



**Chronic Low Back Pain Experience, Pain Management Strategies,  
and Quality of Life Among Family Caregivers of Persons With  
Physical Disability in Nepal**

**Pasang Doma Sherpa**

**A Thesis Submitted in Partial Fulfillment of the Requirement for the  
Degree of Master of Nursing Science (International Program)**

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Physical Disability in Nepal  
**Author**                                Miss Pasang Doma Sherpa  
**Major Program**                    Nursing Science (International Program)

---

**Major Advisor**

.....  
(Asst. Prof. Dr. Luppana Kitrungrote)

**Examining Committee:**

.....Chairperson  
(Assoc. Prof. Dr. Waraporn Kongsuwan)

.....Committee  
(Asst. Prof. Dr. Luppana Kitrungrote)

**Co-advisor**

.....  
(Asst. Prof. Dr. Wipa Sae-Sia)

.....Committee  
(Asst. Prof. Dr. Wipa Sae-Sia)

.....Committee  
(Dr. Yanat Wauters)

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

.....  
(Assoc. Prof. Dr. Teerapol Srichana)  
Dean of Graduate School

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

..... Signature

(Asst. Prof. Dr. Luppana Kitrungrrote)

Major Advisor

..... Signature

(Ms. Pasang Doma Sherpa)

Candidate

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

..... Signature

(Ms. Pasang Doma Sherpa)

Candidate

ชื่อวิทยานิพนธ์	ประสบการณ์ความปวดหลังส่วนล่างเรื้อรัง กลวิธีการจัดการความปวด และคุณภาพชีวิตของญาติผู้ดูแลผู้พิการทางกายในประเทศเนปาล
ผู้เขียน	นางสาว พาชาง โดมา เซอร์ปา
สาขาวิชา	พยาบาลศาสตร์ (หลักสูตรนานาชาติ)
ปีการศึกษา	2559

### บทคัดย่อ

การศึกษาเชิงบรรยายแบบตัดขวางมีวัตถุประสงค์เพื่อศึกษาประสบการณ์ความปวดหลังส่วนล่างเรื้อรัง กลวิธีการจัดการความปวดและคุณภาพชีวิตของญาติผู้ดูแลผู้พิการทางกายในประเทศเนปาล ญาติผู้ดูแลจำนวน 103 รายซึ่งอาศัยอยู่ใน 8 ตำบลของโซนเบคมาดิในประเทศเนปาลได้ถูกคัดเลือกแบบเจาะจง การเก็บข้อมูลโดยใช้แบบสอบถามด้วยตนเองประกอบด้วย (1) ข้อมูลส่วนบุคคล สุขภาพและสิ่งแวดล้อม (2) แบบสอบถามประสบการณ์ความปวด (3) แบบสอบถามการจัดการความปวดหลังส่วนล่างเรื้อรัง และ (4) แบบสอบถามคุณภาพชีวิตขององค์การอนามัยโลกฉบับย่อ (เวอร์ชันเนปาล) แบบสอบถามถูกตรวจสอบความตรงโดยผู้ทรงคุณวุฒิจำนวนสามรายและความเที่ยงของแบบสอบถามได้ค่าสัมประสิทธิ์อัลฟาครอนบาคของแบบวัดความรุนแรงของความปวด แบบวัดของผลกระทบของความปวด(ซึ่งเป็นแบบวัดหนึ่งในแบบสอบถามประสบการณ์ความปวด) และแบบสอบถามคุณภาพชีวิตเท่ากับ .71, .87 และ .90 ตามลำดับ สถิติบรรยายและการวิเคราะห์เนื้อหาอย่างง่ายนำมาใช้ในการวิเคราะห์ข้อมูล

ผลการวิจัยพบว่าญาติผู้ดูแลมีประสบการณ์ความปวดในระดับปานกลาง ( $M = 4.5$ ,  $SD = 1.1$ ) ส่วนใหญ่มีอาการปวดทุกวัน (70.9%) และผลกระทบของความปวดรบกวนการดำเนินชีวิตในระดับปานกลาง ( $M = 4.2$ ,  $SD = 1.7$ ) ซึ่งการรบกวนที่พบบ่อยได้แก่ การทำงานตามปกติ กิจกรรมทั่วไปและอารมณ์

ญาติผู้ดูแลใช้วิธีการจัดการความปวดแบบไม่ใช้ยามากกว่าแบบใช้ยา การจัดการความปวดแบบไม่ใช้ยาที่พบบ่อยได้แก่ การอดทน (40.7%) การนวด (20.4%) และการประคบความร้อน (15.5%) นอกจากนี้มีการใช้ยาแก้ปวด (30%) โดยยาที่นิยมใช้บ่อยคือ ยาไอบูโพรเฟน (Ibuprofen)

ส่วนใหญ่ญาติผู้ดูแลเลือกวิธีการจัดการความปวดด้วยตนเองที่บ้านเกือบตลอดเวลาที่มีความปวดโดยให้เหตุผลว่าการจัดการความปวดด้วยวิธีดังกล่าวสามารถลดความปวดได้ ยาไอบูโพรเฟนลดปวดได้ผลระดับปานกลางถึงสูง ในขณะที่การจัดการความปวดแบบไม่ใช้ยาลดปวดได้ผลระดับเล็กน้อย

ญาติผู้ดูแลรับรู้คุณภาพชีวิตโดยรวมในระดับปานกลาง ( $M = 71.2, SD = 12.1$ ) เมื่อพิจารณาทางด้านของคุณภาพชีวิต พบว่าด้านสัมพันธภาพทางสังคมมีคะแนนเฉลี่ยสูงสุด ( $M = 52.1, SD = 14.4$ ) ในขณะที่ด้านจิตใจ ( $M = 40.1, SD = 16.4$ ) และด้านสิ่งแวดล้อมมีคะแนนเฉลี่ยต่ำสุด ( $M = 41.3, SD = 12.3$ ) ตามลำดับ

ผลการศึกษาครั้งนี้แสดงให้เห็นว่าญาติผู้ดูแลมีความปวดหลังส่วนล่างและคุณภาพชีวิตระดับปานกลาง ดังนั้นเจ้าหน้าที่สุขภาพควรให้ความรู้เกี่ยวกับการจัดการความปวดหลังส่วนล่างแก่ญาติผู้ดูแลและส่งเสริมด้านจิตใจและสิ่งแวดล้อมเพื่อพัฒนาคุณภาพชีวิตขณะให้การดูแลผู้พิการทางกาย

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Author	Miss Pasang Doma Sherpa
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### **ABSTRACT**

This descriptive cross-sectional study was conducted to determine the chronic low back pain (LBP) experience, pain management strategies and quality of life (QoL) among family caregivers of persons with physical disability in Nepal. One hundred and three family caregivers residing in the communities of eight districts of the Bagmati Zone of Nepal were selected with inclusion criteria. Data were collected by using self-report questionnaires including (1) Demographic, Health and Environment-related Data Form (DHEDF); (2) Pain Experience Questionnaire (PEQ); (3) Chronic Low Back Pain Management Questionnaire (CLBPMQ); (4) World Health Organization Quality of Life BREF (WHOQOL-BREF) Nepali Version. The questionnaires were validated content by three experts and their reliability was tested which yielded Cronbach alpha of .71 for pain intensity scale and .87 for pain interference scale of PEQ, and .90 for WHOQOL-BREF. Descriptive statistics and simple content analysis were used.

The results of this study showed that the family caregivers experienced a moderate level of pain intensity ( $M = 4.5$ ,  $SD = 1.1$ ). The majority of the family caregivers (70.9%) experienced pain every day. The overall pain interference was at a

moderate level ( $M = 4.2$ ,  $SD = 1.7$ ) with common interferences in normal work, general activities, and mood.

The family caregivers used non-pharmacological pain management more than pharmacological management. The non-pharmacological pain management methods that family caregivers commonly used include endurance (40.7%), massage (20.4%), and hot application (15.5%). Pain medications were used by 30 % of caregivers; in particular, Ibuprofen was the most commonly used. The majority of family caregivers managed LBP by themselves at home and they gave reasons that these pain management strategies could minimize pain. Most of them used pain management most of the time during pain. Ibuprofen was found to be moderately to highly effective, whereas non-pharmacological managements commonly used were little effective.

Overall, the family caregivers perceived a moderate level of QoL ( $M = 71.2$ ,  $SD = 12.1$ ). Considering each domain of QoL, the social relationship domain had the highest mean score ( $M = 52.1$ ,  $SD = 14.4$ ), whereas the psychological domain had the lowest mean score ( $M = 40.1$ ,  $SD = 16.4$ ) followed by the environment domain ( $M = 41.3$ ,  $SD = 12.3$ ).

The findings of this study showed that the family caregivers had LBP and QoL at moderate levels. Therefore, the healthcare providers should provide education about LBP management to family caregivers and promote their psychological health and environment to enhance their QoL while caring for persons with physical disability.



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## CONTENTS

	Page
ABSTRACT (Thai).....	v
ABSTRACT (English).....	vii
ACKNOWLEDGMENT.....	ix
CONTENTS.....	x
LIST OF TABLES.....	xiii
LIST OF FIGURES.....	xiv
 CHAPTERS	
1. Introduction	
Background and Significance of the Problem .....	1
Objective of the Study.....	5
Research Questions .....	5
Conceptual Framework of the Study .....	6
Definition of Terms.....	10
Scope of the Study.....	11
Significance of the Study.....	12
2. Literature Review	
Overview of Persons With Physical Disability and the Impact on Family Caregivers.....	13
Symptom Management Model.....	17
Chronic Low Back Pain Experience Among Family Caregivers of Persons With Physical Disability.....	21

## CONTENTS (Continued)

	Page
Chronic Low Back Pain Management Strategies Among Family Caregivers of Persons With Physical Disability.....	38
Quality of Life Among Family Caregivers of Persons With Physical Disability.....	51
Overview of Caregiving and Health Care in the Context of Nepal.....	63
Summary of Literature Review.....	65
<b>3. Research Methodology</b>	
Research Design.....	68
Setting.....	68
Population and Sample .....	69
Instruments.....	70
Data Collection Methods.....	76
Ethical Consideration.....	77
Data Analysis.....	78
<b>4. Result and Discussion</b>	
Result.....	79
Discussion .....	91
<b>5. Conclusion and Recommendations</b>	
Conclusion .....	101
Strength of the Study .....	102
Limitation of the Study .....	103

**CONTENTS (Continued)**

	Page
Implication and Recommendations .....	103
References .....	105
APPENDICES	
A. Informed Consent Form.....	123
B. Demographic, Health and Environment Related Data Form.....	126
C. Pain Experience Questionnaire.....	128
D. Chronic Low Back Pain Management Questionnaire.....	130
E. World Health Organization Quality of Life BREF .....	131
F. Steps of Computing Domain Score of WHOQOL-BREF.....	134
G. Approval Letters.....	135
H. Permission of Research Instruments .....	140
I. Query for Scoring Level of Quality of Life.....	143
J. Name List of Experts .....	144
K. Name List of Instrument Translators.....	145
VITAE.....	146

## LIST OF TABLES

Tables	Page
1. Frequency and Percentage of Family Caregivers Classified by Demographic and Health Related Data ( <i>N</i> =103) .....	80
2. Frequency and Percentage of Family Caregivers Classified by Environment Related Data ( <i>N</i> =103) .....	82
3. Frequency, Percentage, Minimum, Maximum, Mean, Standard Deviation, and Level of Chronic Low Back Pain Intensity, Pain Frequency, and Pain Interference Among Family Caregivers ( <i>N</i> =103) .....	84
4. Frequency and Percentage of Family Caregivers Perceived About Frequency of Pain Management ( <i>N</i> =103).....	86
5. Frequency and Percentage of Family Caregivers About Reasons of Using Pain Management ( <i>N</i> =103) .....	87
6. Frequency and Percentage of Family Caregivers About Time, Person, and Place of Pain Management ( <i>N</i> =103).....	88
7. Frequency and Percentage of Family Caregivers Perceived About Pain Management's Effectiveness ( <i>N</i> =103) .....	89
8. Rang, Mean, Standard Deviation, and Level of Quality of Life of Family Caregivers ( <i>N</i> =103) .....	90

**LIST OF FIGURES**

Figures	Page
1. Conceptual Framework of the Study.....	10
2. Map of Bagmati Zone .....	69

## **Chapter 1**

### **Introduction**

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

#### **Background and Significance of the Problem**

The growth in aging populations, chronic disease, injuries, and the advancement of modern technologies to save lives have increased the number of disabilities worldwide (The World Bank, 2016). According to the World Health Organization[WHO](2016), more than one billion people are suffering from disabilities worldwide. Among them, nearly 110 to 190 million are suffering from significant disabilities that limit their functioning (The World Bank, 2016). In Nepal, the national census report of 2011 reported 513,321 (1.94%) people with disabilities, among which 186,457 were the persons with physical disability (Resource Center for Rehabilitation and Development Nepal, 2011).

A physical disability causes severe disabling consequences on the physical functioning and sensitivity resulting in loss of functional independence (Nogueira et al., 2015; Yalcinkaya, Ones, Ayna, Turkyilmaz, & Erden, 2010). As a result, person with physical disability requires support that extends from assistance in activities of daily living (ADL) to complete personal care in the community (Lawang, Horey, & Blackford, 2015; Nogueira, Rabeh, Caliri, & Haas, 2013; Yalcinkaya et al., 2010). The family caregivers are the important persons responsible for providing hours of

personal care and assistance in ADL for long term in the community (Darragh et al., 2015; Lawang et al., 2015). However, continuous caregiving activities for a person with a physical disability, that include lifting, transfer, bathing, dressing, and toilet care can cause low back pain (LBP) among family caregivers (Darragh et al., 2015; Suzuki, Tamakoshi, & Sakakibara, 2016). Relevantly, a high prevalence of LBP was found in family caregivers of persons with physical disability (Darragh et al., 2015; Yalcinkaya et al., 2010).

Caregiving for persons with physical disability is associated with high intensity, frequency, and interference of LBP. Previous studies conducted in family caregivers of physically disabled children in Turkey (Tonga & Duger, 2008) and Kenya (Geere et al., 2013) revealed that mothers of disabled children experienced the moderate intensity of LBP. The number of studies regarding the frequency and interference due to LBP in family caregivers is limited; however, it is evident that professional caregivers (i.e., nurses) working for dependent patients experienced frequent LBP almost once a week (June & Cho, 2011; Ovayolu, Ovayolu, Gene, & Araz, 2014). The pain experienced by caregivers had moderate to severe interference on general activities, mood, walking, normal work, sleep quality, and enjoyment of life (Lin et al., 2014). Frequent LBP with increased intensity may lead to the development of chronic LBP. Chronic LBP may cause functional disability, work interference, psychological distress and affect in standard and quality of care to disabled (Currie & Wang, 2004; Emmanuel, Ezhilarasu, & Bheemaroo, 2015). Thus, management of chronic LBP is crucial.

According to the Symptom Management Model (SMM), the goal in the management of symptoms is to minimize the symptom experience through



biomedical, professional, and self-care strategies (Dodd et al., 2001). However, the current evidence of chronic LBP management strategies in family caregivers of persons with physical disability is still lacking. The management of chronic LBP has been studied in professional caregivers (i.e., nurses) and patients with chronic LBP. The managements were conducted either by health care providers or the individuals themselves. The management conducted by the health care providers included pharmacological therapy (i.e., NSAIDs, Opioid, antidepressant) (White, Arnold, Norvell, Ecker, & Fehlings, 2011) and non-pharmacological therapies including massage (Borges, Kurebayashi, & Silva, 2014), heat therapy (Dehghan & Farahbod, 2014), exercise (Chen, Wang, Chen, & Hu, 2014), and yoga (Tilbrook et al., 2011). The methods for the chronic LBP management conducted by the individuals (i.e., patients, workers) themselves were medications, exercise, hot and cold applications, massage, distraction, and lifestyle modifications (Crowe, Whitehead, Gagan, Baxter, & Panckhurst, 2010; Kawi, 2014; Tveito, Shaw, Huang, Nicholas, & Wagner, 2010). Effective management is important to increase positive outcomes and reduce negative consequences (Dodd et al., 2001).

According to the SMM, symptom experience and symptom management were related to outcomes (i.e., quality of life) (Dodd et al., 2001). According to WHO (1997), quality of life (QoL) is defined as an individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. It is a broad ranging concept incorporating in a complex way by the person's physical health, psychological state, independence, social relationships, personal beliefs, and their relationships to salient features of the environment.

The QoL of family caregivers of persons with physical disability was found to be low compared to the general population. Previous studies conducted in family caregivers of the disabled revealed a low QoL in all four domains (i.e., physical health, psychological, social relationships, and environment) measured by the World Health Organization Quality of Life-BREF (WHOQOL-BREF) when compared to the general population (Alshubaili, Ohaeri, Awadalla, & Mabrouk, 2008; Chou, Lin, Chang, & Schalock, 2007; Malhotra, Khan, & Bhatia, 2012). Furthermore, various studies conducted in family caregivers of persons with physical disability such as spinal cord injury, traumatic brain injury, and stroke reported a low QoL in the domains of bodily pain, general health, vitality, and role-emotional as measured by the Short Form Health Survey 36 (SF-36) (Arango-Lasprilla et al., 2011; Morimoto, Schreiner, & Asano, 2003; Nogueira et al., 2015).

Based on the SMM, symptom experience, symptom management strategies, and symptom outcomes are highly influenced by the personal, health and illness, and environmental factors (Dodd et al., 2001). In this regard, the findings of previous studies (Crowe et al., 2010; Suzuki et al., 2016; Tonga & Duger, 2008; Tveito et al., 2010) were mostly derived from developed countries such as the Turkey, Japan, New Zealand, and USA, which may not be fully relevant to the chronic LBP experience, pain management strategies, and QoL of family caregivers of persons with physical disability in developing countries such as Nepal because of the differences in personal and environment factors (e.g., personal beliefs, socioeconomic status, and health care system).

Moreover, the chronic LBP experience, pain management strategies, and the QoL in family caregivers of persons with physical disability in Nepal have not been

studied yet. Therefore, it is necessary to study the chronic LBP experience, pain management strategies, and QoL in family caregivers of persons with physical disability in Nepal. The findings of this study will benefit the healthcare providers to become aware of the LBP of family caregivers and plan to prevent or manage LBP of family caregivers and maintain their QoL during providing continued care for persons with physical disability.

### **Objectives of the Study**

The objectives of the study were as follows:

1. To identify the chronic low back pain experience among family caregivers of persons with physical disability including the level of pain intensity, pain frequency, and the level of pain interference in Nepal.
2. To describe the chronic low back pain management strategies among the family caregivers of persons with physical disability in Nepal.
3. To identify the level of quality of life among the family caregivers of persons with physical disability in Nepal.

### **Research Questions**

The research questions of the study are as follows:

1. What was the chronic low back pain experience on the level of pain intensity, pain frequency, and the level of pain interference among family caregivers of persons with physical disability in Nepal?
2. What were the chronic low back pain management strategies among the family caregivers of persons with physical disability in Nepal?

3. What was the level of quality of life among the family caregivers of persons with physical disability in Nepal?

### **Conceptual Framework of the Study**

Symptom Management Model (SMM) (Dodd et al., 2001) with the integration of literature regarding chronic LBP, pain management, and quality of life was used to guide the study. The SMM consists of three dimensions: (1) symptom experience; (2) symptom management; and (3) outcome (Dodd et al., 2001). In addition, these dimensions are influenced by three domains which are conceptualized as contributing factors. These domains are the person, health and illness, and the environment.

#### **Symptom experience**

The symptom experience refers to the individual's perception of the symptom, evaluation of the symptom, and response to the symptom (Dodd et al., 2001). Perception of the symptom refers to the changes that an individual notice in their usual feeling or behavior. Once the symptom is perceived, it is evaluated by making a judgment about the intensity, frequency, location, and affective impact of the symptom on the individual's life. Symptom response is the individual's response to the symptoms in terms of change in physical, mental, and behavioral aspects (Dodd et al., 2001).

#### **Symptom management strategies**

Symptom management is the strategy to avert or delay, or minimize the symptom experience through biomedical, professional, or self-care strategies (Dodd et al., 2001). Management starts with the assessment of the symptom experience from the individual perspective. It includes the specifications of symptom management

strategies of what, how, how much, why, when, where, whom, and who. Self-management strategies are being given more attention in order to shift the responsibility of managing symptoms to the individual. An evaluation of symptom management is important to determine its effectiveness on a positive outcome and reduce negative consequences (Dodd et al., 2001).

### **Outcomes**

The outcome results from the management strategies or symptom experience. It includes eight components: (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).

Moreover, the above three dimensions of SMM are framed within the context of nursing domains of person, health and illness and environment (Dodd et al., 2001).

### **Chronic low back pain and its management**

Chronic LBP can be defined as the persistent discomfort, muscle tension, stiffness, and soreness localized in the anatomical area below the 12<sup>th</sup> rib posteriorly and below the costal margin and above the inferior gluteal folds or sacral region that persists for more than 12 weeks (Borenstein, 2011; Irwin & Sherman, 2014; Middelkoop et al., 2010).

Caregiving for persons with physical disability is associated with a high physical burden that results in a high prevalence of LBP (Tong et al., 2003; Tonga & Duger, 2008; Yalcinkaya et al., 2010). The family caregivers experienced the moderate intensity of LBP (Geere et al., 2013; Tonga & Duger, 2008). Similarly, professional caregivers (nurses) working for a dependent person experienced pain as frequently as almost once a week (June & Cho, 2011; Ovayolu, Ovayolu, Gene, &

Araz, 2014). LBP has moderate to severe interference on general activities, mood, walking, normal work, sleep quality, and enjoyment of life (Lin et al., 2014). The frequent LBP with increased intensity may lead to chronic LBP. Chronic LBP may cause functional disability, work interference, psychological distress and may affect the standard and quality of care (Currie & Wang, 2004; Emmanuel et al., 2015). Therefore, the management of chronic LBP is important to reduce negative outcomes.

The management of chronic LBP conducted by the healthcare providers include pharmacological therapies including NSAIDs, opioids, and antidepressants (White et al., 2011) and non-pharmacological therapies consisting of massage, heat therapy, exercise, and yoga (Borges et al., 2014; Chen et al., 2014; Dehghan & Farahbod, 2014; Tilbrook et al., 2011). The management conducted by the individual themselves may include medications, exercise, hot and cold applications, massage, distraction, and lifestyle modifications (Crowe et al., 2010; Kawi, 2014; Tveito et al., 2010). The effectiveness of managing chronic LBP can influence the QoL.

### **Quality of life**

According to WHO (1997), QoL is defined as an individual's perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. It is a broad ranging concept incorporating in a complex way by the person's physical health, psychological state, independence, social relationships, personal beliefs, and their relationships to salient features of the environment. QoL incorporates multidimensional concepts comprising physical health, psychological state, social relationship, and environment (WHO, 1997). The concept of QoL in family caregivers usually consists of physical, psychological, social well-being, and

fulfillment of personal expectation, economic assurance, and functional capacity (Arai, Nagatsuka, & Hirai, 2008; Caqueo-Urizar, Gutierrez-Maldonado, & Miranda-Castillo, 2009).

In this study, the concepts of SMM were integrated to assess the chronic LBP experience, pain management strategies, and QoL among family caregivers of persons with physical disability. With regards to the symptom experience dimension of SMM, the chronic LBP perceived and evaluated by the family caregivers of person with physical disability in terms of the level of pain intensity, pain frequency, and the level of pain interference were included.

With regards to symptom management strategies dimension of SMM, pain management strategies of the family caregivers of persons with physical disability to minimize or relieve chronic LBP were assessed. The pain management strategies included the specifications of what, how often, why, when, where, who and effectiveness.

With regards to the third dimension or outcome of the SMM, this study included QoL. The domains of the SMM (i.e. personal, health and illness, and environment) were collected to explain the chronic LBP experience, pain management strategies, and QoL among family caregivers of persons with physical disability in Nepal.

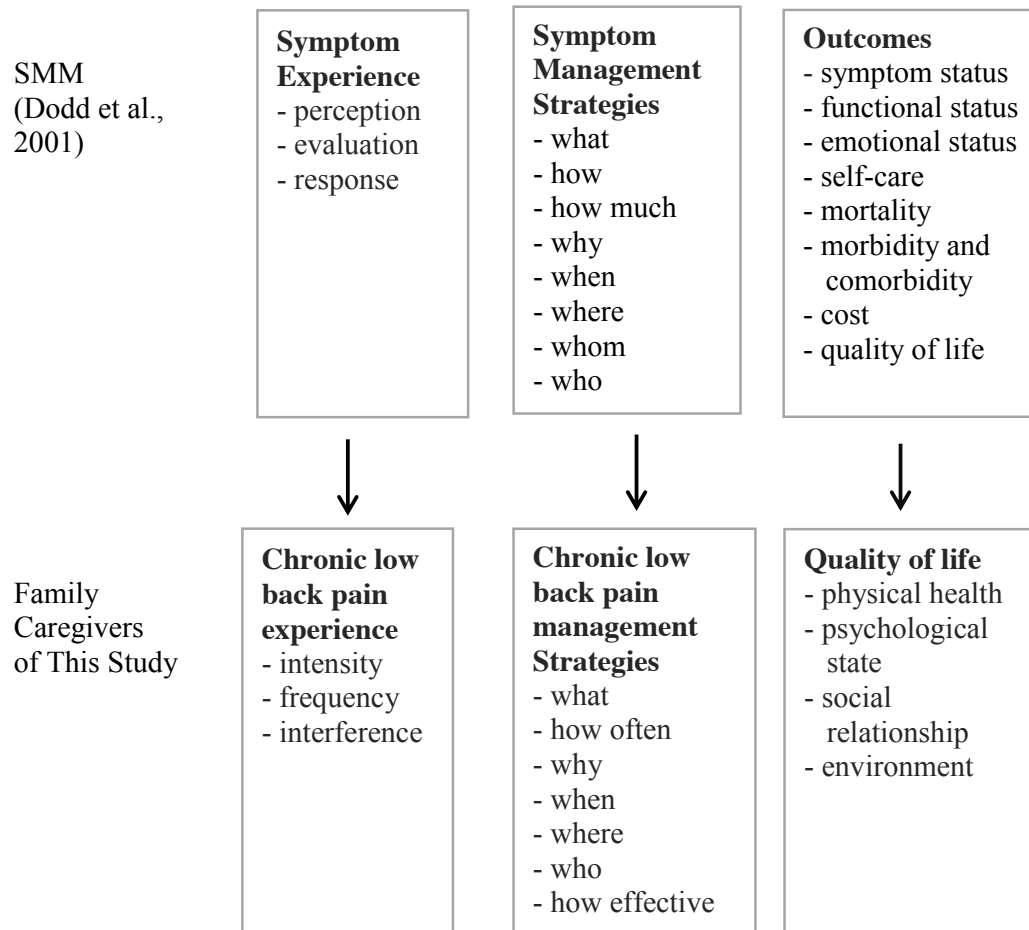


Figure 1. Conceptual framework of the study

## Definition of Terms

### Chronic low back pain experience

Chronic LBP experience refers to the discomfort or unpleasant sensation localized at the area below the 12<sup>th</sup> rib posteriorly and below the costal margin and above the sacral region for more than three months which is perceived and evaluated by family caregivers in regards to pain intensity, pain frequency, and pain interference. Chronic LBP intensity and pain interference was assessed by the pain



intensity and pain interference scales of the Short Form Brief Pain Inventory (SF-BPI) (Cleeland, 2009). Higher scores indicated a higher intensity and interference of pain. Pain frequency was measured by a questionnaire developed by the researcher based on the literature review.

### **Chronic low back pain management strategies**

Chronic LBP management strategies refer to any method used by the family caregivers to minimize or relieve chronic LBP. It includes types of pain management (what), frequency of pain management (how often), the reasons for pain management (why), the time of pain management (when), the places for pain management (where), pain management by themselves or by others (who), and the effectiveness of pain management (how effective). Chronic LBP management strategies were assessed using the Chronic LBP Management Questionnaire developed by the researcher based on the SMM (Dodd et al., 2001) and the literature review.

### **Quality of life**

The quality of life refers to the family caregiver's perception of well-being regarding physical health, psychological state, social relationship, and the environment. QoL was measured using the WHOQOL-BREF Nepali Version (WHO, 1996). Higher scores represented a higher QoL.

### **Scope of the Study**

A descriptive cross-sectional study was conducted to determine the chronic LBP experience, pain management strategies, and QoL among family caregivers of persons with physical disability in Nepal. The study was carried out in Nepal among family caregivers of persons with physical disability who have lived in community

settings of eight districts of Bagmati Zone. The data was collected from January to March 2017.

### **Significance of the Study**

The findings of this study will benefit the health care providers for awareness of LBP among family caregivers in Nepal. Furthermore, they will provide basic information to educate the family caregiver for self-management to effectively prevent or manage their LBP and improve their QoL. Moreover, they will provide baseline data for future research related to the chronic LBP experience, pain management strategies, and QoL of family caregivers of persons with physical disability in Nepal.

## **Chapter 2**

### **Literature Review**

This chapter presents a literature review related to the chronic low back pain experience, pain management strategies, and QoL among family caregivers of persons with a physical disability. The outline of the literature review is presented as follows.

1. Overview of persons with physical disability and the impact on family caregivers
2. Symptom Management Model
3. Chronic low back pain experience among family caregivers of person with physical disability
4. Chronic low back pain management strategies among family caregivers of person with physical disability
5. Quality of life among family caregivers of person with physical disability
6. Overview of caregiving and health care in the context of Nepal
7. Summary of the literature review

#### **Overview of Persons With Physical Disability and the Impact on Family Caregivers**

In recent years, the number of persons with disabilities has been increasing due to aging populations, chronic diseases, severe injuries, and advancement in life-saving technologies (The World Bank, 2016). It has been reported that more than one billion people are suffering from disabilities worldwide (WHO, 2016) among which nearly 110 to 190 million people are suffering from significant disabilities that limit

their functioning (The World Bank, 2016). In Nepal, the recent authentic data of disability is limited. However, the national census report of 2011 has reported 513,321 (1.94%) disabilities, among which 186,457 were persons with physical disability (Resource Center for Rehabilitation and Development, 2011).

According to Accardo and Whiteman (as cited in Werner & Shulman, 2015), physical disability refers to a broad category of disability involving the motor system which causes restriction on person's mobility. More specifically, physical disability can be defined as the person's inability to perform the activities of daily living due to physical deficiency, defect or deformity by birth, and accident or disease (Japan International Cooperation Agency Planning and Evaluation Department, 2002). Consequently, a physical disability affects a person's mobility and dexterity which require some sort of assistance (National Educational Association for Disabled Students, 2016).

Physical disabilities are usually the result of acquired, congenital causes (Physical and Mobility, 2016). The acquired causes include major trauma and diseases such as spinal cord injury, traumatic brain injury, amputation, fractures, stroke, multiple sclerosis, and heart disease (Physical and Mobility, 2016). Congenital causes include cerebral palsy, muscular dystrophy, and deformities (Liu & Luan, 2008; Physical and Mobility, 2016 ).

A physical disability can impact the health of both the person and their family caregivers. Persons with physical disabilities may suffer from various physical and psychosocial health problems depending on their level of disability. They often suffer from physical health problems such as breathing problems, lack of bowel and bladder control, pain, fatigue, or pressure sore (Bloemen-Vrencken, Post, Hendriks, De Reus,

& De Witte, 2005; Bowe, 2000; Center for Disease Control and Prevention, 2016). Additionally, they may suffer from psychosocial problems such as anxiety, depression, and stress due to changes in values, family role, and social stigmas toward disabilities (Psychological and Social Aspects of Disability, 2016). These physical and psychosocial problems in persons with physical disability may impact the health of their family caregivers.

Due to physical health problems, the persons with physical disability may require care that extends from assistance for activities of daily living (ADL) to complete personal care in the community setting (Lawang et al., 2015; Nogueira et al., 2013; Yalcinkaya et al., 2010). The family caregivers are the important persons responsible for providing physical caregiving activities and assistance in ADL including lifting, transfer, bathing, changing clothes, toilet care, and frequent position change in the community (Darragh et al., 2015; Lawang et al., 2015; Nogueira et al., 2015). Additionally, the family caregivers need to provide hours of care each day (Lawang et al., 2015).

Ultimately long term care for those physical disabilities may lead to physical and psychological health problems in the family caregivers (Elmore, 2014). The increased demand of caregiving activities puts a great strain on the health of the family caregivers (Elmore, 2014). As a result, the physical health of the caregivers becomes worst. For instance, a previous study conducted in family caregivers of physically disabled persons depicted worse physical health of family caregivers compared to the non-caregiver (Lawang et al., 2015).

Common physical health problems encountered by the family caregivers of persons with a physical disability include musculoskeletal problems (Darragh et al.,

2015; Sharan, Ajeesh, Rameshkumar, & Manjula, 2012; Soke, Goz, Kahrman, Genc, & Ozturk, 2015), hypertension, and sleep disturbance (Lawang et al., 2015). Among them, the musculoskeletal problem is one of the most common (Sharan et al., 2012; Soke et al., 2015) and one of the most common musculoskeletal problems experienced by family caregivers of persons with a physical disability is low back pain (LBP) (Darragh et al., 2015; Sharan et al., 2012; Soke et al., 2015). The previous studies have found a high prevalence of LBP in family caregivers (Darragh et al., 2015; Yalcinkaya et al., 2010).

LBP in family caregivers has several negative impacts. The negative consequences, such as reduced physical functioning, limited ADL, increased bodily pain, and negative general health perception among the family caregivers have been reported in previous studies (Habib, Khanam, Hafez, & Islam, 2014; Kaya et al., 2010; Suzuki et al., 2016). Additionally, LBP in family caregivers was associated with increased psychological problems such as depression (Tong et al., 2003). LBP in family caregivers may reduce the QoL (Neves, Pietrovski, & Claudino, 2015).

In conclusion, physical disability refers to a broad category of disability involving the motor system which causes restriction on person's mobility. The physical disability may result from acquired causes that include spinal cord injury, traumatic brain injury, amputation, fractures, stroke, multiple sclerosis, and heart disease or congenital or genetic causes including cerebral palsy and muscular dystrophy. The physical and psychological problems among persons with physical disability make them depend on family caregivers for activities of daily life to complete personal care in the community. Ultimately, long term care for physical disabilities may lead to physical and psychological health problems in the family

caregivers. The most common physical health problem is LBP. Low back pain may reduce physical functioning, limited ADL, increased bodily pain, and negative general health perception and reduce the QoL among the family caregivers.

### **Symptom Management Model**

Symptom Management Model (SMM) was initially introduced at the University of California, San Francisco (UCSF) in 1994 by a group of researchers and faculty (Smith & Liehr, 2013). The model was developed based on the conceptualization of prior theories such as Orem's Self-care Model and related models from anthropology, sociology, and psychology at that time (Smith & Liehr, 2013). However, the faculty of UCSF concluded that none of the models could fully address the person's role of self, experience, his or her tested management strategies, and desired outcome. Consequently, with further testing of the model and continued discussion with the faculty, the SMM was revised in 2001 (Dodd et al., 2001).

The model has defined 'symptom' as a subjective experience reflecting changes in bio-psychological functioning, sensation or cognition of the individual. In contrast, the sign is defined as any abnormal indicator of disease which can be identified by the individual themselves or by others (Dodd et al., 2001). Both signs and symptoms indicate problems which need attention. Hence, they are both important for individual and health care providers. However, the absence of signs or symptoms does not necessarily mean optimal health and well-being (Dodd et al., 2001).

The SMM model has several assumptions. They are: (1) the self-report of the symptom experienced by the individual is the gold standard for a study of the

symptoms; (2) for application of the model the symptom does not have to be experienced by the individual; the individual may be at risk of a symptom due to context variables and interventions that can be initiated before experiencing symptoms; (3) the symptom experienced by non-verbal patients are assumed from the caregivers to be accurate for intervention; (4) the management strategies may be targeted to an individual, a group, a family, and the working environment; and (5) symptom management is a dynamic process which is modified by individual outcomes and influenced by personal, health and illness, and environmental domains of nursing (Dodd et al., 2001).

#### **Dimensions of symptom management model**

The SMM consists of three essential dimensions: (1) symptom experience; (2) symptom management; and (3) outcome (Dodd et al., 2001).

*Symptom experience.* Symptom experience refers to the individual perception of symptom, evaluation of the meaning of symptom and response to the symptom (Dodd et al., 2001). The three components are interrelated with each other.

*Perception of symptoms.* Perception of symptom refers to the individual's notice in changes in the usual feelings or behavior. The self-report of an individual's perception of symptoms is the gold standard. The reports of symptom perceptions vary according to the context (Dodd et al., 2001).

*Evaluation of symptom.* Once the symptom is perceived, it is evaluated by making a judgment on the intensity, frequency, location, and the affective impact of the symptom on the life of the individual. It also includes the evaluation of threats posed by symptoms which may be dangerous or have disabling effects.



*Response to symptoms.* Symptom response is the individual's response to the symptoms in terms of change in physical, mental, and behavioral aspects (Dodd et al., 2001). The physiological response to the symptom includes alteration in functioning. The psychological response may include cognition and mood and the behavioral aspect includes the objective expression of symptoms verbally or non-verbally. The symptoms change over time and become more complicated. To prevent complications and adverse outcomes the individual needs symptom management.

*Symptom management strategies.* Symptom management strategies are used to avert, delay or minimize the symptom experience through biomedical, professional, and self-care strategies (Dodd et al., 2001). Symptom management strategies can be effective in three ways: (1) reduce the frequency of symptom experience; (2) minimize the experience of symptoms or (3) relieve the distress associated with the symptoms. Management begins with an assessment of the symptoms from the individual's perspectives (Dodd et al., 2001). Management strategies are targeted to one or more symptoms experience to achieve one or more desired outcomes. Symptom management is a dynamic process which requires change over time or in response to acceptance or lack of the acceptance of the intervention strategies. Management includes a specification of symptom management strategies such as what (the nature of strategies), when (time), where (place), why (reason), how much (intervention does), to whom (recipient of the intervention), how (method) and who (delivered). Self-management strategies are being given more attention in order to shift the responsibility of managing symptoms to the individual (Dodd et al., 2001). Symptom management is important to evaluate its effectiveness for a positive outcome and reduce negative consequences (Dodd et al., 2001).

**Outcome.** The outcome results from the management strategies or symptom experience. It includes eight components: (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). The duration of symptom evaluation depends on its persistence, need for continued intervention, and response to treatment. Direct management and measurement of the symptom outcome continue if the symptom is recurring.

### **Nursing domains**

The above three dimensions of SMM are framed within the context of nursing domains of person, health and illness, and environment. These domains are also considered as factors that influence symptom experience, symptom management, and outcome (Dodd et al., 2001).

**Person.** The person domain refers to the intrinsic way an individual views and responds to the symptom experiences. The person domain includes demographic, psychological, sociological, and physiological variables which can affect the individual perception and management of his or her symptoms. The demographic variables may include age, gender, marital status, and financial status. The psychological variables consist of personal traits, cognitive capacity, and motivation. The sociological variable represents the family units, culture, and religion. The physiological variables are activities, rest, and physical capacity.

**Health and illness.** The health and illness domain takes into account the health and illness state of the individual that consists of risk factors, injuries or disabilities.

***Environment.*** The environmental domain refers to the overall condition or context in which the symptoms occur and include the physical, social, and cultural variable (Dodd et al., 2001). The physical environment encompasses home, work, and hospital. The social environment includes the individual social support network and interpersonal relationships. The cultural environment includes beliefs, values, and practices that are unique to each ethnic, racial or religious group.

The model has a bidirectional relationship between the interrelated dimensions and domains. The relationship was explored based on the findings of the research and experiments (Dodd et al., 2001).

In summary, the SMM consists of three essential dimensions including symptom experience, symptom management, and outcome. The three dimensions of SMM are influenced by three nursing domains which are also known as factors. These domains are person, health and illness, and environment.

## **Chronic Low Back Pain Experience Among Family Caregivers of Persons With Physical Disability**

### **Definition of chronic low back pain (LBP)**

Chronic LBP can be defined as the persistent discomfort, muscle tension, stiffness, and soreness localized in the anatomical area below the 12<sup>th</sup> rib posteriorly and below the costal margin and above the inferior gluteal folds or sacral region for more than 12 weeks (Borenstein, 2011; Irwin & Sherman, 2014; Middlekoop, Rubinstein, Verhagen, Ostelo, Koes, & Tulder, 2013).

### **Prevalence of chronic LBP**

Knowledge on the prevalence of chronic LBP in family caregivers of persons with physical disability is not known yet. However, the prevalence of LBP was studied in several studies related family caregivers of children and adult with physical disabilities. According to previous studies conducted in family caregivers of children with physical disabilities, the prevalence of LBP ranged from 71 to 90% (Tong et al., 2003; Tonga & Duger, 2008). Similarly, a study conducted among 64 family caregivers of stroke survivors revealed that 82% of the family caregivers experienced LBP (Yalcinkaya et al., 2010). Consistently, a study conducted in family caregivers of persons with physical disability reported that among the musculoskeletal problems, 76% of the family caregivers experienced LBP (Darragh et al., 2015). The persons with a physical disability demand frequent caregiving activities which put a great strain on the physical health of the family caregiver which results in a high prevalence of LBP (Darragh et al., 2015).

### **Characteristics of chronic low back pain**

In general, around 50 to 80% of the population experience at least one episode of LBP in their life (Rubin, 2007). Most of them recover within a few months after the onset however, some will not recover and develop into chronic LBP which can be disabling (Van Tulder, Koes, & Bombardier, 2002). The person with chronic LBP may experience various characteristics such as aching, burning, stabbing or tingling, sharp or dull, and well defined or vague in nature with an intensity from mild to severe (Moussa, Ezaby, & Mowafy, 2015; North American Spine Society, 2009). The pain may be specific to the midline lumbar region known as axial or simple mechanical or the pain can refer to other areas including the para spinal region,

posterior pelvis, hip, posterior buttocks or thigh depending upon the cause of the pain (Integrative Medicine, 2016). Axial pain can be sharp or dull and can be felt constantly or intermittently. The referred limb from LBP may have the characteristics of numbness, sharp pain, cramp or weakness (Mellin & Hurri, 1990).

### **Causes of chronic low back pain**

The causes of a substantial number of chronic LBP are non-specific (Chau, 2011). However, some of the possible causative factors can be categorized into mechanical, non-mechanical, neurological, biomedical, and psychological (Integrative Medicine, 2016). The mechanical causes include factors associated with the anatomical and physiological abnormalities of the spine that include muscle strain, osteoarthritis, spinal stenosis, disco genic disease, spondylolisthesis, vertebral fractures, and congenital diseases of the spine (Integrative Medicine, 2016). Non-mechanical factors include disease including neoplasm, or infections of the spine, such as osteomyelitis, discitis, paraspinous abscess, and epidural abscess (Integrative Medicine, 2016; Jarvik, Jeffrey, & Richard, 2002). Neurological causes are related to the nerve roots traveling through the spine due to a spine disorder, such as osteoarthritis, trauma, and rarely a tumor (Integrative Medicine, 2016; Langevin & Sherman, 2007). The biomechanical factors include unsuitable posture, maladaptive movement of the spine during activities which cause wear and tear on the spine, joints, and muscles (Integrative Medicine, 2016; Langevin & Sherman, 2007). Psychological factors comprise of major depression and anxiety (Polatin, Kennedy, Gatchel, Lillo, & Mayer, 1993).

### **Medical assessment of chronic low back pain**

The evaluation of chronic LBP in the clinical setting depends on the two categories of LBP; specific and non-specific LBP. Specific LBP refers to the symptoms of LBP caused by the specific pathological mechanism (e.g., herniated disc, infection, tumor, or fractures) (Koes, Van Tulder, & Thomas, 2006). The non-specific LBP represents the symptoms of LBP without clear known causes. Around 90 % of the patients with LBP have nonspecific LBP (Koes et al., 2006). Furthermore, in the clinical settings, triage of patients with LBP is elucidated focusing on serious underlying pathology. When serious underlying pathology is not apparent, the patient is considered as non-specific LBP (Koes et al., 2006).

The exact reliable diagnosis of non-specific LBP in clinical settings is not available. However, non-specific LBP is classified on the basis of the duration of complaints. LBP lasting less than six weeks is termed as acute LBP. The LBP of duration between six weeks to three months is sub-acute and LBP lasting longer than three months is called as chronic LBP (Koes et al., 2006; Last & Hulbert, 2009)

Since the LBP involves both the underlying pathophysiological causes (specific LBP) and unknown causes (non-specific), the assessment of LBP may be carried out with history, physical examination, laboratory test, and imaging in clinical settings.

**History.** The medical history related to the specific diseases such as osteoporosis, osteoarthritis, and tumors and duration of pain (Koes et al., 2006). Similarly, history related stress, anxiety, and social factors are asked to identify the psychological factors (O'Sullivan, 2005). Furthermore, history of inciting events (e.g.,

heavy lifting, twisting or bending, prolonged sitting) is obtained to elucidate physical factors.

***Physical examination.*** The physical examination involves the assessment straight leg rise test and neurological assessment. The straight leg raise test is used to check the mechanical movement of the neurological tissues and their sensitivity to mechanical compression (e.g., lumbar disc herniation). Deep tendon reflexes, and sensation can be used to identify the involvement of nerve root (Last & Hulbert, 2009). Similarly, positive neural stretch test, neurological deficit (sensory, motor, reflex impairment), paranesthesia's test, ankle, toe and knee reflexes may be examined to identify the underlying causes (Samanta, Kendall, & Samanta, 2003).

***Laboratory assessment.*** When the serious underlying pathology is suspected, the laboratory investigations may be indicated. The laboratory assessment may include erythrocyte rate, complete blood count, and C-reactive protein level (Last & Hulbert, 2009). Urine analysis may be indicated for suspected urinary tract infection and alkaline phosphate and calcium levels for suspected Paget disease of bone (Last & Hulbert, 2009).

***Imaging.*** For the patients with serious underlying rapidly progressive diseases such as radiculopathy, spinal stenosis, or specific spinal causes, magnetic resonance imaging or computed tomography may be used for diagnosis (Last & Hulbert, 2009). However, the imaging may be limited because most of the patients with chronic LBP have non-specific findings (Koes et al., 2006).

### **Existing studies related to chronic low back pain experience among family caregivers of persons with physical disability**

Caregiving for persons with physical disability causes substantial physical exertion on the family caregivers that results in increased severity of LBP (Darragh et al., 2015). However, despite the high care burden and risk of chronic LBP, the number of existing studies related to the chronic LBP experience, that includes pain intensity; pain frequency; and pain interference among family caregivers of persons with a physical disability, is limited. Therefore, the literature review was extended to professional caregivers such as nurses.

*Pain intensity and frequency.* The number of studies related to the intensity and frequency of chronic LBP is few. However, some studies reported LBP pain intensity in family caregivers of disabled children (Geere et al., 2013; Tonga & Duger, 2008). These studies showed moderate to severe intensities of pain. For example, a study conducted in the mothers of physically disabled children with cerebral palsy and muscular dystrophy in Turkey revealed that the mothers experienced a moderate intensity of LBP (Tonga & Duger, 2008). Furthermore, the intensity of pain was found to be significantly higher in the mothers of non-ambulatory disabled children than in the mothers of ambulatory disabled children. Similarly, a study conducted in Kenya with family caregivers of children with physical disabilities found that the family caregivers experienced moderate to severe LBP (Geere et al., 2013).

The intensity of LBP has been extensively studied in professional caregivers including nurses who worked for dependent patients in the hospital such as nurses working in intensive care units. The studies conducted among nurses of intensive care



units have revealed moderate to the severe intensity of LBP with a pain frequency of almost once a week (Mohamed, 2012; Ovayolu et al., 2014). Similarly, a large-scale study conducted among 1,345 nurses in 65 intensive care units in 22 hospitals in South Korea found that the majority of the nurses experienced LBP once a week and more than 20% reported pain for every day (June & Cho, 2011).

***Pain interference.*** Pain interference refers to the extent to which pain interferes with physical, psychological, and social functioning (Varni et al., 2010). LBP in family caregivers interferes with general work, caregiving activities, and other life activities (Darragh et al., 2015; Suzuki et al., 2016). Similarly, previous study conducted in 677 care workers of persons with intellectual, autistic, and associated multiple disabilities in Taiwan found that the caregiver's LBP interfered moderately and severely in general activities, mood, walking, normal work, sleep quality, and enjoyment of life for more than 20 % of the caregivers (Lin et al., 2014). The increased severity of LBP reduced physical functioning secondary to disability induced by LBP. It was found that the increased severity of LBP was associated with physical disability and changed in the mood of family caregivers of disabled children (Tong et al., 2003). Consistent results were shown in professional caregivers where the severity of LBP was significantly associated with physical disability (Solaimanzadeh, Jafar, Nassehi, & Pourhaji, 2016). Similarly, LBP resulted in moderate disability in mothers of children with physical disabilities (Khanam, 2013). Furthermore, LBP interfered with job performance, general work, and the quality of care among professional caregivers (Adhikari & Dhakal, 2015).

In conclusion, the prevalence of LBP among family caregivers is high. Due to limited studies on LBP experience including pain intensity, frequency and pain

interference among family caregivers of persons with physical disability, review of the literature was extended to professional caregivers (i.e., nurses). The studies reported that both the family caregivers and professional caregivers experienced moderate to a severe intensity of LBP. The professional caregivers of dependent patients experienced moderate to a severe intensity of pain with a frequency of almost once a week. The pain had moderate to severe interference on the physical and psychological functioning of caregivers that included mood, walking, normal work, sleep quality, and enjoyment of life. Similarly, LBP caused physical disability and interfered in the job, general work, and quality of care among professional caregivers. These studies demonstrated that caregivers who provided care for dependent people experienced a higher intensity, frequency, and interference of LBP. However, despite the high prevalence of LBP, a study on the chronic LBP experience in family caregivers of person with physical disability is still lacking.

#### **Factors related to chronic low back pain among family caregivers of persons with physical disability**

The SMM model explains three factors that influence the symptom experience: personal; health and illness; and environment (Dodd et al, 2001). Therefore, these factors are used to explain the factors related to the chronic LBP in the family caregivers of persons with physical disability.

*Personal factors.* Personal factors refer to the demographical, psychological, sociological, and physiological variables (Dodd et al., 2001). From the current literature review, the number of reports on the personal factors related to the experience of chronic LBP is few among family caregivers. A previous study conducted in family caregivers of stroke survivors found a higher prevalence of LBP

in female gender (Yalcinkaya et al., 2010). Similarly, the mood of the family caregivers was associated with the intensity of LBP in female caregivers of children with physical disabilities in the rehabilitation outpatient clinic (Tong et al., 2003).

Among professional caregivers, age, gender, body mass index (BMI) was associated with LBP. Age has been identified as one of the personal factors for LBP among nurses (El-Soud, El-Najjar, El-Fattah, & Hassan, 2014; Emmanuel, Ezhilarasu, & Bheemaroo, 2015; Lin, Tsai, Chen, & Huang, 2012; Thon, Feng, & Lian, 2016). Although, the age group of the nurses ranges from 25 to 50 years in aforementioned studies, the prevalence of LBP was associated with increasing age. It is argued that the nurses with older ages may have longer working experience and longer exposure to physical and psychological hazards at the workplace which may predispose to LBP (Chang et al., 2016). Additionally, musculoskeletal problems may be associated with increasing age of nurses (Emmanuel et al., 2015). Gender is another personal factor. Being female gender has been associated with LBP (Abolfotouh et al., 2015; Sikiru & Shmaila, 2009). The anatomical, physiological and structural differences along with weakness of back muscle resulting in sprain and strain are common among females than male (Sikiru & Shmaila, 2009). BMI has been identified as a factor for LBP in various studies (El-Soud et al., 2014; Emmanuel et al., 2015; Ghilan et al., 2013). The studies have asserted that increased body weight may contribute to the development of LBP.

***Health and illness factors.*** The factors of health and illness refer to the health and illness state of the individual (Dodd et al., 2001). Health and illness include a history of previous LBP and the presence of comorbidities. A descriptive cross-sectional study conducted in 90 family caregivers of children with physical

disabilities reported that a previous history of LBP in family caregivers was associated with LBP (Tong et al., 2003). If the caregivers had LBP before providing care, the experience of chronic LBP was more prevalent after providing care. Similarly, pre-existing health conditions of the caregivers, such as the presence of pain or injuries, were intensified by caregiving activities which influenced LBP among family caregivers (Darragh et al., 2015).

Similarly, the presence of other comorbidities than LBP (Abolfotouh et al., 2015; Ghilan et al., 2013), history of LBP and fall injury (Chang et al., 2016; Rezaee & Ghasemi, 2014) were associated with LBP among professional caregivers.

***Environmental factors.*** Environmental factors include the overall condition or context in which the symptoms occur (Dodd et al., 2001). The environmental factors include the dependency level and behaviors of persons with physical disability, caregiving activities and household tasks, and the physical environment.

***Dependency level and behaviors of persons with physical disability.*** The dependency level of persons with physical disability on family caregivers demands an increased physical strain and psychological stress that results in increased LBP. Previous studies conducted in family caregivers of children with physical disabilities revealed that dependence of children on mothers for transfer and mobility was associated with increased severity of LBP (Tong et al., 2003; Tonga & Duger, 2008). Similarly, a study conducted in informal caregivers of adults with physical disabilities reported that the limited functional mobility of a patient impacted musculoskeletal pain including LBP in family caregivers (Darragh et al., 2015). Additionally, the behavior problems of the persons with physical disability secondary to deteriorating health condition were associated with LBP among family caregivers (Suzuki et al.,

2016). It was argued that psychological stress of abnormal behavior (e.g. hallucination, and abusive behavior) could affect LBP. The psychological stress due to behavioral problems of the disabled patients had negative impacts on LBP.

Similarly, the cooperative behavior of disabled children was associated with less LBP in mothers of children with physical disabilities (Sharan et al., 2012). When the children were more cooperative, the mother needed to do less lifting and transferring which influenced LBP.

*Caregiving activities and household tasks.* Caregiving for persons with physical disability is a challenging task. The caregiving activities involve lifting and transfer, static body posture for a long term and repositioning, and activities involving household work are responsible for LBP among family caregivers of persons with physical disability (Darragh et al., 2015; Suzuki et al., 2016; Tong et al., 2003; Tonga & Duger, 2008). The details are explained as follows:

1. Due to a wide range of difficulties related to mobility, the person with a physical disability is dependent on the family caregiver for mobility. The caregiving activities that involve lifting and transfer, standing up, moving around indoors and outdoors, assisting the disabled person in climbing stairs, lifting and transferring the patient from bed to chair to toilet, and showering the disabled person are associated with LBP in family caregivers (Darragh et al., 2015; Suzuki et al., 2016; Tong et al., 2003; Tonga & Duger, 2008).

2. Providing care to the physically disabled person requires static posture for a long time. The caregivers who provide constant care for a long time in an unsuitable and static posture can develop LBP. Previous studies reported that caregiving activities, such as feeding, bathing, changing diapers, sponge bathing, maintaining

hygiene, toilet care, and night care involve several postural changes (bending forward or unsuitable postures) that are related to LBP (Darragh et al., 2015; Suzuki et al., 2016; Tong et al., 2003; Tonga & Düger, 2008). Caregiving activities are complex and require extended time to accomplish the tasks and need to be performed several times a day which increase the physical burden on the caregivers (Darragh et al., 2015). Furthermore, these physically demanding activities, that include giving assistance in activities of daily life, require the family caregivers to assume awkward postures or overexert themselves (Darragh et al., 2015). Consequently, these caregiving activities result in the development of chronic LBP.

3. Based on the severity of the disability, the person with a physical disability requires caregivers for basic position change frequently. Previous studies reported that activities involved in frequent repositioning, such as turning in bed, standing up, lying down were associated with LBP (Darragh et al., 2015; Suzuki et al., 2016; Tong et al., 2003; Tonga & Duger, 2008).

4. In addition to caregiving activities, the family caregivers are also involved in household tasks. According to Tong et al. (2003), besides caregiving activities, housework is one of the factors associated with severity of LBP. Basic housework, that includes cleaning, washing clothes, shopping, and cooking, requires frequent bending and heavy lifting which leads to the development of LBP (Suzuki et al., 2016).

*Physical environment.* The physical environment may also influence the development of LBP. Previous studies found that barriers in the physical environment, such as stairs, lack of an elevator, narrow doors, cramped space in the bathroom, and a narrow corridor, cause additional physical burdens for the family

caregivers (Darragh et al., 2015; Tonga & Duger, 2008). Caregiving activities along with physical environmental barriers may have an influence on the development of chronic LBP.

In conclusion, caring for a person with a physical disability demands an intense physical effort that can result in the development of chronic LBP. Various factors including personal, health and illness, and environmental factors are responsible for LBP. The personal factors include age, gender, and mood of the family caregivers. The health and illness factors include a history of LBP and the presence of other comorbidities before providing care. The environmental factors refer to the overall condition and context in which the symptoms occur. The environmental factors related to chronic LBP include dependency level and behaviors of persons with a physical disability, caregiving activities and household tasks, and the physical environment of the caregiving situation.

#### **Assessment of chronic low back pain among family caregivers of persons with physical disability**

Various assessment tools are used to assess the chronic LBP in research. Since pain is a subjective experience, self-report of the pain is the gold standard for the assessment of pain (Dansie & Turk, 2013). The assessment tools for chronic LBP are unidimensional and multidimensional. The details are explained below.

***Unidimensional tools.*** The Visual Analogue Scale and Numerical Rating Scales are the well-known tools to assess one dimension of pain (i.e. pain intensity).

***Visual Analogue Scale (VAS).*** VAS is a single item continuous scale consisting of a horizontal or vertical line of 10 centimeters(cm) or 100 millimeters (mm) in length. The left side of the scale is labeled with ‘no pain’ and the right end

with ‘pain as bad as it could be’ and the rest of the line is blank (Mannion, Balagué, Pellisé, & Cedraschi, 2007). The participant is asked to mark the line to denote their pain intensity at the present, over the past week or past two weeks. The distance between the mark and the origin is measured to score the pain intensity. The VAS may be marked with descriptive terms such as mild, moderate, and severe. In the 100-mm VAS, ratings of 0 to 4 mm can be considered as no pain, 5 to 44 mm is considered as mild pain, 45 to 74 mm as moderate pain, and 75 to 100 mm as severe pain. The higher the score, the greater is the pain intensity (Hawker, Mian, Kendzerska, & French, 2011).

The VAS was correlated with self-report measures of pain with correlation coefficients that range from .70 to .78 with the Verbal Rating Scale and .62 to .91 with the Numeric Pain Rating Sale (Hawker et al, 2011). It is considered to be a generic pain measure and is widely used in research for a broad population including LBP (Olaogun, Adedoyin, Ikem, & Anifaloba, 2004). However, use of the tool is limited in older populations and people with physical and cognitive impairments.

*Numeric Pain Rating Scale (NPRS).* NPRS is a unidimensional measure of pain intensity. The NPRS is a single 11 point numeric scale provided with empty boxes or a line with numbers of 0–10 at equal intervals where 0 indicates ‘no pain’ and 10 indicates the pain ‘as bad as it could be’ (Mannion et al., 2007). The participants tick or circle the number that best represents their current pain intensity (Mannion et al, 2007) where higher scores indicate higher pain intensity (Hawker et al, 2011). The level of pain can be categorized into mild, moderate, and severe with mild = 1-3, moderate = 4-6, and severe = 7-10 (Jones, Vojir, Hutt, & Fink, 2007).



The NPRS is highly correlated with the VAS with correlational coefficients of .86 to .95. It was shown to be highly reliable in both the literate and illiterate with a test-retest reliability of .90 and .95 (Hawker et al, 2011). The NPRS can be administered verbally or graphically by self-completion where the respondent is asked to indicate the numeric value on the segmented scale that best describes their pain intensity. It is a valid and reliable measurement tool for pain intensity with a simple scoring method (Ostelo & de Vet, 2005).

***Multidimensional tools.*** The commonly used multidimensional tools are Short Form McGill Pain Questionnaire and Brief Pain Inventory.

*Short Form McGill Pain Questionnaire (SF-MPQ).* The SF-MPQ is multi-dimensional pain questionnaire derived from original McGill pain questionnaire developed by Ronald Malzak and Torgerson in McGill University in 1971. The SF-MPQ is designed to measure the perceived pain intensity and pain quality in adult with chronic pain including low back pain (Beaton & Hughes, 2013; Cramer, Lauche, Haller, & Dobos, 2013; Kuijpers et al., 2011).

The tool consists of 15 words containing sensory and affective subscale. Among 15 words, 11 words are related to sensory and four words are related to affective domain. Each item is rated on the basis of intensity such as 0 = no, 1 = mild, 2 = moderate and 3 = severe. The tool also has one item representing present pain and another item represent average pain. There is no critical cut off point. The higher score represent worse pain (Hawker et al., 2011).

The tool had reliability with internal consistency of Cronbach alpha of .77-.93 (Dworkin et al., 2015) . This tool is convenient in terms of time to administer.

However, the limitation of the tool is that new user needs supervision to complete the questionnaire (Hawker et al., 2011).

*Short Form Brief Pain Inventory (SF-BPI)*. The SF- BPI is a multidimensional pain assessment tool. The tool was initially developed from the Wisconsin Brief Pain Questionnaire to assess cancer pain (Cleeland & Ryan, 1994). But later the tool shown validity and reliability for non-malignant chronic pain (Tan, Jensen, Thornby, & Shanti, 2004). The long form BPI was later modified to the short form BPI (SF-BPI). The SF-BPI has two dimensions of pain including pain intensity and pain interference. The tool uses a 0-10 NRS on horizontal lines with numbers for pain intensity and interference. The pain intensity component of BPI asks the patients to rate their pain intensity as pain right now, pain at its worst, at its least, and pain on average (Breivik et al., 2008). The tool also consists of pain interference with seven aspects of life: (1) general activity; (2) walking; (3) normal work; (4) relationships with other people; (5) mood; (6) sleep; and (7) enjoyment of life. The scoring of the SF-BPI pain intensity of worst, least, average, and now can be done with a composite mean score of the four scales or individual severity items. For pain interference, either individual or the mean of the seven items is scored. Furthermore, the level of pain intensity and interference of the BPI can be categorized into mild (1.00-3.99), moderate (4.00-6.99), and severe (7.00-10) (Archer, Castillo, Wegener, Abraham, & Obremskey, 2012). Higher scores represent higher intensity of pain.

The BPI has shown excellent validity and reliability. The reliability from the Cronbach's alpha test showed excellent results of internal stability from .80 to .87 for the pain intensity scale and .89 to .93 for the pain interference scale. The test retest reliability ranged from .83 to .88 for the pain intensity scale and .83 to .93 for the pain

interference scale (Cleeland, 2009). The instrument was proven to be valid and reliable in LBP (Bann, Dodd, Schein, Mendoza, & Cleeland, 2004). In addition, a previous study used the BPI for pain intensity and interference (Lin et al., 2014).

It can be self-administered or given in a clinical interview or even administered over the telephone. The amount of time to administer the instrument requires only 2-3 minutes (Breivik et al., 2008). Additionally, the tool is simple and easy to understand with multidimensional aspects of pain including pain intensity and pain interference.

*Pain frequency.* Frequency is another dimension of the chronic LBP experience. However, there is no specific tool for the measurement of frequency of LBP (Mannion et al., 2007). Previous studies used the absolute number of days with LBP within a given period of time such as pain all the time, once a week, once a month, or more than once a month to measure the frequency of LBP (Mohamed, 2012; Mannion et al., 2007; Ovayolu et al., 2014). In this study, the researcher used the SF-BPI for the assessment of pain intensity and pain interference because of the multidimensionality of the tool. This single tool provides both the intensity and interference of LBP whereas the NPRS and VAS give only single dimensions of pain. The MPQ includes the intensity but does not give the level of pain interference in each aspects of life. Therefore, SF-BPI was used in current study. For pain frequency, the specific question, 'How often do you experience chronic LBP?' with options of everyday, more than twice a week, twice a week, once a week, more than twice a month, twice a month, and once a month was used.

## **Chronic Low Back Pain Management Strategies Among Family Caregivers of Persons With Physical Disability**

Symptom management strategy is one of the domains of the Symptom Management Model (SMM) and it is a dynamic process which requires changes in strategies over time or in response to acceptance or lack of acceptance of the strategies method (Dodd et al., 2001). The ultimate goal of symptom management is to avert, delay or minimize the symptom experience through biomedical, professional, and self-care strategies (Dodd et al., 2001).

Virtually, no studies are available that address chronic LBP management strategies among family caregivers of persons with physical disability. Hence, the literature review was extended to other populations (i.e., nurses, patients). A further review was based on the findings in these populations.

### **Chronic low back pain management strategies**

Since chronic LBP is a long term problem, multidisciplinary management is essential. Health care providers and the individuals themselves need to work together to effectively minimize the symptoms. Chronic LBP management strategies can be divided into two parts: chronic LBP management strategies conducted by the health care providers (e.g., nurses, physiotherapists, and physicians) and by the individuals themselves.

*Pain management conducted by the health care providers.* For the effective management of chronic LBP, several pain management strategies are used by healthcare providers (nurses, physiotherapists, and physicians). These strategies can be categorized into pharmacological and non-pharmacological therapies.

*Pharmacological management.* The pharmacological management of chronic LBP refers to the use of drugs for the management of pain. The most commonly used drugs for the management of chronic LBP are opioids, nonsteroidal anti-inflammatory drugs (NSAIDs), and antidepressants (White et al., 2011).

Opioids are pain relievers used in an increasing number of conditions including the treatment of chronic LBP (Deshpande, Furlan, Mailis-Gagnon, Atlas, & Turk, 2007). Opioids were found to be effective in the management of chronic LBP in adults as reported in systematic reviews (Kuijpers et al., 2011; White et al., 2011). Tramadol was the most commonly used opioid (Deshpande et al., 2007; White et al., 2011). The systematic reviews concluded that opioids were more effective than placebo in chronic pain relief (Kuijpers et al., 2011; White et al., 2011). However, the long term effectiveness of opioids is still questionable (Deshpande et al., 2007). Additionally, it is reported to have decreased effectiveness with habituation in long-term use (White et al., 2011). Furthermore, the use of opioids is associated with common side effects such as dry mouth, drowsiness, headache, constipation, and nausea (White et al., 2011) and it was found that opioids were not more effective than NSAIDs. Despite the effectiveness of opioids in the relief of chronic LBP, the increased side effects and lack of superiority over NSAIDs has made it a second option for the management of chronic LBP (White et al., 2011).

NSAIDs are the most frequently prescribed drugs and recommended an option for chronic LBP management worldwide (White et al., 2011). A meta-analysis of four clinical trials that compared NSAIDs with placebo found that NSAIDs were significantly effective in reducing pain intensity compared to placebo (White et al., 2011). Consistent results were demonstrated by a systematic review conducted by

Kuijpers and colleagues (2011). NSAIDs were superior to opioids in effectiveness. Consequently, NSAIDs were recommended as the first line drugs for the treatment of chronic LBP in the short duration (White et al., 2011). However, some people found exacerbation of pain after stopping treatment by NSAIDs (Kuijpers et al., 2011). Furthermore, NSAIDs were associated with moderate to severe side effects such as abdominal pain, diarrhea, edema, dry mouth, rash, dizziness, headache, and tiredness which may be clinically meaningful and precautions should be taken in long-term use (Kuijpers et al., 2011; White et al., 2011).

Antidepressants are sometimes prescribed for analgesic purposes since depression is common in chronic LBP (Staiger, Gaster, Sullivan, & Deyo, 2003). The commonly prescribed antidepressants are tricyclic antidepressants (e.g., Maprotiline, Desipramine, and Imipramine) and selective serotonin reuptake inhibitors (e.g., Paroxetine, Fluoxetine) (White et al., 2011). The use of antidepressants was found to be effective for the management of depression in chronic LBP; however, antidepressants were not effective in chronic LBP management (Staiger et al., 2003). Systematic reviews revealed that antidepressants were no more effective than placebos in various clinical trials (Kuijpers et al., 2011; White et al., 2011). Due to the lack of antidepressant effectiveness in chronic pain relief, antidepressants are not recommended routinely for chronic LBP.

Since chronic LBP is a long term problem, pharmacological therapy alone may not always be effective due to its short term effectiveness and adverse effects. Alternatively, non-pharmacological management strategies are essential for management.

*Non-pharmacological management.* Non-pharmacological management methods have become an important part of managing chronic pain (Chang, Fillingim, Hurley, & Schmidt, 2015). Since chronic LBP is a long term problem, non-pharmacological management plays an important role in reducing pain by both physical and psychological effects. Non-pharmacological management includes alternative therapies such as massage, heat therapy, stretching exercises, and yoga.

Massage is a technique of touching the soft tissues of the body with the hands. The goal is to reduce pain and increase comfort in patients (Eghbali, Safari, Nazari, & Abdoli, 2012). The massage was found to be an effective intervention for the management of chronic LBP. A randomized control trial (RCT) conducted in 50 nurses with chronic LBP in a university hospital in Iran found that a 40-minute session of reflexology at twice a day and three times a week significantly reduced chronic LBP compared to its counterpart unspecific massage (Eghbali et al., 2012). Furthermore, the study found that the pain score of the non-specific massage group (control) was also lower compared to the pre-intervention group which indicated that the massage therapy was effective for chronic LBP. Consistently, a study conducted among nurses with LBP in Brazil has revealed that 12 sessions of protocol wise massage therapy significantly reduced pain score (Borges et al., 2014).

Myofascial release is a type of manual therapy which applies a low load stretch on the myofascial complex to restore the optimal length and reduce pain (Barnes, 1990). It is believed that fascial restriction is one part of the body that causes undue tension on another part of the body due to the continuous nature of the fascia. The applied pressure restores the length and health of the connective tissue which reduces pain caused by sensitive structures such as nerves and blood vessels

(Ajimsha, Daniel, & Chithra, 2014). Myofascial release is an effective method to minimize pain in chronic LBP. A recent RCT conducted in 80 nurses in India found that an 8-week myofascial release intervention reduced pain intensity more than 50% from the baseline (Ajimsha et al., 2014).

Heat application is one of the non-pharmacological modalities for reducing the severity of LBP. A study conducted among 87 patients with LBP in an orthopedic clinic in Iran has revealed that a week thermotherapy consisting of hot water bag along with naproxen reduced pain significantly than cold therapy and naproxen (Dehghan & Farahbod, 2014). Similarly, a study conducted among forty patients with chronic LBP in pain management clinic in the USA has revealed that a seven weekly Infrared therapy reduced chronic LBP significantly from baseline (Gale, Rothbart, & Li, 2006). Furthermore, a systematic review of nine clinical trials revealed that there was moderate evidence that heat wrap therapy reduces pain and disability for acute LBP (French, Cameron, Walker, Reggars, & Esterman, 2006). However, evidence of the effectiveness of heat therapy for longer duration has not been identified.

Exercise has proved to be one of the effective methods for the management of chronic LBP. A previous study conducted in Taiwan in 127 nurses, who worked in hospitals and experienced chronic LBP for six months, showed that after providing stretching exercises more than 80% reported moderate to a high reduction of chronic LBP (Chen et al., 2014). The 50-minute stretching exercises at three times a week for six months were provided by a trained research assistant. Additionally, the participants also reported comfort and relaxation (Chen et al, 2014).

Yoga was found to be effective for chronic LBP symptoms. A previous study conducted in 313 adults with chronic LBP in a non-medical center of the United



Kingdom revealed that yoga was effective in low back function and pain control (Tilbrook et al., 2011). The participants were recruited from an advertisement in the local media and provided 12 classes of 75 minutes of a yoga intervention for 12 weeks. Similarly, a study conducted in 228 adults with chronic LBP in the USA compared the effectiveness of yoga classes to stretching classes of comparable physical exertion and to self-care for chronic non-specific low back pain. The study reported that the 12-week Vini yoga and stretching exercises had significantly reduced bothersome of chronic LBP (Sherman et al., 2011). The participants in the yoga and stretching groups were satisfied with control of their back pain and felt much better.

In conclusion, management conducted by health care providers includes pharmacological and non-pharmacological management. The pharmacological management includes opioids, NSAIDs, and antidepressants. Opioids and NSAIDs are effective for short-term relief of chronic LBP but their effectiveness in the long term is questionable and they are associated with clinically meaningful adverse effects. Due to the lack of superior effectiveness compared to placebo, antidepressants are not recommended for routine use. Alternative therapies, such as massage, heat therapy, stretching exercises, and yoga were found effective in the management of chronic LBP among nurses and general adults.

***Pain management strategies conducted by the individual.*** According to the SMM, self-management strategies are being given more attention in order to shift the responsibility of managing symptoms to the individual (Dodd et al., 2001). Additionally, effective management of the symptoms depends on the individual's understanding of their own body and needs which help in successful self-management

(Holm, 2005). Hence, it is important to explore the management strategies used by individual themselves.

The literature related to self-management of chronic LBP in family caregivers is still lacking. However, a few studies on self-management strategies in patients and workers with chronic LBP have been studied and they described various management strategies. For example, a study conducted in 64 adult patients with chronic LBP in New Zealand found that participants used medication, exercise, heat application, modification of the working environment, and distraction as management strategies (Crowe et al., 2010). The study revealed that participants used medication such as Ibuprofen and Acetaminophen when they had severe pain. The participants reported doing low impact exercise including stretching, relaxation, cycling or walking by themselves or with the help of a physiotherapist. Additionally, the participants used heat application in the form of a shower or electric blanket. Environmental modifications, such as keeping a cushion in the car and sitting at the proper level and distraction from pain with the help of music, were the strategies used to minimize LBP (Crowe et al., 2010).

Consistent results were depicted in a study conducted in workers with chronic LBP in the USA (Tveito et al., 2010). The study reported that workers with LBP used hot showers, stretching exercises, avoiding high heels, massage, listening to music, communicating the pain with others, and maintaining a support group as strategies for their LBP. Furthermore, besides taking medications, exercise, and hot applications, a study conducted in patients with chronic LBP in the USA revealed that the participants used lifestyle modifications including eating a healthy diet, weight control, and keeping a positive mood (Kawi, 2014).

Regarding the effectiveness of management strategies, most of the participants did not mention the level of effectiveness for each strategy. The effectiveness of only a few strategies has been reported. For example, hot application really helped to relieve pain, low impact exercise really worked to minimize pain, and distraction with music was very effective in minimizing LBP (Crowe et al., 2010). Similarly, wearing comfortable shoes alleviated pain (Tveito et al., 2010), and taking medication was extremely beneficial (Kawi, 2014). The study also revealed that many participants had a sense of resignation and frustration about the effectiveness of management strategies for relieving their chronic LBP. As a result, these participants endured pain to cope with it (Crowe et al., 2010). The effectiveness of the management strategies used by individual dependent upon the nature, duration, and frequency of management strategies. The effectiveness of the management strategies for chronic LBP conducted by family caregivers themselves has not been studied yet. However, a systematic review on the self-management of chronic LBP revealed that self-management strategies had a little effectiveness on pain and disability of chronic LBP among patients with chronic LBP (Oliveira et al., 2012).

In brief, management strategies for chronic LBP conducted by family caregivers are lacking. However, various management strategies were studied in patients and workers with chronic LBP. It was concluded that the individual with chronic LBP used medication, exercise, hot application, modification of working environment, distraction, and lifestyle modifications as self-management strategies. The effectiveness of only a few strategies was reported. The self-management strategies conducted among patients with chronic LBP had reported little effectiveness.

### **Factors related to chronic low back pain management**

According to the SMM, the three factors namely personal, health and illness, and environment influence the perception of symptom management (Dodd et al, 2001). These factors are used to guide the factors related to chronic LBP management. Due to the lack of studies related to the factors of chronic LBP management among the family caregivers of persons with physical disability and limited literature available on factors of chronic LBP management, the factors related to chronic pain management such as chronic musculoskeletal pain in adult patients were reviewed.

***Personal factors.*** Personal factors involve belief in pain and illness, knowledge, coping strategies, a desire for health improvement, and motivation.

***Belief about pain and illness.*** Belief has been defined as the personally or culturally shared cognitive configuration (Pons, Shipton, & Mulder, 2012). Belief about the pain was found to be a factor related to pain endurance and management. It was found that although LBP was common among Nepalese people in rural areas, people believe it as a normal process and do not seek medical help (Anderson, 1984). Additionally, the religious beliefs about the perception of pain may influence pain endurance. Hindu people have strong beliefs that one should endure pain as a consequence of the past life and cope with the suffering that satisfies past negative behavior (Whitman, 2007) in contrast to the modern belief of pain as bad and should be quickly eliminated (Nayak et al, as cited in Callister, 2003). Such belief may influence in developing the habit of pain endurance.

Furthermore, the patient's belief about the illness was related to adherence of the management strategies. For example, a previous qualitative study conducted

among 34 patients with chronic neck or LBP attending home exercise program has reported that those patients who believe their problem as chronic condition tend to have resigned attitude and consequently decide not to adhere to exercise program (Medina, Escolar, Canovas, Herrador, & Collins, 2009). Similarly, those who doubt about the effectiveness of advice for management were less likely to adhere the exercise.

*Knowledge.* The knowledge about the prevention and management of LBP is essential for effective management. The knowledge about the personal risk factors for LBP aids in better management and prevention of LBP (Cilliers & Maart, 2013). Similarly, the lack of knowledge was reported for the non-adherence of yoga therapy among adults with chronic LBP (Combs & Thorn, 2014). The adequate information about the illness and effectiveness of management strategies increases the probability of adherence to management strategies (Escolar et al., 2009).

*Coping strategies.* Coping strategies adopted by the individual with chronic LBP is one of the factors that influence the management of chronic musculoskeletal pain. A previous qualitative study in adults with musculoskeletal pain, including chronic LBP, revealed that coping strategies, including hoping for a positive outcome of treatment and coping with the current pain intensity, increased adherence to the management strategies (Franklin, Smith, & Fowler, 2015). Coping with the pain intensity was related to increased mobility and improved activities that enhanced self-management.

*Individual desire.* The individual desire for the improvement of one's own health is one of the factors for adherence to management. A previous qualitative study in adults with chronic LBP among individuals who attended yoga intervention

reported that individual personal desires for health and well-being were the factors which encouraged them to adhere to the management strategies (Combs & Thorn, 2014).

*Motivation.* The motivation for the management strategies is another factor for self-management. A previous study conducted in adults with chronic LBP in a physical therapy and rehabilitation clinic in Korea found that motivation for self-management was associated with improved self-management behavior (Jung & Jeong, 2016) and self-behavior is important for effective management. Consistent results were reported in a qualitative study conducted in patients with musculoskeletal pain where the participants reported that motivation is a facilitating factor for self-management (Bair et al., 2009).

*Health and illness factors.* The health and illness factors include chronic pain, fear of pain during physical therapies, and comorbidities.

*Chronic pain.* The physical effect of chronic pain is one of the factors related to management strategies. A previous study conducted in adults with chronic LBP reported that the physical effects of chronic pain interfered with adherence to management strategies (Combs & Thorn, 2014). The limitations of movement due to chronic pain interfered with physical therapies. A consistent result was reported in various studies conducted in adults with chronic LBP and musculoskeletal pain (Bair et al., 2009; Franklin et al., 2015; Medina et al., 2009).

*Fear of pain during physical therapies.* The fear of pain during physical therapies prevented individuals from performing self-management strategies. Previous studies conducted in adults with chronic LBP revealed that the individual

lacks adherence to management strategies due to the fear of increased pain during movement (Bair et al., 2009; Combs & Thorn, 2014).

*Comorbidities.* Comorbidities are health factors that prevent effective management. A study conducted in adults with musculoskeletal pain reported that the presence of comorbidities along with chronic pain was related to problems of adherence to home exercise for chronic pain (Medina et al., 2009). Comorbidities such as depression were reported for no-adherence of management strategies in patients with musculoskeletal pain (Bair et al., 2009).

*Environmental factors.* Environmental factors include time constraints, transportation difficulties, financial burdens, social support, and healthcare providers' service.

*Time constraints.* The time limitation is one of the factors in management adherence. A previous study conducted in adults with chronic LBP reported that individuals had limited time for yoga therapy that resulted in a lack of adherence to the management strategy (Combs & Thorn, 2014). Consistent results of time constraints were reported in studies conducted in adults with chronic musculoskeletal pain (Bair et al., 2009; Medina et al., 2009).

*Physical environment problems.* Physical problems like transportation difficulties and financial burdens are factors related to non-adherence of management strategies. Previous studies showed that the lack of transportation facilities and financial burdens including expensive health care were factors that resulted in a lack of adherence to management strategies (Bair et al., 2009; Combs & Thorn, 2014).

*Social support.* Social support was reported as an enhancing factor for the adherence of self-management strategies. Previous studies reported that support from

the family, friends, and health care providers influenced adherence to management strategies (Bair et al., 2009; Combs & Thorn, 2014, Medina et al, 2009). In contrast, a lack of social support was associated with non-adherence of management strategies.

*Healthcare providers' service.* The service of the healthcare providers, especially among the clinicians, was crucial factors for management. A previous study conducted in adults with chronic musculoskeletal pain and found that a caring and friendly attitude of the clinician encouraged the individual to effectively manage chronic pain (Franklin et al., 2015). The study reported that the individual adhered more if the clinician took the time to listen and understand their problems for pain assessment and provided information regarding the management process (Franklin et al., 2015).

In conclusion, the lack of studies on factors related to the management of chronic LBP in caregivers of persons with physical disability has led to the extension of literature in other populations such as patients or adults with musculoskeletal pain including chronic LBP. The studies identified personal factors such as belief about pain and illness, knowledge, coping strategies, individual desire and motivation. The health and illness factors included the physical effects of chronic pain, fear of pain during physical therapies, and comorbidities. Similarly, the environmental factors including time constraint, lack of transportation facilities, financial burdens, social support, and the health care providers' service were related to pain management.

### **Assessment of chronic low back pain management**

Management begins with an assessment of the symptom experience from the individual perspectives (Dodd et al, 2001). Since pain is a subjective experience, the assessment of management and evaluation of its effectiveness depends on individual



perceptions. Chronic LBP management strategies involve the personal experience in ways to minimize or manage the pain. Therefore, there are no specific tools to measure the management strategies of chronic LBP. The exploration of individual perceptions of self-management of chronic LBP was carried out with open-ended questions. For example, a previous study conducted in 64 adults with chronic LBP in New Zealand used the question “What do you do to manage the pain?” (Crowe et al., 2010) and a study conducted in 110 individuals with chronic LBP in the USA used “What are the ways you manage your chronic low back pain?” (Kawi, 2014).

For this study, the researcher used an open-ended, semi-structured questionnaire. The question was “What are the ways you use to manage your chronic low back pain?” The question was further probed with the specifications of what, how often, why, when, where, and who based on the SMM (Dodd et al., 2001) and the literature review. Since the effectiveness of management is important for an effective outcome, the effectiveness of management was added. The effectiveness included ‘no effective’, ‘a little effective’, ‘moderate effective’, and ‘high effective’.

### **Quality of Life Among Family Caregivers of Persons With Physical Disability**

The SMM model has listed eight outcomes of symptom experience and symptom management. The quality of life (QoL) is one of the outcomes (Dodd et al., 2001). According to WHO (1997), quality of life is defined as individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and

their relationship to salient features of their environment. Based on the definition and concept, the QoL incorporates multidimensional concept consisting of broad domains including physical health, psychological, social relationship, and environment (WHO (1997).

Caring for the disabled is associated with a restricted relationship, limited leisure activities, limited employment opportunities, financial insecurity, and frustration (Yoong & Koritsas, 2012). Additionally, emotional and behavioral changes in the disabled person reshape the relationship and interaction of the family caregivers and the person with a physical disability (Glozman, 2004). All of these consequences result in physical and psychological stress on the caregiver (Glozman, 2004). Frequent physical and psychological burden reflect negatively on the well-being of the family caregivers which results in a decreased QoL (Costa, Gomes, Viana, Martins, & Costa, 2016).

Moreover, the concept of QoL in family caregivers usually consist of different aspects including physical, psychological and social well-being fulfillment of personal expectation and goal, economic assurance and functional capacity (Arai et al., 2008; Caqueo-Urizar et al., 2009). QoL measures the comprehensive health status of the family caregivers covering physical, psychological, and social aspect rather than assessing health status from certain dimensions only (Xie et al., 2016). Therefore, assessment of QoL is important for family caregivers.

### **Existing studies of quality of life among family caregivers of persons with physical disability**

Family caregivers of persons with physical disability suffer from a lower QoL. Various studies revealed that family caregivers of persons with physical

disability experienced a significantly low QoL at the domain level as measured by the WHOQOL-BREF. For instance, a previous study conducted in family caregivers of children with developmental disabilities revealed that family caregivers of children with developmental disabilities reported significant impairment in all four domains (i.e. physical, psychological, social, and environmental) of the QoL compared to the family caregivers of healthy children (Malhotra et al., 2012). Similarly, a study conducted in Taiwan with family caregivers of adults with profound intellectual disabilities revealed a low QoL in all domains compared to their general population (Chou et al., 2007). Consistently a study conducted among family caregivers of multiple sclerosis revealed low QoL in all domains compared to the general population (Alshubaili et al., 2008). Additionally, a study conducted among family caregivers of children with physical disability showed lower score in the domain of environment of QoL (Neves et al., 2015).

Furthermore, the QoL of family caregivers of persons with physical disability, such as spinal cord injury, traumatic brain injury, and stroke was studied using the Medical Outcomes Study Short Form 36-Item Health Status Survey (SF-36). Lower scores were found in different domains of the QoL. For example, previous studies conducted in family caregivers of persons with spinal cord injury in the outpatient clinic and community revealed that the QoL of family caregivers was more compromised in the domains of role physical, bodily pain, vitality, and role emotional (Blanes et al., 2007; Nogueira et al., 2015). The score of the role physical domain was the lowest. Similarly, a study conducted in the primary family caregivers of persons with traumatic brain injury from a community in Mexico showed that the QoL was significantly low in the domains of role emotional, social function, bodily pain, and

general health as compared to the healthy control (Arango-Lasprilla et al., 2011). The researcher reported that the day to day caring responsibilities of caregivers possibly produced interruptions in the emotional well-being, physical health, energy, and ability to participate in social activities. Likewise, a study conducted in stroke survivors and their family caregivers at 6-month follow-up in Sweden revealed that the role emotional and mental component of family caregivers were significantly lower than the stroke survivors (Jonsson, Lindgren, Hallstrom, Norrving, & Lindgren, 2005).

Additionally, studies conducted in the primary family caregivers of frail disabled elderly revealed that all domains QoL (i.e. physical functioning, role physical, bodily pain, general health, vitality, social functioning, role-emotional, and mental health) of the family caregivers were lower (Rosler, Stummer, & Ostermann, 2011). Similarly, a cross-sectional study conducted in family caregivers of disabled elderly with chronic disease found lower scores in the domains of role physical, general health, vitality, role emotional, and mental health (Xie et al., 2016).

In summary, current studies revealed that the family caregivers of persons with physical disability have a low QoL compared to their healthy counterparts measured with WHOQOL-BREF. Similarly, a low QoL was seen mostly in the physical and psychological domains including bodily pain, general health, vitality, and role emotional as measured by SF-36.

### **Factors related to quality of life among family caregivers of persons with physical disability**

Several factors related to the QoL among family caregivers of persons with physical disability have been explored. The findings of the factors were derived from

individual studies rather than a study of disabilities as a whole. Findings from separate physical disabilities such as spinal cord injury, traumatic brain injury, elderly disabled, and stroke were considered as physical disabilities. Hence, the identified factors from the evidence were categorized into three groups based on the factors described by Dodd and colleagues (2001). These factors include personal, health and illness, and the environment.

***Personal factors.*** According to the SMM, personal factors refer to the demographic, psychological, sociological, and physiological factors denoting intrinsic ways individual views and response (Dodd et al., 2001). Personal factors related to QoL were identified from demographic data which were age, gender, the level of education, and income.

***Age.*** The age of family caregivers is one of the personal factors related to QoL. A previous study conducted in 59 primary family caregivers of persons with SCI in Brazil found that age was significantly and negatively associated with QoL (Nogueira et al., 2015). Consistent results were found in several cross-sectional studies conducted in the family caregivers of various disabilities (Chen et al., 2010; Ebrahimzadeh et al., 2013; Xie et al., 2016). The studies found that an increase in the age of family caregivers was associated with a decrease in physical functioning and reduced mental domain of QoL (Chen et al., 2010; Ebrahimzadeh et al., 2013; Xie et al., 2016). Similarly, a study conducted in stroke family caregivers in Sweden found that an increasing age of caregivers was associated with decreased physical, emotional, and general health, and increased bodily pain (Jonsson et al., 2005). It was asserted that the increased age of family caregivers led to reduced functional capacities and energy and was associated with the disease which consequently

reduced the physical health of the caregivers which led to a worse QoL (Chen et al., 2010). Conversely, the younger family caregivers were less likely to perceive lower QoL as compared to older family caregivers (Chou, Lee, Lin, Kroger, & Chang, 2009). Furthermore, young people tended to have a more active functioning, energy to work, less likely to complain about bodily pain and involve in social activities which provide temporary relief from caregiving burden (Morley et al., 2012).

*Gender.* Gender is another person factor related to the QoL. A previous cross-sectional study conducted in 123 family caregivers of stroke survivors in China showed that female gender was related to a worse mental domain of QoL (Chen et al., 2010). Uniform results were depicted in a study conducted in family caregivers of the disabled elderly with chronic disease in China (Yang, Hao, George, & Wang, 2012). However, a study conducted in family caregivers of stroke revealed that male gender was one of the factors for a poor QoL (McCullagh, Brigstocke, Donaldson, & Kalra, 2005).

*Level of education.* The education level of the caregiver is positively related to the QoL. Previous studies found that a higher level of education attained by primary family caregivers was associated with a better QoL (Chen et al., 2010; Ebrahimzadeh et al., 2013; Serrano-Aguilar, Lopez-Bastida, & Yanes-Lopez, 2006; Yang et al., 2012). It was argued that a higher education and better knowledge of different circumstances in life bring better life situations which ultimately result in a better QoL (Ebrahimzadeh et al., 2013). It is also argued that highly educated caregivers had more realistic expectations about the disease or disability as well as better social and financial support, which helped them better adapt to the stress and to the changing care needs (Serrano-Aguilar et al., 2006).

*Income.* Income of the family is one of the factors of QoL. Previous studies revealed that a lower monthly income in the family is related to a decreased QoL (Chou, Chiao, & Fu, 2011; Xie et al., 2016; Yang et al., 2012). Greater health expenses were related to decreases in both the physical and mental domains of QoL (Xie et al., 2016; Yang et al., 2012). It was argued that the caregivers had to use their own income to care for the disabled, which interfered with the family economy and dynamics (Xie et al., 2016). In addition loss of employment due to caregiving activities adds another financial burden (Yang et al., 2012). Ultimately, financial burdens create stress and a deteriorating QoL.

*Health and illness factors.* Health and illness factors involve the variables unique to health or illness state of an individual (Dodd et al., 2001). Health and illness factors related to the QoL include the caregiver's comorbidities.

*Comorbidities.* The presence of disease in family caregivers were associated with a decreased QoL (Chen et al., 2010; Nogueira et al., 2015; Yang et al., 2012). A previous study conducted in family caregivers of SCI in Brazil reported that chronic diseases of family caregivers such as hypertension and depression were related to a worse QoL (Nogueira et al., 2015). Consistent results were depicted in a study conducted in China with family caregivers of disabled elderly with chronic disease (Yang et al., 2012). Similarly, a cross-sectional study conducted in family caregivers of stroke survivors found higher levels of symptoms of depression in family caregivers due to caregiving burdens which were related to the worse mental domain of the QoL (Chen et al., 2010).

*Environmental Factors.* Environmental factors refer to conditions or context of outcomes that include physical, social, and cultural variables (Dodd et al., 2001).

From the current evidence, environmental factors related to QoL include dependency of patients for activities of daily living, the number of family members, and social support.

*Dependency of patients on activities of daily living (ADL).* Previous studies conducted in family caregivers of the disabled elderly with chronic disease in China showed that increased dependency of the disabled for ADL on family caregivers was related to a worse overall QoL (Xie et al., 2016 and Yang et al., 2012). A study conducted in Thailand in family caregivers of adults with disabilities also revealed that the physical and mental health status was lower in the caregivers who reported high dependency of persons with disabilities (Lawang et al., 2015). Limitations in the social lives of the caregivers due to the caregiving activities and dependency of the patients for ADL were argued for a worse QoL (Xie et al., 2016). Similarly, a study conducted in family caregivers of Alzheimer disease in Spain found that the QoL of life was inversely proportional to the dependency of patients on family caregivers (Serrano-Aguilar et al., 2006). A study conducted in Sweden with family caregivers of stroke survivors also reported that the dependency of stroke survivors was associated with a decrease in the role emotional and mental component domains of the QoL of family caregivers (Jonsson et al., 2005). A lower functional status for the persons with a disability was associated with a lower QoL in family caregivers (Ogunlana, Dada, Oyewo, Odole, & Ogunsan, 2014). The moderate dependency of stroke survivors was associated with the lowest scores of the role emotional and mental component.

*Number of family members.* Family support is important for the QoL. A previous study conducted in family caregivers of stroke survivors in China found that



a fewer number of family members was associated with a worse QoL (Chen et al., 2010). However, a larger number of children of the disabled was related to a poor QoL (Ebrahimzadeh et al., 2013).

*Social support.* Social support was one of the determinants of QoL among family caregivers of persons with disabilities in Japan (Arai et al., 2008). The higher the social support the family caregivers received was associated with better physical and mental QoL. Similarly, a study conducted among family caregivers of elderly disabled in rural Thai community has reported that the family caregivers who perceived higher social support had better QoL (Netchang, 2012).

In conclusion, personal factors such as age, gender, the level of education, and incomes are related to the QoL. Similarly, the health and illness factors involving the chronic disease conditions of family caregivers and depressive symptoms due to the caregiving burden were associated with a worse QoL. The environmental factors, including dependence of patients for ADL, fewer family members, and lack of social support were related to a worse QoL.

### **Assessment of quality of life among family caregivers of persons with physical disability**

The following contents describe the assessment measures for quality QoL widely used in the literature related to QoL among family caregivers of persons with physical disability including Medical Outcomes Study Short Form 36 (SF-36) and World Health Organization Quality of Life (WHOQOL)-BREF.

#### ***Medical Outcomes Study Short Form 36-Item Health Status Survey (SF-36).***

The SF-36 is a generic instrument developed by Ware and Sherburne in 1992 to assess the health-related QoL. The tool consists of 36 questions related to eight

domains that include (1) physical functioning, (2) role physical, (3) role-emotional, (4) bodily pain, (5) general health status, (6)vitality,(7) mental health, and (8) social functioning.

The physical functioning subscale consists of 10 questions and indicates the extent to which the state of health limits the physical functioning from basic activities, such bathing or dressing, to vigorous activities. The physical role functioning consists of four questions which indicate the extent to which physical health interferes with the activities of daily living. The bodily pain subscale consists of two questions that measure the extent to which daily activities interfere with pain and influence it. The general health domain consists of five questions related to a self-report of the current health status and prospects of the future health. The vitality domain consists of five questions related to dynamics and energy. The social subscale consists of two questions that indicate the extent to which the status of physical health and emotional health limit the social performance of the individual. The role emotional subscale consists of three questions which indicate the extent to which emotional problems interfere with work and activities of daily life. Lastly, the subscale of mental health consists of five questions which show depression, anxiety, emotional and behavior related control, and general positive mood (Rosler et al., 2011).

The scale also consists of two summary scores called physical component score (PCS) and mental component score (MCS) (Ware, 2000). The PCS consists of physical function (PF), role limitation due to physical function (RP), bodily pain, and general health (GH). The MCS consist of vitality (VT), social function (SF), mental health (MH), and role limitation due to emotional problems (RE).

The score ranges from 0 to 100 where 0 represents the worst and 100 represents the best possible health status representing the QoL (Ware, Kosinski, Dewey, & Gandek, 2000). The validity and reliability of the tool are maintained. The construct validity and practical applicability of the SF 36 are maintained (Hollingworth et al., 2002). The reliability of the SF 36 is maintained at Cronbach's alphas of .64 to .94 across the scales (McHorney, Ware Jr, Lu, & Sherbourne, 1994). It takes around 10 minutes for the administration of the questionnaire.

***World Health Organization Quality of Life (WHOQOL)-BREF.*** The WHOQOL 100 was initially developed by the WHOQOL group with 15 international field centers to develop the QoL assessment that would be applicable across cultures (WHO, 1996). Since the WHOQOL 100 was lengthy, the WHOQOL-BREF was derived from the WHOQOL100 to assess the QoL at a domain level profile.

The purpose of the tool is to assess the QoL within individual cultures, value systems, personal goals, and standards. The WHOQOL-BREF consists of 26 questions under four domains including physical health, psychological, social relationship, and environment (WHO, 1996). Two items are examined separately. Question No. 1 asks about the individual's overall perception of QoL and question No. 2 asks about the individual's overall perception of their health (WHO, 1996). The remaining questions in four domains represent the individual's perception of QoL in each domain. The physical health domain consists of seven items which assess the activities of daily living, dependence on medical substances, energy and fatigue, pain and discomfort, mobility, sleep and rest, and work capacity. The psychological domain consists of six items including bodily image and appearance, negative feelings, positive feelings, self-esteem, spirituality or religion or personal beliefs, and

thinking, learning memory and concentration. The social relationship domain consists of three items including personal relationship, social support, and sexual activity. The environment domain consists of eight items including financial resources, freedom, physical safety and security, health and social care, home environment, opportunity to acquire new information, recreation, physical environment, and transport.

The items are rated on a 5-item Likert scale with scores of 1-5 that represent the raw item score. The domain scores are scaled in a positive direction so that a higher score represents a higher QoL. The negatively scored three phrased items are reversed to form positive direction. The mean scores of the items in each domain are calculated to form each domain score. Then, the mean scores are multiplied by 4 to make the domain score comparable to the WHOQOL-100. The first transformation converts the scores to a range of 4-20 and the second transformation converts the domain scores to 0-100 (WHO, 1996). A higher score indicates a higher QoL (WHO, 1996). However, the total score of all the 26 items ranges from 26 to 130. Since WHOQOL- BREF has not provided cut off point, the score can be categorized into 3 levels using maximum score minus minimum score divided by the number of categories and interpreted as high QoL for score 96.00-130.00, moderate for 61.00-95.00, and low for the score of 26.00-60.00 (Pensri, 2007).

The reliability of the tool has been tested among 11,830 adults from 23 culturally diverse countries (Skevington, Lotfy, & O'Connell, 2004). The results showed good internal consistency reliability with a Cronbach's alpha of more than .70 for the physical health, psychological, and environmental domains. The social relationship had a Cronbach's alpha of .68. The tool has validity for use in various cultures (Skevington et al., 2004). The WHOQOL-BREF has been translated in

Nepali version in the previous study which yielded internal consistency reliability of Cronbach's alpha .71 (Giri et al., 2013). The tool does not require training for administration. The administration time of the questionnaire may range from 10 to 15 minutes.

For the current study, the researcher used the WHOQOL-BREF as the tool for assessment of QoL in family caregivers of persons with physical disability. The tool is widely used for assessment of QoL and was tested in many cultures which show evidence for use in the context of multiple cultures (WHO, 1997). Additionally, the tool is easy to understand and available in Nepali version.

### **Overview of Caregiving and Health Care in the Context of Nepal**

Nepal is a country with a multicultural, multi-religious, multilingual, and mosaic society. The country occupies more than 103 ethnic communities with their own sociocultural practices (Adhikari, 2016). The country is divided into three types of geographical regions that include mountainous, hilly, and Tarai regions with distinct cultural blends in each region. Being a Hindu country, the Hindu religion is dominant throughout the country (Adhikari, 2016). The personal and environmental factors depicted by the SMM (Dodd et al., 2001) may pertain to the context of Nepal.

Recently, the number of patients with trauma has increased due to fall injuries, road traffic accidents (Karkee & Lee, 2016), and disasters (Sheppard & Landry, 2016) in Nepal. The increased number of traumatic disabilities are common in the working age group of 15-59 with a high incidence in the urban areas (Khanal, 2015). Persons with physical disabilities that resulted from severe traumatic disabilities, such as spinal cord injury, severe traumatic brain injury require

continuous care for a long time. However, Nepal faces limited health resources for persons with physical disabilities. Only a few community long term facilities are available and professional community care facilities are still lacking. As a result, most of the persons with physical disabilities are dependent on family caregivers.

Moreover, family caregivers are the important persons who provide direct care that includes providing medications, feeding, caring for bodily needs, switching positions, toileting, transferring and lifting, and hours of care (Boreson & Askesjo, 2015). Unlike developed countries (Goh, Muslimah, Ng, Subramanian, & Tan, 2014), the family caregivers lack the necessary assistive devices for patient care.

Furthermore, environmental factors including geographical hardiness and the health care system may influence health. The geographical difficulties challenge the access of health care services for more than 80% of the population living in the rural areas (Boreson & Askesjo, 2015). The health care facilities are more centralized in the urban areas and most of the people residing in the rural areas lack modern health facilities. It is reported that only 15-20% of the population residing in urban areas has access to modern health care, whereas the remaining 80% of the population still depends on local and traditional medicine (Uprety et al, 2010 ). Many people practice self-medication and willingly seek out traditional healers for their minor ailments (Adhikari, 2016; Bhattarai, Parajuli, Rayamajhi, Poudel, & Jha, 2015). The low socioeconomic conditions, geographical difficulties, and ethnic beliefs influence the use of ethnic medicine including herbs for their health (Uprety et al., 2010). Furthermore, according to Parnes and colleagues (2001), the environmental factors related to the situation of disability influence the health of both the disabled persons

and their family caregivers. In this regards, the family caregivers may use these local health management strategies for their health.

Additionally, the heavy responsibility of caregiving activities can influence the QoL of family caregivers. Family caregivers have responsibilities for both the caregiving and normal work including farming. Due to the lack of access to healthcare facilities and heavy responsibilities as family caregivers, family caregivers often ignore their own health. Consequently, the intense caregiving burden and deteriorating physical health may decrease the QoL.

However, despite taking heavy responsibilities and the increased burden, the health care system is more focused on curative services that give priority to patients only (Rijal, 2013). Unlike developed countries (Goodhead & McDonald, 2007), there are no specific policies or practices to address the health care for family caregivers in Nepal. Hence, the health of family caregivers is not almost concerned. Therefore, attention to the health of family caregivers is essential.

### **Summary of Literature Review**

The physical and psychological impacts of persons with physical disability increase the demands of caregiving which put a great strain on the physical health of family caregivers. One of the common physical health problems is chronic LBP. However, the number of studies concerning the chronic LBP among family caregivers is limited. Therefore, the population was extended to professional caregivers including nurses with chronic LBP for the literature review. Studies have shown that family and professional caregivers experienced a high prevalence, moderate to severe intensity, frequency, and interference of LBP. The increased severity of chronic LBP

in family caregivers may impact the health of both family caregivers and persons with physical disabilities. Chronic LBP in family caregivers of persons with physical disabilities may lead to psychological problems such as depression and a reduced QoL. Hence, effective management is essential for effective outcomes.

Studies of the management of chronic LBP in family caregivers of persons with physical disabilities, were limited. However, the studies conducted in professional caregivers (i.e., nurses) and adult patients revealed that pharmacological and non-pharmacological management strategies were used to manage chronic LBP. The pharmacological strategies conducted by health care providers included opioids and NSAIDs. The non-pharmacological strategies conducted by health care providers included massage, myofascial release, heat therapy, stretching exercises, and yoga. Similarly, the pain management strategies conducted by individual themselves included analgesic drugs, exercise, hot application, massage, distraction, communicating the pain with others, life style modifications, and pain endurance for coping. Effective management practices are related to a better QoL.

Concerning the QoL in family caregivers of persons with physical disability, it was found that QoL was low compared to their counterparts. Various personal, health and illness, and environment factors were related to QoL.

According to the SMM, the symptom experience, symptom management, and outcome are influenced by personal, health and illness, and environmental factors (Dodd et al, 2001). These factors influence the chronic LBP experience, pain management strategies, and the QoL may differ in each context. The previous studies were conducted mostly developed countries. The findings from those studies may not fully describe the chronic LBP experience, pain management strategies, and QoL of



family caregivers of Nepal due to the differences in personal and environmental factors. Therefore, a study of the chronic LBP experience, pain management strategies, and QoL of family caregivers of persons with physical disability is essential to aware health care providers that they can provide education for the family caregivers to manage their chronic LBP and improve QoL in Nepal. Consequently, the family caregivers will be able to maintain an effective continuing care for their family members with physical disability.

## **Chapter 3**

### **Research Methodology**

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

#### **Research Design**

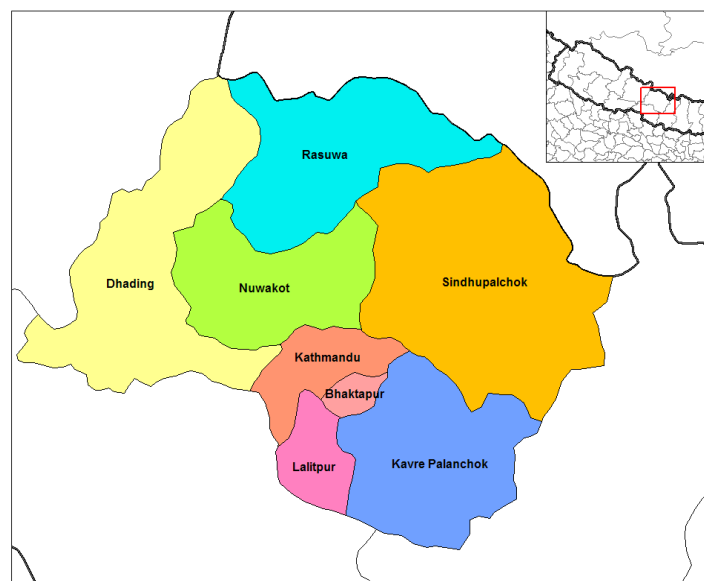
The study was conducted using the descriptive cross-sectional design. The aim of the study was to identify the chronic LBP experience, pain management strategies, and QoL among family caregivers of persons with physical disability in Nepal.

#### **Setting**

The study was conducted among family caregivers of persons with physical disability who were discharged from the Spinal Injury Rehabilitation Center (SIRC), Nepal Orthopedic Hospital (NOH), National Institute of Neurological and Applied Sciences (NINAS), and residing in the communities of eight districts of the Bagmati Zone of Nepal.

SIRC is the only specialized and major rehabilitation center for persons with spinal cord injury in Nepal located in the Kavrepalanchok district which is 23 km away from the capital city, Kathmandu. NOH is a major hospital and referral center for major orthopedic trauma from different parts of the country located at the center of Kathmandu. Similarly, NINAS is a major hospital and referral center for major neurological disorders and trauma in Nepal located in Kathmandu. The patients with

physical disabilities, after discharge from these centers, were residing in eight districts of the Bagmati Zone of Nepal, namely (1) Kathmandu; (2) Bhaktapur; (3) Lalitpur; (4) Sindupalchok; (5) Kavrepalanchok; (6) Nuwakot; (7) Rasuwa; and (8) Dhading. Hence, the researcher collected data from these eight districts of the Bagmati Zone (Figure 2).



*Figure 2.* Map of Bagmati Zone

## **Population and Sample**

### **Target population**

The population of the study included family caregivers of persons with physical disability.

### **Sample and sampling**

The sample consisted of the family caregivers who met the inclusion criteria and agreed to participate in the study with written consent. The inclusion criteria

were: (1) family caregivers who provide care for adults and elderly persons with physical disability; (2) aged more than 18 years; (3) serving as the primary family caregiver for more than three months; and (4) having perceived LBP for more than three months after taking caregiver's role.

The participants were selected on the basis of convenient sampling technique which involves the method of data collection from participants who are conveniently available to participate in the study (Polit & Beck, 2012). The researcher selected participants on the basis of feasibility.

#### **Sample size estimation**

The researcher used a proportion of the known population to determine the sample size. According to Singchanchai, Khampalikit, and Na-Sae (1996), if the sample size is above 10,000, approximately 1% of its subjects can be used to represent the sample. According to the latest national census of 2011, the total number of persons with physical disabilities from the eight selected districts was 18,290 (Resource Center for Rehabilitation and Development Nepal, 2011). Therefore, 1% of the given population required a sample size of 182 individuals. However, 200 family caregivers were approached for the study. Among 200 family caregivers, 103 family caregivers had perceived LBP for more than three months. Hence, 103 family caregivers were recruited for this study.

#### **Instruments**

The data of chronic LBP experience, pain management strategies, and QoL of family caregivers were obtained using four sets of self-report questionnaires including (1) Demographic, Health and Environment related Data Form (DHEDF); (2) Pain

Experience Questionnaire (PEQ); (3) Chronic Low Back Pain Management Questionnaire (CLBPMQ); and (4) World Health Organization Quality of Life-BREF (WHOQOL-BREF) Nepali Version.

### **Demographic, Health, and Environment Related Data Form (DHEDF)**

The questionnaire was developed by the researcher based on the literature of chronic LBP experience, pain management strategies, and QoL among family caregivers of persons with physical disability. The questionnaire consists of two parts. The first part consists of demographic and health-related data including age, gender, religion, marital status, the level of education, occupation, monthly income, the adequacy of income, number of family members, relationship of the caregivers to the person with a physical disability, and the presence of comorbidities. The second part consists of environment related data including types of persons with physical disability, dependency level of person with physical disability, duration of caregiving, hours of caregiving, common physical caregiving activities, presence of assistance in caregiving, social support, social support type, and physical environmental barriers in caregiving (Appendix B).

### **Pain Experience Questionnaire (PEQ)**

The pain experience questionnaire consists of three parts including Pain Intensity Scale, Pain Frequency Questionnaire, and Pain Interference Scale (Appendix C).

***Pain intensity Scale.*** The Pain Intensity Scale is a part of the Short Form Brief Pain Inventory (SF-BPI). It consists of four items assessing pain at worst, at least, the average, and pain now. The recall period for the worst, least, and the average pain was modified to last week due to the nature of chronic LBP. The Numerical Rating Scale

is used to present pain intensity from 0 (no pain) to 10 (pain as bad as you can imagine).

The level of pain was categorized into mild (1.00-3.99), moderate (4.00-6.99), and severe (7.00-10.00) (Archer et al., 2012). Higher scores represent a higher intensity of pain.

***Pain Frequency.*** The Pain Frequency Questionnaire was developed by the researcher on the basis of the literature review. It consists of one question: “How often you experience low back pain?”. The response options were 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 indicates a higher frequency of pain.

***Pain Interference Scale.*** The Pain Interference Scale is a part of the SF-BPI. The scale measures how the pain interferes with functional aspects of life. The scale consists of seven items including how the pain interferes with (1) general activities; (2) mood; (3) walking; (4) normal work; (5) relationship with others; (6) sleep; and (7) enjoyment of life. Each item is rated with 0-10 numerical ratings where 0 represents non-interference and 10 means complete interference. The score can be computed on composite or individual components.

The level of pain interference was classified into mild (1.00-3.99), moderate (4.00-6.99), and severe (7.00-10.00) (Archer et al., 2012). Higher scores indicate a higher interference due to pain.

### **Chronic Low Back Pain Management Questionnaire (CLBPMQ)**

The CLBPMQ was developed by the researcher based on the SMM (Dodd et al., 2001) and the literature review (Appendix D). The CLBPMQ consists of an open-

ended question: “What are the ways you use to manage your low back pain”. Further specifications include what, how often, why, when, where, and who. Additionally, the effectiveness of the pain management strategies was assessed as no effect, a little, moderate, and high effective.

### **World Health Organization Quality of Life (WHOQOL)-BREF Nepali Version**

The WHOQOL-BREF Nepali Version was used to assess QoL of family caregivers of persons with physical disability (Appendix E). The questionnaire consists of 26 questions. The initial two questions (i.e., 1, 2) ask about the general perceptions of health and quality of life and remaining 24 questions are categorized into four domains including physical health (7 items), psychological (6 items), social relationship (3 items), and environment (8 items). The items are rated on a 5-item Likert scale with scores of 1-5.

The score of four domains are derived from 24 items. The mean scores of each domain is calculated by the summation of the score of each item divided by the number of items in each domain. Then the mean score of each domain is multiplied by 4 to make the domain score comparable to the score used in WHOQOL-100 and eventually transformed into 0-100 scale (WHO, 1997). The detail steps of computing domain score are presented in Appendix F.

The score of the overall QoL (26 items) ranges from 26 to 130, whereas higher scores represent a higher QoL. However, since the WHOQOL-BREF has no cut-off points to determine the level of QoL (Appendix I), the level of overall QoL was determined by dividing the maximum score minus minimum score by number of

categories ( $[(130 - 26)/3]$ ). The mean score of overall QoL is interpreted as low for the score of 26.00-60.66, moderate for 60.67-95.33, and high for 95.36-130.00.

### **Translation of the instruments**

Except for the WHOQOL-BREF, all the instruments were developed in the English language. The instruments were translated into Nepali by using the back translation process proposed by Brislin (1970) (as cited in Polit & Beck, 2012) which involves three steps.

In the first step, two bilingual translators and one bilingual reviewer were selected (Appendix K) who were familiar with both English and Nepali language and were capable of understanding the culture and construct of the study variables. The questionnaire in English was translated into the Nepali version by the first translator. Then the Nepali version questionnaire was translated back into an English version without consulting the original version by the second translator.

In the second step, both the translated Nepali and English versions were compared by the reviewer who was a Ph.D. scholar with the health background. The reviewer identified and elucidated minor differences and ensured the equivalency of meaning of translated instruments with the original. Finally, the translated instruments were pretested.

### **Validity and reliability of the instruments**

*Validity of the instruments.* The validity of the instruments refers to the content validity which is concerned with the degree to which the current instruments have the items which measure the chronic LBP experience, pain management strategies, and QoL of the family caregivers of persons with physical disability in Nepal. The instruments were validated by three experts from orthopedic and physical



rehabilitation. Two experts were from Prince of Songkla University in Thailand and one expert was from Nepal. The two experts from Prince of Songkla University were a nurse educator expert in physical rehabilitation and an orthopedic physician expert in orthopedic and physical rehabilitation. The expert from Nepal was a nurse educator with work experience in orthopedic trauma (Appendix J). Each item was evaluated for the appropriateness, accuracy, and congruency with the construct of the current study. The instruments were revised according to the recommendations of the experts (i.e., added two more options in the frequency of pain including twice a week, and twice a month). The content validity index (CVI) of each instrument was calculated by the experts. The scale content validity indexes (S-CVIs) of the PEQ, CLPMQ, and WHOQOL-BREF were 1.0, .89, and 1.0, respectively, which were valid to measure the variables in the study (Polit & Beck, 2012).

***Reliability of the instruments.*** The reliability of the instruments was tested for internal consistency to measure the construct by using Cronbach's alpha coefficient. In this study, the reliabilities of the translated versions of the instruments including the Pain Intensity Scale and Pain Interference Scale of the PEQ and the WHOQOL-BREF were tested in 20 family caregivers of persons with physical disability who had similar characteristics with the actual study population. The results yielded Cronbach's alphas of .71 for the Pain Intensity Scale and .87 for the Pain Interference Scale of the PEQ. Similarly, the WHOQOL-BREF Nepali version yielded a Cronbach's alpha of .90. The results indicated that the instruments were reliable to measure the study variables (Polit & Beck, 2012).

## **Data Collection Methods**

The data were collected in two phases as the preparation phase and the data collection phase.

### **Preparation phase**

In the preparation phase, ethical approval was obtained from these institutions: (1) Research Ethics Committee (REC) of the Faculty of Nursing, Prince of Songkla University, Thailand and (2); the administrator of Nepal Health Research Council (NHRC), Spinal Injury Rehabilitation Center (SIRC), Nepal Orthopedic Hospital (NOH), and National Institute of Neurological and Applied Sciences (NINAS), Nepal.

### **Data collection phase**

In this phase, participants were recruited and data were collected with following steps:

1. The researcher introduced herself to the administrators of Spinal Injury Rehabilitation Center (SIRC), Nepal Orthopedic Hospital (NOH), and National Institute of Neurological and Applied Sciences (NINAS) and explained in details about the purpose and procedure of the study. The researcher then maintained a good interpersonal relationship with the concerned authority of the aforementioned centers. Then the name and contact address of the persons with physical disability who were discharged to communities were obtained. All total, the name, and addresses of 348 persons with physical disability were collected.
2. The researcher identified the primary family caregivers of persons with physical disability through telephone contact. After that, the potential participants were informed in advance about the purpose, procedure, risks, and benefits of the

study. If the participants were willing to participate (verbal consent) in the study, the researcher made appointments to meet them. Then, the researcher visited the participants at the appointed place and time.

3. The researcher introduced herself to the participants and explained in detail the purpose and procedure of the study.

4. After explaining the details of the study, the consent form was described to the participants and their right to stop or withdraw from the study at any time (Appendix A). If the participants were interested in participating, they were requested to sign the written informed consent form.

5. After the detailed explanation of the study and completing the consent form, the questionnaires were explained to the participants. Then, the researcher did a face to face interview which took around 30-40 minutes.

6. The researcher re-checked for completion of the questionnaires.

7. The participants were given needed information concerning the management of LBP at the end of the interview.

### **Ethical Considerations**

Permission was taken from the Research Ethics Committee (REC) of the Faculty of Nursing, Prince of Songkla University, Thailand, Nepal Health Research Council (NHRC), Nepal and concerned authorities of the selected hospitals of Nepal. The participants were provided adequate information on the purpose, procedure, potential risks, and benefits of the study. Informed consents were obtained from each participant on their own will (Appendix A). Furthermore, the participants were provided the needed information for management of LBP at the end of the data

collection. The participants were assured that confidentiality would be maintained by keeping anonymity through a coding system. The data were kept secure with the researcher only and will be destroyed at the completion of this study (within three years). The participants were allowed to withdraw from the study at any time at their own convenience. Additionally, permission was obtained from the developers of the tools for translation and use.

### **Data Analysis**

The data were analyzed using descriptive statistics. Frequency and percentage were used to present categorical data of demographic, health and environment related data. Maximum, minimum, mean, and standard deviation were used to present normally distributed continuous data of demographic, health and environment data pain intensity, pain frequency, pain interference, and quality of life. Maximum, minimum, median, and interquartile range values were used for non-normally distributed data including family income, duration of caregiving, and hours of caregiving. The simple content analysis was used for open-ended questions of CLBPMQ. Then, the responses were grouped and presented in frequency and percentage.

## Chapter 4

### Result and Discussion

This chapter presents the results and discussion about the chronic LBP experience, pain management strategies and QoL among family caregivers of persons with physical disability. The results and discussion of this study are presented in four parts: (1) demographic, health, and environment data; (2) chronic low back pain experience; (3) chronic low back pain management strategies; and (4) Quality of life.

#### Results

##### **Demographic, health and environment data**

*Demographic and health related data.* The findings of this study were obtained from 103 family caregivers of persons with physical disability. The mean age of the family caregivers was 37 years (*Range* =18-65). The majority of the family caregivers were female (83.5%), Hindu (72.8%), and married (83.5%). Forty-one percent of the family caregivers had no education and nearly half (47.6%) of them were farmers. Approximately half (50.5%) of the family caregivers had a monthly income less than 10,000 Nepali rupees (97.08 USD) which were an inadequate income for most (62.1%). The majority of the family caregivers (67%) were living with 2-4 family members. More than half of the family caregivers (53.4%) had a spousal relationship with person with physical disability. Nearly one third (29%) had comorbidities. The details of the demographic and health related data of the family caregivers are presented in Table 1.

Table 1

*Frequency and Percentage of Family Caregivers Classified by Demographic and Health-Related Data (N=103)*

Characteristics	<i>n</i>	%
Age (year) ( <i>M</i> = 37.8, <i>SD</i> = 12.8, <i>Range</i> = 18-65)		
18-30	37	35.9
31-45	38	36.9
46-60	24	23.3
>60	4	3.9
Gender		
Male	17	16.5
Female	86	83.5
Religion		
Hindu	75	72.8
Buddhist	18	17.5
Christian	10	9.7
Marital Status		
Single	17	16.5
Married	86	83.5
Education level		
No education	43	41.7
Primary	12	11.7
Secondary	25	24.3
Higher level	23	22.3
Occupation		
Employed (e.g. government and private job)	20	19.4
Self-employed (e.g. business)	15	14.6
Farmer	49	47.6
Others (e.g. household work, student )	19	18.4
Family income (Nepali rupees/months)* ( <i>Mdn</i> =10,000, <i>IQR</i> =14,000, <i>Range</i> = 3,000-40,000)		
<10,000	52	50.5
10,000- 20,000	30	29.1
20,001 – 30,000	18	17.5
30,001 – 40,000	3	2.9
Adequacy of income		
No	64	62.1
Yes	39	37.9

Table 1 (continued)

<b>Characteristics</b>	<i>n</i>	<i>%</i>
<b>Number of family members</b>		
<b>2-4</b>	69	67.0
<b>&gt; 5</b>	34	33.0
<b>Relationship of family caregiver and person with physical disability</b>		
<b>Spouse</b>	55	53.4
<b>Parent</b>	26	25.2
<b>Children</b>	17	16.5
<b>Sibling</b>	5	4.9
<b>Comorbidities (e.g. hypertension, diabetes, arthritis)</b>	30	29.0

Note\* 1 USD = 103 Nepali rupees. *M* = mean. *SD* = Standard deviation. *Mdn* = median. *IQR* = interquartile range

***Environment-related data of family caregivers.*** The majority of persons with physical disability (63.1%) had spinal cord injury. The majority of the persons with physical disability (62.1%) were totally dependent on others for their activities of daily living (ADL). Nearly half of the family caregivers (48.5%) had provided care for 3-6 months. Two third of the family caregivers (68%) were providing 9-24 hours of care per day. Regarding caregiving activities, the most common physical caregiving activities were lifting and transfer, bathing, and toilet care. Forty-one percent of the family caregivers had family members to assist in caregiving. Nearly one-third (30.1%) of the family caregivers received social support including financial support which was the most common followed by psychological support. Nearly half (49.5%) of the family caregivers had barriers in caregiving due to the physical environment at home. The details of the environment related data are presented in Table 2.

Table 2

*Frequency and Percentage of Family Caregivers Classified by Environment Related Data (N=103)*

Characteristics	<i>n</i>	%
Types of persons with physical disability		
Spinal cord injury	65	63.1
Stroke	15	14.6
Orthopedic injuries (e.g., hip fractures, amputee)	10	9.7
Cerebral palsy	6	5.8
Traumatic brain injury	2	1.9
Others (e.g., Parkinson syndrome, muscular dystrophy)	5	4.9
Dependency level of person with physical disability <sup>a</sup>		
Total (0-24)	64	62.1
Severe (25-49)	23	22.3
Moderate (50-74)	15	14.6
Mild (75-90)	0	0.0
Minimal (91-99)	1	1.0
Independent (100)	0	0.0
Duration of caregiving (month), ( <i>Mdn</i> = 8, <i>IQR</i> = 17, <i>Range</i> = 3-324)		
3-6	50	48.5
7-12	11	10.7
>12	42	40.8
Hours of care per day, ( <i>Mdn</i> = 12, <i>IQR</i> = 18, <i>Range</i> = 3-24)		
3 – 8	33	32.0
9 -16	39	37.9
17- 24	31	30.1
Common physical caregiving activities <sup>b</sup>		
Lift and transfer	99	96.1
Bathing	96	93.2
Toilet care	91	88.3
Help in getting up and lying down	88	85.5
Grooming and dressing	74	71.0
Position change	69	67.9
Presence of assistance in caregiving		
No	60	58.3
Yes	43	41.7



Table 2 (continued)

Characteristics	n	%
Social support (e.g., family, friends, organization)		
No	72	69.9
Yes	31	30.1
Support Type		
Financial support	24	77.4
Physical support	2	6.4
Psychological support	12	38.8
Informational support	1	0.9
Physical environmental barriers in caregiving (e.g., height of stair, lack of way for wheelchair, cramped space in room, bathroom and toilet)		
No	52	50.5
Yes	51	49.5

*Note.* <sup>a</sup> The level was measured using Modified Barthel Index, <sup>b</sup> One family caregiver provided more than one answer

### **Chronic low back pain experience**

The chronic LBP experience included the level of pain intensity, frequency, and the level of pain interference of chronic LBP.

Table 3 presents chronic LBP intensity, frequency, and pain interference. The family caregivers experienced a moderate levels of overall pain intensity with a mean of 4.5 ( $SD = 1.1$ ). Considering each component of pain intensity, the level of worst pain was severe ( $M = 7.0$ ,  $SD = 1.5$ ) and the level of pain at least was mild ( $M = 2.3$ ,  $SD = 1.3$ ). In terms of pain frequency, the majority of the family caregivers (70.9%) experienced pain every day. Overall, the family caregivers experienced a moderate pain interference with a mean of 4.2 ( $SD = 1.7$ ). Considering the scores of each item, the top three most pain interferences were normal work ( $M = 5.3$ ,  $SD = 2.2$ ), general activities ( $M = 5.1$ ,  $SD = 2.0$ ), and mood ( $M = 4.3$ ,  $SD = 2.2$ ), respectively.

Table 3

*Frequency, Percentage, Minimum, Maximum, Mean, Standard Deviation, and Level of Chronic Low Back Pain Intensity, Pain Frequency, and Pain Interference Among Family Caregivers (N=103)*

Variables	<i>n</i> (%)	<i>Min</i>	<i>Max</i>	<i>M</i> ( <i>SD</i> )	Level
<b>Pain intensity</b>					
Overall pain intensity		1.7	7.7	4.5 (1.1)	Moderate
Pain at worst		4.0	10.0	7.0 (1.5)	Severe
Pain on the average		1.0	9.0	5.0 (1.1)	Moderate
Pain now		1.0	8.0	4.0 (1.8)	Moderate
Pain at least		1.0	7.0	2.3 (1.3)	Mild
<b>Pain frequency</b>					
Every day	73 (70.9)				
More than twice a week	13 (12.6)				
Twice a week	13 (12.6)				
Once a week	4 (3.9)				
<b>Pain interference</b>					
Overall pain interference		1.7	8.4	4.2 (1.7)	Moderate
Normal work		1.0	10.0	5.3 (2.2)	Moderate
General activities		1.0	10.0	5.1 (2.0)	Moderate
Mood		1.0	10.0	4.3 (2.2)	Moderate
Walk		1.0	9.0	4.0 (2.1)	Moderate
Enjoyment of life		1.0	10.0	3.9 (2.2)	Moderate
Sleep		1.0	8.0	3.8 (2.4)	Mild
Relationship with others		1.0	10.0	3.5 (2.0)	Mild

*Note.* *Min* = minimum, *Max* = maximum, *M* = mean, *SD* = standard deviation.

### **Chronic low back pain management strategies**

Overall, the family caregivers used both pharmacological and non-pharmacological pain management. However, they used non-pharmacological pain management more than pharmacological pain management. The most commonly used non-pharmacological managements were endurance (40.7%), massage (20.4%), and hot application (15.5%). Among the pharmacological management, pain medications

were used by 30% of caregivers; particularly, Ibuprofen was the most commonly used. The majority of the family caregivers used the pain management most of the times during the pain (Table 4).

Table 4

*Frequency and Percentage Family Caregivers Perceived About Frequency of Pain Management (N=103)*

Pain Management *	Frequency			
	n (%)	Rarely n (%)	Sometimes n (%)	Most of the times n (%)
<b>Pharmacological management</b>				
Pain medications				
Ibuprofen (tablet)	31 (30.0)	-	-	31 (100.0)
Acetaminophen (tablet)	14 (45.2)	-	-	14 (100.0)
Local application (e.g., Diclofenac gel)	9 (29.0)	-	-	9 (100.0)
Non pharmacological management	8 (25.8)	1 (12.5)	2 (25.0)	5 (62.5)
Endurance	42 (40.7)	-	-	42 (100.0)
Massage (e.g., massage with oil, massage therapy)	21 (20.4)	1 (4.7)	9 (42.8)	11 (52.5)
Hot application (e.g., hot water bag, heated brick or stone wrapped in clothes, sun bath, sit near firewood)	16 (15.5)	-	7 (43.8)	9 (56.2)
Lumbar support (e.g., lumbar belt, local clothing [ <i>pattnki</i> ]**)	15 (14.5)	1 (6.7)	1 (6.7)	13 (86.6)
Rest	15 (14.5)	-	1 (6.7)	14 (93.3)
Exercise (e.g., stretch, walk)	14 (14.0)	-	11 (78.6)	3 (24.4)
Distraction (e.g., watch movies, talk)	4 (3.8)	-	3 (75.0)	1 (25.0)
Traditional medicine (e.g., believed foods, and blowing of breath at the site of pain)	3 (2.9)	3 (100.0)	-	-

*Note.* \*One family caregiver used more than one pain management, \*\**Pattnki* is a long cloth used to support the lower back.

The family caregivers reported various reasons for using pain management. The majority of the family caregivers (88.3%) used pain management such as pain medicine, massage, hot application, and exercise to minimize pain. Meanwhile, 40% of caregivers endured pain to cope with pain when other pain management methods were not effective or they did not know of other ways for pain relief (Table 5).

Table 5

*Frequency and Percentage of Family Caregivers About Reasons of Using Pain Management \* (N=103)*

Reasons	<i>n</i>	%
1. To minimize pain (e.g., pain medication, massage, exercise, hot application)	91	88.3
2. To cope with pain when other pain management strategies are not effective or they do not know about pain relief ways (e.g., endurance)	42	40.7
3. To get support and comfort to the low back pain and prevent further pain (e.g., lumbar support)	15	14.5
4. Easy to perform and economic (e.g., rest)	15	14.5
5. To divert mind from pain (e.g., distraction by watching movies, talking, traditional medicine)	7	6.7

*Note.* \* One family caregiver reported more than one answer.

Considering time (when), person (who), and place (where), the majority of the family caregivers used pain management whenever the pain occurred. The majority of pain managements were conducted by the caregivers themselves at home (Table 6).

Table 6

Frequency and Percentage of Family Caregivers About Time, Person and Place of Pain Management (N=103)

Pain Management *	Time (when)			Person (Who)				Place (Where)		
	Whenever the pain occurred n (%)	Leisure time n (%)	Before work n (%)	Caregivers themselves n (%)	Health care providers n (%)	Family members n (%)	Healer <sup>a</sup> n (%)	Home n (%)	Health care center n (%)	Healer <sup>b</sup> center n (%)
<b>Pharmacological management</b>										
Pain medication (n=31)	29 (93.5)	-	2 (6.5)	23 (74.2)	8 (25.8)	-	-	27 (87.1)	4 (12.9)	-
Ibuprofen (n=14)	14 (100.0)	-	-	9 (64.3)	5 (35.7)	-	-	12 (85.7)	2 (14.3)	-
Acetaminophen (n=9)	7 (77.8)	-	2 (22.2)	8 (88.9)	1 (11.1)	-	-	9 (100.0)	-	-
Local application (n=8)	8 (100)	-	-	6 (75.0)	2 (25.0)	-	-	6 (75.0)	2 (25.0)	-
<b>Non pharmacological Management</b>										
Endurance (n=42)	42 (100)	-	-	42 (100)	-	-	-	42 (100)	-	-
Massage (n= 21)	11 (52.4)	10 (47.6)	-	16 (76.2)	3 (14.3)	2 (9.5)	-	18 (85.7)	3 (14.3)	-
Hot application (n=16)	10 (62.5)	6 (37.5)	-	16 (100.0)	-	-	-	16 (100)	-	-
Lumbar support (n=15)	4 (26.7)	-	11 (73.3)	15 (100.0)	-	-	-	15 (100)	-	-
Rest (n=15)	14 (93.3)	1 (6.7)	-	15 (100.0)	-	-	-	15 (100)	-	-
Exercise (n=14)	7 (50.0)	6 (42.9)	1 (7.1)	11 (78.6)	3 (21.4)	-	-	12 (85.7)	2 (14.3)	-
Distraction (n=4)	4 (100)	-	-	4 (100.0)	-	-	-	4 (100)	-	-
Traditional medicine (n =3)	1 (100)	-	-	-	-	1 (33.3)	2 (66.7)	1 (33.3)	-	2 (66.7)

Note. <sup>a</sup>One family caregiver has more than one answer, <sup>a</sup> traditional healer, <sup>b</sup> traditional healer center.

For the effectiveness of the pain management, the majority of the pain management had little effect. Considering pharmacological pain management, half of the family caregivers (50 %) found Ibuprofen to be moderate to highly effective. The majority of the commonly used non-pharmacological pain management methods (i.e., endurance, massage, hot application) had little effect (Table 7).

Table 7

*Frequency and Percentage of Family Caregivers Perceived About Pain Management's Effectiveness (N=103)*

Pain management *	Effectiveness			
	No effective <i>n (%)</i>	A little effective <i>n (%)</i>	Moderate effective <i>n (%)</i>	High effective <i>n (%)</i>
<b>Pharmacological management</b>				
Pain medication ( <i>n</i> = 31)	1 (3.2)	20 (64.5)	7 (22.6)	3 (9.7)
Ibuprofen ( <i>n</i> = 14)	-	7 (50.0)	4 (28.6)	3 (21.4)
Acetaminophen ( <i>n</i> = 9)	-	6 (66.7)	3 (33.3)	-
Local application ( <i>n</i> = 8)	1 (12.5)	7 (87.5)	-	-
<b>Non-pharmacological management</b>				
Endurance ( <i>n</i> = 42)	-	42 (100)	-	-
Massage ( <i>n</i> = 21)	-	19 (90.5)	2 (9.5)	-
Hot application ( <i>n</i> = 16)	1 (6.3)	10 (62.5)	5 (31.2)	-
Lumbar support ( <i>n</i> = 15)	1 (6.7)	12 (80.0)	2 (13.3)	-
Rest ( <i>n</i> = 15)	2 (13.3)	12 (80.0)	1 (6.7)	-
Exercise ( <i>n</i> = 14)	1 (7.1)	9 (64.3)	3 (21.5)	1 (7.1)
Distraction ( <i>n</i> = 23)	-	3 (75.0)	1 (25.0)	-
Traditional medicine ( <i>n</i> = 3)	1 (33.3)	1 (33.3)	-	1 (33.3)

*Note.* \*One family caregiver used more than one management.

### **Quality of life**

Overall, the family caregivers perceived a moderate level of QoL ( $M = 71.2$ ,  $SD = 12.1$ ). Considering the mean score of each domain of QoL, the social relationship domain had the highest mean score ( $M = 52.1$ ,  $SD = 14.4$ ). However, the psychological domain ( $M = 40.1$ ,  $SD = 16.4$ ) had lowest mean score followed by environment domain ( $M = 41.3$ ,  $SD = 12.3$ ) as shown in Table 8.

Table 8

*Range, Mean, Standard Deviation, and Level of Quality of life of Family Caregivers*

*(N=103)*

Variables	Possible Range	Actual Range	M (SD)	Level
Overall QoL	26.0-130.0	42.0-99.0	71.2 (12.1)	Moderate
Physical domain	0.0 - 100.0*	7.1-67.8	46.0 (10.1)	
Work capacity	1.0 - 5.0	1.0 - 5.0	3.2 (0.8)	
Independence of medical aids	1.0 - 5.0	2.0 - 5.0	3.1 (0.8)	
Sleep	1.0 - 5.0	1.0 - 5.0	3.1 (1.0)	
Activities of daily living	1.0 - 5.0	1.0 - 5.0	3.1 (0.8)	
Energy and Fatigue	1.0 - 5.0	1.0 - 5.0	2.8 (0.7)	
Mobility	1.0 - 5.0	1.0 - 5.0	2.8 (0.7)	
Pain and discomfort	1.0 - 5.0	1.0 - 3.0	2.1 (0.5)	
Psychological domain	0.0-100.0*	4.1-75.0	40.1 (16.4)	
Self esteem	1.0 - 5.0	2.0-5.0	3.0 (0.8)	
Bodily image and appearance	1.0 - 5.0	1.0-5.0	2.9 (0.7)	
Memory/ concentration	1.0 - 5.0	1.0-4.0	2.6 (0.8)	
Negative feeling	1.0 - 5.0	1.0-5.0	2.5 (1.0)	
spirituality/ religion belief	1.0 - 5.0	1.0-4.0	2.2 (0.9)	
Positive feeling	1.0 - 5.0	1.0-5.0	2.2 (0.9)	
Social relationship domain	0.0 - 100.0*	8.3-100.0	52.1 (14.4)	
Personal relationship	1.0 - 5.0	1.0-5.0	3.1 (0.8)	
Social support	1.0 - 5.0	1.0-5.0	3.0 (0.7)	
Sexual activity	1.0 - 5.0	1.0-5.0	3.1 (0.8)	
Environment domain	0.0 - 100.0*	12.5-75.0	41.3 (12.3)	
Home environment	1.0 - 5.0	1.0 - 5.0	3.0 (0.8)	
Transport	1.0 - 5.0	1.0 - 5.0	2.9 (0.8)	
Health, social care accessibility	1.0 - 5.0	1.0 - 5.0	2.7 (0.8)	
Physical environment	1.0 - 5.0	1.0 - 5.0	2.7 (0.8)	
Opportunity for new information	1.0 - 5.0	1.0 - 5.0	2.7 (0.7)	
Physical safety security	1.0 - 5.0	1.0 - 5.0	2.4 (0.9)	
Financial resource	1.0 - 5.0	1.0 - 4.0	2.4 (0.7)	
Opportunity for leisure activities	1.0 - 5.0	1.0 - 4.0	2.3 (0.8)	

*Note.\** The domain score is transformed to 0-100 scale based on WHOQOL-BREF (Appendix F).



## **Discussion**

### **The demographic, health and environment data**

The mean age of the family caregivers of persons with a physical disability was in young adult. A possible reason for the young adult caregivers was that the majority of persons with physical disabilities had SCI and SCI is common among young adults in Nepal (Shrestha, 2014). Additionally, marriage at an early age is highly prevalent among rural women in Nepal (Choe, Thapa, & Mishra, 2005). With reference to the age group of persons with SCI, it is possible that most of the spousal family caregivers in this study were younger. Regarding gender, the majority of the family caregivers were female. The predominance of female gender may be related to the traditional role of females as the primary caretaker in the Nepalese cultural context. Females are the predominant providers of informal care for chronic disease and physical disabilities worldwide (Sharma, Chakrabarti, & Grover, 2016). Forty-one percent of the family caregivers had no education. This was possible because the majority of the family caregivers were female. Consistent with a national report, which reported 42% of females were illiterate (Central Bureau of Statistics, 2014).

With regards to income, the majority of family caregivers had a monthly income less than 10,000 Nepali rupees (97.08 USD) which were perceived as inadequate. The possible reasons for an inadequate income were related to the fact that the majority of persons with physical disability of this present study were totally dependent on their family caregivers. Furthermore, the persons with physical disability may frequently require medical treatment. In such situations, the family caregivers need to manage the medical expenses from a limited income. It was reported that the caregivers of person with physical disability had to use their own

income to care for the disabled, which interfered with the family economy and dynamics (Xie et al., 2016). Therefore, the family caregivers possibly perceived to have an inadequate monthly income.

Regarding environment-related data of family caregivers, the majority of persons with physical disability had spinal cord injury and were totally dependent on others. The increased dependency of persons with a physical disability could be related to the fact that SCI is a chronic health condition causing severe disability by deteriorating the functions of vital organs such as locomotion, sensitivity, elimination, and the autonomic nervous system (Nogueira et al., 2015). These functional disabilities may restrict independent ADL.

The common caregiving activities included lift and transfer, bathing, toilet care, help in getting up and lying down, grooming and dressing, and positional changes. These are the common caregiving activities for persons with a physical disability which is consistent with previous studies (Darragh et al., 2015; Suzuki et al., 2016; Tonga & Duger, 2008).

### **Chronic low back pain experience**

In the current study, the family caregiver experienced pain every day with moderate level. These may be explained by possible factors such as environmental factors (e.g., dependent persons, caregiving activities, duration of caregiving, normal family responsibilities, and environment barriers) and personal factors (e.g., belief about pain and lack of knowledge in LBP management). Firstly, the majority of the family caregivers in the current study provided physical caregiving activities to totally dependent persons with physical disability for more than nine hours per day including lifting and transfer, bathing and toilet care along with normal family responsibilities.

Furthermore, the family caregivers also reported barriers in caregiving due to the physical environment. Consistently, evidences show that the activities of the family caregivers of persons with physical disability, who needed to lift the patient, give help in getting up and lying down, perform frequent positional changes, bend frequently for caregiving, and perform activities in a static body position for the long term, were associated with increased severity of LBP (Suzuki et al., 2016; Tonga & Duger, 2008). Additionally, normal family responsibilities and barrier of physical environment was associated with the development of LBP (Suzuki et al., 2016; Tonga & Duger, 2008).

Secondly, the family caregivers in the current study had the lower level of education that may influence of lack of knowledge of how to lift and transfer patients and manage their chronic LBP effectively. It is reported that knowledge about the risk factors aids in prevention and management of LBP (Cilliers & Maart, 2013).

The frequency of pain is higher in this study compared to LBP among nurses (June & Cho, 2011; Ovayolu et al., 2014). The possible reason for the higher frequency of chronic LBP in family caregivers could be due to the fact that unlike nurses who work shift duty and sole caregiving activities, the work of family caregivers for persons with a physical disability entails providing round-the-clock continuous caregiving along with normal family duties (Lawang et al., 2015). Therefore, the finding of chronic LBP intensity of this study was consistent with a previous study that the mothers of non-ambulatory children with a physical disability experienced the moderate intensity of LBP (Tonga & Duger, 2008).

The pain had moderate interference on various aspects of life that most commonly affected normal work, general activities, and the mood. It was reported

that chronic LBP interfered significantly with work hours, income, and psychological outcomes (Mathew, Singh, Garis, & Diwan, 2013). The literature concerning chronic LBP interference among family caregivers is limited. However, using the professional caregiver as a reference, it was found that LBP interfered variably. A study conducted among nurses in Nepal revealed that due to LBP, 44% of nurses could not perform their job properly, 33% became less productive, 28% had a restriction in work, and 26% could not provide quality care to the patients (Adhikari & Dhakal, 2015). Similarly, more than 20% of the care workers of persons with intellectual, autistic, and associated multiple disabilities experienced moderate or severe interference in their daily functions including normal work, general activities, mood, walking, relationships with other people, sleep, and enjoyment of life (Lin et al., 2014). Additionally, the severity of LBP was associated with a physical disability and a change in mood of the family caregivers (Tong et al., 2003). Hence, frequent LBP with increased intensity secondary to heavy caregiving activities and other family responsibility possibly may relate to pain interference among family caregivers in the current study.

#### **Chronic low back pain management strategies**

Chronic LBP management strategies used by family caregivers are discussed on the basis of pain management strategies (i.e., what, how often, why, when, where, who) and their effectiveness. Overall, the family caregivers used non-pharmacological management more than pain medications to reduce their chronic LBP. Considering non-pharmacological management, endurance, massage, and hot application were the most commonly used methods. Pain medication, in particular, Ibuprofen was the most

common pharmacological management used by the family caregivers. The reasons of using these pain management strategies are explained as follows.

Ibuprofen was the most common pain medication used by the family caregivers in the current study which was consistent with a previous study conducted among individuals with chronic LBP where Ibuprofen was the most common drug used to minimize severe LBP (Crowe et al., 2010). Moreover, Ibuprofen is one of the most commonly available over the counter drugs for pain management in the community settings of Nepal (Bhattarai, Basyal, & Bhattarai, 2014; Thapa, Shankar, Palaian, & Aljadhey, 2016). For family caregivers who have no time to visit a doctor, using such drugs from a nearby pharmacy shop can be more convenient for pain management. Consistently, the family caregivers commonly used Ibuprofen to minimize pain for themselves.

Considering the effectiveness of pharmacological pain management, the family caregivers found that Ibuprofen was moderate to highly effective in pain management. Ibuprofen is a drug in the class of NSAIDs. The possible mechanism involved in pain reduction is by inhibiting the cyclogenesis responsible for the production of prostaglandin (Bushra & Aslam, 2010). The literature has reported that NSAIDs are the most effective and recommended drugs for chronic LBP management to relieve pain in the short term (White et al., 2011).

Moreover, pain endurance was one of the common non-pharmacological management used by the family caregivers most of the time. There could be several reasons that pain endurance was the most common pain management. Firstly, the family caregivers in the current study had a lower level of education. Due to the low level of education, the family caregivers possibly did not have adequate knowledge on

pain management. Consistently, many family caregivers in this study reported that they did not know about the pain management. Consequently, the lack of knowledge on pain management might cause them to believe that LBP is a normal process (Peacock & Patel, 2008). Secondly, chronic LBP is complex in nature that is a challenge to manage (Weiner, Sakamoto, Perera, & Breuer, 2006). The pharmacological and non-pharmacological management used for chronic LBP may not work for the long term (Van Tulder, Koes, & Malmivaara, 2006). As a result, the individual needs to cope with the pain. Consistently, the family caregivers of current study reported that they endured pain because other pain management strategies were not effective. Thirdly, the majority of the family caregivers were providing care for highly dependent persons with physical disability with intense physical care and maintaining their jobs. In such situations, the family caregivers may not have the time to seek other pain managements. Hence, these factors possibly contributed to endurance as the alternative way to deal with LBP.

Moreover, the family caregivers used massage to reduce their LBP. Simple oil massage is common in Nepalese communities for minor aches. For the family caregivers, a simple massage with local oil can be an easy and accessible method for pain management. Furthermore, massage is a technique of touching the soft tissues of the body with the hands and the goal is to reduce pain and increase comfort (Eghbali et al., 2012). Hence, the easy accessibility and comfort probably caused the family caregivers to use oil massage.

The hot application was one of the commonly used management in the current study. This is consistent with studies conducted among individuals with chronic LBP where the participants commonly used hot water and hot objects to relieve chronic

LBP (Crowe et al., 2010; Tveito et al., 2010). It is reported that hot application reduces LBP through various possible mechanisms. First, a hot application dilates the blood vessels of the muscles around the lumbar spine and increases the uptake of oxygen and nutrients in the muscle. Second, it decreases the transmission of pain signals to the brain and provides comfort. Third, heat application facilitates stretching of the soft tissue and decreases stiffness (Mooney, 2017).

Even though the non-pharmacological managements were used most of the time, the majority of the family caregivers found them to have a little effect. There could be two possible reasons for the outcome. First, the non-pharmacological managements in the current study were mostly performed by family caregivers themselves at home. However, in previous studies, the non-pharmacological managements were performed by health care providers in clinical settings with specific methods, duration, and frequency of intervention (Cherkin et al., 2011; Dehghan & Farahbod, 2014; French et al., 2006). In such situations, it could not be confirmed that the family caregivers in the current study used the appropriate methods of pain management. Second, the majority of the family caregivers used the pain managements whenever the pain occurred. This indicated that the pain managements were focused mainly on instant relief of pain rather than any longer effect or prevention. Furthermore, it was found that a non-pharmacological management usually had a short-term effect on pain (Chou et al., 2017). These factors were possibly related to the little effectiveness of the non-pharmacological management.

### **Quality of life**

The family caregivers in this study perceived moderate QoL. Considering each domain of QoL, the family caregivers perceived the highest level in the social relationship domain but lowest scores in the psychological followed by environment domain.

The highest score in the social relationship domain may be caused by social support and personal relationships. This was possibly related to the fact that many family caregivers had the presence of assistance in caregiving, and lived mostly with family members and in spousal relationships. Furthermore, nearly one-third of the family caregivers received support from family, friends, and organizations. It was found that the family caregivers who had someone to assist in care had better QoL (Amendola, Oliveira, & Alvarenga, 2011). It was also found that with a greater number of family members, family caregivers received more social support and had a better QoL (Yamashita, Amendola, Gaspar, Alvarenga, & Oliveira, 2013). Additionally, receiving support from others and being spousal caregivers indicated that the family caregivers had good interpersonal relationships. Furthermore, the majority of the family caregivers in the current study were young adults. Young people tended to function more actively, work more energetically and be more involved in social activities which provided temporary relief from caregiving burdens (Morley et al., 2012). These factors were possibly related to better social relationships.

The low score in the domains of psychological and environment were consistent with a previous study conducted among family caregivers of the intellectually disabled persons (Chou et al., 2007) and family caregivers of children



with physical disabilities (Neves et al., 2015). The lower score in the psychological domain, especially in negative feeling, spirituality or religion/personal belief facets, and positive thinking may be related to the fact that half of the persons with a physical disability were totally dependent on family caregivers for their ADL. In such situations, the family caregivers may perceive frequent worries and be emotionally weak. It was found that family caregivers with dependent patients may perceive the heavy responsibilities of caregiving, constant worries, restraints in social life, and the feeling that the patient relies only on their care which impair their psychological well-being (Reimer, Haan, Rijnders, Limburg, & Bos, 1998). Furthermore, the family caregivers may experience deprivation of affection exchange, inability to share enjoyable activities, household problems, and uncertainty of prognosis which creates emotional stress and constant worries about future (Glozman, 2004).

Moreover, the possible reasons for a lower score in the environment domain, especially in physical safety and security, financial resources and opportunities for recreation and leisure activities, could be related to the fact that the majority of the persons with physical disability were total dependent and the family had an inadequate monthly income. It has been reported that the family caregivers of persons with disability may perceive fear and insecurity about the unknown future (Farnades & Angelo, 2016). Regarding income, previous studies revealed that a lower monthly income in the family was related to a decreased QoL (Chou, Chiao, & Fu, 2011; Xie et al., 2016; Yang et al., 2012). Greater health expenses for frequent medical treatment for persons with a physical disability were related to decreases in both the physical and mental domains of QoL (Xie et al., 2016; Yang et al., 2012). The family caregivers needed to use their own income to care for the disabled, which interfered

with the family economy and dynamics (Xie et al., 2016). Concerning the opportunities for leisure activities, the majority of the family caregivers in this study were providing care for totally dependent persons with a physical disability for more than nine hours per day. The nature of persons with physical disability and caregiving activities as discussed earlier limit the leisure time and social interaction. Limitations in the social life of a family caregiver due to the caregiving activities and dependency of patients for ADL reduce the QoL among family caregivers (Xie et al., 2016). Hence, the dependency of persons with a physical disability and financial problems might be related to a low score in the environment domain.

According to the SMM, symptom experience and symptom management are related to outcome (Dodd et al., 2001). In this regard, the chronic LBP experience, pain management strategies and QoL of the family caregivers were interrelated. The personal (e.g., knowledge and belief about pain and LPB management) and environment factors (e.g., the dependency of patients for ADL, caregiving activities, family and social support, interpersonal relationship, family income, physical environment barriers) possibly influenced the chronic LBP experience, pain management strategies, and QoL which were discussed in the earlier section. Therefore, it is important for the health care providers to be aware of chronic LBP management and QoL enhancement for family caregivers of persons with physical disability in Nepal.

## Chapter 5

### Conclusions and Recommendations

This chapter presents the conclusion, strengths, and limitations of the study. Further recommendations and implications of the study are provided.

#### Conclusions

A descriptive cross sectional design was used to examine the chronic LBP experience, pain management strategies, and quality of life among family caregivers of persons with physical disability in Nepal. The study was carried out from January to March, 2017. The data were collected using self-report questionnaires including: (1) Demographic, Health and Environment Related Data Form (DHEDF); (2) Pain Experience Questionnaire (PEQ); (3) Chronic Low Back Pain Management Questionnaire (CLBPMQ); and (4) World Health Organization Quality of Life-BREF (WHOQOL-BREF) Nepali version. The questionnaires were validated content by three experts. The reliability of the instruments was tested among 20 participants and the results yielded Cronbach alphas of .71 for the Pain Intensity Scale and .87 for the Pain Interference Scale of the PEQ. Similarly, the WHOQOL-BREF Nepali Version yielded a Cronbach alpha of .90. The descriptive statistics and simple content analysis were used.

#### Summary of the findings

The findings were derived from 103 family caregivers with chronic LBP. The family caregivers experienced a moderate intensity of pain ( $M = 4.5$ ,  $SD = 1.1$ ). The majority of the family caregivers (70.9%) experienced pain every day. The

overall pain interference was at a moderate level ( $M = 4.2$ ,  $SD = 1.7$ ) and the top three common interferences were in normal work, general activities, and mood, respectively.

The family caregivers used non-pharmacological pain management more than pharmacological management. The commonly used non-pharmacological methods include endurance (40.7%), massage (20.4%), and hot application (15.5%). Pain medications were used by 30 % of caregivers; in particular, Ibuprofen was the most commonly used. The majority of family caregivers managed LBP by themselves at home because they believed that these pain management strategies could minimize pain. Most of them used pain management whenever the pain occurred. Ibuprofen was found to be moderate to highly effective, whereas the commonly used non-pharmacological managements were little effective.

Overall, the family caregivers perceived a moderate level of QoL ( $M = 71.2$ ,  $SD = 12.1$ ). Considering the mean score of each domain of QoL, the social relationship domain had the highest mean score ( $M = 52.1$ ,  $SD = 14.4$ ). However, the psychological domain ( $M = 40.1$ ,  $SD = 16.4$ ) had lowest mean score followed by environment domain ( $M = 41.3$ ,  $SD = 12.3$ ).

### **Strengths of the Study**

This is the initial research to study among family caregivers of persons with physical disability in Nepal. The findings of this study provide important basic information about the chronic LBP experience, pain management strategies, and QoL of the family caregivers of persons with physical disability for healthcare providers to

design appropriate interventions for reducing chronic LBP and enhancing QoL among family caregivers.

### **Limitations of the Study**

1. The sample of family caregivers was selected based on their self-perceived chronic LBP which may not be relevant to medical diagnosis of LBP.

2. Psychological and behavioral problems of persons with physical disability were not collected in this study that may impact to chronic LBP experiences and QoL of family caregivers.

### **Implications and Recommendations**

The findings of the study offer the following implications and recommendation for nursing practice and nursing research as follows:

#### **Nursing practice**

1. The results of the study revealed a moderate LBP intensity level, pain every day and moderate pain interference. Thus, health care providers should educate or train the family caregivers regarding prevention of LBP while providing caregiving activities for persons with physical disability, prior to patients' discharge from hospital. Using available assistive devices may protect or minimize LBP. Moreover, the respite of caregiving for family caregivers who provide care in long term should be suggested to avoid LBP.

2. The family caregivers who developed chronic pain should be advised to use the pain medications (e.g., Ibuprofen) prescribed by physician and combined with the proper non-pharmacological approaches to increase effectiveness of LBP relief. The

commonly used non pharmacological management (e.g., massage, hot application) were little effective possibly due to inappropriate technique use. Thus, the nurses can educate the family caregivers for proper way of using these non-pharmacological management strategies with proper duration, time, and method.

3. The results showed that the family caregivers had a moderate level of QoL. The family caregivers perceived a low level of psychological and environment domain. Thus, health care providers should consider for providing psychological counseling and considering the spiritual well-being of family caregivers. Furthermore, they can promote family support for helping in caregiving activities, and advocate with concerned organization or government to support the patient's medical expenses in order to maintain QoL of family caregivers.

#### **Nursing research**

1. Future research on predictive factors of chronic LBP (e.g., religious coping), pain management (e.g., knowledge and beliefs), and quality of life (e.g., patients' psychological problems, functional disability, social support) among family caregivers of persons with physical disability should be studied.

2. Interventions concerning psychoeducation and pain management to enhance QoL of family caregivers with chronic LBP can be conducted.

3. Replication of similar study in other family caregivers (e.g., intellectual disability, chronic illness) is recommended.

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## **APPENDIX A**

### **Informed Consent Form**

Dear Participants:

My name is Pasang Doma Sherpa and I am a master level student in the Faculty of Nursing, Prince of Songkla University, Thailand. I am conducting a research study on “Chronic Low Back Pain Experience, Pain Management Strategies, and Quality of life Among Family Caregivers of Persons with Physical Disability in Nepal.” This study aims to identify the chronic low back pain experience, pain management strategies, and quality of life among family caregivers of persons with physical disability in Nepal.

This study has been approved by the Research Ethics Committee of the Faculty of Nursing, Prince of Songkla University, Thailand. I am requesting your participation which involves the administration of four sets of questionnaires. Your participation in this study is voluntary. If you choose not to participate or withdraw from the study at any time, there will be no penalty. If you choose to participate in the study, you will be asked personal information related to demographics and health. The remaining questions are about low back pain, the management strategies you use to reduce low back pain and questions related to your quality of life. The whole process may take around 20-30 minutes.

**Risk and discomfort:**

There is no evidence of potential risk to complete the questionnaires. However, there may be a possibility that some questions may be a burden for you. In that case, please let me know. If you want to stop or withdraw from the study at any time, there will be no penalty. I would like to inform you that your information will be used for my thesis, conference, and publication in academic journals.

**Benefits:**

Currently, you may not receive a direct benefit from this study but the information derived from this study will benefit the health care system to become aware of the health of family caregivers in Nepal, provide basic information to health care providers to educate family caregivers for self-management of low back pain, and improve the quality of life of family caregivers.

**Confidentiality:**

All the information and your responses will be kept confidential to the researcher and the researcher's advisor to access the data. All data will be destroyed after completion of the study. To ensure your confidentiality and anonymity, I will use a code. Neither your name nor your identity will be exposed in any report of the study.

**Autonomy:**

You have the full right to withdraw from the study at any time convenient to you without completion of the data. If you have any questions about your rights as a participant in this study, you can contact me at this address:

Name: Pasang Doma Sherpa

Boudha 6, Jorpati, Kathmandu

Tele phone number: 977-9849960685

Email: domapasang000@ yahoo.com

Lastly, signing the written informed consent form or agreeing verbally to participate indicates that you have understood what is involved and you agree to participate. If you choose to participate in this study, please sign your name on the Informed Consent Form. Thank you for showing interest in this study.

.....

Name and signature of participant

Date.....

.....

Pasang Doma Sherpa

Date .....

## APPENDIX B

### Demographic, Health and Environment Related Data Form (PHEDF)

#### Part I: Demographic and Health Related Data

Direction: Please write tick “√” against the answer that is appropriate to you or fill in the blanks as indicated.

1. Age: ..... (years)
2. Gender:             1) Male                             2) Female
3. Religion:             1) Hindu                             2) Buddhist  
 3) Christian                             4) Islam  
 5) Other, please specify.....
4. Marital status         1) Single                             2) Married  
 3) Widow/Divorced/Separated
5. Level of education:  1) No formal education     2) Elementary school  
 3) Secondary school         4) Higher Secondary  
 5) University level
6. Occupation             1) Government officer     2) Private  
 3) Business                             4) Agriculture  
 5) Others, please specify.....
7. Monthly Income:    .....(Rupees)
8. Adequacy of income:  
 1) No  
 2) yes
9. Number of family members who stay with you during providing care.....
10. Relationship of caregivers to person with physical disability:  
 1) Spouse                             2) Parents  
 3) Children                             4) Siblings  
 5) Relatives                             6) Other, please specify....
11. Presence of comorbidities:  
 1) No  
 2) Yes, you can choose more than one from following:  
 1) Hypertension             2) Diabetes  
 3) Heart disease             4) Arthritis  
 5) Others, please specify.....

**Part III: Environment related data**

12. Types of persons with physical disability:  
 1) Spinal cord injury  2) Traumatic brain injury  
 3) Stroke  4) Other, please specify .....
13. Dependency level of person with physical disability  
 1) Total  2) Severe  
 3) Moderate  4) Mild dependence  
 5) Minimal  6) Independent
14. Duration of caregiving (months).....
15. Hours of caregiving each day.....
16. What are the most common care giving activities to your beloved one? Please choose from following: (you can choose more than one option)  
 1) Changing position  2) Up and lie down  
 3) Lifting and transfer  4) Bathing  
 5) Feeding  6) Toilet care  
 7) Grooming and changing clothes  8) Medication  
 9) wound care  10) Catheterization  
 11) Other, please specify.....
17. Member to assist in caregiving  
 1) No  
 2) Yes, please identify who.....
18. Do you get help from others?  1) No  
 2) Yes, please identify as follows:
- | <b>Person</b>                              | <b>Type of support</b> |
|--------------------------------------------|------------------------|
| <input type="checkbox"/> 1) Family members | .....                  |
| <input type="checkbox"/> 2) Relatives      | .....                  |
| <input type="checkbox"/> 3) Friends        | .....                  |
| <input type="checkbox"/> 4) Organization   | .....                  |
19. Do you find difficulties in providing care due to the physical environment at home?  
 1) No  
 2) yes, please identify as follows: (you can choose more than one)  
 1) Stairs  2) Narrow doors  
 3) Cramped space in room  4) Narrow corridor  
 5) Height of Bed  6) Wheelchair  
 7) Bathroom  8) Toilet  
 9) Other, please specify.....

## APPENDIX C

### Pain Experiences Questionnaire (PEQ)

#### Part I. Pain Intensity Scale

1. Please rate your low back pain by circling the one number that best describe your pain at Worst in the last week.

<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>
<b>No Pain</b>										<b>Pain as bad as you can imagine</b>

2. Please rate your low back pain by circling the one number that best describe your pain at LEAST in the last week.

<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>
<b>No Pain</b>										<b>Pain as bad as you can imagine</b>

3. Please rate your low back pain by circling the one number that best describe your pain at the AVERAGE.

<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>
<b>No Pain</b>										<b>Pain as bad as you can imagine</b>

4. Please rate your low back pain by circling the one number that tell how much pain you have RIGHT NOW.

<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>
<b>No Pain</b>										<b>Pain as bad as you can imagine</b>

#### Part II Pain Frequency

Instruction: Please tick (√) the choice that best describes “how often you experience low back pain?”

- |                               |                     |                      |
|-------------------------------|---------------------|----------------------|
| ( ) 1) Everyday               | ( ) 2) Once a week  | ( ) 3) Twice a week  |
| ( ) 4) More than twice a week | ( ) 5) Once a month | ( ) 6) Twice a month |
| ( ) 7) More twice a month     |                     |                      |







## APPENDIX E

### World Health Organization Quality of Life-BREF (WHOQOL-BREF)

The following questions ask how you feel about your quality of life. I will read out each question to you, along with the response options. 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 Satisfied	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

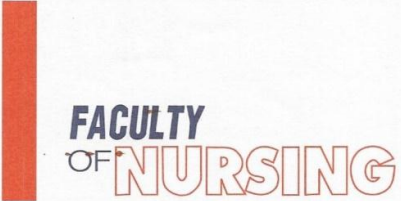

## APPENDIX F

## Steps of Computing Domain Score of WHOQOL-BREF


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

**APPENDIX G**  
**Approval Letters**



1. Ethics committee Approval from Prince of Songkla University

		<p><b>PRINCE OF SONGKLA UNIVERSITY</b></p> <p>P.O. BOX 9, KHOR HONG, HATYAI SONGKHLA, THAILAND, 90112 FAX NO. 66-74-286421 TEL. NO. 66-74-286456, 66-74-286459</p>
<p>MOE 0521.1.05/2748</p> <p>Ethics Committee Approval</p> <p>November 8, 2016</p> <p>To whom it may concern:</p> <p style="padding-left: 40px;">This letter is to confirm that the Nursing Faculty Ethics Committee approved the research study of Ms.Pasang Doma Sherpa ID. 5810420050 entitled “Chronic Low Back Pain Experience, Pain Management Strategies, and Quality of Life Among Family Caregivers of Person with Physical Disability in Nepal” on October 22, 2016. The study is a major part of Ms.Pasang Doma Sherpa’s Master Degree at the Faculty of Nursing, Prince of Songkla University, Thailand. The study ensures the rights, safety, confidentiality, and welfare of research participants and it was determined that the study would not be harmful to the participants in the future.</p> <p>Sincerely,</p> <p style="text-align: center;"><i>Aranya Chaowalit</i></p> <p>Associate Professor Aranya Chaowalit, RN., Ph.D Dean, Faculty of Nursing, Prince of Songkla University, Hat Yai, Songkhla, 90112, Thailand Tel: 66-74-286400 Fax: 66-74- 286421</p>		

## 2. Letter of Ethical Approval from Nepal Health Research Council, Nepal



Government of Nepal  
**Nepal Health Research Council (NHRC)**

Ref. No.: 1191

**06 January 2017**

**Ms. Pasang Doma Sherpa**  
Principal Investigator  
Prince of Songkla University

**Subject: Approval of research proposal entitled Chronic low back pain experience, pain management strategies and Quality of Life among family caregivers of person with Physical Disability in selected Districts of Nepal**

**Dear Ms. Sherpa,**

It is my pleasure to inform you that the above-mentioned proposal submitted on **04 December 2016 (Reg.no. 431/2016)** please use this Reg. No. during further correspondence) has been approved by NHRC Ethical Review Board on **05 January 2017**.

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


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

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

As per your research proposal, the research amount is **NRs. 1, 00,000.00** and accordingly the processing fee amount to **NRs. 10,000.00**. It is acknowledged that the above-mentioned processing fee has been received at NHRC.

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


Thanking you,




**Dr. Khem Bahadur Karki**  
Member-Secretary



## 3. Letter of Data Collection from Spinal Injury Rehabilitation Center, Nepal



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



March 15, 2017  
 Ref No: 200/073/074

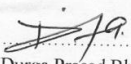
**To Whom It May Concern**

It is our pleasure to inform that **Miss Pasang Doma Sherpa**, a master student from Faculty of Nursing, Prince of Songkla University, Thailand has completed her data collection of thesis entitled **“Chronic Low Back Pain Experience, Pain Management Strategies, and Quality of Life Among Family Caregivers of Person with Physical Disability in Nepal”** from **January 6 to March 14, 2017**. She has conducted **pretest** in the SIRC from 6 January to 13 January 2017. The SIRC provided contact details of all potential participants to her. She has conducted her data collection in community settings from January 14, 2017 to March 14, 2017. The findings from this study will be beneficial for identifying the potential physical problems of family caregivers who are the central part of rehabilitation and helps in implementation of necessary intervention for family caregivers of person with physical disability.


We wish for the successful completion of her thesis.

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

Thank you

  
 Durga Prasad Bhattarai  
 Research and Development Officer  
 Spinal Injury Rehabilitation Centre  
 Sanga, Kavre

#### 4. Letter of Data Collection from National Institute of Neurological and Allied Sciences, Nepal



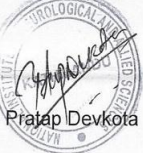

March 16, 2017

To Whom It May Concern

This is to confirm that **Miss Pasang Doma Sherpa**, a master student from Faculty of Nursing, Prince of Songkla University, Thailand has completed her data collection of thesis entitled "**Chronic Low Back Pain Experience, Pain Management Strategies, and Quality of Life Among Family Care givers of Person with Physical Disability in Nepal**" from 14<sup>th</sup> of January to 14<sup>th</sup> of **March, 2017**. She conducted her data collection from out-patient department and community setting. This will be beneficial for identifying the potential physical problems focused on low back pain and quality of life of family caregivers of person with physical disability.

We wish her for the successful completion of her thesis. If you got any queries please do not hesitate to contact me.

Thanking you,






Pratap Devkota

Hospital Manager



## 5. Letter of Data Collection from Nepal Orthopaedic Hospital, Nepal

  
NDA

 **NEPAL ORTHOPAEDIC HOSPITAL** 

Date: March 16, 2017



**To Whom It May Concern**

It is our pleasure to inform that **Miss Pasang Doma Sherpa**, a master student from Faculty of Nursing, Prince of Songkla University, Thailand has completed her data collection of thesis entitled “**Chronic Low Back Pain Experience, Pain Management Strategies, and Quality of Life Among Family Caregivers of Person with Physical Disability in Nepal**” from **January 6 to March 14, 2017**. She has conducted **pretest** in this hospital from 6 January to 13 January 2017. She has conducted her data collection from out-patient department and community setting from January 14, 2017 to March 14, 2017. The findings from this study will be beneficial for identifying the potential physical problems of family caregivers of person with physical disability.

We wish for the successful completion of her thesis.

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

Thank you

  
.....  
  
Meena Gurung  
Matron  
Nepal Orthopaedic Hospital

## APPENDIX H

### Permission of Research Instruments

#### 1. Permission for SF-BPI

**Pasang Sherpa** <domapasang000@gmail.com>

Thu, Oct 20, 2016 at  
8:29 AM

To: ccleeland@mdanderson.org

Respected sir

My name Pasang Doma Sherpa. I am a master level student in Prince of Songkla University faculty of Nursing in Thailand. I am going to conduct my thesis on chronic low back pain experience including intensity and interference in family caregivers. This research will be conducted in Nepal. For this reason, i would kindly like to request for your permission to use Brief Pain Inventory Short form in my thesis. your permission will be highly appreciated. Thank you

with best regards

Pasang

---

**Cleeland, Charles** <ccleeland@mdanderson.org>

Thu, Oct 20, 2016 at 5:34 PM

To: Pasang Sherpa <domapasang000@gmail.com>

You have my permission to use BPI in your study

Sent from my iPhone

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**Pasang Sherpa** <domapasang000@gmail.com>

Thu, Oct 20, 2016 at 6:53  
PM

To: "Cleeland, Charles" <ccleeland@mdanderson.org>

Respected sir

Thank you very much for your kind permission. Since my study is in family caregiver in Nepal, I have to translate the tool in Nepali because the participants may not understand English version. In this regards, i would like to request for your permission for translate in Nepali. Thank you

With best regards

Pasang

---

**Cleeland, Charles** <ccleeland@mdanderson.org>

Fri, Nov 4, 2016 at 8:56 PM

To: Pasang Sherpa <domapasang000@gmail.com>

My permission includes translation.

Charles S. Cleeland, Phd

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## 2. Permission for WHOQOL- BREF

<b>Subject:</b>	Request for WHOQOL BREF
<b>From:</b>	pasang (domapasang000@yahoo.com)
<b>To:</b>	WHOQOL@who.int;
<b>Date:</b>	Sunday, October 23, 2016 6:18 PM

Respected sir

My name is Pasang Doma Sherpa. I am Master level student in Faculty of Nursing, Prince of Songkla University, Thailand. Currently i am ging to conduct my thesis on chronic low back pain experience, pain management strategies and health related quality of life among family caregivers of person with physical disability. In this regards, I would like to request your permission for using WHOQOL BREF in my study. Thank you

With best regards  
Pasang

---

<b>Subject:</b>	RE: Request for WHOQOL BREF
<b>From:</b>	whoqol (whoqol@who.int)
<b>To:</b>	domapasang000@yahoo.com;
<b>Date:</b>	Thursday, October 27, 2016 6:35 PM

Dear Pasang,

Thank you for your interest in the WHOQOL-BREF. Please fill in the attached user-agreement form and return a signed copy to me by email; I will then send you the questionnaire, for free.

Best regards,  
Sibel  
Sibel Volkan (Mrs)  
WHOQOL

---

<b>Subject:</b>	RE: Request for questionnaire
<b>From:</b>	whoqol (whoqol@who.int)
<b>To:</b>	domapasang000@yahoo.com;
<b>Date:</b>	Wednesday, November 2, 2016 3:26 PM

Dear Pasang Doma Sherpa,  
Thank you for the form. Please find attached the Nepali version of the tool, along with related materials.  
Best regards,  
Sibel Volkan (Mrs)  
WHOQOL  
Information, Evidence and Research (IER) Department  
The World Health Organization  
20 Avenue Appia  
CH-1211 Geneva 27  
Switzerland

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## APPENDIX I

### Query for Scoring Level of Quality of Life

● **Pasang Doma Sherpa** <domapasang000@yahoo.com> Mar 27 at 1:54 PM ★

To whoqol

Respected sir,  
I would like to request for your help in WHO QOL bref. In my thesis i have to calculate the level of quality of life. I would like to request if there is any method. Current instrument has not provided the level. How can we interpret the level? For example low qol, moderate qol, and high.  
Thank you  
With best regards  
Pasang

Sent from my iPhone

> Show original message

← Reply   ← Reply to All   → Forward   ... More

---

● **whoqol** <whoqol@who.int> Mar 28 at 9:16 PM ★

To 'Pasang Doma Sherpa'

Hello,

We do not have any thresholds for defining what is good or bad quality of life; each individual study needs to do this for their own purpose.

Best regards,

Sibel Volkan (Mrs)  
WHOQOL  
Information, Evidence and Research (IER) Department

**APPENDIX J****Name List of Experts**

1. Dr. Suttipong Tipchatyotin  
Department of Orthopedic Surgery and Physical Medicine  
Songklanagarind Hospital, Thailand
2. Assist. Prof. Dr. Natenapha Khupantavee  
Lecturer  
Faculty of Nursing, Prince of Songkla University, Thailand
3. Assoc. Prof. Mrs. Narbada Khanal  
Chairperson and lecturer  
Faculty of Nursing, Om Health Campus, Kathmandu, Nepal

**APPENDIX K****Name List of Instrument Translators**

1. Miss Shneha Acharya, BSN

Instructor

Faculty of Nursing, Nepal Institute of Health Sciences, Kathmandu, Nepal

2. Mrs. Rekha Timalina, MN

Lecturer

Faculty of Nursing, Lalitpur Nursing Campus, Lalitpur, Nepal

3. Dr. Sampurna Kacchapati, Ph.D,

Post-doctoral in Research Methodology

Faculty of Science, Prince of Songkla University, Patani, Thailand

## VITAE

**Name** Miss Pasang Doma Sherpa

**Student ID** 5810420050

### **Educational attainment**

Degree	Name of Institute	Year of Graduation
Bachelor of Science in Nursing	Nepal Institute of Health Sciences, Kathmandu, Nepal	2010

### **Scholarship Awards during Enrolment**

Thailand's Education Hub for Southern Region of ASEAN Countries (THE-AC)

Scholarship, Graduate School, Prince of Songkla University

### **Work and Address**

Instructor, Faculty of Nursing, Nepal Institute of Health Sciences, Kathmandu Nepal

### **List of publication**

1. Timalisina, R., Sherpa, P. D., & Dhakal, D. (2014). Factors associated with depression among elderly living in old age homes in Kathmandu Valley. *Journal of Institute of Medicine*, 37(1), 90-96. Retrieved from <http://www.jiom.com.np/index.php/jiomjournal/article/viewFile/702/652>
2. Sherpa, P.D., Kitrungrrote, L., Sae-Sia, W., (2017, July). *Chronic low back pain, pain interference, and functional disability among family caregivers of persons with spinal cord injury in Nepal*. Abstract presented at International Nursing Conference on Ethics, Esthetics, and Empirics in Nursing: Driving Forces for Better Health, Prince of Songkla University, Songkhla, Thailand