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## “I tell them what I can feel and how far my legs can bend”: Optimizing sexual satisfaction for women with spina bifida

Courtney S. Streur, MD<sup>a</sup>, Christine L. Schafer, BS<sup>a</sup>, Valerie P. Garcia<sup>a</sup>, Elisabeth H. Quint, MD<sup>b</sup>, John Wiener, MD<sup>c</sup>, David E. Sandberg, PhD<sup>d</sup>, Claire Kalpakjian, PhD<sup>e</sup>, Daniela A. Wittmann, PhD<sup>a</sup>

<sup>a</sup>Department of Urology, University of Michigan

<sup>b</sup>Department of Obstetrics and Gynecology, University of Michigan

<sup>c</sup>Department of Surgery, Duke University

<sup>d</sup>Department of Pediatrics, University of Michigan

<sup>e</sup>Department of Physical Medicine and Rehabilitation, University of Michigan

### Abstract

**Background:** There is a high reported rate of sexual dysfunction among women with spina bifida, but little is known about the etiology of this or how sexual satisfaction could be improved.

**Aim:** To identify, through the words of the women with spina bifida, perceived causes of diminished sexual satisfaction and recommendations to optimize partnered sexual encounters.

**Methods:** In this qualitative study, we conducted semi-structured individual interviews with 22 women with spina bifida (median age 26.5 years, range 16-52) who have had a romantic partner. Using Grounded Theory, interviews were independently coded by 3 reviewers. Disagreements were resolved by consensus.

**Outcomes:** We identified overlapping themes of issues women experienced during sexual intimacy and strategies they learned to improve sexual encounters.

**Results:** Seven salient themes emerged from the data: 1) fear of rejection with resulting difficulty setting boundaries and risk of coercion; 2) conflict between spontaneity versus self-care in sexual encounters; 3) worry about incontinence during sex; 4) trial and error in learning optimal sexual positions; 5) decreased genital sensation; 6) safety considerations; and 7) sharing advice with other women with spina bifida.

**Clinical Implications:** As their sexual satisfaction is influenced by physical features as well as psychological, interpersonal, and sociocultural factors, optimizing the sexual satisfaction of

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**Corresponding Address:** Courtney S. Streur, Department of Urology, Michigan Medicine, 1500 E. Medical Center Drive, Taubman F3055, Ann Arbor, MI 48109, coshepar@med.umich.edu, 734-615-3038.

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women with spina bifida is best managed with a holistic approach utilizing a biopsychosocial model.

**Strengths and Limitations:** The sample included women with a diverse range of functional impairment. Women were forthright with their comments and thematic saturation was reached. Recruitment was primarily from a single Midwestern institution, which may have limited sampled perspectives.

**Conclusions:** While women with spina bifida encounter challenges during sexual encounters, strategies focused on improving communication with partners and addressing specific physical considerations can potentially enhance their sexual experiences.

### Keywords

Myelomeningocele; spinal dysraphism; sexual health; orgasm

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### Introduction

Although commonly perceived by society and health care providers as asexual,<sup>1-3</sup> women with disabilities in general, and those with spina bifida specifically, are interested in and engage in sex. In fact, up to 55% of women with spina bifida are sexually active by age 35, and the majority who have not yet experienced intercourse are nonetheless interested.<sup>4,5</sup> However, sexually active women with spina bifida also report a high incidence of sexual dysfunction and diminished satisfaction.<sup>6-10</sup> This may be because their condition, caused by incomplete closure of the neural tube during development and occurring in up to 4 per 10,000 live births born in the United States each year,<sup>11</sup> has the potential to negatively impact a sexual encounter. While the impact of this congenital defect varies greatly between women, it is often associated with physical manifestations, including mobility limitation, diminished sensation, and abnormal bladder and bowel function. These physical sequelae affect people with spina bifida psychosocially, with research revealing delays in social development, poor self-image and limited confidence in voicing their opinions.<sup>12-15</sup> Such factors conceivably influence how a woman with spina bifida experiences a sexual relationship.

Yet, the sexual experiences of women with spina bifida remains poorly described, which limits providers' abilities to provide targeted counseling. Although up to 55% of women with spina bifida are sexually active, research on sexual health for people with spina bifida has primarily focused on men.<sup>16</sup> Emerging research on women has concentrated on describing how spina bifida impacts a sexual encounter physically. For example, it has been demonstrated that urinary and fecal incontinence during sex, or associated worry, is pervasive and may impact sexual function and satisfaction.<sup>7-9,17</sup> Genital sensation and ability to orgasm varies by level of lesion, with women with higher levels of lesion experiencing less sensation and ability to orgasm.<sup>17,18</sup> Approximately 80% of women have some sensation and 37% experience orgasm, compared to an estimated 65-86% of women without spina bifida who experience orgasm.<sup>18-20</sup> Vaginal lubrication may also be decreased.<sup>21</sup> To date, little is known about how the physical aspects of spina bifida in women influences their perception of a sexual encounter, what additional relational, psychological,

and social considerations influence their intimate relationships, or what could be done to improve their sexual satisfaction.

Adopting a biopsychosocial framework, we sought to characterize the partnered sexual experiences of women with spina bifida, factors contributing to their sexual satisfaction, and advice they would offer their peers with spina bifida. As this is an area of limited understanding, we conducted an exploratory qualitative study to characterize the experiences, concerns and recommendations using the women's own voices.

## Materials and Methods

The analysis presented here is part of a larger study investigating the education and experiences of women with spina bifida regarding their sexual and reproductive health.<sup>3,22,23</sup> Institutional Review Board approval was obtained from a large tertiary referral institution and informed consent was obtained from all participants.

### Research Team

A pediatric urologist who cares for women with spina bifida (CSS), a sex therapist, licensed social worker, and sexual health researcher with qualitative research expertise (DW), and two undergraduate students trained in qualitative research methods for the purpose of this study (CS and VG), participated in data acquisition and analysis.

### Study Sample

Women with spina bifida or spina bifida occulta, ages 16 years or older, were invited to participate. Women with spina bifida occulta were included based on preliminary data demonstrating that sexual and reproductive health may be impacted by the diagnosis.<sup>24</sup> Sixteen was used as the minimum age as that is the youngest age participants can consent independently. This ensured that the women could participate without their parent's knowledge due to the potential of this influencing their responses. Women were excluded if they had intellectual disability, determined by a relevant diagnosis code in their medical record or inability to answer questions appropriately and independently, or if they were younger than age 16. Whereas the larger study included women with and without partnered sexual experiences, only women with current or previous romantic partners were included in the current analysis.

### Recruitment

A convenience sample of participants were recruited by two methods. First, we sent a letter to 132 women with spina bifida or spina bifida occulta followed by any type of health care provider at a single academic medical center, who were identified by *International Classification of Diseases* coding (ICD-10 Codes: Q05.9, Q05.4, Q05.8. ICD-9 Codes: 741.91, 741.00). The letter explained the goal of the study and study requirements. Second, we placed a Facebook advertisement, inviting women to learn about the study through a link to a description of the study on our institution's research website. All participants were offered a \$25 incentive.

Interested potential participants contacted the project coordinator who screened the women for eligibility based on the inclusion and exclusion criteria, and answered questions about the study. They were then scheduled for individual interviews, conducted in-person or over the phone. In the case of the latter the project coordinator instructed participants to be in a private place for the interview to ensure confidentiality. Consent was obtained either by using a secure online survey program (REDCap<sup>®</sup>), by phone, or in written form.

### Data Collection

Interview guides were created by CSS and DW, based on their clinical expertise in spina bifida and research expertise in sexual health, respectively (Appendix A). These guides were iteratively modified during the course of the study, based on feedback from the women and new information obtained. Questions were open-ended, such as “what about sex may be different for you than for someone without spina bifida?” One of three investigators (CSS, CS, VG) conducted the interviews, which were audio recorded and transcribed verbatim and de-identified. The interviewers wrote field notes to indicate their impression of the interviewee’s comfort and openness during the interview, as well as any relevant experiences women described (e.g., homosexual sexual encounters or history of sexual abuse) to ensure minority and other important perspectives were included in the analysis.

### Data Analysis

Demographic and clinical characteristics of the participant sample, all obtained through self-report, were summarized using descriptive statistics.

Qualitative data analysis employed Grounded Theory methodology, as this is a poorly understood area without pre-existing assumptions.<sup>25,26</sup> Grounded Theory methodology allows for the creation of new concepts, based on recurring themes identified in the qualitative data. Three authors (CSS, CS, DW) independently coded all interviews.

During the independent review of each interview transcript, the researcher (CSS, CS, DW) identified quotes that were informative responses to the underlying research questions. The individual researchers then created an “open code” for each of these quotes, summarizing the meaning of that quote. The coding research team then reviewed the codes and consensus was reached on all meaningful quotes that would be included. Open codes that were related to each other were then assigned “axial codes,” which are short phrases that describe a higher level concept reflective of the summarized meaning of the related codes.<sup>27</sup> Axial codes were then grouped into conceptually related themes. During this process, field notes were reviewed to contextualize the individual quotations and to ensure that relevant but minority perspectives were coded appropriately to not overlook their unique but important perspectives. The three researchers participated in all levels of analysis until consensus on themes was reached. After interviewing 22 women, no new material was identified from the transcripts, indicating that thematic saturation had been reached.

We ensured the trustworthiness of our data in four important ways: 1) engaging women with different levels of ambulatory and bladder management status and diverse sexual experiences; 2) coding each transcript independently and then discussing the findings until consensus was reached; 3) conducting interviews and analysis until thematic saturation was

reached; and 4) by utilizing the investigators' expertise in sexual health research (DW) and knowledge of spina bifida (CSS) to create the interview guide and contextualize the results. 28,29

## Results

### Participant characteristics

Twenty-five women participated in the larger study, 24 recruited from our hospital and 1 recruited from the Facebook ad. Twenty-three women participated in phone interviews and 2 were interviewed in-person, based on their preference. Twenty-two of these women, median age 26.5 years (range 16-52), had a current or previous romantic partner and were included in this analysis. Participant demographic and clinical characteristics are described in Table 1. Twelve (12/22, 54.5%) performed intermittent catheterization or had a urostomy and 11 (11/22, 50%) required ambulatory assistance. Eighteen (18/22, 81.8%) had experienced vaginal and/or anal sexual intercourse.

### Interview themes

Seven salient themes emerged reflecting the women's sexual experiences, reasons for diminished satisfaction, and strategies for improving sexual encounters:

1. fear of rejection with resulting difficulty setting boundaries and risk of coercion
2. conflict between spontaneity versus self-care in sexual encounters
3. worry about incontinence during sex
4. trial and error in learning optimal sexual positions
5. decreased genital sensation
6. safety considerations
7. sharing advice with other women with spina bifida.

### **Fear of rejection with resulting difficulty setting boundaries and risk of coercion.**

Women worried about rejection by potential sexual partners, whether due to negative reactions about their surgical scars, incontinence, their sexual abilities, or their disability in general. For some, this was the result of experiences with unsupportive partners, such as one woman whose boyfriend did not view her as sexually desirable.

“I remember one really horrible experience with a guy that I dated... I thought we were really into each other... I think he saw me as a non-sexual being because... we started kissing and fooling around... but... when it got to taking clothes off each other and we [were] gonna have sex he was like no I can't do this.” Participant 20, 36 years

Even women who had not experienced embarrassment or rejection from a partner were fearful, often related to their negative body image and low self-confidence.

“...I feel like there’s always that risk of embarrassment for me in that there’s always going to be a chance that my partner’s not going to be understanding.”  
Participant 5, 22 years

“...when I was younger I had absolutely no confidence... which is why you end up just dating someone who abuses you because... at least they’re dating you, right? And at least they’re having sex with you, even though...I have scars all over my back...” Participant 13, 29 years

This fear of rejection and a desire for acceptance had several negative consequences. Many women admitted to not disclosing their diagnosis to their partner due to their anticipation of embarrassment and wish to be viewed as attractive, capable sexual partners. Some became more comfortable doing so with age and growth in confidence.

“[My] first two [partners] I really didn’t [tell about my spina bifida]. I’d just try to scoot around everything and leave all that out.” Participant 19, 35 years

This desire for acceptance also made it difficult for some women to set and enforce boundaries in regards to their sexuality. For some, this led them to tolerate poor treatment from their partners.

“...he didn’t respect anything with my back and wasn’t very considerate...”  
Participant 17, 33 years

Others described experiences of sexual coercion and abuse. One woman explained how her desire for affection led to her to seek sexual attention from men, mistaking their physical intimacy to be a reflection of their emotional commitment.

“...they took advantage of [me] and I took it as love and that was not love... I didn’t realize at the time that [was] what they were doing, I was just looking for love no matter how I could get it.” Participant 22, 52 years

Women’s prior experiences or fear of potential rejection and their desire for acceptance led some to conceal their diagnosis, avoid setting and enforcing boundaries, or tolerate inconsideration from their partners. This left them vulnerable to physical and emotional harm, sexual coercion, and abuse.

### **Conflict between spontaneity versus self-care in sexual encounters.**

A sexual encounter requires advance preparation for women with spina bifida in order to improve the experience for themselves and for their partners. For example, before a first sexual encounter with a new partner, women have to decide if they want to explain the diagnosis of spina bifida, how it may impact sex, and what modifications can be made to optimize the encounter. Additionally, they have to secure latex-free barrier contraceptives and most have to empty their bladder and bowels to prevent leakage. Some women compromised this preparation because they could not accept the loss of spontaneity.

“not always do I go cath myself beforehand because that really does suck when it comes to my quality of life... because how do you tell somebody, ‘Hold on. I gotta... go catheterize my bladder and then we can have sex.’” Participant 12, 27 years

The need to plan in advance of a sexual encounter was both frustrating and embarrassing for women, although for some their confidence in doing this improved with age. Neglecting to adequately prepare for sex increases their risk of incontinence during sex, urinary tract infections, sexually transmitted infections, unintended pregnancies, and pain from improper positioning, while also missing an opportunity to help their partner best maximize their sexual experience.

### **Worry about incontinence during sex.**

Leakage from the bladder and/or bowel during sex was a nearly universal and distressing concern among the women interviewed. Women described incontinence from both bladder and bowel during intercourse despite having complete control otherwise. For example, several women who were otherwise completely continent described urinary incontinence during orgasm.

“...I sometimes urinate when I orgasm...” Participant 6, 22 years

One woman with a urostomy bag worried about it falling off during intercourse.

“...if I’m turning on my side and it hits my bag... there goes the bag busting all over the place.” Participant 22, 52 years

Bowel incontinence occurred less frequently than urinary incontinence for this group of women, but was more unpredictable and embarrassing.

“The bowel—there’s really nothing I can do about that because it seems to have a mind of its own so I just pretty much pray.” Participant 19, 35 years

While bowel incontinence was concerning for most, it was a particular issue for women who engaged in anal sex.

“...I clear [my bowels] out manually before sex [but] sometimes if you do anal play, shit happens, literally.” Participant 6, 22 years

However, an incontinent episode did not need to occur in order for it to impact a sexual encounter. The concern about the potential of incontinence preoccupied nearly all women during sex.

“...I’m constantly worried about the incontinence happening. I’m always worried that I’m going to get distracted during [sex] in worrying about that too much.” Participant 19, 25 years

Bladder and bowel incontinence was highly stressful for women. It impacts their sexual relationships not only when the incontinence actually occurs, but also by causing distress and distraction due to fear of a potential incontinent event.

### **Trial and error in learning optimal sexual positions.**

Considerations, such as hip or back pain, limited ability to bend, decreased pelvic mobility, diminished sensation, pelvic organ prolapse (common in this population), and weight gain that often occurs with age, often made finding safe and pleasurable sexual positions challenging.



“...[in] my experience, a lot of [positions] hurt.” Participant 10, 26 years

Finding the best position for them often took trial and error. Women also noted that their comfort with different positions varied based on their pain and activity that day.

“...judging [by] how I’m feeling that day [I’m] like this [position is] a yes or a no...” Participant 16, 32 years

No matter the position, women often relied on their upper body for movement.

“I have very good upper body strength so I can move myself around with my arms mostly.” Participant 19, 35 years

Daily variation in fatigue from other activities, pain, and physical anatomy made finding ideal sexual positions challenging.

### **Decreased genital sensation.**

Many women commented that they had diminished genital sensation, although others were unsure whether their sensation was “normal” or not.

“So not like 100% numbness but there is a little bit of numbness...” Participant 9, 24 years

“...you know it’s hard for me to know if I have low sensation and like people will ask do you have low sensation in your vagina? Well, I don’t know. I’ve had the same sensation I’ve always had.” Participant 13, 29 years

Some noted that their sensation varied by the amount of activity they had during that day or how tired they felt.

“...if I’m incredibly [tired] I have more numbness issues than I normally would, so then it’s just sort of boring for me.” Participant 18, 35 years

The ability to orgasm or recognize an orgasm also varied. While some women reported being able to orgasm and some were not, others were uncertain whether or not a sensation they experienced was an orgasm.

“I don’t know if I orgasm. I’ve asked my partner—and I feel silly asking them- ‘do you feel this?’” Participant 12, 27 years

The amount of genital sensation and the ability to orgasm varied between women and also depended on how fatigued they were from other physical activity.

### **Safety considerations.**

Women described specific safety concerns during sex related to their diagnosis. As their condition predisposes them to a high risk of anaphylactic shock when exposed to latex, women with spina bifida have to avoid latex barrier contraceptives such as traditional condoms. Importantly, latex-free condoms are usually not sold in retail stores.

“...you should just use everything latex-free, because what if one of those times you are having sex and you have an allergic reaction during it?” Participant 12, 27 years



“...[I] had to find non-latex options which most [stores] don’t have.” Participant 18, 35 years

The women noted that their diminished sensation and mobility placed them at higher risk of injury during sex.

“Be careful if you have any sort of numbness issues or anything in your legs then be careful you don’t accidentally injure yourself or anybody else. Like you have to be careful and think of things like that. Like you’re more likely to fall and hurt yourself.” Participant 18, 35 years

“I have to worry about if my legs are together or on top of each other too long, I have to worry about skin breakdown...” Participant 20, 36 years

Pain was a concern for many women during intercourse. Some women felt uncomfortable telling their partners about their pain or were more focused on their partner’s enjoyment than on their own.

“...I was just trying to satisfy a person, so if it hurt me it didn’t matter...” Participant 22, 52 years

Women described their risk of injury during intercourse, whether from an anaphylactic reaction to latex or due to injury because of their decreased sensation and different body habitus. While the women were aware of these safety concerns, they did not always feel empowered to protect themselves due to either a fear of inconveniencing their partner.

### **Sharing advice with other women with spina bifida.**

Women described strategies they had learned through experience that could help other women improve their sexual satisfaction. Women reflected on the importance of getting to know a partner well and feeling completely comfortable with the partner before considering intimacy.

“...I was never going to go have random sporadic sex, you know what I mean?... the relationship has to be established before anything could happen.” Participant 12, 27 years

“I would make sure it was a person I could trust and knew what problems I had... being just comfortable with them and whatever could happen, because I didn’t really know what was going to happen.” Participant 2, 17 years

“...when you’re with somebody that understands... it doesn’t make the pressure of is [sex] going to go bad as much.” Participant 19, 35 years

Women also wanted to encourage other women to be proud and confident of their bodies, which they felt would help them choose partners who treated them with respect, improve communication with their partners, and better cope when sex does not go as planned.

“...I think women with spina bifida should feel confident in their bodies... if someone wants to have sex with you I’m going to go ahead and bet they’re not going to be turned off [by your scars] when you take off your clothes... I’m still hot

naked and I would bet... other women with disabilities and their scars... are still hot naked.” Participant 13, 29 years

“...part of it is learning about body positivity... so if you find a partner who doesn't accept [how you may be different from other women] then just move on.”

Participant 18, 35 years

“Like are you gonna have a bowel movement all over the place... [when you're] younger, you're devastated, now that I'm older [and more confidence] I'm like, 'Well, it happens'.” Participant 22, 52 years

Despite the possible awkwardness, women felt that taking time to explain spina bifida and how it may impact sex to prepare their partners made the sexual encounter less stressful.

“...if you're gonna have sexual intercourse with somebody be honest... and open with them and let them ask questions. Because there is a possibility that you... could pee on them or you could have a bowel movement on them or you may or may not orgasm or... if your bones are really brittle you might have to worry about a broken bone... so just be open and let them ask questions too...” Participant 20, 36 years

“...I tell them what I can feel and how far my legs can bend... so they are aware of it... And like certain positions that I'm able to lay...” Participant 4, 19 years

Additionally, women suggested setting clear boundaries prior to engaging in sexual activity.

“...identifying with your partner what you feel comfortable or what your abilities are and what they aren't so that everyone is, you know, on the same page going in. I know it can be hard to have those conversations up front...” Participant 11, 26 years

They encouraged women to be empowered to tell their partners about any concerns they have with positioning or if they experience pain during intercourse in order to prevent injury.

“...don't ignore what your body is telling you.” Participant 10, 26 years

Open communication with their partners was considered key not only for ensuring sex is safe, consensual, and less awkward, but also for improving pleasure.

“I genuinely believe that I have a better sex life than most of my friends because I have to communicate what I need during sex and that has made it a lot easier for me to communicate what I want as well.” Participant 13, 29 years

Women recommended preparing for sex by emptying their bladder or urostomy bag immediately before intercourse to decrease the leakage of urine. Some women also felt emptying their bowels before sex was helpful, although this certainly is not convenient.

“...try to poop before you have sex... It's not the sexiest thing to be like, 'Oh I see that we're having foreplay right now. Can we please stop right now so I can go to the bathroom real quick...?'” Participant 13, 29 years

One woman described being careful with her diet for several days before she expected a sexual encounter to avoid any foods that may promote leakage. She also emptied her bowels well earlier in the day before she planned to see her partner.

“...the advice I can give when it comes to leakage with the bowel is just try to keep yourself as cleaned out as possible... You know, just watching what you’re eating, what you’re drinking... monitoring if [you’re] on a bowel regimen.” Participant 12, 27 years

In order to discretely prepare for leakage, women used mattress protectors or hid absorbent disposable pads under sheets. Having wipes readily available was also recommended.

“...have wipes on hand, have a bed protector...” Participant 6, 22 years

Women had several recommendations for sexual positions that worked well for them. Many women felt that the missionary position was most comfortable for them as it demands less back strength and mobility.

“I prefer the guy on top because I don’t move very well.” Participant 20, 36 years

Other positions that women liked included laying on their stomach, side by side, and positioning themselves at the end of the bed. These positions may be particularly helpful if the woman has gained weight.

“...now I’m heavier so... I like side by side... scooting all the way to the edge of the bed for the woman is another good position...” Participant 22, 52 years

One woman with pelvic organ prolapse struggled with dyspareunia until receiving advice for positioning from her gynecologist.

“...I actually took my partner to my gynecologist with me and said, you know, it’s hurting every time we have sex... And so that’s when he told me about the doggy style position...” Participant 12, 27 years

The women described several strategies for maximizing their sexual sensation. They found that body areas other than genitals were erotically sensitive. They recommended learning one’s own body erotic sensitivities and sharing the information with the partner. Experimenting was also considered important.

“...explore your body and see what feels good to you and then you’ll be able to share that with your partner.” Participant 6, 22 years

“You just have to be willing to try new things and be open to suggestions from your partner too...” Participant 20, 36 years

Some women learned that while they had diminished vaginal sensation, they did have erotic stimulation from anal penetration.

“...for me with spina bifida... I think that anal sex is how I get off versus vaginal. For me, I guess anal, oral...” Participant 12, 27 years

Having other alternative intimate activities was also helpful.

“...we have a lot of toys and that’s super useful if my back’s not feeling great one day.” Participant 6, 22 years

Finally, one woman commented that her staying fit and active helped decrease pain during intercourse and improve her experiences.

“...I found that being as active at the gym as possible has really helped...”  
Participant 16, 32 years

While women faced challenges during sex, they also found practical and feasible ways to mitigate these issues and enhance their sexual experiences.

## Discussion

The purpose of this exploratory qualitative study was to learn about the sexual experiences of women with spina bifida, factors that influenced their sexual satisfaction, and ways that they discovered to increase sex pleasure. These women’s perspectives demonstrate that their sexual satisfaction is impacted not simply by physical features of spina bifida, but also by psychological, interpersonal, and sociocultural factors. Indeed, the impact of a woman’s physical features on sexual satisfaction appear to be moderated by psychological and interpersonal factors, in particular a woman’s relationship and communication with her partner. Women who feared rejection from their partners found it difficult to discuss how spina bifida impacts sex, their needs and desires, and boundaries. For some, this led to tolerating inconsiderate or harmful treatment, while for others it led to anxiety about potential incontinence during sex and a missed opportunity to improve their own experience. On the other hand, women who had open communication with their partners could explain their need to prepare before sex, warn them about the possibility of incontinence, set boundaries to ensure their safety, and give feedback about where and how they experience the most erotic sensation.

Interestingly, many of the concerns of these women and advice they gave are not unique to the diagnosis of spina bifida, although they potentially have greater implications. Specifically, in the general population, emotional connection with a partner has been shown to be more predictive of decreasing sexual distress than physiologic sexual responses such as orgasm.<sup>30</sup> Similarly, open communication with a partner about sexual preferences and desires has been linked with increased sexual and relational satisfaction in the general population.<sup>31-36</sup> Indeed, open communication and healthy emotional relationships with a partner are specifically correlated with increased sexual desire, arousal, less pain, more frequent orgasm, and greater overall sexual function.<sup>31,37</sup> Specific to people with spina bifida, a qualitative study of young people with spina bifida by Heller and colleagues demonstrated that disclosing and explaining the diagnosis of spina bifida with a partner led to increased self-confidence and improved relationships.<sup>38</sup> In our study, women felt such discussions as well as good relationships with a supportive partner also improved their sexual satisfaction by helping a partner understand how to best facilitate pleasure and decreasing their worry during sex. However, in both studies of the spina bifida population, many admitted to not doing so out of a lack of self-confidence and fear of rejection.<sup>38</sup> While low self-confidence and poor body image is common among women in general,<sup>39</sup> it is even

lower among those with spina bifida.<sup>15,40</sup> This could potentially make open communication more difficult, resulting in not just diminished pleasure, but also possible physical harm or unintended pregnancies. This underscores the importance of the psychological and interpersonal aspects of managing sexuality for women with spina bifida.

Although it is important to consider how the physical features of spina bifida can impact a sexual relationship, this study demonstrates that sexuality in this population, as in all women, should be interpreted and addressed using a biopsychosocial model. This model recognizes that sexual function in women with spina bifida is impacted not only by biological factors, such as genital sensation, but also by psychological factors, such as confidence, and interpersonal factors, such as partner communication and support. However, all of this needs to be considered within the woman's sociocultural context, which impacts both what concerns they have, the gravity of those concerns, and their acceptance of potential solutions.<sup>41</sup> For example, these women were acutely aware that society views them as asexual,<sup>1-3</sup> and that their partners will notice how certain aspects of a sexual encounter with them, such as the loss of spontaneity and need to be careful with positioning, is different than with other women. This may influence women's confidence, decisions such as whether or not to empty their bladder before intercourse, and willingness to tell their partner if they experience pain. Unfortunately, current or previous sexual and physical abuse may also influence a woman's sexual experiences. Abuse is significantly more common in women with disabilities, often unreported, and also may not be recognized by the women themselves.<sup>42-44</sup> We have previously reported on experiences of abuse in this population due to low self-confidence and desire to be seen as a sexual being.<sup>3</sup>

These findings have several implications for health care providers who care for women with spina bifida. Most providers feel uncomfortable or unprepared to discuss sexual health with women,<sup>45-47</sup> and in particular those with chronic conditions including spina bifida.<sup>23,48-50</sup> As a result, they often avoid the topic altogether.<sup>3,23</sup> Recognizing this barrier, but also the importance of appropriate sexual health counseling for these women, it is imperative that providers bring up the topic and make referrals to appropriate sexual health experts as indicated (the American Association of Sexuality Educators, Counselors and Therapists offers a directory by location at <https://www.aasect.org/referral-directory>). Utilizing the biopsychosocial model, those sexual health experts should discuss methods for improving the physical aspect of a sexual relationship, such as finding comfortable positions and performing body mapping to discover the most erotic areas, while also empowering the women to explain to partners how spina bifida impacts sex, set and enforce boundaries to ensure safety, and vocalize their needs and preferences. Providers should also screen for abuse. The Abuse Assessment Screen-Disability<sup>51</sup> together with the disability-inclusive screening questions proposed by Salwen and colleagues<sup>52</sup> are recommended for women with disabilities.<sup>53</sup>

The results of this study provide a framework that will inform larger, quantitative studies to further explore these salient themes and evaluate if they are generalizable to the broader population of women with spina bifida. More work is needed to understand the link between self-confidence and communication about sex and ways in which risk can be effectively mitigated. Finally, this line of research will inform interventions that will educate women

about their sexual health, communicate effectively with providers on the topic, and enhance their sexual satisfaction.

The limitations of this study include recruitment from a single academic medical center in the United States and a focus on only partnered sexual activity. Women in this study were less physically impaired than the population that typically attends spina bifida clinics. Additionally, women who chose to participate in this study may be systematically different from those who did not volunteer, leading to bias. This potentially could have resulted in a limited perspective of sexuality in women with spina bifida. However, we did include a diverse sample of women with various degrees of physical disability, affording an understanding of how sexuality is impacted across the spectrum of disability associated with this diagnosis. Additionally, participants were open in talking about their sexuality, which allowed for the development of novel concepts and also enabled the attainment of thematic saturation, a notable strength of the study. An additional limitation is our inability to ascertain the level of lesion of women in this study to understand how this may have correlated with their experiences and sensation. Although we asked women questions about their spina bifida, we found that most had very limited understanding of their condition and could not name their level of lesion. However, we were able to ascertain ambulatory status and bladder management as a marker of their level of physical disability.

## Conclusions

Women with spina bifida face unique challenges that impact their overall sexual satisfaction. Their concerns were not simply physical in nature, with most related to or mitigated by sociocultural, psychological, and interpersonal factors. Therefore, addressing sexual satisfaction for these women is best done through a comprehensive biopsychosocial model. A primary focus of sexual counseling for these women should be on empowering women to learn about how their bodies function and establish open communication with their partner about their boundaries, needs, and desires. Providers who care for these women should bring up this topic and refer to an appropriate sexual health expert as indicated.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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**Table 1.**

Participant demographic and clinical characteristics.

Participant	Age	Bladder management	Ambulatory Status	Current or previous romantic partner	Experienced sexual intercourse
1	16	CIC	AFOs	Y	N
2	17	CIC	No assistance	Y	Y
3	19	None	No assistance	Y	N
4	19	CIC	Wheelchair	Y	Y
5	22	Medication only	UNK	Y	Y
6	22	CIC	AFOs	Y	Y
7	23	CIC	Crutches/ Wheelchair	Y	N
8	23	CIC	Crutches	Y	Y
9	24	None	No assistance	Y	Y
10	26	None	No assistance	Y	Y
11	26	None	No assistance	Y	Y
12	27	CIC	Wheelchair	Y	Y
13	29	None	AFOs/ Wheelchair	Y	Y
14	30	None	No assistance	Y	Y
15	32	None	No assistance	Y	Y
16	32	None	No assistance	Y	Y
17	33	None	No assistance	Y	N
18	35	CIC	No assistance	Y	Y
19	35	CIC	Wheelchair	Y	Y
20	36	Urostomy	Wheelchair	Y	Y
21	36	CIC	AFOs	Y	Y
22	52	Urostomy	Wheelchair	Y	Y

CIC: clean intermittent catheterization; AFOs: ankle foot orthosis; UNK- unknown