

Adolescent boys with an Autism Spectrum Disorder and their experience of sexuality: an interpretative phenomenological analysis.

Autism (In press)

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Abstract

This qualitative study explored how adolescent boys with autism spectrum disorder (ASD) experience their sexuality. Previous research has demonstrated that sexuality is a developmental task for boys with ASD, as it is for their peers. Case studies have suggested a relation between ASD and atypical sexual development; empirical studies on this subject, however, are scant and inconsistent. This study is based on interviews with eight boys, aged 16 to 20, with Asperger's disorder or autistic disorder. Interpretative phenomenological analysis of the data revealed three major themes relating to (a) how they experience sexual feelings, think about sexuality and think about themselves as sexual beings; (b) how they perceive messages relating to sexuality in their surroundings; and (c) how they experience finding and having a partner and partnered sex. We believe that attention to these themes is needed in assessment, education and further research.

Keywords

Adolescents, sexuality, autism, qualitative research, interpretative phenomenological analysis

Introduction

Sexuality is a complex phenomenon, expressed and experienced in feelings, thoughts, desires, fantasies, behaviours, identity, roles and relationships (WHO, 2006). Most research on sexuality in adolescence has focused on the prevalence of sexual experiences, the age of

sexual debut and sexual trajectories (Fortenberry, 2013). In-depth studies on sexuality development in adolescence are scarce (Diamond and Savin-Williams, 2009). Most studies on sexuality in individuals with ASD, as in the case of the general population, focus on the prevalence of sexual behaviours and on sexual knowledge (Dewinter et al., 2013; Kellaheer, 2015). Studies based on self-report (Byers et al., 2012, 2013; Dewinter et al., 2015; Mehzabin and Stokes, 2011; Ousley and Mesibov, 1991) and parental or caregiver reports (Haracopos and Pedersen, n.d.; Hellemans et al., 2007, 2010; Holmes and Himle, 2014; Stokes and Kaur, 2005) have shown that sexuality is a part of life for individuals with ASD. Especially high-functioning adolescents and adults with ASD reported or demonstrated interest in relationships and partnered sexuality (Haracopos and Pedersen, n.d.). However, several studies (Bertilsson Rosqvist, 2014; Dewinter et al., 2013; Kellaheer, 2015) suggested a high prevalence of feelings of asexuality, same-sex attraction, gender identity issues (De Vries et al., 2010; Jones et al., 2012), sexually inappropriate behaviours, deviant fantasies and offending (’t Hart-Kerkhoffs et al., 2009; Bleil Walters et al., 2013) in people with ASD.

Although adolescence is a critical period in sexuality development, studies on how sexuality is experienced by adolescents with ASD themselves are scarce. Complex sexuality-related issues, such as the development of sexual attraction, sexual identity and relationship experiences, are hardly studied in adolescents with ASD. Research on how adolescents experience their sexuality and relationships could offer insight into these issues, add to a better understanding of the possible impact of ASD on sexual development and offer cues for support (Barnett and Maticka-Tyndale, 2015; Byers and Nichols, 2014; Byers et al., 2013). The central aim of this study was to explore how high-functioning adolescent boys with ASD experience and give meaning to their sexuality and sexual development.

Method

Methodological approach

Interpretative phenomenological analysis (IPA) (Smith et al., 2009) is used as a framework for collecting and analysing data. IPA was developed to study people's lived experience and how they make sense of it. This approach has phenomenological (focus on lived experience), hermeneutic (interpretation by the researcher as a way to gain insight into the experience of the participants) and ideographical (focus on in-depth analysis of particular participants) roots (Finlay, 2011; Smith, 2011b). In IPA 'the researcher tries to make sense of the participant trying to make sense of what is happening to him'. This process is also referred to as a 'double hermeneutic' (Smith, 2011a: p.10). IPA recommends in-depth analysis of data obtained from one or more individuals. If the study includes different participants, then the accounts are studied in-depth successively. Following this phase, the researcher looks for divergent and convergent patterns across cases. Earlier studies showed that IPA can be applied in research on people with ASD (Cridland et al., 2014; Humphrey and Lewis, 2008; Huws and Jones, 2008, 2015).

Participant characteristics

This study included participants who were male, aged 16 to 20, diagnosed with autistic disorder or Asperger's disorder (American Psychiatric Association, 2000), with at least below average to higher range scores on a standardised intelligence measure (full scale IQ>70) and free of florid psychotic symptomatology. Boys who scored high on the Autism Diagnostic Observation Schedule (Lord et al., 2012), module 4, were included. Sexual experience was not a criterion for inclusion. We invited 18 boys to take part in this study; eight of them were willing to participate (see Table 1).

Insert Table 1: Participant characteristics

Procedure

Eligible candidates had participated before in a longitudinal study on sexual development of adolescent boys with ASD. They agreed to be contacted for further research. The boys were approached after approval by the Medical Ethical Committee Brabant, Tilburg, the Netherlands (NL49082.028.14). The first author, who is a clinical psychologist, interviewed all participants. As he administered the ADOS to all the participants in the previous study, he was relatively familiar to them. The interviews took place at their homes (five), after classes in school (one), in the centre where the first author worked (one) and in the community institution where one of the participants resided. The interviews lasted 53 minutes on average (range 41.06 to 80.18 minutes). All interviews were semi-structured, starting with the question ‘Can you explain what sexuality means to you?’ The interviewer built on the answers of the participants by asking for details, examples, elaboration and clarification. The interviews were conducted in the boys’ native language. Translations of the relevant quotes are included in this manuscript. The participants’ names were replaced with pseudonyms. The following topics were discussed with each boy: falling in love, having a relationship, bodily changes, masturbation, partnered sexual experiences, sex education and pornography. Verbal expressiveness and the extent of sharing personal experiences differed between participants, resulting in variable richness of the data. All interviews were audiotaped and transcribed verbatim by the first author. The participants received a 5€ voucher after the interview.

Analysis

Every transcript was analysed as an individual case (Smith et al., 2009). In the first phase, descriptive (content), linguistic (language use) and conceptual (possible meanings)

comments were noted next to each line in the transcript. Next, emergent themes were identified in these initial comments and the data. The themes were clustered on the basis of related content, as positions on the same dimension and by using abstraction. Finally, a descriptive report was written for each participant with the focus on how the participant experienced sexuality in his life. This was done, successively, for all interviews. Finally, all themes were integrated into one table, clustered and renamed, while staying close to the data.

Different strategies were used to support the credibility of the analysis. The researcher kept a diary during the data collection, transcription and analysis. This reflective document helped the researcher to be attentive to or 'bracket' ideas and feelings during analysis and be open to other meanings. The first author conducted, transcribed and analysed all interviews. The second and third author audited the analyses by reading the case reports, checking how these related to the themes and quotes, and challenging the meaning derived from the transcripts during analysis. In the light of these remarks, the first author went back to the manuscripts to look for support for alternative possible meanings and themes and clarified the wording of the overarching themes. This discussion resulted in a better differentiation between individual (developing sexual self) and relational experiences, and on the grouping of subthemes within this developing sexual self (e.g. what I think is right vs. ideas about myself).

Findings

The participants described a variety of solo and partnered sexual behaviours and relationship experiences. Five boys were or had been in a romantic relationship. The nature of these relationships varied from long-lasting (i.e. several months or more) and frequent face-to-face contacts, to mostly online contacts and short flirtations. All participants had

experimented with masturbation, although not satisfactorily in the case of two of them. One boy never experienced sexual arousal, in contrast to another who was medically treated for hypersexuality. Five boys had partnered sexual experience; for four of them this included penile-vaginal penetration. One boy did not enjoy penetration and asked girls to undress before the webcam. A number of boys had sexual contacts outside a dating context, with friends or peers (three) and a professional sex-worker (one).

Three main themes emerged out of the analysis. The first theme, '*Developing sexual self*', referred to learning from the sexual responses of the body, personal ideas and norms relating to sexuality and defining oneself as a sexual being. Second, '*Interpreting sexuality-related information in my surroundings*' encompassed the interpretation of parents' and caregivers' messages and expectations and how peers dealt with sexuality. The boys also learned from sex education, the internet and internet porn. The third theme, '*Exploring relationships and partnered sex*', involved the interest in a relationship and learning about sex and relationships during interaction with partners. The themes are elaborated below and illustrated with quotes.

Developing a sexual self

All participants described sexuality as part of human functioning and had been exploring their sexuality. Bodily experiences seemed to be guiding this process (subtheme 1). The boys expressed a variety of beliefs about sexuality and relationships (subtheme 2) that related to their sexual behaviour. Furthermore, how they defined themselves as sexual beings (subtheme 3) related to the evaluation of their experiences and personal capabilities.

All boys described curiosity about sexual behaviours. Some boys spontaneously explored their own body and bodily reactions, whereas others only became curious after peers referred to sexual behaviour or experiences. The *body and bodily feeling of pleasure and*

attraction appeared central in different accounts; these experiences offered cues to explore and learn about sexuality. Andy (18) described his feelings for a boy at school and concluded that he was bisexual. Later on, he agreed with a boy to have sex. He described that he “had only once, (...) sexual contact with a... boy, however that was like... I thought that having sex with a boy was...not... not my thing... I had feelings like that for boys however the sexual part felt a bit strange”. This experience led him to decide that he preferred sex with girls. Because of the arousal he felt after watching porn, Zack (17) was eager to experience sex. However, he described the actual experience as scaring and confusing. He explained that “sex was always on my mind, however... when I had sex myself, it was like ‘ugh, no, I don’t need that”. Other boys reported pleasure and positive experiences.

Nathan (20) did not recognise sexual pleasure or attraction, although he recognised bodily changes (growing a beard) and physical sexual reactions (e.g. nocturnal emissions). He wondered about a ‘brain helmet’ to detect his sexual feelings in order to get to know them. He hardly felt any intrinsic motivation, other than cognitive interest, to gain sexual experiences. This is illustrated by the way he explained how he experimented with masturbation: “I thought it’s just a part of it... but... no... I don’t feel any need.”. He also explained that feeling in love was unknown to him, for example by stating that:

People sometimes ask (...) have you ever been in love, then I say no, I don't think so, because it is... falling in love isn't a thing of which you can say ‘my toe nail gets blue, so I'm in love’ (...) it's not measurable to me.

Just as Nathan seemed to feel little control over his absent or hidden sexual feelings, Zack (17) experienced little *agency* relating to his sexual interest and arousal. He discovered porn at the age of 10 and started to masturbate soon afterwards. At the time of the interview, he used medication to suppress his arousal. He described his sexual interest as obsessive: “I was

constantly, constantly thinking about it, so every time I saw a girl, I thought ‘wow’. That really was no good, because sometimes this happened in public places”.

The boys held a variety of *ideas relating to sexuality* (e.g. which sexual experience one should have by when, what is appropriate) *and relationships* (e.g. the need for a relationship before one can have sex, the importance of consent). For instance, Nicolas (17) thought masturbation was a normal activity for boys of his age: “Yeah, for as far as I know, everybody does it”. However, Ben (16) said: “ It’s dirty (his penis), it’s... you don’t do that... all those bacteria, it’s a bacteria spot”

All participants described how they thought about themselves as sexual beings (sexual self): some felt confident, whereas others doubted their capacities and the kind of sexual experiences they had. For example, Neville (19) had several consecutive partners and expressed confidence in his ability to find a partner and to have sex: “It all went... I don’t know... I’m rather good at it”. However, other boys evaluated their sexual experiences as different from what they perceived as normal. Nathan (20) seemed to feel different given the absence of recognisable sexual feelings: “People could regard it (absence of sexual and relationship interests) as a burden, however I see it as a benefit, it is cheaper”. Zack (17) felt different, because he did not like penetration. His confusion became clear when he said “Why... why this, this isn't normal, I mean... how can you enjoy looking at it, while you don’t enjoy doing it (...)”.

Interpreting sexuality-related information in my surroundings

The participants referred to different sources of (in)direct information relating to sexuality and relationships. Boys derived ideas from the way their *parents and teachers talk and react* to issues pertaining to sexuality (subtheme 1), from remarks and jokes made by

peers (subtheme 2) and from information they found on the internet (subtheme 3). Both watching porn and contact with peers seemed to stimulate sexual interest, whereas parents were perceived as communicating sexual norms and limits.

Several boys described and interpreted the hesitation of *parents and caregivers* to discuss sexuality. For example, Tom (17) reported that sexuality was hardly discussed in his family and he had concluded that his parents would be against it if he would date someone. A number of quotes revealed the taboo around the subject of sexuality. Ben (16) referred to ‘*confessing*’ when he discussed his sexual experience with his parents; Andy (18) stated that it felt good that he did not ‘*have to hide*’ anything during the interview, compared with the need to keep his sexuality hidden from parents and professionals. Only one participant, Neville (19), felt comfortable communicating about sexuality with his parents, which he related to his own lack of shame (again referring to a taboo). He found that his parents saw it as important that he knew about sex. Ben (16) explained that his parents did not initiate a discussion of sexuality or offer guidance, until he discussed his BDSM experience. “They never told me what to do or not, not that, only that one thing that I couldn't do (BDSM), but never told me what I could do, and so... they never told me what was allowed”. Also Nicolas (17) seemed to experience his parents mainly as limit-setters, rather than as willing to discuss sexuality openly, recounting his mother’s reaction when he asked her permission to let a girlfriend stay overnight: “She (mother) thought it was a bit too soon, I knew her (girlfriend)... for two days... if you think about it: it was too soon”.

The way *peers* talk about sexuality was often mentioned as a stimulus to experiment with sexuality. Participants derived ideas about how to deal with sexuality from observing and talking with friends and schoolmates. For example, Nicolas (17) explained “Well, just like I heard friends talking about it (masturbation) and so, yes, tried it out myself and... “.

The participants referred to the *internet* as an easily accessible source of information and as a place where one could find pornographic materials. Nathan (20) for instance, described the internet as “a source for information that, in this kind of situation, if you feel insecure, can be of help“. The majority of boys (six) had been watching pornographic websites to get aroused. Although they all indicated that porn is not always realistic, it did offer them information on sexual behaviour. Andy stated that porn was like a fairy tale, which seemed to reflect that he understood that sex in porn is not always representative. However, after watching specific sexual behaviours on the internet, he wanted to “feel it for himself” and he stated that “You first look at the image you see, for instance in porn... it might be fantasy so you want to know how it is for real... so you look for information”. Most boys received sexuality education in school, as part of regular classes, and referred to the sex education classes as complete and good. Only one participant, Ben, described this as “childish” and stated that he had wanted more information.

Experimenting with relationships and partnered sex

Subthemes in this section included looking for a partner (subtheme 1), exploring relationships and partnered sex (subtheme 2) and adapting to a partner (subtheme 3). All but one of the boys felt *interest in a relationship and partnered sex*. Nathan (20) ascribed his absence of interest in a romantic relationship to his unawareness of sexual attraction and arousal. He also negatively anticipated the idea that another person would intrude on his personal space. When the interviewer asked about his interest in having a romantic relationship, he responded: “I don't want to think about it, honestly... I understand that others like it though, like you hear people say”.

Apart from being interesting, it seemed challenging for several boys *to find and approach a partner*. Steven (17) described internal and external conditions hampering his

opportunity to find a partner. On the one hand, he found it hard to get to know a girl well enough as he said that “If I have contact with someone and there is a basis of trust, then..., however I never trusted anyone enough that it could happen”. On the other hand, he experienced situational obstacles in finding a partner: he argued that his chances of meeting a girl were reduced because he mostly met boys with ASD, or, in a rare case, a girl with ASD.

I don't meet anyone because one in ten autists is, in my experience, female, so statistically seen and demographically, there is a strong lack in my surroundings in the percentage of women and then it also becomes difficult to find a relationship.

Tom (17) described the influence of ASD-related communicative and social impairments on his ability to develop a relationship and felt inhibited about approaching girls: “It is difficult for me to get information out of conversations, so to say, to filter the main from the side-issues is very hard to me, so... yeah, that could be problematic in a relationship”.

Although the boys were aware of the possible risks of online dating, several participants described the internet as a medium to meet and have contact with potential partners.

Five of the boys had been in a *relationship and had experimented with partnered sex*. This sexual experimentation was situated both within romantic relationships and outside a dating context. For example, Nicolas (17) told he once had sex with a female friend when she stayed overnight to watch a movie.

Actually (it happened) a bit strange... a close female friend came over to stay overnight and... we made it cosy in my room, watched a movie and so on and then... we just started kissing and then... and one thing turned into another.

Most boys evaluated their partnered sexual experiences as positive and pleasurable, and tried to fit in with the wishes and limits of their partners. Andy (18) experimented with different kinds of sex partners. He felt that having a relationship added value to sex, stating that a relationship “makes the puzzle round”. As he mixed expressions, so he also struggled with the

understanding of relationships. He described the emotional distance he experienced in different short sexual relationships and how he valued feeling close to his partner. He explicitly described the negotiation of his sexual desires with his new partner and felt more confident that he would not coerce her unintentionally. Andy found his partner willing to experiment sexually so that he could find out what he liked. However, he remained concerned that she did not dare resist his proposals: “You could say it’s OK and afterwards you think that is not like that... (...) I really have to see that she actually agrees, because she says so but...”. Several other boys stressed the importance of consent by their partners and emphasised that they did not apply pressure to their sex-partners. This emphasis on consent in sexual interaction possibly reflected the concern of parents and educators that these boys might coerce partners. One boy was convicted for sexual offending and described the use of coercion to get others to fulfil his sexual needs. His main concern was that these girls would not want to have contact with him later on, reflecting limited insight into the perspective of his victims.

Finally, having a relationship posed demands on some of the boys, as illustrated by Andy (18) saying “Spending the weekend together is enough (laughs) just because (...) she has a totally different pace and you feel that it doesn't work out well”. All boys who had been in a romantic relationship referred to the effort *needed to adapt* to the pace, habits and demands of a partner. This adaptation was challenging for different boys. Zack (17) described how he dared not to refuse to have penile-vaginal intercourse: “I really did not like it (penetration), it was because I did not want it myself, but I could not say it, so...”.

These quotes illustrate the effort it demands from some participants to change their own habits and routines, share personal domains or indicate personal limits, apart from the desire to have a partner or to have partnered sex.

Discussion

All boys in this study had thought about and experimented with sexuality and relationships, albeit in different ways. Earlier studies mainly focused on sexual behaviour, knowledge or education (e.g. Dewinter et al., 2015; Hellemans et al., 2010; Stokes et al., 2007) and were hardly based on self-report (Dewinter et al., 2015). This study, based on first hand information, illustrates the complex interaction between information processing, education, social learning and interaction, and identity development in relation to sexuality and romantic relationship development.

Our findings do not support a predominant problematising view on sexuality in adolescents with ASD (Byers et al., 2012; Kellaher, 2015). However, next to common and age-appropriate sexual experiences, several challenges for these boys with ASD, which related to sexuality and relationships, came to light in the interviews. Sensory and information processing issues related to ASD, such as recognising one's own bodily signs and feelings (e.g. feeling arousal and attraction) or obsessive interests, and social and communication difficulties, such as understanding explicit and implicit messages from parents and peers, influenced how participants experienced and thought about sexuality, and how they interacted with (potential) partners. The boys also learned from observing peers and surfing on the internet. The perception of their sexual and relational experience, their social and communicative skills and their ideas about how things should be, seemed related to the way in which they defined themselves as (in)competent, strange or even dangerous sexual beings. Although some boys were self-confident, others felt ashamed or different because of their sexual functioning, described negative experiences or experienced rejection by others and even legal consequences. These findings support the importance of healthy sexual development in general well-being and identity development (Tolman and McClelland, 2011; WHO, 2006).

Although the participating boys lived in countries with liberal sexual attitudes (De Looze et al., 2014) and were allowed to participate in research on sexuality, the taboo around sexuality was recognisable in their reactions and expressions. Most boys in this study were not used to discussing their experience of developing as a sexual being. Reluctance to discuss sexuality by adolescents with ASD, their parents (Holmes and Himle, 2014; Nichols and Blakeley-Smith, 2009) and professionals (Holmes et al., 2014) might reinforce each other and hamper personal discussion of this topic. Yet discussing the boys' experiences with and ideas about sexuality and relationships, as done in this study, is an important way to gain insight into the challenges that some of them are facing.

The importance of different sources for sexuality related information, already studied by Stokes and colleagues (2007), is illustrated by our findings. Apart from explicit education about sexuality by parents and teachers, the boys interpreted implicit information (e.g. what is not said, non-verbal reactions) on sexuality and relationships provided by parents and teachers. In contrast to other studies (Brown-Lavoie et al., 2014; Stokes et al., 2007), peers were often mentioned as a source of information and as a trigger to explore sexuality and relationships. Last, the internet is an important, although not always reliable, source for sexuality-related information.

Strengths, limitations, considerations and directions for future research

This study offered insight into how sexuality is experienced by adolescent boys with ASD. Discussion continues about the need to adapt hermeneutic phenomenological methodology for data collection and analysis in people with ASD (e.g. by using visual support in interviews) (Chown, 2011; Cridland et al., 2014; Newman et al., 2010). In this study, the richness of the data was influenced by the limited expressive language of two participants and by the extensive use of formal language of another participant. Five boys gave extensive

reports, using complex and expressive wordings. ASD features were recognisable in these accounts (e.g. a stereotypical interest in numbers, literal interpretations and expressions). We consider knowledge about ASD features and information processing crucial for the understanding and interpretation of the data.

The results should be replicated and be supported by further quantitative and qualitative research. Further research into the role of bodily perception of arousal, the kind of relationships that offer a context for partnered sexuality and how sexual experiences in those contexts are evaluated also seems warranted.

Clinical implications: discussing experience

This study confirms that sexuality and building relationships are part of adolescent development in boys with ASD that can offer pleasure and add to self-confidence, as well as distress. Uncertainty or negative experiences and feelings regarding sexuality can impede general well-being. Researchers in the field of sexual development and functioning in adolescents and adults with ASD have already stressed the need for early and comprehensive sex education (CSE) including attention to relational and social skills (e.g. Attwood et al., 2014; Byers and Nichols, 2014; Dewinter et al., 2015; Stokes, 2007; Stokes and Kaur, 2005). Parents and professionals can, actively and repeatedly, invite adolescents to discuss personal feelings and ideas about sexuality and relationship-related issues as a way to identify and understand possible challenges in the adolescents' experiences and offer them attuned support. Sensory perception, self-perception, ideas about sexuality, interpretation of (expectations from) others and of online information, expectations relating to relationships and interaction with potential partners are important issues in sexuality education of adolescents and should get attention in discussing sexuality throughout life with individuals with ASD. Although recent studies refute a problematizing view on sexuality and ASD,

attention to possible harmful sexual and relational behaviours and experiences is warranted, in order to intervene timely and offer support. This study also suggests that these boys have experiences outside the traditional heteronormative discourse (e.g. same sex contacts, sexual contacts outside of a romantic relationship), which we should be prepared to discuss openly.

Conclusion

All boys in this study experienced sexuality as a part of their development, even if they did not experience sexual arousal, or had no partnered sexual experience. Spontaneously discussing personal sexuality and relationship experiences seemed challenging for several boys and their surroundings, although this probably offers an important way to get support when needed. Parents, caregivers and professionals should initiate discussion on the way in which adolescents with ASD experience their sexuality and relationships, and support sexuality development and well-being.

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Table 1: Participant characteristics

Participant	Age	DSM-IV- TR ¹	Intelligence range	ADOS score	Living situation	Education/ work	Relational status
1. Andy	18	AS	Average	7 (ASD)	Independent	Unemployed	Relationship
2. Neville	19	AD - ADHD	Low average (PIQ>VIQ)	13 (Autism)	With parents	Employed	Relationship
3. Nathan	20	AD - ADD	Superior	14 (Autism)	With parents	Student	Single
4. Ben	16	AD – ADHD	Average	9 (ASD)	Group home / with parents	Student	Single
5. Nicolas	17	AD	Average	14 (Autism)	With parents	Student	Relationship
6. Tom	18	AD	Average	9 (ASD)	With Parents	Student	Single
7. Steven	18	AS	Superior	13 (Autism)	Independent with support	Student	Single
8. Zack	17	AD – ADHD	Average	5 (non-ASD)	Group home	Student	Single

¹AS: Asperger's disorder, AD: autistic disorder, ADHD: attention deficit hyperactivity disorder, ADD: attention deficit hyperactivity disorder, inattentive type