

Qualitative Exploration of Sexual Experiences Among Adults on the Autism Spectrum: Implications for Sex Education

CONTEXT: *The increasing prevalence of autism since the 1990s has led to growing demand for sex education that meets the needs of persons on the autism spectrum. Yet there is a dearth of research documenting the firsthand experiences and perspectives of autistic individuals.*

METHODS: *A thematic analysis was conducted of in-depth, Internet-facilitated interviews with 24 adults on the autism spectrum who were recruited from Internet community spaces between November 2012 and May 2013. Inclusion criteria were self-identification as a person on the autism spectrum, being a U.S. resident, being aged 18 or older, and having the ability to communicate orally or through writing.*

RESULTS: *Participants were aged 18–61 and were living in the community at the time of interview, most with limited extrafamilial support. They were less likely than the general population to be heterosexual or gender-conforming and were more likely to have experienced romantic or sexual debut after age 18. Participants' most common concerns were courtship difficulties and sensory dysregulation in the context of partnered sexuality. These concerns were exacerbated by inadequate and inappropriate sex education experiences. Participants addressed challenges by using sensory barriers (e.g., latex gloves); planning when and how to have sex; negotiating alternatives to sexual scripts predicated on nondisabled experience; and practicing explicit and intentional communication.*

CONCLUSIONS: *Individuals on the autism spectrum would benefit from sex education that normalizes differences (e.g., in identities and experiences of sexuality), is offered throughout young adulthood, addresses disability-relevant sensory and communication needs, and includes practicing neurotypical sociosexual norms.*

Perspectives on Sexual and Reproductive Health, 2015, 47(4):171–179, doi: 10.1363/47e5715

By Jessica Penwell
Barnett and
Eleanor Maticka-
Tyndale

Jessica Penwell Barnett is assistant professor, Wright State University, Dayton, Ohio; and an affiliate faculty member, University of Windsor, Windsor, Ontario, Canada. Eleanor Maticka-Tyndale is distinguished university professor and Canada Research Chair in Social Justice and Sexual Health, University of Windsor.

Researchers and service providers increasingly advocate sex education for individuals on the autism spectrum* and provide guidelines for best practices.^{1,2} Unfortunately, these efforts occur amid a dearth of research documenting the firsthand experiences and perspectives of persons on the spectrum. Studies of sexuality in the lives of autistic individuals rely primarily on reports from family members, teachers or caregivers. We address this lacuna using data from in-depth, Internet-facilitated interviews with 24 adults on the autism spectrum who were living in the community.

BACKGROUND

In 2010, the Centers for Disease Control and Prevention estimated that one in 68 children aged eight years qualify for an autism spectrum disorder diagnosis.³ The diagnostic criteria for autism spectrum disorder are impaired social communication and repetitive or unusual interests and behaviors;⁴ such behaviors may include responses to sensory sensitivities or desensitization. These are salient aspects of the experience of autism and of particular relevance to this study. Of cases assigned an autism spectrum diagnosis in 2010, some 31% were classified as intellectually disabled (i.e., they had an IQ of less than or equal to 70).³ The substantial minority of instances in which autism

co-occurs with intellectual disability, along with the perceived impact of autism on self-awareness and ability to communicate, has led many researchers to use secondary sources for collecting information on sexuality in the lives of autistic people.⁵ This has produced a literature on caregiver and public perceptions of the sexuality of persons on the spectrum. We located 18 published studies assessing sexuality or intimate relationships in the lives of adults on the spectrum;^{5–22} only seven^{11,14–17,20,22} relied on data gathered from autistic people themselves, and all seven were quantitative.

Previous studies have tended to focus on “problem behaviors,” such as public masturbation, nonnormative expression of arousal or sexual interest (e.g., persistent courting), masturbation with objects (e.g., pillows) or in response to nonnormative stimuli (e.g., feet), and nonheteronormative arousal and behavior (e.g., same-sex).^{5–9} Realmuto and Ruble observed that many of these “problematic” behaviors are part of normal sexual development and common in children.¹⁰ Children “grow out” of these behaviors as

*There are debates about the most respectful way of referring to a person's disability identity; some prefer “people first” language, and others reject it. We use the terminology preferred by the participants in this study: “persons on the spectrum” or “autistic persons.”

they learn sociosexual norms through peer interaction and formal education. Persons on the spectrum are often excluded from these opportunities, particularly the social learning opportunities that are key to gaining knowledge about norms for sexualized or intimate interactions.^{1,9-12}

The discomfort that parents and caregivers often feel about autistic individuals' being sexual^{8,13,23} is reflected in delay or failure to provide sex education and concerns that its provision will introduce or increase sexual interest.^{9,24} Such concerns reflect the desexualization of people on the spectrum and people with disabilities generally.^{15,24-27} Researchers and parents sometimes discount the potential existence of reciprocal intimate relationships for autistic people.^{1,24} Nichols and Blakeley-Smith found that parents of adolescents with "higher skills" commonly expected, and hoped, that their children would have intimate relationships in the future, whereas parents of autistic adolescents with "limited abilities" were likely to discount the possibility of intimate relationships and expressed greater concern about sexual exploitation and abuse.²³ In contrast with these expectations, Byers et al. found that the degree of autism symptomatology was not associated with relationship experience among autistic adults who lived in community settings.¹⁵

Previous findings confirm that autistic individuals demonstrate sexual arousal, interest in sexuality and romantic relationships, and participation in sexual behaviors and relationships.⁵⁻²² Byers et al. found that autistic individuals with relationship experience who lived in the community reported moderate sexual satisfaction, infrequent sexual problems and low sexual anxiety.¹⁴ Greater sexual anxiety was more common among those with no relationship experience, as were lower levels of arousability, desire for partnered sex and pleasing thoughts about sexuality.¹⁵

Comparisons of autistic individuals with peers from the general population presumed to be nonautistic, or neurotypical, have primarily documented similarities in sexual experiences. No significant differences have been found between "high-functioning" autistic individuals (i.e., those with an IQ greater than 70) and their neurotypical peers in sexual experience or interest,^{18,20} formal sexual knowledge (e.g., anatomy identification, behavior description),^{12,18,20} marital satisfaction¹⁶ or romantic functioning (e.g., desire and experience).¹² In the sample studied by Byers et al., those in romantic relationships reported greater sexual satisfaction than those not in relationships,¹⁴ as has been found in neurotypical samples. Mehzabin and Stokes found, however, that high-functioning autistic individuals scored significantly lower than neurotypical controls on both social sexual knowledge (e.g., privacy rules) and amount of sexual experience.¹¹ Byers et al. suggested that lower levels of sexual activity for adults on the spectrum are best attributed to lack of partner availability.^{14,15}

Alongside these similarities, however, significant differences have been found in sexual orientation.^{14,15,20} In a study using a multidimensional measure of sexual orientation, individuals on the autism spectrum scored lower on

heterosexuality and higher on homosexuality, bisexuality and asexuality than did a neurotypical comparison group.²⁰ In addition, the proportions of autistic individuals in Byers and colleagues' samples who identified as sexual minorities (32%¹⁴ and 42%¹⁵) were substantially higher than the proportions of people in the general population who identify as homosexual or bisexual (4%) or as "something else" (4%).²⁸

Finding a life partner, being misunderstood and knowing how to behave in sexual situations are concerns expressed more often by people on the spectrum than by their neurotypical peers.^{11,29} These concerns reflect the relatively low rates of marriage and intimate relationships among autistic individuals. The highest rates of reported intimate partner relationships were in Renty and Royers' high-functioning sample (33%)³⁰ and in Byers et al.'s sample of individuals living in community settings (59%).¹⁵

METHODS

The current study used semistructured, Internet-facilitated interviews with adults on the autism spectrum to explore their sexual identities and experiences. The goal of the current analysis was to begin to develop an understanding of how autistic individuals describe their own sexuality and sexual experiences, and to examine the implications of those descriptions for the delivery of sex education. We were guided by an epistemological commitment to understanding identities and experiences, as well as the contexts in which they occur, as perceived by participants.³¹ Interviews were intended to provide a "big picture" of individuals' sexual identities and histories and how these were shaped by interactions with key institutions, such as schools and disability support services. Topics included receipt of support services and sex education, gender identity, sociosexual experiences, satisfaction with sexuality and intimacy, perceptions of how autism shapes sexuality and intimacy, desired supports for sexual health and hopes for research outcomes.

To ensure this work's accessibility and relevance to the autistic community, and its capacity to generate knowledge from the perspective of autistic individuals, a community advisor (an autistic person active in the Internet communities from which the sample was drawn) was recruited early on. The advisor reviewed study protocols and materials, providing suggestions for modification, and facilitated access to Internet community spaces (e.g., forums) for the purposes of recruitment. She also read the final analysis to check for neurotypical misperceptions or misinterpretations of the findings; none was indicated.

Following clearance from the University of Windsor research ethics board, participants were recruited between November 2012 and May 2013 through announcements on websites and Listservs serving the autistic community. Inclusion criteria were self-identification as a person on the autism spectrum, being a U.S. resident, being aged 18 or older, and having the ability to communicate orally or through writing. Advertisements contained a link to

the study webpage with information on study aims and a consent form. Upon giving consent, participants were redirected to a 21-question survey asking for basic demographic information and an e-mail address for further contact. Participants wrote in their racial or ethnic background and gender identity; for sexual identity, they were provided with a list of choices and a write-in option, and could give multiple responses.

Participants completed interviews (conducted by the first author) in the Internet-facilitated format of their choice: e-mail, chat or streaming audio (i.e., Skype). Eighteen e-mail interviews proceeded through several iterations of sending 3–5 questions to participants, receiving their responses, and responding with probes or an additional 3–5 questions. These extended over three months, on average (range, 1–12 months). Two chat interviews and four streaming audio interviews followed a back-and-forth rhythm of question and answer; these lasted an average of 4–4.5 hours. Chat and streaming interviews of more than 2–2.5 hours were broken into two sessions.

E-mail and chat interviews were exported and formatted for analysis in a word processor. Streaming audio interviews were professionally transcribed, then read and corrected by the first author; sections requiring clarification were noted. All transcripts were sent to participants for a member check, wherein participants were asked to respond to clarifying questions and invited to make changes that would render their meaning clearer, enhance understanding of their experiences or perspectives, or make them more comfortable with what they had shared. No participant made substantive changes.

This article reports results of a descriptive analysis of the demographic survey and an inductive, semantic-level thematic analysis of the interview data related to participants' sexual and romantic experiences. (Semantic-level analysis focuses on what participants actually say, rather than on possible underlying conceptualizations.³²) The purpose was to sketch commonalities of experience among participants, and so provide a "rich thematic description"^{32(p. 83)} of important themes in the sexual and relationship experiences of adults on the autism spectrum who live in community settings. Themes that emerged from the analysis were organized under three research questions: What concerns do autistic adults living in the community have about sexuality? How do they address these concerns? How can professionals support autistic individuals in pursuing the sociosexual outcomes they desire?

The analysis, conducted by the first author, followed the phases of thematic analysis outlined by Braun and Clarke.³² First, the author read each transcript, jotting down initial impressions and potential themes. This stage occurred contemporaneously with data collection and member checking, and informed avenues of inquiry in later interviews. Next, the author generated a set of initial codes based on the close reading of transcripts. Codes were then collated into preliminary themes. In the final phase, the author checked the integrity of the preliminary themes in relation to their

component coded extracts, as well as to the data set as a whole. Conceptualizations of each theme were then refined, and extracts that exemplified the themes were selected.

RESULTS

Sample Characteristics

The sample consisted of 24 individuals aged 18–61 (mean, 37). Twenty-two identified themselves as white or Caucasian, and one of these individuals also identified as Jewish. Twenty-one participants had completed some post-secondary or professional education. Although we did not seek to assess either IQ or severity of autism symptomatology among participants, this level of education suggests that most had average or above-average IQs. In addition, individuals' participation in oral or text-based interviews suggests certain capacities for social communication.

At the time of the interviews, all participants were living in the community. Many lived independently with no support other than from a spouse or family member. Others benefited from supports such as supplemental income, health insurance or a personal assistant. The most commonly reported types of support were therapy (e.g., individual psychological, behavioral, physical), social groups and vocational rehabilitation. The majority of participants were in a romantic relationship: Nine were married; two were in a domestic partnership (one legally recognized, and one self-described); three were cohabiting; two were in serious, noncohabiting relationships; and eight were single.

Distinctive Features of Sexuality

The sample was characterized by considerable gender nonconformity. This has important implications for dating and mating in a society that is heterosexually organized (e.g., in perceived desirability or access to mates). Thirteen participants endorsed a feminine identity, six a masculine identity and five a genderqueer or androgynous one. This proportion of gender-variant identities is substantially higher than what would be expected in the general population.^{33,34} Few who endorsed a binary identity perceived themselves, or were perceived by others, to be typically masculine or feminine. This level of gender nonconformity was acknowledged by both the community advisor and participants. For example, one participant commented:

"Gender has been one of those terms that I'm trying so hard to accurately define.... A lot of ... self-advocates do ... perceive gender differently than a lot of [neurotypical] individuals, and perhaps we don't quite identify as solidly with a gender as we're growing up [as neurotypical people do]."—Vivian, 31, *heterosexual/bicurious, woman**

A second, related, distinctiveness was the distribution of sexual identities. Eleven participants identified as

*Quotations are identified using pseudonyms chosen by participants, participants' age, and their sexual and gender identities. This information provides context for the quotations and respects the subjectivity of participants, who may experience objectification and depersonalization in their interactions with professionals.

Every participant discussed struggles with sensory regulation that were frequently emotionally upsetting or physically painful.

heterosexual, and three of them claimed additional identities, including bicurious, asexual and sapiosexual (denoting primary attraction to intelligence). Six participants identified as asexual, but also cited identities that related to relationship style or (nonsexual) intimate partner preferences: bisexual, pansexual, polyamorous, heterosexual and heteroromantic. Four individuals identified as bisexual-queer (one also endorsed a polyamorous identity), and three as lesbian or gay.

Finally, participants reported later sexual or romantic debut than that found in a previous study of the general population.³⁵ Only four reported dating in high school, and the remainder had had their first relationship experiences after age 18 (five after age 30).

Common Concerns

•**Courtship.** The delayed timeline for sexual and relationship initiation contributed to courtship concerns, especially for those who were older or identified as male. For male-identified participants, expectations for adept sociality were a key barrier to relationship formation and sexual experience. One participant remarked:

“Yes, it’s just like the Justin Timberlake song with the line ‘funny, how a few words can turn into sex.’ So true and also why sex is so very awkward and hard for autistic men.... Autism influences how we can interact with others, and dating can be soooooo hard. Girls are prone to fall for smooth talkers.”—*Jack, 43, asexual/heterosexual, man*

The nonverbal and indirect (often purposefully oblique) communication style that characterizes flirting and other early courtship behaviors posed challenges for most participants. CS, a 43-year-old heterosexual woman, expressed a common difficulty with flirting, relating that she had a “steep learning curve with nonverbal facial/body cues.” Difficulty with indirect communication was encapsulated by the experience of abby normal, a 52-year-old bisexual man:

Interviewer (I): You [and your new girlfriend] corresponded for a long time before [you met]. Do you think she was interested in having a romantic relationship during this correspondence with you, prior to her decision to meet? If so, did you realize it?

Participant (P): I did not realize it, but she later told me, yes. It all caught clueless me by surprise. 😬

Difficulty with or inability to interpret nonverbal and oblique verbal communication—or to communicate in these ways—put participants at risk for missing out on relationship opportunities or pursuing where no opportunity existed. This often left participants feeling insecure. For instance, millie33, a 55-year-old genderqueer lesbian, described her experience: “I’ve always been baffled by everything, people. I get blindsided. Then I think that I don’t pick up on cues that people think are very obvious about being rejected and/or being interested, both, everything.”

Many participants experienced difficulties both receiving and sending messages of interest or disinterest. Difficulty sending messages of interest was due both to participants’

not using nonverbal facial or body cues in a neurotypical way and to ignorance and violation of unstated rules governing sociosexual interactions. For example, one participant talked about how his nonautistic partner’s expectations did not match his own:

“When [my partner] and I were first dating, he wasn’t sure if I was into him—he was used to kissing on a first date and sex soon after, and it took a long time for me to want to try kissing (which I soon found out was really unpleasant due to sensory sensitivity on my face and lips and motor control issues with fine lip movements). I also was telling him that I was interested, but in a low-key, not exuding or explicitly sexy sort of way.”—*Hank, 33, queer, transgender/genderqueer*

•**Sensory dysregulation.** The experience of sensory dysregulation and mismatch between personal sensory needs and social context (e.g., preferences of relationship partners, construction of sociosexual spaces) that Hank indicated was the most frequently occurring theme in the data. Every participant discussed struggles with sensory regulation that were frequently emotionally upsetting or physically painful.

Many participants experienced sensory overload or found particular sensations associated with sex (e.g., sounds, textures) painful or extremely unpleasant. For some, this meant that all (or all partnered) sex was painful. For others, overstimulation and sensitivity to particular sensations needed to be managed to achieve a pleasant sexual experience. Often, management of stimulation levels was complicated by delays in conscious awareness of sensations or delayed ability to communicate shifting needs during sex. M, a 39-year-old heterosexual woman, described her experience this way:

“My sensory processing differences make some kinds of touch too intense or even physically painful. I sometimes have trouble recognizing this in real time while it’s happening and/or communicating this to a partner. Sometimes I will realize that I’ve been gritting my teeth and enduring something unpleasant for five minutes or so without noticing it, before I get my act together to push someone’s hand away or ask for a different kind of touch.”

In addition to delayed conscious awareness, several participants reported limited conscious awareness of physical sexual sensations, including arousal and stimulation, as illustrated in the following exchange:

I: How do you define sexual arousal?

P: Not sure, maybe body-feeling desire for sex.

I: What do you do when you’re aroused and don’t have a partner available?

P: Nothing different than usual. Not sure would recognize it anyways.

I: How often do you feel aroused?

P: Less than once a year, maybe. Hard to know for sure, not likely to actually notice.

—*Dragonfly, 30, asexual/pansexual/polyamorous, odd*

Sexual receptivity was hampered when participants’ general state of anxiety or overstimulation created a barrier

to feeling sexual or being receptive to intimacy. Rusty, a 61-year-old heterosexual man, identified physical and mental tension as his chief sexual concern:

I: What are the things you would change?

P: The inner tension that stops me from being sexually aroused or in physical contact with people.

When the interviewer asked Rusty if the inner tension was mental, physical or both, he replied, "It is both, though it is more mental."

•Inadequate sex education. Participants identified inadequate and disability-irrelevant sex education as a contributor to their courtship and sensory dysregulation concerns. Few individuals reported receiving useful sex education from their parents, and several said their parents had never discussed sexuality with them. Parents most often had merely provided a book about reproductive biology. Vivian, the 31-year-old heterosexual and bicurious woman, said, "The only instance where my parents ever talked to me about sex when I was growing up was a little pop-up book my mom had showed me about reproduction. But that's the only time."

Reproductive information was also the type of knowledge most likely to be provided in school. Some participants had not received even this limited education at school, whether because of general education norms at the time, because they skipped the grade in which it was provided or because they were segregated into special education classrooms. Consonant with previous findings,²⁴ participants who described having greater functional limitations or using more support also tended to report an absence of both parental and school sex education, in contrast to participants who described fewer limitations and support, even though the former were not less likely to have sexual experience. Dragonfly, who uses assistive communication devices, had been sequestered in a special education classroom for much of public schooling and had not received any school-based sex education. This participant's parents had deemed requests for information about sexuality "inappropriate" and conveyed only condemnation of sexuality. When asked what they had ever told the participant about sex, Dragonfly replied: "Only to say it is bad. Not explain anything else. Found out about special parts of body from books."

Participants who had received sex education at school found it wanting in a number of consistent ways. They typically had received no education about nonheterosexuality and identified this as a gap. They also identified several social aspects of sexuality that needed to be explicitly taught, including negotiation of competing sexual needs and sensory experiences, courtship skills, the signs of a good relationship, and subtle signs of abuse or exploitation. Vivian said: "I only learned about the obvious indicators of sexual assault (physical force, rape, etc.) and not the subtle indicators (grooming techniques)." Elle, an 18-year-old woman who is asexual and bisexual, reported: "I think autistic people should be given more specifics, instead of the vague generalizations ('when you love somebody...') that sex ed sometimes devolves into. I like specificity."

The need for explicit sex education was also relevant to complaints about what had been taught. For example, participants identified graphic images of diseased genitals and morality tales as misleading. Rick, a 26-year-old heterosexual male, related:

"I felt as though I was being told that sex was extremely dangerous, and I could contract hellish diseases if I wasn't careful. Yet they only told us (in a deliberate choice of words) to wait until marriage, which seemed to me quite odd. How did marriage protect against these awful diseases? I couldn't figure it out."

Finally, participants indicated that sex education often had not seemed relevant when it had been provided, largely because it had not covered topics of interest, or because they had not yet developed sexual feelings or were asexual. Several individuals commented on these aspects. Jack recalled:

"No mention was made about how you were supposed to feel about sex. How did you ask a girl out on a date? School talked about the mechanics of sex, but none of the moral or social conventions around sex. And no mention was made if you were not interested in sex. The impression is that you were supposed to be interested, no questions."

Billy Joel, a 23-year-old asexual woman, had this to say:

"I understand how crucial it was to learn at school even though it was boring, because I didn't get any of it at home. At the same time, I feel like it was learning about something not real. There was no conceptualization for what sex really is, and as an adult (well, a college student), it took people literally telling me that it was fun, enjoyable, and felt good for me to get why people engage in those behaviors."

When participants were asked what sexual health supports they would like to have received, they gave several common responses, which Dragonfly summed up in the following remarks:

"Reasonable education about risks, methods, tools, and diversity in sexual desires. Especially how to help make [sex] not painful, or less painful. When bodies are not reacting right. Instead of just creating fear of pregnancy and death. Using appropriate words. Penis, vagina, breasts, testicles, etc. Not kid-words or 'polite' words. Education about some alternative or unconventional sexual activities. Education about difference between real life and pornographic fantasies, movie sex, book sex. Education about slang words people use to describe sexual activities, body parts, that get used in invitations for sexual activities."

Shared Strategies for Success

In the absence of adequate, disability-relevant sex education, participants independently formulated a number of strategies for achieving desired sexual and relationship outcomes. A key strategy for maintaining mutually satisfying connection in the context of general anxiety or overstimulation was partner accommodation in the form of downtime, followed by participant-centered reengagement (i.e., the type of physical or sexual intimacy preferred by participants). One participant described a recent situation in which she and her partner had used this strategy:

Participants identified inadequate and disability-irrelevant sex education as a contributor to their courtship... concerns.

“The last time we had sex was after a very busy, busy day. We had made plans to have sex that night after our child went to bed, but I was so wound up and overstimulated from the day that I couldn’t even fathom sex at that moment. I just wanted to be left alone for a bit. An hour later, my wife started to slowly touch and caress me, and that helped me to get into the mood, and thus we had sex.”
—C.Byrd, 29, lesbian, woman

The intentional, open and explicit communication required to plan sex or maintain flexibility... was the central strategy that emerged.

The strategy of planning sex was mentioned by several participants. Planning was helpful for establishing shared expectations, increasing the likelihood of a receptive body-mind state and preparing for particular needs, including those relevant to the additional disabling conditions that many participants and their partners experienced. In contrast, many conditions called for flexibility. As Dragon Tears, a 35-year-old heterosexual woman, remarked: “It’s hard to say sometimes [when we’ll have sex], because we both have medical issues that can be unexpected, so one has to go with the flow, so to say, on how we both are doing.”

The intentional, open and explicit communication required to plan sex or maintain flexibility with regard to competing needs was the central strategy that emerged. This strategy, which we call “literal declaration,” was discussed by every participant, and is characterized by direct, explicit disclosure. It stands in contrast to nonverbal and oblique verbal (e.g., euphemism- or innuendo-based) communication, which relies on assumptions of shared knowledge for its effectiveness. In the context of dating and relationships, literal declaration was particularly important for communicating feelings, intentions and agreements. Planning and literal declaration were especially important for participants at times of heightened emotions, anxiety or overstimulation, because verbal communication was more difficult for many at these times. Laura, a 30-year-old heterosexual woman, explained it in this way:

“I am also learning to write on a paper what I like [sexually] ... and he follows my INSTRUCTIONS ;) and he is EXCITED about it :) !

“I personally need to write some things down because first of all, I have difficulties verbalizing my thoughts and second because I am a bit conservative and as my husband would say BASHFULL about THIS TOPIC :p !”

Literal declaration was also key to enacting other strategies for mutually satisfying sensual pleasure, such as the use of barrier techniques and “alternative” sexual activities. Some participants successfully used direct contact barriers, such as latex gloves and blankets, to mitigate the sensory dysregulation caused by partnered sex. The use of these barriers must be negotiated. Negotiation was also required to develop sexual repertoires that are not dependent on sexual scripts based on the experiences and functioning of unimpaired and nondisabled individuals. For example, participants frequently needed to negotiate alternatives to sexual interactions structured by the strong sociocultural priority placed on penile-vaginal intercourse (i.e., the coital imperative) or even genital contact. Negotiation

was complicated because this norm renders intercourse (or genital contact) as the unspoken, assumed basis for sexual interactions, and because this contact is what most sexual partners expect from “sex.” Participants also needed to negotiate other sensual practices that accommodated their sensory needs. Rick described how he and his neurotypical girlfriend collaborate to meet his needs:

“As of now, I am unable to climax without me manually stimulating myself, even with her. We’re working on that, though, trying out different topical solutions and other methods.... One thing I’m working with her is to replicate my self-stimulation technique; she was astonished when I showed her how strong my grip was on my penis, and was worried she might damage me.”

Another successful strategy was described by Billy Joel, who accesses physical intimacy in the context of her friendships, which serve as her intimate relationships: “I love hugs and hug people as much as I can. I really like long and strong hugs. I like holding hands with my friends, especially in strange places or when I am stressed because then I feel a little better.”

DISCUSSION

Comparing the sexual and romantic experiences of autistic participants with those of neurotypical individuals reaffirms the normativity of neurotypical ways of doing and being while pushing autistic ways of doing and being to the margins. Yet in tailoring educational interventions to meet the needs of adults on the autism spectrum, it is critical to address the features of sexuality for this population that are distinctive relative to the neurotypical norm. We reject the idea that neurotypical individuals’ ways of experiencing sexuality should be taken as a standard for comparison, and we understand differences between neurotypical persons’ sexual experiences and those of the autistic individuals in our sample as ones of degree rather than of kind.

Study participants’ sexuality was distinctive from normative, neurotypical sexuality in three key ways. First, participants expressed a considerable degree of gender nonconformity in both identity and presentation. Second, more participants endorsed a nonheterosexual identity than a heterosexual one. Third, delayed sexual and relationship debut was common. Each of these was experienced by participants as a deviation from the norm and exacerbated the inadequacy of available sex education.

With few exceptions, participants did not report having received adequate sex education at home or in school, and the education they described was pervasively heteronormative. They also expressed concern about its failure to address the disability-relevant sexual experiences presented here and to convey information in a fashion consonant with literal declaration. Complaints about the inadequacy of sex education in school are not unique to this sample, or to persons with disabilities, as youth in general report that they do not receive adequate information or opportunities to build sociosexual skills.^{36,37} While this speaks to the need for more robust sex education for all students, inadequate

school-based programs are especially problematic for anyone whose life does not fit the cisgendered,* heterosexual, abled norm. When one fits this norm, one can learn about sociosexuality by observing the social world around oneself. When one does not fit this norm, it is not possible to learn through observation, and forums for self-education (e.g., websites, books) are severely limited. Reliance on self-education through observation and interaction is further problematic for persons on the autism spectrum, who often do not learn information this way, and instead require information to be directly and explicitly communicated.

Participants' two most salient sexual concerns—courtship and sensory dysregulation—were linked with the two criteria used to distinguish autism spectrum disorder: social communication difficulties and unusual or repetitive behaviors. These distinctions are not considered here as deficits, but as disadvantages to pursuing romantic and sexual satisfaction in the context of ableist cultural norms and social institutions. Participants articulated several strategies for managing these concerns, including the use of sensory barriers, planning when and how to have sex, negotiating alternatives to dominant, abled sexual scripts and practicing literal declaration.

Our findings align with previous findings documenting that compared with rates in the general population, rates of nonheterosexuality^{14,15,20} and gender nonconformity are higher among persons on the spectrum.^{38–40} They also contextualize earlier findings that autistic adults are less likely to be in romantic relationships than are their neurotypical peers,^{15,28} particularly the finding of Byers et al.¹⁵ that young, heterosexual autistic males were the subgroup of autistic adults least likely to have relationship experience. For participants in the current study, the most challenging aspect of dating and mating was finding a romantic partner.

In concurrence with previous research, we found that two components of this challenge were deficits in knowledge about neurotypical sociosexual norms and expectations^{1,9–12} and limitations on social communication. These made it difficult to perform typical dating behaviors such as flirting and oblique communication of romantic interest or disinterest. The demand for an abled performance of adept sociality was particularly onerous for males seeking relationships with females, owing to dominant heterosexual scripts. Because access to romantic partners was more dependent on adept sociality for males seeking relationships with females, it is not surprising that they are less likely to have relationship experience than are others on the spectrum. Identifying dominant sociosexual communication (including nonverbal communication) and relationship scripts, then adapting and practicing scripts that are more compatible with autistic individuals' needs and preferences, would be important aspects of comprehensive sex education for autistic individuals.

Earlier findings that autistic youth have a reduced likelihood of having romantic relationship experience,¹⁵ and that romantic “outcomes” are poorer for autistic adults in their 20s than for those in their 30s,⁴¹ are contextualized by our

finding that most participants did not even begin dating until after age 18—and several did not date until their 30s. Sixteen of the 24 participants were, however, in romantic relationships at the time of their interviews. Taken together, these findings indicate that delayed romantic debut should not be confused with forgone debut, and that milestones of sociosexual development for this population may well differ from those for the neurotypical population. Making sex education available throughout the life course is critical for persons on the autism spectrum, as are normalizing and providing strategies for diffusing partner expectations that are discordant with sociosexual debut among individuals in their 20s or older.

Though participants identified courtship as the most challenging part of sexuality, sensory dysregulation was the most commonly occurring theme. This is particularly salient given that extant research and sex education programming pay substantial attention to how social communication differences affect sexuality, while sensory dysregulation is not often, or robustly, addressed. The salience of sensory dysregulation and participants' strategies for success in the context of such dysregulation suggest that some of the “unusual” sexual behaviors noted in previous studies may be adaptive responses to sensory experiences. The pathologization of such adaptive responses to body-mind differences parallels that embedded in the diagnostic criteria themselves, which define behavioral responses to aversive sensory sensitivities, rather than the sensitivities themselves, as impairment.

Strengths and Limitations

The contribution of qualitative inquiry is its detailed description and potential to provide nuanced understanding of the experiences of research participants who have some shared characteristic. Here, this is an individual's own identification as a person on the autism spectrum. Generalizability is not a claim of qualitative research. All participants were living in the community at the time of interviews, most with limited extrafamilial support. Most had some postsecondary or professional education and identified themselves as white. Participants' level of education suggests that they have IQs in the typical range. All data generated in this study were self-reported; thus, all participants had the relative ability to report somewhat complex information in oral or written form, a degree of skill that not all autistic individuals possess. The findings of this research should be understood within this scope.

Conclusions

Generally inadequate, ableist and heterosexist sex education left participants with few resources to navigate difficult situations or capitalize on opportunities to achieve desired ends. To support comprehensive sexual health for autistic individuals, sex education should be disability-friendly and

Making sex education available throughout the life course is critical for persons on the autism spectrum.

*A cisgendered person is one whose gender identity aligns with the sex-gender assigned at birth.

developmentally appropriate. Our findings suggest that for individuals on the autism spectrum, such education should be offered at regular intervals throughout the life course, particularly in young adulthood; communicate information factually, explicitly and in detail; describe and allow for the practice of sociosexual norms and skills; provide examples of the subtle signs of abuse and exploitation; and be autism spectrum–normative by normalizing sexuality and gender variance, sensory differences and delayed sociosexual milestones. The findings also suggest the need for additional research on the sexual and sex education experiences of persons on the autism spectrum that includes the perspectives of autistic persons themselves, particularly those who experience more comprehensive communication limitations than did participants in this research. In particular, further research is needed on the sensory experiences of autistic individuals and their implications for sexual health.

REFERENCES

- Koller R, Sexuality and adolescents with autism, *Sexuality and Disability*, 2000, 18(2):125–135.
- Wolfe P, Condo B and Hardaway E, Sociosexuality education for persons with autism spectrum disorders using principles of applied behavior analysis, *Teaching Exceptional Children*, 2009, 42(1):50–61.
- Centers for Disease Control and Prevention, Prevalence of autism spectrum disorder among children aged 8 years—autism and developmental disabilities monitoring network, 11 sites, United States, 2010, *Morbidity and Mortality Weekly Report*, 2014, Vol. 63, No. SS-2.
- American Psychiatric Association (APA), *Diagnostic and Statistical Manual of Mental Disorders*, fifth ed., Washington, DC: APA, 2013.
- Hellemans H et al., Sexual behavior in high-functioning male adolescents and young adults with autism spectrum disorder, *Journal of Autism and Developmental Disorders*, 2007, 37(2):260–269.
- Dozier CL, Iwata BA and Worsdell AS, Assessment and treatment of foot-shoe fetish displayed by a man with autism, *Journal of Applied Behavior Analysis*, 2011, 44(1):133–137.
- Haracopos D and Pedersen L, Sexuality and autism: Danish report, Kettering, United Kingdom: Autism Independent UK, 1992, http://www.autismuk.com/?page_id=1293.
- Ruble LA and Dalrymple NJ, Social/sexual awareness of persons with autism: a parental perspective, *Archives of Sexual Behavior*, 1993, 22(3):229–240.
- Tissot C, Establishing a sexual identity: case studies of learners with autism and learning difficulties, *Autism*, 2009, 13(6):551–566.
- Realmuto GM and Ruble LA, Sexual behaviors in autism: problems of definition and management, *Journal of Autism and Developmental Disorders*, 1999, 29(2):121–127.
- Mehzabin P and Stokes MA, Self-assessed sexuality in young adults with high-functioning autism, *Research in Autism Spectrum Disorders*, 2011, 5(1):614–621.
- Stokes M, Newton N and Kaur A, Stalking, and social and romantic functioning among adolescents and adults with autism spectrum disorder, *Journal of Autism and Developmental Disorders*, 2007, 37(10):1969–1986.
- Kalyva E, Teachers' perspectives on the sexuality of children with autism spectrum disorders, *Research in Autism Spectrum Disorders*, 2010, 4(3):433–437.
- Byers ES et al., Sexual well-being of a community sample of high-functioning adults on the autism spectrum who have been in a romantic relationship, *Autism*, 2013, 17(4):418–433.
- Byers ES, Nichols S and Voyer SD, Challenging stereotypes: sexual functioning of single adults with high functioning autism spectrum disorder, *Journal of Autism and Developmental Disorders*, 2013, 43(11):2617–2627.
- Lau W and Peterson CC, Adults and children with Asperger syndrome: exploring adult attachment style, marital satisfaction and satisfaction with parenthood, *Research in Autism Spectrum Disorders*, 2011, 5(1):392–399.
- Ousley OY and Mesibov GB, Sexual attitudes and knowledge of high-functioning adolescents and adults with autism, *Journal of Autism and Developmental Disorders*, 1991, 21(4):471–481.
- Stokes MA and Kaur A, High-functioning autism and sexuality: a parental perspective, *Autism*, 2005, 9(3):266–289.
- Van Bourgondien ME, Reichle NC and Palmer A, Sexual behavior in adults with autism, *Journal of Autism and Developmental Disorders*, 1997, 27(2):113–125.
- Gilmour L, Schalomon PM and Smith V, Sexuality in a community based sample of adults with autism spectrum disorder, *Research in Autism Spectrum Disorders*, 2012, 6(1):313–318.
- Hellemans H et al., Sexual behavior in male adolescents and young adults with autism spectrum disorder and borderline/mild mental retardation, *Sexuality and Disability*, 2010, 28(2):93–104.
- Konstantareas MM and Lunsy YJ, Sociosexual knowledge, experience, attitudes, and interests of individuals with autistic disorder and developmental delay, *Journal of Autism and Developmental Disorders*, 1997, 27(4):397–413.
- Nichols S and Blakeley-Smith A, “I’m not sure we’re ready for this”: working with families toward facilitating healthy sexuality for individuals with autism spectrum disorders, *Social Work in Mental Health*, 2009, 8(1):72–91.
- Ballan MS, Parental perspectives of communication about sexuality in families of children with autism spectrum disorders, *Journal of Autism and Developmental Disorders*, 2012, 42(5):676–684.
- Gougeon NA, Sexuality and autism: a critical review of selected literature using a social-relational model of disability, *American Journal of Sexuality Education*, 2010, 5(4):328–361.
- Rosqvist HB, Becoming an “autistic couple”: narratives of sexuality and couplehood within the Swedish autistic self-advocacy movement, *Sexuality and Disability*, 2014, 32(3):351–363.
- Shakespeare T, Disabled sexuality: toward rights and recognition, *Sexuality and Disability*, 2000, 18(3):159–166.
- Mosher WD, Chandra A and Jones J, Sexual behavior and selected health measures: men and women 15–44 years of age, United States, 2002, *Advance Data from Vital and Health Statistics*, 2005, No. 362.
- Sperry LA and Mesibov GB, Perceptions of social challenges of adults with autism spectrum disorder, *Autism*, 2005, 9(4):362–376.
- Renty JO and Royers H, Quality of life in high-functioning adults with autism spectrum disorder: the predictive value of disability and support characteristics, *Autism*, 2006, 10(5):511–524.
- Smith DE, *The Conceptual Practices of Power: A Feminist Sociology of Knowledge*, Boston: Northeastern University Press, 1990.
- Braun V and Clarke V, Using thematic analysis in psychology, *Qualitative Research in Psychology*, 2006, 3(2):77–101.
- Olsson S-E and Möller AR, On the incidence and sex ratio of transsexualism in Sweden, 1972–2002, *Archives of Sexual Behavior*, 2003, 32(4):381–386.
- Rosser BRS et al., Capturing the social demographics of hidden sexual minorities: an Internet study of the transgender population in the United States, *Sexuality Research and Social Policy*, 2007, 4(2):50–64.

35. Eaton DK et al., Youth Risk Behavior Surveillance—United States, 2009, *Morbidity and Mortality Weekly Report*, 2010, Vol. 59, No. SS-5.
36. Byers ES et al., An adolescent perspective on sexual health education at school and at home. I. High school students, *Canadian Journal of Human Sexuality*, 2003, 12(1):1–17.
37. Byers ES et al., An adolescent perspective on sexual health education at school and at home. II. Middle school students, *Canadian Journal of Human Sexuality*, 2003, 12(1):19–33.
38. Bejerot S et al., The extreme male brain revisited: gender coherence in adults with autism spectrum disorder, *British Journal of Psychiatry*, 2012, 201:116–123.
39. Ingudomnukul E et al., Elevated rates of testosterone-related disorders in women with autism spectrum conditions, *Hormones and Behavior*, 2007, 51(5):597–604.
40. de Vries ALC et al., Autism spectrum disorders in gender dysphoric children and adolescents, *Journal of Autism and Developmental Disorders*, 2010, 40(8):930–936.
41. Marriage S, Wolverson A and Marriage K, Autism spectrum disorder grown up: a chart review of adult functioning, *Journal of the Canadian Academy of Child and Adolescent Psychiatry*, 2009, 18(4):322–328.

Acknowledgments

The authors thank Emily Lynn Williams for contributions as a community advisor, and the Canada Research Chair program for funding this research.

Author contact: jessica.p.barnett@wright.edu