

# How Iranian Women with Spinal Cord Injury Understand Sexuality

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## Abstract

**Background:** Spinal cord injury (SCI) is a life-altering experience that affects sexuality as well as other aspects of an individual's life. However, sexuality of women with SCI has received less attention than that of men.

**Objectives:** This study focused on the sexual understanding of a sample of Iranian women with SCI.

**Methods:** This qualitative study was conducted with 24 semi-structured interviews. Women with SCI were recruited from the brain and spinal injury research center (BASIR) registry system at the Imam Khomeini hospital in Tehran, Iran. Barun and Clarke's thematic analysis approach was adapted to analyze the narrative data.

**Results:** According to participation viewpoints, the following three main themes were explored: the dilemma that lead to limited sexual activity, seeking positive sexual adjustment, and the lack of client-based sexuality education in the rehabilitation process.

**Conclusions:** Our findings revealed that women with SCI expressed a need to be recognized as capable sexual beings regardless of their disability. The narratives highlighted their desire to seek help in order to prevent the adverse impact of SCI on their sexuality and marital life. These women could seek an active and pleasurable sexual life if they are informed about sexuality changes post-injury, accept sexual behavior changes, and apply various sexual skills to their post-injury lives. Therefore, sexuality education and counseling soon after SCI is recommended. These services would be delivered by a rehabilitation team to women and their spouses during initial caregiving and be ongoing as long as needed.

**Keywords:** Spinal Cord Injury, Sexuality, Women, Thematic Analysis, Iran

## 1. Background

It has been established firmly that spinal cord injury (SCI) as a life-altering experience affects sexuality, as well as other aspects of an individual's life (1). This effect on sexuality depends on the location and degree of injury and is of concern in both women and men (2-4). However, sexuality of women with SCI has received less attention than that of men (5, 6). In addition, sexual impairment could be more perceived by women. One possible explanation for this is that women with SCI are more prone to psychological disorders than men (7) and this condition could lead to a more disturbed female sexual response (8, 9). Decreased sexual arousal and orgasmic problems are common sexual problems in women with SCI (2, 3). Although SCI and its related complications alter women's sexual capacity, these women are not often portrayed as asexual (10-12). In addition, this lifelong physical disability does not change one's need for intimacy and romantic and passionate relationships (13). Although there have been several studies conducted on women's sexuality post-SCI (5, 11, 13, 14), little is known about how women with SCI understand sexuality and remain sexual beings (10, 14).

In a study aimed to explore sexual experiences and per-

ceptions, women with SCI stated that, despite their disability, they need to be recognized as sexual beings. They also emphasized this need must be met by their rehabilitation team (15). In another study conducted to assess the sexual concerns of men and women with spinal cord injuries, only 37% of women compared with 66% of men declared that they received sexuality-related information (16). In another study, women with complete SCI reported that their rehabilitation team could little supply for their sexuality understanding needs through educational programs (17). In addition, more than half the women who participated in a study on sexual issues of women with SCI stated that the sexuality information they received during the rehabilitation process had been inadequate (18).

Based on our knowledge, limited research has been conducted on Iranian women with SCI for the following reasons: 1) as in other developing countries, women only comprise approximately 25% of SCI cases (19); 2) following potential changes in the physical, psychological, and social role within marital relationships after SCI, marital dissolution may occur, making it more difficult to conduct research in this population of women (20), and women may be easily abandoned post-SCI; and 3) there is lim-

ited research-based information due to the culture-bound nature of sexuality in the Iranian context, especially in women with SCI (21, 22).

## 2. Objectives

In response to the call for exploration, this study focused on the sexual understanding in a sample of Iranian women with SCI.

## 3. Methods

The study sample was recruited over a four-month period, from August 2014 to February 2015, from patients referred to the Brain and Spinal Cord Injury Research (BASIR) clinic, a referral rehabilitation center for spinal cord injury in Imam Khomeini hospital in Tehran, Iran. Participation was limited to married women at least 18 years of age with injury in the thoracic and lumbar state, with at least one year having passed since SCI and no pre-existing condition that might be exacerbated by SCI, and who had been in stable heterosexual partnerships for more than six months after injury. Women were eligible for inclusion in the study if they were willing to share their sexual experiences and were able to speak Farsi. Ethical approval for the study was granted by the Tehran University of Medical Sciences. Participation was entirely voluntary and women were free to withdraw at any stage. Signed consent was obtained from each participant prior to the first interview. Individual interview was employed as the data-collection approach. This method is an effective data-collection technique for obtaining in-depth information. In addition, through interview, instead of being directed by a predetermined hypothesis, participants could express themselves, in their own words, in an open and flexible process (23). We interviewed 24 women over the phone because they had mobility restrictions and could not attend to the BASIR clinic. Our focus was on describing and interpreting experiences and meanings associated with understanding the sexuality aspect of life post-SCI. Participants were asked to talk about their sexual experiences after injury. Where possible, we avoided using the word so as not to lead the participants. Individual interviews took 30 - 45 minutes and were tape-recorded and transcribed. Participants were assured of anonymity, and all gave permission for conversations to be recorded.

Data was analyzed by Barun and Clarke's thematic analysis approach, which was adopted to extract the sexual understanding in women with SCI who participated in the present study. Thematic analysis is a type of qualitative analysis for classifications and present themes that relate

to the data. This analysis is considered the most appropriate for any study that seeks to discover interpretations and also provides a systematic element to data analysis. In addition, thematic analysis is capable of detecting and identifying factors or variables that influence any issue generated by the participants (24). Data analysis was arranged in six phases: familiarization with the data, coding, searching for themes, reviewing themes, defining and naming themes, and the final write-up (24). The analysis was finalized by identifying a number of themes that emerged to describe the meanings and current practices in the participants' sexual lives. Credibility of the data was established through prolonged engagement, immersion in the data, and member check. Dependability was considered through external check. Confirmability, also, was established by peer check. In this study, we tried to consider the maximum variation for establishing the transferability of the data (23).

## 4. Results

In order to explore women's sexual understanding post-SCI, semi-structured interviews were conducted. Socio-demographic and clinical characteristics of participants are shown in Table 1. A total of three themes and examples of 75 extracted codes from the interviews are shown in Table 2. Each theme and related codes have been explained, and for each, the exact phrases expressed by some participants have been quoted in italic font. The type of injury of the participant has been placed in parentheses at the end of the quote in abbreviated form according to the American spinal cord injury association (ASIA) scale (e.g., woman with complete spinal cord injury have been represented by "ASIA A").

### 4.1. Dilemma Leading to Limited Sexual Activity

All participants believed that their sexual relationship was affected notably by their injury as well as other aspects of their life. They compared their sexual experiences from pre- and post-SCI and described that their sexual ability was decreased. Moreover, they highlighted sexual problems, including anorgasmia, no genital sensation, as well as low sexual desire and inadequate vaginal lubrication:

After injury, I struggled with having sex, but it was fruitless. No sensation occurred. I had no lubrication in my genitalia honestly; I didn't have a good feeling (Zahra, 33 years old, ASIA A).

Depression, hopelessness, urinary incontinence, bowel incontinence, limitation in mobility, and spasticity were another SCI-related concern voiced by some of the respondents:

**Table 1.** Socio-Demographic and Clinical Characteristics of Participants

Parameters	Value
Age (mean ± SD)	31.72 ± 3.11
Length of marriage (mean ± SD)	11.20 ± 7.31
<b>Education (No. %)</b>	
High school	18 (75)
College	6 (25)
<b>Occupation (No. %)</b>	
Housewife	22 (93)
Employed	2 (7)
Duration of SCI (months)	33.12 ± 14.67
<b>Degree of incompleteness (No. %)</b>	
A	10 (41.66)
B	8 (33.33)
C	4 (16.66)
D	2 (8.34)
<b>Cause of SCI (No. %)</b>	
Traffic injuries	19 (79.16)
Fall in	4 (16.66)
Side effect of surgery	1 (4.18)

**Table 2.** The Relationship between Themes and Codes

Themes	Example of Codes Associated With Themes
<b>Dilemma leading to limited sexual activity</b>	No genital sensation
	Inadequate vaginal lubrication
	Depression
	Fading out emotional intimacy
	Urinary incontinence
	Limitation in mobility
<b>Seeking positive sexual adjustment</b>	How to cope with new condition
	How to have sex with SCI-related problems
<b>Lack of client-based sexuality education in the rehabilitation process</b>	No focus on sexual changes post-SCI
	No attention paid to sex education
	Absence of sexual counseling

Well, living with this problem is awful. I'm not in a good mood, my tears will not stop. I have no hope for living, let alone sex! (Fateme, 28 years old, ASIA B).

I am not comfortable with sex. I don't have sex because I don't want to feel spasms. It is harmful (Maryam, 38 years old, ASIA A).

Voiding and defecation are two of my major concerns.

I fear urination during sex (Sara, 26 years old, ASIA B).

Difficulties in marital relationships were the other worries that most participants expressed. The women understood fading out emotional intimacy and believed that coping with it is not easy.

There is no intimacy and warm relationship between us. Most of the time, we are silent, let alone having sex

(Mahnaz, 36 years old, ASIA A).

We lived together some months after my injury, but my husband did not tolerate the current condition, and then left me alone (Tooba, 37 years old, ASIA B).

#### 4.2. Seeking Positive Sexual Adjustment

For most women in this study, SCI was the hindrance to sexual activity. Almost all expressed that their sexual activity was limited post-injury. However, they declared that they did tend to the sexual relationship but were not coping with their recent dilemma:

After injury, I did not know how to be sexually active again. I suppose that I have never ever sexual relationship. Despite this, my husband tried to test different sexual styles to promote our sexual relationship. We didn't know how to adapt with the effect of SCI on our sexual relationship (Shahnaz, 37 years old, ASIA C).

#### 4.3. Lack of Sexuality Education in SCI Rehabilitation Process

All participants pointed out that the main focus of the rehabilitation team was on physical rehabilitation and that there was very little attention paid to sexuality education. All of them declared that they were not provided with problem-solving-based sexual counseling:

Frankly we are blind about sex after injury. I never got any solution for my problem from doctors. I think that there is not a chance for me again for having sex with my husband (Sahar, 34 years old, ASIA C).

We are not asked about our problem. Nobody gave us counseling in that. How can we solve our sexual concerns? (Golnar, 29 years old, ASIA D).

## 5. Discussion

Overall, SCI highly influences the sexuality of affected women and depends on the neurological level and type of injury (2). Based on our findings, SCI limits women's sexual activities and directly and indirectly restricts it through physical and psychological complications. A damaged spinal cord disturbs the sexual response pathway, and in this case, anorgasmia, no genital sensation, low sexual desire, and inadequate vaginal lubrication is experienced. Moreover, depression, hopelessness, and fading out emotional intimacy emerged as the chief psychological complaints among women living with SCI. In line with Basson's model, women's sexual response, especially arousal, is strongly affected by psychological-emotional stimulants (8). Therefore, expressing and receiving love and sharing affection are the most important factors for having active and satisfying sexual performance in women with SCI (8, 25). Likewise, urinary and bowel incontinence, limitation

in mobility, and spasticity are the main physical problems perceived by woman with limited sexual function after injury. Our findings provide more support for literature, in that they have confirmed that these complications affect the sexuality aspect for women with SCI (2, 26, 27).

Our findings also showed that coping with perceived problems with sexual adjustment require being aware of any sexuality changes after injury and pursuing counseling and education during the rehabilitation process (28). According to Purnine and Carey (1997) (29), sexual adjustment is defined as sexual agreement between couples, which means dyadic or mutual understanding of sexual preferences and priorities of each other and the level of harmony in their sexual activities. In SCI, sexual adjustment can cover two personal and interpersonal aspects. Women with SCI are more likely to adapt to sexual changes as well as her partner cope with this problematic condition (2, 3). According to our findings, being aware of sexual changes after injury is an enabling factor for the coping process. Moreover, lack of sexual awareness due to counseling unavailability in the rehabilitation process was reported by all participants. This result is in agreement with several studies that indicated that often little or no education is provided to women with SCI during the rehabilitation process (15-18).

Based on the women's experiences in the present study, rehabilitation teams often did not address sexuality issues or had a lack of awareness and training related to sexuality and the sexual needs of women with SCI. Our findings provide more support for Parker and Yau's study (2012) (15), which reported that rehabilitation teams must develop an understanding of how injury may affect sexuality in women with SCI and, in addition, a willingness and comfort with discussing such issues.

The present study can be criticized since the qualitative study does generalize the findings in a lower level. Hence, the findings should be interpreted cautiously. While we successfully interviewed women with SCI, it is possible that we missed important data obtainable only from women who did not participate. As a further step, we recommend exploration of women's sexual self-concept and sexual identity post-SCI in the Iranian context.

Overall, it seems that the present findings have been acknowledged by the majority of Iranian women with SCI under study. Our results reveal that women with SCI expressed their need to be recognized as capable sexual beings regardless of disability. The narratives highlighted their desire to seek help in order to prevent the adverse impact of SCI on their sexuality and marital life. These women could seek an active and pleasurable sexual life if they are informed about sexuality changes post-injury, accept sexual behavior changes, and apply various sexual skills to

their post-injury lives. For this, sexuality education and counseling soon after SCI is recommended. These services should be delivered by rehabilitation teams to women and their spouses during initial caregiving and be ongoing as needed.

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## Footnotes

**Authors' Contribution:** Raziye Maasoumi collected and analyzed the data and wrote the manuscript. Fatemeh Zarei interpreted the data and revised the manuscript. Seyyed Hasan Emami Razavi and Effat Merghati Khoei designed and supervised the study as well as critically revised the manuscript.

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