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Patient Characteristics Associated with Sexual Interest and Activity Among Adults with Spina Bifida

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OBJECTIVE To identify factors associated with sexual interest and activity among adults with spina bifida and to describe the sexual profile of those who were sexually active. Sexual health of adults with spina bifida is often neglected and current knowledge on the topic is limited.

METHODS An anonymous web-based survey was advertised and administered between March 2018 and September 2018 and participants 16 years and older with spina bifida were included in this study. Respondents were asked about sexual interest, activity, and function using the validated Patient-Reported Outcomes Measurement Information System Sexual Function Profile. Bivariate and multivariable models with ordinal logistic regression were fitted to evaluate predictors of sexual interest and sexual function.

RESULTS Of the 261 respondents with a self-reported diagnosis of spina bifida (mean age of 38.5 years), 73.2% noted at least a little bit of interest in sexual activity. In multivariate analysis, women were less likely to report higher sexual interest than men (odds ratio (OR) = 0.53, 95% CI 0.31-0.92, P = .03) whereas those with higher physical functioning were more likely to have higher sexual interest (OR = 1.04, confidence interval (CI) 1.01-1.07, P = .03). Just less than half of respondents (46.4%) were sexually active in the past 30 days, and those with a ventriculoperitoneal shunt were less likely to engage in sexual activity compared to those without (OR = 0.36, 95% CI 0.19-0.68; P < .01).

CONCLUSION The mismatch between sexual interest and sexual activity highlights the importance of exploring issues related to sexual health when counseling adult patients with spina bifida. UROLOGY 185: 143–149, 2024.

Today, 75%-85% of children with spina bifida are expected to reach adult years.[1] The majority of patients with spina bifida in the United States are now older than 18 years of age.[2] Of the number of challenges patients with spina bifida may face in adulthood, sexual health is often neglected.[2,3] Sexual health for patients with spina bifida can be complicated by cognitive impairment, reduced motor and sensory function, incontinence, need for personal assistance, and erectile dysfunction.[4-7] Yet, only 5%-39% of spina bifida patients report ever discussing sexual health with a physician.[6,7] Although patients express interest in wanting more guidance when it comes to sexual function, many health care providers feel unprepared to facilitate such discussions, citing a lack of formal training and knowledge gaps on the topics of sexuality in the spina bifida population.[8]

Moreover, most of the literature on sexual function in spina bifida was published over a decade ago and used non-validated questionnaires.[6,7,9-11] Some studies obtained sexual history by the use of formal interview,[4,12] or questionnaire in the presence of parents or solely from a parent, which might bias the responses.[9,13] More recent studies have utilized validated questionnaires but were limited by small sample sizes drawn from a single institution.[4,13-18]

In this context, we used a comprehensive validated questionnaire to evaluate the sexual interest, activity, and function among adult men and women with spina bifida. We aimed to understand the patient characteristics

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associated with sexual interest and activity among this patient population, hypothesizing that higher independence with care and better physical and mental health would be associated with greater sexual interest and activity. We also sought to describe sexual function among those who were sexually active.

MATERIALS AND METHODS

Participants and Setting

An anonymous web-based survey was developed at the University of California, San Francisco, and distributed using Facebook advertising from March 22, 2018, to September 30, 2018. Advertisements were targeted to Facebook users who expressed an interest in Facebook pages and groups related to the spina bifida and congenital genitourinary anomalies. Respondents who completed the survey were entered in a drawing to win 1 of 2 free iPad minis. This study was approved by the Institutional Review Board.

Participants were at least 13 years old, living in the United States, and could read and comprehend the survey independently. While the survey included participants with a variety of congenital genitourinary anomalies, this current study focused only on the data of respondents with a self-reported diagnosis of spina bifida who filled out the sexual function assessment.

Outcome

Our outcomes were sexual interest, activity, and function, assessed using the Patient-Reported Outcomes Measurement Information System (PROMIS) Sexual Function and Satisfaction Measures Brief Profile (version 1.0). PROMIS was developed to provide clinically meaningful domain-specific rather than disease-specific measures to be used with both the general population and individuals living with chronic conditions.[19] A higher score represents a higher level of the domain (eg, more satisfaction with sexual life).

While the Sexual Function and Satisfaction Measure was initially developed based on patients with cancer, the instrument was designed to be used in diverse populations, with or without conditions that could affect sexual function.[19] Questions were answered with a 5-point Likert scale assessing interest in sexual activity and sexual activity, however defined by respondent, in the past 30 days. Respondents who had any type of sexual activity in the past 30 days were then asked to rate their satisfaction with their sex life and ability to achieve orgasm. Participants self-identified themselves as women or men. Sexually active men were asked about erections, with the use of erectile function aids if applicable. Sexually active women were asked about their experience with lubrication and vaginal discomfort.

With the exception of the orgasm subdomain, all subdomain scores are translated into T-scores. A T-score of 50 corresponds to the mean response among the reference population. The 6 subdomains of the questionnaire correlate well with the corresponding subdomains of the International Index of Erectile Function and the Female Sexual Function Index, with Pearson correlation coefficients ranging between 0.62 and 0.90.[19]

Covariates

Sociodemographic and clinical characteristics were surveyed, including income, education, health care access and utilization, ventriculoperitoneal (VP) shunt, and prior urologic surgeries. Bladder function was assessed using the Neurogenic Bladder Symptoms Score (NBSS). Level of independence for self-care was assessed using the disease-neutral Transition Readiness Assessment Questionnaire (TRAQ). Physical function was assessed using the PROMIS Physical Function with Mobility Aid Short Form. Mental health was assessed using the PROMIS Anxiety, Depression, and Social Isolation measures.

Statistical Analysis

To facilitate comparisons, respondents who reported a diagnosis of spina bifida and completed the PROMIS Sexual Function questions were stratified according to their sexual interest T-score. These were categorized as much less interested (T-score < 45), similarly interested (T-score 45-55), and much more interested (T-score < 55) than the reference population.

Bivariate analyses of the associations between patient characteristics, sexual interest, and sexual activity in the past 30 days, were conducted using chi-square test (or Fisher's exact test when cell counts were less than 5) and Student's *t* test. Multivariable ordinal logistic regression models were fitted to evaluate predictors of sexual interest and activity, based on covariates that were found to be significant in their respective bivariate analyses.

For respondents who were sexually active in the past 30 days, their ability to achieve orgasm/climax, erectile function, vaginal discomfort, and vaginal lubrication were summarized using descriptive statistics. All analyses were done using STATA 15.1 with a $P < .05$ considered statistically significant.

RESULTS

Patient Characteristics

Sociodemographic and clinical characteristics are presented in Table 1. The mean age of our 261 respondents was 38.5 years (SD 12.7). The majority were female (75.5%), had undergone at least one urologic surgery (68.2%), and used clean intermittent catheterization for bladder management (71.6%). The mean overall NBSS score was 28.9 (SD 11.4) and the mean overall TRAQ score was 4.2 (SD 0.4). As expected, our cohort reported significantly lower physical functioning compared to the general public (T-score of 39.5, SD 7.4). Respondents had greater anxiety, depression, and social isolation

Table 1. Sociodemographic and clinical characteristics of the study cohort.

Age, mean ± SD	38.5 ± 12.7
Gender, n (%)	
Male	64 (24.5)
Female	197 (75.5)
Race, n (%)	
White	208 (82.9)
Non-White	43 (17.1)
Household education, n (%)	
High school or less	134 (53.4)
College or more	117 (46.6)
Household income, n (%)	
< $50,000	127 (60.8)
≥$50,000	82 (39.2)
Health insurance, n (%)	
No	7 (2.7)
Yes	248 (97.3)
Health insurance type, n (%)	
Public	124 (50.0)
Private	124 (50.0)
VP shunt, n (%)	
No	126 (48.3)
Yes	125 (47.9)
Unsure	10 (3.8)
Had urologic surgery, n (%)	
No	83 (31.8)
Yes	178 (68.2)
NBSS bladder management, n (%)	
Indwelling catheter/urostomy	34 (13.0)
Condom catheter	3 (1.2)
Intermittent catheterization	187 (71.6)
Spontaneous voiding	37 (14.2)
NBSS overall score, mean ± SD	28.9 ± 11.4
TRAQ overall score, mean ± SD	4.2 ± 0.4
PROMIS Physical Function	
T-score, mean ± SD	39.5 ± 7.4
PROMIS Anxiety	
T-score, mean ± SD	55.0 ± 11.8
PROMIS Depression	
T-score, mean ± SD	55.5 ± 10.7
PROMIS Social Isolation	
T-score, mean ± SD	52.7 ± 10.8
Under the care of any urologist, n (%)	
No	64 (24.5)
Yes	197 (75.5)
Under the care of a pediatric urologist, n (%)	
No	230 (88.1)
Yes	31 (11.9)
Under the care of an adult urologist, n (%)	
No	90 (34.5)
Yes	171 (65.5)
ER visit for urologic condition in the past year, n (%)	
No	187 (71.6)
Yes	74 (28.4)
Hospital stay for urologic condition in the past year, n (%)	
No	212 (81.2)
Yes	49 (18.8)

ER, emergency room; NBSS, Neurogenic Bladder Symptom Score; PROMIS, Patient-Reported Outcomes Measurement Information System; SD, standard deviation; TRAQ, Transition Readiness Assessment Questionnaire; VP, ventriculoperitoneal.

compared to the general population, with a T-score of 55.0 (SD 11.8), 55.5 (SD 10.7), and 52.7 (SD 10.8), respectively. The majority of respondents (75.5%) had seen a urologist in the past year, with 11.9% identifying a pediatric urologist and 65.5% an adult urologist as their primary urologic provider.

Sexual Interest

Nearly three-quarters of participants (73.2%) reported that they were at least a little interested in sexual activity and two-thirds (65.5%) reported wanting to have sex sometimes, often, and always. By T-scores, 36.4% had a much lower level of sexual interest than the reference population and 35.6% had a level of sexual interest near the average of the reference population. Just over one-quarter (28.0%) endorsed a much higher level of sexual interest.

In bivariate analysis, gender, household education, and PROMIS physical function were significantly associated with sexual interest (Table 2). Women were more likely to report a lower sexual interest than men ($P < .01$). Respondents who completed college or advanced degrees were more likely to report the lowest tertile of sexual interest, compared to those with no college degree ($P = .04$). Lower physical functioning was associated with lower sexual interest ($P = .03$). In the multivariable model with ordinal logistic regression, only gender (odds ratio (OR) = 0.53 for females, 95% confidence interval (CI) 0.31-0.92, $P = .03$) and PROMIS physical function T-score (OR = 1.04 for each unit increase in T-score, 95%CI 1.01-1.07, $P = .03$) remained significant predictors for sexual interest.

Sexual Activity

Less than half of the respondents (n = 121, 46.4%) were sexually active in the past 30 days. Those who were sexually active were likely to be older ($P = .02$), have a higher household income ($P = .02$), and have no VP shunt ($P < .01$) (Table 2). Those with a pediatric urologist were less likely to be sexually active ($P < .01$). In the multivariable model with ordinal logistic regression, only VP shunt remained as a significant factor (OR = 0.36, 95%CI 0.19-0.68, $P < .01$), such that those with VP shunt were less likely to have been sexually active.

Sexual Function

Those who were sexually active in the past 30 days were then asked about their sexual function (Figure 1). Over 80% rated their sexual enjoyment and satisfaction as "quite a bit" or "very much." However, only 50% reported their ability to have a satisfying orgasm/climax as "good," "very good," or "excellent." Based on their T-scores, 15.7% were much less satisfied, 26.5% were similarly satisfied, and 57.8% were much more satisfied with their sexual life than the reference population.

Of all men in our cohort, irrespective of sexual activity, almost 50% rated their ability to have an erection as poor

Table 2. Sociodemographic and clinical characteristics significantly associated with (A) sexual interest and (B) sexual activity in past 30 days among adults with spina bifida.

	Bivariate analysis				Multivariable analysis	
A) Sexual interest						
Variable	*T-score < 45*	*T-score 45-55*	*T-score > 55*	*P value*	*OR (95% CI)*	*P value*
Gender, n (%)						
Male	19 (29.7)	16 (25.0)	29 (45.3)	**< .01**	Ref	
Female	76 (38.6)	77 (39.1)	44 (22.3)		0.53 (0.31-0.92)	**.03**
Household education, n(%)						
High school or less	39 (29.1)	56 (41.8)	39 (29.1)	**.04**	Ref	
College or more	50 (42.7)	33 (28.2)	34 (29.1)		0.67 (0.42-1.08)	.10
PROMIS Physical Function Mean T-score ± SD	38.97 ± 6.93	38.61 ± 6.73	41.43 ± 8.44	**.03**	1.04 (1.00-1.07)	**.03**
B) Sexual activity						
Variable		*Not sexually active*	*Sexually active*	*P value*	*OR (95% CI)*	*P value*
Age, mean ± SD		36.8 ± 13.0	40.5 ± 12.19	**.02**	0.99 (0.97-1.02)	.49
Household income, n (%)				**.02**		.14
< $50,000		70 (55.1)	57 (44.9)		Ref	
≥$50,000		32 (39.0)	50 (61.0)		1.56 (0.86-2.84)	
VP shunt, n (%)				**< .01**		**< .01**
No		46 (36.5)	80 (63.5)		Ref	
Yes		86 (68.8)	39 (31.2)		0.36 (0.19-0.68)	
Under the care of a pediatric urologist, n (%)				**< .01**		.08
No		115 (50.0)	115 (50.0)		Ref	
Yes		25 (80.7)	6 (19.4)		0.36 (0.12-1.11)	

CI, confidence interval; OR, odds ratio; PROMIS, Patient-Reported Outcomes Measurement Information System; SD, standard deviation; VP, ventriculoperitoneal.
All variables in Table 1 were analyzed and were not included here if not significant on bivariate analysis.

or very poor. Of the 48 men who were sexually active, about 60% reported little or no difficulty in *getting* an erection. However, only about 45% reported little or no difficulty in *maintaining* an erection. Based on their T-scores of 4.2%, 41.7%, and 54.1%, sexually active men had much worse, similar, and much better erectile function compared to the reference population, respectively.

Regarding lubrication, when sexually active women were asked "how often did you become lubricated ['wet'] during sexual activity or intercourse?," 80% responded "most of the time" or "better." Similarly, when asked "How difficult has it been for your vagina to get lubricated ['wet'] when you wanted it to?," 80% responded "a little bit" or "not at all." Based on their T-scores, lubrication for women respondents was similar (25.6%) or much better (73.1%) than that of the reference population, respectively. Only one respondent (1.3%) reported a lubrication score much worse than that of the reference population.

In assessing vaginal discomfort, over 70% of sexually active women reported that sexual activity was comfortable and denied having difficulty with or having to stop sexual activity early because of vaginal pain. Based on aggregate T-scores, 39.7%, 55.2%, and 5.1% of sexually active women reported worse, similar, and less discomfort compared to the reference population, respectively.

DISCUSSION

In this cross-sectional study, we evaluated patient characteristics associated with sexual interest and activity of adults with spina bifida using validated questionnaires. We hypothesized that higher independence with care and better physical and mental health would be associated with greater sexual interest and activity. We found that while most of our cohort expressed interest in sexual activity, females and those with poorer physical functioning were more likely to have lower levels of sexual interest. Overall, just less than half of the cohort had been sexually active in the past 30 days and having a VP shunt was associated with decreased likelihood of sexual activity.

Our findings are concordant with published results reporting that most adults with spina bifida are interested in engaging in sexual activities.[10,12,18,20] Within our study cohort, male gender and greater physical function

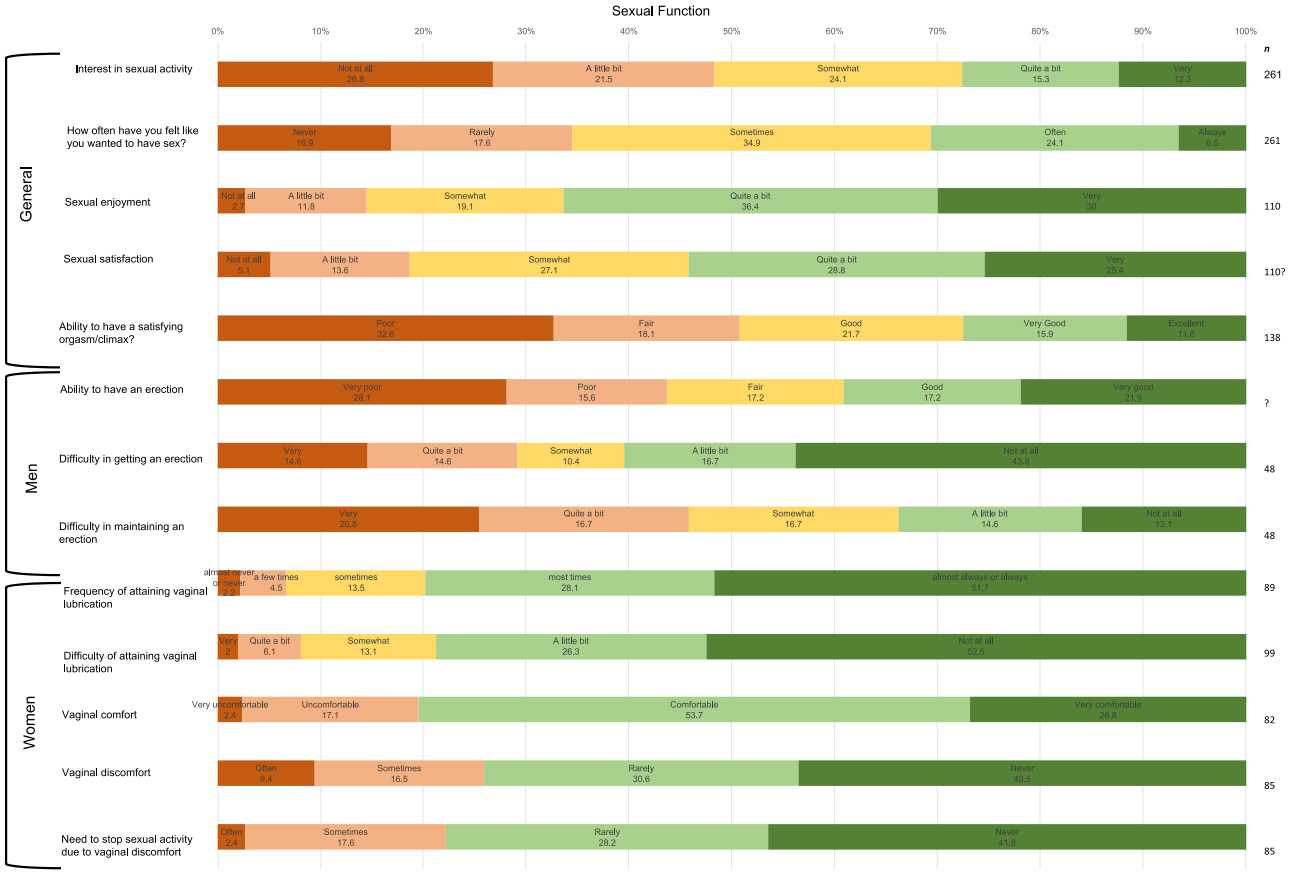

Figure 1. Sexual function and satisfaction measures. One hundred and twenty-one young adults with spina bifida who were sexually active in the last 30 days answered questions using 5-point Likert scales about sexual interest, enjoyment, function, and comfort. (Color version available online.)

were associated with higher sexual interest. Similarly, prior studies of the general U.S. population and of the spina bifida population found that men are more likely than women to express an interest in becoming sexually active or to rate sex life as important.[13,21] However, the link between physical function and sexual interest is not as well defined in the literature. Previous studies of patients with spina bifida have not demonstrated an association between ambulatory status and sexual desire or activity.[16,18] Literature on broader disability population, including adults with multiple sclerosis, traumatic brain injury, or traumatic spinal cord injury, suggests that greater impairment may be associated with lower sexual esteem and restricted opportunities to express their sexuality, though sexual interests and desires remain strong.[22,23]

Given that sexual interest was high among the spina bifida population, it is important to consider how interest aligned with sexual activity. While 73% of participants reported having at least a little bit of interest in sexual activity, only 46% reported being sexually active in the past 30 days, which is consistent with published literature. Previously reported rates of sexual activity among the adult spina bifida population range from 10% to 57%, compared to a survey of the general population of U.S. adults which ranged between 58% and 68% in the past 30 days.[13,16,24,25] While rates of sexual activity are mixed in the literature, having hydrocephalus has consistently been shown to be associated with less sexual contacts, as found in this study.[12,26] Patients with hydrocephalus may have lower cognitive and social skills and therefore have more difficulties establishing and maintaining relationships.[12] Surprisingly, while urinary incontinence is often cited as an obstacle to sexual activity in the literature,[6,7,12,16] markers of urinary function and symptoms (bladder management type and overall NBSS score) were not associated with sexual activity status in the present study. The mismatch in sexual interest and sexual activity may also be explained by social barriers. Dependence on caregivers often restricts opportunities to engage in sexual activity due to lack of privacy.[23] Stigmatization and social isolation, especially among those residing in supportive accommodations, may further limit opportunities to develop intimate relationships.

The majority of our cohort reported sexual function that was more favorable than that suggested by other studies.[4,5,16-18,27] For instance, over half of the men in our cohort rated their ability to have an erection as fair or better, whereas the prevalence of erectile dysfunction among men with spina bifida has been described as

ranging from 12%-75% in the literature.[5,18,27] Similarly, the sexual function pertaining to lubrication and comfort of the women in our cohort was better than that described in other studies. This is in comparison to a study of 28 adult women with spina bifida that reported sexual dysfunction in up to 89% based on Female Sexual Function Index score.[18] One possible explanation for the encouraging sexual function in our study is that our participants have less severe spina bifida. It is conceivable that our sample of patients answering an online survey was healthier and had sexual function different than that of adult patients who continued to receive care at spina bifida clinics. This perspective may be missing from clinic-based recruitment which may overly represent individuals with more severe disease.

Most participants in our cohort rated sexual enjoyment and satisfaction as moderate to high. In understanding sexual health, it is important to note that the perception of one's sexual function may be influenced by both physical and psychosocial factors, including expectations and beliefs about what constitutes sexual experiences.[4,21] Literature on traumatic spinal cord injuries has demonstrated that patients who were younger at the time of injury adapt their sexual behaviors more easily than those who were older when injured.[28] That sexual satisfaction can be maintained despite functional impairment highlights the opportunity for provider guidance during the adaptation process. Furthermore, providers should not assume that sexual dysfunction limits sexual satisfaction, but instead engage patients in discussion about their sexual health.

In practice, however, providers and patients rarely talk about sexual health. As few as 5% of adult patients with spina bifida had ever received information about sex from their physician.[7] Providers often cite lack of knowledge and training in discussing sexual health with patients as a barrier to these conversations. This contemporary profile of sexual function in adults with spina bifida may serve as a starting point for providers to discuss sexual health with this patient population. Having conversations regarding the highly individualized interplay between physical function, ambulatory status, and sexual interest, in addition to strategies in overcoming challenges to sexual expression, is a critical gap that providers can help their patients navigate.

Our study has several limitations. First, the spina bifida diagnosis of our respondents could not be verified but they had independently expressed an interest in spina bifida on social media prior to the survey advertisement and administration. Second, we would likely find a higher number of sexually active respondents had we inquired about sexual activity beyond the previous 1 month, as in other studies. However, a longer reporting period would lead to greater recall bias. Third, our patient selection method likely resulted in a cohort different from that of prior studies. Instead of surveying adult patients seen in spina bifida clinics, we sampled the general adult spina bifida population, which likely includes patients whose level of disability does not necessitate continued multidisciplinary follow-up at spina bifida clinics at tertiary centers. This survey did not include information regarding lesion level; however, we used PROMIS physical functioning questions to obtain a sense of ambulatory status. While the distribution of bladder management approaches of our cohort is similar to that described in a systematic review of urologic outcomes of adult patients with spina bifida,[29] our study has substantially less patients with VP shunts compared to others studies,[18,27] suggesting that our cohort may have had less severe disease. As such, our findings should be interpreted in this context of potentially fewer individuals with developmental and functional limitations, though we feel this is an important population to capture. Notwithstanding these potential differences, leveraging social media to advertise our online survey allowed us to maximize the sample size by reaching patients across the country, including those not receiving routine urologic follow-up. Further, having patients complete the survey in their everyday environment likely minimized discomfort associated with addressing sex life in health care settings, which had been a significant challenge for other studies.[13,18] Finally the authors recognize potential differences in the complex biopsychosocial context of the PROMIS reference population of surgical cancer patients and the spina bifida population. As a result, we emphasized the raw data rather than T-score comparisons with the reference population to maximize the interpretation and impact of our findings.

CONCLUSION

This cross-sectional study presents the sexual profile of a national sample of adult men and women with spina bifida. The majority of respondents reported interest in sexual activity, though less than half were sexually active in the past 30 days. Over 80% of participants who are sexually active reported high levels of sexual satisfaction, suggesting that there might be an adjustment process that helped some adults with spina bifida overcome sexual barriers and express their sexuality. Future studies should examine the barriers responsible for the mismatch between sexual interest and sexual activity, as well as mechanisms underlying the favorable sexual functions reported by the adult spina bifida population. Accordingly, discussions surrounding sexual health should be integrated into routine care for patients with spina bifida.

Declaration of Competing Interest

The authors have no declarations of interest to disclose.

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