

ORIGINAL ARTICLES

**AN INTERNATIONAL COMPARATIVE STUDY ASSESSING
IMPAIRMENT, ACTIVITIES, AND PARTICIPATION IN
SPINAL CORD INJURY REHABILITATION - A PILOT STUDY**

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ABSTRACT

This qualitative comparative cross-sectional study attempted to identify existing gaps and differences in health care processes and societal structures supporting the spinal cord injury population in two countries with different socioeconomic profiles, Nepal and Canada, by looking at incidence of preventable complications, and measures of activities and participation. Subjects were recruited from two comparably sized spinal cord injury rehabilitation units in both countries, during a two-week period at each site. Interviews were held, along with brief physical assessment for injury classification and preventable complications. Prior to rehabilitation, preventable complications had already developed in 15 of the 17 subjects: 12 pressure ulcers, 10 urinary tract infections, 3 blood clots, and 6 joint contractures. Results show a need for greater consistency in efforts to prevent complications in this population, particularly within acute care settings. Activity (Barthel Index) and participation (P-scale) scores were higher in the Canadian setting ($p=0.06$ and 0.05 respectively).

INTRODUCTION

The International Classification of Functioning, Disability and Health (1) clearly sets the framework that one should consider when assessing disability of any kind. Even though not yet specifically outlined, it does acknowledge environmental and personal factors as contributing to disability and disablement, in addition to impairments and their effects on body functions. In evaluating rehabilitation programmes, one needs to gather information to evaluate all four categories of factors included in the framework (body structures and functions, activities, environmental factors, and personal factors).

This study was undertaken to identify improvements that could be made in health care provision, and societal structures, for persons with spinal cord injury (SCI), particularly in the immediate post-injury period. The question studied was whether there exists a difference in the occurrence of preventable complications after SCI in countries of vastly different economies and social structures. By definition, preventable complications need not occur, if

appropriate health care processes and subject compliance with recommendations are applied. Since complications cause impairments, they would be expected to impact negatively upon activities and participation. Level of activities and participation of individuals living in settings of different societal structures was also looked at in this study.

As a starting point, two inpatient rehabilitation units that the authors are affiliated with, were chosen for study, one in Nepal, one in Canada. The units are relatively similar in size, serving regional catchment areas, and localised within mid-sized cities (150-300 000 population). It was recognised at the start that such a cross-sectional study would provide only a snapshot, and its value would lie more in qualitative information gained, than in allowing definitive quantitative conclusions.

METHODS

During the months of August and September 2003, the principal investigator obtained consents from, and interviewed, all inpatients that were on the SCI rehabilitation unit in a two-week period, at each site. Approval to conduct the study had been obtained from the appropriate research ethics boards. Individual interviews were conducted in each subject's usual language of communication, through an interpreter where necessary.

Measures collected included the Barthel Index (2) to measure activities of daily living, Cantril Self-Anchoring Striving Scale (3) to measure personal ratings of various aspects of their life (such as spiritual, emotional, independence ratings), Participation Scale (4), and Community Outcome Scale (5), as an indicator of each subject's community participation. There were no available records indicating whether initial post-injury instructions were given, for any of the subjects. Participants were asked to provide details about their SCI, and recall any instructions or procedures they may or may not have been provided with, as pertaining to preventing complications such as urinary tract infections, pressure ulcers, joint contractures, and deep vein thromboses or pulmonary emboli. Information regarding supports, home accessibility, and transportation was also obtained from each subject.

Descriptive statistics were used, including two-tailed t-testing for demographics and scales, and Fisher's exact tests to look for differences in preventable complication rates between the two groups.

RESULTS

All eligible subjects consented to be participants; 9 Nepali and 8 Canadian subjects were recruited in consecutive two-week periods. Ages ranged from 24-60 (mean 38) in the Nepali setting, and 18-73 (mean 49) in the Canadian setting. Median time from injury at the time of data collection was 10 months in the Nepali setting (range 1.5 months to 9 years), and

10.5 months in the Canadian setting (range 2 months to 34.5 years). 5 Nepali and 4 Canadian subjects were at 12 months or less post injury. Most subjects sought help almost immediately (6 in Nepal and 5 in Canada presented on the day of injury to hospital or clinic, whilst 2 from each setting presented within 10 days, and 1 from each within 3 months). 1 incomplete paraplegic Nepali subject only had access to a local clinic acutely, was advised on leg massage, and sent home. It was not until years later that admission to a rehabilitation unit was sought by the subject for skin ulcer complications. 1 Canadian subject was offered stabilisation surgery acutely, but decided against it until months later. Time to admission to a rehabilitation unit after initial spinal cord injury varied from 7 days to 9 years (median 2 months) in the Nepali setting, and 18 to 300 days (median 1.5 months) in the Canadian setting. Table 1 shows demographics of the subjects. All the Nepali subjects with complete injuries were paraplegics. The non-traumatic causes of SCI were: tuberculosis (Nepali), multiple sclerosis, myelomeningocele, spinal abscess, and cancer.

Table 1. Demographic information of subjects

	Nepal	Canada
Male:Female	5:4	5:3
Age <60: 60 years or older	8:1	5:3
SCI level Cervical: Thoracolumbar	4:5	4:4
Traumatic:non-traumatic SCI	8(1 iatrogenic):1	4:4
Complete: incomplete SCI	3: 6	0: 8
Acute rehab: post-acute management	5:4	5:3

With respect to complication prevention prior to rehabilitation, only 2 Nepali and 5 Canadian subjects recalled any instructions about preventing skin ulcers acutely after SCI. Of the 3 Canadian subjects that did not recall instructions about skin ulcer prevention, one had been managed 13 years prior, one was managed in a remote northern community, and one in a smaller community hospital in the region, before the current rehabilitation admission. None of the Nepali subjects recalled being provided any bowel or bladder care instructions, or instructions regarding prevention of joint contractures or deep vein thromboses. Little is known as to the standards of complication prevention efforts in acute hospitals in Nepal. Both rehabilitation settings from which subjects were recruited routinely emphasise prevention of skin ulcers, and joint contractures. However, in the prevention of urinary infections and blood clots, care processes differ between the settings, due to differences in availability of diagnostic equipment and medications. No statistical differences were found in rates of preventable complications in the two settings.

Table 2 outlines preventable medical complications present prior to admission to the in-patient rehabilitation units. While on the rehabilitation unit, 1 Nepali subject developed contractures, 2 Canadian subjects had joint contractures released, and 1 Canadian subject had experienced complete healing of a pressure ulcer, while the other subjects with pressure ulcers continued in their healing. One Canadian subject was still on an anti-thrombotic agent to dissolve a blood clot, and 4 of 5 subjects with urinary tract infection on each unit had been successfully treated. Table 3 indicates other common medical issues that were being managed in these subjects. 8 of 9 Nepali and 4 of 8 Canadian subjects experienced ongoing bowel or bladder concerns of retention/ constipation or incontinence.

Table 2. Preventable complications present prior to rehabilitation admission

Preventable complications	Nepal (n=9)	Canada (n=8)
Pressure ulcers	7	5
Urinary Tract Infections	5	5
Blood Clots	1	2
Joint Contractures	2	4

Measures of activities (Barthel and Modified Barthel scores), participation (P-Scale and Community Outcome Scale), and quality of life (Cantril Self-anchoring Striving Scale) are presented in Table 4. When trying to determine the main differences between groups contributing to the trend seen in Barthel Index scores, p values were determined for each category of the Barthel Index for tetraplegics and paraplegics. The only categorical difference that reached statistical significance was in "controlling bladder" (p=0.04) for tetraplegics. A differing trend was seen in "walking" (p=0.09). For paraplegics, differing trends were found in the categories of "bathing" (p=0.07) and "controlling bladder" (p=0.09).

Table 3. Ongoing medical issues reported by subjects in rehabilitation

	Nepal (n=9)	Canada (n=8)
Musculoskeletal pain	2	4
Neuropathic pain	3	2
Autonomic symptoms	1	1
Urinary retention/incont	5	3
Bowel incont/constipation	7	3
Spasticity	4	6

Table 4. Activities, Participation, and Quality of Life scores

Scores Mean \pm S.D. (best possible score)	Nepal	Canada	P value between groups
Barthel Index (100/100)	39 \pm 32	68 \pm 23	0.06
Modified Barthel Index (100/100)	45 \pm 32	72 \pm 24	0.07
P-scale (0/72)	36 \pm 13 (3 unable to complete)	20 \pm 13	0.05
Community outcome scale (0/24)	13 \pm 5	8 \pm 5	0.07
Cantril scale (60/60)	34 \pm 12	39 \pm 8	0.3

In terms of seeking paid employment, only 1 Nepali subject indicated that this was expected. Another thought of possible self-employment activities that could be pursued from home. Eight of the 9 Nepali subjects reported, or could envision, a contributory role in their household. One was retired. Of the Canadian subjects, 2 continued self-employment businesses while in hospital, 1 had a job to return to, and 1 felt optimistic about returning to work. Another younger subject had firm plans to return to school, and one was retired. Seven of the eight reported a contributory role in their households.

In order to understand activities and participation in context, contributory factors are listed in Table 5. One Canadian subject in a northern community had limited public support to the home, and had to re-locate to another community with a nursing facility. This same subject had variable access to public transportation, and was dependant upon a functioning hospital

Table 5. Environmental factors contributing to activities and participation

	Nepal (n=9)	Canada (n=8)
Access to family support	9	6
Access to government (villager) support	0 (5)	8
Access to some funds	5	8
Access to transportationown: public: private	0: 3: 5	5: 3: 0
Access to equipment	4	8
Accessible accommodation	6	8

vehicle. No Nepali subjects owned cars, and most had to use public or private transportation means, including porters, and non-adapted buses, jeeps, or taxis. The Nepali subjects who reported access to funding usually meant that they could borrow it, or obtain funds from relatives. Only one had a pension, and one could rely on some insurance money to cover expenses. Access to equipment meant that the subjects were provided with equipment intended to enhance their functional abilities, during their stay on the rehabilitation unit.

DISCUSSION

The mix of subjects during the period of study was surprisingly similar in the two units. Subjects were generally older in the Canadian setting (11 year difference in mean values). This seems consistent with a previous study by McKinley, that found, in a group of 220 subjects, those affected by non-traumatic causes of SCI, to be older than those with SCI from traumatic causes (mean ages of 61.2 and 38.6 years, respectively) (6). In our study, there were more subjects with non-traumatic causes of SCI in the Canadian group than Nepali group. In some studies, up to one-third of SCI admissions were due to non-traumatic causes (7). Life-expectancy in Canada is also higher (74 years for men, 81 years for women) than that in Nepal (60 years for men and women) by about 15 to 20 years (8,9); therefore such a difference is not surprising. More of the Canadian subjects had lived with their SCI for longer periods of time. Three Canadian and four Nepali subjects were admitted to the inpatient SCI rehabilitation unit for management of issues other than their initial SCI because of special care considerations required for this population. In this subgroup, the Canadians as a group were older, and further along in time after their initial SCI. A similar proportion of tetraplegics to paraplegics were admitted in the units during the two-week periods studied.

The number of subjects who had experienced preventable complications was similar. While only 2 of the 9 Nepali patients stated that instructions were provided for prevention of pressure ulcers, the fact that only 5 of 8 Canadian patients recalled receiving such instructions indicates a need for better attention to complication prevention in acute care settings. In Canada, information about prevention of pressure ulcers has been known for decades in the Canadian setting, is found in standard textbooks, and should routinely be provided to patients. Even if instructions had been provided to subjects who did not recall receiving them, they were perhaps not impressed well enough, therefore leading to poor recollection. Of course, some subjects may have been well aware about the risks, yet permitted pressure ulcers to form. In both settings, the majority of subjects who experienced skin ulcers developed them prior to admission to the rehabilitation unit. Periodic educational campaigns targeting health care providers in hospitals and clinics where persons with SCI are regularly seen acutely could be beneficial in both countries. In addition to providing instructions for prevention, such as regular changes of position at least every two hours, it is clear from the subjects that the

gravity of developing skin ulcers, and prolonged healing periods, needs to be stressed in patient education. For example, some subjects admitted to being instructed about pressure sore prevention, but did not realize how difficult and serious the situation would be once these ulcers develop.

Joint contractures occurred in both populations, indicating that range of motion exercises and control of spasticity might not have been optimised in either setting. It is clear from the results that spasticity is a significant cause of ongoing medical concern for many of the subjects, both in the short and long-term. Deep vein thromboses and pulmonary emboli were experienced by more Canadian than Nepali subjects, despite the widespread use of anti-thrombotic medications in the former setting and the complete lack of such use in Nepal. There could exist a difference in population susceptibility to such incidences, or there may be a decreased level of detection in Nepal, given the lack of diagnostic equipment available. If detection rates are different, then one cannot realistically compare the rates of blood clots in the two populations. Occurrence of urinary tract infections could be dependent upon health care practices, such as the use of intermittent catheterisations, as opposed to indwelling catheterisations, as well as cleanliness of technique. However, in this study, similar numbers in both groups experienced urinary tract infections, despite the preferred application of clean intermittent catheterisation in the Canadian setting, and prevalent use of indwelling catheters in the Nepali setting. Prevention of urinary infections, joint contractures, and blood clots is generally considered, but not necessarily equally applied in all Canadian acute care settings. Once again, education of health professionals in acute care settings would be desirable for these complications that are generally considered preventable.

Little is known about the standards of complication prevention efforts in acute hospitals in Nepal. Both rehabilitation settings from which subjects were recruited routinely emphasise prevention of skin ulcers and joint contractures. However, in the prevention of urinary infections and blood clots, care processes differ between the settings, due to differences in availability of diagnostic equipment and medications. In a recently published article (10), six common complications presenting early after SCI included trophic skin changes (skin ulcer), heterotopic ossification, urinary complications, respiratory complications, pulmonary embolisms, and deep vein thromboses. Of these, skin complications were the most frequent (up to 30%). They too found at least one complication on admission, in up to 40% of subjects in Italian rehabilitation centres. Complication rates increased with duration between SCI onset and admission to the rehabilitation centre. They concluded that the most desirable set up for care of SCI patients is one that spans acute care, immediately post-SCI, through rehabilitation, to discharge home. Therefore, it would seem reasonable to educate acute care hospitals about the existence of rehabilitation centers, to facilitate timely referral and coordination of transfer after SC stabilization.

Other preventable complications, such as renal failure and hydronephrosis, could not be studied because regular monitoring for them only occurred in one setting. The necessary tools for detection of these long-term complications were not available in the Nepali setting. We did not study the incidence of complications such as respiratory conditions, or heterotopic ossification, as they are not necessarily preventable.

The Barthel Index is a measure of ability to perform activities of daily living. It was chosen instead of other measures, because of its universal availability and non-proprietary nature. It has also been shown to be sensitive to change over time, predictive of rehabilitation outcome, and useful for follow-up of subjects (11). A score of less than 100 indicates the presence of some disability. According to Shah's guidelines (12), the average Nepali subject scored in the severe dependence range, while the average Canadian subject scored in the moderate dependence range. However, these results could have stemmed from the differences in proportion of complete injuries between the two groups. A larger study with matched subjects would be able to examine if such differences truly exist. There was only one subject with neoplasm as a cause for SCI, in the Canadian group. Previous research suggests that subjects with neoplasm may not experience as much of a gain in functional ability during inpatient rehabilitation, when compared with subjects with traumatic causes of complete injury (13). This information may be helpful when planning a future study, with respect to comparisons between subgroups of subjects.

The Modified Barthel Index, developed in an attempt to increase sensitivity for stroke rehabilitation, did not seem to have any advantage in discriminating between groups. In general, Modified Barthel Index scores were higher than the Barthel Index scores. Given the results, and the relative difficulty and interpretational variability in scoring the Modified Barthel Index when compared to the ease of applying the Barthel Index, it would seem more practical to employ the Barthel Index in future studies.

The Participation Scale is a newly developed measure based on the ICF, that provides a quantitative measure of individuals' participation restrictions. Its validity, reliability, and stability has been checked in Brazil, India, and Nepal, by the development team (4). The authors felt that this might be an appropriate tool to use in this study, since it had been partially developed in one of the countries in our study.

With respect to community participation, it would appear that Canadian subjects are more able to participate in community activities than are Nepali subjects, possibly a result of differing access to resources and physical environmental access. The former system is a social democratic one, in which public services are available. The latter is largely a user pay system, with little in terms of municipal or national infrastructure, whether it be road or building accessibility, accessible transportation, or publicly funded supports, for disabled persons.

Nepali subjects are more dependent upon family and neighbours, and therefore benefit from a strong community belonging, whereas autonomy in Western countries is highly influenced by the individualist-liberal view, in which freedom of choice and action is important (14), and money can be an important means of enhancing autonomy (15). In studies based in user pay systems in the United States of America, where standards of living are generally higher, access inequities are acknowledged (16), with the poorest individuals being less able to pay for needed care. Negative long-term consequences of unmet health care needs may result in declining health and reduced social participation (17).

With respect to employment, the social environment in Canada seems to be more supportive of employment in the SCI population. One subject who was not employed was on a disability pension. It is common for disabled persons in Canada to receive funding support from government. Canada's Constitution outlines citizens' rights; perhaps this has strengthened the importance of supportive environments (18). Specific Acts have been developed in individual provinces to protect the rights of disabled persons (19). It is interesting to know that until recent years in Nepal, patients with SCI were often sent home to die, without receiving rehabilitation. There seems to be a need for better ongoing supportive environments in the community in Nepal. As the disability rights movement in Nepal gains prominence (20), perhaps changes in health care provision and social systems will follow.

Interestingly, self-reported quality of life seemed comparable in the two groups, as indicated by Cantril Self-Anchoring Striving Scale scores. Quality of life is a complex concept, and if it is an indicator of overall well-being of subjects, our results point to comparable states of well-being in the two groups, in spite of large differences in circumstance. Past research into life satisfaction in persons with SCI has indicated that satisfaction is not related strongly to impairment severity, but to measures of activities and participation; for example, life satisfaction is greater for those involved in productive activity (21). Unless one understands the various contributory contextual factors in each setting, validity of comparing self-reported quality of life measurements may be limited, and may be more appropriately used to measure changes in time for each subject. Some advocate the use of quality of life measures that include both objective and subjective components; these could be considered in future studies, for comparing two groups.

It is recognised that this cross-sectional study has many limitations in ability to generalise its findings. Sample size is small, and may not be representative of the majority of patients seen in each rehabilitation unit. Ideally, a larger prospective study, which matches SCI levels and types would be conducted. Participation scales can only be completed by those who have had opportunity to experience life in their own communities. In this study, all Canadian subjects but only two-thirds of the Nepali subjects could complete the P-scale. This is because the Canadian subjects had opportunity to experience life in their communities during the

weekend passes that are incorporated into their rehabilitation. Weekend passes are not currently part of standard practice in the Nepali rehabilitation setting, and not likely to be easily implemented due to geographical challenges. Therefore, follow-up measures of participation would be more beneficial to more accurately measure participation.

CONCLUSION

Our study outlines the importance of providing early education about complication prevention after spinal cord injury, since they often occur before patients arrive on rehabilitation units. Acute care settings and primary care providers should be targeted in efforts to improve education, and coordination of referral to rehabilitation centres. The study also demonstrates differences in activities and participation in the two settings, which are related to contextual factors such as environment and available resources. It is therefore inevitable that one should examine health care systems, when attempting to assess care for disabled populations. In order to improve activities and participation in the SCI population, changes would be required in health care provision, as well as societal factors.

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