THESIS

EXPLORATION OF FACTORS IMPACTING CAREGIVERS' COMFORT DISCUSSING SEXUALITY WITH ASD YOUTH

Submitted by

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ABSTRACT

EXPLORATION OF FACTORS IMPACTING CAREGIVERS' COMFORT DISCUSSING SEXUALITY WITH ASD YOUTH

The present study aims to understand factors impacting caregivers' comfort and education goals related to their autistic youth's sexuality through secondary data analysis. Individuals with Autism Spectrum Disorder (ASD) are a vulnerable group to sexual victimization and experience unique psychosexual development. There is little known about sex education efficacy for autistic individuals and how to support caregivers' comfort in addressing issues of sexuality with their youth. This study utilizes secondary analysis of pre-intervention data collected prior to a small (n = 8) pilot study for a sexuality education intervention for parents of autistic youth in 2006. In this project, the following questions will be addressed via narrative analysis and visual inspection: what are caregivers' goals for their autistic youth related to sexuality/sex education and what are the factors impacting caregiver's comfort in talking about their autistic youth's sexuality? Results highlight the heterogeneity of individuals with ASD suggest the need for multi-level and multi-system interventions to promote healthy psychosexual development for autistic youth as sexuality is impacted by several systems and impacts several domains of functioning. Lastly, implications and future directions for research and clinical practice will be discussed.

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Overview of ASD

Surveillance studies using record review methods suggest that 1 in 36 8-year-old children in the US presents with symptoms of ASD that merit further evaluation (CDC, 2022). There is not a single known cause of ASD; given the complexity and heterogeneity of symptoms there are likely many causes, but it is generally accepted that both genetic and environmental factors contribute to its' origin (Mayo Clinic, 2018). ASD is characterized by qualitative impairments in social interaction, verbal and nonverbal communication, and cognitive and behavioral flexibility (APA, 2013; Green et al., 2019; Hillier et al., 2020). ASD impacts how an individual communicates and interacts with others, processes sensory stimuli, organizes new information, and behaves in a variety of settings (American Psychological Association, 2013). Common symptoms of ASD include a lack of inherent understanding of social norms (Lazzaro et al., 2018), heightened sensory sensitivity, restricted and/or repetitive behaviors, and challenges with emotion regulation (CDC, 2022; Mayo Clinic, 2018).

ASD is a complex medical condition that is associated with neurological symptoms such as increased risk of seizures, dystonia, and dyspraxia (Jeste, 2011; NIMH, 2023). There are also high rates of co-occurring medical conditions among children with ASD including gastrointestinal conditions (46-84%), metabolic disorders (~5%), immune disorders (25%), and sleep disorders (~80%) (Al-Beltagi, 2021). From a sample of youth (ages 5-15) who met DSM-V criteria for ASD (n = 57), it was found that 67% also met DSM-V criteria for ADHD, 61% for OCD, 93% for anxiety and 42% for severe anxiety, 35% for severe eating disorders, and 28%

had engaged in self-harm behaviors (Romero et al., 2016). Estimates for prevalence of depression among youth with ASD ranges from 2-30% depending on the operationalization of depression and sampling methods (DeFilippis, 2018; Matson & Nebel-Schwalm, 2007). It is estimated that 30% of individuals with ASD have a co-occurring intellectual disability (Baio et al., 2018; Vas et al., 2021). There is limited research on individuals with ASD who are non-verbal and/or have an intellectual disability; the remainder of this literature review is focused on research from samples of individuals with ASD who are verbally fluent and without intellectual impairment.

Given the common symptoms of ASD related to socioemotional development, it is common for autistic individuals to have difficulty forming and maintaining relationships, of experience social isolation, and lack social support (Lazzaro et al., 2018). Additionally, autistic individuals report concerns about the likelihood of having a long-term romantic relationship, higher levels of anxiety in relationships, and difficulty expressing their sexuality compared to neurotypical samples (Byers et al., 2013).

ASD and sexuality

There have been recent advancements in understanding the sexuality of autistic individuals regarding their attitudes toward sex, barriers to sex and education, and sexual behavior throughout the lifespan, particularly in adolescence (Dewinter et al., 2013; Dewinter et al., 2020; Hannah & Staggs, 2016; Pecora et al., 2019). Many stereotypes around sexuality and ASD presume that all autistic people are asexual, and that sexual behaviors/desires are inherently problematic and require intervention. The sexuality of autistic individuals is often pathologized, information about sex is withheld, and trusted adults in youths' lives typically do not feel

comfortable initiating conversations about sexuality (André et al., 2020; Apsy et al., 2006; Ballan, 2011; Corona et al., 2016).

Although research about autistic individuals' sexuality remains limited, existing literature supports that levels of interest in sexuality and romantic relationships are comparable to the general population (Byers et al., 2013a; Byers et al., 2013b; Dewinter et al., 2017; Dewinter et al., 2013). Interest in sexuality and romantic relationships is a normative and expected element of autistic youths' development. Symptoms of ASD may impact the way that individuals meet potential partners, form relationships, and engage in sexual behavior (Dewinter et al., 2013; Dewinter et al., 2020). Studies also indicate that there is greater diversity in sexual attraction among the ASD community (i.e., sexual orientation, means of arousal, and paraphilic interest), signaling a need for sex education among autistic individuals and their caregivers to provide information to support their psychosexual development (George & Stokes, 2018b). Given the observed and hypothesized gendered differences in ASD phenotypes and development, much of the research conducted on ASD and sexuality is segregated by gender; the following sections discuss existing findings on autistic individuals' psychosexual development for males and for females.

Autistic males

Existing research around autistic males' sexuality shows differences in psychosexual development throughout adolescence and adulthood, as compared to neurotypical males (Dewinter et al., 2015; Pecora et al., 2019). In a study (Byers et al., 2013a) examining the sexuality of autistic adults who are single (n = 129) age 21-73 (M = 35.3 years), those who were male, younger in age, and heterosexual were more likely to report no prior relationship experience. Additionally, compared to peers with relationship experience, this sample reported

higher levels of anxiety related to sex, lower sexual arousability, and less positive sexual cognitions (Byers et al., 2013a). Another unique aspect of autistic males' psychosexual development is a higher prevalence of same gender attraction (12%; Dewinter et al., 2015; Holmes et al., 2020) compared to neurotypical males (8.5%; Dewinter et al., 2017). Similar to neurotypical populations, sexual and romantic experiences increase with age and those with ASD report similar ages of onset and frequency of sexual experiences throughout adolescence and young adulthood (Dewinter et al., 2013).

Much of the prior research on autistic adolescent boys' sexuality comes from parent/caregivers' reports, however, it has been consistently shown that parent reports of sexual behaviors and experiences are less accurate than youth's self-reports (Dewinter et al., 2016). Specifically, masturbation is underestimated by parents (Byers et al., 2013a), as adult autistic males report masturbating more often than non-autistic males (Schöttle et al., 2017).

Autistic youth (from a sample of predominantly males, $n = 326$) report unique barriers to positive sexual experiences (Dewinter et al., 2017). These barriers include limited knowledge about arousal and attraction, lack of sex education (from schools and caregivers), uncertainty about how to be a partner, limited experiences for meeting potential partners, and increased sexual anxiety (Byers et al., 2013b). Other reported barriers to positive sexual experiences related to symptoms of ASD include increased sensory sensitivity, need for structure and routines, and differences in communication with neurotypical partners (Barnett & Maticka-Tyndale, 2015). Autistic adults with an autistic partner report higher relationship satisfaction than those with neurotypical partners (Strunz et al., 2017). More research is needed on how to promote and support romantic relationships and sexual well-being of autistic individuals in a variety of settings (Dewinter et al., 2020).

Based on information gathered in clinical settings, it is supported that some autistic males—both in adolescence and adulthood—undergo different experiences of sexual arousal compared to neurotypical males (Dewinter et al., 2013). Specifically, self-report data from individuals with ASD ranging from 12-21 years of age (n = 37) revealed that some autistic males experience sexual arousal from specific characteristics of partners (e.g., hair) to objects that provide distinct sensations (e.g., a particular fabric) (Hellemans et al., 2006). These behaviors and means of arousal may be considered atypical, however, they are not inherently problematic or require intervention (Dewinter et al., 2013).

Although data on paraphilic interests and behaviors are limited for all populations, a 2017 report showed differences in the prevalence of these interests between autistic (n = 96) and neurotypical (n = 96) individuals based on a matched pairs design utilizing self-report data (Schöttle et al., 2017). The report showed that autistic men (n = 56) compared to neurotypical men (n = 40) report more masochistic fantasies (39.3% vs 10.5%), sadistic fantasies (42.9% vs 7%), and voyeuristic fantasies (39.3% vs. 10.5%) and behaviors (28.6% vs. 3.5%), supporting the hypothesis that adolescents with ASD experience distinctive psychosexual development (Schöttle et al., 2017).

Autistic females

Most of the research around autistic adolescents' sexuality has been conducted with male participants; however, there has been increasing attention to understanding sexuality in autistic females (Stokes et al., 2022). Broadly, research examining sexuality and ASD reveals differences between autistic men and women but minimal differences between neurotypical women and those with ASD. This suggests that sex differences are more likely to do with general population sex differences rather than developmental differences specific to ASD (Byers et al., 2013a;

Pecora et al., 2019). As with their male counterparts, autistic females (n = 343) report greater diversity in sexual orientation (43%) than autistic men (12%) and neurotypical females (13%) (Dewinter et al., 2017). Additionally, there are higher rates of gender diversity and gender non-conforming identities reported by autistic females (22-33% prevalence) than autistic males (8-22% prevalence), and neurotypical females (0.7-1.1% prevalence) (Dewinter et al., 2017; George & Stokes, 2018a).

In the only study to date that examines paraphilic behaviors and fantasies of autistic adults (M = 39.5 years old, SD = 9.5 years), women (n = 40) report lower overall rates of paraphilic behaviors (10% vs 28%) and fantasies (25% vs 43%), as compared to autistic men. When compared to the general population of women, autistic women reported more masochistic behavior and fantasies, but similar rates of the other paraphilic behaviors (Schöttle et al., 2017).

Concerning behaviors, victimization, and bullying

A distinctive factor of psychosexual development that impacts those with ASD is a higher frequency of concerning behaviors (e.g., touching oneself in public or touching others without consent), victimization, coercion, and bullying that occurs related to sexuality (Corona et al., 2015; Holmes et al., 2020). Compared to parents of neurotypical adolescents, parents (n = 298) of youth with ASD aged 12-19, report higher frequency of inappropriate sexual behaviors including talking about sexual topics in public, undressing in public, staring at others, and masturbating in the presence of others (Holmes et al., 2020). Parents of autistic males report more concerning behaviors than parents of autistic females (Holmes et al., 2020). One in seven caregivers from this sample report their child experienced sexual victimization and 14% report their youth had been bullied due to their lack of knowledge around sexuality, regardless of gender identity or level of intellectual functioning (Holmes et al., 2020). Factors contributing to

these behaviors include limited awareness of social expectations while in public, lack of understanding about the impact of sexual behaviors, and overarching lack of sexuality education and information on how to develop satisfying romantic and sexual relationship experiences (Brown-Lavoie et al., 2014; Gotby et al., 2018; Hannah & Stagg, 2016).

Sedgewick and colleagues (2019) interviewed 38 women (n = 19 with ASD, n = 19 neurotypical), and found that women with ASD (79%, n = 15) report more instances of sexual abuse, victimization, and assault than neurotypical women (26%, n = 5). Women with ASD are three times more likely to experience sexual coercion and/or victimization (Gotby et al., 2018) and are at an increased risk for sexual victimization and abuse compared to men with ASD (Cridland et al., 2014; Mandell et al., 2005). Autistic women (65%, n = 88) self-report more regretted sexual experiences than both autistic men (38%, n = 37) and non-autistic women (55%, n = 87) (Pecora et al., 2019). These regretted experiences are linked to increased feelings of loneliness, declines in self-esteem, and internalizing difficulties (Cridland et al., 2014), as women report engaging in sex to combat feelings of social exclusion and isolation, rather than sexual desire (Pecora et al., 2019).

Barriers to accurate information about sexual health, consent, and pleasure are associated with the increased risk of victimization and negative sexual experiences for women with ASD (Cridland et al., 2014; Pecora et al., 2019). Additionally, women report difficulty setting boundaries, identifying high risk situations, and making accurate judgements of others' intentions (Brown-Lavoie et al., 2014; Cridland et al., 2014; Pecora et al., 2019). Taken altogether, data on the frequency and nature of negative sexual experiences of individuals with ASD show the need for additional research on promoting the sexual well-being and safety of this vulnerable population (Dewinter et al., 2020).

Importance of sex education and sexuality knowledge

Expression, exploration, and enjoyment of sexuality is a fundamental right that should be afforded to all populations and individuals (Shtarkshall et al., 2007). Individuals' general well-being is impacted by their sexual well-being, which can be supported in a variety of ways throughout the lifespan (Diamond & Huebner, 2012). One of the most accessible means of supporting individuals' sexual development and well-being is through comprehensive sexuality education. Sex education that is comprehensive (i.e., not focused solely on abstinence or pregnancy and STI prevention) is linked to a wide variety of individual, relational, social, and health outcomes (Diamond & Huebner, 2012; Goldfarb & Lieberman, 2021; Shtarkshall et al., 2007; Starrs et al., 2018). A systematic review reported that comprehensive sex education is associated with acceptance of sexual diversity, prevention of sexual and relationship violence, decreased rates bullying in schools, prevention of child sexual abuse, promotion of healthy relationships, and improved socioemotional learning (Goldfarb & Lieberman, 2021).

Sex education can be delivered in a variety of settings and tailored to address specific population needs, such as children with ASD (Dewinter et al., 2020; Starrs et al., 2018). Evidence from the past 30 years supports that sex education should begin in elementary school and be provided throughout one's schooling years. It should be comprehensive, include LGBTQ+ information, and incorporate social justice to promote healthy sexuality for all (Goldfarb & Lieberman, 2021). It is also supported that effective sexuality education will not be achieved with a single program or methodology; the efficacy of sex education is dictated by individual and cultural differences as healthy sexuality does not have a universal meaning (Goldfarb & Lieberman, 2021).

Barriers and needs of autistic youth

Despite the increased challenges and barriers that autistic youth face while navigating their sexual development, research has consistently shown that this population receives less education around sexuality compared to their neurotypical peers (Corona et al., 2016). Even when youth with ASD do receive sex education through school, the information is not properly retained due to the standardized format of delivery. Providing generic sexuality education is not sufficient for serving this population as it needs to be delivered in a developmentally appropriate manner to ensure youth understand content (Corona et al., 2016).

Several studies have examined the shortcomings of general sex education related to its efficacy with autistic youth. Based on a variety of findings, there are specific recommendations about the content and deliver of sex education to promote the psychosexual development of this population. Sex education should include content related to common ASD symptoms such as cognitive rigidity and challenges with social functioning (Hannah & Stagg, 2016). Social skills should be incorporated into sex education as sexuality does not exist separately from one's social environment (Nichols & Blakeley-Smith, 2009). This would also address common caregiver concerns about their youth's perception of others, adherence to social norms, and sexual victimization (Ballan, 2012; Nichols & Blakely-Smith, 2009). Sexual diversity should be addressed in sex education as LGBTQ+ identifying individuals report more mental health issues and there is a larger proportion of LGBTQ+ individuals among those diagnosed with ASD (George & Stokes, 2018c).

Neurotypical (n = 20) adolescents and adolescents with ASD (n = 20) who received some form of sex education in school (n = 40, aged 18-25 years old) report feeling that the information provided is not adequate based on their curiosities and questions pertaining to sexuality (Hannah & Stagg, 2016). These same youth report relying on peer interactions to supplement information

not formally provided to them. Psychosexual development through peer conversations is inaccessible for the majority of autistic youth due to social and communication difficulties (Hannah & Stagg, 2016; Lazzaro et al., 2019). Without peer interactions, youth with ASD have decreased awareness of the inadequacy of the sex education and do not gain generation/age specific information about sex (Hannah & Stagg, 2016).

Caregiver perspectives on ASD and sexuality

Parents are known to be a strong influence on youth sexual behavior, attitudes, and awareness throughout psychosexual development. Studies indicate that parent-child communication promotes safer sex practices (i.e., use of birth control and condoms, understanding and implementing consent, and lower rates of STI's and unplanned pregnancies) (Apsy et al., 2007). Research on sexuality and education within family systems has consistently shown that parents experience difficulty and discomfort in talking to their children about sexuality; these challenges are amplified for caregivers of autistic children (André et al., 2020; Travers & Tincani, 2010).

Parents report increased difficulty in educating their youth about sexual development because autistic individuals are better able to understand and retain information that is clear, precise, and specific. Although, most parents do not feel confident enough to deliver information to their youth in this way (Kenny et al., 2012; Lehan Mackin et al., 2016). Given that parents often don't have the confidence or knowledge base to have conversations about sexuality with their youth, it is important that they are able to seek guidance from professionals as they navigate changes in their youth's sexuality.

However, a qualitative analysis of semi-structured interviews with parents (n = 18) of youth with ASD aged 6-13 years old highlighted an important barrier caregivers face when

navigating their youth's psychosexual development—lack of help from professionals (Ballan, 2012). Parents in this study report that professionals (including special educators, school administrators, pediatricians, psychologists, and therapists) lacked initiative and receptivity to addressing sexual development, unless there were concerning sexual behaviors present. Many parents report they did not expect for their children to undergo a "normal" psychosexual development timeline given their child's delays in other domains (Ballan, 2012).

From this same sample and qualitative analysis of parent interviews, it was found that parent perceptions of their child's sexual behavior was a strong determinant of initiating conversations about sex (Ballan, 2012). A commonly reported reason for parents to not discuss sexuality with their youth is the perceived improbability of their child having a romantic and/or sexual relationship (Ballan, 2012); this perspective contradicts the desires and experiences of autistic individuals (Byers et al., 2013a).

It is common for parents to be one of the primary sources of sexuality education for autistic adolescents. However, these parents report struggling to navigate and initiate these conversations with their youth as they are unsure about what information related to sexuality they should share (André et al., 2020; Ballan, 2012). In a recent systematic review of the literature on parent communication with autistic youth on topics of sexuality (André et al., 2020), the most commonly discussed topics from parent's self-reports were physical hygiene, types of physical contact, privacy of body parts, and puberty. The topics that parents were the least likely to discuss with their autistic youth were sexual abuse, types of relationships, STIs, pregnancy, safe sex practices, masturbation, and menstruation (André et al., 2020). Data from a pilot program assessing sex education efficacy with parents and autistic adolescents (n = 8, youth aged

12-16 years old) showed that parents were most concerned for their youth in regard to sexual abuse, forming relationships, and misconceptions about sex (Corona et al., 2016).

The Present Study

Although there is a wide base of literature on sex education, parent-child communication about sex, and factors affecting autistic individual's psychosexual development, there are several gaps in the literature that this investigation aims to address. The first major gap is that it is unknown what factors impact caregiver's comfort level in talking to their autistic youth about sexuality. It is well-documented that parents experience discomfort in talking about sex, but there is not information available about what factors affect their comfort level such as youth experiences and severity of ASD symptoms.

Additionally, there is little understanding of caregiver's goals for their autistic youth as they are receiving sex education. It is important for clinicians and educators to have an understanding for what parents are needing from their youth's sex education in order to promote healthy psychosexual development. Lastly, given the barriers that parents face in getting help from professionals on issues of sexuality, it is vital to know what systems and people (i.e., schools, teachers, health care providers, other family members) caregivers feel comfortable talking to about their youth's sexuality. With this information, interventions can be tailored to align with caregiver's goals and comfort to promote autistic youths' psychosexual development.

The present study aims to understand factors impacting caregivers' comfort and education goals related to their autistic youth's sexuality through secondary data analysis. This is a non-experimental, hypothesis generating, descriptive study based on data from a mixed-methods study conducted in 2006 assessing caregiver's comfort discussing sexuality with their autistic adolescent.

Research questions

Based on the existing literature on parents, ASD, and sexuality, our hypothesis-generating research questions are as follows:

1. What are caregivers' goals for their autistic youth related to sexuality/sex education?
2. What are the factors impacting caregiver's comfort in talking about their autistic youth's sexuality?
    a. Do differences in youth's characteristics related to ASD symptomology (e.g., symptom severity, communicative competence, and IQ) impact caregivers' readiness to discuss topics of sexuality with their youth?
    b. Do differences in autistic youth's experiences related to socioemotional development (e.g., romantic and/or sexual relationship experiences, bullying, sexual victimization) affect caregivers' comfort in talking to them about sexuality?
    c. Who are the people/systems (i.e., other family members, health care providers, schools) that caregivers are more and less comfortable talking about sexuality in regard to their autistic youth?

Methods

Measures

Child Information Sheet. *The Child Information Sheet* (Wehner, 1996) is a brief demographic and family history survey that was filled out by the youth's caregiver. The survey includes questions about the youth and their family's ethnicity, family structure, SES, brief medical history, previous therapy experience, education, employment, etc.

Autism Diagnostic Observation Schedule (ADOS). The *ADOS* (Lord et al., 2002) is a semi-structured play/interview assessment that is administered and scored by a trained professional to assess current symptoms and severity of ASD. The modules within the *ADOS* assess various traits including social, imagination, and communication skills across all ages, cultural backgrounds, language abilities, and developmental levels. Module 3 was utilized in the original study and is used for participants who are verbally fluent and developmentally in line with young adolescents. In the context of this study, the *ADOS* was used to confirm an existing clinical diagnosis to ensure that all participants fell within ASD range; exceeding the cut off score is widely regarded as a way of characterizing inclusion criteria for ASD in research (Lord et al., 2001).

Weschler Intelligence Scale for Children, 4th Edition. The *Weschler Intelligence Scale for Children, 4th Edition (WISC-IV)* is a measure of intellectual ability for children aged 6 to 16 years old. It was developed as a measure of general cognitive ability while also providing specific information based on subscales verbal comprehension, perceptional reasoning, working memory, and processing speed. The highest possible score is 160 and the lowest possible score is 40, with 100 being the standardized mean score. The qualitative breakdown of scores is 130 or higher is considered extremely high intellectual ability, 110-129 as higher than average ability, 90-109 as average ability, 70-89 as below average ability, and 69 or below as extremely low intellectual ability (Weschler, 2003). Reliability of the WISC-IV based on a sample of children enrolled in school aged 6-11 years old (n = 103) is high (r = .97) (Gygi, et al., 2017).

Behavioral Vulnerability Scale. *The Behavioral Vulnerability Scale* was adapted from the Social Vulnerability Scale (Greenspan & Stone, 2002) to be a parent-report scale rather than a self-report as the original was written for. It is a 25-question Likert scale questionnaire that

assesses caregivers' perceptions of their youth's social judgements and vulnerability to social exploitation. The measure utilizes a 5-point Likert scale ranging from "never" to "always" for all questions; higher scores on most items (some are reverse coded) and overall indicate greater risk of social and behavioral vulnerability. Sample items include "has (s)he been tricked into telling secrets to other people", "does (s)he believe things that other people would view as clearly untrue", and "has (s)he been tricked into taking the blame for something that (s)he did not do." In a factor analysis study to determine the reliability and validity of the original Social Vulnerability Scale, the internal consistency of the scale deemed excellent ($\alpha = .90$) using combined clinical and non-clinical samples. Additionally, factor loadings for both gullibility ($\alpha = .85$) and credulity ($\alpha = .86$) were good indicating that it is an acceptable scale to measure social and behavioral vulnerability (Pinsker et al., 2011).

Parenting and Sexuality Scale. *The Parenting and Sexuality Scale* was created by the study's PI to assess parent's attitudes, concerns, and experiences related to their youth's sexuality and knowledge (Nichols, 2005b). It is a 35-item parent-report measure with 7 subscales, each with 5 questions. The subscales are: Acceptance, Skill, Competence, Comfort Level, Experience, Fear, and Knowledge. Each item has a 5-point Likert scale response ranging from "not true at all" to "very true". Sample items include "I am accepting of my child as a sexual person", "I do not feel competent as a sexual educator for my child", "I have a good understanding of typical sexual development during puberty and adolescence", "I am experienced in teaching my child about sexuality", and "thinking about my child as a sexual person makes me tense and anxious". Although this measure has not been scientifically validated, this measure provides useful information for ascertaining parental attitudes that are relevant to this hypothesis generating inquiry.

Youth Sexuality Development Scale. *The Youth Sexuality Scale* was created by the original study's PI to assess youths' sexuality development, behavior, experiences, and learning (Nichols, 2005d). It is a parent-report questionnaire that includes subsections and topics of privacy, behaviors, education, experiencing, growing up, bullying, and knowledge. As with the previous measure, there are no psychometric validation studies of this measure. However, this measure and its subscales provide necessary information about autistic youths' sexuality and experiences that will be included in this investigation's data analysis.

Privacy. The Privacy section utilizes multiple choice options of "not at all", "somewhat", and "yes" for questions such as "does your child know which body parts are private?" and "does your child understand the rules about privacy regarding touching your own body parts in private places only?" Additionally, the Privacy section uses a 5-point Likert scale ranging from "never" to "always" for questions such as "does your child seek privacy when dressing/undressing?" and "does your child seek privacy when bathing or showering?"

Behaviors. The Behaviors section uses multiple choice options of "never", "rarely", "sometimes", and "often" for all questions as well as a space to leave comments about behaviors. Sample items from this section include "has your child ever masturbated in a public place?", "has your child every intruded on another person's personal space (e.g., stands too close)?", and "does your child talk about sexual activities in a way that is not appropriate for youth his/her age?".

Education. The Education portion of the measure includes a variety of response options from yes/no response, 5-point Likert scales, and checking all that apply. Sample items from this section include a yes/no response to "has your child received any type of sexuality education?", a 5-point Likert response ranging from "not at all" to "very beneficial" in response to "was this

[sexuality education] beneficial for your son or daughter?", and a check all that apply to answer "from whom has your child received sexuality education?".

Experiences. The Experience section utilizes a variety of multiple choice and Likert scale responses to assess youths' experiences with romantic partners, gender identity, and sexual orientation. Sample items that utilized a 4-point Likert scale ranging from "never" to "often" include "has your child expressed a romantic interest in anyone (e.g., said a girl is cute)?", "has your child expressed confusion or conflict about their gender identity (e.g., belonging to the female or male sex)?", and "has your child every expressed a romantic interest in individuals of the same sex?".

Growing up. The Growing Up portion of the measure utilized a 5-point Likert scale ranging from "never" to always" to assess items such as "has your child ever expressed fear, worry, anxiety, nervousness about growing up" and "has your child expressed fear/worry/concern about pubertal changes?". Under this section, there is also a section for caregivers to qualitatively write what their youth's fears about growing up are, as applicable to their child.

Bullying. The Bullying portion of the measure has caregivers check off experiences of bullying that their child has faced; sample items for this question include "having sexual rumors spread about him/her", "having their clothes pulled at in a sexual way," and "being forced to kiss a peer." This section then asks parents to provide information about the frequency of these bullying experiences, if they addressed the issues with the school, and if so, how well the school handled instances of sexual bullying.

Knowledge. The Knowledge section of the survey utilizes a 5-point Likert scale ranging from "does not understand this" to "has a very good understanding" as well as "N/A" and "Don't

Know" options for each item. The section begins with "Does your children know/understand about the following" and has 35 items that caregivers respond to; sample items include "functions of sexual body parts", "orgasm", "sexual abuse", "awareness of different sexual choices/lifestyle", and "sexual responsibility".

Parent Group Goal Attainment Scale. *The Parent Group Goal Attainment Scale—Setting Goals: Pre-Group* is a 4-item measure to identify and track progress of parent-set goals for themselves, their child, family, etc. as they participated in the original intervention study. The measures asks for caregivers to "Select 2 specific, measurable goals which you feel are attainable during the course of the group (8-10 weeks). These may be personal goals, or goals related to your child, family, child's school, and health care providers. Attainment of your goals will be measured during your post-group assessment appointment." The caregiver then writes out two goals then answers "current level of goal attainment" on a 6-point Likert scale ranging from "none" to "complete success" for both goals. The scale was created by the original study's PI to fit the data collection process and timepoints (Nichols, 2005c). Same as the previous measures, this scale has not been psychometrically validated, but provides valuable qualitative data about caregivers' goals for their autistic youth's sex education.

Comfort Ratings. *The Comfort Ratings* is a 5-item scale created by the original study's PI to assess caregiver's comfort in talking about sexual with a variety of individuals/systems (Nichols, 2005a). Each item is responded to on a 10-point Likert scale ranging from "Very low; I am not comfortable at all" to "Very high; I am as comfortable as I need to be". The items in this measure begin with "my level of comfort in discussing the topic of sexuality and my child" and then vary to be "during this group is currently", "with member of my family is currently", "with individuals at my child's school is currently", and "with my child's PCP or health care provider

is currently," with the final item being "my level of comfort in talking with my child about issues related to sexuality/puberty is currently…" Again, with the other measures created for the original study, there are not studies that have validated this scale. Nonetheless, the comfort ratings provided with this measure are necessary to examine caregivers' comfort discussing sexuality with various people and systems.

Procedures

This thesis investigation is a secondary data analysis of pre-intervention data collected prior to a small (n = 8) pilot study for a sexuality education intervention for parents of autistic youth in 2006. The original study's PI was Dr. Susan Hepburn, who is the primary advisor for this thesis investigation; Dr. Hepburn has maintained the pilot study data as it has continued to inform intervention development in the area of ASD research.

The original intervention study was conducted in 2006 at Children's Hospital of Colorado in Denver under the approval of the University of Colorado's IRB. Parents/guardians in the original study filled out several consent forms; the first was an IRB-approved consent form detailing the risks, benefits, and procedures of participating, two consent forms were provided regarding audio recording of group sessions and/or video recording of youth ADOS assessments, two authorization forms regarding HIPPA compliancy, and a final assent form provided to the youth that is developmentally appropriate and clear.

Participating families were recruited through The Autism Research Group's participant database based on the pre-determined inclusion and exclusion criteria. Inclusion criteria were caregivers/parents between the ages of 20-70 years with youth who are between the ages of 11-15 years old. The major inclusion criteria for youth in the study was the presence and diagnosis of ASD. Specifically, youth needed to meet 2/3 of the following criteria: 1) exceeding the cut-off

score for ASD based on the Autism Diagnostic Observation Schedule (ADOS) conducted by the study's investigators, 2) exceeding the ASD cut-off for the Autism Diagnostic Interview, and 3) have been clinically determined to have ASD as determined by a clinical psychologist and consistent with DSM criteria. Given the year that the original study was conducted, ASD criteria came from the fourth edition of the DSM. Lastly, youth needed to have been assessed at a cognitive functioning of 80 or higher on the verbal measures of the WISC-IV. Exclusion criteria for the study were not having a diagnosis of ASD and youth not having at least one parent/caregiver who is able to attend the in-person group sessions at Children's Hospital in Denver.

The intervention for the original study was developed my Shana Nichols and Nancy Lee under the supervision and guidance of Dr. Susan Hepburn. The intervention was delivered in an in-person group setting and data were collected at three time points—pre, during, and post. No data or findings were ever published from the pilot study, however the findings impacted future directions for research and sexuality interventions. The theory of change established by the original investigators was that intervening in caregiver's comfort and knowledge about sexuality would increase their ability to discuss and educate their youth about sexuality. Overall findings from the original investigation were that the intervention lacked the intensity and direct contact with the youth required to see desired changes in sexuality knowledge, comfort, and behaviors. These findings informed the research teams next steps and intervention development for future investigations on sexuality and ASD in adolescents.

This data set was selected for this thesis investigation as it serves as a strong foundation to inform research questions for later, more intensive quantitative investigations in the area of ASD and sexuality. All original data were de-identified prior to analysis to maintain the privacy

and confidentiality of the participants. The original pre-intervention data set included 9 participants; for the purposes of this investigation, participants were only excluded from analysis if they did not have all of the above measures completed at the pre-intervention time point. Exclusion criteria were set to be as broad and inclusive of all cases possible while maintaining consistency across participants for analysis purposes. Once the exclusion criteria were applied, there were eight participants remaining that were used in this investigation's analysis.

Participants

The sample this inquiry includes eight participants (n = 8) with ASD and their caregiver who received the education intervention. The age range of youth participants was 11-13 (M = 12.1). All participants were male—the original study had 1 female, however the full data needed for this inquiry is not available for this participant. The majority of participants (n = 5) were Caucasian/White and the remaining three participants were Hispanic/Caucasian. The education level of participants' caregivers ranged from completed high school to completed graduate school, the mode is "completed undergraduate education". All participants were assessed to be verbally fluent (i.e., able to spontaneously speak in complex sentences with multiple clauses, can talk about the present, future and past events, and at a level of conversational speech). In regard to IQ based on WISC-IV scores, participants intellectual ability was assessed to range from extremely high intellectual ability (n = 1), higher than average (n = 2), and the remaining participants (n = 5) as below average intellectual ability. All participants were evaluated as having mild (n = 2) or moderate (n = 6) ASD symptoms based on the ADOS assessment.

Data analysis

The present study aims to understand factors impacting caregivers' comfort and education goals related to their autistic youth's sexuality through secondary data analysis. To

investigate what caregivers' goals are for their youth's sexuality education, data will be qualitatively examined using narrative analysis to understand themes and differences. To explore what factors impact caregivers' comfort in communicating about their autistic youth's sexuality, Likert scale and categorical data will be visually inspected to provide descriptive data. A table with each participant's characteristics, experiences, and parent's comfort level will be created and examined for patterns and to generate testable hypotheses. From this table, descriptive data and frequencies will be provided, and charts will be generated to inspect for associations between ASD youth characteristics and caregiver comfort level discussing sexuality.

Results

Caregiver goals for their autistic youth related to sexuality/sex education

Thematic analysis of the qualitative goals provided by participants' caregivers revealed four themes: preparation, knowledge, communication, and developmental changes. Table 1 highlights these themes, describes the theme based on the analyzed data, provides example quotes from caregivers' written goals, and the frequency of the theme out of the 16 total goals provided (two goals per participant's caregiver).

Table 1. Summary of thematic analysis of caregiver goals.

Theme	Description	Supporting Quotes	Frequency
Preparation	Several caregivers expressed wanting to have a plan and feel adequately prepared to discuss sexuality with their child including identifying specific resources and educational materials	"Create a more concrete plan to discuss more of these topics…" "To feel more adequately prepared to talk to my child about the changes he's going through"	37.5% (of 16 goals) (n = 5)

		"Identify specific resources that we as a family can read, watch, listen to…"	
Knowledge	Half of the caregivers (n = 4) described wanting to increase their knowledge and resources about sexuality and how to educate their child	"Increase my knowledge…" "Learn more about the issues regarding puberty, sexuality, etc. so that I can talk with my son more effectively." "Develop the skills and knowledge to understand how to talk to my child…"	25% (of 16 goals) (n = 4)
Communication	All participants (n = 8) mentioned at least one goal about increasing their comfort and ability to discuss, educate, and talk with their child about sexuality	"To be able to explain personal boundaries and appropriate interactions and touching with himself and others." "…make the best decisions about how to go about talking to our HFA son about his emerging sexuality." "…have a specific new style of talking to him about these things--rather than in a 'matter of fact' way."	87.5% (of 16 goals) (n = 8)
Developmental changes	Many of the caregivers' goals expressed wanting information, skills, and resources that are developmentally appropriate, attuned to their autistic child's needs, and learning style	"I will identify 3 areas/topics regarding my child's sexual maturation that he is now ready for me to teach him about." "Develop the skills and knowledge to understand how to talk to my child on the spectrum vs my typical child regarding adolescence and sexuality." "…communicate to [child] on his level to help him to understand what is going on in his body."	37.5% (of 16 goals) (n = 5)

Factors impacting caregivers' comfort

Youth characteristics.

Visual inspection of the descriptive data of youth characteristics related to ASD symptomology (ADOS symptom severity, IQ, Behavioral Vulnerability Score) yielded mixed findings. The caregivers of participants with mild ASD symptomology (n = 2) rated their comfort level talking to their youth about sexuality (M = 5.50, SD = 0.71) lower than the group average (M = 7.13, SD = 1.78) and caregivers of participants with moderate ASD symptoms (n = 6, M = 7.76, SD = 2.34) on a 10-point Likert scale. Caregivers of youth with IQ's greater than 100 rated their comfort discussing sexuality with their youth (n = 3, M = 6.33, SD = 2.31) lower than caregivers of youth with IQ's less than 90 (n = 5, M = 7.60, SD = 2.23). The caregivers of participants with Behavioral Vulnerability Scale scores greater than 60 (indicating greater social vulnerability risk) rated their comfort discussing sexuality with their youth (n = 4, M = 6.75, SD = 1.71) lower than caregivers of participants with scores less than 60 (n = 4, M = 7.50, SD = 2.89). Table 2 provides this descriptive data by ASD characteristics and Table 3 shows the breakdown of ratings and scores for each participant.

Table 2. Summary of descriptive statistics of caregiver comfort ratings by ASD symptom.

ASD Characteristic	Category	Caregiver Comfort Rating		
Symptom Severity (ADOS)	Mild (n = 2)	5 6	M = 5.50	SD = 0.71
	Moderate (n = 6)	5 10 5 7 10	M = 7.76	SD = 2.34

ASD Characteristic	Category	Caregiver Comfort Rating		
		9		
IQ (WISC-IV)	Greater than 100 (higher than average to average abilities, $n = 3$)	5 5 9	$M = 6.33$	$SD = 2.31$
IQ (WISC-IV)	Lower than 100 (average to below average abilities, $n = 5$)	10 5 6 7 10	$M = 7.60$	$SD = 2.23$
Behavioral Vulnerability Scale	Greater than 60 (higher risk of behavioral vulnerability, $n = 4$)	5 6 9 7	$M = 6.75$	$SD = 1.71$
	Less than or equal to 60 (lower risk of behavioral vulnerability, $n = 4$)	10 5 10 5	$M = 7.50$	$SD = 2.89$

Table 3. ASD symptom categories and comfort ratings by participant.

Participant	Symptom Severity	IQ	Behavioral Vulnerability Score	Caregiver Comfort Rating
1	Mild	138	43	5
2	Moderate	119	60	5
3	Moderate	80	49	10
4	Moderate	82	61	5
5	Mild	78	70	6
6	Moderate	74	76	7
7	Moderate	88	41	10
8	Moderate	110	72	9

Youth experiences.

Visual inspection of the descriptive data of comfort ratings based on youth socioemotional experiences (experiences of bullying related to sexuality, romantic interest, relationship experience, inappropriate touching in public, and previous sex education experiences) yielded mixed findings. The caregivers of participants who experienced bullying related to sexuality (n = 4) rated their comfort level talking to their youth about sexuality (M = 6.50, SD = 1.92) lower than the caregivers of participants who did not report experiences of bullying (n = 4, M = 7.75, SD = 2.63). Caregivers who reported their youth expressing romantic interest "sometimes" or "often" rated their comfort discussing sexuality with their youth (n = 3, M = 8.67, SD = 1.53) higher than caregivers who reported youth "rarely" expressing romantic interested (n = 2, M = 5.50, SD = 0.71) and higher than caregivers who reported youth have "never" expressed romantic interest (n = 3, M = 6.67, SD = 2.89). Caregivers of youth who had touched their genitals in public reported less comfort discussing sexuality with their youth (n = 4, M = 6.50, SD = 2.38) than caregivers of youth who have touched their genitals in public before (n = 4, M = 7.75, SD = 2.22). Youth who had received sex education previously (from their caregiver, from school, or from other sources) had caregivers who reported less comfort (n = 6, M = 7.00, SD = 2.10) than caregivers of youth who had not received any prior sex education (n = 2, M = 7.50, SD = 3.54). Table 4 provides this descriptive data by youth socioemotional experiences and category. Table 5 shows the breakdown of ratings and scores for each participant and their socioemotional experiences.

Table 4. Summary of descriptive statistics of caregiver comfort ratings by youth experiences.

Experience	Category	Caregiver Comfort Rating		
Bullying related to sexuality	Yes (n = 4)	5 5 7 9	M = 6.50	SD = 1.92
	No (n = 4)	5 10 6 10	M = 7.75	SD = 2.63
Romantic interest	Never (n = 3)	5 5 10	M = 6.67	SD = 2.89
	Rarely (n = 2)	10 5	M = 5.50	SD = 0.71
	Sometimes or Often (n = 3)	7 10 9	M = 8.67	SD = 1.53
Touched genitals in public before	Never or Rarely (n = 4)	5 7 10 9	M = 7.75	SD = 2.22
	Sometimes (n = 4)	5 10 5 6	M = 6.50	SD = 2.38
Received sex education	Yes (n = 6)	5 5 6 7 10 9	M = 7.00	SD = 2.10
	No (n = 2)	5 10	M = 7.50	SD = 3.54

Table 5. Youth socioemotional experience categories and comfort ratings by participant.

Participant	Youth experience of bullying	Romantic interest	Relationship experience	Touch self in public	Previous sex education	Caregiver Comfort (youth)
1	No	Never	No	Sometimes	No	5
2	Yes	Never	No	Rarely	Yes	5
3	No	Never	No	Sometimes	No	10
4	Yes	Rarely	No	Sometimes	Yes	5
5	No	Rarely	No	Sometimes	Yes	6
6	Yes	Sometimes	No	Rarely	Yes	7
7	No	Often	Yes	Never	Yes	10
8	Yes	Sometimes	No	Never	Yes	9

People and systems.

Data from the caregiver comfort ratings were analyzed to compare the average rating across participants for each person/system that caregivers rated, as well as each participant's overall average rating. Caregivers of autistic youth rated their comfort discussing their youth's sexuality with their youth, with other members of the family, with their youth's school, with their youth's primary care provider (PCP), and with the other caregivers in the intervention group on a 10-point Likert scale. Results showed that based on the average ratings across participants (n = 8) for each person/system, caregivers of autistic youth are most comfortable discussing their youth's sexuality with their child's primary care provider (M = 7.88, SD = 1.46). Caregivers

reported the least comfort discussing sexuality with their youth's school (M = 5.25, SD = 2.43). Comfort ratings for discussing their youth's sexuality with the youth directly (M = 7.13, SD = 1.78), other members of the family (M = 6.25, SD = 2.96), and other caregivers in the intervention group (M = 6.00, SD = 2.23) fell in between. The overall average comfort ratings across people/systems for each participant ranged from 4.4 to 9.0. Table 6 shows the descriptive statistics and comfort rating scores provided by caregivers for each person/system.

Table 6. Summary and descriptive statistics for all comfort ratings.

Participant	Caregiver Comfort (Youth)	Caregiver Comfort (Family)	Caregiver Comfort (School)	Caregiver Comfort (PCP)	Caregiver Comfort (Group)	Participant Mean	Participant SD
1	5	4	7	7	7	6	1.41
2	5	8	5	10	7	7	2.12
3	10	10	10	10	5	9	2.24
4	5	5	5	7	4	5.2	1.10
5	6	2	2	8	4	4.4	2.61
6	7	4	5	6	5	5.4	1.14
7	10	10	5	8	9	8.4	2.07
8	9	7	3	7	7	6.6	2.19
Person/System Mean	7.13	6.25	5.25	7.88	6.00		
Person/System SD	1.78	2.96	2.43	1.46	2.23		

Discussion

Prior research has consistently shown that individuals with ASD experience unique barriers to sex education despite the increased need for support of their psychosexual development. In addition to these barriers to sexuality resources, caregivers of autistic youth report feeling uncomfortable and unequipped to support their youth's sexual development. The goal of the current study were to fill gaps in the literature by describing what caregivers' goals are for their autistic youth's sex education and sexual development and examining what factors impact caregiver's comfort discussing sexuality with their autistic youth. In addition to being a hypothesis generating investigation to support future research in autism and sexuality.

Caregiver goals

We found that caregivers' goals for their youth's sex education and their own participation in the intervention revealed four common themes that were present across the 16 goals provided: preparation, knowledge, communication, and developmental changes. This finding suggests that caregivers of autistic youth are wanting to ensure they are getting accurate information to teach their youth about sexuality, but also want to feel prepared and confident in delivering this information. It is also noteworthy that several of the participants caregiver's expressed wanting specific information about developmental expectations and differences for their autistic youth as compared to neurotypical youth and/or siblings. This is important because it shows that caregivers of autistic youth acknowledge that their youth will likely need specialized and individualized support as their experiences of sexual development will likely differ from neurotypical youth. The themes found in caregiver goals demonstrate the need for multi-level interventions for supporting autistic youths' psychosexual development through individual intervention, but also family and school level interventions.

Youth characteristics

Analysis of potential factors impacting caregivers' comfort discussing sexuality yielded mixed results. These mixed results highlight the heterogeneity of autism phenotypes, experiences, and development that caregivers, health care providers, and educators should be attuned to. Our results tentatively suggest that caregivers of youth with moderate ASD symptomology, IQ's lower than 100, or higher behavioral vulnerability risk have higher comfort discussing sexuality with their autistic youth compared to those with mild ASD symptomology, IQ's greater than 100, and lower behavioral vulnerability risk. The authors hypothesize that that caregivers of autistic youth with mild ASD symptomology, IQ's greater than 100, and lower behavioral vulnerability risk have lower comfort talking about their youth's development as their symptoms and risk level are closer to that of neurotypical youth. These caregivers may have less exposure to discussing sexuality as it may not be deemed as necessary compared to caregivers of autistic youth with greater risk factors and developmental differences.

Factors related to youth socioemotional experiences also yielded mixed results about factors that may impact caregivers' comfort discussing sexuality. Results from our descriptive and visual analysis tentatively suggest that caregivers of autistic youth who have not experienced bullying related to sexuality, have expressed romantic interest in others, have not touched themselves in public, or have not received any prior sex education have greater comfort discussing sexuality than those who have experienced bullying, have not expressed romantic interest, have touched themselves in public, and have received prior sex education. The authors hypothesize that caregivers of youth who have experienced bullying related to sexuality or have touched themselves in public have greater discomfort talking to their child about sexuality due to feeling unequipped on how to respond to sexual victimization and socially inappropriate

behaviors. Additionally, similar to the youth's ASD characteristics and behavioral risk, caregivers of youth who have expressed romantic interest or have not had prior sex education experiences report higher comfort discussing sexuality as it is deemed necessary for their youth's safety and development. Whereas caregivers of youth who have not expressed romantic interest or have received sex education may see discussions of sexuality as less necessary based on their youth's experience and already receiving some information about sexuality.

People and systems

Results from our analysis of caregiver comfort discussing sexuality with a variety of people/systems yielded results that support the need for multi-level interventions to support autistic youths' sexual development. Based on the descriptive statistics analysis, caregivers have the most comfort discussing sexuality with their child's primary care provider and the least comfort discussing sexuality with educators and people at their child's school. Caregivers on average also reported greater comfort discussing sexuality with their youth directly as compared to other members of the family. These findings suggest that caregivers are most comfortable supporting their youth's sexual development from a medical perspective and are less comfortable talking about it from an educational or social perspective. It is also noteworthy that caregivers reported feeling less comfortable talking to other members of the family about their youth's sexuality than with the youth directly; this could suggest that even within one family system that topics of sexuality are uncomfortable, unacceptable, or taboo. Taken together, these results show the need for multi-level and multi-system interventions to promote healthy psychosexual development for autistic youth as sexuality is impacted by several systems and impacts several domains of functioning. To ensure that youth's sexual development is being support,

interventions should be delivered to parents, broader family systems, and supported by sex education at school.

Clinical implications

The overall findings of this study have clinical implications for understanding the intersection of autism and sexuality. The main takeaway from this study for clinicians and care providers should be that no two autistic people have the same developmental experiences and symptomology. With this, clinicians should be sure to take their time to understand the person they are working with, get the individual's perspective on their symptoms and impact of ASD diagnosis, and be sure to ask about how ASD has impacted their sexuality and sexual development including their identity, experiences of victimization, and knowledge about sexual health.

Our findings also support that family system work should be considered when working with issues of ASD and sexuality given the impact that caregivers' comfort and knowledge has on their ability to support their youth's sexual development. Given the barriers to information about sexuality and increased risk factors for sexual victimization that autistic individuals face, clinicians should make sure to inquire about trauma, experiences, and goals related to sexuality when working with autistic individuals.

In addition to working with and inquiring about clients' family systems, clinicians should also be attuned to the various people and systems that impact individuals' sexual development. Our results highlight the importance of systemic intervention related to sexuality as it is impacted by and impacts several domains of functioning including emotions, cognition, relationships, physical health, and mental health. Clinicians should be assessing for impacts from several

domains and tailoring interventions to support third-order and multi-level change in clients' lives.

Strengths and limitations

There were several strengths and limitations to this investigation. The main limitation of this study is the small sample size and characteristics that limits the type of data analysis that can be conducted. Due to the small sample size and type of data, only descriptive analysis and visual inspection could be conducted. And these findings have limited external validity as our sample was eight participants and mostly homogenous. Our sample was entirely male youth with ASD with limited variety in race/ethnicity and other social factors. Due to this, our findings are potentially limited in their applicability to females with ASD, other races and ethnicities, and geographic locations. Additionally, the data was collected in 2006 which limits the external validity of our findings given the sociocultural changes that have occurred in the past 17 years related to sexuality, sex education, and acceptance of diversity.

In addition to the analysis limitations due to our sample, we were also limited as several of the measures used in our investigation have not been psychometrically validated. These measures were created and used for the original study this data comes from which also limits the validity of our data and findings. Lastly, it is known that caregiver reports are less accurate than self-report data from youth and this study utilized caregiver report and perspectives. Although the ASD symptomology and characteristic data came directly from observation of the youth from highly trained researchers, all of the sexuality related data and qualitative goals came from caregivers.

Although the above limitations constrain the study's applicability and validity, there are several strengths to this study. The main strength of our study is that it utilized mixed methods

design that analyzed both qualitative and quantitative data. Given the limitations on quantitative data analysis of our data, it is important that we also used thematic analysis of the qualitative caregiver goals to learn more about the intersection of ASD and sexuality and the needs of the caregivers of autistic youth. Secondly, our data analysis of factors impacting caregiver comfort included many diverse factors from characteristics related to ASD and youth functioning, to youth's experiences with peers, dating, and sex education. Although there are many other factors that could be investigated, the authors attempted to review as many factors as the data allowed. Lastly, a strength of our study design is that we used pre-intervention data from the original intervention study to examine what caregivers' goals and comfort is regarding sexuality prior to receiving an intervention. This time point was selected to try and reduce confounding factors that may impact caregiver comfort and to provide information that can be used to tailor future interventions related to ASD, sexuality, and family systems.

Future directions

Given the heterogeneity of our sample and findings, future research should focus on understanding the lived experiences of autistic individuals by examining what their needs are related to their sexuality development, access to sex education, and how to prevent sexual victimization. Research investigating the intersection of ASD and sexuality is already limited; further inquiry about interventions is needed to better understand how to tailor sexuality interventions that are accessible, effective, and holistic in support autistic youths' psychosexual development. Additionally, further exploration of factors that impact caregiver's comfort discussing sexuality is needed as our data was limited in the number of participants, what factors could be examined, and came from youth self-report rather than caregiver report. There may be several other factors that impact caregivers' comfort in the cognitive, emotional, and other areas

of social domains that we were unable to examine and/or detect in our analysis. Additionally, there may be specific caregiver factors and experiences characteristics that we were not able to examine with the scope of our data that may impact their comfort discussing sexuality that are unrelated to youth. Finally, future directions for research should focus on the efficacy and impact of multi-level interventions for support autistic youths' sexual development.

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APPENDIX: COPY OF STUDY MEASURES

Child Information Sheet

Child's Name:

Date of Birth:

Gender: M F

Ethnicity: __ African American __ Hispanic __ Asian __ Native American

__Caucasian __ Other

Your child's autism spectrum diagnosis:
__Autism __High-Functioning Autism __Asperger's Disorder __PDD-NOS

At what age was your child diagnosed?

What kind of educational program is your child attending? Grade:____ Not in school:____

___ Fully included classroom
___ Included with resource support
___ Segregated special education
___ Home schooled
___ Supported employment setting
___ Independent job
___ College program
___ Other: please explain

Parent(s)/Guardian(s) Name(s):

Address:

Home Phone:

Work Phone:

Is your child adopted or a foster child? No:____ Adopted:____
Yes:____ Foster Child:____

We are interested in learning a little bit about your child and his/her family. Please fill out all of the questions below.

Child Medical Information

Was your child born prematurely? Yes____ No____
If yes, how premature was your child?
Did your child ever lose language or motor skills? Yes____ No____

Has your child ever had genetic testing? Yes____ No____

Is yes, did your child test positive for any genetic disorders? Yes____ No____
What type of genetic testing was performed?
What were the results of the genetic testing?

Has your child ever had any 3D pictures taken of his/her brain, such as fMRI or CT scan?

Yes____ No____
If yes, please describe the results:

Does your child have a history of seizures? Yes____ No____

Does your child usually sleep through the night? Yes____ No____

Has your child had any significant head injuries? Yes____ No____
If yes, please describe:

Has your child had any significant illnesses (e.g., meningitis, encephalitis, etc.)? Yes___ No___
If yes, please describe:

Has your child been diagnosed with any other major medical conditions? Yes____No____
If yes, please describe:

Is your child currently taking any medications or vitamin therapies? Yes____ No____
If yes, please provide a list of medications and dosages:

Does your child have ongoing problems with either diarrhea or constipation? Yes __ No_

Is your child potty trained? Yes____ No____
If yes, if your child potty trained for: Daytime___ Nighttime___ Urinating___Bowel ___

Is your child on a restricted diet? Yes____ No____
If yes, which foods are restricted for your child?
Who restricted the diet? Parent___ Child___ Doctor___

Family Information
Please answer the following questions about the **mother of the child**.

Age:

Is she currently employed outside of the home? Yes____ No____
If yes, please list her occupation(s) and amount of time per week spent at each job.
Occupation (please be as specific as possible): Hours per week:

What is her highest level of education?
___ Some high school
___ High school graduate
___ 1-3 years of college (also business schools)
___ College graduate (B.A., B.S., etc.)
___ Some graduate training or terminal masters
___ Professional degree (lawyer, Ph.D, MD, etc.)

Please answer the following questions about the **father of the child**.

Age:

Is he currently employed outside of the home? Yes____ No____
If yes, please list his occupation(s) and amount of time per week spent at each job.
Occupation (please be as specific as possible): Hours per week:

What is his highest level of education?
___ Some high school
___ High school graduate
___ 1-3 years of college (also business schools)
___ College graduate (B.A., B.S., etc.)
___ Some graduate training or terminal masters
___ Professional degree (lawyer, Ph.D, MD, etc.)

Are the child's parents currently married? Yes____ No____
If yes, how long have they been married?
If no, are they ___ Never married to each other ___ Separated
___ Living together (how long?___) ___ Divorced ___ Widowed

If the parents are separated or divorced, who has legal custody of the child? _____

Behavioral Vulnerability Scale
Date:
Your Relation to the Child (circle one):

1. Mother
2. Father
3. Aunt or Uncle
4. Grandparent
5. Carer
6. Other_____

Instructions: The following questionnaire contains examples of everyday behavior which require social judgements. For each item, please rate the frequency with which s(he) engages in the behavior (or has engaged in the behavior in the past) by marking the appropriate column on the right.

To the best of your knowledge, how often…

1.	Has (s)he been tricked into telling secrets to other people	Never	Rarely	Sometimes	Often	Always
2.	Does (s)he believe what (s)he is told regardless of how reliable the source might be	Never	Rarely	Sometimes	Often	Always
3.	Does (s)he believe what (s)he is told regardless of whether that person has deceived him/her in the past	Never	Rarely	Sometimes	Often	Always
4.	Has (s)he been tricked into giving up objects of value to another person	Never	Rarely	Sometimes	Often	Always
5.	Does (s)he believe things that other people would view as clearly untrue	Never	Rarely	Sometimes	Often	Always
6.	Has (s)he given in to other children's suggestions to say something that would get him/her into trouble (e.g., an insult or obscene remark)	Never	Rarely	Sometimes	Often	Always
7.	Has (s)he been tricked into taking the blame for something that (s)he did not do	Never	Rarely	Sometimes	Often	Always
8.	Does (s)he believe many things that (s)he reads or sees in advertisements on the internet	Never	Rarely	Sometimes	Often	Always
9.	Has (s)he been talked into doing unreasonable favors for others even when there is little chance of repayment or reciprocation (e.g., homework, assignments)	Never	Rarely	Sometimes	Often	Always
10.	Has (s)he been taunted or insulted by other children to the point of distress	Never	Rarely	Sometimes	Often	Always

11.	Has (s)he been taken in by practical jokes or April fools jokes even when (s)he has been tricked by the same person before	Never	Rarely	Sometimes	Often	Always
12.	Is (s)he the victim of provocation by other children that results in her/him getting into trouble while the other child does not	Never	Rarely	Sometimes	Often	Always
13.	Has (s)he lent money or possessions to a person from whom repayment is unlikely e.g., someone (s)he hardly knows, or a person who has borrowed something in the past and never repaid it	Never	Rarely	Sometimes	Often	Always
14.	Has (s)he been deceived by someone who has deceived him/her before	Never	Rarely	Sometimes	Often	Always
15.	Has (s)he given in to other children's suggestions that (s)he do something that would get him/her into trouble (e.g., something irritating or offensive to another person, or against the rules)	Never	Rarely	Sometimes	Often	Always
16.	Has (s)he gone along with strangers' suggestions to get in a car with them or go somewhere with them	Never	Rarely	Sometimes	Often	Always
17.	Has (s)he been persuaded to let someone touch her/him in a way that is sexually inappropriate	Never	Rarely	Sometimes	Often	Always
18.	Does (s)he question things that (s)he is told	Never	Rarely	Sometimes	Often	Always
19.	Without a suggestion from another child, does (s)he get into trouble for saying or doing something because (s)he doesn't understand the social rules	Never	Rarely	Sometimes	Often	Always
20.	Does (s)he believe what another person tells him/her even when (s)he is aware that the person has lied in the past	Never	Rarely	Sometimes	Often	Always
21.	Has (s)he been tricked into buying another child's lunch or treats at a tuck shop	Never	Rarely	Sometimes	Often	Always
22.	Has (s)he been persuaded to …	Never	Rarely	Sometimes	Often	Always
23.	Has (s)he been suspicious of other people's motives	Never	Rarely	Sometimes	Often	Always
24.	Is (s)he easily fooled	Never	Rarely	Sometimes	Often	Always
25.	Does (s)he believe rumors even when they come from an unreliable source	Never	Rarely	Sometimes	Often	Always

Thank you!

Any additionally comments:

Youth Sexuality Development Scale

Date:

Please answer all of the following questions regarding your child's sexual development, behavior, experiences, and learning.

Privacy

1. Does your child know which body parts are private?
   Not at all
   Somewhat
   Yes

2. Does your child respect other people's privacy?
   Not at all
   Somewhat
   Yes

3. Does your child seek privacy (circle your answers):
   - While dress/undressing Never Rarely Sometimes Often Always
   - When bathing or showering Never Rarely Sometimes Often Always
   - While using the toilet Never Rarely Sometimes Often Always
   - While masturbating Never Rarely Sometimes Often Always DK
   - When they want to be alone. Never Rarely Sometimes Often Always

4. Does your child understand the following rules about privacy (circle your answer):
   - Touch own private body parts in private places only Not at all Somewhat Yes
   - Close the bathroom door Not at all Somewhat Yes
   - Undress in private Not at all Somewhat Yes
   - Undo pants only in the bathroom or bedroom Not at all Somewhat Yes
   - Don't walk around in the house nude Not at all Somewhat Yes
   - Knock on closed doors and wait to be asked to enter Not at all Somewhat Yes

5. How did you teach your child about rules concerning privacy? (check all that apply)
   ___ Modeled appropriate behavior
   ___ Providing instructions and directions
   ___ Repeating instructions
   ___ Parental discipline
   ___ Rewarding and reinforcing appropriate behaviors
   ___ Others:

Comments about privacy:

Behaviors

1. Has your child ever touched his/her private body parts in public?
   ___Never
   ___ Rarely
   ___ Sometimes
   ___ Often
   Comment:

2. Has your child ever masturbated in a public place?
   ___Never
   ___ Rarely
   ___ Sometimes
   ___ Often
   Comment:

3. Has your child ever masturbated with unusual objects (e.g., socks, food)?
   ___Never
   ___ Rarely
   ___ Sometimes
   ___ Often
   Specify Object:
   Comment:

4. Has your child ever refused to touch his or her private body parts (e.g., penis, vagina)?
   ___Never
   ___ Rarely
   ___ Sometimes
   ___ Often
   Comment:

5. Has your child ever intruded on another person's personal space e.g., stands too close)?
   ___Never
   ___ Rarely
   ___ Sometimes
   ___ Often
   Comment:

6. Has your child ever touched another person in an inappropriate way (e.g., attempted to hug or kiss, attempted to touch private body parts)?
   ___Never
   ___ Rarely
   ___ Sometimes
   ___ Often
   Comment:

7. Has your child ever removed his or her clothing in public when it was inappropriate to do so?
   ___Never
   ___ Rarely
   ___ Sometimes
   ___ Often
   Comment:
   If you answered yes, when was the last time your child removed his/her clothing in public? How old were they?

8. Has your child ever looked at internet porn sites?
   ___Never
   ___ Rarely
   ___ Sometimes
   ___ Often
   Comment:

9. Does your child talk about sexuality and sexual activities in a way that is not appropriate for youth his/her age?
   ___Never
   ___ Rarely
   ___ Sometimes
   ___ Often
   Comment:

10. Has your child ever acted in an inappropriate way towards someone whom they were romantically interested (e.g., called them too frequently, followed them around school)?
   ___Never
   ___ Rarely
   ___ Sometimes
   ___ Often
   ___ Has not been romantically interested in anyone
   Specify behavior:
   Comment:

11. Has your child developed sexual obsessions (e.g., sexuality has become the sole source of interest and stimulation such as: obsessed with idea of having sex, obsessed with having a girlfriend, compulsive masturbation, repetitive fantasies)?
   ___Never
   ___ Rarely
   ___ Sometimes
   ___ Often
   Specify obsession:
   Comment:

12. Other challenge behaviors not mentioned here?

___ Rarely
___ Sometimes
___ Often
Specify behavior:
Comment:

Education

1. Has your child received any type of sexuality education?
   ___ No
   ___ Yes
   Comment:

2. If you answered YES, from whom has your child received sexuality education?
   ___ from you
   ___ at school
   ___ from another family member
   ___ through pictures, videos, reading books
   ___ from peers, classmates, and friends
   ___ in a therapeutic context (e.g., from a counselor)
   Comment:

3. What this beneficial for your son or daughter?
   1 2 3 4 5
   Not at all Very beneficial

4. Will you let your child participate in the sexuality education programming through your child's school?
   ___ Yes, my child participated already
   ___ Yes, I will let my child participate when the time arises
   ___ No, I opted out of this program for my child
   ___ No, I will not let my child participate when the time arises
   ___ My child's school does not have sexuality education programming
   Comment:

5. Would your child benefit from appropriate sexuality education?
   1 2 3 4 5
   Not at all Yes, absolutely
   Comment:

Experience

1. Has your child expressed a romantic interest in anyone (e.g., said a girl is cute)?
   ___ Never

___ Rarely
___ Sometimes
___ Often

Comment:

2. Has your child gone on a date? (e.g., to a movie, to prom)?
   ___ Too young to do so
   ___ Never
   ___ Rarely
   ___ Sometimes
   ___ Often

   Comment:

3. Has your child had a girlfriend/boyfriend (i.e., someone whom they have dated more than 5 times)?
   ___ Too young to do so
   ___ Never
   ___ Rarely
   ___ Sometimes
   ___ Often

   Comment:

4. Has your child expressed confusion or conflict about their gender identity (e.g., belonging to the female or male sex)?
   ___ Never
   ___ Rarely
   ___ Sometimes
   ___ Often

   Comment:

5. Has your child expressed a romantic interest in individuals of the same sex?
   ___ Never
   ___ Rarely
   ___ Sometimes
   ___ Often

   Comment:

6. As part of healthy development, has your child had a complete physical examination by a doctor of their sexual body parts?
   ___ Not yet but planning to
   ___ No
   ___ Yes

   If you answered YES, or PLANNING TO, how did you/will you prepare your child for this appointment?

7. Other experiences not mentioned here?

___ Rarely
___ Sometimes
___ Often

Specify experience:
Comment:

Growing Up

1. Has your child every expressed fear, worry, anxiety, nervousness about growing up?
   ___ Never
   ___ Rarely
   ___ Sometimes
   ___ Often
   ___ Always

2. Has your child expressed a strong desire to NOT grow up?
   ___ Never
   ___ Rarely
   ___ Sometimes
   ___ Often
   ___ Always

3. Has your child expressed fear/worry/concern about pubertal changes?
   ___ Never
   ___ Rarely
   ___ Sometimes
   ___ Often
   ___ Always
   ___ Has not yet undergone pubertal changes

   Concerned about what pubertal changes:

4. What are your child's fears/worries about growing up?
   1. _____
   2. _____
   3. _____
   4. _____
   5. _____

   Comments about growing up:

Bullying

1. Has your child *ever* experienced sexual *bullying* such as (please check):
   ___ being "flashed" or "mooned"
   ___ having sexual rumors spread about him/her

___ being teased about sexual orientation
___ being taunted or teased about sexual body parts (e.g., “hey, nice boobs”)
___ lewd and sexual gestures or looks (e.g., making a masturbating gesture)
___ sexual comments or jokes
___ receiving phone calls of a sexual nature
___ being passed unwanted notes, messages, photographs, or pictures about sex
___ being called “fag”, “homo”, “dyke”, “queer”, “gay”, “lesbo”
___ having their clothes pulled at in a sexual way
___ being teased about their attractiveness (e.g., “you’re fat and ugly”)
___ being brushed up against in a sexual way
___ being touched, grabbed, or pinched in a physically intrusive sexual way
___ being forced to kiss a peer
___ being forced by a peer to do something sexual other than kissing
___ being spied on while dressing or showering at school
___ having sexual messages/graffiti written about them on bathroom walls, the locker room, etc.
___ Other:

2. If you answers YES to any of the above, how frequently does the sexual bullying occur:
   ___ once a month or less
   ___ a few times a month
   ___ once a week
   ___ a few times a week
   ___ almost every day

3. If you answered YES to the above questions about sexual bullying, have you tried to address these issues with your child’s school?
   ___ no
   ___ yes
   ___ not yet, but planning to

4. If you talked with your child’s school, how have they handled the issue of sexual bullying?
   1 2 3 4 5
   Handled very poorly Handled very well
   Comments about bullying:

Knowledge

Sexuality education involves teaching about a number of different important concepts and skills. Does your child know/understand about the following (check the appropriate box):

	0 does not understand this	**1**	**2**	**3**	**4**	**5**	**N/A**	**Don't know**
Functions of sexual body parts								
Physical changes that occur during puberty								
Sexual intercourse								
Human reproduction (e.g., conception, pregnancy, birth)								
Birth control								
Being attracted to someone								
Sexual impulses and sexual feelings								
Orgasm								
Masturbation as sexual release								
Acceptable and unacceptable touch								
Private body parts								
Concept of self-protection								
Understanding of a safety plan (e.g., who to talk to)								
Right to say "no" and setting sexual limits								
Potentially dangerous situations								
Sexual abuse								
Sexual harassment								
Date rape								
Personal hygiene								
Menstrual hygiene								
Sexually transmitted infections								
Romantic love								
Awareness of different relationships (e.g., dating, boy/girlfriends, marriage)								
Awareness of different sexual choices/lifestyles								
Awareness of deviant behavior as defined by society								

	0 does not understand this	**1**	**2**	**3**	**4**	**5**	**N/A**	**Don't know**
Sexual responsibility								
What to do if he or she is thinking about having sexual intercourse								
Media portrayals of sexuality								
Your family values about premarital sex								
Your religion's views of sexuality								
Important qualities in a romantic partner								
The kind of relationship he/she should have before having sex								
Body image								
Sexual fantasies								
Gender roles								

Comments:

Parenting and Sexuality Scale
Date:

Listed below are a number of statements. Please respond to each item indicating your agreement or disagreement with each statement in the following manner:

1 = Not true at all
2 = Mostly not true
3 = Somewhat true
4 = Mostly true
5 = Very true

1.	I am accepting of my child as a sexual person.	1	2	3	4	5
2.	I have all of the skills I need to address sexuality issues with my child as they arise.	1	2	3	4	5
3.	I worry about my child's sexual development.	1	2	3	4	5
4.	I use effective teaching methods appropriate for my child's learning style when teaching my child about sexuality.	1	2	3	4	5
5.	I do not feel competent as a sexual educator for my child.	1	2	3	4	5
6.	I have the knowledge I need about anatomy, physiology, biology, etc., if my child were to ask me a question about one of these topics.	1	2	3	4	5
7.	I am comfortable talking with child about sexuality	1	2	3	4	5
8.	I have developed a plan for my child's sexual learning.	1	2	3	4	5
9.	I am able to research information to help me better understand my child's sexual development.	1	2	3	4	5
10.	I feel confident in my ability to help my child grow and develop in their sexuality.	1	2	3	4	5
11.	I have a good understanding of typical sexual development during puberty and adolescence.	1	2	3	4	5
12.	Thinking about my child as a sexual person makes me tense and anxious.	1	2	3	4	5
13.	I am accepting of my child exploring his/her sexuality in a socially appropriate manner.	1	2	3	4	5
14.	I feel that it is acceptable and natural for my child to masturbate.	1	2	3	4	5
15.	I am experienced in teaching my child about sexuality.	1	2	3	4	5
16.	I do not feel able to advocate for my child around issues related to his/her sexuality.	1	2	3	4	5
17.	I have good judgement about protecting my child but also enabling sexual learning experiences.	1	2	3	4	5

18.	I am too worried about my child to be hopeful about their sexual learning and development.	1	2	3	4	5
19.	I am able to handle problems that arise with my child's sexual behavior/development.	1	2	3	4	5
20.	I know what resources are available to help me with teaching my child about sexuality, puberty, and growing up.	1	2	3	4	5
21.	I am anxious about my child's sexual behavior when he/she is not supervised	1	2	3	4	5
22.	I would feel comfortable taking about my child's sexuality/sexual behavior with his/her teacher if concerns arose at school.	1	2	3	4	5
23.	I am able to communicate effectively with my child about sexuality and puberty.	1	2	3	4	5
24.	I worry that my child will be abused.	1	2	3	4	5
25.	When I think about sexuality and my child, I focus on all the bad things that can happen.	1	2	3	4	5
26.	I have talked with my child's doctor about my child's sexual development.	1	2	3	4	5
27.	I have had direct experience with other youth going through adolescence and sexual development.	1	2	3	4	5
28.	I am aware of the sexuality issues related to my child's disorder.	1	2	3	4	5
29.	I feel awkward watching movies or television programs with my child that have sexual content.	1	2	3	4	5
30.	I am able to make good decisions about what my child needs with respect to his/her sexual learning.	1	2	3	4	5
31.	I have learned what I need to know to help foster my child's sexual development and learning.	1	2	3	4	5
32.	I would like my child to ask me questions about sexuality and growing up.	1	2	3	4	5
33.	I want my child to have a sexual relationship when they are ready and if they choose to.	1	2	3	4	5
34.	Addressing issues related to my child's sexual development with his/her doctor makes me feel uncomfortable.	1	2	3	4	5
35.	I feel very inexperienced with regards to addressing my child's sexual development.	1	2	3	4	5

I am ready to start addressing issues related to sexuality with my child

0 1 2 3 4 5 6 7 8 9 10

Not at all ready Completely Ready

Any additional comments:

Comfort Ratings

My level of comfort in discussing the topic of sexuality and my child ***during this group*** is currently:

1	2	3	4	5	6	7	8	9	10
Very low I'm not comfortable at all									Very high I'm as comfortable as I need to be.

My level of comfort in discussing the topic of sexuality and my child ***with members of my family*** is currently:

1	2	3	4	5	6	7	8	9	10
Very low I'm not comfortable at all									Very high I'm as comfortable as I need to be.

My level of comfort in discussing the topic of sexuality and my child ***with individuals are my child's school*** is currently:

1	2	3	4	5	6	7	8	9	10
Very low I'm not comfortable at all									Very high I'm as comfortable as I need to be.

My level of comfort in discussing the topic of sexuality and my child ***with my child's PCP or health care provider*** is currently:

1	2	3	4	5	6	7	8	9	10
Very low I'm not comfortable at all									Very high I'm as comfortable as I need to be.

My level of comfort in ***talking with my child*** about issues related to sexuality/puberty is currently:

1	2	3	4	5	6	7	8	9	10
Very low I'm not comfortable at all									Very high I'm as comfortable as I need to be.

Parent Group Goal Attainment Scale

Setting Goals: Pre-Group

Select 2 SPECIFIC, MEASURABLE goals which you feel are attainable during the course of the group (8-10 weeks). These may be personal goals, or goals related to your child, family, child's school, or health care providers. Attainment of your goals will be measured during your post-group assessment appointment.

Goal 1:

_____

_____

_____

_____

Current Level of Goal Attainment:

0 1 2 3 4 5

None Complete Success

Goal 2:

_____

_____

_____

_____

Current Level of Goal Attainment:

0 1 2 3 4 5

None Complete Success