

A Qualitative Study on Parents' Perceptions of Problems in Children with Autism Spectrum Disorders

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ABSTRACT

Objectives: As primary caregivers of children with autism spectrum disorder (ASD), parents gain significant insight into their children's developmental concerns and challenges. The study utilized a qualitative technique to understand parents' perceptions of issues in their children with ASD. **Methods:** A qualitative study was conducted on 35 parents of children with ASD (33 mothers and 2 fathers) selected by purposive sampling. Semi-structured interviews were used to collect study data, which was then verbatim transcribed from the recordings. We used Graneheim and Lundman's (2003) content analysis approach, which involves extracting meaning units, initial codes, subthemes, and themes sequentially. **Results:** We identified five primary themes: developmental, linguistic comprehension and expression, social communication, behavioral, and general health concerns. Each of the aforementioned themes contains multiple subthemes. **Discussion:** The study found that parents' evaluations of their ASD children's issues were similar to those reported by experts in other related studies. Parents' personal experiences with their children with ASD might provide valuable insights into the issues they face. Consider such data while assessing and intervening with this group of children.

Keywords: *Parents' Perceptions of Problems, Children, Autism Spectrum Disorders*

- **Highlights:** Parents reported difficulties with growth, linguistic comprehension, social communication, conduct, and overall health.
- The study categorized children's concerns and issues into two key themes: social communication and language.

Brief Summary in Plain Language

Autism spectrum disorder (ASD) is characterized by two basic symptoms: difficulties with social interaction and repetitive, limited, and stereotyped activities. The study found that parents saw five types of difficulties in their children: developmental, language understanding and expression, social communication, behavioral, and general health problems. Language and communication were among the subjects that troubled parents the most.

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In 1943, autism was first described. Since then, experts have continued to try to make this clear, complex issue. The Diagnostic and Statistical Manual's most recent edition. All problems identified in children with autism spectrum disorder (ASD) fell into one of two categories, according to the Manual of Mental Disorders: 1) social communication and interactions, and 2) repetitive, limited, and stereotyped behaviors [1]. However, as the most recent research demonstrated [2–5], it is crucial to comprehend these kids and their problems through their parents. This group of kids need these parents to spend a lot of time with them, and any supportive services should consider their viewpoints, beliefs, and expectations prior to any programming or planning [6]. Early childhood is when this complicated, prevalent, and diverse neurodevelopmental condition first appears [7]. It impacts roughly one out of every 54 children, and 6.26 out of every 1000 in Iran [8]. In addition to those provided by the DSM, there are other indications and symptoms of ASD that vary in frequency and severity have been documented, including decreased eye contact, delayed expressive and receptive language, and problems with social involvement, self-expression, accountability, and self-control; sensory-seeking behaviors, issues with gross and fine motor development, a decreased commitment to hygiene practices, sleep, digestion, and emotional and psychological disorders (aggression, rage, and anxiety) [9–16].

The International Classification of Functioning, Disability, and Health Core Sets (ICF) for Autism Spectrum Disorder states that it is crucial to develop functional, condition-specific profiles of people with ASD [17] using the appropriate instruments and methodologies. The ICF takes "family" into consideration.

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]. 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 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

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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 This would assist therapists in identifying and prioritizing problems in research or clinical settings, taking into account both limitations and strengths. The current study used a qualitative approach to explore parents' views of issues in their children with ASD.

MATERIALS & METHODS

The study protocol was authorized by Semnan University of Medical Sciences' Ethics Committee (Code: IR.SEMUMS.REC.1399.289). Parents were informed about the research objectives and methodology, and their personal information was treated with confidentiality. Participants had the option to withdraw from the research at any moment, as participation was optional.

Study Participants

The study included all Iranian parents (fathers and mothers, separated) of children with ASD who were admitted to rehabilitation institutions across the country. The study included children with ASD identified by a psychiatrist, aged 3-13 years, and from a Persian-speaking home. The exclusion criteria included physical or mental diseases other than ASD in children. Between January and February 2021, 35 interviews were conducted in Iran. Purposive sampling included parents from diverse cultural, ethnic, and educational backgrounds, enhancing the research's trustworthiness. Interviews were conducted in person or over social media platforms like "WhatsApp". In Semnan Province, Iran, three parents agreed to participate in this study and were interviewed in person. The group received speech therapy from both private and academic clinics. The remaining parents (n=32) responded to the invitation via social media. After signing the consent form (provided through their WhatsApp private account), this group participated in an online interview. The group included individuals from several provinces (Sistan and Baluchestan, South Khorasan, Razavi Khorasan, Semnan, Gilan, Mazandaran, Golestan, Markazi, Tehran, and West Azerbaijan) who received rehabilitation services from a private clinic. The average ages of the parents and their children were 36.02 and 6.08 years. Of the parents, 2 were men and 33 were moms. The youngsters included 31 boys and 4 girls. Table 1 displays the demographic features of parents of children with ASD.

Data Collection

A master's student in speech therapy (supervised by supervisors) conducted semi-structured interviews with parents of children with ASD to assess their perceptions of ASD-related

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issues. The research objectives and conditions were conveyed to parents, and those who agreed to participate were advised of the interview time and location. The interviews began with a general, planned, and open-ended inquiry to gather further information from participants after a brief overview of the research and objectives. The interviewer asked questions about children's speech and language, such as "Does your child speak?" and "How are they talking?" Exploratory and introspective questions were used to clarify and complete replies, such as "Could you provide an example?" and "Could you elaborate?". The interviewer questioned questions about speech and language, such as whether it was one-word or entire sentences, and if it was understood. Do you need to translate someone's speech for others? Questions were asked with similar directions, and there was no duty to answer any of them. The interviewer asked more information from the parents to improve future communication with the interviewees. Interviews were recorded and transcribed verbatim. Interviews lasted until data saturation. Data saturation is a fundamental notion in qualitative research. To ensure a thorough understanding of parents' perceptions of problems in children with ASD, two additional interviews were conducted to ensure saturation.

Data Analysis

Graneheim and Lundman [35] presented a five-step strategy for data analysis. The interview process involves transcribing each interview immediately after completion, reviewing transcriptions for meaningful units, determining initial codes, categorizing codes based on similarities and differences, and identifying main themes within each category. A qualitative content analysis was conducted by analyzing each interview multiple times to extract relevant units and initial codes. Subthemes were created by combining related codes, and core themes were extracted. The research team evaluated interviews multiple times and provided feedback on code and unit analysis.

Rigor

We utilized Guba and Lincoln's [36] criteria to assess the study's rigor. We used sustained involvement, a coding system, member checks, and external audits.

(External observer and Transferability). The results were confirmed by a research team with over 5 years of clinical expertise with ASD. The researchers thoroughly evaluated and analyzed the interviews to confirm the criterion of long-term participation. To create a coding system, interview questions were planned and sent to families with particular instructions. After the interviews, families were asked to review the material, provide feedback, and accept the content. We consulted an external supervisor to confirm the results and provide specifics on the research processes, including content analysis.

RESULTS

This study evaluated the challenges faced by parents of children with autism spectrum disorder (ASD). A content analysis of interviews with parents of children with ASD identified meaning units, initial codes, subthemes, and 5 themes. Themes covered growth, language understanding, social communication, behavioral issues, and general health concerns. Table 2 shows the themes and subthemes identified from the interviews.

Social communication issues

Parents identified deficiencies in social communication skills as the most common problem in their children with ASD. Children with ASD may exhibit social communication disorders such as social avoidance, difficulty communicating with strangers, difficulty maintaining

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conversation, difficulties initiating and retaining conversations, decontextualized language, difficulty describing events and stories, difficulty making eye contact, and other communication issues. One parent attributed their child's incapacity to communicate with strangers to their presence in the same room as his teacher. His minimal eye contact prevents him from communicating effectively with others. He hides behind my back when communicating to avoid showing his shyness. "This is entirely due to his shyness." (Participant 2) A parent said that their child struggles with conversation introduction and retention. He needs someone else to continue the conversation. He ignores a child who wants to make friends with him because he lacks the ability to use multiple phrases. As a result, he is eventually left alone. (Participant #10) Two parents expressed concern about their child's inability to play with other children, stating that he sometimes ignores their activities. Occasionally, he participates in games but lacks understanding of the rules. (Participant #4) "He rarely plays with his peers and wants to play with his toy cars by himself." (Participant #10)

Behavioral problems

The study found that parents of children with ASD frequently reported behavioral concerns, including aggression, restlessness, poor temper, and self-harm. "He frequently expresses his emotions through aggressive behavior." For example, if we do not give him what he wants, he may tumble to the floor and hit his head against the ground or hurl anything on the floor. He is under pressurized due to these reactions. He hits me if I don't give him what he wants. In fact, I take the most hits in the family compared to his sister, younger brother, and mother. (Participant 2) One parent said that their child bites and pulls the hair of others, making them avoid him. He feels abandoned despite loving and hugging others. (Participant #6)

General health issues

Parents of children with ASD reported issues with diet, immune system, digestion, personal hygiene, and blood (cholesterol and glucose levels). Two parents reported that their child with ASD has a weakened immune system. Most of his health issues stem from kidney disorders. I am unable to follow the treatment plan for some of his ailments. For example, he does not comply with the dentist during dental care. The hospital canceled his anesthesiology appointment due to his autism diagnosis. He suffered greatly. He has impaired blood glucose and thyroid hormone levels and refuses blood tests. Our son is experiencing significant pain but is unable to articulate it. (Participant 15.) "It's challenging when your child can't tell you if they're hot or cold, or if the food heat hurts their tongue." He wouldn't notice if a needle was pushed into his foot. As a child, he didn't cry when he fell since he didn't feel it. He was like a statue. He is unable to express his feelings or complain about stomach or dental pain. For a while, I saw my youngster was uncomfortable. Despite brushing his teeth every night, I discovered something lodged in his teeth that bothered him, but he refused to discuss it. If the water is too hot, he is unable to speak. "He just stands up or his skin turns red." (Participant #22).

DISCUSSION

The purpose of this qualitative research was to evaluate parents' perspectives on ASD-related issues for children with ADS. The results classified children with ASD's main issues into five themes: developmental, receptive and expressive speech, social-communication, behavioral, and general health concerns. The parents' concerns are consistent with earlier quantitative research using questionnaires, standardized exams, and clinical and para-clinical

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evaluations. The current study found agreement among parents and specialists regarding ASD-related issues. We used a qualitative approach to assess parents' perceptions of these concerns, resulting in a thorough understanding of their impacts. Quantitative research have not adequately addressed this issue. Parents in this study identified developmental abnormalities, such as sensory, motor, and cognitive issues, as one of the most significant challenges for children with ASD. Locke et al. and Herlihy et al. found that parents of children with ASD aged 10-19 months were most concerned about motor abnormalities, which aligns with our findings. To diagnose and treat ASD, it's important to monitor neonate and baby growth indices. Early speech development is crucial for socialization in children with ASD, according to parents and clinicians [12, 37].

CONCLUSION

The current study found that behavioral issues were the primary indicator of ASD, which is consistent with Maskey et al. findings. The current study [16] found that children with ASD tend to be nervous and aggressive, with a higher risk of harming themselves or others. The findings from parent interviews align with past research in this area. Effective therapies to decrease or eradicate these behavioral abnormalities can benefit both children with ASD and their families. Despite extensive data, parents in our study placed less emphasis on eating, sleeping, digestive, and health difficulties. However, this does not diminish the importance of overall health for children with ASD. Research suggests that hunger and sleep disorders can impact speech, linguistic, cognitive, and motor development (14, 40). Parents of children with ASD should seek proper knowledge and adopt a different approach to these issues. 5. Conclusion. The study found that parents identified developmental, language, social communication, behavioral, and health issues as the main concerns for their children with ASD. Our results are consistent with previous quantitative investigations. Finally, parents' experiences with their children with ASD might provide valuable insights into their challenges.

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Conflict of Interest

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