Parental sexuality-related concerns for adolescents with autism spectrum disorders and average or above IQ

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ABSTRACT

This study examined the relationship between symptoms of autism spectrum disorder, parental sexuality-related concerns, and parent–child sexuality communication in a sample of 131 parents of youth with ASD (aged 12–18 years) and parent-reported average or above IQ. A principal component analysis was conducted on responses to the Parent Sexuality Concerns Inventory with four sexuality-related concern factors emerging. Parents of children with more severe autism spectrum disorder symptoms (e.g., deficits in social cognition, communication, motivation) had greater sexuality and relationship concerns for their child. Parental concerns were not associated with the number of sexuality topics parents reported having discussed with their child. However, some concerns were associated with parental preparedness to address sexual development and parent self-efficacy for communicating with youth about sexuality.

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1. Introduction

Autism spectrum disorders (ASDs) are estimated to affect 1 in 68 children in the United States (Centers for Disease Control and Prevention, 2014). Despite deficits in social functioning, research indicates that many individuals with ASD are interested in sexual contact and pursuing intimate relationships (e.g., Byers, Nichols, & Voyer, 2013a; Byers, Nichols, Voyer, & Reilly, 2013b; Hellemans, Colson, Verbraeken, Vermeiren, & Deboutte, 2007; Hellemans, Roeyers, Leplae, Dewaele, & Deboutte, 2010; Van Bourgondien, Rechle, & Palmer, 1997). However, many individuals with ASD have difficulty initiating and maintaining romantic relationships (Byers et al., 2013a), which some suggest may contribute to feelings of loneliness and depression (Lasgaard, Nielsen, Eriksen, & Goossens, 2010; Mazurek, 2014; Whitehouse, Durkin, Jaquet, & Zitas, 2009). Further complicating the issue, it has been shown that individuals with ASD may be at greater risk for atypical courtship and sexual behavior (e.g., persistent and inappropriate interest), inappropriate sexual behavior (Hellemans et al., 2007, 2010; Stokes, Newton, & Kaur, 2007) and may be less knowledgeable about sex than their neurotypical peers. One study, for example, found that individuals with ASD and intact intellectual functioning had lower sexual knowledge than neurotypical individuals and that lower levels of sexual knowledge were associated with likelihood of having been sexually assaulted (Brown-Lavoie, Viecili, & Weiss, 2014). Together, this research highlights the importance of tailored sexuality and relationship education for youth with ASD in order to both promote healthy sexual outcomes and to minimize the possibility of negative outcomes (e.g., unwanted pregnancy, HIV/AIDS, inappropriate sexual behavior; Koller, 2000; Sullivan & Caterino, 2008; Tullis & Zangrillo, 2013).

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Experts recommend that parents be the primary sexuality educators for their children (Sexuality Information and Education Council of the United States, 2012). Ideally, parent–child sexuality communication (PCSC) should be an ongoing, bidirectional process beginning in early childhood and extending through adolescence and early adulthood. Parents are expected to developmentally tailor parent–child sexuality discussions to the needs of their child by choosing what topics to cover, at what age to discuss them, how much information to provide, and to ensure that their child learns and is able to apply the information that they convey. While this is a difficult task for any parent, parents of youth with ASD face unique challenges in this regard. Parents of youth with ASD have reported being unsure about what topics will be relevant to discuss with their child, when to discuss sexuality, and uncertainty regarding what healthy sexuality will look like for their child (Ballan, 2012; Nichols & Blakeley-Smith, 2010).

Part of parents’ hesitation about engaging in PCSC may be due to their uncertainty about their ability to communicate effectively and ensure that their child understands the information provided, especially given the tendency for physical development to outpace emotional development in youth with ASD (Ballan, 2012). Parents have reported a need for guidance on how to developmentally tailor sex and relationship education for their child with ASD and a need for more effective teaching techniques (Ballan, 2012; Nichols & Blakeley-Smith, 2010). Parents also reported that despite seeking advice from various school personnel and healthcare providers, they felt ill informed and underprepared to address their child’s sexual development and behavior (Ballan, 2012). By adolescence, parents’ perception of their effectiveness in teaching about nuanced social topics has likely been shaped by numerous conversations with their child. Parents who feel ill informed and underprepared to engage in PCSC may feel it is less likely that they can do so effectively, and research on parents of neurotypical youth indicates that poor self-efficacy for ability to engage in PCSC is associated with lower likelihood of providing PCSC (Dilorio et al., 2000).

In addition to the aforementioned challenges to engaging in sexuality communication, research has shown that parents of youth with ASD express a number of sexuality-related concerns. Ruble and Dalrymple (1993) surveyed 100 parents and caregivers of individuals with ASD (aged 9–39 years), classified as verbal (n = 38), minimally verbal (n = 29), or non-verbal (n = 33). The most common concerns among parents (regardless of the child’s verbal ability) were that nonsexual behavior would be misinterpreted as sexual (84% of parents of boys, 76% of parents of girls), that sexual behaviors would be “misunderstood” (76% of parents of males, 72% of parents of females), and that their child would be sexually abused or exploited (80% of parents of both males and females). In addition, parents also reported concerns that their child might experience unwanted pregnancy (61% of females and 19% of males), contract a sexually transmitted disease (50% of females and 43% of males), or would not have the opportunity to enjoy sexual relations (48% of females and 64% of males). In contrast to Ruble & Dalrymple’s (1993) finding of similar parental concerns across levels of verbal ability, Kalvya (2010) found that teachers reported greater sexuality-related concerns for their students with ASD and intact intellectual functioning despite reporting that students with ASD and comorbid intellectual disability had less adaptive social behavior, less understanding of privacy and sexuality education, and more inappropriate sexual behavior. This indicates that it is important to consider intellectual functioning when investigating the sexuality-related concerns of parents and educators.

More recently, Nichols and Blakeley-Smith (2010) conducted focus groups with 21 parents of youth aged 8–18 years with a documented diagnosis of ASD. Parents reported a strong desire for their child to have fulfilling relationships, but also noted several concerns. In particular, many parents reported being concerned that their child’s difficulties in understanding social cues, privacy, boundaries, and personal space might make it difficult for their child to form and maintain meaningful relationships and lead to isolation and loneliness. Furthermore, several parents noted concerns that their child’s sexual decision-making skills and lack of an open-minded, flexible attitude toward sexuality and relationships would increase their child’s risk for being sexually exploited or behaving in a sexually inappropriate manner. Together, these studies suggest that child variables, including ASD symptoms, may be important in understanding a parent’s sexuality-related concerns.

Understanding parental sexuality-related concerns is important because they may influence whether or not a parent engages in PCSC with their child. For example, Ballan (2012) conducted semistructured qualitative interviews with 18 parents of children with ASD (aged 6–13 years) who were enrolled in mainstream classes and found that, consistent with previous research, parents were concerned that their child’s sexual behavior would be negatively received or that non-sexual behavior would be misperceived as sexual or dangerous by others. Although some parents might be driven to engage in PCSC by their sexuality-related concerns, Ballan (2012) reported that sexuality-related concerns seemed to impede rather than motivate parents. For example, some parents reported concern that sex education could lead to their child developing an obsessive fixation on sexuality, especially for children with preexisting fixations on innocuous objects or interests (e.g., trains). Parents of children who exhibited repetitive behaviors (e.g., hand-flapping) feared that education about masturbation might cause children to replace nonsexual self-stimulating behaviors with compulsive masturbation. Additionally, parents reported concern that sexuality education or communication could lead to (rather than prevent or remediate) negative outcomes (e.g., inappropriate sexual behavior, sexual perseveration). Parents were concerned that their child would not fully understand sexuality topics if they were discussed and might overgeneralize information or be unable to apply it appropriately guide their behavior. Additionally, although parents in this study did not expect their child to have a romantic relationship in the future, this was reportedly not of particular concern, potentially due to the younger ages of children on whom parents reported. However, one parent did report concern about the effects of repeated romantic rejection. Parents with these concerns might understandably avoid or delay providing sexuality and relationships education to their child.
Fortunately, most parents of children with ASD do engage in some sexuality-related conversations with their child. Holmes and Himle (2014) surveyed 198 parents of adolescents with ASD aged 12–18 years (mean age = 14.51; 86.8% male) and found that most parents covered basic topics but were less likely to report covering more sophisticated relationship and sexual health-related topics during adolescence (Holmes & Himle, 2014). For youth with ASD and parent-reported average or above IQ, most parents reported having covered topics like privacy, private body parts, what kinds of touch are appropriate/inappropriate, hygiene, and how to report sexual abuse. However, relatively fewer parents reported having covered important topics such as how to say no to pressured sex and the importance of not pressuring other people to have sex. Similarly, while the majority of parents (86.9%) spoke to their child about what qualities are important in choosing close friends, fewer parents discussed how to decide whether to have sex (48.8%) or how to ask someone on a date (45.4%). For context, studies suggest that up to 97% of parents raising neurotypical youth report discussing similar topics with their adolescents (Dilorio, Kelley, & Hockenberry-Eaton, 1999; Jordan, Price, & Fitzgerald, 2000). Regarding sexual health, most parents of youth with ASD talked to youth about why they should not have sex, but were less likely to discuss how to prevent STDs (49.2%) or pregnancy (43.8%), or how to use a condom (19.5%; Holmes & Himle, 2014). Studies suggest that parents of neurotypical youth might be more likely to discuss birth control (65%) and using a condom (74%; Miller, Kotchick, Dorsey, Forehand, & Ham, 1998). Holmes and Himle (2014) suggested that parental sexuality-related concerns might partially account for parents’ tendency to avoid covering sophisticated, nuanced topics. Additionally, parents who had difficulty teaching their child how to apply basic information about appropriate privacy and hygiene might also avoid more complicated sex and relationship topics due to low self-efficacy.

In order to ensure that parents can engage in parent–child sexuality communication with youth with ASD and average or above IQ in a manner that promotes healthy sexual outcomes, it is important to understand barriers, including sexuality-related concerns, which impede parents’ ability or willingness to engage in PCSC with youth with ASD. The primary goals of the current study were (a) to provide a quantitative description of parental sexuality-related concerns, (b) to determine whether child characteristics, including ASD symptom severity and profile, were related to parental sexuality-related concerns, and (c) to examine whether parental sexuality-related concerns were associated with PCSC and related variables (i.e., self-efficacy and preparedness to address sexual development). Given previous research in this area, we hypothesized that (a) greater ASD symptom severity would be associated with greater parental sexuality-related concerns, (b) that greater parental concerns would be associated with parental coverage of fewer PCSC topics, and (c) that greater parental concerns would be associated with lower parental self-efficacy for engaging in PCSC and lower perceived preparedness for managing sexual development and behavior, which would in turn be related to PCSC.

2. Method

The methods and participants section are fundamentally the same as reported in Holmes and Himle (2014) and have been provided here in brief for context. Preliminary analyses of these data as well as tables containing information about the sexual behaviors of youth with ASD and topics covered by parents during parent–child sexuality communication for this sample are available in Holmes and Himle (2014). Research has shown that families provide sexuality and relationship education differently for children with average cognitive functioning compared to those with intellectual disability, and thus it is important to conduct separate analyses for these populations (Holmes & Himle, 2014). In this sample, the subset of participants whose parents reported their child had below average IQ was not large enough to provide power for thorough analyses of parental sexuality concerns, so only those with average or above IQ were included in the analyses.

2.1. Participants

Participant recruitment took place thorough local and national autism support groups via electronic postings (e.g., emails, newsletters). Parents were invited to complete an anonymous online survey about ASD and sexuality education. Parents were eligible to participate if they reported that they had a child aged 12–18 years who had been diagnosed with ASD by a healthcare professional. In total, 131 parents who reported that their child had average or above IQ and no comorbid intellectual disability diagnosis completed the survey. Parents were predominantly Caucasian (89.2%) females (92.2%) with a median age of 46 years (M = 47.06, SD = 6.38). Parents completed the survey about adolescents who were predominantly Caucasian (90%) males (87%) with a median age of 14 years (M = 14.54, SD = 1.95). Parents were also asked to report their adolescent’s measured IQ (N = 123) or, if they were not sure of their child’s IQ, to provide an estimate based on descriptive guidelines (e.g., average, above average; N = 8). Based on parent report, 52.7% of the adolescents fell in the average range (IQ = 86–115) and 47.3% were above average (IQ = 116+). Social Responsiveness Scale, 2nd edition (SRS-2) total standard scores ranged from 55–90, (M = 77.49, SD = 9.34), which is consistent with a diagnosis of ASD. The majority of youth (N = 82, 62.6%) fell within the “severe” range SRS-2, with others scoring within the moderate range (33, 25.2%), mild range (11, 8.4%), or just below the threshold for diagnosis (5, 3.8%). Given that all youth had received a professional ASD diagnosis according to parent report, the five parents of youth falling below the SRS-2 cutoff were included in the sample. As previously reported in Holmes, Himle, & Strassberg, (2015), participants’ mean scores for SRS-2 social awareness (M = 72.73, SD = 10.38), social cognition (M = 74.94, SD = 9.78), social communication (M = 76.37, SD = 9.02), social motivation (M = 71.44, SD = 11.14), and restricted/repetitive behavior (M = 75.47, SD = 11.04) were all consistent with ASD diagnosis.
<table>
<thead>
<tr>
<th>Item</th>
<th>Parents of males (N = 112*)</th>
<th>Parents of females (N = 17)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Not at all</td>
<td>Slightly</td>
</tr>
<tr>
<td>10 My child's sexual decision-making ability (e.g., risky sexual behavior)</td>
<td>12.5 (14)</td>
<td>23.2 (26)</td>
</tr>
<tr>
<td>11 Accidental pregnancy</td>
<td>29.7 (33)</td>
<td>35.1 (39)</td>
</tr>
<tr>
<td>12 Contraction of STDs or HIV/AIDS</td>
<td>31.2 (34)</td>
<td>27.5 (30)</td>
</tr>
<tr>
<td>16 My child being sexually coerced or manipulated by peers</td>
<td>23.4 (26)</td>
<td>25.2 (28)</td>
</tr>
<tr>
<td>17 My child being a victim of rape or sexual assault</td>
<td>36.9 (41)</td>
<td>34.2 (38)</td>
</tr>
<tr>
<td>19 Misinterpretation of my child's behavior as a sexual come-on, or as dangerous</td>
<td>33.3 (37)</td>
<td>27.9 (31)</td>
</tr>
<tr>
<td>21 Lack of awareness about ASD and sexuality issues among professionals, schools, and community members</td>
<td>8.1 (9)</td>
<td>20.7 (23)</td>
</tr>
<tr>
<td>13 Maladaptive sexual behavior (e.g., masturbating in public)</td>
<td>64.0 (71)</td>
<td>18.9 (21)</td>
</tr>
<tr>
<td>14 Strange sexual behavior</td>
<td>70.3 (78)</td>
<td>15.3 (17)</td>
</tr>
<tr>
<td>15 Sexual fixation or fascination, obsessions, compulsions</td>
<td>56.8 (63)</td>
<td>20.7 (22)</td>
</tr>
<tr>
<td>18 My child raping or sexually assaulting another individual</td>
<td>70.3 (78)</td>
<td>19.8 (22)</td>
</tr>
<tr>
<td>20 My child being arrested for sexual behavior</td>
<td>66.4 (73)</td>
<td>17.3 (19)</td>
</tr>
<tr>
<td>6 The effect of poor social skills on dating and marriage</td>
<td>3.6 (4)</td>
<td>6.3 (7)</td>
</tr>
<tr>
<td>7 My child finding a life partner or spouse</td>
<td>3.6 (4)</td>
<td>9.0 (10)</td>
</tr>
<tr>
<td>8 Lack of future opportunities for sexual fulfillment with others</td>
<td>13.4 (15)</td>
<td>19.6 (22)</td>
</tr>
<tr>
<td>9 My child's ability to have emotionally reciprocal or fulfilling relationships</td>
<td>2.7 (3)</td>
<td>8.0 (9)</td>
</tr>
<tr>
<td>1 Not knowing how ASD affects (or will affect) sexuality and sexual development</td>
<td>11.6 (13)</td>
<td>20.5 (23)</td>
</tr>
<tr>
<td>2 Not knowing what to expect (e.g., sexual attraction, behavior, relationships)</td>
<td>12.5 (14)</td>
<td>19.6 (22)</td>
</tr>
<tr>
<td>3 Practical aspects of puberty and sexual hygiene (e.g., menstruation, cleaning genitals)</td>
<td>41.1 (46)</td>
<td>20.5 (23)</td>
</tr>
<tr>
<td>4 Whether or how to provide sex education</td>
<td>28.6 (32)</td>
<td>25.0 (28)</td>
</tr>
<tr>
<td>5 My child's understanding of social cues, boundaries, privacy, and physical personal space</td>
<td>5.4 (6)</td>
<td>16.1 (18)</td>
</tr>
</tbody>
</table>

*Not all parents of males provided complete data (range = 109–112).
2.2. Measures

2.2.1. Social Responsiveness Scale—2nd edition (parent report) (SRS-2)

The SRS-2 (Constantino & Gruber, 2012) is a 65-item rating scale designed to measure the severity of autism spectrum symptoms with emphasis on social impairment. It provides a total score and several subscale scores (i.e., social motivation, social cognition, social awareness, social communication, and repetitive behavior) and has acceptable psychometric properties (Constantino & Gruber, 2012). T-scores of 60–75 suggest deficiencies in reciprocal social behavior with mild to moderate interference in everyday social interactions. T-scores above 75 suggest that symptoms severely interfere with everyday social functioning.

2.2.2. Online sexuality survey

Parents completed a 50-item online sexuality survey containing questions about parent and child demographics, parent-child sexuality communication, and parental sexuality-related concerns. Parents rated their self-efficacy for engaging in PCSC and their preparedness for managing their child’s sexual development and behavior on 5-point Likert-type scales (1 = “not at all”, 5 = “very”). Parents also rated the likelihood that sexuality education would lead to inappropriate sexual behavior on a 5-point Likert-type scale (1 = “not at all”, 5 = “very”).

2.2.3. Parental sexuality concern inventory (PSCI)

Parents completed the parental sexuality concern inventory (PSCI) and rated their level of concern regarding 21 outcomes or issues (e.g., maladaptive sexual behavior, my child’s ability to find a life partner or spouse, my child being sexually coerced or victimized) on a 5-point Likert-type scale (0 = “not at all concerned” to 4 = “extremely concerned”). For each parent, concern ratings were summed to create a PSCI summed score variable (PSCI total score, range = 0–84), with higher scores indicating greater concerns. Concerns were closely based on previous research on this topic (Ballan, 2012; Nichols & Blakeley-Smith, 2010; Ruble & Dalrymple, 1993; Stokes & Kaur, 2005).

2.2.4. Parental sexuality education inventory (PSEI)

The PSEI is a self-report measure designed for this study assessing provision of family-based sexuality and relationship education for youth with ASD. Parents reviewed a list of 39 sexuality and relationships topics and endorsed those that they had covered with their child. Topics included privacy, sexual abuse prevention, physical development of boys and girls, 

Table 2

<table>
<thead>
<tr>
<th>Item</th>
<th>Factor 1 Concerns about negative outcomes</th>
<th>Factor 2 Concerns about sexual deviance</th>
<th>Factor 3 Concerns about relationships</th>
<th>Factor 4 Practical concerns and expectations</th>
</tr>
</thead>
<tbody>
<tr>
<td>10</td>
<td>My child’s sexual decision-making ability (e.g., risky sexual behavior)</td>
<td>.712</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Accidental pregnancy</td>
<td>.829</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Contraction of STDs or HIV/AIDS</td>
<td>.838</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>My child being sexually coerced/ manipulated by peers</td>
<td>.821</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>My child being a victim of rape or sexual assault</td>
<td>.861</td>
<td></td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>Misinterpretation of my child’s behavior as a sexual come-on, or as dangerous</td>
<td>.477</td>
<td></td>
<td></td>
</tr>
<tr>
<td>21</td>
<td>Lack of awareness about ASD and sexuality issues among professionals, schools, and community members</td>
<td>.448</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>Maladaptive sexual behavior (e.g., masturbating in public)</td>
<td>.826</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>Strange sexual behavior</td>
<td>.885</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>Sexual fixation or fascination, obsessions, compulsions</td>
<td>.775</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>My child raping or sexually assaulting another individual</td>
<td>.734</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>My child being arrested for sexual behavior</td>
<td>.545</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>The effect of poor social skills on dating and marriage</td>
<td>.584</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>My child finding a life partner or spouse</td>
<td>.952</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Lack of future opportunities for sexual fulfillment with others</td>
<td>.872</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>My child’s ability to have emotionally reciprocal/ fulfilling relationships</td>
<td>.939</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Not knowing how ASD affects (or will affect) sexuality and sexual development</td>
<td>.699</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Not knowing what to expect (e.g., sexual attraction, behavior, relationships)</td>
<td>.755</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Practical aspects of puberty and sexual hygiene (e.g., menstruation, cleaning genitals)</td>
<td>.898</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Whether or how to provide sex education</td>
<td>.834</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>My child’s understanding of social cues, boundaries, privacy, and physical personal space</td>
<td>.449</td>
<td></td>
<td>.583</td>
</tr>
</tbody>
</table>
reproduction, pregnancy and STD prevention, sexual decision-making, relationships, consent and coercion, and sexual health. Topics were adapted from Beckett et al. (2009), Koller (2000), Nichols and Blakeley-Smith (2010), Travers and Tincani (2010), and Wolfe, Condo, and Hardaway (2009). Responses were summed to create a number of sexuality topics covered (NSTC) variable for each parent (range = 0–39), with higher scores indicating a greater number of topics covered.

3. Results

Prior to conducting analyses, all variables were inspected to ensure normality. A previous publication includes preliminary analyses of these data as well as tables containing information about adolescent sexual interests and behaviors (as reported by parents) and percentage of parents who covered each topic topics (Holmes & Himle, 2014). As reported in Holmes and Himle (2014), number of sexuality topics covered (NSTC) ranged from 0 to 39 (M = 21.95, SD = 9.58). Parent sexuality concerns inventory (PSCI) responses are provided in Table 1. PSCI total score ranged from 0 to 84 (M = 34.74, SD = 16.49).

3.1. Principal component analysis of the PSCI

A principal component analysis was conducted to determine the underlying latent structure of the PSCI. We confirmed the adequacy of this dataset for factor analysis using the Kaiser–Meyer–Olkin measure of sampling adequacy (KMO = .883), and Barlett's test of sphericity (X²(210) = 2024.09, p = .000). Theoretically, it was expected that there would be dependency among factors. Based on this and due to inter-item correlations, we used principle components analysis with an oblique, promax rotation (Tabachnik & Fidell, 2013). The optimal factor structure was selected by examining the pattern structure, scree plot, and by considering the Kaiser Criterion and comprehensibility of the factors (Costello & Osborne, 2005). All items with correlations of .40 were retained for the factor (Matsunaga, 2010). In examining internal consistency, alpha values of .80 were preferred for a new scale (Clark & Watson, 1995).

The factor analysis yielded a four-factor solution, accounting for 70.403% of the variance after rotation. A five-factor solution yielded a fifth factor that did not meet guidelines for reliability (Tabachnik & Fidell, 2013). Thus, a four-factor solution was selected. In the four-factor solution, factor 1: concerns about negative outcomes accounted for 45.079% of the variance, factor 2: concerns about sexual deviance accounted for 12.547% of the variance, factor 3: concerns about relationships accounted for 7.395% of the variance, and factor 4: practical concerns and expectations accounted for 5.382% of the variance. No items failed to meet the .40 criteria for inclusion and thus none were removed. One item loaded on more than one factor (see Table 2 for items and factor loadings), and there was a clear best-fit based on loading and comprehensibility.

Next, the reliability of the four factors of the PSCI was examined. Cronbach’s alpha for the entire scale was .938. All items met the item-total correlation recommended cut-off and were retained for the scale. Factor alpha values, and factor means and standard deviations were as follows for the four factors identified for the PSCI: factor 1 (α = .893; M = 11.85; SD = 6.95), factor 2 (α = .914; M = 3.25; SD = 4.88), factor 3 (α = .878; M = 10.45; SD = 3.67), and factor 4 (α = .863; M = 9.24; SD = 4.77). Factor 1 consisted of items about negative consequences such as STDS, sexual assault, and unwanted pregnancy, and will be called “concerns about negative outcomes”. Factor 2 consisted of items about inappropriate or unusual sexual behavior and sexual offending, and will be called “concerns about sexual deviance”. Factor 3 consisted of items covering difficulties with romantic or sexual relationships, and will be called “concerns about relationships”. Factor 4 consisted of items about concerns such as whether to provide sexuality education and how to teach about puberty and hygiene, and will be called “practical concerns and expectations”. PSCI Factor 2 was zero-inflated with significant positive skew (skewness = 1.937, SE of skewness = .215), indicating that a number of participants reported no concern about factor 2 items. PSCI total score and PSCI factors 1, 3, and 4 were normally distributed.

3.2. Analytic plan

All variables were examined for normality and outliers. If a participant was missing data for one item loading on a factor, that factor was coded as missing for the purpose of these analyses. For normally distributed variables, Pearson’s correlations and simple/multiple linear regressions were conducted. For variables with non-normal distributions (i.e., PSCI factor 2), Spearman rank-order correlations and negative binomial regressions were conducted. Negative binomial regressions were the best fit for the data as they corrected an overdispersion issue that arose in Poisson regression models (Gardner, Mulvey, & Shaw, 1995).

3.3. Parental concerns and child characteristics

A series of analyses were first conducted to determine whether child age or gender were associated with PSCI total score or PSCI factors. Neither PSCI total score nor individual PSCI factor scores correlated with child age (all ps > .105). A series of t-tests showed that PSCI mean scores differed by child sex for factor 1 (concerns about negative outcomes; t(124) = 3.337, p = .001; Mf = 16.88, SD = 7.27, Mm = 11.06, SD = 6.59) but not for PSCI total score or PSCI factors 2, 3, or 4 (all ps ≥ .084).
To determine whether ASD symptom severity predicted PSCI total score, a simple linear regression was performed. Consistent with our expectations, SRS-2 total T-score predicted PSCI total score \( (B = -0.341, SE = .147, p = .000, F(1,126) = 16.627, R^2 = .117) \). Next, SRS-2 subscales were entered together in a multiple linear regression model to determine whether any subscale predicted PSCI total score when controlling for the others. Multicollinearity did not reach problematic levels in the model. After accounting for shared variance, only SRS-2 Social Communication score predicted PSCI total score \( (B = .391, SE = .287, p = .014) \), with greater symptom severity associated with higher total parental concerns \( (F(5,122) = 4.723, p < .001, R^2 = .162) \).

A series of multiple regressions were conducted to determine whether SRS-2 total T-score predicted specific PSCI factors. SRS-2 total T-score predicted PSCI factor 1 (concerns about negative outcomes; \( B = .281, SE = .065, F(1,124) = 10.627, p = .001, R^2 = .079 \)), factor 3 (concerns about relationships; \( B = .286, SE = .033, F(1,126) = 11.374, p = .002, R^2 = .083 \)), and factor 4 (practical concerns and expectations; \( B = .361, SE = .042, F(1,127) = 19.064, p < .001, R^2 = .131 \)). SRS-2 total T-score did not predict factor 2 (concerns about sexual deviance; \( X^2(1, N = 127) = 3.268, p = .070 \)).

3.4. Parental concerns and parent–child sexuality communication

A simple linear regression was conducted to determine whether parental concerns (PSCI total score) predicted number of sexuality-related topics covered (NSTC). In contrast to our expectations, PSCI total score did not predict NSTC \( (F(1,125) = .322, p = .571) \). In order to determine whether specific PSCI factors were associated with NSTC, a series of correlations were then conducted. In contrast to our expectations, PSCI factors were not correlated with NSTC \( (all ps > .092) \). Additionally, a linear regression showed that parental rating of the likelihood that sexuality education would lead to inappropriate sexual behavior did not predict NSTC \( (B = .031, SE = 1.012, F(1,1127) = .126, p = .723, R^2 = .001) \).

Finally, correlation analyses were conducted to determine whether PSCI factors were associated with parental preparedness to manage their child’s sexual development and behavior and parental self-efficacy for engaging in PCSC. Parental preparedness was correlated with PSCI factor 4 (practical concerns and expectations; \( r = .357, p < .000 \)) and PSCI factor 2 (concerns about sexual deviance; \( r = .269, p = .002 \)), but was not correlated with PSCI factor 1 (concerns about negative outcomes; \( r = .101, p = .263 \)) or PSCI factor 3 (concerns about relationships; \( r = .106, p = .242 \)). Parental self-efficacy was correlated only with PSCI factor 4 (practical concerns and expectations; \( r = .195, p = .030 \)). Finally, parental preparedness \( (B = .251, SE = .932, p = .014) \) and self-efficacy \( (B = .365, SE = .902, p < .000 \) predicted NSTC \( (F(3,124) = 21.677, p < .000, R^2 = .344) \) when controlling for child age \( (B = .163, SE = .361, p = .029) \).

4. Discussion

This study was one of the first to thoroughly examine parental sexuality and relationship-related concerns for parents of adolescents with ASD and intact intellectual functioning. The study expanded on previous qualitative research \( (Ballan, 2012; Nichols & Blakeley-Smith, 2010) \) and foundational studies \( (Ruble & Dalrymple, 1993; Stokes & Kaur, 2005) \) on parent sexuality-related concerns for parents of individuals with ASD to quantify the frequency and intensity of parental concerns and explore how they might affect parent–child sexuality communication practices.

Consistent with previous research, parents in the current study reported concern about whether their child will have romantic relationships or the opportunity for partnered sexual experiences \( (e.g., Nichols & Blakeley-Smith, 2010; Ruble & Dalrymple, 1993; Stokes & Kaur, 2005) \). Indeed, 90.7% of parents were at least moderately concerned about the negative effect of poor social skills on dating and marriage, and 89.9% were concerned about their child’s ability to have emotionally reciprocal or fulfilling relationships. Furthermore, 66.7% were concerned about the possibility that their child would not have opportunities for partnered sexual experiences, and 88.3% were concerned about their child finding a partner/spouse. Parents of adolescents with more severe ASD symptoms reported greater concern about these partnered sex and relationship items. Given that social isolation can lead to loneliness and depression for individuals with ASD \( (Bauminger & Kasari, 2000; Mazurek, 2014) \), these concerns about the sexual and marital prospects of individuals with ASD should be addressed by healthcare providers and school personnel in terms of providing effective training in both sexuality and relationships \( (e.g., Davies & Dubie, 2011) \).

Parents in the current study also expressed moderate concerns about negative sexual health outcomes \( (e.g., accidental pregnancy, HIV) \). This is consistent with Ruble and Dalrymple’s \( (1993) \) study showing that 38% of parents were concerned about their child contracting an STD, and that 56% of parents of verbal females and 21% of parents of verbal males were concerned about accidental pregnancy. On the other hand, Ballan \( (2012) \) or Nichols and Blakeley-Smith \( (2010) \) did not report parental concerns about sexual health except to note that PCSC tended to omit topics like dating, intercourse, or birth control \( (Ballan, 2012) \). As reported in Holmes and Himle \( (2014) \), less than half of parents in the current sample talked to their child about how to prevent STDs and pregnancy, and less than one-fifth discussed how to use a condom. It is important to note that only 10% of parents in this study reported that their child had experienced a romantic relationship \( (Holmes & Himle, 2014) \), and thus parents might not have thought that their child was at-risk for accidental pregnancy or STDs. Alternatively, parents might have assumed that their child learns about sexual health and prevention from school. Parents should be encouraged to think of these topics as important foundational knowledge for any individual, and medical professionals are encouraged to assess for knowledge of sexual risk and prevention in youth with ASD \( (Holmes et al., 2014; Murphy & Elias, 2006) \).
In previous research, parents reported being concerned about their child engaging in inappropriate sexual behavior (Ballan, 2012). In the current study, few parents reported being seriously concerned about their child’s inappropriate or unusual sexual behavior. Indeed, most parents indicated that they were not at all concerned about inappropriate or strange sexual behavior, sexual fixation or compulsion, or about the possibility that their child might sexually assault someone or be arrested for sexual behavior. As reported in Holmes and Himle (2014), some youth in this sample had purposefully looked at someone bathing or undressing (15.5%), touched people inappropriately in a sexual way (7.7%), or had masturbated in the presence of others (3.8%), showing that such behavior was relatively rare. Despite being infrequent, the consequences of inappropriate or boundary-crossing behavior can be very serious (e.g., incarceration, loss of inclusion in the community, romantic rejection; Stokes et al., 2007; Sullivan & Caterino, 2008; Walters et al., 2013). Although research has not yet clarified whether inappropriate sexual behavior among people with ASD is caused by a lack of understanding of sexual boundaries, knowledge of such boundaries is a necessary (if not sufficient) foundation for appropriate sexual and romantic behavior.

Another primary goal of the study was to determine whether parental sexuality and relationship concerns were associated with parental engagement in parent–child sexuality communication. Previous research suggested that parental concerns might be an impediment to engagement in PCSC (Ballan, 2012). Alternatively, parents’ concerns could act as motivators for them to engage in PCSC to protect their children, especially if they believed that they could do so effectively (Bandura, 1990). In contrast to our expectations, the results of the current study suggested that parental sexuality and relationship concerns were not strongly associated with PCSC. For example, although concerns about relationships were among the most frequently reported concerns for parents, the factor representing these concerns was not related to the number of sexuality topics covered by parents during PCSC. It is possible that parental concerns may simply be a less important factor in parental behavior than are other parent or child variables (e.g., child age, ASD symptom profile; Holmes & Himle, 2014). Another possibility is that parental concerns may be associated with an aspect of PCSC not assessed in this study, such as positive or negative tone, depth/frequency of coverage, or specific information provided (e.g., the fallibility of condoms compared to abstinence vs. how to put on a condom). Although parental sexuality concerns were not directly associated with number of topics covered, they were associated with whether parents felt that they could communicate effectively about sexuality with their child and how prepared they felt to manage their child’s sexual development and behavior, and both of these predicted number of topics parents covered, suggesting that parental concerns may affect PCSC indirectly through their influence on other important variables, and this is a direction for future research.

It is important to consider the limitations of this study when interpreting the results. First, participants for this study were recruited online through support groups. The parents included in this study are a smaller subset of the entire sample, and were included based on parent report of child IQ. Although we expect that parents of adolescents would be able to report whether or not their adolescent has average intellectual functioning given years of school involvement, parent report may have been inaccurate in some cases. It would be ideal for future research to better characterize participants through cognitive and ASD testing. Furthermore, the views of youth with ASD were not explored. It would be ideal for future research to elicit youth perspectives on how parents engaged in PCSC to provide a more comprehensive understanding of how families engage in sexuality and relationships education.

Additionally, Internet-based sampling methods require participants to have access to a computer and the Internet. Indeed, participants in this study were predominantly White, married, well-educated, and had a relatively high average income. Furthermore, individuals who volunteer for sexuality studies tend to be more comfortable with sexuality in general (Strassberg & Lowe, 1995), and thus parents in this study may have approached their child’s sexual development differently than the broader population of parents with ASD. Additionally, gender of both child and parent has been shown to be an important variable in parent–child sexuality communication (Dilorio, Pluhar, & Belcher, 2003). Female adolescents with ASD were underrepresented in this sample, and there is a need for more research on the sexual development, sexuality, and romantic relationships of females with ASD. Finally, PCSC-related processes likely differ for youth with ASD and comorbid intellectual disability, and it is important that their families also be included in research about sexual development.

5. Conclusions

To conclude, this study was the first that sought to determine the significance of parental sexuality and relationship concerns and whether such concerns affected parents’ ability to engage in PCSC with adolescents. Consistent with previous research, the results of this study indicate that parents have a number of significant concerns about sexual abuse or exploitation, sexual health, and community attitudes and perceptions about their child’s sexuality. This is important information for healthcare providers and school personnel, who have the opportunity to discuss sexual development and behavior with parents in order to allay some fears and provide appropriate support (e.g., classes, teaching techniques, basic information) for parents to encourage greater engagement in PCSC. Researchers and healthcare professionals may also want to consider other barriers impeding parents’ ability or willingness to engage in PCSC, some of which are fixed but important for providers to consider (e.g., religious beliefs, educational level), and some which may benefit from intervention (e.g., communication skills, sexual knowledge).

An important contribution of this study is the finding that parents have significant concerns about their child’s future prospects for sexual and romantic relationships. Most individuals feel that their romantic relationships are central to their well-being (e.g., Barger, Donoho, & Wayment, 2009; Kim & McKenzie, 2002), yet there is little research on relationship status and quality for adults with ASD among adult outcomes research (for a notable exception, see Byers et al., 2013b). Loneliness
has been conceptualized as a chronic stressor, and is tied to a host of poor psychiatric and physical health outcomes, while romantic relationships and sexual contact are associated with positive mental and physical health outcomes including decreased morbidity and mortality and improved quality of life (e.g., Diamond & Huebner, 2012; Holt-Lunstad, Birmingham, & Jones, 2008; Mazurek, 2014; Roelfs, Shor, Kalish, & Yoge, 2010). Romantic relationships are therefore an important topic for future research within the field of adult outcomes and ASD.

References


Available at: http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6302a1.htm?s_cid=ss6302a1_e


