JCN Journal of Clinical Nursing

Journal of
Clinical Nursing

SEXUALITY OF CLIENTS WITH SPECIAL NEEDS

Autism and normative sexual development: a narrative review

Jeroen Dewinter, Robert Vermeiren, Ine Vanwesenbeeck and Chijs van Nieuwenhuizen

Aims and objectives. To explore the existing knowledge on sexuality and autism spectrum disorders. To this end, the concept of normative sexual development was used as an organising framework.

Background. Sexual health can be seen as a developmental task for all children, adolescents and adults. Core autism features are related with skills central to sexual development and functioning. More insight in sexual development in people with autism is relevant for education, support and interventions by parents and professionals in somatic and mental health care.

Methods. A comprehensive search of scientific online databases and reference lists was conducted. Publications based on qualitative and quantitative research, including case studies, were selected.

Results. Fifty-five articles and reports were selected and discussed. Information was grouped according to three domains: sexual behaviour, sexual selfhood and sexual socialisation.

Conclusion. Sexual development is a part of life for people with autism of all developmental levels and is generally understudied in this population. Most information was available on behavioural aspects and experiences of socialising agents, such as parents and professionals. Developmental processes and the relation between sexual behaviour, selfhood and socialisation remained unclear.

Relevance to clinical practice. Nurses working in schools, institutions and general health care support children, adolescents and adults with autism and advice their families, teachers, other educators and caregivers on sexuality issues. They can have an important role in daily assessment and support of this developmental domain by actively enquiring about the different aspects of sexual development and by offering information. Our findings offer an overview on the existing knowledge and support the idea that sexual development is normative for people with autism just as for anybody else.

What does this paper contribute to the wider global clinical community?

This article offers:

- an up-to-date review of scientific knowledge on sexuality in people with autism spectrum disorders.
- an integration of knowledge related to sexual behaviour, sexual selfhood and sexual socialisation in people with autism spectrum disorders and their contexts.
- points for attention related to sexual health for nurses and other professionals working with people with autism spectrum disorders.

Key words: Asperger's disorder, autism, review, sexual development, sexual health

Accepted for publication: 12 April 2013

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Introduction

Impairments in social interaction, communication and limited, repetitive and stereotyped patterns of behaviour, interests and activities (American Psychiatric Association 2000) are the core features of autism spectrum disorders (ASDs). Skills on these domains are important for sexual development and sexual health. There is a growing consensus on the importance of thinking about sexuality and sexual health as a normative and positive aspect of child and adolescent development (SIECUS 2004, Tolman & McClelland 2011). This necessitates understanding of the interaction between ASDs and the developmental domain of sexuality. The potentially positive role of sexuality in development and daily functioning, and the importance for caregivers and society to support this, has been stressed (World Health Organization 2006). In 1985, however, a discussion in the parent section of an autism journal stated that '… sex is not for the majority of autistic people…' (Torisky & Torisky 1985). This led to an extensive discussion on sexuality and the need for sex education in people with ASDs.

In this article, research publications on sexuality and ASDs are reviewed. The framework of sexual health and normative sexual development by Tolman and McClelland (2011) is used. Normative sexual development indicates sexual maturation and physical growth as facts of life that are to be integrated in daily functioning so that these do not hamper an individual's well-being or that of others. Sexual health (World Health Organization 2006) can be seen as an outcome of a positive sexual development, that is, growing up to be a healthy sexual adult (SIECUS 2004). Tolman and McClelland (2011) discerned three domains in their review of literature on normative sexuality development: (1) sexual behaviour – the behavioural repertoire related to sexuality, solitary or in relation to others, (2) sexual selfhood – the internal development of people including knowledge, attitudes, identity and ideas on the self as a sexual being, as a partner in a relationship, etc., and (3) sexual socialisation – the different contexts (home and parents, peers, school, partners, Internet, etc.) in which people learn about relationships and sexuality and in which they experience sexuality.

Aims

We undertook this review of research publications in order to describe knowledge related to sexual health in people with an ASD whilst distinguishing between sexual behaviours, sexual selfhood and sexual socialisation.

Methods

A computerised search was conducted in the following databases: Web of Science, PubMed, Psych Info and ERIC. Key words used were '*sociosexual**, *psychosexual**, *sexual**, *autis**, *Asperger**'. All abstracts were screened and empirical studies related to sexual development and functioning were included. Studies on the screening of autism symptoms in specific populations (e.g. juvenile offenders) were excluded. Also excluded were review and discursive articles, descriptions of test construction and intervention development, book reviews, studies on the influence of vasopressin and oxytocin, legal cases and articles on facilitated communication in the disclosure of sexual abuse. Only English publications were selected, covering the period 1980 till October 2012. Reference lists were checked for additional relevant articles. Both quantitative and qualitative studies, including case reports on sexuality (behaviour, selfhood and socialisation) in people with an ASD, were included.

Results

First, the selected studies and their characteristics are briefly discussed (methods used, participants – See Tables 1 and 2 for an extensive overview). Subsequently, the information from the studies was grouped according to domains described above: sexual behaviour, sexual selfhood and sexual socialisation.

Number of studies

Twenty-six empirical studies and 29 case reports were selected. Two articles (Konstantareas & Lunsky 1997, Lunsky & Konstantareas 1998) reported on the same study, so one was excluded. An unpublished report by D. Haracopos and L. Pedersen (http://www.autismuk.com/?page_id=1293) and an article published as an appendix of a book (Hénault & Attwood 2006) were included in these 26 articles, because of their relevance and the fact they were often referred to in other publications.

Research methods used

Six studies only used qualitative methods (Gray 1994, Sperry & Mesibov 2005, Nichols & Blakeley-Smith 2009, Hatton & Tector 2010, Bekirogullari *et al.* 2011, Ballan 2012). Three of these qualitative studies concerned parental experiences and concerns (Gray 1994, Nichols & Blakeley-Smith 2009, Ballan 2012) or that of teachers and

Table 1 Studies examining sexual functioning and socialisation in individuals with autism spectrum disorders

Author	Focus	Method	*n*	Diagnosis	Sex	Age	Intelligence	Control group
Balfe and Tantam (2010)	Living, employment and psycho-social situation	Questionnaire [quantitative method (quant)] self-report	42	HFA or AS	37 male, 5 female	M = 26·21 SD 11·9 range 13–64	IQ > 70	No
Ballan (2012)	Content of communication about sexuality between parents and children	Semi-structured interview [qualitative method (qual)] parent-report	18 parents of 20 children with ASD	ASD	Parents: 16 female 3 male Children: 19 male, 1 female	Children between age 6–13	Unknown	No
Bedard *et al.* (2010)	Sexual orientation and gender identity	Questionnaires (quant) self-report	32	Developmental disabilities 2 ASD	16 male, 16 female 1 male, 1 female	M = 39 years, range 20–64	Borderline intelligence to high moderate level of developmental disability	No
Bekirogullari *et al.* (2011)	Information level and attitudes of professionals offering sex education	Semi-structured interviews (qual) teacher-report	30 special education teachers and 30 educational psychologists	n/a	2 × 15 males and 2 × 15 females			No
Byers *et al.* (2012)	Factors associated with sexual well-being in people with HFA/AS	Questionnaires (quant) self-report	141	Professional diagnosis of ASDs (AQ > 26)	56 male, 85 female	M = 39·6 range 21–73	High functioning 60% had completed an under-graduate or graduate degree	No
Gilmour *et al.* (2012)	Sexual attitudes and behaviours of adults with an ASD	Online survey (quant) self-report	82	Self-reported ASD, confirmed by AQ	55 female, 17 male	M = 28·9 years, SD 9·3	Unknown	282 people in general population/ students
Gray (1994)	Coping stresses and strategies in parents of children with autism	Survey (quant) Interviews (qual) parent-report	172 parents 33 parents	Children with ASD	Unknown	Unknown	Unknown	No
D. Haracopos and L. Pedersen (unpublished manuscript)	Sexual behaviour in people with autism, experience of staff and assessment of sexual behaviour	Questionnaires filled out by staff	81 people with an ASD	ASD: 22 high functioning, 42 moderate functioning, 17 low functioning	57 male, 24 women	Range 16–40	25 with good language, 29 fairly well-spoken language, 27 very little or no spoken language	No

Table 1 (Continued)

Author	Focus	Method	*n*	Diagnosis	Sex	Age	Intelligence	Control group
Hatton and Tector (2010)	Experiences with sex education	Questionnaires In-depth interviews (qual) self-report	12 4	ASD AS and HFA	Unknown	Unknown	Unknown	No
Hellemans *et al.* (2007)	Sexual knowledge and behaviours of adolescents HFA boys	Semi-structured interviews of caregivers (quant)	24	14 AD 6 AS 4 PDD-NOS	All male	M = 17 years range 15–21	IQ M = 90 range 71–113	No
Hellemans *et al.* (2010)	Sexual knowledge and behaviours of adolescent boys with autism and MR and boys with MR	Semi-structured interviews of care-givers (quant)	20 19	ASD and MR MR	12 female, 5 male 6 female, 12 male	M = 35 years, range 27–52 M = 38 years, range 21–50	M IQ = 67·95, SD = 7·22, range: 54–78 M IQ = 67·89, SD = 6·97, range: 55–78	Autism vs. nonautism
Hénault and Attwood (2006)	Sexual profile of people with ASDs	Questionnaire Self-report	28	21 AS 5 HFA 2 PDD-NOS Confirmed with AQ	19 male 9 female 3 trans-sexual (2 F, 1 M)	M = 34 Range 18–64	Unknown	50 controls
Kalyva (2010)	Teachers' perceptions of sexual behaviours of pupils with ASDs	Questionnaire filled out by teachers (quant)	56 children 20 children	LFA HFA or AS	38 male 18 female 16 male 4 female	M = 10 years and 7 months Range 7–14	IQ<70 Average IQ	No
Konstantareas and Lunsky (1997)	Sexual interest, knowledge, attitudes and behaviours	Questionnaire and interview (quant) self-report	15 16	ASD DD	9 male, 6 female 8 male, 8 female	M = 28·1, SD = 7·7, range 16–46	2/3 mild MR 1/3 moderate–severe MR	ASD vs. DD
Lunsky and Konstantareas (1998)	Socio-sexual attitudes of people with developmental disabilities	Questionnaire and interview (quant) self-report	15 16	ASD Developmental delay	9 male, 6 female 8 male, 8 female	M = 28·1, SD = 7·7, range 16–46	2/3 mild MR 1/3 moderate–severe MR	2 control groups: 25 undergraduate students 28 controls
Mandell *et al.* (2005)	Abuse in children with autism in the community	Existing data-file (quant)	156 children with autism	AD AS	108 male 48 female	M = 11·6, SD 3·8	Unknown	No

Table 1 (Continued)

Author	Focus	Method	*n*	Diagnosis	Sex	Age	Intelligence	Control group
Mehtar and Mukaddes (2011)	Post-traumatic stress disorder in children with ASD	Assessment, questionnaires and interview (quant) parent- and self-report	69 children and adolescents	59 AD, 5 AS 5 PDD-NOS	53 male 16 female years. On	M = 11 years 7 months, SD 3 years 3 months, range 6–18	Unknown	n/a
Mehzabin and Stokes (2011)	Sex education, socio-sexual knowledge, behaviours and worries in people with HFA	Questionnaire (quant) self-report	21 people with HFA	HFA AS	12 males 9 females	M = 25·3 years, SD = 3·6 M = 23·4 years, SD = 1·9	Unknown	HFA<>TD
			39 TD		15 males 24 females	M = 23·7 years, SD = 3·1 M = 22·6 years, SD = 2·1		
Nichols and Blakeley-Smith (2009)	Concerns and needs of parents regarding sex education of their children with an ASD and evaluation of an intervention	Focus-groups (qual)	21 parents of youth with an ASD	11 AD 8 AS 2 PDD-NOS	13 male, 8 female	M = 13, range 8–18	IQ< 65: 3 65–84: 6 85–114: 7 >115: 4	No
		Questionnaire pre-/post-test (quant)	10 parents	4 AD 6 AS	5 male 5 female	Range 10–14	Low average to above average	
Ousley and Mesibov (1991)	Sexual knowledge and interests in people with HFA and MR	Questionnaire (quant) Self-report	21 HFA	HFA (CARS)	11 male 10 female	M = 27 years 4 months SD=5·4 M = 27 years 3 months SD=5·9	M IQ 84·4 SD 8·1 M IQ 73·9 SD 15·8	ASD<>MR
			20 MR		10 male 10 female	M = 27 years 11 months SD=5·9 M = 27 years 5 months SD=7·9	M IQ 56·9 SD 11·1 M IQ 54·6 SD 13·4	
Ruble and Dalrymple (1993)	Parental views on sexual awareness, education and behaviour	Questionnaire (quant) parent-report	100	ASD	68 male 32 female	M = 19·5 range 9·1–38·9	84% MR	No
Sperry and Mesibov (2005)	Perceptions of social challenges by adults with autism	Focus group (qual)	18	ASD	17 male 1 female	M = 34 Range 22–49	Unknown, Highly educated sample	No

Table 1 (Continued)

Author	Focus	Method	*n*	Diagnosis	Sex	Age	Intelligence	Control group
Stauder *et al.* (2011)	Masculinisation of gender role behaviour in people with autism	Questionnaires (quant) Self-report	25 25 controls Age & sex-matched	9 AS 8 AD 8 PDD-NOS	16 male 9 female	M = 34·81 SD 9·37 M = 27·89 SD 10·87	Normal range	ASD<>controls
Stokes and Kaur (2005)	Parental views on sexual knowledge, education and behaviour	Questionnaire (quant) parent-report	23 HFA 50 controls	HFA or AS	17 male 6 female 33 male 17 female	M = 12·6 SD 1·9 M = 13 SD 0·6 M = 13·5 SD 1·4 M = 13·1 SD 1·5	Unknown	HFA<>controls
Stokes *et al.* (2007)	Parental views on social and romantic functioning in people with autism	Questionnaire (quant) parent-report	25 ASD 38 controls	3 AD 3 HFA 19 AS	16 male 9 female 32 male 6 female	M = 22·21 SD 4·83 Range 13–36 M = 20·83 SD 4·83 Range 13–30	>70	HFA<>controls
Van Son-Schoones and Van Bilsen (1995)	Sexual development of autistic persons	Questionnaire (qual) Interviews (qual)	37 parent-couples 14 parents 4 healthcare workers 4 ASD men	ASD	Unknown	Age 12–30 Age 18–30	Not specified Normally gifted	No
Van Bourgondien *et al.* (1997)	Sexual behaviour of people with autism living in group homes	Questionnaire on sexual behaviour and group policy filled out by professional (quant)	89	26 mild autism 23 moderate autism 51 severe autism	72 male 17 female	M = 28 Range 16–59	18 mild MR 22 moderate MR 60 severe MR 33% nonverbal	No

Quant, quantitative method; Qual, qualitative method; M, mean; SD, standard deviation; SE, standard error; HFA, high-functioning autism; AS, Asperger's disorder; AD, autistic disorder; ASD, autism spectrum disorder; AQ, autism quotient; CARS, Childhood Autism Rating Scale; MR, mental retardation.

Table 2 Case reports on sexual behaviours in individuals with ASDs

Study	Focus	No. of cases	Diagnosis	Information on development	Age	IQ
Baron-Cohen (1988)	Relational violence of male towards his 71-year-old partner	1 male	AS	Yes	21	TIQ 80, VIQ 92, PIQ 69
Chan and Saluja (2011)	Sexual inappropriate behaviours since age 11. Change in autism features after Traumatic Brain Injury	1 male	Autism	Yes	25	TIQ 65
Cooper *et al.* (1993)	Transvestism and history of sexually offensive behaviours	1 male	AS	Yes	38	TIQ 54
Coskun *et al.* (2009)	Psychopharmacological treatment of excessive masturbation and inappropriate behaviours	10 (8 male, 2 female)	AD	No	5·2–16·4 Mean 12·4 SD 3·58	Unknown
Coskun and Mukaddes (2008)	Psychopharmacological treatment of offensive fetishism in a 13-year-old boy with autism	1 male	AD	Yes	13	Probably Moderate mental retardation
Dozier *et al.* (2011)	Behavioural intervention in a man with an offensive shoe fetish	1 male	Autism	Yes	36	Little expressive language
Early *et al.* (2012)	Behavioural intervention in an adolescent with an offensive preoccupation with female feet	1 male	Autism	Yes	16	Normal range
Gallucci *et al.* (2005)	Gender identity problems in a men with Asperger's disorder	1 male	AS GID	Yes	41	Probably normal range
Griffin-Shelley (2010)	Treatment of adolescent boy with Asperger's disorder referred because of sexually offensive behaviours and sex addiction	1 male	AS	Yes	14 followed till adulthood	VIQ 121 PIQ 86
Jones and Okere (2008)	Hormonal treatment of hyper sexuality and offensive behaviours	1 male	Autism	No	23	Unknown
Kohn *et al.* (1998)	Adolescent boy with Asperger's disorder presenting with repeating sexual assault and physical aggression	1 male	AS	Yes	16	IQ 120
Kraemer *et al.* (2005)	Assessment of a women with Asperger's disorder and GID	1 female	AS GID	Yes	35	Verbal intelligence 125
Landén and Rasmussen (1997)	Girl with autism and transsexuality	1 female	AD	Yes	14	IQ 110
Lewis (2006)	Psychodynamic treatment of 3 boys with developmental disabilities during adolescence	3 males	1. Bipolar disorder and PDD-NOS 2. AS 3. MCDD	Yes	8 through adolescence and both 10 through adolescence	Unknown
Milton *et al.* (2002)	Assessment and treatment of a man with Asperger's syndrome, paraphilic and offensive behaviours	1 male	AS	Yes	Early 1930s	IQ 80

Table 2 (Continued)

Study	Focus	No. of cases	Diagnosis	Information on development	Age	IQ
Mukaddes (2002)	Gender identity problems in 2 boys with autism	2 males	AD AD	Yes Yes	10 7	IQ 75 IQ 85
Müller (2011)	MRI research on amygdala-hippocampal lesions in a man with autism convicted for murder. Sadomasochism and hyper sexuality	1 male	AD	Yes	29?	IQ 81, VIQ 76 PIQ 94
Murrie *et al.* (2002)	Case studies of forensic patients with Asperger's disorder convicted for different types of crimes (2, 4, 5, 6 concerning sexual offensive behaviours)	6 males	AS	Yes	1. 31 2. 27 3. 44 4. 33 5. 22 6. 31	1. Borderline low average range 2. VIQ average, PIQ borderline to mental deficit 3. Above average 4. Average 5. Normal range 6. Unknown
Parkes *et al.* (2009)	Cross-dressing and gender dysphoria in 13 people with learning disabilities	12 males 1 female	1 ASD	No	Unknown	Unknown
Perera *et al.* (2003)	Girl with AS and OCD and gender dysphoria during adolescence	1 female	AS OCD GID	Yes	Followed from age 9 till 20	Unknown
Ray *et al.* (2004)	Reflection on sexual development in adolescents with AS and treatment for problems. 4 cases: Tim, Bill (offensive fetish), Will (offensive fetish) and Max (traumatised, sexually offensive)	4 males	AS	Yes (limited)	Age 15 Age 17 Age 16·5 Age 14	Unknown
Realmuto and Ruble (1999)	Definition of sexual behaviour and problems, illustrated with case report (deviant sexual arousal, public masturbation)	1 male	AD	Yes	Young adult	Low average
Ritvo *et al.* (1988)	11 possible parents with autism	2 female 9 male	No formal diagnosis	Limited	Adults	Unknown
Silva *et al.* (2002)	Case report on serial sexual homicidal behaviour	1 male	Assumed AS	Yes	Adult	Above average to high
Singh and Coffey (2012)	Case report on a boy with excessive masturbation, gender dysphoria and deviant sexual interest and intrusive sexual thoughts	1 male	PDD-NOS OCD Bipolar disorder-NOS	Yes	16	59
Stefanos *et al.* (2011)	Psychodynamic treatment of adolescent aimed at addressing sexuality and emotional problems	1 male	AS	Limited	15	Unknown High school education

Table 2 (Continued)

Study	Focus	No. of cases	Diagnosis	Information on development	Age	IQ
Tateno *et al.* (2008)	Assessment of five-year-old boy with gender dysphoria	1 male	AS GID	Yes	Entered at age 5	TIQ 92, VIQ 90 PIQ 96
Tissot (2009)	School policy on sexuality in their pupils: 6 case reports 1. Public masturbation 2. Inappropriate touching 3. Distress at menstruation 4. Public undressing and masturbation 5. Homosexual relation 6. Inefficient masturbation technique	5 male (1, 2, 4, 5, 6) 1 female (2)	Autism spectrum disorders	No	1. 11 2. 12·5 3. 12 4. 16 5. Both 19 6·11	Unknown
Williams *et al.* (1996)	Two children with cross-gender preoccupations (playing with dolls, cross-dressing)	2 males	1. AD 2. AD	Yes	1. 5 2. 3·7	1. 105 2. Developmental delay

AS, Asperger syndrome; AD, autistic disorder; GID, gender identity disorder; MCDD, Multiple Complex Developmental Disorder; OCD, obsessive compulsive disorder; PDD-NOS, pervasive developmental disorder not otherwise specified.

other professionals (Bekirogullari *et al.* 2011). One quantitative study was based on the examination of case files (Mandell *et al.* 2005). In the remaining studies ($n = 25$), semi-structured interviews and questionnaires were used for data gathering (see Tables 1 and 2).

Subjects under study

Seventeen studies focused on high-functioning people with an ASD of different age groups. Nine studies reported about children and adolescents (<age 21) (Mandell *et al.* 2005, Stokes & Kaur 2005, Hellemans *et al.* 2007, 2010, Stokes *et al.* 2007, Nichols & Blakeley-Smith 2009, Kalyva 2010, Mehtar & Mukaddes 2011, Ballan 2012).

In the case reports, 65 people (57 male) are described. Thirty-one reports contain developmental information. Thirty-seven cases were children and adolescents. All report on specific or deviant problems and behaviours (23 on gender dysphoria and cross-dressing and seven on fetishism, inappropriate masturbation and offensive behaviours).

Sexual behaviour

In this section, the findings on observable, behavioural aspects of sexual health are described.

Solitary sexual behaviour

Masturbation was observed in 40–77·8% of the men with ASDs (Ousley & Mesibov 1991, Konstantareas & Lunsky 1997, Van Bourgondien *et al.* 1997, Hellemans *et al.* 2007, 2010, D. Haracopos & L. Pedersen, unpublished manuscript), and self-reports revealed weekly solitary sexual activity, with higher desire and activity in males than in females (Byers *et al.* 2012). Masturbation frequency reported in females was 20–54·2%. Masturbation habits often were unknown to caregivers, which is in line with D. Haracopos and L. Pedersen (unpublished manuscript) stating that higher-functioning people with an ASD are more appropriately private in their sexual behaviour. These observed rates are lower than self-reported rates of typically developing adolescents. In the Netherlands, 93% of boys between age 18–20 and 73% of girls reported masturbation (De Graaf *et al.* 2012). Masturbating techniques were often (29%) instructed by caregivers (Hellemans *et al.* 2007), and masturbation did not always lead to orgasm (men: 64·3–69% of those who masturbated, women: 25–46·1%) (Van Bourgondien *et al.* 1997, D. Haracopos & L. Pedersen, unpublished manuscript). In the typically developing adolescents aged 18–20 in the Netherlands, 93% of boys and 77% of girls experienced an orgasm (De Graaf *et al.* 2012). Hellemans *et al.* (2007) found compulsive masturbation in 17% of the boys with an ASD in his sample, and this behaviour was also described in several case studies (Coskun *et al.* 2009, Griffin-Shelley 2010, Singh & Coffey 2012). It is not clear how compulsivity was defined, although in most case reports, it was the public character of masturbation that led to such labelling. Public masturbation, in general, was noted in several studies (Coskun *et al.* 2009, Tissot 2009, Dozier *et al.* 2011), although it was

reported less frequently in higher-functioning people (Hellemans *et al.* 2007, D. Haracopos & L. Pedersen, unpublished manuscript). Particular sexual behaviours and interests were found in low frequencies but in several studies: arousal in the presence of certain objects or specific characteristics of people (such as hair or feet) (Van Bourgondien *et al.* 1997, Hellemans *et al.* 2007), the use of specific objects (e.g. a belt, hard objects) for masturbation (Hellemans *et al.* 2007, 2010, D. Haracopos & L. Pedersen, unpublished manuscript) and deviant interests (e.g. in prepubertal children) (Realmuto & Ruble 1999, Hellemans *et al.* 2007). Deviant or unusual sexual behaviours and interests were also described in multiple case studies, such as fetishism (Cooper *et al.* 1993, Ray *et al.* 2004, Coskun & Mukaddes 2008, Dozier *et al.* 2011, Early *et al.* 2012) and an interest in young children (Realmuto & Ruble 1999, Chan & Saluja 2011).

Sexual interaction and relationships

Despite the social difficulties central in ASDs, a clear interest in romantic and/or sexual dyadic relationships was found in many of the studies of adolescents and adults with an ASD. About half of people with high-functioning autism (HFA) demonstrated sexual behaviours towards others (Byers *et al.* 2012, D. Haracopos & L. Pedersen, unpublished manuscript) or talked about their need for being in a relationship (Hellemans *et al.* 2007). Also, about half of the group of adolescents in the study by Hellemans *et al.* (2007) was or had been in a romantic and physical relationship. In the group of adults with Asperger syndrome studied by Hénault and Attwood (2006), 43% of the 28 participants had been in a relationship, and Byers *et al.* (2012) studied sexual well-being of 141 people with an ASD who all were or had been in a romantic relationship.

Information on other sexual behaviours remains scarce. The number of people engaging in kissing varied from 9–100% in males and little less in females. Hugging and petting was reported in 0 to around 50%. Experience of mutual masturbation, oral sex, penile–vaginal or anal intercourse was explored in only a few studies. Hellemans *et al.* (2007, 2010) studied sexual behaviours of adolescents (age 15–21) with an ASD with and without mental retardation (MR). In the HFA group, 13% of 24 had had sexual intercourse (vaginal or anal) and another 13% had attempted this. In the group with ASD and MR, two of 20 participants had an experience of mutual masturbation. Of the 21 adults with HFA in the study by Ousley and Mesibov (1991), only one of the 10 females and none of the male participants reported 'to have gone further than hugging and kissing'. Van Bourgondien *et al.* (1997) found that only one participant in their group of adults ($n = 89$) with an ASD and MR had sexual intercourse (not specified) and four had attempted to (three male, one female). D. Haracopos and L. Pedersen (unpublished manuscript) found that one female had experienced sexual intercourse, but this was against her will. However, a substantial number of people who were interested in a sexual relationship had no or little experience of one (Ousley & Mesibov 1991, D. Haracopos & L. Pedersen, unpublished manuscript). Stokes *et al.* (2007) looked at parent-reports and found a clear relation between social and romantic functioning. In adolescents, the subjects of their romantic interests were more diverse compared with typically developing controls and more frequently unattainable, with unrealistic infatuations reported (e.g. caregivers, celebrities) (Stokes *et al.* 2007, D. Haracopos & L. Pedersen, unpublished manuscript).

Sexually inappropriate behaviours among people with an ASD of all different functional levels have been reported in quite a number of case studies (Baron-Cohen 1988, Cooper *et al.* 1993, Kohn *et al.* 1998, Milton *et al.* 2002, Murrie *et al.* 2002, Silva *et al.* 2002, Ray *et al.* 2004, Griffin-Shelley 2010, Chan & Saluja 2011). These varied from solitary behaviours (e.g. public masturbation) to inappropriate romantic behaviours (e.g. unwanted courting) to sexual offenses (e.g. assault and rape). In many cases, it was unclear whether the person was aware of the consequences of his/her behaviour. Some authors have developed discussion on what they have termed 'counterfeit deviance' (Hellemans *et al.* 2007, Nichols & Blakeley-Smith 2009, Gougeon 2010): deviant behaviours resulting from a lack of knowledge and support. Stokes *et al.* (2007) found that adolescents and adults in their group with ASDs demonstrated more inappropriate courtship behaviours (inappropriate touching, threatening…) and less appropriate strategies (e.g. asking someone out) compared with controls. Different mechanisms underlying these offensive behaviours have been suggested: a lack of social insight and skills, limited empathy, limited understanding of social information or social awareness, a lack of inhibition and knowledge, but also preoccupations, sensory preferences, reduced emotion recognition, persistent, repetitive and stereotyped behaviours (Hellemans *et al.* 2007, Stokes *et al.* 2007, Nichols & Blakeley-Smith 2009, D. Haracopos & L. Pedersen, unpublished manuscript). Children who experienced physical and sexual victimisation were also more likely to demonstrate sexual abusive behaviours towards others (Mandell *et al.* 2005). Thirty-seven case studies reported on offensive behaviours, including developmental

information on the subject. These inappropriate behaviours (public masturbation, inappropriate touching, deviant interest) frequently seemed to start early in adolescence.

Sexual selfhood

Next to the visible, behavioural aspects of sexuality, sexual health also refers to mental and emotional aspects.

Sexual interest and orientation

The studies on sexual behaviour revealed an interest in sexuality in the majority of people with an ASD (Van Son-Schoones & Van Bilsen 1995, Hellemans *et al.* 2007, Byers *et al.* 2012, Gilmour *et al.* 2012), although feelings of asexuality were also reported (Gilmour *et al.* 2012). Konstantareas and Lunsky (1997) found, in 15 individuals with ASD and a cognitive impairment, an interest in marrying and having children rather than in sexuality. Hénault and Attwood (2006) found that their adult participants reported that the age of first interest in sexuality was 14 on average. The age of first sexual experiences was 21 on average. In general, sexual interest and desire was higher in men compared with women (Ousley & Mesibov 1991, Hénault & Attwood 2006).

In different studies, a higher than expected rate of homo- or bisexual interest was found (Hellemans *et al.* 2007, Byers *et al.* 2012, D. Haracopos & L. Pedersen, unpublished manuscript), 12–35% compared with 3·1% of boys and 2·4% of girls aged 12–25 who reported attraction towards a same-sex partner in a recent survey in the Netherlands (De Graaf *et al.* 2012). Gilmour *et al.* (2012) found higher scores on a dimensional measure of homosexuality in females in their group with ASDs compared with their control group. Many participants in the study of Hénault and Attwood (2006) reported homosexual fantasies.

Sexual knowledge

Results on sexual knowledge are inconclusive. Comparison of people with and without ASDs, also when matched on intelligence levels, revealed contradicting results, with average knowledge levels in HFA groups (Ousley & Mesibov 1991, Hatton & Tector 2010, Byers *et al.* 2012, Gilmour *et al.* 2012) and lower scores compared with controls in other studies (Konstantareas & Lunsky 1997, Hénault & Attwood 2006, Mehzabin & Stokes 2011). In their study of HFA adolescent boys, Hellemans *et al.* (2007) found adequate basic knowledge on self-care and socio-sexual skills, but this was not reflected in the actual behaviour and functioning. In their later study with adolescents (2010) with ASD and MR, this adequate theoretical knowledge was confirmed and no problems were seen in the transfer to daily functioning. The authors remarked that the institutions supporting this group had paid attention to training these knowledge and skills.

Worth noticing is that sexual knowledge was operationalised in different ways ranging from basic vocabulary knowledge, broad socio-sexual knowledge, judgments of parents and caregivers on knowledge to more complex knowledge on sexual physiology and behaviour. This may, in part, explain the differences found.

Sexual well-being is a broad term including knowledge, attitudes and behaviours towards the self, sexuality and others. This way, it covers aspects of sexual behaviour and selfhood. Two studies concerned sexual functioning and well-being. Byers *et al.* (2012) included 141 high-functioning people with ASDs who were or had been in a romantic relationship. In the other study (Hénault & Attwood 2006), 43% of participants had been in a relationship. Both studies found that being in a relationship positively correlated with emotional and sexual satisfaction. Byers *et al.* (2012) found that people with lower levels of social functioning or communication skills showed less satisfaction and self-esteem and higher anxiety in the context of a relationship. No relation was found between ASD symptoms and solitary sexual well-being, based on sexual knowledge, moderate desire, thoughts (1–2 times/week) and activity (1 time/week). Men reported higher desire, thoughts and masturbation, whilst women scored higher on knowledge measures. Hénault and Attwood (2006) used the Derogatis Sexual Functioning Inventory and found, compared with normal controls, a more negative body image, more distress symptoms and more negative affects. The sexual satisfaction in their group was lower, but general sexual satisfaction was comparable to the normal controls. They found average scores on scales concerning fantasy, sexual desire and gender roles. The longing for a relationship and sexuality, combined with the absence of it, could be an explanation for the high number of people with ASDs in a community sample (56%) reporting sexual frustration (Balfe & Tantam 2010).

Finally, of relevance in adolescence are reactions to pubertal bodily changes. Anxiety and distress in reaction to secondary sexual characteristics (physical changes, sexual reactions) were reported by caregivers (Ruble & Dalrymple 1993, Hellemans *et al.* 2007) and in case studies.

Gender identity

In nine case reports, gender problems (gender dysphoria, gender identity disorder) in people with ASDs were

described. There is no systematic research into this phenomenon, only research on ASD symptoms and diagnosis in larger groups of people with gender identity problems (GID). Underlying mechanisms and processes were not studied. Stauder *et al.* (2011) found less masculinised gender roles in men with an ASD using MMPI-2, compared with the instrument's norm group. Discussion on the differentiation between gender dysphoria and obsessive–compulsive behaviour emerged in different cases. It was unclear which condition was primary and whether gender problems could be seen as a separate condition (Landén & Rasmussen 1997, Perera *et al.* 2003, Gallucci *et al.* 2005).

Sexual socialisation

The third domain relevant to sexual development and sexual health is that of education and socialisation in different ecological systems (home, school, institution, peers, partners, society). Research on sexuality in adolescents and adults with an ASD has mainly been focused on experiences of socialising agents: parents (views and attitudes, communication and education by parents) and professionals in group homes (policies, training of professionals) and in community services. Some studies explored other contexts such as peer contacts, school and media. Victimisation will also be discussed below, because this should also be viewed as a contextual influence on sexual development.

Parents as socialising agents

An explorative study on the living situation of a community sample of adolescents and adults with Asperger's disorder showed that most of these individuals lived with their parents. The majority of the group under study had limited social contacts and a small social demography (Balfe & Tantam 2010). This suggests that parents and professionals remain, for a long time and for many people with autism, important sources of information and support concerning sexuality.

Studies on parental perceptions and attitudes often revealed concerns or problems perceived by parents. Nichols and Blakeley-Smith (2009) report concerns about abuse or sexual exploitation of and by their children. Parents of younger children also worried that behaviours of their children would be seen as having sexual content (Ballan 2012). In an older and lower-functioning group of people, Ruble and Dalrymple (1993) found that parents were concerned that the behaviour of their children would be misunderstood by others as sexually intended on the one hand, and on the other hand that their sexual behaviours would be misinterpreted. A small number of parents reported worries about sex education to nonverbal adolescents and about their sons having a sexual relationship. Parents were concerned about sexual abuse of their children by men. Parents of males had questions on controlling masturbation, whilst parents of girls had questions on the use of contraception. One study reported that concerns seemed to increase with age of the adolescents with ASD, but the content of these concerns was not explored (Stokes & Kaur 2005). In another study, the concerns changed from confusion about bodily reactions such as an erection in younger children to broader worries on interpretation of behaviours, the use of contraceptives and condoms, control of masturbation and the need for sex education (Ruble & Dalrymple 1993). Attitudes and cognitions among parents influenced if sex education was offered: negative expectations about sexual functioning vs. the conviction that sexuality was important for children with ASD; worries about preoccupations (e.g. wanting to know everything about sex), persistent behaviours or overgeneralisation (e.g. asking everybody questions about sex); the expectancy that their children could have relationships; and opinions about who was responsible for sex education. Despite this, parents of children with ASDs seemed prepared to discuss sexuality with their children with an ASD (Ballan 2012), especially parents of higher-functioning children and adolescents (Ruble & Dalrymple 1993). Parents reported a strong need to discuss sexuality and sex education with others and specifically with professionals. However, parents reported negative reactions to sexual behaviours, including from professionals, even when behaviours were age appropriate. Spontaneously offering information or informing about sexual development by professionals was lacking (Nichols & Blakeley-Smith 2009, Ballan 2012).

Professionals as socialising agents

Van Bourgondien *et al.* (1997) found that only a minority of professionals working in group homes received formal training in supporting residents in managing their sexual feelings. D. Haracopos and L. Pedersen (unpublished manuscript) described an open and positive attitude towards sexuality in their residents amongst professionals, but a majority thought a sexual relationship was unrealistic and openness was not reflected in daily support. Teachers also observed sexual behaviour and assessed knowledge of adolescents with ASDs and were concerned about their further development (Kalyva 2010), but it is not clear whether they knew how to handle this. A study among educational psychologists and special education teachers in Cyprus showed

a lack of knowledge on sexuality and sex education (Bekirogullari *et al.* 2011).

Sex education

There is no systematic outcome research on sex education for adolescents with ASDs. Two studies looked at the perception of sex education by adolescents with ASDs. A qualitative study with four participants (Hatton & Tector 2010) revealed the need for more insight into their own ASD symptoms and functioning and basic insight into social and romantic relationships. These participants were thought to have enough 'technical' knowledge, but lacked the insight to use this well. Mehzabin and Stokes (2011) compared self-report data on sex education of HFA adolescents with typically developing adolescents and found that the HFA adolescents reported lower levels of sex education and knowledge. There are no extensive studies on the effect of Internet use on sexual development of adolescents with an ASD. In one study, it was assumed that younger people would benefit from the availability of information on the Internet and would score higher on sexual well-being measures, but this was not confirmed (Byers *et al.* 2012).

Treatment and interventions

No effect studies on interventions in case of sexual problems were found. Case reports described behavioural interventions (applied behavioural analysis, social stories, visualisation, explicit teaching, rewarding) and their positive effects. In some cases, a behavioural approach was used to teach adolescents with autism acceptable sexual behaviours, whereas in other cases, sexuality was inhibited or primarily treated as a medical disorder.

Sexual victimisation

The study on victimisation in children with ASDs by Mandell *et al.* (2005) revealed a prevalence of 12·2% of sexual abuse and 4·4% of combined sexual and physical abuse in a community-based sample of children with ASD in the USA. Afterwards, these children demonstrated a significant higher level of sexually acting out and sexually abusive behaviours, and they ran away from home or attempted suicide more often when compared with other children. In line with this, another study in the UK found that 40% of the adolescents with Asperger's disorder were reported to have been sexually or financially exploited (Balfe & Tantam 2010). In contrast, Mehtar and Mukaddes (2011) found trauma history in 26·1% of their sample, but sexual abuse was uncommon (1·45%).

Discussion

In this study, scientific publications on sexuality and ASDs were reviewed. It showed that, in general, sexual development is understudied in this population. Sexual behaviours and desires were observed in, and reported by, many adolescents and adults with ASDs, and sexuality proved to be an issue for children, their parents and other caregivers. This supports the view on sexuality as a normative aspect of adolescent development in people with an ASD. First, some methodological limitations are discussed. The methods, participants, data collection methods and instruments used in the available studies were very diverse and have varying quality. In most studies, parents or caregivers were the source of information, and in only a few studies, people with an ASD were directly questioned. The number of participants in all studies was small, and the groups studied often had wide ranges in age, intelligence and level of functioning. Several samples consisted of people living in institutions, and this living situation can be of influence on sexual socialisation. Only a few studies described high-functioning people with an ASD living in the community. Typically developing control groups were lacking in most studies. The sex ratios in some of the studied groups were not corresponding to that found in ASD. Finally, ASDs were labelled in different ways (e.g. autism vs. autistic disorder), and it was not always clear how, and by whom, people were diagnosed. Instruments to confirm autism features varied from short questionnaires to extensive semi-structured interviews and observations (e.g. autism quotient vs. ADI-R). These methodological limitations hamper the possibilities to generalise and compare results. Nevertheless, these studies offer insight into a developmental domain in a very specific population that is hard to study.

This review shows that research on sexual development in people with ASDs is scarce. Studies on sexual behaviour were mainly explorative, looking for the occurrence of different sexual behaviours. Masturbation was observed and reported in many of the male samples and also, but less, in female ones. These observational reports showed lower frequencies compared with self-reports in typically developing adolescents and adults. Person-oriented behaviours were observed, although not always with mutual consent, especially in less able groups. Being in a relationship was related to social skills and led to more dyadic sexual behaviours. No research was found concerning sexual risk behaviour (e.g. on the use

of contraception and condoms), but there has been attention to offending behaviours. The relationship between sexual offending, sexually deviant behaviours and ASDs remained unclear. A relationship has been suggested based on the prevalence of these behaviours in inpatient ASD groups, and by case reports. No systematic research on the development of these behaviours is available. In two (excluded) studies were screened for ASD symptoms in specific groups to explore a relationship between ASD and offensive behaviours: one in detained adolescents suspected of sex offences ('t Hart-Kerkhoffs *et al.* 2009) and another in files of adult murderers (Lester *et al.* 2011). Sound diagnostic assessment lacked in both studies, but they also suggested a relationship between ASD and offensive sexual behaviours. In general, no systematic research was found on factors that influence sexual development. Little information was available about the sexual partners of the person with an ASD, their skills or knowledge, nor about the interactional processes between partners.

Next to information on sexual behaviours, sexual selfhood is an understudied domain. In general, the majority of people with an ASD demonstrated interest in sexuality. The level of adequate sexual knowledge was unclear, although basic knowledge tended to be average. This did not imply that this knowledge was used in daily living. Again, the level of social functioning was of influence in this transfer. Sexual orientation varied, with indications of high numbers of bi/homosexuals and sometimes feelings of asexuality. No studies compared these youngsters and adults with typically developing people with corresponding sexual orientations, and little is known about the well-being of homosexual people with an ASD. In general, sexual well-being and satisfaction was linked with relationship status. The influence of solo-sex on well-being is unknown. There are no studies on the decision-making processes of people with an ASD regarding sexual behaviours (e.g. when feeling ready to engage in sexual intercourse). Gender identity problems frequently arose in case studies, but little is known about these youngsters and gender development in ASDs. de Vries *et al.* (2010) described a high incidence of ASD in children with GID in a gender clinic, and Jones *et al.* (2012) screened for ASD symptoms in their GID sample, again without formal ASD diagnosis, but systematic research of gender and identity problems in people with ASDs still lack.

Research on sexual socialisation has mainly been focused on experiences of parents and caregivers. They appeared crucial in the support of people with an ASD, but, as it seems, they themselves need training and support in dealing with sexuality in children and adolescents with an ASD. Other sources of information such as peers and media, relevant for typically developing adolescents, are understudied, and their importance remains unclear. The research of Mandell *et al.* (2005) revealed that sexual victimisation was frequently a reality for children, an ASD influencing their further sexual development, although these findings were not confirmed in other studies.

Other domains, relevant in autism and in sex research, are underexplored such as information processing in ASDs (sensory, communication, social) and influences on sexuality, decision-making processes, the development of expectancies and norms.

Conclusion

The existing knowledge on sexual health in adolescents and adults with an ASD is preliminary. Despite this, it is clear that sexuality and relational functioning is an important developmental domain for people with ASDs in contemporary society. Sexuality, as a developmental domain, appears, as in typical development, normative for adolescents with autism. The factors and mechanisms underlying sexual development and sexual health in people with an ASD remain understudied, despite of their relevance for education, prevention and treatment. Parents, caregivers and teachers need specific support in dealing with this developmental task. Furthermore, additional training seems relevant for professional caregivers (psychologists, psychiatrists and allied disciplines) to discuss this topic with youngsters and their families, to give them advice and to offer treatment if necessary.

Implications and directions for further research

More research is needed to explore sexual development in adolescents and adults with ASDs, and longitudinal and intervention studies are needed to gain more insight into the relationship between the different domains. A theory- or framework-driven approach, combining the actual knowledge on sexual health and ASD, could be valuable in developing future research designs and interventions.

Nurses have an important role in general health care, schools and institutions. In daily practice, nurses and other professionals can actively pay attention to sexuality in their work with people with an ASD. They can offer information, support, inform caregivers and other professionals about aspects of sexuality and refer to a specialist when needed.

Sexuality, not least among adolescents with ASDs, is a complex domain of individual and social functioning,

driven by biological, intra- and interpersonal processes in interaction with many contextual forces, as is true for typically developing people. Awareness of this developmental domain as a part of general well-being is a responsibility of all professionals involved.

Contributions

Study design: JD, RV, IV, ChvN; data collection and analysis: JD, RV, IV, ChvN and manuscript preparation: JD, RV, IV, ChvN.

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