the fact that they have unfulfilled needs in these areas. The process of diagnosis of ASD in a child by parents has been reported to be long and complex. In fact, there is no clear diagnostic process for ASD in hospitals and clinics. Each clinic uses different diagnostic procedures and tools, and there are no specific diagnostic guidelines for centers to follow to identify a patient with ASD, so parents often receive different diagnoses from different doctors and experts. This finding was consistent with the results of other studies in which parents reported the process of ASD diagnosis as complex and confusing (12, 13). Studies show that some parents experience conflict and ambiguity before seeking ASD diagnostic tests for their children (14). Parents acknowledged that often specialists did not pay enough attention to their concerns or recognize the issues introduced by them. Some parents also experienced being blamed or labeled as neurotic or anxious by physicians. In this regard, nice believes that parents' concerns should be taken seriously when considering the diagnosis of autism. This lack of recognition or ignorance of concerns can significantly delay the early start of intervention programs (15).

Parents also reported being reprimanded and mistreated by doctors and health care professionals. These findings indicate information gaps in the awareness of some physicians and health care professionals about the factors contributing to ASD. The process of autism diagnosis should be more dignified, accessible, and patient-centered. Health sections should be more widely available to people to help reduce parents' anxiety about the diagnostic process of ASD. Self-assessments and post-diagnosis support for patients should be upgraded to an appropriate level. However, it is essential to listen to and respect the views and needs of people with autism and their families and to discover supportive ways with as many positive adjustments as possible (14). Findings show that a good relationship with a physician can significantly help improve some of the discomfort experienced by parents

facing ASD diagnosis in their child (16). In this study, another need identified by parents was the need for an appropriate support and treatment system. The present study showed that not all parents of children with ASD who care for their children at home receive financial or professional support. Financial pressure was reported as an obstacle to proper care for children with ASD in Iran, where there is a lack of free public health services for children with autism, in particular, and for children with various disabilities, in general. Therefore, most parents go to private clinics to receive health services, and all costs are paid by the parents themselves. According to our participants, treatment costs and lack of insurance support were the biggest financial challenges. The inefficient insurance coverage of the services needed by children with ASD and insufficient support from relevant institutions can increase financial pressure on families (5). Parents of children with autism are imposed with higher health costs than parents of children with other disabilities (8). Studies have shown that treatment costs for children with ASD are three times higher than that for normal children at the same age, as well as that for children with other mental and physical disabilities (17).

Another finding of this study encompassed parenting issues and problems. In this study, parents reported the lack of sufficient knowledge and understanding of ASD as one of their essential challenges. These results are consistent with those of other studies, highlighting the need for booting awareness about the etiology, symptoms, and treatment of ASD as one of the priorities of families with autistic children. According to previous studies, parents of children with autism may blame themselves for their child's disorder which may aggravate and worsen their child's problems. Thus, providing parents with guidance and information can familiarize them with facts about ASD and boost their understanding (18, 19). In addition, in the early stages of ASD diagnosis, parents of these children are overwhelmed with questions about the disorder and the characteristics of affected children. At first, the diagnosis of this disorder leaves parents confused and stressed as they are faced with an unknown and unexpected situation. In this regard, the presence of specialists to guide parents and provide them with information about this disorder is essential (2). Meanwhile, limited knowledge and awareness of the community and professionals, and especially parents, about ASD leads to negative consequences for the families of these children (18, 19), limiting the opportunity for early interventions and improving the child's development. Studies have shown that the lack of information about autism is a barrier for families of children with disabilities to access the required support (20). Shilubane and Mazibuko (21) showed in their research that professionals

should have had more information about this disorder to help parents understand autism which is consistent with the findings of the present study. Similarly, Shrestha et al., in their study, reported an urgent need for implementing programs to boost knowledge and awareness about autism (6).

The present study also highlighted the need for parents to receive training and counseling to acquire specific parenting skills, including how to deal with their child's behavioral problems in different situations. This finding indicates a two-way relationship between the caring pressure and parents' ability to cope effectively with their child's behaviors and learn appropriate parenting practices. Some parents of children with disabilities may not have enough understanding of their child's developmental and behavioral needs or may fail to use positive skills when creating parent-child interactions and reinforcing appropriate child behaviors. In contrast, parents who have positive parenting experiences often identify their undertakings as influential. This finding was consistent with other reports noting that the education of parents of children with ASD increase their communication skills required and the necessary awareness and knowledge about their child's behaviors (13, 22).

Another parental challenge identified in this study was parents' poor life skills in caring for a child with ASD. The parents stated that the knowledge of themselves and those around them about ASD was low, and they were upset and frustrated by the attitude and judgment of these people and their pity. Most of the complaints of parents have been about not being understood by those around them. It seems that families are judged because people do not have enough information about this disorder and how to communicate with a person with ASD in society. This causes many parents to avoid going out and adopt a different lifestyle. Studies have shown that some parents, due to the severe stress imposed by long-term, extensive care provision, completely withdraw from social life due to the child's behavioral problems and the conflicts caused when others try to deal with the autistic child (23). Research has shown that negative judgments by others increase depression, anger, and stress in parents (6). These parents' participation in cultural events and activities would provide an opportunity for them to discuss each other's experiences and be distracted from their child's problems temporarily. Thus, parents engaged in social experiences and events seem to have higher levels of independence and the life skills required for providing care for their children (24).

Another important need and problem reported by parents in this research included familial and marital problems. Most participants acknowledged that the presence of a child with ASD in the family reduced the quality of

their marital and social relationships and the intimacy of family members with each other. In this regard, it can be said that the mother of an autistic child faces major challenges due to the affected child's disabilities that can manifest in different ways and cause stress for the mother and the whole family. Women in such families need social, emotional, and psychological support from their spouses and relatives. Participants in the present study reported that the presence of a child with ASD in the family reduced the quality of marital relationships and created conflicts among family members, hardly pushing these couples toward divorce and separation. The stress associated with raising autistic children and their behavioral problems are believed to increase the possibility of divorce. Consistent with the results of this study, Hartley et al. found that divorce rates among parents who had autistic children were twice as high as among parents with normal children (25). It seems that providing family counseling can help repair and develop marital relationships. In accordance, parents of children and adolescents with ASD have been reported to be less likely to enjoy psychological well-being compared to the parents of normal children or of children and adolescents with other types of disabilities (14).

Social support from family, friends, neighbors, and professionals is a powerful and appropriate approach to reducing stress and improving the well-being of families with children with ASD (26). Although autism poses parents with many challenges and stressful experiences, they still need to support their child's needs and help him/her cope with a variety of problems and deal with unexpected events. The higher the severity of autism, the more stress is imposed on the family, and the more time it takes for care provision. Studies have shown that mothers of children with ASD spend an average of 9.5 hours a day fulfilling the needs of a child with ASD, compared to an average of only 5.3 hours for taking care of a normal child. This has general consequences, such as extreme social isolation, less school attendance, and more absenteeism. Siblings also have emotional problems when they grow up in a special and stressful family environment. The results of some research show that almost half of such siblings experience less attention, learning and language problems, and mood swings (24). These findings suggest that mental health professionals should focus on the whole family instead of merely on the child with ASD.

Other major challenges identified by parents were financial, cultural, and social issues, especially the wrong culture of the society in dealing with children with autism and the low level of knowledge and awareness of people about this disease and their inappropriate and negative judgments. Most frequently, most people assume that a child with ASD is not properly raised by their par-

ents. In addition, the comparison of an autistic child with a healthy child may end in the humiliation and ridicule of parents. The results of studies in this field show that negative and false judgments of the behaviors of children with autism in the community, arising from the lack of awareness and knowledge of people about ASD, increase depression, stress, and anger in parents (6). The stigmatization of the parents of these children by people shows the discriminative and close-minded views of the community towards this disorder. In addition, parents who find the received social support inadequate for themselves or their children are more likely to experience high levels of stress. Research has shown that the lack of social support, including stigmatizing a child's behaviors or characteristics, can lead caregivers of children with autism to withdraw from social gatherings. Similarly, qualitative research has shown that the lack of social support is one of the key challenges to caregivers' well-being and that parents report high levels of stress and isolation, including feelings of "labeling" by others (27). Therefore, it can be said that communication institutions and the media play an important role in creating a public culture and increasing the level of awareness and knowledge of society about this disease.

In addition, parents expressed financial pressure due to the overall costs of diagnostic tests and care provision measures, including the current and future therapeutic procedures. These findings were consistent with the results of several studies showing that having a child with autism decreased the family's income, compelling parents to increase their working hours or change jobs to cover the high costs of special education and medications (8, 28). Raising and caring for a child with ASD require approximately more than 30 hours of work per week, explaining why many mothers are forced to quit their jobs to care for their children. This exerts enormous economic pressure on families and exposes them to other stressful conditions (16). Most of the problems and needs identified in the present study were not only related to health but also to other areas, requiring multidisciplinary strategies to solve them. That is, the problems, challenges, and needs of the parents of children with ASD are solvable only through multidimensional communication and collaboration. According to this study, it is suggested to create more information sources and materials to boost public knowledge about the nature of ASD and how to deal with children with this disorder in Iran.

The problems cited by parents of children with ASD highlighted the need for medical, educational, and counseling services and emotional support from the community and the government. Planning and implementing support programs are essential to empower parents to deal with these issues and ultimately improve their overall

quality of life. Accordingly, policymakers, educators, service providers, and welfare organizations need to identify the needs of parents of children with ASD and provide appropriate services to patients with ASD and their families. Information institutions and the media also have a great responsibility to improve public knowledge and social culture about ASD.

## Footnotes

**Authors' Contribution:** Dr. Jalal Younesi designed the study and drafted the manuscript. Amirhossein Hosseinpour participated in designing the study, collecting and interpreting the clinical data, performed parts of the statistical analysis, and helped in drafting the manuscript. Dr. Akbar Biglarian re-evaluated the clinical data, revised the manuscript, and performed the statistical analysis. Dr. Manoochehr Azkhosh and Dr. Mohammad Hadi Safi re-analyzed the clinical and statistical data and revised the manuscript. All authors read and approved the final manuscript.

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**Data Reproducibility:** The dataset presented in the study is available on request from the corresponding author during submission or after its publication. The data are not publicly available due to confidentiality issues and sensitive content.

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**Table 1.** Needs and Challenges of Parents Caring for Children with Autism Spectrum Disorders

Theme	Sub-theme	Code
<b>Issues and problems related to diagnosis, treatment, and rehabilitation</b>	Issues and problems of diagnosis and treatment	Late diagnosis of the disease
		The time-consuming and tedious process of diagnosis and treatment
		Dissatisfaction with the doctor and therapist because of not spending enough time with the child
		Different diagnoses by doctors and contradictory opinions of experts
		The lack of a reliable and inexpensive unit detection system
		Lack or shortage of diagnostic specialists in the city
		Expensiveness and numerous diagnostic tests
		Loss of parental trust in professionals due to conflicting opinions
		Parents' frustration with the ultimate certainty of the diagnosis
		Experts' lack of empathy, preparation, and understanding for presenting bad news
		Insufficient explanation of symptoms, problems, how to deal with the child, treatment, and rehabilitation
	Issues and problems in the field of rehabilitation	Unpleasant experiences of dealing with rehabilitation therapists such as bad tone, judgment, lack of empathy, lack of adequate training
		Feelings of lying and magnifying the problem on the part of the therapist for financial gain
		The therapist's misbehavior and physical mistreating of the child
		The child's lack of progress despite the staggering costs
		Lack of training parents to help with the rehabilitation process at home
		Lack of providing accurate and sufficient information to parents in this area and not helping them better understand this disorder
		Failure to give a roadmap to parents
		Spending insufficient time for parents
	Inadequate treatment and support systems	Ignoring the points made by parents
		Lack of comprehensive rehabilitation centers
		Crowded medical centers
		Inadequate and low-quality schools for autistic children
		Lack of part-time and full-time care centers
		Lack of financial support
		Lack of efficient insurance
	Parents' lack of knowledge and awareness about autism	Lack of autism schools
		Lack of government support
Lack of knowledge about the symptoms and nature of autism		
Not knowing where to start		
Confusion and despair in finding the right diagnostician and therapist		
Ignoring the warnings of teachers, caregivers, nurseries, and nurses		
Ignoring the initial suspicion resulting in delayed referring to specialists for diagnosis		
Lack of life skills		Lack of communication skills
		Lack of problem-solving skills
		Lack of decision-making and stress management skills
	Lack of creative and critical thinking skills	
	Displeasure caused by others' lack of knowledge and information	

		Displeasure with the attitudes and judgment of others	
		Displeasure with the pity and compassion of others	
		Displeasure with not being understood by others	
		Feeling tired and frustrated by others' judgments and reactions	
		Feeling anxious and ashamed of the child's behavioral problems	
	Daily parenting problems	Lack of knowledge about how to communicate and deal with the child properly	
		Lack of knowledge on how to meet the needs of a child with autism	
		Lack of knowledge on how to meet the needs of a non-autistic child	
		Child abuse	
		Improper nutrition of the child	
		The child's self-harm	
		Care and maintenance	
		Ransom for the child	
		Prolonged diapering of the child	
		The child's refusing the treatment	
		Comparing the child with a healthy peer	
		Jealousy of other children	
		Disobedience and stubbornness of the child	
		The child's encounter with people	
		Family problems and marital issues	The couple's decreased empathy
	Marital conflicts		
	Feelings of rejection and exclusion		
	Inability to divide tasks		
	Overshadowed sex life and sexual coldness		
	Parents not dedicating time to each other		
	Decreased freedom		
	Sleep issues		
	Fatigue due to caretaking		
	Chronic stress		
	Lack of entertainment and leisure		
	Inadequate nutrition		
	<b>Financial, cultural, and social issues</b>		Financial Problems
		High costs of treatment	
High cost of caretaking			
Cultural and social problems		Cultural issues	
		Displeasure with the behavior and attitudes of people	
		Issues with neighbors	
		People's low knowledge of the disorder	