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New trends and practices to overcome challenges in providing affordable Spinal Cord Injury Rehabilitation

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Abstract

Spinal cord injury (SCI) and the resultant paralysis has devastating physical, mental, social, sexual and vocational consequences for the injured. SCI results in major financial burden to individuals and society as a whole. Comprehensive rehabilitation management is important for improving quality of life of a person with SCI and helps their integration into community. A developing country like India has meager resources, and is demographically large. Along with standardized quality of care, rehabilitation processes/management also needs to cater to individualized needs of patients with SCI. It is therefore important to identify an affordable and sustainable model which would expand the coverage of rehabilitation services for persons with SCI. This will require proper and judicious use of resources and a multi-sectoral approach. Such practices will involve improving access through increasing the infrastructure for SCI and creating a network, increasing awareness about SCI and its management, appropriate human resource development, networking amongst stakeholders, telemedicine & promoting research.

Keywords

Spinal Cord Injury, Rehabilitation management, developing countries, affordable, sustainable

Introduction

Spinal Cord Injury (SCI) is the most devastating ailment that could affect the mankind.^{1,2} Every year SCI affects a large number of young to middle aged population, which are the most productive years of their life.^{3,4} Every year 250000-500000 people suffer from SCI globally.⁵ The average annual incidence of SCI in India is 15,000 with a prevalence rate of 0.15 million.⁶ According to the World Health Organization (WHO).The incidence of SCI in developing countries like India is increasing because of rapid development and increase in number of vehicles.The injury results in physical, psychological, emotional and financial burden not only on the individual but also on the family and the societyand therefore poses a major public health challenge.^{7,8} Management of SCI was revolutionized during and after the II World War.^{9,10} The management of SCI is not limited to the injury alone, but necessary inputs from medical, social and legislative fields are required lifelong. The economic impact due to SCI in developing countries is expected to increase in similar proportion to that of the developed nations.¹¹ As per the statistics from USA, depending on the severity, SCI can cost an injured individual \$334,000 to 1 million the first year after injury. Costs in each subsequent year range from \$41,000 to 178,000.¹² Although similar data is lacking amongst other countries like India, the enormity of the expenses involved can be imagined.¹³ The major goal of SCI rehabilitation is to make the individual as independent as possible in his/her activities of daily living and to get him/her back to a near normal life style. It is therefore imperative that sustainable and affordable rehabilitation services are expanded in developing countries like India.

Improving access: increasing the infrastructure for SCI and creating network

The rehabilitation services are integral component of comprehensive management of patients with SCI and continuous advancements in technology has improved the outcomes and quality of life in these individuals. However, there are factors in developing countries like India, which create an immense challenge to comprehensive management and community inclusion of patients with SCI.¹⁴ The incidence of SCI is comparatively low in comparison to other ailments. Also the management of SCI is much more expensive and for the same cost, a bigger population can be covered for management of other ailments with more noticeable results.¹³ It has been mainly in the past 2-3 decades that the countries like India have focused on setting up SCI management services and dedicated centers. However the numbers of such exclusive centers are frequently insufficient to meet the needs of the population.¹⁵ Lack or mismanagement of patient with SCI in countries like India begins at the site of injury. Most of the patients with suspected SCI are transported by vehicles which are not meant or equipped for proper positioning and transfer of injured patients.¹⁶ Also, patients with SCI should ideally reach definite SCI centre within 2 hours of injury,¹⁷ whereas, in an Indian study, 22% of patients with SCI reached the definitive SCI centre after 1 month of injury.¹⁵ The services available in current health care services in countries like India lack proper medical and rehabilitative facilities, with minimal availability of specialized assistive technology and no opportunity for vocational, recreational rehabilitation processes, hence impeding quality of life and community inclusion.^{15,18} Management of patients with SCI in India face many challenges, and this affect all aspects of

comprehensive rehabilitation management. Community inclusion and Quality of life for patients with SCI can only be improved if a multipronged action is initiated. Improving access and increasing the infrastructure for SCI management would involve sensitizing government officials & health care providers as well as medical/paramedical professionals about the impact of SCI prevention and management on the quality of life following SCI and the need for setting up SCI management centres. There is a need for all the stakeholders to collaborate pool resources. Another strategy to improve access is to ensure proper grading of services for judicious use of resources. At present there are different type of SCI units including Acute + Rehabilitation care under one facility, only acute care, only rehabilitation care, inpatient Rehabilitation facility, outpatient Rehabilitation facility, SCI Units under General hospitals and home based Follow-up care.

In the past few years/decades great advances have been made in the rehabilitation management of patients with serious traumatic as well as non traumatic spinal injury. Special spinal centres cum research have played an important part in these advances. An important component of such specialized management SCI centres would be the standardization of medical care protocols and procedures which are now an established practice that helps create a safer and more affordable patient culture. Proper grading of such SCI centres would help in judicious utilization of resources, which are always meager in countries like India. Standardization of management of SCI would help improve quality of care, safety and efficiency of medical centres.

Despite the revolutionisation of SCI management, there is no global consensus on a standardized definition of a spinal cord injury (SCI)

unit. Specialized care SCI units have shown to reduce the length of stay, complications and better neurological recovery in patients with SCI.1 Studies have also shown decreased neurological deficit in Level 1 and 2 Trauma Centres, especially where surgical volumes are high.2 Hence it is important to identify the requirements both in terms of facilities and manpower available in defining the level/grading of a spinal cord injury unit. International Spinal Cord Society (ISCoS) - Spinal Trauma Study Group (STSG) is doing this exercise to define a SCI unit and develop a grading system which would hold relevance both in developed and emerging countries. This would help in standardization of management of SCI and help improve quality of care, safety and efficiency of medical establishments working in this field. ISCoS-STSG has proposed a grading system of a SCI Unit based on the resources and the elements of spinal cord injury care available. It has broadly classified management of SCI as 'Acute Care' and 'Comprehensive Rehabilitation', supported by ancillary functions/departments and divided SCI Units into Level 1 (provides highest tertiary level of acute and rehabilitation care for a patient with SCI) to Level 5 (provides basic rehabilitation, community outreach and home care services to persons with spinal cord injury). The level wise manpower requirements and the other resource requirements as defined by the STSG have also been defined as have been measures (matrices) to assess the quality of service being provided by the SCI unit. 'Peer counselor' and other support staff from within SCI community to be accommodated at all levels of functioning of a SCI Unit.

The grading system thus proposed foresees levels which could perform as a network such that all patients with SCI would be able

to re-integrate within community. Every Level 3 - 5 SCI Unit should be attached to a Level 1 or 2 SCI Unit for easy transfer of patients as and when necessary. There should be a build up a culture of meetings to talk about the individual course of patients between the SCI Units and they should conduct regular scientific meetings amongst the SCI professionals.

However, this will need to go through a validation process before implementation. Furthermore, like any such system, it is expected to gradually evolve as practical issues get obvious with implementation.

Increasing awareness about SCI and its management

Another strategy for sustainable, affordable practices for expanding the coverage of SCI rehabilitation would be to increase awareness amongst all stakeholders including policy makers, health Care providers, professionals, consumers and society. It would involve creating awareness Programs for Prevention & Management of Spinal Ailments, emphasizing the need for Collaborating with WHO, NGO's and Consumer groups for policy /guidelines development and demonstration of their effectiveness, sensitizing policy makers for enforcement of region specific regulations and guidelines, promoting community awareness about SCI acute management, long term management and community inclusion and promotion of SCI awareness programs by various means including social media and telehealth. The goal of rehabilitation management of patient with SCI is to lead an inclusive life. Because of the permanence of disability in complete SCI injuries, prevention assumes special significance. The common saying is, 'Prevention is better than cure'. But in fact, where a SCI is concerned, 'Prevention is Cure'. Awareness Programs amongst general public for Prevention & Management of

SCI would facilitate an inclusive life for persons with disability and ensure success of prevention programs. In the endeavor to increase awareness, IScoS and its affiliated societies have been observing 5th September as SCI day since 2016. They are working towards promoting SCI Day via various means like social media, consumer groups, increasing awareness amongst all related Societies and lobbying to get recognition for SCI day.

Appropriate Human Resource Development

Another important strategy for expanding SCI management would be development of trained human resources. It is important to liaise with concerned local authorities for inclusion of SCI management within the curriculum of health professional degree programs at all levels.

Networking

There is a dire need for promoting sustainable, affordable practices for expanding the coverage of SCI rehabilitation but the challenge is equally big. Thus there is a need for promoting networking of various NGOs/Societies /organizations working in this field. There is a need for them to pool resources and collaborate in order to overcome this challenge. There is a need for Collaborating with WHO, NGO's and Consumer groups for policy /guidelines development and demonstration of the effectiveness of such awareness programs. There is a need to sensitise policy makers for enforcement of region specific regulations and guidelines for prevention of SCI.

Telemedicine

'Telehealth' is the next step in the continuity of health care, allowing patients and caregivers to receive the quality of follow-up care at their homes using common technologies audio or video based. This assumes all the more importance in people with

impairments/disabilities since they face multiple challenges accessing healthcare and the complexity of patients needs changes in post discharge care. Telemedicine provides an alternative service delivery model.

Advantages of telehealth include, improved quality of care, continuity of follow-up care, customized Client Centered Care, better access to specialist care and reduced travel time and costs for the patient.

Promoting research

The bigger the challenge, the more the need to come and with innovative techniques. Hence Research assures importance to promote sustabnable and affordable practices for expanding coverage of SCI rehabilitation. It is thus important to coordinate with SCI Centres/Units to contribute data to a centralized database, promote newer techniques for management of spinal cord injury and promote researchers to highlight newer techniques

Conclusion

There are numerous challenges in India for provision of affordable access for SCI management. As we move forward in 21st Century, we need to have a patient centric approach while providing quality of care. This is achievable by a sustained multi-strategic, multi-pronged approach with involvement of all stake holders including patients, medical professionals, media, NGOs, healthcare industry and government bodies. Sustainable and affordable practices for expanding the coverage of SCI rehabilitation in India would involve improving access through increasing the infrastructure for SCI and creating a network, increasing awareness about SCI and its management,appropriate human resource development, networking amongst stakeholders,telemedicine & promoting research.

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