

Impact of bladder management methods and other factors on sexual activity in women with chronic spinal cord injury/disease

Jasmin Lea Mahler, MSc¹, Salome Schneider, MSc², Jens Wöllner, PD, MD^{1,2} , Jürgen Pannek, MDProf^{1,2,3} , Jörg Krebs, PhD^{1,*} 

¹Swiss Paraplegic Research, Neuro-Urology, Nottwil, 6207, Switzerland

²Swiss Paraplegic Centre, Nottwil, 6207, Switzerland

³Department of Urology, Inselspital, Bern University Hospital, University of Bern, Bern, 3010, Switzerland

*Corresponding author: Neuro-Urology, Swiss Paraplegic Research, Nottwil CH-6207, Switzerland. Email: joerg.krebs@paraplegie.ch

Abstract

Background: Spinal cord injury/disease (SCI/D) profoundly affects both sexuality and urinary function. Catheterization is often necessary to manage bladder voiding and it can interfere with sexual activity.

Aim: We aim to investigate the effect of the bladder evacuation method on sexual activity in women with chronic SCI/D.

Methods: This cross-sectional study at a specialized SCI/D rehabilitation center recruited women ≥ 18 years with chronic SCI/D using intermittent or suprapubic catheterization. We assessed sexual activity and sexual function with the German version of the Sexual Behaviour Questionnaire and the Female Sexual Function Index (FSFI) and a study-specific questionnaire.

Outcomes: The primary outcome was sexual activity and secondary outcomes included factors influencing sexual activity, such as age and SCI/D characteristics.

Results: Around half of the evaluated women were sexually active, regardless of bladder evacuation method. However, significantly ($P = .018$) more women using intermittent catheterization (IC) (66.7%, 20/30) were sexually active compared to those with a suprapubic catheter (SPC) (29.4%, 5/17). The main concern for women using IC was urinary incontinence during sex (43.3%, 13/30), while those with a SPC struggled with self-image due to the catheter (58.8%, 10/17). Not having a partner was the most common reason for sexual inactivity in both groups (59.1%). The median FSFI total score was significantly ($P = .049$) greater in the IC group (median 26.4, lower quartiles [LQ] 8.9/upper quartiles [UQ] 28.8) compared to the SPC group (median 11.5, LQ 5.4/UQ 25.5), which represents a lower grade of sexual dysfunction in women using IC.

Clinical Translation: Sexual education is crucial and should be adapted to the different types of bladder management.

Strength & Limitations: This study shows first data on the effect of catheter on sexual activity in women. Limitation of our study is the small sample size and response bias by the high rejection rate of women with SPC.

Conclusions: Few women with SPC remain sexually active after SCI/D, while the majority of women using IC do, highlighting issues around self-image and urinary incontinence.

Keywords: spinal cord injury/disease; sexual activity; intermittent catheterization; suprapubic catheter; urinary incontinence; self-image.

Introduction

Sexuality and health are intertwined, with sexual well-being playing a paramount role in overall health and quality of life, and vice versa.¹ Research has indicated that individuals in good health exhibit increased interest in sexual activity and are more sexually active.² However, when body functioning is compromised, as in spinal cord injury/disease (SCI/D), various aspects of sexuality undergo profound changes, such as erogenous zones, sexual intercourse, and ability to orgasm. In addition, other consequences of SCI/D such as decreased sensibility, limited mobility, diminished desire, and lack of acceptance by partner can affect sexuality.³

Furthermore, SCI/D also affects urinary tract function, including the ability to void the bladder. The gold standard for

bladder evacuation after SCI/D is intermittent catheterization (IC).⁴ However, limited hand function dependent on the SCI/D lesion level and severity or comorbidities can lead to the need of a permanent, suprapubic catheter (SPC) for bladder evacuation.⁵ Neurogenic lower urinary tract dysfunction affects sexual activity after SCI/D due to urinary or bowel incontinence during sexual activity. This may necessitate preparatory actions, such as bladder or bowel emptying before sexual activities or using protective devices. Furthermore, an indwelling catheter may physically interfere with sexual activities.^{3,6}

Understanding the multifaceted consequences of SCI/D on both the lower urinary tract and sexual health are crucial for providing comprehensive care for affected individuals.

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However, knowledge on sexuality after SCI/D is based primarily on data from men.⁶ Although we know that even mild levels of sexual dysfunction in women with SCI/D result in poorer sexual quality of life,⁷ studies regarding sexuality in women with SCI/D are limited.

Various factors can influence one's sexual life after a life-altering event like SCI/D, such as bladder management, SCI/D characteristics, and body image. A person must adapt to a new reality and use different strategies to maintain well-being, including sexual satisfaction. The recovery of sexual function is among the top priorities for individuals with SCI/D.⁸ Especially in women, there is a lack of data regarding the influence of bladder management on sexual activity. Therefore, we have investigated the effect of the bladder evacuation method on sexual activity in women with chronic SCI/D. Furthermore, our secondary aim was to identify other factors influencing sexually activity, such as age, being in a relationship, and SCI/D characteristics like lesion level and completeness of injury.

Methods

Study design

This was a cross-sectional study (competent ethics committee approval No. 2021-01394) conducted from August 2022 to July 2023 at a rehabilitation and acute center for SCI/D. The study adheres to the Strengthening the Reporting of Observational Studies in Epidemiology statement (<https://www.strobe-statement.org/>).

Setting

We have reviewed the patients' files of women planned for a regular urologic check-up or catheter change at the Neuro-Urology department to check for eligibility. The study information was sent to eligible women a minimum of 2 days in advance, and they were asked regarding study participation during their visit. All participating women have provided written consent.

Participants

Female outpatients aged 18 years or older, with chronic SCI/D (≥ 12 months) using SPC or IC were recruited. Exclusion criteria included cognitive or language barriers, gender-affirming surgery, and prior surgeries or current therapies affecting sexual activity.

The target sample was based on the expected number of eligible (ie, 50% of screened women/ $n = 60$) and consenting (ie, 50% of eligible women/ $n = 30$) female outpatients with a SPC among those who present at the Neuro-Urology department over 12 months for a regular check-up or catheter change (ie, $n = 120$).⁹ This resulted in a target recruitment number of 30 participants for both the SPC and IC groups.

Outcomes

The primary outcome of this study was patient-reported sexual activity (binary variable). In this study, we defined sexual activity as engaging in a variety of sexual behaviors, such as oral and manual stimulation, foreplay, and intercourse.

The secondary outcomes were sexual dysfunction (total and sub-scores from Female Sexual Function Index), sexual function prior to SCI/D (total score from Sexual Behavior Questionnaire), reasons for not being sexually active as well

as bladder and bowel management. Furthermore, data on age, SCI/D characteristics (date, etiology, level, completeness), comorbidities, and current medication affecting the libido were extracted from the electronic patient charts. The medications used was classified by a urologist (JW) concerning the effect on libido based on the information in the pharmaceutical compendium into "effect" / "no effect".

Assessments

Participants completed three questionnaires:

- 1) German version of the Female Sexual Function Index (FSFI-d),¹⁰ a validated self-assessment questionnaire with six domains that grades sexual dysfunction which evaluates a period of the last 30 days. The domains of the FSFI-d are desire, arousal, lubrication, orgasm, satisfaction, and pain. Evaluation of the domains and total score was performed according to published instructions.¹⁰ Communal et al. considered a total FSFI score of 30 and above as good sexual function, from 23 to 29 as intermediate and below 23 as poor.¹¹
- 2) German version of the Sexual Behavior Questionnaire (SBQ-G)¹² to identify sexual dysfunction before SCI/D. The SBQ-G is a validated self-assessment questionnaire with 11 items about desire and frequency of sexual intercourse, frequency of masturbation, satisfaction with sexual activity, orgasm, pain during sexual activity, and menstruation. The individual items show a profile which is evaluated. The mean global index of sexual dysfunction is calculated as the arithmetic means of items 1 (libido), 4 (arousal), 5 (sexual pleasure), 6 (sexual satisfaction), and 8 (satisfaction with orgasm). A score of 2.0 and higher indicates no pre-existing sexual dysfunction.¹²
- 3) Self-developed questionnaire assessing aspects of sexual activity, bladder, and bowel management which are not covered in existing questionnaires (Supplement 1). The questionnaire contained questions regarding sexual activity (yes/no), reasons for not being sexually active, effects of bladder management on sexuality ("My self-image is negatively affected by the catheter" / "The catheter bothers me during sexual activity / I am inhibited during sexual activity because of my catheter": Likert scale from 0 "I don't agree" to 3 "I agree"), urinary incontinence (yes/no), acceptance by sexual partner (yes/no), type of bladder management, frequency of bladder evacuation, urinary incontinence in daily life (yes/no), satisfaction with bladder management (numeric rating scale [NRS] 0-10), stool incontinence, and satisfaction with bowel management (NRS 0-10).

Completion of the three questionnaires took 30 to 40 min, and all data were entered coded into a secure web-based data management system (secuTrial®, iAS Systems, Berlin, Germany).

Statistical methods

The data were calculated as mean and standard deviation (SD) or median and lower quartiles (LQ)/upper quartiles (UQ) or frequency and percentage depending on the type and distribution of the data analyzed. Differences between the SPC and IC group were investigated using the independent T-test for normally distributed data, Mann-Whitney-U test for skewed data or Fisher's exact test for nominal data. The

Table 1. Patient characteristics.

	Total (n = 47)	IC (n = 30)	SPC (n = 17)	p
Age in years, mean \pm SD	50 \pm 15	47 \pm 15	55 \pm 14	0.1*
SCI/D duration in years, median (LQ/UQ)	19.0 (10.7/28.5)	22.8 (11.7/30.3)	14.3 (9.2/20.5)	0.044**
Etiology, n (%)				
Traumatic	22 (46.8)	10 (33.3)	12 (70.6)	n.t.
Non-traumatic	25 (53.2)	20 (66.7)	5 (29.4)	
Lesion level, n (%)				
Cervical	12 (25.5)	4 (13.3)	8 (47.1)	n.t.
Thoracic	17 (36.2)	10 (33.3)	7 (41.2)	
Lumbar	12 (25.5)	11 (36.7)	1 (5.9)	
Sacral	3 (6.4)	3 (10.0)	0 (0.0)	
Unknown	3 (6.4)	2 (6.7)	1 (5.9)	
AIS, n (%)				
A	18 (38.3)	11 (36.7)	7 (41.2)	n.t.
B	8 (17.0)	2 (6.7)	6 (35.3)	
C	5 (10.6)	3 (10.0)	2 (11.7)	
D	8 (17.4)	8 (26.7)	0 (0.0)	
Unknown	8 (17.4)	6 (20.0)	2 (11.8)	

n (%): Number of participants with percentages. SD: standard deviation. LQ: lower quartile. UQ: upper quartile. SCI/D: spinal cord injury /disease. IC: intermittent catheterization. SPC: suprapubic catheter. AIS: American Spinal Injury Association Impairment Scale. *: independent T-test. **: Mann–Whitney–U test. n.t.: not tested.

statistical analyses were performed using the SPSS software (Version 25, IBM, Somers, NY, USA). A two-tailed *P*-value of $\leq .05$ was considered significant.

Results

A total of 123 female outpatients with a SPC were screened. Of these, 66 patients (53.7%) were excluded. The primary reasons for exclusion were either having a diagnosis other than SCI/D (23/34.9%) or language (not speaking German: 10/15.2%). Eighteen of 57 eligible women (31.6%) consented to participate in our study. However, one woman withdrew her consent later and thus, was excluded from analysis. Among 43 women using IC who were eligible, 30 (69.8%) agreed to participate. The reasons for refusing study participation (39 women with SPC and 13 with IC) were lack of interest (10/19.6%), not having sufficient time (3/5.9%) or not feeling comfortable with the topic (2/3.9%).

Therefore, the data of 47 participants (50 \pm 15 years old) were evaluated. Their characteristics are shown in Table 1. The duration of SCI/D was significantly (Mann–Whitney–U test *P* = .044) longer in women using IC (median 22.8 years, LQ 11.7/UQ 30.3 years) compared to those with a SPC (median 14.3 years, LQ 9.2/UQ 20.5 years). Women using SPC had higher lesion levels (47.1% vs 13.3% cervical lesions) and AIS scores (76.5% vs 43.4% A and B) compared to the IC group (Table 1).

Sexual activity

The detailed results from the self-developed questionnaire are shown in Table 2. Twenty-five of the 47 (53.2%) of the evaluated women reported to be sexually active. The percentage of sexually active women in the group using IC (66.7%, 20/30) is significantly (Fisher's exact test *P* = .018) higher compared to the group with a SPC (29.4%, 5/17). Having no partner is the most common reason for not being sexually active in both groups (59.1% of all sexually inactive participants). There are no significant (Fisher's exact test *P* = .7) differences in the frequency of mentioned reasons for not being sexually active between the two groups. For women who use IC,

fear of urinary incontinence during sexual activity (43.3%) is a major challenge (Table 2). In women using a SPC, 10 of 17 (58.8%) agreed or rather agreed to “my self-image is negatively impacted by the catheter”.

Sexual function

The median total score is significantly (Mann–Whitney–U test *P* = .049) greater in the IC group (median 26.4, LQ 8.9/UQ 28.8) (*n* = 28) compared to the SPC group (median 11.5, LQ 5.4/UQ 25.5) (*n* = 16), which represents a lower grade of sexual dysfunction for women with IC. Figure 1 shows the different FSFI sub-scores for the two groups. There were no significant (Mann–Whitney–U test *P* > .08) differences in the sub-scores between the two groups apart from the pain sub-score. The pain sub-score was 4.0 (LQ 0.0/UQ 6.0, *n* = 29) and 0.0 (LQ 0.0/UQ 4.4, *n* = 17) for the IC and SPC group, respectively (Mann–Whitney–U test *P* = .038).

Sexual function prior to SCI/D

There is no significant difference (Mann–Whitney–U test *P* = .65) regarding sexual function prior to SCI/D between the two groups (IC *n* = 17, SPC *n* = 14).

Bladder management

Women with IC emptied their bladders a mean 6.1 \pm 2.3 times per day. Approximately half of the women in both groups are experiencing urinary incontinence during their daily activities (IC 14/30, 46.7%; SCP 9/17, 52.9%). In the IC and SPC group, 10 (33.3%) and seven women (41.2%), respectively, are incontinent at least once a week. The satisfaction with bladder management is significantly (Mann–Whitney–U test *P* = .034) greater in the IC group (median 8.8, LQ 7.9/UQ 9.9) compared to the SPC group (median 7.25, LQ 6.5/UQ 8.1).

Bowel management

All evaluated women experience stool incontinence. In the IC and SPC group, 24 (80.0%) and 13 women (76.5%), respectively, experience stool incontinence at least once a week. There is no significant (Mann–Whitney–U test *P* = .47) difference in the satisfaction with bowel management between

Table 2. Sexual activity outcomes.

	Total (n = 47)	IC (n = 30)	SPC (n = 17)	p
	n (%)	n (%)	n (%)	
Sexually active	25 (53.2)	20 (66.7)	5 (29.4)	0.018*
Sexually inactive	22 (46.7)	10 (33.3)	12 (70.6)	n.t.
^a No partner	13 (59.1)	5 (50.0)	8 (66.7)	0.7*
^a No interest	8 (36.4)	3 (30.0)	5 (41.7)	0.7*
In a partnership	31 (66.0)	22 (73.3)	9 (52.9)	0.2*
^b Rejection by sexual partner	7 (14.9)	4 (13.3)	3 (17.6)	0.9*
Urinary incontinence				
Incontinence during sexual activity	16 (34.0)	13 (43.3)	3 (17.6)	0.11*
Preparation prior to sexual activity	^c 28 (59.6)	23 (76.7)	5 (29.4)	0.11*
Effect of SPC on sexuality				
Disturbed self-image		n.a.	10 (58.8)	
Hinderance during sexual activity		n.a.	8 (47.1)	
Feeling inhibited by SPC		n.a.	7 (41.2)	

n (%): Number of participants with percentages. IC: intermittent catheterization. SPC: suprapubic catheter. *: Fisher's exact test. n.t.: not tested. n.a.: not answered. ^aReasons for not being sexually active. ^bHaving experienced rejection by potential sexual partner due to bladder management. ^cSome women who are not sexually active have indicated that they would need to make preparations regarding urinary incontinence before sexual activities. Preparations regarding urinary incontinence before sexual activities included voiding the bladder, usage of protective pads and emptying the bowel. Only participants with SPC were asked the questions about the influence of the catheter on self-image or if it was a hindrance during sexual activity.

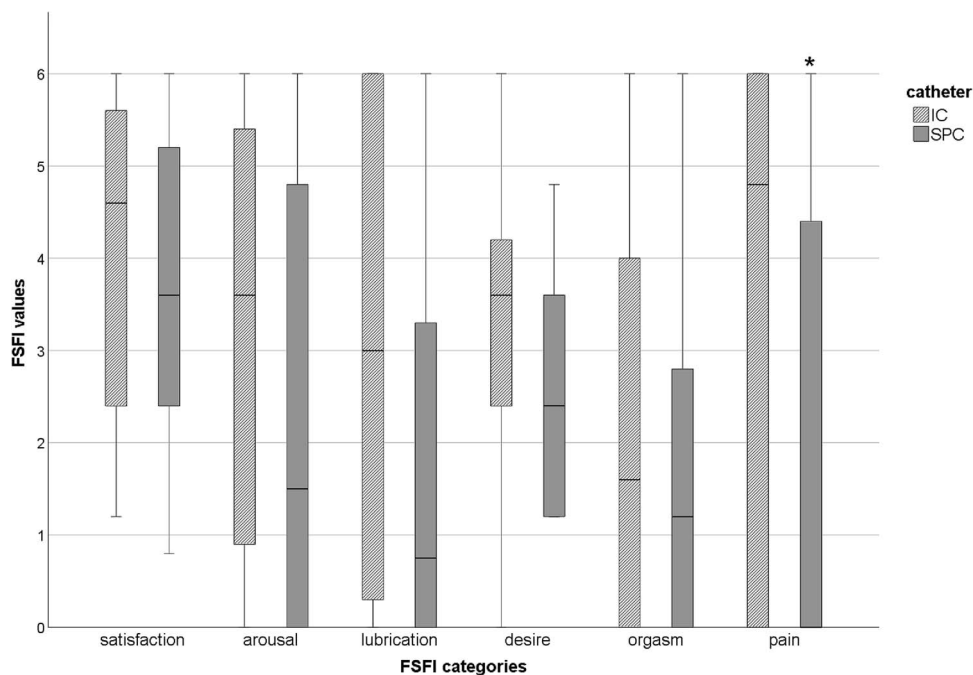


Figure 1. Boxplot showing the sub score results of the female sexual function index (FSFI) for the two investigated bladder evacuation groups intermittent catheterization (IC) and suprapubic catheterization (SPC). The pain sub score is significantly (* $P = .038$) smaller in the SPC group compared to the IC group.

the two groups (IC median 7.0, LQ 6.8/UQ 8.1 and SPC median 7.0, LQ 5.0/UQ 8.0).

Medication with effect on libido

Twenty-one of the 47 evaluated women (44.7%) take medication which affects libido and 10 (21.3%) take medication which may affect libido. In the SPC group, 88% are taking libido affecting medication (15/17) compared to 46.7% (14/30) of women using IC ($P = .005$). There is no significant (Fisher's exact test $P = .36$) difference in sexual activity between women taking libido-reducing medication (15/31, 48.4%) and those who do not (10/16, 62.5%).

Discussion

Slightly more than 50% of the evaluated women with SCI/D are sexually active, regardless of the bladder evacuation method. However, twice as many women who use IC are sexually active (~67%) than those with a SPC (~29%). The main worry of women using IC is urinary incontinence during sexual activities, whereas women with a SPC struggle with their self-image because of the catheter. Not having a partner is the most common reason for not being sexually active. Sexual function and satisfaction with the bladder management was significantly better in women using IC compared to those with a SPC.

There is a common misperception that women, or individuals in general, do not wish to be sexually active after

experiencing a disability. However, our findings emphasize the importance of maintaining sexual identity for women after SCI/D. In our study, most women with IC remain sexually active. However, we found a difference in sexual activity between women with IC or SPC. One reason for that could be that women with SPC are significantly older compared to women with IC in our study. However, women in a similar age category but without SCI/D were sexually active in almost 3/4 of the cases (compared to ~29% of women with SPC).¹³ For these women having a partner was also a determinant factor. Women without a partner were substantially less sexually active (less than half for 41–50 years, only 8% for 61–70 years).¹³ In our study, women with IC are more often in a relationship (73.3% IC vs. 52.9% SPC), and the most mentioned obstacle to sexual activity is the absence of a partner. Reitz et al. reported a significant correlation between having a partner and satisfaction with one's sexual life.¹⁴

Additionally, Kreuter et al. observed that women with SCI/D and higher lesion levels have fewer sexual experiences,¹⁵ aligning with our findings: our participants with a SPC have higher lesion levels and more often complete lesions compared to those using IC (see Table 1), leading to greater limitations in mobility and sensitivity that will influence sexual activity (66.7% of women using IC were sexually active compared to 29.4% of women with a SPC). A poorer health status is associated with reduced sexual activity,² while a higher degree of independence is associated with better quality of sexual life.⁷ This could also impact the sexual dysfunction, reflected by the intermediate overall FSFI score in women using IC and the poor median value in women with SPC, indicating relevant sexual dysfunction. Furthermore, women with SPC are more affected by pain during sexual activity.

Urinary incontinence represents a common problem during sexual activity, which was reported by 34.0% of our participants. However, according to Karbage et al., urinary incontinence alone does not seem to prevent sexual activity, as 70.1% of the participants with UI in that study were sexually active. Nevertheless, urinary incontinence can reduce sexual arousal and orgasm frequency.¹⁶

In addition, women with SPC struggle with their self-image. Poor self-image can reduce sexual desire and satisfaction.¹⁷ Furthermore, the physical presence of the SPC represents a hindrance during sexual activity, which has been reported by almost 50% of the evaluated women. This fits with the significantly poorer satisfaction with bladder management reported by women with a SPC. Even though a SPC may represent an appropriate bladder management solution in women with compromised hand function, general health or physical agility, bladder management should be re-evaluated regularly from a holistic rehabilitation perspective. There seems to be a special need to optimize bladder management and thus, satisfaction in women with SCI/D.¹⁸ Furthermore, guidance from healthcare providers, particularly from urologists and gynecologists, is essential in helping women regain a fulfilling sex life after SCI/D.¹⁷ Guidance should include advice on managing catheters during sexual activity, alternative sexual practices, and addressing body image concerns.

The limitations of our study are the small sample size and response bias introduced by the higher rejection rate of women with a SPC and missing data in the analysis of the FSFI and SBQ. Some participants have reported that some questions were too personal to answer. Furthermore, it needs to be considered that the FSFI only covers the last

30 days, which may not be representative of the general sexual function. However, the present study provides insight into sexual activity and relevant associated issues in women with SCI/D which needs to get explored further in future studies. Furthermore, the observed differences in reasons for sexual inactivity between women with IC and SPC will provide valuable information for the support of women with SCI/D regaining a satisfying sex life. Future studies should not only focus on sexual intercourse, but include a wider range of sexual behavior, such as masturbation, oral sex, and anal stimulation or penetration.¹⁹ After SCI/D, sexual desire and body image have an impact on sexuality as well, and therefore sexual life extends beyond sexual function alone,¹⁴ which further supports the need for a wide definition of sexual activity. Furthermore, sexual satisfaction does not appear to be strongly associated with sexual functions like genital arousal, ability to have intercourse, or ability to reach orgasm.¹¹ Finally, we excluded the specific subpopulation of trans-women, so our results do not necessarily apply to this subpopulation.

Thrusell et al. have emphasized that sexual rehabilitation should commence early because sexuality remains a crucial aspect of women's lives after SCI/D. Today, sexual rehabilitation in women mainly focuses on fertility.²⁰ However, sexuality involves more than getting pregnant and having children. Affected women need to be educated about their changed sexuality after SCI/D to effectively cope with challenges such as loss of sensory input, reduced mobility, and decreased ability to orgasm. Their erogenous zones may alter along with the experience of sexuality, which extends to sexual activities beyond intercourse. Despite these changes, Sramkovka et al. found that intercourse remains the preferred sexual activity of women after SCI/D.³ Therefore, sexual rehabilitation of women should include education on strategies to facilitate intercourse and sexual activity in a wider sense. Effective sexual rehabilitation can improve the quality of sex for women with SCI/D, who tend to have worse sexual lives than peers without SCI/D.⁷ Depending on the type of catheter, different challenges regarding sexual activity arise that should be addressed individually. An empowering environment during rehabilitation after SCI/D is crucial to lay a foundation for a more fulfilling sexual life after discharge. Therefore, it is important that healthcare professionals receive appropriate training and create a safe environment for persons with SCI/D to discuss these matters.²⁰ Sexual education after SCI/D should use a gender-specific approach that fosters a positive and fulfilling engagement in female sexuality despite the disability.²¹

Conclusion

Most women using IC are sexually active, emphasizing that sexuality is still an important aspect of female identity after SCI/D. There is a need for action regarding women with a SPC where rather few reported to be sexually active. Special attention should be paid to self-image in women with SPC and urinary incontinence in women using IC.

Ethics of approval statement

Approved by the competent ethics committee (project ID 2021-01394).

Patient consent statement

Written informed consent has been obtained from all trial participants.

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Author contributions

JLM: Data curation, formal analysis, interpretation of data, writing—original draft, writing—review & editing, approval of the final manuscript.

SS: Data curation, writing—review & editing, approval of the final manuscript.

JW: Conceptualization, writing—review & editing, approval of the final manuscript.

JP: Conceptualization, methodology, supervision, interpretation of data, writing—review & editing, approval of the final manuscript.

JK: Conceptualization, methodology, regulatory affairs, supervision, formal analysis, interpretation of data, writing—review & editing, approval of the final manuscript. Attribution of work: Swiss Paraplegic Centre and Swiss Paraplegic Research, Nottwil, Switzerland.

Supplementary material

Supplementary material is available at *Sexual Medicine* online.

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Conflicts of interest

Nothing to disclose.

Data availability

The generated and analyzed datasets are available from the corresponding author on reasonable request.

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