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UNIVERSITY OF SAN DIEGO

Hahn School of Nursing and Health Science

DOCTOR OF PHILOSOPHY IN NURSING

Spiritual Well-Being and Quality of Life among Persons with Paraplegia

by

Darlene Nelson Finocchiaro, MSN, RN, CRRN

A dissertation presented to the

FACULTY OF THE HAHN SCHOOL OF NURSING AND HEALTH SCIENCE

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In partial fulfillment of the requirements for the degree

DOCTOR OF PHILOSOPHY IN NURSING

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Dissertation Committee

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## **Abstract**

With the advent of better emergency response and medical advances, the life expectancy of persons with spinal cord injury (SCI) is about 85% to 90% compared to that of non-disabled persons. Since SCI survivors are living well into their 70s, quality of life (QOL) is a major concern. The purpose of this study, informed by Ferrell and Grant's Quality of Life Model, was to examine relationships between spiritual well-being (SWB), existential well-being (EWB), religious spiritual well-being (RWB), depression, length of injury, age, gender, ethnicity, and QOL while living with paraplegia one year and longer. A descriptive, correlational, cross-sectional design, with convenience sampling of 75 participants was implemented. Instruments used to measure the influence of variables included Ellison's Spiritual Well-Being Scale, The Center for Epidemiologic Studies Depression Scale, and a Quality of Life scale measuring subjective quality of life directly through a visual analog. Findings included relatively high SWB scores, with existential well-being (EWB) having a strong relationship with QOL ( $r = .63, p = .01$ ). Other significant relationships included SWB Total and QOL ( $r = .47, p = .01$ ) and inversely between depression and QOL ( $r = -.59, p = .01$ ). Regression analysis indicated that the variables of existential well-being, spiritual well-being total, and depression were the primary predictors of quality of life. In conclusion, participants who had a strong sense of purpose and meaning in life, whether or not religious, were more likely to have a higher subjective QOL. Implications of this study for future research include conducting a qualitative study addressing the questions: What does spiritual well-being mean to the person with paraplegia, and what contributes to the person's subjective quality of life?

*Keywords:* Spiritual well-being, religious well-being, existential well-being, quality of life, depression, paraplegia, spinal cord injury

## **Dedication**

This dissertation is dedicated to God, my parents, and my husband:

Jesus Christ, who is my Lord and Savior, who answered my prayers, gave me strength when I wasn't sure I would survive, and directed me on this path to USD and my PhD degree.

My parents, Harold and Cecelia Nelson, for always believing in me, and encouraging me to further my education throughout life.

My husband, Dr. Michael Finocchiaro, who is the love of my life, my greatest supporter and listener, and whom without I never would have completed this accomplishment.

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## **Table of Contents**

<b>Chapter I Statement of the Problem</b>	<b>1</b>
Statement of the Problem	1
Purpose of the Study	4
Specific Aims	4
Conceptual Framework	5
Definition of Terms	7
Significance of Study	11
<b>Chapter II Review of the Literature</b>	<b>13</b>
Conceptual Framework	15
Spiritual Well Being and Terminal Illness	21
Spiritual Well Being and Chronic Illness	23
Spiritual Well Being and Physical Disabilities	27
Spiritual Well Being and Depression	29
Depression and Spinal Cord Injury	30
Quality of Life and Spinal Cord Injury	32
Spiritual Well Being, Quality of Life, and Spinal Cord Injury	36
Analysis and Critique of the Literature	39



<b>Chapter III Methodology</b>	44
Research Aims and Questions	45
Research Design	46
Independent Variables	47
Dependent Variable	48
Setting and Sample	49
Data Collection	50
Measures	51
Data Analysis	56
Human Subjects Protection	59
<b>Chapter IV Results</b>	61
Characteristics of the Sample	61
Findings Related to Research Aims and Questions	66
Summary	75
<b>Chapter V Discussion of Findings</b>	77
Research Questions	78
Critique and Implications	88
Implications for Nursing	89
Theory Development	89
Research	90

Practice	91
Education	92
Conclusion	93
<b>References</b>	95
<b>Appendices</b>	117
Measures	117
Letters of Authorization and Permission	119

## Tables

<b>Table 1</b>	<b>Subject Characteristics.....</b>	<b>63</b>
<b>Table 2</b>	<b>Descriptive Statistics of Variables.....</b>	<b>67</b>
<b>Table 3</b>	<b>Descriptive Statistics of Selected SWB and CES-D Items.....</b>	<b>68</b>
<b>Table 4</b>	<b>Correlation Matrix of Predictor Variables.....</b>	<b>70</b>
<b>Table 5</b>	<b>Correlation Matrix of Predictor Variables.....</b>	<b>71</b>
<b>Table 6</b>	<b>Pearson Product-Moment ( <math>r</math> )Correlations Between SWB (Existential and Religious), Depression, Length of Injury, Gender, Age, and Quality of Life.....</b>	<b>72</b>
<b>Table 7</b>	<b>Regression Analysis of Paraplegic Patient's Quality of Life On Six Predictor Variables.....</b>	<b>73</b>
<b>Table 8</b>	<b>Regression Analysis of Paraplegic Patient's Quality of Life On Five Predictor Variables.....</b>	<b>74</b>
<b>Table 9</b>	<b>Regression Analysis of Paraplegic Patient's Quality of Life On Four Predictor Variables.....</b>	<b>75</b>

## Illustration

<b>Figure 1</b>	<b>Quality of Life Model.....</b>	<b>6</b>
-----------------	-----------------------------------	----------

## Appendices

<b>Appendix Measure: Demographic Profile Questionnaire.....</b>	<b>117</b>
<b>Appendix Measure: Center for Epidemiological Studies Depression (CES-D) Scale.....</b>	<b>118</b>
<b>University of San Diego Committee on the Protection of Human Right Committee Approval.....</b>	<b>119</b>
<b>Rancho Los Amigos National Rehabilitation Center Investigational Review Board Approval.....</b>	<b>122</b>
<b>Quality of Life Model Copyright Permission.....</b>	<b>123</b>
<b>Spiritual Well-Being Scale copyright permission letter.....</b>	<b>124</b>
<b>The Quality of Life Scale copyright permission letter.....</b>	<b>125</b>

## **Chapter 1**

### **STATEMENT OF THE PROBLEM**

A Priority of Healthy People 2010 is to help persons of all ages increase life expectancy and improve their quality of life (Healthy People 2010, 2003). Quality of life is an individual subjective perception captured in a cultural, social, and environmental context (Frank-Stromborg & Olsen, 2004). Based on many studies, there are approximately 260,000 persons in the United States living with a spinal cord injury, and it is estimated 12,000 persons suffer a spinal cord injury annually (National Spinal Cord Injury Statistical Center, 2009). A more rapid emergency response and continuous effective medical care following a spinal cord injury has resulted in a much longer life expectancy than previously experienced. The greatest risk of mortality occurs during the first year following injury onset; survivors of spinal cord injury continue to live longer despite the risk of fatal medical complications, such as pulmonary emboli (National Spinal Cord Injury Statistical Center, 2009), pneumonia, and septicemia (Hoeman, Lyszner & Alverzo, 2007; National Spinal Cord Injury Statistical Center, 2009).

For example, the life expectancy for a 40-year-old who survives at least one year post injury, living with low tetraplegia (C5-C8) is 64.4 years of age, while a paraplegic is 68.3 years. A 60-year-old who survives at least one year post injury, living with low tetraplegia may live to be 70.6 years of age, while a paraplegic may live to be 73.3 years (National Spinal Cord Injury Statistical Center, 2009).

Before World War II, life expectancy of a spinal cord injured person was only one to ten years; today a person with spinal cord injury can expect to live five fewer years than a person without a spinal cord injury at the same age (Laskowski-Jones, 2007), or approximately 85% to 90% of a nondisabled person's lifespan (Sasma, Patrick, & Feussner, 1993). Indeed, these individuals are and can live long beyond their 70's. Living longer, while aging naturally, poses the concern about what one's quality of life can be while living with a spinal cord injury (Kemp & Ettelson, 2001).

Tetraplegia, also known as Quadriplegia, refers to paralysis of all extremities with a cervical region lesion resulting from a spinal cord insult; whereas paraplegia refers to paralysis of the lower extremities with a motor lesion in the thoracic, lumbar, or sacral region of the spinal cord (National Spinal Cord Injury Statistical Center, 2009). It is well documented that with increased life expectancy, greater potential for the experience of complications, such as pressure ulcers, respiratory disease, urinary tract infections, pain, and deep vein thrombosis arises (Cardenas, Hoffman, Kirshblum & McKinley, 2004; De-Santo-Madeya, 2006; Johnson, Gerhart, McCray, Menconi & Whiteneck, 1998). These secondary conditions following spinal cord injury can also affect the person's subjective view of his/her quality of life or life satisfaction (Brillhart, 2005; Chase, Cornille, & English, 2000).

view of his/her quality of life or life satisfaction (Brillhart, 2005; Chase, Cornille, & English, 2000).

Besides physiological complications, finding hope for the future and demonstrating positive coping strategies are often difficult for persons living with spinal cord injury (Finocchiaro, 2007). Lohne and Severinsson (2005) found that patients experience different emotions of suffering, such as loneliness, impatience, disappointment, bitterness, waiting, and dependency; moving through these feelings back and forth. These researchers suggested that hope was one approach to breaking the continuous cycle of suffering.

Hope can occur through a heightened spiritual well-being. Helping a patient establish hope while encountering an illness or serious disability is a nursing intervention used in response to a patient's experience of spiritual distress or poor spiritual well-being (Dochterman & Bulechek, 2004). Psychological conditions, such as depression, lack of motivation, and chronic stress can also affect the patient's long term response to the spinal cord injury (Chase, Cornille & English, 2000; Finocchiaro & Herzfeld, 1998). Feeling hopeless, experiencing depression, and considering suicide or self harm are thoughts considered by some persons with spinal cord injury (Gerhart, Koziol-McLain, Lowenstein, & Whiteneck, 1994). Having to live with high risk medical conditions, immobility, and self care limitations is perceived by those with spinal cord injury to be unacceptable living or having a poor quality of life (Dijkers, 2005; Gerhart, Koziol-McLain, Lowenstein, & Whiteneck, 1994). As the life span for persons with spinal cord injury is increasing, a variety of health related problems, as well as functional challenges are heightened, resulting in a decreased subjective quality of life (Duggan & Dijkers,



along with improving post injury outcomes and subjective quality of life is imperative. A rarely discussed phenomenon is the factor of a person's spiritual well-being.

Previous research indicates that improved health outcomes and quality of life following illness or disability result if a person's spiritual well-being is assessed and spiritual needs are addressed (Boswell, Knight, & Hammer, 2001; Brillhart, 2005; Coleman, 2004). Spiritual well-being has been suggested by Ellison (1983) as meaning and purpose in one's life (existential) and a relationship to a higher power (religious).

### **Purpose of the Study**

In recognizing the importance of faith in one's God or reason for survival following a catastrophic injury or illness, the overall purpose of this study was to examine the relationship between spiritual well-being, depression, and quality of life for persons living with paraplegia one year and longer.

### **Specific Aims**

The specific aims of the study were as follows and refer to a person living with paraplegia one year and longer:

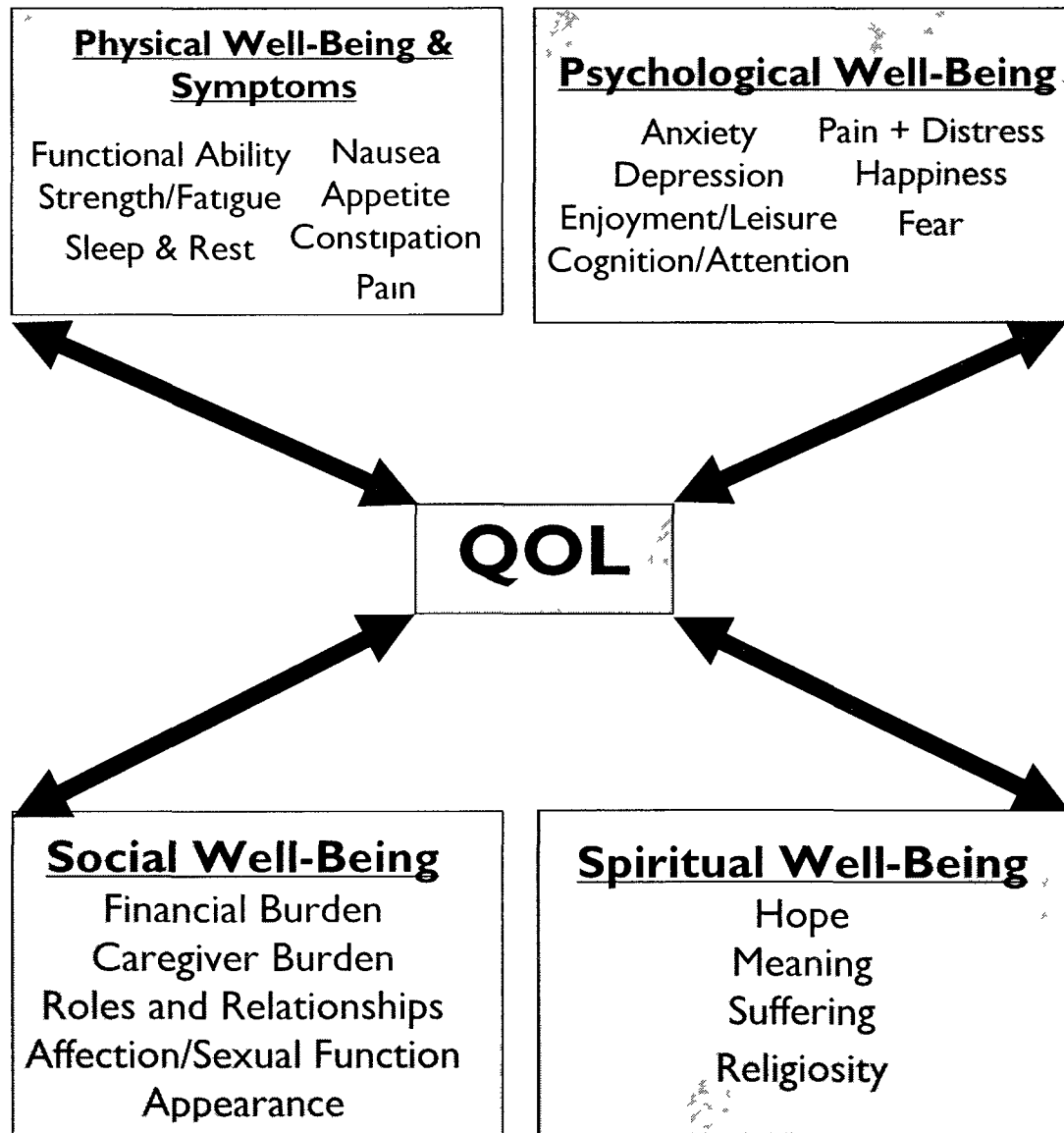
Aim # 1: Describe spiritual well-being (existential and religious), depression, and quality of life while living with paraplegia.

Aim #2: Examine the relationship between spiritual well-being (existential and religious), depression, years/months post injury, selected demographic variables (age, gender), and quality of life while living with paraplegia.

### **Conceptual Framework**

The conceptual framework for this study is based upon concepts derived from the literature and informed by Ferrell and Grant's model of "Quality of Life Model." Quality of life encompasses the physical, psychological, social, and spiritual dimensions of the person (Ferrell & Grant, 2000). The dimensions are interrelated and the relevance of one or several of the aspects within the dimensions may be affected by change in individual circumstances, such as life changes from a spinal cord injury. Even though Ferrell and Grant's model focuses on persons dealing with end of life issues, their model can be applicable to those living with spinal cord injury. For example, the physical well-being dimension includes functional ability. As the person experiences multiple symptoms related to the disease or its progression, functional ability is affected. The psychological well-being is affected as emotional responses to illness can occur, such as anxiety, sadness, fear, depression, denial/acceptance, and hope/hopelessness (Ferrell, 2005). A person's sense of spirituality or spiritual well-being is often what helps the person cope with losses and find meaning in life (Ferrell, 2005). This is necessary for the person while dealing with the losses associated with a spinal cord injury. All dimensions of the "Quality of Life Model" affect the person living with paraplegia (Figure 1). This study focuses on the interrelatedness of quality of life to the dimensions of psychological well-being (depression) and spiritual well-being (religiosity and meaning) to quality of life.

Figure 1 – Quality of Life Model



“Quality of Life Model” by B.R. Ferrell and M. Grant  
 (2000) Duarte, CA: City of Hope National Medical Center  
 © 2000 by Ferrell and Grant. Printed with permission

## **Definition of Terms**

*Quality of life* has been defined in many ways and there are instruments that measure the concept, such as the “Quality of Life Profile: Physical and Sensory Disabilities Version” (Rudman, Renwick, Rapheal & Brown, 1995). Currently there is no agreed upon definition to what quality of life is. Looking at the concept from either an economic, social, or medical/health reason, the meaning can be different. “Quality of life” may refer to health-related quality of life (HRQOL). HRQOL includes the physical, psychological, and social functioning associated with an illness, or its treatment (Revicki, 1989). Quality of life is sometimes synonymous with satisfaction with life (Matheis, Tulskey, & Matheis (2006); Siosteen, Lindquist, Blomstand, Sullivan, & Sullivan, 1990). McDowell and Newell (1996) define quality of life as “both the adequacy of material circumstances and people’s feelings about circumstances....It is a personal assessment of one’s condition compared to an external reference standard or to one’s aspirations,” (p. 204). Life satisfaction is often conceptualized to be a subjective part of one’s quality of life, dealing with feelings of persons concerned about their functioning and circumstances (Post, Van Dijk, Van Asbeck, & Schrijvers, 1998).

For purposes of this study, “quality of life” referred to subjective quality of life and was measured directly. According to Renwick and Brown (1996), subjective quality of life refers to a person’s satisfaction with multiple circumstances of life quality, including health relations, emotional, social and physical function, as well as happiness and satisfaction with living situation and finances. While Renick and Brown (1996) were looking at subjective quality of life indirectly through life satisfaction items, subjective quality of life can also be measured directly, stressing the person’s own opinion about

quality of life, basing it on what is important to the person at a given time. With the subjective approach, the person's own personal experience is captured, rather than relying on outside events, such as personal income, years of education, employment, and marital status (Kemp & Ettelson, 2001). It also does not depend on one's state of health or functional ability. Kemp and Kahan's (1995) Quality of Life Scale, which measures quality of life directly and subjectively using a visual analog, was used to assess quality of life for this study. Because of the severity of a spinal cord injury and having an expanded life span, measuring quality of life has the potential to be significant in establishing outcome parameters after initial rehabilitation and re-entry into the community (Hallin, Sullivan, & Kreuter, 2000).

The concepts of *spirituality* and *spiritual well-being* have often been used interchangeably and described differently by many scholars. There is a general agreement that spirituality or spiritual well-being is an awareness of having meaning in life (Harrison, 1993). The meaning of life and being aware of it, is what makes a person real. Spirituality is one's own reality, the inner self or soul (McEwan, 2004). Watson (1985) suggests that the spirit refers to the soul while Harrison (1993) conceptualizes spirit as a force that provides the person with a push or strong desire to keep going forward despite life's difficulties. Thus it could be argued that the soul is linked to the spirit.

Martsof and Mickely (1998) mention words such as meaning, value, transcendence, becoming, and connecting, as commonly used to describe the concept of spirituality, whereas Coyle (2004) includes words such as faith, purpose and hope to convey spirituality. According to O'Brien (2008), spirituality is all about relationship

and connection to one's transcendent or God. Religiosity, in contrast, refers to how one practices their faith and increases personal spiritual well-being. Ladwig and Ackley (2006) also discuss how connectedness to self, others, nature, art, music, or to a higher power can result in an enhanced spiritual well-being; that this enhanced spiritual well-being is when the person has the "ability to experience and integrate meaning and purpose in life through this connectedness" (p. 819). The opposite of enhanced spiritual well-being or readiness for enhanced spiritual well-being is described or identified as spiritual distress due to an absence of connectedness with self, others, or higher power (Wilkinson & Ahern, 2009).

Ellison (1983) conceptualizes spirituality or *spiritual well-being* in two dimensions: a relationship to a higher power (religious), and a spirituality of meaning and purpose (existential). *Religious spirituality* or *spiritual well-being* can be defined as a relationship with God or a higher power (Colon, 1996). It is usually seen among individuals attending organized religious services within a community setting (Matheis, Tulskey, & Mathesis, 2006). *Existential spirituality* or *spiritual well-being* differs as it is not related to a place of worship or set of accepted ideals or doctrines. It refers to a phenomenon in which individuals seek purpose in their life and come to recognize that their world has meaning and value (Brady, Peterman, Fitchett, Mo, & Cella, 1999). Ellison's (1983) Spiritual Well-Being Scale (SWBS) was used to measure spiritual well-being for this study.

*Depression* has been defined in many terms or behavioral patterns. Ferszt and Leveillee (2006) describe depression as "feeling immobilized or stuck, hopelessness, a loss of connection with self and others" (p. 60). A feeling of having fallen into a black

hole and fearing it is impossible to get out is another expression of depression. When problems of fatigue, insomnia, and indecisiveness persist from two weeks to several months, depression is present (Ferszt & Leveillee, 2006). Depression coincides with life changes (Heitkemper, Hansen & Lewis, 2004) and is considered part of the mourning process for persons with spinal cord injury; experiencing behaviors such as sadness, pessimism, suicidal preoccupation, and refusal to participate in self-care activities (Warms, 2004).

Depression is the most common psychological disorder following a spinal cord injury. The rate of disabled individuals with depression is much higher compared to the non-disabled population (Elliot & Frank, 1996). Despite this occurrence, it is unclear what causes depression in the disabled person. In a study by Kemp, Krause, and Adkins (1999), neither the level of injury nor the completeness of injury to the spinal cord were significantly related to depression, indicating that depression was unrelated to the severity of physical disability and must be related to some other cause. It is possible that the person's spiritual needs are not being met, or their spiritual well-being not assessed, resulting in depression and affecting their quality of life post injury.

In this study, depression is defined as a lack of harmony or peace with one's life situation, while experiencing feelings of hopelessness, helplessness and/or powerlessness for an extended period of time (more than two weeks), due to an unexpected crisis event, such as a spinal cord injury. This conceptualization is based on the main components of depressive symptomatology identified from clinical literature and factor analyses: depressed mood, feelings of guilt, worthlessness, helplessness, hopelessness, psychomotor retardation, loss of appetite, and sleep disturbances (Radloff, 1977).

Radloff's (1977) Center for Epidemiologic Studies Depression Scale (CES-D) was used to measure depression for this study.

### **Significance of Study**

This study was significant as it provides valuable information for nursing professionals caring for patients with spinal cord injury. Using Ferrell and Grant's Quality of Life Model, this study showed the interrelationships between spiritual well-being (religiosity and meaning), psychological well-being (depression), and quality of life with persons living with paraplegia. As such, further theory building of the model is possible beyond patients with cancer and end-of-life medical conditions. The model can be adapted to address persons who are encountering spinal cord injury; as well as other physical disabilities or neurological disorders.

There has been much research conducted on the quality of life and spiritual well-being of persons living with chronic and terminal illnesses, but limited research in persons with spinal cord injury. This study shows that there is a significant relationship between spiritual well-being, depression, and quality of life. As such, the need for further research looking at other modalities or spiritual interventions to enhance one's subjective quality of life following a spinal cord injury is necessary.

A positive relationship between spiritual well-being and quality of life has implications for spiritual care by clergy and nursing during the rehabilitation phase and beyond. Whether a person is dealing with chronic illness, terminal illness, or with a permanent disability, such as a spinal cord injury, one's faith or spirituality is tested. An individual's subjective quality of life determination can also be affected. Looking at a



patient's cultural norms and context, along with their religious or spiritual needs is a component of nursing practice and addressing these concerns may enhance the patient's journey through illness and recovery, possibly leading to successful rehabilitation and re-entry into the community setting following a spinal cord injury. The results of this study illustrate the importance of nurses performing a more thorough spiritual assessment as part of their initial and continuous patient assessment; as well as considering the implementation of some spiritual interventions.

## **Chapter 2**

### **REVIEW OF THE LITERATURE**

A priority of Healthy People 2010 is to help individuals of all ages increase life expectancy and improve their quality of life (Healthy People 2010, 2003). For spinal cord injury survivors an increase in life expectancy over the past decade is well documented (Hoeman, Lyszner, & Alverzo, 2007; National Spinal Cord Statistical Center, 2009). With this increased life expectancy, the potential for life threatening complications affecting the person's quality of life is evident (Brillhart, 2005; Chase, Cornille, & English, 2000). Although studies have indicated that people with spinal cord injury, on average, report a lower level of quality of life than the average person without an injury (Dijkers, 1997), a spinal cord injury does not necessarily lessen a person's quality of life (Brown, Gordon & Ragnarsson, 1987). Since individuals with spinal cord injury are expected to live longer, goal-setting and treatment planning should focus on achieving the highest level of quality of life possible considering age, culture, religion, person's choices, comorbidities, and premorbid functioning (Gerhart, Bergstrom, & Charlifue, 1993).

The Consortium for Spinal Cord Medicine has established clinical practice guidelines for health-care professionals looking at expected outcomes and measurement following traumatic spinal cord injury, addressing motor recovery, functional independence, social integration, and quality of life. Expected quality of life outcomes include: 1) assess quality of life for individuals with spinal cord injury using direct perceptions of the individual involved and 2) facilitate opportunities for optimal quality of life within the full continuum of health care and rehabilitation programs (Consortium for Spinal Cord Medicine, 1999, p. 1).

Analysis of factors that may influence quality of life may help to determine future interventions by nursing and other health care professionals in caring for persons with spinal cord injury. Although prior findings have shown associations of quality of life with support system attributes: social integration, mobility, occupation, and family roles (Dijkers, 1997), scientific study is needed to examine if there is also an association between spiritual well-being, depression, and quality of life for those living with spinal cord injury. In this chapter, the phenomenon of spiritual well-being and quality of life for those living with illness or disability will be presented. Depression and the effect it has on quality of life will also be discussed. First, Ferrell and Grant's (2000) quality of life model, serving as the guiding framework for this author's study, will be presented, followed by a thorough review of the science on spiritual well-being/spirituality, depression, and quality of life. Finally, an analysis and critique of the literature will be discussed.

## Conceptual Framework

To examine the relationship between spiritual well-being, depression, and quality of life for persons living with paraplegia, it was necessary to utilize an underlying conceptual framework. Ferrell and Grant's (2000) model of quality of life provided the conceptual framework which informs this study. As previously stated in chapter one, "quality of life model" encompasses the physical, psychological, social, and spiritual dimensions of the person (Ferrell & Grant, 2000; figure 1, Chapter 1). The dimensions are interrelated or bidirectional to quality of life. The relevance of one or several of the aspects within the dimensions may be affected by change in individual circumstances. Quality of life is defined differently from person to person. It can only be defined by the patient, based on his or her own life experiences, values, and beliefs (Ferrell, 2005). However, for purposes of the model, it is a personal sense of well-being encompassing physical, psychological, social, and spiritual dimensions (Ferrell, 1996). In this model, negative and positive characteristics are considered throughout the illness or dying experience (Ferrell, 2005).

*The physical well-being dimension* addresses the effect on the person from multiple symptoms due to disease progression, debility, and bodily changes. It looks at pain and fatigue, and how these symptoms affect the quality of life for the patient, their family members, or caregivers. The physical aspects of functional ability, sleep, rest, and appetite are evaluated as well (Ferrell, 2005). Ferrell and Grant's quality of life model has evolved over the years, adapting to various patient symptoms or conditions. For example, pain or fatigue, become the center of the model instead of quality of life, as it interrelates with the four dimensions. These different versions of the model clearly

illustrate how pain or fatigue, from cancer, become the focus point of one's quality of life (Ferrell, 1996; Ferrell, Grant, Dean, Funk, & Ly, 1996).

*The psychological well-being dimension* assesses the patient's social support resources, and communication methods and quality between the patient and others. The meaning of the illness to the patient and family is also discussed and can impact emotional responses. Depression, as a psychiatric syndrome, must be recognized as being different from the experience of sadness related to multiple losses in one's life. Also, the emotional responses of anxiety, fear, loneliness, denial/acceptance, and anger/guilt, are considered. How the patient is dealing with death and end-of-life issues are addressed in this dimension of the model as well. Self-esteem evaluation and decision-making capabilities are also assessed (Ferrell, 2005).

*The social well-being dimension* looks at the social dynamics and strength of the family unit. Relationships and roles usually change following an illness. Being a burden to the family is a common potential problem. Sexual functioning, care of children, and financial responsibilities affect one's quality of life as well (Ferrell, 2005).

*The spiritual well-being dimension*, used to inform this study, looks at the patient's religion, beliefs, values, and practices. Religion provides answers to questions asked about suffering, death, illness, and pain (Highfield, 2000). The spiritual well-being dimension goes beyond religion, looking at the "spiritual", as the person deals with losses and finds meaning in life (Borneman & Brown-Saltzman, 2006) or meaning in the life experience that is happening to the person (Cassidy & Davies, 2004). The search for the meaning of suffering, forgiveness, and acceptance also affects one's spiritual well-being (Ferrell, 2005).

The concept of suffering is included in the spiritual well-being dimension of the model. Suffering involves the whole person and transcends the physical, psychological, and spiritual dimensions. It can arise when any aspect of the person is threatened.

Failure to respond to the psychological and spiritual needs of the person coping with life threatening illnesses may further the degree or severity of suffering (Ferrell, 1996).

Lastly, this dimension addresses hope and despair, and how a person views their illness or death. Maintaining a person's definition or meaning of hope can enhance their quality of life and give meaning to their end-of-life experience (Ersek, 2006).

"Quality of life model" has been applied to studies of patients living with breast cancer (Ferrell, Grant, Funk, Otis-Green, & Garcia, 1997; Ferrell, Grant, Funk, Otis-Green, & Garcia, 1998), colon cancer (Krouse, Grant, Ferrell, Dean, Nelson, & Chu, 2007), cancer survivorship (Ferrell, Cullinane, Ervin, Melancon, Uman, & Juarez, 2005; Ferrell, Smith, Juarez, & Melancon, 2003), fatigue (Ferrell, Grant, Dean, Funk, & Ly, 1996), and pain (Ferrell, 1996).

This model was originally developed for the study of breast cancer patients and has been tested extensively from 1984 to the present. Initial validity was established with a convenience sample of 21 cancer survivors, representing three different age groups, responding to the following questions: 1) What are the items and domains of quality of life in breast cancer?, and 2) What is the impact of breast cancer on quality of life? In addition, three instruments were used to measure quality of life in breast cancer survivors: 1) QOL-Breast cancer version (revised based on an earlier QOL study of cancer survivorship), 2) semi-structured interview guide, and 3) Brief pain inventory. The QOL-Breast cancer version includes 43 items representing the four dimensions of

quality of life: psychological well-being (20 items), physical well-being (8 items), social well-being (8 items), and spiritual well-being (7 items). The semi-structured interview guide asked specific questions addressing the four dimensions of quality of life (Ferrell, Grant, Funk, Garcia, Otis-Green, & Schaffner, 1996).

Qualitatively, common areas of need were identified in all four dimensions, with the psychological domain demonstrating the greatest area of concern. Thirteen themes evolved when participants were asked, “What makes quality of life better or worst?” Throughout interviews with participants, regarding effects of treatment, constant themes were related to the four domains of quality of life and identified in the model.

Quantitatively, using the QOL-Breast cancer version instrument, the analysis regarding quality of life was limited due to the small sample size and qualitative focus. However, analyzing cultural issues was helpful due to its 43% ethnic minority representation of sample. Results were limited to descriptive statistics. Data from questions resulted in the following means, such as zero equals the worst outcome and ten equals the best outcome. The overall QOL-breast cancer score from all items was 6.53; psychological well-being (5.77), social well-being (6.76), physical well-being (7.37), and spiritual well-being (7.43) (Ferrell, Grant, Funk, Garcia, Otis-Green, & Schaffner, 1996). Findings from the QOL-Breast cancer instrument and qualitative analysis of interview data provided initial validity of the quality of life model used to study patients living with breast cancer.

Using focus group methodology, specific quality of life concerns of breast cancer survivors across the four domains of the quality of life model were identified. Through the use of a convenience sample, 16 women participated in one of three focus group

sessions. A semi-structured interview, addressing the domains of quality of life was conducted with each participant. Analysis of the interview data was used to facilitate discussion in the focus group settings. Quality of life themes emerged in all domains. One major theme frequently mentioned from the discussion on spiritual well-being was strength from faith (Ferrell, Grant, Funk, Otis-Green & Garcia, 1997).

Results of the qualitative, descriptive study evaluating the quality of life for the 21 breast cancer survivors previously discussed were later presented (Ferrell, Grant, Funk, Otis-Green, & Garcia, 1997a). Themes identified included the problem of pain during active treatment, fear of pain and future pain, fatigue, weight gain, menopause symptoms, fertility, vaginitis, nausea, and hearing loss (physical well-being). Social well-being themes centered on issues of work, family, and sexuality, due to loss of a breast, as well as vaginal changes (Ferrell, Grant, Funk, Otis-Green & Garcia, 1997a). Psychological well-being themes included concern for the future, survivorship, sources of psychological distress, and emotional responses to breast cancer. Three major themes were identified within the domain of spiritual well-being. One theme was the support of spirituality through: a) churches or other formal religious practices, and b) existential faith or beliefs to assist with cancer survival. Some women stated that they had not experienced any changes in spiritual needs during their illness. The second theme was the uncertainty of the future and signs of hope. The final theme was the disruption of altered life priorities, altered life meaning, and thoughts regarding transcendence from their current life to their death (Ferrell, Grant, Funk, Otis-Green, & Garcia, 1998). This study provided further support for the conceptual model of quality of life in the population of breast cancer survivors.



Spirituality or spiritual well-being is an important aspect of Ferrell and colleagues' quality of life model. Spirituality has been described as an aspect of quality of life for patients with cancer that includes religiosity, but also hopefulness, transcendence, and purpose (Ferrell, 1996). An ethnographic study, using a sample of 21,806 letters, cards, and emails from ovarian cancer survivors from 1994 through 2000, was conducted to describe spirituality and the meaning of illness by participants. Data came from members of a support group established through a newsletter. Findings showed that participation in religious activities through churches and prayer groups was a major support resource. Many believed that God was in control of their disease. Positive or negative experiences in spiritual well-being could occur. Whereas some women were thankful for each day of living and what God had given them, others felt loss of faith, uncertainty, and hopelessness. Other spiritual themes included a new purpose or reason to keep living, hopefulness, and mortality awareness (Ferrell, Smith, Juarez, & Melancon, 2003).

The Ferrell and Grant (2000) quality of life model informed this author's study by addressing the following questions: 1) is existential spiritual well-being (meaning and purpose in life) related to quality of life, 2) is religious spiritual well-being (relationship to a higher power) related to quality of life, and 3) is depression related to quality of life? This model was used to address these relationships among persons living with paraplegia for one year and longer. Even though Ferrell and Grant's (2000) quality of life model focuses on end-of-life issues, the model was applicable to those living with spinal cord injury as well.

### **Spiritual Well-Being and Terminal Illness**

There have been numerous studies conducted on the essence of spirituality and spiritual well-being of patients enduring chronic and terminal illnesses (Kaye & Raghausen, 2002). Spirituality and health related quality of life (HRQOL) for men with metastatic prostate cancer, was significantly correlated in a study conducted by Zavala, Maliski, Kwan, Fink, and Litwin (2009). Eighty-six subjects completed written questionnaires and phone interviews. Instruments included: a) The Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale (FACIT-Sp, Peterman, Fitchett, Brady, Hernandez, & Cella, 2002), measuring two domains of spiritual well-being: faith and meaning/peace; b) The RAND Medical Outcomes Study 12-item Health Survey (SF-12), version 2 (Ware Jr., Kosinski, & Keller, 1996), measuring health related quality of life, quantified in physical and mental domains, including an item to assess pain; and c) The UCLA Prostate Cancer Index (PCI) Short Form to evaluate disease-specific HRQOL urinary, bowel, and sexual functioning (Litwin, Hays, Fink, Ganz, Leake, & Brook (1998). Individuals scoring  $\leq 33$  on the FACIT-Sp were identified as having low spirituality or spiritual well-being; whereas a score  $> 33$  reflected a high spiritual well-being.

Results demonstrated that African American and Latino men with less than a high school education ranked the highest among FACIT-Sp total scores, and within the subscales of faith and meaning/peace (Zavala et al., 2009). Zavala and colleagues' also found that higher spirituality scores indicated higher HRQOL and psychosocial item scores. The meaning/peace subscale was also positively associated with six HRQOL and psychosocial items at  $p > .05$ ; whereas the main effect of faith was not significantly

related with any of the HRQOL items. Interestingly, high faith scores were inversely correlated with HRQOL. Faith scores trended downward as they were inversely related to HRQOL mental and physical components, including pain, urinary, and sexual functioning. However, if the participant had a high faith and meaning/peace rankings, this resulted in lower pain and enhanced physical functioning (Zavala et al., 2009).

The FACIT-Sp instrument was also used in a study by Whitford, Olver, and Peterson (2008), investigating the association between spiritual well-being and quality of life for cancer patients. The 449 Australians participating in this study were 57% Christian, but in contrast to most studies, a large percentage (42.5%) stated an absence or indifference to religion. Study analyses were conducted using Pearson product-moment correlations, hierarchical multiple regression, and chi square analyses to determine differences between low and high spiritual well-being scorers. Findings included a significant, positive relationship between SWB and Total QOL ( $r = .59, p = .000$ ), subscale meaning/peace and Total QOL ( $r = .69; p = .000$ ), and a weak significant relationship between faith and Total QOL ( $r = .25; p = .000$ ). Although Christians had higher faith scores compared to other groups, there was no difference in meaning/peace scores. It was found that having meaning/peace while living with cancer was associated with one's view of a good quality of life and was independent of one's faith tradition and practice (Whitford, Olver, & Peterson, 2008).

Through multiple regression, Whitford and colleagues' (2008) found that spiritual well-being made a unique addition to the person's overall quality of life assessment. While the person's physical, emotional, and social well-being accounted for 39% of the variance in QOL, the inclusion of SWB to the model increased the total variance of QOL

to 47% ( $R^2_{adj}$ ). Whitford and colleagues' (2008) reported that "the  $R^2$  change was significant at .08;  $F(1, 426) = 61.74, p = .000$ ," (p.1125). Other findings illustrated that persons with increased meaning/peace experienced life enjoyment despite their chronic symptoms; whereas persons with a strong faith indicator reported a lower incidence of finding enjoyment in life while dealing with cancer and its chronic symptoms, including pain (Whitford, Olver, & Peterson, 2008).

### **Spiritual Well-Being and Chronic Illness**

A cross-sectional quantitative study, examining spirituality and quality of life, was conducted with 101 adults living with HIV (Grimsley, 2006). A convenience sample was obtained from individuals attending a rural clinic in Georgia; therefore generalizations to the population are limited. Instrumentation included demographic data, the Spiritual Perspective Scale (SPS; Reed, 1986, 1987) and the WHOQOL short-form BREF instrument (World Health Organization, 1996). Eleven research questions were generated for the study looking at various relationships between the dependent variable quality of life, and the independent variables of spirituality, age, education, ethnicity, marital status, and gender. There was a positive significant relationship between spirituality and psychological quality of life ( $r = .31; p = .01$ ), and age and psychological quality of life ( $r = .20; p = .05$ ). A non significant difference in spirituality by gender, and a non significant positive relationship between age and spirituality and quality of life was determined.

Grimsley (2006) found a highly significant positive relationship between ethnicity and spirituality, with higher average spirituality scores reported for Black

participants than for the White participants. The belief that persons with higher education have higher quality of life was evident in this study ( $F = 3.28$ ;  $p = .05$ ), as well as a higher total spirituality score, even if not at a significant level ( $F = 3.28$ ;  $p = .23$ ). Marital status had little to no relationship with spirituality or quality of life. The findings support the notion that spirituality or spiritual well-being and quality of life have an association with HIV positive participants, and that spirituality exerted the largest independent effect on quality of life (Grimsley, 2006).

A study conducted by a group of University of Michigan researchers (Riley, Perna, Tate, Forchheimer, Anderson, & Luera, 1998), found that spiritual patients have a better quality of life than those who are not spiritual or have a low spiritual well-being. The purpose of the study was to determine classifications of well-being with patients experiencing chronic illness or disability, looking at their health, quality of life, and life satisfaction. Adult patients, which included 74 amputees, 37 post-polio patients, 36 women with breast cancer, 35 men with prostate cancer, and 34 patients with spinal cord injury, were studied.

Cluster analyses, using several quality of life outcome measures, were performed. Classifications of religious, existential, and non-spiritual were established. Scaled items from the Spiritual Well-Being Scale (SWBS) and the Functional Assessment of Cancer Therapy-Spiritual (FACT-SP) were used to compare and contrast the different versions of spirituality or spiritual well-being within the clusters. Significant cluster differences ( $p < .03$  to  $p < .001$ ) were observed across all quality of life domains and life satisfaction. However, the non-spiritual group had a significantly poorer quality of life and less life

satisfaction than the religious and existential groups, experiencing poorer health and less vitality (Riley et al., 1998).

Even though there was little difference in the quality of life between both spiritual groups, the religious patients were more at peace, more productive and purposeful, and less stressed regarding the future. Patients in the religious group found comfort and strength from their faith, while the existentialists, particularly those who had no relationship with God, enjoyed the highest degree of vitality and physical, social, emotional, and mental health function (Riley, et al., 1998).

A qualitative study conducted by Narayanesamy (2002) looked at the unique spiritual coping methods in 15 chronically ill patients in the United Kingdom. A purposive sample of ten men and five women between 23-80 years of age, indicating, either Christian (9), Hindu (2), or “no religion” (4), were used to explore this lived experience. Four participants were cancer patients, the other 11 were diagnosed with various chronic illnesses. Using descriptive phenomenology, 45-90 minute unstructured interviews were conducted. The interviews had an absence of specific questions, as the researcher was cautious to avoid suggestive or leading questions. Recurrent themes of spiritual coping interventions included the use of faith, prayer, and related sources of support. Five categories were established, such as “reaching out to God in the belief and faith that help will be forthcoming.” Study findings indicated participants viewed chronic illness as an experience in which spiritual coping methods were necessary to keep going. “Connecting with God or with another person made a difference in getting through the illness” was another finding (Narayanesamy, 2002).

The study had strong themes emphasizing the importance of addressing a patient's spiritual well-being. Limitations included the reflection of a mostly Judeo-Christian approach to coping, and the lack of separating the end-of-life context of someone who is dying and the context of someone who may live for years in chronic pain or discomfort. Context matters and someone with untreatable cancer or other disease may have different spiritual needs, as they are more focused on the next life and issues of forgiveness in the present life (Wright, 2002). Coping interventions of non-believers are different as well, even though connection with family and friends was the theme identified by these participants (Narayanesamy, 2002).

Walton, Craig, Derwinski-Robinson, and Weinert, (2004) conducted a qualitative study with ten chronically ill women who were participating in a larger quantitative study of 111 people, examining the link of spirituality and chronic illness. The larger, mostly female sample was recruited from rural areas in five U.S. states. For the qualitative portion, two phone interview questions were asked: "What does spirituality mean to you?" and "In what way does your illness relate to your spirituality?" Themes evolved: "My spirituality means the world to me", "I am not alone", "The need to put on a happy face because loved ones and society don't want to share in another's suffering", and "Recognition that others are in a worst situation than they are." Another theme was that participants were able to use spiritual coping methods to change despair into a feeling of hope and let go of despair (Walton, Craig, Derwinski-Robinson, & Weinert, 2004). The study was limited by the use of women participants only, ethnicity (Euro-American Caucasian population), and participants living in lower economic rural areas.

### **Spiritual Well-Being and Physical Disabilities**

McColl, Bickenbach, Johnston, Schumaker, Smith and colleagues (2000) explored spiritual issues associated with traumatic onset disability, using a qualitative design for theory building. The population studied included eight spinal cord injury persons and eight acute brain injury persons. A semi-structured interview was initiated to provide greater flexibility in the discussion of unanticipated aspects of spirituality. The purpose of this study was to answer the following questions: What spiritual issues do people raise following an onset of disability, and does the type of disability affect the spiritual issues one experiences? Analysis was done by NUO-IST (non-numeric unstructured data-informing, searching, and theorizing) and coded according to concept definitions. Using an inductive approach, a model was developed showing a horizontal axis of spirituality (relationship to self, to others, and with transcendence concepts) blending with a vertical axis of disability specific themes. Themes included awareness, closeness, dependency, purpose, and vulnerability.

Study results found that persons with brain injury placed more emphasis on family support, while persons with spinal cord injury took a spiritual direction focusing on their connection with a higher power and willingness to accept social support from family and friends for assistance in their needs (McColl, et al., 2000). The study used eight specific interview questions which clearly related to the spiritual well-being of the disabled, therefore the questions were useful for theory development. The concepts studied have clear definitions, but it would be helpful to test the taxonomy on larger samples and of different durations, perhaps performing a longitudinal study, to determine if the results differ over time.



A study by Boswell, Knight, Hamer, & McChesney (2001) showed a reciprocal relationship between spirituality and disability. Using a critical social feminist approach of knowing, the PI, who suffers from spastic cerebral palsy and quadriplegia, completed the interview process initially before giving it to six women with severe physical disabilities: cerebral palsy, quadriplegia, paraplegia, post-polio syndrome, and congenital glaucoma. Participants were 35 to 55 years of age, Caucasian, and practiced different Christian religions. These six women were part of a larger population involving adults living with a disability through purposive sampling.

The researcher, living with the experience, was a subjective viewer and was not separate from the participants' experience. The researcher understood the women's pain and story. The women reported that spirituality and disability were interrelated and described both concepts as being core dimensions of their lives. Disability shaped their views on spirituality, as their spirituality shaped their views on disability. The women were found to be more spiritual having the disability, then previously before living without the disability (Boswell, Knight, Hamer, & McChesney, 2001). This study provided the context of women's lives and the living experience of being disabled; clearly showing how a relationship exists between one's spirituality and having a disability.

Individuals who have physical disabilities are sometimes considered different or the "other" in society. Family members are not always compassionate or accepting of disabled adult persons, and often perceive the person's limitations as an inconvenience and burden. According to Nosek and Hughes (2001), the perception of being a burden, different, and sometimes useless, leads to poor self-concept and questioning whether or

not they are made in the image of God. There is limited literature available about what having a disability means from a religious perspective. However, a qualitative study by Treolar (2002) illustrated how persons with physical disabilities were living in thankfulness and joy, had a strong faith in God, and that their spiritual beliefs transcended them through the crisis. Their spiritual beliefs also provided meaning to their disability and helped with coping effectively.

Treolar's (2002) study consisted of interviewing 30 adults with a physical disability ( $n=13$ ) and family members of those with a disability ( $n=18$ ). All those interviewed were predominately Caucasian, Euro-American, and attended churches of a Christian-Bible base denomination. The purpose of the study was to explore how people with disabilities and their families used their spiritual beliefs to establish meaning for disability and to respond to the challenges of a disability. The participants were asked two questions addressing these issues, while also asking "what are your perspectives of the church's influences on your spiritual experience related to disability?" Findings indicated that participants with a disability experienced a spiritual challenge. If the individual relied on self, a brokenness of self occurred; whereas, if the individual relied on God, an increase in faith resulted (Treolar, 2002).

### **Spiritual Well-Being and Depression**

Coleman (2004) has conducted several studies looking at associations with spirituality relationships, such as spiritual well-being and depression for the African-American population living with HIV and AIDS. Coleman's conceptualization of spirituality or spiritual well-being stems from the propositions of Ellison's (1983)

Spiritual Well-Being Scale (SWBS). This descriptive correlational study examined the contribution of religious well-being (RWB) and existential well-being (EWB) to the mental health of 49 heterosexuals drawn from a larger data of 117 individuals, collected in California for an earlier study (Coleman & Holzemer, 1999). Methodology included the use of the SWBS and the Beck Depression Inventory (Beck, Ward, Mendleson, Mock, & Erbaugh, 1961). Regression analysis showed that having a higher sense of being and purpose (EWB) inversely correlated to the depression score. The predictors of EWB and RWB explained 32% of the variance in depression and were significant at  $p < .001$  (EWB) and  $p < .05$  (RWB) levels (Coleman, 2004). This study's findings, that RWB had a significant inverse relationship to depression, was in contrast to the Coleman & Holzemer (1999) study where only EWB showed a significant inverse relationship with depression. Coleman's (2004) study addresses the unique African-American spirituality, but lacks generalization to other cultural groups, as the sample was limited to African-Americans living with HIV and AIDS.

### **Depression and Spinal Cord Injury**

Disorders of depression are the most common form of psychological distress in spinal cord injury, and are more common in this population versus the non-disabled population (Elliot & Frank, 1996; Fuhrer, Rintala, Hart, Clearman, & Young, 1993). Frequency and severity of depression after spinal cord injury varies for each person with clinically significant symptoms affecting physical function ranging from 14% to 35% (Fuhrer et al, 1993) and major depression being reported in 10% to 15% of people with spinal cord injury (Elliot & Frank, 1996). Fuhrer and colleagues (1993) sampled 100

men and 40 women with spinal cord injury, using the Center for Epidemiologic Studies Depression Scale (CES-D, Radloff, 1977). The mean depression score of 12.1 (SD = 9.60) was higher for persons with spinal cord injury, than previously reported for the general population of 9.2 (SD = 8.6) and 8.7 (SD = 8.4), but not clinically significant as it is less than the cutoff point of 16 or greater.

Findings also indicated women had a higher incidence of depressive symptoms than men, and that mobility was a significant factor in the determination of depression (Fuhrer et al., 1993). There is evidence indicating that women tend to be more prone than men to depressive symptoms (Radloff, 1977). One of the possible reasons or variables could be the degree of mobility within one's home and community. In the Fuhrer et al. study, women reported being less mobile than men. This is important since less mobility was associated with behaviors representative of depressive symptomatology. Restrictive mobility may also contribute to or be a reflection of depressive symptoms experienced (Fuhrer et al, 1993). There was also no significant relationship between depression and the incidence of pressure ulcers or urinary tract infections, which are considered common complications following a spinal cord injury, and may affect the person's quality of life (Fuhrer et al, 1993).

In a later study, Kemp, Krause, and Adkins (1999) found ethnic differences in depressive symptoms, with Latino participants reporting more symptoms than either Caucasian or African-American participants. Using the Older Adult Health and Mood Questionnaire (Kemp & Adams, 1995) to measure depression, Krause, Kemp, and Coker (2000) found that 48% of 1,391 persons with spinal cord injury, reported clinically significant symptoms, with minority participants, especially women, at a higher risk.

That risk, however, declined if the participants had a high level of education or income. Age was also a factor in this study, as depressive symptoms were positively correlated with both age and age at injury onset. Depressive symptoms were most commonly found among those with the shortest and longest length of injury (Krause, Kemp, & Coker, 2000). Limitations to this study include the use of a cross-sectional design, precluding the determination of causality. Factors, such as whether or not the person is receiving managed care services, family unit stability, and home environment, also need evaluation in the cause of depressive symptoms.

### **Quality of Life and Spinal Cord Injury**

The emphasis that quality of life is a problem for persons incurring a spinal cord injury was well documented in a comparison study by Barker, Kendall, Amsters, Pershouse, Haines, and Kuipers (2009), which illustrated there was a significant lower quality of life between persons with spinal cord injury than those who were nondisabled based on the Australian norm ( $p < .001$ ). A random diverse sample of 270 participants, living with spinal cord injury was obtained from a statewide rehabilitation service. Participants, age ranging between 16 – 54 years, were equally divided into six age groups. Among several instruments used for this study, the WHOQOL-BREF Assessment (WHO, 1996) self report questionnaire measured categories of physical health, psychological health, social relationships, and perceived health and quality of life.

Correlation and regression analyses, followed by a 2 sample *t*-test to compare results with the Australian norm found the following: Although there was a significant difference between QOL for those with SCI (lower) and those without disability (higher);

level of injury, length of injury, and age had no significant bearing on study results. Decreased function, secondary impairments, activity limitations, and the inability to participate in community or social events were the causes or predictors explained for a poorer QOL (Barker et al., 2009). Secondary impairments had the highest correlation ( $sr = .51$ ;  $p = < .001$ ), and was the highest predictor variable accounting for 32% variance in QOL (Barker et al, 2009).

The association between quality of life and self-esteem for persons with paraplegia, living in Brazil, was studied by Blanes, Carmagnani, and Ferreira (2008). The population consisted of 60 individuals who primarily sustained their injury from firearms (63%), were uneducated, and held low income or undesirable jobs (74%). Quality of life was measured using The Medical Outcomes Study 36-Item Short Form Health Survey (SF-36), consisting of eight domains: physical functioning, role physical, bodily pain, general health, vitality, social functioning, role emotional, and mental health (Ware & Sherbourne, 1992). The Rosenberg Self Esteem (RSE) Scale (Rosenberg, 1965) was conducted to assess a person's self-esteem.

Higher scores on the SF-36 and the RSE instruments in this study's results reflected a person's best state of health or quality of life and enhanced self esteem. The lowest scores affecting quality of life were in the categories of physical and emotional roles, as well as physical functioning. A significant difference ( $p = .001$ ) was shown between mental health scores of persons who developed a pressure ulcer (57.5/100) and those who did not (78.45/100), as participants with pressure ulcers experienced "nervousness, depression, and despondency," (Blanes, Carmagnani, & Ferreira (2008, p. 19), as well as low self-esteem and occupation ( $p = .008$ ). Overall the results of this

study indicated that the participants who were living with pain, pressure ulcers, demeaning or lack of employment, poor vitality, or significant impaired physical function reported lower subjective quality of life (Blanes et al., 2008). Limitations of the study included a small sample size resulting in a low statistical power, and lack of generalization to the entire population due to limited diversity of sample characteristics (Blanes et al, 2008).

In contrast to Blanes and colleagues (2008), a longitudinal study by Charlifue and Gerhart (2004) reported a high perceived quality of life by persons with SCI, indicating that their perceived quality of life actually stabilizes over time. The authors emphasized that perceived quality of life generally looks at health and its complications post spinal cord injury, which is something one adapts to. In other words, although society may view a spinal cord injury as resulting in a poor quality of life, persons who are living with the injury indicate that there is an adjustment to make and gradually this occurs; it is just part of living and does not decrease their perceived quality of life and life satisfaction (Charlifue & Gerhart, 2004).

Over nine years, 189 participants from a British population were monitored and evaluated on the concepts: stress, life satisfaction, depression, and psychological well-being (Charlifue & Gerhart). These individuals were 43-83 years of age (mean = 59.4) and had a length of injury 29-55 years (mean = 36). Participants rated their quality of life as either “excellent/good,” “fair,” or “poor,” at different intervals. These ratings were correlated with the identified concepts. Quality of life ratings of “excellent/good” was 78.1% (initial interview), 82.8% (1<sup>st</sup> interval-3 years later), 75.5% (2<sup>nd</sup> interval-6 years later), and 75.2% (3<sup>rd</sup> interval-9 years later). Charlifue and Gerhart reported significant

relationships ( $p < .05$ ) between perceived quality of life and perceived well-being, depressive symptoms, and life satisfaction, each time participants responded to the measures of the Life Satisfaction Index (LSI, Wood, Wylie, & Sheafor, 1969), Index of Psychological Well-Being (IPWB, Berkman, 1971), and Center for Epidemiological Studies Depression (CES-D) Scale (Radloff, 1977). A significant correlation developed two of the three times that the Perceived Stress Scale (PSS, Cohen, Kamarek, & Mermelstein, 1983) was administered (Charlifue & Gerhart, 2004). Throughout the three interval time periods, later quality of life was not strongly predicted; however it was found that earlier subjective quality of life correlated with later stress, depression, and psychological well-being (Charlifue & Gerhart, 2004).

A longitudinal study by Stensman (1994) used interviews from 17 individuals with traumatic spinal cord injury between six months and five years after injury, to determine personal adjustment and quality of life. A total of 102 interviews were conducted over the five years at specific intervals with the 17 persons. The subjective quality of life was reported on a zero to ten interval scale at all interviews and showed four patterns. Findings indicated that five participants were coping well without much difference prior to injury. Six participants said they were coping better after an initial low quality of life in the first few years after injury. Two participants had an unstable quality of life, and four persons commented a low quality of life continuously throughout the experience, without any improvement. Severe pain, age above 35 years at the time of injury, and being blameless for the accident causing the injury, were factors related to poor coping and unstable quality of life (Stensman, 1994). A higher age at injury has



been correlated to difficulty in adjustment due to loss of energy and difficulty in adjusting to changes in life (Krause & Crewe, 1991).

In Stensman's (1994) study, the subjective report of quality of life was used to estimate coping degree, along with including a global judgment. The global judgment included categories of good coping, good coping after initial low quality of life, unstable coping, and unsatisfactory coping, for identification. "Good coping or stable" was reported by those with no physical complications or pain, and by those who were working following the injury. Those reporting "good coping" three to five years after the injury, were fairly young men; five living with quadriplegia, two with immediate pain, and one had problems with bowel management. Four of these participants returned back to work. The two "unstable coping" men had pain and other problems. They were not employed and were dependent for basic care in their daily life. Severe depression was reported by three persons in the "unsatisfactory coping" category. Findings of this study indicated independent persons with paraplegia had the highest response of "good coping or stable," concluding that having some control of caring for oneself and not being totally dependent on others can effect coping ability and perception of quality of life (Stensman, 1994).

### **Spiritual Well-being, Quality of life, and Spinal Cord Injury**

Mathesis, Tulskey, and Mathesis (2006) conducted a descriptive correlational study to determine if there was a relationship between spiritual coping and quality of life for 75 spinal cord injury survivors. A telephone interview survey with mostly Caucasian adult men, enrolled in the Northern New Jersey Spinal Cord Injury Model System, was

conducted. Measures included the Spiritual Well-Being Scale (SWBS; Ellison & Smith, 1991), Diener's Satisfaction with Life Scale (SWLS, Pavot & Diener, 1993), the Duke Health Profile (DHP, Parkerson, Broadhead, & Tse, 1990), the Craig Handicap Assessment and Reporting Technique (CHART, Whiteneck, Brooks, & Mellick, 1997), and demographic data looking at gender, age, marital status, ethnicity, employment, education, and level of injury. Quality of life was measured with the SWLS and the CHART. Global quality of life was measured with the General Health subscale of the DHP. Physical quality of life was measured with the Physical Independence and Mobility subscales of the CHART.

Almost all participants (98.7%) reported engaging in some type of spiritual belief or practice. Most individuals scored in the high range of the SWBS. Quality of life was found highest among participants who used existential spirituality as opposed to religious spiritual coping. Standard multiple regression analyses were done to determine if an association existed between spiritual well-being and quality of life. Existential spiritual well-being shared 27% variance with overall subjective quality of life. The relationship between spiritual well-being and quality of life was highly significant existentially, whereas religious spiritual well-being did not emerge as a significant predictor in any of the tested models. Quality of life appeared to be more related to a person's perspective and search for purpose in life, rather than related to a set of religious values or practices (Matheis, Tulskey & Matheis, 2006). These findings were consistent with previous studies discussed (McColl, et al, 1998; Riley et al., 1998). This study also supports the positive relationship reported between effective coping abilities and perceived quality of

life for both paraplegics ( $n = 20$ ) and tetraplegics ( $n = 20$ ), in a study by Nieves, Charter, & Aspinall (1991)

The strength of the study by Mathesis and colleagues' was acquiring an adequate sample size and the use of well established standardized instruments. Limitations included a sampling bias towards individuals living in one location and with persons with injury duration of one year or longer. Generalization to spinal cord injured persons living in other regions, especially those areas with a greater religious domination of faith practice or importance is unclear. The degree of spiritual coping for those who sustained a spinal cord injury closer to the initial onset of injury, or who were completing the rehabilitation process while hospitalized, were not presented in this study.

Brillhart (2005) also used a descriptive correlational design to examine the relationship between an individual's spiritual well-being and satisfaction with life of 230 long term spinal cord injury persons. Measures included The Satisfaction with Life Scale (SWLS, Pavot & Diener, 1993), Quality of Life Index (QLI, Ferrans & Powers, 1985), and a demographic data form. According to Ferrans and Powers (1992), Factor III of the QLI questionnaire focuses on the psychological/spiritual domains, dealing with peace of mind and one's faith in God. The SWLS and the Factor III of psychological/spiritual of the QLI had a positive significant correlation ( $r = .621, p = .001$ ), including both domains demonstrating positive correlations with life satisfaction, peace of mind ( $r = .65$ ) and faith in God ( $r = .47$ ), (Brillhart, 2005).

The findings of this study supported previous studies conducted by Freijat (1998) and Riley and colleagues (1998), which indicated that levels of life satisfaction correlated with levels of spirituality (Brillhart, 2005). The study included community-dwelling

persons with spinal cord injury nationwide, contacted by various health-related organizations, reaching a variety of participants. Limitations of the study were that 25% of participants studied were female and active religious participation or affiliation was not addressed. Looking at whether religious affiliation would have had any significant difference in study results would have been helpful. Adding a qualitative piece to this empirical study could have been beneficial as well, adding further insight to the relationships discussed.

### **Analysis and Critique of the Literature**

This literature review presented, discussed the phenomenon of spiritual well-being, spirituality, depression, and what effect or relationship it has on one's quality of life, satisfaction with life, and outcomes following injury or illness onset. Studies illustrated that quality of life is a concern for persons living with chronic illnesses and physical disabilities; that as individuals live longer, determining what will improve their health and subjective life satisfaction or quality of life matters. It is well documented that depression is an incidence with spinal cord injury survivors and that higher levels of depression resulted in poor quality of life perception. Studies showed that depression inversely affects the spiritual well-being of persons experiencing a major disease, such as HIV Positive/AIDS.

In the literature review, spiritual coping mechanisms were helpful to persons with chronic and terminal illnesses, enhancing their quality of life. It was also evident that practices of prayer, having faith, and having connection with family and friends made a difference in one's spiritual well-being and quality of life. Finally, the studies in this

chapter, found that there was a relationship between disability and spiritual well-being for persons with chronicity, terminal illnesses, and physical disabilities; as well as an association between spiritual well-being and quality of life for those living with cancer. Predominantly studies indicated that having meaning/peace or purpose in life (existential well-being) increased a person's quality of life. Although persons with disabilities and other illnesses showed strong spiritual well-being overall, incorporating religious practices and having a belief in a higher power (religious well-being), did not necessarily result in higher subjective quality of life.

Studies demonstrated that spiritual well-being and quality of life are interrelated using Ferrell and colleagues versions of their quality of life model, adapting it to mostly cancer survivors. The "Quality of Life Model" demonstrates how QOL interrelates with physical well-being qualities experienced by persons with SCI, such as decreased functional ability, decreased strength, higher levels of fatigue, difficulties with balancing rest and sleep. These persons also express feelings of fear, distress, anxiety, leisure activity limitations, and symptoms of pain and depression, which are qualities of the model's psychological well-being domain. Socially, a spinal cord injury can result in a financial crisis and caregiver burden; as well as dysfunctional relationships and sexual dysfunction. One's spiritual well-being is affected as *hope* is what is looked for, *meaning* in life and in the traumatic experience searched for, enduring a sense of *suffering* and loss of what life could have been, and lastly turning to one's faith tradition or higher power (*religiosity*) for comfort and direction (Ferrell & Grant, 2000, 2005).

As this chapter presented the model's interrelation between quality of life and the various elements within the four dimensions for persons with cancer or end-of-life

demands identified, the “Quality of Life Model was adapted for use with persons living with paraplegia. Since the demands and experience of illness or disability are similar, Ferrell and Grant’s (2000) Quality of Life Model informed this author’s study focusing on the dimensions of the spiritual well-being domain: meaning and religiosity, and within the psychological domain: the dimension of depression.

There are more than 1, 500 articles published on spiritual well-being or spirituality (Taylor, 2005); as well as a number of studies which have illustrated that health benefits increase to those patients with medical and psychological conditions, who have spiritual beliefs or practice religious rituals (Antonovsky, 1987). However, there is limited research on a spinal cord injured person’s spiritual well-being and its effect on their health or quality of life. Most research focuses on the spirituality or spiritual well-being of persons living with a chronic or terminal illness. Studies are mostly qualitative, although recently there is an increase in quantitative approaches. Qualitatively, there are beginnings of the critical social feminist method occurring as women and the disabled are able to share their stories and have their voices heard. These survivors of spinal cord injury can move forward, being emancipated from internal and external barriers of the lived experience, having hope that their life event might be better understood as “real” by those who have not suffered a life changing physical disability (Boswell, Knight, & Hamer, 2001).

A variety of instruments have been used to assess spirituality or spiritual well-being and health (Ellison & Poloutzian, 1982; Peterman, Fitchett, Brady, Hernandez, & Cella, 2002; Reed, 1986, 1987). Most instruments, however, are strongly Judeo-Christian biased, making it difficult to evaluate other beliefs. The results from studies

obtained from Christian, Euro-American adults, excluding Asian or Hispanic spirituality experiences; as well as those individuals who do not believe in a “god.”

More quantitative studies, looking at the extent to which quality of life is shaped by the potential health-related benefits or positive outcomes, associated with spirituality among persons living with spinal cord injury, are needed. Studies that focus on persons with spinal cord injury are few; these individuals are often part of the overall disabled population being studied. More studies looking at religion and disability, especially beyond the Judeo-Christian perspective, are needed.

Quality of life studies are numerous, sometimes referring to satisfaction with life (Brillhart, 2005; Mathesis, Tulskey, & Mathesis, 2006). However, quality of life in relationship to spirituality or spiritual well-being is rarely discussed. Often, it is part of the psychological domain in a study, but not necessarily a separate dimension. Ferrell and colleagues (1996, 1997a, 2000, 2003, 2005) clearly demonstrate the relationship between spiritual well-being and quality of life in their versions of the quality of life model. Quality of life studies for the spinal cord injured person are usually focused on functional ability, employment status, and family or social support resources, and are less concerned with the relationship to one’s spirituality (Barker, Kendall, Amsters, Pershouse, Haines, & Kuipers, 2009; Blanes, Carmagnani, & Ferreira, 2008; Glass, Jackson, Dutton, Charlifne, & Orritt, 1997; Putzke, Barrett, Richards, & DeVivo, 2002).

As the literature indicates, quality of life has a diversity of definitions and is often associated with life satisfaction. There is a lack of a unified approach for examining quality of life, as most quality of life scales have a variety of dimensions to assess; as

well as differences of when and how quality of life is measured (Ferrans & Powers, 1985; Pavot & Diener, 1993; WHO, 1996; Wood, Wylie, & Sheafor, 1969).

There are some studies looking at depression and quality of life for the person with spinal cord injury (Fuhrer, 1993; Krause, Kemp, & Coker, 2000), but rarely are spirituality and its effect on depression addressed. Coleman (2004), however, in his study illustrated how there is an inverse relationship between spiritual well-being and depression for African-American persons living with HIV positive or AIDS diagnoses. Further research is needed to examine spiritual well-being, depression, race/ethnicity, and quality of life for persons living with a spinal cord injury.



## **Chapter 3**

### **METHODOLOGY**

People with paraplegia are challenged in many ways; as such their quality of life and spiritual well-being can be affected. In recognizing the importance of faith in one's God or reason for survival following a catastrophic injury or illness, the overall purpose for this study was to examine the relationship between spiritual well-being and quality of life for persons living with paraplegia one year and longer. Ferrell and Grant's Quality of Life model (2000) supports the interrelatedness among the constructs of spiritual well-being (religiosity and meaning) and psychological well-being (depression) with a person's quality of life. This chapter provides a description of the research design, including how the constructs are operationalized. It will also discuss the sample and setting, data collection procedures, instrumentation, and analytic techniques. The protection of human subjects with the risks and benefits of study participation will also be presented.

## **Research Aims and Questions**

The specific aims of the study are as follows, and refer to persons living with paraplegia one year and longer:

### *Specific Aims*

Aim # 1: Characterize spiritual well-being (existential and religious), depression, and quality of life while living with paraplegia.

Question # 1: What is the level of spiritual well-being (existential and religious), depression, and quality of life among persons living with paraplegia?

Question #2a: Is there a statistically significant difference between quality of life mean scores among persons living with paraplegia by race/ethnicity?

Question #2b: Is there a statistically significant difference between quality of life mean scores among persons living with paraplegia by depression?

Question #2c: Is there a statistically significant difference between depression mean scores among persons living with paraplegia by race/ethnicity?

Aim # 2: Examine the relationship between spiritual well-being (existential and religious), depression, years/months post injury, selected demographic variables (age, gender), and quality of life while living with paraplegia.

Question # 3: What is the relationship of spiritual well-being (existential and religious), depression, length of time injured, age, gender, and quality of life for persons living with paraplegia?

### **Research Design**

A descriptive, correlational, cross-sectional design, with purposive sampling was selected for this study. Correlation designs are used to describe relationships among variables without seeking a cause and effect (Burns & Grove, 2007). This type of non-experimental design was appropriate for the current study because the intent was simply to assess whether or not a relationship exists between variables without concern for the original reason or cause of variables being studied (Burns & Grove, 2007; Polit and Beck, 2006). With this type of design, no manipulation or treatment of variables is necessary (Burns and Grove). “Cross-sectional designs are especially appropriate for describing the status of phenomena or relationships among phenomena at a fixed point,” (Polit & Beck, 2006, p. 192). A cross sectional design usually entails gathering information, or observing the subject at one specific time or moment. However, data from the participant might be collected more than once, within a brief time span, such as two times within one hour or one day (Polit and Beck).

The advantage of this design was ease in the use of instruments, the opportunity for participants to become more aware of their individual spiritual well-being, and the possibility that several relationships might be concluded, which could enhance the quality of life for persons living with paraplegia. Disadvantages included: (a) the inability to establish if constant relationships between variables could occur over time or change with new circumstances (Polit and Beck); (b) the possibility of faulty interpretation of data since participants from a pre-existing group were self-selected; (c) the use of a heterogeneous population, in which bias cannot be controlled, limiting the ability to generalize results (Polit & Beck). Clinic attendees were given an opportunity to participate in this research study, meeting certain criteria, and agreeing to it.

### **Independent Variables**

The independent variables for this study included spiritual well-being (religious and existential well-being), depression, age, gender, length of time post injury onset, and ethnicity.

*Spiritual well-being* is defined as the whole of the two dimensions of well-being, religious and existential. As discussed by Poloutzian and Ellison (1979), it involves a type of transcendence, moving beyond the present and reaching deep within oneself. According to Moberg and Brusek (1978), and for the purposes of this study, *religious well-being* (vertical) is defined as one's relationship with God or Supreme Being. It reflects a person's sense of satisfaction and positive connection with God (Ellison & Paloutzian, 1982). *Existential well-being* (horizontal) is defined as one's general sense of life satisfaction, meaning, and purpose, absent from any religious reference (Moberg &

Brusek). Spiritual well-being, religious well-being, and existential well-being were measured using the Spiritual Well-Being Scale (SWBS) (Ellison & Paloutzian).

*Depression* is defined as the incidence or level of experiencing clinical symptoms: “depressed mood, feelings of guilt and worthlessness, helplessness and hopelessness, psychomotor retardation, loss of appetite, and sleep disturbances” (Radloff, 1977, p. 386); occurring within a seven day period, and measured using the Center for Epidemiological Studies Depression (CES-D) Scale (Radloff).

*Age* is defined as how old the person is in years and was measured by self report on the patient demographic profile survey.

*Gender* is defined as either male or female and was measured by self report on the patient demographic profile survey.

*Length of injury* is defined as the amount of time in years and months since the onset of spinal cord injury. It was measured by self report on the patient demographic profile survey, subtracting the date of injury onset from the interview date.

*Ethnicity* is defined in the following categories: Hispanic, Black, White, Asian, American Indian, and other. It was measured by self report on the patient demographic profile questionnaire.

### **Dependent Variable**

*Quality of life* is defined as a subjective opinion about one’s experience of living based on what is internally important to the person, not considering external events, specific situations, or limitations (Kemp & Ettelson, 2001). It was measured using the Quality of Life Scale (Kemp & Kahan, 1995).

## Setting and Sample

The sample included patients with paraplegia who were outpatient clinic attendees at a large urban rehabilitation healthcare center in Southern California between October and December 2009. A purposive sample was obtained as patients were recruited through flyer advertisement and word of mouth in clinic settings. As inferred by Burns and Grove (2007), subjects participating in a study through the convenience or purposive approach, happen to be in the right place, at the right time; they are available solely by accident. Those consenting to participate in the study by signing a research study consent form, completed questionnaires on-site in a private room. The PI of this study read the items from the surveys directly, and recorded the participant's responses.

Inclusion criteria included: (a) spinal cord injury attendee who was classified as a paraplegic. Persons with paraplegia experience thoracic or lumbar cord injury resulting in loss or impaired movement and sensation in the legs (Laskowski-Jones, 2007); (b) participant's diagnosis of paraplegia date was one year or later; (c) participant was an adult; 18 years or older; (d) participant had the capacity to speak and read the English language; (e) willingness to participate in the study. Exclusion criteria included: (a) spinal cord injury clinic attendee classified as a tetraplegic. A person with tetraplegia has damage to the cervical region of the spine resulting in absence or partial use of both arms and legs (Laskowski-Jones); (b) a recently diagnosed spinal cord injury within the last year.

Based on power analysis (Cohen, 1988), with an alpha (level of significance) set at .05, a desired power of .80, and a moderate effect size, the appropriate number of participants for the current study was 98. However, according to Nunnally and Bernstein (1994), a minimum of 10 subjects per variable is acceptable for a stable regression

equation to occur. In this current study, six independent variables were analyzed through multiple regression. Thus, a final sample of 75 provided data for the analysis. A smaller sample could result in lesser representativeness and a higher probability of sampling error (Polit & Beck, 2006).

### **Data Collection**

Participants completed a survey comprised of a demographic profile questionnaire and three standardized measures. The three standardized measures included: (a) the Spiritual Well-Being Scale (SWBS) which measures religious and existential well-being (Ellison & Paloutzian, 1982); (b) the Center for Epidemiologic Studies Depression Scale (Radloff, 1977), which had been used to study the incidence of depression and spinal cord injury in community settings (Fuhrer, Rintala, Hart, Clearman, & Young, 1993; Miller, Anton, & Townson, 2008; Schulz & Decker, 1983); and (c) the Quality of Life Scale (Kemp & Kahan, 1995), which was used to measure the subjective quality of life directly of individuals who had sustained spinal cord injury and other impairments affecting their sensory and motor functioning (Kemp & Ettelson, 2001). The profile questionnaire collected data on incidence of pressure ulcers requiring hospitalization in the last year, age, gender, ethnicity, months/years post injury onset, education, employment status, support system including children, whether or not practicing religion, cause of injury, other medical conditions, and whether or not taking antidepressant medication. Approximately 45 minutes to an hour was required for completion of consent form, questionnaires, and additional sharing.

## Measures

The demographic items previously mentioned were presented in a self reported questionnaire to develop the individual's personal profile and to measure age, gender, ethnicity, and months/years post injury onset (See Appendix, Measures).

*The Spiritual Well-Being Scale* (SWBS; Ellison & Paloutzian, 1982) was used to measure the construct of spiritual well-being and consists of two subscales: Existential Well-Being (EWB) and Religious Well-Being (RWB). It is a 20-item Likert-type scale that was developed by Ellison and Paloutzian to assess a person's spiritual well-being from a vertical and horizontal perspective. According to Moberg & Brusek (1978), the vertical domain reflects a person's relationship with God and deals with religion, whereas the horizontal domain addresses meaning, purpose, and satisfaction with life. The scale (10 items each subscale) reflects the belief that SWB involves both dimensions (Ellison, 1983); for example, the statement, "I have a personally meaningful relationship with God" refers to RWB, and "I believe that there is some purpose in my life" refers to EWB. Possible responses and scoring for each item are the following: "Strongly Agree" = 1; "Moderately Agree" = 2; "Agree" = 3; "Disagree" = 4; "Moderately Disagree" = 5; and "Strongly Disagree" = 6. Scores from both subscales range from 6-60, while the total SWB ranges from 20-120. A higher total score represents a greater level of well-being. Reverse scoring is used for negatively worded items. Odd-numbered items assess religious well-being, whereas even-numbered items assess existential well-being.

Following factor analysis of the SWBS, the scale was administered to 100 student volunteers at the University of Idaho. Ellison and Paloutzian (1982) reported test-retest reliability coefficients for SWB (.93), RWB (.96) and EWB (.78), as well as face validity



and SWBS theoretical correlation with other scales such as the Intrinsic Religious Orientation, whose purpose was to measure spirituality.

Although the SWBS has demonstrated face validity and reliability, the potential for a biased effect toward a Judeo-Christian perspective has been noted by Ellison (1983), which could discourage some participants to answer honestly or cause discomfort in completing the survey. The Judeo-Christian view interprets God in personal terms, where God is present, not distant, but relational (O'Connor, 1992), which is in contrast to an Eastern religion perspective. Ellison (1983) indicated that it is possible for persons from other religions, such as Hinduism and Buddhism, to complete the scale if they can correctly understand the statements about relationship with God, as it relates to their own beliefs or philosophy. Another criticism of the scale is the problem of ceiling effects that result in extreme high scores from participants practicing specific Christian religious traditions, such as the Pentecostal denomination. However, when reviewing subjects who were experiencing difficulty with faith issues, the ceiling effect did not appear (Scott, Agresti & Fitchell, 1998). In the current study, scale items were assessed for multicollinearity ( $r > .90$ ) with the correlation less than .80. Alpha reliabilities obtained were SWB (.93), RWB (.95), and EWB (.88).

*The Center for Epidemiologic Studies Depression (CES-D) Scale* (Radloff, 1977) was used to study the construct of depression (See Appendix, Measures). The CES-D is a self report instrument and consists of 20 items that were selected from other validated depression scales, including the Beck Depression Index (BDI) and the Schedule for Affective Disorders (Radloff). The scale was developed for the purpose of determining the frequency of depressive symptoms occurring in persons of the general population (Miller, Anton, & Townson, 2008). According to Radloff, there are six major symptom

areas identified, representing the items presented in the instrument: depressed mood, guilt/worthlessness, helplessness/hopelessness, psychomotor retardation, loss of appetite, and sleep disturbances.

The CES-D requires respondents to indicate how often they experienced specific depressive symptoms in the past week, and the items are scored on a four-point Likert-type scale with the following ratings: “Rarely or none of the time (less than 1 day)” = zero; “Some or a little of the time (1-2 days)” = 1; “Occasionally or a moderate amount of the time (3-4 days)” = 2; and “Most or all of the time (5-7 days)” = 3. Scores can range from 0-60, with higher scores indicating a higher level of depressive symptomatology. A score of 16 or more is considered depressed (Radloff). Radloff noted that four positively worded items require reverse scoring and a total score with four or more blank responses becomes invalid. Examples of individual items on the CES-D include: “Were you bothered by things that usually don’t bother you?”, “Have you had trouble keeping your mind on what you are doing?”, and “Have you felt depressed?”

Radloff reported high internal consistency with Cronbach’s alphas of .84-.90 and test-retest reliability of .57. Hann, Winter, & Jacobsen (1999) reported an alpha > .85 in the CES-D measurement of depressive symptoms, experienced by cancer patients. Strong internal consistency of an alpha .91 and test retest reliability of .87 was demonstrated with the use of the CES-D, measuring depressive symptoms and spinal cord injury (Miller, Anton, & Townson). As illustrated, the reliability of the CES-D has been tested on several clinic populations (Radloff, 1977), community households (Comstock & Helsing, 1976), and with persons living with spinal cord injury (Miller, Anton, & Townson, 2001; Schulz & Decker, 1985), indicating that the scale has high internal consistency reliability, acceptable test-retest stability, and good construct

validity. In the current study, Cronbach's Alpha was .92, demonstrating strong reliability.

*The Quality of Life Scale* (Kemp & Kahan, 1995), developed at Rancho Los Amigos National Rehabilitation Center in Downey, California, was used to measure the construct of quality of life. Quality of life has been measured by various scales subjectively and objectively, questioning which method is most accurate for assessment. According to Dijkers (1999), objective measures are ideal for measuring quality of life in the community setting, considering a person's external needs and desires. For purposes of this study, quality of life was measured subjectively. According to Kemp and Ettelson (2001), "An objective definition stresses observable, countable objects or events in the environment or in the lives of persons to measure quality of life....a subjective approach stresses the person's own opinion about quality of life, basing it on what is important to the person" (p. 117). With this subjective approach, the person's own personal experience is realized and emphasized, instead of depending on outside events or external rewards to foster a good quality of life, such as personal income, education achievements, health status, or family relationships (Kemp & Ettelson). According to Kemp and Ettelson, it is believed that a person can determine his/her own personal quality of life, which might be very different than what society expects or anticipates. As such, even a person with a spinal cord injury can experience a positive quality of life.

Direct and indirect measures have been used to measure subjective quality of life. Indirectly, subjective quality of life is measured according to how a person rates life satisfaction to external events or values, as survey participants are asked to rate their satisfaction with physical health, family life, income, using a 4-point or 5-point rating scale (Kemp & Ettelson, 2001). In contrast, the Quality of Life Scale, a visual analog

method of measurement, facilitated a direct subjective approach to rate life satisfaction at the present moment, asking the individual the following: “Taking everything in your life into account, rate your current overall quality of life by placing an X on this 7-point scale.” Further instructions state: “A 7 means life is great; it’s really hard to imagine how it could be much better. A 1 means life is very distressing; it’s really hard to imagine how it could get much worse. A 4 means life is neither good nor bad.” (Kemp & Ettelson, 2001; Kemp & Kahan, 1995).

A visual analog scale requires the person to look at the position of two specific values or feelings, which are opposite from each other, marking the location of stimulus rating on an extended line between the extreme values (Burns and Grove, 2007). This type of scale has demonstrated accurate measurement in studies regarding personal attitudes and severity of clinical symptoms (Wewers & Lowe, 1990). The visual analog scale is useful in assisting the research investigator to study a person’s low, as well as high quality of life at the current moment in time (Kemp & Ettelson).

Kemp and Ettelson (2001) utilized the Quality of Life Scale (Kemp & Kahan, 1995) to measure the effects of living and aging with spinal cord injury. The evaluation of three questionnaires, addressing quality of life for disabled and nondisabled persons was performed. Following the scoring and analysis of the surveys, the Quality of Life Scale (Kemp & Kahan) was deemed equivalent to the other indirect methods of measurement. The scale had as much predictive validity as a longer measure of life satisfaction (11-item life satisfaction scale similar to that used by Fuhrer, Rintala, Hart, Clearman, & Young, 1992).

Kemp and Ettelson (2001) reported a moderate correlation between the Quality of Life Scale and the Life Satisfaction Scale ( $r = .60$ ;  $p < .001$ ). It was also noted that the

disabled scored a mean of 5.1 on the QOL Scale; whereas the nondisabled scored a 6.0. In similarity, the current study produced a mean of 5.24 for persons with paraplegia. Scores of 6-7 are viewed as high QOL; whereas scores of 1-4 indicate a low QOL, as based on observed clustering of participant scores (Kemp & Ettelson). The results from this study supported that persons with spinal cord injury and other disabling conditions had the capacity to make an accurate assessment about their quality of life with this direct, subjective, and visual scale (Kemp & Ettelson). Kemp and Ettelson illustrated that the one item on the visual analog scale presented face validity to participants in the study, as well as a high test-retest reliability of .91. This was evident as participants repeated same scale ratings a month later, and therefore agreement was present. Whenever agreement is present, a score is within one unit of the previous score obtained (Kemp & Ettelson).

### **Data Analysis**

Data analysis was conducted using the SPSS, version 16, statistical software program. Descriptive statistics, analysis of variance (ANOVAs), and multivariate progressions were computed.

“Descriptive statistics are used to describe or characterize data by summarizing them into more understandable terms without losing or distorting much of the information,” (Munro, 2005, p. 4). Descriptive statistics of each item scored per instrument, as well as for each variable studied, were performed. Frequencies of all the variables and demographic data were also obtained. Summary tables and charts are presented in Chapter 4.

calculation of a Pearson's  $r$  and establishment of a two-dimensional correlational matrix was established (Polit & Beck, 2006). According to Polit and Beck, this is important as relationships between two variables are usually described through correlational procedures. The calculation of a correlational coefficient (Pearson's  $r$ ) was determined to help answer questions regarding the existence of relationships between the variables being studied. According to Polit and Beck, correlational coefficients ranging between .00 and + 1.00 indicate a positive relationship; whereas correlational coefficients between .00 and -1.00 express a negative or inverse relationship. An absence of a relationship between two variables results in a correlational coefficient of zero; whereas a correlational coefficient of .20, for example, demonstrates a low relationship between variables (Burns & Grove, 2007).

Six independent (predictor) variables were studied to determine if a possible relationship existed between them and one dependent variable, quality of life. As such, the calculation of the multiple correlation coefficient ( $R$ ) was the next step in analysis. The coefficient varies from .00 to 1.00, does not reflect any negative value or direction, and is helpful in assessing the relational strength of variables (Polit & Beck, 2006). According to Polit and Beck, the multiple correlational coefficient ( $R$ ) helps in determining the true significance that all the independent variables as a group play in predicting an outcome (dependent variable). The  $R$  value provides a greater understanding of what is affecting the established relationship through inclusion of more independent variables, providing greater information to the study results (Polit & Beck). This is accomplished through the process of multiple regressions. As stated by Polit and Beck, "Multiple regression analysis indicates whether an independent variable is significantly related to the dependent variable even after the other predictor variables are

controlled” (p. 379). For the purposes of this study, standard multiple regressions were performed to analyze the data.

Standard regression entails that all independent variables be placed together simultaneously to establish a prediction model (Mertler & Vannatta, 2005). This was done in a similar way as to putting all ingredients of a cake mixture together, in no particular order, and mixing them up in a bowl. Initially the independent variables of RWB, EWB, CES-D, age, gender, and years/months post injury were entered for Model 1. Additionally two other standard or simultaneous regressions were conducted, first entering four variables of SWB Total, CES-D, gender, and years/months post injury, followed by the insertion of three variables of SWB Total, CES-D, and years/months post injury (Models 2 and 3). The entry of these variables resulted in a final *R* calculation and an ANOVA presentation, assessing for any differences among groups. The ANOVA value is useful in determining the statistical significance of the *R* result following multiple regression analysis, which is possible through computing an *F* ratio (Munro, 2005).

Following the multiple regressions, the *R* value was squared in order to explain what percentage of the independent variables accounted for the variance in the dependent variable. This is a valuable statistic in determining how much variance of the dependent variable is due to unknown reasons or unmeasured factors (Polit & Beck).

Finally, two analysis of variance (ANOVA) tests, one-tail method, were performed to: (a) determine if there were any significant differences between ethnic groups studied and their subjective quality of life, and (b) if there were any significant differences between persons who scored 16 and higher on the CES-D Scale (depressed), versus those who scored below 16 and their subjective quality of life.

ANOVAs are conducted for the purposes of determining if there are differences between or within group variable means, examining data from two or more groups (Burns & Grove, 2007). A total variance was calculated since both types of variances were assessed for ethnicity (six groups) and presence or absence of depression (two groups). Since six ethnic groups participated in this study, and ethnicity is a categorical variable, an ANOVA was performed to address quality of life, instead of correlational analysis.

### **Human Subjects Protection**

Institutional Review Board approval was obtained through the standard regulatory procedures at the rehabilitation facility and at the University of San Diego, CA. All subjects completed a consent form prior to participating in this current study. All study data was coded by numbers and personal information de-identified to protect the identities of respondents. All source documents were stored in a locked cabinet in the researcher's home. The PI of this study was the only person having access to the locked cabinet. There was no use of electronic data or patient chart review necessary to complete this study.

All research studies have potential risks and benefits which were clearly identified in the informed consent. Possible risks from this research study included anxiety and discomfort from answering questions which dealt with depressive symptoms and spiritual well-being. Fatigue was also a concern, since the estimated time of survey completion was 45-60 minutes. In order to decrease these risks, participants had the option to complete the questionnaire the day of consent, reschedule to another day, or finish it at another time. Participants were assured that it was acceptable to refuse to participate without any negative consequences to them in the present or in the future. Participants



were also told that they could withdraw from the study at any time even if they had already started the study. Completed questionnaires and consent forms were placed in separate sealed envelopes in the locked cabinet. Questionnaires were labeled with a client number code, and known only to the research investigator, for analysis in a private location. None of the 75 participants reported any feelings of emotional distress or physical discomfort. All subjects who signed a consent form to participate in the study completed the survey on the same day.

Possible benefits included the opportunity for the participant to have a greater awareness of their own spiritual well-being and whether or not they were experiencing any symptoms of depression, leading to consultation with their SCI clinic primary physician for possible monitoring if necessary. This study might have also resulted in the participant seeking out spiritual care by clergy or nursing, as well as in the awakening of the participant's faith experience with God. Many participants freely shared their personal faith stories or what gives them positive quality of life following the completion of the survey. Often times, participants just wanted to express how their spiritual well-being had changed or been affected by their spinal cord injury experience. Even if the participant had not benefit from the study in any direct way, indirectly he or she was contributing to the body of nursing and behavioral science, and to the health assessment and care of patients in the future. Their input is of value and importance to the potential well-being and quality of life of persons living with paraplegia today and tomorrow.

## **Chapter 4**

### **RESULTS**

The purpose of this study was to examine the relationships between spiritual well-being, depression, and quality of life for persons living with paraplegia one year and longer. In this chapter the study findings are presented. First a descriptive profile of participants, including their scores on the independent variables of spiritual well-being (religious and existential), depression, and the dependent variable of quality of life is presented. The chapter concludes with the findings associated to the specific research questions identified.

#### **Characteristics of the Sample**

Data was obtained from 75 participants who attended clinic appointments at a rehabilitation facility between October and December 2009. The patients ranged in age from 18 to 78 years with the majority (96%) between 18-57 years, male (82.7%), minority (92.9%); 56% Hispanic and 29.3% Black. The etiology of injury for most participants (69.3%) was a gunshot wound, with the length of injury ranging between 1 year and 39 years. Approximately a quarter (22.7%) had less than a high school

education, although 45.3% had some degree of college education with 13.3% receiving a Bachelors' or Masters' Degree. A high percentage (85.3) lacked current employment, and 57.3% were not actively involved in support, sports, or church groups. Religious affiliation was primarily from the Christian denomination (82.7%). Nine subjects (12%) did not communicate a religious preference; however these persons did state belief in a God or Supreme Being. Forty percent of participants were either married (21.3%) or had a significant partner in their lives (18.7%); forty percent stated they were single. A majority had children (56%), but of those 42 subjects, only 18 (42.9%) were living in the same household. Approximately two thirds (64%) scored below 16 on the CES-D scale, illustrating an absence of depression (Radloff, 1977); and only eight participants (10.7%) were currently prescribed antidepressant medication. See Table 1 for further sample characteristics.

**Table 1****Subject Characteristics: (n = 75)**

Characteristic	Variable	n	Percentage
Gender	Male	62	82.7
	Female	13	17.3
Age	18-37 years	28	37.3
	38-57 years	44	58.7
	58-78 years	3	4.0
Ethnicity	Hispanic	42	56.0
	Black	22	29.3
	Asian	5	6.7
	White	4	5.3
	Native American	1	1.3
	Armenian	1	1.3
Cause of Injury	Gunshot Wound	52	69.3
	Motor Vehicle Accident	12	16.0
	Medical Complication	7	9.3
	Miscellaneous Accident	2	2.7
	Occupational Injury	1	1.3
	Stab Wound	1	1.3
Months/years post Injury	1 - 11 years	22	29.3
	11-21 years	29	38.7
	21-31 years	21	28.0
	31-39 years	3	4.0

**Table 1 continued**

Characteristic	Variable	n	Percentage
Education	Less than High School	17	22.7
	High School or GED	24	32.0
	Some College	24	32.0
	Bachelors' Degree	7	9.3
	Masters' Degree	3	4.0
Employment	Currently Employed	11	14.7
	Not Employed	64	85.3
Marital Status	Married	16	21.3
	Significant Other	14	18.7
	Single	32	42.7
	Divorced	7	9.3
	Separated	4	5.3
	Widow/Widower	2	2.7
Children	Yes	42	56.0
	No	33	44.0
Children Living with Participant (n = 42)	Yes	18	42.9
	No	24	57.1

**Table 1 continued**

Characteristic	Variable	n	Percentage
Religion	Catholic	29	38.7
	Christian	24	32.0
	Baptist	8	10.7
	Islam	3	4.0
	Methodist	1	1.3
	Buddhism	1	1.3
	None Identified	9	12.0
Practicing Religion (n = 66)	Yes	40	60.6
	No	26	39.4
Other Social Support Systems/Socialization: Involved in Support, Sports, or Church Groups	Yes	32	42.7
	No	43	57.3
Incidence of Depression	Scored 16 or Higher on CES-D: Depressed	27	36.0
Absence of Depression	Scored below 16 on CES-D: Not Depressed	48	64.0
Taking Antidepressant Medication	Yes	8	10.7
	No	67	89.3
History of Pressure Ulcer in the last year requiring hospitalization	Yes	17	22.7
	No	58	77.3

Note: n = Number of participants; Practicing religion refers to whether or not the person goes to church and/or follows the doctrine and rituals of their faith community.

## Findings Related to the Research Aims and Questions

Aim # 1: Characterize spiritual well-being (existential and religious), depression, and quality of life while living with paraplegia.

Question #1: What is the level of spiritual well-being (existential and religious), depression, and quality of life among persons living with paraplegia?

Means, standard deviations, and Confidence Intervals (CI) were computed for the overall and subscale scores of the study sample and are presented in Table 2.

The mean scores of spiritual well-being (SWB Total) (100.87, sd = 16.03)), RWB (51.97, sd = 9.57), and EWB (48.89, sd = 8.80), were relatively high, indicating strong spiritual well-being. The CES-D mean (13.27, sd = 11.90)) was 2.73 points below the cutoff score of 16 (depressive symptomatology), illustrating that persons in this sample, on an average, did not demonstrate significant amount of depressive symptoms to be classified *depressed*, according to Radloff (1977). Participants also viewed their quality of life better than, *it's neither good nor bad*, with a mean of 5.24, sd = 1.47. As such, despite living with paraplegia, participants responded that life is still good. The study was well represented throughout the adult lifespan, including the young adult to the elderly injured. The average number of years living with paraplegia was 16.65, sd = 9.56 years.

**Table 2****Descriptive Statistics of Variables**

Variable	n	Range	M	SD	95% CI
Age	75	22-78 years	40.65	10.79	38.21-43.09
Years/months post Injury	75	1-38 years/ 4 months	16.66	9.56	14.50-18.82
RWB	75	21-60	51.97	9.57	49.80-54.14
EWB	75	30-60	48.89	8.80	46.90-50.88
SWB Total	75	56-120	100.87	16.03	97.24-104.50
CES-D	75	0-56	13.27	11.90	10.58-15.96
QOL	75	1-7	5.24	1.47	4.91-5.57
Length of time taking Antidepressant medication	8	1-15 yrs	5.88 yrs	5.82	1.85-9.91

Note: n = Number of Participants; range = minimum and maximum value/score obtained; QOL= Quality of Life; RWB = Religious Well-Being Subscale; EWB = Existential Well-Being Subscale; SWB Total = Spiritual Well Being Total score; CES-D = Center of Epidemiologic Studies-Depression Scale; M = mean/average; SD = Standard Deviation; CI = Confidence Interval at 95%

Instrument item scores which resulted in high mean values are presented in Table 3.



**Table 3****Descriptive Statistics of Selected SWBS and CES-D Items: (n = 75)**

Item	Range	Mean	SD	95% CI
I believe that God loves me and cares about me (RWB).	1-6	5.49	1.04	5.23-5.75
I have a personally meaningful relationship with God (RWB).	1-6	5.04	1.21	4.77-5.31
I believe that God is concerned about my problems (RWB).	1-6	5.39	1.13	5.13-5.65
My relationship with God helps me not to feel lonely (RWB).	1-6	5.16	1.31	4.86-5.46
I feel most fulfilled when I am in close communion with God (RWB).	2-6	5.17	1.17	4.91-5.43
My relationship with God contributes to my sense of well-being (RWB).	2-6	5.24	1.07	5.00-5.48
I feel that life is a positive experience (EWB).	2-6	5.21	1.02	4.98-5.44
I believe that there is some real purpose in life (EWB).	3-6	5.59	0.82	5.40-5.68
I felt that everything I did was a real effort (CES-D).	0-3	1.45	1.20	1.18-1.72
My sleep was restless (CES-D).	0-3	1.11	1.81	0.70-1.52

Note: n = Number of participants; SWBS = Spiritual Well-Being Scale Total (Ellison & Paloutzian (1982); RWB = Religious Well-Being subscale (Ellison & Paloutzian); EWB = Existential Well-Being subscale (Ellison & Paloutzian); CES-D = Center for Epidemiologic Studies-Depression Scale (Radloff, 1977); range = minimum and maximum score obtained; M = mean/average; SD = Standard Deviation; CI = Confidence Interval at 95%.

Question #2a: Is there a statistically significant difference between quality of life mean scores among persons living with paraplegia by race/ethnicity?

Question #2b: Is there a statistically significant difference between quality of life mean scores among persons living with paraplegia by depression?

Question #2c: Is there a statistically significant difference between depression mean scores among persons living with paraplegia by race/ethnicity?

One way ANOVA indicated there was no statistically significant difference on the quality of life mean scores by race/ethnicity,  $F(5,69) = .410, p = .84$ , or by those classified as depressed ( $CES-D > 15$ ),  $F(5,69) = .753, p = .58$ . There was no statistically significant difference on the depression mean scores by race/ethnicity,  $F(5,69) = .696, p = .63$ .

Aim #2: Examine the relationship between spiritual well-being (existential and religious), depression, years/months post injury, selected demographic variables (age, gender), and quality of life while living with paraplegia.

Question #3: What is the relationship of spiritual well-being (existential and religious), depression, length of time injured, age, gender, and quality of life for persons living with paraplegia?

A correlational matrix (Table 4) was computed to identify the potential for multicollinearity among the continuous predictor variables. Multicollinearity exists when independent variables are highly correlated with each other (Huck, 2007); as argued by Munro (2005), problems are indicated when correlations are greater than .85. A review of the correlation matrix found multicollinearity was not a problem.

**Table 4**

**Correlation Matrix of Predictor Variables**

Variable	1	2	3	4	5	6
1. Gender	--	--	--	--	--	--
2. Age	-.057	--	--	--	--	--
3. Length of injury	.050	.496**	--	--	--	--
4. RWB	.087	.075	.071	--	--	--
5. EWB	.038	-.011	.149	.523**	--	--
6. CES-D	.014	.049	-.077	-.191	-.655**	--

Note: \*\* Correlation is significant at the .01 level (2-tailed). The numbers from the variables listed on the left column indicate the same variables as the numbers across the top of the table.

**Table 5****Correlation Matrix of Predictor Variables**

Variable	1	2	3	4	5
1. Gender	--	--	--	--	--
2. Age	-.057	--	--	--	--
3. Length of injury	.050	.496**	--	--	--
4. SWBS Total	.072	.039	.124	--	--
5. CES-D	.014	.049	-.077	-.473	--

As can be seen in Tables 4 and 5, age was significantly positively related to length of injury, older participants reported a longer time of being paralyzed. Religious spiritual well-being was positively correlated with existential well-being. Existential well-being had a significant inverse relationship with depression. Total well-being had a significant inverse relationship with depression.

Next a correlation matrix was computed to examine the relationships between the key continuous independent variables and quality of life (Table 6).

**Table 6**

**Pearson Product-Moment (  $r$  ) Correlations between Spiritual Well-Being (existential and religious), Depression, Length of Injury, Gender, Age, and Quality of Life**

<u>Independent Variables</u>	<u>Quality of Life ( <math>r</math> )</u>
Spiritual well-being (SWBS total)	.47**
Existential (EWB)	.63**
Religious (RWB)	.21
Depression (CES-D)	-.59**
Length of Injury	.10
Gender	.19
Age	-.05

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Note:  $n = 75$ ; \*\*  $p = .01$  (2-tailed)

Existential well-being had a strong positive correlation ( $r = .628, p = .01$ ), spiritual well-being total score had a moderate positive correlation ( $r = .47, p = .01$ ), and depression had a large inverse correlation ( $r = -.59, p = .01$ ) with quality of life. Religious well-being trended toward a small positive correlation with quality of life ( $r = .216, p = .06$ ).

To examine which predictors influence the quality of life of persons with paraplegia, three regression models were generated. Several regression models were generated to determine if there would be differences in the primary predictors of quality of life. First, a simultaneous multiple regression was generated to determine the accuracy of the independent variables: spiritual well-being (existential and religious), depression, length of time injured, gender, age, in predicting patient's quality of life (Table 7).

**Table 7****Regression Analysis of Paraplegic Patient's Quality of Life on Six Predictor Variables**

Predictor Variable (Independent Variable)	B	$\beta$	Standard Error (SE)	<i>t</i>	<i>p</i> -value
Age	-.003	-.02	.01	-.23	.13
Gender	.71	.18	.34	2.09	.04
Length of Injury	.002	.02	.02	.15	.88
RWB	-.02	-.11	.02	-1.03	.31
EWB	.08	.48	.02	3.52	.001
CES-D	-.04	-.29	.02	-2.49	.02

Multiple R = .70      R squared<sub>adjusted</sub> = .45  
R squared = .49       $F(6, 69) = 10.92, p = .000$

Note: RWB = Religious well-being Subscale; EWB = Existential well-being subscale; CES-D = Center for Epidemiologic Studies-Depression Scale; B = regression coefficient; SE = Standard Error;  $\beta$  = Beta Coefficient; *t* = *t* test statistic comparing a difference between means of two groups; *p* = significance; *F* = *F* ratio: variation between and within groups; *R* = multiple correlation coefficient;  $R^2$  = amount of variance in dependent variable due to the independent variable (Polit & Beck, 2006).

Regression results indicate that the overall model significantly predicts quality of life,  $= .49, R^2_{adj} = .45, F(6, 68) = 10.92, p < .001$ . This model accounts for 49 percent of the variance in paraplegics' quality of life. A summary of the regression coefficients is presented in Table 6 and indicates three (gender, EWB, and depression) of the six variables significantly contributed to the model.

Next, a simultaneous multiple regression was generated to determine the accuracy of the independent variables: spiritual well being (total scores), depression, length of time injured, gender, age, and quality of life (Table 8).

**Table 8****Regression Analysis of Paraplegic Patient's Quality of Life on Five Predictor Variables**

Independent Variable	B	$\beta$	Standard Error	<i>t</i>	<i>p</i> -value
Age	-.008	-.06	.02	-.54	.59
Gender	.67	.17	.36	1.90	.06
Length of Injury	.01	.09	.02	.51	.61
SWB	.02	.23	.01	2.23	.03
CES-D	-.06	-.48	.01	-4.57	.00
Multiple R = .66 $R^2_{adj} = .39$					
$R^2 = .43$ $F(5, 69) = 10.45, p = .000$					

Note: RWB = Religious well-being Subscale; EWB = Existential well-being subscale; CES-D = Center for Epidemiologic Studies-Depression Scale; B = regression coefficient; SE = Standard Error;  $\beta$  = Beta Coefficient; *t* = *t* test statistic comparing a difference between means of two groups; *p* = significance; *F* = *F* ratio: variation between and within groups; *R* = multiple correlation coefficient;  $R^2$  = amount of variance in dependent variable due to the independent variable (Polit & Beck, 2006).

Regression results indicate the overall model significantly predicts quality of life,  $R^2 = .43$ ,  $R^2_{adj} = .39$ ,  $F(5, 69) = 10.48$ ,  $p < .001$ . This model accounts for 43 percent of the variance in the paraplegic's quality of life. A summary of the regression coefficients is presented in Table 8 and indicates two (SWB Total and depression) of the five variables significantly contributed to the model.

A simultaneous multiple regression was done to determine the accuracy of the primary variables of interest: spiritual well being (total scores), depression, length of injury, and gender (Table 9).

**Table 9****Regression Analysis of Paraplegic Patient's Quality of Life on Four Predictor Variables**

Independent Variable	B	$\beta$	Standard Error	<i>t</i>	<i>p</i> -value
Gender	.69	.18	.35	1.97	.05
Length of Injury	.004	.03	.02	.28	.78
SWB	.02	.23	.009	2.23	.03
CES-D	-.06	-.48	.01	-4.68	.00
Multiple R = .66 $R^2_{adj} = .40$ $R^2 = .43$ $F(4, 70) = 13.12, p = .000\backslash$					

Note: RWB = Religious well-being Subscale; EWB = Existential well-being subscale; CES-D = Center for Epidemiologic Studies-Depression Scale; B = regression coefficient; SE = Standard Error; Beta = Beta Coefficient; *t* = *t* test statistic comparing a difference between means of two groups; *p* = significance; *F* = *F* ratio: variation between and within groups; *R* = multiple correlation coefficient;  $R^2$  = amount of variance in dependent variable due to the independent variable (Polit & Beck, 2006).

Regression results indicate that the overall model significantly predicts quality of life,  $R^2 = .43$ ,  $R^2_{adj} = .40$ ,  $F(4,70) = 13.12$ ,  $p < .001$ . This model accounts for 43 percent of the variance in paraplegics' quality of life. A summary of the regression coefficients is presented in Table 9 and indicates three (gender, SWB, and depression) of the four variables significantly contributed to the model.

### Summary

In this chapter, the results following data analysis was presented. Initially sample characteristics were described, continuing with the process of multiple regressions of variables. Four different models are illustrated inserting one less variable each time. The



research questions were answered. The aims of the study to examine the relationships between spiritual well-being (religious and existential), age, gender, length of injury, and quality of life were accomplished, and demonstrated by the findings presented in correlation coefficients (Pearson  $r$  calculations) and multiple variable predictor analysis.

## **Chapter 5**

### **DISCUSSION OF FINDINGS**

This chapter will discuss the research design and methods, data analysis and overall study results in relationship to the literature presented, as well as how it is linked to the “Quality of Life Model,” which provided the conceptual framework for this study. In addition to responding to the study’s research questions and aims, the implications for nursing theory, practice, and education will be presented. Recommendations for future nursing research, using different approaches and methodology will also be discussed.

This study was conducted between October and December 2010 in a large rehabilitation facility in Southern California. The Sample consisted of 75 participants who sustained a diagnosis of paraplegia and had been injured one through 39 years. All participants completed the three standardized instruments surveyed and demographic profile. The results of the questionnaires were analyzed through Pearson Product - Moment ( $r$ ) correlations and multiple regressions. The majority of participants were male and of the Hispanic and Black ethnic descent, ranging in age from 18 to 78 years.

### Research Questions

Question #1: *What is the level of SWB (existential and religious), depression, and quality of life among persons living with paraplegia?*

The levels of spiritual well-being total, as well as existential and religious well-being, were relatively high for persons with paraplegia. Despite living with paraplegia, the majority of patients found a sense of purpose and meaning in their lives. Although 39.4% of patients reported a lack of religious involvement or practice, most patients indicated a strong faith in God or Higher Being. In conversation, several patients explained that this catastrophic event resulted in a stronger faith and that “God was giving me a second chance.” This study suggests that despite living with a major disability, such as paraplegia, a person’s SWB may be strong existentially in most cases, but even stronger religiously. This was supported qualitatively for patients with physical disabilities, including spinal cord injury (Boswell, et al., 2001; McColl et al., 2000; Treolar, 2002) and quantitatively for clients with SCI (Mathesis, Tulskey, & Mathesis, 2006).

A higher sense of SWB was also reported with patients of the Black population diagnosed HIV positive (Grimsley, 2006), and with those experiencing a variety of other chronic illnesses (Walton, Craig, Derwinski-Robinson, 2004). Turning to God (religious well-being), or family, friends, or what brings meaning to a person’s life (existential well-being), is an effective coping mechanism when dealing with a life changing illness or physical disability. It can explain why most patients with these health issues tend to report high SWB levels. However, there are incidences where having chronic conditions of a physical disability can result in the person being angry with God for their suffering,

doubting their faith, trending towards a lower religious SWB and affecting the person's total SWB. (Exline & Rose, 2005).

The *level of depression* was lower in this study than the cutoff score of 16 (depressive symptomatology) on the CES-D Scale, illustrating that persons in this sample, on an average, did not demonstrate significant amount of depressive symptoms to be classified depressed, according to Radloff (1977). However, the mean score of the current study (13.27) was slightly higher than previously recorded by Fuhrer and colleagues (1993) of 12.1, and higher than that of the general population.

The level of depression based on the CES-D Scale mean score (13.27), was lower than the mean reported by Miller, Anton and Townson (2008), but higher than previously reported by Fuhrer and colleagues (1993) of 12.1. Thirty six percent of the current study was classified as depressed, scoring above 15, which is similar to the Miller et al. study of 39%. Decreased mobility has been associated with higher incidence of depressive symptoms (Fuhrer et al., 1993; Miller et al., 2008), as well as Latinos reporting a greater incidence of symptoms compared to other ethnic groups (Kemp, Krause & Adkins, 1999). In the current study, 56% of participants were Hispanic, and limited mobility is a major problem for persons with spinal cord injury. Paraplegias in the Miller et al. study scored 14.3, slightly higher than the current study of 13.3, and only slightly lower in comparison to persons with tetraplegia. Participants in the current study scored higher on items, "I feel everything I did was a real effort" and "My sleep was restless," as they expressed "Dressing, transferring, bathing, and the normal things one does to get going in the morning are time consuming and tiring." Many participants indicated it was difficult

to sleep due to “the inability to move freely” and “sometimes pain and spasms contribute to the restlessness” experienced.

The *level of quality of life* for persons with paraplegia is moderate, as life is still good; it is better than “It’s neither good nor bad,” with a mean of 5.24. This result supports Kemp & Ettelson’s (2001) earlier study results of the disabled population’s QOL (5.1). The notion of good perceived QOL while living with paraplegia was also supported by Charlifue & Gerhart (2004).

However, persons with paraplegia who lacked a desirable occupation and consistent employment, were living with pain, had poor physical functioning, and/or endured frequent pressure ulcer incidences reported a lower perceived QOL (Blanes, Carmaghani & Ferreira, 2009). Most persons living with paraplegia still perceive their life to be good, as they adapt and learn how to cope with their new body over time. According to previous studies, many factors influence this perception, as length of injury, employment, support system, and degree and frequency of post injury complications can make a difference. However, participants in the current study had violence as cause of injury (69.3%) high school or less education (54.7%), lacked employment (85.3%) were not married or had significant others (60%), and were not involved in a social or religious group (57.3%), yet still reported better than average quality of life.

Question #2a: *Is there a statistically significant difference between quality of life mean scores among persons living with paraplegia by race/ethnicity?*

Question #2b: *Is there a statistically significant difference between quality of life mean scores among persons living with paraplegia by depression?*

Question #2c: *Is there a statistically significant difference between depression mean scores among persons living with paraplegia by race/ethnicity?*

There was no statistically significant differences on the QOL mean scores by race/ethnicity. This supports study findings by Hampton (2004), but is in contrast to Krause, Saladin and Adkins (2009), who reported that Caucasians indicated the best subjective well-being followed by African Americans. This was determined using stratified sampling, which included men and women, as well as racial/ethnic groups: Caucasians, African Americans, Hispanics, and American Indians. Study results showed that although there were disparities between groups, these differences did not increase over time, but stabilized (Krause et al.). These differences in QOL or subjective well-being might be caused from poor access to resources, lower income status, lack of health insurance, lower level of education, and the need for vocational training and psychological counseling. Since the majority of the current study's participants are of the Hispanic (56%) and Black population (29.3%), and only a small percentage of the Caucasian race (5.3%), this might explain the lack of differences between ethnic groups

and subjective QOL. The use of stratified sampling would be useful for a future research study looking at ethnicity, quality of life, and spinal cord injured patients.

There was also a non-significant difference between quality of life mean scores and those persons classified as depressed ( $p = .58$ ), however, this is surprising as there is an inverse significant association between the two variables ( $r = -.589$ ;  $p = .01$ ), suggesting that persons who are classified as “depressed” or experiencing more depressive symptoms are less likely to perceive themselves as having a good quality of life, which would be expected. This association will be discussed further in the following research question studied.

Question #3: *What is the relationship of spiritual well-being (existential and religious), depression, length of time injured, age, gender, and quality of life for persons living with paraplegia?*

Existential well-being had a strong positive correlation ( $r = .628$ ,  $p = .01$ ) and spiritual well-being total score had a moderate positive correlation ( $r = .47$ ,  $p = .01$ ) with quality of life. This suggests that persons with paraplegia who had purpose, peace, and meaning in life, are more likely to indicate a higher subjective quality of life. This is in contrast to religious well-being, which trended toward a small positive correlation ( $r = .216$ ,  $p = .06$ ) to quality of life, illustrating that even though the participants on an average scored high on religious well being, a significant association with QOL did not exist. This implies that having a strong faith in God or Supreme Being does not necessarily result in a better perceived quality of life. These results are consistent with

previous studies conducted (Mathesis, et al., 2006; Riley, et al., 1998) with SCI patients; as well as with patients diagnosed with chronic illnesses (Delgado, 2007; Riley, et al., 1998). Brillhart (2005) and McColl et al.(2000) also reported that high levels of life satisfaction or quality of life correlated with high levels of spirituality for persons with paraplegia. Among persons with paraplegia, 49% of variance in quality of life was explained by three predictor variables: existential well-being, spiritual well-being total, and depression.

The first model of six predictors (Chapter 4, Table 6) illustrated that EWB, having purpose in life, was the dominant predictor of QOL. The other models that followed, which inserted the SWB total instead of RWB and EWB resulted in SWB total as the second predictor of QOL. Interestingly, by including EWB in the first model, 49% of the variables accounted for the person's QOL, in comparison to 43% in other models when SWB Total was inserted and RWB and EWB removed (Chapter 4, Tables 7 & 8), suggesting a possibly stronger impact by EWB on a person's QOL. Although Total SWB is significantly related to QOL and is the second highest predictor of the person's QOL, existential well-being or having purpose, peace, meaning in life had a stronger association with QOL and was the best predictor of QOL on its own. Koenig (1999) would argue however that RWB does have a significant impact on a person's life satisfaction or QOL, if the person has a strong "intrinsic religiosity." Allport and Ross (1967) define intrinsic religiosity as one's faith, which is the motivating force in their lives; faith is the core of what gives a person purpose, meaning and peace during illness or trials. According to Koenig, "Every life event has purpose and meaning...the religious



person is capable of transforming the worst situations into positive experiences,” (1999, p. 29).

Ferrell & Grant’s (2000) Quality of Life Model supports the interrelatedness between spiritual well-being and quality of life. A person’s sense of spirituality or SWB is often what helps the person cope with losses and find meaning in life (Ferrell, 2005). This is necessary for the person while dealing with physical changes following an SCI. Persons living with paraplegia are searching for the meaning of their suffering, and working on “acceptance” of what is now life (Ferrell, 2003). The person’s religiosity and whether it is strong or weak affects their perceived QOL, as well as looking at the “spiritual,” establishing what provides meaning in life. The spiritual well-being of “The Quality of Life Model” is representative of this current study and demonstrates how hope, meaning, suffering and religiosity affect a person’s QOL while living with paraplegia.

Depression had a large inverse correlation ( $r = -.59, p = .01$ ) with quality of life. It is expected that persons with more depressive symptoms would have a lower sense of quality of life, and this is evident in a study by Kemp and Krause (1999), which found that social support and health satisfaction were negatively correlated to depression scores for persons with spinal cord injury. High depression scores and low quality of life was determined from a study conducted by Casebolt (1996), which also showed a suicide rate of five times higher among persons living with SCI in contrast to the nondisabled population at the same age.

Positive coping methods can make a difference in decreasing depression and enhancing one’s QOL (Kemp & Krause, 1999). Spiritual interventions may be an

effective coping strategy, as Coleman's (2004) study showed a higher sense of being and purpose (EWB) inversely correlated to the depression score and the predictors of EWB and RWB explained 32% variance in depression for persons living with HIV/AIDS.

Similar results were indicated in the current study as EWB and SWB total were highly significantly inversely related to depression scores (CES-D), emphasizing that having a strong SWB can result in lower depressive symptomatology. These findings are supported by studies with clients living with terminal cancer (McClain, Rosenfeld & Breitbart, 2003; Nelson, Rosenfeld, Breitbart & Galleta, 2002), prostate cancer (Nelson, Jacobson, Weinberger, Bhaskaran, Rosenfeld, Breitbart & Roth, 2009), breast cancer (Yanez, Edmonson, Stanton, Park, Kwan, Ganz, & Blank, 2009) and with heart failure (Bekelman, Dy, Becker, Willstein, Hendricks, Yamashita, & Gottlieb, 2007).

Depression is a symptom assessed in the psychological well-being dimension of "The Quality of Life Model." A person's degree or presence of depressive symptoms affects their quality of life, showing a bidirectional relationship (Ferrell & Grant, 2000).

*Gender* had a weak, non-significant correlation to quality of life; however it was the third predictor of QOL in two of the models. It is suggested that this occurred due to a high percentage (82.7) of male participants, which is similar to the reported spinal cord injury population statistics (National Spinal Cord Injury Statistical Center, 2009). There was no gender differences found in association with QOL while living with paraplegia, which supports previous findings within the SCI population (Hampton, 2004; Krause, Saladin & Adkins, 2009).

Woin, Duvdevany, & Mazor (2009) argue that women with physical disabilities, including spinal cord injury, have a significantly lower quality of life compared to the non-injured population related to sexual dysfunction. Often women with physical disabilities have difficulty establishing close, intimate relations and are less likely to marry (Taleporos, Dip, & McCabe, 2002) decreasing subjective quality of life. Women with spinal cord injury also have higher levels of depression, decreasing their subjective quality of life (Elliott & Frank, 1996). Incidence of depression is even greater with African-American women (Krause, 1998). In a study by Krause, Broderick and Broyles (2004), it was reported that African-American women with spinal cord injury had more depressive symptoms, a lesser quality of life, and a decreased sense of purpose in life, in comparison to African American men. However, in this study, women reported significantly greater satisfaction with their sex life compared to men. Stratified sampling of the current study participants might have produced differences and greater association within gender and QOL variables.

*Age* and *length of injury* were not significantly correlated to a person's quality of life. This was demonstrated in all the regression models, with age having the least correlation and lowest predictor for QOL. Many studies indicate that the person's subjective QOL or satisfaction in life improves as length of time post injury increases, as one adjusts to life and bodily changes (Kemp & Krause, 1999). In a study by Post, Van Dijk, Van Asbeck and Schrijvers (1998), life satisfaction trended to increase each year post injury, however not significantly, and the age of the person had only a weak association. However, several studies show that as age increases, quality of life

decreases, as well as an increase in depressive symptoms (Putzke, Barrett, Richards, & DeVivo, 2003). This tends to result from declining function and more secondary medical conditions; whereas the longer one is injured, learning how to live with SCI and finding what brings satisfaction and happiness, results in higher life satisfaction, or perceived QOL (Krause & Crewe, 1991; Weitzenkamp, Jones, Whiteneck & Young, 2001). Those of younger age tended to have a greater QOL, but this was explained by having good employment, stable relationships and socialization (Franceschini, Clemente, Rampello, Nora, & Spizzichino, 2003).

In the current study, there was a significant moderate correlation between age and length of injury ( $p = .01$ ) and older participants reported a longer period of being injured. The mean of age was 40.65 years; which is similar to the reported average of 40 years, with a majority of injuries occurring in a person's 20's (National SCI Statistical Center, 2009). The average length of injury for participants of the current study was 16.66 years. As survivors of spinal cord injury increase in age, symptoms of decreased functional ability, decreased strength, increased fatigue, problems with pain, and inconsistencies with sleep and rest may increase as well (Kemp & Krause, 1999; Price, Kendall, Amsters, & Pershouse, 2004). These physical symptoms which affect and have relationship with the person's quality of life, were identified as symptoms of the "Quality of Life Model" in the physical well-being dimension (Ferrell & Grant, 2000).

### **Critique of Study and Implications**

This study had several strengths as it dealt with a topic which had limited research. It focused on individual spiritual well-being and perceived quality of life; two areas which are understudied in persons with spinal cord injury and other neurological disorders. The sample size was adequate including persons of multi-cultural, multi-ethnic diversity.

The process of collecting data included performing direct one-to-one personal interviews with each participant. With this method, the PI was able to obtain equally reliable and more comprehensive data. Statements were read to the participants. This was helpful as some statements on the SWBS and CES-D were confusing to participants and needed clarification by the PI. In addition to the three questionnaires and demographic profile, many of the participants wanted to share their story, which provided additional rich, meaningful insight. The three standardized instruments used had sound psychomotor properties, which enhanced the credibility of the study results. The SWBS was useful in addressing the religious and existential well-being of the person.

A limitation to the study was that the SWBS was not appropriate to persons who did not believe in God or a Supreme Being. The participants were primarily of the Christian faith, decreasing its generalization to all faith traditions. The religious (RWB) statements would need to be deleted from the instrument, so as to measure the person's existential well-being and making it adaptable to these individuals.

Age, years/months post injury, gender and ethnicity were assessed through Pearson ( $r$ ) correlations and multiple regression analyses. It was difficult to determine

differences or significant relationships without the use of stratified samples of these variables.

Other limitations included the use of a cross-sectional study; as such the person's responses to SWB and QOL were based on that day's events and feelings. There were several patients who were experiencing a fever, and other infection related symptoms, or had not slept well the previous night. As such, their responses were based on that moment and might not reflect their overall feeling or opinion once recovered from illness. Another limitation is a small representation of 13 women (17.3%), which is expected with the SCI population, but having more women in the study would have provided more information on their unique spirituality and perception of QOL. It would have added more strength to the study results regarding the relationship between gender and quality of life.

## **Implications for Nursing**

### **Theory Development**

This study build upon the "Quality of Life Model", using it to show the bidirectional relationship between QOL and the characteristics or symptoms within all four dimensions, even beyond depression in the psychological well-being dimension and meaning and religiosity in the spiritual well-being dimension. All of the dimensions in this model have characteristics common of persons with SCI. Ferrell & Grant's (2000) Quality of Life Model has primarily focused on individuals with cancer or dealing with end of life issues or conditions. Additional concepts in this model could be further

studied with the physical disability population, such as suffering, fear, hope, caregiver burden, and functioning ability.

## **Research**

This study has implications for future research. A qualitative addition to this study would provide deeper insight and meaning to how an enhanced spiritual well-being contributes to a higher subjective quality of life. The following questions could be studied: What does spiritual well-being mean to the person with paraplegia or spinal cord injury and what contributes to the person's subjective quality of life? Is it spiritual well-being, relationship with a Higher Being, or some other factor or factors?

Studies done longitudinally are lacking, and would demonstrate whether a person's spiritual well-being and quality of life changes over time and if so, why? A type of longitudinal design that could be used is called panel studies. The same participants for the current study would produce data at different points in time. In panel studies, the researcher is able to identify which individuals have different responses over time, determining the reason for those responses (Polit & Beck, 2006).

Future research could also explore the following: a) Identifying specific spiritual care interventions (religious and existential), quantifying which methods are effective and improve rehabilitation outcomes and community re-entry; b) A comparison study of paraplegics and tetraplegics, looking at the variables and determining if there is a difference in quality of life or spiritual well-being between the two groups; and c) Consider the use of other instruments that measure spiritual well-being or spirituality, as well as a different instrument to assess quality of life, perhaps looking at health-related

quality of life. These suggestions would be helpful in furthering the results of the current study.

### **Practice**

A positive significant relationship between existential well-being (EWB) and quality of life (QOL) has implications for nursing practice. Recognizing and helping patients determine what gives meaning to their lives despite disability could be useful in outcome and intervention planning during rehabilitation and re-entry into the community. Asking patients on admission, “What provides meaning to your life?” as part of the nursing assessment could be included in the psychosocial domain.

Addressing spiritual needs early as part of nursing practice may also result in better health care outcomes, decreased depressive symptoms, and better quality of life. Spiritual issues impact health and patients can benefit when spiritual care is provided and assessed for (Carson & Koenig, 2008). A moderate significant relationship between spiritual well-being and quality of life has implications for nurses in providing spiritual care to patients. Nurses have a responsibility to provide spiritual care, as supported by the American Nurses’ Association. The code of ethics for nurses states, “An individual’s lifestyle, value system and religious practice should be considered in planning healthcare with and for each patient,” (American Nurses’ Association, 2001, p. 7). Spiritual care includes religious, non-religious, and existential needs. Care addressing what brings purpose and meaning to the patient is essential for the promotion of enhanced quality of life.



## **Education**

This study has implications for nursing education. According to the American Association of Colleges of Nursing (2008), spiritual assessment and care should be an integral component of the nursing curriculum for students. Spiritual awareness, if addressed within the curricula of programs often focuses on holistic care, care of the dying patient, and cultural preferences and differences, with limited references to religion (McEwen, 2005). A nervousness or feeling that it is not the nurse's role, often results in the religious component of spiritual well-being not being addressed in nurse education. According to Pesut, "Researchers have found that many patients consider God as a significant source of health and healing. To exclude discussions of God from spiritual education in nursing is to exclude the beliefs of a significant portion of the population our graduates care for," (2003, p. 291).

This study found that spiritual well-being and existential well-being have a strong association with subjective quality of life for persons with paraplegia. Religious well-being and quality of life also have an association, although not significant. As such, educating current and future nurses on how to assess spiritual well-being, and how to respond to that assessment can result in better healthcare outcomes and quality of life for patients in all populations.

## **Conclusion**

This study showed how the interrelatedness of SWB and QOL in Ferrell & Grants' (2000) "Quality of Life Model" can be applied to the spinal cord injured population and was used successfully to inform this current study of persons living with paraplegia. The model can be adapted to individuals with a physical disability or neurological disorder. The results of this study can provide valuable information for nursing professionals caring for patients with spinal cord injury, as well as with patients with other medical conditions.

This study identified persons with paraplegia having a moderate high spiritual well-being (SWB) and better than average quality of life (QOL). SWB total, but largely, existential well-being (EWB) had a strong significant relationship with QOL. A person's spiritual well-being matters and contributes to the QOL of a person living with paraplegia and possibly lowers the incidence of depression. As expected, depression had a moderate inverse relation to QOL; whereas relationships between age, gender, length of injury and QOL were non-significant. Differences between ethnic groups were also non-significant.

Despite having high spiritual well-being and religious well-being mean scores, it was surprising that the relationship between religious well-being and quality of life was weak and non-significant; that having faith in God and/or a Supreme Being played only a minor role in the person's perceived quality of life. Having purpose and meaning in life, whatever the cause or causes, had a strong association with the person's perceived quality of life. Further studies to explore what constitutes a high quality of life and what factors

contribute to a sense of purpose and meaning for persons living with paraplegia are needed.

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## Appendix Measures

## Demographic Profile Questionnaire

1. Age \_\_\_\_\_
2. Gender M/F \_\_\_\_\_
3. Level of SCI \_\_\_\_\_
4. Complete or Incomplete Injury \_\_\_\_\_
5. Cause of SCI \_\_\_\_\_
6. Month/Year of Injury (Diagnosed with Paraplegia) \_\_\_\_\_
7. Other Medical Conditions: \_\_\_\_\_  
\_\_\_\_\_
8. History of pressure ulcer incidence since injury or within the last year \_\_\_\_\_  
Stage \_\_\_\_\_ Requiring Hospitalization \_\_\_\_\_
9. Ethnicity \_\_\_\_\_
10. Highest Education/Schooling \_\_\_\_\_
11. Occupation/Employed Y/N \_\_\_\_\_
12. Religion \_\_\_\_\_ Practicing Y/N \_\_\_\_\_
13. Support Family System
  - Married \_\_\_\_\_
  - Divorced \_\_\_\_\_
  - Significant Other \_\_\_\_\_
  - Separated \_\_\_\_\_
  - Widow/Widower \_\_\_\_\_
  - Children Y/N \_\_\_\_\_
  - Children living with you Y/N \_\_\_\_\_
  - Other support systems and socialization
    - Other family members \_\_\_\_\_
    - Friends \_\_\_\_\_
    - Community or social groups \_\_\_\_\_
    - Professional groups \_\_\_\_\_

## Appendix Measures

Center for Epidemiologic Studies Depression (CES-D) Scale  
(L.S. Radloff, 1977)

Directions: Below is a list of some ways you may have felt or behaved. Please indicate how often you have felt this way during the last week by playing an "X" in the appropriate space.

(zero) (1) (2) (3)

	<b>During the Past Week</b>	<b>Rarely</b> or none of the time (less than 1 a day)	<b>Some or a little</b> of the time (1-2 Days)	<b>Occasionally</b> or a moderate amount (3-4 Days)	<b>Most</b> or all the time (5-7 Days)
<b>1</b>	I was bothered by things that usually don't bother me.				
<b>2</b>	I did not feel like eating; my appetite was poor.				
<b>3</b>	I felt that I could not shake off the blues even with help from my family and friends.				
<b>4</b>	I felt I was just as good as other people.				
<b>5</b>	I had trouble keeping my mind on what I was doing.				
<b>6</b>	I felt depressed				
<b>7</b>	I felt that everything I did was an effort				
<b>8</b>	I Felt Hopeful about the future.				
<b>9</b>	I thought my life had been a failure				
<b>10</b>	I felt fearful				
<b>11</b>	My sleep was restless.				
<b>12</b>	I was happy.				
<b>13</b>	I talked less than usual.				
<b>14</b>	I felt lonely.				
<b>15</b>	People were unfriendly				
<b>16</b>	I enjoyed life				
<b>17</b>	I had crying spells.				
<b>18</b>	I felt sad.				
<b>19</b>	I felt that people disliked me.				
<b>20</b>	I could not get going.				

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**INSTITUTIONAL REVIEW BOARD**

**Notification of Approval**

**Date:** July 20, 2009

**To:** Primary Investigator  
Finocchiario, Darlene

Subinvestigators/Coordinators  
Patricia Roth

**IRB Number:** IRB #060

This number is a LAREI number which should be used on all consent forms and correspondence.

**Study Number:** 7333

**Study Title:** Spiritual Well-Being and Quality of Life for Persons with Paraplegia

**Approval Date:** 7/20/2009

**Risk Assignment:** Minimal

**Review Period:** **Expiration Date:** 7/19/2010 (based upon date recommended for approval)

**Subjects Approved:** 75

**Controls Approved:** 0

**IRB Recommendations: NEW PROPOSAL UNANIMOUSLY APPROVED**

**This approval is for a period of 12 months. You should receive electronic notification 60 days prior to the expiration of this project's approval. However, it is your responsibility to insure that an application for continuing review approval has been submitted by the required time. In addition, you are required to submit a final report of findings at the completion of the project.**

**Consent Form** (if applicable): The approved and stamped consent form must be used when enrolling subjects. You are responsible for maintaining signed consent forms for a period of at least three years after study completion.

**Reporting:** The principal investigator must report to the IRB any serious problem, adverse effect, or outcome that occurs with frequency or degree of severity greater than that anticipated. In addition, the principal investigator must report any event or series of events that prompt the temporary or permanent suspension of a research project involving human subjects.

**Modifications:** Changes or modifications in a research project **must have prior approval** by the IRB. When deemed necessary to prevent immediate harm to a subject, changes or modifications must be reported to the IRB within 24 hours.

IRB members abstaining from discussion/vote due to a potential, or actual, conflict of interest (if applicable): N/A

The Los Amigos Research & Education, Inc. Institutional Review Board is duly constituted (fulfilling FDA requirements for diversity), allows only those IRB members who are independent of the investigator and sponsor of the study to vote/provide opinion on the study, has written procedures for initial and continuing review, prepares written minutes of convened meetings, and retains records pertaining to the review and approval process; all in compliance with requirements defined in 21 CFR (Code of Federal Regulations) Parts 50 and 56, and ICH (International Conference on Harmonization) guidance relating to GCP's (Good Clinical Practice).

Signature applied by Marijke Weightman on 07/20/2009 02:34:05 PM PDT

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SPIRITUAL WELL-BEING SCALE

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