



## Original Article

# Health Professionals' Experience of Barriers in Empowering People with Spinal Cord Injury: a Qualitative Inquiry

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## ABSTRACT

**Introduction:** Empowering an individual with spinal cord injury as far as possible is an experience with various social and cultural aspects. This study investigated health professionals' experiences of barriers in empowering individuals with spinal cord injuries.

**Methods:** This was a qualitative inquiry with a conventional content analysis approach. A number of 11 healthcare professionals who were members of Iran Spinal Cord Injuries Research National Network or had been working in a related research center for at least three years participated in the study. A purposive sampling method was applied until reaching data saturation. The data were collected by semi-structured interviews. The collected data were managed with MAXQDA software version 13.

**Results:** Three main themes as barriers in empowering people with spinal cord injury emerged: 1) Lack of patient-and-family-centered education, 2) Failure in providing sufficient healthcare services and 3) Inappropriate setting for using rehabilitation services.

**Conclusion:** These findings can help policymakers to provide better social facilities and more support services for people with spinal cord injuries and their families. Further research is needed to investigate barriers to empowerment from the perspective of individuals with SCI and their families.

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## Introduction

Spinal cord injury (SCI) is a critical central nervous system problem classified among the costliest diseases.<sup>1</sup>

In November 2013, the World Health Organization declared that 250000-500000 people are suffering from SCI throughout the world, and this situation has considerable costs for societies.<sup>2</sup> Prevalence of traumatic SCI was 1.2-11.4 per 10,000 people in Tehran during 2008-2009.<sup>3</sup> People with SCI have many problems during their life and suffer from various physical, psychological, familial, occupational and social complications.<sup>4,6</sup>

Empowering them is essential to decreasing their problems.<sup>7</sup> The aim of empowerment programs is to improve and maintain self-care activities among individuals with SCI and their family in order to promote their health.<sup>8</sup> On the other hand, empowerment can improve people's quality of life. It also reduces unnecessary dependencies on the health professionals.<sup>9</sup>

Indeed, empowerment is a personal and multi-dimensional concept due to the various social and cultural factors.<sup>10</sup> Hence, studying the facilitators or barriers of empowering people with SCI had better be done through studying personal and social life experiences of those who are involved with this phenomenon every day.<sup>11</sup> The interdisciplinary healthcare team, including specialist physicians, nurses, physical and occupational therapists and other health

professions have an important role in creating an opportunity for facilitating the empowerment.<sup>12</sup> They encounter various problems during treatment and rehabilitation processes for individuals with SCI. Moreover, they can understand the difficulties experienced by individuals with SCI and their families.<sup>13</sup>

Therefore, experiences and perception of people who are actually dealing with this special condition provides an opportunity to develop the medical and nursing deep knowledge.<sup>14,15</sup> In view of the paucity of research in the area, unavailability of related information in Iran, and the overreliance of individuals with SCI on their families, it seems essential that the barriers to empowering people with SCI be explored and understood. This study investigated healthcare professionals' experiences regarding the barriers to empowering people with SCI.

## Materials and methods

The conventional content analysis approach was applied to describe the phenomenon of study. Hence, direct information from the study participants without imposing preconceived categories or theoretical perspectives was gained by this approach.<sup>16</sup> The participants were 11 healthcare professionals who were members of Iran Spinal Cord Injuries Research National Network or were healthcare providers who were working in a SCI research center in Tehran. A purposive

sampling method was used to recruit potential participants. In order to have more accurate and in-depth data, maximum variation of sample was considered based on sex, age, education level, job and duration of work experience of participants. The inclusion criteria were: 1) willingness to participate in the study and sharing the information and experiences; 2) having at least three years of clinical work experience with people with SCI; and 3) being Iranian and speaking Farsi (Persian). Sampling continued until data saturation.

The data were collected using face to face semi-structured interviews until data saturation. The interview analyses continued until no new data was obtained from them and no new category or subtheme was added. The interviews were held in a private room and at the participants' preferred time when they had enough time for an interview. Each interview began with a general question such as, 'How is the situation for the care of people with SCI in Iran?'. Other questions that were asked included for example: "What factors prevent the empowerment of people with SCI?", "What programs can improve the living conditions of these patients?", "What are the most important services needed for these patients?", etc. The sequence of questions depended on the interview process. The participants were asked to express their experiences and point of views of empowering people with SCI. The interviews were continued for acquiring a deep understanding of the phenomenon. All interviews were conducted in Persian and were recorded, using a digital sound recorder. They were transcribed verbatim and were analyzed at the end of each interview session. Each interview session was 30 to 80 minutes, depending on the participants' patience and their interest in explaining their experiences. If necessary, a second interview session was arranged. In this study, two of the participants had complementary interviews. One of the interviews was 15 minutes and the other lasted 30 minutes.

Data analysis by the first author (MS); was performed according to the proposed procedure of Graneheim and Lundman.<sup>17</sup> At first, each of the typed manuscript was read out and reviewed several times. The data (sentences) were broken down into meaningful segments and considered a conceptual label (codes). The codes that were semantically similar were grouped into one category. With the text repeatedly reviewed, the overlap and redundancy among the categories were reduced. The extracted codes and categories compared constantly with other interviews. Finally, themes emerged to describe the participants' experiences and viewpoints<sup>18</sup> regarding barriers in empowering people with SCI. In general, 712 initial codes emerged in this section, which eventually became three themes. The data were managed by MAXQDA software version 13 (IBM, Armonk, NY, USA). For credibility, the researcher had prolonged engagement with the data and validated the emerging codes and list of categories by getting the opinion of other researchers who had adequate experience in qualitative research. Also, the initial codes were reviewed by the interviewees

through member checking. The prolonged engagement with the participants helped the researchers to build trust and a better understanding of the research fields. In addition, the credibility of the data increased with maximum sampling variation. This sampling method enables the investigator to catch a wide range of views and experiences. To audit the study, the whole process was documented and all the steps followed in the research along with different stages of the research were reported in accordance with the decisions made and the suggested method.<sup>19</sup>

This study was approved by the ethics committee of Tehran University of Medical Sciences.) No. IR.TUMS.REC.1394.1493) The study purpose and research questions were explained for each potential participant by a researcher. The participants who agreed to participate were asked to sign written consent forms.

## Results

The participants' age range was 35 to 53 years and their mean age was 43.90 (6.26). Totally, 11 health professionals participated in the study. Most of the participants were married and their minimum and maximum duration of work experience with individuals with SCI were 3 and 26 years, respectively. Moreover, their mean duration of work experience was 9.54 (06.02.).

The rest of the participants' information is listed in Table 1.

**Table 1.** Demographic characteristics of the studied participants

Code*	Sex	Education	Job
1	Male	Neurosurgery specialist	Neurosurgeon
2	Male	Neurosurgery specialist	Neurosurgeon
3	Male	Ph.D. in Rehabilitation management	Head of the Welfare Organization's Empowerment Office
4	Male	Specialized in psychiatry	Psychiatrist
5	Male	Master of science	Occupational therapist
6	Female	Post-doctoral of Sexual behaviour	Sexologist
7	Female	Preventive medicine specialist	Preventive medicine specialist
8	Female	Master of science in nursing	Nurse
9	Female	Master of science of psychologist	Psychologist
10	Female	Bachelor of social work	Social work
11	Female	Bachelor of Physiotherapy	Physiotherapist

\*It is the numbers that assigned to each participant

Data analysis revealed three main themes as barriers in empowering people with SCI: 1) Lack of patient-and-family-centered education (its subthemes: insufficient information, inadequate education, and wrong attitude); 2) Failure in providing sufficient healthcare services (its subthemes: inadequate professional competence, lack of teamwork, follow-up care and homecare systems); and 3)

Inappropriate setting for using rehabilitation services (its subthemes: shortage of specialized centers, lack of social facilities, poor financial situation, and executive limitations of professional rehabilitation). Main themes and subthemes are listed in Table 2 and also they are described below in details: 1.

**Table 2.** Theme and sub-theme extracted from health professionals' experience of barriers in empowering people with SCI

Main themes	Subthemes
Lack of patient-and-family-centered education	Insufficient information of individuals with SCI and their families
	Inadequate educational program
	Wrong attitude toward disability
Failure in providing sufficient healthcare services	Lack of teamwork
	Inadequate professional competence
Inappropriate setting for using rehabilitation services	Lack of follow-up care systems
	Lack of homecare system
	Shortage of specialized centres
	Shortage of social facilities
	Poor financial situation
	Executive limitations of professional rehabilitations

Lack of patient-and-family-centered education.

The need for training injured people and their families was an issue noted by all participants. Most of them mentioned that people with SCI and their families do not know much about this condition or disability and they do not receive adequate training from the healthcare system. This theme had three subthemes: 1.1. Insufficient information of individuals with SCI and their families The participants stated that individuals with SCI and their families have insufficient information on various care issues." Injured people and their families do not have enough information about pressure sore and some of them have deep and old pressure sores. Although they have been disabled for many years, they still have urinary problems. They still use the catheter; it means they have not been trained to understand the time to empty their bladder." (Code 7) Also, regarding the lack of information about the sexual problems after SCI, a sexual behaviour expert stated: "Injured people and their families do not have proper information on the sexual issues, and some of them believe people with SCI are completely impotent. Also, the community stigmatizes them as impotent". (Code 6) 1.2. Inadequate educational program Some of the participants in this research stated that lack of adequate education is a barrier in the path of empowerment in individuals with SCI. "Unfortunately, no proper education is given to people with SCI on immobility or physical/psychological complications; most of my patients and their families do not have sufficient information even after many years of SCI. I think a special training must be provided for the caregivers of people with SCI. They truly need

educational programs."(Code 4) Also, a nurse cited: "With a proper educational program for individuals with SCI and their families, SCI complications can be decreased in paraplegic and tetraplegic people." (Code 8)

1.3. Wrong attitude toward disability most participants argued that some of the families believe that people with SCI are completely disabled. So, the family members are responsible for doing all their daily activities. "Some families do the entire daily task. So their disabled family member becomes lazy and cannot even do a simple task for him/herself." (Code 10) Also, some families thought that palsy is temporary and did not believe in disability of their family member. Thus, they had a poor follow-up care. "Some families think that the injured person will sooner or later get better; so there is no need to learn the healthcare activities. They pray to their God everyday instead of doing proper care. I think the denial of disability is a wrong attitude." (Code 9) 2. Failure in providing sufficient healthcare services some participants said that there are some problems in the way of empowering people with SCI beyond the family and the individual, which prevent the medical staff and family from helping the individual. This theme had five subthemes: 2.1. Lack of teamwork Most participants noted poor teamwork within groups and between different institutions. "In this center, there is no connection between the sexual health department and the other departments that provide service to people with SCI. The medical staff does not know about my sexual health protocols and I do not know about theirs, while they are located exactly in the next room." (Code 6)

The man who was a psychiatrist said: "some public institutions and non-governmental organizations (NGOs) have no scientific or process management; when they work together, most of the times they face some conflicting financial matters and their collaboration comes to an end very soon." (Code 4)

2.2. Inadequate professional competence

Poor communication skills, not caring or not having enough skills for taking care of the disabled individuals were mentioned by the participants who show inadequate professional competence. "I have seen that some of the healthcare staff do not greet the people with SCI". The woman who was a nurse stated: "Some people with SCI ask questions of nurses, psychologists or occupational therapists that are somehow easy and routine, but they say 'I do not know' most of the time; they tell them 'ask your doctor'." (Code 5) Another woman who was a preventive medicine specialist said: "Nurses tell me that they have so much work with many patients that they have no time and thus neglect bed sores of people with SCI at the hospital." (Code 7)

2.3. Lack of follow-up care systems

In the interview, the participants noted that an individual with SCI needs follow-up care system: "We had a patient who had fallen off the bed and broken his leg. He did not come for two months and when he showed up, he had sore pain on his hip. He suffered from a knee contracture and in general, his condition was bad. We have no

follow-up systems even by phone for people with SCI and they themselves can be too negligent." (Code 5)

#### 2.4. Lack of homecare system

Some participants stated that most services are provided in the clinics or rehabilitation centers. The few available homecare services are provided by NGOs and it has limited services which are not covered by insurance.

"Some people with SCI spend so much on having a doctor, nurse or therapist visit them at home because they are rich enough; but most people cannot afford such expenses and cannot use homecare services in this country". (Code 2)

Another participant stated: "We have no home visits as a routine. The best way to set up homecare in Iran is through getting governmental support". A woman who was a social worker noted: "Some people with SCI complain about the costs; they complain why there is no insurance covering healthcare services at home". (Code 1) Also, a few participants stated that, currently, Iran's Welfare Organization cannot achieve the desired results for empowering individuals with SCI and cannot provide homecare services for them. "The Welfare Organization is doing some work indeed, for example, they give out a few catheter and diapers, or they just give some money, or very short 10-session rehabilitation. But they should be doing more, I think, they should provide homecare services and go to patient's home, for example, to prevent bed sore." (Code 2)

#### 3. Inappropriate settings for using rehabilitation services

Most participants believed that there are no appropriate social services for empowering people with SCI. The sub-themes were as follows:

##### 3.1. Shortage of specialized centers

The participants were concerned about the shortage of specialized centers for acute care and rehabilitation of people with SCI. "There are so many people with SCI, but there are only few specialized centers for them. There are not enough acute rehabilitation hospitals in our country." (Code 3)

Also a nurse stated: "Most people with SCI stay at non-specialized hospitals; these hospitals have not been designed to rehabilitate; so their complications become worse." (Code 8)

##### 3.2. Shortage of social facilities

All the participants considered that there are not enough social facilities in the city, and the responsibility lies with governmental organizations to help. "Most streets have a rough surface; it is even difficult for a mother to push a baby carriage in the street, and the buses are not suitable for people with SCI; they further lessen the injured individuals' motivation to go out." (Code 7)

Another participant referred to tasks of governmental organizations: "Because of the financial situation, some families cannot make the home suitable for movement of their member with SCI and governmental organizations such as municipality and Welfare Organization might have been able to help them." (Code 10)

##### 3.3. Poor financial situation

Some participants argued that poor financial situation is a barrier to empowering individuals with SCI. Some people with SCI cannot afford to pay for good quality rehabilitation in the long run. The man who was a psychiatrist stated: "Some people with SCI are in a bad financial situation. I think poor financial situation delays the empowerment process." (Code 4)

Also, another participant remarked: "Some people with SCI cannot afford to pay for nongovernmental health services such as home visits. These patients cannot even use the cheap services of NGOs regularly." (Code 11)

#### 3.4. Executive limitations of professional rehabilitations

The small number of the specialists concerned about legal rights of people with disabilities in employment. "Organizations do not care about the legal rights of people with disabilities (about 3-4%) in employment. In fact, there is no way to guarantee their right." (Code 1)

Another participant mentioned lack of jobs as an Executive limitation of professional rehabilitations: "Generally in our country, there is a shortage of jobs; this also affects unemployment of people with disabilities." (Code 3)

## Discussion

The findings revealed some of the barriers for empowering people with SCI from the perceptions and experiences of healthcare professionals. The barriers included lack of patient-and-family-centered education, failure in providing sufficient healthcare services, and inappropriate setting for using rehabilitation services. This showed that various familial, social, economic, and governmental factors are influential in empowering people with SCI. Lack of patient-and-family-centered education, included three sub themes, namely, the insufficient information of individuals with SCI and their families, inadequate educational program, and wrong attitude toward disability.

Norrbrink Budh and colleagues<sup>20</sup> showed that an educational program can have a great impact on reducing complications of individuals with SCI. Davidson<sup>21</sup> stated that families have a central role in taking care of their disabled members and also, some patients and their family didn't often receive enough information about their health problems. Hence, education can help them. Both of these studies came to findings similar to the results of the present study.

Failure in providing sufficient healthcare services was another theme of this study. This theme included lack of teamwork, inadequate professional competence, lack of follow-up care systems, and lack of homecare system. Some studies have mentioned the empowerment barriers related to the healthcare system structure, culture, new learning, and unavailability of services.<sup>22-26</sup> Among them, Long and colleagues<sup>23</sup> found out that there was no cooperation between the team members in providing rehabilitation services to people with SCI. Also, team work was weak. This was in agreement with the present study results. Inadequate professional competence was

another subtheme. People with SCI require special care, which is sometimes provided by non-professionals such as nurses or therapists who have no experience with people with SCI or have had no training in this regard. Some studies suggested that personal and professional capabilities, skills, and ethical and human values should be considered in the professional competence.<sup>27,28</sup> According to the participants' perceptions in the present study, homecare services are limited for people with SCI because of high costs and lack of systemic services. Some studies show that fear of costs is the main reason for not using homecare service.<sup>29,30</sup> Also, Nikbakht-Nasrabadi and Shabany-Hamedan<sup>29</sup> have shown that providing home care services is a necessity in Iran, but there are complications in its way, such as lack of insurance regulations and absence of a registration and identification system.

Another barrier of empowerment was lack of follow-up care by the healthcare system. In this regard, the present study findings are consistent with Schiff's study.

He showed that the reasons for deficiency of follow-up system are multifactorial. One barrier is lack of systematic approaches for follow-up.<sup>31</sup> Inappropriate settings for using rehabilitation services was the last theme which included the shortage of specialized centers, lack of social facilities, poor financial situation, and executive limitations for professional rehabilitation.

Shortage of specialized centers was a problem in empowering people with SCI. Parents and colleagues<sup>32</sup> showed that early transformation of people with SCI to an integrated specialized center can generally reduce the mortality and complications. So the number of specialized centers in Iran should be increased.

According to the participants' experiences in the present study, there is a lack of social facilities. In a qualitative study, Wright and colleagues<sup>24</sup> found that lack of community facilities can act as a barrier for physical activities among people with disability. Also, Bezyak and colleagues<sup>33</sup> stated that individuals with disabilities still experience barriers to public transportation. The poor financial situation of people with SCI was another barrier. Loignon<sup>34</sup> found that poor financial situation affects people's access to healthcare.

Gobelet and colleagues showed that in the European Union specifically, the number of people with disability who were employed was 22.3%, less than those without disability.<sup>35</sup> This finding was similar to the present study in which the results showed executive limitations in professional rehabilitation

## Conclusion

Empowerment in people with SCI in Iran faces various obstacles. Increasing the awareness of government, society, and families about the barriers to empowering people with SCI is important. Patient-and-family-centered education should be considered in health care services. Setting up a home care system under insurance coverage and a follow up care system can have many

benefits for helping people with SCI and their families. Moreover, training health care teams about SCI including nurses, physiotherapists, specialists, etc., is equally important. The findings can help policymakers, especially in developing countries, to provide better social facilities and more support services for people with SCI and their families. Further research is needed to investigate barriers to empowerment from the perspective of individuals with SCI and their families.

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## Ethical issues

None to be declared.

## Conflict of interest

The authors declare no conflict of interest in this study.

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