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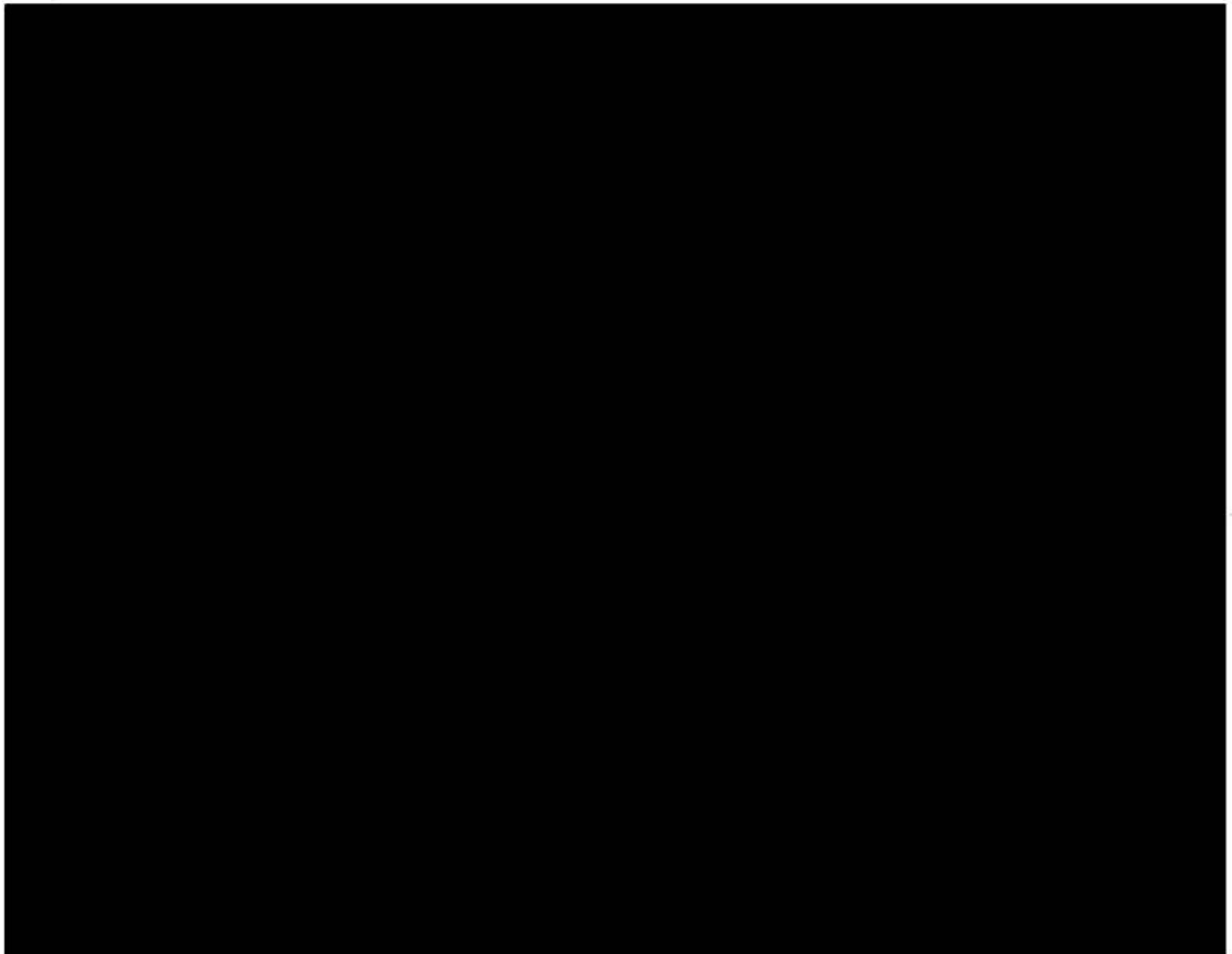
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This is to certify that the dissertation prepared by Ronald R. Alligood, II entitled
“WHAT IS THE LIFE PATTERN OF PEOPLE WITH SPINAL CORD INJURY?”
has been approved by his committee as satisfactory completion of the dissertation
requirement for the degree of DOCTOR OF PHILOSOPHY.



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The Life Pattern of People with Spinal Cord Injury

A dissertation submitted in partial fulfillment of the requirements for the degree of
Doctor of Philosophy at Virginia Commonwealth University

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Abstract

THE UNITARY LIFE PATTERN OF PEOPLE WITH SPINAL CORD INJURY

Ronald R Alligood, II

A dissertation submitted in partial fulfillment for the degree of Doctor of Philosophy at
Virginia Commonwealth University

Virginia Commonwealth University
2006

Major Director: Judith Lewis, RN, PhD,
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This aim of this study was to answer the research question: “What is the Life Pattern of the Person with Spinal Cord Injury?” The unitary appreciative inquiry design, which was conceptualized through Rogers’ (1986) science of unitary human beings, provided an approach for understanding the phenomenon in the context of human wholeness. The data, obtained through the methodology of unitary appreciative inquiry, led to the development of individual synopses for each of the participants. Once the synopses were completed, a composite pattern profile was constructed by the researcher that was indicative of the life pattern of people with spinal cord injury. The participants in the study validated the synopsis and pattern profile as accurate representations of their experience with spinal cord injury. This qualitative study, which was comprised of eight people who had undergone a spinal cord injury more than two years prior to the study, discovered three shared pattern manifestations: depersonalization; loss; and hopelessness. Although each person within this inquiry had a very good physical outcome concerning their spinal cord injury, the participants were not pleased with their current state of being.

The pattern of despair, which was validated by the participants, was manifested through the profound sense of depersonalization, loss, and hopelessness.

SPINAL CORD INJURY: THE PATHWAY TO INQUIRY

Chapter One

Introduction

Purpose of the Study

This aim of this study was to answer the research question: what is the life pattern of the person with spinal cord injury? The information obtained from this inquiry led to the development of an appreciative pattern profile as detailed in Cowling's (2001) unitary appreciative inquiry. The unitary appreciative inquiry design, which was conceptualized through Rogers' (1986) science of unitary human beings, provided an approach for understanding the phenomenon in the context of human wholeness.

The qualitative research approach, unitary appreciative inquiry, focused on the inter-subjective expression of a group of people of people who had undergone spinal cord injury; the researcher and participants co-investigated spinal cord injury in order to develop a consensus that evolved into a pattern profile expressive of the informative dimensions of spinal cord injury (Cooperrider & Srivastava, 1987; Cowling, 2001; Heron, 1996).

Current data indicated that the person who acquires a spinal cord injury is most often a young person who is in the beginning stages of adulthood. The person, upon acquiring the trauma, is suddenly thrust into an alternative reality that is unlike anything she or he has previously encountered. A great deal of research has been explored on the care of the spinal cord injured person; however, it focuses primarily on the acute medical care and subsequent rehabilitation of the injury. To date, little, if any, information has been

available about the life pattern of the person with spinal cord injury following the initial rehabilitation process. There have been previous studies on spinal cord injury that examined depression, hopelessness, and quality of life (Krause, 1998); however, there was a gap in the knowledge regarding the life pattern of the person with spinal cord injury, which considers the person with spinal cord injury in the context of wholeness.

Rogers' Science of Unitary Human Beings.

Nursing is a creative and imaginative art as well as science, which is based in the foundation of compassion, abstract knowledge, and intellectual judgment (Rogers, 1970). Rogers conceptualized that we, as unitary human beings, live as in a pandimensional human energy field that is in mutual process with a pandimensional environmental energy field.

Rogers (1986) stated that energy fields are always open and that the environmental and the human energy field are in constant interaction. Rogers (1986) described the concept of pattern as that which gives identity to the field and as an expression of the wholeness of the field and its environmental connection. She indicated that every human energy field has a unique pattern, which is under constant change through its interaction with the ever-changing environmental energy field. Barrett (1996) explained that this concept portrays the human energy field as devoid of spatial or temporal attributes and unitary human beings as irreducible wholes that are greater than the sum of their parts.

When a unitary conceptualization was applied to the person with spinal cord injury, she or he is perceived of as a whole person, who like a person who does not have spinal cord injury, is constantly creating new patterns of being at each moment through mutual interactions with a pandimensional energy field. The person with a spinal cord injury is a

human energy field pattern that interacts with the environmental energy field expressed and manifested in a pattern that is unique to each individual person with spinal cord injury.

Postulates

Rogers (1986, 1992) described the science of human beings through four postulates: energy fields, openness, pattern, and pandimensionality. She indicated that energy and field are two descriptives of the human and environment. Rogers (1986, 1992) explained that the concept of energy describes the ongoing quality of the field. It is one of continuous, immeasurable power. Parse (2001) expounded that humans and the environment are interacting and interchanging because humans and the environment do not have fields; rather they are fields that are in constant co-existence. The person with spinal cord injury is a human energy field that is constantly creating new ways of being with the environmental energy field.

Causality. Rogers (1986) postulated that causality is not an option in a universe of open systems. She stated that energy fields are always open and that the environmental and the human energy field are in constant interaction. Rogers (1986) summarized that the abstract concept of pattern is to give identity to the field. She indicated that every human energy field has a unique pattern, which is under constant change through its interaction with the ever-changing environmental energy field. Barrett (1996) explained that this concept reflects that reality is devoid of spatial or temporal attributes and that unitary human beings are irreducible wholes that are greater than the sum of their parts. The person who has acquired a spinal cord injury is a whole person, for the loss of

physical function cannot reduce the human energy field pattern for the human is a unitary entity that is without spatial or temporal attributes.

Pandimensionality. Rogers (1992, p. 29) described pandimensionality as the “non-linear domain that is without spatial or temporal attributes.” The concept of pandimensionality places humans in a context of actualization that is without any limits, albeit time, place, space, or death. Cowling (2000) wrote that Rogers’ view of reality is one of humans as patterning energy fields that are evolving simultaneously in a mutual process with environmental energy fields in a pandimensional universe growing and changing unpredictably without causal connectivity. This reconceptualizes humans beyond the physical, psychological, and spiritual parts, for as unitary entities they imply a unity of substance or existence that releases the scientist and practitioner from any notion of parts.

Examples of experiencing pandimensionality can be described as mentally reliving a horrific event such as in the case of a veteran returning with post-traumatic stress disorder. The veteran may relive the experience and during that time of reliving, she or he is actually removed from the current view of reality into a previous event. This event is not in the past, but is current and in the moment for that individual as his/her reality. Pandimensionality also reflects future presence, for due to a current job lay-off; a person may experience what the loss of a job may mean to his family. The visualization of losing one’s home to a job lay-off may feel as if it is occurring at the moment, although that reality may or may not occur. The former worker may experience anxiety, or other physical or mental manifestations, however, the person feels as if the event is occurring at that moment. Cowling (2000) stated that pandimensionality and the integral nature of the

human energy field pattern give rise to the concept that human beings carry collapsed space, time presence and their environment around with them as relative presence.

Cowling (2000) wrote that Rogers' (1992) concept of pandimensionality and Moss' (1995) concept of unitive consciousness are perspectives describing very similar concepts. Moss (1995) explained that within pandimensionality one's feelings, sensations and even one's thinking are a unified whole which are not held back by one's corpus. Moss (1995) continued that pandimensionality enables a new birth within each moment of the cosmos that is in continuous orchestration with, not only past, present, and future, but with the infinite.

Carboni (1992) wrote that the universe is constantly changing and evolving in patterns of increasing diversity that is within a pandimensional reality. She continued that the pandimensional universe is a reality of openness and dynamic wholeness, which manifests dynamic and integral energy fields that are innovatively and unpredictably changing without boundaries or constraint.

Homeodynamics. Rogers (1986, 1992) stated that the concept of energy fields, openness, pattern, and pandimensionality are the foundation for the principles of homeodynamics, which are helicy, resonancy, and integrality. Rogers (1992, p.31) wrote, "helicy is the continuous, innovative, unpredictable, increasing diversity of human and environmental field patterns." Resonancy, according to Rogers (1992, p.31), is "the continuous change from lower to higher frequency wave patterns in human and environmental fields... Integrality is the continuous mutual human field and environmental field process." Barrett (2002) wrote that Rogers (1994) described nursing

as a practice and an art, which enables a discipline to acquire knowledge about unitary human beings in mutual process with their environment for human betterment.

Pattern. The concept of unitary pattern focuses on the entire human and does not reduce the human into individual parts or pieces. Phillips (2004) explained that the human and the environmental energy field are pandimensional and that reality is perceived with dissimilar concepts of time and space than are generally accepted in a conventional three-dimensional world. He continued that the human and the environmental energy fields are integral on one another and thus dimensionality is something that cannot be manipulated or even a dimension that can be moved into from three dimensionality. Phillips (2004) continued to state that this pattern, which is unique to each field, identifies the human field from the environmental field, although these two fields are integral with one another. Phillips (2004) reinforced that pattern manifestations illustrate that changes in energy fields are experienced and these changes offer insight into the characteristics that define the pattern.

A unitary pattern, defined by Alligood and Fawcett (2004), is an entity that is both an abstraction and a noun; patterning is the dynamic or active process of the life of the human being and manifestations of patterning are visible to the senses. Manifestations of patterning are observable events in the real world (Alligood & Fawcett, 2004; Rogers, 1970).

Cowling (1993a) expressed that the human energy field pattern is the basic referent of nursing practice. A unitary perspective pattern is the focus because it does not separate the person into boundaries or parts; rather the unique pattern distinguishes or differentiates fields. The human energy field pattern enables one to recognize the unique

entity and view the increasing diversity of the field. Cowling (1993a) continued that the human energy field pattern that emerges from the human and environmental field mutual process is the central focus for considering nursing strategies.

Spinal Cord Injury and the Science of Unitary Human Beings

The person with spinal cord injury is a human energy field pattern manifestation that is without spatial or temporal constraints. Roger's (1992) conceptual model emphasized the individual's development and complexity. The Rogerian framework offers, not a static process of timely goals or expectations, rather it indicates that nursing is an ever-changing process that is constantly evolving within the human-environmental energy field in an untiring wave of energy that helps people, groups, and individuals achieve maximum well being and actualization.

The person with spinal cord injury is a whole person, for in an open system all energy fields are whole without reduction. The person who has acquired a spinal cord injury is a human energy field who has co created new ways of interacting with the environmental energy field. Cowling (1990) indicated that human and environmental fields are integral and in mutual process, for the assessment of the human energy field also captures the environmental field assessment; thus, pattern reflects the human-environmental process and it is not clear if the environmental assessment can be extracted from the general pattern manifestation for they are in mutual process. Cowling (1990) explained that what is described as psychological, physiological, spiritual, or emotional phenomena are manifestations of the whole, which is the encompassing of integral human and environmental energy fields which cannot be reduced to parts. The person with spinal cord injury is no less a whole because she or he has a spinal cord lesion or decreased

innervation to the extremities, rather the person with spinal cord injury is a complete whole. Cowling (1990) contended that all phenomena have relevance because all phenomena are manifestations of the whole.

Design and Methodology

The life pattern of the person with spinal cord injury is represented in the medium of an appreciative pattern profile based upon data collected through a unitary appreciative inquiry (UAI) process. According to Cowling (2001, p.31), “unitary appreciative inquiry was developed as a method of seeking the wholeness, uniqueness, and essence of human life as context for understanding phenomena and conditions of concern to nursing and guiding action in nursing practice.” Unitary appreciative inquiry was developed to add to the ever-increasing, vast body of nursing knowledge to include information that is consistent with the underlying pattern of the human existence, which is based on one’s experiences, expressions, and perceptions.

Unitary appreciative inquiry provides the techniques for representing an individual or group pattern, which is expressed through wholeness, uniqueness, and essence that is exclusively, distinctive to the entity (Cowling, 2001). Pattern understanding is dependent on what is important and valued by the group members. Cowling (2001) explained that as the participants begin their inquiry into a phenomenon, knowledge will assimilate based on what was or is experienced by the participants. Unitary appreciative inquiry incorporates strategies aimed at capturing the wholeness of life existences. The participatory group will create a representative pattern based on their experiences of the subject or topic. Cowling (2001) maintained that the pattern will emerge through the assignment of meaning and validation on the experience and that the continued

exploration will reveal a pattern, which is reflectant of the particular human experience as manifested in the lives of the group members. These data are not a replacement of conventional research methodologies; rather they offer another window with which to view the universal human condition.

The Significance of Spinal Cord Injury Research

The National Spinal Cord Injury Statistic Center (NSCISC) (2003) reported that there are over 243,000 people alive today in the United States of America who are spinal cord injured and 11,000 people suffer a spinal cord injury each year.

Demographics. Spinal cord injury is a prominent, often debilitating injury that is prone to affect people who are at the beginning of their life, careers, and relationships. The national spinal cord injury statistical center (NSCISC) (2003) estimated that there are 40 cases per million population in the United States of new cases each year of spinal cord injuries. The NSCISC (2003) stated that there are between 721 and 906 people per million who have some form of spinal cord injury. Spinal cord injury is predominately a young man's injury. According to the NSCISC (2003) fifty-three percent of people with spinal cord injury are between the ages of 16-30, while the average age of injury is 32.6 years; males comprise 81.2 percent of people with spinal cord injury, which creates a 4:1 ratio of men to women in this category.

The National Spinal Cord Injury Statistic Center (2003) indicated that since 1990, Caucasians have comprised 59.1% of the people with spinal cord injury, whereas 27.6% were of African-American decent, 5.7% were Hispanic, 0.4% were Native American, 2.1% were Asian, 0.5% were unknown, and 2.5% were unclassified. Automobile accidents created 40.9% of the reported spinal cord injury cases; whereas violent crimes

caused 21.6%, falls 22.8%, sports, 7.5% and other causes 7.6% (NSCISC, 2003). According to the National Spinal Cord Injury Statistic Center (2003), incomplete quadriplegia (30.8%) is the most common, while complete paraplegia (26.6%), incomplete paraplegia (19.7%), and complete quadriplegia (18.6%) complete the categories. Spinal cord injury is a phenomenon that follows ethnic lines and affects young people between the ages of 16-35 years of age.

Life issues. According to the National Spinal Cord Injury Statistic Center (NSCISC) (2003) over one-half of the people (62.9%) who acquire a spinal cord injury are employed at the time of injury. Following the tenth year post injury, 31.8 % of people with paraplegia are employed whereas only 26.4% of people with quadriplegia are employed at this milestone (NSCISC, 2003). The NSCISC reported that 88.3% of all living persons who are discharged from the hospital or rehabilitation system are discharged to their pre-injury home or to another private residence. Nursing homes become the new homes to 5.1 percent of the people with spinal cord injury, and the remaining people are discharged to group homes or to hospitals for additional concerns (NSCISC, 2003).

The National Spinal Cord Injury Statistic Center (2003) indicated that the majority of the people who acquire a spinal cord injury are single (53%) when they experience a spinal cord injury and that the marriage rate remains lower for the person with spinal cord injury than the general population. The people who are married at the time of injury and marry post- spinal cord injury exhibit a slightly higher rate of separation or divorce (NSCISC, 2003).

The National Spinal Cord Injury Statistic Center (2003) pointed out that the days spent in the hospital immediately following injury have reduced from 25 days in 1974 to 17 days in 2001 and the downward trend is also evident in the number of days spent in the rehabilitation unit which have declined from 115 days to just 44 days.

Cost of living. The National Spinal Cord Injury Statistic Center (NSCISC) (2003) indicated that the severity of injury greatly increased the cost of living for the person with spinal cord injury even if the person retains her/his wages and benefits. A person who is considered a high quadriplegic (C1-C4) will spend US \$626,588 during the first year of his/her injury, and an additional US \$112,237 each year thereafter (NSCISC, 2003). A person who experiences a C1-C4 injury at 25 years of age will incur a cost that is directly related to the injury of US \$ 2,393,507 over her/his lifetime (NSCISC, 2003). A 25-year-old person who experiences a paraplegia injury will incur lifetime costs of over US \$ 799,721 directly related to the injury (NSCISC, 2003). Spinal cord injury is a debilitating injury that increases the physical and monetary burden to the people and families who undergo this neurological conundrum.

This study offers an additional window of understanding on the life pattern of the person with spinal cord injury. Through this new understanding, additional nursing knowledge will be generated that will offer increased insight into the life pattern of the person with spinal cord injury. The data assimilated from this qualitative study will enhance understanding through the voices of the people who live each day with a spinal cord injury. The new data may lead to improvements in the psychosocial health, rehabilitation, and to improvements or even new techniques in nursing interventions.

Chapter Two

The State of the Science

Spinal cord injury is a traumatic, life-altering event that often leaves the affected individual with some type of functional deficits. The functional deficits that are incurred often result in some change of lifestyle, which must be navigated by the person who has undergone spinal cord injury. While there were considerable data concerning depression, and quality of life in the person with spinal cord injury, little data are available on the life pattern of people with spinal cord injury. According to the National Spinal Cord Injury Statistical Center (NSCISC, 2003), spinal cord injury was experienced by an estimated 2.5 to 5 percent per 100,000 of the population of the United States of America. As the number of spinal cord injury survivors has grown, Herculean research efforts have produced considerable data on many aspects of spinal cord injury. The research selected for presentation in this literature review focuses primarily on the psychosocial research concerning depression, quality of life, and life satisfaction in the person with spinal cord injury. The research presented is comprised of qualitative and quantitative studies that gave insight into the issues and challenges that affect the person with spinal cord injury.

Epidemiology

Recent data indicate that traumatic spinal cord injury is projected to increase in prevalence in the US from the 1994 data of 11,500 cases per year to 13,400 cases per year by the year 2010. This 20% rise in spinal cord injury has increased the number of people in the US with spinal cord injury from 207,000 to 247,000 in 2004 (Lasfargues, 1995; Sullivan, 1999). Gunshot wounds caused almost 17 % of the spinal cord injuries

during the period of 1984-1993 and indicated that gun related spinal cord injury would continue to rise over the next 10 years (Farmer et al., 1998; Sullivan, 1999). Traumatic spinal cord injury affects an ever-growing population of our society which includes not only the people who had undergone the actual spinal cord injury but also the lives of the family members and friends.

The Psychology of Spinal Cord Injury

Many people who acquire spinal cord injury often bear psychological repercussions as a result of the instantaneous loss of their motor functions. The loss of body functions fosters a need to depend on family members and healthcare providers for daily personal care. The dependence on others for the assistance with the activities of daily living (ADLs) often creates anxiety and depression in the person with spinal cord injury. This loss of independent function may include bowel, urinary tract, or even sexual alterations and the symptoms may manifest as pain, a decrease in future expectations, or the loss of social or work status (Scivoletto, Petrelli, Di Lucente, & Castellano, 1997). Scivoletto et al. (1997) indicated through a quantitative study of 100 participants who sustained either traumatic or non-traumatic spinal cord injury that only 20% of people with spinal cord injury experienced psychological distress, which was caused by and maintained by the difficulties that the person with spinal cord injury encountered in day-to-day living. The ever-present barriers to the ADLs replaced the initial difficulties that were encountered in the hospital upon injury. Scivoletto et al. (1997) also found the lack of privacy, the loss of autonomy, and the separation from family and friends that was encountered in the initial hospitalization contributed to anxiety and depression over time; however, the continuity of psychological distress, albeit depression or anxiety, was maintained through the

constant physical limitations which are placed on the person who lives with a spinal cord injury.

The Process of Bearing Illness and Injury

The self. Dewar and Lee (2000) used grounded theory in their qualitative study to discover that individuals who lived with significant physical limitations due to catastrophic injuries encountered many obstacles in the course of their daily lives that required the modification of activities and social roles. Dewar and Lee (2000) continued that the physical and emotional stress caused by the increased difficulty of the daily living with a disability had often been the etiology in caregiver abuse and emotional distress. The injury and resultant disability caused the person to lose view of the self, the central focus of identity, which was formed through one's interactions with others (Dewar & Lee, 2000). The effect of chronic illness and injury changed the view of the self and resulted in the loss of the old self; the injury forced the individual to acquire new patterns of interaction that were not viable for the old self (Dewar & Lee, 2000). Following the traumatic injury, the individual rebuilt the self, for the old self did not meet the needs of the new body; the assimilation of the new and old self was a complex task that was difficult to master. Dewar and Lee (2000) determined that the rebuilding of the self, following catastrophic illness, enabled the person with spinal cord injury to adapt to new ways of being.

The phases. According to Dewar and Lee (2000), the process of bearing illness and injury involved three non-distinct phases: finding out; facing reality; and managing reality. The three separate phases often overlapped as the person with spinal cord injury attempted to assimilate the old self with the new self. The initial phase of bearing illness

and injury was finding out the extent of the injury. Dewar and Lee (2000) continued that the process of finding out was of such magnitude that one was unable to comprehend the ramifications of the injury at the initial onset. Although the individuals were told clearly what damage the injury had caused to their bodies, they were unable to fully comprehend the concept due to the global, catastrophic affect. Dewar and Lee (2000) used the following excerpt from an individual concerning his reaction to a resultant quadriplegic injury following a traumatic accident:

When they tell you it's not just black and white. And its sinking in, you're thinking of all the things, well not all the things---your mind can't go that fast, but just one problem after the other surfaces. You think: That's not gonna be very good. Then there's the spin offs and spin offs and spin offs. There's the first problem showing up, and then there's the next one, and the next one. It's like how long's a piece of string? (Dewar & Lee, 2000, p. 917)

According to Dewar and Lee (2000), the second phase described by the participants was facing the reality. The facing of reality was an integral step in the ascension of their self-understanding. As the individual faced reality, she or he developed an understanding that their life had changed and their life's choices were now limited by the injury. Dewar and Lee indicated that the individuals who had achieved the milestone of facing reality had comprehended that their physical condition would not become better and, in fact, it could actually deteriorate. Dewar and Lee (2000) found that the final phase of bearing illness and injury was managing reality: the attempt to continue on with life even though the situation and the individual's ability have greatly changed. Dewar and Lee described the final stage as a difficult transition; frequent emotional adjustment was needed because of

the continued decline of physical abilities due to the deteriorating condition. The continuance of life and the ability to function with the resultant disability was the final and most difficult task for the person coping with spinal cord injury.

Three main strategies. Dewar and Lee (2000) discovered that participants used three main strategies to traverse the three phases of bearing illness and injury: protecting; modifying; and boosting. According to Dewar and Lee (2000), protecting was the act of avoiding interaction with others in an attempt to shield oneself from further emotional pain. An example of protecting was the method of avoidance behavior; it may have been implemented by lashing out at a caregiver in order to avoid the humiliation of having one's personal hygiene performed by another. Dewar and Lee (2000) described modifying as the second principal strategy; the ability to manage the physical, social, and emotional aspects of a situation, which enabled one to become actively involved and learn new skills in order to adjust to new physical limitations. Dewar and Lee (2000) illustrated the concept of physical adjustment to the new body through the following description:

It is just a matter of finding out what I can do and then enjoying what I can do now. I hadn't done any painting or drawing for 30 years. I gave it up in my early 20's. They asked me what I wanted to do when they got me into a chair and I said, "I want to paint." (p. 920)

Dewar and Lee (2000) found that boosting, which was the third strategy implemented by people who bear injury and illness, was the act of enhancing the individual's self-esteem through downgrading or reducing their own disabilities. According to Dewar and Lee, comparing one's self to another was the most commonly used method of boosting. The

boosting effect was the comparison of one's self with another person who was perceived to be in a worse health or predicament than the individual in question. The comparison with someone who was perceived to be in worse health or predicament actually enabled one to feel better about themselves and their current state of health. Dewar and Lee (2000) used the following participant dialogue to accent the concept of boosting:

It is bad enough to be quad, but to be a paraplegic and deteriorate into a quad. So it is worse for him, you know, sort of a double shock. You can't dwell on what's happened. You can't change it. So you just live life as best you can by seeing other people out there who are in a worse condition than I'm in. I'm lucky not to be on a respirator. They are people out there who are on it 20 hours each day and get only a couple of hour's relief from that. There are people who can't move their arms. They have to drive the chair and punch computer keys with a stick in their mouths and all of that sort of stuff. (Dewar & Lee, 2000, p. 921)

People who were bearing illness and injury were the only entities who could pick and choose their own comparison target. A healthcare professional could not verbalize to the injured person how fortunate she or he was in comparison to other patients for it seemed uncaring and non-supportive to the individual in question (Dewar & Lee, 2000).

Boosting was an independent process by which the person with a traumatic injury compared his injury and lifestyle with someone who was perceived to have a more severe injury. The act of boosting enabled the people with spinal cord injury to feel better about their injuries for they assessed that many people have more difficult lives and debilitating injuries than they did.

Three phases. According to Dewar and Lee (2000) finding out, facing reality, and managing reality were the three primary phases that were traversed as the participants negotiated the process of bearing illness and injury. The process of bearing injury and illness was unique to each individual; each person may maneuver the three steps differently, or incompletely; however, it was a process of individuality that fostered a new self-image from the assimilation of the old self with the needs of the new body.

Critique. Dewar and Lee (2000) studied 28 male and 28 females to examine how individuals with catastrophic illness and injury managed their personal and social roles. The researchers used the standard grounded theory methodology as described by Glaser and Strauss (1966). A noted weakness of this study was the lack of information concerning methodology. It was not stated if any of the 58 participants dropped out of the study during the process of grounded theory. The loss of participants, if any, could have caused a noted change in the outcome of the study. The data were also lacking information concerning the age range of the participants and the efficacy of their participation. It was reported in the data that the time since injury or debilitation was between 3 and 25 years. It was concerning that the length of time since injury or debilitation may have had an effect on the outcome of the study because Stensman (1994) indicated that people have an unstable mental construct until at least two years post spinal cord injury. Although the research has potential deficits in the selection of participants and the adherence to the prescribed methodology is unclear, the data offered insight into the barriers that manifested feelings that were encountered as people with disabilities attempt to regain their personal and social roles.

Depression and Spinal Cord Injury

The sudden and traumatic loss caused by the injury creates many new life style challenges for the person with spinal cord injury. According to the majority of the research, longitudinal studies of depression have been lacking in today's state of the science and the few available longitudinal studies are contradictory (Kennedy & Rogers, 2000; see also Elliot, Wilkinson, Hanger, Gilchrist, Sainsbury & Shamy, 1996; Hancock, Craig, Dickson, Chang & Martin, 1993). Major depressive disorder (MDD) is a pathological syndrome that is manifested as a depressed mood, a loss of pleasure, lack of energy, feelings of hopelessness, self-criticism, and suicidal ideation; MDD affects almost 5 percent (11 million people) of the population of the USA (Bombardier, 2001). Although many studies indicated that depressive disorders were the most common manifestation of psychological distress in people with spinal cord injuries, few studies contend that people with spinal cord injuries have no more depressive episodes than the people of general population (Kennedy & Rogers, 2000).

Early research. According to the early studies, depression had been identified as a major component in as many as 100% of the people who obtained a spinal cord injury; the stage theory indicated that depression was not only paramount but also essential for the rehabilitation of the person with spinal cord injury (Kennedy & Rogers, 2000; see also Frank, Chaney, Clay, Shutty, Beck & Kay, 1992). Kennedy and Rogers explained that the early researchers believed that depression was a key element in the grieving process and the absence of depression manifested denial of the global catastrophe of spinal cord injury. As the individual adjusted to the new body, the person grieved over the loss of the old body, past activities, and lifestyle. The spinal cord injury and the

resultant loss of function, lifestyle, and subsequent perceived social standing was often the etiology of a bereavement response. The bereavement response could lead to a post bereavement response that manifested as depression. Langer (2001) indicated that clinical depression, as a post bereavement response, was believed to result from grieving over the lost object. Langer continued that the predictable human response to loss included sadness, bitterness, anger, shock, and pining for the lost object. The stage model indicated that an individual with a newly acquired spinal cord injury must ascend through depression in order to adjust to spinal cord injury. Kennedy and Rogers (2000) maintained that the stage model illustrated that the spinal cord injury was the primary etiology to the depression and that premorbid personality characteristics or situational differences that may affect post-injury behavior were non-considerations.

Current Research. People with spinal cord injury may develop a depressive disorder that ranges from a minor depression (14%-35%) to a major depressive episode (10%-15%) (Krause, Kemp & Coker, 2000; see also Elliot, Wilkinson, Hanger, Gilchrist, Sainsbury & Shamy 1996; Frank, Chaney, Clay, Shutty, Beck & Kay, 1992; Fuhrer, Antonucci & Dartigues, 1992). A longitudinal study by Hancock et al. (1993) that examined 41 patients who had acquired some disability after a traumatic spinal cord injury revealed that people with spinal cord injury had significantly higher scores on the Beck Depression Inventory (Beck, 1979) and the Spielberger State Trait Anxiety Inventory Hansen (2005) than the control group from the general population. Hancock et al. (1993) continued that people with spinal cord injury maintained the high scores over the course of one year from the date of injury, which indicated that the levels of anxiety and depression had not decreased over time. Bracken and Shepard (1980) found that

people who acquired a spinal cord injury developed depression at the time of injury and later developed chronic depressive disorder. Bracken and Shepard's (1980) longitudinal analysis also reported that people with spinal cord injury had a higher rate of depression following injury and that over a period of four years post injury that only a moderate positive change in mentation had been affected in the people with spinal cord injury. Bracken and Shepard's (1980) study was limited, for the study used one item questions to measure affective reactions which, according to Kennedy and Rogers (2000), did not provide sufficient empirical data that was relevant for comparison.

Tirch, Radnitz, and Bauman (1999) determined through a monozygotic twin study that spinal cord injury was not the etiology of depression. The study examined 13 pairs of monozygotic twins, of which one of each pair of twins had undergone a spinal cord injury, to ascertain, through the Beck Depression Inventory, if spinal cord injury was the etiology of depression. The study concluded through the use of paired t-tests that depressive symptomatology between co-twins with and without spinal cord injury was not found. According to Tirch et al. (1999), the preceding study was the largest study ever conducted on spinal cord injury and monozygotic twins; however, the authors cautioned that this study had a very small sample size (13), which was due to the relatively low number of monozygotic twins who suffer spinal cord injury. Tirch et al. (1999) explained that the twins were emotionally close and that it was unknown to what degree the spinal cord injury had affected the twin who had not suffered the physical disability; it was concluded that the secondary traumatization of the twin without spinal cord injury may have contributed to depression in the non-injured twin; thus, the study would have been in error due to the fact that spinal cord injury would have been the

etiology of depression in not only the twin with spinal cord injury but also in the physically unaffected twin.

Krause, Kemp, and Coker (2000) implemented a mediational model in a research study of 1391 people with spinal cord injury to analyze the association of demographic cross sectional data and scores from the older adult health and mood questionnaire; the study revealed that 42% exhibited a depressive disorder whereas 21% tested for major depression.

Demographics of spinal cord injury and depression. Ethnic differences were found to be diverse in depressive symptoms following spinal cord injury. People of Hispanic background were found to report more symptoms than people of either African-American origin or those of Caucasian decent; however, minority women were reported to exhibit an overall rate of 73% for depressive disorder and 34% for major depression (Krause et al., 2000). Additional research indicated that the subjective outcomes were only limited to certain aspects of life acculturation rather than a general affect score for people with spinal cord injury. Krause et al. (2000) continued that minority participants and Caucasian participants reported very similar scores on the general measurement of life engagement and negative affect; however, the minority participants reported lower well being related to financial and career areas.

Chronological age, depression, and spinal cord injury. Krause et al. (2000) stated that aging and psychological outcomes have shown a correlative relationship. Krause et al. (2000) found a negative correlation between the chronological age of the person when spinal cord injury was acquired and the number of years since the injury. The study illustrated that chronological age was negatively correlated with general life satisfaction

and life adjustment (-.19 and -.25), although the number of years passed since the initial spinal cord injury was positively correlated with similar outcomes (+.15 and +.16). Krause et al. (2000) determined that the older chronological age of the person at the time of the initial spinal cord injury was associated with the poorest psychological outcome, whereas the study correlated a higher level of social well being with the younger the person's chronological age was at the time of spinal cord injury. Krause et al. (2000) continued that emotional distress was also negatively correlated to time since injury (-.11).

Krause, Kemp, and Coker (2000) expressed that this work harbors several limitations that may have affected the outcome of the data. The authors explained that causality was undeterminable due to the cross sectional design and they continued that environmental factors such as managed care, or even rehabilitation practices could have affected the lives of the participants and in turn been confounding to the final data. Krause, Kemp, and Coker (2000) surmised that it is possible that the prevalence of depression was elevated in this study due to a result of using one sole instrument of depression.

Degree of handicap. Tate, Forchheimer, Maynard, and Dijkers (1994) found that the degree of handicap the person manifested was directly contributory to the depression and psychological distress in people with spinal cord injury. The study measured the responses of 163 volunteers with spinal cord injury who were between two and seven years post injury on the Zung Self-Rating Scale, the Brief Symptom Inventory, and the Craig Handicap Assessment and Reporting Technique (CHART) in addition to the Perceived Handicap Questionnaire (PHQ). The study by Tate et al. (1994) was performed over a two-year period to ascertain if the level of the participants' depression

was correlated with changing levels of handicap. Using multivariate analysis the study determined that a higher prevalence of depression was directly correlated with a greater degree of handicap as experienced by the person with spinal cord injury.

The preceding research study by Tate et al. (1994) used a large number of participants to successfully obtain sufficient statistical power and the data were obtained via proven research tools; however, little insight was given on possible confounding factors, which may be reflected in the data. The study indicated that gender was a significant predictor of post-discharge distress, which was surmised by the authors as possibly due to the inability to meet general male social expectations. Although the research study stated that it controlled for possible extraneous effects and that education level was no longer associated with either outcome, it appeared that career choice, or in particular the job the subjects held at time of accident, was not included in the control for confounding factors. One can deduce that the final analysis may be questionable for data were not given for the type of job held by the participants prior to injury, although the researchers suggested that men have higher levels of mental distress due to the inability to meet the social expectations required by them for their job and social obligations. It would be in error to assume a preconceived, stereotypical view that women have sedentary jobs and men have careers that require more physical activity; thus, one cannot deduce from the data if mental distress and depression were due to gender or to career choice.

Elapsed time since injury. Kennedy and Rogers (2000) used a prospective, longitudinal, multiple wave panel design which measured the responses of 104 participants with spinal cord injury via the Beck Depression Inventory, the Beck Hopelessness Scale, the State Anxiety Inventory, the Functional Independence Measure,

and the Social Support Questionnaire. The assessments were taken on 14 observational periods, which ranged from initial contact in the acute stages of hospitalization to two years post discharge into the community. Statistical analysis revealed that the amount of time since injury and the amount of time since discharge were negatively correlated with depression in people with spinal cord injury. Kennedy and Rogers (2000) found that depression was positively correlated with the amount of time the person with spinal cord injury spent in the actual hospital setting and upon discharge a slight reduction in the mean scores for depression and anxiety was observed. Kennedy and Rogers (2000) concluded that additional work was needed to ascertain the psychosocial ramifications of spinal cord injury due to the prevalence of people with spinal cord injury in this research study that obtained scores indicating the probability of depression and anxiety.

The research study by Kennedy and Rogers (2000) used sufficient participants to obtain statistical power and validated tools were used to obtain data on anxiety and depression in the population. The researchers expressed that the Beck Depression Inventory was not developed expressly for people with spinal cord injury; thus, more research was needed to develop a tool that would take in account the special needs that were associated with the spinal cord injured population.

Discussion. Clearly, depression seems to be a disorder that is reflected in people with spinal cord injury. Although the literature was contradictory on spinal cord injury as an etiology of depression, it was certain that many people with spinal cord injury suffered from this treatable disorder. This literature review has focused on depression and spinal cord injury in an attempt to illustrate the work that was ongoing in the field of research within spinal cord injury. The research studies which have been cited illustrated that

additional work is needed to fully understand depression and spinal cord injury.

Depression is a multifaceted disorder that is difficult to understand in the spinal cord injury population due to the vast differences that are associated with the group.

Superficially, one can deduct that men aged 18-35 were the majority of people affected by spinal cord injury; however, even within this small population many variables are present in the subsets that made understanding depression and spinal cord injury very difficult to ascertain. According to Krause et al. (2000), four aspects that evoked the perception of the incident of depression after spinal cord injury was largely dependent on: (a) the study in question; (b) the definition of depression; (c) the measurement tool; and (d) when the study was performed in relation to rehabilitation. Depression in people with spinal cord injury exhibited data which were both conflicting and dependent on the methodology of the study. The various studies have indicated that perhaps depression was prevalent in some people with spinal cord injury, but it is with certainty that additional work is needed to fully explore the concept of depression and spinal cord injury. The studies cited here employed research approaches and methodologies that were not created for the spinal cord injured population. Additional work is needed to create a validated measure of depression in spinal cord injury that will provide valid data through increased sensitivity of the concerns of the person with spinal cord injury. Depression is the result of a constellation of the many factors that influence the psychological resources of the individual when faced with spinal cord injury. Langer (2001) surmised that spinal cord injury and the resultant disability or loss, when combined with the individual's psychological comorbidities that include concurrent life stressors, prior life history, social

and financial resources, psychodynamic issues, and social and personal issues, may lead to the manifestation of depression.

Quality of Life

The definition. The short phrase “quality of life” yields many different interpretations to as many different people. In our modern society, quality of life may be determined by one’s material or monetary wealth, the quantity of actualized interpersonal relationships, the shape and fitness of one’s body, or even one’s perception of their mental or spiritual well being; however, according to Dijkers (1997), most people recognized that a spinal cord injury greatly affects one’s quality of life. Scherer and Cushman (2001) indicated that quality of life was measured as a personal, global evaluation of well being or general satisfaction with life experienced by people under their current conditions. Scherer and Cushman described quality of life as life satisfaction, subjective well-being, and a positive general affect, as it was also associated with satisfaction in specific areas of life such as work, social relationships, and being able to go where one wishes beyond the mere physical capability to do so.

Dijkers (1997) discovered, through a meta-analysis of 22 studies with an average sample size of 102, that quality of life was often measured by one’s health and personal safety, independence, the ability to earn an income, access to material comforts, the ability to have and to raise children, the likelihood of developing a close relationship with a member of the opposite sex, a close and supportive network of friends, and a positive body image. Brown, Renwick and Raphael (1995) found that quality of life refers to an individual’s satisfaction with various domains of life quality, which include health, relationships, social, emotional, and physical function as well as happiness, and

satisfaction with living situation and finances. Brown et al. (1995) concluded that the loss of perceived quality of life may affect the self-concept, and one's understanding of the self may be globally altered by the spinal cord injury and the resultant quality of life.

Variables of quality of life. Lucke, Coccia, Goode, and Lucke (2004) found through a mixed method, descriptive, longitudinal feasibility study which used the SF-36 and analog visibility scales that the time since injury, as opposed to the level of injury, was directly related to an improvement of quality of life in people with spinal cord injury, who have achieved adequate levels of social support, income, education, and employment. The study further revealed that a lower quality of life score was associated with a higher pain level, greater spasticity, incontinence, less physical independence, and the inability to return to work; whereas, satisfying relationships, maximizing function, access to the environment, and meaningful activities were associated with a higher quality of life. The small quantitative study yielded several limitations that might have affected the final data. The research used a convenience sample of 10 people with spinal cord injury and their family caregivers. The exact number of participants in the study was not given; however, it is conceivable with only 10 people with spinal cord injury and their respective caregivers that the sample size would not reach statistical power. The authors pointed out that the instrument of measure, the SF-36, has not demonstrated reliability and validity in the spinal cord injury population. This research offered preliminary data in a population that warrants further study. The validity of the findings was questionable due to the small sample size and the unproven tool; however, it offered initial data of the quality of life of both the person with spinal cord injury and the family caregivers.

A study by Siosteen, Lundqvist, Blomstrand, Sullivan, and Sullivan (1990) was performed in Sweden, a country known to have fewer physical barriers to people with disabilities than other countries, to determine if people with spinal cord injury have more or less quality of life than that of the general population. The study indicated that people with spinal cord injury had the same level of perceived quality of life as people in the general population (see also Lucke et al., 2004; Lundqvist et al., 1991; Stensman, 1985, 1994). A similar study conducted in the United States, which offers more physical barriers to people with spinal cord injury, determined that people with spinal cord injury who were living in the community exhibited a lower level of perceived quality of life than people in the general population (Lucke et al., 2004; see also Decker, & Schultz, 1989; Putzki, Richards, Hicken, & DiVivo, 2002). Lucke et al. (2004) surmised that these studies suggested that the perceived difficulty with the desired availability and accessibility of community resources might precipitate lower scores in the perceived quality of life in the person with spinal cord injury.

Putzke et al. (2002) discovered through a prospective, predictive study which used longitudinal data from 18 spinal cord injury model systems, which included the Satisfaction with Life Scale (SWLS) at one and two years post spinal cord injury along with predictor variables, that mobility, occupation, social integration, social support, and perceived control were indicated to be predictors of quality of life. Putzke et al. continued that perceived quality of life was significantly higher in people with spinal cord injury who have exercised freedom of choice in their living arrangements, spent more time in social and recreational access, and who were able to interact with the physical environment. The quantitative work had yielded a sample size of 940 participants who

were drawn from 18 spinal cord injury model systems. Although the large sample size enabled the work to acquire statistical power, Putzke et al. (2002) cited two limitations associated with the study. The people included in the final study were less educated and represented minority groups, thus the results of this inquiry may be skewed towards a particular population. Putzke et al. (p. 560, 2002) stated that the predictive validity of the variables might have been influenced on how the construct was operationalized; thus, “the lack of a significant relationship between some of the examined predictor variables and life satisfaction did not necessarily rule out their predictive value.” The large sample size may have helped the study achieve validity; however, the SWLS was not validated nor deemed reliable for the spinal cord injured population. This work offered insight to the predictors of life satisfaction within the population of people with spinal cord injury; however, further work needs to be performed on both the SWLS to validate the instrument for use with the spinal cord injured population and on the sample selection in order to assure a diverse population for study.

Institutionalization. Putzke and Richards (2001) determined through a case control design which matched nursing home and community residents with similar medical and demographic backgrounds that institutionalization of people with spinal cord injury resulted in lower quality of life scores. The two groups consisted of 37 participants each who were matched on age, education, race, impairment level, and marital status; each group’s quality of life was measured via the satisfaction with life scale (SWLS), and the Craig Handicap Assessment and Reporting Technique (CHART). The study revealed that people with spinal cord injury, who are in nursing homes, have a lower quality of life as exhibited by satisfaction with life scale (SWLS). Putzke and Richards (2001) indicated

that self-reported quality of life was significantly lower among nursing home residents with spinal cord injury than with people of people of similar impairment who lived in community. Putzke and Richards found that the overall handicap was significantly higher in the nursing home group in regards to areas of physical independence, mobility, economic self-sufficiency, and occupational functioning. Nursing home patients with spinal cord injury exhibited lower quality of life scores that were directly correlated with the severity of their injury or impairment. The sample size of the study by Putzke and Richards (2001) was small for a quantitative work (N=74) and the participants were not chosen via stratified random sampling of the spinal cord injured population, rather the sample was selected based on whether or not they had a matching case. Putzke and Richards (2001) remarked that the definition of community resident within the study was broadly defined to include participants who lived in facilities that ranged from assisted living to nursing homes. Putzke and Richards furthered that the CHART economic self-sufficiency scale manifested missing data within both subject groups. It was concerning that data were lost from both groups for this lack of information could have changed the final outcome of the inquiry. The data from this study were notable; however, it appears that the lack of random sampling, the inclusion of non-nursing home facilities and the missing information from the CHART scale leads one to question the final outcome of this quantitative research study.

Erectile dysfunction. Hultling, Giuliano, Quirk, Pena, Mishra, & Smith (2000) determined through a randomized, placebo-controlled, double blind, crossover study concerning the erectile dysfunction, and quality of life of 178 men with spinal cord injury that quality of life could be improved in males with spinal cord injury through the use of

sildenafil citrate. The study, which used the International Index of Erectile Function (IIEF), Medical Outcomes Survey (MOS) Short form 12, Psychological General Well-Being Index, and MOS Family Survey, showed that men with spinal cord injury improved the conditionally specific quality of life measures which were related to sexual function through the use of sildenafil citrate. Hultling et al. (2000) stated that the most dramatic improvement in quality of life was seen in the overall satisfaction with sexual life domain and subsequently by being less bothered by erectile problems. The decrease of erectile difficulties granted improvements in mental health and in feelings of depression. Hultling et al. found that, although quality of life scores were elevated, no significant improvements were noted in perceived general health, physical function, emotional stability, general communication or in satisfaction with their respective partner. The large sample size, varied demographics, and the proven tools that were used in this study indicated that this inquiry contributed significant, useful data to the knowledge base of the spinal cord injury population. A limitation of this study was that the duration of the inquiry was only six weeks. Insightful information may be gained from a longitudinal study over the course of two years or more years, rather than just six weeks, for the initial excitement of the renewed erectile function may have positively skewed the data. Another concern of the study is that Pfizer, who is the manufacturer of the drug sildenafil citrate which is trademarked, Viagra, funded the study. While the research study appeared well constructed, an inquiry that could be performed by a third disinterested party may prove more valid due to the lack of obvious association.

Ethnography. Manns and Chad (2001) discovered through a focused ethnographic study that explored the concept and experience of quality of life for 15 people with spinal

cord injury that life quality encompassed nine distinct areas: physical function and independence; accessibility; emotional well-being; stigma; spontaneity; relationships and socialization; occupation; finances; and physical well-being without regards to severity of impairment. Manns and Chad (2001) explained that, although each of the participants identified the parameters that affected their quality of life, physical function, independence, and physical well being had the largest effect in the quality of life scores from the people who acquired a quadriplegic injury. The investigation by Manns and Chad (2001) used a sample of 6 females and 9 men of whom 7 people had quadriplegia and 8 people had paraplegia. The data were acquired from the subjects based on open-ended questions presented by the interviewer. The interviews were tape-recorded and themes were developed by the interviewers and later member checked by the group to ensure validity. This study used Lincoln and Guba's (1985) guidelines to ethnography and gave voice to the people who are living the experience of spinal cord injury.

Hammell (2004) maintained that quality of life is the ultimate objective of rehabilitation. Kennedy and Rogers (2000) expressed that quality of life has been examined in people with spinal cord injury in relation to the specifics of their injury: level of injury, time since injury, age at onset of injury and the associated pain level. Quality of life was found to be high in such areas as family relationships, living arrangements, social life, and passive recreation; however, quality of life satisfaction was found to be low in finances, sexual life, and employment (Kennedy & Rogers, 2000; Tate, Forchheimer, Maynard, and Dijkers, 1994).

Lucke et al. (2004) expressed that the life span for people with spinal cord injury was quickly approaching that of the non-injured person; thus, the quality of life for the person

with spinal cord injury has become a more pressing concern. Although modern science is helping people with spinal cord injury live longer lives, the ability to define and measure quality of life is challenging. Lucke et al. (2004) indicated that quality of life measures, as well as disease specific measures, must have an established reliability, validity, and sensitivity to the important aspects and to the changes that may occur over time in the population of people with spinal cord injury. Although studies have fractionated the various qualifiers, which were reported to be summative of one's life satisfaction and quality of life, additional studies are needed to examine the overall life satisfaction of people with spinal cord injury.

Health Related Quality of Life

The definition. Leduc and Lepage (2002) stated that the concept of health related quality of life, a state of physical, mental and social well-being was proposed in 1958 by the World Health Organization (WHO). The definition of health related quality of life, as stated by Patrick and Erickson (1993, p. 22), was "the value assigned to duration of life as modified through the impairments, functional status, perceptions, and social opportunities that are influenced by disease, injury treatment, and policy" (see also Leduc & Lepage, 2002). Life satisfaction was the conceptualization of subjective quality of life for it is the self-assessment of person's functioning and circumstances (Richards, Bombardier, Tate, Dijkers, Gordon, Shewchuk & Devivo, 1999). The concept of subjective well-being was composed of three separate aspects: (a) positive affect; (b) negative affect; and (c) life satisfaction (Diener, Wirtz, & Oishi 2001; Richards et al., 1999). Life satisfaction was further defined as the cumulative measurement of a person's quality of life as determined by his/her own decisive factors (Richards et al., 1999; see

also Shin, Johnson, Pasternack, & Economou, 1978). Satisfaction with life or subjective quality of life was the assessment of one's life satisfaction as measured by the individual who is experiencing the event.

Spinal cord injury and health related quality of life. Leduc and Lepage (2002) showed in their study, which studied 587 people with spinal cord injury in Quebec, Canada, that quality of life was lower for people with spinal cord injury as indicated in eight health related categories of the SF-36; the results indicated that people who acquired their injury at an earlier age were associated with a higher quality of life. Leduc and Lepage's (2002) research suggested that people with spinal cord injury experienced reactive depressions more frequently (20-40%) and that the suicide rate was higher than the general population. Leduc and Lepage (2002) found that people who obtained a spinal cord injury while married and those who became married post injury had a higher rate of divorce than general population. Leduc and Lepage (2002) suggested, based on the findings as measured by the SF-36, that the health related quality of life scores remained lower in people with spinal cord injury than with the people in the general population. According to Leduc and Lepage (2002), the study used a large sample size; however, the participants are all members of the same association and thus a selection bias may be evident in the final data. Even though the study was performed in Quebec, normative values for SF-36 were based on the general North American population because normative values for the general Quebec population were not available at the time of data acquisition that may have altered the final data.

Spinal cord injury and chronological age. Kannisto, Merikanto, Alarant, Hokkanen and Sintonen (1998) used the 15 D questionnaire to ascertain the health related quality of

life in people with spinal cord injury. The 15D questionnaire measured 15 health related dimensions through 15 dimension specific multiple choice questions. The final score was said to represent the overall health related quality of life (Kannisto et al., 1998). The 15D was used to measure health related quality of life in three subgroups of people with spinal cord injury: people who had sustained a pediatric spinal cord injury (N =36), mean time from injury 20 years; newly injured patients who were at the beginning of acute rehabilitation (N = 31); and patients who had chronic spinal cord injury (N=34). The study found that health related quality of life scores correlated positively with number of years post injury when the person acquired the injury under age 20. Kannisto et al. (1998) indicated that there was a clear margin between the people who acquired the injury early in life and the people who acquired the injury in later years. The study by Kannisto et al. (1998) used a sufficient sample size that indicated statistical power and the health related quality of life was measured via a proven tool.

Life satisfaction was not influenced by their disability status, but rather by the performance of the patient's social role or handicap. Lundqvist, Siosteen, Sullivan, Bloomstrand, Lind, and Sullivan (1997) administered the Sickness Impact Profile (SIP), Mood Adjective Check List, and the Hospital Anxiety and Depression Scales to 98 participants with traumatic spinal cord injury and discovered that the spinal cord injury groups exhibited higher disability scores in the physical function categories of the sickness impact profile than the respective control group; however, scores reflecting psycho-social function did not exhibit significant values between the spinal cord injury group and the control group. Health related quality of life is a dynamic, changing, and

multifaceted perception of the self that is influenced by one's onset of spinal cord injury, the social role, the perceived handicap, and the physical function (Lundqvist, 1997).

Life Satisfaction

Definition. According to Siosteen et al. (1990a), life satisfaction was almost a synonym for quality of life. Post, Van Dijk, Van Asbeck, and Schrijvers (1998) expressed that life satisfaction was the feeling or subjective understanding that one has concerning their individual functioning within their life circumstances. Subjective well-being was a construct thought to exhibit an emotional component and a cognitive-judgment component, which was deemed life satisfaction (Dijkers, 1999, Putzke et al., 2002). Dijkers (1999) continued that quality of life was often conceptualized differently and two major schools of thought were evident within the conceptual framework. Dijkers (1999) surmised that quality of life could be examined through an objective lens, which focused on the external characteristics of the person, or through the subjective eye, which suggested that only the person who was experiencing the presence or absence of life satisfaction could be the instrument of measure. The conceptualization of life satisfaction and quality of life were defined differently by two compelling methodologies: life satisfaction was the self's subjective evaluation of one's function in life; quality of life was the objective evaluation of one's station in life as perceived by another.

Life satisfaction and spinal cord injury. Dijkers (1999) analyzed the correlates of life satisfaction in a study which involved 2,183 people with spinal cord injury who ranged from 1-20 years post injury, who were self-selected for annual research follow-up by one of the 18 participating model systems of spinal cord injury care. The study used stepwise linear regression analysis from data obtained from demographic information, the

Satisfaction with Life Scale (SWLS), as well as sociocognitive disability that was measured by the Functional Independence Measure and three handicap components which were measured via the CHART. Dijkers (1999) study revealed that income, meaningful social activities, and educational status were the predictors of life satisfaction in people with spinal cord injury and that life satisfaction had also been directly related to physical functioning, physical symptoms, and psychosocial factors. Dijkers (1999) discovered that many people in our society felt that to have a spinal cord injury befall them was one of the greatest difficulties which could have occurred to them and regarded death as an improvement in state; however, most people with a spinal cord injury did not reflect the idea of death being an improvement over the injury. Dijkers (1999) found that although suicide rates among people with spinal cord injury were at a rate five times that of the general population, family relationships, living arrangements, social life, and passive recreation were areas that reflected high life satisfaction ratings, even though finance, sexual life, and employment have most often reflected low life satisfaction ratings.

Demographics. Demographics played a strong role in the determination of one's life satisfaction following spinal cord injury. Dijkers' (1999) meta-analysis indicated that one's sex, ethnic group, age, and education level had a determinant effect on the life satisfaction of people with spinal cord injury. Dijkers found women scored slightly higher in life satisfaction than men and that non-white Hispanics had a higher life satisfaction than people of African-American origin and white Hispanics. According to Dijkers, the ethnic group that held the highest score on the satisfaction with life score was demographically classified as the "other" ethnic group, which included Native

Americans, Pacific Islanders, and people of Asian decent. According to Dijkers (1999), married people with spinal cord injury scored higher on the satisfaction with life scale while people with spinal cord injury who were institutionalized in a nursing home scored the absolute lowest on the satisfaction with life scale.

Dijkers (1999) also found that one's career or life pursuits affected the well being of the person with spinal cord injury. People with spinal cord injury who were either homemakers or students scored a higher life satisfaction score when compared with people who were unemployed or retired. Dijkers determined that education had a positive impact on one's well-being, for people with advanced education generally scored higher on the satisfaction with life scale than people who had less education; people with the least education also earned the lowest score on the satisfaction with life scale.

Dijkers (1997) postulated that the major determinants of life satisfaction associated with spinal cord injury were sex, time since injury, and handicap. Dijkers expressed that people in ethnic minority groups, people with less education, or the unemployed yielded a decreased life satisfaction that was due to the indirect effects of the disability. Dijkers continued that the inability to secure employment or the lack of sufficient income, added a cumulative effect to the person's decreasing satisfaction with life; thus, the determinants of life satisfaction were contingent on what the person with injury felt was lacking in their life since the spinal cord injury.

Leisure activities. Post et al. (1998) measured life satisfaction via the Life Satisfaction Questionnaire, in a study that drew 318 participants with spinal cord injury from a nationwide sample (Netherlands) and 507 participants (control) from a large city in the Netherlands. The Life Satisfaction Questionnaire, which contained on question about

general life satisfaction and eight questions on domain specific life satisfaction reported that the mean scores of general life satisfaction, satisfaction with leisure activities, self-care abilities, career pursuits, and sexual relationships were lower in people with spinal cord injury; however, the mean score of satisfaction with family life was higher. Post et al. (1998) determined that the extent of neurological involvement was also a contributing factor to reduced life satisfaction for participants with quadriplegia because they had a lower reported life satisfaction than the participants who had experienced paraplegia.

The study by Post et al. (1998) added pertinent data to an area that is lacking in today's state of the science. Due to the size of the sample, the study achieved statistical power; however, the sample selection of the study could have altered the final data of the study. It was concerning that the members of the control group were all chosen from one large city in the Netherlands rather than from the country at large. Post et al. (1998) explained that the population (control) group had a higher percentage of women, students, and younger respondents than in the spinal cord injury group; however, the percentage of men and women who were in the sample was not included in the data. The age of the sample group and the possible generational differences of the respondents could have affected the data and altered the final outcome. It was unclear from reading the results if the demographics of both groups were taken into consideration. The spinal cord injury group contained participants who had suffered spinal cord injury from both traumatic injury as well as illness. While both of the two subgroups within the spinal cord injury group had undergone debilitating spinal cord injuries, it is unclear how the etiology of the spinal cord injury could have affected the data.

Degree of handicap and life satisfaction. Kemp and Krause (1999) used The Geriatric Depression Scale, The Older Adult Health and Mood Questionnaire and a 10-item life satisfaction scale to assess the depressive symptomology and quality of life in three groups formed from a sample of 360 people. The groups were composed of a non-disabled control group (N= 62) and participants who had undergone either a spinal cord injury (N =177), or who were post polio survivors (N= 121). This study offered an additional view to life satisfaction and indicated that life satisfaction did not relate to age, age at onset of disability, duration of disability, gender, or severity of impairment. Life satisfaction appeared to be related to measures of handicap. Kemp and Krause (1999) pointed out that life satisfaction was directly correlated with the level of handicap; the lower one's handicap, the higher one's perception of life satisfaction. Kemp and Krause found that, as the person with spinal cord injury ages, their satisfaction with life may decrease due to less social interaction and increasing degrees of handicap. McColl and Rosenthal (1994) supported this concept as their study showed that among aging people with spinal cord injury that social support was positively correlated with life satisfaction; people with increased social interaction have increased life satisfaction.

Kemp and Krause (1999) determined that their study was limited by the demographic characteristics between the polio and spinal cord injury groups. The authors stated that the spinal cord injury group was most often unemployed due to the nature of their injury and thus this lack of societal congruence may have affected that data comparison. The use of two different scales for the measurement of depression between the spinal cord injury and the post-polio group added to the difficulties of data assimilation. The data obtained was entirely subjective in nature. Although an objective scale may seem

unnecessary in a study that was measuring subjective data, Kemp and Krause suggested that an objective scale was needed to validate results.

Hicken, Putzke, Novack, Sherer, and Richards (2002) conducted a research study that measured the responses of 57 participants with traumatic brain injury and 190 individuals with spinal cord injury via The Satisfaction with Life Scale (SWLS) and The Functional Impairment Measure (FIM) and determined that family support which was perceived to be satisfying and lower self-blame for the injury were the two strongest predictors of increased life satisfaction among people with spinal cord injury. Hicken et al. (2002) discovered that life satisfaction was unrelated to demographic variables (gender and race) and that functional disability measured via the FIM was an accurate predictor of life satisfaction.

The study by Hicken et al. (2002) used a sample size which demonstrated statistical power and the validated SWLS and the FIM; however, the authors pointed out that the samples chosen from their study were selected from only two facilities, of which, both were located in the southeastern United States. The authors continued that the study only acquired data on life satisfaction at one-year post injury and they suggested that additional work was needed at longer durations post-injury to facilitate valid understanding of these two groups.

Discussion. The information concerning the demographics, degree of handicap, and the prevalence of life satisfaction were both confusing and oppositional. Additional research is needed to ascertain the importance of one's gender, employment, marital status, and race to determine if it creates an effect on the person's with spinal cord injury life satisfaction. Dijkers (1997) continued that additional research within subjective

quality of life is needed for little is known about how traumatic injury affects the subjective well-being of the individual. The research presented on the life satisfaction contained valuable insight into the subjective insights of the person with spinal cord injury; however, the data assimilated were from a new arena of research that needed additional work to ascertain the validity of the studies for subjective quality of life was a relatively new field of study.

The Impact of Spinal Cord Injury

Dependency, depression, drug addiction, and divorce. Gill (1999) expressed in his article that spinal cord injury was an ongoing challenge to the physical, mental, and social well being of the victim, the family members, and even friends; the struggle with spinal cord injury yielded social and psychological ramifications that were often left unresolved. Gill found that spinal cord injury created a multitude of emotional and psychosocial ramifications. According to Gill (1999), many people with spinal cord injury experienced low self-esteem with decreased self worth and self-efficacy that was due to the increased dependency necessitated by the lack of mobility. Gill (1999) continued that lowered self-esteem and the trauma of spinal cord injury could foster the four D's of spinal cord injury: dependency, depression, drug addiction, and divorce. The person with spinal cord injury must often be dependent on someone else for his or her daily care, ADLs, bowel elimination, and even respiration. According to Gill (1999), this increased dependency could enable one to give up rather than feel obliged or dependent on someone else. Dewar and Lee (2000) indicated that dependency on significant others for daily care was difficult, embarrassing, and often left the dependent person feeling powerless, vulnerable, devalued, and obligated to the person performing the care tasks.

Depression often occurred following a spinal cord injury; however, according to Gill (1999), what appeared to be a major depression might be part of a coping process with the traumatic injury. Gill found that people with spinal cord injury often used excessive prescription medication or street drugs to numb the reality of the pain of spinal cord injury. The use of non-prescribed medications offered to the person with spinal cord injury a brief escape from the ongoing monotonous daily routine of spinal cord injury. The simplest tasks, which were often taken for granted by people without physical impairment, may become major issues for the person with spinal cord injury. According to Gill, divorce is the final D that affected many people with spinal cord injury. Gill (1999) suggested that spinal cord injury heralded in a period of social, physical, emotional, and interpersonal adjustment, which might strain the mate's coping ability due to a dark and uncertain future that was associated with spinal cord injury. The non-injured significant other often experienced daily stress from the 24 hour care of the person with a spinal cord injury. The significant other, who may have dreamed of a bountiful life with a new home and fluid finances, is now suddenly faced with a life of bowel management and bed sore prevention. Gill continued that this change of focus caused some life partners to reexamine their position in life, and, even though they were often committed to one another for better or worse, to leave the relationship.

Spinal Cord Injury and Sexuality

Sexual functioning and reproduction were prevalent issues in the life of the person with spinal cord injury. Fisher, Laud, Byfield, Brown, Hayat, and Fiedler, (2002) explained that feelings of sexual inadequacy, emotional distress, loss of self-esteem, and a marked physiologic impairment were barriers that complicated the sexuality of people

with spinal cord injury. Fisher et al. used the Responses to Sexual Health Needs Survey to conduct a longitudinal analysis of 40 people with spinal cord injury (32 men and 8 women) at four time intervals that were between initial inpatient rehabilitation and 18 months following hospital discharge. Fisher et al. (2002) reported that during the initial hospital stay that the people with the newly acquired spinal cord injury did not expect to experience a reduction in their sexual frequency; however, upon returning home, the subjects reported a noted decrease in their sexual activity. Fisher et al. (2002) maintained that sexual desire and sexual satisfaction often declined for people with spinal cord injury due to concerns of feeling sexually unattractive, of not satisfying their partner, and experiencing decreased or non-existent sexual satisfaction. The participants of the study exhibited an increase in sexual activity at six months post spinal cord injury; the sexual frequency did not increase throughout the subsequent time intervals to the termination of study at 18 months post spinal cord injury. Fisher et al. (2002) continued that sexual interest and the need for sexual expression were evident in people with spinal cord injury even though they had acquired changes in their sexual functioning due to spinal cord injury. Fisher et al. continued that sexual education for people with spinal cord injury, which is paramount, should be implemented in the time period immediately following discharge from the hospital. Fisher et al. (2002) found that people with spinal cord injury were often looked upon as asexual; however, new medications for erectile dysfunction have enabled men with spinal cord injury to participate in active intercourse. This quantitative study by Fisher et al. (2002) exhibited limitations due to the small sample size, which was largely self-selected, and the disproportionate number of men to women. The final results might have been affected by the participant's marital status; however

information concerning marital status was unknown. Changes in the participants' marital status, which could have resulted in the loss of a sexual partner, might have reduced the frequency of sexual activities. Further weakness was observed in the time intervals selected for the study. Stensman (1994) indicated that a person with a new spinal cord injury has an unstable construct for at least two years post injury; the farthest time interval post spinal cord injury used in this research was 18 months, which falls 6 months short of the two years that were needed to rebuild a stable mental construct. Although this study illustrated the sexual frequency and concerns of people with spinal cord injury during the initial 18 months post spinal cord injury, the long term issues surrounding the sexuality of people with spinal cord injury cannot be concluded due to the disproportion of the sample, the small sample size, and the timing of the data gathering in relation to the initial date of spinal cord injury.

Women and Spinal Cord Injury

According to Pentland et al. (2002), women comprised almost 20% of the population of people who have undergone a spinal cord injury. Pentland et al. discovered through a qualitative study that used the technique of Explanatory Models to capture the idiosyncratic cognitive and personal phenomena of ageing in women with spinal cord injury. The study by Pentland et al. used three focus groups (n=10 per focus group) and key informant interviews (N=19) of women with spinal cord injury who ranged in age from 31-70.

The female experience. Pentland et al. (2002) indicated that although it is widely accepted that men and women have differing viewpoints, realities, and lived experiences, few studies have been performed concerning women and their experience of spinal cord

injury. Pentland indicated that women with spinal cord injury had a much lower rate of marriage than the women in the general population, and due to the lower rate of marriage, they had faced the process of aging solitarily and with less income. Pentland et al. (2002) discovered that women with spinal cord injury expressed anger concerning the lack of education, support, and understanding about gynecological and sexual issues. The research indicated that women had increased concerns about menstruation for they indicated that the menstrual flow becomes heavier as one ages and that wheelchair transfers caused “flooding” through the creation of surges in menstrual flow. Pentland et al. furthered that ovulation often heralded a trilogy of difficulties for women with spinal cord injury. The women continued that menstruation manifested initially as symptoms of a bladder infection that soon evolved into a cycle of diarrhea that created a urinary tract infection from frequent bouts of bowel incontinence. The resultant urinary tract infection was often treated with antibiotics that frequently became the etiology of a yeast infection. Pentland et al. (2002) found that this conundrum of medical mismanagement fostered feelings of anger, frustration, and helplessness in women with spinal cord injury.

Women and their family. Pentland et al. (2002) learned that women with spinal cord injury suffered increased fatigue, reduced energy, and found that napping was a needed commodity during the day, although housework and childrearing made it almost impossible to obtain. Women with spinal cord injury were fearful that they would be abandoned by their spouse as they age, which would necessitate increased dependence on caregivers; the women with spinal cord injury attempted to show their usefulness to the family unit through active participation in heavy housework such as floor scrubbing and toilet cleaning. Pentland et al. found that the family often believed that the woman with

spinal cord injury should function at the same level or better than she did upon discharge from the rehabilitation center; however, most women with spinal cord injury had a decline in their physical abilities as they aged. A direct quote from Pentland's (2002) inquiry reads:

I worry that as I deteriorate I might be taken away from my children. I might not be able to be with them or selfishly to experience some of the things I would have with them...maybe even as a grandmother....I know my disability is shortening my life. (p. 381)

Women with spinal cord injury encountered additional obstacles due to social norms, increased longevity and physical needs that placed increased burden on them as they attempted to fulfill their familial and social roles.

The qualitative study by Pentland et al. (2002) maintained a sufficient sample size (N=29) by qualitative standards, and the members who lived the experience validated the data obtained from the explanatory work. The data, which were rich and unique, gave first person insight into the difficulties of being a female living with a spinal cord injury through the ageing process. The sample size included women who were from both rural and urban areas of Canada to communicate their ongoing life experience as they aged.

Adapting and Coping with Spinal Cord Injury

The ability to adapt and cope with a spinal cord injury is a process, which takes place over a period of time. Gill (1999) expressed that the process of adaptation was comprised of three levels: individual, social, and environmental. Gill continued that a person with a history of alcohol or drug abuse, limited social support, a sense of hopelessness, low self-esteem, a dysfunctional family or a non-spiritual or religious background might encounter

increased difficulty coping with a spinal cord injury. Gill (1999) determined that in order to accept a resultant disability from spinal cord injury, the successful person often demonstrated faith in a higher power, a solid social and emotional support system, and a strong desire to be independent. Gill (1999) found that becoming an active person in both work and the community could foster social adaptation, albeit through reentering the work force or volunteering services and that environmental adaptation was fostered through the physical manipulation of private and public buildings and venues. Gill (1999) concluded that the person's with spinal cord injury adaptive coping mechanism, use of available social resources, and the continued adaptation of the physical environment to aid accessibility were paramount for the successful reentry of the person with spinal cord injury into mainstream society.

Adaptation and the unitary perspective. While the thoughts of adaptation to one's environment are paramount to a successful reclamation of one's life following spinal cord injury when viewed through the general systems theory, adaptation is not congruent with the unitary perspective that focuses on creative and emergent patterning. Cowling (1993) stated that the general systems theory, which was comprised of: causality, variables, boundaries, and the permanent object, viewed the world through cause and effect, interdependency, boundaries, and self-existing entities. Cowling (1993) continued that the unitary view promoted an extreme difference from conventional systems thinking, for the unitary perspective contended that time and space were not merely one temporal dimension and three independent spatial dimensions, rather the three spatial and temporal dimensions were interdependent on each other in a four dimensional space-time continuum. Cowling (1993, p.202) stated "phenomena are interconnected and

consequently are important aspects of the unitary pattern, not parts of a system.
Because time-space is in flow and continuity, phenomena are not discrete, compartmentalized and sequential.” Cowling (1993) explained that variables, which were objects, forces, and their characteristics, were in unity with the human pattern and not independent abstracts that might be manipulated. Cowling (1998) contended that reality was composed of human and environmental energy fields which were evolving, changing and growing unpredictably in simultaneous mutual process in a pandimensional universe without causal connectivity.

Summary

Spinal cord injury is often a life altering injury that leaves the individual with disabilities that can last a lifetime. Galvin and Godfrey (2001) determined through a literature review which spanned 30 years that the need for ongoing psychological adjustment for psychological distress in spinal cord injury recovery did not reduce significantly over time. The ongoing psychological adjustment was evident in the spinal cord injury population; thirty to forty percent of people with a spinal cord injury developed a depressive disorder, twenty-five percent exhibited an anxiety disorder, and the suicide rate was almost six times higher than the general population (Galvin & Godfrey, 2001; see also Charlifue & Gerhart, 1991; Craig, Hancock & Dickson, 1994; Frank, Umlauf, Wonderlich, Askanazi, Buckelew & Elliot, 1987; Hancock, Craig, Dickson, Chang & Martin, 1993; Kennedy & Rogers, 2000). Dewar and Lee (2000) found that people who had a catastrophic injury with significant physical limitations were forced to change their social roles and modify their daily activities. Spinal cord injury forced the individual to depend on others for daily care, and the injury could create

physical, social, and emotional dynamics that can lead to loss of employment, emotional distress and a deterioration of lifestyle (Dewar & Lee, 2000).

Further study. As the literature review indicated, there have been many research studies that have investigated the psychosocial aspects of spinal cord injury. The previous studies have focused on depression, quality of life, health related quality of life, and life satisfaction. Although qualitative studies have been performed in the realm of spinal cord injury, additional studies are needed to add to the comprehensive understanding of the person with spinal cord injury.

Chapter Three

Methodology

The Research Approach

Unitary appreciative inquiry. Unitary appreciative inquiry was the qualitative research design that was used in this inquiry. Unitary appreciative inquiry, which has been in use for over a decade, has been the chosen tool of inquiry for both national and international nurse researchers (Cowling, 1993a, 1998, 2000, 2001). Cowling's method of qualitative research, unitary appreciative inquiry, is based on Roger's science of unitary human beings and the method integrates cooperative and appreciative inquiry approaches within the unitary framework (Cowling, 2001; see also Cooperrider and Srivastva, 1987; Heron, 1996). According to Cowling (p.33, 2001), unitary appreciative inquiry was developed as a method of seeking wholeness, uniqueness, and the essence of human life as a context for understanding phenomena and conditions of concern to nursing and guiding action in practice. Cowling described the function of unitary appreciative inquiry was to capture "the pattern of wholeness inherent in individuals, groups, families, communities, or organizations for developing knowledge related to phenomena of concern to nurses". Unitary appreciative inquiry adds to the ever-increasing vast body of nursing knowledge to include information that is consistent with the underlying pattern of the human existence, which is based on one's experiences, expressions, and perceptions (Cowling, 2001).

Unitary appreciative inquiry is a visualization of the individual's pattern manifestation which is expressed through wholeness, uniqueness, and essence that is exclusively distinctive to the entity (Cowling, 2001). The pattern understanding is dependent on what

is important and valued by the participants in the study. As the participatory group begins the inquiry into a phenomenon, knowledge is assimilated based on what was or is experienced by the individual. The participatory group creates a viable pattern based on the individual experiences of the subject or topic. The pattern emerges through the assignment of meaning and validation to the experience. The continued exploration reveals a pattern, which is reflectant of the particular human experience as manifested collectively in the lives of the individual group members (Cowling, 2001). These data are not a replacement of conventional research methodologies; rather, they added an additional window to aid in the understanding of the universal human condition.

Rationale for the research approach. Modern nursing science offered various methodologies for acquiring data. This research viewed the human being through the simultaneity paradigm which defines whole as unitary and contended that the unitary human had characteristics that are more than just the sum of parts that could be understood through a comprehension of pieces: the human cannot be separated from the entirety of the universe; as both the human and the universe change through continuous, innovative, and unpredictable ways, the core value of health is defined by the individual (Barrett, 2002; see also Parse, 2000; Rogers, 1992).

Various nursing frameworks and the resultant theories have given rise to many research instruments; however, Rogerian science is perceived to be the only framework or theory which uses the simultaneity paradigm which enables the nurse researcher to utilize either qualitative or quantitative methodology (Barrett, 2002). Fawcett (2000) explained that nurse researchers must remove themselves from the research methods of other disciplines such as phenomenology, grounded theory, and randomized controlled

trials (see also Barrett, 2002). Barrett (1998, 2002) continued that research methods, which are unique to nursing, are a propellant that pushes nursing towards a more comprehensive and individualized definition that was not reliant on other disciplines for explanation. Nursing is a unique science that enables its nurse researchers to further the concept of the discipline as an independent science through the study of unique questions that are explicit and unique to nursing science and practice.

Unitary Appreciative Inquiry and Phenomenology

Phenomenology. According to Orleans (2004) (see also Silvers, Darroch, 1982), phenomenology is an orientation that did not generate knowledge that could be empirically tested. Orleans (2004) continued that phenomenology operates on a metasociological level that helps one understand how the concept in question, as originated in human consciousness, come to be experienced as features in the world through the descriptive analyses of the procedures of self-situational, which is the private self-awareness of the individual (Govern & Marsch, 2001), and social constitution, which, according to L'Vinas and Cohen (1998) was the participation in society that makes us what we are. Linschoten as explained by Van Manen (1997) indicated that the phenomenologist does not give the reader a concrete set of ideas, essences or insights, rather, she or he attempts to be allusive by reflectively orienting the reader to a lived experience where the phenomenon in question is recognizable. Van Manen (1997) continued, that a phenomenological text should not be read merely for what the print indicates; rather the phenomenological text is read to evoke an epiphanic sense, an acute awareness, of life meaning to the reader.

The phenomenological method utilizes seven essential processes: (a) investigating the particular phenomenon; (b) investigating the general essences; (c) apprehending the essential relationships among essences; (d) watching modes of appearing; (e) watching the constitution of a phenomenon in consciousness; (f) suspending (bracketing) belief in the existence of the phenomenon; and (g) interpreting the meaning of the phenomenon (Parse, 2001, see also Spiegelberg, 1972). Phenomenological investigative techniques utilize the concept of bracketing. Bracketing is the removal of meaning from the item under investigation, thus all former meanings or interpretations of the item or concept in question are suspended and a reduction is performed in which the item or concept in question is examined in terms of how it operates within consciousness (Bentz, 1995; Ihde, 1967, 1977; Peele, 1985; Truan, 1993). The researcher attempts to remove all preconceived definitions and ideas that she or he may possess concerning the phenomenon in question in hopes that the researcher may arrive at an accurate understanding of the phenomenon as expressed by the individual or group transcripts.

Parse (2001) indicated that the phenomenological researcher may study a group or an individual; the researcher tape-records the sessions and reviews or dwells with the data following the session in an attempt to ultimately understand the meaning of a phenomenon. Parse (2001) voiced that the researcher will utilize hermeneutical interpretation, which is the comprehension of the phenomenon as understood through learning and knowing the whole of the entity; thus, as she or he dwells with the individual or group descriptions, the concept moves from the concrete to the abstract. Dzurec (1989) asserted that hermeneutical interpretation demands that the phenomenon in question be viewed in complete fullness and the integral relationship of subject and

object will be recognized. Colaizzi (1973) continued that once the researcher dwells with the subject's descriptions, she or he is able to construct a structure of the lived experience that captures the meaning that the participants have given the phenomenon.

Unitary appreciative inquiry. Cowling (2001) explained that unitary appreciative inquiry addresses the metaphysical concerns of an appreciating orientation toward human life through a research approach that actualizes the ontologic and epistemologic assumptions of a unitary worldview. Unitary appreciative inquiry is a method which was developed for uncovering the wholeness, uniqueness, and essence of the human existence to inform the development of nursing science and to guide nursing practice (Cowling, 2001). Cowling (2001) continued that unitary appreciative inquiry is a research and practice method which is constituted from the assumptions, principles, and concepts of unitary science and that unitary appreciative inquiry is a conscious choice which is freely made by the researcher to use the metaphysics of the unitary perspective as a means of viewing, seeking, and envisioning human life and possibilities.

Unitary appreciative inquiry demonstrates an appreciation of the pattern of the human; albeit individual, group or family. Unitary appreciative inquiry differs from phenomenology for it ascertains how the individual or group manifests their diversity of change as illustrated by the pattern profile.

According to Cowling (2001), appreciative knowing, participatory, synoptic, and transformative are the four quintessential ideals that guide the research process of unitary appreciative inquiry.

Cowling (2001) expressed that appreciative knowing is the process of going beyond the question of epistemology and realizing that human life is a miracle and, as defining of

miracles, cannot ever be fully explained. Cowling continued that appreciative knowing seeks information that can truly never be totally understood for it deals with the mystery of life. Cowling stated (2001, p.35), “through the process of appreciative inquiry, the researcher can attempt to illustrate human life patterns that go beyond fragmentation, normative thinking and superficial comprehension.”

Participatory consciousness, according to Cowling, (2001) indicated that the researcher is not just an observer, but a participant as well. The researcher is referred to, as are all the participants, as co-participants. This ideal of participation is indicative of the unitary framework, for the ability for humans to knowingly participate in change and in the patterning is a major theme of unitary human beings.

The synopsis is the sensing of an emerging pattern that is reflective of the wholeness, uniqueness, and essence of human life. The synopsis attempts to capture the aspects of human life that reflect the experiences, perceptions, and expressions that are viewed together in such a way that it paints the most complete picture of the inherent wholeness of the phenomenon in question (Cowling, 2001).

Unitary appreciative inquiry can be transformative to the people who are participating in the phenomenon. Cowling (2001) explained that the three ways which the appreciative process is transformative are: (a. the method in which the process seeks understanding of the patterns; (b. the inclusion of a unitive consciousness; and (c. the development of the researcher as instrument. The participants within unitary appreciative inquiry have the possibility to not only look at their particular life situation, but to change their life within the perspective of pandimensional awareness, which is when individuals realize infinite time-space-movement change and potential (Cowling, 2001).

The pattern profile is an illustration of the co-participants life pattern that can be visualized through narrative, art, dance or other methods of illumination. The pattern profile is an appreciative illustration, which conveys the essence of the individual or group's increasing diversity, which is manifested as change (Cowling, 2001).

Methodological differences. Unitary appreciative inquiry, unlike phenomenology, does not use bracketing, or reductionism in an attempt to find the base meaning of a concept, rather unitary appreciative inquiry understands that the person is an irreducible human energy field who cannot be truncated into isolated parts or pieces of the corpus. Unitary appreciative inquiry attempts to illustrate the pattern of the individual or group through the illustration of continued diversity that manifests itself as change in the medium of an appreciative pattern that has been assigned meaning by the group and validated through member checking, which is the validation of the data by the members of the participatory or study group. Cowling (p. 142, 1998) indicated, "in unitary pattern appreciation, the aim or mark of the artist (scientist/practitioner) is reaching for the essence of unitary pattern". Unitary appreciative inquiry offers the co-participants illumination and often understanding of the unitary pattern that is reflectant of the human and environmental energy fields.

Chapter Four

Gathering the Data

Selection of Research Participants

The initial contact. Once approval was obtained through the Virginia Commonwealth University Institutional Review Board (VCU IRB), the participants were recruited via VCU IRB approved advertisements that were distributed over a three month period in the east coast of the United States of America. The local chapters of the national spinal cord injury association (NSCIA) were contacted and advertisements were distributed through their venues and meetings.

The advertisement listed a toll-free number to call if one was interested in participation in the study. The number, attended by the researcher, was monitored daily from 0800 to 2200.

The participants. The participants in this inquiry were volunteers who had acquired a traumatic spinal cord injury and who were currently living in and around the east coast of the United States of America. The criteria for inclusion into this research study were: (a) traumatic spinal cord injury; (b) high school graduate or equivalent; (c) at least 21 years of age; (d) mentally competent; (e) consent to participate, and (f) English speaking.

Protection of subjects. Twelve participants contacted the researcher via the toll-free number listed on the advertisement. Of the twelve interested participants, seven participants had learned of the study via word of mouth from friends or family members who had seen the advertisement and one person had seen the advertisement first hand. The purpose, process, as well as the potential dangers, were explained to each participant over the telephone. During the initial telephone screening four potential contributors

were disqualified from the research study for not meeting the qualifications for admission to the study. In regards to the four participants who were disqualified from participation in the study, two potential contributors declined an invitation to participate in the research due to lack of financial inducement and the other two people were unable to participate because they did not qualify for admission due to the lack of a GED or high school diploma.

Once each participant expressed an understanding of the inquiry and a desire to participate in the study, a face-to-face meeting with each participant was scheduled in a location of the participant's choice.

The primary interview. The interview was held at the home of each of the participants per the request of the participant. The individual was once again instructed in the purpose, process, and potential dangers of the study. The individuals were further advised that the information that was to be obtained from them was totally anonymous. Once the participant expressed an understanding of the purpose, process, and potential dangers of the study, informed consent was obtained and the consent form was signed by the researcher and the co-participant. The co-participant was given a packet of information which contained a copy of the consent form, the advertisement, as well as the contact numbers for the researcher, local hospital, and emergency services so that the participant could access if she/he began experiencing bad feelings or thoughts.

The researcher began the interview by reviewing the format and purpose of the individual interview. Once the participant voiced understanding, open discussion began that allowed for questions, comments, or concerns that related to the life pattern of people with spinal cord injury.

Cooperative inquiry. The life pattern of people with spinal cord injury was illustrated through the implementation of Cowling's (2001) unitary appreciative inquiry. Through Cowling's method, which was congruent with Heron's (1996) concept of cooperative inquiry, each session was consistent with cooperative inquiry that was made up of three facets. The initial facet was the methodology which is the why are we here initiation. The second facet was the collaboration and the third aspect was the emotional and interpersonal strand that created a climate that was conducive of expressing emotions (Cowling, 2001).

The facilitator evaluated the individual's understanding of the purpose of the sessions. The participant was asked to share information concerning the level of his injury and his basic demographic information. Following the completion of the demographic data sheet, the major question was posed to the each participant for discussion: "What do we need to know in order to understand the life pattern of people with spinal cord injury?" The following sub-questions were discussed: (a) what are you (the individual participant) willing to share, (b) what are the different kinds of information or mediums that are needed in order to fully understand the life pattern with spinal cord injury. Each participant began expressing what she/he wanted to share concerning the life pattern of spinal cord injury.

Recording and Maintaining the Data

Throughout the course of the data gathering, I utilized a four-method approach of recording the data. Each of the interviews was recorded on a digital and a conventional micro-cassette recorder and written notes were also utilized in representing that data. According to Janesick (2001), written work performed during the course of the inquiry is

very useful for describing the role of the researcher, and it is also a useful source of data that helps foster understanding during the data analysis.

Field notes. Field notes, according to Butcher (1998), are tools which are not only useful for processing the data during the actual data collection but also throughout final synthesis. Butcher continued that field notes are composed of three categories: observational notes, theoretical notes, and methodological notes.

Observational notes include actual observations of what the researcher observed during the time of the data collection. Butcher (1998) stated that basic information should be included in the observational note such as non-verbal expressions that could be insightful to illustrating manifestations of energy field patterns, through descriptions which include the location of interview and the setting of the interview. Butcher continued that, immediately following each interview, the observations should be recorded in a separate notebook. The observational notes within this inquiry gave insight into the interaction of the participants with the researcher. The information gave detail on the participant's environment as well as data that was used by the researcher to aid understanding of the life pattern of people with spinal cord injury.

Theoretical notes are data that were gathered during the interview process that were recorded following the session. Butcher (1998) indicated that theoretical notes contained the data which were recorded that interpreted meaning to the perceptions and experiences by the researcher as indicated through the implementation of the Rogerian framework. Throughout the data collection aspect of this inquiry, theoretical notes were written following each participant encounter. The notes served to illuminate within this inquiry the changing co-creating patterns of interaction with the human and environmental

energy field. The notes were informally written and helped enable the researcher to piece together the data and form concepts that reflected the life pattern of people with spinal cord injury.

Methodological notes were the third tactic utilized to ensure appropriate understanding of the human environmental energy field. Butcher (1998) expressed that methodological notes are used to keep the researcher on track in reference to the method used for data collection. This researcher reviewed the methodological notes, which contained the planned structure for inquiry. The research topics as well as the supporting questions were listed within the methodological notes as well as the plan for data acquisition. Following each encounter, the researcher reviewed the session and critiqued his performance in reference to following the intended plan. Over the course of the encounters, changes were made to the interview format based on the review of the methodological notes. The methodological notes were a valuable tool in maintaining the integrity and goal of each interview for the notes were a static outline which served to maintain the direction of the inquiry process.

Although Butcher (1998) stated that he used separate notebooks to record the observational, theoretical, and methodological data during his inquiry which utilized unitary field pattern portrait, this researcher used one partitioned notebook. The solitary notebook made access to each interview and topic rapid and comprehensive. The field notes enabled the researcher to analyze the observation, theoretical, and methodological data through the progression of the chronological inquiries. These additional written data offered the researcher a third person view that helped the development of not only the gathering of data but also aided in the synthesis of the data which led to the uncovering of

despair as the principal pattern manifestation within the life pattern of people with spinal cord injury.

A reflexive journal was also utilized throughout the course of data gathering. Notes were taken immediately before, during, and after each interview. Once the researcher had completed the interview and had returned to his home, the researcher examined the notes and recounted the interview experience. Carboni (1992) indicated that the researcher should maintain a reflexive journal throughout the course of the inquiry for reflexivity was a category of critical thinking that integrates the values, beliefs, and interests, which were aspects of the researcher and the field, into the study. According to Butcher (1998), reflexive journaling was a beneficial tool which was used to acknowledge personal experiences, values of the researcher, and participants, and other values that are within Rogers' unitary paradigm. Butcher (1998, p.18) continued that personal visionary insights, intuitions, inferences, mystical insights, feelings, ideas, and reflections are recorded in the reflexive journal which coordinated with Rogerian inquiry that was value bound and allowed the researcher's individual values to be recognized during the process of data synthesis.

These data within the reflexive journal were accessed throughout the research process. The journal was very useful to acknowledge the researcher's personal experiences with spinal cord injury. Through the use of the reflexive journal, the researcher was able to recognize and process through personal experiences that may have otherwise entered the data. The data, which could have come from the researcher if not recognized in the journal, may have skewed the data which was obtained from the participants in the group. The reflexive journal enabled the researcher to identify personal experiential data and

separate the researcher's biases and values from that of the actual participant. Following each interview, the data were stored in a locked file cabinet in the home of the researcher.

Audio recording. Following each interview, the digital recorder was down loaded into the researcher's home personal computer and a password-protected file was created for both. Following the down loading of data and the creation of pass word protected voice files; each interview recording was examined for completeness by the researcher. The CD and the micro-cassette were maintained in a locked file cabinet in the researcher's home. Upon completion of all the interviews, the micro-cassettes were hand delivered to the home of the transcriptionist. Once the transcriptionist had taken the data from all the interviews from the micro-cassette into a word file, the word file CD and the micro-cassettes were obtained from the transcriptionist. The data on the word file were closely compared to the data on the micro-cassettes to ensure the accuracy of the data by the transcriptionist. Once the researcher had determined that each interview was in its entirety, the researcher down loaded the word file CD into his personal computer. The word file CD was placed with the voice file CD, informed consents, reflexive journal, and demographic data in the locked file cabinet that was in the researcher's home.

Demographic and healthcare data. The demographic and health care data were obtained verbally from each participant and recorded on the demographic data sheet (please see appendix E). Once each interview was completed, the demographic data were entered into the SPSS statistical software on the researcher's home computer. Each interview was identified by a pseudonym that represented the participant. Once the data were entered from the demographic data sheet into the home computer, the demographic

data sheet was stored with the informed consent in the locked file cabinet in the researcher's home.

Secondary affirmation. Once all the transcripts, as transcribed by the professional transcriptionist, had been correlated with the word and voice files as accurate and complete by the researcher, the researcher began reading each transcript, line by line, to determine if the data had remained within the context of the inquiry, "What is the life pattern of people with spinal cord injury?" Throughout this process, the researcher was reviewing the transcripts for grammatical syntax, such as pauses in speech, use of idioms, colloquialisms, and word redundancy. The researcher, upon locating the grammatical syntax and verbal expressions, circled and highlighted that part of the sentence that held these data.

Language and meaning.

Phenomenology. Van Manen (1997, p.361), who was a pioneer in the methodology of phenomenology, indicated that the language of the semantic and mantic designative and expressive meaning does not entail an "either/or" distinction; rather discourse depends on the cognitive meaning, the argument, the logic, conceptual, intellectual, and moral intelligibility. The changes in intonation, and pauses between sentences conveyed meaning. An example of this is a frequent pause that was evident in several of the participants as illustrated by this example, "Things really changed for me (pause) I can't do like I could before." This pause, combined with a decreasing crescendo, conveyed a sense of hopelessness to the researcher.

Van Manen (1997) expressed that in phenomenology five steps must be adhered to in order find true meaning: lived throughness, evocation, intensification, tone, and

epiphany. The first rung of the process of phenomenology, as explained by Van Manen (1997), is lived throughness, which is the placing of the phenomenon in the life world. The phenomenon is placed in the life world so that the reader can experientially recognize it. The concrete recognition can be illustrated through prose or even poetry; however, the objective is to have the reader fully recognize the phenomenon through the recollection of any previous experiential encounters. Evocation is a technique used within phenomenology that brings the experience in question vividly into our thoughts. The phenomenon is encountered in such a method as to enable the reader to phenomenologically reflect on the concept. Van Manen (1997) continued that vividness is not the goal of the encounter; rather, it acquires the power of nearness or presence. Intensification, according to Van Manen (1997), was the empowering of key words with their full value so that the multiple phenomenological meanings became firmly intact within the text. Van Manen (1997) explained that tone, in reference to the quality of the sound in expressed words, was influenced by any number of linguistic factors. Wittgenstein (1968) as explained by Van Manen (1997, p. 363) conveyed that when one reads with a particular tone that the words take on their own meaning which is outside the definition of the word and while the public can easily grasp the denotation of a word, the contextual meaning or secondary meaning is of a more difficult understanding. Van Manen continued that the lack of contextual understanding of a particular word includes the disability to grasp the inner meaning of tone, sentiment, and tactile dimensions. One of the participants, Oilman, stated, "I can't care for my yard." The preceding sentence, as presented here, does not convey the sense of hopelessness, loss, or despair for it is lacking the inflection of the secondary meaning through the use of tone, pause, or word

redundancy. However, the sentence, audio recorded with the tone, and pause intact, within the context of the interview, defines the secondary meaning which after through synthesis was despair: Oilman stated: I (pause) can't care for my....yard. Van Manen (1997) maintained that tone can be utilized to express either message or for its tone, which carries not just a written statement, but rather a sense of meaning and a felt human experience that underlies the phenomenological experience. According to Van Manen (1997), the final step within the phenomenological process is the epiphany. Van Manen continued that the epiphany is the transformative effect which creates a sudden perception of the life meaning concerning the phenomenon in question; the epiphany brings about a deeper meaning that is conveyed to the reader. Van Manen concluded that the human science researcher is not just a writer of reports; rather the researcher is an author who writes about the life experiences that convey meaning of the human condition.

McNamara (1991) explained that Saussure (1983) contended that words not only build the conceptual framework for the analysis of reality but also the descriptive linguistic framework. McNamara continued that Saussure believed language to be a single sheet paper with thought and sound occupying opposite sides of the paper, and, as such, the two could never be separated, for if one attempted to tear away one side of the paper, the backside of the paper would also be torn. Saussure continued that thought and sound defined the concept through comparison and contrast with other concepts without any regard to the person reading the text. Saussure (1983) indicated that words are concepts that are signs which draw meaning from their relationship with other signs. Saussure (1983) continued that one has to compare similar words with one another and words

cannot be understood in isolation; thus, the value of a word can only be comprehended by other words, which delimit the word in question.

Derrida (1981) conveyed that text interpretation or textuality is the primary task of the reader; thus the meaning of the text in question does not have an independent meaning, rather the text could have multiple meanings based on who is reading the text. Derrida, as explained by McNamara (1991) indicated that the meaning of a text is never in the here and now; rather, the meaning emerges from the interpretation of the contextual differences that are present in the work, as they undergo a continual metamorphosis of meaning based on the particular knowledge and value set of the decoder.

Cowling (2001) indicated that within a unitary framework that the entire person makes up the whole of the human energy field; thus, this researcher was attempting to create a pattern profile that was indicative of the human energy field pattern and, as such, all words, grammatical syntax, verbal expressions, and thoughts are imperative in the creation and understanding of the profile. This inquiry, which focused on the life pattern of people with spinal cord injury, utilized unitary appreciative inquiry. Unitary appreciative inquiry, like phenomenology, attempts to gain understanding of the human experience through verbal accounts which are expressed through language. While phenomenology looks particularly for final themes which build concepts; the goal of unitary appreciative inquiry examines the participant data in an attempt to discover the patterns of the human and environmental energy fields. Cowling (2001) indicated that the final product of unitary appreciative inquiry is the pattern profile which illustrates the pattern manifestation through dance, song, narrative, visual arts or other mediums as determined and validated by the participants within the study.

Synopsis and Pattern Profile Development

Once the researcher was satisfied that the data were complete and the verbal expressions, word redundancies, colloquialisms and verbal expressions had been highlighted for synthesis, the researcher began listening to voice files while simultaneously reading each transcript. As the researcher began listening and rereading the transcripts and reflexive journal, he wrote down the stories, themes, and thoughts that became apparent to him during the session on a single numbered line of a sheet of paper. Each sheet of paper was identifiable only by the pseudonym, which corresponded with the digital voice file. This process continued until all eight interviews had been interpreted. The researcher utilized one full week of time to analyze the data on the first immersion.

The second immersion. Following the initial immersion, the researcher left the data for one week, as to allow the data to go cold in the mind of the researcher. Once the “cold week” was completed, the researcher printed off new paper transcripts and began listening to the voice files as before. The researcher began underlining the verbal expressions, word redundancies, colloquialisms, and verbal expressions to determine if additional themes were present that may have been missed during the first immersion.

Once the highlighting was performed, the researcher once again began re-listening and rereading the data in an effort to find the thoughts, stories and themes pertaining to the life pattern of people with spinal cord injury. The researcher reread the reflexive journal and highlighted pertinent data that were suggestive of the research question. The researcher, as before, recorded the stories, thoughts, and themes on a numbered sheet of

paper that was only identifiable by synonym. The second immersion was completed in one week.

The individual synopsis. Once the word redundancies, colloquialisms, verbal expressions, and themes had been extracted from the data over two separate occasions, the researcher began to write each individual synopsis. The synopsis was an overview of each interview that presented the pattern as a biographical story that was rich with insight of each person's life before, during, and after the traumatic spinal cord injury. According to Cowling (2001), the goal of the synopsis was to seek out the most astute visualization of the unitary pattern that was obtained by the researcher from the individual participants. The participants were very straightforward in their speaking and of their abilities, hopes, and limitations. Cowling (2001) continued that the synopsis in unitary appreciative inquiry, is finding and recording the underlying fabric that is indicative of the wholeness, uniqueness, and essence of the human experience.

The group pattern profile. The group pattern profile was one profile that was representative of each individual's experience as it related to the research topic, concerning the life pattern of people with spinal cord injury. The pattern profile was created from each individual synopsis. The individual members of this inquiry group chose a narrative format. They each believed that their story could best be told via words that conveyed a story that was expressive of the life pattern of people with spinal cord injury. Cowling (1993) indicated that the pattern profile was a cooperative process and that the profile may be represented by a medium that has meaning for understanding for the individual participants.

Narrative Research Technique

The expressive narrative. Parse (2001) indicated that within narrative research the words that are used to tell a story of the everyday discloses meanings that were paramount in our society; thus, a word used to disclose meaning took on a broader scope than was defined by its definition. Parse continued that the narrative was a linguistic approach that is used to comprehend the human condition. Parse (2001) furthered that narrative research was a linguistic method that fostered understanding of the human experience as a whole. Narrative research has been associated with the paradigm shift from realism to constructivism and, as such, the concept of human knowledge has developed from the universal view of reality to a plurality which is composed of small bits of insight that are solitary, personal and, thus; remain under construction.

Polkinghorne (1988), as explained by Parse (2001) indicated that the narrative meaning, which is based on narrative discourse, discovered meaning through the linguistic devices that were put in place by the writer. Parse (2001) continued that discourse was language that was integrated into the sentence to convey meaning; thus, a meaning of the human condition was assigned to the narrative through the interaction of the reader with the words as composed by the author. Polkinghorne (1998) indicated that narrative data could be in the format of narrative interviews, journals, autobiographies, or in the format of an essay which recollected an experience even though the narrative data may not have been originally created for the purpose of data assimilation. Parse (2001) continued that narrative research was used to discover and illustrate a life event through linguistic devices. Parse (2001, p. 43) continued that the following assumptions are the foundations of the narrative research method:

1. In human existence, matter, life, and meaning are fused.
2. Polkinghorne (1988, p.15) stated, Human experience was enveloped in personal and cultural realm of non-material meanings and thought.
3. Experience is constructed through interpretation of meaningful recollections, perceptions and experiences.
4. Stories about life events shed light on the meanings of the human experiences.

The descriptive narrative format was utilized within this inquiry to illustrate through linguistic devise the life pattern of people with spinal cord injury. Parse (2001) continued that a story which recounts a meaningful life experience as told by the actual participants is the defining characteristic of the descriptive narrative.

Although unitary appreciative inquiry was the chosen method for data acquisition within this inquiry, the basic tenets of the narrative method were utilized to discover and illustrate the life pattern of people with spinal cord injury. Several studies (Agar & Hobbs, 1982; Brooks, 1984; Denzin & Lincoln, 2000; Giorgi, Fischer, & Murray, 1975; Labov, 1982; Mishler, 1986; Parse 2001, p. 44; Pelto & Pelto, 1981; Polkinghorne, 1988; Ricoeur, 1984, 1985, 1988, 1991) explained the basic process of narrative research:

1. Interviewing in which the participant orders and sequences moments into whole stories that are grounded in context and explicate meaning.
2. Dialoguing with documents in which discrete explanations are related to situations and events.
3. Detecting patterns across stories derived from participants' interviews and documents.
4. Identifying common themes and core plots in the stories.

5. Interpreting core plots to describe and explain life processes or events.

Although unitary appreciative inquiry was utilized to discover and illustrate the life pattern of people with spinal cord injury, the core elements of narrative research as described by Polkinghorne (1983) were utilized within this inquiry. Polkinghorne (1988) indicated that the researcher must interview the participants in reference to a common event and examine their individual stories so that common themes and plots can be discovered, interpreted, and illustrated through a central story that is expressive of the whole of the event.

Trustworthiness

Credibility. Credibility, which Carboni (1992) referred to as the truth-value, is the equivalent of the positivist-empiricist criterion defined as internal validity. Carboni continues that truth-value is an earnest attempt to ensure that the researcher has accurately interpreted the meaning of the data. The researcher in this inquiry has attempted to maintain credibility by repeated exposures to the data through the process of deep immersion and the final outcome was member checked by the participants. The credibility was maintained and established during this inquiry through the implementation of Lincoln & Guba's (1985) five research activities: prolonged engagement in the field, persistent observation, multiple sources of data, participant checks, and peer debriefing, as explained for the use in unitary research by Carboni (1992).

Unitary integrity. Unitary integrity was, according to Carboni (1992), reality resonance. Carboni (1992, p. 36) continued that unitary integrity was the unitary paradigmatic equivalent of the positivist-empiricist research criterion identified as

external credibility and, as such, the findings of the inquiry reflect the actual reality. Throughout this research study, through deep immersion in the data and member checking, earnest findings and reporting have been ensured. Carboni's (1992) criteria for unitary integrity have been integrated during the research process. Carboni (1992, p.36) criteria for unitary integrity include:

1. Do the findings transcend the natural setting where the study takes place and apply pandimensionally?
2. Does the audience view the findings as meaningful and applicable in terms of their own knowledge and experiences?
3. Do findings with the study resonate with the data from which they are derived?

The findings in this study have been adhered with the exception of the audience viewing of the findings, for the data have not been published at this time.

Auditability. Auditability, within the unitary paradigm of research, was, according to Carboni (1992), the equivalent of reliability within the positivist-empiricist criterion. Carboni (1992, p. 36), stated that auditability was defined as the consistency of interpretations and findings across different nurse scientists. During the process of this inquiry, each step including data gathering, demographic information, reflexive journal, and input from colleagues, mentors, and synthesis has been outlined and defined in sufficient detail so that a similar outcome could be achieved should this study be performed by another unitary scientist.

Summary. The initial portion of chapter four has explained in detail the data gathering technique as well as the safeguards taken to protect the subjects and the data. Great care

was taken to provide consistent, accurate information that was reflective of the life pattern of people with spinal cord injury.

The Participatory Paradigm

Lincoln and Guba (1985) defined a paradigm as a unique world view that illustrates not only the world, but also the person's place in the world and the possibilities that the world may hold for the individual as manifested by the holder's belief structure. Heron and Reason (1997) asserted that through the participatory paradigm that humans can not obtain or hope to obtain any final or absolute experience about what there is; however, through participative knowing, as obtained by face-to-face encounters, the person who seeks to know through experiences shapes her/his perceptions about what there is.

Herron and Reason (1997) continued that when we seek out experiential knowing, what we are doing is interacting with something or someone else; thus, the interlude with the other does not tell us about ourselves; rather, the interlude tells us about the interrelation and co presence with the other entity. Herron and Reason (1997) continued that experiential reality is subjective and objective in nature. Experiential reality is subjective for it is only known, both perceptually and conceptually, through the mind of the individual who is experiencing the reality. Experiential reality is considered objective, according to Heron and Reason, for the human mind interacts, penetrates, and shapes the cosmos.

Four ways of knowing. Heron (1996) indicated that the subjective and objective reality of a participative worldview includes an epistemology that enables the individual to know, articulate, and even shape the world through four ways of knowing: experiential, presentational, propositional, and practical. Herron and Reason (1997)

postulate that these four forms of knowledge are based within the realm of subjectivity and as such create an awareness of the constant interaction and of the ways of creating a reality that is based in the subjective and objective.

Experiential knowledge. Herron and Reason (1997) indicated that experiential knowledge is the process of sharing an experience, through a direct encounter, or feeling and imaging another presence; albeit, energy, person, entity, process, thing, or place. The experiential knowledge can be the physical act of doing an activity or the sharing of an activity with someone through verbal, written, or other medium. Experiential knowledge was obtained in this inquiry through the mutual interaction of the researcher and the participants. Each participant within this inquiry gave the researcher key insight into the life pattern of people with spinal cord injury through frank discussion and first person accounts of what it is like to experience and live with a spinal cord injury.

Although the co-participants within the study shared their accounts individually and had common experiences, each person's overall experience was slightly different. The age of the participants, level of education, residence location, family and public support, and coping styles all helped shape the individual's experience of living with a spinal cord injury. Each person recounted the fear and horror that they experienced when they first realized that they had obtained a spinal cord injury and that knowing that their life had suddenly changed forever. The participants told the story of their support mechanisms and their initial disability to proceed through life as originally planned. Through close interaction with each participant, the researcher felt an emotional first-hand reliving of the participant's experience that can only be achieved through the action of sharing the event with another. Through this process of inquiry, each participant conveyed the

experience of depersonalization, loss, and hopelessness, which illustrated to the researcher a pattern that was inclusive of despair in people spinal cord injury.

Presentational knowledge. Herron and Reason (1997) indicated that presentational knowledge is based on experiential knowledge and thus it is illustrated through symbols that include art forms, story telling, musical, graphic and plastic mediums. Presentational knowledge is the act of expressing the experiential experience through a medium such as dance, music, art, poetry, narratives, or story telling. Each participant in this inquiry was asked:

1. What is the best way to understand the life pattern of spinal cord injury?
2. How can you best share this experience?

Each of the participants, within this inquiry, chose to share their experience through a verbal account of their journey through spinal cord injury.

Participants began their story through chronological events. The accounts each began with the actual recount of the accident. Each individual shared with the researcher the same order of events:

1. How the accident occurred.
2. The continual daily pain.
3. A sense of loss with the disability to perform daily tasks.
4. Despair over the loss of ability.
5. The need to depend on others.
6. Hopelessness over any improvement in their physical condition that would allow them to perform their activities as they did before the traumatic spinal cord injury.

Each of the stories was very similar in plot line, although the characters and circumstances were different. The verbal accounts gave insight into the individual shared experiences of the life pattern of people with spinal cord injury. The participants chose the narrative method as a way to express the presentational knowing concerning the experience of spinal cord injury.

Propositional knowledge. Herron and Reason (1997) indicated that propositional knowing is the knowledge of a concept through a description of some energy, person, entity, process, or thing. Propositional knowledge within this inquiry was obtained about spinal cord injury and was illustrative of the life pattern of people with spinal cord injury. Propositional knowledge was the knowledge which was acquired during an inquiry. Propositional knowledge was composed of themes and data which supported theories. Once a thorough review was completed of all the data, which includes the recordings, reflexive journal, and transcripts, as outlined earlier in this chapter, propositional data was discovered and used within this inquiry to illustrate shared pattern manifestations. The individual accounts from each participant were used to develop the individual synopsis that was paramount in the development of the all participant inclusive pattern profile. The solitary pattern profile was indicative of the life pattern of the people within this inquiry. The principal pattern which was discovered during the research process was despair. In addition to the principal pattern, the shared pattern manifestations included: depersonalization; loss; and hopelessness.

Practical knowledge. Heron (1996) indicated that practical knowledge was knowing a skill, or how to do something. Practical knowledge within this inquiry was obtained about the life pattern of people with spinal cord injury. Practical knowledge was shared that

gave insight on how to live life with spinal cord injury. The practical knowledge obtained during this inquiry was based on the experiential knowledge of the spinal cord injury, as illustrated by presentational knowledge through the participatory interviews which recounted the experience. The presentational knowledge illustrated the experience of the life pattern of people with spinal cord injury. These data led to the development of the shared pattern manifestations which resulted in the discovery of the principal pattern of spinal cord injury, despair as illustrated through the pattern profile.

Practical knowledge, within this inquiry, was the information that was shared by the participants in order to help others. Practical knowledge, within this study, pertains to data that can be implemented to help other people with spinal cord injury navigate the torrid waters of decreased spinal innervation. The participants in this study have experienced spinal cord injury, and, as a result, have acquired practical knowledge along the way that has helped them with their current life style. Although the majority of the participants were mostly satisfied with the overall care that they received from the health care system, the participants repeatedly expressed the following practical knowledge:

1. The necessity for an earlier, second medical opinion.
2. The need of sound legal advice.
3. The urgent need of daily exercise and movement.
4. The support of family and friends.
5. The absolute need to not anticipate a speedier recovery.

Through the practical knowledge which was shared by the participants with the researcher, information was obtained that gave a practical, utilitarian view of the daily life of the person with spinal cord injury. The practical knowledge was included in the

group pattern profile in an effort to provide a more comprehensive view of the human-environmental energy field interaction.

The Findings

The sample. The final sample was composed of eight participants who ranged in age from 21 to 71 years of age who stated that they had experienced a spinal cord injury. The researcher had originally planned to include 10 participants in this study; however, it became clear through the reemergence of consistent patterns that saturation and redundancy of information had been reached by the eight participants in regards to the life pattern of people with spinal cord injury. Carboni (1992, p. 29) expressed that “the purpose of sampling in a unitary paradigm is not to identify a representative sample for generalization or an idiographic sample that is bound to a particular time and space; rather, the purpose is to draw upon a sample that allows the researcher to access energy fields that transcend both the general and the particular.” Carboni continued that the sample size becomes less relevant for the researcher within the unitary paradigm. Sample size, as explained within the paradigm, is dynamic and under continual change within the openness and free movement of the unitary process of inquiry.

The following table lists under each participant’s pseudonym, the age, age at time of injury, race, the level of spinal injury, the educational level, the location of their home, the availability of public and private resources and if the participants were involved in any form of professionally served physical rehabilitation.

The Final Meeting

Once the researcher completed the individual synopses and the group pattern profile, individual meetings were scheduled with each participant to validate the participant's individual synopsis and the group pattern profile.

Synopsis. A copy of the individual's synopsis was given to each person while the researcher read the synopsis out loud to the participant. Following the reading, the participant was allowed to quietly self-reflect on the synopsis. Once a sufficient time of self-reflection had passed, as determined by the individual's verbalization, the participant was asked if the synopsis was an accurate account of their personal experience with spinal cord injury. Each individual member agreed that the synopsis was an accurate account that was reflective of his or her personal experience with spinal cord injury.

Individual Synopses

The following participant synopses utilized a pseudonym to ensure confidentiality. Each participant's synopsis was presented in detail that is reflective of the encounter. The profile was meant to convey a generalized overview of the individual and the current life transition.

Guitarman. Guitarman was a 43-year-old man who was reared in a rural community; he stated he always had to make a living with his hands. Guitarman had been married for 20 years and had a son who was 17 years of age. Over the years Guitarman had always worked hard; he had begun working in house construction following his high school years. Guitarman excelled at home building and he soon left the job that he had had for over 10 years to become a building contractor. He was a very successful contractor; however, he always felt his purpose in life was something more. More than anything

else, Guitarman loved to play his guitar and sing when he was not working. Whenever Guitarman was not helping provide people homes in which to live in, he was playing in his band. He became a local celebrity and people from miles around would come to hear him play the steel guitar. Guitarman was very proud that he could play the steel guitar because it was a very difficult instrument to master. Many of the people who heard Guitarman sing and play told him he should go to Nashville and become a professional singer. One day while Guitarman was rebuilding a roof for a person, he fell off the roof onto a stack of wood.

Guitarman was very determined to get off the wood pile and get back to work; however, upon attempting to stand, his left leg began to burn and feel as though it was asleep. Guitarman could not walk. His right leg would not hold weight and his lower back felt as though a hot poker was trying to rip him apart. Guitarman screamed for the homeowner to call EMS; the ambulance arrived and took Guitarman to the hospital where he learned that he had fractured a lumbar vertebrae and he had damaged his spinal cord.

Guitarman was told he needed an operation to reattach his vertebrae with rods and screws; Guitarman was told he would be good as new following the operation. That was seven years ago.

Guitarman tried to resume working, but he could not work. Guitarman must take pain medication each day for his back pain. He could not work because his left leg is very weak and he could not climb, bend or move like he used to do before. Guitarman had a hard time standing or sitting in one position for longer than 10 to 15 minutes. Guitarman

tried to play with his band, but he could not perform on stage for he had to be constantly standing and sitting. Guitarman said: "I want to do something; anything; but I can't."

Nurse. Nurse was a 21 year old female who was reared in a rural area in the South. Her life was moving ahead and Nurse was looking forward to getting married in the spring. Nurse had always wanted to help people. When she was in middle school she knew that she wanted to enter a helping profession. While in high school, she took all the health/biology related courses that the little rural school had to offer. Nurse even became a working emergency medical technician (EMT) before she graduated from high school and she was the youngest EMT to ever work in the state.

Nurse had worked as an EMT for two years when she decided that she really wanted to become a registered nurse. She soon began taking classes at the local community college even though she was still working full time as an EMT. One night after working a very long shift at the ambulance station, she fell asleep while driving home and crashed her car into a tree.

Nurse had her accident in a very remote area; she was knocked unconscious by the impact. She regained consciousness and felt a tremendous pain accompanied by a burning sensation in her neck. She was unable to move her head; each time she tried to move her head she felt incredible pain with the sensation of electricity running down her arms. Her arms felt unusually heavy to her, but she managed to call 911 on her cell phone. Nurse stated that she lost consciousness again but she awoke to a familiar voice and the bright lights of an emergency helicopter setting down in an adjacent field.

Nurse was taken to the local teaching hospital, where she was told she had fractured her neck and obtained a spinal cord injury. She was told that she needed an operation to fuse the vertebrae in her neck.

Nurse underwent the operation and she was told that she might have residual weakness in her arms because the boney fragments of her vertebrae damaged one area of the spinal cord. Nurse underwent physical therapy; however, her neck remained very painful and she did not feel well. Nurse stated that she was unable to pick up any objects over the weight of a milk jug and that she was often very groggy from the narcotics that she took for pain.

Nurse tried to go back to school, but she said that her neck pain and narcotic use really made her an ineffective student. Nurse said she attempted to go back to work with EMS; however, no jobs were available for someone “like her.” Nurse spends her day sitting in her mother’s house; nurse wants to move forward with her life.

Traveler. Traveler is a 67-year-old female who lives in a small city. Traveler did not go to college because she married very young in life and began raising children. Traveler had worked hard raising her children and now her children were raising their own families. Traveler also worked hard everyday at the local plant; she was in charge of billing. Finally, one day, after 30 years of working, she was able to retire. She was very excited to retire so she could begin traveling the country with her husband in her new recreational vehicle (RV). Traveler had wanted to travel the entire USA in her RV. She and her husband joined an online RV support group and begin talking with other RVers. She had even mapped out her first trip to Florida. Traveler had planned to make a short trip to Florida as their maiden voyage in her new RV.

One day, while Traveler was walking in her driveway to the mailbox, she fell down on the hard asphalt curbing and crushed one of her thoracic vertebrae. Traveler's husband, who was home at the time of the fall, witnessed the accident. The husband ran to help his wife who was lying on her back. She stated that her back hurt horribly. An ambulance was summoned and Traveler was taken to the local hospital. The doctor advised Traveler that she had fractured one of her thoracic vertebrae and that she may have damaged her spinal cord. Traveler was transported to a large teaching hospital where she underwent an operation for her back.

Following the operation, Traveler went to a rehabilitation facility. The therapists and nurses at the rehabilitation facility tried to help Traveler with her injury. Traveler was unable to walk without a walker; she was unable to use her legs as before and she was only able to sit or stand for short periods of time. Traveler says that she was unable to travel with her husband; she hopes one day soon she will be able to take that trip with her husband and begin enjoying her retirement as she had planned.

Planter. Planter was a 49-year-old man when he obtained a spinal cord injury four years ago. Planter had been married for 26 years and he and his wife were raising a 13-year-old daughter. Planter, having just completed his vegetable crop for the year, was busy repairing his farm equipment for the upcoming growing season. Planter had been a farmer since he graduated from college. He and his brother were carrying on the family tradition of farming, which had been in their family for over 150 years. Planter was working late one evening, when he fell 10 feet from the cab of a large tractor. Planter landed on his buttocks; he felt his legs at once become numb and begin tingling simultaneously. Planter, lying on the floor, was in intense pain alone for a long time.

Finally, he was able to call EMS on his cellular phone. EMS arrived and transported Planter to a large teaching hospital where he was told he needed a lumbar spinal fusion with hardware. Planter stayed in the hospital for two weeks learning how to care for himself.

Planter continued to have severe back pain and he did not feel well. Planter began to take prescription pain medications that made him feel sleepy, even though it did not relieve the pain. Planter was unable to grow vegetables. He was unable to climb up and down on the tractors. Planter's brother told him that he could manage all the physical work and suggested that Planter handle the finances and paper work. Planter tried to do as his brother asked; however, he was unable to keep his thoughts together in order to perform the task. Planter continued to take his pain medicine and sometimes Planter had to "borrow" pain medicine from people he knew. Planter did not like to feel drowsy. Planter wanted to stop the pain and get on with his life as before. Planter felt useless, and no good. Planter wanted to resume farming and take care of his family-like he used to do.

Oilman. Oilman was 52 years old when his truck ran off the road and hit a tree. Oilman had been married for 21 years and he and his wife had decided to not have any children. Oilman and his wife were happy living together in their home located in the countryside. Oilman was returning home from a service call late one night in the dead of winter when he dozed off at the wheel and lost control of his truck. Oilman states that he remembered a large tree coming towards him and then he recalled hearing the sound of breaking glass and twisted metal. He tried to get out of his truck, but his legs would not work. He was bleeding and in terrific pain. Oilman managed to crawl to the road ditch; he

was trying frantically to dial 911 when a man with a friendly face patted him on the shoulder.

Oilman was rushed to the small county hospital where he was told that he had suffered a fractured a lumbar vertebra. Oilman could not move his body; he was strapped down to a board from his head to his feet. Oilman was told that he must be transported to a large teaching hospital so that he could be further evaluated and treated. Oilman remembered being rolled from the local ED outside into the cold where he was placed into a medical helicopter. People kept asking Oilman the same questions: “How did it happen?....Are you having any pain?....Where does it hurt?....On a scale of 1-10 what number would you assign your pain?” Oilman wondered when the questions would stop. Oilman just wanted to the pain in his lower back to stop; Oilman wanted to wake up from the nightmare.

Oilman arrived at the large teaching hospital and he was shuttled to a holding area with other people who were lying on stretchers. Oilman waited; Oilman was alone; Oilman thought he had been forgotten.

Oilman was told that he needed more tests and a man he didn't know soon whisked him down that hall on his stretcher. The man looked friendly and Oilman actually found himself trying to have a conversation for a moment. Oilman wanted to have a conversation and forget about the right now. Oilman was rolled into a large illuminated, humming cylinder. Oilman felt trapped; a voice told him: “Don't move! Lay still!” Oilman was soon rolled back out of the large cylinder. Oilman thought that he must be dead and that he was in the morgue. The lady with the cartoon frogs on her shirt told Oilman that she was giving him something to help him be still. Oilman awoke in the

hallway with his back throbbing with pain. Oilman wondered if the cylinder had been a dream.

A young man with tired eyes who was wearing a long white coat soon approached Oilman. The young man with the tired eyes told Oilman that he needed surgery; he would be having his surgery very soon. The young man with the white coat and tired eyes began asking a lot of questions and he told Oilman that his wife had consented for the operation. Oilman said, "Okay."

Oilman awoke to tremendous pain in his lower back. He tried to move but he could not move his arms. Oilman's arms were tied to the bed and he had a hard rubber hose hanging from his nose down to the bed. Oilman called for help and a young woman approached his bed; she started that she would tell his wife that he was awake.

Oilman left the hospital two weeks later; he continued to have back pain. His doctor told him that he needed to build himself up with exercise; however, he did not think he would be able to deliver oil and pull the long hoses from the truck like he had done before.

Oilman was determined to go back to work and he started back to work four months following the crash. Oilman's boss told him that he would try him on light duty, but that he had to stop taking narcotics in order to work there. Oilman tried to stop the medicine like his boss told him to do; however, Oilman could not stop the pain without the medicine. Oilman could only sit for five minutes before the pain made him need to stand. Even though his co-workers wanted to help him, they soon began to tire of his constant movement. Oilman was tired of the pain. Oilman told his boss he needed the medicine; the boss told Oilman he could not keep him on board because of the narcotics.

Oilman left his job of twelve years and went home to his wife. Oilman applied for unemployment and began looking for new jobs. Oilman was told that he was not qualified for any jobs because of his back injury and his use of pain medication.

Oilman applied for disability with his state representative. He was told that he must wait at least six months and that he must have proof that he needs disability. Oilman and his wife were having financial difficulty with only one salary coming into the household. Oilman began selling off his belongings in an attempt to keep his home. Oilman's wife began a second job; however, it was still not enough money.

A friend of Oilman suggested an attorney that could help him with obtaining disability. Oilman followed the suggestion and about six months later, following an intense medical exam, he was able to draw disability. Oilman appreciated the money, but what he really wanted was for the pain to go away and to work as an oilman. Oilman enjoyed helping people stay warm in winter; he liked talking with people at work and on the road. Oilman wanted to be useful. Oilman didn't like sitting at home; Oilman wanted to help his neighbors and contribute to his town. Oilman said he just wanted to get out there and do something, anything, but he can't, so he sat in his house each day and took his medicine like the bottle told him to do.

Granddad. Granddad was 58 when he underwent a spinal cord injury after being hit by a speeding automobile. Granddad had been a farmer for his entire life, although he was now slowing down with thoughts of retirement in mind. Granddad had two children who were now married with their own children. Granddad enjoyed being a grandfather and he enjoyed helping his family with both small and large projects. Grandpa enjoyed helping his children and he liked to make their life easier.

One evening in the summer after Granddad had finished up with his farming project for the day, he noticed that his son's yard was in need of mowing. Granddad knew his son worked a great deal and Granddad was always looking for ways to help his family. Granddad decided to help his son out with his chores and mow his yard for him.

Granddad had finished mowing the yard just as the evening was beginning to give way to the stars. Granddad began driving his lawnmower down the driveway and, as always, he looked both ways to stay out of the way of cars with his slow moving lawnmower. Granddad had just started driving across the rural highway when, out of the corner of his eye, he noticed a pickup truck speeding directly towards him. Granddad was unable to make the mower move any faster. The driver of the truck did not see him. Granddad remembered seeing the front bumper of the truck bear down on him and then he felt the horrible smack of the truck's bumper against his ribcage.

Granddad was lying in street, writhing with intense pain in his lower back. He had difficulty feeling any sensation in his legs. The man driving the truck leaped out frantically yelling, "I didn't see you! I didn't see you!" Granddad waited for help; he wanted some relief, any relief. Soon the ambulance arrived and transported him to a local hospital, where he was quickly assessed and transported to a large teaching hospital.

Granddad was told he needed an operation to make his back whole again. Granddad underwent the operation and was transferred 10 days later to a rehabilitation center. Granddad continued to have pain in his neck and back. He was told to perform his daily exercises and to take the pain medicine as indicated. Granddad soon returned home; however, he found that he still suffered with pain. Granddad took the narcotics like his doctor told him to do. Granddad found that the narcotics made him feel drowsy and lazy.

Granddad quickly gained 75 pounds in only six months and his back hurt even more each day.

Granddad continued to try to work on his farm. He found he was unable to even ride the tractor or walk for any distance. Granddad wanted his life back. Granddad had always been a strong, fair man and he wanted things like they were before. Granddad felt that this just wasn't fair. He wanted to help people like he did before. Granddad did not want to need help. Granddad had always been eager to work his farm and help his family; however, he could do as he always did and he needed to ask for help for both simple and complex tasks. Granddad wanted things back, just like they were before.

Resource. Resource was 43 years of age, married, and the father of a young son and daughter, when he took a fall while holding up a heavy piece of air conditioning equipment. Resource was the person at work that people always went to when they had a question or a problem. Resource was a physical plant manager for a large university. Resource had been working at the university for 23 years. He knew a lot of people and he enjoyed his job. Since Resource had been at the university for so long, the people who worked with him always knew they could count on him for help or solutions to difficult problems. Resource enjoyed his work a great deal and, even though his job was mainly in the office since his promotion, he would help out in the field if he had an opportunity.

One day in the late fall, a team of his employees were having difficulty installing a new piece of air conditioning equipment. The area was very small where the equipment was supposed to fit. The employees were having a difficult time and they were unable to install the new piece of equipment. Resource was eager to help as he responded to the call of his employees. Resource positioned himself on a ladder and began walking one

side of the unit up the ladder. Suddenly something happened and someone let go of the heavy piece. Resource fell down off the ladder and hit his back on a dull edge of furniture. Resource was lying on the floor and he found his legs and back in severe pain. The employees helped Resource up from the floor. Resource was barely able to walk and his feet did not feel the floor. The boss told Resource to go home that day and rest.

Although he had intense back pain Resource returned to work the next day. He tried to sit at his desk but he was unable to sit for more than two to three minutes. Resource's boss noticed the strange behavior and the look of pain of the face of Resource. Resource was sent to occupational health where he was radiographed and diagnosed with a fractured lumbar disk. The occupational health doctor advised him that he needed to follow up with his primary care provider.

Two weeks went past before Resource was able to see his primary care provider. Once he was evaluated, he was seen the following day by an orthopedic surgeon. The surgeon advised Resource that he needed a spinal fusion with metal rods placed in his spine. Resource checked in to a large private hospital and underwent the procedure the next day.

Resource had very good care while he was in the private hospital. He underwent rehabilitation and learned how to adjust to his new limitations. Resource was still experiencing a great deal of pain in his back that radiated down his legs. Resource was given a prescription for narcotic medication to help with his back pain. Resource took the pain medication as directed even though it only took the edge off the pain; it never completely resolved the issue.

Resource was eager to go back to work after being out on sick leave for three months. He returned on the day suggested by his boss and he found he was unable to sit or stand

for long periods of time. Resource, who had always been a very physical fit person, was unable to walk across campus. Resource was taking more and more pain medications-just like his provider prescribed. Resource's boss called him in his office one day. The boss offered Resource a one-time check of \$50,000 USD if he would sign a statement that released the university from any costs that were associated with his work injury.

Resource was told that quitting was the best thing and that he could take the money and find a new job. The boss, whom he thought a friend, emotionally injured Resource with this request. Resource did not want to quit his job. He wanted to work; he did not want to sue his company; he liked his job and the people who worked there.

Resource was given the name of a disability attorney who he contacted as his friend had advised. The attorney helped Resource apply for disability and workmen's compensation. Resource just wanted to work for his old job; he felt guilty that he had to sue for workmen's compensation. Resource continued to live with his wife and son in a rural community. Although Resource underwent three additional operations over the next two years, he still suffered from a tremendous amount of pain in his back and his legs. Resource did not go to work each morning as he used to do. Instead, Resource took the pain medication that was prescribed by his doctor. Resource wanted to work, just like he used to do; however, he could not. Resource felt betrayed by his company; he was made to sue for disability and workmen's compensation. He didn't want to sue; he just wanted to work-like before.

Solo. Solo was a 51-year-old widower when he had a car accident that resulted in a spinal cord injury. Solo had lived for 27 years with wife when she died of lung cancer. He was very sad to have lost his wife at such an early age. Solo had many things that he

wanted to do with his wife during retirement. He was now living all alone; his daughter had moved away to another state four years earlier.

Solo was driving his car back from a local restaurant when a drunken driver ran him off the road. Solo struck a road ditch pipe with the bumper of his car. The accident had driven the steering wheel into his abdomen and the resulting force had fractured his rib and one of his thoracic vertebrae. Solo remained conscious throughout the wreck and he remembers the EMS arriving to help him. Solo was taken to a local hospital and then he was transferred to a teaching hospital where he underwent treatment for his fractured thoracic vertebrae.

Once Solo left the hospital he was discharged home without rehabilitation or home visits. Solo had difficulty with cooking, cleaning, and taking care of his personal needs and he said that he really depended on his friends to help him with his cooking and grocery shopping. Solo had been working for a large corporation and, even though he had undergone a spinal cord injury, the company found a place for him to work when he was ready to come back to work.

Solo was eager to return to work because his coworkers had become an extended family for him since his wife had died. Solo was reassigned when he returned to work. He was given a supervisor position, which enabled him to stand and sit frequently, which greatly aided his comfort and reduced his pain level. Although he had been offered supervisor positions before his accident, he had always turned the job down because the supervisor position was a salaried position that meant that he could not make overtime pay. Solo gladly took the new position at his old job. He was very happy to return to work and to his friends the co-workers. At home, Solo found that he continued to have

difficulty with the daily chores, such as house keeping, cleaning, and cooking. Solo, recognizing his limitations, hired a housekeeper/cook, who came into his home every other day to clean and to help with meal preparation. Solo was content that he was able to live independently and to continue working at his job.

The Pattern Profile

Despair and the pattern profile. Once each individual had indicated that their individual synopsis was an accurate representation of their experience, the appreciative pattern profile, which included the synthesis, synopsis, and representation of the knowledge generated by the summation of sessions through the vehicle of the inquiry process, was distributed to each co-participant. The appreciative pattern profile was a single, narrative story that was representative of each of the participant's experiences with the life pattern of people with spinal cord injury. The appreciative pattern profile was reviewed for accuracy by the co-participants to ensure the knowledge generated was accurate. Each participant was asked if they felt that the pattern profile reflected the life pattern of people with spinal cord injury. The participants were accepting of the pattern profile as being representative of life pattern of people with spinal cord injury.

The researcher asked each individual if the participant felt that the pattern profile was illustrative of despair. Each of the participants agreed that the pattern profile, not only illustrated the life pattern of people with spinal cord injury, but it did reflect the feelings that they had experienced. The participants indicated that despair was not a word which they often used. The most common word used by the participants was hopeless, sad, and depressed; however, the participants, who each understood the definition of the concept of despair, agreed that despair most often accurately reflected their feelings in regards to

the experience and limitations imposed on them by spinal cord injury. Each of the eight individual participants agreed that they felt that the pattern profile was indicative of the concept of despair.

The Validated Pattern Profile

The Accident. We were supposed to go to Florida with my brother-in-law and then to the Panama Canal. It was one of those freak accidents. I just sneezed and ran off the road. How many times have you just gone down the road and just sneezed. I recall looking but I didn't see a vehicle coming, but evidently it was and I did not see it, and I pulled out in front of this truck and that was when I got hit. I fell. Fell down! The seat belt hit me at 60 miles an hour. It was locked tight.

Realization. My leg felt like it was on fire. It felt like I was being held on a fire flame. Part of my leg was dead. I could hardly stand it. There was pressure on the nerve. That was what was causing the burning. A man, who was driving down the road, saw me and stopped to help. Since I could not walk, I rolled out to the road ditch and he saw me. He took my cell phone and called 911. I was trying to call 911, but I was hysterical and could not dial. The ambulance came and took me to Hospital.

Waiting for surgery. The doctors were standing there with open arms waiting for me when I arrived at hospital. There was a surgeon and he had an intern and another doctor with him. They x-rayed me at least forty-one hundred times. I feel myself going into x-ray and being rolled back to the hallway once again. I was told the accident had crushed the vertebrae in my back. I felt like I was going to die. I thought I was going to leave this world. It was the worst feeling that I have ever experienced. I felt like I could not breathe. I had problems! They said they could hear me screaming a death cry from

the emergency room to the parking lot because there was no way to numb the pain. I overheard Dr. A. say, when you get him back, I will operate. I didn't know much about spinal cord injuries, but I knew enough to know it was bad.

I remember that when I went back to the operating room that a large man was there. I told the large man how frightened I was. I asked him to pray for me; He said he certainly would. He held my hand because I was so frightened. The two doctors worked on me for nine hours in surgery. The surgeons had to put a plate and screws into my spine to hold me together because my vertebrae were so badly fractured.

After the surgery. I woke up from surgery and I could not stand the pain. I saw the man in the ICU who held my hand as I went to the Operating room. I remembered him the moment I saw him; I told him you are the man that held my hand in the operating room. I told him thank you for holding my hand and praying for me.

My back pain was so bad on the morning after my operation that I vomited. My legs had knots in them with pain. It is hard to explain the feelings that I was having and it took me a long time to distinguish what was real and what was not real, although the pain never really went away. After the operation it felt like my brain had a skin or fog over it. I could hear people talking but my brain did not process it as quickly as it use to do. I knew someone was talking to me and, all at once, I became confused.

The scary part for me was when I got home from the hospital, I did not have any feelings in my legs for a long time. Finally, I began to have a little sensation, but I could not put pressure on my feet. I could not stand up. That was when I really got upset and discouraged. Some days my back was so stiff that I could not even get out of the bed.

Coming back. My surgeon told me to come back to see him one year post operation for an MRI of my spine. When I went back for the MRI, my surgeon had moved away and his replacement said that if I was not in intense pain or any worse condition that my insurance company would not approve to have another MRI because it was so expensive. Therefore, the insurance company was more in control of my healthcare than the physician.

I even had to fight to keep my job. I had been with this company for approximately 28 years at that time. One of the owners of the company came to me after my operation and asked me how I would feel if the company gave me a lump sum of money for signing papers that released the company and the insurance carrier from anything related to my back such as surgery, medication, or etc. He asked me, how did I feel about that? How would he feel about that! The insurance company was more in control of that than the physician. My supervisor, who threatened me with job loss, knew more about what was going on than I, the patient, knew. He talked to my doctor. I felt like that was not right. My medical treatments should have been between me, workman compensation, and my doctor- not my boss.

Years pass. Now that more than two years have passed since my accident, I might go a week that the pain doesn't bother me as bad and so I don't think about it as much. Then I might hit a spell and my back hurts like Hell. The painful spells started lasting longer and longer. The pain hurt so bad that sometimes I even threw up. Vomiting and heaving made my back hurt even more. After this I could not straighten my back up because of the pressure on my nerve. My back was killing me and it felt like I was having a heart attack. I could hardly breathe.

Loss. I am not the same person that I was before the accident. I cannot do the same things that I used to do. I have had to make adjustments in my daily activities and I have had to ask for assistance. In regards to household chores, I can put dishes in the top rack of the dishwasher, but the bottom rack makes me strain the muscle down through my back. When I finish my housework, I have knots in my muscles and it hurts very badly. The knots are very big and sometimes I get them in my buttocks. Even in the shower, I have trouble bathing myself completely. I can't turn too far to the right and I can't bend over far enough to even trim my toenails. It is a nightmare. Everyday tasks are very difficult. A lot of times I become depressed because there are a lot of things in the yard that need attention; I can't get out there and fix it like I should.

Same mind/different body. My son asked me to go fishing with him. Fishing is something that I do not do any more. I can't even climb in and out of the boat anymore. So, I don't fish anymore. I used to fish all the time. There are a whole lot of things that I can't do anymore. I used to enjoy jogging, but now I am just limited to a little walking. Sometimes when I walk up a hill, I become very tired, although I don't smoke. My breathing is good. I walk some with people that do smoke and they huff and puff and I am still walking, although my legs make walking very difficult.

I want to do the things that I use to do but I did not have enough strength to even open some of those heavy public bathroom doors. My partner has to wait outside the bathroom and I knock on the door for him to open it for me. I was 58 years old on the day before I was injured and I handled over 250 bags of fertilizer that day. However, now I cannot even think about doing that type of activity. You don't ever think about losing that type of strength. There are just a lot of things that I used to do that I can't do any more.

Life plans. We had to cancel our plans due to my back condition. I have missed out on a lot of things that way. If I can just get rid of this pain, I can do things that I used to do. I am trying to deal with my life, but it has been an imposition on me. I wish all of this was over and I could go back to work and finish school. I do want to finish school, and I want to go back to my career. It has been over a year since I have been working. It kills me every day that I am not able to go back to work. I liked what I did. I like to make a difference with people. But, the doctor says you can't jump rope, can't swim, no mountain climbing, no bicycle jumping. The doctor told me, you will never be able to push a lawn mower or weed eater. Just mark that off of your list.

Living with pain. I have very bad muscle spasms right before daybreak. When I roll over in bed, the pain causes horrible muscle spasms. People can hear me hollering and screaming all over the house. I was in so much pain that I could not do physical therapy. The doctor prescribed Vioxin and a muscle relaxor. The pain pills made me sick, so I only took them at night in order to sleep. However, I hardly ever slept because of the pain. My threshold for pain was very strong, but no one can survive when the pain was as bad as it was then.

Unresolved pain. One day I went to my primary care doctor's office and he would not see me because I owed him money. This is the second time he would not see me because of money. He would not see me no matter how much pain I was having. They don't ever give me any pain pills for my back and leg pain. I find black market Percocet and stuff like that. That gets to be pretty expensive. The doctor said there was medication for my back pain, but I have not had the money to get the medication. It cost anywhere from \$1250.00 to \$1300.00 dollars depending on where you got it. That was just for one of the

prescriptions; I took three prescription medications for my injury. There was nothing I could do about it except lie there and scream. When I straightened out my leg, I had muscle spasms in my side. Then my legs would lock up because the muscles were pulling. I talked to the doctor about it and he said that one part of the muscle is dead and the other part is alive.

Medication issues. Even though the pain medication helped take the edge off of my back pain, I was having problems when I was on the pain medication. I think I have suffered with depression from the medications. I did have depression from the medications, but it worked well for the pain. That was horrible; you don't feel like doing anything. It is not like being drunk or anything; you just don't feel like doing anything. I don't have any ambition whatsoever; I have horrible pain on rainy days. I had to get off of the strong narcotics and all those other pills. I stayed so drunk on these medications; I talked so much foolish stuff that it was pitiful. It made me feel very loopy. I thought the doctors might have to take me to the psychiatric hospital and put me in a rubber room.

My body was not used to high-powered drugs. Well, if you have a toothache in your back for twenty-four hours a day, seven days a week, its makes a difference. It was very depressing to me the way I had been living. Even sitting in chairs makes my back and legs stiffen up and I always have to stand up for a while before I move again. I can't sit or stand for a long period of time. I think they are turning me into a robot or something. Now, I am not nothing but a computer sucking up someone else's air. I am just a burden in the way. It is like I do the same thing over and over again from day one to day two. Everything is the same; there is no difference.

The finality of spinal cord injury. I asked Dr. X if my spinal cord could be fixed by an additional operation. He said that he could not repair my spinal cord, although another operation could help with the pain. Well, I don't think I will ever get rid of the pain in my back. That is why I worry about the operation. They can't guarantee that I will not have pain. They can help the problem, but he told me that he could not guarantee that I would quit hurting. Things are going to be different from now on.

Despair. There is not too much of a future holding for me no more like it used to be. All my dreams have gone down the drain. I wanted to build my own home since I do carpentry work. I really wanted to build my own home, but I won't be in shape to do it. I had started to build my home before the accident; however, now that I cannot finish it. Some people have said they would help me so I won't lose it. However, I just don't know at this time.

Advice to others. Be patient, go slow and don't expect to get well over night. It is a pain that you have every day. It will not go away. It is a life long problem; you will never get over it you are stuck with it.

If you have your own medical insurance, stay away from workman compensation if you possibly can. Make sure you have a lawyer or a caseworker in the community to help you in case your employer gives you problems. You have to make the best of what you have now.

In regards to the pain medication, it made me feel better; however hiding the symptoms could make the condition worse. You would feel better, but the problems could be progressing, according to the surgeon. Of course, surgeons want to operate anyway. It is a long drawn out process and it depends on how good you react. I would

suggest that you do what the doctor says to do but do not put up with the crap that I had to put up with during my initial recovery. Don't listen to the doctor when he tells you that you will come out of surgery 100% better- don't expect that. I think when the spinal cord is injured there is nothing you can do.

Coping. It is hard for miracles to happen. I think it would take a miracle to get me right. Your life changes, you have to change with it. There are a whole lot of things that you have to change in your life after you injure your spine. The best thing to do, if you know in the back of your mind you are really going to be stuck with a disability, is to psych your mind up in order to cope with your problems.

A person who has undergone a spinal cord injury needs to know what they can do and what they can't do. Some people say, after I get over this little spell I can go back and do everything like I used to do before. But, really, a person has to sit down and think if I try to do this activity, is it going to hinder me down the road later. At the present time, one has to accept the disability. That is why some people have trouble with coping with what happened to them. There are a lot of people that can't drive anymore. I am grateful that I am able to drive, but it has to be certain types of vehicles. If I attempt to ride up the street in a small Jeep for example, I can't get in the vehicle. My back won't allow me to get in the Jeep. Certain vehicles I can get in and certain vehicles I can't get in; I have to accept that. If a person has to learn how to walk with crutches and a walker, the person needs to really take time and really listen to the therapist on how to do it correctly.

There are a lot of things you can do and a lot of things you can't do. A whole lot of things you want to that you cannot do. There are a lot of things that I will never be able to

do. Just remember, your life has stopped, and you have to learn how to do almost everything over again.

Shared Pattern Manifestation

The pattern of despair, which was evident in each participant encounter, was illustrated through three supportive and shared pattern manifestations: depersonalization, loss, and hopelessness. Despair is described as being stuck and without choices concerning the future. It is a state that is without hope of change or aspirations.

The shared pattern manifestations: depersonalization, loss, and hopelessness were outlined and discussed within the concept of propositional knowledge as detailed in the unitary paradigm as outlined by Cowling (2001) and Rushing (2005), who defined pattern manifestation as the mutual, shared process of the interaction between the human and environmental energy field. The following table lists statement from the actual transcripts that the participants used to illustrate the meaning of depersonalization, loss, and hopelessness through the verbal medium of the interview process.

Table 1

Verbal Expressions of Depersonalization

DEPERSONALIZATION

1. It feels like your brain has a skim or fog over it.
2. I can hear people talking and my brain does not process it as quickly as it use to.
3. It took me a long time to distinguish what was real and what was not real.
4. I hardly ever slept.
5. I think they are turning me into a robot or something.
6. I lay in the floor for about an hour before I could move.
7. My leg felt like it was on fire. It felt like I was being held on a fire flame. When they did the operation it quit burning, but that part of the leg is dead.
8. I recall looking but I didn't see a vehicle coming, but evidently it was and I did not see it, and I pulled out in front of this truck and that was when I got hit.
9. I get upset just thinking about it now.
10. People just don't know what I have been through.
11. It could have happened to them.
12. If you have a toothache in your back for twenty-four hours a day, seven days a week, its makes a difference.
13. They (doctors) are more worried about the damn money than they are anything.
14. The doctors are going to do nothing if they aren't going to get paid for it.
15. Your life stops.
16. Now I am nothing but a computer sucking up someone else's air.

Table 2

Verbal Expressions of Loss

LOSS

1. I have missed out on a lot of things that way.
2. My significant other gets aggravated because we can't do things that we use to do like going to the lake skiing.
3. They took everything that I love from me except my family.
4. It has slowed me up a lot
5. I have suffered from depression with it.
6. It did hurt my sex life.
7. I just could not do anything because of the pain.
8. It took all my dreams away and all that stuff.
9. It is putting a burden on my family.
10. I haven't had any income in years.
11. I can't do a lot of things that I did before.
12. Everything I used to do for myself, someone else has to do.
13. They (employees) would give you a hassle about that- they would say you are sitting on your fat ass not doing anything.
14. There are a lot of things that I don't do any more.
15. It just whipped me and took it all out of you just to walk.
16. There are a lot of things that I will never be able to do.

Table 3

Verbal Expressions of Hopelessness

HOPELESSNESS

1. Knots just come and stay there.
2. Are you having a pity party? If so, I would like to join you.
3. The pain did not go away.
4. I have exchanged one pain for another pain.
5. I would rather people would not give me false hope.
6. I wish all of this was over with and I could go back to work and finish school.
7. It is a life long problem; you will never get over it you are stuck with it.
8. It is a pain that you have every day. It will not go away.
9. I don't think I will ever get rid of the pain in my back.
10. I stay depressed and it took me a long time to accept what I am now.
11. No one is going to pay me out there to work like that.
12. It is hard for miracles to happen. I think it would take a miracle to get me right.
13. I get a lot of times real depressed because there is a lot of stuff out here in the yard messed up and I can't get out there and fix it like I should.
14. There is not too much of a future holding for me no more like it used to be. All my dreams have gone down the drain.
15. It is a long drawn out process.
16. Sap comes up and sap comes down and you can kiss it good bye because your leg and back will hurt.

Despair

The principal pattern of people with spinal cord injury, despair, is defined through the shared pattern manifestations of depersonalization, loss and hopelessness. The following tables illustrate the defining characteristics of despair through a propositional matrix of the three shared pattern manifestations which were derived from the participant encounters. It is the shared pattern manifestations that give definition to the primary pattern of despair. Lifton (1979) explains that despair is the self's inability to see a brighter future. Goldsmith (1987) interprets Lifton's conceptualization of the despairing person as one who perceives that an immediate action must be taken in order to revitalize movement; however, the action is blocked and a sense of a permanent, unalterable future creates an enduring death state that is constant and without any opportunity of change. Each of the shared pattern manifestations supports, illustrates, and defines the pattern of despair with data taken from the transcripts that is illustrative of experiences, perceptions, and expressions within the methodology of unitary appreciative inquiry as outlined by Cowling (2001).

Table 4

Propositional Matrix of Shared Pattern Manifestations: Depersonalization

DEPERSONALIZATION
<ul style="list-style-type: none">• Depersonalization is manifested by feelings of the surreal and a loss of self;• The desire to wake up from the nightmare;• The feeling of “now what” and “this can’t be happening to me”.
EXPERIENCES OF DEPERSONALIZATION
<ul style="list-style-type: none">• Person encounters intense pain from accident• Person is taken to ED for emergency care.• Exam performed/pain medication given.• Person advised that spine is fractured and an operative procedure is required.• Procedure is performed and person undergoes therapy and returns home to family.• Pt encounters obstacles in his daily routine that were not apparent before injury.

Table 4 (continued).

Propositional Matrix of Shared Pattern Manifestations: Depersonalization

PERCEPTIONS OF DEPERSONALIZATION

- This can't be happening to me.
- Person feels a total loss of control.
- Person feels embarrassment over sudden dependence on others for daily needs.
- Person feels numb and cold.
- Person feels worthless.
- Person feels trapped in a shell of pain.
- Person feels guilty that she/he have done something wrong to deserve the injury.
- Pt feels he/she has let down and betrayed family by a "mistake".
- Loss of the perception of time.
- Feelings of unreality.
- Feelings of being a victim

EXPRESSIONS OF DEPERSONALIZATION

- Lying in bed or sitting in chair not wanting to interact or participate in activities.
- Brooding or contemplating over injury.
- Asking questions about accident and prognosis.
- Retreating into self.
- Recalling a vivid, graphic account of the story.
- Expressing feelings of detachment, and confusion.

Table 5

Propositional Matrix of Shared Pattern Manifestation: Loss

LOSS
<ul style="list-style-type: none"> • Loss is experienced as a reduction in previously held physical and or mental abilities. • Change in the human-environmental energy field pattern mutual process.
EXPERIENCE OF LOSS
<ul style="list-style-type: none"> • Person tries old method of performing activities, such as rolling over in bed, putting on clothes or walking. • Old ways of doing things don't work. • A good day, physically, is followed by a very painful bad day. • Assistive devices are used for routine activities- reluctantly. • Family and friends visit less and less and friends soon disappear. • Person is "looked at" while on outings. • Pain experienced daily. • Bowel/bladder habits take up large portion of day.

Table 5 (continued).

Propositional Matrix of Shared Pattern Manifestation: Loss

 PERCEPTIONS OF LOSS

- I can't do as before. Who am I now?
- I can't work and earn my income.
- Why me? Person attempts to resolve why this injury had to happen.
- Person wonders how he can pay bills and meet family obligations.
- Person feels guilty that wife/husband or other family members may have to provide total monetary and physical support.
- Person is mad/angry/sad that this happened to him/her.
- Person is anxious about keeping family together as a whole.
- Person is sad over bowel/bladder performance and habits.

 EXPRESSIONS OF LOSS

- Person tries to do activities as before.
- Person becomes more independent through the use of assistive devices.
- Person expresses despair over disability to perform tasks as before.
- Person expresses resentment at using daily pain meds.
- Person attempts to "hang on" to old self through usual style of dress and activities.
- Person becomes coarse in language when commenting on personal condition.

Table 6

Propositional Matrix of Shared Pattern Manifestation: Hopelessness

HOPELESSNESS

- Hopelessness is experienced as fruitless, indefinite waiting for an improvement in spinal cord innervation that does not come.
- The person has the knowledge that they will never be as before.

EXPERIENCES OF HOPELESSNESS

- Attempts new ways of doing activities in an attempt to resume the previous pattern of being.
- Revisiting familiar places in an attempt to make things “right” like they were before.
- Seeks medical advice and information about spinal cord injury in an attempt to find a “cure”, although soon learns a cure is impossible.

Table 6 (continued).

Propositional Matrix of Shared Pattern Manifestation: Hopelessness

PERCEPTIONS OF HOPELESSNESS

- There is no cure for spinal cord injury; it is forever.
- Person finds he has good days and bad days.
- A change in the weather causes a great deal of musculo-skeletal pain which often results in a “bed day”.
- The person’s hopelessness changes in degrees daily based on current condition and accomplishments.
- Person wonders if and when he will become more disabled or sick and need to depend more on others.
- I must keep moving and exercising or I will become in worse physical condition and be a larger burden on my family.

Table 6 (continued).

Propositional Matrix of Shared Pattern Manifestation: Hopelessness

EXPRESSIONS OF HOPELESSNESS

- I am a survivor of spinal cord injury—now what do I do?
- I am doing great...considering.
- Outward expression to higher power and use of religion/spirituality.
- Person continues to use course language with public and family.
- Person accepts the finality his physical condition.
- Person attempts to regain his prior ways of interacting with environment; realizes it is impossible.
- The human and environmental energy fields are rhythmically co creating new ways of being and interacting.

Depersonalization. The understanding of the severity of the injury, which resulted in the realization of a change of life style, was described as the initial experience following the traumatic spinal cord injury. Each of the participants indicated that they felt they were in a surreal world where the event of traumatic spinal cord injury could not be happening to them, but yet it was happening to them. The participants within this study indicated that the severity of the injury resulted in an immediate understanding that their body had undergone a tremendous physical insult. The participants indicated that the realization of this instantaneous, traumatic, event was inescapable as the intense pain constantly reminded them; however, it could not be real.

Traveler explained that she had a difficult time of differentiating between what was real and what was a dream. She continued that her thinking was “not right” and she was concerned about her thinking process once she awoke from her injury.

Traveler stated:

I cried; I was so frightened. Because when I woke up I was frightened of everything. It is hard to explain and it took me a long time to distinguish what was real and what was not real. Even now my brain is not working right exactly and my friend talked to a friend at church and she said it took her mind one year to clear up.

I was operated on December 14. What I can remember about that operation was when I went into the operating room there was a large man there. I didn't know if he was real or a dream. I told him how frightened I was. I asked him to pray for me. He said he certainly would. Then he held my hand for a long time because I was so frightened.

Traveler outlines feelings of depersonalization, which, in her situation, was a feeling of unreality. Dougherty (1990) explained that depersonalization could be manifested by a traumatic event that resulted in the person having a subjective feeling of unreality and altered attention. Traveler understood the extent of her injury; however, she felt that something was “not right” because she was detached from reality and that she was questioning what was real and what was unreal in her world.

The experience of realization came on slowly for Planter; he remembered the effects of the injury and his attempts to stand. He did not remember how long he was lying on floor before he was able to regain his faculties and call for help. He was unable to realize the extent of his injury, until he had proved to himself that he was unable to get off of the floor. Planter recounts the following vivid description:

It (back) hurt like Hell. I don't know how long I lied in the floor before I could move. Then tried and I tried to get up. My back was sore and hurting. They x-rayed and scanned it and whatever and said that it (vertebra) was broke in between the one and two vertebrae.

Planter experienced depersonalization as evident by his loss of ability to keep time and the feeling of detachment. While on the floor he explained that he was conscious; however, he was in a state when he could not move or attempt to call for assistance. He was detached from his self and physical condition. Dougherty (1990) indicated that a componet of depersonalization is an altered conception of time, an inability to communicate, and a sense of personal detachment.

Guitarman verbalized the intense pain that heralded the recognition of spinal cord injury and the non-functioning of his leg. Guitarman expressed his initial experience and his perception “that part of the leg is dead” because of the spinal cord injury.

Guitarman stated:

Well, my leg felt like it was on fire. It felt like I was being held on a fire flame. That part of the leg is dead. When the burning sensation was there, I could not hardly stand it. There was pressure on the nerve. That was what was causing the burning.

Guitarman gave great detail of the physical sensation of his spinal cord injury. He used words like, “burning,” “fire,” “dead,” “pressure,” and “nerve.” These words conveyed a graphic and sensate description to the physical pains that Guitarman underwent.

Dougherty (1990) explained that panoramic memories that were distinct, vivid, and were of a great intensity were components of the concept of depersonalization.

Granddad told about the accident and how he obtained a spinal cord injury; he explained how he came to realize that he had experienced the accident. His recollection was matter-of-fact and he did not speak emotionally or offer vivid descriptions. He told of looking for oncoming traffic but not seeing the approaching vehicle until it was too late. The psychological impact of the trauma was emphasized by the exacting time, date, and details of the event and the lack of a sense of attachment or of any emotion surrounding the accident. Granddad conveyed depersonalization, as outlined by Dougherty (1990) as a sense of detachment and a great sense of calm.

Granddad stated:

I was mowing my son's yard. His yard and my yard face each other with the road in between. After finishing mowing his yard on April 1st, 1998 about 5:30 or 6:00 P.M. in the afternoon, I was going to come across the road with the riding lawn mower. I recall looking but I didn't see a vehicle coming, but evidently it was and I did not see it, and I pulled out in front of this truck and that was when I got hit.

Oilman indicated the shock upon the realization that his legs were not functioning. He explained the disbelief that he was unable to ambulate, and call 911. He furthered that the accident greatly impacted his wife as she became anxious to ensure that Oilman was having the best medical care possible.

Oilman stated:

I got out of the truck and tried to step down but there was no leg there. The leg was there, but it had shot up my back. The impact was from a straight gear truck and I was trying to stop it. My foot was on the clutch. The (gear) stick pulled it (leg) out and jammed it back into my lower back. A fellow, Mr. XX was coming by and since I could not walk, I rolled out to the road ditch and he saw me. He took my cell phone and called 911. I was trying to call 911, but I was hysterical and could not dial. The ambulance came and took me to Hospital. My wife almost tore the Hospital all to pieces.

Oilman continued that he did not find relief at the Emergency room and that the pain of the spinal cord injury was unrelieved. Oilman continued that he felt out of control and victimized because no one was able to stop the pain or help him, although he was undergoing many radiographs and being treated by several doctors.

They x-rayed me at least forty-eleven hundred times. I feel myself going into x-ray and being rolled back. They said they could hear me screaming from the emergency room to the parking lot. I was screaming a death cry because there was no way to numb it. My wife said they were holding me in a room where the doctors come in and study and watch.

Oilman used words that conveyed vivid, emotional meaning such as “jammed into my back,” “hysterical,” “tore the hospital to pieces,” “screaming,” and “death cry”. The words reflected depersonalization through graphic panoramic memories. Dougherty (1990) (Noyes & Kletti, 1977) explained the concept of panoramic memory as a graphic, vivid account of a previous intense experience. Oilman furthered expressed depersonalization through loss of control. Oilman expressed that he was screaming, because he had no escape from the pain and that no one could help him because the doctors just watched. Dougherty (1990) explained that loss of control and altered attention were also feelings associated with depersonalization.

Loss. The concept of loss was portrayed as a shared pattern manifestation through the personal accounts of each participant. Throughout the interviews, the participants vividly expressed and identified what they had lost through the traumatic injury. The loss was explained by the participants as physical and mental activities which they were unable to perform since the traumatic spinal cord injury; however, each person assigned a degree of personal self onto the loss of abilities, for the injury took away what they were; thus, the participant was unable to continue their previous life’s path and new paths or new ways of being were thrust upon the participant. Throughout the interviews, each participant

expressed a desire to return to their former physical/mental state and the participants were not content with the new life pattern.

Traveler, who was retired at the time of injury, stated that she missed getting out and seeing people. She explained that the small things in life, such as using a restroom and taking care of housework were very difficult for her now and that she must often needed to use help for these tasks.

Traveler stated:

We were supposed to go the Florida with my brother-in law and then to Panama Canal. However, we had to cancel due to my condition. I have missed out on a lot of things that way. If I can just get rid of this pain, I can do things like that.

One of the oddest things is that went I first came home and started going out, I did not have strength enough to open some of these bathroom doors because they were so heavy. My husband had to hang around outside the bathroom and I would knock on the door for him to open the door. You don't ever think about losing that type of strength... This happens in restaurants and other public places.

It has changed my life so much that I can't pull anything heavy out of the washer. I can wash my own clothes. It hurts to get things out of the dryer. I can put dishes in the top rack of the dishwasher good, but the bottom rack makes me strain the nerve, the muscle down through my back and then I get knots in my muscles, and it hurts so bad. The knots are very big and sometimes I get them in my buttocks.

Nurse was a young professional when she sustained a spinal cord injury. She expresses a great deal of loss over the normal activities that she used to enjoy.

Nurse stated:

I guess I am lazy now because I can't do as much. I used to think I was a tom boy and could do anything that I wanted to do, lift furniture and do whatever I wanted to. However, now, I cannot do any of those things. My significant other gets aggravated because we can't do things that we use to do. We are both young, and want to do things that young people do before we get old.

Nurse continued that she is unable to pursue her occupation and she wants to resume her previous lifestyle and career path.

I am trying to deal with my life, but it has been an imposition on me. I wish all of this was over with and I could go back to work and finish school. I do want to finish school, but I want to go back to my career. It has been over a year since I have been working.

It kills me every day that I am not able to go back to work. I liked what I did.

I liked to make a difference with people.

Planter used his body each day for the physical job of farming. Planter stated he continues to work; however, he experiences difficulty.

Yes, it has slowed me up a lot. Especially, when it hurts, I can't stand for a long period of time. I have severe pain when I stand too long.

Guitarman, who was self-employed as a carpenter and the father of teenage son, indicated that the spinal cord made his life very difficult. He complained of a loss of wages, loss of dreams, and he felt that he was a burden on his family.

Guitarman explained:

It (spinal cord injury) has affected my life pretty bad. I stay depressed and it took me a long time to accept what I am now. It took all my dreams away and all that stuff. I go through a lot of pain with it.

Guitarman explained that he wants to work; yet he is unable to provide an income for his family. Guitarman was frustrated over his lack of income and his disability to work and help his family.

Guitarman continued:

I can't get out there and make money. I feel like it is putting a burden on my family. I can't hold out to doing nothing. I have to take a whole lot of breaks in between stuff. It seems like it takes me forever to do something. Because I have to stop and start back; because I can't do it. No one is going to pay me out there to work like that. I haven't had any income in years. I have not had any significant income since 1999. I have done some random work when I felt like I could; however, the lady did not pay me when I did try to work. I tried to work because I felt like I had to, but really I was unable to do it.

It is hard for a family of three to make it on one person's income.

All of your income goes to pay bills and you know when you plan for the future you count on two incomes and try to save something. You plan for the whole future and nothing happens.

Granddad expressed a loss over his life long occupation of farming. He stated the difficulty he had doing the simple tasks around the farm.

Granddad stated:

There are a lot of things that I don't do any more; particularly, here on the farm. I can't do any farming anymore. It is very little that I can do. I can ride a tractor, but I can't hook up anything to the tractor. I can't tighten or loosen bolts. For example, the day before I was injured, I was 58 years old; I handled over 250 100-pound fertilizer bags the day before. However, now I cannot even think about doing it. I can't do a lot of things that I did before and anything that involves lifting or bending; Now, I can still tie my shoes, but that is as far as I can bend. I guess it is because of the rod in my back. I just can't fold over but so much.

Granddad expressed that the traumatic spinal cord injury has globally affected his life, for has lost the physical ability to perform his chosen occupation and he had difficulties with his activities of daily living.

Resource, who was employed by a large university, indicated that his spinal cord injury has taken away his job, his ability to self-care, and his hobbies.

Resource stated:

Well, everything I used to do for myself, someone else has to do it now. Even in the shower, I have trouble bathing myself completely.

I can't turn too far to the right and I can't bend over far enough to even trim my toenails. It is a nightmare. Stuff like that you know is hard. There are a lot of things; even my sex life is affected. I couldn't hold my job because I was supposed to be at work at 6:00 AM. At one time, I could be there at 6:00 and then the pain got so bad in the morning that it took me a while to get going. I

would still get up at 4:30 AM, and would be lucky to get to work at 8:00. It got so that I could not run the computer and take my medication. I took it (pain med) one day and got so drowsy that I could not run the computer because I thought I would make a mistake. I could make a mistake and cost thousands of dollars.

So, it got to the point that I could not take my medication at work anymore. Therefore, I could not sit in a chair and answer the phone and run the computer because it started to hurt so badly. The pain medicine makes me foggy; I have trouble with simple things now.

I called my doctor's office the other day for a refill for my high blood pressure and I asked if the doctor needed to see me. The person on the telephone said, this is not the doctor's office, but the Newspaper Office. I dialed the wrong number.

Resource indicated that he has lost his health, his job and his ability to function independently in our society. Resource brought to light the chain of events that begins with traumatic spinal cord injury. He continued that the spinal cord injury led to intense pain that made it necessary to utilize pain medication that made him groggy and sleepy. Resources contended that without the pain medication, the pain from his spinal cord injury made it impossible to rest or function.

Oilman also expressed feelings of loss from his spinal cord injury. Oilman, who was a man who made his income from delivering fuel to people, was extremely physically fit and proud of his abilities. Oilman stated that he has lost a great deal from his spinal cord

injury and he has had to rely on family and friends to aid him in his personal care and his household tasks.

Oilman explained:

Water and sweat just jump off of me. I am so weak. I thought I was in good physical shape because I drove a gas truck and I pulled that hose 125 feet at a time.

There was not anything wrong with my leg muscles or arm muscles, but it just whipped me and took it all out of you just to walk. You don't know how good it felt just to step in the shower and hold to the walls. Before I had to take a pan bath because, I could not stand up in the shower. If you got down in the tub, there was nobody here to help me up. My wife was working.

Other things- think about putting your stocks on and can't do it. That is why I wear slip on shoes. That is why sometimes you see me in the summer time with no socks. I wear these little moccasin shoes. I still have trouble to this day putting a sock on my feet if I want to go to church or anything. I have to get my wife to put my sock on. I can't stretch that leg and I can't cross my leg. I can drive my tractor, but I have to leave it in one gear, I can't change gears. I can't even walk to spray garden herbicide. I have to get my friend to do it. I can't tote anything. I have to watch the ground that I walk on.

Solo was a widower and he indicated that his spinal cord injured had resulted in a partially paralyzed diaphragm muscle. He continued that over the years it has become increasingly difficult to breathe and now, as he is in his 70's, he has been put on oxygen.

Solo stated:

Recently, I was treated for shortness of breath... It stated slowly, I could not get my breath. I was rushed to the hospital and put in intensive care. It seems that my partially paralyzed diaphragm was not letting my lungs work like they should. The doctor told me I had shortness of breath, pneumonia and an enlarged heart because my lungs didn't work right because of my car wreck. I am on oxygen and I am in poor physical health. I hope that I can be weaned from the oxygen soon...but I just don't know.

Loss was a shared pattern manifestation that was encountered in each of the participant's stories. Through the interviews, the pattern of loss was discovered to exist on a physical, mental, and emotional level. Every participant conveyed the pattern of loss over the decreased innervation caused by the spinal cord injury. The participants furthered that an emotional loss was encountered by the changing of roles. Each participant, prior to the spinal cord injury, had enjoyed general good health. The participants were able to care for themselves and did not need assistance in either their personal care or in their livelihoods; however, once the injury had occurred, the participants found themselves in a completely different role that required the help of their friends and family. This transition into a new role was not desired or welcomed by the participants; rather, they felt at a loss to deal with their new life circumstances.

Hopelessness. Hopelessness was a shared pattern manifestation that was evident in each of the interviews. Hope and hopelessness are closely related as the opposite ends of a continuum according to Farran, Herth, & Popovich (1995). Lynch (1974) indicated that hopelessness is a feeling of despair and a sense of the impossible. The participants within this inquiry each implied that they were hopeless over the course of their recovery from

spinal cord injury. The participants used words that indicated the finiteness of their situation and the permanent change that spinal cord injury had inflicted on their lives.

Traveler indicated that she often became despondent and needed to rely on friends to help her through difficult days.

Traveler stated:

Sometimes, I call my friend and ask are you having a pity party? If so, I would like to join you.

Nurse was a young professional when she experienced a spinal cord injury. The injury caused Nurse to lose her job because she was unable to perform the physical tasks that were required by her position. During the interview, Nurse indicated that she is unable to continue with her life's vocation. She continued that she wants to progress and continue life as before; however, now she is unable. Nurse stated:

I am trying to deal with my life, but it has been an imposition on me. I wish all of this was over with and I could go back to work and finish school. I do want to finish school and I want to go back to my career. It has been over a year since I have been working.

It kills me every day that I am not able to go back to work. I liked what I did. I like to make a difference with people. I would not care about getting paid; I would have done it on a volunteer basis. I would volunteer for self-satisfaction... I love what I was doing and I will do it for free.

Nurse implied that she has lost everything she loved with the exception of her family. She continued that the injury was not her fault as it was beyond her control.

Nurse stated:

The injury took everything that I love from me except my family. This was not my fault, it was something that I could not control and could not help.

Nurse continued that she had been given positive information concerning her spinal cord injury, although the hope, as she described, was a false hope. Nurse expressed her feelings in reference to the good prognosis that was promised by her surgeon that did not reflect her actual course of recovery.

Nurse stated:

I would rather people would not give me false hope. Give me the worse case scenario. In that way I can expect the worse and hope for the best. After giving me false hope on something and I don't get it. That is hard to understand. You feel like you have been lied to. You think, they lied to me about this- what else would they lie to me about.

Planter expresses hopelessness over any improvement in his spinal cord injury. He continues that he is trying to live with it, although he has to use "black market pain pills" in order to maintain his current state of physical function.

Planter stated:

It is a pain that you have every day. It will not go away. I feel it everyday. However, I might go a week that it doesn't bother me as bad and I don't think about it as much. Then you might hit a spell and it hurts like Hell for a while. They don't ever give me any pain pills for it. I find Black market Percocet and stuff like that. That gets to be pretty expensive.

Planter continues that he was unable to cope with the back pain that he feels each day and that he must utilize street drugs for pain control. Planter expressed hopelessness over the improvement of his back pain and his private medical care.

I think I have suffered from depression with it. But I have spells, your back hurts like Hell, and you get a little depressed about it. As long as you keep moving, you are better off. I feel it everyday. It is a pain that you have every day. It (pain) will not go away.

Planter indicated that the pain is always present with him and at times the pain becomes even more severe. Planter expresses hopelessness concerning his condition and his emotions manifest as “a little depressed.” Planter continued that he must keep going, even through the pain will not cease. Planter conveyed hopelessness concerning his spinal cord injury.

Guitarman expressed hopelessness over any improvement in his spinal cord injury. He complained of a painful condition that he or anyone else is able to cure.

Guitarman stated:

I stay depressed and it took me a long time to accept what I am now. It took all my dreams away and all that stuff. I go through a lot of pain with it.

Guitarman indicated that he is depressed and hopeless concerning his spinal cord injury and that he has accepted the fact that he will not accomplish his aspirations and that daily pain is unavoidable. Guitarman expressed how the pain affected his daily life and on his feeling of hopelessness:

I ache all the time; especially, in damp weather. When it is cold and wet I have to stay inside as much as possible. The pain in my back and hip are still

there. I have good and bad days. But there is no fixing to it by the way they see it. They said it was a slow healing process and that it could take a year or two for it (innervation) to come back. However, it has never come back. So, he (surgeon) already sees it himself that it won't come back.

Guitarman continued to express hopelessness over any improvement in his spinal cord injury. Guitarman expressed the never ending daily routine that he is forced to live as a result of his spinal cord injury.

Guitarman continued:

It is hard for miracles to happen. I think it would take a miracle to get me right. It is very depressing to me the way I have been living. It is like I do the same thing over and over again from day one to day two. All running the same; it is no difference.

Guitarman conveyed hopelessness over his leg pain by what he referred to as “depressed” because there are things are “messed up in the yard” and he was unable to fix them.

Guitarman validated his feelings of hopelessness when his surgeon informed him that a muscle in his leg is “dead.” The word “dead” was defined as the opposite of alive; thus, if something is dead, it is not coming back to life and Guitarman furthered that all he can do was “holler” Guitarman feels a need to “holler” because he was hopeless that he will have any improvement in his painful condition.

Guitarman stated:

I get a lot of times real depressed because there is a lot of stuff out here in the yard messed up and I can't get out there and fix it like I should. I get depressed pretty bad. There is nothing I can do about it except lay there and

holler. When I straighten out my leg, I get muscle spasm in my side. Then my legs will lock up because the muscles are pulling. I talked to the doctor about it and he said that one part of the muscle is dead and the other part is alive. It is like they are working against each other and that is why I get the spasms.

Guitarman surmised his feeling of hopelessness when he stated his personal outlook on the prognosis of his spinal cord injury and of his future.

Guitarman expressed:

I think when the spinal cord is injured there is nothing you can do. There is not too much of a future holding for me no more like it used to be. All my dreams have gone down the drain. I wanted to build my own home since I do carpentry work. I really wanted to build my own home, but I won't be in shape to do it. I have a building setting out in the back yard right now that I cannot finish.

Granddad expresses hopelessness over his ability to perform his life's vocation of farming independently. Granddad stated:

There are a lot of things that I don't do any more. The day before I was injured, I was 58 years old; I handled over 250 bags of fertilizer the day before. However, now I cannot even think about doing it.

Resource expressed hopelessness concerning his ability to supervise his department once he experienced a spinal cord injury.

Resource explained:

There are just a lot of things that I used to do that I can't do any more.

So, it was useless for me to take over a position that I could not supervise. I could probably do the paper work, but after I got on the medication, I could not do the paper work.

Resource conveyed that the pain from the spinal cord injury created a feeling of hopelessness. He attempted to explain the intensity of the suffering that he was feeling to his co-workers in an attempt to validate his work ethic.

Resource contended:

Well, if you have a toothache in your back for twenty-four hours a day, seven days a week, its makes a difference. I told one of them (co-worker), I wish you could walk in my shoes for one day. But, I said no, I am glad that you won't have to. I hope you never have to; because it is something else to go through what I have.

Oilman explained the finiteness of his spinal cord injury. He indicated through his interview the hopelessness of any improvement in his condition. Oilman explained that his life had changed forever and he has had to accept and change his activities in order to cope with his new abilities.

Oilman explained:

Your life stops (after spinal cord injury). There are a lot of things that I will never be able to do. There are a lot of things that I cannot do. You have good days and bad days. The wintertime is the worse. Especially, when the weather changes. Sap comes up and sap comes down and you can kiss it good-bye because your leg and back will hurt. I am scared. I am not trying to get in that wheel chair yet. I know years on down the road I will probably

have to go to a wheelchair. But, I am trying to stay away from that as long as I can. Your life changes, you have to change with it. There are a whole of things that you have to change. The best thing to do if you know in the back of your mind you are really going to have a disability is to psych your mind to deal with the coping factor. What you can do and what you can't do.

Oilman continued to express hopelessness in his spinal cord injury, although he expounded on the need to accept the fact of living with a disability. He conveyed that the person with spinal cord injury must understand and learn to cope with the change in one's physical abilities.

Oilman continued:

At the present time, you have to accept the disability. People go through a whole lot of stressful minds. They have been in the hospital and thinking about coming home and telling themselves: I will get over this and I can go back to doing things, although the doctor says you can't jump rope, can't swim, no mountain climbing, no bicycle jumping. The doctor told me, you will never be able to push a lawn mower or use a weed eater. Just mark that off of your list. My back cannot be repaired; Things are going to be different from now on.

Hopelessness is a shared pattern manifestation that is evident in the participant interviews. Hopelessness within the scope of spinal cord injury is the realization that one's condition will not improve and that one's life has changed forever. Farran, Herth & Popovich, (1995) explained that hope and hopelessness represent a contrary relationship that is related to one another. Throughout the preceding section, examples taken from the

actual transcripts have been used to illustrate the concept of hopelessness experienced within the life pattern of people with spinal cord injury.

Previous researchers (Bay, 2001; Lohne, 2001; Morse & Dobemeck, 1995) explained that although different authors have attempted to explain the concept of hope and its opposite hopelessness, the defining definition of this concept appeared to be general and abstract while explanations to explain the conceptual differentiation have not produced significant results. Research on hope has resulted in empirical and philosophical studies that have discovered concepts that are related to hope such as freedom, inner power, goal achievement, mutuality, optimism, trust, faith, and meaning (Herth, 1990; Jones, 1998; Lohne, 2001; Marcel, 1967; Miller & Powers, 1988; Stotland, 1969).

At present, there are limited data within the body of scientific knowledge concerning the concept of hopelessness as a pattern manifestation within the life pattern of people with spinal cord injury. This inquiry has discovered new data that illustrated through the actual words of the participants the shared pattern manifestation of hopelessness in the person with spinal cord injury.

Summary

The shared pattern manifestations of depersonalization, loss, and hopelessness were the concepts that were illustrative of the people who live each day with spinal cord injury. Each of sentences that were used as examples to illustrate the three shared pattern manifestations was extracted directly from the participant's transcripts. The three shared pattern manifestations that continued to surface during the analyzing of the transcripts were named in concept and supported in definition by a literature review. Once the three shared pattern manifestations were discovered and defined, it became evident by

rereading the field notes, reflexive journal and through the intense reflection of the transcripts and recordings that the shared pattern manifestations, depersonalization, loss, and hopelessness were not three lone entities that were expressive of the life pattern of spinal cord injury; rather, they were components that explained and illustrated the primary pattern of people with spinal cord injury-despair. Chapter Five will discuss the synthesis of despair as manifested through the shared pattern manifestations of depersonalization, loss, and hopelessness.

Chapter Five

Synthesis, Conclusions and Implications

The inquiry was designed to illustrate the life pattern of people with spinal cord injury through the venue of unitary appreciative inquiry. Through the implementation of unitary appreciative inquiry, data were discovered from the individuals who had experienced spinal cord injury that: (a) illustrated three shared pattern manifestations: depersonalization, loss, and hopelessness; (b) illuminated the primary pattern, despair; (c) gave insight on living with a spinal cord injury; and (d) will increase the dynamics of nursing science through new methods and topics of research. Unitary appreciative inquiry was chosen as the methodology because it enabled each participant to be an active participant who not only created and shared the data but who also validated the data.

This inquiry successfully illustrated the experiences of the people with spinal cord injury through active participation. Cowling (2000) indicated that unitary appreciative inquiry was a method which illustrated and validated the aspects of life that created an awareness of the wholeness of the human spirit. The experiences of the people with spinal cord injury created rich text that gave insight to the phenomenon of spinal cord injury. Through the methodology of unitary appreciative inquiry, the three shared pattern manifestations; depersonalization, loss, and hopelessness were discovered which lead to the illumination of the primary pattern of people with spinal cord injury: despair.

Synthesis

Synoptic. The process of pattern appreciation is not akin to the usual method of understanding data; rather, the process of pattern appreciation is consistent with the

science of pandimensional unitary human beings. Synopsis, the foundation of unitary knowing, is the method in which the fullness of pattern is understood. Cowling (1998) indicated that the synopsis is the illumination of the particular human experience, which is generally not within the vision of the average person or even professional scientists. Cowling (1998) continued that the object of the synopsis is to move away from the inter-relatedness of particular aspects and pursue a human pattern which manifests wholeness and integrality of the human field; thus, the outcome is not to understand how data are interrelated but in illustrating the pattern as reflected in the participant's data. Synthesis, which is based on the comprehension of the synopsis, is the pathway to pattern knowing. Cowling (1998) indicated that to comprehend the essence, within unitary science, was to comprehend the pattern. Cowling maintained that the pattern profile illustrated the human wholeness through the pattern information which was the manifestations of experience, perception, and expressions.

Participatory. The individuals who comprised the population of the inquiry equally participated in the decision process of not only selecting what vehicle of expression was suitable for the pattern profile, but in deciding what was important to discuss in order to determine the life pattern of people with spinal cord injury. The inquiry group included eight co-participants who were active throughout the inquiry. Cowling (1998) indicated that the researcher and the co-participants have equal responsibilities for the engagement and the pattern discovery. Cowling (1998) continued that every aspect of the inquiry is negotiated within the group and that the establishment of purpose, engagement methods, documentation and the construction of the pattern profile, and the formulation of the conceptual-theoretical synthesis were totally co-participatory.

Transformative. Unitary pattern appreciation is, by design, transformative. Rogers (1992) indicated that human beings are moving towards more diversity, innovation, and complexity. Cowling (1998) indicated that this movement will occur regardless of pattern appreciation; thus, by asking the participants to focus on a particular phenomenon, unitary appreciation creates a new understanding and awareness of the unfolding stream of continuity.

The pattern profile. The pattern profile was created from the synthesis of all the data, including the synopsis that emerged from the appreciative encounter. Cowling (2001) indicated that the form that the appreciative pattern profile manifests was determined by the participants' experiences, perceptions, and expressions that captured the wholeness, uniqueness, and essence of human life. Cowling (1993) continued that synoptic processing, the creating of the pattern profile, includes two key considerations that must be utilized by the researcher. Cowling (1993) indicated that the researcher must be open to the unitary paradigm and, as such, must be willing to accept a diverse variety of information that pertains to the unitary pattern and he furthered that the unitary researcher must be in a state of mental development that enabled the participant to disclose information, for without disclosure, one has not data.

The participants within this study were given the choice of art, dance, photography, poetry, narrative, or any other medium of expression as suggested by the individual participants. Cowling (1993) indicated that a profile may be one sentence, a single word, a drawing, a piece of music, a story, a poem, or even an object that reflects the pattern of the human energy field. Each participant, when asked what method was best to convey the pattern of spinal cord injury, chose the narrative. The participants conveyed that they

wanted to use their own words to convey their story of spinal cord injury. The participants furthered that a story that was illustrative of the continuum of spinal cord injury would be most beneficial to convey the life pattern of the people with spinal cord injury.

The pattern profile, as directed by the participants, was created largely with the words and sentences taken directly from the actual transcripts. Additional sentences, punctuation, and grammar corrections were added for clarity of expression and in keeping with the goal of the pattern profile, which was to express the uniqueness, wholeness and essence of the life pattern of people with spinal cord injury.

The pattern profile within this inquiry is a narrative expression that conveys the life pattern of people with spinal cord injury through the medium of a story. Cowling (2001) instructed that when the researcher writes the pattern profile that it is necessary to use the voice of the participants rather than the researcher. The story is composed of the actual words of the participant in first person singular as taken from the transcripts. Cowling (1993) indicated that the purpose of the synoptic pattern profile was to create an image of the underlying field pattern as it was portrayed in the person's human expression, experiences, and perceptions. The pattern profile described chronologically the continual event of living with a spinal cord injury. The pattern, which was created through intense reflection from the synopsis, audio tapes, reflexive journal, and field journal, describes the subjective, personal events of spinal cord injury through the collective voice of the individuals as recounted by the participants. The data and the synopsis of each of the participants were indicative of despair as portrayed through three shared manifestations: depersonalization, loss, and hopelessness as outlined in Chapter Four.

Despair

As indicated earlier, the researcher determined, through synthesis of the data and synopsis, that depersonalization, loss, and hopelessness were three shared pattern manifestations that were evident in the data. The three shared manifestations were interpreted by the researcher to be supportive and defining of the principal pattern of people with spinal cord injury- despair. Cowling (1993) indicated that through the expression of pattern, the researcher could derive knowledge of the underlying pattern which is obtained by the researcher through the tapping into of multiple modes of awareness. Cowling (1993) continued that the participant's expressions of underlying pattern included such things as sensations, gait, posture, muscle strength, tears, meditative insight, sadness, dreams, activity level or anything expressed which could be considered relevant to the unitary pattern for we, humans, are unitary creatures. The researcher, who interpreted the shared pattern manifestations of depersonalization, loss, and hopelessness to be indicative of the principal pattern, despair, asserted a literature review of despair to ascertain if the concept of despair was definable by depersonalization, loss, and hopelessness.

The concept of despair. Despair has been the subject of countless discussions through the ages. Despair, according to Webster's Revised Unabridged dictionary (1970), is derived from the Old English desperiren and Old French, desperer and finally from the Latin word, de- + sperare. Sperare translates to mean hope, whereas desperare is to be hopeless, to have no hope and to give up all hope or expectations. Webster defines despair as to possess utter hopelessness or complete despondency.

Literature. Despair has been used as a descriptive condition in many works of literature. The despair that is described in prose and poetry conveys a sense of unyielding end that is without mercy or salvation. Despair is a continuous finite end that bespeaks total abandonment and loss of quest.

Selected works about despair include Joseph Addison's reference to despair in *Cato* (act IV, section 3) "I will indulge my sorrows, and give way to all the pangs and fury of despair." John Bunyan (Bunyan & Brown, 1895) wrote in *Pilgrim's Progress* (pt. I, chapter II), "The name of the Slough was Despond." Byron (1816) in *Childe Harold* (canto IV, section 115) stated, "The nympholepsy of some fond despair." Dryden (Virgil & Dryden, 1937) in his translation of Virgil's *Aeneid* stated, "Night was our friend, our leader was despair." Milton (1935) described despair in *Paradise Lost* (book II, 1, 141) "Thus repuls'd, our final hope is flat despair." Shelley (1818) described despair as a solitary, bleak abandonment in *Revolt of Islam-Dedication* (section 5) "...then black despair, the shadow of a starless night, was thrown over the world in which I moved alone."

Despair has been described as a solitary experience of total bleak abandonment. Despair is an experience that leaves the individual bereft of hope. It is a hopelessness that robs one of any opportunity of future progression or hope. Despair is a finitude that is without recourse. H.P. Lovecraft (1971) described his concept of despair as "Damn'd demons of despair" in his poem entitled *Despair*. Despair is conveyed as a solitary experience of the soul. Despair is often referred as being without hope. It is the individual's solitary interpretation of the self that is bereft of any hope of salvation.

Depression and despair. Throughout the psychological literature, despair is conceptualized as a component of depression. Although this unitary inquiry did not find that clinical depression was a component of spinal cord injury, the current literature suggested that despair could be a component of depression. Despair has been used as to describe the feelings of depression. Rado (1928) as described by Goldsmith (1987) sees melancholia as a despairing cry for love. It is the term despair, which was used to describe this condition of melancholia. Kovacs and Beck (1979) continued with their description of depression through the terminology of despair. The authors indicated that the depressed person was of the contention that the future is completely void and yields an experience that is of despair. Schwab (1971) proposed the use of despair as a qualifier of depression in his application of despair as one of the five manifestations of depression. Benton (1972) continued with the use of despair as a manifestation of depression as he conceptualized depression as the person's ability to despair over him/herself. Tallenbach (1980) included despair as the initial stage of depression for it is the foremost melancholic state. Lifton (1979) summarizes that being in a state of despair can not only predispose someone to a depressive episode but delay recovery from depression as well. Despair, as suggested by the literature, has been used as a defining characteristic of depression.

Although despair is not a diagnosis on the DSM-IV, it has been delineated from the concept of depression. Fine (1980) described a relation between despair and depression, but suggests the two are not the same. Fine as described by Goldsmith (1987) indicated that depression was a nomothetic-like category, whereas despair was a phenomenological feeling state. The state of despair is a phenomenon that is perceived by the self of the self,

while depression is a clinical manifestation that has objective characteristics that can be observed by entities other than the self.

Goldsmith (1987) continued that depression is an acute disorder that incapacitates the person. Although it does not always include despair it is also a condition that manifests stagnation, loneliness, and self-destruction.

Despair is a feeling of emotion, which is often described as someone being down, blue or even depressed. Despair can exist within in the framework of depression or solitarily. Despair is described as ongoing mental anguish and discontent that often lasts many years if not a lifetime. The concept of despair does not figure largely in the psychological literature. Despair is often discussed as a symptom of depression, although it is not a diagnosis in the DSM-IV. Despair, while considered a global symptom of the psychological manifestations of depression, has not been granted its own supporting identity.

Depersonalization and despair. Depersonalization is a psychological term that defines a clinical state that often follows an intense emotional experience, according to Phillips and Sierra (2003). The authors continued that patients describe depersonalization as an emotional numbness and feelings of unreality. Despair is often encountered when one does not accept his/her life, life events, and expresses dissatisfaction with a regret that is unchangeable. Rylands and Rickwood (2001) indicated that negative affectivity, which is a generalization of subjective distress assumes many negative mood states, such as fear, anxiety, hostility, scorn, and disgust, may be an outcome for people who cannot accept past experiences. Rylands and Rickwood continued that people encountered despair when

one's life cycle was not accepted and there was insufficient time or opportunity to try an alternate route or begin again.

Noyes et al. (1977) discovered that depersonalization syndrome was identified in 33 percent of the people who encountered a life threatening accident. Each of the participants in the spinal cord injury inquiry encountered a life threatening accident that resulted in a regrettable, unchangeable physical condition that resulted in feelings of extreme dissatisfaction and feelings of being held back and stopped. The participants furthered that their current life style was not acceptable and they each desired to resume their old, pre-accident ways of living.

Grostein (1990) states that often a psychosis is manifested by feelings of a globalized incompleteness of self that stops and does not continue on its intended path. This mental manifestation is described as being lost in a dark void where chaos, horror, and complete dysfunction reign over the suffering individual. This feeling of complete terror and chaos has been described by Lipsyte (1995) as being descriptive of the concept of despair. Lipsyte (1995) described that Ogden's (1989) theory on despair and he contended that one does not know what one feels and that the person is unable to recognize himself. Ogden proposed that one's escape of the self is actually a defense mechanism against the angst of not knowing the true self, for this lack of knowing, as indicated by the extraction by Lipsyte (1995) would create further alienation of the self and result in feelings of panic, confusion and loss.

The participants in the spinal cord injury inquiry voiced feelings of unreality and that they could not believe that this accident had actually befallen them. As Lipsyte (1995) described in the preceding paragraph, the subjective feelings of unreality and denial are

defense mechanisms which guard against the true recognition of the self, for with true recognition comes angst; however, within the spinal cord injury inquiry, each person over a period of time came to realize that the injury was in fact a reality of life and this realization manifested feelings of loss, panic, and confusion which became the etiology of despair.

Despair has been discussed within the confines of wartime atrocities. Lifton (1961) researched hibakusha, who are the survivors of the Hiroshima atomic blast. Lifton indicated that the initial human response to the horrific destruction was psychic numbing, which is described by Goldsmith (1987) as the cessation of feeling which precedes the emerging feelings of depression and despair. Khazaal, Zimmerman and Zullino (2005) defined the symptoms of depersonalization as the emotional detachment of one's own feelings, thoughts, or actions, which is what Goldsmith (1987) referred to as the precedent of despair that was present in the hibakusha.

Depersonalization, which is the subjective feelings of emotional numbness and detachment of reality (Phillips & Sierra, 2003), is a component in the etiology of despair as explained within the current literature. Throughout the individual interviews, the participant within this inquiry verbalized that they had experienced during the course of their spinal cord injury a) feelings of a detachment from reality, b) fear that they were being turned into a robot, c) feelings that their brain was not working correctly, d) the belief that spinal cord injury could not be happening to them, and e) vivid accounts of the accident. Each of these subjective feelings that were experienced by the participants was well within the clinical definition of depersonalization as defined by the current scientific

literature. The concept that depersonalization is a component of despair was confirmed by the literature review.

Loss and despair. Each of the participants within this unitary inquiry verbalized that they had lost the ability to live life, as they wanted to live it. The participants recounted activities and actions that they wanted to perform, although now they were unable to perform these activities due to the restrictions that were imposed on them by the spinal cord injury. The disability to work, travel, tie shoes, play sports, pursue an education, or even use the restroom independently were seen by the participants as a loss. The feelings of loss permeated the dialogue of each interview and loss was determined through data to be a component of despair.

A literature review indicated that loss was a component of spinal cord injury. Erickson (1950) wrote that the development of one's personality is determined by the successful ascension of eight developmental stages. The final stage that was surmised by Erickson was ego integrity versus despair. Ego integrity can be assessed by the individual's feelings concerning his/her life process. The person who has lived a life such that death seems less important than his/her previous contribution to family and society is deemed to have ego integrity.

Although the people in the final stage, who were usually at the autumn of their years, would find solace by knowing that the promising future, which would not include them, was made possible by their successful contributions (Peachy, 1992). A study by Woods and Witte (1981) indicated that the people who ascended to the final stage of Erickson's theory have unregretably accepted their life through the summation of their failures and accomplishments. Kimmel (1974) and Peachy (1993) continued that unresolved conflicts,

or the failure to affirm people, time or life, or be affirmed in Erickson's final stage will lead to despair. The awakening of knowledge upon introspection may be a causative agent for despair if the epiphany uncovers regrets or inadequacies in the person's life that are now unchangeable due to age, health or other circumstances.

Glenwick and Whitbourne (1977) indicated that, according to Erickson's eighth stage of ego integrity versus despair, one's successful transcendence into ego integrity is the accomplishment of both reevaluation of the past and the consideration of the future, which inevitability comes to the final milestone of a person's life-death. One's life and life events must be accepted if one is to avoid despair. An older adult as described by Erickson also manifests despair in the perception of a misspent life. Erickson contended that if the adult, when facing the comprehensive examination of his/her life, perceived that his/her life course did not meet his/her life goals that despair was evident. Erickson continued that despair manifested in the person who comprehended that their remaining life span was too short or ill equipped for the accomplishment of the individual's goals.

Goldberg (2000) suggested that vigorous self-reflection of one's limitations and finitude of mortal existence may place the individual in jeopardy for despair. Goldberg posited that self-esteem and the feeling that one is successful in life were due to being accepted and appreciated by others and that the rejection by significant others lead to negative self-feelings such as loneliness, inadequacy, and even antisocial behavior towards self and others.

According to Bowlby, (1980), the mourning process can lead to despair through the sense of loss and the need to develop new life patterns. Bowlby (1980) continued that

mourning was manifested by a sense of loss and that numbness, followed by yearning, searching, and anger lead to disorganization and despair.

The literature review indicated that loss is a component of despair. Each of the participants within the inquiry verbalized that they had a great sense of loss. The sense of loss was manifested by concrete examples of loss that were a result of the spinal cord injury. Erickson indicated that if the aging adult did not perceive that his/her individual goals were met that the aging adult would not acquire ego integrity. This lack of ego integrity would result in the subjective feelings of despair. Although only three of the participants were aged 60 and above, despair was expressed by all participants through a sense of loss and the disability to proceed down their intended life's course. Bowlby (1980) indicated that mourning over one's loss can lead to despair. It was evident through the process of the inquiry that the participants with spinal cord injury felt a great deal of loss over the loss of their previous physical abilities. Despair was a contention of the aging adult who comprehends that time is no longer available in the completion of his/her life goals and the mourner faces concrete realities over loss that must lead to new life patterns. Loss was found to be a component of despair as illustrated in the current scientific literature.

Hopelessness and despair. Hopelessness was found to be a shared pattern manifestation throughout the course of the unitary inquiry, what is the life pattern of people with spinal cord injury. Participants in this inquiry believed that their physical condition would not improve, become better or transfer to a wellness state. The participants expressed hopelessness over their physical limitations and their ability to become better, in fact, seven of the participants believed that they would eventually

become less healthy and would need total assistance in their activities of daily living. It was through the shared pattern manifestation of hopelessness, along with the manifestations of depersonalization and loss that led to the discovery that despair was the primary pattern of people with spinal cord injury. The literature review indicated that hopelessness is a component of despair.

The literature review revealed that despair is the non-acceptance of an unchangeable life, lifestyle, or life event by the individual who is experiencing the life-situationess. Haight, Michel, and Hendrix (1998) determined through their study that despair is composed of three elements: depression, hopelessness, and suicide ideation. Kylma, Vehvilainen-Julkunen, and Lahdevirta (2001) described despair as the opposite of hope. Kylma et al. (2001) indicated that through this ground theory method that despair is a normal part of life and that to be in despair is to be stuck in a situation without a glimmer of hope. The study finds that despair evoked subcategories from the participants that included: giving up, sinking down into a narrow existence, closing down in chilly loneliness, experiencing a lack of alternatives, being unable to see ahead, and experiencing inability. The participants articulated that “despair is a situation in which I feel that there is no way out of the situation and the individual is stuck; Despair is like a wall, it is like stopping, it is difficult to get over or be strong; Despair suggests giving up and going down; Despair is like being on the bottom; Having no future (Kylma et al., 2001)”. Kylma, Vehvilainen-Julkunen and Lahdevirta (2001) summarized their participants definition of despair as being a fluctuating, deeply black condition, painfully pressing, dangerous, independent of one’s will, non-rational, and culturally and religiously dependent and that it is possible that despair gives rise to hope; however,

becoming locked up, having symptoms, and committing suicide are other potential consequences to despair.

Kierkegaard described despair (1849) as not being able to die when there is no hope of life, thus hopelessness does not exist for not even the hope of death is available to the individual. Kierkegaard indicated that despair is when one is unable to die and must live, although the act of living is merely a prologation of sickness without death (1849).

Kierkegaard illustrated (1843) that to be in despair is being unable to escape one's self. The individual is constantly confronted with his self, thus he/she is unable to escape the self through the usual methods of condoned societal escape measures. The usual day-to-day routine is filled with thoughts of the self, thus the individual is unable to escape the self-truth, which is inescapable when one is confronted by the constant self. This sense of being stuck and unable to advance is despair.

People who are in despair are often stuck in one fatal aspect of life that is a void without any hope for a dynamic life change that is congruent with growth and personal satisfaction. Safran (1999) proposed that people who are in despair have the ongoing feeling of trying and failing. The failure results not in affirmation of support and help by others but in condemnation by self and others. The will, which was once like a powerful muscle, is now atrophied from lack of use.

Lifton (1979) explained that despair is the self's inability to see a brighter future. He continued that the human existence is one, which is a search for the symbols of immortality. Goldsmith (1987) interpreted Lifton's conceptualization of the despairing person as one who perceives that an immediate action must be taken in order to revitalize movement, however the action is blocked and a sense of a permanent,

unalterable, future creates an enduring death state that is constant and without any opportunity of change.

The participants within this unitary inquiry verbalized that their life had stopped and they were unable to continue their intended pathway. The participants indicated that they wanted to complete tasks, take trips, finish school or just work in the yard; however, since the spinal cord injury, it was impossible to achieve these goals for the injury had stopped their life progression. Each participant described spinal cord injury as a hopeless condition that left them cut off from their dreams, hopes and even society. The participants each gave a foreboding prognosis of their injury that would or could not improve. The participants conveyed that they believed that their future was set; they could not progress; they had stopped and the future was a continuation of the present. The literature review revealed that hopelessness is a component of despair. Despair is often defined as being without hope; hopelessness is a component of despair.

Manifestations of despair. Depersonalization, loss, and hopelessness were found to be three shared pattern manifestations of people with spinal cord injury. The three shared manifestations are indicative of the principal pattern of despair as determined through the process of synoptic inquiry. The literature review revealed that depersonalization, loss, and hopelessness are supported by the current scientific literature as being components of despair. As the literature review indicated there are many threads to the concept of despair. Despair has been described as being stuck, being in a numb, non-feeling state, recognition of loss, being without hope, and as a component of depression. However, all of these definitions of despair had a common thread of sameness. All the articles reviewed state that to be in despair is to be with a grim or foreboding future that is devoid

of positive human interaction and is only encompassed by the darkness of failure, hopelessness, and alienation that is absent of progression.

Effects of Participation

At the conclusion of each interview, each participant was asked if they felt they had any benefits or negative experiences from this of unitary inquiry. Each participant stated that they had not experienced any negative or bad feelings from participation in this inquiry. Overall, the participants indicated that it was a positive experience and six of the eight participants conveyed that they sincerely hoped that someone could benefit from the story of their experience.

Transformative. Two of the participants indicated that they felt better about their spinal cord injury since they participated in the study. One participant indicated that she did not feel like the only person with a spinal cord injury and that she did not feel “so alone” in her condition. The other participant who voiced the positive affects of the inquiry indicated that following the initial interview he realized that he could do more than he was doing. He furthered that he began a small wood-working project with his son and he was now planning on working on a larger project.

The remaining six participants indicated that it had been an overall good experience; however, no change in their life or affect had been encountered. Each of the eight participants thanked the researcher for inclusion into the inquiry and they reported that they had enjoyed the interaction, as it was good to talk with a new person. Each participant again recounted to the researcher that the inquiry had been a good experience and that they had not experienced any negative feelings or emotions.

It is unclear why a transformative effect was not perceived by each of the participants. One can postulate that perhaps two meetings are not sufficient in order for participants to undergo a transformative effect. Cowling's (1993) early work indicates that at least six meetings of inquiry are needed for unitary appreciative inquiry. One could also conceive that this group of participants, which were composed largely of white middle aged men who live in the rural South, were not acculturated to sharing personal feelings and perhaps a transformative effect was achieved; however, it was not expressed by the participants.

Credibility and Trustworthiness

Credibility. Credibility, which Carboni (1992) referred to as truth value in the unitary paradigm, is the judged validity or truth of the product which illustrates the mutual process of energy fields. Within this inquiry, the product was the synopsis and the pattern profile, which were both judged and validated to be an actual representation of truth by the co-participants who were the people with spinal cord injury. Credibility of this inquiry was ensured by the implementation of prolonged engagement, persistent observation, multiple sources of data, participant checks, and peer debriefing as outlined in Lincoln and Guba (1985). The examples of how each of these techniques was utilized within this inquiry are outlined in the texts within chapters four and five.

Unitary integrity. Unitary integrity is what Carboni (1992) referred to as reality resonance, which indicates that every effort was maintained within the inquiry to reflect the actual truth of the pattern in question. Carboni (1992) continued that within the unitary paradigm, three criteria must be met to assure unitary integrity. The initial criterion is do the findings transcend the natural setting where the interview took place

and apply pandimensionality? Within this inquiry, the findings did transcend that actual time and place of the interview and dynamically transformed via the vehicle of language and expression to a dimension that was reflective of despair. The transcendence which was created through the medium of the pattern profile enabled the participants to express their world through a dimension that was not within the confines of the here and now. The pattern of despair transported the reader to a place that enabled visualization of the interaction of the human field and environmental field pattern which was indicative of despair.

The second criterion which was described by Carboni (1992) is whether an audience of Rogerian scholars would view the findings of the data as applicable and meaningful. This second criterion is, as yet, undecided, for the findings have neither been published nor have the findings been articulated to other Rogerian scholars. It is hopeful that the findings of this inquiry will be presented to experienced Rogerian scholars so that the information within this study will be discussed and disseminated.

The third and final criterion that was explained by Carboni (1992) was whether the findings of the inquiry, the pattern profile, resonate with the data from which it was created? The findings within this unitary inquiry do resonate with the raw data, for this pattern profile was composed and created with the actual sentences of the participants as taken from the audio transcripts. The synopsis and pattern profile was also member checked to assure validity and integrity.

Through the application of Carboni (1992) criterion, unitary integrity was sincerely attempted, although the second criteria, the audience of Rogerian scholars, has yet to be applied for the inquiry has not been published or presented at this time. Although the

proposal for this inquiry was presented to a group of Rogerian scholars at a national conference and was subsequently indicated to be an appropriate course of inquiry, the final pattern profile has yet to be revealed to the Rogerian audience.

Auditability. Carboni (1992) wrote that auditability is defined as the ability for other Rogerian scientist to arrive at the same conclusion through consistent interpretations. As stipulated in Lincoln and Guba (1985), a second nurse scientist should be able to arrive at the same conclusion given the same data set. Throughout this inquiry, auditability was maintained through the retention of the audiotapes, synopsis and the representation of the scientific literature.

Credibility, unitary integrity, and auditability as described by Carboni (1992) were maintained in a sincere effort to assure that the data was an accurate reflection of the life pattern of people with spinal cord injury. The pattern profile, which utilized the participants' own words and was further scrutinized through participant member checking, enabled the researcher to present new information that was a collective expression of the life pattern of people with spinal cord injury.

Implications of the Study

Although much attention has been focused on the restoration of function following a spinal cord injury, there is still a great deal of need within the population of people with spinal cord injury. This inquiry examined data which was reflective of the person with spinal cord injury. The data, which were obtained from people who were at least two years post spinal cord injury, gave tremendous insight on the life of the person with spinal cord injury. The inquiry acquired data on people who are often forgotten about within our society. The participants, many of whom had undergone physical

rehabilitation, were experiencing despair as manifested through the three shared pattern manifestations; depersonalization, loss, and hopelessness.

Nursing research. Despair, which is not a nursing diagnosis in the North American Nursing Diagnosis Association or diagnosis in the DSM-IV, is a very real phenomenon that is a daily reality for many people. The patients who suffer from spinal cord injury and perhaps other chronic physical illnesses would benefit from the inclusion and acceptance of despair as a viable diagnosis. While each of the participants within this inquiry had a very good physical outcome in regards to their accident, they began to experience despair. The phenomenon of despair, as indicated within this chapter, leaves the individual with feelings of hopelessness that leaves the person with feelings of defeat.

The patient may benefit if despair were included within the nursing assessment. The assessment, within the population of people with spinal cord injury, would perhaps be best inserted during the orthopedic surgeon appointments that are spaced over the period of five years from the date of injury. The assessment could also be asserted during intake into the physical rehabilitation, although, within our current healthcare system, people often only undergo no more than six weeks of therapy. Despair is a valid healthcare concern that is expressed through feelings of depersonalization, loss, and hopelessness. The nursing assessment of despair may enable people with spinal cord injury to live more productive and happy lives through the acknowledgement of this phenomenon.

Although most of the current medical and scientific data concerning spinal cord injury focuses on surgical techniques, rehabilitation, psychiatry, and devices which aid the physical activities of daily living, very little detail is present in the literature that speaks to the daily life of the person with spinal cord injury. This small qualitative study gave

voice to the people who live each day with a spinal cord injury. The data, which were obtained from these participants, indicated that, even though each person had a very good physical outcome concerning their spinal cord injury, they were not pleased with their current state of being. The participants each portrayed a tremendous sense of loss and hopelessness that conveyed the extreme loss of the self that accompanied the loss of their spinal innervation. The pattern of despair was manifest through the profound sense of depersonalization, loss, and hopelessness. Although hope and depression is discussed within the psychological literature, little data are present that focused on despair, much less despair and spinal cord injury.

Clearly, additional research, which examines despair through the nursing framework, is needed to fully understand, not only the physical needs of the person with spinal cord injury, but how to recognize, assess, and treat the person with the symptoms of despair. Despair, which may not be recognizable until years have passed since the traumatic injury, may be difficult to detect and may be confused with depression. Research which focuses on the despair may enable people with spinal cord injury to live more happy and productive lives; however, much work is needed in this field in order to truly recognize and treat despair as a primary diagnosis.

Strengths and Limitations of the Inquiry

Strengths of the inquiry. The unitary appreciative inquiry, “what is the life pattern of people with spinal cord injury?” gave insight into the lives of people who live each day with a spinal cord injury. The inquiry focused its attention of participants who were more than two years post trauma in an attempt to examine the life of the person with spinal cord injury who lives in the community. The inquiry sought out participants who had

been living in the community for more than two years so that an understanding of pattern could be illustrated that was defining of the person who lives with a spinal cord injury.

Expressions. A strength of this inquiry is that the data, which were used to create the synopsis and pattern profile, are more than words on a page that articulate information; rather, the field notes, reflexive journal, along with the interpretation of the participant's tone, body language and even natural surroundings were compiled and synthesized in order to achieve meaning. The strength of this inquiry was that the pattern profile was written in the actual words and sentences of the participants. Although the pattern profile is not verbatim of each word, the majority of the pattern profile is composed of the actual words of the participants. The words within the pattern profile were only changed when necessary to stay true to the pattern profile and for clarity of expression. The synopsis and the pattern profile were member checked to assure that they presented an actual representation of the people with spinal cord injury. Each participant was individually scheduled for a second meeting in which the participants was read and shown the synopsis and pattern profile. The participant was allowed to reflect on the data and then the individual judged if the synopsis and pattern profile was an actual representation of the life pattern of people with spinal cord injury. Throughout each of the second encounters, the synopsis and the pattern profile was validated to be an actual representation of the people with spinal cord injury.

The final product, the pattern profile, reflects the actual life pattern of people with spinal cord injury. The pattern profile, which is a product of unitary appreciative inquiry, has never been utilized to express the life pattern of people with spinal cord injury. Although more research is needed, the pattern profile, which is reflective of despair,

manifests new information that can be used to facilitate care of the people with spinal cord injury.

Unitary appreciative inquiry is a method of research that enables the individuals within the study to be the actual participants who create and validate the data. The data that were obtained from the participants was member checked for validity to assure the pattern profile is an actual representation of the phenomenon in question. The unitary appreciative inquiry, what is the life pattern of people with spinal cord injury, offers new information in the voice of the person with spinal cord injury in an attempt to facilitate understanding of the life pattern.

Limitations. The limitations that may have negatively affected the final data within this inquiry include demographics of participants, researcher bias, and methodology. Although measures were taken to assure validity and credibility, limitations were evident within this inquiry.

A limitation of this inquiry was the actual demographics of the participants. The participants within this inquiry were of Caucasian origin that lived within the small cities, and the countryside of North Carolina. It is unknown why people of minority background did not volunteer for participation in this inquiry; however, it was a deficit within the study. People of minority status may have undergone a different experience that was, perhaps, not indicative of the pattern of despair; however, this information is unknown for minorities did not participate within the inquiry. The inquiry group was composed of eight participants of whom only two were females. Although the number of women with spinal cord injury is significantly lower than the number of men with spinal cord injury within the general population of the US, the inclusion of more females may

have significantly changed the data; however, only two females volunteered for participation.

The age of the volunteers was another limitation within the study. The participants, who had a mean age of 46, only included one participant who was within the 20 year old age group. The average age of people with spinal cord injury within the USA is 31 years of age; thus, the average age did not correlate with the national averages.

The degree of spinal cord injury was another limitation within this inquiry. Each person who volunteered to participate in this inquiry was a partial spinal cord injury; thus, each participant was able to provide basic self care and walk for at least short distances. It is unknown why no one of complete spinal cord injury volunteered to participate in the study; for, advertisements were placed in rehabilitation facilities and distributed through the national spinal cord injury association.

Although every effort was made to eliminate researcher bias, it is conceivable that bias may have entered the data. The synopsis and resulting pattern profile was member checked by each participant to assure accuracy and validity; however, one cannot determine if in fact some degree of bias is present in the data.

The methodology, unitary appreciative inquiry, may be a source of limitation. The methodology, although proven in many aspects of healthcare, has not been proven with the people who have spinal cord injury. The pattern profile, which is the collective, subjective expression of the participants, is member checked by each individual within the inquiry. Derrida (1981) indicated that the reader of text is the one who creates the meaning, not the author; thus, is the meaning of the pattern profile only viable to people who have spinal cord injury? If, one takes Derrida's position, textuality, and the reader is

the one who bestows meaning to the text, might this pattern profile be non-expressive of the life pattern of people with spinal cord injury to those who read it who do not have a spinal cord injury? Does the reader, as indicated by Derrida, create the interpretation of the text? If so, one cannot account that this pattern profile is the expression of the life pattern of people with spinal cord injury, for one cannot determine what value set the reader may have. In contrast, Saussure (1983) indicated that words supply the conceptual framework for the human's analysis of reality and the linguistic framework for the description of man's interpretation; thus, the reader, whether or not they may have experienced a spinal cord injury, may be able to read the pattern profile and understand the life pattern of the people with spinal cord injury. The ability to interpret the pattern profile that expresses the life pattern of people with spinal cord injury may be a limitation within the study based on the human's ability to interpret data via the written word.

Conclusion

The unitary appreciative inquiry described the life pattern of eight people with spinal cord injury through the medium of the synopsis and the pattern profile. The synopsis of the participants expressed the three shared pattern manifestations; depersonalization, loss, and hopelessness. Through the synthesis of the individual synopsis and the final creation of the collective pattern profile, the shared pattern manifestations; depersonalization, loss, and hopelessness were determined to be primary components of the life pattern of people with spinal cord injury-despair. Once the shared pattern manifestations; depersonalization, loss, and hopelessness were discovered to be components of despair, an intense literature review was taken to determine if the concept of despair was supported by the three shared manifestations. The literature review revealed that

depersonalization, loss, and hopelessness were supportive components of the concept of despair. Once the pattern profile and the literature were completed, the researcher shared the findings with the participants in the study. The participants viewed their individual synopses for accuracy and to determine if the pattern profile was illustrative of the life pattern of people with spinal cord injury-despair. Each participant validated their synopsis and the completed pattern profile as an accurate representation of despair, which is the life pattern of people with spinal cord injury.

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Appendix A

Virginia Commonwealth University Institutional Review Board Research Approval

Letter

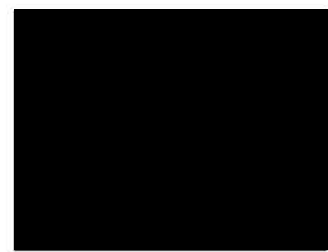
Office of Research
Office of Research Subjects
Protection

DATE: May 15, 2006

TO: Judith A. Lewis, PhD
School of Nursing
[REDACTED]

FROM: Ann Nichols-Casebolt, PhD *ANC*
Chairperson, VCU IRB Panel B
[REDACTED]

RE: **VCU IRB #: HM10216**
Title: What is the Life Pattern of People with Spinal Cord Injury.



On May 9, 2006, the following research study was approved by expedited review according to 45 CFR 46.110 Category 7. This approval reflects the revisions received in the Office of Research Subjects Protection on May 9, 2006. This approval includes the following items reviewed by this Panel:

RESEARCH APPLICATION/PROPOSAL: NONE

PROTOCOL: The Life Pattern of People with Spinal Cord Injury (received 05/09/06)

CONSENT/ASSENT:

- Research Subject Information and Consent Form (received 05/09/06, 4 pages)

ADDITIONAL DOCUMENTS:

- Flyer "Traumatic Spinal Cord Injury" (received 03/17/06)

This approval expires on April 30, 2007. Federal Regulations/VCU Policy and Procedures require continuing review prior to continuation of approval past that date. Continuing Review report forms will be mailed to you prior to the scheduled review.

This Institutional Review Board is in compliance with good clinical practices (GCP) as defined under the U.S. Food and Drug Administration (FDA) regulations and the International Conference on Harmonization (ICH) guidelines. Virginia Commonwealth University is approved by DHHS to conduct human subjects research under a Federal Wide Assurance #FWA00005287. **All correspondence related to this research study must include the IRB protocol number and the investigator's name(s) to assist us in locating your file. Please note that the CCHR number is no longer valid, if applicable.**

The Primary Reviewer assigned to your research study is Sonya Lawson, PhD. If you have any questions, please contact Dr. Lawson at [REDACTED] you may contact Dana Andrews, IRB Coordinator, VCU Office of Research Subjects Protection, at [REDACTED]

Attachment – Terms of Approval

TERMS OF APPROVAL

In order to comply with federal regulations, industry standards, and the terms of this approval, the investigator must (*as applicable*):

- 1) Conduct the research as described in and required by the approved protocol.
- 2) Obtain informed consent from all subjects without coercion or undue influence, and provide the potential subject sufficient opportunity to consider whether or not to participate (unless Waiver of Consent is specifically approved).
- 3) Document informed consent using only the most recently dated consent form bearing the VCU IRB "APPROVED" stamp (unless Waiver of Consent Documentation is specifically approved).
- 4) Provide non-English speaking subjects with a translation of the approved consent form in the subject's first language. The panel must approve the translated version.
- 5) Obtain prior approval from the VCU IRB before implementing any changes whatsoever in the approved protocol or consent form, unless such changes are necessary to protect the safety of human research subjects. Any departure from these approved documents must be reported to the VCU IRB immediately.
- 6) Adverse Event/Unanticipated Problem Reporting Timeline: Please refer to the VCU IRB Written Policies and Procedures (specifically WPP #: VIII-7) available at <http://www.research.vcu.edu/oeco/fedreg-info/vcuirbwpp.doc>
- 7) Other Reporting Timelines:
 - Report in writing to the VCU IRB within 10 days of any such changes made to protect the safety of human subjects enrolled on this study.
 - Report to the VCU IRB within 10 days the receipt of any new information that may adversely affect the safety of the subjects or the conduct of the trial.
- 8) Obtain prior approval from the VCU IRB before use of any advertisement or other material for recruitment of study subjects.
- 9) Promptly report and/or respond to all inquiries by the VCU IRB concerning the conduct of the approved research when so requested.
- 10) All protocols that administer acute medical treatment to human research subjects must have an emergency preparedness plan. For additional information, please refer to guidance on Emergency Preparedness Plans at http://www.research.vcu.edu/oeco/guidance_epp.html
- 11) The VCU IRBs operate under the regulatory authorities as described within:
 - U.S. Department of Health and Human Services Title 45, Part 46, Subparts A, B, C, and D (for all research, regardless of source of funding)
 - U.S. Food and Drug Administration Chapter 1 of Title 21 CFR 50 (for FDA regulated research only)
 - U.S. Food and Drug Administration Chapter I of Title 21 CFR 56 (for FDA regulated research only)
 - Commonwealth of Virginia Code of Virginia 32.1 Chapter 5.1 Human Research (for all research)
- 12) If you plan to involve subjects in this study at a site under the jurisdiction of an institution other than VCU or the VCU Health System, you must refer to the guidance on the Use of a Non-VCU Site/Facility in the VCU IRB Written Policies and Procedures (specifically WPP #: XVII-6) available at <http://www.research.vcu.edu/oeco/fedreg-info/vcuirbwpp.doc> . This guidance includes the requirements to: (1) request permission to do so in writing from the office of the person at that institution who has responsibility for protecting the rights and well being of human research subjects; and (2) determine that adequate resources are available at the site to conduct your study safely and effectively in full accordance with the approved protocol. You may proceed to conduct your study at the site only if that office or that person provides you with written permission to do so.

Appendix B
Research Synopsis

Title: The life pattern of people with spinal cord injury.

Investigators: Dr Judith Lewis, Professor, Virginia Commonwealth University School of Nursing, Primary Investigator (PI). Dr Lewis will provide guidance and will supervise the project as performed by the researcher/investigator, Mr. Ronald Alligood, doctoral candidate. Mr. Alligood will conduct the study as partial fulfillments of the requirement leading to the degree of PhD in Nursing. Mr. Alligood will maintain communication and report to Dr Lewis throughout the course of the investigation.

Hypothesis: The primary goal of this inquiry is to determine via a unitary pattern profile what is the life pattern of people with spinal cord injuries. The outcomes of this unitary appreciative inquiry will be inclusive of the four forms of knowledge: experiential, presentational, propositional, and practical (Cowling, 2001). Using Cowlings methodology of Unitary Appreciate Inquiry (2001), the experiential aspect will be illustrated by any participant transformations or experiences that may have occurred while participating in this study. The presentational findings will be represented through a written narrative or story that will be inclusive of symbolic imagery or patterns that are representative of the life pattern of people with spinal cord injury. The propositional outcomes will explain how the data were collected and the assertion of the data through the method of unitary appreciative inquiry. The final form of knowing, practical knowing, will give insight into any skills used or developed by the participants that enabled transformative action or participation in the inquiry (Cowling, 2001). The question, "What is the Life Pattern of People with Spinal Cord Injury", will offer insight into the life of people who live each day with a spinal cord injury. Unitary appreciative inquiry offers the researcher an opportunity to explore spinal cord injury in an environment that is participatory and non-hierarchical. The specific goals of this inquiry are to apply nursing research in an attempt to illustrate through a unitary pattern profile the experiences, perceptions, and expressions of people with spinal cord injury (Cowling, 2001).

Specific Aims: The specific aim of this inquiry is to apply nursing research in an attempt to illustrate through a unitary pattern profile the experiences, perceptions, and expressions of people with spinal cord injury (Cowling, 2001). The profile will incorporate information from each participant into a pattern profile that is expressive of the life pattern of people with spinal cord injury. Through the incorporation of the participants data, new information will be obtained and assimilated that will be expressive of the life pattern of people with spinal cord injury. The information will (1) illustrate the lives of people with spinal cord injury through the collective qualitative pattern profile; (2) add to the body of qualitative knowledge that is reflectant of the people with spinal cord injury; (3) generate knowledge that will be used by health care professionals that will offer increased understanding of the life pattern of the people with spinal cord injury.

Background and Significance: The National Spinal Cord Injury Statistic Center (NSCISC) (2003) reports that there are over 243,000 people alive today in the United States of America who are spinal cord injured and 11,000 people suffer a spinal cord injury each year. Spinal cord injury is a prominent, often debilitating injury that is prone

to affect people who are at the beginning of their life, careers, and relationships. The national spinal cord injury statistical center (NSCISC) (2003) estimates that there are 40 cases per million population in the United States or approximately 11,000 new cases each year of spinal cord injuries. The NSCISC (2003) states that there are between 721 and 906 people per million who have some form of spinal cord injury; this number equates to over 230,000 people who are alive today with some form of spinal cord injury. Spinal cord injury is predominately a young man's injury. According to the NSCISC (2003) fifty-three percent of people with spinal cord injury are between the ages of 16-30, while the average age of injury is 32.6 years; males compose 81.2 percent of people with spinal cord injury, which creates a 4:1 ratio of men to women in this category.

The National Spinal Cord Injury Statistic Center (2003) indicates that since 1990, Caucasians have composed 59.1% of the people with spinal cord injury, whereas 27.6% were African-Americans, 5.7% were Hispanics, 0.4% were Native American, 2.1% were Asian, 0.5% were unknown, and 2.5% were unclassified. Automobile accidents created 40.9% of the reported spinal cord injury cases; whereas violent crimes caused 21.6%, falls 22.8%, sports, 7.5% and other causes 7.6% (NSCISC, 2003). According to the National Spinal Cord Injury Statistic Center (2003), incomplete quadriplegia (30.8%) is the most common, while complete paraplegia (26.6%), incomplete paraplegia (19.7%), and complete quadriplegia (18.6%) complete the categories. Spinal cord injury is a phenomenon that follows ethnic lines and affects young people between the ages of 16-35 years of age.

According to the National Spinal Cord Injury Statistic Center (NSCISC) (2003) over one-half of the people (62.9%) who acquire a spinal cord injury are employed at the time of injury. Following the tenth year post injury, 31.8 % of people with paraplegia are employed whereas only 26.4% of people with quadriplegia are employed at this milestone (NSCISC, 2003). The NSCISC reports that 88.3% of all living people whom are discharged from the hospital or rehabilitation system are discharged to their pre-injury home or to another private residence. Nursing homes become the new homes to 5.1 percent of the people with spinal cord injury, and the remaining people are discharged to group homes or to hospitals for additional concerns (NSCISC, 2003).

The National Spinal Cord Injury Statistic Center (2003) indicates that the majority of the people who acquire a spinal cord injury are single (53%) when they experience a spinal cord injury and that the marriage rate remains lower for the person with spinal cord injury than the general population. The people who are married at the time of injury and marry post- spinal cord injury exhibit a slightly higher rate of separation or divorce (NSCISC, 2003).

The National Spinal Cord Injury Statistic Center (2003) points out that the days spent in the hospital immediately following injury have reduced from 25 days in 1974 to 17 days in 2001 and the downward trend is also evident in the number of days spent in the rehabilitation unit which have declined from 115 days to just 44 days. The National Spinal Cord Injury Statistic Center (NSCISC) (2003) indicates that the severity of injury greatly increases the cost of living for the person with spinal cord injury even if the person retains her/his wages and benefits. A person who is considered a high quadriplegia (C1-C4) will spend 626,588 USD during the first year of his/her injury, and an additional 112,237 USD each year thereafter (NSCISC, 2003). A person who experiences a C1-C4 injury at 25 years of age will incur a cost that is directly related to the injury of 2,393,507

- USD over her/his lifetime (NSCISC, 2003). A 25-year-old person who experiences a paraplegia injury will incur lifetime costs of over 799,721 USD directly related to the injury (NSCISC, 2003). Spinal cord injury is a debilitating injury that increases the physical and monetary burden to the people and families who undergo this neurological conundrum. Spinal cord injury is an expensive and life altering event that occurs most often in people who are at the beginning of their life and careers. Spinal Cord injury affects an increasing number of people each year. This study offers an additional window of understanding on the life pattern of the person with spinal cord injury. Through this new understanding, additional nursing knowledge will be generated that will offer increased insight into the life pattern of the person with spinal cord injury. The data assimilated from this qualitative study has the potential to enhance understanding through the voices of the people who live each day with a spinal cord injury. This new data could lead to improvements in the psychosocial health, rehabilitation and to improvements or even new techniques in nursing interventions.

Preliminary Progress/Data Report: N/A

Research Method and Design: Qualitative synopsis. The life pattern of people with spinal cord injury will be studied through the implementation of Cowling's (2001) unitary appreciative inquiry. Through Cowling's method, which is congruent with Heron's (1996) concept of cooperative inquiry, each session will be consistent with cooperative inquiry that consists of three facets. The initial facet is the methodology which is the why are we here initiation. The second facet is the collaboration and the third aspect is the emotional and interpersonal strand that creates a climate that is conducive of expressing emotions (Cowling, 2001). The unitary appreciative inquiry will be composed of 10 co-participants who will participate individually with the researcher/co-participant in two meetings of inquiry. The data will be obtained individually with each participant through open-ended interviews that focus on the life pattern of people with spinal cord injury; the discussion may include the characteristics, manifestations, evolutions, and the experiences with family, society, and healthcare workers that the person with spinal cord injury has encountered (Cowling, 2001). Following Cowling's methodology (2001), the two sessions will be organized in the following structure:

Session One: Orientation to the Unitary Appreciative Inquiry.

1. Open discussion with the participant that allows for questions, comments or concerns relating to the topic of discussion, "What is the life pattern of people with spinal cord injury".
2. The facilitator will evaluate the participant's understanding of the purpose of the sessions.
3. The major question will be posed to the participant for discussion: What do we need to know in order to understand the life pattern of people with spinal cord injury?
4. The following sub-questions will be discussed: "What are you willing to share about your experiences with spinal cord injury? What are the different kinds of

- information or mediums (photographs, graphic art, narratives, or dance) that are needed in order to fully understand the life pattern with spinal cord injury?
5. The participant will decide what they wanted to share.
 6. Through the one-on-one interviews, the participant will share personal information about the life pattern of people with spinal cord injury.
 7. The answers to the sub-questions will be discussed by the individual and will be considered for inclusion.
 8. The facilitator will summarize the content of the session.

Session Two: Synthesis, Synopsis, and the Pattern Profile Creation.

1. Each participant's transcript, which will be condensed into a synopsis from session one, will be distributed to that participant to ensure accuracy of information.
2. The appreciative pattern profile, which included the synthesis, synopsis, and representation of the knowledge generated by the summation of sessions through the vehicle of the inquiry process, will be distributed to each participant.
3. The appreciative pattern profile will be reviewed for accuracy by all the co-participants individually to ensure the knowledge generated is accurate and is as represented.
4. The researcher, at the second and final individual meeting, will discuss the feelings that the participant may experience concerning the conclusion of the project.
5. The researcher will share resources for help and support with each participant.

The objective of each meeting will be to obtain the fullest comprehension of the life pattern of people with spinal cord injury. Each individual interview will be tape recorded, transcribed, and analyzed for themes that will recount the initial session through an individual synopsis of each participant encounter (Cowling, 2001). At the conclusion of the initial tape-recorded meeting, the researcher will transcribe the individual recordings and create a summative synopsis that is inclusive of each individual inquiry as suggested by Cowling's (2001) methodology. The researcher will intently examine the synopsis for threads that are indicative of experiential, presentational, prepositional, and or practical knowledge. Once the researcher has thoroughly examined the synopsis, a unitary appreciative inquiry profile based on his interpretation through the intense reflection of the data that is explicative of unitary knowledge will be created (Cowling, 2001). Once the unitary pattern profile is completed, it will be introduced to each participant at the second and final individual meeting for participatory interpretation. The participant may reject, accept, revise, or even use it as a springboard for new profile creation (Cowling, 2001, Heron, 1996). The pattern profile will be validated through member checking; thus, each co-participant will have equal voice and may reject, or accept, the pattern profile as an accurate representation of the life pattern of people with spinal cord injury.

The expected outcome of this inquiry is to determine via a unitary pattern profile what is the life pattern of people with spinal cord injuries. The outcomes of this unitary

appreciative inquiry will be inclusive of the four forms of knowledge: experiential, presentational, propositional, and practical (Cowling, 2001). Using Cowling's methodology (2001), the experiential aspect will be illustrated by any participant transformations or experiences that may have occurred while participating in this study. The presentational findings will be represented through a written narrative or story that will be inclusive of symbolic imagery or patterns that are representative of the life pattern of people with spinal cord injury. The propositional outcomes will explain how the data was collected and the assertion of the data through the method of unitary appreciative inquiry. The final form of knowing, practical knowing, will give insight into any skills used or developed by the participants that enabled transformative action or participation in the inquiry (Cowling, 2001).

Statistical Analysis: Synopsis and synthesis will be conducted as outlined above.

Human Subjects Instruction:

Description: The participants in this inquiry will be people who have acquired a traumatic spinal cord injury and who are currently living around the greater Richmond Virginia and Raleigh-Durham North Carolina area. The participants will be recruited from spinal cord injury support groups, rehabilitation clinics, medical centers and the general population through fliers and advertisements in the newspapers. It is expected that the volunteers for the study will largely be male as the data indicates that the majority of people with SCI are male. The age range of the participants is unknown; however minors will be excluded from the study. The criteria for inclusion into this research study are: (a) traumatic spinal cord injury; (b) at least 18 years of age; (c) mentally competent; (d) consent to participate, (e) English speaking and (f) high school diploma or GED equivalent.

Research Material: The research material will be composed of the audiotapes, and transcripts of the inquiry sessions as well as the demographic information, synopsis and pattern profile. The audiotapes, transcripts as well as the demographic information will be maintained in a safe, private location secured by the doctoral candidate. All names and personal identifiers will be removed from the data. Following the conclusion of the inquiry, the tapes will be destroyed. The transcripts with the names removed will be stored for three years and then destroyed. Quotes of individuals may be used in the reporting of the data; however, under no circumstances will quotes be used that will include any identifiers.

Recruitment Plan: Ten individuals, through purposeful sampling, will be recruited through advertisements that will be distributed in spinal cord injury support groups, rehabilitation clinics, medical centers and the general population. The advertisement will list a toll-free number to call if one was interested in participation in the study. The number, attended by the researcher/doctoral candidate, will be monitored from 0800 to 2200 each day Monday through Sunday and will offer message service on off hours. Upon a call from a potential contributor, the researcher/doctoral candidate will explain that the qualitative unitary appreciative inquiry study, what is the life pattern of people with spinal cord injury, is designed to be an individual study that would not involve interaction with anyone other than the researcher. The potential participant will be instructed that the unitary appreciative inquiry study will involve a commitment of at least 2 one-hour sessions over a period of no more than 12 weeks. Once an individual

voices interest in participating in the study, the researcher will assess the individual's qualifications for entry into the study as outlined in the eligibility to participate. Once the inclusion criterion is met, a face-to-face meeting will be scheduled at a mutually convenient time and location with the participant and the researcher/doctoral candidate to explain the study in detail as well as the potential risks that could befall the person upon, during, or after participation in the study. Once the researcher/doctoral candidate has determined that the eligibility requirements have been met, the willing participant who expresses an understanding of the inquiry process as well as the potential risks associated with the study will be deemed suitable for participation in the study and the informed consent will be obtained from the participant and witnessed by the researcher/doctoral candidate.

Potential Risks: The participants will be instructed that mental discomfort, agitation, and, or the breach of confidentiality are the potential risks that are associated with this study.

Risk/Benefit: The participants are encouraged to contact the investigator if any ill effects or bad feelings befall the participants during the study. The participants will be given a direct link to the investigator via pager and cellular phone that can be accessed at any time in the event of distress. The co-investigator, Mr. Alligood is a registered nurse with acute care nurse practitioner board certification and over 12 years of nursing experience. Mr. Alligood is trained to recognize emotional distress and he will stop the interview and provided nursing intervention as appropriate. Mr. Alligood will maintain and distribute a list of resources that includes mental health, emergency services (EMS), and transportation services that can be utilized by the participant in the event of anxiety or mental distress. The participants will be advised to proceed to the nearest emergency department if any mental discomfort, physical distress or difficult feelings develop. As there was no data available concerning the life pattern of people with spinal cord injury at the time of literature review, a general benefit of this inquiry is an addition to the body of qualitative knowledge concerning the life pattern of people with spinal cord injury.

Compensation Plan: N/A

Consent Issues: An information packet containing the informed consent, a general demographics form and a copy of the invitational flyer which offers information about the inquiry and the contact number of the investigator will be given to the interested individuals with spinal cord injury. The potential subjects will have one week to decide if they would like to participate in the inquiry. The potential subjects will be urged to contact the investigator if they require additional information.

Comprehension: The consent form is written at a 6th grade reading level. The participants are encouraged to obtain any information which they feel is needed in order to make an informed decision to participate.

Special Consent Provisions: N/A

Assent for Children: No children or persons under 18 years of age will be included in this study.

Waiver of Consent: The VCU consent template will be utilized.

Appendix C
Recruitment Advertisement

Traumatic Spinal Cord Injury

People who have undergone a traumatic spinal cord injury are needed to be participants in a study that focuses on life after spinal cord injury. The research will be gathered in two confidential and individual meetings over a 12-week period. Compensation either monetary or material will not be provided.

The Inquiry:

To join this study, the participant must:

- ✓ Have a history of traumatic spinal cord injury.
- ✓ Be 18 years of age or older.
- ✓ Be English speaking.
- ✓ Be a high school graduate or GED equivalent.

➤ If you are interested in learning more or how you can participate in this research project, Please contact:



APPROVED



Appendix D
Informed Consent

RESEARCH SUBJECT INFORMATION AND CONSENT FORM

TITLE: What is the Life Pattern of People with Spinal Cord Injury

VCU IRB NO. HM10216

This consent form may contain words that you do not understand. Please ask the study staff to explain any words that you do not clearly understand. You may take home an unsigned copy of this consent form to think about or discuss with family or friends before making your decision. The person who is explaining this research study to you is a doctoral candidate at Virginia Commonwealth University School of Nursing.

PURPOSE OF THE STUDY

The purpose of this research study is to learn about the daily experience of living with a traumatic spinal cord injury.

You are being asked to participate in this study because you have a traumatic spinal cord injury and you have stated interest in participating in the research.

DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT

If you decide to be in this research study, you will be asked to sign this consent form after you have had all your questions answered and understand what will happen to you.

In this study you will be asked to participate one-on-one with the researcher in two separate meetings over a 12-week period. Each one-hour meeting will be tape-recorded so that no information will be lost. In the first meeting, you will be asked open-ended questions that focus on your life after spinal cord injury. Examples of the questions are: What do you want to share about your experience with spinal cord injury? What are the different kinds of information or mediums (photographs, graphic art, or story) that are needed in order to fully understand your experience with spinal cord injury? The discussion may include your experiences that you have had with family, society, and healthcare workers.

In the second meeting, a synopsis or report of the first meeting will be shared with you to determine if it is an accurate representation of our first meeting. Following the discussion of the synopsis or report, a pattern profile, which may be a story, photograph or graphic art that expresses your experience of living with a traumatic spinal cord injury, will be shared with you to evaluate for accuracy. Following the discussion of the pattern profile, any thoughts, feelings or concerns about the research will be discussed if applicable.

RISKS AND DISCOMFORTS

The questions in this research study will ask about the life experiences that you have had since your spinal cord injury. Sometimes talking about these subjects causes people to experience emotional distress or anxiety. A contact list of resources will be available to help with emotional distress that includes names and numbers of emergency and mental health facilities as well as contact information for the ambulance (emergency medical services) and additional transportation resources. You do not have to talk about any subjects you do not want to talk about, and you may leave the study at any time. The study staff will give you names of counselors to contact so you can get help in dealing with these issues.

BENEFITS

There are no direct benefits associated with this study. You may not get any direct benefit from this study, but the information we learn from people in this study may help us design better programs for people with spinal cord injury.

COSTS

There are no costs for participating in this study other than the time you will spend in the study participating and filling out questionnaires.

PAYMENT FOR PARTICIPATION

There is no payment for participation in this study.

ALTERNATIVES

This is not a treatment study and the alternative is to not participate in the study.

CONFIDENTIALITY

We will not tell anyone the answers you give us; however, information from the study and the consent form signed by you may be looked at or copied for research or legal purposes by Virginia Commonwealth University. Personal information about you might be shared with or copied by authorized officials of the Federal Food and Drug Administration, or the Department of Health and Human Services (if applicable). What we find from this study may be presented at meetings or published in papers, but your name will not ever be used in these presentations or papers.

We will not tell anyone the answers you give us. But, if you tell us that someone is hurting or injuring you or that you might hurt yourself or someone else, the law says that we have to let people in authority know so that know one will be injured.

The sessions will be audio taped, but no names will be recorded. At the beginning of the session, all members will be asked to use initials only so that no names are recorded. The tapes and the notes will be stored in a locked cabinet. After the information from the tapes is typed up, the tapes will be destroyed.

IF AN INJURY HAPPENS

Virginia Commonwealth University and the VCU Health System (also known as MCV Hospital) do not have a plan to give long-term care or money if you are injured because you are in the study.

If you are injured because of being in this study, tell the study staff right away. The study staff will arrange for someone to care for you if needed.

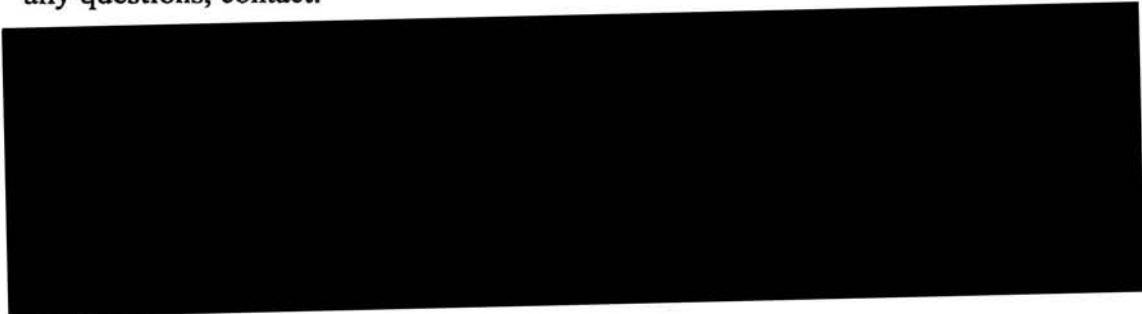
Bills for treatment may be sent to you or your insurance. Your insurance may or may not pay for taking care of injuries that happen because of being in this study.

VOLUNTARY PARTICIPATION AND WITHDRAWAL

You do not have to participate in this study. If you choose to participate, you may stop at any time without any penalty. You may also choose not to answer particular questions that are asked in the study.

QUESTIONS

In the future, you may have questions about your participation in this study. If you have any questions, contact:



If you have any questions about your rights as a participant in this study, you may contact:

Office for Research Subjects Protection
Virginia Commonwealth University



CONSENT

I have been given the chance to read this consent form. I understand the information about this study. Questions that I wanted to ask about the study have been answered. My signature says that I am willing to participate in this study.

Participant name printed Participant signature Date

Name of Legally Authorized Representative ¹
(Printed)

Legally Authorized Representative Signature Date

Name of Person Conducting Informed Consent
Discussion / Witness ²
(Printed)

Signature of Person Conducting Informed Consent Date
Discussion / Witness

Investigator signature (if different from above) Date ³

Appendix E

Demographic/Information Sheet

The Life Pattern of People with Spinal Cord Injury
Demographic Information:

1. Name:
2. Age:
3. Level of spinal cord injury:
4. Age at onset of injury:
5. Year of onset of injury:
6. Years since onset of injury:
7. What caused your injury? (example, sports injury, car accident, etc.)
8. Have you precipitated in a rehabilitation program?
9. Race:
10. What is your highest level of education?
11. Marital Status:
 - a. If divorced or separated, Please list year of divorce or separation.
12. Do you live in a city, suburb or rural area?
13. Do you feel you have sufficient public resources?
14. Do you feel you have sufficient private resources?

Vita

