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Psychosocial challenges of social reintegration for people with spinal cord injury: a qualitative study

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Abstract

Study design Qualitative study, using in-depth, and semi-structured interviews.

Objective To identify the psychosocial challenges of social reintegration for people with spinal cord injury (SCI) in Iran.

Setting People with SCI living in the community in Iran.

Method Eleven individuals with SCI with a median time since injury of 12 years (between 9 and 20 years), two family members, and three specialists (two social workers and one physiotherapist) were selected by purposive sampling with maximum variation. In-depth and semi-structured interviews were conducted and finally the data analyzed through qualitative content methodology.

Results The psychosocial challenges were categorized into four main categories and twelve subcategories: early crises (denial and disbelief; feelings of isolation and depression; dependency crisis; and a sudden change in the normal course of life), disabling society (stigma; discrimination; employment challenges; and educational restriction), environmental barriers to access (lack of barrier-free environments and transportation challenges), and inappropriate services delivery (incomprehensive rules and lack of specialized training).

Conclusions Providing various psychosocial services is essential for the social reintegration of people with SCI. This goal could be achieved by the provision of medical and physical rehabilitation services. The ultimate purpose of rehabilitation is to reintegrate individuals into society after injury or illness; thus, psychosocial issues must also be considered to ensure effective rehabilitation.

Introduction

Spinal cord injury (SCI) is a complex condition that causes bio-psychosocial issues [1], and reduces participation in daily activities, and alters quality of life [2]. The World Health Organization (WHO) reports that 250,000–500,000 people suffer a SCI worldwide each year with an incidence rate of 15–20 individuals per million people [3]. However, in Iran the incidence rate is estimated to be much higher at 40–50 individuals per million. This equates to ~2000 people per year, with accidents accounting for 86% of cases [4].

After SCI, one may experience different feelings such as anger, anxiety, nostalgia, and even despair [5]. Anger and denial are the first psychological experiences of the injured person and his or her family [6]. Zürcher et al. [7] showed that depression and anxiety were reported in 22% and 27% of patients with SCI, respectively. In a study on identification of post-SCI psychosocial problems, Singh et al. [8] showed that 14% of the study population had psychoneurotic disorders such as attention and concentration deficits, memory, learning, and problem-solving disorders. In addition, 22% of them suffered from Post-Traumatic Stress Disorder (PTSD) [8].

There are promising advances in the treatment of psychiatric disorders among people with SCI. However, the social sphere has received less attention. The social needs of individuals are often as important as their physical needs [6]. In a study on the psychosocial consequences of SCI in Iran, Khazaeipour et al. [9] presented items, such as the lack of job opportunities, high living costs, transportation, changes in the place of residence, education, marriage and social relations as important problems following SCI.

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A critical SCI-related concept and the key goal of rehabilitation is social reintegration. A major challenge for individuals with SCI is to establish themselves as community members, despite their injuries [10]. Samuel Kamallesh Kumar et al. [11] argued that the mortality rate is higher in people with SCI who have experienced less social reintegration. Social reintegration is a matter beyond the individual dimension and involves bio-psychosocial aspects. It is important to understand the significance of participation and social reintegration among individuals with SCI [12]. Social reintegration improves clinical and psychosocial attributions and well-being in people with SCI [13, 14]. Successful community integration can be defined as being part of the mainstream of family and community life, fulfilling normal roles and responsibilities and being an active, and contributing member of the social groups and the society, as a whole [15]. Song [16] modeled the social reintegration of people with SCI and showed that emotion-focused coping played an important role in the social reintegration of people with SCI. Family support, information support, perceived stress, and social barriers were also significantly related to social reintegration [16].

Overall, studies have often focused on physical and psychological problems following SCI [17]. Besides, the psychosocial challenges of social reintegration require further understanding and attention. Such challenges are related to the cultural and social context; therefore, recognizing the psychosocial challenges of people with SCI from their experiences could facilitate the social reintegration, increase social participation, and enhance their quality of life. Most studies in Iran have investigated the consequences of SCI, and only a few studies have explored the social reintegration of individuals with SCI [9, 13]. Therefore, this study aimed to identify the psychosocial challenges of social reintegration experienced by people with SCI in Iran.

Method

Study design and setting

The present qualitative study was conducted based on an interpretive paradigm and a qualitative content analysis approach. This study aimed to understand the experiences of people with SCI and the psychosocial challenges involved in their social reintegration in Iran. This research was part of a larger study aimed at developing a psychosocial guideline in SCI rehabilitation. One purpose was to examine the psychosocial challenges of individuals with SCI through semi-structured and in-depth interviews and qualitative content analysis of the information collected.

Participants

The study participants included people with SCI, their families, and health and social care providers. Therefore, they had a rich experience, knowledge or useful information and expertise about the psychosocial challenges and experiences of people with SCI. The total number of participants was 16 individuals, including 11 people with SCI, two family members, and three specialists in providing services to people living with SCI. The study inclusion criteria for people with SCI included individuals aged 18–65 years, individuals suffering from SCI for more than four months, and appropriate cognitive status to provide information. The study inclusion criteria for family members were living with and caring of the person with SCI and for experts were up to 5 years working with people with SCI and having knowledge about SCI.

Sampling method

The sampling method was purposive and maximum variation and included people with SCI of varying severities and levels of injury, gender, marital status, age, family, and professionals. Sampling continued until data saturation. The purposive sampling is a technique used in qualitative research studies and involves identifying and selecting individuals or groups that are especially knowledgeable about or experienced with a phenomenon of interest. Maximum variation is a purposive sampling technique used to capture a wide range of perspectives relating to the thing that you are interested in studying [18].

Data collection

Data were collected from January 2019 to July 2019. The participants' demographic characteristics data, such as age, gender, educational level, marital status, injury level, and injury time were collected through a structured questionnaire. Most of the information was obtained through semi-structured and in-depth interviews. To conduct the interviews, the researcher referred to relevant centers such as the Welfare Organization and SCI associations after obtaining permission from the university in January 2019. After selecting potential participants and explaining the study purposes, they were invited to participate in the study, and after informed consent was obtained, individual interviews were conducted with participants from February 2019 to May 2019. The conversations were all audio-recorded based on the consent of the participants. After each session, the audio content of the interview was transcribed and analyzed. The sessions continued until data saturation.

Data analysis

Data analysis was carried out using qualitative content analysis method, which is a research method for subjectively interpreting the content of textual data through systematic classification processes, coding, and theming or designing known paradigms [19]. It is also a flexible data analysis method [19]. In the present study, qualitative data analysis was simultaneously performed with data collection and by the repeated reading of interviews. At this point, this study continued by encoding the data, i.e., dividing the text into smaller units (phrases, sentences, and paragraphs) and adopting a title for each unit. Similar data were then categorized. The emphasis was on identifying paradigms in the data and their interrelationships. Finally, the categories were formed by the organization of the early categories, which linked the basic themes and meanings of the categories. These categories illustrated the psychosocial challenges of social reintegration among people with SCI.

Reliability

Four criteria of credibility, transferability, dependability, and conformability were considered to ensure the accuracy and robustness of the data in this study. To ensure data credibility, the following approaches were used: long-term engagement with data and spending adequate time collecting and analyzing data, integrating information sources, and employing multiple data collection methods (interviews, field notes, and reviews by participants). To facilitate the transferability, the processes of selecting participants, data collection, and data analysis were thoroughly described. The dependability of the data was determined in a way that the data obtained in the interviews, were also recorded in field notes, and by memoing. Finally, all study stages, especially the data analysis steps, were recorded in detail to meet the conformability criterion.

Results

Sixteen participants were interviewed, including eleven individuals with SCI, two family members, and three specialists (two social workers and one physiotherapist). The eleven individuals with SCI consisted of eight males and three females with a median time since the injury of 12 years (between 9 and 20 years and SD: 4.4) and with a median age of 35 years (between 26 and 58 years and SD: 9.8). There were three, six, and two people living with SCI suffering from cervical, thoracic, and lumbar injuries, respectively. Table 1 shows the demographic characteristics of the participants.

Table 2 shows the results of the analysis of the interviews in response to the research questions on the psychosocial challenges of social reintegration for individuals with SCI.

Early crises

The early crises were referred to by the participants as the first SCI-related experiences. This category consisted of four subcategories, as follows: denial and disbelief, feelings of isolation and depression, dependency crisis, and a sudden change in the normal course of life.

Denial and disbelief

One of the issues referred to by the participants as their first post-SCI experiences were disbelief and denial of disability and the loss of mobility. People with SCI initially have unrealistic hopes of recovery and do not accept disabilities in some areas, especially the inability to walk.

Regarding the hope for recovery and disbelief during the first months after the incident, a 37-year-old female participant stated:

“I was alive and tolerated the conditions with the hope that I would be able to walk six months later. I’m not the one to fool myself, but sometimes I marked somewhere on my bed and I was counting down the days in the hope of walking again” (p1).

Feelings of isolation and depression

Other topics emphasized by participants were feelings of isolation and depression. Individuals reported experiencing post-SCI critical periods mentally and experienced isolation, depression and suicidal tendencies.

A participant, who was the spouse of a 44-year-old man with SCI, acknowledged:

“Everyone might suffer from an illness during their lives, have an accident that deprives them of normal activity in some body organs. The fact is that, if no one helps the injured, they will think of committing suicide. If this thought didn’t come to their minds, they would be so isolated and depressed. So, it is a kind of suicide” (F1).

Dependency crisis

Overwhelming dependency on others in many personal and daily activities and being a burden was one of the most important crises and issues dealt with by participants and

Table 1 Demographic information of the participants.

Code	Gender	Age	Cause of injury	Injury site	Length of SCI	Degree of education	Occupation	Occupation before SCI	Marital status	Number of children
P1	Female	37	Car Accident	Thoracic	12 years	BA	Employee	University student	Married	0
P2	Male	35	Car Accident	Cervical	10 years	High school	Unemployed	Driver	Married	2
P3	Male	48	Falling	Thoracic	13 years	BA	Retired	Employee	Married	1
P4	Male	44	Falling	Thoracic	20 years	MA	Unemployed	Unemployed	Married	0
P5	Male	26	Car Accident	Thoracic	10 years	BA	Unemployed	Unemployed	Single	0
P6	Male	58	Falling	Lumbar	20 years	High school	Employee	Unemployed	Married	2
P7	Female	52	Falling	Thoracic	20 years	Elementary	Housewife	Housewife	Married	4
P8	Male	30	Beat	Thoracic	10 years	High school	Unemployed	Driver	Married	0
P9	Male	33	Disease	Lumbar	9 years	High school	Unemployed	Freelance	Married	0
P10	Female	35	Car Accident	Cervical	15 years	BA	Unemployed	Unemployed	Single	0
P11	Male	35	Car Accident	Cervical	11 years	High school	Freelance	Unemployed	Divorced	0
F1	Female	40	Wife			High school	Housewife	–	Married	0
F2	Female	35	Wife			High school	Housewife	–	Married	0
E1	Female	35	Social worker with 5 years work experience			–	–	–	–	–
E2	Female	40	Social worker with 15 years work experience			–	–	–	–	–
E3	Male	45	Physical Therapist with 20 years experience			–	–	–	–	–

P person with SCI, *F* family member, *E* expert.

Table 2 Categories and subcategories of psychosocial challenges.

Subcategories	Categorise
Denial and disbelief	Early crises
Feelings of isolation and depression	
Dependency crisis	
A sudden change in the normal course of life	Disabling society
Experience of stigma	
Discrimination	
Employment challenges	
Educational restriction	
Lack of barrier-free environments	Environmental barriers to access
Transportation challenges	
Incomprehensive rules	Inappropriate service delivery
Lack of specialized training	

regarded by participants as one of the most difficult situations in their lives. People with SCI are humiliated by asking for help with personal activities, especially for bathing and using the toilet. In this regard, a 37-year-old woman said:

“It was very difficult for me. I felt offended to let someone else do my daily tasks. It might be funny and too usual for a person who didn’t experience it. Maybe I was too sensitive. It was very hard for me to have someone else come to my house to take off my clothes, for example, to insert the catheter and take me to the bathroom. I can’t stand imagining one person to come and take me to the toilet. For example, some people would come to take me to the bathroom. It was so hard for me” (P1).

A sudden change in the normal course of life

Participants considered SCI as a crisis and stated that they were deprived of all physical and motor abilities at once; thus, they experienced dramatic and significant changes in all daily activities.

A 37-year-old female participant said:

“The condition will suddenly become hard for you and the life stops and takes a weird model. People’s behavior, family’s behavior, their thinking, the fact

that you were an independent person before the accident, you were studying, you were working, you had a different appearance and face, and then you are sitting in a wheelchair” (p1).

Concerning a change in all daily living activities, a 30-year-old male participant also stated that:

“But for me who ran for 20 years, I did all the work. I went mountain climbing and used to swim. I rode on a bike. I rode on a motorcycle. Suddenly, you’re deprived of all of them. You can’t do anything anymore. It is what it is and you are sitting in your wheelchair forever” (p8).

Disabling society

Another category identified in this study included the disabling society, which was referred to by the participants as a factor decreasing their presence in the society. Its subcategories included experience of stigma, discrimination, employment challenges, and educational limitations.

Experience of stigma

Participants said they withdrew from society because of the way people looked at them using a wheelchair. The stigma of disability and how individuals perceive it has a significant effect on their social reintegration.

A 35-year-old female participant, as a wife of a man with SCI, said:

“People’s gaze is important. It is one of the important issues that a person with SCI experiences in society. This look is very different from the time when the person is healthy and everyone is looking at him/her as a normal person. For example, my spouse had to buy a three-wheel motorcycle for commuting. When I was driving with my spouse, I had to sit next to him on that tricycle. When we went outside, we saw many people pointing fingers at us because it was unusual for some people to see a person sitting on a three-wheel motorcycle, and a young lady, sitting next to him. It would have a negative effect on me and my spouse” (F2).

Discrimination

Participants stated that they experienced discrimination and exclusion because of the disregard by society and authorities

of the issues facing people with SCI, and the disrespect for and negligence of people with SCI.

Concerning the inferiority of the disabled in the society, a 48-year-old male participant said:

“The authorities think that every person with SCI is an inferior person in society and allow themselves to treat us in any manner” (p3).

A 58-year-old male participant commented on discrimination and rejection in society:

“I may say that I changed three or four jobs. First of all, our society didn’t accept us very much. They said you couldn’t. Everywhere we went, they told us that you had a medical exemption, and you aren’t physically able to this work” (P6).

Employment challenges

One of the major problems reported by participants was the loss of their former job due to decreased physical abilities. In addition, insufficient skills training and inappropriate employment for their situation reduced their social participation.

Regarding the lack of skill training and job support, a 30-year-old male participant stated:

“There’s no place where I can refer and receive training and they then employ me. Not even at Kahrizak center (Kahrizak is an institute in Iran that provides day care services to people with SCI). I am a good marquetry artist; for example, they establish a workshop and train 10 people so that we create job; I do a manual job, for example I have leather and sew it by hand; however, there is no market where I can offer it for selling, or we don’t have a sponsor to support us” (P8).

Educational restriction

Forced dropouts, changing disciplines, and inability to access educational and training facilities were the most important educational restrictions referred to by the participants.

Regarding the coercion to changing the field of study, a 35-year-old female participant stated:

“It wasn’t possible for me to continue studying food engineering because it was all about experimenting within labs and most of its credits are practical. The

only discipline that would fit my circumstances and allow me to study remotely and have a job in the future was English translation” (p10).

Environmental barriers to access

One of the categories extracted in this study as the main reason for the absence of people with SCI in the community was the environmental barriers to access the community and services. This category consisted of two subcategories: lack of barrier-free environments and transportation challenges.

Lack of barrier-free environments

One of the main problems reported by the participants in the community was the lack of barrier-free environments (e.g., streets, passages, and urban furniture), which discouraged them from leaving their homes and decreased their social participation.

Regarding the inaccessibility of public places and offices, a 30-year-old male participant said:

“You want to go to university, but it lacks barrier-free sanitation. Another university has stairs and no ramps. Well, when you see there is no barrier-free university, you have to quit your studies. When you want to go to the municipality and follow it up, the municipality itself is still disabled, and has no ramps. I want to open a bank account; I see 20 stairs. They want to lift me up the stairs in my wheelchair, and the guy doesn’t know how to do this, he is likely to hurt me, I then have to go to another bank. Then I have to go around the whole city to find an accessible bank. For example, once the head of the bank came to my car to obtain my signature (laughter), he had to come in! This is their problem, not mine. If they construct a ramp, I will enter the bank, but when they do not, he has to enter my car” (p8).

Transportation challenges

The lack of barrier-free vehicles and public transport, the need for taxis to support wheelchair users, and consequently, high transportation costs were among the issues referred to by the research participants as problems while joining the society.

Regarding the problems of not having a personal car and using taxis, a 35-year-old man said:

“It’s very hard for me to go somewhere because I don’t have a personal car. I don’t have the tools. I

can’t use vehicles. I have to hire a taxi. Taxies often don’t accept me because my wheelchair is an electric non-folding wheelchair so their trunks remain half-open, and most of them do not accept me and those who accept, nag so much and charge us a lot of money. Because of this wheelchair, they say that your wheelchair occupies much space” (p2).

Inappropriate services delivery

Inappropriate services delivery was another category referred to by the participants as one of their social challenges. This category consisted of two subcategories: incomprehensive rules, and the lack of specialized training.

Incomprehensive rules

The absence of appropriate rules and guidelines and failure to follow instructions, were referred to by the participants as a problem in the Welfare Organization.

Regarding inappropriate guidelines, the provincial social work experts with 15 years of experience working with people with SCI said:

“One of the arguments being raised is that plans and guidelines are often formulated at the national and expert levels. In other words, those who work in the executive branch as well as the people with SCI themselves are not involved in the formulation of plans. Therefore, the guidelines are not feasible because they have not been worked upon properly” (E2).

An executive social worker with five years of experience working with people with SCI said:

“One issue is that legislators are people who know more about the credentials and capabilities of the organization, not the needs of the people with SCI. So, the plans are not feasible because they totally disregard the conditions of the disabled person” (E1).

Lack of specialized training

The participants stated that they were struggling with lack of inadequate knowledge about SCI and its characteristics, i.e., the lack of information on how to cope with the problem and accept it, and the lack of training on how to perform daily living activities and personal tasks.

Regarding the need for basic skills training, a 37-year-old female participant stated:

“One of the problems was that I had no idea that one is suddenly told that he/she can’t walk, go to the bathroom, go to the toilet anymore. What could he/she do? I wish there were a group where SCI guys learned how to live. I wish there were a place where we could receive training in case of an accident, when something happens, and the persons suffer from SCI for always - you might find it a bit trivial - we need someone to tell how to dress, for example” (p1).

Discussion

The data in this study provided four main themes and twelve subcategories reflecting the participants’ experiences of the psychosocial challenges of social reintegration. One of the challenges that participants in this study faced in the early months after SCI was early crises. Other studies have shown that individuals with SCI experience different crises, such as anxiety, depression, attempted suicide, the conflict between dependence and independence, and the denial of disability [20–23]. Khazaeipour et al. [24] indicated that 49% of people with SCI in Iran suffer from mild to severe depression. Olckers [15] also found in a study that one of the factors influencing the psychosocial reintegration of individuals with SCI was their reliance on caregivers. Thus, the lack of attention to the emotional and psychological aspects and the shock resulting from the fact that an active and healthy person is currently encountering disability have generated various psychosocial problems for individuals with SCI that can have devastating consequences.

Regarding restrictions, barriers, and specific social conditions of individuals with SCI, some research has highlighted cultural issues and socially restrictive attitudes [25, 26]. In a qualitative research, Barclay et al. [27] revealed that accessible resources and environments, social interactions, health issues, financial resources, and social support networks positively impacted social participation; however physical environment, socially restrictive attitudes, and mental health problems were identified as barriers to social participation. Garcia et al. [28] also showed that societal attitudes, rejection, stigma, repression, and discrimination influenced social participation of individuals with SCI. Anderson et al. [29] also found in their study of education and occupation that five factors are strongly related to social reintegration, including education level, occupation, income, independence of performance, and health status. The findings support the importance of the social rehabilitation field for individuals with SCI. This information also suggests that the rehabilitation of individuals with SCI, regardless of their sociocultural context, cannot alone pave the way for social interconnection.

Numerous studies have pointed to environmental barriers and limitations, leading to reduced social participation [23, 27, 30–32]. Akter et al. [33] also identified inaccessible environmental structure and the presence of slopes and stairs as one of the study themes. They also showed that transportation-related challenges constituted 23% of the barriers to social reintegration and the most frequent barrier was the inability to move the wheelchair [33]. Wehman et al. [34] also identified transportation problems as a barrier to the social reintegration of individuals with SCI. Therefore, facilitating social reintegration among individuals with SCI requires diminishing environmental barriers and facilitating access to community services through a standardized barrier-free environment that offers convenient transportation service.

Inappropriate service delivery was also identified as another barrier to social reintegration among individuals with SCI in this study. Chang et al. [35] showed that social policy factors along with other environmental characteristics, influenced the social participation of people living with SCI. Yue Cao et al. [31] investigated environmental barriers to the mental health of people with SCI; 20% of these individuals experienced at least one legal barrier. Moreno [36] concluded that service delivery should consider the expressed and unmet needs. Furthermore, addressing these requirements at different stages of rehabilitation will help the social reintegration of individuals with SCI [37]. To highlight the importance of paying attention to the educational needs of people with SCI in Iran, Boluki et al. [38] revealed that awareness and learning are important in the perception and experience of independence in people with SCI. These findings demonstrated the importance of being aware of the need for integrated, comprehensive, and continuous services. Overall, providing services to people with SCI, it is very important to be cognizant to the needs of people living with SCI while formulating guidelines and rules and considering their autonomy. Autonomy is a key ethical principle in the health care profession. The most important factors affecting the autonomy are: self-development skills, self-evaluations and scope for action within a social context [36]. Therefore, these factors must be addressed when formulating principals and guidelines. Another important point in this section is that rehabilitation programs should assist people with SCI through training by achieving existing realities; consequently, they will be able to maintain their psychosocial well-being and take steps toward achieving their independence.

Suggestions

Several suggestions are extracted from the results of this study. Reforming laws and structures, such as reducing environmental barriers, is suggested in the aspect of policy-making. Providing necessary training, appropriate services

and follow-up after hospital discharge, suggested for the executive dimension. For the research field, developing of protocols and interventions to facilitate social reintegration of people with SCI is suggested.

Limitations

The major limitation of this study was the physical characteristics of the participants and the difficulty of accessing and communicating with people living with SCI. This study does not represent an overall picture of the challenges of all individuals with SCI in Iran. The sampling method was purposive and maximum variation; accordingly, data were collected from a limited sample of individuals. Therefore, the findings cannot be generalized to other locations that do not have similar environmental, cultural, and socioeconomic characteristics. Additionally, this study was conducted in literate people with SCI aged 18–65 years. Therefore, it cannot be generalized to the whole society.

Conclusion

This qualitative study revealed the importance of psychosocial challenges of social reintegration in people with SCI. Therefore, to achieve comprehensive rehabilitation, the psychosocial issues of people with SCI must be considered. In this regard, it is essential to provide these services by psychosocial rehabilitation teams.

Data availability

The datasets generated or analyzed in this study are available from the relevant author on reasonable request.

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Author contributions FM was responsible for data collection, data analysis, and drafting and revising the report. FA drafted and provided critical revision of the manuscript and was responsible for the analyses and interpretation of the data. GhR and NH were responsible for designing the research protocol and data analysis.

Compliance with ethical standards

Conflicts of interest The authors declare that they have no conflict of interest.

Statement of Ethics We certify that all applicable institutional and governmental regulations concerning the ethical use of human

volunteers were followed during this research. The present research study was conducted after obtaining permission from the University Ethics Committee (Code of Ethics: IR.USWR.REC.1396.3144).

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