Predictive Factors of Spiritual Well-Being in Nepalese Patients With End Stage Renal Disease Receiving Hemodialysis

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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.

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ชื่อวิทยานิพนธ์ ปัจจัยทำนายความผาสุกทางจิตวิญญาณในผู้ป่วยชาวเนปาล โรคไตเรื้อรังระยะสุดท้ายที่เข้ารับการฟอกเลือดด้วยเครื่องไตเทียม

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บทคัดย่อ

วิจัยนี้เป็นการศึกษาแบบภาคตัดขวาง มีวัตถุประสงค์เพื่อศึกษาระดับความผาสุกทางจิตวิญญาณและปัจจัยทำนายความผาสุกทางจิตวิญญาณในผู้ป่วยโรคไตเรื้อรังระยะสุดท้ายที่รับการฟอกเลือดด้วยเครื่องไตเทียม กลุ่มตัวอย่างเป็นผู้ป่วยที่รับการฟอกเลือดด้วยเครื่องไตเทียม จำนวน 100 ราย ณ ศูนย์ไตแห่งชาติ ประเทศเนปาล โดยทำการคัดเลือกกลุ่มตัวอย่างแบบเฉพาะเจาะจง เครื่องมือที่ใช้ในการเก็บรวบรวมข้อมูลประกอบด้วย แบบสอบถามข้อมูลส่วนบุคคล (Patient Data Form; PDF) สำหรับเครื่องมือประเมินความปวด ความเหนื่อยล้า การสนับสนุนทางสังคม ความเชื่อทางศาสนา และความผาสุขทางจิตวิญญาณ ประเมินโดยใช้แบบประเมินความปวด (Pain Assessment Scale; PAS) แบบประเมินความเหนื่อยล้า (Fatigue Assessment Scale; FAS) แบบประเมินการสนับสนุนทางสังคม (The Medical Outcomes Study Social Support Survey; MOS-SS) แบบประเมินความเชื่อทางศาสนา (Religiosity Assessment Scale; RAS) และแบบประเมินความผาสุกทางจิตวิญญาณ (Spiritual Well- being Assessment Tool; SWBAT) ตามลำดับ สำหรับแบบประเมิน SWBAT ประกอบด้วย 2 ส่วน ดังนี้ ส่วนที่ 1 คือ มาตรวัดความผาสุกทางจิตวิญญาณชนิด Likert Scale และส่วนที่ 2 คำถามปลายเปิด เครื่องมือทั้งหมดได้รับการตรวจสอบความตรงของเนื้อหา โดยผู้เชี่ยวชาญ จำนวน 3 ท่าน และผ่านการตรวจสอบความเที่ยงโดยค่าสัมประสิทธิ์แอลฟาของครอนบาค ของแบบประเมินความเหนื่อยล้า แบบประเมินการสนับสนุนทางสังคม แบบประเมินความเชื่อทางศาสนา และแบบประเมินความผาสุกทางจิตวิญญาณส่วนที่ 1 เท่ากับ .72, .97, .84, และ .79 ตามลำดับ การวิเคราะห์ข้อมูลโดยใช้สถิติเชิงบรรยาย สัมประสิทธิ์สหสัมพันธ์ของเพียร์สัน และการวิเคราะห์การถดถอยเชิงพหุคูณ

ความผาสุกทางจิตวิญญาณของผู้ป่วยอยู่ในระดับปานกลาง ($M = 22.44$, $SD = 10.62$) ทั้งนี้ ความเหนื่อยล้า ($\beta = -.23$, $p = .02$) การสนับสนุนทางสังคม ($\beta = .23$, $p = .01$) และความเชื่อทางศาสนา ($\beta = .22$, $p = .02$) สามารถทำนายความผาสุกทางจิตวิญญาณในผู้ป่วยไตเรื้อรังระยะสุดท้ายที่ได้รับการฟอกเลือดด้วยเครื่องไตเทียมอย่างมีนัยสำคัญทางสถิติ ซึ่งปัจจัยทั้งหมดสามารถทำนาย

ความผาสุกทางจิตวิญญาณได้ร้อยละ19.7 ดังนั้น พยาบาลควรจัดโปรแกรมที่ช่วยส่งเสริมการสนับสนุนทางสังคม ความเชื่อทางศาสนา และลดความเหนื่อยล้า เพื่อเพิ่มระดับความผาสุกทางจิตวิญญาณในผู้ป่วยไตเรื้อรังระยะสุดท้ายที่เข้ารับการฟอกเลือดด้วยเครื่องไตเทียม

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Abstract

This was a cross-sectional study aimed to identify the level and factors predicting spiritual well-being of patients suffering from end stage renal disease (ESRD) receiving hemodialysis (HD). A hundred eligible participants who were receiving HD in National Kidney Center, Nepal were selected purposively. Information regarding the demographic and clinical data of the participants was collected using the Patient Data Form (PDF). Data related to pain, fatigue, social support, and spiritual well-being were collected using the Pain Assessment Scale (PAS), Fatigue Assessment Scale (FAS), Medical Outcomes Study Social Support Survey (MOS-SS), Religiosity Assessment Scale (RAS), and Spiritual Well-Being Assessment Tool (SWBAT), respectively.

The SWBAT consists of two parts including part I: FACIT-Sp-12 (12-Item Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being) and part II: Interview Guide. Content validity of all measurements was examined by three experts. Cronbach's alpha coefficient of FAS, MOS-SS, RAS, and FACIT-Sp-12 were .72, .97, .84, and .79, respectively. Data analysis was carried out using descriptive statistics, Pearson's Product Momentum Correlation, and standard multiple regression.

The level of spiritual well-being of the participants was at a moderate level (M = 22.44, SD = 10.62). The study demonstrated fatigue (β = -.23, p = .02), social support (β = .23, p = .01), and religiosity (β = .22, p = .02) as the variables that could statistically predict spiritual well-being in patients receiving HD. The total variance of the significant factors in spiritual well-being was 19.7%. Therefore, nurses are recommended to design interventions to enhance social support and religiosity and decrease fatigue. This will serve to increase the level of spiritual well-being in patients with ESRD receiving HD.

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Rajkumari Jugjali

Contents

Contents (continued)

Contents (continued)

Contents (continued) Pages

List of Tables

List of Tables (continued)

List of Figures

Chapter 1

Introduction

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

Background and Significance of the Problem

The number of end stage renal disease (ESRD) patients are increasing globally with the growth of healthcare demand and expenditure (Wetmore & Collins, 2016). The estimated cases of ESRD worldwide are around two million (Bethesda, 2014). In the United States (US), 117,162 new patients of ESRD were reported by the end of 2013 (United States Renal Data System [USRDS], 2015) and is growing by five percent per year in the US (Bethesda, 2014). A population-based study in India and Pakistan showed the incidence of 152 cases per million per year and the number of patients receiving dialysis are increasing at the rate of 10 to 20% per year (Jha, 2013). In Nepal, the estimated cases suffering from ESRD were 3,131 in 2016 and will be 3,415 in 2021 (Hada, 2009).

In order to sustain their lives, patients suffering from ESRD have to depend on Renal Replacement Therapy (RRT). The therapies available are hemodialysis (HD), peritoneal dialysis (PD) and kidney transplant (KT) (Rodger, 2012). Globally, HD is the most common therapy used to mange ESRD (Fresenius Medical Care, 2012). In the United States, the percentage of patients with ESRD receiving HD, PD and KT were 63.9%, 6.9%, and 29.3% , respectively (Saran et al., 2016). Similarly, in Asia

also, the number of ESRD patients who received HD has increased (Prasad & Jha., 2015). In Nepal, 41.7% of patients with ESRD were treated with HD (Hada et al., 2009).

The life expectancy of patients suffering from ESRD receiving HD has increased (Yusop, Mun, Shariff, & Huat, 2013). However, this group of people continually experiences various stressors and problems due to disease condition and/or treatment. Most frequently identified stressors in HD patients are a limitation of food and water, unable to continue the job, feeling of being dependent on staff, fatigue, sexual problems (Shinde & Mane, 2014) and pain (Weisbord, 2016). Additionally, anxiety, depression, and suicidal thoughts are also prevalent in patients receiving HD (Macaron et al., 2014). As a result of the persistent aforementioned problems, HD patients are often troubled with feelings of hopelessness and suffering (Fayer, Nascimento, & Abdulkader, 2011), these feelings of despair will raise the question of meaning and purpose of their life (Alshraifeen, 2015).The difficulty in finding the meaning and purpose in life due to chronic illness and stress will result in a deficit of spiritual well-being (Bulkley et al., 2013; Promkaewngam, Pothiban, Srisuphan, & Sucamvang, 2014).

World Health Organization [WHO] (1998) and biopsychosocial-spiritual model (Sulmasy, 2002) has viewed spiritual well-being as an essential component of health and human life. Spiritual well-being is related with adjustment of distressful situation and disease condition (Tanyi & Werner, 2003). Spiritual well-being is defined as one's self-perception of peace and happiness in life, understanding own self, and character of life (Promkaewngam et al., 2014). Whitford and Olver (2012) have conceptualized spiritual well-being as composed of three subcomponents; they

are meaning, peace, and faith. Spiritual well-being is an important aspect of every individual. However, the literature review revealed low (Reig-Ferrer et al., 2012) and moderate level of spiritual well-being in HD patient (Ebrahimi, Ashrafi, Eslampanah, & Noruzpur, 2014; Eslami, Rabiei, Khayri, Nooshabadi, & Masoudi, 2014).

Low level of spiritual well-being will lead to different negative consequences, and has been negatively associated with various constructs such as hopelessness, desire to hasten death, suicidal ideation (McClain, Rosenfeld, & Breitbart, 2003), anxiety (Rawdin, Evans, & Rabow, 2013), and depression (Dalmida, Holstad, Diiorio, & Laderman, 2009; Rawdin et al., 2013). In addition, HD patients with low spiritual well-being reported poor mental health, psychological distress, and psychosomatic problems (Martinez & Custodio, 2014). Moreover, patients suffering from chronic illness who were not interested in spiritual matters had significant low social, functional, physical, and emotional well-being (Riley et al., 1998). Hence, spiritual well-being of HD patients should be considered in order to improve health and quality of life (QOL).

Different factors contribute to the status of spiritual well-being (Lo, Zimmermann, Gagliese, Li, & Rodin, 2011). A person with physical symptoms has decreased ability for self-reflection and tends to engage less in social and other activities that gives a sense of purpose and meaning in life (Lo et al., 2011). This may lead to decrease in spiritual well-being. Similarly, previous studies conducted in chronic illness such as patients with cancer also reported association between physical symptoms and spiritual well-being (Lo et al., 2011; Wang & Lin, 2015).

Pain is a common and unavoidable symptom in HD patients (Calls et al., 2009). Pain in HD patients can occur due to disease condition and treatment itself

(Brkovic, Burilovic, & Puljak, 2016). Musculoskeletal pain is the most common cause of pain in ESRD patients receiving HD (Davison, 2003). Continue suffering from pain in patients will lead to hopelessness and feeling that their life is not valuable continuing or lose the meaning of their life (Jones, Huggins, Rydall, & Rodin, 2003). Similarly, a study conducted by Kharame, Zamanian, Foroozanfar, and Afsahi (2014) in patients receiving HD revealed a significant relationship between bodily pain and spiritual well-being.

Additionally, fatigue is another frequent and debilitating symptom found in ESRD patients receiving HD (Horigan, 2012) which occurs due to conditions such as anemia, pre-dialysis weight, and poor nutritional status (Sakkas & Karatzaferi, 2012). Fatigue in HD patients can be mental (decrease in the capacity of remembering things) and physical (lack of physical power) (Horigan, Schneider, Docherty, & Barroso, 2013). Patients who are fatigue are unable to perform their daily activities and this will result in decreased self-esteem and demoralization (Lo et al., 2011). This may affect the spiritual well-being of the patients. A study undertook by Ebrahimi, Ashrafi, Eslampanah, and Noruzpur (2014) in ESRD patients receiving HD reported relationship between fatigue and existential well-being which is one dimension of spiritual well-being.

Social support plays a vital role in the life of HD patients (Plantinga et al., 2010). HD patients with a higher level of social support experience greater satisfaction, Health-Related Quality of Life (HRQOL), reduced hospital admission (Plantinga et al., 2010) and less depression (Tezel, Karabulutlu, & Sahin, 2011). This will help the patient to retain the belief that their life has value. Reig-Ferrer et al. (2012) also mentioned that spiritual well-being and social support of HD patients are

related to each other. Similarly, a study conducted in HD patients reported the relationship between spiritual well-being and social performance (Ebrahimi et al., 2014; Kharame, Zamanian, Foroozanfar, & Afsahi, 2014).

Religiosity is associated with decreased depression, increased coping and enhanced QOL in patients receiving HD (Al Zaben et al., 2015; Cruz et al., 2016; Lucchetti, Almeida, & Lucchetti, 2012). Religiosity refers to religious affiliation, religious activities, and religious beliefs that are expressed in an intrinsic and extrinsic way (Koenig, King, & Carson, 2012). Religiosity is used as a source of strength and a way to alleviate stress by the patients suffering from chronic diseases (Lucchetti et al., 2012). Similarly, in comparison with religious HD patients, those patients who are atheists have depression (Lucchetti et al., 2012). In addition, they are at eight times greater risk of suicide (Martiny, e Silva, Neto, & Nardi, 2011). A study undertook by Reig-Ferrer et al. (2012) revealed the significant positive relationship between spiritual well-being and religiosity in patients suffering from ESRD receiving HD.

The literature shows a relationship between pain, fatigue, social support, religiosity and spiritual well-being in HD patients. However, studies conducted on these aforementioned variables in HD patients (Ebrahimi et al., 2014; Kharame et al., 2014; Reig-Ferrer et al., 2012) did not explain the predicting values. The predicting values will provide empirical data to anticipate how the variables will behave (Polit & Beck, 2012). Therefore, how pain, fatigue, social support, and religiosity will influence the spiritual well-being of patients receiving HD is still unknown. Furthermore, previous studies conducted did not use any specific instrument that measured pain, fatigue, religiosity, and social support. This may affect the results of the study.

In addition, Nepal is a country with diverse tradition guided by the norms, customs, and practices of Hindu religion (Davis & Miroshnikova, 2013). Culture shapes how we see the world and give meaning to our experiences, religion is the most common form of cultural illustration (Eckersley, 2007). However, previous studies were conducted in countries with different religions and cultures from Nepal such as Spain (Reig-Ferrer et al., 2012) and Iran (Ebrahimi et al., 2014; Kharame et al., 2014). Consequently, the findings of the previous studies may not be an exact reflection of the Nepalese population. Moreover, there is no published research article that addresses the predicting factors of spiritual well-being in Nepalese ESRD patients receiving HD.

Therefore, to bridge the gap of knowledge on predicting factors of spiritual well-being in HD patients, this research study investigated the factors predicting spiritual well-being in Nepalese ESRD patients receiving HD. The study elicited primary data that could help nephrology nurses to understand spiritual well-being and identify effective interventions to improve spiritual well-being in HD patients.

Objectives of the Study

The objectives of the study were as follows:

1. To describe the level of spiritual well-being in Nepalese patients with ESRD receiving HD.
2. To examine the relationship between pain, fatigue, social support, religiosity, and spiritual well-being in Nepalese patients with ESRD receiving HD.
3. To identify predicting factors of spiritual well-being in Nepalese patients with ESRD receiving HD.

Research Questions

The research questions of the study were as follows:

1. What is the level of spiritual well-being in Nepalese patients with ESRD receiving HD?

2. Is there a relationship between pain, fatigue, social support, religiosity, and spiritual well-being in Nepalese patients with ESRD receiving HD?

3. What are the predicting factors of spiritual well-being in Nepalese patients with ESRD receiving HD?

Conceptual Framework

The conceptual framework of this study was based on two concepts 1) concept of spiritual well-being purposed by Whitford and Olver (2012) and 2) predicting factors of spiritual well-being. The predicting factors of spiritual well-being are derived from a study conducted by Lo, Zimmermann, Gagliese, Li, and Rodin (2011) and review of relevant literature.

The concept of spiritual well-being. Whitford and Olver (2012) conceptualized spiritual well-being as a multidimensional concept composed of three components 1) meaning, 2) peace and 3) faith.

Meaning refers to having congruence between the global and situational sense of meaning. A global sense of meaning is developed over time of experience, whereas, a situational sense of meaning develops in the current situation. An individual with a sense of meaning alters their goals, finds meaning, and sees unfortunate situations such as illness as an opportunity to achieve positive growth (Whitford & Olver, 2012).

Peace is reconciliation and accepting an individual's situation. Peace is experienced whenever something inharmonious or dissonant happen in someone's life and when there is a need to resolve the discordant (Whitford & Olver, 2012). Peace is, to be or become peaceful, be in a state of harmony, and comfort. A sense of peace influences an individual's experience, therefore, patients' with a strong sense of peace enjoy their lives to the fullest even during illness (Whitford & Olver, 2012).

Faith is an individual concept that provides comfort, and strength, and the belief that whatever happens with their illness, things will be alright. Patients with a high level of faith enjoy their life more than those with low levels of faith even during chronic symptoms (Whitford & Olver, 2012).

Spiritual well-being is an essential, unique and core domain. A strong sense of meaning, peace, and faith can impact an individual's experience of spiritual well-being. ESRD patients receiving HD lose their normal lifestyle (Cheawchanwattana, Chunlertrith, Saisunantararom, & Johns, 2014) as they have restriction in food and beverages intake, and have difficulty in performing daily activities. These all changes may affect in the meaning in life, and may have difficulty in finding peace and faith. The concept purposed by Whitford and Olver (2012) was used to assess spiritual well-being of patients receiving HD in previous study (Cheawchanwattana et al., 2014). Therefore, in this study, the components of spiritual well-being including meaning, peace, and faith purposed by Whitford and Olver were used to evaluate the status and the predicting factors of the spiritual well-being of the Nepalese ESRD patients receiving HD.

Predicting factors of spiritual well-being. Predicting factors of spiritual well-being in the study are based on a study undertaken by Lo et al. (2011) and

review of relevant literature. Lo conducted a study in 747 patients diagnosed with various advanced cancer (gastrointestinal, breast, genitourinary, gynecological, and lung cancer), the study concluded that the spiritual well-being was significantly predicted by physical symptoms, religiosity, self-esteem, and social relatedness.

Advanced cancer and ESRD are both life limiting diseases and share some similarities. The illness trajectory of patients suffering from the ESRD and cancer is alike (Worth, 2014). In both diseases, after the diagnosis of the disease there is the maintenance of functions followed by a rapid decline of health status (Murtagh, Murphy, & Sheerin, 2008).

In addition, cancer and ESRD patients also experience similar kinds of symptoms and prognosis. A systematic review by Solano, Gomes, and Higginson (2006) mentioned patients suffering from ESRD and cancer face a similar pathway of symptom experience, 11 symptoms were found common in both groups of patients such as pain, fatigue, breathlessness, insomnia, and anorexia. Furthermore, ESRD and cancer patients also share similar prognosis (Eneanya et al., 2015), those patients who withdraw themselves from the treatment have quick deterioration in health and functional status (Murtagh et al., 2008). Therefore, the predicting factors purposed by Lo et al. (2011) were used to guide the study. In addition, the relevant literature review was used to support the predicting factors.

The physical symptoms of the disease is one important predicting factor of spiritual well-being (Lo et al., 2011). Patients with ESRD receiving HD suffer from various physical symptoms. Pain in patients receiving HD is inevitable and frequently reported (Leinau, Murphy, Bradley, & Fried, 2009) and can occur as a result of HD treatment and the disease itself. The pain experienced by patients can influence

spiritual factors as spiritual beliefs may impact cognitive and emotional processes (Wachholtz, Pearce, & Koenig, 2007). Continue suffering from pain in patients will lead to hopelessness and feeling that their life is not valuable continuing or lose the meaning in their life (Jones et al., 2003). In addition, a study conducted by Kharame et al. (2014) in ESRD patients receiving HD reported the relationship between bodily pain and spiritual well-being.

Similarly, fatigue is another most common problem that develops in HD patients due to anemia, pre-dialysis weight, poor nutritional status, poor sleep, and co-morbidities (Sakkas & Karatzaferi, 2012). An individual suffering from physical symptoms has limitation in the capacity for self-reflection, and experiences restrictions in social engagements and other activities that provide a sense of purpose and meaning (Lo et al., 2011). In a similar way, patients receiving HD who experience fatigue cannot get involved in society and other activities that provide a sense of purpose and meaning which may influence their spiritual well-being. A previous study undertook in HD patients also reported a correlation between fatigue and the existential dimension of spiritual well-being (Ebrahimi et al., 2014). Therefore, pain and fatigue were included as predicting factor of spiritual well-being.

Social support in patients receiving HD plays a crucial role, HD patients with higher level of social support reported decreased level of fatigue (Karadag, Kilic, & Metin, 2013), increased survival (Karadag et al., 2013; Thong, Kaptein, Krediet, Boeschoten, & Dekker, 2007), decreased depressive symptoms, and increased overall QOL (Khalil & Abed, 2014). Social relatedness will increase the capacity to rely on and trust other people in times of need and enhance spiritual well-being (Lo et al., 2011). In addition, a study conducted on HD patients revealed the relationship

between spiritual well-being and social functioning (Ebrahimi et al., 2014; Kharame et al., 2014). Hence, social support was considered one predicting factor for spiritual well-being in HD patients.

Religiosity is another predicting factor for spiritual well-being (Lo et al., 2011). Religiosity is defined as an individual's organized belief system usually involving practice or participation in rituals of an organized religion (Kaye & Raghavan, 2002; Leyva, Nguyen, Allen, Taplin, & Moser, 2015). Patients who have religious beliefs may provide a sense of meaning to their illness and hope for better days (Al Zaben et al., 2015). Nepalese people consider religious belief as an essential element of their society and also incorporate religious practices in their daily life (Yadav, 2016). Religiosity can be considered one way through which an individual can make sense of their life (Chokkananthan, 2013). Furthermore, Reig-Ferrer et al. (2012) reported a significant relationship between religiosity and spiritual well-being in patients receiving HD.

To conclude, previous studies undertaken reported that pain, fatigue, social support, and religiosity can influence spiritual well-being. Therefore, on the basis of knowledge obtained from previous studies and predicting factors proposed by Lo et al. (2011), pain, fatigue, social support, and religiosity were included as predicting factors of spiritual well-being in Nepalese patients with ESRD receiving HD. The conceptual framework of the study is depicted in figure 1.

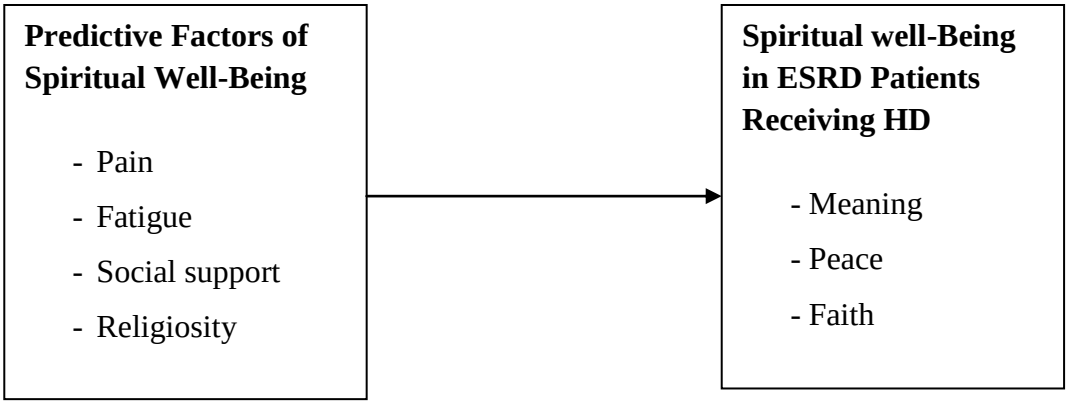

Figure 1. Conceptual framework

Research Hypothesis

Pain, fatigue, social support, and religiosity can predict spiritual well-being in Nepalese patients with ESRD receiving HD.

Definition of the Terms

Spiritual well-being. Spiritual well-being refers to an expressed feeling of being in a state of having 1) meaning 2) peace, and 3) faith by ESRD patients receiving HD for the past seven days. Meaning refers to having congruence between the global and situational sense of meaning. Peace refers to reconciliation and accepting an individual's situation. Faith is an individual concept that provides comfort, and strength, and the belief that whatever happens with their illness, things will be alright. Spiritual well-being was measured using the 12-Item Functional Assessment of Chronic Illness Therapy- Spiritual Well-Being Scale (FACIT-Sp-12) (Peterman, Fitchett, Brady, Hernandez & Cella, 2002). A higher level of score indicates a higher level of spiritual well-being in the participants.

Pain. Pain refers to subjective unpleasant sensation experienced during HD treatment and ESRD for the past one month by the ESRD patients receiving HD. Pain during HD is the unpleasant sensation experienced during HD treatment. Pain due to ESRD is the unpleasant sensation experienced during non dialysis periods. Pain Assessment Scale (PAS), developed by the researcher was administered twice to obtain information regarding pain during HD and due to ESRD. PAS measured intensity, causes, and location of pain. The Numeric Rating Scale (NRS) was adapted to measure pain intensity. A higher score indicates higher pain intensity.

Fatigue. Fatigue refers to the subjective feeling of mental and physical weakness usually experienced by the ESRD patients receiving HD. Fatigue experienced by the participants was measured using the Fatigue Assessment Scale (FAS) developed by Michielsen, De Vries, and Van Heck (2003). A high score indicates a high level of fatigue experienced by the participants.

Social support. Social support refers to the emotional/informational, tangible, affectionate, and positive social interaction support received by the ESRD patients receiving HD. Social support was measured by the Medical Outcomes Study Social Support Survey (MOS-SS) developed by Sherbourne and Stewart (1991). A higher score indicates higher social support.

Religiosity. Religiosity refers to religious practices and beliefs of the ESRD patients receiving HD. Religiosity was measured using Religiosity Assessment Scale (RAS) developed by the researcher. A high score indicates a high level of religiosity in the participants.

Scope of the Study

This study was conducted to identify the predicting factors of spiritual well-being in Nepalese ESRD patients receiving HD in Nepal. The participants were those patients receiving HD treatment regularly at least two times a week for more or equal to three months in the National Kidney Center, Kathmandu, Nepal.

Significance of the Study

The findings of the study provide basic information regarding the level and predicting factors of the spiritual well-being of ESRD patients receiving HD in Nepal. This information can be used for designing interventional research to enhance the spiritual well-being of HD patients. In addition, the findings of the study can contribute to developing nursing practices regarding spiritual well-being. This will help in the improvement of spiritual well-being and QOL of people receiving HD.

Chapter 2

Literature Review

Chapter two describes an overview of end stage renal disease (ESRD) and hemodialysis (HD), ESRD and HD in Nepal, an overview of spiritual well-being, and factors related to spiritual well-being.

1. Overview of end stage renal disease and hemodialysis
    1.1 Definition of end stage renal disease
    1.2 Risk factors of end stage renal disease
    1.3 Clinical manifestations of end stage renal disease
    1.4 Management of end stage renal disease
2. Impacts of hemodialysis treatment on patients
3. Patients with end stage renal disease and hemodialysis in Nepal
4. Overview of spiritual well-being
    4.1 The concept and definition of spiritual well-being
    4.2 Dimensions of spiritual well-being
5. Significance of spiritual well-being and end stage renal disease patients receiving hemodialysis
6. Spiritual care of end stage renal disease patients receiving hemodialysis
7. Measurements of spiritual well-being in patients receiving hemodialysis
8. Factors related to spiritual well-being
9. Summary of literature review

Overview of End Stage Renal Disease and Hemodialysis

This section includes definition, risk factors, sign and symptoms, management of ESRD and impacts of HD treatment on patients.

Definition of end stage renal disease. Chronic kidney disease (CKD) is an irreversible and progressive kidney disease. In CKD, there is a decrease in the glomerular filtration rate (GRF) < 60 mL/min/1.73 m^2 for ≥ 3 months with or without kidney damage (Bolton, Culleton, & Harvey, 2002; Kidney Disease Improving Global Outcomes [KDIGO], 2013). However, in some CKD cases, there is evidence of kidney damage such as hematuria, albuminuria, structural, and pathological abnormalities with or without decreased in GFR for ≥ 3 months (Kidney Health Australia, 2015). The GFR is the amount of plasma filtered through the kidneys per unit of time (Hinkle & Cheever, 2014). The GRF categories in CKD are divided into five stages (Table 1). In stages 1 to 3, the GFR reduces from normal to a moderate level but there is a lack of clinical manifestations in the patients. On the other hand, in stages 4 and 5 there is a marked decrease in GFR with the occurrence of signs and symptoms. In the final stage (G5), the GFR decreases to < 15 mL/min/1.73 m^2 and the kidneys will no longer be able to maintain the homeostasis of the body (KDIGO, 2013).

Table 1

Glomerular Filtration Rate (GFR) Categories in Chronic Kidney Disease (CKD)

GFR category	Description GFR	(mL/min/1.73m^2)
G1	Normal or high	≥90
G2	Mildly decreased	60-89
G3a	Mildly to moderately decreased	45-59
G3b	Moderately to severely decreased	30-44
G4	Severely decreased	15-29
G5	Kidney failure	<15

Note. Adapted from "KDIGO 2012 Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease," by Kidney Disease Improving Global Outcome, 2013, *Kidney International Supplements, 3*, p. 6.

One main objective of management of CKD is to halt or decrease the progression of the disease. The management strategies of CKD are management of blood pressure, renin angiotensin aldosterone system interruption, glycemic control, and dietary/lifestyle modification (KDIGO, 2013). Initiation of dialysis is recommended when the GRF falls between 5 and 10 mL/min/1.73 m^2 and KT is considered when the GFR is < 20 mL/min/1.73 m^2 (KDIGO, 2013). Continuous monitoring should be done for early identification and timely referral for planning RRT.

The last stage (G5) or stage 5 of CKD is considered ESRD which is synonymous with kidney failure (Bolton et al., 2002). In ESRD, there is a destruction

of the nephrons resulting in a reduction of renal function. As a result, the kidneys are unable to excrete excess water, metabolic waste products such as blood urea nitrogen, and serum creatinine from the body (Hinkle & Cheever, 2014; Black & Hawkins, 2009) which leads to the development of uremic symptoms. Loss of kidney functions in ESRD is irreversible which has fatal complications over a period of days and weeks without RRT (Abbasi, Chertow, & Hall, 2010; Rodger, 2012). Similarly, Brenner et al. (2001) defined ESRD as condition needing either long-term dialysis or KT.

In short, ESRD is a chronic, irreversible damage of nephrons that leads to the development of uremic symptoms which requires RRT without which patients suffering from ESRD can no longer survive.

Risk factors of end stage renal disease. There are various risk factors of ESRD. From a literature review, the risk factors of ESRD can be divided into personal factors, systemic medical disorders, renal disorders, environment, medications used and unknown cause.

***Personal factors*.** Various personal factors can contribute to the development of ESRD. A 25 year follow-up study conducted in 177,570 individuals in Northern California concluded that personal factors such as older age, male gender, lower education attainment, African American race, and people with high body mass index as risk factors that contributed to ESRD (Hsu, Iribarren, McCulloch, Darbinian, & Go, 2009). Similarly, Dalrymple et al. (2011) also reported male gender, African American race, and higher body mass index as risk factors of ESRD. In addition, Wesson (2003) identified smoking as one of the risk factors for developing ESRD.

Systemic medical disorders. ESRD can be caused by systemic diseases. Systemic problems, such as diabetes mellitus, and hypertension are the leading cause of ESRD worldwide (Jha, Wang, & Wang, 2012). ESRD caused by a systemic medical disease is similar in various countries, only the rank of the medical disease is different. The leading systemic medical diseases that cause ESRD categorized by country are illustrated in Table 2.

Table 2

Category of Systemic Disease Causing End Stage Renal Disease According to Country

Leading systemic medical disease causing ESRD	Country
Diabetes mellitus followed by hypertension	The United States (USRDS, 2015) Palestine (Khader, Snouber, Alkhatib, Nazzal, & Dudin, 2013)
Hypertension followed by diabetes mellitus	Sudan (Elamin, Obeid, & Abu-Aisha, 2010) Nepal (Chhetri, Manandhar, Tiwari, & Lamichhane, 2009)
Leading cause diabetes mellitus followed by chronic glomerulonephritis then hypertension	Saudi Arabia, the United Arab Emirates, Kuwait, Bahrain, and Oman (Gulf Cooperation Council) (Hassanien, Al-Shaikh, Vamos, Yadegarfar, & Majeed, 2012) Taiwan (Hwang, Tsai, & Chen, 2010) Korea (Jin, 2015) India (Jha, 2013)

The incidence of hypertension and diabetes mellitus is increasing worldwide; one in every three adults and one in every ten adults have hypertension and diabetes

mellitus respectively (WHO, 2012). The increase in the incidence of hypertension and diabetes mellitus will result in an increase in the number of ESRD cases. In addition, glomerulonephritis and systematic lupus erythematosus as causes of ESRD was reported in a systemic review on epidemiology of ESRD (Hassanien et al., 2012).

Renal disorder. Different renal diseases can cause ESRD. Hassanien et al. (2012) reported renal disorders such as glomerulonephritis, interstitial nephritis, obstructive uropathy, pyelonephritis, and congenital kidney diseases (polycystic kidney disease) as causes of ESRD. Chronic glomerulonephritis was the first and second leading cause of ESRD in Pakistan (Jha, 2013) and Taiwan (Hwang et al., 2010) respectively. In Sudan, the causes of ESRD such as obstructive uropathy, glomerulonephritis, polycystic kidney disease, and pyelonephritis accounted for 7.7%, 5.5%, 2.6%, and 1.1% respectively (Elamin et al., 2010).

Environmental factors. People get exposed to different toxic agents in natural and occupational environments that may lead to the development of ESRD. A study conducted in Egypt reported some environmental factors such as unsafe drinking water, pesticide use, and people living in rural areas may develop ESRD (Emad & Osama, 2010). Heavy metals such as lead, cadmium, arsenic, mercury, and uranium also result in the development of CKD that may progress to ESRD (Soderland, Lovekar, Weiner, Brooks, & Kaufman, 2010).

Medications used. Various medications can result in the development of ESRD. A retrospective case-crossover study that investigated the association between short-term use of non-steroidal anti-inflammatory drugs (NSAIDs) and the progression of ESRD concluded that the use of NSAIDs was a significant risk factor

for developing ESRD. Furthermore, the study also reported the parenteral use of NSAIDs had a significantly higher risk for development of ESRD than oral NSAIDs (OR=8.66, 95% CI=6.12-20.19) (Chang, Liu, Hsu, Tarng, & Hsu, 2015). In addition, commonly abused substances such as morphine, heroin, cocaine, nicotine, and alcohol lead to renal toxicity and may develop renal failure (Singh, Singh, & Jaggi, 2013). Over the counter drugs such as paracetamol are considered safe and are used without physician's prescription. Even when prescribed by a physician, many people ignore the instructions and consume more than the recommended dosage which may lead to failure of the kidneys (Sheldrick, 2015). In addition, long-term regular use of Chinese herbal medicines was also found to be one factor for developing CKD which progresses to ESRD (Hwang et al., 2010; Wen et al., 2008). Studies conducted in Taiwan also have documented the relationship between the use of aristolochic acid-containing herbs and the development of renal failure (Lai et al., 2010; Yang, Wang, Lo, & Chen, 2011).

Unknown cause. The factors mentioned above are risk factors for the progression of ESRD, however, in some patients, the causes of ESRD are unknown (Hassanien et al., 2012). Hence, sometimes the exact cause of ESRD cannot be ruled out in some patients.

Clinical manifestations of end stage renal disease. Different patients who suffer from ESRD demonstrate different clinical manifestations. Black and Hawkins (2009) have categorized the clinical manifestations of ESRD as electrolyte imbalance, metabolic, hematologic, gastrointestinal, immunologic, cardiovascular, respiratory,

musculoskeletal, integumentary, neurologic, reproductive, endocrine, and psychosocial changes.

Electrolyte imbalances. One important role of kidneys is to maintain the balance of different electrolytes such as sodium, potassium, magnesium, calcium, and phosphate. In ESRD, the kidneys are unable to excrete and reabsorb the electrolytes. This impairment results in imbalances of different electrolytes which will develop into electrolyte abnormalities such as hyperkalemia, hypocalcemia, and hyponatremia (Black & Hawkins, 2009).

Metabolic changes. In ESRD, the blood urea nitrogen and serum creatinine accumulate in the blood because the kidney function to excrete waste products from the body is affected. Metabolic acidosis also occurs due to the inability of the kidneys to excrete hydrogen ions. Furthermore, carbohydrate intolerance occurs due to a reduction in insulin utilization. In addition, there are metabolic changes in calcium, phosphorus, parathyroid hormone, and vitamin D. Also the level of triglyceride is elevated which is known as hyperlipidemia (Black & Hawkins, 2009).

Additionally, there is a change in the pharmacokinetics including absorption, distribution, metabolism, and excretion in patients suffering from ESRD (Black & Hawkins, 2009). Therefore, dosages of medicines should be adjusted accordingly.

Hematologic changes. There is no production of erythropoietin in patients suffering from ESRD. This leads to a decreased production of red blood cells which in turn leads to anemia. Due to anemia, patients manifest different sign and symptoms such as fatigue, weakness, and cold intolerance. Furthermore, with increase in the

severity of disease leads to hemolysis, gastrointestinal losses, and clotting abnormalities are also seen (Black & Hawkins, 2009).

Gastrointestinal changes. Anorexia, nausea, and vomiting are the most common gastrointestinal changes that occur in patients suffering from ESRD. In addition, patients experience a constant bitter, metallic, or salty taste, esophagitis, gastritis, colitis, gastrointestinal bleeding, and diarrhea. Constipation is another common manifestation, which occurs due to the use of phosphate binding agents, restriction of fluids and high-fiber diet, and decreased physical activity (Black & Hawkins, 2009).

Immunologic changes. Different immunologic changes occur in ESRD such as decreased production of antibodies, suppression of delayed hypersensitivity, and reduced function of the leukocytes which impairs the immune system of the patients (Black & Hawkins, 2009). Impairment in the immune system causes patients to be more prone to infection. (Black & Hawkins, 2009). For patients receiving dialysis, vascular access devices are the common entry point of pathogens (Grossman & Porth, 2014).

Cardiovascular changes. Hypertension is the most common cardiovascular manifestation in ESRD patients and occurs due to fluid volume overload, stimulation of the rennin-angiotensin system, sympathetically mediated vasoconstriction, and absence of prostaglandins. The increased fluid volume will also lead to left ventricular hypertrophy and finally, results in heart failure (Black & Hawkins, 2009).

Respiratory changes. Lung and kidney function are interrelated. Therefore, the effect in kidney function will alter the function of lungs. A respiratory problem

such as pulmonary edema can occur in ESRD patients due to fluid overload. In addition, pleuritis (Black & Hawkins, 2009), pericardial effusion, tuberculosis, pulmonary calcification, and sleep apnea is also observed in patients suffering from ESRD (Pierson, 2006).

Musculoskeletal changes. Renal osteodystrophy, which can be osteomalacia, osteitis fibrosa, osteoporosis, and osteosclerosis is found in 90% of ESRD cases. Renal osteodystrophy occurs due to kidney-bone-parathyroid and calcium-phosphate-Vitamin D connections. Reduced GFR causes a decrease in excretion of phosphate. The parathyroid hormone will mobilize calcium from the bones and helps in elimination of phosphate. As a result, there is a decrease in bone calcium causing renal osteodystrophy. In addition, the kidneys cannot convert vitamin D into its active form (1, 25-dihydroxy-cholecaciferol) which interferes with calcium absorption from the intestine that leads to a decrease in the calcium level in the blood. Furthermore, calcium deposition also occurs in subcutaneous, vascular, and visceral tissues (Black & Hawkins, 2009). Pain due to musculoskeletal changes is common in this group of patients (Davison, 2003).

Integumentary changes. Patients suffering from ESRD often have dry skin due to atrophy of the sweat glands. Pruritus can result from deposition of calcium due to hyperparathyroidism. In addition, patients suffering from ESRD also tend to bleed more which results in bruising, petechiae, and purpura (Black & Hawkins, 2009). Bleeding tendency in ESRD patients is high due to platelet dysfunction. Platelet dysfunction occurs due to intrinsic platelet abnormalities and impaired platelet-vessel wall interaction (Kaw & Malhotra, 2006).

Neurologic changes. Some patients manifest neurologic changes such as peripheral neuropathy and seizure. Patients with central nervous system involvement demonstrate forgetfulness, inability to concentrate, and impaired reasoning. In addition, cranial nerve involvement demonstrates hearing problems, and uremic amaurosis which causes sudden bilateral blindness (Black & Hawkins, 2009).

Reproductive changes. The change in the sexual dysfunction can occur due to multifactorial reasons. Both males and females have a significant decrease in their libido which may be due to both physical and psychological distress. In females, the most common changes are amenorrhea and infertility. In males, impotence is the common manifestation (Black & Hawkins, 2009).

Endocrine Changes. Patients suffering from ESRD have endocrine changes such as insulin utilization, increased functions of parathyroid hormone, and an increased level of pituitary hormones (growth and prolactin hormone) (Black & Hawkins, 2009). The decrease in kidney function results in a decline in the sexual hormones, hypothalamic-pituitary axis, and thyroid hormones. Various mechanisms, for instance, abnormal hormone production and transportation, alteration in hormone metabolism and elimination and modification in feedback mechanism cause endocrine changes (Singha, Raeda, & Karib, 2014).

Psychosocial changes. Patients suffering from ESRD face various psychosocial distresses and problems, for example, the stress of a chronic and life-threatening disease, treatment regimen, feeling of powerlessness, changes in body appearance, and sexuality (Black & Hawkins, 2009). In addition to the aforementioned problems, worries about fistula, the limitation of drinking water,

treatment cost, and traveling difficulties to the dialysis center are also prevalent in this group of patients (Gorji et al., 2013). All of these previously mentioned problems will lead to a change in lifestyle which has a significant impact on social functioning and relationships. Many patients try to hide their disease from others and, some do not join social gatherings as they have limitations in food and liquid intake. Various changes in physical appearance will affect the level of social interaction (Kazemi, Nasrabadi, Hasanpour, Hassankhani, & Mills, 2011). Moreover, modifications in their lifestyle will impair the sense of personal control which will lead to anxiety and depression and inhibit the ability to cope and adjust.

ESRD also has an impact on the spiritual well-being. Patients who suffer from ESRD experience different physical, mental, and social stressors due to the chronic illness and treatment regimen. When individuals suffer from ESRD and receive HD, the values they ascribe to the meaning in life will also be compromised (Finnegan-John & Thomas, 2012) and they will experience feelings of hopelessness (Fayer et al., 2011). These feelings will have an effect on the spiritual dimensions of the patients.

Management of end stage renal disease. The main aim of management of ESRD patients is to maintain the functions of the kidneys and homeostasis of the body. Different pharmacologic therapies along with RRT (PD, HD, and KT) are used for management of ESRD. For patients suffering from ESRD, RRT is the only possibility to survive (Agarwal, 2016). The methods to manage ESRD are explained below.

Kidney transplant. KT is the procedure in which patients with ESRD receive a human kidney from a compatible donor and is the most desired RRT for patients with

ESRD (Abecassis et al., 2008). Kidneys for transplant can be from non-living donors or living donors (National Kidney Foundation, 2015a). A successful KT increases the life expectancy and increases their QOL (Black & Hawkins, 2009). KT is considered the best and most cost effective option of RRT (Rodger, 2012). However, different barriers make KT difficult to perform in every patient who suffers from ESRD, such as a lack of medical fitness, lack of availability of suitable kidneys, misperceptions about kidney transplantation (Abdelwahab, Shigidi, Ibrahim, & El-Tohami, 2013), and financial constraints (Abdelwahab et al., 2013; Dageforde, Box, Feurer, & Cavanaugh, 2015; Schold et al., 2011).

Additionally, a study undertaken among African American health care personals mentioned pre-existing medical conditions, financial concerns, reluctance to ask family members and /or friends, distrust of the medical community, fear of surgery, and a lack of awareness of living donor KT as the obstacles perceived regarding living kidney donation (Shilling et al., 2006). In addition, several hindrances such as 1) low literacy and poverty, 2) lack of a renal registry to generate data for policy making, 3) absence of well-formulated health policies and guidelines, 4) lack of adequately trained and motivated health personnel to run kidney transplant programs, 5) lack of an effective national health insurance that includes patients suffering from ESRD, and 6) lack of transplant edicts resulted in a low rate of KT in developing countries (Bamgboye, 2009).

Peritoneal dialysis. PD is a method by which the patient's peritoneum and dialysate are used to clear the excess fluid and waste products from the body. This method is performed by the patients themselves in the home setting and has two

types. They are cycler-assisted peritoneal dialysis (CCPD) and continuous ambulatory peritoneal dialysis (CAPD). CCPD needs cycler machine and is done in night time while sleeping. The cycler machine will fill the peritoneum with dialysate through the catheter, which dwells in the peritoneum for the correct time and then the dialysate is drained. The number of cycles of CCPD is from three to five during night. The last dialysate is kept inside the peritoneum for the whole day until the patient goes to bed again. CAPD is a manual procedure in which the dialysate is filled inside the peritoneum by gravity and drained after the dwelling time has completed (American Kidney Fund, 2016).

PD is an effective RRT alternative to HD. PD has various benefits such as 1) its lower cost, 2) convenience of home therapy 3) has a flexible schedule, 4) patient's increased perception of freedom and 5) higher QOL (Chaudhary, Sangha, & Khanna, 2011). However, the prevalence of patients receiving PD is low (Moreiras-Plaza, 2014). The trend of utilization PD is decreasing in developed countries (Jain, Blake, Cordy, & Garg, 2012; Pajek, 2015). Different factors such as insufficient medical training, lack of infrastructure, an increase in the number of HD centers, inadequate patient education regarding choices of dialysis methods, and trends in government reimbursement have caused decreased utilization of PD (Moreiras-Plaza, 2014). On the other hand, in some Asian countries such as Hong Kong and Thailand, the policy of 'PD as the first considered therapy' has been implemented in managing ESRD patients (Dhanakijcharoen, Sirivongs, Aruyapitipan, Chuengsaman, & Lumpaopong, 2011; Kwong & Li, 2015). In Thailand, the benefit of PD over HD has

been shown in terms of medical expenditure and cost-effectiveness (Dhanakijcharoen et al., 2011).

Although PD is considered a safe procedure, patients under PD can develop a number of complications such as peritonitis, catheter-related complications, and dialysis- related complications. Peritonitis occurs due to the inability to maintain aseptic technique during handling of the catheter, tubing, and dialysate solution. Catheter-related problems include displacement and obstruction of the catheter. Obstruction may occur because of malposition, infection, or adherence of the catheter tip to the omentum. Dialysis-related complications include pain during dialysis due to rapid instillation, incorrect pH or temperature, low back pain because of abdominal weight, hernias, hypotension, and respiratory difficulty during the dwelling time due to pressure on the diaphragm (Black & Hawkins, 2009).

Hemodialysis. HD is a procedure in which the patient's blood is pumped out of the body and circulated through the dialyzer, to remove waste products and excess fluid. The cleaned blood is then returned to the patients. The dialyzer is an artificial kidney that extracts excess water and nitrogenous waste products from the blood by the principles of diffusion, osmosis, and ultrafiltration (Hinkle & Cheever, 2014; Black & Hawkins, 2009). In diffusion, the solutes move from the region of higher to lower concentration without utilizing any energy. During HD, the toxins in the blood (higher concentration) shift to dialysate (lower concentration) by the process of diffusion and decrease the level of waste products in the blood (Hinkle & Cheever, 2014). Osmosis is defined as the process by which the fluid shifts across a semi-permeable membrane from the region of low solute to high solute concentration and

the process continues until the solute concentrations become the same on both sides of the semi-permeable membrane. In HD, excess fluid from the blood is removed by this process, that is, water shifts from the low concentration (the blood) to the higher concentration (the dialysate bath) (Hinkle & Cheever, 2014). Ultrafiltration is the process by which the fluid moves from high pressure to an area of lower pressure. Ultrafiltration is more effective than osmosis for removal of fluid. During HD, a negative pressure or a suctioning force at the dialysis membrane is applied in order to remove excess fluid (Hinkle & Cheever, 2014).

Before the option of HD was invented, a diagnosis of ESRD was a sentence of death for the patients. The management of ESRD was possible from 1827 when Richard Bright explained the relationship between urinary albumin and renal disease. The HD became an effective means to treat ESRD in the 1960s after Scribner developed a method of permanent access which is the arterio-venous shunt for blood circulation (Bevan, 2000). The HD management regimen for patients with ESRD is most commonly prescribed three times a week the physicians (Diaz-Buxo, White, & Himmele, 2013).

For the HD procedure, the vascular access must be established in the patient's vascular system, in order to, allow blood to be removed, cleaned, and returned to the patient's blood circulation at the rapid rates of 300 and 800 mL/min (Hinkle & Cheever, 2014). Vascular access can be created by one of three methods: aterio-venous fistula, arterio-venous graft, and immediate access. In aterio-venous fistula, the artery and vein are connected surgically. The arterio-venous graft is created by implanting a plastic tube surgically to join an artery and vein.

However, the arterio-venous fistula or arterio-venous graft access site cannot be used immediately after surgery. Fistula needs six weeks to mature before they can be used for HD. Similarly, graft can be used only after two weeks (Black & Hawks, 2009). Therefore, during an emergency situation, immediate access is created by inserting a double-lumen, non-cuffed, large bore catheter into the subclavian vein, internal jugular vein, or femoral vein (Hinkle & Cheever, 2014).

HD can be performed in a health care center or in home. HD performed in a health care center is prevalent worldwide with a decreasing trend in home hemodialysis (HHD). Countries such as Canada, Netherlands, Iceland, Finland, Denmark, Australia, New Zealand, Mexico, and Hong Kong have reported the use of home HD (Wilkie, 2011). However, in Nepal, HD is performed in health care centers only (Hirachan, Kharel, Shah, & Ball, 2010). The complexity of HD machines has made it difficult to perform HD at home (Kraus et al., 2007).

In addition, patients on HHD and their family members should be responsible for recognizing and dealing with the emergency condition that will arise in home (Schatell, 2005). Hence, patients and families may not be willing to take responsibility. Furthermore, some patients may not be suitable for HHD, for instance, patients who are living alone and those who are employed may not have enough time for training sessions. Some patients may feel a burden to family members as the families have to take responsibility for HHD, and hence, deny HHD (Miller, 2010).

Those patients who receive HD in health care centers have to be away from home approximately three times per week for several hours per treatment (Kraus et al., 2007). However, routine HD prolongs the life of the patients with ESRD by

removing the metabolic waste products and will help patients to return to a state of possible wellness (Bevan, 2000).

Impacts of Hemodialysis Treatment on Patients

Patients suffering from ESRD receiving HD treatment for survival have to face many problems or stressors that have impacts in different aspects of life. A study by Shinde and Mane (2014) in patients receiving HD concluded that almost all of the patients (97%) reported having severe stress and the remaining 3% had moderate stress. None of the participants had mild or no stress. On the basis of the literature reviewed, the impacts of HD treatment on patients can be categorized as physiological, psychosocial, financial, marital, activity limitations, and treatment-related problems.

Patients receiving HD have to endure many physiological impacts. A study conducted in 50 HD patients in three outpatient HD centers in Hong Kong reported fluid and food restriction, itching, and fatigue as the most frequent physiological impact (Mok & Tam, 2001). In addition, other physiological impacts such as reduced mobility, vascular access surgeries, and length of treatment were also reported by the patients receiving HD in Brazil (Bezerra & Santos, 2008). A systemic review on the prevalence of symptoms in patients suffering from ESRD receiving HD mentioned dyspnea as the most common respiratory problem (Murtagh, Addington-Hall, & Higginson, 2007).

In addition, patients receiving HD face different psychosocial problems. A cross sectional study conducted among 80 HD patients reported psychological problems such as worry about the fistula, a decrease in QOL, difficulty in traveling to

the dialysis center, the cost of treatment, and decreased life expectancy (Gorji et al., 2013). A study conducted to describe the lived experience of Iranian HD patients showed they had experience of altered social inter action and try to hide their disease from others leading to social isolation and reduced social interaction (Kazemi et al., 2011).

Psychiatric disorders such as depression and anxiety are common in patients receiving HD. In comparison to the general population, depression is three times more common in this group of patients (Feroze, Martin, Reina-Patton, Kalantar-Zadeh, & Kopple, 2010). Furthermore, a study undertaken in patients receiving HD demonstrated increased suicidal ideation (Keskin & Engin, 2011; Macaron et al., 2014) and increased mortality rate and frequent hospitalization (Lopes et al., 2002) with increased depressive symptoms. There is a significant change in body appearance of the patients receiving HD such as enlarged arm after creating an arterio-venous fistula, generalized edema, loss of body weight, change in skin color, and decreased muscle tone. This can further aggravate anxiety and psychological stress in patients. In addition, psychological problems can also occur due to financial dependency, a feeling of uncertainty about the future, sleep disturbance, and the feeling of being dependent on medical personnel and family members (Gerogianni & Babatsikou, 2013).

HD is a source of economic burden (Gorji et al., 2013). HD treatment is a continuing process and should be regularly performed for the survival of the patients. The annual cost of HD ranges from $3,424 to $42,785 which makes it difficult to carry out regular HD for patients with low economic status and those who do not have

a reimbursement provision (Mushi, Marschall, & Fleßa, 2015). A cross-sectional study conducted in Iran concluded that 41.5% of the patients reported the treatment cost of HD was a financial burden (Gorji et al., 2013). A qualitative study conducted explore the lived experience of Jordanian patients receiving HD revealed that they were not able to maintain their jobs as they have to adhere to the treatment regimen or HD sessions, and experience physical symptoms (Al Nazly, Ahmad, Musil, & Nabolsi, 2013). Therefore, they cannot make a financial contribution. A study in Nepal by Mishra and Koirala (2015), reported that one-third (37%) of the patients had to sell their property in order to continue their treatment. Consequently, financial constrains or burden leads to withdrawal from the HD.

HD can also lead to marital problems. A case-control study conducted by Tavallaii et al. (2009) in 40 HD patients and 40 healthy participants concluded that HD patients had significantly poor 1) marital consensus 2) affection 3) marital satisfaction 4) marital cohesion and 5) overall marital relationship in comparison with healthy participants. Furthermore, both the physiological and psychological stress that arises due to HD treatment causes sexual problems in this group of patients (Gerogianni & Babatsikou, 2013) that may aggravate the marital problems.

A number of complications also arise due to HD treatment and can be immediate and/or long-term complications. Immediate complications that occur during HD session are vomiting and hypotension due to rapid fluid shifts, shortness of breath, and muscle cramps due to the removal of fluid and electrolytes from the extracellular space (Hinkle & Cheever, 2014). Long term complications are cardiovascular problems, anemia, and renal osteodystrophy. There is also a

disturbance in calcium metabolism which leads to fracture, pain, and disturbance in mobility. Furthermore, exsanguination may occur due to dislodged dialysis needles in the separate blood lines (Hinkle & Cheever, 2014).

There is an imbalance of mind, body, and spirit when an individual suffers from a chronic illness. When patients have to face different problems due to a chronic illness and treatment spiritual aspects and spiritual well-being are affected (Promkaewngam et al., 2014). Patients with ESRD receiving HD suffer from various kinds of stressors such as physical, psychological, marital, and treatment related problems. All of these impacts due to ESRD and treatment will affect the spiritual well-being of the patient receiving HD.

Patients With End Stage Renal Disease and Hemodialysis in Nepal

Nepal is a developing country located between the two big countries, China and India (Hirachan et al., 2010). Nepal has a total population of 26.5 million people with a growth rate of 2.25%. The majority of Nepalese people follow the Hindu religion (81.34%), followed by Buddhism (9.04%), Islam (4.38%), Kirat (3.04%), and Christianity (1.41%) (Central Bureau of Statistics, 2014). Nepalese people believe health and illness are related to the spirit world of Gods and anti-gods such as demons or devils. They worship, ask for boons, give offerings, and attend rituals of various Gods and Goddesses for protection from disease and illness, not only during periods of stress but also for future comfort (Wasti, 2011).

The number of cases suffering from ESRD is increasing in Nepal. A retrospective study in ESRD patients of four hospitals from 1990 to 1999 showed an

increase in the number of patients with ESRD from 61 patients in 1990 to 270 patients in 1999 (Hada et al., 2009). Similarly, Khakurel, Agrawal, and Hada (2009) conducted a retrospective study of five years of data in a tertiary care center (2001-2006) and reported that the number of ESRD patients increased from 102 to 178. The paucity of data related to renal disease in Nepal makes it difficult to have exact incidence and prevalence data of ESRD (Hada et al., 2009). The estimated incidence of ESRD is around 2700 per year (Khakurel, Agrawal, & Hada, 2009).

Two studies in Nepal revealed the causes of ESRD in Nepalese patients. A study by Khakurel et al. (2009) in a tertiary care center reported that the top four causes of ESRD were chronic glomerulonephritis (41%), diabetic nephropathy (16.8%), unknown etiology (18%), and hypertensive nephrosclerosis (13.7%). However, Chhetri, Manandhar, Tiwari, and Lamichhane, (2009) revealed that hypertension, diabetes mellitus, and chronic glomerulonephritis were the top three causes for the development of ESRD in Nepalese HD patients accounting for 55%, 24%, and 15%, respectively. Thus, it can be summarized that diabetes mellitus, chronic glomerulonephritis, unknown reasons, and hypertension are the prevalent causes of ESRD in Nepal. The majority of patients with ESRD in Nepal die without diagnosis of the disease and without reaching a central hospital (Hada et al., 2009) due to negligence, illiteracy, and poverty (Hada, 2009).

As in other countries, ESRD patients in Nepal are also treated with RRT (HD, PD, and KT). RRT services only fulfill a small portion of the current needs in Nepal (Hirachan et al., 2010). HD is the most common method of RRT in Nepal. HD was first started in Bir Hospital in 1987 (Chhetri, Satyal, Khakurel, & Pradhan, 1991 as

cited in Chhetri et al., 2009). In Nepal, there are 22 HD centers with a total of 101 HD machines. However, most of these service centers are located only in the central region of Nepal (Hada, 2009). PD was started in 1972 in Nepal but only two centers provide PD services to around 40 Nepalese ESRD patients (Hirachan et al., 2010). Hence, PD only covers a small number of patients suffering from ESRD. On the other hand, KT service is just in its initial stage in Nepal. It was started on 8 August, 2008, at Tribhuvan University Teaching Hospital (Shrestha, Raut, Sigdel, Kafle, & Shah, 2013). Only three tertiary hospitals in Nepal including 1) Tribhuvan University Teaching Hospital, 2) Bhaktapur Human Organ Transplant Center, and 3) Bir Hospital provide kidney transplant services (Paudel, 2014).

In Nepal, withdrawal from HD is the primary cause of mortality in patients suffering from ESRD receiving HD and the main reason for discontinuation is due to economic constraints (Hirachan et al., 2010). The number of survival years of patients under HD treatment is also low. Hada et al. (2009) reported that the survival rate of patients who receive HD for more than one year is also low. Recently, the Government of Nepal announced provision of lifelong HD treatment for patients with ESRD. This provision of free HD treatment may increase the number of patients who undergo continuing HD therapy ("Free Dialysis Service", 2016).

The Kidney Disease Outcomes Quality Initiative (KDOQI) updated the clinical practice guideline for the adequacy of HD (National Kidney Foundation, 2015b). However, practicing the KDOQI guideline both for physicians and the patients in Nepal is difficult. The difficulty in practicing the guideline is due to lack of transportation, inadequate and centralized HD services, the rural residence of the

Nepalese population, political instability (Hirachan et al., 2010) and low socio-economic status (Manandhar, Chhetri, Tiwari, & Lamichhane, 2009; Mishra & Koirala, 2015). Adequacy of HD in Nepalese patients receiving HD is not satisfactory.

A study conducted by Manandhar, Chhetri, Tiwari, and Lamichhane (2009) reported that dialysis is inadequate in 75% of the patients. Generally, Nepalese ESRD patients receive HD twice a week for four hours per session (Sedhain, Hada, Agrawal, Bhattarai, & Baral, 2015). Twice a week HD may be inadequate for the patients. In addition, dialyzers are reused in Nepal to make HD cost effective, to eliminate first use syndrome, and to improve the compatibility of the dialyzer. However, the processing procedure done before reusing the dialyzer may affect the performance of the dialyzer (Manadhar et al., 2009). The adequacy of HD in Nepalese ESRD patients can be increased by increasing the frequency of HD, implementing insurance or a reimbursement policy, and reusing the dialyzer according to standard protocol (Manandhar et al., 2009).

Malnutrition is highly prevalent in Nepalese HD patients. A study conducted by Manandhar, Chhetri, Pahari, Tiwari, and Chowdhary (2008) to assess the nutritional status of 26 patients receiving HD from a single hospital revealed that 84.6% had mild to moderate malnutrition and severe malnutrition was present in 7.7% of the sample population. Only the remaining 7.7% had a normal nutritional status. However, a recent cross-sectional study in 54 HD patients using the modified quantitative subjective global assessment (MQSGA) and anthropometric measurements showed a decrease in cases of malnutrition. The study revealed 66.7%

of patients had mild to moderate malnutrition and 33.3% had a normal nutritional status with no cases of severe malnutrition (Sedhain et al., 2015). Even though the study showed no cases of severe malnutrition, the study was conducted in a single center with a small sample size and is difficult to generalize. Nevertheless, one-third of the patients still suffered from mild to moderate malnutrition that may be because of poor dietary intake (Sedhain et al., 2015) and inadequacy of the HD (Manandhar et al., 2008). In order to improve the nutritional status of the patients receiving HD regular assessment of the nutritional status and creating awareness of the importance of dietary intake could be helpful.

In summary, the prevalence of ESRD is growing in Nepal. Hypertension, chronic glomerulonephritis, and diabetes mellitus are the leading causes of ESRD in Nepal. RRT services in Nepal are available to only a limited number of ESRD patients. HD is the most common method of RRT. However, adequacy of the HD is not satisfactory. In addition, many HD patients have malnutrition because of poor dietary intake and the inadequacy of HD.

Overview of Spiritual Well-Being

This section includes the concept and definition, and dimensions of spiritual well-being.

The concept and definition of spiritual well-being. "The concept of soul/spirit refers to the inner essence of self-associated with an expanded self-awareness, higher consciousness, inner strength and a power to extend human capacities" (White, 2005, p.16). The spiritual dimension of an individual is considered

as an important component of life (Sittipran, 2007) and every individual is wrapped with a spiritual dimension (Reig-Ferrer et al., 2012). Spirituality is defined as, "a sense of transcendence beyond one's immediate circumstances, and other dimensions such as purpose and meaning in life, reliance on inner resources, and a sense of within-person integration or connectedness" (Monod et al., 2011, p.1346). Spirituality can be positive or negative. Spiritual well-being is a state which represents positive aspects of spirituality (Butt, n. d.).

Various definitions of spiritual well-being have been proposed. Spiritual well-being refers to:

> A state of being reflecting positive feelings, behaviors, and cognitions of relationships with oneself, others, the transcendent and nature, that in turn provide the individual with a sense of identity, wholeness, satisfaction, joy, contentment, beauty, love, respect, positive attitudes, inner peace and harmony, and purpose and direction in life (Gomez & Fisher, 2003, p. 1976).

Fukui, Starnino, and Nelson-Becker (2012) defined spiritual well-being as a process and outcome. The process is having faith in one's capacity to reach aims of life in the face of challenges. The outcome is one's sense of relation with those facets of life that give a sense of purpose and meaning. Spiritual well-being is defined as an individual's perception of having peace, harmony, and happiness in life, understanding himself/herself and nature of life, and to have a sense of connectedness and faith (Promkaewngam et al., 2014).

According to Fisher (1988), spiritual well-being is the quality of the relationship between the personal, communal, environmental, and God

(transcendental) domains. Personal domain refers to how one intra-relates with oneself in regards to meaning, purpose, and values in life. The communal domain is expressed as the quality and depth of interpersonal relationships. Environmental domain refers to the unity with the environment (physical, ecological, and social). Transcendental domain deals with the relationship of an individual with something or someone beyond the level of the human being such as a cosmic force, transcendental reality or God (Fisher 1998).

Whitford and Olver (2012) conceptualized spiritual well-being as a multidimensional concept of three components meaning, faith, and peace. Meaning refers to having congruence between a global and situational sense of meaning (Whitford & Olver, 2012). Park and Folkman (1997) expressed meaning as the perception of significance consisting of two levels of meaning. They are global meaning and situational meaning. Global meaning is an individual's enduring basic goals and fundamental assumptions, beliefs, and expectations about the world. Situational meaning develops from the interaction between an individual's global meaning and situation or circumstances of a particular individual and environment transaction (Park & Folkman, 1997).

Peace is reconciliation and acceptance of an individual's situation (Whitford & Olver, 2012). Peace is interpreted as 1) feeling at peace, 2) peace as a relationship with others, 3) spiritual beliefs, and 4) as a concern related to health and health care. Feeling at peace is described as 1) being relaxed 2) happy 3) positive and free 4) not worrying 5) not grieving, and 6) not feeling disturbed (Selman et al., 2013). Peace as the relationship with others is having harmonious, supportive and open relationships

with friends, family members, and community. Peace related to health and healthcare involves obtaining adequate information about an illness and good symptom management (Selman et al., 2013). A qualitative study conducted among patients of oncology and palliative units reported the degree of peace experience did not depend on the stage of the illness, physical state, prognosis, or religion (Best, Butow, & Olver, 2014).

Faith is an individual concept that provides comfort, and strength, and the belief that whatever happens with their illness, things will be alright (Whitford & Olver, 2012). Faith provides a platform for discovery and developing meaning within human experiences. Furthermore, it provides a sense of their world and situations (Dyess, 2011). Faith is developing a pattern of believing and consists of four attributes: 1) focusing on beliefs 2) foundational meaning for life 3) living authentically in accordance with beliefs, and 4) interrelating with self, others and/or the Divine (Dyess, 2011).

In summary, spiritual well-being is a state, process or outcome of an individual's perceptions which provides a sense of purpose and meaning, peace and harmony, and faith and connectedness. Spiritual well-being is also conceptualized as multidimensional concepts consisting of meaning, peace, and faith. Spiritual well-being provides a sense of identity and positive attitudes. In this study, spiritual well-being is conceptualized as being in a state of having meaning, peace, and faith.

Dimensions of spiritual well-being. Dimensions of spiritual well-being have been divided into two: the religious well-being (RWB) and the existential well-being

(EWB) (Ellison and Paloutzian, 1982 as cited in Finocchiaro, Roth, & Connelly, 2014).

Religious well-being. It is identified as a horizontal dimension. This dimension is described as one's perception of the relationship with a Supreme Being or God and represents an individual's sense of satisfaction and positive relationship with God (Ellison and Paloutzian, 1982 as cited in Finocchiaro, Roth, & Connelly, 2014).

Existential well-being. It is identified as a vertical dimension. This dimension refers to an individual's perception of meaning in life, purpose, and satisfaction with one's life. This dimension is separate from religious references (Ellison and Paloutzian, 1982 as cited in Finocchiaro, Roth, & Connelly, 2014).

However, Whitford and Olver (2012) have conceptualized spiritual well-being as having three dimensions. They are meaning, peace and faith.

Meaning. Meaning refers to having congruence between a global and situational sense of meaning (Whitford & Olver, 2012).

Peace. Peace is reconciliation and acceptance of an individual's situation (Whitford & Olver, 2012).

Faith. Faith is an individual concept that provides comfort, and strength, and the belief that whatever happens with their illness, things will be alright (Whitford & Olver, 2012).

Many people consider religion and spiritual well-being as inseparable and in order to obtain spiritual well-being one should have belief in a deity or deities (Crompton & Jackson, 2004). However, in the recent decades, religion has been

considered separate from spirituality and is considered accredited beliefs and behaviors of certain faith groups (Peterman et al., 2002; Reig-Ferrer et al., 2012). In addition, Lo et al. (2011) considered religiosity as one factor of spiritual well-being. Therefore, the dimensions purposed by Withford and Olver (2012) were used to guide the study.

Significance of Spiritual Well-Being and End Stage Renal Disease Patients Receiving Hemodialysis

Spiritual well-being is accepted and recognized as an important component of human life. Spiritual well-being strongly affects how patients interpret and respond to illness, provides inner strength to cope with distress and promotes positive and active adjustments during stress (Unsanit, Sunsern, Kunsongkeit, O'Brien, & McMullen, 2012). Similarly, previous studies have explained the importance of spiritual well-being in patients suffering from different chronic illness such as cancer (Clay, Talley, & Young, 2010; McClain et al., 2003; Rawdin et al., 2013), people living with HIV/AIDS (Dalmida et al., 2009; Lyon et al., 2014), multiple sclerosis (Allahbakhshian, Jafarpour, & Parvizi, 2011; McNulty, Livneh, & Wilson, 2004), patients receiving HD (Ebrahimi et al., 2014), and end of life care (McClain et al., 2003). Spiritual well-being is an essential component, however, the number of studies conducted in patients with kidney disease is limited (Cheawchanwattana et al., 2014). Although there is a paucity of studies in patients receiving HD, the studies undertook consistently reported that spiritual well-being was important to HD patients.

Spiritual well-being is considered as one essential component of HRQOL (Bredle, Salsman, Debb, Arnold, & Cella, 2011). Similarly, a study conducted in 165 ESRD patients receiving HD revealed spiritual factors as an important determinant of QOL (Kimmel, Emont, Newmann, Danko, & Moss, 2003). A study entitled "Religious wellbeing as a predictor for the QOL in Iranian HD patients" was conducted in 95 HD patients. The study concluded that religious well-being, which is one dimension of spiritual well-being, is an important predictive factor for a better QOL. Multiple regression analysis showed an association between religious well-being and a better QOL in both domains: physical ($OR = 1.17$, $p = 0.01$) and mental ($OR = 1.14$, $p = 0.02$) (Kharame et al., 2014). Additionally, a study conducted by Reig-Ferrer et al. (2012) in HD patients revealed a significant relationship between spiritual well-being and QOL variables, health status, and personal happiness.

In addition, spiritual well-being also has demonstrated a relationship with quality of sleep in patients receiving HD. A study conducted in 190 HD patients with the objective to determine the relationship between spiritual well-being and sleep quality in Iran reported a significant relationship between sleep quality and spiritual well-being ($p < 0.04$, $r = 0.149$) (Eslami et al., 2014). Hence, the spiritual well-being of HD patients should be considered for improving the quality of sleep.

In addition to sleep and QOL, spiritual well-being also plays a vital role in other aspects of life. A descriptive correlational study in 65 ESRD patients receiving HD in the United States reported that an increased level of spiritual well-being was related to increased overall psychosocial adjustment with distress (Tanyi & Werner, 2003). Furthermore, Yodchai, Dunning, Savage, and Hutchinson (2016) conducted an

exploratory qualitative study of 20 HD patients. The study reported the religious and spiritual beliefs and practices of the participants helped them understand why they developed CKD and why they had to receive HD treatment. An understanding of the disease process and the need for HD may help patients more positively adjust and enhance coping.

Furthermore, the bodily pain, vitality, social functioning and mental health domains of the HD patients were significantly associated with spiritual well-being (Kharame et al., 2014). Song and Hanson (2009) conducted a study among 51 African American ESRD patients. One objective of the study was to assess the association between psychosocial-spiritual well-being and the acceptance of possible outcomes of life-sustaining treatment. End of life treatment was assessed using two scenarios which describe the medical condition (terminal illness and advanced dementia) that were commonly present in patients with ESRD. The study concluded that spiritual well-being was related to the choices of participants in the goals of care in end of life scenarios. Participants who desired to use life-sustaining treatment in both scenarios had a significantly low level of spiritual well-being, whereas, participants who wished to stop life-sustaining treatments and those who favored comfort care in both scenarios had a high level of spiritual well-being (Song & Hanson, 2009). The spiritual well-being of patients who receive HD is associated with 1) social support, 2) level of satisfaction, 3) decreased symptoms of depression, 4) improved satisfaction with nephrological treatment, and 5) higher survival rates (Reig-Ferrer et al., 2012).

Literature reviews continually show the importance of spiritual well-being in HD patients. However, the level of spiritual well-being in patients receiving HD is not

satisfactory. A study conducted by Eslami, Rabiei, Khayri, Nooshabadi, and Masoudi, (2014) with an objective to examine the relationship between spiritual well-being and sleep quality in patients receiving HD reported 85.78% of participants had a moderate level of spiritual well-being. In addition, Reig-Ferrer et al. (2012) reported a low level of spiritual well-being in HD patients.

To sum up, spiritual well-being plays a crucial role in patients suffering from ESRD receiving HD. HD patients with high spiritual well-being cope and adjust better with the illness and treatment-related distress. Furthermore, spiritual well-being is essential to enhance sleep quality, mental health, social support, and determine better choices of goals in end of life care. In addition, spiritual well-being is also one component to determine QOL. However, the level of spiritual well-being in patients receiving HD is only low to moderate. Therefore, it is necessary to identify the factors that influence the spiritual well-being in this group of patients.

Spiritual Care of End Stage Renal Disease Patients Receiving Hemodialysis

Spiritual care is an important component of nursing and is unique, personal and dynamic. Spiritual care consists of seven attributes: 1) healing presence; 2) therapeutic use of self; 3) intuitive sense; 4) exploration of the spiritual perspective; 5) patient-centeredness. 6) meaning-centered therapeutic intervention; and 7) creation of a spiritually nurturing environment. Providing spiritual care to patients will result in positive consequences for both patients and nurses. Spiritual care will help patients in psychological adjustment, the enhancement of spiritual well-being, satisfaction, and the promotion of healing. Likewise, those nurses who provide spiritual care have an

increased spiritual awareness and satisfaction towards the job (Ramezani, Ahmadi, Mohammadi, & Kazemnejad, 2014).

Nursing practice is based on the foundation of holistic care. Holistic nursing care refers to taking care of the bio-psycho-social and spiritual aspects of a human being (Frisch, 2001). Burkhart and Hogan (2008) also mentioned spiritual care as an essential aspect of nursing care. Nephrology nurses in the HD unit have more contact with patients receiving HD compared with other health personnel (Castner, 2011; Martchev, 2008). Therefore, they have close relationships with the patients. Nephrology nurses are in a unique position to assess the spiritual needs and provide appropriate interventions related to spiritual care (Tanyi, Werner, Recine, & Sperstad, 2006).

Nephrology nurses can provide spiritual care by respecting the spiritual beliefs and cultural and religious values of the patients (Ramezani et al., 2014), and being a caring person (Grant, 2004). In addition, spiritual interventions of nephrology nurses could be 1) praying with and for the patients, 2) reading holy writings, 3) playing music that lifts the patient's spirit, and 4) calling for spiritual advisors (Deal & Grassley, 2012). Other basic spiritual interventions such as listening to the patients, integrating humor into the practice, displaying competency in caring, continually explaining the procedures, and providing reassurance can also be provided (Tanyi et al., 2006). However, in context of Nepal, there is shortage of nurses resulting in extra job duties (Joshi, 2015). This may affect the spiritual care among the Nepalese nurses as they will be more focused on task-oriented caring of patients.

Spiritual care is an important component of the holistic nursing care and nephrology nurses are in a unique position to provide spiritual care to the patients receiving HD as they have close relationship with patients. Spiritual care enhances the spiritual well-being of the patients. Nephrology nurses can provide spiritual care by providing spiritual interventions for example, praying with and for patients, listening to the patients, and providing reassurance.

Measurements of Spiritual Well-Being in Patients Receiving Hemodialysis

A review of the literature demonstrated the use of different measurement tools to measure spiritual well-being. A systemic review by Monod et al. (2011) on instruments to measure spirituality revealed five scales which measure spiritual well-being. They are the FACIT-Sp-12, the Spiritual Well-Being Scale (SWBS), WHOQOL SRPB (Spirituality, religion, and personal beliefs), JAREL Spiritual Well-Being Scale, and the Spirituality Index of Well-being. In addition, to these five instruments, four other tools were also identified from the literature review that measures spiritual well-being. They are, Spiritual Health And Life-Orientation Measure (SHALOM), Thai Spiritual Well-being Assessment Tool for Elders with Chronic Illness (TSWBATECI), Thai Buddhist Adults with Chronic Illness (SWS-TBACI), and the Meaning in Life Scale (MiLS). However, the review of the literature revealed the use of FACIT-Sp-12 and SWBS to measure the level of spiritual well-being in patients receiving HD. In addition, the Meaning in Life Scale (MiLS) was adapted and is a validated questionnaire which measures the spiritual well-being of patients receiving HD (Reig-Ferrer et al., 2012). Since this study aims to conduct a

study in ESRD patients receiving HD, the measurement tools, FACIT-Sp, SWBS, and MiLS are explained in detail.

12-Item Functional Assessment of Chronic Illness Therapy – Spiritual Well-Being Scale (FACIT-Sp-12). The spiritual well-being subscale of FACIT-Sp is referred to as FACIT-Sp-12. This scale measures the spiritual well-being of an individual with content not limited to any religious beliefs (Bredle et al., 2011). FACIT-Sp-12 was originally composed of two subscales: Meaning/Peace and Faith (Peterman et al., 2002). However, Canada, Murphy, Fitchett, Peterman, and Schover (2008) proposed a three-factor model: meaning; peace; and faith. This three factor model was further confirmed in a study by Murphy et al. (2010). The scale is composed of 12 items, four items in each of three subscales (meaning, peace, and faith). FACIT-Sp-12 has a 4- point Likert scale from 0 to 4 (0 = Not at all; 1 = A little bit; 2 = Somewhat; 3 = Quite a bit; and 4 = Very much). Item 8, "My life lacks meaning and purpose" and item 4, "I have trouble feeling the peace of mind" are the items of the reverse scoring. The possible range of scores is from 0 to 48, a higher score represents higher spiritual well-being (Bredle et al., 2011; Monod et al., 2015).

The recall period of the instrument is seven days. This scale has good internal consistency with a Cronbach's alpha coefficient of .87 for the total score. The subscales of the scales, which are Meaning/Peace and Faith, have Cronbach's alpha coefficient of .81 and .88 respectively (Peterman et al., 2002). A recent systemic review reported that the FACIT-SP-12 is the most validated and widely used instrument for measuring spiritual well-being (Monod et al., 2011). This scale can be used to measure spiritual well-being in those populations who consider themselves as

spiritual but not religious. This scale has been translated and validated in 15 different languages and has been used by many studies (Bredle et al., 2011). Recently, this scale was also validated in the Greek language (Fradelos et al, 2016).

From the literature review, the use of the FACIT-Sp-12 to assess the level of spiritual well-being in patients receiving HD was revealed; as in studies conducted by Cheawchanwattana, Chunlertrith, Saisunantararom, and Johns (2014). Additionally, Bredle, Salsman, Debb, Arnold, and Cella (2011) reported the use of FACIT-Sp-12 in many research studies. This scale is less time consuming and does not make any reference to any religious practice. Hence, this scale can be used to assess the spiritual well-being of non-religious people. Therefore, FACIT-Sp-12 was used in this study to assess the level of spiritual well-being in ESRD patients receiving HD.

While answering the Likert scale questionnaires participants have tendency to stay neutral as it is easy and least controversial. Hence, the responses of the participants may come down to middle and may affect the true response (Pros and cons, n.d.). Therefore, to add the greater certainty in inferences and conclusions of the data obtained from FACIT-Sp-12, open ended questions were added. The tool was named Spiritual Well-Being Assessment Tool (SWBAT) in the study.

Spiritual Well-Being Scale (SWBS). The SWBS was developed by Paloutzian and Ellison in 1982. This scale assesses an individual's subjective perception of spiritual well-being as defined by religious factors (relationship with God) and existential factors (life satisfaction). The SWBS is composed of two subscales: the RWB and EWB. The RWB subscale measures an individual's relationship beyond the level of human beings such as with God. The EWB subscale

does not assess the issues specific to religion, rather it assesses the general issues related to the relationship to the world about us, the purpose of life, satisfaction and meaning in life (Ellison, 2006). This scale consists of 20 items; ten items measure the RWB and the remaining ten items measure the EWB.

The items of the scale are scored based on a six-point Likert scale ranging from1 to 6 (1= Strongly agree to 6= Strongly disagree). The overall score of the SWBS ranges from 20 to 120 and the scores of the subscales range from 10 to 60. A higher score represents a higher level of spiritual well-being (Ellison, 2006). Overall, the score of the spiritual well-being is divided into three levels: high (100-120); moderate (41-99); and low (20-40) (Ebrahimi et al., 2014; Eslami et al., 2014). The test-retest reliabilities were .89 for spiritual well-being, .87 for the RWB and .78 for the EWB (Ellison, 2006). Many authors have stated good face validity and sufficient content validity regarding the items. In addition, SWBS was also validated in various samples such as religious groups, college students, caregivers of terminally ill hospice patients, and outpatients (Bufford, Paloutzian, & Ellison, 1991).

SWBS is used by the researcher in many studies to measure spiritual well-being. However, this instrument could be more helpful in a group of people who follow a certain religion. In addition, there is a need for further validation in ethnic groups and groups other than Judeo-Christian.

Meaning in Life Scale (MiLS). The MiLS was developed by Reig-Ferre et al. (2012). The MiLS is a 21-item questionnaire and consists of four different dimensions. They are 1) Life Perspective, Purpose and Goals 2) Lessened Meaning 3) Harmony and Peace, and 4) Benefits of Spirituality. The first dimension of the MiLS

is Life Perspective, Purpose, and Goals which, is composed of seven items. This first dimension measures the patient's current feeling of personal fulfillment and satisfaction. Additionally, it reflects the patient's level of commitment to1) activities, 2) self-comprehension, and 3) optimism for the future (Reig-Ferrer et al., 2012). The second dimension, Lessened Meaning, is composed of seven items and indicates 1) the loss of motivation to perform important functions, 2) a sense of confusion regarding the sense of self and life in general, and 3) the belief that life is a negative experience (Reig-Ferrer et al., 2012). The third dimension, Harmony and Peace, consists of four items and evaluates the 1) level of inner peace and harmony, 2) personal equilibrium, 3) the experience of an inner feeling that provides happiness, and 4) a positive outlook (Reig-Ferrer et al., 2012). The final dimension is Benefits of Spirituality, that has three questions and evaluates 1) the level of strength, 2) fortitude, and 3) consolation that religious faith or other spiritual beliefs may provide that fall outside of a traditional religious framework (Reig-Ferrer et al., 2012).

The responses to the first dimension (Life Perspective, Purpose, and Goals) and the second dimension (Lessened Meaning) range from 1 to 6 (1 = Somewhat in agreement to 6 = Very much in disagreement). The responses to the third dimension (Harmony and Peace) and fourth dimension (Benefits of Spirituality) range from 0 to 4 (0 = Not at all to 4 = Very much). The reliability of the overall scale is good with a Cronbach's alpha coefficient of .93.The reliability of each dimension of the scale is also good. Cronbach's alpha coefficients of the first dimension, a second dimension, the third dimension, and fourth dimension are .90, .84, .87, and .91, respectively. The responses to the questionnaire are divided into a high-value group and a low-value

group. High-value group responses include (Somewhat in agreement, In agreement, and Very much in agreement) for items 1 to 14 and (Quite and Very much) for items 15 to 21. The low-value group responses include (Somewhat in disagreement, In disagreement, and Very much in disagreement) for items 1-14, along with (Not at all, Very little, and Somewhat) for items 15-21 (Reig-Ferrer et al., 2012).

The MiLS questionnaire is evaluated in HD patients. It is a valid instrument to measure the spiritual well-being of HD patients. However, the instrument was validated in 94 convenience samples, which may not be enough to determine the psychometric measurement of the instrument. In addition, this scale only measures the concept of meaning. Therefore, this instrument was not employed in this study.

Factors Related to Spiritual Well-Being

Patients receiving HD face many problems and struggle to maintain their HRQOL. Spiritual well-being is an essential component of HRQOL (Bulkley et al., 2013). Literature review revealed various factors that were associated with spiritual well-being. They were, physical symptoms, social relatedness, self esteem, and religiosity (Lo et al., 2011), age (Cheawchanwattana et al., 2014; Kharame et al., 2014), gender (Cheawchanwattana et al., 2014), marital status (Cheawchanwattana et al., 2014; Kharame et al., 2014), sleep quality (Eslami et al., 2014), and mental health (Kharame et al., 2014; Martinez & Custodio, 2014). The details of the factors affecting spiritual well-being are presented in the following section.

Age. Compared to the young, older people lose their materialistic view of life and form more transcendental and spiritual perspectives (Saleem & Sajid, 2015;

Velasco-Gonzalez & Rioux, 2014). Therefore, older people may engage themselves in spiritual activities that lead to enhanced spiritual well-being.

Similarly, previous studies undertaken in patients receiving HD reported age as one factor that could affect spiritual well-being. A study undertaken by Cheawchanwattana et al (2014) among 63 pre-dialysis patients and 31 patients who were on chronic HD reported age as one factor that affected participants' spiritual well-being. In the study when the participants were divided into two age groups: above and below 60 years, the participants in the above 60 years group had higher spiritual well-being than the younger participants. Similarly, a study undertaken by Kharame et al. (2014) also revealed the association between age and spiritual well-being.

Gender. There are gender differences in spiritual beliefs. A previous study reported females had a significantly higher score in domain of benefit from spiritual belief than males (Reig-Ferrer et al., 2012). Therefore, as females are perceived to have more benefit from spiritual belief they tend be more spiritual. A study undertaken by Kao et al. (2009) among Taiwanese HD patients reported significantly lower spiritual well-being in male than female participants. Similarly, Cheawchanwattana et al. (2014) also reported greater spiritual well-being in females as comapred to males.

Marital status. Regarding marital status, previous studies reported inconsistent result. A study undertaken by Cheawchanwattana et al. (2014) reported low level of spiritual well-being in married participants suffering from ESRD. On the

other hand, Kharame et al. (2014) revealed significant positive correlation between the marital status and spiritual well-being.

Mental health. Spiritual well-being is associated with minor psychiatric disorders (Volcan, Sousa, Mari, & Horta, 2003). A study in Hong Kong among patients receiving HD demonstrated that the participants were unable to perform their daily activities and had limitations of food and liquid (Mok & Tam, 2001). As a result patients will lose their normal life. These all changes result in the psychological stress. Similarly, the relationship between the mental health and spiritual well-being among patients receiving HD is revealed in previous studies (Kharame et al., 2014; Martinez & Custodio, 2014).

Sleep quality. Sleep is one of the most important physical, mental, and emotional needs of human beings. Poor sleep quality has affect on daytime activities, cognitive functioning and increases anxiety and depression (Novak, Shapiro, Mendelssohn, & Mucsi, 2006). A study conducted by Tel, Tel, and Esmek (2007) reported that 78.7% of the patients receiving HD had sleep problem.

A study conducted in 190 HD patients revealed a significant association between sleep quality and spiritual well-being. Poor sleep quality will intensify the physical complications that may have a negative effect on spiritual well-being (Eslami et al., 2014).

Self esteem. Self esteem is described as an individual's sense of self-worth or personal values (Cherry, 2016). A study undertaken in terminal cancer patients revealed the relationship between spiritual well-being and self esteem (Lo et al., 2011). However, according to the researcher's best knowledge a study conducted to

examine the relationship between the self esteem and spiritual well-being in HD patients could not be identified.

Pain. Pain is a complex, multidimensional, and unpleasant experience (Wachholtz et al., 2007). Pain is inevitable in the life of people receiving HD. Davison (2003), conducted a prospective cohort study in 205 Canadian patients receiving HD with an objective to explain the prevalence, cause, severity, and management of pain. Instruments such as the Brief Pain Inventory (BPI), McGill Pain Questionnaire (MPQ), and Pain Management Index (PMI) were used. The BPI score of the study revealed that 82.5% of participants had moderate or severe pain in the previous 24 hours and 55.4% experienced pain at the time of the interview. The pain was moderate or severe in severity (Davison, 2003). Additionally, a recent systemic review undertook to evaluate the existing literature on the prevalence and severity of pain in patients receiving HD concluded that the prevalence of acute pain in HD was up to 82% and chronic pain up to 92% (Brkovic et al., 2016). People who receive HD perceived different types of pain. Yodchai, Dunning, Savage, Hutchinson, and Oumtanee (2014) conducted a qualitative study in 20 patients receiving HD. They reported three main types of pain experienced by patients who receive HD. They were physical, psychological, and social pain. Physical pain occurred due to needle insertion during HD, vascular access surgery, cramps, joint, and muscle pain. Change in family roles, unfulfilled hopes and dreams caused psychological pain and the perceptions of the disease by other people influenced social pain.

One common source of pain in patients with ESRD receiving HD is musculoskeletal pain. A study conducted in 205 Canadian HD patients reported

musculoskeletal pain as the most common cause of pain, prevalent in 63.1% of HD patients (Davison, 2003). Various types of musculoskeletal pain are found in ESRD patients on HD such as cramps, joint pain, backache, muscle pain, and carpel tunnel syndrome (Brkovic et al. 2016). Musculoskeletal pain in HD patients occurs due to mineral metabolism and bone disease. This condition is called Chronic Kidney Disease-Mineral and Bone Disorder (CKD-MBD). CKD-MBD includes abnormal mineral metabolism, changes of structure and composition of the bone structure, and extraskeletal calcification which is induced by secondary hyperparathyroidism, deficiency of vitamin D, deposition of calcium pyrophosphate dehydrate and β2-microglobulin amyloidosis (Santoro et al., 2013).

Furthermore, the causes of pain in patients receiving HD are multifactorial and can be categorized as pain from consequences of renal failure, co-morbid conditions, primary kidney disease, and HD treatment itself. Consequences of renal failure such as calciphylaxis, nephrogenic sclerosing fibrosis, dialysis-related amyloidosis (DRA) or calcific uremic arteriolopathy, renal osteodystrophy (Davison, 2007), and peripheral neuropathy (Santoro et al., 2013) cause pain in patients who receive HD. Co-morbid conditions (diabetic nephropathy, vascular disease) and primary renal disease (polycystic kidney disease) are also responsible for the cause of pain (Davison, 2007; De Castro, Murphy, & Battistella, 2013; Santoro et al., 2013). Additionally, another etiology of pain is from the HD treatment itself for example, headache (Brkovic et al., 2016; Göksan, Karaali-Savrun, Ertan, & Savrun, 2004; Sav, Sav, Senocak, & Sav, 2014), arterio-vascular access (Brkovic et al., 2016; De Castro et al., 2013), and muscle cramps (Calls et al., 2009; Hinkle & Cheever, 2014). There

is a large shift of water and electrolytes during HD which may result in a headache and muscle cramps.

The relationship between pain and spiritual well-being has been revealed by different studies. Spiritual well-being helps in an effective coping and psychological adjustment to distress (Unsanit et al., 2012). Hence, patients with high spiritual well-being tend to tolerate and cope with pain in an effective manner. Higher levels of pain are associated with increased levels of spiritual distress (Siddall, McIndoe, Austin, & Wrigley, 2016), and increased level of spiritual distress will lower the spiritual well-being of the patients. A study in 81 patients suffering from multiple sclerosis revealed there was a significant relationship between pain and meaning/peace which is one subscale of spiritual well-being (Nsamenang, Hirsch, Topciu, Goodman & Duberstein, 2016). Similarly, Rabow and Knish (2015) also reported that a higher level of spiritual well-being was associated with a low level of pain.

Likewise, Rawdin, Evans, and Rabow (2013) undertook a study of outpatients diagnosed with cancer and reported pain experienced by these patients was mediated by spiritual well-being. Similarly, a qualitative study conducted among 20 HD Thai patients summarized that pain experienced by this group of patients had an effect on the spiritual well-being (Yodchai, Dunning, Savage, Hutchinson, & Oumtanee, 2014). In addition, a cross-sectional study was conducted with the objective to explore the relationship between spiritual well-being and QOL in 95 patients receiving HD. The study results showed a significant positive relationship between spiritual well-being and pain ($r = .33$, $p < .01$) (Kharame et al., 2014). However, a study by Siddall, McIndoe, Austin, and Wrigley (2016) in a group of population with and without

spinal cord injury revealed a moderate but significant negative relationship between spiritual well-being and pain (r = -.43, p < .00002). In summary, there is an inconsistency in the relationship between pain and spiritual well-being.

Fatigue. Fatigue is a complex, multidimensional, and multi-factorial phenomenon (Artom, Moss-Morris, Caskey, & Chilcot, 2014). Ream and Richardson (1997) defined fatigue as a subjective, unpleasant feeling that ranges from tiredness to exhaustion and interferes with a person's ability to function normally. Fatigue is one common distressing symptom in ESRD patients receiving HD. Fatigue in patients receiving chronic HD was prevalent in 60% to 97% (Horigan et al., 2013). Similarly, a recent study conducted by Zyga et al. (2015) among ESRD patients undergoing HD revealed 47.3% of them had fatigue and 13.7% were extremely fatigued. A qualitative study conducted in 14 adult patients receiving HD with the objective to describe the experience and self-management of fatigue categorized the nature of fatigue into physical and mental fatigue. Physical fatigue was described as having a lack of physical power and strength which made them feel lifeless, weak, washed out, and drained. Furthermore, participants reported mental fatigue affected their capacity to remember conversations, the names of people, and their destination when driving (Horigan et al., 2013).

Various factors contribute to fatigue in people receiving HD. They are demographic (age, gender, race), clinical variables (anemia, nutritional status, sleep disturbance, co-morbidities), and laboratory values (serum creatinine and urea, and levels of parathyroid hormone) (Bossola, Vulpio, & Tazza, 2011). Post-dialysis fatigue is more common in patients receiving HD. A descriptive study conducted in

103 patients receiving HD reported the means of pre-dialysis and post-dialysis fatigue were 63.4 and 86.8, respectively. There was a significant increase in between the pre- and post-dialysis fatigue (Han & Kim, 2015). Post-dialysis fatigue can be due to osmotic disequilibrium, blood membrane interactions, ultrafiltration, and diffusion (Artom et al., 2014). Studies also showed a significant relationship between the fatigue and duration of HD (Letchmi et al., 2011; Mollaoglu, 2009), longer duration of HD increases the fatigue. Depression and anxiety are common in patients with ESRD receiving HD. Psychological factors such as depression and anxiety significantly contributed to fatigue (Artom et al., 2014; Williams, Crane, & Kring, 2007).

Fatigue is a distressing phenomenon that can have an impact on the spiritual well-being dimension of the patients (Lewis, Salins, Rao, & Kadam, 2014). Rabow and Knish (2015) undertook a retrospective study from 2008 to 2011 in 883 patients who were receiving oncologic and palliative care. In the study, the Edmonton Symptom Assessment System (ESAS) questionnaire and two additional statements "How would you rate your overall QOL?" and "I feel at Peace" were used. The study reported a high level of spiritual well-being was related to less fatigue.

Similarly, Lewis, Salins, Rao, and Kadam (2014) conducted a study in 200 patients receiving active cancer treatment. The linear regression analysis of the study concluded that fatigue was a significant negative predictor of spiritual well-being ($\beta = -.23$, $p < 0.001$). However, a descriptive analytical study conducted with the aim to explore the relationship between spiritual well-being and QOL in 72 patients receiving HD revealed a significant positive correlation between fatigue and

existential well-being which is one dimension of spiritual well-being (p = .02, r = .26) (Ebrahimi et al., 2014). To summarize, the relationship between spiritual well-being and fatigue showed both a positive and negative correlation.

Social Support. Social support makes an individual to believe that he or she is cared for and loved, esteemed, and is a member of a network of mutual obligations (Cobb, 1976). Videbeck (2013) defined social support as emotional sustenance which arises from friends, family members, and health care providers. These groups of people help a person when they face problems. There are four types of social support: emotional, instrumental, informational, and appraisal support. Emotional support refers to empathy, care, love, and trust obtained from others. Instrumental support refers to having direct relevant help such as financial, labor, and time to modify the environment. Informational support represents getting information, suggestions, and directions which help to cope with the current stressors and problems. Appraisal support is achieving information for self-assessment such as reassurance and feedback from others that will enhance one's self-esteem (House, 1981 as cited by Peterson & Bredow, 2009).

Social support has been identified as an important factor that helps to improve a patient's health outcome. Similarly, social support provided greater patient satisfaction, HRQOL, and a reduction in hospital admissions in patients receiving HD (Plantinga et al., 2010). Furthermore, various studies showed a relationship between spiritual well-being and social support. Pace and Stables (1997) undertook a study in 221 participants with the aim to evaluate the perception of spiritual well-being, loneliness, social support, health hardiness, pain, and functional status between

terminally ill patients suffering from AIDS and terminally ill patients having cancer. The multiple regressions showed loneliness and social support together accounted for 47% of the variance in spiritual well-being and each variable showed a 10% unique variance in spiritual well-being. Additionally, another study in 117 HIV-infected patients who were receiving treatment at an antiretroviral clinic in Thailand reported a moderate level of correlation ($r = .496$, $p < .01$) between social support and spiritual well-being. In addition, multiple regressions revealed social support as the strongest predicting variable ($\beta = .503$, $t = 6.347$, $p < .01$) (Sittipran, 2007).

Studies in patients HD patients also reported the relationship between social support and spiritual well-being. A descriptive, analytical study with an aim of exploring the relationship between spiritual well-being and QOL concluded that a significant relationship existed between existential well-being (one dimension of spiritual well-being) and social performance ($r = .27$, $p = .01$) (Ebrahimi et al., 2014). In addition, a study by Kharame et al. (2014) in 95 patients who were diagnosed with ESRD and receiving HD reported a significant relationship between spiritual well-being and social functioning.

Religiosity. Religiosity is defined as a set of common beliefs, practices, and rituals connected to sacred deities that may be either good spirits (angels) or bad spirits (demons) that originate from the community. These beliefs, practices, and rituals may be practiced in the community, alone or in private (Koenig et al., 2012). Concept analysis by Bjarnason (2007) summarized religiosity as religious affiliation, religious activities, and religious beliefs which are expressed as personal (intrinsic or internal) or public (extrinsic or external) devotion. Religiosity is divided into three

dimensions: organizational; non-organizational; and subjective religious practices. Organizational religiosity included practices such as attending holy places such as a church and temples, whereas, non-organizational religiosity denotes private practices, for example, reciting prayers, and reading holy books. In addition, subjective religiosity refers to the importance of religion in an individual's life (Chokkanathan, 2013).

Religiosity has a positive association with mental and physical well-being (Ahmadi, Darabzadeh, Nasiri, & Askari, 2015; Thege, Pilling, Székely, & Kopp, 2013). Patients suffering from chronic and incurable diseases use religion as a source of strength and approach to alleviate distress (Lucchetti et al., 2012). A study undertaken among HD patients revealed participants with high level of religious inspiration and a greater degree of intrinsic religiosity had a high HRQOL (Cruz et al., 2016) and QOL (Lucchetti et al., 2012). Additionally, in comparison with religious HD patients, those patients who are atheists had eight times greater risk of suicide (Martiny et al., 2011) and more depression (Lucchetti et al., 2012).

Relationship between religiosity and spiritual well-being have been reported by previous research. Patients suffering from cancer have shown a positive correlation between spiritual well-being and intrinsic religiosity (Fehring, Miller and Shaw, 1997 as cited in Musgrave & McFarlane, 2003). A cross-sectional correlation study conducted among Filipino Christian HD patients, reported participants who spent more time in their private religious activities (praying, meditation, and Bible study) had more satisfaction in their spiritual dimension of life (Cruz et al., 2016).

A qualitative study was undertaken with four separate interviews and three separate focused group discussions with community-based nephrologists and specialized (dialysis and nephrology) nurses, respectively. The objectives were to identify the information and reaction of patients suffering from CKD as experienced by nephrologists and nephrology nurses. The study concluded that there were different themes and one theme was "thoughts on God". They reported the majority of the patients diagnosed with CKD believed that God will help them face their problems. Similarly, nephrologists also agreed that a belief in higher being such as God or Divine was beneficial to improve the patient's condition and also provided support for the patients (Kazley, Johnson, Simpson, Chavin, & Baliga, 2014). In addition, a study conducted by Reig-Ferrer (2012) in patients receiving HD also reported a significant positive relationship between spiritual well-being and religiosity.

To sum up, there is paucity of studies conducted to identify the factors that affect the spiritual well-being in ESRD patients receiving HD. Hence, the predicting factors of this study were selected on the basis of the critical appraisal of existing relevant literatures. Therefore, in this study, pain, fatigue, social support, and religiosity were selected.

Summary of Literature Review

The literature review describes information regarding an overview of ESRD and HD, and an overview of spiritual well-being including factors affecting spiritual well-being. ESRD is a chronic and irreversible disease which is increasing worldwide.

Hypertension and diabetes mellitus are the two leading causes of ESRD globally. HD is the most common method of RRT in patients suffering from ESRD.

Although the life expectancy of ESRD patients receiving HD has increased they suffer from various problems and stressors such as physiological, psychosocial, financial, marital problems, limited activities, and treatment related problems. Since, the patients who receive HD continually suffer from the aforementioned problems; they will raise questions about their meaning of life, and also feel that they do not have any hope or aims. This will consequently lead to low spiritual well-being.

Different authors have proposed definitions of spiritual well-being. In this study, spiritual well-being was conceptualized as a state of having meaning, peace, and faith. Spiritual well-being is an important aspect of a human being and is necessary to deal with a distressful situation. However, the literature review showed a low to moderate level of spiritual well-being in ESRD patients receiving HD. The literature review also revealed associations between spiritual well-being, pain, fatigue, social support, and religiosity in HD patients. However, the predicting values of these factors in HD patients are unknown. Predicting values would provide empirical evidence to anticipate how the variable will behave. In addition, in previous studies specific instruments that measures pain, fatigue, religiosity, and social support was not used. This may affect the results of the study.

In addition, people with different religions and cultures express meaning and purpose of life in different ways. Almost all of the previous studies were conducted in countries with different cultures and religions from Nepal and therefore, previous

studies may not be an exact reflection of Nepalese HD patients. To date, literature related to predicting factors of spiritual well-being in Nepal is relatively unknown.

Chapter 3

Research Methodology

Chapter three presents the research design, population and sample, instrumentation, the validity and reliability of the instruments, the translation of the instruments, data collection procedures, ethical considerations, and data analysis.

Research Design

The study was a cross-sectional research design, which aimed to assess the level of spiritual well-being, examine the relationship between pain, fatigue, religiosity, social support, and spiritual well-being, and determine predicting factors of spiritual well-being in Nepalese patients with ESRD receiving HD.

Population and sample. This study was conducted among 100 Nepalese ESRD patients receiving HD in National Kidney Center, Kathmandu, Nepal. Purposive sampling method was used to select participants in the study.

Inclusion criteria for the participants. Inclusion criteria used to select participants for the study were

1. age ≥ 18 years old and willing to participate in the study;
2. able to communicate or read and write the Nepali language;
3. patients receiving regular (at least twice a week) HD for ≥ 3 month;
4. patients who are able to provide informed consent; and
5. patients who do not have acute physical symptoms such as dyspnea, nausea, and vomiting that may interfere in the data collection process.

Sample size estimation. The sample size estimation for the study was determined by power analysis. The number of respondents needed in the study was estimated by function of effect size, the number of predictors, desired power, and significance criterion. According to Polit and Beck (2008), the formula to calculate sample size for multiple regression was:

$N = L / \gamma + \kappa + 1$

Where,

N = estimated number of the subjects needed

L = tabled value for the desired α and power

γ = estimated effect size

κ = number of predictors

The value of estimated effect size (γ) was calculated as:

$\gamma = R^2/1- R^2$

A previous study by Sittipran (2007) among people living with HIV infection resulted in R^2 value of .246 at the level of significant criterion (α) = .05 and the power of the test = .90, therefore, γ = .31

From the power analysis table, 23.4 value of L is 11.94 (Polit & Beck, 2008). Hence, the using aforementioned formula the total number of sample was 43.51.

However, for this study, the effect size was reduced to moderate, R^2 = .13, as the study population of the previous study was different from the current study. Therefore, the value of γ was .14. Finally, the sample size for the study was:

$$N = L / \gamma + \kappa + 1$$

$$= 90.28$$

As a result, the final sample size of the present study was 91. In the study, the participants were round up to 100 (Appendix A).

Setting. The population of the study was patients suffering from ESRD receiving HD. The study was conducted in National Kidney Center, which is located in the capital city of Nepal. This center has the largest capacity to provide HD service to Nepalese patients suffering from ESRD and is the referral center. The patients are not admitted to this center as they come to receive HD and after completion of each HD session they return home. National kidney center has recently started services outside of the capital city, in Biratnagar, Chitwan, and Damauli. In addition, this organization also provides HD services in collaboration with Sumeru hospital inside the capital city.

However, in the present study, only patients receiving HD in National Kidney Center were included. National Kidney Center is the main center and has the largest number of patients from different parts of the country. This center has the capacity to provide HD service for up to 105 patients per day with 35 HD machines. Additionally, National Kidney Center provides six months training on HD (3 months = basic training course and additional 3 months = advanced training course). Altogether there are 100 registered nurses and 10 physicians working. The number of patients receiving HD from the National Kidney Center only is 304. The center conducts HD three times a day. However, there are only two duty shifts morning (7am-2pm) and afternoon (2 pm- till patients go home).

Instrumentation. The data collection instruments for this study were divided into six parts. They were 1) Patient Data Form (PDF), 2) Spiritual Well-Being

Assessment Tool (SWBAT), 3) Pain Assessment Scale (PAS), 4) Fatigue Assessment Scale (FAS), 5) Religiosity Assessment Scale (RAS), and 6) The Medical Outcomes Study Social Support Survey (MOS-SS). The instruments are described below.

Patient Data Form (PDF). PDF was used to collect the information regarding participant's characteristics. This instrument was developed by the researcher and was composed of two parts: part I (Demographic data) and part II (Clinical data). Part I included eight questions about the demographic data of the participants as follows: age, gender, religion, marital status, education level, occupation, monthly family income, and way of medical payment. Part II included four items: months diagnosed with renal disease, 'How long have you been on HD?', 'How often do you receive HD per week?', and co-morbidities (Appendix B).

Spiritual Well-Being Assessment Tool (SWBAT). In this study, the FACIT-Sp-12 (Peterman et al., 2002) was extended and named SWBAT (Appendix C). SWBAT consisted of two parts. Part I encompassed the original FACIT-Sp-12 and Part II consisted of the interview guide developed by the researcher.

Part I (FACIT-Sp-12) was used to measure the level of spiritual well-being of the participants. As mentioned earlier FACIT-Sp is widely used and the most validated 12 item instrument and has good reliability. The original instrument of the FACIT-Sp-12 examined the two factors: meaning/peace and faith (Peterman et al., 2002). Recently, the three-factor model was utilized namely meaning, peace, and faith. The three-factor model has been shown to be psychometrically superior to the two-factor construct (Bai, Lazenby, Jeon, Dixon, & McCorkle, 2015; Canada, Murphy, Fitchett, Peterman, & Schover, 2008; Whitford & Olver, 2012).

Therefore, the three-factor model (meaning, peace, and faith) was used in this present study. Meaning is assessed by items 2, 3, 5, and 8; peace is measured by items 1, 4, 6, and 7, and faith is assessed by items 9, 10, 11, and 12. The response of the items is a 5-point Likert scale ranging from 0 to 4 (0 = Not at all, 1 = A little bit, 2 = Somewhat, 3 = Quite a bit, and 4 = Very much). Item-8, "My life lacks meaning and purpose" and item-4, "I have trouble feeling peace of mind" are items of reverse score (Bredle et al., 2011). The possible range of score is 0 to 48; higher score represented higher spiritual well-being. A higher score of the instrument indicated higher spiritual well-being. The score obtained was interpreted using the formula (Maximum-Minimum/Number of category) (Grouped Frequency Distribution, n.d.). Therefore, the level of spiritual well-being in the study was categorized as:

Low spiritual well-being: 0-16

Moderate spiritual well-being: 17-32

High spiritual well-being: 33-48

Part II consisted of the interview guide developed by the researcher. The interview guide was developed using the concept proposed by Whitford and Olver (2012), this concept which was used as a conceptual framework to guide the study. The interview guide was used to obtain data on the participant's experience of spiritual well-being (their meaning and purpose in life, feeling of peace and belief of whatever happens everything will be fine) after being diagnosed with ESRD and undergoing HD treatment. Qualitative content analysis method purposed by Polit and Beck (2008) was used to analyze the qualitative data obtained from the interview guide.

Pain Assessment Scale (PAS). PAS was used to measure the pain experienced by the patients. PAS was administered for two times to obtain the information regarding pain during HD treatment and due to ESRD in past one month. This scale was developed by the researcher. PAS measured the intensity, causes, and location of pain due to HD treatment and ESRD. The item to measure the intensity of pain was adapted from the NRS. The NRS consists scores of 0-10 number at equal intervals, 0 indicates "no pain" and 10 indicates "worst pain possible" (Hjermstad et al., 2011). A higher score indicated higher pain. Scores of pain were categorized as 0 "no pain", 1-3 "mild pain", 4-6 "moderate pain" and 7-10 "severe". NRS can be administered verbally or self-completed, it is easy to understand, and can be administered in patients who do not have a clear vision (Breivik et al., 2008). Therefore, NRS was used to measure the pain intensity of participants. Causes of the pain were assessed using a single question ("Please specify the causes of pain during HD treatment and due to ESRD"). The location of the pain was assessed with the front and back body diagrams. The participants marked the location of pain in the diagram (Appendix D).

Fatigue Assessment Scale (FAS). This scale was used to measure the fatigue experienced by the participants. The FAS is a unidimensional self-reported instrument used to measure the level of perceived fatigue usually experienced by the patients. The FAS was developed by Michielsen et al. (2003). Answers to the questions should be provided by the patients even if the patients do not have any complaints at the time of providing scores. The FAS measures the mental and physical fatigue perceived by the patients and has ten items. Items 3, 6, 7, 8, and 9 indicate mental fatigue whereas remaining items 1, 2, 4, 5, and 10 represent physical fatigue. The FAS has a 5-point

Likert scale and responses to the items ranges from 1 to 5; 1= Never, 2= Sometimes (about monthly or less), 3= Regularly (about a few times a month), 4= Often (about weekly), and 5= Always (about every day).

The scores of item 4 (I have enough energy for everyday life) and 10 (When I am doing something, I can concentrate quite well) were reversed scores while calculating the total score (Drent, Lower, & De Vries, 2012). The total score was calculated by summing the scores and possible scores ranged from 10 to 50. The cut-off score of the scale is 21, therefore, score <22 represents "non-fatigued", score higher or equal to 22 is "fatigued", and higher or equal to 35 indicates "extremely fatigued"(Zyga et al., 2015). This scale has been translated and validated in 12 different languages (Drent et al., 2012). The FAS has good reliability with Cronbach's alpha coefficient of .90 (Michielsen, Vries & Van, 2003) (Appendix E).

The Medical Outcomes Study Social Support Survey (MOS-SS). The MOS-SS was used to measure the social support of the participants. The scale was developed from a study undertaken in patients with chronic illness. The MOS-SS was developed by Sherbourne and Stewart (1991). This scale measured the functional social support, the degree to which interpersonal connection provided particular functions in four different dimensions. They are emotional/informational, tangible, affectionate, and positive social interaction. Emotional support includes expression of love, empathy, understanding, and cares, whereas informational support involves providing advice, information, guidance, and feedback. Tangible support involves physical or behavioral assistance, for instance, helping patients prepare meals if they are unable to prepare. Affectionate support involves the love and affection provided

by others felt by the patients. Positive social interaction involves the availability of other people for social integration.

Emotional/informational support consists of 8-items, tangible support is composed of 4-items, affectionate support has 3-items, and positive interaction has 4-items. The items have five response choices from 1 to 5 (1 = None of the time, 2 = A little of time, 3 = Some of the time, 4 = Most of the time, and 5 = All of the time) (Sherbourne & Stewart, 1991). An observed score of the overall and domain-specific score was calculated and the observed score was transformed to into a 100-point scale: 100 *[(observed score – minimum possible score)/ (maximum possible score – minimum possible)] (Rand Health, n. d.). Therefore, the minimum possible score was 0 and the highest possible score was 400. A score 0-100 indicates poor support, 101-200 borderline support, 201- 300 fair support, and 301-400 good support (Szeto et al., 2008). The scale has high internal consistency with Cronbach's alpha coefficient of .97. In this present study, one more column to indicate the support person that is family, friends, health care personals, or peers was added (Appendix F).

Religiosity Assessment Scale (RAS). RAS was used to measure the religiosity of the ESRD patients receiving HD. This scale was developed by the researcher on the basis of previous questionnaires that were used to measure religiosity. In order to make the questionnaire fit to the cultural context of Nepal, the researcher developed RAS tool. RAS measured the religious practices and the religious beliefs of the participants. Religious practice was assessed using two items “I spend time in public religious events such as prayer groups, religious meetings” and “I spend time in personal religious activities such as prayer, meditation, listening to religious songs or

poetry about God, reading holy books, making promises '*bhakal', 'baitarni', 'lakh batti ballne'*." Religious belief was measured using the four items. They were "Because of God's will, I am adjusting well to end stage renal disease", "Because of God's will, I am adjusting well to hemodialysis", "I am suffering from end stage renal disease and have to undergo hemodialysis because God has punished me for my bad deeds" and "I believe God can help me and accepts me even with my faults." The response to the items was a 4 point Likert scale (1 = Strongly disagree, 2 = Disagree, 3 = Agree, and 4 = Strongly agree) (Appendix G). A higher score of the instrument indicated higher religiosity. The score obtained was interpreted using the formula (Maximum-Minimum/Number of category) (Grouped Frequency Distribution, n.d.). Therefore, the level of religiosity in the study was categorized as:

Low religiosity: 6-12

Moderate religiosity: 13-18

High religiosity: 19-24

Validity of the Instruments

The validity of the instruments is the extent to which an instrument measures what it is supposed to measure (Polit & Beck, 2012). The validity of the instruments was analyzed by panel of three experts (Appendix H). Two lecturers were from Prince of Songkla University and Boromarajonani College of Nursing Songkhla, Thailand. A lecturer from Prince of Songkla University (Faculty of Nursing) was an expert in research methodology with extensive experience in the field of research. Another lecturer from Boromarajonani College of Nursing Songkhla had experience of

conducting research related to spiritual facets. The third expert was a lecturer from Faculty of Nursing, Purbanchal University College of Medical and Allied Sciences, Nepal. The third lecturer also had experience in the field of research, medical surgical, caring for patients receiving HD, and the cultural context of Nepal. The changes in the instruments were made on the basis of the experts' opinion. The scale content validity (S-CVI) value of equal to greater than .80 is considered acceptable (Polit & Beck, 2012). In this study, S-CVI of PAS and RAS were calculated and the value of S-CVI of these tools were 1 and .80, respectively.

Reliability of the Instruments

The reliability of the instruments refers to the consistency of the measurement of the construct the instrument intends to measure (Polit & Beck, 2012). The reliability of the translated version questionnaire can be assessed by examining the internal consistency by conducting a pilot study among 15 to 30 patients (Radhakrishna, 2007). The pilot study was conducted in 20 ESRD patients receiving HD who met the inclusion criteria or those who had a homogeneous characteristic as the study population in Aarogya Foundation located in Kathmandu. Cronbach's alpha coefficient was calculated to determine the reliability of the instruments and Cronbach's alpha coefficient of greater than .70 is acceptable (Polit & Beck, 2012). Cronbach's alpha coefficients for the FAS, MOS-SS, RAS, and FACIT-Sp-12 were .72, .97, .84, and .79, respectively (Appendix I).

Translation of the Instruments

All instruments used in this study were originally developed in the English language. The questionnaire was translated into the Nepali version as the study population was Nepalese. Therefore, the back translation method purposed by Brislin (1980 as cited in Eremenco, Cella, & Arnold, 2005) was used for translation of the instruments.

For translation of the instruments, two bilingual translators and one bilingual reviewer who were fluent in both English and Nepali language and familiar with the cultural context of Nepal were selected (Appendix J). Firstly, instruments were translated into the Nepali version by the first translator who was a lecturer in a Nursing College. Then the second translator who was also a lecturer in Nursing College back translated the Nepali version of the questionnaire to English. Finally, both the translated Nepali version and the English versions (original and translated) of the instruments were reviewed by the third translator. The third translator was a Ph.D scholar with a health background. The changes in the questionnaire were done according to the comments from the third translator.

Data Collection Method

Data collection was conducted in two phases, preparation, and implementation. The phases of data collection are described below.

Preparation phase. The preparation phase of data collection involved obtaining ethical approval and permission, selecting the measurement tools and preparing the tools. This phase included the following steps.

1. Ethical approval was obtained from the Research Committee of Faculty of Nursing, Prince of Songkla University, Thailand, Nepal Health Research Council (NHRC) and National Kidney Center, Nepal.

2. Preparation of the required instruments such as translation of tools and informed consent was carried out.

3. Validity and reliability of the tools were tested. The translated Nepali version of the questionnaire was pretested in 20 participants who had similar characteristics as the study population.

Implementation phase. This phase involved recruitment of the respondents and data collection. This phase consisted of two parts, quantitative and qualitative data collection.

***Quantitative data collection*.** The following were the steps of quantitative data collection.

1. After receiving the ethical approval from the Research Committee of Faculty of Nursing, Prince of Songkla University, Thailand, and NHRC, Nepal, the researcher went to National Kidney Center and introduced herself to the Director, Nursing Director, and head nurse. The researcher explained the nature of the research and data collection procedure. Then permission for data collection was obtained.

2. The researcher went to different units of the National Kidney Center and requested the registered nephrology nurse to identify eligible participants and ask permission from the eligible patients to participate in the study.

3. After gaining permission from the patients, the researcher met the eligible participants with the help of the staff in the HD unit and introduced herself

and explained the objectives, benefits of the study and procedure of data collection. Then the participants were asked for a convenient time and place for data collection. Data collection was not done during the time of HD.

4. Before data collection, the researcher read and explained the informed consent until the participants understood. Then they were asked to sign the informed consent. A copy of the consent was provided to the participants and one copy was kept by the researcher.

5. After obtaining consent, the questionnaire was provided to the participants and the instructions to fill in the questionnaire were explained by the researcher. However, the researcher read and filled in the questionnaire for all the participants as they requested the researcher to do.

6. The researcher rechecked the questionnaire for completeness and reconfirmed the responses with the participants before leaving. If there were any missing answers then the researcher requested the missing information. Lastly, the researcher thanked the participants before leaving.

Qualitative data collection. The following steps were used to recruit the participants for qualitative data collection.

1. Participants who participated in providing information regarding quantitative data were asked whether they were interested in being interviwed to obtain qualitative data.

2. If the participants were interested then the researcher requested their phone number so that the researcher could make contact with the interested participants later on.

3. Those participants who were interested in being interviewed using open-ended questionnaire were listed.

4. Then the researcher called the participants to again request permission to participate in the interview using the open-ended questionnaire.

5. The researcher then selected 10 participants who were willing to participate. The participants and the researcher mutually decided the time and venue for the interview.

6. Before interviewing the participants the researcher asked permission to audio record each interview, the duration of interview was 20 to 30 minutes. A good relationship between the researcher and participant was maintained by carrying out socially acceptable behavior, clarifying the participant's doubt, and by talking in language that was easy to understand.

Ethical Consideration

Ethical consideration in this study was based on the ethical principles purposed by Polit and Beck (2012). These ethical principles consist of beneficence, respect for human dignity, and justice. In order to preserve human rights, data collection was conducted after obtaining permission from Research Ethics Committee of the Faculty of Nursing, Prince of Songkla University, Thailand and NHRC, in Nepal. Furthermore, permission for conducting the study from the National Kidney Center, Kathmandu was obtained (Appendix K). In addition, permission to use and translate the instruments in the study was obtained from the authorized person or organization (Appendix L). The ethical principle of beneficence refers to the

researchers' responsibility to maximize benefit and minimize harm during the study (Polit & Beck, 2012). In this study, participants were not exposed to any harm or discomfort and exploitation or damages. The information provided by the participants was not used against them.

The second ethical principle, respect for human dignity (Polit & Beck, 2012) was also maintained in this study. Full disclosure of the nature of the study such as the objectives, procedures, risks, and the benefits of the study were explained to the participants who met the inclusion criteria and willing to participate. Participants were not coerced to participate. Verbal and written informed consent was obtained from the participants (Appendix M). They were explained that they could withdraw from the study at any time during the study and assured that they would receive all the routine care offered by the hospital, even if they withdrew from the study. Patients were also allowed to ask questions.

The principle of justice incorporates a participant's right to fair treatment and privacy (Polit & Beck, 2012). Participants were treated fairly and were not discriminated. Confidentiality of the information was maintained using code numbers instead of the names of participants. The data obtained from the participants was only accessible to those people who worked on the study and those who made sure the study was conducted in the appropriate manner. Research data will be kept with the researcher for five years from the date of publication, after five years, the paper records will be shredded and recycled. The record stored on a computer hard drive will be erased using commercial software applications (Institutional Review Board for Social and Behavioral Sciences [IRB-SBS], 2012).

Data Analysis

Data analysis consisted of two parts, quantitative and qualitative data analysis. Quantitative data analysis was analyzed using descriptive and inferential statistics. Qualitative data obtained from the interview was analyzed using qualitative content analysis.

Data analysis of quantitative data. The following steps were included in quantitative data analysis.

1. Descriptive statistics were used to describe demographic data clinical data, the level of spiritual well-being, pain, fatigue, social support, religiosity, location and causes of pain. These data were shown in frequencies, percentages, mean, and standard deviations.

2. Inferential statistic (Pearson's Product Moment Correlation) was used to examine the relationship between spiritual well-being, pain, fatigue, religiosity, and social support. The predicting factor of spiritual well-being was also examined using inferential statistics (standard multiple regression). Before employing inferential statistics, the test assumptions of normality, linearity, homoscedasticity, multicollinearity, and non-autocorrelation were examined (Appendix N).

3. Assumptions of normality, linearity, homoscedasticity, multicollinearity, and non-autocorrelation were met. Therefore, the relationship between the variables was examined using Pearson's product moment correlation.

4. Standard multiple regression was employed to predict the variance of spiritual well-being by pain, fatigue, religiosity, and social support.

The tests of assumptions examined in the study are explained below:

Normality. The assumption of normality can be checked by the value of Skewness and Kurtosis, if the value lies between -3.29 and + 3.29 then the data has a normal distribution (Kim, 2013). The Skewness and Kurtosis of spiritual well-being, fatigue, social support, and religiosity were within the range of ± 3.29 (Appendix N). However, the value of study variable pain during HD and pain due to ESRD was not within the specified range. Transformation of the data can be performed for the skewed data (Tabachnick & Fidell, 2013). Thus, the researcher used the Log transformation of variables to improve the normality. After data transformation, the Skewness and Kurtosis were within the acceptable range.

Linearity. The assumption of linearity was examined by visual inspection of the scatter plot. The overall shape of the scatter plot should be rectangular if the assumption of linearity is met (Tabachnick & Fidell, 2013). The assumption in the present study is met as the scatterplot showed a rectangular shape (Appendix N).

Homoscedasticity. Homoscedasticity is the assumption that the standard errors of the dependent variable exhibit a similar amount of variance across the independent variables. The assumption of homoscedasticity will not be met if the band becomes wider at larger predicted values (Tabachnick & Fidell, 2013). This assumption was also examined using scatter plot (Appendix N).

Multicollinearity. The assumption of Multicollinearity was examined by testing tolerance and variance inflation factor (VIF). The tolerance values less than .10 or a VIF values more than 10 is considered having problem of multicollinearity (Statistics solutions, 2017). The assumption in the present study was met as the tolerance values were more than .01 and VIF values were less than 10.

Autocorrelation. The value of The Durbin-Watson statistics for correlation should be 1.5 to 2.5 for the absence of autocorrelation (Statistics solutions, 2017). In the present study, the value was 1.94 indicating no autocorrelation.

Data analysis of qualitative data. Qualitative content analysis was conducted to analyze the data obtained from the interview guide. Qualitative content analysis is the analysis of the narrative data to identify themes or patterns through coding (Polit & Beck, 2008). Before conducting qualitative content analysis, the tape recordings of the interview were transcribed verbatim into the text. The interview was conducted in the Nepali language; therefore, the transcripts were transcribed in Nepali by the researcher who conducted the interview. Qualitative content analysis was performed as follows:

1. Breaking down data smaller units: the transcripts were read repeatedly until sense of whole was obtained. The data was read word by word carefully and the exact words of the text that appear to capture key thoughts or concepts were highlighted. Names were then given to the units that emerged.

2. Grouping units based on the shared concepts: the units were then categorized into groups of content based on the commonality they share. Then subthemes and themes were developed from the codes based on how different codes were related and linked. The themes and subthemes were confirmed with the advisors.

Chapter 4

Results and Discussions

This study was conducted with an objective to find the predicting factors of spiritual well-being among 100 participants who were suffering from ESRD and receiving HD. This chapter contains the results of the study and discussions.

Results

The results of the study are depicted into demographic characteristics, clinical data of the participants, causes and location of pain due to ESRD and during HD treatment, level of study variables (spiritual well-being, pain, fatigue, social support, and religiosity), their relationship and predictive value of the study variables.

Demographic characteristics of the participants. The participants in the study were between the ages of 18 and 78 years (M = 40.65, SD = 13.72) and nearly half of the participants (44%) fell under the age group of younger adults. The highest percentage (63%) of participants was male. About two thirds of the participants were Hindu (72%) and married (72%). Twenty-four percent of the participants had completed secondary level education. Regarding the occupation, 76% of the participants were unemployed. Thirty-nine percent of the participants had a monthly family income of 10,000 to 30,000 Nepalese Rupees (NPR) (approx. 1NPR = 103 US dollars) and about two-thirds (67%) reported that their monthly family income was inadequate. The demographic characteristics of the participants are shown in Table 3.

Table 3

Frequency and Percentage of Demographic Characteristics of the Participants (N = 100)

Characteristics	*N*	%
Age		
Younger adults (18 to 35 years)	44	44.00
Middle aged (36 to 55 years	40	40.00
Older adults (> 55 years)	16	16.00
M = 40.56 *SD* = 13.72 Min = 18 Max = 78		
Gender	63	63.00
Male	37	37.00
Female		
Religion		
Hindu	72	72.00
Buddhist	20	20.00
Christian	8	8.00
Marital status		
Married	72	72.00
Unmarried	22	22.00
Widow/widower	3	3.00
Divorced	2	2.00
Separated	1	1.00
Level of education		
No formal education	18	18.00
Primary	13	13.00
Lower secondary	15	15.00
Secondary	24	24.00
Higher secondary	14	14.00
University	16	16.00
Occupation		
Unemployed	76	76.00
Housewife	8	8.00
Business	5	5.00
Agriculture	2	2.00
Student	1	1.00
Others (Teacher, Engineer, Lawyer, Policeman, Singer)	8	8.00

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

Table 3 (continued)

Characteristics	*n*	%
Monthly family income		
< NPR 10,000	25	25.00
NPR 10,001 to 30,000	48	48.00
NPR 30,001 to 50,000	20	20.00
>NPR 50,001	7	7.00
Min = NPR 1,000 Max = NPR 2,00,000		
Mdn = 15,000		
Monthly family income adequate		
Yes	33	33.00
No	67	67.00

Note. Min = Minimum, Max = Maximum, *Mdn* = Median, NPR = Nepalese Rupees, 1 NPR = 103 USD

Clinical data of the participants. Around two-thirds of the participants (61%) were diagnosed with renal disease for ≤ 3 years and majority (76%) had received HD for three months to three years. Most of the participants (82%) did HD twice a week and the majority of the participants (83%) reported having comorbidities. Hypertension was reported by 92.8% of the participants as their comorbidity. The clinical data of the participants is illustrated in Table 4.

Table 4

Frequency and Percentage of Clinical Data of the Participants (*N* = 100)

Clinical data	*n*	%
Duration diagnosed with renal disease (years)		
≤ 3	61	61.00
4 – 6	23	23.00
≥ 7	16	16.00
Min = 3months Max = 15 years *Mdn* = 3 years		
Duration receiving hemodialysis (years)		
3months – 3 years	76	76.00
4years – 6 years	18	18.00
≥ 7 years	6	6.00
Min = 3months Max = 10 years *Mdn* = 2 years		
Frequency of hemodialysis (per week)		
2	82	82.00
3	18	18.00
Have comorbidities		
Yes	83	83.00
No	17	17.00
Comorbidities (n^a = 83)		
Hypertension	77	77.00
Diabetes Mellitus	21	21.00
Heart disease	7	7.00
Hyperparathyroidism	1	1.00
Other diseases (cholelithiasis, gout, prostate cancer, lymph node tuberculosis)	9	9.00

Note. Min = Minimum, Max = Maximum, *Mdn* = Median, [a] comorbidities is multiple responses

The level of the study variables. Five variables (pain, fatigue, social support, religiosity, and spiritual well-being) were studied in this present study. The level of spiritual well-being of the participants was moderate (*M* = 22.44, *SD* = 10.62). Both pains, during HD treatment and due to ESRD were mild with a mean of 2.82 (*SD* = 2.76) and 2.06 (*SD* = 2.68) respectively. The mean of fatigue was 24.47

(*SD* = 5.78) and the level was fatigued. Participants had fair social support (*M* = 286.96, *SD* = 106.89). The religiosity of the participants was moderate level (*M* =15.07, *SD* = 4.58). The descriptive statistics of the study are displayed in Table 5.

Table 5

Possible Score, Minimum, Maximum, Mean, Standard Deviation, and Level of the Study Variables (N =100)

Variables	Possible score	Min-Max	*M*	*SD*	Level
Spiritual well-being	0-48	0-47	22.44	10.62	Moderate
Pain during hemodialysis	0-10	0-10	2.82	2.76	Mild
Pain due to end stage renal disease	0-10	0-10	2.06	2.68	Mild
Fatigue	10-50	13-38	24.47	5.78	Fatigued
Social support	0-400	18-400	286.96	106.89	Fair
Religiosity	6-24	6-24	15.07	4.58	Moderate

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

The relationship between the study variables. The relationship was analyzed using Pearson correlation as the assumptions of normality, linearity, and homoscedasticity were met. Pearson correlation analysis showed a significant positive relationship between social support ($r = .28$, $p < .01$), religiosity ($r = .24$, $p < .05$) and spiritual well-being. On the contrary, the correlations of fatigue and spiritual well-being were inversely related ($r = -.32$, $p < .01$). However, the relationship between

pain and spiritual well-being was not depicted. The relationship between the study variables is illustrated in Table 6.

Table 6

Pearson's Correlation Coefficient Between Pain, Fatigue, Social Support, Religiosity and Spiritual Well-Being (N = 100)

Variables	1	2	3	4	5	6
1. Pain during hemodialysis	1					
2. Pain due to end stage renal disease	.32**	1				
3. Fatigue	.24*	.28**	1			
4. Social support	-.12	-.20*	-.27**	1		
5. Religiosity	-.11	.05	-.15	-.07	1	
6. Spiritual well-being	-.11	-.08	-.32**	.28**	.24*	1

Note. $*p < .05$ $**p < .01$

Predictive value of pain, fatigue, social support, and religiosity on spiritual well-being in patients receiving hemodialysis treatment. The variables under study, pain (due to HD and ESRD), fatigue, social support, and religiosity were entered into the standard multiple regression (Table 7). From the analysis, it was revealed that 19.7% ($R^2 = .197$) of the variance in the spiritual well-being of the patients receiving HD was due to the study variables. Fatigue ($\beta = -.23$, $p = .02$), social support ($\beta = .23$, $p = .01$), and religiosity ($\beta = .22$, $p = .02$) were the variables that could statistically predict the spiritual well-being in patients receiving HD. Using

the information of regression analysis, the multiple regression equation for this study is:

R^2 Spiritual well-being = 16.31 + (-.19) (Pain HD) + (.60) (Pain ESRD) + (-.42) (Fatigue) + (.12) (Social support) + (.51) (Religiosity)

Table 7

Standard Multiple Regression Analysis Predicting Spiritual Well-being in Patients Receiving Hemodialysis Treatment

Variables	*B*	*SE*	β	*t*	Sig
Pain during Hemodialysis	-.19	3.02	-.006	-.06	.94
Pain due to ESRD	.60	2.89	.021	.21	.83
Fatigue	-.42	.18	-.23	-2.28	.02*
Social support	.12	.05	.23	2.43	.01*
Religiosity	.51	.22	.22	2.33	.02*
Constant = 16.31	R = .44		R^2 = .197		F = 4.61
SE = 9.76	R^2_{adj} = .15		*a* = 16.31		*(p < .05)

Discussions

The discussion of the study comprises demographic data, clinical data of the participants, the level of spiritual well-being, the relationship between the pain, fatigue, social support, religiosity, and spiritual well-being, and predicting factors of spiritual well-being.

Demographic characteristics. In the study, 100 patients receiving HD in National Kidney Center participated. The mean age of participants was 40.56

(*SD* = 13.72) and age ranged between 18 to 78 years old. The age of the participants was comparable with another study conducted in Nepal by Chhetri et al. (2009). The mean age of the participants in the study was 42.33 (*SD* = 15) and age ranged between 18 and 74 years. However, the mean age of the participants receiving HD in the present study was relatively younger in comparison with other developing and developed countries. For example, the mean age of patients receiving HD in Egypt was 51.34 (Ahmed, Yassine, Tawafe, & Ebazaway, 2015); the USA 64.7 (USRD, 2015), and the median age in the UK 67 (MacNeill, Casula, Shaw, & Castledine, 2016). Several factors might have contributed to the loss of timely preventive measures leading to decreased mean age such as, poor availability of healthcare due to the rural nature of the population, the difficulty of transportation (Hirachan et al., 2010) and lack of health education (Hada et al., 2009).

More than half of the participants (63%) in the study were male. Various factors might contribute to the development of ESRD in males compared to females. The previous study reported the progression rate of renal disease in males is comparatively faster than in females (Kummer, von Gersdorff, Kemper, & Oh, 2012). Furthermore, there are lifestyle differences between males and females, males usually consume a high protein and high calorie diet (Goldberg & Krause, 2016). Increased level of low-density lipoprotein (LDL), triglyceride and low levels of high-density lipoprotein are related to the progression of renal disease (Kummer et al., 2012). The result of the present study regarding the percentage of males is approximately similar to previous studies for instance 65% (Mishra & Koirala, 2015; Reig-Ferrer et al.,

2012), 64% (Ghimire, Pahari, Das, & Das, 2015), 62% (Martinez & Custodio, 2014), and 60.4% (Eslami et al., 2014).

Seventy-two percent of the participants followed Hindu religion in the present study. This result is not surprising as most of the Nepalese people are Hindu (Central Bureau of Statistics, 2014). The result of the present study resembles the finding of the study conducted in Nepal by Sapkota, Sedhain, and Rai (2013) in which it reported that 79% of the study participants were Hindu followed by Buddhist. More than half of the participants (72%) in the study were married which was similar to other studies (Ghimire, Neupane & Haque, 2016; Eslami et al., 2014; Sapkota, Sedhain, & Rai, 2013).

Regarding education, the majority of the participants (82%) had obtained a formal education from school and the level of education achieved was highest at the secondary level. This finding is similar to the study conducted in Nepal by Sapkota et al. (2013) in which it was 88.7%. Around two-thirds of the participants (67%) in the present study reported that their monthly family income was not sufficient. The majority (84%) of the participants falls under the working age group; however, only 15% of participants in the present study were employed. This might have contributed to a decrease in the economic level of the family.

Clinical data of the participants. More than half of the participants (61%) have been diagnosed with the renal disease for three months to three years. Various factors might have played role in seeking late medical attention. A study undertook in Nepal revealed 85% of the patients were not aware of kidney disease and its treatment (Chhetri et al., 2009). Similarly, qualitative data in the present study revealed that four

participants mentioned they had a lack of information regarding kidney disease and HD. One participant said, *"I did not know much about HD and I have not seen any people doing HD"* [P4]. As the people are unaware of the disease there is a decrease in health information seeking behavior and they will suffer from various complications due to lack of information about progression and prevention of diseases (Lalazaryan & Zare-Farashbandi, 2014). Similarly, decreased health information may lead to late diagnosis of kidney disease as people are not aware about the disease and when diagnosed, they have advanced stages of CKD accompanied by uremic complications. In addition, other factors such as lack of health education, low socioeconomic condition, and inadequate referral to the central hospital (Hada et al., 2009) might have resulted in the decreased health seeking behavior of participants.

Regarding the duration of receiving HD treatment, majority of the participants (76%) had received HD treatment for ≤ 3 years. However, only 6% of them received treatment for ≥ 7 years. Various causes might have contributed to shorter duration of HD treatment. Most of the centers that provide HD services are located in the capital city and are not accessible to the majority of the Nepalese population. Furthermore, access to dialysis centers may be difficult due to the lack of transportation facilities and rural residence of the population. In addition, it might be difficult for the patients to continue treatment due to financial constraints (Hirachan et al., 2010).

Additionally, there might be increased mortality and morbidity due to the inadequacy of the HD treatment that may lead to decrease in the duration of the HD treatment. A study conducted by Manadhar, Chhetri, Tiwari, and Lamichhane (2009) reported dialysis treatment was not adequate for those Nepalese patients who receive

HD treatment for twice a week. In the present study, the majority of participants (82%) received HD treatment twice a week. Therefore, the HD may be inadequate for the participants in the present study. Increased hospitalization, hospital days, and inpatient expenses were related to the inadequacy of HD (Sehgal, Dor, & Tsai, 2001).

Regarding the comorbidities of the participants, hypertension was present in 77% of the patients followed by diabetes mellitus. In a similar way, Sapkota et al. (2013) also reported hypertension as the most prevalent comorbidity present in patients receiving HD. This result is not surprising as hypertension was a leading cause for developing ESRD in Nepalese patients followed by diabetes mellitus (Chhetri et al., 2009).

The level of spiritual well-being. The level of spiritual well-being in the study was moderate with a mean of 22.44 (*SD* = 10.62) (Table 5). The patients receiving HD continually suffered from various problems, for instance, restriction in food and fluid, loss of job, frequent hospital admission, increased dependency, disturbed sleep, fatigue, uncertain about the future, change in lifestyle, and limitation of physical activities (Gerogianni & Babatsikou 2013). In the present study, two-thirds of the participants had reported that their monthly family income was not sufficient, they were fatigued, and the majority (83%) had comorbidities. Additionally, more than half of the participants reported pain due to ESRD and HD (Table 12 and 13). In addition, the open ended questionnaire in the study also revealed that the participants had to face many problems due to ESRD and HD, such as inability to accomplish their objectives in life, restrictions in consumption of food and drink, emotional distress, and decline in their economic status. One participant

expressed his decreased economic status: *"I spend all my money that I have earned and even sold my lands."* [P6]

When an individual encounters with various stressors there is a crisis in personal meaning (Bulkley et al., 2013). Patients those who suffer from different stressors feel hopelessness which will lead to difficulty in finding meaning and purpose in life (Alshraifeen, 2015). This will result in negative impacts on spiritual well-being (Bulkely et al., 2013; Promkaewngam et al., 2014; Get-Kong et al., 2010). In the present study, participants expressed their inability to achieve their objectives in life, one participant said, *"Even though, I have the capacity and caliber I could not achieve what I am capable of in my life."* [P8] Similarly, difficulty in finding aims in life was stated by one participant said, *"There is no purpose in my life. I am not confident about my health."* [P3]

The level of the spiritual well-being in the present study was similar with other studies conducted among patients receiving HD. For instance, a moderate level of spiritual well-being was reported by two studies conducted in Iran among 72 (Ebrahimi et al., 2014) and 190 patients (Eslami et al., 2014) receiving HD. In addition, low level of spiritual well-being was reported by the study conducted by Reig-Ferre et al. (2012) among 94 patients receiving HD in Spain.

The relationship between the pain, fatigue, social support, religiosity, and spiritual well-being. In the present study, the relationship between the study variables were examined by using Pearson correlation and the result revealed no significant relationship between spiritual well-being and pain. However, there was a weak ($r = .28$, $p < .01$), but significant relationship between spiritual well-being and

social support. Similarly, a weak ($r = .24$, $p < .05$,) but significant correlation was observed between spiritual well-being and religiosity. Furthermore, a moderate ($r = -.32$, $p < .01$) and negative correlation between spiritual well-being and fatigue was demonstrated in the present study (Table 6).

The relationship between pain and spiritual well-being. The results of the study demonstrated no relationship between the spiritual well-being and pain. Various factors such as sex, culture, and religion might have influenced the experience of pain in the present study. Increased pain sensitivity and risk for clinical pain is noticed more among females as compared to males. This difference may be due to differences between pain coping strategies, and stereotypical gender roles between males and females. The pain coping among males use problem focused strategies whereas females tend to use emotion focused strategies (Bartley & Fillingim, 2013). In Nepalese culture, the stereotypical gender roles for males are, for instance, they should be strong, earn an income and should care for the family (Care, 2015). Therefore, males should not cry and express their pain, if they feel pain then they should suppress inside.

As the majority of the participants were males, their culture might have swayed their experience of pain. In the present study two-thirds of the participants were male. In addition, culture determines how pain is perceived, experienced, and communicated by an individual (Peacock & Patel, 2008). Furthermore, the majority of the participants followed the Hindu religion and consequently the beliefs and traditions of Hindu religion also might have influenced the experience of pain. Hindu religion promotes acceptance of pain as just the work of *Karma* (the principle that

guides the unfolding of incidents that is based on his/her previous lived lives) (Whitman, 2007).

In addition, a study conducted by Yodchai et al. (2014) reported that patients receiving HD get used to their pain (due to kidney disease and treatment) and eventually accept it as part of their lives. Similarly, in the present study, participants discussed the importance of accepting the problem as one participant stated, *"If we do not accept the problem and stick with the problem then the problem will be bigger."* [P1] Furthermore, in the present study, the pain experienced by the participants was mild (Table 5). Hence, participants in the present study might have accepted mild pain as a part of their lives, thus, yielding in no relationship between spiritual well-being and pain.

Previous studies mentioned continuous pain lead to a feeling of hopelessness and felt their lives was not worth continuing or lost their meaning in life (Jones et al., 2003). On the other hand, a study conducted by Kharame et al. (2014) among patients receiving HD revealed a significant positive relationship between spiritual well-being and pain. However, correlation between the spiritual well-being and pain was not observed in the present study.

The relationship between fatigue and spiritual well-being. A negative relationship between the spiritual well-being and fatigue was seen in the present study. Fatigue has a negative impact on spiritual well-being (Lewis et al., 2014). Spiritual well-being refers to the capacity of human beings to hold a sense of meaning and purpose in life (Fukui et al., 2012). However, patients receiving HD have difficulty in performing simple daily activities such as walking upstairs and doing

household chores due to fatigue (Horigan et al., 2013). The restrictions in physical activities due to fatigue can affect their self-care abilities, employment activities and social performance (Biniaz, Tayybi, Nemati, Shermeh, & Ebadi, 2013).

Similarly, in the present study, 76% of participants were unemployed and participants expressed the feeling of being a burden to their family. Inability to perform daily activities was expressed by one participant: *"We cannot do our activities as normal people...I am not able to walk step and it is difficult to go upstairs...I am easily fatigued."* [P6] Being jobless and unable to perform their daily activities will develop the feeling of low self-esteem and demoralization (Gerogianni & Babatsikou, 2013) that may decrease the sense of meaning and purpose in life.

The relationship between spiritual well-being and fatigue aligns with prior research studies. Previous studies undertaken in cancer patients also reported a significant inverse relationship between fatigue and spiritual well-being (Lewis et al., 2014; Rabow & Knish, 2015). However, the result contrasts with the study undertaken by Ebrahimi et al. (2014) in patients receiving HD. This study reported the positive correlation between the fatigue and existential well-being which is one dimension of spiritual well-being.

The relationship between social support and spiritual well-being. The study revealed a significant positive relationship between spiritual well-being and social support. Increased social support has different positive impacts such as a decrease in the level of depression, increase in patient's perception of QOL, and enhance the immune system (Kannan, 2016). On the other hand, patients who lack social support tend to blame themselves for the event, and are angry, withdrawal, or depressed

(Tezel et al., 2011). Furthermore, social support helped an individual to cope with problems that occurred due to disease and enabled them to adapt to treatment that lead to satisfaction in their life (Silva et al., 2016). A higher level of social support was also correlated with increased survival in patients receiving HD (Spinale et al., 2008). In the present study, the qualitative data of participants revealed that support from their family and friends helped them to overcome their frustration and enhance their self-esteem. Married patients receiving HD had higher social support compared to single patients (Sarıtaş & Işık, 2016). In the present study, the majority of the participants might have obtained necessary social support as 72% of them were married. Hence, the relationship between social support and spiritual well-being might have been observed. The positive relationship between spiritual well-being and social support was also demonstrated in previous studies (Ebrahimi et al., 2014; kharame et al., 2014; Sittipran et al., 2007).

The relationship between religiosity and spiritual well-being. The study revealed a positive relationship between religiosity and spiritual well-being. Religiosity is used as a source of strength, is related to decreased depressive symptoms, and increased QOL (Lucchetti et al., 2012) and is used as a coping strategy (Green, Emery, Kozora, Diaz, & Make, 2011; Lucchetti et al., 2012). Religious practice, which is one dimension of religiosity, was used as the most common method of religious coping strategy (Green et al., 2011). Religiosity can be considered one way through which an individual can make sense of their life (Chokkanathan, 2013). Previous studies reported the relationship between religiosity and enhanced spiritual well-being (Taheri-Kharameh, 2016; Tanyi & Werner, 2003).

The open-ended questionnaire interview in the present study expressed that the participants accepted their disease condition and HD treatment and had made sense of their lives. In addition, participants in the present study reported use of religious practices to enhance their self esteem. One participant said, "*I engage myself in religious activities, I listen to songs and talks related to God. I participate in Satsang* [gathering]. *All these activities have helped me to control my emotions and to enhance my will power."* [P1] Religion is deemed one essential element of Nepalese society and the daily life of the Nepalese people (Yadav, 2015). They worship, make promises and attend rituals related to religion for protection, to relieve stress, and for future comfort (Wasti, 2011). Therefore, the relationship between spiritual well-being and religiosity may be depicted in the present study. A study undertaken by Reig-Ferrer (2012) among HD patients also reported a significant relationship between spiritual well-being and religiosity.

Predictive factors of spiritual well-being. In the present study, multiple regression analysis revealed fatigue, social support, and religiosity as statistically significant contributing factors for spiritual well-being. These factors explained the variant of spiritual well-being with 19.7% (R^2 = .197). To the researcher's best knowledge there are paucity of studies that have been undertaken to examine the predicting values of fatigue, social support, and religiosity on spiritual well-being in patients receiving HD. Therefore, the discussion references other studies conducted in other populations in the following paragraph.

Fatigue is one common problem that develops in patients receiving HD (Sakkas & Karatzaferi, 2012). The study undertaken by McCann and Boore (2000)

reported whenever patients receiving HD are fatigued, they limit their activities. The patients suffering from physical symptoms, decrease in their capacity of self-reflection, and restrict their engagement in activities that provide a sense of meaning and purpose (Lo et al., 2011). Inability to engage in the activities was reported by one patient as, *"We even cannot walk a short distance due to fatigue, just forget about doing job."* [P7] The current study validated the study conducted among patients receiving active cancer treatment by Lewis et al. (2014) which reported fatigue as a negative predicting factor of spiritual well-being.

Social support is a modifiable factor that has a number of positive effects on patients receiving HD such as they have decreased level of depression, increased perception of QOL, and increased compliance with treatment regimen (Cohen et al., 2007). Social support enhances the ability to rely on and trust other persons and will help to increase their level of spiritual well-being (Lo et al., 2011). A study undertaken by Sittipran (2007) among HIV-infected patients revealed social support as predicting factor for spiritual well-being which is consistent with the present study. The qualitative data of the present study also revealed that the social support obtained had helped participants to overcome the frustration and enhance their self-esteem. One participant said, *"I got help from my friends and family then I was able to boost my spirit...come out of frustration and make my heart happy...I am happy. The main role is played by a family."* [P1]

Furthermore, the present study confirmed religiosity as one contributing factor of spiritual well-being. Religious belief, which is one dimension of religiosity, may help the patient to develop a sense of meaning in their illness and provide hope for

better days (Al Zaben et al., 2015). Similarly, religious belief helped patients receiving HD to understand the reason for developing kidney disease (Yodchai et al., 2016). In the present study, all participants followed a religion and 72% of them followed the Hindu religion. Hindu religion promotes acceptance (Whitman, 2007), this may help the participants to accept their disease condition. In addition, open ended questions revealed that religious activities helped the participants to enhance their self esteem. One participant said, *"Religious activities have helped me to control my emotions and to enhance my will power."* [P1] The results of the study resembled the study undertaken by Lo et al (2011) in cancer patients which reported religiosity as a predictive factor of spiritual well-being.

To sum up, the predicting factors of spiritual well-being among Nepalese patients with ESRD receiving HD were fatigue, social support, and religiosity. Social support enhanced spiritual well-being by decreasing frustration and increasing self-esteem. Similarly, religiosity was used as coping strategy to relieve suffering aided in increasing spiritual well-being. However, fatigue hindered spiritual well-being as patients receiving HD had difficulty in participating in activities that provided meaning and purpose in life.

Chapter 5

Conclusion and Recommendations

This chapter comprises conclusion, strengths, limitations, and recommendations of this study.

Conclusion of the Study

This was a cross-sectional study conducted in National Kidney Center, Nepal with the aim to explore the predictive factors of the spiritual well-being of patients suffering from ESRD receiving HD. Total 100 samples were recruited in the study using purposive sampling technique. Information regarding the demographic and clinical data of the participants was collected using the Patient Data Form (PDF). Data related to pain, fatigue, social support, and spiritual well-being were collected using the Pain Assessment Scale (PAS), Fatigue Assessment Scale (FAS), Medical Outcomes Study Social Support Survey (MOS-SS), Religiosity Assessment Scale (RAS), and Spiritual Well-Being Assessment Tool (SWBAT), respectively.

The SWBAT consists of two parts including part I: FACIT-Sp-12 (12-Item Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being) and part II: Interview Guide. Qualitative data using the interview guide was obtained from 10 participants to gain deep understanding of spiritual well-being. The questionnaires were validated by three experts and the reliability was examined in 20 patients who met the inclusion criteria of the study at Aarogya Foundation, Nepal. Cronbach's alpha coefficient of FAS, MOS-SS, RAS, and FACIT-Sp-12 were .72, .97, .84, and .79, respectively.

The quantitative data were analyzed using descriptive and inferential statistics and content analysis was done for the qualitative data. The data met the assumption of normality, linearity, and homogeneity, therefore, Pearson correlation was used to examine the relationship between the study variables. The mean age of the participants was 40.56 (*SD* = 13.72) and majority were male. Results revealed moderate level of spiritual well-being. In addition, the results of the analysis demonstrated a significant negative relationship between spiritual well-being and fatigue. On the other hand, there was a significant positive relationship between spiritual well-being, religiosity, and social support.

However, results revealed no relationship between spiritual well-being and pain. Furthermore, in order to identify the predictive value of the variables standard multiple regression was performed, which explained the 19.7% variance in spiritual well-being. Results divulged fatigue (β = -.23, *p* = .02), social support (β = .23, *p* = .01), and religiosity (β = .22, *p* = .02) as the variables that could statistically predict the spiritual well-being in patients receiving HD. The qualitative data revealed that the participants meaning and purpose in life changed after being diagnosed with ESRD and undergoing HD treatment.

Strengths of the Study

The following are the strengths of the study.

1. All the instruments used in this study have acceptable value of Cronbach's alpha coefficients. The religiosity scale used in the present study was appropriate according to Nepalese context as the instrument was developed by the researcher after

reviewing the previous instruments. In addition, S-CVI and Cronbach's alpha coefficients of instrument that measured religiosity were also at acceptable value.

2. This study was conducted at National Kidney Center in Kathmandu, which serves as the national referral center for HD. Hence, patients from different parts of Nepal participated.

Limitations of the Study

This study also has various limitations;

1. The generalization of the study findings might be impacted as the participants were recruited purposively from only one center. However, the center where the study was conducted is the largest center which provides HD service and participants were from different parts of Nepal.

2. In the present study, only the physical symptom burden that is pain and fatigue was addressed. However, other psychological stressors such as anxiety, depression, and sleep disturbance were not included.

3. Pain during HD and due to ESRD of past one month was measured. Therefore, there is possibility of recall bias.

Recommendations

The findings of the study would be useful for nursing education, future nursing research and for the development of nursing practices and to formulate guidelines for providing nursing care regarding spiritual well-being.

Nursing practice.

1. Fatigue is one common and devastating physical symptom experienced by patients suffering from ESRD receiving HD. The results of this study demonstrated fatigue as one negative predictive factor of spiritual well-being. Hence, to enhance the spiritual well-being of the patients receiving HD, nurses should plan and implement interventions that decrease the fatigue.

2. The study provided evidence that religiosity was a positive predictor of the spiritual well-being of the participants. Hence, nurses should incorporate the interventions that enhance the religiosity while providing nursing care. For instance, every nurse should respect patients' religious beliefs, assess their religious needs, and imply the religious activities related that enhances religiosity.

3. The study showed social support as a positive significant predictor of spiritual well-being and majority of the participants in the study obtained social support from their family members. Therefore, nurses should involve the family members while providing care to the patients. In addition, nurses should maintain good communication and cooperation with the family members.

Nursing education.

In order to improve the spiritual well-being of the ESRD patients receiving HD, nursing students and nurse should be educated regarding measures to enhance social support and religiosity and decrease fatigue.

Nursing research.

1. Present study revealed fatigue, social support, and religiosity as the predicting factors of spiritual well-being in patients suffering from ESRD receiving HD. Therefore, an interventional study with regards to aforementioned factors can be conducted to enhance spiritual well-being.

2. The present study was conducted in only one setting. Therefore, it is suggested future studies be conducted in different settings such as government hospitals and non-government health care centers and in a large number of health care centers.

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APPENDICES

APPENDIX A

Sample Size Estimation

The sample size estimation for the study was determined by the power analysis. The number of respondents for multiple regression was estimated as a function of effect size, the number of predictors, desired power, and significance criterion. According to Polit and Beck (2008), the formula to calculate sample size for multiple regression is:

$$N = L / \gamma + \kappa + 1$$

Where,

N = estimated number of the subjects needed

L = tabled value for the desired α and power

γ = estimated effect size

κ = number of predictors

The value of estimated effect size (γ) is calculated as:

$$\gamma = R^2/1- R^2$$

The previous study by Sittipran (2007) among people living with HIV infection result in R^2 value of .246 at the level of significant criterion (α) = .05 and the power of the test = .90.

Hence, the value of estimated effect size $\gamma = R^2/1- R^2$

Therefore,

$$\gamma = .246/1-.246$$

$$= 0.31$$

From the power analysis table 23.4, the value of L is 11.94 (Polit & Beck, 2008).

So, the total number of sample is calculated as,

$$N = L / \gamma + \kappa + 1$$

$$= 11.94/0.31 + 4 + 1$$

$$= 43.51$$

However, for the study, the effect size was reduced to moderate, R^2 = .13, as the study population of the previous study was different from the current study.

Therefore, the value of γ was:

$$\gamma = R^2/1- R^2$$

$$= .13/1-.13$$

$$= 0.14$$

Finally, the sample size for the study was:

$$N = L / \gamma + \kappa + 1$$

$$= 11.94/.14 + 4 + 1$$

$$= 90.28$$

As a result, the final sample size of the study was 91. However, in the study, the participants up to 100 were included.

APPENDIX B

Patient Data Form

Code No: _____ **Date of data collection**: _____

The questionnaire consists of two sections: Section A (Demographic Data) and Section B (Clinical Data).

Instruction: Please give the cross mark (X) in the box suitable to your answer where indicated and fill in the blank.

Section A: Demographic Data

1. Age :_____ years
2. Gender:

   ☐ Male ☐ Female

3. Religion:

   ☐ Hindu

   ☐ Buddhist

   ☐ Christian

   ☐ Muslim

   Others (please specify)_____

4. Marital status

   ☐ Married

   ☐ Single

   ☐ Divorced

   ☐ Separated

   ☐ Widow/Widower

5. Education Level:

- ☐ No formal education
- ☐ Primary level
- ☐ Lower secondary
- ☐ Secondary level
- ☐ Higher secondary level
- ☐ University

6. Occupation:

- ☐ Student
- ☐ Housewife
- ☐ Agriculture
- ☐ Business
- ☐ Unemployed
- Others (please specify)_____

7. Monthly family income: _____ Rupees

8. Way of medical payment (multiple response):

- ☐ Self payment
- ☐ Total reimbursement
- ☐ Partial reimbursement
- ☐ Government support
- Others (please specify)_____

Section B: Clinical Data

1. Month (s) diagnosed with renal disease: _____
2. How long have you been on hemodialysis? _____ year _____months
3. How often do you receive HD per week? _____
4. Do you have co-morbidities:

   ☐ Yes

   ☐ No

4.1. If yes, please put (X) sign in the co-morbidity or co-morbidities you have (multiple responses)

   ☐ Diabetes mellitus

   ☐ Hypertension

   ☐ Hyperparathyroidism

   ☐ Chronic glomerulonephritis

   ☐ Heart disease

   Others (please specify) _____

APPENDIX C

Spiritual Well-Being Assessment Tool (SWBAT)

SWBAT will measure the spiritual well-being and consists two parts: Part I (FACIT-Sp-12) and Part II (Interview Guide)

Part I: 12-Item Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale (FACIT-Sp-12)

Direction: Below is a list of statements that other people with your illness have said are important**. Please circle or mark one number per line to indicate your response as it applies to the past 7 days.**

0 = Not at all
1 = A little bit
2 = Somewhat
3 = Quite a bit
4 = Very much

Items	Not at all	A little bit	Some what	Quite a bit	Very much
1. I feel peaceful	0	1	2	3	4
2. I have a reason for living	0	1	2	3	4
3. My life has been productive	0	1	2	3	4
4. I have trouble feeling peace of mind	0	1	2	3	4
5. I feel a sense of purpose in my life	0	1	2	3	4
6. I am able to reach down into myself for comfort	0	1	2	3	4
7. I feel a sense of harmony within myself	0	1	2	3	4
8. My life lacks meaning and purpose	0	1	2	3	4
9. I find comfort in my faith or spiritual beliefs	0	1	2	3	4

Items	Not at all	A little bit	Some what	Quite a bit	Very much
10. I find strength in my faith or spiritual beliefs	0	1	2	3	4
11. My illness has strengthened my faith or spiritual beliefs	0	1	2	3	4
12. I know that whatever happens with my illness, things will be okay	0	1	2	3	4

Part II: Interview Guide

1. Can you tell me about the sense of meaning and purpose of your life after being diagnosed with ESRD?
2. Has HD affected your sense of purpose and meaning in life?" If yes how/ if no why?
3. After being diagnosed with ESRD, how difficult is it for you to find peace and harmony?
4. Can you explain whether the HD treatment has brought peace and sense of harmony within you?
5. Has ESRD and HD affected your faith of whatever happens everything will be fine? If yes how/ if no why?
6. Is there anything else that you would like to share with me?

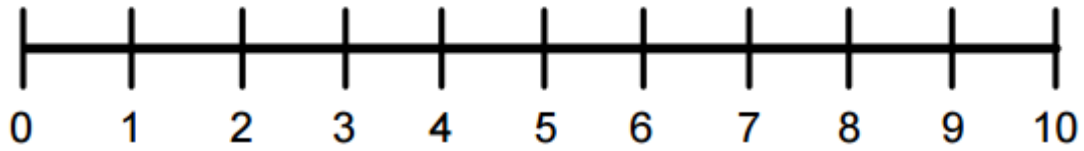
APPENDIX D

Pain Assessment Scale (PAS)

This scale assesses the causes, location, and intensity of pain you have experienced during hemodialysis treatment and end stage renal disease for past one month. This scale consists of two parts (I and II).

Part I: Pain Experienced During Hemodialysis Treatment

1. **Pain intensity:** Please circle the number that best represents your pain experienced during treatment. If your answer is 0, please go to part II.



No Pain **Worst Pain Possible**

2. **Causes of pain:** Please specify the causes of pain during hemodialysis treatment

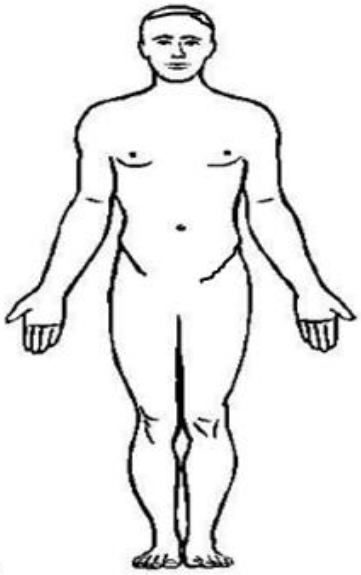
   1.

   2.

   3.

3. **Location of pain:** On the diagram, please shade in the areas where you feel pain during hemodialysis treatment.

.



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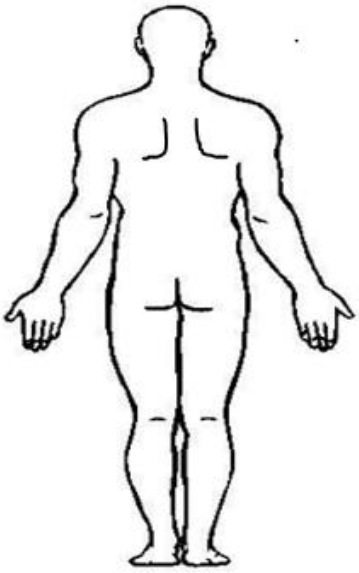

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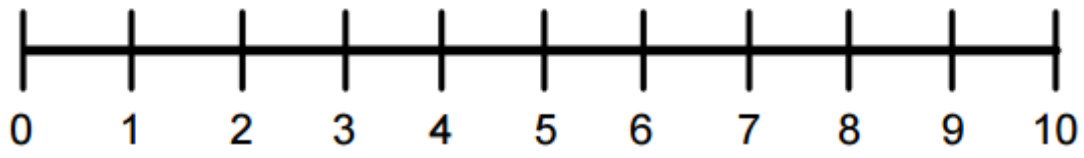
Part II: Pain Experienced due to end stage renal disease

1. **Pain intensity:** Please circle the number that best represents your pain experienced due to end stage renal disease. If you answer is 0, no need answer 2 and 3.



No Pain

Worst Pain Possibl

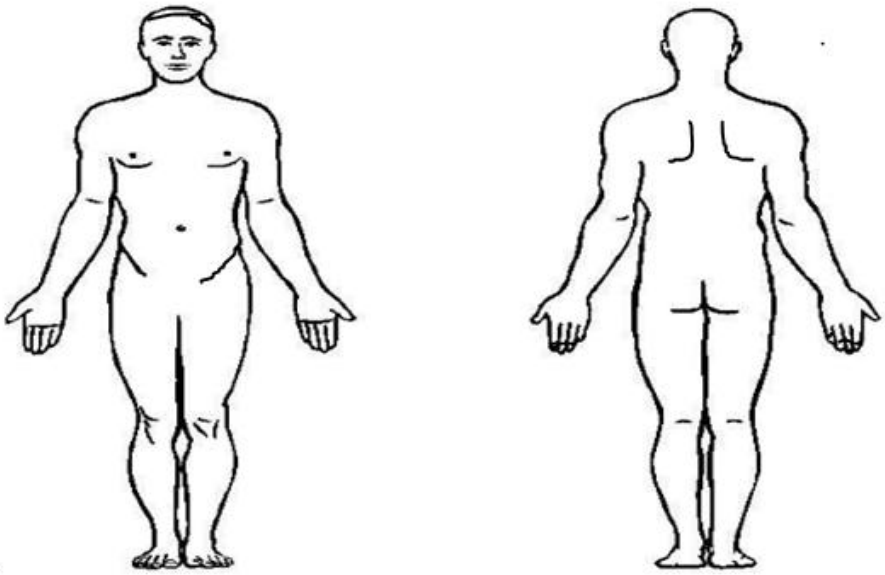
2. **Causes of pain:** Please specify the cause of pain due to end stage renal disease

   1.

   2.

   3.

3. **Location of pain:** On the diagram, please shade in the areas where you feel pain due to end stage renal disease.



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APPENDIX E

Fatigue Assessment Scale (FAS)

Direction: The following 10 statements refer to how you usually feel. Per statement you can choose one out of five answer categories, varying from never to always. Please **circle** the answer to each question that is applicable to you. Please give an answer to each question, even if you do not have any complaints at the moment.

1 = Never
2 = Sometimes (about monthly or less)
3 = Regularly (about a few times a month)
4 = Often (about weekly)
5 = Always (about every day)

Items	Never	Sometimes	Regularly	Often	Always
1. I am bothered by fatigue	1	2	3	4	5
2. I get tired very quickly	1	2	3	4	5
3. I do not do much during the day	1	2	3	4	5
4. I have enough energy for everyday life	1	2	3	4	5
5. Physically, I feel exhausted	1	2	3	4	5
6. I have problems to start things	1	2	3	4	5
7. I have problems to think clearly	1	2	3	4	5
8. I feel no desire to do anything	1	2	3	4	5
9. Mentally, I feel exhausted	1	2	3	4	5
10. When I am doing something, I can concentrate quite well	1	2	3	4	5

APPENDIX F

The Medical Outcomes Study Social Support Survey (MOS-SS)

Direction: Following are the statement of social support. Read each statement carefully and indicate how you feel about each statement. Please **circle** only one number per line. Per statement you can choose one out of five answer categories, varying from none of the time to all of the time.

1 = None of the time 4 = Most of the time

2 = A little of the time 3 = Some of the time 5 = All of the time

* Peers in the study means the patients suffering from end stage renal disease receiving hemodialysis

* HCPs in the study includes healthcare providers such as doctors and nephrology nurses

Items	None of the time	A little of the time	Some of the time	Most of the time	All of the time	Put (X) mark in the boxes or fill in the blanks below to indicate the persons you get support from
1. Someone to help you if you were confined to bed	1	2	3	4	5	☐ Family ☐ Friends Others (please specify)_____
2. Someone you can count on to listen to you when you need to talk	1	2	3	4	5	☐ Family ☐ Friends ☐ Peers * Others (please specify)_____

Items	None of the time	A little of the time	Some of the time	Most of the time	All of the time	Put (X) mark in the boxes or fill in the blanks below to indicate the persons you get support from
3. Someone to give you good advice about a crisis	1	2	3	4	5	☐ Family ☐ Friends ☐ Peers ☐ HCPs* Others (please specify)_____
4. Someone to take you to the doctor if you needed it	1	2	3	4	5	☐ Family ☐ Friends Others (please specify)_____
5. Someone who shows you love and affection	1	2	3	4	5	☐ Family ☐ Friends ☐ Peers Others (please specify)_____
6. Someone to have good time with	1	2	3	4	5	☐ Family ☐ Friends ☐ Peers Others (please specify)_____
7. Someone to give you information to help you understand a situation	1	2	3	4	5	☐ Family ☐ Friends ☐ Peers ☐ HCPs Others (please specify)_____

Items	None of the time	A little of the time	Some of the time	Most of the time	All of the time	Put (X) mark in the boxes or fill in the blanks below to indicate the persons you get support from
8. Someone to confide in or talk to about yourself or your problem	1	2	3	4	5	Family Friends Peers Others (please specify)_____
9. Someone who hugs you	1	2	3	4	5	☐ Family ☐ Friends ☐ Peers Others (please specify)_____
10. Someone to get together with for relaxation	1	2	3	4	5	☐ Family ☐ Friends ☐ Peers Others (please specify)_____
11. Someone to prepare your meals if you were unable to do it yourself	1	2	3	4	5	☐ Family ☐ Friends Others (please specify)_____
12. Someone whose advice you really want	1	2	3	4	5	☐ Family ☐ Friends ☐ Peers ☐ HCPs Others (please specify)_____

Items	None of the time	A little of the time	Some of the time	Most of the time	All of the time	Put (X) mark in the boxes or fill in the blanks below to indicate the persons you get support from
13. Someone to do thing with to help you get your mind off things	1	2	3	4	5	☐ Family ☐ Friends Others (please specify)_____
14. Someone to help with daily chores if you were sick	1	2	3	4	5	☐ Family ☐ Friends Others (please specify)_____
15. Someone to share your most private worries and fears	1	2	3	4	5	☐ Family ☐ Friends ☐ Peers Others (please specify)_____
16. Someone to turn to for suggestions about how to deal with a personal problem	1	2	3	4	5	☐ Family ☐ Friends ☐ Peers ☐ HCPs Others (please specify)_____
17. Someone to do something enjoyable with	1	2	3	4	5	☐ Family ☐ Friends ☐ Peers Others (please specify)_____

Items	None of the time	A little of the time	Some of the time	Most of the time	All of the time	Put (X) mark in the boxes or fill in the blanks below to indicate the persons you get support from
18. Someone who understands your problems	1	2	3	4	5	☐ Family ☐ Friends ☐ Peers Others (please specify)_____
19. Someone to love and make you feel wanted	1	2	3	4	5	☐ Family ☐ Friends ☐ Peers Others (please specify)_____

APPENDIX G

Religiosity Assessment Scale (RAS)

Direction: Following statements measure the religious practice and religious belief. Please read the statement carefully and choose one out of four categories per statement, varying from **strongly disagree** to **strongly agree**. **Circle** the number that indicates how much you agree or disagree with the following statement.

1 = Strongly disagree
2 = Disagree
3 = Agree
4 = Strongly agree

Items	Strongly disagree	Disagree	Agree	Strongly agree
1. I spend time in public religious events such as prayer groups, religious meetings	1	2	3	4
2. I spend time in personal religious activities such as prayer, meditation, listening to religious songs or poetry about God, making promises *'bhakal', 'baitarni', 'lakh batti ballne'*	1	2	3	4
3. Because of God's will, I am adjusting well to end stage renal disease	1	2	3	4
4. Because of God's will, I am adjusting well to hemodialysis	1	2	3	4
5. I am suffering from end stage renal disease and have to undergo hemodialysis because God has punished me for my bad deeds	1	2	3	4
6. I believe God can help me to overcome the problems and accepts me even with my faults	1	2	3	4

APPENDIX H

List of Experts

Content validity of the questionnaires used in this research was validated by three experts. They were:

1. Dr. Binita Kumari Paudel

   Lecturer, Faculty of Nursing, Purbanchal University College of Medical and Allied Sciences, Nepal

2. Dr. Charuwan Kritpracha

   Lecturer, Faculty of Nusing, Prince of Songkla University

3. Dr. Rodchana Wiriyasombat

   Lecturer, Faculty of Nursing, Boromarajonani College of Nursing Songkhla

APPENDIX I

Reliability Test of the Questionnaires

Reliability of the translated questionnaires was examined doing pilot testing. According to Radhakrishna (2007), the reliability of the translated version of the questionnaires can be performed in 15 – 30 similar samples. Therefore, in this present study, the pilot testing was conducted among 20 patients who met the inclusion criteria of the study participants.

From the pilot study, it was observed that all most all of the participants answered the questionnaires in the same time and could understand the instructions provided in the question. Therefore, the researcher did not change any components of the questionnaires. Furthermore, the Cronbach's alpha coefficient of FAS was .72, MOS-SS was .97, RAS was .84, and FACIT-Sp-12 was .79. Following are the data results of the reliability.

Reliability Statistics of FACIT-Sp-12

Cronbach's Alpha	N of Items
.791	12

Reliability Statistics of FAS

Cronbach's Alpha	N of Items
.723	10

Reliability Statistics of RAS

Cronbach's Alpha	N of Items
.846	6

Reliability Statistics of MOS-SS

Cronbach's Alpha	N of Items
.979	19

APPENDIX J

List of Instrument Translators

Instruments used in the study were translated into Nepali version with the help of three translators. They were:

1. Dr. Bidur Chalise, Ph.D. Nepali

   Lecturer, Nepal Institute of Health Sciences, Nepal

2. Ms. Monica Bhattachan , Master in Psychiatric Nursing

   Lecturer, Little Angles College for Higher Studies, Nepal

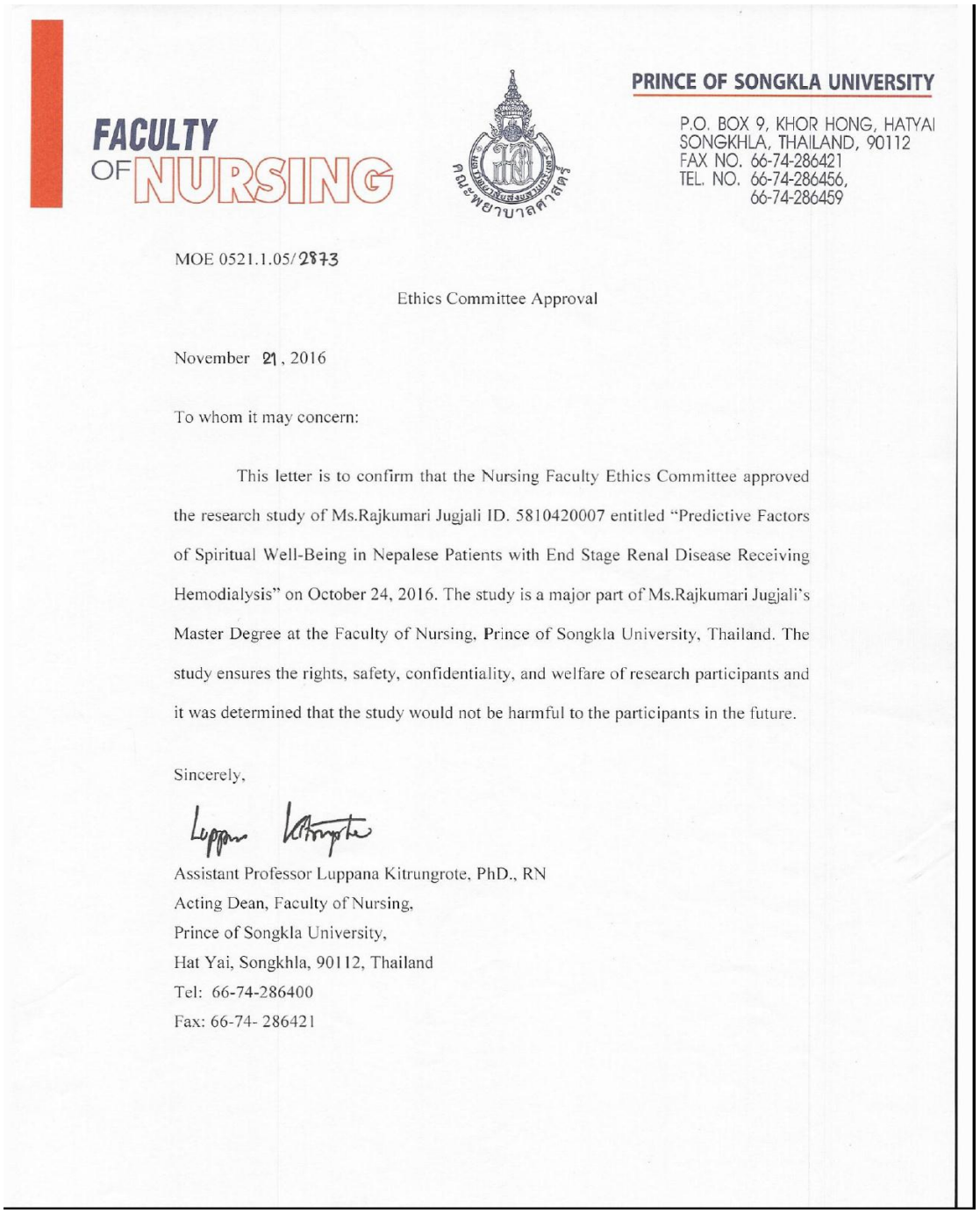
3. Dr. Sampurna Kacchapati, Ph. D. Research Methodology

   Post Doctoral, Prince of Songkla University Pattani Campus, Thailand

Appendix K

Letters of Ethical Consideration and Permission

Ethics Committee Approval Letter from the Faculty of Nursing, Prince of Songkla University, Thailand



FACULTY OF NURSING

PRINCE OF SONGKLA UNIVERSITY

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

MOE 0521.1.05/2873

Ethics Committee Approval

November 21, 2016

To whom it may concern:

This letter is to confirm that the Nursing Faculty Ethics Committee approved the research study of Ms.Rajkumari Jugjali ID. 5810420007 entitled "Predictive Factors of Spiritual Well-Being in Nepalese Patients with End Stage Renal Disease Receiving Hemodialysis" on October 24, 2016. The study is a major part of Ms.Rajkumari Jugjali's Master Degree at the Faculty of Nursing, Prince of Songkla University, Thailand. The study ensures the rights, safety, confidentiality, and welfare of research participants and it was determined that the study would not be harmful to the participants in the future.

Sincerely,

Assistant Professor Luppana Kitrungrote, PhD., RN
Acting Dean, Faculty of Nursing,
Prince of Songkla University,
Hat Yai, Songkhla, 90112, Thailand
Tel: 66-74-286400
Fax: 66-74- 286421

Letter of Ethical Approval from Nepal Health Research Council (NHRC), Nepal

Government of Nepal

Nepal Health Research Council (NHRC)

Ref. No.: 1377

12 February 2017

Ms. Raj Kumari Jugjali
Principal Investigator
Prince Of Songkla University
Thailand

Ref: **Approval of Research Proposal** entitled **Predictive Factors of Spiritual Well-Being in Nepalese Patients With End Stage Renal Disease Receiving Hemodialysis**

Dear Ms. Jugjali,

It is my pleasure to inform you that the above-mentioned proposal submitted on 03 January 2017 (**Reg. no. 06/2017**) has been approved by Nepal Health Research Council (NHRC) National Ethical Guidelines for Health Research in Nepal, Standard Operating Procedures Section 'C' point no. 6.3 through Expedited Review Procedures.

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

If the researcher requires transfer of the bio samples to other countries, the investigator should apply to the NHRC for the permission.

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

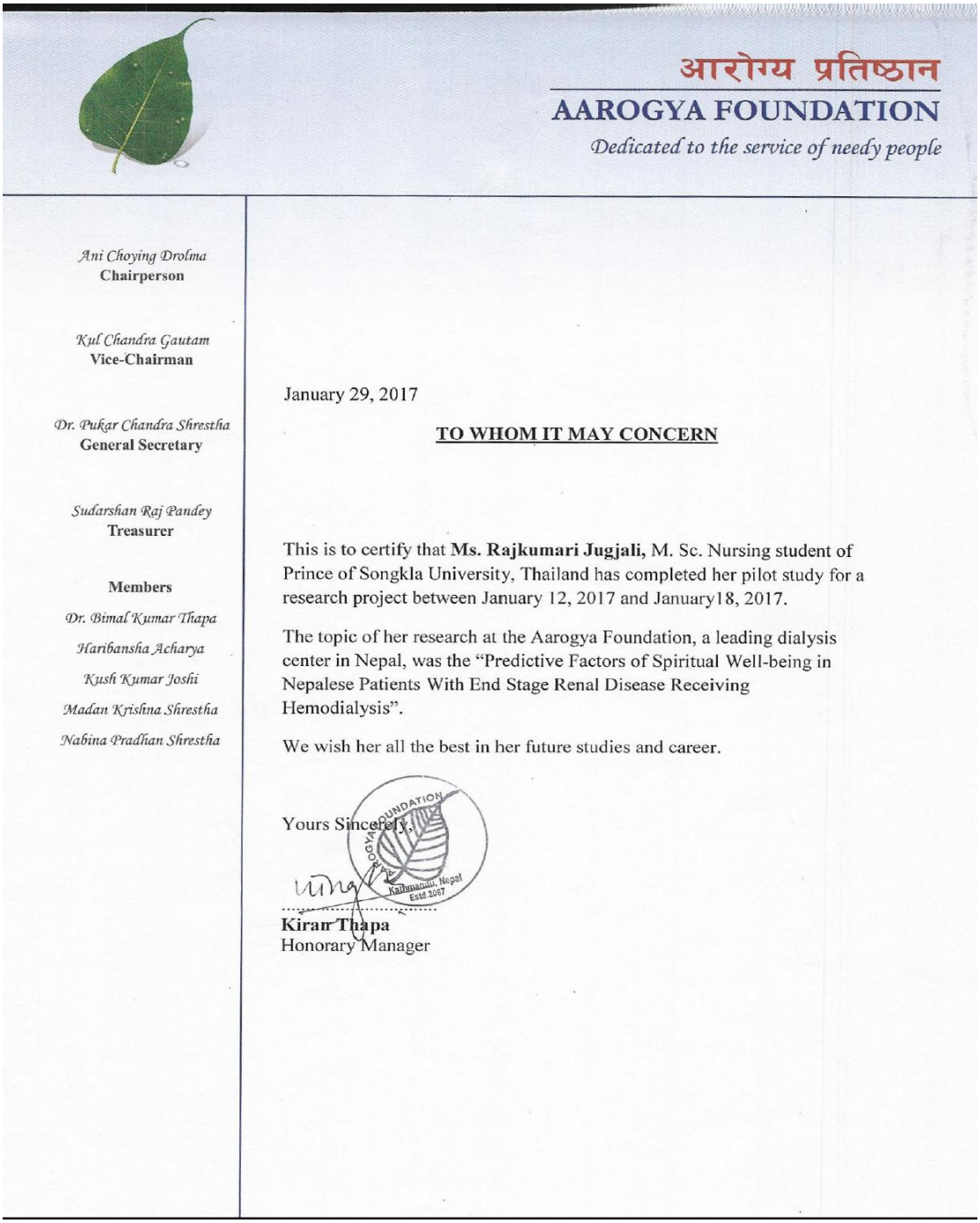
If you have any questions, please contact the Ethical Review M & E Section at NHRC.

Thanking you,

Dr. Khem Bahadur Karki
Member- Secretary

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

Letter of Completion of Data Collection for Try-Out from Aarogya Foundation, Nepal



आरोग्य प्रतिष्ठान
AAROGYA FOUNDATION
Dedicated to the service of needy people

Ani Choying Drolma
Chairperson

Kul Chandra Gautam
Vice-Chairman

Dr. Pukar Chandra Shrestha
General Secretary

Sudarshan Raj Pandey
Treasurer

Members
Dr. Bimal Kumar Thapa
Haribansha Acharya
Kush Kumar Joshi
Madan Krishna Shrestha
Nabina Pradhan Shrestha

January 29, 2017

TO WHOM IT MAY CONCERN

This is to certify that **Ms. Rajkumari Jugjali,** M. Sc. Nursing student of Prince of Songkla University, Thailand has completed her pilot study for a research project between January 12, 2017 and January18, 2017.

The topic of her research at the Aarogya Foundation, a leading dialysis center in Nepal, was the "Predictive Factors of Spiritual Well-being in Nepalese Patients With End Stage Renal Disease Receiving Hemodialysis".

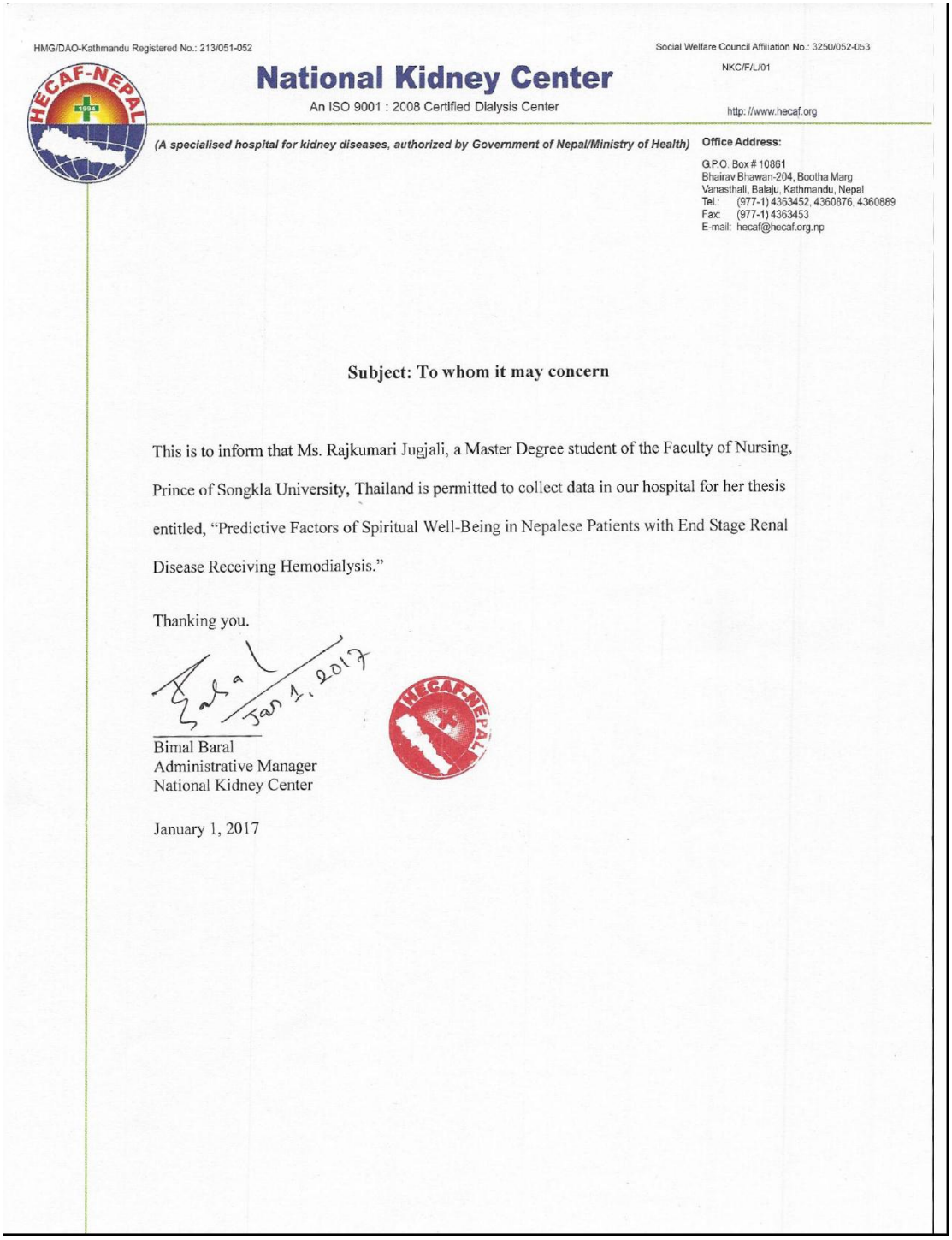
We wish her all the best in her future studies and career.

Yours Sincerely,

AAROGYA FOUNDATION Kathmandu, Nepal Estd 2057

Kiran Thapa
Honorary Manager

Letter of Permission for Data Collection from National Kidney Center



HMG/DAO-Kathmandu Registered No.: 213/051-052

Social Welfare Council Affiliation No.: 3250/052-053

NKC/F/L/01

National Kidney Center

An ISO 9001 : 2008 Certified Dialysis Center

http://www.hecaf.org

(A specialised hospital for kidney diseases, authorized by Government of Nepal/Ministry of Health)

Office Address:

G.P.O. Box # 10861
Bhairav Bhawan-204, Bootha Marg
Vanasthali, Balaju, Kathmandu, Nepal
Tel.: (977-1) 4363452, 4360876, 4360889
Fax: (977-1) 4363453
E-mail: hecaf@hecaf.org.np

Subject: To whom it may concern

This is to inform that Ms. Rajkumari Jugjali, a Master Degree student of the Faculty of Nursing, Prince of Songkla University, Thailand is permitted to collect data in our hospital for her thesis entitled, "Predictive Factors of Spiritual Well-Being in Nepalese Patients with End Stage Renal Disease Receiving Hemodialysis."

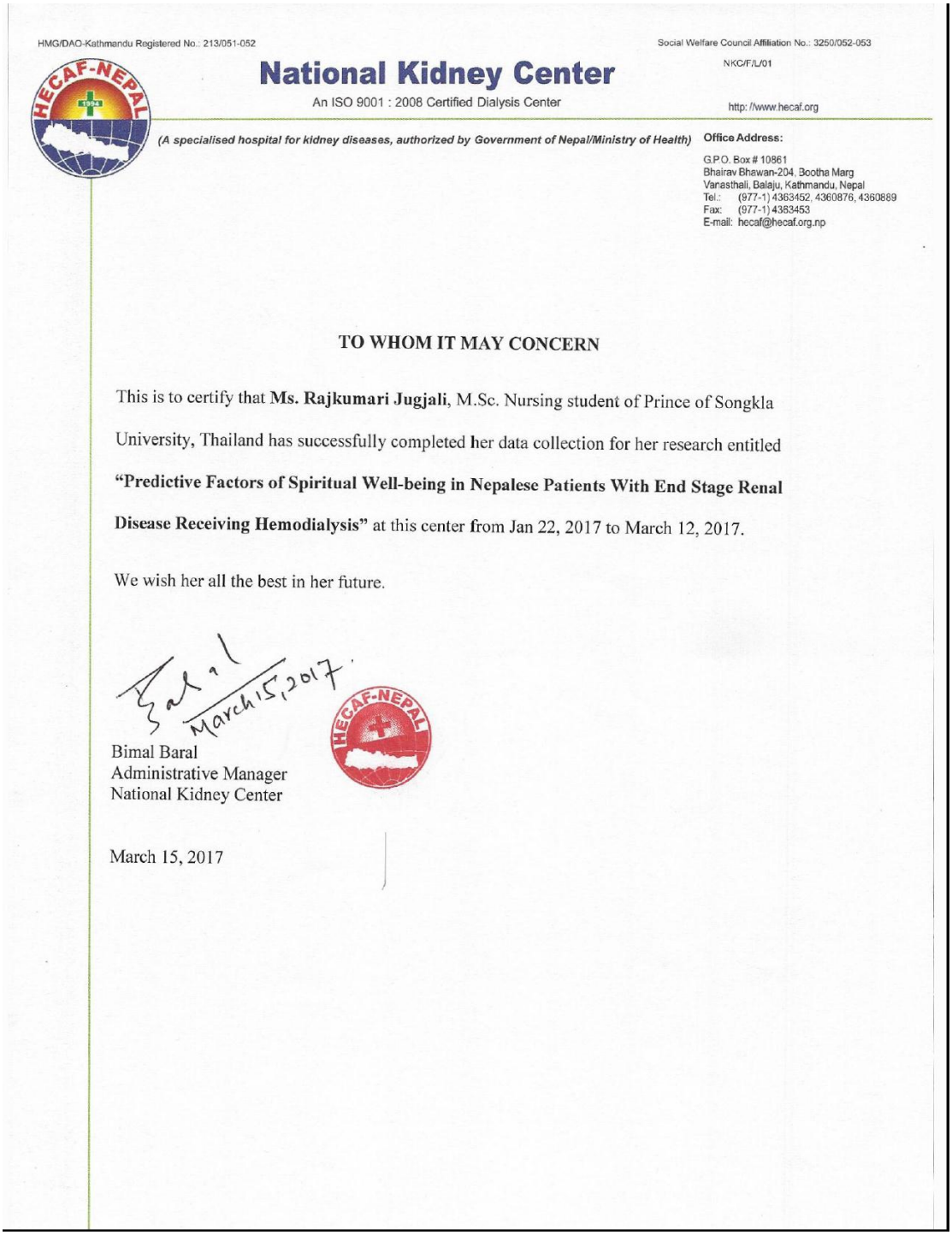
Thanking you.

Jan 1, 2017

Bimal Baral
Administrative Manager
National Kidney Center

January 1, 2017

Letter of Completion of Data Collection from National Kidney Center



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Fax: (977-1) 4363453
E-mail: hecaf@hecaf.org.np

TO WHOM IT MAY CONCERN

This is to certify that **Ms. Rajkumari Jugjali**, M.Sc. Nursing student of Prince of Songkla University, Thailand has successfully completed her data collection for her research entitled **"Predictive Factors of Spiritual Well-being in Nepalese Patients With End Stage Renal Disease Receiving Hemodialysis"** at this center from Jan 22, 2017 to March 12, 2017.

We wish her all the best in her future.

March 15, 2017.

Bimal Baral
Administrative Manager
National Kidney Center

March 15, 2017

APPENDIX L

Permission for Research Instruments

Sp-12 Nepali

Shannon Romo <sromo@facit.org> 9/20/16

To: Rajkumari Jugjali <rjugjali@gmail.com>

Hello Rajkumari Jugjal,

Thank you for your interest in translating FACIT-SP-12. I must inform you that any questionnaire that carries the FACT or FACIT name is a copyrighted translation owned by Dr. David Cella, the developer of this measurement system. In order to maintain the scientific integrity of the FACIT Measurement System and to ensure that all translations are equivalent for measurement purposes, we require that all FACT and FACIT translations follow the official FACIT translation methodology. The official methodology has been published in a number of journal articles and it is publicly well-known. For this reason, we must make sure that all translations follow this methodology to protect our name and our measurement system.

For FACIT to translate the document, which is our preference, cost to the requestor is $12,000 estimated and the time estimate is 12 weeks per questionnaire and language. Again this is a rough estimate and the translation team would give you an exact figure. However, we realize this cost is not always feasible for every requestor. Therefore, we have developed a set of requirements in cases such as yours, in which a collaborator has expressed interest in translating one of the FACIT questionnaires for his or her own research purposes.

In order to translate the FACIT-Sp-12 you will need to follow our translation and linguistic validation methodology, which is somewhat complex. It requires 2 forward translations from English to the target language by 2 translators working independently from one another, a reconciliation of the 2 forward translations provided by a third translator, a back translation into English performed by a fourth translator, 1 review/finalization by a fifth translator, proofreading and then testing on a small patient population of 5-10, who complete the test version of the questionnaire and then answer questions from a cognitive debriefing script that we'd prepare and have you translate and administer.

We cannot give permission for translation unless this methodology is used. Our questionnaires must be translated using this methodology and approved by FACIT in order to be considered or sited as a FACIT document and not in violation of international copyright laws. I am sure you are aware but I still must state that this is a rather complex under undertaking. In the past individuals have started out with the best of intentions but when realizing it is not as simple as they originally thought or realized they did not have all of the necessary resources they stop a quarter way through. This obviously slows down their own project and also keeps our team away from their regular work and projects. So I very kindly ask that you please consider carefully. Think about whether you have access to translators and a patient population to test etc. If you think you can resource all of these steps, let me know, and I will pass your request on to my colleague for consideration and approval.
If approved, we can provide you with the formats to perform the translations (we perform translations outside of the questionnaire template in order to keep track of all of the steps). All of the FACIT translations undergo this methodology in order to ensure they are valid for use in clinical practice and clinical trials.
Thank you for your understanding.

Kind Regards,

Shannon C Romo
sromo@facit.org

PROVIDING A VOICE FOR PATIENTS WORLDWIDE

FACIT.org FACITtrans | 381 S Cottage Hill Avenue | Elmhurst, IL 60126 | USA
www.FACIT.org

Rajkumari Jugjali 9/21/16

To: Shannon **<sromo@facit.org>**

Dear Shannon,

Thank you for your response.
I would like to inform you that I will follow all the steps of translation as mentioned.
Therefore, would kindly request to provide me approval for translating FACIT-Sp-12 English version to Nepali version.

Thank you.
With best regards,
Rajkumari Jugjali

Shannon Romo 9/21/16

To: Rajkumari Jugjali <rjugjali@gmail.com>

Rajkumari,

I have passes your request on to my translation team. You should hear from the by Friday at the latest. If you don't hear from them by then feel free to contact me.

Shannon

Request for Fatigue Assessment Scale

Rajkumari Jugjali <rjugjali@gmail.com> 9/21/16

To: j.devries

Dear Si/Madam,

I am Rajkumari Jugjali, from Nepal, currently studying in Prince of Songkla University, Thailand.

I am preparing proposal for my thesis. One variable of my study is "fatigue" and want to use "Fatigue Assessment Scale" for the measurement. Therefore, I want to take permission to use and translate the tool in my country language for my study. I tried to contact Dr. Helen J. Michielsen but unfortunately the email sent was not delivered.

Therefore, I would be very thankful if you could help me to contact Dr. Helen.

Look forward to hearing from you soon.
Thank you.
With best regards,
Rajkumari Jugjali

J. de Vries <J.deVries@uvt.nl> 9/21/16

To: Rajkumari

Dear Rajkumari,

Nowadays dr Michielsen has a totally different job. She is no longer doing research. I am the contact person for the FAS. I give you permission to translate the FAS into your language. The only conditions are:
1. use forward and backward translation method to reach the best translation (cf WHOQOL translation method);
2. I would like to receive the FAS in your language, when it is ready.
I wish you luck with your research.

Kind regards,
Jolanda De Vries, PhD
Professor at Tilburg University
Chair of the departement of Medical and Clinical Psychology

Van: Rajkumari Jugjali [rjugjali@gmail.com]
Verzonden: woensdag 21 september 2016 11:29
Aan: J. de Vries
Onderwerp: request

Request for The Medical Outcomes Study Social Support Survey (MOS-SS)

Auto Reply RAND Health Inquiries

Maples, Ingrid <imaples@rand.org> Jan 18

To: Rajkumari Jugjali

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APPENDIX M

Informed Consent

Informed Consent Form for Patients Receiving Hemodialysis Services in National Kidney Center, Vanasthali, Kathmandu

This Informed Consent Form is for those patients who receive hemodialysis from National Kidney Center, and who we are invited to participate in a research study entitled "**Predictive Factors of Spiritual Well-being in Nepalese Patients With End Stage Renal Disease Receiving Hemodialysis.**"

Principal Investigator:	**Advisor:**
Ms Rajkumari Jugjali	Asst. Prof. Kantaporn Yodchai
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The Informed Consent Form consists of three parts:

1) Information Sheet (to share information about research with you)
2) Certificate of Consent
3) Researcher's statement

Part I: Information Sheet

Dear participant,

I am Rajkumari Jugjali, a student of Master of Nursing Science in Prince of Songkla University, Thailand. I am going to conduct a research study entitled "**Predictive factors of Spiritual Well-being in Nepalese Patients With End Stage Renal Disease Receiving Hemodialysis.**" This study is conducted as the requirement for the fulfillment of my Master degree. I am going to give you required information and invite you to be part of this research. You do not have to decide today whether or not you will participate in the research. Before you decide whether you would take part in the study or not, you can talk to anyone you feel comfortable with about research. If you get any queries or get confused then please feel free to ask me anytime, I will be happy to explain.

End stage renal disease (ESRD) is increasing in Nepal with the increase in hypertension and diabetes mellitus. Patients receiving HD face with different problems that will have an impact on spiritual well-being. Therefore, the study aims to explore the level of spiritual well-being and factors influencing it in patients with ESRD receiving hemodialysis. This study will help in getting information about the spiritual well-being and further aid in determining the interventions to enhance spiritual well-being. We are asking people like you to participate who come for hemodialysis in this center.

Your participation in this study is very valuable. However, it is your will whether to participate or not. Even though, if you choose not to participate in the study, all the services routinely offered in this center will continue and will not affect

your treatment in any way. If you wish to take part then I will provide you the questions or ask questions if you are unable to read. This will take 30-40 minutes of your time. The six questionnaires are:

1) Patient Data Form
2) Questionnaire related to pain
3) Questionnaire related to fatigue
4) Religiosity Questionnaire
5) Questionnaire related to perceived social support
6) Questionnaire related to spiritual well-being

If you wish, you may discontinue at any time you like. It is your rights and will be respected. All the documents and information provided will be kept confidential and confirm that your name will not appear in any reports. The only people permitted to see your information will be people who work on the study and those who make sure the study is conducted in the right way. In addition, the result of the study will be used in publications and presentations.

Participating in this study will not have any harm or risk to you. In addition, the procedures of the study have been approved by the ethical committee of the University. This study will not provide you any payment. Participation is entirely voluntary.

Lastly, if you have any questions then you may ask at any time without hesitation. You may contact me or my advisor via phone or e-mail provided in this paper. Thank you.

Part II: Certificate of Consent

Before signing the consent, please read and tick the box for each statement.

1. I have read or had read out and understood all statement in the consent Yes ☐ No ☐

2. I have opportunity to ask questions and all of my questions have been answered — Yes ☐ No ☐
3. I was guaranteed that my identity will not be revealed. However, the result can be used for publication and presentation — Yes ☐ No ☐
4. I understood that I have the right to withdraw from the study at any time without penalty — Yes ☐ No ☐
5. I realize that my participation in this study is entirely voluntary — Yes ☐ No ☐
6. If I need to, I can contact the researcher or the advisor — Yes ☐ No ☐

I am ……, I do hereby agree to voluntarily participate in the study entitled "**Predictive factors of Spiritual Well-being in Nepalese Patients With End Stage Renal Disease Receiving Hemodialysis"** and consent to provide information needed.

…….	……
Signature of Participant	Signature of Researcher
Date: …….	Date: ……...

Part III: Researcher's Statement

I have explained the participants about the study and its procedure, to the best of my ability. I confirm that all the questions asked have been answered correctly and I also provide the contact address, in case participants have any further questions. The consent by the participants has been given freely and voluntarily, and they were not coerced. A copy of the informed consent form has been provided to the participants.

Signature of Researcher …….
(Ms. Rajkumari Jugjali)
Date: ……..

Appendix N

Assumptions

Test Assumption of Normality

Table 8

Skewness and Kurtosis of the Study Variables

Variables	Skewness/SE	Value	Kurtosis/SE	Value
Total spiritual well-being	.096/.241	0.39	-.575/.478	-.1.20
Pain during hemodialysis	-.138/.241	-.57	-.1.381/.471	-2.88
Pain due to ESRD	.458/.241	1.900	-1.536/.478	-3.21
Fatigue	.213/.241	0.88	-.642/.478	-1.34
Social support	-.759/.241	-3.14	-.540/.478	-1.12
Religiosity	-.118/.241	-.48	-561/.478	-1.17

Note. SE = Standard error

If the values of Skewness/SE and Kurtosis/SE lies between the ± 3.29 then the data is considered having a normal distribution (Kim, 2013).

Scatter plot of the Regression Standardized Residual and Regression Standardized Predictive Value (Normality, Linearity, and Homoscedasticity of Residuals)

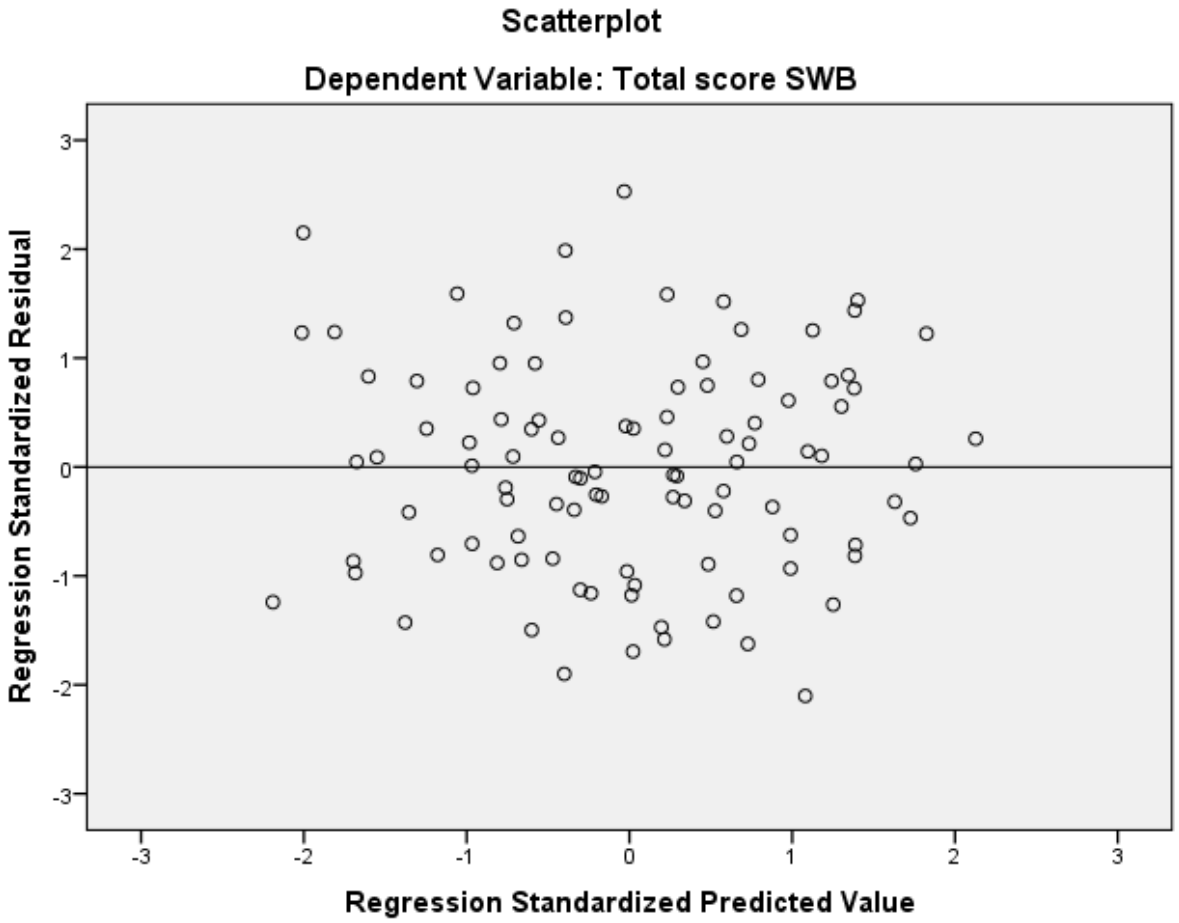

Figure 2: Scatter plot of the regression standardized residual and regression standardized predicted value

Test Assumption Multicollinearity

Table 9

Coefficient Table Showing Value of Variance Inflating Factor (VIF)

Coefficients

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	Correlations			Collinearity Statistics	
		B	Std. Error	Beta			Zero-order	Partial	Part	Tolerance	VIF
1	(Constant)	16.317	7.888		2.069	.041					
	Log10HDpain	-.195	3.023	-.006	-.064	.949	-.112	-.007	-.006	.855	1.170
	Log10ESRDpain	.609	2.893	.021	.211	.834	-.082	.022	.019	.826	1.211
	Fatigue total	-.428	.188	-.233	-2.284	.025	-.329	-.229	-.211	.820	1.220
	TotalSSorginal	.127	.052	.237	2.433	.017	.282	.243	.225	.896	1.116
	Total score of RAS	.516	.221	.222	2.330	.022	.244	.234	.215	.938	1.066

a. Dependent Variable: Total score SWB

Test Assumption of Autocollinearity

Table 10

Model Summary Showing the Value of Durbin-Watson

Model Summary[b]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics					Durbin-Watson
					R Square Change	F Change	df1	df2	Sig. F Change	
1	.444[a]	.197	.154	9.766	.197	4.610	5	94	.001	1.936

a. Predictors: (Constant), Total score of RAS, Log10ESRDpain, TotalSSorginal, Log10HDpain, Fatigue total

b. Dependent Variable: Total score SWB

Appendix O

Additional Results

This section of additional results exhibits the support person of the participants from whom they get social support.

Table 11

Frequency and Percentage of the Person From Whom the Participants get Support

Social support category/items	Person from whom the participants get support							
Emotional social support	Family		Friend		Peer		Other	
	Yes *n* (%)	No *n* (%)	Yes *n* (%)	No *n* (%)	Yes *n* (%)	No *n* (%)	Yes *n* (%)	No *n* (%)
2. Someone you can count on to listen to you when you need to talk (*n* = 91)	85 (93.4)	6 (6.6)	20 (22)	71 (78)	1 (1.1)	90 (98.9)	5(5.5)	86 (94.5)
8. Someone to confide in or talk to about yourself or your problem (*n* = 86)	74 (86)	12 (14)	19 (22.1)	67 (77.9)	2 (2.3)	84 (97.7)	3 (3.5)	83 (96.5)
15. Someone to share your most private worries and fears (*n* = 76)	65 (85.5)	11 (14.5)	7 (9.2)	69 (90.8)	3 (3.9)	73 (96.1)	1 (1.3)	75 (98.7)
18. Someone who understands your problems (*n* = 84)	79 (94)	5 (6)	10 (11.9)	74 (88.1)	-	-	-	-

Note. *n* = Multiple responses; Others = relatives, neighbors, religious member

Table 11 (continued)

Social support category/items	Person from whom the participants get support									
Emotional social support	Family		Friend		Peer		Health		Other	
	Yes *n* (%)	No *n* (%)	Yes *n* (%)	No *n* (%)	Yes *n* (%)	No *n* (%)	Yes *n* (%)	No *n* (%)	Yes *n* (%)	No *n* (%)
3. Someone to give you good advice about a crisis (*n* = 85)	74 (87.1)	11 (12.9)	16 (18.8)	69 (81.2)	3 (3.5)	82 (96.5)	5 (5.9)	80 (94.1)	5 (5.9)	80 (94.1)
7. Someone to give you information to help you understand a situation (*n* = 80)	68 (85)	12 (15)	19 (23.8)	61 (76.8)	2 (2.5)	78 (97.5)	-	-	9 (11.3)	71 (88.8)
12. Someone whose advice you really want (*n* = 78)	65 (83.3)	13 (16.7)	15 (19.2)	63 (80.8)	2 (2.6)	76 (97.4)	4 (5.1)	74 (94.9)	3 (3.8)	75 (96.2)
16. Someone to turn to for suggestions about how to deal with a personal problem (*n* =86)	78 (90.7)	8 (9.3)	10 (11.6)	76 (88.4)	2 (2.3)	84 (97.7)	1 (1.2)	85 (98.8)	5 (5.8)	81 (94.2)

Note. *n* = Multiple responses; Others = relatives, neighbors, religious member

Table 11 (continued)

Social support category/items	Person from whom the participants get support					
Tangible social support	Family		Friend		Others	
	Yes *n* (%)	No *n* (%)	Yes *n* (%)	No *n* (%)	Yes *n* (%)	No *n* (%)
1.Someone to help you if you were confined to bed (*n* = 95)	92 (96.8)	3 (3.2)	8 (8.4)	87 (91.6)	13 (13.8)	81 (86.2)
4.Someone to take you to the doctor if you needed it (*n*= 95)	92 (96.8)	3(3.2)	2 (2.1)	93 (97.9)	6 (6.3)	89 (93.7)
11.Someone to prepare your meals if you were unable to do it yourself (*n* = 94)	94 (100)	0 (0)	1 (1.1)	93 (98.9)	2 (2.1)	92 (97.9)
14.Someone to help with daily chores if you were sick (*n* = 90)	85 (93.4)	6 (6.6)	3 (3.3)	88 (96.7)	8 (8.8)	83 (91.2)

Note. *n* = Multiple responses; Others = relatives, neighbors, religious member

Table 11 (continued)

Social support category/items	Person from whom the participants get support							
Affectionate social support	Family		Friend		Peer		Other	
	Yes *n* (%)	No *n* (%)	Yes *n* (%)	No *n* (%)	Yes *n* (%)	No *n* (%)	Yes *n* (%)	No *n* (%)
5. Someone who shows you love and affection (*n* = 91)	87 (95.6)	4 (4.4)	6 (6.6)	85(93.4)	2 (2.2)	89 (97.8)	-	-
9. Someone who hugs you (*n* = 84)	77 (91.7)	7 (8.3)	14 (16.7)	70 (83.3)	2 (2.4)	82 (97.6)	-	-
19.Someone to love and make you feel wanted (*n* = 91)	89 (97.8)	2 (2.2)	-	-	2 (2.2)	89 (97.8)	5 (5.5)	86 (94.5)

Note. *n* = Multiple responses; Others = relatives, neighbors, religious member

Table 11 (continued)

Social support category/items	Person from whom the participants get support							
Social interaction	Family		Friend		Peer		Other	
	Yes *n* (%)	No *n* (%)	Yes *n* (%)	No *n* (%)	Yes *n* (%)	No *n* (%)	Yes *n* (%)	No *n* (%)
6. Someone to have good time with (*n* = 80)	71 (88.8)	9 (11.3)	13 (16.3)	67 (83.8)	2 (2.5)	78 (97.5)	-	-
10. Someone to get together with for relaxation (*n* = 91)	87 (95.6)	4 (4.4)	12 (13.2)	79 (86.8)	1 (1.1)	90 (98.9)	1 (1.1)	90 (98.9)
17. Someone to do something enjoyable with (*n* = 77)	56 (72.7)	21 (27.3)	32 (41.6)	45(58.4)	3 (3.9)	74 (96.1)	2 (2.6)	75 (97.4)

Note. *n* = Multiple responses; Others = relatives, neighbors, religious members

This section of additional result illustrates the causes and location of pain due to end stage renal disease and hemodialysis.

Table 12

Frequency and Percentage of Causes of Pain due to End Stage Renal Disease (n = 46)

Causes of pain	Yes		No	
	n	%	*n*	%
Low back pain	28	60.9	18	82.6
Joint pain	14	30.4	32	76.1
Muscle pain	11	23.9	35	69.6
Bone pain	8	17.4	38	39.1
Abdomen pain	2	4.3	44	95.7
Chest pain	1	2.2	45	97.8

Note. n = Multiple responses

Table 13

Frequency and Percentage of Causes of Pain during Hemodialysis Treatment (n=69)

Causes of pain	Yes		No	
	n	%	*n*	%
Arterio-vascular fistula insertion	39	56.5	30	43.5
Headache	36	52.2	33	47.8
Muscle cramps	33	47.8	36	52.2
Chest pain	6	8.6	63	91.3
Musculoskeletal pain	5	7.2	64	92.8
Stomach pain	5	7.2	64	92.8
Backache	4	5.7	65	94.2

Note. n = Multiple responses

Table 14

Frequency and Percentage of the Location of Pain due to End Stage Renal Disease Hemodialysis Treatment

Location of pain	End stage renal disease (*n* = 46)		Hemodialysis (*n* = 69)	
	Yes *n* (%)	No *n* (%)	Yes *n* (%)	No *n* (%)
Head	-	-	36 (52.2)	33 (47.8)
Chest	1 (2.2)	45 (97.8)	6 (8.7)	63 (91.3)
Abdomen	2 (4.3)	44 (95.7)	5 (7.2)	64 (92.8)
Back	30 (65.2)	16 (34.8)	6 (8.7)	63 (91.3)
Legs	20 (43.5)	26 (56.5)	32 (46.4)	37 (53.6)
Hands	8 (17.4)	38 (82.6)	45 (65.2)	24 (34.8)

Note. *n* = Multiple responses

This section of additional result exhibits the result of qualitative data. Various themes were identified from the qualitative data and are listed in Table 15.

Table 15

Content Analysis of Spiritual Well-Being of Patients with End Stage Renal Disease Receiving Hemodialysis

Interview Statement	Themes
"We cannot eat everything... we cannot eat what our heart wants...we cannot eat salt and drink water…if we do not control our food habits then it will be difficult and we have to come to the hospital." [P5]	Diet and fluid challenges
"We need to control our food and drinking habits." [P2]	

Table 15 (continued)

Interview Statement	Themes
"Whenever, I am alone I think about my condition and I feel tense. Sometimes I want to cry looking at my life. Sometime I feel my life is not worthy…I feel tense and frustrated because of my life." [P2] "I am not confident about my health. We do not know what will happen next…anything can happen...I have to come away from family [HD center and home is far] and I fear something might happen to me." [P3]	Emotional distress
"I am not able to work... My wife goes to the office. I married my wife to take care of her but instead she has to take care of me... she cares for me as her own child." [P2] "My mother and sister had expectations that I would become a responsible adult and do something for my family. But instead they have to take care of me... I can see the difficulties others [family members] are having because of me." [P1]	Changed family roles
"When I was diagnosed with ESRD, I was in London to complete my higher studies...I had to return to my country without accomplishing my objectives." [P1]	Unfulfilled hopes and dreams

Table 15 (continued)

Interview Statement	Themes
"I am not able to complete my aim. What I need is time to complete it [aim] but I cannot give time. Not being able to give time is the biggest obstacle to complete my objectives of life." [P4]	
"There are many things we need to follow under HD treatment we need to be disciplined. If we are not disciplined then it is difficult... there is restriction of food and have to think many times before doing anything." [P1] "People who suffer from this disease need to be disciplined...we cannot eat the food we like…we cannot eat salt and drink water...if we do not control our food habits then it will be difficult and we have to come to the hospital." [P5]	Being disciplined
"I got help from my friends and family then I was able to boost my spirits…come out of frustration and make our heart happy…I my happy…The main role is played by a family. If there is no support from the family we cannot do anything. If there is family support then everything will be accomplished. In my experience and opinion family plays a vital role." [P1]	Obtaining support

Table 15 (continued)

Interview Statement	Themes
"I need to do my HD twice a week and had to take my medicines. It is really difficult to maintain the expenses…because of this [expenditure] many patients had expired untimely in the past…Government of Nepal has made HD treatment free…this facility has increased my self esteem… I feel lucky." [P8]	
"In the beginning, I felt that I would not survive...I did HD... as the time passed...now I feel HD had helped me a lot. The thing [ESRD and HD] has happened already. If there was no HD then we would not have survived. We need to do transplant for survival. Until we go for transplant the only option for survival is HD. I have been doing HD for four years and I have survived until now. Let's think it as positive, I am surviving and living with my family, wife and son."[P2]	Accepting and living with ESRD and HD

Table 15 (continued)

Interview Statement	Themes
"There is a problem if we do not accept the problem and stick with the problem... then the problem will be bigger. If we accept the problem then we can come out of the situation…if we do not accept and stick with the problem then we will be frustrated. If we accept the problem early it will be easy for us. It is okay, the thing [ESRD and HD] has happened already…this is called acceptance." [P1]	Accepting and living with ESRD and HD

VITAE

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List of Publication and Proceeding

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