

Sexuality and Disability
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Measuring Sexual Performance: Development and Psychometric Properties of the Sexual Performance Questionnaire in Iranian People with Spinal Cord Injury

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Abstract

Sexual performance refers to activities served by sexual capacity and motivation. As a culturally sensitive issue, to date the scalar invariance of sexual performance has not been examined for Iranians with spinal cord injuries (SCIs). Aim: To develop and assess properties of an instrument evaluating sexual performance of an Iranian population with SCIs., in Brain and Spinal Cord Injury Research Center (BASIR), Neuroscience Institute, Tehran University of Medical Sciences, Tehran, Iran. Using multi-modal methods, we developed and assessed the Sexual Performance Questionnaire (SPQ). This included collecting expert opinions; engaging with patients with SCI referred to BASIR; pilot testing to assess the scale; and a formal investigation. Participants (men = 156, women = 58) completed the SPQ. Internal consistency and reliability were measured using Cronbach's α coefficient. Content and face validity were examined by academic experts. Construct validity was assessed by examining convergent and discriminant validity. Finally, exploratory factor analysis was used to extract the factor structure of the questionnaire. The Cronbach's α coefficient was 0.77. There was a significant ($p=0.04$) correlation ($r=-0.23$) between the SPQ score and age. Those with a partner scored higher ($p=0.001$). We found three components: Spouse as initiator, self-initiation, and genital-oriented sex which accounted for 59% of the observed variance. The face and content validity was approved by an expert committee. The development and application of the 13-item SPQ provides a thorough understanding of sexual performance amongst persons with SCI. It facilitates the development of efficient sexual rehabilitation interventions and SCI-specific sexuality education programs.

Keywords Disability · Iran · Psychometric · Sexual performance · Spine

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Introduction

Sexual activity is a result of a dyadic relationship and solitary desire among able or disabled adults [1–3]. The term sexual activity includes all actions and responses related to experiences with a sexual motivation, from holding hands or kissing to sexual intercourse; sexual interest and performance are not limited to genital sex [4].

A few empirical studies have reported a significant positive association between satisfactory sexual activities and quality of marital life [5–10]. Reports show that higher levels of sexual satisfaction are related to greater relationship quality, stability and intimacy [11], regardless of one's physical ability or disability.

Among people with SCI (PwSCI), dyadic sexual desire remains similar to those of their non-SCI peers. Despite the possibility of genital impairment, PwSCI should not be considered asexual, and can continue to perform sexual activities; nevertheless, spinal cord injury may inevitably affect the person's sexual and reproductive behaviors. Sexuality has been discussed as an important part of PwSCI's quality of life. Sexual life is considered a high priority for both men and women with SCI [12].

Both the ISCoS¹ Scientific and Executive Committee and the ASIA² board of directors have recommended that the sexuality of PwSCI needs to be addressed in a comprehensive manner, including a recommendation for ongoing documentation of SCIs' sexual status through their medical records [13, 14]. Despite reporting supportive attitudes toward the sexuality of PwSCI [15], the lay population has revealed an implicit bias against the sexual lives of PwSCI [13]. In other words, they are often considered asexual [16].

Impact of physical disabilities on one's sexual expression has been measured by various scales [17], but limitations of existing measures make it difficult to determine PwSCI's sexual interests or intimacy [16]. Their sexual expression may be affected not only by their particular physical condition but also adversely influenced by the culture and societal attitudes or their partners' attitudes toward sex and sexuality. Moreover, PwSCI's own view of themselves, body image and sexual self-concept may strongly influence their self-confidence, sexual performance, and interpersonal relationships [18]. A study with Brazilian adult men with SCI revealed significant association between being sexually active with the participants' sexual satisfaction and their socio-demographic characters [14]. In contrast, another study conducted with 32 women reported that variables such as age, neurological level, time of SCI, Spinal Cord Independence Measure score, urinary incontinence, chronic pain and spasticity were not related to the level of sexual activity, but important predictors included not having a stable partner ($p=0.02$) and a lack of genital sensation ($p=0.04$) [19, 20].

Recent findings highlight the emotional and social impact of sexual disability of persons with spinal cord injuries rather than genital functionality like erection [21]. SCI occurs most often in men particularly at their reproductive age.

The approximate annual incidence of SCI is reported as 54 cases per one million people in the United States compared with 12.1–57.8 cases per million in Iran [22, 23]. In Iran, the prevalence of SCI was estimated to be 318 (95% CI: 313–325) per million [24]. Evidence shows that health problems in post SCI life adversely affect the person's entire life, including social activities, and more often their sexual life [25].

¹ The International Spinal Cord Society.

² American Spinal Injury Association.

Moderate to poor quality of sexual life is widely reported among PwSCI, especially among women [26, 27].

Over the years, multiple measures have been introduced into the literature regarding sexuality and disability. A recent review paper reported on various patient-reported outcome measures (PROMs) reflecting patients' views of their own health status as well as sexual function in populations with neurologic problems including SCI. It has been concluded that proper PROMs are limited and more research is needed to develop high quality measures [28].

Specifically, few measures have been introduced to assess sexual health outcomes among the SCI population, e.g. Emotional Quality of Relationship, Sexual Activity and Satisfaction, Sexual Attitude and Information, Sexual Interest and Satisfaction, Sexual Attitude and Information Questionnaire [29], as well as newly introduced tools including sexual health measures for PwSCI or the Sexual Adjustment Questionnaire in the Iranian population with spinal cord injury [4, 30].

Sexual issues have different meanings in different cultures, and the socio-cultural structure affects people's attitudes toward sexual activity as well as best practice of clinicians in maintaining sexual activity and sexual health of clients [31, 32]. Sexuality is an unspoken matter in the Iranian culture, as opposed to other Westernized cultures in which sexuality is more freely discussed. While sexuality-related questions are sensitive and difficult to ask even in Western cultures, it is far more difficult for the participants and their health providers working in conservative cultures such as Iran. In addition, institutional review boards overseeing research ethics in Iran often find it difficult to allow the use of Westernized questionnaires relating to human sexuality [30]. Accordingly, the aim of this study was to design and evaluate a culturally appropriate instrument that measures sexual performance among PwSCI in Iran.

Methods

This study was designed and conducted in two phases: (1) item generation and (2) assessment of psychometric properties of the produced questionnaire. In the first phase, item generation was performed using the information gathered through formal and informal encounters with persons with spinal cord injuries, who had been referred to the Brain and Spinal Injury Research Center (BASIR), Tehran, Iran. In the first version, the total number of items was 74, which was reduced in the later versions to 65, and in the end, the sexual assessment tool was reduced to 13 questions.

The conceptual framework of the study and the dimensions of the intended concept were determined, and then the initial version of SPQ-SCI was generated based on an extensive literature review including textbooks, journal articles, and expert opinions gathered from twelve different disciplines including sexologists, urologists, epidemiologists, psychiatrists, midwives, general practitioners and religious leaders. After assessing the CVI (content validity index) and CVR (content validity ratio) of items, and expert comments at the end of this phase, as was reported in our previous work [30], finally 13 items were selected to assess sexual activity in persons with spinal cord injuries. Each item was rated on a five-point scale (from "completely agree" to "completely disagree").

Design and Data Collection

In this cross-sectional study, we employed convenience sampling to recruit 214 individuals with SCI (156 men and 58 women) referred to the BASIR center in Imam Khomeini Hospital in West Tehran, Iran. Inclusion criteria for the participants were age 18 and above, being sexually active (self-report), Iranian nationality, willing to participate in the study, and having no medical diseases other than SCI affecting the person's sexual health. All cases were evaluated based on the ASIA impairment scale (AIS) as a modified measure of the Frankel scale. The ASIA is a standardized examination consisting of a myotomal-based motor examination, dermatomal based sensory examination, and an anorectal examination. The degree of spinal cord injury is graded on a 5-point scale as follows: (A) complete,³ (B) Sensory incomplete,⁴ (C) Motor incomplete,⁵ (D) Motor incomplete,⁶ (E) normal.⁷ However, the Frankel scale had considerable limitations. It did not specify the level of spine injury in its classification. It also did not define the difference between 'motor useful' and 'motor useless' grades, leading to subjective grading [33, 34]. Most participants (41%) were categorized in the C category, followed by 20% in A, 23% in D, and 16% in B.

Statistical Analysis

We employed several statistical tests to assess the psychometric properties of the SPQ-SCI.

Validity and Reliability

Content and face validity of the SPQ-SCI were examined by an expert committee. Construct validity was assessed by examining convergent validity for age and discriminant validity by making a comparison between subgroups of the PwSCI based on having or not having a partner. We assumed that individuals with a partner would attain a higher SPQ-SCI score, and its score would be lower in older patients. Internal consistency reliability and test–retest reliability both were used to examine the reliability of the SPQ-SCI. Test–Retest reliability of the SPQ-SCI was assessed by administering the measure to 30 adults similar to the study participants, randomly recruited from BASIR clinics. They completed the SPQ-SCI at baseline and two weeks later, allowing us to compute the inter-class correlation coefficient (ICC). We considered satisfactory ICC values to be 0.40 or above ($r \geq 0.81$ –1.0 as excellent, 0.61–0.80 very good, 0.41–0.60 good, 0.21–0.40 fair and 0.0–0.20 poor) [35]. Cronbach's α -coefficient was used to assess the internal consistency reliability. We considered satisfactory values for Cronbach's alpha to be 0.60 or above [36].

³ No sensory or motor function is preserved in the sacral segments S4-5.

⁴ Sensory but not motor function is preserved below the neurological level and includes the sacral segments S4-5 AND no motor function is preserved more than three levels below the motor level on either side of the body.

⁵ Motor function is preserved at the most caudal sacral segments for voluntary anal contraction (VAC) OR the patient meets the criteria for sensory incomplete status.

⁶ Motor incomplete status as defined in level C, with at least half (half or more) of key muscle functions below the single NLI having a muscle grade ≥ 3 .

⁷ If sensation and motor function as tested with the ISNCSCI are graded as normal in all segments, and the patient had prior deficits, then the AIS grade is E.

Table 1 Demographic and clinical pathologic characteristics of the study samples (n=214)

	Men	Women	Total
Age (mean \pm SD)	33 \pm 10	31 \pm 8	32 \pm 9
Marital status			
Married	156 (100%)	58 (100%)	214 (100%)
Duration of marriage (mean \pm SD)	10 \pm 10	11 \pm 9	10.5 \pm 9.5
Duration of SCI (mean \pm SD)	9 \pm 7	8 \pm 7	8.5 \pm 7
Educational status (N (%))			
Under diploma	66 (79%)	14 (21%)	80 (100%)
Diploma or more	80 (67%)	40 (33%)	120 (100%)
Occupation			
Housewife or jobless	73 (73%)	27 (27%)	100 (100%)
Employee	18 (78%)	5 (22%)	23 (100%)
Self-employee	65 (71%)	26 (29)	91 (100%)
Degree of SCI incompleteness			
A	33 (77%)	10 (23%)	43 (100%)
B	26 (77%)	8 (23%)	34 (100%)
C	62 (71%)	25 (29%)	87 (100%)
D	35 (70%)	15 (30%)	50 (100%)

Factor Analysis

The sample included for factor analysis consisted of 214 SCI adults. This method was used to cluster items into common components in the SPQ-SCI questionnaire. To analyze total variance, we used Principal Component Analysis (PCA) with varimax rotation [37]. The diagonals of the anti-image correlation matrix were all over 0.5, and the communalities were all above 0.34 (Table 2), indicating overall support and justification for our factor analysis including all 13 items.

Ethics

We obtained approval for this study from the Research Ethics Committee of Tehran University of Medical Sciences and the steering committee of BASIR (ethics code # 94-01-85-29-422). All participants were provided with an explanation of the study and its aim as well as verbal and written informed consent before completing the questionnaire.

Results

The Study Sample

The mean age of 214 participants was 32 \pm 9 years. The demographic characteristics of participants are presented in Table 1.

Table 2 Factor loading and communalities based on a principal components analysis with oblimin rotation for 13 items in the SPQ-SCI

Items	Spouse as Initiator	Self-sexual initiation	Genital sex	Commonality
Q7: Our sexual relationship is proceed by my partner	0.86			0.69
Q3: My partner approaches me and does themselves best to satisfy me sexually	0.84			0.65
Q4: We start our sex with foreplay	0.68	0.48		0.58
Q8: We have intercourse once a week at least	0.66			0.51
Q5: Our sexual performance is completed with intercourse	0.61		0.41	0.49
Q9: I used to perform hands job to arouse my partner	0.61	0.41		0.52
Q2: I, myself,do initiate		0.83		0.65
Q10: I would use different means to satisfy my partner sexually	0.45	0.51		0.43
Q11: Our sexually intercourse is successful		0.50		0.34
Q1: Sexual performances make me relax	0.44	0.50		0.43
Q12: My partner is only satisfied with sexual intercourse			0.77	0.58
Q13: I am only satisfied with sexual intercourse	0.44		0.69	0.52
Q6: I am not interested in foreplay			-0.55	0.39
Explained variance (%)	38	11.5	9.5	-
Eigen value	4.9	1.5	1.2	-

Validity and Reliability

The Cronbach's α -coefficient and the interclass correlation coefficient for the SPQ-SCI were 0.77 and 0.75, respectively. These results showed that the SPQ-SCI had internal consistency and a dependable consistency between two assessments of 30 patients with an interval of 2 weeks.

The results of formal and content validity assessments were verified by qualitative methods, and the grammar, wording and item allocation was found to be suitable. In the assessment of face validity, all participants reported that they understood the questions and considered them easy to answer. The majority (90%) of the participants found the appearance and formatting acceptable.

Upon evaluating the content and formal validity of the tool, its construct validity was also examined. The SPQ_SCI scores were compared between subgroups of patients based on having a partner or not. As anticipated, the participants with a partner scored significantly ($p=0.001$) higher than the others (30 ± 12 for those with no partner, vs. 39 ± 9 for those with a partner). Other researchers have noted that individual factors as well as external social forces can influence the development of sexual relationships in the context of disability [38]. This underscores the importance of better understanding the establishment and maintenance of sexual relationships among this population. Furthermore, there was a significant negative correlation between SPQ-SCI score and age of the participants ($p=0.04$, $r=-0.23$).

Factor Analysis

Initially, factor analysis was used to evaluate the 13 SPQ-SCI items. Firstly, the Kaiser–Meyer–Olkin measure of sampling adequacy was 0.85, above the commonly recommended value of 0.6, which indicates the adequacy of the sample size and suitability of the collected data for factor analysis. Secondly the Bartlett’s test of sphericity was highly significant ($X^2=559$, $p < 0.001$).

We used principal components analysis since the primary intention was identifying the factors underlying the short version of the SPQ-SCI. With varimax rotation, regarding eigenvalues > 1 and factor loading ≥ 0.4 on 214 people with SCI, we detected a 3-component construct accounting for 59% of the observed variance.

These three components comprised the following: “Spouse as initiator” (6 items: Qs 3, 7, 9, 5, 8 and 4), “self-sexual initiation” (4 items: Qs 1, 2, 10 and 11) indicating how active a person is in approaching a sexual partner, and “genital sex” (3 items: Qs 6, 12 and 13) which encompasses genital-based activities such as sexual intercourse. The factor loading distribution for identification of patterns in the SPQ-SCI is shown in Table 2.

Discussion

We found the SPQ-SCI to be a unique, valid and reliable instrument to assess the sexual performance of PwSCI in Iran. Employing multi-modal methods, the SPQ-SCI was developed and tested with Iranian PwSCI. Based on our findings, we suggest that the SPQ-SCI appears to accurately capture the targeted construct. The Cronbach’s alpha coefficient confirmed the SPQ-SCI reliability, and the ICC indicated good stability [39]. The current questionnaire includes three components: (1) Spouse as Initiator, (2) Self-Initiation, and (3) Genital Sex as the main constructs of the instrument, which can provide an assessment of the state of sexual performance in Iranian PwSCI.

Sexual initiation is defined as an interest in sexual activity prior showing overt sexual behavior by the person or his/her partner [40]. To contextualize sex initiation by ‘self’ or ‘spouse’, we argue that current sexuality-related measures may be insufficient to adequately assess the level of comfort and attitudes of Iranian couples toward initiation of sexual activities [31]. In the Iranian culture, gender bias is identified between men’s and women’s perceptions of their own and the opposite sex’s roles and responsibilities in sexual life. A husband is generally expected to approach his sexual partner and initiates sex, whereas the wife is defined as a receptive and responsive partner [41]. Similarly, a previous study with heterosexual daters’ sexual initiation reported that men initiate sex more often than women, and they are socially respected for their sexual initiation intentions [42]. Possibly, any form of disability can alter initiation-related perceptions and behavior and may need to be examined as part of clinical care. Indian women with SCI reported their positive response to their husbands’ sexual initiation even though they felt low desire for sex (60%) or no interest to initiate sex (30%) after injury [43].

In some cultures, genital stimulation is the only means people, including Iranian couples have of active sexual intimacy. Genital sex which needs healthy body parts becomes very important to people with disability. A study with Spanish women suggested that lack of sensation in the genital area of PwSCI negatively affects the sex life [19]. An empirical study with Iranian women suggested that genital function is synonymous with

sexual function [44] and this determines many of Iranians' attitudes toward acceptable sexual performance. This attitude may need to be changed as part of sexuality education and clinical care by emphasizing on the brain rather than genital sex.

Although we found some similarities between SPQ-SCI subscales and other well-used instruments targeting SCIs, such as the Female Sexual Function Index (FSFI), the International Index of Erectile Function (IIEF), and The Perceived Sexual Distress Scale (PSDS) [45, 46], nonetheless there are important differences in meanings and partner-related issues. The PSDS informs the rehabilitation team's work regarding the level of perceived sexual distress in PwSCI. In contrast to the PSDS, which assesses only distress surrounding changes in sexual life due to SCI, the SPQ-SCI evaluates normative sexual performance in the context of a sexual couple. In the Iranian culture, sexuality is only understood in the marital context [47]. People living with SCI can go beyond genital sex and promote their sexual motivation, capacities, and performance. Importantly, however, research findings have found that couples must receive sexual rehabilitation after SCI to maintain their partnership [48].

Sexual health services for PwSCI are complex and impacted by both health providers' personal attitudes and the sexual health needs of this population [49]. Health providers face clear challenges in dealing with sexuality-related topics at the time of care delivery for SCIs, mainly because of the sensitive nature of sexuality-related discussions in the clinical setting [47]. The possible conceptualization of PwSCI as 'asexual' is a misconception that jeopardizes sexual health care delivery to them [49], and that can be related to the health providers' own sexuality or their attitudes toward sexuality in general [49].

The SPQ-SCI may help health care providers to more holistically assess the health and function of PwSCI. They can deliver informed sexual health care to this population in a culturally-sensitive manner in light of the contextual restraints or fear of jeopardizing patients' cultural safety. Despite rigorously designed methods, this study had some limitations. The first methodological limitation was the lack of examination for convergent and known-groups validity, due to time and funding issues. In addition, our preliminary tests of the SPQ-SCI may not support wide generalizability, until further studies are performed to assess its validity with a larger sample size.

Conclusion

Given the complexity of the sexual lives of PwSCI, some challenges exist in sexual health care delivery for this population. Arguably, a culturally sensitive, reliable and valid measure is necessary to be applied not only in research, but also in clinical settings. Using the SPQ-SCI would assist professionals in screening patients for their sexual performance impairments as well as their sexual health care needs. In sum, professionals should be aware that they may remain unable to deliver efficient care and interventions to the community of PwSCI unless a comprehensive assessment is performed using valid and reliable tools.

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Compliance with Ethical Standards

Conflict of interest The authors declare that they have no competing interests.

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