Common Symptoms Experience, Symptoms Management, and Quality of Life of Nepalese People With Spinal Cord Injury and Family Caregivers

Mandira Baniya

A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of Master of Nursing Science in Adult and Gerontological Nursing (International Program)
Prince of Songkla University
2019

Common Symptoms Experience, Symptoms Management, and Quality of Life of Nepalese People With Spinal Cord Injury and Family Caregivers

Mandira Baniya

A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of Master of Nursing Science in Adult and Gerontological Nursing (International Program)
Prince of Songkla University
2019

Thesis Title	Common Symptoms Experience, Symptoms Management, and Quality of Life of Nepalese People With Spinal Cord Injury and Family Caregivers
Author	Ms. Mandira Baniya
Major Program	Adult and Gerontological Nursing (International Program)

Major Advisor	**Examining Committee:**
……………………………………… (Asst. Prof. Dr.Luppana Kitrungrote)	…………………………......Chairperson (Assoc. Prof. Dr.Waraporn Kongsuwan)
Co-advisor	……………………………….Committee (Asst. Prof. Dr.Luppana Kitrungrote)
……………………………………… (Asst. Prof. Dr.Jintana Damkliang)	……………………………….Committee (Asst. Prof. Dr.Jintana Damkliang)
	……………………………….Committee (Asst. Prof. Dr.Sudsiri Hirunchunha)

The Graduate School, Prince of Songkla University, has approved this thesis as partial fulfillment of the requirements for the Master of Nursing Science Degree in Adult and Gerontological Nursing (International Program).

………………………………………
(Prof. Dr.Damrongsak Faroongsarng)
Dean of Graduate School

This is to certify that the work here submitted is the result of the candidate's own investigations. Due acknowledgement has been made of any assistance received.

………………………………...Signature
(Asst. Prof. Dr.Luppana Kitrungrote)
Major Advisor

………………………………...Signature
(Ms. Mandira Baniya)
Candidate

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

………………………………...Signature
(Ms. Mandira Baniya)
Candidate

Thesis Title	Common Symptoms Experience, Symptoms Management, Quality of Life of Nepalese People With Spinal Cord Injury and Family Caregivers
Author	Ms. Mandira Baniya
Major Program	Adult and Gerontological Nursing (International Program)
Academic Year	2018

ABSTRACT

The descriptive study was aimed to describe common symptoms experience, symptoms management, and the level of the quality of life (QoL) among people with spinal cord injury (SCI) and family caregivers (FCs) in Nepal. A total number of 123 people with SCI and 98 FCs were randomly recruited from the 13 districts of Province No. 3, Nepal. A set of questionnaires for people with SCI consisted of (1) Demographics, Health and Illness, and Environment Data Form of People with Spinal Cord Injury, (2) International Spinal Cord Injury Pain Basic Data Set version 2.0 (ISCIPBDS-2), (3) Penn Spasm Frequency Scale (PSFS), (4) Patient Health Questionnaire (PHQ-9), (5) Symptoms Management Questionnaire of People with Spinal Cord Injury (SMQ-SCI), and (6) Spinal Cord Injury Quality of Life-23 (SCI QL-23). The instruments for data collection of the FCs were: (1) Demographics, Health and Illness, and Environment Data Form of Family Caregivers, (2) Pain Experience Questionnaire (PEQ), (3) Zarit Burden Interview-short Form (ZBI-12), (4) Patient Health Questionnaire (PHQ-9), (5) Symptoms Management Questionnaire of Family Caregivers (SMQ-FCs), and (6) World Health Organization Quality of Life (WHOQOL-BREF). The questionnaires were validated by five experts (S-CVI=1.0). For the total number of samples of SCI, Cronbach’s alphas were .73 for the

ISCIPBDS-2, .89 for the PSFS, .84 for the PHQ-9, and .78 for the SCI QL-23. For the total number of FCs, Cronbach’s alphas were .78 for the PEQ, .85 for the ZBI-12, .79 for the PHQ-9 of FCs, and .86 for the WHOQOL-BREF. Descriptive statistics were used to analyze the data of study variables. Simple content analysis was used to analyze the open-end questions of symptoms management. The findings showed the following;

People with SCI had common symptoms experiences that were pain (100%), spasticity (59.3%), and depressive mood (84.5%). The worst first three most common pain locations were back, buttocks/hip, and upper leg/thigh. Pain severity was at a moderate level (*M* = 3.5, *SD* = 0.9) and pain frequency was at a high level (*M* = 6.0, *SD* = 1.6). The frequency and severity of spasticity were at moderate levels (*M* = 2.2, *SD* = 0.8, *M* = 2.1, *SD* = 0.5, respectively). Depressive mood was at a moderate level (*M* = 11.0, *SD* = 4.2). The participants used non-pharmacological management more than pharmacological management to reduce these symptoms based on beliefs, preferences, convenience, and community resources. The non-pharmacological management methods commonly used by SCI people to relieve pain were tolerance followed by distraction and massage; to decrease spasticity exercise was used, followed by positioning, and eating animal nutrients (traditional usage); and to reduce depressive mood distraction was used, followed by sharing feelings, and spiritual practices. Half of the people with SCI sometimes used medications such as anticonvulsants and non-opiate drugs to relieve pain and they used muscle relaxants to reduce spasticity. The effectiveness of using non-pharmacological management was found to be slightly better in controlling the symptoms, whereas the levels in the use of medications were found to be slightly to much better in controlling symptoms.

Moreover, the three domains of QoL, which included problems (perceived loss of independence and other issues relating to injury) (*M* = 56.9, *SD* = 21.5); functioning (physical and social limitations) (*M* = 52.2, *SD* = 30.7); and mood (distress and depressive feelings) (*M* = 45.6, *SD* = 16.9), were found at moderate levels.

The FCs had common symptoms experience that were burden (100%), LBP (71.4%), and depressive mood (54.1%). FCs had a moderate level of LBP (*M* = 4.1, *SD* = 1.7) with a frequency of more than two times a week. Overall, the severity of burden was at a moderate level (*M* = 19.2, *SD* = 8.0), and severity of depressive mood was at a mild level (*M* = 8.7, *SD* = 2.9). The types of management for common symptoms used by FCs were non-pharmacological methods with similar reasons as the persons with SCI as mentioned above. They used tolerance followed by massage, and exercises to reduce LBP; they used spiritual practice, distraction, and sharing of feelings to lessen burden; and they used spiritual practice, distraction, and crying to decrease depressive mood. The FCs evaluated the effectiveness of these management methods at slightly better to much better levels of relieving symptoms. In using pain medications, one-fourth of the FCs used NSAIDs to reduce LBP whenever, and most of them reported feeling much better. The four domains of the QoL of FCs were at moderate levels. The scores of the physical domain and social relationship domain were at 56, whereas the psychological domain and environment domain scores were at 50.

The findings of this study are beneficial for the health professionals in being aware of the common symptoms experienced and in providing continuing care by developing symptom management strategies for people with SCI and FCs while living in the community in order to improve QoL related to the context of Nepal.

ACKNOWLEDGEMENT

First and foremost, it is a genuine pleasure for me to express my sincere gratitude and appreciation to my advisor Asst. Prof. Dr. Luppana Kitrungrote for her meticulous scrutiny, scholarly advice, scientific approach and the dedication to help me accomplish this task in every possible way. I also would like to extend my heartiest gratitude to my co-advisor Asst. Prof. Dr. Jintana Damkliang, who has encouraged and guided me throughout the study period. I owe a deep gratitude to the chairperson of International Program of Master of Nursing Science, Assoc. Prof. Dr. Waraporn Kongsuwan for her unconditional support, inspiration, and motivation to achieve my goals. A special thanks to all the lecturers at the Faculty of Nursing, Prince of Songkla University, for their willingness to guide me and answer my queries related to my study.

I would like to extend my appreciation to the Thailand Education Hub for Southern Region of ASEAN Countries (TEH-AC) for their full scholarship for my study and Graduate School, Prince of Songkla University for partial thesis grant support. Furthermore, my gratitude to the Spinal Injury Rehabilitation Center (SIRC), National Trauma Center, and Tribhuvan University Teaching Hospital, Nepal for the support during the data collection. I cannot thank enough to all the keen participants of the study for sharing their personal and sensitive information. Finally, I am truly indebted to my family for their unconditional love and support throughout this study.

Mandira Baniya

Contents

Contents (Continued)

Contents (Continued)

List of Tables

List of Tables (Continued)

Table **Page**

List of Figure

Figure **Page**

Chapter 1

Introduction

This chapter consists of the background and significance of the problem, objectives, research questions, conceptual framework, the definition of terms, the scope of the study, and the significance of the study**.**

Background and Significance of the Problem

According to the World Health Organization (2013), globally every year, between 250,000 and 500,000 people sustain spinal cord injury (SCI). In the United States, 17,700 new SCI cases were identified (National Spinal Cord Injury Statistical Center, 2018). The incidence of SCI ranges from 13 to 220 per million people from 2005 to 2007 in developing countries (Sabre et al., 2015). In Nepal, the incidence of people with SCI ranged from 600-3,500 annually (Rahimi-Movaghar et al., 2013).

Spinal cord injury results in motor and sensory deficits along with somatic and autonomic dysfunctions (den Braber-Ymker, Lammens, van Putten, & Nagtegaal, 2017). These consequences lead to a wide range of physical and psychological problems in people with SCI (Jensen, Kuehn, Amtmann, & Cardenas, 2007). Previous studies showed that patients after SCI experienced physical and psychological symptoms. Sequentially, the physical symptoms frequently found were pain (62-88%) (Inoue, Taguchi, Yamashita, Nakamura, & Ushida, 2017; Naghosi et al., 2016), spasticity (71-86%) (Bravo-Esteban et al., 2013; DiPiro, Li, & Krause, 2018), fatigue (31-54%) (Nooijen et al., 2015; Smith et al., 2016), sleep problems (20-50%) (January, Zebracki, Chlan, & Vogel, 2015; Sauri et al., 2017), and neurogenic bladder and bowel (40%) (Cameron et al., 2015). Likewise, psychological symptoms were depression (74%) (Abuddi et al., 2017) and anxiety (32%) (Le & Dorstyn, 2016). Studying both physical and psychological symptoms commonly found in people with SCI is important for health professionals to understand and provide proper symptom management strategies.

Chronic pain had the highest occurrence in people with SCI, and it was constant or intermittent (Inoue et al., 2017). The majority of people with SCI perceived severe pain (Andresen et al., 2016; Muller et al., 2017). Spasticity was the second-highest occurred symptom. In a longitudinal study, the severity of spasticity was found to increase in more than half of respondents at six months follow-up (Bravo-Esteban et al., 2013; DiPiro et al., 2018). The frequency of spasticity can be 1 to 10 or more spasms per day (McKay, Sweatman, & Field-Fote, 2018). In addition, psychological symptoms of people with SCI generally developed when physical symptoms occurred in the long-term. The most common psychological symptom was depressive mood (Abuddi et al., 2017; Khazaeipour, Taheri-Otaghsara, & Naghdi, 2015). The severity of depressive mood was at moderate to severe among the majority of people with SCI (Al Abbudi et al., 2017).

According to the Symptom Management Model (SMM), Dodd et al. (2001) reported that persons who have symptoms will seek strategies to delay or decrease symptoms experience by using pharmacological and non-pharmacological methods on their own or with the help of others. For example, SCI people in the communities used analgesics such as opioids, non-steroidal anti-inflammatory drugs (NSAIDs), antidepressants (Fann et al., 2011; Heutink, Post, Wollaars, & Asbeck, 2011), anticonvulsants (Sadosky, Parsons, Emir, & Nieshoff, 2016), sedatives, and muscle relaxants (Karsy & Hawryluk, 2017) to reduce their symptoms. Moreover, previous studies conducted in Western countries showed that in the communities, non-pharmacological methods used by people with SCI were physical modalities (e.g., massage, exercise, heat application), psychological interventions (Hearn & Finlay, 2018), cognitive modalities, and spiritual practices (Li, Lin, Tsai, & Tsay, 2017).

Symptoms experience and symptoms management are related to a person’s outcomes (e.g., symptom status, functional status, self-care, and quality of life) (Dodd et al., 2001). Quality of life (QoL) is amongst the outcomes that refer to the general well-being of individuals and societies (WHO, 1997) that sums up the negative and positive features of life (Dijkers, 1997). A previous study found lower QoL as reported by people with SCI (Andresen et al., 2016). There was a greater impact on physical health compared to mental health (Guest, Perry, Tran, Middleton, & Craig, 2014). Another study showed a lower score on environmental health, and the physical health, psychological health followed, with the lowest score in the social health of the people with SCI (Franca, Coura, França, Basílio, & Souto, 2011). However, QoL among Nepalese people with SCI was at a moderate level with higher psychological health and lower environmental health (Thapa, Kitrungrote, & Damkliang, 2017).

Due to the presence of mobility impairment and various symptoms in people with SCI, they usually depend on caregivers for daily activities, relief of symptoms, self-care, and financial needs (McCoy, 2016). However, continuous caregiving for personal care resulted in family caregivers (FCs) developing physical and psychological symptoms (Darragh et al., 2015).

Previous literature showed a high occurrence, severity, and frequency of physical and psychological symptoms experienced among the FCs of SCI patients such as burden (88%) (Khazaeipour et al., 2017), low back pain (LBP) (64.6%)

(Paieemas, Patpiya, Preeda, & Siriwan, 2018), and depressive mood (40%) (Rodawisky, Skidmore, Rogers, & Schulz, 2013). Caregiver burden was the highest occurring symptom that usually was displayed at a moderate to severe level (Khazaeipour et al., 2017; Ma, Lu, Xiong, Yao, & Yang, 2014). Low back pain was the second common symptom of FCs of SCI patients with moderate severity (Sherpa, Kitrungrote, & Sae-Sia, 2017). LBP frequency was found to occur daily (20%), ‘always’ (12.5%), and ‘almost always’ (18.9%) (Suzuki et al., 2016). Moreover, some individuals with sensitivities and responsibilities such as taking care of SCI patients are very susceptible to developing depression (Otaghsara Matin, Latifi, & Norouzi, 2014). Therefore, several researchers found that depression was the most common psychological symptom reported among the FCs of people sustaining SCI (Arango-Lasprilla et al., 2010; Rodawisky et al., 2013). For example, in a study conducted among FCs of people with SCI, 17%, 12%, and 8% had mild, moderate, and severe depressive levels, respectively (Kelly et al., 2011). Arango-Lasprilla et al. (2010) found that 43% of the FCs of SCI people had mild depression. The impacts of those common symptoms of the FCs decreased in functioning impairment, negative general health, and low QoL (Suzuki et al., 2016).

To reduce or delay the negative consequences of symptom experiences, FCs used several strategies including pharmacological and non-pharmacological approaches. For example, they used NSAIDs and opioids (White, Arnold, Norvell, Ecker, & Fehling, 2011), massage, and heat therapy to reduce their LBP (Dehghan & Farahbod, 2014). Social support, coping skills, and good family functioning were reported to mediate caregiver burden (Baker, Barker, Sampson, & Martin, 2017). A previous study showed that psychosocial intervention significantly decreased depression among the FCs (Elliott, Brossart, Berry, & Fine, 2008).

Symptoms experience and symptoms management are related to QoL among the FCs of people with SCI (Lynch & Cahalan, 2017; McCoy, 2016). The QoL of the FCs was low in the physical domain followed by pain, vitality, and emotional aspect (Nogueira, Rabeh, Caliri, & Dantas 2016). In a study conducted in Nepal, the overall QoL of FCs of people with SCI was at a moderate level with higher social health and low environmental health (Sherpa, Kitrungrote, & Sae-Sia, 2018).

According to the SMM (Dodd et al., 2001), three domains including personal, health and illness, and environment influenced an individual's perception in symptoms experience, symptoms management, and outcomes. Most of the previous researches were conducted in developed nations (e.g., European countries, United States of America, Canada, Australia, and Turkey) that had different contexts from Nepal such as religion and beliefs, health care services, and the physical environment. Nepal is a country with Hinduism as a dominant religion. Hindu followers believe that pain or suffering is caused by the wrong or inappropriate activities conducted in the past or present also known as "Karma." Hence, Hindu people generally cope with the pain by tolerating the pain (Whitman, 2007). In contrast, the people in the Western cultures prefer to get suggestion from the health professionals for minor or major health related problems (Carteret, 2011). The high cost related to medical care and comparatively cheaper traditional health care may be the reason that several Nepalese people seek traditional methods to solve their health related problems (Bhattarai, Parajuli, Rayamajhi, Paudel, & Jha, 2015).

Moreover, the geographical diversity, predominance of mountain regions, and lack of accessible transportation system still pose a challenge in several parts of the country (Government of Nepal Ministry of Health, 2017). Therefore, to reach a nearby city, a majority (around 90%) of people residing in rural areas may require to walk several hours or even days (The University of British Columbia, n.d.). In Nepal, the health care system is centralized (Shah, Shrestha, & Subba, 2013) but in the health care services of developed countries, the government enforces that the health of the citizens are protected by insurance system with added provisions for individual with disability (Ridic, Gleason, & Ridic, 2012). Therefore, in the light of these differences, the previous findings may not be generalized to symptoms experience, symptoms management, or QoL of Nepalese people with SCI and the FCs.

In Nepal, there is little existing knowledge related to symptoms experience, symptoms management, and the QoL of people with SCI and the FCs. Thapa et al. (2017) conducted a study of 120 Nepalese people with SCI and found that they had a moderate level of chronic pain. Most of them used non-pharmacological measures more than pharmacological measures and their QoL was at a moderate level. Sherpa et al. (2017) conducted a study in 103 Nepalese FCs of people with a physical disability and found they had LBP at a moderate level. Most of them used non-pharmacological measures for pain relief and their QoL was at a moderate level. Moreover, Bhattarai, Maneewat, and Sae-Sia (2018a) studied 82 Nepalese SCI people from the earthquake of 2015 and found that 54% of SCI people had a low level of resilience.

Although previous studies in Nepal contributed important information, gaps of knowledge still exist because they focused on pain symptoms of people with SCI and the FCs of people with a physical disability. However, these groups of people have experience in several symptoms and used various management strategies to maintain their QoL. Moreover, the previous researchers used non-random sampling by recruiting samples from a single center (the Spinal Injury Rehabilitation Center) that possibly limited the generalization of their findings. Therefore, this study aims to describe common symptoms experience (i.e., pain, spasticity, and depressive mood in Nepalese people with SCI and LBP, burden, and depressive mood in the FCs), based on the highest prevalence in previous studies, symptoms management, and their QoL. The results of this study will provide essential information for the nurses and health care professionals to understand and plan effective symptoms management to improve the QoL of Nepalese people with SCI and the FCs.

Objectives of the Study

1. To identify the common symptoms experience (i.e., pain, spasticity, and depressive mood), symptoms management, and the QoL of people with SCI.
2. To identify the common symptoms experience (i.e., low back pain, burden, and depressive mood), symptoms management and the QoL of the FCs of people with SCI.

Research Questions

1. What are the common symptoms experience (i.e., pain, spasticity, and depressive mood), symptoms management, and QoL of people with SCI?
2. What are the common symptoms experience (i.e., pain, spasticity, and depressive mood), symptoms management, and quality of life of the FCs of people with SCI?

Conceptual Framework of the Study

The SMM (Dodd et al., 2001), along with the integration of the concept of QoL obtained from the literature, was used to guide this study regarding common symptoms experience, symptoms management, and the QoL of SCI patients and the FCs. According to Dodd et al. (2001), the SMM consists of three dimensions: (1) symptom experience; (2) symptom management; and (3) outcomes. Furthermore, three domains conceptualized as contribution factors, influence the three dimensions. The domains are person, health and illness, and the environment.

Nursing dimensions

Symptom experience. According to Dodd et al. (2001), symptom experience includes the individual's perception of the symptoms, evaluation of the symptoms, and response to the symptoms. Perception of the symptoms refers to a change which an individual observes in their feelings or behavior. After a symptom is perceived, an individual makes a judgement and evaluate the intensity, frequency, location, and the affective impact of the symptom on their lives. The response of the symptom refers to the response of an individual related to the physical, mental, and behavioral changes (Dodd et al., 2001).

Symptom management strategies. The goal of symptom management is to avert or delay a negative outcome through biomedical, professional, and self-care strategies (Dodd et al., 2001). The revised model of symptom management includes the specification of what (the nature of the strategy), how much/how often (dose of intervention), who/whom, why (reason), how it is delivered, when (time), and where (place) of management. The effectiveness of the strategy is also measured. Management of symptoms begins with an assessment of the symptom experience based on individual perspective. Symptom management comprises the specifications of symptom management strategies i.e., what, how much, why, when, where, whom, and who. Evaluation of symptom management is vital to determine the effectiveness of the symptom management on a positive outcome and decrease the negative consequences (Dodd et al., 2001).

Outcomes. The outcomes result from management strategies or symptoms experience. The eight components are: (1) symptom status; (2) functional status; (3) emotional status; (4) self-care; (5) mortality; (6) morbidity and comorbidity; (7) cost; and (8) QoL (Dodd et al., 2001). QoL was selected in this study. However, Dodd et al. (2001) did not provide the details of QoL in the SMM. Therefore, the researcher provides the following explanation for QoL.

QoL refers to the general well-being of individuals and societies (WHO, 1997) and sums up the negative and positive features of life (Dijkers, 1997). QoL is “an individuals’ perception of their position in life in the context of culture and value system in which they live and in relation to their goals, expectations, standards, and concerns” (WHOQOL Group as cited in Skevingkton et al., 2004, p. 299). QoL is encapsulated within the four broad concepts which are multidimensional namely physical health, psychological condition, social relationship, and relationship with the environment (WHO, 1997). Apart from general well-being, specific health status and health-related QoL are both important for people with illness because they can vary from person to person due to different disease. The major aspects of life can be evaluated including physical state and activities in daily life, emotional status and intellectual functioning, social interaction and performance of social roles, and feelings of general satisfaction or well-being (Lundqvist et al., 1997).

Nursing domains

Three dimensions of the SMM influence the three nursing domains which are (1) person domain, (2) health and illness domain, and (3) environment domain (Dodd et al., 2001). In this study, the common symptoms experience and symptoms management and QoL are described, whereas the nursing domains will be used for discussion.

SCI usually occurs because of vertebral injuries leading to damage of the peripheral nervous system, somatic nervous system, and autonomic nervous system. The loss of sensory, motor and autonomic functions occurs and induces secondary complications among SCI people (Hou & Rabchevsky, 2014). Therefore, they perceive changes in their physio-psychological health, evaluate them by making a judgment, and provide a response to the symptoms. They use several management strategies to reduce or delay the symptoms and maintain outcomes (e.g., QoL). However, the physical impairment and mental alternations from the chronic illness caused by an SCI requires long-term care from their family members and the task of continuous caregiving negatively changes the health of the FCs. Once the FCs perceive and evaluate their symptoms, they will use various methods to effectively relieve their symptoms and maintain their QoL.

Definition of Terms

Common symptoms experience. This refers to the perception and evaluation of physical and psychological changes in people with SCI and the FCs while providing care at home. It consists of three frequent symptoms of people with SCI, namely (1) pain, (2) spasticity, and (3) depressive mood and the three symptoms of the FCs are (1) low back pain, (2) burden, and (3) depressive mood. A high score means high symptom frequency and severity.

The symptoms experience in people with SCI and FCs was measured by questionnaires related to each symptom, namely (1) International Spinal Cord Injury Pain Basic Data Set-2.0, Nepali version (Thapa et al., 2018), (2) Penn Spasm Frequency Scale (Adams, Ginis, & Hicks, 2007), and (3) Patient Health Questionnaire-9, Nepali version (Bhattarai et al., 2018b) for people with SCI. For the FCs, the questionnaires included (1) Pain Experience Questionnaire, Nepali version (Sherpa et al., 2018), (2) Short Form Zarit Burden Interview (Bedard et al., 2001), and (3) Patient Health Questionnaire, Nepali version (Bhattarai et al., 2018b). High scores mean high symptom frequency and severity.

Symptoms management. This refers to any kind of strategy, activity or action used by the SCI people and FCs to relieve or delay each symptom. The management includes (1) what was the strategy, (2) how often/how much of the strategy, (3) who/whom helped/delivered the strategy, (4) why/the reasons of using the strategy, (5) how the strategy was conducted, and (6) when they managed the symptom. These symptom managements were measured using the Symptoms Management Questionnaire of people in the Spinal Cord Injury and the Symptoms Management Questionnaire of Family Caregivers developed by the researcher based on the literature review.

Quality of life. The QoL of people with SCI refers to how people with SCI perceived/felt about their functioning, mood, and problems. The QoL of FCs refers to the perception of FCs regarding physical, psychological, social, and environmental health (WHO, 1996). The QoL of SCI people was measured using the Spinal Cord

Injury Quality of Life Questionnaire and QoL (SCI QL-23) and QoL for the FCs was assessed using the World Health Organization Quality of Life (WHOQOL-BREF) (Nepalese version).

Scope of the Study

This study was conducted among people with SCI and FCs residing in the 13 districts of Province No. 3 in Nepal from February to May 2019.

Significance of the Study

The findings of this study contribute to providing baseline data for future research related to the common symptoms experience, symptoms management, and QoL in people with SCI and FCs in Nepal. Therefore, the nurses and health care professionals are able to apply the proper symptoms management strategies to people with SCI and the FCs to improve QoL related to the Nepal context.

Chapter 2

Literature Review

This chapter includes the review of literature related to common symptoms experience, symptoms management strategies, and quality of life of people with spinal cord injury and family caregivers. The literature review topics are as follows.

1. Overview of Spinal Cord Injury and the Impacts on People With Spinal Cord Injury and Family Caregivers
2. Symptom Management Model
3. Common Symptoms Experience of People With Spinal Cord Injury, and Factors, and Assessments
4. Symptoms Management of People With Spinal Cord Injury, and Factors and Assessments
5. Quality of Life of People With Spinal Cord Injury, and Factors and Assessments
6. Common Symptoms Experience of Family Caregivers of People With Spinal Cord Injury, and Factors and Assessments
7. Symptoms Management of Family Caregivers of People With Spinal Cord Injury, and Factors and Assessments
8. Quality of Life of Family Caregivers of People With Spinal Cord Injury, and Factors and Assessments
9. Health Care Service for People With Spinal Cord Injury and Family Caregivers and Existing Studies in Nepal
10. Summary

Overview of Spinal Cord Injury and the Impact on People With Spinal Cord Injury and Family Caregivers

This section will include location of injury, pathophysiology, SCI and impact on people with SCI, and impact on the FCs.

Spinal cord injury refers to any damage to the spinal cord resulting from trauma, disease or degeneration (WHO, 2013). Up to 90% of SCI is due to traumatic causes (WHO, 2013). In developing countries, the leading cause of SCI was a fall from a height (Mathur et al., 2015; Shrestha, 2014). However, in developed countries, road traffic accidents were the major cause of SCI (White & Black, 2018).

Locations of injury

The locations of SCI are categorized based on the levels of vertebrae that cervical (C1-C8) level vertebra, thoracic (T1-T12) vertebrae, and lumbar (L1-L5) (Smeltzer, Bare, Hinkle, & Cheever, 2010).

Cervical injury. Cervical injury commonly includes the 5th, 6th, and 7th level of cervical spine (Smeltzer et al., 2010). Cervical spine is comparatively more susceptible to SCI due to less stable. Cervical level injury causes paralysis of bilateral upper and lower limbs resulting in tetraplegia or quadriplegia (Smeltzer et al., 2010). Higher-level injuries at C1-4 are the most severe of the SCI levels and require artificial breathing assistance and complete assistance with all activities of daily living (ADL) (Chhabra, 2015).

Thoracic level injury. Since the rib cage protects the thoracic level vertebra T1 to T10, extreme injury causes damage at the thoracic level (Smeltzer et al., 2010). Amongst the thoracic vertebrae, the 12th vertebra is the most common site of SCI. The patients with T1-L1 level injury can perform the ADL with minimal assistance and can operate a manual wheelchair (Chhabra, 2015). The patients with the level of injury at T1 (first thoracic spinal nerve) and below, do not normally have a neurological deficit in their upper limbs and this is referred to as paraplegia (Smeltzer et al., 2010).

Lumbar level injury. The first lumbar vertebra is the most common site of SCI among the lumbar vertebrae (Smeltzer et al., 2010). The cauda equina can be affected (Chabbra, 2015). Most people injured at a lumbar level can independently perform the activities daily life and can also perform functional ambulation with the help of their knee, ankle, foot orthoses, crutches or cane (Chabbra, 2015).

Pathophysiology

SCI most commonly occurs because of vertebral injuries, as a result of acceleration, deceleration, or deformation forces leading to effects in three divisions of the peripheral nervous system; somatic nervous system affecting sensation and muscle function, autonomic nervous system affecting autonomic function of the bowel; bladder; renal and sexual functions and the enteral nervous system affecting bowel motility (den Braber-Ymker et al., 2017; Karlsson, 2006). Initially, there is primary mechanical damage that involves compression, contusion, a laceration to a complete transaction of the spinal cord followed by the second phase where vascular damage, hemorrhage and biochemical change can lead to a reduction in the cord tissue perfusion (Chhabra, 2015; Smeltzer et al., 2010). In addition to a decrease in tissue perfusion, neurons are unable to store glucose. Thus, ischemia and cell death can occur very quickly (Chhabra, 2015). Normal activities of spinal cord cells below the level of activity are disturbed because of the loss of continuous tonic discharge from the brain which leads to compromised cardiovascular, respiratory, urinary, gastrointestinal, thermoregulatory, and sexual activities (Chhabra, 2015; Karlsson, 2006). Physical impairments below the level of injury include paralysis, flaccidity in muscles, loss of sensation, loss of bowel and bladder control, hypotension, and poor venous circulation (Chhabra, 2015). These impairments can potentially cause several symptoms that severely interfere with the daily living of people with SCI.

Severity of injury

According to the American Spinal Injury Association (ASIA), SCI is classified based on the sensory and motor function preserved after SCI. SCI is categorized neurologically into “complete” or “incomplete” (Kirshblum et al., 2011). A complete SCI is a total loss of sensory, motor and autonomic functions below the level of injury. Incomplete SCI has some sensory or motor fibers, or both preserved below the level of injury which must include the last two sacral segments (S4-5). The ASIA Impairment Scale (AIS) is used in grading the degree of impairment in the following way (Kirshblum et al., 2011):

a) ASIA-A (complete injury): No motor or sensory function is preserved in the sacral segments S4–S5.

b) ASIA-B (incomplete injury): Sensory function preserved but not motor function is preserved below the neurological level and includes the sacral segments S4-S5.

c) ASIA-C (incomplete): Motor function is preserved below the neurological level, and more than half of the key muscles below the neurological level have a muscle grade less than three.

d) ASIA-D (incomplete): Motor function is preserved below the neurological level, and at least half of the key muscles below the neurological level have a muscle grade of three or more.

e) ASIA-E (incomplete): Motor and sensory functions are normal.

Spinal cord injury and the impacts on people with spinal cord injury

Physical functional alterations. The dysfunctions of the peripheral nervous system and autonomic nervous system will interfere with the physical functions that are respiratory, cardiovascular, urinary bladder, bowel, musculoskeletal, sensation, as well as nutrition and exercise depending on the level and severity of the SCI**.**

Respiratory function alterations. The respiratory alteration following an SCI is the result of ventilatory dysfunction due to the weakened or paralyzed ventilatory muscles (Chhabra, 2015). The ability to breathe deeply and cough forcefully is impaired depending on the level and completeness of the SCI, with greater dysfunction seen at higher injury levels (Berlowitz, Wadsworth, & Ross, 2016). A patient with a complete injury above C5 will typically have impaired diaphragm function and is likely to require a period of endotracheal intubation and mechanical ventilation. SCI above T9 causes greater impairment of the lungs. Secretions may accumulate in the lungs either through increased production or decreased clearance secondary to impaired cough (Berlowitz et al., 2016).

Cardiovascular function alterations. The changes in the cardiovascular system following an SCI are caused by loss of supraspinal sympathetic control, which correspond to a relatively increased parasympathetic and decreased sympathetic activity. This results in changes in the heart rate and the arterial blood pressure causing arrhythmia, in particular, bradycardia with the risk of cardiac arrest or tachyarrhythmia mostly in those with cervical or high thoracic injuries (Berlowitz et al., 2016; Biering-Sørensen et al., 2018).

Autonomic dysreflexia is a constellation of signs and/or symptoms following SCI in response to noxious or non-noxious stimuli below the neurological level of injury usually seen in individuals injured at or above the T6 spinal cord level (Bauman, Milligan, Lee, & Riva, 2012). This condition is characterized by transient episodes of severe hypertension resulting from massive sympathetic discharge (Biering-Sørensen et al., 2018) and with or without the following symptoms: headache, flushing, piloerection, stuffy nose, sweating above the neurological level of injury, vasoconstriction below the neurological level of injury, and dysrhythmias (Bauman et al., 2012). The presentation of this syndrome may range from asymptomatic to mildly uncomfortable or even life-threatening.

Bowel function alterations. Bowel dysfunction is more frequent in patients with motor complete SCI (ASIA Grades A and B) but is also present in those with motor incomplete SCI. However, the mechanism of bowel dysfunction is similar in complete and incomplete injuries (Cameroon et al., 2015; Valles, Vidal, Clavé, & Mearin, 2006). Colonic transit time is an important mechanism in bowel dysfunction in SCI patients. Bowel dysfunction is categorized into three patterns (Valles et al., 2006). Pattern A corresponds to an SCI with a neurologic level above T7 (without voluntary control of abdominal muscles). It is characterized by frequent constipation and infrequent incontinence with moderate delay in colonic transit time, and the absence of anal relaxation during the defecatory maneuver. Pattern B corresponds to patients with a neurologic level below T7 (with voluntary control of abdominal muscles) and is characterized by frequent constipation associated with significant defecatory difficulty and occasional incontinence and with a moderate delay in colon transfer time, the capacity to increase intra-abdominal pressure, and increased anal resistance during the defecatory maneuver. Lastly, pattern C presents in below T7 injuries without sacral reflexes, characterized by not very frequent constipation with less defecatory difficulty and greater severity of incontinence associated with a severe delay in colonic transit time (Valles et al., 2006).

Bladder function alterations. The bladder function is reliant on co-ordination between both central and peripheral nervous systems. There is reciprocal innervation of the bladder and external sphincter to facilitate storage and emptying phases. After SCI, either of these can be altered (Hamid et al., 2018). The consciousness of bladder filling might not be totally absent after SCI; however, voluntary inhibition of the micturition reflex is lost. Typical urodynamic findings include detrusor overactivity and detrusor striated sphincter dyssynergia. The discoordinated contraction will result in high voiding pressure, residual urine volume, and urinary incontinence that, if not treated, will result in upper tract deterioration and renal failure (Al Taweel & Seyam, 2015).

Spinal cord injury at the sacral level results in parasympathetic decentralization of the bladder and denervation of the sphincter. In cases of a complete lesion, conscious awareness of bladder filling is lost, and the micturition reflex is absent. Clients can have highly compliant, acontractile bladder with a competent but non-relaxing smooth and striated sphincter that retains a fixed tone. However, low bladder compliance can occur (Al Taweel & Seyam, 2015).

Musculoskeletal function alterations. Spinal cord injury alters or eliminates supraspinal control of structures distal to the injury**.** Loss of supraspinal control results in a decrease in locomotor capabilities (Clark & Findley, 2017). A musculoskeletal problem arises due to neurological damage that causes continued loss of neural transmission below the site of injury, and there is a decrease or loss of both voluntary and autonomic functions and the emergence of some neurochemistry (Betz, Murray, Patel, & Nanda, 2015; Clark & Findley, 2017). Energy utilization and glucose metabolism are fundamentally altered in SCI, and there are muscle catabolism and wastage in the lower limbs (Clark & Findley, 2017). There is a rapid and sustained loss of bone mass in the sub-lesional skeleton. After approximately 18 months, bone mass density is reduced by around 30% compared to the time of injury. The bone loss in SCI is important because it greatly increases fracture risk (Betz et al., 2015; Clark & Findley, 2017).

Sensation/pain alterations. Spinal cord injury results in the altered or absent sensory function below the level of injury. Due to varying degrees of preserved motor function, the individual with SCI is limited in his/her ability to increase sensory feedback through his/her interaction with the environment. Sensory deprivation is defined as an 'absolute reduction of sensory input' (Crossman, 1996). Pain is a consequence of sensory dysfunction. According to Yezierski (as cited in D’Angelo et al., 2013), although the pain mechanism after SCI is not fully explored, pain could occur because of the physiological change due to interaction of four main components namely, anatomical, neurochemicals, excitotoxicity, and inflammatory changes in the spinal cord, brain or peripheral nerve (D’Angelo et al., 2013). Two major types of pain are acute pain and chronic pain (Smeltzer et al., 2010).

Nutrition and exercise reduction. Persons with chronic SCI have several metabolic disturbances. As a consequence of inactivity and the body compositional changes of decreased skeletal muscle with a relative increase in adiposity, a state of insulin resistance and hyperinsulinemia has been demonstrated to exist, associated with abnormalities in oral carbohydrate handling. In most scenarios, overestimation of basal metabolic needs and may lead to excessive caloric intake. In a person with a thoracic level injury, the basal metabolic rate may range between 1,500-1,700 kcal/day and may become as low as 900 kcal/day in a person with tetraplegia (Khalil et al., 2013).

Although exercise guidelines are not fully established following SCI, there is a consensus among researchers and rehabilitation scientists that engaging in an active lifestyle including daily exercise is highly recommended for persons with SCI to reverse several of the negative adaptations (Khalil et al., 2013). SCI results in denervation of the sub-lesional bones and the neural lesion itself may play a pivotal role in the development of osteoporosis after SCI

Psychosocial alterations. Psychosocial health can be described as the state of being mentally, emotionally, and socially well. Three key components of psychosocial health are a psychological condition, community participation, psychological condition and QoL which may be particularly compromised among individuals with SCI (Kelly & Vogel, 2013). Psychological adjustment to SCI is a gradual and individualized process and can continue throughout a person’s life demanding new challenges to overcome (Ducharme & Parashar, 2015).

Among the psychological problems after SCI, depression is the most common (Agtarap et al., 2017; Williams & Murray, 2015). In the early phase of SCI, it is common to have temporary depressed mood (Post & Leeuwen, 2012). However, severe depression can affect physical functioning and QoL (Chhabra, 2015;

Ebrahimzadeh, Soltani-Moghaddas, Birjandinejad, Omidi-Kashani, & Bozorgnia, 2014). Furthermore, body image refers to a psychological experience of embodiment which is more than physical appearance (Cash, 2004) and affects the psychological health (van Diemen, van Leeuwen, van Nes, Geertzen, & Post, 2017). SCI has consequences on how the patients with SCI perceive themselves and interact with their surroundings, including potential partners (Bassett, Martin, & Buchholz, 2009). After SCI, the changes in body posture might result in a changed body image as a seated posture drastically changes the position of the body's center of mass. People with SCI are generally in a seated or lying position and must integrate these new postures and devices such as a wheelchair, into their daily lives (Chhabra, 2015). Similarly, employment is a form of participation after SCI for a psychosocial adjustment (Murphy, Middleton, Quirk, De Wolf, & Cameron 2011). However, employment rates after SCI ranged from 27-35% (Huang, 2017; Kang, Shin, & Kim, 2014; Monreo, Zidarov, Raju, Boruff, & Ahmed 2017; Ottomanelli & Lind, 2009) which is a cause for concern since lack of employment increase financially dependency on others.

Impacts of people with spinal cord injury on family caregivers

With the advancement in medical treatments, people with SCI are living longer (Strauss, DeVivo, Paculdo, & Shavelle, 2006). However, they have chronic morbidities and live with mobility impairment, paraplegia or quadriplegia (Monreo et al., 2017). A person who was once dependent to perform his/her daily activities has different needs now and is dependent on a family caregiver (FCs) for necessity care after discharge from a health center (McCoy, 2016). Common caregiving tasks include providing ADLs (e.g., bathing, dressing, toileting, and eating), cooking, laundry, shopping, wound dressing care, performing urinary catheterization, monitoring the patient’s medical state, medications, accompanying the patient to health care appointments, assisting a patient with transportation, and managing any emotional problems.

However, providing care to people with a disability along with other routine responsibilities in the long term (Lawang, Horey, & Blackford, 2015) could predispose the FCs to physical and psychological problems. Previous studies showed that common physical problems among FCs are low back pain (LBP) (Bardak, Erhan, & Gunduz 2012; Paieemas, et al., 2018), burden (Khazaeipour et al., 2017), and depression (Arango-Lasprilla., 2010; Otaghsara, Matin, Latifi, & Norouzi, 2014). Along with the negative impact on the FCs’ health, it also affects their abilities to provide ongoing care to the people with SCI (Lawang et al., 2015) which can ultimately compromise the health of people with SCI.

In summary, SCI causes alterations in physical and psychological functions in the patients. The effect on the peripheral nervous system, both somatic and autonomic nervous system, causes the physical symptoms after an SCI. Moreover, psychosocial problems occur secondary to prolonged physical symptoms. People with SCI need continuing care from family caregivers throughout their lives. FCs are the key persons who maintain people with SCI in a community by giving them for ADL, health maintenance, financial and emotional support. However, caregiving in the long-term influences the FCs’ physical and psychological health.

Symptom Management Model

The Symptom Management Model (SMM) (Dodd et al., 2001) was first introduced by a group of researchers from the University of California, in the year 1994. The SMM has influences from the concept of Orem’s self-care model and additional related models i.e., anthropology, sociology, and psychology. Since, the Orem’s self-care model and other related models could not completely represent the role of an individual in self-care and the person’s experience, his/her chosen management strategies or the desired outcome. Hence, based upon this limitation of the previous models and further testing, Dodd and colleague revised the model in 2001 (Smith & Liehr, 2013).

Dimensions of the Symptom Management Model. The SMM has three conceptualized dimensions which are the main variables of the SMM. They are (1) symptom experience; (2) symptom management; and (3) outcomes.

Symptom experience. The SMM defines ‘symptom’ as “a subjective experience reflecting changes in bio-psychological functioning, sensation or cognition of the individual” (Dodd et al., 2001, p. 669) whereas a sign refers to any abnormal disease indicator which either an individual themselves or others can identify (Dodd et al., 2001). In SMM, symptom experience is a combination of three subsets; perception of the symptom followed by evaluation of the symptom, and finally, the response to that symptom. The SMM has a bidirectional relationship (Dodd et al., 2001).

1. Perception of symptoms. Perception of symptom refers to any change that an individual notice in his/her usual feelings or behaviors. It can be interpreted as the ability of the individual to notice changes in his/her normal body functions or recognizing, or/and feeling such symptoms. Assessment requires subjectivity on the part of the person to report the experience of any symptoms (self-report). However, another person may not be able to objectively see the symptom experience.

2. Evaluation of symptoms. After perception of a symptom, an individual makes a judgment and evaluates the symptom in term of intensity, frequency, location along with the affective impact in the life of an individual. A meaning or value is given to the symptom. The value can be measured numerically, by a face or visual scale of the symptom.

3. Response to symptoms. Symptom response refers to the response of an individual to the symptom regarding the changes in the aspects of physical, mental and their behavior (Dodd et al., 2001). The response of one individual can be different from another even though they report the same severity.

Symptom management. The second dimension of the SMM is symptom management strategies. The goal of symptom management is to avert or delay a negative outcome through biomedical, professional and self-care strategies (Dodd et al., 2001). The revised SMM includes the specification of what (the nature/type of the strategy), how much (dose of intervention), how the strategy was delivered, why (reason), who/whom, and when (time), and where about the strategies of symptom management. Symptom management begins with an assessment of individual perspective elated to the symptom experience. The intervention or management program can be performed by the patient himself/herself and/or with the assistance from the caregivers, and health care providers such as nurses or physicians. The intervention program must be evidence-based. One intervention can be effective to manage one symptom or more than one symptom (Dodd et al., 2001).

Outcomes. The outcomes emerge from the management strategies and symptom experience. In the revised SMM, the outcomes dimension focuses on eight factors: (1) symptom status; (2) functional status; (3) emotional status; (4) self-care; (5) mortality; (6) morbidity and comorbidity; (7) cost; and (8) quality of life (Dodd et al., 2001).

Furthermore, there is a simultaneous interaction between the three dimensions of the SMM. The symptom experience is conceptualized to influence and be influenced by symptom management, strategies, and outcomes. When an individual is aware of the symptoms, she or he will initiate strategies to manage the symptom experience, assess the outcome of the symptom and the perception of symptom experience can be altered (Humphreys et al., 2008).

Domains of the Symptom Management Model. The three dimensions of the SMM as mentioned above are enclosed within the three domains namely person, health and illness, and environment. These domains are regarded as the factors influencing the three dimensions symptoms experience, symptoms management, and outcomes (Dodd et al., 2001).

Person. This domain includes an essential way in which an individual view and responds to the experiences related to the symptom. This domain covers several other variables namely psychological, sociological, and physiological variables affecting the perception and management of a symptom. The demographic related variables may consist of age, gender, marital status, and financial status. Similarly, the physiological variables could be activities, rest, and physical capacity and the psychological variables consist of personal traits, cognitive capacity, along with motivation. Finally, the sociological variable consists of the family unit, culture, and religion.

***Health and illness*.** The domain of health and illness include the state of health and illness of an individual consisting of risk factors, injuries or disabilities.

***Environment*.** The environment domain is related to the overall condition or context of occurrence of symptoms including the physical, social, and cultural aspects (Dodd et al., 2001) where home, work, and hospital fall under physical environment. The social environment constitutes of the social support network including the interpersonal relationships. Similarly, the cultural environment comprises of beliefs, values, and practices based on the ethnic, racial or religious background of an individual.

Common Symptoms Experience of People With Spinal Cord Injury, and Factors and Assessment

This section includes common symptoms experience and the factors and assessment of the symptoms experience among the people with SCI.

Common symptoms experience of people with spinal cord injury

Previous researchers studied common physical and psychological symptoms experience of people with SCI. The top three common symptoms found were: (1) pain (62 -88%) (Inoue et al., 2017; Naghosi et al., 2016), (2) spasticity (71-86.5%) (Bravo-Esteban et al., 2013; DiPiro et al., 2018), and (3) depressive mood (74%) (Khazeipour et al., 2015). The details of each symptom experience are presented as follows.

1. Pain. Pain refers to an individualized experience which is unpleasant and emotional and related to actual or potentially occurring tissue damage. Two major types of pain are acute pain and chronic pain. Pain is believed to occur following a physiological change in spinal and supraspinal neurons due to the interaction of neurochemicals, excitotoxicity, anatomical process and inflammation (Yezierski, 2009). Bryce et al. (2012) classified pain in SCI into nociceptive, neuropathic, and other or unknown pain.

1.1 Nociceptive pain. Activation of nociceptors i.e., A-delta and C-fibers result in nociceptive pain following an actual or threatened damage to the non-neural tissue (i.e., musculoskeletal structures and visceral organs) (Bryce et al., 2012).

Musculoskeletal pain. Musculoskeletal pain can arise from any trauma, inflammation, spasms, overuse of joints, muscles or ligaments. This type of pain can be persistent or recurrent (Bryce et al., 2012; Treede et al., 2015). Musculoskeletal pain among people with SCI can occur in the upper extremities pain, back pain or muscle spasms. Due to frequent use and weight-bearing on the upper extremities, while performing activities of daily living including mobility and used assistive devices, pain can occur in the upper extremities (Alm, Saraste, & Norrbrink, 2008). However, pain in the back results also results from immobility or prolonged sitting related muscle weakness and strain (Cardenas & Jensen, 2006).

Visceral pain. Perception of visceral pain occurs in the somatic tissue (i.e. skin, subcutaneous tissue, muscular tissues). These somatic tissues have a higher sensitivity to painful stimuli in areas other than the primary area, also known as secondary hyperalgesia. The causes of visceral pain include the vascular mechanism (ischemia, thrombosis), inflammation (due to irritants e.g., kidney stone), gastrointestinal disturbances, alteration in nerve structure, transferred pain rooting from urinary tract infections and other locations (Bryce et al., 2012; Treede et al., 2015).

1.2 Neuropathic pain. Neuropathic pain can result from any injury or pathology related to the somatosensory nervous system (Bryce et al., 2012) where the heightened sensation occurs due to the pain signaling mechanism activation and sensitization at below or above the level of injury (Hulsebosch, Hains, Crown, & Carlton, 2009). Two types of neuropathic pain can be central or peripheral. Central neuropathic pain arises from the spinal cord is damaged whereas peripheral pain develops from a lesion or injury to the peripheral nerves, plexus, dorsal root ganglion or root including cauda equine (Finnerup & Baastrup, 2012). Neuropathic pain is at-level and below-level neuropathic pain (Finnerup & Baastrup, 2012).

At-level neuropathic pain. At-level neuropathic pain occurs in the dermatome which is within or below three dermatomes from the level of SCI (Bryce et al., 2012). This type of pain is characterized by (1) sensory deficit, (2) allodynia or hyperalgesia (pain from non-painful stimuli e.g., light touch, brushing of hair) and (3) pain including at least one of the following pain descriptors i.e., burning, pricking, tingling, pins and needles, sharp, squeezing, shooting, cold, and electric shock-like (Bryce et al., 2012).

Below-level neuropathic pain. Below-level neuropathic pain occurs in the area of body which is three dermatomes below the neurological level of injury with the following characteristics (1) sensory deficit, (2) allodynia or hyperalgesia, and (3) pain with at least one of the pain descriptors as mentioned above (Bryce et al., 2012).

1.3 Other pain. Other pain is neither nociceptive neuropathic in origin. In the conditions such as, intestinal cystitis, fibromyalgia in absence of signs of inflammation or nervous system damage, this type of pain can occur (Bryce et al., 2012).

Previous studies found that most people with SCI have experienced moderate to severe pain. Among people with SCI, 22-44% reported moderate pain, and 28-41% severe pain. (Andresen et al., 2016; Muller et al., 2017). In a study conducted in Nepal, the average pain intensity of SCI patients was moderate (Thapa, Kitrungrote, & Damkliang, 2018). Especially, neuropathic pain had moderate-to-severe severity among nearly half of the people with SCI (Naghosi et al., 2016). In a qualitative approach, SCI participants shared feeling horrible, low and depressed without hope due to chronic pain which suggests damaging psychological consequences (Hearn, Cotter, Fine, & Finlay, 2015). It was reported that neuropathic pain intensity was higher in the night than the morning, the noon and the evening (Celik, Erhan, & Lakse, 2012). Neuropathic pain was significantly more severe after more than a year of SCI. Below-level superficial neuropathic pain was significantly more intense than at-level pain (Nagoshi et al., 2016).

Pain in SCI can be constant or intermittent pain (Inoue et al., 2017). Neuropathic pain is comparatively more difficult than another type of pain to identify and characterize because it manifests in a variety of ways (Soler et al., 2017). People with SCI reported neuropathic pain occurred with a variation from short-lived intermittent pain that lasted only seconds to six months or more of constant pain (Inoue et al., 2017). Some experience of neuropathic pain which was very severe but was (Soler et al., 2017).

2. Spasticity. Spasticity is a symptom of upper motor neuron damage. The most often used definition of spasticity is given by Lance (as cited in Adams & Hicks, 2005, p. 577) which is as follows; “Spasticity is a motor disorder characterized by a velocity-dependent increase in tonic stretch reflexes (muscle tone) with exaggerated tendon jerks, resulting from hyperexcitability of the stretch reflex, as one component of the upper motor neuron syndrome.” The increased muscle tone in spasticity is velocity-dependent which means that faster stretch, greater is the resistance (Chhabra, 2015). The experience of spasticity is highly individualized and is often distributed differently across arms, trunk, and legs. Among the tetraplegics, stiffness was more common than spasms in the arms and trunk whereas, in the legs both stiffness and spasms are equally prevalent (McKay et al., 2018).

There was a significant increase in the severity of spasticity from 82.5% at baseline to 86.5% ($p < .001$) (DiPiro et al., 2018). At follow-up, severity levels of spasticity were 37% at mild, 30.3% at moderate, and 19.2% at severe. The majority of people with SCI reported an increase in average spasticity severity (54.3%) and 20% of them reported a decrease in spasticity severity. Severe spasticity was sometimes violent and sudden that stops the breath of sufferers, they shoot their arms and several times they fall from the wheelchair and break their legs (Mahoney et al., 2007). Frequency and duration varied and were context-dependent. For some, the occurrence was rare, whereas for others it occurred quite often. Spasticity was experienced daily among 95% of SCI participants with 10 or more spasms per day. For nearly half of patients with SCI, 1-5 spasms per day occurred (McKay et al., 2018). Spasticity up to 30 to 40 times a day was reported by SCI participants in a qualitative study (Mahoney et al., 2007). The spasms might last only a few seconds or may have a constant tone or they can have more frequent spasms in response to specific health problems such as a urinary infection or an ingrown toenail (Mahoney et al., 2007). Moreover, spasticity ratings fluctuated over time. Soon after the injury, the movements were more intense. With increasing time post-injury, the severity decreased. However, most of the people with SCI had the opposite experience, where greater intensity and frequency of spasticity was present with an increase in the time since injury (DiPiro et al., 2017).

3. Depressive mood. Depression is a common mental health outcome after traumatic injury (Agtarap et al., 2017; Williams & Murray, 2014). Depressive symptoms may contribute to increased hospital stays limited physical function, and increased risk of mortality and morbidity (Muller, Peter, Cieza, & Geyh, 2012). The prevalence of depression after SCI is substantially greater than in other general medical conditions (Williams & Murray, 2014).

Previous studies mentioned the severity of depressive mood. It was found that 41-74% of people with SCI had minimal to mild ranges of depressive mood where 20-70% had mild to moderate and 9-44% had a moderate to severe range of depressive mood. (Agtarap et al., 2017; Al Abbudi et al., 2017; Khazaeipour et al., 2015; Xue et al., 2016**)**.

Factors of common symptoms experience of people with spinal cord injury

There are several factors that aggravate or alleviate the symptoms experience among people with SCI which can be categorized into the three main factors of personal, health and illness, and environmental.

Personal factors. Based on previous studies, age; gender; the level of education; employment status, beliefs, and smoking are person-related factors of common symptoms experience among people with SCI.

Age. Older aged people with SCI were found to have increased symptoms experience compared to younger people with SCI. It was found that with increasing age, people with SCI had increased chronic pain sensation and neuropathic pain sensation was also higher (Inoue et al., 2017; Muller et al., 2017). Similarly, older age people with SCI had higher depression and anxiety (Koca et al., 2014; Munce et al., 2015). In one study, the frailty of old age (e.g., weight loss, exhaustion, low activity and/or weakness, complex co-morbidity) was associated with moderate to high pain perception (Shega et al., 2012).

Gender. In comparison with the male population with SCI, females had higher symptoms experience of pain (*Lowery, Fillingim, & Wright, 2003;* Muller et al., 2017) and depression (Al Abbudi et al., 2017). Several biological and psychosocial mechanisms could affect the severity of pain among females including hormonal, genetic factors, cognitive function, and cultural beliefs (related to masculinity and femininity) (Bartley & Fillingim, 2013).

Level of education. People with SCI with a low level of education or illiterate individuals were found to have a high level of depression (Al Abbudi et al., 2017; Al Owesie et al., 2017; Munce et al., 2016).

Employment status. Employment status can be considered as a factor of symptoms experience in people with SCI since individuals who were employed before SCI reported lower pain scores compared to those who were not previously employed. Similarly, a high level of depression was seen among unemployed and retired respondents (Al Abbudi et al., 2017; Ataglu et al., 2013).

Ethnicity. Among different ethnic and cultural context, pain experiences differed in previous studies which suggested higher perception of pain in the Western context compared with the Eastern context (Campbell & Edwards, 2012). African American patients were found to perceive higher pain sensitivity because of pain modulation and pain regulation alteration (Campbell & Edwards, 2012) whereas pain was a negative signal for Chinese patients and tolerated pain more and hence report less pain. Similarly, with the Chinese point of view Hindus considered pain as a punishment from God for any misconduct in the past days or past life and hence endured pain (Whiteman, 2007).

Beliefs. The beliefs of "catastrophizing" may lead to higher pain perception and greater pain severity (Molton et al., 2009). Hindus believed pain as a punishment from God for any misconduct in the past days or past life and reported less pain because they think that they must go through the pain experience as the will of almighty God (Whiteman, 2007).

Smoking. Among the smoker individuals, it was found that there was a decrease in pain experience (neuropathic and mixed pain) when the use of nicotine was tested in smoking versus non-smoking group of people (Richardson, Richards, Stewart, & Ness, 2012).

Health and illness factors. Based on previous studies, health and illness-related factors of symptoms experience in people with SCI are the level of SCI, duration of injury, functional independence, and other health problems.

Level of SCI. The higher the level of injury, the higher the levels were of the neuropathic experience, spasticity, and depression (Andresen et al., 2016; Celik et al., 2012). However, nociceptive pain was higher among people with lumbosacral injury and neuropathic pain was more common in cervical level injuries (Siddall, McClelland, Rutkowski, & Cousins, 2003).

Duration of SCI. Findings of previous studies show a negative correlation of duration of injury and depression such that, a higher level of depression was identified among people with greater duration of injury (Al Abbudi et al., 2017; Munce et al., 2016).

Functional independence. Depression was negatively correlated with functional independence, such that, people with higher functional independence had a lower level of depression (Koca et al., 2014).

Other health problems. The occurrence of other health problems increases symptoms experience. Spasticity increases with bladder and bowel issues (urinary tract infections, full bladder, blocked catheter, constipation), fever, inflammation, fractures, stress (mental stress, anxiety), and skin conditions (pressure ulcers, hemorrhoids, scabies) (McKay, Sweatman, & 2018). Spasticity was positively correlated with fatigue (*rho* = 0.160; $p < 0.01$) (Cudeiro-Blanco et al., 2017). Psychological problems such as anxiety and depressive moods increased pain perception (Celik et al., 2012; Cruz-Almeida, Felix, Martinez-Arizala, & Widerström-Noga, 2009).

Environment factors. Social support, family environment, and environmental stimuli were environment factors of symptoms experience in people with SCI.

Social support. Previous studies found that social support reduced symptoms experience in people with SCI. Celik et al. (2012) found that family support reduced pain experience. Emotional support and appraisal support were negatively correlated with depression. Similarly, compared to professional caregiving, family caregiving significantly lowered depression among people with SCI (Huang et al., 2015; Kang et al., 2018).

Family environment. It was assumed that social support increased in the presence of a positive family environment that can enhance good coping and satisfaction of life among the people with SCI (Muller et al., 2012). In a review article, excessive support offered by family members caused an increase in pain experience which could be because of being depended upon others for the decisions of comfort and care provided to the individual (Goossens, Dousse, Ventura, & Fattal, 2009).

Environmental stimuli. People with SCI had increased pain sensation at night. Other factors such as touch, excessively hot or cold weather, humidity were related to higher pain sensation (Celik et al., 2012; Lofgren & Norrbrink, 2012).

Assessments of common symptoms experience of people with spinal cord injury

Assessments of common symptoms experience (i.e., pain, spasticity, and depressive mood) were done using several unidimensional and multidimensional tools in previous studies.

1. Pain Assessment. Visual Analogue Scale (VAS), Numeric Rating Scale (NRS), McGill Pain Questionnaire (MPQ), and the International Spinal Cord Injury Pain Basic Data Set version 2 (ISCIPBDS-2) were tools used to measure pain. The details of each pain assessment are explained below.

1.1 Visual Analogue Scale. The VAS is widely used to assess pain intensity (Bryce et al., 2007; Hawker, Mian, Kendzerska, & French, 2011). It consists of a single item (Hawker et al., 2011). The anchor with a line generally represents from “no pain” to “the pain as bad as it could be” or “worst imaginable pain” in the last 24 hours. The 100 mm VAS rating is categorized into four parts i.e., no pain (0-4mm), mild pain (5 to 44 mm), moderate pain (45 to 74 mm), and severe pain (75 to 100 mm). Higher scores represent higher pain intensity. The VAS is easy to use (less than one minute to administer) and requires little training. However, compared to the numeric rating scale, VAS had higher failure rates (Bryce et al., 2007). The test-retest reliability was higher ($r = .94$, $p < .001$) among literate populations compared to illiterate populations ($r = .71$, $p < .001$) (Hawker et al., 2011).

1.2 Numeric Rating Scale. The NRS is another unidimensional pain scale, verbal or written, used in the SCI population as a first choice (Bryce et al., 2007). In NRS, 0-10 is the commonly used range where one end is labeled as ‘no pain’ and other end labeled as ‘worst possible pain (Bryce et al., 2007). Regarding the cutoff points of NRS, 1 to 3 for mild, 4 to 6 for moderate, and 7 to 10 for severe pain intensity was the preferred set for the worst pain problems in SCI (Hanley, Masedo, Jensen, Cardenas, & Turner, 2006). Similar to the VAS, in NRS, higher scores represent higher pain intensity and the administration time is less than 1 minute (Hawker et al., 2011). The test-retest reliability was high (Cronbach's alpha =.95).

1.3 McGill Pain Questionnaire. Ronald, Malzak, and Torgerson developed the scale MPQ at McGill University in 1971. The purpose of the tool was to evaluate aspects of pain i.e., sensory, affective, and evaluative aspect along with the pain intensity (Bryce et al., 2007; Hawker et al., 2011). The long-form MPQ (LF-MPQ) consists of 4 major subscales and 20 subclasses with 78 pain descriptors (Bryce et al., 2007) whereas the short form MPQ (SF-MPQ) consists of 2 subscales. The two subscales consist of 15 words or items (11 sensory and 4 affective).

Additionally, the SF-MPQ includes one item for assessment of pain intensity and a VAS. The pain rating index of the tool ranges from 0 to 78 and the pain intensity scale ranges from 0-5 where a higher score represents higher pain intensity. Administration time for the LF-MPQ is as long as 20 minutes, whereas for the SF-MPQ is 2-5 minutes. Very minimal training is required to use the tool. However, a special ability is required to interpret the words. SF-MPQ had high Cronbach's alpha coefficient (Cronbach's alpha = .81) respectively (Hawker et al., 2011).

*1.4 The International Spinal Cord Injury Pain Basic Data Set version 2 (ISCIPBDS-2)***.** The ISCIPBDS was proposed in 2008 by the working group of International Association for the Study of Pain as standard tool for multi-dimensional assessment of pain experience among in SCI population **(**Widerstorm**-**Noga et al**.**, 2014**).** The ISCIPBDS was shortened and revised in 2013 to develop the ISCIPBDS**-**2. The short version includes pain in the last seven days in the following components**:** pain interference, number of different pain problems, and description of three worst pains which include the location of pain, type of pain, intensity of pain, date of pain onset, and treatment for pain problem. Assessment of pain intensity includes, a 0-10 NRS is used where '0' refers to 'no pain' and '10' refers to pain 'as bad as could be imagined'. In addition, a checklist format with option boxes is provided to assess the experience of any pain, number of different pain problems, type of pain, location of pain, and receiving any treatment (Widerstrom-Noga et al., 2014).

Thapa et al. (2017) further modified the tool by removing two items and translated into the Nepali language. The two items from the ISCIPBDS-2 deleted were the type of pain because as a self-report measure it was inappropriate to differentiate between neuropathic or nociceptive pain (Jensen et al., 2010), and the item related to the treatment of pain was removed which can be covered in the symptoms management section.

The items of ISCIPBDS support the utility and validity in people with SCI. Internal consistency of the interference scale was excellent (Cronbach's alpha = .94). The validity for the pain intensity of three worst pain location was strongly supported. Concurrent validity of self-report items have been established (Jensen et al., 2010). The internal consistency of the components of the tool ranged from .89 to .94 with well supported concurrent validity (Jensen et al., 2010). The adapted version was used in previous studies to assess pain among people with SCI (Muller et al., 2017; Thapa et al., 2018) with excellent intra-class correlation coefficient .91 and the Cronbach’s coefficient alpha of .85 (Thapa et al., 2018).

In this study, the ISCIPBDS-2 (Nepalese version) was selected to assess the locations and intensity of pain because this tool was designed for pain assessment among people with SCI in Nepal. In addition, the frequency of the pain was added from a previous study (dela Cruz et al., 2014) which consisted of a 5-point Likert scale. Pain frequency levels were ‘never = 0’, ‘some of days = 1-2’, ‘about half of the days = 3-5’, ‘most of the days = 6-7’, and ‘everyday = 8’.

2. Spasticity assessment. Assessment of spasticity among people with SCI commonly involved the use of unidimensional and multidimensional tools i.e., NRS, Patient-reported impact of spasticity measure (PRISM), and Penn Spasm Frequency Scale (PSFS).

2.1 Numeric Rating Scale. The NRS was used to assess spasticity in SCI (Andresen et al., 2016) and multiple sclerosis (Farrar, Troxel, Stott, Duncombe, & Jensen, 2008). Commonly, an NRS of 0 (no spasticity) and 10 (worst possible spasticity) is used, and patients are asked to indicate their level of spasticity by identifying a whole number between those two anchors. Among patients with multiple sclerosis, the test-retest reliability analysis found an interclass correlation coefficient of .83 (***p*** < 0.001) between 2 measures of the 0-10 NRS (scores recorded over a 7 to 14-day period). In the same study, a significant correlation was found between change on 0-10 NRS and change in the Spasm Frequency Scale ($r = .63$; $p < .001$) (Farrar et al., 2008). However, this scale was not used in this study, since it is a unidimensional tool.

2.2 Patient-Reported Impact of Spasticity Measure (PRISM). The PRISM is a newer instrument developed by Cook et al. (2007). This self-report tool consists of seven subscales with 41 items that assess the impact of altered motor control with respect to social avoidance and anxiety, psychological agitation, daily activities, need for assistance or positioning, need for interventions, and social embarrassment, as well as the positive impact of altered motor control. The items were scored from 0 to 4, with higher scores corresponding to greater impact. Subscale scores were obtained by averaging item scores and multiplying by the number of items in the subscale. The validity of PRISM is not well established, and internal consistency ranged from .76 - .96 (Cook et al., 2007). Intra-class consistency of the tool was high for all seven subscales (Cronbach's alpha .82 to .91). However, the tool is used in very few studies (Ertzgaard, Nene, Kiekens, & Burns, 2019). This tool was not used in this study because it consists of a wide range of items and takes approximately 15 minutes or more to complete the questionnaire for paraplegics and tetraplegics.

2.3 Penn Spasm Frequency Scale (PSFS). The PSFS is a five-point scale for spasticity developed by Penn et al. (as cited in Hsieh, Wolfe, Miller, & Cutt, 2008), which was later modified by Priebe, Sherwood, Thornby, Khara, and Markowski (1996) by adding one more component of the severity of spasticity. The PSFS is a two component self-report scale which provides a comprehensive understanding of an individual's spasticity occurrence, frequency, and severity (Heish et al., 2008). The first component is a five-point scale assessing the occurrence and frequency of spasticity which ranges from '0 = no spasms' to '4 = spontaneous spasms occurring more than 10 times per hour'. The second component is a three-point scale assessing the severity of spasms ranging from '1 = mild' to '3 = severe'.

Validity for the PSFS has been partially established through correlations with other clinical tools (Heish et al., 2008). PSFS had significant positive correlation with two tools, Spasticity Severity ($r = .58$, $p <.001$) and Spasticity Impact ($r = .67$, $p <.01$) (Adams et al., 2007). The intra-rater reliabilities were .81 for occurrence and frequency (part 1) and .73 for severity (part 2) of the PSFS. The inter-rater reliability of the PSFS was .86 for part 1 and .86 for part 2 (Mills, Vakil, Philips, Kel, & Kwon, 2018). The previous study used the PSFS to assess spasticity in the SCI population (Culha, Unsal-Delialioğlu, Egüz, Kulaklı, & Ozel, 2017).

In this study, PSFS was selected to assess the occurrence, severity, and frequency of spasticity in people with SCI because it had high reliabilities and was easy to use.

3. Depressive mood assessment. Beck Depression Inventory (BDI), Depression Anxiety Stress Scale (DASS), and Patient Health Questionnaire (PHQ-9) were most commonly used to assess depressive mood.

3.1 Beck Depression Inventory. The BDI is a 21-item self-reporting questionnaire for evaluating the severity of depression in normal and psychiatric populations developed by Beck et al. in 1961 (Khazaeipour et al., 2015). It underwent revisions in 1978 and the BDI-II was developed in 1996. The questionnaire was developed from clinical observations of attitudes and symptoms occurring frequently in depressed psychiatric patients and infrequently in non-depressed psychiatric patients. Twenty-one items were consolidated from those observations and ranked 0-3 for severity (Beck, Ward, Mendelson, Mock, & Erbaugh, as cited in Jackson-Koku, 2016). The questionnaire is commonly self-administered although initially designed to be administered by trained interviewers. Self-administration takes 5-10 min (Jackson-Koku, 2016). The recall period for the BDI-II is 2 weeks for major depressive symptoms. The BDI-II contains 21 items on a 4-point scale from 0 (symptom absent) to 3 (severe symptoms) (Jackson-Koku, 2016). Scoring is achieved by adding the highest ratings for all 21 items. The score ranges from 0 to 63. Higher scores indicate greater symptom severity. In non-clinical populations, scores above 20 indicate depression. In those diagnosed with depression, scores of 0-13 indicate minimal depression, score 14-19 mild depression, 20-28 indicate moderate depression, and 29-63 indicate severe depression (Jackson-Koku, 2016).

Content validity of the BDI-II has improved following item replacements and rewording to reflect DSM-IV criteria for major depressive disorders. Mean correlation coefficients of .72 and .60 have been found between clinical ratings of depression and the BDI for the psychiatric and non-psychiatric population. Construct validity was high for the medical symptoms ($\alpha = .92$) for psychiatric outpatients and .93 for college students. For internal consistency, Cronbach’s alpha was .91 (Jackson-Koku, 2016), and .86 (Khazaeipour et al., 2015). The cutoff scores used were 0 to 13 for minimal depression; 14 to 19 for mild depression, 20 to 28, moderate depression; and 29 to 63 for severe depression. Patients with a score ≥14 were termed the depressive group (Khazaeipour et al., 2015).

Short form of BDI consists of 13 sets of items that each represents a state in patients. The score of each item ranges between 0 and 3 and the total score will be between 0 and 39. The main advantage of the short-form of this inventory is that it takes about five minutes to fill it out (Mousavi, 2017). In an Iranian study, reliability and validity coefficients of the BDI-SF were reported to be .78 and .70 - .90, respectively (Azkhosh, as cited in Mousavi, 2017). However, this tool was not used in this study because this tool was less commonly used for the SCI population.

3.2 Depression Anxiety Stress Scale. The DASS-21 was developed by Lovibond and Lovibond in 1995 to measure emotional distress in three sub-scales of depression, anxiety, and stress (Oei, Sawang, Gohm, & Mukhtar, 2013). Each subscale is composed of seven items referring to the past week. The DASS-21 is quick and easy to administer, requiring less than 10 minutes to complete and excludes many somatic items that may not be relevant to those with SCI (Mitchell, Burns, & Dorstyn, 2008). Each item is scored on a 4-point scale (0 = did not apply to me at all, to 3 = most of the time). Subscale scores are calculated as the sum of the responses to the seven items from each subscale multiplied by 2 (Mitchell et al., 2008). This tool was used to assess depressive symptoms, anxiety, and stress in both clinical and non-clinical samples of adults (Beaufort, Oene, Buwalda, Leeuw, & Goudriaan, 2017). A total score of 32 is considered as clinically elevated levels of general psychological distress, while a score of 10-12 represents probable depression (Guest, Tran, Gopinath, Cameron, & Craig, 2018).

The DASS-21 had excellent criterion validity in a motor vehicle-related physically injured population (Guest et al., 2018). However, the depression subscale has a lower sensitivity of 57% and specificity was 76%, (Mitchell et al., 2008). The cutoff score of 10 had higher sensitivity (76.4%) and specificity (70.4%) (Guest et al., 2018). Internal consistency in the original study was high with Cronbach's alpha coefficient of .88 for depression, .82 for anxiety, .90 for stress, and .93 for the total scale (Lovibond & Lovibond, as cited in Oei et al., 2013). Among substance use disorder patients Cronbach's alpha coefficient was .91 for depression subscale (Beaufort et al., 2017). In an Asian study conducted among employees, internal consistency was .86 for depression, .81 for anxiety, .70 for four items of stress, and .91 for overall score (Oei et al., 2013). However, this tool was not selected in this study because it has many items and consists of items for anxiety and stress,

3.3 Patient Health Questionnaire. In 2001, Spitzer, Kroencke, William, and Group developed a self-report measure, Patient Health Questionnaire (PHQ-9) to assess the symptoms and severity of depressed mood. The PHQ-9 has nine items rooting from diagnostic criteria for depressive disorder in the Diagnostic and Statistical Manual of Mental Disorders-IV. The response was reported by a 4 - point Likert scale, where 0 = not at all, 1 = several days, 2 = more than half the days, and 3 = nearly every day. The total score ranges from 0 to 27, with 5 levels of severity i.e. none = 0-4, mild = 5-9, moderate = 10-14, moderately severe = 15-19, and severe = 20-27. In the PHQ-9, there was no distinction made between intensity and frequency of depressive symptoms, hence, the researcher has to give due weight to both intensity and frequency of depressive mood, while making the judgment for the experience of depressive mood (Cameron, Reid, & Lawton, 2010).

Regarding the cutoff score, based on the Youden Index, the PHQ-9 was optimized at a cutoff of 11 or more, slightly above the standard cutoff of 10 with unchanged sensitivity and specificity (Bombardier et al., 2012). According to

Kroencke, Spitzer, and William, (2001) and Spitzer, Kroenke, William, and Group, (1999) the cutoff score of 10 was established where the score of 10 or higher indicates the occurrence of depressive symptoms.

The tool showed good validity and reliability among people with SCI with Cronbach's alpha of .85 and .79 (Dodd et al., 2015; Driver et al., 2015). PHQ-9 had a sensitivity of 100% and a specificity of 84% compared with the Structured Clinical Interview for DSM-IV (Bombardier et al., 2012). In this study, PHQ-9, Nepali version (Bhattarai et al., 2018b) was used to assess the severity of depressive mood experience of people with SCI.

In conclusion, in this study, ISCIPBDS 2.0, PSFS, and PHQ-9 were selected for the assessment of top three common symptoms of people with SCI i.e., pain, spasticity, and depressive mood respectively.

Symptoms Management of People with Spinal Cord Injury, and Factors and Assessments

This section presents symptoms management including pharmacological and non-pharmacological approaches used by people with SCI, health professionals and FCs. Symptoms management factors and assessment are described in the following.

Symptoms management of people with spinal cord injury

1. Pain management

Pain management among people with SCI included use of pharmacological and non-pharmacological strategies. The details are explained below.

1.1 Pharmacological management. Anticonvulsants, antidepressants, opioids, non-steroidal anti-inflammatory drugs (NSAIDs), muscle relaxing agents, sedatives, and others were commonly used for pain in pain management.

Anticonvulsants. Gabapentin and Pregabalin are the first-line drugs for neuropathic pain (Heutink et al., 2011; Sadosky et al., 2016). Pregabalin (up to 600 mg) (D'Angelo et al., 2013) and Gabapentin (1200 mg or more as tolerable) was required for greater neuropathic pain relief (Barrera-Chacon et al., 2011; Sadosky et al., 2016). Anticonvulsants are believed to inhibit the calcium channels in the nerve cells and relieve pain (Guay, 2005). Gabapentin was found more helpful than NSAIDs to reduce pain among people with SCI (Turner, Cardenas, Warms, & McClellan, 2001). In a randomized control trial, Pregabalin significantly decreased pain compared to placebo treatment (Cardenas et al., 2012; Hegan & Rekand, 2015). However, the combination of opioid (oxycodone) and anticonvulsants (Gabapentine and Pregabalin) was effective to decrease pain from severe to moderate level in 1-3 months (Mehta et al., 2016). Common side effects were dizziness, dry mouth, fatigue, edema, and drowsiness (Hegan & Rekand, 2015).

Antidepressants. Tricyclic antidepressants, Amitriptyline is the first choice of drug in pain in persons with SCI with depression (Finnerup & Basstrop 2012; Mehta et al., 2016). It is believed that antidepressants increase noradrenaline in the spinal cord to decrease pain (Obata, 2017). Amitriptyline (up to 150 mg) can provide moderate pain relief in chronic neuropathic pain (D'Angelo et al., 2013). In a review, Amitriptyline and anticonvulsant (Pregabalin) were identified as first-line treatment for neuropathic pain in SCI (Finnerup & Baastrup, 2012) and it was found that they are more effective in reducing pain in SCI when used in combination (Turner et al, 2001). Common side effects were dry mouth, drowsiness, constipation, urine retention, increase in spasticity (Hegan & Rekand, 2015).

Opioids. Opioids were commonly used analgesics and were found to be effective medications in chronic pain of severe intensity in SCI (Cardenas & Jensen, 2006). An opioid (oxycodone) was effective to decrease pain from a severe to moderate level when used in combination with anticonvulsants (Mehta et al., 2016). Tramadol is a second-line drug in SCI pain management. Tramadol was found effective to decrease SCI related pain (Norrbrink & Lundeberg, 2009). Parenteral administration of opioids was more effective; however, they are not suitable for use in the long term (Siddhal, 2009). Common side effects were nausea, constipation, cognitive deprivation along with the risk of dependence (Norrbrink & Lundeberg, 2009).

Non-steroidal anti-inflammatory drugs (NSAIDs). Ibuprofen is the most common used by people with SCI. In one study, Ibuprofen was the most commonly used pain medication among people with SCI that they bought from nearby pharmacy shop without a doctor’s prescription (Thapa et al., 2018). Ibuprofen was a commonly used drug for all types of pain in SCI (Heutink et al., 2011; Thapa et al., 2018).

Muscle relaxants. Oral baclofen and phenol nerve block were found effective for relieving pain in the SCI population. Baclofen was moderately effective to reduce pain (Cardenas & Jensen, 2006). In another study, phenol nerve block used for spasticity decreased pain among people with SCI (Mehta et al., 2016).

Sedatives. The sedative drug use was found to completely relieve pain for nearly one-fourth of the participants with SCI (Widerstrom-Noga & Turk, 2003). The effectiveness of diazepam was reported as very helpful to extremely helpful among SCI cases with chronic pain (Cunningham, Craner, Evans, & Hooten, 2017).

Others. Topical application of Capsaicin ointment was found effective in neuropathic pain and diclofenac gel for nociceptive pain (Thapa et al., 2018). The new approach of botulinum toxin is used but its effectiveness is less clear in traumatic SCI (Hegan & Rekand, 2015; Siddal et al., 2003). Cannabinoids were effective to reduce pain in SCI in some studies (Finnerup & Basstrop, 2012; Hegan & Rekand, 2015).

1.2 Non-pharmacological strategies. Non-pharmacological management strategies for pain in people with SCI were commonly used due to the fear of side effects of drugs (Heutink et al., 2011), and inadequate and ineffective pain relief with pain medication use (Hearn et al., 2015; Li et al., 2017). Physical modalities, cognitive and emotional coping modalities, spiritual modalities, traditional methods, and substance abuse were the non-pharmacological approaches for pain among the people with SCI.

Physical modalities. The use of physical activity, exercise, massage, acupuncture, heat application, body energy balancing, and rest were the physical modalities (Heutink et al., 2011; Lofgren & Norrbrink, 2012). Attempted self-movement and increased physical activity such as walking, wheeling, or gardening induced positive coping mechanisms as well as effective in neuropathic pain relief (Lofgren & Norrbrink, 2012). Regular exercises and a range of motion exercises and home-made belt '*Patuka*' were used by people with SCI (Thapa et al., 2018). Exercise was found effective for pain relief (Li et al., 2017).

Additionally, yoga, massage, acupuncture, and relaxation were some complementary therapies used by people with SCI for pain relief. Yoga helped in pain relief for several days (Lofgren & Norrbrink, 2012). The massage was a common intervention for chronic pain conditions in Nepal used by nearly half of the SCI respondents. Massaging was relaxing and good for pain relief and the alleviation of chronic pain (Thapa et al., 2018). A previous study mentioned that massage improves energy through the release of serotonin and melatonin neurotransmitter mediators, which promotes relaxation and improves sleep (Babaee, Shafiei, Sadeghi, Yazdan, & Valiani, 2012). It is believed that massage increase the pain threshold (Gate Control Theory). In compared to a pressure stimulus, pain stimulus takes a longer time to reach the brain (Field, Diego, & Hernabdez-Reif, 2007). Hence, massage was found as most helpful in reducing pain (Turner et al., 2001).

However, massage is not recommended for people with SCI under anticoagulant therapy or those who have circulatory problems below the level of injury. Furthermore, deeper massage can trigger autonomic dysreflexia, severe spasms, which can be very unpleasant and uncomfortable or even further damage paralysed and atrophied muscles. Hence, massage should begin with a gentle light touch and slowly progress to deeper massage (Craig Hospital, 2015).

Acupuncture was effective to relieve all types of chronic pain among people with SCI (Pannek et al., 2015). Relaxation was a common method among people with SCI and neuropathic, musculoskeletal, visceral pain or injury with better or very relaxing effectiveness. Body energy balancing methods were able to reduce pain and maintain at a tolerable level (Lofgren & Norrbrink, 2012; Thapa et al., 2017)

Furthermore, warmth was a common means of pain relief for neuropathic pain (Lofgren & Norrbrink, 2012) and it provided temporary but the highest relief from pain (Cardenas & Jensen, 2006). Other commonly used heat applications methods for management of neuropathic pain in people with SCI were warm shower, saunas, hydrotherapy, hot packs, and warm clothes or heaters (Lofgren & Norrbrink, 2012).

Cognitive and emotional coping modalities. Cognitive and emotional coping modalities were internal pain control, learning to live with pain, distraction that were used for pain relief in SCI. Methods used are those such as endurance, learning to live with the pain, diverting the patients' minds into eating, playing, sleeping, going out, spiritual sustenance by singing, reciting Buddha sutras, taking a bath with lukewarm water and massage (Li et al., 2017). Chronic pain intensity, pain-related anxiety, and avoidance decreased with the use of 'acceptance' (Henwood, Ellis, Logan, Dubouloz, & D' Eon, 2012).

Another study mentioned that increased physical activities such as, gentle moving, stretching, walking, wheeling or gardening, swimming was effective in neuropathic pain management (Lofgren & Norrbrink, 2012). Additional distraction methods were watching movies, listening to music, internet usage, keeping yourself busy at work or being sociable by meeting friends as reported for pain relief in SCI to relieve numbness, shooting, electric, burning, and pricking pain sensations (Lofgren & Norrbrink, 2012). According to Johnson (2005), a distraction from pain can occur as a competition between the exogenous (e.g., pain) and endogenous information processing. During the use of distraction, the perception of pain is suppressed by consciously focused attention to non-pain stimuli/stimulus. The stimulus is preferred by the individual suffering from pain and the effectiveness depends upon the maintenance of engagement with it. Increased adherence to distraction can improve mood and reduce anxiety related to pain as well as provide comfort (Johnson, 2005).

Spiritual modalities. Spiritual modalities such as praying, worshipping helped in realization and acceptance of the reality along with to cope with the stressing situations among people with SCI. Developing hopefulness also assisted people with SCI in acceptance of reality and seek independence to deal with stressful situations (Babamohamadi, Negarandeh, & Dehghan-Nayeri, 2011). In addition, spiritual sustenance by reciting Buddha sutras and praying was used (Li et al., 2017; Thapa et al., 2018).

Traditional herbs. In a study conducted in Nepal, traditional herbs were used by people with SCI for chronic pain relief because of the failure of pain medications. They used the herbs either orally or by incision on the skin (Thapa et al., 2018).

Substance use. Substances such as cannabis and alcohol for chronic pain relief were used by people with SCI who reported that their pain was relieved (Heutink et al., 2011; Thapa et al., 2018).

2. Spasticity management

Spasticity management comprises the use of pharmacological, and non-pharmacological strategies by health professionals, people with SCI and FCs.

2.1 Pharmacological strategies**.** A muscle relaxant such as Baclofen, Tizanidine, and Dantrolene sodium are used in spasticity. Baclofen is a drug of choice for the treatment of SCI-induced spasticity (Karsy & Hawryluk, 2017). In a large-scale study, 49.6% of people with SCI used Baclofen and Baclofen also had higher adherence of 30% compared to other anti-spastic drugs (Halpern, Gillard, Graham, Varon, & Zorowitz, 2013). Intrathecal Baclofen administration is a long-term treatment with continuous, direct intraspinal administration which allows higher concentrations in the spinal cord rather than using the oral route. Tizanidine is a centrally acting α 2-adrenergic agonist, equally beneficial as Baclofen Dantrolene sodium effects directly at the level of skeletal muscles (Chang et al., 2013; Rabechvsky & Kitzman, 2011). Common side effects of the muscle relaxant group of drugs were systemic muscle relaxation, sedation, fatigue, hypotension, and hallucinations (Chang et al., 2013; Rabchevsky & Kitzman, 2011). Pregabalin (anti-convulsant) and Diazepam (Benzodiazepine) were used which reduced muscle tone in spasticity. Similarly, Cannabinoids were also found effective in reducing spasticity in the previous study (Rabchevsky & Kitzman, 2011).

2.2 Non-pharmacological strategies. The non-pharmacological strategies to reduce spasticity are (1) exercise (2) positioning, and (3) others.

Exercises. Exercise to decrease spasticity were those such as active and passive movement, stretching, standing, and weight-bearing exercises. Previous studies have reported that stretching, regular physiotherapy, and physical activities affected spasticity which should be considered as a therapeutic approach prior to pharmacological approach or surgical procedures. Passive movement may be performed by a therapist/caregiver or self-mediated limb movement focusing on muscle stretching or on preserving the full range of motion over joints that may be immobilized and improve blood circulation (Harvey, 2016; Elbasiouny, Moroz, Bakr, & Mushahwar, 2010). Exercise also induces tissue extensibility, maintains muscle length and has a positive effect on joint mobility and ROM (Katalinic, Harvey, & Herbert, 2011). Prolong standing using parallel bars was effective in spasticity management. Standing helps to stretch the muscles and weight-bearing for the lower limbs (Elbasiouny et al., 2010). However, aggressive ROM may further damage the muscle fibers, cause bruises in the area with sensory disturbance (Craig Hospital, 2015).

Positioning. The previous study mentioned that correct and comfortable posture/positioning helps to maintain trunk control and maximize motor stability (Graham, 2013) and decrease spasticity. For example, the frog leg positioning was found useful to break or stop the spasms (Bryce, 2009). In this position, the patient lies on his/her back or sits on his/her buttocks, bends his/her knees, abducts his/her thighs, and draws his/her heels toward his/her pelvis.

Others. Heat application (moist heat pad), acupuncture, acupressure, relaxation, praying, massage, meditation, substance abuse (marijuana, alcohol) were used by people with SCI. Similarly, techniques such as staying still if they know symptom is going to occur, having a regular bowel program, changing position, breathing techniques lifting of toes during a spasm were helpful in preventing or reducing spasticity (Mahoney et al., 2007).

3. Depressive mood management

Only a few studies were found about depressive symptom management among patients after SCI. In a study, 29% reported that they currently were taking an antidepressant. The most commonly prescribed antidepressant classes were selective serotonin reuptake inhibitors and serotonin-norepinephrine reuptake inhibitors (Fann et al., 2011).

Non-pharmacological strategies were mindfulness, psychotherapy, sharing/expression of feelings, and spiritual practices. In one study, eight weeks of mindfulness reduced depression significantly more than psychoeducation ($p < .05$) (Hearn & Finlay, 2018). Another study showed that psychotherapy and a self-help group were used to manage depression among people with SCI (Fann et al., 2011). Sharing of feelings occurred during activities such as painting (Dalebroux, Goldstein, & Winner, 2008), singing, writing poems which could help in improving one’s mood (Thayer et al., as cited in Davidson & Garrido, 2015). In addition, coping training was used to reduce depression and anxiety. In the study, people with SCI after admission into the health center received coping training and were followed up after six months after discharge. Using the skills of coping at home, the people with SCI showed a reduction in symptoms of depression (Kennedy, Duff, Evans, & Beedie, 2003). In the follow-up, it was found that there was a significant improvement in self-concept after the training. There was a decrease in the discrepancy between 'ideal' self and 'as I am', and between 'as I would be without the injury' and 'as I am'. In developing countries, traditional spiritual methods are often used to manage mental health problems. A previous study mentioned spiritual practices of praying and worshiping through traditional healers were effective to treat psychological problems (Khatry, 2011).

Factors of symptoms management of people with spinal cord injury

There are several factors that enhance or hinder the symptoms management among people with SCI which can be categorized under the three main factors of personal, health and illness, and environment related factors.

1. Personal factors. Based on previous studies, age, gender, education, income, beliefs and misconceptions, perceived efficacy, and resilience were related to personal factors of symptoms management among people with SCI.

Age. Age was a factor in general pain management. Elderly group of people reported less pain possibly resulting in inadequate pain management (Campbell &

Edwards, 2012). In addition, among elderly people low hepatic and plasma albumin may cause a lower analgesic response (Coldrey, Upton, & Macintyre, 2011).

Gender. Symptoms management differed in terms of gender. In depression management, more women were found to receive guideline-based treatment compared to males, however, the finding could be due to small sample size (Fann et al., 2011).

Education: Low education level can lead to less treatment-seeking. In a prospective cohort study, individuals with high school graduation were found to seek treatment for pain more than individuals with lower educated participants (Wen et al., 2013).

Income: High cost of medical treatment and cost of traveling to urban areas for modern medicine was amongst the reasons why people with a low income used non-pharmacological methods of symptom management (Kunwar, Shrestha, & Bussmann, 2010).

Belief and misconception. Some beliefs and misconceptions may decrease the need to use or seek management strategies and result in negative outcomes of health. Many people with SCI considered pain as normal. The fear of side-effects and fear of being drug-dependent were some causes for less use of pain management measures (Li et al., 2017; Norrbrink, Löfgren, Hunter, & Ellis, 2012).

Perceived efficacy. In spasticity management, people with SCI had low perceived efficacy related to oral anti-spasticity medication which could have led to the decreased adherence to oral drugs (McCay et al., 2018).

Resilience. Resilience and depressive mood had a significant negative correlation among people with SCI following a natural disaster which indicates that the participants with higher depressive mood had lower resilience (*r* = - .50, *p* < .001) (Bhattarai et al., 2018a).

2. Health and illness factors. Based on previous studies, health and illness-related factors of symptoms management in people with SCI are level and type of injury, type of pain, and side effects of treatment and complications of the illness.

Level/type of injury. Level of injury impact on symptoms management of SCI people. Paraplegics more than tetraplegics reported more effectiveness of oral medication for pain management (MacCay et al., 2018).

Type of pain. Neuropathic is often difficult to manage and this type of pain responded less than nociceptive pain to pharmacotherapy. Combined therapies (pharmacotherapy and non-pharmacotherapy) were more effective for pain relief, especially for neuropathic pain. (Hegan & Rekand, 2015).

Side effects of treatment and complications of illness. The occurrence of side effects and complications either increased or decreased the use of certain management strategies. For instance, participants with the complication of spasticity such as contracture and pressure ulcers were more adherent to the oral mediation therapies which could be because they had greater need to continue treatment (Halpern et al., 2013). However, side effects of pain medications were the reasons for non-adherence in people with SCI. High dosages of Gabapentin had side effects of drowsiness and dizziness, anti-depressant drugs were associated with risk of addiction, dry mouth, drowsiness or tiredness, constipation, urinary retention, and increased spasticity. Side effects of opioids were constipation, nausea and cognitive deprivation (Hegan & Rekand, 2015; Widerstorm-Noga, 2017). Similarly, the side effects of oral anti-spastic drugs such as drowsiness and dizziness were considered as a possible cause of poor adherence to medication (Halpern et al., 2013).

3. ***Environmental factors.*** Environment factors were the approach of health professionals, social support and family environment, insurance policy, and wheelchair accessibility.

The approach of health professionals. Previous studies on pain and spasticity management mentioned about good and adverse effects of approaches from a health professional on symptoms management. Participants reported inadequate communication from health professionals regarding their problems, drug use, and the side effects influenced their pain management (Norrbrink et al., 2012). Adversely, positive attitude, active listening, respecting patients' experiences and desires, positively influenced pain management (Lofgren & Norrbrink, 2012). Problem-focused and need-based communication with the clients can improve adherence to pharmacotherapy in spasticity management (Halpern et al., 2013).

Social support and family environment. It was found that a positive family environment increased social support and enhanced coping skills among people with SCI (Muller et al., 2012). However, it should be also concerned that comfort and care offered by close family members sometimes decrease independency in people with SCI and caused stress and increase in pain experience (Goossens et al., 2009).

Insurance policy. In developing countries, lack of financial support or insurance decreased pain management (Khatry & Eliade, 2013; Kumar, Shrestha, & Bussmann, 2010; Thapa et al., 2017). In contrast in developed countries, people with SCI have financial support and medical insurance but they reported dissatisfaction that the insurance policies should increase their coverage to include a wider range of management strategies such as complementary therapies which were preferred and also highly effective to relieve pain in SCI therapies (Henwood & Ellis, 2004).

Wheelchair accessibility. Architectural and environmental barriers to wheelchair accessibility such as public transport, crossing road in traffic, lack of lifts were identified by people with SCI that were barriers to access the health care services (Akyuz, Yalcin, Selcuk, & Degirmenci, 2014). Studies conducted in Nepal mentioned that most people in the rural areas did not use modern medicine but use traditional herbs because of the high cost and long traveling distances to the health centers (Khatry & Eliade, 2013; Kumar et al., 2010).

Assessment of symptoms management among people with spinal cord injury

Previous studies regarding assessment tools designed to assess the symptoms management in people with SCI were limited. Previous quantitative and qualitative studies have identified some questions related to the use of pharmacological and/or non-pharmacological approach, the method of delivery, and the effectiveness of the strategies for relief of symptoms.

Regarding the assessment of the use of strategies, a multiple-choice question was provided to the respondents that included a list of pharmacological and non-pharmacological methods. The participants could select multiple items (Cardenas & Jensen, 2006; Heutink et al., 2011). In another study, open-ended questions were provided to the respondents (Henwood & Ellis, 2004; Heutink et al., 2011). Similarly, the assessment of methods of delivery of management strategies was also done using a checklist or an open-ended questionnaire which was assessed by a 6-point Likert scale, from 1 (totally disagree) to 6 (totally agree) (Wollaars, Post, van Asbeck, & Brand, 2007).

For the assessment of effectiveness, the participant in the previous study reported the effectiveness of the management strategies as very good, good, rather good, insufficient or no effect (Norrbrink & Lundeberg, 2004), no relief (0) to complete relief (10), pain treatment made symptom worse, had no effect, slightly better, considerably better or disappeared (Widerstrom-Noga & Turk, 2003), and 0 (not at all), 1 (somewhat), or 2 (to a large extent) (Heutink et al., 2011). However, the formats of the symptoms management assessment tools mentioned above were not consistent to the SMM; hence, in this study, open-ended symptom management measures were developed by the researcher based upon the concepts of symptom management of the SMM (Dodd et al., 2001). Therefore, the researcher will use this questionnaire to assess the common symptoms management (pain, spasticity, and depressive mood) of people with SCI in this study.

Quality of Life of People With Spinal Cord Injury, and Factors and Assessments

The SMM mentioned outcomes as the third variable (Dodd et al., 2001). Among the eight outcomes in the model, quality of life (QoL) is one of them which the researcher used in this study because QoL is one of the outcomes referring to the general well-being of individuals and societies, outlining negative and positive features of life.

QoL is defined as “an individuals’ perception of their position in life in the context of culture and value system in which they live and in relation to their goals, expectation, standards, and concern” WHOQOL Group (as cited in Skevingkton et al., 2004, p. 299). QoL, a broad and multidimensional concept, combines physical health, psychological state, social relationship, and their relationship with the environment (WHO, 1997).

Apart from general well-being, the health-related quality of life (HRQoL) is important because it can vary from person to person due to different disease conditions. HRQoL is perceived as a multidisciplinary concept that in addition to physical symptoms associated with the disease, should also embrace physical, physiological and social functioning (Hays, Bjorner, Revicki, Spritzer, & Cella, 2009). Because of improvements in medical care, the life expectancy of people of SCI has increased considerably in recent decades. However, people with SCI still have a serious physical disability and a large number of secondary complications as mentioned previously in the topic of impacts of SCI on the victims. Therefore, an evaluation of QoL in these patients is a crucial issue for future planning as well as a needs assessment. Lundqvist et al. (1997) stated that QoL can be viewed both in terms of handicap and resilience because it is the individual’s own subjective evaluation of satisfaction derived from his or her life. The major aspects in the life of a person with SCI to be evaluated include physical state and ADL, emotional status and intellectual functioning, social interaction and performance of social roles, and feelings of general satisfaction or well-being. Therefore, QoL is probably more important in relation to how patients adapt to their condition.

SCI can lead to severe neurological deficits and functional limitation (Sezer, Akkus, & Ugurlu, 2015) resulting in various health problems. Previous studies showed inconsistent findings of QoL of SCI people which maybe because of the differences in the health systems, resources, and cultures and beliefs of participants.

Studies from Western countries revealed that people with SCI perceived low QoL (Ebrahimzadeh et al., 2014; Franca et al., 2011; Guest et al., 2014). In studies conducted in developing countries among people with SCI, overall QoL was perceived at a moderate level (Thapa et al., 2017; Shah, Rafiullah, & Ilyas, 2017).

In regard to the domain of QoL of the persons with SCI, one study conducted in Brazil showed the highest score in the social health domain, followed by psychological health, physical health, and environmental health (Franca et al., 2011). In contrast, a study conducted among veterans with SCI in India showed the highest score for the environment domain of QoL and the lowest mean score for social functioning (Kumar & Gupta, 2016). A Pakistani study showed the lowest score in the psychological domain (Shah et al., 2017).

Studies exploring sub-domains of QoL identified that the impact of SCI was greater on physical health compared to the mental health of the persons with SCI (Guest et al., 2014; Trgovcevic, Milicevic, Nedovic, & Jovanic, 2014). In the physical domain, many participants were dissatisfied with the capacity to work. In the psychological domain, a mood problem was mostly reported. Similarly, in the social domain personal relationship was a greater problem, and in the environmental domain, difficulties to access the physical environment were reported (Shah et al., 2017). In another study, it was found that people with SCI were the least satisfied with sexual life whereas personal relations and support had the highest scores of QoL (Franca et al., 2011).

Factors of quality of life in people with spinal cord injury

The factors of QoL among people with SCI based on the SMM are personal, health and illness, and environment.

1. Personal factors. Personal factors are age, gender, educational status, marital status, and employment/occupational status.

Age. Younger people had higher levels of QoL. Age was a significant predictor of emotional well-being (p <.001) and was independently associated with general health (p <.001) (Kivisild et al., 2014). However, in another study, there was no association between age and QoL among male veterans with SCI (Ebrahimzadeh et al., 2014).

Gender. Females had lower mental health scores compared to males (Andresen et al., 2016). But another study showed no significant association between gender (Gurcay Bal, Eksioglu, & Cakci, 2010).

Educational status. Participants with higher education had significantly better mental health in comparison with the participants with low education (p <.05) (Gurcay et al., 2010). In another study, similarly, patients with a higher level of education had better psychological and environmental health (Kumar & Gupta, 2016).

Marital status. Being married was a factor to increase life satisfaction among people with SCI. However, no significant difference was seen in the marital status of soldiers which could be because they had adequate resources and needed less assistance from a spouse or other family members (Kumar & Gupta, 2016).

Employment or occupation status. Employment status is considered an important aspect to maintain QoL. Among people with SCI, the decrease in QoL is also due to the obstacles in returning to their previous work. Hence, being employed was related to improved QoL (Kivisild et al., 2014) with a better score in physical functioning and physical role (Gurcay et al., 2010). However, poor scores in physical and mental components of QoL were found among veterans with SCI (Saadat et al., 2010).

2. Health and illness related factors. Level of injury**,** completeness of injury, duration of injury, medical comorbidities were health and illness-related factors.

Level of injury. Cervical level of injury was associated with a lower physical health score (Andreson et al., 2016; Lude, Kennedy, Elfstorm, & Ballert, 2014). Psychological health among paraplegic patients was better than quadriplegic patients (p <.02) (Kumar & Gupta, 2016).

Completeness of injury. Completeness of injury was negatively correlated with QoL (Kivisild et al., 2014). Persons with complete injury reported lower physical QoL (Lude et al., 2014). In a recent finding, physical functioning and physical component score were higher among the patients who had an initial incomplete injury with AIS-D, when compared with participants who had initial AIS score A, B or C. Mental component score was significantly increased in AIS A when compared with AIS-D ($p < .05$) (Richard-Denish, Thompson, & Mac-Thiong, 2018).

Duration of injury. Shorter the duration of injury lower was the QoL scores for both physical and mental health scores (Andresen et al., 2016). However, there was no association found between duration of injury with QoL in a study of male veterans with SCI (Ebrahimzadeh et al., 2014).

Medical comorbidities. The presence of medical comorbidities showed the most significant influence on QoL in a study where 35% of participants suffered from medical problems such as hypertension, asthma, and diabetes (Kumar & Gupta, 2016). Depression and anxiety were significant predictors of emotional well-being ($p < .001$) and independently associated with general health ($p < .001$) (Kivisild et al., 2014). Another study revealed similar results in that depression and anxiety have a negative relationship with the mental and physical component of QoL respectively (Ebrahimzadeh et al., 2014). Furthermore, common symptoms such as pain, spasticity, and depression, etc. cause a decrease in the QoL in people with SCI (Andresen et al., 2016; Finnerup et al., 2016; Guest et al., 2014).

3. Environmental factors. Environmental factors include the use of technology and social support.

Use of technology. Among the people with SCI who used the internet, pain decreased significantly with an improvement in physical aspects of QoL compared to those who did not use the internet ($p < .05$) (Celik et al., 2012).

Social support. In a study conducted by Muller et al., (2012) among the people sustaining traumatic SCI, social support positively correlated with improved physical and mental health along with coping, adjustment, and life satisfaction, and overall functioning.

Assessment of quality of life of people with spinal cord injury

The most commonly used tools assessing the QoL in people with SCI were the Medical Outcomes Study Short-Form 36-Item Health Survey *(*SF-36*)* and WHOQOL-BREF.

1. The Medical Outcomes Study Short-Form 36-Item Health Survey (SF-36). The SF-36 was introduced by Ware and Sherbourne in 1992. The tool assesses the health status of a general or specific population and compares disease burdens along with the benefits of management strategies and screenings. The 36 multiple items of physical and mental health are grouped in eight health concepts as follows: two items physical functioning (PF), four items on role limitations due to physical functioning

(RP) , two items on social role functioning (SF), two items on bodily pain (BP), five items on mental health (MH), three items on role limitations due to emotional problems (RE), four items on vitality (VT), and five items on general health (GH) (Ware & Sherbourne, 1992). A Likert scale ranging from 0 to 100 is used with a total score of 0-800 with a higher score referring to better health status. The administration time of this tool is 5 to 10 minute (Ware & Sherbourne, 1992) and for people with SCI, it may take up to 41 to 47 minutes among paraplegia and tetraplegia respectively (Andresen, Fouts, Romeis, & Brownson, 1999).

The SF-36 is a validated and reliable tool with the intra-class correlation coefficients (ICCs) ranging from 0.71 to 0.99 and excellent discriminant validity between the constructs of the physical capacity and mental capacity score (Forchheimer, McAweeney, & Tate, 2004) with an excellent to adequate convergent validity of 0.32 to 0.72 (Lin, Hwang, Chen, & Chiu, 2007). However, the SF-36 cannot be used in this study because of the unavailability of the tool in the Nepali language and the original researcher does not permit to translate the instrument.

2. The Spinal Cord Injury Quality of Life Questionnaire. The SCI QL**-**23 is an SCI specific HRQoL assessment tool developed by Lundqvist et al. (1997). The SCI QL-23 consists of 23 items and 3 variables and the last item of measures of Global Quality of Life (GQOL). The 22 items are divided into three variables of (1) functioning (FUNC), (2) mood state (MOOD), and (3) problems related to injury (PROB). Each of these is described as follows:

2.1 FUNC/functioning. Functioning domain refers to the limitation in functional capacity for activities such as mobility, body care, movement, and social interaction. There was 10 items or statements describing the possible conditions of persons with SCI within these areas. The respondents are required to indicate only those items with which she or he agrees. Each of the 10 item carries a certain value. The key test-results are ranged on the scale from 0-100; a lower score represents a better result (Elfstorm, Rydén, Kreuter, Taft, & Sullivan 2005; Lundqvist et al., 1997).

2.2 MOOD/Mood. The domain includes six items related to the presence of depressive feelings and bad mood. Each item has four levels of answers provided. A participant marks the answer that best describes him or her.

2.3 PROB/Problem. Problem domain refers to the assessment of the perception of physical dependence, complications and social stigma related to the specificity of injury. It consists of six items with four levels of answers offered. The participants are asked to circle the answer to each specific item which was closest to their feeling.

2.4 GQOL/Global quality of life. The GQOL means the overall rating of a life situation containing a single question, and the participants should choose an answer on the scale 1-7.

The SCI QL-23 had acceptable psychometric properties. During the development of the tool, internal consistency, Cronbach's alpha coefficient was 0.85 in both FUNC and MOOD and 0.86 in PROB (Lundqvist et al., 1997). Previous studies also showed SCI QL-23 presented with excellent reliability with Cronbach's alpha coefficient more than .80 (Jain, Sullivan, Kazis, Tun, & Garshick, 2007) and .76 (Ebrahimzadeh et al., 2014). The content validity of SCI QL-23 was according to a conceptual model that includes condition-specific aspects as well as general aspects of physical and psychosocial functioning and well-being, and overall HRQoL (Jain et al., 2007). To find the correlation between different domains of the questionnaire, Pearson's correlation was applied, and it revealed a significant correlation between different dimensions. Mood and Function showed the highest correlation, among others. There was no ceiling or floor effects (Ebrahimzadeh et al., 2014).

In this study, SCI QL-23 was used to assess the QoL of people with SCI because it is an SCI specific tool, short and easy to complete, and comprehensive in identifying possible items that are important to measure HRQoL in SCI (Jain et al., 2007).

Common Symptoms Experience of Family Caregivers of People With Spinal Cord Injury, and Factors and Assessments

This section includes the common symptoms experience among the FCs of people with SCI and the factors and assessments. The details are as followed.

Common symptoms experience among the family caregivers

After patients with SCI are discharged from the health care center, FCs provide long-term care including continuous personal care and assistance in ADL which predispose them to various physical and psychological problems (Darragh et al., 2015; Lawang et al., 2015). Previous studies identified common physical and psychological symptoms among the FCs of people with SCI. The three most common symptoms are: (1) burden (above 85%) (Khazaeipour et al., 2017; Ma et al., 2014), (2) low back pain (LBP) (65-80%) (Pajeemas et al., 2018; Suzuki et al., 2016), and (3) depression (40%) (Rodakowsky et al., 2013).

1. Burden. The burden of care among FCs is a multidimensional response of FCs to the negative appraisal and perceived stress resulting from caregiving to the patient (Kim, Chang, Rose, & Kim, 2012). According to Zarit et al. (as cited in Chou, 2000), caregiver burden includes emotional, and physical health, social life, and financial status as perceived by the caregiver and is the product of a specific, subjective, and interpretative process. This could be the reason that burden is considered a multidimensional concept.

Previous studies show some variabilities in the severity of burden symptoms among FCs of SCI patients. Among the participants, 11.7% FCs of SCI patients reported mild burden, 43.6% described a mild-to-moderate burden and 33.1-88% reported moderate-to-severe burden (Khajaeipour et al., 2017; Ma et al., 2014). In a Turkish and Iranian study, the majority of the caregivers reported 'mild-to-moderate' burden (Khajaeipour et al., 2017) whereas, in a Chinese study, the moderate-to-severe burden was identified (Ma et al., 2014). The variation can be due to the social and cultural differences between these two communities in terms of the responsibilities felt by people for taking care of a disabled member of the family, the pattern of traditional family structures, where it is considered a duty to sacrifice for the family. It may also be due to the different political background of a country which is closely connected to families' economic statuses, as well as different public health policies (Khajaeipour et al., 2017).

2. Low back pain. Low back pain (LBP) refers to a persistent, muscle tension along with stiffness, and soreness which is localized below the 12th rib posteriorly and below the costal margin and above the inferior gluteal folds or sacral region whereas chronic LBP is defined as "low-back pain lasting longer than 12 weeks" (Rubinstein, van Middelkoop, Assendelft, de Boer, & van Tulder, 2013, p. 2). The majority of LBP improves in 6 weeks; however, unresolved pain develops to chronic LBP (Leboeuf-

Yde, Jensen, & Wedderkopp, 2015). The various characteristics of LBP include aching, burning, stabbing or tingling, sharp or dull, and well defined or vague pain with an intensity of mild to moderate (Moussa, Ezbay, & Mowafy, 2015). People with a disability often require frequent caregiving activity which puts a great strain on the physical health of FCs resulting in a higher occurrence of LBP (Darragh et al., 2015). In a study of FCs of a stroke survivor, a high incidence of LBP (82.8%) was found (Yalcinkaya, Önes, Ayna, Turkyilmaz, & Erden, 2010). The FCs of people with SCI have a high risk of developing chronic LBP (Pajeemas et al., 2018; Suzuki et al., 2016).

A study conducted in Japan among female caregivers who took care of people with multiple disabilities including SCI mentioned the frequency of LBP. About 20% of the FCs of people with SCI reported experiencing LBP daily, 12.5% responded ‘always’ and 18.9% reported ‘almost always’ (Suzuki et al., 2016). In another study conducted among the caregivers of persons with multiple disabilities, 45.2%, 19.1% and 7.2% of respondents reported mild, moderate and severe LBP respectively (Lin et al., 2014). Among 16 caregiving activities, 14 activities were significantly related to the severity of LBP. The pain was highest during ‘carrying heavy things’ followed by ‘going up and downstairs’, ‘reaching up to take heavy things down from shelves’ and for ‘miscellaneous housework’, such as vacuuming. Moreover, most of the FCs of people with SCI reported the severity of chronic LBP as either moderate or severe (Suzuki et al., 2016). In a study conducted among FCs of people with SCI in Nepal, the average chronic LBP intensity was moderate (Sherpa et al., 2017).

3. Depressive mood. Depression is a major health problem which leads to social dysfunction and important life-threatening consequences, such as suicide. In this regard, some individuals with sensitive responsibilities, such as taking care of SCI patients are very susceptible to developing depression (Otaghsara et al., 2014). A study indicated that greater SCI impairments and caregiver stress due to those impairments were associated with higher caregiver depression and anxiety (Trapp et al., 2015).

In a study conducted among FCs of youths with SCI, 17%, 12%, and 8% had mild, moderate and severe depression respectively (Kelly et al., 2011). In another study, 43% of the FCs of people with SCI reported mild depression (Arango-Lasprilla et al., 2010). In contrast, the prevalence of depression among FCs of people with SCI in Tehran showed that 9.7% had mild, 5.6% had moderate and 2.1% suffered from a severe depressive disorder and this prevalence did not differ from the general population (Otaghsara et al., 2014). The prevalence of 43% could be because of a small sample size of 37 whereas, in the latter study the sample size was 119 and the self-report measure was not used for data collection.

Factors of common symptoms experience of family caregivers

According to the SMM, the factors related to the common symptoms experience are studied under the three domains of person, health and illness, and environment.

1. Personal factors. Personal factors include age, gender, educational status, level of income, marital status, number of children, history of smoking, and history of regular exercises.

Age. Higher age was associated with a higher level of burden, LBP and depression among caregivers. Among the FCs of people with SCI, those aged above 35 years or more had a higher level of caregiving burden compared to those aged less than 35 years (Molazem & Vagharseyyedin, 2014). Furthermore, chronic LBP in FCs of people with SCI was higher among those aged less than 60 years ($p < .01$) (Pajeemas et al., 2018). The age was not further specified in the study; however, LBP is a massive problem among women of 45-60 because they are going through perimenopausal and post-menopausal periods of life which is a result of a slower production of sex hormones (Kozinoga, Majchrzycki, & Piotrowska, 2015).

Gender. The previous study showed a higher prevalence of LBP among females whereas depression had conflicting findings and burden was not associated with the gender of FCs. Female caregivers have been also associated with LBP ($p < .02$) with high prevalence (Pajeemas et al., 2018) which could be due to the difference in anatomical, physiological and structural features among females with a greater weakness of back muscles than among males (Suzuki et al., 2016). In addition, perimenopausal and post-menopausal periods of life can have an impact on LBP among females (Pajeemas et al., 2018). Depression in two studies had greater prevalence among female FCs (Kelly et al., 2011; Kim, 2017) whereas, in another study, gender showed a non-significant relation to depression (Otaghsara et al., 2014). Moreover, gender was not related to burden among FCs of people with SCI (Khajaeipour et al., 2017; Secinti, Yavuz, & Selcuk, 2017). However, the majority of the caregivers in previous studies were women (Khajaeipour et al., 2017; Ma et al., 2014; Molazem & Vagharseyyedin, 2014; Secinti et al., 2017). It could be because of the historical role of women in the family and even in society.

Educational status. Educational status was inversely associated with burden and depression among caregivers. People with higher education had a low burden which could be because higher education involves several years of struggle and achievements and such individuals are considered more capable of handling stressful situations and new roles. These individuals can improve their knowledge regarding SCI individuals, their needs and method of coping with the new situation. In addition, since older people generally have a low education level, and aging is one of the factors associated with a higher caregiving burden (Khajaeipour et al., 2017). Depression was also inversely related to higher education in a study (Kelly et al., 2011). However, in another study educational status was not related to depression **(**Otaghsara et al., 2014).

Level of income. The previous study presented a negative relationship between employment and/or income with burden, and depression among caregivers. Among the FCs of SCI, income ($r = -.25$, $p < .05$) was negatively associated with the burden (Khajaeipour et al., 2017; Secinti et al., 2017) and depression (Kim, 2017).

Marital status. Greater number of FCs who were married had depression (Kelly et al., 2011) and a higher burden than the caregivers who were single ($p < .05$) (Molazem & Vagharseyyedin, 2014).

Number of children. Having children was related to LBP and higher burden. The majority of caregivers with children had LBP (Moussa, et al., 2015). FCs who had 5 or more children reported greater burden compared to those who had 1 or 2 children ($p < .05$) (Molazem & Vagharseyyedin, 2014).

History of smoking. Caregivers with a history of smoking had a higher occurrence of chronic LBP ($p < .001$) which can be because chronic nicotine usage causes the muscles to be malnourished or maybe that smokers have other negative lifestyles such as inactivity and being overweight (Pajeemas et al., 2018).

History of regular exercises. FCs with a history of regular exercise had comparatively less prevalence of LBP than caregivers without a history of regular exercise (Pajeemas et al., 2018).

2. Health and illness factors. In the presence of a history of LBP and other injuries can increase the occurrence of chronic LBP among FCs (Darragh et al., 2015). A study among FCs of children with physical disabilities showed that LBP was higher among those who had a previous history of LBP before their caregiving role (Tong et al., 2003). Among professional caregivers, a history of injuries or physical trauma was associated with LBP experience (Darragh et al., 2015). LBP was also negatively associated with burden ($r = -.23$, $p <.01$) (Khajaeipour et al., 2017; Molazem & Vagharseyyedin, 2014).

3. Environmental factors. Environment factors includes characteristics of people with SCI (e.g., level of injury, duration of injury, functional independence, occupational status, and behavior problems), caregiving activities, hours of caregiving, relationship with care recipient, living with care recipient, physical environment and social support that are related to symptom experiences of FCs.

Characteristics of People with SCI: For the level of injury, tetraplegics have higher-level injuries and they are more dependent on their caregivers for daily life activities and need more hours of care (Khajaeipour et al., 2017). Caregivers who take care of patients with a lower functional independence score ($p < .001$) and higher injury level ($p < .01$) had significantly high levels of depression (Bardak et al., 2012; Otaghsara et al., 2014). Similarly, chronic LBP (Secenti et al., 2017) and burden of caregivers ($p <.05$) had an inverse relation with the level of SCI (Khajaeipour et al., 2017).

In addition, there was also a positive relationship between duration of injury of SCI people with caregiving burden ($r = .17$, $p < .05$), (Khajaeipour et al., 2017) and LBP ($p < .01$) (Bardak et al., 2012). A longer duration of injury leads to a higher caregiver burden which may be because early on caregivers might expect the patient's condition to be temporary. However, when they later realize the permanent nature of the injury as a lifelong disability, FCs may be frustrated and feel more burdened. In addition, over time caregivers become older and their physical and mental ability, as well as flexibility, may decrease (Khajaeipour et al., 2017).

The occupational status of people with SCI people and burden of FCs were related. The burden score was lower when the people with SCI had a job after injury ($p < .05$) which could be because individuals with a job after an injury have generally SCI at a lower level with higher ability to perform daily activities being less dependent on FCs. As a result, caregivers might feel less burden (Khajaeipour et al., 2017).

Behavioral problems of the people with SCI (secondary to their health condition) were found to be associated with LBP among FCs (Pajeemas et al., 2018; Suzuki et al., 2016) and increased psychological stress adding up to physical strain also increased LBP among caregivers (Darragh et al., 2015).

Caregiving activities. Specific caregiving activities were reported to increase symptoms experience in caregivers because such activities/tasks required the caregiver to assume awkward postures and/or overexert themselves. In a study, carrying heavy things followed by using stairs increased chronic LBP the most (Suzuki et al., 2016) and in another study, transfers were identified as physically most demanding than any other activity of caregiving in a challenging environment (Darragh et al., 2015).

Hours of caregiving. Hours of the care for SCI individuals provided by the FCs had a positive relationship with the care burden (r = .25, p <.001) (Khajaeipour al., 2017) and LBP. FCs involved in caregiving activities for patients with SCI for more than 8 hours had a higher occurrence of LBP (p <.001) (Bardak et al., 2012; Pajeemas et al., 2018).

Relationship to care recipient. The previous study showed that FCs relationship with people with SCI was related to symptom experiences. Parents in comparison with spouses or other family members (p < .001) had a higher burden of care (Khajaeipour et al., 2017) whereas, in another study, spouse caregivers had significantly higher scores for burden than daughter or son caregivers (p <.05) (Molazem & Vagharseyyedin, 2014).

Living with the care recipient. Previous studies showed that when FCs and people with SCI live together there was a high burden of care (p < .05) (Khajaeipour et al., 2017), and predicted caregiver depression (p < .05) (Rodakowsk et al., 2013). Mostly, all parents and spouses live together with the care recipient, which may be the reason that parents and spouses had higher levels of burden (Khajaeipour et al., 2017). Additionally, FCs had less opportunity for leisure activities because of caregiving for people with SCI and other regular daily activities such as work and taking care of children (Yoong & Koritsas, 2012).

Physical environment. The physical environment in the home including a stair but no ramp or an elevator, narrow doors, bathroom, and corridor adds to the physical burden upon the FCs causing LBP (Darragh et al., 2015).

Social support. Social support from family and friends were negatively related to depression and indirectly affected the burden among caregivers. Higher support received from family and friends lowered FCs depressive feelings which later resulted in less burden in caregivers (Secenti et al., 2017). Premorbid family relationships (Fauth et al., 2012) and family cohesion (Torossian & Ruffins, 1999) were associated with less burden and depression among family caregivers.

Assessments of common symptoms experience of family caregivers

Various unidimensional and multidimensional assessment tools have been used to assess the LBP, burden, and depressed mood in previous studies. The details are explained below.

1. LBP assessment. Visual Analog Scale (VAS), Numeric Rating Scale (NRS), Short-form McGill Pain Questionnaire (SF-MPQ), and Short Form Brief Pain Inventory *(*SF-BPI*)* were tools used to measure LBP severity.

1.1 Visual Analog Scale .VAS .VAS is a unidimensional tool used to assess pain in a wide range of disease including SCI. VAS consists of a horizontal or vertical line, 10 centimeters)cm (or 100 millimeters)mm (in length. The left side of the scale labels as‘ no pain ’and the right labels as‘ pain as bad as it could be ’)Hawker, Mian, Kendzerska, & French, 2011 .(The respondents are supposed to point the line to indicate their pain intensity which is occurring at present and over the past week or past two weeks .The intensity of pain is categorized as mild (5 to 44 mm), moderate (45 to 74 mm), and severe (75 to 100 mm). A higher score represents greater pain intensity) Hawker et al., 2011; Mannion, Balagué, Pellisé, & Cedraschi, 2007).

The correlation coefficients of VAS were higher in Verbal Rating Scale ranging from .70 to .78 compared with the Numeric Rating Scale that ranges from .62 to .91 (Hawker et al, 2011). Self-report assessment is considered the gold standard for the assessment of pain. VAS has been widely used among a wide population including individuals with LBP (Olaogun, Adedoyin, Ikem, & Anifaloba, 2004. But the use of the tool is limited among the older people and people with physical and cognitive impairments.

1.2 Numeric Rating Scale. The NRS is another unidimensional tool to assess pain intensity consisting of numbers from 0-10 where 0 indicates ‘no pain’ and 10 indicates the pain ‘as bad as it could be’. Higher scores indicate higher pain intensity. The level of pain is categorized into mild (1-3), moderate (4-6), and severe (7-10) (Hawker et al, 2011 Mannion et al., 2007). NRS is a valid and reliable assessment tool for pain intensity and has an easy scoring method (Ostelo & de Vet, 2005).

1.3 Short-form McGill Pain Questionnaire. The SF-MPQ is a multidimensional pain assessment tool to assess the perceived pain intensity and pain quality in among adults with LBP (Kuijpers et al., 2011). The tool has 15 words referring to sensory (11 words) and affective subscales (four words). Each item is rated as 0 = no, 1 = mild, 2 = moderate and 3 = severe. A high score refers to worse pain (Hawker et al., 2011). The internal consistency of the tool was, Cronbach’s alpha of .77-.93 (Dworkin et al., 2015).

1.4 Short Form Brief Pain Inventory. The SF-BPI is a multidimensional pain assessment tool developed from the Wisconsin Brief Pain Questionnaire to assess cancer pain (Cleeland & Ryan, 1994). It consists of two dimensions of pain i.e., pain intensity and pain interference. This tool consists of a 0-10 NRS on horizontal lines with numbers for pain intensity and interference. The participants are required to rate their pain intensity as pain right now, pain at its worst, at its least, and pain on average (Breivik et al., 2008). Additionally, the pain interference scale has seven aspects of life as follows: (1) general activity; (2) walking; (3) normal work; (4) relationships with other people; (5) mood; (6) sleep; and (7) enjoyment of life. The level of pain intensity and interference of the BPI was categorized as mild (1.00-3.99), moderate (4.00-6.99), and severe (7.00-10.00) (Archer, Castillo, Wegener, Abraham, & Obremskey, 2012). Higher scores represent a higher intensity of pain.

Regarding internal consistency, Cronbach’s alpha for the tool was .80 to .87 for the pain intensity scale and .89 to .93 for the pain interference scale. The test-retest reliability of the pain intensity scale and the pain Interference scale range from .83 to .88 for and .83 to .93 respectively (Cleeland, 2009). Hence, the tool was considered a valid and reliable tool to assess LBP.

The BPI can be self-administered or through a clinical interview or even administered over the telephone. It requires only 2-3 minutes to administer the instrument (Breivik et al., 2008). In addition, BPI is a multidimensional tool but simple and easy to understand.

In this study, SF-BPI was used for the assessment of pain intensity because it is a multidimensional tool that provides information about both the intensity in regards to pain at worst, pain at least, pain in average and pain right now. Moreover, for pain frequency, no specific tool measures the frequency of LBP (Mannion et al., 2007). In some studies, there was the use of a number of days in a specified period of time as pain all the time i.e., once a week, once a month, or more than once a month to measure the frequency of LBP (Mannion et al., 2007; Mohamed, 2012). Therefore, the researcher used this tool to measure pain frequency in this study.

2. Burden assessment. Family Burden Interview Schedule (FBIS) and Short-form Zarit Burden Interview (SF-ZBI) or ZBI-12 were commonly used in the previous studies to assess caregiving burden among FCs.

2.1 Family Burden Interview Schedule. The FBIS was primarily developed for the FCs of schizophrenia patients by Pai and Kapur in India in 1981 (Ren et al., 2014). FBIS is a semi-structured interview instrument composed of 25 items that are grouped into the following scales: financial burden (items 1-8), disruption of family routine activities (items 7-11), disruption of family leisure (items 12-15), disruption of family interactions (items 16-20), the effect on the physical health of others (items 21-22), and the effect on the mental health of others (items 23-25). Each item was rated on a three-point scale, where 0 was no burden, 1 was a moderate burden, and 2 was a severe burden. The total scores ranged from 0 to 50 with 50 indicating the highest burden of care (Ren et al., 2014). Duration of scale application was approximately 60 min (Bandeira, Calzavara, Freitas, & Barroso, 2006; Lasebikan, 2012).

Among Nigerian FCs, good reliability and validity were found. For internal consistency, a Cronbach’s alpha was between .62 and .82 for each item. The intraclass correlation coefficient for the total score of FBIS was .85, test-retest reliability of individual scales was .83 for total objective scale score. Convergent validity was shown by the significant positive correlation (r = .83) between the objective burden score and subjective burden score (Lasebikan, 2012). Among psychiatric patients, Cronbach’s alpha coefficients ranged from .58 to .90 for global and domains scores. Pearson correlation coefficients and intra-class correlation coefficients for test and retest ranged from .54 to .90 (Bandeira, Calzavara, Freitas, & Barroso, 2006). However, this tool was not used in this study because of the longer time required for administration.

2.2 Short Form Zarit Burden Interview. In 1980, Zarit Buden Interview was introduced by Zarit, Reeve, & Bach-Peterson (as cited in Bedard et al., 2001). Hebert, Bravo, and Preville (as cited in Bedard et al., 2001) revised the initial 29 items tool into 22 items. The tool was further shortened by Bedard et al. (2001) to the short 12-item ZBI.

ZBI-22 was proved to be valid and reliable in many clinical settings, countries, and cultures with excellent internal consistency (Cronbach's alpha coefficient 0.83 and 0.89). It was reported that ZBI-12 is as competent as the 22-item ZBI in terms of validity and reliability. The magnitude of the correlations obtained for the ZBI-22 and ZBI-12 versions was similar (Bedard et al., 2001). The tool was further shortened by Bedard et al. (2001) short 12-item ZBI based on two factors i.e., Personal strain and Role strain. The two factors were developed in 1991 by Whitlatch, Zarit, and von Eye (as cited in Knight, Fox, & Chou, 2000). Personal strain means 'how personally stressful the experience is' and role strain is 'the stress due to role conflict or overload' (Kumamoto & Arai, 2004). For ZBI-12, the Cronbach alphas for the personal strain factor was .89 and role strain factor was found to be .77 with an overall Cronbach's alpha of .88 (Bedard et al., 2001). In a recent validation study of ZBI-12 for spouses of chronic SCI population, it showed strong overall internal consistency with Cronbach's alpha of .78. Intraclass correlation between different items of ZBI-12 at test-retest was also done to find the correlation between questions which was found to be .78. There was a significant correlation between most of the questions. To find out the relationship between various items of the ZBI-12 and SF-36, Pearson's correlation was conducted. The findings showed that a significant negative relation between items of ZBI-12 and the psychological section of the SF-36 which confirms the convergent validity of the survey to assess items that are related to the mental health of the caregivers (Rajabi-Mashhadi et al., 2015). In another study, ZBI-12 demonstrated good consistency among FCs of people with SCI with a Cronbach's alpha coefficient of .7 (Molazem & Vagharseyyedin, 2014).

In this study, ZBI-12 was used for assessing the experience of the burden of FCs of people with SCI because it is simple and takes only a few minutes to administer.

***3*. *Depressive mood assessment*.** Beck Depression Inventory (BDI), Depression Anxiety Stress Scale (DASS), and Patient Health Questionnaire (PHQ-9) were the most commonly used self-report depressive mood assessment of FCs.

3.1 Beck Depression Inventory. The BDI is a 21-item self-reporting questionnaire for evaluating the severity of depression in normal and psychiatric populations developed by Beck et al. in 1961 (Khazaeipour, et al., 2015). It underwent revisions in 1978 and the BDI-II was developed in 1996. The questionnaire was developed from clinical observations of attitudes and symptoms occurring frequently in depressed psychiatric patients and infrequently in non-depressed psychiatric patients. Twenty-one items were consolidated from those observations and ranked 0-3 for severity (Beck, Ward, Mendelson, Mock, & Erbaugh, as cited in Jackson-Koku, 2016). The questionnaire is commonly self-administered although initially designed to be administered by trained interviewers. Self-administration takes 10 minutes (Jackson-Koku, 2016). The recall period for the BDI-II is 2 weeks for major depressive symptoms. The BDI-II contains 21 items on a 4-point scale from 0 (symptom absent) to 3 (severe symptoms) (Jackson-Koku, 2016). Scoring is achieved by adding the highest ratings for all 21 items. The score ranges from 0 to 63. Higher scores indicate greater symptom severity. In non-clinical populations, scores above 20 indicate depression. In those diagnosed with depression, scores of 0-13 indicate minimal depression, score 14-19 mild depression, 20-28 indicate moderate depression, and 29-63 indicate severe depression (Jackson-Koku, 2016).

Content validity of the BDI-II has improved following item replacements and rewording to reflect DSM-IV criteria for major depressive disorders. Mean correlation coefficients of .72 and .60 have been found between clinical ratings of depression and the BDI for the psychiatric and non-psychiatric population. Construct validity was high for the medical symptoms, Cronbach’s alpha was .92 for psychiatric outpatients and was .93 for college students. For internal consistency, Cronbach’s alpha was .91 (Jackson-Koku, 2016), and .86 (Khazaeipour et al., 2015). Cut scores used were, 0 to 13 for minimal depression; 14 to 19 for mild depression, 20 to 28, moderate depression; and 29 to 63 for severe depression. Patients with a score ≥14 were termed the depressive group (Khazaeipour et al., 2015).

The short form of BDI consists of 13 sets of items that each represent a state in patients. The score of each item ranges between 0 and 3 and the total score will be between 0 and 39. The main advantage of the short-form of this inventory is that it takes about five minutes to fill it out (Mousavi, 2017). In an Iranian study, the reliability and validity coefficients of BDI-SF were reported to be .78 and .70 - .90, respectively (Azkhosh, as cited in Mousavi, 2017).

3.2 Depression Anxiety Stress Scale. The DASS-21 was developed by Lovibond and Lovibond in 1995 to measure emotional distress in three sub-scales of depression, anxiety, and stress (Oei et al., 2013). Each subscale is composed of seven items referring to the past week. The DASS-21 is quick and easy to administer, requiring less than 10 minutes to complete and excludes many somatic items that may not be relevant to those with SCI (Mitchell et al., 2008). Each item is scored on a 4-point scale (0 = did not apply to me at all, to 3 = most of the time). Subscale scores are calculated as the sum of the responses to the seven items from each subscale multiplied by 2 (Mitchell et al., 2008). This tool has been used to measure symptoms of depression, anxiety, and stress in both clinical and non-clinical samples of adults (Beaufort et al., 2017). A total score of 32 is considered clinically elevated levels of general psychological distress, while a score of 10-12 represents probable depression (Guest et al., 2018).

The DASS-21 had excellent criterion validity in the SCI population (Guest et al., 2018). In a large-scale Asian study conducted among employees, internal consistency was .86 for depression, .81 for anxiety, .70 for four items of stress, and .91 for overall score (Oei et al., 2013). However, this tool was not selected in this study because it has many items and also consists of items for anxiety and stress.

3.3 Patient Health Questionnaire. The PHQ-9 is a self-report questionnaire developed by Spitzer et al. (1999) to assess the depressive mood. There are nine items in this tool which are derived from the nine diagnostic criteria for depressive disorder as mentioned in the Diagnostic and Statistical Manual of Mental Disorders-IV. A 4-point Likert scale is used where ‘0 = not all’, ‘1= several days’, ‘2 = more than half the days’, and ‘3 = nearly every day’. The total score of PHQ-9 ranges from 0 to 27.

The higher score indicates higher depressive mood experience. In PHQ-9, there was no distinction made between intensity and frequency of depressive symptoms, hence, the researcher has to give due weight to both intensity and frequency of depressive moods, while making a judgment for the experience of depressive moods (Cameron et al., 2010).

The PHQ-9 has accepted psychometric properties as shown in the previous studies. The scale presented adequate internal consistency (α = .86) and test-retest reliability (ICC = .87). It also presented good construct validity, as overall scores and severity levels were strongly associated with functional and symptoms subscales. PHQ-9 had a sensitivity of 100% and a specificity of 84% compared with the Structured Clinical Interview for DSM-IV (Bombardier et al., 2012). PHQ-9 was used in previous studies among the FCs of people with SCI (Stevens et al., 2016; Trapp et al., 2015). A PHQ-9 score $\geq$10 had a sensitivity of 88% and a specificity of 88% for major depression (Kroenke et al., 2001). In the study, PHQ-9, Nepali version (Bhattarai et al., 2018b) was used to assess the severity of depressive moods of FCs of people with SCI.

In conclusion, for the common symptom assessment of FCs of people with SCI i.e., LBP, Burden, and depressive mood, three selected tool were SF-BPI, ZBI-12, and PHQ-9 respectively.

Symptoms Management of Family Caregivers of People With Spinal Cord Injury, and Factors and Assessments

This section includes symptoms management of the FCs of people with SCI and the factors and assessment as described in the following.

Symptom management of family caregivers

1. Burden management. Limited literature was found related to the management of caregiving burden among FCs of people with SCI. Hence, the literature review was extended to FCs of people with neurological problems.

In a review on a caregiver intervention for SCI and traumatic brain injury (TBI) patients, good family functioning, coping skills, and social support were reported to mediate caregiver burden and promote positive outcomes in burden management (Baker et al., 2017). Another study among caregivers of veterans with TBI, an in-home program for veterans was applied to reduce symptoms such as burden symptoms. The intervention by health professionals included (1) introduction of compensatory strategies to enhance cognitive functioning; (2) emotion-regulation strategies to manage behavioral and interpersonal difficulties; and (3) home environment modifications to support functioning. The role of FCs was to use their insights and perspectives to identify TBI-related problems; list their support and cooperation to implement and reinforce intervention strategies; to maintain use over time and apply to new situations, receive TBI education; and receive support through the provision of coping and problem-solving strategies. After 3-4 months of the intervention, there was a significantly lower burden score (Moriarty et al., 2016).

FCs of SCI patients who used wishful thinking as a coping strategy had a greater level of burden than those who confronted problems and sought information and social support for dealing with them (Beinart, Weinman, Wade, & Brady, 2012). Social support received from both families and friends helped the FCs of SCI patients to alleviate the depressive feelings of caregiving and, in return, burden decreased (Secinti et al., 2017).

A variety of psychosocial interventions have shown mild to moderate effectiveness in managing caregiver burden (Adelman et al., 2014). Support groups or psycho-educational interventions for caregivers of dementia and Alzheimer patients were effective. Psycho-education for caregivers of Alzheimer's disease included the provision of information about care planning, advice about patient management and the importance of self-care, skills training to aid patient management, stress management training, and problem-solving and decision-making guidance (Beinart et al., 2012).

Furthermore, in a literature review, pharmacological management of anticholinergics or antipsychotic medications in dementia or dementia-related behaviors in the patients reduced the caregiving burden among caregivers. It was found that many studies about the non-pharmacological interventions aimed at decreasing caregiver burden symptoms significantly decreased symptoms associated with caregiver burden (mood, coping, self-efficacy) but not the burden itself. However, the improvement in the burden related symptoms can indirectly decrease burden symptoms. Hence, the interventions were considered effective in caregiver burden management even though the effect sizes on burden were small (Adelman et al., 2014).

2. LBP management. Pharmacological and non-pharmacological strategies were used for LBP management among FCs. The details are explained below. Pharmacological management. Opioids (Tramadoi) was themost commonly used drugs for LBP relief (Kuijpers et al., 2011; White et al., 2011) followed by NSAIDs and antidepressants) White et al., 2011). NSAIDs are the most frequently prescribed and first-line drug)White et al., 2011 (and significantly effective (Kuijpers et al.,

2011) for LBP. However, there was an exacerbation of pain after stopping the use of NSAIDs, with common side effects such as abdominal pain, diarrhea, dry mouth, rash, dizziness, headache, and tiredness (Kuijpers et al., 2011; White et al., 2011). In a study conducted in Nepal, 30% FCs of people with physical disabilities used pain medication to relieve their LBP (Ibuprofen, Acetaminophen) with moderate to high effectiveness (Sherpa et al., 2017).

Non-pharmacological management. Non-pharmacological management includes massage, heat therapy, stretching exercises, weight loss, physiotherapy, physical exercises, and yoga. Massage therapy was effective intervention for LBP management among professional caregivers with LBP (Allen, 2016; Almeida, Saragiotto, Richards, & Maher 2018; Shipton, 2018). Heat application with a hot water bag along with naproxen (Dehghan & Farahbod, 2014), yoga, and stretching exercises were found to be effective methods for the management of LBP (Chen et al., 2014).

Among patients with chronic LBP in a physiotherapy clinic, medication was the most commonly used strategy and was reported as being effective in managing pain (Crowe et al., 2010). They used anti-inflammatory and analgesics drugs (Paracetamol and Ibuprofen) twice a day and for breakthrough pain (Crowe et al., 2010; Kawi, 2014), exercise (stretching, relaxation, cycling or walking), heat application (shower, electric blanket), modification of the working environment (cushion in the car, proper sitting positions and distraction with music) (Crowe et al., 2010), lifestyle modifications (healthy diet, weight control, and keeping a positive mood) and wearing comfortable shoes alleviated pain (Kawi, 2014). Walking an hour every day, 3 days a week, cycling for 10–15 minutes, and swimming for half an hour reduced LBP among adults. Direct heat in the mornings was applied in the form of showers or baths or electric blankets or wheat packs. Participants also tolerated pain and coped with the pain because other management strategies were not effective for them. Other commonly used strategies were pacing with the work, environmental awareness (modification of car) and diversional activities (music) (Crowe et al., 2010). According to Sherpa et al. (2017), Nepalese FCs of people with a physical disability used more non-pharmacological strategies rather than pharmacological. However, the effectiveness was less compared to pharmacological strategies.

3. Depressive mood management. Previous studies show the use of psychosocial interventions to reduce depressive symptoms among FCs of SCI, TBI and cancer patients. Problem-solving training was used by health professionals followed by practice by the caregivers themselves to decrease depression among the FCs of SCI patients (Elliott et al., 2008). In the problem-solving training, five steps of problem solving were illustrated by the health professionals at the FCs homes, which were (1) problem definition, (2) optimism and orientation toward problem-solving, (3) creativity and generating alternatives, (4) understanding and decision-making, and (5) solving the problem with implementation and evaluation of a solution. Follow-up was conducted monthly for 12 months, through video conferencing, to assess the use of the learned skills. It was found that after six months of applying the problem-solving training by the FCs at home, there was a significant decrease in depression among the FCs (Elliott et al., 2008).

Similarly, in a study among caregivers of veterans with TBI, a Veterans' in-home program was applied to reduce symptoms such as depressive symptoms and burden. The intervention by health professionals included the introduction of compensatory strategies and home environment modifications to support functioning. The role of FCs was to use their insights and perspectives to identify TBI-related problems; listing their support and cooperation in implementing and reinforcing intervention strategies; to maintain use over time and apply to new situations, receiving TBI education; and receiving support through the provision of coping and problem-solving strategies. After 3-4 months of the intervention, there were significantly lower depressive symptoms (Moriarty et al., 2016). In a study among the FCs of cancer patients, social support such as care from others, love, and affection, the chance to talk about household work and the chance to talk to someone they trusted about personal and family problems decreased the occurrence of depression among FCs (Jeong & An, 2017).

Factors of symptoms management of family caregivers

Based on the three domains of SMM, person, health/illness and environment, the factors of symptoms management in FCs of people with SCI are explained. Due to the limited literature available on the factors of the symptoms management among FCs of people with SCI, the factors related to LBP management in professionals and adults, burden management, and depression management in other populations with disabling health conditions were also reviewed.

1. Personal factors. Understanding the problem, and beliefs are the personal factors related to symptoms management in family/caregivers identified from previous studies.

Understanding the problem. Understanding the pattern of a symptom can affect its management in a positive way. Adults with LBP who participated in a qualitative analysis expressed that despite the effectiveness of oral medication and non-pharmacological measures, sometimes, LBP is unmanageable. They shared that they know when the pain is not going to decrease. In such a situation, they find it helpful to “go with the flow” rather than taking extra medication and either sleep or continue their usual activities. This approach has been used by them for 30 years (Crowe et al., 2010).

Belief. Certain beliefs were identified and shared in a qualitative study which assisted the FCs to manage pain as well as it might have decreased the need of management (Singh, Newton, O’Sullivan, Soundy, & Heneghan, 2018; Whitman, 2007). The religious belief among the followers of the Hindu religion influenced pain management because they believe that pain is a consequence of sin in the past life and pain should be endured (Whitman, 2007). In a qualitative analysis, people with LBP in an out-patient department believed that the back is a very important part of their body and they need to take care of their back. They used the terms “precious” and “one back”. They believed that when the pain was going to start, their back would give them some message that something was wrong, and they need to stop the current physical activity and take a rest. Similarly, other participants believed that the pain was ‘will of God’ and they wished or prayed for the pain to go away as they wake up after sleeping (Singh et al., 2018).

2. Health and illness factors. The caregivers who had a history of LBP before caregiving to people with health problems, the dosage, and duration of an intervention may vary in comparison to the caregiver who never had symptoms of back pain before acting as a caregiver. Similarly, physically unhealthy or sick caregivers face more difficulties, which in turn may cause them to experience more burden (Vagharseyyedin & Molazem, 2014).

3. Environmental factors. Environmental factors of symptoms management among caregivers were the use of technology, focusing on a problem, social support, and access to health care.

Use of technology. The quality of internet resources can affect the outcome of caregivers' symptoms management. Websites and online resources are frequently accessed by caregivers and are increasingly becoming an important service-delivery tool. Yet such online resources were not well-described and might be outdated (Baker et al., 2017).

Focus on a problem. In a randomized controlled trial related to an intervention to manage depression among FCs expected outcomes were not achieved. The control group received an education program only whereas the intervention group received problem-solving training monthly for a year. Interventions focused on a specific, unique personal problem experienced by the caregiver are more likely to be successful and increase the relevance of the intervention (Elliot et al., 2008).

Social support. Social support was found to enhance management strategies in a study where support from family, friends along with health professionals had an influence on the adherence to management strategies (Combs & Thorn, 2014).

Access to health services. Studies conducted in Nepal mentioned that most people in rural areas do not use modern medicine but use traditional herbs because of the high cost and long traveling distances to the health centers (Khatry & Eliade, 2013; Kunwar et al., 2010).

Assessment of symptoms management of family caregivers

Previous studies regarding assessment tools designed to assess the symptoms management among FCs were limited. Some studies have generated questions regarding the use of pharmacological and non-pharmacological methods, the method of delivery of agents or strategies, and the effectiveness of those strategies on symptom relief.

However, the format of symptoms management assessment tools of previous studies were not consistent with the SMM; hence, in this study, open-ended symptoms management assessment measures (similar as in people with SCI) were developed including some components of questionnaires by the researcher based upon the concepts of the SMM (Dodd et al., 2001).

Quality of Life of Family Caregivers of People With Spinal Cord Injury, and Factors and Assessments

Caring for people with a disability may include a restricted relationship, decrease in leisure activities and job opportunities, financial insecurity, and frustration among FCs (Yoong & Koritsas, 2012). Frequent physical and psychological stress on caregivers reflects negatively on the wellbeing of the FCs which results in a decreased QoL among FCs (Costa, Gomes, Viana, Martinn, & Costa, 2016).

Previous studies show that QoL of the FC is affected after taking care of people with SCI (Ebrahimzadeh et al., 2013; Nogueira et al., 2016). In a Brazilian study conducted among FCs of SCI people, the Health Survey Short Form-36 was used to assess QoL. Findings showed that QoL was very low in the physical health domain, bodily pain, vitality and role emotional (Nogueira et al., 2016). Another study conducted in Iranian wives of veterans found that SF-36 scores of the spouses were lower than the normal population (Ebrahimzadeh et al., 2013).

In a recent study in Nepal, QoL of FCs of people with physical disabilities including SCI was perceived at a moderate level (Sherpa et al., 2017). The participants had the highest level of QoL in social relationship and the lowest in the psychological domain. The higher score in the social domain could be due to living in a joint family with caregiving assistance from the relatives. Furthermore, it was found that nearly one-third of FCs received support from family, friends, and organizations (Sherpa et al., 2017).

Factors of quality of life of family caregivers

1. Personal factors. Personal factors of QoL among the FCs were age, gender, educational status, income, and the number of children.

Age. Previous studies showed a negative association between age and QoL. In a study of FCs of individuals with SCI, age was significantly negatively related to QoL in older caregivers ($p < .05$) (Nogueira et al., 2016). Similarly, there was a negative correlation between age and physical functioning among wives of SCI veterans ($r =-.34$, $p < .01$) (Ebrahimzadeh et al., 2013). The age of FCs was associated with reduced physical functioning and reduced mental health domain (Chen et al., 2010; Ebrahimzadeh et al., 2013).

Gender. There were some variations in gender and its relation to QoL among FCs. Female caregivers had lower HRQoL in the physical and emotional role domains of HRQoL whereas male caregivers had lower HRQoL in the domains of physical functioning, bodily pain, general health status, and social aspects (Noguiera et al., 2016). In another study conducted in Chinese FCs of stroke survivors, female FCs had the worst mental health domain (Chen et al., 2010).

Educational status. A significant positive correlation was observed between the education level ($r = .24$, $p < .05$) and vitality ($r = .26$, $p < .01$) with the physical functioning domain of HRQoL (Ebrahimzadeh et al., 2013).

Income. Family income was a factor of QoL among caregivers. Previous studies presented the finding that in the families with lower monthly income, the FCs had lower QoL (Xie et al., 2016; Sherpa et al., 2018).

The number of children. Number of children had a negative correlation with vitality ($r = -.28$, $p < .05$) and emotional role ($r = -.24$, $p < .05$) domains of HRQoL (Ebrahimzadeh et al., 2013).

2. Health and illness factors. Health and illness factors were comorbidities among caregivers. In the Brazilian study, chronic diseases i.e., hypertension and depressive mood were related to decreasing QoL among FCs of SCI people (Chen et al., 2010; Noguiera et al., 2012). Similarly, burden and HRQoL were negatively correlated indicating higher burden worsened caregiver's HRQoL (Noguiera et al., 2012).

3. Environment factors. Environmental factors were the dependency of the care recipient and social support.

The dependency of the care recipient. A study conducted in Thailand showed that the physical and mental health of FCs was lower in those who reported a higher dependency level of their patients (Lawang et al., 2015). Tetraplegia contributed to greater care burden and worse HRQoL among the FCs of SCI people ($p < .05$) (Noguiera et al., 2012).

Social support. Higher social support was related to better physical and mental health of FCs of people with a disability in a study conducted in Thailand (Nightangale, Curbow, Wingard, Pereira, & Carnaby, 2016).

Assessments of quality of life of family caregivers

The QoL assessments among FCs of people with SCI commonly used were Medical Outcomes Study Short-Form 36-Item (SF-36) and World Health Organization Quality of Life (WHOQOL-BREF).

1. Medical Outcomes Study Short-Form 36-Item. As mentioned in the section of people with SCI, the SF-36 is a generic instrument introduced by Ware and Sherburne in 1992 for assessment of the health-related QoL. SF-36 comprises of 36 items categorized into eight domains which are (1) physical functioning, (2) physical role, (3) emotional role, bodily pain, (5) general health status, (6) vitality, (7) mental health, and (8) social functioning. The reliability and validity of SF-36 are maintained. The qualities of the tools are mentioned in the section of SCI.

2. World Health Organization Quality of Life. The WHOQOL-100 was introduced by the WHOQOL group aiming to develop a QoL assessment tool that could be applicable cross-culturally (WHO, 1996). WHOQOL consists of 100 items. The shorter form of WHOQOL, WHOQOL-BREF was developed to analyze the QoL domain level profile.

This tool aims to assess the QoL within the context of individual cultures, value systems along with the personal goals, and standards. The WHOQOL-BREF has 26 questions grouped into four domains namely, (1) physical health, (2) psychological, (3) social relationship, and (4) environment (WHO, 1996). The first two items among the 26 items are examined separately. The first question is related to the individual's overall perception of QoL and the second question is related to the overall perception of the health of an individual (WHO, 1996). The remaining 24 questions are categorized into the four domains of QoL. There are seven items in the physical health domain as follows: ADL, dependence on medical substances, energy and fatigue, pain and discomfort, mobility, sleep and rest, and work capacity. Similarly, the psychological domain comprises of six items which are bodily image and appearance, negative feelings, positive feelings, self-esteem, spirituality or religion or personal beliefs, and thinking, learning memory and concentration. The three items of social relationship domain are personal relationship, social support, and sexual activity. The environment domain consists of eight items which are financial resources, freedom, physical safety and security, health and social care, home environment, opportunity to acquire new information, recreation, physical environment, and transport.

In this tool, a 5-item Likert scale was applied with scores of 1-5 items used to represent the raw item score. The scores in the domain are scaled in a positive direction to represent higher QoL with a higher score .The items with a negative score are reversed in a positive direction. Furthermore, the mean scores of each domain are calculated to obtain the domain score in the following step, the mean scores are multiplied by 4 to make the domain score comparable to the WHOQOL-100. In the first transformation, scores are converted to a range of 4-20 and in the second transformation, the domain score is converted into the domain scores of 0-100. A higher score indicates a higher QoL) WHO, 1996). Moreover, the total score of the 26 items ranges from 26 to 130. Since WHOQOL -BREF does not have a cut-off point, the score may be categorized into 3 levels using the maximum score minus minimum score divided by the number of categories. The scores are interpreted as high QoL (96.00-130.00), moderate (61.00 -95.00), and low (26.00-60.00) (Pensri, 2007).

Regarding the psychometric properties of the tool, previous studies mentioned the reliability coefficients. In a large-scale study from 23 culturally different nations (Skevington, Lotfy, & O'Connell, 2004), the internal consistency was good (Cronbach's alpha >.70) for the physical health, psychological, and environmental domains. However, the social relationship domain had a Cronbach's alpha of .68 (Skevington et al., 2004). Another study conducted among Nepalese FCs of people with physical disabilities showed a Cronbach's alpha coefficient of .71 (Sherpa et al., 2017). The WHOQOL-BREF is translated into a Nepali version with the internal consistency reliability of Cronbach's alpha of .71 (Giri et al., 2013). The administration time of the questionnaire may range from 10 to 15 minutes. In this study, The WHOQOL-BREF (Nepalese Version) was selected to study the QoL among FCs of people with SCI.

Health Care Service for People With Spinal Cord Injury and Family Caregivers and Existing Studies in Nepal

The Constitution of Nepal 2007 addresses health as a fundamental right, stating that every citizen has the right to basic health services free of cost. But in reality, only 61.8% of the Nepalese households have access to health facilities within 30 minutes of their homes. Among these, most people are from urban areas (85.9%) (Mishra, Khanal, Karki, Kallestrup, & Enemark, 2015).

The incidence of SCI has been increasing in recent years. The major etiology of spinal injury in Nepal is related to fall injuries unlike in western countries where motor vehicle accidents top the list. Injury prevention and emergency management is another challenge for Nepal to prevent spinal cord injury. Trauma patients often reach the hospital without neck or spine immobilization (Shrestha, 2014). In a four-year retrospective study conducted in an SCI rehabilitation center, it was found that almost half of the admitted patients were from the central region of the country or Province No. 3. Nearly 75% of people with SCI admitted were male and had fallen from a height which was the major cause of their injuries. The young and productive age groups were most affected (Shrestha, Shrestha, & Shrestha, 2013).

In Nepal, management of SCI is extremely difficult (Shrestha, 2014) whereas, SCI is addressed in the developed countries with standard trauma care system commencing immediately after injury continuing to the specialized rehabilitation units (Shah et al., 2013). Besides economic constraints, other limiting factors are lack of trained personnel and well-equipped centers, awareness among patients and family members regarding the available services (Shrestha, 2014), and hindrances due to the infrastructure, for example, the bad condition of the roads, and inaccessible/inadequate transportation. In 2014, the Ministry of Health and Population announced the financial support of Nepali rupees one lakh to the patient of SCI. But this fund is available through only a few designated hospitals in Kathmandu such as the National Trauma Center, and Tribhuvan University Teaching Hospital, and hence the patients with SCI need to travel to the capital city to benefit from the financial help from the government. Many patients, hospitals and even health care personnel may not be aware of government financial support to the SCI patients. The SCI patients usually do not benefit from the financial support provided by the government during the rehabilitation phase because the support is usually spent on acute management in the hospital rather than on rehabilitation (Shrestha, 2014).

Furthermore, SCI management does not end with spinal instrumentation or stabilization, and conservative management of the acute phase. SCI rehabilitation is the only intervention that ensures a successful community reintegration of an SCI patient as an active member (Rathore, 2010). Rehabilitation after SCI is an emerging concept in Nepal (Shah et al., 2013). There is only one spine rehabilitation center in the whole of Nepal, which is situated near the capital city (Kathmandu) (Munakomi, Bhattarai, & Cherian, 2017). The SCI rehabilitation incorporates multidisciplinary services for people with SCI and FCs which include medical and nursing care (focus on bowel, bladder, skincare and other common health problems, pain, spasticity, thrombosis etc.), physiotherapy, occupational therapy, psychosocial counseling, vocational rehabilitation, disability rights counseling, educational, and recreational activities (Chabbra, 2015).

In the setting of the Nepalese community, people with SCI face lack of home and community accessibility as a major barrier for mobility. Even though many used mobility aids (74%), they could not access the community independently. The roads do not provide access to their homes (some of them lived at a distance of 6-7 hours from access to public transportation). People with SCI in this study indicated ‘severe’ or ‘extreme’ restrictions to community access. Most of the patients required a caregiver. Caregivers were most frequently wives followed by parents, including in-laws and husbands, with help from children or siblings. Most caregivers were present during hospitalization (caregiver required for the patient’s hospital stay) (Scovil, Ranabhat, Craighead, & Wee, 2012).

Moreover, few studies have explored people with SCI and FCs in Nepal. In a study related to health problems after discharge to the community, people with SCI reported pain, spasticity or contractures, depressed moods, sleep problems, and drug and alcohol issues (Scovil et al., 2012). Some studies mentioned about pain management. The majority of people in Nepal were found to rely on traditional healers for pain management before they visited any health center and this could be due to the distinct healing belief and practices among diverse ethnic groups in Nepal (Adhikari, 2016). Another reason, as reported in a cross-sectional study, was the high cost of medical services compared to the traditional healing methods (Bhattarai et al., 2007).

Few studies have recently been conducted in Nepal among SCI patients and FCs (Bhattarai et al., 2018a; Sherpa et al., 2017, 2018; Thapa et al., 2017, 2018). However, in each study, a single symptom was only investigated whereas there is several physical and psychological symptoms present after sustaining an SCI and each affects the QoL of these patients differently. Additionally, FCs suffer from various health problems as a result of caregiving to the people with SCI giving rise to physical and psychological symptoms.

A study on chronic pain among people with SCI was conducted using a purposive sampling technique. The participants were individuals who were previously admitted in an SCI rehabilitation center. The samples included in the study had a duration of SCI that ranged from one to 24 years. The finding presented a high prevalence of moderate level of chronic pain. The most common locations of chronic pain were back, lower legs and buttocks/hips (Thapa et al., 2018). Furthermore, SCI patients used non-pharmacological measures more than pharmacological management. Ibuprofen was the most commonly used medicine. Non-pharmacological methods used were massage, exercise, distraction, tolerance, praying, and traditional herbs. QoL of people with SCI was assessed using WHOQOL BREF, which is not an SCI specific assessment tool, and a moderate level of QoL was found (Thapa et al., 2017). Moreover, a study assessed the level of resilience compared with demographic variables among the people who sustained SCI after the earthquake in Nepal. The finding showed that 54% of participants had a low level of resilience. Higher resilience was found among male participants, those who were employed, paraplegic and those who had no pain (Bhattarai et al., 2018a).

Sherpa et al. (2017) conducted a study among Nepalese FCs of people with a physical disability using a convenient sampling technique. The care recipients included people with SCI, stroke, traumatic brain injuries, cerebral palsy and others. The results of the study found that FCs had chronic LBP at a moderate level. They mostly used non-pharmacological measures at home by themselves, however with less effectiveness than pharmacological measures. The reason could be management was done at home without supervision from health professionals and hence, inappropriate techniques of massage and other measures might have been used (Sherpa et al., 2017). In addition, predictive study was conducted to determine the factors predicting QoL among Nepalese FCs with chronic LBP while providing care for people with SCI. The result showed that the functional independence of persons with SCI, monthly household income, and caregivers’ functional disability predicted to QoL of these FCs (Sherpa et al., 2018).

Summary

Spinal cord injury is one of the common causes resulting in a loss of function and physical impairment and disability worldwide. SCI follows several physio-psychological symptoms. Previous studies found that the three common symptoms experience of SCI were pain, spasticity, and depression. People with SCI reported their symptoms were at moderate to severe level. The occurrence and severity of symptoms lead the persons with SCI to use pharmacological and non-pharmacological approaches by themselves or seek help from others. These consequences may have an impact on their QoL. Due to the chronic SCI, these people need continuous care for activities of daily life and psychological support from a family member in the long term. The caregiving situation may cause FCs' symptoms. Previous studies found that the three common symptoms experienced among FCs of people SCI were burden, LBP, and depression. The FCs relieve their symptoms by using pharmacological and non-pharmacological methods to maintain their caregiving work and QoL.

Dodd et al. (2001) stated that three contributing factors of symptom experiences, symptom management, and outcomes were personal, health and illness, and environmental factors. However, previous studies about symptom experiences, symptom management, and QoL of SCI people and FCs were mainly carried out in developed or western countries. Therefore, these findings may be limited in revealing the symptom experiences, symptom management, and QoL of SCI people and FCs in Nepal because of the differences between western countries and Nepal regarding personal beliefs, socio-culture aspects and religion, physical environment, social resources, and the health care system.

Moreover, current knowledge about symptoms experience, symptom management, and QoL of Nepalese SCI people and FCs was rare. The Nepalese studies mentioned above were conducted to study a single symptom (pain) by using non-random sampling techniques, hence the generalizability of the findings of these studies are limited. However, over a long period, people with SCI and FCs may experience an array of multiple co-occurring symptoms that have a negative impact on both SCI patients and FC health outcomes if these symptoms remain underdiagnosed and undertreated. Hence, there is a necessity to conduct a study of common symptoms experience, symptoms management, and QoL of people with SCI and FCs. The knowledge findings are valuable to provide essential information for nurses and health professionals to develop symptoms management interventions for Nepalese people with SCI and FCs in order to improve their QoL.

Chapter 3

Research Methodology

This chapter describes the research methodology including setting, population and sample, instruments, ethical considerations, data collection methods, and data analysis.

Research Design

A descriptive design was selected in this study to identify the common symptoms experience, symptoms management, and QoL of people with SCI and FCs in Nepal.

Setting

Nepal is a small, landlocked country. The majority of the population lives in the Terai (flatland) and the Hills. However, most of the people living in Terai have comparatively easier access to India for health services than traveling to the capital city, Kathmandu. However, the people who live in the hills travel to the major cities in the country for access to health services. In 2015, the country was divided into seven provinces.

The health centers with SCI management services are located mostly in the major cities in Nepal (Garha, 2016; Shrestha, 2014). Kathmandu and other large cities are located in Province No. 3 (Figure 1). People with SCI receive acute health services from hospitals in Kathmandu and nearby cities. Most patients receive services at the National Trauma Center (NTC) and Tribhuvan University Teaching Hospital (TUTH).

The health centers for specialized SCI management in Province No. 3 have three settings. They are (1) the TUTH which is a government-affiliated university hospital, (2) the NTC is a government hospital and the only trauma hospital in the country, and (3) the Spinal Injury Rehabilitation Center (SIRC) is the largest spinal rehabilitation center which is a non-government/non-profit organization providing multidisciplinary SCI rehabilitation.

After recovery at an acute hospital, SCI patients are referred to a rehabilitation center (for example, SIRC) or discharged to home. Referral to the SIRC is based on the main criteria of independent breathing and advised by the attending doctor at the acute hospital to be mobilized in a wheelchair. The patients at the SIRC are able to receive multidisciplinary SCI rehabilitation and have chances to discover new perspectives of life after SCI, such as physical problems and management, activities of daily living (ADL), assistive devices, psychosocial aspects, peer support, and vocational rehabilitation. Usually, they receive comprehensive rehabilitation in the SIRC for three months on average. However, some SCI patients with financial problems, less physical recovery, or lack of family caregivers, decide to return home to manage their lives on their own after discharge from the acute hospital.

After discharge from the acute hospital or rehabilitation center, most SCI patients live in the districts of Province No. 3. Therefore, the study was conducted in people with SCI and FCs living in the 13 districts of Province No. 3, namely (1) Kathmandu, (2) Bhaktapur, (3) Lalitpur, (4) Kavrepalanchowk, (5) Nuwakot, (6) Rasuwa, (7) Dolakha, (8) Sindhuli, (9) Ramechhap, (10) Sindhupalanchowk, (11) Dhading, (12) Makawanpur, and (13) Chitwan (Figure 1).

Figure 1. Map of Province No. 3, Nepal

Population and Sample

Target population. People with SCI and the FCs living in the communities of Province No. 3, Nepal.

Inclusion criteria. The participants were selected according to the inclusion criteria. The inclusion criteria for the SCI people were: (1) age 18 years or older, (2) living in communities of Province No. 3 within 3-12 months, (3) had experienced at least one common symptom (pain, spasticity, and depressive mood) as reported by the SCI people, (4) able to communicate in the Nepali language, and (5) willing to participate in this study. The samples within 3 to 12 months of residing in the community were selected because of the possibility of common symptoms experience increases after 3 months (Arango-Lasprilla., 2011; DiPiro et al., 2016). Similarly, for the FCs, after three months of caregiving, the researcher could determine the adaptation role as a family caregiver for people with SCI.

The inclusion criteria for the FCs were: (1) persons who identified themselves as the primary caregiver and who provided direct care for SCI people in the community for at least three months, (2) age more than 18 years, (3) able to communicate in the Nepali language, (4) had experienced at least one common symptom (LBP, burden, or depressive mood) as reported by the FCs while providing care for SCI, and (5) willing to participate in this study.

Sample and sampling technique

Sample size. The sample was calculated using a proportion of the known population. According to Singchanchai, Khampalikit, and Na-Sae (1996), if the sample size is between 100 and 999, approximately 25% of its subjects can be used to represent the sample. According to the data collected from the medical records department of the three major hospitals/centers, the estimated total population of people with SCI was 490 in 2018. Therefore, 25% of the given population required sample size of 123 individuals with SCI. However, 25 people with SCI were independent for ADL and did not require assistance from FCs every day. Hence, 98 FCs of SCI people were included in this study.

Sampling technique. The sample was drawn using a stratified sampling technique (probability sampling). The total sample was grouped into three strata based on the three hospitals of TUTH, NTC, and SIRC and the numbers of people from those three hospitals with SCI were 78 (16%), 98(20%), and 314 (64%), respectively. Hence, the numbers of participants for data collection from TUTH, NTC, and SIRC were 20, 23, and 80 respectively.

After receiving permission from the hospitals, the contact details of the SCI patients and FCs were collected from the medical records of the hospitals. Then, using the following steps, the researcher selected samples randomly from the population.

1. The people with SCI ages 18years or older were randomized into a lottery from the total cases.

2. The first SCI case from TUTH was contacted and screened for the rest of the inclusion criteria. If the case met all inclusion criteria, the SCI case was included in the sample as the first sample among a total of 20 cases needed from TUTH. However, if the criteria of the first case did not meet the criteria, the researcher moved to the second case from the lottery of TUTH until the total number of SCI cases of each hospital was met. The same steps were followed for NTC and SIRC.

3. A similar process was followed to recruit the FCs of the SCI people.

Instruments

The instruments consisted of two parts. Part one was related to the profile of SCI people and part two was related to the profile of the FCs. The details of each profile are shown as following.

Part 1 People with Spinal Cord Injury Profile. This part included four components: (1) Demographic, Health and Illness, and Environment Data Form of People of Spinal Cord Injury (Data-SCI); (2) Symptoms Experience Questionnaire of People with Spinal Cord Injury (SEQ-SCI); (3) Symptoms Management Questionnaire of People with SCI (SMQ-SCI); and (4) Spinal Cord Injury Quality of Life-23 (SCI QL-23). Each tool contained occurrence, severity and/or frequency. If any participant did not have occurrence of symptoms, she/he did not complete the remaining part of that questionnaire (Appendix B, pp. 233-244).

1. Demographics, Health and Illness, and Environment Data Form of People of Spinal Cord Injury (Data-SCI). This was used to identify the demographics, health and illness, and environment of the people with SCI. It consisted of three sections. The first section was personal data including age, gender, religion, marital status, level of education, employment status, monthly income status, and smoking and alcohol habits. The second section included health, illnesses, and age at the time of SCI, duration of injury, level of injury, completeness of injury, type of SCI, cause of SCI, independence level, and other health problems (e.g., history of illness and physical complications after SCI). The final section included environmental characteristics: family type; place of residence; use of assistive devices/technology; and support from external sources.

The data collected by the researcher from the medical records were related to the duration of injury, level of injury, completeness of injury, type of SCI, and cause of injury, other health problems/complications after SCI.

2. Symptoms Experience Questionnaire of People with Spinal Cord Injury (SEQ-SCI) This tool was used to measure the common symptoms experiences that included (1) pain, (2) spasticity, and (3) depressive mood. This questionnaire was composed of three sections.

2.1 International Spinal Cord Injury Pain Basic Data Set version 2 (ISCIPBDS-2). In this study, the ISCIPBDS-2 (Thapa et al., 2017) was modified to use the location and intensity of pain but pain interference and pain onset were removed and frequency of the pain was added (dela Cruz et al. 2014).

For the pain experience questions, the occurrence was assessed using a dichotomous question containing two options either “Yes” or “No”. The three worst pain locations were assessed using a checklist with eight principal areas of the body: (1) head, (2) neck/shoulders, (3) arms/hands, (4) frontal torso/genitals, (5) back, (6) buttocks/hips, (7) upper legs/thighs, and (8) lower legs/feet. Further, the pain locations are divided into specific locations where people with SCI were asked to identify the three worst pain locations with and indicate the sites (i.e., right, midline, and/or at the left side) (Widerstrom-Noga et al., 2014). The first worst pain location and the overall pain intensity of the pain were assessed using a 0-10 numeric rating scale where ‘0’ meant ‘no pain’ and ‘10’ meant pain ‘as bad as you can imagine’ (Widerstrom-Noga et al., 2014). Interpretation of the pain intensity was categorized into three levels of mild, moderate, and severe. The calculation was 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). The interpretation was classified as mild (0.01-3.33), moderate (3.34-6.67), and severe (6.68-10.00) (Gray, Grives, & Sutherland, 2017).

Pain frequency was assessed on a 5-point Likert scale based on the days in a week. Pain frequency levels are ‘never = 0’, ‘some of days = 1-2’, ‘about half of the days = 3-5’, ‘most of the days = 6-7’, and ‘everyday = 8’ (dela Cruz et al., 2014). The frequency score was interpreted at three levels as low (1.00-3.33), moderate (3.34-5.66), and high (5.67-8.00) (Gray et al., 2017).

2.2 Penn Spasm Frequency Scale (PSFS). In this study, the PSFS was used to assess the occurrence, severity, and frequency of spasticity among people with SCI. The spasticity occurrence and frequency were assessed on a 5-point scale which ranges from ‘0 = no spasms’ or no occurrence of spasticity, to ‘4 = spontaneous spasms occurring more than 10 times per hour’. Severity was assessed on a 3-point scale assessing the severity of spasticity as follows: 1 = mild; 2 = moderate; and 3 = severe.

Interpretation of the severity was made at three levels as mild (1.00-1.66), moderate (1.67-2.33), and severe (2.34-3.00) and the interpretation of spasm frequency was low (1.00-1.99), moderate (2.00-2.99), and high (3.00-4.00) (Gray et al., 2017).

2.3 Patient Health Questionnaire-9 (PHQ-9). In this study, the PHQ-9, Nepali version (Bhattarai et al., 2018b) was used to assess the severity of depressive mood experience of people with SCI. Higher severity corresponded to a higher frequency of depressive mood in people with SCI. The response was reported on a 4-point Likert scale, where 0 = not at all, 1 = several days, 2 = more than half the days, and 3 = nearly every day. The total score of the PHQ-9 ranges from 0 to 27.

Severity of depressive mood was interpreted as mild = 5.00-9.99, moderate = 10.00-14.99, moderately severe = 15.00-19.99, and severe = 20.00-27.00.

3. Symptoms Management Questionnaire of People with Spinal Cord Injury (SMQ-SCI). The SMQ-SCI has open-ended questions to ask the participants about any kind of strategy they used within the past one month for management of each of the three selected symptoms with regards to (1) what is the strategy, (2) how often/how much of the strategy, (3) who/whom helped/delivered the strategy, (4) why, the reason of conducting the strategy, (5) how the strategy was used, and (6) when or at what time was the symptom management conducted. The effectiveness of the strategy was rated on a 4-point Likert-scale: (1) = had no effect; (2) = slightly better; (3) = much better; and (4) = disappeared (Widerstorm-Noga & Turk, 2003).

4. Spinal Cord Injury Quality of Life-23 (SCI QL-23). In this study, the SCI QL-23 was used to assess the QoL of people with SCI because it is a SCI specific tool for people with SCI is short and easy to complete and yet it is comprehensive in identifying possible items that are important to measure the health-related QoL in SCI (Jain et al., 2007). The three domain scores of the SCI QL-23 were converted to obtain a scale with a range of 0 to 100 based on the Spinal Cord Injury Quality of Life Questionnaire, Scoring Instruction (Appendix C, pp. 254-255).

4.1 Functioning (physical and social limitation. This consists of 10 items that carry a certain value/weight. The weights are summed, divided by the maximum weight of 700, and multiplied by 100 to convert the scale into a range of 0-100. A lower score represents a better result (Elfstorm et al., 2005; Lundqvist et al., 1997).

4.2 Mood (distress and depressive feelings). This includes six items with four levels of answers offered. The response value of each item was recoded. Then, the recoded values are summed, divided by the maximum score of 18, and multiplied by 100 to transform the scale into a range of 0-100 (Elfstorm et al., 2005; Lundqvist et al., 1997).

4.3 Problem (perceived loss independence and other issues relating to injury). It includes six items with four levels of answers offered. The response value of each item was recoded. Then, the recoded values are summed, divided by the maximum score of 18, and multiplied by 100 to transform the scale into a range of 0-100. A lower score represents a better result (Elfstorm et al., 2005; Lundqvist et al., 1997).

4.4 GQOL/Global quality of life. Participants should choose an answer on a scale of 1-7. The recoded value is divided by the maximum score of 6 and multiplied by 100 to transform the scale into a range of 0-100. A higher score represents a better result (Elfstorm et al., 2005; Lundqvist et al., 1997).

Interpretation of the Global QoL SCI and domains of SCI QL-23 were categorized into three levels of low, moderate, and high. The calculation was based on the possible maximum total mean score minus from the possible minimum total mean score and then divided by the number of levels (i.e., three) as shown below (Gray et al., 2017).

Range of Transformed Score of QoL	Interpretation
00.00-33.33	Low
33.34-66.66	Moderate
66.67-100.0	High

Part 2 Family Caregiver's profile. This part includes (1) Demographic, Health and Illness, and Environment Data Form of Family Caregivers (Data-FCs), (2) Symptoms Experience Questionnaire of Family Caregivers (SEQ-FCs), (3) Symptoms Management Questionnaire of Family Caregivers (SMQ-FCs), and (4) World Health Organization Quality of Life (WHOQOL-BREF) (Nepalese version) (Appendix B, pp 245-253).

1. Demographics, Health and Illness, and Environment Data Form of Family Caregivers (Data-FCs). This form was used for the FCs. It consisted of two sections. The first section included personal and health-related data including age, gender, marital status, other dependent family members, relationship to the people with SCI, level of education, employment status/occupation, monthly income, adequacy of income, and comorbidities. The second section included environment-related data including, caregiving activities, duration of caregiving, hours of caregiving, living with the care recipient, behavioral problems in the care recipient, any support received, and physical environment barriers at home.

2. Symptoms Experience Questionnaire of Family Caregivers (SEQ-FCs). The SEQ-FCs included questionnaires related to low back pain, burden, and depressive mood: (1) Pain Experience Questionnaire (PEQ); (2) Short Form Zarit Burden Interview (SF-ZBI), and (3) Patient Health questionnaire-9, (PHQ-9).

2.1 Pain Experience Questionnaire (PEQ). The PEQ consisted of two parts, pain intensity scale, and pain frequency scale. In this study, LBP was assessed with the PEQ (Nepali Version) (Sherpa et al., 2017). The intensity of pain was categorized into mild (1.00-3.99), moderate (4.00-6.99), and severe (7.00-10.00). Higher scores represented a higher intensity of LBP. The frequency was assessed with one item: “How often you experience low back pain”. The options provided were as follows, every day, once a week, twice a week, more than twice a week, once a month, twice a month, and more than twice a month. The more frequent experience of LBP was used to indicate a higher frequency of pain.

2.2 Short Form Zarit Burden Interview (SF-ZBI). In this study, the ZBI-12 was used to assess the experience of the burden in the FCs of people with SCI. The ZBI-12 consisted of 12 items in two domains: personal strain and role strain. Each question was scored on a 5-point Likert scale from 0 to 4 (never to almost always). The range of the summed score is 0-48, where, 0-10 = no to mild burden 10-20 = mild to moderate burden, and greater than 20 = high burden.

The obtained score was interpreted as mild (1.00-16.67), moderate (16.68-32.33), and high (32.34-48.00). A higher score represented a higher severity of the burden.

2.3 Patient Health Questionnaire-9 (PHQ-9). In the study, the PHQ-9, Nepali version (Bhattarai et al., 2018b) was used to assess the severity of depressive mood of the FCs of people with SCI. Higher severity corresponded to a higher frequency of depressive mood in people with SCI. The response was reported on a 4-point Likert scale, where 0 = not at all, 1 = several days, 2 = more than half the days, and 3 = nearly every day. The total score of PHQ-9 ranges from 0 to 27. The severity of depressive mood was interpreted as mild (5.00-9.99), moderate (10.00-14.99), moderately severe (15.00-19.99), and severe (20.00-27.00).

3. Symptoms Management Questionnaire of Family Caregivers (SMQ-FCs). SMQ-FCs has open-ended questions used to ask the participants about any kind of strategy they used over the past one month for management of three selected symptoms experience with regards to (1) what was the strategy, (2) how often/how much of the strategy, (3) who/whom helped/delivered the strategy, (4) why, the reason of conducting the strategy, (5) how the strategy was used, and (6) when or at what time was the symptom management of the FCs conducted. The effectiveness of the strategy was rated on a 5-point Likert-scale: (1) = had no effect, (2) = slightly better, (3) = much better, and (4) = disappeared (Widerstorm-Noga & Turk, 2003).

4. World Health Organization Quality of Life (WHOQOL-BREF) (Nepalese version). The outcome of symptoms management was measured in terms of QoL in this study. The WHOQOL-BREF (Nepalese Version) was used in this study. The items were rated on a 5-item Likert scale with scores of 1-5, where a higher score represented a higher QoL. The domain score of the WHOQOL was derived from the 24 items of the instrument (except Question 1 and Question 2). The steps of scoring and converting raw scores into a transformed score of the WHOQOL-BREF are available in the WHOQOL-BREF Introduction, Assessment, Scoring and the Generic Version of the Assessment (Appendix C, pp. 256-258).

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

Range of Transformed Score of QoL	Interpretation
00.00-33.33	Low
33.34-66.66	Moderate
66.67-100.0	High

Translation of the instruments. The ZBI-12 and SCI QL-23 questionnaires were translated into the Nepali language based on the steps of back-translation developed of Brislin (as cited in Polit & Beck, 2012) which involved three steps.

1. Firstly, two bilingual translators and a bilingual reviewer were identified who were well-known with the English and Nepali languages with capabilities of analyzing the cultural aspects along with the construct of the study variables. The first translator translated the English version of the questionnaire to a Nepali version and the second bilingual translator translated the Nepali version of the questionnaire back into the English version without looking at the original version.

2. In the second step, the third bilingual reviewer checked for the presence of discrepancies between the original version and the back-translation version along with the comparison of the similarities of the languages, and evaluation of the relevancy to the culture and correctness of the meaning of the questionnaires.

3. Minor differences were identified and resolved with the advisor to ascertain the consistency and equivalence of the Nepali and English versions of the instruments and based on the inclusion criteria, instrument were tested in a pilot study.

Qualities of the instruments

Validity of the instruments. In this study, five experts assessed the content validity of the research instruments (Appendix F, p. 297). The experts were: (1) a nursing professor who was an expert from the Faculty of Nursing, Prince of Songkla University in Thailand; (2) an Advanced Practice Nurse and SCI expert from Songklanagarind Hospital in Thailand; (3) a Consultant Neurosurgeon from TUTH, Nepal; (4) a rehabilitation doctor and Medical Director from SIRC, Nepal; and (5) a

SCI expert Nurse Specialist with experience providing care to SCI people in Nepal. The experts analyzed the contents to determine accuracy, appropriateness, and congruency of the items included in the instruments to answer the research questions. The scale content validity indexes (S-CVI) of the tools for SCI people including the ISCIPBDS-2.0, PSFS, PHQ-9, and SCI QL-23 and the FC tools including the PMQ, PEQ, ZBI-12, PHQ-9, and WHOQOL-BREF were all found to be 1.00.

Reliability of the instruments. The reliabilities of the instruments were tested using Cronbach's alpha coefficient for the test of internal consistency. In this study, the instruments for the SCI people (ISCIPBDS-2, PSFS, PHQ-9, and SCI QL-23) and the instruments for the FCs (PEQ, ZBI-12, and WHOQOL-BREF) were tested for reliability in 20 people with SCI and 20 FCs using the Cronbach's alpha coefficient. The reliability results showed an acceptable range of Cronbach's alphas of .87 for the ISCIPBDS-2.0, .84 for the PSFS, .81 for the PHQ-9, and .84 for the SCI QL-23 among people with SCI. The Cronbach's alphas for the FC tools were .83 for the PEQ, .84 for the ZBI-12, .75 for the PHQ-9, and .84 for the WHOQOL-BREF.

For the total number of samples of SCI (N = 123), Cronbach's alphas were .73 for the ISCIPBDS-2.0, .89 for the PSFS, .84 for the PHQ-9, and .78 for the SCI QL-23. For the total number of FCs (N = 98), Cronbach's alphas were .78 for the PEQ, .85 for the ZBI-12, .79 for the PHQ-9 of FCs, and .86 for the WHOQOL-BREF.

Ethical Considerations

The study was conducted after obtaining the ethical approval from (1) the Center for Social and Behavioral Sciences, Institutional Review Board Prince of Songkla University, Thailand, (2) Nepal Health Research Council, Nepal, and (3) the

Directors of the three selected hospitals (Tribhuvan University Teaching Hospital, National Trauma Center, and Spinal Injury Rehabilitation Center) (Appendix H, pp. 304-308). Additionally, the human rights of all respondents were respected by equality and without any bias. The researcher provided a detail explanation to all participants regarding the procedure, purpose, benefits, and risks of the study along with the rights of participants that they may end the participation without requiring any explanation at any time. The researcher assured the respondents about the anonymity and confidentiality with a numeric code different for each participant. After the participants agreed to participate in this study, they gave their signature on the informed consent form (Appendix A, p. 231). Furthermore, the instruments used in the study were used only after obtaining permission from the original researcher (Appendix G, pp. 298-303).

Data Collection Procedure

The steps of data collection were as follows:

1. From the registration unit of the selected hospitals, (1) TUTH, (2) NTC, and (3) SIRC, the researcher identified the details of the participants and the contact addresses with the help of staff personnel in the hospitals. Details of the participants included home address, phone number, and the medical diagnosis, cause of the injury, and the level and completeness of the injury.

2. The contact list of participants included all potential participants residing in the community of Province No. 3 in Nepal who were discharged from the three selected hospitals.

3. The researcher provided a brief explanation to the potential respondents about the procedure, purpose along with the risks and benefit of the study through a mobile phone. Through a self-report, the researcher asked, “Do you have any one or more of common symptoms experience such as pain, spasticity, or depressive mood?” If the respondents agreed to participate in the study, researcher took an appointment with the time and place to meet.

4. For the respondents attending the out-patient department, after completion of a regular check-up, the staff personnel in the department introduced the researcher to the participants. The researcher gave a brief explanation similar to step number 3. After agreement from the participant to participate in the study, data was collected in a private yet comfortable area for the respondent.

5. For the participants with whom face-to-face interaction was not possible due to inaccessibility of the roadways, need to walk for more than one hour, and possible risk to the researcher, the researcher collected data via the telephone with verbal consent (people with SCI, n = 20; FCs, n = 12).

6. The researcher requested each respondent for signature in the informed written consent form after explaining the objective, purpose, procedure, risks, and benefits of the study. For participants unable to sign (people with SCI), the FC was requested to sign on behalf of the patient.

7. The researcher provided the set of questionnaires to the eligible respondents with clear instructions. The time to administer the questionnaires was 30 minutes to one hour. For the participants unable to read and write, the researcher read and facilitated the answers in 60% of the participants.

8. The researcher checked for completeness of the questionnaires before leaving and acknowledged the participants for their responses.

In this study, the researcher appointed a research assistant (RA) with at least an undergraduate degree in Nursing and experience in data collection in a community setting. Before collecting data, the RA was educated by the researcher on the study regarding the purpose and procedure of the study, informed consent, the set of questionnaires, and steps of data collection. The RA observed the data collection process during the pilot study of 15 people with SCI and 10 FCs. The RA demonstrated data collection in 3 participants each for both groups and the researcher provided feedback. Then, the RA assisted in the data collection from 17 people with SCI and 15 FCs of the participants under the researcher's supervision.

Data Analysis

Regarding the data analysis, descriptive statistics, and simple content analysis was used. Descriptive statistics included frequency, percentage, minimum and maximum, mean and standard deviation for the analysis the demographic, health and environment-related data along with the study variables. In addition, the median and interquartile range were used for the not normally distributed data.

Simple content analysis was performed for the analysis of the qualitative data from the open-ended questions of symptoms management. Content analysis process consisted of firstly, breaking down the data into smaller coherent parts. In the next step, the parts of data were organized according to the content they represented, and finally the theme was categorized based on shared concepts (Polit & Beck, 2012).

Chapter 4

Results and Discussion

This chapter presents the results and discussion. The results consist of the data of the people with spinal cord injury and the family caregivers. Next, the discussion is presented according to the data results of people with spinal cord injury and the family caregivers.

Results

Part A: Results related to people with spinal cord injury

1.Demographics, health and illness, and environment. Among the 123 participants with SCI, their average age was 32 years (18-57 years). More than half of the participants were male (56.9%) and the majority were Hindu (74.8%). Nearly half of the participants (47.2%) were single and 45.5% were married. They had completed education at college and bachelor level (39.8%) and secondary level (35.0%). Seventy percent of the participants had employment before injury whereas nearly 40% of them had employment after injury. Forty-two percent of the participants had a monthly family income of 10,000-20,000 Nepalese Rupee (1 USD =110 NPR). Almost eighty percent of participants received financial support from family, friends, and the government. Seventy percent of the participants reported their monthly family income was inadequate (Table 1).

Table 1

Frequency, Percentage, Mean, Standard Deviation, Minimum, and Maximum of People With SCI Classified by Demographics and Environment Related Characteristics (N = 123)

Characteristics	*n*	%
Age (Years) (*M* = 32.15, *SD* = 9.84, *Min* = 18, *Max* = 57)		
18-30	63	51.2
31-40	37	30.1
41-50	14	11.4
50-57	9	7.3
Gender		
Male	70	56.9
Female	53	43.1
Religion		
Hindu	92	74.8
Buddhist	20	16.3
Christian	11	8.9
Marital status		
Single	58	47.2
Married	56	45.5
Divorced/Widowed/Separated	9	7.3
Education level		
Illiterate	11	9.0
Primary	18	14.6
Secondary	43	35.0
College and Bachelor	49	39.8
Master	2	1.6
Employment before SCI		
No (i.e., student/housewife)	38	30.9
Yes	85	69.1
Self-employed (e.g., farmer, local business)	*44*	*51.8*
Employed (e.g., teacher, officer, driver)	*41*	*48.2*
Employment after SCI		
No	74	60.2

Table 1 (Continued)

Characteristics	*n*	%
Yes	49	39.8
Self-employed (e.g., local business, tutor)	*35*	*71.4*
Employee (e.g., online job, receptionist)	*14*	*28.6*
Family monthly income (Nepalese Rupee [NPR],1 USD =110 NPR)		
10,000-20,000	52	42.3
20,001-30,000	35	28.5
30,001-40,000	25	20.3
> 40,000	11	8.9
Adequacy of income		
No	86	69.9
Yes	37	30.1
Live with family or friends		
No	3	2.4
Yes	120	97.6
Place of residence		
Urban	39	31.7
Rural	84	68.3
Type of support and resources *		
Physical assistance (family, friends)	120	97.5
Psychological support (family, friends)	110	89.4
Financial support (family, friends, government**)	98	79.8
Informational support (family, friends, health professionals, Traditional healers)	85	69.1

Note. *one participant had more than one answer

** Government provided medical expense one time up to 1,000 USD to the poor SCI patients

For the health and illness-related data, the average duration of injury was 12 months. Sixty-two percent of participants were injured at the thoracic level. The majority of them had paraplegia (76.4%). Ninety-one percent had physical complications (i.e., constipation, pressure ulcers, urinary tract infections). Forty percent of participants had dependency at a moderate level and a minimal level (27.6 %) (Table 2).

Table 2

Frequency, Percentage, Mean, Standard Deviation, Minimum, and Maximum of People With SCI Classified by Health and Illness Characteristics (N=123)

Characteristics	*n*	%
Duration of injury (months) (*M* =12.0, *SD* = 4.0, *Min* = 4, *Max* =21)		
4-6	10	8.1
7-12	52	42.3
13-18	55	44.7
19-21	6	4.9
Level of injury		
Cervical	29	23.4
Thoracic	77	62.6
Lumbar	17	12.2
Severity of injury		
Paraplegia	94	76.4
Tetraplegia	29	23.6
Physical complications		
No	11	9.0
Yes*	112	91.0
Constipation	*71*	*63.4*
Pressure ulcer (sacrum, trochanter, & heel)	*21*	*18.7*
Urinary tract infection (UTI)	*18*	*16.1*
Pressure ulcer, UTI, and constipation	*14*	*12.5*
Level of dependency (Scores from Modified Barthel Scale)		
Complete dependency (0-24)	12	9.8
High dependency (25-49)	24	19.5
Moderate dependency (50-74)	50	40.7
Minimal dependency (75-90)	34	27.6
Independent (91-100)	3	2.4

Note. *one participant had/used more than one answer

2. Common symptoms experience. Among 123 participants, all of them had experience of pain (100%), seventy-three cases had spasticity (59.3%), and one hundred and four cases had depressive mood (84.5%). Details of each symptom experience are described as follows.

2.1 Pain. All participants had pain in at least one location. The first three worst pain locations were (1) back (*n* = 33, 26.8%), (2) buttocks/hip (*n* = 29, 23.6%), and (3) upper leg/thigh (*n* = 27, 22%) (Table 3). Moreover, the overall mean score of pain severity was at a moderate level (*M* = 3.5, *SD* = 0.9) (moderate level, *n* = 67, 54.5%, mild level, *n* = 56, 45.5%). The mean score of pain frequency was at a high level (*M* = 6.0, *SD* = 1.6) ("most of the days" = 35.8%, "half of the days" = 35%, "everyday" = 27.6%, and "some of the days" = 1.6%). Sixty participants (48.7%) reported burning and/or tingling sensation below the level of injury.

Table 3

Frequency and Percentage of Three Worst Pain Locations of People with SCI (N=123)

Worst pain locations*	1st worst pain (*n* =123)		2nd worst pain (*n* = 84)		3rd worst pain (*n* = 27)	
	n	%	*n*	%	*n*	%
Neck/shoulder (*n* = 9)	6	4.9	1	1.2	2	7.4
Arms/hand (*n* = 4)	2	1.6	1	1.2	1	3.7
Frontal torso/genitals (*n* = 14)	9	7.3	5	6.0	-	-
Back (*n* = 53)	33	26.8	12	14.3	8	29.6
Buttocks/hip (*n* = 38)	29	23.6	6	7.1	3	11.1
Upper leg/thigh (*n* =55)	27	22.0	23	27.4	5	18.5
Lower leg/feet (*n* = 61)	17	13.8	36	42.8	8	29.7

Note. *one participant had more than one pain location

2.2 Spasticity. Seventy-three participants have experienced spasticity (59.3% of the total 123 SCI participants). Of these participants, the average scores of their spasticity frequency and severity were at moderate levels (*M* = 2.2, *SD* = 0.8, *M* = 2.1, *SD* = 0.5, respectively) (Table 4).

Table 4

Frequency, Percentage, Mean, and Standard Deviation of People With SCI Classified by Spasticity Frequency and Severity (N=123)

Spasticity	*n*	%	*M(SD)*	Level
Frequency (*N* =123)				
No spasm	50	40.7		
Have spasm	73	59.3	2.2(0.8)	Moderate
Mild spasm	*12*	*16.5*		
Infrequent spasms less than once per hour	*39*	*53.4*		
Spasms occurring more than once per hour	*18*	*24.6*		
Spasms occurring more than 10 times per hour	*4*	*5.5*		
Severity (*n* = 73)			2.1(0.5)	Moderate
Mild	6	8.1		
Moderate	51	69.9		
Severe	16	22.0		

2.3 Depressive mood. One hundred and four cases had a depressive mood (84.5% of 123 SCI participants). Of these, the average score of depressive mood severity was at a moderate level (*M* = 11.0, *SD* = 4.2) (Table 5).

Table 5

Frequency Percentage, Mean, and Standard Deviation of People With SCI Classified by Severity of Depressive Mood (N=123)

Severity of depressive mood (scores)	*n*	%	*M(SD)*	Level
None (0-4)	19	15.5		
Yes	104	84.5	11.0(4.2)	Moderate
Mild (5-9)	*41*	*39.4*		
Moderate (10-14)	*3*	*35.6*		
Moderately severe (15-19)	*23*	*22.2*		
Severe (20-27)	*3*	*2.8*		

3. Symptoms management. SCI participants used pharmacological and non-pharmacological management to manage pain, spasticity, and depressive mood experience. The details of types, frequency of use, and effectiveness of each symptom management are as follows (Table 6).

3.1 Pain management. All participants with pain used non-pharmacological methods and 53.6% (*n* = 64) used pain medications (e.g., non-opiates, anticonvulsants). The top three non-pharmacological managements commonly used were (1) tolerance (*n* = 41), (2) distraction (*n* = 36) (e.g., watching movies, listening to music, keeping busy at work), and (3) massage (*n* = 35). Most of the time, they used distraction (55.6%) and sometimes they used massage (48.6%) and tolerance (51.2%). Fifty percent of them reported that the effectiveness of distraction for the relief of pain was at a much better level. Tolerance and massage were effective at a slightly better level (44.0% and 40.0%, respectively).

In addition, 39% of 64 participants used pain medications in the morning and evening, and 31.3% used them at night (Table D5 Appendix D, pp. 270-271). More than half of the participants evaluated that the effectiveness of anticonvulsants was at a much better level (51.8%) and non-opiate medication was at a slightly better level (53.8%) for pain relief.

3.2 Spasticity management. All participants (*n* = 73) used non-pharmacological strategies, 40 % of them also used medications (*n* = 29) (i.e., muscle relaxants and anticonvulsants). The most common methods of non-pharmacological use were (1) exercise (*n* = 39), (2) positioning (*n* =30), and (3) eating animal nutrients (traditional usage) (*n* = 20). They used exercise most of the time (64.1%) and change position (60%) and sometimes ate animal nutrients (70%). They evaluated the effectiveness of the relief of spasticity for exercise (51%) and positioning (40%) at a much better level and eating animal nutrients (50%) at a slightly better level.

In addition, they used medications (e g., muscle relaxants) in the morning (34.5%) and morning and evening (27.6%) (Table D8 Appendix D, pp 275-276). The effectiveness of muscle relaxants (53.6%) was slightly better for the relief of spasticity.

3.3 Depressive mood management. All participants (*n* = 104) who had a depressive mood used non-pharmacological strategies. A few of them used sleeping medications (unknown name) (*n* = 2). The most common non-pharmacological types used were: (1) distraction (*n* = 49), (2) sharing feelings (*n* = 31), and (3) spiritual practices (*n* = 31). In addition, several participants used distraction (57.2%) most of the time and sometimes used spiritual practice (61.2%) and the sharing of feelings (64.5%) (Table D11 Appendix D, p. 278).

Nearly half of them reported that their depressive mood disappeared when they shared their feelings. Moreover, the effectiveness of distraction (51%) and spiritual practice (42%) were much better level for relief depressive mood.

Table 6

Frequency and Percentage of People with SCI Classified by Types, Frequency of Use, and Effectiveness of Pain, Spasticity, and Depressive Mood Management Commonly Used (N=123)

Symptoms management *	Frequency			Effectiveness				
	Rarely	Sometimes	Most of time	Worst Effect	No effect	Slightly better	Much better	Disappear
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
Pain management (*n* = 123, 100%)								
1. Pharmacological (prescribed *n* = 38, non-prescribed *n* = 26) (*n* = 64, 53.6%)								
1.1 Non-opiate (i.e., NSAIDs, Paracetamol (*n* = 39, 31.7%)	2(5.1)	19(48.8)	18(46.1)	-	-	21(53.8)	12(30.8)	6(15.8)
1.2 Anticonvulsants (i.e., Gabapentin, Pregabalin (*n* = 29, 23.6%)	4(13.7)	14(48.3)	11(38.0)	-	4(13.7)	10(34.5)	15(51.8)	-
1.3 Antidepressants (i.e., Amitriptyline) (*n* = 4, 3.2%)	-	4(100.0)	-	-	-	2(50.0)	2(50.0)	-
2. Non-pharmacological (*n* = 123, 100%)								
2.1 Physical (*n* = 98, 79.7%)								

Table 6 (Continued)

Symptoms management *	Frequency			Effectiveness				
	Rarely	Sometimes	Most of time	Worst Effect	No effect	Slightly better	Much better	Disappear
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
2.1.1 Massage with mustard or Ayurvedic oil (*n* = 35, 28.4%)	3(8.6)	17(48.6)	15(42.8)	-	-	14(40.0)	17(48.6)	4(11.4)
2.1.2 Exercise (*n* = 29, 23.6%)	-	9(31.0)	20(69.0)	-	-	10(34.5)	13(44.8)	6(20.7)
2.2 Emotional coping (*n* = 44, 45%)								
2.2.1 Distraction (e.g., work, internet usage- movies, games, social media) (*n* = 36, 29.3%)	-	16(44.4)	20(55.6)	-	2(5.6)	10(27.7)	18(50.0)	6(16.7)
2.3 Tolerance (*n* = 41, 33.3%)	6(14.6)	21(51.2)	14(34.2)	-	10(24.3)	18(44.0)	8(19.5)	5(12.2)
Spasticity management (*n* = 73, 59.3%)								
1. Pharmacological (*n* = 29, 40%)								
1.1 Muscle relaxant (i.e., Baclofen, Tizanidine) (*n* = 28, 38.3%)	3(10.7)	10(35.7)	15(53.6)	2(7.2)	6(21.4)	15(53.6)	5(17.8)	-
1.2 Anticonvulsant (i.e., Gabapentin, Pregabalin) (*n* = 5, 6.8%)	-	3(60.0)	2(40.0)	-	-	2(40.0)	3(60.0)	-

Symptoms management *	Frequency			Effectiveness				
	Rarely	Sometimes	Most of time	Worst Effect	No effect	Slightly better	Much better	Disappear
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
2.Non-pharmacological (*n* = 73, 100%)								
2.1 Physical modalities (*n* = 73)								
2.1.1 Exercise (e.g., ROM, stretching, weight bearing) (*n* = 39, 53.4%)	2(5.1)	12(30.8)	25(64.1)	-	4(10.2)	15(38.5)	20(51.3)	-
2.1.2 Positioning (e.g., frog's leg position, prone, lateral) (*n* = 30, 41.1%)	3(10.0)	9(30.0)	18(60.0)	-	5(16.7)	13(43.3)	12(40.0)	-
2.2 Traditional usage (*n* = 30, 41.1%)								
2.2.1 Animal nutrients (e.g., jackal, slug, quail egg) (*n* = 20, 27.4%)	6(30.0)	14(70.0)	-	-	6(30.0)	10(50.0)	4(20.0)	-
Depressive mood (*n* = 104, 84.5%)								
1. Pharmacological (*n* = 2, 1.9)								
1.1 Sleeping pills (*n* = 2, 1.9%)	2(100.0)	-	-		-	2(100.0)	-	-
2. Non-pharmacological (*n* = 104, 100%)								

Symptoms management *	Frequency			Effectiveness				
	Rarely	Sometimes	Most of time	Worst Effect	No effect	Slightly better	Much better	Disappear
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
2.1 Emotional coping (*n* = 85, 81.7%)								
2.1.1 Distraction (e.g., work, internet usage-movies, games, social media) (*n* = 49, 47.1%)	3(6.1)	18(36.7)	28(57.2)	-	-	10(20.4)	25(51.0)	14(28.6)
2.1.2 Share feelings (*n* = 31, 29.8%)	3(9.7)	20(64.5)	8(25.8)	-	-	5(16.1)	11(35.5)	5(48.4)
2.2 Spiritual practices (e.g. praying, worshipping ‘*Graha Shanti*’‘*Bhakal*’ (*n* = 31, 29.8%),	4(13.0)	19(61.2)	8(25.8)	-	5(16.0)	9(29.0)	13(42.0)	4(13.0)
2.3 Accepting (*n* = 12, 11.5%)	-	12(100.0)	-	-	-	4(3.3)	6(50.0)	2(16.7)

Note. *one participant used more than one symptom management method

4. Quality of life. People with SCI perceived the four domains of QoL at moderate levels. The mean score of “Global quality of life (overall rating of life situation)” was 54.2 (*SD* = 22.8) which was at a moderate level. Among the three domains, “Problems” (perceived loss of independence and other issues relating to injury) had the highest mean score of 56.9 (*SD* = 21.5), followed by “Functioning (physical and social limitations)” with a mean score of 52.2 (*SD* = 30.7) and “Mood (distress and depressive feelings)” had a mean score of 45.6 (*SD* = 16.9) (Table 7).

Table 7

Possible Range, Actual Range, Mean, Standard Deviation, and Level of Quality of Life of People With SCI (N = 123)

Domains*	Possible Range	Actual Range	*M(SD)*	Level
1. Functioning (physical and social limitations)	0-100	0-100	52.2(30.7)	Moderate
2. Mood (distress and depressive feelings)	0-100	0-100	45.6(16.9)	Moderate
3. Problems (perceived loss of independence and other issues relating to injury)	0-100	0-94	56.9(21.5)	Moderate
4. Global quality of life	0-100	0-100	54.2(22.8)	Moderate

Note. *The domain score is transformed to 0-100 scale based on the scoring in the instruction of SCIQL-23 (Appendix C, pp. 254-255)

Part B: Results related to family caregivers

1. Demographics, health and illness, and environment

Among the 98 FCs of people with SCI, the average age was 37 years. Approximately, three-fourths of the FCs were female (76.5%), Hindu (78.6), and married (75.5%). Forty-one percent of FCs had completed primary education level and 25.6% had completed secondary education level. Sixty-one percent of FCs was employed (e.g., business at home, farmers). Thirty-eight percent of FCs had a family monthly income of 20,001- 30,000 Nepali rupees (1 USD = 110 NPR) and 32.7% of them had an income of 10,000-20,000 NPR. Fifty-seven percent of them had inadequate income. The relationships of FCs with SCI patients mostly were parents (37.8%) and wife (25.5%). Nearly half of FCs had co-morbidities (e.g., hypertension, arthritis, diabetes mellitus) (Table 8).

Table 8

Frequency, Percentage, Mean, Standard Deviation, Minimum, and Maximum of Family Caregivers Classified by Demographic and Health and Illness Related Characteristics (N = 98)

Characteristics	*n*	%
Age (Years) (*M* =37, *SD* =1.2, *Min* =18, *Max* = 68)		
18-30	35	35.7
31-45	36	36.7
46-60	25	25.6
60-68	2	2.0
Gender		
Male	23	23.5
Female	75	76.5
Religion		
Hindu	77	78.6
Buddhist	16	16.3

Table 8 (Continued)

Characteristics	*n*	%
Christian	5	5.1
Marital status		
Single	18	18.4
Married	74	75.5
Divorced/Widowed/Separated	6	6.1
Education level		
Illiterate	7	7.1
Primary	40	40.8
Secondary	25	25.6
College and bachelor	20	20.4
Master	6	6.1
Employment		
No (e.g., student, household worker)	38	38.8
Yes	60	61.2
Self-employed (e.g. business at home, farmer)	*39*	*65.0*
Employee (e.g., teacher, officer, cook)	*21*	*35.0*
Monthly family income (Nepali rupees =NPR) (1 USD =110 NPR)		
< 10,000	2	2.0
10,000-20,000	32	32.7
20,001-30,000	37	37.8
30,001-40,000	13	13.3
> 40,000	14	14.3
Adequacy of income		
No	56	57.1
Yes	42	42.9
Type of family		
Nuclear	36	36.7
Extended	62	63.3
Other dependent family members		
No	73	74.5
Yes (parents, children)	25	25.5
Relationship of FCs with people with SCI		
Parents	37	37.8

Table 8 (Continued)

Characteristics	*n*	%
Wife	25	25.5
Husband	6	6.1
Son/daughter	15	15.3
Sibling	12	12.2
Relatives	3	3.1
Body mass index (BMI)		
Underweight (< 18.5)	10	10.2
Healthy weight (18.5-24.9)	65	52.8
Overweight (25-29.9)	40	40.8
Menopause (for women, *n = 75*)		
No	*58*	*77.3*
Yes	*17*	*22.7*
Co-morbidities		
No	50	51.0
Yes	48	49.0
Hypertension	*14*	*14.3*
Arthritis	*11*	*11.2*
Diabetes mellitus	*8*	*8.2*
Heart disease	*4*	*4.1*
Others (i.e., renal disease, gastritis, hemorrhoids, uterine infection)	*11*	*11.2*

Note. M=Mean, SD=Standard Deviation, Min=Minimum, Max=Maximum

For environment data related to caregiving, the duration of caregiving ranged from 3-6 months (42.9%) and 7-12 months (39.8%) (*Min* = 2, *Max* = 20). The average amount of caregiving was five hours per day (*Min* = 2, *Max* =10). Seventy-six percent high (21.4%). Forty percent of SCI patients were moderately dependent (40.0%) and twenty-seven percent of SCI was minimally dependent (26.5%). Sixty-two percent of FCs received training in caregiving. Most of the caregiving activities were lifting/positioning (77.6%), feeding/cooking (61.2%) and bowel/bladder care (59.2%). The majority of FCs received social support (86.7%) (Table 9).

Table 9

Frequency, Percentage, Mean, Median, Standard Deviation, Interquartile Range, Minimum, and Maximum of Family Caregivers, Classified by Environment Related Characteristics (N = 98)

Characteristics	*n*	%
Duration of caregiving (months) (*Mdn* = 8, *IQR* = 6.3, *Min* = 3, *Max* = 20)		
<6	42	42.9
7-12	39	39.8
13-18	8	8.1
>19	9	9.1
Hours of caregiving (*M* = 5, *SD* = 1.8, *Min* = 2 *Max* = 10)		
2-4	44	44.9
5-8	47	48.0
>8	7	7.1
Types of SCI patients		
Paraplegia	74	75.5
Tetraplegia	24	25.5
Level of dependency of SCI patients (Scores from Modified Barthel Scale)		
Complete dependency (0-24)	12	12.2
High dependency (25-49)	21	21.4
Moderate dependency (50-74)	39	40.0
Minimal dependency (75-90)	26	26.5
Caregiving activities*		
Lifting/positioning	76	77.6
Feeding/cooking	60	61.2
Bowel/bladder care	58	59.2
Bathing/laundry	55	56.1

Table 9 (Continued)

Characteristics	*n*	%
Medication/wound care	55	56.1
Physical environment difficulties at home*		
No ramps	91	92.9
Stairs	85	86.7
Narrow bathroom	70	71.4
Narrow door/corridor	70	71.4
No toilet/bathroom	10	10.2
Behavioral problems of SCI people		
No	73	74.5
Yes (i.e., stubborn, short-tempered, aggressive)	25	25.5
Training in caregiving		
No	37	37.7
Yes (e.g., transferring, lifting, positioning, bowel/bladder care)	61	62.2
Social support (e.g., family, friends, organization)		
No	13	13.3
Yes*	85	86.7
Financial support (e.g., daily expenses, medical payment for SCI patient)	*64*	*65.3*
Physical support (e.g., lifting, cooking)	*51*	*52.0*
Psychological support (e.g., counseling, assurance for helping in caregiving need "we are here for you")	*50*	*51.0*
Informational support (e.g., provide information for decision making)	*32*	*32.6*

Note. *family caregivers had more than one answer

2. Common symptoms experience. Among 98 FCs, 70 cases had low back pain (LBP) (71.4%), 98 cases had burden (100%), and 53 cases had depressive moods (54.1%).

2.1 Low back pain. Among the total FCs (*n* = 98), seventy cases had LBP experience (71.4%). LBP on average was at a moderate level (*M* = 4.1, *SD* = 1.7). Nearly half of them had LBP frequency more than twice a week (48.6%) and thirty-six percent of them had pain everyday (35.7 %) (Table 10).

Table 10

Frequency, Percentage, Minimum, Maximum, Mean, Standard Deviation, and Level of Low Back Pain Intensity and Pain Frequency Among Family Caregivers (N = 98)

LBP	*n* (%)	*Min*	*Max*	*M (SD)*	Level
No	28(28.6)				
Yes (pain duration[month])	70(71.4)				
1- 3	*25(35.7)*				
>3	*45(64.3)*				
Severity *(n* = 70*)*					
Pain at worst		3.0	10.0	6.3(1.6)	Moderate
Pain at least		1.0	4.0	1.8(0.9)	Mild
Pain on average		2.0	7.0	4.1(1.7)	Moderate
Pain now		1.0	7.0	3.0(1.2)	Mild
Pain frequency *(n* = 70*)*					
Everyday	25(35.7)				
More than twice a week	34(48.6)				
Twice a week	8(11.4)				
Once a week	3(4.3)				

2.2 Burden. All FCs experienced burden (*n* = 98, 100%). Overall, the mean score of burden was at a moderate level (*M* = 19.2, *SD* = 8.0) (Table 11).

Table 11

Frequency, Percentage, Minimum, Maximun, Mean, Standard Deviation, and Level of Burden Among Family Caregivers (N = 98)

Burden (scores)	*n* (%)	*Min*	*Max*	*M(SD)*	Level
Overall burden		6	31	19.2(8.0)	Moderate
Mild (0-10)	10(10.2)				
Moderate (11-20)	53(54.1)				
High burden (>20)	35(35.7)				

2.3 Depressive mood. Fifty-four percent of 98 FCs had depressive mood (*n* = 53). Of these, the average score of their depressive mood severity was at a mild level (*M* = 8.7, *SD* = 2.9) (Table 12).

Table 12

Frequency, Percentage, Minimum, Maximun, Mean, Standard Deviation, and Level of Depressive Mood Among Family Caregivers (N = 98)

Depressive mood (scores)	*n* (%)	Min	Max	*M (SD)*	Level
None (0-4)	45(45.9)				
Overall depressive mood severity	53(54.1)	5	18	8.7(2.9)	Mild
Mild (5-9)	*34(64.1)*				
Moderate (10-14)	*17(32.1)*				
Moderately severe (15-19)	*2(3.8)*				
Severe (20-27)	*0*				

3. Symptoms management

Family caregivers used pharmacological (*n* = 24) and non-pharmacological (*n* = 60) strategies to manage LBP and used non-pharmacological strategies to manage burden and depressive mood. The details of types, frequency of use, and effectiveness of each symptom management are as follows (Table 13).

3.1 LBP management. Most FCs with LBP used non-pharmacological management (*n* = 60, 85.7 %) The most common methods of non-pharmacological use were: (1) tolerance (*n* = 33), (2) massage (*n* = 29), and exercise (*n* = 21). Most of the time, they used massage (65.5%) and tolerance (51.6%) and sometime practiced exercise (57.1%). They evaluated their effectiveness of LBP relief at much better for exercise (66.7%) and massage (48.3%), and slightly better for tolerance (48.5%).

In addition, twenty-four FCs (34.3 % of total FCs) used pain medications (NSAIDs) to reduce LBP. More than half of those FCs used them whenever (58.4 %) and nearly 21% of them used these drugs 1-2 times per day (Table E7 Appendix E, p. 292). Most of them reported that they felt much better in LBP (41.7%).

3.2 Burden management. All FCs used only non-pharmacological management strategies to reduce the burden. The most common methods used were (1) spiritual practice (*n* = 32), (2) distraction (*n* = 29), and (3) sharing feelings (*n* = 21). More than half of the FCs performed spiritual practice (56.2%) and distraction (58.6%) for most of the time and shared feelings with family and friends for some of the time (76.2%). Several FCs evaluated the effectiveness of these methods at much better for diminishing their burden (sharing feelings 52.3%, spiritual practice 40.6%, and distraction 48.3%).

3.3 Depressive mood management. All depressive FCs used non-pharmacological management strategies. The most common methods used were (1) spiritual practices (*n* = 32), (2) distraction (*n* = 24), and (3) crying (*n* = 20). Most FCs used distraction (58.3%) and spiritual practice (56.2%) for most of the time and used crying for some of the time (70%). Several FCs reported that the effectiveness of these methods was at a much better level for decreasing depressive moods (distraction 50%, crying 45%, and spiritual practice 43.8%).

Table 13

Frequency and Percentage of Family Caregivers Classified by Types, Frequency and Effectiveness of LBP, Burden, and Depressive Mood Management Commonly Used (N = 98)

Management *	Frequency			Effectiveness				
	Rarely	Sometimes	Most of the time	Worst	No effect	Slightly better	Much better	Disappear
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
LBP management (*n* = 70, 71.4%)								
1. Pharmacological (*n* = 24, 34.3%)								
1.1 NSAIDs (i.e. Ibuprofen, and diclofenac ointment) (*n* = 24, 34.3%)	4(16.7)	18(75.0)	2(8.3)	-	2(8.3)	8(33.33)	10(41.7)	4(16.7)
2. Non-pharmacological (*n* = 60, 85.7%)								
2.1 Physical modalities								
2.1.1 Massage (e.g., mustard oil, ayurvedic oil) (*n* = 29, 41.4%)	-	10(34.5)	19(65.5)	-	-	9(31.0)	14(48.3)	6(20.7)
2.1.2 Exercise (e.g., stretching, yoga exercises) (*n* = 21, 30%)	3(14.3)	12(57.1)	6(28.6)	-	-	3(14.3)	14(66.7)	4(19.0)
2.2 Tolerance (*n* = 33, 47%)	6(18.2)	10(30.3)	17(51.5)	5(15.2)	7(21.2)	16(48.5)	-	5(15.1)

Table 13 (Continued)

Management *	Frequency			Effectiveness				
	Rarely	Sometimes	Most of the time	Worst	No effect	Slightly better	Much better	Disappear
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
Burden management (*n* = 98, 100%)								
1. Spiritual practices (e.g., praying, worshipping, meditation) (*n* = 32, 32.6%)	-	14(43.8)	18(56.2)	-	4(12.5)	9(28.1)	13(40.6)	6(18.8)
2. Emotional coping (*n* = 56, 57.1%)								
2.1 Distraction (e.g., work, internet usage- games, social media) (*n* = 29, 29.6%)	-	12(41.4)	17(58.6)	-	-	10(34.5)	14(48.3)	5(17.2)
2.2 Sharing feelings with family and friends (*n* = 21, 21.4%)	5(23.8)	16(76.2)	-	2(9.5)	-	8(38.1)	11(52.4)	-
3. Positive thinking (*n* = 15, 15.3%)	-	4(26.7)	11(73.3)	-	-	2(13.3)	5(33.3)	8(53.4)
Depressive mood management (*n* = 53, 54.1%)								
1. Emotional coping (*n* = 36, 70.6%)								
1.1 Distraction (e.g., work, internet usage - movies, games, social media, listening to music) (*n* = 24, 47%)	-	10(41.7)	14(58.3)	-	-	4(16.7)	12(50.0)	8(33.3)

Table 13 (Continued)

Management *	Frequency			Effectiveness				
	Rarely	Sometimes	Most of the time	Worst	No effect	Slightly better	Much better	Disappear
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
1.2 Crying (*n* = 20, 39.2%)	2(10.0)	14(70.0)	4(20.0)	-	2(10.0)	4(20.0)	9(45.0)	5(25.0)
1.3 Sharing of feelings (*n* = 15, 29.4%)	-	15(100.0)	-	-	-	9(60.0)	6(40.0)	-
2. Spiritual practices (e.g. praying, worshipping, ‘*Graha shanti’, ‘Bhakal’*) (*n* = 32, 62.7%)	-	14(43.8)	18(56.2)	-	2(6.2)	7(21.9)	14(43.8)	9(28.1)
3. Accepting (*n* = 14, 26.4%)	2(14.3)	8(57.1)	4(28.6)	-	-	4(28.6)	10(71.4)	-

Note. *each participant used at least one symptom management method

4. *Quality of life*

After transforming the scores of the four domains of the QoL of the FCs based on the instruction of WHOQOL-BREF, these were at moderate levels. The scores of the physical domain and social relationship domain were equal at 56, whereas, the scores of the psychological domain and environment domain were equal at 50 (Table 14).

Moreover, for two items of question No.1 and question No. 2, FCs reported that they felt neither satisfied nor dissatisfied with their health (*M* = 2.9, *SD* = 0.7) and rated their QoL at neither a poor level nor a good level (*M* = 2.9, *SD* = 0.6).

Table 14

Raw Score, Transformed Score, and Level of Quality of Life of Family Caregivers (N = 98)

Domains of QoL*	Raw score	Transformed score	Level
Physical	23.2	56	Moderate
Psychological	18.7	50	Moderate
Social relationship	9.7	56	Moderate
Environment	23.3	50	Moderate

Note * The domains scores are transformed to 0-100 score based on the instruction of WHOQOL-BREF (Appendix C, pp. 256-258)

Discussion

Part A: Discussion related to the results of people with Spinal Cord Injury

1. Demographics, health and illness, and environment

The average age of the participants was 32 years, thus belonging to the young adult age-group (Bhattarai et al., 2018a; Sherpa et al., 2017) and more than half were males. These findings were consistent with the previous studies conducted in developing countries (Rahimi-Movaghar et al., 2013; Thapa et al., 2018). Most participants of this study had paraplegia because their injury occurred at the thoracolumbar level which is most commonly found among all spinal injuries (Chhabra, 2015). Therefore, most participants were minimally to moderately dependent. Moreover, physical complications i.e., pressure ulcers, UTIs, constipation were present among the participants with SCI which is consistent with earlier studies findings (Sezer et al., 2015; Stillman, Barber, Burns, Williams, & Hoffman, 2017; Thapa et al., 2018). These complications could be because of reduced mobility due to paraplegia and tetraplegia (Table 2, p.125). Similarly, Almeida et al. (2013) found that most people with SCI with pressure ulcers had a depressive mood. This possibly is because a depressive mood may result in decrease need for mobility and self-care (Charalambous et al., 2018; Osuwala, 2014).

After SCI, unemployment in participants increased from 30.9 to 60.2% which could be due to paraplegia or tetraplegia. Consistently, previous studies showed that unemployment rates after SCI were approximately 70% (Huang, 2017; Ottomanelli, & Lind, 2009). In addition, 70% of participants reported their income was inadequate which may be because of loss of employment, lack of work productivity, and increasing medical payments (e.g., dressing materials, urinary catheter, antibiotics). Additionally, several of them (42.3%) had a family monthly income (< 20,000 NPR) that was less than the average monthly household income in Nepal which was 30,121 NPR (Nepal Rastra Bank, 2015). These findings were comparable with a previous study which presented very low monthly incomes among people with SCI (Mathur et al., 2015).

2. Common symptoms experience

2.1 Pain. In this study, all participants reported pain at least in one location, at, or below the level of injury. The three first worst pain locations of this study were back, buttocks/hip, and upper leg/thigh which could possibly be related to the thoracolumbar injuries (Chabbra, 2015).

In this study, the average intensity of pain for SCI participants was at a moderate level congruent with previous findings (Nagoshi et al., 2016; Thapa et al., 2018). This possible causes were: (1) neuropathic pain results from any injury related to the somatosensory nervous system which activates the pain signaling mechanism followed by sensitization at or below the injury level (Bryce et al., 2012), (2) presence of physical complications (e.g., pressure ulcer and UTI) might have induced nociceptive or visceral pain (Treede et al., 2015), and (3) concurrent symptoms such as spasticity and depressive mood can result in pain perception. These findings were congruent with a Swiss population-based study where participants who had spasticity (Muller et al., 2017) and depression (Celik et al., 2012) reported more pain.

However, to reduce pain, several SCI participants sometimes to most times used non-pharmacological methods (e.g., tolerance [*n* = 41], distraction [*n* = 36], and massage [*n* = 35]) and pharmacological methods (e.g., NSAIDs and Paracetamol [*n* =

39], anticonvulsants [*n* = 29]). The effectiveness levels of using these methods were reported by these participants at slightly to much better for relieving pain. Therefore, the findings of this study showed moderate pain.

In this study, the mean score of pain frequency of SCI participants was at a high level that was consistent with a result of a previous study (Widerstorm-Noga, 2017). This finding may be caused from neuropathic pain that mostly occurs at below the level of injury and is burning pain (Bryce et al., 2012; Nagoshi et al., 2016) which never goes away completely (Hearn et al., 2015; Lin et al., 2017). This is supported by nearly half of the participants in this study reporting the burning nature of pain below the level of injury (buttocks, upper leg, and lower leg) (Table 3, p.126) suggesting neuropathic pain.

Moreover, the SCI participants in this study possibly used inappropriate and inadequate pain management. Although anticonvulsants (drug of choice for neuropathic pain) were used, they were used at a low dosage and frequency (Table D5 Appendix D, p. 270). Therefore, this was not enough to maintain a decrease in pain for a longer period of time resulting in a high frequency of pain. Consistently, previous researchers claimed that neuropathic pain is difficult to cure because the high dosage of pharmacological medications in combination with several non-pharmacological approaches for a long period of time can only achieve some decrease in pain (D’Angelo et al., 2013; Soler et al., 2017).

2.2 Spasticity. Spasticity occurred in 59.3% of 123 SCI participants which was slightly less compared to the findings of previous studies where spasticity occurred among 70-86% of persons with SCI (Bravo-Esteban et al., 2013; DiPiro et al., 2018). However, the average scores of spasticity in this study were at moderate severity and frequency levels. These results may be explained by several issues. The spasticity occurrence could be possibly due to the injuries involving cervical and higher thoracic level SCI. Injuries above the 6th thoracic vertebra (T6) usually involve upper motor neuron lesions where there is a breakdown in the control of the spinal stretch mechanism (Adams & Hicks, 2005; Graham, 2013). Moreover, bowel and bladder problems (i.e. constipation and UTIs), and pressure ulcers among more than half of the participants in this study might increase spasticity (Graham, 2013; McKay et al. 2017). Another possible reason could be because of the fear of the side effects of drugs, therefore, participants used inappropriate muscle relaxants such as adjusting drugs to lower doses. Consequently, they evaluated the effectiveness of these drugs at a level of slightly relieving spasticity.

However, to reduce the severity and frequency of spasticity, nearly half of SCI participants used exercise and positioning most of the time and evaluated that these methods could relive their spasticity at a much better level (Table 6, p.131). Consistently, previous studies found that exercise such as ROM, stretching or standing (Harvey, 2016) and changing position such as adopting the frog position, prone position could lessen spasticity (Graham, 2013). Therefore, the spasticity of SCI patients in this study was found at moderate severity and frequency levels.

2.3 Depressive mood. In 123 participants, 104 cases had a depressive mood (84.5%). Of these, the participants had depressive severity at a moderate level (Table 5, p.128). These findings were different from previous studies that ranged from 41-74 % (Al-Abbudi, et al., 2017; Ataglu et al., 2013; Khazaeipour et al., 2015; Xue et al., 2016). Considering each item of depressive mood (Table D1 Appendix D,

p. 259), the top three items with the highest mean score were (1) Trouble falling or staying asleep, or sleeping too much (*M* =1.3, *SD* = 0.9), (2) Feeling tired or having little energy (*M* =1.3, *SD* = 0.8), and (3) Little interest or pleasure in doing thing (*M* = 1.2, *SD* = 0.8). These results may be due to several reasons. Firstly, some SCI participants who had tetraplegia and high paraplegia causing physical functional impairments resulted in highly (19.5%) and completely (9.8%) being dependent upon their family members' help for a long period (*M* = 12 months). Secondly, the presence of concurrent symptoms (i.e., moderate pain and spasticity) and physical complications.

Thirdly, most of them had lost their jobs or changed employment after their SCI, since they belong to the working age-group and males are supposed to earn money and raise families. These situations may make the participants with SCI feel as though they have no control over events, be troublesome, and cause stress, and anxiety resulting in difficulty in sleeping, having little energy or interest in doing things. This is supported by the study of Altindab, Karagullu, and Gur (2014). They reported that pain, spasticity, immobility, daily stressors, and many anti-spasticity medications can disrupt sleep in people with SCI (Altindag et al., 2014). Pain (Hoffman et al., 2011; Inoue et al., 2016) spasticity and physical complications i.e., pressure ulcers (Almeida et al., 2013), and UTIs can possibly decrease their interest in doing things. Similarly, previous studies found that long-term dependence can develop into depression (Arango-Lasprilla, 2011; Koca et al., 2014).

However, the three items with the lowest mean score were: (1) Thought that would be better off dead or of hurting own-self (*M* = 0.5, *SD* = 0.7), (2) Poor appetite or over-eating (*M* = 0.7, *SD* = 0.7), and (3) Trouble concentrating on things (*M* = 1.0, *SD* = 0.9) (Table D1 Appendix D, p. 259). These findings possibly explained that all participants used non-pharmacological methods to reduce their depressive mood based on their health beliefs (Hindu religion), their preferences and/or family support. For example, they sometimes used spiritual practices (e.g., "*Puja", "Bhakal", and "Graha Shanti*") to reduce the effects of bad luck, evil eyes, for peace of mind (Table D9 Appendix D, p. 276). They promised God an offering of something or special worship after the fulfillment of a special wish. So, traditional practices are effective to call on the good spirits and remove the bad ones based on supernatural beliefs (Khatry, 2011). Moreover, the SCI participants use distractions most of the time to divert their mind and forget about their negative feelings/thoughts (Table 6, p. 134). Family and friends' support also provided to SCI people were in the forms of physical assistance, and information and psychological support (Table 1, p. 124).

3. Symptoms management

Participants of this study used both pharmacological and non-pharmacological strategies to manage pain, spasticity, and depressive mood. However, most of the participants commonly used non-pharmacological management methods more than pharmacological methods. Some used one or several non-pharmacological methods (i.e., distraction, exercise) to reduce one or several symptoms (i.e., pain, spasticity, depressive moods). The details of the management of each symptom are discussed as follows.

3.1 Pain management. In this study, people with SCI used non-pharmacological management strategies more than pharmacological strategies. Similar findings were presented in previous studies (Heutink et al., 2011; Lofgren & Norrbrink, 2012). Possible reasons for the higher use of non-pharmacological strategies could be because these methods had a longer effect with no side effects and were cheap (Table D3 Appendix D, p. 267). The SCI patients had low monthly incomes and difficulty in accessing health care service.

Non-pharmacological management. Tolerance (*n* = 41), distraction (*n* = 36), and massage (*n* = 35) were the top three types of pain management that participants used in this study that were consistent with previous studies (Hearn et al., 2015; Li et al., 2017; Lofgren & Norrbrink, 2012).

1. Tolerance. Tolerance is the highest method the participants used to manage pain. This may be explained in that most participants were male (57%). Clinical studies in the Journal of Psychosomatic Medicine found that “men had higher pain thresholds and tolerances and lower pain ratings than women” and men are motivated to tolerate and suppress expression of pain because of the masculine gender role, whereas the feminine gender role encourages pain expression and produces lower motivation among women to tolerate pain (*Lowery et al., 2003; Muller et al., 2017).*

Moreover, perhaps the fear of the side effects of pain medications led participants to use pain medications at inappropriate times (Table D5 Appendix D, p. 270). Therefore, pain is still at a high frequency and some of the participants felt that no one was around to help them (Table D3 Appendix D, p. 267). Such a situation might have been influenced by the Hindu belief about punishment from God, and thus they have a high frequency of pain. Therefore, the situation of suffering with pain developed the use of tolerance most of the time in the participants although they perceived that its effectiveness only slightly relieved pain.

2) Distraction. Consistent with previous studies, distraction was another common method used by the participants in this study (Lofgren & Norrbrink, 2012;

Thapa et al., 2018). The participants reported using this method because they could not go out of the house and do the things that they used to do as before their injury (e.g., hanging out with friends, going to the pub). Hence, to divert their mind, they used cell phones and the internet, chatted with friends, kept busy with work, watched movies most of the time because these provided pain relief for longer times, feelings of relaxation, comfort, and they were able to forget about their pain while involved in these activities. This was supported by previous qualitative studies (Hearn et al., 2015; Li et al., 2017; Thapa et al., 2018).

In addition, according to Johnson (2005), a distraction from pain can occur as a competition between the processing of exogenous (e.g., pain) and endogenous information and hence the perception of pain is suppressed by consciously focusing attention on non-pain stimuli/stimulus. Furthermore, with increased adherence, distraction can improve mood and reduce anxiety related to pain and provide comfort (Johnson, 2005). These could be the reasons that the participants in this study evaluated distraction as much better for pain relief.

3) Massage. The third most common method the participants used in this study for pain management was massage, which is similar to previous studies (Hearn et al., 2015; Lofgren & Norrbrink, 2012; Thapa et al., 2018). The use of massage was advised by the family members based on their past experiences of pain relief. They believed that massage helps in relieving pain as well as promoting the relaxation of muscles and nerves and provides comfort. A previous study mentioned that massage improves energy through the release of serotonin and melatonin neurotransmitter mediators, which promote relaxation, and improves sleep (Babaee et al., 2012). Based on gate control theory, massage may elevate the pain threshold because compared to the pain message the pressure message reaches the brain faster (Field, Diego, & Hernabdez-Reif, 2007).

The common reasons reported by the participants using massage were a longer effect of pain relief, feelings of relaxation and comfort when using oil or ointment, and it was easily available. However, nearly half of the participants sometimes used massage (48%) which could be the reason that its effectiveness was slightly better (40%), and this is consistent with previous findings (Heutink et al., 2011; Lofgren & Norrbrink, 2012).

Pharmacological management. Regarding the pharmacological strategies, approximately half of the participants (*n* = 60, 48.8%) commonly used non-opiates (i.e., NSAIDs and Paracetamol) and anticonvulsants (i.e., Gabapentin, Pregabalin) in this study which is similar to the previous studies (Hearn et al., 2015; Li et al., 2017). NSAIDs inhibit the prostaglandins synthesis and result in reducing pain sensations and anticonvulsants are believed to inhibit the calcium channels in the nerve cells and relieve pain (Guay, 2005).

However, approximately half of the participants used pain medications (*n* = 64). Of these, several participants used them inappropriate time (i.e., in the night only or morning and evening) (Table D5 Appendix D, p. 270) and self-adjusted the dosage to lower doses. It may be because these medicines are expensive to use in high dosages in the long term, the participants lacked the knowledge about the pain medication dosages and action effects, and they were fearful of the side effects (e.g., drowsiness, nausea). Therefore, when evaluating the effectiveness of pain medications, half of the participants reported that these medications reduced pain at slightly better (non-opiates) to much better (anticonvulsants) levels.

3.2 Spasticity management. Similar to pain management, participants in this study have higher use of non-pharmacological strategies in the management of spasticity compared with pharmacological strategies. The details are described as follows.

Non-pharmacological management. In this study, participants commonly used exercise (*n* = 39) followed by positioning (*n* = 30), and animal products as nutrients (traditional usage i.e., meat, eggs, bones) (*n* = 20) to reduce spasticity. The participants gave several reasons for using these methods such as health beliefs, cheapness, community availability, good longer effects (e.g., comfort, relaxation), and the ability to do at home (Table D6 Appendix D, p. 272).

1) Exercise. More than half of the participants used most of the time for exercises (*n* = 39). They performed exercises 30 minutes to 2 hours per day and reported that exercise was considerably better to reduce spasticity (Table 6, p. 133). Their joints would be stiff if they did not exercise even a single day. Some participants performing a standing exercise with assistive devices 2-3 hours twice a day reported that there was no need for medications for spasticity management. This is because exercise such as stretching induces tissue extensibility, maintains muscle length and has a positive effect on joint mobility and ROM (Katalinic et al., 2011). Consistent with previous studies, common forms of spasticity reducing exercises used were passive movement i.e. slow ROM, stretching, or standing (standing frame), or weight-bearing exercises (Elbasiouny et al., 2010; Harvey, 2016).

2) Positioning. Common positioning used in spasticity management were the frog position, prone position, and lateral position based on comfort. A previous study reported that correct and comfortable posture/positioning helps to maintain trunk control and maximize motor stability (Graham, 2013). Relevantly, participants used positioning most of the time and reported that its effectiveness was considerably better (Table 6, p. 133).

3) Eating animal nutrient. Nutrition is the process in which growth, repair, and maintenance of the body are accomplished by consuming and utilizing food substances. In this study, the participants with SCI had consumed snails, quail bird eggs, jackal meat, and vulture neck with family members' suggestions and believed that these foods are nutritious for the muscles, bones, and nerves which can also reunite the broken bones and the nerves in the spinal cord. However, little is known about the role of nutrition following SCI and it is unclear how it impacts on body composition and the metabolic profile (Khalil et al., 2013) So, the participants sometimes ate these foods and reported that they felt slightly better (Table 6, p. 133).

Pharmacological management. Forty percent of participants with spasticity used Baclofen (*n* = 29) which is the drug of choice for SCI-induced spasticity (Chang et al., 2013; Halpern et al., 2013). It acts by normalizing the altered inter-neuron activity and decreases alpha moto-neuron activity and helps to decrease calcium reflux (Milanov, 1992). However, most of the participants inappropriately used this drug, in the morning only, whenever or when they have severe spasticity (Table D8 Appendix D, p. 275). Similar to using pain medications, participants lowered the dose of their medicine by themselves because of financial problems and the fear of the side effects of the drugs such as drowsiness, dizziness.

In addition, some participants combined the medicine with non-pharmacological methods because they thought that it would be more effective (Table D6 Appendix D, p. 272). This result was congruent with previous researches (DiPiro et al., 2018; van Cooten, Snoek, Nene, De Groot, & Post, 2015). Therefore, nearly half of the participants who used Baclofen reported that it was only slightly effective in relieving spasticity.

3.3 Depressive mood management. Most participants used non-pharmacological strategies to reduce depressive moods. Two participants also bought sleeping medications to lessen their depressive mood. The top three non-pharmacological methods used to manage depressive mood were: (1) distraction (*n* = 49), sharing of feelings/problems (*n* = 31), and spiritual practices (*n* = 31)

1) Distraction. Distraction was the most common method that the participants in this study used to reduce depressive moods. This may be because having paraplegia or tetraplegia resulted in them staying at home most of the time and they were not able to go out with friends like before their injury. Therefore, they were involved in activities related to in their work (i.e., household work, employment) or entertainment (e.g., listening to music, playing games, watching movies, singing, writing poems/diaries, creating paintings, and using social media) to divert their mind from sinking into a depressive mood.

Moreover, these SCI participants reported feeling better (i.e., relaxed, comfortable) after using the method of distraction. It could be because when they used distractions, a positive mood was elevated due to the release of chemicals such as serotonin and endorphins that provided a source of distraction from negative thoughts, and a sense of purpose or meaningfulness (Searle et al., 2011). Additionally, according to Johnson (2005), distraction can improve mood, reduce depressive feelings and reduce anxiety. Therefore, several participants in this study used distraction most of the time (57.2%) and they evaluated its effectiveness in the management of their depressive mood was at a much better level (51%).

2) Sharing of feelings. The second common method used was the sharing of feelings. They shared their feelings with family and friends or via social media to relieve their depressive mood. This may be because it related to their previous practices of sharing during stressful situations and their family and friends suggested that they share their feelings. Therefore, they sometimes used this method and it was helpful to reduce depressive moods. Nearly half of them reported that their depressive mood would disappear when they shared feelings. Consistently, a previous study mentioned that the sharing of thoughts and feelings through laughter and tears were considered natural ways in managing stress (Dugan, 1989). Activities such as painting, singing, writing poems could help in improving one’s mood according to Thayer et al. (as cited in Davidson & Garrido, 2015). The participants in this study also reported feeling more relaxed after activities such as venting, sharing a post on social media which were also mentioned in the previous study (Dalebroux et al., 2008).

3) Spiritual practices. Hindu followers believe that a wrong turn of the planet can cause harmful effects on our lives (e.g., injuries or accidents, loss of valuables) (Khatry, 2011). The common reasons for using spiritual practices reported by participants with SCI were to reduce the effects of bad luck, evil eyes, for peace of mind, and their family and relatives had advised them to use these. The spiritual practices used were *“Puja”, “Bhakal”, “Graha Shanti*”, “*Puja”* or worship involving ritual offerings (e.g., flowers, fruit, money) and praying to the God and Goddesses (reciting the “mantras” which are statements or slogans from the holy books) which can be conducted daily or weekly, but typically performed on special days decided by a Hindu priest (Das, 2019; Richard, 2013). "*Bhakal"* is another common practice in Hindu religion, which means, a promise to God to offer something or special worship after the fulfillment of a special wish e.g., recovery of the people with SCI. Similarly, "*Graha Shanti*" is another form of worship related to the planets (Das, 2019; Richard, 2013).

Previous studies mentioned that traditional healers are effective in treating problems related to social deprivation and their role is to manage social conflicts often by calling good spirits and removing bad ones based on supernatural beliefs (Giri & Shankar, 2005; Khatry, 2011). Spiritual practices were performed sometimes by 61% of participants and the effectiveness was reported as considerably better by 42% of participants.

Pharmacological management. Two participants in this study used an antidepressant drug. Although the depressive mood was found in several participants of this study (moderate level, n = 37; moderately severe level, n = 23; severe level, n = 3), they may not know that the depressive mood relating a risk of depression commonly happens along with chronic pain. Additionally, many of them did not go to the hospital to follow up on their health because of problems of incomes and transportation. In the same way, after patients have been discharged from health centers, they might not receive a follow up, or a home visit from health care providers.

4. Quality of life

Consistent with previous studies, QoL among people with SCI was at a moderate level (Thapa et al., 2017). All domains of QoL were at moderate levels. Among the three domains, the problems domain had the highest mean score (*M* = 56.9, *SD* = 30.7), followed by functioning domain (*M* = 52.2, *SD* = 30.7), and mood domain (*M* = 45.6, *SD* = 16.9). These findings were consistent with previous studies conducted in developed countries (Elfstorm et al., 2005; Kljajic et al., 2016; Kreuter et al., 2005). The possible causes of each domain are described as follows.

Problems domain. This domain score was at a moderate level. It meant that the SCI participants perceived a moderate loss of independence and other problems after the injury. Regarding each item of the problems domain (Table D12 Appendix D, p. 281), the top two items with the highest percentage were (1) not being able to walk, move about freely (very hard, *n* = 40 [32.5%] and hard, *n* = 50 [40.7%]) and (2) not being able to do as you want to - when you want to (very hard, *n* = 25 [20.3%] and hard, *n* = 72 [58.5%]).

The possible reasons might be related to the young adult age, illness, and difficulties of the home physical environment. In this study, most of the participants were in the young adult group (18-30 years, 51.2%) (Bhattarai et al., 2018a; Sherpa et al., 2017) who were living an active life before SCI, whereas, at present, their mobility is highly decreased due to the physical disability from paraplegia and tetraplegia. Moreover, the participants reported that the rehabilitation professionals oriented them about home modifications before discharge from the rehabilitation center. However, it was far from possible to apply in real practice because of the low availability of resources and technical assistance. Therefore, several participants with

SCI who had high (19.5%) and complete (9.8%) dependency levels and physical home environment difficulties such as no ramps, narrow doors and corridors, had to wait for the FCs to perform their desired activities, which is consistent with a previous study (Akyuz et al., 2014).

However, the two items with the lowest percentages were (1) having problems with bowel (very hard, *n* = 11 [8.9%] and hard, *n* = 48 [39.0 %]) and (2) being in pain (very hard, *n* = 9 [7.3%] and hard, *n* = 62 [50.4%]) (Table D12 Appendix D, p. 281). The possible reasons for comparatively fewer problems in these items could be because they perceived bowel problems as a consequence of SCI. However, the people with SCI can manage bowel problems by applying bowel training, diet modification, or the use of laxatives (Chhabra, 2015). Hence, less than 10% of the participants perceived bowel problems at a very hard level. Similarly, several participants in this study reported mild pain intensity because they used distraction (e.g., watching movies, news, listening to music) most of the times relating to their previous experience and sometimes used anticonvulsants which were much better for pain relief (Table 6, p.131).

Functioning domain. The second highest score was the functioning domain that meant the SCI participants perceived moderate physical and social limitations. In the item analysis (Table D12 Appendix D, p. 279), two items that had a high number of persons with SCI agreeing on were: (1) my sexual activity is decreased (*n* = 106, 86.2%) and (2) I am doing fewer social activities with groups of people (*n* = 97, 78.9%). SCI is known to have a major impact on human sexual function. The possible reason of decrease in sexual activity could be the direct effects of the SCI on motor, sensory and autonomic pathways that alter sexual responses which is specifically genital sensation and also because most people affected by SCI were young adults and in their reproductive years (Elliot & McBride, 2014). The indirect effects of the SCI could be related to bladder and bowel changes, and co-existing symptoms of spasticity, depression, chronic pain, and alterations in sexual self-view (Elliot & McBride, 2014). Moreover, the participants agreed that “they are doing fewer social activities with groups of people” (*n* = 97, 79%). The possible reasons could be young age, physical disability, and physical environment difficulties. In this study, most of the participants were in the young adult group who were living a socially active life before SCI (e.g., work outside of home, outdoor activities with friends), whereas, at present their mobility was highly decreased due to their physical disabilities (paraplegia and tetraplegia) resulting in loss of job and contact with friends. In addition, in Nepal, the physical environment inside and outside the home are mostly wheelchair inaccessible. Roads are not accessible to their homes which were mostly in rural areas. They lived a distance of 5-7 hours from vehicle access (Scovil et al., 2012) and the people with SCI needed to be carried by at least two people to reach the health facility. They needed assistance every time when using transportation facilities because the vehicles are not wheelchair friendly (Scovil et al., 2012) which is also a possible reason for the people with SCI doing fewer social activities and going out less than before.

However, the lowest percentage of two items that the participants agreed on were: (1) I am staying in bed more (*n* = 25, 20.3%) and (2) I get dressed only with someone’s help (*n* = 30, 24.4%) (Table D12 Appendix D, p. 279). This may be because the majority of participants were male, who are more active in physical and leisure activities (Ginis et al., 2010). Hence, instead of staying in bed all the time, several participants who were paraplegia (76.4%) and had minimal dependence (27.6%) attempted to improve their physical functioning or ADL by performing getting dressed, exercising or working at home independently.

Mood domain. Mood domain (distress and depressive feelings) had the lowest score among the three domains. The top two items that a high number of persons with SCI reported were (1) I look forward with enjoyment to things (*n* = 66.7% reported “not quite so much now”) and (2) I still enjoy the things I used to enjoy (*n* = 56.1% reported “not quite so much”) (Table D12 Appendix D, pp. 279-280). Mostly belonging to a young age group and despite having common symptoms and physical complications, the people with SCI in this study could see the funny side of things and continued to enjoy life by diverting their mind towards activities such as inviting friends to their home, sharing their feelings, playing games, watching movies together, and connecting to others through social media (Table 6, p. 134). Participants also reported that they had evolved as a better person compared to before their injury because they learned to value and emphasize the abilities that they have and it helped them to forget what they had lost. Similarly, Searle et al. (2011) showed that due to the release of chemicals such as serotonin and endorphins, using distraction and positive thinking increases a positive mood and a sense of purpose or meaningfulness.

However, the two items with the lowest percentages that participants reported were (1) I feel cheerful (*n* = 51.2% reported “not often”) and (2) I feel as if I have slowed down (*n* = 52% reported “very often”) (Table D12 Appendix D, pp. 279-280). The possible reasons could be the loss of the sensory and motor dysfunction (paraplegia and tetraplegia) resulting in physical functioning limitations. At present, their life had slowed down due to loss of jobs, low level of social activities with friends; in particular and on the contrary, tetraplegia people when they were physically active before their injury such as doing an outdoor job and recreational activities. To improve their mood or to help make up their mind, they shared feelings with family and friends and used spiritual practices sometimes.

Part B. Discussion related to the results of family caregivers

1. *Demographics, health and illness, and environment*

Most FCs of people with SCI were middle aged adults and females and their relationship to the patient with SCI was a parent or wife. These findings are similar to previous studies (Gopal, Baburaj, & Balakrishnan, 2017; Sherpa et al., 2018). A possible reason was that SCI is commonly found among young to middle aged adult males in Nepal (Shrestha, 2014). Traditionally in Nepal, like in other countries, females have to take a role of primary caregiver in providing care for family members with disabilities or chronic illness (Sharma, Chakrabarti, & Grover, 2016). The education of FCs was low, which could be because of the predominance of female participants. Based on a national report, 42% of females were uneducated (Central Bureau of Statistics, 2014).

Sixty-one percent of FCs had employment, and 37.8% of the family monthly income ranged from 20,000-30,000 NPR (1 USD =110 NPR). The majority of FCs reported inadequacy of their family monthly income (57.1%). It may be because of the loss or decrease in income of SCI patients and the increase of medical payments. Since the medical cost related to SCI needed to be covered by the family income, the economy of the family was imbalanced (Sherpa et al., 2018).

Furthermore, average caregiving was five hours per day which was less compared to a previous study (Sherpa et al., 2018). The reason may be because SCI patients in this study had higher levels of independence in ADL than SCI patients of the study by Sherpa et al. (2018). All FCs performed daily caregiving activities such as lifting, positioning, cooking, feeding, bowel and bladder care that were common and congruent with previous findings (Lawang et al., 2015; Suzuki et al., 2016). FCs reported physical environment difficulties for providing care to the people with SCI and the most common barriers were no ramps, the presence of stairs, and narrow bathroom/door/corridor. This finding also was similar to previous findings (Darragh et al., 2015; Sherpa et al., 2018).

2. Common symptoms experience

2.1 Low back pain. In this study, 70 FCs reported experienced LBP (71.42%), The prevalence of LBP in FCs is similar to previous studies (Pajeema et al., 2018; Yalcinkaya et al., 2010). The pain intensity of FCs in this study was at a moderate level. Their pain frequency was then twice a week among 48.6 % FCs and 36 % of them had pain every day. The findings of pain intensity and frequency were similar to previous studies (Sherpa et al., 2018).

The reasons may be explained by several factors including gender, the health and any illnesses of the FCs, and the caregiving environment. Firstly, the majority of FCs were females which could be a reason for the development of the LBP because of the difference in terms of the anatomy, physiology, and structure accompanied by weak back muscles which could possibly result in a sprain among females than males (Suzuki et al., 2016). Secondly, nearly half of the FCs had menopause which is a factor of LBP and is related to hormonal deficiency causing a decrease in bone mineral density which predisposes females for LBP (Kim et al., 2012). Similarly, in this study, 40.8% of FCs were found to be overweight (BMI = 25 to 29.9). BMI is another factor for LBP. Previous findings showed that overweight had a significant correlation with LBP (Chowdhury et al., 2014; Su, Kusin, Li, Ahn, & Ahn, 2018). Eleven percent of FCs in this study had arthritis that may contribute to LBP. Baykara et al. (2013) found that chronic LBP coexists in 64.5% of patients with rheumatoid arthritis. Thirdly, the most common caregiving activities were lifting, transfering and positioning, requiring the FCs to bend and lift heavy loads almost every day apart from their other daily responsibilities. Moreover, physical environments inside the home were a barrier of caregiving because of stairs, no ramps for wheelchairs, and a narrow bathroom/corridor. Evidence shows that FCs involved in activities such as lifting, transferring, and positioning for people with SCI with a higher level of dependency and barriers of the physical environment were associated with the occurrence of LBP (Pajeemas et al., 2018; Sherpa et al., 2018; Suzuki et al., 2016).

However, the FCs sometimes used non-pharmacological methods to manage LBP such as tolerance (*n* = 33) relating to the Hindu belief about punishment from God and they used massage (*n* = 29), and exercise (*n* = 21) because these were easily applicable at home. They evaluated the effectiveness of LBP relief at much better for exercise and massage but slightly better for tolerance. This is similar to the study by Sherpa et al. (2017). Twenty-four FCs used NSAIDs that they bought easily from a nearby pharmacy shop when they were in severe pain and the effectiveness of these was much relief pain. Therefore, overall, the FCs of this study felt moderate LBP.

2.2 Burden. Consistent with previous studies, all FCs of this study reported having burden experience (Khazaeipour et al., 2017; Ma et al., 2014). Overall, its severity level was moderate which was similar to a study of Ma et al. (2014). In addition, the burden of items analysis in FCs was conducted (Table E1 Appendix E, pp. 282-283). The three items with the highest mean scores of burden for FCs, in order, were: (1) You should be doing more for your relative with SCI (*M* = 2.9, *SD* = 1.2), (2) You could do a better job in caring for your relative with SCI (*M* = 2.8, *SD* = 0.9), and (3) stressed between caring for your relative with SCI and trying to meet other responsibilities (work/family) (*M* = 2.3, *SD* = 1.2). The possible reasons may be related to the level of injury and dependency of SCI patients and the several roles of FCs. In this study, most FCs were married women (Table 8, p. 136) who lived with family members and performed other routine activities (i.e. job, home care, children care) and at the same time they had to provide various activities of daily living by spending time 5-8 hours per day in caring for dependent SCI patients (Table 9, p. 139) who were injured at the thoracic injury level, paralyzed, and bedridden. These situations may influence the FCs to have stress/strain to divide or manage their time to perform routine activities and caregiving for their relative with SCI, especially in the first year after the patient's injury (72.7%). Studies show that FCs who went through those various situations in carrying out their roles can experience caregiver burden (Khzaeipour et al., 2017; Robinson, Fortinsky, Kleppinger, Shugrue, & Porter, 2009).

In contrast, the three items with the lowest mean scores of FCs' burden, in order, were: (1) That your relative with SCI currently affects your relationship with family members or friends in a negative way(*M* = 0.4, *SD* = 0.7), (2) That you have lost control of your life since the illness of your relative with SCI (*M* = 0.6, *SD* = 0.7), and (3) That you don't have as much privacy as you would like because of your relative with SCI (*M* = 0.8, *SD* = 0.9) (Table E1 Appendix E, pp. 282-283). The possible reasons were that most relationships of the FCs with the SCI were parents (37.8%) or wife (25.5%) who had a close bond with the person with SCI before injury onset (Table 8, p. 137). So, closer family relationship or marital relationships predict more positive caregiver outcomes such as higher levels of effective caregiver communication and lower caregiver burden (Steadman, Tremont, & Davis, 2007). In addition, having extended family in this study (63.3%) was a benefit for FCs to receive the various support types from family members (e.g., financial support, physical support, psychological support) (Table 9, p. 140). This situation helps them to keep their ADL and work capacity (Table E8 Appendix E, p. 296) and possibly resulting in less caregiving burden.

Depressive mood. Among the total of 98 FCs, fifty-three cases (54.1%) in this study reported depressed moods which were slightly higher compared to previous studies reporting 40-43 percent depression (Arango-Lasprilla, et al. 2010; Rodakowsky et al., 2013). The average score of depressive mood severity was at a mild level and this was similar to the results of the study by Arango-Lasprilla et al. (2010). These details possibly explained that in every day the FCs heavily took care of the person with SCI in regards to bowel and bladder care (toilet care) and bathing, lifting, positioning with the difficulties of the physical arrangement at home. These environments are likely to cause a lack of interest or pleasure in practice and make the FCs have LBP, feel tried, or burdened.

In addition, a mild level of depressive mood may also be due to the love and closer relationships between the FCs and SCI patients (e.g., parent or wife), several supports received from family members (extended family = 63.3%, Table 8, p. 136) relatives, and friends (e.g., "*we are here for you (FCs)*" (Table 9, p. 139). In addition, faith and attachment towards the God based on Hindu religion helped the FCs have peace of mind and feel self-value as a key family member who is able to mainly be responsible for providing the best care to the SCI loved one. So that, although the FCs of this study have a moderate level of LBP and burden, they have a depression mood at a mild level. These are supported by previous studies. Social support from family and friends were negatively related to depression and indirectly affected the burden among caregivers. Higher support received from family and friends lowered their depressive feelings which later resulted in less burden in caregivers (Secenti et al., 2017). Fauth et al. (2012) found that caregivers' relationship closeness with people with dementia predicted high mental health and lower depression levels of caregivers. A study of Torossian and Ruffins (1999) also showed that spouse caregivers with a higher score on family cohesion experienced significantly less burden and depression than caregivers with lower cohesion scores.

3. Symptoms management

Family caregivers in this study used pharmacological and non-pharmacological strategies to manage the common symptoms including LBP, burden, and depressive moods. Obviously, to reduce symptoms overall, FCs used the non-pharmacological management methods more than used the pharmacological methods. The details of symptoms management of FCs are discussed as follows.

3.1 LBP management. Family caregivers of this study used both pharmacological and non-pharmacological strategies to reduce LBP. However, the majority of FCs used non-pharmacological strategies that were consistent with previous studies (Almeida et al., 2018; Sherpa et al., 2017). Three commonly non-pharmacological managements that several FCs used were tolerance, massage, and exercise. Some FCs used NSAIDs.

1) Tolerance. Pain endurance or tolerance was the highest used (*n* = 33) at most of the time to reduce LBP. This is consistent with the finding of Sherpa's study (2017). The reasons may be because of (1) low education level, (2) the complexity of chronic LBP, (3) financial issues, along with lack of time, and (4) religious beliefs among Hindus. Firstly, several FCs had a low education level (primary level 40.8%, no education 7.1%). Therefore, they had inadequate knowledge about pain management, fear about the side effects of drugs and dependency of pain medications (Table E4 Appendix E, p. 289). Next, the nature of chronic LBP is complex, and the management is even more challenging (Weiner, Sakamoto, Perera, & Breuer, 2006). Using the pharmacological and non-pharmacological methods to reduce chronic LBP may not be effective enough in the long term (Van Tulder, Koes, & Malmivaara, 2006). Therefore, some FCs reported that when no pain management methods helped or there was no hope to relieve the pain, they tried to endure LBP.

Thirdly, due to taking care of their loved one with SCI suffering from physical and psychological symptoms, the FCs may ignore their own pain and other problems and thought that caring for people with SCI was the first priority (Frederick, 2018). Hence, they did not have time to seek other LBP management or meet the physician at the hospital because of time constraints and payment of transportation. Finally, majority of the FCs were Hindu, who mostly believe that pain is a consequence of past wrong activities and punishment from God and should be tolerated (Whiteman, 2007). Therefore, several FCs used the tolerance of pain most of the time and nearly half of them reported that this method was slightly effective in relieving pain (48.5%).

2) Massage. The second common method the FCs used to reduce LBP was massage (*n* = 29) with mustard oil, Ayurveda oil, and Diclofenac gel. They used this massage at home as applied from their past experiences and a family member suggestion. The majority of FCs used massage for most of the time (69.0%), and nearly half of them assessed its effectiveness as much better. This is because massage promoted relaxation, relieved pain and decreased disabilities (Allen, 2016). This is consistent with previous findings that mentioned massage is an effective passive measure among other physical therapies for LBP management (Almeida et al., 2018; Shipton, 2018).

3) Exercise. The third common method the FCs used was exercise (*n* = 21) such as back strengthening, and back stretching exercises. The FCs learned the exercise techniques from internet usage and a physical therapist teaching during SCI patients' admission at the hospital (Table E7 Appendix E, p. 292). They exercised 2-3 minutes of the back stretching alone and 15-20 minutes of stretching and back strengthening exercise at home. In addition, several FCs reported that their LBP relief at much better. This was consistent with previous studies that recommended back exercises for LBP management (Allen, 2016; Chen et al., 2014).

4) NSAIDs. NSAIDs (i.e., Ibuprofen, Flexon, and Diclofenac gel) were used by FCs with LBP (*n* = 24). This finding was consistent with previous studies in that NSAIDs were the most common drugs used for LBP (Crow, 2010; Sherpa et al., 2018). These drugs are believed to reduce pain by hindering the cyclogeneses which cause prostaglandin release (Bushra & Aslam, 2010). In this study, several FCs used NSAIDs as suggested by friends/relatives because, in Nepal, the medicines were easily available in the nearby drug stores (Bhattarai, Basyal, & Bhattarai, 2014;

Shankar, Palaian, Thapa, Ansari, & Regmi, 2016). Most of them used the NSAIDs sometimes and combined with the non-pharmacological method (i.e., massage) or when having severe pain. Most of FCs reported the effectiveness of using NSAIDs in the relief of pain at a much better level.

3.2 *Burden and depressive mood management.* In this study, FCs only used non-pharmacological strategies relating to palliative and emotional coping to manage the feelings of burden and depressive moods. The top three methods FCs used for reducing burden were spiritual practices (*n* = 32) followed by distraction (*n* = 29) and sharing of feelings (*n* = 21). For decreasing depressive moods, the FCs commonly used spiritual practice (*n* = 32), distraction (*n* = 24), and crying (*n* = 20). The details of using these methods are described as follows.

1) Spiritual practices. Since the majority of FCs followed the Hindu religion, the spiritual practices of Hinduism were most commonly reported among the FCs who had burden and depressive moods. Spiritual practices including praying, worshipping (i.e., "*Puja*", "*Bhakal*", "*Graha Shanti*") (Table 13, pp. 145-146) which were used when some FCs felt that what had happened was inevitable and they were unable to reverse the cause of the illness such as the unpredictability of SCI inpatients and their long term caregiving role or when nothing worked for them and they did not know which way to go, what to do or how to deal with the stressful caregiving situations. So, they prayed and asked that God take care of their troubles and problems and loved ones. In their worship, they asked for the fulfillment of a good wish (i.e., their bad luck to decrease, health recovery, and to have a peaceful mind). Therefore, religious or spiritual help-seeking is an important part of mental health help for FCs to bear the distress or burden of caregiving. Subsequently, spiritual practices were used by several FCs at most of the time, and their effectiveness was reported at much better among 41% of the users. Consistently, previous studies found that religious beliefs or practice facilitate coping with the stress and the burden of caregiving (Malthotra, & Thapa, 2015; Pearce, Medoff, Lawrence, & Dixon, 2016).

2) Distraction. Another method that FCs used to decrease feelings of burden and the depressive mood was a distraction through the concentration in work other than caregiving such as watching movies/news, listening to music and playing games that they previously practiced. FCs reported that distraction helped them to forget the burden, refresh themselves, and create positive energy to continue caregiving. FCs used these distraction methods at most of the time (58.6%) and nearly half of FCs reported that these methods were much better to lessen the burden and depressive mood. This is supported by a recent study that investigated the effect of coping strategies and found that self-distraction was related to diminished emotional distress (Muscat & Scerri, 2018).

3) Sharing of feelings. FCs shared feelings with the family, relatives, and friends as the third commonly used method to reduce the feelings of burden. This method was used by FCs whenever they had available time. They released emotion during the sharing of positive and negative feelings (e.g., increased workload, frustration, embarrassment, and difficulties of caregiving whereas happiness or excitement related to tiny improvements seen in their SCI patients). FCs felt being cared for when someone listened to them as they vented. This finding was consistent with the evaluation of the effectiveness of the sharing of feelings' that was much better. Also, a previous study showed having a chance to talk as social support decreased feelings of depression and stress (Jeong & An, 2017).

4) Crying. Crying was the third commonly used method to decrease a depressed mood. FCs reported constantly being faced with various stressful situations during the caregiving process (e.g., financial deficiency, physical environment difficulties, health problems i.e. LBP, feelings of burden). The distress or hopeless situations caused several FCs sometimes to burst out into tears or to cry which helped them release their depressive moods. Crying was considered a self-soothing behavior in terms of the homeostatic process of mood and stress regulation and provided relief (Gracanin, Bylsma, & Vingerhoets, 2014). This is supported in this study as the FCs reported that they felt much better after crying.

4. Quality of life

Overall, FCs felt neither satisfied nor dissatisfied with their health and QoL. Moreover, the four domains of QoL for the FCs were at moderate levels. This finding was similar to Sherpa et al. (2017). The transformed scores of the physical domain and social relationship domain were equal at 56, whereas, the transformed scores of the psychological domain and environment domain were equal at 50 (Table 14, p. 148). The reasons for the findings of each domain are explained as follows.

Physical domain. The physical domain was at a moderate level (transformed score = 56). The possible reasons were two issues. Firstly, “Sleep” (*M* = 4.0, *SD* = 0.5) and “Activities of daily life” (*M* = 3.8, *SD* = 0.7) were among the highest scores in this domain (Table E8 Appendix E, p. 296). These results meant that they were satisfied with sleep and the ability to perform ADL which were consistent with a previous study (Nogueira et al., 2016). FCs reported the difference in their sleep quality while they were taking care of their SCI patients in the hospital and now when they were in their home environment. The FCs could not sleep for several days or nights due to exposure in the new environment of the hospital room and the constant interruption of sleep from the patient's problems/needs and the nurse's routine activities compared to better sleep in their home environment. Furthermore, at the present time, after completing their routine work and caregiving activities, the FCs would have a rest and sleep to reduce their LBP and caregiving burden. Moreover, the FCs of this study considered themselves able to perform their activities of daily living because they can maintain their routine work (i.e., job, home, and family care) and provide ADL care for their SCI patients.

Secondly, "pain and discomfort" (*M* = 2.0, *SD* = 1.0) was the lowest mean scoring item in this domain (Table E8 Appendix E, p. 296). This meant that they felt that physical pain had little effect on doing what they need to do. This may be supported by the finding of this study, although the FCs have moderate LBP and/or co-morbidities, they tried to endure LBP and other problems (Table 13, p. 145). It is because providing care for their loved one who was suffering from SCI is the first priority (Frederick, 2018).

Social relationship domain. The social relationship domain was at a moderate level (transformed score = 56). This study found that "personal relationship" (*M* = 3.3, *SD* = 0.8) and "social support" (*M* = 3.1, *SD* = 0.7) were among the highest-scoring items in this domain (Table E8 Appendix E, p. 296). This meant that the FCs were satisfied with the personal relationship and were quite satisfied with social support. This may be due to the relationships of the FCs with the care recipients which were parents (37.8%) and wife (25.5%) who had a close attachment before injury onset. When the family member or the loved one had SCI and needed daily dependent care from their FCs in the long term, this caregiving situation creates more frequent interactions in the relationship. So, closer family relationships or marital relationships (before illness onset) predict more positive caregiver outcomes such as higher levels of effective caregiver communication and lower caregiver burden (Steadman, Tremont, & Davis, 2007). Similarly, Netto, Jenny, and Phillip (2009) found that some caregivers feel emotionally closer to the care recipient after the dementia onset because caregiving necessitated more frequent interaction in the relationship. Moreover, because almost all of them lived with their families (extended family) and received several supports (e.g., physical caregiving, financial, psychological support) from family, relatives, and friends (Table 9, p. 140). Consistently, a previous study presented that with higher numbers of family members, FCs received higher assistance (Yashmita et al., 2013). In addition, FCs with assistance in caregiving had higher QoL (Amendola, Oliveira, & Alvarenga, 2011).

Psychological domain. The psychological domain was at a moderate level (transformed score = 50). Considering each item of this domain, “Bodily image and appearance” (*M* = 3.7, *SD* = 0.6) and “Spirituality” (*M* = 3.5, *SD* = 0.5) were among the highest-scoring items in this domain (Table E8 Appendix E, p. 296). These meant that the FCs mostly accepted their bodily appearance and were satisfied with themselves. The possible reasons were that more than half of the FCs were middle-aged adult women (*M* = 37 years) who had a healthy weight (BMI = 18.5-24.9) (52.8%) and most of them were still menstruating (77.3%) (Table 8, p. 138) with no physical disabilities. Therefore, these possibly infer that they were highly accepting of their bodily image and appearance. They were also satisfied in their life (spirituality) and that may be because they were able to perform their work and were significant persons who mainly provided care for their SCI loved one, as well as received social support from family, relatives, and friends.

However, the items of self-esteem (*M* = 2.4, *SD* = 0.8) and positive feelings (*M* = 2.5, *SD* = 0.9) showed at the lowest level in this domain (Table E8 Appendix E, p. 296). These may be explained that during the caregiving process, most FCs had a moderate burden and mild depressive mood. These negative feelings may lead FC to have little self-esteem. This finding is supported by a previous study that showed that self-esteem negatively and significantly correlated with caregiving stress and depression (Kim, 2017).

Environment domain. This domain was at a moderate level (transformed score = 50). This may be caused by positive and negative issues. The positive issues were transport (*M* = 3.4, *SD* =1.1) and physical safety security (*M* = 3.3, *SD* = 1.0) (Table E8 Appendix E, p. 296). These two items were the highest score among this domain. This meant that they were satisfied with transport and moderately felt safe in their daily life. This may be because they are familiar with traveling to perform their work/ADL in rural and urban areas. Moreover, most FCs have family members and neighbors who provide physical, psychological, and financial support (Table 9, p. 140) when they felt tired, had LBP or burden from their work/caregiving. Therefore, the FCs in this study felt moderately safe in their daily life.

However, negative issues were found. The FCs had little opportunity for leisure activities (*M* = 2.5, *SD* = 0.5). This may be because of spending time on caregiving and other regular daily activities which were similar to a previous study (Wakui, Saito, Agree, & Kai, 2012). Moreover, the physical environment (*M* = 2.6, *SD* = 0.5) was perceived by FCs at a moderate level for their health. This may be explained that in rural areas of a developing country such as Nepal, people use biomass fuels (e.g., firewood) inside their home for cooking, warmth, and light and improperly perform waste management that may cause household pollution (e.g., air/smoke and water pollution). Because of their customary involvement in cooking, women/FCs' exposure is much higher than men (Ranabhat et al., 2015). In addition, FCs were less satisfied with health and social care accessibility (*M* = 2.7, *SD* = 0.8) (Table E8 Appendix E, p. 296). This could be possible because most of FCs and SCI patients lived in rural areas where there are primary care centers providing basic health care (e.g., sanitation, vaccination, nutrition). When people are facing the complexity/emergency of illness, they have trouble travelling to hospitals in the urban areas because the modern health facilities in Nepal did not reach the rural areas (Khatry & Eliade, 2014). However, most of the FCs in this study had low education and low income that may be an obstacle to seek health information and access to those modern health care facilities.

In conclusion, according to the Symptom Management Model, a bidirectional relationship exists between the interrelated dimensions (symptom experience, symptom management, and the outcome) and nursing domains (personal, health and illness, and environmental factors) (Dodd et al., 2001). The results of this study showed that the peoples with SCI had moderate levels of pain, spasticity, and depressive mood and the FCs had a moderate level of LBP and burden, and mild depressive mood. Both of them commonly used non-pharmacological management higher than medication use. Their QoL was at moderate levels. These results might have been in influenced by the three factors of SCI people and the FCs as follows: personal factors (e.g., gender, age, education, employment, income, religion, belief, and preferences), health and illness (e.g., patients' level of injury and dependency level and FCs' BMI, menopause, and co-morbidities,), and environment (e.g., relationships with FC and SCI people, caregiving duration, physical arrangement inside and outside home, social support, and health care accessibility). Therefore, these findings and their related factors will be useful for further study to manage symptoms and improve the QoL of people with SCI and the FCs in Nepal.

Chapter 5

Conclusion and Recommendations

This chapter presents the conclusion, strengths of the study, and implications and recommendations.

Conclusion

This study was conducted to describe the common symptoms experience, symptoms management, and examine the QoL level among people with SCI and the FCs. The study was conducted in the 13 districts of Province No. 3 in Nepal from February to May 2019. One hundred and twenty-three people with SCI and ninety-eight FCs were recruited using a stratified sampling method.

The instruments used to collect the data of people with SCI were: (1) Demographics, Health and Illness, and Environment Data Form of People with Spinal Cord Injury, (2) International Spinal Cord Injury Pain Basic Data Set version 2.0 (ISCIPBDS-2), (3) Penn Spasm Frequency Scale (PSFS), (4) Patient Health Questionnaire (PHQ-9), (5) Symptoms Management Questionnaire of People with Spinal Cord Injury (SMQ-SCI), and (6) Spinal Cord Injury Quality of Life-23 (SCI QL-23). The instruments for data collection of FCs were: (1) Demographics, Health and Illness, and Environment Data Form of Family Caregivers, (2) Pain Experience Questionnaire (PEQ), (3) Zarit Burden Interview-short Form (ZBI-12), (4) Patient Health Questionnaire (PHQ-9), (5) Symptoms Management Questionnaire of Family Caregivers (SMQ-FCs), and (6) World Health Organization Quality of Life (WHOQOL-BREF). Five experts validated the research questionnaire (S-CVI = 1.0).

The reliability results showed acceptable ranges. For the total number of samples of SCI, Cronbach's alphas were .73 for the ISCIPBDS-2, .89 for the PSFS, .84 for the PHQ-9, and .78 for the SCI QL-23. For the total number of FCs, Cronbach's alphas were .78 for the PEQ, .85 for the ZBI-12, .79 for the PHQ-9 of FCs, and .86 for the WHOQOL-BREF. Descriptive statistics were applied for the analysis of the study variables including simple content analysis for the analysis of the open-end questions of symptoms management. The findings of this study are summarized as follows.

Among 123 people with SCI, common symptoms experiences were pain (100%), spasticity (59.3%), and depressive mood (84.5%). The three most common locations of first worst pain were (1) back, (2) buttocks/hip, and (3) upper leg/thigh. Pain intensity was at a moderate level (*M* = 3.5, *SD* = 0.9) and frequency was at a high level (*M* = 6.0, *SD* = 1.6). Spasticity severity and frequency were at moderate levels (*M* = 2.2, *SD* = 0.8, *M* = 2.1, *SD* = 0.5, respectively). Depressive mood was within moderate level (*M* = 11.0, *SD* = 4.2). The use of non-pharmacological strategies was more than the pharmacological strategies for symptoms relief because of beliefs, preferences, convenience, and community resources. The non-pharmacological management methods commonly used by SCI people to relieve pain were tolerance followed by distraction and massage; to decrease spasticity using exercise, followed by positioning, and eating animal nutrients (traditional usage); and to reduce depressive moods using distraction followed by sharing feelings, and spiritual practices. Half of the people with SCI sometimes used medications such as anticonvulsants and non-opiate drugs to relieve their pain and they used muscle relaxants to reduce spasticity. The effectiveness of using non-pharmacological management was found slightly better to reduce the symptoms, whereas the use of the medication was found slightly to much better levels. Moreover, the three domains of QoL including problems (perceived loss of independence and other issues relating to injury) (*M* = 56.9, *SD* = 21.5), functioning (physical and social limitations) (*M* = 52.2, *SD* = 30.7), and mood (distress and depressive feelings) (*M* = 45.6, *SD* = 16.9) were found at moderate levels.

Among 98 FCs, common symptoms experience was burden (100%), LBP (71.4%), and depressive mood (54.1%). FCs had a moderate level of LBP (*M* = 4.1, *SD* = 1.7) and its frequency was more than two times a week. Overall, the severity of burden was at a moderate level (*M* = 19.2, *SD* = 8.0), and severity of depressive mood was at a mild level (*M* = 8.7, *SD* = 2.9). The common symptoms management FCs used were non-pharmacological methods and the reasons for this were similar to the people with SCI as mentioned above. They used tolerance followed by a massage, and exercises to reduce LBP; used spiritual practice, distraction, and the sharing of feelings to lessen burden; and used spiritual practice, distraction, and crying to decrease depressive moods. They evaluated the effectiveness of these management methods at slightly better to much better levels of relieving symptoms. For using pain medications, one-fourth of FCs used NSAIDs to reduce LBP whenever and most of them reported feeling much better. The four domains of the QoL of the FCs were at moderate levels. The scores of the physical domain and social relationship domain were at 56, whereas the scores of the psychological domain and environment domain were at 50.

Strengths of the Study

The stratified random sampling technique and randomly selected samples were used that accurately reflected the population studied which has increased the external validity of the findings of this study. Therefore, the results of the study can be generalized among the people with SCI and FCs living in the hilly regions of Nepal.

Implications and Recommendations

The findings of this study propose the implications and recommendations for the health policy, nursing practice, nursing education, and nursing research as follows:

Health policy and nursing practice

The findings of this study showed that SCI patients had moderate levels of pain, spasticity, and depressive mood. The FCs had moderate levels of LBP and burden, and mild depressive mood. Therefore, continuing care for SCI patients and the FCs after patients are discharged is necessary in order to effectively maintain their QoL while living in the community.

Discharge planning programs by coordinating with the interdisciplinary team should be established for SCI patients and the FCs. The features of the education program should correspond with the prevention of the common symptoms experienced by patients with SCI (e.g., pain, spasticity, depressive mood). For example, minimizing bladder and bowel problems and pressure ulcers to reduce SCI patients' spasticity occurrence. Controlling or managing concurrent symptoms (pain, spasticity, and depressive mood) because they are interrelated. Monitoring or screening probable depression for SCI patients in the short-term and long-term phase.

For the common symptoms experienced by FCs (e.g., LBP, burden, depressive mood), the health care providers should educate them regarding the prevention of LBP while providing caregiving activities. Likewise, the FCs should be advised about the use of available assistive devices to reduce LBP. In addition, a respite or a short break from caregiving for FCs should be suggested to avoid the common symptoms; in particular, FCs with co-morbidities. Monitoring or screening the health of FCs should be recommended.

The people with SCI who develop chronic pain, spasticity, and/or depressive moods and the FCs who develop chronic LBP, burden, and depressive moods should be advised to consult a physician about using medications and managing their side effects along with the rational use of non-pharmacological strategies for effective symptoms relief. The non-pharmacological management methods commonly used which had effective relief of symptoms as reported by the people with SCI and the FCs, were those such as pain management (e.g., distraction, massage), spasticity management (e.g., exercise, frog or prone positioning), depressive mood management (e.g., distraction, sharing feelings, spiritual practice), LBP management (e.g., massage, exercise), and burden and depressive mood management (e.g., spiritual practice, sharing feelings, distraction). Therefore, the nurses should educate the SCI people and the FCs regarding the appropriate procedure for applying those non-pharmacological methods including their duration, time, and methods. In addition, regular evaluation of these symptoms and QoL through the programs of home/community visits and audio or video communication should be conducted.

Moreover, the results of this study showed that the people with SCI the FCs had QoL at moderate levels. The SCI people felt a loss of independence and other problems after the injury because they were not able to move freely and able to do as that they wanted. The barriers are possibly caused by difficulties in their physical home environment and the SCI people/the FCs may lack of knowledge about home modifications (Glennie et al., 2017). Therefore, people with SCI and FCs should be educated about the benefits of home modifications. However, since most SCI participants in this study may have financial difficulties, therefore, the health care team and the community organizations associated (e.g., NGO) should co-ordinate to assist them to set priorities and decide on home modifications (e.g., toilet, kitchen, or ramp). Moreover, using the soil, stones, bricks, and wood that are available locally should be suggested for the participants to build a wheelchair friendly/ accessible home environment.

For the QoL of FCs, their psychological and environment domains were the lowest scores. In particular, they felt little self-esteem while spending time caregiving over a long period. Therefore, psychological support to help them accept themselves as valuable and to help them deal with issues positively should be provided. It is important to facilitate the realization of positive experiences that can be derived from caregiving as well as the negative experiences. Moreover, the physical environment domain of the FCs was healthy at a moderate level that may be because of air pollution/waste management problems in the rural household. So, education about ventilation to control indoor air quality and proper waste management to FCs and family should be provided. In addition, FCs; especially in rural areas, felt less satisfied with health care social accessibility. Improving access to health care services in rural areas requires a multisectoral commitment involving several organizations (e.g., health, transportation, finance, finance, labor, and other relevant organizations).

This need to explore underutilized interventions that can better connect the patients /FCs and health care providers to enhance the quality of health care in rural areas. Coordination of care, improved communication between the health care providers and patients/ FCs, the use of innovative technologies (e.g., telephone, media applications devices) to bridge distance barriers, support for informal care networks (e.g., self-help group), and efforts to improve affordability are essential to improve access to health care service in rural areas.

Nursing education

The findings of this research exemplify the need to integrate nursing education about the symptom management among the people with SCI and the FCs in the form of short training or workshops with the nursing students and/or nurses in Nepal to provide continuing care for the SCI population and their families.

Nursing research

1. The researches in future should be conducted about symptoms cluster of the people with SCI and the FCs in Nepal or associated factors of QoL of people with SCI and the FCs such as income, employment, types of SCI, pain, spasticity, LBP, depressive mood, and caregiving burden.

2. A development model or interventions of symptoms management for Nepalese people with SCI and the FCs to improve QoL should be conducted by a multidisciplinary team.

References

Adams, M. M., Ginis, K. A. M., & Hicks, A. L. (2007). The spinal cord injury spasticity evaluation tool: Development and evaluation. *Archives of Physical Medicine and Rehabilitation*, *88*, 1185-1192. doi:10*.1016/j.apmr.2007.06.012*

Adams, M. M., & Hicks, A. L., (2005). Spasticity after spinal cord injury. *Spinal Cord, 43,* 577-568. doi:10.1038/sj.sc.3101757

Adelman, R. D., Tmanova, L. L., Delgado, D., Dion, S., & Lachs, M. S. (2014). Caregiver burden: A clinical review. *Journal of American Medical Association*, *311,* 1052-1060. doi:10.1001/jama.2014.304

Adeosun, I. I. (2013). Correlates of caregiver burden among family members of patients with schizophrenia in Lagos, Nigeria. *Schizophrenia Research and Treatment*, *2013,* 1-7. doi:10.1155/2013/353809

Adhikari, L. M. (2016). Ethnomedical Health Care Practices among the Satar tribe of Nepal: Linking to development agenda. *Journal of Advanced Academic Research*, *3*, 55-65. doi:10.3126/jaar.v3i2.16755

Agtarap, S., Boals, A., Holtz, P., Roden-Foreman, K., Rainey, E. E., Ruggero, C., & Warren, A. M. (2017). The effect of depressive symptoms on social support one year following traumatic injury. *Journal of Affective Disorders*, *207,* 398-405. doi:10.1016/j.jad.2016.08.067.

Akkoç, Y., Ersoz, M., Yıldız, N., Erhan, B., Alaca, R., Gok, H., ...Alemdaroglu, E. (2013). Effects of different bladder management methods on the quality of life in patients with traumatic spinal cord injury. *Spinal Cord*, *51,* 226–231. doi:10.1038 /sc.2012.131

Akyuz, M., Yalcin, E., Selcuk, B., & Degirmenci, I. (2014). The barriers limiting the social integration of wheelchair users with spinal cord injury in Turkish society. *Neurosurgery Quarterly*, *24,* 225-228. doi:10.1097/WNQ.0000 000000000116

Al Abbudi, S. J., Ezzat, K. I., Zebala, A. A., Hamdy, D. J., Al-Beedany, M. S., Farhan, M. S. (2017). Prevalence and determinants of depression among traumatic spinal cord injured patients attending Ibn-Al-Quff Hospital, Baghdad, Iraq. *Journal of Psychiatry*, *20*(6), 1-6. doi:10.4172/2378-5756.1000428

Allegri, M., Montella, S., Salici, F., Valente, A., Marchesini, M., Compagnone, C., ...Fanelli, G. (2016). Mechanisms of low back pain: A guide for diagnosis and therapy. *F1000Research*, *5,* 1-13. doi:10.12688/f1000research.8105.2

Allen, L. (2016). Case study: The use of massage therapy to relieve chronic low-back pain. *International Journal of Therapeutic Massage & Bodywork*, *9,* 27-30. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5017818/

Alexander, M., Courtois, F., Elliott, S., & Tepper, M. (2017). Improving sexual satisfaction in persons with spinal cord injuries: Collective wisdom. *Topics in Spinal Cord Injury Rehabilitation, 23*, 57-70. doi:10. 1310/sci2301-57

Almeida, M., Saragiotto, B., Richards, B., & Maher, C. G. (2018). Primary care management of non-specific low back pain: Key messages from recent clinical guidelines. *Medical Journal of Australia*, *208*, 272-275. doi:10.5694/ mja17.01152

Almeida, S. A. D., Santo, P. F. D. E., Silveira, M. M., Openheimer, D. G., Dutra, R. A. A., Bueno, M. D. L. G. B.,...Pereira, M. T. D. J. (2013). Depression in patients with traumatic spinal cord injuries and pressure ulcers. *Revista Brasileira de Cirurgia Plástica*, *28*, 282-288. doi:10.1590 /S1983-51752013000200019

Alm, M., Saraste, H., & Norrbrink, C. (2008). Shoulder pain in persons with thoracic spinal cord injury: Prevalence and characteristics. *Journal of Rehabilitation Medicine, 40,* 277-283. doi:10.2340/16501977-0173

Al-Owesie, R. M., Moussa, N. M., & Robert, A. A. (2012). Anxiety and depression among traumatic spinal cord injured patients. *Neurosciences, 17*, 145-150. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/22465889

Al Taweel, W., & Seyam, R. (2015). Neurogenic bladder in spinal cord injury patients. *Research and Reports in Urology*, *7,* 85-99. doi:10.2147/RRU. S29644

Altindag, O., Karagullu, H., & Gur, A. (2014). Sleep disturbances in patients with spinal cord injury. *Orthopedic Muscular System*, *3*(3), 1-4. doi:10.4172/2161-0533.100 0164

Amendola, F., Oliveira, M. A. D. C., & Alvarenga, M. R. M. (2011). Influence of social support on the quality of life of family caregivers while caring for people with dependence. *Revista da Escola de Enfermagem da USP, 45,* 884-889. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/21876888

Andresen, S. R., Biering-Sorensen, F., Hagen, E. M., Nielsen, J. F., Bach, F. W., & Finnerup, N. B. (2016). Pain, spasticity and quality of life in individuals with traumatic spinal cord injury in Denmark. *Spinal Cord, 54,* 973-979. doi:10.1038/sc.2016.46

Arango-Lasprilla, J. C., Plaza, S. L. O., Drew, A., Romero, J. L. P., Pizarro, J. A. A., Francis, K., & Kreutzer, J. (2010). Family needs and psychosocial functioning of caregivers of individuals with spinal cord injury from Colombia, South America. *Neuro Rehabilitation, 27,* 83-93. doi:10.3233/NRE-2010-0583

Archer, K. R., Castillo, R. C., Wegener, S. T., Abraham, C. M., & Obremskey, W. T. (2012). Pain and satisfaction in hospitalized trauma patients: The importance of self-efficacy and psychological distress. *Journal of Trauma and Acute Care Surgery, 72*, 1068-1077. doi:10.1097/TA.0b013e3182452df5

Ataoglu, E., Tifik, T., Kara, M., Tunc, H., Ersoz, M., & Akkus, S. (2013). Effects of chronic pain on quality of life and depression in patients with spinal cord injury. *Spinal Cord, 52,* 23-26. doi:10.1038/sc.2012.51

Babaee, S., Shafiei, Z., Sadeghi, M. M. M., Nik, A. Y., & Valiani, M. (2012). Effectiveness of massage therapy on the mood of patients after open-heart surgery. *Iranian Journal of Nursing and Midwifery Research, 17*, S120-S124. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/ PMC3696961/

Babamohamadi, H., Negarandeh, R., & Dehghan-Nayeri, N. (2011). Coping strategies used by people with spinal cord injury: A qualitative study. *Spinal Cord, 49,* 832-837. Retrieved from https://www.nature.com/articles/sc201110.pdf

Baker, A., Barker, S., Sampson, A., & Martin, C. (2017). Caregiver outcomes and interventions: A systematic scoping review of the traumatic brain injury and spinal cord injury literature. *Clinical Rehabilitation, 31*, 45-60. doi:10.1177/ 02692 15516639357

Bandeira, M., Calzavara, M. G. P., Freitas, L. C., & Barroso, S. M. (2007). Family Burden Interview Scale for relatives of psychiatric patients (FBIS-BR): Reliability study of the Brazilian version. *Brazilian Journal of Psychiatry*, *29,* 47-50. doi:10.1590/S1516-444620 06005000015

Bardak, A. N., Erhan, B., & Gündüz, B. (2012). Low back pain among caregivers of spinal cord injured patients. *Journal of Rehabilitation Medicine, 44,* 858-861. doi:10.2340/16501977-1043

Barrera-Chacon, J. M., Mendez-Suarez, J. L., Jauregui-Abrisqueta, M. L., Palazon, R., Barbara-Bataller, E., & Garcia-Obrero, I. (2011). Oxycodone improves pain control and quality of life in anticonvulsant-pretreated spinal cord-injured patients with neuropathic pain. *Spinal Cord*, *49*, 36-42. doi:10.1038/sc. 2010.101

Bartley, E. J., & Fillingim, R. B. (2013). Sex differences in pain: A brief review of clinical and experimental findings. *British Journal of Anaesthesia*, *111*, 52-58. doi:10.1093/bja/aet127

Bassett, R. L., Ginis, K. M., & Buchholz, A. C. (2009). A pilot study examining correlates of body image among women living with SCI. *Spinal Cord*, *47*, 496-498. doi:10.1038/sc.2008.174

Bauman, C. A., Milligan, J. D., Lee, F. J., & Riva, J. J. (2012). Autonomic dysreflexia in spinal cord injury patients: An overview. *The Journal of the Canadian Chiropractic Association*, 56, 247-250. Retrieved from https://www.ncbi. nlm.nih.gov/pmc/articles/PMC3501908/

Baykara, R.A., Bozgeyik, Z., Akgul, O., & Ozgocmen, S. (2013). Low back pain in patients with rheumatoid arthritis: Clinical characteristics and impact of low back pain on functional ability and health related quality of life. *Journal of Back and Musculoskeletal Rehabilitation*, 26, 367-374. doi:10.3233/BMR-130393

Beaufort, I. N., De Weert-Van Oene, G. H., Buwalda, V. A., de Leeuw, J. R. J., & Goudriaan, A. E. (2017). The Depression, Anxiety and Stress Scale (DASS-21) as a screener for depression in substance use disorder inpatients: A pilot study. *European Addiction Research*, *23*, 260-268. doi:10.1159/000485182

Bedard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J. A., & O'Donnell, M. (2001). The Zarit Burden Interview: A new short version and screening version. *The Gerontologist*, *41*, 652-657. doi:10.1093/geront/41.5.652

Beinart, N., Weinman, J., Wade, D., & Brady, R. (2012). Caregiver burden and psychoeducational interventions in Alzheimer’s disease: A review. *Dementia and Geriatric Cognitive Disorders Extra*, *2*, 638-648. doi:10.1159/ 000345777

Berlowitz, D. J., Wadsworth, B., & Ross, J. (2016). Respiratory problems and management in people with spinal cord injury. *Breathe, 12*, 328-340. doi:10.1183/20734735.012616

Betz, R. R., Murray, H. H., Patel, N., & Nanda, A. (2015). Musculoskeletal complication. In Chabbra, H. S (Ed). *ISCoS Textbook on Comprehensive Management of Spinal Cord Injuries* (pp. 731-735). Haryana, India: Wolter Kluwer.

Bhattarai, B., Pokhrel, P. K., Tripathi, M., Rahman, T. R., Baral, D. D., Pande, R., & Bhattacharya, A. (2007). Chronic pain and cost: An epidemiological study in the communities of Sunsari district of Nepal. *Nepal Medical College Journal*. *9*, 6-11. Retrieved from http://imsear.li.mahidol.ac.th/bitstream/ 123456789/46788/2/ nmcj%20vol.9_no.1_article.2.pdf

Bhattarai, M., Maneewat, K., & Sae-Sia, W. (2018a). Determinants of resilience among people who sustained spinal cord injury from the 2015 earthquake in Nepal. *Spinal Cord, 56*, 78-83. doi:10.1038/sc.2017.93

Bhattarai, M., Maneewat, K., & Sae-Sia, W. (2018b). Psychosocial factors affecting resilience in Nepalese individuals with earthquake-related spinal cord injury: A cross-sectional study. *BMC Psychiatry*, *18*(60), 1-8. doi:10.1186/s12888-018-1640-z

Bhattarai, S., Parajuli, S. B., Rayamajhi, R. B., Paudel, I. S., & Jha, N. (2015). Health seeking behavior and utilization of health care services in Eastern hilly region of Nepal. *Journal of College of Medical Sciences-Nepal*, *11,* 8-16. doi: 10.3126/jcmsn.v11i2.13669

Biering-Sørensen, F., Biering-Sørensen, T., Liu, N., Malmqvist, L., Wecht, J. M., & Krassioukov, A. (2018). Alterations in cardiac autonomic control in spinal cord injury. *Autonomic Neuroscience*, *209,* 4-18. doi:10.1016/j.autneu.2017 .02.004

Bombardier, C. H., Kalpakjian, C. Z., Graves, D. E., Dyer, J. R., Tate, D. G., & Fann, J. R. (2012). Validity of the Patient Health Questionnaire-9 in assessing major depressive disorder during inpatient spinal cord injury rehabilitation. *Archives of Physical Medicine and Rehabilitation*, *93,* 1838-1845. doi:10.1016/ j.apmr.2012.04.019

Bravo-Esteban, E., Taylor, J., Abian-Vicen, J., Albu, S., Simon-Martinez, C., Torricelli, D., & Gomez-Soriano, J. (2013). Impact of specific symptoms of spasticity on voluntary lower limb muscle function, gait and daily activities during subacute and chronic spinal cord injury. *Neuro Rehabilitation*, *33,* 531-543. doi:10.3233/NRE-131000

Breivik, H., Borchgrevink, P. C., Allen, S. M., Rosseland, L. A., Romundstad, L., Breivik Hals, E. K., ...Stubhaug, A. (2008). Assessment of pain. *British Journal of Anaesthesia*, *101*, 17-24. doi:10.1093/bja/aen10

Bryce, T. (2009). *Spinal cord injury: Rehabilitation medicine quick reference*. New York, NY: Springer.

Bryce, T. N., Biering-Sorensen, F., Finnerup, N. B., Cardenas, D. D., Defrin, R., Lundeberg, T., ...Treede, R. D. (2012). International spinal cord injury pain classification: Part I. Background and description. *Spinal Cord*, *50,* 413-417. doi:10.1038/sc.2011.156.

Bryce, T. N., Budh, C. N., Cardenas, D. D., Dijkers, M., Felix, E. R., Finnerup, N. B... Siddall, P. (2007). Pain after spinal cord injury: An evidence-based review for clinical practice and research: Report of the national institute on disability and rehabilitation research spinal cord injury measures meeting. *The Journal of Spinal Cord Medicine, 30*, 421-440. doi:10. 1080/10790268. 2007.11753405

Burns, A. S., St-Germain, D., Connolly, M., Delparte, J. J., Guindon, A., Hitzig, S. L., & Craven, B. C. (2015). Phenomenological study of neurogenic bowel from the perspective of individuals living with spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, *96*, 49-55. doi:10.1016/j. apmr. 2014.07.417

Bushra, R., & Aslam, N. (2010). An overview of clinical pharmacology of Ibuprofen. *Oman Medical Journal*, 25, 155-161. doi:10.5001/omj.2010.49

Cameron, A. P., Rodriguez, G. M., Gursky, A., He, C., Clemens, J. Q., & Stoffel, J. T. (2015). The severity of bowel dysfunction in patients with neurogenic bladder. *The Journal of Urology*, *194*, 1336-1341. doi:10.1038/sc.2008.137

Cameron, I. M., Reid, I. C., & Lawton, K. (2010). PHQ-9: Sensitivity to change over time. *British Journal of General Practice*, *60*, 535-536. doi:10.3399/ bjgp10X514909

Campbell, C. M., & Edwards, R. R. (2012). Ethnic differences in pain and pain management. *Pain Management*, *2*, 219-230. doi:10.2217/pmt.12.7

Cardenas, D. D., & Jensen, M. P. (2006). Treatments for chronic pain in persons with spinal cord injury: A survey study. *The Journal of Spinal Cord Medicine*, *29*, 109-117. doi: 10.1080/10790268.2006.11753864

Cardenas, D. D., Nieshoff, E. C., Suda, K., Goto, S. I., Sanin, L., Kaneko, T.,...Whalen, E. (2013). A randomized trial of pregabalin in patients with neuropathic pain due to spinal cord injury. *Neurology*, *80*, 533-539. doi: 10.1212/WNL.0b013e318281546b

Carteret, M. (2010). *Cultural aspects of pain*. Retrieved from https://www.dimensionsofculture.com/2010/11/cultural-aspects-of-pain-management/

Cash, T. F. (2004). *Body image: Past, present, and future*. *1*, 1-5. doi:10.1016/ S1740-1445(03)00011-1

Celik, E. C., Erhan, B., & Lakse, E. (2012). The clinical characteristics of neuropathic pain in patients with spinal cord injury. *Spinal Cord*, *50*, 585-589. doi:10.1038 /sc.2012.26

Central Bureau of Statistics, (2014). *Population monograph of Nepal*. Retrieved from https://lac.unfpa.org/sites/default/files/pub-pdf/Population%20Monograph%20V03.pdf

Cetinel, B., Onal, B., Turegun, F. A., & Erdogan, S. (2014). Urologic health condition of spinal cord-injured patients living in Turkey. *Spinal Cord*, *52*, 302-306. doi:10.1038/sc.2013.173

Chang, E. Y., Ghosh, N., Yanni, D., Lee, S., Alexandru, D., & Mozaffar, T. (2013). A Review of spasticity treatments: Pharmacological and interventional approaches. *Critical Reviews in Physical and Rehabilitation Medicine,* 25, 11–22. doi:10.1615/CritRevPhysRehabilMed.2013007945

Charalambous, C., Vassilopoulos, A., Koulouri, A., Eleni, S., Popi, S., Antonis, F., ...Roupa, Z. (2018). The impact of stress on pressure ulcer wound healing process and on the psychophysiological environment of the individual suffering from them. *Medical Archives*, *72*, 362-366. doi:10.5455/medarh. 2018.72.362-366

Chhabra, H. S. (2015). *ISCoS textbook on comprehensive management of spinal cord injuries*. Haryana, India: Wolter Kluwer.

Chen, S. F., Jiang, Y. H., Jhang, J. F., Lee, C. L., & Kuo, H. C. (2014). Bladder management and urological complications in patients with chronic spinal cord injuries in Taiwan. *Tzu Chi Medical Journal*, *26*, 25-28. doi:10.1016/j.tcmj.2013.09.010

Choi, J., Tate, J. A., Hoffman, L. A., Schulz, R., Ren, D., Donahoe, M. P., ...& Sherwood, P. R. (2014). Fatigue in family caregivers of adult intensive care unit survivors. *Journal of Pain and Symptom Management*, *48*, 353-363. doi:10.1016/j.jpainsymman.2013.09.018

Chou, K. R. (2000). Caregiver burden: A concept analysis. *Journal of Pediatric Nursing*, *15*, 398-407. doi:10.1053/jpdn.2000.16709

Chowdhury, D., Sarkar, S., Rashid, M. H., Rahaman, A., Sarkar, S. K., & Roy, R. (2014). Influence of body mass index on low back pain. *Mymensingh Medical Journal*, *23*, 125-129. Retrieved from http://europepmc.org/abstract/ med/24584385

Clark, J. M., & Findlay, D. M. (2017). Musculoskeletal health in the context of spinal cord injury. *Current Osteoporosis Reports*, *15*, 433-442. doi:10.1007/s11914-017-0400-1

Cleeland, C. S. (2009). *The Brief Pain Inventory User Guide.* Retrieved from https://www.mdanderson.org/documents/Departments-and-Divisions/ Symptom-Research/BPI_UserGuide.pdf

Cleeland, C. S., & Ryan, K. M. (1994). Pain assessment: Global use of the Brief Pain Inventory. *Annals, Academy of Medicine, Singapore*. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/8080219

Coldrey, J. C., Upton, R. N., & Macintyre, P. E. (2011). Advances in analgesia in the older patient. *Best Practice & Research Clinical Aesthesiology*, *25*, 367-378. doi:10.1016/j.bpa.2011.06.003

Combs, M. A., & Thorn, B. E. (2014). Barriers and facilitators to yoga use in a population of individuals with self-reported chronic low back pain: A qualitative approach. *Complementary Therapies in Clinical Practice*, *20*, 268-275. doi:10.1016/j.ctcp.2014.07.006.

Cook, K., Williams, A., Teal, C., Robinson-Wheelen, S., Mahoney, J., Engebretson, J. C., ...Sherwood, A. M. (2007). The patient-reported impact of spasticity measure (prism): A new measure assessing the impact of spasticity on persons with spinal cord injury. *Journal of Neurologic Physical Therapy*, *29*, 204-205. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/18247233

Costa, T. F. D., Gomes, T. M., Viana, L. R. D. C., Martins, K. P., & Costa, K. N. D. F. M. (2016). Stroke: Patient characteristics and quality of life of caregivers. *Revista Brasileira de Enfermagem*, *69*, 933-939. doi: 10.1590/0034-7167-2015-0064

Courtois, F., Alexander, M., & McLain, A. B. (2017). Women's sexual health and reproductive function after SCI. *Topics in Spinal Cord Injury Rehabilitation*, *23*, 20-30. doi:10.1310/sci2301-20

Craig Hospital. (2015). *Therapeutic massage*. Retrieved from https://docplayer.net/29611932-Therapeutic-massage-what-is-massage-what-are-the-benefits-how-does-it-work.html

Crossman, M. W. (1996). Sensory deprivation in spinal cord injury-an essay. *Spinal Cord*, *34*, 573-577. doi:10.1038/sc.1996.102

Crowe, M., Whitehead, L., Jo Gagan, M., Baxter, D., & Panckhurst, A. (2010). Self-management and chronic low back pain: A qualitative study. *Journal of Advanced Nursing*, *66*, 1478-1486. doi:10.1111/j.1365-2648.2010.05316.x

Cruz-Almeida, Y., Felix, E. R., Martinez-Arizala, A., & Widerström-Noga, E. G. (2009). Pain symptom profiles in persons with spinal cord injury. *Pain Medicine*, *10*, 1246-1259. doi:10.1111/j.1526-4637.2009.00713.x

Cudeiro-Blanco, J., Onate-Figuérez, A., Soto-León, V., Avendano-Coy, J., Mordillo-Mateos, L., Brocalero-Camacho, A., ...Oliviero, A. (2017). Prevalence of fatigue and associated factors in a spinal cord injury population: Data from an internet-based and face-to-face surveys. *Journal of Neurotrauma*, *34*, 2335-2341. doi:10.1089/neu.2016.4950.

Çulha, C., Ünsal-Delialioğlu, S., Egüz, P., Kulaklı, F., & Özel, S. (2017). Spasticity in patients with traumatic spinal cord injury: From the patients' and physicians' perspective. *Turkish Journal of Physical Medicine & Rehabilitation*, *63*, 23-30. doi:10.5606/tftrd.2017.08634

Cunningham, J. L., Craner, J. R., Evans, M. M., & Hooten, W. M. (2017). Benzodiazepine use in patients with chronic pain in an interdisciplinary pain rehabilitation program. *Journal of Pain Research*, *10*, 311-317. doi:10.2147/JPR.S123487

Dalebroux, A., Goldstein, T. R., & Winner, E. (2008). Short-term mood repair through art-making: Positive emotion is more effective than venting. *Motivation and Emotion*, *32*, 288-295. doi:10.1007/s11031-008-9105-1

D'Angelo, R., Morreale, A., Donadio, V., Boriani, S., Maraldi, N., Plazzi, G., & Liguori, R. (2013). Neuropathic pain following spinal cord injury: What we know about mechanisms, assessment and management. *European Review Medical Pharmacological Sciences*, *17*, 3257-3261. Retrieved from http://europepmc.org/abstract/med/24338470

Darragh, A. R., Sommerich, C. M., Lavender, S. A., Tanner, K. J., Vogel, K., & Campo, M. (2015). Musculoskeletal discomfort, physical demand, and caregiving activities in informal caregivers. *Journal of Applied Gerontology*, *34*, 734-760. doi:10.1177/0733464813496464

Das, S. (2019). *"What is Puja?"* Learn Religions. Retrieved from https://www.learnreligions.com/what-is-puja-1770067

Davidson, J. W., & Garrido, S. (2015). Singing and psychological needs. *Oxford Handbook of Singing.* Abstract retrieved from https://researchdirect.westernsydney.edu.au/islandora/object/uws:33986

Dehghan, M., & Farahbod, F. (2014). The efficacy of thermotherapy and cryotherapy on pain relief in patients with acute low back pain, a clinical trial study. *Journal of Clinical and Diagnostic Research*, *8,* 1-4. doi:10.7860/JCDR/2014/7404.4818

dela Cruz, A. M., Bernstein, I. H., Greer, T. L., Walker, R., Rethorst, C. D., Grannemann, B., ...Trivedi, M. H. (2014). Self-rated measure of pain frequency, intensity, and burden: Psychometric properties of a new instrument for the assessment of pain. *Journal of Psychiatric Research, 59,* 155-160. doi:https://doi.org/10.1016/j.jpsychires.2014.08.003

den Braber-Ymker, M., Lammens, M., van Putten, M. J., & Nagtegaal, I. D. (2017). The enteric nervous system and the musculature of the colon are altered in patients with spina bifida and spinal cord injury. *Virchows Archive, 470,* 175-184. doi:10.1007/s00428-016-2060-4

Deshpande, A., Furlan, A. D., Mailis-Gagnon, A., Atlas, S., & Turk, D. (2007). Opioids for chronic low-back pain. *Cochrane Database of Systematic Reviews*, *3,* 1-25. doi:10.1002/14651858.CD004959.pub3

DiPiro, N. D., Li, C., & Krause, J. S. (2018). A longitudinal study of self-reported spasticity among individuals with chronic spinal cord injury. *Spinal Cord*, *56,* 218-225. doi:10.1038/s41393-017-0031-5

Dodd, M., Janson, S., Facione, N., Faucett, J., Froelicher, E. S., Humphreys, J., ...Taylor, D. (2001). Advancing the science of symptom management. *Journal of Advanced Nursing*, *33,* 668-676. doi:10.1046/j.1365-2648.2001.01697.x

Driver, S., Warren, A. M., Reynolds, M., Agtarap, S., Hamilton, R., Trost, Z., & Monden, K. (2016). Identifying predictors of resilience at inpatient and 3-month post-spinal cord injury. *The Journal of Spinal Cord Medicine*, *39,* 77-84. doi:10.1179/2045772314Y.0000000270

Dudley-Javoroski, S., & Shields, R. K. (2006). Assessment of physical function and secondary complications after complete spinal cord injury. *Disability and Rehabilitation*, *28*, 103-110. doi:10.1080/09638280500163828

Ducharme & D. Parashar (2015). Psychosocial management. In Chhabra H. S (Ed.), *ISCoS textbook on Comprehensive Management of Spinal Cord Injuries* (pp. 667-720). Haryana, India: Wolter Kluwer.

Dugan, D. O. (1989). Laughter and tears: Best medicine for stress. *Nursing Forum, 24,* 18-26. Abstract retrieved from https://onlinelibrary.wiley.com /doi/abs/10.1111/j.1744-6198.1989.tb00814.x?sid=nlm%3Apubmed

Dworkin, R. H., Turk, D. C., Trudeau, J. J., Benson, C., Biondi, D. M., Katz, N. P., & Kim, M. (2015). Validation of the Short-form McGill Pain Questionnaire-2 (SF-MPQ-2) in acute low back pain. *The Journal of Pain*, *16*, 357-366 doi:10.1016/j.jpain.2015.01.012

Ebrahimzadeh, M. H., Shojaei, B. S., Golhasani-Keshtan, F., Soltani-Moghaddas, S. H., Fattahi, A. S., & Mazloumi, S. M. (2013). Quality of life and the related factors in spouses of veterans with chronic spinal cord injury. *Health and quality of life outcomes*, *11,* 1-6. Retrieved from http://www.hqlo.com / content/11/1/48

Ebrahimzadeh, M. H., Soltani-Moghaddas, S. H., Birjandinejad, A., Omidi-Kashani, F., & Bozorgnia, S. (2014). Quality of life among veterans with chronic spinal cord injury and related variables. *Archives of Trauma Research*, *3*, 1-6. doi:10.5812/atr.17917

Elbasiouny, S. M., Moroz, D., Bakr, M. M., & Mushahwar, V. K. (2010). Management of spasticity after spinal cord injury: Current techniques and future directions. *Neurorehabilitation and Neural Repair*, *24*, 23-33. doi:10.1177/1545968309343213

Elfstrom, M., Rydén, A., Kreuter, M., Taft, C., & Sullivan, M. (2005). Relations between coping strategies and health-related quality of life in patients with spinal cord lesion. *Journal of Rehabilitation Medicine*, *37*, 9-16. doi:10.1080/ 1650 1970410034414

Elliott, S., & McBride, K. (2014). Sexual and reproductive health following spinal cord injury. *Spinal Cord Injury Rehabilitation Evidence, Version*, *5*, 44-84. Retrieved from https://scireproject.com/wp-content/uploads/SCIRE-Sexual-Health-Version-6-chapter_Nov.23.18-v.FINAL-1.pdf

Elliott, T. R., Brossart, D., Berry, J. W., & Fine, P. R. (2008). Problem-solving training via videoconferencing for family caregivers of persons with spinal cord injuries: A randomized controlled trial. *Behaviour Research and Therapy*, *46*, 1220-1229. doi:10.1016/j.brat.2008.08.004

El-Soud, A. M. A., El-Najjar, A. R., El-Fattah, N. A., & Hassan, A. A. (2014). Prevalence of low back pain in working nurses in Zagazig University Hospitals: An epidemiological study. *Egyptian Rheumatology and Rehabilitation*, *41*, 109-115. doi:10.4103/1110-161X.140525

Ertzgaard, P., Nene, A., Kiekens, C., & Burns, A. S. (2019). A review and evaluation of patient-reported outcome measures for spasticity in persons with spinal cord damage: Recommendations from the ability network–an international initiative. *The Journal of Spinal Cord Medicine, 13,* 1-11. doi:10.1080/107 90268.2019.1575533

Fann, J. R., Bombardier, C. H., Richards, J. S., Tate, D. G., Wilson, C. S., Temkin, N., & PRISMS Investigators. (2011). Depression after spinal cord injury: comorbidities, mental health service use, and adequacy of treatment. *Archives of Physical Medicine and Rehabilitation*, *92*, 352-360. doi:10.1016/j. apmr.2010.05.016

Farrar, J. T., Troxel, A. B., Stott, C., Duncombe, P., & Jensen, M. P. (2008). Validity, reliability, and clinical importance of change in a 0-10 numeric rating scale measure of spasticity: A post hoc analysis of a randomized, double-blind, placebo-controlled trial. *Clinical Therapeutic*, *30*, 974-985. doi:10.1016/j. clinthera.2008.05.011

Fauth, E., Hess, K., Piercy, K., Norton, M., Corcoran, C., Rabins, P., ...Tschanz, J. (2012). Caregivers' relationship closeness with the person with dementia predicts both positive and negative outcomes for caregivers' physical health and psychological well-being. *Aging & Mental Health*, *16*, 699-711. doi:10.1080/13607863.2012.678482

Field, T., Diego, M., & Hernandez-Reif, M. (2007). Massage therapy research. *Developmental Review*, *27*, 75-89. doi:10.1016/ j.dr. 2005.12.002

Finnerup, N. B., & Baastrup, C. (2012). Spinal cord injury pain: Mechanisms and management. *Current Pain and Headache Reports, 16*, 207-216. doi:10.1007/s11916-012-0259-x

Fletcher, B. A. S., Dodd, M. J., Schumacher, K. L., & Christine Miaskowski, R. N. (2008). Symptom experience of family caregivers of patients with cancer. *Oncology Nursing Forum, 35*, E22-E44. doi:10.1188/08.ONF.E23-E44

Fogelberg, D. J., Hughes, A. J., Vitiello, M. V., Hoffman, J. M., & Amtmann, D. (2016). Comparison of sleep problems in individuals with spinal cord injury and multiple sclerosis. *Journal of Clinical Sleep Medicine*, *12*, 695-701. doi:10.5664/jcsm.5798

Fogelberg, D. J., Leland, N. E., Blanchard, J., Rich, T. J., & Clark, F. A. (2017). Qualitative experience of sleep in individuals with spinal cord injury. *OTJR: Occupation, Participation and Health*, *37*, 89–97. doi:10.1177/1539449 217691978

Forchheimer, M., McAweeney, M., & Tate, D. G. (2004). Use of the SF-36 among persons with spinal cord injury. *American Journal of Physical Medicine & Rehabilitation*, *83*, 390-395. Retrieved from https://www.ncbi.nlm. nih.gov/pubmed/15100631

Franca, I. S. X. D., Coura, A. S., França, E. G. D., Basílio, N. N. V., & Souto, R. Q. (2011). Quality of life of adults with spinal cord injury: A study using the WHOQOL-bref. *Revista da Escola de Enfermagem da USP*, *45*, 1364-1371. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/22241194

Frederick, D. (2018). Mitigating burden associated with informal caregiving. *Journal of Patient Experience*, *5*, 50-55. doi:10.1177/2374373517742499

Garha, M. (2016). Health care in Nepal: An observational perspective. *Journal of Nursing Education and Practice*, *7*, 114-117. doi:10.5430 /jnep.v7n1p114

Ginis, K. A. M., Latimer, A. E., Arbour-Nicitopoulos, K. P., Buchholz, A. C., Bray, S. R., Craven, B. C.,...Smith, K. (2010). Leisure time physical activity in a population-based sample of people with spinal cord injury part I: Demographic and injury-related correlates. *Archives of Physical Medicine and Rehabilitation*, *91*, 722-728. doi:10.1016/j.apmr.2009.12.027

Giri, S., Neupane, M., Pant, S., Timalsina, U., Koirala, S., Timalsina, S., & Sharma, S. (2013). Quality of life among people living with acquired immune deficiency syndrome receiving anti-retroviral therapy: A study from Nepal. *HIV/AIDS (Auckland, NZ), 5*, 277-282. doi:10.2147/HIV.S50726

Glennie, R. A., Batke, J., Fallah, N., Cheng, C. L., Rivers, C. S., Noonan, V. K., ...Street, J. T. (2017). Rural and urban living in persons with spinal cord injury and comparing environmental barriers, their health, and quality-of-life outcomes. *Journal of Neurotrauma*, *34*, 2877-2882. doi:10.1089/neu. 2016.4931

Glozman, J. M. (2004). Quality of life of caregivers. *Neuropsychology Review, 14,* 183-196. doi:10.1007/s11065-004-8158-5

Goosens, D., Dousse, M., Ventura, M., & Fattal, C. (2009). Chronic neuropathic pain in spinal cord injury patients: What is the impact of social and environmental factors on care management?” *Annals of Physical and Rehabilitation Medicine 52*, 173-179. doi:10.1016/j.rehab.2008.12.008

Gopal, V.V., Baburaj, P.T., Balakrishnan, P.K. (2017). Caregiver’s burden in rehabilitation of patients with neurological deficits following traumatic spinal cord injury. *The Journal of Spinal Surgery*, *4*, 9-13. doi:10.5005/jp-journals-10039-1117

Government of Nepal of Health. (2017). *County Profile*. Retrieved from http://www.mohp.gov.np/content/country-profile.

Gracanin, A., Bylsma, L. M., & Vingerhoets, A. J. (2014). Is crying a self-soothing behavior? *Frontiers in Psychology*, *5*, 502. doi:10.3389/fpsyg.2014.00502

Graham, L. A. (2013). Management of spasticity revisited. *Age and Ageing*, *42*, 435-441. doi:10.1093/ageing/aft064.

Gray, J. R., Groves, S. K., & Sutherland, S. (2017). Measurement concepts. In D. Ciper (Ed.), *The practice of nursing research* (pp. 363-391). Missouri, MO: Elsevier.

Guay, D. R. (2005). Pregabalin in neuropathic pain: A more “pharmaceutically elegant” gabapentin? *The American Journal of Geriatric Pharmacotherapy*, *3*, 274-287. doi:10.1016/j.amjopharm.2005.12.008

Guest, R., Perry, K. N., Tran, Y., Middleton, J., & Craig, A. (2014). A prospective study of the change in quality of life in adults with a newly acquired spinal cord injury. *International Journal of Physical Medicine and Rehabilitation*, *2*(222), 1-5. doi:10.4172/2329-9096.1000222

Guest, R., Tran, Y., Gopinath, B., Cameron, I. D., & Craig, A. (2018). Prevalence and psychometric screening for the detection of major depressive disorder and post-traumatic stress disorder in adults injured in a motor vehicle crash who are engaged in compensation. *BioMed Central Psychology*, *6*(4), 1-12. doi:10.1186/s40359-018-0216-5

Guilleminault, C., Davis, K., & Huynh, N. T. (2008). Prospective randomized study of patients with insomnia and mild sleep disordered breathing. *Sleep*, *31,* 1527-1533. doi:10.1093/sleep/31.11.1527

Gurcay, E., Bal, A., Eksioglu, E., & Cakci, A. (2010). Quality of life in patients with spinal cord injury. *International Journal of Rehabilitation Research*, *33,* 356-358. doi:10.1097/MRR.0b013e328338b034.

Hagen, E. M., & Rekand, T. (2015). Management of neuropathic pain associated with spinal cord injury. *Pain and Therapy*, *4*, 51-65. doi:10.1007/s40122-015-0033y

Halpern, R., Gillard, P., Graham, G. D., Varon, S. F., & Zorowitz, R. D. (2013). Adherence associated with oral medications in the treatment of spasticity. *Physical Medicine & Rehabilitation*, *5*, 747-756. doi:10.1016/j.pmrj. 2013.04.022

Hammell, K. W. (2007). Quality of life after spinal cord injury: A meta-synthesis of qualitative findings. *Spinal Cord*, *45*, 124-139. doi:10.1038/sj.sc.3101992

Hanley, M. A., Masedo, A., Jensen, M. P., Cardenas, D., & Turner, J. A. (2006). Pain interference in persons with spinal cord injury: Classification of mild, moderate, and severe pain. *The Journal of Pain*, *7*, 129-133. doi:10.1016/ j.jpain.2005.09.011

Harvey, L. A. (2016). Physiotherapy rehabilitation for people with spinal cord injuries. *Journal of Physiotherapy*, *62,* 4-11. doi:10.1016/j.jphys. 2015.11.004

Hawker, G. A., Mian, S., Kendzerska, T., & French, M. (2011). Measures of adult pain: Visual analog scale for pain (VAS pain), numeric rating scale for pain

(NRS pain), McGill pain questionnaire (MPQ), short-form McGill pain questionnaire (SF-MPQ), chronic pain grade scale (CPGS), short form-36 bodily pain scale (SF-36 BPS), and measure of intermittent and constant osteoarthritis pain (ICOAP). *Arthritis Care & Research*, *63,* S240-S252. doi:10.1002/acr.20543

Hays, R.D., Bjorner, J.B., Revicki, D.A., Spritzer, K.L., & Cella D. (2009). Development of physical and mental health summary scores from the patient-reported outcomes measurement information system (PROMIS) global items. *Quality of Life Research*, *18,* 873-880. doi:10.1007/s11136-009-9496-9

Hearn, J. H., Cotter, I., Fine, P., & A. Finlay, K. (2015). Living with chronic neuropathic pain after spinal cord injury: An interpretative phenomenological analysis of community experience. *Disability and Rehabilitation*, *37*, 2203-2211. doi:10.3109/09638288.2014.1002579

Hearn, J. H., & Finlay, K. A. (2018). Internet-delivered mindfulness for people with depression and chronic pain following spinal cord injury: A randomized, controlled feasibility trial. *Spinal Cord*, *56*, 750-761. doi:10.1038/s41393-018-0090-2

Henwood, P., & Ellis, J. A. (2004). Chronic neuropathic pain in spinal cord injury: The patient's perspective. *Pain Research and Management*, *9,* 39-45. doi: 10.1155/2004/863062

Henwood, P., Ellis, J., Logan, J., Dubouloz, C. J., & D'eon, J. (2012). Acceptance of chronic neuropathic pain in spinal cord injured persons: A qualitative approach. *Pain Management Nursing*, *13*, 215-222. doi:10.1016/j.pmn. 2010.05.005

Heutink, M., Post, M. W., Wollaars, M. M., & Van Asbeck, F. W. (2011). Chronic spinal cord injury pain: Pharmacological and non-pharmacological treatments and treatment effectiveness. *Disability and Rehabilitation*, *33,* 433-440. doi:10.3109/09638288.2010.498557

Hoffman, H. G., Chambers, G. T., Meyer III, W. J., Arceneaux, L. L., Russell, W. J., Seibel, E. J., ...Patterson, D. R. (2011). Virtual reality as an adjunctive non-pharmacologic analgesic for acute burn pain during medical procedures. *Annals of Behavioral Medicine*, *41*, 183-191. doi:10.1007/s12160-010-9248-7

Hou, S., & Rabchevsky, A. G. (2014). Autonomic consequences of spinal cord injury. *Comprehensive Physiology*, *4*, 1419-1453. doi:10.1002/cphy.c130045

Hsieh, J. T. C., Wolfe, D. L., Miller, W. C., & Curt, A. (2008). Spasticity outcome measures in spinal cord injury: Psychometric properties and clinical utility. *Spinal Cord*, *46*, 86-95. doi:10.1038/sj.sc.3102125

Huang, C. Y., Chen, W. K., Lu, C. Y., Tsai, C. C., Lai, H. L., Lin, H. Y., ...Chen, C. I. (2015). Mediating effects of social support and self-concept on depressive symptoms in adults with spinal cord injury. *Spinal Cord*, *53*, 413-416. doi:10.1038/sc.2014.158.

Huang, I. C. (2017). Employment outcomes following spinal cord injury in Taiwan. *International Journal of Rehabilitation Research*, *40*, 84-90. doi:10.1097/ MRR.0000000000000208

Humphreys J., Lee, K. A., Carrieri-Kohlman, V., Puntillo, K., Faucett, J., Janson, S., Aouizerat, B. & Donskey-Cuenco, D. (2008). Theory of symptom management. In M. J. Smith & P. R. Liehr (Eds.), *Middle Range Theory for Nursing* (pp.145-149). New York, NY: Springer.

Inoue, S., Taguchi, T., Yamashita, T., Nakamura, M., & Ushida, T. (2017). The prevalence and impact of chronic neuropathic pain on daily and social life: A nationwide study in a Japanese population. *European Journal of Pain*, *21*, 727-737. doi:10.1002/ejp.977

Inskip, J. A., Lucci, V. E. M., McGrath, M. S., Willms, R., & Claydon, V. E. (2018). A community perspective on bowel management and quality of life after spinal cord injury: The influence of autonomic dysreflexia. *Journal of Neurotrauma*, *35*, 1091-1105. doi:10.1089/neu.2017.5343

Jackson-Koku, G (2016). Beck depression Inventory. Questionnaire Review. *Occupational Medicine*. *66*, 174-175. doi:https://doi.org/10.1093/ occmed/kqv087

Jain, N. B., Sullivan, M., Kazis, L. E., Tun, C. G., & Garshick, E. (2007). Factors associated with health-related quality of life in chronic spinal cord injury. *American Journal of Physical Medicine & Rehabilitation/Association of Academic Physiatrists*, *86*, 387-396. doi:10.1097/PHM.0b013e31804a7d00

January, A. M., Zebracki, K., Chlan, K. M., & Vogel, L. C. (2015). Sleep, well-being, and psychological symptoms in adults with pediatric-onset spinal cord injury. *Rehabilitation Psychology*, *60,* 328-334. doi:10.1037/rep0000061

Jeong, A., & An, J. Y. (2017). The moderating role of social support on depression and anxiety for gastric cancer patients and their family caregivers. *PloS One*, *12*(12), 1-9. doi:10.1371/journal.pone.0189808

Jensen, M. P., Kuehn, C. M., Amtmann, D., & Cardenas, D. D. (2007). Symptom burden in persons with spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, *88*, 638-645. doi:10.1016/j.apmr.2007.02.002

Jensen, M. P., Widerström-Noga, E., Richards, J. S., Finnerup, N. B., Biering-Sorensen, F., & Cardenas, D. D. (2010). Reliability and validity of the International Spinal Cord Injury Basic Pain Data Set items as self-report measures. *Spinal Cord*, *48*, 230-238. doi:10.1038/sc.2009.112

Johnson, M. H. (2005). How does distraction work in the management of pain? *Current Pain and Headache Reports*, *9*, 90-95. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/15745617

Kang, E. N., Shin, H. I., & Kim, H. R. (2014). Factors that influence employment after spinal cord injury in South Korea. *Annals of Rehabilitation Medicine*, *38*, 38-45. doi:10.5535/arm.2014.38.1.38

Kang, M. G., Kim, C. H., Park, E., Huh, J. W., Yang, W. J., Nam, T. W., ...Jung, T. D. (2018). Effect of family caregiving on depression in the first 3 months after spinal cord injury. *Annals of Rehabilitation Medicine*, *42*(1), 130-136. doi:10.5535/arm.2018.42.1.130

Kang, Y., Ding, H., Zhou, H., Wei, Z., Liu, L., Pan, D., & Feng, S. (2018). Epidemiology of worldwide spinal cord injury: A literature review. *Journal of Neurorestoratology*, *6,* 1-9. doi: https://doi.org/10.2147/JN.S143236

Karlsson, A. K. (2006). Overview: Autonomic dysfunction in spinal cord injury: Clinical presentation of symptoms and signs. *Progress in Brain Research*, *152*, 1-8. doi:10.1016/S0079-6123(05)52034-X

Karsy, M., & Hawryluk, G. (2017). Pharmacologic management of acute spinal cord injury. *Neurosurgery Clinics of North America*, *28,* 49-62. doi:10.1016/j.nec. 2016.07.002.

Katalinic, O. M., Harvey, L. A., & Herbert, R. D. (2011). Effectiveness of stretch for the treatment and prevention of contractures in people with neurological conditions: A systematic review. *Physical Therapy*, *91*, 11-24. doi:10.2522/ptj.20100265

Kawi, J. (2014). Predictors of self-management for chronic low back pain. *Applied Nursing Research*, *27*, 206-212. doi:10.1016/j.apnr.2014.02.003

Keller, S., Bann, C. M., Dodd, S. L., Schein, J., Mendoza, T. R., & Cleeland, C. S. (2004). Validity of the brief pain inventory for use in documenting the outcomes of patients with noncancer pain. *The Clinical Journal of Pain*, *20*, 309-318. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/15322437

Kelly, E. H., Anderson, C. J., Garma, S. I., Russell, H. F., Klaas, S. J., Gorzkowski, J. A., & Vogel, L. C. (2011). Relationships between the psychological characteristics of youth with spinal cord injury and their primary caregivers. *Spinal Cord*, *49*, 200-205. doi:10.1038/sc.2010.78

Kelly, E., & Vogel, L. (2013). Overview of psychosocial health among youth with spinal cord injury. *Topics in Spinal Cord Injury Rehabilitation*, *19*, 129-141. doi:10.1310/sci1902-129

Kennedy, P., Duff, J., Evans, M., & Beedie, A. (2003). Coping effectiveness training reduces depression and anxiety following traumatic spinal cord injuries. *British Journal of Clinical Psychology*, *42*, 41-52. doi:10.1348/014466503 762842002

Khatry, P. K., & Eliade, M. (2013). The Nepalese traditional concepts of illness and treatment. In A. L. Palmisano (Ed.), *DADA Rivista di Anthropologia Post-globale*, (pp. 45-54). Retrieved from http://www.dadarivista.com/Archivio/2011DADAn1Dicembre2011.

Khalil, R. E., Gorgey, A. S., Janisko, M., Dolbow, D. R., Moore, J. R., & Gater, D. R. (2013). The role of nutrition in health status after spinal cord injury. *Aging and Disease*, *4*(1), 14. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/23423356

Khazaeipour, Z., Rezaei-Motlagh, F., Ahmadipour, E., Azarnia-Ghavam, M., Mirzababaei, A., Salimi, N., & Salehi-Nejad, A. (2017). Burden of care in primary caregivers of individuals with spinal cord injury in Iran: Its association with sociodemographic factors. *Spinal Cord, 55*, 595-600. doi:10.1038/sc.2016.195

Khazaeipour, Z., Taheri-Otaghsara, S. M., & Naghdi, M. (2015). Depression following spinal cord injury: Its relationship to demographic and socioeconomic indicators. *Topics in Spinal Cord Injury Rehabilitation*, *21,* 149-155. doi:10.1310/sci2102-149

Kim, D. (2017). Relationships between caregiving stress, depression, and self-esteem in family caregivers of adult with a disability. *Occupational Therapy International, 375,* 75-83. doi:/10.1016/j.jns.2017.11.018

Kim, H., Chang, M., Rose, K., & Kim, S. (2012). Predictors of caregiver burden in caregivers of individuals with dementia. *Journal of Advanced Nursing*, *68,* 846-855. doi:10.1111/j.1365-2648.2011.05787

Kim, K. Z., Shin, A., Lee, J., Myung, S. K., & Kim, J. (2012). The beneficial effect of leisure-time physical activity on bone mineral density in pre-and postmenopausal women. *Calcified Tissue International*, *91*, 178-185. doi:10.1007/s00223-012-9624-3

Kirshblum, S. C., Burns, S. P., Biering-Sorensen, F., Donovan, W., Graves, D. E., Jha, A., ...Schmidt-Read, M. (2011). International standards for neurological classification of spinal cord injury (revised 2011). *The Journal of Spinal Cord Medicine*, *34,* 535-546. doi:10.1179/204577211X13207446293695

Kivisild, A., Sabre, L., Tomberg, T., Ruus, T., Korv, J., Asser, T., & Linnamagi, U. (2014). Health-related quality of life in patients with traumatic spinal cord injury in Estonia. *Spinal Cord*, *52,* 570-575. doi:10.1038/sc.2014.47

Kljajić, D., Eminović, F., Dopsaj, M., Pavlović, D., Arsić, S., & Otašević, J. (2016). The impact of sports activities on quality of life of persons with a spinal cord injury. *Slovenian Journal of Public Health, 55,* 104-111. doi:10.1515/sjph-2016-0014

Knight, B. G., Fox, L. S., & Chou, C. P. (2000). Factor structure of the Burden Interview. *Journal of Clinical Geropsychology*, *6,* 249-258. doi:https://doi.org/10.1023/A:1009530711710

Koca, I., Ucar, M., Unal, A., Tutoglu, A., Boyaci, A., BulBul, F., ...Gur, A. (2014). Anxiety and depression level and related factors in patients with spinal cord injury. *Acta Medica Mediterranea*, *30*, 291-295.

Kozinoga, M., Majchrzycki, M., & Piotrowska, S. (2015). Low back pain in women before and after menopause. *Menopause Review*, *14*, 203-207. doi:10.5114/pm.2015.54347

Krassioukov, A., Cragg, J. J., West, C., Voss, C., & Krassioukov-Enns, D. (2015). The good, the bad and the ugly of catheterization practices among elite athletes with spinal cord injury: A global perspective. *Spinal Cord*, *53*, 78-82. doi:10.1038/sc.2014.208

Kreuter, M., Siösteen, A., Erkholm, B., Byström, U., & Brown, D. J. (2005). Health and quality of life of persons with spinal cord lesion in Australia and Sweden. *Spinal Cord*, *43*, 123-129. doi:10.1038/sj.sc.3101692

Kroenke, K., Spitzer, R. L., & Williams, J. B. (2001). The PHQ-9: Validity of a brief depression severity measure. *Journal of General Internal Medicine*, *16*, 606-613. doi:10.1046/j.1525-1497.2001.016009606.x

Kuijpers, T., van Middelkoop, M., Rubinstein, S. M., Ostelo, R. W. J. G., Verhagen, A., Koes, B. W., & Van Tulder, M. W. (2011). A systematic review on the effectiveness of pharmacological interventions for chronic non-specific low-back pain. *European Spine Journal*, *20*, 40-50. doi:10.1007/s00586-010-1541-4

Kumar, N., & Gupta, B. (2016). Effect of spinal cord injury on quality of life of affected soldiers in India: A cross-sectional study. *Asian Spine Journal*, *10*, 267-275. doi:10.4184/asj.2016.10.2.267

Kumamoto, K., & Arai, Y. (2004). Validation of ‘personal strain’ and ‘role strain’: Subscales of the short version of the Japanese version of the Zarit Burden Interview (J-ZBI_8). *Psychiatry and Clinical Neurosciences*, *58*, 606-610. doi:10.1111/j.1440-1819.2004.01310.x

Kunwar, R. M., Shrestha, K. P., & Bussmann, R. W. (2010). Traditional herbal medicine in Far-west Nepal: A pharmacological appraisal. *Journal of Ethnobiology and Ethnomedicine*, *6*(35), 1-18. doi:10.1186/1746-4269-6-35

Lapeyre, E., Kuks, J., & Meijler, W. J. (2010). Spasticity: Revisiting the role and the individual value of several pharmacological treatments. *Neuro Rehabilitation, 27*, 193-200. doi:10.3233/NRE-2010-0596

Lasebikan V. O. (2012). Validation of Yoruba Version of Family Burden Interview Schedule (Y-FBIS) on caregivers of schizophrenia patients. *International Scholarly Research Network Psychiatry, 2012*(165179), 1-8. doi:10.5402/ 2012/165179

Lawang, W., Horey, D. E., & Blackford, J. (2015). Family caregivers of adults with acquired physical disability: Thai case-control study. *International Journal of Nursing Practice, 21,* 70-77. Retrieved from https://onlinelibrary.wiley. com/doi/epdf/10.1111/ijn.12215

Leboeuf-Yde, C., Jensen, R. K., & Wedderkopp, N. (2015). Persistence of pain in patients with chronic low back pain reported via weekly automated text messages over one year. *BioMed Center Musculoskeletal Disorders, 16*(299), 1-6. doi:10.1186/s12891-015-0754-4

Le, J., & Dorstyn, D. (2016). Anxiety prevalence following spinal cord injury: A meta-analysis. *Spinal Cord*, *54*, 570-578. doi:10.1038/sc.2016.15.

Li, C. C., Lin, H. R., Tsai, M. D., & Tsay, S. L. (2017). Neuropathic pain experiences of spinal cord injury patients. *The Journal of Nursing Research.* Retrieved from https://insights.ovid.com/crossref?an=00134372-900000000-99861 &isFromRelatedArticle=Y

Lim, S.-W., Shiue, Y.-L., Ho, C.-H., Yu, S.-C., Kao, P.-H., Wang, J.-J., & Kuo, J.-R. (2017). Anxiety and depression in patients with traumatic spinal cord injury: A nationwide population-based cohort study. *PLoS ONE, 12*(1), 1-14. doi:10.1371/journal.pone.0169623

Lin, J. D., Lin, L. P., Su, S. F., Hsu, S. W., Chou, Y. C., Lin, F. G., ...Chu, C. M. (2014). The interference of low back pain on everyday functions of life in care workers for persons with intellectual, autistic, and associated multiple disabilities: The Brief Pain Inventory Short Form (BPI-SF) survey. *Research in Autism Spectrum Disorders*, *8*, 692-700. doi:10.1016/j.rasd.2014.03.011

Lin, M. R., Hwang, H. F., Chen, C. Y., & Chiu, W. T. (2007). Comparisons of the brief form of the World Health Organization Quality of Life and Short Form-

36 for persons with spinal cord injuries. *American Journal of Physical Medicine & Rehabilitation*, *86,* 104-113. doi:10.1097/01.phm.0000247780. 64373.0e

Löfgren, M., & Norrbrink, C. (2012). “But I know what works”-patients’ experience of spinal cord injury neuropathic pain management. *Disability and Rehabilitation*, *34,* 2139-2147. doi:10.3109/09638288. 2012.676146

Lowery, D., Fillingim, R. B., & Wright, R. A. (2003). Sex differences and incentive effects on perceptual and cardiovascular responses to cold pressor pain. *Psychosomatic Medicine, 65,* 284-291. doi:10.1097/01.PSY.00000 33127.11561.78

Lude, P., Kennedy, P., Elfström, M., & Ballert, C. (2014). Quality of life in and after spinal cord injury rehabilitation: A longitudinal multicenter study. *Topics in Spinal Cord Injury Rehabilitation*, *20*, 197-207. doi:10.1310/sci2003-197

Lundqvist, C., Siösteen, A., Sullivan, L., Blomstrand, C., Lind, B., & Sullivan, M. (1997). Spinal cord injuries: A shortened measure of function and mood. *Spinal Cord*, *35*, 17-21. doi:10.1038/sj.sc.310034

Lynch, J., & Cahalan, R. (2017). The impact of spinal cord injury on the quality of life of primary family caregivers: A literature review. *Spinal Cord*, *55,* 964-978. doi:10.1038/sc.2017.56

Mahoney, J. S., Engebretson, J. C., Cook, K. F., Hart, K. A., Robinson-Whelen, S., & Sherwood, A. M. (2007). Spasticity experience domains in persons with spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, *88*, 287-294. doi:10.1016/j.apmr.2006.12.029

Ma, H. P., Lu, H. J., Xiong, X. Y., Yao, J. Y., & Yang, Z. (2014). The investigation of care burden and coping style in caregivers of spinal cord injury patients. *International Journal of Nursing Sciences*, *1*, 185-190. doi:10.1016/j.ijnss.2014.05.010

Malhotra, M., & Thapa, K. (2015). Religion and coping with caregiving stress. *International Journal of Multidisciplinary and Current Research*, *3,* 613-619. Retrieved from http://ijmcr.com

Mannion, A. F., Balagué, F., Pellisé, F., & Cedraschi, C. (2007). Pain measurement in patients with low back pain. *Nature Reviews Rheumatology*, *3*, 610-618. doi:10.1038/ncprheum0646

Mathur, N., Jain, S., Kumar, N., Srivastava, A., Purohit, N., & Patni, A. (2015). Spinal cord injury: Scenario in an Indian state. *Spinal Cord*, *53*, 349-352. doi:10.1038/sc.2014.153

McAdam, J. L., Dracup, K. A., White, D. B., Fontaine, D. K., & Puntillo, K. A. (2010). Symptom experiences of family members of intensive care unit patients at high risk for dying. *Critical Care Medicine*, *38*, 1078-1085. doi:10.1097/CCM. 0b013e3181cf6d94

McCoy, A. D. (2016). *An exploration of the lived experiences of the caregiving role and life satisfaction in caregivers following traumatic spinal cord injury* (Doctoral dissertation). University of Nevada, Nevada, NV, united States of America

McKay, W. B., Sweatman, W. M., & Field-Fote, E. C. (2018). The experience of spasticity after spinal cord injury: Perceived characteristics and impact on daily life. *Spinal Cord*, *56*, 478-486. Retrieved from: https://www.nature.com/articles/s41393-017-0038-y.pdf

Mehta, S., McIntyre, A., Janzen, S., Loh, E., Teasell, R., & Team, S. C. I. R. E. (2016). Systematic review of pharmacologic treatments of pain after spinal cord injury: an update. *Archives of Physical Medicine and Rehabilitation*, *97*, 1381-1391. doi:10.1016/j.apmr.2015.12.023

Mills, P. B., Vakil, A. P., Phillips, C., Kei, L., & Kwon, B. K. (2018). Intra-rater and inter-rater reliability of the Penn Spasm Frequency Scale in People with chronic traumatic spinal cord injury. *Spinal Cord*, *56*, 569-574. doi:10.1038/s41393-018-0063-5

Mishra, S. R., Khanal, P., Karki, D. K., Kallestrup, P., & Enemark, U. (2015). National health insurance policy in Nepal: Challenges for Implementation. *Global Health Action*, *8*(28763), 1-3. doi:10.3402/gha.v8.28763

Mitchell, M. C., Burns, N. R., & Dorstyn, D. S. (2008). Screening for depression and anxiety in spinal cord injury with DASS-21. *Spinal Cord*, *46*, 547-551. doi:10.1038/sj.sc.3102154

Modirian, E., Pirouzi, P., Soroush, M., Karbalaei-Esmaeili, S., Shojaei, H., & Zamani, H. (2010). Chronic pain after spinal cord injury: Results of a long-term study. *Pain Medicine*, *11*, 1037-1043. doi:10.1111/j.1526-4637.2010.00865

Mohamed, N. M. A. (2012). Low back pain: Frequency, severity of, and influencing factors in nurses working in surgical care units. *Asian Academy of Management Journal*, *10,* 380-395. Retrieved from http://www.aamj.eg.net/ journals/pdf/2112.pdf

Molazem, Z., & Vagharseyyedin, S. A. (2013). Burden, resilience and happiness in family caregivers of spinal cord injured patients. *Middle East Journal of Psychiatry and Alzheimers,* 84(406), 1-7. doi:10.5742/MEJPA.2013.41181

Molton, I. R., Stoelb, B. L., Jensen, M. P., Ehde, D. M., Raichle, K. A., & Cardenas, D. D. (2009). Psychosocial factors and adjustment to chronic pain in spinal cord injury: Replication and cross-validation. *Journal of Rehabilitation Research and Development*, *46*, 31-42. Retrieved from https://www.ncbi. nlm.nih.gov/pubmed/19533518

Moreno, A., Zidarov, D., Raju, C., Boruff, J., & Ahmed, S. (2017). Integrating the perspectives of individuals with spinal cord injuries, their family caregivers and healthcare professionals from the time of rehabilitation admission to community reintegration: protocol for a scoping study on SCI needs. *British Medical Journal Open*, *7*(8), 1-9. doi:10.1136/bmjopen-2016-014331

Morgan, B. D. (2014). Nursing attitudes toward patients with substance use disorders in pain. *Pain Management Nursing*, *15*, 165-175. doi: 10.1016 /j.pmn.2012. 08.004

Moriarty, H., Winter, L., Robinson, K., Piersol, C. V., Vause-Earland, T., Iacovone, D. B., ...Gitlin, L. N. (2016). A randomized controlled trial to evaluate the veterans' in-home program for military veterans with traumatic brain injury and their families: Report on impact for family members. *Physical and Rehabilitation Medicine, 8,* 495-509. doi: https://doi.org/10.1016/ j.pmrj.2015.10.008

Moussa, M. M. M., El-Ezaby, H. H., & El-Mowafy, R. I. (2015). Low back pain and coping strategies' among nurses in Port Said City, Egypt. *Journal of Nursing Education and Practice*, *5,* 55-62. doi:10.5430/ jnep. v5n7p55

Mousavi, V. A. (2017). Quality of life in patients with spinal cord injury: The role of depressed mood. *Iranian Journal of Neurosurgery, 2,* 9-14. doi:10.29252/ irjns.2.4.9

Müller, R., Brinkhof, M. W. G., Arnet, U., Hinrichs, T., Landmann, G., Jordan, X., & Bechir, M. (2017). Prevalence and associated factors of pain in the Swiss spinal cord injury population. *Spinal Cord, 55,* 346. Retrieved from https://www.nature.com/articles/3101116.pdf

Müller, R., Peter, C., Cieza, A., & Geyh, S. (2012). The role of social support and social skills in people with spinal cord injury: A systematic review of the literature. *Spinal Cord, 50,* 94-106. doi:10.1038/sc.2011.116

Munakomi, S., Bhattarai, B., & Cherian, I. (2017). Prospective observational research on the clinical profile and outcome analysis among a cohort of patients sustaining traumatic cervical spine and cord injury in a peripheral tertiary spine care centre in Nepal. *F1000Research*, *6*(1957), 1-16. doi:10.12688/ f1000research.12911.1

Munce, S. E., Webster, F., Fehlings, M. G., Straus, S. E., Jang, E., & Jaglal, S. B. (2016). Meaning of self-management from the perspective of individuals with traumatic spinal cord injury, their caregivers, and acute care and rehabilitation managers: An opportunity for improved care delivery. *BioMed Center Neurology*, *16*(11), 1-9. doi:10.1186/s12883-016-0534-2.

Murphy, G. C., Middleton, J., Quirk, R., De Wolf, A., & Cameron, I. D. (2011). Predicting employment status at 2 years' postdischarge from spinal cord injury rehabilitation. *Rehabilitation Psychology, 56,* 251-256. doi:10.1037/ a0024524

Muscat, M., & Scerri, C. (2018). Coping with anxiety, depression, burden and quality of life in informal primary caregivers of community-dwelling individuals with dementia. *The Journal Aging Research and Clinical Practice, 7*, 128-135. doi:10.14283/jarcp.2018.22

Nagoshi, N., Kaneko, S., Fujiyoshi, K., Takemitsu, M., Yagi, M., Iizuka, S., ...Asazuma, T. (2016). Characteristics of neuropathic pain and its relationship with quality of life in 72 patients with spinal cord injury. *Spinal Cord*, *54*, 656-661. doi:10.1038/sc.2015.210

Nakipoglu-Yuzer, G. F., Atci, N., & Ozgirgin, N. (2013). Neuropathic pain in spinal cord injury. *Pain Physician, 16*, 259-264. Retrieved from https://www.painphysicianjournal.com/

National Spinal Cord Injury Statistical Center. (2018). *Facts and figures at a glance.* Retrieved from https://www.nscisc.uab.edu/Public/Facts%20and%20Figures%20-%202018.pdf

Nepal Rastra Bank. (2015). *Fifth household budget survey*. Retrieved from https://www.nrb.org.np/red/publications/study_reports/Study_Reports--Fifth_Household_Budget_Survey_2014-2015.pdf

Netto, N.R., Jenny, G.Y.N., Philip, Y.L.K. (2009). Growing and gaining through caring for a loved one with dementia. *Dementia, 8*, 245–261. doi: https://doi.org/10.1177/1471301209103269

Nightingale, C. L., Curbow, B. A., Wingard, J. R., Pereira, D. B., & Carnaby, G. D. (2016). Burden, quality of life, and social support in caregivers of patients undergoing radiotherapy for head and neck cancer: A pilot study. *Chronic Illness*, *12*, 236-245. doi:10.1177/1742395316644305

Ning, G. Z., Wu, Q., Li, Y. L., & Feng, S. Q. (2012). Epidemiology of traumatic spinal cord injury in Asia: A systematic review. *The Journal of Spinal Cord Medicine*, *35*, 229-239. doi:10.1179/2045772312Y.0000000021

Nogueira, P. C., Rabeh, S. A. N., Caliri, M. H. L., & Dantas, R. A. S. (2016). Health-related quality of life among caregivers of individuals with spinal cord injury. *Journal of Neuroscience Nursing*, *48*, 28-34. doi:10.1097/JNN.0000000 000000177

Nogueira, P. C., Rabeh, S. A. N., Caliri, M. H. L., Dantas, R. A. S., & Haas, V. J. (2012). Burden of care and its impact on health-related quality of life of caregivers of individuals with spinal cord injury. *Revista Latino-Americana de Enfermagem*, *20*, 1048-1056. doi:10.1590/s0104-11692012000600006

Nooijen, C. F. J., Vogels, S., Bongers-Janssen, H. M. H., Bergen, M. P., Stam, H. J., Van Den Berg-emons, H. J. G., & Act-Active Research Group. (2015). Fatigue in persons with subacute spinal cord injury who are dependent on a manual wheelchair. *Spinal Cord*, *53*, 758-762. doi:10.1038/sc.2015.66

Norrbrink, C., Löfgren, M., Hunter, J., & Ellis, J. (2012). Patients' perspectives on pain. *Topics in Spinal Cord Injury Rehabilitation*, *18,* 50-56. doi:10.1310/sci1801-50

Norrbrink, C., & Lundeberg, T. (2011). Acupuncture and massage therapy for neuropathic pain following spinal cord injury: An exploratory study. *Acupuncture in Medicine*, *29,* 108-115. doi:10.1136/aim.2010.003269

Norrbrink, C., & Lundeberg, T. (2009). Tramadol in neuropathic pain after spinal cord injury: a randomized, double-blind, placebo-controlled trial. *Clinical Journal of Pain. 25*, 177-85. doi:10.1097/AJP.0b013e31818a744d

Obata, H. (2017). Analgesic mechanism of antidepressants for neuropathic pain. *International Journal of Molecular Science*, *18*(11), 1-12. doi:10.3390/ijms18112483

Oei, T. P., Sawang, S., Goh, Y. W., & Mukhtar, F. (2013). Using the depression anxiety stress scale 21 (DASS-21) across cultures. *International Journal of Psychology*, *48,* 1018-1029. doi:10.1080/00207594.2012.755535

Ogunlana, M. O., Dada, O. O., Oyewo, O. S., Odole, A. C., & Ogunsan, M. O. (2014). Quality of life and burden of informal caregivers of stroke survivors. *Hong Kong Physiotherapy Journal*, *32*, 6-12. doi:10.1016 /j.hkpj.2013.11.003

Ostelo, R. W., & de Vet, H. C. (2005). Clinically important outcomes in low back pain. *Best Practice & Research Clinical Rheumatology*, *19,* 593-607. doi:10.1016/j.berh.2005.03.003

Osuala, E. O. (2014). Innovation in prevention and treatment of pressure ulcer: Nursing implication. *Tropical Journal of Medical Research*, *17,* 61-66. doi:10.4103/1119-0388.140411

Otaghsara, S. M. T., Matin, M., Latifi, S., & Norouzi, A. (2014). Depressive disorders and emotional status in caregivers of spinal cord injured individuals: A referral center report. *Archives of Neuroscience*, *1*(3), 1-8. doi:10.5812/archneurosci.16246

Ottomanelli, L., & Lind, L. (2009). Review of critical factors related to employment after spinal cord injury: Implications for research and vocational services. *The*

Journal of Spinal Cord Medicine, *32,* 503-531. Retrieved from https://www.ncbi.nlm.nih. gov /pmc/articles/PMC2792457/

Ozisler, Z., Koklu, K., Ozel, S., & Unsal-Delialioglu, S. (2015). Outcomes of bowel program in spinal cord injury patients with neurogenic bowel dysfunction. *Neural Regeneration Research*, *10,* 1153-1158. doi:10.4103/1673-5374.160112

Pajeemas, K., Patpiya,S., Preeda, A., & Siriwan, S.N. (2018). Factor associated with low back pain in non-professional caregivers of dependent spinal cord lesion patients. *International Journal of Caring Sciences, 11*, 471-477. Retrieved from http://www.internationaljournalofcaringsciences.org/docs/55_patpiya_original_11_1.pdf

Paris, G., Gourcerol, G., & Leroi, A. M. (2011). Management of neurogenic bowel dysfunction. *European Journal of Physical and Rehabilitation Medicine*, *47,* 661-676. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed22222963

Pearce, M.J., Medoff, D., Lawrence, R.E., & Dixon, L. (2016). Religious coping among adults caring for family member with serious mental illness. *Community Mental Health Journal*, *52,* 194-202. doi:10.1007/s10597-015-9875-3

Pensri Rukwong, M. N. S. (2007). Quality of life perceptions of middle-aged women living with a disability in Muang District, Khon Kaen, Thailand: WHOQOL perspective. *Journal of Medical Association of Thailand*, *90,* 1640-1646. Retrieved from http://www.medassocthai.org/journal

Petry, N. M. (2002). A comparison of young, middle-aged, and older adult treatment-seeking pathological gamblers. *The Gerontologist*, *42,* 92-99. doi: 10. 1093/ geront/42.1.92

Polit, F. D., & Beck, T. C. (2012). Conceptualizing and planning a study to generate evidence for nursing. *Nursing Research* (9th ed.). Philadelphia, PHL: Wolters Kluwer.

Post, M. (2014). Definitions of quality of life: what has happened and how to move on. *Topics in Spinal Cord Injury Rehabilitation*, *20*, 167-180. doi:10.1310/ sci2003-167

Post, M. W. M., & Van Leeuwen, C. M. C. (2012). Psychosocial issues in spinal cord injury: A review. *Spinal Cord*, *50*, 382-389. doi:10.1038/sc.2011.182

Priebe, M. M., Sherwood, A. M., Thornby, J. I., Kharas, N. F., & Markowski, J. (1996). Clinical assessment of spasticity in spinal cord injury: A multidimensional problem. *Archives of Physical Medicine and Rehabilitation*, *77*, 713-716. doi: 10.1016/S0003-9993(96)90014-3

Rabchevsky, A. G., & Kitzman, P. H. (2011). Latest approaches for the treatment of spasticity and autonomic dysreflexia in chronic spinal cord injury. *Neurotherapeutics*, *8*, 274-282. doi:10.1007/s13311-011-0025-5

Rajabi-Mashhadi, M. T., Mashhadinejad, H., Ebrahimzadeh, M. H., Golhasani-Keshtan, F., Ebrahimi, H., & Zarei, Z. (2015). The Zarit Caregiver Burden Interview Short Form (ZBI-12) in spouses of veterans with chronic spinal cord injury, validity and reliability of the Persian version. *Archives of Bone and Joint Surgery*, *3*, 56-63. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/25692171

Rahimi-Movaghar, V, Sayyah, M. K., Akbari, H., Khorramirouz, R., Rasouli, M. R., Moradi-Lakeh, M., ...Vaccaro, A. R. (2013). Epidemiology of traumatic spinal cord injury in developing countries: A systematic review. *Neuroepidemiology*, *41*, 65-85. doi:10.1159/000350710

Ranabhat, C. L., Kim, C. B., Kim, C. S., Jha, N., Deepak, K. C., & Connel, F. A. (2015). Consequence of indoor air pollution in rural area of Nepal: A simplified measurement approach. *Frontiers in Public Health*, *3*, 1-6. doi:10.3389/fpubh.2015.00005

Rapson, L. M., Wells, N., Pepper, J., Majid, N., & Boon, H. (2003). Acupuncture as a promising treatment for below-level central neuropathic pain: A retrospective study. *The Journal of Spinal Cord Medicine*, *26*, 21-26. doi:10.1080/10790268.2003.11753655

Rathore, M. F. A. (2013). Spinal cord injuries in the developing world. *International Encyclopedia of Rehabilitation*. Retrieved from https://www.researchgate.net/publication/51997860

Rekand, T., Hagen, E. M., & Grønning, M. (2012). Chronic pain following spinal cord injury. *Tidsskrift for den Norske laegeforening: tidsskrift for praktisk medicin, ny raekke, 132,* 974-979. doi:10.4045/tidsskr.11.0794

Ren, H., Yu, Y., Hu, J. Y., Shi, Y., Lu, Y. H., & Meng, W. (2014). Caregiver burden and its determinants among family members of patients with chronic viral hepatitis in Shanghai, China: A community-based survey. *BMC infectious diseases*, *14*(82), 1-10. doi:10.1186/1471-2334-14-82

Richard-Denis, A., Thompson, C., & Mac-Thiong, J. M. (2018). Quality of life in the subacute period following a cervical traumatic spinal cord injury based on the initial severity of the injury: A prospective cohort study. *Spinal Cord, 56,* 1042-1050. doi:10.1038/s41393-018-0178-8

Richard, H. L. (2013). Counting Hinduism. *Journal of Adventist Mission Studies, 9,* 1-13. Retrieved from https://digitalcommons.andrews.edu/cgi/viewcontent. cgi?article =1221&context=jams

Ridic, G., Gleason, S., Ridic, O. (2012). Comparison of health care systems in the United States, Germany and Canada. *Journal of Academy of Medical Sciences of Bosnia Herzegovina, 24*, 112-120. doi:105455/msm.2012.24.112-120

Robinson, J., Fortinsky, R., Kleppinger, A., Shugrue, N., & Porter, M. (2009). A broader view of family caregiving: Effects of caregiving and caregiver conditions on depressive symptoms, health, work, and social isolation. *The Journals of Gerontology, 64*, 788-798. doi:10.1093/geronb/gbp015

Roche, V., & Palmer, B. F. (2009). The hidden patient: addressing the caregiver. *The American Journal of the Medical Sciences*, *337*, 199-204. doi:10.1097/MAJ.0b013e31818b114d

Rodakowski, J., Skidmore, E. R., Rogers, J. C., & Schulz, R. (2013). Does social support impact depression in caregivers of adults ageing with spinal cord injuries? *Clinical Rehabilitation, 27,* 565-575. doi:10.1177/0269 2155 12464503.

Rubinstein, S. M., van Middelkoop, M., Assendelft, W. J., de Boer, M. R., & van Tulder, M. W. (2011). Spinal manipulative therapy for chronic low-back pain. *Cochrane Database of Systematic Reviews, 2,* 9-32. doi:10.1002/ 14651 858.CD008112

Saadat, S., Javadi, M., Divshali, B. S., Tavakoli, A. H., Ghodsi, S. M., Montazeri, A., & Rahimi-Movaghar, V. (2010). Health-related quality of life among individuals with long-standing spinal cord injury: A comparative study of veterans and non-veterans. *BioMed Center Public Health*, *10*(1), 1-7. doi: 10.1186/1471-2458-10-6

Sabre, L., Remmer, S., Adams, A., Väli, M., Rekand, T., Asser, T., & Kõrv, J. (2015). Impact of fatal cases on the epidemiology of traumatic spinal cord injury in Estonia. *European Journal of Neurology*, *22*, 768-772. doi:10.1111/ene.12478

Sadosky, A., Parsons, B., Emir, B., & Nieshoff, E. C. (2016). Pain relief and functional improvement in patients with neuropathic pain associated with spinal cord injury: An exploratory analysis of pregabalin clinical trials. *Journal of Pain Research*, *9*, 405-416. doi:10.2147/JPR.S97770

Sakakibara, B. M., Miller, W. C., Orenczuk, S. G., & Wolfe, D. L. (2009). A systematic review of depression and anxiety measures used with individuals with spinal cord injury. *Spinal Cord*, *47*, 841-856. doi:10.1038/sc.2009.93.

Saltychev, M., Vastamäki, H., Mattie, R., McCormick, Z., Vastamäki, M., & Laimi, K. (2016). Psychometric properties of the pain numeric rating scale when applied to multiple body regions among professional musicians. *PloS One*, *11*(9), 1-9. doi:10.1371/journal.pone.0161874

Saurí, J., Chamarro, A., Gilabert, A., Gifre, M., Rodriguez, N., Lopez-Blazquez, R., ...Soler, D. (2017). Depression in individuals with traumatic and nontraumatic spinal cord injury living in the community. *Archives of Physical Medicine and Rehabilitation*, *98*, 1165-1173. doi:10.1016/j.apmr.2016.11.011

Scovil, C. Y., Ranabhat, M. K., Craighead, I. B., & Wee, J. (2012). Follow-up study of spinal cord injured patients after discharge from inpatient rehabilitation in Nepal in 2007. *Spinal Cord*, *50*, 232-237. Retrieved from https://www.nature.com/articles/sc2011119

Searle, A., Calnan, M., Lewis, G., Campbell, J., Taylor, A., & Turner, K. (2011). Patients' views of physical activity as treatment for depression: A qualitative study. *British Journal of General Practice, 61,* e149-e156. Retrieved from https://bjgp.org/content/bjgp/61/585/e149.full.pdf

Secinti, E., Yavuz, H. M., & Selcuk, B. (2017). Feelings of burden among family caregivers of people with spinal cord injury in Turkey. *Spinal Cord*, *55*, 782-787. Retrieved from https://www.nature.com/articles/sc20176

Sezer, N., Akkuş, S., & Uğurlu, F. G. (2015). Chronic complications of spinal cord injury. *World Journal of Orthopedics*, *6*, 24-33. doi:10.5312/wjo.v6.i1.24

Shah, S. Z. A., Rafiullah, I. S., & Ilyas, S. M. (2017). Assessment of the quality of life of spinal cord injury patients in Peshawar. *Journal Pakistan Medical Association*, *67*, 434-437.

Shah, N., Shrestha, B., & Subba, K. (2013). Spinal cord injury rehabilitation in Nepal. *Journal of Nepal Medical Association, 52*, 421-437.

Sharma, N., Chakrabarti, S., & Grover, S. (2016). Gender differences in caregiving among family-caregivers of people with mental illnesses. *World Journal of Psychiatry*, *6*, 7-17. doi:10.5498/wjp.v6.i1.7

Shega, J. W., Dale, W., Andrew, M., Paice, J., Rockwood, K., & Weiner, D. K. (2012). Persistent pain and frailty: A case for homeostenosis. *Journal of the American Geriatrics Society*, *60*, 113-117.

Sherpa, P, Kitrungrote, L. & Sae-Sia, W. (2017). *Chronic low back pain experience, pain management strategies and quality of life among caregivers of physical disabilities in Nepal* (Master’s Thesis). Prince of Songkla University, Songkhla, Thailand.

Sherpa, P, Kitrungrote, L. & Sae-Sia, W. (2018). Predicting quality of life among family caregivers of people with spinal cord injury having chronic low back pain in Nepal: A cross-sectional pilot study. *Spinal Cord Series and Cases*, *4*(72), 1-6. doi:10.1038/s41394-018-0110-7

Shipton, E. A. (2018). Physical therapy approaches in the treatment of low back pain. *Pain and Therapy, 7*, 127-137. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/30229473

Shrestha, D. (2014). Traumatic spinal cord injury in Nepal. *Kathmandu University Medical Journal*, *12*, 161-162. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/25855104

Shrestha, P., Shrestha, S., & Shrestha, R. K. (2013). Retrospective study of spinal cord injury patients admitted to Spinal Injury Rehabilitation Centre, Sanga, Banepa, Nepal. *Nepal Medical College Journal*, *16*, 169-172. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/26930739

Siddall, P. J. (2009). Management of neuropathic pain following spinal cord injury: Now and in the future. *Spinal Cord*, *47*, 352-539. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/19002150

Siddall, P. J., McClelland, J. M., Rutkowski, S. B., & Cousins, M. J. (2003). A longitudinal study of the prevalence and characteristics of pain in the first 5 years following spinal cord injury. *Pain*, *103*, 249-257. doi:10.1016/S0304-3959(02)00452-9

Singchangchai, P., Khumpalikit, S. & Nasae, T. Nursing Research: Principle and process (2nd ed.). Prince of Songkla University, Songkhla, Thailand.

Singh, G., Newton, C., O'Sullivan, K., Soundy, A., & Heneghan, N. R. (2018). Exploring the lived experience and chronic low back pain beliefs of English-speaking Punjabi and white British people: A qualitative study within the NHS. *British Medical Journal Open*, *8*(2), 1-12. Retrieved from http://dx.doi.org/10.1136/bmjopen-2017-020108

Skevington, S. M., Lotfy, M., & O'Connell, K. A. (2004). The World Health Organization's WHOQOL-BREF quality of life assessment: Psychometric properties and results of the international field trial. A report from the WHOQOL group. *Quality of Life Research*, *13*, 299-310.

Smeltzer, S. C., Bare, B. G., Hinkle, J. L., & Cheever, K. H. (2010). *Brunner and Suddharth's textbook of medical-surgical nursing* (12th ed.). Philadelphia, PHL: Lippincott Williams & Wikins.

Smith, E. M., Imam, B., Miller, W. C., Silverberg, N. D., Anton, H. A., Forwell, S. J., & Townson, A. F. (2016). The relationship between fatigue and participation in spinal cord injury. *Spinal Cord*, *54*, 457-462.

Smith, M. J., & Liehr, P. R. (Eds.). (2018). *Middle range theory for nursing*. New York, NY: Springer.

Soler, M. D., Moriña, D., Rodríguez, N., Saurí, J., Vidal, J., Navarro, A., & Navarro, X. (2017). Sensory symptom profiles of patients with neuropathic pain after spinal cord injury. *The Clinical Journal of Pain*, *33*, 827-834. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/27977425

Spitzer, R. L., Kroenke, K., Williams, J. B., & Patient Health Questionnaire Primary Care Study Group. (1999). Validation and utility of a self-report version of PRIME-MD: The PHQ primary care study. *Journal of American Medical Association*, *282*, 1737-1744. doi:10.1001/jama.282.18.1737

Steadman, P.L., Tremont, G., & Davis, J.D. (2007). Premorbid relationship satisfaction and caregiver burden in dementia caregivers. *Journal of Geriatric Psychiatry and Neurology, 20*, 115-119.

Stevens, L. F., Lehan, T., Durán, M. A. S., Plaza, S. L. O., & Arango-Lasprilla, J. C. (2016). Pilot study of a newly developed intervention for families facing serious injury. *Topics in Spinal Cord Injury Rehabilitation*, *22,* 49-59. doi:10.1310/sci2201-49

Stillman, M. D., Barber, J., Burns, S., Williams, S., & Hoffman, J. M. (2017). Complications of spinal cord injury over the first year after discharge from inpatient rehabilitation. *Archives of Physical Medicine and Rehabilitation 98,* 1800-1805. doi:10.1016/j.apmr.2016.12.011

Strauss, D. J., DeVivo, M. J., Paculdo, D. R., & Shavelle, R. M. (2006). Trends in life expectancy after spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, *87*, 1079-1085.

Su, C. A., Kusin, D. J., Li, S. Q., Ahn, U. M., & Ahn, N. U. (2018). The association between body mass index and the prevalence, severity, and frequency of low back pain: Data from the Osteoarthritis Initiative. *Spine*, *43*, 848-852.

Suzuki, K., Tamakoshi, K., & Sakakibara, H. (2016). Caregiving activities closely associated with the development of low-back pain among female family caregivers. *Journal of Clinical Nursing*, *25,* 2156-2167. doi:10.1111/ jocn.13167

Thapa, S., Kitrungrote, L., & Damkliang, J. (2017). *Chronic pain experience, pain management strategies, and quality of life in persons with spinal cord injury in Nepal* (Master’s Thesis). Prince of Songkla University, Songkhla, Thailand.

Thapa, S., Kitrungrote, L., & Damkliang, J. (2018). Chronic pain experience and pain management in persons with spinal cord injury in Nepal. *Scandinavian Journal of Pain*, *18,* 195-201. doi:10.1515/sjpain-2018-0019

The University of British Columbia. (n.d.). Spinal cord injury collaboration/Nepal. Retrieved from http://spinepal.orthopaedics.med.ubc.ca/.

Tong, H. C., Haig, A. J., Nelson, V. S., Yamakawa, K. S. J., Kandala, G., & Shin, K. Y. (2003). Low back pain in adult female caregivers of children with physical disabilities. *Archives of pediatrics & adolescent medicine*, *157*, 1128-1133. doi:10.1001/archpedi.157.11.1128

Torossian, C.L., Ruffins, S. (1999). Relationship between family dynamics of caregivers, depression, and the likelihood of institutionalization of Alzheimer's patients. *Journal of Contemporary Psychotherapy*, 29, 127-142.

Trapp, S. K., Leibach, G. G., Perrin, P. B., Morlett, A., Olivera, S. L., Perdomo, J. L., ... Arango-Lasprilla, J. C. (2015). Spinal Cord Injury Functional Impairment and Caregiver Mental Health in a Colombian sample: An exploratory study. *Psicología desde el Caribe*, *32*, 380-392. doi:10.14482 /psdc.32.3.6593

Treede, R. D., Rief, W., Barke, A., Aziz, Q., Bennett, M. I., Benoliel, R., ... Giamberardino, M. A. (2015). A classification of chronic pain for ICD-11. *Pain*, *156*, 1003. doi:10.1097/j.pain.00000000 00000160

Trgovcevic, S., Milicevic, M., Nedovic, G., & Jovanic, G. (2014). Health condition and quality of life in persons with spinal cord injury. *Iranian Journal of Public Health*, *43*, 1229-1238. Retrieved from https://www.ncbi.nlm.nih.gov/ pubmed /26175977

Turner, J. A., Cardenas, D. D., Warms, C. A., & McClellan, C. B. (2001). Chronic pain associated with spinal cord injuries: A community survey. *Archives of Physical Medicine and Rehabilitation, 82*, 501-508. doi:10.1053/apmr. 2001.21855

Valles, M., Vidal, J., Clavé, P., & Mearin, F. (2006). Bowel dysfunction in patients with motor complete spinal cord injury: Clinical, neurological, and pathophysiological associations. *The American Journal of Gastroenterology*, *101*, 2290-2307. doi:10.1111/j.1572-0241.2006.00729.x

Van Cooten, I. P., Snoek, G. J., Nene, A. V., De Groot, S., & Post, M. W. M. (2015). Functional hindrance due to spasticity in individuals with spinal cord injury during inpatient rehabilitation and 1 year thereafter. *Spinal Cord*, *53*, 663.

van Diemen, T., van Leeuwen, C., van Nes, I., Geertzen, J., & Post, M. (2017). Body image in patients with spinal cord injury during inpatient rehabilitation. *Archives of Physical Medicine and Rehabilitation, 98*, 1126-1131.

van Tulder, M. W., Koes, B., & Malmivaara, A. (2006). Outcome of non-invasive treatment modalities on back pain: An evidence-based review. *European Spine Journal, 15*, S64-S81.

Wakui, T., Saito, T., Agree, E. M., & Kai, I. (2012). Effects of home, outside leisure, social, and peer activity on psychological health among Japanese family caregivers. *Aging & Mental Health, 16*, 500-506.

Ware, J. E., & Sherbourne, C. D. (1992). The MOS 36-item short-form health survey (SF-36): I. Conceptual framework and item selection. *Medical Care, 30*, 473-483. Retrieved from https: //pdfs.semanticscholar.org /.../0076e 310136 d0ca8b5 6cc8585ec2bf43e...

Weiner, D. K., Sakamoto, S., Perera, S., & Breuer, P. (2006). Chronic low back pain in older adults: Prevalence, reliability, and validity of physical examination findings. *Journal of the American Geriatrics Society, 54*, 11-20.

Wen, H., Reinhardt, J. D., Gosney, J. E., Baumberger, M., Zhang, X., & Li, J. (2013). Spinal cord injury-related chronic pain in victims of the 2008 Sichuan earthquake: A prospective cohort study. *Spinal Cord, 51*, 857-862.

White, A. P., Arnold, P. M., Norvell, D. C., Ecker, T., & Fehlings, M. G. (2011). Pharmacological management of chronic low back pain. *Spine, 36*, 5131-5143. doi:10.1097/BRS.0b013e31822f178f

Whitman, S. M. (2007). Pain and suffering as viewed by the Hindu religion. *The Journal of Pain, 8*, 607-613. doi:10.1016/j.jpain.2007.02.430

Widerström-Noga, E. (2017). Neuropathic pain and spinal cord injury: Phenotypes and pharmacological management. *Drugs, 77*, 967-984. doi:10.1007/ s40265-017-0747-8

Widerström-Noga, E., Biering-Sørensen, F., Bryce, T. N., Cardenas, D. D., Finnerup, N. B., Jensen, M. P., ...Siddall, P. J. (2014). The international spinal cord injury pain basic data set (version 2.0). *Spinal Cord, 52*, 282-286. doi:10. 1038/ sc.2014.4

Widerström-Noga, E. G., & Turk, D. C. (2003). Types and effectiveness of treatments used by people with chronic pain associated with spinal cord injuries: Influence of pain and psychosocial characteristics. *Spinal Cord*, *41*, 600-609. Retrieved from https://www.nature.com/articles/3101511

Williams, R., & Murray, A. (2015). Prevalence of depression after spinal cord injury: A meta-analysis. *Archives of Physical Medicine and Rehabilitation*, *96*, 133-140. doi:10.1016/j.apmr.2014.08.016

Wiseman, T., Foster, K., & Curtis, K. (2013). Mental health following traumatic physical injury: An integrative literature review. *Injury*, *44*, 1383-1390. doi: 10.1016/j.injury.2012.02.015

Wollaars, M. M., Post, M. W., van Asbeck, F. W., & Brand, N. (2007). Spinal cord injury pain: the influence of psychologic factors and impact on quality of life. *The Clinical Journal of Pain*, *23*, 383-391.

World Health Organization. (1997). *WHOQOL: Measuring quality of life World health organization: Division of mental health and prevention of substance abuse.* Geneva: World Health Organization

World Health Organization. (1996). *WHOQOL-BREF: Introduction, administration, scoring and generic version of the assessment: Field trial version, December 1996* (No. WHOQOL-BREF). Retrieved from https://www.who.int/mental_health/media/en/76.pdf

World Health Organization. (2013). *Spinal cord injury.* Retrieved from http://www.who.int/news-room/fact-sheets/detail/spinal-cord-injury

Xue, S., Arya, S., Embuldeniya, A., Narammalage, H., da Silva, T., Williams, S., & Ravindran, A. (2016). Perceived functional impairment and spirituality/ religiosity as predictors of depression in a Sri Lankan spinal cord injury patient population. *Spinal Cord*, *54*, 1158. doi:10.1038/sc.2016.5

Yamashita, T., Takahashi, K., Yonenobu, K., & Kikuchi, S. I. (2014). Prevalence of neuropathic pain in cases with chronic pain related to spinal disorders. *Journal of Orthopedic Science*, 19, 15-21. doi:10.1007/s00776-013-0496-9

Yezierski, R. P. (2009). Spinal cord injury pain: Spinal and supraspinal mechanisms. *Journal of Rehabilitation Research & Development*, *46*, 95-108. doi:10.1682/JRRD.2008.06.0074

Yalcinkaya, E., Önes, K., Ayna, A., Turkyilmaz, A., & Erden, N. (2010). Low back pain prevalence and characteristics in caregivers of stroke patients: A pilot study. *Topics in Stroke Rehabilitation, 17*, 389-393. doi:10.1111/j.1365-2788.2011.01501.x

Yoong, A., & Koritsas, S. (2012). The impact of caring for adults with intellectual disability on the quality of life of parents. *Journal of Intellectual Disability Research, 56*, 609-619. doi:10.1111/j.1365-2788.2011.01501.

APPENDICES

Appendix A

Informed Consent Form

1. Researcher

My name is Mandira Baniya. I am a student of Master of Nursing Science in Faculty of Nursing International Program of Prince of Songkla University, I am conducting a study entitled "**Common Symptoms Experience, Symptoms Management, and Quality of Life of Nepalese People With Spinal Cord Injury and Family Caregivers**" This study is conducted under supervision of major advisor; Assist. Prof. Dr. Luppana Kitrungrote (Advisor).

Your participation in this study is voluntary. You have the right to participate or withdraw from this study at any time. Whether, you participate or not, there will be not any consequence on your career or your personal life. If you agree to participate in this study, you will be asked to sign an informed consent form. Your information will be kept confidential.

The result of this study will be published, and no one will be able to identify your personally in the report. Your signature below will only indicate that you agree to participate in this study and your signature will not be used for any other purpose. If you have any question about the study, you may directly contact by email at university email address 6010420002@email.psu.ac.th. You will receive a copy of this informed consent.

And if you have any question about the study, you can contact to Miss Chayanit Pudpong, Center for Social and Behavioral Sciences Institutional Review

Board, Prince of Songkla University cellphone number +66-74286475 and by email at chayanit.p@psu.ac.th

Thank you,

Mandira Baniya (Student ID: 6010420002)

2. Consenting Participant

I am (Mr./ Mrs./ Miss), Name……………………… Surname…………….

If I have any suspect about this study, I have right to ask any question from the researcher. If the explanation from the researcher is unpleasant, I also have the right to withdraw my participation at any time during the study without any consequence on my career.

I was informed and I understand all information according to the study and to participate in this study.

……………………………........	…………………………………
(Signature of Participant)	(Date/ Month/ Year)
……………………………........	……………………………………
(Signature of Researcher)	(Date/ Month/ Year)
……………………………........	……………………………………
(Signature of Witness)	(Date/ Month/ Year)

Appendix B

Research Instruments

Section 1 People with Spinal Cord Injury Profile

Date of data collection: **Code No.:**

PART A- Demographic, Health and Illness, and Environment Data Form of People with Spinal Cord Injury (Data-SCI)

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 ( ) Other

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

4) Marital status: ( ) Single ( ) Married ( ) Divorced/Widow

5) Education
   ( ) No education ( ) Primary school
   ( ) Secondary school ( ) Higher Education (Please specify…………………..)

6) Occupation before SCI
   ( ) No ( ) Yes (Please specify………………..)

7) Occupation status at present
   ( ) No ( ) Yes (Please specify…………………)

8) Family monthly income: …………………………. Nepali Rupees

9) Adequacy of income ( )No ( )Yes

Health and Illness Characteristics

1) Duration of injury ………………months

2) Age at injury………………years

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

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

5) Type of SCI: ( ) Paraplegia ( )Tetraplegia

6) Cause of injury: ( ) Non Traumatic

( ) Traumatic (Please specify……………….……)

7) Dependency level

( ) complete dependency ( ) high dependency

( ) moderate dependency ( ) mild dependency

( ) independent

8) Other health problems/complications after SCI

( ) No

( )Yes (please specify)

( ) pressure ulcer ( ) urinary tract infection

( ) Other (please specify…………………..)

Environmental Characteristics

9) Number of family members ..…….

10) Place of residence:

( ) Urban

( ) Rural

11) Use of assistive and mobility devices/technology

( ) Wheelchair ( ) upper/lower limb orthosis

( ) Resting splints ( ) walker/cane

( ) other (please specify………………..…)

11) Live with family/friends

( ) No ( ) Yes (Please identify……………..……..)

12. Support from family/society

( ) Family members	……………….
( ) Relatives/friends	………………
( ) Government	………………
( ) Non-Government	………………
( ) Others	……………….

PART B Symptom Experience Questionnaire of people with Spinal Cord Injury (SEQ-SCI)

Part B-1 International Spinal Cord Injury Pain Basic Data Set version 2.0 (ISCIPBDS-2)

Have you ever had any pain during the **last seven days** including today?
No Yes

If yes, please describe your three worst pain problems in the three tables below respectively. Each worst pain problem will consist of location/site of pain and the intensity of the pain:

Worst pain problem:

Pain location/sites: Can be more than one, so check all that apply) right (R), midline(M) or left (L)	**R**	**M**	**L**	**Intensity of pain.** Please circle on a number from 1 to 10 below to indicate the intensity of pain of **past 1 week** for the selected location/site
Head				Intensity of pain 0=no pain; 10=pain as bad as you can imagine. ( ) 0; ( )1; ( )2; ( )3; ( )4; ( )5 ( )6; ( )7; ( )8; ( )9; ( )10
Neck /shoulder Throat				
Neck				
Shoulder				
Arms/hands Upper arm				
Elbow				
Forearm				
Wrist				
Hand/fingers				
Frontal torso/genitals Chest				
Abdomen				
Pelvis/genitalia				
Back Upper back				
Lower back				
Buttocks/hips				
Buttocks				
Hip				
Anus				
Upper leg/thigh				
Lower legs/feet				

Knees				
Shin				
Calf				
Ankle				
Foot/toes				

Second worst pain problem:

Pain location/sites: Can be more than one, so check all that apply) right (R), midline(M) or left (L)	**R**	**M**	**L**	**Intensity of pain.** Please circle on a number from 1 to 10 below to indicate the intensity of pain of **past 1 week** for the selected location/site
Head				Intensity of pain 0=no pain; 10=pain as bad as you can imagine. ( ) 0; ( )1; ( )2; ( )3; ( )4; ( )5 ( )6; ( )7; ( )8; ( )9; ( )10
Neck /shoulder Throat				
Neck				
Shoulder				
Arms/hands Upper arm				
Elbow				
Forearm				
Wrist				
Hand/fingers				
Frontal torso/genitals Chest				
Abdomen				
Pelvis/genitalia				
Back Upper back				
Lower back				
Buttocks/hips				
Buttocks				
Hip				
Anus				
Upper leg/thigh				
Lower legs/feet Knees				
Shin				

Calf				
Ankle				
Foot/toes				

Third worst pain problem:

Pain location/sites: Can be more than one, so check all that apply) right (R), midline(M) or left (L)	**R**	**M**	**L**	**Intensity of pain.** Please circle on a number from 1 to 10 below to indicate the intensity of pain of **past 1 week** for the selected location/site
Head				Intensity of pain 0=no pain; 10=pain as bad as you can imagine. ( ) 0; ( )1; ( )2; ( )3; ( )4; ( )5 ( )6; ( )7; ( )8; ( )9; ( )10
Neck /shoulder Throat				
Neck				
Shoulder				
Arms/hands Upper arm				
Elbow				
Forearm				
Wrist				
Hand/fingers				
Frontal torso/genitals Chest				
Abdomen				
Pelvis/genitalia				
Back Upper back				
Lower back				
Buttocks/hips				
Buttocks				
Hip				
Anus				
Upper leg/thigh				
Lower legs/feet Knees				
Shin				
Calf				
Ankle				
Foot/toes				

Numeric Pain Rating Scale

Please indicate the intensity of average pain of **past 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**	

Pain Frequency

Please circle on the number that describe the frequency of your **WORST** pain in the **past 1 week.**

Never	Some of days		About Half of the days			Most of the Days		Everyday
0	1	2	3	4	5	6	7	8

Part B-2 Penn Spasm Frequency Scale (PSFS)

Instruction: Please tick (√) on the best option that describe your experience of spasticity in **previous week**. If you do not have a symptom, you will not complete the remaining questions.

Frequency of spasm

Level	Description
☐ 0	No spasm
☐ 1	Mild spasm induced by stimulation
☐ 2	Infrequent full spasms occurring less than once per hour
☐ 3	Spasms occurring more than once per hour
☐ 4	Spasms occurring more than 10 times per hour

Severity of Spasm

Please tick (√) in the box for the best option to assess the severity of spasticity you experience in the **previous week**

Level	Description
☐ 1	Mild
☐ 2	Moderate
☐ 3	Severe

PART B-3 Patient Health Questionniare-9 (PHQ-9)

Over the **last 2 weeks**, how often have you been bothered by any of the following problems? Tick (√) the number that best indicated your answer.

Depressive mood items	**Not at all**	**Several days**	**More than half the days**	**Nearly every day**
1. Little interest or pleasure in doing thing	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying sleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or over-eating	0	1	2	3
6. Feeling bad about yourself	0	1	2	3
7. Trouble concentrating on things	0	1	2	3
8. Moving or speaking so slowly or being so fidgety or restless	0	1	2	3
9. Thoughts that would be better off dead or of hurting own self	0	1	2	3

Part C Symptom Management Questionnaire of People with Spinal Cord Injury (SMQ-SCI)

Instruction: Please review your symptom management strategies that you used to manage each symptom in the **past 2 week**s. Please identify how did you apply the strategy, how often you used the strategy, reason to use the strategy, who administered the strategy, when did you used the strategy, and how effective was the strategy to reduce your symptom.

a. Symptom management

Management strategies	What	Who	Why	How	How often			When	How Effective			
					Rarely	Sometimes	Most of time		No effect	Slightly better	Much better	Symptom disappear
………………… ………………… ………………… ………………… ………………… ………………… ………………… ………………… ………………… ………………… …..……………… …………………..												

Part D Spinal Cord Injury Quality of Life -23 (SCI QL-23)

Read each statement. Please respond to (check) only those statements that you are sure describe you today and are related to your state of health/injury.

1. Functioning (FUNC)

If you agree, put a tick in the right column (below 'agree'), after each statement on the left column.

Items	**Agree**
I am doing fewer social activities with groups of people	
I get dressed only with someone's help	
I am getting around only within one building	
My sexual activity is decreased	
I am going out less to visit people	
I do not move into or out of bed or chair by myself but am moved by a person or mechanical aid	
I stay home most of the time	
I am staying in bed more	
I am cutting down the length of visits with friends	
I make difficult moves with help, e.g. getting into or out of vehicles, bathroom	

2.Mood state (MOOD)

How have you felt during the past week? Please choose the response alternative that best applies to you for each question.

a. I look forward with enjoyment to things: (Please circle one number)

As much as I always could 1

Not quite so much now.............................2

Definitely not so much now......................3

Not at all ……..4

b. I can laugh and see the funny side of things: (Please circle one number)

As much as I always could....................... 1

Not quite so much now 2

Definitely not so much now..................... 3

Not at all...…4

c. I have lost interest in my appearance: (Please circle one number)

Definitely 1
I don't take so much care as I should ……. 2
I may not take quite as much care............. 3
I take just as much care as ever 4

d. I feel cheerful: (Please circle one number)

Not at all..1
Not often 2
Sometimes 3
Most of the time 4

e. I still enjoy the things I used to enjoy: (Please circle one number)

Definitely as much 1
Not quite so much 2
Only a little 3
Hardly at all 4

f. I feel as if I am slowed down: (Please circle one number)

Nearly all the time 1
Very often..2
Sometimes 3
Not at all...4

3. Problem related to injury (PROB)

How do you feel about the following situations? For each question (a-f), choose the response category that best corresponds to how you feel. If you have no problems, a circle around 4 = not at all hard.

How hard is it for you:	Very hard	Hard	Not very hard	Not hard at all
not being able to walk, move about freely?	1	2	3	4
needing help with many things	1	2	3	4
not being able to do as you want to - when you want to?	1	2	3	4
not being able to hide yourself in the crowd?	1	2	3	4
having problems with your bowels, e.g. diarrhea, constipation, leakage?	1	2	3	4
being in pain?	1	2	3	4

4. Global Quality of Life (GQOL)

How would you rate your overall quality of life during the past week? Please circle the number between 1 and 7 that best applies to you.

1	2	3	4	5	6	7
Very poor						Excellent

Section B Family Caregiver's Profile

Date of data collection: **Code No.:**

PART A Demographic, Health and Illness, and Environment Data Form of Family Caregivers (Data-FCs)

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. Marital status: ( ) Single ( ) Married
   ( ) Divorced/Widow
4. Number of other dependent family members that you take care at present.
   ( ) No ( ) Yes (Please identify……………..)
5. Relationship with people with SCI:
   ( ) Spouse ( ) Parent
   ( ) Children ( ) Sibling
   ( ) Relatives ( ) others (Please specify…………………….)
6. Education
   ( ) No formal education ( ) Primary school
   ( ) Secondary school ( ) Higher Education (Please specify………..)
7. Occupation: ( ) No ( ) Yes (Please specify……………..…..)
8. Family monthly income: …………………………. Nepali Rupees
9. Adequacy of the income: ( ) No ( ) Yes
10. Presence of co-morbidities:
    ( ) Hypertension ( ) Heart disease
    ( ) Arthritis ( ) Diabetes
    ( ) Others, please specify………………
11. Body Mass Index (KG/m^2)**:**
12. Did you have menopause? ( ) No Yes ( )

Environment related Characteristics

13. Caregiving activities:
    - ( ) changing position
    - ( ) feeding
    - ( ) bowel care
    - ( ) catheterization
    - ( ) medication
    - ( ) lifting and transfer
    - ( ) bathing
    - ( ) grooming
    - ( ) wound care
    - ( ) others (Please specify………………..)

14. Duration of caregiving ……………. months

15. Hours of caregiving each day……………….

16. Are you living with people with SCI: ( ) No ( ) Yes

17. Is there any behavioral problem in people with SCI, if have please specify

    ………..………………

18. Do you receive any support from others? ( ) No ( ) Yes

Support from	Type of support
( ) Family members	……………….
( ) Relatives	………………
( ) Friends	………………
( ) Organization (Government/Non-Government)	………………
( ) Others	………………

19. Do you find difficulties in providing care due to physical environment at home?
    - ( ) No
    - ( ) Yes, please specify
        - ( ) stairs
        - ( ) narrow bathroom
        - ( ) wheelchair
        - ( ) narrow doors
        - ( ) narrow corridor
        - ( ) others (Please specify…………….)

20. Are you trained knowledge and/or skill about taking care of SCI patients (i.e. bowel/bladder/skin care, transfer, deal with common patient’s problems etc.)

    ( ) No ( ) Yes

PART-B Symptoms Experience Questionnaire of Family Caregivers (SEQ-FCs)

Part B1 Pain Experience Questionnaire (PEQ)

Pain Intensity

Please rate your low back pain by circling the one number that best describe your **pain at Worst** in the last week

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
No Pain										**Pain as bad as you can imagine**

Please rate your low back pain by circling the one number that best describe your **pain at Least** in the last week

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
No Pain										**Pain as bad as you can imagine**

Please rate your low back pain by circling the one number that best describe your pain in the **AVERAGE**

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
No Pain										**Pain as bad as you can imagine**

Please rate your low back pain by circling the one number that tell you how much pain you have **Right Now**

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
No Pain										**Pain as bad as you can imagine**

Pain Frequency

Instruction: Please tick (√) the choice that best describes “how often you experience low back pain?”

( ) Everyday ( ) Once a week ( ) Twice a week

( ) More than twice a week ( ) Once a month

Part-B2 Short Form Zarit Burden Interview (ZBI-12)

Please tick (√) on the boxes below the best option to describe your burden experience

Do you feel….	**Never** **‘0’**	**Rarely** **‘1’**	**Some-times** **‘2’**	**Quite frequently** **‘3’**	**Nearly always** **‘4’**
That because of the time you spend with your relative with SCI that you don’t have enough time for yourself					
Stressed between caring for your relative with SCI and trying to meet other responsibilities (work/family)					
Angry when you are around your relative with SCI					
That your relative with SCI currently affects your relationship with family members or friends in a negative way					
Strained when you are around your relative with SCI					
That your health has suffered because of your involvement with your relative with SCI					
That you don’t have as much privacy as you would like because of your relative with SCI					
That your social life has suffered because you are caring for your relative with SCI					
That you have lost control of your life since illness of your relative with SCI					
Uncertain about what to do about your relative with SCI					
You should be doing more for your relative					
You could do a better job in caring for your relative					

Part B-3 Patient Health Questionniare-9 (PHQ-9) (FCs)

Over the **last 2 weeks,** how often have you been bothered by any of the following problems? Tick (√) the number that best indicated your answer.

Depressive mood items	**Not at all**	**Several days**	**More than half the days**	**Nearly every day**
1. Little interest or pleasure in doing thing	0	1	2	3
2.Feeling down, depressed, or hopeless	0	1	2	3
3.Trouble falling or staying sleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or over-eating	0	1	2	3
6. Feeling bad about yourself	0	1	2	3
7. Trouble concentrating on things	0	1	2	3
8. Moving or speaking so slowly or being so fidgety or restless	0	1	2	3
9.Thoughts that would be better off dead or of hurting own self	0	1	2	3

PART C Symptoms Management Questionnaire of Family Caregivers (SMQ-FCs)

Instruction: Please review your symptom management strategies that you used to manage each symptom in the past **2 weeks.** Please identify how did you apply the strategy, how often you used the strategy, reason to use the strategy, who administered the strategy, when did you used the strategy, and how effective was the strategy to reduce your symptom.

a. Symptoms management

Management strategies	What	Who	Why	How	How often			When	How Effective			
					Rarely	Sometimes	Most of time		No effect	Slightly better	Much better	Symptom disappear
………………… ………………… ………………… ………………… ………………… ………………… ………………… ………………… ………………… ………………… …..…………….												

Part D-World Health Organization Quality of Life-BREF (WHOQOL-BREF)

The following questions ask how you feel about your quality of life. Please choose the answer that appears most appropriate. If you are unsure about which response to give to a question, the first response you think of is often the best one. The numbers after responses indicates the scores of the responses.

	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 four 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	Extremely
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 about how completely you experience or were able to do certain things in the last four weeks.

	Not at all	A little	Moderately	Mostly	Completely
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 extent 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

	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 for 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

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
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 four 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 C

Scoring Instruction of Spinal Cord Injury Quality of Life 23 and World Health Organization Quality of Life –BREF

1. Spinal Cord Injury Quality of Life 23 Scoring Instructions

SCI QL-23 comprises 23 statements/questions, 22 of which are aggregated into three variables:

1. **Functioning (FUNC)** - physical and social limitations;
   10 items derived from the health status measure Sickness Impact Profile. Question no. 1a - 1j. Range of weighted scale scores: 0-100.

2. **Mood state (MOOD)** - distress and depressive feelings;
   6 items derived from the Hospital Anxiety and Depression scale.
   Question no. 2a - 2f. Range of scale scores: 0-18.
   Scores 7-9 = possible clinical depression; 10-18 = probable depression.

3. **Problems re. injury (PROB)** - perceived loss of independence and other issues relating to injury;
   6 items derived from a condition-specific questionnaire.
   Question no. 3a - 3f. Range of scale scores: 0-18.

4. **Global quality of life (GQOL)** - overall rating of life situation;
   Single question from the European Organisation on Research and Treatment of Cancer Quality of Life Questionnaire Core 30.
   Question no. 4. Response range: 1-7.

Before calculating scale scores, code the responses according to the following schema:

Functioning (FUNC) Item number	Response value	Recoded value
1a, 1b, 1c, 1d, 1e, 1f, 1g, 1h, 1i, 1j	Cross in the box = agree Empty box = skip	**1 ⇒ weight**: 1a=36, 1b=88, 1c=86, 1d=51, 1e=44, 1f=121, 1g=66, 1h=81, 1i=43, 1j=84; **0**

Weights are summed, divided by the maximum weight of 700 and multiplied by 100. Scale range: 0-100.

Mood state (MOOD) Item number	Response value	Recoded value
2a, 2b, 2e	1 2 3 4	0 1 2 3
2c, 2d, 2f	1 2 3 4	3 2 1 0

Recoded values are summed, divided by the maximum score of 18 and multiplied by 100. Transformed scale range: 0-100.

Problems re. injury (PROB): Item number	Response value	Recoded value
3a, 3b, 3c, 3d, 3e, 3f	1 2 3 4	3 2 1 0

Recoded values are summed, divided by the maximum score of 18 and multiplied by 100. Transformed scale range: 0-100.

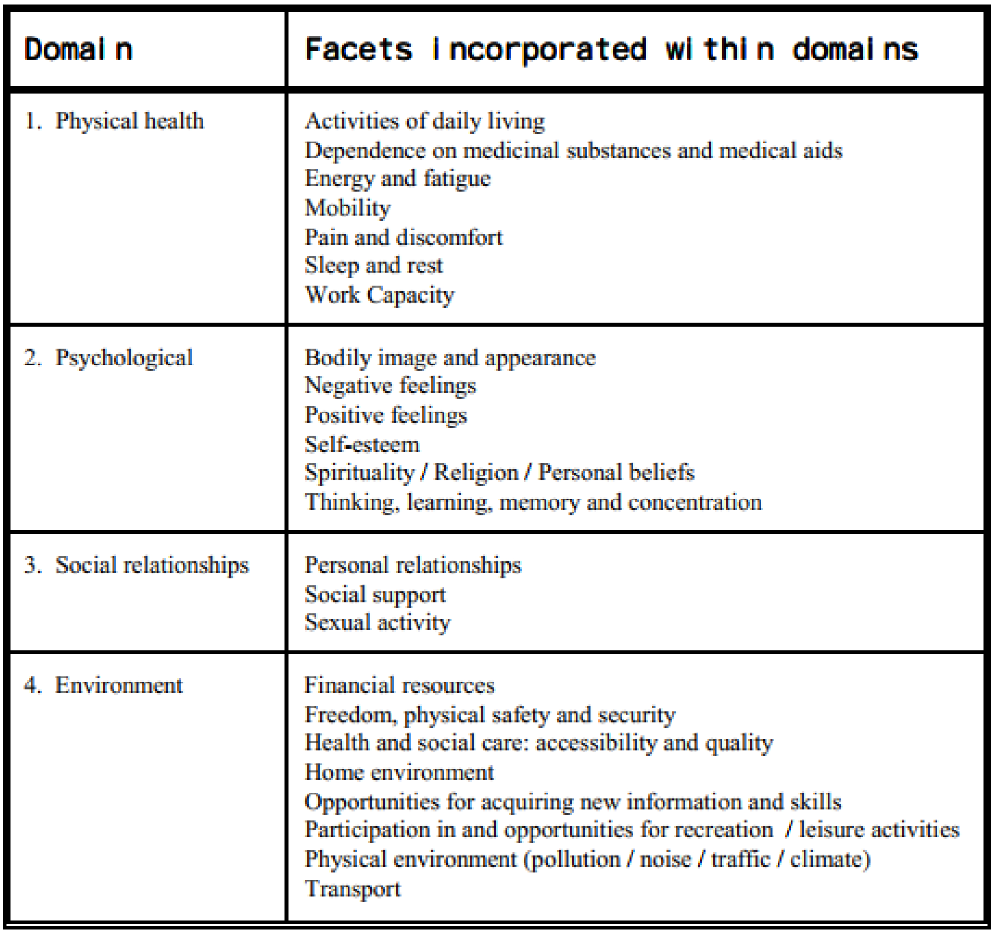
Handling of missing responses:
If there are missing responses to questions 2a - 2f or 3a - 3f, the scale score can be calculated if half or more of the questions are answered, i.e., at least 3 for MOOD and PROB, respectively. The missing values should be changed to the mean value for the responded questions in MOOD and PROB, respectively.

Global quality of life (GQOL): Item number	Response value	Recoded value
4	1 2 3 4 5 6 7	0 1 2 3 4 5 6

The recoded value is divided by the maximum score of 6 and multiplied by 100. Transformed scale range: 0-100.

2. World Health Organization Quality of Life BREF (WHOQOL-BREF) Scoring Instruction

Table 1 - WHOQOL-BREF domains



Domain	Facets incorporated within domains
1. Physical health	Activities of daily living Dependence on medicinal substances and medical aids Energy and fatigue Mobility Pain and discomfort Sleep and rest Work Capacity
2. Psychological	Bodily image and appearance Negative feelings Positive feelings Self-esteem Spirituality / Religion / Personal beliefs Thinking, learning, memory and concentration
3. Social relationships	Personal relationships Social support Sexual activity
4. Environment	Financial resources Freedom, physical safety and security Health and social care: accessibility and quality Home environment Opportunities for acquiring new information and skills Participation in and opportunities for recreation / leisure activities Physical environment (pollution / noise / traffic / climate) Transport

Table 3 - Steps for checking and cleaning data and computing domain scores

	Steps	SPSS syntax for carrying out data checking, cleaning and computing total scores
1.	Check all 26 items from assessment have a range of 1-5	RECODE Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12 Q13 Q14 Q15 Q16 Q17 Q18 Q19 Q20 Q21 Q22 Q23 Q24 Q25 Q26 (1=1) (2=2) (3=3) (4=4) (5=5) (ELSE=SYSMIS). (This recodes all data outwith the range 1-5 to system missing).
2.	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)
3.	Compute domain scores	COMPUTE DOM1=MEAN.6(Q3,Q4,Q10,Q15,Q16,Q17,Q18)*4. COMPUTE DOM2=MEAN.5(Q5,Q6,Q7,Q11,Q19,Q26)*4. COMPUTE DOM3=MEAN.2(Q20,Q21,Q22)*4. COMPUTE DOM4=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).
4.	Delete cases with >20% missing data	COUNT TOTAL=Q1 TO Q26 (1 THRU 5). (This command creates a new column 'total'. 'Total' contains a count of the WHOQOL-100 items with the values 1-5 that have been endorsed by each subject. The 'Q1 TO Q26' means that consecutive columns from 'Q1', the first item, to 'Q26', the last item, are included in the count. It therefore assumes that data is entered in the order given in the assessment). FILTER OFF. USE ALL. SELECT IF (TOTAL>=21). EXECUTE. (This second command selects only those cases where 'total', the total number of items completed, is greater or equal to 80%. It deletes the remaining cases from the data set).
5.	Check domain scores	DESCRIPTIVES VARIABLES=DOM1 DOM2 DOM3 DOM4 /STATISTICS=MEAN STDDEV MIN MAX. (Running descriptives should display values of all domain scores within the range 4-20).
6.	Save data set	Save data set with a new file name so that the original remains intact.

Table 4 - Method for converting raw scores to transformed scores

DOMAIN 1		
Raw Score	Transformed scores	
	4-20	0-100
7	4	0
8	5	6
9	5	6
10	6	13
11	6	13
12	7	19
13	7	19
14	8	25
15	9	31
16	9	31
17	10	38
18	10	38
19	11	44
20	11	44
21	12	50
22	13	56
23	13	56
24	14	63
25	14	63
26	15	69
27	15	69
28	16	75
29	17	81
30	17	81
31	18	88
32	18	88
33	19	94
34	19	94
35	20	100

DOMAIN 2		
Raw score	Transformed scores	
	4-20	0-100
6	4	0
7	5	6
8	5	6
9	6	13
10	7	19
11	7	19
12	8	25
13	9	31
14	9	31
15	10	38
16	11	44
17	11	44
18	12	50
19	13	56
20	13	56
21	14	63
22	15	69
23	15	69
24	16	75
25	17	81
26	17	81
27	18	88
28	19	94
29	19	94
30	20	100

DOMAIN 3		
Raw score	Transformed scores	
	4-20	0-100
3	4	0
4	5	6
5	7	19
6	8	25
7	9	31
8	11	44
9	12	50
10	13	56
11	15	69
12	16	75
13	17	81
14	19	94
15	20	100

DOMAIN 4		
Raw score	Transformed scores	
	4-20	0-100
8	4	0
9	5	6
10	5	6
11	6	13
12	6	13
13	7	19
14	7	19
15	8	25
16	8	25
17	9	31
18	9	31
19	10	38
20	10	38
21	11	44
22	11	44
23	12	50
24	12	50
25	13	56
26	13	56
27	14	63
28	14	63
29	15	69
30	15	69
31	16	75
32	16	75
33	17	81
34	17	81
35	18	88
36	18	88
37	19	94
38	19	94
39	20	100
40	20	100

Appendix D

Additional Tables of Results of People With Spinal Cord Injury

Table D1

Frequency and Percentage of the Items of Depressive Mood of People with SCI (N = 123)

items	Not at all (0)	Several days (1)	More than half the days (2)	Nearly every day (3)	*M(SD)*
1.Little interest or pleasure in doing thing	23(18.7)	58(47.2)	35(28.5)	7(5.7)	1.2 (0.8)
2. Feeling down, depressed, or hopeless	23(18.7)	49(39.8)	45(36.6)	6(4.9)	1.3 (0.8)
3. Trouble falling or staying sleep, or sleeping too much	31(25.2)	37(30.1)	40(32.5)	15(12.2)	1.3(0.9)
4.Feeling tired or having little energy	23(18.7)	56(45.5)	40(32.5)	4(3.3)	1.2 (0.8)
5. Poor appetite or over-eating	44(35.8)	39(31.7)	31(25.2)	9(7.3)	1.0 (0.9)
6. Feeling bad about yourself	35(28.5)	50(40.7)	35(28.5)	3(2.4)	1.0 (0.8)
7. Trouble concentrating on things	54(43.9)	51(41.5)	16(13.0)	2(1.6)	0.7 (0.7)
8. Moving or speaking so slowly or being so fidgety or restless	32(26.0)	38(30.9)	48(39.0)	5(4.1)	1.2 (0.9)
9. Thoughts that would be better off dead or of hurting own self	76(61.8)	34(27.6)	12(9.8)/24	1(0.8)	0.5 (0.7)

Table D2

Frequency and Percentage of People with SCI Classified by Types, Frequency of Use, and Effectiveness of Pain, Spasticity, and Depressive Mood Management (N = 123)

Management*	Frequency			Effectiveness				
	Rarely	Sometimes	Most of time	Worst effect	No effect	Slightly	Much better	Disappear
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
Pain management (*N* = 123, 100%)								
1. Pharmacological (prescribed = 38, non-prescribed = 26) (*n* = 64, 53.6%)								
1.1 Non-opiate (i.e., NSAIDs, Paracetamol) (*n* = 39, 31.7%)	2(5.1)	19(48.8)	18(46.1)	-	-	21(53.8)	12(30.8)	6(15.8)
1.2 Anticonvulsants (i.e., Gabapentin, Pregabalin) (*n* = 29, 23.6%)	4(13.7)	14(48.3)	11(38.0)	-	4(13.7)	10(34.5)	15(51.8)	-
1.3 Antidepressants (i.e., Amitriptyline) (*n* = 4, 3.2%)	-	4(100.0)	-	-	-	2(50.0)	2(50.0)	-
1.4 Opiate (*n* = 2, 1.6%)	2(100.0)	-	-	-	-	-	2(100.0)	-
2. Non-pharmacological strategies (*n* = 123, 100%)								

Management*	Frequency			Effectiveness				
	Rarely	Sometimes	Most of time	Worst effect	No effect	Slightly	Much better	Disappear
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
2.1 Physical (*n* = 98, 79.7%)								
2.1.1 Massage with mustard or Ayurvedic oil (*n* = 35, 28.4%)	3(8.6)	17(48.6)	15(42.8)	-	-	14(40.0)	17(48.6)	4(11.4)
2.1.2 Exercise (*n* = 29, 23.6%)	-	9(31.0)	20(69.0)	-	-	10(34.5)	13(44.8)	6(20.7)
2.1.3 Rest and sleep (*n* = 24, 19.5%)	2(8.3)	12(50.0)	10(41.7)	-	-	5(20.8)	14(58.4)	5(20.8)
2.1.4 Positioning/ position change frequently (*n* = 19, 15.4%)	-	4(21.0)	15(79.0)	-	-	9(47.4)	10(52.6)	-
2.1.5 Heat/cold Application (e.g., hot water bag, sand- bag, ice pack (*n* = 12, 9.7%)	-	12(100.0)	-	-	-	4(33.3)	8(66.7)	-
2.1.6 Deep breathing (*n* = 5, 4.0%)	-	5(100.0)	-	-	-	2(40.0)	3(60.0)	-
2.1.7 Acupuncture (*n* = 7, 5.7%)	-	7(100.0)	-	-	2(28.6)	3(42.8)	2(28.6)	-
2.2 Emotional coping (*n* = 44, 45.8%)								
2.2.1 Distraction (*n* = 36, 29.3%)	-	16(44.4)	20(55.6)	-	2(5.6)	10(27.7)	18(50.0)	6(16.7)

Management*	Frequency			Effectiveness				
	Rarely	Sometimes	Most of time	Worst effect	No effect	Slightly	Much better	Disappear
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
2.2.2 Substance abuse (*n* = 17, 13.8%)	-	7(41.2)	10(58.8)	-	-	-	10(58.8)	7(41.2)
2.2.3 Crying (*n* = 12, 9.7%)	2(16.7)	10(83.3)	-	2(16.7)	3(25.0)	7(58.3)	-	-
2.3 Tolerance (*n* = 41, 33.3%)	6(14.6)	21(51.2)	14(34.2)	-	10(24.3)	18(44.0)	8(19.5)	5(12.2)
2.4 Traditional usage (*n* = 35, 28.4%)								
2.4.1 Eating animal nutrients (*n* = 28, 22.7%)	11(39.3)	17(60.7)	-	-	10(35.7)	11(39.3)	7(25.0)	-
2.4.2 Ayurvedic medicine (*n* = 17, 13.8%)	-	4(23.5)	13(76.5)	-	4(23.5)	11(64.7)	-	2(11.8)
2.4.3 Traditional herbs (*n* = 16, 13.0%)	3(18.8)	7(43.7)	6(37.5)		7(43.7)	9(56.3)	-	-
2.5 Spiritual (*n* = 7, 5.7%)	-	4(57.0)	3(43.0)	-	-	4(57.0)	-	3(43.0)
Spasticity management (*n* = 73, 59.3%)								
1. Pharmacological (*n* = 29, 40%)								
1.1 Muscle relaxant (*n* = 28, 38.3%)	3(10.7)	10(35.7)	15(53.6)	2(7.2)	6(21.4)	15(53.6)	5(17.8)	-
1.2 Anticonvulsant (i.e., Gabapentin, Pregabalin) (*n* = 5, 6.8%)	-	3(60.0)	2(40.0)	-	-	2(40.0)	3(60.0)	-

Management*	Frequency			Effectiveness				
	Rarely	Sometimes	Most of time	Worst effect	No effect	Slightly	Much better	Disappear
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
2. Non-pharmacological management (*n* = 73, 100%)								
2.1 Physical (*n* = 73)								
2.1.1 Exercise (e.g., ROM, stretching, weight bearing) (*n* = 39, 53.4%)	2(5.1)	12(30.8)	25(64.1)	-	4(10.2)	15(38.5)	20(51.3)	-
2.1.2 Positioning (e.g., frog's leg position, prone, lateral) (*n* = 30, 41.1%)	3(10.0)	9(30.0)	18(60.0)	-	5(16.7))	13(43.3)	12(40.0)	-
2.1.3 Protect the body from harsh conditions (*n* = 16, 22.0%)	-	-	16(100.0)	-	-	10(62.5)	6(37.5)	-
2.1.4 Management of co-existing Illness (*n* = 12, 16.4%)	-	12(100.)	-	-	-	-	12(100.0)	-
2.1.5 Hold the limbs firmly during spasms (*n* = 14, 19.2%)	-	-	14(100.0)	-	-	4(28.6)	10(71.4)	-
2.1.6 Relaxation of limbs (*n* = 12, 16.4%)	-	5(41.7)	7(58.3)	-	-	4(33.3)	8(66.7)	-

Management*	Frequency			Effectiveness				
	Rarely	Sometimes	Most of time	Worst effect	No effect	Slightly	Much better	Disappear
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
2.1.7 Acupuncture (*n* = 7, 9.6%)	-	7(100.0)	-	1(14.3)	2(28.6)	4(57.1)	-	-
2.1.8 Applying pressure on limbs (*n* = 5, 6.8%)	-	-	5(100.0)	-	-	-	5(100.0)	-
2.1.9 Icing (*n* = 5, 6.8%)	-	5(100.0)	-	-	5(100.0)	-	-	
2.1.10 Electric muscle stimulation (*n* = 3, 4.1%)	-	3(100.0)	-	-	-	-	3(100.0)	-
2.2 Traditional usage (*n* = 30, 41.1%)				-	-	-	-	-
2.2.1 Eating Animal nutrients (*n* = 20, 27.4%)	6(30.0)	14(70.0)	-	-	6(30.0)	10(50.0)	4(20.0)	-
2.2.2 Ayurvedic medicine/ procedure (*n* = 15, 20.5%)	-	10(66.7)	5(33.3)	-	3(20.0)	6(40.0)	6(40.0)	-
2.2.3 Traditional herbs (*n* = 12, 16.4%)	-	12(100.0)	-	-	2(16.7)	4(33.3)	6(50.0)	-
2.3 Emotional coping (*n*=20, 27.4%)								-
2.3.1 Substance abuse (*n* = 17, 23.3%)	-	17(100.0)	-	-	-	-	5(29.4)	12(70.6)
2.3.2 Self-control (*n* = 5, 6.8%)	-	5(100.0)	-	-	-	-	5(100.0)	-
2.4 Spiritual* (*n* = 7, 9.6%)	-	4(57.0)	3(43.0)	-	-	4(57.0)	-	3(43.0)

Management*	Frequency			Effectiveness				
	Rarely	Sometimes	Most of time	Worst effect	No effect	Slightly	Much better	Disappear
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
Depressive mood management **(***n* = 104, 84.5%)								
1. Pharmacological- Sleeping pills (non-prescribed) (*n* = 2, 1.9%)	2(100.0)	-	-		-	2(100.0)	-	-
2. Non-pharmacological (*n* = 100%)								
2.1 Emotional coping (*n* = 85, 81.7%)								
2.1.1 Distraction (*n* = 49, 47.1%)	3(6.1)	18(36.7)	28(57.2)	-	-	10(20.4)	25(51.0)	14(28.6)
2.1.2 Share feelings (*n* = 31, 29.8%)	3(9.7)	20(64.5)	8(25.8)	-	-	5(16.1)	11(35.5)	5(48.4)
2.1.3 Substance abuse (*n* = 21, 20.2%)	4(19.0)	9(42.9)	8(38.1)	2(9.5)	-	3(14.3)	9(42.9)	7(33.3)
2.1.4 Crying (*n* = 15, 14.4%)	-	15(100.0)	-	2(13.3)	4(26.7)	4(26.7)	5(33.3)	-
2.1.5 Stay alone (*n* = 8, 7.7%)	-	8(100.0)	-	-	-	4(50.0)	4(50.0)	-
2.1.6 Go away from stressor friends (*n* = 7, 6.7%)	-	7(100.0)	-	-	-	3(42.9)	4(57.1)	-
2.2 Spiritual practices (*n* = 31, 29.8%)	4(13.0)	19(61.2)	8(25.8)	-	5(16.0)	9(29.0)	13(42.0)	4(13.0)

Table D2 (Continued)

Management*	Frequency			Effectiveness				
	Rarely	Sometimes	Most of time	Worst effect	No effect	Slightly	Much better	Disappear
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
2.3 Accepting (*n* = 12, 11.5%)	-	12(100.0)	-	-	-	4(3.3)	6(50.0)	2(16.7)
2.4 Positive thinking (*n* = 11, 10.6%)	-	11(100.0)	-	-	-	2(18.2)	9(81.8)	-

Note: *one participant used more than one management methods

Table D3

Frequency and Percentage of People with SCI Classified by Reason of Using Pain Management Strategies (N = 123)

Reasons of using pain management *	*n* (%)
Pain medication (*n* = 64)	
1. Prescribed by doctor (e.g., Gabapentin, Pregabalin, Amitriptyline)	30(46.9)
2. Severe pain, not managed by non-pharmacology (e.g., Ibuprofen, Gabapentin)	19(29.7)
3. Easily available, fast action, faster relief (e.g., Ibuprofen Tramadol)	19(29.7)
4. For a combined effect with non-pharmacological method such as relaxation, comfort (e.g., Gabapentin, Ibuprofen)	5(7.8)
Non-pharmacological management (*n* = 123)	
1. Longer effect (e.g., massage, distraction, tolerance, meditation)	55(44.7)
2. Cheaper and readily available at home or surrounding (traditional herbs, massage oil, tolerance)	50(40.6)
3. No side effects like medicine (e.g., massage, distraction, tolerance)	48(39.0)
4. Have multiple effects such as pain relief, relaxation, comfort (e.g., massage, distraction)	20(16.3)
5. Nobody is around to help (e.g., crying, deep breathing, praying, tolerate)	15(12.2)
6. To help reduce the effect of bad luck, evil eyes (e.g., praying, worshipping, offerings)	13(10.6)
7. Regeneration of broken vertebra and nerves (i.e., traditional herbs)	13(10.6)
8. Provides energy to fight against pain (i.e., eating animal product, exercise)	13(10.6)
9. No dependency or addiction like any drugs (e.g., massage, heat application)	7(5.7)
10. Prevention of pain perception (i.e., distraction, tolerance, meditation)	7(5.7)

Note: *one participant had more than one reason of pain management

Table D4

Frequency and Percentage of People with SCI Classified by People Who Help and Place of Pain Management (N = 123)

Pain management*	People who help				Place of management			
	Self	Family/ friends	HP	TH	Home	Hospital/ clinic	Pharmacy	Community
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
1. Pharmacological (*n* = 60)	25(41.6)	35(58.3)	-	-	-	22 (36.7)	38(63.3)	-
2. Non-pharmacological (*n* = 123)								
2.1 Physical modalities (*n* = 98)								
2.1.1 Massage (*n* = 35)	6(17.1)	29(82.9)	-	-	35(100.0)	-	-	-
2.1.2 Exercise (*n* = 29)	10(34.5)	19(65.5)	-	-	20(68.9)	9(31.1)	-	-
2.1.3 Rest and sleep (*n* = 24)	24(100)	-	-	-	24(100.0)	-	-	-
2.1.4 Positioning (*n* = 19)	8(42.1)	11(47.9)	-	-	19(100)	-	-	-
2.1.5 Heat or cold application (*n* = 12)	-	12(100)	-	-	9(75.0)	3(25.0)	-	-
2.1.6 Acupuncture (*n* = 7)	-	-	7(100)	-	-	7(100.0)	-	-
2.1.7 Deep breathing (*n* = 5)	5(100)	-	-	-	5(100.0)	-	-	-
2.2 Emotional coping (*n* = 44)								
2.2.1 Distraction (*n* = 36)	16(44.4)	20(55.6)	-		27(75.0)	-	-	9(25.0)
2.2.2 Crying (*n* = 12)	12(100)	-	-		12(100)	-	-	-

Table D4 (Continued)

Pain management*	People who help				Place of management			
	Self	Family/ friends	HP	TH	Home	Hospital/ clinic	Pharmacy	Community
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
2.2.3 Substance abuse (*n* = 17)	-	17(100)	-		9(52.9)	-	-	8(47.1)
2.3 Tolerance (*n* = 41)	41(100)	-	-	-	41(100)	-	-	-
2.4 Traditional usage (*n* = 35)								
2.4.1 Animal nutrients (*n* = 28)	-	23(82.1)	-	5(17.9)	-	-	-	28(100.0)
2.4.2 Ayurvedic medicine/ procedure (*n* = 17)	-	-	12(70.6)	5(29.4)	-	10(58.8)	-	10(58.8)
2.4.3 Traditional herbs (*n* = 16)	-	11(68.7)	-	5(31.2)	5(31.3)	-	-	11(68.7)
2.5 Spiritual practices (*n* = 18)	5(27.8)	-	-	13(66.7)	10(55.5)	-	-	12(66.7)

Note: *one participant used more than one management, HP-health professional; TH-Traditional healer

Table D5

Frequency and Percentage of People with SCI Classified by Time of Pain Management (N = 123)

Pain management*	Time of pain management				
	whenever	morning	Evening/ night	Morning & evening	Morning, afternoon & night
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
1. Pharmacological management (*n* = 64)	11(17.2)		20(31.3)	25(39.0)	8(12.5)
2.Non-pharmacological (*n* = 123)					
2.1 Physical (*n* = 98)					
2.1.1 Massage (*n* = 35)	8(22.8)	6(17.2)	8(22.8)	13(37.2)	-
2.1.2 Exercise (*n* = 2)	-	12(41.4)	-	17(58.6)	-
2.1.3 positioning* (*n* = 19)	19(100.0)	-	8(42.1)	-	-
2.1.4 rest and sleep (*n* = 24)	24(100)	-	-	-	-
2.1.5 heat/cold application (*n* = 12)	6(50.0)	6(50.0)	-	-	-
2.1.6 deep breathing (*n* = 5)	5(100.0)	-	-	-	-
2.1.7 Acupuncture (*n* = 7)		7(100.0)	-	-	-
2.2. Emotional coping (*n* = 44)					
2.2.1 Distraction (*n* = 36)	36(100.0)	-	-	-	-
2.2.2 Crying (*n* = 12)	12(100.0)	-	-	-	-
2.2.3 Substance abuse* (*n* = 17)	8(47.1)	-	12(70.6)	-	-
2.3 Tolerance (*n*= 4)	41(100.0)	-	-	-	-
2.4 Traditional usage					
2.4.1 Animal nutrients (*n* = 28)	20 (71.4)	-	-	8(28.6)	-

Pain management*	Time of pain management				
	whenever	morning	Evening/ night	Morning & evening	Morning, afternoon & night
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
2.4.2 Ayurvedic medicine/ procedure* (*n* = 17)	7(41.2)	4(23.5)	-	15(88.2)	-
2.4.3 Traditional herbs (*n* = 16)	-	10(62.5)	-	6(37.5)	-
2.5. Spiritual practices * (*n* = 18)	4(22.2)	12(66.7)	-	4(22.2)	-

Note: *one participant used more than one pain management

Table D6

Frequency and Percentage of People with SCI Classified by Reason of Spasticity Management Strategy (N = 73)

Reasons of using spasticity management *	*n* (%)
Pharmacological (*n* = 29)	
1. Prescribed by doctor (Baclofen, Tizanidine, Gabapentin)	12(41.4)
2. Severe spasticity, not managed by non-pharmacology (Baclofen)	5(17.2)
3. Does not let to increase spasticity (Baclofen)	10(34.5)
4. Need to combine medicine and nonpharmacological methods for better effect (Baclofen)	6(20.7)
Non-pharmacological management (*n* = 73)	
1. Longer effect of decreasing spasticity (e.g., exercise, positioning)	38(52.0)
2. Have multiple effects like comfort, relaxation, loosening of joints completely, bowel empty, good quality sleep (e.g., exercise, positioning, substance)	32(43.8)
3. Cheaper and readily available at home or surrounding (e.g., traditional, massage, exercise)	28(38.3)
4. No side effects like medicine (e.g. dry mouth, weakness) (e.g., exercise, positioning, animal product)	15(20.5)
5. To help reunion of the broken bones and nerves, and decrease the problems related such as spasticity (i.e. traditional herbs)	10(13.7)
6. Nobody is around to help (e.g., self-control, relaxation of limbs)	7(9.6)
7. To help reduce the effect of bad luck, evil eyes (e.g., praying, worshipping)	5(6.8)

Note: *one participant had more than one reason for spasticity management

Table D7

Frequency and Percentage of People with SCI Classified by People Who Help and Place of Spasticity Management (N = 73)

Spasticity Management*	People who help				Place of management			
	Self	Family/ friends	HP	TH	Home	Hospital/ clinic	Pharmacy	Community
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
1. Pharmacological (*n* = 29)	10(34.5)	19(65.5)	-	-	-	21(72.4)	8(27.6)	-
2. Non-pharmacological (*n* = 73)								
2.1 Physical modalities (*n* = 73)								
2.1.1 Exercise (*n* = 39)	29 (74.4)	10(25.6)	-	-	30(76.9)	9(23.1)	-	-
2.1.2 Positioning* (*n* = 30)	10(33.3)	24(80.0)	5(16.7)	-	30(100.0)	-	-	-
2.1.3 Protect the body from harsh conditions (*n* = 16)	5(31.2)	11(68.8)	-	-	16(100.0)	-	-	-
2.1.4 Management of co-existing illness (*n* = 12)	6(50.0)	6(50.0)	-	12 -	16.4 14(100.0)	-	-	-
2.1.5 Hold the limbs firmly during spasms (*n* = 14)	14(100.0)	-		-	14(100.0)	-	-	-
2.1.6 Relaxation of limbs (*n* = 12)	6(50.0)	6(50.0)	-	-	12(100.0)	-	-	-
2.1.7 Applying pressure on the spastic limbs (*n* = 5)	5(100.0)	-	-	-	5(100.0)	-	-	-
2.1.8 Acupuncture (*n* = 7)	-	-	7(100)	-	-	7(100.0)	-	-

Table D7 (Continued)

Spasticity Management*	People who help				Place of management			
	Self	Family/ friends	HP	TH	Home	Hospital/ clinic	Pharmacy	Community
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
2.1.9 Icing (*n* = 5)	-	-	5(100)	-	-	5(100.0)	-	-
2.1.10 Electric muscle stimulation (*n* = 3)	-	-	3(100)	-	-	3 (100.0)	-	-
2.2 Traditional usage (*n* = 30)								
2.2.1 Animal nutrients (*n* = 20)	-	20(100)	-	-	7(41.2)	-	-	10(58.8)
2.2.2 Ayurvedic medicine/procedure (*n* = 15)		15(100)	-	-	5(100.0)	-	-	-
2.2.3 Traditional herbs (*n* = 12)	-	4(33.3)	-	8(66.7)	-	-	-	-
2.3 Emotional modalities (*n* = 20)	-	-	-	-	8(40.0)	-	-	12(60.0)
2.3.1 Substance abuse *(n* = 17)	-	17(100)	-	-	-	10(66.7)	-	5(33.3)
2.3.2 Self-control (*n* = 5)	5(100.0)	-	-	-	-	4(33.3)	-	8(66.7)
2.4 Spiritual* (*n* = 7)	3(42.9)	4(57.1)	-	-	3(42.9)	-	-	4(57.1)

Note. *one participant used more than one spasticity management, HP-health professional; TH-Traditional healer

Table D8

Frequency and Percentage of People with SCI Classified by Time of Spasticity Management (N = 73)

Spasticity management*	Time of spasticity management				
	whenever	morning	Evening/ night	Morning & evening	Morning, afternoon & night
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
1. Pharmacological (*n* = 29)	7(24.1)	10(34.5)	-	8(27.6)	4(13.8)
2. Non-pharmacological management (*n* = 73)					
2.1 Physical modalities (*n* = 73)					
2.1.1 Exercise (*n* = 39)	5(12.8)	19(48.7)	-	15(38.5)	-
2.1.2 Positioning (*n* = 30	14(46.7)	-	-	16(53.3)	-
2.1.3 Protect the body from harsh conditions (*n* = 16)	16(100.0)	-	-	-	-
2.1.4 Hold the limbs firmly during spasms (*n* = 14)	14(100.0)	-	-	-	-
2.1.5 Management of co-existing illnesses (*n* = 12)	12(100.0)	-	-	-	-
2.1.6 Relaxation of limbs (*n* = 12)	12(100.0)	-	-	-	-
2.1.7 Acupuncture (*n* = 7)	-	7(100.0)	-	-	-
2.1.8 Applying pressure on the spastic limbs (*n* = 5)	5(100.0)	-	-	-	-
2.1.9 Icing (*n* = 5)	-	5(100.0)	-	-	-
2.1.10 Electric muscle stimulation (*n* = 3)	-	3(100.0)	-	-	-
2.2 Traditional modalities					
2.2.1 Eating animal products (*n* = 20)	-	7(35.0)	-	13(65.0)	-
2.2.2 Ayurvedic medicine/ procedure (*n* = 15)	-	6(40.0)	-	9(60.0)	-

Spasticity management*	Time of spasticity management				
	whenever	morning	Evening/ night	Morning & evening	Morning, afternoon & night
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
2.2.3 Traditional herbs (*n* = 12)	12(100.0)	-	-	-	-
2.3 Emotional coping					
2.3.1 Substance abuse (*n* = 17)	2(11.8)	-	15(88.2)	-	-
2.3.2 Self-control (*n* = 5)	5(100.0)	-	-	-	-
2.4 Spiritual* *(n* = 7)	-	7(100.0)	-	-	-

Note: *one participant used more than one spasticity management

Table D9

Frequency and Percentage of People with SCI Classified by Reason of Using Depressive Mood Management (N = 104)

Reasons of using depressive mood management *	*n* (%)
1. Related to previous practices or hobbies (e.g., distraction, sharing)	30(28.8)
2. Advised by close family members and friends that these measures can elevate mood, peace of mind, decrease the suffering (e.g., distraction, sharing, change of religion)	20(19.2)
3. For the peace of mind for self and family members (e.g., spiritual practices, sharing)	12(11.5)
4. Have multiple effects such as peace of mind, relaxation (e.g., meditation, spiritual, diversion, substance use)	20(19.2)
5. To reduce the effects of bad luck, evil eyes (e.g., praying, worshipping)	18(17.3)
6. Find no other things to provide comfort (e.g., accepting, go away from home, crying)	15(14.4)
7. Easy to apply (e.g., diversion, sharing)	15(14.4)

Note: *one participant had more than one reasons for depressive mood management

Table 10

Frequency and Percentage of People with SCI Classified by People Who Help and Place of Depressive Mood Management (N = 104)

Depressive mood management*	People who help				Place of management		
	Self	Family/ friends	HP	TH	Home	Pharmacy	Community
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
1. Pharmacological							
1.1 Sleeping pills (*n* = 2)	-	2(100.0)	-	-	-	2(100)	-
2. Non-pharmacological (*n* = 104)							
2.1 Emotional coping (*n* = 85)							
2.1.1 Distraction (*n* = 49)	49(100)	-	-	-	49(100)	-	-
2.1.2 Share feelings (*n* = 31)	31(100)	-	-	-	31(100)	-	-
2.1.3 Substance abuse (*n* = 21)	-	21(100)			16(76.2)	-	5(23.8)
2.1.4 Crying (*n* = 15)	15(100)	-	-	-	15(100)	-	-
2.1.5 Stay alone (*n* = 8)	8(100)	-	-	-	8(100)	-	-
2.1.6 Go away few hours from family friends (*n* = 7)	7(100)	-	-	-	-	-	7(100)
2.2 Spiritual practices (*n* = 31)	5(16.1)	16(51.6)	-	10(32.3)	5(48.4)	-	16(51.6)
2.3 Acceptance (*n* = 12)	12(100)	-	-	-	12(100)	-	-
2.4 Positive thinking (*n* = 11)	11(100)	-	-	-	11(100)	-	-

Table D11

Frequency and Percentage of People with SCI Classified by Time of Using Depressive Mood Management (N = 104)

Depression management	Time of depression management			
	whenever	morning	Evening/ night	Morning, afternoon & night
	n (%)	*n* (%)	*n* (%)	*n* (%)
1. Pharmacological				
1.1 Sleeping pills (*n* = 2)	2(100)	-	-	-
2. Non-pharmacological (*n* = 104)				
2.1 Emotional coping (*n* = 85)				
2.1.1 Diversion (*n* = 49)	20(17.8)	-	29(25.9)	-
2.1.2 Sharing feelings (*n* = 31)	31(100)	-	-	-
2.1.3 Substance abuse (*n* = 21)	-	-	21(100)	-
2.1.4 Crying (*n* = 15)	15(13.4)	-	-	-
2.1.5 Stay alone (*n* = 8)	8(100)	-	-	-
2.1.6 Go away from family friends for few hours (*n* = 7)	7(100)	-	-	-
3. Spiritual practices (*n* = 31)	10(32.3)	21(67.7)	-	-
4. Acceptance (*n* = 12)	12(10.7)	-	-	-
5. Positive thinking (*n* = 11)	11(100)	-	-	-

Note: *one participant used more than one depressive feeling management

Table D12

Frequency and Percentage of the Items of Quality of Life (Functioning, Mood and Problem domain) of People with SCI (N = 98)

Functioning domain	Agree	Disagree
	n (%)	*n* (%)
a) I am doing fewer social activities with groups of people	97(78.9)	26(21.1)
b) I get dressed only with someone's help	30(24.4)	93(75.6)
c) I am getting around only within one building	68(55.3)	55(44.7)
d) My sexual activity is decreased	106(86.2)	17(13.8)
e) I am going out less to visit people	90(73.2)	33(26.8)
f) I do not move into or out of bed or chair by myself but am moved by a person or mechanical aid	44(35.8)	79(64.2)
g) I stay home most of the time	84(68.3)	39(31.7)
h) I am staying in bed more	25(20.3)	98(79.7)
i) I am cutting down the length of visits with friends	81(65.9)	42(34.1)
j) I make difficult moves with help, e.g. getting into or out of vehicles, bathroom	86(69.9)	37(30.1)

Mood domain	*n* (%)
a. I look forward with enjoyment to things	
As much as I always could ……………..……1	7(5.7)
Not quite so much now………………...……2	82(66.7)
Definitely not so much now…………….……3	28(22.8)
Not at all……………………………….……...4	6(4.9)
b. I can laugh and see the funny side of things	
As much as I always could……………………1	26(21.1)
Not quite so much now…………………...…..2	66(53.7)
Definitely not so much now………..……...3	30(24.4)
Not at all……………………...............……4	1(0.8)

Table D12 (Continued)

Mood domain	*n* (%)
c. I have lost interest in my appearance	
Definitely……………1	12(9.8)
I don't take so much care as I should……………2	67(54.5)
I may not take quite as much care……………3	31(26.0)
I take just as much care as ever……………4	13(10.6)
d. I feel cheerful	
Not at all ……………1	2(1.6)
Not often ……………2	63(51.2)
Sometimes……………3	32(26.0)
Most of the time……………4	26(21.1)
e. I still enjoy the things I used to enjoy	
Definitely as much……………1	19(15.4)
Not quite so much……………2	69(56.1)
Only a little……………3	31(25.2)
Hardly at all……………4	4(3.3)
f. I feel as if I am slowed down	
Nearly all the time……………1	18(14.6)
Very often……………2	64 (52)
Sometimes……………3	34(27.6)
Not at all……………4	7(5.7)

Table D12 (Continued)

Problem Domain	Very hard (1)	Hard (2)	Not very hard (3)	Not hard at all (4)
	n (%)	*n* (%)	*n* (%)	*n* (%)
a) not being able to walk, move about freely?	40(32.5)	50(40.7)	22(17.9)	11(8.9)
b) needing help with many things	25(20.3)	57(46.3)	29(23.6)	12(9.8)
c) not being able to do as you want to - when you want to ?	27(22)	72(58.5)	15(12.2)	9(7.3)
d) not being able to hide yourself in the crowd?	17(13.8)	62(50.4)	23(18.7)	21(17.1)
e) having problems with your bowels, e.g., diarrhea, constipation, leakage?	11(8.9)	48(39.0)	45(36.6)	19(15.4)
f) being in pain?	9(7.3)	62(50.4)	40(32.5)	12(9.8)

Appendix E

Additional Tables of Results of Family Caregivers

Table E1

Frequency and Percentage of the Items of Burden of Family Caregivers (N = 98)

Items	Never (0)	Rarely (1)	Sometimes (2)	Quite frequent (3)	Nearly always (4)	M(SD)
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
1.That because of the time you spend with your relative with SCI that you don't have enough time for yourself	10(10.2)	38(38.8)	25(25.5)	16(16.3)	9(9.2)	1.8(1.1)
2.Stressed between caring for your relative with SCI and trying to meet other responsibilities (work/family)	10(10.2)	10(10.2)	38(38.8)	21(21.4)	9(19.4)	2.3(1.2)
3. Angry when you are around your relative with SCI	39(39.8)	20(20.4)	24(24.5)	10(10.2)	5(5.1)	1.2(1.2)
4. That your relative with SCI currently affects your relationship with family members or friends in a negative way	67(68.4)	20(20.4)	11(11.2)	-	-	0.4(0.7)
5.Strained when you are around) your relative with SCI	25(25.5)	18(18.4)	36(36.7)	19(19.4)	-	1.5 (1.1)

Items	Never (0)	Rarely (1)	Sometimes (2)	Quite frequent (3)	Nearly always (4)	M(SD)
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
6. That your health has suffered because of your involvement with your relative with SCI	24(24.5)	20(20.4)	24(24.5)	16(16.3)	14(14.3)	1.8 (1.4)
7.That you don't have as much privacy as you would like because of your relative with SCI	44(44.9)	44(44.9)	5(5.1)	-	5(5.1)	0.8 (0.9)
8. That your social life has suffered because you are caring for your relative with SCI	30(30.6)	33(33.7)	11(11.2)	24(24.5)	-	1.3 (1.2)
9. That you have lost control of your life since illness of your relative with SCI	49(50.0)	34(34.7)	15(15.3)	-	-	0.6 (0.7)
10. Uncertain about what to do about your relative	20(20.4)	18(18.4)	39(39.8)	10(10.2)	11(11.2)	1.7 (1.2)
11. You should be doing more for your relative	5(5.1)	10(10.2)	5(5.1)	39(39.8)	39(39.8)	2.9 (1.2)
12. You could do a better job in caring for your relative	-	5(5.1)	40(40.8)	19(19.4)	34(34.7)	2.8 (0.9)

Table E2

Frequency and Percentage of the Items of Depressive Mood for Family Caregivers (N = 98)

Depressive mood items	Not at all (0)	Several days (1)	More than half the days (2)	Nearly every day (3)	M(SD)
1. Little interest or pleasure in doing thing	24(24.4)	53(54.1)	16(16.3)	4(4.1)	1.0 (0.7)
2. Feeling down, depressed, or hopeless	40(40.8)	43(43.9)	13(13.3)	2(2.0)	0.7 (0.7)
3. Trouble falling or staying sleep, or sleeping too much	39(39.8)	38(38.8)	18(8.4)	3(3.1)	0.8 (0.8)
4. Feeling tired or having little energy	27(27.6)	54(55.1)	15(15.3)	2(2.0)	0.9 (0.7)
5. Poor appetite or over-eating	57(58.2)	34(34.7)	5(5.1)	2(2.0)	0.5 (0.7)
6. Feeling bad about yourself	64(65.3)	26(26.5)	8(8.2)	-	0.4 (0.6)
7. Trouble concentrating on things	41(41.8)	51(52.0)	4(4.1)	2(2.0)	0.6 (0.6)
8. Moving or speaking so slowly or being so fidgety or restless	56(57.1)	28(28.6)	12(12.2)	2(2.0)	0.6 (0.8)
9. Thoughts that would be better off dead or of hurting own self	87(88.8)	8(8.2)	3(3.1)	-	0.1 (0.4)

Table E3

Frequency and Percentage of Family Caregivers Classified by Types, Frequency of Use, and Effectiveness of LBP, Burden and Depressive Mood Management (N = 98)

Management*	Frequency			Effectiveness				
	Rarely	Sometimes	Most of time	Worst	No effect	Slightly better	Much better	Disappear
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)		*n* (%)
LBP Management (*n* = 70, 71.4%)								
1. Pharmacological strategies (*n* = 24, 34.3%)								
1.1 NSAIDs (i.e., Ibuprofen, and diclofenac ointment) (*n* = 24, 34.3%)	4(16.7)	18(75.0)	2(8.3)	-	2(8.3)	10(41.7)	18(75.0)	4(16.7)
2. Non-pharmacological strategies (*n* = 60, 85.7%)								
2.1 Physical modalities*								
2.1.1 Massage (mustard or ayurvedic oil) (*n* = 29, 41.4%)	-	10(34.5)	19(65.5)	-	-	9(31.0)	14(48.3)	6(20.7)
2.1.2 Exercise (back stretching, yoga exercises) (*n* = 21, 30%)	3(14.3)	12(57.1)	6(28.6)	-	-	3(14.3)	14(66.7)	4(19.0)
2.1.3 Rest and sleep (*n* = 19, 27.1%)	-	15(79.0)	4(21.0)	-	-	11(58.0)	8(42.0)	-

Management*	Frequency			Effectiveness				
	Rarely	Sometimes	Most of time	Worst	No effect	Slightly better	Much better	Disappear
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)		*n* (%)
2.1.4 Lumbar support (‘patuka’ home made lumbar support, lumbar belt) (*n* =12, 17%)	-	4(33.3)	8(66.7)	-	2(16.7)	4(33.3)	6(50.0)	-
2.1.5 Heat application (*n* = 9, 12.8%)	-	4(44.4)	5(55.6)	-	-	2(22.2)	6(66.7)	1(11.1)
2.2 Tolerance (*n* = 33, 47%)	6(18.2)	10(30.3)	17(51.5)	5(15.2)	7(21.2)	16(48.5)	-	5(15.1)
2.3 Emotional modalities (*n* = 12, 17%)								
2.3.1 Crying (*n* = 5, 7.1%)	-	5(100)	-	-	2(40.0)	3(60.0)	-	-
2.3.2 Distraction (*n* = 5, 7.1%)	-	3(60.0)	2(40.0)	-	-	3(60.0)	2(40.0)	-
2.3.3 Substance abuse (*n* = 3, 4.3%	-	3(100)	-	-	-	-	3(100)	-
2.4 Traditional usage (*n* = 5, 5.5%)	-	5(100)	-	-	-	5(100)	-	-
Burden management (*n* = 98, 100%)								
1. Spiritual practices (*n* = 32, 32.6%)	-	14(43.8)	18(56.2)	-	4(12.5)	9(28.1)	13(40.6)	6(18.8)
2. Emotional coping (*n* = 56, 57.1%)								
2.1 Distraction (*n* = 29, 29.6%)	-	12(41.4)	17(58.6)	-	-	10(34.5)	14(48.3)	5(17.2)
2.2 Sharing feelings (*n* = 21, 21.4%)	5(23.8)	16(76.2)	-	2(9.5)	-	8(38.1)	11(52.4)	-

Management*	Frequency			Effectiveness				
	Rarely	Sometimes	Most of time	Worst	No effect	Slightly better	Much better	Disappear
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)		*n* (%)
2.3 Crying (*n* = 18, 18.4%)	5(27.8)	13(72.2)	-	-	6(33.3)	12(66.7)	-	-
2.4 Staying with friends (*n* = 6, 6.1%)	6(100)	-	-	-	-	6(100)	-	-
2.5 Substance abuse (i.e. Alcohol) (*n* = 5, 5.1%)	1(20.0)	4(80.0)	-	-	-	5(100)	-	-
2.6 Expressing anger with the SCI patient (*n* = 4, 4.1%)	2(50.0)	2(50.0)	-	2(50.0)	-	-	-	2(50.0)
3 Positive thinking (*n* = 15, 15.3%)	-	4(26.7)	11(73.3)	-	-	2(13.3)	5(33.3)	8(53.4)
4 Accepting (*n* = 12, 12.2%)	2(16.7)	8(66.6)	2(16.7)	-	-	4(33.3)	8(66.7)	-
5 Rest and sleep (*n* = 5, 5.1%)	-	5(100)	-	-	-	5(100)	-	-
Depressive mood management (*n* = 53, 54.1%)								
1. Emotional coping (*n* = 36, 68.0%)								
1.2 Distraction (*n* = 24, 45.3%)	-	10(41.7)	14(58.3)	-	-	4(16.7)	12(50.0)	8(33.3)
1.2 Crying (*n* = 20, 37.7%)	2(10.0)	14(70.0)	4(20.0)	-	2(10.0)	4(20.0)	9(45.0)	5(25.0)
1.3 Sharing of feelings (*n* = 15, 28.3%)	-	15(100.0)	-	-	-	9(60.0)	6(40.0)	-
1.4 Going away for few days (*n* = 6, 11.3%)	4(66.7)	2(33.3)	-	-	-	3(50.0)	3(50.0)	-
1.5 Substance abuse (*n* = 5, 9.4%)	1(20.0)	4(80.0)	-	-	-	5(100)	-	-

Management*	Frequency			Effectiveness				
	Rarely	Sometimes	Most of time	Worst	No effect	Slightly better	Much better	Disappear
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)		*n* (%)
2.Spiritual practices (*n* = 32, 60.4%)	-	14(43.8)	18(56.2)	-	2(6.2)	7(21.9)	14(43.8)	9(28.1)
3.Accepting (*n* = 14, 26.4%)	2(14.3)	8(57.1)	4(28.6)	-	-	4(28.6)	10(71.4)	-
4.Positive thinking (*n* = 8, 15.1%)	-	4(50.0)	4(50.0)	-	-	-	8(100)	-
5.Rest and sleep (*n* = 5, 9.4%)	-	5(100)	-	-	-	-	5(100)	-

Note. *one participant used more than one method of management

Table E4

Frequency and Percentage of Family Caregivers Classified by Reason of Using LBP Management Strategies (N = 70)

Reason *	*n* (%)
Pain medication (*n* = 24)	
1. Severe pain, not managed by non-pharmacology (i.e., Brucet, Flexon)	10(41.7)
2. Easily available, fast action, faster relief (i.e., Brucet, Flexon)	8(33.3)
3. For a combined effect with non-pharmacological method such as massage (i.e., diclofenac gel)	7(29.2)
Non-pharmacological management (*n* = 60)	
1. Longer effect (e.g., massage, tolerance, yoga)	31(51.7)
2. No side effects like medicine i.e., headache, nausea, dizziness (e.g., massage, exercise, rest and sleep)	26(43.3)
3. Cheaper and readily available at home or surrounding (e.g., massage oil, exercise, homemade belt ‘patuka’)	17(28.3)
4. Have multiple effects i.e., pain relief, relaxation, comfort (i.e., massage, rest and sleep)	15(25.0)
5. To prevent dependency on medication	15(25.0)
6. When there is no hope, and nothing helps (i.e., crying, tolerance)	5(8.3)
7. Not to waste the product not used by people with SCI (i.e., ayurvedic medicine)	5(8.3)

Note. *one participant had more than one reason of LBP management

Table E5

Frequency and Percentage of Family Caregivers Classified by Reason of Using Burden Management Strategies (N = 98)

Reason *	*n* (%)
Non-pharmacological management (*N* = 98)	
1. For the peace of mind (e.g., praying, worshipping, positive thinking)	40(40.8)
2. Attachment the God who knows all (e.g., praying, worshipping, accepting)	25(25.5)
3. Related to previous practices or hobbies (e.g., listening to music, games, sharing)	20(20.4)
4. To forget the feelings of burden (i.e., distraction)	20(20.4)
5. To reduce the effects of bad luck, evil eyes (i.e., worshipping)	18(18.3)
6. When there is hopelessness (i.e., crying)	15(15.3)
7. Has multiple effects e.g. relaxation, promote sleep (i.e., distraction, sharing, alcohol, meditation)	8(8.1)
8. Advised by friends and relatives (i.e., change of religion)	5(5.1)
9. Release of extreme of emotion (i.e., angry with care recipient, crying)	5(5.1)
10. Easy to apply (i.e., distraction)	4(4.1)

Note. *one participant had more than one reason for burden management

Table E6

Frequency and Percentage of Family Caregivers Classified by Reason of Using Depressive Mood Management Strategies (N = 53)

Reason *	*n* (%)
Non-pharmacological management	
1. For the peace of mind (e.g., praying, worshipping, positive thinking)	34(64.1)
2. Attachment the God who knows all (e.g., praying, worshipping, accepting, crying)	24(45.3)
3. Related to previous practices or hobbies (e.g., listening to music, games)	20(37.7)
4. To forget the depressive feelings (i.e., distraction)	20(37.7)
5. When there is hopelessness (i.e., crying)	20(37.7)
6. To reduce the effects of bad luck, evil eyes (i.e., worshipping)	15(28.3)
7. Have multiple effects e.g. relaxation, promote sleep (i.e., alcohol, meditation)	8(15.1)
8. Advised by friends and relatives (i.e., change of religion)	5(9.4)
9. Easy to apply (e.g., diversion)	4(7.5)

Note. *one participant had more than one reasons for depressive mood management

Table E7

Frequency and Percentage of Family Classified by Time, People Who Help, and Place of LBP, Burden and Depressive Mood Management (N = 98)

Management*	Time (*When*)			People (*Who*)				Place (*Where*)		
	Whenever	Morning or day	Morning & evening	Self	HP	Family/ friends	TH	Home	Health center	Community/ pharmacy
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
LBP Management (*n* = 70, 71.4%)										
1. Pharmacological NSAIDs (i.e. Brucet, Flexon, and diclofenac ointment (*n* = 24)	14(58.4)	5(20.8)	5(20.8)	15(62.5)	9(37.5)	-	-	-	9(37.5)	15(62.5)
2. Non-pharmacological strategies (*n* = 60)										
2.1 Physical modalities*										
2.1.1 Massage (*n* = 29)	8(27.6)	10(34.5)	11(37.9)	6(20.7)	-	23(79.3)	-	29(100)	-	-
2.1.2 Exercise (*n* = 21)	8(38.1)	-	13(61.9)	17(81)	4(19)	-	-	17(81)	4(19)	-
2.1.3 Rest and sleep (*n* = 19)	10(52.6)	9(47.4)	-	19(100)	-	-	-	19(100)	-	-
2.1.4 Lumbar support (*n* = 12)	2(16.7)	10(83.3)	-	4(33.3)	4(33.3)	4(33.3)	-	8(66.7)	4(33.3)	-
2.1.5 Heat application (*n* = 9)	6(66.7)		3(33.3)	-	-	9(100)	-	9(100)	-	-
2.2 Tolerance (*n* = 33)	33(100)	-	-	33(100)	-	-	-	33(100)	-	-

Table E7 (Continued)

Management*	Time (*When*)			People (*Who*)				Place (*Where*)		
	Whenever	Morning or day	Morning & evening	Self	HP	Family/ friends	TH	Home	Health center	Community/ pharmacy
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
2.3 Emotional modalities (*n* = 12)										
2.3.1 Crying (*n* = 5)	5(100)	-	-	5(100)	-	-	-	5(100)	-	-
2.3.2 Distraction (*n* = 5)	5(100)	-	-	5(100)	-	-	-	5(100)	-	-
2.3.3 Substance abuse (*n* = 3)	3(100)	-	-	3(100)	-	-	-	3(100)	-	-
2.4 Traditional usage (*n* = 5)	-	5(100)	-	5(100)	-	-	-	-	5(100)	-
Burden management (*N* = 98, 100%)										
1. Emotional coping (*n* = 56)										
1.1 Distraction (*n* = 29)	20(69.0)	9(31.0)	-	18(62.1)	-	11(37.9)	-	22(75.8)	-	7(24.2)
1.2 Sharing of feelings (*n* = 21)	21(100)	-	-	10(47.6)	-	11(52.4)	-	9(42.9)	-	12(57.1)
1.3 Crying (*n* = 18)	18(100)	-	-	18(100)	-	-	-	18(100)	-	-
1.4 Stay with friends (*n* = 6)	6(100)	-	-	-	-	6(100)	-	-	-	6(100)
1.5 Substance abuse (*n* = 5)	5(100)	-	-	3(60.0)	-	2(40.0)	-	5(100)	-	-
1.6 Express anger (*n* = 4)	4(100)	-	-	4(100)	-	-	-	4(100	-	-

Management*	Time (*When*)			People (*Who*)				Place (*Where*)		
	Whenever	Morning or day	Morning & evening	Self	HP	Family/ friends	TH	Home	Health center	Community/ pharmacy
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
2. Spiritual practices (*n* = 32)	7(21.9)	-	25(78.1)	7(21.9)	-	10(31.2)	15(46.9)	20(62.5)	-	12(37.5)
3. Positive thinking (*n* = 15)	15(100)	-	-	10(66.7)	-	5(33.3)	-	15(100)	-	-
4. Accepting (*n* = 12)	12(100)	-	-	10(83.3)	-	2(16.7)	-	12(100)	-	-
5. Rest and sleep (*n* = 5)	5(100)	-	-	5(100)	-	-	-	5(100)	-	-
Depressive mood management (*n* = 53, 54.1%)										
1. Emotional coping (*n* = 36)										
1.1 Distraction (*n* = 24)	18(75.0)	6(25.0)	-	14(58.3)	-	10(41.7)	-	16(66.7)	-	8(33.3)
1.2 Crying (*n* = 20)	20(100)	-	-	20(100)	-	-	-	20(100)	-	-
1.3 Sharing of feelings (*n* = 15)	15(100)	-	-	8(53.3)	-	7(46.7)	-	6(40.0)	-	9(60.0)
1.4 Go away for few days (*n* = 6)	6(100)	-	-	6(100)	-	-	-	-	-	6(100)
1.5 Substance abuse (*n* = 5)	-	-	5(100)	5(100)	-	-	-	5(100)	-	-
2 Spiritual practices (*n* = 32)	7(21.9)	-	25(78.1)	7(21.9)	-	10(31.2)	15(46.9)	20(62.5)	-	12(37.5)
3 Accepting (*n* = 14)	14(100)	-	-	10(71.4)	-	4(28.6)	-	14(100)	-	-

		Time (*When*)			People (*Who*)				Place (*Where)*		
	Management*	Whenever	Morning or day	Morning & evening	Self	HP	Family/ friends	TH	Home	Health center	Community/ pharmacy
		n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
4	Positive thinking (*n* = 8)	8(100)	-	-	8(100)	-	-	-	8(100	-	-
5	Rest and sleep (*n* = 5)	5(100)	-	-	5(100)	-	-	-	5(100)	-	-

Note. *one participant used more than one method of management; HP=Health professional; TH= Traditional healer

Table E8

Mean, Standard Deviation of Items of Quality of Life of Family Caregivers (N = 98)

QoL	*M(SD)*
1. Satisfaction of QoL (Q1)	2.9(0.6)
2. Satisfaction of health (Q2)	2.9(0.7)
Domain 1 (Physical)	
1. Pain and discomfort (Q3)	2.0(0.7)
2. Dependence of medical aids (Q4)	3.4(1.0)
3. Energy and fatigue (Q10)	3.2(0.9)
4. Mobility (Q15)	3.3(0.9)
5. Sleep (Q16)	4.0(0.5)
6. Activities of daily living (Q17)	3.8(0.7)
7. Work capacity (Q18)	3.3(0.5)
Domain 2 (Psychological)	
1. Positive feelings (Q5)	2.5(0.9)
2. Self-esteem (Q6)	2.4(0.8)
3. Memory/concentration (Q7)	3.4(0.9)
4. Bodily image and appearance (Q11)	3.7(0.6)
5. Spirituality (Q19)	3.5(0.5)
6. Negative feelings (Q26)	3.1(1.0)
Domain 3 (Social relationship)	
1. Personal relationship (Q20)	3.3(0.8)
2. Social support (Q22)	3.1(0.7)
3. Sexual activity (Q21)	3.3(0.8)
Domain 4 (Environment)	
1. Physical safety security (Q8)	3.3(1.0)
2. Physical environment (Q9)	2.6(0.5)
3. Financial resource (Q12)	2.9(0.8)
4. Opportunity for new information (Q13)	2.8(0.7)
5. Opportunity for leisure activities (Q14)	2.5(0.5)
6. Home environment (Q23)	3.2(0.7)
7. Health social care accessibility (Q24)	2.7(0.8)
8. Transport (Q25)	3.4(1.1)

Appendix F

List of Experts

1. Assist. Prof. Dr. Wipa Sia-Sae

   Lecturer, Department of Surgical Nursing, Faculty of nursing, Prince of Songkla University, Thailand

2. Ms. Daungkamol Suwan

   Advance Practice Nurse, Trauma Ward, Songklanagarind Hospital, Thailand

3. Dr. Raju Dhakal

   Medical Director, Spinal Injury Rehabilitation Center, Nepal

4. Ms. Chanda Rana

   Rehabilitation In-charge, Spinal Injury Rehabilitation Center, Nepal

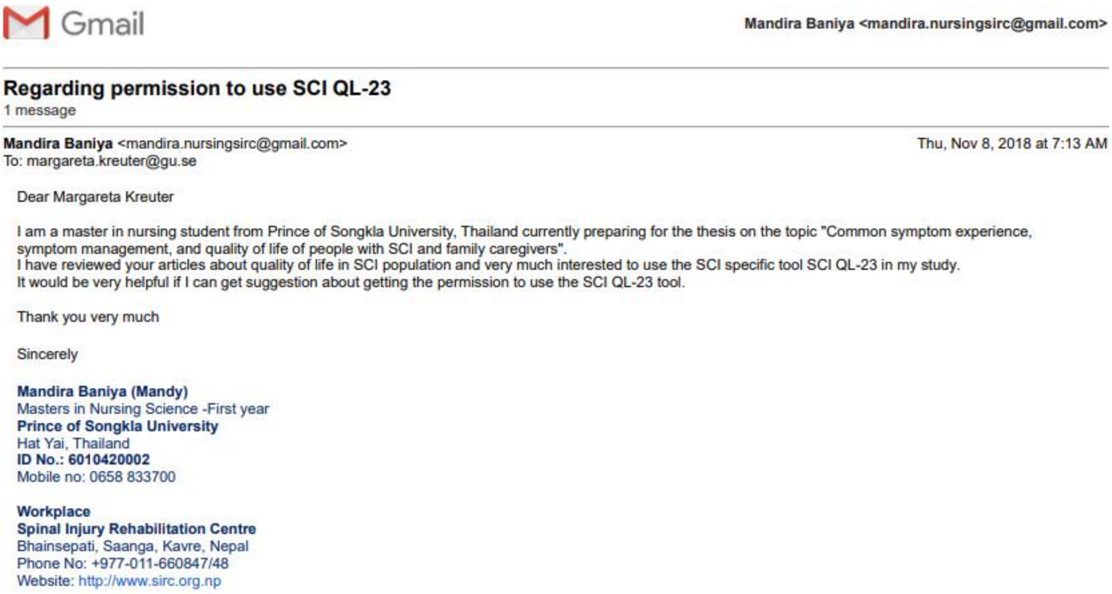
5. Dr. Christine Groves

   Consultant Physiatrist, Spinal Injury Rehabilitation Center, Nepal

Appendix G

Permission to use Research Instruments

1. Permission to use SCI QL 23



Gmail Mandira Baniya <mandira.nursingsirc@gmail.com>

Regarding permission to use SCI QL-23

1 message

Mandira Baniya <mandira.nursingsirc@gmail.com> Thu, Nov 8, 2018 at 7:13 AM

To: margareta.kreuter@gu.se

Dear Margareta Kreuter

I am a master in nursing student from Prince of Songkla University, Thailand currently preparing for the thesis on the topic "Common symptom experience, symptom management, and quality of life of people with SCI and family caregivers".
I have reviewed your articles about quality of life in SCI population and very much interested to use the SCI specific tool SCI QL-23 in my study.
It would be very helpful if I can get suggestion about getting the permission to use the SCI QL-23 tool.

Thank you very much

Sincerely

Mandira Baniya (Mandy)
Masters in Nursing Science -First year
Prince of Songkla University
Hat Yai, Thailand
ID No.: 6010420002
Mobile no: 0658 833700

Workplace
Spinal Injury Rehabilitation Centre
Bhainsepati, Saanga, Kavre, Nepal
Phone No: +977-011-660847/48
Website: http://www.sirc.org.np

Gmail Mandira Baniya <mandira.nursingsirc@gmail.com>

Re: SCI-QL-23 Research project in spinal cord injury patients

2 messages

Margareta Kreuter <margareta.kreuter@neuro.gu.se> Tue, Nov 13, 2018 at 11:35 AM

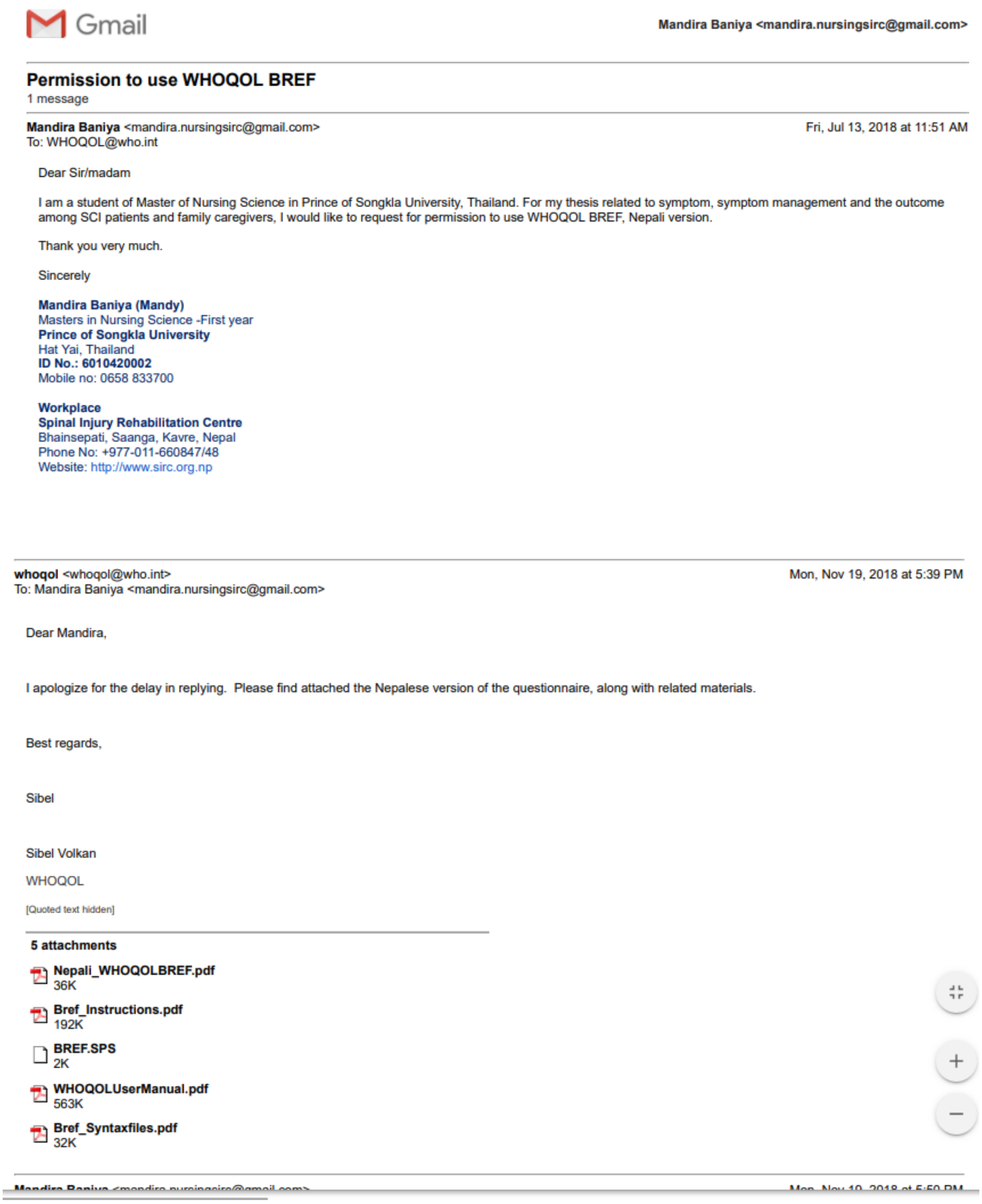
To: Mandira Baniya <mandira.nursingsirc@gmail.com>

Dear Mandira,
I hereby give you the permission to translate the SCI QL-23 from the English version into the Nepali language. I attach to this mail the instructions of the translation procedure as well as references and the manual how to score. I am looking forward to receive the translated version of the questionnaire and your proposal. Please let me know if I can be of any further help. Don´t hesitate to ask me any question you may have.

I wish you good luck with the project.
Kindest regards,
Margareta Kreuter

Associate professor, Senior lecturer
Institute of Neuroscience and Physiology
Sahlgrenska Academy at the University of Gothenburg
Box 455
SE 40530 Göteborg
Sweden
Phone: +46 31 786 5724
Mobile: +46 709 623162
email: margareta.kreuter@gu.se**Från:** Mandira Baniya <mandira.nursingsirc@gmail.com>

2. Permission to use WHOQOL BREF



Mandira Baniya <mandira.nursingsirc@gmail.com>

Permission to use WHOQOL BREF

1 message

Mandira Baniya <mandira.nursingsirc@gmail.com> Fri, Jul 13, 2018 at 11:51 AM
To: WHOQOL@who.int

Dear Sir/madam

I am a student of Master of Nursing Science in Prince of Songkla University, Thailand. For my thesis related to symptom, symptom management and the outcome among SCI patients and family caregivers, I would like to request for permission to use WHOQOL BREF, Nepali version.

Thank you very much.

Sincerely

Mandira Baniya (Mandy)
Masters in Nursing Science -First year
Prince of Songkla University
Hat Yai, Thailand
ID No.: 6010420002
Mobile no: 0658 833700

Workplace
Spinal Injury Rehabilitation Centre
Bhainsepati, Saanga, Kavre, Nepal
Phone No: +977-011-660847/48
Website: http://www.sirc.org.np

whoqol <whoqol@who.int> Mon, Nov 19, 2018 at 5:39 PM
To: Mandira Baniya <mandira.nursingsirc@gmail.com>

Dear Mandira,

I apologize for the delay in replying. Please find attached the Nepalese version of the questionnaire, along with related materials.

Best regards,

Sibel

Sibel Volkan

WHOQOL

[Quoted text hidden]

5 attachments

Nepali_WHOQOLBREF.pdf
36K

Bref_Instructions.pdf
192K

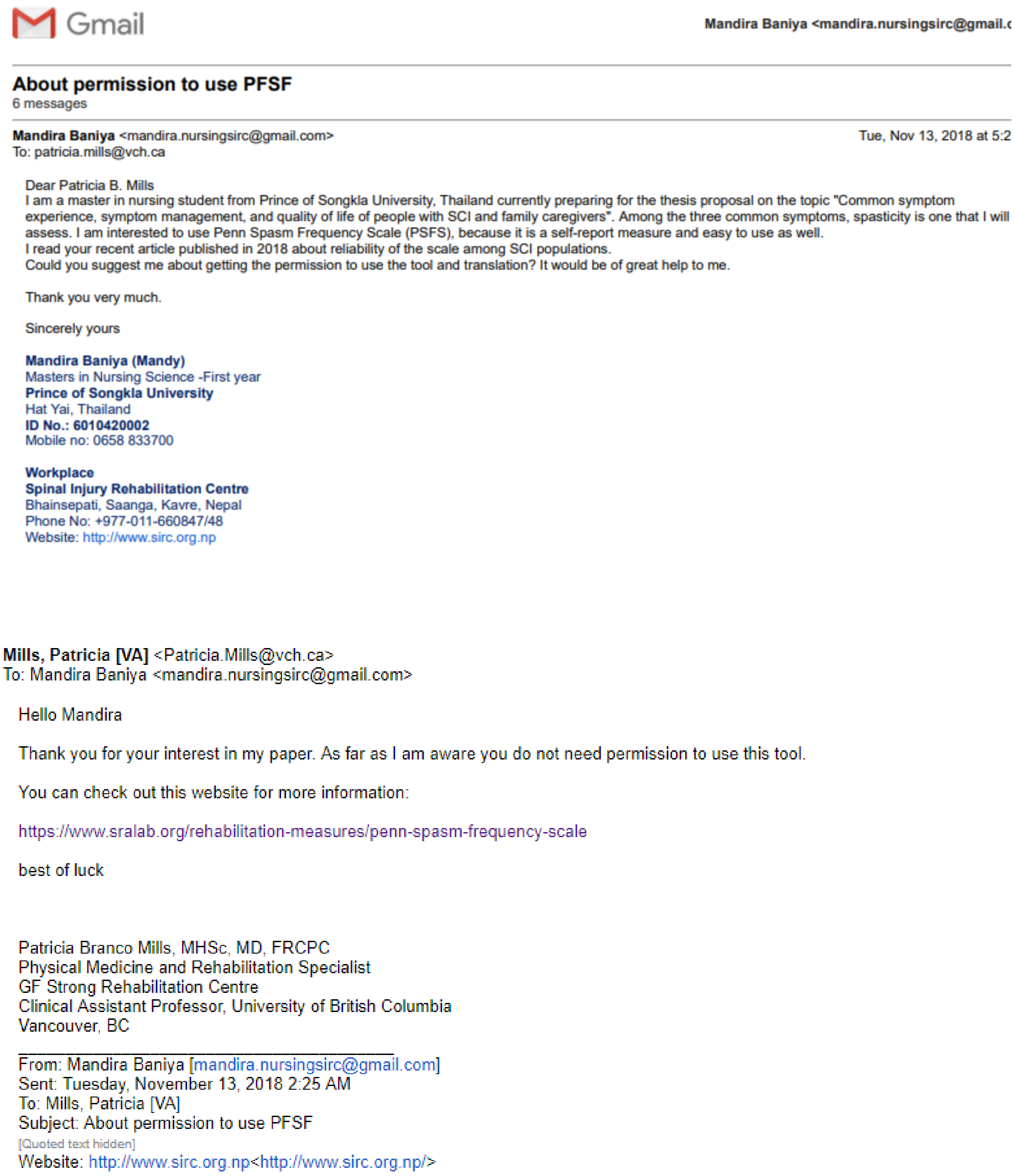
BREF.SPS
2K

WHOQOLUserManual.pdf
563K

Bref_Syntaxfiles.pdf
32K

Mandira Baniya <mandira.nursingsirc@gmail.com> Mon, Nov 19, 2018 at 5:50 PM

3. Permission to use PSFS



Mandira Baniya <mandira.nursingsirc@gmail.c

About permission to use PFSF
6 messages

Mandira Baniya <mandira.nursingsirc@gmail.com>
To: patricia.mills@vch.ca

Tue, Nov 13, 2018 at 5:2

Dear Patricia B. Mills
I am a master in nursing student from Prince of Songkla University, Thailand currently preparing for the thesis proposal on the topic "Common symptom experience, symptom management, and quality of life of people with SCI and family caregivers". Among the three common symptoms, spasticity is one that I will assess. I am interested to use Penn Spasm Frequency Scale (PSFS), because it is a self-report measure and easy to use as well.
I read your recent article published in 2018 about reliability of the scale among SCI populations.
Could you suggest me about getting the permission to use the tool and translation? It would be of great help to me.

Thank you very much.

Sincerely yours

Mandira Baniya (Mandy)
Masters in Nursing Science -First year
Prince of Songkla University
Hat Yai, Thailand
ID No.: 6010420002
Mobile no: 0658 833700

Workplace
Spinal Injury Rehabilitation Centre
Bhainsepati, Saanga, Kavre, Nepal
Phone No: +977-011-660847/48
Website: http://www.sirc.org.np

Mills, Patricia [VA] <Patricia.Mills@vch.ca>
To: Mandira Baniya <mandira.nursingsirc@gmail.com>

Hello Mandira

Thank you for your interest in my paper. As far as I am aware you do not need permission to use this tool.

You can check out this website for more information:

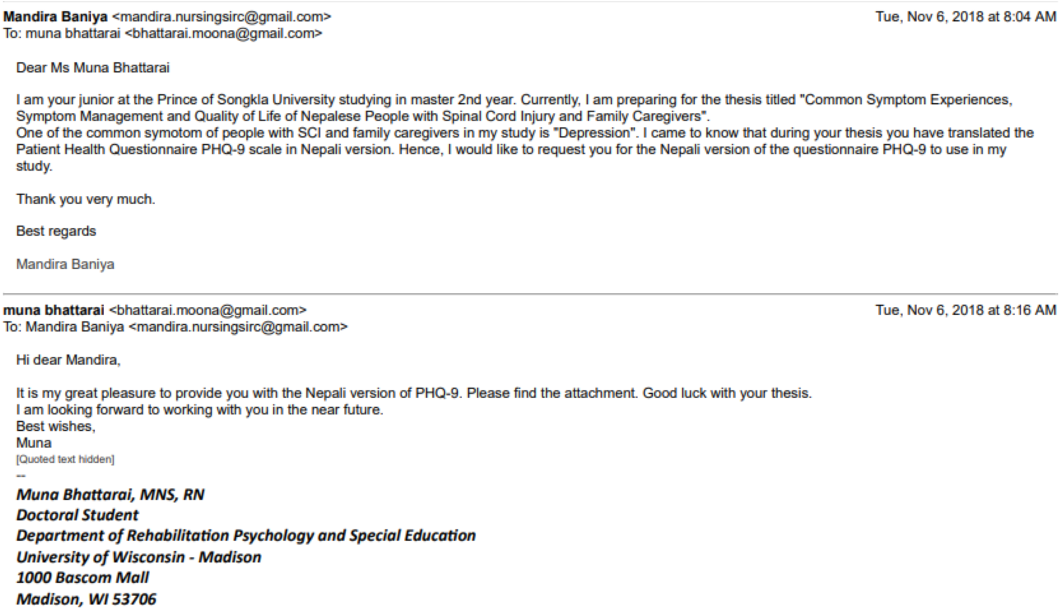
https://www.sralab.org/rehabilitation-measures/penn-spasm-frequency-scale

best of luck

Patricia Branco Mills, MHSc, MD, FRCPC
Physical Medicine and Rehabilitation Specialist
GF Strong Rehabilitation Centre
Clinical Assistant Professor, University of British Columbia
Vancouver, BC

From: Mandira Baniya [mandira.nursingsirc@gmail.com]
Sent: Tuesday, November 13, 2018 2:25 AM
To: Mills, Patricia [VA]
Subject: About permission to use PFSF
[Quoted text hidden]
Website: http://www.sirc.org.np<http://www.sirc.org.np/>

4. Permission to use PHQ-9 (Nepali Version)



Mandira Baniya <mandira.nursingsirc@gmail.com>
To: muna bhattarai <bhattarai.moona@gmail.com>

Tue, Nov 6, 2018 at 8:04 AM

Dear Ms Muna Bhattarai

I am your junior at the Prince of Songkla University studying in master 2nd year. Currently, I am preparing for the thesis titled "Common Symptom Experiences, Symptom Management and Quality of Life of Nepalese People with Spinal Cord Injury and Family Caregivers".
One of the common symotom of people with SCI and family caregivers in my study is "Depression". I came to know that during your thesis you have translated the Patient Health Questionnaire PHQ-9 scale in Nepali version. Hence, I would like to request you for the Nepali version of the questionnaire PHQ-9 to use in my study.

Thank you very much.

Best regards

Mandira Baniya

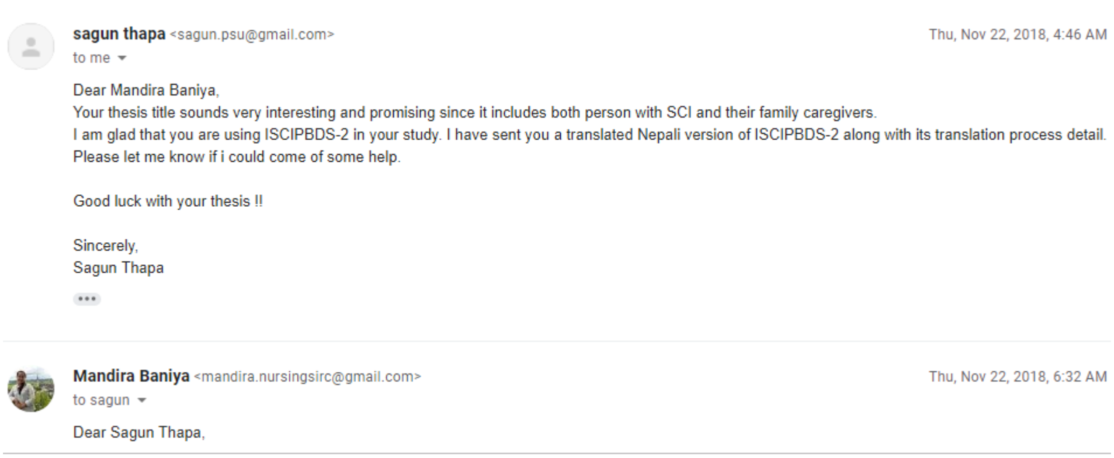
muna bhattarai <bhattarai.moona@gmail.com>
To: Mandira Baniya <mandira.nursingsirc@gmail.com>

Tue, Nov 6, 2018 at 8:16 AM

Hi dear Mandira,

It is my great pleasure to provide you with the Nepali version of PHQ-9. Please find the attachment. Good luck with your thesis.
I am looking forward to working with you in the near future.
Best wishes,
Muna
[Quoted text hidden]
--
Muna Bhattarai, MNS, RN
Doctoral Student
Department of Rehabilitation Psychology and Special Education
University of Wisconsin - Madison
1000 Bascom Mall
Madison, WI 53706

5. Permission to use ISCIPBDS (Nepali version)



sagun thapa <sagun.psu@gmail.com>
to me
Thu, Nov 22, 2018, 4:46 AM

Dear Mandira Baniya,
Your thesis title sounds very interesting and promising since it includes both person with SCI and their family caregivers.
I am glad that you are using ISCIPBDS-2 in your study. I have sent you a translated Nepali version of ISCIPBDS-2 along with its translation process detail.
Please let me know if i could come of some help.

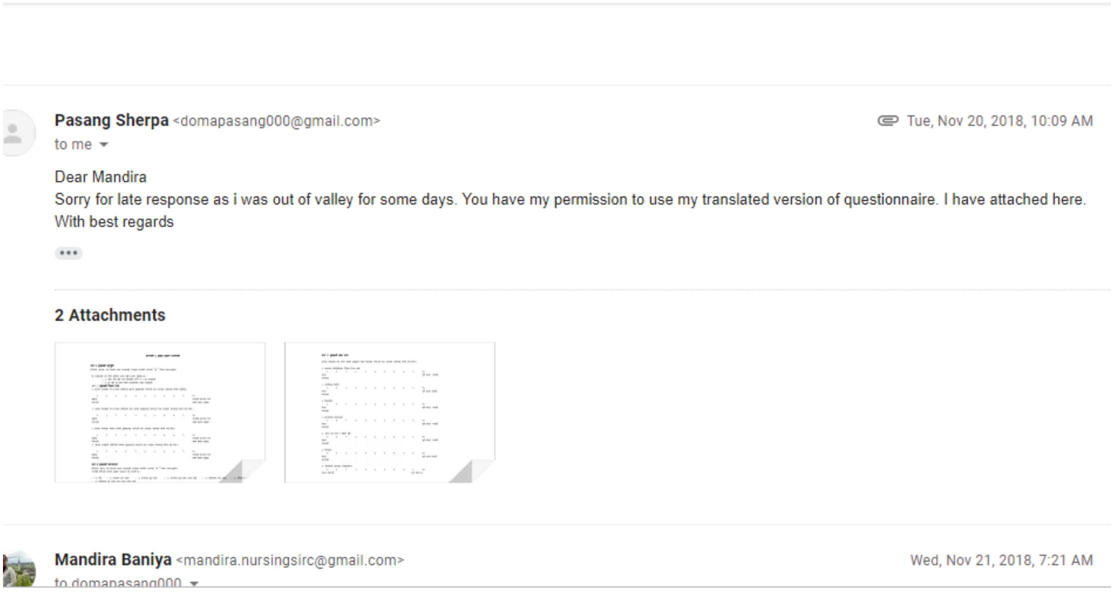
Good luck with your thesis !!

Sincerely,
Sagun Thapa

Mandira Baniya <mandira.nursingsirc@gmail.com>
to sagun
Thu, Nov 22, 2018, 6:32 AM

Dear Sagun Thapa,

6. Permission to use PEQ (Nepali version)



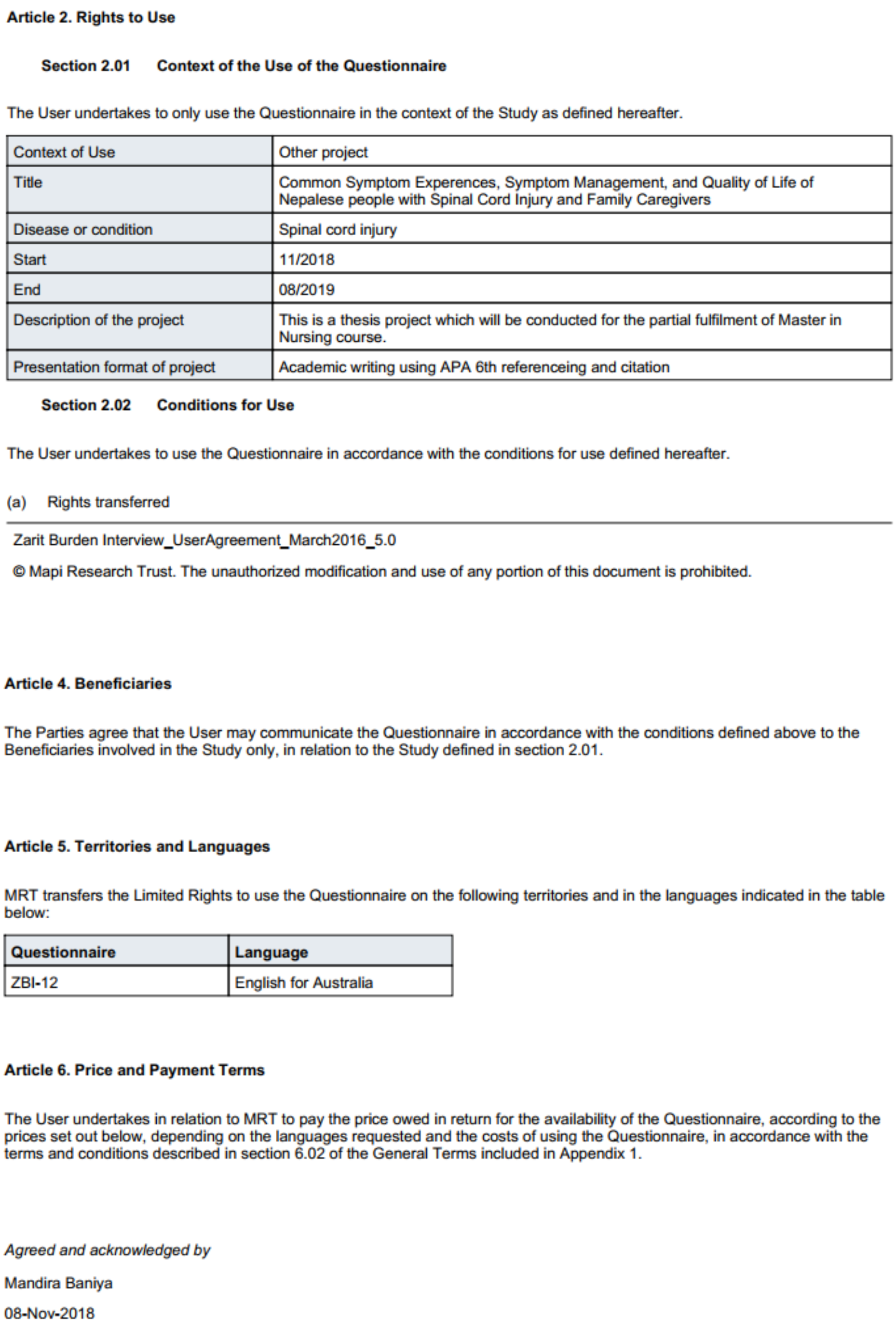
Pasang Sherpa <domapasang000@gmail.com>
to me
Tue, Nov 20, 2018, 10:09 AM

Dear Mandira
Sorry for late response as i was out of valley for some days. You have my permission to use my translated version of questionnaire. I have attached here.
With best regards

2 Attachments

Mandira Baniya <mandira.nursingsirc@gmail.com>
to domapasang000
Wed, Nov 21, 2018, 7:21 AM

7. Permission to use ZBI-12



Article 2. Rights to Use

Section 2.01 Context of the Use of the Questionnaire

The User undertakes to only use the Questionnaire in the context of the Study as defined hereafter.

Context of Use	Other project
Title	Common Symptom Experences, Symptom Management, and Quality of Life of Nepalese people with Spinal Cord Injury and Family Caregivers
Disease or condition	Spinal cord injury
Start	11/2018
End	08/2019
Description of the project	This is a thesis project which will be conducted for the partial fulfilment of Master in Nursing course.
Presentation format of project	Academic writing using APA 6th referenceing and citation

Section 2.02 Conditions for Use

The User undertakes to use the Questionnaire in accordance with the conditions for use defined hereafter.

(a) Rights transferred

Zarit Burden Interview_UserAgreement_March2016_5.0

Article 4. Beneficiaries

The Parties agree that the User may communicate the Questionnaire in accordance with the conditions defined above to the Beneficiaries involved in the Study only, in relation to the Study defined in section 2.01.

Article 5. Territories and Languages

MRT transfers the Limited Rights to use the Questionnaire on the following territories and in the languages indicated in the table below:

Questionnaire	Language
ZBI-12	English for Australia

Article 6. Price and Payment Terms

The User undertakes in relation to MRT to pay the price owed in return for the availability of the Questionnaire, according to the prices set out below, depending on the languages requested and the costs of using the Questionnaire, in accordance with the terms and conditions described in section 6.02 of the General Terms included in Appendix 1.

Agreed and acknowledged by

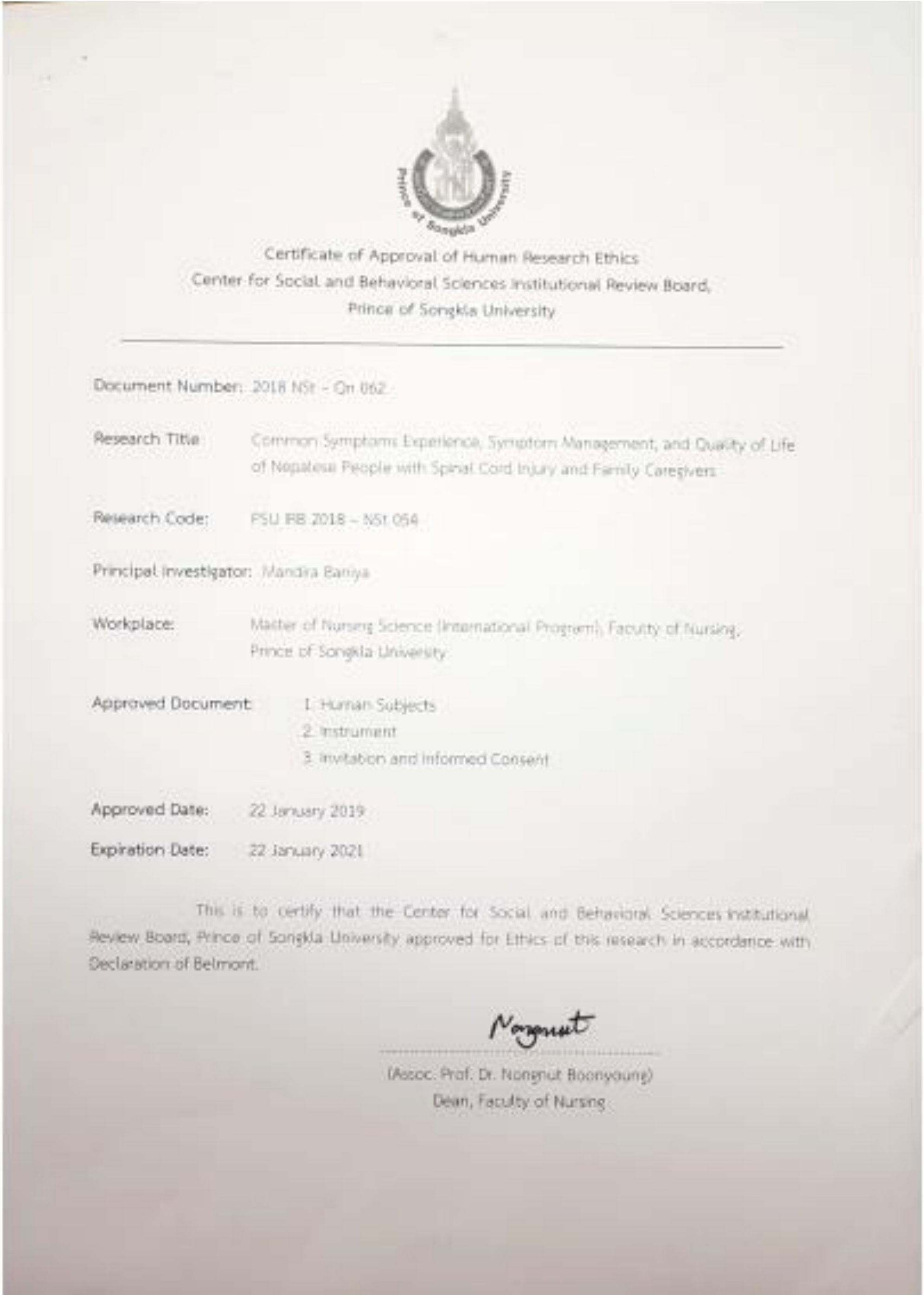
Mandira Baniya

08-Nov-2018

Appendix H

Ethical Approval Letters

1. Prince of Songkla University – IRB



Certificate of Approval of Human Research Ethics
Center for Social and Behavioral Sciences Institutional Review Board,
Prince of Songkla University

Document Number: 2018 NSt – Qn 062

Research Title: Common Symptoms Experience, Symptom Management, and Quality of Life of Nepalese People with Spinal Cord Injury and Family Caregivers

Research Code: PSU IRB 2018 – NSt 054

Principal Investigator: Mandira Baniya

Workplace: Master of Nursing Science (International Program), Faculty of Nursing, Prince of Songkla University

Approved Document:
1. Human Subjects
2. Instrument
3. Invitation and Informed Consent

Approved Date: 22 January 2019

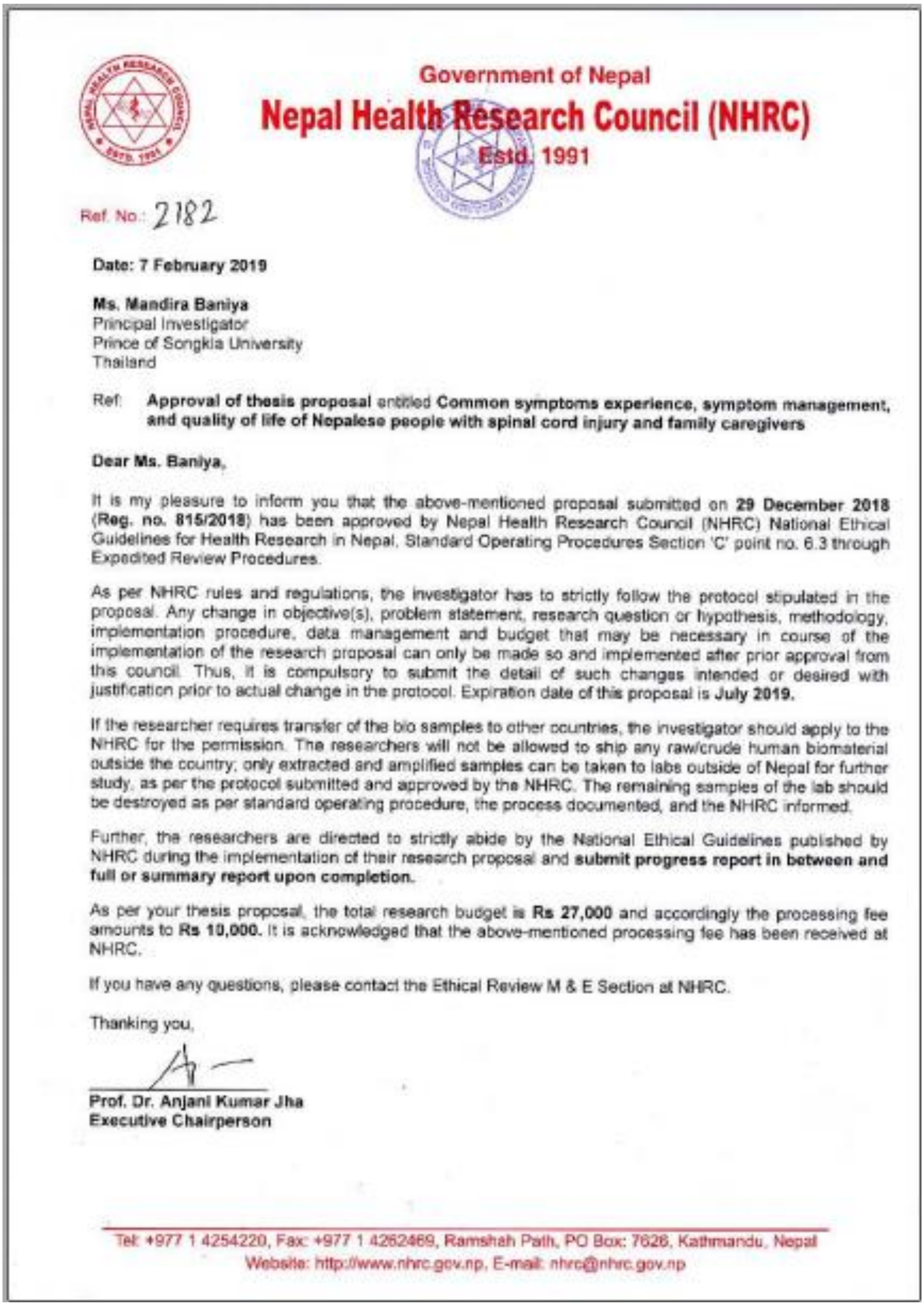
Expiration Date: 22 January 2021

This is to certify that the Center for Social and Behavioral Sciences Institutional Review Board, Prince of Songkla University approved for Ethics of this research in accordance with Declaration of Belmont.

Nongnut

(Assoc. Prof. Dr. Nongnut Boonyoung)
Dean, Faculty of Nursing

2. Approval Letter – Nepal Health Research Council



Government of Nepal
Nepal Health Research Council (NHRC)
Estd. 1991

Ref. No.: 2182

Date: 7 February 2019

Ms. Mandira Baniya
Principal Investigator
Prince of Songkla University
Thailand

Ref: **Approval of thesis proposal** entitled **Common symptoms experience, symptom management, and quality of life of Nepalese people with spinal cord injury and family caregivers**

Dear Ms. Baniya,

It is my pleasure to inform you that the above-mentioned proposal submitted on **29 December 2018** (**Reg. no. 815/2018**) has been approved by Nepal Health Research Council (NHRC) National Ethical Guidelines for Health Research in Nepal, Standard Operating Procedures Section 'C' point no. 6.3 through Expedited Review Procedures.

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. Expiration date of this proposal is **July 2019.**

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 in between and full or summary report upon completion.**

As per your thesis proposal, the total research budget is **Rs 27,000** and accordingly the processing fee amounts to **Rs 10,000.** It is acknowledged that the above-mentioned processing fee has been received at NHRC.

If you have any questions, please contact the Ethical Review M & E Section at NHRC.

Thanking you,

Prof. Dr. Anjani Kumar Jha
Executive Chairperson

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

3. Approval Letter – Spinal Injury Rehabilitation Center, Nepal

स्पाइनल
इन्जरी संघ नेपाल
Spinal
Injury Sangh Nepal

जि.प्र.का.ल.द.नं. [illegible]
स.क.प.आ.नं. १५३५४
Reg. No. 160/1345
SWC: 15354

Ref: ३६/७५/०७६

Date: 15th Jan 2019

Dear Mandira Baniya,

Re: Permission to collect data for research on topic "Common Symptoms Experience, Symptom management and Quality of Life of Nepalese People with Spinal Cord Injury and Family Caregivers)"

Following the careful consideration by the Research and Development Committee (Ethics), I am delighted to inform you that the committee has given you approval for data collection for your research on **Common Symptoms Experience, Symptom management and Quality of Life of Nepalese People with Spinal Cord Injury and Family Caregivers)"**

Your focal contact person is Dr. Raju Dhakal who will supervise your process of data collection for completion of this research.

Additionally, if you wish to publish your findings in a journal you will need to submit the manuscript and get a written no objection permission from the organization.

We would also like to request you to submit your final report along with relevant approval document after completion of the research.

Yours Sincerely,

Esha Thapa

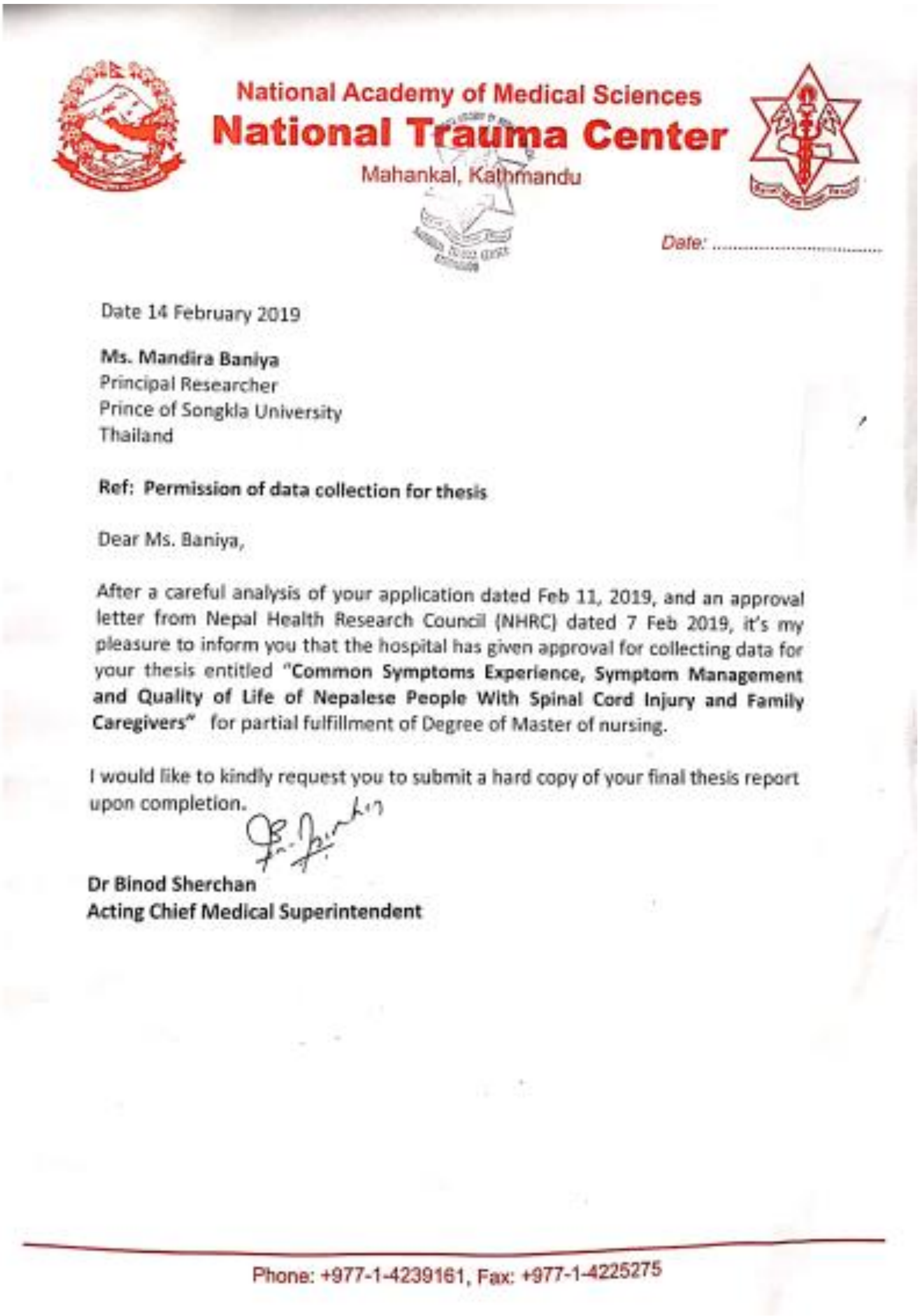
Executive Director -SISN

(Member , Research and Development Committee)

स्पाइनल
इन्जरी संघ नेपाल
Spinal
Injury Sangh Nepal

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, spinalnepal@gmail.com, Website: www.sirc.org.np

4. Approval Letter - National Trauma Center, Nepal



National Academy of Medical Sciences
National Trauma Center
Mahankal, Kathmandu

Date: ....

Date 14 February 2019

Ms. Mandira Baniya
Principal Researcher
Prince of Songkla University
Thailand

Ref: Permission of data collection for thesis

Dear Ms. Baniya,

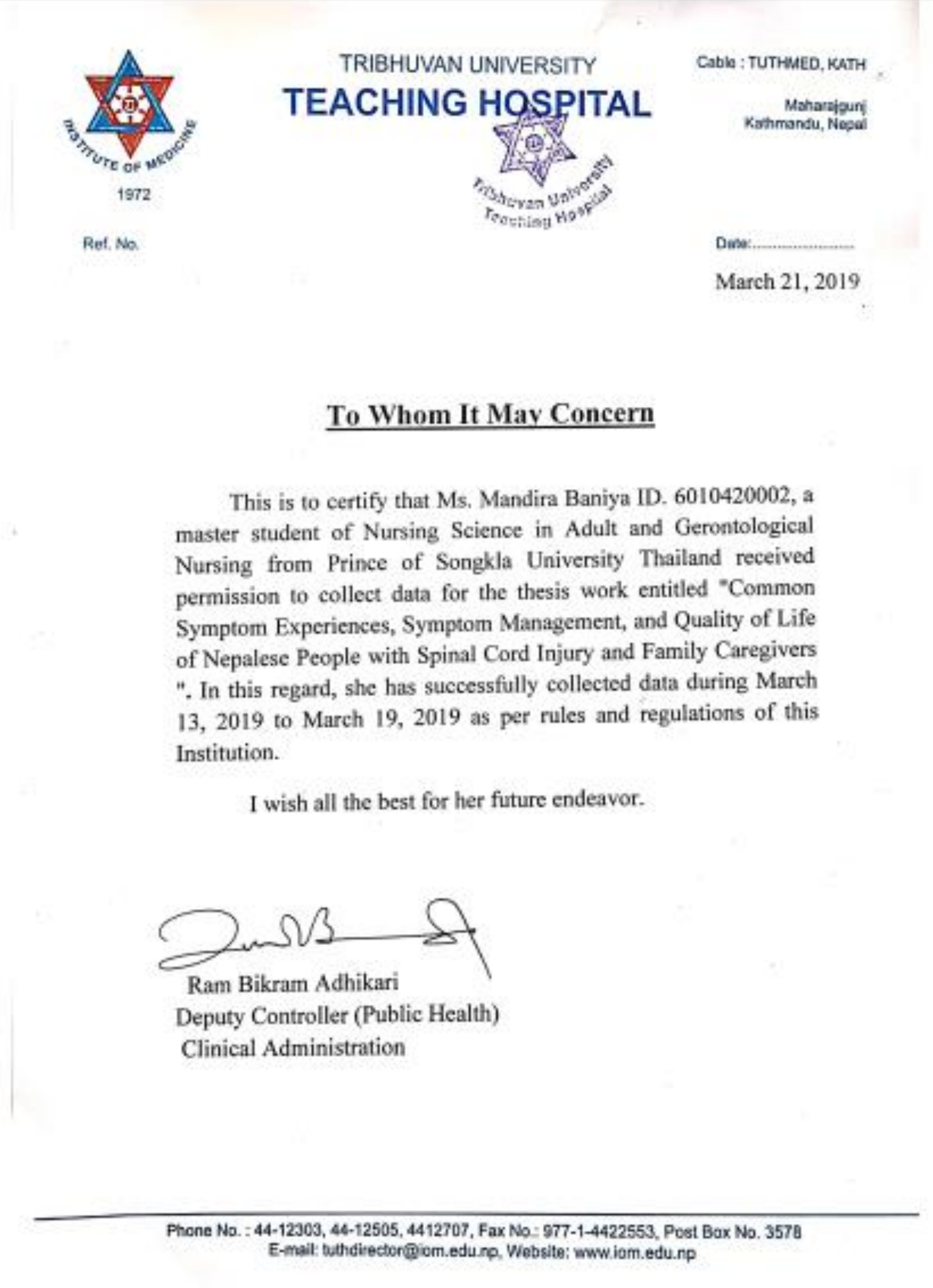
After a careful analysis of your application dated Feb 11, 2019, and an approval letter from Nepal Health Research Council (NHRC) dated 7 Feb 2019, it's my pleasure to inform you that the hospital has given approval for collecting data for your thesis entitled "**Common Symptoms Experience, Symptom Management and Quality of Life of Nepalese People With Spinal Cord Injury and Family Caregivers**" for partial fulfillment of Degree of Master of nursing.

I would like to kindly request you to submit a hard copy of your final thesis report upon completion.

Dr Binod Sherchan
Acting Chief Medical Superintendent

Phone: +977-1-4239161, Fax: +977-1-4225275

5. Approval Letter – Tribhuvan University Teaching Hospital, Nepal



TRIBHUVAN UNIVERSITY
TEACHING HOSPITAL

INSTITUTE OF MEDICINE
1972

Cable : TUTHMED, KATH

Maharajgunj
Kathmandu, Nepal

Ref. No.

Date:.......................
March 21, 2019

To Whom It May Concern

This is to certify that Ms. Mandira Baniya ID. 6010420002, a master student of Nursing Science in Adult and Gerontological Nursing from Prince of Songkla University Thailand received permission to collect data for the thesis work entitled "Common Symptom Experiences, Symptom Management, and Quality of Life of Nepalese People with Spinal Cord Injury and Family Caregivers ". In this regard, she has successfully collected data during March 13, 2019 to March 19, 2019 as per rules and regulations of this Institution.

I wish all the best for her future endeavor.

Ram Bikram Adhikari
Deputy Controller (Public Health)
Clinical Administration

Phone No. : 44-12303, 44-12505, 4412707, Fax No.: 977-1-4422553, Post Box No. 3578
E-mail: tuthdirector@iom.edu.np, Website: www.iom.edu.np

Appendix I

VITA

Name Ms. Mandira Baniya

Student ID 6010420002

Educational Attainment

Degree	**Name of Institution**	**Year of Graduation**
Diploma in Nursing	Tribhuvan University	2006
Post Basic Bachelor in Nursing	Tribhuvan University	2012

Scholarship Award during Enrollment

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

Work Experience

Year	**Position**	**Workplace**
2007-2009	Staff nurse/counselor	Association of Medical Doctors of Asia (AMDA-Nepal)
2009-2011	Staff Nurse	Tribhuvan University Teaching Hospital
2013-at present	Nursing supervisor	Spinal Injury Rehabilitation Center