

PARENTS' EXPERIENCES IN DEALING WITH THE DEVELOPMENT OF ADOLESCENT AUTISTIC SEXUALITY IN WEST JAVA PROVINCE: A PHENOMENOLOGICAL STUDY

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ABSTRACT

Families who have autistic children may experience a burden in their lives. Many conditions can trigger behaviour, especially in the face of sexual development. Little is known about how parents deal with their autistic children who are entering adolescence and are experiencing sexual development. What parents do to deal with the development of adolescent autistic sexuality can be found in qualitative research. The participants are parents with children who are autistic. The researcher contacted the parents and explained the informed consent; if the parents agreed, they would sign the informed consent and then decide to place a time to interview the participant with the researcher, interviews with participants from January 2023-March 2023. This study aims to explore family experiences in dealing with sexuality development in adolescents with autism spectrum disorders. This phenomenological study collected data through in-depth interviews with semi-structured open-ended questions of seven child participants with autism spectrum disorders. Eleven themes constructed from this study are shy children when reminded not to hold their genitals, children are distracted when holding their genitals, children going through menstruation, children showing sexual behaviour by opening their pants, children holding their genitals, children hugging their mothers and seek attention, children stimulate themselves and others, children are easily aroused, children cannot distinguish boys and girls children like to clamp their genitals, And the child likes the prone position on the floor. Parents who feel that their child is currently facing the developmental phase of adolescent sexuality independently. They recommend that Parents provide adequate support, including appropriate education and open dialogue about the changes their child is experiencing.

KEYWORDS Adolescent Autistic, Development, Sexuality, Parents' Experiences



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INTRODUCTION

Puberty is when a person undergoes major changes related to physical changes that occur as part of the transition from childhood to adulthood. (Cummins, Pellicano, & Crane, 2020). All people are born sexual beings and must develop their sexual potential in some way. (Rashikj-Canevska, Nikolovska, Ramo-Akgun, Troshanska, & Chichevska-Jovanova, 2023). It becomes a challenge for autistic individuals, especially for those entering adolescence, because they become interested in their sexuality. Previous literature has shown that autistic adults' sexual desire and satisfaction are at no different levels than those of non-autistic peers. However, some differences have emerged based on sex, sexual orientation, and sexual desire. (Kohn, Vidal, Chiao, Pantalone, & Faja, 2023). It should be noted that autistic adults can and do have sexual and romantic relationships. Evidence shows that their relationships are shorter in duration, although this is not universal. Autistic people can be happy for decades, just like non-autistic people. (Douglas & Sedgewick, 2023).

Life experiences of autistic people tend to be more damaging than non-autistic people, from bullying and ostracism to being victims of crime to being victims of sexual violence. 90% of autistic people experience these forms of abuse in some form during their lives (Pedgrift & Sparapani, 2022), and this is a concern for parents in dealing with the sexual development of their children who have adolescent autistic children. Individuals with neurodevelopmental disabilities are more vulnerable to sexual violence, in part due to limited access to effective interventions as well as barriers associated with their disability (e.g., lack of control over decisions and limited communication skills). These obstacles can be minimised with targeted instructions. Although they develop sexual desire and interest in relationships just like neurotypical individuals, they are often excluded from education that addresses sexual health and social development (Pedgrift & Sparapani, 2022). Parents worry that if their children grow up in adolescence and adulthood, they will show sexual behaviour that hurts themselves and others around them. So, it is necessary to discuss the experience of parents in accompanying their children who are experiencing autistic sexual development after adolescence. This is rarely researched, considering this is something taboo to talk about and ignored by families who have autistic children and adolescents. We sought to uncover how autistic adults' sexual development and how they feel can help them prepare for safer sexual enjoyment. While parents express fears related to the onset of puberty in this population (e.g., unwanted sexual exposure and childhood loss), these fears are rarely actualised. The purpose of the study was to explore the experiences of parents accompanying their children who are experiencing sexual development in autism in adolescent adulthood.

RESEARCH METHOD

Research design: Qualitative phenomenology. The participants are parents with autistic children recruited by snowball sampling. The researcher came to disability

school and explained the result aim to the teacher. They had a teacher give the name of the parent with autistic children. The researcher contacted the parents and explained the informed consent; if the parents agreed, they would sign the informed consent and then decide to place a time to interview the participant with the researcher. The participant's data is not published with anybody; we respect their privacy by not sharing it with another party. One-to-one interviews collect personal data. The interview is transcribed verbatim, and then the same coding is grouped into the same sub-sub theme until we have the last theme. The parents have the right to reject and withdraw as the participant. Research subjects: Parents who have autistic children in their teens. Seven participants participated in this study. Our research subjects were parents of autistic children. Data Collection Techniques: In one interview, we collected data using a Sony Voice Recorder ICD-PX440, then transcribed word for word. Data Collection Instrument: Topic Guide Interview. We use the Topic Guide Interview as a tool for collecting data. Data was analysed using thematic analysis by following these steps: Data Collection through in-depth interviews or written. This research has received permission for STIKES research ethics with number 026/D/KEPK-STIKes/I/2023.

RESULT AND DISCUSSION

Seven participants were recruited as samples for this interview. They are parents of children with autism. The parents of children >55 years old are all Sundanese, have bachelor-level education (4), and are retired from work (2).

The range of their children with ASD is 15-17 years; six of them are boys; one is a girl; boys show sexual development behaviour which is shown in different ways, while girls have menstruation. Participant demographic data can be seen in the table below.

Table 1: Characteristics of Respondents

Criteria	Total
<i>Gender</i>	
Female	7
<i>Family caregivers/parents</i>	7
<i>Age</i>	
25-45 yo	2
46-55 yo	2
>55 yo	3
<i>Tribe</i>	
Sunda	7
<i>Educational level</i>	
High school	2
Bachelor	4
Master	1
<i>Occupation</i>	
Government employ	1
Teacher	1

Pensioner	2
Handyman/worker	1
Wife household	2

We found 11 themes of sexual development in adolescents with autism from interviews with participants from January 2023 to March 2023. The described by 7 participants (seven participants), as can be seen from the following expressions:

1. Children are embarrassed when reminded not to touch their genitals, as seen from the following expressions: participants (seven participants), as seen from the following expressions:

"No, he is not angry; it seems like he knows that, if he is seen in front of someone, he is embarrassed or something like that. Actually, he is aware" (P1)

"We are worried, right?" (P3)

"He is embarrassed to be reminded of it" (P5)

2. The child is distracted when touching his genitals, as can be seen from the following expression:

"I just leave it alone, but sometimes I leave it alone, but if it has been too long, I usually divert it, for example, towards Mas; there is this food; come on, let us go." "Usually until he takes off his trousers or not" P6

"Yes, I want the child not to take off his trousers." P3

"The family's hopes will not be diverted for long" P7

3. The child goes through the menstrual period, as can be seen from the following expression:

"If it is us, then we will just support it; the child wants to be clean" P1

Yes, he is a cleaning person." (P2)

"If there is a problem, usually it is us, who can handle it, because we are teenagers, and the child is a girl, then it is the mother" P1

"I train even though it is a bit difficult and takes a long time, at least the child knows it has to be cleaned" (P6)

4. The child shows sexual behaviour by opening his trousers, as can be seen from the following expression:

"On his stomach while exposing his genitals?"

Yes, his pants were also opened, coincidentally my son is a boy" (P1)

"likes to masturbate alone (P2)

"likes to show inappropriate sexual desires..." (P7)

5. The child holds his genitals, as can be seen from the following expression:

"Oh yes, he likes to touch his genitals, which when he wants to sleep, sometimes he pinches them, maybe he feels better when they are warm all the time" (P6)

sometimes he puts his hand in his genitals" (P2)

6. The child hugs his mother and seeks attention, as can be seen from the following expression:

"He's just aggressive, aggressive; how can you say that he likes hugging, he likes hugging, looking for attention" P1

7. Children stimulate themselves and others, as can be seen from the following expression:

sometimes holding her breasts, holding her own breasts.

Hold her own breasts? or the child who is sleeping?

He holds her own breasts, makes her aroused, then shows them to her...

sometimes to her friend, sometimes to her sister, that is it..."P1

"Sometimes he kisses, sometimes he sticks to her body" (P7)

8. Children are easily aroused, as can be seen from the following expressions:

"At most, how many minutes, more or less 1 minute, because he sees the situation too, if he, she, is at a loss, well, look at this therapist, look at him, look at him, he will immediately change again, become normal again, but if the therapist is distracted, he is like that again, we sometimes come here and there, right, we already know his behaviour..."(P2)

9. Children cannot differentiate between men and women, as can be seen from the following expression:

"He cannot differentiate, yes he cannot differentiate between women and men, that is his position.... "If he sees a child or friend lying down, he feels aroused, he likes to come around too," P1

10. Children like to pinch their genitals, as can be seen from the following expression:

"At home, yes, at least he has started to pinch his genitals in his room" P1

11. Children like to lie prone on the floor, as can be seen from the following expression:

"As for the boy, he just seems like that, maybe around the age of 17 I saw him lying on his stomach on the floor like that." P1

Discussion

This study presents an exploration of parents' experiences in accompanying their children who are experiencing sexual development in adolescents with autism. The findings in this article are that parents always remind their children if they see their child's inappropriate sexual behaviour, even though their child always shows sexual behaviour by opening their trousers or touching their genitals. In this case, children try to find a comfortable place for them to carry out their sexual behaviour by holding their genitals, pinching their genitals, and up to a prone position, which means the child is comfortable with their sexual behaviour and enjoys it. Parents also discuss that children like to seek attention by hugging their mothers as a sign that they are seeking attention, so their children show behaviour that makes their mothers comfortable so that their mothers will leave their children, and their children will repeat the same thing by opening their trousers and touching their genitals. The findings in this article show that autistic teenagers often play with their genitals at home without looking at the place. Can be in the living room, on a chair, on the floor and in a room alone in a prone position, where their genitals touch the floor, and the child enjoys what he is doing. This study also found that

teenage autistic children have high sexual desires/desires, which are also like other normal children. In this case, children cannot be left alone because their children can approach and touch people around them, whether male or female. Often parents do not dare to leave their children alone at home if there are other people around, so they must be accompanied and given extra attention so that their children do not show sexual behaviour in the wrong places. In this case, the teenage autistic child lacks the education they receive, which means they are not ready for relationships and the things they want to learn to equip them better.

The study also found that the participants' sexual behaviour was masturbation. However, they explored various things by touching their genitals and opening their trousers and doing it on the floor of the house, on the floor, in the bedroom, and in rooms where other people were not present or quiet. Broader issues, such as when other family members are in difficult work situations. Overall, this research reinforces that masturbation is very common among autistic people. This study seeks to build on that knowledge by exploring how children stimulate themselves and others. They are easily stimulated. Autistic people feel that being autistic means interacting with other people and with themselves, so it is possible that they could do harmful things that have the potential to harass them. One of the new findings from this work is the description of how the perpetrator deliberately opened his trousers, grabbed his genitals, and touched them to the floor or sofa. The most frequently discussed are playing with one's genitals without caring about where one is or who is around them in social situations to strengthen one's desire and attraction to other people of one's age who are around them - emphasising the message that they do not understand social interaction properly to pretend that the behaviour is not wrong.

Autism is a heterogeneous neurodevelopmental condition characterised by repetitive patterns of behaviour, restricted interests (Cho et al., 2023). It turns out that even though they are autistic, girls want to clean their menstrual scars and show their perfectionism by frequently cleaning their sanitary napkins during menstruation. The main implication is that autistic girls may be more likely to be missed because their social interaction profile is poorly understood and is only just beginning to be systematically explored. Families need to understand their child's conversational language profile, which can inform the development of support to meet the unique needs of girls and women. (Cho et al., 2023).

Most parents have significant concerns about their daughters' future, either about their ability to live independently or their potential vulnerability to exploitation. (Sedgewick, Hill, & Pellicano, 2018)

Lack of understanding of sexuality and adequate sexual education makes autistic adolescents more vulnerable to risks and unwanted or problematic sexual experiences. (Pecora et al., 2020). The results of this study show that autistic teenage children can be aroused when they see friends of the same age, whether male or female. It turns out that autistic boys and girls are the same as non-autistic boys and girls in referring to friendship when defining the meaning of friendship. (Libster, Knox, et al., 2023). Many autistic children have a desire to form relationships with others but often have difficulty developing and maintaining friendships. Autism spectrum disorder (ASD) is a neurodevelopmental condition

characterised by challenges in social interactions and communication, difficulties with peer relationships, and restricted and repetitive behaviours, interests, and activities.(Libster, Knox, et al., 2023). It turns out that autistic adolescents have a higher rate of various types of violence than non-autistic adolescents.(Gibbs, Hudson, & Pellicano, 2023).

Autistic adolescents are more likely to be victims of sexual abuse, but they are less likely to be perpetrators of sexual abuse than non-autistic adolescents (Bowden et al., 2022). This study found that the risk of experiencing these types of sexual violence was not greater in autistic students compared to non-autistic students (Libster, Kasari, & Sturm, 2023). They are more susceptible to situations where they may be forced or persuaded to engage in sexual activity that they do not want or fully understand. (Pecora et al., 2020), to effectively support their sexuality, there needs to be a paradigmatic shift in sexual education approaches and support for people with autism (Morais Brilhante et al., 2021). The way the brain processes language and social functions in individuals with ASD can differ between men and women due to differences in brain structure or function that are influenced by gender (Allen, Leon-Attia, Shaham, Shefer, & Gabis, 2020). Individuals with high levels of emotion show difficulty maintaining calm and are usually sensitive to stimuli that evoke negative emotions (Pisula, Kawa, Danielewicz, & Pisula, 2015).

CONCLUSION

Sex is an important factor that affects relationships. This study also found that teenage autistic children have high sexual desires/desires, which are also like other normal children. The sexual development of autistic adolescents needs extra assistance and attention from their parents so that their children do not show sexual behaviour in the wrong place. They recommend that Parents provide adequate support, including appropriate education and open dialogue about the changes their child is experiencing.

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