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ORIGINAL PAPER

Aspects of Sexuality in Adolescents and Adults Diagnosed with Autism Spectrum Disorders in Childhood

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Abstract The literature concerning sexuality in autism spectrum disorders (ASDs) is limited regarding inappropriate sexual behaviours and paraphilias and its relation to age, verbal ability, symptom severity, intellectual ability, or adaptive functioning. A cohort of 184 adolescents and young adults (ages 15–39 years) with ASD diagnosed in childhood, including both low and high functioning individuals, was examined. The large majority were found to have a sexual interest and showed interest towards the opposite sex. Inappropriate sexual behaviours and paraphilias were reported for about a fourth of the individuals. No relationships were found between inappropriate sexual behaviours and any of the background variables listed above. However, associations were found between paraphilias and ASD symptom severity, intellectual ability, and adaptive functioning.

Keywords Autism spectrum disorders · Asperger syndrome · Autistic disorder · Sexuality · Paraphilia

Introduction

The majority of individuals with autism spectrum disorder (ASD) go through puberty and experience the same physical and psychosexual aspects of sexual development as their peers (Koller 2000; Lawson 2005; Murphy and Elias 2006; Van Son-Schoones and van Bilsen 1995), but do not follow typical stages of development in social communication and social interaction (Schroeder et al. 1996). The deficits in social communication and social interaction may become particularly apparent in adolescence and young adulthood, when individuals are expected to achieve several important developmental stages, such as the development of close peer relationships, romantic relationships and sexuality (Seltzer et al. 2003). Because individuals with ASD have deficits in the abilities required to develop and maintain interpersonal relationships, they usually have fewer friends, romantic partners, and sexual experiences than typically developing individuals (Mehzabin and Stokes 2011). This may imply that they are not provided with a context in which they can develop their sexuality, which in turn may have consequences for later adjustment and wellbeing in adulthood (Collins et al. 2009). The ability to understand subtle rules of social interaction and to empathize with others (i.e. social 'know-how') might be especially important in adolescence as it is a time when one is required to manage peer pressure, new relationships, awakened sexual feelings and romantic desires (Collins et al. 2009). The imbalance between physical and social development can be confusing for both the individual with ASD and their parents/caregivers. Many are not aware of how core autistic symptoms interact with processes of maturation and development and it is suggested that they may bring about behavioral problems and increased rates of psychopathology (Hellemans et al. 2010; Herbert 2003; Holmes et al. 2014).

A recent study found that, in comparison with typically developing individuals, adolescents with ASD engage in fewer social behaviors, have fewer sexual experiences, are more sexually frustrated, depressed and concerned with

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finding a partner (Mehzabin and Stokes 2011). However, recent studies have also reported good sexual functioning as well as satisfactory relationships, marriage and raising families successfully among individuals who have average and above cognitive and language abilities) (Byers et al. 2013a, b; Dewinter et al. 2015; Howlin 2004).

The development of sexuality in individuals with ASD has largely been neglected in the literature because it has previously been assumed that affected individuals are sexually immature and/or uninterested in sex (Konstantareas and Lunsky 1997). However, recent studies have shown that many individuals with ASD do have a sexual interest, engage in a wide range of sexual behaviors, are interested in having romantic and/or sexual relationships with others and actively seek them out (Balfe and Tantam 2010; Hellemans et al. 2010; Ousley and Mesibov 1991; Ruble and Dalrymple 1993; Stokes et al. 2007; van Bourgondien et al. 1997). However, asexuality has also been found within this group (Gilmour et al. 2012; Marriage et al. 2009).

With regard to sexual orientation, it has been suggested that gay male sexual interest, lesbian sexual interest and bisexual sexual interest is more common in individuals with ASD, and particularly in individuals that are characterized as having little or no language skills and that often also are diagnosed with an intellectual disability (ID) (Haracopos and Pedersen 1992). However, this relationship has not been confirmed, due to lack of empirical studies that have examined the prevalence of gay male sexual interest, lesbian sexual interest and bisexual sexual interest in ASD populations (Lawson 2005). In individuals with ASD who have average or above average cognitive ability, heterosexual sexual interest has been reported for the majority (Dewinter et al. 2013) but with significantly higher rates of gay male sexual interest and bisexual sexual interest than in the general population (Byers et al. 2013a, b).

While some of the sexual behaviors that individuals with ASD display are socially appropriate (e.g., hugging and kissing with partner's consent or sexual activity with a consenting partner in private) it is not unusual that they also display sexual behaviors that are perceived as problematic. Among the socially inappropriate, harmful and deviant sexual behaviors that have been reported are public or excessive masturbation (Haracopos and Pedersen 1992; Realmuto and Ruble 1999), undressing in the presence of others (Ruble and Dalrymple 1993), and stalking (Realmuto and Ruble 1999). The underlying mechanisms of these sexual behaviors have been proposed to originate in a lack of social awareness and skills, difficulty reading social cues and a deficit in mentalisation (the ability to understand one's own and others' mental states, e.g., thoughts, beliefs, desires), which are all characteristic impairments of ASD. It has also been suggested that other features, such as preoccupations, sensory preferences and repetitive and stereotyped behaviors, can explain them (Dewinter et al. 2013; Hellemans et al. 2007; van Bourgondien et al. 1997). In addition, inappropriate sexual behaviors may also be caused by punitive attitudes of caregivers, lack of education, or limited opportunities for privacy (Grandin and Barron 1995; Holmes et al. 2014; Koller 2000).

Deviant or unusual sexual behaviors and interests (paraphilias as described in DSM-IV, APA 2000) have been reported in the literature on sexuality and ASD (Gillberg 1984; Hellemans et al. 2007). Case studies describing pedophilia (Murrie et al. 2002; Robinow 2009), transvestism (Landén and Rasmussen 1997), exhibitionism (Beddows and Brooks 2015), voyeurism (Milton et al. 2002; Murrie et al. 2002), fetishism (Dozier et al. 2011), and partialism (sexual arousal characterized by focus on one part of the body) (Haracopos and Pedersen 1992) in individuals with ASD have been presented. Information on the prevalence of paraphilias in this group of individuals is scarce (Realmuto and Ruble 1999) but in the general population paraphilias have been found at a prevalence rate of 0.4–7.7 % (Långström and Seto 2006; Långström and Zucker 2005). A relationship between ASD, psychopathology and specific paraphilias has been proposed as related to neuropsychiatric and developmental perspectives (Silva et al. 2002). Specifically, it has been proposed that features such as social deficits and preoccupations with restricted and repetitive interests may contribute to paraphilia-related psychopathology, however, there are no indications of ASD being specific to paraphilia (Milton et al. 2002).

The primary aim of the present study was to examine the prevalence of sexual interest and sexual orientation, sexual activity, problems with sexuality, inappropriate sexual behaviors and paraphilias in ASD. The relationship between inappropriate sexual behaviors and certain demographic variables has been studied. ASD severity (Hellemans et al. 2007), sex, and intellectual ability (Ousley and Mesibov 1991) have been proposed to be mechanisms behind sexually inappropriate behavior among people with ASD but verbal ability per se has not been reported to be associated with exhibition of sexual behavior (Ruble and Dalrymple 1993). No published study has reported any association between inappropriate sexual behavior in ASD and adaptive functioning. Therefore, a second aim was to assess if a relationship exists between inappropriate sexual behaviors or paraphilias and symptom severity, sex, intellectual ability, verbal ability, and adaptive functioning. Finally, we also wanted to examine whether (or not) aspects of sexuality differ between individuals with ASD and ID compared to those with ASD without ID.

Method

Procedure

The present study was based on data collected from two longitudinal follow-up studies, the "autism study" (Study 1) and the "Asperger study" (Study 2) which included individuals in young adult and adult age who had been diagnosed in childhood at the Child Neuropsychiatry Clinic (CNC) at Sahlgrenska University Hospital in Gothenburg, Sweden. The participants were not compensated for participation. In Study 1 the majority of the participants were seen at their residential home by a psychiatrist and psychologist, both well experienced in the field. In Study 2, all participants were seen by an experienced psychiatrist and psychologist at the CNC.

Study 1

One hundred and twenty individuals with infantile autism/autistic disorder or atypical autism/PDD-NOS (Pervasive developmental disorder not otherwise specified) from three population-based studies of autism were approached for inclusion in a long-term prospective follow-up study (Billstedt et al. 2005). All individuals had been diagnosed before the age of 10 according to DSM-III or DSM-III-R criteria for autism/PDD (APA 1980, 1987) after in-depth examination, and were considered representative of all children who had received the diagnoses infantile autism/autistic disorder or PDD-NOS (as conceptualized in the 1980s) born in 1962–1984 and living in the Gothenburg region. One of the aims of the follow-up study was to gain further insight into sexuality by examining outcome after puberty.

Participants

Among the 120 individuals who were approached for inclusion, 6 declined participation and 6 had died at the time of the follow-up. Therefore, the sample in the follow-up study consisted of 108 individuals. Ninety-two of these had been diagnosed with infantile autism/autistic disorder and 16 with PDD-NOS. Because there were few differences across symptom level between the diagnostic groups, they were collapsed into one group. Verbal ability (phrase speech) was determined through clinical observations. The level of intellectual ability ranged from severe ID to average IQ, and the vast majority (94 %) had tested IQs below 70 at the time of diagnosis. Only a handful ($n = 25$, 23 %) of all individuals were able to take a complete Wechsler scale IQ-test (Wechsler 1981, 1991). Therefore, remaining individuals in the group were assessed with Vineland Adaptive Behavior Scale (Sparrow et al. 1984) to inform decisions about IQ group membership (Table 1). The total group had a mean Global Assessment of Functioning (GAF) score (DSM-IV-TR; APA 2000) of 21.0 ($SD = 16.3$). The GAF was used as a clinician-rated instrument, where the assessor based the ratings on all the information that was available for each individual. Due to the level of intellectual ability and adaptive functioning, and more specifically lack of self-reflective capabilities, it was impossible to use a self-report questionnaire for a majority of the individuals in this group. (Table 1).

Of the 108 individuals (mean age 25 years, 6.4 SD) in the follow-up study, parents ($n = 90$) or caregivers/staff ($n = 5$) of a total of 95 individuals were interviewed and asked about their (adult) child's sexual interest and sexual orientation (information missing for 13 individuals). There were no significant differences between the individuals for whom information on sexual interest and sexual orientation was available ($n = 95$) and where it was missing ($n = 13$) on any of the following variables: age, intellectual ability, verbal ability, and adaptive functioning. However, there was a significant difference between individuals with regard to sex ($p = .043$), with more information on sexual interest and sexual orientation available for males, compared to females.

In 86 cases parents/caregivers also responded to the questions from the Diagnostic Interview for Social and Communicative Disorders (DISCO) regarding inappropriate sexual behaviors (information missing for 22 individuals). There were no significant differences between the individuals for whom information on inappropriate sexual behaviors was available ($n = 86$) and where it was not ($n = 22$) on any of the following variables: sex, verbal ability and adaptive functioning. However, there was a difference between the individuals in respect of age ($p = .026$) and intellectual ability ($p = .03$). More information on inappropriate sexual behaviors was available for younger individuals and those with severe ID or near average IQ, compared to individuals with mild ID or average IQ.

Measurements

Interview Questions

As part of a clinical interview, parents and/or caregivers were asked whether the individual showed any interest in sex, and if sexual interest was directed towards the opposite sex or not. A "no" response on the second question meant that the individual showed sexual interest that was directed

Table 1 Sample characteristics in Study 1 and Study 2

	Study 1 (n = 108)	Study 2 (n = 76)
Age mean (SD)	25 (6.4)	22 (4.5)
Male/female (%)	78/30 (72/28)	76 (100)
Verbal ability yes/no (%)	72/32 (70/30)	76 (100)
GAF score, mean (SD)	21 (16.3)	59 (9.2)
Intellectual ability (FSIQ), mean (SD)	–	104 (15.4)[a]
IQ < 50 (%)	77(71)	0
IQ 50–70 (%)	25 (23)	1 (1)
IQ 71–85 (%)	2 (2)	5 (7)
IQ > 85 (%)	4(4)	65 (92)
Symptom severity (ASDI), mean (SD)	–	41 (87)[b]
Diagnosis autistic disorder or Asperger syndrome/PDD/NOS	92/16 (85/15)	0/76 (0/100)

GAF Global Assessment of Functioning, *ASDI* The Asperger Syndrome Diagnostic Interview

[a] n = 71

[b] n = 65

towards the same sex, or engaged in solitary sexual behavior.

The Diagnostic Interview for Social and Communication Disorders (DISCO)

DISCO (Wing et al. 2002) is a semi-structured interview intended for parents or caregivers (someone who knows the individual with ASD well). The DISCO was used to collect identifying information (e.g., age, sex) and aspects of the individual's skills, deficits and untypical behaviors (e.g., verbal ability). The inter-rater reliability of the DISCO is low-excellent with kappa-values ranging from .35 to .91 and it is highly valid for assigning diagnoses (including common co-morbid diagnoses) of ASD (Nygren et al. 2009). A specific part in DISCO *(Part 8, Section ii)* includes 6 semi-structured questions to detect the presence of inappropriate sexual behaviors; (1) masturbation in public, (2) inappropriate heterosexual behavior, (3) inappropriate homosexual interest, (4) sexual interest towards much younger children, (5) indecent exposure and (6) other inappropriate sexual behavior. (Due to copyright we report the original wording from the DISCO interview. We are aware that it is not in accordance with current nomenclature.) For all of the 6 items the parent/caregiver was asked about the extent of the problem ("No problem", "Minor problem", "Marked problem") regarding inappropriate sexual behavior. Furthermore, each behavior was indicated as occurring currently (C) and ever (E). In this study, no distinction was made between minor and marked problems; problems were reported as either present or not present. Additionally, only ever responses were reported, as they included past and current behavior.

The Wechsler Intelligence Scales

The Wechsler Adult Intelligence Scale-Third edition (WAIS-III, Wechsler 1997) was used with a subgroup of individuals ($n = 25$). Of these individuals, seventeen were tested using the Wechsler Adult Intelligence Scale-Revised (WAIS-R, Wechsler 1981) and eight were tested using Wechsler Intelligence Scale for Children-Third edition (WISC-III, Wechsler 1991). The remaining participants were assessed using the Vineland Adaptive Behavior Scales (Sparrow et al.1984).

The Vineland Adaptive Behavior Scale (VABS)

VABS (Sparrow et al. 1984) is a semi-structured interview with a parent or caregiver that provides a comprehensive assessment of the individual's adaptive behavior. Individuals who could not participate in the Wechsler test (particularly those with severe intellectual disability (IQ < 50) were assessed with VABS, which enabled us to make reasonable clinical assessments regarding IQ group membership.

Statistical Analyses

A significance level of $p < .05$ was applied for all statistical tests and confidence intervals. A Mann–Whitney U test was conducted to compare groups with and without inappropriate sexual behaviors. Contingency analyses were conducted to examine group differences in the prevalence of inappropriate sexual behaviors for categorical variables. Missing data from parental interviews is explained by the incidence of refraining to ask sensitive questions due to circumstances during specific interviews, or time restriction (The present study protocol included diagnostic

criteria, Vineland adaptive behavior scale, psychiatric comorbidity etc., which meant that these questions were omitted in some cases). No imputation for missing values was performed.

Results

Sexual Interest and Sexual Orientation

While most individuals were reported as having a sexual interest, nearly a third (32 %) was reported as having no evident sexual interest. Of the individuals who had a sexual interest, more than half ($n = 39$, 60 %) showed sexual interest towards the opposite sex. About a third of the individuals ($n = 19$, 29 %) showed sexual interest towards the same sex or engaged in solitary sexual behavior. In about a tenth of all cases (11 %), the respondents were not sure about sexual interest (Table 2).

Inappropriate Sexual Behaviors

Information regarding inappropriate sexual behaviors, which was collected by the parental/caregiver interview DISCO, were found in a nearly a third (29 %) of individuals. The most commonly reported inappropriate sexual behavior was masturbation in public (21 %), followed by indecent exposure (7 %) and inappropriate heterosexual behavior (6 %). There were no reports of inappropriate homosexual behavior or sexual interest towards much younger children. Of individuals with inappropriate sexual behaviors, most (23 %) displayed only one type of inappropriate sexual behavior (Table 3).

There were no differences in age between individuals with inappropriate sexual behaviors and individuals without inappropriate sexual behaviors ($p = .341$). No relationships were found between sex and inappropriate sexual behaviors ($p = .795$), verbal ability and inappropriate sexual behaviors ($p = .205$), or intellectual ability and inappropriate sexual behaviors ($p = .452$). In addition, there was no difference in GAF-scores between individuals with inappropriate sexual behaviors and individuals without inappropriate sexual behaviors ($p = .057$).

Study 2

One hundred men with Asperger syndrome (AS) were approached for inclusion in a follow-up study (Cederlund et al. 2008). They were born 1967–1988 and had been diagnosed at ages 5.5–24.5 years. They all met the Gillberg and Gillberg criteria for AS (Gillberg and Gillberg 1989), which have been in use at the CNC since 1985—long before the publication of DSM-criteria for Asperger disorder. Criteria for inclusion in the follow-up study were (1) normal intelligence (IQ > 70) based on the result on the Wechsler scales (Wechsler 1974, 1981, 1991), (2) AS diagnosis established five or more years prior to follow-up, and (3) age 16 or over at the census date June 30th, 2006. Only males were included as no more than seven females met the criteria for inclusion. The individuals approached for inclusion have been discussed elsewhere (Cederlund and Gillberg 2004) as being representative of all males who received an AS diagnosis, whose parents/caregivers requested clinical assessments and help for them in the late 1980s and throughout the 1990s, in the Gothenburg region at the time of the original diagnosis.

The purpose of the two follow-up studies, apart from studying sexuality, was to examine outcome in late adolescence/young adult life.

Participants

Of the 100 males with AS approached for inclusion, 24 declined participation in the follow-up study. The sample in the follow-up study consisted of 76 individuals, who had varying degrees of symptom severity and IQ scores at the

Table 2 Frequency distributions: sexual interest and sexual orientation in Study 1 and Study 2

		Study 1[a] (n = 95)	Study 2[b] (n − 55)
Sexual interest	Yes (%)	65 (68)	51 (93)
	No (%)	30 (32)	1 (2)
	Unknown	0 (0)	3 (5)
Sexual orientation towards opposite gender	Yes (%)	39 (60)	49 (89)
Sexual orientation towards same gender	Yes (%)	19 (29)	3 (5)
Sexual orientation towards both genders	Yes (%)	*	3 (5)
Unknown sexual orientation	Unknown (%)	7 (11)	0 (0)

[a] Data was collected by interviewing parents

[b] Data was collected by using the self-report Sexuality Questionnaire

* This item was not asked about

Table 3 Frequency distributions: inappropriate sexual behaviours in Study 1 and Study 2, data from the DISCO interview

		Study 1 n = 86 (%)	Study 2 n = 39 (%)
Inappropriate sexual behaviour	Yes (%)	25 (29)	4 (10)
	No (%)	61 (71)	35 (90)
Masturbation in public		18 (21)	0
Inappropriate heterosexual sexual behaviour		5 (6)	1 (3)
Inappropriate homosexual sexual behaviour		–	0
Sexual interests towards children		–	2 (5)
Indecent exposure		6 (7)	1 (3)
Other inappropriate sexual behaviour		4 (5)	1 (3)
No. of inappropriate sexual behaviour	1	20 (23)	3 (8)
	2	3 (3)	1 (3)
	3	1 (1)	–
	4	1 (1)	–

time of the follow-up study that ranged from 66 to 143. The individuals in Study 2 were generally considered (much) higher functioning than the individuals in Study 1; the mean GAF score in Study 2 was 58.9 (SD = 9.2, $t(182) = 118.3$, $p < .001$) (Table 1).

In the sample, parents/caregivers of 39 individuals responded to the questions from the DISCO regarding inappropriate sexual behaviors (information missing for 37 individuals). There were no significant differences between the individuals where information on inappropriate sexual behaviors was available ($n = 39$) and where it was not ($n = 37$) on any of the following variables: age, symptom severity, intellectual ability, and adaptive functioning.

Of the 76 individuals with AS in the follow-up study, 55 completed the Sexuality Questionnaire (SexQ) (information missing for 21 individuals). Attrition (27 %) was accounted by the individual's wish to not complete the questionnaire. There were no significant differences between those who completed the SexQ ($n = 55$) and those who did not ($n = 21$) on any of the above-mentioned variables.

Measurements

DISCO

The semi-structured interview DISCO was also used in Study 2.

Sexuality Questionnaire (SexQ)

SexQ (Cederlund and Gillberg 2004) is a 14-item questionnaire that was developed for the purpose of the follow-up study of individuals with AS. It was intended for use with individuals with ASD with average and above intellectual ability and partly overlapped with questions from Part 8, Section ii of the DISCO, but it also included other aspects of sexuality. Specifically, it was used to identify sexual interest, sexual orientation, sexual activity, problems with sexuality, and paraphilias as conceptualized in the DSM-IV-TR (APA 2000). The paraphilias that were examined were: fetishism, transvestic fetishism, exhibitionism, voyeurism, sadism, and masochism. Follow-up questions were also formulated after some of the items. For all questions three response options were given: "Yes", "No", "I don't know". In the present study, the responses to follow-up questions are not reported since they were inconsistently answered. As the SexQ is not a standardized assessment instrument, the reliability and validity of the instrument is unknown.

The Asperger Syndrome Diagnostic Interview (ASDI)

The ASDI (Gillberg et al. 2001) is a semi-structured interview, based on the Gillberg and Gillberg (1989) criteria for AS, that assessed the severity of problems in social interaction, narrow interests, imposition of routines/rituals, speech and language peculiarities, non-verbal communication, and motor problems in individuals with AS. The inter-rater reliability is reported to correspond to a kappa of 0.91 and the intra-rater reliability to a kappa of 0.92 (Gillberg et al. 2001). No formal validity study has been performed. In this study we used the parent/caregiver responses. For further information on the correspondence between the personal and parent interview in this sample see Cederlund et al. (2010).

The Wechsler Intelligence Scales

The Wechsler Adult Intelligence Scale-Third edition (WAIS-III, Wechsler 1997) was used with all of the participants in the group.

Statistical Analyses

A significance level of $p < .05$ was applied for all statistical tests and confidence intervals. A Mann–Whitney U test was conducted to compare groups with and without inappropriate sexual behaviors/paraphilias. Contingency analyses were conducted to examine group differences in the prevalence of inappropriate sexual behaviors for categorical variables and the Pearson's Chi-square statistic was used to assess the degree of association between the variables. In Study 2, where self-reports were handed out, the reason for missing questionnaires was that certain individuals in the study group declined to answer questions.

Results

Sexual Interest and Sexual Orientation

A large majority of individuals that responded to the SexQ questionnaire (93 %) reported that they had a sexual interest and most of them (89 %) were identified as having a heterosexual sexual interest. There was a minority of individuals who reported that they were sexually interested in individuals of the same sex (5 %) or both sexes (5 %) (Table 2).

Inappropriate Sexual Behaviors

Information regarding inappropriate sexual behaviors, which was collected by the DISCO, were found in a subgroup (4 of 39, 10 % of those responded). The inappropriate sexual behaviors that were reported were sexual interest towards younger children (5 %), indecent exposure (3 %), inappropriate heterosexual behavior (3 %), and other inappropriate sexual behavior (3 %). There were no reports of masturbation in public or inappropriate homosexual behavior. Individuals with inappropriate sexual behaviors displayed either one (8 %) or two (3 %) inappropriate sexual behaviors (Table 3).

There were no differences in age between individuals with inappropriate sexual behaviors and individuals without inappropriate sexual behaviors ($p = .873$), or differences in ASDI scores between individuals with inappropriate sexual behaviors and individuals without inappropriate sexual behaviors ($p = .354$). No differences in either FSIQ or GAF-scores were found between individuals with inappropriate sexual behaviors and individuals without inappropriate sexual behaviors ($p = .832$ and $p = .505$).

Sexual Activity, Problems with Sexuality and Paraphilias

Data from the SexQ showed that some individuals (7 %) reported that they engaged in more than seven instances of sexual activities per week or sexual activities for more than 1 h per day (4 %). A few (7 %) individuals responded that they did not know. While most individuals did not find their level of sexual activity worrying or uncontrollable (81 %), there were a few who responded that they did find it worrying/uncontrollable (4 %), and a considerable number of individuals who reported that they did not know (15 %). The majority (75 %) reported that they did not experience any problems with their sexuality. When individuals were asked about specific paraphilias, they were confirmed by almost a fourth (24 %) of all individuals. The most reported paraphilia was fetishism, followed by voyeurism. There were no reports of exhibitionism (Table 4). The majority of those who reported paraphilias confirmed one paraphilia ($n = 10$, 18 % of the total group), however three individuals (5 %) confirmed 2 paraphilias (Table 4).

There were no differences in age between individuals with or without paraphilias ($p = .781$). However, a difference was found in ASDI scores between individuals with ($Md = 48$, $n = 12$) or without paraphilias, the later having lower ASDI scores ($Md = 40$, $n = 37$, $U = 97.5$, $p = .003$, $r = 0.40$), and in FSIQ between individuals with ($Md = 96$, $n = 13$) or without paraphilias ($Md = 112$, $n = 40$, $U = 162$, $p = .42$, $r = -.28$, higher FSIQ in the latter group). There was also a difference in GAF-scores between individuals with paraphilias ($Md = 52$, $n = 13$) and individuals without paraphilias ($Md = 60$, $n = 40$, $U = 135$, $p = .009$, $r = -.35$), with higher GAF scores in the group without paraphilias.

Discussion

This study suggests that the majority of individuals with ASD have a sexual interest, regardless of ASD subtype or level of adaptive functioning. However, there were also a considerable number of individuals with ASD in the present study who had no evident sexual interest-findings consistent with previous studies (Hellemans et al. 2010; Marriage et al. 2009; Ousley and Mesibov 1991; Ruble and Dalrymple 1993). Sexual interest was reported to a greater extent in individuals with ASD and no ID, compared to individuals with ASD and ID. Moreover, a complete lack of sexual interest was reported more often in individuals with ID in comparison with individuals without ID. Although previous studies have found sexual interest in individuals with ASD at all levels of intellectual func-

Table 4 Frequency distributions: sexual activity, problems with sexuality and paraphilias in Study 2, data from the Sexuality Questionnaire

	Study 2 $n = 52$–55 (%)		
	Yes	No	I don't know
More than 7 sexual activities per week	4 (7)	46 (85)	4 (7)
Sexual activity >1 h per day	2 (4)	46 (87)	5 (9)
Levels of sexual activity worrying or uncontrollable	2 (4)	42 (81)	8 (15)
Problems with sexuality	6 (11)	41 (75)	8 (14)
Presence of any paraphilias	13 (24)	35 (64)	0
Fetishism	6 (11)		
Transvestic fetishism	1 (1)		
Exhibitionism	0		
Voyeurism	7 (13)		
Sadomasochism	2 (3)		

tioning (e.g., Haracopos and Pedersen 1992), these findings may indicate that individuals with a higher intellectual functioning are more sexually interested, which is supported by the Dewinter et al. study (2015).

Most of the individuals who expressed a sexual interest reported sexual interest towards the opposite sex, albeit a large minority in the Study 1 showed sexual interest towards the same sex. A smaller minority showed interest in both sexes. Some individuals did not have any person-oriented sexual behavior, but engaged in solitary sexual behaviors (e.g. masturbation). The findings from this study indicate that the prevalence of gay male, lesbian or bisexual sexual interest in individuals with ASD may not be as high as previous studies have suggested (Bejerot and Eriksson 2014; Hellemans et al. 2007). However, it is possible that those who did not complete the SexQ declined to participate due to the sensitivity of the questions or because they did not feel comfortable about handing in questions about their sexuality during a visit to a medical clinic when accompanied by their parents. There were also a few individuals whose sexual orientation could not be determined, so no definite conclusions can be made in this matter.

With regard to sexual activity a majority of the Study 2 study group reported that they did not engage in seven instances of sexual activities per week or sexual activities for more than 1 h per day. Furthermore, most of these individuals did not perceive their level of sexual activity as worrying or uncontrollable, and they generally reported that they did not experience problems with their sexuality. A small subgroup in Study 2 reported that they did experience problems with their sexuality, or that they did not know if they did. Problems related to sexuality in ASD has been suggested to be related to having fewer sexual experiences, being sexually frustrated, and being more concerned with finding a partner than typically developing individuals (Mehzabin and Stokes 2011). However, population-based epidemiological studies report that prevalence rates of sexual difficulties in men varies from 3.2 to 28.5 % depending on specific sexual difficulty, (Hendrickx et al. 2014; Quinta Gomes and Nobre 2014), which indicates that our results correspond well with the prevalence in the general population.

Inappropriate sexual behaviors were reported to a far greater extent in individuals with ASD and no ID, compared to individuals with ASD and with ID, supporting results from other studies (Haracopos and Pedersen 1992; Hellemans et al. 2007; Koller 2000). In addition, the type of inappropriate sexual behaviors also varied between these groups. Masturbation in public was the most commonly reported inappropriate sexual behavior in Study 1, while sexual interest towards much younger children was the most often reported (albeit relatively infrequent) inappropriate sexual behavior in Study 2. Because of the lack of other outlets for sexual tension, masturbation has been argued as an important means of sexual release for individuals with ASD (Koller 2000). However, it is of utmost importance that these individuals are given the opportunity to learn how to express their sexual impulses in the same ways that are socially acceptable for others. Consequently, it is relevant for parents and caregivers to have an accepting approach and provide education about how to masturbate and when and where it is appropriate to do so. The incidence of sexual interest towards much younger children is of particular concern as it has serious consequences for both the victim and offender in the situation. It urgently emphasizes the need to teach individuals with ASD that sexual contact with children is never acceptable. Several researchers have suggested that intensive social training and sexual education should be imparted at an early age to *prevent* the development of problems related to sexuality, rather than implementing interventions after the problems have arisen (Gerland 2004; Realmuto and Ruble 1999; Stokes and Kaur 2005). Moreover, a concrete and

highly structured approach is important in educational settings because of the difficulties that children with ASD have with abstract thinking, comprehension and communication. Also, due to difficulties with generalizing skills learned from a particular setting to other settings, individuals with ASD need continuous support in their learning about sexual behaviors (Silovsky et al. 2013).

Paraphilias were present in almost one fourth of the study group in Study 2. Overall, the prevalence rates of paraphilias in this group far surpassed those known in the general population (Långström and Seto 2006; Långström and Zucker 2005). In our study, no relationships were found between inappropriate sexual behaviors and age, sex, verbal ability, intellectual ability or adaptive functioning, regardless of study group. Concerning the relationships between inappropriate sexual behaviors and verbal ability or adaptive functioning, our data was supported by previous studies (Kalyva 2010; Ruble and Dalrymple 1993). Regarding paraphilias, relationships between paraphilias and ASD symptom severity, intellectual ability, and adaptive functioning, showed significant correlation with effect sizes ranging from medium to high, suggesting that paraphilias may be found more often in individuals that have more ASD symptoms (measured with ASDI), lower FSIQ and lower GAF-scores.

Although knowledge about several aspects of ASD has increased (e.g. prevalence, diagnostic assessment, intervention), sexuality in individuals with ASD is often unacknowledged, repressed, or deemed irrelevant (Hénault 2006; Lawson 2005). Awareness about ASD and sexuality needs to be increased to eliminate misperceptions and pressures on individuals with ASD to control their sexuality. When instinctive behaviors are inhibited and personal needs are not met it is likely that these individuals end up frustrated, confused and insecure, which in turn may lead to the development of more problematic behaviors, e.g. aggressive or self-harming behavior towards self or others (Van Bourgondien et al. 1997) or excessive masturbation (as an important mean of sexual release) (Koller 2000). With the right education, support and intervention by parents/caregivers and professionals in primary and mental health care, we may in the future be able to promote healthy sexual development in individuals with ASD (Dewinter et al. 2013).

Strengths and Limitations

We find that the present study has several important strengths. The comprehensive examination of adolescents and adults, both with ID and without ID, provided an important insight into similarities/differences across age and daily functioning. Furthermore, the use of self-reports, which are seldom used when studying individuals with ASD, is an additional strength. The individuals in Study 1 were diagnosed in childhood as part of population-based studies, and hence considered representative of all children with infantile autism/autistic disorder or PDD-NOS (as conceptualized in the 1980s) living in the Gothenburg region at the time of diagnosis. In addition, we argue that the individuals in Study 2 were clinically representative of males with AS (as conceptualized in the 1980s).

Although there are several strengths, there are also a number of limitations in the present study. Firstly, different measures were used in the two groups, which meant that comparisons between the study samples could not be made satisfactorily. Secondly, a relatively low number of assessments were included the study, particularly in the AS group. After accounting for attrition and missing data, the samples presented in the current study, may not be representative for the total ASD population. Additionally, other significant concerns are that no differentiation was made between showing sexual interest towards the same sex and engaging in solitary sexual behavior in the first study group, no females were included in the second study group, and that no non-ASD group was included for comparison.

Future Research

Future research of intimate/sexual relationship behaviors in ASD groups, including also female participants and comparisons groups, is required. Females with ASD have been understudied. Because females possibly have different clinical presentations compared to males with ASD (Cridland et al. 2014), it might be likely that their sexual functioning is also different from their male counterparts. Furthermore, research on ASD and sexual functioning has mostly focused on negative aspects and excluded positive aspects of sexual well-being. As defined by The World Health Organization (WHO 2006) sexual health does not only indicate the absence of sexual problems and inappropriate sexual behaviour, it also includes positive emotional, psychological and social sexual functioning. Any research that is conducted on the sexuality of individuals with ASD should therefore reasonably discuss a wide range of positive and negative aspects of sexual experience, e.g. sexual knowledge, sexual behaviour with a partner, sexual behaviour alone, sexual cognitions, sexual affect and sexual response (Byers et al. 2013a, b). Finally, there are only a few studies that have compared individuals with ASD to typically developing individuals (Byers et al. 2013a, b; Hénault 2006). The examination of sexual development and sexual behaviours in both individuals with ASD and typically developing individuals could elucidate when individuals with ASD and their families need support to manage problems related to sexuality.

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Author Contributions LF participated in the interpretation of the data, performed the statistical analysis and drafted the manuscript; CIG participated in the design of the study and performed the measurement; MC participated in the design and the coordination of the study and performed the measurement; BH participated in the design of the study and performed the measurement; CG conceived of the study and participated in the design of the study, EB participated in the design and the coordination of the study, participated in the measurement, in the interpretation of the data and helped to draft the manuscript. All authors read and approved the final manuscript.

Compliance with Ethical Standards

Conflict of interest Lucrecia Cabral Fernandes, Carina I. Gillberg, Mats Cederlund, Bibbi Hagberg, Christopher Gillberg and Eva Billstedt declares that they have no conflict of interest.

Ethical Approval The Medical Ethical Committee of Gothenburg University approved the follow-up studies (no 292-99 and 615-02). All procedures performed in the study were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent Informed consent was obtained from all individual participants included in the study.

References

American Psychiatric Association. (1980). *Diagnostic and statistical manual of mental disorders* (3rd ed.). Washington, DC: Author.

American Psychiatric Association. (1987). *Diagnostic and statistical manual of mental disorders* (3rd rev. ed.). Washington, DC: Author.

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th rev. ed.). Washington, DC: Author.

Balfe, M., & Tantam, D. (2010). A descriptive social and health profile of a community sample of adults and adolescents with Asperger syndrome. *BMC Research Notes, 3*, 300.

Beddows, N., & Brooks, R. (2015). Inappropriate sexual behaviour in adolescents with autism spectrum disorder: what education is recommended and why. *Early Intervention in Psychiatry,*. doi:10.1111/eip.12265.

Bejerot, S., & Eriksson, J. M. (2014). Sexuality and gender role in autism spectrum disorder: A case control study. *PLoS One, 9*, e87961.

Billstedt, E., Gillberg, I. C., & Gillberg, C. (2005). Autism after adolescence: Population-based 13- to 22-year follow-up study of 120 individuals with autism diagnosed in childhood. *Journal of Autism and Developmental Disorders, 35*(3), 351–360.

Byers, E. S., Nichols, S., & Voyer, S. D. (2013a). Challenging stereotypes: Sexual functioning of single adults with high functioning autism spectrum disorder. *Journal of Autism and Developmental Disorders, 43*(11), 2617–2627.

Byers, E. S., Nichols, S., Voyer, S. D., & Reilly, G. (2013b). Sexual well-being of a community sample of high-functioning adults on the autism spectrum who have been in a romantic relationship. *Autism, 17*(4), 418–433.

Cederlund, M., & Gillberg, C. (2004). One hundred males with Asperger syndrome: A clinical study of background and associated factors. *Developmental Medicine and Child Neurology, 46*(10), 652–660.

Cederlund, M., Hagberg, B., Billstedt, E., Gillberg, I. C., & Gillberg, C. (2008). Asperger syndrome and autism: A comparative longitudinal follow-up study more than 5 years after original diagnosis. *Journal of Autism and Developmental Disorders, 38*(1), 72–85.

Cederlund, M., Hagberg, B., & Gillberg, C. (2010). Asperger syndrome in adolescent and young adult males. Interview, self- and parent assessment of social, emotional, and cognitive problems. *Research in Developmental Disabilities, 31*(2), 287–298.

Collins, W. A., Welsh, D. P., & Furman, W. (2009). Adolescent romantic relationships. *Annual Review of Psychology, 60*, 631–652.

Cridland, E. K., Jones, S. C., Caputi, P., & Magee, C. A. (2014). Being a girl in a boys' world: Investigating the experiences of girls with autism spectrum disorders during adolescence. *Journal of Autism Developmental Disorders, 44*(6), 1261–1274.

Dewinter, J., Vermeiren, R., Vanwesenbeeck, I., Lobbestael, J., & Van Nieuwenhuizen, C. (2015). Sexuality in adolescent boys with autism spectrum disorder: Self-reported behaviors and attitudes. *Journal of Autism and Developmental Disorders, 45*(3), 731–741.

Dewinter, J., Vermeiren, R., Vanwesenbeeck, I., & Van Nieuwenhuizen, C. (2013). Autism and normative sexual development: A narrative review. *Journal of Clinical Nursing, 22*(23, 24), 3467–3483.

Dozier, C. L., Iwata, B. A., & Worsdell, A. S. (2011). Assessment and treatment of foot-shoe fetish displayed by a man with autism. *Journal of Applied Behavior Analysis, 44*(1), 133–137.

Gerland, G. (2004). Autism: Relationer och sexualitet. Stockholm: Cura.

Gillberg, C. (1984). Autistic children growing up: Problems during puberty and adolescence. *Developmental Medicine and Child Neurology, 26*(1), 125–129.

Gillberg, I. C., & Gillberg, C. (1989). Asperger syndrome—Some epidemiological considerations: A research note. *Journal of Child Psychology and Psychiatry, 30*(4), 631–638.

Gillberg, C., Gillberg, C., Råstam, M., & Wentz, E. (2001). The Asperger syndrome (and high-functioning autism) diagnostic interview (ASDI): A preliminary study of a new structured clinical interview. *Autism, 5*(1), 57–66.

Gilmour, L., Schalomon, P. M., & Smith, V. (2012). Sexuality in a community based sample of adults with autism spectrum disorder. *Research in Autism Spectrum Disorders, 6*(1), 313–318.

Grandin, T., & Barron, S. (1995). *The unwritten rules of social relationships*. Arlington, TX: Future Horizons Inc.

Haracopos, D., & Pedersen, L. (1992). *Sexuality and autism: Danish report*. www.autismuk.com

Hellemans, H., Colson, K., Verbraeken, C., Vermeiren, R., & Deboutte, D. (2007). Sexual behavior in high-functioning male adolescents and young adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 37*(2), 260–269.

Hellemans, H., Roeyers, H., Leplae, W., Dewaele, T., & Deboutte, D. (2010). Sexual behavior in male adolescents and young adults with autism spectrum disorder and borderline/mild mental retardation. *Sexuality and Disability, 28*(2), 93–104.

Hénault, I. (2006). *Asperger's syndrome and sexuality: From adolescence through adulthood*. London, UK: Jessica Kingsley Publishers.

Hendrickx, L., Gijs, L., & Enzlin, P. (2014). Prevalence rates of sexual difficulties and associated distress in heterosexual men and women: Results from an internet survey in Flanders. *Journal of Sex Research, 51*(1), 1–12.

Herbert, M. (2003). *Typical and atypical development: From conception to adolescence*. (pp. 164–176; pp. 325–348). Malden, MA: BPS Blackwell.

Holmes, L. G., Himle, M. B., Sewell, K. K., Carbone, P. S., Strassberg, D. S., & Murphy, N. A. (2014). Addressing sexuality in youth with autism spectrum disorders: Current pediatric practices and barriers. *Journal of Developmental and Behavioral Pediatrics, 35*(3), 172–178.

Howlin, P. (2004). *Autism and Asperger syndrome: Preparing for adulthood* (2nd ed.). London, UK: Routledge.

Kalyva, E. (2010). Teachers' perspectives of the sexuality of children with autism spectrum disorders. *Research in Autism Spectrum Disorders, 4*(3), 433–437.

Koller, R. (2000). Sexuality and adolescents with autism. *Sexuality and Disability, 18*(2), 125–135.

Konstantareas, M. M., & Lunsky, Y. J. (1997). Sociosexual knowledge, experience, attitudes, and interests of individuals with autistic disorder and developmental delay. *Journal of Autism and Developmental Disorders*, *27*(4), 397–413.

Landén, M., & Rasmussen, P. (1997). Gender identity disorder in a girl with autism—A case report. *European Child and Adolescent Psychiatry, 6*(3), 170–173.

Långström, N., & Seto, M. (2006). Exhibitionistic and voyeuristic behavior in a Swedish national population survey. *Archives of Sexual Behavior, 35*(4), 427–435.

Långström, N., & Zucker, K. J. (2005). Transvestic fetishism in the general population. *Journal of Sex and Marital Therapy, 31*(2), 87–95.

Lawson, W. (2005). *Sex, sexuality and the autism spectrum*. London, UK: Jessica Kingsley Publishers.

Marriage, S., Wolverton, A., & Marriage, K. (2009). Autism spectrum disorder grown up: A chart review of adult functioning. *Journal of the Canadian Academy of Child and Adolescent Psychiatry, 18*(4), 322–328.

Mehzabin, P., & Stokes, M. A. (2011). Self-assessed sexuality in young adults with high-functioning autism. *Research in Autism Spectrum Disorders, 5*(1), 614–621.

Milton, J., Duggan, C., Latham, A., Egan, V., & Tantam, D. (2002). Case history of co-morbid Asperger's syndrome and paraphilic behavior. *Medicine, Science and the Law, 42*(3), 237–244.

Murphy, N. A., & Elias, E. R. (2006). Sexuality of children and adolescents with developmental disabilities. *Pediatrics, 118*(1), 398–403.

Murrie, D. C., Warren, J. I., Kristiansson, M., & Dietz, P. E. (2002). Asperger's syndrome in forensic settings. *International Journal of Forensic Mental Health, 1*(1), 59–70.

Nygren, G., Hagberg, B., Billstedt, E., Skoglund, A., Gillberg, C., & Johansson, M. (2009). The Swedish version of the diagnostic interview for social and communication disorders (DISCO-10). Psychometric properties. *Journal of Autism and Developmental Disorders, 39*(5), 730–741.

Ousley, O. Y., & Mesibov, G. B. (1991). Sexual attitudes and knowledge of high-functioning adolescents and adults with autism. *Journal of Autism and Developmental Disorders, 21*(4), 471–481.

Quinta Gomes, A. L., & Nobre, P. J. (2014). Prevalence of sexual problems in Portugal: Results of a population-based study using a stratified sample of men aged 18 to 70 years. *Journal of Sex Research, 51*(1), 13–21.

Realmuto, G. M., & Ruble, L. A. (1999). Sexual behaviors in autism: Problems of definition and management. *Journal of Autism and Developmental Disorders, 29*(2), 121–127.

Robinow, O. (2009). Paraphilia and transgenderism: A connection with Asperger's disorder? *Sexual and Relationship Therapy, 24*(2), 143–151.

Ruble, L. A., & Dalrymple, N. J. (1993). Social/sexual awareness of persons with autism: A parental perspective. *Archives of Sexual Behavior, 22*(3), 229–240.

Schroeder, S., LeBlanc, J., & Mayo, L. (1996). Brief report: A life-span perspective on the development of individuals with autism. *Journal of Autism and Developmental Disorders, 26*(2), 251–255.

Seltzer, M. M., Krauss, M. W., Shattuck, P. T., Orsmond, G., Swe, A., & Lord, C. (2003). The symptoms of autism spectrum disorders in adolescence and adulthood. *Journal of Autism and Developmental Disorders, 33*(6), 565–581.

Silovsky, J. F., Swisher, L. M., Widdifield, J., & Turner, V. L. (2013). Children with sexual behaviour problems. In D. S. Bromberg & W. T. O'Donahue (Eds.), *Handbook of child and adolescent sexuality* (pp.171–192). New York, NY: Elsevier, Inc.

Silva, J. A., Ferrari, M. M., & Leong, G. B. (2002). The case of Jeffrey Dahmer: Sexual serial homicide from a neuropsychiatric developmental perspective. *Journal of Forensic Science, 47*(6), 1347–1359.

Sparrow, S. S., Balla, D. A., & Cicchetti, D. V. (1984). *Vineland adaptive behavior scales*. Circle Pines, MN: American Guidance Service.

Stokes, M. A., & Kaur, A. (2005). High-functioning autism and sexuality: A parental perspective. *Autism*, *9*(3), 266–289.

Stokes, M., Newton, N., & Kaur, A. (2007). Stalking, and social and romantic functioning among adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 37*(10), 1969–1986.

Van Bourgondien, M. E., Reichle, N. C., & Palmer, A. (1997). Sexual behavior in adults with autism. *Journal of Autism and Developmental Disorders, 27*(2), 113–125.

Van Son-Schoones, N., & van Bilsen, P. (1995). Sexuality and autism. A pilot-study of parents, health care workers and autistic persons. *International Journal of Adolescent Medicine and Health, 8*(2), 87–101.

Wechsler, D. (1974). *Manual of the Wechsler intelligence scale for Children—Revised*. New York, NY: The Psychological Corporation Limited.

Wechsler, D. (1981). *Wechsler adult intelligence scale—Revised*. San Antonio, TX: The Psychological Corporation Limited.

Wechsler, D. (1991). *Wechsler intelligence scale for children* (3rd ed.). New York, NY: The Psychological Corporation Limited.

Wechsler, D. (1997). *Wechsler adult intelligence scale* (3rd ed.). San Antonio, TX: Psychological Corporation.

Wing, L., Leekam, S. R., Libby, S. J., Gould, J., & Larcombe, M. (2002). The diagnostic interview for social and communication disorders: Background, inter-rater reliability and clinical use. *Journal of Child Psychology and Psychiatry, 43*(3), 307–325.

World Health Organization. (2006). *Defining sexual health: report of a technical consultation on sexual health, 28–31 January 2002*. Geneva, Switzerland: World Health Organization.

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