

# The Challenges Experienced by Parents Regarding Sexual Maturation of Children with Autism Spectrum Disorder: A Qualitative Study

Moein Masuri<sup>1</sup>, Farideh Malekshahi <sup>2\*</sup>, Mozhgan Masoudi<sup>3</sup>

<sup>1</sup> General Practitioner, Lorestan, Khorramabad

<sup>2</sup> Social Determinants of Health Research Center, School of Medicine, Lorestan University of Medical Sciences. Khorramabad, Iran

<sup>3</sup> School of Nursing and Midwifery, Lorestan University of Medical Sciences, Khorramabad, Iran

---

## ABSTRACT

*Individuals with autism spectrum disorder exhibit sexual preferences comparable to those of their typically developing peers; however, their sexuality and sexual maturation are frequently overlooked. This qualitative study was conducted to ascertain parents' experiences of perceived challenges and problems related to the sexual maturation of children with autism spectrum disorder. This qualitative investigation utilized a study population comprising parents of children with autism spectrum disorder who met the inclusion criteria. The study was conducted in two autism education and rehabilitation centers in Khorramabad. Data were collected through semi-structured interviews with 20 parents and analyzed using a conventional content analysis approach. The findings revealed that 17 of the participating parents were female and 3 were male, with the average age of the affected children being  $13.40 \pm 2.98$  years. Seven subcategories were extracted from the study: lack of knowledge regarding sexual maturity of the affected individuals, lack of sexual education skills, concern about vulnerability, fear of social reactions, unclear future of sexual life, confrontation with sexual behaviors, and care deficiencies. Through the merging of similar subcategories, three main categories emerged: educational need, psychological stress, and ineffective actions. The primary challenges faced by parents in addressing the sexual maturity of their adolescent children with autism spectrum disorder stem from insufficient knowledge of autism spectrum disorder and the impact of this developmental condition on various aspects, particularly sexual maturity. Educating parents and children will contribute to improving the reproductive and sexual health of this vulnerable population.*

**Keywords:** Autism; Puberty; Sexual Behavior; Parents; Challenges of Experiences; Qualitative

---

## Introduction

According to the American Psychiatric Association's DSM-5, autism spectrum disorder (ASD) is defined as a persistent deficit in communication and social interaction across multiple domains, characterized by restricted patterns of behavior, interests, or activities. The overall prevalence of ASD in the United States is 2.47%, with a prevalence of 3.63% in boys and 1.25% in girls [1]. The precise number of affected individuals in Iran remains unknown. ASD is a lifelong condition necessitating ongoing rehabilitation services [2]. It is now widely recognized as a multifactorial disorder arising from the

interaction of genetic and non-genetic factors, with its prevalence having increased over the past two decades. The exact number of affected individuals in Iran is uncertain [3].

The severity of ASD is challenging to define due to the absence of clear boundaries between its various types [3]. However, the DSM-5 categorizes ASD into three levels: Level 1, indicating mild impairment that "requires support"; Level 2, indicating moderate impairment that "requires significant support"; and Level 3, indicating severe impairment that "requires very substantial support" [3]. Sexuality and sexual maturation in individuals

---

\* Corresponding author: Farideh Malekshahi. Social Determinants of Health Research Center, School of Medicine, Lorestan University of Medical Sciences. Khorramabad, Iran. Email: [malekshahif@yahoo.com](mailto:malekshahif@yahoo.com)

DOI: [10.22087/ijac.2024.498509.1038](https://doi.org/10.22087/ijac.2024.498509.1038)

This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

with ASD are often overlooked, despite these individuals having similar sexual preferences to their typically developing peers [4]. Puberty is characterized by numerous physical, psychological, and behavioral changes, which often pose challenges for young individuals with ASD and their families.

A significant challenge during puberty for individuals with ASD is the expression of their sexuality. Due to a lack of social understanding, these individuals may struggle to comprehend social rules and norms, potentially leading to the inappropriate display of natural sexual behaviors, such as masturbation, in public settings. Consequently, sexual behaviors represent one of the most significant behavioral issues in autism that emerge with the onset of puberty in adolescence [5].

Sexual behaviors in individuals with ASD are associated with their cognitive level. The term high-functioning autism (HFA) refers to individuals with ASD who do not have an intellectual disability, often possessing an estimated intelligence quotient (IQ) of 70 or higher [6]. The most commonly reported sexual behaviors among individuals with ASD include hugging, caressing, kissing, masturbation, oral sex, and vaginal or anal intercourse [7]. A systematic review found that 13% of adolescents with ASD discussed sex in public in a non-threatening manner, 29% engaged in inappropriate genital touching in public, and 13% masturbated in front of others [8]. Furthermore, the risk of sexual abuse for individuals with autism is a serious concern. Individuals with ASD face a risk of sexual abuse that is approximately three times higher, a risk of sexual violence that is 2.7 times higher, and a risk of sexual assault that is 2.4 times higher than that of the general population [9]. Parents often encounter challenges when their children with ASD exhibit signs of puberty and associated behavioral changes, such as masturbation. These parents seek to integrate these behaviors into their understanding of sex education for adolescents with ASD [10]. A study by Bais et al. examining parental perspectives on puberty in children with developmental disabilities revealed parental

uncertainty regarding the optimal support for their children in this context [11].

Research indicates that families of adolescents with ASD face considerable obstacles in accessing healthcare during puberty. Currently, there is limited evidence concerning sexual health outcomes, fertility, and service utilization among individuals with autism. Addressing this gap could enhance coordination and communication among families, schools, and healthcare professionals, thereby promoting healthy sexual development [12]. The family plays a crucial role in fostering and instilling healthy behaviors in adolescents. However, parents often feel embarrassed discussing sexual matters with their children and lack the requisite skills and experience [13]. Understanding parents' experiences with issues related to the sexual maturation of their children with ASD can aid in resolving these challenges and promoting the sexual and reproductive health of their children, as well as in developing educational and support programs for families of individuals with ASD. Conducting qualitative research to elucidate the challenges parents face in managing the sexual maturation of their children with ASD can provide researchers with a deeper understanding of this field.

Given the distinct social, cultural, and religious context of Iran compared to other countries, and the importance of sexual and reproductive health for individuals with autism, the present qualitative study aimed to explore parents' experiences of perceived challenges and issues related to the sexual maturation of their children with ASD.

## Materials and Methods

This study employed a qualitative approach with a conventional content analysis methodology. Data collection occurred from October to the end of December 2022. The research population comprised parents of children with autism in Khorramabad city who, based on the assessment of a specialist (child psychiatrist, psychiatrist, psychologist) and a written certification from the Disability

Commission of the Welfare Organizations of Lorestan Province, had a definitive diagnosis of high-functioning autism for their child and met the study's inclusion criteria.

The sampling method was purposive, with maximum diversity regarding background factors such as gender, education, marital status, age, and socioeconomic status, to select the most suitable participants [15]. The study's context included two primary autism education and rehabilitation centers in Lorestan province, Iran, affiliated with the province's Exceptional Education in Khorramabad city.

Participants were selected based on the results of continuous comparative analysis and unit questions, ensuring maximum diversity and specificity, so that their perspectives would reflect a comprehensive understanding of the phenomenon under investigation.

Data were collected through semi-structured interviews. If either parent primarily responsible for the care of the child with autism consented, the family was invited to participate in an individual interview. The sample size was determined by saturation, meaning data collection continued until no new and relevant concepts emerged. In qualitative research, saturation refers to the point at which code levels are considered complete [16]. The primary data collection method was in-depth, semi-structured individual interviews, with questions that were adaptable and developed in response to the interview process. Field notes were utilized as necessary, and interview guide questions were employed to ensure consistency. The initial responses of participants informed the subsequent questions in the interview guide. The interview commenced with a question regarding the observation of sexual maturity in the child (e.g., "Have you ever noticed sexual maturity in your child?"), followed by inquiries about the recognition of sexual maturity (e.g., "Are you able to recognize your child's sexual maturity?") and the management of the child's sexual maturity (e.g., "How did you feel when you noticed your child's sexual maturity? And what did you do?"). At the conclusion of the interviews, participating parents were invited

to elaborate on or mention any additional information they deemed necessary. The study's objectives and the confidentiality of the information were communicated to participants prior to each interview, and parental consent was obtained in writing. Arrangements for potential follow-up sessions were made at the end of each interview, contingent on the child's responses to the research questions. All interviews were recorded and transcribed verbatim by two independent authors, and were subsequently reviewed by the participating parents for accuracy.

Inclusion criteria encompassed a confirmed diagnosis of high-functioning autism spectrum disorder, absence of physical and mental retardation and other psychiatric disorders in the child (as verified by a written certificate from the Disability Commission), the presence of secondary sexual characteristics in the child with ASD, a minimum level of education, absence of chronic mental and physical illness, and full parental consent to participate in the study. Exclusion criteria included the unwillingness of participating parents to continue their involvement in the study, as well as a diagnosis of precocious or delayed puberty in the child with ASD.

#### **Data Analysis Method**

The MAXQDA software was utilized to manage qualitative data. Descriptive statistics, including mean, absolute frequency, and relative frequency, were employed to describe the individual characteristics of the parents. The qualitative data analysis in this study followed the steps of 1) implementing the entire interview, 2) determining the unit of analysis, 3) identifying the semantic unit, 4) summarizing the semantic unit, 5) generating initial codes, 6) categorizing similar initial codes into broader categories, and 7) identifying themes based on the method of Granheim and Lundman in 2004 [10].

#### **Ethical considerations**

All ethical considerations were based on research guidelines. Code of Ethics: IR.LUMS.REC.1401.165

## Results

In this study, the participating parents comprised 17 females and three males, with 19 being married and six holding a bachelor's degree. The age of the parents ranged from 30 to 57 years, with a mean age of  $40.75 \pm 6.79$  years. The affected children were aged between 9 and 21 years, with an average age of  $13.40 \pm 2.98$  years. The average number of children per participating parent was  $2.05 \pm 0.98$ . Regarding the number of children with ASD, one parent had three children with autism, while the remaining parents had one child with autism each. Concerning the gender of the affected children, 16 were male and four were female. Notably, none of the participating parents or affected children had received any education on sexual maturity for individuals with ASD.

The study involved the extraction of 985 primary codes from 20 interviews, which were subsequently summarized into meaning units. From these, 82 main codes were derived based on the similarity of the primary codes. Through the classification of similar codes, seven subcategories were identified, which were further consolidated into three main categories.

### 1. Educational Needs

The category of educational needs encompasses two subcategories: a lack of knowledge about sexual maturity in individuals with ASD and a deficiency in skills related to sex education

#### *lack of knowledge about sexual maturity in patients*

In the current study, the majority of parents and participants reported a lack of adequate knowledge regarding sexual maturity in individuals with ASD. Participants indicated that due to insufficient education in this area, they were not fully aware of the cognitive challenges and the communication, emotional, and social deficits experienced by children with ASD. Consequently, they were uncertain whether their children with ASD exhibited normal sexual maturity comparable to their

neurotypical peers in terms of symptoms and behavioral changes.

In a related context, a mother with a high school education, who is a housewife and has a 15-year-old son with ASD (Participant 4), expressed: *"I believe that because these children face challenges and are not like healthy children, they do not comprehend many things. Due to their understanding, I do not think they recognize the changes occurring in their bodies during puberty. I am puzzled as to why my son engages in certain sexual behaviors, such as touching his penis. This behavior seems abnormal to me, suggesting there is another reason beyond puberty."*

The findings of this study revealed that most parents lacked sufficient and accurate information regarding the physical, psychological, and emotional changes that occur during puberty in children with ASD. Furthermore, the results indicated that the majority of participating parents did not possess adequate and precise knowledge about sexual health care.

#### *Lack of Sexual Education Skills*

In the current study, a significant challenge encountered by all participating parents concerning their children's sexual maturation was their lack of ability and skills in educating their children with ASD about sexuality. None of the parents reported that their children received support from educators or therapists. In this context, the mother of a 12-year-old boy with ASD (parent number 20) expressed: *"They want to expel my son from school. His teachers complained about him. They say that your son rubs himself on other people's sensitive and private parts, laughs, and enjoys his work. I told them what to do. Well, teach him. He did not understand that this was inappropriate. His teachers say that our only duty is to teach lessons: it is the duty of therapy and speech therapy. We have no duty, and we do not know how to teach him about sex. I took him to the doctor, who said that this behavior was due to puberty. The patient did not require medication. I do not know how to teach him about sex. I was left wondering what I would do if they expelled him."* Another challenge faced by most of the participating parents was the lack of information regarding the content of puberty education for children with ASD. Most parents indicated that due to difficulties in

comprehension and the potential for misunderstanding, they could not utilize the same content as that used for neurotypical adolescents to teach sexual maturity.

## 2. Psychological Stress

Psychological stress has three subcategories: concern about vulnerability, fear of social reactions, and an uncertain future for sexual life.

### *Concern about vulnerability*

A significant psychological tension experienced by all the parents in this study was the concern regarding the vulnerability of their children with ASD. In this regard, a high school graduate and housewife mother with a 16-year-old son with ASD (parent number 11) stated: *"In our society, relationships between girls and boys who are not related to each other are forbidden, but my son does not understand this. I am afraid that he will go out on the street or elsewhere and see a strange girl like her and hug her. My son does not even understand that he should not change his clothes in front of others and should not get naked, and that is inappropriate."*

### *Fear of social reactions*

Most parents participating in this study were Most parents participating in this study expressed concern about the social consequences of sexual changes in their children with ASD. Parents believe that society lacks a proper understanding of this disorder, and most individuals, upon observing the signs of sexual puberty in the affected child and the manifestation of their sexual behaviors in public, attribute it to poor parenting, which ultimately leads to the isolation of the affected individual, the family, and societal rejection. Accordingly, a mother with secondary education and a housewife of a 13-year-old boy (parent number 10) remarked: *"Since my son grew up, his behavior has changed. He hugs the girls in the family tightly but has nothing to do with their boys. The concern was expressed that the observed behavior of the son might deter family members, such as siblings or the spouse, from visiting the household."*

### *Uncertain future of sexual life*

The study's findings indicate that a significant psychological concern for many participating parents is addressing the future sexual needs of their children with ASD. In this regard, a mother with secondary education, who is a housewife and has a 9-year-old son with ASD (parent number 18), remarked, *"My son has developed a habit of placing his hand inside his pants and touching his penis. A medical consultation revealed that this behavior is considered normal as part of his developmental process. While I am relieved that he is gaining some understanding, I am more troubled by the implications of this growth. He may not be able to marry and enjoy life as others do. What is his comprehension of sexuality? It seems he is destined to endure more hardship."*

## 3. Ineffective Measures

The primary challenge identified by all participating parents in this study was managing the sexual behaviors of their children with ASD and their inability to effectively control these behaviors.

### *Confronting Sexual Behaviors*

A majority of the parents reported employing passive strategies when faced with the sexual behaviors of their children. For instance, the father of a 14-year-old son with ASD, who is a bachelor and employed (parent number 14), stated, *"My son has injured himself by rubbing his penis with his hand. I am at a loss as to how to prevent this behavior. My only recourse has been to physically restrain him, but this only provides a temporary solution, as he resumes the behavior shortly thereafter. I am becoming increasingly frustrated, and there is a lack of guidance available."*

### *Care Deficiencies*

The study's results highlight the inability of participating parents to adequately provide healthcare for their affected children. Many parents reported that their children lack the necessary education and skills to care for their genital health, potentially leading to harm. In this context, a mother with a bachelor's degree, who is self-employed and has a 12-year-old daughter with ASD (parent number 12), expressed, *"My daughter has been menstruating for*

*two months, yet I am hesitant to allow her to manage her sanitary napkin independently. I fear she may inadvertently stimulate herself or misplace the pad, causing irritation or soreness, as she has not been taught how to handle this, and I am uncertain how to instruct her."*

## Discussion

The present study, which aimed to explain the challenges experienced by parents regarding the sexual maturation of children with ASD, showed that the most important challenge experienced by participating parents was the lack of sufficient knowledge and the need for training to recognize the characteristics of sexual maturation in individuals with ASD [17].

An additional educational need identified by parents in the current study was their lack of skills in providing sex education to children with ASD, particularly concerning the selection of content and methods. A 2018 study by Hash-Pride et al. on mothers' experiences in supporting the sexual maturation of boys with autism and intellectual disabilities highlighted a significant dilemma faced by mothers in delivering sex education to their ASD sons. These mothers acknowledged the importance of helping their sons comprehend social rules and norms, yet they expressed apprehension about the potential consequences of imparting sexual information.

The findings of the present study indicate that psychological stress is a primary challenge experienced by parents. From the parents' perspective, their concern primarily stemmed from the heightened vulnerability of children with ASD to sexual abuse. Many parents believed that their child with ASD could be targeted by abusers due to their inability to comprehend and report sexual abuse, as well as their lack of understanding of social rules and norms. A qualitative study by Naut et al. in 2017 on the experiences of mothers raising girls with autism spectrum disorder identified concerns regarding the sexual desires and vulnerability of children with ASD in sexual relationships [19]. The psychological stress

reported by parents in the present study was also linked to fears of societal reactions to the sexual behaviors of their child with ASD, and the potential ostracization of the family due to inappropriate behaviors, such as public masturbation. In a study by Pride et al. in 2018, some mothers reported their children's lack of social understanding manifesting as inappropriate public masturbation, and these mothers were particularly concerned about societal reactions to such behaviors [5].

Another significant challenge faced by parents in this study was the perceived ineffectiveness of their efforts to manage sexual behaviors and provide reproductive healthcare for their children with ASD. A 2020 study by Kenney et al. on a parental program for communicating with children with ASD about sexuality and sexual misconduct found that participating parents often realized they lacked sufficient skills and knowledge to address their child's sexuality and sexual behaviors, leading to concerns about the efficacy of their methods in this domain [20].

## Conclusion

According to the results of this study, the main factor influencing the emergence of parents' challenges in dealing with the sexual maturation of their children with ASD is the lack of adequate knowledge of autism spectrum disorder and the impact of this developmental defect on various aspects of the affected person's life, especially sexual maturation, which, along with the cultural sensitivity of society towards sexual issues, has created many psychological challenges for parents. Therefore, by educating parents and affected children about the sexual maturation of ASD adolescents, we can take an effective step in promoting the reproductive and sexual health of this vulnerable group of society, as well as reducing psychological and social tensions and, ultimately, the well-being of families of people with autism spectrum disorder.

### Recommendations and Limitations:

-Parents felt embarrassed and ashamed of expressing their ASD child's sexual problems, which was controlled by conducting individual interviews in a private setting and assuring parents that the information would remain confidential.

The interview session was boring. To control this limitation, the maximum interview session time was 120 minutes (including a 20-minute break), and subsequent sessions were held, if necessary, based on the parents' requests.

### Conflict of Interests

The authors declare that they do not have any conflict of interests.

### Acknowledgments

The authors thank the Vice Chancellor for Research and Technology, Lorestan University of Medical Sciences, for approving this study. We also thank all participating families for their valuable cooperation.

## References

1. Maenner MJ, Shaw KA, Baio J, Washington A, Patrick M, DiRienzo M, et al. Prevalence of autism spectrum disorder among children aged 8 years—autism and developmental disabilities monitoring network, 11 sites, United States, 2016. *MMWR Surveillance summaries*. 2020;69(4):1.
2. Noori F, Tiwari S, Padickaparambil S, Pothiyil DI. Parenting Challenges and Reasons for Not Availing Rehabilitation Services Among Families of Adolescents with Autism Spectrum Disorder: A Qualitative Study. *Indian Journal of Psychological Medicine*. 2022;02537176221096769.
3. Williams T. *Autism Spectrum Disorders: From Genes to Environment: BoD—Books on Demand*; 2011.
4. Bölte S, Girdler S, Marschik PB. The contribution of environmental exposure to the etiology of autism spectrum disorder. *Cellular and Molecular Life Sciences*. 2019;76(7):1275-97.
5. Pryde R, Jahoda A. A qualitative study of mothers' experiences of supporting the sexual development of their sons with autism and an accompanying intellectual disability. *International Journal of Developmental Disabilities*. 2018;64(3):166-74.
6. Alvares GA, Bebbington K, Cleary D, Evans K, Glasson EJ, Maybery MT, et al. The misnomer of 'high functioning autism': Intelligence is an imprecise predictor of functional abilities at diagnosis. *Autism*. 2020;24(1):221-32.
7. Hayward B, Saunders K, editors. *Sexual behaviours of concern in young people with autism spectrum disorders*. 10th Annual Conference of the Australasian Society for the Study of Intellectual Disability; 2010: Department of Human Services Victoria
8. Hellemans H, Colson K, Verbraeken C, Vermeiren R, Deboutte D. Sexual behavior in high-functioning male adolescents and young adults with autism spectrum disorder. *Journal of autism and developmental disorders*. 2007;37:260-9.
9. Brown-Lavoie SM, Vecili MA, Weiss J. Sexual knowledge and victimization in adults with autism spectrum disorders. *Journal of autism and developmental disorders*. 2014;44(9):2185-96.
10. Gunarhadi G, Sugini S, Supratiwi M, editors. *Parents' Experience in Coping with Sexuality Matters in Adolescents with Autism Spectrum Disorders*. Proceedings of the 5th International Conference on Learning Innovation and Quality Education; 2021.
11. Biswas S, Tickle A, Golijani-Moghaddam N, Almack K. The transition into adulthood for children with a severe intellectual disability: parents' views. *International Journal of developmental disabilities*. 2017;63(2):99-109.
12. Holmes LG, Shattuck PT, Nilssen AR, Strassberg DS, Himle MB. Sexual and reproductive health service utilization and sexuality for teens on the autism spectrum. *Journal of Developmental & Behavioral Pediatrics*. 2020;41(9):667-79.
13. Alldred P, Fox N, Kulpa R. Engaging parents with sex and relationship education: A UK primary school case study. *Health Education Journal*. 2016;75(7):855-68.
14. Creswell JW, Creswell JD. *Research design: Qualitative, quantitative, and mixed methods approaches*: Sage publications; 2017.
15. Gentles SJ, Charles C, Ploeg J, McKibbin KA. Sampling in qualitative research: Insights from an overview of the methods literature. *The qualitative report*. 2015;20(11):1772-89.
16. GLOBAL I. What is Challenges? USA: Timely Know ledge; December 31, 2022. Available from: <https://www.igi-global.com/dictionary/sustainability-of-social-enterprises/3642>.
17. Goli S, Noroozi M, Salehi M. Parental experiences about the sexual and reproductive health of adolescent girls with intellectual disability: A qualitative study. *Iranian journal of nursing and midwifery research*. 2020;25(3):254.
18. Pownall JD, Jahoda A, Hastings R, Kerr L. Sexual understanding and development of young people with intellectual disabilities: Mothers' perspectives of within-family context. *American journal on intellectual and developmental disabilities*. 2011; 16(3): 205-19.
19. Navot N, Jorgenson AG, Webb SJ. Maternal experience raising girls with autism spectrum disorder: A qualitative study. *Child: care, health and development*. 2017;43(4):536-45.
20. Masoudi M, Maasoumi R, Effatpanah M, Bragazzi NL, Montazeri A. Exploring experiences of psychological distress among Iranian parents in dealing with the sexual behaviors of their children with autism spectrum disorder: a qualitative study. *Journal of Medicine and Life*. 2022;15(1):26.