How Do Iranian People with Spinal Cord Injury Understand Marriage?

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Background: Spinal cord injury (SCI) is a life-altering experience. There is little information about the perspectives of people with SCI toward marriage. **Purpose:** To explore the understandings of Iranian adults with SCI about marriage. **Methods:** In this qualitative inquiry, using a semi-structured interview guide, we collected data from 53 single adults with SCI (41 men and 12 women) who were referred to the Brain and Spinal Cord Injury Research Center, Tehran University of Medical Sciences in Tehran. Barun and Clarke's thematic analysis approach was applied for data analysis. **Results:** "Marriage" was thematized in outer and inner scenarios. The outer scenario was explored in terms of physical disability identified as a seminal determinant in successful marriage. "Attractiveness," "able body for breadwinning," "sexually active," and "reproduction" were dominant concepts extracted from the participants' narratives. The participants' inner scenarios revealed that marriage would be welcomed if a potential partner accepted them as a "whole person" regardless of their SCI condition. **Conclusion:** The findings suggest that adults with SCI do not ignore or reject marriage, however it was not their life priority due to major concerns that they had internalized. Considering the quality of care, people with SCI must be reassured about their potential to get married. SCI-based sexuality education and premarital counseling support the patients in their postmarital lives. Our findings will provide decision makers and health providers with significant insight for utilizing culturally appropriate services for people with SCI.

Key words: Iran, marriage, spinal cord injury, thematic analysis

Marital status significantly influences quality of life (QOL).¹ Spinal cord injury (SCI) is also a life-altering experience, with motor, sensory, and autonomic problems that may adversely affect one's life plan.² Several reports indicate a lower QOL among people with SCI compared to those without SCI.²⁻⁵ Married and unmarried people with SCI from Albania reported lower QOL if they remained single through their post-injured lives.¹ Kreuter pointed out that marital status is a powerful predictor of independent living; marriage is a main lifelong concern. A spinal cord injury (SCI) can affect intimacy, both physically and emotionally. The injury may result in changes in relationships, sexual activity, and the desire for a happy marriage.⁶ Marital stability is another important variable affecting overall well-being. This variable is assessed by the rate of divorce (8% to 48%).^{6,7} For persons with SCI, being

married has been related to higher life satisfaction, better adjustment, better quality of life,⁸ longer life expectancy,⁹ and less self-reported handicap.¹⁰ Persons with SCI who married after injury indicate higher marital satisfaction and stability than people married before injury.⁹

Individuals with SCI are less likely to engage in community and social activities; accordingly, the spousal relationship is particularly important in providing social support.¹¹ Notably, a higher divorce rate is seen in people with SCI who married before the injury than in those who married after the injury.⁷ Similar to people without any injury, marriage can be important to people with SCI. Yet there are characteristics of their injuries and sequelae that influence their marriage quality and decisions about marriage in post SCI life. Those factors obviously differ from those found in people without SCI.^{6,12} Economic issues are a concern for

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many dating couples, and people with SCI are no exception. Employment can be another major concern.¹³ Impaired sexuality, however, may be the adverse sequela most feared by people with SCI. Matters related to sexuality are a considerable source of anxiety among persons with SCI¹⁴ and may cause them to postpone marriage or even relegate it to their last priority. Scholars point out that the life transition constituted by marriage is an important process that any person, including those with SCI, may want to experience.^{6,14} Regardless of sexual function impairment, Korean couples with SCI showed greater dyadic adjustment and marital satisfaction. They were more cohesive than able-bodied couples.¹⁵ In contrast, Peters et al reported that people with spinal cord and head injury experienced adjustment difficulties through their marital relationships.¹⁶

In Iran, there is little information about the life transition by marriage in post SCI life. The prevalence and the point prevalence of traumatic SCI in Tehran, the capital of Iran, was reported from 1.2 to 11.4 and 4.4 (95% CI, 1.2-11.4) per 10,000 people, respectively. The majority of the Iranian population with SCI is male; according to the Iranian culture, they are young at their marital age.¹⁷ Nevertheless, people with SCI purposefully (ie, searching for a caregiver) may get married even in middle age. It seems that the Iranian population with SCI may experience much more difficulty regarding their marriage in comparison to their counterparts in other societies. In Iran, marriage is mainly constructed by religious and sociocultural norms. In this context, men are usually defined by traditional standards as breadwinners, and loss of health or an able body can compromise this status after marriage.¹⁸ In this culture, a man with SCI is more likely to lose his chance to marry due to his injury. Again in this culture, a woman is valued and validated by her fertility post marriage.¹⁴ There is a misunderstanding that women with SCI are sexually impaired and infertile.^{19,20} There is consensus among Iranian scholars that sadness, depression, irritability/anger, suicidal thoughts, lack of self-confidence, financial hardship due to unemployment, high cost of living, and limitation in social interactions are major factors adversely affecting the marital lives of people with SCI.¹³

There are no published data about the views of single individuals with SCI. Even in the health care settings, health providers, decision makers, and other relevant professionals do not put the marriage of people with SCI at the center of their attention. In other words, there is little attention paid to the matter of marriage and its underlying determinants in Iran among people with SCI. Based on our years of work experience, we hypothesize that Iranian individuals with SCI have their own reasons for choosing or refusing marriage. In this article, we explore the attitudes of Iranian single people with SCI toward marriage.

Methods

Design and data collection

This was a qualitative study conducted from 2013 to July 2015.

Participants

The participants were 53 individuals with SCI, 41 men and 12 women, who voluntarily agreed to be interviewed. They were referred from all parts of Iran to the outpatient clinics in the Brain and Spinal Cord Injury Research (BASIR) Center, Tehran University of Medical Sciences, Tehran, Iran. People with SCI who were 18 years old or older, not married, and able to speak Persian were included in the study.

Procedure

Using a short lecture, we explained the research goals and aims and invited the patients to be interviewed if they were not married. Data were collected through semi-structured individual in-depth interviews. The interviews were conducted in a manner through which participants could express themselves, in their own words, in an open and flexible process.²¹ Each interview lasted for 30 to 60 minutes. The focus of the interview was the participants' viewpoints toward marriage post SCI. To minimize bias in participant responses, we avoided the assumption that people with SCI are better off not marrying due to their disabilities and SCI-related consequences.

The research-trained assistants used the interview guides to ask open-ended questions exploring the perspectives of the participants toward marriage in the context of SCI. The interviews were recorded and transcribed verbatim. The sampling process continued until we achieved data saturation. Sociodemographic and clinical characteristics of participants are shown in **Table 1**. A total of 2 themes and 20 extracted codes from the interviews are shown in **Table 2**. Each theme and related codes have been explained; for each theme, the exact phrases expressed by some participants are quoted in *Italic font*. The type of injury sustained by the participant being quoted is shown in parentheses at the end of the quote in abbreviated form according to American Spinal Injury Association Impairment Scale (AIS) (eg, people with complete SCI are represented by AIS A).

Analysis

Barun and Clarke's thematic analysis approach was applied to extract the meanings the informants used to conceptualize the concept of marriage. Thematic analysis is a type of qualitative analysis that allowed us to classify and present themes relating to the data.²¹ Thematic analysis is able to detect and identify factors or variables that influence any issue generated by the participants.^{21,22} In the present

Table 1. Demographic and clinical characteristics of participants with SCI (*N* = 53)

Variable	Men	Women
	Mean $\pm$ SD	Mean $\pm$ SD
Age, years	24.4 $\pm$ 5.7	29.5 $\pm$ 8.3
Duration of SCI, months	46.0 $\pm$ 41.6	97.3 $\pm$ 99.6
Age at time of SCI, years	20.5 $\pm$ 5.7	20.9 $\pm$ 7
	<i>n</i> (%)	<i>n</i> (%)
Level of injury		
Paraplegia	21 (67.7)	5 (100)
Tetraplegia	10 (32.3)	0 (0)
Completeness		
Incomplete	12 (42.9)	3 (100)
Complete	16 (57.1)	0 (0)
Education level		
$\leq$ 12 years	31 (77.5)	5 (45.5)
>12 years	9 (22.5)	6 (54.5)

study, each interview's text was evaluated as a whole and the fundamental meaning or its general context was described in 1 or 2 paragraphs. Throughout 6 stages recommended by Barun and Clarke, we coded the narratives to familiarize ourselves with the data and proceeded through the stages of analysis. Searching for themes, reviewing themes, defining and naming themes, and writing were the remaining steps we took to complete the analysis.

Trustworthiness

Credibility of the data was established through prolonged engagement, immersion in the data, and member check (response validation) with 10 participants. Dependability by external audit and conformability were established by peer review (our colleagues from other research centers). In this study, we tried to consider the maximum variation by selecting participants with various SCI states and sociodemographic status to establish the generalizability of the data.²³

Table 2. Relationship between themes and codes

Theme	Subtheme	Codes
Outer scenario toward marriage	<i>Physical disability and able body for breadwinning</i>	Mobility limitation
		Urinary incontinence
		Bowel incontinence
		Spasticity
		Loss of job
	<i>Psychological concerns (attractiveness)</i>	Unemployment
		Feel like a financial burden
		Social status change
		Feeling of sadness
		Feeling of inadequacy
Inner scenario toward marriage	<i>Sexual activity and reproduction</i>	Feeling of frustration
		Feeling of hopelessness
		Feeling negative body image
		Fear of abundance
		Being nervous
	<i>Accept as a "whole" regardless of SCI condition</i>	No genital sensation
		Lack of sexual attractiveness
		Worries about sexual function
		Fear about child bearing
		Marriage to have a caregiver
		Temporary marriage
		Testing sexual function

Ethics

The Ethics Committee of Tehran University of Medical Sciences, Tehran, Iran, approved the study. All participants were informed about the objectives of the study and were assured about confidentiality. In addition, they were assured of anonymity, and all gave permission for the conversation to be recorded. All participants provided written informed consent.

Results

“Marriage” was thematized in both outer and inner scenarios. The outer scenario was explored in terms of physical disability that was identified as a seminal determinant in constructing a successful marriage. Attractiveness, able body for breadwinning, sexual activity, and reproduction were issues mentioned by the participants in explaining their hesitation about marriage after SCI. The participants’ inner scenario described marriage as a welcomed event if a partner would approach and accept them as a “whole person” regardless of their SCI condition.

Outer scenario: Factual lived experience

Physical disability and able body for breadwinning

Most of the participants experienced several challenges related to their physical well-being after injury. Mobility limitation, urinary incontinence, bowel incontinence, and spasticity were major concerns voiced by the participants. Moreover, they believed that physical difficulties had important negative consequences in the marital relationship.

Voiding and defecation are two of my major concerns. I fear the possibility of urination during sex. (Mina, 36-year-old woman, tetraplegia, AIS A)

I can't walk, so, no girls like me... Being married is difficult for me. (30-year-old man, paraplegia)

All male participants pointed out that it was their financial problems after losing their job and experiencing unemployment that created a negative change in their social status. Moreover, they declared that they perceived insufficient social support. In other words, they believed that they were unable to overcome financial problems after marriage.

After falling, I lost my job because my work was manual. Still, I should have responsibilities as a man. How can I achieve this? (30-year-old man, diploma, paraplegia, AIS C)

I was a foreman; after my injury, my boss shifted my position. Then, my salary decreased. Therefore, I am unable to afford marital responsibility. (27-year-old man, diploma, paraplegia, AIS A)

Psychological concerns (attractiveness)

A continuum of cognitive and emotional feelings casts a shadow on participants’ perspective toward marriage. Being nervous; having negative body image; having feelings of inadequacy, sadness, hopelessness, and frustration; and being overwhelmed were common psychological deterrents to marriage that respondents expressed.

Am I an attractive daughter with this situation, with a disability, and with a wheelchair? I am not attractive anymore. How do I marry with this unattractive sense? (24-year-old woman, diploma, tetraplegia, AIS A)

I am not a useful person. Why would I marry and catch up another person in my own problems? It is not fair. (22-year-old man, university education level, paraplegia, AIS C)

I don't like to marry because I am afraid of loneliness. Maybe he will not tolerate my problems. (28-year-old woman, university education level, paraplegia, AIS B)

Sexual activity and reproduction

The majority of participants believed that marital life after SCI is not meaningful. They thought that their sexual relationship as a fundamental aspect of marriage would be affected by their injury. Moreover, they highlighted their concerns about no genital sensation, lack of sexual attractiveness, worries about sexual function, and reproductive status.

Before my accident, I was eager to marry, but after my injury I supposed I would be in trouble after marriage, because I don't have any sensation in my genitals and my body doesn't achieve a full erection. (32-year-old man, diploma, tetraplegia, AIS A)

After my injury I became overweight, and then I lost my fitness. I think that there isn't a chance of marriage for an obese girl in a wheelchair. (28-year-old woman, university education level, paraplegia, AIS B)

Inner scenario: Beliefs

Some of the men believed that their current physical limitations led them to marry temporarily. Temporary marriage refers to a marriage in which a man and woman who do not have any restrictions, such as lack of parent permission for getting married, willingly perform a marriage contract, along with mentioning a specific mahr (dowry) and time length for the marriage. This type of marriage has no divorce, and the couple is separated when the time stipulated in the marriage contract ends.²⁴ Temporary marriage provides men with a context to test their sexual function. Sexual dysfunction after injury was the male participants' major concern. They believed women were unlikely to select them as a complete husband:

Well, no chance for us to marry permanently, the best choice is temporary marriage ...in this case, I can test my ability in having sex. (34-year-old man, diploma, paraplegia, AIS B)

I would prefer to marry a woman who cares for me in sex and my personal tasks. (36-year-old man, diploma, tetraplegia, AIS A)

Discussion

The main contribution of our study is the finding that the participants' decision making toward marriage is undermined by their understanding of marriage from inner and outer scenarios.

Certain participants perceived marriage as an opportunity to find a solution for their postinjury needs. In other words, they believed in permanent as well as temporary marriage. Most of them understood the benefit of a long-term marriage in terms of their needs for care. Otherwise some participants, especially men, pointed out the benefit of temporary marriage for testing sexual function. The perception of marriage among our participants post SCI seems to be goal oriented.

A healthy sexual relationship is closely related to positive feelings about one's role as a man or woman.²⁵ In our current culture, receiving a sense of meaning and contentment is possible in permanent marriage. Although temporary marriage can be a strategy to satisfy the sexual

needs of participants with SCI, there may be a lack of fulfillment in a sexual relationship in temporary marriage that is focused on sexual function testing. Likewise, the major concern in a permanent marriage post SCI is that the participant may expect his or her spouse to assume a caregiver role. Although roles may be altered, the burden of caregiving can influence the QOL of spouses and cause health problems.²⁵

According to the present study, most participants declined marriage because of varied physical, psychological, sexual, reproductive, and socioeconomic concerns. The understanding of marriage post SCI among our participants is barrier oriented. Physical as well as psychological problems are prevalent in post SCI life.^{13,26} Most participants believed that these problems affected their decision making about marriage. These perceived barriers to health-related problems and mobility restrictions after SCI are the main reasons participants with SCI decline marriage.

Sexual activity may be altered due to neurological changes after injury, depending on the location and degree of the SCI.^{14,27-29} Sexual and reproductive concerns related to the marital transition were perceived as barriers by our participants. In our culture, a successful marriage is defined by 2 activities — reproduction and sexual activity. Therefore, SCI jeopardizes the transition to marriage.

Participants perceived that they had insufficient social support, including emotional (eg, nurturance), tangible (disability insurance, unemployment insurance, financial assistance), informational (education), companionship (sense of belonging), and intangible (personal advice). They believed that they were not able to overcome their financial problems, so they thought that marriage was not possible. Therefore, it seems that social support is important to facilitate marriage.

Unemployment, high cost of treatment, rehabilitation, and living with SCI are the major economic complications post injury.¹³ Although our participants confirmed that they had economic problems after SCI, they highlighted social concerns as perceived barriers affecting their decision making about marriage. They believed that any negative changes in their social status post

injury decreased their value as a marriage partner. In our current Iranian culture, the main role in marriage is breadwinning for men and childbearing for women. It seems that participants understood the loss of vocational competency and economic autonomy as the most disturbing dimensions of their marital lives.

Limitations

In this study, we tried to explore the understanding of marriage in a sample of Iranian people with SCI. However, we only accessed people who were looking for medical treatment at BASIR clinic. To develop a contextual map of marital transition post SCI, further studies with a causal approach, a larger sample, and recruitment from multiple centers are recommended to expand the generalizability of results.

Conclusion

The findings reveal that although adults with SCI do not ignore or reject marriage, it is not a life priority due to major concerns they had internalized. We recommend a thorough education for people with SCI about their potential for mate selection, SCI-based sexuality education, premarital counseling, and support for their postmarital life. Our findings will provide the decision makers and health providers with significant insight about utilizing culturally appropriate services for people with SCI.

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