The Impact of Communication Deficits on Puberty and Sexual Development in Adolescents on the Autism Spectrum

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THE IMPACT OF COMMUNICATION DEFICITS ON PUBERTY AND SEXUAL DEVELOPMENT IN ADOLESCENTS ON THE AUTISM SPECTRUM

by

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College of Charleston, 2015

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Dedication

Written for adolescents with autism spectrum disorder and all who support them.

“I might hit developmental and societal milestones in a different order than my peers, but I am able to accomplish these small victories on my own time.” - Haley Moss, autism advocate
Acknowledgements

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Abstract

Transitioning into a sexually mature adult is a challenging time for both an adolescent with autism spectrum disorder (ASD) and his or her family. Sexual development begets challenges due to the demands it places on the social and communication skills needed to explore developmental changes that are occurring physically, emotionally and hormonally. A diagnosis of ASD is largely established by quantifying impediments in social and communication skills through observation. With deficits in these skills, one can assume that social and communication difficulties can create obstacles in the sexual development of affected individuals. Our study used quantitative and qualitative measures to determine how severity of communication correlates with sexual development in adolescents with ASD. We found statistically significant relationships between communication and frequency of the adolescent displaying sexual behaviors that are inappropriate. Additionally, we determined that the severity of communication deficit has a negative impact on adolescents’ understanding of sexual development. Furthermore, our research explored current sexual education sources, healthcare provider efficacy, and contemporary perspectives of what parents and guardians feel the biggest challenges and concerns are for adolescents navigating sexual development with a diagnosis of ASD. Ultimately, our study demonstrates the importance of communication ability in relation to sexual development and sexual education in adolescents with ASD.
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Chapter 1

Background

Defining Autism Spectrum Disorder

Autism spectrum disorder (ASD) is the term used to describe a heterogeneous group of conditions most notably characterized by impairments in social interaction and communication. Additionally, individuals can display repetitive behaviors, have restricted interests and have inflexible adherence to routines. Autism was first noted as a condition in 1980 by the American Psychiatric Association (APA) in the third edition of the Diagnostic and Statistical Manuel for Mental Disorders (DSM) (Christensen et al., 2016). In 1994, the DSM-IV provided diagnostic criteria for five subtypes of Pervasive Developmental Disorders, which included Autistic Disorder, Asperger Disorder, Pervasive Developmental Disorder-Not Otherwise Specified, Childhood Disintegrative Disorder, and Rett Syndrome. This version of the DSM highlighted five discrete disorders, as opposed to the DSM-5, published in 2013, which combined Autistic Disorder, Asperger Disorder and Pervasive Developmental Disorder-Not Otherwise Specified under one diagnostic criterion, ASD (Christensen et al., 2016).

A diagnosis of ASD is supported by the DSM-5 if certain criteria are met in two symptom domains: i) social and communication deficits, and ii) atypical behaviors and/or interests (American Psychiatric Association [APA], 2013). The criteria require that all features described in the social and communication category are met. These include i) deficits in social-emotional reciprocity, ii) impairment in nonverbal behaviors, and iii)
deficits in developing and maintaining relationships (APA, 2013). In the category of repetitive behaviors and restricted interests, an individual must display at least two of the following: 1) stereotyped or repetitive behaviors or speech, 2) insistence on sameness, 3) restricted interests, and 4) sensory issues (APA, 2013). The DSM-5 further includes criteria stating that symptoms must be persistent from early childhood, as well as impede on everyday functioning (APA, 2013).

Table 1.1: DSM-5 Diagnostic Criteria for Autism Spectrum Disorder

<table>
<thead>
<tr>
<th>Social and Communication Deficits</th>
</tr>
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<tbody>
<tr>
<td>1. Deficits in social-emotional reciprocity</td>
</tr>
<tr>
<td>2. Impairment in nonverbal behaviors</td>
</tr>
<tr>
<td>3. Deficits in developing and maintaining relationships</td>
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</table>

All three domains must be met to support a diagnosis (APA, 2013).

<table>
<thead>
<tr>
<th>Repetitive Behaviors and Restricted Interests</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Stereotyped or repetitive behaviors or speech</td>
</tr>
<tr>
<td>2. Insistence on sameness</td>
</tr>
<tr>
<td>3. Restricted interests</td>
</tr>
<tr>
<td>4. Sensory issues</td>
</tr>
</tbody>
</table>

At least two out of the four domains must be met to support a diagnosis (APA, 2013).

The simplification of core symptom domains from prior DSM versions, along with the consolidation of the ASD classification, has brought changes revolving around the sensitivity of the DSM-5 in making a diagnosis of ASD (Lobar, 2016). By no longer having discernible diagnoses, the DSM-5 has attempted to make detection of ASD easier
and allow for earlier intervention to be available (Craig et al., 2017). However, this change has altered the classification of ASD altogether, encompassing a different population of individuals and excluding others that previously met criteria, particularly those diagnosed with Asperger’s Disorder and Pervasive Developmental Disorder-Not Otherwise Specified (McPartland, Reichow & Volkmar, 2012). These two disorders both are considered to have milder symptomology than “classic” autism.

**Etiology of ASD**

The variability in the presentation and severity of ASD contributes to its etiological complexity. ASD is caused both by isolated, as well as varied combinations, of genetic and environmental factors. There is not one known cause responsible for all affected individuals. Understanding the etiological complexity of ASD can be daunting for genetic and medical professionals alike. Current molecular testing tools, such as chromosomal microarray, allow for an underlying genetic cause to be determined for approximately 25% of those with ASD (Griesi-Oliveira & Sertie, 2017). Known genetic causes for ASD include copy number variants (CNVs) and single gene changes. CNVs at 15q11-13, 16p11 and 22q11-13 have been seen more frequently than other deletions or duplications across the genome (Griesi-Oliveira & Sertie, 2017). However, the vast majority of genetic changes that have been detected are rare (Andrews et al., 2017). Concurrently, ASD is associated with genetic disorders of known etiologies; examples include Prader-Willi syndrome and Fragile X syndrome. These genetic causes can be inherited as well as *de novo*, or new genetic variant. The causation for those without a detected genetic cause is less well defined, and the pathogenesis is generally believed to be multifactorial or epigenetic.
It is suggested that some individuals could have a genetic predisposition to ASD and then have an environmental exposure that triggers a pathway causing symptoms to present. This idea is comparable to Knudson’s “two-hit hypothesis”. Proposed environmental factors vary from prenatal exposures to illnesses in early-childhood; however, the implications of these events are still not fully understood. Research has found epigenetic changes, or changes not related to the nucleotide sequence that manipulate gene expression, are associated with ASD. These changes vary based on tissue type, therefore it would be important to carefully consider the type of tissue used for diagnostic testing, such as brain versus skin, in cases of ASD (Andrews et al., 2017). Both blood and brain tissues have been utilized to observe epigenetic changes in those with ASD (Andrews et al., 2017). Specifically, there have been epigenetic changes detected in prefrontal cortical tissue from subjects with ASD that down-regulate the mRNAs associated to gamma-aminobutyric acid (GABA) expression (Zhubi, Chen, Guidotti, & Grayson, 2017). GABA is a neurotransmitter believed to be involved in the pathogenesis of ASD (Zhubi et al., 2017). Other epigenetic mechanisms include histone modification and RNA editing; these changes have been observed in the ASD population (Tordjman et al., 2014). Overall, epigenetic changes are controversial when it comes to a meiotic, or parental, origin as extensive epigenetic remodeling happens during gametogenesis and again during early embryogenesis (Loke, Hannan, & Craig, 2015). Moreover, epigenetic changes most commonly occur through mitotic processes (Loke et al., 2015).

In sum, the pathogenesis of ASD is complex and still quite mystifying. However, the hereditability of ASD is more easily quantified than the etiology and has been
estimated to be 50-90% (Griesi-Oliveira & Sertie, 2017). Furthermore, the relative recurrence risk is estimated to be 10.3% for full siblings of individuals with ASD (Sandin et al., 2014). These statistics are significant in demonstrating the role of genetic factors in the pathological process of ASD. In cases indicating a heritable component, it is expected that each parent harbors unspecified low-risk genetic changes that, when inherited together in the offspring, cause ASD (Griesi-Oliveira & Sertie, 2017). This is opposite of other instances when affected individuals have de novo single-gene changes or copy number variants that are causative (Griesi-Oliveira & Sertie, 2017). The lone causes for ASD are liable to be more pathogenic, with a risk of recurrence as high as 50%. Ultimately there are endless combinations of genetic and environmental factors supporting the foundation of the vast phenotype or the “spectrum”. With new genetic and genomic technologies becoming more advanced, comprehensible, utilized and inexpensive, it is likely that the causes of ASD will become only more broad and complex.

**Gender Bias**

There is a rapidly growing prevalence in the number of ASD cases being diagnosed worldwide in both males and females. As of 2012, it is estimated that 1 in every 68 children at the age of eight years old in the United States has diagnosis of ASD (Christensen et al., 2016). This disorder is known to present more frequently in males, with a current ratio of 4.5 affected males to every 1 affected female (Christensen et al., 2016). The reasoning for more males being affected is not fully understood by the scientific community. To attempt to explain the increased prevalence in males, is suggested that males may have more risk factors than females, or that females may be
under-diagnosed (May, Pang, O’Connell, & Williams, 2017). Further exploring the ideology of males having more risk factors, one must consider the differences between sex chromosomes and sex hormones in males and females. This has been an area of increased interest in the scientific community as of recent; however, Hans Asperger first presented the idea of “the extreme male brain” theory of autism in 1944 (Baron-Cohen, 2002). This suggests that the brain in males is “hyper-masculinized” due to the high levels of exposure to androgens, particularly testosterone, in utero (Baron-Cohen, 2002; May et al., 2017; Ruta, Ingudomnukul, Taylor, Chakrabarti, & Baron-Cohen, 2011).

There is currently conflicting evidence as to whether or not exposure to androgens is related to the development of ASD, as well as the gender split seen in ASD. A positive correlation between the level of fetal testosterone and autistic traits in both males and females has been observed (Auyeung et al., 2009). Inversely, a study of 39 male individuals, both pre- and post-pubescent, along with 21 control subjects, found no evidence for a discrepancy in the secretion of androgens, as well as gonadal steroids, in relation to ASD, amongst the two groups (Tordjman et al., 1995). Another study measuring testosterone in umbilical cord blood found no correlation with testosterone concentration and presence of autistic-like symptoms in a sample of 707 males and females containing five individuals with a clinical diagnosis of ASD (Whitehouse et al., 2012). Therefore, the role of androgens in the development of ASD is not yet clear and cannot be accredited as the source for the increased prevalence in males.

There is another theory that supports the higher prevalence in males compared to females. This theory is called the “female protective model” and suggests that females require a higher burden of genetic changes in order to manifest ASD than males.
(Jacquemont et al., 2014). There is supportive evidence in the literature of this phenomenon, demonstrating that females have more autosomal “neurodevelopmentally deleterious variants” than males do when examining cohort of individuals with neurodevelopmental disorders (Jacquemont et al., 2014). Furthermore, numerous genes on the X chromosome have been associated with neurodevelopmental disorders, like ASD. Therefore, one can assume that X-inactivation can also be considered a protective factor for females against changes in these genes. As further evidence of females requiring a greater genetic load, there is a higher observed recurrence risk in siblings if the affected child is a female (Griesi-Oliveria & Sertie, 2017). The extreme male brain theory and female protective model are two examples of the many models attempting to determine causality for the gender split.

**Females with ASD**

There is evidence in the literature stating that females may fall on the more mild-end of the ASD spectrum compared to males of the same age (Cridland, Jones, Caputi, & Magee, 2014; Holtmann, Bölte, & Poustka, 2007; McLennan, Lord, & Schopler, 1993; Van Wijngaarden-Cremers et al., 2014; Ormond, Brownlow, Garnett, Rynkiewicz, & Attwood, 2018). It is also believed that the features of ASD manifest differently in females compared to males, therefore resulting in a female under-diagnosis (Ormond et al., 2018). Consequently, diagnosing ASD using DSM-5 criteria could be biased towards the presentation observed in males.

Recently it has been discovered that females with ASD tend to have higher cognition and language abilities than their male equals (Navot, Jorgenson, & Webb, 2017). When a female possesses higher cognitive and linguistic skills, it is generally not
until adolescence that an underlying social impairment becomes of concern and a delayed diagnosis of ASD is given (Cridland et al., 2014). Features associated with ASD are present in the early developmental period; however, they may not fully manifest until the social demands of early adolescence exceed limited capacities, and the body begins undergoing puberty. It has been suggestive that females with ASD do particularly well at observing and imitating play settings and social settings, therefore appearing to have more advanced social skills (Ormond et al., 2018). However, the lack in severity of features in early childhood, followed by the exacerbation of puberty, suggests the significant importance of communicative skills and sociability when beginning sexual development. This is not just true for females, but for males as well. Current research is suggesting that females who have been misdiagnosed or have delayed diagnosis have more emotional instability, vulnerability in sexual relationships and at increased risk for sexual abuse (Or mond et al., 2018). Parental concern for both males and females with developmental disabilities experiencing sexual abuse as well as engaging in inappropriate sexual behaviors is by no means novel (American Academy of Pediatrics, 1996). Parents are justified in expressing concern and worry. However, this fact is supportive of the concept that adolescents with ASD need effective sex education regarding their sexual development and puberty to not only minimize abuse and inappropriate behaviors from occurring, but also because these individuals are sexual beings and have the same needs and rights as their typically developing peers in this regard.

**Puberty**

Adolescence undoubtedly begets biological transformations, particularly ones that are physical, emotional and hormonal. These changes are commonly denoted as puberty.
Puberty encompasses numerous processes such as acne development, hair growth, and voice changes; however, these changes are not attributed to a single event (Shirtcliff, Dahl, & Pollak, 2009). Pubertal physical changes, on average, can be observed in individuals as early as nine years old and as late as 14-years-old (Urbano, Hartmann, Deutsch, Polychronopoulos, & Dorbin, 2013). Puberty can develop earlier, known as precocious puberty. This is defined as beginning puberty before eight years of age in females and nine years of age in males (Carel & Léger, 2008). Puberty is described by James Tanner, a British pediatrician, as involving 5 stages of development (see figure 1.1). These stages are numerical and range from 1 to 5, completely immature to completely mature, respectively (Shirtcliff et al., 2009). His stages, designated the Tanner scale, involve secondary sexual characteristics such as hair growth, breast development and growth of testes (Shirtcliff et al., 2009). Changes in hormone levels, such as dehydroepiandrosterone (DHEA), testosterone, and estradiol are responsible for differences in puberty observed within the two sexes (Shirtcliff et al., 2009). It has been hypothesized that puberty occurs earlier in persons with ASD compared to typically developing peers (Baron-Cohen, 2002; Tordjman, Ferrari, Sulmont, Duyme, & Roubertoux, 1997). However, there is conflicting evidence of precocious puberty in individuals with ASD. One study found four out of 12 children between the ages of six and ten with ASD displayed signs of precocious puberty (Tordjman et al., 1997). Additionally, a case study of three females with ASD found that the range of pubertal onset was from 6 years, 9 months of age to 9 years, 6 months of age (Yoshimura, Naiki, Horikawa, & Tanaka, 2005). Another study explored the timing of puberty in children with and without ASD, and found no significant differences in pubertal timing in the
A small sample size of 35 women with ASD were compared to 38 age-matched controls and found that the group of women with ASD had delayed puberty by 8 months (Knickmeyer, Wheelwright, Hoekstra, & Baron-Cohen, 2006). While there is conflicting evidence of whether or not puberty is occurring earlier in individuals with ASD, it is still inevitable that puberty will occur and therefore, so will sexual development.
Sexual Development

Sexual development coincides with puberty; the adolescent becomes capable of reproducing and generally has their first experiences with sexuality (Suleiman & Harden, 2016; Stokes & Kaur, 2005). Sexual development is complex and involves both visible physical changes and changes in sexual behavior and interests (Baams, Overbeek, Dubas, & van Aken, 2014). There is a multitude of factors influencing sexual development. Beliefs about sexuality, knowledge, feelings and behaviors, along with the biochemical, physiological and anatomical aspects of sexual response are all stakeholders (Urbano et al., 2013). When going through sexual development both intrapersonal and interpersonal sexuality is being explored and established (Urbano et al., 2013). Adolescents may seek self-pleasuring behaviors or become sexually active during this time. In the United States, females tend to display sexual behaviors at a later age than their male equivalents and have fewer sexual partners, even though physical maturity typically is complete at a younger age (Baams et al., 2014).

Historically, it was assumed that individuals with neurodevelopmental disabilities had no sexual desires and were sometimes involuntarily sterilized. Fortunately, this is no longer notion. The Treatment and Education of Autistic and related Communication-handicapped Children (TEACCH) Report was one of the first to acknowledge that individuals with ASD have the same sexual desires and interests as those without ASD (Urbano et al., 2013). Like everyone, individuals with ASD have a right to have sexual relationships, marriages and reproduce if they so desire; however, it is important for sexual education to be provided in a way that is appropriate to their needs. An appropriate
presentation of sex education can compensate for the general lack of proper social communicative skills, as it is vital in healthy sexual development.

**Communication and ASD**

Of the impairments seen in those with ASD, social communication deficits may be the least researched (Koegel, 2000). While these difficulties are essential for DSM-5 criteria to be met, the severity is variable. Some children have difficulties with verbal skills, others with receptive language; many have difficulties with both (Chiang & Lin, 2008). The DSM-5 has three different categories to evaluate the severity of social communication troubles (Craig et al., 2017). These three categories are: 1) requires very substantial support, 2) requiring substantial support, and 3) requiring support (Craig et al., 2017). While there are not specific statistics available in the literature regarding the percentage of individuals that fall into each of these categories, all with an ASD diagnosis must display social communication limitations (Kulage, Smaldone, & Cohn, 2014). More specifically, the category “requiring very substantial support” is defined by severe limitations in the ability to socially communicate, and individuals in this category are primarily non-verbal (Craig et al., 2017). Whereas, individuals who “require support” are verbal. However, there are noticeable deficits in their social communication and in initiating social interactions (Craig et al., 2017). For a diagnosis of ASD to be supported by DSM-5, an individual must identify with one of these three categories establishing the severity of the social communication impairment.

It is a fact that many young children with ASD are considered nonverbal; however, over half are able to develop verbal communication with appropriate interventions (Koegel, 2000; DiStefano, Shih, Kaiser, Landa, & Kasari, 2016). Current
estimates suggest approximately 30% remain minimally verbal, even after they become of school age (DiStefano et al., 2016). Many children have the intellectual ability to acquire language, and learn techniques to be able to interact in social situations, as intellectual disability is not a feature of ASD but can present simultaneously. Social skills typically develop as the individual ages, but not enough to foster complete social proficiency (Stokes, Newton, & Kaur, 2007). Therefore, of those who develop verbal skills, most still have difficulty with conveying feelings, thoughts, or emotions to others, also known as expressive communication (Chiang & Lin, 2008). This often leads to “empathic inaccuracy of expression”, meaning there is difficulty in one’s ability to understand thoughts and feelings felt by another individual (Stokes et al., 2007). It is important to note that expressive communication is far more arduous to develop than receptive language (Chiang & Lin, 2008). To reach their full potential, individuals with ASD need interventions and therapies that provide support and guidance; examples of these include an individualized education plan, applied behavioral analysis and pragmatic language skills development. Additionally, assistive technology devices are also frequently utilized to assist with communication deficits.

**Communication and Behavior**

Behavioral problems displayed by adolescents with ASD, specifically stemming from communication difficulty with puberty and lack of sexual education, have yet to be thoroughly explored. However, research has shown direct correlations with behavioral problems and level of communicative ability (Koegel, 2000). Therefore, one can infer the impact social communication has on puberty in adolescents with ASD, resulting in potentially dangerous and concerning behaviors. Children with communication problems
have been observed to have behavioral concerns, and vice versa (Helland, Lundervold, Heimann, & Posserud, 2014). One study, observing children in both preschool and elementary settings, found that there is a direct association between language and behavioral problems as a child ages due to the increased reliance on communication to regulate behavior and interact with peers (Hartas, 2012). Another study found that children aged seven to nine years old with behavioral problems scored higher on a parent survey of language problems (Helland et al., 2014). The same study further found that behavioral problems with peers and poor language skills were predictors of difficulties utilizing pragmatic language in adolescence (Helland et al., 2014). Furthermore, up to 75-80% of behavioral problems may be associated with communication deficits (Koegel, 2000). Functional communication training efficacy has been thoroughly explored in regards to the disability population and it has been proven to be highly effective in minimizing problem behaviors. Functional communication is utilized to communicate basic needs and wants. Functional communication therapy teaches and reinforces appropriate communication skills to reduce problem behaviors and is also highly individualized to the individual based on their specific needs (Kurtz, Boelter, Jarmolowicz, Chin, & Hagopian, 2011). In a study of four children with varying disabilities, one with a diagnosis of autism, all were found to display lower levels of disruptive behaviors when taught a relevant communicative response when asked to complete a series of tasks (Carr & Durand, 1985). Another study found that when individuals who consistently displayed self-injurious behaviors were reinforced with attention for communicating appropriately, there was a simultaneous decrease in the self-injurious behavior (Derby et al., 1992). Four preschool aged children diagnosed with
ASD were found to display a decrease of problem behaviors and an increase in appropriate communication with the initiation of functional communication training (Rispoli, Camargo, Machalicek, Lang, & Sigafous, 2014). It has been observed that providing the individual with an appropriate replacement behavior does decrease the amount of behavioral issues (Koegel, 2000). Part of an intervention being suitable for a behavioral issue is teaching an appropriate mode of communication to be used (Koegel, 2000). One can assume by empowering the adolescent with ASD with the appropriate methods for accurate communication, there will be fewer behavioral concerns associated with the stressors that are a product of sexual development.

**Significance of Communication in Development**

Language-related interventions that are established early in life, and progress through adolescence, provide the greatest successes in fostering appropriate social communication. Interventions are targeted towards initiating language that is spontaneous and functional, for all individuals with ASD, regardless of severity (Koegel, 2000). Other forms of communication such as communication boards, illustrations, and gestures, have also been useful in fostering communication (Chiang & Lin, 2008). Nonetheless, the arduous task of developing and using socially normative language can cause individuals to appear socially incompetent and result in social isolation amongst peer groups. Those who have limited verbal skills are found to generally have more restricted and cloistered adulthoods than those who develop these skills (DiStefano et al., 2016). Likewise, individuals with ASD tend to avoid social scenarios, which furthers isolation and limits the opportunity to learn, practice, and develop language skills (Koegel, 2000). Another factor that can further cause social difficulties is the use of atypical physical behaviors,
such as tantrums, head banging or arm flapping. These behaviors can be utilized as a means of communication due to their simplicity compared to verbal and socially appropriate forms of communication (Koegel, 2000; Stokes et al., 2007).

The absence of socially normative mannerisms is often isolating for many adolescents, further handicapping the individual in social environments. Strong social communicative skills are important in establishing, as well as maintaining, social and personal relationships with others. These relationships are important for individuals in order to build social skills, exercise appropriate behaviors and build communication. Observing and interacting with typically developing peers may complicate times of transition for individuals with ASD undergoing puberty and sexual development, especially if these events are negative or harmful. Inversely, positive observations and interactions may have potential in facilitating transition by providing the individual with ASD appropriate models of acceptable behavior. Therefore, exerting social skills that are developmentally appropriate could minimize complications and maximize positive experiences and peer-to-peer based learning.

**Sexual Development and ASD**

For families of children with ASD, adolescence has been denoted as the “second crisis” due to the challenges specifically associated with sexual development, and the sense of joint unpreparedness amongst the adolescent and parent that follows (Nichols & Blakeley-Smith, 2009). With the increasing prevalence of ASD diagnoses, it is important to address issues of sexual development and the impact it has on those affected, their families and society. While important, historically, little attention has been given to
sexual development in adolescents with ASD (Travers & Tincani, 2010; Nichols & Blakeley-Smith, 2009; Kellaher, 2015; Stokes et al., 2007).

Learning deficits associated with ASD can cause poor understanding of sexual development, resulting in inappropriate behaviors and actions (Travers & Tincani, 2010). Individuals with ASD may have difficulties communicating information that is being presented, and this can be misleading to parents, healthcare providers, and teachers. Difficulties with pragmatic language and non-verbal communication can result in empathic inaccuracy of expression, which can add another component of complexity to positive sexual development (Stokes et al., 2007). Problems with communication and language may be the source of a misunderstanding that individuals with ASD do not seek interaction or romantic relationships with other individuals, particularly of the opposite sex. Conversely, many individuals with ASD have great desires for intimate and romantic relationships, but lack the appropriate knowledge to initiate (Stokes et al., 2007). Social impairments are barriers for individuals with ASD, creating a disadvantage in positively expressing their sexuality (Koller, 2000). Likewise, communication impairments are also barriers. Both the social and communication impairments are obstacles for the nexus between family members and peers that construct the individual’s, likely limited, social circle.

Sexual or courting behaviors deemed as inappropriate or abnormal, displayed by affected individuals, are likely due to sexual education not being provided in a way that is suitable, or education simply not being provided at all (Travers & Tincani, 2010). Many individuals will innocently act in ways that are inappropriate or pushy as an attempt at courtship (Stokes et al., 2007). These behaviors can even be sexually offensive to others.
('t Hart-Kerkhoffs et al., 2009). In a comparative study of 95 high-functioning young adults with ASD and 117 age-matched controls, it was observed that the ASD group had significantly less sexual knowledge and were two times less likely to have received sexual education from a reliable source such as a parent, teacher or peer, and four times more likely to acquire knowledge from the television or internet (Brown-Lavoie, Viecili, & Weiss, 2014). This same study compared sexual knowledge in men and women with and without ASD to each other and found, again, that both groups with ASD had less knowledge compared to their comparison group (Brown-Lavoie et al., 2014). This is one example of why individuals with ASD may struggle with behaving in a way that is socially accepted regarding puberty and sexual development. Individuals with ASD are at a disadvantage compared to their peers, as effective and dependable sexual education is collectively not being administered to this group. Additionally, the study reports individuals with ASD are experiencing sexual abuse more frequently than those without; 78% of participants with ASD reported at least one incidence of sexual abuse compared to 47.4% of participants without ASD (Brown-Lavoie et al., 2014). Sexual education must be provided to promote self-advocacy and awareness of ways sexual victimization can occur. Furthermore, the need for better sex education for individuals with ASD is evident in a comparative study of 51 typically developing adolescents and 23 adolescents with high-functioning ASD. This study found that typical adolescents displayed significant improvement in sexual education and behaviors with the progression of age, whereas the individuals with high-functioning ASD remained stagnant (Stokes & Kaur, 2005). Again, this is suggestive of a need for better sex education methods uniquely created for individuals with ASD.
Sexual development education should also come from qualified healthcare providers. It appears that there is a lack of and discomfort with sexual education being provided from physicians, not only for adolescents with ASD, but also typically developing adolescents (Fuzzell, Shields, Alexander, & Fortenberry, 2017). Healthcare providers are one of the most knowledgeable sources of information to provide education regarding puberty and sexual development. In general, there is an obligation from parents, healthcare providers and other educators to do a better job providing sex education that is targeted and effective to individuals with ASD. It is not fortuitous that individuals with ASD have difficulties understanding appropriate sexual behaviors and fall victim to sexual abuse.

**Sexual Education**

An appropriate sexual education lesson should be based upon the level of communication the individual is capable of receiving and producing, as language is a vital part of the educational process. There is great variability in nonverbal cognition and receptive language, both of which are difficult to accurately quantify (DiStefano et al., 2016). If an individual is not able to express that he or she has understood what is being discussed, or is able to verbalize understanding of its relevance, is the individual truly able to retain and then apply the information presented? This would be hard to measure and therefore difficult to assess the effectiveness of the lesson. It has been noted that parents are the best sex educators (Koller, 2000). However, it is possible parents of youth with ASD may feel uncomfortable with speaking to their child about sexual development or responding to unusual behaviors or feelings (Nichols & Blakeley-Smith, 2009). This could be a factor contributing to the child not receiving the appropriate approach to sex
education, resulting in negative emotions or embarrassing behaviors. Adolescents also commonly learn about sexual development through their peers, by being a part of social situations, as well as through structured sex education programs. Individuals with ASD may not have those experiences, or may struggle learning about sexual development in those environments (Travers & Tincani, 2010). This is supported by individuals with ASD generally having limited sex education knowledge compared to others who are of the same age and not on the spectrum (Nichols & Blakeley-Smith, 2009). This can be attributed to the individual with ASD having difficulty with communication amongst peers and taking part in social interactions (Koller, 2000). A study observing the influence of language abilities and behaviors concluded that one’s “social cognition” is responsible for supporting a child’s repertoire of understanding emotional and social cues, which likely influences their social experiences with parents, peers and teachers (Hartas, 2012). Social and emotional cues are largely important in navigating sexual development, puberty and establishing and maintaining relationships; therefore, it is discerning that educational programs either focus on individuals who have mild symptoms or involve methods that emphasize social skills (Tissot, 2009). It is important for adolescents with ASD to have a stable sex education foundation so that they may understand the physical changes that are occurring and discern any feelings or behaviors they have. Furthermore, it is imperative because it encourages good hygiene and healthy behaviors, also minimizing risk of sexual abuse or sexually transmitted diseases. By lacking a clear understanding of what is appropriate and normal during sexual development, there is an increase in the amount of harmful and inappropriate behaviors displayed by adolescents with ASD (Travers & Tincani, 2010).
Study Aims

By understanding how communication impacts the sex education process for adolescents with ASD, both patient and healthcare management during sexual development can be better specified. Many healthcare providers feel unprepared to discuss issues related to sexuality with adolescents in general (Holland-Hall & Quint, 2017). For those with disabilities, health professionals likely feel even less adequate. By exploring the effects communication has on sexual development with individuals who have ASD, greater insight will be provided for navigating the “second crisis”. Parents, health professionals and other individuals who are providing information about sexual development to this population will have greater insight in regards to barriers. This will nurture greater positive sexual development experiences and receipt of appropriate services and approaches. It is hypothesized that individuals with ASD who have poorer social communication skills would: (i) have a more difficult transition with the onset of puberty; (ii) display more inappropriate sexually related behaviors; and (iii) have a poorer understanding of sexual development. Furthermore, it is hypothesized that females with ASD will have greater social communication skills and display fewer inappropriate sexually related behaviors, as well as possess a greater understanding of sexual development.
Chapter 2

The impact of communication deficits on puberty and sexual development in adolescents on the autism spectrum

Abstract

Transitioning into a sexually mature adult is a challenging time for both an adolescent with autism spectrum disorder (ASD) and his or her family. Sexual development begets challenges due to the demands it places on the social and communication skills needed to explore developmental changes that are occurring physically, emotionally and hormonally. A diagnosis of ASD is largely established by quantifying impediments in social and communication skills through observation. With deficits in these skills, one can assume that social and communication difficulties can create obstacles in the sexual development of affected individuals. Our study used quantitative and qualitative measures to determine how severity of communication correlates with sexual development in adolescents with ASD. We found statistically significant relationships between communication and frequency of the adolescent displaying sexual behaviors that are inappropriate. Additionally, we determined that the severity of communication deficit has a negative impact on adolescents’ understanding of sexual development. Furthermore, our research explored current sexual education sources, healthcare provider efficacy, and contemporary perspectives of what parents and

guardians feel the biggest challenges and concerns are for adolescents navigating sexual development with a diagnosis of ASD. Ultimately, our study demonstrates the importance of communication ability in relation to sexual development and sexual education in adolescents with ASD.

**Introduction**

ASD is characterized by impairments in social interaction and deficits in communication. Repetitive behaviors, limited interests and inflexible adherence to routines are also distinguishable features. ASD appears to be caused by various genetic, epigenetic and environmental factors, which all likely attribute to the phenotypic variability. Ultimately, there is not one known cause responsible for all affected individuals, which can make pinpointing the etiology and providing accurate recurrence risk an arduous task for healthcare providers and researchers. There is a rapidly growing prevalence in the number of ASD cases being diagnosed worldwide in both males and females. The current estimate in the United States is 1 in 68 affected children (Christensen et al., 2016). This disorder is known to present more frequently in males than females. The current frequency is approximately 4.5 affected males to every 1 affected female (Christensen et al., 2016). For families of children with ASD, adolescence has been denoted as the “second crisis” due to the challenges specifically associated with sexual development, and the sense of joint unpreparedness amongst the adolescent and parent that follows (Nichols & Blakeley-Smith, 2009).

The age of adolescence brings about physical, emotional and hormonal changes. More specifically, sexual development occurs during this time and the adolescent becomes capable of reproducing and generally has their first experiences with sexuality.
(Suleiman & Harden, 2016; Stokes & Kaur, 2005). Sexual development involves both visible physical changes and changes in sexual behavior and interest, varying between males and females (Baams et al., 2014). Variability is believed to be due to differences in hormone levels and pubertal age of onset, which typically occurs earlier in females than males (Baams et al., 2014). Literature states that females may display milder ASD symptomatology compared to males of the same age (Cridland et al., 2014; Holtmann et al., 2007; McLennan et al., 1993; Van Wijngaarden-Cremers et al., 2014). For females with a milder symptomology, it is possible that a diagnosis of ASD will not be made until adolescence when an underlying social impairment is detected (Cridland et al., 2014). Symptoms are present in the early developmental period, however they may not fully manifest until the social demands of early adolescence exceed limited capacities. This demonstrates the importance of proper communicative skills and appropriate sociability when beginning sexual development. Adolescence, for individuals on the spectrum, is when unique challenges navigating both the social and personal complexities of puberty and sexual development present (Tissot, 2009). Additionally, challenges for the creation of appropriate and effective interventions are also evident (Tissot, 2009).

Historically, little attention has been given to sexual development in adolescents with ASD (Travers & Tincani, 2010; Nichols & Blakeley-Smith, 2009; Kellaher, 2015). Learning deficits associated with ASD can cause poor understanding of sexual development, resulting in inappropriate behaviors and actions (Travers & Tincani, 2010). Likewise, individuals may additionally have comorbid intellectual disabilities that further complicate learning about developmental processes. Furthermore, individuals with ASD may have difficulties communicating information that is being presented regarding their
sexual development; therefore, gauging the level of understanding can be challenging for parents, healthcare providers, and teachers.

Problems with communication and language may be the source of a misunderstanding that individuals with ASD do not seek interaction or romantic relationships with other individuals, particularly of the opposite sex. These deficits are barriers for individuals with ASD, creating a disadvantage in positively expressing their sexuality (Koller, 2000). Behaviors deemed as inappropriate or abnormal, displayed by affected individuals, are likely due to sexual education not being provided in a way that is suitable, or education simply not being provided at all (Travers & Tincani, 2010). Appropriateness of a sexual education lesson should be based upon the level of communication the individual is capable of receiving and producing.

Additionally, it is also possible parents of youth with ASD may feel uncomfortable with speaking to their child about sexual development, or responding to unusual behaviors or feelings displayed by their child (Nichols & Blakeley-Smith, 2009). This could be a factor contributing to the child not receiving the appropriate approach to sex education, resulting in personal feelings of negative emotions or displaying embarrassing behaviors. Yet, it is known that parents are the best sex educators (Koller, 2000).

Language is a vital part of education and social interactions. It is standard for many typically developing adolescents to learn about sexual development through their peers, by being a part of social situations, as well as through structured sex education programs. Individuals with ASD may not have those experiences, or may struggle learning about sexual development in those environments (Travers & Tincani, 2010).
Individuals with ASD, like their typically developing peers, desire relationships and have increased sexual feelings and interest (Nichols & Blakeley-Smith, 2009). It is known that individuals with ASD do have limited sex education knowledge compared to others who are of the same age (Nichols & Blakeley-Smith, 2009). This can be attributed to the individual’s level of social communication with peers and his or her ability to take part in social interactions (Koller, 2000). It can also be attributed to the fact that educational programs likely either focus on individuals who have more mild symptoms or involve methods that emphasize social skills (Tissot, 2009).

It is important for individuals with ASD to be able to apply sexual education lessons so that they may appreciate the physical changes that are occurring and discern any feelings or behaviors they have. This will help empower the individual and facilitate the process of sexual development, therefore providing a better likelihood of positive outcomes in regards to sexual actions and romantic relationships. Furthermore, it is necessary because it encourages good hygiene and healthy behaviors, also minimizing risk of sexual abuse. By lacking a clear understanding of what is appropriate and typical during sexual development, there is an increase in the amount of potentially harmful and inappropriate behaviors displayed by individuals with ASD (Travers & Tincani, 2010).

By understanding how communication impacts the sex education process for adolescents with ASD, management during sexual development can be better specified. Many healthcare providers feel unprepared to discuss issues related to sexuality with adolescents in general (Holland-Hall & Quint, 2017). For those with disabilities, health professionals likely are more uncomfortable and unprepared. This study benefits parents of adolescents with ASD, individuals with ASD, and health professionals who are
providing information about sexual development; greater insight has been provided for navigating the sexual development experience and receipt of appropriate services and interventions.

**Methods and Materials**

A survey (see appendix B) evaluating adolescents’ level of autism severity, functional communication, and sexual knowledge and behaviors, was administered online to parents and/or guardians through Survey Monkey. By participating in the survey, individuals were giving their implied consent to participate. Participants had the option to either opt-in or opt-out of participating in a telephone administered semi-structured interview. By providing their contact information in the comment box below the question asking if they are willing to partake in an interview, participants were giving their implied consent to be contacted directly.

Participants included parents or guardians of adolescents who have a diagnosis of ASD. Participants were recruited via online autism support groups, as well as through local and national organizations that work with families and individuals who have ASD. Furthermore, the study was described in person at a local autism support group where information on how to access the survey online was provided. At a neurodevelopmental conference, preliminary results were presented, and contact information for the lead investigator was provided to individuals who were interested in participating.

The inclusion criteria for participation was that the parent or guardian must currently have a child between the ages 10 and 18 years old with a diagnosis of ASD. The semi-structured interview consisted of six open-ended questions (see appendix C). Interviews were recorded for data analysis purposes following the permission of the
participant. During the interviews, probes were used to encourage clarification or examples of concepts such as: sexual development challenges, utility of healthcare providers during this developmental stage, and unique challenges of ASD that complicate sexual development.

Each participant was able to drop out of the study at any point throughout the survey or interview should they chose. No questions in the survey or interview were mandatory and participants were able to opt-out of answering a question at their choosing. Participation was tallied if the participant completed 80 percent or more of the survey. An interview was considered completed if the interviewee answered all six questions.

**Survey Design.**

A self-administered anonymous survey was designed for this research. A total of 40 questions were designed for the survey. Survey length varied based on whether or not the participant was answering questions regarding a male or female adolescent. Male specific surveys were 34 questions in length and female specific surveys were 37 questions. The final survey question allowed parents to provide their contact information to participate in the semi-structured interview.

The survey of parents and guardians evaluated severity of autism, communication ability, individual knowledge of sex education, frequency of behaviors related to sexual development, degree of puberty achieved, and questions regarding appropriateness of various healthcare providers discussing puberty and sexual development, respectively. Basic demographic information was asked at the end of the survey (e.g. age of parents or guardians, relationship of participant to subject, level of education). The beginning part
of the survey adapted questions from the Behavior Assessment System for Children third edition (BASC-3) and DSM-5 autism severity scale to evaluate the severity of ASD and extent of communication deficits of the subjects (Reynolds & Kamphaus, 2015; APA, 2013). The second part of the survey, which asked about knowledge and awareness regarding sex education and puberty, was adapted from an anonymous parental questionnaire in a study of high functioning adolescents with ASD and sexual behaviors (Stokes & Kaur, 2005). The frequency of sexual related behaviors was derived from the BASC-3 (Reynolds & Kamphaus, 2015). The degree of pubertal development was adjusted from an adolescent self-administered scale to a more appropriate scale for parental report (Crockett, 1988). Following this section, parents were asked about appropriateness and helpfulness of addressing sex education with various health professionals. Survey data was downloaded from Survey Monkey and Statistical Package for the Social Sciences (SPSS) version 24 was used for all data analysis.

Participant replies to free response questions in the survey were analyzed and coded using a single independent coder. Thematic analysis, using grounded theory, was used for identifying themes within the participants’ responses. Themes were determined based on patterns observed in the written responses. Therefore, multiple participants providing a similar response defined a theme. Additionally, subthemes were determined if there were differences observed within a theme (i.e. physical change versus emotional change).

**Autism severity.**

Autism severity ($\alpha = 0.75$) was evaluated by using parental report based on the need for supports for communication problems and restricted interests and behaviors.
Parents could choose a response from “no difficulties” to a description of severe impairments in communicating or functioning as seen in the DSM-5 clinician autism severity scale (APA, 2013). Since the DSM-5 incorporates social and communication deficits in establishing a diagnosis of ASD, we extrapolated autism severity to make inferences regarding the impact of social communication.

**Communicative abilities.**

Level of functional communication ($\alpha = 0.80$) was analyzed utilizing questions specifically from the BASC-3 to determine the frequency of behaviors related to communication (Reynolds & Kamphaus, 2015). Participants were offered a choice of four different responses to distinguish the frequency of behavior (e.g. 1 being never; 4 being always) observed in the subject within the last six weeks. Functional communication was selected as a quantitative measure of communication as there are no validated measures for social communication for this age range. Again, autism severity encompasses report of social communication and therefore can be extrapolated to formulate inferences regarding social communication ability.

**Sex Education.**

The extent of sex education understood by the subject was analyzed by a combination of yes or no questions and short answer. The yes and no questions were adopted from Stokes and Kaur (2005), whereas the short answer questions were developed based on the interests of this study.

**Sexual Behaviors.**

Behaviors related to puberty and sexual development ($\alpha = 0.782$) were analyzed utilizing questions specifically from the BASC-3 to determine the frequency of these
displayed by the subject (Reynolds & Kamphaus, 2015). Participants were offered a choice of four different responses to distinguish the frequency of behavior (e.g. 1 being never; 4 being always) observed in the subject within the last six weeks.

**Degree of Puberty.**

Questions in this section of the survey varied based on whether or not the subject was male ($\alpha = 0.74$) or female ($\alpha = 0.94$). Questions were all multiple choice and taken from the “Pubertal Developmental Scale: Adolescent Report” but were adjusted so that they were appropriate for the participants to answer about the subject (Crockett, 1988). The questions specific for the male subjects inquired about height, changing of voice and presence of facial hair. The questions for the female subjects inquired about height, growth of body hair (e.g. armpit hair), skin changes such as acne, breast growth and menstruation.

**Utility of Healthcare Provider.**

To assess the parent perception of the appropriateness in discussing the subject’s sexual development with various healthcare providers, participants were presented with five different healthcare professions and asked to rank them from most appropriate to least appropriate (1 being the most appropriate, 5 being the least). The health provider options provided to participants were: pediatrician, family practitioner, registered nurse, genetic counselor and psychologist/therapist. Open-ended questions were also included in this section. Participants were asked to provide examples of how they believed healthcare providers could be most helpful to both adolescents with ASD and their parents/guardians regarding sexual development.
Interview Design.

To make the data acquired from the survey more robust, in-depth, semi-structured interviews were conducted. Participants were able to elect to choose to participate in semi-structured interviews by providing their contact information at the end of the survey. Participants were contacted prior to their interview to schedule a time that would best accommodate their personal and work schedules. All interviews were audio recorded with the permission of the participant for transcription and data analysis purposes. The audio recordings were stored in a password-protected device to insure participant privacy until each interview was transcribed verbatim. Each interview was conducted by the lead investigator via telephone conversation, with the exception of one interview, which was conducted via Skype at the request of the participant. Examples of some of the interview questions include: “What about your child’s diagnosis of ASD, do you think makes sexual development challenging?” and “Is there anything that you have found to be helpful to your child during their sexual development?” (e.g. management, educational classes). The audio-recordings were destroyed following transcription. The average length of the interviews was thirteen minutes and four seconds. The length of interviews ranged from four minutes and fifty-four seconds to thirty-two minutes and thirty-four seconds.

Interview transcriptions were analyzed and coded using multiple independent coders. Thematic analysis methods using grounded theory were used for identifying themes within the interviews. Codes were jointly reviewed and then themes were established by a majority consensus between the coders. Kappa coefficients revealing inter-rater reliability ranged from 0.522 to 0.674.
Results

Demographics.

A total of fifty-seven participants completed the survey. The participant pool consisted of 46 mothers, 3 stepmothers and 1 primary caregiver. The remaining eight participants did not specify their relationship to the adolescent. The data is reflective of 41 male adolescents with ASD and 11 female adolescents with ASD, all currently 10 to 18 years old (see table A.1).

Statistical analysis of both qualitative and quantitative data provided insight for each of the study aims. Utilizing the data analysis methods portrayed earlier, insight was provided for sexually related behaviors and understanding of sexual development, as well as transition into puberty. Furthermore, information regarding the utility of healthcare providers in providing information regarding sexual development was also found. Due to the small sample size of females, information regarding sexual development and communication unique to the female group was not statistically significant.

To assess pubertal development, participants reported information regarding physical signs of puberty (e.g. growth in height, hair growth) in the adolescents. Participants reporting for adolescent females most commonly reported: growth in height had definitely begun but was not complete, body hair (e.g. under armpits) had begun growing and was visible, pimples and other skin changes were visible, breasts had begun to grow and menstruation had begun (see figure 2.1). Additionally for females, four of the eleven had not begun menstruation yet. Of the seven who had begun menstruation participants reported an average onset of menstruation at 12.14 years of age ($\sigma = 2.17$) with a range varying from nine to 15 years of age. For male adolescents, participants
most commonly reported: growth in height had definitely begun but was not complete, voice changing was currently happening but not complete and facial hair had not yet begun to grow (see figure 2.2).

For conceptualization of other adolescents and/or children in the household, participants were asked to report about the ages and sexes of other individuals residing in the household who are under the age of 18 years old. Sixty-three percent (n = 57) of the participants responded that there was at least one other individual in the household under the age of 18 years old. Of the group of individuals under the age of 18 living in the household, 50% (n = 29) were males and 39% (n = 22) were females. The average number of individuals under the age of 18 per household (not including the individual of focus with ASD) was 2.7 (σ = 0.90, R = 1-5). The average age of other individuals in the household was 11.3 years (σ = 3.92, R = 1-17).

Sexually related behaviors.
Results demonstrated a statistically significant relationship between autism severity and display of inappropriate sexual behaviors, as well as functional communication and display of inappropriate sexually related behaviors. A Pearson's product-moment correlation was run to assess the relationship between autism severity and inappropriate sexual behavior (Laerd Statistics, 2017). Preliminary analyses showed the relationship to be linear with both variables normally distributed, as assessed by Shapiro-Wilk's test (p > .05), and there were no outliers (Laerd Statistics, 2017). There was a moderate positive correlation between autism severity and inappropriate sexual behaviors, r(45) = 0.293, p < 0.05 (Laerd Statistics, 2017). This indicates that autism severity has an impact on a
Figure 2.1 Participant report of female pubertal development; (b) “spurt” was defined as more growth than usual.
Figure 2.2 Participant report of male pubertal development; (b) “spurt” was defined in survey as more growth than usual.
greater frequency of displaying inappropriate sexual behaviors. Specific relationships between autism severity and specified inappropriate behaviors can be observed in table 2.1 and figure 2.3. Additionally, functional communication was found to have a statistically significant relationship with displaying certain sexually inappropriate behaviors. Sexual behavior as a whole was not found to have a statistically significant relationship with functional communication. Table 2.2 and figure 2.4 demonstrate the

Table 2.1 Autism severity and inappropriate sexual behaviors

<table>
<thead>
<tr>
<th>Behavior</th>
<th>Pearson Correlation</th>
<th>N</th>
<th>Sig. (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Touches private body areas in public</td>
<td>0.575***</td>
<td>51</td>
<td>0.000</td>
</tr>
<tr>
<td>Touches anyone inappropriately (e.g. attempted to kiss or fondle, touched another’s body regions)</td>
<td>0.437***</td>
<td>50</td>
<td>0.002</td>
</tr>
<tr>
<td>Removes clothing inappropriately in public</td>
<td>0.408***</td>
<td>51</td>
<td>0.003</td>
</tr>
<tr>
<td>Indicates concern about sexual physical responses</td>
<td>0.290*</td>
<td>51</td>
<td>0.039</td>
</tr>
</tbody>
</table>

***. Correlation is significant at the 0.01 level (2-tailed). *. Correlation significant at the 0.05 level (2-tailed).

negative correlations found between functional communication and touching private body areas in public, as well as touching others inappropriately.

Post hoc analysis demonstrated significant correlations between the adolescent indicating concern about sexual physical responses and displaying inappropriate sexual behaviors (see table 2.3), which could be suggestive of adolescents not having the appropriate responses as a Pearson's product-moment correlation was run to assess the relationship between indicating concern about sexual physical responses and awareness of sexual physical responses (Laerd Statistics, 2017). Preliminary analyses showed the
Figure 2.3 Correlation between autism severity and frequency of inappropriate sexual behaviors; the graphs demonstrate the relationship between (a) autism severity and frequency of touching private body areas in public, (b) autism severity and frequency of touching others inappropriately, (c) autism severity and frequency of removing clothing inappropriately in public, and (d) autism severity and frequency of indicating concern about sexual physical responses. The data points are averages of the severity of autism for each frequency. Frequency of behavior is denoted by a number along the y-axis; 0 is equivalent to the behavior never occurring, 1 is equivalent to the behavior occurring sometimes, 2 is equivalent to the behavior occurring often, and 3 is equivalent to the behavior always occurring. Autism severity values are determined based on parental report of questions taken from DSM-5.
Table 2.2 Functional communication and inappropriate sexual behaviors

<table>
<thead>
<tr>
<th></th>
<th>Pearson Correlation</th>
<th>Sig. (2-tailed)</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Touches private body areas in public</td>
<td>-0.376**</td>
<td>0.006</td>
<td>52</td>
</tr>
<tr>
<td>Touches anyone inappropriately (e.g. attempted to kiss or fondle, touched another’s body regions)</td>
<td>0.437*</td>
<td>0.014</td>
<td>51</td>
</tr>
</tbody>
</table>

**. Correlation is significant at the 0.01 level (2-tailed). *. Correlation significant at the 0.05 level (2-tailed).

Figure 2.4 Correlation between functional communication and frequency of inappropriate sexual behaviors; these graphs demonstrate the relationship between (a) functional communication ability and frequency of touching private body areas in public, and (b) functional communication ability and touching others inappropriately. The data points are averages of the level of functional communication for each frequency. Frequency of behavior is denoted by a number along the y-axis; 0 is equivalent to the behavior never occurring, 1 is equivalent to the behavior occurring sometimes, 2 is equivalent to the behavior occurring often, and 3 is equivalent to the behavior always occurring. Functional communication values are determined based on parental report of questions taken from BASC-3.

There was a moderate positive correlation between indicating concern about sexual physical responses relationship to be linear with both variables normally distributed, as assessed by Shapiro-Wilk's test ($p > .05$), and there were no outliers (Laerd Statistics, 2017). There was a
and awareness of sexual physical responses, \( r(48) = 0.313, p < 0.05 \) (Laerd Statistics, 2017). Therefore, adolescents with ASD are aware of sexual responses and are expressing concern; however, there appears to be some disconnect in their understanding of when and where these behaviors are acceptable and/or how to control sexual impulses.

Table 2.3 Indicating concern about sexual physical responses and inappropriate sexual behaviors

<table>
<thead>
<tr>
<th>Indicates concern about sexual physical responses</th>
<th>Pearson Correlation Sig. (2-tailed)</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Touches private body areas in public</td>
<td>0.300</td>
<td>52</td>
</tr>
<tr>
<td>Touches anyone inappropriately</td>
<td>0.487**</td>
<td>51</td>
</tr>
<tr>
<td>Masturbates in public</td>
<td>0.385*</td>
<td>51</td>
</tr>
<tr>
<td>Displays sexualized behaviors where it is difficult for them to understand what is and is not appropriate</td>
<td>0.357*</td>
<td>49</td>
</tr>
</tbody>
</table>

*. Correlation is significant at the 0.01 level (2-tailed). **. Correlation significant at the 0.05 level (2-tailed).

**Understanding of sexual development.**

Significant relationships were found between functional communication, autism severity and knowledge or understanding of different components of sexual development. A Pearson's product-moment correlation was run to assess the relationship between functional communication and awareness of various types of sexual relationships in males and females with ASD aged 10 to 18 years (Laerd Statistics, 2017). Preliminary analyses showed the relationship to be linear with variables normally distributed, as assessed by Shapiro-Wilk's test \( (p > .05) \), and there were no outliers (Laerd Statistics,
There was a moderate positive correlation between functional communication and awareness of different sexual relationships, $r(52) = 0.380$, $p < 0.01$ (Laerd Statistics, 2017). Using the same analysis technique, a negative correlation between autism severity and awareness of different sexual relationships was calculated, $r(51) = -0.381$, $p < 0.01$. Additionally, autism severity was found to have a moderate negative correlation with: understanding the human reproductive process ($r[51] = -0.286$, $p < 0.05$), knowledge of sexual hygiene ($r[51] = -0.274$, $p < .05$), and understanding of what is and is not considered appropriate behavior toward someone they are romantically interested in ($r[50] = -0.304$, $p < 0.05$). There was also a moderate positive correlation found using Pearson's product-moment correlation between functional communication and understanding of behaviors that are and are not appropriate towards a person of romantic interest ($r[51] = 0.342$, $p < 0.05$).

Participants reported specifically on if the adolescent has received sexual education, as well as if they felt like the adolescent would benefit from sexual education. A Pearson's product-moment correlation was run to assess the relationship between adolescent benefiting from sexual education and their level of functional communication (Laerd Statistics, 2017). Preliminary analyses showed each relationship to be linear with all variables normally distributed, as assessed by Shapiro-Wilk's test ($p > .05$), and there were no outliers (Laerd Statistics, 2017). There was a moderate positive correlation between functional communication and participants reporting that the adolescent would benefit from sexual education, $r(52) = 0.274$, $p < .05$ (Laerd Statistics, 2017). Additionally, this analysis was also completed to determine a relationship with autism severity. A moderately negative correlation was found between autism severity and
participants reporting that the adolescent would not benefit from appropriate sexual education, $r(51) = -0.333, p < 0.05$. This is reflective of participants reporting that adolescents who were considered to have more severe ASD were less likely to have received sexual education by either the participant or someone else ($r[51] = -0.378, p < 0.01$).

Sixty-five percent of the group reported that their adolescent had received sexual education. Of those who said yes, 34 participants provided information regarding who was the primary provider of sexual education for the adolescent (see Figure 2.5). The primary providers of sexual education for the adolescents were parents and school programs. Other resources that were being utilized for sex education were siblings, books, healthcare professionals and autism programs. It is also significant that 55.8% (N

Figure 2.5 Primary sources of sexual education for adolescents with ASD; the category of “other” includes siblings, autism programs and books; this graph is not representative of the combinations of sources for those who reported more than one source of sexual education for their adolescent.
of the participants reported more than one source of sexual education, most commonly reporting that the adolescent was receiving information from both the parents and school. Furthermore, 63% (N = 54) of participants felt like their child had knowledge of sexually related behavior.

Of the 57 participants recruited to the study, 54 provided feedback in regards to whether or not their child had knowledge of sexually related behavior and was provided sex education. A chi-square goodness-of-fit test was conducted to determine whether an equal number of participants from each of the variables were recruited to the study (Laerd Statistics, 2017). The minimum expected frequency was 27. The chi-square goodness-of-fit test indicated that the two variables were not equally represented by the participants recruited to the study (χ²(2) = 11.977, p = .001), with majority of the participants stating that their child had received sex education (Laerd Statistics, 2017). Figure 2.6 is representative of the relationship between provision of sexual education and whether or not the adolescent has knowledge of sexually related behavior.

**The role of healthcare providers.**

Participants were asked to rank the following list of healthcare providers in order of appropriateness for discussing sexual development pertaining to the adolescent: pediatrician, family practitioner, registered nurse, genetic counselor and psychologist/therapist. Collectively, the participants felt like a psychologist/therapist was the most appropriate healthcare provider to discuss sexual development with adolescents with ASD. The remaining healthcare providers are listed from most appropriate to least appropriate: pediatrician, family practitioner, registered nurse and genetic counselor. Furthermore, the survey provided areas for written responses allowing participants to
describe how healthcare providers can be most helpful to both the adolescents with ASD and the parent or guardian of that adolescent during sexual development.

Figure 2.6 Demonstrates adolescents with ASD and whether or not they have received sexual education, as well as whether or not their parent or guardian perceives that they have knowledge of sexually related behavior.

Responses from participants regarding healthcare provider utility during sexual development for the adolescent revealed one major theme. Forty-one participants provided a written response for this question. Participants, almost collectively, felt that healthcare providers needed to provide factual information regarding the clinical aspect of sexual development (e.g. physical changes that the body goes through). Within the theme, a sub-theme emerged; parents and guardians stated that healthcare providers needed to be better equipped to speak about sexual development with individuals who have ASD. This included speaking to the individual in a way that he or she would best comprehend, as well as providing information that is unique to sexual development for those with ASD.
Two themes were found based on coding survey responses in regards to how healthcare providers can be best utilized during sexual development for the parents or guardians of adolescents with ASD. Free responses for this section included forty-one participants. It was reported that healthcare providers would be most helpful by (i) providing information or resources on sexual development to parents and (ii) speaking directly to the adolescent about sexual development. Within the theme of providing information and resources, two sub-themes emerged. Participants felt that they themselves would benefit from the healthcare provider discussing and educating on typical sexual development. Other participants felt like healthcare providers could provide strategies to parents as to how to have conversations regarding sexual development with their child.

In order to further explore the role of the healthcare provider during sexual development for adolescents with ASD, those who participated in the interviews were asked about how healthcare providers could be valuable during this process. Two major themes emerged from participants’ responses during the interview: (i) healthcare providers providing education to parents, and (ii) healthcare providers providing education to adolescents. Each of these themes support the themes from the written responses.

**Theme 1: Parental education.**

Participants indicated that it would be beneficial for healthcare providers to provide information on sexual development to parents so that they could know what to expect, as well as provide proper education to their adolescent.

...the best way to help these children would be to help the parents by providing the information, to provide background knowledge on why it might be hard for a
child to learn from being told once or being told twice, why they might need to be told 100 times, so I think the best way of helping children would be to educate the parents for the individuals on a daily, hourly, minutely basis because that is where the work has to be done (interview 6).

Additionally, many parents also stated that healthcare providers could provide tangible educational resources (i.e. pamphlets, social stories) for parents to take with them to utilize at home with their adolescent.

...I don’t know if anything exists that are like really good videos that are kind of like social stories but um that talk about different things such as you are not supposed to take a picture of your private part and text it to somebody...umm...I think that if pediatricians had access to um like videos or social stories or different things that you could do with your child that has autism about those topics and then warn you (interview 4).

**Theme 2: Adolescent education.**

Participants specified that healthcare providers were a valued source of information regarding sexual development for the adolescent, indicating that healthcare providers would be most beneficial by providing education that was equivalent to the developmental level of the child.

*I think it helps for them to be honest and to approach them at their developmental level so not to talk down to them and to be clear... use um appropriate language for anatomy and to just talk to them at an appropriate developmental level* (interview 1).

**Transition with the onset of puberty.**

Assessing the ease of transition into puberty was done via qualitative analysis based on written and verbal responses given in the survey and interview. Several questions were asked in the interview in addition to written questions in the survey to assess transition. Themes were extracted from all responses to analyze the adolescent’s transition with the onset of puberty and sexual development. Table 4.4 provides specific details regarding the questions asked to participants and their subsequent themes.
Challenges in sexual development unique to ASD.

Several themes emerged from survey participant responses in regards to the question “What about ASD makes sexual development challenging?” The three common themes between the interview and survey group will be further analyzed. It is important to note participants also included comments regarding difficulties with physical and emotional change, as well as emotional immaturity throughout the interviews; however, this was not mentioned enough to qualify as a theme.

Theme 1: Difficulties with social cues.

Participants indicated that adolescents with ASD struggle with social cues, leading to complexities during their sexual development. This was the most frequent code in both the interview responses and survey responses. Social cue difficulties were
indicated in several different facets. Participants indicated concern that adolescents had
difficulty applying social cues in regards to consent.

*I do not think he understands consent, even in like consent for you to record my
voice, or consent that you can tell somebody else my information...even taking
advantage of someone else and not understanding because of pragmatic speech
issues, and not understanding yes and no and the things that kind of go with that
regarding sexual relationships, like you can say yes one time and say no the
second time or you can change your mind* (interview 10).

Another participant commented about the nuances of social cues and verbal cues.

*Current conversations are about consent, this is difficult because while someone
may say "yes" or "no", "stop" or "don't stop", there are social cues to interpret
too* (survey participant).

Understanding what is socially appropriate to share with another individual was another
topic that some participants mentioned.

*You know he does not think anything of you know, asking someone which armpit
has a longer hair which you know isn't something another kid, a typical, you
know what I am saying, would ask and stuff* (interview 4).

**Theme 2: Communication difficulties.**

Participants spoke about difficulties with their adolescent communicating, both in
regards to establishing and maintaining relationships, as well as communicating
effectively in general. Additionally, communication difficulties are concerning for
caregivers in regards to assessing the level of understanding of the adolescent following a
discussion pertinent to his or her sexual development.

*...it is communication because he does not have questions. He listens um and
sometimes he does come back later with a question but it is hard for me to
confirm understanding because if I say, about any topic, “Do you understand?”
he knows that the expected response is “Yes”. Um so I try to say, “Do you have
any questions?” or “Did what I say make sense for you?” um but sometimes I
can’t tell* (interview 10).

*Because a lot of [sexual development] has to do with, you know, with
relationships and you know interactions with people, appropriate interaction,
and um so much of it is being able to communicate and understand um feelings and what is okay (interview 7).

**Theme 3: Defining appropriate versus inappropriate behavior.**

Understanding of appropriate behavior has overlap in both themes described above; however, participants specifically mentioned explicit concerns regarding behaviors or actions either displayed by their adolescent, or concerns for unknowingly being victims of sexual abuse.

Well I will say that one thing with my son um and his diagnosis is he is very forthcoming about stuff. Like he like he social norms that most people um understand. As an example when he was old enough to start actually masturbating um if I would call him or call his name or something he would actually come out of the bedroom and say “Mom what do you want I am masturbating!” (interview 8).

Yeah because he can’t explain. He can’t you know, his understanding is little and he himself doesn’t know like what is appropriate behavior and if someone is doing something you know with him, he also won’t know and he can’t tell us or tell anyone else you know if he needs help…this is a concern for us (interview 11).

My son doesn’t understand fully what is happening to his body. He doesn’t understand that he can’t just touch himself whenever he feels like it. It is difficult to get him to understand hormones and the changes his body is going through (survey participant).

**When to discuss sexual development.**

Participants provided both qualitative and quantitative responses to this question. Participants from the survey on average stated that 10 years old was the best age to begin having conversations about sexual development (mode = 10, average = 10.63, R = 6 – 18). However, there were two primary themes that emerged from qualitative responses. Participants felt that conversations about sexual development should begin (i) prior to puberty beginning, and (ii) when the adolescent begins to display interest. Additionally, several made comments about how information should be presented at a developmentally
appropriate level. Interview analysis revealed one key theme: (i) conversation should begin prior to puberty beginning.

Theme 1: Prior to puberty beginning.

Interview participants almost collectively stated that they felt discussions about sexual development should begin prior to the onset of puberty. During this conversation participants indicated that this was warranted for two primary reasons. The first being that adolescents with ASD needed to be prepared for the impending physical changes that were going to happen to their bodies.

[Participant] heard one speaker say “Listen, this is happening. Your kids are going to go through this just like every other kid they are just going to, you just don’t want them to be alone in their feelings and their experience with it, whereas their typically developing peers, even if it is not a healthy discussion, at least they have peers that they are discussing it with...they can understand the concept of it earlier on and um you know have some type of outlet.”...we started discussing the good touch and bad touch very, very early on...we started reading books and just talking about in general what sex was probably I would say he was in, it was like the summer before fifth grade and then um since then the more male topics, you know things like erections and things like that, his father has discussed those types of things with him...at one point [name of adolescent] thought that it had to do with his autism and we had to explain to him...this is what happens to boys this is your body...this is what boys bodies do and so um that um that is where we are at now (interview 7).

The second point was to normalize conversations about sexual development to facilitate open communication between the parents or guardians and adolescent with ASD.

I mean I think kind of from the beginning of a child’s life it is good to use anatomically correct words and stuff like that...You know so I think starting really simple like that is the way to go because it is much more natural especially for parents who have a harder time with some of the more detailed information, which can be a little embarrassing, and you know I think that is a good way because uh you are kind of used to it and then it is not that big of a jump to have “the talk” you know it is more of a long term conversation like “hey, you are developing and this is what is changing” (interview 10).

You just have to make sure that you keep the channels for conversation open with the child and at the same time don’t overwhelm them because they get frightened
very easily by things that they do not understand...so if you are babbling at them about stuff that they cannot process yet, that is going to scare them and close off that channel of conversation because they are going to be like “no, let's not do that again” (interview 6).

Theme 2: When an adolescent begins to display interest.

While this theme was found from survey response analysis, interview participants provided additional evidence for this key point. In the interviews participants most frequently suggested that this was a good way to keep open communication with the adolescent about puberty and sexual development.

...starting to have those conversations pre-puberty about hey your body is going to be going through some changes you know and making them comfortable in saying “Hey mom this is going on, what does that mean?” (interview 3)

So the first time he [showed interest] actually asked about having periods because he heard that somewhere...at that point I did not go into great detail but I started explaining to him that was a big part of sexual development for girls and that was necessary for them to be able have children. So basically taking whatever interest they show and using that to make conversation out of it (interview 6).

Aids in sexual development.

Participants generally felt that it was most beneficial for information regarding sexual development and puberty to be provided in a sex education curriculum that was (i) fact based and direct, and (ii) geared towards the developmental stage and learning style of the adolescent. Participants did not specifically state that this was unique to a formal educational setting, but to whomever would be providing the information to the adolescent. Additionally, participants commonly reported that (iii) supplemental lessons or resources were helpful in reiterating information.

Theme 1: Fact based and direct information.

Due to the difficulty of individuals with ASD understanding the subtleties of sexual development and puberty, it has been suggested by participants to present
information in a clear and concise way so that the adolescents can more easily conceptualize the information. Whether or not the information is being presented in a formal educational setting such as a sexual education course at school or by a parent informally at home, providing the information straightforward and factually is preferred.

Uh...kind of just being more upfront and a little bit more direct about things and a little bit more like fact based is a little bit more helpful as far as trying to explain things to him...um for my son he just doesn’t understand the grey areas of things so I kind of just have to tell him point blank what is going on and not beat around the bush or create a way to describe things you just have to be kind of to the point (interview 2).

**Theme 2: Developmentally appropriate curriculum.**

It is helpful for adolescents to have information presented to them in a developmentally appropriate way. Developmentally appropriate not only meant the adolescent's intellectual capacity, but also level of comfort in the pace of the receipt of information, as well as the environment that the learning took place.

What helped him when they started doing sex ed in school, was that they did not have to do it with girls together... Talking in front of peers is tough anyways and then talking about something that is so personal makes it even harder. Um so yeah I think that really helped. And getting some of the question cues from the other boys and something they might be interested in and then taking that question back home to me and “OK mom this is what these other boys were asking about can you sit down and explain it to me again”, because it was just too fast for him um so what also helps is slowing things down and breaking everything down into teeny-tiny steps... so that is where parents once again have to come in and take up that slack...and break it down into tiny tiny portions and say “Ok did you understand that part, ok lets move on to the next,” until the child basically says ok I am done for today, I do not have any further questions, can we please pick it up some other time (interview 6).

So I think, what we have noticed is that because we have two boys [with ASD]...the one that is actually at or above grade level intellectually, gets it remembers it everything. The one that is intellectually disabled, when we ask him questions he does not remember it so we have to reinforce that at home so I think part of that is making sure the curriculum is appropriate for the student, so even though our oldest child is intellectually disabled, he is in with the general population so he is getting that same curriculum but it is not really sinking in so I
think their needs to be some adjustment made...so I think as parents we need to reinforce that at home...(interview 1).

I said send me the information that will be presented, and so he and I, I kind of went over it with him and I said they are going to talk about this at school and here is how it is going to work, the boys and girls are going to be separated um you know to prepare him, and the day of the event, and I told them “do not make him do this”, and um so he did not attend but the good thing is we were all on the same page and he had all of the information (interview 10).

Theme 3: Supplemental resources.

Participants frequently discussed that supplemental sources of sexual education were beneficial. This is reflected in 60.7% of participants reporting more than one source of sexual education. Supplemental resources extend to parents reviewing material from a sex education course with their adolescent to reinforce the material and ensure learning.

There are a couple of books that I have given my son over the years about living with autism and there is a teenagers guide to Asperger’s syndrome that we have that talks about sexual development and that type of stuff... I think for my son it has been giving him the information so that when he wants to address it he either can find it in what I have given him or he knows enough that he would not mind having someone talk to him about it (interview 3).

Impact of other adolescents in the household.

Seventy-two percent of the participants stated that there was another individual under the age of 18 living in the household, with the average number being 1.74 additional individuals per household. Furthermore the average age of additional males in the household was 10.7 years and the average age of females is 11.8 years (see table 2.2 for complete demographic information). Interview participants were inquired about other individuals under the age of 18 living in the household and whether or not they felt this had an impact on the adolescent with ASD sexual development. Of the eleven interview participants, three did not have another individual under the age of 18 in the household.
Of the remaining eight, three felt that having another individual in the household within this age group had an impact whereas the five others did not.

Theme 1: Yes, it has impacted.

Of this group, participants felt like it had impacted mostly because of learning through observation from older siblings. One participant felt that the male adolescent with ASD was not being impacted from his older sister’s sexual development, but more so from observing her boyfriends when they would be in the house.

*I think that maybe her indirectly being around, say she has a boyfriend, so I think that makes [him] want to act more mature, like her boyfriend* (interview 1).

Observing older siblings sexual development had impact, but not always positive impact like one might presume. A participant reports that observing an older sibling go through physical changes brought about fear for his own physical changes.

*Seeing how puberty brings on change actually scared him while he was watching his older brother because he is so opposed to things changing that even the thought of his voice changing was a big problem for him...so seeing that has actually made it worse for him because he developed a fear before it actually happened and I kept telling him just you know, your body is going to grow in its own time and you don’t have to worry because it is just going to do it and you are going to grow up with it but um seeing what was going to happen scared him because he does not want the changes to happen now that they are happening he is better with it but every once in a while he will walk up to me and say “Mom, I would love to turn my body back to before puberty started,”...that is another tough thing on our autism kid is that puberty is change and change is something that they do not deal with really well* (interview 6).

Theme 2: No, it has not impacted.

The remaining participants did not feel like being around other adolescents under the age of 18 years of age had impact on the adolescent with ASD. Each participant provided different rationale supporting why they felt this way. Reasons included: information regarding sexual development kept separate from adolescent with ASD and other siblings, age gap between siblings, adolescent feeling embarrassed discussing
sexual development with sibling, and adolescent being not appearing to recognize different levels of physical development in other siblings or peers.

For now I am going to say I do not think it has because I think he is pretty clueless about what is happening with [sibling] but I know he will at some point realize or be given information um and I think he will probably have a pretty strong reaction to when he realizes “Wait she is changing too?!?” (interview 10).

I think that um [adolescent with ASD] is…much more private about things and is much more aware of things therefore things are much more embarrassing to him whereas they are not to [sibling] (interview 7).

Discussion

We used quantitative and qualitative methods to explore communication and the impact it has on the sexual development of adolescents with ASD. The results from this study provide a glimpse into other factors that affect sexual development in this population, more specifically those that impact the adolescent’s understanding of sexual development and display of inappropriate sexual behaviors. Additionally, we have found evidence supporting adolescents with ASD having a more difficult transition with the onset of puberty. Furthermore, we inquired about the desired role of healthcare professionals in providing assistance to parents and adolescents during this time. In this regard, our study provides insight into the complexities that surround ASD and sexual development, therefore having implications for adolescents with this disorder, as well as healthcare professionals and caregivers providing information.

There has been little research exploring the impact of communication directly on sexual development in individuals who have ASD. This is worrisome in the fact that our study demonstrates that there is a statistically significant correlation between functional communication and sexual development, as well as between autism severity and sexual development. This information provides awareness for potential difficulties with the
onset of puberty, allowing parents, caregivers and healthcare professionals to be aware of the potential challenges their adolescent may soon be facing, if they are not already.

Interview participants’ greatest concerns regarding their child’s sexual development were elicited during interviews. Responses revolved around the theme of safety for the adolescent. Participants were subsequently asked to comment on what about ASD they felt made sexual development challenging. The responses encompassed understanding social cues, communication difficulties and understanding what is considered an appropriate behavior. Each of the difficulties associated with ASD can have severe implications for the safety of the individual. For example, an individual with ASD may think a relationship is more serious than it actually is, and engage in behaviors that are inappropriately promiscuous or offensive to the romantic interest. Stokes, Newton, and Kaur (2007) reported that adolescents and adults with ASD more frequently engaged in inappropriate courtship behaviors compared to typical adolescents and adults. Stokes et al. (2007) went as far as describing the courting behaviors that were found to more likely occur in individuals with ASD to include touching the person of interest inappropriately, making inappropriate comments towards that person, believing that the person must reciprocate romantic feelings, and stalking the person (Stokes et al., 2007). Urbano et al. (2013) elaborates on the implications of one’s inability to interpret nonverbal signals, leading to miscommunication between partners, embarrassment, shame, psychological pain, etc. Furthermore, our quantitative data provides supportive evidence for the qualitative themes found in the interviews regarding the features of ASD that complicate sexual development. We have found that communication difficulties have implications in both understanding social cues and understanding appropriate behavior.
Therefore, our findings suggest that communication difficulties may be the root of many complications adolescents with ASD face in regards to sexual development, particularly in the problem behaviors that they display.

It is known that fostering appropriate communication is effective in managing problem behaviors in individuals with disabilities (Kurtz et al., 2011). Therefore, it is not surprising that our study found a correlation between poorer functional communication and adolescents displaying more frequent inappropriate sexual behaviors. Additionally, adolescents who were more severe were found to be more likely to display a greater frequency of inappropriate sexual behaviors. Since autism severity encompasses the domain of social communication, autism severity can be extrapolated to assume the level of the individual’s social communication skills. Therefore, results demonstrate that poorer functional and social communication contribute to the manifestation of inappropriate sexual behaviors. Unexpectedly, a statistically significant correlation was not found between the type of sexually inappropriate behavior being displayed and functional communication and autism severity. This could be due to the differences in social communication and functional communication, with social communication encompassing more abstract abilities such as the understanding of social cues and reciprocity of information. The increased display of behaviors found to be statistically significant with poorer functional communication and greater autism severity are touching private body areas in public and touching other individuals inappropriately. Additionally, autism severity was positively correlated with an increased frequency of adolescent’s removing their clothing inappropriately in public and indicating concern regarding sexual physical responses. The other behaviors we inquired about include:
having a romantic interest in another person, seeking privacy when masturbating, displaying sexualized behaviors when it is inappropriate, awareness of sexual physical responses, masturbating in public, and speaking about sexual activities in an atypical fashion. These additional behaviors may not have correlations with functional communication or autism severity due to a lack of parental awareness of these behaviors occurring. Additionally, adolescents reflected in our study may not be far enough in sexual development to begin displaying these behaviors, as some behaviors may not occur until the adolescent is more sexually developed. Nevertheless, a negative correlation between communicative ability and increased frequency of inappropriate sexual behaviors is supported by our results.

In addition, we found that adolescents with ASD are indicating concerns regarding their sexual physical responses, but are still displaying inappropriate sexual behaviors. This suggests that there is some disconnect in the adolescent’s understanding of sexual development and how it applies to himself or herself. Additionally, this could explain why no statistically significant correlation was found between communication and awareness of sexual physical responses. Adolescents with ASD are having difficulty understanding the various biological changes that occur during sexual development in regards to themselves. Display of inappropriate behaviors is not unfamiliar in the research regarding sexuality and ASD, as one study has found that individuals with ASD have difficulties discerning between appropriate sexual behaviors in public and private, as well as with members of the opposite sex (Urbano et al., 2013). Therefore, one could argue that individuals with ASD are either not able to apply sexual education material that is being provided to them, or are not receiving sexual education at all or in the proper
manner. This argument is based on the apparent disconnect with how physical, hormonal, and emotional changes are causing evident difficulties in how adolescents with ASD are managing sexual maturation. Our results indicate that individuals with ASD are acknowledging concern regarding their body’s biological reaction to sexual development, which implies they are aware of physical changes. The root of the issue may be that adolescents are not communicating these concerns effectively. Therefore, they are not able to advocate for the appropriate information and educational tools they need to learn how to make behavior changes. Qualitative data found the majority of our participants reported sexual education being provided to their adolescent. Additionally the majority of that group reported more than one primary source of sexual education. The issue is not necessarily adolescents with ASD not receiving sexual education, but that current sexual education techniques are not meeting the unique needs of adolescents with ASD.

To assess the extent adolescents understood sexual development, we questioned participants about the knowledge they felt their adolescent currently possessed regarding topics such as human reproduction, sexual hygiene, and birth control. We also wanted to know if the participant felt the adolescent would benefit from sexual education. Similar to the relationships determined between frequency of inappropriate sexual behaviors, autism severity and functional communication, we found a relationship between the adolescents’ understanding of sexual development and functional communication and autism severity. Functional communication was positively correlated with the adolescent’s understanding of various sexual relationships and understanding of the appropriate behavior to exhibit towards a romantic interest. Autism severity was found to have a negative correlation with these two behaviors. This is further evidence supporting how communication has an
impact on understanding of aspects of sexual development and the impact this can have on establishing healthy sexual relationships.

When analyzing the relationships between the various aspects of sexual development and functional communication and autism severity, it became obvious that adolescents with poorer communication experience greater difficulties in sexual development. This can be observed in the difficulties understanding how to engage with others, how to appropriately display sexual feelings, and how to communicate those feelings in an appropriate manner. Adolescents are not demonstrating the communication skills or social awareness to be able to act appropriately on feelings brought about by a romantic interest or sexual arousal. A study by Holmes and Himle (2014) found that parents of low functioning youth with ASD were less likely to provide information regarding “relationships, sexual health and prevention of unwanted behaviors and outcomes, or general sexuality” (p. 2968). Additionally, these parents were not supplementing the information they were providing with topics pertaining to advanced sexual development as their child aged (Holmes and Himle, 2014). Since sexual education needs are not being adequately met for adolescents with ASD, particularly those who are lower functioning, they are reacting to their biological sexual needs based on impulse and intuition (e.g., touching private body areas in public). Our study demonstrates that adolescents with poor communication do not understand what is and what is not appropriate behavior both personally and interpersonally. What needs to be acknowledged by parents, caregivers and healthcare professionals is that these behaviors are not due to the adolescent necessarily being “maladaptive”, but using these as a means of communication (Koegel, 2000). Therefore, sexual education needs to play a role in
teaching interventions to subside these behaviors and reinforce appropriate replacement behaviors and apposite communication. With the provision of appropriate and effective sexual education, adolescents would develop the knowledge on how to react appropriately.

Furthermore, sexual education is related to functional communication and autism severity. Participants felt as if an adolescent would benefit from sexual education if they had greater functional communication or less severe autism. Additionally, individuals with more severe autism, and therefore poorer social communication, were less likely to receive sexual education. Holmes and Hilme (2014) found that adolescents with ASD who displayed greater social skills were more likely to receive sexual education from a parent. Overall, this suggests that parents and caregivers believe more severely affected individuals with ASD may not experience sexual feelings or undergo sexual development. Additionally, the lack of receipt of sexual education could be reflective of individuals with more severe autism having less expressive communication (Chiang & Lin, 2008). Therefore, adolescents are not prompting parents and caregivers to provide the necessary information, or in some cases, any information at all. Not only are adolescents classified as being “more severe” going to have greater difficulties due to their social and communication limitations, but they may miss the opportunity for sexual education, therefore putting them at greater disadvantage.

When delving deeper into how sexual education is currently being provided, it appears that healthcare providers are under-utilized as a resource for sexual education. Six percent of participants reported using a healthcare provider as a source of sexual education for their adolescent. In both the survey and interviews participants were probed
to provide greater insight into how healthcare providers could be better utilized. Generally, participants felt that healthcare providers were valuable sources of information regarding sexual development. However, it is interesting that participants felt this way but did not report utilizing their services. Of the healthcare providers we inquired about, it is not surprising that a psychologist/therapist was ranked as the most appropriate healthcare provider to discuss sexual development. This is likely due to their expertise with discussing psychosocially challenging subjects and their general familiarity with ASD. Participants frequently reported that healthcare providers would be more helpful if they were more familiar with ASD, as this is a barrier to proper care. Research has found that healthcare providers have an overall discomfort with discussing sexual education with patients in general (Fuzzell et al., 2017). With the unfamiliarity in working with someone who has ASD and then with a discomfort of discussing sexual development, it is not surprising participants reported on the underutilization of healthcare providers and comment on the lack of knowledge of ASD in the medical community as a whole. It is important to mention that genetic counselors can be a valuable asset to individuals with ASD when it comes to topics related to sexual development, particularly reproduction. Those in this profession are not unfamiliar to ASD, as education regarding ASD is a part of their educational curriculum. They specialize in the etiology and recurrence risks of ASD, and therefore would be most beneficial for providing education regarding the chance of having a child with ASD, as well as the etiology of the individual’s ASD. While this is not something that is in the forefront of parent and caregiver’s minds, this would be something to consider when the adolescent reached young adulthood.
Since healthcare providers are underutilized, our study asked participants how a healthcare professional would be most helpful during their adolescent’s sexual development. Participants stated that healthcare providers would be best utilized by providing factual information about sexual development to both the adolescent and parent. By providing this information to the adolescent, healthcare providers would be acknowledging the developmental stage of the child and bring about awareness of health-related issues that correspond with sexual development. By providing information to parents and caregivers, healthcare providers would be educating on what to expect during sexual development and providing resources for parents to utilize when reinforcing or introducing new information from home. Furthermore, healthcare providers should begin introducing this information prior to the onset of puberty. Participants felt like it was most beneficial for adolescents to be prepared for the changes to come, followed by introducing new information and concepts when the adolescent displayed interest. Ultimately, it seems like parents and caregivers are suggesting that healthcare providers can initiate the conversation about biological changes and then the parent or caregiver can introduce new information when the adolescent inquires about it.

Ensuring new information and concepts are being presented to adolescents who have communication difficulties is troublesome. These are the individuals that are likely being passed over when it comes to receiving important information regarding sexual development. If they are not able to clearly communicate that they have concerns about a certain feeling, physical change, or behavior, they may not ever receive sexual education that can facilitate their understanding and/or change problem behaviors. Additionally, it can be difficult to assess their level of understanding of sexual education if they are
unable to communicate understanding or relevant questions back to the source, especially since it is difficult to quantify nonverbal cognition and receptive language (DiStefano et al., 2016). This disconnect between the provider of sexual education and recipient, due to communication challenges, can lead to adolescent endangerment or engaging in behaviors that are harmful to himself or herself and/or someone else.

Additionally, participants acknowledged developmental issues can be challenging for providing sexual education. While it was clearly communicated that information should be factual, as well as clear and concise, participants felt it should be based on the adolescents level of comfort and developmental level. It was implied that this was to foster open communication with the adolescent, and to not deter them from discussing sexual development related material. Tailoring the information to the developmental level of the adolescent could be problematic if the information presented is not matching the adolescent’s stage of sexual development. It is important to remember that individuals with disabilities have the same sexual desires and interests as those without (Urbano et al., 2013). Therefore, it is important to present information in a way that can be conceptualized by the individual, but to not coddle adolescents with ASD to the extent that they do not have the tools they need to navigate sexual development.

Lastly, we wanted to see if social interaction with adolescents in the household had any impact on their sexual development. It is hard to assess as to whether or not this has strong impact on the sexual development of adolescents with ASD. Some participants felt that it did, as the adolescent would make observations regarding changes in their older sibling. Others felt that the individual with ASD was naïve to changes occurring in siblings, and was therefore not impacted by another adolescent in the household. Further
research in this area is necessary to evaluate the potential positive impact observational learning could have. Additional research could warrant greater use of social groups to provide sexual education to individuals with ASD. Use of peers groups could allow for observational learning, allowing specific physical changes in development in siblings and peers to be clearly pointed out. This could aid adolescents in conceptualizing physical changes (e.g., voice deepening, facial hair growth, etc.) as a result of sexual development.

**Conclusion**

Communication deficits are a diagnostic feature of ASD. Additionally, communication is a key part of understanding the subtleties and ramifications brought on by sexual development. There are various types of communication; however, our study specifically analyzed functional communication and social communication. Each of these forms of communicating has continuous impact throughout the process of sexual development in adolescents with ASD. Our study suggests that some adolescents with ASD are displaying inappropriate sexual behaviors, likely due to the inability to clearly communicate the physical and emotional changes that are occurring, as well as not being able to apply sexual education information to cope with these changes in a socially typical way. Our results suggest that new and more effective sexual education materials and methods need to be developed to meet the unique needs of this population, specifically regarding communication differences. Healthcare providers can be at the forefront of this change, providing adolescents and parents/guardians with the information and tools they need to facilitate a smooth transition for the adolescent into adulthood. Healthcare providers can better educate themselves regarding the differences between the needs of typical adolescents and adolescents with ASD in order to provide
better services. The themes from the qualitative data serve as an indication of the unique challenges these adolescents face, and the concerns that their parents/guardians have for their sexual development. It is important to encourage communication in adolescents with ASD by methods such as the provision of therapies or utilization of assistive communication devices. This will allow adolescents to be more involved in the conversation and educational process that occurs during sexual development.

Ultimately, we found that adolescents with ASD who have poorer communication skills will (i) have a more difficult transition with the onset of puberty; (ii) display more inappropriate sexually related behaviors; and (iii) have a poorer understanding of sexual development. Additionally, we explored sexual education providers for the adolescents, as well as participant perspectives on sexual education benefits. We found that parents and school programs are the two most common providers of sexual education. However, participants reported that adolescents with poorer communication skills would less likely benefit from sexual education being provided. It is suggested that there is a need for the advent of new sexual education material and methods that are tailored to the developmental needs of the adolescent with ASD. Furthermore, by having more sources of sexual education (e.g., healthcare providers) for these individuals, we can hopefully reinforce information in various ways therefore helping the adolescent to better adapt to changes with sexual development.

We were not able to answer our hypothesis stating females with ASD will have greater social communication skills and display fewer inappropriate sexually related behaviors, as well as possess a greater understanding of sexual development. The population of female adolescents with ASD was not large enough for our data to be
statistically significant. Further research in this area would be beneficial to elucidate the differences between males and females that have been noted in the literature regarding the differences of males and females with ASD. Additionally, we did not inquire about the ages of the adolescents for this study. By having more information regarding their ages, we may have had greater insight into the impact of age on our variables. Another limitation is our study population. Respondents were a fairly homogenous group of individuals; therefore, our data does not encompass the entirety of parents and guardians who have a child with a diagnosis of ASD.

Future research is needed to further explore various types of communication (e.g., verbal, nonverbal, written, etc.) and the impact they have on sexual development in adolescents with ASD. Additionally, new educational programs and means of providing sexual education are other areas of research that could be of great benefit to this population. Research analyzing the extent of information healthcare providers possess regarding ASD could provide greater understanding into where and what kind of information needs to be supplemented in additional training or recertification. With the increased prevalence of ASD diagnoses, it is safe to assume that healthcare professionals will at some point interact with an individual affected with ASD.
References


Appendix A: Adolescent Demographic Information

Table A.1: Adolescent demographic information

<table>
<thead>
<tr>
<th>Gender</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Males</td>
<td>41</td>
<td></td>
</tr>
<tr>
<td>Females</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>Total (N)</td>
<td>57</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age of ASD Diagnosis (years)</th>
<th>Group</th>
<th>Mean</th>
<th>Standard deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Males</td>
<td>7.31</td>
<td>4.55</td>
</tr>
<tr>
<td></td>
<td>Females</td>
<td>7.30</td>
<td>4.75</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>White or Caucasian</td>
<td>43</td>
</tr>
<tr>
<td>Black or African American</td>
<td>3</td>
</tr>
<tr>
<td>Asian</td>
<td>2</td>
</tr>
<tr>
<td>Biracial</td>
<td>1</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1</td>
</tr>
<tr>
<td>No response</td>
<td>7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age of Parents/Guardians (years)</th>
<th>Male (n = 46)</th>
<th></th>
<th>Female (n = 50)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>Standard deviation</td>
<td>Mean</td>
<td>Standard deviation</td>
</tr>
<tr>
<td></td>
<td>46.6</td>
<td>6.35</td>
<td>43.9</td>
<td>5.40</td>
</tr>
<tr>
<td></td>
<td>Range</td>
<td></td>
<td>Range</td>
<td></td>
</tr>
<tr>
<td></td>
<td>36 - 64</td>
<td></td>
<td>34 – 55</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Highest level of education in the household</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>High school degree or equivalent (e.g., GED)</td>
<td>2</td>
</tr>
<tr>
<td>Some college but no degree</td>
<td>9</td>
</tr>
<tr>
<td>Associate degree</td>
<td>9</td>
</tr>
<tr>
<td>Bachelor degree</td>
<td>12</td>
</tr>
<tr>
<td>Graduate degree</td>
<td>14</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
</tr>
<tr>
<td>No response</td>
<td>9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Region of residency</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>United States</td>
<td>45</td>
</tr>
<tr>
<td>International</td>
<td>4</td>
</tr>
<tr>
<td>No response</td>
<td>8</td>
</tr>
</tbody>
</table>
Appendix B: Participant Survey

Welcome to My Survey

Dear Potential Participant,

You are invited to participate in a graduate research study exploring parent and guardian’s report of sexual development in adolescent son or daughter with Autism Spectrum Disorder (ASD). I am a graduate student in the genetic counseling program at the University of South Carolina School of Medicine. My research investigates sexual development and effective communication in individuals with ASD. This research will involve the completion of this survey, which will collect information about you, your child and information about their sexual development. Your responses will help genetic counselors and other health professionals learn more about sexual development in those with ASD. This information will allow health providers to continue to make improvements in sexual education and how information about sexual development will be presented.

All responses gathered from the surveys will be kept anonymous and confidential. The results of this study might be published or presented at academic meetings; however, participants will not be identified.

Your participation in this research is voluntary. By completing this survey, you are consenting that you have read and understand this information. At any time, you may withdraw from this study by not completing the survey.

If you have any questions regarding this research, you may contact either myself or my faculty advisor, Jessica Fairey, MS, CGC, using the contact information below.

Ashton Wolfe, BS
Ashton.Wolfe@uscmed.sc.edu

Jessica Fairey, MS, CGC
Jessica.Fairey@uscmed.sc.edu

If you have any questions about your rights as a research participant, you may contact the Office of Research Compliance at the University of South Carolina at (803) 777-7095.

Thank you for your time and consideration to participate!
1. Do you currently have a child who has been diagnosed with Autism Spectrum Disorder and is currently 10-18 years old?
   - Yes
   - No

2. At what age was your child for whom you are completing this questionnaire diagnosed with ASD?

* 3. Based on all the information you have on your child, please check the **social communication problems** as experienced by your child in the past **seven** (7) days.
   - No difficulties.
   - Without supports in place, deficits in social communication cause noticeable impairments. Has difficulty initiating social interactions and demonstrates clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions.
   - Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions and reduced or abnormal response to social overtures from others.
   - Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning; very limited initiation of social interactions and minimal response to social overtures from others.

* 4. Based on all the information you have on your child, please check the **restricted interests and repetitive behaviors (RRBs)** as experienced by your child in the past **seven** (7) days.
   - No difficulties.
   - Rituals and repetitive behaviors [RRBs] cause significant interference with functioning in one or more contexts. Resists attempts by others to interrupt RRBs or to be redirected from fixedated interest.
   - RRBs and/or preoccupations and/or fixeded interests appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress or frustration is apparent when RRBs are interrupted; difficult to redirect from fixedated interest.
   - Preoccupations, fixed rituals and/or repetitive behaviors markedly interfere with functioning in all spheres. Marked distress when rituals or routines are interrupted; very difficult to redirect from fixedated interest or returns to it quickly.

* 5. This section contains phrases that describe how many adolescents act. Please read each phrase and select the response that describes how your child has behaved within the last six weeks.

Select **never** if the behavior **never occurs**.
Select **sometimes** if the behavior **sometimes occurs**.
Select **often** if the behavior **often occurs**.
Select **always** if the behavior **almost always occurs**.

Please mark every item. If you don't know or are unsure of your response to an item, give your best estimate. A "Never" response does not mean that the child "never" engages in a behavior, only that you have no knowledge of it occurring.
<table>
<thead>
<tr>
<th>Behavior</th>
<th>Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Likes to talk about his or her day.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Says, “please” and “thank you”.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Seems odd.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Engages in repetitive movements.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Isolates self from others.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accurately takes down messages.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoids eye contact.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is shy with other children or adolescents.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shows interest in others’ ideas.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is good at getting people to work together.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has difficulty explaining rules of games to others.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communicates clearly.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Compliments others.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has trouble getting information when needed.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Responds appropriately when asked a question.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is unclear when presenting ideas.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Confuses real with make-believe.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Starts conversations.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is effective when presenting information to a group.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acts strangely.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has trouble making new friends.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adjusts well to changes in routine.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adjusts well to changes in family plans.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Offers help to other children or adolescents.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tracks down information when needed.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is able to describe feelings accurately.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prefers to play alone.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Babbles to self.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
<td>Always</td>
</tr>
<tr>
<td>------------------------------------------------------------------</td>
<td>-------</td>
<td>-----------</td>
<td>-------</td>
<td>--------</td>
</tr>
<tr>
<td>Seems unaware of others.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adjusts well to changes in plans.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is clear when telling about personal experiences.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shows basic emotions clearly.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Makes friends easily.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prefers to be a leader.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Answers telephone properly.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoids other children or adolescents.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acts as if other children or adolescents are not there.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Speech is confused or disorganized.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

6. Has your child received any sex education either by you or someone else (e.g. part of a school program)?
   ○ Yes
   ○ No

   If yes, who provided this information?

7. Do you think your child has any knowledge about sexually related behavior?
   ○ Yes
   ○ No

   If yes, at what age did the child begin to display sexual interest?

8. Is your child aware of the physical changes that occur through puberty?
   ○ Yes
   ○ No

9. Do you think your child has knowledge of sexual hygiene (i.e. cleaning private body parts, using feminine products)?
   ○ Yes
   ○ No

10. Do you think your child is aware of the different kinds of sexual relationships (dating, marriage, etc.)?
    ○ Yes
    ○ No

11. Does your child understand the human reproductive process?
    ○ Yes
    ○ No
12. Does your child understand the concept of birth control?
   - Yes
   - No

13. Does your child know about sexually transmitted disease?
   - Yes
   - No

14. Does your child understand what is and what is not acceptable behavior towards someone they are romantically interested in?
   - Yes
   - No

15. Would your child benefit from appropriate sex education?
   - Yes
   - No
   If yes, how would they be best assisted?

16. What do you think is the best time (e.g. age) to discuss sexual development?

17. What about your child’s diagnosis of ASD do you think makes sexual development challenging?

18. This section contains behaviors that adolescents may display during sexual development. Please read each phrase and select the response that best describes how your child has behaved within the last six weeks.

Select never if the behavior never occurs.
Select sometimes if the behavior sometimes occurs.
Select often if the behavior often occurs.
Select always if the behavior almost always occurs.

Please mark every item. If you do not know or are unsure of your response to an item, give your best estimate. A "Never" response does not mean that the child "never" engages in a behavior, only that you have no knowledge of it occurring.
### Questionnaire

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Touches private body areas in public.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Touches anyone inappropriately (e.g. attempted to kiss or fondle, touched another's body regions)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Speaks about sexual activities in a way not normally discussed by adolescents of the same age.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Masturbates in public.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Removes clothing inappropriately in public.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has romantic interest in another person.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is aware of his or her own sexual physical responses (e.g. genital arousal, wet dreams, menstrual cycles).</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Indicates concern about sexual physical responses.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Displays sexualized behaviors where it is difficult for them to understand what is and what is not appropriate (e.g. persistently calling someone of romantic interest after being asked not to).</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Seeks privacy if masturbating.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The next section of questions pertains to physical development in your adolescent. Physical development pertains to changes in growth and sexual maturity.

To answer each question, please select the answer that best describes what is happening to your son or daughter right now. Please choose only one answer for each question.

19. Is your child biologically a male or a female?
   - Male
   - Female
20. Would you say that his growth in height (getting taller)
   ○ Has not yet begun to spurt ("spurt" means more growth than usual)
   ○ Has barely started to spurt
   ○ Has definitely started to happen, but is not finished
   ○ Seems completed (he is about as tall as he will get)

21. Has his voice started to change?
   ○ Not yet started changing
   ○ Has barely started changing
   ○ Voice change is definitely happening but is not finished
   ○ Voice change seems completed

22. Has he started to grow facial hair (beard or mustache)?
   ○ Not yet started to grow facial hair
   ○ Have barely started growing facial hair
   ○ Hair growth has definitely started (enough to shave)
   ○ Probably grows now as fast as it will ever grow

23. Would you say that her growth in height (getting taller)
   ○ Has not yet begun to spurt ("spurt" means more growth than usual)
   ○ Has barely started to spurt
   ○ Has definitely started to happen, but is not finished
   ○ Seems completed (she is about as tall as she will get)

24. How about the growth of body hair (e.g., under her arms)? Would you say that body hair has:
   ○ Not started growing
   ○ Barely started growing
   ○ Definitely started growing
   ○ Seems completed (he has as much body hair as he is going to get)

25. Have you noticed any skin changes, especially pimples?
   ○ Not yet started showing changes
   ○ Have barely started showing changes
   ○ Skin changes have definitely started but are not finished
   ○ Skin changes seem completed
26. Have her breasts begun to grow?
   - Not yet started growing
   - Have barely started growing
   - Breast growth has definitely started but is not finished
   - Breast growth seems completed

27. Has she begun to menstruate? ("menstruate" means get your period)
   - No
   - Yes

   If answered yes, how old was she when she got her first period?

28. Please rank the following health care providers on level of appropriateness in discussing your child's sexual development (1 being the most appropriate, 5 being least appropriate).

   - [ ] 1 Pediatrician
   - [ ] 2 Family practitioner
   - [ ] 3 Registered nurse
   - [ ] 4 Genetic counselor
   - [ ] 5 Psychologist/therapist

29. How do you best think healthcare providers (e.g. genetic counselor, pediatrician) could be helpful during sexual development to adolescents with ASD?

30. How do you think healthcare providers (e.g. genetic counselor, pediatrician) could be helpful during sexual development to parents and guardians of adolescents with ASD?
31. Define your relationship with the child for whom you are completing this questionnaire (i.e. mother, father, stepmother, etc.).

32. What are the current ages of the parents (mother and father) of the child?
   Mother's age
   Father's age

33. What is the highest level of school you have completed or the highest degree received in the household?
   - Less than high school degree
   - High school degree or equivalent (e.g., GED)
   - Some college but no degree
   - Associate degree
   - Bachelor degree
   - Graduate degree
   - Other (please specify)

34. What is the ethnicity of the child for whom you are completing this questionnaire? Please select all that apply.
   - White or Caucasian
   - Black or African-American
   - American Indian or Alaskan Native
   - Asian
   - Native Hawaiian or other Pacific Islander
   - Some other race (please specify)

35. Does the child for whom you are completing this questionnaire have any other diagnoses besides autism spectrum disorder?
   - No
   - Yes
   If yes, please specify.
36. What is your current zipcode?

37. Do you have any children under 18 living in your household?
   ○ Yes
   ○ No
   If yes, please specify biological sexes and ages.

38. Are there any other individuals in the household with ASD who have completed sexual development? If yes, please list gender and age.

39. If you would be willing to participate in an interview regarding your child's sexual development, please provide your contact information (i.e., name, email address, phone number, etc.) in the space below. This is optional and will not eliminate you from this study should you not want to be interviewed.
Appendix C: Interview questions

1. What are your greatest concerns about your child’s sexual development?

2. What about your child’s diagnosis of ASD, do you think makes sexual development challenging?

3. How do you best think healthcare providers (e.g. genetic counselor, pediatrician) could be helpful during sexual development to individuals with ASD?

4. What do you think is the best time (e.g. age) to discuss sexual development?

5. Is there anything that you have found to be helpful to your child during their sexual development (e.g. management, educational classes)?

6. Are there any other individuals in the household who have completed sexual development? If yes, has this impacted sexual development in your child with ASD? If yes, how has it impacted?
Appendix D: Study Flyer

RESEARCH VOLUNTEERS NEEDED
Do you have a child who is between the ages of 10 and 18 years old with an autism diagnosis? Has communication complicated puberty?

This study is evaluating how communication differences in adolescents with autism spectrum disorder impact their sexual development.

PLEASE TAKE OUR ANONYMOUS SURVEY
www.surveymonkey.com/r/QVC3PR7

To participate you must be the parent or guardian of a child age 10 – 18 years old who has a diagnosis of autism spectrum disorder.

Questions? Please contact Ashton Wolfe at Ashton.Wolfe@uscmed.sc.edu

Website for survey

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