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Educational Needs in Sexual-Reproductive Health among Women with Spinal Cord Injury: A Qualitative Study

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Abstract

Backgrounds and Aim: Sexual-reproductive health (SRH) is considered as a major part of general health, and education in this domain can have significant effects on it. Moreover, physically disabled individuals need special healthcare and education in this respect; however, there is insufficient information about SRH in women with this disability. The purpose of the present study was to explore educational needs in SRH among women with spinal cord injury (SCI).

Methods and Materials: In this qualitative research, content analysis method was applied. Participants included women between 18 and 55 suffering from SCI. They were clients of Social Welfare Organization and Association of Spinal Cord Disabilities and selected with purposive sampling method. In-depth semi-structured interviews were individually performed with 15 women and 8 key informants. Graneheim and Lundman's method was used for data analysis. Furthermore, Lincoln and Guba's evaluative criteria were applied for trustworthiness.

Results: Educational needs in SRH among women with SCI were divided into 4 categories and 10 subcategories. They included "providing education by the Ministry of Health and Medical Education", "improving education", "enhancing performance of healthcare staff", and "reforming educational structure of SRH for physically disabled individuals."

Conclusion: Women with SCI could improve their quality of life if they get information about SRH via educational books, CDs, and Internet resources. Moreover, modifying viewpoints of medical students and healthcare providers is assumed as an important factor for this aim.

Keywords: Reproductive Health, Sexual Health, Spinal Cord Injury, Educational Needs

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Introduction

SRH is considered a major part of general health. It has been acknowledged that SRH can influence economic condition, education, employment, and quality of life [1]. In contrast, disabilities can affect individuals' healthcare status [2] and physically disabled individuals are those who may have lost their limbs, are suffering from spinal cord injury (SCI), may be unable to hear or see, or have been affected with incurable diseases [3].

According to the World Health Organization (WHO), over one billion people are living with some forms of disabilities in developing countries. Meanwhile, 10% of these individuals are in reproductive age [3]. In fact, sexual issues in women with SCI are still under study because SCI is often more common in men than women [4,5]. At present, approximately 282,000 Americans are living with SCI, and 80% of them are male [6].

The annual cases of traumatic spinal cord injury (TSCI) in developing countries were 22.5 million in 2022 [7]. In Iran, the prevalence of SCI in 2015 has been reported 318.45 cases in 1 million [8]. In addition, women with disabilities are often regarded as asexual or non-reproductive; therefore, they do not have access to sexual education, reproductive information, and gynecological care including annual examinations and contraceptive methods [9, 10]. Women with SCI have often lack knowledge about SRH and are not provided with necessary information [11]. This reality exists despite knowing that individuals' attitudes regarding their physical status can be changed with education [12].

Additionally, disabilities are negatively correlated with individuals' access to healthcare services [13]. In this respect, some factors have been introduced as reasons for lack of access to healthcare services in this group such as insufficient knowledge of healthcare providers about overall health status of clients with SCI [14], negative attitudes of healthcare and social service providers [15], and their unawareness about disabilities [16-18]. Lack of knowledge and social support are mentioned as the main barriers [19]. There are a few qualitative studies on SRH needs in individuals with disabilities, but majority of investigations have concentrated on SRH or SRH educational needs among individuals without disabilities [20-23]. To fill this gap, the present study was conducted to explain SRH educational needs among women with SCI.

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Methods:

In this qualitative study, content analysis method was applied. To this end, the participants included married women with SCI between 18 and 55, that were supported by Social Welfare Organization and Association of Spinal Cord Disabilities. A group of key informants were also interviewed, including healthcare providers and women's husbands who had lived with their wives for at least six months. In-depth semi-structured interviews were performed individually to collect the required data with one interviewer. More participants were included until data saturation [24]. All the interviews were tape-recorded and immediately transcribed verbatim.

A total number of twenty-three interviews (15 women and 8 key informants) were performed. To verify the trustworthiness of the findings, Lincoln and Guba's evaluative criteria (1985) were applied. To meet credibility, the researchers dedicated sufficient time for data collection through reviewing the relevant transcriptions. The integration of data collection method, data resources, research environments, and variations in participants' characteristics was also observed to enhance credibility. In terms of conformability, a few interviews were coded and then returned to the participants to ensure the reflection of women's viewpoints. Considering dependability, some researchers outside of the study reviewed the data analysis process and provided feedback.

The researchers also attempted not to include their own presumptions in the process of data collection and analysis to improve validity. In terms of transferability, the researcher presented findings to a couple of women with physical disabilities who were not involved in this study. A comprehensive description of personal and cultural background, participants' characteristics, data collection and analysis methods along with some examples of participants' statements also helped with transferability. Data were analyzed with conventional qualitative content analysis method suggested by Graneheim and Lundman [25]. Permission to conduct the study was granted by ethics committee (decree code: 2015/12/15 with IR.SBMU.IASB.REC, No: 8217).

Results

Mean age of women was 39.1(25-52). They were mainly housewives, had high school diploma, and were also suffering from thoracic injury (Table 1). The women's husbands (3 individuals)

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included healthy men, between 34 and 60; they were mostly drivers and employees. The duration of their marriage was between 3 and 36 years. The women had undergone car accidents and their injuries were at cervical, thoracic, and lumbar spine. Duration of their injuries varied from 9 months to 14 years.

The key informants included a social worker, an occupational therapist, a physiotherapist, a gynecologist, and the director manager of Association of Spinal Cord Disabilities. They were between 25 and 48 with 3-20 years of work experience. They also had bachelor to PhD degrees and were interviewed in their workplaces.

Table 1: Demographic characteristics of participants

	Frequency	**Percentage**
Education		
-University degree	5	33.3
-High-school diploma	6	40
-Middle-School or less	4	26.7
Occupation		
- Employee	2	13.3
- Housewife	13	86.7
Causes of Injury		
- Car accident	11	73.4
- Congenital	2	13.3
- Others	2	13.3
Level of Injury		
- Cervical	1	6.7
- Thoracic	8	53.3
- Lumbar	3	20
- Unknown	3	20

The educational needs regarding SRH in women with SCI were described with four categories and ten subcategories. The categories included “providing education by the Ministry of Health and Medical Education”, “improving education”, “enhancing performance of healthcare staff”, and “reforming educational structure of SRH for physically disabled individuals” (Table 2).

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Table 2: Extracted codes, categories and subcategories

Category	Subcategory	Code
Providing education by the Ministry of Health and Medical Education	Healthcare during pregnancy and childbirth	Pregnancy
		Breastfeeding
	Screening prevalent gynecological conditions	Pap smear
		Mammography
	Sexual healthcare	Sexually transmitted diseases
		Sexual health
	Prevention of unwanted pregnancies	Contraceptive methods
		Premarital counseling
Improving education	Sexual-reproductive education for individuals with physical disabilities	Pregnancy-related issues
		Self-care for urination and defecation
		Sexual health in women with SCI
		Physical exercises during pregnancy for SCI
		husband's sexual-reproductive health status
	Providing education based on needs of individuals with disabilities	educational books on sexual-reproductive health
		educationl CDs on sexual-reproductive health
Enhancing performance of healthcare staff	Modification of viewpoints	Recommended screening and routine checkups for women
		Request for pregnancy test if needed
		Correction of time-wasting thinking
		Gynecologists' perception of the importance and the problems of screening cancer among women with SCI
		Support for pregnancy
		Support for breastfeeding
		Physicians' beliefs about normal vaginal delivery
		Physicians' positive viewpoints about sexual relationships of women with SCI
	Improving behaviors	Medical examination if needed
		Improving relationships with caregivers
		Strengthening conscientiousness
Reforming educational structure of SRH for physically disabled individuals	Reforming curriculum of sexual-reproductive health	Increasing awareness among gynecologists and midwives regarding SCI
		Making revisions in courses of family planning
	Holding interdisciplinary seminars on gynecology and rehabilitation	Submission of papers on SCI in gynecological seminars
		Allocating one section of rehabilitation seminars to sexual-reproductive health
		Participation in seminars about SCI

1. Providing education by the Ministry of Health and Medical Education

This category composed of four subcategories:

1.1. Healthcare during pregnancy and childbirth

The participants emphasized the necessity of education about healthcare during pregnancy and childbirth. The experiences of these women regarding SRH needs consisted of two aspects of childbirth and breastfeeding. These women also described their needs for education in these aspects.

"I do not have much information about pregnancy and childbirth. I have heard just

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a few things from others." (35 years old, lumbar injury)

1.2. Screening prevalent gynecological conditions

The participants stated that education in terms of screening prevalent gynecological conditions was of utmost importance. This subcategory comprised of two aspects as pap smear and mammography. They also emphasized the need for increasing their awareness of pap smear and mammography.

"I do not know much about mammography." (45 years old, cervical injury)

1.3. Sexual healthcare

Sexual health education was assumed with high significance among the participants. This subcategory included two aspects of sexually transmitted diseases (STDs) and sexual health. These women also drew attention to the importance of sexual health education.

"I do not know what to do to make my marital relationships better." (37 years old, lumbar injury)

1.4. Prevention of unwanted pregnancy

The participants highlighted the need for prevention of unwanted pregnancies. This subcategory consisted of two aspects: contraceptive methods and premarital counseling services. They further referred to the necessity of education in using contraceptive methods.

"Now, my contraceptive pills is finished … I thought I would start taking them after next menstrual period." (37 years old, lumbar injury)

2. Improving Education

The participants stated that education would be improved through appropriate methods in the field of SRH based on special needs of women with disabilities.

This category composed of two subcategories:

2.1. Sexual-reproductive education for individuals with physical disabilities

The participants reiterated that education should be based on their condition. Women's experiences contained five aspects including pregnancy-related issues, self-care for urination and defecation, sexual health in women with SCI, physical exercises during pregnancy for SCI, and husband's SRH status. These women also referred to the necessity of improving education about special issues during pregnancy and SCI.

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"There must be an advisor to explain pregnancy and breastfeeding and to tell what to do under certain circumstances." (37 years old, lumbar injury)

Moreover, they had great concern about self-care for urination and defecation. They also pointed out the significance of increasing their knowledge in this regard.

"Education concerning muscle control exercises related to urination and defecation is required." (Occupational therapist, 25 years old, 3 years of work experience)

One main issue addressed in this subcategory was the improvement of education regarding SRH for husbands of these women.

"It would be fine if some sessions are held for my husband, so that he learns how to take care of me." (50 years old, cervical injury)

2.2. Providing education based on needs of individuals with disabilities

These women needed education and requested for provision of educational packages. This subcategory consisted of two aspects including educational books as well as CDs on SRH. The participants also highlighted the provision of educational books on SRH for individuals suffering from SCI.

"Books and educational pamphlets are needed. The Red Crescent Society and Social Welfare Organization can offer such educational packages, so that I can make use of them." (25 years old, thoracic injury)

3. Enhancing performance of healthcare staff

The participants stated that enhancing the performance of healthcare staff was indispensable. Participants' experiences in this regard included the following two subcategories:

3.1. Modification of viewpoints

This subcategory included recommended screening and routine checkups for women, requests for pregnancy tests if needed, correction of time-wasting thinking, gynecologists' perceptions of the importance and problems of screening cancer in women with SCI, support for pregnancy, support for breastfeeding, physicians' beliefs about normal vaginal delivery, and physicians' positive viewpoints about sexual relationships in these women.

"I know about pap smear, but nobody has ever told me about screening for cervical cancer." (45 years old, spinal stenosis)

Correction of time-wasting thinking was the other point.

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"This clinic is always busy; there are as many as 50 people and the physicians want to finish the visits as soon as possible" (Gynecologist, 45 years old, 12 years of work experience)

Gynecologists' perceptions of the importance and problems of screening cancer in women with SCI were also highlighted.

"For example, I prescribe pap smears and mammography, … I do not know how difficult this for them is to perform the tests." (Gynecologist, 45 years old, 12 years of work experience)

These participants also emphasized the importance of pregnancy prevention among women.

"A midwife told that: You are mad! How, on earth, you are to get pregnant under such circumstances." (45 years old, spinal stenosis)

Support for breastfeeding was also a major issue raised by most women.

"They had written … a diabetic and disabled mother with high blood pressure … they did not allow me to breastfeed." (45 years old, thoracic injury)

One major issue of this subcategory was the significance of physicians' beliefs about normal vaginal delivery.

"Physicians told me I would not be able to have a normal vaginal delivery at all." (25 years old, thoracic injury)

3.2. Improving behaviors

These women stressed on changing behaviors of medical and healthcare staff. This subcategory consisted of three aspects: medical examinations if needed, improving relationships with caregivers, and strengthening conscientiousness.

Some participants mentioned performing medical examinations if necessary.

"They did not perform an overall check-up to see what problem I had." (30 years old, lumbar injury).

Improving relationships with caregivers was also underscored.

"I am stuck between two devices, and they put pressure on me; it aches, and they tell me not to bend. It results in body spasms." (51 years old, thoracic injury)

Some participants mentioned strengthening conscientiousness.

"Sometimes I have gone for an ultrasound and they deliberately said that the machine cannot be used." (25 years old, thoracic injury)

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4. Reforming educational structure of SRH for physically disabled individuals

This reform should be performed with accurate supervision of the Ministry of Health and Medical Education. This category included two subcategories: reforming curriculum of SRH and holding interdisciplinary seminars on gynecology and rehabilitation.

4.1. Reforming curriculum of SRH

This subcategory comprised of increasing awareness among gynecologists and midwives regarding SCI as well as making revisions in family planning academic courses. The participants shed light on the necessity of awareness about SCI in gynecologists and midwives.

"For my first childbirth, the physician told me to refer to her if I had pain though I did not have any." (29 years old, thoracic-lumbar injury)

4.2. Holding interdisciplinary seminars on gynecology and rehabilitation

This subcategory included submission of papers on SCI in gynecological seminars, allocation of one section of rehabilitation seminars to SRH, and participation in seminars about SCI. In this respect, a participant mentioned the importance of submitting papers related to SCI in interdisciplinary gynecological seminars.

"The focus of papers should be on the problems of women with SCI." (Gynecologist, 45 years old, 12 years of work experience)

One of the participants also stated the need for the participation of patients with SCI in relevant seminars.

"A relevant seminar at a university of medical sciences did not invite individuals with disabilities." (The director manager of Association of Spinal Cord Disabilities, 41 years old, 10 years of work experience).

Discussion

This study was the first qualitative research on educational needs regarding SRH in women with SCI. The findings showed that most women emphasized the necessity of special training on pregnancy and childbirth health. In this regard, Abedi et al. reported that prenatal care (except for blood and urine tests) was provided for less than 40% of women with disabilities and prenatal recommendations were just undertaken for 35% of these women (excluding nutrition and breastfeeding) [26]. Moreover, a study in England revealed that despite positive attitudes of most women with physical disabilities towards their own health status, a few of

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them had participated in counselling sessions on pregnancy and childbirth [27]. In general, it is concluded that appropriate guidelines are required for these women to deal with problems they face.

All participants stated that education concerning prevalent gynecological conditions was quite essential. Studies also showed that women with severe disabilities received fewer pap smear and mammograms for screening or routine checkups [28,29]. The participants also highlighted the necessity to increase awareness about pap smears. An investigation indicated poor levels of screening during women's childbirth as well [26]. Thus, it is concluded that interviewees needed to extend their knowledge about mammograms. It should be noted that education about breast self-examination in these women was reported quite poor [26].

Based on this research, sexual health education is of paramount significance. A study showed that most caregivers had never provided sexual health counselling to patients with SCI. The perceived barrier to the lack of sexual health counselling was insufficient training, and a sexual health team need to be created [30]. Other studies also reported that individuals with physical disabilities received less sexual education [31], exposing them to STDs [32, 33]. Most participants similarly emphasized the significance of education about STDs. In this respect, Abedi et al. concluded that women with disabilities received poor sexual education [26] and providing preventive services for STDs to women with special needs was urgently needed in healthcare system [34].

The physically disabled women in this study also referred to the importance of sexual education. Investigations in the US similarly reported that American women with disabilities learned about physical aspects of sexual intercourse like their normal counterparts [33, 35]. All interviewees also called attention to the necessity of education regarding the use of contraceptive methods. According to a study, individuals facing disabilities received less family planning care [26].

The participants also stated that education about SRH needed to be promoted and provided according to the needs of clients with SCI. Meanwhile, studies showed that provision of high-quality services during delivery could reduce mortality rates [36]. Furthermore, poor education during pregnancy was reported [26]. Self-care in urination and defecation was a major concern. Thus, the participants referred to the necessity of improving education about it. Similar findings demonstrated that a

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prominent issue in body image and self-esteem in individuals with SCI was health maintenance extremely affected by lack of control in urination and defecation [33, 37, 38].

Since women with SCI are suffering from immobility, the interviewees suggested education about physical exercises during pregnancy. Studies also illustrated that physical activities could improve body system functioning. Physical exercises during pregnancy could also reduce the rates of Cesarean-section [39]. One of the critical issues was to promote SRH in patients' husbands. In this respect, Dyck et al. reported that group education in the initial stages of the injury could have positive and long-term effects [40]. Moreover, the participants needed education with educational packages. In the US study mentioned before, American women with disabilities learned their materials in printed and digital forms [35]. The interviewees also referred to the significance of educational CDs for SRH. In this regard, Chen et al. showed that educational CDs could be useful for home rehabilitation, improving self-concept and self-efficacy. [41]

The women emphasized on enhancing performance in medical and healthcare staff. In this respect, a study in Cameron reported the importance of viewpoints of medical staff about sexual health status of women [11]. In this study, the participants referred to the modification of viewpoints in medical and healthcare personnel. The barriers in other investigations included lack of access to healthcare services during pregnancy and childbirth, inconsistency between healthcare services and women's needs [42], negative attitudes [18,42], and incompetent as well as unskilled healthcare staff. [18]

Implementing reforms in educational programs and curriculum of SRH was further suggested by the participants. According to the curriculum of obstetrics and gynecology approved by the Ministry of Health and Medical Education, according to the course headings of the training program and the regulations of the specialized field of obstetrics and gynecology, approved by the Ministry of Health, they should be trained in different fields as well [43]. However, courses on neurological and psychological conditions should be included in curriculums, focusing on physical disabilities, childbirth, and methods to deal with these problems. The participants also referred to the necessity of revisions in family planning courses. Given the changes in policies to increase population, medical and nursing students were encouraged to

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learn about maternal-child care [44]. Moreover, some students highlighted interdisciplinary seminars in gynecology and rehabilitation. Furthermore, a few qualitative studies had been conducted on health needs regarding SRH in women with SCI [45]. There was a need to benefit from cooperation of midwives and rehabilitation centers in this field.

Conclusion

Women with SCI can improve their sexual-reproductive quality of life. Sexual-reproductive education (pregnancy, delivery, contraceptive method, screening for gynecological diseases, etc.) based on types of injury is also important to improve quality of life. This can be achieved by modifying viewpoints of medical students and healthcare providers, creating positive changes in curriculums, and increasing individuals' access to workshops, educational books, and CDs as well as web resources.

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Conflict of Interest

The authors declare no conflict of interest.

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