Research Paper

Parents' Perceptions of the Problems in Children With Autism Spectrum Disorders: A Qualitative Study

Masume Zareei[1], Seyed Abolfazl Tohidast[2], Masoomeh Salmani[2*]

1. Department of Speech Therapy, Faculty of Rehabilitation, Semnan University of Medical Sciences, Semnan, Iran.
2. Neuromuscular Rehabilitation Research Center, Semnan University of Medical Sciences, Semnan, Iran.

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ABSTRACT

Objectives: Parents of children with autism spectrum disorder (ASD) have valuable experiences of the possible developmental problems and other issues of their children as the primary caregivers. The present study aimed to obtain proper information by considering these experiences using a qualitative approach to explain the parents' perception of problems in their children with ASD.

Methods: This study with a qualitative design was performed on 35 parents of children with ASD (33 mothers and 2 fathers) who were selected via purposive sampling. The study data were collected using semi-structured interviews, and all sessions were recorded and immediately transcribed verbatim. We followed the Graneheim and Lundman (2003) content analysis approach (a step-by-step extraction of meaning unit, initial codes, subtheme, and theme).

Results: We extracted 5 main themes of developmental, language comprehension and expression, social communication, behavioral, and general health problems. Each of these mentioned themes has several subthemes.

Discussion: According to the results, the parents' perceptions and experiences of their ASD children's problems were similar to the findings reported by experts in a few related studies. Given the lived experiences of the parents of children with ASD, they could help enrich the references regarding the problems of children with ASD. Such data should be considered during the assessment and intervention for this group of children.

*** Corresponding Author:**
Masoomeh Salmani, PhD.
Address: *Neuromuscular Rehabilitation Research Center, Semnan University of Medical Sciences, Semnan, Iran.*
Tel: *+98 (912) 8310924*
E-mail: *salmani_masoome@yahoo.com*

Highlights

• Our study revealed that parents felt the main problems in development, language comprehension and expression, social communication, behavior, and general health.

• Social communication and language were two main themes that received many subcategories regarding children's problems and issues.

Plain Language Summary

Autism spectrum disorder (ASD) is an umbrella term that defines children with ASD with two main symptoms: 1) problems in social communication and interactions, and 2) repetitive, restricted, and stereotyped behaviors. However, the present study revealed that parents perceived many different problems in their children that could be classified into 5 themes: developmental, language comprehension and expression, social communication, behavioral, and general health problems. Among these themes, language and communication made parents more concerned.

1. Introduction

Autism was first described in 1943. Since then, professionals kept working to clarify this complicated problem. In the most recent version of DSM (The Diagnostic and Statistical Manual of Mental Disorders), all conditions known in children with autism spectrum disorder (ASD) came under two categories: 1) social communication and interactions, and 2) repetitive, restricted, and stereotyped behaviors [1]. However, it is important to understand these children and their issues through their parents as the most recent studies did [2-5]. These parents must spend a lot of time with this group of children and any supportive service should undertake their perspectives, opinions, and expectations before any planning and programming [6].

This complex, common, and heterogeneous neurodevelopmental syndrome, which manifests in early childhood [7] affect approximately one in 54 children and Iran 6.26 per 10000 [8]. Various signs and symptoms of ASD with different severity and frequency besides what DSM introduced have been reported, such as impaired social engagement, self-expression, accountability, and self-control; limited eye contact; delayed language (expressive and receptive); motor development problems (gross and fine); sensory-seeking behaviors; a lower adherence to hygienic matters, digestive, and sleep, and psychological and emotional disorders (anxiety, anger, and aggression) [9-16].

According to the International Classification of Functioning, Disability, and Health Core Sets (ICF) for ASD, it is important to create condition-specific, functional profiles of individuals with ASD [17] based on proper tools and approaches. Part of the ICF considers 'family' as an environmental factor, a factor that received limited systematic exploration (on how a child with ASD affects the family, and how the family perceives and copes with the signs and symptoms of the ASD) [18]. While the parents' perception and the influential role of parental beliefs in different issues such as learning disabilities have been well documented [19-21].

Parents' perceptions or beliefs are two terms used interchangeably in research and refer to parents' ideas about how their children learn and develop [22]. Parental perceptions include two components: an objective component (referring to actual child characteristics), and a subjective component (comprising parent-related factors) [23]. The parents' perceptions of the child could be influenced by the child's behaviors and they affect the development of a parent-child relationship [24-26]. Moreover, a positive parent-child relationship is a prerequisite for normal development [27-30] (Figure 1).

Capps et al. examined the parents' perceptions of their children's emotional expressiveness in a completely refined sample of the older group of children with ASD without mental retardation. The researchers found that parents of children with ASD perceived more negative emotions from their children than parents of controls did [31]. In another study to assess the parents' perceptions of communication difficulties in ASD, Balestro, and Fernandes developed a questionnaire with 4 subcategories: parents' personal difficulties, parents' impression about themselves regarding their child, parents' impressions of other persons' reactions to their child, and parents' impression about their child [32]. In 2014, Sun and Fernandes evaluated parents' perceptions of communication difficulties with a questionnaire developed by Balestro

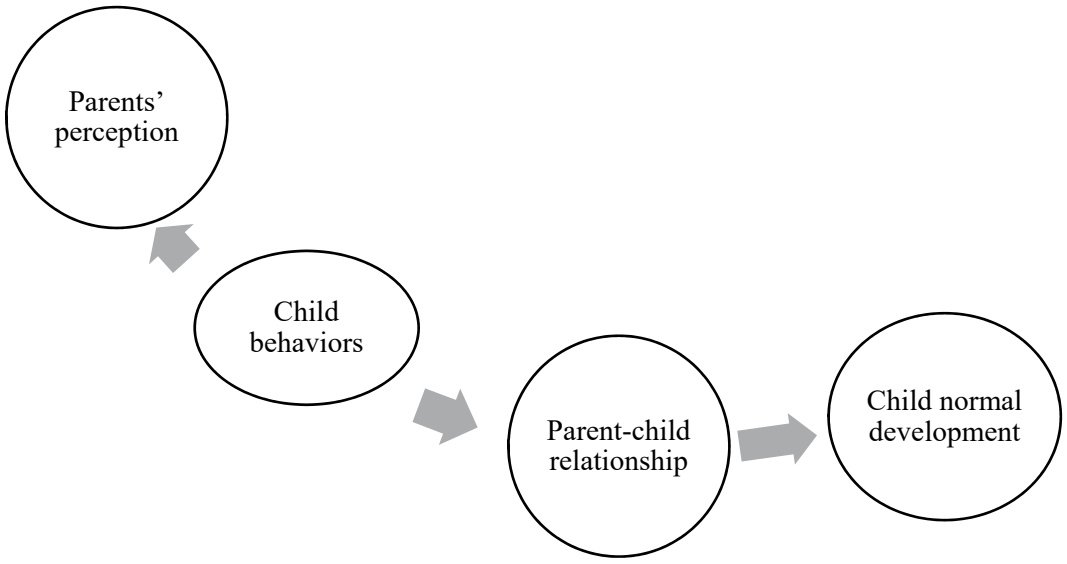

Figure 1. A Scheme of the possible relationship between parents and children

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and Fernandes in 3 different disorders (ASD, Down syndrome, and specific language impairment). Their results indicated that parents of children with ASD had significant differences from the other two groups in 3 out of 4 subcategories of Balestro's questionnaire [33].

In summary, parental perceptions are very important irrespective of whether they are compatible or not with results from more objective sources of information [23]. Because the existing literature throws little light on parents' beliefs, their experiences, and the kinds of problems they encounter in the process of developing a child with ASD, the need for further studies exploring how parents perceive or 'make sense' of the special circumstances of ASD has been highlighted. When the existing complexities within this area have been demonstrated, the proper conclusions could be drawn accordingly.

In this project, we were interested in empirically addressing some of the existing shortcomings in the literature by adopting the qualitative methodology. Qualitative methods explore systematically a small number of participants' subjective experiences, to yield rich insights into the phenomenon under investigation. The present study has neither been restricted to a specific area such as emotion nor limited to specific types of children with ASD. Besides, the research team did not implement any questionnaire with the hope to leave parents open to talking. In addition, to investigate the parents' perception of problems that children with ASD have, the research team undertook a problem-focused approach. This approach may not provide a holistic understanding of children and their problems [34] (a holistic approach includes both weaknesses and strengths); however, it would help the therapists target and prioritize the problems in research or clinical settings. Therefore, the current study was conducted to determine parents' perceptions about problems in children with ASD using a qualitative method.

2. Materials and Methods

The study protocol was approved by the Ethics Committee of Semnan University of Medical Sciences (Code: IR.SEMUMS.REC.1399.289). The research objectives and processes were explained to the parents, and they were ensured confidentiality terms regarding their personal information. Participation was voluntary, and the participants were allowed to withdraw from the research at any given time.

Study participants

The research population included all Iranian parents (fathers and mothers as two separated parents) of children with ASD referred to various rehabilitation centers across the country to receive rehabilitation. The inclusion criteria of the study were having a child or children with ASD having been diagnosed by a psychiatrist, children aged between 3 and 13 years, and growing up in a Persian language-speaking family. The exclusion criterion was other physical or mental disorders than ASD in children. Accordingly, 35 interviews were performed from January to February 2021 in Iran. The participants were selected via purposive sampling, which led to the inclusion of a diverse range of parents with different cultural, ethnic, and educational backgrounds, which

Table 1. Demographic information of parents and children

Participant Code	Parent's Gender	Parent's Age, y	Parent's Education	Child's Age, y	Child's Gender
1	M	39	High school diploma	7	B
2	F	40	Master	6	B
3	M	37	Bachelor	4	B
4	M	33	Diploma	5	B
5	M	27	Diploma	5	B
6	M	29	High school diploma	5	B
7	M	32	Diploma	10	G
8	M	37	Bachelor	8	B
9	M	30	Bachelor	5	B
10	M	41	Master	6	B
11	M	35	Master	9	B
12	M	31	Diploma	10	B
13	M	29	Bachelor	6	B
14	M	36	Bachelor	6	B
15	M	46	Bachelor	4	B
16	M	28	Bachelor	6	B
17	M	47	Bachelor	8	B
18	M	34	Diploma	11	G
19	M	35	Master	4	B
20	M	39	Diploma	13	B
21	M	33	Bachelor	6	B
22	M	44	Doctorate	5	B
23	M	37	Master	6	B
24	M	42	Diploma	4	B
25	M	34	Bachelor	5	B
26	M	29	Bachelor	6	G
27	M	46	Bachelor	4	B
28	M	40	Doctorate	4	B
29	M	35	Diploma	7	B
30	M	31	Bachelor	5	G
31	M	28	Bachelor	6	B
32	M	38	Diploma	4	B

Participant Code	Parent's Gender	Parent's Age, y	Parent's Education	Child's Age, y	Child's Gender
33	M	40	Master	4	B
34	M	34	Master	5	B
35	F	45	Bachelor	4	B

Abbreviations: F: Female, M: Male, G: Girl, B: Boy

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ultimately increased the credibility of the research. The interviews were taken place in the presence or by social media such as "WhatsApp". All parents who consented to be part of this study in Semnan Province, Iran were interviewed face to face (n=3). This group received speech therapy services from both private and university clinics. The remainders (n=32) were parents who respond to our invitation through social media. This group when signed the consent form (sent through their private account on WhatsApp) was interviewed online. This group comprised people from different provinces (Sistan & Baluchestan, South Khorasan, Razavi Khorasan, Semnan, Gilan, Mazandaran, Golestan, Markazi, Tehran, & West Azerbaijan) who received rehabilitation services from the private clinic.

The mean ages of the parents and their children were 36.02 and 6.08 years. Among the parents, 2 subjects were fathers, and 33 were mothers. Among the children, 31 were boys, and 4 were girls. Table 1 shows the demographic characteristics of the parents of children with ASD.

Data collection

To collect data, a master's student in speech therapy (trained by the supervisors on how to run and ask questions in an interview) conducted in-person or online semi-structured interviews with the parents of children with ASD to evaluate their perception of ASD-associated problems. The objectives and conditions of the research were explained to the parents, and those who were willing to participate were notified of the appropriate time and location decided for the interviews.

After providing a brief description of the research and its objectives, the interviews were initiated with a general, predetermined, and open-ended question to obtain more answers from the participants. For example, regarding children's speech and language, the interviewer asked: "does your child speak?", if so, "how is your child talking?". In addition, exploratory and reflective questions were used to resolve ambiguities and complete the answers (e.g. "Could you provide an example?", and "Could you elaborate?"). In the case of speech and language, for example, the interviewer asked: "is it one-word utterances or full sentences?", "is it understandable for you? For everyone?", "do you need to translate his/her speech for others?" The questions were asked with similar instructions, and there was no obligation regarding answering all the questions. However, the parents were requested to provide complementary information so that the interviewer could better communicate with the interviewees in the future. The interviews were recorded and transcribed verbatim.

The interviews continued until reaching data saturation. Data saturation is a core principle in qualitative studies. When adequate data were obtained from the interviews to develop a robust and valid understanding of the parents' perceptions of the problems in the children with ASD (i.e., the interviews did not end to raise new information or new concept), two further interviews were running to make sure of saturation.

Data analysis

Data analysis was performed using the method proposed by Graneheim and Lundman [35] in 5 steps: 1) the interviewer transcribes each interview immediately after its completion; 2) the interviewer reviews the transcriptions and finds meaningful units; then 3) the interviewer determines the initial codes; 4) the codes are classified based on similarities and difference into subthemes; and finally, 5) the main themes of each category are identified.

A qualitative content analysis of the interviews was carried out by reviewing each interview several times and extracting the meaningful units and initial codes. Afterward, similar codes formed the subthemes, and the main themes were extracted. All the members of the research team reviewed the interviews several times and commented on the analysis of the codes and units.

Rigor

At this stage, we used the criteria proposed by Guba and Lincoln [36] to establish the rigor of our study. We applied prolonged engagement, the development of a coding system, member checking, and external audits

(external observer and transferability). The obtained results were confirmed by the research team who had more than 5 years of clinical experience regarding ASD. Moreover, an in-depth assessment of the interviews and their analysis were performed by the researchers to confirm the criterion of prolonged engagement. To develop a coding system, the interview questions were pre-determined and asked the families with specific instructions. At the end of the interviews, the families were requested to read the interview text, add any comments regarding the subject, and approve the interview content. Moreover, we consulted an external supervisor to confirm the results by explaining the details of the research stages, especially content analysis.

3. Results

The present study aimed to evaluate the problems of children with ASD from the perspective of their parents. A content analysis of the interviews with the parents of the children with ASD led to the extraction of meaning units, initials codes, subthemes, and 5 themes. These themes included development, language comprehension and expression, social communication, behavioral, and general health problems. Table 2 presents the themes and subthemes extracted from the interviews.

Developmental problems

Developmental problems were one of the problems of the children with ASD reported by their parents. Accordingly, developmental disorders included motor, sensory, and cognitive problems and attention deficit disorder. The parents also believed that their children did not grow in different areas as fast as normal children did. Some of the statements of the parents are presented below.

Motor problems

"We expected our child to start walking by the age of one and a half years like other children. However, it did not happen and made us worried. This condition led us to turn to physical occupational therapy." (Participant 26)

Cognitive problems

"We turned to specialists due to a lack of attention and speech in our child by the age of 22 months." (Participant 13)

Language comprehension and expression problems

The parents were asked one question about the speech problems of their children, which led to the extraction of multiple symptoms expressed as children's language comprehension and expression issues. These symptoms included a lack of speech, speech/language problems, impaired pronunciation, limited receptive and expressive vocabulary, syntactic and morphological problems, and echolalia. Furthermore, the parents believed that speech problems could result in a lack of understanding of the child's needs, an inability to ask for help, and the inability of others to understand these children.

In terms of speech problems, one of the parents remarked

"At the age of 2 years and 8 months, my son did not speak at all and did not even respond to the sounds in the environment. Taking my sister's advice, we visited a psychologist to identify the cause of the problem. I also took him to a child psychologist who suggested visiting an occupational therapist or a speech therapist." (Participant 19)

Regarding delayed speech, another parent stated

"We referred to a speech therapist after our child failed to use any words by the age of 2. We were recommended to visit a doctor or a psychiatrist, but my husband did not comply. However, my son's pediatrician strongly suggested examination by a specialist." (Participant 24)

In terms of low speech clarity and pronunciation errors, one of the parents claimed

"My child can express his needs despite his low speech clarity. We have been attending speech therapy and occupational therapy sessions for 2 years now. His speech started with single words, before which he used pointing. Now, he can utter short sentences. He utters 2-3 sentences, and we can somehow understand him. However, I have to explain what he says to our relatives. Because he is still very small, he cannot pronounce all words correctly. Therefore, he might mispronounce a word but use it correctly in terms of meaning. He cannot keep the dialogue going and cannot tell a story." (Participant 2)

Table 2. Classification of themes and subthemes extracted from 35 interviews

N	Themes	Subthemes
1	Developmental problems	Motor problems Sensory problems Cognitive Problems
2	Language comprehension and expression problems	Lack of speech Speech/language problems Impaired pronunciation Limited receptive and expressive vocabulary Syntactic and morphological problems Echolalia
3	Social communication problems	Social avoidance, unwillingness to communicate, defects in communication with strangers, inability to maintain communication, defects in taking turns in conversation, defects in initiating conversation, defects in the retention of conversations, decontextualized language, inability to describe events and stories, inability to make eye contact, defects in nonverbal communication, defects in emotional expression, and inability to play with other children
4	Behavioral problems	Aggression, restlessness, ill temper, and hurting others and themselves
5	General health problems	Problems in terms of nutrition, immune system, digestion, personal hygiene, and blood (blood cholesterol and glucose)

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In terms of limited receptive and expressive vocabulary, two parents remarked

"He cannot talk; he only says a few incomplete words, such as /maa maa/ (i.e., mom) or /mama/ (i.e., something to eat), and /am/ (i.e., water). Some of his words are incomprehensible." (Participants 7)

"He is not as smart as his peers; I have to explain all letters and their meanings to him, and it is not like he learns with a God-given talent." (Participant 13)

Social communication problems

The parents considered impairments in social communication skills as the most evident and prevalent problem in their children with ASD. Accordingly, some of the most important social communication disorders observed in children with ASD included social avoidance, unwillingness to communicate, defects in communication with strangers, inability to maintain communication, defects in taking turns in conversation, defects in initiating conversation, defects in the retention of conversations, decontextualized language, inability to describe events and stories, inability to make eye contact, defects in nonverbal communication, defects in emotional expression, and inability to play with other children.

In terms of the inability to communicate with strangers, one of the parents stated:

"As you saw earlier, he did not enter the room when you were in the room next to his teacher, which was because of your presence. He cannot communicate with others due to his limited eye contact. Even with me, he hides behind my back when he wants to communicate because he does not want me to see that he is shy. This is one hundred percent because of his shyness." (Participant 2)

In terms of defects in the initiation and retention of conversations, one of the parents explained

"He easily starts communicating with others, but cannot retain the conversation. He needs someone else to keep the conversation going. Because he does not use several sentences, he does not respond to a child that wants to be friends with him and continues playing. Therefore, he is left alone after a while." (Participant 10)

Regarding the inability to play with other children, two of the parents stated:

"Sometimes, he does not pay attention to other children's playing at all. Other times, he might join them when they start running around and playing, but does not understand the meaning of the game." (Participant 4)

"He rarely plays with his peers and wants to play with his toy cars by himself." (Participant 10)

In terms of children's unwillingness to communicate, one of the parents claimed

"He does not communicate with his peers at all. Tonight, for instance, we visited the occupational therapy clinic for a group therapy session, which was attended by three other children. However, he clung to me all the way from the car in the parking lot to the physician's office, where he remained upset and was constantly choked up. Other children with ASD would come to him or look at him, but he did not look at them at all and was very upset." (Participant 22)

Behavioral problems

Behavioral problems were frequently mentioned by the parents of the children with ASD in this study, with an emphasis on issues such as aggression, restlessness, ill temper, and hurting others and themselves.

"He often expresses his emotions through aggressive behaviors. For instance, if we do not give him what he wants, he drops to the floor and bashes his head against the ground, or he throws something on the floor. He is under pressure because of these reactions. He also hits me if I do not give him what he asks for. In fact, I take the most hitting in the family compared to his sister, younger brother, and mother." (Participant 2)

Regarding hurting others, one of the parents stated:

"No one wants to be around him because he bites them and pulls their hair. However, it is only because he feels neglected because he loves and hugs others at other times." (Participant 6)

General health problems

The parents mentioned that their children with ASD dealt with several problems in terms of nutrition, immune system, digestion, personal hygiene, and blood (blood cholesterol and glucose). Regarding the general health problems of children with ASD, two of the parents commented:

"He has a weak immune system. Most of the time, his health problems are due to his renal conditions. I cannot follow the treatment course for some of his diseases. For instance, he does not cooperate with the dentist when there is a need for dental care. The hospital was supposed to set an anesthesiology appointment for him, which was canceled after revealing that he has autism. He suffered a lot. He had impaired blood glucose and thyroid hormone levels and does not allow blood tests. This is a big problem for us because our son is in so much pain but cannot express it." (Participant 15)

"It is very difficult when your child cannot say whether he feels hot or cold or whether the food heat has hurt his tongue or not. He would not even realize if a needle was inserted into his foot. When he was a child, he would not cry if he fell because he would not feel anything. He was like a statue. He cannot say how he feels or complain about his stomachache or toothache. For a while, I would see that my son was uncomfortable. Even though I brushed his teeth every night, I realized that something is stuck in his teeth, which disturbed him, but he could not talk about it. If the bathwater is too hot, he cannot say anything. He just stands up or his skin reddens." (Participant 22)

4. Discussion

This qualitative research aimed to assess the views of ADS children's parents toward ASD-associated problems. The obtained results led to the classification of the children with ASD's main problems into 5 themes of developmental problems, receptive and expressive speech problems, social-communication problems, behavioral problems, and general health problems. The problems mentioned by the parents are in line with the findings of previous quantitative studies, which have been obtained by the use of questionnaires, standardized tests, and clinical and para-clinical evaluations.

In the current research, there was a consensus among the parents of children with ASD and specialists regarding ASD-associated problems. We used a qualitative approach to evaluate the parents' perception of these issues, which led to the in-depth identification of the impacts of these problems. This issue has not been sufficiently emphasized in the quantitative studies in this regard. According to the parents in the present study, one of the most important problems of children with ASD was developmental disorders, including sensory, motor, and cognitive problems. Consistent with our findings, Locke et al. and Herlihy et al. realized that motor disorders were the primary concern of the parents of children with ASD aged 10-19 months. Therefore, attention must be paid to the growth indices of neonates and infants for the timely diagnosis and treatment of the problems associated with ASD. Development of receptive and expressive speech in the first few years of life was also considered a major indicator of socialization in children with ASD from the perspective of their parents and specialists [12, 37].

In the current research, all parents mentioned the emergence of receptive and expressive speech problems in the early years of their children's life. Accordingly, the gap between children with ASD and normal children could not be bridged even with relevant interventions. Based on the longitudinal assessments performed by Kozlowski and Artigas, children with ASD's gap from their normal peers starts from birth, and the gap widens over time [11, 38]. Ahadi investigated the receptive and expressive speech skills of children with ASD in Iran and reported language problems in these patients regarding the constructs related to questions with a question word and Yes/No questions, complementary subordinated and relative clauses, and personal pronouns as suffixes, detached, and confrontational pronouns and preposition [10]. Therefore, speech therapists should be a member of the assessment and intervention team for children with ASD from birth to bridge the gap between children with ASD and their peers in terms of speech indices. This goal could be achieved through appropriate assessments and interventions and by identifying the influential factors in the outcomes. Problems in developmental, receptive, and expressive speech predispose children with ASD to difficulties in effective age-appropriate communication and social relations.

In another study, Mahyuddin et al. evaluated the different problems in children with ASD, reporting a significant association between speech problems and social communication disorders [39]. In the mentioned study, parents reported social communication and speech problems in their children, which made communication difficult for both the children and their parents. Further investigation is required to evaluate the efficiency of interventions in this area and assess the social communication aspects of ASD patients and their families.

According to the present study results, behavioral problems were the main sign of ASD, which is congruent with the results obtained by Maskey et al. Overall, children with ASD were reported to be anxious and aggressive most of the time and likely to hurt themselves or others in the current research [16]. Moreover, the results obtained from the interviews with the parents are consistent with the previous findings in this regard. Effective interventions to reduce or eliminate these behavioral disorders could greatly benefit children with ASD and their families. However, the parents in our study less emphasized issues such as eating, sleeping, digestive, and health disorders despite a large volume of data in this regard. Nonetheless, this finding does not render the general health of children with ASD insignificant. According to the literature, malnutrition and sleep disorders could affect speech and language learning, as well as cognitive development skills such as attention and concentration and motor and mental development [14, 40]. Therefore, the parents of children with ASD should obtain adequate information in this regard and adopt a different attitude toward these problems.

5. Conclusion

According to the results, the parents perceived and experienced developmental problems, language comprehension and expression problems, social communication problems, behavioral problems, and general health problems as the primary issues of their children with ASD. Our findings are in line with the results obtained by previous quantitative studies. In conclusion, the lived experiences of parents of children with ASD could enrich the references regarding the problems of these patients.

Study limitations

One of the main limitations of our study was the COVID-19 outbreak, which affected the in-person interviews, and conducting online interviews might have affected the responses of the parents. Therefore, it is suggested that the information obtained virtually and in person be compared in further investigations. Other limitations of this study included the unequal number of parents with boy and girl children and the unequal number of male and female parents. We did not consider the level of ASD, the future studies that undertake a similar approach may reach a different conclusion based on the severity of ASD.

Ethical Considerations

Compliance with ethical guidelines

This study was approved by the Ethics Committee of Semnan University of Medical Sciences (Ethics Code: IR.SEMUMS.REC.1399.289).

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Authors' contributions

Conceptualization, methodology, investigation, writing the original draft, review, and editing: All Authors; Funding acquisition, and resources: Masume Zareei.

Conflict of interest

The authors declared no conflict of interest.

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