Chronic Pain Experience, Pain Management Strategies, and Quality of Life in Persons With Spinal Cord Injury in Nepal

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I hereby certify that this work has not already been accepted in substance for any degree, and is not being concurrently submitted in candidature for any degree.

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ชีวิตของผู้บาดเจ็บไขสันหลังในประเทศเนปาล

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บทคัดย่อ

การศึกษาเชิงบรรยายแบบสหความสัมพันธ์เพื่อศึกษาประสบการณ์ความปวดเรื้อรัง กลวิธีการจัดการความปวดและคุณภาพชีวิต และความสัมพันธ์ของความรุนแรงของความปวดและผลกระทบของความปวดต่อคุณภาพชีวิตของผู้บาดเจ็บไขสันหลังในประเทศเนปาล ผู้บาดเจ็บไขสันหลังที่มีความปวดเรื้อรังถูกคัดเลือกแบบเจาะจงจำนวน 120 รายจาก 8 ตำบลของโซนเบคมาติ ประเทศเนปาล ชุดแบบสอบถามประกอบด้วย (1) ข้อมูลส่วนบุคคล สุขภาพและสิ่งแวดล้อม (2) แบบประเมินชุดข้อมูลพื้นฐานความปวดจากการบาดเจ็บไขสันหลังฉบับสากล เวอร์ชั่น 2.0 (3) แบบสอบถามการจัดการความปวด และ (4) แบบสอบถามคุณภาพชีวิตขององค์การอนามัยโลกฉบับย่อ (เวอร์ชั่นเนปาล) แบบสอบถามดังกล่าวถูกนำไปตรวจสอบความตรงโดยผู้ทรงคุณวุฒิจำนวน 5 ท่าน และความเที่ยงได้ค่าสัมประสิทธิ์ความสัมพันธ์ภายในกลุ่มของแบบวัดความรุนแรงของความปวดเท่ากับ .91 และค่าสัมประสิทธิ์อัลฟ่าครอนบาดของแบบวัดของผลกระทบของความปวด และแบบสอบถามคุณภาพชีวิตเท่ากับ .85 และ .80 ตามลำดับ สถิติบรรยาย การวิเคราะห์เนื้อหาอย่างง่ายและสถิติสัมประสิทธิ์สหสัมพันธ์ของเพียร์สันนำมาใช้ในการวิเคราะห์ข้อมูล

ผลการวิจัยพบว่า ตำแหน่งปวดที่รุนแรงสามอันดับแรก ได้แก่ (1) หลัง (2) ขาส่วนล่าง/เท้า และ(3) ก้น/สะโพก ตามลำดับ ความรุนแรงของความปวดเรื้อรังโดยรวมอยู่ในระดับปานกลาง (*M* =5.12, *SD* =1.80) ส่วนใหญ่ความปวดมักเกิดขึ้นภายใน 6 เดือนแรกภายหลังได้รับบาดเจ็บ และผลกระทบของความปวดโดยรวมอยู่ในระดับปานกลาง (*M*=4.58, *SD* =2.30)

ผู้บาดเจ็บไขสันหลังรายงานว่า ส่วนใหญ่จัดการความปวดด้วยตนเองที่บ้านเมื่อมีความปวดเกิดขึ้น วิธีการจัดการความปวดแบบไม่ใช้ยาที่พบบ่อยได้แก่ การนวด (42.50%) การออกกำลังกาย (34.17%) และการเบี่ยงเบนความสนใจ (22%) เพราะวิธีการดังกล่าวช่วยบรรเทาปวด เบี่ยงเบนจิตใจ และหลีกเลี่ยงผลกระทบของยาบรรเทาปวด ส่วนยาบรรเทาปวดที่นิยมใช้คือไอบรูโพเฟน (Ibruprofen) (25.83%) เพราะช่วยลดความปวดระดับรุนแรง ผู้บาดเจ็บไขสันหลังรายงานว่า

ประสิทธิผลของยาบรรเทาปวดสามารถลดปวดเพียงเล็กน้อย (50.67%) ส่วนวิธีการบรรเทาปวดโดยไม่ใช้ยาสามารถบรรเทาปวดได้เพียงเล็กน้อยเช่นกัน(59.52-78.94%)

คุณภาพชีวิตของผู้บาดเจ็บไขสันหลังโดยรวมอยู่ในระดับปานกลาง (*M*= 73.14, *SD* = 12.90) ความรุนแรงของความปวด และผลกระทบของความปวดมีความสัมพันธ์ทางลบต่อคุณภาพชีวิต (r= -.24, p <.01; r = -.48, p <.01, ตามลำดับ)

ผลการศึกษาครั้งนี้เป็นประโยชน์แก่ทีมสุขภาพในการให้ความรู้แก่ผู้บาดเจ็บไขสันหลังเกี่ยวกับความปวดเรื้อรัง การใช้ยาบรรเทาปวดและการจัดการผลข้างเคียงของยา การบรรเทาความปวดแบบไม่ใช้ยา และการติดตามประเมินผลความปวดอย่างสม่ำเสมอ รวมทั้งการลดผลกระทบของความปวด นอกจากนี้ควรประเมินและดูแลด้านสิ่งแวดล้อมและสุขภาพทางกายเพื่อพัฒนาคุณภาพชีวิตของผู้บาดเจ็บไขสันหลังที่มีความปวดเรื้อรังในประเทศเนปาล

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Abstract

The descriptive correlational study was conducted to examine the chronic pain experience, pain management strategies, quality of life (QoL), and the relationship of pain intensity and pain interference on the QoL in persons with spinal cord injury (SCI) in Nepal. A total of 120 SCI persons with chronic pain were purposively selected from eight districts of Bagmati Zone, Nepal. The set of questionnaires consisted of (1) Personal, Health, and Environment related Data (2) International Spinal Cord Injury Pain Basic Data Set version 2.0 (ISCIPBDS-2), (3) Pain Management Questionnaire, and (4) World Health Organization Quality of Life BREF (WHOQOL-BREF) (Nepalese version). These questionnaires were validated content by five experts. The intra-class correlation coefficient of pain intensity scale was .91 and Cronbrach's alpha coefficient of pain interference scale and WHOQOL-BREF (Nepalese version) yielded values of .85 and .80, respectively. Descriptive statistics, simple content analysis, and Pearson's Product-moment Correlation were used to analyze data.

The results found that the three worst pain locations were (1) back, (2) lower legs/feet and (3) buttocks/hips, respectively. Overall chronic pain intensity was found at a moderate level (M=5.12, SD =1.80). The onset of pain was commonly found within the first six months of injury. Overall pain interference was found at a moderate level (M=4.58, SD =2.30).

The majority of persons with SCI reported that they managed pain by themselves at home whenever pain started. Non-pharmacological management methods, including massage (42.50%), exercise (34.17%), and distraction (22 %), were commonly used because these methods relieve pain, divert mind, and avoid negative impacts of pain medications. Ibuprofen (25.83%) was commonly used pain medication because it relieved severe pain. The persons with SCI reported that the effectiveness of pain medications was slightly better on pain relief (50.67%) and non-pharmacological pain management methods were also slightly better on pain relief (59.52% -78.94%).

The overall QoL of persons with SCI was found to be at a moderate level (M=73.14, SD =12.90). There was a significant negative correlation of pain intensity and pain interference on QoL (r= -.24, p <.01; r = -.48, p <.01, respectively).

The results of this study are beneficial for healthcare providers to provide education regarding chronic pain, use of pain medications and their side effects management; use of non-pharmacological pain management, regular pain follow up and evaluation, and reduction of pain interference. Moreover, the environment and physical health should be assessed and supported to improve QoL in SCI persons with chronic pain in Nepal.

Acknowledgement

First and foremost, I would like to express my sincere gratitude and appreciation to my advisor Asst. Prof. Dr. Luppana Kitrungrote who has always guided me to the right tract with her valuable suggestions. Her feedbacks, hard work and patience have always inspired me to learn more and perform better in every possible way. I also would like to express my heartfelt gratitude to my co-advisor Dr. Jintana Damkliang, who equally has encouraged and guided me throughout the study period with her valuable suggestions. My sincere appreciation goes to the chairperson of International Program of Masters of Nursing Science, Assoc. Prof. Dr. Waraporn Kongsuwan for her kind support, personal space, and motivating me to finish my study on time. A special thanks to all the lectures at the Faculty of Nursing, Prince of Songkla University, for their willingness to guide me and answer my every questions.

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Chapter 1

Introduction

Background and Significance of the Problem

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 (World Health Organization [WHO], 2013). The incidence rate of SCI in Asia and Middle East ranged from 14.6 to 246 cases per million (Furlan, Sakakibara, Miller, & Krassioukov, 2013). Based upon the systematic review done in developing countries, the incidence of SCI in Nepal is expected to be as high as 600 to 3,500 cases annually (Rahimi-Movaghar et al., 2013).

SCI has the potential to impact various facets of an individual including physical, psychological, social, and economic in acute and in long-term phase (WHO, 2013). The physical impact of SCI includes partial or complete loss of motor or sensory function below the injury level (Barker et al., 2009; Somers, 2010). Around 20-30% of persons with SCI are at the risk of developing depression that worsens the functioning and overall state of health (WHO, 2013). Persons with SCI tend to have poor family and social participation, unemployment, loss of earnings, which lead to financial burdens to the individuals, their family and a nation's economy (Singh, Dhankar, & Rohilla, 2008; WHO, 2013). Therefore, the cost of neurological disability of SCI is high affecting various facets of an individual's well-being (WHO, 2013).

Among numerous impacts of SCI, pain is found to be the complicated problem after SCI (Lofgren & Norrbrink, 2012; WHO, 2013). In particular, chronic pain in the forms of neuropathic and nociceptive source is a common problematic condition found (Siddall & Loeser, 2001). Chronic pain is a constant or intermittent pain that persists throughout the course of a person life (Bryce et al., 2012; Smeltzer, Bare, Hinkle, & Cheever, 2010). Therefore, chronic pain is a significantly challenging secondary complication with potential to impact heavily on the well-being and functioning of persons with SCI (Lofgren & Norrbrink, 2012; WHO, 2013).

Previous studies showed that the prevalence of chronic pain in SCI accounted in around 66 to 75 % (Ataoglu et al., 2013; Modirian et al., 2010). The onset of chronic pain in SCI is commonly seen within the first six months after injury (Celik, Erhan, & Lakse, 2012; Cruz-Almeida, Felix, Martinez-Arizala, & Widerstrom-Noga, 2009).The most common pain locations included shoulders, low back, and legs (Molton et al., 2009). The pain intensity of SCI persons was at moderate to severe level (Cruz-Almeida et al., 2009; Molton et al., 2009; Raichle, Hanley, Jensen, & Cardenas, 2007), since pain intensity is based on the level of injury, severity of injury and type of pain associated (Ullrich, Jensen, Loeser, & Cardenas, 2008). Persons with SCI described their pain as burning, shooting, aching, sharping, throbbing, stabbing, electric, penetrating or stinging (Cruz-Almeida et al., 2009; Modirian et al., 2010). The pain intensity moderately interfered with the activities of daily living (Hanley, Raichle, Jensen, & Cardenas, 2008; Jensen et al., 2010). Moreover, chronic pain intensity and pain interference were found correlating negatively with quality of life (QoL) in persons with SCI (Ataoglu et al., 2013; Jensen, Chodroff, & Dworking, 2007). Thus, management of chronic pain experience is necessary to prevent negative outcomes.

According to the Symptom Management Model (SMM), the goal of the management of symptoms is to minimize the symptom experience through multidisciplinary team including self-care strategies (Dodd et al., 2001). There are several pharmacological and non-pharmacological managements used for managing chronic pain by the health care providers and/or by the persons with SCI themselves (Heutink, Post, Wollaars, & Van Asbeck, 2011). As a standard care, ketamine, gabapentin (Amr, 2010), antidepressant, local anesthesia, opioids (Attal, Mazaltarine, Perrouin-Verbe, & Albert, 2009), antiepileptic (Sadosky, Parsons, Emir, & Nieshoff, 2016) were found to be the common pharmacological management provided by health care providers to reduce chronic pain in persons with SCI. However, a lower preference for pharmacological management was found in some persons with SCI because of the short duration of pain relief (Cardenas & Jensen, 2006), inadequate pain relief, medication failure (Henwood & Ellis, 2004), and fear of drug dependency (Wen et al., 2013).

Consequently, several non-pharmacological management used by the persons with SCI included physical activity, hot application (Lofgren & Norrbrink, 2012), massage (Heutink et al., 2011), acupuncture (Pannek, Pannek-Rademacher, & Wollner, 2015), relaxation techniques (Wen et al., 2013), accepting the reality, seeking information, being spiritual (Babamohamadi, Negarandeh, & Dehghan-Nayeri, 2011), and substance abuse (Heutink et al., 2011). However, some SCI did not seek treatments because they considered pain as a normal condition after SCI (Wen et al., 2013). The SMM has mentioned that symptom management strategies could influence on symptom experience and outcomes such as QoL (Dodd et al., 2001).

Quality of life; one of the eight outcomes of the SMM, is a multidimensional and broad ranging concept which includes an individual’s perception and personal belief on physical, psychological, social aspects, and their relationship to the environment (WHO, 1997). Previous studies found that persons with SCI had a lower QoL across all domains (Barker et al., 2009; Guest, Tran, Middleton, & Craig, 2014) with physical as the most compromised domain (Barker et al., 2009; Hu, Mak, Wong, Leong, & Luk, 2008).

Based upon the SMM, symptom experience, symptom management strategies, and outcome are influenced by personal, health and illness, and environmental factors (Dodd et al., 2001). Findings from Western countries on chronic pain experience, pain management strategies, and QoL in persons with SCI have limited generalizability to persons with SCI in Nepal. This is because the culture, beliefs, geographical diversity, health care service, and socioeconomic status in Nepal have been constructed differently from western contexts. Nepal, a country with majority of the Hindu people usually accept the pain and suffering as the consequence of an inappropriate action done in the past or present (Whitman, 2007). Nepal has a wide range of diversity in cultures and ethnic communities with their own distinct healing practices (Adhikari, 2011). With the diversity in ethnicity, religion and geographical location, variation was noted on pain threshold, pain-related belief among Nepalese people. Furthermore, this diversity was perceived as difficulty in providing appropriate management strategies in persons with pain conditions (Timcocksonoi, 2015). In western countries, health care services are secured by the government with special provisions of insurance and other facilities for disabled people (Ridic, Gleason, & Ridic, 2012), while in Nepal, little is known about special provision for persons with SCI. In addition, the centralized health care system (Shah, Shrestha, & Subba, 2013), geographical diversity of the country, and low socioeconomic status of people make treatment seeking behavior more challenging for people (Timcocksonoi, 2015). All above mentioned personal and environmental factors may influence the pain perception, pain management strategies, and the QoL in persons with SCI in Nepal. Moreover, the knowledge of chronic pain experience, pain management strategies, and QoL in persons with SCI in Nepal is limited. Therefore, this study aimed to describe chronic pain experience, pain management strategies, and the QoL in persons with SCI in Nepal. Such knowledge is expected to be helpful for health care providers to provide appropriate chronic pain management interventions and enhance QoL in persons with SCI in Nepal.

Objectives of the Study

There were four main objectives of this study.

1. To describe the chronic pain experience in persons with SCI in Nepal including location, intensity level, onset of three worst pain problems and pain interference level.
2. To describe the pain management strategies in persons with SCI in Nepal.
3. To examine the level of quality of life in persons with SCI in Nepal.
4. To examine the relationship of pain intensity and pain interference on the quality of life in persons with SCI in Nepal.

Research Questions

There were four main research questions of this study.

1. What are the chronic pain experience in persons with SCI in Nepal including location, intensity level, onset of three worst pain problems and pain interference level?
2. What are the pain management strategies in persons with SCI in Nepal?
3. What is the level of quality of life in persons with SCI in Nepal?
4. What is the relationship of pain intensity and pain interference on the quality of life in persons with SCI in Nepal?

Conceptual Framework of the Study

The Symptom Management Model (SMM) of Dodd et al. (2001) was adopted as the conceptual framework for this study. In addition, a literature review about chronic pain and its management in SCI and quality of life (QoL) in persons with SCI was integrated.

The SMM is composed of three dimensions including: (1) symptom experience; (2) symptom management strategies; and (3) outcomes. Detail of these three interrelated dimensions has been explained below.

Symptom experience

Symptom experience is a composite of three interactive and interrelated sub concepts including: (1) perception of symptoms, (2) evaluation of symptoms, and (3) response to the symptoms. Perception of symptoms refers to changes that an individual notices in the way he/she feels or behaves. Evaluation of the symptoms is done by making a judgment about the characteristics of the symptom experience which include severity, cause, treatability, and the effect of symptoms on their lives. Response to the symptoms includes physiological, psychological, sociocultural, and behavioral components. Understanding this interaction is essential for effective symptom management (Dodd et al., 2001).

In this study, perception of symptoms is used to guide in understanding the occurrence of chronic pain in regard to location and onset of the pain experienced by the persons with SCI within the last three months. Evaluation of the symptoms represents the pain intensity in persons with SCI. Response to the symptoms refers to the pain interference in persons with SCI.

Symptom management strategies

Symptom management strategies are dynamic and are used to delay a negative outcome by overcoming or managing the symptoms through professional health care providers or self. The management strategies include the specification of who, what, where, when, why, how much, to whom, and how (Dodd et al., 2001).

Outcomes

Outcome emerges from the symptom experience and symptom management strategies to evaluate the effectiveness of symptom management strategies. Outcome is measured based upon eight indicators: (1) functional status; (2) self-care; (3) costs; (4) quality of life (QoL); (5) morbidity and comorbidity; (6) symptom status; (7) mortality; and (8) emotional status (Dodd et al., 2001).

Moreover, the three dimensions are influenced by three nursing domains: (1) personal domain, (2) health and illness domain, and (3) environment domain (Dodd et al., 2001).

However, this study was conducted among the SCI persons with chronic pain in Nepal. These three dimensions of SMM were selected as main three variables of the study namely chronic pain experience, pain management strategies and QoL. Three domains of SMM were used for data collection and explanation of the three variables of the study. Therefore, in the present study, three domains of the SMM proposed by Dodd et al. (2001) was integrated, where symptom experience dimension (i.e. onset, intensity, location, interference), refers to chronic pain experience, symptom management strategies dimension refers to pain management strategies and outcome dimension refers to QoL in persons with SCI.

Chronic pain is a persistent or recurrent pain lasting longer than three months (Treede et al., 2015). Chronic pain in SCI occurs as a result of physiological change in spinal and supra spinal neuron which occur as a result of interaction of four main component namely neurochemical, excitotoxicity, anatomical and inflammation which occurs soon after the injury (Yezierski, 2009). Changes in anatomical, physiological and neurochemical alteration in spinal cord, brain or peripheral nerve can produce short and long term inflammatory conditions (D’Angelo et al., 2013). Neuropathic pain arises as a result of damage to the spinal cord and associated nerves (Siddall & Loeser, 2001), where nociceptive pain can occur as a result of secondary complications (Bryce et al., 2012), muscle weakness (Cardenas & Felix, 2009), decreased strength in transferring to mobility devices, and carrying out daily activities (Alm, Saraste, & Norrbrink, 2008).

As a result of this nociceptive and neuropathic source, persons with SCI reported chronic pain over multiple body locations (Ullrich et al., 2008) after the injury (Miguel & Kraychete, 2009). Intensity of chronic pain in SCI was found to be at the mild to severe levels (Cruz-Almeida et al., 2009; Molton et al., 2009) with mild to moderate level of pain interference on activities of daily living (Hanley et al., 2008; Jensen et al., 2010).

In current study, with regard to the first dimension of the SMM, namely symptom experience, chronic pain experience was assessed in terms of worst pain problems including: (1) location, (2) onset, (3) intensity, and (4) pain interference in persons with SCI.

With regard to the second dimension of SMM, namely symptom management strategies, pain management strategies were done by health health care providers and/or by the persons with SCI themselves to prevent negative pain outcomes. As a standard care, anticonvulsants, antidepressants, analgesics, opioids, muscle relaxants (Attal et al., 2009; Cardenas & Jensen, 2006; Heutink et al., 2011)**,** physical activity, hot application, massage, substance abuse, acupuncture, relaxation techniques (Heutink et al., 2011; Lofgren & Norrbrink, 2012; Pannek et al., 2015), were the common pharmacological and non-pharmacological pain management strategies used by persons with SCI with themselves or with the help of health care providers. Furthermore, persons with SCI managed their pain management strategies based upon their knowledge and belief (Babamohamadi et al., 2011; Heutink et al., 2011; Lofgren & Norrbrink, 2012). In this study, each pain management strategy was guided by specification of what, why, who, where, when, how and how effectiveness (Dodd et al., 2001).

As for the third dimension, namely outcomes, QoL was selected in this study since QoL is a multidimensional and broad ranging which includes individual’s perception on physical, psychological, social aspects, and their relationship to their environment (WHO, 1996; WHO, 1997).

According to SMM (Dodd et al., 2001), there is a bidirectional relationship of symptom experience, symptom management strategies and outcomes, therefore the relationships of chronic pain experience including pain intensity and pain interference on QoL in persons with SCI was explored in this study.

Research Hypotheses

1. There is a negative relationship between pain intensity and QoL in persons with SCI in Nepal.
2. There is a negative relationship between pain interference and QoL in persons with SCI in Nepal.

Definition of Terms

Chronic pain experience

Chronic pain experience refers to the perception, evaluation and response of persistent discomfort or unpleasant sensation in persons with SCI that lasted for more than a three-month period. This consists of the description of location, intensity, onset of the three worst pain problems and pain interference. Chronic pain experience was measured by using the International Spinal Cord Injury Pain Basic Data Set (ISCIPBDS) version 2.0 (Widerstrom-Noga et al., 2014). Higher scores of pain intensity and pain interference indicated the higher pain intensity level and pain interference level.

Pain management strategies

Pain management strategies refer to the methods conducted by persons with SCI to reduce or delay their chronic pain experience. These strategies include types of pain management (*What*), the reasons of using pain management (*Why*), used by persons with SCI themselves, or with the help from other persons to manage pain (*Who*), place for pain management received (*Where*), time of pain management done (*When*), the frequency of pain management done (*How often*), and the effectiveness of pain management (*How effectiveness*). Pain management strategies were assessed using the Pain Management Questionnaire developed by the researcher based on the SMM (Dodd et al., 2001) and the literature review on chronic pain management in SCI.

Quality of life (QoL)

QoL refers to the SCI person's perceptions regarding the physical health, psychological health, social health and environmental health perceived in the last two weeks. The QoL was assessed using the WHOQOL-BREF (Nepalese Version) where a higher score represents a higher QoL level and a lower score represents a lower QoL level (WHO, 1996).

Scope of the Study

The study was conducted among persons with SCI living with chronic pain in eight districts of the Bagmati Zone of Nepal from January to March 2017.

Significance of the Study

The result of the study provides the important information to guide health care providers to understand the chronic pain experience, pain management strategies and QoL in persons with SCI. Since few studies about pain have been conducted in Nepal, the findings of the study are expected to provide the baseline information for expanding the nursing research regarding chronic pain, pain management and QoL in persons with SCI.

Chapter 2

Literature Review

This chapter presents the literature review related to spinal cord injury (SCI), the Symptom Management Model, pain in SCI, chronic pain experience, pain management strategies, quality of life in persons with SCI, relationship between chronic pain experience and quality of life in persons with SCI, pain and pain management in Nepalese context. This literature review covers the following topics:

1. Overview of Spinal Cord Injury
2. The Symptom Management Model
3. Overview of Pain in Spinal Cord Injury
4. Chronic Pain Experience in Persons With Spinal Cord Injury
5. Pain Management Strategies in Persons With Spinal Cord Injury
6. Quality of Life in Persons With Spinal Cord Injury
7. Relationship Between Chronic Pain Experience and Quality of Life in Persons With Spinal Cord Injury
8. Overview of Pain and Pain Management in Nepalese Context
9. Summary of Literature Review

Overview of Spinal Cord Injury

Spinal Cord Injury (SCI) is a neurological disability that occurs as a result of damage to the spinal cord. In the SCI individual's sensory system, motor reflex is disturbed as a result of blockage of communication between the brain and body (Shepherd Center, 2011). In developed countries, the major etiology of SCI was road traffic accident (RTA) (Chen, Tang, Vogel, & DeVivo, 2013; Singh, Tetreault, Kalsi-Ryan, Nouri, & Fehlings, 2014), unlike fall injuries which tops the list of SCI in developing countries (Lakhey, Jha, Shrestha, & Niraula, 2005; Mathur et al., 2015). Other causes of SCI include assault and violence (Chen, Tang, Allen, & Devivo, 2015; Singh et al., 2014), suicidal tendencies (WHO, 2013), medical and surgical complications (Chen et al., 2015), gunshot or war wound (Ning, Wu, Li, & Feng, 2012) or as a result of sports and recreational activities (Rekand, Hagen, & Gronning, 2012; Singh et al., 2014).

Location of SCI

The location of SCI depends on the level of the vertebrae; therefore, the location of SCI could be cervical (C1–C8), thoracic (T1–T12) or lumbar (L1–L5) (Somers, 2010).

Cervical level injury. The cervical spine is more susceptible to injury because of poor mechanical stability. Cervical spine injuries are usually lower (Somers, 2010) and commonly involve the 5th, 6th, and 7th levels of the cervical spine (Smeltzer et al., 2010).

Thoracic level injury. Extreme violence and injury is needed to cause injury at the thoracic level because the rib cage protects the T1 to T10 vertebrae. Sensory and motor function below the level of injury is less likely to return (Somers, 2010). The

2th thoracic vertebra including the thoracolumbar junction is the most common site of injury (Smeltzer et al., 2010).

Lumbar level injury. The lumber spine is more flexible than the thoracic spine but less flexible than the cervical spine (Somers, 2010). Injuries at this level usually occur at the 1st lumbar vertebra (Smeltzer et al., 2010) and thoracolumbar junction. In addition, the cauda inguina can be damaged as a result of compression, stretching, avulsion or tearing, which is less common and sensitive than a spinal injury (Somers, 2010).

Severity of SCI

According to The American Spinal Injury Association (ASIA) Standard Neurological Classification, the severity of SCI is classified based upon the following five grades (Kirshblum et al., 2011; Somers, 2010).

Category A (complete). Complete injury refers to the lack of both motor and sensory function in the sacral segments (S4-S5).

Category B (sensory incomplete). Sensory incomplete injury refers to an intact sensory function but inhibition of motor function below the neurological level of injury (NLI) including the sacral segments S4-S5. Furthermore, there is no preservation of motor function more than three levels below the motor level on either side of the body.

Category C (motor incomplete). Motor incomplete injury is the state where the motor function below the NLI is intact with functioning of more than half of main muscle below the NLI with a muscle grade less than three.

Category D (motor incomplete). This is the state where motor function below the NLI is intact, with functioning of at least half of key muscles below the NLI. This has a muscle grade more than three.

Category E (normal). A state is said to be normal where motor and sensory function is normal in all segments.

Based upon the severity of injury, paralysis can be of two types: (1) tetraplegia, and (2) paraplegia. Tetraplegia, also known as quadriplegia, is a complete of partial loss of sensory and/or motor function in both upper and lower extremities including trunk and pelvic organs. Paraplegia is an impairment or absence of motor and/or sensory function in lower extremities including trunk and pelvis organs (Somers, 2010).

Impact of SCI

SCI has the potential to impact various facets of an individual including physical, psychological, socio-economic (WHO, 2013).

Physical impact. The physical impact of SCI includes partial or complete loss of motor or sensory function (Barker et al., 2009; Somers, 2010; WHO, 2013). Persons with SCI are at risk of developing life threatening secondary complications, such as impaired bowel and bladder function (Singh et al., 2008; WHO, 2013), urinary tract infections, deep vein thrombosis, muscle spasm, osteoporosis, pressure ulcer, respiratory complications (WHO, 2013), chronic pain (Ataoglu et al., 2013; WHO, 2013). Furthermore, persons with SCI are two to five times more possible to die prematurely than persons without SCI (WHO, 2013).

Psychological impact. A feeling of dependency (Jain, Sullivan, Kazis, Tun, & Garshick, 2007; Singh et al., 2008; WHO, 2013) is a common problem faced by the persons with SCI. It is estimated that around 20-30% of persons with SCI are at risk of developing depression that worsens the functioning and overall state of health (WHO, 2013).

Socio economic impact. Persons with SCI tend to have a poor spousal relationship and deprivation in social participation (Singh et al., 2008; WHO, 2013). The global unemployment rate following SCI is more than 60% (WHO, 2013). Unemployment, loss of earnings, and additional costs associated with the morbidity (Singh et al., 2008) lead to financial burdens on the family and a country's economy (WHO, 2013).

The Symptom Management Model (SMM)

The SMM was first introduced at the University of California, San Francisco (UCSF) School of Nursing in 1994. The SMM was influenced by the Orem's self-care model and other models from anthropology, sociology, and psychology. However, none of the models could fully address the person's role in self-care, symptom experience, management, and outcome of the person. Therefore, based upon the limitations of the previous models, the SMM was further revised by Dodd and colleague in 2001 (Smith & Liehr, 2013).

In the SMM, the symptoms refer to subjective experiences that represent the changes in the bio-psychological functioning, sensation or cognition of the person. The SMM has a bidirectional relationship with interrelated dimensions and nursing domains. The SMM consists of three interrelated dimensions and three nursing domains (Dodd et al., 2001).

Dimensions of the SMM

The three dimensions of the SMM include: (1) symptom experience, (2) symptom management strategies, and (3) outcome.

Symptom experience. Symptom experience is a composite of three interactive and interrelated sub concepts including perception of symptoms, evaluation or meaning of symptoms, and response to the symptoms (Dodd et al., 2001).

Perception of symptoms. Perception of symptoms refers to the way a person feels or behaves in response to recognizable changes in the body. Recognition of the symptom is based upon the consciousness and cognitive interpretation of information regarding the context of the particular environment and situation. Self-report of perception of symptom becomes more complex when viewed by multiple perceivers.

Evaluation of symptoms. Evaluation of the symptoms is done by making a judgment regarding the characteristics of the symptom experience which include severity, cause, treatability, and the effect of symptoms on their lives. Evaluation of the symptoms is a collection of symptoms that reflects the symptom experience characterized by the intensity, location, nature, frequency, and effect of impact. It helps to identify a threat posed by a symptom as to whether or not the symptoms are dangerous or have a disabling effect.

Response to symptoms. Response to symptoms is the patient’s feelings, thoughts or behavior that results in a perception and evaluation of the symptom. Response to symptoms includes physiological, psychological, sociocultural, and behavioral elements. There is a bi-directional relationship among the components of the symptom experience sub dimensions.

Symptom management strategies. A symptom management strategy is the dynamic process of overcoming or managing the symptoms through professional health care providers or by self-care to delay a negative outcome. Symptom management strategies can be effective by reducing or minimizing the frequency, severity and relieving the distress associated with the symptom. The management starts with the assessment of the symptom experience from the individual perspective. Assessment is followed by identification of the focus of the intervention, change of implementation, and evaluation of the outcomes and management process. The intervention strategies are targeted for one or more symptom to achieve better outcomes. The management strategies include the specifications of who, what (nature of the strategy), where, when, why, how much (intervention dose), to whom (recipient of intervention), and how (delivered) (Dodd et al., 2001).

Outcomes. Outcome emerges from symptom experience and symptom management strategies. Outcome can happen in the presence or absence of symptom management. Outcome has eight indicators which include: (1) functional status, (2) self-care, (3) costs, (4) quality of life, (5) morbidity and comorbidity, (6) symptom statues, (7) mortality, and (8) emotional status (Dodd et al., 2001).

Nursing domains of the SMM

Above mentioned three dimensions are directly and indirectly influenced by three nursing domains. First, the personal domain includes personal variables (e.g., demographic, psychological, sociological, physiological, and developmental). Second, the health and illness domain addresses health related information (e.g., risk factor, injuries or disabilities). Third, the environment domain is the context within which the symptom occurs (e.g., physical, social, or cultural) (Dodd et al., 2001).

Overview of Pain in Spinal Cord Injury (SCI)

Pain is an individual unpleasant and emotional experience related with actual or potential tissue damage (International Association for the Study of Pain [IASP], 2012). Types of pain and the mechanism of chronic pain in SCI are discussed in the following paragraph.

Types of pain

Acute pain and chronic pain are the major two types of pain. Acute pain is the indication of damage or injury which occurs differently than chronic pain and provides a useful signal that something is going wrong. Acute pain occurs in a relatively short duration and resolves with a normal healing pattern. However, chronic pain is a constant or intermittent pain that persists beyond the normal healing time or throughout the course of a person's life (Smeltzer et al., 2010). Based upon the WHO and IASP, the current version of the International Classification of Diseases (ICD) defines chronic pain as persistent or recurrent pain lasting longer than three months (Treede et al., 2015). According to the IASP in nonmalignant pain, three months is the most convenient point of division between acute and chronic pain (Merskey & Bogduk, 2002).

Mechanism of chronic pain in SCI

The exact mechanism of pain in SCI is poorly understood; however, it is often believed to occur as a result of physiological change in spinal and supra spinal neuron as an interaction of four main component namely neurochemical, excitotoxicity, anatomical and inflammation (Yezierski, 2009). Changes in anatomical, physiological and neurochemical alteration in spinal cord, brain or peripheral nerve can produce short and long term inflammatory conditions (D'Angelo et al., 2013). Furthermore, the mechanism of chronic pain in SCI can be classified into nociceptive, neuropathic, and other or unknown pain (Bryce et al., 2012).

Nociceptive pain**.** Nociceptive pain arises from an activation of nociceptors as a result of actual or threatened damage to the non-neural tissue (IASP, 2012). Nociceptive pain can arise from musculoskeletal structures and visceral organs (Bryce et al., 2012) as a result of the activation of primary afferent nociceptors, i.e. A-delta and C-fibers (Legome & Shockley, 2011).

Musculoskeletal pain. Musculoskeletal pain following SCI is a persistent or recurrent pain that arises as a result of damage, trauma or inflammation, mechanical instability, muscle spasm, and overuse of the structure, such as bones, muscles, ligaments, related soft tissues, intervertebral disc, facet joints (Bryce et al., 2012; Treede et al., 2015). A pain is said to be musculoskeletal if characterized by one or more of the following features: (1) pain increases/decreases or changes with movement or position, (2) tenderness over musculoskeletal structures on palpation, (3) presentation of pain that is consistent with the skeletal pathology on imaging, (4) pain description is dull or aching, and (5) pain is more responsive to anti-inflammatory drugs or opioids (Bryce et al., 2012).

Musculoskeletal pain in SCI could be upper extremities pain, back pain or muscle spasm. Upper extremities pain occurs as a result of increased use and load on the upper extremities while carrying out daily activities, mobility and using assistive devices (Alm et al., 2008; Irwin, Restrepo, & Sherman, 2007). Back pain occurs as a result of muscle weakness and strain caused by immobility, prolonged sitting, and limited movement (Cardenas & Felix, 2009).

Visceral pain. Visceral pain is a persistent and recurrent pain arising from internal organs of the body including the abdomen (Siddall & Middleton, 2006), thoracic, and pelvic cavities (Bryce et al., 2012; Treede et al., 2015). The pain is perceived in the somatic tissue present in skin, subcutaneous tissue, and the muscle layers of the organ. These areas have secondary hyperalgesia, i.e. an increased sensitivity to painful stimuli in areas other than the primary site. The etiology of visceral pain includes vascular mechanism (ischemia, thrombosis), inflammatory process by mechanical irritants, e.g., kidney stone, disturbance in gastrointestinal motility, alteration in nerve carrying sensation (IASP, 2012), combination of obstruction and inflammation, transferred pain from other locations, urinary tract infections, bowel impaction, and others (Treede et al., 2015).

A pain is said to be visceral if it meets one or more of the following criteria: (1) related with food intake or visceral functions, e.g., constipation, (2) tenderness over visceral structure on abdomen palpation, (3) consistency of pain presentation with visceral pathology on imaging, (4) one or more of the following descriptors including cramping, dullness, tenderness, and (5) symptoms associated with nausea and sweating (Bryce et al., 2012).

Neuropathic pain. Neuropathic pain is a pain caused by an injury or pathology associated with somatosensory nervous system (IASP, 2012). In neuropathic pain, evoked sensation (Siddall & Loeser, 2001) occurs as a result of activation of the pain signaling mechanism and sensitization at, below or above the level of injury (Hulsebosch, Hains, Crown, & Carlton, 2009). Neuropathic pain can be central or peripheral, where central pain originates from direct damage to the spinal cord and peripheral pain originates from a lesion or injury affecting the peripheral nerves, plexus, dorsal root ganglion or root including cauda equine (Finnerup & Baastrup, 2012). The IASP classification and identification of neuropathic pain is based upon location of the pain and features associated namely at-level and below-level neuropathic pain (Finnerup & Baastrup, 2012).

At-level neuropathic pain. A pain is said to be at-level neuropathic pain, when perceived anywhere within the dermatome and/or within the three dermatomes below the level of injury (Bryce et al., 2012). The pathogenesis associated with at-level neuropathic pain is associated as a result of an insult to the central somatosensory system, i.e. spinal cord, and/or as a result of insult to the peripheral somatosensory system, i.e. nerve root. At-level neuropathic pain is characterized by: (1) sensory deficit within the distribution of pain, (2) allodynia or hyperalgesia and (3) pain with one or more of the following descriptions including burning, pricking, tingling, needle and pins, sharp, squeezing, shooting, cold, and electric shock-like (Bryce et al., 2012).

Below-level neuropathic pain. Below-level neuropathic pain is located in the segment including more than three dermatomes below the neurological level of injury (NLI) (Bryce et al., 2012; Cardenas & Felix, 2009). This pain is either spontaneous or evoked and diffused caudal to the NLI (Siddall & Middleton, 2006). Characteristics of below-level neuropathic pain include: (1) sensory deficit within the area of pain, (2) allodynia or hyperalgesia within the distribution of pain (in incomplete injury), and (3) pain with one or more of the following descriptors including hot and burning, pricking, tingling, pins-needles, shooting, sharp, squeezing, cold, and electric shock-like (Bryce et al., 2012).

Other pain. Other pain types can be classified into three categories as other nociceptive pain, other neuropathic pain, and other pain (Widerstrom-Noga et al., 2014).

Other nociceptive pain. Other nociceptive pain results from direct or unrelated consequences of SCI (Widerstrom-Noga et al., 2014) such as autonomic dysreflexic, headache, migraine headache (Bryce et al., 2012; Widerstrom-Noga et al., 2014), and surgical skin incision (Bryce et al., 2012).

Other neuropathic pain. Other neuropathic pain refers to the pain located at, above or below the level of injury that results as indirect or unrelated pain to SCI (Bryce et al., 2012; Finnerup & Baastrup, 2012). Pain following thoracotomy surgery using transthoracic exposure of the spine (Finnerup & Baastrup, 2012), diabetic neuropathy, compressive mono-neuropathy, e.g., carpal tunnel syndrome (Bryce et al., 2012; Finnerup & Baastrup, 2012), pain from lumbar radiculopathy pain, central post stroke pain, multiple sclerosis, and nerve root avulsion are classified as other neuropathic pain (Bryce et al., 2012).

Other pain. Other pain is neither classified as other nociceptive pain nor as other neuropathic pain. intestinal cystitis, Type I complex regional pain syndrome, irritable bowel syndrome, and fibromyalgia without any sign of inflammation or damage to the nervous system are some of the examples of other pain (Bryce et al., 2012; Widerstrom-Noga et al., 2014).

Unknown pain. Unknown pain is not classifiable into any of the types listed above and is of unknown origin (Bryce et al., 2012; Cardenas & Felix, 2009).

In conclusion, pain in SCI is found in acute and chronic phase. Acute pain occurs in a relatively short duration and resolves with a normal healing process;

whereas, chronic pain persists beyond the normal healing time and remains throughout the person's life. Chronic pain in SCI is complicated problem and could be of neuropathic sources and/or nociceptive source. Neuropathic pain in SCI occurs as a result of damage to the spinal cord and associated nerves whereas nociceptive occurs as a result of secondary complications following SCI. Previous studies showed that prevalence of chronic pain after SCI is prevalent in around 66 to 75 % of the total SCI cases (Ataoglu et al., 2013; Modirian et al., 2010). A chronic pain is a significantly challenging complication that has potential to impact heavily on the well-being and functioning of persons with SCI (Lofgren & Norrbrink, 2012; WHO, 2013). Therefore, this study focused on chronic pain experience, pain management strategies and quality of life in persons with SCI. Details has been explained in the following section.

Chronic Pain Experience in Persons With Spinal Cord Injury

This section includes existing studies regarding the chronic pain experience, assessment of the chronic pain experience and factors related to the chronic pain experience in persons with SCI.

Existing studies regarding chronic pain experience in persons with SCI

Existing studies regarding the experience of chronic pain among persons with SCI has been reported based upon location, onset, patterns, intensity, descriptions, and pain interference.

Location of pain. Persons with SCI tend to experience pain over multiple body locations (Ullrich et al., 2008). Pain location could be both internal and external with internal as the more common (Celik et al., 2012). Pain locations include shoulder

(Molton et al., 2009; Ullrich et al., 2008), wrist/hands (Wollaars, Post, Van Asbeck, & Brand, 2007), back/lower back (Cruz-Almeida et al., 2009; Molton et al., 2009), leg (Celik et al., 2012), lower extremities (Modirian et al., 2010), pelvic girdle (Modirian et al., 2010), trunk, hip and buttocks (Henwood & Ellis, 2004). The most common pain locations included shoulders, low back, and legs (Molton et al., 2009).

Onset of pain. The onset of pain depends upon the type of pain and level of injury associated. However, chronic pain in SCI commonly begins within the first six months of the injury and less commonly after six months of injury (Celik et al., 2012; Cruz-Almeida et al., 2009; Modirian et al., 2010). Neuropathic pain develops within six months to one year of injury (Celik et al., 2012), whereas pain at the level of injury has an early onset of days or weeks. Pain below the level of injury has a late onset of months or years (Miguel & Kraychete, 2009).

Patterns of pain. Pain in SCI can be constant continuous pain with short or no break (Cruz-Almeida et al., 2009; Mann et al., 2013; Modirian et al., 2010) or intermittent pain (Modirian et al., 2010). The majority of persons with SCI described the pattern of chronic neuropathic pain for more than six months as a constant baseline of severe pain whereas only some reported intermittent episodes of pain (Henwood & Ellis, 2004).

Pain intensity. Pain intensity level of persons with SCI varied based upon the level of injury or severity of injury associated i.e. (1) with high cervical injuries, the highest pain intensities were found in the buttocks, hips, and knees, (2) with low cervical injuries, the highest pain intensities were found at the buttocks, abdomen, and legs, and (3) with paraplegia, the highest pain intensities were found at the buttocks, hips, and legs (Ullrich et al., 2008). Previous studies found that average intensity of chronic pain following SCI was found to be moderate level (Cruz-Almeida et al., 2009; Mann et al., 2013; Modirian et al., 2010; Molton et al., 2009). And two studies showed that one third of persons with SCI reported pain to be at severe level (Molton et al., 2009; Raichle et al., 2007).

***Descriptions of pain*.** Existing studies reported descriptors of pain based upon either overall chronic pain or chronic pain with neuropathic pain condition only. Almost half of the persons with SCI described their chronic pain as burning (Cruz-Almeida et al., 2009; Modirian et al., 2010) followed by shooting, squeezing or mixed (Modirian et al., 2010), aching, sharp, throbbing, stabbing, electric, penetrating or stinging (Cruz-Almeida et al., 2009). In neuropathic pain conditions in SCI, the common descriptions of pain include tingling, throbbing, tiring, hot, and burning; while others described their pain as stinging, pricking, sharp, penetrating, burning, aching, splitting, suffocating, gnawing, cramping, crushing, vicious, unbearable, numb, and cold (Celik et al., 2012; Mann et al., 2013).

Pain Interference. Chronic pain in persons with SCI was found to interfere negatively on various activities of daily living such as general activity, mood, mobility, normal work, social relationship, sleep, enjoyment of life, self-care, recreational activity, and social activities (Jensen, Hoffman, & Cardenas, 2005). In a longitudinal study done among 40 SCI cases with chronic pain, pain interference on activities of daily living was found to be at a mild to moderate level (Hanley et al., 2008). In a large scale study done among 184 SCI cases to evaluate psychometric properties of the subset of International Spinal Cord Injury Pain Basic Data Set (ISCIPBDS), pain interference on general activities, mood, and sleep was found to be at a moderate level (Jensen et al., 2010). When pain interference was assessed using the 11-point scale ranging from 0 (“does not interfere”) to 10 “completely interferes”, the pain interference scores were found to be 3.3 (Molton et al., 2009) and 3.53 (Raichle et al., 2007).

Assessment of chronic pain in SCI

Several one-dimensional and multidimensional pain assessment scales are used to assess the pain experience in persons with SCI.

One-dimensional pain assessment scales. The Visual Analogue Scale (VAS) and Numeric Rating Scale (NRS) are the well-known and widely used one-dimensional scales to measure the intensity of pain.

VAS. The VAS is widely used to assess intensity (Hawker, Mian, Kendzerska, & French, 2011) and pain unpleasantness (Bryce et al., 2007) in diverse population settings. The VAS is a single item scale composed of a horizontal line or vertical line (Hawker et al., 2011) with the usual length of 10 cm (100 mm). The anchor level varies from study to study but in general one end represents “no pain” and another end represents the “the pain as bad as it could be” or “worst imaginable pain” in the last 24 hours (Bryce et al., 2007; Hawker et al., 2011). A normative value has not been established; however, scores between 0–4 mm are considered as no pain, 5–44 mm are mild pain, 45–74 mm are moderate pain, and scores ranging 75–100 mm are considered to be severe pain. The VAS is easy to use, little training required, and administration takes less than 1 minute. Minimal translation difficulty may lead to difficulty in cross-cultural adaptation (Hawker et al., 2011). Furthermore, the VAS was found to have higher failure rates than the NRS and VRS (Bryce et al., 2007). The test-retest reliability was high among literate populations (r=.94, p<.0001) in comparison to illiterate populations (r=.71, p<.0001) (Hawker et al., 2011).

NRS. The numeric rating scale (NRS) or a Likert scale is a one-dimensional scale used to assess the intensity of pain in diverse population settings (Hawker et al., 2011) and is recommended as a first choice to assess pain intensity in the SCI population (Bryce et al., 2007). The instrument can be used either verbally or self-written. The common format of NRS is a horizontal bar/line. The NRS has ranges of 0–10, 0–20, and 0–100. However, 0-10 is common in practice. One end of the anchor of the scale is labeled 'no pain' and other end is labeled as 'worst possible pain (Bryce et al., 2007). Higher scores represent higher pain intensity. The best set of pain severity cutoff points for the worst pain problems in chronic SCI cases was found to be 1 to 3 for mild, 4 to 6 for moderate, and 7 to 10 for severe (Hanley, Masedo, Jensen, Cardenas, & Turner, 2006). Administration of the scale is easy and takes less than 1 minute (Hawker et al., 2011). The reported failure rates of the NRS were low (0 to 5.3%) (Bryce et al., 2007) and the test-retest reliability was reported to be high in both literate (r =.96) and illiterate populations (r =.95). High construct validity with the correlation ranging from 0.86 to 0.95 was seen in patients with rheumatism and other pain conditions (Hawker et al., 2011).

Multi-dimensional pain assessment scales. Multidimensional tools used to assess the chronic pain experience in persons with SCI include the McGill pain questionnaire (MPQ) and the ISCIPBDS.

MPQ. The MPQ is either an extensively long-form (LF-MPQ) or short-form (SF-MPQ) designed to evaluate sensory, affective, and evaluative aspects of pain and the intensity of pain (Bryce et al., 2007; Hawker et al., 2011). The LF-MPQ consists of 4 major subscales and 20 subclasses with 78 pain descriptors which can be scored individually or in a group (Bryce et al., 2007). Each subclass comes under four main subscale including sensory (subclasses 1–10), affective (subclasses 11–15), evaluative (subclass 16), and miscellaneous (subclasses 17–20). The SF-MPQ consists of 2 subscales with 15 words or items (11 sensory and 4 affective). The intensity of the scale is rated from 0-3, where 0 refers to "none" and 3 refers to "severe".

Furthermore the SF-MPQ scale also consists of one item for a pain intensity scale and one 10 cm VAS. The pain rating index ranges from 0 to 78 whereas the pain intensity scale ranges from 0-5. A higher score represents worse pain. Completion of the LF-MPQ takes about 20 minutes, whereas the SF-MPQ takes around 2-5 minutes for completion. No training is needed to administer the questionnaire and interpret the score; however, the administrator needs special ability to interpret each word. The Cronbach's alpha coefficient was high in one day recall (r=.81) to seven day recall (r=.59) (Hawker et al., 2011).

International Spinal Cord Injury Pain Basic Data Set (ISCIPBDS). The ISCIPBDS is a standardized tool developed in 2008 by the working group of the IASP to assess the multiple dimensions of pain in the SCI population (Widerstrom-Noga et al., 2014). With the changes in the classification scheme of SCI, a previous version was shortened and some items were changed and version 2 was developed in 2013. The updated ISCIPBDS-2 version includes information regarding: (1) the date of data collection, (2) experience of any type of pain during the last seven days including today, (3) is there any pain interference related to general day to day activity, (4) overall mood and sleep (good night's sleep) during the last seven days, (5) how many different pain problems have you had during the last seven days including today, (6) description of three worst pain problems within the last seven days, (7) location of pain, (8) type of pain (if the pain is nociceptive, neuropathic, others or unknown), (9) average pain intensity in the last seven days, (10) date of pain onset, and (11) any treatment the patient is using or receiving for any pain (Widerstrom-Noga et al., 2014).

To assess the intensity of pain, a 0-10 NRS is used where 0 represents no pain and 10 represents pain as bad as could be imagined. To assess the interference of pain, a 0-10 rating scale is used where 0 represents no interference and 10 represents extreme interference. For the date of data collection and date of pain onset, the YYYY/MM/DD format is provided and option boxes are provided to check the items that include experience of any pain, number of different pain problems, type of pain, location of pain, and receiving any treatment (Widerstrom-Noga et al., 2014).

Among the persons with chronic pain and SCI, the items and scales of the ISCIPBDS, that are used to measure interference, intensity, site(s), frequency, duration of timing, support the utility and validity of the items. The total interference scale of the ISCIPBDS demonstrated excellent internal consistency (Cronbach's alpha =.94). The validity of the worst, second worst, and the third worst pain intensity rating was strongly supported. Self-report items have established concurrent validity (Jensen et al., 2010).

ISCIPBDS-2 was used to assess chronic pain experience in this current study because of its multidimensional properties, highly supported utility and validity, and it was specifically designed to assess the pain experience in persons with SCI. Adapted version of ISCIPBDS was also used in the previous study in persons with SCI with chronic pain (Muller et al., 2017).

Factors related to chronic pain experience in persons with SCI

There are several aggravating or alleviating factors related to the chronic pain experience in persons with SCI. These could be personal, health/illness, and environmental factors.

Personal factor. Based upon study findings, age, gender, ethnicity, educational status, socioeconomic and employment status, smoking, pain related belief, pain control and coping, psychological problems, and level of independence, were identified as the personal factors related to the chronic pain experience in persons with SCI.

Age. Older age persons perceived a greater sensation of SCI pain, i.e. older the age, higher the level of pain perception (Gurcay, Bal, Eksioglu, & Cakci, 2010; Margot-Duclot, Tournebise, Ventura, & Fattal, 2009). Reduced physiologic reserve, aging body, and lowered pain tolerance could be the reasons associated with increased pain among elderly persons with SCI (Gurcay et al., 2010).

Gender. Prevalence of nociceptive pain was higher among female participants (Budh & Lundeberg, 2004). Females perceived a higher level of pain intensity, especially in the evening (p <0.05) (Celik et al., 2012). Multiple bio-psychosocial mechanisms such as hormonal and genetic factors, endogenous opioid functioning, coping ability, catastrophizing, and cultural beliefs regarding masculinity and femininity, were believed to be the reasons for greater pain sensation and severity among females (Bartley & Fillingim, 2013). However some studies could not find significant differences because of the low number of female SCI cases (Dijkers, Bryce, & Zanca, 2009).

Ethnicity. Ethnic differences may influence the physiology and coping mechanisms that may alter the differences in pain perception. Pain experiences was found to be different in terms of different cultural and ethnic contexts. African American patients reported greater pain sensitivity as a result of reduced diffuse noxious inhibitory controls on pain modulation and alterations in the pain regulatory mechanism. In contrast, Chinese patients viewed pain as a negative signal; however, they were more likely to tolerate pain and hence report less pain. This suggests that pain perception in the Western context is higher in comparison to the Eastern context (Campbell & Edwards, 2012).

Educational status. Persons with SCI with lower educational status reported slightly more pain than a person with a higher level of education (Wollaars et al., 2007). However, the chronic pain with neuropathic features was found associating independently with lower educational attainment (Torrance, Smith, Bennett, & Lee, 2006).

Socioeconomic and employment status. Socioeconomic and employment status of an individual with SCI were found as negative predictors for the onset of chronicity of pain experience. Despite the disability associated, persons who are able to adjust and work well in the workplace reported a lower level of pain (Goossens, Dousse, Ventura, & Fattal, 2009). Lower NRS scores were found among persons who had been working before the injury (Ataoglu et al., 2013).

Smoking. The use of nicotine gum was tested among smoking and nonsmoking groups. In the group of smokers who used nicotine gum, there was an increase in neuropathic and mixed form of pain. However, in the group of nonsmokers who used nicotine gum, there was a reduction in mixed form of pain (Richardson, Richards, Stewart, & Ness, 2012).

Pain-related beliefs. Pain related beliefs can occur as “catastrophizing” which leads to a negative pain outcome on the pain experience. Persons with greater catastrophizing had a greater pain experience in terms of intensity (Wollaars et al., 2007), pain interference (Hanley et al., 2006), and overall pain outcome (Molton et al., 2009).

Pain control and coping. The ability to control pain, pain coping, and acceptance of pain are important factors that influence the pain experience. The ability to control pain internally (Wollaars et al., 2007) and cope with pain (using passive coping) significantly decreased the pain intensity. Furthermore, persons with SCI with a low control over pain (Molton et al., 2009) and failure to accept the pain condition were found to negatively influence the pain experience (Wollaars et al., 2007). Acceptance of chronic neuropathic pain in persons with SCI led to lower pain intensity, less pain-related anxiety, and avoidance (Henwood, Ellis, Logan, Dubouloz, & D'Eon, 2012).

Psychological problems. Psychological problems such as anger (Henwood & Ellis, 2004; Wollaars et al., 2007), anxiety (Celik et al., 2012), depressive mood (Cruz-Almeida et al., 2009; Henwood & Ellis, 2004), stress (Henwood & Ellis, 2004), helplessness, and frustration (Henwood & Ellis, 2004; Wollaars et al., 2007) were identified as pain augmenters.

Level of independence. A low level of independence due to a SCI related disability seems to be an important indicator for the onset of chronic neuropathic pain

(Goossens et al., 2009). Furthermore, self-perception of being disabled has a negative influence on pain outcome (Molton et al., 2009).

Health/Illness-related factor. Based upon the study findings, health and illness-related factors that could influence the pain experience included the level of SCI, completeness and type of SCI, cause of SCI, nature of pain, associated complications and health problems.

Level of SCI. A lower level of lesion/injury was associated with a higher level of pain perceived. Pain was found to be more frequent and severe among participants with a lower level of injury, e.g., lumbosacral injury (Modirian et al., 2010; Wollaars et al., 2007).

Completeness and types of SCI. Persons with incomplete SCI experienced a higher level of pain sensation compared to persons with complete SCI (Modirian et al., 2010). Alternatively, a smaller difference of higher pain perception was found among complete SCI and paraplegic cases (Dijkers et al., 2009).

Cause of SCI. Persons with non-traumatic SCI reported less pain experience in comparison to traumatic SCI (Wollaars et al., 2007). Congruently, gunshot injury was a predictive factor for the severity and chronicity of pain of a person following SCI (Margot-Duclot et al., 2009). The traumatic nature of the injury could be the cause for the development of more severe pain.

Nature of pain. When the nature of pain is localized (Cruz-Almeida et al., 2009), continuous (Margot-Ducclot et al., 2009), at or below the level of injury (Modirian et al., 2010) and the pain begins early after the injury (Margot-Ducclot et al., 2009; Miguel & Kraychete, 2009), it is described as more severe in nature.

Associated complications and health problems. Persons with SCI are prone to several complications and health problems following SCI. Complications, such as pressure ulcer and infection (Margot-Duclot et al., 2009; Siddall & Middleton, 2006), were found to be triggering factors of chronic pain in SCI. Other health problems such as constipation (Cruz-Almeida et al., 2009; Henwood & Ellis, 2004; Margot-Duclot et al., 2009), muscle spasm, fatigue, and UTI can provoke more severe neuropathic or other types of pain in SCI cases (Cruz-Almeida et al., 2009; Henwood & Ellis, 2004; Margot-Duclot et al., 2009).

Environmental factors. Based upon the study findings, various environmental factors such as environmental stimuli, temporal aspects, and family environment were found to be associated factors related to the chronic pain experience.

Environmental stimuli. Several environmental stimuli such as touch, excessive heat, cold, humidified air, and changes in the weather led to an increase in pain sensation (Celik et al., 2012; Cruz-Almeida et al., 2009; Henwood & Ellis, 2004; Lofgren & Norrbrink, 2012).

Temporal aspects. A study found that the onset, severity, and chronicity of pain were higher during the night than other times of the day, i.e. morning, noon or evening (Celik et al., 2012; Rekand et al., 2012).

Family environment. An individual’s family and social environment can influence the perception and coping mechanism of persons with SCI. The comfort and care provided by the spouse and family may increase the feeling of dependency and also provoke pain as a result of stimulation of pain action mechanisms (Goossens et al., 2009).

Pain Management Strategies in Persons With Spinal Cord Injury

This section includes existing studies regarding chronic pain management strategies in persons with SCI, assessment of chronic pain management in persons with SCI, and factors related to chronic pain management in persons with SCI.

Existing studies regarding chronic pain management strategies in persons with SCI

Based upon the SMM, symptom management strategies include the specifications of what, why, how, when, where, how much, how, and to whom. Persons with SCI together with family members and health care providers work in collaboration to achieve a desired goal to relieve pain. Studies regarding chronic pain management done by persons with SCI include pharmacological pain management and non-pharmacological pain management.

Pharmacological pain management. Pharmacological management for chronic pain in SCI includes the use of analgesics, anticonvulsants, antidepressants, Nonsteroidal anti-inflammatory drugs (NSAIDs), muscle relaxants, sedatives, and standard modalities.

Analgesics. This group of drugs can be categorized as strong analgesics, weak analgesics, and other analgesics. Opioids were commonly used medications for severe chronic pain (Budh & Lundeberg, 2004; Cardenas & Jensen, 2006; Warms, Turner, Marshall, & Cardenas, 2002; Widerstrom-Noga & Turk, 2003). Opioids were found to be very effective in nociceptive pain (Budh & Lundeberg, 2004; Widerstrom-Noga & Turk, 2003). The effectiveness of pain relief was considerably better (Widerstrom - Noga & Turk, 2003) to extremely helpful (Budh & Lundeberg, 2004; Cardenas & Jensen, 2006).

Anticonvulsant. In practice, anticonvulsants were found common and effective in persons with SCI with chronic pain (Budh & Lundeberg, 2004; Heutink et al., 2011). With the use of anticonvulsant drugs, 20% of the respondents rated the effectiveness of anticonvulsant drugs from considerably better to disappearance of the pain (Widerstrom-Noga & Turk, 2003). Dilantin (Phenytoin), Gabapentin, Carbamazepine are the common forms of anticonvulsant drugs (Cardenas & Jensen, 2006). Phenytoin on pain relief was found to have little effectiveness; however, the duration of relief lasted for hours to days (Cardenas & Jensen, 2006). Gabapentin and Carbamazepine were found to relieve moderate to severe chronic neuropathic pain (Henwood & Ellis, 2004). The effectiveness of Carbamazepine on pain relief was found to be partially (Henwood & Ellis, 2004) to least effective (Cardenas & Jensen, 2006). Furthermore, oral Gabapentin together with Ketamine infusion delivered by medical staff was found effective in treating chronic pain condition in SCI without any side effects (Amr, 2010). Likewise, the use of Pregabalin, administered orally by the health care providers was found of greater improvement in neuropathic pain relief (Sadosky et al., 2016).

Antidepressants. Antidepressants were found to be moderately effective for the relief of chronic pain in SCI and the duration of relief lasted for years. Amitriptyline provided least to moderate pain relief in chronic neuropathic pain conditions in SCI (Cardenas & Jensen, 2006; Henwood & Ellis, 2004).

Nonsteroidal anti-inflammatory drugs (NSAIDs). NSAIDs are used commonly for chronic pain relief in SCI for nociceptive, neuropathic, and mixed pain (Heutink et al., 2011, Warms et al., 2002; Widerstrom-Noga & Turk, 2003). These drugs were more helpful in pain relief (Warms et al., 2002) with 20% of the participants reporting its effectiveness considerably better to disappearance of the pain (Widerstrom-Noga & Turk, 2003). Oral acetaminophen is one of the NSAIDs for pain relief used by more than 50% of chronic SCI cases (Warms et al., 2002).

Aspirin and Mexiletine are also found in practice for chronic pain relief in SCI. Oral intake of aspirin used by chronic neuropathic SCI cases was effective in relieving pain for an hour (Henwood & Ellis, 2004). Mexiletine had the greatest pain relief for severe chronic pain in SCI (Cardenas & Jensen, 2006).

Muscle relaxants. Baclofen was found effective for relief in bothersome pain and its effectiveness was rated to be moderate (Cardenas & Jensen, 2006), where the intake of diazepam was from very to extremely helpful among SCI cases with chronic pain (Warms et al., 2002).

Sedatives. The use of sedatives in persons with SCI with chronic pain relief was reported to be better to disappearance of the pain for at least 20% of the participants (Widerstrom-Noga & Turk, 2003).

Standard modalities. There are various standard modalities delivered by the health care providers for chronic pain relief in SCI. Spinal cord stimulation was found to be least helpful in relieving pain in chronic SCI cases (Warms et al., 2002). Chiropractic care in SCI cases resulted in the greatest pain relief for several days to weeks. Cranial electrotherapy stimulation was found to be effective on neuropathic pain relief in SCI (Tan et al., 2011). Other standard treatment modalities like epidural catheter and dorsal column stimulator were also used for chronic pain relief in persons with SCI (Cardenas & Jensen, 2006), however their effectiveness has rarely been studied in persons with SCI.

Non-pharmacological pain management. Non-pharmacological pain management has not been well explored among persons with SCI; therefore, non-pharmacological management is rarely included in the treatment recommendations (Lofgren & Norrbrink, 2012). Yet, in practice, compared to pharmacological management, non-pharmacological chronic pain management in persons with SCI is becoming the preferred mode of management. This may be because of the short duration of pain relief of pharmacological drugs (Cardenas & Jensen, 2006), fear of increased drug's side effects (Heutink et al., 2011), inadequate pain relief from the prescribed medication (Widerstrom - Noga & Turk, 2003) or medication failure (Henwood & Ellis, 2004). Non-pharmacological management for chronic pain in persons with SCI includes physical modalities, psychological modalities, cognitive modalities, spiritual modalities, and substance abuse.

Physical modalities. Physical modalities include physical training/activity, exercise, massage, acupuncture, heat application, body energy balancing, and balance of rest and activities.

Physical activity was common in practice and was found to be very effective (Warms et al., 2002) with 100% satisfaction with different types of chronic pain conditions in SCI (Budh & Lundeberg, 2004). Attempted self-movement (Babamohamadi et al., 2011) and increased physical activity by moving, walking, wheeling or gardening are considered to be positive coping mechanisms that are helpful in the relief of chronic neuropathic pain (Lofgren & Norrbrink, 2012). These activities reduced pain by providing a sense of psychological and physiological balance. These activities can start early in the morning under the bedclothes by a slow pace with gentle movements and stretching (Lofgren & Norrbrink, 2012).

Furthermore changing position was found effective in moderate to severe chronic neuropathic pain relief in SCI (Henwood & Ellis, 2004).

Regular exercise, aerobic and range of motion exercises (Cardenas & Jensen, 2006) were beneficial in chronic pain relief in SCI. Exercises such as wheeling, swimming, strengthening exercises, and biking were found to be positive and pleasant experiences for neuropathic pain relief which helped most of the time and the pain relief lasted for hours. Furthermore, exercise in natural surroundings helped in balancing physical and mental well-being (Lofgren & Norrbrink, 2012). Yoga was also an effective complimentary therapy (Cardenas & Jensen, 2006; Lofgren & Norrbrink, 2012) which helped in pain relief for several days (Cardenas & Jensen, 2006). A supervised exercise training program held twice weekly for nine months was found reducing pain in persons with SCI. Program included warm up (heeling and stretching), arm ergometry and resistance exercise by the therapist (Ditor et al., 2003). Another RCT done in the rehabilitation setting also found the beneficial of exercise on chronic shoulder pain relief in persons with SCI (Boldt et al., 2014).

Massage was a common intervention for pain relief among all types of chronic pain conditions in SCI (Cardenas & Jensen, 2006; Wollaars et al., 2007). Massage was reported to be less satisfying than physical training/activity (Budh & Lundeberg, 2004); however, relief and alleviation of chronic pain was greater (Cardenas & Jensen, 2006; Heutink et al., 2011) which ranged in effectiveness from good (Budh & Lundeberg, 2004) to very good and relaxing (Lofgren & Norrbrink, 2012).

Acupuncture alone was found effective in all types of chronic pain relief in SCI (Budh & Lundeberg, 2004; Heutink et al., 2011) including spasticity and pain from a UTI (Pannek et al., 2015). On average, SCI cases reported general satisfaction with acupuncture (Pannek et al., 2015). The effectiveness of pain relief was found to be better or very relaxing (Heutink et al., 2011; Lofgren & Norrbrink, 2012). However, there are no sufficient studies exploring the effectiveness of acupuncture alone in persons with SCI with chronic pain (Boldt et al., 2014).

Warmth was found to be the common means of pain relief among persons with SCI with neuropathic pain (Lofgren & Norrbrink, 2012) or in all types of chronic pain in SCI (Budh & Lundeberg, 2004; Cardenas & Jensen, 2006). Heat was found to provide less satisfaction than physical activity (Budh & Lundeberg, 2004); however, it was effective for alleviation of pain among persons with SCI with moderate to severe chronic neuropathic pain. Pain relief was for a temporary period (Henwood & Ellis, 2004), but it provided the highest relief from pain (Cardenas & Jensen, 2006). Furthermore, effectiveness of pain relief was reported from rather good to very good (Budh & Lundeberg, 2004). Among SCI cases with moderate to severe chronic neuropathic pain, warm water swimming provided temporary pain relief (Henwood & Ellis, 2004). Hot showers, saunas, hydrotherapy, hot packs, warm clothes and heaters, and a warm environment were other common forms of warm applications used for chronic pain relief in persons with SCI with neuropathic pain (Lofgren & Norrbrink, 2012).

Body energy balancing worked by keeping pain at a tolerable level (Lofgren & Norrbrink, 2012). Relaxation was the most commonly used technique among persons with SCI with neuropathic, musculoskeletal, visceral or other pain or spasm. Relaxation and body energy balancing was found to be very effective (Heutink et al., 2011) with pain relief that lasted for weeks (Cardenas & Jensen, 2006).

Balance of rest and activity can help in lessening the pain experience. Listening to our own body by identifying our own limitations and strengths, balancing between rest and activity, respecting control pain, avoiding stress as much as possible, and waking up every day with well-planned scheduled activities were found to relieve chronic neuropathic pain in SCI (Lofgren & Norrbrink, 2012).

*Psychological modalities***.** Psychotherapy was found effective in chronic pain relief in SCI. Pain relief was low (Cardenas & Jensen, 2006; Warms et al., 2002); however, psychotherapy was found to have years of relief. Hypnotic treatment was effective in minimal pain relief; however, it worked for days to weeks of pain relief in SCI cases. Self-hypnosis was also found in practice (Cardenas & Jensen, 2006).

Cognitive modalities. Internal pain control and coping, distraction, learning to live with the pain are some of the cognitive modalities used for chronic pain relief in SCI. Internal pain control and distraction by oneself was found effective in relieving moderate to severe chronic pain in SCI. Coping mechanisms, which were done by diverting the mind, going to work, smiling in front of people, positive self-statements, and humor (Henwood & Ellis, 2004), were believed to decrease the intensity of the pain (Wollaars et al., 2007). Other distraction methods like staying busy and having a good attitude, indulging in sex, movies, theater, music, surfing internet, working, being physically active or meeting friends, and being sociable were also found in practice for chronic pain relief in SCI (Cardenas & Jensen, 2006; Lofgren & Norrbrink, 2012). Distraction helped to relieve pain briefly in moderate to severe chronic neuropathic pain (Henwood & Ellis, 2004). Distraction was an alleviating factor for numbness, shooting, electric, burning, and pricking pain sensations in different body locations (Wen et al., 2013). Learning to live with the pain and accepting the situation helped in self-adjustment and was helpful in relieving chronic pain in SCI (Henwood et al., 2012; Lofgren & Norrbrink, 2012). When the situation is distressful, persons with SCI sought information by oneself or with the help from professional people and peers to prevent and solve problems to achieve self-control (Babamohamadi et al., 2011).

Spiritual modalities. Spiritual faith was taken as a positive coping mechanism in relieving chronic pain in SCI (Henwood & Ellis, 2004). Praying helped to accept the reality and cope with the stressful situation among persons with SCI. Furthermore, hope helped to accept the reality and seeking independence to cope with stressful conditions among persons with SCI (Babamohamadi et al., 2011).

Substance abuse. Substance abuse is taken as a negative coping mechanism to relieve chronic pain in SCI (Henwood & Ellis, 2004). Use of cannabis for chronic pain relief in SCI was perceived better to a large extent (Heutink et al., 2011). Inhalation of marijuana by oneself was found effective for chronic neuropathic pain relief (Henwood & Ellis, 2004; Warms et al., 2002). The effectiveness of marijuana was temporary (Henwood & Ellis, 2004). But, Warms et al. (2002) found that the persons with SCI reported marijuana to be very helpful on pain relief (Warms et al., 2002). The frequency of marijuana inhalation increased with the onset of pain and was inhaled frequently (Henwood & Ellis, 2004). Alcohol was used in SCI cases for chronic pain relief in SCI. Use of alcohol on pain relief was used to a large extent (Heutink et al., 2011).

Assessment of chronic pain management in persons with SCI

Evidence regarding assessment tools specifically designed to assess the details regarding chronic pain management in persons with SCI is limited. However, the findings of several surveys and qualitative studies have developed the questions regarding current and previous use of pharmacological and non-pharmacological pain management agents or strategies, method of delivery of agents or strategies, and the effectiveness of those agents or strategies on pain relief.

To assess the questions regarding the current and previous use of agents or strategies, the respondents were provided a list of pharmacological and non-pharmacological pain management agents and strategies with multiple choice options. The participants could select more than one item (Budh & Lundeberg, 2004; Cardenas & Jensen, 2006; Heutink et al., 2011; Wollaars et al., 2007) or fill in the open-ended questions (Budh & Lundeberg, 2004; Henwood & Ellis, 2004; Heutink et al., 2011).

The methods of delivery of strategies were assessed by a checklist or an open-ended questionnaire. Coping strategies were done by ignoring the pain and distraction by pleasant thoughts and seeing other people. Thoughts or pain coping strategies, such as ‘‘When I’m in pain, I ignore the pain.’’ and ‘‘whatever I do, I won’t be able to change anything about my pain.’’ were measured by a 6-point Likert scale, ranging from 1 (totally disagree) to 6 (totally agree) (Wollaars et al., 2007).

To assess the effectiveness of those agents and strategies on pain relief, the participant rated and reported their feelings of effectiveness of all the above mentioned management strategies on pain relief in various ways. An open-ended questionnaire was provided for the respondents to answer with the treatment that gave the best pain relief. The participants rated and reported their feelings as very good,

good, rather good, insufficient or no effect (Norrbrink & Lundeberg, 2004), no relief (0) to complete relief (10), pain treatment made their pain worse, had no effect, slightly better, considerably better or disappeared (Widerstrom -Noga & Turk, 2003), pain relief from their current pain treatment(s) 0 (not at all), 1 (somewhat), or 2 (to a large extent) (Heutink et al., 2011), 1 (not at all helpful) to 5 (extremely helpful) for their worst pain and second-worst pain (Warms et al., 2002), treatment satisfaction on a 4-grade scale (very satisfied, somehow satisfied, no success and aggravation of the symptoms), overall importance of a self-management program (1 = very unimportant, 5 = very important) (Munce et al., 2014). The questionnaire developed by Cardenas and Jensen (2006) enquired on the effectiveness of the treatment based upon a 6-point categorical length of time scale, i.e. minutes, hours, days, weeks, months, years.

The construct of the above mentioned pain management assessment tool is not consistent to the pain management strategies of the SMM; therefore, in this study open-ended pain management assessment measures were developed including some components of questionnaires from previous studies and was constructed based upon the concepts of the SMM (Dodd et al., 2001). Furthermore, the assessment tool was adjusted based upon the literature review done regarding chronic pain management.

Factors related to chronic pain management in persons with SCI

Three domains of the SMM (Dodd et al., 2001), namely personal, health and illness, and environment, were used to guide and categorize the factors related to chronic pain management in persons with SCI. Because of limited research done in factors affecting chronic pain management in persons with SCI, the studies regarding factors related to pain management in other groups of populations, such as low back pain, cancer pain, and pain in general, were reviewed.

Personal factors. Various factors such as age, gender, education, obesity, beliefs and misconceptions about pain and pain management, adjustments, and personal reluctance are the personal factors affecting chronic pain management in persons with SCI.

Age. Elderly people tend to report pain which may lead to inadequate pain management (Campbell & Edwards, 2012). Because of the decreased hepatic and plasma albumin, elderly people may have a lower analgesic response (Coldrey, Upton, & Macintyre, 2011).

Gender. Consumption of opiates, NSAIDs, and other peripherally acting drugs was higher among females. The use of NSAIDs was five times greater and the use of opiates was two times greater among females than in male participants (Budh et al., 2003). Males focused on the sensory component of pain by increasing the threshold and tolerance which resulted in a lower negative pain response. However, females focused on the emotional component which led to less coping and a negative response to pain (Keogh & Herdenfeldt, 2002). However, a meta-analysis found no significant association of gender on the prevalence of seeking care for acute and chronic low back pain (Shiri, Karppinen, Leino-Arjas, Solovieva, & Viikari-Juntura, 2010). This could be because of the low number of female SCI cases in comparison to male cases.

Education. A prospective cohort study done among 26 earthquake sustained participants found that high school graduates sought treatment for chronic pain more frequently than those in primary school or illiterate persons (Wen et al., 2013).

Obesity. Obesity has a positive impact on seeking management for chronic pain. A meta-analysis of 24 cross sectional studies found a strong association of obesity with seeking care for acute or chronic low back pain (Shiri et al., 2010).

Beliefs and misconceptions about pain and pain management. Beliefs and misconceptions regarding the condition and therapeutic management can influence pain management. Persons with SCI did not seek treatment for their condition of chronic pain because they regarded it as a normal condition after SCI (Wen et al., 2013) and they were also afraid of being drug dependent (Norrbrink, Lofgren, Hunter, & Ellis, 2012; Sun, Borneman, Piper, Koczywas, & Ferrell, 2008; Wen et al., 2013). Furthermore, the fear of side effects (Oldenmenger, Smitt, Van Dooren, Stoter, & Van der Rijt, 2009; Sun et al., 2008), fear of injection, and concern about tolerance were identified as additional misconceptions associated with analgesics among cancer survivors with a chronic pain condition (Oldenmenger et al., 2009).

Adjustments. Learning to live with pain leads to acceptance of pain, which facilitates adjustment. This leads persons to be less likely to take pain medications and more likely to have active lives despite the pain (Henwood & Ellis, 2004).

Personal reluctance. A study done on cancer pain management showed that a person's reluctance on reporting pain, scoring pain, and reluctance to take opioids can influence pain management (Oldenmenger et al., 2009).

Health and illness factor. Type of pain, therapy preference and disability were the health and illness related factors affecting pain management in persons with SCI.

Type of pain. Neuropathic pain relief responded less to opioids than nociceptive and mixed pain in persons with SCI (Budh & Lundeberg, 2004).

Therapy preference. Persons with SCI with chronic pain were not receiving adequate pain relief from prescribed medications (Norrbrink et al., 2012; Widerstrom -Noga & Turk, 2003). Furthermore, the effects of alternative therapies on pain relief were found to be longer and more effective compared to pharmacological therapy (Cardenas & Jensen, 2006).

Disability. Disability following SCI (paraplegia and quadriplegia) could limit one's ability to go to the hospital for consulting the health professionals. A study done among the rural residents, person with disability expressed their limitation to go to the hospital for periodical checkup to get necessary specialty care because of their physical limitation associated with disability (Iezzoni, Killeen, & O'day, 2006).

Environmental factors. Several factors such as communication with health care providers, health professionals' knowledge, attitudes, and practices, family environment, and insurance policy are the environmental factors affecting pain management in persons with SCI.

Communication with health care providers. Inadequate communication from the health care providers can influence pain and pain management strategies. In a qualitative study on *Patients' Perspectives on Pain*, SCI patients reported dissatisfaction regarding information about the causes and strategies of pain and pain relief from the health care providers (Norrbrink et al., 2012). A systematic review on barriers hindering adequate cancer pain management included poor communication regarding their concerns about pain with health care providers (Oldenmenger et al., 2009).

Health professionals' knowledge, attitudes, and practices. Inadequacy of health care provider's knowledge on pain assessment and basic principles of pain management was found the major impediments in managing the cancer pain (Oldenmenger et al., 2009; Sun et al., 2008). Furthermore, nursing staff reluctance to administer opioids, inadequate services regarding psychological support, lack of access to specialized professionals were also identified as the barriers on providing relief on cancer pain (Oldenmenger et al., 2009). In the other hand, a positive attitude of the health care providers (Yava et al., 2013), such as listening, responding, and respecting the patient's knowledge, experience, and desires, was found influencing the pain management and outcome of the persons with SCI (Lofgren & Norrbrink, 2012).

Family environment. Positive family environment is assumed to increase social support and better coping and life satisfaction in persons with SCI (Muller, Peter, Cieza, & Geyh, 2012). However a review article identified that the comfort and care offered by the spouse and family altered the pain coping mechanism and provoked pain. This could be because of the perceived low degree of independence to the comfort and care provided (Goossens et al., 2009).

Insurance policy. Complementary therapies were much preferred and perceived to be effective for chronic pain relief in persons with SCI. However, persons with SCI with chronic pain expressed frustration regarding the policies of insurance companies which refused to cover the costs of complementary therapies (Henwood & Ellis, 2004).

Quality of Life in Persons With Spinal Cord Injury

Quality of Life (QoL) is defined as an "individual's perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (WHO, 1997, p. 1). QoL is a broad ranging and multidimensional concept embedded in individual's physical health, psychological state, social relationships and their relationship with the environment (WHO, 1996; 1997). The upcoming section includes existing studies on QoL in persons with SCI, assessment of QoL in persons with SCI, and factors related to QoL in persons with SCI.

Existing studies of QoL in persons with SCI

SCI was found affecting the QoL in persons with SCI (Franca, Coura, Franca, Basílio, & Souto, 2011). Previous studies revealed that persons with SCI experienced a significantly lower QoL in compared to the healthy population (Arango-Lasprilla, Nicholls, Olivera, Perdomo, & Arango 2010; Barker et al., 2009; Celik, Gultekin, Beydogen, & Caglar, 2007; Guest et al., 2014; Middleton, Tran, & Craig, 2007). However, in a study done in Thailand, majority of the SCI cases reported the QoL at a fair level (73.3%), followed by good (22.4%) to poor (4.5%) QoL (Dajpratham & Kongkasuwan, 2011).

In regard to the each domain of QoL, a study done in Brazil, comparatively lower score was noted on environment health, followed by physical health, psychological health, and social health of the persons with SCI (Franca et al., 2011). In addition several studies found the largest impact on the SCI on physical health than on mental health of the persons with SCI (Guest et al., 2014; Gurcay et al., 2010; Hu et al., 2008; Trgovcevic, Milicevic, Nedovic, & Jovanic, 2014). Consistently, a study done in the Republic of Serbia found that the physical component was lower than the mental component s in persons with SCI ($p <.001$) (Trgovcevic et al., 2014).

When assessed the subdomains of QoL using SF-36, large impact was seen on the subdomains of the physical health of the persons with SCI including physical functioning, role limitation due to physical functioning and bodily pain (Middleton et al., 2007). However, some studies found no significant differences in the subdomains of the mental health of the persons with SCI including vitality (Arango-Lasprilla et al., 2010), role emotional (Trgovcevic et al., 2014; Wijesuriya, Tran, Middleton, & Craig, 2012), and mental health of the persons with SCI (Arango-Lasprilla et al., 2010; Wijesuriya et al., 2012).

In addition, the QoL in persons with SCI in Finland assessed using the 15-dimensional self-administered instrument, significantly lower score (p<.001) was found on various component of QoL including in mobility, sleeping, eating, elimination, discomfort and symptoms, usual activities, vitality, and sexual activity (Dahlberg, Alaranta, & Sintonen, 2005).

In summary, current studies revealed that the persons with SCI have a lowered QoL compared to their healthy counterparts. Lower QoL was seen mostly in the physical health than in the mental health of the persons with SCI.

Assessment of QoL in persons with SCI

The SF-36 is a widely and frequently used tool in assessing the QoL in persons with SCI followed by the WHOQOL-BREF.

Short Form-36 Health Survey (SF-36). The SF-36 is a multipurpose generic measure developed by Ware and Sherbourne in 1992. The SF-36 usually aims to quantify the health status of a general or specific group of the population. Furthermore, the SF-36 also aims to compare disease burdens and compare the benefits of a wide range of treatment varieties and screenings of an individual. The SF-36 is a single scale with 36 multiple items yielding the physical and mental health in eight health concepts: (1) two items on physical functioning (PF), (2) four items on role physical (RP), (3) two items on bodily pain (BP), (4) two items on social functioning (SF), (5) five items on mental health (MH) , (6) three items on role emotional (RE), (7) four items on vitality (VT), and (8) five items on general health (GH) (Ware & Sherbourne, 1992).

The results from these subscales contribute to the overall physical and mental health score. A Likert scale is used to rate each item. The scores of each subscale range from 0 to 100 with a total score of 0-800. Interpretation has not been established in persons with SCI; however, a higher score indicates a better health status. The length of time for the test is usually about 5 to 10 minute (Ware & Sherbourne, 1992); however, persons with SCI and paraplegia or tetraplegia may take up to 41 minutes in paraplegia and 47 minutes in tetraplegia to complete the test (Andresen, Fouts, Romeis, & Brownson, 1999**).** The recall interval is 4 weeks (Lin, Hwang, Chen, & Chin, 2007).

The SF-36 is a validated and reliable tool. The intra- and interviewer reliabilities measured by the intra-class correlation coefficients (ICCs) among chronic traumatic SCI cases ranged from 0.71 to 0.99 and the inter interviewer reliabilities were found to be fair ranging from 0.41 to 0.98. Adequate to excellent internal consistency was found across all domains of the QoL. In regard to construct validity, an excellent discriminant validity between the constructs of the physical capacity score (PCS) and mental capacity score (MCS) was established (Forchheimer, McAweeney, & Tate, 2004) and there was an establishment of excellent to adequate convergent validity of 0.32 to 0.72 (Lin et al., 2007). Despite its wide range of popularity and well established psychometric properties in persons with SCI, the SF-36 cannot be used in this current study because the instrument is not available in the Nepali language and the author does not allow outsiders to translate the instrument.

WHOQOL-BREF. The WHOQOL-BREF is a generic tool developed by the WHO to assess the QoL within an individual culture, value system, and personal goals and standards. The WHOQOL-BREF is the short version of the WHOQOL-100 and is recommended for use when time is restricted or the burden on the respondent needs to be minimized. WHOQOL-BREF consists of a total of 26 items. Two items are on the overall quality of life and general health and 24 items address four QoL domains including physical health (7 items), psychological (6 items), social relationship (3 items), and environment (8 items). To determine the raw item score, the items are rated using a 5-point Likert scale (low score of 1 to high score of 5). Domain scores are scaled in the positive direction, where a higher score indicates a higher QoL except for items 3, 4, and 26 that needed to be reversed for the scoring.

Following the WHOQOL-BREF instrument guidelines and SPSS syntax provided, the domain scores were transformed and scaled from 0 to 100 to afford comparisons of scores between the domains with unequal numbers of items. This transformation is done using SPSS syntax, where in first step it converts the scores to range from 4 to 20. The second step converts scores to range between 0 to 100 scale (Appendix B).The WHOQOL-BREF can be self-administered or administered by interview, which does not require any training for administration. The length of time for the test ranges from 6 to 30 minutes with 2 weeks of recall duration (WHO, 1996). The WHOQOL-BREF has no cut off points to determine the level of QoL, however; in the previous study done among disable women (Pensri, 2007), level of QoL was determined by dividing the result of maximum score minus minimum score by 4 ([130 ─ 26]/3) to form a number categories as high QoL for 96.00-130.00, moderate for 61.00-95.00, and low for 26.00-60.00.

The inter-rater or intra-rater reliability across all domains of the WHOQOL-BREF was found to be excellent ranging from an ICC of 0.84 to 0.98. Internal consistency of the instrument was found to be adequate to excellent. Construct validly of each domain of the WHOQOL-BREF was adequate to excellent**.** Among chronic SCI cases internal consistency of the tool was found to be adequate except for the social relationship (Lin et al., 2007). An adequate to excellent floor and ceiling effect was established (Jang, Hsieh, Wang, & Wu, 2004; Lin et al., 2007). Use of the WHOQOL-BREF in assessing the QoL in persons with SCI was less frequent in practice, yet the WHOQOL-BREF is one of the most acceptable tools with an established psychometric property used in assessing generic QoL in persons with SCI (Hill, Noonan, Sakakibara, & Miller, 2010; Lin et al., 2007). Furthermore, WHOQOL-BREF was translated in Nepalese language using Brislin's model of translation and internal consistency was tested among people living with acquired immune deficiency syndrome receiving anti-retroviral therapy in Nepal. Cronbach's alpha yielded value of .71 among all four domains of WHOQOL-BREF (Nepalese Version) (Giri et al., 2013). Therefore, WHOQOL-BREF (Nepalese Version) was used to assess the QoL in persons with SCI in this study.

Factors related to QoL in persons with SCI

Several factors related to the QoL among persons with SCI are discussed below based upon the SMM, i.e. personal, health/illness related or environmental factors.

Personal factors. Personal factors affecting the QoL in persons with SCI included age, age at injury, gender, culture, marital status, educational status, professional status, and psychological parameters.

Age. Younger people had a better QoL compared to older people (Gurcay et al., 2010; Jain et al., 2007; Kivisild et al., 2014). Elderly participants had a lower QoL on the functioning domain (Jain et al., 2007) and bodily pain which was probably because of their reduced physiologic reserve associated with an aging body or by their lower pain tolerance (Gurcay et al., 2010). Conversely the study showed a better score on all subdomains of the QoL in ages greater than 40 years old (Hu et al., 2008). Furthermore, based upon a review of 10 individual studies, the results remained inconclusive regarding whether or not the age factor impaired the QoL in persons with SCI (Ku, 2007).

Age at injury. Older people may have a reduced capacity to cope with the injury and thus there may be a negative impact on recovery. In a literature review done by Ku (2007), the majority in the study supported that being older at the age of the injury showed a lower score on the QoL. Age at injury was found to correlate negatively to the mental health score of persons with SCI (p=.008) (Celik et al., 2007). However, a study done by Middleton et al. (2007) found no significant association between the variables.

Gender. Females showed a lower QoL in comparison to males**.** The vitality (Ku, 2007; Lidal, Veenstra, Hjeltnes, & Biering-Sorensen, 2008) and mental health scores among female participants was found to be lower (Andresen et al., 2016; Ku, 2007). However, some studies found no significant association of gender on QoL in persons with SCI (p>.05) (Gurcay et al., 2010; Middleton et al., 2007). This variation in the results could be because of an unbalanced distribution of sex samples.

C*ulture.* Cultural and traditional support from relatives and family members could positively contribute to the QoL in persons with SCI. However, the details of the cultural variable on QoL have not been described sufficiently (Gurcay et al., 2010).

Marital status. Being married has proven effective in maintaining a powerful degree of life satisfaction. In a literature review done by Ku (2007), some studies showed lower vitality, role emotional, and mental health scores in persons with SCI. In another study, marital status was identified as the factor affecting some components of QoL; however, no significant differences were identified between the groups (Gurcay et al., 2010; Lidal et al., 2008).

Educational status. Higher education leads to better opportunities and employment. Low education together with physical deprivation among persons with SCI leads to deprivation from physically challenging work thus lowering the QoL in persons with SCI (Ku, 2007). Another cross sectional study showed that participants with an education level higher than high school had a significantly higher score on mental health when compared with below or high school level education (p=.032) (Gurcay et al., 2010).

Employment status. Employment status was considered an important indicator for a good QoL as this variable was strongly influenced by economic and social opportunities, as well as by age and educational level (Conroy & McKenna, 1999). A reduced QoL after SCI is not only caused by the injury but also because of the difficulties in returning to previous professional work (Kivisild et al., 2014). Being employed was identified as an important factor associated with an improved QoL among persons with SCI (Kivisild et al., 2014; Ku, 2007; Lidal et al., 2008). Full or part time job holders had significantly better outcome with better scores on physical functioning (Gurcay et al., 2010; Kivisild et al., 2014; Lidal et al., 2008), role physical

(Gurcay et al., 2010; Lidal et al., 2008), bodily pain, social functioning (Lidal et al., 2008), mood, and global functioning (Jain et al., 2007). However, in a review article done by Ku (2007), occupation alone showed no significant impact on the perceived scores of QoL. Furthermore, in contrast to its hypothesis, poor scores were found in both physical and mental components of the QoL among veterans ($p<.001$) compared to non-veterans, thus further studies in the future were recommended (Saadat et al., 2010).

Psychological parameters. Several psychological parameters such as poor coping ability (Ku, 2007), depression (Kivisild et al., 2014; Ku, 2007), anxiety, and panic (Kivisild et al., 2014) were identified as factors impairing global QoL in persons with SCI. Furthermore, persons with low self-efficacy regarding beliefs and confidence on his/her own ability had significantly lower scores on QoL (Middleton et al., 2007).

Health/illness related factors. Health and illness related factors include level of injury, severity of injury, completeness of injury, duration of injury, health complications and medical problems, history of previous hospitalization, pain intensity, and independence in activities of daily living.

Level of injury. A higher level of injury is associated with higher costs and a negative impact on the QoL in persons with SCI (Ku, 2007). Injury in the cervical region was found to influence negatively on both the physical ($p=.001$) and mental ($p=.02$) components of QoL (Saadat et al., 2010). The motor level of injury was an independent factor associated with QoL (Dahlberg et al., 2005; Jain et al., 2007; Middleton et al., 2007). Improved physical functioning were found in a descending pattern of level of injury ($p=.002$) (Celik et al., 2007).

Severity of injury. A SCI person with paraplegia has a comparatively higher QoL than a tetraplegic person (Gurcay et al., 2010; Ku, 2007; Lidal et al., 2008; Trgovcevic et al., 2014). Paraplegic SCI cases acquired a significantly higher score than tetraplegic cases on the physical functioning (p<.05) (Gurcay et al., 2010; Lidal et al., 2008; Middleton et al., 2007), role physical (p <0.01), social functioning (p <.01), and role emotional (p <.01) (Gurcay et al., 2010). Likewise, persons with tetraplegia exhibited a higher score on role emotional (Lidal et al., 2008).

Completeness of injury. Several studies showed that completeness of injury had a negative correlation with the QoL in persons with SCI (Dahlberg et al., 2005; Hu et al., 2008; Jain et al., 2007; Kivisild et al., 2014; Lidal et al., 2008). Complete injury cases affected the physical functioning (Lidal et al., 2008), general (p=.031) and environmental domains (p=.036) in persons with SCI (Hu et al., 2008).

Duration of injury. Time duration since injury was correlated positively with the physical functioning (p=.01) (Celik et al., 2007). A longer time duration since injury was associated (p=.01) with a better physical QoL (Saadat et al., 2010).

Health complications and medical problems. The presence of secondary conditions was identified as the single most important predictor lowering the QoL in persons with SCI (Barker et al., 2009). Health complications and medical problems associated with SCI were found to be factors lowering the QOL in persons with SCI (Ku, 2007). In persons with SCI for more than 20 years of duration, the participants in the ‘no health problem’ group scored significantly higher in the majority of the subscales compared with participants with “health problem(s)” (Lidal et al., 2008). Various health complications that affected QoL included bowel and bladder incontinence, spasticity (Gurcay et al., 2010; Ku, 2007*)*, pressure ulcer *(*Ku, 2007;

Lourenco, Blanes, Salome, & Ferreira, 2014), and sexual dysfunction (Ku, 2007). Likewise, medical problems that lowered QoL included pain (Celik et al., 2007), fatigue (Wijesuriya et al., 2012), insomnia (Kivisild et al., 2014), and respiratory problems such as chronic cough and phlegm, persistent wheezing, and dyspnea. These medical problems interfered with daily activities of living, such as talking, eating (Jain et al., 2007), dressing, moving, and exercising, thus lowering the QoL in persons with SCI (Lourenco et al., 2014).

History of previous hospitalization. Persons with SCI with a previous experience of hospitalization had better QoL compared to persons with SCI who never had a past experience of hospitalization (Ku, 2007).

Independence in activities of daily living. A higher QoL was found among the SCI participants who were able to get around more independently with the help of assistive aids, such as crutches or canes and manual or motorized wheelchairs, than in participants walking without any assistance (Jain et al., 2007). The inability to perform self-catheterization was identified as a factor impairing body image, self-esteem, and perceived loss of independence which lowered the QoL in persons with SCI (Ku, 2007).

Environmental factors. Environmental factors include technology, and physical and social dysfunctions.

Technology. A prospective cohort study (N=60) showed that the frequency of surfing the internet increased with the onset of SCI. Furthermore, there was a significant reduction in bodily pain and improvement in overall physical aspects of QoL among the internet users group compared to the non-internet users group (p<.05) (Celik et al., 2014).

Societal participation and social support. Societal participation was identified as the second most important predictor for a lower QoL in persons with SCI (Barker et al., 2009). Increased social support was found to be positively related with better physical and mental health, coping, adjustment and life satisfaction, and overall functioning in individuals with traumatic spinal cord injury (Muller et al., 2012).

Relationship Between Chronic Pain Experience and Quality of Life in Persons With Spinal Cord Injury

This section includes the relationship of pain intensity on QoL in persons with SCI and relationship of pain interference on QoL in persons with SCI.

Relationship of pain intensity on QoL in persons with SCI

Intensity of chronic pain was found associated with greater impairments in a number of important QoL domains (Jensen et al., 2007; Middleton et al., 2007). SCI cases with high pain intensity had a significantly lower QoL than those with lower pain intensity for almost all domains of the SF-36 (Middleton et al., 2007). In regard to the each domain, a significant negative correlation was found between the NRS and bodily pain (r= - .237), physical functioning (PF) (r=.201) in persons with SCI (Ataoglu et al., 2013). The total SF-36 score, including bodily pain, was found to significantly correlate negatively in the intensity score during noon and evening. When the correlation of the daily intensity pattern and SF-36 was assessed, a significantly moderate positive correlation of role emotional was observed with the VAS intensity score in the morning (r=.317), noon (r=.467), evening (r=.419), and night (r=.373) (Celik et al., 2012). When the correlation between the pattern of daily pain intensity and SF-36 was assessed, the total SF- 36 score was significantly correlated with noon (*r*=.292) and evening pain intensity (*r*=.332) (Celik et al., 2012).

In a prospective cohort study done among earthquake survivors in China, a significant negative correlation was found in total QoL score (*r*=-.27, *p*<.01) and almost all domains of the WHOQOL including overall QoL rating (*r*=-.24, *p*<.01), overall health satisfaction (*r*=-.32, *p*<.05), psychological health (*r*=-.25, *p*<.01), and environmental (*r*=-.26, *p*<.01); however the study could not explore the significant correlation of WHOQOL-BREF with physical health (*r*=-.20, *p*>.05) and social health (*r*=-.15, *p*>.05) (Wen et al., 2103). Likewise in an another study done among participants with other types of chronic pain condition such as multiple sclerosis and fibromyalgia, the NRS pain intensity scale had a significant negative effect on all domains of QoL except for social health (Douglas, Wollin, & Windsor, 2009). However the, presence of chronic pain was found to provide a negative impact on psychological functioning and social integration in persons with SCI (Jensen et al., 2005). Furthermore, the study done by Wen et al. (2013) recommended an exploration of the correlation of chronic pain with related outcomes in the SCI population.

Relationship of pain interference on QoL in persons with SCI

Chronic pain intensity was found strongly associated with interference of a number of important basic activities of daily living. As pain becomes severe, it can have a substantial negative impact on daily activities such as sleep, mood, mobility, and self-care, thus affecting psychological functioning and social integration (Jensen et al., 2005). Furthermore, a change in pain interference was found in changing the status of the QoL in persons with SCI. The most affected domain of QoL by a change in pain interference included overall life satisfaction, physical health, and mental health (Putzke, Richards, Hicken, & Devivo, 2002). However, there are limitations in the studies that examine the relationship of pain interference on QoL in persons with SCI or persons with other chronic pain conditions. Therefore, this study also aims to provide new knowledge examining the relationship of pain interference on QoL in persons with SCI.

Overview of Pain and Pain Management in Nepalese Context

The following section includes the incidence and prevalence of pain in Nepal, perception of Nepalese people on pain, health practices of Nepalese people on pain management, and barriers to the accessibility of health care services in Nepal.

Incidence and prevalence of pain in Nepal

A first ever epidemiological study was done among general people with pain living in the single district of Nepal. Half of the total participants of the study had pain, and almost ninety-four percent of them had chronic pain problem. The most common reported painful condition included: backache (25.8%), headache (20.1%) and peptic related abdominal pain (12.5%) (Bhattarai et al., 2007).

Perception of pain in Nepalese people

Nepal is a Hindu dominant country. Hindu people view pain and suffering as a result of their unfolding "*karma*" or an inappropriate action done in the past or present. Therefore, Hindu people usually endure pain and cope well with the situation (Whitman, 2007), unlike Western cultures where people may need greater reassurance from their health care providers even for minor symptoms (Carteret, 2011).

Health practices of pain management in Nepalese people

Nepal has a wide range of diversity in ethnicity, culture, and languages with more than 103 ethnic communities with their own distinct healing practices (Adhikari, 2011). The majority of people believed in traditional healers and try all other ways of pain management before visiting a hospital (Timcocksonoi, 2015). Consequently, a cross sectional study done in Nepal found that one-fifth of the populations sought services from traditional healers because of the high costs associated with modern medicine and the availability of the traditional healers at a low cost (Bhattarai, Parajuli, Rayamajhi, Paudel, & Jha, 2015). When treatment seeking practices for chronic pain among the economically active population in Nepal were assessed, the majority of the people went to health posts or hospitals. The remaining sought help from faith healers (13.7%), nearby medicine shops (13%), self-medication (1.3%), herbalist (0.6 %) or homeopathy (0.2%). Common medications included the use of NSAIDs, antacids, and Paracetamol (Bhattarai et al., 2007). In Nepal, the traditional method of wrapping a *patuka* (a special piece of cloth) around the waist is a common practice and is also effective in relieving back pain. The *patuka* is believed to provide spinal support (Shah, 1994). A 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 (Shah, 1994). Moreover, Nepal is the arena for several herbal plants and ethnic medicines which are used to treat different health problems. Furthermore, the people of the *Tamang* caste possess a rich knowledge on ethno-pharmacology (Uprety, Asselin, Boon, Yadav, & Shrestha, 2010).

Barriers to the accessibility of health care services in Nepal

Geographically, the terrain of Nepal is divided into three distinct belts: the mountains, the hills and the plains. Because of the geographical diversity and predominance of mountainous regions, transportation facilities are challenging in large parts of the country (Government of Nepal Ministry of Health, 2017). In Nepal, health care systems are centralized (Shah et al., 2013). Around 90% of the total population living in the rural areas need to walk for several days to reach a town (The University of British Columbia, n.d). Accessibility to modern medication is challenging in both the rural as well as in urban communities (Adhikari, 2011), while in developed countries health care services are secured by the government by issuing insurance coverage and special provisions for disabled people (Ridic et al., 2012).

Since the personal and environmental factors of Nepal have been constructed differently in terms of culture, beliefs, socioeconomic status, geographical diversity, health care system, and others, the findings from Western countries have limitations for generalization in the context of Nepal. Dodd et al. (2001) stated that symptom experience, symptom management strategies, and outcome are influenced by personal, health and illness, and environmental factors.

Summary of Literature Review

Chronic pain is a persistent or recurrent pain lasting longer than three months. The classification of chronic pain in SCI includes nociceptive and neuropathic. The onset of chronic pain in SCI commonly develops within the first six months of the injury where pain intensity was found to be at moderate to the higher end of moderate level on average. Pain can be at multiple sites; however, the most common locations of pain include the shoulders, low back, and legs. The patterns of pain can be both constant and intermittent with burning, stabbing, throbbing, and tingling as the common pain descriptors. Pain interference was found to be at mild to moderate levels. There are several widely available pharmacological therapies for chronic pain management in SCI among which are anticonvulsants, antidepressants, analgesics, opioids, and anti-spasticity agents. Common non-pharmacological pain management included physical modalities, psychological modalities, behavioral modalities, substance abuse, and other standard treatments. When compared to healthy adults, the QoL in persons with SCI was found to be lower with a large effect on the physical health component. The intensity of pain was also found to affect several domains of the QoL in persons with SCI.

The three dimensions of the SMM, i.e. symptom experience, symptom management, and outcomes, are influenced by personal, health/illness, and environment factors. Therefore, the findings from studies done in Western countries may not totally fit the Nepalese context. Furthermore, there is a limited number of studies regarding the chronic pain experience, pain management strategies, and QoL in persons with SCI in Nepal. Therefore, an understanding of the chronic pain experience, pain management strategies, QoL, and an exploration of the relationship of the chronic pain experience on QoL is needed in persons with SCI in Nepal.

Chapter 3

Research Methodology

This chapter presents the research design, setting, population and sample, instruments, validity and reliability of the instruments, data collection procedure, ethical considerations, and data analysis.

Research Design

A descriptive correlational study was used to describe the chronic pain experience, pain management strategies, and QoL in persons with SCI and to assess the relationship of pain intensity and interference on QoL in persons with SCI in Nepal.

Setting

The study was conducted in the eight districts of Bagmati Zone; namely: (1) Kathmandu; (2) Bhaktapur; (3) Lalitpur; (4) Dhading; (5) Rasuwa; (6) Sindhupalchowk; (7) Kavrepalanchok; and (8) Nuwakot (Figure 1).

Population and Sample

Target population

The target population of this study included persons with SCI living with chronic pain in eight districts of the Bagmati Zone, Nepal.

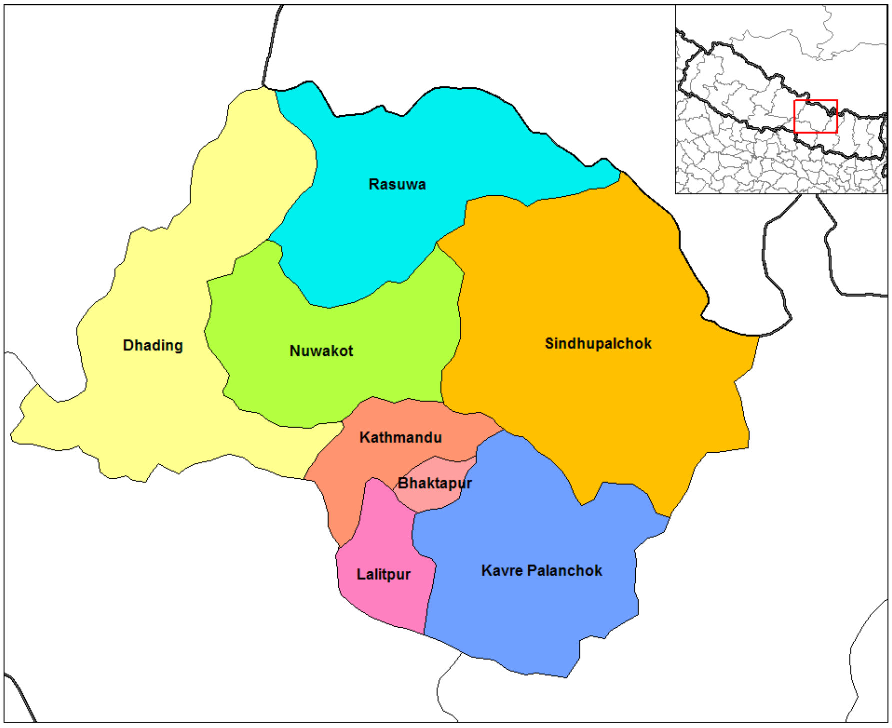

Figure 1. Map of Bagmati Zone, Nepal

Sampling technique

The participants were selected on the basis of purposive sampling technique. The inclusion criteria of the samples were: (1) age ≥ 18 years, (2) able to communicate and understand the Nepali language, (3) experienced persistent pain for more than a three-month, and (4) no cognitive impairment.

Sample size

The sample size was estimated using power analysis based upon a previous study entitled "Spinal cord injury-related chronic pain in victims of the 2008 Sichuan earthquake: a prospective cohort study" (Wen et al., 2013). The study found that Pearson's correlations of the pain scale were significantly negatively correlated on the WHOQOL-BREF QoL total score (r= - .27, p= .001) (Wen et al., 2013). According to Polit and Beck (2012, p. 425), using an effect size of r= .30 with the accepted alpha (α) of .05 and power of .80, the minimal sample size of 88 was required. However, to increase the power of the study a total of 120 persons with SCI with chronic pain were included in this study.

Instruments

Data collection instruments

Data collection instruments in this study consisted of four sets of questionnaire including: (1) Personal, Health and Environment Related Data (PHED), (2) International Spinal Cord Injury Pain Basic Data Set version 2.0 (ISCIPBDS-2), (3) Pain Management Questionnaire (PMQ), and (4) WHOQOL-BREF (Nepalese Version).

Personal, Health and Environment related Data (PHED). The PHED was developed by the researcher based upon the literature review on chronic pain experience, pain management strategies, and QoL in persons with SCI. The PHED consisted of three sections (Appendix D). First, the personal characteristics consisted of age, gender, religion, marital status, level of education, employment status before and after injury, sufficiency of income, smoking and alcohol habits. Second, health related characteristics included age at injury, date of injury, completeness of injury, severity of injury, level of injury, cause of injury, health problems after SCI, and previous trauma related pain experience. Third, environmental characteristics included family type, number of family members, availability of assistive aids, place of residence, resources, and access to technology. Participants were interviewed to obtain personal health related and environmental characteristics. Furthermore, personal and health related data were obtained from medical records from the centers and/or available with the participants.

International Spinal Cord Injury Pain Basic Data Set version 2.0 (ISCIPBDS-2). The ISCIPBDS-2 was used to assess the chronic pain experience in persons with SCI. The ISCIPBDS-2 is composed of the following items: (1) pain interference, (2) number of different pain problems, and (3) description of the three worst pains which includes the location, type, intensity, date of pain onset, and receiving any treatment for the pain problem (Appendix E). Based upon the validator's suggestion, two items from the ISCIPBDS-2 were deleted for this study. First, an item regarding the type of pain was deleted because it was not appropriate as a self-report measure and a clinician was needed to differentiate between neuropathic pain and nociceptive pain (Jensen et al., 2010). Second, the item regarding any treatment being received for the pain problem was deleted because the details regarding treatment were asked in the Pain Management Questionnaire. In addition, the single item 0-10 numeric pain rating scale (0-10 NRS) was added to assess the average pain intensity of overall pain in one week.

To assess pain locations, a checklist was provided to locate the three worst pain site into eight principal areas: (1) head, (2) neck/shoulders, (3) arms/hands, (4) frontal torso/genitals, (5) back, (6) buttocks/hips, and (7) upper legs/thighs, (8) lower legs/feet. Each of the pain locations was further divided into more precise locations where persons with SCI were asked to check the three worst pain location with an indication of the site if right, midline, and/or at left side (Widerstrom-Noga et al., 2014).

For assessment of the pain intensity of three worst pain locations and overall pain intensity, a 0-10 NRS was provided to rate an average pain intensity in the last one week, where 0 meant no pain to a maximum of 10 that meant pain as bad as you can imagine (Widerstrom-Noga et al., 2014). Later, the pain intensity level of the three worst pain problems and overall pain were classified as mild (1.00-3.99), moderate (4.00-6.99), and severe (7.00-10.00) (Hanley et al., 2006).

To assess the onset of pain, the participants needed to specify the date when three worst pain problems started in an open response format including year, month and day (YYYY/MM/DD). Participants needs to specify date in approximation if unknown (Widerstrom-Noga et al., 2014). Later response categories were created in terms of onset of pain relative to the date of injury which included within the first six months of injury or more than more months following the injury.

For assessment of pain interference level, a 0-10 NRS was used to assess the average pain interference on day to day activities, overall mood and a good night's sleep in the last one week, where 0 meant no interference to a maximum of 10 that meant extreme interference (Widerstrom-Noga et al., 2014). The pain interference level was classified as mild (1.00-3.99), moderate (4.00-7.99), and severe (8.00-10.00) (Hanley et al., 2006).

Pain Management Questionnaire (PMQ). The PMQ was used to assess the pain management strategies of the persons with SCI. The PMQ was developed by the researcher based upon the SMM (Dodd et al., 2001) and the literature review on pain management in persons with SCI. The questionnaire was in the form of open-ended questions that includes the detail regarding pain management strategies conducted by the persons with SCI to reduce or delay their chronic pain experience. These strategies include types of pain management (*What*), the reasons of using pain management (*Why*), used by persons with SCI themselves, or with the help from other persons to manage pain (*Who*), place for pain management received (*Where*), time of pain management done (*When*), the frequency of pain management done (*How often*), and the effectiveness of pain management (*How effectiveness*). To assess the effectiveness (*How effectiveness)*, participants were asked to rate the perceived effectiveness of each types of pain management in five point likert scale , i.e. made pain worst, had no effect, slightly better, considerably better and disappear (Widerstrom-Noga & Turk, 2003) (Appendix F).

WHOQOL-BREF (Nepalese Version). The WHOQOL-BREF (Nepalese Version) was used to assess the QoL in persons with SCI. The first two questions (i.e. Q1 and Q2) ask about the general perceptions of health and QoL and remaining 24 questions are categorized into four domains including physical health (7 items), psychological health (6 items) , social health (3 items) , and environmental health (8 items). The items are rated on a 5-item Likert scale with scores of 1-5, where higher the score represented the higher QoL. The negatively phrased questions (i.e. 3, 4, and 26) are reversed to form positive scale (Appendix G).

The domain score of WHOQOL-BREF comes from the 24 items of the instruments (except Question 1 and Question 2). The mean scores of the items in each domain are calculated to form each domain score. Then mean scores are first multiplied by 4 to make the domain score standardized and comparable. Then the second transformation converts the domain scores to a 0-100 scale (WHO, 1996). The detail steps of computing domain are presented in Appendix B.

The interpretation for overall QoL was categorized into three levels of low, moderate, and high. This calculation were based on the possible maximum total mean score minus the possible minimum total mean score, and then divided by the number of levels (i.e. three) as shown.

[Possible maximum total mean score-Possible minimum total mean score]/3

Range of Mean Score of QoL	Interpretation
26.00- 60.66	Low
60.67- 95.33	Moderate
95.34-130.00	High

Translation of the instruments

The ISCIPBDS-2 used to assess the chronic pain experience went through the translation technique recommended by the developer of the instruments (Biering-Sorensen et al., 2011) (Appendix I).

1. The first bilingual translator with the health background independently translated an original version of the instrument into the Nepali language.

2. The second bilingual translator with the public health background who had not seen the original version translated the Nepali version of questionnaire back into the English version.

3. The third bilingual reviewer, a consultant physiotherapist identified any discrepancies between the original version and the back translation version, compared consistency of the languages, and evaluated the cultural relevancy and appropriateness of the meaning of the instruments.

4. Later, the working group of ISCIPBDS-2 was contacted to check the equivalence and appropriateness of the original English version and the 'back-translated' version.

5. When the Nepali and English versions were consistent and equivalent, the instrument was tested in a pilot study based upon the inclusion criteria.

Validity and Reliability of the Instruments

Validity of the instruments

In this study, content validity of the instruments was assessed by five experts. Two experts were consultant anesthesiologists from the Faculty of Medicine at Prince of Songkla University in Thailand. One expert was an Advanced Practice Nurse from the Trauma ward at Songklanagarind Hospital in Thailand. Another expert was a Nurse lecturer and orthopedic expert from the Surgical Nursing Department at Prince of Songkla University in Thailand. The fifth expert was a physiotherapist and a Lecturer from Kathmandu University in Nepal (Appendix H). The experts assessed the content to determine if the items included in the instruments were accurate, appropriate, and congruent to answer the research question or not. The scale content validity index (S-CVI) of the ISCIPBDS-2, Pain Management Questionnaire, and the WHOQOL-BREF were found to be 1.00.

Reliability of the instruments

The translated version of the ISCIPBDS-2 was tested for the test-retest reliability and the pain interference and the WHOQOL-BREF was tested for internal consistency with 20 SCI cases who met the inclusion criteria of the study. The researcher distributed the ISCIPBDS-2 to the samples on two occasions with an interval of two days. The opinions regarding the retest interval varied from an hour to a year, but 2-14 days was the usual interval for test-retest (Streiner, Norman, & Cairney, 2015). The intra-class correlation coefficient (ICC) of the 0-10 NRS was .91. When the internal consistency was assessed, the Cronbach’s alpha coefficient of the interference scale was .85 and WHOQOL-BREF (Nepalese Version) was .80. All above reported scores were at acceptable range for reliability (Polit & Beck, 2012).

Data Collection Procedure

The steps of data collection were as follows.

1. The researcher identified the detail of the participants from the registration unit of the SIRC with the help of the staff personnel. Detail of the participant included their home address, phone number, medical diagnosis, cause of the injury, level and completeness of the injury.

2. The contact list included all potential participants living in a community of the Bagmati Zone who received any kind of services from the SIRC.

3. A brief explanation was provided to the potential participants regarding the objective, purpose, procedure, risks, and benefits of the study via telephone. If the participant agreed to participate, an appointment was made regarding the place and time of the home visit.

4. For the participants who attended the out-patient department of the SIRC, staffs of the SIRC introduced the researcher to the participants after completion of the regular checkup or regular service received. The researcher provided a brief explanation regarding the objective, purpose, procedure, risks, and benefits of the study. If the participant agreed to participate, the data were collected in a private area based upon the comfort of the participants.

5. The researcher asked each eligible participant to sign an informed written consent form. If the participant was unable to sign for themselves, a family member was asked to sign the consent form based upon agreement by the participant. The researcher provided a detailed explanation regarding the objective, purpose, procedure, risks, and benefits of the study.

6. The researcher distributed the set of questionnaires to eligible participants with instructions and allowed participants to respond to the questionnaires by hand written and face to face interview. If the participants were unable to read and complete the questionnaires by themselves, the researcher read the questionnaires to them and facilitated the respondents to answer on their own.

7. The researcher checked for completion of the questionnaires.

8. The researcher acknowledged the participants for their response. The researcher provided knowledge based information to deal with their pain problems (e.g., chanting mantras and/or exercise). Furthermore, it was suggested to the participants along with his/her family that they visit the hospital in case of intolerable pain or some serious complications.

Ethical Considerations

The study was conducted based on the ethical considerations in nursing research and principles of ethics. Ethical approval was obtained from: (1) the Institutional Review Board of the Faculty of Nursing at Prince of Songkla University, (2) Nepal Health Research Council in Nepal, and (3) the Spinal Injury Rehabilitation Center in Nepal (Appendix J). Permission was obtained for the use of the ISCIPBDS-2 and WHOQOL-BREF (Nepalese Version) beforehand (Appendix K). In addition, the human rights of all participants were respected and the participants were treated equally without any bias. The researcher explained the procedure, purpose, benefits, and risks of the study to all participants in detail. The participants were informed of their rights that they could discontinue their participation anytime without any explanation. Moreover, the participants were assured of anonymity and confidentiality by giving a separate numeric code for each participant (Appendix C).

Data Analysis

To analyze the data, simple descriptive statistics, inferential statistics, and simple content analysis were used.

1. Descriptive statistics, such as frequency, percentage mean, standard deviation, minimum and maximum, were used to analyze personal health and environment related data, and the study variables. Median and Interquartile range were used if the data were not normally distributed.

2. Pearson's Product-moment Correlation was used to explore the relationship of pain intensity and pain interference on QoL in persons with SCI. Pearson's product-moment correlation coefficient was used to test the relationship since assumption for normality, linearity, and homoscedasticity were not violated in this study. The assumption for normality was tested using standardized skewness and kurtosis. Linearity and homoscedasticity was tested by the scatter plot from original and residual form of variable (Appendix A).

3. Simple content analysis was done to analyze the qualitative data from open-ended questions of pain management strategies. The process of content analysis included a breaking down of whole data into smaller coherent parts, organizing the parts according to the content they represent, and finally categorizing the theme based on shared concepts (Polit & Beck, 2012).

Chapter 4

Results and Discussion

The results and discussion of the study are presented based upon the objectives of the study. This chapter includes: (1) Personal, health related and environmental data, (2) Chronic pain experience, (3) Pain management strategies, (4) Quality of life, (5) Relationship of pain intensity and pain interference on quality of life in persons with SCI.

Results

Personal, health related and environmental data

Personal data. 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 (75.83%) as the dominant religion. Almost half of the participants (44.17%) attended secondary school and approximately half of the participants (51.67%) were married. 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 (Table 1).

Table 1

Frequency and Percentage of Persons With SCI Classified by Personal Characteristics (N=120)

Personal Characteristics	*n*	%
Age (Years) (*M*=33.19, *SD*=9.19 *Min= 18*, *Max*=65)		
18-30	52	43.33
31-40	44	36.67
41-50	20	16.67
> 50 years	4	3.33
Gender		
Male	86	71.67
Female	34	28.33
Religion		
Hindu	91	75.83
Buddhist	17	14.17
Christian	12	10.00
Marital status		
Single	49	40.83
Married	62	51.67
Divorced, widow or currently not living with spouse	9	7.50
Level of education		
No education	12	10.00
Primary school	20	16.67
Secondary school	53	44.17
Higher education	35	29.16
Employment status before SCI		
Unemployed	44	36.67
Employed	76	63.33
Employment status after SCI		
Unemployed	72	60.00
Employed	48	40.00
Sufficiency of income		
Yes	31	25.83
No	89	74.17
Smoking habit (after SCI)		
Yes	27	22.50
No	93	77.50
Alcohol drinking habit (after SCI)		
Yes	24	20.00
No	96	80.00

Health related data. The number of years since the onset of the SCI ranged from 1 to 24 years *(Mdn*=5, *IQR*=7*)*. Complete injury had occurred in 62.50% of the participants and 90% of the participants were paraplegic. A majority of the participants (81.67%) had injury at the thoracic and lumber level. Fall was found to be the common cause of injury which accounted for 56.67% of all participants, followed by RTA (21.67%), and natural disasters (14.16%). After SCI, 85% of the participants encountered other health problems such as urinary tract infection (UTI) (56.86%), constipation (54.90%), spasticity (38.23%), and pressure sore (32.35%) (Table 2).

Table 2

Frequency and Percentage of Persons With SCI Classified by Health Related Characteristics (N=120)

Health related Characteristics	*n*	*%*
Duration of injury (years) *(Mdn*=5, *IQR*=7, *Min*= 1, *Max*= 24*)*		
Completeness of Injury (Medical record, self-report)		
Complete	75	62.50
Unknown	23	19.17
Incomplete	22	18.33
Severity of Injury (Medical record, self-report)		
Paraplegia	108	90.00
Quadriplegia	12	10.00
Level of injury (Medical record, self-report)		
Thoracic	68	56.67
Lumber	26	21.67
Cervical	11	9.17
Unknown	11	9.17
Thoraco-Lumber	4	3.33
Cause of injury		
Fall (e.g., tree, house roof)	68	56.67
Road traffic accidents	26	21.67
Natural disasters (e.g., earthquake, buried under landscape)	17	14.16

Table 2 (Continued)

Health related Characteristics	*n*	*%*
Others (e.g., Gunshot/ambush, gymnastic, drowned)	9	7.50
Health problems after SCI (self-report):		
No	18	15.00
Yes*	102	85.00
Urinary tract infection	*(58)*	*56.86*
Constipation	*(56)*	*54.90*
Spasticity	*(39)*	*38.23*
Pressure sore	*(33)*	*32.35*
Gastro intestinal disorder (e.g., indigestion, gastritis)	*(12)*	*11.76*
Eliminatory disorder (e.g., diarrhea, worm infestation)	*(9)*	*8.82*
Fever	*(9)*	*8.82*
Respiratory infection (pneumonia, chronic cough)	*(7)*	*6.86*
Insomnia	*(5)*	*4.90*
Others (e.g., headache, hypertension, bladder stone)	*(11)*	*10.78*

Note. * One participant reported more than one health problem

Environmental data. Almost two third (61.67%) of the participants were living in a nuclear family. Financial support from the government or other sectors was received by 33.33 % of the participants (Table 3).

Table 3

Frequency and Percentage of Persons With SCI Classified by Environmental Characteristics (N=120)

Environmental Characteristics	*n*	*%*
Type of Family		
Nuclear	74	61.67
Extended	46	38.33
Number of family member		
None (only one)	19	15.83
2-5	62	26.67
>5	39	32.50
Availability of assisting aid (use of wheelchairs)		
Yes	120	100.00
Place of residence:		
Rural	41	34.17
Urban	79	65.83

Table 3 (Continued)

Environmental Characteristics	*n*	*%*
Financial support		
No	80	66.67
Yes (e.g., government/non-government, private insurance)	40	33.33
Access to technology		
Internet	89	74.17
Non Internet	31	25.83

Chronic pain experience

The chronic pain experience of this section includes: (1) location of three worst pain problems, (2) pain intensity level and onset of pain of three worst pain problems, and (3) pain interference level.

Location of three worst pain problems. Participants reported pain at each body location including the head, neck/shoulder, arms/hands, frontal torso/genitals, back, buttocks/hips, upper leg/thigh, and lower leg/feet. The back (38.33%), lower legs/feet (24.17%), buttocks/hips (23.33%), and upper leg/thigh (23.33%) were the most common worst pain locations. Likewise, the second worst common pain locations were the back (33.69%), lower legs/feet (19.56%), and buttocks/hips (19.56 %). The third worst common pain locations were the lower legs/feet (33.92%), back **(**19.64%), and arms/hands (16.07%) (Table 4).

Table 4

Frequency and Percentage of Persons With SCI Who Reported Location of Three Worst Pain Problems (N=120)

Worst Pain locations*	Worst pain (*n=120*)		2nd worst pain (*n=92*)		3rd worst pain (*n=56*)	
	n	%	*n*	%	*n*	%
Head (*n*=8)	2	1.67	1	1.09	5	8.93
Neck/shoulders (*n*=27)	9	7.50	12	13.04	6	10.71
Arms/hands *n*=21)	4	3.33	8	8.69	9	16.07
Frontal torso/genitals (*n*=34)	14	11.67	15	16.30	5	8.93
Back (*n*=88)	46	38.33	31	33.69	11	19.64
Buttocks/hips (*n*=51)	28	23.33	18	19.56	5	8.93
Upper leg/thigh (*n*=46)	28	23.33	14	15.21	7	12.50
Lower legs/feet (*n*=66)	29	24.17	18	19.56	19	33.92

Note. *One participant reported more than one location

Pain intensity level and onset of three worst pain problems. Overall, the average of pain intensity was found to be at a moderate level (*M*= 5.12, *SD*=1.80). The onset of pain was found within the first six months of the injury, except for the head and frontal torso/genitals where the onset of pain was found most commonly after six months of the injury (Table 5).

Table 5

The Minimum, Maximum, Mean, Standard Deviation of Pain Intensity and Onset of Three Worst Pain Problems in Persons With SCI (N=120)

Location *	Pain intensity					*M*(*SD*)	Onset of pain (months)	
	Min	Max	Mild (1-3)	Moderate (4-6)	Severe (7-10)		Within 6 months	After 6 months
			n (%)	*n (%)*	*n (%)*		*n (%)*	*n (%)*
Head (*n*= 8)	3	10	1(12.50)	4(50.00)	3(37.50)	6.13(2.80)	3(37.50)	5(62.50)
Neck/shoulders(*n*=27)	3	10	3(11.11)	17(62.96)	7(25.93)	5.41(1.92)	14(51.85)	13(48.15)
Arms/hands (*n*=21)	1	10	3(14.28)	14(66.67)	4(19.05)	5.10(1.94)	12(57.14)	9(42.86)
Frontal torso/genitals (*n*=34)	2	10	7(20.59)	17(50.00)	10(29.41)	5.50(2.39)	11(32.35)	23(67.64)
Back (*n*=88)	1	10	22(25.00)	48(54.55)	18(20.45)	4.89(1.95)	52(59.09)	36(40.91)
Buttocks/hips (*n*=51)	2	10	3(5.88)	23(45.10)	25(49.02)	6.47(2.24)	30(58.82)	21(41.18)
Upper leg/thigh (*n*=46)	2	10	4(8.70)	19(41.30)	23(50.00)	6.50(2.39)	33(71.74)	13(28.26)
Lower legs/feet (*n*=66)	2	10	8(12.12)	24(36.36)	34(51.52)	6.32(2.36)	46(69.70)	20(30.30)
Overall (n=120)	1	10	20(16.67)	72(60.00)	28(23.33)	5.12(1.80)		

Note: * One participant had more than one pain location

Pain interference level. Overall, pain interference was at a moderate level (*M*=4.58, *SD*=2.30). In regard to each item of pain interference, the pain interference level on day-to-day activities (*M*=4.78, *SD*=2.44), overall mood (*M*=4.80, *SD*=2.48), and ability to get a good night's sleep (*M*=4.18, *SD*=3.16) was at a moderate level (Table 6).

Table 6

The Frequency, Percentage, Mean, Standard Deviation and Level of Pain Interference in Persons With SCI (N=120)

Variables	Pain interference level				M (SD)	Level
	None (0) *n(%)*	Mild (1-3) *n(%)*	Moderate (4-7) *n(%)*	Severe (8-10) *n(%)*		
Day to day activity	8(6.67)	30(25.00)	66(55.00)	16(13.33)	4.78 (2.44)	Moderate
Overall mood	8(6.67)	25(20.83)	66(55.00)	21(17.50)	4.80 (2.48)	Moderate
Good night sleep	22(18.33)	35(29.17)	38(31.67)	25(20.83)	4.18 (3.16)	Moderate
Overall					4.58 (2.30)	Moderate

Pain management strategies

Types of pain management. Participants used both pain medications and/or non-pharmacological management methods to reduce their chronic pain. However, use of non-pharmacological management strategies (95.83%) was more common than pain medications (50%). The top three methods of non-pharmacological management were massage (42.50%), exercise (34.17%), and distraction (21.67%). Ibuprofen (25.83%) was the pain medication commonly used (Table 7).

Table 7

Frequency and Percentage of Persons With SCI Who Reported Types of Pain Management (N=120)

Types of Pain Management*	*n*	%
1. Pain medications (physician prescribed *n*=16, non-prescribed *n*=54)	60	50.00
1.1 Ibuprofen (Tablet)	31	25.83
1.2 Unknown medication (Tablet)	18	15.00
1.3 Topical pain relieving gel (e.g., Diclofenac, Moov, Unknown)	13	10.83
1.4 Other medications (e.g., Tablet.Gabapentin, Pregabalin, Opoids)	7	5.83
1.5 Acetaminophen (Tablet)	4	3.33
1.6 Unknown intramuscular injection	2	1.67
2. Non- Pharmacological Managements	115	95.83
2.1 Physical modalities	107	89.16
1) Massage (e.g., oil, fenugreek seed, ice, camphor, ayurvedic)	51	42.50
2) Exercise (e.g., exercise, physiotherapy, stretching)	41	34.17
3) Rest and sleep	22	18.33
4) Heat application (e.g., hot water bag, wet warm clothes, hot bricks/ burnt ashes wrapped in the clothes, sun basking)	18	15.00
5) Positioning (e.g., changing position, relieving pressure)	18	15.00
6) Use of belts (e.g., homemade belts *patuka***, belts)	6	5.00
7) Deep breathing exercise	3	2.50
2.2 Distraction (e.g., recreational activities, work, internet)	26	21.67
2.3 Tolerance	10	8.33
2.4 Substance abuse (e.g., alcohol consumption, cigarette smoking)	10	8.33
2.5 Traditional herbs (e.g., oral, incisional)	5	4.16
2.6 Eating food/drinking water	3	2.50
2.7 Meditation and praying	2	1.67

Note. * One participant used more than one types of pain management

***patuka* is the traditional way of wrapping length of cloth around the waist

***Reasons of using pain management*.** Participants stated different reasons for using pain medications and non-pharmacological managements. The common reason to use pain medications was prevention of severe or intolerable pain (*n*=55). Top three reasons for the use of non-pharmacological managements included: (1) prevention and relief of temporary and/or long term pain (*n*=115); (2) diverting the mind away from suffering, negative thoughts, and stress induced by pain (*n*=35), and (3) unsafe profile of the pain medications, e.g., resistance to drugs, fear of drug dependency, and side effects of drugs (*n*=33) (Table 8).

Table 8

Frequency and Percentage of Persons With SCI Classified by the Reasons for Using Pain Management (N=120)

Reasons for using pain management*	*n*	*%*
Pain medications (*n*=60)		
1. Relief, prevention of severe or intolerable pain (e.g., painkillers)	55	91.66
2. Easy availability, rapid access, saves time to go to the hospital	3	5.00
3. Failure and helplessness of massage, rest and sleep (e.g., painkillers)	7	11.67
Non pharmacological managements (*n*=115)		
1. Prevention and relief of temporary and/or long term pain	115	100.0
2. Diverts mind away from suffering, negative thought, pain related stress (e.g., exercise, rest and sleep, distraction)	35	30.43
3. Resistance to drugs, fear of drug dependency, side effects of drugs (e.g., massage, exercise, distraction, herbs, substance abuse)	33	28.69
4. Relaxation by promoting blood circulation (e.g., exercise, massage)	20	17.39
5. Provides warmth or support (e.g., massage, heat application)	15	13.04
6. Refreshment and relaxation of body and mind (e.g., deep breathing, exercise, rest and sleep, substance abuse)	14	12.17

Table 8 (Continued)

Reasons for using pain management*	*n*	%
7. Health promotion, prevention complications (e.g., massage, exercise)	9	7.82
8. Promoting sleep and/or appetite (e.g., exercise, substance abuse)	7	6.09
9. Gives energy to cope with continuous pain, controls infection (e.g., eating food, drinking water)	3	2.62
10. Acceptance of the reality e.g., habitual of pain, pain is permanent, feels less pain in comparison to others, all SCI case have pain (e.g., tolerance, distraction)	10	8.69
11. Unable to perform other remedy or go to the hospital because of the disability (e.g., tolerance, meditation)	2	1.74
12. Unable to afford the medicinal cost (e.g., exercise)	2	1.74

Note. * One participant gave more than one reason for using type of pain management

People and places for pain management. Most of the participants managed their chronic pain themselves by using various forms of pain medications and non-pharmacological management (39.22%-100%). Moreover, their family members helped them to do massage and take pain medications (24.39%-58.82%). The common place for the use of non-pharmacological methods to reduce pain was at the home (90.24%-100 %); however, almost all of the pain medications were bought from a pharmacy (96.00%) (Table 9).

Table 9

Frequency, Percentage of Persons With SCI Regarding People Helping and Places for Pain Management (N=120)

Pain management*	People helping for pain management				Places for pain management		
	Self	Family members	Healthcare providers	Traditional healers	Home	Hospital	Pharmacy
	n (%)	*n (%)*	*n (%)*	*n (%)*	*n (%)*	*n (%)*	*n (%)*
1. Pain medications * (*n*=60)	37(49.33)	26(34.67)	12(16.00)	-	-	3(4.00)	72(96.00)
2. Massage (*n*=51)	20(39.22)	30(58.82)	1(1.96)	-	50(98.04)	1(1.96)	-
3. Exercise (*n*=41)	27(65.85)	10(24.39)	4(9.76)	-	37(90.24)	4(9.76)	-
4. Rest and sleep (*n*=22)	22(100.00)	-	-	-	22(100.00)	-	-
5. Heat application (*n*=18)	18(100.00)	-	-	-	18(100.00)	-	-
6. Positioning (*n*=18)	18(100.00)	-	-	-	13(100.00)	-	-
7. Use of belts (*n*=6)	5(83.33)	1(16.67)	-	-	6(100.00)	-	-
8. Deep breathing exercise (*n*=3)	3(100.00)	-	-	-	3(100.00)	-	-
9. Distraction (*n*=26)	26(100.00)	-	-	-	26(100.00)	-	-
10. Tolerance (*n*=10)	10(100.00)	-	-	-	10(100.00)	-	-
11. Substance abuse (*n*=10)	10(100.00)	-	-	-	10(100.00)	-	-
12. Traditional herbs (*n*=5)	-	2(40.00)	-	3(60.00)	5(100.00)	-	-
13. Eating food/drinking water (*n=3)*	3(100.00)	-	-	-	3(100.00)	-	-
14. Meditation and praying (*n*=2)	2(100.00)	-	-	-	2(100.00)	-	-

Note. * One participant used more than one pain management

Time of pain management. In regard to time of pain management, participants used each pain management at different times. Almost three-fourths (74.67%) of the participants used pain medications whenever pain started (not on a regular basis), whereas physical modalities, such as massage, exercise, and heat application, were done anytime with or without pain (on a regular basis), e.g., morning, afternoon, and evening (Table 10).

Table 10

Frequency, Percentage of Persons With SCI Classified by Time of Pain Management (*N=120)*

Pain management*	Time of pain management					
	Whenever pain	Morning	Afternoon	Evening	Morning and evening	Morning afternoon and evening
	n (%)	*n (%)*	*n (%)*	*n (%)*	*n (%)*	*n (%)*
1. Pain medications * (*n*=60)	56(74.67)	1(1.33)	-	5(6.67)	7(9.33)	6(8.00)
2. Massage (*n*=51)	23(45.10)	1(1.96)	-	23(45.10)	4(7.84)	-
3. Exercise (*n*=41)	7(17.07)	6(14.63)	2(4.88)	4(9.76)	21(51.22)	1(2.44)
4. Rest and sleep (*n*=22)	20(90.91)	-	2(9.09)	-	-	-
5. Heat application (*n*=18)	8(44.44)	-	1(5.56)	8(44.44)	1(5.56)	-
6. Positioning (*n*=18)	15(83.33)	-	-	2(11.11)	1(5.56)	-
7. Use of belts (*n*=6)	4(66.66)	-	1(16.67)	1(16.67)	-	-
8. Deep breathing exercise (*n*=3)	3(100.00)	-	-	-	-	-
9. Distraction (*n*=26)	26(100.00)	-	-	-	-	-
10. Tolerance (*n*=10)	10(100.00)	-	-	-	-	-
11. Substance abuse (*n*=10)	9(90.00)	-	-	1(10.00)	-	-
12. Traditional herbs (*n*=5)	2(40.00)	1(20.00)	1(20.00)	-	1(20.00)	-
13. Eating food/drinking water (*n*=3)	3(100.00)	-	-	-	-	-
14. Meditation and praying (*n*=2)	2(100.00)	-	-	-	-	-

Note. * One participant used more than one pain management

Frequency and effectiveness of pain management. In regard to the frequency of pain management methods, 88% of the participants used pain medications only sometimes. The effectiveness of pain medications was slightly better in half of the participants (50.67%) (Table11). For non-pharmacological management such as massage (54.55%), exercise (80.95%), and distraction (92.86%) were used most of the time. However, their effectiveness was slightly better (50% -78%) (Table11).

Table 11

Frequency and Percentage of Persons With SCI Classified by Frequency and Effectiveness of Pain Management (*N=120)*

Pain management*	Frequency			Effectiveness				
	Rarely	Sometimes	Most of the time	Pain worst	No effect	Slightly better	Considerably better	Disappear
	n (%)	*n (%)*	*n(%)*	*n (%)*	*n (%)*	*n(%)*	*n(%)*	*n(%)*
1. Pain medication *	1(1.33)	66(88.00)	8(10.67)	-	3 (4.00)	38 (50.67)	19 (25.33)	15(20.00)
1.1 Unknown medication	1(5.56)	13(72.22)	4(22.22)	-	1(5.56)	11(61.11)	1(5.56)	5(27.77)
1.2 Ibuprofen	-	29(93.54)	2(6.46)	-	2(6.45)	12(38.71)	9(29.03)	8(25.81)
1.5 Pain relieving gels	-	12(92.31)	1(7.69)	-	-	9(69.23)	3(23.08)	1(7.69)
1.4 Other medication	-	6(85.71)	1(14.29)	-	-	3(42.86)	4(57.14)	-
1.3 Acetaminophen	-	4(100.00)	-	-	-	2(50.00)	1(25.00)	1(25.00)
1.6 Intramuscular injection	-	1(50.00)	1(50.00)	-	-	-	1(50.00)	1(50.00)
2. Massage	-	23(45.45)	28(54.55)	-	5 (9.10)	39 (78.18)	6 (10.91)	1(1.81)
3. Exercise	1(2.38)	6(16.67)	34(80.95)	-	2 (4.76)	24 (59.52)	14 (33.34)	1 (2.38)
4. Rest and sleep	-	7(33.33)	15(66.67)	-	1 (4.17)	17 (75.00)	3 (12.50)	1 (8.33)
5. Heat application	-	7(42.11)	11(57.89)	-	-	14(78.94)	2 (10.52)	2 (10.52)

Table 11 (Continued)

	Frequency			Effectiveness				
Pain management*	Rarely	Sometimes	Most of the time	Pain worst	No effect	Slightly better	Considerably better	Disappear
	n (%)	*n (%)*	*n(%)*	*n (%)*	*n (%)*	*n(%)*	*n(%)*	*n(%)*
6. Positioning	-	-	18(100.00)	-	5(27.78)	10(55.55)	3(16.67)	-
7. Use of belts	-	1(12.50)	5(87.50)	-	-	5 (75.00)	1 (25.00)	-
8. Deep breathing exercise	-	-	3(100.00)	-	-	1 (33.33)	-	2 (66.67)
9. Distraction	-	2(7.14)	24(92.86)	-	7(25.00)	12 (50.00)	7 (25.00)	-
10. Tolerance	-	-	10(100.00)	1(10.00)	7(70.00)	2 (20.00)	-	-
11. Substance abuse	-	1(10.00)	9(90.00)	1(10.00)	-	6 (60.00)	1 (10.00)	2 (20.00)
12. Traditional herbs	-	2(40.00)	3(60.00)	-	2(40.00)	-	1 (20.00)	2 (40.00)
13. Eating food/drinking water	-	-	3(100.00)	-	-	2 (66.67)	-	1 (33.33)
14. Meditation and praying	-	-	2(100.00)	-	-	-	2 (100.00)	-

Note. *One participant used more than one pain management

Quality of life

The overall QoL in persons with SCI was at the moderate level (*M*=73.14, *SD*=12.90). Considering each domain of OoL, the highest mean score was found on the psychological health followed by social health, physical health and environmental health, respectively.

Table 12

Range, Mean and Standard Deviation of QoL in Persons With SCI (N=120)

QoL	Range		*M* (*SD*)	Level
	Possible	Actual		
1. Physical health*	0-100	7.14-85.71	45.65(15.39)	
Energy and fatigue	1-5	1-5	2.49 (0.97)	
Mobility	1-5	1-5	2.59 (1.08)	
Dependence on medical substance and medical aids	1-5	1-4	2.82(0.85)	
Work capacity	1-5	1-5	2.95(0.95)	
Rest and sleep	1-5	1-5	2.97(0.97)	
Activities of daily living	1-5	1-5	2.98 (0.85)	
Pain and discomfort	1-5	1-5	2.99 (0.94)	
2. Psychological health*	0-100	4.17-95.83	47.91 (16.07)	
Spirituality /religion/ personal beliefs	1-5	1-5	2.62 (0.98)	
Positive feelings	1-5	1-5	2.69 (0.94)	
Thinking, learning, memory and concentration	1-5	1-5	2.74 (0.96)	
Body image and appearance	1-5	1-5	2.78 (1.04)	
Self-esteem	1-5	1-5	3.04 (0.88)	
Negative feeling	1-5	1-5	3.63 (0.86)	

Table 12 (Continued)

QoL	Range		*M* (*SD*)	Level
	Possible	Actual		
3. Social health*	0-100	0.00-83.33	47.22(15.85)	
Sexual activity	1-5	1-4	2.52 (0.88)	
Social support	1-5	1-5	3.02 (0.97)	
Personal relationship	1-5	1-5	3.12 (0.84)	
4. Environmental health*	0-100	3.12-78.12	43.41(12.56)	
Financial resources	1-5	1-5	2.08 (0.83)	
Opportunities for acquiring new information and skills	1-5	1-5	2.62 (0.95)	
Physical environment pollution/noise/traffic/climate	1-5	1-5	2.63 (0.81)	
Freedom, physical safety and security	1-5	1-5	2.65 (0.91)	
Transport	1-5	1-5	2.78(0.99)	
Health and social care: accessibility and quality	1-5	1-5	2.85 (0.87)	
Home environment	1-5	1-5	3.07(0.79)	
Participation in and opportunities for recreation/ Leisure activities	1-5	1-5	3.21(0.94)	
Overall QoL	26-130	34-112	73.14 (12.90)	Moderate

Note. * See the details of computing domain score in Appendix B

Relationship of pain intensity and pain interference on quality of life in persons with SCI

As shown in Table 13, there was a significant negative correlation of pain intensity with overall QoL (*r*= -.24, *p*<.01) and three domains of QoL including physical health (*r*= -.28, *p*<.01), psychological health (*r*= -.18, *p*<.05) and social health (*r*=-.20, *p*<.05). Moreover, there was significant negative correlation between pain interference and overall QoL (*r*= -.48, *p* <.01) and four domains of QoL including physical health (*r*= -.52, *p* <.01), psychological health (*r*= -.42, *p* <.01), social health (*r*=-.30, *p* <.01) and environment health (*r*=-.31, *p* <.01).

Table 13

Correlation of Pain Intensity and Pain Interference on QoL in Persons With SCI (N=120)

Variables	Pain intensity	Pain interference
Physical health	$-.28^{**}$	$-.52^{**}$
Psychological health	$-.18^{*}$	$-.42^{**}$
Social health	$-.20^{*}$	$-.30^{**}$
Environmental health	-.10	$-.31^{**}$
Overall QoL	$-.24^{**}$	$-.48^{**}$

Note. * *p*<0.05, ** *p*<0.01

Discussion

This part discusses about (1) personal, health related and environmental characteristics (2) chronic pain experience, (3) pain management strategies, (4) quality of life, and (5) relationship of pain intensity and pain interference on QoL in persons with SCI.

Personal, health related and environmental characteristics

The average age of the participants was 33 years with more than 70% male participants. The study findings in regard to age and gender were somewhat congruent to a systematic review done to assess the epidemiology of SCI in developing countries where the average age of the participants was 32.4 years with 82.8% male participants (Rahimi-Movaghar et al., 2013). The participants in the current study were comparable to the developed and developing countries globally (WHO, 2013), where 60% of the participants were unemployed after SCI.

In a reported series from developed and developing countries, road traffic accident was found to be the most common cause of injury (Chen et al., 2013; Singh et al., 2014). The current study findings were consistent with previous findings of developing countries such as Nepal (Lakhey et al., 2005), India (Mathur et al., 2015), and Turkey (Ataoglu et al., 2013) where fall was identified as the major cause of SCI. Around 80% of the people in Nepal live in the rural areas (Rural Poverty Portal, 2014; Trading economics, 2017) and depend upon farming for their livelihood (Shrestha, Garg, Singh, Singh, & Sharma, 2007). Most people in Nepal are involved in agriculture; therefore, people climb trees, hills, and slopes to collect fodder for their cattle. Thus, these people are more vulnerable to fall related injuries (Shrestha et al., 2007).

The common causes of injury, such as falls and road traffic accident which resulted in more thoracolumbar injuries (Mathur et al., 2015; Somers, 2010), were consistent with the majority of the participants in this study who had thoracolumbar injuries (81.67%). In this study, urinary tract infection was identified as the most common problem after SCI which was consistent with previous studies from developing countries where urinary tract infection was reported to be the most commonly reported life threatening secondary complication after SCI (Hu et al., 2008; Rahimi-Movaghar et al., 2013).

Chronic pain experience

Pain location. Various pain locations were reported among participants in this study; at least 10% of the participants reported pain at every site of the body. However, the back, and lower legs/feet were identified as the most common pain locations in this study. The current findings were similar to a previous study done in SCI persons with chronic pain (Ataoglu et al., 2013; Cruz-Almeida et al., 2009; Molton et al., 2009).

The reason for back pain was possibly because of the level of injury and/or mechanical factors. Since the majority of the participants had an injury at the thoracolumbar level, the injury could have given rise to “at level” or “below level” neuropathic pain as a result of anatomical, physiological, and neurochemical alterations in the associated structures (D’Angelo et al., 2013). Furthermore, several mechanical factors, such as muscle weakness, straining produced by immobility, limited movement, prolonged sitting, and pressure exerted by the use of wheelchair (Alm et al., 2008; Cardenas & Felix, 2009; Irwin et al., 2007), could have contributed to back pain and buttocks/hips pain among the participants of this study.

Likewise, the common prevalence of pain in the lower legs/feet could be because of a pathology and level of SCI. First, atrophy to the primary motor and sensory cortex of the brain could have caused phantom limb syndrome in the participants of this study (D’Angelo et al., 2013). Second, the reason for lower legs/feet pain was possibly due to injury at the thoracolumbar level. Among persons with injury at the thoracolumbar level, the distal lower extremities were identified as locations of commonly reported pain (Modirian et al., 2010).

Pain intensity. The average pain intensity of this study was at a moderate level. This finding was consistent with previous studies (Cruz-Almeida et al., 2009; Mann et al., 2013; Molton et al., 2009; Ullrich et al., 2008). There are three reasons that could be possibly explained for moderate pain intensity of persons with SCI including pain mechanism, secondary complications, and inappropriate use of pain management. First, anatomical, physiological, and neurochemical alterations in the spinal cord, brain or peripheral nerves can produce inflammation and give rise to chronic pain in SCI (D’Angelo et al., 2013). Second, the secondary complications of persons after SCI in this study e.g., urinary tract infection (56.86%), constipation (54.90%), spasticity (38.23%), and pressure sore (32.25%), could have heightened the pain intensity since these factors were identified as triggering factors for chronic pain in SCI (Cruz-Almeida et al., 2009; Margot Duclot et al., 2009; Siddal & Middleton, 2006). Third, the majority of persons with SCI used inappropriate pain management because of lack of knowledge about pain management and fear of drug dependency (Table 7-9). Consequently, 50% -78% SCI persons reported that the effectiveness of pain management they used was slightly effective for pain relief (Table 11).

Onset of pain. The common onset of pain in this study was found within the first six month of the injury. The interaction of four main components is the reason for the early onset of pain, namely, neurochemical, excitotoxicity, anatomical, and inflammation in the spinal and supra spinal neurons which occurs soon after the injury

(Yezierski, 2009). The findings of this study was consistent with previous studies where the onset of the pain was seen within the first six months of the injury (Ataoglu et al., 2013; Cruz-Almeida et al., 2009; Miguel & Kraychete, 2009; Modirian et al., 2010).

On the other hand, pain at several locations of the body, such as the torso/genitals and head, were commonly seen after six months of injury in this study. The reason for the late onset of pain at the frontal torso/genitals could be because of a nociceptive source which occurs later as a result of stimulation or activity of peripheral nociceptive afferents (Masri & Keller, 2012). Furthermore, existence of constipation or urinary tract infection in the participants of this study could have contributed to the late onset of pain at the frontal torso/genitals. In previous studies, headache (McKinley, Jackson, Cardenas, & Michael, 1999), urinary tract infection (Rahimi-Movaghar et al., 2013), and constipation (Siddal and Middleton, 2006) were noted later as long term secondary complications following SCI.

Pain interference. Overall pain interference was at moderate level (*M* = 4.58). Pain interference in mood (*M* = 4.80), activities (*M* = 4.78) and night sleep (*M* = 4.18) were also at the moderate level. These results may be because of the biochemical pain mechanism, fatigue, and temporal aspects. Pain interference on mood occurs as a result of compromised regulation in the synthesis of serotonin transporter, opioid receptors, and inflammatory mediators (Psychiatric Times, 2009). For pain interference on activities, this finding was consistent with a previous study done in persons with SCI (Jensen et al., 2005). They said that, as the pain become severe, it 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 (Douglas et al., 2009). This is consistent with this current study, where the persons with SCI had the low mean score of energy and fatigue in physical health (M = 2.49, range 1-5) (Table 12), that possibly relate that pain had contributed difficulties in performing daily activities. Furthermore, severity and chronicity of pain was higher at night than during the daytime that could have caused a disturbance in sleep among the persons with SCI (Celik et al., 2012; Rekand et al., 2012). In addition, disturbance in sleep 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 (Lautenbacher, Kundermann, & Krieg, 2006).

Pain management strategies

Pain management strategies of the participants in this study were discussed based on the SMM of Dodd et al. (2001) that included *What* (types of pain management), *Why* (the reasons of using pain management), *Who* (used by person with SCI themselves or with the help from other persons), *Where* (place for pain management), *When* (time of pain management done), *How often* (the frequency of pain management), and *How effective* (effectiveness of pain management). Moreover, personal (e.g., gender, perception, knowledge), health and illness (e.g., disability) and environment factors were used to explain the pain management strategies.

In this study, SCI persons with chronic pain used different forms of pain medication and non-pharmacological pain management. However, the use of non-pharmacological management was more common than pain medications. Consistently, previous studies showed that the use of non-pharmacological pain management was found to be common in SCI persons with chronic pain (Heutink et al., 2011; Norrbrink& Lundeberg, 2004). Persons with SCI believed that non-pharmacological pain management methods relieved chronic pain and distracted their mind. Moreover, some participants perceived an unsafe profile of pain medications, e.g., resistance to drugs, fear of drug dependency, and side effects of drugs, and inability to afford the cost of pain medications. This was consistent with a previous study done by Norrbrink and Lundeberg (2004) where pain medications were perceived to be ineffective or associated with unwanted side effects. Furthermore, being male could have contributed to the reduced use of pain medications and the use of non-pharmacological management instead. In comparison to females, males had an increased threshold and tolerance to pain (Keogh & Herdenfeldt, 2002) and were found less likely to take pain medications (Budh et al., 2003; Keogh & Herdenfeldt, 2002).

Massage. Massage was the most frequently used non-pharmacological pain management in this study. The participants of this study stated different reasons for massage in chronic pain relief which included promoting circulation and relaxation, providing warmth or support in the area of pain, preventing complications, and avoiding the use of drugs. To date no extensive studies have assessed the efficacy of massage on chronic pain relief in persons with SCI (Cardenas & Felix, 2009). However, massage is believed to increase pain thresholds by the gate control theory whereby the pain message takes longer to reach the brain than the pressure message (Field, Diego, & Hernandez-Reif, 2007). Despite frequent use, massage was found less satisfying than exercise; the majority of the participants (78.18%) reported that massage to be only slightly effective on pain relief in this study. This finding was in contrast to previous studies (Heutink et al., 2011; Norrbrink & Lundeberg, 2004) which reported that massage provided the greatest pain relief. There are two possible reasons that could have contributed to the different results between this study and the previous studies. First, massage was done either by the SCI participants (39.22%) or with the help of family members (58.82) with the use of locally available oil and seeds without any formal training. So, in this case, there is no assurance the massage was delivered in a correct technique. Second, pain intensity was found to be at the moderate level. In this situation the use of non-pharmacological management alone may not be beneficial for chronic pain relief in persons with SCI (Siddall & Middleton, 2006).

Exercise. Exercise was another commonly used non-pharmacological management for the alleviation of chronic pain in this study. The frequent use of exercise was possible because of its cost effectiveness and could be carried out independently since the majority of the participants in this study exercised on their own at home. Furthermore, the participants perceived that exercise was beneficial on diverting the mind away from pain and unpleasant thoughts, and provided relaxation by promoting blood circulation. Some participants exercised because they feared the side effects associated with taking drugs. Adherence to exercise is challenging; however, if maintained, exercise has proven to be effective in decreasing stress and bodily pain in individuals with SCI (Ditor et al., 2003). Accordingly, in this study, 80.95% of the participants were in the habit of exercising most of the time. The benefit of exercise could be the release of beta-endorphin which is an important pain relieving hormone (Bender et al., 2007). Furthermore, almost all of the participants of this study were rehabilitated at the Spinal Injury Rehabilitation Center (SIRC) where exercise sessions were held twice weekly by professionals (personal communication, February 1, 2017). This study finding was consistent with previous studies (Cardenas

& Jensen, 2006; Heutink et al., 2011; Lofgren & Norrbrink, 2012) where exercise was a commonly used pain management method and was also perceived effective for chronic pain relief in persons with SCI. Exercise was found improving the physical and psychological well-being in persons with SCI. (Hicks et al., 2003) and also was beneficial for various SCI related secondary complications e.g., muscle atrophy, spasticity (Cardenas & Felix, 2009).

Distraction. In this study distraction was found to be the third commonly used non-pharmacological pain management by SCI persons with chronic pain. The participants responded with several reasons for using distraction which included diverting the mind away from pain, suffering and unpleasant thoughts or stress, and adjusting and accepting the reality of pain. Despite the frequent use of distraction, one-quarter of the participants reported that distraction had no effect on pain relief and half of the participants stated that it offered slight improvement. The reasons for the ineffectiveness may be due to the moderate level of pain intensity, and the participants feared the use of pain medications. In earlier studies (Henwood & Ellis, 2004; Wen et al., 2013; Wollaars et al., 2007), the use of distraction for chronic pain relief in SCI was found to be common; however, the effectiveness and mechanism on pain relief is not well understood.

Pain medications. Consistent with a previous study (Norrbrink & Lundeberg, 2004), half of the participants in this study used pain medications to reduce their chronic pain. Ibuprofen was the most commonly used medication for chronic pain relief in this study since it is readily available and it is a commonly used drug in Nepal (Bhattarai et al., 2007). Ibuprofen is a NSAID that was found to provide better pain relief than other oral pain medications in this study. NSAIDs work by inhibiting the effects of cyclo-oxygenase (COX) enzyme which is an enzyme involved in the synthesis of inflammatory mediators, i.e. prostaglandins (Wojek, 2014).

However, valid conclusions on the effectiveness of pain medications in general could not be drawn because half of the participants evaluated pain medications to be only slightly better on pain relief. This result was possibly caused from disability and lack of knowledge regarding the use of pain medications. First, in this current study, disability associated with SCI (i.e. paraplegia and quadriplegia) could limit them to go to the hospital for follow up with the health professionals about pain medications. Consistently, a previous study done among persons with disability, expressed their limitation to go to hospital for periodical checkup to get necessary primary care because of their disability associated (Iezzoni et al., 2006)

Second, persons with SCI in this study may lack the knowledge regarding the use of pain medication resulting in use of inappropriate pain medications. This is supported as most of participants (84-96%) used pain medications by themselves and with the help of their family members, as well as bought drugs from pharmacy without consultation with a doctor. Consequently, pain medications were prescribed in only 16 % of the participants. This finding was consistent with a previous study done in Nepal where self-medication and use of non-prescribed drugs were commonly practiced (Shankar, Partha, & Shenoy, 2002). Similarly, in earlier study, pain medications were prescribed in 40% of the participants by general practitioners (Widerstrom-Noga & Turk, 2003). A study done in developing country among cancer pain found that the dearth of pain specialist, pain specialized clinic, knowledge among public and health professionals are the major impediments to chronic pain relief (Size, Soyannwo, & Justins, 2007).

In addition, the majority of participants who used pain medications (*n* =60) did not regularly used it, but only sometimes (88 %) or when the pain started (74.67%). It is universally known that the right drug, at the right dose, at the right time interval is needed for better efficacy on chronic pain relief (WHO, 1996). Furthermore, 15% (*n* =18) of the participants in this study were unaware of the types and names of the drugs used in relief of their chronic pain. Therefore, it was questionable whether the drugs were administered properly with the right dose and at the right time.

Quality of life

In this study, the QoL in persons with SCI was at a moderate level. This finding was not comparable to earlier studies (Barker et al., 2009; Dajpratham & Kongkasuan, 2011; Hu et al., 2008) since none of the studies interpreted the level of the scores but compared the results with other general and diseased populations. However, the moderate level of QoL among SCI participants in this study was presented as participants had lower scores on environmental and physical health domain and higher scores on psychological and social heath domain. The findings of this study was not consistent to the previous studies since lowest score was found on physical health of the persons with SCI (Hu et al., 2008; Trogovcevic et al., 2014) and higher score was found on environmental health (Barker et al., 2009). These results differences may be because of the difference in the personal and environmental contexts of Nepal to those of developed country. Possible explanations for the reasons of lower and higher score of each domain are stated below.

In regard to each domain, comparatively lowered score was found on environmental health (*M* = 43.41) (e.g., financial resources, opportunities to acquire new information and skills, and physical environment) of persons with SCI. Certain environmental factors, such as being employed and sufficiency of the income, were associated with a good QoL (Dajpratham & Kongkasuan, 2011; Lidal et al., 2008). Furthermore, a higher income is assumed to assist with getting more information about rehabilitation (Hu et al., 2008) which could facilitate acquiring new information and skills in persons with SCI. These were supported by the results of this study that 60% of participants were unemployed after SCI and almost three-fourths of the participants stated that their income was not sufficient for daily living. In a western context, health care services are secured by the government with special provisions of insurance and other health facilities for disabled people (Ridic et al., 2012), while in this study only one-third of the participants (33.33%) received health insurance coverage from government and non-governmental sectors. Moreover, the roadway and transport system of Nepal is still not wheelchair friendly which endangers the security of persons with SCI. Similarly, a previous study from Hong Kong advocated for more support to meet the needs of persons with SCI in the areas of transportation and medical care (Hu et al., 2008).

This study also demonstrated comparatively lower score in physical health (*M*= 45.65) (e.g., energy and fatigue, mobility, dependence on medical substances and medical aids) in persons with SCI. The reason for low score in energy and fatigue may be because of the moderate level of chronic pain among the participants of this study. Since, persons with chronic pain were nine times more likely to have chronic fatigue (Craig et al., 2013). Likewise, the reason for low score in physical mobility and work capacity in the participants of this study could be the disability associated with SCI, i.e. paraplegia and quadriplegia. Previous researchers have identified an association of physical mobility with QoL (Forchheimer et al., 2004; Putzke et al., 2002). Furthermore, difficulties in the road and transport system of Nepal could have made the physical health of the SCI participants more challenging. This can be supported by a previous study done in Hong Kong where the physical activities and mobility of persons with paraplegia were limited by the overcrowded environmental situation in Hong Kong (Hu et al., 2008). Another reason for the lower score on physical health could be because of the common complications in the participants of this study such as chronic pain, urinary tract infection, constipation, pressure sore, spasticity, and insomnia. The existence of health related complications after SCI were found to impair the QoL in persons with SCI (Lidal et al., 2008; Middleton, Leong, & Mann, 2008; Middleton, Mann, & Leong, 2008). The presence of these complications could have caused SCI participants to be dependent on medical substances and medical aids. A previous study advocated for the increased need of medical care in persons with SCI (Hu et al., 2008). The findings of this study, in regard to the lower score on physical health, are consistent with a previous study done in persons with SCI (Hu et al., 2008; Saadat et al., 2010; Trgovcevic et al., 2014).

In contrast, higher score was found on psychological health and social health domain. Various factors (e.g., belief in pain, chronic illness, and marital support) may contribute in better psychological and social health of the persons with SCI. First, Nepal is a country with a majority of Hindu people who usually accept and cope well to situations because they believe that suffering is a consequence of an inappropriate action done in the past or present (Whitman, 2007). In this study, the participants stated that they had adjusted to the challenging consequences and accepted the reality of the situation. A long term period of SCI (1 to 24 years) in this study could be the second reason that contributed in persons with SCI to develop coping strategies over time and adjust well to the challenging consequences of SCI (Crewe & Krause, 2009; Westgren & Levi, 1998). Furthermore, more than half of the participants were married in this study. Marriage is believed to increase the social support (Cutrona, 1986; Holt-Lunstad, Birmingham, & Jones, 2008). Increased social support was found to be positively related with better mental health, coping adjustment, life satisfaction and overall functioning in persons with SCI (Muller et al., 2012). This could be the reason for better psychological and social health in this study.

Relationship of pain intensity on quality of Life in persons with SCI

In this study, a significantly negative correlation was found between pain intensity and overall QoL and its domains including physical, psychological and social health in persons with SCI. This finding is consistent with the SMM of Dodd et al. (2001) that stated that symptom experience influences the outcome of the participants. Similarly, in a study done among persons with multiple sclerosis, better scores were seen across almost all domains of QoL in the non-pain group compared with the pain group (Douglas et al., 2009). This suggests that pain intensity could be an independent factor that lowered the QoL in persons with SCI beyond that caused by a neurological disability. Moreover, the possible explanations for the significant negative relationship of pain intensity with physical, psychological and social health domain of QoL are stated in the following paragraph.

Physical health. In line with a previous study (Douglas et al., 2009), this study found a significant negative correlation between pain intensity and the physical health domain of QoL. In a study done among participants with other types of chronic pain, such as fibromyalgia and multiple sclerosis, the pain intensity had a significant influence on physical activity of daily living (Douglas et al., 2009; Jones, Rutledge, Jones, Matallana, & Rooks, 2008), mobility and dependence on medication and continuous care (Douglas et al., 2009). This could be because of the fatigue induced by pain since persons with high chronic pain were nine times more likely to have chronic fatigue (Craig et al., 2013).

Psychological health. The presence of chronic pain was found to provide a negative impact on the psychological health of persons with SCI (Jensen et al., 2005). In line with a previous study done among persons with SCI (Wen et al., 2013) and multiple sclerosis (Douglas et al., 2009; Kalia & OConnor, 2005), the current study showed a significant negative correlation between pain intensity and the psychological health of persons with SCI. Participants with a high level of pain are more likely to have an elevated depressive mood (Ataoglu et al., 2013; Craig et al., 2013; Hoffman, Bombardier, Graves, Kalpakjian, & Krause, 2011). Furthermore, a depressive mood (Craig et al., 2013; Duenas, Ojeda, Salazar, Mico, & Failde, 2016; Hoffman et al., 2011), frustration, irritability, impatience, and anger are the common psychological emotions induced by chronic pain (Henwood & Ellis, 2004), which could endanger one’s coping skills resulting in a lower QoL (Duenas et al., 2016).

Social health. The finding in the present study found a significant negative correlation between pain intensity and the social health of persons with SCI that was consistent with a previous study (Ataoglu et al., 2013). In regards to a spousal relationship, persons with neuropathic pain reported difficulty in maintaining the spousal relationship and physical intimacy (Closs, Staples, Reid, Bennett, & Briggs 2009). Sexual arousal, positioning, aggravating pain, loss of confidence, and fear of lowered performance were the common sexual complaints reported by persons with chronic pain conditions (Ambler, de C Williams, Hill, Gunary, & Cratchley, 2001).

Previous studies have identified a negative association between pain intensity and sexual activity among persons with chronic pain conditions (Biering-Sorensen, Hansen, & Biering-Sorensen, 2012; Douglas et al., 2009). Furthermore, the presence of chronic pain limits one's ability to perform the usual family role, reduces contact with family and friends, develops social withdrawal and difficulty planning social activities in advance due to fear of unavoidable pain (Closs et al., 2009). This limitation influenced negatively on social integration in SCI persons with chronic pain (Jensen et al., 2005; Wen et al., 2013).

Environmental. In this study no significant negative association was found between pain intensity and the environmental health of persons with SCI. This can be supported by a previous study done among persons with multiple sclerosis where no significant difference was found between the participants with pain and participants without pain in environmental health (Douglas et al., 2009).

Relationship of pain interference on quality of life in persons with SCI

In this study, pain interference was significantly negatively correlated to the QoL in persons with SCI. This finding was consistent with a previous study of Andresen et al. (2016) and Modirian et al. (2010) where pain interference influenced the QoL in persons with SCI. Pain can interfere with the basic activities of daily living including general activities, mood, and sleep which affected the physical functioning, psychological functioning, and social integration in persons with SCI (Jensen et al., 2005; Stoelb et al., 2008).

In this study, there was a significant association of overall pain interference (daily activities, mood, and sleep) and the overall QoL and all QoL domains in persons with SCI. Pain interference in daily activities could have decreased the work capacity and mobility (Douglas et al., 2009) that provoked negative feelings (Miguel & Kraychete, 2009), and deprivation on family and societal participation (Closs et al., 2009), thus lowering the QoL in participants of this study.

Likewise, the presence of pain causes frequent awakening which interfered with the ability to maintain a sleep pattern (Smith, Perlis, Smith, Giles, & Carmody, 2000). Since, a reciprocal relationship was identified between sleep disturbance and pain in earlier studies (Moldofsky, 2001), disturbance of sleep could have provoked pain which decreased the QoL in persons with SCI as in the earlier paragraph explanation of the association of pain intensity with the QoL in persons with SCI was provided.

Overall, greater fatigue associated with pain could have increased the pain related interference with daily activities (Douglas et al., 2009), sleep disturbance (Henwood & Ellis, 2004), and a negative influence on mood (Miguel & Kraychete, 2009). Moreover, a change in pain interference was found to change the status of the QoL in persons with SCI including overall life satisfaction, physical health, and mental health (Putzke et al., 2002).

According to the SMM, symptom experience and symptom management are related to outcome (Dodd et al., 2001). The results of this study showed that chronic pain experience, pain management strategies, and quality of life in persons with SCI seemed to be related with each other. Moreover, they were possibly influenced by three factors which included the personal (e.g., gender, knowledge, employment, income, perception about pain and pain management), health and illness (e.g., pain mechanism, type and level of injury, secondary complications and disability), and environment (e.g., night time, health insurance, marital support).

Chapter 5

Conclusion and Recommendations

A descriptive correlational study design was used to describe the chronic pain experience, pain management strategies, and examine the level of QoL in persons with SCI in Nepal, and to examine the relationship of pain intensity and pain interference on the QoL in persons with SCI. The study was conducted in eight districts of the Bagmati Zone, Nepal from January to March 2017. The instruments used for the collection of data included: (1) Personal, Health and Environment related Data (PHED); (2) International Spinal Cord Injury Pain Basic Data Set version 2.0 (ISCIPBDS-2); (3) Pain Management Questionnaire (PMQ); and (4) WHOQOL-BREF (Nepalese Version). All the questionnaires were validated by five experts (S-CVI=1.00). The test-retest reliability of the ICC for the NRS was found to be .91. Cronbach’s alpha coefficients of pain interference scale and WHOQOL-BREF yielded values of .85 and .80, respectively. Descriptive statistics was used to analyze the study variables and simple content analysis was used to analyze the open-ended questions of pain management strategies. Pearson’s Product Moment Correlation was used to test the relationships of pain intensity and pain interference with the QoL in persons with SCI.

Summary of the Findings

1. Back, lower legs/feet, and buttocks/hip were the most commonly perceived pain locations in the participants of this study. The average pain intensity was at the moderate level (*M*=5.12, *SD*=1.80). In general, the onset of pain was seen within the

first six months of injury. Overall pain interference was at the moderate level (*M*=4.58, *SD*= 2.30).

2. Participants used non-pharmacological pain management strategies more than pain medications to relieve chronic pain. Non-pharmacological management methods, including massage (42.50%), exercise (34.17%), and distraction (22 %), were commonly used because they helped to relieve temporary and chronic pain, distract their mind from suffering and avoid negative consequences of pain medication . Ibuprofen (25.83%) was commonly used as a pain medication because it helped to reduce severe pain. Most of the pain management modalities were done by the participants at home whenever pain started. Half (50.67%) of the participants reported that the effectiveness of pain medications was slightly better. 50 to 78 percent of participants evaluated the effectiveness of non-pharmacological pain management methods as slightly better on pain relief.

3. The QoL in persons with SCI was at the moderate level (*M*=73.14, *SD*=12.90). There was a significant negative correlation of pain intensity and pain interference on QoL in persons with SCI (*r*= -.24, *p* <.01; *r*= -.48, *p* <.01, respectively).

Strengths of the Study

This is the first study done in Nepal that addressed the chronic pain experience, pain management strategies, and QoL in persons with SCI. Moreover, an open ended questionnaire was used to capture detailed information on pain management strategies of persons with SCI. The findings of the study can be useful to provide important information for policy makers and health care providers in Nepal to develop interventions for chronic pain relief and improvement of the QoL in persons with SCI.

Limitations of the Study

The findings of the study were limited because they may not be generalized to persons with SCI in Nepal due to the purposive sampling technique and samples were only from Bagmati Zone of Nepal.

Implications and Recommendations

The implications and recommendations provided for the health policy and health care professionals are as follows.

Health policy and nursing practice

1. The results of the study indicated that persons with SCI living in the community had pain at the moderate level. Based on the study findings, in regards to the fear or misunderstanding of pain medications, health care providers should assess, understand, and provide education for persons with SCI accordingly. The details of the education should be related to the chronic pain in SCI along with the appropriate methods of using pain medications, managing with their side effects and evaluation of the outcomes. Moreover, health care providers should give continuous consultation and regular evaluation on chronic pain by home visits and/or using communication technology (e.g., telephone, internet applications).

2. The findings in this study showed that most participants used massage, exercise, and distraction to reduce chronic pain. Although their effectiveness was

slightly better, these supplemental methods can be used to minimize or cope with chronic pain problems.

3. The results of this study showed that the participants had a QoL at a moderate level. The environment (e.g., financial resource, opportunity for acquiring new information and skills, and physical environment), and the physical health of the QoL(e.g., mobility, dependence on medical aids) showed low scores. Moreover, pain intensity and pain interference were significantly related to QoL. Thus, rehabilitation professionals, occupational workers, social workers, and the government should assess these health problems and provide care and support such as creating more employment opportunities, making transportation accessible, providing insurance and health care facilities, providing adequate information and skills (e.g., psycho-education, relaxation, distraction, and pressure sore management, promoting self-management and preventing secondary complications) to improve the QoL in SCI persons with chronic pain.

Nursing research

1. Future research should be conducted regarding the predictive factors of chronic pain and QoL in persons with SCI such as religious coping and community support. Chronic pain management or QoL enhancing interventions should be conducted by multidisciplinary teams related to the cultural context of Nepal.

2. Replication of the study with a larger sample size extended to other settings is needed for the generalization of the study findings among SCI persons with chronic pain.

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Appendices

Appendix A

Assumption Testing

Table 14

Assumption of Normality by Skewness and Kurtosis of Variables

Variable	Skewness	Std. Error of Skewness	Kurtosis	Std. Error of Kurtosis
Pain intensity	.366	.221	.162	.438
Total quality of life	.023	.221	.756	.438

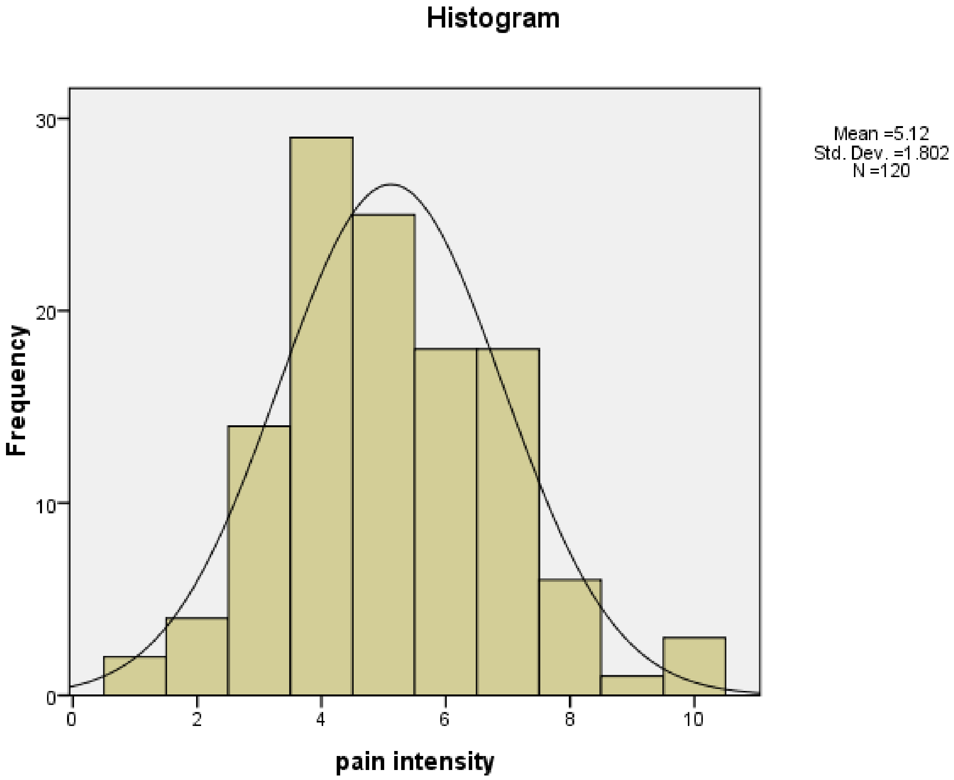


Figure 2. Assumption of Normality of Independent Variable

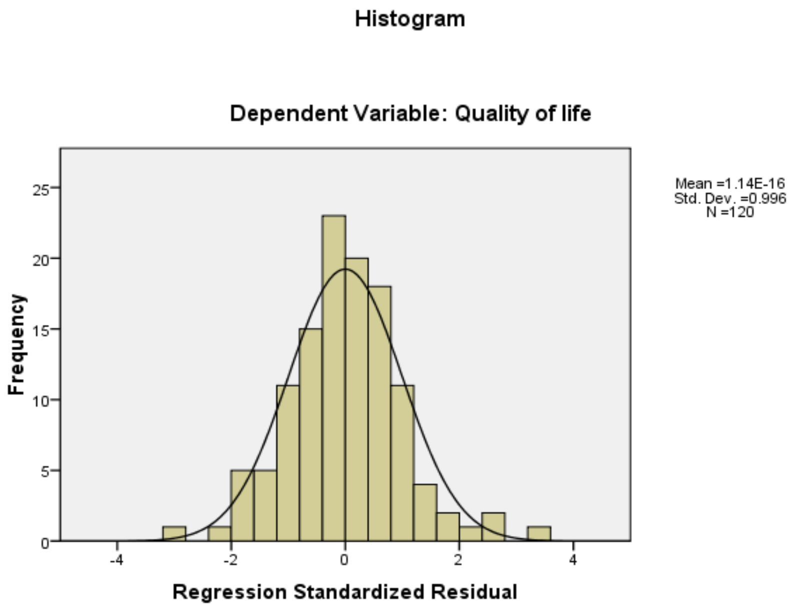


Figure 3. Assumption of Normality of Dependent Variable

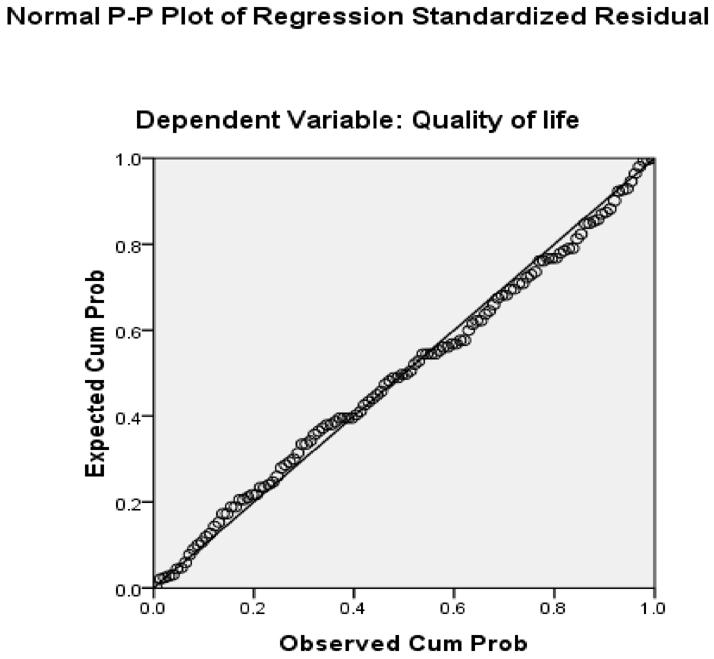


Figure 4. Assumption of Normality and Linearity

Scatter plot

Dependent Variable: Quality of Life

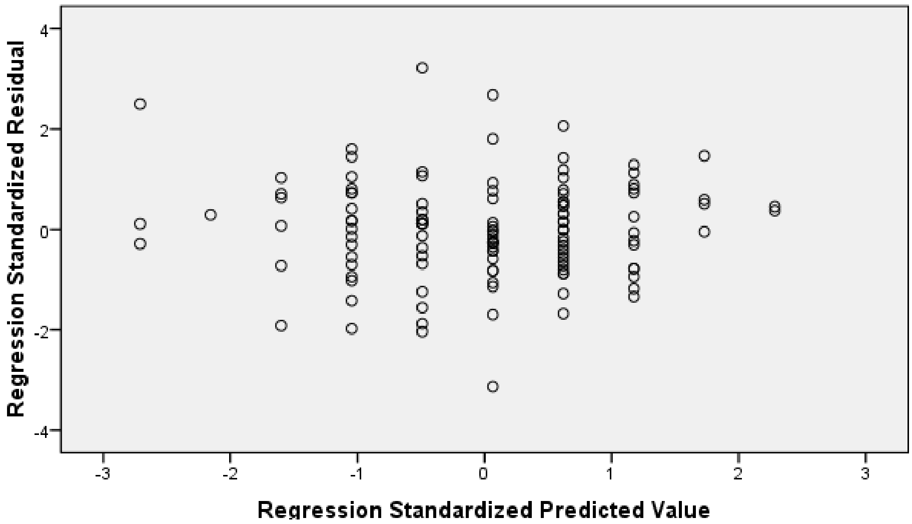


Figure 5. Assumption of Homoscedasticity

Appendix B

Table 15

Steps for Checking, Cleaning, and Computing Domain Scores for the WHOQOL-BREF

Steps	**SPSS syntax for carrying out data checking, cleaning and computing total scores**
Check all 26 items from assessment have a range of 1-5	RECODE Q1Q2Q3Q4Q5Q6Q7Q8Q9Q10Q11Q12Q13Q14Q15Q16 Q17 Q81 Q19 Q20 Q21 Q22 Q23 Q24 Q25 Q26 (1=1) (2=2) (3=3) (4=4) (5=5) (ELSE=SYSMIS).
Reverse 3 negatively phrased items	RECODE Q3 Q4 Q26 (1=5) (2=4) (3=3) (4=2) (5=1). (This transforms negatively framed questions to positively framed questions.)
Compute domain scores	COMPUTE PHYS=MEAN.6(Q3,Q4,Q10,Q15,Q16,Q17,Q18)*4. COMPUTE PSYCH=MEAN.5(Q5,Q6,Q7,Q11,Q19,Q26)*4. COMPUTE SOCIAL=MEAN.2(Q20,Q21,Q22)*4. COMPUTE ENVIR=MEAN.6(Q8,Q9,Q12,Q13,Q14,Q23,Q24,Q25)*4. (These equations calculate the domain scores. All scores are multiplied by 4 so as to be directly comparable with scores derived from the WHOQOL-100. The '.6' in 'mean.6' specifies that 6 items must be endorsed for the domain score to be calculated.)
Transform scores to a 0-100 scale	COMPUTE PHYS=(PHYS-4)*(100/16). COMPUTE PSYCH=(PSYCH-4)*(100/16). COMPUTE SOCIAL=(SOCIAL-4)*(100/16). COMPUTE ENVIR=(ENVIR-4)*(100/16).

Appendix C

Informed Consent Form

Dear participant,

My name is Sagun Thapa. I am a Masters of Nursing Science student at Faculty of Nursing, Prince of Songkla University, Thailand. I am conducting a study entitled “Chronic Pain Experience, Pain management strategies, and Quality of Life in persons with Spinal Cord Injury in Nepal”. This study fulfills the requirement of the Master of Nursing Science Program at Prince of Songkla University. I would like to clarify you about some points that will help you to make a decision to participate in this study.

Procedure:

All the procedures of this study have been approved by: (1) Institutional Review Board of Faculty of Nursing, Prince of Songkla University (2) Nepal Health Research Council, Nepal and (3) Spinal cord Injury Rehabilitation Center, Nepal. If you agree to participate in this study you will be asked some structured and semi structured questions regarding your chronic pain experience, pain management strategies, and Quality of Life. An estimated time will take around 45 minutes.

Purpose and Benefit:

Purpose of the study is to describe the existing status of chronic pain experience, pain management strategies and quality of life of person with Spinal Cord Injury in Nepal. In addition the study aims to explore the relationship between chronic pain experience and quality of life of person with Spinal Cord Injury in Nepal.

Though there is no any direct benefit for you if you participate, but information from the study will be valuable for identifying the need of person with Spinal Cord Injury. This information will help to guide health professional in designing culturally relevant pain relief interventions and to promote quality of life of person with spinal cord injury in future. In addition, if you wish, researcher (being a health professional) will provide you some home remedies that may help you to relieve pain to some extent.

Risks/Harms:

There is no known risk or harm for your participation in this study, however you may feel despair, embarrassed or tired while answering some questions or filling the questionnaires. So if you feel uncomfortable while responding any of the questions you can refuse to participate or skip some question, or withdraw from this study anytime you like without explanation. Refusal to participate in this survey will not affect the service or treatment you have been receiving. Furthermore, if you have more questions about risk and harm of this study, the researcher will clarify without hiding anything.

Anonymity and Confidentiality:

Name of the participants will not be revealed, separate numeric code will be given for each. All the personal information’s of this study will remain confidential. Only the researcher and the research team can access the data. All the information will be used for the purpose of this research project only. The questionnaire will be destroyed after the completion of research and you have right to request verification of data at any time.

Finally, you can review the questionnaires and this consent form for your understanding and decision for the participation. If you have any questions or need more information, please feel free to contact me on +977-9841-142597 or email me at thapa_sagun@yahoo.com**.** If you have any doubt or queries regarding the study or need more information you can also contact my thesis advisor Assistant Professor Dr. Luppana Kitrungrote, Faculty of Nursing, Prince of Songkla University, Hat Yai , email: luppana.k@psu.ac.th

Statement of Consent:

I have read the above description of the study. I have been informed about the procedure, risk and benefits involved, and all my questions have been answered to my satisfaction. In addition, I have been assured that any future questions I may have will be answered by the member of research team. I voluntarily agree to participate in this study.

…………………………	..…………………	…………………
Name of Participant	Signature	Date
…………………………	……………………	…………………
Name of Researcher	Signature	Date

Appendix D

Personal, Health and Environment related Data (PHED)

Section 1: Personal Characteristics

Instruction: Please give the check list (√) on the parenthesis bracket appropriate to your answer where indicated and fill in the blank area.

1) Age : ....years

2) Gender: ( ) Male ( ) Female

3) Religion: ( ) Hindu ( ) Buddhist ( ) Christian ( ) others

4) Marital status: ( ) Single ( ) Married
( ) Divorced, widow or currently not living with spouse

5) Level of education
( ) No education ( ) Primary school
( ) Secondary school ( ) Higher Education

6) Employment status before SCI
( ) Unemployed ( ) Employed (Please specify the profession) …………

7) Employment status after SCI
( ) Unemployed ( ) Employed (Please specify the profession) …………

8) Sufficiency of income: ( ) Yes ( ) No

9) Smoking habit (after SCI) ( ) Yes ( ) No

10) Alcoholic habit (after SCI) ( ) Yes ( ) No

Section 2: Health related Characteristics

1) Age at injury …………………………

2) Date of injury …………………………..

3) Completeness of injury: ( ) Complete ( ) Incomplete ( ) Unknown

4) Severity of injury: ( ) Quadriplegia ( ) Paraplegia

5) Level of injury : ( ) Cervical ( ) Thoracic ( ) Lumbar ( ) Unknown

6) Cause of injury

( ) Road Traffic Accident (specify the cause ………..…)

( ) Fall (specify the cause ………..…)

( ) Natural disaster (specify the cause ………)

( ) others (specify)……………

7) Self-reported health problems/complications after SCI :

( ) Not any ( ) UTI ( ) Constipation ( ) Spasticity

( ) Pressure sore ( ) others …………………

8) Previous trauma related pain experience.

( ) No ( ) Yes (please specify)………

Section 3: Environmental Characteristics

1) Family type: ( ) Nuclear ( ) Extended

2) Number of family member ……….

3) Availability of assisting aids:

( ) No use of assisting aid ( ) Use of assisting aid (specify the types…..)

4) Place of residence: ( ) Rural ( ) Urban

5) Support from external source: (Government/ Non-government)

( ) Not any ( ) Financial ( ) Material ( ) Insurance ( ) Others…….

6) Access to technology ( ) Internet users ( ) Non Internet Users

Appendix E

International Spinal cord Injury Pain Basic Data Set version 2.0 (ISCIPBDS-2)

Date of data collection: YYYY/MM/DD

Have you had any pain during the last seven days including today:

No ☐ Yes ☐

If yes:

Please note that the time period during the last week applies to all pain interference questions.

In general, how much has pain interfered with your day to day activities in the last week?

No Interference Extreme Interference

0	1	2	3	4	5	6	7	8	9	10

In general, how much has pain interfered with your overall mood in the last week?

No Interference Extreme Interference

0	1	2	3	4	5	6	7	8	9	10

In general, how much has pain interfered with your ability to get a good night's sleep?

No Interference Extreme Interference

0	1	2	3	4	5	6	7	8	9	10

How many different pain problems do you have?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ ≥ 5

Please describe your three worst pain problems:

Worst pain problem:

Pain locations/sites **(Can be more than one, so check all that apply):** **right (R), midline(M), or left (L)**	**R**	**M**	**L**	**Intensity and Date of pain onset**
Head				**Intensity and Date of pain onset** **0=no pain ; 10= pain as bad as you can imagine** ☐0; ☐1; ☐2; ☐3; ☐4; ☐5; ☐6; ☐ 7; ☐ 8; ☐9; ☐10 **Date of onset: …...……/……../…….** **YYYY / MM / DD**
Neck/shoulders	▨	▨	▨	
Throat				
Neck				
Shoulder		▨		
Arms/hands	▨	▨	▨	
Upper arms		▨		
Elbow		▨		
Forearm		▨		
Wrist		▨		
Hands/fingers		▨		
Frontal torso/genitals	▨	▨	▨	
Chest				
Abdomen				
Pelvis/genital				
Back	▨	▨	▨	
Upper back				
Lower back				
Buttocks /hips	▨	▨	▨	
Buttocks		▨		
Hip		▨		
Anus	▨		▨	
Upper leg/thigh		▨		
Lower legs/feet	▨	▨	▨	
Knee		▨		
Shin		▨		
Calf		▨		
Ankle		▨		
Foot/toes		▨		

Second worst pain problem:

Pain locations/sites **(Can be more than one, so check all that apply):** **right (R), midline(M), or left (L)**	**R**	**M**	**L**	**Intensity and Date of pain onset**
Head				**Intensity and Date of pain onset** **0=no pain ; 10= pain as bad as you can imagine** ☐0; ☐1; ☐2; ☐3; ☐4; ☐5; ☐6; ☐ 7; ☐ 8; ☐9; ☐10 **Date of onset: …...……/……../…….** **YYYY / MM / DD**
Neck/shoulders	▨	▨	▨	
Throat				
Neck				
Shoulder		▨		
Arms/hands	▨	▨	▨	
Upper arms		▨		
Elbow		▨		
Forearm		▨		
Wrist		▨		
Hands/fingers		▨		
Frontal torso/genitals	▨	▨	▨	
Chest				
Abdomen				
Pelvis/genital				
Back	▨	▨	▨	
Upper back				
Lower back				
Buttocks /hips	▨	▨	▨	
Buttocks		▨		
Hip		▨		
Anus	▨		▨	
Upper leg/thigh		▨		
Lower legs/feet	▨	▨	▨	
Knee		▨		
Shin		▨		
Calf		▨		
Ankle		▨		
Foot/toes		▨		

Third worst pain problem:

Pain locations/sites **(Can be more than one, so check all that apply):** **right (R), midline(M), or left (L)**	**R**	**M**	**L**	**Intensity and Date of pain onset**
Head				**Intensity and Date of pain onset** **0=no pain ; 10= pain as bad as you can imagine** ☐0; ☐1; ☐2; ☐3; ☐4; ☐5; ☐6; ☐ 7; ☐ 8; ☐9; ☐10 **Date of onset: …...……/……../…….** **YYYY / MM / DD**
Neck/shoulders	▨	▨	▨	
Throat				
Neck				
Shoulder		▨		
Arms/hands	▨	▨	▨	
Upper arms		▨		
Elbow		▨		
Forearm		▨		
Wrist		▨		
Hands/fingers		▨		
Frontal torso/genitals	▨	▨	▨	
Chest				
Abdomen				
Pelvis/genital				
Back	▨	▨	▨	
Upper back				
Lower back				
Buttocks /hips	▨	▨	▨	
Buttocks		▨		
Hip		▨		
Anus	▨		▨	
Upper leg/thigh		▨		
Lower legs/feet	▨	▨	▨	
Knee		▨		
Shin		▨		
Calf		▨		
Ankle		▨		
Foot/toes		▨		

Numeric Pain rating Scale

Please indicate the intensity of average pain of 1 week on a scale of 0 (No pain) to 10 (Worst pain imaginable)

0 1 2 3 4 5 6 7 8 9 10

No pain	**Worst pain imaginable**

Appendix F

Pain Management Questionnaire (PMQ)

	Strategies to manage chronic pain in SCI for the pain problems…………………………											
	What	Why	Who	Where	When	How often		Effectiveness of pain management				
						Method	Frequency	Made pain worse	had no effect	slightly better	considerably better	Disappear
1												
2												
…												

Note (Please explain in detail):

1. What are the pharmacological or non-pharmacological strategies you use to manage your chronic pain in SCI?
2. Why do you use those pharmacological or non-pharmacological strategies to manage your chronic pain in SCI?
3. Who help you to receive those pharmacological or non-pharmacological strategies to manage your chronic pain in SCI?
4. Where do you get those pharmacological or non-pharmacological pain managements strategies from/at?
5. When do you get those pharmacological or non-pharmacological strategies to manage chronic pain in SCI?
6. How do you deliver those pharmacological or non-pharmacological strategies to manage your chronic pain in SCI?
7. How often do you deliver those pharmacological or non-pharmacological strategies to manage your chronic pain in SCI?
8. Rate the perceived effectiveness (how effectiveness) of those pharmacological or non-pharmacological strategies to manage your chronic pain in SCI

Appendix G

WHOQOL-BREF (Nepalese Version)

Instructions

This assessment asks how you feel about you quality of life, health or other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response.

Please read each questions, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

		Very poor	Poor	Neither poor nor good	Good	Very good
1	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about how much you have experienced certain things in the last two weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5	How much do you enjoy life?	1	2	3	4	5

6	to what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	An extreme amount
7	How well are you able to concentrate?	1	2	3	4	5
8	How safe do you feel in your daily life?	1	2	3	4	5
9	How healthy is your physical environment?	1	2	3	4	5

The following questions ask you about how completely you experience or were able to do certain things in the last two weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
10	Do you have enough energy for everyday life?	1	2	3	4	5
11	Are you able to accept your bodily appearance?	1	2	3	4	5
12	Have you enough money to meet your needs	1	2	3	4	5
13	How available to you is the information that you need in your day to day life?	1	2	3	4	5
14	To what extend do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very Good
15	How well are you able to get around?	1	2	3	4	5

The following questions ask about how good or satisfied you have felt about various aspects of your life over the last two weeks.

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16	How satisfied are you with your sleep	1	2	3	4	5
17	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18	How satisfied are you with your capacity of your work?	1	2	3	4	5
19	How satisfied are you with yourself?	1	2	3	4	5
20	How satisfied are you with your personal relationships?	1	2	3	4	5
21	How satisfied are you with your sex life?	1	2	3	4	5
22	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24	How satisfied are you with your access to health services?	1	2	3	4	5
25	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last two weeks.

		Never	Seldom	Quite often	Very often	Always
26	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

Appendix H

List of Experts for Validation of Instruments

1. Dr. Sumidtra Prathep (M.D)

   Anesthesiologist

   Department of Anesthesiology, Faculty of Medicine, Prince of Songkla University, Thailand

2. Assist. Prof. Dr. Sasikaan Nimmaanrat (M.D)

   Anesthesiologist

   Department of Anesthesiology, Faculty of Medicine, Prince of Songkla University, Thailand

3. Assoc. Prof. Dr. Natenapha Khupantavee

   Department of Surgical Nursing, Prince of Songkla University, Thailand

4. Mrs. Duangpen Waewwanjit

   Advanced Practice Nurse

   Trauma Unit of Songklanagarind Hospital, Thailand

5. Assist. Prof. Saurab Sharma

   Consultant Physiotherapist

   Kathmandu University School of Medical Science, Nepal

Appendix I

List of Experts for Translation of Instruments

1. English version to Nepalese Version

   Assist. Prof. Kalpana Poudel Aryal, MN

   Medical & Surgical Nursing

   Tribhuvan University, Nepal

   Email: kalpanapaudel1@gmail.com

2. Back translations from Nepali version to English version

   Dr. Prabhat Lamichhane , A PhD student of public health

   Email: prabhatone@gmail.com

3. Checked discrepancy, clarity and cultural relevancy of two versions of English questionnaires by an independent reviewer

   Assist. Prof. Saurab Sharma, Physiotherapist and a Lecturer

   Kathmandu University School of Medical Science, Nepal

   saurabsharma1@gmail.com

4. Working group of ISCIPBDS-2 was contacted for identifying to check the equivalence and appropriateness of the original English version and the 'back-translated' version.

   Dr. Mark Jensen

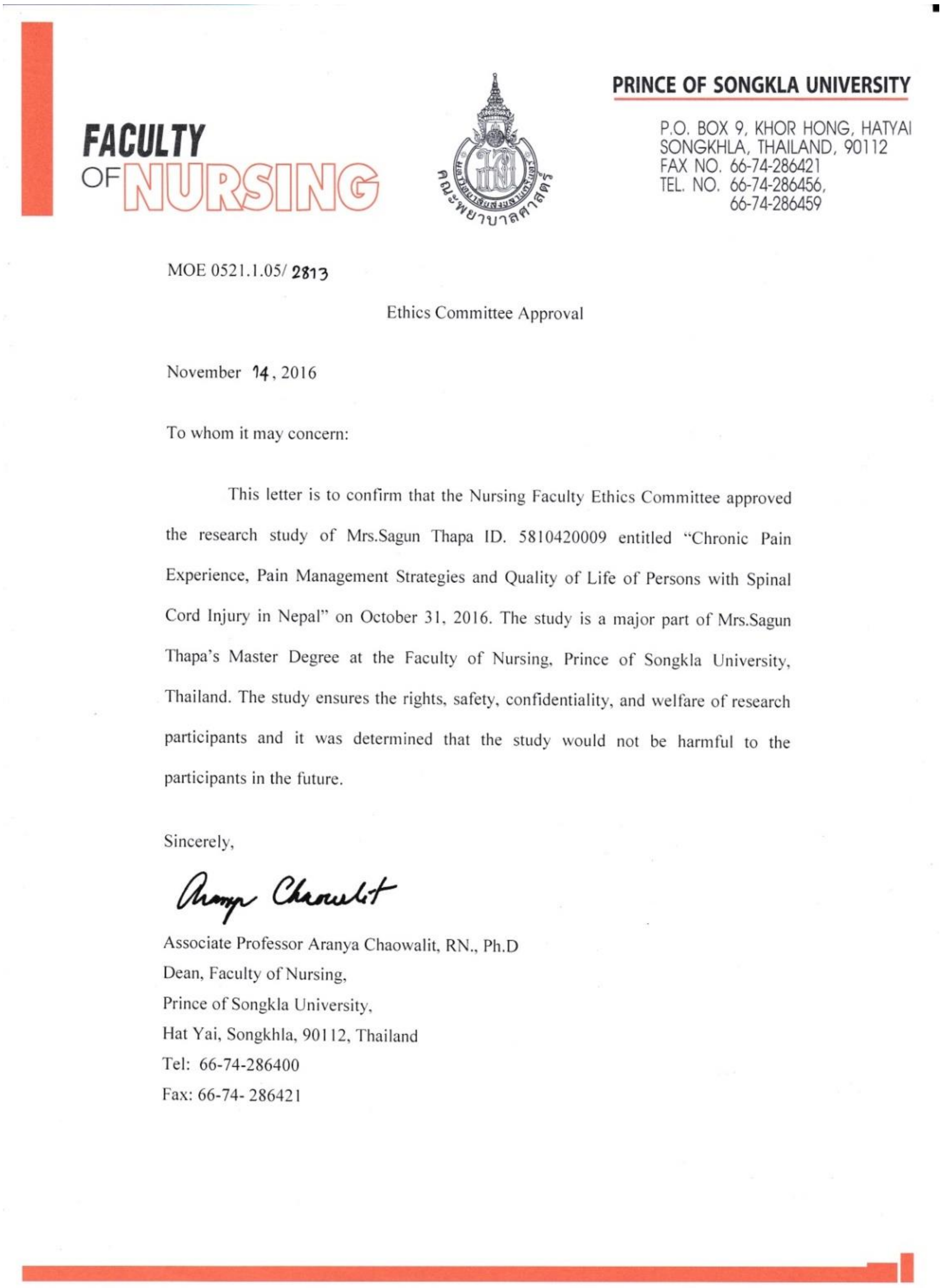
   Professor and vice chair for research of the Department of Rehabilitation Medicine

   mjensen@uw.edu

Appendix J

Letters of Ethical Consideration and Permission

1. Ethics Committee Approval Letter From Faculty of Nursing, Prince of Songkla University



FACULTY OF NURSING

PRINCE OF SONGKLA UNIVERSITY
P.O. BOX 9, KHOR HONG, HATYAI
SONGKHLA, THAILAND, 90112
FAX NO. 66-74-286421
TEL. NO. 66-74-286456,
66-74-286459

MOE 0521.1.05/ 2813

Ethics Committee Approval

November 14, 2016

To whom it may concern:

This letter is to confirm that the Nursing Faculty Ethics Committee approved the research study of Mrs.Sagun Thapa ID. 5810420009 entitled "Chronic Pain Experience, Pain Management Strategies and Quality of Life of Persons with Spinal Cord Injury in Nepal" on October 31, 2016. The study is a major part of Mrs.Sagun Thapa's Master Degree at the Faculty of Nursing, Prince of Songkla University, Thailand. The study ensures the rights, safety, confidentiality, and welfare of research participants and it was determined that the study would not be harmful to the participants in the future.

Sincerely,

Aranya Chaowalit

Associate Professor Aranya Chaowalit, RN., Ph.D
Dean, Faculty of Nursing,
Prince of Songkla University,
Hat Yai, Songkhla, 90112, Thailand
Tel: 66-74-286400
Fax: 66-74- 286421

2. Letter of Ethical Approval From Nepal Health Research Council (NHRC), Nepal

Government of Nepal
Nepal Health Research Council (NHRC)

Ref. No.: 1298

22 January 2017

Ms. Sagun Thapa
Principal Investigator
Prince of Songkla University

Subject: Approval of research proposal entitled **Chronic pain experience, pain management strategies and Quality of life of persons with spinal cord injury in Bagmati zone, Nepal**

Dear Ms. Thapa,

It is my pleasure to inform you that the above-mentioned proposal submitted on **15 December 2016** (**Reg.no. 449/2016** please use this Reg. No. during further correspondence) has been approved by NHRC Ethical Review Board on **18 January 2017**.

As per NHRC rules and regulations, the investigator has to strictly follow the protocol stipulated in the proposal. Any change in objective(s), problem statement, research question or hypothesis, methodology, implementation procedure, data management and budget that may be necessary in course of the implementation of the research proposal can only be made so and implemented after prior approval from this council. Thus, it is compulsory to submit the detail of such changes intended or desired with justification prior to actual change in the protocol before the expiration date of this approval. Expiration date of this study is **July 2017.**

If the researcher requires transfer of the bio samples to other countries, the investigator should apply to the NHRC for the permission. The researchers will not be allowed to ship any raw/crude human biomaterial outside the country; only extracted and amplified samples can be taken to labs outside of Nepal for further study, as per the protocol submitted and approved by the NHRC. The remaining samples of the lab should be destroyed as per standard operating procedure, the process documented, and the NHRC informed.

Further, the researchers are directed to strictly abide by the National Ethical Guidelines published by NHRC during the implementation of their research proposal and submit progress report and full or summary report upon completion.

As per your research proposal, the research amount is **NRs. 36,000** and accordingly the processing fee amount to **NRs. 10,000.** It is acknowledged that the above-mentioned processing fee has been received at NHRC.

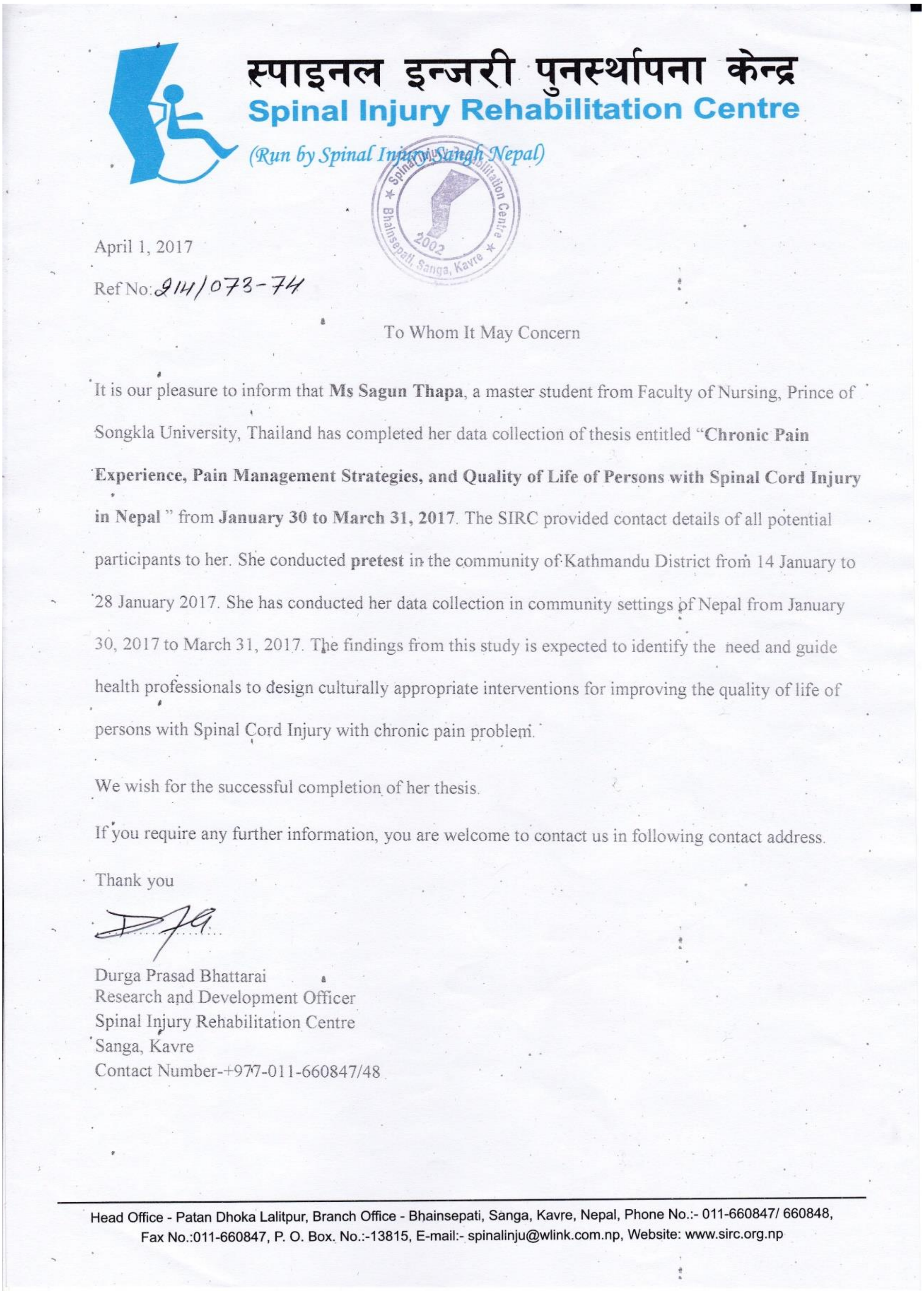
If you have any queries, please feel free to contact the Ethical Review M & E section of NHRC.

Thanking you,

Dr. Khem Bahadur Karki
Member-Secretary

Tel: +977 1 4254220, Fax: +977 1 4262469, Ramshah Path, PO Box: 7626, Kathmandu, Nepal
Website: http://www.nhrc.org.np, E-mail: nhrc@nhrc.org.np

3. Letter of Ethical Approval From Spinal Injury Rehabilitation Center, Nepal



स्पाइनल इन्जरी पुनर्स्थापना केन्द्र
Spinal Injury Rehabilitation Centre
(Run by Spinal Injury Sangh Nepal)

April 1, 2017

Ref No: 914/073-74

To Whom It May Concern

It is our pleasure to inform that **Ms Sagun Thapa**, a master student from Faculty of Nursing, Prince of Songkla University, Thailand has completed her data collection of thesis entitled "**Chronic Pain Experience, Pain Management Strategies, and Quality of Life of Persons with Spinal Cord Injury in Nepal** " from **January 30 to March 31, 2017**. The SIRC provided contact details of all potential participants to her. She conducted **pretest** in the community of Kathmandu District from 14 January to 28 January 2017. She has conducted her data collection in community settings of Nepal from January 30, 2017 to March 31, 2017. The findings from this study is expected to identify the need and guide health professionals to design culturally appropriate interventions for improving the quality of life of persons with Spinal Cord Injury with chronic pain problem.

We wish for the successful completion of her thesis.

If you require any further information, you are welcome to contact us in following contact address.

Thank you

Durga Prasad Bhattarai
Research and Development Officer
Spinal Injury Rehabilitation Centre
Sanga, Kavre
Contact Number-+977-011-660847/48

Head Office - Patan Dhoka Lalitpur, Branch Office - Bhainsepati, Sanga, Kavre, Nepal, Phone No.:- 011-660847/ 660848,
Fax No.:011-660847, P. O. Box. No.:-13815, E-mail:- spinalinju@wlink.com.np, Website: www.sirc.org.np

Appendix K

Letters of Permission of using the instruments

1. Permission Letter of using ISCIPBDS-2

From Mark P. Jensen (mjensen@uw.edu)

Date and Time 3 June, 2016, 7:24 PM

To Sagun Thapa (thapa_sagun@yahoo.com)

Dear Sagun Thapa,

The SCI International Data Set is in the public domain, which means that you have permission to use any or all of the items as you wish, and you do not need specific permission to do so. So please, feel free to use the items in your thesis!

Best regards,

Mark Jensen

Professor and Vice Chair for Research

Department of Rehabilitation Medicine

University of Washington

Mail address:

Harborview Medical Center

325 Ninth Avenue

Seattle, WA 98104-2499

Voice Mail: 206-543-3185

2. Permission Letter of using WHOQOL-BREF (Nepalese Version)

From	whoqol@who.int
Date and Time	03 September, 2016, 5:25 PM
To	Sagun Thapa (thapa_sagun@yahoo.com)

Dear Sagun Thapa,

Thank you for the form. Please find attached the Nepali version of the tool, along with related materials.

Best regards,

Sibel Volkan (Mrs)
WHOQOL
Information, Evidence and Research (IER) Department
The World Health Organization
20 Avenue Appia
CH-1211 Geneva 27
Switzerland

VITAE

Name Mrs. Sagun Thapa

Student ID 5810420009

Educational Attainment

Degree	Name of Institution	Year of Graduation
Diploma in Nursing	C.T.E.V.T	2008
Post Basic Bachelor in Nursing	Chakrabarti HaBi Education Academy (CHEA), Nepal	2012

Scholarship Award during Enrolment

Thailand Education Hub for Southern Region of ASEAN Countries (TEH-AC), Scholarship, Funded by the Graduate school, Prince for Songkla University, Thailand

Work Experience

Worked as a Research assistant in Center for Research on Environmental Health and Population Activities (CREHPA), Kathmandu, Nepal since February 2009 to January 2011

Worked as a Nursing Instructor in HAMS Nursing College, Kathmandu, Nepal since September 2013 to November 2014