

# Personal, family and societal educational needs assessment of individuals with spinal cord injury in Iran

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## ABSTRACT

**الأهداف:** استكشاف إدراك الأفراد للاحتياجات التعليمية الشخصية والعائلية والاجتماعية بعد إصابة الحبل الشوكي (النخاع الشوكي).

**الطريقة:** أصيب 61 باصابات النخاع الشوكي المؤلمة بين مارس 2015 و يونيو 2016م حولوا إلى مركز أبحاث إصابات الدماغ والحبل الشوكي (BASIR) وادرجوا في دراسة مقطعية مستعرضة وأكملوا استقصاء عبر الإنترنت يحتوي على أسئلة مفتوحة ومغلقة في إيران. تم تحليل ردود المشاركين باستخدام نهج نوعي مع تحليل موضوعي.

**النتائج:** بعد تحليل موضوعي للاحتياجات التعليمية المتصورة للمريض ، تم تحديد 3 محاور و 14 موضوعاً فرعياً. تضمنت الموضوعات 3 الاحتياجات التعليمية، الشخصية، والعائلية والاجتماعية. ضمن الاحتياجات التعليمية الشخصية، كان هناك 7 مواضيع فرعية تضمنت الاستقلال الشخصي والنقل والاستقلال المالي وتعديل المهارات الحياتية والمعرفة حول اصابات النخاع الشوكي والوقاية من مضاعفات النخاع الشوكي والعلاقات والوظيفة الجنسية والتعدلات النفسية. ومن بين الاحتياجات التعليمية للأسرة، كانت المواضيع الفرعية 3 هي مهارات مقدمي الرعاية، والتواصل، والإسعافات الأولية، ومهارات الطوارئ، والدعم العاطفي والنفسي. بالنسبة للاحتياجات التعليمية الاجتماعية، فإن الموضوعات الفرعية 4 التي تم وصفها هي التكامل الاجتماعي، ومهارات التواصل بين الأشخاص، والوقاية من اصابات النخاع الشوكي والوقاية من الإصابات، والتعاطف مع تجنب الشفقة.

**الخاتمة:** وفقاً للنتائج التي توصلنا إليها ، فإن الأشخاص المصابين باصابات النخاع الشوكي لديهم احتياجات مختلفة تحتاج إلى المعالجة. وينبغي أن يكون الدعم التعليمي جزءاً من برنامج إعادة تأهيل شامل وموجهاً نحو تلبية الاحتياجات الشخصية والأسرية للمرضى، مع تثقيف المجتمع حول اصابات النخاع الشوكي من أجل السماح بإعادة الدمج في المجتمع.

**Objectives:** To explore individuals' perception of the personal, family and societal educational needs following a spinal cord injury (SCI).

**Methods:** Sixty-one patients who sustained a traumatic SCI between March 2015 and June 2016 referred to Brain and Spinal Cord Injury Research

Center (BASIR) were included in a cross sectional study and completed an online survey containing open-and closed-ended questions, in Iran. Participants' responses were analyzed using a qualitative approach with a thematic analysis.

**Results:** Following a thematic analysis of the patient's perceived educational needs, 3 themes and 14 subthemes were identified. The 3 themes included personal, family, and societal educational perceived needs. Within personal educational needs, there were 7 subthemes which included personal independence and transportation, financial independence, life skills modification, knowledge about SCI, prevention of SCI complications, relationships and sexual function, and psychological adjustments. Among family educational needs, the 3 subthemes were caregiver skills and communication, first aid and emergency skills, and emotional and psychological support. For societal educational needs, the 4 subthemes described were social integration, interpersonal communication skills, SCI awareness and injury prevention, sympathize while avoiding pity.

**Conclusion:** According to our findings, people with SCI have various needs that need to be addressed. Educational support should be a part of a comprehensive rehabilitation program and geared towards addressing the patients' personal and family needs, while educating the community about SCI in order to allow for reintegration into society.

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A spinal cord injury (SCI) is an insult to the spinal cord resulting in devastating and commonly occurs following a traumatic event.<sup>1</sup> The global prevalence and annual incidence of SCI is estimated to be 236-4,187 cases per million and 10.4-83 cases per million, respectively.<sup>2</sup> In Iran the prevalence of SCI is estimated to be 318 cases per million.<sup>3,4</sup> Patients with SCI often have devastating and permanent neurological changes resulting in significant and unique disabilities. Individuals with SCI are especially at risk for debilitating consequences such as chronic pain, pressure ulcers, deep vein thrombosis, urinary tract infections, muscle spasms, osteoporosis,<sup>5</sup> and respiratory complications which are the main causes of death in low-income countries.<sup>1</sup> Moreover, SCI can lead to a loss of bowel and bladder control, sexual dysfunction, limitations of limbs sense and movement, and difficulty breathing.<sup>6</sup> In addition, SCI is frequently associated with depression and other mental comorbidities which result in significant psychosocial disability.<sup>7,8</sup> About 20-30% of patients show clinical signs of depression, which negatively impacts functional status and overall health.<sup>1</sup> Individuals with SCI also encounter unique challenges which limit their ability to fully participate in society as demonstrated by a nearly 60% unemployment rate.<sup>1</sup> Many of these barriers can be mitigated by educating patients early and often by using different teaching strategies.<sup>9</sup>

All patients with a SCI should undergo a thorough assessment of their needs. Patient's needs might be different across multiple societies with various cultures and socioeconomic status. There are significant implications on functional status, psychosocial support, emotional needs, and vocation for patients, family, and society. Patients depend on others to assist them with activities of daily living such as toileting, bathing, eating, and transferring. Educating patients, family, and the community has a significant impact on improving delivery of care, preventing complications, and improving the quality of life for individuals with SCI. Categorizing educational needs as personal, family-related, and society-related can help better organize the aftercare. Due to the paucity of literature, we aim to analyze and better understand these areas of needs for individuals with SCI in order to enhance their quality of life through needs-based education and rehabilitation.

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**Methods. Design.** A literature search was first conducted using the MESH specific research we used the specific search strategy which included the following three terms: Needs assessment, spinal cord injuries, and education. A qualitative approach was adopted with a systematic subjective approach used to describe life experiences and perceptions of individuals who suffered a traumatic SCI. To encourage full disclosure and expression of each individual's unique perception, participants were asked to complete an anonymous, open-ended questionnaire through a web-based application from March 2015 to June 2016.

#### Participants

Individuals who suffered a traumatic SCI, were at least 18 years of age, and spoke Persian language were included in the study. Those who did not want to take part in the study or did not answer the questions were excluded. Informed consent was obtained from each person after receiving approval from The Ethical Boards of Sina Trauma and Surgery Research Center; Tehran University of Medical Sciences approved the study. We confirm that the study is according to principles of Helsinki Declaration. There were a total 61 patients who were enrolled and completed the questionnaire. The participants were recruited through various methods, including social media, email, and direct communication from personnel from the Brain and Spinal Cord Injury Research Center (BASIR), a large referral center in Tehran University of Medical Sciences, Tehran, Iran, and other non-governmental organizations. The sample size was determined when the investigator were convinced that theoretical saturation was achieved, which was the point at which sampling more data did not demonstrate any new findings.<sup>10</sup> The researcher is empirically confident that each of the 3 categories is saturated.

**Procedure.** An online questionnaire was administered from March 2015 to June 2016. Prior to administering it patients were informed about the purpose of the study and assessed for willingness to participate. The first portion of the questionnaire provided information about demographics and injury-related characteristics which included age, gender, occupation, marital status, education level, mechanism of injury, and level of injury. The second part of the questionnaire pertaining to the patients' educational needs. In addition, participants were asked about their preferred method of learning which could be either through self-learning, by involving family members, or through group-learning.

**Data analysis.** Descriptive coding was utilized to initially analyse the qualitative data from the participant's questionnaires. Descriptive coding summarized the primary topic of the patient's response into a word or

**Table 1** - The demographic and injury characteristics.

Variables	n (%)
Age in years (range)	37.6±11.5 (18-62)
Duration of injury in years (range)	10.6±6.2 (1-20)
<i>Gender</i>	
Female	14 (23)
Male	47 (77)
<i>Marital status</i>	
Single	25 (41)
Married	36 (59)
<i>Level of injury</i>	
Paraplegic	46 (75)
Tetraplegic	15 (25)
<i>Cause of injury</i>	
Car accident	40 (65.5)
Falling	9 (14.7)
Gunshot injury	8 (13.3)
Others	4 (6.5)
<i>Education level</i>	
High school	9 (14.8)
Diploma	18 (29.5)
University	34 (55.7)
<i>Occupation</i>	
Unemployed	24 (39.4)
Employed	20 (32.8)
Retired	6 (9.8)
Student	3 (4.9)
Unanswered	8 (13.1)

short phrase. This coding approach is particularly useful when different types of data are gathered from interview transcripts, field notes, documents, and visual materials. After the data was coded, it was further summarized using Thematic Qualitative Data Analysis (QDA) as previously described by other authors.<sup>11-13</sup> Thematic analysis is a higher level of categorization which involves identifying patterns within different texts and linking them to a common idea or theme. Unlike codes, which are most often single words or short phrases summarizing a single transcript, themes are phrases or even sentences that summarize the overall meanings of several transcripts. Themes can also be categorized or listed into a superordinate or subordinate outline format as an analytic method.<sup>11-15</sup>

We checked our data with 10 participants to evaluate if our data was reliable or not. Our consultation with experts from other research centres confirmed trustworthiness of our study.<sup>16</sup>

**Results.** Sixty-one participants completed the questionnaire with a mean age of 37.6±11.5 years and 77% were male. The most common mechanism of injury

was motor vehicle collision (65.5%). The demographic and injury characteristics are shown in Table 1. In order to further analyse the educational needs of individuals with SCI, a thematic analysis was performed which extracted a total of 3 main themes and 14 subthemes from the questionnaires (Table 2). The 3 themes were personal, family, and societal educational needs.

**Personal educational needs.** Personal educational needs could be broken down into 7 subthemes which included personal independence and transportation, financial independence, life skills modification, prevention of SCI complications, knowledge about SCI, relationships and sexual function, and psychological adjustments. More specifically, patients were concerned with issues such as personal hygiene, functional capacity, accessibility of transportation, utilizing wheelchairs, exercise activities, and financial independence. For example, one patient inquired about finding job that suits their modified abilities. Although financial independence is important, the patient was also concerned with having a job that would allow them to be independent, productive, and give them a sense of fulfillment.

Another major concern for patients was the lack of medical knowledge or understanding about their injury. The emphasis was on the need for a better education from their providers about the potential sequel and complications of SCI in order to prevent them and manage them appropriately. Dealing with complications such as pressure ulcers, urinary incontinence, muscle atrophy, neuropathic pain, and spasticity were among the most relevant complications for patients.

**Family educational needs.** Patients are also concerned about the educational needs of their family since they can play a significant role during the initial recovery and rehabilitation phases. More specifically, three subthemes were identified which included caregiver skills and communication, first aid and emergency skills, and emotional and psychological support. Most of the participants believed family members would benefit from being educated on psychological issues and communication skills. They emphasized that family members need further guidance on emotional support, patience, tolerance, and understanding. Knowledge about first aid treatments, emergency preparedness, and prevention of secondary complications were also noted as important issues that family members should be familiar with.

The impact of the disability on aspects such as each partner's sexual relations and activities, as well as, each partner's role in the relationship was a considerable source of anxiety, especially for females. The additional duties

**Table 2 -** Perceived educational needs from individuals with SCI perspective.

Perceived educational needs	Perspective
<i>Personal educational needs</i>	
Personal independence and transportation	"..I need knowing about hydrotherapy because it helps me to prevent pressure ulcer, and spasticity." (A 36-year-old bachelorette man with complete paraplegia).
Financial independence	"...I wonder to know how to prevent my muscular atrophy"(A 36-year-old female with complete paraplegia).
Life skills modifications	"... I really need to know how to have an enjoyable sex..."(A25-year-old graduated man with incomplete tetraplegia).
Prevention of SCI complications	"... I am so interested to be trained in art or music to have an independent financial life..."(A 30-year-old graduated man with incomplete paraplegia).
Knowledge about SCI	"... I wonder if I can learn computing and information technology (IT), to facility my life style more (a 45-year-old bachelorette man with incomplete paraplegia).
Relationships and Sexual function	".. Well I really need to know about how can be adjusting on transportation vehicles such as wheelchair ..." (A 30-year-old bachelorette woman with complete tetraplegia).
Psychological adjustment	"...I am interested in knowing about how SCI effect on reproductive organs and digestive system..."(A 45-year-old bachelorette man with incomplete paraplegia). "..."I think it is very important to know about how I can accept my current state..." (A 33 year old graduated man with complete paraplegia).
<i>Family educational needs</i>	
Caregiver skills and communication	"...I truly need my family to understand my distraught and respect my mental privacy and independence..." (A 30-year-old post graduate women with complete paraplegia).
First Aid and Emergency skills	"...I believed that family and caretakers need to receive proper briefings and training even prior to us..." (A 29-year old associated degree man with complete paraplegia)
Emotional and psychological support	"... even though my family are very cooperative and have learned a lot in the past decade there are still many ways to ease the tasks..." (A 30-year-old graduate women with incomplete tetraplegia).
<i>Societal educational needs</i>	
Social integration	"...I stated that the society should learn to embrace a person with SCI without discrimination and bias, and most importantly provide a convenient social environment where those with SCI and disabilities can continue their education and enter the job market..."(An 18-year-old graduate man with complete paraplegia).
Interpersonal communication skills	"...Member of the society must learn about social dignity and cease pitying or staring at parson with SCI in an unpleasant way..."(A 42-year-old man with Primary education and complete paraplegia).
SCI awareness and injury prevention	"...general public are truly unaware of the significance of the nervous system, how it operates, and how the possible injuries can be prevented..."(a retired 53-year-old associate degree man with incomplete paraplegia).
Sympathize while avoiding pity	"...the society should have a more realistic understanding of the shortcomings that a spinal cord injured person struggles with, particularly about marriage and sex-life..." (A 36-year-old woman with incomplete paraplegia).

SCI - spinal cord injury

created by the disability and the shift of responsibilities to the other partner can produce severe stress within the family unit. Also, these concerns were more frequent as the severity of the injury increased. For example, a female with paraplegia receiving education mainly pertaining to sex-related activities, while a female with tetraplegia was also significantly distressed about pregnancy and therefore demanded additional education pertaining to prenatal, childbirth, and postnatal care.

***Societal educational needs.*** Societal educational needs focused on issues relating to navigating tense social interactions arising from the stigmatizing effects of the patient's disability. Participants recognized the need for educating the public on social encounters and communication skills with SCI patients. Specifically, participants felt that social concepts such as discrimination, prejudice, and disrespect towards SCI patients' needs to be addressed. Patients believed their

local communities have not received adequate cultural and behavioural competency training. Also the lack of access to civic life through disabled-friendly facilities is another setback, chiefly inadequacy of the designated routes for their transportation. As an illustration, a housewife with paraplegic SCI stated that people with disabilities do not enjoy from any convenient means of transportation. Overall, communities should be aware of issues such as negative attitudes, physical limitations, basic care needs, social integration, and lack of appropriate services and facilities for SCI patients in order to address them and improve their quality of life. One of the participants suggested that apart from expanding the rehabilitation facilities, the existing ones should work to educate surrounding communities.

***Effective educational methods.*** In addition, we asked participants about their preferred method of being educated. They indicated that face-to-face education (40%) was the most effective method, followed by

education online resources (32%), mass media (radio and television) (30%), mobile device (20%), self-learning method via DVD and CD compact (10%), and educational material (pamphlets booklets, and books) (8%).

**Discussion.** Spinal cord injuries are devastating events that have a significant impact on not only patients but also on others around them. In this study, patients who suffered a SCI identified three main educational needs which included personal, family, and societal ones.

Participants expressed that personal independence, caretaking, physical ability, secondary complications and sexual activity were among the most important personal topics that needed to be addressed, which is consistent with previous studies.<sup>17-23</sup> Hart et al<sup>17</sup> reviewed 5 important topics for community-residing individuals with SCI which included exercise programs, neuromuscular testing, bladder or kidney issues, pain, and sex-related issues. May et al<sup>18</sup> demonstrated that bowel, bladder, and skin care were among the most important areas to review during rehabilitation. More broadly, physical and social independence have been shown to be key determinants of quality of life for individuals with SCI.<sup>19</sup> Also, secondary medical complications following a SCI such as pressure sores, respiratory tract infections, motion limitation, urine incontinence, and sexual disorders are important aspects of quality of life for individuals with SCI.<sup>21</sup>

Following a SCI, there are significant changes in the family dynamic that can occur and family members need assistance navigating their new roles. We demonstrated that communication, caretaking, and emotional support were essential skills for family members to be aware of. Effective communication and shared decision-making can help reduce the burden of one individual's responsibility for the entire family's wellbeing. As caregivers, family members need to receive proper education on how to be more accepting of the new changes. Also, family members should be understanding of the need for privacy and independence of a person with SCI.

Many of the participants mentioned that their family members lack these skills and need additional education and training in order to develop or improve qualities such as patience, tolerance, understanding, and communication. These results are congruent with Kennedy et al.'s<sup>19,20</sup> who revealed that relationships with family, spouses or partner, and friends were among the most influential factors on the quality of life for individuals with SCI. The majority of patients with SCI choose to live with family so they can live

to independent lives, as opposed to living in different care facilities.<sup>24</sup> This highlights the importance of the relationships between individuals with SCI and their families and the need for all parties to adapt to the changing environment. Such relationships can influence the attitudes of an individual with SCI towards not only their disability but also their rehabilitation.<sup>25,26</sup> These relationships are also a powerful predictor of independent-living outcome variables and<sup>27</sup> and the improvement of chronic pain.<sup>28</sup>

Lastly, participants also acknowledged that there were societal needs and obstacles they often face. Communities should be cognizant and sympathize with patients, but also avoid pitying them. This only hampers their ability to reintegrate within the community. Cultural and sensitivity training of the community members may create an effective social support environment for people who suffer from SCI.

In our study, the most preferred educational methods by participants were face to face education, followed by education via online resources, radio and television, cell phones, DVD, and pamphlets and books. Matter et al<sup>29</sup> showed that education directly from providers was the most preferred method for people with SCI, however, patients reported that online resources was the most frequently used sources information due to accessibility. However, this may not always be the case and other factors need to be considered. Others have shown that the preferred method of education in an Iranian population with SCI were educational movies, lectures, TV programs, brochures, online resources.<sup>9</sup> It is important that SCI education programs consist of active learning or contextual-based strategies and considers the different preference of patients in order better educate and prepare patients.<sup>18,30</sup>

**Limitations.** This study is at risk of sampling bias due to the exclusion of patients with a lack of internet accessibility and computer literacy. Certain population such as those from a higher socioeconomic background are represented to a greater degree than those who are from a lower socioeconomic background, elderly, or from an underserved population. Due to this sampling bias and the smaller sample size these results cannot be generalized. However, advantages of the online questionnaire include lower cost, ease of administration, comparable response rates, and the ability to obtain responses from patients who are geographically displaced.

**Implications.** The findings of this study reveal there are some unmet need from the victim's perspective. It is important to assess potential educational needs prior to designing, planning, and implementing any interventional rehabilitative health care program,

especially when focusing on sensitive issues. In terms of individual educational needs, it is crucial to develop an effective educational program according to the patient's specific educational needs. For family educational needs, it is important to consider that SCI not only hampers individuals with SCI, but also have significant impact on families and caregivers as well.<sup>31,32</sup> It brings physical, mental, financial, as well as social dysregulations and thereby has a ripple effect.

There are also "post-injury shifts in relationship dynamics" among family members to care providers. High levels of burden placed on the caregiver can manifest them self as physical and emotional stress, burnout, fatigue, anger, resentment and depression among caregivers.<sup>31</sup> Therefore, there is a need to educate them on issues relating to these changes and maintaining a good rapport with them.

In regards to social education needs, reintegrating patients is a very important topics that need to be covered. Development of social skills will enhance their social participation, communication, and employability skills, all of which help prevent depression and increase quality of life<sup>7,8</sup> Future researches with inclusions of larger series of individuals with SCI including those from an underprivileged society would further provide the real gravity of the problem.

In conclusion, SCI individuals have various unmet educational demands that need to be addressed in order to optimize their quality of health care. Educational health support should address personal, family, and social needs, and should be a part of a comprehensive rehabilitation program. Education support should address the patients' personal and family needs, while educating the community about SCI in order to allow for their reintegration into society. It is important to continue assessing the needs of SCI individuals from a patient-centered perspective in order to directly address them and improve their quality of life.

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Acquisition of funding, collection of data, or general supervision of the research group, alone, does not justify authorship.

An author should be prepared to explain the order in which authors are listed.