

Priorities of Spinal Cord Injured Population – A Survey

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Abstract: In the united states alone, there are more than 200,000 individuals living with a chronic spinal cord injury (SCI). Healthcare for these individuals creates a significant economic burden for the country, not to mention the physical, psychological, and social suffering these people endure every day. Regaining partial function can lead to greater independence, thereby improving quality of life. To ascertain what functions are most important to the SCI population, in regard to enhancing quality of life, a novel survey was performed in which subjects were asked to rank seven functions in order of their importance to their quality of life. The aim of present study was to evaluate the priorities of spinal cord injured population depending on their level of lesion and improvement of which function will make improvement in quality of their life. A total number of 71 subjects were taken. The questionnaire was made to be filled by all the participants through personal interview, Emails and telephonic interviews. There was a significant variation in priorities of spinal cord injured population.

Keywords: Quality of Life, Spinal Cord Injury, Priorities

1. Introduction

Spinal cord injury (SCI) causes many deficits that often restrict the lives of the individuals as well as their contributions to society. The worldwide impact is dramatic [1]. Many impairments resulting from neurological damage not only limit physical function but also influence an individuals' psychological well-being, social integration, financial status, and life aspirants, to varying degrees [2, 3].

Chronic paralysis of all forms, not just spinal cord injury (SCI) is a long term health, economic and social issue worldwide. (national spinal cord injury database, 2001; dijkers et al., 2000). Currently scientists are pressured on many fronts to develop an all encompassing "cure" for paralysis [4].

Although 'curing' all functional deficits associated with SCI is the ultimate end goal of our research, such an endeavor involves much more than repairing, protecting, or regenerating motor tracts- the traditional focus of most - related research.

The autonomic nervous system and the sensory system are equally important, yet relatively understudied. Thus research efforts should equally reflect autonomic, sensory and motor

contributions to SCI.

In addition it is probable that discoveries leading to incremental improvements in specific functions will occur well before a single, all encompassing 'cure'.

An incremental improvement in neurologic function could translate into a significant improvement in quality of life (QOL) of a person living with SCI. Therefore, we contend that SCI research emphasis should be broadened to develop therapies that contribute directly to QOL.

The SCI community understands and indeed embraces the idea of incremental functional recovery [5]. They have also indicated that walking is not the most important function to recover in order to improve QOL.

Regaining bladder and bowel function, eliminating autonomic dysreflexia (AD), and improving arm/hand function are among the top most priorities of individuals with SCI⁵, all of which require more extensive research at basic science and clinical level.

Chronic pain and dysesthesia are important and frequent complaints in patients with spinal cord injury (SCI) with a reported prevalence varying between 27% and 94% [6-15]. The classification of post- SCI pain is not clarified, which in part may explain the large variation in reported frequency

[16-18]. The SCI pain task force of IASP broadly classifies SCI pain into nociceptive (musculoskeletal and visceral) and neuropathic (above-level, at-level and below-level) pain [19].

Neuropathic types of pain in SCI may include peripheral (nerves and nerve roots) as well as central components. Neuropathic pain is considered to be a particular bothersome symptom in SCI because it often persists and generally is considered resistant to conventional analgesic treatments.

Neuropathic pain has several distinct features: lesion of nervous tissue, pain in area with sensory deficits, dysesthesia, allodynia, hyperalgesia and abnormal spatial and temporal summation. Several of these features are also seen in SCI pain.

Sexual function is an important part of spinal cord injury (SCI), yet it has traditionally been considered a low priority in regard to research topics and funding. Like many other aspects of SCI, sexual function is influenced by the integrity of motor, sensory, and autonomic pathways as well as psychological and social factors.

Sexual impairments occur to some degree in nearly every SCI and individuals living with SCI rate improving sexual function as a highest priority to improving quality of life [20-21].

The two most extensively researched areas in men are erectile dysfunction and ejaculatory compromise in males after SCI. Briefly the neurologic injury level and severity have a significant impact on erectile ability and on the occurrence of reflexogenic or psychogenic erections [22, 23]. The neurogenic injury level and severity have a significant impact on erectile ability and on the occurrence of reflexogenic or psychogenic erections.

Ejaculation is a more complicated process and ejaculation results in a significant number of spinal injured men. Reflexes, somatic responses and electro-physiological parameters have been used to try to predict the ability to successfully induce ejaculation [24, 25].

A significant side effect of assisted ejaculation is that both penile vibro stimulation and electro ejaculation can induce autonomic dysreflexia in men with injuries above T6 [26]. Woman's ability to become pregnant and carry and deliver a child is largely unaffected following spinal cord injury, it was assumed that her sexuality was similarly unaffected. Consequently, female sexuality was equated with child bearing and scientific interest was confined to pregnancy and its complications.

There are various questions that arises in women mind after SCI:

- Does my SCI affect my sexual function?
- What kind of physical changes can I expect?
- Will I have orgasms?
- Will I be able to satisfy my partner?
- What do I do with my catheter during sex?
- What about bowel and bladder accidents?
- Can I still have baby?
- If I decide to have a baby, will I have special problems?
- Are there risks to the baby?
- Will I need a caesarean section for delivery ?[27]

Sustaining a spinal cord injury (SCI) is a life- changing event. There is a physical loss of function as well as psychological, social and economic losses. Having an injury in the cervical spinal cord is even more significant because arm and hand impairments greatly reduce one's ability to care for oneself, which forces one to rely on attendants for daily, life sustaining needs. Relying on attendants is financially over-whelming, unpredictable, and extremely stressful. Regaining arm/hand function has been documented as the highest priority for people with cervical SCI [28-30]. One intervention that exists and has been well-documented to enhance the function is reconstructive surgery of the upper limb through tendon transfers [31-36]. The primary outcomes targeted with these interventions are elbow extension, key pinch, and hook grip. All these are movements vital for the independent performance of multiple activities of daily living (ADL).

A primary goal for rehabilitation is to regain as much function and control of the upper body musculature as possible, to enable everyday life tasks to be performed from a sitting position. In this context the trunk muscles become critical, since they provide the necessary trunk stabilization. Trunk muscles are however, not included in the assessment tool routinely used to classify motor function in persons with SCI, i.e. the International Standard of Neurological Classification of Spinal Cord Injury [37, 38]. Thus, conclusions about motor connectivity to trunk muscles are precluded and classification of the neurological lesion level in persons with thoracic SCI will be based solely on sensory function.. Approximately half of motor recovery occurs within the first 2 months after initial injury, with a decreasing rate after 3 to 6 months. At 2 years after injury, neurologic recovery is assumed to be nearly complete. In patients with an initial motor incomplete SCI, more than 75% regain some form of ambulatory function. Although conventional rehabilitation programs enhance performance of functional tasks, the loss of strength and coordination substantially limits one's capacity for over ground ambulation training.

2. Materials and Methods

Study design: Survey Study

Methods & Procedure

The research work has been approved by research committee of college of applied education and health sciences. Spinal cord injured population was taken as subjects. The source of data is from CAEHS OPD, telephonic conversations and through Emails. Subjects were told about the survey and were explained about how to grade their priorities in their native language.

Each and every aspect of questionnaire was explained to subjects clearly as how to answer.

The first question was about their level of injury and in which year it occurred? The second question was targeted to find out their priorities in terms of outcomes. Third question was about their view point to does exercise rehabilitation plays a part in recovery? Fourth question was aimed at

knowing how active they are to the exercise regime or if they are not accountable to it. Fifth question gathered basic information about the subjects like name, age, gender, contact number, Email ID.

In last question we asked subjects for any further suggestions or comments.

A total number of 71 participants were included in which 38 were quadriplegics and 33 were paraplegics in the age group above 18 years. The subjects signed consent as an approval for their participation in study. Majority of subjects had injury for more than 3 years.

Prior to commencement of data collection subjects were asked to read and acknowledge the consent form.

3. Result

There were total number of 73 subjects of spinal cord injury. 38 individuals were quadriplegics and 33 individuals were paraplegics. We have calculated the frequencies of their priorities. Table number 1 showed the first or highest priority of quadriplegics and paraplegics. The first priority of quadriplegics were arm/hand function whereas, for paraplegics first priority was improvement of bladder and bowel function, elimination of dysreflexia.

Table 2 Projects the second highest priority of quadriplegics and paraplegics. Quadriplegics rated the upper body /trunk strength and balance. On the other hand for paraplegics it remain same i.e recovery of bladder and bowel function and elimination of dysreflexia.

Table 1. First priority (paraplegics and quadriplegics).

	1 st optn	2 nd optn	3 rd optn	4 th optn	5 th optn	6 th optn	7 th optn
Quadri 1	23	3	10	0	1	0	1
Para 1	0	4	21	1	1	3	3

Table 2. Second priority (paraplegics and quadriplegics).

	1 st optn	2 nd optn	3 rd optn	4 th optn	5 th optn	6 th optn	7 th optn
quadri	12	22	2	0	1	0	1
Para	0	3	9	4	4	6	7

Table 3. First and second priority quadriplegics and paraplegics (correlation).

Quadri 1	23	3	10	0	1	0	1
Quadri 2	12	22	2	0	1	0	1
Para 1	0	4	21	1	1	3	3
Para 2	0	3	9	4	4	6	7

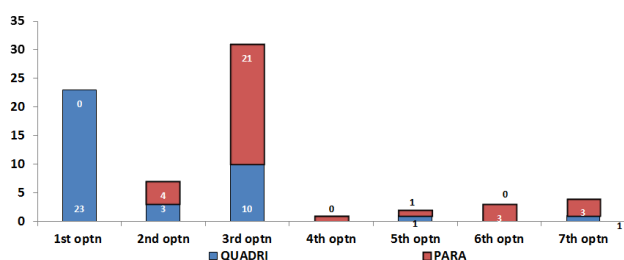


Figure 1. (Depicting table no. 1).

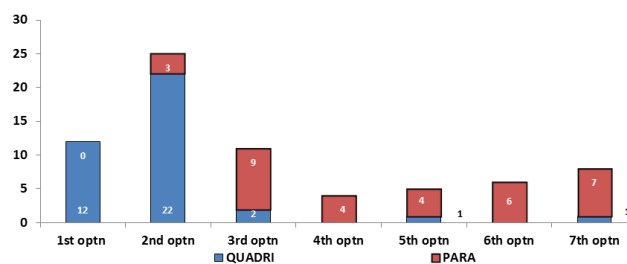


Figure 2. (Depicting table no. 2).

4. Discussion

The study was conducted to find out priorities of spinal cord injured population.

A total of 71 number subjects were taken. Of all the participants 54% were quadriplegics and 46% were paraplegics.

In addition 15% female and 75% male.

4.1. Priorities of Quadriplegics

To most appropriately assess the priorities of the SCI population, the responses were grouped into quadriplegics and paraplegics.

For quadriplegics 60% of the participants indicated that regaining arm and hand function would most improve their quality of life. 26% ranked bladder & bowel and elimination of autonomic dysreflexia regain. 7% said upper body/ trunk strength and control would improve their quality of life. whereas both elimination of chronic pain and walking movement were priorities of only 2% and 2% of the population of a total making 4%.

Sexual function and normal sensation together made a total of only 0% priority for quadriplegics.

4.2. Priorities of Paraplegics

In case of paraplegics participants 63% ranked bladder & bowel and elimination of autonomic dysreflexia function to be the most important to their quality of life. This was followed by improving upper body / trunk strength and balance (12%). Regaining walking movements was higher by paraplegics (9%) than by quadriplegics, as was normal sensation (9%). Sexual function was desirable to only 3% of the population. elimination of chronic pain ranked higher in quadriplegics (2%) than paraplegics (1%).

The data from the survey demonstrate the preferences of the spinal cord injured population in terms of regaining partial functional recovery to the quality of life. The return of arm and hand function was by far the highest priority to quadriplegics. for paraplegics the most desirable function was bladder & bowel and elimination of autonomic dysreflexia.

Finally the overwhelming majority of all participants regarded exercise as an important part of functional recovery, yet more than half of these did not have access to a trained therapist or proper guide.

Not surprisingly regaining arm and hand function was the most desired function for quadriplegics. This is

consistent with the fact that recovering even partial arm and hand function can have an enormous impact on independence.

The majority of paraplegics participants regarded bladder & bowel and elimination of autonomic dysreflexia to be most important to improve their quality of life.

It can take months to years for a person with SCI to develop a reliable, effective bowel routine. The amount of time required to perform a bowel movement can vary from person to person and even from day to day within the same person. Having bowel accidents is not only physically uncomfortable but also socially humiliating. For those individuals whose injury severity requires another person to conduct their bowel management, there are multiple physical, psychological and social humiliations to be endured. Anything that can be done to increase function and independence regarding bladder & bowel function will be a great advance in medical science.

Another aspect that must be addressed in clinical setting is a long term exercise for chronic SCI. there are some studies demonstrating the benefits of long term exercise in humans with SCI.

Clearly exercise is likely to be beneficial to outcome of SCI. However the results of current study indicate that only of the participants who had access to long-term exercise were supervised by a trained therapist. Aside from already known benefits of exercise to overall health, lack of access to exercise and therapists to guide this exercise will be a problem if clinical treatments are developed for SCI which require the reversal of muscle atrophy.

The quality of life of people living with SCI is determined by a range of factors. Not only to health issues, including motor, bowel bladder and sexual function have a substantial impact on the individual well – being, other social aspects of life such as relationships with friends and family members or employment are equally important detriments [39].

5. Conclusions

The present study concluded that there was a significant variation in the priorities of spinal cord injured population depending on their level of injury.

- The first priority in quadriplegic population is regaining arm and hand function (60%).
- The first priority in paraplegic population is improvement in bladder & bowel function and elimination of autonomic dysreflexia (63%).
- The least priority of quadriplegics were regaining sexual function (0%).
- The least priority of paraplegics were arm and hand function as they are functionally active (0%).

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