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Discovering the Culture Care Meanings and Care Expressions of Men with a Spinal Cord Injury from the Appalachian Region of West Virginia: An Ethnonursing Study

Helen Susan Berry Imes

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DISCOVERING THE CULTURE CARE MEANINGS AND CARE EXPRESSIONS OF MEN
WITH A SPINAL CORD INJURY FROM THE APPALACHIAN REGION OF WEST
VIRGINIA: AN ETHNONURSING STUDY

A Dissertation

Submitted to the School of Nursing

Duquesne University

In partial fulfillment of the requirements for
the degree of Doctor of Philosophy

By

Helen Susan Berry Imes

December 2013

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ABSTRACT

DISCOVERING THE CULTURE CARE MEANINGS AND CARE EXPRESSIONS OF MEN WITH A SPINAL CORD INJURY FROM THE APPALCHIAN REGION OF WEST VIRGINIA: AN ETHNONURSING STUDY

By

Helen Susan Berry Imes

December 2013

Dissertation supervised by Dr. Rick Zoucha

The purpose of this ethnonursing study was to discover and describe the culture care meanings and care expressions of men with a spinal cord injury from the Appalachian region of West Virginia. Spinal cord injury is a sudden, traumatic, and life altering event. The impact of this type of injury on the person and their family is devastating. The literature review revealed studies primarily focused on quality of life and life satisfaction. The nature of the phenomena required an open discovery method and the researcher selected the ethnonursing qualitative research method. The guiding framework, research method, and plan for data analysis were developed by Leininger (1991). The setting for the study was the Appalachian region of West Virginia. Approval from the Institutional Review Board was received and data collection commenced. The Four Phases of Qualitative Data Analysis developed by Leininger (1991) provided the plan and method for data management and data analysis. Recruitment was accomplished using the snowball method, was successful due to the promotion from informants

participating in the study, and the researcher's continued presence at the monthly SCI support group meetings. Data collection and data analysis were conducted concurrently. Entry in to the field was accomplished via an established spinal cord injury support group in a large city in West Virginia. Twenty-three informants participated in the study: eighteen general informants and five key informants. Procedures to ensure the anonymity and confidentiality of the informants were developed and strictly adhered to during the course of the study. The informants chose the physical location for the interviews to be conducted. Informed consent was obtained and a pseudonym was chosen for use during the interview. A semi-structured interview guide based on the guiding framework of the study was used to facilitate the interview process. Interviews were digitally recorded and transcribed verbatim. Ethnodemographics were collected to describe the informants. Field notes and reflections from the etic view were documented for use by the researcher in the data collection and data analysis process. When saturation was evident from rigorous analysis of the data, thirteen categories were revealed during the second phase of analysis. Five patterns were derived during the third phase of analysis and in the fourth phase, the highest level of data analysis, three themes were abstracted. The categories, patterns, and themes were discussed with key informants to verify their emic view was reported accurately and to enhance the credibility and reliability of the findings. The themes were conceptualized pictorially to depict the essence of the findings of the study. The themes abstracted from the data were: 1. Caring and concern for family, friends, neighbors, and place combined with being inspired by other men with a SCI to promote a sense of belonging; 2. Belief in God, holding onto hope and keeping a positive attitude helps men remain focused on what they can do and not dwell on what they can't do; and 3. A spirit of independence, hard work, changing the environment, and believing you can figure things out are essential for getting back to living.

Consistent with the literature, the informants did not identify themselves as Appalachian when asked about culture. A worldview of realism was validated by the informants. The informants exhibited a positive attitude, shared an optimistic narrative, and demonstrated a belief in God, faith, and hope with the realities of life and living with a spinal cord injury.

DEDICATION

This dissertation is dedicated to the men who participated in this research study. Twenty-three courageous, kind-hearted, independent, caring, “good” men entrusted me with their stories. The irony is I was expecting men to talk to me and share feelings when what I learned from the study was talking and sharing feelings is the LAST thing men want to do or will do! I hope to stay active with the SCI support group and the Challenged Sports Program. I have more to learn. A journey (with stops and starts) discovering where I feel at home: in Almost heaven, West Virginia. Who knows, I may even try deer jerky one day....maybe....

ACKNOWLEDGEMENT

I would like to thank the members of my dissertation committee: Dr. Rick Zoucha for agreeing to be my advisor and chair of my dissertation committee. I thank Dr. Lynn Simko and Dr. Chris Green for sharing their knowledge and expertise as members of my committee. Your willingness to invest your time and energy with a novice researcher says much about your character.

Thank you to my family at Marshall University for without your kindness and support I would not be completing my degree. I am grateful to my family and friends for their love and support during my journey. To my husband Tim, you are my heart and together we have endured much but have been equally blessed. To T. N. you were the first person I worked with who truly “saw me” and encouraged me to have faith in myself.

I was very fortunate to meet Dr. Leininger and Dr. Zoucha at the Transcultural Nursing Conference in the fall of 2001. Their passion and conviction about culture and transcultural nursing convinced me to jump on board the culture train, destination to be determined. I packed my bags and bought a ticket. Only a seasoned conductor, like Dr. Rick Zoucha, could keep the train on the tracks and ensure the passengers arrived at their final destination. Sorry Cohort six, I am afraid I was the caboose of our train!

In conclusion, it is true God sends us angels when we need them most. Thank you to the angels who have surrounded us the past four years. To P. H. for always telling me how fabulous I am and supporting my dreams. Finally, to my fur baby Pandora Hope Imes who chose me to be her mommy. I enjoy saying Hope lives with me.

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CHAPTER 1

1.1 Introduction and Background

With the advent and acknowledgement of transcultural nursing, greater emphasis on meeting the diverse and complex cultural needs of society is possible. A process known to facilitate the discovery of these unique and complex cultural needs is through the use of the qualitative ethnonursing research method. The ethnonursing research method assists the researcher in the “discovery of new insights or the reaffirmation of knowledge about many life situations related to keeping people well or to relieving human suffering, illness, or other unfavorable conditions...”(Leininger, 1998; Leininger & McFarland, 2002, p. 71). Of interest to the researcher is the life situation of men with a spinal cord injury (SCI) within the cultural context of the Appalachian region of West Virginia.

Understanding the cultural context of an individual, family, and community requires an acceptance of *knowing* the culture as an expectation of care. So what is culture and why is it important? Leininger (1991) defines *culture* as “...the learned, shared, and transmitted values, beliefs, norms, and lifeways of a particular group that guides their thinking, decisions, and actions in patterned ways” (p. 47). Whereas the construct of *culture care* “refers to the subjectively and objectively learned and transmitted values, beliefs, and patterned lifeways that assist, support, and facilitate, or enable another individual or group to maintain their well-being, health, to improve their human condition and lifeway, or to deal with illness, handicaps, or death” (Leininger, 1991, p. 47). Understanding culture and culture care is required to facilitate the provision of the ideal nursing care known as *cultural congruent (nursing) care*. *Cultural congruent (nursing) care* “refers to those cognitively based assistive, supportive, facilitative, or enabling acts or decisions that are tailor made to fit with individual, group, or institutional

cultural values, beliefs, and lifeways in order to provide or support meaningful, beneficial, and satisfying health care, or well-being services” (Leininger, 1991, p. 49). The provision of cultural congruent (nursing) care for men with a SCI from the Appalachian region of West Virginia is necessary to mitigate the impact of a SCI and to provide care that is meaningful and beneficial.

A SCI is a traumatic, sudden, and life altering event for the person as well as their family and community. The National Spinal Cord Injury Database has been collecting data since 1973. The estimated number of persons living in 2013 with a SCI is between 238,000 to 332,000, averaging 273,000, with an average age of 40.6 years and where 80.7 % are male. The data base reflects national level data (Spinal Cord Injury Information Network, 2013). Despite a review for state level SCI data, the researcher was unable to locate data for individual states.

In the United States, there is an average of 12,000 new cases of SCI per year. One new case of paraplegia has an initial estimated monetary cost of \$508,904 with subsequent yearly costs of \$67, 415 for ongoing basic care (Spinal Cord Injury Information Network, 2013). The “initial determination of the degree and level of injury is the cornerstone of clinical management for acute spinal cord injuries” (Mitcho & Yanko, 1999, p. 61). The physical exam includes differentiating between a *complete* and an *incomplete* injury. A *complete* designation means no evidence of residual neurological function is present below the level of injury whereas an *incomplete* designation means sensory or motor function is present below the level of injury. The grading scale known as the American Spinal Injury Association Impairment Scale (AISIA) is the standardized process of classifying patients based on the degree of motor and sensory preservation. It ranks the injuries from A to E where A is a *complete* injury (the most severe) and E is normal (recovery of normal motor and sensory function) (Mitcho & Yanko, 1999). The

terms paraplegia and tetraplegia assist in the differentiation of the level of spinal cord injury. Paraplegia refers to lesions in the thoracic, lumbar, and sacral segments (T2-S4) and tetraplegia once termed quadriplegia refers to injury to one of the eight cervical segments and the first thoracic segment (C1-T1) (Senelick, 1998). The vertebrae most frequently involved in a SCI are the fifth, sixth, and seventh cervical vertebrae; the twelfth thoracic vertebrae and the first lumbar vertebrae. The range of motion in these areas is greater which makes these areas more vulnerable to injury (Smeltzer, Bare, Hinkle, & Cheever, 2010).

Specific physiological systems effected by a SCI are neurological, cardiovascular, pulmonary, genitourinary, gastrointestinal, musculoskeletal, and the integument. In addition, psychosocial issues and pain management are a concern. An optimal outcome post SCI is dependent on immediate and comprehensive care in the acute care phase. The literature supports the delivery of high dosages of steroids in the first hours post SCI. The window for steroid delivery is within four to six hours of injury (Smeltzer et al., 2010). In the acute care phase of treatment, stabilization of the vertebral column is necessary to prevent further injury to the spinal cord and to provide optimal care and conditions for neurological recovery (Mitcho & Yanko, 1999; Smeltzer et al., 2010). Stabilization implies either non-surgical or surgical interventions. Examples of non-surgical processes are the halo vest and skeletal traction. Candidates for surgical stabilization are patients who are worsening neurologically, those who have intra-spinal compression, or those with a correctable problem (Senelick, 1998; Mitcho & Yanko, 1999).

Once stabilization of the injury has been achieved (surgical or non-surgical) and the patient is deemed clinically stable the next phase is rehabilitation. The rehabilitation program may be offered in a freestanding institution or located within a medical facility. The process of rehabilitation is traditionally based on the medical model. Treatment is based on “professional

perceptions of need related to the causes and pathologies of disease or injury” (Kendall, Ungerer, & Dorsett, 2003, p. 1009). According to Senelick (1998),

Rehabilitation is all about helping you help yourself to make profound changes, to explore new avenues of thinking, behaving, and doing things to achieve the independence that is within your reach. Rather than a cure, it is a process designed to restore your life. (pp. 26-27)

Kendall et al., (2003) explains “to assist the individual to gain greater independence and functional skills for use in activities of daily living, the very nature of hospitals may negatively impact on the ability to achieve this goal” (p. 1009). Within the rehabilitation setting a movement toward or a reaffirmation of patient centered or patient focused care has begun. A philosophical shift from the medical model to a patient focused model where function is the focus not the disease or injury. Including the patient (consumer) in identifying their needs and empowering them to see these needs are met is an integral goal of this new model (Gage, 1995; Poulton, 1999; Sumsion & Smyth, 2000). According to Gage (1995),

There is a growing expectation that clients will be treated as individuals and that their individual experience of their condition will be understood. There is a growing demand that health care services meet the needs of health care clients as defined by the health care client. (p. 199)

The paradigm shift presented by Gage (1995) will not be actualized without recognizing the power of culture. One should never underestimate the power of a patient’s culture (Imes & Landry, 2002). According to Leininger and McFarland (2002) “culture is a very powerful and comprehensive construct that influences and shapes the way people know their world, live and develop patterns to make decisions relative to their lifeworld” (p. 9).

As stated earlier, the provision of cultural congruent (nursing) care for men with a SCI is imperative to mitigate the impact of a SCI and to provide care that is meaningful and beneficial. Negative outcomes of a SCI documented in the literature are suicide, depression, alcohol and drug abuse, septicemia, pulmonary embolism, urinary tract infections, pressure sores, pain, social isolation, divorce, unemployment, barriers to care, and fragmented care (Craig & Hancock, 1998; Mitcho & Yanko, 1999; Wood-Dauphine, Exner, & SCI Consensus Group, 2002; Fries, 2005). Realizing there are *known* negative outcomes/issues following a SCI, a nurse should want to and choose to provide cultural congruent (nursing) care to transform the response to and the impact of complications for patients with a SCI.

In West Virginia there are known and accepted existing barriers effecting access to health care. Eliminating or minimizing these barriers is crucial to improving the quality of life of individuals with disabilities (A Healthier Future for West Virginia – Healthy People 2010). These barriers, identified through surveys, are physical, informational, adequate transportation, lack of access to assistive technologies, and limiting governmental policies. Physical barriers may impede working, impede participating in recreational activities, pursuing educational opportunities, and participating in their community. Transportation barriers may impede access to health care and further social interaction while informational barriers may impede the ability to care for self. The lack of funds and other governmental policies may limit or impede health care opportunities and social support. Finally, a lack of recreational and leisure opportunities for individuals with disabilities reduces their potential to become active in their community and impairs their ability to relieve stress (A Healthier Future for West Virginia – Healthy People 2010).

For individuals who live in West Virginia where barriers are known to further impede their health and well-being (A Healthier Future for West Virginia – Healthy People 2010) calls for research focused on cultural congruent nursing care. By treating everyone the same, nurses lose the individualization necessary to promote and provide meaningful and quality care. Consider the patient who has sustained a SCI; nurses need to *know*, value, and understand the patients' beliefs and values within their cultural context. Recognizing cultural barriers to be addressed or mitigated ensures the patient has a solid foundation to care for and to advocate for themselves across their lifespan. Unfortunately, a lack of research conducted on discovering the culture care meanings and care expressions of men with a SCI from the Appalachian region of West Virginia may be construed as one more barrier impeding the provision of meaningful and beneficial nursing care.

1.2 Purpose

The purpose of this study is to discover and describe the culture care meanings and care expressions of men with a SCI from the Appalachian region of West Virginia. This study proposes that care meanings and care expressions of men with a SCI from the Appalachian region of West Virginia are influenced by shared cultural values, beliefs, and practices. Findings from this study will facilitate an understanding of the culture care needs and cultural barriers of men with a SCI. The goal of the study is to promote and advocate for an environment where a client's culture is recognized, considered, and valued so their personal conceptualization and context of what health and illness means may be integrated into the process of care across the lifespan. Understanding the cultural values and beliefs about health, illness, and care in the context of the person's culture may promote cultural competent nursing care with satisfying outcomes.

1.3 Domain of Inquiry

Leininger and McFarland (2002a) define the *domain of inquiry* as “a succinct tailor-made statement focused directly and specifically on culture care and health phenomenon” (p.92). The domain of inquiry (DOI) for this transcultural ethnonursing study is to discover and describe the culture care meanings and care expressions of men with a SCI from the Appalachian region of West Virginia.

1.4 Specific Aims

The specific aims for this study are:

1. To discover and describe the culture care meanings and care expressions of men with a SCI from the Appalachian region of West Virginia.
2. To discover and describe the generic (folk) practices and professional practices that influence care of men with a SCI from the Appalachian region of West Virginia.
3. To discover and describe how men with a SCI from the Appalachian region of West Virginia describe the role of the nurse in promoting nursing care within their cultural context.

1.5 Research Questions

The research questions for this study are:

1. What are the culture care meanings and care expressions of men with a SCI from the Appalachian region of West Virginia?
2. What are the generic (folk) and professional practices that influence the care of men with a SCI from the Appalachian region of West Virginia?

3. How do men with a SCI from the Appalachian region of West Virginia describe the role of the nurse in promoting nursing care within their cultural context?

1.6 Orientational Definitions

To better understand the theoretical context of the study, the following orientational definitions are shared:

1. *Culture* “refers to the learned, shared, and transmitted values, beliefs, norms, and lifeways of *men with a SCI from the Appalachian region of West Virginia* that guides their thinking, decisions, and actions in patterned ways” (derived from Leininger, 1991, p. 47).
2. *Care* “refers to abstract and concrete phenomena related to assisting, supporting, or enabling experiences or behaviors toward or for others with evident or anticipated needs to ameliorate or improve a human condition or lifeway” (Leininger, 1991, p. 46).
3. *Culture care* “refers to the subjectively and objectively learned and transmitted values, beliefs, and patterned lifeways that assist, support, and facilitate, or enable *men with a SCI from the Appalachian region of West Virginia* to maintain their well-being, health, to improve their human condition and lifeway, or to deal with illness, handicaps, or death” (derived from Leininger, 1991, p. 47).
4. *Cultural congruent (nursing) care* “refers to those cognitively based assistive, supportive, facilitative, or enabling acts or decisions that are tailor made to fit with cultural values, beliefs, and lifeway’s of *men with a SCI from the Appalachian region of West Virginia* in order to provide or support meaningful, beneficial, and satisfying health care, or well-being services” (derived from Leininger 1991, p. 49).

5. *Generic (folk) practices* refer to knowledge and skill learned through the family system to assist, support, enable, or facilitate acts toward or for *men with a SCI from the Appalachian region of West Virginia* to improve their health condition (Leininger, 1991).

6. *Professional practices* (nursing) refer to knowledge and skills that are formally taught, learned, and transmitted within professional institutions (Leininger, 1991).

1.7 Assumptions

The assumptions concerning this study are:

- a. The informants in this study will be willing participants and will offer truthful information.
- b. Men who sustain a SCI will describe the event within their cultural and environmental context.
- c. Cultural congruent (nursing) care may improve the health and well-being of men with SCI across their lifespan.
- d. *Knowing* the culture care meanings and care expressions of men with a SCI may facilitate nursing knowledge and promote understanding.
- e. The culture care meanings and care expressions of human care become clear when viewed within the cultural context.

1.8 Significance to Nursing

The study's significance to nursing is to discover and describe the role of culture and its impact and influence on men with a SCI from the Appalachian region of West Virginia.

Thompson (1990) noted a rehabilitation facility did not ask about an individuals' culture during the initial intake process. The individuals were expected to *conform* to be considered successful in the rehabilitation program. The process of "not participating in the program; or trying

activities, taking risks or chances as part of their own self-testing” (Thompson, 1990, p.191) was labeled *diversity*. Finally, Thompson (1990) concluded “diversity of expectations and actions by patients was often mentioned by rehabilitation staff as an explanation for patient’s failure in achieving the goals of rehabilitation” (p. 191).

Since 1990 medical facilities have been evolving in their understanding of the importance of culture. The Joint Commission on Accreditation of Healthcare Agencies (2009) emphasized the need to assess and respect a person’s culture. Specifically, Standard RI.01.01.01, Elements of Performance, number six, states “the hospital respects the patient’s cultural and personal values, beliefs, and preferences”, (p. 324). In reviewing the Hospital Accreditation standards it is evident respecting culture is a woven thread in the standards (JCAHO, 2009). The researcher is interested to discover how *respect* is interpreted, actualized, and measured within medical facilities.

In identifying the culture care needs of men following a SCI within a cultural context the literature revealed no such studies. However, within a cultural context of a rehabilitation setting, the study by Thompson (1990) was identified. She addressed the inpatient rehabilitation nursing process using Leininger’s theory as a framework for the study. To date, the majority of the literature and research related to SCI has focused on quality of life measurements, measuring satisfaction post SCI, and investigating medically oriented outcomes following the rehabilitation phase of care. The researcher hypothesizes, men with a SCI from the Appalachian region of West Virginia who have their cultural context *known*, valued, and integrated will experience fewer and less impactful negative outcomes post SCI across their lifespan.

1.9 Summary

The focus of the study is men with a SCI from the Appalachian region of West Virginia.

The goal of the research study is to discover and describe the culture care meanings and care expressions of men with a SCI from the Appalachian region of West Virginia. Understanding and *knowing* the culture care meanings and care expressions of men with a SCI from the Appalachian region of West Virginia may promote the provision of cultural congruent nursing care thereby lessening the incidence of negative outcomes post SCI across their lifespan.

CHAPTER 2

2.1 Introduction

Discovering the culture care meanings and care expressions of men with a SCI from the Appalachian region of West Virginia requires a deeper appreciation of how Appalachian culture influences men during their recovery, post injury, and across their lifespan. In this chapter, an ethnohistory of Appalachia is presented and organized using the *rays* of Leininger's Sunrise enabler (Leininger, 1991); next, Leininger's (1991) Theory of Culture Care Diversity and Universality as the guiding framework for the study is discussed; and lastly a synthesis of the literature related to the domain of inquiry with emphasis on SCI quality of life/life satisfaction and research on the health beliefs and values of the Appalachian culture is shared.

2.2 Ethnohistory of Appalachia

According to Leininger (1991), " Ethnohistory refers to those past facts, events, instances, experiences of individuals, groups, cultures, and institutions that are primarily people-centered (ethno) and which describe, explain, and interpret human lifeways within particular cultural context and over short or long periods of time" (p. 48). In this section of the dissertation, the researcher is presenting an ethnohistory of the setting for this study, the Appalachian region of West Virginia. The information contained in the ethnohistory is organized and presented using the framework of the *rays* of Leininger's Sunrise enabler: Religious and Philosophical Factors, Kinship and Social Factors, Educational Factors, Cultural Values and Lifeways, Political and Legal Factors, Economic Factors, and Technological Factors (Leininger, 1991; Leininger & McFarland, 2002). The ethnohistory is not an exhaustive representation of Appalachian West Virginia but provides a contextual snapshot of the culture and its' people. To learn more about Appalachia, visiting the website of the Appalachian

Regional Commission (www.arc.gov) is an excellent starting point. Another excellent resource is the Loyal Jones Appalachian Center at Berea College in Berea, Kentucky. Mr. Jones is recognized for his knowledge and understanding of Appalachia and is known a “Mr. Appalachia”.

The specific boundaries of the Appalachian region have swayed and changed based on the time period and the particular authors. However, the Appalachian Regional Commission (ARC) was established by an act of Congress in 1964 and they define Appalachia by continuity of socioeconomic factors such as poverty, deficits in education, and poorer living conditions (Appalachian Regional Commission, 2013).

In 2013, the Appalachian region spans 200,000 square miles across 410 counties and through 13 states. The federal designation is roughly congruent with the Appalachian mountains from New York to Mississippi, including counties in Kentucky, Alabama, Georgia, Maryland, Mississippi, New York, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, Virginia, and West Virginia (Appalachian Regional Commission, 2013).

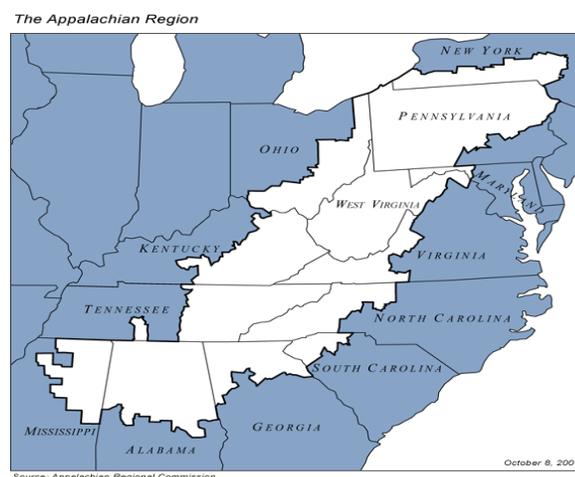


Figure 1: ARC Boundaries

ARC is a unique partnership between the federal government and the governors of the 13 states represented by the Appalachian federal designation. To stimulate economic development, every year Congress allocates funds to the ARC for distribution to the federally defined areas. Various projects may receive funding from ARC including; highway system, education, health care, water and sewer systems and others deemed appropriate (Appalachian Regional Commission, 2013).

West Virginia (WV) is the only state in the ARC region where every county has been designated as Appalachian; WV is also considered the most rural with fewer than 10% of WV towns having populations greater than 2,500 people (Rosswurm, Dent, Armstrong-Persily, Woodburn, & Davis, 1998; Huttlinger & Purnell, 2008; Small, 2013). Generally speaking, the challenges faced in the rest of Appalachia are amplified in West Virginia, largely because of its rural mountainous nature.

Even though the region is nationally recognized, most people from the area when asked about culture will not identify themselves as being Appalachian (Small, 2013). Perhaps this is due to the breadth of cultures over the region as a whole as well as being caused by many Appalachians' close identification with their locality. Nevertheless, some generalities can be made about central Appalachia, a region including southwestern Virginia, eastern Kentucky, north eastern Tennessee, and most of West Virginia (Obermiller & Maloney, 2002).

Historically, the primary groups who settled the central Appalachian Mountains can trace their roots to German, Scotch-Irish, Welsh, French, Italian, African American, or British origins as peoples from those lands migrated into the region from the colonial era through the early 20th century setting the tone for the culture, in the colonial and early federalist era. The people who migrated to the area were seeking religious freedoms, to claim land for themselves and their

families, and for control over their personal choices (Huttlinger & Purnell, 2008; Appalachian Regional Commission, 2013; Small, 2013).

Much of Appalachia is characterized by the topography of the mountains and valleys which resulted in relatively restricted access and exchange with other parts of the nation. However, this isolation has facilitated a feeling of community for the rural areas, especially those more remote from urban areas. WV the landlocked and mountainous state in Appalachia is relatively isolated; the Ohio and Potomac rivers form part of the state's boundaries. Nearly every corner of the state is mountainous thus developing a climate similar to that of the New England states (Huttlinger & Purnell, 2008; Appalachian Regional Commission, 2013; Small, 2013). Within this geographic and political framework, the researcher will now use the *rays* of Leininger's Sunrise enabler (1991), listed earlier in this chapter, to guide the presentation of central Appalachian cultural dimensions.

Religious and Philosophical Factors

According to Loyal Jones (1994), one of the nations' most respected authorities on Appalachian culture, "What such outside observers fail to see is that our religion has helped to sustain us and has made life meaningful in grim situations" (p. 46). The traditional Appalachian worldview is "being" oriented-meaning living for today in contrast with a worldview of "doing" orientation where one makes plans for tomorrow. This fatalistic worldview implies one has no control over their destiny and makes preventive care, health promotion activities, and illness prevention difficult (Huttlinger & Purnell, 2008).

Jones (1994) also explains, "Mountain people are religious. This does not mean we go to church regularly, but we are religious in a sense that most of our values and meaning we find in life spring from the Bible" (p. 39). Furthermore, "life in the mountains until recently did not

allow for an optimistic gospel. Hard work did not always bring a sure reward, and so perhaps some of the mountain religion is more fatalistic than elsewhere” (Jones, 1994, p. 46.) Notably, “the beliefs are more realistic than idealistic...” (Jones, 1994, p. 46). For additional reading on religion in Appalachia:

Jones, L. (1999). *Faith and Meaning in the Southern Uplands*. Chicago, IL: University of Illinois Press.

McCauley, D. (1995). *Appalachian Mountain Religion: A History*. Chicago, IL: University of Illinois Press.

Kinship and Social Factors

The value of familism is deep in the Appalachian culture (Tripp-Reimer, 1980; Small, 2013). Familism “emphasizes interdependence over independence, affiliation over confrontation, and cooperation over competition” (Andrews & Boyle, 2012, p. 26). Jones (1994) affirms this understanding, “Appalachian people are family-centered. Mountain people usually feel an obligation to family members and are more truly themselves when within the family circle” (p. 75). Individuals from Appalachia are family focused and assume personal responsibility for nuclear and extended family members. Both nuclear and extended family members may assist with decisions on personal issues such as employment, living arrangements, church, health care practices, and health care decisions (Huttlinger & Purnell, 2008; Small, 2013).

Family members feel responsible for each other’s problems and therefore participate in problem solving. It is not unusual to discover members of the extended family or two families residing in one home. In general, elderly family members are respected and considered an asset to the group. Elderly parents may live with children and/or the children will live in close

proximity to their parents. Appalachian families tend to be patriarchal and the typical roles are for the men to work and provide the financial resources and for the women to care for the home and have children (Huttlinger & Purnell, 2008; Small, 2013).

However, a cultural shift is happening where women are working more outside the home and decisions are made as a unit or at least with consultation and discussion (Huttlinger & Purnell, 2008). Women in central Appalachia have lower employment rates and earn less than women elsewhere in Appalachia (Appalachian Regional Commission, 2013). Children are valued in Appalachian society and seen as securing the future. Even though the father tends to make the general decisions for the family, the women, especially grandmothers, tend to make decisions regarding health promoting activities and when to seek healthcare (Huttlinger & Purnell, 2008; Small, 2013).

Interestingly, because of their familism, members of the Appalachian culture may prefer and expect a closer relationship with health care providers. Notably, a healthcare provider may be evaluated and praised for their interpersonal skills rather than professional competencies (Huttlinger & Purnell, 2008; Andrews & Boyle, 2012; Small, 2013). In essence, the nurse must care for the family, rather than the individual. The family and their collective needs must be the focus of nursing care (Huttlinger & Purnell, 2008).

Educational Factors

When the Appalachian region welcomed the original immigrants to the area they were highly educated when they arrived. Due to limited access to more formal education later generations had fewer educational opportunities. Education was not perceived as important as was working in the coal mines or farming; therefore children may not have had the opportunity to attend school. Teachers were also hard to find in the rural areas (Huttlinger & Purnell, 2008).

There are generations of coal miners, who until the later part of the 20th century depended on the natural resources. That picture is changing. There are fewer natural resources (coal and timber) to sustain employment opportunities (Huttlinger & Purnell, 2008). The Appalachian region has a majority of people in semiskilled or unskilled jobs, with Appalachian whites three times more likely to be of a lower socioeconomic status (SES) than non-Appalachian whites (Huttlinger & Purnell, 2008). According to the ARC, 11.4% of persons 25 years or older have less than an eighth grade education; 35.4% have some high school education but no diploma; 69.4% have a high school diploma or qualifying exam; and 15% have a college degree or higher (Appalachian Regional Commission, 2013).

Cultural Values and Lifeways

The people of Appalachia value a deep-seated work ethic, they value family, and they value independence (Huttlinger & Purnell, 2008). In his book *Appalachian Values*, Jones (1994) relayed,

We mountain people are the product of our history and the beliefs and outlook of our fore parents. We are a traditional people, and in our rural setting we valued the things of the past. More than most people, we avoided main-stream life and thus became self-reliant.

We sought freedom from entanglements and cherished solitude. All of this was both our strength and our undoing. (p.13)

According to Jones (1994), “all work in Appalachia must be based on the genuine needs as expressed by mountain people themselves. Whatever work is done must be done with the recognition that Appalachian culture is real and functioning” (p. 10). The Appalachian value system “that influences attitudes and behavior is different in some ways from that held by our modern countrymen, although it is similar to the value system of an earlier America” (p. 37).

The values include: religion, independence, self-reliance, pride, neighborliness, hospitality, familism, personalism, humility or modesty, love of place, patriotism, sense of beauty, and a sense of humor (Jones, 1994). For additional information, a plethora of data on the socioeconomic realities of Appalachia and West Virginia is accessible via the Appalachian Regional Commission (www.arc.gov) website.

Political and Legal Factors

The establishment of the Appalachian Regional Commission (ARC) has led to the allocation and influx of federal dollars to the region (Appalachian Regional Commission, 2013). The money facilitated growth and improvements in the region. Appalachians are patriotic and have a deep love of country and of place. The ideal of individualism and self-reliant behavior are important in Appalachia. The people tend to be private, do not trust easily, and are wary of others who are viewed as outsiders (Huttlinger & Purnell, 2008; Small, 2013). For additional information, a plethora of information on the socioeconomic realities and historical influences of Appalachia and West Virginia is accessible via the Appalachian Regional Commission (www.arc.gov) website.

Economic Factors

Appalachia tends to have lower wage jobs, higher unemployment, lower educational attainment, and increased poverty. Appalachia has a long history of economic instability with unemployment rates higher than the national average. Grown children of Appalachian residents typically move out of the area for employment and return to the area to retire (Small, 2013). “In reality, Appalachians value a deep-seated work ethic, a low cost of living, and a high quality of life” (Huttlinger & Purnell, 2008, p. 96). For additional information, a plethora of information

on the socioeconomic realities and historical influences of Appalachia and West Virginia is accessible via the Appalachian Regional Commission (www.arc.gov) website.

Technological Factors

Because mountainous terrain makes traveling and navigating difficult many communities are only now able to support public utilities. Areas of the Appalachian region lack medical services and technology; therefore, the Appalachian Regional Healthcare program continues to have great emphasis on technology (Giger & Davidhizar, 1995; Andrews & Boyle, 2012; Appalachian Regional Commission, 2013; Small, 2013).

In the study by Rosswurm et al., (1998), the researchers learned a lack of funds for medicines, transportation, and help at home was a concern for 12% of the population. They found that Appalachians believe a hospital is a place where people go to die. A lack of mobility with the people of Appalachia discussed in previous literature was confirmed. The movement of mainstream America into Southern Appalachia has been slow. Dependency upon family stems from a lack of community resources and driving times in rural areas is an average of 25 minutes (Rosswurm et al., 1998). The concerns with access to health care and barriers are part of the Healthy People initiative was discussed early in this document. For additional information, a plethora of information on the socioeconomic realities and historical influences of Appalachia and West Virginia is accessible via the Appalachian Regional Commission (www.arc.gov) website.

2.3 Literature Review

The researcher conducted a literature review using the research databases of Ovid, CINAHL, Proquest, Medline, and dissertation abstracts. The researcher used search terms/constructs of Appalachia, health beliefs and values, SCI and life satisfaction/quality of life,

and the cultural meaning of SCI. The search revealed no research studies have been conducted in this domain of inquiry; however, there is supporting literature on life satisfaction/quality of life, a dissertation whose focus was on the inpatient rehabilitation nursing process, and research has been completed (although not on men with a SCI) considering the impact of the Appalachian culture on definitions of health, health beliefs, and values.

Appalachia and Health Beliefs/Values

Hansen and Resick (1990) studied the health beliefs and health care of rural Appalachian women using ethnography. They interviewed five young mothers who the researchers felt offered a representation of the health beliefs of the community; mothers' being responsible for health care is a traditional part of Appalachian culture. Interestingly, all mothers denied susceptibility of disease and sought medical care only when they deemed it "very serious". "In the Appalachian culture, illness is accepted as a cultural norm. Help from family members, including extended family, is both expected and accepted. The dependency that results from illness is also accepted" (Hansen & Resick, 1990, p.7). The two major themes that emerged from the data collection process revealed the "old" folk ways of the culture have been lost in the translation and "new ways" of the mainstream culture have not been learned (Hansen & Resick, 1990).

Elnicki, Morris, and Shockcor (1995) studied patient-perceived barriers to preventive health care among indigent, rural Appalachians. The study assessed six preventive health measures with new patients who sought care from a clinic for indigent patients located in a rural section of north central West Virginia. The measures were: blood pressure screening, cholesterol level, diphtheria-tetanus immunization, mammography, cervical Papanicolaou smear, and physical examination. One hundred eighty eight patients were surveyed and data was collected

over a four month period. The patients identified cost and lack of knowledge as the major reasons for lacking these preventive measures. A limitation of the study was the convenient sample of patients who were actively seeking medical care. The surveys validated the desire for prevention as an option; it appears education is crucial in improving use of prevention strategies.

Gates, Helmkamp, Wilson, Denning, and Beaver (2002) studied deer stand related injuries in West Virginia. They analyzed data from January 1994 through December 1999. Ninety individuals were identified as having been injured from a deer stand fall. Hunting is a cultural activity, especially in West Virginia. The authors report 350,000 people deer hunt every year. West Virginia is not alone with this problem. Georgia reported 594 deer related injuries between the years of 1979 to 1989, with one third caused by falls. The authors warn that the velocity and impact trauma from a fall needs to be evaluated as a SCI.

For additional information on the health beliefs and values of the Appalachian people: Keefe, S. (2005). *Appalachian Cultural Competency: A Guide for Medical, Mental Health, and Social Service Professionals*. Knoxville, TN: University of Tennessee Press.

Ludke, R. & Obermiller, P. (Eds.) (2012). *Appalachian Health and Well-Being*. Lexington, KY: The University Press of Kentucky.

<http://www.libraries.wvu.edu/collections/bibliography/health/>

Quality of Life/Life Satisfaction Post SCI

Carpenter (1994) conducted a phenomenological/ethnography qualitative study when discovering the experience of spinal cord injury. She conducted semi-structured interviews with 10 informants; nine men and one woman. The informants were from the Vancouver area of British Columbia, Canada. Her informants had sustained their injury three to five years prior to the interview. The researcher identified three main themes from the data. They were

rediscovering self, redefining disability, and establishment of a new identity. She found there was a “gap” between what the informants experienced and what may be defined as a standard of rehabilitation care. Carpenter (1994) further delineates the findings with the following insight and challenge.

In facilitating a clearer appreciation, on the part of health professionals, of the transformational and individual nature of the experience of spinal cord injury, the gap between what is offered and what is deemed relevant in the ‘real world’ of each individual might be narrowed. (p. 626)

Spencer, Young, Rintala, and Bates (1995) studied a single patient with a spinal cord injury (SCI) during the rehabilitation period. They used ethnography as the method for addressing their research goal, “to identify in depth how an individual patient adapted over time” (p.53). The informant, a 30 year old male, sustained a T-12 incomplete spinal cord injury due to a fall. In addition to the SCI he fractured his left arm in four places: a definite challenge for rehabilitation. The informant was interviewed daily. Members of the rehabilitation team were interviewed as well. Data analysis was accomplished using the constant comparative method and five sub-themes were identified related to the culture of the institution. These sub-themes were physical surroundings, system for providing care, scheduled round of activities, staff members, and fellow patients. In addition to the stated culture themes, a central theme revealed itself related to the rehabilitation experience. The central theme was the rehabilitation staff failed to recognize and integrate the informant’s past experiences and competencies with those “new” competencies in the rehabilitation period.

This central theme is familiar and reminds the researcher of cultural bias. The construct of cultural bias “refers to a firm position or stance that one’s (in this case the rehabilitation staff)

own values and beliefs must govern the situation or decisions” (Leininger & McFarland, 2002, p. 51).

Krause and Anson (1997a) studied employment and life adjustment post SCI. They believed employment leads to greater life satisfaction and subsequently a higher quality of life. A sample of 362 individuals returned the survey and the instrument for a return rate of 63%. The main study instrument was the Multidimensional Adjustment Profile (MAP). The MAP measures psychosocial, vocational, and health outcomes. Reliability coefficients were acceptable. The results from the study found employed participants reported superior overall adjustment. Krause and Anson (1997b) extrapolated data from the previous study (Krause & Anson, 1997a) and focused on adjustment after SCI focusing on the factors of gender and race. Using the same sample and instruments, but focusing on new hypotheses they found of the two factors (race and gender), race was more consistently related to differential outcomes.

Boswell, Dawson, and Heininger (1998) conducted a qualitative study of the meaning of the quality of life as defined by adults with SCI. They interviewed 12 participants, eight men and four women, ages 26-66. The data analysis revealed quality of life was developmental and depended on the priorities and are changeable. It is subjective and changes through the life span. When asked about quality of life and the experience of a disability, their priorities were different and cognitive abilities became more pronounced after the injury. Three main themes emerged: attitude toward life, opportunities to work, and level of resources. Satisfaction and satisfaction with life are intertwined with quality of life; in essence, the greater the satisfaction, the higher the quality of life and vice versa. As one participant so succinctly stated, “you can’t go out and look at the stars without taking care of the wheelchair or without attendant care” (p. 29).

Duggan and Dijkers (1999) conducted a qualitative study on quality of life post SCI, specifically reflecting on what the researchers called peaks and valleys. Forty men and women were interviewed using a biography style with questions framed to see their life as a book with events as chapters. High points were described as “after recovering something felt to have been irretrievably lost”, “affirmation, that their lives, however changed, had meaning for others as well as themselves”, and “accomplishments achieved in spite of (or because of) spinal cord injury” (p. 83). The most mentioned low point was the actual SCI injury or the time during the acute phase of care. Next was the slow realization of living with a SCI. Low points included the actual injury whatever the causative agent. The authors stressed patients with a new SCI experience a major drop in quality of life. One aspect of the study that surprised the authors was the ease and value of telling a story (Duggan & Dijkers, 1999).

Dijkers (1999) surveyed 2,183 persons with SCI and asked them to complete the Satisfaction With Life Scale (SWLS). It measures demographics, social, functional, and clinical characteristics associated with SCI. The instrument was determined to be valid and reliable. The highest life satisfaction was found to be persons who were married; and the lowest for persons living in a nursing home or long-stay hospital. Being employed and being educated were correlated with higher life satisfaction. Level of injury (LOI) but not the completeness of injury (whether the injury to the spinal cord is complete or incomplete) is related to life satisfaction; the higher the LOI the lower the life satisfaction scores.

Wehman, Wilson, Parent, Sherron-Targett, and McKinley (2000) looked at employment and unemployment variables for individuals with SCI. A sample of 226 spinal cord injured persons agreed to participate in the study. The instrument, the Employment Satisfaction Survey (ESS), was modified for the population and a pilot study was conducted. The ESS was given to

the employed subjects and another form was given to the unemployed subjects. The study was triangulated in that it contains qualitative as well as quantitative data. The open ended questions were analyzed looking for themes. The quantitative data was analyzed using frequency distributions and percentages. When asked about what would make their medical care after injury better; more provider training and knowledge about SCI issues, increased communication between provider and patient/family, and improved access to care were identified.

Unemployment was attributed to, health problems, inability to find a suitable job, transportation issues; negative impact on disability benefits, and fears to navigate the community. Of concern is 50% of the unemployed sample said their medical management of their injury was a barrier to employment. The authors validated the study question regarding employment and discovered if an individual is employed their satisfaction and quality of life are greater.

Inpatient Rehabilitation Nursing Care

In her classic study, Thompson (1990), conducted a qualitative study of rehabilitation nursing care in inpatient rehabilitation units using Leininger's theoretical framework. The setting for the study was two inpatient rehabilitation units in the Midwest, very similar in size and services offered. One hospital served as the primary site with the second as a reflective one. The caregiver-care receiver dyad of primary nurse and patient served as the key informants: the general informants were other nurses and patients not in an identified dyad. There were eighteen key informants; fifteen from the primary site and three from the reflective site. The researcher used the Observation-Participation-Reflection Method to initiate data gathering. The researcher gained entry into the daily functions of the rehabilitation unit and progressed from the stranger to friend over time. The researcher did not provide direct patient care; all data and findings are from observation and review of documents pertaining to the rehabilitation unit. The researcher

conducted interviews based on the domain of inquiry. The interviews lasted twenty to sixty minutes for each interview: an average of three and ½ hours per informant. The general informant interviews were not focused on the dyad per se but about their experiences with rehabilitation and views about care.

Data analysis revealed the rehabilitation setting as a sub-culture. The features were

1. Role expectations for all participants which derived from the social structure.
2. A social system with features of identifiable lifeways with day-night routines.
3. Philosophical beliefs of the social structure which emphasized the rehabilitation program norms. (Thompson, 1990, pp. 191-192)

The three main themes that emerged from the data were: rehabilitation enculturation, teamcare, and independence and conformity. Interestingly, Thompson (1990) noted an area of significance to nursing practice, “nurses need to recognize the client’s viewpoint in order to help him/her in the rehabilitation process” (p. 211). One last area of interest to this researcher was the idea that as rehabilitation nurses gain experience they may be more likely to accommodate the patient’s viewpoint; however, typically new specialty nurses follow the program plan and aren’t able to deviate (Thompson, 1990).

The findings of the key studies by Thompson (1990), Carpenter (1994), and Wehman et al., (2000) substantiate the need for more research focused on learning about the impact of culture on health and care. Specifically, nurses need to recognize the client’s viewpoint (their worldview); increased communication is indicated between the provider and the patient (evidence of cultural imposition, cultural bias, and ethnocentrism); and one (nurse and/or other healthcare provider) must embrace the past (the cultural context) of the patient to facilitate care that is meaningful and beneficial.

The researcher intends to address this gap in knowledge by focusing on the cultural context of men with a SCI from the Appalachian region of West Virginia. The next logical step is to return to the people and learn from them. The theoretical framework provides a basis for the study and guides the researcher through the development and implementation of the study. Leininger (1991) promotes a level of discovery focused on the people and their emic view while teaching health care providers their etic view is not the end but the beginning of the care process; and yes both perspectives have value and merit to be considered.

The studies presented in the literature review substantiate a lack of qualitative data focused on the culture care needs of men post SCI, specifically, how culture influences their definition of health and how they view themselves as men who now have a disability. Research substantiated that a higher life satisfaction and a greater quality of life exists when the individual is educated, is able to participate in activities that are valued, and is employed all of which facilitate the resources (internal and external) necessary to care for their self and their family (Carpenter, 1994; Spencer et al., 1995; Elnicki et al., 1995; Krause & Anson, 1997a; Krause & Anson, 1997b; Boswell et al., 1998; Duggan & Dijkers, 1999; Dijkers, 1999; Wehman et al., 2000; Gates et al., 2002).

2.4 Guiding Framework

The domain of inquiry (DOI) of this study is to discover and describe the culture care meanings and care expressions of men with a SCI from the Appalachian region of West Virginia in order to facilitate and promote care that is meaningful and congruent with their needs. The theoretical framework for this research study is based on Leininger's Theory of Culture Care Diversity and Universality (Leininger, 1991).

Leininger's (1991) theory will serve as the guiding framework for the study. The theory itself guides and stimulates the discovery of hidden phenomena. Using the theory in tandem with the ethnonursing research method developed by Leininger (1991) will enable the researcher to learn directly from the people and discover the emic view.

The assumptive premises of Leininger's theory used as a basis for this study are:

1. Care is the essence of nursing and a distinct, dominant, central and unifying focus.
2. Care (caring) is essential for well-being, health, healing, growth, survival, and to face handicaps or death.
3. Every human culture has generic (lay, folk, or indigenous) care knowledge and practices and usually professional care knowledge and practices which vary transculturally.
4. Culture care values, beliefs, and practices are influenced by and tend to be embedded in the worldview, language, religious (or spiritual), kinship (social), political (or legal), educational, economic, technological, ethno-historical, and environmental context of a particular culture.
5. Culture care differences and similarities between professional caregiver(s) and client (generic) care-receiver exist in any culture worldwide.
6. Clients who experience nursing care that fails to be reasonably congruent with the client's beliefs, values, and caring lifeways will show signs of conflicts, noncompliance, stresses, and ethical or moral concerns. (Leininger, 1991, pp. 44-45)

According to Leininger (1991), "discovering ways to guide nurses to learn about different lifeways of people in daily living, crises events, health struggles, and sickness episodes from a transcultural perspective remains a difficult challenge" (p. 392).

An individual who sustains a SCI embodies the above stated challenges: including a sickness episode with the actual spinal cord injury and time spent in an acute care setting, a crises event with the ramifications of a SCI and not knowing the final outcome, and the ongoing health struggles of managing activities of daily living to mitigate complications and negative outcomes.

In addition to the assumptive premises, a central premise of the theory the researcher hopes to clarify through a better understanding and description of is, *Culture Care*. *Culture Care* as defined by Leininger (1991) is

the subjectively and objectively learned and transmitted values, beliefs, and patterned lifeways that assist, support, and facilitate, or enable another individual or group to maintain their well-being, health, to improve their human condition and lifeway, or to deal with illness, handicaps, or death. (p. 47)

Inherent in facilitating culturally congruent care is the illumination of the emic view. The emic view (of the people) is in stark contrast to the etic view (outside view of the nurse/provider). As Leininger (1991) holds “the emic culture knowledge could provide the truest knowledge base for culturally congruent care...” (p. 36). Research confirms the client’s culture has the potential to exert considerable influence on their experiences, including the perception of health/illness, and acceptance of, and response to health care (Andrews & Boyle, 2012). Knowing the potential impact of culture on health, the health care provider has a duty to incorporate the client’s culture in his/her care. Failure to do so could precipitate cultural pain, cultural conflicts, noncompliance, cultural stress, and lead to ethical or moral concerns (Leininger, 1991). Consequently, “the nursing profession has an ethical obligation to provide

culturally congruent care; care that is meaningful and beneficial to the client” (Imes & Landry, 2002, p.175).

Leininger’s theory has processes or enablers to assist the researcher in discovering hidden data (Leininger, 1991). The primary enabler used in this study will be the Sunrise enabler. (See Appendix A for Sunrise enabler) The Sunrise enabler serves as a template to facilitate holistic inquiry. The major areas of worldview, environmental context, and social structure factors will be utilized in facilitating this research study. Worldview is how the individual interprets the world: the lens they use to see the world (Leininger, 1991). The environmental context refers to “the totality of the event, situation, or particular experiences that give meaning to human expressions, interpretations, and social interactions in particular physical, ecological, sociopolitical and/or cultural settings” (Leininger, 1991, p. 48). The environmental context is extremely important in this study since the aim of the research is to discover and describe the culture care meanings and care expressions of men with a SCI from the Appalachian region of West Virginia. Each informant will have and hopefully share their unique environmental context when describing their injury and subsequently how the injury has affected their lives.

The purpose of the ethnohistory is to learn about historical events and experiences of a particular culture to begin to understand their story: their past to better understand their present (Leininger, 1991). It is not intended to provide an in-depth overview of the history of the area. The information included in each of the *rays* is intended to spark interest in learning more about the history of the area, its geography, and its people. The *rays* of the Sunrise enabler provided a framework for organizing an ethnohistory of Appalachia with emphasis on the Appalachian region of West Virginia. The social structure factors will further facilitate the design of the semi-structured interview guide and the plan for data collection. To review, the *rays* of the

Sunrise enabler are: Religious and Philosophical Factors, Kinship and Social Factors, Educational Factors, Cultural Values and Lifeways, Political and Legal Factors, Economic Factors, and Technological Factors (Leininger, 1991; Leininger & McFarland, 2002). (See Appendix A for Sunrise enabler)

Once the emic view has been discovered and composed, Leininger (1991) conceptualized three modalities of care designed to provide culturally congruent care leading to health and well-being and to face death or disability. These modalities are cultural care preservation or maintenance, cultural care accommodation or negotiation, and cultural care repatterning or restructuring. The modalities are meant to facilitate professional actions and decisions which are predicted to assist people of different cultures retain, adapt to, and modify their lifeways to promote healthier outcomes (Leininger, 1991). Notably, Leininger (1991) prefers to view the nursing modes of action as co-participative and chooses to avoid the terminology of nursing interventions. Nursing interventions by their name imply the use of authority, reflect ethnocentrism, and promote cultural imposition.

2.5 Chapter Summary

The brief ethnohistory provides an overview of Appalachia with emphasis on the region of West Virginia. An ethnohistory represents a contextual snapshot into the environmental as well as the cultural context of the Appalachian region. The literature review substantiates a gap in the current knowledge regarding how men from Appalachia describe and define having a SCI. In essence what does it mean (from a cultural perspective) to men with a SCI from the Appalachian region of West Virginia? The theoretical framework for the study is based on Leininger's Theory of Culture Care Diversity and Universality (1991). The theory facilitates and promotes care that is meaningful and congruent when the emic view is *known*.

CHAPTER 3

3.1 Introduction

The ethnonursing research method allows the researcher to discover hidden phenomena about a culture and its people. A qualitative method, the ethnonursing research method was developed by Leininger (1991) to explicate the Theory of Culture Care Diversity and Universality. This chapter will review the details of the methodology, recruitment of informants, and outline the plan for data analysis.

3.2 Method

The nature of the research questions and the cultural aspects of the inquiry, leads the researcher towards a qualitative method of inquiry using the ethnonursing method. The ethnonursing method was selected because it is designed to “discover how things really were and the way people knew and lived in their world” (Leininger, 1991, p.79). The ethnonursing method refers to a qualitative nursing research method “focused on naturalistic, open discovery, and largely inductive (emic) modes to document, describe, explain, and interpret informants’ worldview, meanings, symbols, and life experiences as they bear on actual or potential nursing care phenomena” (Leininger, 2002b, p. 85).

3.3 Synopsis of Mini Ethnonursing Study

In 2005 a mini ethnonursing study was initiated as part of a post master’s in transcultural nursing completion process. The study focused on men with a SCI in the Appalachian region of West Virginia. A total of four interviews were conducted. The researcher interviewed two men with a SCI (potential key informants) as well as two interviews with their family (general informants); one mother and one father. The major lessons learned were 1. the men did not recognize Appalachia as their culture; 2. the semi-structured interview guide was ineffective; it

was too prescriptive, eliminated the natural telling of their story, and felt forced; and 3. the interviewing of family did not provide the researcher with the intended validation of the men's experiences but rather the family discussed the SCI from their perspective and how it impacted on the family as a unit. After discussion with the researcher's advisor the mini study was halted and work began on the larger study, the dissertation. The lessons learned from the experience of working on the mini study influenced the current study with emphasis on the number and types of questions on the semi-structured interview guide (Imes, 2005).

3.4 Research Enablers

Leininger (1991) identified several processes known as enablers to assist the researcher in "teasing out" the hidden phenomena. For this study the researcher used the Stranger to Trusted Friend enabler, the Specific Domain of Inquiry enabler, and the Sunrise enabler (See Appendix A for Sunrise enabler).

Stranger to Trusted Friend Enabler

Stranger to Trusted Friend enabler promotes a relationship with the people. As the name implies, the researcher must transcend the title of stranger to one of trusted friend in order for the people to share of themselves. It is through this process of sharing which then leads to meaningful and beneficial data. Most people will not share their most intimate thoughts with strangers (Leininger, 1991). The researcher attended a SCI committee meeting and shared the plan for the research study with the committee members. The researcher attended a banquet honoring athletes from the Challenged Sports Program in early November. The banquet was the first meeting with potential informants. The researcher met and visited with several men at the banquet. Three men shared an interest in learning more about the study and provided contact information. They eventually participated and their interviews were completed in 2012. The

researcher posted information about the study in the medical facility and spent time in the environment meeting the staff of the rehabilitation unit. Every opportunity to share the details of the study was taken. The researcher attended the outpatient clinic with the medical director. In February, the researcher began attending the SCI support group meetings. The holidays meant the group did not meet for a couple of months. Two of the informants interviewed in 2012 attended the SCI support group meetings. They decided to share they had been interviewed and encouraged other men to participate. The majority of the informants who participated in the study were recruited by the men themselves. The informants would promote participation in the study during the SCI support group meetings and by contacting men with SCI's in their communities.

The researcher's consistent presence at the SCI support group meetings facilitated recognition and promoted trust from the men and facilitated the identification of key informants and additional general informants. The progression from Stranger to Trusted Friend was tracked through reflection in the field notes written by and for the researcher. Further evidence (deeper and more personal responses) was revealed through the transcribed audiotapes of the interviews.

Specific Domain of Inquiry Enabler and Sunrise Model Enabler

The Specific Domain of Inquiry enabler also known as a semi-structured interview guide was developed by the researcher and reflects the interests and focus of the study (Leininger, 1991). (See Appendix B for Interview Guide) The semi-structured interview guide reflects the domain of inquiry (DOI) and was facilitated with the Sunrise enabler to ensure the data collection process was holistic and comprehensive. As previously mentioned, the semi-structured interview guide was modified based on the researcher's experiences and lessons learned during a mini study conducted in 2005 (Imes, 2005). There are fewer directed questions

and more opportunities for the men to “tell their story”. The interview is one of the most important data gathering tools. The open-ended nature of the interview questions allow informants to respond in their own time, reflect upon questions when asked, and time to connect with their authentic self when answering a specific question (Leininger, 1998; Munhall, 2001; Yow, 2005).

3.5 Protection of Human Subjects

Data collection began after approval was obtained by the Duquesne University Institutional Review Board (IRB) and the medical facility. (See Appendix C for Approval Letter). To ensure confidentiality of the informants those individuals who participated in the study will be known only by researcher. There was no monetary reward or token provided for participating; however a thank you card was mailed following their interview. Participation was voluntary and informed consent was obtained. (See Appendix D for Consent) All data collected was protected and the informants’ identity was known only by the researcher. Interestingly, men who were part of the study chose to inform others that they were participants in the study. Their positive comments and willingness to promote the study facilitated informant recruitment. The digital audio files were named with the informant’s pseudonym to ensure confidentiality and anonymity of the informants. The computer which stored the audio files was located in the researcher’s locked office and was password protected. The pseudonyms used were chosen by the informants. An independent transcription service was used to transcribe the digital audio files verbatim. The transcription service signed a confidentiality agreement prior to receiving any digital audio files to transcribe. (See Appendix E for Signed Confidentiality Agreement). To protect the privacy of the informants, all data collected whether computer based or paper (digital audio recordings, digital files, transcribed notes/files, and field journals) has been kept in

a locked file in the researcher's office or secured on the researcher's password protected computer. Paper work products will be incinerated while computer based products will be deleted after all aspects of the study are completed.

Participation was voluntary and informed consent was obtained. The identities of the study informants remain confidential and are anonymous to everyone with the exception of the researcher. Pseudonyms were chosen by the informants for use during the interview. Names of people or places were redacted by the researcher to further protect the confidentiality of the informants.

3.6 Method of Data Analysis

Leininger's Four Phases of Qualitative Data Analysis Guide was used for data analysis in this study (Leininger, 1991). The Qualitative Data Analysis Guide offers four sequenced phases of data analysis. The data are continuously processed and reflected upon by the researcher at each phase (Leininger, 1991). Concurrent data collection and analysis was facilitated by Leininger's data analysis process. The four phases are:

1. The first phase is the collecting, describing, and documenting of raw data.
2. The second phase is where data are coded and classified based on the domain of inquiry. The goal is to identify and categorize descriptors; to study recurrent components.
3. In the third phase patterns and contextual analysis is occurring. Looking for saturated ideas and recurrent patterns as outlined by the domain of inquiry.
4. The last phase, the fourth phase, is the synthesis phase. The goal is to abstract and present major themes.

Of interest is the “final check” where the researcher rechecks the themes synthesized in phase four with the raw data in the first phase to ensure there is “substantiation of findings” (Leininger, 1991). A software program NVivo 10 was used to assist with raw data management. The coding of data and data analysis is conducted by the researcher.

3.7 Summary

This ethnonursing study sought to discover and describe the culture care meanings and care expressions of men with a SCI from the Appalachian region of West Virginia. Field notes and informant interviews were analyzed using Leininger’s Four Phases of Qualitative Data Analysis Guide (1991). The process of informed consent was discussed and additional measures to protect informants’ confidentiality were outlined. The use of specific research enablers used in the study was shared. A systematic review of confidentiality measures were described emphasizing details for the informant interviews and storage of data.

CHAPTER 4

4.1 Introduction

This chapter presents the findings from the study: *Discovering the Culture Care Meanings and Care Expressions of Men with a Spinal Cord Injury from the Appalachian Region of West Virginia: An Ethnonursing Study*. The study sought to discover and to understand the culture care meanings and care expressions of men with a SCI from the Appalachian region of West Virginia. The domain of inquiry (DOI) was to discover and describe the unique culture care meanings and care expressions of men with a SCI from the Appalachian region of West Virginia. The DOI, specific aims, and research questions served to guide the study.

The setting for the study and the ethnodemographic information of the informants will be discussed. The method for entry into the field, the process for data collection, and data analysis will be shared. The data was analyzed using Leininger's Four Phases of Qualitative Data Analysis Guide (1991). In the first phase the researcher begins with data collection and the management of raw data; the second phase of data analysis the researcher searches for recurrent components and descriptors in the data known as categories; the third phase of data analysis, the researcher scrutinizes the data to discover saturation ideas and patterns. Data are examined to reveal patterning of meanings. The end result of the third phase is the identification of contextualized patterns. In the fourth phase, the data are further analyzed, synthesized, and interpreted to reflect the phenomena being studied. The end result of the fourth phase is the presentation of the major themes of the study.

4.2 Setting

The setting for this study was the Appalachian region of West Virginia. WV is the only state where all counties meet the federal designation of Appalachia. The federal designation is

based on socioeconomic terms of poverty, deficits in living standards and education, and lack of urbanization (Huttlinger & Purnell, 2008; Appalachian Regional Commission, 2013; Small, 2013). Jones (1994) discussed the fundamental differences of worldview and the people of Appalachia. In Appalachia, a worldview of “being” oriented (living for today) is dominant as compared to a worldview of “doing” oriented (planning for tomorrow) (Jones, 1994). Huttlinger and Purnell (2008) discussed a worldview of fatalism being evident with the people of Appalachia. A fatalistic worldview implies the individual has no control of their destiny; what will be will be (Huttlinger & Purnell, 2008; Small, 2013).

In order to gain access to men with a SCI, the researcher learned of a SCI support group that meets monthly in a large city in West Virginia. The SCI support group was small and the majority of the members were men. The medical facility has an established rehabilitation program accredited by the Commission on Accreditation of Rehabilitation Facilities (CARF); caring for individuals who sustain a SCI is one of their programs. Individuals and their families who are currently receiving inpatient rehabilitation services for a SCI are encouraged to attend the SCI support group meetings.

The rehabilitation department includes an eighteen bed inpatient unit and an outpatient clinic. The inpatient unit and outpatient clinic are located in the same geographic area along with the adjunctive therapies; conducive for patients who receive their services. Individuals who may be candidates for rehabilitation services are evaluated by a physician who specializes in rehabilitation medicine. The physician evaluates an individual to determine their potential for functional improvement and appropriateness for admission to a rehabilitation program. Once admitted to the inpatient rehabilitation unit, the individual’s rehabilitation team is formed. The team members chosen for a particular individual is dependent on their medical diagnosis and

their potential for functional improvement. Members may include a physical therapist, a social worker, a recreation therapist, a dietician, a nurse, an occupational therapist, a speech pathologist, and a psychologist. The physician, patient, and a family member/care-giver are central members of a rehabilitation team. The patient is expected to be an active member of their team.

The location or site to conduct interviews was selected by the informants. The researcher met informants in their homes, in restaurants, in their vehicles, in a gym, and at various medical facilities. Interviews were conducted beginning in November of 2012 and were completed in August of 2013. The juxtaposition from an urban area to a rural area was quite a journey. Though driving on unfamiliar roads, a sense of the familiar in the vista developed over time and miles. If the researcher was lost (which happened many times) and stopped to ask for help; the people were welcoming, friendly, and helpful. The informants were patient with the researcher as they dictated driving directions to the location for the interview. When lost, the researcher would call the informant for additional directions or clarification of directions. The men remained patient as they re-directed the researcher no matter how many times they were called.

When the informants learned the researcher was from Kentucky, they voiced concern with the researcher's navigation skills; they agreed to keep their telephones close and the researcher agreed not to drive after dark. Most of the time, once the interview was completed the researcher was escorted out to her vehicle by the informant.

4.3 Entry into the Field

The site for entry into the field was chosen due to the presence of an established SCI support group. The researcher learned the SCI support group was one of the services offered as part of the medical facility's rehabilitation program. The researcher met with the administrator

of the rehabilitation services at the medical facility and discussed the proposed research study. With approval to proceed from administration, IRB approval was sought and granted from Duquesne University as well as the medical facility. (See Appendix C for IRB Approval)

The researcher was asked to attend the medical facilities' SCI Committee meeting to present an overview of the research study. The SCI committee met the first week of November 2012. The researcher presented highlights of the study and explained the methodology to the members of the SCI committee. The researcher met the medical director of the rehabilitation services (Inpatient and Outpatient services) and the director of the rehabilitation department. Other members of the SCI Committee included representatives from nursing, recreational therapy, social services, a psychologist, physical therapy, and occupational therapy. The researcher requested assistance in identifying prime locations for the recruitment materials. (See Appendix F for Recruitment Flyer) With the SCI committee's assistance, the placement of the recruitment materials was decided. (See Appendix G for Recruitment Poster)

The materials were placed in the main waiting area where patients wait for outpatient appointments, inside the outpatient clinic area, the physical and occupational therapy area, and the desk area of the inpatient rehabilitation unit. The researcher supplied extra copies of the flyers to the department director who agreed to re-stock the recruitment materials as needed. In addition, the researcher physically visited the medical facility weekly to verify recruitment materials were present in the identified areas.

The researcher met the recreational therapist who coordinated the SCI support group. The researcher learned the next SCI support group meeting was not being held until December 2012 due to the Thanksgiving holiday. The December meeting was planned as a holiday party

for the members of the SCI support group and therefore not conducive for recruitment for the study. The first SCI support group meeting the researcher could plan to attend would be in 2013.

However, during the SCI committee meeting, the medical director invited the researcher to attend the Challenged Sports Program's award banquet sponsored by the medical facility being held the next week. The researcher was encouraged to bring recruitment materials to the venue. During the banquet, the researcher was introduced to the group in attendance and information about the research study was provided. The recreational therapist who coordinates the Challenged Sports Program encouraged men with SCI's to introduce themselves to the researcher at the conclusion of the program. When the program ended, the researcher met many men who were interested in participating in the study. A few of them felt comfortable sharing their names and contact information while others left with the informational flier.

The journey for the researcher to transition from Stranger to Trusted Friend (Leininger, 1991) began at the Challenged Sports Program banquet. Upon reflection, for the recreational therapist to take the time to introduce the researcher during the ceremony and to encourage men to participate was crucial in recruiting informants and completing this study. During this past year, the researcher learned how respected and valued the recreational therapist is to the men and the SCI community. Inevitably, when the subject of rehabilitation was discussed during the interview for the research study the men remembered him and wanted to know if the researcher knew him!

In addition to attending SCI support group meetings, the researcher spent time in the outpatient clinic, the inpatient unit, and worked with the recreational therapist. When requested by the members of the SCI support group, two educational presentations were developed and presented at their meetings. In the spring, the researcher volunteered to help with the Challenged

Sports Program archery event. A few of the informants from the study were competing. That day State and National records were broken. During SCI support group meetings, the men would discuss the study and encourage others to participate as well. It was common to see members of the SCI support group participating as athletes with the Challenged Sports Program.

An opportunity for a small group of athletes to attend a national event was discussed at a spring SCI support group meeting. It was the first time the athletes were considering participating in a national event. A lack of funds has hindered their participation in events outside the state. The plan was to send a small group of athletes and their coach (the recreational therapist). To save money, the researcher volunteered to prepare food to send with the athletes. They chose baked spaghetti, barbeque beef for sandwiches, and baked beans. The food was placed in containers ready for the oven and then frozen. Specific cooking instructions were placed on each pan. The athletes said they ate better than anybody else and ate their meals together. More potential athletic records were made that weekend.

4.4 Data Collection

The researcher contacted the men from the Challenged Sports Program banquet who had verbalized interest in participating in the study and had provided their contact information. Once contact with the men was made via telephone, an overview of the purpose of the study and the inclusion criteria were discussed. The informant's eligibility to participate in the study was verified during this conversation. The inclusion criteria were, 18 years or older, born, reared, and currently living in West Virginia, male, and sustained a spinal cord injury as a result of trauma. The inclusion criterion related to West Virginia sought to achieve homogeneity of the culture; the Appalachian culture.

If the informant met the inclusion criteria and verbally agreed to participate in the study, a date and time were chosen to meet. The physical location of the interview was decided by the informant. The researcher advised the informant the location for the interview should be conducive to audio recording and convenient for the informant. Privacy was encouraged for anonymity and for confidentiality purposes. Interestingly, the interviews were scheduled for the week after the beginning of deer hunting season; nothing interferes with deer hunting season.

Once a plan for the interviews was created, the researcher would call each informant the day before and the morning of the interview to confirm the details. The researcher would obtain driving directions from the informant to facilitate driving and navigation to the location of the interview. The driving time for the researcher to reach the location for the interview ranged from an hour and forty-five minutes to six hours; one direction.

The informant interviews began in late November 2012 and continued until saturation of the data occurred in August 2013. A total of 23 informants (key and general) were recruited, met the inclusion criteria, and participated in the study. Of the 23 informants, there were 18 general informants and five key informants. The method for consent and preparing for the interview was used consistently with each informant. The first ten to fifteen minutes of time was spent on introductions and general conversation. The researcher considered the environment and the needs of the informant prior to beginning data collection.

The consent form was read by the informant; an opportunity for questions or explanations was provided. (See Appendix D for Consent Form) The informant was provided a copy of an unsigned consent form while the signed consent form was kept by the researcher. Prior to beginning the digital recording, the informants chose a pseudonym to use during the interview. Choosing a pseudonym was an additional strategy implemented to facilitate anonymity and

confidentiality for the informant. Once the interview was completed, closure was initiated and the informant was thanked for participating. A formal thank you hand-written note was mailed to the informant a few days following the interview.

Of the 23 informants, informants were recruited from the inpatient rehabilitation facility, the banquet, at a craft fair, from the outpatient clinic, during the Challenged Sports Program wheelchair basketball tournament, the researcher attending the SCI support group meetings, and the majority of the informants were recruited by other informants who were participating in the study.

The interviews were digitally recorded. Following each interview, the audio digital files were reviewed, saved using the informants' pseudonym for identification purposes, and transmitted to a transcription service for processing. The audio data files were transcribed verbatim by an independent transcription service who signed a confidentiality agreement. (See Appendix E for Agreement) All data were stored on a password protected computer located in the researcher's locked office.

Data collection and analysis occurred concurrently. Leininger's Four Phases of Qualitative Data Analysis Guide (1991) was used to analyze data generated from this study. In the first phase, data is collected with initial coding of the data. In the second phase, the researcher combines the data into meaningful categories. In the third phase, the researcher further contextualizes the data to broader patterns. In the fourth phase, the researcher analyzes, synthesizes, and interprets data abstracting themes (Leininger, 1991). The software program NVivo 10 assisted the researcher with the handling of raw data.

The key informants participated in the confirming and clarifying of the data during each phase of the data analysis process enhancing the validity and credibility of the categories,

patterns, and themes. In addition, the researcher included the dissertation chair during the analysis of data. Although time intensive and rigorous, this process was critical to further validate the reliability and credibility of the findings and to verify the emic view of the informants was being explicated.

4.5 Descriptions of the Informants

There were eighteen general informants and five key informants who participated in the study. Their ages ranged from 24 years of age to 70 years of age; with a median age of 50 years. The informants' age at the time of injury was 13 years to 60 years of age; median age of 32 years. The ethnicity of the group was 21 Caucasians; one American Indian; one African American. The informants did not identify Appalachia when asked about their culture. This finding is consistent with the literature and the findings of the mini ethnonursing study (Imes, 2005; Small, 2013).

Thirteen of the informants were married, six were single, and four were divorced. The question regarding years of education revealed; 17 earned a High School Diploma, seven earned an Associate Degree or Vocational Certificate, one earned a General Education Development (GED), and five of the men did not complete high school. The traumatic events causing their SCI's were; nine motor vehicle accidents (MVA), four construction accidents, three coal mining accidents, two all-terrain vehicle accidents (ATV), two motorcycle accidents, one fall from a tree, one skiing, and one crushing accident (working under a truck).

Of the twenty-three informants, 12 were un-insured at the time of their accident, three were covered by their parent's insurance, three were covered by Worker's Compensation, one of the informants' expenses were covered by automobile insurance coverage, and four had health care insurance. Nineteen of the informants received their medical care and rehabilitation within

the state of West Virginia; two completed their rehabilitation in Georgia; one in Pennsylvania, and one in Ohio. Twenty-one of the informants received acute medical treatment in West Virginia; one informant was transferred to a medical facility in Ohio for his medical care and rehabilitation; and one was transferred to Pennsylvania for his medical care and subsequent rehabilitation.

The informants provided their city of birth as part of verifying the informant inclusion criteria. The researcher identified the informants' county of birth from the raw data. (see Table 1: County of Informant Birth, County Economic Status and Number of Distressed Areas in West Virginia, and Poverty Rate by County). The counties listed in the table are randomly listed and the actual number of informants born in each county is not identified to protect their confidentiality. The counties and data regarding the economic status as determined by the ARC are presented to highlight the issues with poverty and resources in the Appalachian area. The individual county poverty index is listed and the poverty index for the United States is included for comparison (Appalachian Regional Commission, 2013).

The first column is a listing of the counties in WV where the informants were born. The second and third columns list the ARC economic rankings for the county with the number of distressed areas in the county. The last two columns are the poverty indices of each county compared to the poverty index for the United States which is 13.8%. The Appalachian Regional Commission (www.arc.gov) website contains a wealth of history, information, and data on Appalachia and the counties federally designated as such. What is evident from reviewing the information is the poverty indices are higher than the national average in every county with one exception: Kanawha County (13.7% as compared to the national average of 13.8%). The two counties labeled distressed are Lincoln and McDowell (data in bold on Table 1).

Table 1

County of Informant Birth, County Economic Status and Number of Distressed Areas in West Virginia, and Poverty Rate by County

Informant County of Birth	Economic Status	Number of Distressed Areas	Poverty Rate by County 2006-2010	Poverty Rate United States 2006-2010
Kanawha	Transitional	7	13.7%	13.8%
Wood	Transitional	5	16.4%	13.8%
Raleigh	Transitional	3	17.5%	13.8%
Lincoln	Distressed		26.6%	13.8%
Logan	At-Risk	3	21.8%	13.8%
McDowell	Distressed		32.6%	13.8%
Randolph	Transitional	2	17.1%	13.8%
Wyoming	At-Risk	1	17.3%	13.8%

(Appalachian Regional Commission, 2013)

In the Sunrise enabler , Leininger (1991) identifies economic factors as a *ray* or cultural dimension to be explored. The influence of economics cannot be ignored.

4.6 Presentation of Findings

Leininger’s Four Phases of Qualitative Data Analysis Guide (1991) was used to analyze the data generated during this study. The findings of the study are presented according to the four phases of data analysis developed by Leininger (1991). To protect the informant’s identity, a pseudonym was chosen by the informant before beginning their interview. The informant

names used in the findings section are the false names the informants chose. Unless the informants choose to identify themselves; their true identity remains with the researcher. Information to de-identify the informants is kept in a locked file cabinet and the code to de-identify the informants is known only by the researcher.

4.7 First Phase

In the first phase of data analysis, the researcher begins collecting data via interviews with the key and general informants, being present in the field, making observations, and beginning to analyze the data (Leininger, 1991). Phase one of data analysis began when the researcher attended the Challenge Sports Program banquet in November 2012; the first encounter with potential informants. Twenty-three informants (five key and eighteen general) were recruited and participated in the study.

4.8 Second Phase: Categories

During the second phase of data analysis, data are coded by the researcher using NVivo 10 software program and further analyzed for descriptors within context. The collected data when thoroughly analyzed by the researcher leads to the identification of descriptors and recurrent components labeled as categories (Leininger, 1991). The second phase of data analysis for this study was accomplished by reading and reflecting on the transcribed informant interviews searching for commonalities of words, phrases, and meanings used by the informants. NVivo nodes (codes) were created and labeled using words and phrases used by the informants. The thirteen categories in this study were *support of family and friends, role of neighbors, role of hard work, reflecting on rehab, rather be outside, positive attitude, men like me, got to have hope, figuring out what works best for me, fierce spirit of independence, caring, beliefs in God, and a different way of living*. Each of the categories will be discussed with supportive evidence

from the key and general informants using their collective voice as well as direct quotes to explicate the categories.

Support of Family and Friends. The *support of family and friends* was very important to the informants. Each of the informants spoke about the support and love of family and friends. Allen, when speaking of his family stated “I got a cousin lives on the hill right above us. He comes and helps whenever I call him if need be”. He described his birthplace as “a mining community. Family all around me. I’d describe as the Andy Griffith childhood. Company store and all”. Allen was 21 years old when he was injured. He was living at home with his parents and working in the coal mines. His spinal cord injury was a result of a MVA. He sustained a complete injury at the level of the sixth and seventh cervical vertebrae. “I remember a lotta family pain too. It just hurt them, but I had a lotta family support back then too. They’ve never left me”.

Bill, a key informant, when asked who lived in the home, said “My wife and I. They're three daughters that live in the neighborhood”. The majority of the informants either had family living close by or within a thirty minute drive. Elrod, a key informant, has a sister who is a nurse. When he was injured, he said “she handpicked everybody to come and work on me. I got extra screws [*laughter*]”. Elrod, described his home as “Grand Central Station”; where everybody gathers. Several informants shared similar stories regarding their homes as a gathering place for family and friends; logically, the informant’s home has been modified to meet their physical needs and is easier for them to navigate.

Elrod, a key informant, was injured while working construction. He was helping a “buddy” who was building a house. He fell 15 feet from a deck to a concrete pad. He sustained a complete injury at the waist level (exact level unknown by the informant). When Elrod was

receiving inpatient rehabilitation, he shared how the staff recognized how important his friends were to him. He shared,

They knew my friends would come on Monday night and smuggle beer in. They were drinking beer and stuff, and we never got loud or did anything. They let us. They knew that my friends loved me. They were just here for me.

Elrod spoke of his friends as part of his family. As he explained it, there is a difference in asking for help or assistance and how it makes you feel. You try not to ask your family for help. You can ask your friends to help you and not think about it or feel like a burden. One example, is when he wants to go horseback riding; he needs lifting assistance to mount the horse.

I have my saddle in place. I just reach up and grab a hold of the horn in the back right there, and my buddies just grab me by the back of the britches, and I start to pull myself up; and they just WHOOSH! Push me up.

Role of Neighbors. The *role of neighbors* or having “good” or “close” neighbors was described by each informant. For the informants, getting to know your neighbors was critical. The relationship between the informant and their neighbors were described as reciprocal; doing for each other. Neighbors will watch out for each other and property. Frank shared the following regarding his neighbors. He said, “I mean it’s real small, close knit people, close knit neighbors. They all help you out if you see somebody and somebody needs help. It’s a real close knit community”. Bubby said,

I’ve had wonderful neighbors and if it wasn’t for them and wasn’t for other people that live around here and my wife, of course, that’s what helped me mentally wise to get through what had happened to me.

Dave shared “just I got good neighbors. The neighbors are good. I love it here”. DG shared,

Usually I would get—one of my neighbors would come with me, and he would help me if I didn’t have one of—I have another nephew named Shane. Sometimes he would take me. Then my other neighbor would take me when I couldn’t go myself, like to my appointments after I had surgery, then they would usually take me.

The informants spoke of the importance of “good” or “close” neighbors. The informants spoke of making it a point to introduce yourself and “get to know” your neighbors. The symbiotic relationship with neighbors was described as “give and take”. The knowledge of having a “good” neighbor who “knows” you in case of immediate need or in an emergency was the essence of this category.

Role of Hard Work. The informants’ collective opinion regarding the *role of hard work* was; it is a way of life. The informants spoke about learning the value of hard work as children. The researcher learned the majority of the informants worked physically demanding jobs prior to injury; primarily coal mining and construction. The informants were hard workers before their injury and weren’t afraid of hard work. Hank, a key informant, worked as a welder for a coal mine; above and underground. He made “good money” and “he made a good living for his family”. He was injured in a motorcycle accident. He sustained a complete injury at the level of ninth thoracic vertebrae. Bubby, shared about recovering from his accident, “even though it may take a lotta hard work and it may take some sufferin’”. Gandolph, a key informant, shared,

If you wanna recover, you gotta work hard and you gotta keep workin’. I strongly recommend abdominal exercises cuz that helps you—I think that helps you get up, you know, like I say, to where you can get up yourself.

Gandolph sustained an incomplete injury to the level of the fourth and fifth cervical vertebrae as

a result of a motorcycle accident. Gandolph's recovery began with him only being able to move his index finger to ambulating with a walker. During his recovery, even though he was able to ambulate with a walker independently; he was unable to reach a standing position without physical assistance. As he told the story,

I've had nine super therapists who were very helpful and very encouraging, and pardon the language, but I had one worthless bitch. She told me its window dressing if you can walk, but you can't get up by yourself. Instead of working with me to get to where I could get up by myself, she was worried about sitting up straight in my wheelchair.

Henry reflected, "I worked my butt off since I've been here". "You can beat everybody's expectations if you just work hard". Tim shared, "I just looked at it like I gotta do this. It'd be better get up and do it for my kids. Show 'em can't quit, can't give up, so I did it".

Reflecting on Rehab. From bolts with skeletal traction to surgical stabilization of the fractured vertebrae, the surgical care (acute care management) of spinal cord injuries has evolved with advances in medical science. Junior was injured in a MVA in 1974, 38 years ago, at the age of 18. He sustained an incomplete spinal cord injury at the waist level (exact level unknown by the informant). His mother, a nurse, oversaw his recovery. Junior shared,

I was down there about seven months. They started, first off, teaching me how to just to dress myself. It's a whole lot dressing yourself sitting down than it is standing up. They gave me physical therapy to make me stronger. I was down there with a lot of people that were worse off than I was. I saw that right away.

Allen said,

It was good down there cuz they had a lotta spinal cord injuries together, so it was real good. As bad as my injury was, it was good in the fact that they would get you on the

mat and I was always told them they was teaching us like a dog. They'd teach you to roll over, to sit up [*chuckles*] and to transfer, and then they would give you—do our bowel program and a shower and stuff.

Allen was injured in 1980 and he was 21 years old. The researcher was told by several informants, the rehabilitation programs in place today were not available when they were injured. The previous site for rehabilitation in the state was described as a vocational rehabilitation setting.

Bill, a key informant, shared how his admission to a rehabilitation program was delayed for a pressure ulcer to heal. "I was bedfast for all but three hours a day for two or three months". Bill was 53 years old when he was injured. He fell from a ladder while trimming a tree in his backyard. He sustained a complete injury at the level of the sixth thoracic vertebrae. He is angry his rehab was delayed for three months; he said he wonders if his level of function would have been better.

Bubby, was 46, when he was injured in a coal mining accident. He worked underground in a coal mine for 24 years. He was working in a coal mine when part of a ceiling caved in; his left leg was crushed and he was trapped by debris. He sustained an incomplete injury at the level of the third lumbar vertebrae when the rest of the ceiling caved in on top of him. His rehabilitation was delayed for a year due to a recurrent infection in his left leg. He reported he had surgery on his left leg six times and received intravenous antibiotics as well as oral antibiotics many times during the first year following his accident. He worked with physical therapists in between surgeries on his left leg. At the time of the interview, Bubby was ambulatory, reported ongoing difficulty navigating steps (has ramps at his house), and was playing with his grandchildren. Dave spoke of his time in rehab. He said,

seemed like it was backwards to me when I was there 'cause I wanted to do one thing to get myself straightened out to where I could—when I was sitting in my wheelchair in the hospital, I was like Eeyore trying to find my tail.

The researcher met Dave the day before he was discharged from a rehabilitation facility. He sustained a complete spinal cord injury at the level of the fourth cervical vertebrae. The truck he was working under fell off the supports and snapped his neck forward. He agreed to participate in the study. Together, we decided it was best to wait until after he was discharged to conduct the interview. Dave was the first interview the researcher conducted in their home.

Elrod, a key informant, said he spent half the time in rehab than he was scheduled to. “They told me I didn’t need rehab, to keep doing whatever I was doing, because I push myself harder than they did”. Max stated “I’m basically self-taught. I taught myself everything I know about being in the chair”. The majority of the informants stated they benefited from the rehab experience. The informants shared the experience of meeting a SCI survivor for the first time. The benefit of meeting a SCI survivor was shared by all of the informants; some went months before meeting a SCI survivor following their accidents.

The majority of the informants told the researcher the statement “You will never walk again” should never be said. They are fully aware they are very hurt and as they said we aren’t stupid; we know we can’t move. But why must we (doctors and nurses) take their hope away? Talking about it (the spinal cord injury) takes energy and they need their energy to get busy, learn what they have to, and get out of there. Then once home they start figuring out what works best for them; their new normal.

Rather be Outside. The category *rather be outside* was shared by all of the informants.

Elrod, a key informant, said when he was in the hospital he couldn't wait to be outside. "I was just trying to get outside, just trying to get out there and hang out with the birds and stuff".

Many of the informants' spoke of being outdoor people; going hunting, fishing, and camping.

George said, "I mean with my friends we like to go four-wheeler riding and stuff like that.

Hunting. We get together and do some shooting". He spoke of his four-wheeler.

I mean like four-wheeler riding is a little more difficult to get on the four-wheeler, and I don't have the balance and everything, but I traded in my regular ATV for a side-by-side that I can actually set in, and then I put a hand control in it kinda like a car. Hank, a key informant, said "yeah, I have a Polaris Razor Side by Side that I put hand controls in. I use it to get in the woods now".

Max shared his feelings for the outdoors. He said "something about these hills, the mountains, something about—I want to say fresh air, but I don't think that really qualifies. It's something about home. It makes you feel like you're home". Max loves to fish.

I love fishing. Fishing is great. I enjoy that. It's not really about the fishing. I could go all day and not catch a thing and be just as happy as can be because it's the fact of being outside and enjoying the outside and the fresh air and the sunshine and just enjoy that greatly. My wife and I have taken many camping trips.

The majority of the informants spoke of loving the outdoors of being outside enjoying the land. Elrod, a key informant, spoke of the time he (a special design so they could roll their wheelchairs on the boat) tested to see if the boat could float. Elrod said,

The first one we made out of wood. They just shoved me out there. You're either gonna sink or swim! *[Laughter]* We put the lifejackets on our chairs, cuz even though you're paralyzed, you can still swim. A lot of people don't know that. You just doggy paddle.

You can drag your legs right behind you. When we go out fishing out on the boat, we put our lifejackets on the chairs, cuz these chairs are like three grand. Save that chair! Cuz you make it to the bank, it doesn't do you any good if you don't have a chair. You're not gonna go anywhere.

Positive Attitude. The category *positive attitude* centered on how informant's view life. Bill, a key informant said "just try to immediately keep a positive attitude following the accident". Bob said, "attitude's 90 or 95 percent of gettin' better. That's one thing that always helped me". Dean said, "keepin' a positive attitude" was the answer. Fred shared, "Cuz they tell you you'll never walk or never—and I remember—it's amazing how far you can come. That's why you gotta have a positive mind". George said, "just to try to keep your head up and keep a positive attitude". Henry said, "You gotta keep your spirits high". Hank, a key informant, shared "I was doin' well, in a good state of mind".

Elrod, a key informant, shared "when people see me out getting around and smiling, they tell me, 'Bless your heart', this and that. Who else is gonna do it?" During the interview, Elrod was talking about having a spinal cord injury. He said "I never paid any attention to it. Like I said, I don't on any level. I just know I can't move my legs. I still do all kinds of stuff". He further shared,

It sucks, but I'd rather be in this wheelchair than be blind. I'd rather be in this wheelchair than have a gambling or a drug addiction, or an alcohol addiction. Those people are the ones that are hurting. They've lost everything. They don't give a damn about anything. They have no quality of life. If you're in a wheelchair, you still have a quality of life. Hell, I got the cleanest house on the block. You can still have a good, quality life. I'd rather be in this wheelchair than a lot of the stuff I deal with, the people.

Elrod said, “my friends tell me I probably got more girls now than before I got hurt. They say that to me all the time. Dammit! They wanna borrow my wheelchair. Alright, the bidding start at 1:00 pm for the weekend ”.

Men Like Me. The category *men like me* facilitated dialogue and sharing amongst the informants. The data reflected a desire to meet other men with spinal cord injuries (survivors); the sooner the better. Meeting with, speaking with, asking questions, and hearing the survivors’ story and their journey from hospital to home inspired them to as they would say “get busy” and “get to work”. Several of the informants expressed anger at anyone not in a wheelchair telling them “I know how you feel”. Some made connections with other men with spinal cord injuries while in rehab; while others were the only spinal cord injury patient in rehab at that time. The researcher was told by the majority of the informants that meeting men like me was a turning point in their recovery. The informants stressed the need for a peer counselor for newly injured men and women (80% of spinal cord injuries are male). Bill, a key informant, said,

when they would have somebody in there that'd been in an accident, and I listened to him. I take that as Gospel. He's tellin' me the facts. He can relate his life—how it was before. He's in a wheelchair now. Let him tell me. Let him tell everybody in here, this is the way you're gonna feel.

Bubby shared his experience of meeting a SCI survivor while in the hospital.

The doctor, he sent a young man that had been injured but he'd been injured for like three months or so, or four, and he'd been through some physical therapy also. He sent him up to my room to talk to me. He come up on crutches and sat down and we talked. He said, "I know about how you're feelin'." He said, "You're feelin' like this is it for you, ain't you? You're gonna be in that bed the rest of your life." I said, "Yeah, I do. I can't get

out." I said, "How am I gonna—with my back broke like it is and I can't have no use of my legs and stuff." He said, "Some of that may come back." He said, "I was that way when I first got hurt." He said, "But look at me now." He said, "Now I'm up walkin' on crutches." He said, "I'm takin' therapy and stuff." That was really encouraging.

The SCI support group and the Challenged Sports Program are methods to stay connected and reap the benefits of being around men like me. Elrod, a key informant, said "I learn something new from everybody, from my buddy that's in a wheelchair, other paraplegics. It's mostly me helping them out, because I've suffered so long in trying to figure everything out". Several of the informants (SCI survivors) will come to medical facilities to meet men who are newly injured. A feeling of brotherhood, a sense of community, and concern for others is evident.

Got to Have Hope. The category *got to have hope* begins with a positive attitude. This category is grounded in faith, belief, and hope of them walking again; and if not here, then in heaven. The informants shared stories about when and how they were told of their spinal cord injury. The group shared their anger and rage for anyone who told them "You will never walk again". The men are not in denial as the health care professionals (emic view) may believe; they know they are hurt and hurt bad. What they want is to hang on to hope while dealing with today. Allen was told by his neurosurgeon, "by our medical books, you will never walk again, but always believe in the good book, and one day you may walk again". Allen said, "So, I'm still believin. I've got a pair of shoes on the altar waitin' on me". Dave shared "I'm feeling a lot more than what they said I'd ever feel, so you do got to have hope and it'll come". Gandolph, a key informant, asked his doctor, "Doc, you can bring me back, can't ya?" He says, "I know you, and I think I can." Since then, he's told me that he is very surprised that I walk, but knew that I

needed to start gettin' busy".

Hank, a key informant, said, "after surgery and all that, they wouldn't say nothin' about my spinal cord. They wanted you to keep hope". Many of the informants shared their beliefs about walking again or being healed. "Who are they (doctors/surgeons) to tell me I will never walk again? How do they know?"

Based on what the informants' shared, the researcher developed the following scenario to share the emic view of the men who have sustained a SCI. Imagine, here I am, lying in this bed. I can't move my legs. I am in tremendous pain. I know I have really done it this time. I am hurt really bad. I am used to staying busy: working, camping, hunting, and spending time with my family and friends. From sun up to sun down, I am working on something. Now, as I lie here I have nothing to do but think. My mind races, I worry about my family and work. What will life be like? Will I be able to have sex? I tell myself I just need to get busy and if I work hard I can go home. What no one seems to understand is I don't want to talk about my injury right now. I am not in denial and nobody better mention depressed around me. Talking about something when it will not change the outcome is a waste of precious energy and encourages negative thinking.

This is a challenge, an ad "venture", and I will do the work. Just do not tell me I am NEVER going to walk again. Instead tell me what I need to learn and accomplish so I can go home. The harder I work, the faster I will be able to get out of here. Let's deal with the here and now. The fact is, when well-meaning health care professionals (authority figures), tell me "you will NEVER walk again" it makes the work of moving forward even more difficult.

As the collective voice of the informants shared, drawing attention to and focusing on what they cannot physically do anymore threatens their mind-set. In order to face the challenges

associated with a SCI and to keep moving forward, the informants shared you “got to have hope”.

Figuring out What Works Best for Me. The category *figuring out what works best for me* was woven in the interviews. The informants shared information about a process of learning what works best for them after their spinal cord injury. They are taught how to care for their activities of daily living during rehab. However, the informants spoke of the time after discharge, when you first come home and start figuring things out for yourself. Elrod, a key informant, shared his frustration in learning how to take care of himself. He said,

What would you do? How do you do that? There was no one to tell me. It was a tough thing to figure out. There’s so many little things, subtle changes that you can make, that make everyday life just totally different, totally different.

In this category, informants shared many lessons learned with the researcher. From the modifications necessary to their homes, to figuring out how to drive, and figuring out what works best for their body. The creativity and problem solving abilities of these informants was inspiring. Bill, a key informant, figured out his arms was not long enough for him to push up and clear the surface when transferring. Bill told a friend about the problem.

This is what I need built. Need two pieces—like, 3/4-inch plywood—smooth on both sides. You can radius the corners. Sand 'em in. I need two handles put on top of 'em that are 90 degrees with this plate so's I can grab a hold of 'em, and that will get me a couple of inches up above her. At the same time, these things are like a foot square, and they provide stability and a platform.

Bill knew he couldn’t come home without a ramp at his house; “some close friends of mine built my ramp on the front of the house. I had to have that done before I could home”. Several of the

informants spoke about learning to listen to their bodies; paying closer attention.

Max shared his routine for the evenings. He does his bowel program every night. He figured out over the years having daily bowel movements was best for him and his health. Since his mornings are very busy he elects to take care of his “business” in the evening. Once he has finished his bowel program he transfers himself into a tub of warm water to soak.

The nightly warm bath serves many purposes. He has learned the water helps to relax his muscles and helps with muscle spasms. He has fewer urinary tract infections and he sleeps better at night. He said the “professionals” told him he needed a handicapped accessible shower and shower chair. Max has not made any modifications to the tub. Because of his excellent physical condition, he is able to transfer himself in and out of the tub. Bubby shared,

I've found out that when my back gets to hurting too bad and stuff like that and I get too tired, the best thing to do is to lay down and take a nap. Then when I get up, then the pain is gone a lot.

Many of the informants discussed the dangers of pain medication. They prefer other methods such as, soaking in a hot tub, lying down and resting, and the use of ice and heat on sore muscles. They stressed the dangers of taking pain medication on a regular basis and encouraged others to “get off of it”.

Fierce Spirit of Independence. The category *fierce spirit of independence* was described by Allen as “I’ve had to go from the old Allen that worked to a new person that he’d either have to ask for help or you just learn how to do it yourself”. “I’ve done a lotta things since my injury that they said I would never do. I went snow skiing here in West Virginia”. Bob shared with the researcher, “I’ve got a Yamaha Rhino with hand controls. My granddaughter and myself, we ride back on the hill a lot of times in the evening, go back ‘ere and look for deer,

so I can leave my house and go back on the hill”. Bubby decided one day during his recovery he was ready to drive.

When I first drove, I ran into a back of a car because I was gonna try to drive, and it was an automatic, it's my wife's car. I was gonna try to drive. In my mind I knowed I could drive. As I kept shoving the brake, the car kept going. I had my foot on the brake and the gas.

He shared “the best thing to do is not to think about the things that you used to do, but it takes you time to realize this. The thing to do is think about the things that you're gonna do”.

Fred decided he was ready to drive. He also was not going to use hand controls, he did not need them. His muscle control over his knees was improving every day. So, he drove with a *two by four (piece of wood)* in his truck and used the *two by four* to apply pressure to pedals.

Hank, a key informant, spoke about his truck.

It's a quad cab, so there's a seat that comes out from under the driver's-side door, and I transfer from my chair onto that seat, and then hook it to my crane, and put my chair in the back of the truck.

Of the twenty-three informants interviewed, six of the informants own and drive trucks. In order to transfer into a truck, the men must have excellent upper body strength and risk injuring their upper limbs. Consistently, the informants, no matter their level of injury, fight to be as independent as possible. One of the informants did not have a driver's license so he drove his ATV instead. The majority of the informants owned more than one method of transportation. They owned cars, trucks, boats, and various forms of ATV's.

Dave was three months post injury when we met. He sustained a complete injury at the level of the fourth cervical vertebrae. Dave was the only informant physically unable to be

independent with mobility. When he was discharged, he required the functionality of a hospital bed due to his level of injury. When the hospital bed was brought to his home, it would not fit through the hallway to the master bedroom. So, the hospital bed was set up in what was their dining room. Dave was dependent on his fiancée for everything or so the researcher thought.

During the interview, he asked for a cigarette. The researcher thought, he cannot smoke a cigarette and why would she give him one? The researcher observed her light a cigarette, place a bath towel on his chest, and place the cigarette in his mouth. Dave smoked a cigarette. The towel was necessary to catch the ashes as they fell from the cigarette. He told her when he was done. She removed the remainder of the cigarette from his mouth and put the fire out. Then, she took the towel, went outside, and shook the towel to remove the ashes. The researcher observed her staying close by and watching Dave smoke. The etic view of the nurse wanted to educate them on the hazards of smoking, discuss the risks of him being burned by a falling cigarette, and the possibility of a house fire. However, if he can do nothing else independently he can smoke a cigarette.

Caring. The category *caring* encompasses caring for self, caring for family, caring for friends, caring for neighbors, caring for animals, land, place, and caring for others. Allen said caring is, “It’s just people that go out of their way to help you or they just love you and you can tell it. You don’t have to ask; you can just sense it”. Arnie said, “Caring, that’d be worrying about others and caring about what others doing, think, and stuff”. Bill, a key informant, said caring is “respect and love”. Bob shared his thoughts about his rearing his granddaughter. That’s like with that girl. It’s great to be able to do what I can for her and care for her cuz she needs it”. Bubby said, “I may not be able to do a whole lot, but some of the elderly they either maybe can't get meals or they can't get to the doctor. And I take them”.

Dave said, “You can't be a selfish person because everyone else has got feelings too and in order for you to care for others you have to care for yourself”. Dean said, “I mean it means that they're very—usually they're very good listeners or they're empathetic. They get to learn. Everybody can grow from one another no matter whether you're walkin' or not”. DG spoke about compassion as caring “you learn to be compassionate”.

Elrod, a key informant, shared “nobody has to take care of me. I take care of them. The way it was before I got hurt and the way I wanted it to be after I got hurt”. Elvis said, “caring for one another, each other”. Frank spoke about visiting schools and talking with the children.

I'm always in the community helping people. I mean just to care about other people and like their feelings, and just like think about other people and think about what they would want, and just think about like not just about your-self. Selfless.

Fred said,

I could tell by your facial expressions or your talk, your language and the way you act. If you didn't smart me off or throw things around or things like that. You could tell by the voice. The smile means everything too I guess.

Gandolph, a key informant, shared “I tell people the accident was no big deal, but losin' my wife sucked big time”. He shared with the researcher that his wife died from a ruptured aneurysm a year after his accident. He said his mother moved in after his wife died to help him. He regained control of his bladder one month before his wife died. He was relieved his mother would not have to catheterize him.

George said, “I mean like a caring person is somebody that, you know, gives their time. I mean they're a giver. I mean they're not self-involved or anything like that”. Hank, a key informant, shared, “Do all you can for yourself. It really changed my relationship with my wife.

She turned into a caretaker and there's really no affection in our relationship now". Henry's point of view was "caring about others and their health. Being nice". Junior said, "Let's see. I think it means, to be concerned. I care a lot about, I get emotional anymore about things that I see". "I think your actions have to speak louder than just your thoughts".

Justin said, "you care about what they think and how they feel. You do anything you could to make them feel better or help take care of their needs too". Luke, shared, "I do what I can". Luke shared with the researcher that his overall health had deteriorated over the past three years so he moved in with his sister in the spring. He said he knew the time was coming when he could not stay alone. He wanted it to be his decision and on his time.

Mark, a key informant, mentioned caring being reciprocal. He spoke about his son who has brain cancer. Mark spent a month at his son's bedside when he was first diagnosed with cancer at the hospital. His son was 12 years old when Mark sustained his SCI. Mark remembers his son being with him during his recovery after his accident. Max shared,

There are some people who will need things that will not ever say it. They won't ever say it. You have to figure that out. You know what I'm sayin'? It's like I was mentionin' about some of the older people that I help out. I know they need things, but they—they're proud. They refuse to ask for it.

Beliefs in God. The majority of the informants (22 out of 23) shared their beliefs about God freely and discussed the role faith played in their lives. Allen and Dave told stories of how they became believers and how their faith was strengthened on the day they were injured. Allen shared,

I went to church before I got hurt, but I was never a Christian. When I got injured, had a car wreck, I was dying and God came to me in a voice and told me I could get saved and

live or not and die. In the Bible, it talks about the 23rd Psalm, the shadow of death.

When I asked God to forgive me of my sins, I watched that shadow come outta my body, my black cloud.

Dave said,

before my injury, I didn't go to a church. I'm godly now. I believe in the lord and everything and I always have. Right now, when I get better, I got to find a good fireball church. What I mean by that is I like to—if I'm gonna go to a church, I want to see them up and bouncing and praising God like that. I don't like to set back and relax. It's not really church to me.

Dave's accident happened at his home in the driveway. He was working under his truck when the supports slipped and the truck fell on top of him. He told the researcher his head snapped forward and he could feel his body becoming paralyzed. As he described the experience, a feeling or numbing sensation began at his neck and slowly went down his body to his toes. He sustained a complete injury at the level of the fourth cervical vertebrae. His interview was the first to be conducted at home, his level of injury was the most severe of the informants interviewed, and his length of time injured at the time of interview was the shortest at 3 months.

Dave shared,

I'm a firm believer. The way my accident happened that I was leaving this world there, and I told my fiancée' and my son that I loved them. Tell everybody I love them, and my breath was leaving my body, and I started praying. It's like somebody stuck an air compressor in my mouth and my chest just—I was full of air. My eyes, my vision come back. I was really at peace, and I was actually calming the people down around me after it happened. I was just at peace.

DG spoke about his faith and what it means to him. DG shared, I am like I am, but—I'll give you a good example. You wonder—you go through your depression stage, as your pity party, I guess you would say, in your life. I ended up like this. There's questions why sometimes. But then you realize, you know what? God is still in control. He's not went anywhere. He's still there. You have 24 hour a day contact. I finally come to the point to where I realize like, you know what? The devil is a battle every single day. He's as real as anything. I finally just got to the point one day to where I said, 'You know what? You might fight me. You might hurt me. But, you are not gonna destroy me'.

DG's spinal cord injury was the result of a construction accident. He sustained an incomplete injury at the waist level (exact level unknown by informant). He shared with the researcher he wishes he could go to church but he is afraid of accidents (bowel and bladder). Several of the informants who have less physical independence, have concerns about accidents. In some cases where transportation is an issue, the informants shared they miss attending church. DG celebrates his faith through singing. He shared a story about when he first started singing gospel music.

When Fred had that sermon he says, "Sometimes you just have to step out on faith". It was like someone hit me with a hammer. It was like, okay, I know what that's for. I said, okay, I'm gonna do this with music, but I warn you ahead of time, when I first started singin', the cats would not even stay in the same room. Is that tellin' you have a long ways to go. I just tell 'em, I'm not a professional singer. I can only sing what I know I'm supposed to sing. That's just the way it is. If I hear a song and I like it and it's

meant for me to sing it, then I'll go get it and I'll learn it. It's just how God works, I guess.

Max shared his experience of a hearing a sermon on how God punishes people for wrong doings. Max sustained multiple injuries from a construction accident. He sustained a complete injury at the level of the 12th thoracic vertebrae. Max was injured at the age of 21 and has been injured for 33 years. Max shared,

I'm a Christian believer. I attended church for many years. I was really looking forward to gettin' back there and seein' some of the people. Just I guess it's just a good feeling. It gives you a good feeling. One of the things that the pastor brought up was the fact that he welcomed me back and told the congregation. A lot of people came over and shook my hand and hugged me and talked to me. It made me feel really well, really good. He said "I had a sermon for today, but since Max is back today, what we'll do is we'll have a sermon on how God punishes His children for wrong doings in their life".

Max said "It gave me a lack, not of faith in God, but it gave me a lack of faith in man. I don't attend church very often. I do attend church with my wife but not very often because I do not place a lot of faith in the words of man".

Sting shared "God's always in my mind". When asked if his beliefs changed after his accident he shared "no, they didn't change. They just strengthened, I think". Sting was injured in a MVA when he was 28 years old. He sustained a complete injury at the level of the sixth and seventh thoracic vertebrae.

The category *Beliefs in God* reflects the faith and beliefs of the informants. The strength the informants find through their beliefs and faith is inspirational. The accounts of feeling God's presence and comfort at the time they were injured was faith affirming.

A different way of living. The category, *a different way of living*, developed from informants' descriptors of the meaning of a spinal cord injury. Allen said it was "just a different way of life". Bob shared, "it slows you down on things you do, but with a little imagination, you can still do alotta stuff". DG stated, "it just means a change. You're whole world is flipped upside down. You just have to basically start all over again, mentally and physically, to cope with what you have". Elrod, a key informant, shared his view.

I always worked around it. If you spend too much time thinking about it, you're just going backwards. It's just like us (Elrod and Hank) building that boat; building that hover truck. We just built things so that we can do what we did before.

Elrod and Hank shared many instances of their ingenuity and creativity for living their lives; doing what they used to do with fishing and hunting at the top of their list. Elvis shared, "it's just a path that was chosen that you don't have an option. You just have to take good in one with whatever you have left". Gandolph (a key informant) said, "means that my movements to all four of my limbs are impaired. It's a challenge [*chuckles*]". George stated, "I mean just the way that I do things have changed".

Hank, a key informant, shared "another big change of life; that you can't walk. Gotta learn how to do things differently". Junior said,

my whole life changed whenever I got hurt. I can just say it, just putting my pants on is different. Whenever I'm gonna go somewhere, I wanna make sure that there's a place to park for me, where I can put my lift down and get out. I like to say it means, it doesn't mean that much, but it does. Like I said, I try to do everything that I can to live as normal a life as I can live. There's still things that I'm not gonna be able to do. I can't—well, I can't do that. See, I've been in this thing so long that most things that I start to say I

can't do, I've done. It just, to me, it means having to think about, I can't just jump up and run somewhere and pick something up or get something. I have to think about what I'm gonna do before I do it. There's usually a way, if I just sit down and think about it. Justin said, "It hadn't changed a whole lot, 'cause I'm still real active and do everything I done before, pretty much. You just have to do it a little different ways sometimes". Justin, was injured when he was 19 years old. He sustained a complete injury at the level of the 11th thoracic vertebrae. His accident occurred while driving an (ATV). Justin shared how he decides where to shop and eat in his community. His primary criterion was the state of the bathroom. It had to be clean; large enough to maneuver and the actual door on the stall had to swing out of the toilet area. When the researcher was preparing to leave his home Justin's father shared a story. He spoke about the day Justin came home from rehab. The family was having a get together to celebrate Justin being home. When they could not find Justin they asked his father where he was. He told them Justin was down in the field installing hand controls on his car. Justin stressed the importance of creating a wheelchair friendly environment to minimize the barriers so you can maximize your independence. Several of the informants' spoke of their environment and changes they had made to their homes and vehicles. Luke shared,

Mercy. It completely turns your life 360 degrees. It's really what you wanna make out of it. If you wanna lay around and give up, that's good, that's alright, too, I guess, if that's what some wants to do. Like I said, they told me five years was a long life.

Luke was 24 years old when he was injured in 1980. Luke was working in an underground coal mine and he was pinning the ceiling using a piece of equipment that forced bolts into the ceiling of the mine to stabilize the area. During the process, his clothes caught in the machine and he was thrust into the ceiling of the coal mine. The impact broke his hard hat and light. He finished

his shift with a borrowed light from the supervisor. He spoke about being sore and being unable to turn his head. He worked his next two shifts and went on vacation as planned.

The family made a camp at their favorite spot on the river (been there many times). He told the researcher the soreness in his neck was improving. He dove into the river and rolled on the bottom. He was immediately paralyzed and floating in the river. His friends at first thought he was “kidding around” floating in the water. They rescued him and drove him to a hospital. The doctor told Luke the x-rays of his neck showed evidence of a previous injury to the bones in his neck. Luke unknowingly fractured his cervical vertebrae when he was slammed into the ceiling of the coal mine. Luke was told he may live five years after his SCI and that was 33 years ago. “He had girls to watch grow up”.

The categories have been explicated with supportive evidence from the informants. Each of the categories was presented with informant stories woven into the fabric of the data analysis. The third phase of data analysis resulted in the discovery of patterns.

4.9 Third Phase: Patterns

The third phase of data analysis contextualizes the categories into patterns (Leininger, 1991). The patterns emerged from commonalities within the 13 categories identified during the second phase of data analysis (Leininger, 1991). In this study, five patterns emerged during the third phase of data analysis. The patterns were: A pattern of valuing independence, privacy, creativity, and determination as a mind set for self-care; A pattern of realism and optimism described as doing the work necessary to move forward; A pattern of faith described as firm believer, strength, and the hope of being healed; A pattern of community where challenges, opportunities, and lessons are learned; and A pattern of caring as described by presence, concern, and assistance with and from others.

Pattern One

A pattern of valuing independence, privacy, creativity, and determination as a mind set for self-care. Pattern one is supported by the categories of caring, fierce spirit of independence, figuring out what works best for me, and rather be outside. The desire to optimize their level of independence was shared by each of the informants. Informants discussed during the interviews how they faced their reality, a spinal cord injury; can't change what happened; get busy, and get me out of here. All of the informants sustained a spinal cord injury as a result of trauma and many had additional initial injuries or complications develop while in the hospital. A few informants were self-taught and learned what worked best for them. The majority were taught the basics of self-care; management of bowel and bladder, prevention of pressure ulcers, and mobility (individualized on type and level of injury).

The desire and ability to drive a vehicle (hand controls, in a van with a lift, on an ATV) fueled the determination to learn what was necessary and be discharged. The age range when injured was thirteen years to sixty years of age. It is disconcerting when one day you have control of your body and bodily functions and in a "blink of an eye" you are injured and totally dependent on others to help you, bathe you, turn you, feed you, and take care of your bodily functions.

The key informants provided further insight into the reality of a spinal cord injury. The informants used terms such as exposed, embarrassed, humiliated, frustrated, and degrading. The key informants explained how these feelings listed above (despised feeling dependent) sparked the determination and mind-set to get busy, get better, show me what I need to do, let me do it, and an I want out of here (hospital) attitude.

Clearly, regaining any level of independence and taking care of things themselves created

forward movement toward recovery and discharge. Elrod, a key informant, discovered he could empty his bladder using digital stimulation. During his rehabilitation, he was taught how to insert a catheter every four to six hours to empty his bladder. He was taught digital stimulation to facilitate a bowel movement. After many urinary tract infections, accidents during the night, the concern of accidents when awake, the frustration of “peeing on my girlfriend” at night, and searching for an alternative method for bladder management he discovered what works best for him. Wear a condom catheter with a collection device secured to his lower leg and perform digital stimulation to empty his bladder. Elrod figured out what worked best for him and reduced his incidence of urinary tract infections in the process.

Pattern Two

A pattern of realism and optimism described as doing the work necessary to move forward. Pattern two is supported by the categories role of hard work, a different way of living, and positive attitude. The informants were used to hard work. The majority worked in construction, in coal mines, or in factories. Hard work pays off. Hank, a key informant, graduated from high school, went to college for two years, and then went to work in a coal mine as an underground welder. Before his motorcycle accident, he was making “good money” working in a coal mine. He provided well for his family. “I started out in welding when I was about 14. I worked in an aluminum fab shop for about a year-and-a-half, and then I got into the coal mines”. Hank shared his experience with rehabilitation. “I was doin’ well, in a good state of mind, and they just treated me like family, more or less”.

The key informants assisted in validating this pattern. All of the informants talked about staying focused on “getting busy” and learning how to care for their self-care requirements. It was made clear, men take care of their families. The majority of the informants had never been a

patient in the hospital prior to their accident. These informants did not like being in the hospital or being confined to a hospital bed. The informants were used to physical activity: being outside, working, in the woods, camping, hunting, fishing, working in their garage, and doing things with friends. The majority of the informants knew or had a sense they were “hurt badly” at the time of their accident. Realism became evident when they were recovering from surgery. They did not need anybody telling them they were hurt. They knew they were hurt. What they wanted were the facts. The informants wanted to focus on today. Being “tied” to a hospital bed was torture for these informants. The solitude threatened their mental attitude: too much time to think, no use dwelling on what is done, and I cannot change it.

Appalachia has been described in the literature as having a fatalistic worldview (Jones, 1994; Huttlinger & Purnell, 2008; Small, 2013). The informants were realistic about their spinal cord injury. They described a realistic worldview. I am hurt. I can’t change it. So, let me “get busy”. They also exhibited optimism as they worked toward going home and shared stories about why they needed to “get busy”. Each day when drenched in sweat from physical therapy, there was the knowledge they were moving forward getting closer to home. If they choose not to discuss their injury with anybody, it does not automatically mean they are in denial. They know the truth but their emic view shared was “why talk about something that cannot be changed”? They are conserving energy. The energy needed to work hard in physical therapy, to improve, and to move forward closer to home. So, please refrain from saying “you will never walk again” or “I know how you feel” unless you have sustained a SCI.

Pattern Three

A pattern of faith described as firm believer, strength, and the hope of being healed.

The third pattern is supported by the categories of beliefs in God and got to have hope. The

informants when sharing their faith and beliefs in God spoke of God as their strength and the source of their strength. God provides a “firm believer” the strength to face adversity. Many of the informants used the phrase “firm believer”. Several of the informants did not participate in organized religion or attend church. God is everywhere. The hope of being healed was shared by all of the informants. There is always hope; hope in research and the belief anything is possible. One informant talked about how he walked in his dreams. Another informant shared he knew he would walk again; maybe not in this life. As he said, “There is a pair of shoes waiting for me on the altar in heaven”.

Pattern Four

A pattern of community where challenges, opportunities, and lessons are learned.

Pattern four is supported by the categories of men like me and reflecting on rehab. The informants spoke of how important seeing and hearing from a SCI survivor is; they speak the “gospel truth”. The informants who were visited by a SCI survivor or who received rehab with others with a SCI spoke of how important being with men like me was to their recovery and mind-set. One informant described having a survivor visit as the moment he knew he was going to be ok. The men recognized life would be different but they would be ok. The collective voice of the informants was meeting a SCI survivor gave them a sense of hope and they were able to see with their own eyes what was possible. By listening to the survivor’s story, hearing how they fought to get better, and what lessons they learned along the way was inspirational and validated that with hard work anything is possible. The need for community is actualized by participating with the SCI support group and/or the Challenged Sports Program. The men share a common bond. They see men like me. They support one another, show concern, mentor new members to the group, share ideas, discuss new products, learn together, compete against each

other, and plan recreational outings. The leader of both groups is the recreational therapist at the medical facility. He has been with the rehabilitation program for over twenty years. He challenges the men to get active, get busy, do something, and stay connected. He is very tenacious and rarely takes no for an answer.

Pattern Five

A pattern of caring as described by presence, concern, and assistance with and from others. The pattern of caring is supported by the categories of support of family and friends and role of neighbors. The informants shared feelings of gratitude and appreciation for those who stood by them after they were injured. Most required assistance during their recovery and until they figured things out. They reclaimed their independence as quickly as possible so they could do for others as is their nature. Interestingly, family, friends, and neighbors have distinct roles.

Family is blood. They will be there for you in times of need because they are supposed to be there. Friends, you choose. A friendship is based on shared beliefs, activities, and common interests. Good friends may also be considered family. Friends choose to be there for you because they want to be and not out of a sense of obligation.

Neighbors are “close” or “good” in nature. All of the informants spoke of having good neighbors. Neighbors who know each other keep watch. Since a neighbor lives next door or in close proximity of your home, they are close by in case of an emergency. The relationship of neighbors or being neighborly is reciprocal. A good neighbor provides peace of mind and promotes a feeling of connectedness.

The five patterns have been explicated and supported with evidence from the data. The fourth phase of data analysis is the discovery and presentation of themes. The data revealed three themes from the study.

4.10 Fourth Phase: Themes

The fourth phase of data analysis is the highest phase of analysis. Themes are extracted from the data; creativity and abstract thinking is expected during this phase of data analysis (Leininger, 1991). The three themes derived from the data were: Caring and concern for family, friends, neighbors, and place combined with being inspired by other men with a SCI promote a sense of belonging; Belief in God, holding onto hope, and keeping a positive attitude helps men remain focused on what they can do and not dwell on what they can't do; and, A spirit of independence, hard work, changing the environment, and believing you can figure things out are essential for getting back to living.

Theme One

Caring and concern for family, friends, neighbors, and place combined with being inspired by other men with a SCI promote a sense of belonging. The informants shared stories about the way they care for their family, friends, and neighbors. The informants used words and phrases to describe caring. Respect, love, compassion, selfless, good listener, empathic, anticipate needs, give of your time, think of others, unselfish, take care of, and a 'smile says it all'. The idea of being around men with similar injuries were crucial for the informants to see their future, see what is possible, and start moving forward to get home.

The informants' love of the mountains and need to be outside reflected a core value of belonging to the land. Home is not just a place; home is the land, the shared values of belonging to and with the land. They are hunters who show care, concern, and respect for the animals they hunt. The informants shared stories of being outdoors, enjoying the sunshine, being free and independent in the woods, figuring out how to be a part of the land in a wheelchair, and hunting and fishing again. The researcher could hear the joy and excitement in the informant's voices

when they spoke about their adventures outdoors. It was not unusual for their faces to relax when they spoke about being outdoors and even smile; a knowing smile of private thoughts and cherished memories.

Theme Two

Belief in God, holding onto hope, and keeping a positive attitude helps men remain focused on what they can do and not dwell on what they can't do. The informants in this study reflected an attitude of realism. Yes, they are hurt; very hurt. However, there is no sense of dwelling on what is done, time to move forward. Their positive attitude and optimism for the future was inspiring. From the etic view, when men with a spinal cord injury refuse to discuss their injury or stop health care professionals from bringing it up may be perceived or interpreted as in denial. From the emic view, the men are trying to stay focused on what they can do and not think about what they can't do. Dwelling on what you can't change, could disrupt a positive attitude and interfere with moving forward and going home. Don't tell anybody "you will never walk again" it takes away hope. As Elrod, a key informant, shared, "Are you God? You can't say that, cause you don't know".

Theme Three

A spirit of independence, hard work, changing the environment, and believing you can figure things out are essential for getting back to living. The reason men survive their injuries and go home after a spinal cord injury is their need for independence (how independent depends on their level of completeness and level of injury), their willingness to work hard (they know what hard work is), and an innate creative spirit laced with determination to change the environment; make it functional. Believing in yourself and tweaking things until they work for you will facilitate the journey to the new normal whatever that ends up being. Two key

informants, Elrod and Hank decided to build a boat so they could roll their wheelchairs directly onto the boat (the idea that someone has to pick you up to put you in a boat-no thank you). Hank designed the boat and Elrod tested the boat for seaworthiness.

The first one we made out of wood. They just shoved me out there. You're either gonna sink or swim! [Laughter] We put the lifejackets on our chairs, cuz even though you're paralyzed, you can still swim. A lot of people don't know that. You just doggy paddle. You can drag your legs right behind you. When we go out fishing out on the boat, we put our life jackets on the chairs, cuz these chairs are like three grand. Save that chair! Cuz you make it to the bank (of the river) it doesn't do you any good if you don't have a chair. You're not gonna go anywhere.

4.11 Summary

This ethnonursing study sought to discover and describe the culture care meanings and care expressions of men with a spinal cord injury from the Appalachian region of West Virginia. The entry into the field was through an established support group and the snowball method facilitated recruitment. Twenty three informants (five key and eighteen general) were recruited, met the inclusion criteria, and were interviewed. Informed consent from the informant was obtained prior to beginning the interview. The interviews were digitally recorded and transcribed verbatim. Data analysis was accomplished using Leininger's Four Phases of Qualitative Data Analysis Guide (1991). The categories, patterns, and themes were presented with supportive dialogue and evidence from informant's interviews and reflection of the time spent with the informants in SCI support group meetings and at Challenged Sports Program events; actualizing the enabler Stranger to Trusted Friend (Leininger, 1991).

CHAPTER 5

5.1 Introduction

In chapter four, the results of the data analysis were presented. Leininger's Four Phases of Qualitative Data Analysis Guide (1991) provided a detailed method for collecting, managing, analyzing, and presenting the data collected in the study. The results of this rigorous process were 13 categories, five patterns, and three themes.

The categories were *support of family and friends, role of neighbors, role of hard work, reflecting on rehab, rather be outside, positive attitude, men like me, got to have hope, figuring out what works best for me, fierce spirit of independence, caring, beliefs in God, and a different way of living.*

The five patterns identified from the data were: Pattern one: *A pattern of valuing independence, privacy, creativity, and determination as a mind set for self-care.* Pattern two: *A pattern of realism and optimism described as doing the work necessary to move forward.* Pattern three: *A pattern of faith described as firm believer, strength, and the hope of being healed.* Pattern four: *A pattern of community where challenges, opportunities, and lessons are learned.* Pattern five: *A pattern of caring as described by presence, concern, and assistance with and from others.*

The three themes derived from the data were: Theme one: *Caring and concern for family, friends, neighbors, and place combined with being inspired by other men with a SCI promote a sense of belonging.* Theme two: *Belief in God, holding onto hope, and keeping a positive attitude helps men remain focused on what they can do and not dwell on what they can't do.* Theme three: *A spirit of independence, hard work, changing the environment, and believing you can figure things out are essential for getting back to living.* In this chapter, each of the three

themes will be discussed in further detail. Explication will include how the themes relate to the domain of inquiry and the research questions. The three modes of nursing care actions and decisions related to the Culture Care Theory (Leininger, 1991) will be discussed with support from the literature. The goal of the research study was to discover and to describe the culture care meanings and care expressions of men with a SCI from the Appalachian region of West Virginia to facilitate and promote the provision of cultural congruent care.

5.2 Theme One

The first theme derived was *Caring and concern for family, friends, neighbors, and place combined with being inspired by other men with a SCI promote a sense of belonging*. The common bond and thread found in this theme is belonging; being part of a family (functional or not; like them or not; they are your family; your blood) , creating a group of friends or “buddies” whose foundation is common interests and values, establishing relationships with neighbors to promote a sense of community and safety, encouraging men who have been injured to get outside and connect with the land or place, and finally becoming involved with the SCI community where you see men like me; where other men inspire you to get busy, do more, try harder.

An unwritten rule for men who participate in the SCI support group or the Challenged Sports Program is no whining. The researcher witnessed fellow members of the SCI support group remind other men of the no whining policy; their behavior was addressed within the group. The informants discussed how destructive whining can be with relationships. Many of the informants voiced an opinion that family and friends don’t like whiners. The attitude is a negative one and will push people out of your life.

Another reality of being around other men with SCI’s is you meet men who are “worse

off than me”. Men with different levels of injury with corresponding functional abilities; men experiencing complications related to their SCI; men who have lost their fighting spirit. The informants shared being around other men with a SCI “it helps to keep things in perspective” and helps them see and count their blessings; family, friends, neighbors, friends with SCI’s, and the freedom to be outdoors.

The informants discussed “taking care” of their family as their most important role. They described large extended families which included “blood” family as well as close friends; many of them still live in the geographic area in which they were born. When the informants spoke of family, the researcher could see the pride in a father’s face when talking about his son; the joy in a husband’s face when sharing stories about his wife; a sense of anticipation of future adventures when discussing their friends. The informants have created a network of care and work hard to balance their need for independence with the interdependence of belonging to and with others.

5.3 Theme Two

The second theme derived from the data was *Belief in God, holding onto hope, and keeping a positive attitude helps men remain focused on what they can do and not dwell on what they can't do*. To appreciate the importance and implications of this theme, understanding the “known” or “accepted” worldview of Appalachia is needed. A fatalistic worldview has been presented as an accurate descriptor of the worldview of Appalachians (Jones, 1994; Huttlinger & Purnell, 2008; Small, 2013). What exactly is worldview? Leininger (1991) defines worldview as “the way people tend to look out upon their world or their universe to form a picture or value stance about life or the world around them” (p.15). A culture’s worldview stems from their religious beliefs and values. The people of Appalachia believe in God and have faith but do not always belong to a church or attend church regularly. The informants shared their beliefs in

God, especially how their strength to move forward came from their faith. Five of the twenty-three informants discussed attending church on a regular basis or being active in their church. These findings are reflective of what Jones (1994) shared and validate his viewpoint. “Mountain people are religious. This does not mean we go to church regularly, but we are religious in a sense that most of our values and meaning we find in life spring from the Bible” (Jones, 1994, p. 39).

When beliefs and religion were discussed during the interview process 22 out of the 23 informants shared their beliefs immediately with the researcher. One informant was hesitant to voice his beliefs about God or his views about religion when first asked during the interview. However, later in the interview when he was discussing his rehabilitation experience he discussed his beliefs. The researcher learned informants share information when they are ready. The semi-structured interview guide is just that, a guide not a roadmap.

A realistic worldview was discovered during the data analysis process. Data analysis revealed the informants exhibited characteristics of a worldview of realism with an optimistic point of view. The informants’ worldview derived from rigorous data analysis was a surprise and unexpected. Despite personal tragedy and a life changing injury, a positive attitude and optimism were conveyed by the informants. Jones (1994) wrote, “life in the mountains until recently did not allow for an optimistic gospel. Hard work did not always bring a sure reward, and so perhaps some of the mountain religion is more fatalistic than elsewhere” (p. 46). However, “the beliefs are more realistic than idealistic...” (Jones, 1994, p. 46). The voices of the informants support the realistic worldview Jones (1994) described.

The researcher discovered the informants’ optimistic point of view has deep roots in believing in God and was supported by their faith. The informants spoke about asking questions;

asking God “why” when they sustained a spinal cord injury. They also shared when the big questions come to mind it is time to get “busy” and find something to keep your mind occupied. The informants warned that dwelling on the “whys” can disturb a positive attitude and jeopardize the momentum needed to face each day.

The informants said when the mind wanders, negative thoughts bubble to the surface, and unsettling questions come to mind. That is the time to get busy doing something for distraction. Faith combined with a strong belief in God facilitates a positive “mind-set” or positive attitude. Remember, “God is everywhere”. Hanging onto hope makes you feel warm inside where once you felt cold; or maybe nothing at all. If you doubt God does exist go outside and witness his presence; “God is everywhere”; the state is “Almost heaven, West Virginia”! If one is a “firm believer” in God then one has faith in God. A loving God who doesn’t punish his children but who inspires them and gives them hope. You can’t have hope without first having faith. Hope is a feeling deep inside whispering anything is possible. Hope inspires and sustains a positive attitude. The insight regarding religion and a transition from a fatalistic worldview to one of realism (Jones, 1994) was verified and validated with the findings of this study.

5.4 Theme Three

The third theme derived from the data was *A spirit of independence, hard work, changing the environment, and believing you can figure things out are essential for getting back to living*. Key values discovered in this theme were independence, self-reliance, pride, humility or modesty, and familism. The reality of a spinal cord injury impacts on independence immediately. A spinal cord injury that results from trauma means “I was fine when I left home but did not make it home for a couple of months”. The suddenness of the situation and the reality of hearing the words spinal cord injury send ripples of fear through men and their

families. Once the initial shock occurs, families tend to come together and “rally” around their loved one. During the interviews, informants spoke of *knowing* they had really hurt themselves and a few spoke of *knowing* they were paralyzed at the time of the accident.

The 23 informants who participated in the study were active (youngest was 13 years of age when injured skiing), independent, the majority were taking care of their families by working hard, and enjoyed being outdoors (hunting, fishing, camping). There are many factors that influence recovery; completeness of the spinal cord injury, the level of injury, and other injuries resulting from the accident. Physiological functions (micturition and defecation) the men did not think about before their accident take on new meaning. When the men are still recovering from surgery, the nurse assists with these activities. With time and if physically able, men are taught and learn to care for, these physiological functions themselves; if they are unable to perform these independently a family member or caregiver is taught. Key informants discussed how embarrassing and humiliating it is for a female nurse to catheterize them or perform their bowel program.

The researcher is paraphrasing from the collective voices of the informants. At first I wasn't sure what was going on. I knew I was in the Intensive Care Unit and was in pain. They were giving me pain medicine; I was real groggy and things didn't make sense. It was about three days later I remember I started waking up, less groggy, still hurting. I couldn't move; I felt as if I was strapped down; naked; no privacy. I didn't really understand what was happening at first but I remember when the nurse came in to bathe me. I was mortified and humiliated. It wasn't the nurses' fault. She was really kind to me; talked to me, and explained what she was doing. When she left, was the first time I cried. Then when they came in and turned me over and put something up my butt. I could smell it...I was pooping in the bed! They explained to

me about digital stimulation (dig stim). How in order to have a bowel movement I would have to do that (dig stim) to myself. Are you kidding me! I never thought about when I had to go to the bathroom. I just did it. Now I have to do things to my body to take care of something that used to be on auto pilot!

The values of pride, privacy, independence, self-reliance, implode with a spinal cord injury. These values and the determination to regain them, inspire the men to “get busy”, start taking back their body, and regain some control over the situation. Nurses are taught to step in and provide care. The researcher learned how important privacy was to these men (the emic view) and how they would prefer for “private care” to be taken care of by men. Two key informants shared some information about their sex lives. Most of the informants told the researcher that the topic of sex was not usually discussed while in the hospital; it felt taboo!

The informants approached rehab as a life or death situation. The need to start fighting for their independence, fighting for their privacy, and fighting for their dignity. Men from Appalachia know about hard work and are taught the value of hard work at an early age. One day you go to work or leave the house and you do not come home. In a split second, your life and body are never the same! Your car was hit by a drunk driver at noon; you were headed to play softball with your friends. You were driving to work early one morning, a semi-truck runs a red light and you wind up under the truck! You are driving your semi-truck on a new section of interstate, you miss a sharp turn, fly off the interstate, and land on the highway below. These are but a few examples of how the informants were injured.

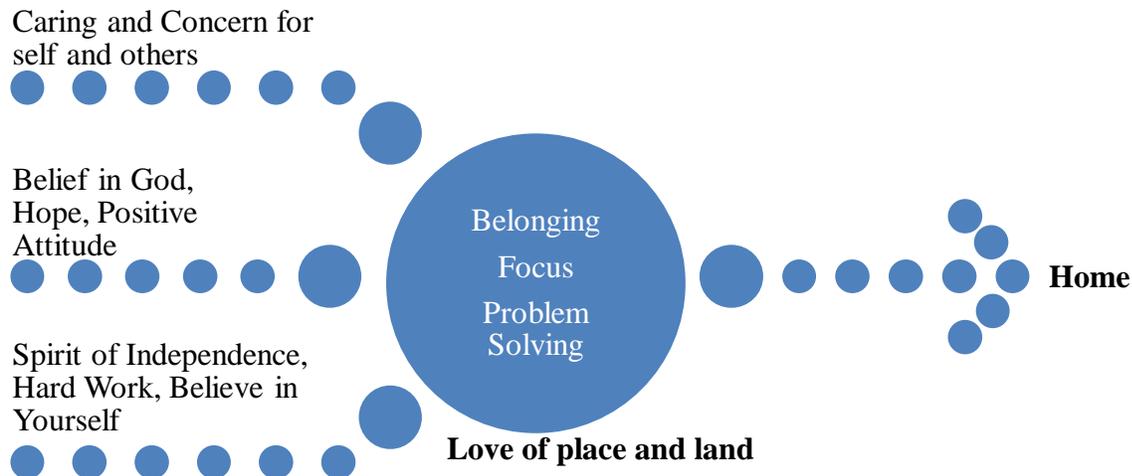
You wake up and figure out you are really hurt. As the days progress you figure out just how bad you are hurt. Nobody has to say the words aloud because you know! You are faced with the greatest challenge of your life. There are two paths: one where you lie there and give up

or the one where you do whatever it takes to get home. First, you have to believe you are up for the challenge. You have to believe in yourself. Once that hurdle is crossed, your recovery moves forward, start rehabilitation, and are headed home. The values of independence, privacy, and self-reliance combined with *knowing* you can do what it takes (if your body is able to) to get home. Once home, with support from family and friends, you continue to figure out what works best for you. The path of your new normal.

5.5 Summary

The three themes derived from the data have been explicated with supportive findings. Each of the themes stands alone but collectively they tell the story of men with a spinal cord injury from the Appalachian region of West Virginia. Yow (2005) discussed the role of oral history and memory. “For oral historians, memory is a vital concern. As in-depth interviewers, we provide an opportunity for the narrator to remember, to convey details, to provide explanation, and to reflect, because we listen” (p. 35). Yow (2005) spoke about collective memory or social memory. The phenomena of collective memory or social memory was defined as, “we listen to people who have shared the same experience with us, and we gain a feeling of identity with them when we remember as people in our group remember” (p.36). The phenomena was reflected when the informants shared about meeting men like me, learning from men like me, and being with men like me. Their collective memory was actualized in this study.

5.6 Themes Pictorially Conceptualized



The pictorial conceptualization of themes is depicted on page 90. The essence of the three themes, *caring and concern for self and others*, *belief in God, hope, a positive attitude*, *a spirit of independence, hard work, and believe in yourself* are pictorially represented separately; the beliefs and values represented converge with care expressions of belonging, focus, and problem solving. The forward motion and movement depicted in the diagram leads towards the “battle ground” known as home. Home represents hope for the future. Once home with family and friends figuring out their new normal begins.

5.7 Discussion of Findings Related to Guiding Framework

The findings are presented using Leininger’s (1991) nursing modes of action with supportive evidence from the literature. The three modes of action the nurse researcher examines with informants are culture care preservation/maintenance, culture care accommodation/negotiation, and culture care repatterning/restructuring. In accordance with Leininger’s Culture Care Theory, this study discovered and described the culture care meanings and care expressions of men with a spinal cord injury from the Appalachian region of West Virginia.

In line with the guiding framework, findings from this study may facilitate an

understanding of the culture care needs and cultural barriers of men with a SCI. Once these culture care meanings and care expressions are *known*, an environment of culture care would be actualized. An environment of culture care where an individual's culture was recognized, considered, and valued while preparing them for a life changing traumatic event known as a SCI.

The informants described the experience of a SCI as life changing, life altering, and life turned upside down. In most cases, the hospitalization for their SCI was the first time they were in a hospital. Men, who woke up one day, go outside and are never the same.

Culture Care Preservation/Maintenance. Culture care preservation and maintenance refers to “assistive, supportive, facilitative, or enabling professional actions and decisions that help people of a particular culture to retain and/or maintain meaningful care values and lifeways for their well-being, to recover from illness, or to deal with handicaps or dying” (Leininger & McFarland, 2002, p. 84). The informants shared many opportunities to preserve and maintain their values and beliefs following a SCI were we listening? There were opportunities applicable during the acute care management period of their injury, during rehab, and then once home.

First and foremost, the nurse must know themselves, be aware of biases or prejudices, and have the desire to learn about and from other people. The nurse must have the strength of character to advocate and “speak” for those in our care: the vulnerable. The nurse must see, value, and wish to *know* who they are caring for. Recognize individuals/patients belong to and are important to someone. When caring for a man with a spinal cord injury don't see a man who is broken and will never be the same again. Instead see their totality of presence as a husband, a father, a son, a brother, an uncle, a cousin, a friend, a neighbor, and a child of God. See them and not the wheelchair!

The provision of cultural congruent care is possible by recognizing, embracing, and

actualizing culture care meanings and care expressions from the emic view, the individual's point of view. Care and caring is a conscious process requiring thought, planning, effort, energy, soul, and "hard work". Certainly not, an unconscious feeling, that is warm and fuzzy where everybody is treated the same; that is the antithesis of caring.

Recognizing the value and importance of familism in Appalachia is crucial when providing care in any setting; intensive care unit, rehab, or home. Informants spoke about the importance of family and friends to their recovery and journey home. Friends are instrumental in "keeping their minds busy" and friends remind them of the activities they enjoy doing together. The art of future planning involves making plans and talking about activities they will be doing once home. A belief in God was discussed by the informants. The nurse should be open to discussing their beliefs about God. The nurse pays close attention to clues and cues from the individual regarding their faith. Be prepared you may be asked to pray with them.

Culture Care Accommodation/Negotiation. Culture care accommodation/negotiation refers to those "assistive, supportive, facilitative, or enabling creative professional actions and decisions that help people of a designated culture (or sub-culture) to adapt to or negotiate with others for meaningful, beneficial, and congruent outcomes" (Leininger & McFarland, 2002, p. 84). An example of this mode of action would be for the nurse to recognize from the emic perspective the patient and family is one unit unable to be separated from each other. Nurses should welcome the family and friends who come to the hospital and not antagonize them. The number of visitors may be overwhelming to the nurses but being present at times of crisis is a part of the culture. The visitors (valued people to the individual) will know if they are welcome by the environment, the facial expressions of staff, and the tone of voice.

The initial meeting with staff when someone you love is critically ill will set the stage for

future encounters. As with Leininger's enabler Stanger to Trusted Friend (Leininger, 1991), the same principles can be applied to this situation. Establishing a rapport and bond with the "family" (the collective group) is paramount. The nurse caring for the patient should send a message to the "family". The message should contain the nurse's name that is caring for their loved one. An explanation as to how much time before they can see the patient and their nurse will come and meet with them as soon as possible. In reality, the patient and family is one unit and should be cared for as such. These steps will assist in defusing anxiety and easing the minds of the family especially before the first visit with the patient. The nurse encourages the family to call her or him by their first name which will initiate a trust and strengthen the bond. A calmer family who trusts the nurse will lead to a calmer and less frightened patient.

The informants spoke about the times they didn't want to go to therapy. As one informant said "no one plans to fail; they fail to plan". Sting shared a story about going to therapy one morning. The researcher is paraphrasing. He was lying in bed. He said he could smell the odor of stool and knew his bowels had moved. The physical therapist came into his room and told him it was time to get up for therapy. He explained the situation and said he had to call for someone to clean him up before he could go or could they go get help? The physical therapist explained they were on a schedule and they (others) could clean him up when he got back from physical therapy.

As the researcher listened to the story, a confused look came over his face. Did the physical therapist actually tell me I could go to therapy covered in "poop" and imply their schedule was more important than him? Of course, he said he wasn't going to therapy with "poop" all over himself! When he was scheduled for physical therapy that afternoon, a different physical therapist came to get him. Sting was told he really needed to go to physical therapy

refusing sessions didn't look good. Sting did not refuse to go to his therapy appointment he simply wanted to be clean when he went.

Inherent during the rehabilitation process is a schedule of therapies. Negotiating and promoting input into a schedule would be beneficial for all involved. The very values that get men busy doing the hard work of physical therapy and learning how to take care of themselves (independence, privacy, and self-reliance) will be exhibited during their time in rehab.

Informants stressed the importance of information; not too much (as in a book), not too little, but just enough information to understand how the activities are linked to skills needed to go home.

They do not have the etic view of rehab and knowledge is power. Building in flexibility in a schedule will enhance participation and may lessen power struggles.

Culture Care Repatterning and/or Restructuring. Culture care repatterning and/or restructuring refers to “the assistive, supportive, facilitative, or enabling professional actions and decisions that help clients reorder, change, or modify their lifeways for new, different and beneficial outcomes” (Leininger & McFarland, 2002, p. 84). The realities of a spinal cord injury and the changes (spiritual, physical, emotional, psychological, and physiological) men face are overwhelming. The informants were very clear about what they need to be present following their injury and during rehab; the goal is going home as soon as possible.

They shared their need to meet *men like me* seeing with their own eyes what their future may look like. Utopia would be to experience rehab with other men who have been injured *men like me*. If that is not possible, having someone newly injured come and visit (the sooner the better according to the informants) makes a difference in their approach to rehab and keeping a positive attitude. The informants knew exactly how to achieve repatterning. They focus on what they can do and do not dwell on what is lost. As the informants shared many times, they prefer

health care professionals do not say the obvious; “you cannot walk”. A primary finding is for health care professionals to consider the impact of the phrase “you will never walk again” on men’s mental attitude and mind set. The balance between facilitating their holding onto hope without health care providers believing they would be supporting and encouraging a belief in false hope.

Based on the results of this study, rehabilitation programs would benefit from a review of their current SCI program, observing staff and patient interactions, and interview previous patients in order to gain insight on their experiences of the SCI rehab program. The medical facility and the rehabilitation inpatient unit could participate in nursing research efforts related to the process of goal setting and goal attainment during the SCI rehab program. It would be interesting to review the goals set by men with a SCI at the beginning of their rehab program. Based on information shared by the 23 informants who participated in this study, the researcher would guess one of their goals set in the beginning of their rehab program was “I plan to walk again”.

5.8 Nursing Implications

All studies conducted need to demonstrate significance to the discipline of study in this case nursing. The following sections will examine the implications and future research as related to nursing theory, nursing education and practice, and research and policy.

Implications for Nursing Theory. In this study, Leininger’s Culture Care Theory (1991) served as a guiding framework to discover and describe the culture care meanings and care expressions of men with a spinal cord injury from the Appalachian region of West Virginia. The findings of this study will facilitate an understanding of the culture care needs and cultural barriers of men with a SCI. Thompson (1990) discovered during the rehabilitation phase

individuals were expected to conform to be successful and any deviation was labeled diversity.

In this study, the informant interviews were conducted in multiple locations (medical facilities, restaurants, homes, gyms, and vehicles) chosen by the informant and was not focused on one facility's SCI rehabilitation program. The SCI rehabilitation programs the informants attended, experienced, and reflected upon during their interviews took place in four states and spanned thirty-three years.

The findings of this study confirm what Thompson (1990) found with regard to the environment of rehabilitation and the need for cultural respect and sensitivity. Thompson (1990) concluded in her study, "diversity of expectations and actions by patients was often mentioned by rehabilitation staff as an explanation for patient's failure in achieving the goals of rehabilitation" (p. 191). This finding is reflective of the negative outcomes Leininger discussed were possible when cultural congruent care is not reasonably provided (1991). When patients are labeled noncompliant with the medical regimen the blame is shifted towards the patient and a spirit of inquiry of investigating why is lost (Leininger, 1991).

The findings of this study support Leininger's (1991) stance that culture care meanings and care expressions are discoverable using the ethnonursing method. The Sunrise enabler (Leininger, 1991) provided a framework for the development of the semi-structured interview guide used in this study. The novice researcher learned attempts to adhere to the interview guide were unsuccessful. The informants' method of story-telling was more effective and the information provided addressed the questions in the interview guide. The end result of their story-telling was deeper and richer data and facilitated the researcher paying closer attention to their facial expressions and body language during the interview.

Implications for Nursing Education and Practice. The findings in this study have

implication for nursing education and practice. The importance of family is not new in the literature. Familism is well documented as a core value within Appalachia (Jones, 1994; Tripp-Reimer, 1980; Small, 2013). Discovering the various roles and expected level of support from family, friends, and neighbors was insightful. The complexity of a spinal cord injury on the body and spirit requires nurses pay attention to detail and subtle cues from patients and their families. The culture care expression and lifeway discovered in this study regarding the nurse *seeing* the patient and family as one unit (do not separate the parts) coincides with Leininger's stance on interconnectedness as integral to families (Leininger, 1991).

Nurses meet individuals and their families unexpectedly. Meeting someone after they have sustained a spinal cord injury is a time of crises; for all involved. There is a specialty certification process for registered nurses who work in a rehabilitation setting. One informant shared a story of an intensive care nurse telling him she was afraid to turn him. Unfortunately, this informant developed a pressure ulcer to the coccyx area while a patient in the intensive care unit. He is convinced the pressure sore developed because the nurses were afraid to turn him. His transfer to a rehabilitation facility was delayed for about three months to facilitate wound healing.

Teaching transcultural nursing concepts in undergraduate and graduate nursing programs should be mandatory. Integrating the transcultural concepts into curricula would be a first step. Fundamental courses in nursing curricula should teach the importance of oral history. The emphasis on completing nursing assessment documents must be replaced with teaching the art of active listening. If students would simply go "sit a spell" with a patient and listen to their story they would learn more than their forms could hold. The researcher challenges fellow nurse educators to consider and evaluate the value and importance of paperwork in nursing curricula.

Have nurse educators responded to the pressure from affiliated medical facilities and shifted value away from the nurse/patient/family relationship? Is the value with completing paperwork, charting using the electronic medical record, or with establishing a caring connection with the patient/family dyad?

Sadly, the researcher has even considered creating a nursing course where caring is taught; practiced; demonstrated; actualized. Students are not learning how to care through osmosis during nursing courses and nurse educators must teach them about caring. Gone are the days when one was “called” to be a nurse instead nursing is primarily being selected for employment opportunities.

Medical facilities and departments of nursing (and patients) would benefit from focusing on the patient and family as one unit and accepting their interconnectedness. In general, hospitals are not organized or designed to be welcoming to a family. In the researcher’s experience, the nursing staff are conflicted because they want family at the hospital to take physical care of the patient but then they must interact and answer questions posed by the family.

Implications for Nursing Research and Policy. In the United States, there is an average of 12,000 new cases of spinal cord injury each year and the majority of those injured are male. A SCI is a sudden life altering injury that impacts the patient and their world. The estimated health care cost for a new case of complete paraplegia is \$292,740.00 with yearly care costs of \$29,789.00 (Spinal Cord Injury Information Network, 2013). In the state of West Virginia, the researcher was informed by the medical director of the rehabilitation facility that the medical facility does not receive reimbursement from the state if the patient is receiving or approved to receive Medicaid. The medical facility is reimbursed for the acute care provision of care but not the rehab phase of care. Medications and surgical/interventional procedures to assist

with erectile dysfunction and fertility issues are not covered by Medicaid in West Virginia. Now with the Affordable Care Act, the future of health care reimbursement and payment is to be defined from a national as well as state level.

No matter who pays the bill, being prudent with resources and exhibiting fiduciary responsibility makes sense. The dialogue and call for nurses to be prepared to care for people of many cultures (beliefs and values) has been ongoing as has the debate on entry level for practice. Implications for research and policy related to the state of the nation and its people are immense. Rehab nurses need to cultivate an environment of culture care where newly injured men with a spinal cord injury can set a goal of “I will walk again” and share it with the rehab team. The rehab team will support the essence of their goal and not think another patient is in denial. Do not dismiss the goal out right but rather discuss the goal with the patient to understand their thought process. With limited time and resources, optimizing the rehab experience and preparing them for their new normal is imperative.

A gap in knowledge and understanding existed to support this study. Nurses need to recognize the client’s viewpoint (worldview), a need for enhanced communication, and an understanding of an individual’s known abilities (Thompson, 1990; Carpenter, 1994; Wehman et al., 2000). Research conducted on quality of life revealed, quality of life indices are the lowest immediately after injury (Duggan & Dijkers, 1990). The time to discover and learn about the patient/family and establish a connection (patient/family) is immediately after their spinal cord injury. The need for peer support and to meet men like me is critical for recovery. The sooner the better the informants shared. The mind set and positive attitude for men to “get busy” is influenced by peer support (meeting men like me) and hearing their story.

Recommendations for Future Research. The following are research topics to consider

for future studies.

1. Replicate the study in West Virginia with women who have a SCI and compare with findings from this study.
2. Replicate the study with men from other geographic regions of Appalachia and compare the findings from this study.
3. Conduct research on discovering how men with a SCI prefer to learn about the required self-care behaviors associated with their injury.

5.9 Limitations of the Study

All studies have limitations for the transferability of findings to other populations outside of the study sample. The nature of an ethnonursing study is to discover unknown phenomena within a people's cultural context (Leininger, 1991). The qualitative method in and of itself is a leap of faith and a priori. The findings represent the collective emic view of 23 men with a spinal cord injury from the Appalachian region of West Virginia who chose to participate in the study.

5.10 Conclusions

The research study sought to discover and describe the culture care meanings and care expressions of men with a SCI from the Appalachian region of West Virginia. The research questions were,

1. What are the culture care meanings and care expressions of men with a SCI from the Appalachian region of West Virginia?
2. What are the generic (folk) and professional practices that influence the care of men with a SCI from the Appalachian region of West Virginia?

3. How do men with a SCI from the Appalachian region of West Virginia describe the role of the nurse in promoting nursing care within their cultural context?

The nurse must create an environment based on mutual trust so men will share their innermost thoughts and feelings. This *knowledge* is critical in order for men to receive meaningful and beneficial care. What the researcher learned about the informants was: they are good hearted men, who sustained a horrible accident, who just want to get busy and move forward. They are very private (and prefer personal care not be given by female nurses) and see function not “pretty” with environmental modifications. The men stay connected, stay busy, enjoy being outdoors, and enjoy time with family and friends.

5.11 Summary

Men who sustain a spinal cord injury (SCI) have complex care requirements immediately after injury and across their life span. The researcher became interested in men with SCIs while working as a case manager and as a member of the hospital’s skin care team. One morning a young man arrived at the emergency department and said the reason he was there was “I can’t go to bed”. At first, his statement was confusing the staff. He had developed pressure ulcers and had been sleeping prone to relieve pressure to the areas. Then, he developed a rash on the front of his thighs and he realized “I can’t go to bed”. You had to understand things from ‘his point of view’ in order to care for him. He delayed seeking medical attention until he “literally” could not go to bed.

This ethnonursing study sought to discover and describe the culture care meanings and care expressions of men with a SCI from the Appalachian region of West Virginia. Twenty-three informants (5 key and 18 general) participated in this study. Informed consent was

obtained, inclusion criteria were confirmed with each potential informant, and a pseudonym was chosen for use during the interview to enhance their anonymity. Leininger's Four Phases of Qualitative Data Analysis (1991) was used as a process to "tease out" the hidden phenomena. Concurrent data analysis with oversight by the dissertation chair resulted in three major themes, five patterns, and thirteen categories. This study generated more questions than answers for the researcher. The researcher's belief men do not take "good" care of themselves was unfounded. Seeing the emic view compared to the etic view is accomplished by switching a one letter in the word.

References

- Andrews, M., & Boyle, J. (2012). *Transcultural concepts in nursing care* (6th ed.). Philadelphia, PA: Lippincott.
- Appalachian Regional Commission (2013). Retrieved from <http://www.arc.gov/> on October 19, 2013 and November 14, 2013.
- Boswell, B., Dawson, M., & Heininger, E. (1998). Quality of life defined by adults with spinal cord injuries, *Journal of Rehabilitation*, 64(1), 27-32.
- Carpenter, C. (1994). The experience of spinal cord injury: the individual's perspective-implications for rehabilitation practice. *Physical Therapy*, 74(7), 614-627.
- Craig, A., & Hancock, K. (1998). Living with Spinal Cord Injury: Longitudinal Factors, Interventions and Outcomes. *Clinical Psychology and Psychotherapy*, (5), 102-108.
- Dijkers, M. (1999, August). Correlates of life satisfaction among persons with spinal cord injury. *Archives of Physical Medicine Rehabilitation*, 80, 867-876.
- Duggan, C., & Dijkers, M. (1999). Quality of life-peaks and valleys: a qualitative analysis of the narratives of persons with spinal cord injuries. *Canadian Journal of Rehabilitation*, 12(3), 179-191.
- Elnicki, D., Morris, D., & Shockcor, W. (1995, February). Patient-perceived barriers to preventive health care among indigent, rural Appalachian patients. *Archives of Internal Medicine*, (155), 421-424.
- Fries, J. (2005). Critical Rehabilitation of the Patient with Spinal Cord Injury. *Critical Care Nursing Quarterly*, 28(2), 179-187.
- Gage, M. (1995). Reengineering of health care: opportunity or threat for occupational therapists. *Canadian Journal of Occupational Therapy*, 62(4), 197-207.

- Gates, R., Helmkamp, J., Wilson, S., Denning, D., & Beaver, B. (2002, October). Deer stand-related trauma in West Virginia: 1994 through 1999. *The Journal of Trauma*, 53(4), 705-708.
- Giger, J. & Davidhizar, R. (1995). *Transcultural Nursing Assessment & Intervention*. St. Louis, MO: Elsevier.
- Hansen, M., & Resick, L. (1990, May). Health beliefs, health care, and rural Appalachian subcultures from an ethnographic perspective. *Family & Community Health*, 1-10.
- Huttlinger, K. & Purnell, L. (2008). People of Appalachian heritage. L. Purnell & B. Paulanka (Eds). *Transcultural Health Care*. (3rd ed.) (pp. 95-112). Philadelphia, PA: F. A. Davis Company.
- Imes, S. (2005). *Discovering the culture care meanings and care expressions of men with a spinal cord injury from the Appalachian region of West Virginia: A Mini-Ethnonursing Study*. (Unpublished paper). Duquesne University, Pittsburgh, PA.
- Imes, S., & Landry, D. (2002). Don't underestimate the power of culture. *SCI Nursing*, 19(4), 172-175.
- Joint Commission on Accreditation of Health Care Organizations (2009). *Accreditation Manual for Hospitals*. Chicago, IL: J.C.A.H.O.
- Jones, L. (1994). *Appalachian Values*. Ashland, KY.: The Jessie Stuart Foundation.
- Jones, L. (1999). *Faith and Meaning in the Southern Uplands*. Chicago, IL: University of Illinois Press.
- Kendall, M., Ungerer, G. & Dorsett, P. (2003). Bridging the gap: Transitional rehabilitation services for people with spinal cord injury. *Disability and Rehabilitation*, 25(17), 1008-1015.

- Krause, J., & Anson, C. (1997a). Adjustment after spinal cord injury: relationship to participation in employment or educational activities. *Rehabilitation Counseling Bulletin*, (3), 202-225.
- Krause, J., & Anson, C. (1997b). Adjustment after spinal cord injury: relationship to gender and race. *Rehabilitation Psychology*, 42(1), 31-46.
- Leininger, M. (1991). *Culture care diversity & universality: A theory of nursing*. New York, NY: NLN Press.
- Leininger, M. (Ed). (1998). *Qualitative research methods in nursing*. Dayton, OH: Greyden Press.
- Leininger, M. (2002a). Transcultural nursing and globalization of health care: Importance, focus, and historical aspects. In M. Leininger & M. McFarland (Eds.), *Transcultural nursing concepts, theories, research & practice* (3rd ed.) (pp. 3-43). New York, NY: McGraw Hill.
- Leininger, M. (2002b). Part I. The theory of culture care. In M. Leininger & M. McFarland (Eds.), *Transcultural nursing concepts, theories, research & practice* (3rd ed.) (pp.71-98). New York, NY: McGraw Hill.
- Leininger, M., & McFarland, M. (Eds.) (2002). *Transcultural nursing concepts, theories, research & practice* (3rd ed.). New York, NY: McGraw Hill.
- McCauley, D. (1995). *Appalachian Mountain Religion: A History*. Chicago, IL: University of Illinois Press.
- Mitcho, K., & Yanko, J. (1999, August). Acute care management of spinal cord injuries. *Critical Care Nursing Quarterly*, 22(2), 60-79.

Munhall, P. (2001). *Nursing research: A qualitative perspective* (3rd ed.). Boston, MA: Jones and Bartlett.

Obermiller, P., & Maloney, M. (Eds.) (2002). *Appalachia: Social Context Past and Present*. Dubuque, IA: Kendall Hunt Publishing.

Poulton, B. (1999). User involvement in identifying health needs and shaping and evaluating services: Is it being realized? *Journal of Advanced Nursing*, 30(6), 1289-1296.

Rosswurm, M., Dent, D., Armstrong-Persily, C., Woodburn, P. & Davis, B. (1996). Illness experiences and health recovery behaviors of patients in Southern Appalachia. *Western Journal of Nursing Research*, 18 (4), 441-460.

Senelick, R. (1998). *The Spinal Cord Injury Book for Patients and Their Families*. Birmingham, AL: HealthSouth Press.

Small, C. (2013). Appalachians. In J. Giger (Ed.), *Transcultural Nursing Assessment & Intervention* (6th ed.) (pp. 260-278). St. Louis, MO: Elsevier.

Smeltzer, S., Bare, B., Hinkle, J., & Cheever, K. (Eds.) (2010). *Brunner's and Suddarth's textbook of medical-surgical nursing* (12th ed.). Philadelphia, PA: Lippincott.

Spencer, J., Young, M., Rintala, D., & Bates, S. (1994). Socialization to the culture of a rehabilitation hospital: an ethnographic study. *The American Journal of Occupational Therapy*, 49(1), 53-62.

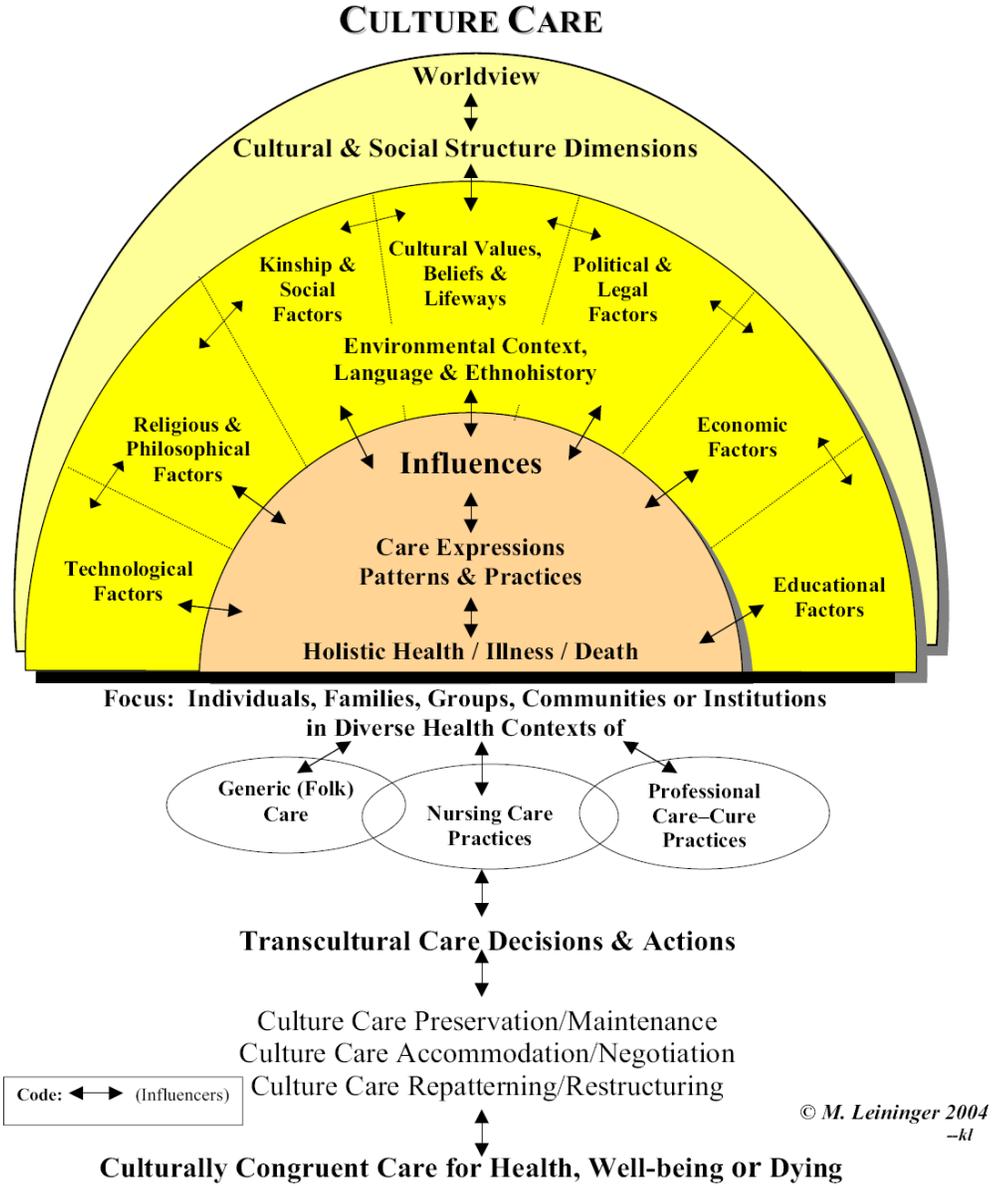
Spinal Cord Injury Facts and Figures at a Glance 2013 Retrieved October 19, 2013 from the Spinal Cord Injury Information Network:

<http://www.spinalcord.uab.edu/show.asp?durki=21446>

- Sumsion, T., & Smyth, G. (2000). Barriers to client-centeredness and their resolution. *The Canadian Journal of Occupational Therapy*, 67(1), p. 15-21.
- Thompson, T. (1990). *A qualitative investigation of rehabilitation nursing care in an inpatient rehabilitation unit using Leininger's theory*. (Doctoral Dissertation). Retrieved from U.M.I. (9118944).
- Tripp-Reimer, T. (1980). Appalachian health care: from research to practice. *Transcultural Nursing Care*, 5, 48-59.
- Wehman, P., Wilson, K., Parent, W., Sherron-Targett, P., & McKinley, W. (2000). Employment satisfaction of individuals with spinal cord injury. *American Journal of Physical Medicine & Rehabilitation*, 79(2), 161-169.
- West Virginia Healthy People 2010: Objective 6- Disability and Secondary Conditions
Retrieved October 19, 2013 from the
<http://www.wvdhhr.org/bph/hp2010/objective/6.htm>
- Wood-Dauphine, S., Exner, G. & SCI Consensus Group (1999). Quality of life in patients with spinal cord injury-basic issues, assessment, and recommendations. *Restorative Neurology and Neuroscience*. 20, 135-149.
- Yow, V. (2006). *Recording Oral History A Guide for Humanities and Social Sciences*. (2nd ed.)
Lanham, MD: Altamira Press.

Appendix A

Leininger's Sunrise Enabler to Discover Culture Care



Note: From website: <http://Medeleine-leininger.com/>. Reprinted with Permission

Appendix B

SEMI-STRUCTURED INTERVIEW GUIDE

Informant Name _____ **Date of Interview** _____

Address _____

Telephone Number/email _____

Pseudonym for Interview _____

Other pseudonyms _____

KEY Informant _____ **GENERAL Informant** _____

Thank You Note Sent (date) _____

Ethno demographics:

Informant Code:	Age:
Date of SCI:	Level of Injury:
Years of Education:	Occupation:
Sex:	Marital Status:
City of Birth:	Years in West Virginia:

Open-Ended Questions

Environment/Technological Factors:

Can you tell me about the place where you were born?

Where do you live now? Describe your home.

Have you made (or do you need to make) any modifications to your home to accommodate your SCI?

Is there anything else you would like to tell me about where you live?

Do you drive a car? Have you made (or do you need to make) any modifications to your vehicle in order to drive?

Do you have access to the internet at home? Do you have a cell phone?

Kinship/Social Factors:

Do you live alone or with others? If you live with others, who lives with you in your home?

Do family/friends live nearby?

Do you visit with family/friends on a regular basis?

If so, what are your favorite activities to do when you get together? Have these activities changed

since your injury?

How are decisions made in the family?

How do you spend a typical day and night? What about since the SCI?

When you were first injured, who helped you with your care? Now, who helps you when you are

sick or need help with your care?

Cultural/Religious Factors:

What cultural group do you identify yourself with?

Do you belong to a church or other religious group?

Does religion or faith have any meaning for you?

Have your beliefs changed since your SCI?

Economic/Political Factors:

What is your occupation? Have you been able to return to work since your SCI?

Do you have health insurance?

Were your hospital bills paid following your accident? What about the cost of your rehabilitation?

Since your SCI, are you able to obtain supplies or equipment you need to take care of yourself?

Do you anticipate any financial concerns with regards to meeting your specific health care needs related to your SCI?

Are you affiliated with a political party? Do you participate in the voting process?

Are you active in your community?

Caring and Health:

Would you tell me how you were injured? How soon after the accident were you told you had injured your spinal cord?

How long were you in the hospital? What do you remember about that time?

Would you share with me your rehabilitation experience?

What does it mean to be healthy or to have “your health”?

What does it mean to be “caring”? Are there any specific behaviors or attitudes that come to mind

if someone is viewed as “caring”?

Do you have a health care provider you see on a regular basis? Do you or does someone in the family make the appointment?

What does it mean to you to have a spinal cord injury?

Do you use any herbal or folk remedies?

Describe how you take care of yourself....especially your bowel care, urinary care, skin care.....

Is there anything else about the experience of a SCI you would like to share?

Appendix C

DUQUESNE UNIVERSITY
INSTITUTIONAL REVIEW BOARD
*301 ADMINISTRATION BUILDING * PITTSBURGH PA 15282-0202*

Dr. Joseph C. Kush
Chair, Institutional Review Board
Human Protections Administrator
Phone (412) 396-6326 Fax (412) 396-5176
e-mail: kush@duq.edu

September 4, 2012

Dr. Rick Zoucha
School of Nursing
Duquesne University
Pittsburgh PA 15282

Re: Discovering the culture care of meanings and care expressions of men with a spinal cord injury from the Appalachian region of West Virginia: an ethno-nursing study (Protocol # 10-96)

Dear Dr. Zoucha:

Thank you for submitting the amendment to the research proposal of your student, Ms. Susan Imes, #10-96.

You propose to make minor changes, specifically updating the wording of the consent form, updating the recruitment flyer, and modifying the Semi-Structured Interview Guide. The changes are consonant with procedures and documents originally approved by the IRB. The intended research poses no greater than minimal risk to human subjects. Consequently, the research is approved under 45CFR46.101 and 46.111 on an **expedited basis** under 45CFR46.110.

The consent form is attached, stamped with IRB approval and expiration date. You should use the stamped form as original for copies you display or distribute.

The research remains subject to all stipulations put forth in this IRB's original approval letter and annual review remains on the cycle determined by the original approval. The protocol number is shown above. Please use it in correspondence with our office.

The amended consent form is attached, stamped with current approval date but original expiration date. You should use the amended stamped form as original for copies that he distributes or displays. Thank you for contributing to Duquesne's research endeavors. If you have any questions, feel free to

contact me at any time.

Sincerely yours,

Joseph C.

Joseph C. Kush, Ph.D.

C: Ms. Susan Imes
Dr. Kathleen Sekula
IRB Records



Appendix D

Duquesne University
IRB-Protocol 10-96
Approval Date: 09/03/2010
Amendment Approved: 09/04/2012
Expiration Date: 09/04/2013

DUQUESNE UNIVERSITY

600 FORBES AVENUE ♦ PITTSBURGH, PA 15282

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

- TITLE:** Discovering the Culture Care Meanings and Care Expressions of Men with a Spinal Cord Injury from the Appalachian Region of West Virginia: An Ethnonursing Study
- INVESTIGATOR:** Susan Imes, RN, MSN
2600 Pleasant Avenue
Ashland, Ky. 41102
(h) 606-324-3529 or (w) 304-696-2619
Mobile: 606-923-0247
- ADVISOR:** Dr. Rick Zoucha
Duquesne University School of Nursing
521 Fisher Hall
600 Forbes Avenue
Pittsburgh, PA 15282
412-396-6545
- SOURCE OF SUPPORT:** This study is being conducted as partial fulfillment of the requirements for the degree of Doctor of Philosophy in Nursing at Duquesne University.
- PURPOSE:** You are being asked to participate in a research study that seeks to discover how men with a Spinal Cord Injury (SCI) from the Appalachian region of West Virginia define care as it relates to culture.

You are being asked to allow me to interview you 1 to 3 times. The interview may last from one to two hours. The interviews will be digitally recorded and transcribed word for word. During the interview, you will be asked questions related to your spinal cord injury, your family, your culture, your finances/insurance, and your health. As part of the interview, demographics (items to help describe you) will be collected. There is a possibility the researcher may ask you to participate in future interviews. You have the option to refuse this and future interviews. These are the only requests that will be made of you.

RISKS AND BENEFITS:

There are no physical or psychological risks anticipated with this study. However, if you feel uncomfortable or wish to end the interview at any time you are free to say **STOP**. If you become tired and want to take a break at any time; all you need to do is say **STOP**. In addition, you are free not to answer an individual question posed to you by the researcher.

There is no direct benefit for you to participate in this study. Although, there is the knowledge that you are sharing very important information about how men with a spinal cord injury from the Appalachian region of West Virginia describe the role of culture and the impact the spinal cord injury has had. Lastly, that someone in the future may benefit from this new knowledge.

COMPENSATION:

There is no compensation for participating in this research study and participation in the project will require no monetary cost to you.

CONFIDENTIALITY:

Shared transcriptions will delete all identifying material of you and anyone you talk about. Your name will never appear on any survey or research instrument used for this study. The person who will assist in transcribing the digital files will sign a confidentiality agreement. When the digital files are

transcribed, pseudonyms will be used for you or anyone you talk about. No identity will be made in the data analysis. Your response(s) may appear as de-identified quotes in summaries of findings and in reports of the data presented in publications and/or presentations. De-identified quotes may also be shared with members of my dissertation committee. All written materials, consent forms, and digital files used in this study will be stored in a locked file or in a password protected computer in my office and will be destroyed when all activities related to the study are completed.

RIGHT TO WITHDRAW: You are under no obligation to participate in this study. You are free to withdraw your consent to participate at any time.

SUMMARY OF RESULTS:

A summary of the results of this research will be supplied to you, at no cost, upon request.

VOLUNTARY CONSENT:

I have read the above statements and understand what is being requested of me. I also understand that my participation is voluntary and that I am free to withdraw my consent at any time, for any reason. On these terms, I certify that I am willing to participate in this research project.

I understand that should I have any further questions about my participation in this study, I may contact Dr. Joseph Kush, Chair of the Duquesne University, Institutional Review Board (412) 396-6326 or CAMC/WVU-Charleston Division IRB at (304) 388-9973.

Participant's Signature

Date

Researcher's Signature

Date

Appendix E

CONFIDENTIALITY STATEMENT

I understand that as a transcriptionist for a study being conducted by Susan Imes, RN, MSN a doctoral student at Duquesne University, under the supervision of Dr. Rick Zoucha, I am privy to confidential information. I agree to keep all data collected during this study confidential and will not reveal it to anyone outside the research team. I will return all documentation to Susan Imes, RN, MSN and delete the original transcriptions (the digital files and the word files) from the hard drives of my computer whenever she instructs me to.

Name: Karen E. Beckwitt, Ph.D., CEO Asher Consulting, LLC

Signature: _____ Date: 12/17/12

Witness Signature: Susan Imes, RN, MSN

Appendix F

Duquesne University
IRB-Protocol 10-96
Approval Date: 09/03/2010
Amendment Approved: 09/04/2012
Expiration Date: 09/04/2013

Hello,

My name is Susan Imes, RN, MSN and I am working on my PhD at Duquesne University in Pittsburgh, PA. As part of my studies I am conducting research.

Who am I?

I graduated from Marshall University in 1986 with a Bachelor's Degree in Nursing. By 1990, I returned to school and in 1996 received a Master's Degree in Nursing from Bellarmine University. For the past 12 years I have been teaching nursing at Marshall University in Huntington West Virginia.

Why Spinal Cord Injury?

I became interested in spinal cord injury while a nurse at the local Veterans Affairs Medical Center (VAMC). I became involved with the skin care team and subsequently met several men with a spinal cord injury who were dealing with pressure sores. I often wondered why some men seemed to have greater issues with skin care and other health problems related to their spinal cord injury than others. Most recently, I have started thinking about how culture may influence how we look at and define health. Does being from West Virginia (an Appalachian region) influence our view of the world? By the way, there is little nursing research available to nursing on men with a spinal cord injury from the Appalachian region of West Virginia.

I am trying through my research study to discover more about the role of culture as it relates to your spinal cord injury and how it may influence your view of health and illness; specifically, men who were born and live in West Virginia.

I would very much appreciate the opportunity to meet with you. By the way, I plan to attend the spinal cord injury support group meetings once the study is approved by the university and hospital.

It is true, without you my study has no meaning!

Because of privacy issues, it is up to you to contact me if you want to learn more about the study and wish to participate. So, please call me or send me an email and I will be in touch.

Contact Information:

Susan Imes, RN, MSN

606-923-0247

imes@marshall.edu

If you leave a message or send an email, please include your name, telephone number, and a time that is best to call.

Do You Have a Story to Tell?

*If,
you are 18 or older, male, born and reared in
West Virginia, and have had a Spinal Cord
Injury...I would like to hear your story!*

*So,
If you are willing to share your story, or if
you wish to learn more about my research
study, I would like to hear from you.*

*Then, Contact Susan Imes, RN, MSN at 606-
923-0247;email imes@marshall.edu or look for
the recruitment flyer!*