Review Article

Access this article online

Quick Response Code:

Website: www.joas.in

DOI: 10.4103/joas.joas_2_17

Community reintegration postspinal cord injury: Indian scenario

Roop Singh, Sidharth Yadav, Vijay Meena

Abstract:

Patients who suffer from spinal cord injury because of their permanent mobility and/or cognitive impairment will usually face difficulties in reentering into the community. The aim of this paper is to review the relevant architectural and attitudinal barrier, transportation difficulties in the current Indian scenario. MEDLINE®, Embase™, the Science Citation Index, and Google™ Scholar were used to look for relevant articles published in English literature. Rehabilitation should promote the full inclusion and participation of people with disabilities in the physical and psychosocial environment. The past two decades have seen a renewed interest in India to improve services for spinal injured. Although there are number of barriers to successful community reintegration in India; a holistic and empathetic approach to prioritize this issue is the need of the hour. Recent initiatives taken by the government, namely, "Sugamya Bharat Abhiyan - Accessible India" and Person with Disability Act 1995 are welcome steps in this direction.

Keywords:

Community reintegration, rehabilitation, rehabilitation barriers, spinal cord injury

Introduction

Spinal cord injury (SCI) is devastating and takes a toll on patient life at various levels such as physical, social, mental, and even adds a financial burden to the family. During the Second World War, SCI was associated with increased morbidity. Donald Munro is regarded as the father of treatment of paraplegia. He emphasized on bladder and skin care. The best treatment of bed sore which is prevention, and the concept of rehabilitation of SCI are due to his pioneer work.[1]

Due to the recent advances in the management, the scenario has changed which has decreased the morbidity of the patient's associated with the various degree of functional limitation. Ludwig Guttmann is considered as the father of modern treatment of SCI. The concept of early transfer of the patient to a spinal injury unit was due to his pioneer work.[1]

Even today, the condition of spinal injury patients in many developing countries is comparable to 1940's situation in Europe and North America,[2] which is due to lack/unavailability of qualitative assistive devices, medical and rehabilitation services.

The concept of rehabilitation took time to grow among the medical fraternity. Advances in the management of SCI patient are mainly due to the holistic approach toward the patient which has led to the increase in the life expectancy of the patient with these injuries. However, increase in the life expectancy has also raised another issue such as interaction with the society as these patients are also prone to "four D syndrome" which are a dependency, depression, drug addiction, and divorce (if married). Later on two more "Ds" were e added to this list – debilitation and demanding.[3]

The goal of rehabilitation is to promote the assumption or resumption of culturally and developmentally appropriate social roles after injury or illness. Community integration is a complex issue, with obvious

Department of Orthopaedic Surgery, Paraplegia and Rehabilitation, Pt. B.D. Sharma, PGIMS, Rohtak, Haryana, India

Address for correspondence:
Dr. Roop Singh, 52/9-J, Medical Enclave, PGIMS, Rohtak - 124 001, Haryana, India.
E-mail: drroopsingh@rediffmail.com

How to cite this article: Singh R, Yadav S, Meena V. Community reintegration postspinal cord injury: Indian scenario. J Orthop Allied Sci 2017;5:15-20.

and not-so-obvious barriers and opportunities that affect its success. Advocacy for accessibility, both physical and societal, has had a major impact on the ability of people with SCI to resume many of their preinjury roles.[4] The aim of this paper is to review the relevant architectural and attitudinal barrier, transportation difficulties in the current Indian scenario.

Epidemiology and Demographics

Most of the patients with SCI are treated at the centers lacking the spinal trauma units. The exact incidence of the SCI cannot be estimated as it requires the regular collection of data which should include both the prevalence and the incidence, which is due to the lack of availability of National data registry in developing nations. There is an increase in the incidence of the SCI due to the rapid industrialization, which is an unfortunate phenomenon of modernization. Worldwide the incidence is expected to be 250,000–500,000 cases every year. Patients with SCI are at increased risk of death within the 1st year of injury even in the developed nations where advanced care has improved the survival.[5]

In spite of recent advances in the treatment of SCI there is a rapid increase in the prevalence of SCI at an annual rate of 3%, but due to the lack of research on epidemiology of traumatic spine injury and national registry, it is hard to describe the characteristics of the SCI.[6] Males are more at risk with a bimodal presentation 20–29 years and 70+ age. Male to female ratio may vary from 1.73 in China, 7.55 in Pakistan,[7] to 3.6 in India.[8] In most of the studies, male are found to be more prone as compared to female which is due to the fact that males are usually engaged more in outdoor activities hence are more prone to road traffic accidents, fall from tree, etc., whereas fall into well is commonly seen in females. However, change in the trend has been observed.[9] Furthermore, reducing the prehospital time helps in reducing both morbidity and mortality of a SCI patient.[10]

Scenario in India

In India, the situation is quite different from that of developed nations. Majority of the Indian population is in rural area which lacks the basic necessity and safety precautions such as lack of fencing to the wells, roof, and staircase and have poorly built/substandard homes (mud homes), therefore, people are at a greater risk of having spinal injury either due to fall from height or fall of a heavy object.[11] Other cause is road traffic accidents which are increasing due to lack of strict implementation in smaller cities and villages and also the lack of awareness regarding the traffic rules. According to the WHO, the incidence of this disease is on the rise in developing countries like India and road traffic accidents will become the third most disabling condition by 2020.[12]

Trauma care services in India are in its initial stage or evolving, and there is inconsistency in their distribution. There is a lack of coordination between the trauma care facilities and ambulance services. Only 4% of prehospital networks have a proper coordinated service. Efforts have been made to develop the trauma care system, but these are mainly seen in the private sector.[13] According to national health policy, 2015 majority of the health-care facility are provided by the private sector (80% of the outpatient and 60% of the inpatient) which is mainly due to the lack of funding in the government sector.[14]

Training in trauma life support has been available for quite some time which has improved the quality of care and also helped in decreasing the chances of further injury during the shifting of the patient from the site to the health facility. Recently in National Health Draft 2015 Government of India has planned to improve the emergency care system by a network of life support ambulances linked to trauma management centers 1/30 lakh population in urban and 1/10 lakh population in rural areas and also to improve rehabilitative care at the community and health institutions.[14]

In developing and poor nations, delayed presentation is a common scenario. The lack of awareness regarding the severity of the situation and awareness regarding the existence of spinal care units leads to the delayed presentation of the patient. A study conducted by Pandey *et al*.[11] found an average of 45 days delay between the injury and the presentation. Similarly, a delay of 3–42 days has been noted in Sierra Leone.[15]

Delayed presentation can be either due to:
1. Delay in seeking medical care
2. Delay in referral to spine care unit.

In India till 1966, there were no dedicated facilities for spinal injury patients. The first program for SCI patient was started at CMC Vellore hospital by Dr. Mary Varghese. Later on, various dedicated institutes for SCI have opened.

Barrier to Community Reintegration

In India and some other developing nations, disability is often considered to be the result of witchcraft/wrath of god/punishment from ancestors which cause a major restriction in the active participation in the society. This kind of beliefs affects all the aspect of life, i.e., marriage, employment, education, and access to the treatment. Apart from this, various cultural and traditional beliefs also act as a barrier.[16] Environmental factors have a

remarkable effect on the quality of life after SCI, but there are certain barriers which hinder such patients to lead a comfortable life thereby decreasing the chances of successful integration in the society. These factors are housing condition, transportation, public infrastructure, and attitude.[17]

Housing

Fight of a patient begins right from his home. The first barrier encountered by the patient is housing condition. In rural areas, people still prefer going to fields for their bowl needs, usually, there is a lack of in-house toilet facilities, even if the facility is available it is inappropriate for a SCI patient as they are in ground fixed commodes which require squatting.[18] Other difficulties which a patient faces at his/her home are overcrowding, lack of proper beds, stairs which make them "prisoners in their own home,"[19] thereby forcing a patient for long stay in hospital even when they are fit to go home this situation is referred as "bed blocking."[5]

Transportation

The evidence on the impact of these factor having an impact on the participation in the society are sparse, but the physical and transportation barrier are the key environmental barrier for people with SCI.[5] The majority of population in India resides in rural area which lacks the basic transportations facilities. Although after independence the scenario has changed majority of the areas have some facilities. The most common and most used mode of transportation in India is bus followed by train which are usually overcrowded and have no special arrangements for the SCI patients such as low floor, unavailability of safety features such as protective bars, automatic barrier system. Due to this reason either patient does not report to the medical facility or are forced to choose other modes such as bullock cart/jeep/bike which increases the damage to the already injured spine.[9]

Public infrastructure

"Inaccessible physical environments create disability by building barriers to full participation and inclusion in the community."

Disability Rights Promotion International, 2011

People with disability constitute a significant section of population in developing country. Obstacle free access to public infrastructure for all is a cornerstone of social inclusion. In recent years various measure and a number of commitments have been made to ensure accessibility to public spaces for people with disability, whether physical, cognitive, or sensory, but results have not met expectations. Those regulation and standards which do exist are not always applied. The majority of public places including medical facilities in India and in other developing countries are unfriendly for a disabled person. Major areas where the accessibility is must for a disabled person for participation in the society are parking spaces, public building entrance, and restroom/toilets.[4,17] It is essential to establish standards and references if measures are to be taken to build an environment more accessible. There has been an Endeavour by the government of India to provide barrier-free environment, but we still need to go a very long way in this regard especially considering the rural population.

Attitude

"The only disability in life is a bad attitude."

By Scott Hamilton

Attitude is the most important barrier as it can act in both ways as a barrier or as a facilitator.[20] This includes the attitude and behaviors of the family members, friends, and healthcare personal which ultimately have an effect on the attitude of a disabled person.

Even if all the conditions are in favor and patient does not have a proper attitude he will not be able to indulge himself into the society. Assistance and support provided by the people in social network and by others with disability decreases fear and anxiety and also promotes them to participate into the society.[17,21] Actions of a nondisabled person such as staring and ignoring can have a negative effect on the attitude of a disabled person.[22-24]

Availability

Apart from the physical and attitude barrier, the availability of proper medical care is an issue which needs to be addressed. As care of a spine injury patient requires a range of services which includes a team of professional and resources which are usually not available in rural and remote areas.[17,25] Studies conducted in the USA and rural Australia concluded that distance from a health-care facility have an impact on utilization of the facility.[26,27] Except for few such intergraded facilities under one roof are still lacking in medical setups of India.

Cost and accessibility

Medical equipment which are available today can make life of a disabled person easy but their cost and accessibility act as a barrier. Most of the equipment are well suited for the urban environment, but the same equipment are not appropriate for a rural environment which has harsh terrains.[28] The majority of time these equipment are prescribed without considering the need/requirement of patient which ultimately leads to

discontinuation and decreased acceptability for future use.[29] Attitude like "something is better than nothing" and "one size fits all" are common where resources are limited, which ultimately results in negative consequences.[30-32] The majority of the patient with SCI are from poor strata; they cannot afford the expensive medical assistive aids. There is a need for indigenous improvisation in these devices to suite our patients and local environment. Distributing these aids by nongovernmental organization (NGO)'s/Government on Republic Day and Independence Day without taking into the cognizance of need of the patient is not helping the case.

Rehabilitation

SCI patient require continuous care as they have to face both long and short-term complication after discharge from a medical facility.[33,34] Due to lack of education and awareness regarding the SCI even educated patients and their families take long time to accept the sudden change in their lifestyle which is survival and self-care.

Rehabilitation of a SCI is a complex and chronic process which begins soon after injury and requires teamwork (multidisciplinary approach)[35] for a lifetime. This team constitutes of professionals from different field-neuro-urology, occupational therapy, physiotherapy, psychiatry, psychology, social services, rehabilitation, and community liaison. It has also been found in studies that environmental factors have a little effect as compared to family support, attitude in community reintegration which have a direct effect on quality of life.[36,37] Therefore, rehabilitation of such patients should also include promoting social independence, emotional adaptation, and community reintegration along with optimizing physical condition and minimizing medical complication.[38] It is also correctly stated that "collaboration, not isolation" is the key to the success of rehabilitation.[12]

Recently from past two decades, the focus of rehabilitation of these patients has shifted from minimizing the functional disability to the quality of life. The concept of quality of life is not new and has been studied extensively in the past and has been accepted in the western world as a key measure for outcome.[39] However, there is disagreement on the definition and measurement of the quality of life.

Types of rehabilitation: Rehabilitation can be broadly divided into three categories

1. Acute rehabilitation
2. Subacute rehabilitation
3. Chronic rehabilitation.

Acute and subacute rehabilitation begins with the admission of the patient and aim of this is to prevent complication whereas chronic rehabilitation aim at independent mobilization.[40]

Rehabilitation services can be provided into two ways:[16]

Active rehabilitation services in these patients are provided with education and training which helps a person to lead an independent life and also increase better social integration.

Passive rehabilitation services are those in which patients are not provided with the training and education, and care is provided by the caretakers.

Person with SCI can avail these services in three ways[41] either as:

- Institution-based rehabilitation (IBR)
- Outreach-based rehabilitation
- Community-based rehabilitation (CBR).

IBR can be provided in a residential setting or in hospital. In this approach, patient receive special care/treatment and short intensive therapy but very little care or attention to the family and other social factors. Although IBR is an important part of rehabilitation it has its shortcomings such as high cost and its location which is usually urban which make it inaccessible.[42]

Out reached rehabilitation are usually provided by the health-care personnel based in institution and provide visit to the homes or centers in the area. Community involvement is there but to a minimal extent. Educational and vocational training are usually not provided in these services. It plays a crucial part in providing services in extremely remote areas, but the cost of treatment is also high.[42]

Community-based rehabilitation in this the knowledge and the basic training is not only provided to the disabled person but also to the family and community members. The characteristic feature of CBR is active participation of the family and community members, which ultimately helps the disabled person to overcome his/her attitudinal and other barriers.[42]

The WHO adopted Alma Alta Declaration in 1978 thereby shifting support from institution to community leading to evolution of community-based rehabilitation. Since then the WHO has been continuously upgrading the guidelines to strengthen CBR programs. CBR main objective is to utilize opportunities and to maximize their physical and mental abilities for successful integration in the community.[43] Basic principle of a CBR program are inclusion, participation, sustainability, empowerment,

and advocacy. These principles are overlapping, complementary and interdependent and they cannot be addressed in isolation.

There is a paucity of facilities and services for the disabled in all the sectors whether governmental or private sectors and also these services are limited to urban areas. The government of India has taken several steps including the Disability Act 1995 for rehabilitation of disabled person. In spite of all the measures still, there is a lack of access to opportunities such as education, health, vocational guidance, employment apart from their emotional and psychological needs being neglected.[44]

Recently, government of India has launched a campaign "Sugamya Bharat Abhiyan - Accessible India"[45] with the main motto for creation of the accessible environments for the persons with disability so that these people can gain access for equal opportunity and live independently and can participate fully in all aspects of life in an inclusive society. Person with disability act 1995 under section 44, 45, 46 categorically provides for nondiscrimination in transport, on road and in built environment. While addressing the meeting our honorable prime minister Narender Modi also suggested to use the term "Divyang"[46] which means divine body in spite of "Viklang" for person with a disability. However, there is a lack of consensus among the consultants, activists, and government functionaries on this proposed nomenclature shift.

Conclusion

Community integration is a complex issue, with obvious and not-so-obvious barriers and opportunities that affect its success. The past two decades have seen a renewed interest in India to improve services for spinal injured. Although there are number of barriers to successful community reintegration in India; a holistic and empathetic approach to prioritize this issue is the need of the hour. Recent initiatives taken by the government, namely, "Sugamya Bharat Abhiyan - Accessible India" and Person with Disability Act 1995 are welcome steps in this direction; but still lot is required from the society, NGOs, and government to make the community environment accessible to SCI persons.

Financial support and sponsorship
Nil.

Conflicts of interest
There are no conflicts of interest.

References

1. Silver JR. History of the treatment of spinal injuries. Postgrad Med J 2005;81:108-14.
2. Liverman CT, Altevogt BM, Joy JE, Johnson RT (Edrs.). Spinal Cord Injury: Progress, Promise, and Priorities. Washington, DC, National Academics Press; 2005.
3. Singh R, Rohilla RK, Siwach R, Dhankar SS, Kaur K. Understanding psycho-social issues in person with spinal cord injury and impact of remedial measures. Int J Psychosoc Rehabil 2012;16:95-100.
4. Scelza WM, Kirshblum SC, Wuermser LA, Ho CH, Priebe MM, Chiodo AE. Spinal cord injury medicine 4. Community reintegration after spinal cord injury. Arch Phys Med Rehabil 2007;88 3 Suppl 1:S71-5.
5. WHO. International Perspective on Spinal Cord Injury; 2013. Available from: http://www.who.int/disabilities/policies/spinal_cord_injury/en/. [Last accessed on 2016 Jan 12].
6. Lalwani S, Singh V, Trikha V, Sharma V, Kumar S, Bagla R, *et al.* Mortality profile of patients with traumatic spinal injuries at a level I trauma care centre in India. Indian J Med Res 2014;140:40-5.
7. Chiu WT, Lin HC, Lam C, Chu SF, Chiang YH, Tsai SH. Review paper: Epidemiology of traumatic spinal cord injury: Comparisons between developed and developing countries. Asia Pac J Public Health 2010;22:9-18.
8. Agrawal P, Upadhyay P, Raja K. A dermographic profile of traumatic and non traumatic spinal injury cases: A hospital based study from India. Spinal Cord 2007;45:597-602.
9. Singh R, Sharma SC, Mittal R, Sharma A. Traumatic spinal cord injury in Haryana: An epidemiological study. Indian J Community Med 2003;28:10-2.
10. Mock C. Strengthening prehospital trauma care in the absence of formal emergency medical services. World J Surg 2009;33:2510-1.
11. Pandey V, Nigam V, Goyal TD, Chhabra H. Care of post-traumatic spinal cord injury patients in India: An analysis. Indian J Orthop 2007;41:295-9.
12. Chhabra HS, Mittal R. Status of Disability in India; 2012. Available from: http://www.rehabcouncil.nic.in/forms/sublink1.aspx?lid=827. [Last accessed on 2015 Nov 11].
13. Joshipura MK, Shah HS, Patel PR, Divatia PA, Desai PM. Trauma care systems in India. Injury 2003;34:686-92.
14. Ministry of Health and Family Welfare. National Health Policy 2015 Draft. Available from: http://www.mohfw.nic.in/showfile.php?lid=3014. [Last accessed on 2015 Dec 10].
15. Gosselin RA, Coppotelli C. A follow-up study of patients with spinal cord injury in Sierra Leone. Int Orthop 2005;29:330-2.
16. Olaogun MO, Nyante GG, Ajediran AI. Overcoming the barriers for participation by the disabled: An appraisal and global view of community-based rehabilitation in community development. Afr J Physiother Rehabil Sci 2009;1:24-9.
17. Chhabra HS, Batra S. Spinal cord injury and its impact on the patient, family, and society. Int J Recent Surg Med Sci 2016;2:1-4.
18. Burns AS, O'Connell C. The challenge of spinal cord injury care in the developing world. J Spinal Cord Med 2012;35:3-8.
19. Toran K. Accessible Housing Database and Manual. Berkeley, CA: World Institute on Disability; 2000. Available from: http://www.wid.org/publications/accessible-housing-database-and-manual. [Last accessed on 2015 Oct 17].
20. Chan F, Da Silva Cardoso E, Chronister JA, editors. Understanding Psychosocial Adjustment to Chronic Illness and Disability: A Handbook for Evidence-Based Practitioners in Rehabilitation. New York: Springer Publishing; 2009.
21. Hampton NZ, Qin-Hilliard DB. Dimensions of quality of life for Chinese adults with spinal cord injury: A qualitative study. Disabil Rehabil 2004;26:203-12.
22. Weinberg N. Another perspective: Attitudes of people with disabilities. In: Yuker HE, editor. Attitudes toward Persons with Disabilities. New York: Springer; 1988. p. 141-53.
23. Wright B. Attitudes and the fundamental negative bias: Conditions and corrections. In: Yuker HE, editor. Attitudes toward Persons with Disabilities. New York: Springer; 1988. p. 3-21.

24. Garland-Thomson R. Staring: How We Look. Oxford: Oxford University Press; 2009.
25. WHO. World Report on Disability. Geneva: World Health Organization; 2011. Available from: http://www.who.int/disabilities/world_report/2011/report.pdf. [Last accessed on 2015 Nov 16].
26. LaVela SL, Smith B, Weaver FM, Miskevics SA. Geographical proximity and health care utilization in veterans with SCI & D in the USA. Soc Sci Med 2004;59:2387-99.
27. Middleton JW, McCormick M, Engel S, Rutkowski SB, Cameron ID, Harradine P, *et al.* Issues and challenges for development of a sustainable service model for people with spinal cord injury living in rural regions. Arch Phys Med Rehabil 2008;89:1941-7.
28. Levy LF, Makarawo S, Madzivire D, Bhebhe E, Verbeek N, Parry O. Problems, struggles and some success with spinal cord injury in Zimbabwe. Spinal Cord 1998;36:213-8.
29. Whalley Hammell K. Experience of rehabilitation following spinal cord injury: a meta-synthesis of qualitative findings. Spinal Cord 2007;45:260-74.
30. Chan SC, Chan AP. User satisfaction, community participation and quality of life among Chinese wheelchair users with spinal cord injury: A preliminary study. Occup Ther Int 2007;14:123-43.
31. Pearlman J, Cooper RA, Krizack M, Lindsley A, Wu Y, Reisinger KD, *et al.* Lower-limb prostheses and wheelchairs in low-income countries. IEEE Eng Med Biol Mag 2008;27:12-22.
32. Pearlman J, Cooper R, Chhabra HS, Jefferds A. Design, development and testing of a low-cost electric powered wheelchair for India. Disabil Rehabil Assist Technol 2009;4:42-57.
33. Anson CA, Shepherd C. Incidence of secondary complications in spinal cord injury. Int J Rehabil Res 1996;19:55-66.
34. Bloemen-Vrencken JH, de Witte LP. Post-discharge nursing problems of spinal cord injured patients: On which fields can nurses contribute to rehabilitation? Clin Rehabil 2003;17:890-8.
35. Cox RJ, Amsters DI, Pershouse KJ. The need for a multidisciplinary outreach service for people with spinal cord injury living in the community. Clin Rehabil 2001;15:600-6.
36. Whiteneck G, Meade MA, Dijkers M, Tate DG, Bushnik T, Forchheimer MB. Environmental factors and their role in participation and life satisfaction after spinal cord injury. Arch Phys Med Rehabil 2004;85:1793-803.
37. Song HY. Modeling social reintegration in persons with spinal cord injury. Disabil Rehabil 2005;27:131-41.
38. Dijkers MP. Correlates of life satisfaction among persons with spinal cord injury. Arch Phys Med Rehabil 1999;80:867-76.
39. Inman C. Effectiveness of spinal cord injury rehabilitation. Clin Rehabil 1999;13 Suppl 1:25-31.
40. Johannesson M. QALYs, HYEs and individual preferences – A graphical illustration. Soc Sci Med 1994;39:1623-32.
41. Nas K, Yazmalar L, Sah V, Aydin A, Önes K. Rehabilitation of spinal cord injuries. World J Orthop 2015;6:8-16.
42. Kumar SG, Roy G, Kar SS. Disability and rehabilitation services in India: issues and challenges. J Family Med Prim Care 2012;1:69-73.
43. WHO. Community-Based Rehabilitation and the Health Care Referral Services: A Guide for Programme Managers. Available from: http://www.who.int/management/community/services/CommunityBasedRehabilitation.pdf. [Last accessed on 2015 Dec 10].
44. Sharma AK, Praveen V. Community based rehabilitation in primary health care system. Indian J Community Med 2002;27:139-42.
45. Ministry of Social Justice & Empowerment, Government of India. Accessible India Campaign. Available from: http://www.disabilityaffairs.gov.in/content/accessible_india.php. [Last accessed on 2016 Apr 20].
46. Salelkar S. Divyang Vs. Viklang: Disabled, Disenfranchised But Divine. Available from: http://www.indianexpress.com/article/blogs/divyang-vs-viklang-disabled-disenfranchised-but-divine/. [Last accessed on 2016 Apr 20].