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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.

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, Reichle, & 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, & Ziatas, 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 (DiIorio 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% parents of males expressed concern, 76% parents of females), that sexual behaviors would be "misunderstood" (76% parents of males, 72% 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 suggests 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 to 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.