# **Original Research Article**

DOI: https://dx.doi.org/10.18203/2394-6040.ijcmph20211210

# Sexual education for adolescent autism spectrum disorders: an interpretative phenomenological analysis

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**Received:** 07 September 2020 **Revised:** 08 November 2020 **Accepted:** 12 November 2020

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#### **ABSTRACT**

**Background:** The need for sexual education for adolescents with ASD in the formal education setting is increasingly important. The "taboo" perception of talking about sexual development and the absence of sexual education for adolescents with ASD in schools and therapy centers, then forces parents to take full responsibility for the sexual development of adolescents with ASD. The imbalance between the needs of sexual development, sexual education facilities, and the limitations of adolescents due to ASD disorders suffered, placing adolescents with ASD are in a group that is vulnerable to sexual exploitation and abuse. This study discusses the experiences of parents in meeting the sexual development needs of adolescents with ASD.

**Methods:** In-depth semi-structured interviews were conducted with 10 parents who have teenagers with ASD in West Kalimantan, Indonesia.

**Results:** The results showed a sexual orientation, romantic behavior of adolescents with ASD, sexual harassment committed, and experienced by adolescents with ASD and sexual education efforts provided by parents to adolescents with ASD.

**Conclusions:** These findings indicate the emergence of sexual education emergencies needed by ASD adolescents in the formal education setting to facilitate the needs of the adolescent stage of sexual development, especially those with ASD as part of improving adolescent quality of life and preventing sexual harassment.

Keywords: Adolescents, Autism spectrum disorders (ASD), Sexual education, Sexual harassment

#### **INTRODUCTION**

Sexual education in adolescents with Autism Spectrum Disorders (ASD) is an urgent need at this time. In addition to improving health status, sexual education can also improve the emotional, mental, and social well-being of adolescents with ASD. The rise of cases of sexual harassment in adolescents with ASD that is happening now also reinforces the importance of sexual education to be immediately carried out.<sup>1-5</sup> Unfortunately, cultural factors and eastern values adhered to by people in Indonesia have resulted in sexual education in Indonesia

is considered a taboo subject to be discussed or even held, so that the need for sexual education for adolescents with ASD has not been able to be implemented in school settings or therapy centers. On the other hand, parents are required to meet the needs of adolescents with ASD, not least the needs related to adolescent sexual development to maintain quality of life and prevent acts of discrimination related to sexual behavior aimed at adolescents with ASD for example in cases such as exposing genitals, doing masturbation in public space.<sup>67</sup>

ASD in adolescents has a broad impact, not only for adolescents themselves, but also for parents, caregivers,

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families, communities, and countries. This is because ASD disorders can result in a decrease in the quality of life of children, whether it is in the present and in the future. ASD also causes stress and depression for parents, caregivers and families due to the full dependence of children, discrimination in society, and an increased burden on the nation's future generation of people diagnosed with ASD. The stage of sexual development is a stage of development that adolescents must go through, as well as adolescents with ASD. In adolescence, an individual with ASD will experience sexual development that is no different from adolescents in general, such as secondary sex development, namely hair growth in the armpits, genitals, mustache, nocturnal orgasm in boys and menstruation in girls. 4.10-12

ASD is a comprehensive developmental disorder that occurs in children that affects the skills of thinking, behaving, behaving and repeating movements with an increase in the incidence of the fastest cases in the world.9,13-16 Data from WHO in 2019 revealed that at present 1 out of 160 children in the world is detected ASD.7 This data is supported by a report from the CDC in 2018 which revealed that currently there has been an increase of 15% in the world's ASD population.<sup>17</sup> Although the ASD population in developing countries is not yet known with certainty, the tendency to increase in the population of people with ASD is also expected to occur in this region. In Indonesia, an increase in cases of ASD occurs significantly, as many as 500 children each year are diagnosed with ASD for reasons that are not yet known.<sup>7,18</sup> One of the provinces that have become targets of emergency response to ASD is West Kalimantan. West Kalimantan is a province with 194 people with ASD each year.<sup>19</sup> Increased cases and the unpreparedness of adolescents with ASD in dealing with this stage of adolescence can result in anxiety that can worsen the condition of ASD sufferers and the repetition of the burden that continues to occur in parents. 4,10-12,20,21

The absence of sexual education programs for adolescents with ASD makes parents the primary agent in meeting the sexual development needs of ASD adolescents, amid limited information and support felt by parents, lack of experience in providing sexual education to ASD adolescents, low levels of parental confidence, confusion about when and the right way to start providing sexual education, as well as concerns about the appropriateness of sexual education provided. 1,4,22-26 This study aims to explore the experience of parents in providing sexual education to children or adolescents with ASD.

## **METHODS**

The data collection of this research was carried out in the city of Pontianak, West Kalimantan for six months (January 2019 to June 2019). The process of recruiting study participants was carried out at schools for children with special needs (ASD) and therapy centers in Pontianak. Qualitative phenomenological analysis using a

maximum variety of purposive sampling techniques was carried out to explore, analyze and describe the experiences of parents from diverse backgrounds in providing sexual education to their children (adolescents with ASD). 1,27,28 The study participants' inclusion criteria were as follows: parents who have teenagers with ASD, ages 10-19 years, signed informed consent, can speak Indonesian. Exclusion criteria: parents who have teenagers with ASD and double handicaps. Each participant who underwent an interview received a transportation change fee of 5 USD. All interviews conducted involving participants were conducted with deep semi-structured techniques which were recorded with a recording device and equipped with field notes.

In-depth interviews were conducted at a place mutually agreed upon by participants such as at home, school, and a quiet cafe, and comfortable for participants to tell. Data analysis in this study was performed using the seven stages of Collaizi in the qualitative research method of interpretative phenomenological analysis: transcripts and reading the results of interviews to understand the meaning of conveyed by research participants, determining keywords, giving meaning to each keyword, form sub-themes, and themes, describing phenomena, narrating phenomena to be more easily understood, and validating participants regarding statements and findings obtained. 28,29 For the validity of the data, this study uses four ways namely credibility, transferability, dependability, and confirmability. <sup>28,30</sup> This research has been through an ethical testing process and is declared to have passed the ethical test number 54.A / II.I.AU / KET.ETIK / II / 2019 from STIK Muhammadiyah Pontianak, West Kalimantan, Indonesia.

# **RESULTS**

The study population included 10 parents who cared for their children with ASD in West Kalimantan. The average age of study participants was 40 years with an age range of 32-54 years. The majority of participants have higher education status. Four participants came from the Malay tribe, and the rest came from different tribes. Six participants were mothers (five biological mothers and one adoptive mother) and four participants were biological fathers with ASD. The majority of participants have teenagers with ASD aged 13 years. This study produced four main themes, namely: 1. Adolescent sexual orientation with ASD; 2. Romance behavior of adolescents with ASD; 3. Sexual harassment in adolescents with ASD; 4. Attempts made by parents to provide sexual education.

# Adolescent sexual orientation with ASD

Parents who participated in this study described the same phenomenon of sexual development between adolescents with ASD and adolescents in general. They hinted at the awareness and shock towards puberty behavior exhibited by adolescents with ASD, especially behaviors of

attraction towards the opposite sex. Behavior of interest towards the opposite sex shown by adolescents with ASD, illustrates the sexual orientation shown by adolescents that occur naturally in accordance with human nature in general. This study did not find any deviation in sexual orientation that occurred in adolescents with ASD:

- "... recently...maybe he is going through puberty ... he likes holding hands (opposite sex), likes his girlfriends, towards me as his mother he likes to kiss me, he likes to see a beautiful teacher .. haha ... that's how he behaves ... (P1)
- "... when walking with me, he becomes embarrassed when he sees a girl at the mall ... he plays his cellphone by looking at a Korean girlband ... a ... he likes it ... sometimes he likes to smile by himself ... I reprimand him .. what is that ... he becomes embarrassed .. no ..no he said .. but we understand, right .. "(P4)
- "... she seems like she likes her male teacher ... when she goes to school ... or for tutoring ... she uses sexy clothes ... something short. Then when she is in class she likes to smile on her own because she sees her male teacher ... "(P5)

On the other hand, the results of this study also revealed that there were still parents who did not know that adolescents with ASD had the same sexual development as teenagers in general. This is possible because of a lack of parental knowledge about the stage of adolescent growth and development with ASD and the absence of signs of puberty shown by adolescents with ASD:

"... not yet ... there hasn't been any interest ... as usual ... I don't know if a child like this (child with ASD) is also having puberty ... I don't know yet" (P9).

The majority of participants in this study revealed that they only realized that their foster children had reached adolescence after finding signs of secondary sex (mustache growth, armpit hair, pubic hair, nocturnal emissions and menstruation) which generally appear in adolescents:

- "... yes!! his voice ... his voice turned deeper. I noticed a thin mustache growing on his chin ... hmmm ... my child is a teenager now ... "(P3)
- "... there was hair growing on her genitals. she also has menstruation ... she said that she was sick ... usually when she had menstruation ... yes ... she had a stomachache ... "(P7)
- "... he's holding his genitals ... and I once found his pants was wet in the morning ... smells like sperm ... maybe it's a wet dream ... (P6)

Another sign of sexual development experienced by adolescents with ASD is sexual activity like masturbation. Participants in this study revealed that prior to masturbation, their teenagers first performed self-stimulating activities aimed at gaining sexual satisfaction. This self-stimulating activity indicates that adolescents with ASD show the development of sexual function that they do to fulfill their sexual desires:

- "... I often see him watching a video of a female singer on his cellphone, then he wants to hold his penis ... I see his genitals become tense ... I often see him like that ..." (P4)
- I: Have you ever seen a child channel his sexual desire?
- P: I have ... several times.
- I: what did he do? How?

P: Hm ... hahaha ... shake his butt ... pinch his hand in the groin, using a pillow ... (P5)

Unfortunately the participants in this study claimed not to know how to behave if they found their adolescents who masturbated to channel their sexual desires. So far the participants will prohibit if their child shows signs of sexual desire. The taboo attitude towards sexual activity shown by adolescents is also still expressed in this study:

- I: What do you do if you see your child masturbating?
- P: Ban ... no ... you can't !! I will definitely stop my child. Don't we know that he has started shaking his butt ... rubbing against his pillow or hand like that...
- I: What is your child's reaction?
- P: He stopped ... (P5)
- "... I said haa ... yeah ... what was that ... girl huh ... I immediately startled my child as soon as I saw him holding his tensed penis ... hahaha ... sometimes I'm embarrassed to see him. I am confused, what should I do ... I will stop it, right? I will not allow him to be like that (masturbation) "(P3).

This phenomenon reveals the existence of normal sexual orientation experienced by adolescents with ASD, as a form of development of the normal sexuality stage that occurs in general. Parents have also been able to recognize sexual signs in adolescents, but they are still confused about how to behave if their teenagers want to channel their sexual desires. The taboo attitude towards sexual activity exhibited by their teenagers is also still expressed in this study, which may represent the perception of Indonesian people in general about sexual development and the people of West Kalimantan in particular.

#### Romance behavior of adolescents with ASD

Participants in this study revealed the existence of romantic behavior to attract the opposite sex shown by adolescents with ASD. This romantic behavior further confirms that there is no difference between the stages of sexual development between adolescents with ASD and other adolescents in expressing their feelings towards the opposite sex. In addition, participants in this study also described the phenomenon of adolescent attraction towards the opposite sex in adolescents with ASD who cannot be forced with whom and how feelings of love or love can grow in the hearts of adolescents with ASD, both towards friends, teachers or older people "love can't choose who, when and how it comes ":

- "... I saw him going to school wearing perfume ... that was just now ... maybe he wanted to be close to the girl in his class ... someone he liked ... before (when children were 5-8 years old) it was never like that ... this was still new ... "(P1)
- "... she seems to like her male teacher ... if she goes to school ... for tutoring ... she wears sexy clothes ... something short. When she is in class she also likes to smile on her own when she sees a male teacher ... "(P5)

Participants in this study also revealed the suspicion of jealous behavior shown by adolescents with ASD, this is indicated when the opposite sex they like close to others:

"... just yesterday... the teacher reported to me ... my son hit his friend ... it was because the girl he liked was close to another guy's friend ... he hit the boy ... uh ... it surprised me ... he was angry ... angry at the teenager man .. hahaha ..maybe he is jealous .. "(P3)

This study also revealed the physical contact made by adolescents with ASD in expressing feelings of affection towards the opposite sex such as holding and holding hands, kissing, leaning the body to the body of the opposite sex:

- "... recently maybe he is having puberty ... he likes to hold the hands of a friend (opposite sex), he is fond of his girlfriends, towards me (his mother) he likes to kiss, likes to see a beautiful teacher..hahaha ..that's the behavior. "(P1)
- "... with the teacher that he likes ... he likes to lean his body against the teacher ... he rests his head on the shoulder or arm on the teacher he likes ..." (P10)

Romantic behavior such as love, longing and loss are also felt by teenagers with ASD who are in love. This was also expressed in this study. ASD teenagers express their feelings into pictures and imagine the figure they like as they look at a photo:

- "... at home ... she is drawing ... drawing cartoons ... her drawing are about boys and girls running around ... then she gives a name to the picture ... the woman is named Mita ... the a man named Rahul .. then another picture .. picture of him with Rahul holding hands .. then she draws love so .. she told about Rahul to me .. she always mentioning Rahul .. "(P7)
- "... there is a teacher that he likes ... a female teacher ... then this teacher moves school ... there is a photo of his teacher on his cellphone ... he keeps looking at the photos of his teacher ... maybe he thinks where the teacher went ... maybe he is missing .. "(P10)

#### Sexual harassment in adolescents with ASD

The results of this study reveal the existence of a phenomenon of conscious and unconscious sexual abuse that occurs in adolescents with ASD, both as perpetrators and victims in this case. Sexual harassment experienced and carried out by adolescents with ASD such as peeking at the genitals of the opposite sex, holding breasts, kissing, and holding genitals of the opposite sex. Harassment in the school environment was also revealed in this study. But unfortunately, parents in this study revealed difficulties in getting information related to the identity of the perpetrators of harassment committed at school. Participants felt that the school had deliberately covered up the identity of the perpetrators of sexual harassment especially if the perpetrator was a teacher:

- "... he peeked when his girlfriend's friend was peeing .. he was chasing ... his teacher said he often peeked on the girl he likes when she urinates .. he wants to look at the girl's genitals .." (P1)
- "... yes ... he held his hand with his friend (opposite sex) ... I saw this ... when they were playing ... he was held by his girlfriend's breasts ... poking around here and there ... kissing ... uh ... there was something like that. I growled ... I as his mother when I saw that, I thought I would be angry with the child who did that ... but I thought this child did not understand what he was doing ... so I just called my child. my son also told me that his genitals had been held by the teacher ... what should I say ... poked out like that ... but he didn't clearly tell me ... so I asked the teacher ... he said he did hold it ... but this teacher didn't want to tell the teacher in question .. ahhhh annoyed .. "(P7)

# The efforts made by parents in providing sexual education

The results of this study reveal the efforts made by parents in providing sexual education to meet the stages of development of adolescents with ASD such as forbidding their children from beating other people, forbidding their children to peek from genitals of the opposite sex, forbid their children from holding parts of the opposite sex body (breasts, tools sex), forbid their

children to kiss the opposite sex, must not mention the body parts that should not be held and seek information about menstrual preparation in girls.

In addition, sexual education is also provided by parents to prevent sexual harassment in adolescents with ASD that may occur in schools and in the community:

"... when he peeked at his girlfriend, when she was urinating ... well, I forbid ... I don't allow it ... no ... no ... that's what I said ..." (P1)

"... no ... that can't be ... don't hit a friend ..." (P3)

"... I used to often ask my friend whose child also has ASD ... I asked about his daughter when menstruating, how do you do? ... my friend say it should be taught ... of course..slowly ... how to use pads, how to dispose ..." (P5)

"... I do not allow him ... I said do not hold the breasts, do not kiss the cheek, this is mita ... if anyone wants to hold the breasts ... vagina ... no ... no ... report mama .. I emphasize ... no. "If there is an older brother or a father figure who wants to hold the genitals, say no ... my child already knows now ..." (P7)

Table 1: Demographics of parents of children with ASD.

Number	Relationship to child	Age	Race/ethnicity	Level of education	Child age
P1	Mother	32	Malay	High School	13
P2	Father	41	Java	High School	9
P3	Father	44	Dayak	Bachelor Degree	13
P4	Mother	45	Tionghoa	Bachelor Degree	14
P5	Adoptive Mother	38	Malay	Master Degree	13
P6	Father	50	Batak	High School	13
P7	Mother	43	Malay	Master Degree	10
P8	Father	54	Dayak	Ph.D	13
P9	Mother	40	Tionghoa	Bachelor Degree	12
P10	Mother	42	Malay	Master Degree	13

### **DISCUSSION**

Our findings reveal the stages of sexual development that occur in adolescents with ASD according to their age. It is said that adolescents with ASD experience the same sexual development as teenagers in general. The presence of secondary sex signs, menstruation, and masturbation activity in adolescents with ASD was also reported in this study. This study also shows the consistency of research results with other literature related to sexual development in adolescents with ASD that are not different from adolescents in general at the same age, such as physical changes, feelings of attraction towards the opposite sex, masturbation. 5,9,23,31-34 menstruation and unfortunately, the parents in this study did not know the right way to deal with teenage sexual activity (masturbation). Sexual education provided by parents regarding the sexual activities and desires of adolescents with ASD is blocking or stopping these activities. Sexual activity of adolescents with ASD is a normal development that occurs in adolescents. In adolescents with ASD the attitude that must be done by parents in dealing with this activity is to provide opportunities, provide privacy and teach children not to do this activity in public.35-37

Our research also reveals the unique unexpected behaviors exhibited by adolescents with ASD while in love such as imagining the opposite sex, expressing feelings with pictures, holding the body of the opposite sex, showing jealousy by hitting. These signs indicate that parents of teenagers with ASD need a good sexual education to be able to direct the behavior as described above following adolescent development. The phenomenon of falling in love cannot choose the time and place to be present and with who to fall in love is also experienced by adolescents with ASD. Unfortunately, until now there has not been found an adequate sexual education program for adolescents with ASD.<sup>2</sup>

On the other hand, sexual harassment is not realized by teenagers, parents, and the school environment is also described in the results of this study. The findings in this study revealed that the perpetrators of sexual harassment in adolescents with ASD not only occur in the community but also in schools where the perpetrators are fellow adolescents with ASD or teachers in schools. The closed attitude of the school towards sexual harassment that occurs in adolescents with ASD is also very disappointing for parents. Schools which should be a means of education for adolescents and a means to provide a safe atmosphere for teenagers and parents who entrust their children to go to school are already out of function. ASD adolescents with ASD, especially girls, need help to protect themselves from sexual abuse that they are not aware of. This can be done through sexual knowledge that can be taught through collaboration between parents and school. Adolescents with ASD are very vulnerable to

abuse because of their limitations. Harassment can cause deep trauma to people with ASD.<sup>38</sup>

At present, the burden of sexual education for adolescents with ASD is still the full responsibility of parents. Parents of adolescents with ASD are in amid limited information and knowledge. Even though they have also realized that sexual education is very important and needed by their children. Sexual education is not only about the stages of adult sexual intercourse, but more important than that is education about integration of feelings, body parts that must be protected from unwanted touches, physical changes, mental and emotional changes, hygiene during menstruation and self-care related to the development of sex secondary to adolescents. 12,39 Some efforts that parents can do are still limited to general activities such as prohibiting children from engaging in sexual acts. In expressing the feelings of adolescents with ASD towards the opposite sex and mentioning body parts that should not be touched by others. Sexual education provided by these parents can cause confusion among adolescents with ASD. It is feared that adolescents will fail to understand the right feelings and actions when it comes to liking the opposite sex, because expressive activities carried out by children with ASD usually get a parent ban. Parents of ASD adolescents also do not explain in detail the body parts that may be touched by others. This can affect the social relations of adolescents with ASD with others. Whereas sexual education for adolescents with ASD must also contain an explanation of the parts of the body that may be touched and those that should not be touched, so that they are able to understand what touches can be done and with whom they can touch. Touches that can be done are like shaking hands. This condition can affect the process of adolescent growth and development, especially puberty in adolescents.<sup>37,40</sup>

# CONCLUSION

The findings of this study indicate the emergence of sexual education emergencies in a more formal setting such as in schools or therapy centers that must be given to parents, and in adolescents with ASD to protect adolescents with ASD from sexual harassment, and maintain sexual development at the teenage stage. Besides sexual education in the formal setting is also assumed to be a support for parents, so that the burden of ASD adolescent sexual education is not only the full responsibility of parents, which is expected to reduce stress, depression and discrimination felt by parents. Sexual education requires a standardized curriculum that is appropriate to the needs and able to protect ASD adolescents, which can be used throughout the formal order to be able to collaborate, health workers, teachers, therapists, and parents. This sexual education curriculum also functions as a guide in providing sexual information to adolescents with ASD and as a strategy in providing quality sexual education.

#### ACKNOWLEDGEMENTS

Thanks to STIK Muhammadiyah Pontianak for providing moral support and material in this study.

Funding: This study funding was supported by Research, Public Devotion, and Innovation Center of STIK Muhammadiyah Pontianak

Conflict of interest: None declared

Ethical approval: The study was approved by the Institutional Ethics Committee ethical test number 54.A / II.I.AU / KET.ETIK / II / 2019 from STIK Muhammadiyah Pontianak, West Kalimantan, Indonesia

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Cite this article as: Lestari L, Aunurrahman. Sexual education for adolescent autism spectrum disorders: an interpretative phenomenological analysis. Int J Community Med Public Health 2021;8:1625-31.