

The Burden And Public Health Importance Of Spinal Cord Injury In India: A Review

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ABSTRACT

An accident or traumatic injury to the spinal cord may result in a serious and irreversible spinal cord injury. Such spinal injury causes significant changes in the life of the injured person and his or her family members. Spinal cord injury can require extreme physical, locomotor and psychological adaptation which exerts enormous pressure on the patients' families, who plays critically vital roles in providing support and care. It is a struggle for both the victims and their families. Few studies have captured exactly not mere the major physical injury but also the long-term consequences of spinal cord injury in the patients living with such injuries over time. Besides impacting the health, well-being and psychosocial behaviors of individual victims but also the interpersonal relationship within the family members. The objectives of the study are to identify the burdens of Spinal cord injury and the challenges faced by persons with spinal cord injury in their day-to-day life in India and to know the intervention strategies to enhance the quality of life of persons with spinal cord injury. Therefore, the current study besides highlighting the issues faced by SCI patients also helps in greater understanding of the burden of spinal cord injury and its public health importance in India.

Keyword List: Spinal Cord injury, Burden, Public Health, Disability, Trauma, Injury

INTRODUCTION

The spinal cord is an extension of the brain and is comprised of a large bundle of nerves. Nerves convey messages to the rest of our body from our brain. These signals help us move our body, notice pressure, and maintain vital functions such as breathing, blood pressure, bladder, and digestive system⁽¹⁾. The interaction between our brain and the rest of our body is disturbed when the spinal cord is damaged, resulting in a loss of movement and sensation below the injury level. In paraplegia, the movement and feeling of your legs and probably some abdominal muscles are affected and in tetraplegia, all four limbs, stomach, and some chest muscles affect movement and feeling. Spinal cord injury (SCI) is a traumatic incident that has greater impact on the physical, emotional, and social well-being of a patient and creates a major financial burden on health care systems⁽²⁾. This is a plenary review and it aims to

summarize available literature on the Burden of Spinal cord injury. The objectives of this study are: to identify the burdens of Spinal cord injury; to describe the varied challenges faced by SCI patients; to discuss the intervention strategies that would possibly enhance the quality of life of persons with spinal cord injury and to identify the stature of developing countries in understanding the public health importance of spinal cord injury.

SCIs are graded according to the American Spinal Injury Association (ASIA) grading scale, which describes the severity of the injury⁽³⁾. The scale is graded with letters:

ASIA A: complete Spinal cord injury with no sensory or motor function.

ASIA B: An incomplete sensory injury with complete loss of motor control.

ASIA C: An incomplete motor injury, where there is some activity

ASIA D: Incomplete motor injury with anti-gravity affecting more than half of the muscle groups

The life process is an experience where the individual struggles to fulfill their needs within their limitations⁽⁴⁾. To achieve these daily needs at every level of life is greatly more difficult for persons with spinal cord injury. They require an intense modification in lifestyle. From having been free to engage in all activities connected with ordinary living, post-injury even simple routine tasks now become a challenge⁽⁵⁾. According to WHO "Health is the complete state of complete Physical, Mental and Social Well-Being and not merely the absence of diseases or infirmity" Unfortunately SCI affects all dimensions of Health which leads to negative life indicators. For Example, suicide rates in SCI populations are four to five times higher than that of the general population⁽⁶⁾ Being male, depressed, engaging in alcohol and other drug abuse, and having poor family support has also been shown to be risk factors for suicide⁽⁷⁾. There is a need for special consideration to know about Persons with Spinal Cord Injury and their Mental Health, Quality of Life, and burden in day-to-day life in India⁽⁸⁾.

Method

The search strategy using keywords "spinal cord injury," "traumatic spinal cord injury," "non-traumatic spinal cord injury," and "Burden," was adopted to search literature published in PubMed, Medline, EMBASE, and the Web of-Science. All those articles mentioning the incidence, etiology, prevalence, patient demographics, accident level and severity, complications, and psychological and social problems were examined. Only papers that were published in English language were included and largely restricted to articles on human beings. Also, meeting abstracts, case reports, and editorials were excluded from our review. Studies that were original work involving patients with spinal cord injury were included for the review independently by the authors. All the relevant articles, open source data providing regional or national data on injury to the spinal cord were also systematically screened.

Incidence and Prevalence:

The global incidence of spinal cord injury is 40 to 80 new cases per million population every year, indicating that about 250,000 to 500,000 individuals suffer from spinal cord injury⁽⁵⁾ per year. The annual incidence of SCI in different countries has been reported to vary between 11.5 and 57.8 cases per million people⁽⁹⁾. Unfortunately, because of the lack of accuracy in data reporting, the worldwide incidence of SCI cannot be calculated. Although no accurate prevalence rate is available worldwide⁽¹⁰⁾. In India, as per report 15 lakh individuals are affected by Spinal Cord Injury, with an estimated increase of 20,000 cases every year Falling from height in India seemed to be the most common mode of injury⁽¹¹⁾. Neelamegan Sridharan et al. found that falls from a height that involves falls from the tree and falls into the well was the most common cause of injury in both sexes. Spinal cord damage due to falls

was 63% in males and 62% in females, while damage due to a road traffic accident in males and females was only 27% and 38%, respectively. An injury happens in the cervical level segments in males. On the other hand, an injury occurring at the lumbar level segments was high in the female population⁽¹²⁾.

Also, a study by N Mathur et al found that 577 patients (21.2 percent) had fallen from the rooftop of the rural population out of 1145 patients (42.2 percent) who suffered the injury after fall. After falling into a dry well while digging or inadvertently, ninety-nine patients (3.6 percent) suffered spinal injuries⁽¹³⁾. After the collapse of a heavy object overhead, which is a typical mode of transport of goods in rural areas, eighty-four patients (3 percent) sustained trauma. This is a popular mode of carriage of goods in rural areas⁽¹⁴⁾. After the dropping of a large object over the back, two hundred ninety-one patients (10.7 percent) suffered the injury when removing mud from the dry well to increase its depth or putting or removing grain bags in the storage room. After falling from the electric pole or height after the electric shock, one hundred and ten patients (4 percent) experienced trauma⁽¹³⁾. In addition to SCI, electric burns were also incurred. This was an unusual trauma pattern observed in the Indian population⁽¹⁵⁾. At the same time, the main cause of SCI in developed countries was a road traffic accident, consisting of up to 58 percent⁽⁹⁾ and found mainly in younger age groups⁽¹⁶⁾. Among these countries, falls are the second leading cause of SCI, with a prevalence of up to 46.6 percent and still found mostly in the elderly, there is a significant gap between developed and developing nations⁽¹⁷⁾.

Challenges

Early crises

The early crises were the first experiences associated with SCI. There were four subcategories in this group, as follows: denial and uncertainty, feelings of loneliness and depression, the crisis of dependence, and a drastic shift in the normal course of life⁽¹⁸⁾. Unbelief and denial of disability and loss of mobility are some of the problems of post-SCI experiences⁽¹⁹⁾. People with SCI initially have unrealistic expectations of recovery and in some places, especially the inability to walk, do not understand disabilities. Concerning the possibility of recovery and denial, other subjects were feelings of loneliness and depression during the first months after the incident⁽²⁰⁾. Experiencing psychologically critical phases of post-spinal cord injury and experiencing loneliness, depression, and suicidal impulses⁽²¹⁾. During their lives, anyone can suffer from an illness, have an accident that harms them of normal activity in certain organs of the body⁽²²⁾. The truth is that they would dream of committing suicide if no one helps the disabled. They would be so lonely and depressed if this idea did not originate in their minds. So, it's a suicide of a kind⁽²³⁾.

Dependency crisis

One of the most serious crises and difficulties was excessive dependence on others in many personal and everyday activities and being a burden. SCI individuals often feel embarrassed for asking helps with personal activities, especially for bathing and toilet use. It was very difficult for them to let someone else do everyday tasks in this respect. For a person who hasn't seen it, it may be humorous and too normal⁽²⁴⁾. It was really painful for to make anyone else come to house to strip clothes off, to insert a catheter, and strip me to the toilet, for example. can't bear to picture one person coming and taking to the bathroom. There will be some people coming to take to the toilet. It'll be too painful⁽²⁰⁾. A sudden shift in the normal course of life Participants viewed spinal cord injury as a disaster and said that both physical and motor skills were lost of them at once; thus, all everyday activities underwent dramatic and substantial changes. The situation is going to get difficult unexpectedly and life stops and follows an

unusual model⁽²⁵⁾. The behavior of people, the actions of the family, their thought, the fact that before the accident you were an independent individual, you were studying, you were working, you had a different look and face and then you are sitting in a wheelchair. About a shift in all daily living habits, and considering a guy who ran for 20 years, did all the jobs, including mountain climbing, and used to swim, ride a bike⁽²⁶⁾. You're immediately stripped of them all. Nothing can't do anymore. It's what it is and now you're permanently locked in your wheelchair⁽²⁷⁾.

Employment challenges

The loss of their employment due to decreased physical capabilities is a major challenge faced by the persons with spinal cord injury⁽²⁸⁾. Also, their social engagement was limited by inadequate skills training and insufficient jobs for their situation⁽²⁹⁾. Jobs are seen by society as a measure of efficiency, rank, esteem, and source of income concerning the lack of skill training and work support. Income meets needs such as survival, protection, and self-esteem⁽³⁰⁾. A study by⁽³¹⁾ found that a successfully re-settled spinal injured person has a positive relationship with the individual's emotional state and a smooth family and social relationship. For those who are working and active, the increased quality of life of people with spinal cord injury has been shown⁽³²⁾. Also, due to their working status, they tend to be happier with their lives as they have good physical, psychological, and social wellbeing⁽¹²⁾. The employment rate for people with Spinal Cord Injury, however, is lower than the non-disabled population in the United States, where around 35 % of people with Spinal Cord Injury are working⁽³³⁾. All the physiological problems linked to Spinal Cord Injury are supposed to be tackled and effectively with a great deal of confidence⁽³⁴⁾.

Lack of barrier-free environments

The absence of a barrier-free facilities in highways, passages, urban furniture, etc., stopped them from leaving their homes and reducing social participation⁽³⁵⁾. Regarding the inaccessibility of public places and places of work, if a person with a disability wants to go to university, for example, but lacks barrier-free infrastructure⁽³⁶⁾. There are stairs at another university and no ramps. Well, you have to leave your studies when you see there is no barrier-free university. The government office itself is also disabled and has no ramps when you want to go to the government bureau. In the barrier-free area, not just in colleges, all public service locations are missing⁽³⁷⁾.

Transportation challenges

Among the problems at the time of entering society was the lack of barrier-free cars and public transport, the need for taxis to help wheelchair users, and, subsequently, the high cost of transport. Since all disabled people do not have a personal vehicle, it's very difficult to go anywhere. They've got a taxi to hire. Taxis also do not accept them because wheelchairs remain half-open so that their trunks remain half-open, and most of them do not accept them. This wheelchair occupies a lot of space because of it., they hesitate so much and charge a lot of money for those who accept⁽¹⁴⁾.

Mental Health Issues

A discussion about whether individuals with spinal cord injury suffer depression since the onset of spinal cord injury has continued for decades⁽³⁸⁾. The Spinal Cord Medicine Group (1998) indicated that depression is not a single entity, since it requires many potential diagnoses. They also found that when they are in the acute or treatment stages, individuals with spinal cord injury may not have faced the full extent of the changes placed on them due to spinal cord injury. Therefore, when returning home (or

later in life), they may be more vulnerable to depression because of a decline in social and medical support and the burden of pain⁽³⁹⁾. The Spinal Cord Medicine Group (1998)⁽⁹⁾ explained that dealing with spinal cord injury may include types of grief (e.g., sorrow, feelings of loss, nostalgia) and that these reactions must be separated from the more extreme and common depressive reactions (e.g., helplessness, hopelessness, feeling useless, excessive remorse or self-reproach, suicidal thoughts). Several factors may increase depression,(e.g. decreased physical functioning, inaccessible environment, lack of social support, lack of a reason or job) as well as the risk of suicide after spinal cord injury⁽⁴⁰⁾ The mean ages of people with spinal cord injury and caregivers were 34.8 (11.0) and 33.6 (12.3) years, respectively, studied by Shambu P et al⁽⁹⁾. Most of the TSCI participants were male (67.4 percent) and had paraplegia (73.7 percent). The caregivers were predominantly female (61.1%). In 68 percent of those with spinal cord injury, the depressed mood was seen and 91.6 percent of caregivers reported the burden. The depressed mood has been significantly linked to gender, education, a form of injury, and duration of the injury⁽⁴¹⁾. The burden of the caregiver was related to the profession, education, injury degree, duration of treatment, and depressed mood level of the person with spinal cord injury. The economic burden was found to be the largest (71.5 percent), followed by responsibility (22.2 percent) and time-related burden (6.3 percent). Among people with spinal cord injury, the incidence of depressed mood, and the strain of caregiving in caregivers were high. Depressed mood was correlated with caregiver burden in those with spinal cord injury⁽⁴²⁾.

Spiritual

Spirituality is one resource that individuals use to coping with a massive life change such as having a spinal cord injury. Even though spirituality means different meanings to different people, after experiencing a spinal cord injury, people with stronger spiritual beliefs appear to be happier and less depressed and indicate that religion and spirituality may play a major role in the rehabilitation process following spinal cord injury⁽⁴³⁾. Many people facing a chronic illness or permanent disability can ask the question, "Why?"⁽⁴⁴⁾Pargament (1997)has indicated that certain answers to this question could be given by religious faith."For example, suffering may be viewed as a spiritual opportunity, the consequence of human sinfulness, the effect of a past existence now influencing this one, a means of finding redemption or approval, the intervention of a God who punishes the devil, or vice versa. Instead, religious faith can lead one to the understanding that misery "has nothing to do with you," but is part of the human being's natural course⁽⁴⁵⁾. The relationship between spiritual well-being and health-related quality of life (QOL) among patients with spinal cord injury (SCI) was examined by MarziehHajiaghababaei, et al, with 213 patients, and found that the mean age of patients was 43.5 (SD = 10.8) years, with the majority being male (77.5%)⁽⁴⁵⁾. Religious well-being and existential well-being were important factors contributing to enhanced vitality, social functioning, mental wellbeing, and emotional role, the outcomes of regression analysis The findings indicate that in people with spinal cord injury, having higher levels of spiritual well-being might enhance the quality of life⁽⁴⁶⁾.

Acute Care

A very crucial step in the care of accident victims is the management of acute spinal cord injury at the site of injury. Immediate therapy can lessen long-term effects; appropriate therapy typically involves medication and rehabilitation therapy. As part of the treatment of all patients with acute spinal cord injury, the following procedures should be incorporated. The significance of recognition and early treatment, such as usage of the cervical collar or spinal board, is adequate first aid. Proper transport

strategies were used to carry the patient to the emergency center. The time needed to transport patients from the site of the accident to the treatment centers and the delay in reaching the treatment centers. Surgery Timing⁽⁴⁴⁾. Financial burden and efforts to resolve this burden and the logistics involved in transportation, preparation, and execution are involved. For the prevention of secondary spinal cord injury, early care of patients with acute spinal cord injury is very important. 133 patients with acute spinal cord injury were examined in a study performed by Prasad et al from NIMS, Hyderabad. Data obtained from the study showed that only 7 (5.2 percent) of the total number of patients entered the hospital within 8 hours. And another 23% of patients arrived within 24 hours. Patients reached 42 percent between 24 and 72 hours. Ramani and Laud from Mumbai had also reported similar results for the time taken by patients with spinal cord injury to reach the hospital. Reports collected from the USA, and on the other hand, showed that almost 50.2% of patients were admitted within 1 h of the accident. Data obtained from a study conducted at MIOT Hospitals, Chennai, between April 2005 and March 2007 showed that only 4 (4.9 percent) of 81 patients with spinal cord injury were admitted within less than 8 hours. Two of these patients sustained an injury at a place 3-4 km from the hospital, indicating that only if they were inside the hospital area could timely care to be administered⁽⁴⁷⁾.

Discussion

In India, the most common factors hindering management during a hospital stay are financial constraints and patients not reaching the final institution, and lack of adequate facilities at the definitive institution, psychological factors, illiteracy, and insufficient patient education are other factors hindering hospitalization⁽⁴⁸⁾. Factors that prevent integration into the mainstream society are insufficient recovery, a barrier-ridden climate, challenges in accessing government/other agencies' assistance, poor society knowledge, financial obstacles, lack of assistive technology availability, and unrealistic beliefs. In the context of spinal injuries, things are bound to improve and the government will play a major role through community awareness and preventive initiatives, and promotion of education and science⁽⁵⁾. We have come to the beginning of the end. It is time to start consolidating our winnings and taking the message to our community that the patient with spinal cord injury dramatizes this danger with a paradox, requiring a lot of highly specialized treatment, but his overall treatment remains of primary importance⁽⁴⁹⁾. Things are bound to change in the case of spinal injuries and the government will play a major role through community awareness and preventive measures, and promotion of education and science⁽⁵⁾.

Way Forward

We have entered the end of an era. It's time to start consolidating our winnings and take the message to our community that the patient with spinal cord injury dramatizes this disaster with a paradox, requiring a lot of highly specialized treatment, but his general treatment remains of primary importance.

Recommendation

- Mental health aspects should be given importance in persons with Neuro-disability condition
- All district hospitals should be equipped with specially trained rehabilitation professionals
- The intensity and severity of the problem have to be taken into account whenever new schemes are formed.
- Strict regulation should be followed inaccessibility in all public utility places.
- Public Transportation should be accessible for wheelchair users.

Conclusion

Spinal cord injury creates physical, psychosocial, emotional, and economic problems that affect not only the injured person but also the family(50). These issues can lead to life dissatisfaction and thus decrease the QOL of both patients and caregivers. All aspects of care in all groups, except the elite tier, were affected by financial constraints(51). Therefore, a very large percentage of the Indian population is projected to find it very hard to access SCI management and community integration expenses. A better understanding of the types of symptoms experienced by individuals with SCI and their frequency, severity, levels, and impacts on day-to-day functioning is a significant step in recognizing comprehensive information and understanding the burden of spinal cord injury and its complication in patient's perception to address their needs in the holistic approach(52).

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