

Sex Education, Sexual Health, and Autism Spectrum Disorder

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Abstract

Sex education is an important but often inadequately addressed topic for patients with autism spectrum disorder. A dominant theory in autism, Theory of Mind, helps to explain why the sex education needs of people with this disorder are unique. This paper argues the importance of high quality sex education from the perspective of the World Health Organization's recent comprehensive definition of sexual health. Each point from the World Health Organization's definition is addressed with discussion of its application to people with autism spectrum disorder, suggestions for remediation, and public health implications. Seven points are addressed: physical well-being in relation to sexuality; emotional and mental well-being in relation to sexuality; social well-being in relation to sexuality; disease, dysfunction, or infirmity; positive and respectful approaches to sexuality and sexual relationships; freedom from coercion and violence; and freedom from discrimination. Sex education is important to the quality of life and safety of people with autism. The needs of this population are apparent in all seven areas identified.

Keywords: Autism; Asperger; Sexuality; Sex education; Autism spectrum disorder; Sexual health

Commentary

The sexuality education needs of patients with autism spectrum disorder (ASD) are unique, and are seldom adequately addressed in existing educational programs. Unfortunately, intensive sexuality education at the level required by patients with this disorder may not occur until after a person with ASD has been the victim of a sexual crime or has (often unknowingly) committed a social error, such as undesired touching [1], that meets the criteria for a sex offense [2].

Autism spectrum disorder is characterized by deficits in social-communication and by restricted, repetitive patterns of interests or behavior [3]. Both domains of symptoms can present along a continuum of severity from rather mild to severe. Autism spectrum disorder can co-occur with intellectual disability or psychiatric disorders [4]. A continuum of severity was not always recognized. Although Hans Asperger identified traits of a higher functioning social disability in 1943, it was not until a paper by Lorna Wing revived his observations in 1981 that people with fewer debilitating symptoms were diagnosed with a disorder. In 1994, the diagnosis of Asperger Disorder was added to the DSM-IV. Literature prior to that time refers exclusively to individuals with what now would be considered severe autism, although this is not specified in the papers. The terms Asperger Syndrome (AS), high-functioning autism (HFA), and pervasive developmental disorder not otherwise specified sometimes have been used interchangeably and have not been differentiated reliably by researchers and clinicians. In part, the challenges of identifying AS versus HFA led to a new set of diagnostic criteria in the DSM-5 that includes only one disorder, ASD.

Sexuality is central to being human [5] and sex is an important component of quality of life [6].

According to the World Health Organization (WHO):

Sexual health is a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence [5].

Sex education specifically designed for people with ASD may be essential to ensuring that sexual health is achieved according to these WHO guidelines. To illustrate why the sex education needs of people with ASD are unique, it is helpful to conceptualize the disorder according to one of the dominant theories of ASD, Theory of Mind (ToM). The ToM theory asserts that "mindblindness" is at the root of social difficulties of this disorder, meaning that people with ASD have difficulty attributing mental states (beliefs, desires, and intentions) to others versus oneself, and also have difficulty understanding that others have internal states that differ from one's own [7]. In typically developing children, the ability to understand one's own mind and the minds of others seems to develop naturally at a very young age [8]. The majority of school age children with ASD, however, cannot pass basic ToM tasks that 3-4 year old children without ASD can pass, such as understanding that others have beliefs that differ from their own. These challenges cannot be accounted for by IQ or developmental level alone [9].

Others with ASD can pass higher order theory of mind tasks, such as reasoning about what one person thinks about another's thoughts [10]. Yet even for those capable of more complex social thinking, important social cognitive abilities that are critical to effective social interaction, including understanding deception, often remain elusive. For example, both the production of deception, and the detection and understanding that others are being deceptive, are a challenge in ASD [11].

Deficits in ToM impact relationship development in people with ASD. Higher mindreading accuracy, for example, correlates with

positive relationship outcomes such as relationship satisfaction [12]. Delays in ToM development are also expected to adversely affect the key relationship skills of empathy, trust, and sharing [13]. The development of healthy intimate relationships, particularly sexual relationships, depends upon partners understanding and responding to the internal states of the other.

We advocate for sex education to improve the sexual health of individuals with ASD. We organize the discussion from the perspective of the WHO definition of sexual health [5], which includes seven components: physical well-being in relation to sexuality; emotional and mental well-being in relation to sexuality; social well-being in relation to sexuality; disease, dysfunction, or infirmity; positive and respectful approaches to sexuality and sexual relationships; freedom from coercion and violence; and freedom from discrimination. We chose the WHO definition because it is comprehensive and applies to countries around the world. The components relate to human rights that are already recognized in national laws, international human rights documents, and other consensus documents. Our method was to perform a Boolean search of PsycINFO, PubMed, and Google Scholar using the terms: ((autism OR Asperger) AND ("sex education") AND sexuality)).

Physical Well-Being in Relation to Sexuality

It is frequently reported [14] that there are no apparent differences in physical maturation between typically developing individuals and those with ASD. However, there is some evidence to suggest that puberty may occur earlier in males with ASD than in age matched controls [15] whereas menarche may occur later in females with ASD than in controls [16]. This information may have implications for the timing of sex education for people with ASD. Adolescents with ASD may find social concepts and norms complex, may not learn them naturally, and may require more role play and repetition in order to effectively use strategies, suggesting that sex education of these youth should begin earlier.

Sex education provides a venue in which to teach personal hygiene (e.g., menstrual hygiene) thus promoting the physical well-being of those with ASD. Further, young women with ASD may experience higher rates of premenstrual syndrome and would benefit from learning to predict and ameliorate these symptoms [17]. Hygiene, in general, and self-care routines can be a challenge for people with ASD, and targeted instruction will need to be coupled with supports to make sure that routines are implemented. Visual supports, such as visual schedules of the steps required to complete hygiene routines and reminders of when to initiate routines, will be necessary for many patients with ASD [18]. Sex education should include how and when to clean one's genitals, when to seek medical attention, including for sexual symptoms, and whom to consult.

Sex education to promote the physical well-being in relation to sexuality of young people on the spectrum is critically important to reduce the "burden of disease" (i.e., the impact of a health problem as measured by financial cost, mortality, morbidity, or other indicators). Improved physical well-being should result in fewer medical visits. Visits to medical professionals treating adolescents with ASD may be particularly costly due to a need for specialized training in communication skills. Learning when and from whom to seek medical attention should decrease inappropriate medical visits, or decrease postponing medical attention until an illness has progressed and is more difficult to treat. Someone may need to accompany an autistic

individual to medical visits, so improving physical well-being should reduce the parent or caretaker's lost productivity and wages. All of these factors contribute to the burden of disease including the costs of ASD to society.

Emotional and Mental Well-Being in Relation to Sexuality

While physical maturation occurs in adolescents regardless of ASD, the emotional development of adolescents with ASD, particularly related to sexuality, may not unfold in the same manner as for their neurotypical peers. Emotional development (or, the development of emotional competence) is impacted in many ways in ASD and has a notable effect on success in adulthood [19]. As an example of how this might occur, typically developing people certainly may feel the urge to engage in sexual behaviors (e.g., self-stimulation) while in public. However, they are more likely than their neurotypical counterparts to discern peer perceptions and be influenced by social expectations so as to keep such behaviors private [20]. When ASD adolescents display atypical behaviors, this may lead to rejection, painful emotions, and even mental illness [21].

The benefits of sex education include self-enhancement, empowerment and increased confidence, which are particularly important during emotional development in adolescence when gender identity and values are at a critical point in development [22]. The emotional concepts of sexuality and relationships can be a challenge to explain even to individuals without a social disability.

People with ASD require more extensive education that is clear and concrete, including where and when particular sexual behaviors are acceptable, in order to reap these benefits. According to the ToM, most individuals with ASD will not be able to intuitively understand the internal states of their partners and will need to be told how other people will perceive their actions and words, as well as clear cues for assessing how their partner feels. For example, a 17-year old male patient with ASD described a friendship with a female classmate whom he wanted to date. The girl was friendly and smiled when he spoke with her. Each time he asked to see her outside of school, however, the girl said, "I already have plans that day" or "I don't think my parents will let me." A typically developing teenager would likely realize that the girl was not interested in dating and understand that the girl was trying to spare his feelings by offering the other excuses. The patient with ASD, on the other hand, took her responses at face value and wanted to persist in asking until she said, "Yes." This example is not at all unusual for young adults with ASD. The level of detail that the person with ASD may require in order to understand how to request a date is significant. "Ask someone out once. If they say that they are not available, you may ask one other time. If they refuse again, even if they offer an excuse for why, you may not ask again".

The impact on society of emotional and mental well-being in relation to sexuality of people with ASD is great. Sexual health is strongly related to mental health [23]. Yet characteristics of ASD make sexual health difficult. Comorbid mental illness rates among adolescents with ASD appear high. An estimated 53% of individuals with AS have a lifetime mood disorder and 50% have a lifetime anxiety disorder [24]. Depression is a leading cause of disability worldwide and a major contributor to the global burden of disease [25]. Education fostering the sexual health of adolescents with ASD also should foster their mental health and help to ameliorate this burden of disease.

Social Well-Being in Relation to Sexuality

Many individuals with ASD express interest in having a sexual relationship [26], are sexually attracted to someone [27], or engage in sexual behavior [28]. Moreover, Gilmour, Schalomon, and Smith [28] did not find significant differences in the breadth and strength of sexual behaviors between individuals with high-functioning ASD and those without ASD. These data run “counter to social stereotypes that portray individuals with disabilities, including individuals with intact intellect and ASD, as asexual or having sexual behavior problems [26]”.

Despite these optimistic findings, however, most studies of ASD and sexuality do report higher rates of asexuality among people with ASD compared to the general population estimate of 1%. Estimates of asexuality range from less than 5% in a group-home sample [1] to anecdotal reports of a third in one community sample [29]. Many (24%) of the latter sample had a comorbid psychiatric disorder and some had tried but failed to have a sexual relationship, which certainly could dissuade one from trying again.

People in general associate sexual activity with a social relationship rather than viewing it as merely a physical function [6]. Thus despite the interest in sex of individuals with ASD, differences in social reciprocity, social-communication, and the ability to develop interpersonal relationships that are inherent in the disorder would be expected to affect the ability of adults with autism to develop a sexual relationship. Holmes and Himle’s [27] finding that only 10% of individuals with ASD had a sexual relationship with someone highlights the importance of education to teach young people the social skills they require to develop healthy relationships. Perhaps surprisingly, for those individuals with ASD who are able to develop a committed intimate relationship, Lau & Petersen [30] did not find significant differences in marital satisfaction or frequency of divorce cognitions regardless of which partner had an ASD diagnosis [30].

Social challenges are inherent in ASD and naturally these deficits interfere with the development of meaningful relationships. Most individuals with ASD will require intensive social skills instruction separate from their sexuality education. Group-based programs to develop social competencies, such as the PEERS program from researchers at UCLA, have demonstrated effectiveness as a venue for teaching and practicing social skills [31]. Physicians can talk with patients with ASD and refer them to the Autism Speaks website to locate available social resources in the area.

Sexuality is an important consideration in relationships during adolescence and beyond. Whether and with whom to have a sexual relationship are among important decisions that adolescents with ASD may face. Sexual behavior has the potential to contribute to an intimate interpersonal relationship, and having a positive intimate relationship in turn can benefit the physical and mental health of people with ASD. Social integration, social support, and negative interaction all are associated with health outcomes [32]. Individuals with ASD who are healthy reduce the burden of disease including the costs of healthcare, which are passed on to society.

Disease, Dysfunction, or Infirmity

There are no data regarding sexually transmitted diseases (STD) including HIV/AIDs among adolescents or adults with ASD. Likewise, the effects of sex education on these aspects of sexual health among persons with ASD have not been investigated.

A 2012 Centers for Disease Control meta-analysis of 66 comprehensive sex education programs for youth regardless of ASD diagnosis found that the programs reduced the frequency of unprotected sexual activity, increased the use of protection (either condoms and/or hormonal contraception), reduced pregnancy, and reduced sexually transmitted diseases [33]. Moreover, research indicates that states that include sexuality education (and not simply abstinence education) have the lowest mean rates of infection among the overall population and among adolescents [34]. Medical cost savings to society in the United States associated with sex education appear substantial. Avertable medical costs in the year 2000 were estimated to be \$4.1 billion associated with STDs and \$6 billion with unwanted pregnancy [35].

As with instruction about hygiene issues, patients with ASD require concrete, direct instruction about disease and its prevention. Perhaps the clearest depiction of the level of detail and clarity this population may require is the instructions on the inside of a box of condoms. These directions include both written and picture depictions of the steps required to use them appropriately. This, at minimum, is the level of detail and clarity that patient with ASD, regardless of intelligence, may require.

There are no data regarding sexual dysfunction in un-medicated patients with ASD. However, medications prescribed to patients with ASD have been associated with sexual dysfunction and other sexual side effects. For example, risperidone was associated with gynecomastia, and sexual dysfunction including problems with desire, erection, orgasm, and ejaculation in males 10-20 years old [36]. In a single case ABA design study, olanzapine was associated with self-stimulation 4-6 times per day [37]. Physicians should be made aware of potential sexual side effects of medications.

Positive and Respectful Approach to Sexuality and Sexual Relationships

Unfortunately, most studies of sexuality and sexual behavior approach these topics from a negative rather than a positive perspective. As such, there is some evidence that individuals with ASD are at increased risk for problematic sexual behaviors that can include undesired touching, public masturbation and other illegal activity [1]. Few investigations of problem sexual behavior in ASD exist, but one related study found that 60% of a sample of 37 male adolescents adjudicated for sexual offenses and sentenced to treatment met diagnostic criteria for ASD [38]. Further, even when problem behaviors are not illegal, inappropriate sexual behaviors can limit employment and inclusion opportunities for individuals with ASD [20]. There is a clear lack of knowledge and understanding about sexuality, and many of these situations might have been prevented if the person with ASD had been better educated about their bodies, sexuality, and legal issues.

Without training, the communication, social, cognitive and behavioral characteristics associated with ASD may be compounded by intellectual and psychiatric co-morbidities and place individuals at risk for engaging in unsuitable and invasive social and sexually offensive behaviors [39]. Lack of friendships exacerbates the difficulty of acquiring social behaviors that are significant predictors of successful romantic functioning. Unfortunately, oftentimes education and training related to sexual/romantic functioning is in reaction to problems and does not focus on positive skills.

Guidelines from the American Academy of Pediatrics specify that young people with disabilities, such as ASD, have the right to the same education about sexuality as their peers and specify that this information needs to be presented in a way that is meaningful for the individual [40]. Instruction for individuals with ASD must be positive in order to be effective. In effective school-based intervention, for example, people with ASD are told what to do rather than what not to do [41]. That is, “keep your hands in your lap or pockets” rather than “don’t touch.” Without such direct and clear instruction in what to do, many people with ASD are not sure how to behave. When it comes to teaching the necessary social skills for dating and relationship development, a similar positive approach is needed. This may include, but is certainly not limited to, practicing precise wording to request a date and consenting to or refusing a sexual encounter.

Free of Coercion or Violence

In addition to the possibility of experiencing positive aspects of sexuality, individuals with ASD may experience particular challenges. They are at an increased risk of sexual abuse [42] and victimization in sexual situations [43,44]. The increased risk of victimization of individuals with ASD appears to be partially mediated by their actual knowledge, suggesting the importance of sex education. The risks of sexual coercion and violence, including rape and assault, are clear. However, other risks that occur in the context of relationships are less obvious. Many patients with ASD, both male and female, have been taken advantage of financially by a sexual partner. In one example, a patient met with a woman he met online to have sexual encounter. When they finished, she refused to leave his apartment, he was unsure how to get her to leave, and she remained there for several weeks. There are many stories of a person with ASD “loaning” money to someone who flirts with him or her only to never be repaid. These examples do not illustrate sexual coercion, but they are examples of the ways that people with ASD can become confused when sex or intimacy are used to manipulate.

Freedom from coercion and violence applies to both the individual with ASD and to his or her partner. People with ASD are more likely than their peers to engage in inappropriate courting behavior. The distinctions between appropriate and inappropriate behaviors in the early stages of relationship building are subtle. Behaviors such as waiting outside of work or school to see a person, texting and calling, and sending gifts can be welcome and romantic gestures or, in a different context, alarming and upsetting. Without proper instruction, it is common for a young adult with ASD to persist in courting behaviors when they are not welcome. This can be intrusive and even frightening for the other person, and may be misinterpreted as stalking [39]. The social skills impairments of ASD affect the knowledge young people with this diagnosis acquire. The development of sexual expression typically emerges in adolescence, and adolescence is a time when typically developing children rely on friends and media for knowledge about appropriate sexual behaviors, relationships and sexual activity. Most adolescents with ASD do not develop close reciprocal friendships, the types of relationships that lead to the sharing of important information about sexuality. The social differences between typically developing adolescents and those with ASD may make it more likely for those with ASD to possess sexual behaviors, knowledge, and identity that are outside of mainstream experience [45]. Sex education can help to compensate for lack of peer instruction.

The social and, specifically, the ToM deficits in ASD can lead to inappropriately frank disclosures about intimate sexual information. Patients have discussed their sexual orientation in job interviews, disclosed fetishes to parents and acquaintances who did not desire this information, and made sexual jokes to authority figures, such as teachers and bosses. When they do not acquire social guidelines from their peers, people with ASD are at risk of crossing cultural taboos and experiencing serious consequences (e.g., firing, expulsion, removal from inclusive community settings) and disclosing this type of personal sexual information can make the person with ASD a target of discrimination.

Free of Discrimination

There are no data, but it is arguably the case that the public perceives individuals with ASD as predators. Evidence for this comes from our informal survey of Google News for a single week [11/16/2014 - 11/23/2014 using the search terms: (autism OR Asperger) AND (sexual OR sex) AND (offence OR offend OR illegal OR assault OR pornography OR pedophilia)]. Of 534 “hits,” 2 news stories mentioned autism in a predatory light. One reported an attempted kidnaping and rape by a man who lived with his parents and was “perhaps autistic.” The other reported that service users with dementia and autism were most likely to assault social care staff. However, the article went on to say that most staff did not require medical attention and only 6% required first aid. Another article reported that an 8-year old autistic child died during an attempt to exorcize her demons. Some announced support group meetings for autistic individuals or their caregivers.

When crimes are committed, even if the individual with ASD had no idea what he was doing, there is rarely consideration of the individual as unfit for trial, allowance of an insanity defense, or mitigation of sentence.

Assumptions also may be made about the level of interest in sex and sexual orientation of people with ASD. As noted elsewhere, people with ASD may have an increased rate of asexuality, yet most people on the spectrum desire a sexual relationship. Certainly, having a sexual orientation that is outside of the mainstream can have serious mental health consequences. A paucity of research exists regarding sexual orientation and gender identity in the development of individuals with ASD. However, some reports suggest higher levels of sexual minority identification among people with ASD. In a sample of 18 high functioning males with autism, for example, 14 identified as heterosexual, one as homosexual, and three as bisexual [1]. In addition, one study revealed that in a sample of 204 individuals with gender identity disorder, the incidence of ASD was 7.8% [46], significantly higher than expected rates of ASD in the general population (i.e., ~1.4%). It is unknown whether intellectual development, social appropriateness, and gender role identification influence sexual orientation among individuals with ASD. However, one empirical article did report less masculine gender roles in ASD males when assessed with the MMPI [47]. These data are important because there are significant health disparities affecting adults who identify as lesbian, gay, bisexual, or transgender (LGBT). If the percentage of people with ASD who identify as LGBT is high, individuals with ASD may be similarly susceptible to health disparities.

The LGBT population is at increased risk for physical and mental health problems [48]. Of particular concern, people who identify as LGBT are at increased risk of suicide [49], and it also appears that risk

for suicide is higher among people with ASD than in the general population [50]. What is not yet known is whether being LGBT and having ASD places one at an even greater risk for suicide. One recent study suggests that the risk of suicide is particularly high among people with LGBT and a history of trauma [51], and we also know that ASD people experience higher rates of trauma [52]. Further, LGBT people experience social disadvantage due to their sexual orientation, such as homophobic bullying [53], rejection from family and friends, and increased risk of homelessness [54]. There are striking parallels in health statistics for people with ASD and LGBT, which could be driven by discrimination in both groups. However, attributing the parallels to discrimination is a hypothesis at this point and remains to be tested. It will be useful for clinicians, educators and parents to better understand such factors in order to prevent and respond to issues of both trauma and suicidal ideation in young people with ASD.

Sex education for people with ASD may reduce inappropriate behavior by explaining social norms in an explicit manner that is understandable to people with ASD. Education of the public at large as well as the person with ASD appears to be needed. In particular, it would be useful to provide community members who are likely to encounter people with ASD (e.g., law enforcement, educators) with accurate information about the sexual vulnerabilities and risks that this population may pose.

Conclusion

There is a paucity of data regarding sex education, sexual health, and persons with ASD. Many individuals with ASD have not received adequate education and treatment that they require to meet the basic WHO sexual health guidelines. A glaring gap is that there are no outcome studies of the effects of sex education on the sexual health of autistic adolescent and adults. The few data that do exist suggest that sex education for individuals with ASD is both beneficial and needed.

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