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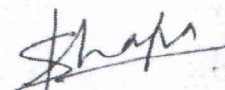
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The abstract, introduction, methods, results and discussion-sections are all fine.



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## Chronic Pain Experience and Pain Management in Persons with Spinal Cord Injury in Nepal

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<b>Abstract:</b>	<p><b>ABSTRACT</b></p> <p><b>Background and aims:</b> Chronic pain is the frequent and significantly challenging complications in persons with spinal cord injury (SCI). Socio-cultural background may lead people perceive and manage pain differently. The study aims to describe the chronic pain experience and pain management of SCI persons in Nepal.</p> <p><b>Methods:</b> A descriptive cross sectional study was conducted among purposively selected sample of 120 SCI persons with chronic pain living in the eight districts of Bagmati Zone of Nepal. The data were collected using the International Spinal Cord Injury Pain Basic Data Set Version 2 (ISCIPBDS-2) and Open-ended Pain Management Questionnaire. The data were analyzed using descriptive statistics and content analysis method.</p> <p><b>Results:</b> The back (n=84), lower legs/feet (n=63) and buttocks/hips (n = 51) was found as the common pain locations. In common, the onset of pain was found within the first six month of the injury. Overall pain intensity and pain interference were found to be at the moderate level. The SCI persons used pain medications and non-pharmacological pain management. Ibuprofen was the commonly used pain medication and commonly used non-pharmacological pain management methods included physical support (e.g., massage, exercise), relaxation (e.g., distraction, substance abuse), coping (e.g., acceptance, praying), and traditional herbs.</p> <p><b>Conclusions:</b> SCI persons had chronic pain experience which interfered with their daily living. They used pain medications and non-pharmacological pain management methods based on their beliefs, knowledge, and community resources in Nepal.</p> <p><b>Implications:</b> This study provides some evidence to help the team of rehabilitation professional to plan and help SCI persons with chronic pain. Based on these findings, chronic pain management intervention for SCI persons should be developed and supported continuously from hospital to home based community context of Nepal.</p>



## Chronic Pain Experience and Pain Management in Persons with Spinal Cord Injury in Nepal

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### HIGHLIGHTS

- Persons with spinal cord injury (SCI) in Nepal had chronic pain experience and pain interfered with daily activity, mood and night sleep.
- SCI persons used several pain management methods based on their belief, knowledge, and community resources.
- Half of SCI persons used pain medications commonly bought from a pharmacy shop without doctors prescription.
- Almost all of SCI persons used non-pharmacological pain management methods such as physical support, relaxation, coping, and traditional herbs.

### ABSTRACT

**Background and aims:** Chronic pain is the frequent and significantly challenging complications in persons with spinal cord injury (SCI). Socio-cultural background

may lead people perceive and manage pain differently. The study aims to describe the chronic pain experience and pain management of SCI persons in Nepal.

**Methods:** A descriptive cross sectional study was conducted among purposively selected sample of 120 SCI persons with chronic pain living in the eight districts of Bagmati Zone of Nepal. The data were collected using the International Spinal Cord Injury Pain Basic Data Set Version 2 (ISCIPBDS-2) and Open-ended Pain Management Questionnaire. The data were analyzed using descriptive statistics and content analysis method.

**Results:** The back ( $n=84$ ), lower legs/feet ( $n=63$ ) and buttocks/hips ( $n = 51$ ) was found as the common pain locations. In common, the onset of pain was found within the first six month of the injury. Overall pain intensity and pain interference were found to be at the moderate level. The SCI persons used pain medications and non-pharmacological pain management. Ibuprofen was the commonly used pain medication and commonly used non-pharmacological pain management methods included physical support (e.g., massage, exercise), relaxation (e.g., distraction, substance abuse), coping (e.g., acceptance, praying), and traditional herbs.

**Conclusions:** SCI persons had chronic pain experience which interfered with their daily living. They used pain medications and non-pharmacological pain management methods based on their beliefs, knowledge, and community resources in Nepal.

**Implications:** This study provides some evidence to help the team of rehabilitation professional to plan and help SCI persons with chronic pain. Based on these findings, chronic pain management intervention for SCI persons should be developed and supported continuously from hospital to home based community context of Nepal.

**Keywords:** Spinal cord injury; chronic pain; pain management

## 1. Introduction

Globally, every year around 250,000 and 500,000 people suffer from spinal cord injury (SCI) with a poor survival rate in low and middle income countries [1]. The incidence rate of SCI in Asia and Middle East ranged from 14.6 to 246 cases per million [2] and the incidence of SCI in Nepal is expected to be as high as 600 to 3,500 cases annually [3].

Prevalence of chronic pain following SCI is high as around 75 percent experienced chronic pain [4] and around one third of the SCI persons with chronic pain reported severe pain [5]. Chronic pain was challenging complication that can remain throughout the life with the potential to impact heavily on the wellbeing and functioning of SCI persons [6]. It can limit physical activity of daily living, make dependence on medication and continuous care [7], develop social withdrawal [8], and lead to depressive mood as well [9,10]. Thus chronic pain management is essential in SCI persons.

There are several pharmacological and non-pharmacological managements used for managing chronic pain by the SCI persons. As a standard care, opioids, antidepressant, local anesthesia [11] or anticonvulsant [12] were found to be the common pharmacological management provided by health care providers to reduce chronic pain in SCI persons. Non-pharmacological management used or sought by the SCI persons included physical activity, hot application [6], massage [13], acupuncture [14], relaxation techniques [15] and substance [13]. Some made self-adjustments by distracting [15], seeking information, being spiritual [16], being religious [17] and accepting pain as a normal condition after SCI [15]. The effectiveness or



ineffectiveness of pain management will ultimately influence the health outcomes in SCI persons .

With the diversity in ethnicity, religion and geographical locations, variation was noted on pain threshold, pain related belief and pain management seeking behavior among Nepalese people [18]. However, the knowledge of chronic pain experience and pain management perceived by SCI persons in Nepal is limited. Therefore, this study aimed to describe the chronic pain experience and pain management in SCI persons in Nepal. Such knowledge is expected to be helpful for health care providers to understand and provide appropriate chronic pain management for SCI persons in Nepal.

## 2. Materials and methods

### 2.1 Participants and procedure

The participants ( $n=120$ ) of this descriptive study included SCI persons with chronic pain purposively selected from community of eight districts of the Bagmati Zone, Nepal. Inclusion criteria of the study included (1) aged 18 years or older, (2) can communicate Nepali language; (3) experienced persistent pain for at least three months and (4) no history of cognitive impairment.

The participants were identified through the contact detail provided by a Spinal Injury Rehabilitation Center (SIRC) in Nepal. All participants were informed in advance regarding the purpose, procedure, risk and benefits of the study through telephone. Based upon the willingness of the participants, the researcher made appointment regarding the preferred place and time to visit them.



The participants were asked to sign the informed consent and if they were not able to read or write at their own, their family witnesses were asked to sign. Data collection was conducted from January to March, 2017. Individual assessment was done by a self-report and interview at participants' preferred place (at their home or the outpatient clinic of SIRC), by the first researcher who is a Nepalese nurse.

## 2.2 Measures

**2.2.1 Demographic and SCI characteristics.** Participants were asked to provide information regarding age, gender, religion, educational level, duration of SCI, severity of injury, level of injury, health problems after SCI, employment status and sufficiency of income.

**2.2.2 International Spinal Cord Injury Pain Basic Data Set Version 2 (ISCIPBDS-2).** It is a self-report standardized tool developed by *Widerstrom-Noga et al.* [19] to assess the multiple dimensions of pain in SCI population. The validity of self-reported items has established concurrent validity. In this study, it was modified to assess the chronic pain experience in SCI persons consisting of (1) pain locations including eight principle areas, (2) a 0-10 pain intensity Numeric Rating Scale (overall pain intensity and each body location), (3) onset of pain, and (4) pain interference (a 0-10 Numeric Rating Scale). The ISCIPBDS-2 was translated from English language into the Nepali language recommended by the developer of the instrument [20].

**2.2.3 Open-ended Pain Management Questionnaire.** The questionnaire was in the form of open-ended questions developed by the researcher that includes the detail regarding (1) the pain management methods, (2) reason for using the methods, and (3) effectiveness of the methods. The interview lasted approximately for 40-50 minutes.

## The quality of measures

In this study, content validity of the measures was assessed by five experts. The scale content validity index of the ISCI-PBDS-2 and the Open-ended Pain Management Questionnaire was found to be 1.00. The intra-class correlation coefficient of the pain intensity scale was .91. The Cronbach's alpha coefficient of the pain interference scale was .85.

### 2.3 Data Analysis

Descriptive statistics was used to analyze demographic and SCI characteristics and chronic pain experience using frequencies, percentage, mean and standard deviation. Simple content analysis process was done to analyze the qualitative data from open-ended questions of pain management.

## 3. Results

### 3.1 Demographic and SCI characteristics

A total of 120 participants were recruited into the study with an average age of 33 years (*Min*=18, *Max*=65). Almost three-fourths of the participants (71.67%) were male with Hindu as the dominant religion (75.83%). Almost half of the participants attended secondary school (44.17%). Duration of injury ranged from 1 to 24 years (*Mdn*=5, *IQR*=7). More than half of the participants (56.67%) had injury at the thoracic level and one-fifth of the participants had injury at lumbar level. Complete injury had occurred in almost two third of the participants (62.50%) and ninety percent of the total participants were paraplegic. After SCI, 85.00% of them had physical complications such as urinary tract infection, constipation, spasticity and pressure sore. Sixty percent of the participants were unemployed after SCI, and almost than three-

fourths (74.17%) of all participants reported that their income were not sufficient for their daily living.

### 3.2 Chronic pain experience

Participants had pain in at least one body location. Back ( $n=88$ ), lower legs/feet ( $n=66$ ), and buttocks/hips ( $n = 51$ ) were found to be the most common pain locations. The onset of pain was found within the first six months of the injury, except for the head and frontal torso/genitals. Overall pain intensity was found to be at the moderate level ( $M = 5.12$ ,  $SD = 1.80$ ). Considering pain score of each location, the upper leg/thigh had the highest pain intensity score ( $M = 6.50$ ,  $SD = 2.39$ ) followed by buttock/hips ( $M = 6.47$ ,  $SD = 2.24$ ) (Table 1). On average, the pain interference was found to be at the moderate level ( $M = 4.58$ ,  $SD = 2.30$ ) (Table 2).



**Table 1**

Pain location, pain intensity level and onset of pain (N=120)

Locations*	Pain intensity level				Onset of pain (months)	
	Score 1-3	Score 4-6	Score 7-10	<i>M</i> ( <i>SD</i> )	≤6	> 6
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)		<i>n</i> (%)	<i>n</i> (%)
Back ( <i>n</i> =88)	22(25.00)	48(54.55)	18(20.45)	4.89(1.95)	52(59.09)	36(40.91)
Lower legs/feet ( <i>n</i> =66)	8(12.12)	24(36.36)	34(51.52)	6.32(2.36)	46(69.70)	20(30.30)
Buttocks/hips ( <i>n</i> =51)	3(5.88)	23(45.10)	25(49.02)	6.47(2.24)	30(58.82)	21(41.18)
Upper leg/thigh ( <i>n</i> =46)	4(8.70)	19(41.30)	23(50.00)	6.50(2.39)	33(71.74)	13(28.26)
Frontal torso/genitals( <i>n</i> =34)	7(20.59)	17(50.00)	10(29.41)	5.50(2.39)	11(32.35)	23(67.64)
Neck/shoulders( <i>n</i> =27)	3(11.11)	17(62.96)	7(25.93)	5.41(1.92)	14(51.85)	13(48.15)
Arms/hands ( <i>n</i> =21)	3(14.28)	14(66.67)	4(19.05)	5.10(1.94)	12(57.14)	9(42.86)
Head ( <i>n</i> = 8)	1(12.50)	4(50.00)	3(37.50)	6.13(2.80)	3(37.50)	5(62.50)
Overall ( <i>n</i> =120)	20(16.67)	72(60.00)	28(23.33)	5.12(1.80)		

Note \* one participant reported more than one location

**Table 2**

Pain Interference level (N=120)

Variables	Pain interference level				<i>M</i> ( <i>SD</i> )
	None (0)	Score (1-3)	Score (4-7)	Score (8-10)	
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	
Day to day activity	8(6.67)	30(25.00)	66(55.00)	16(13.33)	4.78 (2.44)
Overall mood	8(6.67)	25(20.83)	66(55.00)	21(17.50)	4.80 (2.48)
Night sleep	22(18.33)	35(29.17)	38(31.67)	25(20.83)	4.18 (3.16)
Overall					4.58 (2.30)



### 3.3 Pain management

Participants used pain medication and/or non-pharmacological management method to reduce their chronic pain. Fifty percent of SCI person used pain medications and ninety six percent of them used non pharmacological pain management methods. Detail regarding each has been mentioned below.

#### Pain medications

SCI persons who used pain medications said that most of them bought pain medications from a pharmacy shop without doctor's prescription (96.00%). The common reason of use pain medications was to reduce intolerable pain. Commonly used pain medication included Ibuprofen ( $n = 31$ ), unknown medications ( $n = 18$ ), topical pain relieving gel ( $n = 13$ ), Gabapentin or opioid ( $n = 7$ ). A 14 years old male with paraplegia stated:

*"I have been using pain killers since I got SCI. It is easily available in the pharmacy. It saves time to go to the hospital. ...I usually take two tablets at once for intolerable pain, however it doesn't work completely..."*

#### Non-pharmacological pain management

Non-pharmacological pain managements were used by participants themselves, family member and a traditional healer. The common reasons of using non-pharmacological pain management were to relieve a temporary or long term pain, divert the mind away from suffering and be safe from undesirable effects of pain medications. The non-pharmacological pain management methods were (1) physical support, (2) relaxation, (3) coping, and (4) traditional herbs.

**Physical support.** The physical support was the most common method used by SCI persons to relief severe pain. Physical support included (1) massage (42.50%), (2) exercise (34.17%), (3) rest and sleep (18.33%), (4) heat compression (15.00%), (5) change positioning (15.00%), (6) use of *patuka* (homemade belts) (5.00%), (7) deep breathing exercise (2.50%), and (8) eating food or drinking water (2.50%). Following are the statement revealed by the participants for physical support:

*"Massage helps to provide warmth to the painful area. It improves blood circulation ...and provides pain relief to some extent. I am afraid of taking drugs and its side effects. I heat mustard oil in the bowl.. I put some fenugreek seed in the bowl heat it until it is roasted black, allow it to cool and then apply it in the leg and back".*  
[a 26 years old female with paraplegia]

A 35 year old male paraplegic participant stated *"Exercise helps for relaxation of body, improves appetite and sleep. It helps to divert mind away from unpleasant thought"*.

Some participants wrap a hot brick with thick clothes to relief pain. As one participant stated:

*"In winter...for the severe pain. I put a brick in the chulo [homemade mud stove heated] until it gets hot. I wrap the hot brick with thick clothes, and then apply it on my back or wherever the pain is. Its pressure and warmth provides relief for long period of time."* [a 37year old male with paraplegia]

Homemade belt (*patuka*) was used by participants to support back pain. A paraplegic woman stated:

*"This back pain is always present. I use patuka for my back pain. I wrap the shawl firmly around my waist before I go to sleep."*

Deep breathing exercise was also done by participant themselves. A quadriplegic participant said:

*"I inhale air deeply and exhale air slowly around 1 to 2 minutes. I repeat the procedure .... It helps me a lot to deal with severe and intolerable pain."*

**Relaxation.** Some participants used the distraction (e.g., work, internet) (21.67%) or substance abuse (i.e., alcohol drinking and smoking) (8.33%) for diverting mind from pain suffering and promoting sleep. One participant said:

*"I drink alcohol usually during severe pain. This has been proven as a holy water for me. I can sleep well and feel better after drinking it."*

**Coping.** The participants had pain permanently although they tried using all the methods. They used acceptance and tolerance (8.33%) and meditation and praying (1.67%) as a coping method. One of the participants with paraplegia from past 10 years said:

*"I don't have any option left rather than tolerating this pain. I am helpless of trying all the methods for this dead body. This pain is permanent and I know that it will remain throughout my life."*

One Hindu respondent said:

*"I know this pain is permanent. Praying helps to cope with pain and everyday suffering. I am helpless since I don't have money to go to the hospital and show it to the doctor."* [A 23 years old female with paraplegia]

**Traditional herbs.** Four percent of participants used oral or incisional traditional herbs from traditional healer to relief their chronic pain because of their belief on traditional herbs and failure of other previously used pain management methods. A forty-two years male with paraplegia stated:



*"I have tried a lot of methods.... Use of herbs has been proven to be providing best pain relief among all....my wife bought a baidhya (traditional healer). He made multiple small incisions at my back and applied herbs paste ... pain was decreasing....very effective especially for this burning leg pain relief"*

#### **4. Discussion**

##### **4.1 Chronic pain experience**

In this study, the common onset of pain was found within the first six month of the injury. This finding was consistent with previous studies [9,21]. Similarities are noted between current study findings and to that of previous studies [5,22] where back and lower legs was identified as the common pain location. Majority of the participants in this study had SCI at thoracic and lumbar level, this could have given pain in the lower legs/feet, since distal lower extremities were identified as the commonly reported pain locations among persons with injury at thoracolumbar level [21]. Moreover, it has been assumed that back and lower body pain were perceived more frequently possibly because they are more likely to be neuropathic in origin. However, this interpretation remains speculative in the absence of data classifying pain as neuropathic versus nociceptive in this study [23]. Furthermore, SCI persons in Nepal were found using seriously despaired wheelchair and low quality foam or cushions [24]. This could have exerted more pressure on their back. Since, several mechanical factors such as muscle weakness and straining produced by prolonged sitting [25], activity and positioning [26] were found contributing to the back pain among the SCI persons.



This study finding in regard to moderate level of pain intensity was consistent with previous studies [5,22,27]. The moderate level of pain intensity in this study could be due to the pain mechanism, secondary complications and an inadequate or inappropriate use of pain management methods.

Chronic pain has a negative impact on basic activities of daily living because higher pain intensity was associated with higher pain-related fatigue which influenced pain related interference with daily activities [7]. Furthermore, severity and chronicity of pain was higher at night than during the daytime that could have caused a disturbance in sleep among the SCI persons [28]. Sleep disturbance occurs as a result of a change in serotonergic neurons which resulted in hyperalgesia, thus interfering with the mood of the persons with chronic pain [29].

#### **4.2 Pain management**

Consistent with a previous study [30], half of the participants in this study used pain medications to reduce their intolerable pain. Ibuprofen was the most commonly used pain medication in this study since it is readily available in a pharmacy and it is a commonly used drug in Nepal [31]. This finding was consistent with the study done in Nepal among general population where self-medication and use of non-prescribed drugs were commonly practiced [32].

However, use of pain medications was lower than non-pharmacological pain management methods [13]. This result was possibly caused due to the lack of knowledge on the use of pain medication, disability associated and medical expense. Some participants stated the unsafe profile of pain medications, e.g., resistance to drugs, fear of drug dependency, side effects of drugs, and inability to afford the cost of pain medications. Consistently, previous studies showed that pain medications were

1  
2  
3 perceived to be ineffective, unwanted side effects [30,33], and cost effective among  
4  
5 SCI persons [33]. A previous study done among persons with disability, expressed  
6  
7 their limitation to go to hospital for checkup to get necessary primary care because of  
8  
9 their disability associated [34].  
10

11  
12 In previous study massage was done either by hands or special devices using  
13  
14 some specific technique for relief of low back pain [35], while in this study massage  
15  
16 was done either by the person with SCI themselves or with the help of family members  
17  
18 with the use of locally available mustard oil, fenugreek seed, camphor etc. without any  
19  
20 formal training. Moreover, the frequent use of exercise was possible because it is cost  
21  
22 effectiveness and could be carried out independently by SCI persons at home.  
23  
24 Participants were expected to possess some knowledge on doing general exercises,  
25  
26 since almost all of them were rehabilitated at the SIRC where exercise sessions were  
27  
28 held regularly by the health professionals.  
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30  
31 Consistent to the previous study [15,36], distraction was found to be the  
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33 common method of relaxation. Distraction was found as an alleviating factor for numb,  
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35 distending, shooting, electric, burning and pricking pain sensations in different body  
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37 locations [15], thus believed to decrease the pain intensity [36].  
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41 Coping was also performed among some participants of this study, for  
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43 example, tolerance to pain and meditation and praying. This could be because of the  
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45 dominance of Hindu people in Nepal. Hindu people view pain and suffering as a result  
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47 of their unfolding "*karma*" or an inappropriate action done in the past or present.  
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49 Therefore, Hindu people usually endure pain and cope well with the situation [37].  
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51 Furthermore, spiritual faith has been taken as a positive coping mechanism in relieving  
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chronic pain in SCI [17]. Consistently, prayer helped to accept the reality and cope with the stressful situation among SCI person in Tehran [16].

Unlike to the developed countries the participants of this study were found using natural or homemade resources in Nepal such as hot compression (hot brick with clothes), use of *patuka*, and traditional herbs for their chronic pain relief. In Nepal, the traditional method of wrapping a homemade belt (*patuka*) around the waist is a common practice and is believed to provide spinal support for back pain relief [38]. A cross-sectional survey done in the central region in Nepal supported the hypothesis regarding the traditional use of wearing a *patuka* for the prevention of back pain among the groups of heavy workers and porters with back pain [38]. However, the mechanism of *patuka* on pain relief has rarely been known.

Moreover, Nepal is the arena for several herbal plants and ethnic medicines which are used to treat different health problems [39]. Asian traditional herbs were found alleviating cancer pain. However, an extensive evaluation of the effect of traditional Asian herbs on pain relief is lacking [40].

## 5. Conclusion

Persons with SCI had onset of pain within the first six months of the injury in at least one body location. The pain was at moderate level which interfered with their daily activity, mood and night sleep. Participants used non pharmacological management methods more than pain medications to relief their chronic pain because of belief and culture, knowledge, and community resources. Therefore, the health care providers should assess and understand the chronic pain and pain management among SCI persons in Nepal in order to plan and provide them care in a community context.



## 6. Implications

The findings of the study indicated that persons with SCI living in the community had chronic pain and this pain interfered in their daily lives. Based on the study findings, in regards to the fear of pain medications, health care providers should assess and provide pain management education of SCI persons and give continuous consultation and evaluation on chronic pain. Furthermore, most of the SCI persons in Nepal reported massage, exercise, and traditional herbs effective to minimize intolerable pain. Therefore, further evaluation of non-pharmacological pain management deserves more attention. The chronic pain management interventions should be conducted based on the cultural context of Nepal. The study was conducted at a single site with a limited sample, therefore the replication of this study with larger sample size and other settings is necessary.

### Conflict of interest

None.

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