



## Spinal Cord Injury Rehabilitation in Nepal

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### ABSTRACT

Spinal cord injury is a major trauma, with its short and long term effects and consequences to the patient, his friends and family. Spinal cord injury is addressed in the developed countries with standard trauma care system commencing immediately after injury and continuing to the specialized rehabilitation units. Rehabilitation is important to those with spinal injury for both functional and psychosocial reintegration. It has been an emerging concept in Nepal, which has been evident with the establishment of the various hospitals with rehabilitation units, rehabilitation centres and physical therapy units in different institutions. However, the spinal cord injury rehabilitation setting and scenario is different in Nepal from those in the developed countries since spinal cord injury rehabilitation care has not been adequately incorporated into the health care delivery system nor its importance has been realized within the medical community of Nepal. To name few, lack of human resource for the rehabilitation care, awareness among the medical personnel and general population, adequate scientific research evidence regarding situation of spinal injury and exorbitant health care policy are the important hurdles that has led to the current situation. Hence, it is our responsibility to address these apparent barriers to successful implementation and functioning of rehabilitation so that those with spinal injury would benefit from enhanced quality of life.

**Keywords:** *rehabilitation; spinal injury..*

### INTRODUCTION

Spinal cord injury (SCI) is an insult to the spinal cord resulting in a change, either temporary or permanent, in its normal motor, sensory, or autonomic function.<sup>1</sup> It is accounted either due to trauma or non traumatic causes like malignancy, degenerative diseases, demyelination diseases, infections like tuberculosis and others with its devastating short and long term effects for the patient himself, his friends and family.

The reported global prevalence of SCI is about 236-1009/million.<sup>2</sup> The major causes of Spinal Injury in the developed country are traffic accidents, whereas falls are the leading cause in developing countries.<sup>3</sup> Reported incidence of SCI is 10.4 and 83 per million per year on a

worldwide estimate with one third of patients with SCI being reported as tetraplegic, and 50% of patients with SCI is reported to have a complete lesion.<sup>4</sup> The mean age of patients sustaining injury as evident is 33 years old with men to women distribution in ratio of 3.8:1.<sup>4</sup>

### HISTORY

With the rise of war, during early 1940s there arose multiple health problems including nervous system problems as a result of massive air raid and bombings. This not only included military personnel but also huge number of civilian casualties. In Germany and USA

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“Peripheral Nerve Centers” were developed shortly after the First World War.

During and after the Second World War, the first co-ordinated system of care for spinal cord injured came into existence with development of National Spinal Injuries Centre at Stoke Mandeville Hospital in Aylesburg, England by Sir Ludwig Guttman, and in the US, in Massachusetts by Dr. Donald Munro.<sup>5</sup>

It was during this era, the concept of Physical Medicine and Rehabilitation was established as a medical specialty. Since then, many things have changed and as a result the first world countries stand in a position that the spinal cord injured patients now do not have to succumb to death within weeks of the injury but can have a near normal life. Until the 20<sup>th</sup> century, those suffering from Spinal injury died shortly afterward. However, with the advent of comprehensive treatment centres and as the concept of rehabilitation has been revolutionised, scenario has been different at the present century.

With the recent establishment of highly specialized units for spinal cord injury care, many problems that those spinal injured face in day-to-day life have been addressed. There is pre-hospital care/retrieval (emergency services) then acute care and management and finally sub-acute care/rehabilitation and management and last but not the least community reintegration along with support transition within the continuum of care. Secondary consequences and complications are today identified as health complains that resulted in additional functional difficulties superimposed on the original functional losses that resulted from SCI itself.<sup>5</sup> With this visionary start, significant spectrum of reducing the functional limitations of people with disability came into existence.

## CURRENT GLOBAL TREND

The emergency management professionals provide spinal injury care from the initial site of injury, to the spine surgeons who take care of the injury either surgically or conservatively, to the physiatrist who is responsible for providing the post injury rehabilitation starting from the acute care until the patient is discharged from the hospital or the rehabilitation units. Those injured are on life long care and follow up with provision of community based rehabilitation (CBR).

Rehabilitation following SCI is started with team members of physical therapists, occupational therapists, rehabilitation nurses, psychologists, case managers and social workers. The rehabilitation team functions under the direction of a physiatrist, a physician who specializes in physical medicine and rehabilitation. Individualized

care along with the special complications that these group of patients face are also addressed in these specialized units like deep vein thrombosis, postural hypotension, autonomic dysreflexia, respiratory complication, and neuropathic pain management.

For example, every case of spinal injury is managed with standard care that is accepted internationally, so that each case gets appropriate counseling and care required regarding to complications and consequences of spinal injury, for instance, spasticity management, pressure ulcer management, bladder and bowel care, wheel chair and mobility training, gait training, issues related to sexual health and fertility, pregnancy-education and counseling to mention few. Some provide lifetime follow up programs and help them with the challenges they face in activities of daily living.

The real challenge starts after these patients are discharged from the hospital or the rehabilitation centre. Thus, the problems like home modification, bowel and bladder accidents care and community support along with assistive technology programs are provided synonymously with CBR provision.

CBR is the notion, which was initiated after declaration of Alma-Ata in 1978 as a strategy to provide rehabilitation care and services for people with disabilities in the low income and middle income countries and help empower people with disabilities to access and benefit from education, employment, health and social services through the combined efforts of people with disabilities, their family, relevant government and non-government service providers.<sup>6</sup>

## CURRENT SCENARIO IN NEPAL

Soon after the patient has been managed shortly at the acute management setting and after the definitive treatment, the patient is sent for spinal cord injury rehabilitation. In Nepal, the institutions providing rehabilitation services are Spinal Injury Rehabilitation Centre, Nepal Army Rehabilitation Hospital, Green Pasture Rehabilitation, Sahara Hospital, Hospital and Rehabilitation Centre for Disabled Children to name few.

However, Spinal Injury Rehabilitation Centre is the centre working solely to provide rehabilitation to spinal injury in Nepal. Since its establishment in 2002 A.D., 921 patients had been rehabilitated by the end of 2011 with male and female patients being 682 and 239 respectively with the most common mode of injury noted as fall injury followed by RTA.<sup>7</sup> The hospitals, which commonly are sent for rehabilitation referral

are Nepal Orthopaedic Hospital, Tribhuvan University Teaching Hospital, B and B Hospital, Kathmandu Model Hospital and others in decreasing frequency.<sup>7</sup>

Like any comprehensive rehabilitation centre, it has a team lead by a doctor, physical therapist, social worker and psychologist. The team is ideally lead by the Physiatrist who addresses the various issues of the patients, and works to prevent the complications there after the spinal injury. But, due to lack of rehabilitation specialist, it is lead by orthopaedic surgeons at the different rehabilitation centres/units in institutions of Nepal. Nurses who are important members of the team are directly in contact with the patient for the longest time and work for bowel, bladder, back and skin care. A physical therapist works on the functional skills of the patients, primarily on the mobility skills, muscle strengthening and gait training. An occupational therapist deals with the activities of daily living, for example; grooming, bathing, dressing and use of wheelchair. Both of them work to prescribe the wheelchair and various orthotics to assure patient's minimum dependence to maximum independence.

Anyone who suffers the spinal injury along with his/her family has to undergo a major psychological trauma, hence, the psychologist addresses the psychological issues accordingly and helps him or her accept the condition. Foremost but undervalued issue, sexual health, after spinal injury is dealt by the psychologist and social worker and the physician. A social worker deals with the patient throughout the rehabilitation process, from the day of admission to day of discharge, and plans about the financial and the various family issues. Nepal was one of the countries to begin CBR program with the first being implemented in 1985, and there are about 50-60 CBR programs under NGOs and organisation.<sup>8</sup>

Another advancement in spinal injury rehabilitation in Nepal has been the incorporation of the therapeutic recreational activities. Recreational activities like wheelchair sports are frequently used tool to address the functional and the psychological issues of the patient. In Nepal, we have different non-governmental organizations like Nepal Spinal Cord Injury Sports Association, which primarily organises wheelchair race, basketball, table tennis, and swimming which Such has been giving insight, to those with spinal injury with regard to becoming active and independent and thereby improving quality of life.

### IMPORTANCE OF REHABILITATION IN THE ACUTE PHASE

Various studies has shown that outcomes among patients who have been treated or managed in a spinal

cord acute care unit with contrast to those in general trauma care unit, had been varied in terms development of co-morbid conditions like pressure ulcer, contracture, deformity, DVT, frozen shoulder etc. Bagnall AM et al,<sup>9</sup> Devivo et al,<sup>10</sup> their study have documented the benefit of the spinal cord centre acute care. Rehabilitation should be initiated immediately post-injury not compromising the basic and the advanced life support. Pressure ulcer, one of the major hindrances to the rehabilitation process, is commonly prevalent and hence, should be primarily prevented. Thus, skin care with regular skin inspection, positioning and careful transfer of the patients avoiding the shearing forces should be done even at the emergency setup. Similarly, contracture prevention can be done likewise with regular passive movement of the limbs and the use of orthotics. Very less, we see the use of orthotics in the clinical setting of developing countries like ours. Though underestimated but important aspect of rehabilitation, the use of orthotics can be used to prevent various deformity like equino varus, wrist drop etc.

### BARRIER TO REHABILITATION IN NEPAL

The major barrier to successful implementation of rehabilitation of patients with spinal cord injury is lack of rehabilitation specialists including physiatrist and the other vital team members. On the other hand, inadequate knowledge about the rehabilitation itself, among the medical personnel and the general population has been a problem to incorporation of spinal injury rehabilitation in health care provision of Nepal. And the foremost, financial constraint has always been key impediment to successful completion of rehabilitation among patients in Nepal.

In country like Nepal, where political instability has affected the entire health system of the country, the lack of policy has still kept the emergence of spinal injury rehabilitation beyond horizon. Likewise, the rehabilitation centres for spinal injury has not yet been decentralised across the country with major centres or hospitals with rehabilitation unit being located within the capital city with few exception like Green Pasture Rehabilitation Centre being located at Pokhara. Hence, inadequate service centre across the country has been the reason why patients with spinal injury are deprived of rehabilitation care and services. It was documented from research studies in Uttar Pradesh and Tamil Nadu states of India, that cost and the lack of services in was the second most frequent reason for people with disabilities not using health facilities.<sup>11</sup> Hence, all these lead to reluctance of rehabilitation to be included in the health care delivery system of the country.

## ADDRESSING BARRIER TO REHABILITATION

Rehabilitation is considered a good investment because it builds human capacity.<sup>11</sup> In country like Nepal, non-communicable disease, especially injury, should be seen as health priority. With the initiation of such concept, the medical doctors and paramedics should be informed, educated and trained about the importance of rehabilitation in spinal injury and about the various established rehabilitation units within the country.

There should be proper referral policy from the primary, secondary and tertiary health care provider to the established units for rehabilitation. Thus, integrating rehabilitation in the health care delivery system of the country is the only acceptable means to upgrade the scenario of those with spinal injury. Similarly the execution of community based rehabilitation is an important part of the continuum of care with those with spinal injury.

More than 25.2% of people in Nepal are living below the poverty line.<sup>12</sup> Thus, adequate financial planning should be made so that the patients with spinal injury get the rehabilitation care services. While the government has its duty towards integrating rehabilitation in the health care system, the established centers and the unit have the responsibility to improve the quality of service that is being provided and should work with local, national and international partners to decentralize the current

services. Another important aspect of spinal injury rehabilitation is recommendation of home modification, wheelchair accessibility, use of assistive devices including, wheel chair. Therefore, such prerequisite should be made easily available and affordable throughout the country with the implications promoting maximum independence and thereby reducing cost of care and services.

## WAY FORWARDS

The United Nations Convention on the rights of persons with disabilities, 2006,<sup>13</sup> has recognized rights of people with disabilities as equal enjoyment of all the human rights including that of health so that they can benefit without any discrimination because of disability. And, accordingly rehabilitation appears to have been the basic right to attain optimum health of those with spinal injury. Hence, creating co-ordinated and decentralised system of care and implementing accordingly, is of paramount importance to benefit patients with spinal injury to improve quality of life, increase survival and prevent complications. Our health system does not have evident data regarding spinal injury, neither the notification system for spinal injury. Thus, program on research activities should be promoted since it is a pragmatic foundation for policy makers to allocate and reallocate the resources so that the issues of the spinal injury can be addressed accordingly and the quality of care be enhanced.

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