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ORIGINAL ARTICLE

Follow-up study of spinal cord injured patients after discharge from inpatient rehabilitation in Nepal in 2007

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Study design: Observational cohort study.
Objectives: To evaluate ongoing health and community reintegration of patients with spinal cord injury (SCI) after discharge from inpatient rehabilitation in Nepal.
Setting: Nepal.
Methods: This study follows a cohort of 37 patients with SCI in Nepal, 1–2 years after discharge from inpatient rehabilitation in 2007. Participants were visited at home and data were obtained through semi-structured interviews that evaluated health, independence in daily living (Modified Barthel Index), community participation (Participation Scale) and barriers due to socioeconomic issues, housing, accessibility, and availability and use of mobility aids.
Results: One-quarter of the cohort had died (35% of wheelchair users). Secondary health concerns, such as pressure ulcers and urinary tract infections, were common in the 24 patients interviewed, and eight had been rehospitalized to treat them. Inappropriate wheelchairs, inadequate housing and rugged terrain restricted accessibility. 80% of wheelchair users could not enter their homes independently and 74% of those who were using mobility aids could not access the community independently because of the physical terrain. Of all those who were interviewed, half had no accessible toilet, access to a water source or road access to their home. Community participation was a challenge for most using mobility devices, and less than half earned any income.
Conclusion: This study identifies important areas of focus for rehabilitation centres in less-resourced contexts like Nepal to help with reintegration after discharge: vocational training during or after rehabilitation; accessible housing; wheelchairs appropriate to the terrain and the need for strong community-based rehabilitation.
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Keywords: spinal cord injury outcomes; low-resource; community participation; wheelchairs

INTRODUCTION

Spinal Cord Injury (SCI) is a particular challenge in less-resourced countries, where lack of infrastructure and medical facilities limit access to health care, rehabilitation and assistive devices. In rural Nepal and India, many patients live in remote villages where subsistence farming is the primary source of income, and where steep terrain, limited road access and inaccessible housing are often barriers to those using mobility devices.[1–6]

Green Pastures Hospital and Rehabilitation Centre (GPHRC), in Pokhara, Nepal, has been providing rehabilitation for patients with SCI since the mid 1990's,[7] and is one of the two adult rehabilitation centres in Nepal (population 30 million). Pokhara (population 250 000) is situated in the mid-west of Nepal, with employment from tourism, small businesses and government institutions. GPHRC treats patients from the western half of Nepal through referral from primary care hospitals, health centres, community health workers and self-referral. It is unknown as to what proportion of those with SCI have access to a primary or tertiary care hospitals in Nepal.

Incidence and prevalence of SCI in Nepal are unknown. Worldwide incidence of traumatic SCI ranges from 9 to 174 per million population, and prevalence from 50 to 900 per million population.[8] Thus an estimate of yearly incidence of traumatic SCI in Nepal is 300–5000, and prevalence 1500–25 000. One hospital in eastern Nepal reported 149 traumatic SCI admissions from 2001 to 2004[1] and 233 from 1997 to 2001.[2] There are no reports of numbers of non-traumatic SCI in Nepal; one Indian hospital reported that 13% of 207 SCI admissions in 2003–2004 were non-traumatic.[9]

GPHRC is a 70-bed hospital that provides rehabilitation for patients affected by leprosy, SCI, amputation, burns, cerebral palsy and other physical disabilities. The rehabilitation team includes physicians, nurses, physical and occupational therapists, orthopaedic technologists, health educators, counsellors and peer counsellors. SCI patient outcomes after discharge from rehabilitation at GPHRC have been a concern, as approximately one-third of patients were found to require readmission for treatment of secondary complications. However, because of the challenges involved in completing follow-up in rural Nepal, formal evaluation has been limited.

Without good community reintegration, patients are more likely to get secondary health complications, such as pressure ulcers (PU) and urinary tract infections (UTI), resulting in rehospitalization or even death.[4,7,10–13] Based on GPHRC patient statistics, rehabilitating a SCI patient with PU results in hospitalization costs five times greater, and length of stay at least twice as long as compared with that of a patient without PU. In the west, PU account for approximately one-quarter of the cost of care for individuals with SCI, and 7–8% die from related complications.[14]

The objective of this study was to evaluate ongoing health and community reintegration of all patients with SCI discharged in 2007

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from GPHRC at least one year post-discharge, and to evaluate barriers due to socioeconomic issues, housing, accessibility, and availability and use of mobility aids. Reported barriers may inform inpatient and community based rehabilitation (CBR) efforts in Nepal and other less-resourced countries.

MATERIALS AND METHODS

In this study, all persons with SCI discharged in 2007 from GPHRC inpatient rehabilitation were contacted for a follow-up home visit at least one year post-discharge. Medical chart review identified SCI patients discharged in 2007 (none excluded), as well as initial demographics, neurological level, completeness of injury and length of stay. All patients had been discharged home (sometimes a different house than pre-injury), as there are few other options in Nepal. Ethics approval was obtained through the research ethics boards of International Nepal Fellowship and Queen's University, Canada prior to implementation of the study, and informed consent obtained from participants.

Follow-up data were obtained through semi-structured interviews at participants' homes with a national Nepali-speaking rehabilitation staff person and the primary author. Interviews included questions about: PU, UTI, and other secondary health complications, accessibility of home and community environments, employment and financial concerns, sexuality, wheelchair and/or mobility-aid use. All participants were asked the same questions. PU were visually examined, and categorized as either stage 2 (partial-thickness) or stage 3+ (full-thickness) tissue breakdown.[14]

Quantitative measures included the Modified Barthel Index (MBI)[15] and the Participation Scale (P-Scale).[16] The MBI evaluates independence in activities of daily living (ADL) in the areas of self-care, continence and locomotion.[15] The MBI has been used in SCI populations,[7,17,18] and was measured by GPHRC at admission and discharge. The P-Scale evaluates client-perceived community participation in the domains of general tasks, communication, learning, mobility, self care, domestic life, interpersonal interactions and relationships.[16] It was developed to be cross-cultural and has been translated and validated for use in Nepal for various disabilities including SCI.[16,18] Descriptive statistics were applied to describe the quantitative measures and interview results.

RESULTS

Of the 37 individuals discharged in 2007, 9 were reported deceased by family members. Twenty-four of the remaining individuals were contacted and visited 11–27 months post discharge (cohort demographics: Table 1). Of the 37 individuals discharged in 2007, 84% had been injured through falling from heights (15 from trees, 6 from buildings, 4 from ladders/construction and 6 from hill/cliff); the remaining 6 patients each had SCI of different etiologies: motor

Table 1 Demographics of participants

	All SCI patients discharged in 2007	*Deceased*	*Re-admissions in 2007*	*All SCI patients visited*	*Wheelchair users visited*
Number of patients	37	9	7	24	15
Gender					
Male	25	8	5	14	10
Female	12	1	2	10	5
Age at admission (years)	32 (±13)	37 (±17)	30 (±20)	33 (±11)	33 (±13)
Range	13–73	19–73	13–73	14–59	14–59
Injury level					
Lumbar	12	2	2	9	5
Thoracic	17	5	3	11	7
Cervical	8	2	2	4	3
Injury type					
Complete paraplegia	19	7	2	11	10
Incomplete paraplegia	10	0	3	9	2
Complete tetraplegia	3[a]	1	0	2	2
Incomplete tetraplegia	4[a]	1	2	2	1
Time since injury until admission (years)	2 (±4)	1 (±2)	5 (±4)	3 (±4)	3 (±4)
Range	2 day to 14 yrs	2 day to 5 yrs	1 yr to 14 yrs	2 day to 14 yrs	1 wk to 13 yrs
Length of hospital stay (weeks)	12 (±10)	16 (±14)	6 (±6)	11 (±9)	11 (±8)
Range	1–42	1–42	1–19	1–28	1–28
Modified Barthel Index at admission	32 (±32)	19 (±21)	67 (±31)	34 (±34)	24 (±27)
Range	0–98	0–64	21–98	0–98	0–80
Modified Barthel Index at discharge	58 (±28)	46 (±33)	not done	67 (±23)	61 (±22)
Range	3–100	3–85	at discharge	19–100	19–82

Abbreviations: SCI, spinal cord injury; wk, week; yr, year.
Demographics of SCI patients based on GPHRC medical chart, categorized by: all discharged in 2007, those deceased, re-admissions (2007 not first admission to GPHRC), follow-up study participants and wheelchair users interviewed. Four of the original cohort could not be contacted for follow-up. Numerical data presented as: mean (± s.d.) and range. For Injury Type, complete SCI was defined as the American Spinal Injury Association (ASIA) Impairment Scale level A; all other levels were defined as incomplete SCI. For the MBI scale: 0–20 total dependence, 21–60 severe dependence, 61–90 moderate dependence, 91–99 slight dependence and 100 independent.[12]
[a]Injury type was unavailable for one tetraplegic patient.

vehicle accident, gunshot wound, spinal tuberculosis, meningitis, transverse myelitis and unknown cause. Seven patients were readmitted in 2007; of them, two had died, two could not be contacted, and three were included in follow-up (one wheelchair user, two canes). Of the 24 participants visited, 15 were wheelchair users, 4 required walking aids (1 walker, 1 crutches and 2 canes) and 5 could walk unassisted.

The nine deceased patients were somewhat older, had a longer hospital stay and lower ADL independence (reflected by MBI scores) at discharge compared with those of the entire cohort. All nine were wheelchair users; eight were male and eight had complete SCI. It was difficult to determine the cause of death, as it rarely occurred in a medical setting; however, infections, PU and possible suicide (two individuals) were reported by family and caregivers.

Secondary health complications

Secondary health complications were common amongst participants. Ten were rehospitalized because of complications after discharge (all mobility-aid users). At the time of home visit, 9 had unhealed PU; all together 13 (12 wheelchair users) had developed PU since discharge (8 had grade 3+ ulcers). Eight were readmitted to GPHRC because of PU, and one died subsequent to the interview because of PU complications. Eleven participants reported UTI since discharge, and four required hospitalization. At the time of interview, half the patients were self-voiding, six used indwelling catheters, four used intermittent catheters and two needed catheters, but were not using them because of cost or poor access to supplies.

When asked an open question about other health problems, nine reported ongoing pain and six reported problems with spasticity or contractures. Eight participants reported depressed mood, two reported sleep problems, and two reported issues with drugs and alcohol. However, most of them felt reasonably positive about their health. Half of those who were interviewed felt that their health would continue to improve, whereas only five felt that their health would worsen.

Home and community accessibility

Lack of home and community accessibility was a major barrier for most using mobility aids (Table 2). Nearly half of the participants lived in hilly areas; 79% outside the city. In all, 80% of wheelchair users could not enter their homes independently and 74% of those who were using mobility aids could not access the community independently. Six had no community wheelchair access even with assistance, because of steep terrain. Half of those who were interviewed and two-thirds of wheelchair users, had no accessible toilet, could not access a water source and had no road access to their home (three lived at a distance of >30-min walk from a road). These challenges were reflected in P-Scale scores: 79% of all participants (93% of wheelchair users) indicated 'severe' or 'extreme' restrictions to community participation. No statistical analysis was run, because of small numbers however, it appears that although the MBI may have been increased between admission and discharge, no changes in ADL independence were evident between discharge and follow-up visit.

All but two participants lived with family, and all but one reported supportive families. At the time of visit, most of the patients required a caregiver, though seven were independent for ADL. Caregivers were most frequently wives (six participants), followed by parents, including in-laws (five participants), and husbands, with help from children or siblings (four participants). Most caregivers were present during hospitalization (caregiver required for inpatient stay), and would have learned about care alongside the patient.

Table 2 Accessibility and independence

	All SCI participants	*Wheelchair users*	*Other mobility aid users*	*No mobility aid required*
Number interviewed	24	15	4	5
Time since discharge until visit (months)	20 (±4)	19 (±4)	21 (±6)	20 (±3)
Range	11–27	11–26	15–27	17–24
Modified Barthel Index at visit	70 (±28)	57 (±25)	92 (±10)	100 (±0)
Range	10–100	10–82	77–100	
Participation scale at visit	53 (±24)	63 (±16)	50 (±32)	25 (±19)
Range	0–82	20–82	4–75	0–44
Home ownership				
Own	19	12	4	3
Rent	5	3	0	2
Geography				
Hilly	11	7	1	3
Flat	13	8	3	2
Location				
City	5	3	0	2
Village	13	7	3	3
Rural	6	5	1	0
Community accessibility				
Independent	10	3	2	5
Assistance required	8	6	2	0
Inaccessible	6	6	0	0
House entrance/exit				
Independent access	12	3	4	5
Assistance required	5	5	0	0
Inaccessible	7	7	0	0
Toilet accessible to patient at home	12	6	3	3
Water source accessible to patient	11	4	3	4
Road access to house	11	6	3	2
Marital status				
Married	15	9	3	3
Unmarried	9	6	1	2

Abbreviation: SCI, spinal cord injury.
Home and community accessibility, and participant independence as reported in the follow-up home visits. Data are reported for all participants interviewed, wheelchair users, other mobility aid users and those who required no mobility aids. Numerical data are presented as mean (±s.d.) and range. For the MBI: 0–20 total dependence, 21–60 severe dependence, 61–90 moderate dependence, 91–99 slight dependence and 100 independent.[12] P-Scale scores: 53–90 extreme restriction, 33–52 severe restriction, 23–32 moderate restriction, 13–22 mild restriction and 0–12 no significant restriction.[13]

Employment

Lack of finance was a barrier for many. Six participants earned enough to support themselves (two from army pensions), four earned some income, two were in training, seven helped with tasks at home and five

were unemployed. Nearly half (11 participants) expressed financial concerns, and seven wanted training or employment. Only six mobility-device users earned any income at all. Finances were a barrier to implementing accessible solutions at home, and for eight of nine participants who had home improvements, modifications were only possible through financial assistance from local non-governmental organizations. Three wheelchair users relocated to urban areas for more accessible living, training and employment.

Sexuality

In the past few years, GPHRC staff have provided education about changes in sexual function after SCI. At the home visit, half of the participants and spouses recalled having education about sexuality, and 80% found it to be helpful. Two-thirds of married participants reported receiving education, compared with one-third of unmarried participants. Four participants (three unmarried) reported that more information would have been helpful. Half of the married participants reported continuing marital relationships after SCI. Reasons for not continuing sexual relations included concerns about birth control, lack of interest and partner's fear that they were too ill.

Wheelchairs

All wheelchair users were provided with standard folding four-wheel chairs donated by the Wheelchair Foundation. Three had replaced their wheelchairs since discharge, and seven wheelchairs were in serious disrepair. All but one were using wheelchair cushions made of poor-quality locally available foam with vinyl covers (cushions were not included with donated wheelchairs).

Based on self-report, participants spent an average of 5 h per day in their wheelchair, and only four regularly used their wheelchairs for longer than 6 h per day. Three wheelchair users could not mobilize in their wheelchairs at all, because of inaccessible home environments. The remaining time was spent primarily in bed. Two had no mattresses on wooden bed frames; the rest had mattresses made of locally available foam or cotton materials.

DISCUSSION

This study followed 37 SCI patients discharged in 2007 from GPHRC. Although the results from this study may be extrapolated to similar SCI populations, evidence is limited to the cohort measured. Many responses were self-reported, providing an indication of self-perceived reintegration, but could not be independently verified. No statistical analysis was performed because of small numbers and low statistical power. Despite these limitations, this study provides valuable insight into the outcomes after discharge with SCI in Nepal.

The demographics of the patient cohort in this study were similar to others reported in Nepal and India.[1,11,18–20] Most (89%) had traumatic SCI, similar to 87% reported in India,[9] but different from the west, where non-traumatic SCI incidence is similar to traumatic.[18,21] In the west, motor vehicle accidents are the most common cause of SCI,[8] however, in Nepal and India, falls are the most common cause (Tables 3a and b). Falls from trees often occurred when climbing for firewood or fodder for livestock. Safety precautions are rare in Nepal, and thus falling from steep paths, ladders, scaffolding, roofs and verandas is also common.

In this cohort, the mortality rate was at least 24% at follow-up; 35% amongst wheelchair users. This is similar to SCI studies in less-resourced countries: 21% in Nepal,[7] 25% in Zimbabwe,[10] but much higher than the west, where 1-year survival is 90–99%[22].

Secondary health complications

PU (54% all PU; 33% Grade 3+) and UTI (46%) were common after discharge, resulting in rehospitalization for one-third of patients. PU have been reported in about one-third of patients in less-resourced settings,[4,10,13,20] similar to an incidence of 20–31% in the west.[14] UTI were reported in 35%,[4] 44%[20] and 54%[13] of participants in other follow-up studies. In India, readmission was reported for 28%[4]–48%[20] of patients because of health complications. In both cases interventions and follow-up reduced readmissions.[4,20]

Reducing the incidence and severity of complications from PU or UTI is essential for the ongoing health of those with SCI.[4,14] Considerations such as appropriate wheelchairs, seat cushions, bed mattresses, access to catheters and their regular maintenance are important. In addition, teaching PU and UTI prevention strategies is an essential part of rehabilitation for SCI patients and their caregivers during and after hospital stay.[7]

Home and community accessibility

Lack of accessibility was a major barrier for those using mobility devices, particularly wheelchairs. Although MBI scores at discharge and follow-up indicated no decrease in ADL independence, similar to previous reports,[7] most reported 'severe' or 'extreme' restrictions to community participation based on their P-Scale scores. Many required assistance to enter their homes, to get water, for toileting and to access their communities, with heavy reliance on family and neighbours for support.

Table 3b Types of falls causing traumatic SCI in Nepal

Study	*Number of Falls*	*Falls from*				
		Tree	*Slope/cliff*	*Building*	*Ladder*	*Other*
Mid-west Nepal–current	31	48%	19%	19%	13%	
Eastern Nepal 2007[1]	90	44%	24%	17%	4%	10%
Eastern Nepal 2005[2]	181	52%	6%	36%	6%	

Falls are the most common cause of SCI in Nepal and India, and studies from Nepal were subdivided into types of fall, as a percentage of the total falls. Falls from trees, slope or cliff, building, ladder and other (vehicle roof, cart or bed) are included.

Table 3a Incidence of common causes of traumatic SCI in Nepal and India

Study	*Number of traumatic SCI*	*Falls*	*MVA*	*Conflict/Assault*	*Fall of items carried on head*	*Other traumatic*
Mid-west Nepal–current	33	31 (94%)	1 (3%)	1 (3%)		
Eastern Nepal 2007[1]	149	90 (60%)	32 (22%)	5 (3%)	14 (9%)	8 (5%)
Eastern Nepal 2005[2]	233	181 (78%)	16 (7%)		11 (5%)	25 (11%)
Southern India 2007[9]	181	122 (68%)	44 (24%)		15 (8%)	
Northern India 2003[3]	483	224 (46%)	168 (35%)	13 (3%)	17 (4%)	61 (12%)
Southern India 1986[19]	125	69 (55%)	16 (13%)		23 (18%)	17 (14%)

Abbreviations: MVA, motor vehicle accidents; SCI, spinal cord injury.
Common causes of traumatic SCI reported as number (percentage) in studies in Nepal and India. Causes include falls, MVA, conflict or assault, fall of objects carried on/supported by head or other (cave-in while digging, sports and animal-related injury).

Although it has been used elsewhere,[7,17,18] the sensitivity of the MBI to changes in SCI populations has been questioned.[17] This may suggest why no change was apparent between MBI at discharge and home visit (though it appeared sensitive to changes between admission and discharge). This measure was being used at GPHRC for all rehab patients, and was used in the follow-up to provide a comparison with their inpatient stay.

The P-Scale has been widely used to measure community participation,[23] but only a few studies report results in SCI populations. A Canadian study reported a P-Scale of 'severe' or 'extreme' restriction for 19 of 24 (79%) community dwelling participants with disabilities, including 3 with SCI,[24] the same percentage reported in this current study. Another compared the average P-Scale scores of SCI inpatients in Canada (mild restriction) and Nepal (moderate restriction).[18] The lower restriction reported may be due to the accessibility of the inpatient rehabilitation facilities, compared with the greater participation barriers experienced by patients at home.

All primary caregivers were family members, most frequently wives, as has been observed in other studies.[7,12] However, although others were often willing to help in person, only one family had independently done renovations to improve accessibility. Even simple, inexpensive solutions to improve accessibility required external advice and financial support. A study in Afghanistan found that easy home access had a significant influence on self-perceived quality of life (QOL) for those with SCI.[13] Improving home accessibility must be a priority, to allow for better reintegration of patients into their family and communities.

Employment

Employment and finances were major issues for patients after SCI, especially for those requiring mobility devices: only one-third earned any income at all. This is similar to studies in less-resourced countries that report employment rates of 13%,[10] 27%[13] and 35%.[4] In the west, it is estimated that 30–50% are employed after SCI, and that it is associated with social integration and life satisfaction.[25] In Bangladesh, a vocational reintegration program was shown to increase the employment to 50%.[12] Employment and social integration were significantly correlated with QOL after SCI in an Indian study[11].

Having no productive task or job, paid or otherwise, was a problem for one-quarter of mobility-device users in this study. Boredom and lack of purpose due to unemployment were cited as major problems for 33% after SCI in Zimbabwe.[10] Suicide and lack of community integration are more common in those who are not employed.[4] One Nepali SCI study reported that 58% of patients had been primary breadwinner before injury, and 80% were supporting over 6 people.[1] Better vocational training would be beneficial to improve outcomes after SCI[25].

Sexuality

Sexuality after SCI is a topic rarely mentioned in studies in less-resourced countries, presumably because of cultural taboos.[26] In the current study, half of the married couples reported continuing sexual relations, similar to 61% in an Indian study.[26] The Indian study reported most desired more sexual education during rehabilitation and half expressed dissatisfaction with their sex life.[26] Cordial partner relations were found to be correlated with improved QOL after SCI in another Indian study.[11] The current study supports the importance of education around sexuality after SCI for married and unmarried patients, despite cultural taboos.

Wheelchairs

There exists some consensus regarding the need for wheelchair prescription appropriate to the terrain and intended use.[27] Donated standard wheelchairs did poorly in this study. Within two years, two-thirds needed replacement. Most participants could not access their community independently in these wheelchairs, and three were not using them at all. Because cushions were not included with the wheelchair, poor-quality locally-available materials were used for pressure relief. Studies in India found standard wheelchairs 'inappropriate'[28] or 'useless'[29] in the local setting, and 71% were unused or sold.[29] Wheelchairs developed specifically for use in less-resourced, rural contexts would be much more suitable.

Summary

Persons with SCI in Nepal face many challenges after returning home from rehabilitation. This study highlighted several such problems of significance. Ongoing health is a serious issue. One-quarter of those who were discharged in 2007 had died (one-third of wheelchair users), and nearly half had been rehospitalized because of PU or UTI. Rugged terrain and inaccessible housing made access to the community difficult. Inappropriate wheelchairs further restricted accessibility, and poor-quality wheelchair cushions and mattresses made PU prevention more difficult.

Community participation was a challenge for most using mobility devices. Less than half earned any income, and one-quarter of those who were using mobility devices had no employment/tasks in the home or community. Better patient and family education, follow-up and CBR support are needed to help families and communities improve the participation of persons with SCI. All of these issues are challenges in less-resourced countries; however, measures can and are being taken to improve the situation for wheelchair users in Nepal, including training and education for CBR workers and community groups, and advocacy by those with mobility impairments themselves.

This study identifies important areas of focus for rehabilitation centres in less-resourced contexts to help with reintegration after discharge: vocational training during or after rehabilitation is necessary for many patients, accessible housing is essential and must be considered prior to discharge, appropriate wheelchairs and cushions are also necessary. This study highlights the need for strong CBR to improve accessibility and provide support to those with SCI so that they can better participate in and contribute to their families and communities.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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