

Research Paper

Understanding the Experiences of Parents in Raising Children With Autism Spectrum Disorder: A Qualitative Study



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ABSTRACT

Objectives: Autism spectrum disorder (ASD) is a neurodevelopmental disorder that includes abnormal communication, repetitive and limiting interests, and social dysfunction. This study aimed to identify the experiences of parents in raising children with ADS in Iran.

Methods: A total of 18 parents of children with ASD were selected by purposive and convenient sampling method to participate in the study. To collect data, in-depth semi-structured interviews were conducted. The text of the interviews was analyzed using interpretative phenomenological analysis.

Results: Two main themes of positive and negative experiences were identified in the analysis. In the positive experiences two sub-themes of “continuing education and acquiring spirituality” and “increasing life skills” and in the negative experiences five sub-themes of “reduction of communication and lack of social support,” “improper treatment with the child with ASD,” “feeling ashamed,” “lack of adaptability,” and “being judged by others” were identified.

Discussion: These findings can provide a deep understanding of the experiences of caring parents of children with ASD in Iran. In addition, the results of this study can provide valuable information to researchers, clinicians, etc. to indicate the specific needs of families who care for children with ASD.

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Highlights

- The findings of this study indicated that there are two main themes of positive and negative experiences for parents in raising ASD children. In the positive experiences two sub-themes of “continuing education and acquiring spirituality” and “increasing life skills” and in the negative experiences five sub-themes of “reduction of communication and lack of social support,” “improper treatment with the child with ASD,” “feeling ashamed,” “lack of adaptability,” and “being judged by others” were identified.

Plain Language Summary

Autism spectrum disorder (ASD) is a type of neurodevelopmental disorder. This disorder includes defects in interaction and establishing a social relationship, difficulty in processing perception, and repeated behaviors. The term “spectrum” indicates that symptoms are different from person to person and vary in type and intensity. The chain or spectrum of ASD symptoms in individuals varies from mild to severe. In the term, those who experience mild to moderate symptoms have Asperger’s symptoms. However, there is no official category for diagnosis. Autistic people seem apathetic and have difficulty connecting emotionally with others. Their response to sensory experience is also unusual. For example, they will be distracted by the sound of a dripping faucet. Increasing the prevalence of autism requires a greater focus on parenting experiences in caring for these children. The special needs of autistic children affect the child and the lives of other family members involved in the child’s upbringing. Parents of children with ASD experience severe stress during the care of these children. Given the high rates of stress and depression among parents of children with ASD and their negative effects on family relationships in life and the costs that are imposed on families and society, conducting such a study to identify parents’ experiences is important. Results of this study showed that having a child with ASD sometimes gives the parents a hard time and sometimes is good for them. It means parents have both negative and positive experiences in raising a child with ASD. In the positive experiences two sub-themes of “continuing education and acquiring spirituality” and “increasing life skills” and in the negative experiences five sub-themes of “reduction of communication and lack of social support,” “Improper treatment with the child with ASD,” “feeling ashamed,” “lack of adaptability,” and “being judged by others” were identified

Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder specified by abnormal behaviors and defects in communication skills, social interactions, and sensory processing [1]. Symptoms of autism emerge by 12 months to 18 months of age or earlier in many children. However, no specific clinical diagnosis occurs before the age of three [2]. The researchers concluded that the cause of autism is not just a unique factor, but can occur as a result of genetic, perinatal, and environmental factors or a combination of these factors [1]. It is estimated that, worldwide, about one in 100 children has autism [3]. Increasing the prevalence of autism requires a greater focus on parenting experiences in caring for these children. The special needs of autistic children affect the child and the lives of other family members involved in the child’s upbringing [2].

Although the characteristics of children with ASD are common across different cultures, families’ experiences in caring for a child with ASD can be different

[3]. In most cases, parents take full-time care of these children [4]. The characteristics, symptoms, and behavioral problems of these children significantly impact the well-being of their families and parents [5]. The parents of these children experience significant changes in their social life, expectations, family plans, professional life, economic situation, and welfare [6]. Parents’ abilities to manage and respond to the care challenges of children with ASD are usually different. Some parents might experience significant mental health problems, while others experience relatively few of these problems [7]. Studies indicate that parents who focus more on their child’s negative characteristics and disabilities, such as behavioral problems and the severity of symptoms, experience more stress than parents who focus on their child’s positive characteristics and achievements [8]. In addition, the existence of a child with ASD in the family affects various aspects of parent-family life such as marital relationships, child relationships, family socialization patterns, and daily life [2]. Research background shows that parents of children with ASD experience higher levels of anxiety, stress, depression, isolation, and low quality of life compared to parents who have normal children

and parents who have children with other disorders [9]. Although public awareness of autism has increased in recent years, the parents of these children are still judged in the community for their child's behavior and are faced with hostile and avoidant views in public [10, 11]. A literature review in this field shows that stress in parents of children with ASD is not only due to the child's behavior but also due to the judgments of people in society [7]. Since parents of children with autism have unique needs in raising and supporting their children, understanding the experiences of parents of children with ASD is essential in providing the necessary support and facilities [7].

As discussed above, it is obvious that parents of children with ASD experience severe stress during the care of these children. Given the high rates of depression and stress among parents of children with ASD and their negative impacts on family relationships in life and the costs that are imposed on families and society, conducting such a study to identify parents' experiences is important. In addition, studies indicate that most current research on autism is quantitative and focuses on the effects of accessible interventions that parents of children with autism struggle with. While qualitative studies on the experience of parents of offspring accompanying ASD are restricted; On the other hand, these families have very distinct and particular experiences that cannot be explained by quantitative research, and qualitative research is beneficial for profound understanding and explanation of these real experiences. These studies are imperative because service providers appear to play an efficient part in accepting parents as well as defeating issues and challenges related to their child's care and treatment. Therefore, considering the necessity to understand the effects of ASD on parents and to improve their life quality, this study was conducted to determine the experiences of parents in fostering offspring accompanying ASD. This study aimed to describe and deeply understand the experiences of parents in caring for children with ASD.

Materials and Methods

A qualitative approach and content analysis method were employed to conduct the present study. This study was conducted in the Iran Autism Association headquarters in a calm and non-distracting environment where parents had the freedom to express their experiences. The study population consisted of parents who had at least one child under the age of 15 with ASD and sought counseling services from the Iranian Autism Association in Tehran City, Iran.

Qualitative research methods emphasize an in-depth understanding of a phenomenon or concept, often emphasizing how and why a subject, process, situation, or set of social interactions has occurred for many similar examples. Following the suggestion of Morrow et al [12] that the sample size in qualitative research should be determined according to the research project data; in this study, 18 parents were selected voluntarily by the purposeful sampling method.

Data collection

To gather the information, in-depth and semi-structured interviews were used, which were designed and conducted according to the qualitative research questions and focused on the experiences of parents of offspring accompanying ASD. Interviews were initiated with an expansive unrestricted question asking "What is it like to have a child with ASD?" And encouraging the participant to elaborate on their experience. The participants approved the time and location of the interviews; each interview carried on between 30 and 60 minutes in a noiseless, exclusive location in a separate room in the association. Information was collected about demographic characteristics and forms of informed consent of participants. All interviews were recorded audio digitally and completed within 3 months. Gathering data carried on until data saturation had been attained as proved by no new information impending.

Data analysis

First, all interviews were transcribed verbatim by two authors, then the research data were analyzed by Colaizzi's method in seven steps. In step (1), at the end of each interview, the recorded statements of the participants were first repeatedly listened to, and their statements were written word for word on paper. To understand the feelings and experiences of the participants, verbatim transcripts were studied several times. In step (2), sentences that were directly related to the research topic were identified, in step (3), formed meanings were assembled from the significant sentences. In step (4), formed meanings were classified as clusters of themes. In step (5), a comprehensive description of the experiences of parents of offspring accompanying ASD was obtained, in step (6) embodiment of the results into an affluent and comprehensive elaboration of the lived experience was done; in this regard, redundant, vague, and inappropriate descriptions were removed from all sections. In step (7), the results were validated and the findings were provided to the participants, they were asked to confirm the accuracy of the results and their consis-

tency with their experiences. To enhance the credibility and trustworthiness of the study four criteria were used: Credibility, transferability, dependability, and confirmability [13].

Results

Demographic information of the participants

The participants aged between 20 and 50 years. Twelve participants were women and 6 were men. Six participants had government jobs, 7 were housewives, and 5 were self-employed. Nine parents had two or three children. Most of them had average and above-average financial status (Table 1).

Main findings

It was found that two themes of negative and positive experiences shaped the experiences of parents in fostering these offspring. In the negative experiences, five themes were identified, including “reduction of communication and lack of social support,” “improper treatment with the child with ASD,” “feeling ashamed,” “lack of adaptability,” and “being judged by others”. In the positive experiences, two themes of “continuing education and acquiring spirituality” and “increasing life skills” were identified (Table 2), which are described below.

Main theme 1: Negative experiences

Being an offspring with ASD in the family causes parents to face challenges and negative experiences in daily life during care, the negative experiences extracted in this study are described below.

Sub-theme 1: Decreased communication and lack of social support

Parents of offspring with ASD, after their child was diagnosed with the disease, tried to hide the issue by reducing communication with family and relatives; some mothers have encountered a lack of companionship and cooperation of their husbands except in the financial part. They continued to face a lack of social and emotional support from their families and spouses, and have been blamed for their children’s situation. One of the participants said, “my family did not support me at all and it caused me to stop contact. I have no contact with anyone at all” (Participant (P) 3).

Another participant said: “The biggest challenge was that the family members usually do not understand that my child is not healthy and normal, especially my mother-in-law. The words and looks of my husband’s family hurt me a lot, especially their sarcasm” (P 5).

Table 1. Participants’ demographic information

Variables		No. (%)
Gender	Female	12(66.67)
	Male	6(33.33)
Age range (y)	20-30	5(27.75)
	30-40	7(38.88)
	40-50	6(33.33)
Profession	Governmental	6(33.33)
	Self-employed	5(27.75)
	Householder	7(38.88)
Financial status	Below average	11(61.11)
	Average	3(16.67)
	Above average	12(22.22)

Table 2. Positive or negative experiences of parents in raising offspring with ASD

Codes	Sub-theme	Theme
Lack of cooperation of the husband		
Decreased communication with the husband		
Decreased communication with others	Decreased communication and lack of social support	
Lack of emotional support		
Blaming the mother for the child’s disorder		
Ransom	Improper treatment with a child with ASD	
Physical punishment		
Shamed	Feeling ashamed	Negative experiences
Embarrassment		
Conflict with others		
Contradiction	Lack of adaptability	
Resentment of care		
To be labeled		
To be pitied		
To be taunted	Being judged by others	
To be stigmatized		
To be ridiculed		
Strengthening spirituality and meaning in life		
Return to religion and religious beliefs and perform religious duties	Continuing education and acquiring spirituality	
Interest in education		
Increasing patience		Positive experiences
Forgetting and trivializing previous marital problems		
Forgetting previous problems and focusing on the disease	Enhancing life skills	
Acquire problem-solving skills		
Increase bonds between family members		

ASD: Autism spectrum disorder.

Another participant said about financial support: “At the beginning, my husband did not help financially and used to say: You made the kid sick because you took him to this doctor and that doctor” (P 8).

“Early on, because we had not yet dealt with our child’s problem, we did not want any of our acquaintances and neighbors to find out. We always hid and did not want

anyone to know,” said one mother about her child’s disorder secrecy (P 1).

Sub-theme 2: Improper treatment with the child with ASD

Sometimes parents had to physically punish the child or ransom them at home and outside the home to keep

their children calm and quiet. Most parents face challenges in managing their child's behaviors.

One of the participants said: "Sometimes my son hits me so hard that I cry. After a while, I realized that he started hitting his younger sister and, in this situation, I did not know what to do with him. I had to beat him so that he would not do it again. I saw that it got worse, I took him to the psychologist for a few sessions, but he did not change" (P 3).

Another participating mother also said, "I would love to understand my child and find a way for him to adapt to other children. When I go to the house of relatives and acquaintances, he does not stop, he cries, he beats. That's why I decided to stay home because sometimes I get angry in public because of his behavior and I beat him" (P 12).

About the child's behavior at home, one of the fathers said: "In the house, his relationship with his sister was very annoying, and he could never be left alone" (P 9).

Another participant said: "Everywhere we go, we have to take a lot of food or snack with us or buy him whatever he wants quickly to keep him quiet so as not to make us embarrassed" (P 9).

Sub-theme 3: Feeling ashamed

Parents whose ability for commuting is reduced due to the special needs of the children, sometimes have been deprived of other necessities such as having fun and going to parties and hairdressers. Even at parties, parents felt embarrassed for a variety of reasons, including their child's aggression and harm to other children and surrounding items; at parties, closing the doors of the rooms, by the host to prevent the autistic child from harming the furniture, made them upset and embarrassed.

One of fathers said: "Going to occupational therapy and counseling is a bad thing to happen for us who do not have a personal car. Sometimes my child may do something at once and have egg on my face" (P 12).

Another parent said: "I don't know when the last time I went to my mother's house. You know how hard it is not being able to calm your child in public so that it does not become a problem and people do stare" (P 11).

Also, another mother said: "Our whole life and entertainment have been overshadowed. For example, we do not travel anymore. Because if we go by train, Mo-

hammad's noise attracts attention. We cannot go by car because our car is not good at all and we do not have money to do anything else" (P 18).

Another participating mother said: "I feel embarrassed when I leave the house because my child plays with everything (body parts). So, we often decide with our husband not to go anywhere and stay at home" (P 7).

Sub-theme 4: Lack of adaptability

Outside the home and in the social environment, due to people's unawareness of this disorder and things that happened to the children on playgrounds, parents have witnessed different reactions, and in some cases, unfortunately, inappropriate behaviors have caused physical conflicts.

One of the participants said: "Once we were in a park, my child pushed some kid, and he hit my child. I went and said; 'what are you doing?' 'I and his mother started fighting" (P 9).

Another participant spoke about his child's adaptability: "After a long while, we went to a restaurant. My child was making noise, screaming, and shouting. One of the other customers cursed us and we got into a fight" (P 14).

Sub-theme 5: Being judged by others

In some cases, parents of children with ASD have been confronted with pity and sarcasm. They have been accused of not raising their child properly, and their child has been called insane by others around them. They were upset that some others did not apprehend that their child was abnormal and had a problem.

"People have not reached that level of awareness yet. In many places, we are problematic to each other. They do not know that a child with my child's problem does things that are not his own. Everyone thinks that I raised the child inappropriately" said one mother (P 17).

A mother said: "All these were done at home by myself and I did not take him to the clinics at all. I do not believe in the clinics, because they do not take care of my child at all and only think about money" (P 15).

One of the mothers said: "Because Mahdi was noisy and he was pulling the hair of his playmates and shaking his hands so much in the parties all the time till we were embarrassed and had to take him out" (P 14).

One of the parents said: “Once one of our acquaintances or neighbors said: “Why are you not raising your child properly? Why were you not raising him properly? “That day, it caused me to be so much angry and start a fight with that woman” (P 18).

Another mother said: “Sometimes people treat us with pity and sometimes ridicule us and I am so embarrassed” (P 11).

Main theme 2: Positive experiences

According to the findings of the present study, although the parents of children with ASD often had negative experiences during care, some parents have come to terms with their child’s condition and the presence of an autistic child in the family has strengthened family members. They have mostly thought about the positive aspects of the case, so they have mentioned some of their positive experiences during care as described below.

Sub-theme 1: Continuing education and acquiring spirituality

In the meantime, some parents had coped well with their child’s disorder. They have tried to strengthen the soul by increasing their spirituality or learning ways to increase their resiliency. Some have become interested in continuing their education and increasing their knowledge about autism and even other fields.

One of the participants said: “One day I told myself that’s it. It’s enough and I pulled myself together. I wanted to regain peace in my life. I thought a lot. I saw the best thing is to do to continue my education” (P 6).

Another mother: “I was trying to calm myself down by reading the Quran and saying my prayers” (P 10).

Sub-theme 2: Enhancing life skills

Some parents have tried to forget their child’s disorder by acquiring life skills such as problem-solving and strengthening resiliency, or at least coping with the current situation and increasing the emotional bonds with their spouse and other family members.

One of the participants said: “We used to fight a lot and had problems with each other until God gave us Mahdi. From then on, as if we realized that our child had a problem, we forgot ourselves and left other issues aside to raise our child. After that, we feel we became much closer” (P 16).

Regarding marriage and emotional bonding, one participant said, “Since our child was diagnosed with autism, we have become more patient and also more interdependent. Our child’s needs have led us to sit together day and night and talk and discuss sincerely in this regard” (P 4).

Another participant said: “I always try to get my husband to share all the child-related decisions with me, to help each other, and we both enjoy it more” (P 2).

Another participant said: “I have always taken challenges not seriously. It does not matter, he is a child with special needs and a blessing that God has given us” (P 13).

Discussion

This study aimed to determine the experiences of parents in raising offspring with ASD. The research findings led to the emergence of two themes of positive and negative experiences.

The first sub-theme identified from the theme of negative experiences was “reduction of communication and lack of social support”. In this study, all participants were the primary caregivers of a child with autism who were responsible for other daily duties, including earning a living taking care of the needs of other family members, and housekeeping. These caring duties have affected their social relationships and emotional support. The results of this study showed that parents who have a child with autism have experienced a wide range of changes in their relationships. Some parents experienced a decrease in relationship satisfaction in the short or long term and acknowledged that they had distanced themselves from their normal lives. It seems that caregivers of children with autism have fewer opportunities to participate in social interactions and face many challenges in accessing community-based social support [14]. Studies suggest that lack of social support leads to the withdrawal of caregivers of children with autism from social activities [15, 16].

On the other hand, the emotional pressure caused by the child’s diagnosis created a sense of hopelessness and anxiety for the child’s future with their parents. In this regard, it can be said that the family is the first support system that one needs for physical and emotional growth [17]. Therefore, parents of children with autism need the support of their family and community members to promote their emotional health, which has not been reported in the present study. A safe and reliable support

system plays a very important role in the reduction of psychological adverse effects that may occur as a result of caring for a child with autism [16]. In a qualitative study of eight mothers of children with ASD, Nealy et al. found that diagnosing a child with ASD affects four areas: Emotional, family, social, and financial, which is consistent with the results of the present study [16]. Also, in line with the present study, a study by Mansell and Morris [18] found that 73% of parents after receiving an ASD diagnosis were worried about their child's future. They reported that safe and reliable support networks play a very important role in the psychological adverse effects that may occur as a result of raising a child with ASD [19]. The findings of Hoffman's study showed that a strong emotional support system is an integral and important part of coping strategies for parents of offspring with ASD [20]. Mothers of offspring with ASD also reported decreased marital satisfaction and blame from their husbands. Consistent with the present study, Snyder [21] showed that parents with children with autism have experienced a wide range of changes in their relationships. Some parents experienced a decrease in relationship satisfaction in the short or long term and acknowledged that they had distanced themselves from their normal lives. Johnsons' findings [22] that parents of offspring accompanying ASD experience a decrease in relationship satisfaction and increased isolation from each other is consistent with the results of the present study. In recent decades, there have been many social changes in families and the role of parents. Despite these changes, the role of primary care is still the responsibility of mothers. On the other hand, given that mothers interact with these children more than their spouses, sometimes fathers are not as involved as the mother in the autistic child's problems; so, mothers are blamed for the child's problem. In a situation where mothers are very concerned about the child's condition, the spouse's blame is annoying and intensifies the conflict between the parents. The mothers expected to be supported and accompanied by their husbands but they received negative responses. A survey in Saudi Arabia showed that 44% of the 43 mothers who participated in the study reported that they had many problems with care and were not supported enough by their husbands [23]. The concerns expressed by these parents were similar to studies that showed that tensions in the relationship between family members of children with ASD reduced sufficient time and energy for mothers to commit to becoming a wife and the other children [15]. The results of other studies in this field show that the divorce rate of parents of children with ASD is twice as high as that of parents of children without disabilities [2]. In addition, raising

a child with autism has resulted in lower marital satisfaction compared to parents of children without disabilities. Thus, the presence of a child with ASD in a family pervasively affects life and family relationships (family system); which leads to increased stress in the family for the treatment and care of the child [15].

Another sub-theme was "inappropriate treatment with the child with ASD." Parents admit that sometimes they have to physically punish or ransom their child at home and outside the home to keep their child calm. This finding indicated a correlation between the burden of raising and parents' capability to effectively deal with their offspring's behaviors and employ appropriate parenting practices. Some parents of offspring accompanying disabilities may not have an adequate apprehension of their offspring's developmental and behavioral needs, or others may not employ positive skills when creating parent-child interactions and increasing proper child behaviors. In contrast, parents who have positive experiences of parenting often identify themselves as influential parents [15].

Parents have shown that they constantly adjust their parenting behaviors to their child's characteristics (especially those with autism). For example, parents who participated in the study stated that adapting to their children's behaviors requires reducing working hours and even quitting their jobs. This has led to frustration with life or withdrawal from social relationships and has led to the possible formation of violent behaviors with their child [5, 24]. It is clear that not meeting the needs of parents affects their behaviors and reactions to their children. Some parents stated they have been so deprived of their needs (such as having fun, going to the movies, traveling, etc.) that they have reacted to their child's behaviors in a relatively violent way. This finding showed that parents sometimes feel that they are driven to violent reactions due to the pressure of care. It is consistent with other quantitative studies that a child's negative behaviors lead to the failure of parental needs, which in turn leads to parents' negative behavior toward their child [25, 24].

Another subtheme in this study was "feeling ashamed." Some parents expressed feelings of social isolation, stating that their role as caregivers had affected their ability to work, have leisure, and have social relationships.

Consistent with the findings of this study, the findings of other qualitative studies in Palestine indicate that discrimination and labeling by family members and the community have caused parents of offspring accompa-

nying autism in the process of care to experience a sense of shame, embarrassment, isolation, depression, and anger. Parents of offspring accompanying ASD are often skeptical about their disabled child's participation in society because they feel their child's presence in society causes embarrassment [16, 26, 27].

Broady et al. reported that negative public perceptions of children with ASD were associated with their parents' feelings of shame and embarrassment [28]. Consistent with the present study, the results of another study in Australia showed that negative judgments of people in the community about children with ASD are associated with their parents' feelings of shame and embarrassment [28]. Other studies in China have also shown that parents of offspring accompanying ASD have a sense of shame in their culture because of the way people in society view them and are often vulnerable to stigma. These results were consistent with the present study [29, 30].

The fourth theme identified in the negative experiences was "lack of adaptability." Parents participating in the study expressed significant problems with their child's adjustment to society. They complained about their child's harmful behaviors toward themselves and others, such as contention with peers at school, in the park, and on the playground. Some parents, given the harsh distress they face during care and because of the child's behaviors, entirely depart from social life, forget how to treat the child with autism, and get tired of caring for and living with these children [23]. Most of these children are socially vulnerable and, will have difficulty organizing the practical necessities of their lives without the help of others [31]. Behavioral issues are the most considerable obstacle to social relationships and can bring about the child's disengagement from social, familial, and educational environments [32].

The last theme of the negative experiences is identified as "being judged by others." One of the most frequent judgments of parents was the label or accusation of not raising their children properly. The stare of others was another daily annoyance for parents of offspring accompanying autism. Mockery of autistic children and comparing them to healthy children were often upsetting for parents. Negative judgments and misconceptions in society about the behaviors of individuals with autism in society, which arise from the lack of information and awareness of individuals with ASD, increase the risk of depression, stress, and anger in parents [10]. Consistent with the present study, the results of a study in Saudi Arabia showed that increasing public awareness of ASD has played a significant role in reducing negative judgments,

including labeling among the parents of these children [33]. Most parents expressed concern about stigmatizing their child with autism, which in some ways reflects discrimination and a limited view of society. Research has shown that autism-related stigma leads to an increase in mental health-related problems among caregivers [16, 34].

Parents of offspring accompanying ASD, on the other hand, avoid participating in social activities because of their child-care responsibilities and concerns about the outbreak of their child's potential behaviors in public. Most parents expressed concern about stigmatizing their child with autism, which in some ways reflects discrimination and a limited view of society. Research has shown that autism-related stigma increases mental health-related problems among caregivers [35, 36]. In addition, it stigmatizes mothers' trust in parenting skills and negatively affects their self-esteem [37]. According to the current finding, another qualitative study in Greece found that the experience of autism-related stigma in caregivers stems from social exclusion because their child is recognized as abnormal, and less accepted than normal children [38]. In addition, interviews with mothers of autistic children in Egypt show that to avoid stigma, these mothers tend to keep most of their children at home [3].

In addition to the negative experiences they had in raising an offspring with ASD, some participants reported positive experiences in caring for these children. One of the main themes in this category was "continuing education and acquiring spirituality." Some parents cited examples of positive experiences, including positive reactions and support from others, especially family members, neighbors, and the community.

Research shows that some parents achieve positive adjustment by having a child with a disability, and this is due to increased experience of humility, patience, compassion, acceptance, and respect. Although it is sometimes difficult to live with children with autism, there are positive beliefs about the development of children with autism. Having a child with autism strengthens family ties and leads family members to a deeper understanding of meaning, purpose, and personality development [6, 39]. Studies suggest that raising a child with autism increases the spirituality and personality development of parents and potentially protects parents from emotional distress [39].

Beliefs help to organize the lived experience of parents and allow the family to make sense of critical situations and are somehow related to the caregiver's adaptation to the child and minimizing their pain and suffering [40]. Religious and spiritual beliefs help to reduce the negative consequences of the phenomenon and provide the ground for learning and coping with pain and suffering. Despite different beliefs, having realistic expectations of the child and maintaining a quality family atmosphere are two basic aspects of positive family coexistence to prevent possible complications at the individual, family, and social levels [41-44]. The results of Mount and Dillion's study [45] show that support groups help parents of individuals with ASD to more successfully manage challenges because they can share their experiences with others in similar situations. It was following the results of the current study. In addition, cultural influences, level of education, and socioeconomic status also contribute to the formation of parents' beliefs about autism. Higher educated parents are more likely to believe in reducing the child's developmental problems with treatment facilities, although they consider autism a lifelong disease and enable them to seek treatment all the time. Parents with higher levels of education also had greater access to the resources needed to better understand ASD [46]. Having a child with a disability also requires a considerable amount of time to learn about diagnosing and addressing the challenges of children's educational planning. Higher-educated parents may be better prepared to meet these challenges. Studies on the positive aspects of caring are consistent with the positive psychology movement, which emphasizes strengthening positive adjustment rather than negative "correction." The results of qualitative and quantitative studies in this field have shown that the care of children with autism by parents has improved their personality and increased the quality of life and well-being of the family [47].

The second sub-theme in the positive experiences was "enhancing life skills." The results of some studies show that getting a diagnosis of ASD for a child has positive effects on parent-child relationships. Some parents reported increased satisfaction with their relationship, feelings of closeness and dependence on their spouse and other family members, and increased communication skills they had experienced. Increased communication may be the result of parents discussing important new medical decisions about diagnosis and treatment or management of common behavioral problems in a child with autism [7]. Johnson's findings suggest couples in the early stages of diagnosis experience a kind of decrease in marital satisfaction but then try to establish a constructive relationship with each other, which is con-

sistent with the results of this study [22]. Altieri and Von Kluge concluded that the presence of a child with autism in the family does not affect the marital relationship of the parents. This confirms the results of the present study; some participants stated that their child with autism has not had a significant effect on communication and marital relationships [48].

Conclusion

The findings of the present study indicated that parents of children with ASD in Tehran experienced many painful experiences and psychosocial concerns about caring for their children. Lack of professional assistance and lack of support and social resources in Tehran are painful experiences for parents. However, the social stigma, blaming mothers by others and sometimes even their relatives or spouses' should also be considered among their concerns. It is worth mentioning that in addition to negative experiences, parents have gained positive experiences during their child care. They acknowledged that living with a child with ASD increased their spirituality and academic achievement, as well as improved life and communication skills.

Ethical Considerations

Compliance with ethical guidelines

This research approved by the Ethical Committee of [University of Social Welfare and Rehabilitation Sciences](#) (Code: IR.USWR.REC.1399.041). Written consent was obtained from all participants before the interview. Participants were informed that the partnership was willing, and they committed to retract from the study at whatever time outside individual or professional consequences.

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Authors' contributions

Conceptualization: Seyed Jalal Younesi, Amirhossein Hosseinpour and Manoochehr Azkhosh; Methodology: Amirhossein Hosseinpour, Mohammad Hadi Safi and Akbar Biglarian; Investigation: Amirhossein Hosseinpour; Funding acquisition and resources: Amirhossein Hosseinpour; Supervision: Seyed Jalal Younesi, Manoochehr Azkhosh, Mohammad Hadi Safi and Akbar Biglarian; Writing the original draft: Amirhossein Hosseinpour; Review and editing: All authors.

Conflict of interest

The authors declared no conflict of interest.

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