



Family Sexuality Communication for Adolescent Girls on the Autism Spectrum

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Abstract

Families are critical for supporting healthy sexuality and relationship development for youth with autism. The objective of this study was to describe family sexuality communication for adolescent girls with autism. Participants were 141 parents of autistic daughters who completed an online survey about sexuality development. Most parents relied on discussion alone rather than visual supports or skills-based teaching techniques. Intellectual functioning, child age, race/ethnicity, and whether youth expressed sexual interest in others affected family sexuality communication. We discuss how most parents covered important basics, but many did not cover more nuanced relationship or sexual health topics during family sexuality communication. Few used enhanced instructional techniques (e.g., visual supports, social stories), suggesting potential utilization barriers such as a lack of affordable and available resources. There is a need for research accounting for diverse racial/ethnic backgrounds, sexual orientations including asexuality/demisexuality, and for transgender and gender diverse youth.

Keywords Females · Gender · Transition · Sexuality and sexual health · Puberty · Relationships

Sexual and reproductive health are foundational in the transition to adulthood and affect lifetime physical and mental health trajectories. Most young people with autism experience sexual attraction and engage in romantic relationships (May et al. 2017). Intimate relationships are associated with positive health and mental health benefits and are an important part of the transition to adulthood—whether or not a person has opportunities to engage in them (Jobe and White 2007; Strunz et al. 2017). Developing safe and healthy sexual relationships is not always easy for teens, and youth with autism are at higher risk for some negative sexual health outcomes, including abuse and sexual exploitation (Brown-Lavoie et al. 2014; Fernandes et al. 2016; Mandell et al. 2005; Normand and Sallafranke-St-Louis 2016). This may be due to a combination of autism-related social communication impairments (e.g., difficulty recognizing red flags or verbally reporting inappropriate or abusive behavior) and societal attitudes that stereotype people with disabilities as

childlike or asexual, leading to underdevelopment of targeted, proactive sexuality healthcare and education services.

Along with access to appropriate services, knowledge is the foundation for sexual and reproductive health and healthy romantic relationships. Young people learn about sexuality and romantic relationships from their social networks, with family as primary context for learning information and values (both directly and indirectly) during childhood. Parents engage in family sexuality communication (FSC) based on youth maturity (social, cognitive, emotional, physical), perceived needs (e.g., understanding menstruation for girls), and a youth's interest or engagement in sexual or romantic relationships (Beckett et al. 2010). Understanding FSC in families raising daughters with disabilities such as autism is an important step toward adapting existing evidence-based prevention programs for these youth (Ballan and Freyer 2017; Corona et al. 2016; McKleroy et al. 2006; Wolfe et al. 2009).

Research on FSC for adolescents with autism has focused on how child factors (e.g., child age, intellectual functioning, autism symptoms) and parent factors (e.g., expectations, concerns) affect the sexuality-related topics that parents discuss with their child, but has often not meaningfully incorporated gender into these analyses (Holmes and Himle 2014; Holmes et al. 2016a, b). In a national sample of 198 parents

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of teens with ASD (86.8% male), the number of topics parents reported having discussed with youth was used as a proxy for comprehensiveness of FSC. FSC was affected by autism symptoms and intellectual functioning (IF), with IF groups derived from parent-reported IQ scores or estimates of youth as falling into standardized descriptive categories (i.e., above average IQ is 116 or higher, average IQ ranges from 85 to 115, below average IQ is below 85). Parents discussed more topics with youth whom they rated as having less impaired social cognition and motivation, and with youth who had average or above average IF compared to those with below average IF. Furthermore, parents of youth with average or above IF discussed more topics with older children, which was not the case for youth with below average IF, suggesting a plateau for these less cognitively able youth. However, below average IF in this sample ranged from borderline (i.e., IQ between 70 and 85) to profoundly impaired, making it difficult to draw conclusions about FSC for this group. Another limitation of this research was the focus on autism-specific characteristics (e.g., social communication skills) and intellectual functioning while excluding well-established FSC constructs such as a youth's expressed interest in sexual relationships (Beckett et al. 2010). Parents of neurotypical youth time FSC to coincide with youth interest in relationships and their engagement in dating and partnered sexual behavior (Beckett et al. 2010). Given the diversity of sexual attraction patterns for people with autism (Gilmour et al. 2012; May et al. 2017; Rudolph et al. 2018) and the greater complexity parents may face as they attempt to align FSC with their child's developmental needs, a teen's expression of interest in sexuality and relationships may be an important driver of FSC for families raising daughters with autism.

The techniques parents use to talk about sex and relationships are potentially as important as the content they cover. Youth with autism often benefit from the use of targeted or enhanced instructional strategies beyond discussion when learning new information or skills (Bellini and Akullian 2007; Gray and Garand 1993; Matson et al. 2012; Qi et al. 2015; Quill 1997; Shukla-Mehta et al. 2009). For example, Wolfe et al. (2009) have described how applications of applied behavior analysis (e.g., video modeling, visual cues, social stories, social script fading, task analysis, peer tutoring) can be used to teach youth with autism about sexuality and relationships. Strategies range from lower effort (e.g., written conversation topics for dates, calendar to track menstrual cycle) to more intensive (e.g., task analysis for proper condom application, video modeling and rehearsal for self-advocacy when sexual contact is unwanted). Enhanced instructional techniques may include visual support strategies (e.g., pictures, books, pamphlets, videos) to enhance discussion, or skills-based teaching strategies (e.g., video modeling, imitation and role-play, rehearsal, or social

stories) that target youth development of specific skills. Educators and healthcare providers often guide parents to use evidence-based strategies such as token economies at home to shape youth behavior in other domains (Matson and Boisjoli 2009), and many educational curricula incorporate worksheets and visual support strategies (Davies and Dubie 2012). Parents' use of these same strategies to enhance FSC is likely to be an important predictor of efficacy, yet there is currently no information about use of such practices for families raising youth with autism.

Based on recent autism prevalence rates for 8-year-old and 12- to 17-year-old children and estimates of the number of 17-year-olds in the U.S., we estimate that between 70,700 to 111,600 transition-aged youth with autism turn 18 each year (Centers for Disease Control 2018; U.S.; Census Bureau 2016), at least one-quarter of whom are girls. Despite this, we know very little about the experiences of girls and women with autism and their families. The need for more knowledge about the development, characteristics, and needs of women and girls on the spectrum was recently highlighted by Autism Speaks and the Autism Science Foundation (Halladay et al. 2015), who made note of the very limited research on sexuality and relationships. This is a critical research gap because girls and women have different sexual and reproductive health needs than do boys and men, and those needs must be understood and addressed via services and interventions in order to promote lifespan health and well-being.

To date, little research has specifically investigated FSC patterns for girls on the spectrum despite the fact that there are well-established gender differences in FSC for non-autistic youth. In general, in the United States, parents (primarily mothers) communicate more often and provide more information about sex with daughters than sons (DiIorio et al. 1999; Dilorio et al. 2006; Feldman and Rosenthal 2000; Nolin and Petersen 1992; Omar et al. 2003; Pluhar et al. 2008), starting when children are as young as 3–6 years old (Martin and Luke 2010). Mothers discuss sexuality-related risks more for girls compared to boys, including sexually transmitted infections (STIs), contraception (Raffaelli et al. 1998; Regnerus 2005) and sexual assault—although only about one-quarter of girls report that parents talked to them about sexual assault (Omar et al. 2003). Parents are more likely to discuss dating and relationships and moral values about sexual contact that might occur within adolescent relationships with daughters than sons (Jaccard and Dittus 1991; Nolin and Petersen 1992; Raffaelli et al. 1998; Raffaelli and Green 2003; Regnerus 2005). If this research extends to families raising children with autism, there are likely to be important differences in how parents of adolescent girls and boys engage in FSC. Previous research suggesting that parents of boys with autism delay talking about important relationship and sexual health topics compared to

parents of neurotypical youth may be finding gender rather than autism-specific differences (Holmes and Himle 2014; Holmes et al. 2016a). Additionally, developing educational and intervention strategies based on research with parents of boys with autism alone and expecting them to generalize to girls may not be effective as some topics may need more emphasis for girls compared to boys. Notably, women with autism have expressed the need for interventions supporting healthy relationships and avoiding more subtle forms of abuse (e.g., emotional abuse, coerced sexual consent; Barnett and Maticka-Tyndale 2015). Women with autism are also especially likely to experience same-sex attraction and diverse gender identities (Dewinter et al. 2017; George and Stokes 2017; Gilmour et al. 2012; Rudolph et al. 2018; Vermaat et al. 2018), which are topics of FSC for which parents may especially benefit from support to cover effectively.

The aims for this project are as follows: (1) Describe family sexuality communication in families of adolescent girls with autism, including techniques used to instruct. (2) Examine how child age, cognitive and social functioning, and interest in relationships are related to number of sex and relationships topics covered. (3) Examine how parent demographics and social cognitive variables (e.g., self-efficacy, preparedness to manage sexual development) are related to number of sex and relationships topics covered. Results will address a gap in the literature by describing how families support healthy sexuality development for girls with autism. Examining parent and child variables associated with FSC will inform clinicians as they work with families to support healthy development and the transition to adulthood,

suggesting which families may be struggling most and in need of guidance.

Method

Participants

We recruited 150 parents of female teens with autism. Of those, 25 parents were recruited through local and national parent support groups as part of a larger project on FSC and autism and were included in previously reported analyses with a larger gender-combined sample (Holmes and Himle 2014; Holmes et al. 2016a, b; Holmes et al. 2018). An additional 125 participants were recruited through the Interactive Autism Network (IAN; Daniels et al. 2011) and the Children's Hospital of Philadelphia Center for Autism Research participant registries. Parents were eligible to participate if they self-reported having an adolescent daughter (ages 12–18 years) with an autism spectrum disorder diagnosis that had been conferred by a healthcare professional (i.e., a physician, pediatrician, psychiatrist, or psychologist). Three parents did not provide adequate data and were not included in analyses. Autism symptoms were measured using the Social Responsiveness Scale—2nd edition (SRS-2, see below). Those who fell just below the SRS-2 threshold for mild symptom impairment ($n = 2$ from original cohort and $n = 5$ from the second cohort) were also excluded from analyses. The final sample consisted of 141 participants. Parent and youth demographic information is provided in Table 1.

Table 1 Youth and parent characteristics by intellectual functioning groups

	Parent-reported intellectual functioning			
	Below 70 ($n = 37$)	Borderline ($n = 16$)	Average ($n = 44$)	Above Average ($n = 44$)
<i>Youth and parent characteristics M (SD)</i>				
Youth age	13.9 (1.8)	14.0 (1.8)	14.5 (1.9)	14.5 (1.7)
Parent age	46.1 (7.3)	45.4 (7.0)	48.0 (6.5)	46.9 (5.2)
SRS-2 T score	87.9 (9.6)**	82.6 (10.3)	80.3 (8.4)	80.6 (11.8)
SRS-2 Social Communication Index T score	86.2 (9.3)**	81.3 (10.1)	79.9 (8.3)	79.3 (11.4)
SRS-2 Restricted and Repetitive Behaviors Index T score	89.5 (10.7)**	82.4 (12.3)	77.6 (11.9)	81.4 (14.1)
Teen has shown or expressed sexual attraction to others (%)	38.2***	85.7	72.1	79.5
<i>Household demographics %</i>				
Parent identifies as female	88.9	100.0	90.9	95.5
Parent cohabitating or married	86.1	100.0	79.5	77.3
Parent identifies as White	81.1	100.0	88.6	86.4
Parent income below US median (\$59,999)	25.0	25.0	40.9	31.8
Highest level of parent education is college degree or higher	70.3	75.0	56.8	79.5
Moderately or very religious	48.6	31.3	52.3	47.7

Cells report percentages and tests of significance versus Average IF Group: * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$

Parents were predominantly White and not Hispanic/Latinx (88.5%) and female (92.9%), with a median age of 47 years ($M = 46.85$, $SD = 6.40$, range 30–66). Parents identified their race/ethnicity as multiracial (4.3%), Hispanic (2.9%), Black or African American (2.2%), American Indian or Alaskan Native (1.4%), or Asian (0.7%). Most parents reported that they were married or cohabiting (80.8%) and most lived in a suburban setting (70.0%), with 17.1% in urban and 12.9% in rural locales. Most (69.5%) had a Bachelor's degree or higher, and 67.9% reported a household income above the U.S. median of 59,000 (Fontenot et al. 2018). Across all recruitment sources, 38.3% of parents actively participated in a support group for parents of youth with autism. Parents reported on adolescents who were predominantly White and not Hispanic/Latino (79.1%) with a median age of 14 years ($M = 14.27$, $SD = 1.78$, range 12–18). Parents identified youth race/ethnicity as multiracial (7.9%), American Indian or Alaskan Native (5.8%), Hispanic (3.6%), Asian (2.2%), or Black/African American (1.4%). Youth were diagnosed with autism (42.5%), Asperger's (36.9%), pervasive developmental disorder not otherwise specified (10.6%), or indicated a combination of these (9.2%), with a mean age of diagnosis at 7.88 years ($SD = 3.49$). Parents were asked to report their child's measured IQ (if known, 82.3%, $n = 116$) or to provide an estimated IQ ($n = 25$). On the first question, IQ was presented as both standard scores and official descriptive guidelines (e.g., average, slightly below average or borderline, profound intellectual disability/mental retardation; American Psychiatric Association 2000). It was expected that some parents would not know their child's IQ score, and thus parents who indicated "I don't know" on the first question were asked to estimate their child's overall level of intellectual functioning based on official descriptive guidelines. Per parent report, 62.4% of the adolescents fell in the average or above average range ($IQ = 86$ – 116), 11.3% had slightly below average or borderline IQ (71–85), 14.2% had below average IQ or mild intellectual disability (56–70), 8.5% had far below average IQ or moderate intellectual disability (41–55), and 3.5% had severe or profound intellectual disability ($IQ \leq 40$). Most adolescents attended public school (60.7%) or a therapeutic school (15.7%), and 97.9% of adolescents lived at home with their parents at the time of the study. According to parent report, almost all youth (97.9%) had at least begun to show signs of puberty.

Procedures

This study was approved by the authors' Institutional Review Board. Informed consent was obtained from all individual participants included in the study. Participants completed an anonymous online survey about autism and family sexuality communication. In the first cohort ($n = 25$), parents who

completed the survey were entered into a raffle for ten \$40 gift cards and received a list of resources about autism and sexuality. In the second cohort ($n = 125$), which specifically recruited parents of daughters, participants received a \$10 gift card and resources.

Measures

Online Sexuality Survey

Participants completed a 50-item survey that included questions about parent and child demographics and completed the Parent Sex Education Inventory (PSEI) about family sexuality communication (Holmes and Himle 2014). In addition to parent and child gender and race/ethnicity, participants were asked to indicate how religious they were on a 4-point ordinal scale (1 = "Not religious" to 4 = "Highly religious"). Participants also rated how effectively they could communicate with their child about sexuality on a 5-point Likert-type scale (1 = "Not at all" to 5 = "Very effectively") and about how prepared they felt to address sexuality development for their child (1 = "Not at all" to 5 = "Very prepared"). Finally, participants answered questions about child sexual interests and behaviors, including whether youth had "expressed interest in a relationship (e.g., dating, marriage, children)" and "shown or expressed sexual attraction to someone of the same/other sex" (yes/no/not sure). Overall, 64.5% had shown or expressed attraction to someone of the same or other sex (61.7% to other sex, 16.3% to same sex, and 13.5% to both sexes).

Parent Sex Education Inventory

Participants completed the PSEI by indicating which, if any, techniques they used to cover 39 sexuality-related topics. Participants could indicate that they covered topics through use of discussion, visual supports (e.g., pictures, books, pamphlets, videos), and skills-based teaching techniques (e.g., video modeling, social stories, imitation and role-play, rehearsal). Two topics previously included on the PSEI (symptoms of STIs, sexual slang words people might use; Holmes and Himle 2014) were not presented to all participants in the current study and thus were not included in analyses. PSEI topics included sexual abuse prevention, physical development and reproduction, pregnancy and STI prevention, sexual decision-making, relationships, consent and coercion, and sexual health. The PSEI was adapted from previous research with youth with (Ballan 2012; Koller 2000; Nichols and Blakeley-Smith 2010; Travers and Tincani 2010; Wolfe et al. 2009) and without autism (Beckett et al. 2010). Responses were summed to create an indicator of number of sexuality topics covered (total NTC) for each participant, with higher scores indicating more topics

covered (range 0–37). Indicators were created for the number of topics covered with talking alone (range 0–33), with visual supports (range 0–32), and with skills-based teaching (range 0–37).

Social Responsiveness Scale—2nd Edition (Parent report) (SRS-2)

The SRS-2 is a 65-item rating scale intended to measure autism spectrum disorder symptom severity with an emphasis on social impairment (Constantino and Gruber 2012). The total T-Score indicates overall symptom severity and impairment, while subscale T-Scores indicate specific symptom severity (i.e., Social Motivation, Social Cognition, Social Awareness, Social Communication, and Restricted and Repetitive Behavior). The Social Communication Index T-Score combines the four social subscales, while the Restricted and Repetitive Behavior Index T-Score indicates severity of repetitive symptoms. The measure has well-established psychometric properties (Constantino and Gruber 2012). SRS-2 Total T-Scores ranged from 60 to 107 ($M = 82.6$, $SD = 10.49$), which is consistent with a diagnosis of autism. Social Communication Index T-Scores ranged from 57 to 106 ($M = 81.46$, $SD = 10.09$) and Restricted and Repetitive Behaviors Index T-Scores ranged from 52 to 106 ($M = 82.41$, $SD = 13.10$). For Total T-Scores, most youth (74.3%) fell within the “Severe” range, with others falling within the “Moderate” range (18.6%), or “Mild” range (7.1%).

Analytic Plan

Analyses were conducted using SPSS Version 24. Less than 5% of data was missing across and within variables, and missing data were addressed using listwise deletion. Prior to conducting analyses, all variables were inspected for distribution and outliers.

Previous research on activities that support adolescent and adult development for transition-aged youth with autism showed that intellectual functioning (IF) was important in understanding parent practices and youth trajectories (Holmes et al. 2018). IF is an important component of how parents develop expectations for the future, and affects how parents talk to youth about topics like employment and the activities in which youth are engaged to support successful transition (Holmes et al. 2018). Some descriptive information is presented for two traditional IF groups: average or above average IF versus borderline and below 70 IF. We used this grouping in order to support comparison to previous samples composed primarily of male youth with autism (Holmes and Himle 2014). However, going beyond the traditional “high versus low” functioning dichotomy when conceptualizing intellectual functioning has yielded

insights about youth with intellectual impairments who do not qualify for an intellectual disability diagnosis—a group especially at risk for being denied services (Ferrari 2009). Based on this, we conducted analyses with the sample split into four groups based on parent-reported or estimated IQ: Above average IF, Average IF, Borderline IF, and IF < 70. A question about whether youth had “shown or expressed sexual attraction to others” was used because this was deemed to be less confounded by verbal ability compared to a similar question (“expressed interest in relationships”).

Results

Demographics by Intellectual Functioning (IF) Group

Demographic information by IF Group is presented in Table 1. Univariate analyses of variance (ANOVAs) were used to test for mean differences on continuous variables and Pearson Chi-Square tests were used to test for group differences on nominal variables. The groups did not differ in terms of parent or child age, parent relationship status, household income, race/ethnicity (White versus non-White), parent level of education, or parent religiosity. Youth in the IF < 70 Group had higher (more impaired) SRS-2 Total T-Scores and Social Communication and Restricted/Repetitive Behaviors Index T-Scores. Additionally, parents of daughters in the IF < 70 Group were less likely to report that their child had shown or expressed sexual attraction to someone of the same or other sex compared to the other groups.

Family Sexuality Communication Practices by IF Group

To describe FSC practices for families raising daughters with autism, we present the percentages of parents who reported having covered each topic in two groups: an Average and Above Average IF Group and a Borderline and IF < 70 Group (Table 2). Additionally, the total percentages of parents who reported that they covered topics with talking alone, with visual supports, and with skills-based teaching (parents could endorse all that applied) are presented.

Differences in Mean Number of Topics Covered (NTC) by IF Group

To determine whether IF Groups differed on mean total NTC, we conducted an ANOVA (Table 3). There was a main effect of IF Group on mean NTC ($F(3, 139) = 21.69$, $p < 0.001$, $\eta_p^2 = 0.324$), with post-hoc contrasts indicating

Table 2 Percentage of parents who endorsed covering Parent Sex Education Inventory topics and use of instructional techniques

	Total covered (%)		Instructional techniques (%)		
	Average/ Above IF	Border- line/<70 IF	Talking alone	Visual supports ^a	Skills-based teaching ^b
<i>Privacy</i>					
Privacy (e.g., knocking before entering rooms, undressing in private)	98.9	88.7	69.5	11.3	18.4
Private body parts	97.7	92.5	54.6	37.6	12.1
Public and private discussion topics	94.3	74.5	68.3	10.1	11.5
<i>Sexual abuse prevention/consent</i>					
What kinds of touch are okay/not okay	93.2	81.1	60.3	24.1	10.6
How to report sexual abuse	77.3	42.3	53.6	8.6	5.0
How to say no if someone wants to have sex and your child does not	62.5	28.3	39.0	7.1	5.7
The importance of not pressuring other people to have sex	43.2	15.1	25.5	5.0	2.8
<i>Puberty/reproduction</i>					
How girls' bodies change physically as they grow up	95.5	84.6	40.7	47.9	12.9
Menstruation (menstrual periods)	95.4	88.7	36.4	49.3	18.6
Hygiene (e.g., washing genitals)	94.3	98.1	56.0	5.8	22.0
How women get pregnant and have babies	86.4	37.7	31.9	33.3	5.7
How boys' bodies change physically as they grow up	76.1	25.0	33.6	22.9	2.1
Wet dreams	26.7	5.8	12.3	27.7	0.7
<i>Relationships</i>					
What qualities are important in choosing close friends	92.0	56.6	48.9	20.6	20.6
Family types and roles	77.3	41.5	52.5	9.2	4.3
Parenting	75.0	34.0	49.6	7.1	5.0
Dating and marriage	73.9	37.7	51.8	7.8	2.1
How your child will make decisions about whether to have sex	61.4	17.0	34.0	9.2	2.1
How to deal with romantic rejection	43.2	17.0	29.8	2.8	1.4
How your child will know whether s/he is in love	41.4	22.6	29.3	4.3	1.4
How to ask someone out on a date	27.3	9.4	15.6	4.3	2.8
<i>Sexual health/prevention</i>					
Consequences of getting pregnant/getting someone pregnant	81.8	24.5	41.1	15.6	7.1
Reasons why your child should not have sex	73.9	24.5	41.1	12.1	3.5
How well birth control can prevent pregnancy	62.1	22.6	29.3	15.7	4.3
How people can prevent getting STIs	60.9	15.1	28.6	13.6	3.6
The necessity of regular exams by themselves/with doctors (e.g., Pap, breast and testes exams)	54.0	28.3	33.6	9.3	3.6
How well condoms prevent STDs	37.5	11.5	14.3	10.7	4.3
How to choose a method of birth control	24.1	7.5	12.9	2.9	2.9
How to use a condom	23.0	15.1	11.4	6.4	2.9
Symptoms of STIs ^c	17.3	5.1	7.0	6.1	0.9
What to do if a partner doesn't want to use a condom	13.6	9.4	9.2	0.7	2.1
<i>Sexuality</i>					
Homosexuality/people being gay	84.1	35.8	55.3	9.9	3.5
Masturbation (e.g., is it okay? When/where it is appropriate)	62.5	46.2	41.4	12.9	2.9
Reasons why people like to have sex	59.1	17.0	33.3	8.5	2.1
Sexuality as a positive aspect of self	54.5	17.0	31.9	7.8	2.1
Sexual slang terms that people might use ^d	53.3	18.2	28.8	5.8	3.8
Sexual or romantic differences/difficulties that might result from autism	45.5	13.2	27.0	5.7	2.1
Sexual activities other than intercourse	36.4	11.3	17.0	8.5	2.1
What it feels like to have sex	13.6	5.7	5.7	4.3	0.7

Cells report % of sample using each technique by topic. Parents could choose more than one technique for each topic

^aVisual supports were defined as pictures, books, pamphlets, or videos

^bSkills-based teaching was defined as video modeling, imitation and role-play, rehearsal, or social stories

^cNot presented to all parents, $n = 114$

^dNot presented to all parents, $n = 52$. STI = sexually transmitted infections

Table 3 Main effects of intellectual functioning groups on number of topics covered, instructional techniques, and parent social cognitive constructs

	Parent-reported intellectual functioning <i>M</i> (SD)				<i>F</i> (3, 139)	<i>p</i> η_p^2
	IF < 70 (<i>n</i> = 37)	Borderline (<i>n</i> = 16)	Average (<i>n</i> = 44)	Above average (<i>n</i> = 44)		
<i>Parent sex education inventory variables</i>						
Total number of topics covered	10.28 (7.80)***	17.69 (9.09)*	22.45 (9.01)	23.93 (7.21)	21.691	< 0.001 0.324
Talking alone proportion	6.67 (6.06)	12.63 (7.32)	15.02 (7.71)	17.25 (8.35)	0.230	0.876 0.005
Visual supports proportion	1.86 (2.86)	4.06 (5.11)	6.36 (7.79)	5.93 (7.31)	0.235	0.872 0.005
Skills-based techniques proportion	2.58 (6.25)**	1.44 (2.31)	2.52 (4.63)	1.80 (3.75)	4.502	0.005 0.090
<i>Parent social cognitive constructs</i>						
Self-efficacy	2.22 (1.13)***	3.13 (1.15)	3.70 (1.03)	3.70 (1.09)	16.308	< 0.001 0.263
Preparedness	3.11 (1.10)	3.00 (1.32)	3.41 (1.19)	3.73 (1.02)	2.712	0.047 0.056

Bold font indicates significant values

Cells report post hoc comparisons with Average IF Group as the reference group: * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$. η_p^2 effect size, 0.01 = small, 0.06 = medium, 0.14 = large

that parents whose youth fell in the Borderline IF and IF < 70 Groups reported having discussed fewer topics than parents whose youth were categorized as Average IF.

Next, we examined whether there were group differences in number of topics covered using specific instructional techniques (i.e., visual supports, skills-based teaching, talking alone) by conducting a series of ANOVAs with the proportion of topics covered using the specific instructional technique over total NTC (Table 3). Parents of youth in the IF < 70 Group covered a higher proportion of topics using skills-based teaching ($\eta_p^2 = 0.090$) compared to parents in the Average IF Group (post-hoc contrast $p = 0.006$, all other contrasts *n.s.*). There were no IF Group differences in the proportions of topics that parents covered using visual supports or talking alone.

Youth and Parent Characteristics Associated with NTC

To examine predictors of NTC (Table 4), we conducted linear regression analyses. First, we examined whether characteristics predicting NTC for predominantly male samples (Holmes and Himle 2014) were associated with NTC in the current sample using Pearson correlations. For parents of youth in the Average IF and Above Average IF Groups ($n = 88$), total NTC was correlated with child age ($r = 0.269$, $p = 0.011$) and not with SRS-2 Social Communication Index (SCI) T-score ($p = 0.290$) or SRS-2 Restricted and Repetitive Behavior Index (RRBI) T-score

($p = 0.682$). For parents of youth in the Borderline IF and IF < 70 Groups ($n = 51$), total NTC was not correlated with child age ($p = 0.164$) but was correlated with SRS-2 SCI T-score ($r = -0.357$, $p = 0.010$) and SRS-2 RRBI T-score ($r = -0.300$, $p = 0.033$).

Based on these analyses, we examined whether IF Group, child age, SRS-2 SCI T-score, SRS-2 RRBI T-Score, and whether youth had shown or expressed sexual attraction to others predicted NTC. Results showed that parents of youth in the IF < 70 Group discussed fewer topics on average than parents of youth in the Average IF Group ($p < 0.001$; other group differences *n.s.*). Additionally, greater child age predicted higher total NTC ($p = 0.021$). Parent report that their daughter had not shown or expressed sexual attraction to others predicted lower total NTC ($p = 0.019$) after accounting for IF Group, child age, and autism symptoms.

The second linear regression model included parent characteristics as independent variables and total NTC as the dependent variable. Household income, participant educational level, and religiosity were not significant predictors of total NTC (all p 's > 0.115). Parent identification with one or more racial/ethnic minority groups ($n = 17$, Native American, Asian American, African American, Hispanic, or Multiracial) predicted discussing fewer topics compared to parent identification as White ($p = 0.004$). After accounting for these characteristics, parent rating of how effectively they felt they could communicate with their child about sexuality (i.e., self-efficacy) predicted total NTC ($p < 0.001$); however, self-rated preparedness to manage sexual development did not ($p = 0.946$).

Table 4 Linear regression models: Youth and parent predictors of total number of topics covered on Parent Sex Education Inventory

	b	SE	β	p	Part
<i>Youth constructs model</i>					
<i>Model F(7, 132) = 10.651, R² = 0.374</i>				< 0.001	
Average IF (ref)	–	–	–	–	–
Above Average IF	1.13	1.72	0.056	0.511	0.047
Borderline IF	–4.17	2.45	–0.133	0.092	–0.120
IF < 70	–8.99	2.03	–0.401	< 0.001	–0.314
Child age	0.97	0.41	0.181	0.021	0.166
SRS-2 Social Communication Index	0.004	0.10	0.004	0.972	0.002
SRS-2 Restricted and Repetitive Behavior Index	–0.04	0.08	–0.049	0.668	–0.030
Has shown or expressed sexual attraction (ref)	–	–	–	–	–
Has not shown or expressed sexual attraction	3.92	1.66	0.191	0.019	0.168
<i>Parent constructs model</i>					
<i>Model F(6, 136) = 16.879, R² = 0.438</i>				< 0.001	
Parent income is above US median (ref)	–	–	–	–	–
Parent income is below US median	–2.29	1.44	–0.109	0.115	–0.104
Parent education—Bachelor's or higher (ref)	–	–	–	–	–
Parent education – does not have Bachelor's	–0.68	1.44	–0.032	0.637	–0.031
Less religious (ref)	–	–	–	–	–
More religious	–1.33	1.32	–0.068	0.315	–0.066
White (ref)	–	–	–	–	–
Not white	–6.19	2.12	–0.202	0.004	–0.192
Self-efficacy for talking about sex with youth	5.00	0.71	0.635	< 0.001	0.463
Prepared to address youth's sexual development	–0.53	0.79	–0.006	0.946	–0.004

Significant values are indicated in bold font

Ref reference group for nominal variables, SRS-2 Social Responsiveness Scale, 2nd Edition

Discussion

Parents and caregivers play an important role in supporting sexual and reproductive health in youth with autism. In efforts to improve population sexual health for typically developing youth, family sexuality communication (FSC) has been a target for intervention for decades (DiIorio et al. 2003; Hadley et al. 2016, 2018; Kirby and Miller 2002), yet there remains little research on FSC for youth with disabilities like autism. FSC may be especially important for these youth, who appear to have less access to other sources of sexuality education compared to peers (Brown-Lavoie et al. 2014; Stokes et al. 2007), and therefore may rely even more heavily on their parents for knowledge and values related to sexuality and relationships. Parents raising youth with autism report challenges with developmentally tailoring FSC for their youth and the need for more guidance (Ballan 2012; Mehzabin and Stokes 2011; Nichols and Blakeley-Smith 2010). Adults with autism have described receiving inadequate sex education from families and schools, sometimes comprising only negative messages about their sexuality (Barnett and Maticka-Tyndale 2015). Perhaps due in part to these gaps, adults with autism appear to have lower sexual knowledge than their non-autistic peers and are more

vulnerable to sexual abuse and exploitation (Brown-Lavoie et al. 2014; Kalyva 2010). Previous research has focused mostly on how families support healthy sexuality development for boys with autism due to diagnostic disparities and sample size limitations (Holmes et al. 2016b). This project represents the first and largest study investigating the experiences of families raising daughters on the autism spectrum as they support healthy sexuality development. This study also provides information about the kinds of techniques, strategies, and resources that parents are currently using to instruct youth with autism about sexuality, with special consideration for youth with different levels of intellectual functioning.

Parents endorsed covering a variety of sexuality and relationship topics with daughters on the autism spectrum. While most parents covered basics (privacy, identifying sexually abusive behavior, hygiene and menstruation), many left out important topics related to relationships, sexual health, and sexuality in general. This was particularly true for daughters in the IF < 70 group. Around one-quarter to one-half of parents did not discuss relationship topics like dating and marriage, knowing when one is in love, and how to decide when is the right time to engage in sexual intimacy with a partner. Most parents of more cognitively able

youth covered the consequences of getting pregnant and reasons why teens should abstain from sex, yet relatively few covered practical information about preventing unintended pregnancy and STIs. Furthermore, only one-third to one-half of parents had talked to daughters about the necessity of preventative care such as breast exams. This is particularly important because research suggests that women with autism are half as likely to receive preventative sexual health care (i.e., Pap smears) compared to non-autistic women (Nicolaidis et al. 2013). Overall, parents of daughters with autism showed a similar pattern to parents in previous research with male samples, in that almost all reported having covered basics like puberty, privacy, and reproduction, while fewer had covered more nuanced relationship and practical sexual health topics (Holmes and Himle 2014). Particularly notable given parents' high degree of concern about sexual victimization for this population (Holmes et al. 2016b; Teti et al. 2018) were the proportion of parents who had not instructed youth on how to report sexual abuse or about pressure or coercion by peers. It is important to note that youth in this sample had a mean age around 14 years old, and it is very possible that parents cover more of these relationship and sexual health topics later in adolescence or in early adulthood—which may be too late for some young women with autism.

Next, we found that most parents use only verbal discussion when teaching daughters with autism about sexuality and relationships. The proportion of parents who endorsed using visual materials (e.g., pictures or drawings, pamphlets, books, and videos) was quite low across most topics. Notable exceptions included female puberty (47.9%), menstruation (49.3%), private body parts (37.6%), and pregnancy/reproduction (33.3%). Parents were even less likely to report using skills-based teaching techniques that may be useful for teaching some topics (e.g., video modeling, social stories). For most topics, less than 5% of parents used any skills-based teaching techniques, with notable exceptions (i.e., hygiene, menstruation, privacy, and important qualities in choosing close friends), which were still endorsed by only around 1 in 5 parents. Parents of daughters in the IF < 70 group used a slightly higher proportion of skills-based teaching techniques than parents other groups, while there were (perhaps surprisingly) no differences across groups in proportions of parents using visual supports or talking alone to instruct daughters. Regardless of cognitive abilities, many youth with autism require enhanced instructional strategies to learn and generalize knowledge and skills. While discussion may (arguably) suffice for youth without autism, we should not assume that conversation alone will be an effective way to teach youth with autism about safe and healthy sexuality and relationships.

The low proportion of parents who reported using enhanced instructional strategies like visual supports and

skills-based teaching suggests that utilization barriers may exist (e.g., access to resources, knowledge of techniques, time needed to find or create visuals). Importantly, all girls with autism regardless of intellectual functioning (and potentially all teen girls; e.g., Hadley et al. 2014) can derive benefit from more intensive instructional techniques designed to enhance learning about sexual and reproductive health. Indeed, Planned Parenthood created free lessons on consent that use video modeling and are targeted to neurotypical youth and their families (Planned Parenthood Federation of America 2015). While all girls can benefit from learning supports, potential utilization barriers warrant further investigation as they may particularly affect youth with more intensive learning support needs, including those who are minimally verbal—a group at especially high risk for sexual abuse (Shapiro 2018). Currently, few skills-based instructional programs or resources have been rigorously tested for efficacy (even for women with intellectual disabilities, who have been the focus of such work for decades; Barger et al. 2009; Blanchett and Wolfe 2002; Schaafsma et al. 2014; Sullivan and Caterino 2008; Whitehouse and McCabe 1997; Wolfe et al. 2018). While efficacy research is limited, providers may still want to make parents aware of existing, free, online resources (Weitlauf et al. 2013) and low-cost curricula that provide visual components to enhance learning (Davies and Dubie 2012). Additionally, parents and clinicians working with families to increase FSC might welcome the development and dissemination of customizable, attractive, low-cost or free materials for use by daughters (e.g., menstruation social stories/visual schedules, pictures that minimally verbal youth can use to report abuse). In addition to access to resources, parents' belief that schools or mental health professionals in community-based programs are using enhanced instructional techniques to educate youth about sexual health may cause them to feel they do not need to use these strategies, particularly if they have not received guidance in how to do so (Ballan and Freyer 2017; Travers and Tincani 2010; Tullis and Zangrillo 2013). Research on exposure to school- and community-based sexual health education services is needed to know whether youth with autism are being exposed to effective instruction on sexuality and relationships in any setting.

This study identified several important youth and parent characteristics that affect how families engage in FSC, including parent race/ethnicity, daughters' expressed interest in sexuality, and parent self-efficacy. First, consistent with literature on non-autistic youth, we found that number of topics covered varied by parent race/ethnicity (Flores and Barroso 2017). However, there were a limited number of parents who identified as people of color in this study, and constructing race/ethnicity as White/non-White (as we did here) obscures important cultural differences between groups. Race/ethnicity and culture play a role in parent

treatment decisions and the success of educational interventions, and are likely to be important in the dissemination of sexuality-related interventions (Mandell and Novak 2005; Tincani et al. 2009). Researchers might consider differences in healthcare provider outreach to transition-age youth with autism by race/ethnicity, and whether targeted autism-specific resources are accessible and acceptable to people from different backgrounds. To our knowledge, there is currently only one sexuality development resource that has been translated to a language other than English (Weitlauf et al. 2013).

Second, parents of daughters who are not interested in sexual relationships or who have not expressed sexual attraction may be at risk of missing important opportunities for shaping sexuality-related values, knowledge, and behaviors during adolescence. Youth interest in and sexual attraction to others predicted parent engagement in FSC. This is somewhat consistent with previous work indicating that less impaired social motivation predicted parent coverage of more FSC topics (Holmes and Himle 2014). Parents attempt to align FSC with their youths' developmental needs and interest/engagement in sexuality and relationships (Beckett et al. 2010), and parents of daughters with autism are no different (Ballan 2012). However, parents of youth who have not expressed such interest may be missing critical opportunities to support healthy sexuality development. People with autism are less likely to share their interests with others (American Psychiatric Association 2013). Additionally, less access to cultural and peer narratives around developing sexuality (Brown-Lavoie et al. 2014; Stokes et al. 2007) coupled with differences in cognitive processing of emotions may contribute to difficulty acknowledging and expressing sexual or romantic feelings (Hill et al. 2004). Some people with autism may therefore appear less interested than they are. On the other hand, some adults with autism identify as asexual (Byers et al. 2013; Gilmour et al. 2012). Notably, many people who identify as asexual are interested in romantic relationships (Brotto et al. 2010; Carrigan 2011). Regardless of whether girls ever decide to engage in romantic relationships or partnered sexual contact, it is important that they learn about sexuality and relationships in order to effectively interact with others (e.g., online; Normand and Sallafrance-St-Louis 2016) and as a critical part of self-determination and self-advocacy (Travers et al. 2014; Ward and Meyer 1999). Clinicians and educators can help parents determine how to engage youth who appear disinterested in FSC, and autism-specific interventions should account for these parents' experiences.

Finally, the results suggest that parent and family constructs (i.e., household income, parent educational attainment, and religiosity) were less critical to FSC than a parent's rating of themselves as able to effectively communicate about sexuality with their child. Low self-efficacy has been identified as a barrier to FSC in previous research with

non-autistic youth (Hockenberry-Eaton et al. 1996). There is a great deal of research on social cognitive factors that affect engagement in health behaviors (usually self- rather than other or child-focused; Bandura 1977, 1982; Halpern-Felsher et al. 2004; Strecher et al. 1986) and improvements in communication, which may be useful for FSC intervention development. Importantly, this study does not provide evidence of a causal link between self-efficacy and more comprehensive FSC topic coverage. It is likely that self-efficacy changes over time in response to perceived success or failure of instructional efforts (Gist and Mitchell 1992). It is possible that parent self-efficacy is a mechanism for change in parent FSC behavior, and intervention studies can test this hypothesis. If parent self-efficacy is identified as a mechanism for increasing FSC, there is a well-established literature on increasing self-efficacy for health behaviors and communication (Kameg et al. 2010; Morin and Latham 2000; Parle et al. 1997).

Limitations

It is important to keep study limitations in mind when interpreting results. First, this study recruited a sample of convenience, likely including people with more resources than the general population, and results may not generalize to all parents of youth with autism. Second, this study is predicated on a binary conceptualization of gender as male/female. Many people with autism identify as transgender or with other diverse gender presentations (e.g., non-binary, agender; Glidden et al. 2016). Although no parents indicated that youth in this study identified outside of the male/female binary despite being provided with the option to do so, it is possible that some youth did not identify as female and had not acknowledged this to parents. In the past several years, transgender identities have become more mainstream and acceptable in the U.S. (even as transgender youth and adults continue to face discrimination and victimization). Gender identity is likely to affect how parents support healthy sexuality development. Sexual orientation also affects how parents talk to youth about sex and should be included in future research (Flores et al. 2018). Third, number of sexuality and relationship topics covered does not account for constructs found to be important in FSC (e.g., extent to which communication is directive, openness; Flores and Barroso 2017). Observational data from conversations between parents and youth could complement self-reports and provide useful data to inform interventions (e.g., parent behavior when child does not ask questions or otherwise appears disinterested; Hadley et al. 2018). Fourth, topics for this study were generated from literature on parents raising neurotypical youth. Asking parents and teens or adults on the spectrum may generate other important FSC topics (e.g., how to communicate about sensory differences with a romantic partner) or aspects

of these conversations that we as non-autistic researchers have missed (e.g., the possibility that family members may feel more comfortable communicating electronically rather than face-to-face). Finally, research with families shows that youth often have different perceptions than parents on what FSC topics they have discussed. Furthermore, adolescent perceptions and reports have been found to be more predictive of adolescent sexual behavior than maternal reports (Jaccard et al. 1998). Researchers could recruit parent–child dyads to investigate teens’ perceptions of FSC (Teti et al. 2018).

Conclusion

This study was the first to examine how parents of daughters with autism support healthy sexuality and relationship development through the conversations they have during the teenage years. Talking about sexuality and relationships is often challenging for parents regardless of youth abilities and characteristics (Hyde et al. 2010). There are some characteristics of girls with autism that may make FSC especially challenging for parents, including the extent to which intensive instructional strategies are needed (along with the preparation and planning needed to implement such strategies), greater diversity in terms of gender identity and sexual orientation, and the challenge of aligning with the developmental needs of girls who may be less likely to express interest in sexuality and relationships than typically developing peers. The results of this study indicate that parents may benefit from more guidance and resources as they talk to girls about relationships, sexual health, and consent. There is a particular need for research to include people from diverse racial/ethnic backgrounds to understand cultural differences in parents’ engagement in activities to support sexual self-determination. Finally, more research is needed on how parents support youth who are transgender or have other diverse gender presentations as they transition to adulthood.

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Author Contributions LGH conceived of the study, participated in its design and implementation, performed and interpreted the statistical analyses, and drafted the manuscript. DSS and MBH conceived of the study, participated in design and supervised implementation, and MBH contributed to interpretation of the data and drafting of the manuscript.

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Compliance with Ethical Standards

Conflict of interest Laura Graham Holmes, Donald S. Strassberg, and Michael B. Himle each declare that they have no conflicts of interest.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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

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