

Factors influencing the community integration of patients following traumatic spinal cord injury: a systematic review

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Abstract

Background: Spinal cord injury (SCI) is a high-cost disabling condition, which brings a huge number of changes in individual's life. The emphasis of rehabilitation has moved from medical administration to issues that affect quality of life and community integration. This systematic review was conducted to identify the factors associated with community reintegration of patients with spinal cord injury.

Methods: Google Scholar, PEDro, Pakmedinet, AMED, BIOMED central, Cochrane Library, MEDLINE, PsychoINFO, PUBMED, ScienceDIRECT, Scirus and Wiley Online Library databases were searched by using key words 'Spinal cord injury' 'Paraplegia' or 'Spinal Cord Lesion' or Tetraplegia. They were cross-linked with 'Community reintegration', 'Community participation' and 'Community access'. The methodological quality of the studies included was analysed by using McMaster University Tool and Thomas Tool. The data extracted included sample size, intervention, duration, results, outcome measures, and follow-up period.

Results: A total of 11 relevant studies were located. The evidence extracted was classified into four groups; health-related barriers or facilitators, environment-related barriers or facilitators, psychological barriers and social barriers that are associated with community reintegration of such individuals.

Conclusion: The review revealed that there were more barriers in the form of health-related issues, personal and environmental, psychological and social issues that hinder the community reintegration of individuals with spinal cord injury compared to facilitators. Most studies identified special challenges related to environment in the sense of accessibility of home and public buildings and transportation. Removing barriers related to health, environment, and psychological and social factors can enhance community reintegration of such patients.

Keywords: Spinal cord lesion, Paraplegia, Tetraplegia, Community access, Community participation. (JPMA 69: 1336; 2019)

Introduction

Spinal cord injury (SCI) is a high-cost disabling condition that brings a huge number of changes in an individual's life.¹ SCI was believed to be "an ailment not to be treated".² World Health Organisation (WHO) in 2001 reported about 20-40 million individuals acquiring SCI every year around the world.³ Traumatic SCI has great influence on individuals' life and their families. Traumatic SCI not only causes serious disability, but also results in impairment of body organs, including gastrointestinal,

urinary, autonomic nervous system, skin, bone and joints. This involvement of different organs leads to further complications, including movement problems and a high mortality rate.⁴⁻⁶ SCI leaves the patient with one of two main clinical presentations, namely paraplegia or quadriplegia.⁷ SCI patients experience a variety of physical and psychosocial challenges when they return to the community in spite of the massive efforts of rehabilitation carried out by means of education and functional skills training.⁸⁻¹⁰

The focus of rehabilitation has shifted from a biomedical to a bio-psychosocial model, with increasing emphasis on a client-centred approach to rehabilitation.¹¹ The aim of the rehabilitation programmes is to enhance the adjustment to life following SCI by equipping the

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Table-1: Summary of the studies included in the review.

Author	Study design	Sample size	Data collections tools, follow up time	Outcomes
Babamohamdi, et al., 2011 ²⁹	Quantitative	17	Semi-structured interview, 12 Months	Barriers identified were financial resources, employment, social support and inaccessibility of the environment
Dickson, et al., 2011 ²⁸	Qualitative	18	Interpretative Phenomenological Analysis, 12 months	Lack of fellowship into the community and lack of post discharge care in the community were major barrier for community integration
Silver et al., 2012 ⁹	Mixed methods	26	Goal Tracking Form and group discussion with SCI patient, 12 to 18 months	Issues related to mobility and equipment, home assistance, insurance matters and lack of knowledge were main barrier identified by the participants
Hu et al., 2012 ²⁷	Cohort	26	Modified Barthel Scale, Walking index for SCI, Patient Health Questionnaire Depression Module WHOQOL-BRIEF, 12 months	The result shows an improvement in ADLs and walking, an improvement in self-report QOL score, general health, and community satisfaction ($p < 0.05$). But there was no statistically significant improvement in the areas of physical and psychological health. Likewise, satisfaction with the environmental field has decreased
Sekaran et al., 2010 ²⁰	Cross sectional	35	CHART-SF, CHIEF-SF 12 months	Architectural barriers, space limitations around their locality and pressure ulcer were main problems reported by the participants for community integration of these patients
Odell M et al., 2009 ¹⁸	Qualitative	85	Functional Independence Measure, 12 months	No difference in daily life status, community reintegration, ambulatory status, occupational status, bladder problems and pressure ulcer were reported between the two groups
Scovil, et al, 2007 ²³	Cohort	24	Semi-structured Interview, MBI scale, P-scale 12-24 months	Secondary health complications including pressure ulcer and urinary tract infection. Inaccessible buildings, toilets, roads and water sources were identified major barriers into community participation
Carpenter, et al., 2007 ²²	Quantitative	357	Questionnaire with social involvement, transport & Physical activity, SWLS and Happiness Scale	SCI patients were most satisfied with their own transport and with access to public places. Majority of the participants were involved in physical activities
Donnelly, et al. ²⁴ 2005 ²⁴	Prospective Cross sectional	49	FIM, Reintegration to Normal Living, 24 months	Pain while carrying out activities was the major problem reported by the patients
Charlifue and Gerhart, 2004 ²⁵	Longitudinal	187	CHART, Life Satisfaction, Perceived Stress Scale, 9 Years	There was an overall decrease in physical independence, occupation, mobility and social integration in these patients. Life satisfaction was related to reintegration into the community and was refused
Fougeyrollas, et al. 2000 ²⁶	Survey	481	Short form assessment of life habits (LIFE-H)	The results show a significant disruption in all fields of life habits including activity of daily living, home maintenance, and involvement in physical and recreational activities. The ADLs including housing, nutrition, fitness recreation, mobility, interpersonal relations, and employment were reported disturbed.

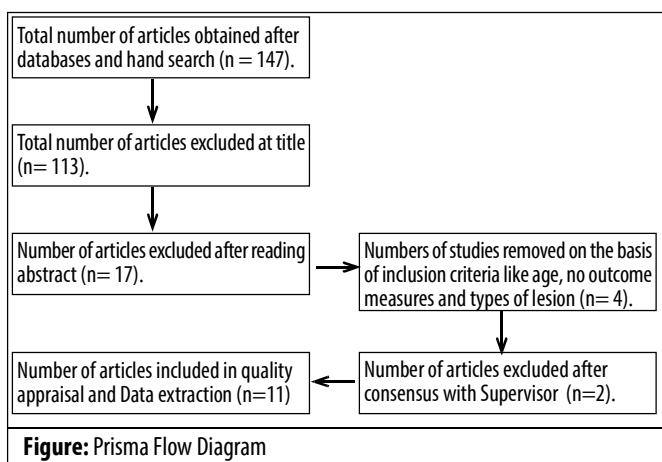
individual with the skills and resources required for community integration.¹² The purpose of the rehabilitation is to capitalise on functional independence, prevent secondary complications, optimise physical functioning and enhance renewed participation in the community.¹³ After discharge from rehabilitation centres, SCI patients have difficulty in community reintegration. The physical barriers in community re-integration include geographical, architectural and transportation issues, which can be regarded as accessibility problems. Community participation or integration is closely related to the quality of life and that is why community reintegration following SCI is an important outcome to evaluate pursuing the rehabilitation of persons with disabilities, including those with SCI.^{14,15} In addition to other barriers, financial support, job issues, acute and long-term rehabilitation needs and secondary

complications are barriers to community reintegration.^{16,17}

The current study was planned to review recent literature on factors that affect the community reintegration of people with SCI. These factors include barriers or facilitators related to health and society.

Methods

The systematic review of literature comprised studies conducted from 2000 to 2018 for which Google Scholar, PEDro, Pakmedinet, AMED, BIOMED central, Cochrane Library, MEDLINE, Psycho INFO, PUBMED, Science DIRECT, Scirus and Wiley Online Library databases were searched with the key words 'Spinal cord injury', 'Spinal Cord Lesion', 'Tetraplegia' or 'Paraplegia'. These were cross-linked with 'Community reintegration' 'Community



participation' or 'Community access'. Studies included had to comprise individuals with diagnosed stable traumatic SCI aged above 14 years (both paraplegic and tetraplegia), or SCI individuals living in community or post-discharge from hospital. Besides, the studies had to measure the outcome-related community reintegration linked with community access, community participation, independent living or quality of life. The studies included mainly assessed or measured factors related to employment or work and sports participation and without primary research, case series studies, and case studies that were excluded. Finally, the studies had to be in the English language. .

Quality Assessment

Thomas Tool was used to assess the quality of quantitative studies, and qualitative studies were evaluated by 8 items of McMaster University Tool. Thomas tool is very flexible in using and assessing the quality of different quantitative studies consisting of randomised control trials (RCTs), uncontrolled and quasi-experiment studies. The content and construct of this tool is assessed and well-documented.¹⁸ Data including information of authors, study design, sample size, phenomenon of interest, geographical location and settings, data collection methods, time since injury and results was noted for both qualitative and quantitative studies (Table).

Results

From all the databases, 147 studies were obtained. Of them, 11(7.5%) studies were selected; 9(82%) quantitative and 2(18%) qualitative. Integrated design was adopted

to do mixed method data synthesis.¹⁹ The evidences extracted from the studies were classified into four groups; health-related barriers or facilitators, environment-related barriers or facilitators, psychological barriers, and social barriers that are associated with community reintegration of SCI subjects. The aim, objective and research of all the studies were clear. Literature review, method, research design, recruitment of sample and rigorous level of the studies were also appropriate. Thus, all the included studies were rated as strong. As per the global rating, 8(89%) quantitative studies^{9,20-26} were moderate, while 1 (11%) study was strong in quality.²⁷ The numbers of participants in the 11 studies were 1313. The maximum number of participants involved in a study was 481²⁶ and the lowest number in a study was 17 in a qualitative study.²⁸ The participants of the studies included in this systematic review were aged from 14-110 years. The total number of male participants were 494 (37.6%) whereas the female participants were 819 (62.4%). The studies were conducted in different countries, including United States, Iran, United Kingdom, Nepal, China, India and Canada. The studies were included from both developed and developing countries and no such study addressing the community reintegration following SCI was found to have been conducted in Pakistan.

Health-related Complications

Five quantitative studies reported a number of health complications, including pain, pressure sores, neurogenic bladder, urinary tract infection (UTI), spasticity, contracture, tightness and sleep problems, which were considered key factors for reducing the mobility and community participation in individuals who sustained SCI.^{9,21,23,24,27}

Two studies reported equipment issues, including inappropriate wheelchairs, cushions and catheters as barriers to reintegrate SCI subjects in the community.^{9,23} Two studies reported mobility problems i.e., wheelchair maintenance issues, transfer and balance, and physical limitation including paralysis, incapacity to get out of wheelchair, unable to walk or stand as the barriers.^{9,22} The study conducted by Dickson among SCI individuals reported the deficiency of post-discharge care with respect to both physical and practical care as well as psychological support.²⁸

Environmental Barriers or Facilitators

Seven studies described the role of environment adaptation or accessibility in community reintegration after SCI.^{13-20,27,29} Six studies assessed and reported natural environment barriers, including architectural barriers, inaccessible and steep terrain, modified homes, hilly areas, inaccessible toilets, absence of ramps, and inaccessible public spaces, including parks, beaches, streets and roads, being the main barriers for people using wheelchair to reintegrate in the community.^{13,14,16,17,20,21,23} Four quantitative studies identified transportation as significant barrier for individuals living with SCI to participate in community activities.^{13,14,16,20}

Attitude of the Community

Two studies talked of the attitude of people living in society and the lack of social support being the barriers for SCI people.^{28,29} A female participant having sustained paraplegia aged 32 explained, "People's attitude is not good at all. They all look at you in a strange way - a pitiful look. Pardon me, but some even think that just because we are in a wheelchair, we must be begging. Unfortunately, society's attitude is not good. They are not accepting. With this view being prevalent, it is not easy to cope with the problem."²⁹

Government Policies

One study²⁰ reported the policy barrier. The measurement tool used was Craig Handicap Assessment and Reporting Technique Short Form (CHART-SF) and the lowest average score was related to policy barriers, which was because most of the participants were not aware of the policies of the government. Majority of government policies facilitate community reintegration but it is not followed in society.

Economic and Financial issues

Four studies reported the economic status and the financial issues as barriers.^{20,22,23,29} Inadequate financial resources were mentioned as another barrier in adjusting to their disability by SCI subjects. A male paraplegic participant aged 46 stated: "The second problem, beyond the physical issues, is the financial difficulties, which most of us are facing." They also regarded the issue as a limitation for using rehabilitation services and assistive devices. The condition gets worse if there is loss of employment and productivity.²⁹

The lack of financial resources and the funding issues were

reported by 10% of the participants in a study.²² Significant decline in occupation also contributed to the financial problems.²⁰

Discussion

The systematic review was planned to record factors influencing community reintegration following SCI. Various factors affecting community reintegration after SCI were revealed by both quantitative and qualitative studies. The most important factors seemed to be health-related, environmental and social factors which the community reintegration of SCI patients.

The review reveals health-related complications which affect the community reintegration process. Similarly, a study reported that people living with SCI had more chances of developing pressure sores than people with other forms of disability. Pressure sores limit the SCI individuals to bed, thus hindering the activity of daily living which in turn limits their participation in the community.³⁰ Other health-related complications, including respiratory infection and bowel dysfunctions, are well documented.^{7,17,31-34} Health-related variables are predominantly involved in life satisfaction of SCI people and their participation in the community.³⁵ Pain also emerged as a barrier in some studies during this review. Literature available proved that pain is significant physical barrier for SCI people. In one study, more than 86% subjects reported pain as a barrier living in community for 6 months.^{24,36,37} This systematic review yielded enormous evidences reporting physical environmental factors as the barriers for SCI individuals to participate or reintegrate in the community. These reported factors are supported by many studies.^{38,39} In the context of physical environmental barriers, a study, using the Craig Hospital Inventory of Environmental Factors (CHIEF) instrument, in which top five environmental barriers; natural environment, transportation, help at home, healthcare and government policy were well documented.⁴⁰ The International Classification of Functioning, Disability and Health (ICF) model proposed by the World Health Organisation (WHO) also defines the physical environmental factors, including buildings and roads, are critical for the participation and reintegration of SCI people.⁴¹ Similarly, the United Nations explained the importance of accessibility to participate in the community for people with physical disability. According to the United Nations, consideration should be focussed on the physical

environmental barriers consisting of home and public places, public transportation around the world. Reintegration in the community is poorly recorded due to unfriendly transport, mobility and social barriers in developing countries.⁴²⁻⁴⁵ The accessibility of public places is a worldwide issue.⁴⁶ Recent studies on western population have shown that physical accessibility is enhanced. Thus, environmental factors now have very minute effect on community integration. These studies were mostly conducted in urban areas, which were well-planned in the context of accessibility to accommodate people with physical disabilities including those with SCI.⁴² Physical barriers include geographical, architectural and transportation issues that have been identified as accessibility problems. Moreover, it is reported that societal barriers consisting of inaccessible buildings and transportation problems are contributing factors to decline in community participation of SCI subjects.⁴⁷ Psychological factors were found in the current literature review. These evidences have been supported in wider literature. Martz and Livneh described that psychological factors, including depression and poor coping skills, are likely responsible for the development of pressure ulcer in people with SCI.⁴⁸ Depression has been investigated as major psychological problem after SCI.³² Medical and psychological issues, especially depression, have been associated with SCI individuals' struggle to return to work. Due to marked changes in the body, as a result of SCI, psychological challenges consisting of depression and stress appeared in these individuals which influenced their participation in community^{35,49} Despite these psychological threats, research has exposed that most SCI people develop a positive psychological modification and that adjustment improved with the passage of time.¹¹ Environmental barriers produced a sense of discrimination in SCI individuals that stopped them from participating in social life, limited their efforts to spend an independent life, and affected their capability to care for themselves.⁵⁰ Social factors, including lack of patient and family education, friend and family relations, financial constraints, unemployment, and social attitudes, were identified as barriers or facilitators for people living with SCI. Literature has shown a number of characteristics which may affect a person's ability to adjust to SCI, consisting of social support, education level, financial status, job security and involvement in social and leisure functions.⁵¹⁻⁵³ It is described that younger patients have more ability to adjust with SCI due to better social support and friends

and family relationships.³⁵

Social support provides fundamental role in both depression and adjustment of SCI individuals. Persons who enjoy more social support recognise them to be the reason behind improvement in their condition, and are less emotionally distressed and report better life satisfaction and quality of life.^{54,55} The identified barriers regarding patient and family education during this review were further supported by studies which proved that enough knowledge and training skills were very useful to adjust with SCI.⁴⁸

Economic and financial constrains were also identified as important barriers faced by SCI people. The possible reasons of financial issues for SCI individuals are unemployment, lack of vocational trainings and skills.⁵⁶ Employment rate is very low, ranging from 13% to 35% in less-resourced countries. A correlation between quality of life of SCI individuals and their employment rate was studied in an Indian study.⁵⁷ Vocational training programme conducted in Bangladesh to empower SCI people showed significant improvement in employment rate up to 50%.⁵⁸

Government policies, especially social policies, comprise a significant environmental factor affecting the participation and reintegration of SCI individuals with physical disability.³ The support system from friends, family and other professional members is very vital to confront challenges faced by people living with SCI which creates difficulty for family as well as the subject himself. SCI patients mostly depend on their friends and family for physical care, social and emotional support, and social connections.⁵⁴

Conclusion

There were barriers in the form of health-related issues, personal and environmental, psychological and social, which obstructed the community reintegration of SCI subjects. Most studies reported special challenges related to environment in the sense of accessibility of home and public buildings and transportation. Patients with SCI living in developing countries were facing more barriers that hindered their participation in community.

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